Breaking barriers in HIV:
Action for legislators to address LGBT+ inequities

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GLOBAL EQUALITY CAUCUS

The Global Equality Caucus (https://www.equalitycaucus.org) is an international network of parliamentarians and elected representatives dedicated to tackling discrimination against LGBT+ people. Membership is open to any current or former elected official who supports LGBT+ equality, regardless of their sexual orientation, gender identity or sex characteristics.

Our members, in partnership with civil society organisations, LGBT-inclusive businesses, and our global network of public supporters, push for laws in their jurisdictions that aim to improve the lives of LGBT+ people. Our work covers multiple strands, including advocating for decriminalisation, anti-discrimination laws, improved data monitoring, better funding for LGBT organisations, and higher standards in the provision of healthcare for LGBT+ people.

The Global Equality Caucus is hosted by the Project for Modern Democracy (https://www.p4md.org), an independent, non-party think tank set up in 2014 to promote more efficient government and good citizenship. It is a company limited by guarantee (no. 8472163) and a registered charity in England and Wales (no. 1154924).

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Gilead Sciences (https://www.gilead.com) is a biopharmaceutical company that has pursued and achieved breakthroughs in medicine for more than three decades, with the goal of creating a healthier world for all people. The company is committed to advancing innovative medicines to prevent and treat life-threatening diseases, including HIV, hepatitis and influenza.

The Global Equality Caucus is grateful to Gilead for partnering with us to facilitate our discussions and research on HIV healthcare.

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Executive summary

In June 2021 the Global Equality Caucus, in partnership with Gilead, hosted two private roundtables to discuss inequities in HIV healthcare that LGBT+ people face and what elected representatives should be doing to push for improvements in the provision of care. The two sessions – one in Europe¹ and one in the United States and Canada² - were attended by elected officials from national, supranational, state and provincial assemblies; LGBT+ civil society advocates, including attendees from the Black, HIV-positive, and transgender communities; as well as healthcare experts and epidemiologists.

The sessions looked at the barriers facing LGBT+ people generally, as well as having a particular focus on a spotlight population. For Europe, this was on HIV prevalence in migrant communities, particularly amongst men who have sex with men (MSM). For the US & Canada, participants discussed the intersectional barriers facing Black and Indigenous populations. Attendees considered policies and strategies that elected representatives could pursue in their assemblies to drive improvements in HIV healthcare for all LGBT+ people.

From these conversations, several key themes and proposals emerged:

- Repeal laws around HIV criminalisation – removing such laws would help to tackle prejudice and refocus HIV incidence as a public health crisis.
- Address the inequitable access to testing and treatment faced by some demographics, and remove socioeconomic, racial, and structural barriers to ensure care reaches marginalised people.
- Remove siloes in healthcare by integrating HIV care into mainstream services.
- Allocate funding, whether that be for HIV services directly, scientific research, or for organisations specialising in community outreach.
- Mandate LGBT-inclusive education, to ensure young LGBT+ people feel seen and valued, in addition to being made aware of the disproportionate impact the HIV epidemic has on the LGBT+ community.

These themes and suggestions have informed the 10 Recommendations we outline on the next page. The policy proposals are set out in full from page 24. We hope the ideas we have proposed will add to conversations about the impact of a disease that too many people in power continue to overlook.
10 Recommendations to drive legislative action

1. Repeal or modernise outdated laws that criminalise HIV transmission.

Many jurisdictions continue to have statutes that criminalise behaviours perceived to lead to HIV infection. Most of these laws are out of step with modern scientific understanding and perpetuate HIV stigma. Legislators at every level of government should take steps to bring HIV-specific statutes and laws on infectious diseases into the 21st century.

2. Form cross-party caucuses in national assemblies.

Parliamentary caucuses have been successful in lobbying colleagues within national assemblies and governments and calling attention to topical issues that affect LGBT+ people. Legislators with a particular interest in resolving the HIV epidemic should sound out supportive colleagues and organise.

3. Address structural barriers for marginalised people, including testing and treatment access.

Certain populations continue to face additional prejudices compared to others in the LGBT+ community. These structural barriers lead to shortfalls in both testing and treatment that contribute to disproportionate HIV prevalence amongst populations facing layers of prejudice, such as LGBT+ migrants and Black MSM.

4. Address siloes in healthcare and integrate HIV healthcare into mainstream services.

A barrier that can reinforce stigma in HIV healthcare is the way medical services are structured in certain countries, with HIV services often siloed into specialist clinics. Elected officials should raise healthcare siloes with ministers and ensure community surgeries and pharmacies are resourced to provide HIV-related advice, care, and medication.

5. Drive common standards in data collection and reporting.

Reliable data collection and reporting can ensure that the right people are being reached and that solutions to the barriers faced by LGBT+ people are tailored to the needs of those most at risk. Parliamentarians should call attention to where there are gaps in HIV demographic data and pressure health ministries to improve their data collection methods.


Where data is collected, anonymity should always be assured. Parliamentarians should ensure government departments are respecting the privacy of citizens and that health data is not being shared with agencies that could present additional barriers to the lives of LGBT+ people, such as immigration authorities or justice departments.

7. Promote LGBT-inclusive education.

Those who are not educated on LGBT+ issues and the nature of the HIV epidemic are unlikely to understand the prejudices that LGBT+ people can face. Parliamentarians should advocate for LGBT-inclusive school curriculums, including the validation of same-sex relationships and identities, and education on LGBT-specific sexual health.

8. Secure funding for organisations that deliver community-based resources and outreach.

LGBT+ people who have not been validated by the education system are more likely to encounter stigma and engage in high-risk behaviours. Parliamentarians should secure funding for organisations specialising in providing LGBT+ and HIV educational resources, as well as community-based groups that support young marginalised people stay in schools.

