

**Research to Reduce Time to Treatment for Heart Attack/Myocardial Infarction
for Rural American Indians/Alaska Natives (AI/AN)**

Attachment 5A

**Focus Group Discussion Guide
for AI/AN Community Members with Prior MI**

Focus Group Discussion Guide For AI/AN Community Members with Prior MI's

Morning Session: Warm Up, Explanation and Introduction

At this time the focus group moderator will talk about the goals of the day's activities and what is hoped to be achieved. The moderator should take the lead and introduce him/herself giving the group a little bit of history about himself/herself.

As a part of the introduction it is important for the MODERATOR TO HELP participants to understand that:

1. The session will be audio taped and why this is being done. The audiotape will not be turned on until after all participant introductions have been made. A report of the discussion will be developed in which no one will be identified and of which they will be given a written copy.
2. Participants should be invited to speak freely.
3. Know that it is OK not to agree with what others are saying, but that each person's opinions will be respected. There are no right or wrong answers, only opinions.

Public reporting burden for this collection of information is estimated to average 5 hours per response, including time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: CDC/ATSDR Reports Clearance Officer, 1600 Clifton Road, NE, MS D-74, Atlanta, GA 30333, ATTN:PRA (0920-xxxx).

4. Participants should speak one at a time so that the information is not blurred on the recorder.
5. Each person's comments and ideas are valuable to better understand and to improve the issues surrounding MI to treatment time.
6. Understand that time is limited but allow for participant to digress. Explain that the focus group discussion will last about 5 hours. Often those anecdotal stories are ways that participants answer the questions that they do not know how to answer any other way.
7. Define the agenda for the focus group which will include the morning session of discussion and then later in the day, review of the message samples which result from the discussion. This session will take place in the afternoon of the retreat.

The mediator should ask each of the participants to spend about 5 minutes each, introducing themselves to the group and telling about their experiences and anything they would want to share. Some items that might be of interest to the group and should be probed include:

Age

Years of Education

Race or community that they are from

Profession

Experiences

Children

How long ago they had a heart attack and if they have had more than one

If they believe they are at risk for another heart attack

If they have a close relative or friend who has had a heart attack

The questions above are to be completed as a part of the warm up exercise. Some will be known in advance and may not be necessary to review at the time of the warm up.

Each question listed below has probes which are intended to be used by the moderator to elucidate the questions. The probes are not intended to be read to the focus group but rather to be used as prompts to further discussion.

Knowledge, attitudes, awareness of symptoms

1. What signs and symptoms (things that you see or things that you feel) did you expect to take place in someone having a heart attack?

Probes: Use the items listed below as probes after the group has discussed this question and has given their list. Each participant should list the signs and symptoms that they are familiar with and then prioritize them by numbering them from 1, 2, 3, 4, etc. The moderator can list them on a white board by priority and then review any of those from the list below that are not named and discuss why they are not listed. Allow the participants the time to give their definitions of the signs and symptoms.

- | | |
|--|-------------------|
| _____ Arm pain | _____ Faint |
| _____ Chest pain | _____ Denial |
| _____ Chest pressure | _____ |
| Dizziness _____ Stomach pain | |
| _____ Vomiting | |
| _____ Rapid or irregular heart beat | _____ Neck pain |
| _____ Numbness & tingling in the Arm | _____ Cold skin |
| _____ Blurred vision | _____ Heartburn |
| _____ Sudden sweating | _____ Indigestion |
| _____ Back pain | _____ Jaw pain |
| _____ Paralysis | |
| _____ Feeling of doom | |
| _____ Shortness of breath | |
| _____ Pain that spreads to your shoulders, neck, back arms | |
| _____ Squeezing sensation or tightness in you chest | |
| _____ Unexplained Weakness or light headedness | |
| Others _____ | |

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2. When you had your heart attack what were the signs and symptoms that you had shortly before or at the time of your heart attack. (Signs are things you see, symptoms are things that you feel)

Again, use the items listed below as probes recording defining information. Ask the participant to recall as much as possible what they actually felt. Encourage them to use their own language and definitions and compare them to the traditional signs and symptoms listed below. Again, each participant should list the signs and symptoms that they are familiar with and then prioritize them by numbering them from 1, 2, 3, 4, etc. The moderator can list them on a white board by priority and then review any of those from the list below that are not named and discuss why they are not listed. Allow the participants the time to give their definitions of the signs and symptoms.

