

Community-Driven Responses to Public Health: An Example from England's HIV Sector

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"We call on researchers to include transgender women, men, and non-binary people, who are at risk of or living with HIV in their research.

[...] Sitting in the audience or appearing in photos in a slide deck does not constitute meaningful involvement of trans colleagues."

(Schein et al. 2019)

Trans Healthcare in England and the UK

Recent years have seen a significant rise in the number of trans/non-binary adults seeking to undergo some form of medically supervised transition via the National Health Service (NHS) in England (The Tavistock and Portman NHS Foundation Trust 2019); with an estimated 240% increase in referrals to England's seven publicly funded Gender Identity Clinics (GICs) between 2013 and 2018 (Torjesen 2018). However, patient numbers from NHS GICs are generally considered to be a poor measure of the overall size of England's trans population. These figures fail to account for the many trans/non-binary people who have already been discharged from NHS services, as well as those who are sourcing gender affirming services abroad (or via private clinics in the UK), and those who acquire hormone therapy without medical supervision. Additionally, GIC patient numbers cannot take into account the number of trans/non-binary people who do not desire (or are unable to seek) medical interventions (Wolton et al. 2018).

These factors combined with the current lack of trans-inclusive national census data (and the fact that the wider NHS only records binary gender markers) mean that the total number of trans people living in England and throughout the rest of the UK is currently unknown. However, the UK is considered likely to be comparable to the US and other high-income countries, suggesting that 0.6% of the population may be gender diverse (Flores et al. 2016).

Without meaningful knowledge of the overall population size, generating accurate prevalence data for a number of health conditions in the UK's trans populations remains an impossibility. This, in turn, impacts the ways in which funding streams for both research and frontline services are allocated and contributes to the numerous ways in which trans/non-binary people are left behind by English healthcare provision.

In addition to the lack of inclusion in data monitoring across our health-care systems, trans people also face a number of barriers when attempting to access services provided by the NHS, despite its constitutional commitment to timely, respectful, patient-centered healthcare for all (Department of Health and Social Care 2012). Waiting times for gender-affirming interventions in England are currently in excess of two years from point of referral to first appointment (Devon Partnership NHS Trust 2019). This is despite clear stipulation that no NHS patients (irrespective of gender identity) should wait longer than 18 weeks from the point of referral to the person's first specialist, consultant-led appointment (Department of Health and Social Care 2012).

For those in England who have had no viable alternative but to wait for publicly funded care, the barriers to gender affirmation extend way beyond the time it takes to be assessed by an NHS gender identity service. These specialist, multidisciplinary clinics do not provide hormone therapy directly. Instead, GICs assess and diagnose Gender Dysphoria (American Psychiatric Association 2013) and subsequently make recommendations for the individual's general practitioner (GP) to commence hormone therapy under their supervision.

Whilst this offers a theoretically acceptable model of shared care delivery, this is often not the reality in practice. As many as one-in-five NHS GPs will go on to refuse to prescribe hormones to their trans/non-binary patients (Barrett, 2016). With these pitfalls well known at the community level, it is unsurprising that as many as 40% of trans/non-binary people will be self-sourcing hormone therapy (without medical supervision) by the time they attend their first NHS GIC appointment (Mepham et al. 2014).

Years of vocal community activism have brought political focus to the numerous issues trans people experience both in and beyond the UK's healthcare systems. As a result, in 2016, the UK Government's Women and Equalities Committee undertook a national inquiry into trans equality. The subsequent report concluded that the NHS is largely failing trans/non-binary people. It described the standard of care delivered by various sections of the health service as discriminatory and often in breach of England's national equality legislation (Women and Equalities Committee 2016). A later government survey also found that nearly half of trans/non-binary people in the UK had reported at least one negative experience of NHS services in 2017-2018 (Government Equalities Office 2018). Long waiting times appear as a significant contributor to these negative experiences:

The waiting lists for GICs need genuine change [...] I have personally used alcohol, cannabis, cocaine and self-harm to survive the last year and a half since referral, and I have now been told I will have to wait several more months because of the backlog. (Trans man, heterosexual, 18-24, North West) (ibid.)

