

*AR***D***AC*

Advance Research and Data Analysis Center

**California Health Interview Survey
Cultural and Linguistic Adaptation**

English Mini-Group Report

DECEMBER 2000

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I. INTRODUCTION AND OVERVIEW

The California Health Interview Survey (CHIS) will collect data on important health issues such as public health status and access to health care and diet. It is important that the survey questions be examined carefully for language problems and cultural bias. ARDAC, along with a team at UCLA, is involving many different cultural and language groups in the review of the surveys. This should help to simplify and clarify the English version and, by extension, the surveys translated into different languages. The major purpose of this project (CHIS cultural and linguistic adaptation) is to produce culturally sensitive, valid and equivalent survey instruments for the CHIS.

We asked community-based organizations to help us test out survey questions that will be on the CHIS survey to be conducted by phone this year. The survey questions were already reviewed for language and cultural bias problems. We wanted to make sure the language in the questions was conversational and clear to all of our target populations. In addition, there were several areas of cultural sensitivity that we wanted to ask about, such as emotional health, access to health care, diet, etc. We decided, along with UCLA staff, to conduct four English focus groups of about 4 people each, two with adults and two with adolescents. The English groups consisted of African Americans and American Indians. Details on the guidelines for selecting participants, recruitment, topics that were discussed, and instructions for CBO coordinators and facilitators follow. Results of the mini-group are included in the report along with recommendations to UCLA. Appendices include Introduction, suggested procedures for conducting a mini-group, parent permission form, eligibility checklist, and transcriptions from the tapes of all four groups.

II. GUIDELINES FOR SELECTING MINI-GROUP PARTICIPANTS

The following guidelines were used to select and recruit mini-group participants. See appendix for eligibility checklists.

ADULT PARTICIPANTS:

- Adults between the ages of 20–70 with one or more children
- Members of the CBO service population
- Lower income of a certain ethnic/language group
- No employees or staff of CBO or relatives of CBO staff
- Can speak English fairly well
- No friends or relatives in the same group

ADOLESCENT PARTICIPANTS

- Adolescents between the ages of 12 and 17, with parent permission
- Members of the CBO service population
- Lower income of a certain ethnic/language group
- Can speak English fairly well
- No employees or staff of CBO, or relatives of CBO staff
- No friends or relatives in the same group

III. RECRUITMENT OF PARTICIPANTS AND MODERATION OF SESSIONS

For all four mini-groups, one or more ARDAC staff attended, and tape-recorded the sessions. They were Anne Hafner and Fery Hejri. These staff took extended notes, and when possible, compared their notes after the session.

African-American adults and adolescents:

ARDAC did the primary recruitment for the African American participants. Their staff recruited a teacher at Jordan High School, Jihad Saleh. Jihad helped in recruiting high school students and parents, using the set criteria. Prior to conducting the sessions, Jihad had obtained parent consent forms. The adult African American participants were relatives of the adolescents or staff in the school. The adolescents were students at Jordan High. All participants were low income.

The date of the mini-group sessions was May 15, 2000. The location was Jordan High School in LA Unified School District. The adolescent session took place in a resource room between 1:45 – 2:45 pm, and refreshments were served. The group consisted of two females (ages 16 and 17) and two males (ages 17 and 18). They received a \$20 honorarium.

The adult session took place in the same room between 3:15 – 4:15 pm, and refreshments were served. The group consisted of two females (ages 41 and 45) and one male (aged 45). They received a \$40 honorarium for their help. No transportation was necessary for participants.

Jihad Saleh was the moderator for both African American sessions. He followed the directions perfectly and was an excellent moderator.

American Indian adults and adolescents.

The mini-groups for American Indian adults and adolescents were held at the offices of CRIHB Association in Sacramento, CA. Gerry Rainingbird, program associate was the moderator and organizer of the sessions. He recruited both adults and adolescents, using the set criteria. All participants were low income and the adults had high school or less education.

The American Indian adults were recruited from the community and consisted of 2 women and 1 man, ages from about 35-50. Their group was held from 1-2:15 pm. They were paid \$40 honorarium. We are not sure as to whether transportation was provided for them.

Rainingbird also recruited the adolescents from the community. There were 2 girls and 1 boy, ages 13, 15, and 17. They were given a ride to the office by staff of CHRIB, and were provided with refreshments. Their group was held between 3pm and 4 pm. They received a \$20 honorarium.

Gerry Rainingbird was the moderator for both of these sessions. He followed the directions perfectly and was an excellent moderator.

IV. MINI GROUP TOPICS – ADULT

The following are the questions that were asked of the mini-group participants.

1. Questions about vigorous vs. moderate activity: do people understand The difference between the two if they know the symptoms (sweating and fast heart rate)? (E31-E37)
2. Kind of health professional people go to when sick or for advice: (H5, see page 39 & H10, see pages 42). Are the options we have enough, or are there others we should include?
3. The places people go to for help when they are sick (H3 and H3a; see page 37).
4. Questions about welfare and insurance programs (AFDC, TANF, WIC, see page 68) Do people understand acronyms or do we need to spell them out?
5. Questions asking zip code, street you live on, etc. (M7-M9, see page 74)
6. Questions about emotional problems: Are they too sensitive? Could they be asked so they would not be problematic or offensive? (B7, B8, B13, B15, J2; see pages 6 and 6a)
7. How can we “lead into” questions about cancer in the least offensive? Why? (Before F1 see page 28, read introduction). Also the questions on sigmoidoscopy, colonoscopy etc.F12-F20, see page 30)
8. How do people feel about questions involving blood, for instance? About blood in stools (especially with Asian groups)(F21-F23, see page 32)?
9. Questions about violence and accidents (C5-C10; see page 14). Are questions clear?
10. US Citizenship questions: are you a citizen, do you have a green card? (H31-H34) These will go last in the survey. Do people think they would answer honestly, with the new introduction re: confidentiality.
11. Sexual orientation: H36a, H36 see page 50), are these questions clear?

ASK THESE ONLY OF FEMALES: EXCUSE MALES FROM THE ROOM:

1. Females only: Questions about female health issues such as age at first period (D1, D2, see page 15); number of live births, Pap smear test, mammograms, (D4, D5, see page 16) questions about menopause and hormones (questions 29-D42, see page 21)

V. MINI GROUP TOPICS – ADOLESCENT

Please read the following questions from the survey aloud to participants. In the exact order listed. For each topic, one or more questions are listed.

Read the introduction to the survey and get feedback from the participants. Is it clear?

1. Questions on injuries, violence, and guns. (C1-C3, C4-C5, C9-C12 are these clear, will people answer honestly?
2. Questions on emotional feelings, are they too personal? First read the introduction (questions D1, D3, D4, D6, D9, D13, D16, D19, see page 9), D3: having “the blues”, F10: have you received emotional or psychological counseling? Are there other ways to ask these questions?
3. Questions on sexual behavior, very sensitive. Do we need an introduction? E31, E32, E33, E34, E37, E38, E41, E42, see page 21.
4. Questions on alcohol and drug use. E22-E30. (see page 18). How would teens lead into this section?
5. How much do your parents know about your alcohol use, sexual behavior, or tobacco use? Appropriate wording? H6d, e and f., see page 32)
6. G4: Do teens know what stalking is? (see page 29)
7. Race/ethnicity: Of these groups, which do you most identify with ? (11a-E2, see page 32). Same as adult questions, A4, A5, A5a, see page 3

VI. MINI GROUP TOPICS – CHILD

Please read the following questions from the survey aloud to adult participants, in the exact order listed. For each topic, one or more questions are listed.

Read the introduction to the survey and get feedback from the participants. Is it clear?

