NEBRASKA CANCER COMMUNITY HEALTH NEEDS ASSESSMENT

LGBTQ+ Listening Session

September 2022

UNMC BREAKTHROUGHS FOR LIFE.

NC2 Nebraska Cancer Coalition www.necancer.org

NEBRASKA NECCCP Comprehensive Cancer Control Program

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EXECUTIVE SUMMARY

The Office of Community Outreach and Engagement at the University of Nebraska Medical Center’s Fred and Pamela Buffett Cancer Center, in collaboration with the Nebraska Cancer Coalition (NC2) and with input from the Nebraska Comprehensive Cancer Control Program, is conducting a statewide cancer community health needs assessment during 2021-2022. As part of the process, cancer centers and community organizations throughout the state were asked to help recruit cancer patients/survivors (hereafter referred to as “survivors”) and caregivers to participate in a series of listening sessions. The sessions used structured interviews and poll questions to solicit participants’ perspectives about the cancer journey from diagnosis through treatment, as well as input specifically focusing on colorectal cancer screening awareness and participation.

Participants were open about the positive and negative aspects of their journey from cancer diagnosis through treatment. The need to feel supported and respected in the journey – from family, friends, community, and treatment providers—was a central theme, as was the intersectionality of various self-identities and how that impacted interactions with the medical community. Participants indicated that anxiety about how medical providers would react to their sexual/gender identity is common, and that being able to identify queer-friendly providers is important.

OVERVIEW

A 75-minute virtual listening session was held on January 21, 2022, with three cancer survivors from eastern Nebraska. Participants were from metropolitan and rural communities. Cancer types represented included uterine (n=1), thyroid (n=1), and colorectal (n=1). All three participants indicated their sex assigned at birth was female; two participants self-identified as women and one participant self-identified as “gender queer trans guy.”

The listening session utilized a structured facilitation guide and included built-in polling questions administered verbally in Zoom. Polls were used to assess overall community health status, cancer as a community health concern, and sources of cancer-related information; discussion focused on people’s experience with diagnosis and treatment and colorectal cancer (CRC) screening.

COMMUNITY HEALTH STATUS

Perceptions of the overall health of the community were mixed, with two participants indicating “fair” and one indicating “good.” One participant explained her holistic view of health, which includes mental, spiritual, and physical. She stated that maintaining spiritual health in the queer community is a challenge.

> *…each of them is struggling spiritually because they don’t have a spiritual community…they’ve been pushed out of their Jewish or Christian or Islam spaces or their general spiritual spaces because of their queer identity, and that spiritual health struggle leads to a mental, or it can lead to a mental health struggle which often manifests itself with physical health issues also.*

Depression and anxiety are mental health problems prevalent in the community. “I don’t think I know anyone in my community who isn’t struggling with depression or anxiety right now in some facet, and so I think that that also just plays a huge role on our health in general.” In addition, another participant stated the community consists of survivors. “Almost all of the members end up being cancer survivors, survivors of domestic violence…it just seems like there’s a lot of folks who are getting through the challenges…I feel like there are a lot of challenges to get through.”

Another factor impacting overall health in the community relates to medical care. One participant reported messaging she got as a woman who has sex with women was that she did not need to see a doctor regularly because she did not need birth control. She did not start having annual exams until she was in her late 20s. Another participant stated that medical care feels

> *…inaccessible because every time they show up, like, it’s a struggle to be named and gendered correctly let alone talk about pregnancy as a non-binary person or talk about uterine cancer as a male, or talk about, you know, all of these things in our society that are so specifically gendered.*

