

HIV in women in Aotearoa New Zealand: 25 years of surveillance data

Ashleigh de Gouw, Susan McAllister, Jane Bruning, Judith Mukakayange, Jerram Bateman, Patricia Priest

ABSTRACT

AIM: We describe the characteristics of women diagnosed with HIV and AIDS in Aotearoa New Zealand over the last 25 years, and of women living with HIV in New Zealand in order to guide the response for HIV prevention and care.

METHODS: Data on women diagnosed with HIV and AIDS in New Zealand (1996–2020) were collected through routine surveillance case reports from healthcare providers. CD4 cell count <350 cells/mm³ was considered a late diagnosis. Women living with HIV by 31 December 2020 included those first diagnosed in New Zealand and those previously diagnosed overseas.

RESULTS: A total of 634 women have been diagnosed with HIV (18% of all diagnoses in this time): most cases were acquired through heterosexual contact (82%). Twenty-eight percent ($n=180/634$) acquired HIV in New Zealand, of whom 43% were diagnosed late. AIDS was diagnosed in 128 women (72% within three months of HIV diagnosis). An estimated 570 women (77% aged ≥ 40 years) were living with diagnosed HIV at the end of 2020.

CONCLUSION: The number of women diagnosed with HIV each year in New Zealand has remained steady over recent years. More timely testing and diagnosis is essential to ensure women with HIV have access to appropriate treatment and support.

The United Nations has a goal to end AIDS by 2030 with targets of 95% of all people with HIV diagnosed, 95% on treatment and 95% having a suppressed viral load—and for these targets to be achieved within all sub-populations and groups.¹ This is particularly challenging in countries with a concentrated epidemic, such as among gay and bisexual men (GBM), who are often the priority group for reaching the goal. Other groups affected by HIV, who sometimes constitute small numbers of people, also require attention.

Aotearoa New Zealand is a low HIV prevalence country, with the epidemic largely concentrated in GBM.² Women in low-prevalence countries are often perceived as being at low risk for HIV infection by both themselves and medical professionals,³ which results in less testing, late diagnosis^{4,5} and barriers to treatment and support services.^{3,6} Each of these are contributing factors towards the increased risk of HIV progressing to an AIDS diagnosis and poorer long-term outcomes.^{5,7} Stigma and discrimination can also lead to hesitancy to test.^{6,8} Once diagnosed, women can feel socially isolated particularly if HIV support services are mostly designed for gay men.⁶

Women living with HIV also have particular needs in the areas of sexual and reproductive health, clinical management and emotional well-being.^{3,9,10} New Zealand has a network of Infectious Disease Specialists, based mostly in the large

urban centres, where people diagnosed with HIV are referred to for treatment. Some of these centres also have a team of HIV nurse specialists, social workers and access to other allied health professionals for the care and support of patients. Positive Women Incorporated was established in 1990 to support and empower women and their families living with or affected by HIV and to provide services unique to women. More recently, Toitū te Ao was established as a Kaupapa Māori organisation to support and uphold the mana of Māori women living with HIV.

New Zealand aims to eliminate local transmission of HIV.¹¹ The total number of people diagnosed with HIV each year has been declining since 2016,¹² but to reach the goal it is important to tailor HIV testing, treatment and support services to those who need them most. To date there is a lack of published data on women diagnosed and living with HIV to guide the response. We therefore describe the characteristics of women diagnosed with HIV and AIDS over the last 25 years and women thought to be living with HIV in New Zealand at the end of 2020.

Methods

Data sources

Since 1996, the AIDS Epidemiology Group (AEG) at the University of Otago has undertaken

enhanced surveillance of HIV, whereby anonymous information on individuals newly diagnosed with HIV in New Zealand has been sought from the clinician who requested the HIV confirmatory test. From 2002, data have also been received from laboratories performing HIV viral load (VL) testing in order to capture information on people living with HIV in New Zealand who had their initial HIV diagnosis overseas. From 2017, HIV became notifiable under the Health (Protection) Amendment Act 2016.

In New Zealand, an individual with HIV infection is defined as having AIDS when they first develop one of a number of specific AIDS-defining conditions.¹³ Clinicians diagnosing AIDS are required to notify the case using unnamed coded information, and to complete a case report.