These difficulties are not unique to the UK. In many ways, the health of UK trans populations is comparable to those of other nations across the globe. Self-harm and suicidality are common. Trans/non-binary people throughout the UK often have poor mental and physical health outcomes (McNeil et al. 2012), and in some metropolitan areas, also experience complications relating to the late diagnosis of HIV (Suchak et al. 2017).

Additionally, the high incidence of unsupervised hormone usage (Mepham et al. 2014) coupled with increased rates of problematic drinking, smoking and substance use within the community (McNeil et al. 2012) pose a significant and under-researched risk of adverse cardiovascular events within this population. Pockets of existing knowledge are generally derived from local or small-scale studies, as erasure of trans populations has, historically, extended to a lack of inclusion in national public health research either as participants or as researchers. This lack of trans/non-binary visibility causes particular difficulties in relation to HIV, since accurate monitoring of the epidemic's progression is essential for understanding health needs, determining public health priorities, allocating resources, and evaluating the efficacy of interventions (Nsbuga et al. 2006).

Trans-led Inclusion in the UK's HIV Research

Approximately 32 million people across the globe have died from complications related to HIV since the early years of the epidemic (WHO 2019). Whilst significant breakthroughs in both preventing and treating the virus have been made in recent years, HIV transmission persists as a major public health concern and affects more than two million people in the World Health Organization (WHO) European Region. Whilst epidemic patterns vary by country, nearly 160,000 people across the region were diagnosed with HIV in 2017 (ECDC 2018).

The WHO, in a bid to reduce onward transmission, has called for international prevention efforts to focus on communities that are most vulnerable to acquiring the virus: substance users, men who have sex with men, sex workers, prisoners, and trans people. These 'key populations' are most at risk of becoming HIV positive and face significantly higher rates of HIV than the general population, accounting for more than 50% of new diagnoses (UNAIDS 2019).

Whilst meaningful HIV prevalence data relating to trans populations remain scarce, meta-analysis of existing studies suggests that as many as 19.1% of transgender women could be living with HIV across the globe (Baral, et al. 2013). Despite these alarming figures, 61% of UN countries, as recently as 2014, failed to include trans/non-binary people in their national HIV strategies or in their national epidemiological reporting (UNAIDS 2014). This, until recently, was also the case in England.

The earliest known efforts to collect meaningful, trans-inclusive sexual health and HIV data within an NHS context, emerged at a local level in 2013. 56 Dean Street, a leading sexual health & HIV clinic in Central London, began piloting an adapted version of Sausa et al.'s (2009) two-stage method of gender identity monitoring in their specialist trans/non-binary sexual health clinic. The service, which is a partnership between trans/non-binary professionals and a number of cisgender colleagues, uses registration forms that collect data concerning service users' current gender identity, as well as their sex assigned at birth.

Following the success of the Sausa et. al. (2009) model at Dean Street, it was adapted and refined for nationwide usage. This involved collaboration between a group of trans/non-binary professionals, Public Health England (PHE), the government agency responsible for England's national HIV reporting, and a number of key trans and LBGTQ-led organizations. The model was

subsequently included in the People Living with HIV (PLWHIV) Stigma Index in 2015. The latter became the first government-sponsored national research initiative to include trans/non-binary populations in HIV survey data. It recruited participants over the age of 18 who were living with HIV from over 120 different community organizations and 46 NHS clinics across the UK.

The survey explored how and in what circumstances and locations (e.g., family events, religious contexts, healthcare settings etc.) participants either experienced or anticipated HIV-related stigma and how this intersected with other commonly stigmatized factors such as age, ethnicity, disability or trans status. Among the 1576 participants, 31 (2%) identified as trans in some way. It was found that trans people living with HIV were more likely than their cisgender counterparts to report negative experience of health services. They were also more likely to report feeling that they had received intentionally delayed treatment or that their treatment had been refused when attempting to access healthcare services in a range of settings (Hibbert et al. 2018).

Additionally, trans respondents exhibited greater psychosocial complexity in comparison to cis respondents, including higher rates of injection drug use, and a greater likelihood of having engaged in transactional sex. Whilst only a small proportion of participants identified as trans, this study highlighted the differences in the care that trans PLWHIV in the UK may receive. However, it is not possible to ascertain how representational this data is in relation to the experiences of all trans PLWHIV, as the prevalence of HIV was still unknown at the time of the study (*ibid.*).

