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Focus Group Guide

AI/AN Adults

Date	January 9, 2024
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Welcome

The goal of this focus group discussion is to learn from you about what you know about concussions and what you think of the Centers for Disease Control and Prevention (CDC)'s current concussion and mild Traumatic Brain Injury (TBI) medical discharge instructions. This information will help us develop appropriate concussion discharge instructions for adult Alaska Natives and American Indians, Native people, and Tribal members. This project is being conducted for the CDC.

Welcome to our discussion and thank you for taking the time to participate today. My name is [NAME], I will be leading this virtual discussion today. I also have [NAME] joining me today to assist with technology and note-taking. We are conducting a series of conversations to learn what you know about concussions and your opinion of the current concussion and Traumatic Brain Injury discharge instructions.

We encourage you to speak openly and honestly today. This will be a discussion. There are no right or wrong answers. Each of your opinions is very important to us. We want to hear your responses, thoughts, feelings, opinions, comments, and questions.

Do you have any questions?

[NAME] will be taking notes on information from our discussion and we will be recording the conversation. Only staff at Banyan will have access to the recording. But we will not start recording until after you've introduced yourselves, and we will edit out any identifying information from the recording and transcript (for example, if someone says your name later during our discussion). We will also be writing a report about what we learned from all of our discussions, but that report will focus on the big picture and what we learned from everyone. We will not include your name or any other identifying information in any reports.

[NAME] will be helping us with technology today. If at any point you are having trouble seeing or hearing me or others in the group, please send a chat message to alert us to your technical difficulties. To access the chat function, click on the chat icon in the toolbar on the

video screen. We would prefer for you to respond to my questions verbally and contribute to the discussion out loud, so please limit the chat use for technical issues.

The focus group will last no more than 1 hour. This discussion is completely voluntary, so you may choose to skip any question you'd rather not answer, and you can also leave the group at any time with no consequence.

Does anyone have any questions at this time? [ANSWER QUESTIONS]

Ground Rules

[DISPLAY SLIDE WITH GROUND RULES ON SCREEN]

To help this session go smoothly, here are some ground rules for our discussion:

- Please speak one at a time – this will help us hear one another and enable us to take good notes.
- Please speak clearly and loud enough for everyone to hear you.
- You can raise your hand to speak or speak up after another person has finished speaking.
- You do not have to speak in any particular order, and you may speak directly to each other. This is a group conversation and you do not have to address your comments to me.
- There are no right or wrong answers.
- You do not have to agree with the views of other people in the group. In fact, if you disagree, we hope you will share your perspective so we can understand the full range of views in the group.
- Respect others and their different viewpoints.
- What's said in the virtual room stays private. Please respect and maintain each other's privacy.
- There are many of you in the room and we'd like to hear from everyone. Some of you may be more comfortable speaking than others, so at times I may ask more talkative people to let others share first or invite a quieter person to share their thoughts.
- Please put away or silence any distractions like phones, tablets, or TVs for our discussion, and mute yourself when you are not speaking by clicking on the microphone icon on your screen.

Introductions

Before we get started, let's introduce ourselves. Let's go around the screen and each of you share:

- The name you would like us to call you today and what pronouns you would like us to use.
- What Tribal group or community you are affiliated with or identify with.

[BEGIN RECORDING]

Current Discharge Instructions

Banyan Communications, on behalf of the Centers for Disease Control and Prevention (CDC), is seeking feedback on mild traumatic brain injury (TBI)/concussion emergency department discharge instructions for adult American Indian and Alaska Native (AI/AN) patients. These discharge instructions contain critical information about what to expect after a mild TBI/concussion, a listing of danger signs that would prompt a return to the emergency department, and a description of return to activity steps. You have been asked to review these discharge instructions and provide feedback based on your perspective as an AI/AN adult.

We are now going to ask you to read the Mild Traumatic Brain Injury and Concussion Discharge Instructions if you have not already. If you have reviewed them already, please review them again. I will mute participants for 3 minutes to give us time to review the discharge instructions in silence.