- | | | | |
|-----------|--|-------|--------------|
| _____ | Arm pain | _____ | Faint |
| _____ | Chest pain | _____ | Denial |
| _____ | Chest pressure | _____ | |
| Dizziness | _____ | _____ | Stomach pain |
| _____ | Vomiting | _____ | Neck pain |
| _____ | Rapid or irregular heart beat | _____ | Cold skin |
| _____ | Numbness & tingling in the Arm | _____ | Heartburn |
| _____ | Blurred vision | _____ | Indigestion |
| _____ | Sudden sweating | _____ | Jaw pain |
| _____ | Back pain | | |
| _____ | Paralysis | | |
| _____ | Feeling of doom | | |
| _____ | Shortness of breath | | |
| _____ | Pain that spreads to your shoulders, neck, back arms | | |
| _____ | Squeezing sensation or tightness in you chest | | |
| _____ | Unexplained Weakness or light headedness | | |
| Others | _____ | | |
| | _____ | | |
| | _____ | | |

3. Do you believe that diabetes adds to your risk for heart disease?

Probe – What if any effect does diabetes have on heart disease? Do you think that controlling blood sugar could lower the risk of getting heart disease? (*hint: diabetes causes blood to be stickier and that causes blood vessels to become thick and hard and when they become clogged, the risk for heart attack greatly increases*).

4. Do men and women have the same signs &/or symptoms of a heart attack?
(Signs are seen, symptoms are felt). Yes ___No___ don't know_____

Probe – What are the differences, what are the similarities? What are some of the problems and issues that might make a difference in women and men calling for help when having a heart attack? (Hint: *As with men, women's most common heart attack symptom is chest pain or discomfort. But women are somewhat more likely than men to experience some of the other common symptoms, particularly shortness of breath, nausea/vomiting, and back or jaw pain.*)

5. Have any close relatives in your family had a heart attack? Yes__ No__

Probe: Do you believe that having a family history of heart attack increases your risk for a heart attack and is there anything you can do about it? (hint: yes, definitely but choosing to make changes in your lifestyle decreases your risk for a heart attack)

Response to a heart attack

6. If you have a history of chronic symptoms like pain in the chest from heartburn or lower back from gallstones your doctor probably told you they were not related to your heart. What change in your symptoms made you or others believe that you were having a heart attack?

Probe the group regarding their own (or that of a person they might know) experiences in signs and symptoms that might be similar to a heart attack – heart burn, gallbladder disease, muscle pain, costochondritis (inflammation of the costochondral joints of the chest causing chest pain) or times that they have gone to the doctor with chest pain and then had a MI protocol rule out an MI.

7. When you thought you were having a heart attack what is the first thing that you did?

Probe - give examples such as take an aspirin, call 911, call a friend or a relative, call the doctor or clinic, jump in the car to go to provider or hospital, wait and see if they felt better, etc. Ask what influenced the person to make the decision to do what they did.

1. _____
2. _____
3. _____
4. _____

8. Did you call for help when you thought you might be having a heart attack?

Yes__ No__

Probe– What were the participant’s thoughts when they first had symptoms of a heart attack or came across someone having a heart attack? Who did they call first and what was the reason for calling this person or provider?

9. Who did you call?

- | | |
|--------------------------|------------------------------|
| a. _____ A Friend | b. _____ An Ambulance or 911 |
| c. _____ A Family Member | d. _____ A medical provider |
| e. _____ Tribal Healer | f. _____ CHR |
| g. _____ Other | |

Other _____

Probe – Have the participant name as many calls as they did or would make and ask them to prioritize the calls. Why or why not did they call certain people? Would they do it differently if they had another heart attack? Would having a heart attack at night or in the daytime make a difference?

10. If you called someone other than 911 or an ambulance, how long did it take you to get in to see a Doctor or other health care provider? _____

Probe – ask the participants to name the person or service they called and then identify the distance that they had to travel to their health care provider. Once they arrived at the provider, how long did it take for them to be seen? Ask if they called ahead to inform the provider that they were coming or made any provisions to alert the clinic that there was a possible heart attack en-route? Why or why did you not call 911?

11. How soon after you thought you were having a heart attack would / did you call for help?

- A___ Right away
- b.___ Less than an hour
- c.___ 1-2 hrs
- d.___ 2-3 hrs.
- e___ 3-4 hours
- f___ more than 4 hours
- g. Other _____

Probe – ask the participant to distinguish between if they were calling for someone else or if they were calling for themselves. What made them decide to call, what were the barriers to making the call - both physical and mental? If extended period of time passed before the call was made, ask why they waited?