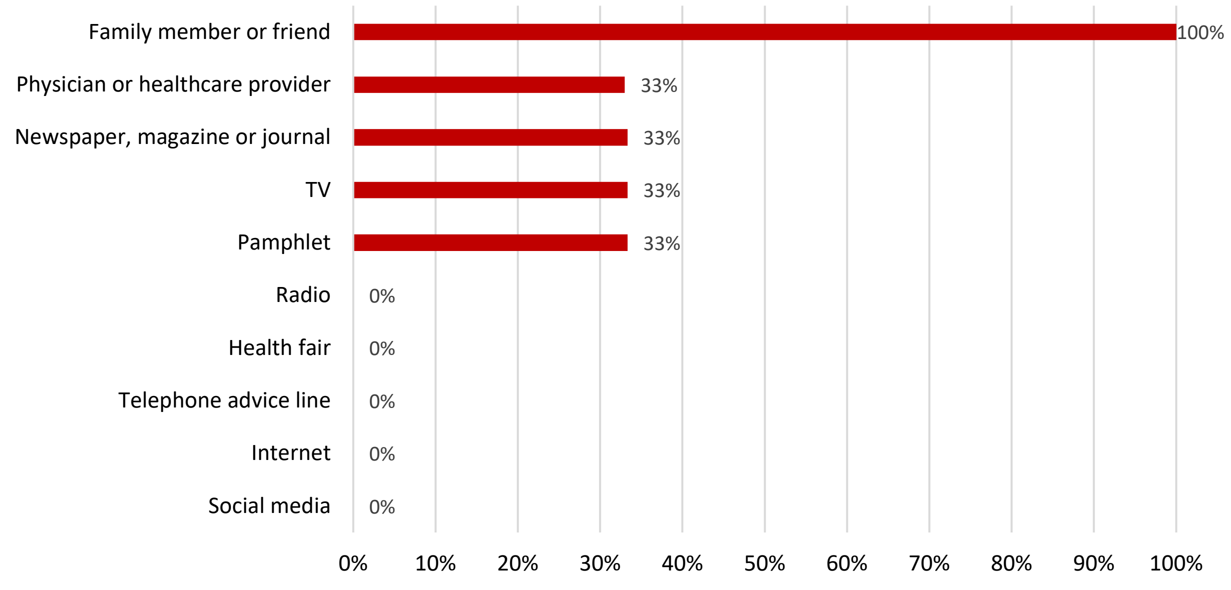
On a more positive note, participants did discuss that recently many LGBTQ+ people are getting HPV shots, which indicates awareness of and access to some preventive care.

Regarding the importance of cancer as a community health concern, two participants thought cancer was moderately important and one said very important. Participants expressed that cancer is something that “feels familiar” but “doesn’t feel like” it is “a dominant disease in my queer community.” Rather, cancer in an important health concern that is dealt with when it comes up but is not a primary concern within the queer community because “there are also a whole lot of other things that are happening in the community that affect folks.”

SOURCES OF INFORMATION ABOUT CANCER AND CANCER PREVENTION

The most common source of information about cancer or cancer prevention was family or friends. Some participants also got information from health care providers, television, newspaper, and pamphlets (Figure 1). One participant got information from her sister who works in a medical facility. Another participant mentioned that he got information about cancer from a gastroenterologist. The third participant used Google to search for cancer information after experiencing symptoms but before her diagnosis. She recommended not to use it because it raised her wife’s anxiety. They all indicated doctors or health care providers as the most trusted source of cancer information.

Figure 1. Sources of information about cancer or cancer prevention



Note: Participants could select multiple responses

CANCER DIAGNOSIS

Cancer diagnosis can generally be grouped as self-identification of symptoms, discovering suspected cancer through annual check-ups or screening without symptoms, and being treated for symptoms that were not initially identified as potential cancer. All three categories were represented in this listening session.

Participant 1 (P1) had sudden onset of severe symptoms. “I woke up in a pool of blood.” She described the blood as being “like menstrual blood.” She was terrified, ashamed, and embarrassed at the same time and felt uncomfortable waking up her fiancée who was lying in the bed. These mixed emotions were “a wakeup call for me about, like, how I see my own womanhood and queerness and just the shame that comes with all of the things that we deal with.” She saw multiple doctors including a gynecologist “I had never seen before ‘cause I needed to get in quickly.” That gynecologist was unable to complete a biopsy and referred her to a specialist. She had to wait 6 weeks for the appointment, during which time she Googled information about cancer and treatments. The specialist was able to complete the biopsy. Ten days before her wedding, P1 received a call from the doctor informing her of uterine cancer. While she was on the phone with the doctor asking questions, she was texting her family and fiancée about the diagnosis. However, “I would maybe do that part differently. Don’t tell your family you have cancer over a text, but it also felt like the best way to feel like people were with me, like, while I was having this conversation.”