1. (A11-A12, see page 5) questions on ADD? Are they clear? Do adults know what this is?
2. In general, is it OK to ask parents about their child's health, either physical or emotional health problems?
3. What kind of health provider does child see (D5, see page 13)? Are choices wide enough? Are there others?
4. D8 (see page 14). "Yellow card" immunization record. Do adults know what This is or should it be explained.
5. Delay in treatment, or delay in getting prescription medicine, reasons for, E3-E9, see page 16) do people understand these questions?
6. Insurance questions. Is it OK to ask questions about these issues? F18, F19a-d, see page 23) what is reason child does not have Insurance? Discuss 2 series of questions (F19 and F27, see page 23): one is For now and one set is for the past 12 months.

VII. INSTRUCTIONS FOR ADAPTATION LEADERS COORDINATORS AND GROUP FACILITATORS

We have asked your community based organization to help us test out survey questions that will be on the California Health Interview Survey to be conducted by phone this year. The survey questions have already been reviewed for language problems or bias as well as for cultural bias.

The person that is designated as the CBO Coordinator will probably also be the person who will facilitate the focus groups. The responsibilities of the CBO Coordinator will be (1) To meet with and work with the adaptation leader and ARDAC to plan mini-groups (2) to recruit adults and adolescents for groups (4 adults and 4 adolescents, both male and female) and (3) schedule mini-groups and obtains rooms for groups.

ARDAC will provide you with adult, child and adolescent questions that will be tested. We will only be testing out items and areas that may have problems or be unclear. Please keep the questions confidential and do not show them to anyone.

At the mini-group sessions, after a brief introduction, we would like you to read the questions aloud and ask participants if the question or series is clear and understandable. If they do not like or understand a word or phrase, ask them to suggest another word or phrase. An ARDAC staff member will attend the focus group to observe, take notes and tape the session if possible. This person will not participate in the discussion.

Adult mini-group participants will receive \$40 for their time (from one hour to one and one-half hours). Adolescent mini-group participants will receive \$20 for their time (about one half to three quarters of an hour).

We would like to acknowledge your organization and cite your name in reports. If your organization does not want to be acknowledged, please let us know.

Thank you for your help in this important project

VIII. RESPONSIBILITIES OF ADAPTATION LEADERS, COORDINATORS AND GROUP FACILITATORS

ADAPTATION LEADERS:

1. Make contact with community based organizations
2. Work with ARDAC to select CBO coordinator & facilitator
3. Meet with and work with coordinator and/or facilitator to
Plan mini-group and recruit people
4. Schedule mini-groups
5. Buy food and drinks for group meetings
6. Make arrangements for payment for focus group participants
7. Attend 2 mini-groups (1 adult, 1 adolescent)
8. Observe mini groups and take notes. Tape record group if possible
9. Write summary report on findings by questionnaire and age group
10. Attend ARDAC meetings as needed.

RESPONSIBILITIES OF CBO COORDINATORS AND FACILITATORS

1. Meet with and work with adaptation leaders to plan mini-groups
2. Recruit adults and adolescents for groups
3. Obtain parent permission forms from adolescents
4. Schedule mini-groups
5. Assist adaptation leader in making arrangements for payment
6. Facilitate/conduct two mini-groups (1 adult, 1 adolescent) in English
or native language
7. Provide feedback to adaptation leader about focus groups

IX. RESULTS and ANALYSIS

This section presents the basic results from the mini-group, including demographics, information and detailed findings by survey question and group. See the transcripts in the Appendix for very detailed comments.

Descriptive Characteristics of Participants

As can be seen in Table 1, only 3 participants were obtained for three of the groups and 4 were obtained for the adolescent African American group. Methods of recruitment included telephone calls or word of mouth. The average age of the adults was 43, and the average age of the adolescents was about 16.

While the adolescent African American group consisted of two boys and 2 girls, the other groups were made up of 2 females and 1 male. The students had not yet graduated high school and the adults all had a high school diploma or less. The American Indians had different tribal affiliations, but all lived in the Sacramento area. All participants were low income.

The adults in the group did not appear to be working. They were, however, very cooperative and helpful.

Table 1. Descriptive Characteristics

Demographic	American Indian/AN adults	American Indian/AN adolescents	African American adults	African American adolescents
# of participants	3	3	3	4
Tel. Recruitment, participation rate	Unknown	Unknown	Unknown	unknown
Average age	42	15	43	17
Ratio: female/male	2/1	2/1	2/1	2/2
Average education level	HS graduation or less	Less than high school	HS graduation or less	Less than high school
Tribal affiliation	Varied	Varied	N/A	N/A
Average income	Low	Low	Low	low
Other demographic	Were not working	Students needed rides	Did not appear to work	Were on site

Findings: African American Mini Groups:

Findings from the African American Mini-Groups are presented next, by questions. Other important comments are also included.

Mini Group Findings – African American Adolescents

Question 1: Issue was raised about the context of survey question C8 regarding guns and assumption that all people own guns.

Question 2: The “blues” as expressed in survey question D3 is unclear to student #4. It seems like an adult term. Another suggested term for “blues” is depressed or sad or down.

D1-D19 survey questions responses “most of the time” and “a lot of the time” is too similar. Suggested eliminating the “a lot of the time” choice.

Question 3: Define confidential more thoroughly such as “between you and me” or “secret”. Use other words to explain the concept.
Survey question E34 suggest using the word protection instead of any method

Question 4: Survey question E23 was too detailed in the description. Define what alcohol is, and then ask questions.

Survey question E27 participants expressed that the idea that one could not predict when they would begin drinking.... Student 3 thought it was an ok question. It was suggested that the questions be reordered.

Question 5: H6d, e and f: Even with privacy and confidentiality they felt the respondents would want to move on.

Question 6: G4: Maybe could define stalking. Stalking is an extreme case of harassment bordering on the obsessive.

Other comments: The caller needs to be real! Make sure they can get your attention. Be professional but not too professional, straightforward and direct. Teens were concerned about confidentiality and the selection process. Suggest revising the script to explain random selection process: “The computer picked your number at random”.

Mini Group Findings: African American Adults

Question 1: There was a small discussion on vigorous vs. moderate and the meaning

Question 3: Survey Question H3b Add doctor, my mother, faith or spiritual person to choices

Question 4: L2: There is a need to use the whole sentence along with acronym using terms like AFDC, TANF or the like.

Question 5: M7-M9: Use term major cross street.

Question 8: Survey question F12 Define each medical procedure separately when presenting the question. Break into separate questions with individual definitions had problems with terms

Question 10: Ask, "Do you own a gun?" " question first before asking if they keep any kind of gun

Question 12: H36a and H36b: Include the choice heterosexual.

Survey question D31 Bone density terminology is unclear

Other comments:

Adults recommend calling at a good time usually after 7 PM.

Adults did not have a problem with discussing women health issues with males present

Findings: American Indian/Alaskan Native Mini Groups:

Findings from the American Indian Mini-Groups are presented next, by questions. Other important comments are also included.

Mini Group Findings: American Indian Adolescents

Introduction to survey/general comments: Teens were concerned about confidentiality; need to define better in the introduction and in sections with sensitive questions.

Question 1: C1 and C2: Two students were unclear about what “medical advice” meant we probably need to define it.

C3-11 OK

Question 2. D1: One student said the interviewer might need to read the introduction to section and questions slowly. For this whole section on feelings, students asked why we could not ask questions vs. making statements. For example, change D6 to “Have you felt depressed in the past week?”

Students felt answer choices were confusing, and should be simplified. (Suggest not at all, sometimes, most of the time)

One student wanted to combine D13 and D16, (change to “How often have you felt lonely or

D19: Two students felt this is too personal. Could use “Is your life so bad you felt you did not

F10: “Psychological counseling,” is confusing could you say, “Have you received any counseling of any kind?”

