

Appendix E

AMERICAN INDIAN AND ALASKA NATIVE MEDICARE BENEFICIARIES' and FAMILY MEMBERS' FOCUS GROUP PROTOCOL

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I. Introduction

All information pertinent to the background and purpose of this study, the recruitment, contact and consent processes, and the logistics of the focus groups are provided in the Supporting Statement. The Focus Group Protocol contains the scripts and guide for the focus group involving AI/AN Medicare beneficiaries and family members.

II. Focus Group Scripts and Guide for Medicare Beneficiaries and Family Members

II.a. Introduction Script

Hello. My name is [insert name], from Kauffman and Associates, Inc. Kauffman & Associates, Inc., is an American Indian, woman-owned company based in Spokane, WA, and we have been contracted by the Centers for Medicare and Medicaid Services (CMS) to conduct a focus group with [insert American Indian or Alaska Native] Medicare Beneficiaries and their family members to understand the transportation barriers to health care.

A focus group is a guided discussion in which all participants are encouraged to respond to a series of broadly-worded questions on a particular topic. For example, today’s topic is about your experiences and perspectives on the effects of transportation issues on your access to the health care services you, your family members, and other members of your community need. We are very interested in hearing about what everyone in the group thinks and there are no wrong comments or responses. My role as moderator is to keep the discussion on focus and to make sure that nothing is misunderstood. It is not to engage in the discussion.

The purpose of today’s focus group is to help determine what kinds of transportation issues you, your family members and members of your communities face regarding access to health care, and what kind of effects transportation has on your/their health and ability to access needed health care.

We have invited you here today because of your experience with Medicare and the health care system. We value your opinions and encourage your honest and complete feedback in response to our questions, and we are thankful that you’ve agreed to come to this group to share your thoughts and perspectives. While we encourage your full participation to help us understand the transportation issues you and your communities face and how they affect your health and health care access, there will be no negative consequences for choosing not to respond to any questions during the course of this group.

[Introduction Continued]:

We want to remind you that everything you tell us today will be kept confidential. What is said here today will be aggregated based on the themes and topics we will be addressing. No names or identifying information will be associated with responses or appear on any presentation or report on this focus group. With your consent, we will be using a recording device to ensure that we preserve a complete rendering of what is shared in this group. Are there any questions? [Respond to any questions.]

II.b. Informed Consent Script

You received the Informed Consent form when you arrived. Everything I have just described is written on this Informed Consent form. We invite you to ask any questions you have regarding the Informed Consent process at this time.

[Moderator answers any questions].

If there are no other questions, we ask that you sign the form to express your written consent to participate in this focus group and place it in this manila envelope. I will sign this form as well. You will receive a copy of this statement for your records, which contains within it the contact information for the persons responsible for this project, should any questions arise after we leave here today.

[Moderator collects consent forms].

II.c. Demographic Survey Script

To begin, we are going to ask each of you to complete this short 7-item demographic survey. This survey contains only general demographic information that will be compiled to help us to characterize the responses shared. No responses will be matched to specific demographic information or personal characteristics.

[Distribute **CMS Beneficiary and Family Members Demographic Survey**. When participants have completed them, they will place them in a large manila envelope that will be sealed immediately.]

II.d. Focus Group Guide

To get us started, we'd like to have you briefly introduce yourself. I will begin. [Moderator will once again give her/his name. After the moderator has completed her/his introduction, (s)he will gesture to the person to her/his immediate left who will then be asked to introduce her or himself. When introductions have been completed, the note taker will turn on the recorder and the moderator will begin the focus group.]

1. *In your own words, describe the kinds of transportation barriers that exist for American Indian/ Alaska Native (AI/AN) Medicare beneficiaries in your community?*

[Prompts will be used to help participants clarify their responses, to encourage further depth, and to ensure that participants touch on all of the salient points addressed by the Question. To reduce the burden on the respondent, if they have already addressed issues covered by the prompts, those prompts will not be asked. Select from the following prompts as needed]:

- Please describe some of the things that contribute to these barriers?
- How do these barriers affect beneficiaries' health care?
- How do these barriers affect the health of the beneficiary?
- How do these barriers involve other people in the beneficiary's life?
- How do these barriers affect the beneficiary's ability to get referred health care to a specialist?

2. *How do transportation issues affect your or your family member's health care access?*

[Select one or more of the following prompts as needed]:

- What options are available to a Medicare beneficiary when s/he has transportation problems?
- What kinds of effects do transportation problems have on the beneficiary's health care?
- How do health care providers respond when a beneficiary has a transportation problem?
- What effects do transportation problems have on the beneficiary's immediate health?
- What is the long-term effect on the beneficiary's health?
- How, if at all, are these problems different for people with and without disabilities?

