



# Trans\* people and HIV:

How can policy work improve HIV prevention, treatment and care for trans\* people in the UK?



## **Our strategic goals**

All our work is focused on achieving five strategic goals:

- effective HIV prevention in order to halt the spread of HIV.
- early diagnosis of HIV through ethical, accessible and appropriate testing.
- equitable access to treatment, care and support for people living with HIV.
- enhanced understanding of the facts about HIV and living with HIV in the UK.
- eradication of HIV-related stigma and discrimination.

## **Our vision**

Our vision is a world in which people living with HIV are treated as equal citizens with respect, dignity and justice, are diagnosed early and receive the highest standards of care, and in which everyone knows how, and is able, to protect themselves and others from HIV infection.

**NAT is the UK's leading charity dedicated to transforming society's response to HIV.**

**We provide fresh thinking, expertise and practical resources.**

**We champion the rights of people living with HIV and campaign for change.**

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## Contents

<b>1. Introduction</b>	<b>4</b>
<b>2. Data quality and research</b>	<b>6</b>
HIV risk among trans* people	6
Data limitations	7
Improvements in UK Data Collection	8
<b>3. Epidemiology and HIV risk factors for trans* people</b>	<b>10</b>
HIV risk in gender affirming medical procedures	10
Other individual factors that increase HIV risk	11
The transphobic context for individual behaviour	11
Differences between and within trans* communities	13
The impact of transphobia in healthcare on HIV treatment, care and prevention	14
<b>4. Strategies and interventions</b>	<b>16</b>
Community empowerment	16
Institutional measures: laws and policies	17
Structural and social measures: tackling socio-economic and cultural injustice	18
Structural measures: addressing barriers to healthcare and prevention	19
Behavioural interventions	21

# 1. Introduction

**Global data show that trans\*<sup>1</sup> people are at significantly increased risk of acquiring HIV. However, there is no robust data for HIV prevalence or new diagnoses among trans\* people in the UK, or even a credible trans\* population count. This lack of data is symptomatic of the generalised peripheralisation of trans\* people within society, as well as in the more specific experience of healthcare.**

To help overcome this erasure of trans\* people in the context of HIV prevention, treatment and care, National AIDS Trust (NAT) has conducted a scoping exercise to:

1. identify what is already known – and not known – about trans\* people and HIV in the UK, in relation to both the likely elevated risk of acquiring HIV and the experience of living with HIV as a trans\* person
2. clarify what scope there could be for NAT to contribute through our policy work to improvements in HIV prevention, treatment and care for trans\* people in the UK.

This exercise involved an evidence review of the major themes found in published literature, and discussions with key informants who provide services for, and / or are part of trans\* communities. For the most part, we have decided not to attribute to individuals the insights drawn from these discussions, but they are an absolutely vital part of the thought process that we have started here and intend to pursue.

In that regard, NAT would like to thank the following people, and acknowledge the importance of their contribution to this briefing:

**Juno Roche**

**Michelle Ross**, CliniQ

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**Dr Nick Douglas**, London School of Hygiene and Tropical Medicine

**Dr Kate Nambiar**, Brighton and Sussex University Hospitals NHS Trust

**the SWISH team at Terrence Higgins Trust.**

We would also like to thank the HIV surveillance team at Public Health England for their sharing of information about data collection and its pitfalls, and the M•A•C AIDS Fund who have funded the production of this briefing.

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<sup>1</sup> We use the term 'trans\*' to emphasise the breadth of gender identities encapsulated in the term.

In line with the World Health Organisation (WHO), we have used a broad definition of trans\*, to include “all people whose internal sense of their gender (their gender identity) is different from the sex they were assigned at birth.”<sup>2</sup>

It is common in academic and policy work about trans\* people, and even among trans\* communities, for trans\* people to identify or be identified as ‘trans\* men’ or ‘trans\* women’.

For some, including some of the people NAT spoke to for this project, this terminology fails to reflect

the range of gender identities that may occur along both the trans\* feminine and the trans\* masculine spectra.<sup>3</sup> However this report largely involves direct reference to data that identifies trans\* men or women, and we have retained the terms used in published research. We use the term ‘nonbinary’ to refer to those people who do not identify within the binary male/female gender classification.

Given the relative paucity of evidence available for trans\* people in the UK, references made to trans\* people in this briefing are not UK specific unless indicated.

Each of the sections of this report concludes with a list of recommendations but there are some more general themes that have come out of the research process. Based on these themes, NAT make the following commitments:

- We will work to maintain contacts within trans\* communities, keep up to date with the dominant topical issues for trans\* people, and co-produce policy work as appropriate.
- We will promote trans\* visibility; support action to remove legal, institutional and structural barriers to trans\* equality; and adopt pro-active measures to challenge trans\* stigma across all societal arenas.
- Where opportunities arise, we will advocate for appropriate resources and funding to be made available for trans\* organisations to conduct equality and anti-discrimination work.
- A comprehensive trans\*-specific research agenda must be developed to address biological, behavioural, and societal factors of HIV risk. Where appropriate, we will play our part in helping to develop this agenda.

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<sup>2</sup> World Health Organization (WHO), *Transgender people and HIV*.

<sup>3</sup> See, for example, Reisner SL *et al.* 'Integrated and Gender-Affirming Transgender Clinical Care and Research' *J Acquir Immune Defic Syndr.* 2016; 72 (suppl 3): S235-S242; Poteat T *et al.* 'Global Epidemiology of HIV Infection and Related Syndemics Affecting Transgender People' *J Acquir Immune Defic Syndr.* 2016; 72 (suppl 3): S210-S219.

## 2. Data quality and research

**The data show that HIV prevalence is far higher among trans\* people than it is among cisgender people,<sup>4</sup> although there is marked difference between sub-groups. However, existing data is far from robust.**

### HIV risk among trans\* people

There have been very few epidemiological studies among trans\* people, but those that exist have identified high HIV prevalence, ranging from 8% to 68%.<sup>5</sup> The data suggest that there is a heavy burden of HIV on trans\* women, especially on those who have sex with men.<sup>6</sup> Worldwide, HIV prevalence among trans\* women is reported to be 19%; trans\* women are 49 times more likely to be HIV positive than the general population.<sup>7</sup>

Interestingly, for the 15 countries with laboratory confirmed data that comprised this global meta-analysis, HIV prevalence among transgender women was lower in low and middle-income countries (17.7%) than it was in high-income countries (21.6%).

Despite this data, some studies have shown that trans\* men and women are equally at risk for HIV acquisition, possibly explained by trans\* men who have sex with men (MSM) being the receptive sexual partner.<sup>8</sup>

In addition, various studies have identified increased vulnerabilities for acquiring HIV among particular sub-groups of trans\* people, including young and ethnic minority trans\* women;<sup>9</sup> racial and ethnic minorities / black, Asian and minority ethnic (BAME) people;<sup>10</sup> young people;<sup>11</sup> migrants;<sup>12</sup> and sex workers.<sup>13</sup>

For example, in 2013 the Joint UN Programme on HIV/AIDS estimated that young people aged 15-24 accounted for 35% of all new HIV infections in

4 Cisgender people are those whose gender identity matches their sex assigned at birth.

5 World Health Organisation (WHO), *Prevention of HIV and Other Sexually Transmitted Infections Among Men Who Have Sex with Men and Transgender People: Recommendations for a Public Health Approach*, Geneva, 2011

6 WHO, 2015, *op. cit.* p.6

7 Baral SD *et al.* 'Worldwide burden of HIV in transgender women: a systematic review and meta-analysis' *Lancet Infect Dis.* 2012; 13 (3): 214–222.

