

Sexually Transmitted Infections**HIV and trans and non-binary people in the UK**

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3 HIV and trans and non-binary people in the United Kingdom
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3 *"What message are we sending to young people who are trans or gender*
4 *nonconforming when we don't even count them? We suggest their identities don't*
5 *even matter."*
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8 Laverne Cox, 2015 Social Good Summit
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12 Trans and non-binary people are key populations whose HIV prevention and
13 treatment needs have been neglected. A 2013 meta-analysis of data from 39 studies
14 conducted in 15 countries, reported a global HIV prevalence among trans women of
15 nearly 20%, with trans women estimated to be 49 times more likely than other adults
16 to be living with HIV¹. Moreover, mortality from HIV/AIDS among trans women in a
17 large cohort study was just over 30 times that of age-matched population controls².
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24 Data on HIV among trans and non-binary people in the United Kingdom (UK),
25 data are scant. This is important as HIV prevalence among trans people in the UK
26 may differ from global estimates given lower rates of undiagnosed HIV infection in
27 the UK, high levels of viral suppression, and access to free healthcare. Prior to 2014,
28 HIV surveillance systems in England used binary gender identity categories,
29 rendering trans and non-binary populations living with HIV invisible. In 2017, Public
30 Health England (PHE) presented preliminary data from the HIV and AIDS Reporting
31 System (HARS), reporting that 199 trans adults accessed HIV care in 2016,
32 representing 0.3% of all people accessing HIV care in England (personal
33 communication, P Kirwan, Public Health England, 03 May 2018). Of note, these
34 data reveal that trans adults with HIV were twice as likely as other adults to be
35 diagnosed late with a CD4 count of <350mm³. It is not possible to determine
36 accurately the HIV prevalence among trans women and men in the UK because
37 there are currently no census data on the overall number of persons who identify as
38 trans or non-binary in the UK. What message indeed are we sending to trans people
39 when we don't even count them?
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51 Trans and non-binary people may experience a constellation of social
52 stressors and structural inequalities placing them at increased risk of HIV infection.
53 Stonewall's recently published Trans Report makes for sobering reading³. Two-in-
54 five trans people have experienced a hate crime because of their gender identity in
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3 the last 12 months. More than a quarter of trans people in a relationship have faced
4 domestic abuse from a partner. One-in-four have experienced homelessness. This
5 complex interplay of social vulnerability and widespread transphobia can impact
6 mental health, manifesting in alcohol and substance misuse⁴ and an increased risk
7 of depression, anxiety and suicidal ideation⁵, all of which are in turn associated with
8 an elevated risk of HIV acquisition. Workplace discrimination, poverty and
9 homelessness may place trans people at further risk of HIV. There is a higher
10 prevalence of history of sex work in trans women than in other groups⁶. International
11 data reveal a higher prevalence of HIV among trans women sex workers compared
12 to cis-gender sex workers, and suggest that condomless sex for economic survival
13 or as a result of sexual violence are important contributing factors⁷. A small study
14 from the UK showed a similar high HIV prevalence (37.5%) among trans sex
15 workers, almost all of whom were trans women⁸.

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

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3 We know that trans people experience significant barriers to accessing
4 healthcare, including HIV care. The 2016 People Living with HIV Stigma Survey
5 demonstrated widespread concerns among a small sample of 31 trans people living
6 with HIV about being treated differently by healthcare providers across a range of
7 settings, with substantial numbers avoiding healthcare as a result¹². Other factors
8 that could potentially impact retention in HIV care and adherence to ART among
9 trans women include concerns about potential drug interactions between ART and
10 hormone therapy, and the psychosocial factors outlined earlier¹³. A recent case-
11 notes review of 32 trans women attending a clinic in London for HIV care found that
12 nearly a third had taken a break from their antiretroviral therapy, and that one fifth
13 had a detectable HIV viral load compared to 4% among cis-gender patients
14 attending the general HIV service¹⁴. In contrast, preliminary data from HARS have
15 shown similar levels of virological suppression in trans and cis-gender people
16 accessing HIV care in the UK (personal communication, P Kirwan, Public Health
17 England, 03 May 2018). Further data are required to better characterise and
18 understand the HIV care continuum among trans women in the UK
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30 Trans and non-binary people are key groups in the HIV epidemic, who may
31 be at higher risk of HIV acquisition due to a complex interplay between biological,
32 social and structural factors. Furthermore, those living with HIV may experience
33 poorer outcomes across the HIV care continuum. However, we note the paucity of
34 data on trans and non-binary people and HIV in the UK. PHE's lead on trans data
35 inclusion, including ongoing work in utilising non-binary gender categories, needs to
36 be followed by other health services. We (RJ and ST) also look forward to
37 publishing findings from our own qualitative study on the experiences of trans
38 women living with HIV. Furthermore, forthcoming British Association of Sexual
39 Health and HIV (BASHH) guidelines on the sexual and reproductive healthcare of
40 gender-diverse populations are an important step towards ensuring quality of care.
41 Finally, it is important to acknowledge the important work of CliniQ, the UK's leading
42 holistic sexual health and well-being service for trans people (<https://cliniq.org.uk/>).
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53 In 2016, leading trans activist Juno Roche convened a meeting bringing
54 together a wide range of stakeholders including trans people, advocacy groups,
55 clinicians and academics to set an agenda for research into trans people's sexual
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3 health in the UK¹⁵. The group identified a number of research priorities as well as
4 highlighting the significant barriers to participation in research including concerns
5 about stigma, fears about drug interactions, and previous experiences of
6 discrimination within healthcare services. It is therefore critical that future research is
7 conducted in partnership with trans people in order to address these concerns. It is
8 time we acknowledge the significant gaps in our understanding of how HIV affects
9 trans and non-binary people in the UK. It is time we count trans and non-binary
10 people.
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18 Group for Trans Health Research for their insights and expertise (Vanessa Crawford,
19 Nick Douglas, Ian Green, Cheryl Gowar, Laura Mitchell, Juno Roche, Aedan
20 Wolton).
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25 Competing interests:

26 RJ sits on the Advisory Board of the Terrence Higgins Trust and is a Trustee of
27 Saving Lives. KN has previously received speaker honoraria from Gilead Sciences
28 Ltd. and Merck, Sharpe and Dohme Ltd., and acted in a consultancy capacity for Viiv
29 Healthcare Ltd. KN is a trustee of the Clare Project (registered charity 1165746)
30 which provides peer support services for trans and non-binary people in Brighton,
31 UK. ST has previously received a travel bursary funded by Janssen-Cilag through
32 the British HIV Association, speaker honoraria and funding for preparation of
33 educational materials from Gilead Sciences, and is a member of the steering group
34 of SWIFT, a networking group for people involved in research in HIV and women,
35 funded by Bristol Myers Squibb. VD has no competing interests to declare.
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