Question 3. E31-E42. Youth want confidentiality to be stressed more before starting this section, very sensitive.

E31, and E32, very personal, students may not want to answer

E34: Change “use any method to prevent pregnancy or disease” to “did you or your partner use protection?”

E42 “family planning counseling” is unclear.

Question 4. E22; could ask the question in a more direct way. Have you drunk alcohol before?

E23 and E24: Do you need all those details about drinks? Confusing

E28-30 might need to remind youth about confidentiality before drug questions

Question 5. H6d – f Add to questions at beginning, “How much do your parents know...about your alcohol use?”

Question 6: No problem, teens know what stalking is.

Mini-Group Findings: American Indian Adults

Introduction Adults did not think 30 or 40 minutes would be enough for the interview, think it is too long for a survey. They also are concerned about confidentiality.

Question 1: Vigorous vs. moderate: E24-E27: two people did not like the word vigorous, too vague. One suggested using “hard” exercise. E25 has too many phrases (per day, per week, per month). Just use one.

Question 2. H5 and H10: Type of health professional. Add “other”, “priest”, “medicine man” to choices

Question 3. H3, H3a. One woman felt the options were too long
Question 4., 5 and 6 OK

Question 7. Questions about emotional problems: B7: Too personal. May need an introduction before this section. Suggest: “There may have been something that happened in the past 4 weeks that caused you stress or emotional problems”.

B8: sound a lot like B7, could delete

B13: delete “downhearted”, use “sad and lonely” instead

B15: item too long, make it shorter J2: Indian people may not answer this, too personal

Question 8. Cancer series. F1: need to explain or define “malignancy”. F12 and F13: terms are too technical. Suggest: “Have you ever had a colon Cancer test?”

Question9: F21 –F23: too much description, too detailed. Leave out details, explain only if necessary. F23: “but not more than” in answer is confusing. Change to: “ a year or less, in between 1 year and 2 years ago, in between 2 years and 3 years ago, in between 3 years and 5 years ago, over 5 years ago.”

Question 10: Violence and accidents: C5 and C6: Indians may not answer this.

C7 and C8: Indians may not answer this.

C9: Put this question (Have you ever been a victim of a crime in which a gun was used) at the beginning of the series (before C6).

Question 12: Sexual orientation: H36a and b, Indians may not answer

Female Questions:

D1: Change to “How old were you when your periods (moon) started?” Delete menstrual cycles

D4: Should clarify that this (Pap test) is a test for cervical cancer, not a STD test

D29: Maybe use “the change” instead of “change of life”

2. C1 and C2: Medical advice: some are not sure what this refers to. May need to define (if needed)
3. Delete D3: “the blues” is not well known. D1-D19: Some teens felt that “most of the time” and “a lot of the time” is too similar. Eliminate “a lot of the time” to clarify.
4. F10: Change to: In the past 12 months, have you received any counseling of any kind?
5. Questions re: sexual activity, teens want confidentiality to be stressed more before starting this section; clarify: “between you and me” or “kept secret”
E34: and E37: Change to “the first time (last time) you had sexual intercourse, did you or your partner use protection to prevent pregnancy or disease?”
6. E42: Term “family planning counseling” is unclear. Could you use “birth control services”?
7. Series on drinking. Teens ask could you be more direct: For examples, “Have you ever drunk alcohol before?” May need to define alcohol dose first (one drink is...) then ask questions.
8. May want to remind youth about confidentiality before drug questions (E28)
9. H6d, e, and f: Add, “How much do your parents know...” to these
10. G4: could define stalking (if needed). : Extreme case of harassment bordering on obsession.

Adult Survey

Introduction: Adults are also concerned about confidentiality. May want to add phrase from adolescent rec. above

1. H3b, H5 and H10: Type of health professional: Add to choices, “other”, “a relative”
2. Questions about emotional problems B7. May need an introduction before this section (for example, “There may have been something that happened in the past 4 weeks that caused you stress or emotional problems”).
3. Cancer series: F1 may need to define malignancy (if needed. F12 and F13: Terms are too technical. Suggest, “Have you ever had a colon cancer test”?
4. F21-23 too detailed, too much description. Explain only if necessary.
F23: “but not more than” phrase is confusing. Change to “a year or less, in between 1 year and 2 years ago, in between 2 years and 3 years ago, in between 3 years and 5 years ago, over 5 years ago.”
5. Gun series, May want to put C9 before C6.

Female questions

1. D31: bone density terminology is unclear (needs a definition)
2. D1: change to “How old were you when your period (moon) started? Delete menstrual cycle.
3. D4 clarify (if needed) that this (Pap test) is a test for cervical cancer, not An STD test.

APPENDIX A
INTRODUCTION FOR FOCUS GROUP PARTICIPANTS
(To be read aloud by facilitator)

Good morning/afternoon. (Or similar greeting). We are here today to look at some telephone survey items that will be in the California Health Interview Survey. This survey will reach about 50,000 households in California and will ask questions about important aspects of health, including exercise, diet, and access to health care.

A company called ARDAC, along with a team at UCLA, is involving many different cultural and language groups in looking at the survey questions to help simplify and clarify the surveys. The project is trying to help produce culturally sensitive and valid surveys to help improve health care in California.

We will be reading some questions to you. In addition, we have a few sensitive topics we want to get your advice on. We need your ideas as to how we can improve and clarify these questions. Please be as honest as you can. However, if you do not feel comfortable answering or discussing a certain question or topic, you do not have to participate in the discussion about that question.

Thank you for coming in today and helping on this important project.

APPENDIX B. SUGGESTED PROCEDURES FOR CONDUCTING A MINI-GROUP

Organize chairs in the room where focus group will be conducted so that participants are sitting comfortably close to each other while also maintaining and respecting each individual's personal space.

Place recorder in a central location.

Test recording equipment before using it during the focus group to ensure that ALL voices are captured on the recorder and are CLEAR and AUDIBLE.

(This may require asking colleagues to sit in on a brief mock focus group to check for this or testing for this with participants.)

Do not use voice activation system (AVS) on the recorder. This option only records when a voice is heard and in some cases, valuable feedback may be lost while the tape transitions from *recording to not recording-to-recording* and so forth.

Before beginning the focus group, emphasize the importance of and ask participants to speak ONE at a time. When participants talk "over" each other, valuable feedback may be lost—garbled.

As the facilitator, speak CLEARLY and SLOWLY (if necessary, i.e., if friends and colleagues tend to tell you that you speak too fast, please, please make a conscious effort to slow down while conducting a focus group. This will also help to control the tempo of the focus group.

7. Place identifying information at the beginning of the tape. Some important pieces of information to consider:
 - Date
 - Location of focus group, e.g., Los Angeles, California
 - Project Name
 - Number of participants AND gender (This helps the transcriber tremendously!)

8. During the introduction, it is important to discuss issues covered in the consent form as well as to assure confidentiality so that all participants are comfortable with responding to the questions. ALSO, inform participants that the focus group will be recorded for transcription and analyses purposes and that no names will be used. In this light, it is

important for the transcriber to differentiate participant responses. Some helpful suggestions:

- a. Assign participants an identification number such as Participant #1, Participant #2, and so on.

AND/OR

- b. Give participants an assignment “name” badge such as Participant #1, Participant #2, and so on to lessen the chance of misidentifying participants.
 - c. Use the assigned identification number, i.e., Participant #1, Participant #2, etc. when referring to a participant. This will especially help out during the beginning of the focus group so that the transcriber can differentiate the voices of each participant.
9. Ask participants to speak up (volume) before and during (if necessary) the focus group. If a response is faint, restate it back in a query format to that participant.