8 Wansom T *et al.* 'Transgender populations and HIV: unique risks, challenges and opportunities' *J Virus Erad.* 2016; 2 (2): 87–93. See also Reisner SL *et al.* 'Sexual risk behaviors and psychosocial health concerns of female-to-male transgender men screening for STDs at an urban community health center' *AIDS Care.* 2014; 26 (7): 857–64; Bauer GR *et al.* 'Sexual health of trans men who are gay, bisexual, or who have sex with men: results from Ontario, Canada' *Int J Transgend.* 2013; 14 (2): 66–74; Rowiak S, Chesla C. 'Coming out for a third time: transmen, sexual orientation, and identity' *Arch Sex Behav.* 2013; 42 (3): 449–61; Bockting W *et al.* 'Gay and bisexual identity development among female-to-male transsexuals in North America: emergence of a transgender sexuality' *Arch Sex Behav.* 2009; 38 (5): 688–701; Schleifer D 'Make me feel mighty real: gay female-to-male transgenderists negotiating sex, gender, and sexuality' *Sexualities.* 2006; 9 (1): 57–75.

9 Garofalo R *et al.* 'Behavioral Interventions to Prevent HIV Transmission and Acquisition for Transgender Women: A Critical Review' *J Acquir Immune Defic Syndr.* 2016; 72 (suppl 3): S220 – S225.

10 Choudrey S, *Inclusivity: Supporting BAME Trans people.* nd. (Available at [www.gires.org.uk](http://www.gires.org.uk)).

11 World Health Organisation (WHO), *HIV and Young Transgender People: A Technical Brief.* Geneva, 2014.

12 National Center for Transgender Equality, *Our Moment for Reform: Immigration and Transgender People.* Washington DC, 2013.

13 Operario D *et al.* 'Sex work and HIV status among transgender women: systematic review and meta-analysis' *J Acquir Immune Defic Syndr.* 2008; 48 (1): 97–103.

adults.<sup>14</sup> Trans\* young people are then subject to the intersecting increased risks associated with both their youth and their gender identity. In another example, international data suggest that trans\* women sex workers have an especially high HIV prevalence of 27%, which is significantly higher than for other categories of people who are at high risk including male sex workers, cisgender female sex workers, and for trans\* women who do not engage in sex work.<sup>15</sup> Interestingly, the SWISH team at the Terrence Higgins Trust told NAT that HIV prevalence is not high among the trans\* sex workers they support. While there could be many reasons for this, it points to the importance of having UK specific data.

concern trans\* women with little focus on trans\* men, and even less on those who identify outside binary gender categories.<sup>16</sup> Moreover, there are concerns that studies designed for the purpose of HIV prevention research recruit in 'risky venues' and therefore overidentify HIV prevalence in certain identity groups.<sup>17</sup>

One of the causes of inadequate data is the absence of disaggregation by gender identity in research, and an associated misidentification of trans\* people. For example trans\* women have often been misclassified as MSM in clinical studies, which both stymies good epidemiological knowledge and exacerbates the invisibility of trans\* people.<sup>18</sup>

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**"The available data has severe limitations. There is no UK specific data. The datasets usually concern trans\* women with little focus on trans\* men, and even less on those who identify outside binary gender categories."**

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It is vital that this variability is taken into consideration in understanding and responding to HIV risk for trans\* people. Therefore, the remainder of this document works from the principle that although some analyses and measures will apply to 'trans\* people', writ large, others will relate to specific sub-groups of trans\* people. This also reflects comments from trans\* people about the existence of multiple trans\* communities, rather than a homogenous 'trans community'.

### Data limitations

Despite being frequently cited, the available data have severe limitations. There are no UK specific data, and 'global' data are drawn from 15 countries with the vast majority of research studies being conducted in North America. The datasets usually

Although this problem is now recognised, and rectified in some cases, additional difficulties in using collected data include inconsistency in defining 'trans\*' across research studies and study participants not always wanting to identify their trans\* status, which may be harder to reconcile.<sup>19</sup>

Collecting good, inclusive data on gender is not a straightforward matter. There are a set of concerns around privacy, acceptability and confidentiality, which relate to whether gender identity questions should be asked at all and how the data must be treated once collected. However, as one trans\* person told NAT "unless we're counted, we don't count", and the priority should be towards collecting, storing and using data in ways that are acceptable to everyone.

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<sup>14</sup> WHO, 2014, *op. cit.*

<sup>15</sup> Operario *et al.*, 2008, *op. cit.*; Joint United Nations programme on HIV/AIDS, *The Gap report 2014: transgender people*. Geneva, 2014.

<sup>16</sup> Mayer KH *et al.* 'Transgender People and HIV Prevention: What We Know and What We Need to Know, a Call to Action' *J Acquir Immune Defic Syndr*. 2016; 72 (suppl 3): S207-S209; WHO, 2015, *op. cit.* p.7.

<sup>17</sup> Mayer *et al.*, 2016, *op. cit.*

<sup>18</sup> Wansom *et al.*, 2016, *op. cit.*; Mayer *et al.*, 2016, *op. cit.*

<sup>19</sup> Wansom *et al.*, 2016, *op. cit.*

In this context, a second set of concerns relates to the range of gender identities and the appropriate terminology for classifying them.<sup>20</sup> This matter is of particular political consequence, in that being able to define one's own gender has been a crucial aspect of securing equality for trans\* people, and yet that desire for flexibility has complicated the data collection that would allow trans\* people to be counted. NAT was made aware of this both through discussions with trans\* people and from attending conferences and workshops where these matters were raised. There is no consistent response to this dilemma from within trans\* communities. Suffice to say here that it remains a contentious issue over which care must be taken, and practices such as clinicians defining the gender identity of their patients are unhelpful.

These definitional matters are not trivial. Initial results from the IPrEX study<sup>21</sup> described 29 participants (1%) who were assigned male at birth but described their gender as 'woman' at the time of the trial. New results published 5 years later from the same data identified 339 trans\* participants (14%) when it included those who identified as trans\* or who used feminising hormones.<sup>22</sup>

It is debateable whether existing data can reasonably be used to make inferences about HIV prevalence and risk among trans\* people worldwide, and even less feasible to extrapolate from global data to explain circumstances in the UK. Beyond not having accurate prevalence statistics for the UK, these data uncertainties effectively lead to the erasure of trans\* people from debates around HIV and healthcare more broadly, and make it difficult to assess the range of services required to address HIV-related need among the trans\* population in the UK.

## Improvements in UK data collection

Poor data and the lack of research studies are mutually causal, and breaking this cycle with good quality data is now a matter of urgency in the UK.<sup>23</sup> There has been a relatively recent upswing in attention to the health of trans\* people in research circles. For example, *The Lancet* published its first series on 'trans\* health' in June 2016, and the *Journal of Acquired Immune Deficiency Syndromes* published a 'call to action' for HIV related research to be re-focused on trans\* people.<sup>24</sup> It is vital that this approach is fostered in the UK.

