

HIV and trans and non-binary people in the United Kingdom

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"What message are we sending to young people who are trans or gender nonconforming when we don't even count them? We suggest their identities don't even matter."

Laverne Cox, 2015 Social Good Summit

Trans and non-binary people are key populations whose HIV prevention and treatment needs have been neglected. A 2013 meta-analysis of data from 39 studies conducted in 15 countries, reported a global HIV prevalence among trans women of nearly 20%, with trans women estimated to be 49 times more likely than other adults to be living with HIV¹. Moreover, mortality from HIV/AIDS among trans women in a large cohort study was just over 30 times that of age-matched population controls².

Data on HIV among trans and non-binary people in the United Kingdom (UK), data are scant. This is important as HIV prevalence among trans people may differ from global estimates given lower rates of undiagnosed HIV infection in the UK, high levels of viral suppression, and access to free healthcare. Prior to 2014, HIV surveillance systems in England used binary gender identity categories, rendering trans and non-binary populations living with HIV invisible. In 2017, Public Health England (PHE) presented preliminary data from the HIV and AIDS Reporting System (HARS), reporting that 199 trans adults accessed HIV care in 2016, representing 0.3% of all people accessing HIV care in England (personal communication, P Kirwan, Public Health England, 03 May 2018). Of note, these data reveal that trans adults with HIV were twice as likely as other adults to be diagnosed late with a CD4 count of $<350\text{mm}^3$. It is not possible to determine accurately the HIV prevalence among trans women and men in the UK because there are currently no census data on the overall number of persons who identify as trans or non-binary in the UK. What message indeed are we sending to trans people when we do not even count them?

Trans and non-binary people may experience a constellation of social stressors and structural inequalities placing them at increased risk of HIV infection. Stonewall's recently published Trans Report makes for sobering reading³. Two-in-five trans people have experienced a hate crime because of their gender identity in

the last 12 months. More than a quarter of trans people in a relationship have faced domestic abuse from a partner. One-in-four have experienced homelessness. This complex interplay of social vulnerability and widespread transphobia can impact mental health, manifesting in alcohol and substance misuse⁴ and an increased risk of depression, anxiety and suicidal ideation⁵, all of which are in turn associated with an elevated risk of HIV acquisition. Workplace discrimination, poverty and homelessness may place trans people at further risk of HIV. There is a higher prevalence of history of sex work in trans women than in other groups⁶. International data reveal a higher prevalence of HIV among trans women sex workers compared to cis-gender sex workers, and suggest that condomless sex for economic survival or as a result of sexual violence are important contributing factors⁷. A small study from the UK showed a similar high HIV prevalence (37.5%) among trans sex workers, almost all of whom were trans women⁸.

With the widespread availability of condoms, the increasing adoption of treatment as prevention (TasP) and the advent of pre-exposure prophylaxis (PrEP), we have entered a new era in which ending HIV transmission seems possible. Trans and non-binary people may experience particular challenges in accessing and adopting HIV prevention interventions. For instance, among trans women, poor mental health and gender-based violence can constrain their capacity to negotiate condom use⁹. Furthermore, we have limited data on PrEP awareness, acceptability and uptake in trans and non-binary people. Some of the landmark PrEP trials have included trans women as participants, although many have either misclassified trans women's gender identities or have not disaggregated data from trans women from those from men who have sex with men. A post-hoc sub-group analysis of data on 339 trans women in the iPrEx trial revealed a high number of HIV seroconversions in the intervention group, all linked to poor adherence¹⁰. In this analysis, trans women who reported use of feminising hormones were less likely to have detectable drug levels¹⁰. One of the only studies to date in the UK, a survey of 44 trans people testing for HIV at a sex-on-premises venue in London, found that over two-thirds reported no knowledge of PrEP or post-exposure prophylaxis (PEP), with many expressing concerns about cost, reliability and potential drug interactions with hormone therapy¹¹.

We know that trans people experience significant barriers to accessing healthcare, including HIV care. The 2016 People Living with HIV Stigma Survey demonstrated widespread concerns among a small sample of 31 trans people living with HIV about being treated differently by healthcare providers across a range of settings, with substantial numbers avoiding healthcare as a result¹². Other factors that could potentially impact retention in HIV care and adherence to ART among trans women include concerns about potential drug interactions between ART and hormone therapy, and the psychosocial factors outlined earlier¹³. A recent case-notes review of 32 trans women attending a clinic in London for HIV care found that nearly a third had taken a break from their antiretroviral therapy, and that one fifth had a detectable HIV viral load compared to 4% among cis-gender patients attending the general HIV service¹⁴. In contrast, preliminary data from HARS have shown similar levels of virological suppression in trans and cis-gender people accessing HIV care in the UK (personal communication, P Kirwan, Public Health England, 03 May 2018). Further data are required to better characterise and understand the HIV care continuum among trans women in the UK

Trans and non-binary people are a key group in the HIV epidemic, who may be at higher risk of HIV acquisition due to a complex interplay between biological, social and structural factors. Furthermore, those living with HIV may experience poorer outcomes across the HIV care continuum. However, we note the paucity of data on trans and non-binary people and HIV in the UK. PHE's lead on trans data inclusion, including ongoing work in utilising non-binary gender categories, needs to be followed by other health services. We (RJ and ST) also look forward to publishing findings from our own qualitative study on the experiences of trans women living with HIV. Furthermore, forthcoming British Association of Sexual Health and HIV (BASHH) guidelines on the sexual and reproductive healthcare of gender-diverse populations are an important step towards ensuring quality of care. Finally, it is important to acknowledge the important work of CliniQ, the UK's leading holistic sexual health and well-being service for trans people (see <https://cliniq.org.uk/>).

In 2016, leading trans activist Juno Roche convened a meeting bringing together a wide range of stakeholders including trans people, advocacy groups,

clinicians and academics to set an agenda for research into trans people's sexual health in the UK¹⁵. The group identified a number of research priorities as well as highlighting the significant barriers to participation in research including concerns about stigma, fears about drug interactions, and previous experiences of discrimination within healthcare services. It is therefore critical that future research is conducted in partnership with trans people in order to address these concerns. It is time we acknowledge the significant gaps in our understanding of how HIV affects trans and non-binary people in the UK. It is time we count trans and non-binary people.

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Competing interests:

RJ sits on the Advisory Board of the Terrence Higgins Trust and is a Trustee of Saving Lives. KN has previously received speaker honoraria from Gilead Sciences Ltd. and Merck, Sharpe and Dohme Ltd., and acted in a consultancy capacity for Viiv Healthcare Ltd. KN is a trustee of the Clare Project (registered charity 1165746) which provides peer support services for trans and non-binary people in Brighton, UK. ST has previously received a travel bursary funded by Janssen-Cilag through the British HIV Association, speaker honoraria and funding for preparation of educational materials from Gilead Sciences, and is a member of the steering group of SWIFT, a networking group for people involved in research in HIV and women, funded by Bristol Myers Squibb.

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