LGBTQ Health Equity & Access in Kentucky

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Executive Summary

PROJECT BACKGROUND AND DESCRIPTION

Following implementation of the Patient Protection and Affordable Care Act (ACA), Kentucky Voices for Health (KVH) sought to discover the experiences of Kentucky's lesbian, gay, bisexual, transgender, and queer (LGBTQ) communities when signing up for health insurance and using health care. KVH asked researchers from the University of Louisville Commonwealth communities from across the state from October to December 2015.

STUDY FINDINGS

- All participants had negative experiences with health insurance providers, and most participants reported negative experiences with health insurance and care providers related, in some way, to their LGBTQ identity.
- Even with improved access to health insurance under the ACA, cost is still a major factor in decisions about how to use health care resources and health insurance.
- Transgender participants shared the most numerous and most negative health care and health insurance experiences.
- All participants agreed that health messaging that explicitly targets the LGBTQ community is important and would be encouraging.
- Most participants agreed that a method of identifying competent and inclusive providers of insurance and health care would be helpful, since information about competency and inclusivity is mostly obtained by trial and error.
- Many participants noted that additional training on equity and inclusion for providers of care and insurance would be helpful in creating a welcoming climate.
- Urban and rural participants' health care priorities differed overall. Urban participants were more likely to have disclosed their LGBTQ identity to providers and were concerned about how their identity intersected with their care and insurance coverage. Rural participants were less likely to have disclosed to their providers and were primarily concerned about issues of cost and access.

LIMITATIONS

Participants were not demographically representative of the broader LGBTQ population or the Kentucky population, limiting the generalizability of the research findings. Due to the limitations of our sample, more research is needed with cisgender lesbian, gay, and bisexual Kentuckians to explore their health needs.

RECOMMENDATIONS

- Improve cultural competency and inclusivity of health services for LGBTQ populations.
- Implement wide-scale cultural competency and anti-discrimination trainings for health care providers and office staff.
- Educate providers about the utility and necessity of using inclusive forms and taking accurate medical histories.
- Collect more and better data on sexual orientation and gender identity in electronic medical records and population health surveys.
- Enhance policies and regulations to support access for LGBTQ populations.
- Ensure robust enforcement of existing nondiscrimination protections such as Section 1557 of ACA.
- Take regulatory action to remove transgender exclusions from insurance policies.
- Create resources for advocacy and meeting LGBTQ populations' unique needs.
- Collaborate with local community leaders to spread information about how to access competent and affirming providers.
- Build a robust coalition of organizations working on LGBTQ health care access. Members could include, for example, consumer advocates, legal services, and LGBTQ organizations
- Create an advertising campaign to educate LGBTQ individuals, in particular those who may not otherwise be connected to the community, about their health care options.

NEXT STEPS FOR KENTUCKY VOICES FOR HEALTH (KVH)

We recommend that KVH:

- Facilitate ongoing coalition building and encourage LGBTQ stakeholders to join the organization to encourage a stronger representation of LGBTQ issues.
- Convene a summit to strategize and create an action plan for LGBTQ health, health policy, and health insurance-related work.
- Work with LGBTQ stakeholders to address inadequate coverage as it relates to health insurance benefit design.
- Work with LGBTQ stakeholders to promote the final rule for section 1557 of the ACA regarding nondiscrimination in health care
- Work with all coalition stakeholders to shift the focus from getting Kentuckians enrolled in health insurance coverage to effectively using coverage to access needed health care services.

LGBTQ Health Equity & Access in Kentucky: Final Report

INTRODUCTION

The purpose of this research was to study the experiences of lesbian, gay, bisexual, transgender, and queer (LGBTQ) Kentuckians when enrolling in and using health insurance, in particular, though not exclusively, through Kentucky's state-based health benefits exchange. This qualitative study served as one mechanism to provide feedback to stakeholders and policy makers regarding the process, successes, and barriers to accessing health coverage and health care in Kentucky following the implementation of the Patient Protection and Affordable Care Act (ACA).