UK specific data absences and inaccuracies have begun to be rectified. Public Health England (PHE) has started collecting data by gender identity in the HIV and AIDS Reporting System (HARS) with the first data expected to be published in late 2017, and the Stigma Index and Positive Voices surveys have already produced data specific to trans\* people.

It is impossible, however, to calculate accurate prevalence statistics without having a good understanding of the size of the trans\* population. One estimate suggests that there may be 650,000 trans\* people in the UK,<sup>25</sup> but without a consistent definition of 'trans\*' and inclusive data collection methods there is wide recognition that statistics are far from robust.<sup>26</sup>

The tendency to use specialist gender identity clinic data for population estimates is a poor solution to the lack of data, because only a minority of trans\* people access these clinics.<sup>27</sup>

In 2009, the Office of National Statistics (ONS) appeared to offset responsibility for the data absence, asserting "those more closely associated with the trans community" should be working towards improved population estimates.<sup>28</sup> Since then, ONS has started consultations on including

20 Office for National Statistics (ONS), *Trans Data Position Paper*, 2009 [<http://www.ons.gov.uk/ons/guide-method/measuring-equality/equality/equality-data-review/trans-data-position-paper.pdf>].

21 IPrEX was the first human study of PrEP as a prevention strategy that used a randomised controlled trial to produce a statistically meaningful result. It reported in November 2010.

22 Grant RM *et al.* 'Transgender Women in Clinical Trials of Pre-Exposure Prophylaxis' *J Acquir Immune Defic Syndr.* 2016; 72 (suppl 3): S226-S229.

23 Personal communication, Dr Kate Nambiar, HIV clinician at CliniciT in Brighton.

24 Mayer *et al.*, 2016, *op. cit.*; Reisner *et al.*, 2016, *op. cit.*

25 Gender Identity Research and Education Service (GIRES), cited in Women and Equalities Committee, *Transgender Equality*, London, 2015 [<http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/390.pdf>].

26 ONS, 2009, *op. cit.*; Women and Equalities Committee, 2015, *op. cit.*

27 Winter S *et al.* 'Transgender people: Health at the margins of society' *Lancet* 2016; 388: 390-400; see also Winter S, Conway L, *How many trans\* people are there? A 2011 update incorporating new data* [<http://www.transgenderasia.org/paper-how-many-trans-people-are-there.htm>].

28 ONS, 2009, *op. cit.* p.3.



gender identity in the census, but it is not expected to appear as a variable in the 2021 survey meaning that we can expect a time lag of about 20 years until good population data may be available.

ONS household surveys, which could include a gender identity question much sooner than the 2031 census, are unlikely to be sufficient for good population estimates due to the relatively small size of the trans\* population.

In relation to improved data collection, some of the trans\* people we spoke to said that overcoming their erasure from society requires creating a new visibility for people from trans\* communities. We are already seeing further attention to trans\* lives, particularly in the media.<sup>29</sup> However, there may be a downside to increased exposure, including the

creation of stereotypes and increased vocalisation of stigmatising attitudes. While the possibility for exacerbating stigma and prejudice is not a good reason to avoid better data collection and consequent improvements in healthcare provision, it is important not to ignore the potential difficulties that increased exposure may generate for individuals.

To develop solutions to the problem of inadequate data that are both effective and acceptable to trans\* communities, it is important that decisions about data collection (including definitions of gender identity, information collected, and methods of collection) take into account the expertise and preferences of trans\* people.

## Recommendations

- ONS must start collecting data disaggregated by gender identity but, given the time lag for achieving useful information, efforts to establish interim measures are crucial.
- As a matter of urgency, Public Health England should be tasked with, and adequately resourced for collecting good data on sexual health and HIV risk for trans\* people.
- NAT should foster joint working with trans\* communities to respond to and utilise HARS and Positive Voices data when it becomes available.
- NAT should explore options for working with trans\* organisations to establish whether existing data that they hold can be used to advocate effectively for improved trans\* healthcare provision. Any such exercise will need to be mindful of confidentiality and information governance requirements, and be based in collaborative working to draw on the expertise of trans\* organisations.
- All those undertaking future work such as data collection and policy analysis must recognise and account for differences between and within trans\* communities in their work.
- Improved delivery of healthcare for trans\* people, support to empower trans\* communities, and efforts to tackle trans\* related stigma cannot wait for more robust data to be available. Where possible, NAT should use emerging policy-related opportunities to advocate for trans\* people's rights and needs.
- It is likely that the impact of advocacy work around trans\* issues will be most appropriately measured in relation to the significance of changes that can be made for a relatively small population. NAT must take this into account when identifying potential work streams.
- The work that is being done by trans\* organisations and individuals to increase the visibility of trans\* people must be supported by organisations working across health and social justice concerns, including NAT.

<sup>29</sup> amfAR, *Trans Populations and HIV: Time to End the Neglect*, Washington DC, 2014, p.4.

# 3. Epidemiology and HIV risk factors for trans\* people

**While there may be similarities across groups considered to be at risk of acquiring HIV, it is important to understand the specificity of HIV risk and epidemiology for trans\* people in order to provide appropriate, targeted services for both prevention and healthcare.**

Trans\* people can have an elevated risk profile based on biological factors and specific behaviours. However, these individual level risks cannot be viewed in isolation as they are affected by the societal context of transphobia operating across multiple arenas. While it is crucial to recognise the role of these broader societal factors in driving certain individual level risks, it is similarly important to acknowledge that they are not necessarily causal. In other words, a trans\* identity does not automatically yield higher risk behaviour.

## HIV risk in gender affirming medical procedures

Trans\* people may choose to undergo medical gender affirmation procedures. Good information about the potential impact of such procedures on HIV prevention and available treatments is crucial to allow both trans\* people and medical professionals to identify the most appropriate strategies for limiting risk.

- Some forms of oestrogen are known to be affected by antiretroviral therapy (ART) which

has resulted in an identified tendency for some trans\* women to prioritise hormone therapy over HIV treatment or pre-exposure prophylaxis (PrEP).<sup>30</sup> Studies have shown that some types of oestrogen do not interact with ART, but no studies have been conducted with trans\* women who take larger hormone doses than cisgender women.<sup>31</sup> Moreover, many trans\* women access hormone therapy by using oral contraceptives without medical supervision.<sup>32</sup>

- Progesterone is known to increase HIV susceptibility by thinning the vaginal epithelium, affecting the immune response, and increasing the availability of target cells for HIV infection. However, robust data are lacking due to an absence of meta-analysis reviews and no research has been conducted with trans\* women.<sup>33</sup>
- Testosterone is not reported to interact with ART but it does cause vaginal atrophy that may increase HIV risk depending on sexual behaviour, although adequate data are not available.<sup>34</sup>

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<sup>30</sup> WHO, 2015, *op. cit.*, p7; Grant *et al.*, 2016, *op. cit.*; Schneiders M, *Values and preferences of transgender people: a qualitative study*. Geneva: World Health Organization, 2014.

<sup>31</sup> Wansom *et al.*, 2016, *op. cit.*

<sup>32</sup> *Ibid*

<sup>33</sup> Wansom *et al.*, 2016, *op. cit.*

<sup>34</sup> Wansom *et al.*, 2016, *op. cit.*; WHO, 2015, *op. cit.*, p7.

