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## DISCUSSION PAPER:

Effective and Meaningful Inclusion of Trans  
and Gender Diverse People in HIV Prevention

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## **ABOUT ACON**

ACON is New South Wales' leading health promotion organisation specialising in HIV prevention, HIV support and lesbian, gay, bisexual, transgender and intersex (LGBTI) health. Established in 1985 as the AIDS Council of NSW, our mission is to enhance the health and wellbeing of our communities by ending HIV transmission among gay and homosexually active men, and promoting the lifelong health of LGBTI people and people with HIV.

## **ABOUT PASH.TM**

The Peer Advocacy Network for the Sexual Health of Trans Masculinities (PASH.tm) is an autonomous Australian working group committed to addressing the sexual health needs of gay, bisexual and queer trans men and other trans masculine people assigned female at birth (trans men who have sex with other men – trans MSM). Established in 2014, PASH.tm has presented workshops at major national HIV and STI conferences, presented to HIV and STI action groups and networks, released position papers on PrEP and on data collection, submitted recommendations for the NSW PrEP access guidelines; the review of the NSW Public Health Act; and the PBS listing of Truvada™ as PrEP, and have produced GRUNT, a national sexual health campaign for trans MSM, their sexual partners and clinicians.

## **ABOUT THE GENDER CENTRE**

The Gender Centre is committed to developing and providing services and activities, which enhance the ability of people with gender issues to make informed choices. We offer a wide range of services to people with gender issues, their partners, family members and friends in New South Wales. We are an accommodation service and also act as an education, support, training and referral resource centre to other organisations and service providers. The Gender Centre is committed to educating the public and service providers about the needs of people with gender issues. We specifically aim to provide a high quality service, which acknowledges human rights and ensures respect and confidentiality.

We acknowledge that this discussion paper has been prepared on Aboriginal land, the sovereignty of which was never ceded. The historical and continuing struggle of Aboriginal and Torres Strait Islander people for sovereignty and self-determination remains unfinished. This paper and the work that we do is possible because we are the continuing beneficiaries of invasion and settler colonialism. This comes with responsibility.

We acknowledge the Gadigal people of the Eora Nation as the custodians of the land on which this paper was drafted, and Aboriginal and Torres Strait Islander peoples across Australia, as custodians of the land on which we continue to hold community conversations, find collaborations and make progress on trans and gender diverse health. In particular, we acknowledge elders past, present and future, and Brotherboys, Sistergirls and other Indigenous LGBTIQ people for their support and guidance in our work. Always was, always will be, Aboriginal land.



Crystal Love, photo by Rhett Hammerton

This paper would not have been possible without the rich contributions of trans and gender diverse people who have generously offered their insights, expertise and lived experience to guide its direction and content. A challenge in coordinating this paper has been that this work remains both crucial and yet unfunded.

The lack of adequate resourcing for peer-led trans and gender diverse programs and representative bodies, in particular for trans women, means we do not always have the necessary consultation processes in place to ensure meaningful inclusion of a broad range of trans and gender diverse voices. There is an ongoing need to develop sustainable, equitable and funded avenues to ensure that trans and gender diverse people are not only meaningfully engaged but are driving policies, research and decision-making that affects their lives.

Oftentimes, HIV research and policy includes blanket statements that all trans or gender diverse people are at significant risk of acquiring HIV. However we know that there is nothing inherent about being trans or gender diverse that puts people at risk. This paper presents a step towards unpacking and looking deeper into the evidence so we can better understand how trans and gender diverse people are affected by and interact with various risks factors, and to consider which sub-sections of these populations are at higher risk and therefore require tailored and targeted programs.

More broadly, the way we situate trans experiences within a health framework continues to shift and evolve. The challenge for our sector remains how we recognise trans and gender diverse communities as priority populations for health policy and programming without reproducing pathological or medical models, and instead employ frameworks that harness the agency, resilience, and knowledge of trans and gender diverse communities. We continue to navigate this space.

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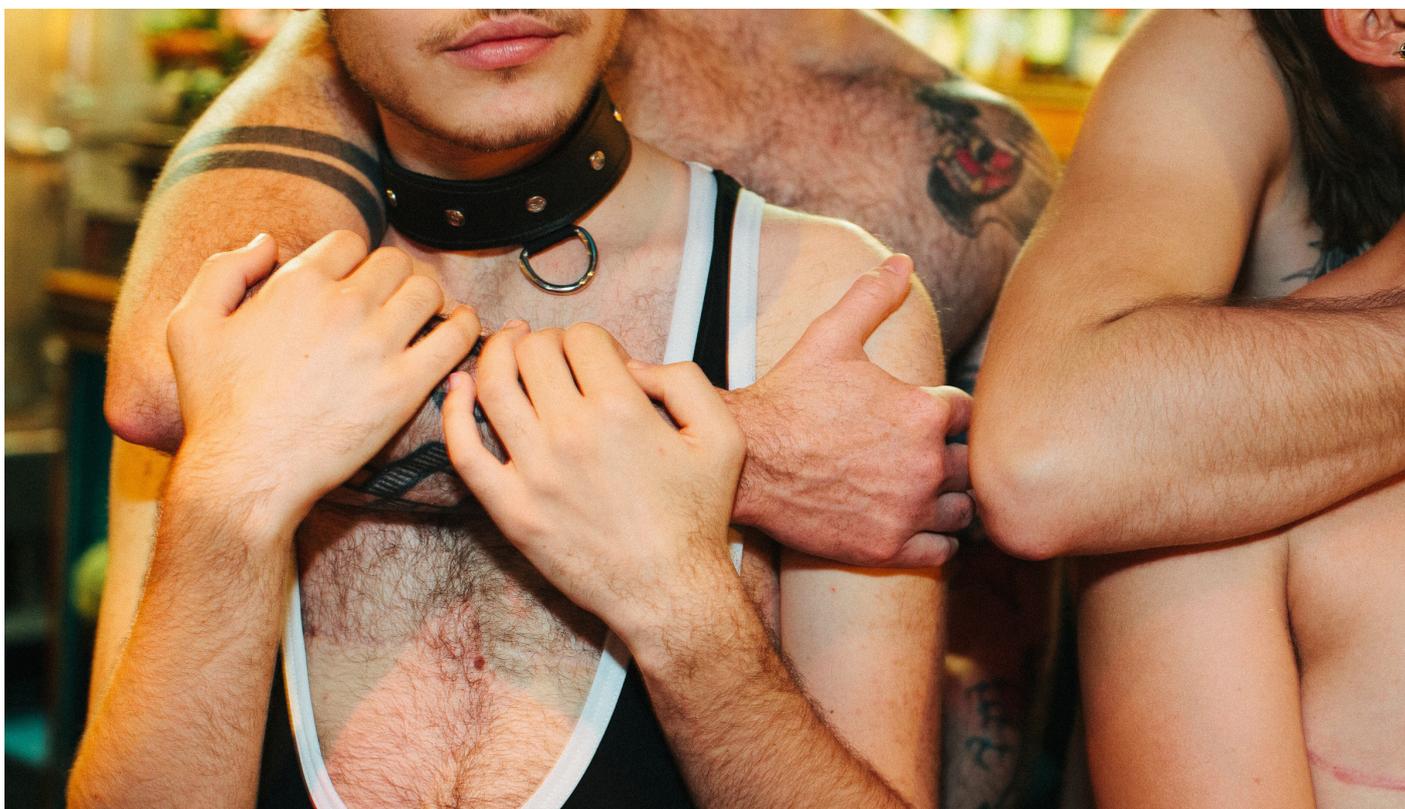


Photo by Morgan Carpenter. Courtesy of PASH.tm

## DEFINITIONS

**TRANS AND GENDER DIVERSE:** These are umbrella terms that describe people who identify their gender as different to what was assigned to them at birth. Some trans people position 'being trans' as a history or experience, rather than an identity, and consider their gender identity as simply being female, male or a non-binary identity. Some connect strongly with their trans experience. The processes of transition may or may not be part of a trans or gender diverse person's life.

Terms such as 'cross dresser' and 'transvestite' aren't typically used by trans and gender diverse people to describe their gender experience.

**NON-BINARY:** This is an umbrella term for any number of gender identities that sit within, outside of, across or between the spectrum of the male and female binary. A non-binary person might identify as gender fluid, trans masculine, trans feminine, agender, bigender etc.