BACKGROUND

Health insurance eases the financial burden that is connected to health care. This often results in more frequent use of preventive services, enhanced continuity of care, and better follow through with recommended treatment, all of which lead to better health outcomes.[1] Furthermore, health insurance has been associated with higher quality care and an increased likelihood of comprehensive examination during a health provider interaction.[2] Studies examining chronically uninsured individuals following their enrollment in the Medicare program have provided evidence that coverage results in notable increases in the use of preventative care.[3] Similarly, evaluation of state policy changes to expand Children's Health Insurance Programs has demonstrated increased utilization of preventative and outpatient services.[4,5]

As a federal law, ACA expands health insurance coverage through a variety of means, including several state options. The former Kentucky administration embraced those options, and in the first year of ACA implementation, more than 521,000 Kentucky residents enrolled in both Medicaid and Qualified Health Plans through the exchange.

Since then, Kentucky's uninsured rate has dropped to 8.5 percent, representing nearly a quarter of a million fewer uninsured Kentuckians.[6]

The ACA implementation process in Kentucky has included outreach and enrollment efforts to target vulnerable populations, who have traditionally experienced low insurance rates and high health disparities. LGBTQ people are disproportionately uninsured and face disparities in access to care, quality of care, and discrimination.[7] LGBTQ people – especially women, people of color, and those raising children – are more likely to live in poverty[8] and face systemic barriers, such as inadequate care and exclusion from care.[9] In the context of the changes brought about by the ACA, is important to understand how LGBTQ people get and use health coverage.

The goal of the study was to capture the experiences of LGBTQ Kentuckians enrolling in health insurance and using the health care system following the implementation of ACA. This study also investigated facilitators and barriers to enrolling in health insurance and accessing health care. Results of the study inform recommendations for policies and outreach to ensure systemic equity for the state's LGBTQ population.

RESEARCH OBJECTIVES

<u>Objective</u> 1: To understand why LGBTQ Kentuckians do or do not enroll in health insurance through the health benefits exchange.

<u>Objective 2</u>: To understand the enrollment experiences of LGBTQ Kentuckians who have used the exchange to enroll in insurance.

<u>Objective 3</u>: To understand the experiences of LGBTQ Kentuckians who signed up for insurance through an insurance broker or employer, or who have decided not to sign up for insurance at all.

<u>Objective 4</u>: To understand the experiences of LGBTQ Kentuckians as they navigate and use the health care system.

METHODOLOGY

This study was conducted using a qualitative research design. Researchers held three focus groups of between four and seven people. The focus groups were held in public meeting places provided by local community organizations, chosen because they are familiar and accessible to members of the community. These locations were also chosen based on their distribution within the state, with two focus groups occurring in rural areas and one in an urban area. One focus group was conducted by conference call, as a result of a poor response to the local in-person focus group recruitment. This study was reviewed and approved by the Institutional Review Board at the University of Louisville.

After consenting to voluntary participation, participants completed a three-page survey that gathered self-reported demographic data, health status, and health coverage. Discussion during the focus groups was semi-structured, and interviewers used open-ended questions and prompts aimed to understand motivations for, and barriers to, enrollment, and the benefits and challenges to having health insurance (see Appendix 1. Topic Guide). These questions were developed iteratively following new information learned during each session. Each focus group was audio recorded and transcribed verbatim.

SAMPLE

Participants included English speaking Kentucky residents aged 18-64 who self-identified as LGBTQ and who wanted to talk about their experiences with health insurance and health care. The research team engaged in targeted recruitment through flyer distribution and word of mouth, using local community groups / organizations, social media, bulletins, community center announcement boards, and email communication. Participants were compensated with a $20 gift card for their time. In total, sixteen participants were recruited.

PARTICIPANT DEMOGRAPHIC DATA

- Sample size: n=16

- Average age: 30 (range: 20-47)

- Identities represented: The most frequently represented identities were transgender, pansexual, queer, lesbian, and genderqueer/nonconforming. The sample was mainly composed of people who were assigned female at birth. No gay men, transgender or cisgender, were represented in the demographic data. This will be explored further in the results section.