Participant 2 (P2) was diagnosed with thyroid cancer during an annual check-up. However, she mentioned that routine check-ups are not common in the LGBTQ+ community and she “had only been going to the doctor for a couple of years.” At the annual exam, she was referred for an immediate blood draw that she described as “kind of a jarring situation, but my worst experience was my biopsy.” The biopsy was “horrible” but quick.

Participant 3 (P3) had been unwell for a long time and was diagnosed and treated for interstitial cystitis or “painful bladder syndrome.” Any pain he had was attributed to this condition, and he took hydrocodone daily for it. He went to the emergency room with pain symptoms on more than one occasion but was discharged with pain medication. Eventually the pain intensified and changed to “stabby kind of pains and I wasn’t able to drink water and things like that” so he went to the emergency room again. This time he was accompanied by his girlfriend and instructed her to not let them send him home with pain medications. A scan identified intussusception of the colon. He had emergency abdominal surgery the next morning and doctors found a colon tumor growing through the bladder wall. However, he was very angry about how he received his cancer diagnosis. He had been hospitalized for a week following the surgery, but 20 minutes prior to discharge a doctor he had never met informed him that “it was cancer” and “we may or may not have gotten all of it.” P3 further stated that he was “really out of it” at the time and “my girlfriend suspected that it was cancer, but I was I was, like, looped; so, I, it caught me completely off guard.” He then “texted all of my family members to tell them what was going on.”

CANCER TREATMENT

P1 had two surgeries. She “felt weird” being required to take a pregnancy test despite having sex with only her female partner. She also felt uncomfortable having a dilation and curettage (D&C, in which the uterine lining is scraped with an instrument), which she associated with abortions, as “sort of an alternative to a biopsy.” Her treatment consisted of a hysterectomy, and she described the oncologist as presenting things “in a way that was, at the time, seemed pretty factual” when he expressed doubts about being able to do the surgery robotically due to her weight. Due to P1’s issues with body image, she felt like she needed to postpone the surgery to try to lose weight to make the oncologist’s job easier. When she shared this with a friend, the friend reached out to another physician to see if the surgery needed to be postponed. The physician called P1 and told her that the oncologist could do the surgery. P1’s general practitioner also reaffirmed that she needed to have the surgery, which was eventually performed.

P2 decided to travel to Omaha for treatment at UNMC due to the reputation of having the best thyroid doctor. Her wife accompanied her to all appointments.

As described above, P3 had emergency surgery after being admitted from the emergency room. “I had to have this medical care and I really had no say, like they wouldn’t even let me go home.” The decision about the doctor performing surgery was dependent on “the hospital that I just happened to go to. It was going to be this doctor that I had no knowledge about.”

Themes related to the participants’ experiences from diagnosis through treatment and maintenance are presented in Table 1 with selected quotes to illustrate concepts.

Table 1. Positive and Negative Experiences with Cancer Treatment

Theme	Positive examples	Negative examples
Facilities	- "Literally felt like I was staying at a hotel." (P1) - "I would definitely go to Omaha for that type of care." (P1)	- "Wouldn't go to a rural community" (P2)
Providers' attitudes and behavior	- "[My wife and I] were always in the room together, like, you know, they looked at me as the patient, but also, like, treated us like a couple." (P2) - "Those nurses were amazing, like always, I mean, it was, I could not have asked for better nurses honestly and providers who took care of me at that time." (P1) - "There was actually a place on the board for the guest's name or visitor's name, and so, I think that one of my nurses had, like, written "wife [name]" on the board, which just like felt affirming to me" (P1) - "Felt really affirming" (P1) - "After that initial time, I think it felt respectful." (P1) - "Now I know I'm bringing somebody on board who, who is, you know, cool, with my body and so that was good." (P3)	- Patient was referred to a specialist and told "they'll call you if they have a provider who's willing to see you." (P1) - Lab tech "was being like super kind, helpful, like, was a warm person, and all of sudden it was, like, a switch flipped [when she found out the patient was lesbian], and it was matter of fact. No more smiles. No more eye contact, and, like, cold, honestly cold towards me" (P1) - "I'm already here to find out whether or not I have cancer, and now I have to deal with how someone who is supposed to be taking care of me, like, someone whose literal job is to make sure I'm healthy, I also need to be, like, defensive about who I am as a human being. That was just hard, I mean, that was hard." (P1) - "the tone or the body language or something felt judgmental" (P1) - "The anesthesiologist came in to like the pre-surgery room and you never for sure, but the way that she asked me and who's this [referring to patient's fiancée], felt icky. Like it just felt icky." (P1) - "When I was coming out of my second surgery, I had a terrible…recovery nurse" who was eating a bag of chips and "telling me that I needed to calm down" because "I would freak out; I could not breathe" due to asthma (P1) - "There was sort of, like, always this, you know, I had this constant sense of kind of, like, worrying about what I might overhear, like, if somebody was going to mis-pronoun me; so, it was, you know, anxious. I was anxious about that, 'cause I was