For example:

Participant #3: Yeah, I would appreciate receiving [inaudible to transcriber] if [talked over by another participant—inaudible to facilitator (and transcriber)] me.

Facilitator: OK, participants, please remember ONE speaker at a time.

Participant #3, you just mentioned that you would appreciate receiving a medical appointment reminder by mail and...

Participant #3: Yeah, a reminder by mail will work if they can't call to remind me. This would help me to keep my appointment.

10. Place identifying information on the cassette tape jacket. Some important pieces of information to consider:

- Date
- Location of focus group, e.g., Los Angeles, California
- Project Name
- Number of participants AND gender (This helps the transcriber tremendously!)

APPENDIX C. PARENT PERMISSION FORM

This form was obtained by the facilitators from parents and will be included in this report later.

APPENDIX D. ELIGIBILITY CHECKLIST FOR MINI-GROUP PARTICIPANTS (African American only)

This form was completed by the facilitators from each participants. See the attached "Eligibility"

APPENDIX E.
**TRANSCRIPT OF AFRICAN AMERICAN ADULT AND
ADOLESCENT MINI-GROUPS**

FOCUS GROUP FOR AFRICAN AMERICAN ADULTS

MAY 15, 2000

F Good evening

So this we are doing focus groups like this for African, Latino, Asian and we are doing adults LSD groups and kids in school 6th period. We ask questions about yeah, okay.

I will tell you about the tape and we are also dealing with ah there maybe questions about children under twelve who are but those questions will be answered through the survey by a parent now we are taping this and that,s why we introduced each other before to get our names out but during the time of the tape I,ll go ah if anyone has any questions I will say um number one, number two, number three if you tape right now know names aren't going to be used okay um, um, issues of clarity and sensitivity

(Laughter)

Cause we started a little late we may not get to the questions about you know children under twelve just keep pertain to this age group. So I supplied pen and paper cause we have a lot of questions to go through. I'll try to read three at a time so if I read one two or three maybe you want to jot down real quick um so we can wait till our break to get responses can just write one so if you know which one write down a phrase word help you remember maybe also in your mind for a second questions you want to bring up

Feedback, which will be of questions and issues here Ah no answer, is right no answer is wrong. Every point is very valuable very important for the success of this for this survey first I am going to read the introduction that will be read once ah concerning the phone survey so it will be read over the phone and people respond verbally over the phone and I'm going ask for a name ask for a name or I,m going to ask to speak to a person or I'll use a fictitious name like Jane Doe, okay? This is a California health survey

Hello my name is Mr. Jihad. I'm calling for from the California Health interview survey on behalf of the University of California, Los Angeles School of Public Health good evening. We are doing a scientific survey with the California department of health services and the National Cancer Institute. This survey is about the health of the people

of California and about health care. Are you 18 years 18 years of age or older? Okay
tape

I would like to speak to an adult or following household or numeration of adults. Family selected by computer. Um, also per that this survey is given ah randomly random numbers so that oh you call name randomly chosen. Any information that is pertains to your personal identity that may be used this evening. Related to your cancer.

My name is continue on say we got a child or something. Hello my name is, ah, Mr. Jihad. I'm calling from the California health interview survey on behalf of the University of California, Los Angeles School of Public Health phone survey with California services and the National cancer center.

The (not audible) information we are asking about tonight is for most communities of California. Therefore the results may help improve health, community health services in the community and across the state. Are you a California resident? Yes? Continue. No? Your phone number has been randomly drawn to be in our scientific sample of Californian households

F This survey is about topics such as your general health, physical activity, mental health, the foods you eat, smoking, drinking and health insurance. We, ll also ask you about your occupation, income, ethnicity, and the number of people in your household. I want you to know that your participation is completely voluntary. The results will be not linked with your name or household. Any identifying information about you will be kept strictly confidential. The interview will take about 30 to 40 minutes. You can skip any questions that you do not that you don,t feel comfortable answering. Do you have any questions about this? Yes? Answer questions, continue. No? I can do this interview now if that's okay? Yes? Continue. No? If another time is more convenient, um if another time is more convenient we can schedule a better time. If you would like more information I can give you the name and a toll free number of the researchers at UCLA in charge of the survey. If I can give you the information now or at the end of the interview if you like. So that's the introduction. Are there any questions? So I guess at this point I will go into the questions about moderate activity. People understand sweating and fast heart rate. This is question E24 page 26. The paper work is right there. E24 first questions are about physical activity that you may do in your free time including exercise, sports, and physical active physically active hobbies. Please do not include any walking or biking that you recorded previously. I, ll move from vigorous to moderate activities. Between three days did you do any vigorous activities in your free time or at least 10 minutes that caused heavy sweating or large increases?

A1 What would be like moderate?

F Three workouts. Sorry (inaudible) not make that very clear that person would never play sports or, um, okay move on to the next set of questions is fine. What kind of

health professional people do you go to when you are sick for advice? What kind of health person or health professional do you usually see when you require care? What kind of health person or Health provider do you see or talk to? What kind of health provider do you talk to who are interested in the opinions we have or others we should include?

Survey looking for usual hospital orientated or mainstream.

A1 Might talk to your pastor.

F Um okay

A1 I'm serious

Options

F They all seem the same um so I'll read them off real quick.

One is a nurse, nurse practitioner, nurse midwife; two is a midwife, non-nurse; three is a physician's assistant; four is a pharmacist; five is an acupuncturist; six is a chiropractor; seven is a Herbalist or herbal healer; eight, um, is a homeopath; nine is a spiritualist; and ten is other kind of healer, um, range from...

A2 Midwife must...

F Um

A2 Pretty

A1 Aspirin

A2 Spiritualist

A3 Common language

F Practitioner

Next section places people go when they are sick page. Page 3. What kind of place do you go to most often? The office of a doctor or some other kind of health professional a clinic, or health centers an emergency room or some other place? Actually, other options would be also um don't, go to one place most often or don't know or

A3 [Laugh.]

A1 You

F How do um

A3 My mama my mama is the doctor.

F So you say when you needed help you go to family?

A3 Uh huh.

A2 Depends on how severe or whatever the problem is.

A1 Situation you mean?

A3 Yeah Right

A1 Most often. Just speaking for my self I go to my pastor for advice. Uh, he directs me in the right way--gets me going.

F Okay A3. So that would be also he recommending where to go or actually give first?

A3 Man, well it depends on the situation. Usually I will talk and try figure it out first and then send me in the proper assistant I need.

F Does that person represent whatever formal training in medicine or in the health or healing spiritual

A3 Thinks its spiritual yeah

F What kind of health professional is he? Is it the office of a chiropractor an herbalist doctor or nurse or some other person.

A2 Insurance program

F Page 68 are you receiving um AFDC works or aid to families with dependent children temporary assistant to families or cal kids.

A3 Wish I did

A2 [Laugh.]

F Do people understand the acronyms the letter s or what the

A3 A lot of people don't

A1 A lot of people don't understand

A3 They are

F ...

A3 What means?

F ...

A2 Say what w means.

F The acronyms people use the letters go straight to the whole sentence

A1 Go straight sentence

A3 For whole thing

A1 ...

A3 ...

A1 Took me a long time to figure out AFDC aid for dependant children

F ...

A3 Like a microwave people quicker thing AFDC and you forget where it comes from

A2 Um that's right.

A3 Come back the long version of aid to dependant children then people would know when they see the AFDC they know.

A2 Exactly.

A3 Just like if you see a church God in Christ then you don't know the creation is...

A2 Somewhere, incorporate the whole?