- There are concerns about trans\* people who inject self-prescribed hormones and soft tissue fillers without medical supervision. While there are a range of attendant health risks which could exacerbate clinical complications of HIV as well as being problematic in themselves, needle sharing increases the risk of acquiring HIV and other blood borne viruses.<sup>35</sup>
- It is recognised that different surgical techniques for construction of neovaginas may affect the risk of HIV acquisition, particularly in relation to the different tissue used, however this has yet to be researched adequately.<sup>36</sup> Even less attention has been paid to the HIV risk attached to genital surgeries undergone by trans\* men.

While these represent different types of biological risks, some – particularly prioritising hormone therapy over ART or PrEP and the use of unsupervised medical processes – could be avoided with access to good information and appropriate healthcare.

However, it is abundantly clear that research and the availability of robust data are lacking in all areas of medical gender affirming procedures.<sup>37</sup>

### Other individual factors that increase HIV risk

While the increased HIV risk associated with gender affirming medical procedures is only a factor for the minority of trans\* people who have opted to follow that route, other individual risk factors can attach to all those who identify as trans\*.

These individual factors include engaging in anal receptive sex and an increased risk of sexual partners with HIV.<sup>38</sup> Trans\* people are also more likely to engage in sex work<sup>39</sup> which carries with

it risk taking behaviour and potential difficulties in negotiating safe sex practice borne out of differential power relations.

Sex work is also significantly associated with STI diagnosis.<sup>40</sup> However, while infection with STIs is a known risk for HIV acquisition in MSM, and some studies show high STI rates among trans people in the US,<sup>41</sup> there is not good data available for STI rates among trans\* people in the UK and inadequate knowledge about the risk contexts for STI acquisition especially in the neovagina.<sup>42</sup>

Depression, anxiety, suicidal ideation, substance abuse and experience of violence are highly prevalent among trans\* people. These psychosocial issues affect inter-personal power relationships, can create a lack of concern for general health and well-being and sexual health, and may manifest in the form of seeking gender affirmation and affection through sex. In turn this leads to vulnerability to HIV acquisition through increased risk taking behaviour in relation to both sexual practices and attitudes towards prioritising of hormone therapy above treatment and prevention.<sup>43</sup>

Trans\* people are also less likely to access services relating to healthcare, including specifically HIV related healthcare and prevention, which would mitigate other risk factors.<sup>44</sup>

### The transphobic context for individual behaviour

Individual choices are not created in a vacuum but are affected by a wider transphobia that establishes stigmatising and discriminatory practices across multiple arenas.<sup>45</sup> Therefore, individual decisions around risk cannot be understood properly without attending to broader societal phenomena.

35 Wansom *et al.*, 2016, *op. cit.*; WHO, 2015, *op. cit.*, p7, p15.

36 Radix A 'HIV and vulnerable populations: transgender medicine' Invited lecture at the 21st Annual British HIV Association Conference, Brighton, Friday 24 April 2015; Wansom *et al.*, 2016, *op. cit.*

37 WHO, 2015, *op. cit.*, p7.

38 Mayer *et al.*, 2016, *op. cit.*

39 Operario *et al.*, 2008, *op. cit.*; amfAR, 2014, *op. cit.*

40 Solomon, MM *et al.* 'Transactional sex and prevalence of STIs: a cross-sectional study of MSM and transwomen screened for an HIV prevention trial' *International Journal of STD & AIDS*. 2015; 26 (12): 879–886.

41 amfAR, 2014, *op. cit.*

42 Wansom *et al.*, 2016, *op. cit.*

43 Mayer *et al.*, 2016, *op. cit.*; Wansom *et al.*, 2016, *op. cit.*

44 amfAR, 2014, *op. cit.*, p4; Winter *et al.*, 2016, *op. cit.*

45 Mayer *et al.*, 2016, *op. cit.*; Wansom *et al.*, 2016, *op. cit.*

The sometime tendency to level blame at individual practices and decisions is unhelpful, not least because discounting transphobic contexts results in a partial understanding of the epidemiology of HIV among the trans\* population. Effectively, failure to understand the impact of transphobia is a failure to understand trans\* lives.

Varying analytical frameworks exist but, broadly, transphobic practices can be classified as social and inter-personal (e.g. stigma, rejection, violence), structural (socio-economic injustice), and institutional (discriminatory law and policy).<sup>46</sup>

as a distinct cultural grouping, which is not a factor in the UK.<sup>48</sup> It would be useful to have a better understanding of how far structural and social stigmatising practices lead to economic and social marginalisation in the UK, and the extent to which that leads to choices, including sex work, that put individuals at increased risk of acquiring HIV.

Institutional level transphobia includes discriminatory laws and policies that establish trans\* people as unequal and help to marginalise them. In some countries this manifests directly, such as through the criminalisation of trans\* identity expression.<sup>49</sup>

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## **"Individual choices are not created in a vacuum but are affected by a wider transphobia that establishes stigmatising and discriminatory practices across multiple arenas."**

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Transphobia at the social and inter-personal level shapes the differential power relations that can manifest in various forms, including violence towards or rejection of the trans\* person. These personal interactions can undermine mental health and self-esteem, and establish trans\* people as vulnerable.

Structural level or socio-economic transphobia includes drivers such as employment-related discrimination resulting in poverty, lack of trans-inclusive education, and media based stigma creating cultural misrepresentations. Some of these phenomena will have a direct impact on HIV risk by driving people into sex work or transactional sex, either to fund expensive gender affirming procedures or simply for survival.<sup>47</sup> However they also go to the individual's general sense of wellbeing, putting them at greater risk of mental health difficulties and substance abuse, and therefore at increased vulnerability for behavioural risk.

The behavioural responses to stigma are particularly seen in cultures where trans\* people are recognised

In the UK institutional transphobia is more subtle and takes the form of inadequate legislation around gender recognition and trans\* equality,<sup>50</sup> or the lack of attention to trans\* people in sexual health strategies, and so forth.

Laws and policies can also have discriminatory effects without necessarily being targeted specifically at trans\* people. The criminalisation of sex work is particularly problematic for trans\* people in countries where encounters with police can lead to further violence. Even where that threat is not pervasive, criminalisation of sex work further marginalises trans\* people who rely on sex work by removing their recourse to legal protection against violence.<sup>51</sup>

These multi-scale, multi-arena factors combine to create a syndemic, whereby psychosocial health problems (depression, substance use, experience of violence, internalised transphobia) exacerbate HIV risk and contribute to poor treatment outcomes for trans\* people.<sup>52</sup> This syndemic can have a direct experience on HIV risk by driving people towards

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46 WHO, 2015, *op. cit.*, p.4; Mayer *et al.*, 2016, *op. cit.*; Poteat *et al.*, 2015, *op. cit.*

47 Operario *et al.*, 2008, *op. cit.*

48 Mayer *et al.*, 2016, *op. cit.*

49 Winter, S. *et al.* 'Synergies in health and human rights: a call to action to improve transgender health' *Lancet*. 2016; 388: 318-321.

50 Neither the Gender Recognition Act (2004) nor the Equality Act (2010) are adequate for real trans\* inclusion.

51 WHO, 2015, *op. cit.*

52 Poteat *et al.*, 2016, *op. cit.*

sex work, but it also has an indirect effect through installing internalised transphobia and generally undermining the wellbeing and mental health of trans\* people,<sup>53</sup> which in turn renders them more likely to engage in behaviours that increase HIV risk.