12. Who is the one person who would most influence you in getting care?

(For example – daughter, son, husband, wife, doctor, neighbor, etc.)

Probe – who are you most likely to listen to regarding health care decisions? List both personal and professional people by priority. Consider how often you are around these individuals and what your access is to them at the time of or when you assisted another person in making the decision to seek care. Who would be the next person most likely to influence a decision to get care, why?

13. Do you believe that a heart attack is a medical emergency that requires immediate attention?

Yes ___ No ___

What do you believe will happen as a result of delaying treatment for a heart attack?

Probe – Do the participants believe that a heart attack can be fatal, or do they believe that it is something that can be fixed? How much time does one have to call for help to prevent heart damage once they have symptoms of a heart attack?

Were their complaints taken seriously by providers? Do they know that quick treatment saves lives? That life saving treatment can be given in the ambulance by trained EMTs? Would they do things differently at night than in the daytime? Would the presence of others (such as minor children) impact their decision to call for help? How long does a person have to call for help? What happens if they delay?

14. Would you like more information or education about heart attack? Yes ___No___

Probe – Determine whether this is an area of interest or not. If not, how do we get the message about time to treatment out to the community members? Why/what reasons are you not interested in getting more information about heart attack? Do you believe/think it applies to you or anyone you know? Are you concerned/afraid that you will be given too much information or information that you do not understand?

15. What kind of information would you like? (prevention/treatment/signs and symptoms)

Probe – What kinds of things are most helpful in helping you to understand the issues surrounding heart attack? Does talking about the symptoms or understanding the reasons why one might have a heart attack help in understanding the significance of time to treatment?

16. How would you like to get more information on heart attacks? What is the best method of getting this information? And who do you want the information from?

Probe – How do you like to learn? What catches your attention? Allow the participants to answer and only use the list as a probe and a checklist for the moderator.

- a. _____ Books
- b. _____ Pamphlets
- c. _____ Doctors - Nurses – Nurse Practitioners – PA’s
- d. _____ Community Meetings
- e. _____ A private meeting with someone that can answer your questions
- f. _____ Television

- g. _____ VCR, CD or Audio Tape
 - h. _____ Posters
 - i. _____ Radio
 - j. _____ Friends
 - k. _____ CHRs
 - j. _____ Other
-

Barriers

17. Name as many barriers that you can think of that might have prevented you from seeking help when you thought you were having a heart attack.

Probe – ask the participant to list as many as possible using the list for the moderator’s checklist and possible prompts if the group runs out of ideas. Again, ask the participants to prioritize their answers by 1, 2, 3, 4, etc. and list on a white board discussing any issues that are not covered in the probes below.

- | | |
|---|----------------------------------|
| _____ No transportation | _____ Family disapproval |
| _____ Denial | _____ Pride |
| _____ Embarrassment if nothing was wrong | _____ Giving up control |
| _____ Losing work time | _____ Cost of medicines |
| _____ Don’t want to bother others | _____ Discrimination |
| _____ Hassle at the hospital | _____ Don’t want to scare family |
| _____ Tried to manage symptoms | _____ No Insurance |
| _____ Don’t want to be a burden to the family | _____ Too busy / No time |
| _____ Don’t trust doctors / hospitals | _____ Child care |
| _____ don’t know how to get help | _____ Lack of privacy |
| _____ Receiving a bill for the ambulance ride | |
| _____ Don’t care about my health, I’m going to die someday anyway | |
| _____ Having to wait for treatment at the hospital | |
| _____ Lights and sirens of the ambulance, police or fire trucks | |
| _____ Receiving a bill from the hospital | |
| _____ Fear of finding out if you are having a heart attack | |
| _____ You feel your questions are dumb | |
| _____ You feel the doctor may think your questions are dumb | |
| _____ Not knowing / confusion about symptoms | |
| Others _____ | |
-

18. How many times in the past year have you been to a doctor? _____

Probe– This list should include seeing a doctor or health provider for all health issues including immunizations. What level of provider do you generally see – a community health nurse, physician’s assistant, nurse practitioner, medical doctor, medicine man, spiritual healer? Who is your regular provider associated with – VA, IHS, private practice?

