

Two decades of surveillance data show late presentation among a diverse group of women diagnosed with HIV in Victoria, Australia

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In 2017, Victoria – the Australian state with the highest population rate of newly diagnosed HIV¹ – launched an ambitious new HIV strategy that aims to virtually eliminate new HIV transmissions by 2020 and reach the UNAIDS global 95-95-95 diagnosis, treatment and viral suppression targets by 2030.² These targets aim for 95% of people living with HIV to be diagnosed, 95% of people diagnosed with HIV to be accessing treatment and 95% of people on HIV treatment having an undetectable viral load. In contrast to the National HIV strategy, the Victorian strategy included “women at greater risk of HIV”² as a priority population. While the epidemic in Australia is largely concentrated among gay and bisexual men, other priority populations, such as sex workers and people who inject drugs, have always been included in the HIV response because of their high risk to HIV exposure.³ The current strategy, however, recognises that many other groups can face unique challenges that place them at greater risk of HIV. Women, specifically, can experience disadvantage and other challenges in relation to their sexual and reproductive health; for example, a lack of control of financial resources, increased likelihood of intimate partner violence, and unequal caring responsibilities.⁴⁻⁶ For women living with HIV (WLHIV), their HIV status can compound all of these.

Women participating in the 2017 HIV Futures survey, an Australian national survey of

Abstract

Objective: To develop an HIV response suited to women and to inform appropriate services, we describe the characteristics of women diagnosed and living with HIV using 22 years of high-quality surveillance data.

Methods: Data on women newly diagnosed with HIV between 1994 and 2016 and women living with diagnosed HIV in Victoria at 31 December 2016 were extracted from the Victorian Public Health Surveillance System. Descriptive analysis by place of birth was performed and Poisson regression used to assess trends over time.

Results: There were 465 new diagnoses among women in Victoria between 1994 and 2016 and 613 women living with HIV in 2016. Women were diagnosed late, and frequently reported no HIV testing history, AIDS-defining illness or other symptoms of HIV at diagnosis. These indicators of delayed diagnosis were even greater for non-Australian-born women.

Conclusions and implications for public health: For Victoria to reach the ambitious targets for diagnosis, treatment and viral suppression in 95% of people living with HIV, prevention programs and efforts to increase early diagnosis as well as support services must consider the epidemiology and diversity of women.

Key words: HIV, women, disease surveillance, late diagnosis

people living with HIV, reported important gender disparities in their experience of HIV, including the added burden of caring responsibilities and perceived isolation from HIV services designed largely for gay men.⁷ The Futures survey data also showed that many women did not perceive themselves to be at risk of HIV prior to their diagnosis. The most common reason for HIV testing was that their partner tested positive or they became ill and, of the 54% who had never previously been tested, 80% thought they were not at risk.⁷ These perceptions and feelings of isolation can act as a significant barrier for

women to access HIV testing, treatment, care and support.⁸ These barriers result in women being diagnosed later in their infection in countries with a low HIV prevalence among the general population and where women have not traditionally been considered a key risk population.⁹⁻¹²

New HIV diagnoses among women in Australia make up approximately 10% of all diagnoses and, among the estimated 26,444 people living with HIV in Australia in 2016, 12% were women. In Australia, a disproportionate rate of HIV diagnosis exists

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among Aboriginal and migrant women compared with non-Aboriginal Australian-born women.¹ Victoria has managed to sustain very low rates of HIV among Aboriginal women; however, like many places in the developed world,^{12,13} the burden of HIV among migrant women in Victoria has persisted. An Australian qualitative study of HIV in minority ethnic communities found high levels of knowledge of where to get an HIV test and a belief in the importance of knowing one's HIV status; however, the use of HIV services and HIV testing was low. The study uncovered many ongoing barriers to testing including the belief that HIV meant social ostracism and death. Further obstacles identified for migrant women were the role of male partners in controlling their access to health services and the fear of disclosure in their ethnic communities.¹⁴

It is important that appropriate investment occurs in health promotion and HIV services designed with the specific needs and experiences of women in mind. Maximising the value of this investment requires accurate data that appropriately characterise women diagnosed and living with HIV; currently a general paucity of such data makes planning and implementation of an HIV response for women challenging.¹⁵ Here we describe the characteristics of women diagnosed over two decades and living with HIV in Victoria at the end of 2016, in order to inform a tailored HIV response for women.

