

ACCESS TO GENDER-AFFIRMING HIV, STI AND TB SERVICES FOR TRANSGENDER WOMEN IN SOUTH AFRICA

This policy brief synthesises evidence of structural and socio-cultural determinants of transgender women's disproportionate HIV, sexually transmitted infections (STIs) and tuberculosis (TB) burden. Embedding HIV, STI and TB services for transgender women in a comprehensive gender-affirming care (GAC) model improves prevention and treatment outcomes and forms the bases of recommendations to integrate GAC through reforms in the current implementation of policies and practices. The brief is underpinned by a participatory approach and written in collaboration with trans-led organisations to harness their voices, lived experiences and practices of this marginalised group. These lived experiences reflect the resilience of transgender women as they continue to advocate for GAC and HIV, STIs and TB prevention, care and treatment for transgender women, and are useful in informing contextualised policy responses that are responsive to transgender women's healthcare needs. The organisations include established NGOs such as **GenderDynamix (GDX)**, the **Social, Health and Empowerment Feminist Collective of Transgender Women of Africa (S.H.E)**, peri-rural based trans-led organisations such as the **Trans Wellness Project** and **Uthingo Network** (formerly known as the Gay and Lesbian Network) and recently established organisations: **Trans Tec SA**, **Trans Hope Care Center** and **Iphimbo Lothingo**. While the focus is on HIV, STIs and TB, other healthcare concerns of transgender women are also prioritised as reflected in the integrated gender-affirming approach that guides this policy brief.



Introduction

Transgender people have a gender identity or gender expression that differs from their sex assigned at birth. Transgender, often shortened as trans*, is also an umbrella term^[1,2]. Transgender people, in addition to having a gender identity opposite to their assigned sex, may also include gender queer/-diverse, gender-fluid, non-binary and gender non-conforming individuals^[3]. Gender identity is independent of sexuality, therefore transgender people may identify as “straight”, “gay”, “bisexual”, or may consider conventional sexuality labels inadequate or inapplicable^[4]. Transgender men (female to male) were assigned female sex at birth but socially identify as men, whereas transgender women (male to female) were assigned male sex at birth but socially identify as women.

Transgender women carry a disproportionately high burden of HIV across several regions, including South Africa^[5-7], fuelled by an interplay of wide-spread stigma and discrimination, socio-economic exclusion, high levels of gender-based violence, and restrictions on accessing resources^[8,9]. A Human Sciences Research Council (HSRC) study found HIV prevalence levels of over 50% across three major urban centres^[10], compared to a prevalence rate of 14.0% in the general population^[11]. There is evidence that STIs are also high amongst transgender women given their association with HIV^[12]. Limited available research indicates that TB is also reported to be high since socio-economic exclusion and stigma contributes to crowded living conditions and barriers to care for many transgender women, which along with a high HIV burden increases TB risk^[13]. Engagement of transgender women in HIV, STI and TB prevention, treatment and care is complicated because of transphobic stigma experienced in healthcare settings, lower self-efficacy amongst transgender women, inadequate provider knowledge and an overall lack of gender-affirming healthcare^[14].

Marginalisation based on gender-nonconformity can increase HIV vulnerability for transgender men and lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI+) persons more generally; however, transgender women confront a distinct interplay of biological, socio-cultural and structural risks^[15]. Further to this, while there is a lack of South African data regarding the prevalence of HIV, STIs and TB amongst transgender men, current global estimates show a low prevalence compared to the very high burden of HIV amongst transgender women motivating the need for a targeted policy and programming response^[16,17]. Yet, while transgender women have been identified as a key and vulnerable population in global, regional and South African HIV policies and frameworks and despite a generally enabling legislative context, several policy and programmatic constraints still hamper full access to gender-affirming HIV, STI and TB services for transgender women in South Africa. Persisting challenges include conflation with other key populations sharing heightened vulnerability to HIV - notably men who have sex with men - leading to a lack of HIV data specific to transgender women; a near complete dearth of data on the prevalence and impact of TB, other STIs; and an overall limited understanding of population size and demographic information^[18,19]. Further to this, existing policies and programmes largely do not embed HIV, STI and TB responses in a GAC framework which decreases engagement in prevention, treatment and care^[20].

This brief provides a review of the policy landscape framing transgender women’s health rights and incorporates available evidence about transgender women’s HIV, STI and TB burden; policy progress and limitations; socio-cultural and structural factors that drive vulnerability; available programmatic research; and best practice principles for integrating GAC and HIV services, before providing policy recommendations to improve holistic healthcare services and support for transgender women.



The South African policy framework for transgender people's rights and wellbeing

There has been significant progress in the South African context to secure protection of the rights of transgender persons (see Table 1). The “equality clause”, the first of its kind in the world, included in the South African 1996 Constitution prohibits discrimination based on sexual orientation and gender (identity) and in principle provides for the protection of the rights of LGBTIQ+ persons, including transgender women^[21].

A key area of policy reform includes the *Alteration of Sex Description and Sex Status Act, 2003* (Act No. 49 of 2003) that makes provision for transgender people to align their legal gender marker to their actual and lived gender identity on condition of “surgical or medical treatment or by evolution through natural development resulting in gender reassignment” (p. 30)^[22].

While an important milestone in the progressive attainment of the full realisation of transgender persons rights, the *Alteration of Sex Description and Sex Status Act* is inherently medicalized and excludes the majority of trans and gender diverse persons from accessing legal gender recognition because access to medical and surgical care as required by the Act is costly, and inaccessible for rural transgender people because the services are limited to academic hospitals located in South Africa's major city centres^[22]. The law requires a medical diagnosis along with medical intervention, these requirements are unobtainable particularly for poor working class, peri-urban, or rural transgender persons^[22]. It is also limited in its scope by only recognizing one of two genders whereas gender identity can also be fluid and non-conforming. It only applies to transgender persons over the age of 18 years and minors if they were able to get parental consent. Ensuring institutional legal gender recognition is a key element to creating self-efficacy and positive health seeking behaviours amongst transgender women. Furthermore, legal gender recognition is associated with positive health seeking behaviours amongst transgender women^[22].