		thinking, you know, like, if I hear the, like, the wrong pronouns while I'm in the middle of having a catheter up my urethra and, I'll just say they missed the first time. So, it was just very vulnerable, a very vulnerable feeling." (P3)
Treatment	• "Overall, my experience was good" (P1) • "I'd say I got really, really good care" (P3) • "I had to have these basically up the urethra into the bladder injections. I don't know what you'd really call them; so, it was really intense as a trans person. And, but I felt, like, the care I got was good." (P3) • "On the flip side of that, I was affirmed by other physicians to be, like, no, like do the [surgery]." (P1)	• Oncologist reluctant to perform surgery on an overweight LGBTQ individual and made excuses why the robotic technique might not work for her (P1).
Support	• "I was assigned, like, a navigator person; and so, I could then start doing all of my queer screening through her and get her to reach out... So, having somebody, like, an ally built into the system was really good" (P3) • "I had my girlfriend, who has since become partner there, who was advocating for me, like, every step of the way." (P3)	• "I know a lot of folks who just don't have the support. I think especially in a rural area." (P1)

Although there are common experiences shared among those who receive a cancer diagnosis, this listening session highlighted several themes unique to the LGBTQ+ community related to their sexual and/or gender identity and how that impacted interactions with the medical community (Table 2).

Table 2: LGBTQ+ Community Themes, Subthemes and Examples

Themes and Subthemes	**Example**
Layers of Identity	
Defining identity	Defining self to the medical community • "I had my girlfriend…who was advocating for me…We, like, wrote my pronouns on the white board and things like that. But, you know, she was basically correcting everybody who was mis-pronouning me and all of that kind of stuff." (P3) • "Filling out the paperwork so that they would, like, let my wife in and things like that" (P2) Defining relationship with significant other to the medical community (explaining who is accompanying the patient to medical appointment) • Medical provider asks "Oh, are you her sister?" (P1) • "My partner and I had only been dating for 2 months when I landed in the hospital. So we kinda had this awkward moment where they were like, you know, 'Who's this?'" (P3)
Vulnerability due to identity	Emergency care (unable to select own provider, no time to identify "friendly" or "safe" provider) • "With mine being sort of, like, an emergency diagnosis, you know, I'm used to, like, finding out who's the queer-friendly dentist, who is the queer-friendly, you know, all of those; so, the idea of being operated on by someone who I knew nothing about was, like, really terrifying." (P3) Anxiety about provider reaction to identity (while hospitalized, a constant stream of new providers) • "I had this constant sense of kind of, like, worrying about what I might overhear, like, if somebody was going to mis-pronoun me; so, it was, you know, anxious" (P3) How to identify safe providers (referral, word of mouth, signs to indicate queer-friendly providers or settings) • "Some visible sign of affirmation would do, like, wonders." (P3)
Intersectionality of identities	Being overweight & sexual/gender minority • "As a fat person, I cannot go to the doctor for an ingrown toenail without having a 45-minute conversation about my diet with a podiatrist…so like that intersectionality of just things that for me personally the fear and the anxiety that comes with discussing all of those things, has in and of itself been a roadblock to getting medical treatment." (P1)
Interactions with the Medical Community	
Advocacy	Who advocates? • Self, partner, some providers, assigned navigator • "I had my girlfriend, who has since become partner there, who was advocating for me, like, every step of the way." (P3) • "I was affirmed by other physicians to be, like, no, like do the [surgery]." (P1) • "I was assigned, like, a navigator person; and so, I could then start doing all of my queer screening through her." (P3) How?

