National Coalition for LGBTQ Health

INAUGURAL STATE OF LGBTQ HEALTH NATIONAL SURVEY™ 2022
INTRODUCTION

The National Coalition for LGBTQ Health administered the Inaugural State of LGBTQ Health National Survey™ to identify the unique primary and supportive healthcare needs of LGBTQ+ people. The goal of this survey was to better inform ongoing advocacy, education, research, and training activities. The results provided insight into patient and provider pathways that optimize primary and support services for these communities. To identify the healthcare needs, the Coalition surveyed providers (clinical and non-clinical) across the United States.

BACKGROUND

A total of 2,344 provider participants responded to questions at the intersection of clinical and behavioral health, stigma, and social justice. Questions further examined the syndemics of STIs and HIV, housing and homelessness, poverty, systemic gaps across racial and ethnic minorities, as well as on LGBTQ+ specific services impacted during COVID-19.

This survey was conducted on behalf of the National Coalition for LGBTQ Health. The Coalition is a partnership of providers and organizations committed to improving the health and quality-of-life of lesbian, gay, bisexual, transgender, and queer or questioning individuals through federal and local advocacy, education, and research.

Formed with the aim of eliminating health disparities across issues of sexual orientation, gender identity and presentation, gender, race and ethnicity, education or income, disability, nationality, geographic location and age, the Coalition represents the rich diversity of the LGBTQ+ communities nationwide and reaches across gender/gender identity, race/ethnicity, disability, education, income, age, and geography.

Coalition membership includes the leading LGBTQ+ health centers and local and state health departments—as well as leaders in LGBTQ+ policy across the US. The Coalition’s individual membership also includes leading researchers and health care providers who work in HIV/AIDS, biomedical prevention, health disparities in minority communities, mental health in the LGBTQ+ communities, and other vital areas of medicine and public health. The Coalition draws its vision and its focus of mission from the breadth of work, experiences, and perspectives lent by its members.
Since this is a ‘state of’ report, respondents were asked how they would describe the current state of LGBTQ+ care in one word. **Improving** was the word most often offered as describing today’s state of LGBTQ+ care. Respondents answered along a continuum from **underserved** to **evolving**, signifying that providers are reporting a vast range of experiences when providing care to the LGBTQ+ communities.
Mental and behavioral health is a significant need for the LGBTQ+ communities. Participating providers reported being unlikely to provide behavioral and mental health services or support. The respondents identified that they need more staff and resources to provide these services to ensure comprehensive behavioral health care to LGBTQ+ patients.

LGBTQ+ providers are experiencing staff shortage, burnout, and retention issues. LGBTQ+ serving providers frequently reported significant burnout, staff shortage, and retention issues. Providers are requesting support to address this including trainings that focus on LGBTQ+ care, more LGBTQ+ focused medical providers, and more staff support to provide wraparound services.

Sexual health histories need to be normalized into routine clinical care for the LGBTQ+ communities. Taking a sexual history is an important element of LGBTQ+ health. However, while the results demonstrate that most providers feel comfortable taking a sexual history (89%), only 76% report taking them with LGBTQ+ patients/clients. Further, only 50% reported that they discuss sexual behaviors and practices at every visit. This signifies a disconnect that needs to be addressed. Providers reported that they do not discuss sexual practices with their clients due to patient flow, knowledge, and accreditation factors.

Need to expand sexual orientation and gender identity supports. The majority of providers in this survey reported that they incorporated a number of sexual orientation and gender identity (SOGI) supports such as gender identity, sex at birth, and sexual orientation questions on intake forms. However, they were less likely to report incorporating pronouns and providing LGBTQ+ materials in the waiting room areas.

LGBTQ+ providers face challenges with insurance and pre-authorizations for sexual health services. Providers indicated that navigating insurance structures and pre-authorizations is a key barrier to providing care and sexual health services to LGBTQ communities. Providers report that employee-sponsored insurance, private insurance, and Medicaid are more likely to require the most time for pre-authorizations for PrEP, HCV Direct Acting Agents, hormone replacement therapy, and HIV treatments.