- Average income: $33,000/year from all sources. All but one participant was employed for wages. This income was low considering the education level of participants. This is significantly lower than the Kentucky median income of approximately $43,000 and is even lower than the national median of $56,516.

- Insurance Coverage: All but one participant had health insurance coverage (93 percent). This is consistent with national demographic data with respect to health insurance, with 34 percent of the population having government health insurance coverage, and 49 percent having employers sponsored coverage, and 10 percent being uninsured. In Kentucky, employer sponsored health insurance covers only 46 percent of residents and government sponsored health insurance covers 40 percent of states citizens, with 7 percent uninsured.

- Relationship Status: 75 percent of participants were either married or partnered.

- Race/ethnicity: The majority of participants were non-Hispanic White (87.5 percent). While this is representative of the Kentucky population (88.1 percent), only 66 percent of American adults are non-Hispanic White.

- Level of education: All participants had completed some college. One-third had undergraduate degrees (37.5 percent) and another third (31.3 percent) had obtained an advanced degree. These two groups combined made up 68.8 percent of the participants, which is in line with national demographic data. Interestingly, these figures are over three times higher than Kentucky state residents, of which 21 percent have a bachelor's degree or higher.

METHODS OF DATA ANALYSIS

A descriptive analysis of the survey data helped us to understand the composition of the sample and to provide context for participants' answers during focus group discussion. The qualitative analysis of focus group and interview data used the constant comparative method, whereby analysis was carried out concurrently with data collection, so that emerging issues could be explored iteratively. Anonymized verbatim transcripts of audio recordings were coded, followed by re-coding and memo writing, in order to generate conceptual themes. Research team members independently read the transcripts, then team meetings were used to achieve a coding framework. Themes were compared within and across cases, paying particular attention to negative cases and possible reasons for differences.

RESULTS

The focus group data revealed key themes relating to challenges faced by LGBTQ people in both health insurance and health care. Difficulty enrolling in health insurance are not necessarily unique to the LGBTQ population. Difficulty using health insurance and accessing health care, however, involved distinct barriers for the LGBTQ population. We begin by discussing insurance enrollment before moving on to examine the obstacles that exist, from using health insurance to receiving affirming and competent care.

Some participants found the process of enrolling through the exchange straightforward, but technological difficulties and onerous bureaucratic processes slowed or stalled their access to coverage. One participant reported that she tried to obtain health insurance through the health benefits exchange, but was unable to complete her enrollment due to what she considered burdensome additional verification requirements.

More than one participant said that they simply did not understand health insurance nor how to navigate signing up for coverage because “it is not something that anyone is taught how to do.”

Cost and affordability was mentioned at least once by each participant. For some, it was the cost of health insurance itself that presented a barrier. For others, it was the cost of using health insurance coverage to their benefit, specifically regarding transgender related care. And for others, the cost of being uninsured was too high, so they sought out coverage. One participant said that they signed up for health insurance before leaving home to go to the hospital, knowing that he couldn’t afford another bill, no matter how stretched out it was.” Another reported that they signed up for health insurance because it was newly affordable for them. A number of participants stated that the cost of health care was their motivating factor in seeking health insurance even, as one participant noted, “just in case something happens.”

The general consensus, when it came to health care and health insurance costs, seemed to be negative. For those who could afford their routine health care and insurance costs, the costs were still burdensome in some way. As one participant stated, “It's not about getting the insurance, so much as it is just being able to use that insurance in a meaningful way.” One participant noted that the cost of health care and health insurance seems out of step with the messaging around both ideas. “It seems like it's more about money than actually helping people,” he said. However, many participants said that without insurance, health care would be categorically unobtainable for them: “Everybody that I know recognizes the benefits that insurance does provide us even if we do complain about it, and we have complained a lot. It's just utilization of that and being able to implement [it].”