**TRANSITION/GENDER AFFIRMING:** The personal process or processes a trans or gender diverse person determines is right for them in order to live as their defined gender identity and so that society recognises this. Transition may involve social, medical/surgical and/or legal steps that affirm a person's gender.

**CISGENDER:** A term used to describe people who identify their gender as the same as what was assigned to them at birth (male or female). 'Cis' is a Latin term meaning 'on the same side as'.

**GENDER EXPERIENCES:** Trans, transgender, gender diverse, cis and cisgender are all experiences of gender and are distinct from male, female and non-binary gender identities.

**AFAB/DFAB:** Assigned female at birth/Designated female at birth.

**AMAB/DMAB:** Assigned male at birth/Designated male at birth.

**GENDER DYSPHORIA:** The distress or unease sometimes experienced from being misgendered and/or when someone's gender identity and body personally don't feel connected or congruent.

Gender dysphoria does not = being trans or gender diverse, many trans and gender diverse people do not experience gender dysphoria and if they do, it may cease with access to gender affirming healthcare (if medical transition is desired). The trans and gender diverse experience is not a mental illness.

**LEGAL SEX:** The marker or classification recorded when a child's birth is registered. In NSW, this is either M or F. This marker can be amended to either M, F or X.

**SEX CHARACTERISTICS:** Physical parts of the body that are related to body development/regulation and reproductive systems. Primary sex characteristics are gonads, chromosomes, genitals and hormones. Secondary sex characteristics emerge at puberty and can include the development of breast tissue, voice pitch, facial and pubic hair etc.

'Sex characteristics' is more accurate than 'biological sex', 'biologically male' or 'biologically female'. Body parts do not have genders.

**CISGENDERISM/CISSEXISM:** A view that the trans experience doesn't exist or is something to be pathologised. That gender identity is determined at birth and is fixed based on sex characteristics (or 'biology') and that only binary (male and female) identities are valid and real.



Chrissy Doyle, photo by Myth Photography (@myth\_photography)

## INTRODUCTION

*'Despite the magnitude of the challenges they face, trans communities around the world are building alliances to promote trans health, fighting to end the violence and invisibility that erase trans lives, and organizing for policies that respect gender diversity and the full human rights of trans people.'*

(Open Society Foundation, 2013, 4)

Trans and gender diverse populations are being increasingly recognised by international bodies as a key priority population in the global HIV response. Trans and gender diverse (TGD) people are a key population in the UNAIDS HIV elimination framework (UNAIDS, 2016-2021 Strategy, 56). TGD people are now recognised by the World Health Organisation as a key population that has been 'neglected in the global HIV response,' whereby 'HIV vulnerability among transgender people is embedded in the structural contexts of stigma and discrimination in employment, education, housing and health care' (WHO, 2015:24).

The 2015 WHO Policy Brief on Transgender People and HIV found that 'Worldwide, transgender women bear an extraordinarily heavy burden of HIV' and 'HIV prevalence among transgender men appears to be low, but further research may be needed in order to determine the risk, particularly among transgender men who have sex with men' (WHO, 2015, 24). Systematic review and analysis shows a prevalence of HIV in transgender women of 19%, compared with 13% among men who have sex with men (MSM) globally (Baral et al., 2013). This review found that trans women were 49 times more likely than the broader population to be living with HIV.

There is very little empirical data on the experiences and needs of non-binary people in relation to HIV. Inaccurate data collection of gender markers means that non-binary people are often not identified in the dataset, which compounds this invisibility. Reisner and Murchison recommend that researchers 'account for a range of gender identities' in their methods (2016, Recommendation 4).

Health promotion responses to infectious diseases are built from a foundation of epidemiology. However, in Australia, surveillance systems developed to inform the public health apparatus and community responses, have failed to accurately capture HIV prevalence among TGD populations. This can be attributed to simply asking inadequate gender-related questions in HIV diagnosis and notification processes.

Trans and gender diverse experiences, histories and identities therefore necessitate administrative changes to the existing process of data collection and knowledge management. Data collection and management processes need to be more accurate and reflective: indeed, they queer these systems and call for a more nuanced approach, informed by evidence and through consultation with affected communities, to improve the validity of the data.

The changing landscape of the HIV sector and biomedical prevention presents opportunities to revitalise the HIV response. An unwillingness to adapt to the experiences and needs of TGD populations, concerns about software or bureaucratic limitations and a lack of political will for inclusion have presented barriers to meaningful inclusion. These concerns are beginning to shift to reflect an emerging environment of considered and pragmatic approaches to inclusion, however more work is needed and urgently so. The HIV sector must continue to grow and change if we are to achieve the very ambitious goal of ending HIV by 2020.

Successful initiatives within community and primary health care settings confirm that it is not only possible to collect accurate and meaningful data that effectively captures this population's sexual practices and healthcare needs, but that appropriate and meaningful inclusion both improves epidemiological rigour and uncovers previously hidden but significant populations of trans and gender diverse people (Grant et al., 2016).

Trans and gender diverse people also face specific and unique HIV risks, including the physical effects of hormones on their susceptibility to HIV, risk of sexual assault, criminalisation, and transphobia, which can contribute to social and economic disadvantage and affecting people's capacity to negotiate safer sex practices. Transphobic attitudes and practices in health care settings mean that TGD populations face barriers to safe, appropriate and relevant care. This manifests as stigma and discrimination, invisibility in health promotion campaigns around safer sex or risk reduction, poverty, mental health issues, risk taking and a lack of targeted peer education. These barriers mean that TGD people can experience poorer health outcomes that may increase HIV risk.

A sophisticated approach to health promotion and intervention involves not merely including key populations, but engaging, consulting with and resourcing peer-led and peer-driven responses. This joint paper is a collaborative effort between ACON, PASH.tm and The Gender Centre in consultation with our relevant stakeholders.

At the time of writing, no funded national or NSW peak peer body existed to represent trans and gender diverse communities. All of PASH.tm's work is volunteer and unfunded. In particular, there was no national or NSW body representing the experiences and needs of trans women in relation to HIV. This remains a gap. Instead, we consulted with organisations such as Scarlet Alliance and the Sex Workers Outreach Project who had either a trans position, trans representatives, trans working groups or who conducted outreach among trans and gender diverse people. This process was limited by the fact that trans and gender diverse people largely contributed in an unfunded and volunteer capacity, and there remains a need to establish consultative mechanisms such as peer advisory groups or steering committees which compensate

community members for their time and expertise. We also needed to allocate more time for consultation than originally anticipated, and this process provided a reminder of the importance of giving adequate notice to allow trans and gender diverse people to participate if organisations are seeking meaningful engagement.

From the earliest days of the HIV epidemic, affected communities have been at the forefront of the HIV response in Australia. Trans women in particular have been pioneers in the global HIV response with some of the most organised advocacy internationally. This work could not continue without the vital work of trans women.

This paper discusses the available evidence and makes a number of policy recommendations to strengthen the HIV response for trans and gender diverse people in NSW. We call to amend the HIV surveillance system and to reform the legal, social and funding environments that affect access to HIV prevention, treatment and care. We recommend the establishment of national clinical guidelines on trans-inclusive care and that trans and gender diverse people be recognised as a population at high risk, with unique needs, in the NSW HIV Strategy and Australia's National HIV Strategy.



Jacqueline, photo by Myth Photography (@myth\_photography)

## METHODOLOGICAL PROBLEMS IN RESEARCH AND CLINICAL DATA COLLECTION

*“The rate of HIV infection among trans people is higher than other most-at-risk groups, such as [cisgender] men who have sex with men, people who inject drugs, and sex workers, yet most tracking systems do not record data on trans people systematically.”*

amfAR, 2014

In order to effectively understand and respond to the health experience and needs of TGD people, properly worded and meaningful sexuality and gender indicators must be utilised across routinely collected clinical data, in research and all other key health related data sets. Clinical data, surveillance systems and social research have poorly captured the gender experience of people at risk of or newly diagnosed with HIV. The poor definitions, including in patient intake and notification forms, make TGD people invisible and perpetuate the health disparities observed in these communities.

Documents that require clinicians to tick a box as either male, female or transgender present many problems. Catch-all ‘transgender’ categories assume that the experiences of trans women, trans men and non-binary people are homogenous and are so distinct from cisgender women and men that they can be aggregated. The methodology positions ‘transgender’ as a gender identity in and of itself and conflates non-binary trans experiences.

