

# Keck School of Medicine of USC

April 6, 2023

Dear community member,

My name is Cynthia Begay, and I am a citizen of the Navajo Nation and Hopi Tribal member. I am a doctoral candidate at the University of Southern California (USC) Keck School of Medicine. I am working alongside my mentor Claradina Soto (Navajo/Pueblo), PhD, MPH on a cancer control research study with the Toiyabe Indian Health Project (TIHP) to gather perspectives from cancer survivors, clinic medical staff, and community members.

You are invited to participate in this study as a community member to provide your perspectives on cancer risks, cancer screening tests and results, and availability and access to cancer prevention and treatment. This virtual interview will last approximately 45-minutes and will be facilitated by myself and another team member. We will provide a \$30 gift card for your time. This study has been approved by the USC institutional review board.

The interview guide and questions are included along with this letter to provide more information on the interview and topics that will be addressed. Participating in this study is completely voluntary and question(s) can be skipped at any time.

Thank you so much for your help with our study as it is very important information to improve cancer health disparities in our communities! If you are interested in participating or have any questions, please contact me at 661-706-1651 or by email to [cbegay@usc.edu](mailto:cbegay@usc.edu).

Sincerely,



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**Rural Cancer Control Research Needs Assessment**  
**for American Indian Populations**  
**Adult Tribal Community Members Interview Guide**

Date:

Time interview started:

Time ended:

Name(s) of facilitator(s):

Name of note-taker:

Thank you for taking the time to speak with me today. Just to review what we are doing: The Rural Cancer Control Research Needs Assessment for American Indian Populations aims to learn about what makes it easier or harder for people to get cancer prevention care or cancer treatment in rural American Indian/Alaska Native communities in California. Our goal is to meet the needs of our Native community by identifying and developing innovative strategies to reduce the cancer burden.

Today we are here to talk with you about cancer screening and prevention behaviors, or what we call “cancer control practices.” We are interested in hearing your concerns, needs, and desires surrounding cancer prevention, treatment, and follow-up care in AIAN communities. We will be asking you about your awareness of cancer risks, attitudes towards screening tests and results, availability of and access to cancer prevention and treatment, and trust/distrust of medical systems and research. This information will help build a partnership and sustained collaboration with USC Norris Comprehensive Cancer Center (NCCC) and Toiyabe Indian Health Project (TIHP) to inform and develop future funding and resources for research and interventions to improve cancer control and prevention in this population.

Before we start, I want to let you know that your participation is completely voluntary. You do not need to answer anything that you do not wish to answer, and we can stop our discussion at any time.

To ensure that we capture all your comments and insights correctly, we would like to record this discussion. Once the recordings have been transcribed, they will be deleted. Any names or Tribal affiliations you use will be removed. Do we have your permission to record our discussion?

We also have *\*\*insert name here\*\** on the call to take notes just in case anything goes wrong with the recording. If you're ready, let's get started.

**1. WHEN AND HOW OFTEN DO YOU VISIT YOUR DOCTOR?**

**Probes (only use if information doesn't come out of broad question)**

- I. *Do you visit your doctor for regular check-ups? Why or why not?*
- II. *Do you only visit your doctor when you have symptoms of being ill?*

**2. AFTER VISITS TO YOUR DOCTOR, HOW LIKELY ARE YOU TO RETURN FOR TEST RESULTS?**

**Probes (only use if information doesn't come out of broad question)**

- I. *If you were given a diagnosis or course of treatment, has there been anything that prevented you from following a doctor's instructions?*

**3. WHAT ARE SOME REASONS THAT MIGHT PREVENT YOU OR SOMEONE IN YOUR COMMUNITY FROM SEEKING CANCER SCREENING OR TREATMENT SERVICES RELATED TO CANCER (e.g., mammogram, pap smear, fecal occult blood test, prostate-specific antigen blood test)?**

**Probes (only use if information doesn't come out of broad question)**

- I. *Are there any cultural attitudes or beliefs that may prevent someone from seeking screenings or treatment?*
- II. *Are there any cultural attitudes or beliefs that might encourage you or someone in your community to seek prevention or treatment services?*

**Questions to assess knowledge, attitudes, and behavioral beliefs surrounding cancer, screenings, signs/symptoms, and risk (30 minutes)**

*You may have heard of cancer prevention and control practices such as screening, early diagnosis, diagnosis, treatment, and palliative care (specialized medical care for people living with a serious illness). We will be asking about your attitudes, behaviors, and beliefs surrounding prevention and control strategies.*

**4. WHEN YOU THINK OF CANCER, WHAT FEELINGS, THOUGHTS, AND BELIEFS COME TO MIND?**

**Probes (only use if information doesn't come out of broad question)**

- I. *What are common beliefs about cancer in your community?*

**5. WHERE DO YOU OR PEOPLE IN YOUR COMMUNITY LEARN ABOUT CANCER AND SCREENING?**

**Probes (only use if information doesn't come out of broad question)**

- I. What types of cancer screenings do you know about?*
- II. How important do you feel screening is for preventing cancer?*
- III. Are you aware of when/how often you should be screened for cancer?*
- IV. What are some strategies to increase knowledge about cancer and screening in the community?*
- V. When visiting your doctor, do they inform you about cancer screenings? Which cancers?*
- VI. Do you feel comfortable asking your doctor about cancer screening?*