A1 Some people you know need aid like that

F Last questions about your zip code what street you live on etc. Okay what is your zip code? Need to know your house address just the name of the street you live on what is the name of your street what is the name of street down from the corner from you the cross street um crosses your street. And what is the name of the street down from the corner of you that crosses your street.

A3 Man. A lot of people ask for like major cross streets.

A1 Yeah.

F Right, right.

A3 My cross street is 114th and the closes major street would be Imperial Hwy.

F Right, exactly

F Group

A3 Exactly

F Okay, um, worry about issues how too intrusive. Do you feel comfortable giving out cross streets or even where you live is that are you fine with that do you think people c correct directions

A3 ...

A1 [Laugh.]

F Okay.

F Process okay.

A2 [Laugh.]

F Information. Personally ah not directly will be kept separate.

A1 Um

F Okay Like this is very general

A3 ...

F What we got we tell people

A3 Personal you know when you take a survey you know just like you already too deep into it though you already know cross roads where...cross the street

A2 Um

F Question, question...

A2 Yes

F Okay

A2 ...

F All right so next we are skipping six okay go to part seven now. Question is about emotional problems mental health.

A1 Ok.

F On page ah um 52. There is one question on page 62 this a section there is also question I n b section question A2 during the past twelve months do you think you needed help ah I think I need to return to read section go back to page 6, B7 introduction. B7 I am going to read some types of activities. During the past 4 weeks did you do less than you like would have liked because of any kind of emotional problems? In the past four weeks did you not do your work or other activities as well as you think because of emotional problems such as feeling depressed or anxious.

A1 ...

F Not Do your work or other activities as well as usual. Question B13. ...Weeks how much of the time how much time has your physical health or emotional problems interfered with your social activities like visiting with friends, relatives, etc.

A1 A lot of people some people you know depressed or you know whatever r or stressed out so fill out the survey maybe they can get help somewhere, huh?

A1 Yeah.

F All right.

A1 People go through a lot of things some don't know how to and some do

F Because question, um, question B13

A1 ???

F Sad.

A1 That was the last one.

F That was the one before last one. Okay. Um during the last 4 weeks how much of the time has your physical health or emotional problems interfered with your social activities like visiting with friends relatives, etc. Fine.

Question A7 through J7

F [Laugh.] Probably. During the past twelve months do you think you needed help or emotional or mental health problems such as feeling blue sad anxious or nervous. We have a slightly different survey geared towards and this developed sad blue or nervous is those appropriate terms.

A1 Would bed.

A1 Blue

F Mostly used as...

A2 ...

F Okay

A1 ...

A2 ...

A1 Every Monday.

A1 [Laugh.]

A1 [Laugh.]

F [Laugh.]

A3 ...

A2 ...

A1 Yeah.

F Okay next section.

A1 Oh my god.

A1 Different language.

A1 Yeah.

F Yes, next generation define. Question F1, page 28 is about emotional problems or I'm sorry...how can you quote read into questions about cancer in the least offensive way? These next questions are about your and your family's history of cancer.

About your families history about cancer doctor or other health professional that you had cancer or a malignancy of any kind.

F1 ...ostimy, sigmstomy , colonoscopy , or a proctosopy done by a doctor looking for signs of cancer or other problems in your colon.

A3 ...

A1 [Laugh.]

A1 I understood. [Laugh.] I understood. I don't, thank you.

F OK, clarification. There is a um there is a section for the survey reader if needed to say a sigmoidoscopy is an examine in which a health care worker inserts a flexible tube into the rectum in the lower part of the colon to look for signs of cancer or other problems.

A1 Clear.

A1 That's clear.

A1 Feel that other word.

F A Colonoscopy is a similar exam, but uses a longer tube to exam the entire colon.

A1 That's clear. Colon cancer in my family prepared my mom.

F Ok. Colonoscopy is done you are usually given medication through a needle in your arm to make you sleepy. A protoscopy.

A1 Ok.

F A protoscopy is an exam that uses a rigid tool all the follow-up information have you ever had this procedure done by a doctor looking for signs of cancer or other problems in your colon?

A3 That's clear.

A3 [Laugh.] Medical slang men people don't know what medical words are don't have very simple ways to break them down. It's very simple, but any generation you look at,
p no medical dictionary.

A1 That's right, yeah, unless they really need to know each word.

F So maybe they need for each word right away needs to be defined.

A3 Yeah

A1 ...scare a person off because they don't know what's going to happen to them. You know, they need to read and understand what that word means and what they are going to have done to them before they sign just paper saying, 'Yeah, Ok, you can do this.'

F ...That's a lot of information to follow up. Could you put that all in one question or do you think that it needs to be broken down.

A2 ...

A1 Needs to be broken down

A1 Yeah.

A1 Um umm.

A3 Needs to be broken down from the beginning.

F Each one individually.

A3 Yeah.

A1 Yeah.

A3 Yeah, I went to medical school and I am still ...exam ...in like some just call by the proper name.

F F12 recommendations to improve that break down into possibly three separate questions?

A1 Yes. Yeah.

F One term and definition.

A3 Yeah. Fine, that's a word

F Definition has to go along with it.

A1 Yeah. My mom when she went for her, she had the doctor write it out so she knew what he was talking about.

F So the definition itself would be understood.

A1 Yeah, yeah, the definition.

A1 A couple of times if they don't understand, read it again some people catch on after reading it once or twice.

A1 Yeah.

F So you were fine with the one, ok. F13, How many of these oscopy, colonoscopy, or proscopy, how many of these exams have you had in the last 10 years?

F14, When did you have your most recent exam? A year ago, a month ago? What was the one main reason you had the exam? And if the respondent says the doctor

told me so, then probe for a more detailed answer--oscopy, coloncopy , proctoscopy when the results were not normal. After these results, did you have additional tests and or treatments? F19, what is the one most important reason why you have one of these exams in the last 10 years? I'm sorry, what is the one most important reason why you have never had, not had, one of these exams in the past 10 years?

A1 ...

F Had a doctor or other health professional recommend that you have a tub, colonoscopy, or ...?

A3 ...

F What is the one most important reason why you have never had, not had, one of these exams? A lot of these questions are dependent...

Moving on to topics, point 9. How do people feel about questions involving blood, ...blood in stools, especially with Question F24 on page 32. The following questions are about the blood stool or cold blood test, a test to determine whether you have bloodier stools or bowl movement. Are those words clear?

A1 Yeah.

F The blood stool test can be done at home using a kit. You smear a small amount of stool on cards at home and give the cards back to the doctor or lab.

A1 The lab, oh that's clear.

F Actually, the question is, have you ever done a blood stool test using a home test kit? ...How many home blood stool tests have you done in the last three years? F23, when did you do your most recent home blood stool test? ...24...

Moving on to point 8 now for the main topics... I'm sorry, not 8, poin accidents. Question C5 on page 14, was a gun, knife, or other weapon used when this injury occurred? How many times were your seriously injured in the past 12 months? What was the cause of the most serious injury? C... you have ... where were you when the injury happened? ...Very detailed...are these questions clear? And I'll just read C5 one more time.

A1 OK.

F Was a gun, knife, or other weapon used when these injury occurred. C6, Do you keep any type of gun in your home, car, or garage? C7, Have you received any formal training on how to use and store these guns? How many of these guns are handguns? Have you been convicted of a crime in which a gun was used?

A3 ...that can eliminate ...like we know that you have a gun.

A1 Yeah, that's right...assumption.

F ...I guess ...a certain person.

A3 You might get some vibes there if...yeah.

F ...Right so if answer is yes.

A3 If it's no, you go through?

F If it's not then it's not appropriate?