Trans men are men, and trans women are women, and all trans people have different lived experiences and identities (PASH.tm, tm4m and Trans Men’s Working Group). This sets up a system of selective or contingent disclosure where a trans or gender diverse person is being diagnosed with HIV.

By invisibilising this population, and without accurate data on how many trans women, trans men and non-binary people are being diagnosed with HIV, prevention, treatment and support resources cannot be properly allocated or prioritised. The HIV notification process in most states and territories of Australia has significant limitations and currently lacks capacity to collect accurate data on the route of transmission of newly diagnosed people.

The NSW HIV notification form currently requires physicians to indicate whether a patient’s sexual exposure history to HIV has been with a person or people of the ‘same sex’, ‘both sexes’, ‘opposite sex’, ‘not known’ or ‘no sexual contact’ (Q17). Further, Q19 captures sexual transmission as ‘heterosexual sex’ when it really seeks to know if someone has engaged in sex with someone from a priority population.

This methodology (referring to binary gender and sexual orientation) is cis-centric and erases non-binary people, limiting a robust understanding of sexual practice and risk. HIV notification forms need to be concerned with accurately reflecting the diversity of bodies, genders and sexual practices in order to elicit more meaningful information about the route of transmission.

The Victorian Government has recently updated its HIV notification form based on PASH.tm’s position statement, following advocacy from VAC and the Burnet Institute. Updating the NSW HIV notification form to include recommended sexuality and gender indicators would provide concrete steps towards meaningful data collection for these populations.

Historically, HIV research has used a working definition of gay men and other MSM that excludes trans MSM while including trans women who have sex with men. Trans women are predominantly included in research either within projects on sex work (largely due to the advocacy work trans women do in that sector) or under the MSM umbrella. It is crucial that we separate trans women from the MSM response, particularly as many trans women identify as heterosexual or have sex with heterosexual men. Emerging research from the US suggests that a majority of trans women actually identify as lesbians – in the US Transgender Discrimination Survey, over 50% of trans women identified as lesbian or gay (Grant et al., 2011) – and so their specific risks are different. While some trans women have sex with gay men and MSM, and sexual relationships that were established prior to transition can continue, trans women have specific health needs and experiences that are different to MSM.

## APPROPRIATE GENDER AND SEXUALITY INDICATORS IN DATA COLLECTION

*In order to effectively understand the health needs of LGBTI people, properly worded gender indicators must be utilised across routinely collected clinical data, research data sets and other key health related data sets. The exclusion of these questions makes LGBTI people invisible and perpetuates the health disparities observed in our communities.*

[ACON]

The opportunity in data collection is to accurately include trans women within research on at-risk women, and include trans men within HIV research on gay men and other men who have sex with men, whilst still recognising that people with trans experiences also have unique needs that differ to cisgender people. It is also to recognise that non-binary people are not a homogenous group and to create systems that allow people to disclose their gender identity, experience and history in a non-stigmatising environment. Separating out identity, experience or history from 'orientation' allows the recognition that TGD people have sex with people of all genders and sexualities, including with cisgender gay men and lesbian women. For many people, trans and cis, their gender is quite a simple construct to make sense of, for others their gender is a shifting experience of complexity. Many people with a trans experience do not identify as 'trans' at all, but simply as male or female. For others, their trans identity is of profound importance. We must build a system that can understand layered, overlapping and fluid genders, sexual practices and behaviours. Identities may be fluid, and gender history/experience can be myriad.

In recent years, survey researchers have developed more nuanced approaches to gender data collection. In order to accurately capture a person's history of gender, sexuality and intersex status, ACON has recommended a two-step system in which participants are asked for both about their current gender identity and their assigned sex at birth.

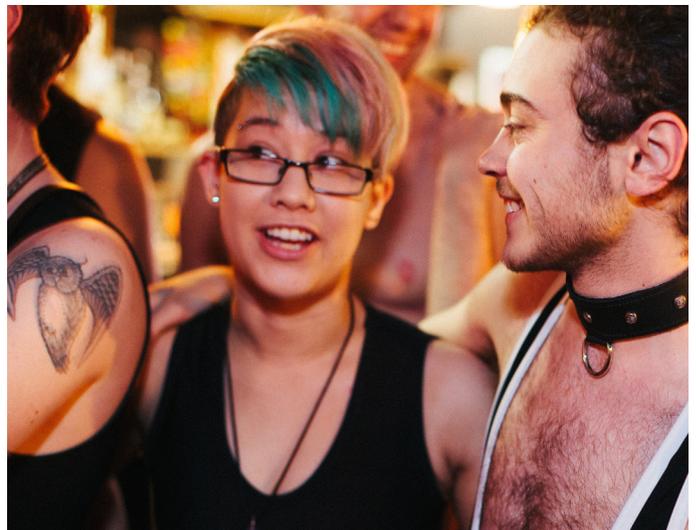


Photo by Morgan Carpenter. Courtesy of PASH.tm

Furthermore, trans men have been widely excluded from HIV-related clinical and social research projects through poor design or invisibility. Research questions that ask gay men and other MSM if they are 'men' or 'trans men', as seen in Australian social research, is unlikely to gain buy-in from trans men because it suggests that trans men are not men. Clinical guidance that situates sexual transmission of HIV between men as only possible through anal sex with a penis further marginalises trans men who do not engage in anal sex with other men but prefer front hole (vaginal) penetration.

There is now a contemporary definition of "men who have sex with men" that includes transgender men who have sex with men (UNFPA et al., 2015). The researchers in the iPreX study write that 'including trans women in studies is helpful only if their participation is specifically reported' (Grant et al., 2016). Research and practice guidelines that present as 'MSM and Transgender People' erases trans MSM and situates all trans women as high risk when this is simply not true. It is important to think carefully about who is included and ensure the evidence base is developed appropriately and accurately to support this.

A considered and meaningful approach to trans and gender diverse inclusion ensures a more accurate and robust understanding and response to HIV. Poor data collection in addition to a lack of adequate data reporting (disaggregated by gender) further prevents identifying the needs of TGD communities, prevents monitoring people's uptake of services and prevents understanding behavioural trends, and subsequently the ability for services to deliver useful tailored and specific health promotion and care for this population. There remains a paucity of research that is useful to advancing the rights and structural changes for TGD people in Australia. Being counted matters.

For example, the following template (figure 1.0) is recommended by ACON as a minimum standard in research data collection:

In a clinical or service intake process, it is helpful to consider the following:

1. Who are you collecting the data from (patients, clients, employees, others)?
2. Why are you collecting the data? Is it relevant?
3. How will the information be stored, accessed and used? Who will have access to this data and to what extent will the data collected be identifiable?
4. What platform do you use to collect the data and does it have any limitations?

In a clinical setting, collecting data on gender identity and sex assigned at birth should be used for reporting purposes and to ensure inclusive care is delivered. While it can be useful for a clinician to understand a patient’s gender experience, they should not make assumptions about patient’s bodies, surgical interventions or experiences of risk. Some men, women and non-binary people, especially those who have had genital reconstruction surgery (e.g. vaginoplasty for women or metoidioplasty or phalloplasty for men), may not feel comfortable or that it is even necessary to disclose their sex assigned at birth. Genital swabs should not be required in cases where urine tests are sufficient for STI testing.

A study by the Burnet Institute in Melbourne analysed data on self-reported gender of clients testing for HIV at a community service PRONTO! and found that including this two-part question captured clients who had previously tested at the service whose TGD experience had been missed in each case. The study found that the two-step question produced ‘more reliable gender data’ and that ‘simple changes to data collection based on community consultation can have a significant impact on the utility of surveillance data to guide HIV/STI prevention & care for TGD people’ (Ryan et al., 2017).

Similarly, in the iPrEX study, when only binary gender indicators were offered only 1% of the enrolled cohort described their gender as women, however when additional response options were added, a total of 14% reported they were women with a trans experience, women assigned male at birth, men taking feminising hormones or had a non-binary trans feminine identity (Grant et al., 2016).

Explicit recognition of TGD people as a priority population group is required to ensure that the health disparities that exist between our communities and the broader population are addressed. Without the collection of sexuality and gender indicators this becomes nearly impossible.

