Improved capture of trans and gender-diverse people diagnosed with HIV infection in Victoria following refinement to notification form

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Introduction

In Australia, as in many other parts of the world, little is known about HIV prevalence and acquisition risk among trans and gender-diverse (TGD) people. Limited international data suggest that the HIV prevalence among trans women is up to 49 times greater than in the general population [1], while data for trans men and non-binary/gender fluid people are almost completely lacking [2].

TGD people have a gender identity different from the sex assigned at birth. *Transgender* is commonly self-perceived as a gender experience, rather than an identity, with many TGD people recognizing their gender as male/female/non-binary/other specific gender identity, not transgender. Surveys that provide gender options "male/female/transgender" are therefore unlikely to reliably identify people with a TGD experience. To overcome this, international guidelines recommend collecting gender as a two-part question; sex assigned at birth and current gender identity [3,4].

Methods

HIV diagnoses are required to be notified to each jurisdiction's Department of Health, with an enhanced surveillance form completed by the diagnosing physician [5]. To improve recording of gender, the Victorian HIV notification form was reviewed and updated in February 2017; the

Correspondence: Dr Kathleen E. Ryan, Burnet Institute, 85 Commercial Road, Melbourne, Vic. 3004, Australia. Tel: +613 8506 2311; fax: +613 9282 2100; e-mail: kathleen.ryan@burnet.edu.au single question "What is the patient's sex?" was replaced with a two-part question: What was the case's sex at birth?" and "What is the case's gender?" (Table 1). We report Victorian HIV notification data before (January 2009 to January 2017) and after (February 2017 to December 2018) the change, describing notified cases of HIV infection among TGD people and their exposure to HIV.

HIV surveillance data are routinely collected and reported for public health purposes under Victoria's Public Health Act and research ethics approval was therefore not required for this study. This article was approved by the Victorian Department of Health and Human Services.

Results

Of the 2560 people diagnosed with HIV infection in Victoria between January 2009 and January 2017, four (0.2%) were recorded as "transgender". Of the 511 people diagnosed with HIV infection in Victoria between February 2017 and December 2018, nine (1.8%) were recorded as TGD. While no additional information was previously available to disaggregate the gender identity of HIV-infected patients, the two-part question identified two (0.5%) trans men (both reported trans male gender) and seven (1.4%) trans women (five reported gender as trans female gender and two reported female gender with male sex at birth) (Table 1). Exposure to HIV among the nine TGD people was: sex with men who have sex with men (MSM) (n = 4), sex with MSM and injecting drug use (IDU) (n = 2), sex with MSM/IDU and IDU (n = 1), IDU (n = 1), and unspecified (n = 1).

Discussion

TGD people diagnosed with HIV infection in this study reported engaging in both sexual and drug-related risk behaviours, highlighting the need to actively encourage

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[[]Correction added on 28 November 2020, after first online publication: The copyright line was changed.]

 Table 1
 HIV notification form questions and reported gender and sex at birth before (January 2009 to January 2017) and after (February 2017 to December 2018) changes to data collection

	Old Version (January 2009– January 2017)	New version (February 2016– December 2018)
Question format	What is the patient's sex?	What was the case's sex at birth?
	Female	Female
	Transgender	Other (e.g. intersex), specify below
		What is the case's gende Male
		Female
		Trans male/man
		Trans female/women
		Indigenous brotherboy
		Indigenous sistergirl
		Non-binary/gender fluid Other, specify below
Gender of new HIV diagnoses		
Cis male	2329 (91.0)	445 (87.1)
Cis female	227 (8.9)	57 (11.2)
Trans male*	0 (0.0)	2 (0.5)
Trans female [†]	0 (0.0)	7 (1.4)
Indigenous brotherboy	0 (0.0)	0 (0.0)
Indigenous sistergirl	0 (0.0)	0 (0.0)
Non-binary/gender fluid	0 (0.0)	0 (0.0)
Transgender, not specified	4 (0.2)	0 (0.0)

*includes notifications that reported trans male gender identity and male gender identity/female sex at birth.

[†]includes notifications that reported trans female gender identity and female gender identity/male sex at birth.

regular HIV testing in this group. Local HIV services have historically targeted gay and bisexual men, creating access barriers for TGD people (particularly trans women). Our findings suggest that service changes are needed to address the specific sexual health needs of this group. General practitioners can help guide targeted testing by accurately capturing patients' gender identity and TGD experience and performing appropriate HIV and sexually transmissible infection (STI) risk assessment. System refinements and training of medical staff in gender diversity are needed to improve capture and risk assessment of TGD people at the clinic level.

Broader refinement to data collection and reporting is needed to overcome the gaps in knowledge and evidencebased services for TGD people. A two-part question should be adopted across all jurisdictions' HIV and STI notification forms. Longitudinal reporting of HIV and STIs among TGD people is needed to identify trends (and determine if this increase is an artefact of improved methodology or a true increase in HIV infection in this group) and prevention needs. This change to the Victorian HIV notification form improved reporting of TGD people diagnosed with HIV infection in Victoria. Victoria is the first state to collect data on the gender identity of TGD people diagnosed with HIV infection. Consideration should be given to replicating this change across Australia to develop reliable estimates of HIV prevalence among TGD people and encourage routine HIV and STI screening among TGD people reporting HIV risk.

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