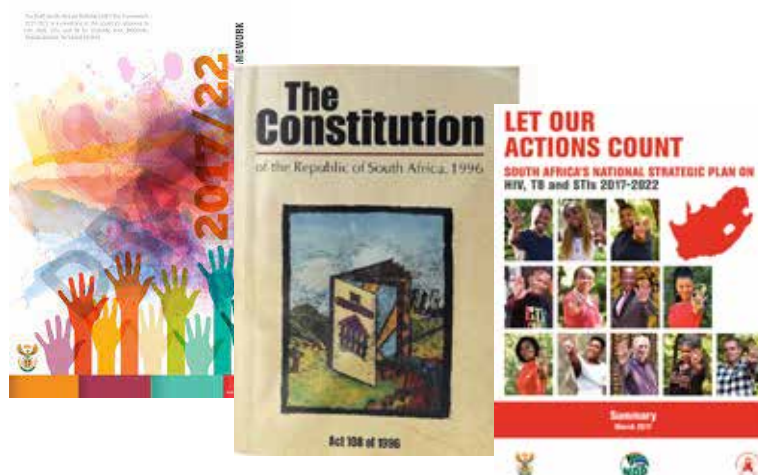
Policy responses specific to transgender women's heightened HIV burden include the *National Strategic Plan for HIV, TB and STIs (NSP) 2017-2022*

of South Africa. The *NSP 2017-2022* grounds the response to HIV, TB and STIs in human rights principles and approaches, to reduce stigma and discrimination, ensure equal treatment for all and to increase access to justice in the context of HIV, TB and STIs for all key and vulnerable populations, including transgender people^[23]. This requires developing and implementing interventions to address all human rights-related barriers to, and gender inequality in, access to services – including healthcare services and access to justice – for transgender people. In the same vein, Goal 3 of the *NSP 2017-2022* calls for all key and vulnerable populations to be reached with comprehensive, targeted and customised interventions. A key limitation of the *NSP 2017-2022*, is the lack of distinction between transgender women and transgender men^[14]. Further to this, in what has been hailed as a world first, the South African National AIDS Council (SANAC) launched the country's *National LGBTI HIV Plan* in 2017 with commendations for a range of interventions that span across health, empowerment, psychosocial, human rights and evaluation domains, but limited in the extent to which it provides a transgender-specific response^[24]. Finally, the *South African National Sex Worker HIV Plan (2016-2019)* includes context-responsive service delivery models and a core package of services to improve the HIV-related health and safety of people who sell sex^[25]. Many transgender women sell sex, often as a result of economic exclusion, placing them at increased risk of HIV and other STIs. The *South African National Sex Worker HIV Plan* is aimed at: i) reducing HIV, STI and TB incidence amongst sex workers; ii) reducing HIV, STI and TB-related mortality amongst sex workers; and iii) reducing human rights violations experienced by sex workers^[25]. Amendments of the *Criminal Law (Sexual Offences and Related Matters) Act 32 of 2007* to decriminalize sex work, however, lags behind and increases sex workers risk of violence, exploitation and abuse as well as stigmatization in healthcare settings, thereby severely constraining the impact of the *National Sex Worker HIV Plan*^[27].



Year	Important milestone	Key elements	Gaps / issues / opportunities
1996	South African Constitution	Prohibits discrimination based on sexual orientation and gender (identity)	Disjuncture between a broadly inclusive, anti-discrimination and rights-based approach at the national level and how this is translated into practice on the ground.
2003	Alteration of Sex Description and Sex Status Act, 2003	Provides for alignment of transgender persons' legal gender marker to their gender identity, on condition of "surgical or medical treatment or by evolution through natural development resulting in gender reassignment".	Inherently medicalized, limited to the gender binary, requires parental consent for minors and does not address rurality and socio-economic status as access barriers to medical and surgical care.
2010	GDX-led position paper, <i>HIV & Transgender Identity: Towards Inclusion and Autonomy</i>	Demonstrates importance of the disaggregation of transgender women from men who have sex with men in research.	
2012	NSP for HIV, TB and STIs (2012-2016)	Prioritises transgender people as a key and vulnerable group for the first time in the NSP.	Conflation of transgender women and men despite evidence of transgender women's increased HIV risk.
2016	National Sex Worker HIV Plan (2016-2019)	Includes context-responsive service delivery models and a core package of services to improve HIV-related health and safety of people who sell sex, including transgender women.	Constrained by continued criminalisation of sex work.
2017	NSP for HIV, TB and STIs (2017-2022)	Transgender women are prioritised as a key and vulnerable group in the HIV response.	Calls for comprehensive, targeted and customised interventions for transgender women.
2017	LGBTI HIV Plan	Developed in response to alarming HIV rates amongst LGBTI+ persons and recommends wide-ranging comprehensive interventions	
2017	Resolution 275 of the African Commission	Aimed at enacting policy and legislation to combat stigma, discrimination and violence as everyday realities of transgender people on the African continent.	
2019	The case of September v Subramoney	Jade September was a transgender woman incarcerated in a men's prison and denied expression of her gender identity.	Supports a GAC approach for incarcerated transgender persons.

