

# NEBRASKA CANCER COMMUNITY HEALTH NEEDS ASSESSMENT

Listening Sessions Summary Report | October 2022



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# Executive Summary

The Office of Community Outreach and Engagement (COE) 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 (NECCCP), conducted 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 and caregivers to participate in a series of listening sessions. The listening sessions used structured interviews and short survey questions to solicit participants' perspectives about the cancer journey from diagnosis through treatment. We also asked about colorectal cancer screening awareness and outreach suggestions.

Listening sessions attempted to reach populations with known cancer disparities in Nebraska, including:

- Rural (Grand Island, Hastings, and North Platte)
- African American (females, males)
- Hispanic (rural, urban)
- American Indian (Urban Indian Lincoln, Urban Indian Omaha, Ponca Tribe of Nebraska)
- Sexual/gender minorities (lesbian, gay, bisexual, transgender, and queer/questioning identities, or LGBTQ)

Reports summarizing the findings from different population groups were released through the COE website (<https://go.unmc.edu/coereports>) as the data became available. This summary highlights key information across the sessions.

- Importance of providers educating patients and allowing them to ask questions (shared decision-making model in which patients are educated about their diagnosis and treatment options in easy-to-understand language)
- Information about support services (psychological counseling, social work, financial assistance, survivorship support groups, etc.) should be offered to all patients at multiple time points. Patients and caregivers appreciated being reminded of available services because their needs can change over time. Some people are reluctant to use the services because they do not want to be a burden, so support services should be normalized.
- Increase accessibility of support services (barriers include travel time/distance, qualification for services)
- Patient navigation is an important service. Cancer diagnosis and treatment can be confusing and complicated, with multiple doctors, tests, and treatments. Having someone there to help with scheduling and to advocate for the patient's needs is valued by patients.
- Need for education about the importance of preventive check-ups and screening



## Overview

**Eleven listening sessions occurred between February 26, 2021 and January 21, 2022, gathering information from 68 cancer survivors and caregivers across the state.**

Most sessions were held virtually via Zoom due to COVID-19, although American Indian sessions were held in-person in Lincoln and Omaha. Sessions ranged in length from 75 to 107 minutes, with most lasting about 90 minutes. Poll questions were administered via Zoom polling, chat, and/or verbally for virtual groups. For in-person groups, the questions were administered as a paper-based survey prior to the start of the discussion. Poll and survey responses were recorded anonymously. Because some participants joined late or left early, all poll results are reported as the percentage of participants who responded to each question. Polls were used to assess overall community health status, cancer as a community health concern, sources of cancer-related information, and awareness of colorectal cancer (CRC) screening methods. Guided discussion focused on participants' experience with cancer diagnosis and treatment. The latter portion of the session specifically focused on CRC screening.



## Methodology

The needs assessment steering committee consisted of representatives from the University of Nebraska Medical Center (UNMC) Fred and Pamela Buffett Cancer Center (BCC), the Nebraska Cancer Coalition (NC2), and the Nebraska Comprehensive Cancer Control Program (NECCCP). The steering committee met throughout September and October 2020 to set the scope of the needs assessment and identify data sources and data collection needs.

The steering committee identified target populations and compiled a list of potential community and recruitment partners. They also conducted a literature review and refined topics, themes, and questions to draft a facilitation guide for the listening sessions. The guide draft was then reviewed by representatives from the BCC's Office of Community Outreach and Engagement Community Advisory Board and potential recruitment partners for input before being finalized (see Appendix A for final version of the virtual session guide). A modified version of the facilitation guide was later created for the in-person sessions by removing references to built-in polling questions (Appendix B).

### Recruitment

The recruitment process varied by target population but was guided by the steering committee to facilitate contacts between the assessment team and community partners. Initial informational meetings between the assessment team and the potential partners introduced the needs assessment, shared the facilitation guide, and discussed questions or concerns. Partner organizations tailored their own recruitment strategies. The assessment team created recruitment flyers which were shared with partners for distribution in clinics, shared on social media, and posted in the community. For some sessions, recruitment was coordinated by the community partners directly, but for other sessions, the assessment team was the point of contact for screening interested participants.

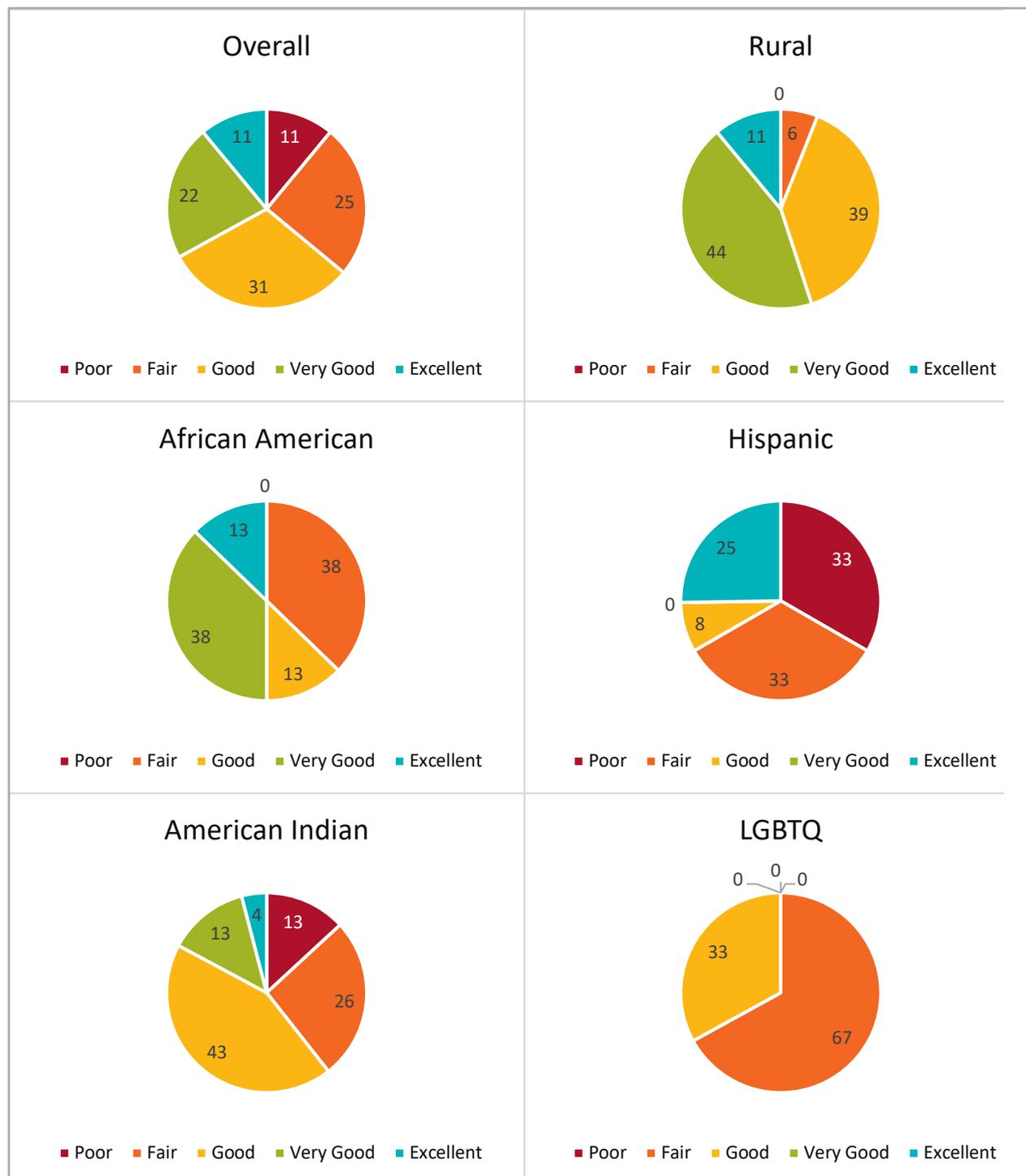
### Data Collection and Management

All sessions were recorded (audio and/or visual) and transcribed for analysis. Hispanic sessions were conducted in Spanish, and transcripts were transcribed and then translated. Transcripts were compared with the recordings and session notes to ensure accuracy. Focus groups were facilitated by Kendra Ratnapradipa, PhD, MSW; Keyonna King, DrPH; Athena Ramos, PhD, MBA, MS; Shinobu Watanabe-Galloway, PhD; Nancie Velasquez; and Ryan Sallans, MA.