9. Fund scientific, medical and social research.

Other stakeholders also have a role to play. Large companies with a stake in ending the epidemic should assist in funding HIV research, such as working with scientific institutions on medical research, with local officials and health agencies on data gathering, or funding research into the barriers that face marginalised groups.

10. Ensure parliamentarians are linked with relevant experts.

Stakeholders can also support parliamentarians wishing to convene and discuss strategy and policy, whether that be providing a safe space for politicians to meet, by funding organisations that assist LGBT-supportive parliamentarians in networking, or linking officials with relevant experts to help improve understanding on the nature and impact of the epidemic.
Background

HIV - the ongoing epidemic

It is estimated that in 2020 around 37.7 million people were living with HIV globally and 1.5 million people became newly infected with HIV. This indicates a 30 per cent decline in new HIV infections since 2010. Despite this drop in HIV incidence there is still work to be done, especially in terms of reducing new infection amongst key populations and ensuring that people living with HIV (PLWH) who are not receiving treatment – accounting for 27 per cent of PLWH – are able to access antiretroviral therapy.

In 2020, key populations – which includes gay men and other MSM, people who inject drugs, sex workers and their clients, and transgender people – accounted for 65 per cent of new HIV infections globally and 93 per cent of new infections outside of sub-Saharan Africa. Compared to the general population, the risk of acquiring HIV is 25 times higher amongst gay men and MSM, and 34 times higher amongst transgender women.

The COVID-19 pandemic has also highlighted how disadvantaged communities are disproportionately affected by public health crises. These entrenched healthcare inequities, a result of societal and structural factors, have only been exacerbated by the COVID-19 response. The physical closure of HIV clinics and sexual health services, the diversion of healthcare workers to other areas, and the financial constraints imposed by a global recession have all compromised the management of HIV for groups most affected. According to the Global Fund to Fight AIDS, Tuberculosis and Malaria, data from 502 health facilities across 32 African and Asian countries shows HIV testing declined by 41 per cent and referrals for diagnosis and treatment declined by 37 per cent during the first lockdowns in 2020, compared with the same period in 2019.

It is also true that PLWH experience more severe outcomes and have higher co-morbidities from COVID-19 than people not living with HIV. In mid-2021, most PLWH did not have access to COVID-19 vaccines, and studies have found that the risk of dying from COVID-19 amongst PLWH was double that of the general population.

Given the global context, this means a concerted effort is required to reach the UNAIDS targets of ensuring 95 per cent of PLWH know their HIV status, 95 per cent of people with diagnosed HIV are on treatment, and 95 per cent of all people receiving treatment are virally suppressed by 2025.
Although there are reasons to be optimistic about reaching the 95-95-95 targets, many challenges persist – not least the barriers and stigma faced by LGBT+ people in accessing HIV healthcare. For example, in June 2021 there were attempts by some members of the United Nations to delete references to LGBT+ people and human rights in the Political Declaration agreed at the UN High Level Meeting on HIV and AIDS. Although these attempts ultimately failed, it is sobering to think that discrimination against LGBT+ people is still a reality as the epidemic enters its fifth decade.

The epidemic in Europe

Although there has been progress in Europe over the past decade, HIV remains a major public health concern and epidemic patterns and trends vary widely. While the number of new diagnoses in the EU/EEA declined by 9 per cent from 2010 to 2019, the wider WHO European Region saw the number of people newly diagnosed with HIV increase by 19 per cent over the same period. By 2019, the rate of new diagnoses in men has grown to be three times higher than that in women, and 53 per cent of people diagnosed with HIV in the European Region were diagnosed at a late stage of infection.

ECDC data shows that sex between men remains the predominant mode of HIV transmission reported in the EU/EEA, making up 39 per cent of all new HIV diagnoses in 2019 and 51 per cent of diagnoses where the route of transmission was known. While the overall EU/EEA trend declined from 2010 to 2019, national trends vary considerably and rates of HIV diagnoses attributed to MSM have increased substantially in Bulgaria, Cyprus, Estonia, Lithuania, Poland, Romania and Slovakia.

Source: ECDC HIV/AIDS surveillance in Europe 2020 (2019 data)
A spotlight population we identified in our European roundtable was migrants – particularly MSM migrants – defined as originating from outside of the country in which they were diagnosed. Data on HIV incidence amongst migrant populations remains limited, but the ECDC reports that 44 per cent of people diagnosed in the EU/EEA in 2019 were migrants, an increase of 4 per cent compared to 2010. At a national level, this figure rises to over 60 per cent of new diagnoses in countries including Denmark, France and the United Kingdom, and is as high as 80 per cent in Iceland, Ireland and Sweden.¹⁶

Source: ECDC HIV/AIDS surveillance in Europe 2020 (2019 data)

ECDC data also shows that despite a sustained downward trend in new diagnoses amongst MSM over the past decade, the trend for MSM migrants as a distinct population does not follow the same trend. New diagnoses for MSM migrants increased in the first half of the decade before seeing a milder decrease from 2015 onwards (see figure on p.9). There is not enough research to explain why this is the case, but our collaborators at IAPAC and the Fast-Track Cities Institute are looking to address the research gaps on HIV incidence in MSM migrants. So far they have conducted a literature review, where only 25 per cent of articles found on the topic of barriers in HIV care addressed access to healthcare and social determinants of migrant MSM related to HIV infection.¹⁷ Due next is a policy paper looking at
migrant MSM-focused interventions, and a regional workshop on how to address this inequity in the HIV response.