Table 1. Policy developments in support of transgender persons' rights



HIV, STI and TB prevalence amongst transgender women in South Africa

Metro-municipality (N=888)	% HIV Prevalence 95% Confidence Interval
Johannesburg, n=324	63.3% (55.5,70.5)
Buffalo City, n=305	46.1% (38.7,53.6)
Cape Town, n=259	45.6% (36.7,54.7)

Table 2. HIV prevalence amongst transgender women in Buffalo city, Cape Town and Johannesburg metropolitan municipalities (2018-2019)

With increasing awareness of the high HIV burden amongst transgender women, HIV programming for this population has received some focused funding for HIV programming yet in some areas remain insufficient^[14]. A more complete understanding of the healthcare needs of transgender women, including their disproportionate burden of HIV, STIs and TB, requires reliable population size estimates. Estimates of population size are needed to inform decisions on resource allocation and distribution for better programme planning and management and to help policy makers and program staff plan appropriate interventions and allocate sufficient resources for impact. Defining transgender women for size estimation purposes is a constant challenge, partly because of limited research engagement with the diversity and intersecting identities and experiences of transgender persons^[18].

The Global Fund through SANAC commissioned a mapping and size estimation activity, implemented by the HSRC, and placed the population size for transgender women at 72,156 (range 67,757-76,554) in 2015^[28] although there were concerns about how transgender women were defined and subsequently included in estimates. The first ever bio-behavioural survey (BBS) conducted amongst transgender women in South Africa was called the *Botshelo Ba Trans* Study. The study was conducted in the Cape Town metro, the Johannesburg metro area and the Buffalo City metro located in the Eastern Cape province of South Africa. In total, 888 transgender women were found to be eligible and were included in the final analysis (see Table 2)^[10]. HIV disproportionately affects transgender women in each of the three metros. The HIV prevalence estimates found in the *Botshelo Ba Trans* Study, reflect HIV prevalence estimates amongst transgender women in Lesotho (50%)^[29] Mumbai, India (63%)^[30] and in a study conducted by the United States of America (USA) Centers for Disease Control and Prevention (CDC) amongst 'black' African American transgender women in the USA (51%)^[31].

The first national TB prevalence survey conducted in South Africa confirmed high TB prevalence and HIV co-morbidity^[32]. Even though transgender women are prioritised as a key population for HIV, they are not included as a key population for TB in the country's strategic response as outlined in the *NSP of 2017-2022*. Currently there are no formal prevalence studies of TB amongst transgender women in South Africa, and there is no gender disaggregated data from routine surveillance statistics. A study in Papua New Guinea showed high prevalence for TB amongst transgender women with similar risk factors^[33]. In South Africa the organisations representing transgender women report a high burden of TB amongst their members^[34]. As a community, transgender women, are at greater risk of TB due to their levels of poverty, high prevalence of HIV, stigma and living conditions^[35].

Transgender women's HIV, STI and TB risk and vulnerability

Transgender women's HIV, STI and TB risk, vulnerability and retention in care and treatment are underpinned by intersecting and mutually reinforcing socio-cultural and structural determinants^[36].

Poverty, unemployment and homelessness are important determinants, not only for HIV risk but as key predictors of low retention in HIV care^[37]. Unemployment rates were found for transgender women in the *Botshelo Ba Trans* Study, ranging from 30% to 60%, with the majority of participants reporting that they had no income^[10].

Social rejection by family and friends as well as school-based victimisation at a very young age contributes to transgender women's educational exclusion, and ultimately, disrupting employment pathways^[38]. This, along with a lack of the support and access to resources provided by family, obstacles posed by official documentation not reflecting their lived gender identity, and workplace discrimination result in many transgender women experiencing homelessness and extreme poverty^[39].

In South Africa, intersections between race, class and gender compound socio-economic vulnerability experienced by 'black' and 'coloured' transgender women^[40]. Socio-economic vulnerability contributes to increased HIV risk through high-risk behaviours such as transactional sex and sex work, as well as increased risk of sexual violence^[41]. The above vulnerabilities have led to transgender women experience at higher rates of incarceration than the general population, all of which have established links to HIV risk^[42].

I remember, I migrated from home to Johannesburg and that moment, I think I was between the age of 12 going 13. And when I came here, I became homeless for about one year and six months, you know? And I hustled my way from the pavement to a hotel somewhere in Hillbrow

a transgender woman participating in the *Botshelo Ba Trans* Study

Stigma and social marginalisation

Pervasive stigma and marginalisation experienced by transgender women converge and compound vulnerability across multiple domains, such that "social exclusion of LGBTIQ+ individuals is a pathway towards poverty, ill health, and a heavily compromised quality of life. Poverty and ill health are also compounded by social exclusion^[43]. The impact of stigma needs to be understood not as a single event or even multiple isolated events in the adult life of a transgender women, but as a continuous process. In the qualitative component of the *Botshelo Ba Trans* Study, multiple transgender women spoke of the fear and vulnerability experienced when they first realised their gender and had no reference points to understand this conflict. As soon as participants spoke of raising questions or expressing their identity, they faced an almost universal world of stigma, resulting in rejection from family, schooling, churches, community structures and previous friendship circles. The transgender women interviewed spoke of this rejection of identity as deeply entrenched and carrying high sensitivity.

The expressions of stigma outlined below stem from this societal basis of stigma and exclusion and emphasise the importance of embracing the identity of the transgender women if effective care is to be provided.

Even before you decide to leave sometimes you get chased out, chased out by your own family then have to learn to make a means out there. We are forced to go back to traditions and religions like our dress code, we are forced to fall under the traditions of our parents and our sisters that we come from not being understand what are we about and what is it that we want

a transgender woman participating in the Botshelo Ba Trans Study

Violence and victimisation

The intersection of HIV, violence and other gender-related health disparities renders transgender women vulnerable because of their feminine social gender position^[44]. Transgender women in South Africa continue to face violence, victimization, harassment, and discrimination in their everyday lives^[45]. A survey indicated that 42% of transgender respondents fear discrimination because of their transgender identity^[46].