Other themes were specific to the LGBTQ community. Several participants noted that parts of their health care were not covered due to exclusions of transition-related care or were covered in such a way as to make that care inaccessible. These participants noted that insurance companies rejected payment for medical bills due to mismatches between the gender marker listed at the time of enrollment and the gender marker used during treatment. One participant explained that when it came to caring for his needs as a transgender person, his his insurance lacked in-network providers:

“[W]ho cares? Because what my insurance is going to pay for, what it would cost me to go out of network [for surgical care], they're not going to start paying for that until I reach a certain amount, which I'm not going to reach elsewhere. The insurance doesn't do me, for specific things, a bit of good. That makes no difference that I have it because there's not a provider in-network to do the service and also takes insurance. It's perfectly useless.”

Additionally, study participants had much to say about the knowledge of both medical and insurance providers when it came to their LGBTQ identity. A few reported that their medical care providers never asked about their identity, and the topic was not broached during care encounters.

Every participant stated or concurred that they were not asked about their identity as part of a sexual health screening. Almost all reported that there was no form or paperwork that asked them to identify themselves as LGBTQ. This did not bother some rural participants; they felt that their identity had little to do with their care and, consequently, were far less likely to have disclosed to providers. The opposite was true for urban participants, especially transgender people, who were concerned about how their identity intersected with their coverage and care.

Participants described having to educate their provider about their identities as part of the office visit. One participant noted the burden that many LGBTQ people face when trying to work with their primary care providers in this way: "This is my doctor's appointment. I'm not coming here as an advocate. I'm not coming here to teach you. I'm actually paying you.” That sentiment was shared by other participants, one of whom framed it thus: “It would just be awesome to have someone who specialized in the LGBTQ community [...] in this area because there's a lot [...] who are willing to try and are willing to help and are willing to learn, but you want someone who already knows and specializes in it.”

One participant, who identifies as a lesbian, said simply “I've almost never had a positive experience with the doctor.” She went on to explain that one doctor essentially told her that “accidents happen” and she would need to take a pregnancy test in order to receive treatment for an injured ankle. She felt that her identity was invalidated and that she was taking unnecessary tests that she “was paying for in one way or another.”

A transgender participant talked about his experience with obtaining gynecological care. He shared that it was already a difficult time – gynecological care can be a triggering experience for trans-masculine people – but the office staff made his experience remarkably negative:

> “I'm not really a paranoid person, but as soon as I left the office I heard this huge cackle of laughter and I knew. You're not dumb. I know that it was about [the staff] just trying to hold it in until I left. ‘What's this dude doing at a gyno office?’”

Other participants had similar experiences and relayed them one after another in the focus group. One participant spoke about how her doctor’s “bedside manner” changed abruptly when she brought her female partner along to an appointment.

“He was actually my doctor for a lot of years and I brought my girlfriend to a visit, just because there were some health problems going on and I wanted someone else there with me and so I brought her. Maybe her sexual identity, her sexual preference is a little bit more obvious to some people than mine, maybe. My doctor was very rude. It was a totally different situation that I had ever encountered with him when it was just he and I. It was never the same past that. We actually left early, because he was asking really inappropriate questions. I was actually on birth control… for other things than just to prevent pregnancy. He kind of made a comment of I guess, "Why do you have birth control? Why are you on birth control?" I just thought that was so insulting. The whole experience was so insulting, so I found a new provider now who is definitely… I feel much more comfortable speaking to her about not only my relationship but issues that come up as a lesbian, bisexual woman.”

Experiences like this were plentiful but did not apply to every participant. Several stated that they had not disclosed their gender identities to their providers because they didn’t want to or feel the need to. Most of the discussion related to transgender people’s lack of access to health care and cisgender women’s access to sexual health care.