Information on women known to be infected with HIV who give birth has been collected by the AEG via the New Zealand Paediatric Surveillance Unit since 1998.

Definitions

Women diagnosed with HIV include all women (including transgender) diagnosed in New Zealand since the beginning of 1996 to the end of 2020. This excludes women who were previously diagnosed overseas.

The estimated number of women living with diagnosed HIV in New Zealand at the end of 2020 includes women first diagnosed in New Zealand between the years 1996 and 2020, as well as those previously diagnosed overseas and notified to the AEG through VL testing, for whom no information has been received to say they had died or gone overseas.

Variables and analysis

From the AEG database, demographic data for women include age and place of residence at the time of diagnosis, current age (calculated as at the end of December 2020), and prioritised ethnicity.¹⁴ Mode of acquisition was categorised into heterosexual contact, injecting drug use (IDU) (including women for whom both IDU and heterosexual contact were reported as possible modes of acquisition), mother-to-child transmission and other or not reported. Place of likely acquisition was categorised as New Zealand, overseas or unknown. Clinical data included the site of, and reason for testing, sexual partner's risk status, previous negative HIV test, and CD4 cell count (available since 2005) categorised to <350 cells/mm³ and 350+

with a CD4 cell count of less than 350 considered a late diagnosis.¹⁵ The characteristics of women diagnosed in New Zealand are presented in two time periods (1996–2010 and 2011–2020) to identify and describe any change over these years. Descriptive analysis was undertaken using Stata SE Version 17. Denominator data for the rate of women diagnosed with HIV was the estimated resident all-female population as in December each year, and for women living with diagnosed HIV the denominator was the estimated resident female population aged 15 and over as in December 2020.¹⁶

Results

Women diagnosed in New Zealand

A total of 634 women (18 of whom were transgender) were newly diagnosed with HIV in New Zealand over the 25 years from 1996 to the end of December 2020—18% of all diagnoses in this time. The main mode of acquisition was heterosexual contact (82%). Most women (76%) were aged less than 40 years at the time of diagnosis, however, in the past 10 years the proportion of women aged ≥40 years at the time of diagnosis has increased (37% compared to 19% between 1996 and 2010) (Table 1).

Almost half of the women (42%) were residing in the Northern region (wider Auckland and Northland District Health Board areas) at the time of diagnosis. The main site of HIV testing was at a general practice (40%) and the main reasons for testing were because of symptoms (19%), or a history of risk (14%). Overall, 13% tested as part of immigration screening and 14% refugee screening. The latter declined from 17% in 1996–2010 to 7% in 2011–2020. Forty three (7%) women were diagnosed through antenatal testing—32 after the introduction of routine antenatal screening in 2006.

The majority (73%) of women diagnosed in the earlier years had acquired HIV overseas (Figure 1) and were mostly of African (52%) or Asian (19%) ethnicity (Table 1). The 3-year average shows a sharp rise to 2005–2007 followed by a rapid decline. In the last 10 years (2011–2020), there has been a similar number of women acquiring HIV overseas and in New Zealand (Figure 1) with wider representation from different ethnic groups (Table 1). The average annual rate of all women diagnosed in the 15 years from 1996 to 2010 was 1.43 per 100,000 females and in the past 10 years almost halved to 0.80 per 100,000.

Table 1: Characteristics of women diagnosed with HIV in New Zealand from 1996 to 2020.