But you know the daily sort of struggle to try and negotiate the city police, people's belongings are destroyed all the time and you are homeless, your stuff is confiscated, your ID book destroyed, all your things can be wiped out overnight. They are trying to push people out of the city ... they are assuming that will stop people from being homeless, but of course that is a ridiculous assumption

a transgender woman participating in the Botshelo Ba Trans Study

An HSRC social attitudes survey revealed that about half a million South Africans over the course of a year have physically harmed women who

dressed and behaved like men in public, and 240,000 have beaten up men who dressed and behaved like women^[45]. Alarming the survey found that about three million South Africans reported that they might commit acts of violence against gender non-conforming people in the future^[45].

Violence and victimization directly or indirectly lead to an increased vulnerability of HIV infection. In some form or another, violence, has become part of the life of transgender women in various manifestations^[38].

Mental health and wellbeing

Item	%
Felt down depressed or hopeless	24.5%
Felt tired or having little energy	24%
poor appetite or overeating	20.2%
Thoughts that they would be better off dead or of hurting themselves in some way	10.8%

Table 3. The Patient Health Questionnaire (PHQ)-9 was used to assess and monitor depression severity in the Botshelo Ba Trans Study amongst 865 transgender women

Social rejection, pervasive stigma, discrimination and trauma such as those experienced by transgender women have been consistently found to be associated with depression, and low self-esteem. Experiencing various manifestations of social oppression from an early age, creates psychological distress and impacts transgender women's overall psychological wellbeing. For many transgender women, social rejection (and oppression) with the accompanying psychological distress leads to body shame and low self-esteem^[47].

Results of a cross sectional analysis of eight African countries, excluding South Africa, show that depression, suicidal ideation and experiences of stigma were common amongst transgender women; with transgender women reporting more poor mental health than cis men who have sex with men^[19]. In a qualitative study of 45 transgender women, between 51% to 64% self-reported that they felt at times that their own life is worth less than others; hate themselves and has had suicidal thoughts^[48]. The only large-scale survey research on mental health outcomes of LGBTQI+ persons in Southern Africa, to our knowledge, indicates disproportionately high levels of depression, anxiety, suicidal-

ty and substance use amongst LGBT people, with history of sexual violence associated with higher likelihood of suicide attempt^[48]. The findings are, however, not disaggregated for transgender women. The lack of existing research is attributed to government, funders, and development partners narrowly viewing transgender women through a biomedical lens focused on their heightened HIV risk, at the expense of generating a more robust evidence base on the complex psycho-social and health issues transgender women experience^[14].

Gender affirmation is important for the mental health and wellbeing of transgender women. The gender affirmation theoretical framework developed by Jae Sevelius (researcher based at the Centre of Excellence for Transgender Health at the University of California, San Francisco in the USA) is premised upon the intersection of the social contexts of racism, transphobia and sexism which results in extreme marginalisation, where a high need for gender affirmation amongst transgender women generally does not get met^[47]. US-based researchers theorise that access to sources of gender-affirming support can offset negative psychological effects of social oppression^[49] such as those experienced by South African transgender women. In a study conducted amongst transgender women to explore which aspects of gender affirmation are related to psychological well-being, researchers found that social, psychological, and medical gender affirmation were significant predictors of lower depression and higher self-esteem while no domains of affirmation were significantly associated with suicidal ideation^[49]. Findings support the need for accessible and affordable transitioning resources for transgender women to promote better quality of life amongst an already vulnerable population^[49]. In line with the gender affirmation framework, the personal experience of feeling affirmed as a transgender person results from individuals' subjective perceptions of need along multiple dimensions of gender affirmation^[49]. Personalized assessment of gender affirmation according to the study investigators may thus be a useful component of counselling and service provision for transgender women^[49].

Access to barriers to healthcare services and programmes

Transgender women's lack of access to HIV, STI and TB treatment and care, as well as fulfilment of their healthcare needs more broadly, is shaped by unresponsive health systems underpinned by pervasive heteronormativity in the design, management and provision of services^[50]. Sexual and reproductive healthcare (SRH) is largely focused on maternal and other reproductive healthcare services, resulting in a narrow focus on heterosexual cisgender women and consequently, a package of care that is not responsive to the needs of diverse populations, including transgender women^[51]. Health services are conceptualised and implemented along the gender binary, i.e., designed to fit male or female bodies these factors lead to the erasure of transgender identities within the health system^[52].

Transgender persons accessing care in Kwazulu-Natal province were met with confusion when attempting to get GAC^[53]. Similarly, in a study conducted on the gender affirmation experiences of transgender women living with HIV in the USA, the researchers found that providers withheld hormones until transgender women are clinically stable on anti-retroviral treatment (ART) or are fearful to co-prescribe hormones and ART^[20]. In addition, the literature consistently cites healthcare worker attitudes as a barrier to healthcare for transgender people^[54]. Healthcare provider prejudice and stigmatisation have been linked to denial of care, provision of substandard care, verbal abuse, ridicule etc.^[55,56]. For many transgender women, fear of healthcare provider prejudice results in delaying or even avoiding seeking healthcare^[53]. South African researchers found that healthcare staff attitudes toward transgender people seeking care is based on their own morals and/or religion^[54]. This presents an ethical dilemma for health practitioners whose service should be offered within the parameters of non discrimination as laid out in our constitution. The Constitution upholds both the rights of the patient seeking care free from prejudice and discrimination, at the same time upholding the healthcare professionals right to belief.

Healthcare worker capacity and their ability to advise transgender clients is a barrier in this community and may cause health service providers to discriminate and violate the rights of transgender individuals through inappropriate and unethical treatment, as well as stigmatizing language^[57].