Ultimately, participants had many ideas and suggestions for improvements to health insurance and health care. Many noted that they would like to see a large scale advertising campaign that attended to the diversity within the community (race, social class, sexuality, gender identity) that would demonstrate and identify welcoming and affirming health insurance for LGBTQ people. Participants in the urban focus group expressed that it was important to identify key community leaders and provide them with information and resources because community members might be more likely to seek help or direction from someone they know. They noted that an advertising campaign was important, but there is no substitute for word of mouth. In the two rural focus groups, the advertising campaign was again suggested. One participant noted that, in rural areas, an ad campaign might reach more people than word of mouth, “my experience with people in Kentucky is that a lot of people are still closeted, so I need to be able to access the messaging and know what my options are without necessarily having to out myself.”

Nearly all participants recommended additional training and education for both insurers and primary care providers (including the non-medical office staff). A participant characterized their experience with the staff as a deciding factor for whether or not she would return to that practice. “I don't seek it out (LGBTQ friendly providers) but once I figure it out, I won't go back.”

Another participant pointed out that choosing an LGBTQ affirming practice is a privilege not everyone enjoys, and so having well-educated providers becomes even more important. “I don't really look for a provider, necessarily, that is LGBTQ friendly. Being on Medicaid, you're kind of limited to your options. You can't really be too choosy. Just anyone that is accepting patients is where I go.” Still another noted that finding competent care in their own town was not possible, in particular for transgender patients. That participant reported that they and everyone they knew drive an hour or more to a larger city to access transgender related medical care.

Several participants, in both the urban and rural focus groups, brought up the idea of a centralized resource: something online that would allow a patient to look up affirming providers by location or specialty and that would catalog and identify the ways that different insurance plans may be received by folks with a particular identity. “[A] centralized database with this information would be good, like a website that has all your local physicians where you just put in your zip code and you could find all the physicians that are LGBTQ-friendly.” In the urban focus group a few participants were aware of local efforts to simply catalog providers that were identified by members of the community as LGBTQ-friendly and regional efforts for similar listings for transgender people.

DISCUSSION

The themes found in the research concerned cost, access, utilization/utility, exclusions, provider competency, and insurance system navigation. Many of the concerns that participants shared around cost, access and utilization could be addressed by an increased focus, at all levels of the health care system, on “coverage to care” and health systems transformation initiatives. The former would help newly insured people understand their coverage and how to use it to their benefit. The latter would ensure that providers are both willing and able to offer the best evidence-based, coordinated, and responsive care.

As discussed, participants described having to educate their providers, falling through cracks in the system around reproductive and sexual health, having nowhere to indicate sexual orientation and gender identity on forms and documents, and insurance exclusion of gender transition related care. These disparate ideas coalesce into the larger perception and experience of a lack of foundational knowledge; health insurance companies and health care providers may not know who their patients are or how to talk to patients about their identities, may see no reason to do so, or may not know how to meaningfully incorporate such information into the care or service of the population.

Given the information collected from the participants and the data available from other studies, the research team has concluded that there are a number of interventions that would ultimately make health insurance and health care more welcoming and equitable for LGBTQ people.

Health care providers should use inclusive forms and take accurate medical histories to understand patients holistically and assess their health risks accurately. More and better sexual orientation and gender identity data should be collected in patient medical records and population health surveys. As a point of reference, the Institute of Medicine, as well as a number of other reports, commissions, and authorized under Section 4302 of the ACA, have recommended that collecting data about the sexual orientation and gender identity of patients is to be encouraged and supported. This must be done in concert with robust enforcement of existing nondiscrimination protections such as ACA Section 1557 to ensure that sharing the information does not put patients at risk. In addition, regulatory action should be taken to remove transgender exclusions from existing insurance policies to ensure equitable access to care.

Since many of the participants noted that they would appreciate a way to determine, before choosing a health insurance plan or arriving at the doctor's office, what plans and providers were affirming, a centralized database might be a worthwhile pursuit, especially in the near future, while waiting for many old ways of thinking and behaving around sexual orientation and gender identity to recede. Participants noted that some resources like this already exist. However, these resources are not searchable, have no oversight or codified quality control, are limited in scope and varied in structure and content, and go out-of-date quickly. Information about inclusive and competent providers should also be shared with local community leaders. Where affirming care exists, the community would benefit from an advertising campaign to highlight these services to potentially isolated patients. This would not address all of patients' fears and concerns, but it would begin to send an implicit message to LGBTQ populations that who they are, as a whole person with a sexual orientation and gender identity, matters.