# General Cancer Experiences

## PERCEPTIONS OF THE COMMUNITY'S HEALTH STATUS

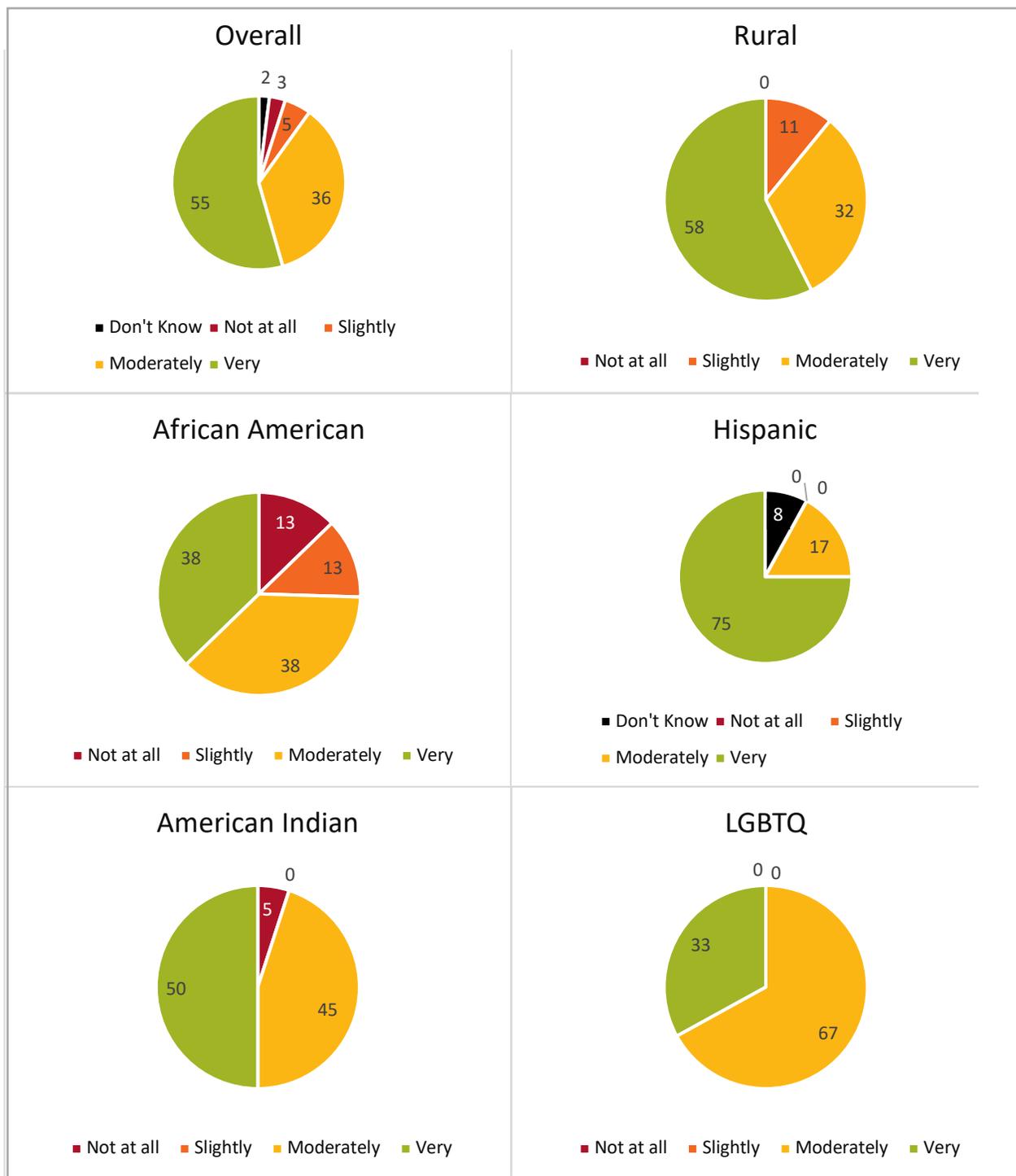
Overall, participants thought their community's health was good, although perceptions varied within and between groups. Only participants from the Hispanic and American Indian groups indicated poor community health (red).



**Figure 1.** Overall, how would you rate the health status of your community?

## IMPORTANCE OF CANCER AS A HEALTH CONCERN IN THE COMMUNITY

Participants thought cancer was a moderately (yellow) or very (green) important concern in the community. Some Hispanic participants did not have an opinion (black).

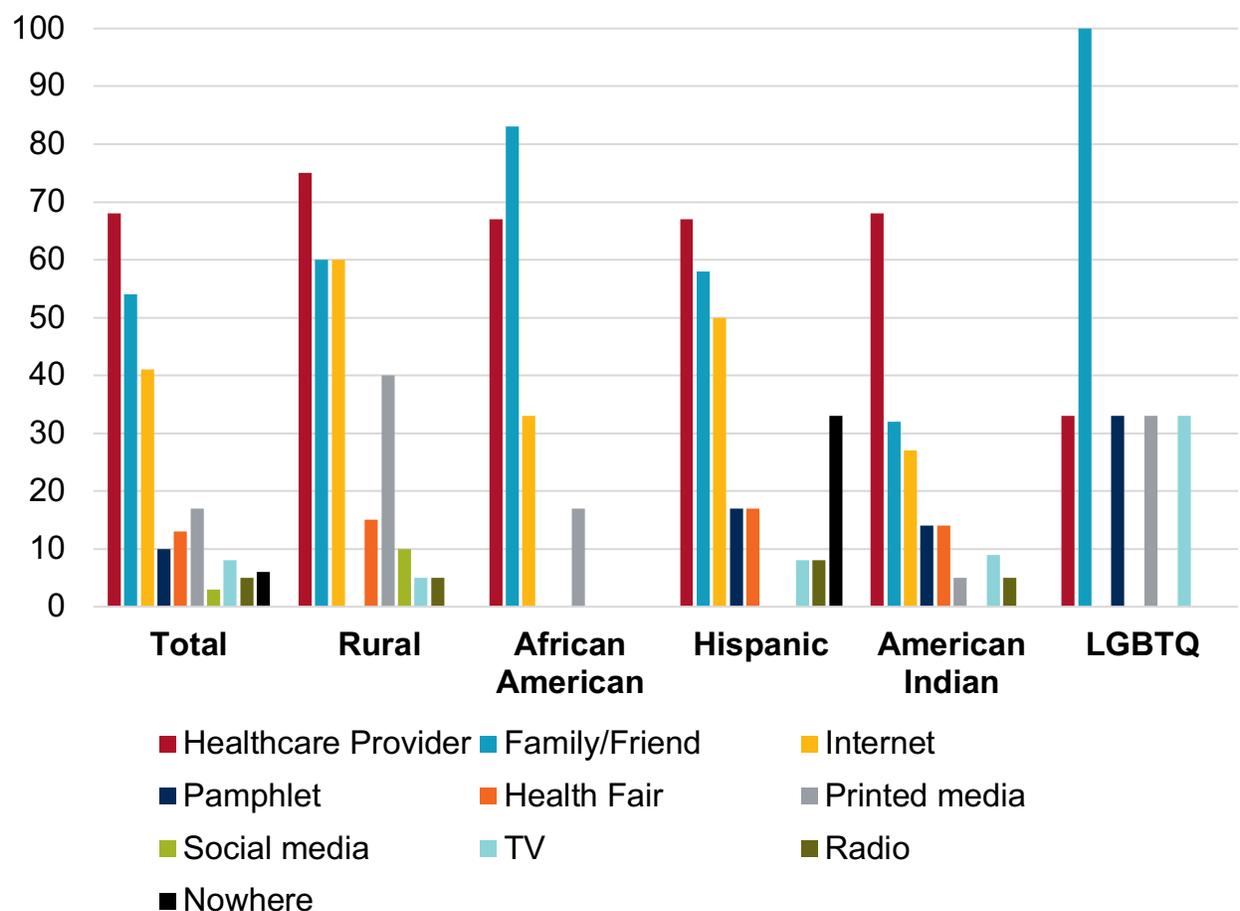


**Figure 2.** Overall, how important is cancer (of any type) a health concern in your community?

## SOURCES OF INFORMATION ABOUT CANCER AND CANCER PREVENTION

Participants receive information about cancer and cancer prevention from many sources. The most common sources of cancer information are health care providers, family and friends, and the internet. Internet sources include using search engines such as Google. Other participants only use internet sites they consider trustworthy. Examples include WebMD, American Cancer Society, UNMC, Mayo Clinic, cancer centers, and cancer societies or professional organizations. After diagnosis, patients and caregivers also rely on books and pamphlets provided by their treatment center. Some participants also receive cancer educational materials or training through their employers, for example, working in cancer screening and outreach programs or reading professional journals.