### Differences between and within trans\* communities

As already discussed, the data identify increased HIV risk for certain trans\* communities, including young people, migrants, sex workers, and BAME people. This heightened risk reflects the specific vulnerabilities for acquiring HIV among these groups, which is in part due to the way in which transphobia intersects with other markers of oppression and marginalisation such as race, class, sexual orientation, HIV status, migrant status, and so forth to both compound and complicate its impact.<sup>54</sup>

According to the Inter Agency Working Group (IAWG), for young trans\* people the experience of violence, stigma and discrimination (including rejection by families, social marginalisation, self-stigma, and denial of access to appropriate healthcare services) intersects with the ‘particular vulnerabilities of youth’, increasing the risk that they will engage in condomless sex and needle sharing.<sup>55</sup>

A US study shows that migrant status increases trans\* people’s vulnerability to discrimination and violence as immigration law compounds the employment insecurity, poverty, health risk, access to services, and social isolation already experienced by trans\* people.<sup>56</sup> Although UK immigration law and context is very different from the US, an HIV clinician recently reported that increasing numbers of her patients are of South American origin, and that they show different cultural responses to HIV alongside the difficulties associated with accessing healthcare as a migrant in the UK.<sup>57</sup>

In part, the impact of migrant status intersects with exclusion based on race in the UK, with BAME trans\* people facing discrimination based on race, gender and religion, as well as under-representation within the trans\* community and in services designed for trans\* people.<sup>58</sup>

All these examples highlight how the clustering of vulnerabilities can multiply the risk of HIV acquisition.

The specificity of experience that distinguishes between different sub-groups of trans\* people show the extent to which it makes sense to refer to ‘trans\* communities’, rather than imply that there is a single, homogenous ‘trans community’. However, differences between trans\* people are more than group based. Individual responses to the pressures of social, structural and institutional transphobias will vary, and it is crucial that models of the transphobia syndemic refrain from casting individual behaviours as necessary responses to broader triggers, which is inaccurate, could exacerbate stigma, and presents a disempowering narrative of trans\* people as vulnerable rather than resilient.<sup>59</sup>

Moreover, as with using global data to describe UK prevalence, using global sociologies to describe a UK-specific version of the syndemic may overstate reality. Certainly trans\* people and their advocates in the UK report versions of transphobia, but legal protections and socio-cultural norms are markedly better in the UK than in some countries, with a mitigating effect on transphobia and its consequences.<sup>60</sup>

Therefore, while some call for urgent research to improve understanding of individual HIV risk factors, including STI correlation, access to healthcare, adherence, and understanding and perception of risk,<sup>61</sup> it is also important to establish the UK-specific (and potentially sub-national) manifestations of the transphobic context for individual choices.

53 Mayer *et al.*, 2016, *op. cit.*

54 Lacombe-Duncan A ‘An Intersectional Perspective on Access to HIV-Related Healthcare for Transgender Women’, *Transgender Health*. 2016; 1 (1): 137-141.

55 WHO, 2014, *op. cit.* p.7

56 National Center for Transgender Equality, 2013, *op. cit.*

57 Dr Charlotte Cohen, presentation given to the All-Party Parliamentary Group on Sexual and Reproductive Health, *Closing the gap: Improving the sexual health outcomes of Black, Asian and Minority Ethnic communities*, October 2016.

58 Choudrey, nd, *op. cit.*

59 Lacombe-Duncan, 2016, *op. cit.*

60 Personal communication, Dr Kate Nambiar.

61 Wansom *et al.*, 2016, *op. cit.*

## The impact of transphobia in healthcare on HIV treatment, care and prevention

Transphobic societal structures exacerbate individual HIV risk factors both directly and indirectly, but transphobia is also embedded in the healthcare provision that should be working to ameliorate transmission risk.<sup>62</sup>

Trans\* people report a range of failures relating to their health services. These can be broadly grouped into cultural insensitivities which deny the trans\* person's gender and its expression, and lack of knowledge which threaten the health of the trans\* person.

health care system that marginalises rather than supports trans\* people concerns how the desire to affirm gender identity through medical procedures is pathologised, as a mental health diagnosis of gender dysphoria is required to access gender identity services. Access to gender identity clinics is also limited due to cost, which can culminate in undertaking unsupervised medical procedures.<sup>64</sup>

This can be a problem even in the UK where people will use private clinics rather than join lengthy waiting lists for NHS services.

Individuals describe receiving referrals for gender affirming surgeries and hormone therapy in gender

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## “Trans\* people often experience health services as discriminatory, ill-informed and inaccessible. This results in inadequate healthcare, and can result in trans\* people dropping out of care altogether.”

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A recent Royal College of Nursing survey of its membership warned that inadequate training resulted in trans\* people experiencing prejudice, lack of understanding and disadvantage in accessing appropriate care, with only 13% of nursing staff feeling prepared to treat trans\* people in their care.<sup>63</sup>

Trans\* people have recounted a range of examples of poor care from GPs, in gender identity clinics and in HIV clinics. For example, in primary care inadequately trained staff often fail to record and use the correct gender, name and pronoun. GPs express inappropriate curiosity about trans\* bodies even when presented with illness that is nothing to do with gender identity, and in some cases refuse to make referrals to gender identity services. GPs also claim lack of knowledge and / or responsibility, for example refusing to do endocrine testing, or not being willing and able to discuss what is safe sex for a trans\* person.

One of the most frequently cited examples of a

identity clinics, but then effectively being left to fend for themselves with broader psychosocial and clinical matters including those that relate to their sexual health. Similarly, trans\* people report HIV clinicians who are unable to answer questions relating to their gender identity, even as it pertains to their HIV status and sexual health. Contrary to promises of integrated care, the experience of health care for trans\* people is thoroughly disjointed.

The consequence of these multiple exclusions is that trans\* people often experience health services as discriminatory, ill-informed and inaccessible. This results in inadequate healthcare, and can result in trans\* people dropping out of care altogether.

There are also barriers to HIV prevention for trans\* people, as evidenced in the exclusion from PrEP research,<sup>65</sup> the lack of guidance on STI testing for trans\* people,<sup>66</sup> and the absence of trans\* targeted images in prevention outreach. In situations where individuals may already be experiencing a complex

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62 *Ibid.*

63 Royal College of Nursing 'Health service failing transgender patients', 11 October 2016 (Available at <https://www.rcn.org.uk/news-and-events/news/health-service-ill-equipped-to-care-for-transgender-patients>).

64 WHO, 2015, *op. cit.*

65 Grant *et al.*, 2016, *op. cit.*

66 Wansom *et al.*, 2016, *op. cit.*

raft of social and medical matters that cisgender people do not face, and medical professionals deprioritise their sexual health, it is easy for trans\* people to defer attention to their sexual health.<sup>67</sup>

These cumulative exclusions from appropriate healthcare, including the lack of relevant research,

suggest that transphobia plays a significant role in the increased HIV risk profile for trans\* people. Therefore, attempts to understand the epidemiology of HIV in the UK trans\* population must include how the context of transphobic institutional, structural and social factors affects individual level HIV risk factors.