Point 11 now. All right, we'll skip that. Point 12, sexual orientation, page 50. H36A. Are you gay? Female, you would add lesbian or bisexual. Are you gay, lesbian, or bisexual?

A1 What's with you? Who would ask a question like that and honestly expect you to write it down saying yes or no. [laugh.]

A3 ...

A1 Yeah.

A3 All the groups there, gay, lesbian, bisexual...

F ...

A3 That's where you going to get ...sensitivity...group up.

F If they only ask questions ...maybe

A3 Don't want to talk...

F Test...

A3 Yeah, directed to the gay and lesbian. Exactly. You don't have my category in there, so.

F So that could change your openness to the questions.

A3 Yeah.

F ...judgment area.

A3 ...

F Say ...would affect those questions.

A3 ...three people...

F ...Gay, lesbian, bisexual, heterosexual

A3 ...

[Laughter.]

F These are very important questions...I mean, certain ethnic cultural groups are not as open with the idea of sexuality...How to words these...as possible...questions, um...woman. OK ... All right, there are a few more questions and these are asked of only females...in the room, so at this point, we'll call

It's just a few questions so we'll give you a dollar.

Ladies, ...uncomfortable. All right, so this is question D4 and D5 on page 16 so, uh. The question is about female ... issues such as ...and first period. Page 15, question D1. How old were you when your period started? How old were you when your menstrual cycle started?

A2 Yeah, pretty much the same. Period or menstrual or monthly.

F Should there be, uh, should only one be used or should we use both ...

A2 Yeah

A4 We both understand...look at it both ways.

F There is no person who you feel or in general will understand each one?

A2 Oh, they're going to understand those two terms.

A4 Yeah.

F OK. Question B2. How many children have you given birth to? Only those that were born alive?

A4 That's clear.

F B4, Have you ever had a Pap smear test? It's a routine test for woman in which the doctor examines the cervix during a gynecological exam. It takes a cell sample from the cervix. It takes a small stick or brush and sends it to the lab.

A4 ...

F So, I'm sorry. So you're saying that the extra should be included.

A4 Yeah...

F So that...pap smears.

A4 Because anyone knows what a pap smear is if you just have ...break it down...second line expand.

F The definition was clear?

A4 Clear.

F Any technical words that a woman would not understand?

A4 No. That one is pretty clear.

F All right, B5. How many pap smears have you had in the last six years?

...Page, B29, quote unquote, change of life or menopause, which of the following applies to you? ...2. My periods have become irregular or stopped because of menopause, 3 I have stopped having periods for medical or surgical reasons, I never had periods, A, Don't know, did not...

A4 Yeah, them is all clear.

F Regarding the change of life for menopause...?

A4 Yeah, because they have a choice to chose. Yeah, them is all clear.

F ...and question...are you currently taking any hormonal replacement supplement prescribed by a medical doctor. This is a supplement, pill, or treatment that gives woman more of a ...supplement to help control symptoms.

A4 That's clear.

A2 Clear.

F Have you ever had a bone density test? A test to determine bone lost.

A4 Yeah, it was clear. I just didn't know. The term.

F So you know the procedure or the idea of what it is, but you're saying have you ever

- A4 No, I just understand that word. That what throw you off, that word. Yeah, without explaining what it is.
- A2 Yaeah.
- F ...I see you're saying ...are also.
- A2 Woman over 40...you guys are...age 50+
- F These are actually questions for 50+. ...31...So, at this age maybe your doctors may have not talked to you about this.
- A4 But I'd heard. You know, my mother and my sister are going through the changes, them making statements on menopause and going through and it isn't nothing that I have never heard of.
- F The formal question that change of life were starting at age 40+.
- A4 Is that it?
- F Yeah...

Transcript of African American Adolescent

FOCUS GROUP

FOR

AFRICAN AMERICAN ADOLESCENTS (TEENAGERS)

MAY 15, 2000

F Questions...We want your feedback, how you feel about the question, how they're worded, or how can they be improved on. ...Because we want to ...California and...people your age, adults, and children age of 12...some of the questions may be sensitive but one way of knowing ...personally. Think of yourself as.... ..mother or friend or someone you know ...understand. Telephone survey, ...I'll start the survey. ...Topics for adolescents... ..Jane Doe. Hello Jane Doe. My name is Mr. Jihad. I am calling for the California Health...Survey on behalf of the University of California at Los Angeles, School of Public Health. We are going to ... survey for the California Department of Health Services and the National Cancer Institute. We are talking with young people like you so we can use this information to possibly help improve the existing health services for young people in ... and across the state. You were selected by chance for this survey and it is completely voluntary and the information you give us will be kept confidential. Your name will not be connected with your answers in the final results. The interview will take about 20 minutes and is all done on the phone. You can stop the interview at any and you can skip any questions that you want to skip. ...Topics we are about to ask.Words that you are not clear about. So I'll be asking some personal questions about your health and also questions about health behaviors like the food you eat, exercise, and also about tobacco, alcohol, and drugs even if you don't use any of these. ...Question about safety, gun, and violence, and a few sexual behavior questions. Again, you can skip any questions that you want to. Would you like to start the interview now? Yes?Name, telephone number, and researchers at UCLA in charge of the survey. I can give you the information now or at the end of the interview if you would like.Phone...questions... .. I think I'll do three at a time then I'll break so. #...1were you injured serious enough that you got medical advice or treatment?Were you injured serious enough that you got medical advice or treatment? How many times in the past 12 months were you injured seriously enough that you got medical advice or treatment? C4. Were you injured with a gun, knife or other weapon? ... Where were you when the injury happened? Where were you when it happened? ...Do you have a gun in the house, car, or garage?

AT1 inaudible

F inaudible

AT1 Female response—inaudible. Yeah like they been shot or hurt by a weapon.

F You're saying that the statement kind an already assumes that someone already been injured?

AT1 Yeah, OK. ...Hurt.

F OK. Inaudible

AT2 inaudible

F See, the question ... sensitive. It maybe seems like. ... Question ...asks someone the question that may be sensitive to it, responding to it. You have to make a point to bring it up. Someone... .. information.

AT1 inaudible

F Not knowing...and that's they way... ..totally confidential ...gun ... How many ... number workresponding ...parent, father, mother ...Question D1. I am going to read a ...statement about how you may feel emotionally about feelings in general. I only want you to think about your feelings in the past week, including today, but not more than a week ago. ... Rarely true, sometimes true, true a lot of the time, and true most of the time. In the past week, things that usually don't bother you bothered you. Was that rarely true, sometimes true, true a lot of the time, or true most of the time? ...Family. Was that rarely true, sometimes true, true a lot of the time, or true most of the time?Some people may not understand that... ..

AT2 inaudible

F One word that comes to your mind. synonym

AT1 inaudible

F Synonym.or ...question ... Do you know that you... ..? Was that rarely true, sometimes true, true a lot of the time, or true most of the time?

AT1 Depressed

AT2 Eliminate one.

F True most of the time. Which one would people understand?

AT1 Inaudible

AT2 Inaudible Most of the time

F Understand most of the time better and um a lot of the time ... should be eliminated?

AT1 Inaudible

AT2 Inaudible

F I am going to ask questions about...I am now going to ask questions about the food

AT2 inaudible

F Skip page...OK. ... I want to remind you that all of your answers will be kept confidential. These next few questions are about sexual orientation and activity.

AT1 inaudible

AT2 inaudible I mean I don't know.

Fso ... so maybe at the beginning at the ...confidential ... a few of the words to request a need?

AT1 Yeah.

F Secret, private.

AT1 Private...Yeah.

F ...time already. ...first page of confidentiality, so um each time should the words be changed?