The epidemic in the United States & Canada

It is estimated that there are 1.2 million people living with HIV in the United States, with 13 per cent of these people unaware of their status and requiring testing. Following a period of general stability, new HIV infections have fallen by 8 per cent from 2015 to 2019 – however, HIV diagnoses are not evenly distributed across all states and the South continues to see the highest rates of new diagnoses. Gay, bisexual and other MSM continue to be the population most disproportionately affected by HIV, with MSM accounting for 69 per cent of new HIV diagnoses in 2019. Transgender people accounted for 2 per cent of new HIV diagnoses in 2019, with the vast majority of cases (93 per cent) being trans women, and the number of diagnoses increasing on 2015.

Racial and ethnic minorities are also disproportionately affected by the epidemic, with Black MSM at particular risk. While much of the progress in declining infection rates can be attributed to a decrease in new infections amongst young gay and bisexual men (ages 13-24) – a drop of 33 per cent from 2015 to 2019 – prevalence in ethnic minority populations has remained largely stable. In 2019, African Americans represented 13 per cent of the US population but accounted for 44 per cent of new HIV diagnoses – Black MSM specifically accounted for 36 per cent of new diagnoses from 2015 to 2019 (compared to 30 per cent for White MSM), and in 2019 accounted for 26 per cent of all new diagnoses and 37.9 per cent of diagnoses amongst all MSM.
Rate of persons living with HIV, general population (AK and HI excluded). Much of the epidemic is concentrated in the Southern United States, but continues to see high prevalence in large urban areas. Source: AIDSVu

Percentage of Black MSM living with HIV (AK and HI excluded). Source: AIDSVu

Studies have demonstrated that the epidemiology of HIV corresponds with various health inequities in the United States, including the prevalence of heart disease, stroke, obesity, poverty rates, and health insurance coverage (see infographic on p.11). This goes some way to illustrate how other disparities have a bearing on HIV incidence, and would suggest there are intersectional and structural factors influencing health outcomes.
A spotlight population we identified in our roundtable was Black MSM in the United States and numerous reasons were put forward for why this population is at such increased risk of HIV infection. The Southern Black Policy & Advocacy Network, who presented at the roundtable, pointed out that Black LGBT+ people are having to manage more than just HIV, such as increased rates of cancer, hypertension, stigma and violence. Other key barriers include: lower uptake rates in Black LGBT+ communities of HIV medical advances, such as PrEP; intersectional discrimination in Black and LGBT+ communities, such as in politics, healthcare systems, and in families and the community; a lack of engagement in HIV planning amongst elected officials at all levels of government, and a lack of knowledge of how to advocate for key impacted populations; and a lack of Black LGBT+ people and PLWH in public health leadership roles.

In Canada there are an estimated 62,050 people living with HIV based on 2018 data. Of these PLWH, it is estimated that 13 per cent are undiagnosed. At the end of 2018, 85 per cent of those diagnosed were receiving antiretroviral treatment and 94 per cent of people on treatment had a suppressed viral load.

As in the United States, the epidemic in Canada continues to have a disproportionate impact on gay, bisexual and other MSM, with this population accounting for 52.2 per cent of new HIV infections in 2018, despite representing around 3-4 per cent of the Canadian adult male population. There is also a geographic disparity, with the overall HIV diagnosis rate ranging from 1.7 per 100,000 population in the Northwestern Territories, to 16.7 per 100,000 in Saskatchewan (see map on p.12).
HIV diagnosis rate (per 100,000 population), by province and territory, Canada, 2019. Source: Public Health Agency of Canada, HIV Surveillance Report 2019

Another spotlight population we discussed in our roundtable was Indigenous people in the US & Canada. Canada in particular has disproportionate rates of HIV in Indigenous populations – in 2018, 14 per cent of new infections occurred amongst Indigenous people despite representing 4.9 per cent of the total Canadian population. This is an increase on 2016, when Indigenous people accounted for 12.3 per cent of new infections. Three quarters of new infections in this population are estimated to be amongst males.27

Although Canada has a universal healthcare system, unlike the United States, the barriers that exacerbate the epidemic’s impact on LGBT+ people appear to be similar. Cited factors include a lack of anonymised testing, limited education on HIV issues, and, particularly in the case of Indigenous people, stigma and discrimination in communities and reservations.28
**Roundtable 1: Europe**

Our first roundtable convened elected officials and parliamentarians from national parliaments and the European Union. Also present were representatives of LGBT+ civil society and HIV activists, including from the International Association of Providers of AIDS Care (IAPAC), the Global Fund, and Positive Voice, as well as independent experts and PLWH. Attendees from the Global Equality Caucus and Gilead were also present.

The session began with a presentation of key data on HIV incidence from across Europe, demonstrating the continued disproportionate impact of HIV/AIDS on the LGBT+ community and particularly on MSM (see pp.7-8 of this report). This was followed by a special presentation by IAPAC on the rates of HIV diagnoses in MSM migrant populations, which showed that while HIV incidence amongst MSM in general is declining this is not the case for MSM migrants (see pp.8-9 of this report).

Attendees then participated in an open forum divided into two halves. In the first discussion, participants identified some of the barriers that LGBT+ people face when accessing HIV healthcare. In the second discussion, participants focused on what parliamentarians could be doing in their assemblies to tackle these barriers and what policies would be effective in reducing healthcare inequities.

Below is a summary of the key themes that emerged from these two discussions. For further analysis, including a synthesis with the issues raised in the US & Canada roundtable, please refer to the *Common themes and priorities going forward* section of this report (pp.21-23).