Only participants in the Hispanic groups indicated a lack of any sources of cancer information (black).

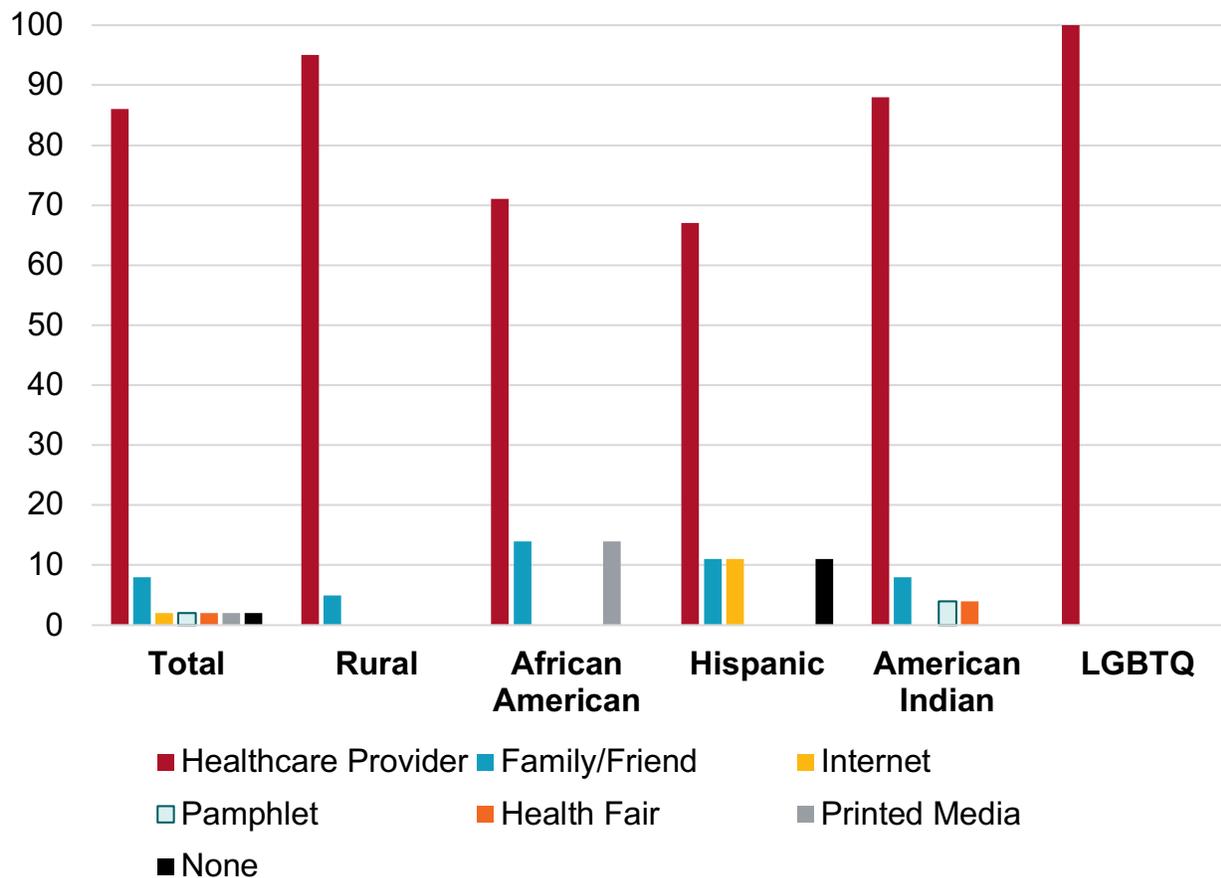


**Figure 3.** Think back to the time before the cancer diagnosis. Where did you get information about cancer or cancer prevention?

## MOST TRUSTED SOURCE OF CANCER INFORMATION

Health care providers are the most trusted source of cancer information. A small number of participants indicated that family or friends are the most trusted source, especially if the family or friend works in a healthcare setting.

Notably, some Hispanic participants indicated that they had no trusted sources of cancer information (black).



**Figure 4.** Of the various sources of information available about cancer and cancer prevention, which source do you trust the most?



## Cancer Diagnosis

Below is a summary of key lessons from the listening sessions about experiences receiving the cancer diagnosis.

### **Importance of having a primary care provider**

- Some participants experienced delayed notification of diagnostic test results and did not know who to contact to get the results. Having a primary care physician seemed to be associated with better follow-up and a better transition to specialist care.

### **Importance of annual check-ups and screenings**

- In the African American, Hispanic, American Indian, and LGBTQ groups, participants indicated that the norm is to only seek medical attention when symptoms are severe, meaning that many people do not utilize regular or preventive care and screenings. This can lead to delayed diagnosis and more severe illness.

### **Providers need to take patient concerns seriously**

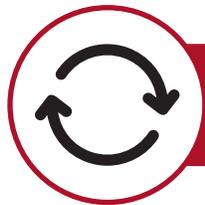
- Some participants related experiences where they noticed a lump or ball, pain, or other concerning symptoms. When they told their doctor about the symptoms, they were not immediately referred for follow-up. This led to delayed diagnosis and a more advanced stage of the disease.

# Themes Related to Cancer Experiences



## Provider Availability

- Some participants were unable to change providers or get a second opinion due to limited provider availability (no other options within a reasonable driving distance).
- Physician turn-over impacted patient experiences. A rural participant jokingly referred to it as “radiation oncologist of the month.”



## Care Coordination

- The transition from primary to specialist care set the tone of the overall cancer experience. Poor professional hand-offs led to patient and caregiver confusion about who to contact with questions, how to get test results, and what follow-up was needed.
- Not all cancer patients had access to a patient navigator, but those who did really appreciated this service.
- Without assistance, it is difficult to keep track of the many tests and appointments.



## Patient-Provider Communication

- Not all cancer providers have an approachable manner. Some participants shared experiences of being treated rudely, not being allowed to ask questions, and not being listened to.
- In contrast, participants had positive experiences when their providers used easy-to-understand language, allowed questions, and shared decision-making with the patients and caregivers.



## Support Services (Organizational)

- Participants used a variety of support services available through their local cancer treatment center.
  - Patient navigators (nurses or trained community members)
  - Social work
  - Psychological counseling
  - Financial support (gas cards, hotel, and meal vouchers, prescription medicine assistance, help with medical bills, rent assistance, utility bill assistance)
  - Help completing paperwork (Family Medical Leave Act, Medicaid)
- Some participants also had support services available through a local community organization, although the geographical range of the support services was limited. Examples of support services included:
  - Financial support
  - Housekeeping assistance
- Patients and caregivers did not want to be a burden and were sometimes hesitant to ask for or accept assistance. They appreciated being reminded that services were available.
- Not all participants were able to use support services. Barriers included:
  - Lack of knowledge of services
  - Language barriers
  - Limited geographical availability (lived too far away)
  - Health insurance status
  - Immigration status



## Social Support

- Most, but not all, participants had informal social support from family, friends, coworkers and colleagues, their religious community, and the larger community.
- Informal support included emotional, spiritual, and physical support. Examples included:
  - Help with yard work

- Transportation to/from medical appointments
- Community wore t-shirts to show solidarity with cancer patient
- Fundraising
- Some people lost their social supports due to the cancer diagnosis. Examples included separation or divorce from spouse and being ostracized by the community due to stigma of cancer.