COVID-19 impacts LGBTQ+ services. Respondents reported that the services most impacted by COVID-19 were linkage to care, HIV testing, and case management. A variety of reasons were provided including workforce shortages, clinic closures, and client disengagement.

Providers are requesting more LGBTQ+ education, trainings, and supports. The top training topic needs identified by participants include: LGBTQ+ health curriculum, trauma-informed care, cultural competency/awareness/humility, and stigma. Further, respondents requested mental health supports in an effort to more comprehensively address LGBTQ+ care through a psychosocial integrated lens.
The survey was developed in response to a call for greater focus on the unique healthcare needs of LGBTQ+ people, a call articulated by LGBTQ+ communities themselves. Further, recent research showed that LGBTQ+ individuals have distinctive health needs that are too often neglected by providers who lack the necessary training to offer comprehensive and culturally responsive services. The survey consisted of quantitative and qualitative questions, which were drawn from validated measures published in the literature and the professional experience of our staff and partners. An external panel reviewed the survey to ensure coverage of all relevant issues and to pilot questions.

DISTRIBUTION, SAMPLING, AND RECRUITMENT
The survey was distributed exclusively online using REDCap, from January 27, 2022 to February 18th, 2022. Participants were recruited through a purposive stratified criterion sampling strategy that leveraged a sampling frame drawn from HealthHIV’s constituent relationship management (CRM) database, SalsaLabs. The CRM encompasses approximately 80,000 persons who reflect the diverse cross-section of populations disproportionately impacted by HIV in the U.S. and the healthcare providers who serve them. Communities reflected in the recruitment cohort include racial and ethnic minorities and sexual and gender minorities, across geographic and educational, and income levels. No incentive was provided for participation.

TOPIC AREAS
The survey included a diverse set of topics including:

- Organizational and Provider Information
- Practices and Services
- Experiences and Perspectives working with the LGBTQ+ community
- Payers: Insurance, Copays, and Access
- Facilitators, Barriers, and Future Implications
- Healthcare Reform
- COVID-19 Impact
- Demographics

DATA ANALYSIS
Basic descriptive statistics were calculated in REDCap. Additional univariate, bivariate, and multivariate statistical analyses, including stratification of data, was calculated using SAS 9.4 statistical software.

ELIGIBILITY REQUIREMENTS
To be eligible to take the survey, participants had to indicate that they provide services directly to people who identify as Lesbian, Gay, Bisexual, Transgender, and/or Queer plus (LGBTQ+). A total of 2344 participants started the survey. 2329 respondents were eligible to participate (99%); meaning they indicated that they provided services to the LGBTQ+ communities.
DEMOGRAPHICS

Respondents hailed from all 50 states as visualized in the map. The majority of respondents came from California, Florida, New York, Michigan, Maryland, and the District of Columbia.

RESPONDENTS BY STATE

The need for providers to be from the communities they serve

Clinical services are better impacted when served by the people that look like them, or can relate to their lives. 40% of survey respondents strongly agreed (34% agreed) that LGBTQ+ patients/clients trust providers who identify more like themselves to provide the best care.

Concordance leads to trust and better health outcomes and lower healthcare expenditures in minority populations. These results (below) emphasize the need for medical education that contextualizes experiences and approaches care and prevention services with cultural humility. This further underscores the importance of working to diversify the healthcare workforce.

RESPONDENTS PRACTICE AND PROVIDER TYPE

Most respondents practiced at HIV/STI/PrEP clinics, community-based organizations, health departments, and health centers. 27% of respondents identify as clinical providers (physicians 8%, physician assistants/associates 2%, advanced practice nurse 7%, nurse 9%, pharmacist 1%). Other respondents included social workers, behavioral health professionals, public health practitioners/community health workers, and administrators.
The majority of respondents identified as white (59%), cisgender women (51.6%), heterosexual (45.7%), and between the ages of 30–59 (70.5%).
FINDINGS

LGBTQ+ SERVICES PROVIDED
Culturally-responsive sexual health services are integral to meeting the unique health needs of LGBTQ+ people. Reducing barriers to health services—especially sexual health services—also improves patient access and retention in more integrated primary health and wellness services.