SEXUAL ORIENTATION	INTERSEX STATUS
Do you consider yourself to be: <input type="checkbox"/> Lesbian, gay or homosexual <input type="checkbox"/> Straight or heterosexual <input type="checkbox"/> Bisexual <input type="checkbox"/> Queer <input type="checkbox"/> Different identity (please state)	Were you born with a variation of sex characteristics? (this is sometimes called ‘intersex’) <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Prefer not to answer
GENDER	
Which of the following best describes your current gender identity? <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Non0binary/gender fluid <input type="checkbox"/> Different identity:	What sex were you assigned at birth (i.e. what was specified on your original birth certificate)? <input type="checkbox"/> Male <input type="checkbox"/> Female

The following template (figure 1.0) is recommended by ACON as a minimum standard in research data collection:

## GLOBAL HIV PREVALENCE

*'The high vulnerability and specific health needs of transgender people necessitates a distinct and independent status in the global HIV response.'*

(World Health Organisation, 2014, xiii)

There remains a lack of HIV prevalence data in most countries. A review of publicly available data by the International Reference Group on Transgender People and HIV/AIDS (IRGT) found that 'data are largely absent across large swaths of the globe'. The majority of research is from the United States and around three-quarters of published studies focus on trans women: 'Where data on trans people do exist their quality is often low, and inconsistent collection practices limit interpretability and utility' (IRGT, 2016).

A 2013 global meta-analysis indicates that 19.1% of trans women worldwide are estimated to be living with HIV (Baral et al., 2013). At risk trans women in the surveys were 49 times more likely to be living with HIV than the general population (Baral et al., 2013). The HIV prevalence was nearly twice as high among trans female sex workers than in trans women not engaging in sex work (Operario, Soma and Underhill, 2008).

However Greta Bauer and Ayden Scheim have noted that 'sampling bias is common in studies of transgender women, in which convenience samples are primarily drawn from urban sites over-representing street-active women, including HIV testing sites' (Bauer & Scheim, 2013). They remind us that such studies cannot be extrapolated to generalise about all trans women and that to do so, although useful for advocacy and inclusion, can also contribute to stigma and stereotyping.

Global prevalence of HIV among trans women is impacted by structural and social determinants including discrimination, violence, criminalisation and poverty.

Trans women and non-binary people assigned male at birth experience intersecting oppressions including cissexism, transphobia and transmisogyny.

A special issue of the Journal of the International AIDS Society, HIV Epidemics Among Transgender Populations: The Importance of a Trans-Inclusive Response (July 2016) states in the editorial that 'transgender people are severely underserved in the global response to HIV. Less than 40% of countries report that their national AIDS strategies address transgender people, despite a growing body of evidence that transgender women, in particular, face a disproportionate and heavy burden of HIV' (Poteat et al., 2016, 1). The authors also recognise the 'heightened HIV vulnerability' among trans MSM and state that 'the stigma, violence and human rights abuses transgender people suffer drive much of their risk for HIV and hinder their access to care' (Poteat et al., 2016, 1).

The International Reference Group on Transgender Women and HIV/AIDS (IRGT) put this elegantly when they said that this 'absence of evidence due to lack of resource allocation and or proper research is usually considered as "evidence of absence", naturalizing the gaps in data collection and analysis' (IRGT 2016). Reisner & Murchison (2016) also provide a comprehensive research synthesis which highlights the paucity of data available about the HIV experience of trans men including risk factors such as who their sexual partners are, the kinds of sex they are having, patterns, numbers and frequency of partnerships, substance use and participation in sex work.

While there have been some more recent studies detailing behavioural interventions among trans men who have sex with cisgender men (Reisner et al., 2016), inequities in access to HIV prevention services (Scheim et al., 2016), and sexual risk among gay, bisexual and queer trans men (Rich et al., 2017; Scheim et al., 2017), the limited data that exists on HIV and sexual health among trans men has mostly very small sample sizes, with no research literature available that looks specifically into the sexual health of non-binary TGD populations (Reisner & Murchison 2016).

The data that exists globally on the HIV experience for trans and gender diverse people remains lacking due to the methodological issues discussed above. Better resourcing of peer advocacy networks for trans women and non-binary people in NSW and Australia are needed so that this community can participate and be more meaningfully engaged.

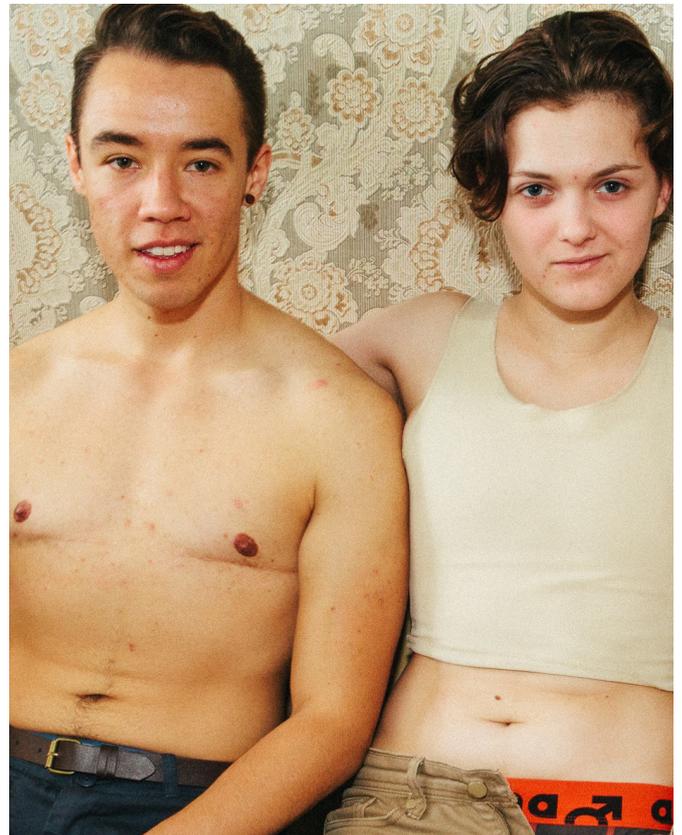


Photo by Morgan Carpenter. Courtesy of PASH.tm

## AUSTRALIAN EXPERIENCE

There is even less data about the Australian experience of HIV for trans and gender diverse people and global statistics do not necessarily translate in Australian contexts, where the HIV response has largely been driven by the affected communities of gay men, sex workers and injecting drug users.

As discussed, in NSW there are no reliable epidemiological data on rates of diagnosis or testing for trans and gender diverse people. Stefan Baral and colleagues' meta-analysis on the global prevalence of HIV among trans women included data drawn from a 2011 retrospective cohort (n=133) from the Taylor Square Private Clinic in Sydney, which showed that trans women had a seroprevalence of 4.5% and were 24.9 times more likely to be living with HIV than the general population. However, it is difficult to draw broader conclusions based on one clinic with a high caseload of patients living with HIV.

In comparison, of the 122 trans women surveyed for the Private Lives 2 study in 2011, 62% of trans women had ever tested and 1.4% were living with HIV (Leonard et al., 2012). These numbers are too small to conduct reliable statistical tests for significance, however the sample provides some interesting insights into the sexual identity of trans women with over 50% of women surveyed reporting being same-gender attracted and 41% reporting being other-gender attracted. Only 18 respondents identified as heterosexual. This challenges the assumption that all trans women have sex with men. This survey, however, was largely promoted through LGBTI community networks, which can have a lower representation of heterosexual trans women and so may have introduced selection bias.

Sexual identity and practice can be fluid across all gender experiences, however, we should challenge any assumption that trans women predominantly have sex with gay men even if some certainly do, just as many cisgender lesbian women also report sex with gay and bisexual men (Mooney-Somers et al., 2014).

The Annual Surveillance Report of HIV, viral hepatitis and STIs for 2014 (Kirby Institute, 2014, Table 1.1.2) shows that since the surveillance system was established, a total of only 88 people diagnosed with HIV in Australia have recorded their sex as 'transgender'.

A 2017 study by the Kirby Institute calculated prevalence estimates of blood borne viruses among trans people attending publicly funded sexual health clinics across the country. This analysis drew upon clinical data extracted via ACCESS (Australian Collaboration for Coordinated Enhanced Sentinel Surveillance). Of the patients recorded as transgender, 192 (28%) were women, 224 (32%) were men and 280 (40%) did not have their gender identity captured. The data indicates that of the 696 patients recorded as transgender, 5.2% of transgender patients were HIV positive.

HIV prevalence among trans women (8.9%) was comparable to cisgender gay and bisexual men while prevalence among trans men (4.5%) was lower than among cisgender gay and bisexual men but almost triple that of cisgender women and heterosexual identified cisgender men. These differences were significant even after controlling for other factors associated with HIV prevalence, namely age, area of residence, Indigenous status and injecting drug use (Callander et al., 2017).