## Treatment & Side Effects

- Some participants lacked understanding about the long-term nature of treatment side-effects. They thought that they could “bounce back to normal” but instead had a very gradual recovery.
- This suggests that additional patient education and survivorship counseling may be needed.



## Facilities & Staff

- Participants were very pleased with the quality of the treatment facilities.
- The majority of participants had positive experiences with the cancer center staff. They felt that the environment was welcoming and supportive.
- A few participants reported experiences of discrimination.



## Financial

- Many participants reported financial difficulties during the cancer journey.
- Cost of care was mentioned, particularly the cost of medications.
- Cancer diagnosis may result in reduction of work hours and loss of health insurance.
- Travel-related costs include gas, meals, and hotels.



## Transportation

- Getting to treatment can be difficult, especially in rural areas with long travel distances (time, gas costs).
- Some patients need to arrange rides because they cannot drive themselves to treatment.
- Timing of appointments needs to be considered in terms of patient travel time (early morning appointments are difficult for those who live far away, or may necessitate additional expenses due to hotel rooms).



## Lack of Support Groups

- Not all patients have access to support groups (limited geographical area).
- Need for balance between specificity and inclusivity of support groups. Participants indicated that the cancer type and age of other participants may be barriers to participating. Participants mentioned that there are groups for breast cancer but not other types of cancer.
- Some caregivers would like to have support groups available for the caregiver.



## Language

- Language barriers include the wide variety of languages and dialects spoken within Hispanic communities.
- Formal interpreter services are not always offered to those who need them.
- Some Hispanic participants reported relying on their young children to translate in medical settings. In other instances, community members informally translate for each other.
- Even some Hispanic participants who considered themselves to be bilingual had difficulty with the medical terminology.
- Medical terminology can be very confusing, even for native English speakers.



## Discrimination

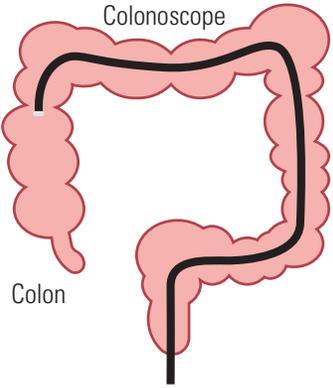
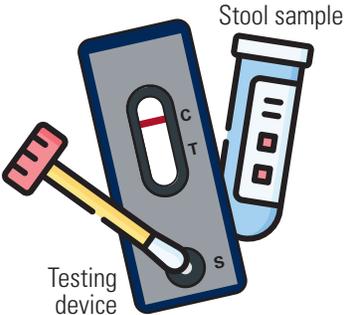
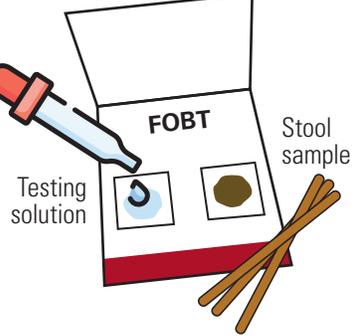
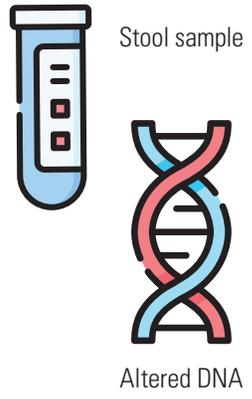
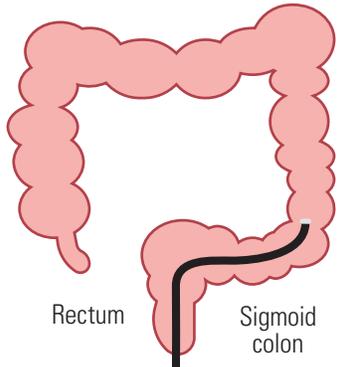
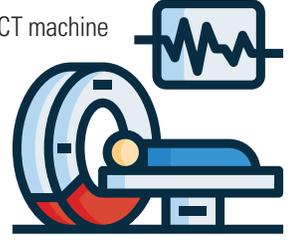
- Participants reported experiencing discrimination in cancer care settings based on race/ethnicity, legal status, language, or sexual/gender identity.



## Lack of Regular Medical Care

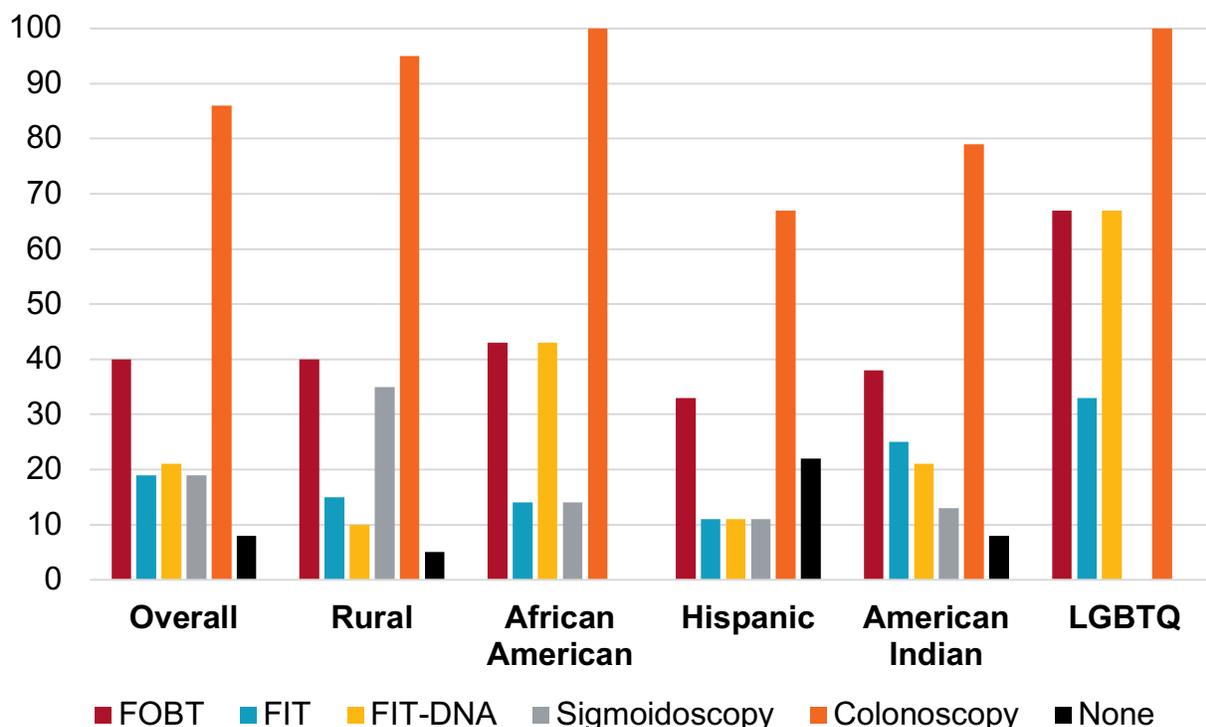
- Across listening sessions, participants shared generational and cultural norms about when to visit a medical provider, including a “walk it off” mentality and self-management of symptoms.
- In the African American, Hispanic, American Indian, and LGBTQ groups, participants shared examples of not seeing a healthcare provider unless symptoms were so severe that they could no longer be ignored.
- Lack of routine (preventive) care decreases opportunities to receive health education and screening.
- Some of this hesitation to utilize health care may be due to historical events of unethical or unfair treatment leading to widespread mistrust of the predominantly White Western health care system.
- Competing priorities and financial constraints of low-wage hourly workers make preventive care difficult.

