

# **Consent Overview and Focus Group Guide**

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# Importance of Consent

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"Before I write my name on the board, I'll need to know how you're planning to use that data."

# Importance of Consent



- Consent forms are required for all research and many evaluation activities, including focus groups, surveys, and key informant interviews
- Consent is necessary in all forms of formal data gathering.
- Project participants need to sign a consent form (18+ years old). Consent forms are to protect your organization and the individual from harm.
- Consent informs the participant what they will be a part of.

# What is consent?

Informs participant about the project.

Shares the risks and benefits of participating.

Gives the necessary information for the individual to voluntarily decide whether to participate or not.

Allows individuals to ask questions before committing.

# Consent Form



## **Parent Consent Form for Community Health Assessment Survey** (For parent or guardian of survey participants ages 13 to 17)

Karuk Tribal staff, the California Rural Indian Health Board, Inc., and the California Tribal Epidemiology Center are inviting youth to take a short survey about health experiences and opinions on new programs. For youth to participate, you as a legal guardian/parent must consent to have your son or daughter participate in this survey. This is being done as part of our Community Health Assessment (CHA). This will help us find ways to improve the health of local youth. Before you decide to participate, please read this form carefully.

### **What is the survey about?**

The survey will ask you for your son's or daughter's opinions on health problems in your community. It will also ask what programs your child might want to take part in. It will take your child about 15 to 30 minutes to complete this survey.

### **What if I don't want my child to take part in the survey?**

It's fine if you don't consent to have your son or daughter participate. They can also choose to not answer any questions, or to stop the survey at any time.

### **Will taking part in the survey cost me anything? Will I be paid?**

Any Tribal services they currently receive will not be negatively impacted by their participation. Taking part in the survey will not cost them anything. Your child will be given a \$25 gift card for their participation.

**What are the benefits of participating in this project?** We expect this project will help improve the health of local youth in your community.

**What are the risks associated with participating in this project?** There is minimal risk associated with the project. When discussing health issues with a high-risk or vulnerable population, there is always the possibility that an individual will be triggered (positively or negatively) regarding their health in some way. Participants may experience mild discomfort in response to being asked personal questions related to their health, particularly relating to stigmatizing topics such as substance misuse. You and your son/daughter are being provided with contact information for individuals that can provide assistance if this is the case.

### **How will my child's information be protected?**

Your son's or daughter's responses will not be connected to their name at all, so no one will know how he/she responded to the survey.

### **What happens with the results?**

Results will be included in a final report. Karuk Tribal staff will use the results to plan future projects for youth on the reservation. Participants will never be identified in any reports, presentations, or papers from this project.

# Youth Assent Form



## Youth Assent Form for Community Health Assessment Survey (For survey participants ages 13 to 17)

Karuk Tribal staff, the California Rural Indian Health Board, Inc., and the California Tribal Epidemiology Center Tribal staff invite youth to take a short survey about health experiences and opinions on new programs. To participate, you must be age 13 or older, be Native American, and is or have been serviced by the Karuk Tribe. This survey is being collected as part of our Community Health Assessment (CHA). This will help us find ways to improve the health of local youth. Before you decide to participate, please read this form carefully.

### What is the survey about?

The survey will ask you for your opinions on problems with health in your community. It will also ask what programs you might want to take part in. It will take about 10 to 15 minutes to complete.

### What if I don't want to take part in the survey?

It's fine if you don't want to be included. You may choose not to answer any questions or stop the survey at any time.

### Will taking part in the survey cost me anything? Will I be paid?

Any Tribal services you currently receive will not be negatively impacted by your participation. Taking part in the survey will not cost anything. You will receive a \$25 gift card for your participation.

**What are the benefits of participating in this project?** We expect this project will help improve the health of local youth in your community.

**What are the risks associated with participating in this project?** There is minimal risk associated with the project. However, when discussing health issues, there is always the possibility that an individual will be triggered negatively regarding their health in some way. You are being provided with contact information for individuals that can provide assistance if this is the case.

### How will my information be protected?

Your responses will not be connected to your name at all, so no one will know how you respond to the survey.

### What happens with the results?

Results will be included in a final report. Karuk Tribal staff will use the results to improve health services provided by the Tribe. Participants will never be identified in any reports, presentations, or papers from this project.

### What should I do if I would like more information about this before I decide to take part?

Please contact Nichole Campbell, a Karuk staff member, at [ncampbell@karuk.us](mailto:ncampbell@karuk.us). You can also email Omara Farooq ([ofarooq@crihb.org](mailto:ofarooq@crihb.org)) at the California Rural Indian Health Board, Inc. Additionally, if you wish to inquire about further Tribal behavioral health services or be linked to Tribal counselors

# Focus Group Consent Collection

- Distribute consent forms and discuss at start of focus group.
- If conducting a youth focus group, get all parental consent beforehand and youth assent as a group.
- Answer any questions about consent.