## Recommendations

- Research into the biological factors that increase risk of HIV among trans\* people must continue. NAT should take available opportunities to advocate for such research, including through communication with British HIV Association (BHIVA).
- NAT should consider a future piece of work, in collaboration with trans\* organisations and researchers, on the impact of transphobia on individual HIV risk factors and the consequences for individual and public health.
- Where it pertains to HIV and trans\* people, NAT should continue to challenge negative media portrayals. Where it falls outside our remit, NAT should support other organisations and individuals in their efforts to oppose stigmatising public narratives.
- NAT should identify how it can best support the collation and dissemination to trans\* people of good knowledge about HIV.
- NAT should consider the possibilities for trans\* inclusion across its policy workstreams, for example in relation to work on prevention, sex and relationships education (SRE), and access to good treatment.
- All healthcare workers should be given the specific training to knowledgeably and sensitively care for trans\* people.
- BHIVA and British Association for Sexual Health and HIV (BASHH) should work together to identify when and how best to conduct an audit of trans\* literacy among clinical staff in GUM and HIV clinics, and identify improvement measures where necessary.
- NAT should collaborate with trans\* organisations to consider where it might be able to promote general trans\* literacy in its existing work.
- Across the sector, it is essential that we do not wait for more robust information before we actively pursue measures to reduce trans\*-related inequality in both health and wider social justice matters.

<sup>67</sup> Personal communication, Juno Roche.

# 4. Strategies and interventions

**Given that HIV risk for trans\* people develops at the scale of the individual (behavioural and biological factors) but also in the context of broader transphobic social structures, interventions need to work across multiple arenas to be successful. Measures to address transphobic structures and service provision and uptake have begun to be implemented, with varying degrees of success.**

In terms of how interventions should be developed, there is a very clear message from trans\* people who advocate for more effective healthcare and HIV services for their communities, which is that they need to be at the centre of decision making and programme delivery if interventions are to be effective.

## Community empowerment

According to WHO guidelines published in 2014, tackling the HIV epidemic requires certain ‘critical enablers’ to facilitate the effectiveness of health sector interventions. These enablers work to overcome the barriers to service uptake that will undermine the provision of HIV services if left unaddressed. One of the five critical enablers identified is “interventions to enhance community empowerment among key populations”.<sup>68</sup>

The United Nations Development Programme (UNDP) followed up WHO’s 2014 guidelines with implementation guidance which has community

empowerment as the foundation of all of its other proposals.<sup>69</sup> This guidance defines community empowerment as “the process whereby trans people are empowered and supported to address for themselves the structural constraints to health, human rights and well-being that they face, and improve their access to services to reduce the risk of acquiring HIV.”<sup>70</sup>

A frequent refrain at trans\* conferences and during discussions with trans\* people has been ‘nothing about us, without us’; a clarion call recognised by other equality and rights movements and which cements the importance of self-determination and community-led programming.

As such, community empowerment is a principle that underpins the development of programmes and services that are trans\*-led or at least collaborative, participatory and inclusionary, and thus appropriate for and able to be trusted by trans\* people who have acquired or are at risk of acquiring HIV.<sup>71</sup> Moreover, community empowerment is important in itself as a

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68 WHO, 2014, *op. cit.*, p. xix

69 United Nations Development Programme (UNDP), IRGT: A Global Network of Transgender Women and HIV, United Nations Population Fund, UCSF Center of Excellence for Transgender Health, Johns Hopkins Bloomberg School of Public Health, World Health Organization, Joint United Nations Programme on HIV/AIDS, United States Agency for International Development, *Implementing comprehensive HIV and STI programmes with transgender people: practical guidance for collaborative interventions*. New York, 2016.

70 *Ibid.*

71 *Ibid.*



challenge to marginalisation and stigma, and their implications for subsequent HIV risk.

towards human rights in the UK might mean that pitching 'trans\* rights as human rights' is not the most effective strategy for securing equality here.

## "Trans\* people need to be at the centre of decision making and programme delivery if interventions are to be effective."

CliniQ in London is an example of community empowerment at work. It is the only fully integrated, trans\*-led sexual health and well-being service for trans\* people in the UK, and as such provides clinical services that are both appropriate and trusted.

However, even as CliniQ's organisers aim to support rolling out similar models across the country, insufficient resources and funding are key barriers to the clinic being able to provide a service to a wider trans\* population.<sup>72</sup> UNDP guidance focuses on methods to support programmes and build capacity among trans\* organisations as the foundation of HIV-related interventions,<sup>73</sup> indicating that this is a crucial consideration for services in the UK which needs to be addressed urgently.

### Institutional measures: laws and policies

Among the five critical enablers defined by WHO, two relate specifically to institutional measures. One concerns implementing laws based in human rights to eliminate stigma and discrimination, and the other concerns establishing laws and policies to support the provision of appropriate health care services as defined by prospective service users.<sup>74</sup>

Using human rights has been a key strategy for trans\* people around the world who are fighting for legal recognition, freedom from degrading treatment, and equality. However, negative attitudes

In terms of existing policy, the Government's 2011 trans\* action plan includes measures to address inequality in education, employment, public services and culture and attitudes.<sup>75</sup> However it has been criticised by trans\* people on the grounds that it remains largely unimplemented,<sup>76</sup> although the Government suggests otherwise.<sup>77</sup>

The Gender Recognition Act (2004) and the Equality Act (2010) have been subject to criticism for their narrow definition of trans\* people, among other matters. In December 2016 a Private Member's Bill, introduced by Maria Miller MP, proposed to extend equality protections based on gender identity rather than the narrower, medicalised 'gender reassignment' and the Government committed to a new action plan for trans\* equality to include a review of the Gender Recognition Act.<sup>78</sup>

The Women and Equalities Committee conducted an inquiry into trans\* equality in 2015 that sparked the more recent of these developments. The inquiry also reported on transphobia in NHS services generally as well as difficulties in primary care with 'gatekeeping' GPs denying access to further services or reducing all trans\* health issues to the question of gender identity. The Committee recommended a 'root and branch review' of transphobia in the NHS.<sup>79</sup> This recommendation was not accepted in the Government's response, although it was suggested that the terms of reference for NHS England's Task and Finish Group

72 Personal communication, Michelle Ross, CliniQ.

73 UNDP *et al.*, 2016, *op. cit.*

74 WHO, 2014, *op. cit.*, p. xix.

75 Home Office, *Advancing transgender equality: a plan for action*. HM Government, 2011.

76 See the testimonies associated with the Women and Equalities Committee report (Women and Equalities Committee, *Transgender Equality*, 8 Dec 2015, HC 390 2016, London: TSO).

77 HC Deb 1 Dec 2016 vol 617 c1721.

78 Government Equalities Office (2016) *Government Response to the Women and Equalities Committee Report on Transgender Equality* (Cm 9301) London: TSO.

79 Women and Equalities Committee, 2015, *op. cit.*

for Gender Identity Services could be extended to consider the problem.<sup>80</sup>

Despite submissions from NAT and other organisations to the Women and Equalities Committee inquiry concerning HIV risk among trans\* people as an equality issue, HIV was not mentioned in the Committee's final report.