19. Do you typically see the same provider each time you go to the doctor?

Yes ____ No ____

Probe – Does the participant see several doctors from different institutions or see several providers in the same institution? How frequently do they see the same provider – sometimes, always, never? Do they have a choice to get the same provider each time they make an appointment; do they have a family doctor?

20. Are there problems in your hospital or clinic that could get in the way of a person’s ability to receive timely treatment for a heart attack? Yes_____ No _____

Probe – If yes, what are they? If no what are the positive aspects of your facility that makes it possible to be receive timely treatment. If yes, identify those issues that interfere with ones ability to be seen by a doctor. Questions 22 through 23 are similar questions but should be asked in different ways in order to give people an opportunity to give input to solutions to the system.

Systems

21. Are there things that you think should be changed at your clinic or hospital when it comes to delivering good care for heart attack care (such as timely treatment), if any?

Probe – What would you change (if you could) within the facility where you seek treatment? We are trying to catch the lay persons perception of what they feel can be changed within a facility. Example: I don't like to go to IHS because I never see the same doctor twice.

22. Do you believe that your local clinic/hospital can do/does a good job of treating and saving the lives of people that have had heart attacks? Why or Why not?

23. Is EMS (emergency medical service) available in your community?
Yes__ No__

If so, did you use the EMS system? Yes____ No ____ Why or why not?

Probe – Ask the participants to define what EMS is and what services they are capable of performing or what this service is generally used for in their communities.

24. What can be done to get people to use the EMS system more for heart attacks?

Probe – Again, what are the social, economic, cultural and physical issues that are preventing people from fully utilizing this service – lack of services, dual hospitals, lack of trust in the system, distances from an EMS system, do they need pre-approval from providers to call for an ambulance, etc.

25. Is there anything that keeps you from using EMS? _____

Probe – what are the physical barriers which keep the participants or his/her community from using the EMS system, such as distance?

26. What are the most important life saving messages about heart attack that you think would get people, in your community/region, to take heart attack seriously and to get medical help as quickly as possible?

Probe: what would the message look like? What would it sound like? Where's the best place to share this message in the community? Who are the best people to take the message to the community?

Afternoon Session

Moderator's Explanation: As you know we have interviewed medical providers, community leaders and individual community members about their opinions about heart attack in Indian country. We asked community leaders and members about a number of things including: their knowledge of the signs of a heart attack; actions they would take if they had a heart attack or saw someone having a heart attack; barriers that would prevent people from seeking help immediately; and how people would like to get informational messages about the importance of knowing the signs of heart attack and the need to call 9-1-1 and get immediate help.

The moderator will discuss a summary of the morning's session, plus interview data, and some concepts/drafts of messages and visual materials (developed through feedback from the interviews). The MI focus group members will then be asked to provide their opinions and further help the staff develop the messages and visual materials, and provide the input on the methods of dissemination for the materials. The following questions are examples of the types of questions we will ask:

1. In reviewing the concepts in front of you, please grade their effectiveness (insert rating scale) and write down a few words to explain your general reaction.
2. Please describe the main idea behind the concepts presented. What is the main message?
3. Does this speak to you? Do you see yourself as part of the audience they're trying to reach? Why or why not?
4. Please describe what about this (image/text/message) is appealing and what is bothersome.
5. Is there any way that this could be made more attention getting/appealing to you?
6. What do you think you would do after seeing this concept?
7. Please take a look at each (insert item name). Is there one that would more likely to catch your attention, that you would be more likely to notice and watch/read?
8. Looking at each (insert item name) individually:
 - Is this easy to read? (if a poster/brochure/fact sheet/print ad)
 - Is it easy to understand?
 - Would the information be helpful to you?
 - Is the amount of information right for you? Too much? Too little?
9. After looking at the (insert item name or specific section) what is the take-away message?

10. What appealed to you about this approach?
11. What did not appeal to you?
12. Do you have any suggestions to make the (insert item name) more appealing?
13. Is this (insert item name) something that you would stop and look at or quickly disregard? _
14. Do you think this would motivate you to (insert call to action included in the material)? Why or why not?
15. Can you think of anything that could improve the likelihood of (insert item name) prompting you to (insert call to action included in the material)?
16. How can this material be improved?
17. Comparing the (insert item name) in front of you, (insert ranking instructions).
18. What other ideas do you have for messages and visual or oral materials to go with the message.
19. What are your ideas about oral messages for the radio or for community gatherings?
20. What is the best way to get the messages and the materials to people in Indian country?