

**Generic Clearance for CDC/ATSDR**

**Formative Research and Tool Development**

**Title: *Formative Testing of CDCs Mild Traumatic Brain Injury and Concussion Discharge Instructions for American Indian and Alaska Native Adult Patients***

Supporting Statement B

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## SUPPORTING STATEMENT: PART B

### ***1. Respondent Universe and Sampling Methods***

The potential respondent universe for this proposed information collection includes Tribal Health Care Providers, Tribal Leaders, and American Indian/Alaska Native (AI/AN) Adults, aged 18 years and older. Individuals within these groups will be recruited via two approaches:

1. We will use a recruitment firm to recruit any final hard-to-reach populations.
2. We will identify partners that focus on serving AI/AN communities (e.g., the Indian Health Service and National Tribal Epidemiology Centers) and leverage the partnership to recruit individuals by sharing recruitment materials with organizational leaders with influence.

All recruitment materials will be in English (ATTACHMENTS 1 through 7). They will include information on the purpose of the data collection, eligibility requirements, contact information for additional questions, and a link to a screening survey for individuals to express their interest in participating.

<b>Method</b>	<b>Sample Eligibility Criteria &amp; Number of Screener Questions</b>	<b>Sample Research Questions &amp; Number of Data Collection Questions</b>
In-Depth Qualitative 1-On-1 Interview	Tribal Leaders 13 Questions	“Overall, what do you see as the main purpose of the discharge instructions, in your own words?” 20 Questions
In-Depth Qualitative 1-On-1 Interview	Health Care Providers that serve Tribal communities or people 11 Questions	“In reviewing the discharge instructions, was there anything in them you found confusing, unclear, or hard to understand?” 22 Questions
Qualitative Focus Group Discussion	AI/AN Adults aged 18 and over 12 Questions	“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?” 20 Questions

## ***2. Procedures for the Collection of Information***

A combination of Focus Group Discussions (FGDs) and In-Depth Interviews (IDIs) will be used to collect information. FGDs consist of a group of participants collaborating together to discuss and provide feedback. An IDI is an individual interview, with only a two-way dialogue between the interviewer and the participant.

Up to sixteen IDIs with Tribal Health Care Providers (clinicians, counselors, or other public health or medical providers that specifically cater to the needs of AI/AN people) will be conducted. Up to sixteen interviews with Tribal Leaders (Tribal elders, councilmen/women, chiefs, or other community members that hold some sort of authority or a position of leadership) will be conducted. Up to four FGDs with up to eight participants in each FGD will be conducted with AI/AN adults over the age of 18. Banyan will take efforts to ensure that participants will be recruited across a range of diverse locations (geographic, urban/rural) and Tribal affiliations.

Recruitment materials will be sent out via the previously described methods and will contain a screening survey that will gather preliminary information on demographic characteristics that will help determine if individuals will contribute via an IDI or FGD.

AI/AN Adults will be segmented into FGDs based on availability and similar characteristics (such as Tribal affiliation, geographic location, urban or rural setting, English proficiency, age, etc.). Individuals who opt into one or more FGDs can select only one to participate in.

Each IDI and FGD will last no longer than 60 minutes and will be conducted virtually via Zoom, an online conferencing platform. Participants will not need to have the software installed in order to participate, however they will need reliable internet access. Each IDI and FGD will be recorded, and the data will be transferred and stored on a shared information system with access restricted to authorized study personnel. Upon arrival at the Zoom meeting, participants will be asked to verbally consent to participate in this non-research data collection. Prior to beginning the IDI or FGD, the facilitator will introduce themselves, describe the study, and answer any questions participants may have. After obtaining verbal consent, the facilitator will follow a predetermined list of questions to guide the interview or discussion (ATTACHMENTS 8 and 9). Transcripts from the interviews and discussions will then be analyzed for common themes and sub-themes using MaxQDA qualitative data analysis software, with personally identifying information (PII) removed.

Analysis of these data will utilize grounded theory and narrative analysis strategies to answer the research questions and identify translatable findings into communication strategies. A codebook will be developed consisting of deductive and inductive codes to identify and compare themes within and across IDIs and FGDs. Findings will be compiled into a report that will highlight recommendations for message and material development.