In 2014, 39% of countries reported that their national HIV/AIDS strategies addressed the needs of trans\* people.<sup>81</sup> In the UK, trans\* people are not mentioned in the now expired National Strategy for Sexual Health and HIV.<sup>82</sup> The more recent Sexual Health Framework<sup>83</sup> recognises health inequalities and lack of recognition in health and social care among 'LGBT people', but otherwise only refers to trans\* people in a set of (now archived) NHS briefings. The briefing for 'Trans People's Health' states that for trans\* people "HIV infections are not a major risk factor in the UK, mainly because sex work or recreational drug use is not usual in UK trans cultures."<sup>84</sup>

While recent developments suggest that the Government is willing to consider laws and policies to foster trans\* equality, there have been mis-steps and clear historical concerns remain about what has been achieved so far. Trans\* advocates will need to continue their work in holding Government to account in relation to institutional measures to improve trans\* equality, health, and HIV risk.

### Structural and social measures: tackling socio-economic and cultural injustice

UNDP guidance suggests addressing socio-economic and cultural injustice through measures to foster equality and prevent social exclusion in schools and to tackle discrimination in the workplace and social services. These measures are designed to reduce school drop-out rates and unemployment that can lead to poverty, and to

foster support if trans\* people need to rely on social services to prevent destitution.<sup>85</sup> All these measures contribute to HIV prevention by promoting general well-being and good mental health, thus reducing the likelihood that risky behaviour, including sex work, become viable options.

Potential structural vulnerabilities are exacerbated by stigma, rejection and violence in social settings, including in the family and with partners. UNDP guidance promotes monitoring stigma and violence, and ensuring that appropriately sensitised support services and legal support are available for trans\* people. The guidance recognises the central role of trans\* communities in monitoring and developing policy and strategy responses.

The impetus for tackling structural and social inequalities is often embedded in policy decisions made in Government and other institutions. For example, the possibility of decriminalising sex work, which would decrease the marginalisation of trans\* people and therefore their vulnerability to HIV, was mooted by the Home Affairs Select Committee in 2016,<sup>86</sup> although the proposal was rejected by the Government.

In relation to schools, as a further example, there has been longstanding resistance in Government to making Personal, Social and Health Education (PSHE) and particularly Sex and Relationships Education (SRE) compulsory. Recently, however, there has been a shift in approach from some Parliamentarians,<sup>87</sup> although often references to inclusive SRE are limited to sexual orientation rather than gender identity.

In practice, a trans\* former teacher reports that materials used for providing trans\* inclusive PSHE are often anachronistic.<sup>88</sup> Similarly, Mermaids, an organisation that supports young trans\* people and their families, report that their efforts to provide schools with trans\*-inclusive PSHE materials are

80 Government Equalities Office, 2016, *op. cit.*

81 Joint United Nations programme on HIV/AIDS, 2014, *op. cit.*

82 Department of Health, *The national strategy for sexual health and HIV*. 2001.

83 Department of Health, *A Framework for Sexual Health Improvement in England*. 2013.

84 Department of Health, *Reducing health inequalities for lesbian, gay, bisexual and trans people - briefings for health and social care staff. Briefing 11 – Trans people's health*. 2007.

85 UNDP *et al.*, 2016, *op. cit.* p.44.

86 Home Affairs Committee, *Prostitution*, 15 Jun 2016 HC26, 2016.

87 See, for example, the debate on the Children and Social Work Bill in the House of Commons (HL Deb 5 Dec 2016 vol 618 c46).

88 Personal communication, Juno Roche.

not always welcomed, and that staff often have inadequate knowledge and understanding of trans\* issues.<sup>89</sup>

More generally, the Government's 2011 trans\* action plan included measures to address inequality and stigma in key settings, but five years on the Transgender Equality inquiry recognised that, still, "discrimination is a part of daily life for trans people"<sup>90</sup>. The inquiry made some recommendations around hate crime, media portrayals and improving education, but there was no mention of how societal inequality and injustice can lead to implications for the health of trans\* people.<sup>91</sup>

Many of the individuals NAT spoke to for this exercise reported personal experience or direct knowledge of discrimination in schools, the workplace and family life, and measures to address this stigma are clearly important. However, the extent to which socio-economic injustice and cultural misrepresentation push trans\* people in the UK either directly (via sex work or transactional sex) or indirectly (via poor wellbeing and mental health) into risk taking behaviour is unknown and open to further investigation.

### Structural measures: addressing barriers to healthcare and prevention

WHO guidelines state that "high vulnerability and specific health needs of trans\* people necessitates a distinct and independent status in global HIV response".<sup>92</sup> WHO and UNDP guidance cite a package of essential health sector interventions for HIV prevention, diagnosis, treatment and care services for trans\* people. These include facilitating access to condoms and lubricants, harm reduction interventions for safe injection practices, testing in clinical and community settings, provision of behavioural interventions such as trans-specific

health information and peer support, HIV treatment and care, prevention and management of co-infections and mental health conditions, and sexual and reproductive health interventions.<sup>93</sup>

Certainly there are recommendations across all these key areas that are specific to trans\* people and that establish variations in what comprises appropriate care. For example, condom use may be different for those with surgically constructed genitalia; there may be greater need for mental health services among trans\* people; and harm reduction strategies could vary for those who inject substances for gender affirmation.<sup>94</sup>

In this context, new developments in HIV prevention might be particularly beneficial for trans\* people. For example, PHE HIV self-sampling data show that trans\* people have a far higher reactive rate, at 4.17%, than the overall reactive rate of 1.14%.<sup>95</sup> Given that it is known that self-samplers tend to be high risk groups and that trans\* people might have difficulties using GUM clinics, self-sampling could be a particularly beneficial testing method for trans\* people.

In relation to PrEP, it is recognised that its apparent failure in clinical trials to reduce transmission among trans\* people was due to suboptimal adherence, rather than drug efficacy.<sup>96</sup> While further studies that address both biological differences and the drivers of non-adherence are called for,<sup>97</sup> there is a clear sense among trans\* communities that PrEP needs to be available for them now.

It is helpful, then, that BASHH has started the process to produce UK specific guidelines for trans\*-specific health sector interventions.<sup>98</sup>

However, the types of interventions specified are not unique to trans\* people, even if the manifestation of need is specific. As Dr Kate Nambiar, an HIV clinician at ClinicT, points out, HIV isn't different in a trans\* person than it is in a cisgender person, and all

89 Personal communication, Deborah Abrahams.

90 Women and Equalities Committee, 2015, *op. cit.*, p55.

91 Women and Equalities Committee, 2015, *op. cit.*

92 World Health Organisation (WHO), *Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations*. Geneva, 2014, p. xiii.

93 UNDP *et al.*, 2016, *op. cit.* p. 70. See also WHO, 2015, *op. cit.*

94 WHO, 2015, *op. cit.*

95 Guerra L 'National HIV self-sampling service' presented at British Association for Sexual Health and HIV Annual Conference, 18 March 2016, Oxford.

96 Mayer *et al.*, *op. cit.*, 2016.

97 *Ibid.*

98 Personal communication, Kate Nambiar.

people have a personalised set of needs.<sup>99</sup>

The necessary key differences in health sector interventions for trans\* people regard how services are implemented and delivered. It is clear from NAT's discussions with trans\* people that healthcare systems – including primary care, gender identity services, and HIV clinics – do not meet their needs. Evidence from institutional bodies shows both discrimination and lack of knowledge about trans\* people within UK health services.<sup>100</sup>

service provision right and to ensure that it can be trusted. Any health service should be able to avoid misgendering or using the wrong pronouns, and to train staff so that stigma is eliminated and confidentiality respected. However, NAT was also told about matters such as the importance of nongendered bathrooms and waiting rooms; the preference for evening clinics when the light is less harsh which can make it easier to 'pass'; and the importance of clinic staff understanding that it can

## "Health services for trans\* people should be safe, confidential, accessible, affordable and integrated."

WHO guidelines state that to be effective interventions, health services need to be non-discriminatory, accessible and acceptable to the people using them.<sup>101</sup> UNDP guidance establishes that health services for trans\* people should be safe, confidential, accessible, affordable and integrated (such that they facilitate access to whatever clinical or psychosocial care is required by an individual, rather than just gender identity or HIV-related care).