Characteristics	Year of diagnosis		
	1996–2010 n (%) (n=445)	2011–2020 n (%) (n=189)	Total n (%) (n=634)
Age at diagnosis (years)			
<30	182 (40.9)	63 (33.3)	245 (38.6)
30–39	180 (40.4)	57 (30.2)	237 (37.4)
40–49	61 (13.7)	36 (19.0)	97 (15.3)
50+	22 (4.9)	33 (17.5)	55 (8.7)
Ethnicity			
Māori	18 (4.0)	21 (11.1)	39 (6.2)
Pasifika	22 (4.9)	13 (6.9)	35 (5.5)
African	231 (51.9)	40 (21.2)	271 (42.7)
Asian	86 (19.3)	52 (27.5)	138 (21.8)
European	74 (16.6)	50 (26.5)	124 (19.5)
Other/not reported	14 (3.1)	13 (6.9)	27 (4.3)
Usual residence at time of diagnosis^a			
Northern	204 (45.8)	65 (34.4)	269 (42.4)
Midland	55 (12.4)	26 (13.8)	81 (12.8)
Central	89 (20.0)	29 (15.3)	118 (18.6)
Southern	59 (13.3)	22 (11.6)	81 (12.8)
Overseas	29 (6.5)	25 (13.2)	54 (8.5)
Not reported	9 (2.0)	22 (11.6)	31 (4.9)
Likely mode of acquisition			
Heterosexual contact	375 (84.3)	142 (75.1)	517 (81.5)
Injecting drug use (IDU) ^b	3 (0.7)	5 (2.6)	8 (1.3)
Mother-to-child transmission	18 (4.0)	1 (0.5)	19 (3.0)
Other ^c /Not reported	49 (11.0)	41 (21.7)	90 (14.2)
Site of testing			
General practice	180 (40.4)	71 (37.5)	251 (39.6)
Infectious disease/other hospital clinician	104 (23.4)	33 (17.5)	137 (21.6)
Refugee centre	76 (17.1)	13 (6.9)	89 (14.0)

Table 1 continued: Characteristics of women diagnosed with HIV in New Zealand from 1996 to 2020.

Characteristics	Year of diagnosis		
	1996–2010 n (%) (n=445)	2011–2020 n (%) (n=189)	Total n (%) (n=634)
Site of testing			
Sexual health clinic	41 (9.2)	9 (4.7)	50 (7.9)
Other ^d	27 (6.1)	23 (12.2)	50 (7.9)
Not reported	17 (3.8)	40 (21.2)	58 (9.0)
Reason for testing			
History of risk ^e	72 (16.2)	19 (10.1)	91 (14.4)
Symptoms	91 (20.4)	30 (15.9)	121 (19.1)
History of risk and symptoms	13 (2.9)	4 (2.1)	17 (2.7)
Antenatal screening ^f	28 (6.3)	15 (7.9)	43 (6.8)
Immigration screening	52 (11.7)	33 (17.5)	85 (13.4)
Refugee screening	76 (17.1)	13 (6.9)	89 (14.0)
Contact tracing	37 (8.3)	11 (5.8)	48 (7.6)
Other ^g	53 (11.9)	22 (11.6)	75 (11.8)
Not reported	23 (5.2)	42 (22.2)	65 (10.3)

^a Regions of usual residence are made up of the following district health board areas:

Northern: Northland, Waitematā, Auckland, Counties Manukau

Midland: Waikato, Lakes District, Bay of Plenty, Tairāwhiti

Central: Taranaki, Hawkes Bay, MidCentral, Hutt District, Capital and Coast, Wairarapa

Southern: Nelson Marlborough, West Coast, Canterbury, South Canterbury, Southern

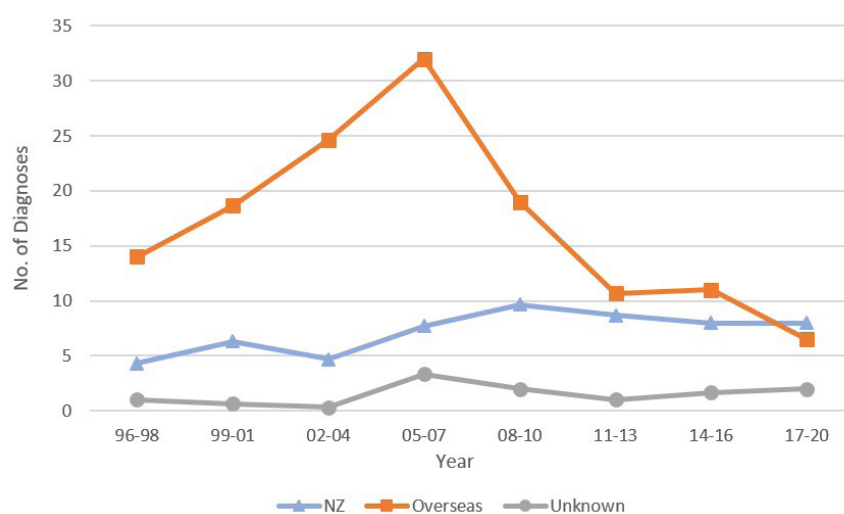
^b Injecting drug use also includes those reported as heterosexual and injecting drug use.