	- Asking questions - Insisting on appropriate treatment for symptoms - "I had my girlfriend with me and I basically was, like, don't let them send me home." (P3) - Another physician affirmed "[Oncologist] can operate." (P1) Sharing pronouns /relationship status - "I, we, like wrote my pronouns on the white board." (P3) - "She was basically correcting everybody who was mis-pronouning me and all of that kind of stuff." (P3) - "One of my nurses had, like, written 'wife [name]' on the board, which just like felt affirming to me." (P1) Why? - "We have to advocate for ourselves, like, there is not an option where you can show up to any medical anything and know that you will be cared for completely." (P1)
Gender-specific medical procedures	Gender-specific medical procedures can be awkward and unpleasant - "Under the trans umbrella, in my community, feel that medical care is inaccessible because every time they show up, like, it's a struggle to be named and gendered correctly, let alone talk about pregnancy as a non-binary person or talk about uterine cancer as a male, or talk about, you know, all of these things in our society that are so specifically gendered." (P1) - "I had to have a D&C first, which is something they often do for abortions, but for me, they were just doing it sort of an alternative to a biopsy." (P1)
Queer-friendliness	Urban communities and health care systems are perceived as more queer-friendly than rural providers
Need for feedback mechanism	Unclear accountability at system level - "I didn't know how to talk about that nurse to let the system know about my experience, right. Like, what is the recourse or where do you go, or how – I mean, I got a survey, like, when I was discharged from the hospital, but like, where's that. I have no idea who's that going to and I think it was from DHHS, not the hospital itself, and so, like, like, who do I tell. Who do I talk to when you have a poor experience, like, where is there any accountability. So, I think that's just one thing I would comment on, is there was an unclear path of accountability." (P1) Being able to tell story is a way to validate the experience - "Sometimes I feel like it's not heard by anyone who has any power, right, and so I think just being heard on a research level gives me hope for a better future." (P1) - "It feels good to be included 'cause my cancer story seems really different than a lot of folks…it's nice to feel like that that's valid, too." (P3)

BARRIERS TO RECEIVING CANCER CARE

Participants identified a few specific obstacles to care in the discussion of experiences with cancer treatment and services, as reported in Table 3.

Table 3. Barriers/Obstacles to Cancer Care

Barrier	**Example**
Support	• "I know a lot of folks who just don't have the support. I think especially in a rural area." (P1)
Rural areas	• Rural areas are "not as progressive when it comes to inclusion unfortunately." (P1) • "I wouldn't go to a rural community and, like, look for services now. I would very much want to be in Omaha and with my doctors." (P2)
Misinformation	• "The messages we get about, like, if we, do we need to go to the doctor, we don't need birth control...". (P2)
Finance or Cost	• "You know, whether or not people are insured, whether or not they have access to, you know, also [inaudible] to take off work, you know." (P2)
Discrimination	• "I'd say discrimination, racism, homophobia, transphobia, sizeism, like, all of those, I know have impacted people in my community around cancer and other health diagnoses, as well." (P3)

COLORECTAL CANCER (CRC) SCREENING

As an introduction to the CRC screening discussion, participants were read the following statement and asked to respond to a poll question in which they could select multiple responses:

> *There are several different colorectal cancer screening methods available. Stool or poop-based tests include the fecal occult blood test or FOBT, the fecal immunochemical test or FIT, and FIT-DNA tests. Other tests insert a long, thin, flexible tube into the rectum or even the entire colon to look for small growths called polyps, and cancer. These tests are known as sigmoidoscopy and colonoscopy. Which of these tests have you heard about prior to today?*

All participants had heard of colonoscopy. The colon cancer survivor had heard about stool tests but not different types of stool test and did not know the differences between them. One participant had prior information on FOBT and FIT-DNA.

Participants had many thoughts about factors that impact CRC screening, with most comments focused on the colonoscopy procedure (Table 4).

Table 4. Factors that Impact CRC Screening

Theme	Example
Perception and emotion	• "colonoscopies are – it's sort of like, like, you know, like it's a joke or, like, a source of humor, or like, they're just seen as weird" (P3)
Stigma	• "anxious about going and what kind of microaggressions, full-out aggressions exists for folks, especially for LGBT folks" (P2)
Timing of the service	• "...her physician only does [colonoscopies] in the morning, and so my mom had to be there at like 7:00 a.m., to, like, for her time slot or whatever and could not get a later time in the day. And so, she either needed to leave…at 5:00 a.m. to be there on time, or do her prep in the hospital, or a hotel room. Neither of those are great choices" (P1)
Lack of information	• No information on signs and symptoms of CRC. "I am in my early forties that we talk about and, you know, we know at 50, they'll get [colonoscopy], but like, what are the signs, what are things to watch out for. Those types of things, I think, are good" (P2)
Colonoscopy prep	• "[Mother's] experience with the prep has been also traumatic and really hard" (P1)

Participant suggestions for improving CRC screening included ideas for increasing public awareness of CRC through social media and healthcare providers and facilities (Table 5).