It is likely that these data do not reflect the true number of trans and gender diverse people attending sexual health clinics due to poor recording of trans experience; there is still a lack of specific data relevant to non-binary people. It is also worth noting that sexual health clinics tend to attract people with higher risk of these infections, which means that these estimates may not represent the general population of trans men and women. Further, two sexual health clinics with large caseloads of trans people were not included in this analysis.

The prevalence of HIV among trans women in Australia may also be influenced by HIV prevalence among trans women born in Asia and the Pacific. Data from Taylor Square Private Clinic in 2011 comparing trans men and trans women patients found that 82.3% of trans men patients were Australian born, compared to only 47.2% of trans women patients (Pell, Prone and Vlahakis, 2011).

While we do not have specific Australian data on trans and gender diverse sex workers or drug users, NSW remains one of the few jurisdictions in the world where sex work is decriminalised and there is easier access to NSPs, and the rates of HIV among sex workers and drug users generally are extremely low. The 2016 Kirby Institute Annual Surveillance Report notes that HIV incidence among female sex workers in Australia is the lowest in the world (with no HIV cases detected in the past 2 years) and the HIV prevalence among people who inject drugs remains very low at 1.7% in 2015 (Kirby Institute, 2016). We cannot assume that trans women sex workers have similar rates to cisgender women sex workers partly because we do not know what accurate prevalence among trans women is to begin with. This is especially because among gay and MSM sex workers the prevalence of HIV is similar to the general MSM population. So it is not necessarily that sex work is reducing HIV within these populations but rather that it is not necessarily impacting on HIV prevalence.

Research on trans and gender diverse street-based sex workers in NSW has previously recommended targeted health services for this group (Harcourt et al., 2001). In NSW, the Sex Workers Outreach Project (SWOP) employs a Trans Worker to implement prevention strategies among this population. The Gender Centre also deliver outreach to trans sex workers. The Network of Alcohol and other Drugs Agencies (NADA) practice resource Working with Women Engaged in AOD Treatment includes a chapter on trans women (NADA, 2016, 3.4) and there have been targeted campaigns towards sex workers and Sistergirls run by SWOP and Anwernekenhe.

## HIV RISK FACTORS

*'Sexual risk differs among different subgroups within the transgender community. For example, sexual risk may be higher among transgender women (male to female) or transgender men (female to male) who have receptive anal intercourse with [cisgender] men than among transgender men or transgender women who have sex only with [cisgender] women. The prevalence of HIV among transgender women in many countries is as high as or higher than among men who have sex with men.'*  
(WHO, 2014, xiv).

Most trans and gender diverse people in Australia live happy, healthy, connected lives. But until this is the case for all trans and gender diverse people, HIV continues to affect all of us. It is these trans and gender diverse people living on the margins who experience the gendered violence of transphobia and poorer social determinants of health that are at increased risk of HIV.

There is evidence to suggest that physical changes due to surgical or hormone intervention may uniquely increase risk of infection for trans or gender diverse people. For example, exogenous testosterone can also cause genital dryness for some trans men along with thinning of the internal walls increasing risk of abrasion.

In a recent review of the medical literature, Dr Vincent Cornelisse suggests that 'It is likely that receptive vaginal sex poses a different level of HIV risk for trans women than it does for cis women, as the lining of the neovagina is fundamentally different from that of the natal vagina.' He suggests that the risk is likely to differ depending on whether the vagina is sigmoid-derived or penile skin-derived that the risk is likely to differ depending on whether the vagina is sigmoid-derived or penile skin-derived and that the risk may increase in cases of neovaginitis due to a breakdown in integrity of the vaginal wall (Cornelisse et al., 2017).

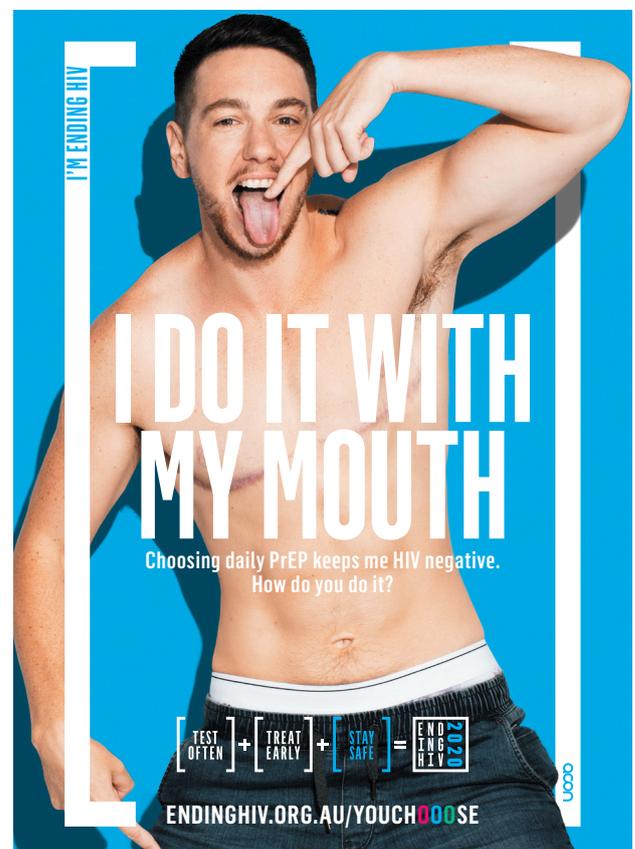
There remains a lack of data on the sexual practices, behaviours, experiences and needs of trans women in Australia and this remains a significant gap in research. International research demonstrates that the fundamental drivers of HIV risk among transgender women include 'stigma and discrimination, lack of social and legal recognition of their affirmed gender, and exclusion from employment and educational opportunities' (Poteat, Reisner and Radix, 2014).

Australian research shows higher risk practices among trans women. A 2017 study from the Kirby Institute (Callander et al., 2017) found that a quarter of transgender patients attending publicly funded sexual health clinics reported recent sex work at least once. Trans women were more likely to report sex work (13%) than other cisgender patient groups (9%). They were also more likely report injecting drug use than gay and bisexual men (7% vs 4%). By contrast, trans men were no more likely than other patient groups to report sex work or injecting drug use (3%). Sex work is not necessarily a

risk practice. However, differences in sex work and drug use practices hint at the different kinds of sexual health-related experiences had by trans men and trans women. More research is needed to fully understand how these practices contribute to infection risk as well as the role they might play as barriers to health and health care for trans and gender diverse people.

The 2016 Australian Red Cross study of ACCESS (Guy et al., 2016) found that a quarter of transgender patients attending publicly funded sexual health clinics reported recent sex work at least once. Trans women were more likely to report sex work (13%) than other cisgender patient groups (9%). They were also more likely than cisgender patients to report injecting drug use (6%). By contrast, trans men were no more likely than other patient groups to report sex work or injecting drug use. While sex work and injecting drug use itself are not risk practices (for example, the act of exchanging sex for money, kind or favours does not make the sex more risky) sex workers and injecting drug users may face stigma, discrimination and other system barriers that affect their access to service provision.

Trans and gender diverse people in custodial settings cannot always access transition related health care, and may be held in institutions that do not correlate with their gender, where they may be subject to violence. Research into trans women's experiences in Australian men's prisons found that incarceration in these settings increase risk factors of HIV including physical and sexual violence (Wilson et al., 2016).



ACON, Ending HIV campaign, 2017.

## LEGAL BARRIERS TO HIV PREVENTION

A review of epidemiological research on HIV in transgender women reported in *The Lancet* recommended that 'substantial reductions in the number of new infections could be accomplished with small changes in risk factors in this population by combination prevention approaches tailored to the setting', such as 'transgender affirming HIV educational material and integration of gender care into HIV care' (Poteat et al., 2015, 274).

In an article examining 'The HIV Risk of Gay Identity' among trans men, Stefan Rowniak and colleagues argue for the need to examine risk factors in sexual behaviours:

In the absence of data, trans men have been considered at low risk of HIV infection. Recent studies challenge this assumption and highlight the dangers of invisibility. While there is limited data on HIV risks for trans men, there are known anecdotal risk factors (Rowniak et al., 2011).