[pause in tape.]

I'll read question #10. Four questions... .. Here's a question ...10, page 27. One question is about psychological and emotional counseling. In the past 12 months, have you received any psychological or emotional counseling? ... And

AT1 inaudible

F inaudible ...Question P31 ... Have you ever had sexual intercourse? Where were you when you had sexual intercourse for the first time? The first time you had sexual intercourse, did you and your partner use any methods for preventing pregnancy or disease?

AT1 ...

F The first time you had sexual intercourse, did you and your partner use any methods for preventing pregnancy or disease?

AT2 Yeah, protection...she used...protects herself.

F Method...much more clear that within your age range you need more protection.

AT2 inaudible.

F The last time you had sexual intercourse did you or your partner use any method to prevent pregnancy or disease? Or I can read a list. Either tells me which methods you used or I can read a list of methods and you can just tell me ...

How many children do you have? This past year, have you received family planning counseling or services?

P22. Have you ever had more than a few sips of any alcohol drink like beer, wine, mixed drink, or liquor?

P23. ...A can, or bottle of beer, a glass of wine, a shot of liquor, or one mixed drink. How many days in the past 30 days did you have at least one drink of alcohol? Want me to repeat that one again?

AT1 It's clear, but ...much.

F One drink would be a can, or bottle of beer, a glass of wine, a shot of liquor, or a mixed drink or how many days in the past 30 days did you have at least one drink of alcohol?

So AT1 you said ...

AT1 Yeah...it was long.

F ...

AT2.

AT1 Yeah

AT2 ...how many times...

F So you're saying ...

AT2 explaining the categories...explain...question straight out...explain the categories.

F So you're saying instead of going through the whole run down, we need to define alcohol first and then you should ask questions.

AT2 Yeah

F I want to remind you, P31, I want to remind you that all your answers will be kept confidential. These two questions are about sexual orientation. Do you feel sexually attracted to ...choice and so on...boy, girl, about the same, don't know. Question... On how many days in the past 30 days did you have five or more drinks in one day?

AT2 Beer, glass wine, shot...

F When you drink alcohol, about how many drinks do you usually have? When you drink alcohol, about how many drinks do you usually have?

I'm sorry

AT2 ...

F A car after you has been drinking? How many are you going to drink alcohol in the next 12 months?

AT1 [laughter.]

F OK, ...funny, if someone may think it seems funny then it's an issue

AT1 ...OK wait. Already drinking or about to start?

F ...will ask...going back ...

AT1 Yeah, ...maybe if the person stops drinking ...they're likedid you have...then they

At2 ...They don't want to do it the next ...time, but then they want to wait, maybe it's not 12 month, but it's somewhere down the road. It's like, 'Oh I don't want to do any of that this month, but next month I'll... ..activities ...so I'm going to do something. Therefore, the question sounds fine. I mean, this is the way you take it. She heard it a different way I heard it. I mean, the question sounded right to me.

AT1 Yeah...

F Issues of making...respect of law-abiding youth.

AT2 I mean, they believe that they were like that ...future...but they want to wait until they're a certain age for certain ages.

F It seems like, but this is very important, this is very important. I agree, some people, the reaction of some people, that's fine. We all drink more...

AT1 They respect the fact that I can't drink, OK.

AT4 That's weird.

F Well take that into consideration, but maybe someone doesn't want to drink so what's the legal age here in California? 18?

AT1 21

F So maybe, is there a way that you want to rephrase that question or ...young ...

AT2 ...12 ...18

F You should not be drinking...

AT4 Is there ...alcoholic

F Would you be offended by that question?

AT4 No, no I wouldn't be offended.

F Question ... Have you ever tried any drugs such as marijuana, cocaine, sniffing glue, or other drugs? Have you ever any drugs such as marijuana, cocaine, sniffing glue, or other drugs.

AT2 ...hear that.

AT4 [Laughter.]

F P29. This next question is only about marijuana. In the past 30 days, on how many days did you smoke marijuana?

AT2 ...

F This question is about glue sniffing, ...aerosol. Just in the past 30, on how many days did you sniff glue, read the content aerosol spray can, or inhale any paint or spray to get high?

AT2 ...Fine.

F We're finished with that section. We'll go on to questions on how much your parents know about your alcohol use, sexual behavior, tobacco use.

H6B. Alcohol use. A prior question would be H6A. These next questions are about how much your parents know about you. How much do your parents or guardian really know about where you go at night? Would you say they know a lot, know a little, or know nothing?

AT2 ...

F The question sets up your choices of answers, so that's the same for H6D under alcohol use.

Tobacco use. Your sexual activity. Page 9. Have you ever been stopped by anyone?

AT2 ...

F

AT2 ...the whole...call in, leave a note, messages and stuff like that. Somebody who, I fill like people who follow you and mug, but stopping? I wouldn't consider that stopping.

F That's good too.

AT2 Car... ..

F Sending letter ...positive or negative? Is it bad?

AT2 It depends on the content of the letter.

F What do you mean by content of the letter?

AT2 Like, ... I could call and AT4 and ask how she is doing today, but if I call and ask her sexual oriented questions...then ...questions people don't want to answer. But then ...

F ... Relationships... All right then, this is the last section. Um, before that the question and at this point I just want to ask you general ...and comments on how you felt about verview on what ...California Health Survey. Some reactions to

it. ...Comfortable. Some of you knowing, actually knowing the kind of things that ...know is going to be on it, but if you knew it was coming. Someone calls you now and says that you were randomly chosen and ...California Health survey, would you want to be a part of it?

AT4 No.

AT3 The thing is like the way that, well the way that I am and what I know about... .. I do talk on the phone a lot. You have to come at a young person that is like teenager like, I could be on the phone with my girlfriend or talking to my boys about the track meet... Calling a person out of the blue, I don't know who is doing the calling for you guys, but make sure the caller is a very open person. The caller has to be a person that can get your attention right off the bat because if somebody calls my house just randomly, like just reading a paper [script], 'Well this is the UCLA doing this...' I'll be like...

AT1 OK, yeah right.

AT3 I have other things that I could be doing. So a word of advice is make sure it's a person that could get your attention, a young person. Well look man, ..., you have to be professional with, but don't make it too professional because we're like open, we're like people, like just to have fun, we could be on the phone talking to our homiest or we prefer doing that then just sitting hear ...questions. Yeah man. Yeah my mom know. Get it over with. Have someone who will get your attention.

Fexcited...

AT2 Yeah.

F Actually, real quick. How many of you four any done surveys, phone surveys before?

AT1 Yeah, I have

AT2 Yeah...

F Overall, have you done one or many? How do you feel about phone surveys?

AT4It's too personal.

F Time. Does time play, ...determine.

AT1 Yeah.

AT3 It does because a lot of people ...at our age, we have things to do like track practice, get home at 5 PM, homework, we have to study for the SAT, or we have to go out, we have a study group coming over our house or we want to go to the movies with our family or out to eat or something like that. So a lot of times just sitting and answering questions...eh, I got this to do, TV show is on, ..., this boy is fine, I got to watch him, that girl is good, ...you know what I am saying about? It's got to be something to get our attention so we won't be sitting on the phone bored, like, hurry up, you got a 1000 questions, you know what I am saying?

F Actually, the introductions states this interview will take about 20 minutes. Does 20 minutes sound excessive?

AT1 Too much.

AT2 ...but it's like it could be a 20 minute phone and people will ask you questions...they going to be looking at their watch..

AT4 I look at a trip to Magic Mountain I don't know if nobody notices this, but me, but on my trip to Magic Mountain, it seems like it takes me forever to get there. Know what I am saying, but it takes me no time to get home, but if you look at your watch it's the same amount of time because like you can't wait for it to be over so if your conversation is like cool and your cool with it, 20 minutes will go by in no time. But if you're boring.