The following questions will address some specific aspects of transportation and related barriers facing AI/AN beneficiaries.

3. *Describe the different kinds of public transportation services available to beneficiaries to get to a doctor's appointment or to a medical procedure.*

[Select one or more of the following prompts as needed]:

- Describe how effectively the schedules of the public transportation services work with the scheduling of appointments?
- Why would a Medicare beneficiary in your community choose or not choose to use the public transportation available to them?
- When a Medicare beneficiary in your community decides to take public transportation, what does that person have to consider when planning this trip?
- Describe the experience and training of the drivers and their understanding of the health issues of the Medicare beneficiaries using public transportation.
- How does the experience and knowledge of the drivers affect the use of public transportation by Medicare beneficiaries?

4. *Describe the role of family members in providing transportation to Medicare beneficiaries.*

[Select one or more of the following prompts as needed]:

- What are the major reasons a family member accompanies/brings a beneficiary to the clinic or health center?
- How does this situation prevent or present a transportation problem?
- What are the challenges of this arrangement for the beneficiary and for the family member?
- What kind of support, financial or otherwise, is available to the beneficiary to use this method to get to appointments?

5. *Please describe the tribally-supported transportation services available to beneficiaries for getting to a doctors' appointment or a medical procedure.*

[Select one or more of the following prompts as needed]:

- What are some of the reasons Medicare beneficiaries use this system to get to medical appointments?
- What are some of the reasons Medicare beneficiaries might not use it?
- How accessible and convenient is tribal transportation for getting to your health center/clinic?
- How effective is the service for getting beneficiaries to appointments away from the local health center/clinic?
- Describe the experience and training of the drivers and their understanding of the health issues of beneficiaries using tribal transportation?

6. *How do road conditions or distance to the health center/clinic influence whether you keep or cancel a medical appointment?*

[Select one or more of the following prompts as needed]:

- In what way or ways does distance affect transportation options?
- What are the health concerns of a beneficiary who has to travel far to get to an appointment?
- How is distance a consideration when making a decision about health care?
- In what ways, if any, has a medical decision that was based on the distance and/or length of time it took to get to an appointment affected a beneficiary's health?

7. *In whatever way that is appropriate for you, please discuss the effect of transportation costs on getting to and from medical appointments.*

[Select one or more of the following prompts as needed]:

- What are the immediate effects of transportation costs on health care?
- What are the long-term effects of transportation costs on health?
- In what ways do transportation costs for doctors' visits and medical procedures affect family members' or household funds?

8. *In what ways, if any, have you noticed doctors or other health care workers consider beneficiaries' transportation problems when making a decision about a medical treatment?*

[Select one or more of the following prompts as needed]:

- How do they respond to the transportation barriers facing beneficiaries?
- In what ways are their expectations of beneficiaries in terms of keeping appointments fair or not fair?
- How do transportation barriers affect a person's medical condition?

Finally, the last couple of questions will deal with some of your ideas for reducing transportation barriers to health care delivery.

9. *What are the most significant aspects of transportation barriers that need to be addressed or fixed?*

[Select one or more of the following prompts as needed]:

- What role should the health center/clinic play in addressing transportation barriers for Medicare beneficiaries?
- What could the different transportation services do to improve their services for Medicare beneficiaries, both with and without disabilities?
- What could the tribe do to implement any necessary change?

10. *What ways, if any, can changes in transportation choices and/or costs affect the way Medicare beneficiaries take care of their health?*

[Select one or more of the following prompts as needed]:

- What could beneficiaries do differently if they had fewer transportation issues?
- What might doctors or other health care workers do differently if beneficiaries had fewer or no transportation barriers to getting to the clinic or health center?

11. *Is there anything else about transportation barriers that was not discussed that you feel should be addressed?*

III. Conclusion and Compensation

At the conclusion of the focus group session, participants will be thanked and will be compensated for their time and effort in the form of a \$50 gift card.

III.a. Conclusion and Compensation Script

This concludes our questions. We are very thankful for your time and your thoughtful responses. As an expression of our gratitude, we have a thank you gift card for each of you, and we ask that you sign that you have received it as you are leaving.

[Note taker records the names of each participant who receives a gift card, and participants sign to indicate their receipt.]

IV. Handling of Data

Focus group data, once transcribed, will be scrubbed of identifiers. All data will ultimately be electronically entered and password protected with limited access.

Viewing of the raw data will be limited to the following personnel: moderator, note taker, project manager, and transcriber. Of the staff, only the moderator and note taker will have direct knowledge of the person who participated in the study. In addition, all members of the focus group will know who their fellow participants are. While it is impossible to ensure that confidentiality will be maintained among all the members of the focus group, participants will be asked to observe and respect the confidentiality of all participants.