SEXUAL HEALTH SERVICES
The following are the top four cited sexual health clinical services provided to the LGBTQ+ clients/patients.

- HIV screening and testing (81%)
- HIV prevention (76%)
- Sexually Transmitted Infections (STIs) Screening (72%)
- Pre-exposure Prophylaxis (PrEP) (66%)

While 81% of respondents provided screening and testing for HIV, there was some drop-off for those providers also offering STI screenings (72%). PrEP services, too, were (slightly) less comprehensively offered (66%). Further down the list was HCV or other viral hepatitis (A,B) services at 53%. STIs are a well-known risk factor for HIV acquisition and transmission, and their burden continues to hit racial and ethnic minority groups, gay and bisexual men, and youth the hardest.

CONSIDERATIONS
With national PrEP uptake hovering around 23%, there is significant room to grow in meeting LGBTQ+ sexual health services needs. Combined with insurance coverage and navigation issues, prior authorizations, and HIV-related stigma, lack of access continues to saddle communities with low uptake. Telehealth can help close gaps in testing and treatment, and better ensure ongoing access to healthcare providers.

The data also show that only 50% of prescribing providers offer the Expedited Partner Therapy program (EPT) to treat the sex partners of patients diagnosed with chlamydia or gonorrhea. EPT is an effective partner management tool—particularly for treatment of male partners of women with chlamydia infection or gonorrhea—and a key opportunity to expand sexual health services. EPT represents a potential area for providers to explore that would contribute to normalizing sexual health conversations and routinizing more site-specific screenings for gay, bisexual and transgender men who have sex with men.
BEHAVIORAL AND MENTAL HEALTH SERVICES

Providers report that many LGBTQ+ clients/patients require support from across a broad continuum of primary care and prevention services that includes behavioral health, sexual health, and clinical services.

The following are the top four cited behavioral health services provided to the LGBTQ+ clients/patients.

- General counseling (62%)
- Smoking/vaping/tobacco cessation treatment (36%)
- Alcohol use treatment (34%)
- Gender identity counseling (30%)

CONSIDERATIONS

Overall, respondents reported offering a lower number of behavioral health services when compared with sexual health and clinical services. Despite being the number one reported healthcare need for LGBTQ communities, only about half (49%) of providers indicated that they discuss mental health issues at every appointment with their LGBTQ+ clients/patients. Only 2% of respondents cited that they never discuss mental health with their clients/patients, and the reasons they do not discuss mental health varied from patient flow, time allotment, knowledge, and accreditation. It is evident that providers need to more thoroughly integrate behavioral health care into primary care and prevention services, in order to create a more comprehensive system of care while also decreasing fragmentation. Providers have cited time and staffing-related issues as barriers to achieving integrated care—in addition to state and federal policies that hinder reimbursement for care.
LGBTQ+ INCLUSIVE AND AFFIRMING PRACTICES

Lack of sexual orientation and gender identity (SOGI) data collection is a barrier to inclusion of sexual and gender minority (SGM) clients/patients, not only in their primary care, but also with specialty care and supportive services settings. To address this, the survey included items that examined what resources are available to collect SOGI data and identified what resources and supports are available to provide inclusive and affirming care.

<table>
<thead>
<tr>
<th>Forms Include:</th>
<th>All Providers</th>
<th>Prescribing Providers</th>
<th>Non-Prescribing Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender Identity and Sex at Birth</td>
<td>84%</td>
<td>89%</td>
<td>73%</td>
</tr>
<tr>
<td>Pronouns</td>
<td>73%</td>
<td>72%</td>
<td>73%</td>
</tr>
<tr>
<td>Preferred/Chosen Name</td>
<td>83%</td>
<td>82%</td>
<td>84%</td>
</tr>
<tr>
<td>Sexual Orientation</td>
<td>84%</td>
<td>78%</td>
<td>85%</td>
</tr>
<tr>
<td>LGBTQ+ health materials in waiting room</td>
<td>77%</td>
<td>64%</td>
<td>80%</td>
</tr>
</tbody>
</table>

CONSIDERATIONS

The data indicates that providers offer inclusive and affirming fields on their forms for the most part. However, 27% of all providers surveyed reported that they do not include any pronouns gathering items in their forms. This represents an area for improvement. Including pronouns in forms is an important step towards normalizing conversations about gender identity and preventing providers from making wrong and potentially damaging assumptions.