Most importantly, health services need to be 'trans-competent', such that they are culturally appropriate, stigma-free and respectful, mindful of human rights and the broader context for trans\* health, and based in technical knowledge about gender identity and health needs.<sup>102</sup>

Primary care providers are often the first and most common point of contact between trans\* people and health services. Therefore it is crucial that they receive effective training in order that they can act as a point of access to care and support services, rather than as barriers.<sup>103</sup>

Discussions with trans\* people and advocates have shown the importance of services being trans\*-led, or at least genuinely inclusionary, to get

be too difficult to get to an appointment because of fear of being in public and subjected to abuse.

Despite demand, there is a worldwide scarcity of clinical services designed specifically for trans\* people.<sup>104</sup> This is true for the UK, where CliniQ in London sees up to 35 people in its weekly 3-hour slot, ClinicT operates in Brighton, and new services are starting in Leeds and Birmingham.<sup>105</sup>

UNDP guidance also stresses the importance of providing integrated care. For example, for trans\* people living with HIV, adherence may require services that integrate hormonal, surgical and HIV care, and address the individual manifestations of structural problems (e.g. poverty, homelessness, or drug use), and thus come as close as possible to one-stop care.<sup>106</sup> Better adherence, treatment outcomes and retention in care is found when the HIV primary care provider also provided hormone therapy, and integrated, gender affirming care has also been found to support PrEP uptake.<sup>107</sup>

Finally, there is the question of encouraging trans\* people to access, and then remain in HIV related prevention and care, when so often bad experiences have made them wary of using healthcare. Trans\*

99 Ibid.

100 Women and Equalities Committee, 2015, *op. cit.*

101 WHO, 2014, *op. cit.* p. xix.

102 UNDP *et al.*, 2016, *op. cit.*

103 Winter *et al.*, 2016, *op. cit.*

104 UNDP *et al.*, 2016, *op. cit.*

105 Personal communication, Michelle Ross.

106 Mayer *et al.*, 2016 *op. cit.*; Grant *et al.*, 2016, *op. cit.*

107 Grant *et al.*, 2016, *op. cit.*

specific services such as gender identity clinics and support groups can be used as points of entry for HIV care.<sup>108</sup> Once in services, peer navigators can reduce the number of people lost to care. Furthermore, having good information is a crucial part of accessing healthcare and CliniQ are in the process of updating trans\* health guides for just that purpose.

### Behavioural interventions

While strategies are largely targeted at removing barriers they can also pro-actively address individual behaviour, either indirectly through altering community level norms or more directly by addressing an individual's choices through risk reduction counselling.

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## "What is clear is that we cannot wait for robust data to be available for the challenge of HIV amongst trans\* communities to be tackled head on."

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Again, trans\*-led services are key here because trans\* people are not 'hard to reach' (as is so often suggested) by members of their own communities.<sup>109</sup> It is worth recalling however that not all trans\* people are necessarily embedded in communities, and outreach is still important for those who tend to be more isolated.<sup>110</sup>

Community level interventions are best designed by trans\* people as programmes will then respond to priorities of the intended audience, and benefit from peer endorsement. For example, the 'Healthy Divas' programme in San Francisco, which helps trans women living with HIV develop skills to cope with stigma and to engage in their healthcare, was adapted by and piloted with trans\* people.<sup>111</sup>

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The UNDP guidance explains in considerable detail how to implement for trans\* people the WHO guidelines for tackling the HIV epidemic. Moreover, its production was a collaborative exercise which foregrounded trans\* people and trans\* advocates, meaning that it is likely to be both appropriate and acceptable for trans\* people.

Arguably, then, we know *how* to foster good HIV prevention, treatment and care for trans\* people, and we know *who* should be charged with making it happen.

Of course, given that the WHO and UNDP guidance both refer to global trans\* populations, rather than being UK specific, the extent to which certain requirements exist among the UK trans\* population is unknown. While the narrative may be less convincing without hard data, the principles still stand. What is clear is that we cannot wait for robust data to be available for the challenge of HIV amongst trans\* communities to be tackled head on.

The key question remains how to advocate effectively for legislation, policy and resources that facilitate that ambition.

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108 UNDP *et al.*, 2016, *op. cit.*; WHO, 2015, *op. cit.*

109 Personal communication, Michelle Ross.

110 Personal communication, Lee Gale.

111 UNDP *et al.*, 2016, *op. cit.* p. 129

## Recommendations

- Community empowerment must be the first principle of strategies and interventions to reduce HIV transmission and improve HIV treatment and care. NAT should support community empowerment, but must recognise that there is already a well-established network of trans\* organisations who have been working with this agenda for some time.
- NAT can specifically support community empowerment by advocating for the importance of funding trans\* organisations, but also by setting an example of inclusion and avoiding tokenism at all costs. All NAT staff should have trans\* awareness training and, having recently appointed a trans\* person to the Advisory Board, NAT should take advice on whether more needs to be done internally to foster trans\* inclusion in the organisation.
- The NHS, local authorities, and other responsible commissioning bodies should fund, across all four UK nations, the provision of trans\*-specific, trans\*-led clinics dedicated to the wellbeing of trans\* people with a focus on sexual health and HIV.
- The co-location of as many as possible of the services around HIV, sexual health, wider health needs, and support services is preferable until 'one-stop shops' become available to provide an integrated service for the health and wellbeing needs of trans\* people.
- Gender identity clinics, sexual health services and HIV clinics should collaborate to better integrate services and standardise referral pathways. NAT, BHIVA, and BASHH should work together with commissioners to help ensure this is possible.
- NAT should continue to hold the government to account on matters pertaining to trans\* people and HIV. This includes responding to Government initiatives, but also pro-actively working for a new trans\* action plan that incorporates health and HIV, and a National Strategy for HIV and Sexual Health Framework that take account of the needs in trans\* communities.
- NAT should aim to take opportunities to challenge the structural drivers of socio-economic and cultural inequality for trans\* people, with the intention of improving general wellbeing in trans\* communities.
- NAT should advocate for new HIV prevention methods, including PrEP, self-sampling and home testing, to be made available and accessible for trans\* people, where appropriate. The sector should also consider how best to improve access to testing in community venues for trans\* people.
- All forms of outreach must recognise that not all trans\* people are well embedded in trans\* communities.
- NAT must recognise that there may be wider reasons why trans\* people will de-prioritise HIV although it jeopardises their health. In this context, it is important for those who are the first point of contact in the health system to be appropriately trained, both in sensitivity to gender identity and with adequate knowledge to treat and refer people. NAT should investigate the possibility of developing guidance to support this aim.



# SHAPING ATTITUDES CHALLENGING INJUSTICE CHANGING LIVES

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