From a healthcare perspective, there are very few healthcare practitioners that actually know what transgender is, to be very frank with you. And the problem that we have in the Eastern Cape is the psychologists are the gateway for any hormone replacement therapy

(Key Informant: Botshelo Ba Trans Study, 2018-2019) [58].

Of equal consideration to the importance of healthcare worker attitudes, is the physical environment in which transgender women access healthcare. Transgender people are often the subject of institutional discrimination, the most controversial being the issue of bathrooms. In a study conducted by South African researchers to explore the experiences of transgender people in Kwazulu-Natal province, all participants recounted having challenges with bathroom use in health facilities that are designed with only male and female individuals in mind^[53]. Participants reported that they had to use the disability bathroom, which in most facilities is also devoid of any gender allocation. In the same vein, healthcare facilities use electronic filing systems that automatically assign according to the patient's identity number, which contains a four digit code denoting a person's sex in South African identity documents^[59]. The result of being referred to by birth names, sex assigned at birth and gender pronouns that are not congruent with a person's current gender identity, is further distress and even violence for transgender people when accessing healthcare^[59,60]. These may result in external and internal stigmatization for transgender women and present barriers to accessing HIV treatment and care services effectively^[60].

Fezeka Blaauw of the Trans Wellness Project, a small NGO in the Matzikama local municipality in the peri-rural Western Cape recalls the following when accessing healthcare:

From the moment you set foot on the premises of the healthcare facility you encounter the stares of a judging community when you express yourself the why you want to. You are then faced with the next problem namely a rude security guard who can only communicate in his mother tongue with poor English and some of the transgender women would not be able to understand [him]. There have been cases where they misgender you in front of the people. Therefore, not legally recognising Me as a Transgender Woman. The record keeping system outs you first... they will ask is this you? If you have HIV, your clinic card is green [that makes you] reluctant...to go to the ... clinic. After you done there, the sister will ask about your sexual practices then send you to the HIV counsellor even if you came for [the] doctor to fill in your SASSA disability form, further adding to the victimization you have already faced from the rude receptionist and healthcare workers. Transgender women and LGBTQ+ people are seen as the face [of] HIV because of the above-mentioned facts. In the rural areas healthcare workers are adding to the stigma, because the sister that needs to give you your hormone therapy has a very rude voice tone and demeanor and talking down [to] you, not trying to understand why you could not come [to the] clinic for medication which is most of the time the case.

Healthcare workers form part of communities that remain largely patriarchal and heterosexist (i.e., prejudiced against people who are not heterosexual or not gender-conforming in terms of socio-cultural appearance and behaviour norms)

Available at: <https://bmcinthealthhumrights.biomedcentral.com/articles/10.1186/s12914-017-0124-4>.

Stigma is another major barrier to healthcare access for transgender women and as demonstrated in Fezeka's vignette, this has a ripple effect on healthcare utilisation, ART adherence, leading to poorer health outcomes.

HIV, STI and TB prevention, treatment and care for transgender women in South Africa

High impact prevention involves using combinations of scientifically proven, scalable interventions targeted to the right populations in the right geographic areas to maximize their impact^[61]. Antiretroviral medications play an important role in high impact prevention^[61]. Transgender women living with HIV generally report lower ART adherence. Research reveals a number of factors that are positively associated with being less adherent to ART. These include: housing instability, incarceration, no health insurance coverage, illicit drug use and alcohol consumption, lower self-efficacy, and not believing the negative effect of being less adherent^[62]. A prominent factor for ART adherence is the concern of drug-drug interactions between ART and feminising hormones, and that transgender women living with HIV, will often prioritise feminising hormones over ART^[63]. Initial data from an HIV program focused on transgender women in South Africa reveal that there is low uptake of HIV services, linkage to care and retention in care^[14]. Through this program, 783 transgender women were reached and 595 were tested for HIV^[14]. Eight per cent of the women (47/595) tested positive for HIV; of these, 85% were referred for HIV services, but only 4% were linked successfully between April 2017 and March 2018^[14].

Pre-exposure prophylaxis (PrEP) is a highly effective biomedical HIV prevention intervention recommended by the World Health Organization for individuals at substantial risk for HIV acquisition^[61].

Top 3 Reasons for Unwillingness to Take PrEP

1. I don't want to take a pill everyday
2. I'm concerned about side effects
3. I don't feel like I'm at risk for HIV

Source: Poteat et al. (2020)

In December 2015, South Africa became the first country in sub-Saharan Africa to fully approve HIV PrEP^[64]. Both the 2017-2022 NSP and the 2017-2022 South African National LGBTI HIV Plan specifically recommends PrEP as a part of the basic package of services for transgender people^[24,25]. However, optimal approaches for engaging transgender women in PrEP, are largely unstudied in this region^[64]. A ground-breaking study, focused on improving engagement of transgender women in PrEP or HIV treatment and care continue found that half of HIV-negative transgender women respondents (45%) had ever heard of PrEP^[65,66]. Of those who had heard of PrEP, 41% reported knowing other transgender women who were taking PrEP^[65,66]. From the same study: A greater proportion of transgender women who had never heard of PrEP reported HIV risk perception^[64].

The researchers found in qualitative interviews that participants accurately described the purpose of PrEP as a medication to prevent HIV^[64]. They had learned about PrEP from workshops or presentations at transgender-friendly support groups and/or health centers^[65-67]. However, when probed, several participants revealed misinformation about how PrEP works (e.g. by boosting the immune system), what PrEP side effects may be (e.g. live damage), and the difference between post-exposure prophylaxis (PEP) and PrEP^[65,66].