## ***3. Methods to Maximize Response Rates and Deal with No Response***

Each focus group and interview participant will receive a \$50 incentive following the focus group discussion or interview as a token of appreciation and reimbursement for opportunity costs and expenses (i.e., babysitter, loss of work) incurred due to participation. Providing incentives to respondents is necessary to successfully recruit individuals. All participants are part of a hard-to-reach population. Research suggests that incentives have proven helpful in recruitment of hard-to-reach groups (Bonevski et al. 2014; George et al. 2014). Incentives can increase the likelihood of obtaining a diverse sample of participants, which would include individuals in hard-to-reach and minority populations who encounter complex social problems that place limitations on their desire and time to volunteer for research studies (Ellard-Gray et al. 2015; Knoll et al. 2012). Literature also reveals the payment of incentives can provide significant advantages to the government in terms of direct cost savings and improved data quality. It also should be noted that message testing is a marketing technique, and it is standard practice among commercial market researchers to offer incentives as part of respondent recruitment.

CDC will apply a health equity lens when selecting our recruitment sample, prioritizing populations that are hardly reached by CDC or concussion prevention information. DIP has had difficulties recruiting sufficient samples of these subpopulations in previous messaging projects. Having insufficient representation from this subgroup means their perspectives are not adequately included in message development which results in less effective messaging to support DIP's goals. An appropriate incentive improves the chances that these subgroups will engage and participate, therefore increasing the government's efficiency in data collection and reducing redundancies for future efforts.

These subgroups have been difficult for DIP to reach for several reasons.

1. For rural AI/AN communities, the social economic situation makes it harder for individuals to utilize PTO or miss work to participate in such projects. Though the data collection will be virtual, low-income populations are less likely to have jobs with remote flexibility, and may have to miss or leave work in order to participate. An appropriate token of appreciation may address this issue.
2. AI/AN subgroups who are being asked to participate are historically less likely to participate in research activities due to mistrust in the medical system fostered by research institutions. Offering a higher token of appreciation addresses health equity issues brought on by historically unjust research practices, by encouraging participation from a more diverse pool of participants.

To encourage participants to complete the eligibility survey, the contractor will email an invitation to eligible participants, and then send up to 2 reminder emails, sent no more than one week apart, encouraging them to complete the eligibility survey. The contractor will collect as many contact options as possible during the sampling phase to account for initial email bounce backs. Only one eligibility survey per eligible respondent will be collected.

#### ***4. Tests of Procedures or Methods to be Undertaken***

For this study, the focus group and interview guides were reviewed by multiple staff members within the contracting agency and by multiple staff members within DIP on the TBI team.

## Research Instrument

*Include if environmental scan or lit review were done:* The questions were developed based on an extensive literature review that focused on:

- Gaining a greater understanding of Black/African American, Hispanic/Latino/a, and American Indian/Alaska Native adults':
  - Concussion/traumatic brain injury (TBI) knowledge
  - Higher-risk concussion behaviors
  - Help-seeking norms
  - Barriers to seeking care
- Gaining a greater understanding of Black/African American, Hispanic/Latino/a, and American Indian/Alaska Native parents':
  - Concussion/TBI knowledge
  - Care-seeking norms
  - Barriers to seeking care
- Understanding current social norms around
  - Higher-risk concussion behaviors
  - Injury help-seeking behaviors

## **5. Individuals Consulted on Statistical Aspects/Individuals Collecting and/or Analyzing Data**

This information collection request does not employ advanced statistical methods. CDC staff consulted are in DIP and include: Kelly Sarmiento, MPH; Jill Daugherty, MPH, PhD; Alexis Peterson, PhD; and Graham Kirkland, MA. These staff were consulted about the methodological design of the study. Their recommendations were incorporated into the study design and instruments on an ongoing basis. Banyan Communications staff will be responsible for overseeing and executing the data collection and analysis, and these staff are listed below.

### **Collaborators**

<b>Name</b>	<b>Organizational Unit</b>
Nora Kuiper, MPH, Project Director	Banyan Communications (contractor)
Chloe Cahill	Banyan Communications (contractor)
Darola Cherenfant	Banyan Communications (contractor)

## **References**

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George, S., Duran, N., & Norris, K. (2014). A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. American Journal of Public Health, 104(2), e16-e31.

Ellard-Gray, A., Jeffrey, N. K., Choubak, M., & Crann, S. E. (2015). Finding the Hidden Participant: Solutions for Recruiting Hidden, Hard-to-Reach, and Vulnerable Populations. International Journal of Qualitative Methods, 14(5), 1609406915621420. <https://doi.org/10.1177/1609406915621420>

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