Despite the small number of trans/non-binary respondents, The Stigma Index UK study marked an important turning point in the inclusion of trans people as expert researchers within the UK's HIV sector. It was a community-led project and was collaboratively created with an advisory group which included trans/non-binary people and other key populations vulnerable to or living with HIV. The study's collection of meaningful gender identity data, alongside effective trans-led community advocacy, became the catalyst for Public Health England to continue to include gender diverse populations in its national HIV surveillance. This included updates to its HIV/AIDS Reporting System (HARS); a public health coding and reporting tool which is utilized in all English and Welsh HIV services to effectively monitor the spread of HIV. Alongside this emerging clinical data, in 2017 PHE also went on to capture the lived experiences of trans/non-binary people in its Positive Voices Survey (an exploration of the lives, experiences and healthcare needs of PLWHIV in

the UK) with responses to the survey validated using data triangulation and clinical follow-up.

PHE found that 0.19% (178/94,885) of people accessing HIV care in England and Wales in 2017 identified as trans/non-binary in some way. Of these, 140 (79%) identified as women, 12 (7%) as men, 20 (11%) as non-binary and 6 (3%) described their gender in another way. Unlike a number of other nations who have included trans/non-binary populations in HIV surveillance, rates of late diagnosis, antiretroviral uptake, and viral suppression were similar amongst trans and cis people (Kirwan et al. 2021).

PHE also found that trans PLWHIV were significantly more likely to be London residents (57% vs 43%) and were younger than their cisgender counterparts. Significantly, trans respondents were more likely than cis individuals to be under active psychiatric care (11% vs. 4%), were more likely to self-report anxiety and depression (41% vs. 24%) and, as previously found in the Stigma Index UK in 2015, were more likely to have been refused or delayed treatment in various healthcare settings. The Positive Voices Survey also highlighted that trans/non-binary people were more likely to describe their health as bad or very bad, as well as more likely to report problems with activities of daily living such as washing and dressing (*ibid.*).

In stark contrast to a number of non-UK studies, PHE found that trans/non-binary PLWHIV were more likely to be from white backgrounds, whereas the burden of HIV in trans people globally is predominantly experienced by trans women of color (Baral et al. 2013). This unexpected finding may be the result of the ways in which the dominant culture in the UK erases and excludes those from Latin American backgrounds from identifying as people of color; as a result, the NHS data dictionary does not allow health services to explicitly record Latin American ethnicities (NHS 2020). Instead, data is likely collected under the vague and erroneous heading of 'Any other white background'. However, Latin American people in the UK have been identified as a key population for HIV prevention (Rawson et al., 2019), and therefore understanding the number (and needs) of trans people of color, including Latin American trans people, in relation to HIV is essential for providing an optimum level of care in the UK in future.

UK Epidemiology and Implications for Further Research

Despite drawing attention to a number of disparities in the context of mental health and broader wellbeing, these early data from PHE suggest that HIV rates in trans people living in England may be significantly lower than a number of countries which have contributed to global prevalence estimates of 19.1% (Baral et al. 2013). However, the mechanism for capturing diverse gender identity data remains new and unfamiliar to predominantly cisgender clinicians, thus highlighting a significant need for the upscaling of training provisions. Until usage is improved, it can be assumed that inaccurate reporting or underreporting will occur. Additionally, the lack of a national trans/non-binary population figure dictates that prevalence data derived from the report can only be estimated at this time.

Significantly, despite its numerous difficulties in sensitively responding to the needs of trans/non-binary populations, England's free-at-the-point-of-access healthcare may be a contributing factor to the lower-than-expected estimate of HIV in trans people in comparison to the global figures. However, trans/non-binary people may be significantly underrepresented in the numbers of people accessing HIV care, as they are understood to be less likely to access sexual health services than their cisgender counterparts (Government Equalities Office 2018; Hibbert et al. 2020). In addition, when trans people do access sexual healthcare, they are more likely than cisgender people to rate the experience as negative (Government Equalities Office 2018) which could result in individuals not returning for necessary follow-up treatment and care.