Despite high risk of transgender women for TB, due to poverty and living conditions; there is little data and research about TB prevention, treatment and care amongst transgender women in South Africa. Many who have TB may not disclose to others and/or take TB medication as required because of fear of rejection^[34]. Transgender women are also less likely to seek care and be diagnosed and treated due to the stigma in the clinics from the clinic staff and other people seeking care. Substance use also contributes to TB treatment interruption^[68]. Concerns have also been expressed about potential interactions between TB medication and the hormones required for transition^[68]. Studies in Sao Paulo, Brazil, have shown that transgender persons had higher risk for TB^[69]. In a systematic review of TB prevalence data amongst transgender populations, the study investigators, found that TB prevalence data were reported in two of the peer-reviewed studies^[70].

Historically trans-friendly interventions in South Africa have been restricted to a few resource-limited NGOs concentrating on human rights, advocacy raising and gender affirmation; these included GDX, S.H.E, Transgender and Intersex Africa (TIA) and the Triangle Project amongst others. The ability of these organizations to offer services and enhance the HIV response had been stifled by a range of issues, particularly funding uncertainty.

Despite constraints, some examples of good practice have emerged. The Ivan Toms Centre for Health serves as a best practice model that can be applied to public healthcare services. It integrated efforts to combat HIV, STIs and TB to provide transgender women with a holistic healthcare package.

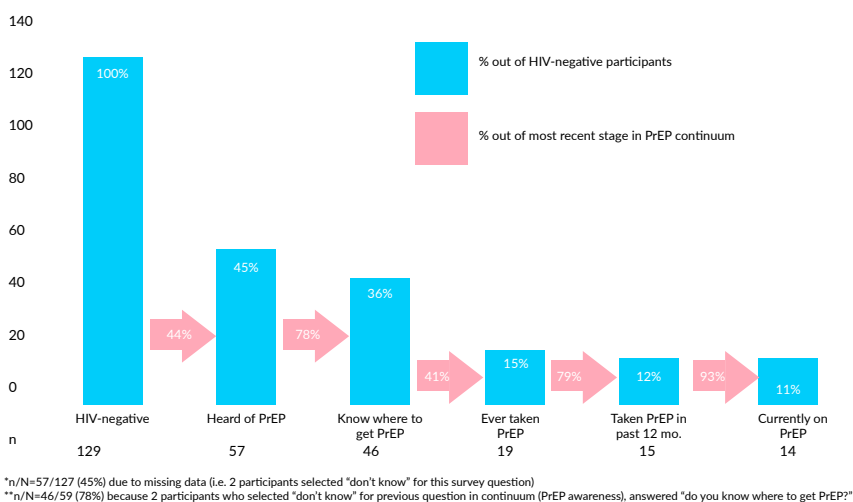


Figure 1. PrEP care continuum amongst HIV-negative transgender women participants
 Source: Poteat et al. (2020)

In Cape Town, the Sex Workers Education & Advocacy Taskforce (SWEAT) formed a support group called “Sista-azHood” for transgender female sex workers^[14]. Soon it became evident that many of the women were HIV positive and as a result the Glitz and Glamour (G&G) support club for HIV positive transgender female sex workers was formed^[14]. The G&G support club provided mental health counselling while an initiative by Anova Health Institute’s Health4Men (H4M) provides biomedical support with a focus on HIV and ART counselling and knowledge^[14].

The Aurum Institute has walk-in clinics in Ekurhuleni site (Tembisa), eThekweni site (Durban), uMgungundlovu site (Pietermaritzburg) and Ehlanzeni site (Nelspruit). These clinics offer free sexual health services, screening/treatment for HIV, STIs and TB including PrEP and ART, counselling and other psycho-social support services and referrals to relevant service providers.

STI screening and treatment as well as TB symptom screening and is conducted by the Wits Reproductive Health and HIV Institute (Wits RHI). The Wits RHI programme focusing on transgender health is funded by the United States Agency for International Development (USAID) and specifically looks at prevention methods and adherence of transgender women on ART. The programme also provides TB preventive therapy (TPT). Unfortunately, from October 2020 to June 2021, of those who started with TPT (N=1286), none were able to complete. This programme is established in four cities, namely the City of Johannesburg, Cape Town, Buffalo city and Gqeberha. Figure 2 indicates transgender women who were screened for STIs and TB from the project inception in 2019 to June 2021. The Wits RHI offers a walk-in service along with a much-known outreach service (which is mostly comprised of peers from the community), where fieldworkers, along with a nurse and community health worker, do outreach to transgender people in nearby townships and communities. Transgender women are provided with medication as well as a minimal healthcare service. The challenge however is that because this is a HIV funded programme, it does not include hormone therapy.

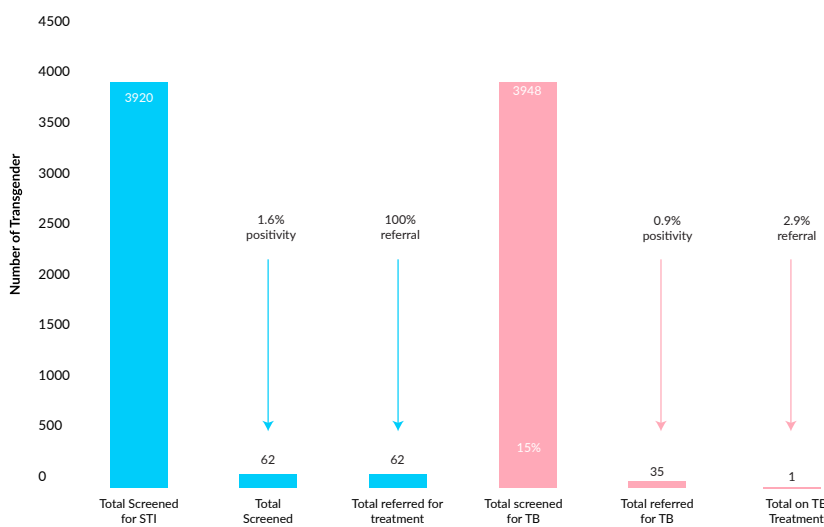


Figure 2. Positivity rate for transgender women screened for STIs and TB from 2019 to 2021 by Wits RHI Transgender Clinics. Source: Wits RHI

To retain patients, Wits RHI included hormone therapy as part of the healthcare service, through the National Department of Health (NDoH). However, shortages in hormone therapy based on government budget restraints and a long waiting list for GAC, hinders retention amongst transgender women in their Transgender HIV programme.