**Removing siloes in healthcare and integrating HIV care into the mainstream**

A major barrier facing LGBT+ people when accessing HIV care that was identified by participants was the structural provision of HIV services common in many European countries, whereby HIV prevention and treatment is only available at specialist clinics and is not yet integrated into mainstream healthcare.

One participant, an HIV-positive trans woman, spoke of her experiences using health systems in two countries in Western Europe. In both countries she found HIV care to be siloed, as was the case for trans-related healthcare, meaning she was required to go to a sexual health clinic for medication and monitoring as opposed to a local doctor or pharmacy. Siloing can therefore serve as a barrier as
sexual health services have limited funding and are often confined to larger population centres, meaning those in need of HIV care could find themselves hundreds of miles from the nearest service. Given HIV disproportionately affects disadvantaged people, including both legal and illegal migrants, high travel costs could be dissuading people from accessing care.

An additional point was made that it is difficult for marginalised people to simply visit a doctor’s practice as they may not be able to address all of their needs – because HIV care has been siloed into a different service, local doctors may lack knowledge on the subject, and in some cases lack of expertise may contribute to prejudice amongst medical staff, as has been found in the provision of transgender care in Germany. Many migrants may not be registered with a medical practice and may choose to avoid care due to concerns over immigration status and data privacy. One MP expressed concern that some migrants are left adrift by the authorities for years and are not signposted to the appropriate healthcare services.

While most European countries have universal healthcare, a point was also made that private health insurance commonly has exclusions, with many providers refusing to cover HIV medication nor trans healthcare and gender identity services. With the vast majority of LGBT+ people therefore reliant on state-provided healthcare, those with HIV-related needs may find themselves in a precarious position as siloed programmes are often the first to be cut or closed in times of financial constraint, as has been observed during the COVID-19 pandemic.

Participants agreed that a solution to this barrier would be to integrate HIV services into mainstream healthcare. This would involve moving HIV healthcare out from sexual health clinics and into local medical practices and hospitals. Instead of collecting medication from specialist clinics, PLWH should be able to collect a prescription from a local pharmacy or GP. Community doctors and local medical professionals should receive adequate training in dealing with LGBT-specific issues and should be able to provide HIV services, including the provision of preventative medication such as PrEP.

**Improving access through technological solutions**

After data privacy in healthcare settings was raised as a potential concern for LGBT+ people, discussion turned to how technology could help eliminate barriers. One parliamentarian suggested, in the context of migrants, that certain firewalls should be in place for health data that stops information being shared with immigration authorities. This may encourage more vulnerable people – particularly undocumented migrants – to come forward and seek HIV healthcare without fear of being traced.
Another legislator questioned how well mapped HIV data was across Europe, particularly in the context of the epidemic’s impact on LGBT+ people. Suggested was a need for stronger data mapping, evidence and online resources to help push scientific arguments to help contain the epidemic, rather than a singular focus on human rights.

One participant proposed remote or digital healthcare as a solution to overcome barriers in accessing care. In this scenario, those at risk of HIV or those requiring medication would be connected to a clinician via an online platform to be assessed and prescribed medication digitally, rather than having to physically travel to a medical practice. Such a service exists in the UK, where the digital service provider Babylon Health powers the mobile app GP at Hand, connecting patients with NHS doctors free of charge. As it stands, this service remains limited to certain parts of the country and does not offer a comprehensive solution given that HIV care remains siloed to sexual health specialists. Further investment and technological innovation would be required to roll out a similar service across Europe, but it could potentially benefit those who find it challenging to access medical services in person, including young LGBT+ people living away from home, migrants, and LGBT+ people with no fixed abode.

Sustaining funding for HIV healthcare

A recurring theme that participants continued to refer back to was that many solutions required additional funding to support HIV programmes, including education and awareness campaigns, further research into HIV incidence amongst those most at risk, wider HIV testing, and state provision of PrEP. The disparate availability of PrEP in particular remains a concern in Europe – while it is provided free of charge through national health services in 15 countries, including the UK, France, Spain, the Netherlands, Germany, Norway and Sweden, those in need of preventative medication must pay from their own pocket in countries including Italy, Austria and Poland, and there has been no formal implementation in much of Eastern Europe.30

One parliamentarian noted that the most important law that legislators vote on is the budget, and a more concerted push should be made in national assemblies to secure government funding for LGBT+ civil society organisations, who are often the ones providing educational resources and community support. Such funding would make politicians feel they have a stake in the success of these charities, and the fostering of such a relationship would encourage more politicians to be educated on HIV issues.
One participant added that the private sector also has a role to play in ensuring there is enough money to improve HIV outcomes. Private companies have a responsibility to their employees and a wider social responsibility to the world – as such they could donate to HIV charities and LGBT+ organisations while simultaneously providing thought leadership on HIV issues to tackle stigma in the workplace and society. Larger companies could also provide their employees with health insurance that covers the costs of both HIV prevention and treatment. Additionally, those with a stake in the health industry – such as pharmaceutical companies, medical providers, and manufacturers – could help to convene meetings with lawmakers, experts and changemakers, as well as taking a more active stance in speaking out in favour of legislation that would benefit LGBT+ people.

**Demonstrating leadership in national parliaments**

While the thought leadership of private companies was noted, participants also agreed that it was vital for politicians to take a similar stand. One parliamentarian suggested there was a need for a broad collective voice for European politicians to advocate on HIV issues – going beyond the European Parliament’s group on sexual and reproductive rights – with a view to exerting pressure on ministers at international summits. One MEP highlighted how the EP’s Intergroup on LGBTI Rights was working to encourage the establishment of more national cross-party parliamentary caucuses dedicated to LGBT+ advocacy issues, an aim shared with the Global Equality Caucus.