The likelihood of losing trans/non-binary patients to follow-up could be reduced by restructuring our HIV services to be more responsive to the needs of our gender diverse communities. Currently, the UK health system is siloed by health condition or medical specialty, such that gender affirming services operate separately from sexual health and HIV care. However, existing research suggests that TPLWHIV consider hormone therapy to be a greater priority to their health than their HIV treatment (Schneiders 2014). Thus, the co-delivery of gender affirming interventions within existing sexual health and HIV services has the potential to increase long-term retention in care. London's 56 Dean Street will in 2020 become the first service in the UK to pilot a multidisciplinary model of this kind.

Despite these advances in service delivery, further academic attention is needed to assess the prevalence of undiagnosed HIV in trans/non-binary people in the UK. Additionally, further research is needed to understand how

to increase the uptake of HIV testing within trans communities, as current reports are conflicting. One UK-wide study observed that trans people who exhibit HIV ‘risk behaviors’ are more likely to attend sexual health services (compared to trans people who experience less risk) and that they were more likely to have an HIV test (Hibbert et al. 2020).

However, pockets of risk have been identified in a small-scale, locality-specific study of trans/non-binary people who accessed a community-led outreach project at a sex-on-premises venue in London. The study found that over half of trans service users had engaged in condomless anal sex in the previous 6 months. However, just over a quarter of the 133 participants reported having tested for HIV in the last year, and the vast majority had no pre-existing knowledge of biomedical HIV prevention methods (i.e., pre- or post-exposure prophylaxis) (Wolton et al., 2018). Comparably, Hibbert et al. (2020) identified that half of trans people who reported condomless anal sex in the preceding 12 months had not attended a sexual health clinic that year.

Whilst both studies took into account various intersections of HIV vulnerability that trans/non-binary people may experience (substance use, sex work status etc.), neither explored the migration status of its participants (as was also the case in the Stigma Index and Positive Voices Surveys). Studies undertaken in non-UK countries demonstrate that undocumented migration status is emerging as a high-risk factor for HIV vulnerability amongst trans/non-binary populations (Palazzolo et al. 2016). Therefore, future UK studies should pay greater attention to migration status.

Conclusion: The Impact of Meaningful Inclusion on Clinical Practice

Whilst there are still a number of areas that require further, more detailed exploration, it is thanks to effective and consistent trans/non-binary community advocacy in the UK’s HIV sector that gender diverse populations are able to be counted for the first time. Additionally, partnership between trans and LGBT+ organizations, trans/non-binary professionals, and the British Association of Sexual Health & HIV (BASHH) has led to the publication of comprehensive recommendations for *Integrated Sexual Health Services for Trans, Including Non-binary, People*. This document provides the first detailed recommendations (both clinical and non-clinical) on best practice when delivering sexual health services that are inclusive to gender diverse communities (BASHH 2019).

Sexual health and HIV research is becoming more inclusive for trans people as participants, researchers and collaborators. This sharing of knowledge and experiences has led to some significant changes in UK research and has also driven change at a frontline level. Effective trans leadership and inclusion has led to the commissioning of a new specialist sexual health and HIV service for trans/non-binary people in South London, the launch of TransPlus, the aforementioned pilot of a sexual health-based gender affirmation clinic. It has also fostered improved trans inclusion in existing sexual health initiatives, including the UK's National HIV Testing Week and a 56 Dean Street's PRIME service, a digital, smart phone intervention for men who have sex with men (MSM) that experience an increased likelihood of acquiring HIV (Nwokolo et al. 2017).

It is hard to imagine that the above would have been possible without consistent, effective advocacy from trans/non-binary communities both as leaders and patient advocates. Too often trans people are constructed as passive recipients of health services, rather than those who drive strategic innovation and positive change in the delivery of health services. It is only inclusion of and leadership from trans/non-binary people in the design and delivery of research, services and policy initiatives that has improved sexual health services in the UK for trans/non-binary communities. It is trans people who fought for their voices to be represented in amongst the narratives of those living with HIV in the UK. From that small spark, we believe there is a fire of radical, meaningful inclusion that is spreading throughout health systems in the UK at both national and local levels.

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