Methods

Data source

Data for this analysis were obtained from the Victorian Department of Health and Human Services (DHHS) Public Health Events Surveillance System (PHESS). The notification of new diagnoses of HIV is mandated by public health legislation in all Australian jurisdictions.¹⁰ Diagnosing doctors must notify health departments using an HIV notification form. Data received at the DHHS and entered into PHESS includes patient demographics (date of birth, gender, postcode of residence, Aboriginal and Torres Strait Islander status, country of birth, year of arrival in Australia, language spoken at home); testing history (reason for HIV test, ever previously tested for HIV, date and result of previous test); clinical details (CD4 cell count, symptoms at diagnosis and seroconversion illness in the past 12 months); and likely modes of transmission. Data

completeness increased significantly from 1994 and additional fields were included on notification forms at this time, therefore this was chosen as the cut-off year for inclusion of new diagnoses and women living with diagnosed HIV (WLHIV).

Definitions

Newly diagnosed women are those who were diagnosed with HIV for the first time in Victoria and therefore excludes women who were previously diagnosed while residing interstate or overseas. Temporary and non-Victorian residents are excluded. The Victorian HIV Notification Form includes the question "Does the case plan to reside permanently in Victoria for at least 12 months?" Those who respond "no" are excluded. If the response is "unknown" and there is no residential postcode or the postcode is not Victorian, cases are also excluded.

The estimated number of WLHIV in Victoria includes *newly diagnosed women* as well as those who were previously diagnosed interstate or overseas and have migrated to Victoria and were Victorian residents at their most recent contact with health services. This is usually known because to access treatment and care in Victoria a confirmatory diagnosis of HIV is performed and notified to DHHS. This occurs because at Victoria's HIV reference laboratory viral load testing is only conducted on patients with documented HIV infection. Where this is not the case, the laboratory will seek permission of the referring doctor to perform an HIV test. This protocol provides an additional means of identifying people who move to Victoria with previously diagnosed HIV infection. All previously notified cases were assumed to be alive and living in Victoria as at 31 December 2016, unless otherwise notified. The number of WLHIV in this paper refers to only those who have been diagnosed.

Regions of birth were those used by the Australian Bureau of Statistics, with the exception of Sudan, which was categorised as Sub Saharan Africa rather than North Africa.¹⁶ *High HIV prevalence countries* were classified as countries with an adult HIV prevalence greater than 1%.¹⁷

Analysis

Descriptive analysis was performed using Stata Statistical Software: Release 14 (StataCorp, College Station, TX: StataCorp LP). Poisson regression assessed annual trends

over time with a statistical significance cut off $p < 0.05$ for all analyses. A two-sample z-test was used to test the difference between two population proportions and chi square tests used to assess associations in categorical data.

Results

Women newly diagnosed with HIV

There were 465 new diagnoses among women in Victoria between 1994 and 2016, increasing from an average of 14 per year between 1994 and 2003 to an average of 26 per year between 2007 and 2016. The majority of women diagnosed were aged between 20 and 39 years with a median age of 32 years, and 16% lived in regional or rural Victoria at the time of diagnoses. Among newly diagnosed women, 38% were born in Australia, of which 3% were of Aboriginal and/or Torres Strait Islander descent (data not shown). Of the Australian-born women, 85% acquired HIV via heterosexual sex and 78% acquired HIV in Australia. The most commonly reported reasons for testing among Australian-born women were recent risk behaviour (26%); followed by symptoms of HIV infection, with half being seroconversion illness (23%); STI screening (13%); and having an HIV-positive partner (11%).

Among non-Australian-born women; 67 different countries of birth were reported, with 28% born in Sub-Saharan Africa and 18% in Asia (Table 1). Of the non-Australian-born 32% reported speaking English at home; the remainder reported speaking one of 39 different languages (data not shown). Of the non-Australian-born women 64% reported acquiring HIV outside of Australia and 49% had lived in Australia for less than five years at the time of their HIV diagnosis. The reported exposure for 58% of all non-Australian-born women was migration from a high HIV prevalence country. Symptoms of HIV infection was the most commonly reported reasons for test among non-Australian-born women (26%), followed by immigration (19%), antenatal screening (15%) and recent risk behaviour (12%).