Another MP expressed concern about attacks on LGBT+ people in the media, especially against trans people, and that these attacks could be marginalising people from accessing health services for fear of discrimination. Participants agreed that parliamentarians should not be drawn into ‘culture wars’ and have a responsibility to be guided by independent evidence and science. Going further, one MP stressed that legislators should be visible spokespeople for LGBT+ and HIV-positive people, and challenge misinformation and discrimination in the media.
Roundtable 2: United States & Canada

Our second roundtable convened elected officials and parliamentarians from the federal legislatures of both the United States and Canada, plus state legislators from Alberta, Massachusetts, Georgia and California. Also present were representatives of LGBT+ civil society and HIV activists, including from the Southern Black Policy & Advocacy Network, the Human Rights Campaign, and AIDS United, in addition to PLWH and trans representation. Also present were academic experts from MacEwan University, the Rollins School of Public Health at Emory University, and the Factor-Inwentash Faculty of Social Work at the University of Toronto. Representatives from the Global Equality Caucus and Gilead also attended.

The session began with presentations of epidemiological data and HIV statistics from both the United States and Canada, demonstrating various disparities including the disproportionate impact of HIV on MSM, people living in the Southern United States, and Black and Indigenous populations (see pp.9-10 of this report). This was followed by a presentation by the Southern Black Policy & Advocacy Network looking specifically at the factors influencing disproportionate HIV prevalence amongst Black LGBT+ people (see pp.10-11 of this report).

As in the Europe roundtable, attendees then participated in an open forum divided into two halves. In the first conversation, participants identified some of the barriers that LGBT+ people face when accessing HIV healthcare, including the unique challenges faced by spotlight populations. In the second discussion, participants focused on what legislators could be doing in their assemblies to tackle these barriers and what policies would be effective in reducing healthcare inequities.

Below is a summary of the key themes that emerged from these two discussions. For further analysis, including a synthesis with the issues raised in the Europe roundtable, please refer to the Common themes and priorities going forward section of this report (pp.21-23).

HIV criminalisation

Participants discussed the impact of laws that criminalise potential HIV exposure and the behaviour of people with HIV. In the United States, 26 states have HIV-specific statutes or regulations that criminalise or control behaviours and another 11 states criminalise behaviours through statutes on STIs or infectious diseases generally. In Canada, following a Supreme Court ruling in 2012, a person may be
charged with *aggravated sexual assault* if they have not disclosed their HIV status to a sexual partner and there is a ‘realistic possibility of transmission’, regardless of intent.  

It was noted that HIV criminalisation perpetuates stigma in both countries and has a disproportionate impact on marginalised PLWH, including Black people, Indigenous communities, and gay men. For example, every Southern state barring Texas retains an HIV-specific or infectious diseases criminalising statute, and in Canada the number of criminal cases against gay men has increased since the Court ruling. Participants expressed concern that criminalising laws may dissuade people from getting tested and knowing their status, and that criminal convictions can have a consequential effect on other issues where LGBT+ people face discrimination, such as housing and employment.

Participants agreed that ongoing HIV criminalisation is incompatible with the science – particularly the fact that someone who is HIV-positive on effective medication with an undetectable viral load cannot transmit HIV (U=U) – and that many laws are relics from the 1980s when far less was known about HIV transmission and there were no widely available treatments. Proposed solutions span different tiers of governance, as in the United States decriminalisation is a matter of state law, whereas in Canada a federal reform of the Criminal Code would be required to offset and update the Supreme Court ruling.

**Inclusive education**

Participants considered that structural discrimination in educational systems could be preventing LGBT+ people from seeking HIV services and accessing prevention options. While HIV criminalisation appears to be a consequence of limited knowledge amongst lawmakers and wider society on HIV issues, participants argued that schools were not equipped with the right resources to educate younger people on matters of sexual health. More specifically, one academic attending the session argued the need for LGBT-inclusive curriculums that teach about LGBT+ history, the specific sexual health needs of LGBT+ people, and existing contraceptive options and treatment medications for HIV and other STIs. One legislator from Alberta in Canada expressed concern that the current government of her province was rolling back on state guidance on an inclusive curriculum, and argued that elected representatives should be advocating for comprehensive sexual health education. Validating LGBT+ identities through state-funded school systems would help to boost the self-worth of marginalised people and help to eliminate misconceptions about the current nature of the HIV epidemic.
One participant from the United States argued that a lack of access to education has a direct impact on HIV acquisition, as those that fall out of the school system may be more exposed to risky behaviours or face stigma in their community. It was highlighted that student support organisations that run before- and after-school programmes, such as the YMCA, should receive more funding, as these are often the organisations that have a direct community impact – school boards and local authorities, meanwhile, can be slower-moving and more obstructive in addressing gaps in the needs of marginalised students.

**Intersectional healthcare**

One participant, a Black trans woman, pointed out that HIV healthcare systems in the United States and Canada were established primarily for white gay men in the 1980s, and consequently remain structured in that image. While HIV continues to disproportionately affect gay men, rates of PrEP uptake are 13 per cent higher amongst white men than Black MSM in the United States. There also remains an inequitable distribution of other healthcare challenges – such as increased rates of heart disease and lower rates of health insurance coverage in the Southern United States (see p.11 of this report) – that intersect with HIV inequities and have a disproportionate impact on racial minority populations.

Another attendee noted that political polarisation meant other healthcare systems that benefit LGBT+ people, such as Planned Parenthood, adoption, and surrogacy services, were being attacked and defunded by some conservative politicians. Such is the lack of bipartisan agreement on the provision of health services that LGBT+ people may feel discriminated against when accessing healthcare, to the point where they may not seek treatment at all.