The Sydney Gay Periodic Survey in 2016 included a small number of trans participants (25), although not enough to draw comprehensive conclusions. In the survey, HIV risk profile was similar: 91% cisgender men compared with 87% of transgender men had ever tested for HIV, 71% of cisgender men compared with 74% of transgender men had tested within the last year. 26% of cisgender men reported having condomless anal sex among casual partners, compared with 28% of transgender men (Hull et al., 2016).

A Canadian study, the Trans PULSE Project, estimated that 63.3% of trans men were gay, bisexual and/or had sex with cisgender men. The researchers found that of this group, 14.1% had five or more sexual partners (with a maximum of 53 over the last year), the primary contributor to HIV risk was unprotected receptive sex, 9.2% had engaged in high-risk activity, and 15.8% of trans MSM had engaged in sex work at some point. A high proportion of trans MSM (42.7%) had never been tested for HIV, while 21.0% had been tested in the past year. Researchers also found that 'among the 34% with a past-year cisgender male sex partner, 29% had high sexual risk' (Scheim, Bauer & Travers, 2017).

Addressing these risk factors and developing targeted and tailored interventions involves not only collecting accurate data but also 'elucidating how stigma shapes syndemic factors to produce HIV and other deleterious effects on transgender health' (Poteat et al., 2016).

The WHO recognises that trans and gender diverse people face 'specific legal and social barriers that further increase their vulnerability' (WHO, 2015, 1.1). The health of trans and gender diverse people can be predicated on a history of pathologisation and poor access to gender-affirming care. The inclusion of 'transsexuality' and gender identity 'disorder' (now 'gender dysphoria') as mental 'disorders' in the International Classification of Diseases and the American Psychiatric Association's Diagnostic and Statistical Manual has positioned care of trans people in health settings as 'specialist medicine' and stigmatised trans experiences.

As a result of this pathologisation, medical professionals (including psychiatrists, endocrinologists and surgeons) have been required to play a role of gatekeeper for trans and gender diverse people accessing transition related health care. These systems can require trans and gender diverse people to meet narrow models of gender dysphoria in order to access support and treatment. This history can affect trans and gender diverse people's relationship to their own health and has left a legacy of distrust in the medical profession.

Trans and gender diverse people may be less willing to access health care with identification that does not match their gender, and legal barriers to obtaining affirmed identity documents remain a barrier to healthcare. Trans people rely on authorisation from physicians to amend their own legal sex classification on cardinal identity documents. For example, to change a birth certificate in NSW requires statutory declarations from two physicians, evidence of surgical intervention to a reproductive organ and divorce from an existing marriage.

In Australia there are substantial barriers to accessing transition related surgeries, particularly for people living in regional areas and in many cases due to the absence of appropriately skilled surgeons. Most trans and gender diverse people travel overseas for genital surgeries. Only a hysterectomy deemed 'medically necessary' is covered by Medicare. In addition, it was only in 2014 that a precedent was set permitting the option to change legal sex to 'non-specific' on a NSW birth certificate (NSW Registrar of Births Deaths and Marriages v Norrie, Case S273/2013, High Court of Australia).

The WHO recognise that 'transgender people are legally unrecognized in many countries (5) and face restrictive policies toward their gender expression.' (WHO, 2014, 5.1.1) They recommend that 'Countries should work towards legal recognition for transgender people (11). (WHO, 2014, 5.1.2).

## CULTURAL BARRIERS TO HIV PREVENTION

The experience of being trans or gender diverse is not a new phenomenon and can be seen throughout the course of human history. The Asia Pacific Forum's manual for National Human Rights Institutions on Promoting and Protecting Human Rights in relation to Sexual Orientation, Gender Identity and Sex Characteristics (APF, 2016, 1.4) describes a range of regional-specific terms for trans and gender diverse people. For example, in South Asia, people assigned male at birth who identify as trans or gender diverse include the hijra in India and Bangladesh, thirunangai and aravani in India, khwaja sira in Pakistan and meti in Nepal. In South East Asia, common terms for trans women are kathoey in Thailand, waria in Indonesia, mak nyah in Malaysia and bakla or transpinay in the Philippines.

In Pacific countries, terms often reference feminine gender expression, including among MSM, and also describe a person's gender role within the family. These terms include fa'afafine in Samoa, fakaleiti or leiti in Tonga, fakafifine in Niue, akava'ine in Cook Islands and palopa in Papua New Guinea (APF, 2016, 1.4). In our neighbouring Aotearoa, whakawahine is used by Māori trans women, and in some nations of Australia, Sistergirl and Brotherboy are used by Aboriginal and Torres Strait Islander people.

There is documented evidence and oral history of Sistergirls living in communities pre-dating colonisation. A number of historic and contemporary words in language exist to describe Sistergirls including 'Kwarte Kwarte' in Arrente, 'Kungka Kungka' in Pitjantjatjara and Luritja, 'Yimpininni' in Tiwi, 'Karnta Pia' in Warlpiri which can be interpreted as 'like a girl'. Whilst 'Kungka Wati' in Pintipi and 'Girriji Kati' in Waramungu literally mean 'woman/man' (Riggs and Toone, 2017).

Of particular concern are the small but increasing rates of HIV diagnosis among Aboriginal and Torres Strait Islander people. Research from the Kirby Institute's annual surveillance report on blood borne viral and sexually transmissible infections in Aboriginal and Torres Strait Islander people (Kirby Institute, 2016) indicates that the rate of newly diagnosed HIV infection in the Aboriginal and Torres Strait Islander population in 2015 was more than two times higher than the Australian-born non-Indigenous population. Between 2011 and 2015, there was a 2-fold increase in HIV notifications rates in Aboriginal and Torres Strait Islander males. Over the same period, the rate in the Australian-born non-Indigenous male population decreased by 13%.

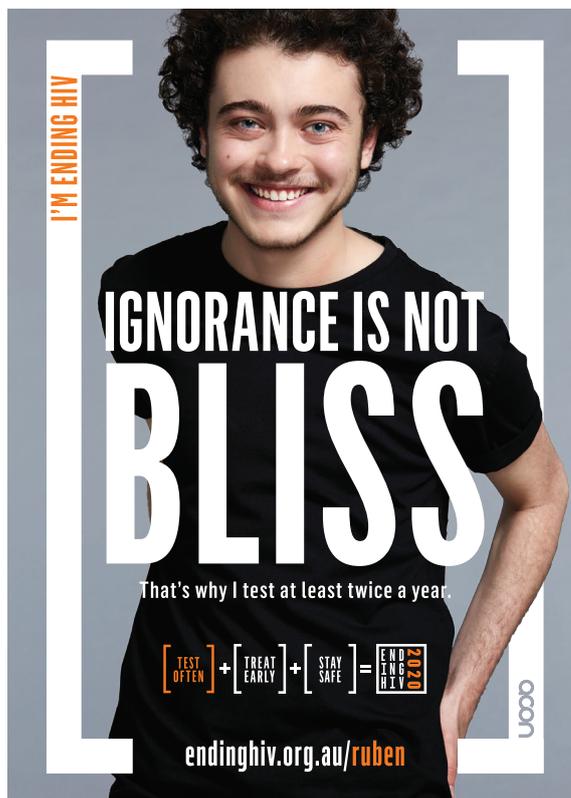
A snapshot of HIV in Australia by the Australian Federation of AIDS Organisations (AFAO) shows that newly diagnosed HIV is becoming higher among Aboriginal and Torres Strait Islander people than non-Indigenous people (6.8 vs 3.1 per 100,000) (AFAO, 2017a). AFAO report different patterns of HIV transmission with a greater proportion of HIV notifications among Aboriginal and Torres Strait Islander people attributed to heterosexual sex (21%) and injecting drug use (16%),

which remain higher than the rates for non-Indigenous Australians (14% and 3%) (AFAO, 2017).

Colonisation continues to impact on Aboriginal and Torres Strait Islander TGD people who face the challenge of staying connected to community and culture throughout the process of affirming their gender, which may include also transitioning between women's business and men's business. There remains some lack of awareness among some Aboriginal health services and community members about Sistergirls and Brotherboys. In addition to low service availability and utilisation, this group experience the intersections of racism, transphobia, over-policing and incarceration. A lack of cultural competence and histories of trauma in health care settings continue to deter Aboriginal and Torres Strait Islander populations from seeking healthcare. Sistergirls and Brotherboys may also experience barriers to transition related health care, sexual health or other screening services in rural and remote areas.