Table 5. Suggestions to Improve CRC Screening

Theme	Example
Information and Awareness	• Information and awareness by people who have used CRC screening services. "...but I think, like, knowing that you know somebody who has that kind of medical care, I think, is important.... it's those, like personal connection, awareness building." (P3) • Recommend using "social media" (P2) and "Instagram ads" (P1) to raise awareness • Involvement of health care providers: "One of my doctors..... part of the people working on lowering the age, and I thought that was just, like, totally bad ass. I was, like, yeah, that's awesome. I like that, I felt like somebody on my team was, like, an activist or was, you know, doing something awesome." (P3) • Involvement of community organization in CRC screening awareness. "An organization that we work with…they work with businesses, they work with, you know, nonprofits, and they're always thinking about...organizations like that, that can kind of tell the story about in work place…about what to look out for, what to be careful about." (P2) • Information on importance of CRC screening. "I'm just promoting that the best medical decision is not always going to be the most fun option, like, yeah do I wanna do that prep every other year or would I rather never do that prep again. I'd rather never do it again, but I've got the, you know, fear of cancer in me now that, you know, I am very happy to get the medical screenings on the cautious side of things." (P3)
De-stigmatization	• "a de-stigmatization about it; so, if it starts to become a part of our vernacular then you, you know, it's something that's not as distant" (P2)
Incentive	• "incentivize getting, like, regular screenings for things or, like, doing my annual exam, or getting certain labs done, as, like, preventative, and I literally got, like, a couple hundred dollars in gift cards" (P1) • "it seems like there would be an opportunity for insurance companies to provide incentives for folks who are insured to get regular things done that we may not know we should be doing" (P1)
Colonoscopy prep	• "I would love some research into how to make the prep less horrible. Like, I really just want to know, like, it's bad, it's really bad. I would love that to be better; so, whoever is researching that, like, they should pay some attention to that." (P3)

COMMUNITY NEEDS AND SERVICES

Participant community needs and services are summarized in Table 6. As indicated earlier in the discussion about general community health, cancer is just one of many issues faced by the LGBTQ+ community.

Table 6: Community Needs and Services

Themes	Example
Support for the LGBTQ+ community	• "I think support is just something that the LGBTQ community lacks" (P1) • "I wish there was an advocate for me..." (P1)
Destigmatize medical care	• "I think trying to make sure that we're destigmatizing just medical care..." (P2) • "I would love to see just, like a pride flag hanging up or some little subtle, something that, you know, maybe wasn't like a giant poster, but that I or other queer folks would see. That would sort of just kind of let me know that the provider at least knew that people like me existed." (P3) • "…some posters that showed me that I was seen." (P3) • "I wish there was just, like, a way to know who's safe when they're walking in the room." (P1) • "I saw that many different people coming in my room to take care of me, and every time I had to, like, bristle a little bit and be ready for how's this, you know, and yeah. I just wish there was a way to know that you're safe. Like, I wish I was guaranteed." (P1)
Concern about pain management	Concern that response to opioid epidemic will limit needed access to proper pain management and access to medical marijuana for pain and treatment side-effects. • "I would say just to jump back into pain management. I hear about the, you know, the opioid epidemic, and I know folks with chronic pain, and I get very afraid for people or for myself down the line that they won't have access to proper pain management." (P3) • "...access to medical marijuana for pain management for helping with appetite for folks who are going through chemo and radiation for cancer treatment itself and I know a lot that is still experimental, but I think at least, like, it is time." (P1)

CONCLUSION

Listening session participants appreciated the opportunity to share their experiences. This session highlighted the need to destigmatize health care and help LGBTQ+ patients easily identify welcoming providers. Continuing efforts are needed to address gaps in both general health care and cancer-specific care services including colorectal cancer screening in the LGBTQ+ community within Nebraska.