The clinical presentation at diagnosis differed between Australian-born and non-Australian-born women. Fewer non-Australian-born women reported ever having tested for HIV prior to their diagnosis (8% compared to 23%, $p < 0.01$); were more frequently diagnosed with AIDS and other symptoms of HIV (30% compared to 20%, $p = 0.01$) and more

frequently had a CD4 cell count <350 µL/ml at the time of diagnosis (51% compared to 24%, $p < 0.01$), see Table 1).

There were no statistically significant trends observed over time in the total number of annual HIV diagnoses in relation to any characteristics listed in Table 1.

Women living with diagnosed HIV

There were 613 WLHIV as at 31 December 2016 with 69% diagnosed for the first time in Victoria, 24% diagnosed outside of Australia and 7% diagnosed interstate. There was a significant increase in the non-Australian-born WLHIV as a proportion of all diagnosed WLHIV between 1994 and 2016 ($p < 0.05$; Figure 1), with a commensurate increase in overseas place of acquisition ($p = 0.01$; data not shown). The majority of WLHIV were not born in Australia, with 31% born in Sub-Saharan African and 21% born in Asia. Among non-Australian-born women, 38% had been living in Australia less than five years as at 31 December 2016. The majority of WLHIV lived in metropolitan Melbourne (80%).

Discussion

Women diagnosed with HIV in Victoria, Australia, frequently reported never testing for HIV prior to diagnosis. A high proportion of women had an AIDS-defining illness or other symptoms of HIV and low CD4 cell counts at the time of diagnosis. The clinical presentation of women with new HIV diagnoses remained unchanged over time, suggesting persistent barriers to their early diagnosis. These indicators of delayed diagnosis were even greater for non-Australian-born women compared to Australian-born women in this analysis of Victorian data. An unintended consequence of the Australian focus on HIV as a disease that predominantly affects MSM is that clinicians are less likely to undertake HIV risk screening among female patients.¹⁸ Added to this is the perception of being at low risk of HIV infection, which can result in HIV being under-diagnosed or diagnosed late in women,^{10,19} resulting in delayed treatment initiation and increased morbidity, mortality, healthcare costs and risk of onward transmission.²⁰⁻²³

There was no significant trend over time in the proportion of Australian-born and non-Australian-born women diagnosed; however, a significant increase in non-Australian-

Table 1: Characteristics of women newly diagnosed with HIV in Victoria between 1994 and 2016, by place of birth