A special edition of HIV Australia reported on a 2015 community consultation with Aboriginal and Torres Strait Islander gay men, MSM, Sistergirls and Brotherboys and over half (56%) reported a lack of acceptance by the wider community, 28% reported lack of support/education about sexual health, 20% reported safety issues and 12% reported barriers to accessing appropriate health and social services (Logue, 2015, Figure 4).

Aboriginal and Torres Strait Islander Sistergirls and Brotherboys require culturally appropriate health promotion and need to be respectfully and meaningfully consulted in the HIV response and supported to drive community initiatives.



ACON, Ending HIV campaign, 2016.

## SYSTEM BARRIERS TO HIV PREVENTION

*'I had to see a respiratory specialist and I decided that I would actually disclose my previous surgeries when she asked for my surgical history. It is incredibly rare for me to do that, for good reason. Once I told her I had had chest surgery and a hysterectomy she asked me a barrage of invasive questions about my genitals, how I have sex, who I have sex with and if I had 'always felt like a boy. I had just been diagnosed with tuberculosis (latent) and made the mistake of telling her that I was both a trans man and gay, I had read that having TB and being at risk of HIV meant I should be treated so figured it was important... she didn't believe that I have sex with gay cisgender men and told me I wouldn't need to be treated for TB because I wasn't at sufficient risk. I still haven't been treated because the specialist doesn't believe I am at risk even though I am now also on PrEP.'*

(Trans man, Sydney)

When seeking health care, trans and gender diverse people can often expect to face a workforce with low literacy about gender diversity and potentially hostile environments. Primary health settings typically have an inadequate understanding about trans and gender diverse experiences and clinicians may not hold contemporary or accurate knowledge about providing appropriate and sensitive sexual health care to trans and gender diverse people.

Qualitative research among trans MSM from Canada demonstrates that barriers to HIV and STI testing include lack of trans health knowledge among providers and 'a perceived gap between trans-inclusive policies and their implementation in practice.' However, enablers included access to trusted and flexible testing providers (Scheim and Travers, 2017).

ACON's community rapid HIV/STI testing service a[TEST] is targeted to gay and bisexual men (cis and trans) as a priority population, however has a policy to include all trans and gender diverse people. There remains a lack of targeted and tailored services for trans women in particular, who are underrepresented in community and health campaign materials.

Health professionals and frontline staff do not always ask appropriate or relevant questions or have up-to-date or relevant information about trans health. Rather, trans and gender diverse people face a lack of knowledge from staff epitomised by invasive, irrelevant questions, judgmental comments or inability to provide appropriate referrals, particularly in regional and rural areas. As such, many hide their gender experience when seeking healthcare.

The knowledge of the health sector workforce is crucial to the delivery of appropriate and best practice healthcare for trans and gender diverse people. Specific training for health providers on gender identity and gender affirmation processes is lacking (Australian Human Rights Commission, 2015). The Tranznation report on the health and wellbeing of trans people in Australia and New Zealand (Couch et al., 2007) found that a central concern for transgender communities in accessing health services is recognition (including formal documentation) of their preferred gender. Respondents' worst experiences with health services usually involved encounters where they were met with hostility and not treated respectfully. Most participants, (87.4%) had experienced at least one form of stigma or discrimination on the basis of gender (Couch et al., 2007).

## SOCIAL BARRIERS TO HIV PREVENTION

There remain social barriers that affect trans and gender diverse people's access to HIV prevention, including a major gap in human rights recognised at an international level (Divan et al., 2016). In their report, Transforming Health: International Rights-Based Advocacy for Trans Health, the Open Society Foundation write:

*'Other barriers to health and health care are the numerous socioeconomic determinants of health that legally, economically, and socially marginalize trans people. These include discrimination in employment, education, housing, and relationship recognition; police harassment, often as a result of actual or assumed association with sex work; and identity document policies that deny many trans people legal recognition in their true gender. They also include aspects of structural violence such as racism, violence against women, and poverty.'*

(OSF, 2013, 4)

Mental health issues for trans and gender diverse people may be a barrier to accessing HIV prevention messaging and health promotion. The First Australian National Trans Mental Health Study found that 43.7% of trans respondents were currently experiencing clinically relevant depressive symptoms; 28.8% met the criteria for a current major depressive syndrome; 5.4% for another depressive syndrome; 18.3% for a panic syndrome; and 16.9% for another anxiety syndrome. One in 5 participants (20.9%) reported thoughts of suicidal ideation or self-harm on at least half of the days in the 2 weeks preceding the survey (Hyde et al., 2014).

## GEOGRAPHICAL BARRIERS TO HIV PREVENTION

In addition, the 2017 Trans Pathways Report into Mental Health Experiences and Care Pathways of Trans Young People found that almost three-quarters (74.6%) of participants had at some time been diagnosed with depression; 72.2% had been diagnosed with an anxiety disorder; 79.7% had ever having self-harmed; and 48.1% had attempted suicide at some point in their life (Strauss et al., 2017).

Poor mental health outcomes can lead to increased risk behaviours and increased black market use of hormones outside medical care. Trans and gender diverse people who use drugs continue to face compounding stigma associated with both drug use and gender diverse experience. Trans and gender diverse people may face stigma for accessing Needle and Syringe Programs, even to access equipment to inject hormones. Stigma can affect people's access to sterile needles and equipment and in turn their risk of acquiring HIV. Poor mental health outcomes can also affect people's ability to access services, negotiate safer sex and advocate for their own needs.

The NSW Council of Social Service (NCOSS) evidence review Beyond the myth of 'pink privilege': Poverty, disadvantage and LGBTI people in NSW reveals that LGBTI people generally face higher levels of disadvantage and are more likely to be unemployed, face workplace discrimination and be paid less (NCOSS, 2015, iii). A national study into the experiences of trans men in Australia found that 15% of participants were unemployed (Jones et al., 2015).

Trans and gender diverse people live across all geographical areas of NSW and there is an emerging visible population in regional areas. Trans and gender diverse people often access sexual health clinics as they have a reputation for being safe and judgment free. Many seek transition-related health care here as there may be no other services available where they live, and because HIV specialist doctors typically have experience with trans patients, particularly in regional areas where GPs visit from Sydney or other sexual health clinics.

Awareness of issues for TGD people is increasing among regional sexual health staff with more frequent media exposure, although it can still be difficult to source and refer to GPs with the requisite experience in prescribing hormones or other transition-related services. Stigma and discrimination are often rife. Trans and gender diverse people have to travel great distances to seek culturally appropriate health care, or move permanently away from their home towns to seek support services and are at risk of homelessness.

There needs to be greater options for people to find local care. Reports from regional sexual health clinics are that the level of knowledge among most staff in primary care is low. In regional areas, it can be difficult to identify GPs and health care workers with a willingness to invest in capacity building and up-skilling in HIV prevention, so patients have to travel to the city to find suitable prescribers. Even where intake forms have multiple gender options, the next challenge is to support staff to improve their understanding of gender and terminology.



Alex, photo by Myth Photography (@myth\_photography)

## BARRIERS TO PARTICIPATION IN BIOMEDICAL PREVENTION

*'PrEP scale-up should include specific funding for services that are tailored for trans women and men in resource rich and resource limited settings.'*

(iPrEX Study: Grant et al., 2016)

With the advent of biomedical prevention technologies such as PrEP and TasP there is significant change across the HIV landscape. Despite this, there remains low representation of trans or gender diverse people in PrEP trials. Although trans men have participated in the IPERGAY trial examining on-demand PrEP, globally trans MSM have been excluded from almost all clinical PrEP studies, and thus no data are available on its efficacy on trans men using testosterone. Trans women have been included in some large PrEP trials and cohort studies but their data has been aggregated with gay men and other MSM. One study found that out of seven trials analyzing PrEP efficacy, trans women comprised only 1.2% of one trial and 0.2% of total trial enrollments (Escudero et al., 2015).

Until recently, emtricitabine/tenofovir (FTC/TDF) as PrEP was thought to take longer to reach protective levels for front hole and vaginal penetration and for people in insertive positions. While Cottrell and colleagues have found that Truvada as PrEP is protective after three days regardless of the person taking it (Cottrell et al., 2016), there remain unanswered questions (such as the impacts of hormonal therapy on drug levels in genital tissue) because trans and gender diverse people were not included in this research.

Researchers from the iPrEX (Pre Exposure Prophylaxis Initiative) study into the efficacy of PrEP argue that 'more information is needed to fully situate PrEP efficacy for trans women, including analysis of drug-drug interactions between PrEP medications and feminizing hormones and PrEP drug penetration into neovaginal tissues' (Grant et al., 2016).

