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 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
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 evidence-based 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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References

1 Baral SD, Poteat T, Strömdahl S, Wirtz AL, Guadamuz TE, Beyrer C. Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. Lancet Infect Dis 2013; 13: 214–222.
2 Poteat T, Scheim A, Xavier J, Reisner S, Baral S. Global Epidemiology of HIV Infection and Related Syndemics Affecting Transgender People. JAIDS J Acquir Immune Defic Syndr. 2016; 72: S210–S219.
3 Bauer GR, Braimoh J, Scheim AI, Dharma C. Transgender-inclusive measures of sex/gender for population surveys: Mixed-methods evaluation and recommendations. Dalby AR, editor. PloS One. 2017; 12: e0178043.
4 Peer advocacy network for the sexual health of trans masculinities. PASH.tm Position Statement Data Collection [Internet]. 2017 [cited 2018 Jan 30]. Available from: http://www.grunt.org.au/wp-content/uploads/PASH.tm-Data-Collection_Nov_2017.pdf.
5 Victorian Department of Health. Confidential Notification of HIV infection [Internet]. 2017 [cited 2017 Dec 15]. p. 1–4. Available from: https://www2.health.vic.gov.au/about/publications/formsandtemplates/notification-of-hiv-infection.