	Australian born		Overseas born						p^e	TOTAL	
	n	%	From HPC		From non-HPC		Total overseas born			n	%
Region of birth											
Australia	176	100.0	-	-	-	-	0	0.0		176	37.9
Sub-Saharan Africa	-	-	128	78.1	0	0.0	128	46.0		128	27.5
Asia	-	-	22	13.4	64	56.1	86	30.9		86	18.5
North Africa and the Middle East	-	-	14	8.5	5	4.4	19	6.8		19	4.1
Europe, UK and Ireland	-	-	0	0.0	26	22.8	26	9.4		26	5.6
Oceania	-	-	0	0.0	14	12.3	14	5.0		14	3.0
Americas	-	-	0	0.0	5	4.4	5	1.8		5	1.1
Unknown	-	-	0	0.0	0	0.0	0	0.0	-	11	2.4
Language spoken at home											
English	154	87.5	50	30.5	38	33.3	88	31.6		247	53.1
Other	2	1.1	81	49.4	59	51.8	140	50.4		143	30.8
Unknown	20	11.4	33	20.1	17	14.9	50	18.0	<0.01	75	16.1
Age at diagnosis											
<15	7	4.0	9	5.5	2	1.8	11	4.0		18	3.9
16-19	11	6.3	10	6.1	3	2.6	13	4.7		24	5.2
20-29	55	31.2	54	32.9	34	29.8	88	31.7		145	31.2
30-39	55	31.2	66	40.2	35	30.7	101	36.3		162	34.8
40-49	25	14.2	16	9.8	23	20.2	39	14.0		66	14.2
50+	23	13.1	9	5.5	17	14.9	26	9.4	0.84	50	10.8
Reported place of acquisition											
Overseas	21	11.9	122	74.4	57	50.0	179	64.4		202	43.4
Australia	137	77.8	20	12.2	44	38.6	64	23.0		206	44.3
Unknown	18	10.2	22	13.4	13	11.4	35	12.6	<0.01	57	12.3
Region of residence											
Metropolitan	134	76.1	132	80.5	101	88.6	233	83.8		377	81.1
Regional/rural	36	20.5	28	17.1	10	8.8	38	13.7		74	15.9
Unknown	6	3.4	4	2.4	3	2.6	7	2.5	0.11	14	3.0
Time in Australia since diagnosis (years)											
0-5	-	-	98	59.8	39	34.2	137	49.3		137	29.5
5-10	-	-	22	13.4	10	8.8	32	11.5		32	6.9
10+	-	-	19	11.6	29	25.4	48	17.3		49	10.5
Unknown	-	-	25	15.2	36	31.6	61	21.9		71	15.3
Not applicable	176	100.0	-	-	-	-	0	0.0	-	176	37.8
Reported exposure											
Person is from a HPC ^d	0	0.0	164	100.0	0	0.0	162	58.3		163	35.1
Injecting drug user	18	10.2	0	0.0	3	2.6	3	1.1		22	4.7
Sexual exposure	150	85.2	0	0.0	103	90.4	94	33.8		251	54.0
Other ^b	7	4.0	0	0.0	4	3.5	11	3.9		18	3.9
Undetermined ^c	1	0.6	0	0.0	4	3.5	8	2.9	<0.01	11	2.4
Reason for test											
Symptoms of HIV infection	40	22.7	40	24.4	31	27.2	71	25.5		114	24.5
Reported recent risk behavior	45	25.6	14	8.5	20	17.5	34	12.2		82	17.6
HIV positive partner ^a	20	11.4	6	3.7	14	12.3	20	7.2		41	8.8
Immigration	0	0.0	36	22.0	16	14.0	52	18.7		52	11.2
Antenatal	16	9.1	27	16.5	15	13.2	42	15.1		58	12.5
STI screening ^a	23	13.1	12	7.3	6	5.3	18	6.5		41	8.8
Confirmation of HIV status	6	3.4	2	1.2	2	1.8	4	1.4		11	2.4
Other	21	11.9	21	12.8	7	6.1	28	10.1		50	10.8
Not reported	5	2.8	6	3.7	3	2.6	9	3.2	<0.01	16	3.4
CD4 at diagnosis (µL/ml)											
<350	43	24.4	86	52.4	56	49.1	142	51.1		188	40.3
>350	90	51.1	42	25.6	36	31.6	78	28.1		172	37.0
Not reported	43	24.4	36	22.0	22	19.3	58	20.9	<0.01	105	22.6

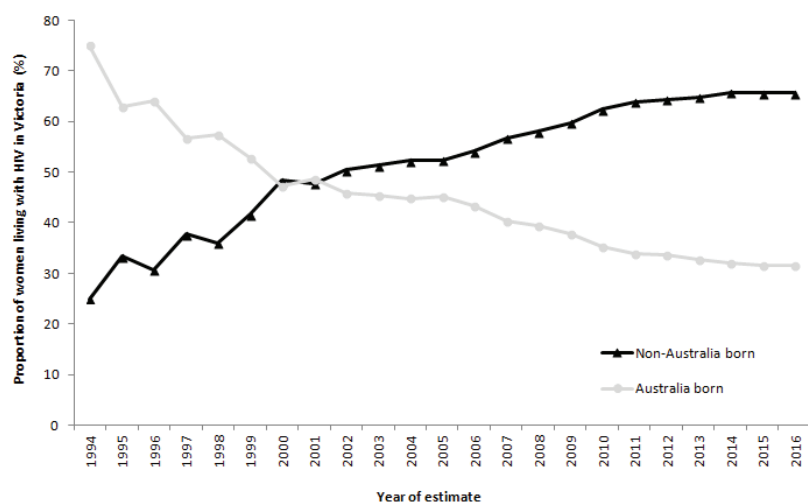
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Table 1 (cont.): Characteristics of women newly diagnosed with HIV in Victoria between 1994 and 2016, by place of birth.