# Internal Review Board (IRB)

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- Depending on your organization, you may have to go through this process, or one similar.





# Focus Groups

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# Focus Groups

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- Provides a forum for community experiences and community specific insight.
- Allows people to express themselves in a forum so that their feedback is heard.
- Helps people feel involved.





# Focus Group Overview

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- Focus groups are made up of community members, stake holders, community leaders, health professionals, administrative staff, etc.
- 4 to 10 participants:
  - Group size matters
  - If you want to analyze differences between age groups then separate out participants by age, for example: (18 to 35 years) and (36+ years old)
  - What is the topic you want to explore? Health.
- Important to have a record of what people say; take notes and digitally record the session.
- Consent is required.



# Tips for Recruitment Step-by-Step

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- Recruit **adult** participants using community focused advertising approaches:
  - Hanging flyers:
    - Tribal offices
    - Tribal Health Programs/Clinics
  - Word-of-mouth promotion:
    - Any/all adults you meet through work
    - Key stakeholders or large families within the community
  - Post flyer on Health Program/Clinic website, social media
  - Tribal newsletter

# Focus Group Recruitment



**Youth Tribal  
Community Health  
Assessment (CHA)**

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***We need your voice!***

The Karuk Tribe and the California Rural Indian Health Board, Inc./California Tribal Epidemiology Center is seeking individuals to take part in **focus group sessions** and **key informant interviews** to be held on \_\_\_\_\_.

Participants will engage in a lively discussion regarding various health and Tribal topics/issues. Voice your views, concerns, and comments on important health matters. **Space is limited, reserve your spot today.**

Individuals will receive a \$25 gift card for their participation.

**Eligibility**  
You must be:

- American Indian/Alaska Native
- 13-17 years old
- Serviced or belonging to the Karuk Tribe

**Location:** \_\_\_\_\_

**Health Program:** \_\_\_\_\_

**Health Program Address:** \_\_\_\_\_

**Time of Focus Group:** \_\_\_\_\_

**Time of Key-Informant Interview:** \_\_\_\_\_

**Interested?**

To participate and sign up or for more information, call or email by: \_\_\_\_\_

## Important Points:

- Add your program logo
- Update contact person information for this project
- Provide information on the focus group
  - Location
  - Date
  - Time

A row of five wooden figures, one red and four white, on a light blue background. The red figure is in the center, and the white figures are on either side. The background is a light blue gradient with a white circular shape on the left side.

# Focus Group Recruitment

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- It can be hard for 4 to 10 people to commit to 1 hour to 2 hours.
  - Consider the weekends or in the evenings.
- Think of people who are strongly engaged in the topic.
- Incentivize participation when possible.
- Make sure there is large representation in the population of the focus group.
- You can hold a focus group for adults ages 18+ to 35 years of age, 35+ years of age.
  - Try to not have an individual that all focus group participants will refer to when answering questions.



# Focus Group Questions

## YOUTH FOCUS GROUP SCRIPT AND QUESTIONS

**Instructions:** This form is to be used as a script and guidelines for Focus groups sessions. Text in italics should be spoken aloud to the group and may be paraphrased. Text in bold is instructional and meant to guide the process, not to be spoken aloud. The space at the bottom of this page should be filled in for project records. No participant names or identifying information should be written. Note: In a Key Informant Interview, the facilitator and note taker may be the same person.

*Hello, and thank you for taking the time to volunteer for this focus group. My name is \_\_\_\_\_, and I am a staff member of [insert name of Tribe or organization]. With me, I have \_\_\_\_\_. They will be taking notes during our conversation to make sure we accurately record what you say. We will not include your names in any of the notes, so what you say will be anonymous.*

*Today we are going to be talking about which health issues are most important to you or that you find most relevant to our community. Discussion topics will include health care access, quality of life, Tribal services/events, education, and Karuk culture. We are interested in your subjective opinions and any stories you feel comfortable sharing with us.*

*This focus group will probably take about an hour but may go as long as an hour and a half. You may choose not to answer a question at any time. We will be taking notes, but your voices will not be recorded. Please feel free to speak openly about any thoughts that come to you. Do we have permission to do this? Is the group ready to proceed? [Await response]*

*Great. Let's start with introductions. Note that your names will not be recorded or linked to any of your responses in any way. [Ask every person present to introduce themselves with their name and age if they are comfortable, noting that names will not be written down in the notes. They may use a fake name if they prefer. If you like, you may also ask for a fun fact or icebreaker question.]*

*We'd like to state a few ground rules for this discussion. [List rules of discussion, and if preferred, write them on a whiteboard. Rules may include "Respect everyone's opinions," "Do not interrupt," "Please do not discuss our conversation outside of this group," or other rules as determined by the facilitator and/or participants.]*

## QUESTIONS

*We will first begin by asking you questions about the community's health.*

1. In your opinion, what are the three most important health issues in the community? Examples of health issues include dental health, diabetes, mental health, substance use, etc.
2. In your opinion, what are the top three unhealthiest behaviors in the community? Examples of unhealthy behaviors include poor eating habits, little exercise, reckless driving, substance use, child or elder abuse, domestic violence, etc.