# Colorectal Cancer (CRC) Screening

|  |   |  |
|--|---|--|
| <h2>Colonoscopy</h2> <p><b>Imaging of entire colon</b></p>  <p>Colonoscope</p> <p>Colon</p> | <h2>Stool Tests</h2> <div data-bbox="625 325 1015 766"><h3>Fecal immunochemical test (FIT)</h3><p>Stool sample</p><p>Testing device</p></div> <div data-bbox="1031 325 1421 766"><h3>Fecal occult blood test (FOBT)</h3><p>Testing solution</p><p>FOBT</p><p>Stool sample</p></div> |  |
| <h2>Stool DNA Test</h2>  <p>Stool sample</p> <p>Altered DNA</p>                            | <h2>Flexible Sigmoidoscopy</h2> <p><b>Imaging of the lower colon</b></p>  <p>Rectum</p> <p>Sigmoid colon</p>  | <h2>CT Colonography</h2>  <p>CT machine</p> |

## AWARENESS OF CRC SCREENING TESTS

Across groups, awareness of colonoscopy (orange) was high, and there was variable awareness of stool-based tests (red, blue, yellow). During discussion, participants expressed confusion about the different stool-based tests, so there is some misclassification of test types. Some participants had seen ads for Cologuard® but did not know how to classify it. Cologuard® is the only FDA-approved stool DNA screening test for CRC currently available in the US market. We did not mention this test by name but did inform participants that it was a FIT-DNA test after they completed the poll/survey. In multiple groups, some participants were unaware of any screening methods (black).



**Figure 5.** There are several different colorectal cancer screening methods available. Stool (poop) based tests include the fecal occult blood test or FOBT, the fecal immunochemical test or FIT, and the FIT-DNA test. 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?

## **BARRIERS TO CRC SCREENING**

### **Information and Awareness**

- Lack of information about colorectal cancer, risk factors, signs, and symptoms
  - “What is colorectal cancer?”
  - “I don’t think a lot of Natives get that type of cancer, do they? I’ve never heard of it until now.”
- CRC screening is not promoted as widely as breast cancer (mammogram)
- Lack of knowledge about screening recommendations (ages, high vs. average risk)
- Perception that CRC is an “old person disease”
- Perception that there is low personal risk
  - “It won’t happen to me.”
  - “I’ll get [screened] later.”
- Patients rely on health care providers to recommend (“urge” or “insist on”) screenings and to inform them of testing options
- Inconsistent recommendations from healthcare providers
  - Not all providers make screening recommendations
  - Some providers only recommend colonoscopy
  - Some providers do not educate about stool-based tests unless or until the patient is resistant to colonoscopy
  - Providers recommend screening but do not convey the information on the importance of screening

### **Fear, Embarrassment & Cultural Norms**

- Not wanting to get a cancer diagnosis (not specific to CRC) because it’s viewed as a death sentence
  - “Rather not know”
- Anxiety about microaggressions during a vulnerable, invasive procedure (colonoscopy)
  - “Anxious about going and what kind of microaggressions, full-out aggressions that exists for folks, especially for LGBT folks.”
  - “I don’t want to go in and have any doctor playing with my butt and I’m glad I’m asleep so I don’t hear them talk about you know and all that stuff.”
  - “Camera is a red flag that put me off.”
- Colonoscopy treated as a joke due to embarrassment and association with sexual innuendo (scope inserted through the rectum, concerns about violating manhood)
  - Hispanic: “Unfortunately, Hispanics are very, very macho and they don’t want to get an exam of that kind.”
  - Hispanic: “Rooted traditionalism...that [CRC] only concerns gay people.”
  - American Indian: “Being too macho”
  - American Indian: “People’s perception of manhood.”

- Concern about bowel preparation for colonoscopy
  - “Horror stories about the prep”
- Discomfort or embarrassment about collecting stool samples
  - “I don’t wanna be digging in my poop...I wouldn’t even do it for money.”

### **Access**

- Cost and health insurance
  - “Not everybody maybe has health insurance coverage or is aware of how to apply for Medicaid or any those other things.”
- Time/scheduling
  - Rural: “Physician only does [colonoscopies] in the morning, so [we] had to be there at like 7 AM to, like, for her time slot...so she either needed to leave at 5 AM to be there on time or do her prep in the hospital or a hotel room. Neither of those are great choices.”
  - Hispanic: “They don’t want to lose work to get a medical exam...The day I miss work is the day I need to put food on my table.”

## **SUGGESTIONS TO IMPROVE CRC SCREENING**

Participants had many suggestions to improve CRC screening. Across groups, participants wanted a combination of in-person contact as well as electronic or printed materials. Messaging should occur in multiple settings to reach a wide audience. Personal connections at health fairs with survivors was suggested to share messages of hope as well as to increase the sense that colorectal cancer can happen to anyone.

### **Provider education to:**

- Consistently recommend screening to all eligible patients
- Know about all test options and know how to educate patients about them in easy-to-understand format, preferably with visuals
- Implement shared decision-making

### **Importance of health care provider recommendations**

- Hispanic: “The doctor influences us a lot on how important this test should be.”
- African American: “There is also some physician bias for additional resources like Cologuard in that they don’t trust that, so maybe education form the physician perspective as well.”
- American Indian: “Stressing the importance of getting checked.”

### **Information Campaigns: Delivery Method**

- Primary care clinics: Flyers, brochures, posters, and “stall stories” in clinic restrooms
- Billboards
- Social Media (Facebook, Instagram)

- Group text messages
- Community events (health fairs, senior meals)
- Community partners (community groups, churches, schools, employers)
- TV or radio

### **Information Campaigns: Messaging**

- CRC is “no joking matter”
- “Give yourself a birthday present so that you have time for family & grandkids”
- CRC is treatable “if they catch it in time.”
- “Diagnosis is not a death sentence. Diagnosis is taking that step to live.”
- “If you get checked, your mind rests too if you know you don’t have it.”
- “If you have a history of cancer in your family, you should get that checked as often as possible.”

### **Incentivize preventive care (gift cards when completing screenings and routine check-ups)**

## **COMMUNITY NEEDS AND SERVICES**

Cancer diagnosis does not happen in a vacuum. The broader health context of the community is an important consideration when planning cancer education and screening outreach campaigns. As such, participants identified several general needs within their communities.

### **Building trust with medical community**

- Mentioned in the African American, Hispanic, American Indian, and LGBTQ sessions

### **Prioritizing regular medical care**

- Need for regular check-ups (not just treatment for severe symptoms)
- Making time for care amidst competing demands
- Mentioned in the African American, Hispanic, American Indian, and LGBTQ sessions

### **Sense of hope (overcoming disease fatalism)**

### **Building sense of community and improving social support networks**

**Health education about a range of health conditions (many of which are risk factors for cancer but may not necessarily be recognized within the community as such)**



## Conclusion

Participants of the listening sessions may not reflect the range of opinions and experiences dealing with cancer in various Nebraska communities. However, participants did share valuable insights into cancer care experiences and identification of areas for improvement to help reduce disparities in cancer screening, incidence, mortality, and survivorship within the state. Here are some final recommendations from the listening sessions:

- Normalize routine check-ups, even at young ages
- Provide better access to free or low-cost primary care and better access to financial assistance for cancer treatment
- Increase awareness of cancer at grassroots level
- Social media campaigns to share information about the importance of screening
- Provider education to encompass staff and clinicians
  - Interpersonal communication and listening skills
  - Diversity, Equity and Inclusion and cultural sensitivity training
  - Addressing language barriers
  - Shared decision-making (patient education)
  - Hand-offs between providers (to improve the referral process)
- Increase access to patient navigators
- Increase access to cancer support groups and psychological services

## APPENDIX A

# Focus Group Facilitation Guide

**Participants of the listening sessions may not reflect the range of opinions and experiences dealing with cancer in various Nebraska communities. However, participants did share valuable insights into cancer care experiences and identification of areas for improvement to help reduce disparities in cancer screening, incidence, mortality, and survivorship within the state. Here are some final recommendations from the listening sessions:**

**PURPOSE:** Gather community input and feedback on cancer-related community health status and health needs, access to services, and potential solutions.