	Australian born		Overseas born						p ^e	TOTAL	
	n	%	From HPC		From non-HPC		Total overseas born			n	%
			n	%	n	%	n	%			
Time since last HIV test at diagnosis											
< 12 months	40	22.7	14	8.5	10	8.8	24	8.6	67	14.4	
1-3 years	19	10.8	15	9.1	9	7.9	24	8.6	45	9.7	
3+ years	27	15.3	19	11.6	13	11.4	32	11.5	59	12.7	
No previous test	76	43.2	88	53.7	63	55.3	151	54.3	231	49.7	
Not reported	14	8.0	28	17.1	19	16.7	47	16.9	63	13.5	
Symptoms at diagnosis											
No symptoms	118	67.1	104	63.4	72	63.2	176	63.3	300	64.5	
Seroconversion symptoms	21	11.9	7	4.3	4	3.5	11	4.0	33	7.1	
AIDS defining illness	13	7.4	18	11.0	17	14.9	35	12.6	48	10.3	
Other HIV symptoms	22	12.5	30	18.3	18	15.8	48	17.3	73	15.7	
Not reported	2	1.1	5	3.0	3	2.6	8	2.9	11	2.4	
Total	176	100.0	164	100.0	114	100.0	278	100.0	465	100.0	

Notes:
 a: HIV positive partner and STI screening were not options as a reason for test on HIV notification forms pre-2006
 b: Other includes: haemophilia/coagulation disorders, receipt of blood, blood products or tissue & vertical transmission
 c: Undetermined refers to those cases who could not be interviewed regarding exposure or whose exposure could not be established
 d: HPC = High Prevalence Country; countries where the adult HIV prevalence is greater than 1%
 e: p-value for chi-square comparisons of Australian born and total overseas born columns.

Figure 1: Proportion of all women living with diagnosed HIV in Victoria at the 31st December each year, by place of birth.



born women was observed among WLHIV between 1994 and 2016. This is indicative of immigration contributing to the population of WLHIV in Victoria. As the proportion of non-Australian-born WLHIV in Victoria continues to increase, culturally appropriate services that encourage women to engage with health services and receive appropriate treatment will become increasingly important for Victoria to meet the 95:95:95 targets in all its priority populations.

Migrant women face additional barriers to HIV testing, such as navigating a foreign health system, language difficulties and

restricted healthcare eligibility, which result in higher rates of late HIV diagnosis among migrant women living in high-income countries.^{24,25} Even when risk is acknowledged or illness identified, women's social and cultural roles within a family have been recognised as barriers to accessing health care, delaying HIV treatment even further.²⁶ This is especially true for women from culturally and linguistically diverse backgrounds. The impact of gender inequality on women's lives and health outcomes has been widely acknowledged globally, and in relation to living with HIV in Australia,

specifically.^{27,28} To improve outcomes for women diagnosed with HIV in Victoria, all are actively followed up by public health officers at the Victorian DHHS to ensure they are linked into care; however, data from this program were not available. A Victorian study aiming to understand retention and loss to follow-up in HIV care estimated that between 91% and 99% of Victorians diagnosed with HIV were retained in care.²⁹ These results were not available by gender, however, and included HIV clinical care sites that were all based in metropolitan areas of Victoria, while 16% of WLHIV live in regional Victoria. Data from Victorian laboratory sentinel surveillance estimated that 87% of WLHIV receiving an HIV viral load test had an undetectable viral load in 2014. This is below the 95% target for viral suppression but, encouragingly, a significant trend was observed with an increase in the proportion of women with an undetectable viral load from 72% in 2009 to 87% in 2014.³⁰

The Victorian DHHS funds Positive Women Victoria, the only Australian program dedicated to WLHIV. Positive Women provides one-on-one peer support, workshops for newly diagnosed women, retreats and peer support training programs. In line with the Victorian HIV strategy, resources have been dedicated to establishing an HIV peer navigator program for all people newly diagnosed, including women.³¹ Such programs are somewhat challenged by the diversity of WLWH in Victoria, who come from more than 65 countries and speak a wide variety of languages. The diversity and potentially limited knowledge of the healthcare system among recent arrivals make the development of inclusive and accessible support services important.^{32,33} In Victoria, 16% of WLHIV live in regional areas, adding to the challenges for HIV support services. However, reaching this small number of women spread over the state is essential, given their reduced visibility and possibly increased isolation and need for support. Unlike services and social engagement networks created by MSM,^{34,35} the lack of an overarching community to unite women means they are more likely to be isolated from services and other people living with HIV. Access to peer support relies heavily on the availability of the previously discussed women-centred programming from community-based organisations.^{7,36} As the proportion of overseas-born women living with HIV in Victoria continues to increase, culturally appropriate services

that are available to women living in urban and regional areas will become increasingly important.