Further, prescribing providers are less likely to have LGBTQ+ health materials in their waiting rooms. Offering LGBTQ+ centered materials is a step towards creating a more inclusive and trusting environment for LGBTQ+ clients seeking care.
SEXUAL HISTORY PRACTICES
76% of all respondents reported taking a sexual history with clients and discussing these top five topics while taking the sexual history:
- Sexual protection (91%)
- Sexual orientation (89%)
- Previous STIs (88%)
- Types of sex/sexual practices (84%)
- Previous/current partners (81%)

89% of respondents stated that they are comfortable with taking a social and sexual history, only three-fourths of respondents are actually taking sexual histories. There appears to be a disconnect between comfort and standards of practice. Providers indicated that patient flow, knowledge, and accreditation reasons are barriers that prohibit them from talking about sexual practices with clients/patients.

Payers and Insurance
Over three-fourths of respondents indicated that they provide health care navigation services either on-site (44%) or through referral to an outside entity (34%). Respondents indicated that they accept a wide variety of public and private insurance/funding sources, but pointed out that employer sponsored insurance, private insurance, and Medicaid are more likely to require the most time for pre-authorizations for PrEP, HCV Direct Acting Agents, hormone replacement therapy, and HIV treatments.

COVID-19 Impact on LGBTQ+ Care
The LGBTQ+ communities have been disproportionately impacted by COVID-19. The pandemic has had far-reaching consequences for the communities, ranging from increased unemployment to worsened mental health. To address this, the survey inquired about COVID-19 impact on the LGBTQ+ provider and communities as a whole. The LGBTQ+ providers in this survey explained that COVID-19 has increased:
- Telehealth
- Negative effects to mental health
- Staff burnout and shortages
- Missed appointments
- Disruption of services

The services that were most impacted by COVID-19 were linkage to care, HIV testing, and case management. Most stated that the funding levels stayed the same; however, 16% reported that funding levels have decreased as a result of the pandemic.
LGBTQ+ CARE AND SERVICES: FACILITATORS AND BARRIERS

Providers indicated that the following were facilitators and barriers associated with providing LGBTQ+ care and services:

<table>
<thead>
<tr>
<th>Facilitators to providing LGBTQ+ care and services</th>
<th>Barriers to providing LGBTQ+ care and services</th>
</tr>
</thead>
<tbody>
<tr>
<td>LGBTQ+ specific training (80%)</td>
<td>Inadequately trained in LGBTQ+ care (54%)</td>
</tr>
<tr>
<td>Working with experienced providers or peer mentoring programs (54%)</td>
<td>Stigma (51%)</td>
</tr>
<tr>
<td>Adequate time to address LGBTQ+ issues (42%)</td>
<td>Lack of mental health and other psychosocial support services (40%)</td>
</tr>
</tbody>
</table>

The data showed that LGBTQ+ specific training needs were a central focus in the facilitators and barriers. 62% of respondents stated that they do not believe that medical schools provide adequate training to provide LGBTQ+ focused care.

Providers were asked what they think are the most important health issues for LGBTQ+ clients/patients in their care. They overwhelmingly responded that mental and behavioral health (71%) was one of the top issues, followed by health insurance (33%), and then HIV prevention (26%).
LGBTQ+ TRAINING NEEDS, RESOURCES, AND ADVOCACY PRIORITIES

The resources most highly requested by respondents focus on training and adequately staffing the workforce that provide LGBTQ+ care and services:

- LGBTQ+ focused trainings (48%)
- More medical providers trained to provide LGBTQ+ care (46%)
- Support staff to provide wraparound services (44%)
- Fiscal health/funding to support LGBTQ+ care (38%)