Feedback will be used to report results in the Buffett Cancer Center's 2021 Cancer Community Health Needs Assessment and shared with Nebraska Cancer Coalition (NC2)'s statewide partners

**This focus group is designed to last approximately 75 minutes and is broken into 4 sections:**

- A. Introductions [5 minutes]
- B. Cancer-related Community Health [40 minutes]
- C. Focus on Colorectal Cancer [25 minutes]
- D. Wrap-up [5 minutes]

**This guide assists UNMC researchers with the facilitation of the Cancer Community Health Focus Groups.**

**Use this document for guidance, adjusting according to the audience (i.e., going into more explanation or depth, modifying words, etc.) when necessary.**

**Note:** Due to the current COVID pandemic situation, all focus groups are planned to be held virtually (Zoom or a similar distance conferencing platform).

## **Key Definitions**

**Poll:** Digital audience response polling system will be used to build participants' responses into a list and to vote on select questions. (This may be done by a co-facilitator within the Zoom platform or by providing a link to an external polling site such as Poll Everywhere.)

**Open Ended Discussion:** Open dialogue discussion facilitated by the research personnel. Participant input is not built into a poll but recorded by the research personnel acting as the notetaker during the session.

## **Personnel Needed**

- **Facilitator** – conduct the discussion and instruct participants when to respond to poll questions.
- **Co-facilitator** – co-host the Zoom meeting and administer polls
- **Notetaker** – record notes about the session, including noting facial expressions and non-verbal clues (to the extent possible in video format) as well as recording main points and relevant quotations from the open-ended discussions.

## **Equipment/Set Up**

- **Equipment Needed:** Computer with stable internet to enable hosting/co-hosting of Zoom conferencing.
- **Zoom Set Up:**
  - Have waiting room so everyone enters the focus group at the same time.
  - Zoom should have the following functions enabled: Chat, participants can mute/unmute themselves; reaction buttons (yes/no, raise hand, etc)
  - Pre-set poll questions

## A. INTRODUCTION [~5 minutes]

### Focus Group Process – Facilitator’s script:

Welcome to the **[insert name]** focus group. Thank you for taking the time to join us to discuss cancer needs in your community. our involvement is important and we value what each of you brings to the needs assessment process. My name is **[facilitator’s name]**, and I will be facilitating this focus group. Assisting me to create online polls is **[tech support’s name, and notetaker’s name]** will serve as notetaker. We are from the University of Nebraska Medical Center.

We are conducting focus groups as part of a collaboration between the Fred & Pamela Buffett Cancer Center at UNMC and the Nebraska Cancer Coalition to conduct a statewide 2021 Cancer Community Health Needs Assessment. As part of this process, we are meeting with small groups of cancer patients and survivors and their caregivers from various communities throughout the state. These **focus groups** are a way for us to gain direct knowledge of your experiences with cancer services in your community.

All personal information gathered for the focus groups will remain anonymous. However, summarized results will be shared with state and local health departments, local cancer centers, and other partners throughout the state working to improve cancer-related services. The report will also be available to the public.

We may include short quotes in the report to provide examples, **but we will not share information about who participated in the focus groups and your name will never be associated with the results.** We do ask that comments remain confidential. This means that comments shared during today’s focus group should not be discussed outside of the session. While it is important that we identify what services are available in your community and what organizations provide services, we ask that you **do not mention the names** of specific doctors.

We want to make sure we accurately report your comments and ideas. This is why we will be **recording** this session as well as having a notetaker.

Your **honest and open feedback** is essential to this process. We want to know what you like, what you don’t like, and how cancer-related programs might be improved. There are no right or wrong answers, and keep in mind that there will be differing points of view. This is an open discussion, and we are interested in all of your related comments.

Before we begin, I want to review the **agenda** for our session today.

**[Welcome slide – share screen, PPT consisting of agenda from p. 1 of FG guide]**

Do you have any questions before we begin?

**[Respond to any questions]**

**[Start Zoom Recording. Co-facilitator & Notetaker should stop their video & mute themselves.]**

Great. Let’s start with introductions. As I call out your name, please identify your role as a cancer patient, survivor, and/or cancer caregiver. **[If patients are from more than 1 cancer center, also ask them to identify the cancer center they primarily use for services].**

**[Notetaker – keep track of attendance for gift card incentives]**

## B. CANCER-RELATED COMMUNITY HEALTH STATUS AND NEEDS [~40 minutes]

**Facilitator note:** Use time during polling to check time points & adjust speed as needed to stay on schedule

**Facilitator dialogue:** To begin the discussion, we have provided some general polling questions about overall cancer-related community health status.

1. Overall, how would you rate the health status of your community? **[Facilitator note: Prompt participants to think about their community]** – Would you say, in general, that your community's health status is **[POLL VOTING]:**
  - Excellent
  - Very Good
  - Good
  - Fair
  - Poor

**Facilitator dialogue:** Here are the results of our first poll.

**[Facilitator note: Show Zoom Poll results]**

**Facilitator dialogue:** Our next question is also a poll.

**Facilitator note:** Show the 2nd poll question now.

2. Overall, how important is cancer (of any type) as a health concern in your community? **[Facilitator note: Prompt participants to think about their community]** – Would you say, in general, that cancer is **[POLL VOTING]:**
  - Very important
  - Moderately important
  - Slightly important
  - Not at all important

**Facilitator dialogue:** Here are the poll results:

**[Facilitator note: Show Zoom Poll results]**

**Facilitator dialogue:** *Now that we have a general sense of cancer in your community, we would like to know more about your experiences with cancer diagnosis. These questions are open dialogue but we want to hear from everyone, so please limit your comments to 1-2 minutes per person.*

3. How did you or your loved one find out you or your loved one had cancer?  
**[OPEN-ENDED DISCUSSION]**
  - *PROMPT:* Where did you go? Where would you tell others to go? How do individuals in your community learn about and access services related to cancer diagnosis?
  - *PROBE:* Which of these services were the most important to you? Which services would you be willing to travel outside of your immediate community for?
  - *PROMPT:* What challenges did you have to get a diagnosis?

- *PROMPT:* How long did it take you to find out? Did you have to wait long to get the results or to see a specialist?
- *PROMPT:* What do you think would improve cancer diagnosis in this community?
- *PROMPT:* If you had a magic wand and could instantly fix things, how would you improve cancer diagnosis services in your community?

**Facilitator dialogue:** *Now we would like to hear your thoughts and experiences about cancer treatment. Again, please remember to limit your comments to 1-2 minutes so we can hear from everyone.*

4. What positive experiences or challenges did you have with cancer treatment?

**[OPEN-ENDED DISCUSSION]**

- *PROMPT:* Where did you go? Were you able to receive treatment in your own community or did you travel elsewhere for treatment?
- *PROBE:* What factors did you consider when making treatment decisions?
- *PROMPT:* Where would you tell others to go?
- *PROMPT:* How do individuals in your community learn about and access services related to cancer treatment?
- *PROBE:* Which of these services were the most important to you? Which services would you be willing to travel outside of your immediate community to receive?
- *PROMPT:* What challenges did you have in accessing treatment services?
- *PROMPT:* After your diagnosis, how long did it take you to start treatment?
- *PROMPT:* What do you think would improve cancer care in this community?
- *PROMPT:* If you had a magic wand and could instantly fix things, how would you improve cancer treatment services in your community?

**TIME PERMITTING**

**Facilitator dialogue:** *Now we would like to hear your thoughts and experiences about accessing cancer information. This is another poll question, and you may need to scroll down to see all the response options.*

5. Think back to the time before your cancer diagnosis. Where did you get information about cancer or cancer prevention? **[POLL VOTING, mark all that apply]:**
  - Physician or healthcare provider
  - Family member or friend
  - Social Media (Facebook, Twitter, Instagram...)
  - Internet (WebMD, search engine, online health risk assessment, etc)
  - TV
  - Radio
  - Newspaper, magazine, or journal article
  - Telephone advice line
  - Health fair or community cancer screening event
  - Fliers, brochures, or pamphlets

**Facilitator dialogue:** *Here are the poll results:*

**[Facilitator note: Show Zoom Poll results]**

**Facilitator dialogue:** *Now we have another poll question about information sources. Again, you may need to scroll down to see all the responses.*

6. Of the various sources of information available about cancer and cancer prevention, which source do you trust the most? [POLL VOTING, select 1]:
  - Physician or healthcare provider
  - Family member or friend
  - Social Media (Facebook, Twitter, Instagram...)
  - Internet (WebMD, search engine, online health risk assessment, etc)
  - TV
  - Radio
  - Newspaper, magazine, or journal article
  - Telephone advice line
  - Health fair or community cancer screening event
  - Fliers, brochures, or pamphlets

**Facilitator dialogue:** *Here are the poll results:*

**[Facilitator note: Show Zoom Poll results]**

- *PROMPT:* For internet sources, how do you find information about cancer? Are there specific sites that you visit? What search terms do you use?