^c Includes, but not limited to, blood transfusion, occupational exposure, and transgender women.

^d Includes family planning, fertility, and antenatal clinics, blood service, immigration or insurance clinic, NZ AIDS Foundation or Body Positive Clinic.

^e Includes contact with a bisexual man, sex work or contact with a sex worker, or history of injecting drug use.

^f Routine HIV antenatal screening commenced 2006. ^g Includes, but not limited to, immigration test for entry to another country, insurance application, blood donation screening, routine sexual health screening

Figure 1: Three-yearly average of women first diagnosed with HIV in New Zealand by place of acquisition.**Table 2:** Characteristics of women diagnosed with HIV (1996 to 2020) with HIV acquired in New Zealand.

Characteristics	Total n (%) (n=180)
Age at diagnosis (years)	
<30	72 (40.0)
30–39	56 (31.1)
40–49	30 (16.7)
50+	22 (12.2)
Ethnicity	
Māori	36 (20.0)
Pasifika	21 (11.7)
Asian	23 (12.8)
MELAA ^a	27 (15.0)
European	73 (40.5)
Likely mode of acquisition	
Heterosexual contact	152 (84.5)
Injecting drug use (IDU)	4 (2.2)
Mother-to-child transmission	4 (2.2)
Other ^b /not reported	20 (11.1)

Table 2 (continued): Characteristics of women diagnosed with HIV (1996 to 2020) with HIV acquired in New Zealand.

Characteristics	Total n (%) (n=180)
Risk status of the sexual partner	
High risk ^c	99 (55.0)
No known risk group	5 (2.8)
Unknown or not reported	76 (42.2)
Previous negative test	
Within past 2 years	20 (11.1)
>2 years or time unknown	32 (17.8)
No	92 (51.1)
Not reported	36 (20.0)
Initial CD4 count^d	
<350	57 (42.5)
350+	65 (48.5)
Not reported	12 (9.0)

^a MELAA: Middle Eastern, Latin American, African

^b Includes, but not limited to, blood transfusion, occupational exposure, and transgender women

^c Sexual partner a bisexual man, a person from a high HIV prevalence country or an injecting drug user

^d CD4 count data is since 2005

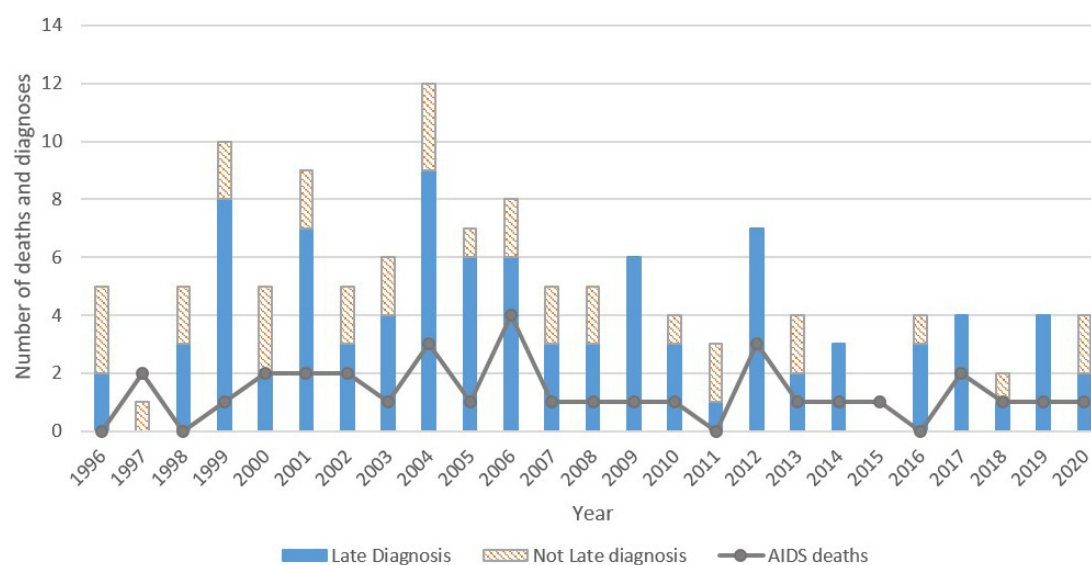
Figure 2: Annual number of women diagnosed with AIDS and deaths among women who were notified with AIDS.