In 2017 the University of Liverpool released a drug interaction guide for transition hormones and ART showing that FTC/TDF is not contraindicated for common gender affirming hormones (University of Liverpool, 2017). One study found that commonly used feminizing hormones had a low likelihood of interacting with PrEP medications, however there remains a need for controlled interaction studies in trans women on the effects of FTC/TDF as PrEP (Anderson, Reirde and Castillo-Mancilla, 2016). Despite the low likelihood of interaction, 'community concerns about potential interactions may limit interest in and uptake of PrEP among trans women' (Sevelius, Deutsch and Grant, 2016).

These concerns about interactions with hormones has been shown to affect uptake and adherence of PrEP among trans women. The iPrEX Trial also found that PrEP was effective among trans women but there were barriers to adherence, particularly among those at highest risk of infection (Deutsch et al., 2015).

PrEP is a highly effective HIV prevention tool, but it only works if the dosage is adhered to. Some at-risk trans and gender diverse people face significant marginalisation and prioritise other health needs over PrEP. Addressing these other social determinants of health is necessary in improving PrEP adherence.

In one qualitative study among trans women, PrEP uptake and adherence relied on the 'ability to obtain PrEP from a trans-competent provider'. Barriers included a 'lack of trans-inclusive marketing of PrEP, prioritisation of hormone use, and medical mistrust due to transphobia' (Sevelius et al., 2016). It is therefore necessary for research and tailored programs to meet trans women's unique needs in relation to HIV prevention (Sevelius, Deutsch and Grant, 2016).

A further step towards enabling greater uptake of PrEP among trans and gender diverse people would be to amend the ASHM HIV PrEP Clinical Guidelines (ASHM, 2017). For example, while the Guidelines include trans women in their references to vaginal and anal sex, in the section for gay men and other MSM the only references are to anal sex, which excludes trans MSM who exclusively engage in front hole sex. The stand-alone section for trans and gender diverse people is effective only if all trans and gender diverse people are meaningfully included in all other sections of these Guidelines. The Guidelines should also reflect practice based sex (such as MSM) rather than referring interchangeably to identity based sex (such as heterosexuality) or population groups (trans and gender diverse people).

Further, NSW Health PrEP Guidelines specify that heterosexual people (which can include trans and gender diverse people) can only access PrEP if they have had a regular HIV positive sexual partner (not on treatment or with detectable viral load) with whom condoms were not consistently used in the past three months, and who are likely to have multiple events of condomless anal (CLAI) or vaginal intercourse (CLVI). This restricts trans women's ability to access PrEP. By comparison, the eligibility criteria for MSM is less restrictive and includes having at least one episode of CLAI with any casual HIV positive male partner, or partner of unknown HIV status in the last three months, having rectal gonorrhoea, chlamydia or infectious syphilis in the last 3 months or at last screening, or methamphetamine use in the last three months. These Guidelines assume that trans women do not have an increased HIV burden nor are at higher risk than cisgender women.

## ENABLING FACTORS

The Tranznation report on the health and wellbeing of trans people in Australia and New Zealand (Couch et al., 2007) found that positive interaction with the medical community could be a profoundly legitimising experience for trans people. Practitioners were greatly appreciated if they were knowledgeable and experienced in trans issues, and if they were sensitive to gender diversity and to the difficulties that many trans and gender diverse people face in health care settings.

Access to transition related health care should be considered an HIV determinant. Informed consent models directly improve health outcomes for TGD people by increasing self-determination and bodily autonomy. An informed consent Protocol for the Initiation of Hormone Therapy for Trans and Gender Diverse Patients has been released by VAC through rigorous consultation with ANZPATH, local GPs, psychologists, psychiatrists and community members (Equinox and VAC, 2017) and is being applied in the Equinox clinic in Melbourne.

The Hunter New England Central Coast Primary Health Network has developed a specific 'Transgender Health and Gender Diversity' pathway as part of their Healthpathways initiative, in partnership with the Hunter Centre for Sex and Gender Diversity (HCSGD) to be used in the HNE Local Health District pathways. The initiative is based on a survey by HCSGD of trans and gender diverse patients' experience of healthcare provision across the region, which highlighted constructive relationships with GPs but a lack of multidisciplinary health-provider knowledge and the absence of referral pathways for specialist care. This is the first Australian pathway of its kind and has been adopted by other primary health networks (PHNs) across Australia and New Zealand. It provides access to culturally appropriate transition care and supports an informed consent model.

## INVESTING IN TRANS AND GENDER DIVERSE COMMUNITIES

Funding and resourcing continues to affect the ability of trans and gender diverse people to respond to HIV. Strong advocacy continues to occur on a volunteer basis, which speaks to the stakes that these communities hold in the HIV response and demonstrates strong community mobilisation and resilience. However this level of volunteering means that trans and gender diverse people shoulder the burden of advocacy often without support, notice or resourcing. Too often, trans and gender diverse people and content are an afterthought in research, programming, policy and health promotion campaigns. Meaningful inclusion consists of providing not only adequate notice but also ensuring all aspects of the HIV response are accommodating, appropriate and co-designed.

Funding in the HIV sector is directed overwhelmingly towards cisgender gay and bisexual men and there is a distinct lack of funding for specific trans and gender diverse health promotion and HIV prevention. While some LGBTI organisations are increasing investment on programs for trans and gender diverse people, much of the advocacy and organising conducted in this space is on a volunteer basis by community groups and individuals who are directly impacted but under-resourced, and at an organisational level there remains low inclusion of issues facing trans women in particular.

There is momentum among trans and gender diverse populations to provide a targeted response to the HIV epidemic but community initiatives face burn out. For populations that face compounding stigma, discrimination, poverty, homelessness and mental health issues, the capacity to engage in research and advocacy without proper funding and resourcing is not only unrealistic but exploitative. Sustained investment into supporting, consulting and engaging peer-driven trans and gender diverse inclusive health promotion and HIV prevention is of critical importance, and is the responsibility of the broader HIV sector, AIDS councils and public health system.

## POLICY RECOMMENDATIONS

*'Due to stigma, neglect, and institutionalized discrimination, the HIV response has largely failed to address the needs of trans people. Achieving an AIDS-free generation will demand more effective, sustained, rights-based programs for this at-risk population.'*

(amfAR, 2014)

In order to achieve effective and meaningful engagement of trans and gender diverse people in the NSW HIV response, ACON and PASH.tn make the following policy recommendations:

### Self determination

- Co-design, implementation and evaluation processes must be established that are equitable and sustainable to ensure that trans and gender diverse people are not only meaningfully engaged but are driving policies, research and decision-making that affects their lives;
- Specific, sustainable and ongoing funding and investment is necessary for trans and gender diverse research, advocacy and health promotion, including rights-based and evidence-based programs;
- Allocated resourcing is necessary for peer mentoring programs to share knowledge and build capacity among trans and gender diverse people to engage in health promotion and advocacy.

### Meaningful inclusion in existing programs

- Amended NSW HIV notifications forms to better reflect route of transmission via sexual practices that are inclusive of trans and gender diverse bodies;
- Uptake of recommended gender and sexuality indicators in data collection, research, STI and HIV surveillance systems, undertake analysis to account for trans and gender diverse people (including analysis of differences between sex assigned at birth and gender identity) and report disaggregated data;
- Ensure language and research questions (general and targeted) are relevant to and appropriate for trans and gender diverse people to accurately capture practice, experience and need;
- Comprehensive needs assessments, focus testing and consultation among trans, gender diverse people and communities is embedded into policy and practice, and informs both the evidence base and service delivery; and
- Workplace inclusion and proactive employment of trans and gender diverse people in the HIV sector. Government funding recipients should be held accountable for inclusion of trans and gender diverse people.

### Health sector capacity building

- Uptake of internationally recognised standards on transition-related health care using an informed consent model; and
- National clinical guidelines and training developed for the inclusive and culturally-competent care of trans and gender diverse people in health care settings and incorporated into the NSW HIV support program.

### Legal and policy frameworks

- Recognition of trans and gender diverse people as a key population in the NSW HIV Strategy and increased recognition in Australia's National HIV Strategy to maintain alignment with the global response;
- Removal of medical intervention requirements in order for trans and gender diverse people to update their NSW Birth Certificate; and
- Maintain decriminalisation of sex work in NSW and easy access to needle and syringe programs in NSW.

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