Similar to HIV, STIs and TB interventions, some examples also exist outside of the urban centres. In the absence of formal services, research conducted by the HSRC indicates that transgender women in rural areas form informal networks of psycho-social support^[71]. According to Scheibe and colleagues (2018), important challenges facing transgender women outreach services in South Africa include the limited interventions for socioeconomic empowerment, harm reduction around substance use and access to GAC^[14].



Gender affirming comprehensive support and care

Research in other developing countries indicates improved retention of transgender women in HIV testing, care and treatment when these services are presented as part of a package of care that includes gender-affirming comprehensive support and care^[72-74].

A gender affirming model of care refers to the process by which individuals' gender identity and expression are acknowledged and affirmed and spans social, legal and/or medical gender transition, such as puberty suppression, gender affirming hormone therapy or surgery^[75]. GAC is defined as:

Healthcare that holistically attends to the physical, mental, and social health needs and well-being of transgender people while respectfully affirming their gender identity^[76]

GAC is part of the South African public healthcare offering but is excluded from the prescribed minimum benefits list of medical aid schemes. The latter is discriminatory and dehumanising whereas the former is extremely limited with a waiting list for hormonal care initiation potentially being as long as two years. In the case of gender affirming surgery, this may be as long as 20+ years with the handful of tertiary hospitals offering both hormonal and surgical reassignment to transgender people being notoriously underfunded and limited to major urban centres, leaving GAC out of reach for the majority of transgender people^[57]. As an important determinant of transgender persons' health and wellbeing, access to GAC is associated with reduced mental health risk, increased self-efficacy and health-seeking behaviours, and better quality of life^[77].

Gender affirming care is more than just transition-related care and refers to an affirming experience in all healthcare encounters - including the use of correct names and pronouns - and incorporates an approach of depathologisation of human gender diversity (transgender as "identity"), rather than a pathological perspective (transgender as "disorder")^[79].

In the face of significant barriers to GAC, "the trans diverse community has developed significant innovation when it comes to accessing trans-specific services (usually through sympathetic individual healthcare providers, or in localities where the trans diverse person is known personally), and hormones (usually through sympathetic allies, the black market, by in essence bribing pharmacists to provide them under the counter, or in Botswana's case simply because they care" (pp.40-41)^[78]. Accessing these much-needed services outside of the public health system carries the risk of treatment interruptions and may increase risk of health complications^[79]. Further to this, while many NGOs offer direct services to transgender persons, resource and funding constraints mean that programming is generally limited to their immediate geographic location, indicating that adoption of a gender affirming model in public health services is key to sustainable and effective GAC and comprehensive support interventions^[80].

Integrating gender-affirming care and HIV services

The integration of ART and hormone therapy for transgender women living with HIV has long been called for by activists and implementers alike and has since become recommended practice^[80]. Combining hormone therapy and ART may facilitate the engagement of transgender women in HIV care, increase patient-provider trust, provide the opportunity to discuss drug-drug interactions, increase the opportunity for linkage and retention, and foster positive interactions so as to reduce barriers to needed services^[79]. For HIV, STI and TB interventions, as well as other health interventions, it is of key importance that these happen within a GAC approach to maximise the participation of transgender women and in turn impact.

Research conducted in other developing contexts have yielded good results in terms of retaining transgender women in HIV care where GAC healthcare is part of a comprehensive healthcare package, and gender affirming practices are implemented^[75]. One example of an integrated GAC service for transgender people is that of the Tangerine Community Health Clinic^[81]. Funded by USAID under the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), the facility was founded in 2015 in Bangkok, Thailand to address the specific healthcare needs of trans-



gender people and improve access and retention in primary care^[82]. The impetus for the Tangerine Community Health Clinic was the high risk of HIV infection amongst transgender women in Thailand, although high levels of stigma and discrimination required that the clinic respond to transgender women's other unmet pressing health concerns as well^[83].

An important first step towards establishing the Tangerine Clinic was to acknowledge that transgender people require access to care in an enabling, human-rights centred environment^[81,82]. Secondly, before the Tangerine Clinic opened, consultations were held with members of the transgender community, discussing their healthcare needs and the design of the clinic's services^[81,82]. Lastly, most of the staff at the clinic are transgender, and all staff members receive annual training in gender-sensitivity to ensure that they can provide trans-friendly services^[81,82].

The clinic offers gender-affirming integrated healthcare, in a comprehensive package of services, including general health check-ups, psychosocial support and counselling, hormone administration and monitoring, vaccination for hepatitis B and human papillomavirus, testing for HIV, other STIs, and hepatitis B and C, Pap smears, PrEP, and other health referrals^[83]. The increasing uptake of a transgender-specific package of services, including co-located gender affirming hormone therapy, suggests this may be an effective model in engaging and retaining transgender women in primary care^[83]. The decrease in HIV prevalence and low HIV incidence across calendar years indicate a possible reduction of HIV acquisition amongst the transgender population served by Tangerine^[83].