Table 3: Women diagnosed with AIDS from 1996 to 2020.

Characteristics	Total n (%) (n=128)
Age at AIDS diagnosis (years)	
<30	31 (24.2)
30–39	49 (38.3)
40–49	32 (25.0)
50+	16 (12.5)
Ethnicity	
Māori	14 (10.9)
Pasifika	7 (5.5)
Asian	35 (27.3)
MELAA ^a	45 (35.2)
European	27 (21.1)
Clinical indicator^b	
Opportunistic infection	86 (67.2)
HIV wasting syndrome	9 (7.0)
Tuberculosis	30 (23.4)
Other clinical condition	11 (8.6)
Late diagnosis^c	
Yes	92 (71.9)
No	36 (28.1)

^a MELAA: Middle Eastern, Latin American, African

^b More than one condition could be indicated

^c AIDS diagnosis within 3 months of HIV diagnosis

Women with HIV acquired in New Zealand

Table 2 shows the age, ethnicity, sexual partner's risk status, previous negative test, and CD4 count information of the 180 women (including 14 transgender) who were reported to have acquired HIV in New Zealand between 1996 and 2020 (10% of all locally acquired HIV diagnoses in this time). The ethnicity of these women differs from that of the overall group diagnosed in New Zealand, with a greater proportion being Māori (20%) or of European (41%) ethnicity. The age is similar to the overall group diagnosed in New Zealand, and there was a greater proportion of older women diagnosed in 2011–2020 (33/82; 40%)

than in 1996–2010 (19/98; 19%). Since 2005 (when CD4+ count information was first collected), 43% had a CD4 count less than 350 cells/mm³ at the time of diagnosis and were therefore considered a late diagnosis. Only a third had ever had a previous HIV test. Of the 14 transgender people, 5 were Māori, 4 European and 5 Pasifika or other ethnicity. Two had a CD4 count less than 350 cells/mm³ at the time of diagnosis, and 4 had had a previous negative HIV test.

Women diagnosed with AIDS

A total of 128 women were diagnosed with AIDS (Table 3), an average of 6.2 women per year in the years 1996 to 2010, and 3.5 women per year

between 2011 and 2020 (Figure 2). Māori women made up 11% of women diagnosed with AIDS, 27% Asian, 35% Middle Eastern, Latin American or African, 21% European, and 6% Pasifika. The most common clinical indicator of AIDS was an opportunistic infection (67%) such as pneumocystis pneumonia, oesophageal candidiasis and cerebral toxoplasmosis. Tuberculosis was frequently reported in the earlier years between 1996 and 2010 ($n=27/93$; 29%) but has reduced considerably since then ($n=3/35$; 9%). The mean age at the time of an AIDS diagnosis was 40 years (standard deviation 12.85 years). Seventy-two percent ($n=92$) had an AIDS diagnosis within three months of their HIV diagnosis and were therefore considered a late diagnosis of HIV (Table 3). A total of 33 women have died from AIDS over the 25 years (Figure 2).

Women living with diagnosed HIV

Of the women who had been notified with HIV between 1996 and 2020 (either diagnosed in New Zealand or previously diagnosed overseas), 184 had died ($n=42$) or gone overseas ($n=142$), leaving an estimated 570 living with diagnosed HIV in New Zealand at the end of 2020 (27.3 per 100,000 females aged 15 and over). Three quarters (77%) are aged 40 or more, and over a third (38%) are aged over 50 years. African (39%), European (22%) and Asian (20%) women make up the greatest proportion, followed by Māori (6%) and Pasifika (6%). The main mode of acquisition was heterosexual contact (78%), mother-to-child transmission (3%), injecting drug use (2%) and for the remainder the mode was unknown or not reported. Nineteen are transgender women.