TOP FOUR TRAINING NEEDS

<table>
<thead>
<tr>
<th>Training Need</th>
<th>Priority Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>LGBTQ+ health curriculum</td>
<td>39%</td>
</tr>
<tr>
<td>Trauma-informed care</td>
<td>28%</td>
</tr>
<tr>
<td>Cultural Competency/Awareness/Humility</td>
<td>28%</td>
</tr>
<tr>
<td>Stigma</td>
<td>21%</td>
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PRIORITY ADVOCACY ISSUES FOR 2022

<table>
<thead>
<tr>
<th>Advocacy Issue</th>
<th>Priority Percentage</th>
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<tbody>
<tr>
<td>LGBTQ+ equality</td>
<td>43%</td>
</tr>
<tr>
<td>Transgender/gender affirming care</td>
<td>40%</td>
</tr>
<tr>
<td>Mental health</td>
<td>34%</td>
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</tbody>
</table>
IMPLICATIONS

Findings of this survey have key implications for supporting the unique health care needs for the LGBTQ+ communities and for meeting the training and development needs for the national network of healthcare providers who serve these communities.

Workforce Burnout and Supporting the Well-being of Healthcare Providers

The constant stress and heavy burden of the COVID-19 pandemic has contributed to widespread healthcare staff burnout and workforce shortages. To encourage healing, resiliency, and retention, LGBTQ+ providers need a holistic approach to workforce management and a diverse portfolio of support to address staff retention including toolkits, training, medical education, and capacity building support. The survey results overwhelmingly demonstrate that providers are requesting more LGBTQ+ focused training. These trainings need to be accessible to providers and relevant to their work, covering topics such as: trauma-informed care, cultural competency, awareness and humility, stigma, and mental health.

Expand Mental Health and Supportive Services

From the provider perspective, mental and behavioral health needs were cited as their number one issue for LGBTQ+ communities—71% of providers reported this as a key issue. Integrating mental and behavioral health services into primary care can work to address health from a comprehensive approach.

About one in five providers talk with their clients/patients about mental health at intake only. One in three discuss mental health services once their patient brings it up. And only half mentioned it at every appointment. This suggests that LGBTQ+ healthcare providers should offer more routine, comprehensive mental health services and mental health referrals during visits.

Housing, food and other supportive services needs were discussed by about 1 in 3 providers during each visit—suggesting a more integrative and sustained approach to address the syndemics of LGBTQ+ behavioral and sexual health needs, and their impacts. Organizations, health systems, and providers need to develop a one door/no wrong door approach—integrating mental and other health and referral services into existing clinical programs to reduce service fragmentation and improve access to care and services.
Between the Intersection of COVID-19 and Other Impactful Health Outcomes

Providers reported seeing their LGBTQ+ clients/patients less often during COVID-19, with more missed appointments further exacerbating chronic conditions and other health disparities and outcomes. Importantly, key demographic (SOGI) information on COVID-19 testing forms is still missing, making it even harder to ascertain how LGBTQ+ fared the past two years. LGBTQ+ communities are not isolate no insular; in fact, they intersect with other communities at increased and disproportionate risk for COVID-19–morbidity and mortality. So, it is interesting to note that only 4% of providers saw COVID-19 as a top LGBTQ+ health concern, yet the past two years have intensified traumas faced by LGBTQ+ communities and have only advanced minority stressors. COVID-19 protections for high risk populations (like People with HIV and People aging with HIV) were still a primary clinical concern for over 11% of providers.

Navigating Insurance and Prior Authorization Issues Are Key Barriers to LGBTQ+ Health

33% of providers indicated that health insurance issues pose the largest barrier to providing LGBTQ+ healthcare, while 26% of providers cited HIV prevention/screenings (including PrEP/PEP), and just over 21% identified alcohol and substance use.

Carrying those access issues forward, over one in five encountered prior authorization issues for their patients trying to access preferred HIV treatment and PrEP regimens and HCV Direct Acting Agents, and as accessing hormone replacement therapy. To that end, 38% provided on-site pharmacy services.