Decentralization of GAC for transgender persons

In addition to providing more equitable access to GAC, engaging primary healthcare in providing gender affirming hormonal care is critical in ensuring the successful integration of GAC and HIV services^[84]. The requirement for an endocrinologist to monitor gender affirming hormonal care management is a major access barrier for transgender persons, given that so few such professionals exist in South Africa notably in rural areas. Primary care physicians are equipped with the expertise to render this level of transgender hormonal care management, in line with clinical management guidelines^[85]. Adequately resourced, iterative decentralisation of access to gender affirming hormonal care to primary health may reduce the health equity gap by taking services closer to where people live and lessen the burden on tertiary healthcare institutions that are simply unequipped due to severe resource constraints.

The South African NDoH launched the Central Chronic Medicines Dispensing and Distribution (CCMDD) program in 2014 to provide patients who have chronic diseases, including HIV, with alternative access to medications via community-based pick-up points^[86]. The CCMDD program is a differentiated service delivery model in which clinically stable HIV patients can access their medications through a service provider outside of a health facility^[86]. This approach was in response to an overburdened healthcare system and to reduce waiting times for treatment dispensing. The program is useful for transgender women who do not have to interface with healthcare workers very often to collect their treatment and demonstrates the feasibility of a decentralised service delivery model for this population^[86].

Innovation prompted by Covid-19 related service provision disruptions also offer potential models for healthcare reform aimed at wider accessibility of GAC. These include expanded availability of health services accessible via telemedicine and the use of social media platforms to share information, offer psycho-social support and link vulnerable and marginalised persons to services^[87].



Policy Recommendations



Crucial to making the changes require to be able to address HIV, STIs and TB amongst transgender in South Africa are the following policy recommendations. We are recommending a broad intervention to address the health needs of transgender women. This broad approach is necessary to create an environment of safety in social and community contexts to facilitate protection and in clinical situations to facilitate access to treatment.

1

A robust response to HIV, TB and STIs for transgender women includes the creation of an enabling environment which includes policy and financial commitment, addressing stigma and discrimination, especially in public health facilities, community empowerment, and addressing violence against transgender women.

Legal changes

The Alteration of Sex Description and Sex Status Act, 2003 (Act No. 49 of 2003)

2

a. Remove legal barriers and advocate for policy reform to ensure equitable access to gender affirming care, including hormone therapy

b. Demedicalise gender recognition law and allow for broader inclusion beyond the gender binary on the basis of gender self-determination

c. Lower the age of consent to access to gender recognition and GAC to trans youth, prisoners, people with disabilities, refugees and asylum seekers etc. The Department of Home Affairs should engage with trans-led NGOs. There is a need for health policies and correctional services policies to support the ability for trans and gender diverse persons in closed settings to get access to at least gender affirming hormonal care and legal gender recognition.

d. Advocate for medical aid scheme policy amendments to remove exclusion of trans affirming care from prescribed minimum benefits (PMBs) in line with equity and social justice goals underpinning the National Health Insurance (NHI) health system reform

3

We recommend that in line with Resolution 275 of the African Commission that there is a need for the South African Parliament to pass the Prevention and Combating of Hate Crimes and Hate Speech Bill into law. This is a piece of proposed law that trans and gender diverse persons can in future rely on to have issues of hate speech and transphobically motivated hate-crimes being addressed. There is also a need to ensure transgender women's issues as well as broader LGBTQI+ persons issues are integrated into the country's gender machinery through the National Strategic Plan on Gender-based Violence and Femicide to combat trans-misogyny, transphobia, and gender-based violence and femicide directed at the community based on being trans and woman.

4

Adopt the National Gender Affirming Healthcare Guidelines (currently developed under auspices of SA HIV Clinicians Society)

Health systems changes: The following changes are the recommended to the health system, to facilitate access to care

Decentralise hormone therapy initiation and continuity of care from tertiary healthcare level to primary healthcare (PHC) level

Sensitise all PHC towards the needs of transgender women

5

Include hormone therapy in the essential medicines list for PHC

Expand the delivery of hormone therapy initiation and continuing of care to primary healthcare level, to make hormone therapy more accessible to transgender women

Use CCMD as distribution points for chronic medications including hormone therapy

Use smart phones to engage and retain transgender women in care

Train primary healthcare workers to provide GAC to transgender women

6

- Include GAC in medical and healthcare curriculums as part of the curriculum together with sensitivity training.

- Train healthcare workers in the delivery of services for transgender women

- Use peer educators to recruit and retain transgender women in care

- Civil society organisations (CSOs) play a key role in providing transgender friendly psychosocial services, the NDoH should invest in already established trans-led CSOs and work in collaboration with PHC to deliver trans-friendly services

- Train family physicians to offer hormone therapy

- Need for broader disaggregation of routine statistics for surveillance gender disaggregation of routine statistics to be captured from PHC level, in a tool like TIER.net

7

Holistic tailor-made SRHR packages for trans and gender diverse persons incl. addressing issues of fertility, etc.

Include critical data gaps in transgender women's health in national research agenda

8

Urgently address data gaps on transgender women's health, notably a lack of data on prevalence, HIV testing, and treatment of TB and STIs

Institutionalise data disaggregation to include transgender and gender diverse persons across research, monitoring and evaluation activities of government departments and other actors

A more complete understanding of the healthcare needs of transgender women, including their disproportionate burden of HIV, STIs and TB, requires reliable population size estimates

9

Involvement of transgender women and their organisations

The transgender women and their organisations involved in the writing of this policy document have requested to be involved in the setting up of the new systems and to be able to monitor and hold accountable those implementing the systems. The work done as indicated in the above document show the capacity and the determination to play a constructive and powerful role. These organisations should also be used as pathways for the implementation of particularly the new gender affirmative care approach to HIV, STI and TB prevention and treatment.



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