Births to women with diagnosed HIV

Between 1998 and 2020, 192 children were born in New Zealand to women with diagnosed HIV. None of these children have been infected with HIV. The majority of women (82%) were diagnosed before their pregnancy, and 34 (18%) diagnosed during their pregnancy. Almost all of the women received antiretroviral treatment (97%). Delivery was by caesarean section for 53% and vaginal delivery for 46%. The majority of women did not breastfeed their children (95%).

Discussion

From routine surveillance data we have shown that the number of women diagnosed with HIV in New Zealand has remained low over the past

25 years, particularly women who acquired HIV in this country. Of concern, however, is the high proportion of women who were diagnosed late. Women living with diagnosed HIV in New Zealand are predominantly older and ethnically diverse.

A strength of our study is the use of national surveillance data collected consistently over a long period of time. Overall, there has been a high return of case report forms from clinicians in this time (89%), however, data are incomplete for some specific questions such as assessment of risk history. Information was obtained from clinicians at the time of diagnosis therefore some data such as the place of residence and whether women are still living in New Zealand may have subsequently changed.

The number of women diagnosed in New Zealand in the earlier years was mostly women who acquired HIV overseas—largely from high HIV prevalence countries in sub-Saharan Africa. Changes to the immigration policy in 2005¹⁷ included introducing HIV testing as part of the visa requirements and is the likely reason for the subsequent decline. The average annual rate of all women diagnosed with HIV in the past 10 years (0.80 per 100,000 female population) has remained steady and is similar to Australia (0.83).¹⁸ However, most Western European countries, for example the United Kingdom (4.49), Denmark (2.04) and Germany (1.42),¹⁹ reported higher rates most likely due to a high proportion of people originating from a country outside of where they were diagnosed. The New Zealand visa requirements were recently reviewed in October 2021 and HIV was removed from the list of medical conditions deemed likely to impose considerable costs to the health system.²⁰ HIV testing remains a requirement for visa applicants intending to stay for more than 12 months, with applications from people with HIV to be considered on a case-by-case basis. Continued surveillance is essential to show how these changes in immigration might impact on the overall number of people notified with HIV in New Zealand and whether there is any increase in women first diagnosed overseas but requiring care in New Zealand.

The HIV epidemic in New Zealand has been concentrated in GBM,² with women making up only 10% of locally acquired infection. About half of these infections have been from sexual contact with a partner traditionally considered to be at high risk such as a bisexual man, a person from a high prevalence country or a person who injects drugs. Such high risk is potentially reduced in the

current era of prevention referred to as “Undetectable=Untransmissible” (U=U)²¹ whereby the risk of transmitting HIV sexually from a person living with HIV who has an undetectable viral load is negligible.²² To be undetectable, however, depends on a high level of people testing for HIV and adherence to HIV treatment in those who are diagnosed. Prevention of HIV in women therefore depends on overall national prevention and control strategies.

Of some initial concern was that 20% of women with locally acquired HIV were Māori, which is higher than the 16% of Māori women aged 15–64 years in the population. However, after removing the five Māori transgender women from this group, the proportion is reduced to 17%. This constitutes 31 women over a 25-year period—approximately one Māori woman per year. To reach the goal of elimination of transmission of HIV in Māori women, and to support Māori women living with HIV in New Zealand, the articles of Te Tiriti o Waitangi need to be upheld, including *kāwanatanga* (ensuring meaningful representation and participation at all levels), *tino rangatiratanga* (self-determination), and *ōritetanga* (ensuring equity between Māori and other citizens of New Zealand).²³

Almost half of the women who acquired HIV in New Zealand were diagnosed late. Similar rates of late diagnosis amongst women have also been reported in Australia (24% in Australian born; 51% in overseas born women),⁶ Western Europe (54%),⁵ and the United Kingdom (51%).²⁴ An analysis of late diagnosis of people diagnosed with HIV in New Zealand from 2011–2020 showed minimal reduction in the proportion of late diagnosis in women from the previous period of 2005–2010. The main risk factors for late diagnosis in both heterosexual women and men were older age (40+) and being of an ethnic group other than European (unpublished data). New Zealand has no specific guidelines for HIV testing in women—apart from the universal offer of testing for all pregnant women, through which 32 women have been diagnosed since its introduction in 2006. Instead, women are included in the overall recommendations for testing that are in accordance with the 2006 US Centers for Disease Control.²⁵ These aim to promote more frequent testing and to “normalise” testing but still recommend testing for persons who are considered high risk and those seeking assessment for sexually transmitted infections (STIs).^{26,27} For almost half of the women in our