## **TIME PERMITTING**

**Facilitator dialogue:** *We have a few minutes before we need to move to the next topic, so we would like to learn more about information or educational resources. We would like to hear from as many of you as possible.*

7. When you were diagnosed or began treatment, where did you go to learn about cancer diagnosis and treatment? **[OPEN-ENDED DISCUSSION]**
  - *PROMPT:* What cancer education resources were you aware of?
  - *PROMPT:* Do you know of places in your community that provide education about cancer and cancer-related services?
  - *PROMPT:* Of those places, or other places in your community, where do you think you and others would feel most comfortable going to get information?
  - *PROMPT:* What got in the way of you getting the information you needed?
  - *PROMPT:* What help you would have liked to receive that was missing?

## C. FOCUS ON COLORECTAL CANCER [~25 minutes]

**Facilitator Introduction to Topic:** *Now that we have discussed cancer topics in general, we are going to focus on issues related to colorectal cancer.*

1. Screening for colorectal cancer is encouraged as part of a general wellness plan. Colorectal cancer screening is recommended for individuals aged 50-75, although some groups recommend that screening begin at age 45. However, not everyone is screened when recommended. In Nebraska, about 69% of older adults are up-to-date with recommended colorectal cancer screening, but only \_\_\_% of [insert subpopulation of interest] are up-to-date with recommended screening. Why do you think this is?

### [OPEN-ENDED DISCUSSION]

#### **QuickFacts CRC Screening in Nebraska infographic based on 2016 BRFSS:**

Overall age-eligible being current = 65.5%

White = 66.8%

AA = 62.4%

Hispanic = 45.4%

AI/AN = 56%

State Cancer Profile, 2018

Overall age-eligible current = 68.7%

- *PROMPT:* If you are 45 or older, how often do you get screened for colorectal cancer? If you do not get screened, what would help you to get screened or screened more often?
  - *PROMPT:* How do people in your community get screened for colorectal cancer?
  - *PROBE:* Who or what influences your decision to get screened for colorectal cancer?
  - *PROMPT:* Tell us about positive experiences you've had with colorectal cancer screening?
2. There are several different colorectal cancer screening methods available. Stool [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? **[POLL VOTING, mark all that apply]:**
    - Fecal occult blood test (FOBT)
    - Fecal immunochemical test (FIT)
    - FIT-DNA
    - Sigmoidoscopy
    - Colonoscopy
    - None of the above

**[Facilitator note: Show Zoom Poll results]**

**Facilitator:** *The next few questions will ask about your sources of colorectal cancer information, and where or how you would like to receive cancer information in the future.*

3. Where do you get information about colorectal cancer screening?
  - *PROBE:* If a healthcare clinic is mentioned, probe for more specific information about who within the organization provided the information (e.g., doctor, nurse, front desk).
  - *PROBE:* Newspapers? Magazines? TV shows or programs?
  - *PROBE:* Have you looked for information online about colorectal cancer?
  - *PROBE:* What types of websites have you visited?
  - *PROBE:* How would you like to receive information about colorectal cancer?
  - *PROBE:* What would you have liked to receive more information support regarding?

#### **TIME PERMITTING**

4. If you were in charge of getting the word out about colorectal cancer, what would you do to make sure everyone knew the topic?
  - *PROMPT:* What groups, organizations, people, or businesses in your community might help spread the word?
  - *PROBE:* Should we work with churches? Local radio stations? Schools?
  - *PROMPT:* What groups of people might be the hardest to reach when spreading the word?
  - *PROBE:* For instance, do you think people who live in certain areas or hold certain beliefs might be harder to reach?
  - *PROMPT:* How do you suggest we reach these populations?
  - *PROBE:* Are there certain groups, people, or organizations that you think could help?
5. What services, programs, and/or resources would be helpful to you or the community regarding colorectal cancer? **[OPEN-ENDED DISCUSSION]**
  - *PROBE:* What kind of support would be most helpful to you?
  - *PROBE:* How can the cancer center be better engaged with the community?

## **D. WRAP-UP [~5 minutes]**

**Facilitator dialogue:** *As we near the conclusion of our focus group, on behalf of myself and my colleagues, we want to thank you for your time and participation. We're going to end with a few more general questions to make sure we haven't missed anything.*

1. What are some of the challenges, barriers, and needs people in your community face when dealing with cancer? **[OPEN-ENDED DISCUSSION; use probes if needed]**
  - *PROBE:* How much of a problem do you think this [challenge, barrier, or need] is that people face when dealing with cancer?
2. Is there anything that we missed that you want to share with us about cancer needs or resources in your community? **[OPEN-ENDED DISCUSSION]**

**Facilitator dialogue:** *This concludes our focus group. Again, we want to thank you for your time and participation. If you have any questions or concerns about this focus group or the statewide needs assessment, please feel free to reach out to Dr. Watanabe-Galloway. Her email was provided on the recruitment materials and is provided in the "Chat" box here in Zoom for your reference.*

*Within the next week, we will be mailing a gift card to you to thank you for your participation. If you have not received the gift card within the next 2 weeks, please reach out to us about it.*

## APPENDIX B

# Listening Session Facilitation Guide Native American Communities

**PURPOSE:** Gather community input and feedback on cancer-related community health status and health needs, access to services, and potential solutions.

Feedback will be used to report results in the Buffett Cancer Center's 2021 Cancer Community Health Needs Assessment and shared with Nebraska Cancer Coalition (NC2)'s statewide partners.

**This focus group is designed to last approximately 75 minutes and is broken into 4 sections:**

- A. Introductions [5 minutes]
- B. Cancer-related Community Health [40 minutes]
- C. Focus on Colorectal Cancer [25 minutes]
- D. Wrap-up [5 minutes]

**This guide assists UNMC researchers with the facilitation of the Cancer Community Health Listening Session.**

**Use this document for guidance, adjusting according to the audience (i.e., going into more explanation or depth, modifying words, etc.) when necessary.**

**Note:** Due to the current COVID pandemic situation, all focus groups are planned to be held virtually (Zoom or a similar distance conferencing platform).

## **Key Definitions**

**Open Ended Discussion:** Open dialogue discussion facilitated by the research personnel. Participant input is recorded by the research personnel acting as the notetaker during the session.

## **Personnel Needed**

- **Facilitator** – conduct the discussion.
- **Notetaker** – record notes about the session, including noting facial expressions and non-verbal clues (e.g., head nodding or shaking to indicate agreement/disagreement with what someone else is saying) as well as recording main points and relevant quotations from the open-ended discussions. Notes serve as back-up documentation should there be any problems with the audio/video recording.

## **Equipment/Set Up**

- **Room set-up:** Room should be large enough to comfortably accommodate the number of registered participants and research personnel. There should be 1 chair per planned participant, arranged in a circle.
- **Audio recorder (2):** We will use two recorders in case one fails.
- **Attendance sheet**
- **Gift cards**
- **Snack table**
- **Survey forms**
- **Pencils or pens**

## A. INTRODUCTION [~5 minutes]

### Focus Group Process – Facilitator’s script:

Welcome to the *[insert name – Urban Indian Program / Tribe]* listening session. Thank you for taking the time to join us to discuss cancer needs in your community. Your involvement is important and we value what each of you brings to the needs assessment process. My name is **[Facilitator Name]**, and I will be facilitating this listening session. Assisting me is *[Note Taker Name]*, who will serve as notetaker.

We are conducting listening sessions as part of a collaboration between the Fred & Pamela Buffett Cancer Center at UNMC and the Nebraska Cancer Coalition to conduct a statewide 2021 Cancer Community Health Needs Assessment. As part of this process, we are meeting with small groups of cancer patients and survivors and their caregivers from various communities throughout the state. These **listening sessions** are a way for us to gain direct knowledge of your experiences with cancer services in your community.