*Now we are going to ask you questions about the community's needs, Tribal services, and education.*

3. In your opinion, are general community needs being met?
  - a. If yes, please describe what needs are being met.
  - b. If no, please describe what needs still need to be addressed.
4. What Tribal services/events would you like to see the Tribe provide?
5. In terms of education, do you believe your educational needs are being met?
  - c. If no, what are some concerns regarding school and education do you have?

*Now we are going to ask you questions about Karuk culture and traditions.*

6. How well do you know your family history and Tribal customs/traditions?
7. Do you believe the Tribe is providing enough cultural events to community members?
  - d. If not, what cultural events/services would you like to see the Tribe provide?

*Lastly, we'll ask you a question regarding potential solutions you would recommend for the various health issues mentioned earlier.*

8. What are some solutions you can think of that could be explored further to resolve the three most important health issues mentioned earlier?

*Thank you for your responses today. They have been very insightful. We will continue working together within our communities and your help today is a step in the right direction.*

*If you have any questions about the community health assessment, please contact Alnino Guarino of the California Rural Indian Health Board, Inc. California Tribal Epidemiology Center at [aguarino@crihb.org](mailto:aguarino@crihb.org). If you require further assistance in terms of substance use services provided by the Tribe, contact Nichole Campbell at (530) 842-9200 ext. 6107.*

To be completed by facilitator or note taker for Focus Groups:

Facilitator name:

Note taker Name:



# Facilitators Role

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- Focus group questions
- Answers and follow-up
- Conversations
- Consensus (or not)



# Tips to Facilitate Focus Groups

- Ask open-ended questions
- Balance participation among participants
- Redirect conversations back to the questions
- Confirm with participants to understand statements
- Avoid taking sides on what has been said
- Focus group questions are a guide, you don't need to read the questions verbatim
- Don't challenge what participants say, they are being asked to come share their thoughts, knowledge, and experience in a SAFE space

# Focus Group Dynamics

- Moderate the process and move the conversation forward *while not creating a tense environment*.
- Do not offer personal opinions, rather allow participants to share their perspective.
  - You can share personal experience if related to the topic.
  - You should not come off as a subjective source of conversation.
  - Your role is to support the focus group process.

# Encourage Equal Participation

- Let everyone respond
- When needed, redirect people who are over taking conversations.
- Redirecting and reframing.

# Techniques for Redirection

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Use statements to give someone else a chance to talk; Examples:

“Thanks for your input. Does anyone else have anything to say or think the same/different?”

“I appreciate those statements/ideas and I think they give good feedback, lets bring this into a larger group discussion.”

“I think your response is a good topic to focus on as group, anyone else want to respond or have other thoughts?”

# Techniques for Redirection

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For a focus group to flow and fit within the timeframe redirect when it gets off topic.

Examples:

“I think this is an interesting point, but I am interested in knowing how it relates to the question.”

“Okay that is a great point.” (then ask a question relating to the focus group topic)

“Those are interesting points, but I want to get back to what we were talking about earlier, related to the question.”

# Focus Group Review

Consent forms are required

Parental consent and youth assent are required for youth focus groups

Focus group facilitators should be Health Program site staff or someone with experience.

With consent, you can digitally record the sessions

Have a note taker present (not the facilitator).

If your organization has time and capacity, do more than one focus group with varied representation (age, gender)

# Focus Group Session Steps Review

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**Step 1:** Once the group gets together, have everyone introduce themselves.

- Ice-breakers are optional.

**Step 2:** Tell everyone why they are there.

- Create facilitator-focus groups attendee relationship.

**Step 3:** Come up with rules and codes of conduct.

- Write on a flip chart, chalk board, white board, large sheet of paper on the wall, multiple regular sheets of paper taped to the wall, etc.

**Step 4:** Go over the process of the focus group.

- A *guided* conversation between participants.

**Step 5:** Ask if there are any clarifying questions, collect signed consents, and begin the focus group session.



Questions?

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# Thank You!

**If you have any questions, feel free to contact**

Project related questions –

Omara Farooq at [ofarooq@crihb.org](mailto:ofarooq@crihb.org)

California Rural Indian Health Board, Inc.

Techniques on conducting focus groups –

Kelley Milligan at [milligan.kell@gmail.com](mailto:milligan.kell@gmail.com)

Allyson Kelley & Associates, PLLC.