database, however, the risk status of their partner was unknown or not reported, which has been a reason for late diagnosis in other studies.^{28,29} The number of women diagnosed late, and the small proportion who had a recent previous HIV test, indicates that more needs to be done to raise awareness of HIV testing among healthcare providers and among women themselves. Moreover, increasing age at the time of diagnosis, as seen in our data, has been reported in other countries. Reasons for this are varied, such as change in risk behaviour patterns, health-seeking behaviour, testing programmes and patterns, levels of stigma and low perceptions of risk by healthcare providers, particularly for older women.^{5,8,30} Further research is required to understand testing rates and patterns in New Zealand that could guide further testing policies and other possible testing options and sites; for example, opportunistic testing in different types of healthcare settings such as gynaecology clinics, emergency departments, or primary care, and greater access to free HIV and other testing for sexually transmitted infections.

The number of women diagnosed with AIDS has been consistently low and declined even further in the past 10 years—a trend also seen in other high-income countries.¹⁹ While this is encouraging, it would be possible to see no AIDS diagnoses in New Zealand if women are tested and diagnosed early.

Women currently living with diagnosed HIV in New Zealand are of diverse ethnicities and are mostly aged over 40. PHARMAC (the Pharmaceutical Management Agency responsible for government subsidised medications including ART) reported 453 women on subsidised ART in mid-June 2020. Our estimated number of 570 women currently living with HIV is likely to be an overestimate as those who have moved overseas since diagnosis cannot be completely ascertained, but could also reflect barriers to access to treatment for some women, especially non-European.^{23,29,31} To uphold *tino rangatiratanga* for Māori women and provide culturally appropriate services to women of diverse ethnic backgrounds is essential for overcoming such barriers. Meeting the changing needs of women as they age is also important.¹⁰ Further research is needed to assess how these needs are being met in New Zealand.

The risk of mother-to-child transmission of HIV is markedly reduced by antiretroviral treatment (ART) and having a suppressed viral load.³² HIV antenatal screening is therefore vital for ensuring women know their status and have the

opportunity to receive ART. A total of 192 women diagnosed with HIV have given birth in New Zealand since the beginning of routine surveillance in 1998, 34 of whom were diagnosed during their pregnancy, and none of these children have been infected with HIV. Implementation of universal, opt-out antenatal testing of HIV began in 2006 and since 2007 there have been no children with perinatally acquired HIV born in New Zealand, giving testament to the importance of ensuring

this screening is maintained to a high standard and is accessible to all women.

In conclusion, it is to be acknowledged that the number of women diagnosed in New Zealand has remained low. More work, however, is required to prevent late diagnosis by ensuring timely and accessible testing, diagnosis and access to treatment that aligns and partners with Māori women and women of other key affected ethnic groups, as well as transgender women.

COMPETING INTERESTS

Nil.

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AUTHOR INFORMATION

Ashleigh de Gouw: Research Assistant, AIDS

Epidemiology Group, Department of Preventive and Social Medicine, University of Otago, Dunedin, New Zealand.

Susan McAllister: AIDS Epidemiology Group, Department of Preventive and Social Medicine, University of Otago, Dunedin, New Zealand.

Jane Bruning: National Coordinator, Positive Women Inc., Auckland, New Zealand.

Judith Mukakayange: Burnett Foundation, Auckland, New Zealand.

Jerram Bateman: Research Fellow, AIDS Epidemiology Group, Department of Preventive and Social Medicine, University of Otago, Dunedin, New Zealand.

Patricia Priest: Epidemiological Advisor, AIDS Epidemiology Group, Department of Preventive and Social Medicine, University of Otago, Dunedin, New Zealand.

CORRESPONDING AUTHOR

Sue McAllister: Department of Preventive and Social Medicine, University of Otago, PO Box 56, Dunedin 9054, New Zealand.

E: sue.mcallister@otago.ac.nz Ph: 03 479 7108

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