A third attendee – who is HIV-positive – raised the fact that due to the availability of effective HIV treatment, PLWH in the United States are an aging population with 51 per cent of people with diagnosed HIV aged 50 or over. Therefore the additional health needs of older people also need to be considered when addressing inequities in care, including coverage gaps in Medicare and Medicaid.

All participants agreed there was a need for greater consideration of intersectionalities in healthcare provision, and that education programmes and medical training should be more sensitive to the cross-cutting and varied needs of HIV patients, who may be dealing with additional stigmas or health problems.
Wider access to testing

One participant from Canada pointed to the lack of access to home test kits in his country, with the first kit only having been licensed at the end of 2020.36 The vast majority of testing in Canada therefore remains in medical and community settings, which may be blocking LGBT+ people from seeking a test should they wish to remain anonymous.

While self-testing is available more widely in the United States, tests may not be covered by some health insurance policies or Medicaid. Some health departments and charities may provide tests free-of-charge but variance in states’ laws may limit availability, meaning marginalised people may have no other option but to purchase a test. Given the correlation between HIV prevalence and poverty rates (see p.11), at-risk populations may be falling victim to the virus simply because they cannot afford to take a test.
Common themes and priorities going forward

The aim of our two roundtables was to facilitate conversations about what lawmakers and other stakeholders should be doing to remove barriers for LGBT+ people in accessing HIV healthcare, and how they should do this.

Parliamentarians and other elected representatives have a unique role to play in law making. They have the power to create and pass legislation, they can approve budgets and funding, they can pressure governments and those with executive authority, and they can lead national debates on topical issues. Utilised correctly, all of these competencies can be harnessed to improve the lives and health of LGBT+ people, across all tiers of governance.

National, state or local government?

A common theme across both roundtables was which level of government is best placed to deliver HIV programmes and drive higher standards in the provision of care. In the United States and Canada, health policy and responsibility is largely held by state or provincial governments, whereas the federal governments reserve the power to issue certain executive directives. A key difference between the two countries is that insurance coverage in the United States comes mostly from private providers, whereas in Canada it is mostly publicly-funded. Universal healthcare is also a common feature across Europe – whether that be national single-payer models as in the UK or Spain or multi-payer public insurance models as in France and Germany. The actual provision of healthcare in Europe is more devolved, with regional governments, city authorities and local councils, and local hospital trusts all holding varying powers over delivery.

Participants across both roundtables agreed that HIV programmes should be as locally targeted as possible – for example, cities in Europe, such as those in the Fast Track Cities initiative, have powers over campaign implementation and data monitoring and reporting. In the United States, city and municipal governments can deliver public information campaigns whereas state governments have the power to address HIV criminalisation laws. In Canada, provincial governments can set the curriculum in state education.

Ultimately, federal and national governments also hold considerable power over HIV policy, and all participants agreed that these authorities should act where they can. In the United States, for example, Congress could pass a bill compelling state governments to act on HIV criminalisation, or the UK government could increase funding for local councils to deliver HIV education programmes in schools.
Creating and passing legislation

One of the most powerful tools at the disposal of legislators is their ability to introduce legislation, which if passed has the legal mandate to compel action on HIV healthcare issues. Even if a bill does not get approved – as is often the case with laws that don’t have government backing and lack a majority – it can have the benefit of establishing parliamentary allies on an issue and help to build consensus and scrutiny in a legislative setting.

Participants at both roundtables agreed in the power of supporting legislation that tackles LGBT+ discrimination as a way to reduce stigma in accessing HIV care, as well as legislation that directly targets HIV-specific needs. For example, Rep. Barbara Lee (US – CA) – who appeared at the United States & Canada roundtable – has introduced the REPEAL HIV Discrimination Act 2021 in the US Congress, which would force a review of federal and state laws on HIV criminalisation. Although the bill is yet to progress, the issue of HIV criminalisation is kept on the federal agenda by way of its introduction.

Additionally, participants at both roundtables highlighted the need for legislators to talk with colleagues who do not typically take an interest in improving HIV healthcare – whether that be ideological opponents or those that lack education on the subject – and seek common ground on beneficial laws. One proposal posited that arguments in favour of removing barriers for LGBT+ people should be made on economic terms, at least to those US Republicans who have a record of opposing LGBT+ equality, instead of with human rights language. Similarly, one politician attending the European roundtable argued that presenting the scientific arguments for tackling the HIV epidemic may cut through more with colleagues and avoid positioning LGBT+ people at the centre of an ideological ‘culture war’.

Approving budgets

Related to legislators’ ability to pass legislation is the power to approve budgets and state funding. Participants at both roundtables highlighted how more financial backing is required for non-governmental organisations and charities working to end HIV stigma and improve community-based outcomes for marginalised people – whether that be organisations providing educational resources to schools, HIV-specialised training to healthcare professionals, or community groups tackling LGBT+ homelessness or violence.

Sustaining these NGOs through a guaranteed amount of state funding would be beneficial, particularly given the financial pressures placed on many third sector
groups during the COVID-19 pandemic. Legislators could push for a minimum level of grant funding for civil society in national budgetary votes, designate certain funds for HIV programmes via national health ministries, or approve increased funding for local authorities and school districts so that education budgets can support ongoing relationships with expert charities.

**Pressuring governments**

A key function of legislatures is to hold governments to account and scrutinise government objectives. Participants at both roundtables recognised the need for parliamentarians to pressure their national governments into further action to remove barriers for LGBT+ people, with suggestions ranging from lobbying ministers on national LGBT+ action plans to coordinating with other legislators across borders to present a unified voice at international conferences.