A key strength of this study is the comprehensiveness and completeness of data on all women diagnosed with HIV in Victoria in the past 23 years. This is the first time these data have been published. Women diagnosed with HIV in Victoria are broadly similar to women diagnosed with HIV Australia-wide,¹ making the findings reported here generalisable to other Australian states. Australian jurisdictions with higher or lower proportions of Aboriginal and Torres Strait Islander women or women born overseas may observe different trends. A limitation of the data used is that HIV notification forms are clinician completed and it is possible that some data may be assumed by the clinician or not accurately represent a women's risk or testing history. Additionally, data were also recorded at the time of diagnosis and information on postcode of residence and language spoken at home may have changed. Finally, the number of diagnosed WLHIV may be overestimated, as information about people's movement out of Victoria and deaths outside of Victoria cannot be ascertained.

Conclusions

Data presented here are the first to detail the epidemiology of HIV among women in Victoria and form a base from which to monitor women as a newly prioritised population in the Victorian HIV strategy. The findings highlight the need for tailored interventions for women to improve timely diagnosis of HIV and address the barriers to testing and provision of culturally appropriate care and support services for the diverse WLHIV in Victoria.

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Table 2: Characteristics of women living with HIV in Victoria as at 31st December 2016, by place of birth.

	Australian born		Overseas born						p ^c	TOTAL	
			From HPC		From non-HPC		Total overseas born				
	n	%	n	%	n	%	n	%		n	%
Region of birth											
Australia	194	100	-	-	-	-	0	0.0	194	31.7	
Sub-Saharan Africa	-	-	192	75.3	0	0.0	192	47.8	192	31.3	
Asia	-	-	43	16.9	87	60.4	130	32.3	130	21.2	
North Africa and the Middle East	-	-	20	7.8	5	3.5	25	6.2	25	4.1	
Europe, UK and Ireland	-	-	0	0.0	30	20.8	30	7.5	30	4.9	
Oceania	-	-	0	0.0	17	11.8	17	4.2	17	2.8	
Americas	-	-	0	0.0	5	3.5	5	1.2	5	0.8	
Unknown	-	-	0	0.0	0	0.0	3 [^]	0.8	-	20	3.3
Language spoken at home											
English	174	89.7	92	36.1	52	36.1	145	36.1	325	53.0	
Other	3	1.6	116	45.5	77	53.5	195	48.5	202	32.9	
Unknown	17	8.8	47	18.4	15	10.4	62	15.4	<0.01	86	14.0
Reported place of acquisition											
Overseas	31	16.0	199	78.0	80	55.6	281	69.9	318	51.9	
Australia	141	72.7	25	9.8	44	30.6	69	17.2	216	35.2	
Unknown	22	11.3	31	12.2	20	13.9	52	12.9	<0.01	79	12.9
Region of residence											
Metropolitan	147	75.8	205	80.4	124	86.1	331	82.3	493	80.4	
Regional/rural	39	20.1	39	15.3	16	11.1	56	13.9	95	15.5	
Unknown	8	4.1	11	4.3	4	2.8	15	3.7	0.05	25	4.1
Time in Australia since diagnosis (years)											
0-5	-	-	176	69.0	69	47.9	246	61.2	247	40.3	
5-10	-	-	30	11.8	10	6.9	40	10.0	41	6.7	
10+	-	-	16	6.3	26	18.1	42	10.5	43	7.0	
Unknown	-	-	33	12.9	39	27.1	74	18.4	88	14.4	
Not applicable	194	100.0	-	-	-	-	0	0.0	-	194	31.6
Reported exposure											
Person is from a HPC ^a	0	0.0	255	100.0	0	0.0	241	59.9	245	40.0	
Injecting drug user	19	9.8	0	0.0	5	3.5	5	1.2	25	4.1	
Sexual exposure	164	84.5	0	0.0	125	86.8	116	28.9	289	47.1	
Other	9	4.6	0	0.0	7	4.9	24	6.0	33	5.4	
Undetermined ^b	2	1.0	0	0.0	7	4.9	16	4.0	<0.01	21	3.4
Total	194	100	255	100	144	100	402	100	-	613	100

Notes:

a: HPC = High Prevalence Country; countries where the adult HIV prevalence is greater than 1%

b: Undetermined refers to those cases who could not be interviewed regarding exposure or whose exposure could not be established

c: p-value for chi-square comparisons of Australian born and total overseas born columns

[^] Includes one country of birth recorded as "overseas" and two recorded as "Africa".

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