[MUTE PARTICIPANTS FOR 3 MINUTES. PULL UP DISCHARGE INSTRUCTIONS ON SCREEN]

Does anyone need more time to review the discharge instructions? [REPEAT PROCESS ABOVE IF PARTICIPANT(S) ANSWER YES]

I'm now going to ask you a series of questions about the information you just read.

First Impressions

1. Overall, what do you see as the main purpose of the discharge instructions, in your own words?
2. Before reading the discharge instructions, were you aware of any of the recovery and care tips or suggestions provided?
 - a. *Probe:* Were you familiar with the information that was shared in the discharge instructions?
3. What were your first reactions to the discharge instructions when you reviewed them?
 - a. *Probe:* What thoughts did you have about the look of the discharge instructions?
 - b. *Probe:* Did the resources seem like something developed with AI/AN patients in mind?
4. What did you think of the images and visuals of the people used?

Clarity and Applicability

5. In reviewing the discharge instructions, was there anything in them you found confusing, unclear, or hard to understand?

6. What challenges, if any, do you think adult AI/AN patients might have while reviewing and or following the discharge instructions?
7. What thoughts do you have about how the information is organized? (This might include the organization of written text, colors used, style of the different text boxes, or anything else you would change to make it easier to read, use, or watch.)
8. Do you feel these discharge instructions are missing any key information you think would be important to include?
9. How motivating do you find this information? How might the information be presented in a more motivating way?
 - a. *Probe:* Which actions described in the discharge instructions sound doable to you? Why?
 - b. *Probe:* Which actions described in the discharge instructions sound less doable to you? Why? What would make them easier?
10. If you were a patient receiving these instructions, what format would you prefer, the written instructions, a video recording of the discharge instructions, or both?
 - a. *Probe:* Why did you choose that particular format? What made you prefer it over the other?

Using & Sharing Discharge Instructions

Now we'd like to ask about how you, as an AI/AN adult, might use CDC's discharge instructions.

11. How do you typically engage with your healthcare provider? (e.g. telehealth appointment, phone call, in person scheduled visit, walk-in, etc.)
 - a. *Probe:* Is there a reason why you are most comfortable engaging your healthcare provider in that way?
12. If you were a patient with a mild traumatic brain injury or concussion would you review these discharge instructions with family or friends? Why or why not?
 - a. *Probe:* How would you share these instructions? Would you prefer to share a video recording of the discharge instructions, the written instructions, or both together?
13. Do you think AI/AN adult patients with a mild TBI or concussion would use these instructions? Why or why not?
14. Which sections of the discharge instructions do you think AI/AN adult patients would be most or least likely to use? Why?
15. What would make AI/AN adult patients with a mild TBI or concussion more likely to use these discharge instructions?

- a. *Probe:* For example, would patients be more likely to use these discharge instructions if an individual (such as a physician or another healthcare provider) or trusted organization gave them out?
- 16. If you were a patient with a mild traumatic brain injury or concussion and you received these discharge instructions from a medical provider, how likely would you be to follow up with your healthcare provider?
 - a. *Probe:* Do the discharge instructions influence *how* you follow up with your healthcare provider (e.g., by phone call, in person, virtual visit, etc.).
- 17. In your opinion, which individuals or organizations would you trust with disseminating these materials to AI/AN adult patients?
- 18. Do you think AI/AN adult patients would be more likely to use these discharge instructions if they were available online or on an app on their phone?
- 19. Overall, what do you think about the idea of having mild TBI/concussion discharge instructions created just for AI/AN patients and Tribal communities?
- 20. Do you have any last comments or thoughts about the mild TBI/concussion adult discharge instructions?

Closing thoughts

If you could share one piece of feedback on these materials with CDC, what would it be?

Conclusion

Thank you for reviewing CDC's Mild Traumatic Brain Injury and Concussion Discharge Instructions and providing your thoughtful feedback. The information you have shared will be used to improve the resources to enhance their relevance for AI/AN adult patients with mild TBI/concussion. You should be receiving your incentive of \$50 shortly.