All personal information gathered for the listening sessions will remain anonymous. We will develop a report for the specific Urban Indian Program and tribes that helped us with the participant recruitment. Summarized aggregated results will be shared with state and local health departments, local cancer centers, and other partners throughout the state working to improve cancer-related services. The report will also be available to the public.

We may include short quotes in the report to provide examples, but **we will not share information about who participated in the listening sessions and your name will never be associated with the results.** We do ask that comments remain **confidential.** This means that comments shared during today’s listening session should not be discussed outside of the session. While it is important that we identify what services are available in your community and what organizations provide services, we ask that you **do not mention the names** of specific doctors.

We want to make sure we accurately report your comments and ideas. This is why we will be **recording** this session as well as having a notetaker.

Your **honest and open feedback** is essential to this process. We want to know what you like, what you don’t like, and how cancer-related programs might be improved. There are no right or wrong answers, and keep in mind that there will be differing points of view. This is an open discussion, and we are interested in all of your related comments.

Before we begin, I want to review the **agenda** for our session today. We will first discuss about the cancer care experience and move on to talk about colorectal cancer screening.

Do you have any questions before we begin?

**[Respond to any questions]**

**[Start audio Recordings]**

Great. Let’s start with introductions. We’ll go around the circle starting on my right. Please identify your role as a cancer patient, survivor, and/or cancer caregiver. Please also identify which cancer center was primarily used for services.

## **B. CANCER-RELATED COMMUNITY HEALTH STATUS AND NEEDS**

**[~40 minutes]**

**Facilitator dialogue:** *You have already been asked to fill out a question about sources of cancer information. I'll read the list of sources. I would like to know a little more about these sources. For example, if you use the internet, how do you find information? What sites do you visit?*

- Physician or healthcare provider
- Family member
- Friend
- Social Media (Facebook, Twitter, Instagram...)
- Internet (WebMD, search engine, online health risk assessment, etc)
- TV
- Radio
- Newspaper, magazine, or journal article
- Telephone advice line
- Health fair or community cancer screening event
- Fliers, brochures, or pamphlets

**Facilitator dialogue:** *Now that we have a general sense of cancer information in your community, we would like to know more about your experiences with cancer diagnosis. We will talk about cancer treatment in a few minutes. These questions are open dialogue but we want to hear from everyone, so please limit your comments to 1-2 minutes per person.*

1. How did you or your loved one find out you or your loved one had cancer? What type of cancer? **[OPEN-ENDED DISCUSSION]**
  - *PROMPT:* Where did you go? Where would you tell others to go? How do individuals in your community learn about and access services related to cancer diagnosis?
  - *PROBE:* Which of these services were the most important to you? Which services would you be willing to travel outside of your immediate community for?
  - *PROMPT:* How long did it take you to find out? Did you have to wait long to get the results or to see a specialist?
  - *PROMPT:* What challenges did you have to get a diagnosis?
  - *PROMPT:* What do you think would improve cancer diagnosis in this community?

**Facilitator dialogue:** *Now we would like to hear your thoughts and experiences about cancer treatment. Again, please remember to limit your comments to 1-2 minutes so we can hear from everyone.*

2. What positive experiences or challenges did you have with cancer treatment? **[OPEN-ENDED DISCUSSION]**
  - *PROMPT:* Where did you go? Were you able to receive treatment in your own community or did you travel elsewhere for treatment?
  - *PROBE:* What factors did you consider when making treatment decisions?
  - *PROMPT:* Where would you tell others to go?

- *PROMPT:* How do individuals in your community learn about and access services related to cancer treatment?
- *PROBE:* Which of these services were the most important to you? Which services would you be willing to travel outside of your immediate community to receive?
- *PROMPT:* What challenges did you have in accessing treatment services?
- *PROMPT:* After your diagnosis, how long did it take you to start treatment?
- *PROMPT:* What do you think would improve cancer care in this community?

## **TIME PERMITTING**

**Facilitator dialogue:** *We have a few minutes before we need to move to the next topic, so we would like to learn more about information or educational resources. We would like to hear from as many of you as possible.*

3. When you were diagnosed or began treatment, where did you go to learn about cancer diagnosis and treatment? **[OPEN-ENDED DISCUSSION]**
  - *PROMPT:* What cancer education resources were you aware of?
  - *PROMPT:* Do you know of places in your community that provide education about cancer and cancer-related services?
  - *PROMPT:* Of those places, or other places in your community, where do you think you and others would feel most comfortable going to get information?
  - *PROMPT:* What got in the way of you getting the information you needed?
  - *PROMPT:* What help you would have liked to receive that was missing?

## C. FOCUS ON COLORECTAL CANCER [~25 minutes]

**Facilitator Introduction to Topic:** *Now that we have discussed cancer topics in general, we are going to focus on issues related to colorectal cancer.*

1. Screening for colorectal cancer is encouraged as part of a general wellness plan. Colorectal cancer screening is recommended for individuals aged 50-75, although some groups recommend that screening begin at age 45. However, not everyone is screened when recommended. In Nebraska, about 69% of older adults are up-to-date with recommended colorectal cancer screening, but only 56% of Native American/Alaska Natives are up-to-date with recommended screening. Why do you think this is?

### [OPEN-ENDED DISCUSSION]

- *PROMPT:* If you are 45 or older, how often do you get screened for colorectal cancer? If you do not get screened, what would help you to get screened or screened more often?
- *PROMPT:* How do people in your community get screened for colorectal cancer?
- *PROBE:* Who or what influences your decision to get screened for colorectal cancer?
- *PROMPT:* Tell us about your experiences with colorectal cancer screening?

**Facilitator:** *The next few questions will ask about your sources of colorectal cancer information, and where or how you would like to receive cancer information in the future.*

2. Where do you get information about colorectal cancer screening?
  - *PROBE:* If a healthcare clinic is mentioned, probe for more specific information about who within the organization provided the information (e.g., doctor, nurse, front desk).
  - *PROBE:* Newspapers? Magazines? TV shows or programs?
  - *PROBE:* Have you looked for information online about colorectal cancer?
  - *PROBE:* What types of websites have you visited?
  - *PROBE:* How would you like to receive information about colorectal cancer?
  - *PROBE:* What would you have liked to receive more information support regarding?

### TIME PERMITTING

3. If you were in charge of getting the word out about colorectal cancer, what would you do to make sure everyone knew the topic?
  - *PROMPT:* What groups, organizations, people, or businesses in your community might help spread the word?
  - *PROBE:* Should we work with churches? Local radio stations? Schools?
  - *PROMPT:* What groups of people might be the hardest to reach when spreading the word?
  - *PROBE:* For instance, do you think people who live in certain areas or hold certain beliefs might be harder to reach?
  - *PROMPT:* How do you suggest we reach these populations?
  - *PROBE:* Are there certain groups, people, or organizations that you think could help?



4. What services, programs, and/or resources would be helpful to you or the community regarding colorectal cancer? **[OPEN-ENDED DISCUSSION]**

- *PROBE*: What kind of support would be most helpful to you?
- *PROBE*: How can the cancer center be better engaged with the community?

## **D. WRAP-UP [~5 minutes]**

**Facilitator dialogue:** *As we near the conclusion of our listening session, on behalf of myself and my colleagues, we want to thank you for your time and participation. We're going to end with a few more general questions to make sure we haven't missed anything.*

1. 1. What are some of the challenges, barriers, and needs people in your community face when dealing with cancer? **[OPEN-ENDED DISCUSSION; use probe if needed]**
  - *PROBE:* How much of a problem do you think this [challenge, barrier, or need] is that people face when dealing with cancer?
2. Is there anything that we missed that you want to share with us about cancer needs or resources in your community? **[OPEN-ENDED DISCUSSION]**

**Facilitator dialogue:** *This concludes our listening session. Again, we want to thank you for your time and participation. If you have any questions or concerns about this listening session or the statewide needs assessment, please feel free to reach out to Dr. Watanabe-Galloway. Her email was provided on the recruitment material.*

*Please make sure you've completed the questionnaire and that you sign on the attendance sheet as you pick up your gift card.*