**6. WHICH TYPES OF CANCER DO YOU THINK ARE MOST COMMON IN YOUR NATIVE COMMUNITY?**

**7. DO YOU THINK THAT CANCER IS PREVENTABLE? WHY OR WHY NOT?**

**Probes (only use if information doesn't come out of broad question)**

- I. If yes, what are some ways that cancer can be prevented?*
- II. Which cancers do you feel are the least preventable?*

**8. DO YOU BELIEVE THAT EARLY DETECTION OF CANCER INCREASES ONE'S CHANCE OF SURVIVAL? WHY OR WHY NOT?**

**Questions to assess cancer risk and resilience**

*This section will ask questions about possible risk factors for cancer that you are aware of as well as individual, family, and/or community strengths that might help during the healing process. A risk factor can be anything that increases a person's chance of getting cancer (e.g., older age, using tobacco, family history of cancer).*

**9. WHAT ARE SOME RISK FACTORS THAT YOU THINK MIGHT CONTRIBUTE TO THE DEVELOPMENT OF CANCER IN YOUR NATIVE COMMUNITY?**

**Probes (only use if information doesn't come out of broad question)**

- I. What is the best way to increase someone's chance for survival if they are at risk for cancer?*
- II. What are some behaviors that might increase one's risk of cancer? (e.g., diet alcohol use, tobacco use, limited physical activity)*
- III. What are some or genetic or environmental factors that may increase one's risk of getting cancer (e.g., second-hand smoke, occupation, family history)?*

**10. WHAT ROLE (IF ANY) DO YOU THINK NATIVE CULTURE MIGHT PLAY DURING A PERSON'S HEALING PROCESS?**

- I. Do you feel that spirituality can help someone during their healing process?*
- II. What are some traditional practices or ceremonies available to help with the healing process?*
- III. Do you believe that eating traditionally harvested indigenous foods reduces one's risk for developing cancer?*
- IV. Do you or people you know use traditional healing/medicine during the course cancer of treatment? Please provide some examples.*
- V. Do you or members of your community seek services from traditional healers? If yes, how easy is it to gain access to them?*

**Questions to assess health care access, availability, quality of services, and trust/distrust of medical systems and research**

**11. HOW DO YOU OR PEOPLE IN YOUR LOCAL COMMUNITY FIND OUT ABOUT HEALTH CARE SERVICES?**

**Probes (only use if information doesn't come out of broad question)**

- I. Specifically, what are ways that you might find out about cancer screening and treatment?*

**12. WHAT KINDS OF SERVICES ARE AVAILABLE IN YOUR COMMUNITY FOR PEOPLE WHO ARE SEEKING CANCER SCREENING, TREATMENT, OR FOLLOW-UP CARE?**

**Probes (only use if information doesn't come out of broad question)**

- I. What are your impressions about the quality of these services?*
- II. Are there traditional activities or services to help those with cancer diagnoses?*
- III. Are these available services being used by your community?*

**13. DO YOU USUALLY TRUST DOCTORS AND MEDICAL PROVIDERS?**

**Probes (only use if information doesn't come out of broad question)**

- I. In the past, have you put off getting medical care when you had health problems because you did not trust doctors or nurses? Why or why not?*
- II. Do you feel comfortable talking to doctors when you have a health problem? Why or why not?*

#### **14. WHAT IS YOUR PERCEPTION OF HEALTH-RELATED RESEARCH?**

**Probes (only use if information doesn't come out of broad question)**

- I. If you have been involved with research before, what was your experience like?
- II. If given the opportunity, would you be willing to participate in clinical trials related to cancer treatment? Why or why not?

#### **15. ARE CANCER CARE SERVICES CULTURALLY-SENSITIVE FOR NATIVES IN THE COMMUNITY?**

**Probes: (only use if information doesn't come out of broad question)**

- I. *Do services draw on Native cultural values and traditions? Does this matter?*
- II. *Would you consider the services available to your community to be culturally relevant?*
- III. *Are there culturally tailored cancer prevention educational materials available?*
- IV. *How would services need to change to be appropriate for Native people in your community?*

#### **Questions regarding the impact of COVID:**

*This section will ask questions about how COVID-19 has impacted your life.*

#### **16. Has COVID-19 impacted your ability to access medical services? For example, not being able to go to clinics due to closures, fear of being exposed to COVID-19, loss of insurance coverage due to unemployment, concerns about finances to pay for services.**

- I. *Have you delayed getting recommended cancer screening tests due to COVID-19?*

#### **17. What do you think would be most helpful in addressing COVID concerns in your community?**

Wrap-up Question

#### **18. WHAT DO YOU THINK WOULD BE MOST HELPFUL TO REDUCE THE BURDEN OF CANCER IN YOUR COMMUNITY?**