A successful example exists in the parliamentary caucus model, where elected officials from different parties work together in a national caucus on a particular interest area. For example, the US Congressional HIV/AIDS Caucus chaired by Rep. Barbara Lee has helped to drive bipartisan support for executive programmes such as PEPFAR and the National HIV/AIDS Strategy; the UK APPG on HIV/AIDS has produced reports which have received debating time in Parliament, forcing a response from government ministers; and the European Parliament Intergroup on LGBTI Rights has co-signed letters to the European Commission calling for a response to LGBT+ rights infringements in member states such as Hungary and Poland.

Where possible, it would be beneficial for legislators to form parliamentary caucuses on HIV/AIDS and LGBT+ rights in their national assemblies as a vehicle to coordinate their lobbying of ministers. Such a group has recently been formed in North Macedonia, and the Global Equality Caucus has helped to facilitate conversations in Canada.

**Leading national debates**

As public figures in the national spotlight, legislators are able to command significant media attention and can help to set the news agenda based on their views and actions. Participants at both roundtables agreed that elected representatives have a responsibility to keep HIV inequities in the national consciousness and keep debates grounded in rationality and science. Such leadership can be demonstrated by securing parliamentary time for LGBT+ healthcare issues, and challenging misinformation about HIV in media and society.
Recommendations

Based on the conversations we have facilitated across the two roundtables, where we identified common themes, unique challenges, and priorities for lawmakers, we make the following recommendations for parliamentarians and other stakeholders:

1) **Repeal or modernise outdated laws that criminalise HIV transmission.**

Many jurisdictions in the United States, Canada and Eastern Europe continue to have statutes that criminalise behaviours perceived to lead to HIV infection, even if certain behaviours – such as spitting or oral sex – have low or negligible risk of transmission, and regardless of whether there is intent. Most of these laws were written in the 1980s when little was known about the nature of HIV, are out of step with modern scientific understanding, and perpetuate outdated HIV stigmas.

Some US states have started to modernise these laws – for example, California now requires intent to transmit, and Michigan no longer criminalises oral sex. These measures need to go further in all jurisdictions where it remains a criminal offence to transmit HIV without intent. Legislation should reflect advances in science, such as U=U, and treat HIV as a public health crisis and not as an assault weapon. Ultimately it is marginalised communities at disproportionate risk of HIV that suffer, as criminalisation perpetuates stigma and dissuades people from testing and accessing medical services.

Legislators at every level of government should take steps to bring HIV-specific statutes and laws on infectious diseases into the 21st century. In the United States, where state governments are failing to act, Congress should seek to pass the REPEAL HIV Discrimination Act to compel attorneys-general to review discriminatory laws. In Canada, the federal government should update the Criminal Code to clarify the Supreme Court ruling on criminalisation. In Europe, MEPs should call attention to those countries that retain HIV-specific criminal laws, such as Poland, Romania and Latvia. Legislators in non-EU countries such as Ukraine and Belarus should review criminal law to ensure it is in line with international standards, including the provisions of the European Convention.

2) **Form cross-party caucuses in national assemblies.**

Existing parliamentary caucuses have been successful in lobbying colleagues within national assemblies and governments and calling attention to topical issues that affect LGBT+ people. The UK APPG on HIV/AIDS, for example, has previously secured parliamentary time to debate World AIDS Day, and the new parliamentary
grouping on LGBT+ rights in North Macedonia has helped to support the implementation of new anti-discrimination laws in that country. Similar parliamentary groupings exist in the European Parliament and in the United States Congress, on both HIV/AIDS advocacy and LGBT+ rights more generally.

These caucuses help to foster bipartisan agreement on policy issues and encourage parliamentary colleagues to work together on workable solutions to crises such as the HIV epidemic. They provide a unified legislative voice on a particular issue and can be at the vanguard of inquiries and data gathering. Investigations and reports into specific HIV inequities, and how they affect marginalised populations, may also be presented to parliaments and to ministers, ensuring these issues and their solutions remain on the agenda and feature in a national debate.

National assemblies that are yet to form these groupings – whether formal or informal – should seriously consider their benefits. Formation is often driven by a select few parliamentary advocates, and those legislators with a particular interest in resolving the HIV epidemic should sound out supportive colleagues and organise. Where this is not possible, the Global Equality Caucus is able to help in connecting legislators and sharing learning from other countries.

3) **Address structural barriers for marginalised people, including testing and treatment access.**

Testing continues to be one of the most important factors in HIV prevention – if an individual does not know their HIV status, they cannot then access the treatment they may need. Yet many LGBT+ people – and particularly those from marginalised demographics, such as migrant populations, Black communities, and Indigenous people – do not have access to regular testing and are not on effective treatment. This could be a result of social and structural barriers such as community-related stigmas, intersectional health priorities where some groups are dealing with more than just HIV, or simply lack of anonymised home testing. Widening the availability of free, anonymous home tests would unlock regular testing for many people who otherwise do not wish to disclose their identity at in-person, community-based testing facilities.

Other legal and structural barriers may persist which means certain populations continue to face additional prejudices compared to others in the LGBT+ community. This could include strict immigration laws that block migrants from accessing state-provided healthcare, laws that directly or indirectly disenfranchise the citizenship and voting rights of Black people, or unrealistic bureaucratic barriers facing people that wish to change their legal gender.
Parliamentarians should be conscious of the intersectional discrimination that many members of the LGBT+ community face, and take steps to address the structural barriers that contribute to disproportionate HIV prevalence amongst populations facing layers of prejudice such as LGBT+ migrants and Black MSM.