Wide-scale cultural competency and antidiscrimination training, developed by and with LGBTQ people, should be implemented for health care providers and staff. This type of training already exist in a few forms; one notable and accessible example is the National LGBT Health Education Center, part of the Fenway Institute. Their website can be found at www.lgbthealtheducation.org.

Finally, a robust, statewide coalition working on LGBTQ health care access would jumpstart work on this issue. Members could include, for example, consumer advocates, legal services, affirming providers, and LGBTQ organizations.

Because the sample was small and limited in several key ways, the findings and their implications may not be generalizable to the LGBTQ community as a whole. The racial composition of the sample was mostly white; therefore, the implications for health care and insurance research may not be similar to racially diverse communities, especially because LGBTQ people of color experience multiple sources of oppression. Future research should address how the intersectionality experienced by LGBTQ people of color impacts their ability to navigate the health care system. Even in attempting to gather information about LGBTQ people's experiences, there was a lack of cisgender lesbian, gay and bisexual voices that should prompt further inquiry into those populations' needs. Despite these limitations, the results are informative. Further inquiry into insurance benefit design and health care access for LGBTQ populations should continue to be pursued.

As other states look to Kentucky to identify best practices in ACA implementation, these findings will contribute to the larger body of knowledge regarding the particular challenges that come from accessing health care and insurance, even under the most successful of circumstances. Moreover, this study highlights the difficulties faced by the LGBTQ population as they attempt to access providers, especially in rural areas. It is the research team's hope that the lessons learned in this study will lead to concrete action to improve health care access and outcomes in Kentucky and, also, that our work will help inform the efforts of other states.

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APPENDIX 1. TOPIC GUIDE

This list of questions served as a guide. The exact questions and probes were developed iteratively as the data were collected.

Introductions

- Moderator introduction (name, background, affiliation with the project)
- Ground rules (purpose of the group, there no wrong answers, allow everyone to speak)
- Participant introductions (first name, pronouns, whether or not they have insurance)

Topic 1: Understanding the current health care situation for LGBTQ people in Kentucky

- Have you looked into coverage through Kynect or Medicaid?
    - If yes, what helped encourage you to explore your options
    - If no, why not?
- What made you decide to sign up or not sign up for health insurance?
    - E.g. Pressing health need? Worried about a tax penalty? Your financial situation?
- For those of you who went through Kynect, what was your experience signing up for health insurance as an LGBTQ person?
    - What worked well in the process and what did not?
    - What did you need more information about or help with?
- How about those of you who signed up for health insurance through your workplace or an insurance broker, what was your experience?
- Why did you choose the plan you did?

Topic 2: Accessing health care as an LGBTQ person

- What has been your experience getting health care as an LGBTQ person (with or without insurance)?
    - Good and bad experiences at the doctor’s office, clinic, pharmacy, hospital, etc.
    - How do you feel your sexual orientation and/or gender identity affected that experience?
- Do your providers know that you identify as LGBTQ?
- Are you able to get LGBTQ affirming and knowledgeable providers close to home?
    - How far do you have to travel to get services?
- How did you find your current provider?
    - E.g. word of mouth, an LGBTQ provider list, phone directory
- Tell me about using your health insurance, especially related to LGBTQ health.
    - Have you had any problems getting appointments, prescriptions, and procedures covered?
- If you have questions about how your health insurance works, who do you contact?

Topic 3: Making it easier for LGBTQ people to get and use health insurance in Kentucky

- What additional information or assistance would help encourage you look into coverage options in the future?
    - Ask them to be specific about Kynect, an insurance broker, or their employer.
- Do messages like LGBTQ-inclusive nondiscrimination policies, the fine, financial assistance, or better quality coverage resonate with you?
- Which messages resonate with you the most, and how should they be delivered?

Wrap-up: Is there anything we have not talked about already that is relevant to the topic?