The findings show that optimal care coordination/patient navigation services are still vitally important—especially in a dynamic environment, like COVID-19. Implementing universal standards of LGBTQ+ care (across all systems, public and private) will improve access and reduce systemic disparities. In fact, 39% of all providers said LGBTQ curriculum was their number one training need. Training to reduce LGBTQ+-related bias among medical, nursing, and dental students and other (care, prevention and supportive service) providers was also identified as a significant need. However, this has proved difficult to attain as 23% of providers said lack of institutional support when providing services to LGBTQ+ patients/clients was a barrier.
Calls for Greater Inclusivity
The literature and findings clearly demonstrate that an inclusive and affirming environment reduces access barriers to LGBTQ+ care. In fact, 73% of respondents said their LGBTQ+ patients/clients avoid discussing aspects of their healthcare due to difficulty communicating with providers. Uncomfortable provider–patient encounters—stemming from assumptions about sexual orientation, gender identity, or personal practices—can serve to define health identities and subsequently, limit health outcomes. And while some respondents provide a number of inclusive and LGBTQ+ affirming resources, including fields that ask about SOGI data (gender identity, sexual orientation, preferred pronouns and names), there is room for improvement in standardizing—and contextualizing—the use of these more inclusive (patient-centered) fields, forms and resources.

Culturally sensitive health services that specifically speak to individualized needs have been shown to be more effective in the prevention, early detection, treatment, and ongoing use of services. They also open the door to a more trusting patient–provider relationship.

Normalizing Social and Sexual Histories into the Standard Care
Providers reported a need to normalize sexual health conversations into the standard of care and a goal to maximize patient outcomes with better, integrated care and supportive services (direct or referral). Findings also suggest that providers need to conduct sexual and social histories more consistently and routinely with their LGBTQ+ patients/clients. This serves as an opportunity to provide whole person health by contextualizing people’s clinical health with other important aspects of their lives. When asked, one in five providers said their administrative decision-makers can serve as gatekeepers to integrating inclusivity and change into their practices.
Through the Providers Looking Glass: Health Advocacy and Policy Issues

According to providers, the top three health advocacy and policy issues were ranked: LGBTQ Equality/Non-Discrimination Protections (43%); Transgender/Gender Affirming Care (40%); Racial/Ethnic Discrimination: Federal and State (40%).

When combined, more than 31% of our providers said Medicaid and Medicare reform were their top health advocacy and policy issue. Providers report that ongoing access issues act as force multipliers and advocacy inflection points. Providers ranked the top health advocacy and policy issues for LGBTQ communities: LGBTQ Equality/Non-Discrimination Protections (43%); Transgender/Gender Affirming Care (40%); Racial/Ethnic Discrimination: Federal and State (40%); and Medicaid and Medicare reform (31%). Prescription drugs copays/coinsurance issues, like the Copay Accumulator Program (CAP) and drug and other out-of-pocket costs, were also mentioned (25%) as a top concern.

Respondents reported that two key areas of focus for policy and advocacy efforts are healthcare access and coverage issues as these serve as key inflection points for the health of many LGBTQ people. This is especially true as whole generations of LGBTQ individuals age into Medicare eligibility and the poverty gap widens for these communities.
CALL TO ACTION

Behind every provider surveyed is a person who is navigating a constantly shifting healthcare landscape, ever-advancing science and services, and a complicated and nuanced insurance system—all while trying to live and work through a pandemic. Meeting the unique healthcare needs of LGBTQ+ communities requires a workforce that is well-supported, well-trained, and well-resourced. This means ensuring that providers have access to LGBTQ+ focused medical education, mentors, training, and resources to address the unique needs and challenges LGBTQ+ communities experience. These supports will empower providers to implement and normalize LGBTQ+ inclusive and affirming practices and create an environment of openness, respect, and trust. Providers will need to work in partnership with LGBTQ+ communities to openly address their health and provide comprehensive, whole-person care which requires the integration of mental and behavioral health and the provision of wraparound services. Through this approach, providers and allies can more fully realize an accessible, affirming, and inclusive healthcare system that truly promotes the welfare and health of LGBTQ+ communities.
References