4) **Address siloes in healthcare and integrate HIV healthcare into mainstream services.**

A barrier that can reinforce stigma in HIV healthcare is the way medical services are structured in certain countries. Some countries in Europe, for example, continue to provide HIV care outside of mainstream health services, with care provided exclusively through sexual health clinics. Where additional siloes exist, such as in transgender services, some LGBT+ people in need of HIV services may find themselves having to visit multiple medical professionals across multiple services, often with geographical barriers.

Parliamentarians have the power to scrutinise how healthcare services are structured and delivered, often in terms of budgetary allocations and funding for local services. Elected representatives should raise the issue of healthcare siloes with the appropriate ministers and ensure that funding exists to equip community surgeries and pharmacies with the training and resources needed to provide HIV-related advice, care, and medication. Such integration would help to address intersectional healthcare needs, where many marginalised people are dealing with more than HIV.

5) **Drive common standards in data collection and reporting.**

An important element to tackling the barriers that LGBT+ people face in accessing HIV healthcare is ensuring that the right people are being reached and that solutions are tailored to the needs of those most at risk. Only reliable data collection and reporting can drive this. For example, the health needs of a 60-year-old HIV-positive Black trans woman living in a rural neighbourhood with no health insurance coverage are likely to be different to a 20-year-old HIV-positive white gay man living in a large city with access to universal healthcare. If there is no granularity in the data on HIV prevalence and incidence, then lawmakers may struggle to design solutions to the inequities that exist.

Parliamentarians should therefore call attention to where there are gaps in HIV demographic data and pressure health ministries to improve their data collection methods. Most data on HIV originates from local authorities reporting to centralised agencies, so voting to approve a common federal or national standard
in data collection/reporting could provide a template to those cities or local
governments falling short in the information they provide.

6) Safeguard data privacy in healthcare settings.

Where data is collected, anonymity should always be assured. This applies to HIV
testing, immigration status, or whatever other circumstances that may place LGBT+ people in danger should their health data be shared with other government authorities.

Parliamentarians have a responsibility to ensure government departments are respecting the privacy of citizens and that health data is not being shared with agencies that could present additional barriers to the lives of LGBT+ people, such as immigration authorities or justice departments. Advocating for these safeguards to be included in data privacy laws is one option for lawmakers, as is scrutinising the data protection policies of relevant ministries.

7) Promote LGBT-inclusive education.

A lot of the stigma and discrimination that LGBT+ people face is rooted in education. Those who are not educated on LGBT+ issues and the nature of the HIV epidemic – including students, teachers, some medical professionals, and indeed some politicians – are unlikely to understand the specific challenges and prejudices that LGBT+ people can face.

As national leaders, parliamentarians have a responsibility to ensure all citizens are treated with equal dignity, and that the reality of society is reflected in the education system. Parliamentarians should advocate for LGBT-inclusive school curriculums, including the validation of same-sex relationships and identities, and education on LGBT-specific sexual health. Such a model exists in the UK, where the government introduced regulations on inclusive sex and relationships education in 2019.

8) Secure funding for organisations that deliver community-based resources and outreach.

Simply promoting inclusive education is inadequate unless teachers are trained and equipped to deliver it. Parliamentarians should therefore also ensure funding is provided in the education budget for organisations and institutions that specialise in providing LGBT+ and HIV educational resources, as well as community-based organisations that help support young marginalised people stay within the schools system. Those LGBT+ people who have not been validated by the education
system, or indeed have dropped out of it entirely, are more likely to encounter stigma and engage in behaviours that increase their risk of HIV infection, such as intravenous drug use, unprotected sex, or prostitution.

9) **Fund scientific, medical and social research.**

The funding needed to end HIV inequities cannot come from the state alone. Given competing budgets and the financial pressures of the COVID-19 pandemic, governments simply may not have the money to drive some of the solutions presented above. Private companies, therefore, also have an important role to play in helping parliamentarians eliminate barriers for LGBT+ people.

Some private companies already play a key role in advocating for LGBT+ rights more generally, such as providing employment protections, inclusive health insurance policies, or sponsoring Pride organisations. With regard to eliminating HIV inequities more specifically, private companies should speak up in favour of relevant legislation and elucidate both the personal benefits to employees and the economic benefits to wider society that eliminating inequities would bring.

Large multinational companies also have the money and resources to assist in funding research on HIV, whether that be working in partnership with scientific institutions on medical research or with local officials and health agencies on data gathering. No less important is the need to fund research into the socioeconomic and structural barriers that face marginalised groups, so that we can better understand why LGBT+ people and other groups disproportionately affected by HIV are not receiving equitable care.

10) **Ensure parliamentarians are linked with relevant experts.**

Stakeholders can also support parliamentarians wishing to convene and discuss strategy and policy, whether that be providing a safe space for politicians to meet or by funding organisations that assist LGBT-supportive parliamentarians in networking.

Those companies that work specifically in the pharmaceutical or educational industries also have the capacity to link elected representatives with relevant experts on HIV, to help improve understanding amongst politicians on the nature of the epidemic and how it has impacted on LGBT+ people.
References

6. Ibid
7. Ibid
13. Ibid
15. Ibid
17. Private workshop, 21 June 2021
20. Ibid
22. Ibid
24. Private workshop, 23 June 2021
27. Ibid
28. Private workshop, 23 June 2021
33 Ibid
35 https://www.cdc.gov/hiv/group/age/olderamericans/index.html
36 CDC (2021), *HIV and Older Americans*, https://www.catie.ca/en/fact-sheets/testing/hiv-self-testing