F Knowing what the subject is about.especially link... People... California Health ... Is it worth having to you?

AT2 ...

F Well, that concludes the survey and any thoughts, questions, anything? Well, thank you very much.

APPENDIX F.
**TRANSCRIPT OF AMERICAN INDIAN
ADULT AND ADOLESCENT MINI-GROUPS**

FOCUS GROUP

FOR

NATIVE AMERICAN ADULTS

MAY 17, 2000

- F: What you do is tell me whether it's clear, whether you understand it or not, and if someone from our community would be willing to answer it in this present form. If you don't think a person from the Indian community would answer it or understand it, then give us suggestions on how we change it, how the question can be changed. Again, I'm just here to help you through this process. This is not my survey, it's not California World Indian Health (mumble) survey, it's not our tobacco program survey, it's a survey being developed by ARDAC and UCLA and the state (mumble). So just to clarify that, so don't feel like you'll offend either Ann or myself by saying, that question is totally (mumble), it's off the mark, or if you hear questions that are good too, let us know—
- NA1 Any questions that will be elders, asking the elders, or are you asking the household?
- F Oh, the question? They'll call the household randomly, the numbers will be generated by a random program, and someone will call that number and if it happens to be an Indian family, they will ask for an adult, or a head of household, or someone of that nature who would be willing to do the health survey.
- NA2 Like a telemarketer.
- F Sort of like that. And what they will say is that we're not trying to sell anything, we're not trying to promote anything, we're just doing this survey to help understand what the health status is of our communities and the purpose of the survey (mumble) if this is a good time to go through the personal answers that (mumble) is willing to do the survey. And so our job, or your job then is to make sure that the questions that they ask, some of these questions are not, there are 40 or 35 pages of questions so I'm not going to go through them all.
- NA1 We only have an hour. I hope not.
- F So we'll just go through some of them, the ones that ARDAC, UCLA, Health, need to be reworked by focus groups. Well, let's go ahead and get started. What they will do is

they will call and say, “Hello, my name is blah. I’m calling from the California Health Interview Survey on behalf of the University of California at Los Angeles School of Public Health. We are not selling anything. We are doing a scientific survey with the California Dept. of Health Services and the National Cancer Institute. This survey is about the health of the people of California and about health care.” And then they ask, “Are you 18 years of age or older?” Yes, then they continue and they will ask the number of adults in the household, and if one of them would be willing to be interviewed. They’ll say something like, “Your telephone number was randomly drawn to be in our scientific sample. This survey is about topics such as your general health, physical activity, mental health, the foods you eat, smoking, drinking, and health insurance. We will also ask about your occupation, income, ethnicity, and the number of people in your household. I want you to know that your participation is completely voluntary. The results will not be linked with your name or household. Any identifying information will be kept strictly confidential. And the interview will take about 30 to 40 minutes. You can skip any question that you don’t feel comfortable answering. Do you have any questions about this?” They would answer yes or no.

NA3 30 to 40 minutes is long.

NA2 That’s a very long time.

NA3 They’ll probably turn it off right about then. It’s too long.

F That’s good feedback.

NA2 Also, before you say, quite a ways before you say we’re not selling anything, it should be more up front, before, because by the time you get to that, it’s already “click.” I used to be a telemarketer so I know.

NA3 Yeah, it is too long.

F That’s a good point. So make it really concise

NA2 Compact.

F Okay, so this first series of questions then are about vigorous vs. moderate activity. So we’re going to ask, will people understand the difference between the two, if they know the symptoms, like sweating and fast heartbeat, fast heart rate. Okay, so this is what they would sound like. “These next questions are about physical activities that you may do in your free time including exercise, sports, and physically active hobbies. Please do not include any walking or biking that you recorded previously. I’ll move from vigorous to moderate activities.” So do you think that our communities would

NA1 Do you think they’re going to know what vigorous means?

F That's the question.

NA2 Unless they have the symptoms.

NA1 Well, how would they know if it's vigorous or what did you say?

F Moderate.

NA1 —or moderate if they don't know what vigorous is?

F So the interview should either explain what vigorous is or do something else.

NA1 I would do something else.

NA3 Use different words.

F Like (click).

(laughter)

F So use a symptom like—

NA1 Is it hard for you, is it hard, moderate, or strong or moderate.

NA4 (inaudible)

F You would keep the terms more direct, simple.

NA1 Yeah, simple.

NA4 (inaudible) ask questions.

NA3 (mumble)

NA1 Because if you're going to be talking to elders too, they're going to go, what's vigorous? What is that?

NA2 What's exercise? No, I'm just kidding.

NA1 Yeah, exercise, what's that? You know.

F So you feel then that vigorous should be changed to something more—

NA1 Yes, definitely.

if I

got the call, I would be trying to hurry you through your questions. To me, I think it would be easier if you had an A, B, or C question, just “Did you do exercises a) in a month, b) in a week, c) biweekly, or none of the above.” Instead of trying to have that person remember, “Did you do it in a month, did you do it in two weeks, did you do it last week?” It’s too hard for them to remember that whole sentence instead of just breaking it down, going, “a) a month, b) a week, c) within the last few days, or none of the above.” To me, if you want to move your questions on faster, because it’s not going to move faster like that. I’m sorry, but...

F No, that’s fine.

NA2 If you call, and you’re starting to use all these big words, say you’re calling a reservation and say, they’re like, “Well, whom are these white people calling me?” You know, that’s how they’re going to see it, and they’re going to hang up the phone.

NA1 “What are they trying to do?”

NA2 Yeah, “why do they want to know all this business?” And there’s going to be a lot of people not wanting to give you the income. Like, what does this have to do with anything?

F Good point. And we'll move onto the next question that says, "On average, how long do you do these vigorous activities each time you do it?" So again...

NA1 Yeah, a, b, or c.

F Okay. "Over the past 30 days, did you do any moderate activities in your free time for at least 10 minutes that caused only light sweating or slight to moderate increase in breathing or heart rate?" (Click)

(Inaudible comments)

F "How many times per day, per week, or per month did you do this over the past 30

NA2 Uh let me think. Let me get my calendar.

F Okay, good. So they need to be consistent and do the, b, c.

NA1 They just need to break them down. Less wording and just breaks them down. Because people don't want to hear all that. By the time you get to the end of your sentence, they had forgotten what you had said at the beginning of the sentence. You know.

NA2 And then you have to realize too that you're asking for the parent. You don't know if it's a single parent or if it's a parent that the other parent's not there at the time, you got all the kids, maybe they just got off of work, maybe they got all the kids acting this and acting that and they're not going to want to sit there and say, "Okay, what was your question again?" So it'll be way more over 30 minutes. You've got to (mumble) real swift.

NA1 Because I think the a, b, c, questions, when you go through them, you cut down your questions, you put them in a, b, it'll go a lot faster, it'll go a lot faster. I know when you say, 30 to 40 minutes, ugh!

NA2 Can you call me back another time?

NA1 That's almost an hour. If you think about it, that's almost an hour, you know?

(Click)

F On average, how often do you do these moderate activities each time?

NA1 If they can remember what activities you're asking about, you know? Because you asked earlier about other activities. What activities is he asking about?

F All right. Okay, moving on to the next (click). What we're going to do is ask, or what they will do is ask the type of health professional's people go for medical advice or for assistance. I'm going to read the question and the list of the (click). You let me know if there needs to be more or less or if there's some I forgot or it needs to be changed. This is how the question reads: "What kind of health person or health professional do you usually see when you get health care?" And the person j to doctor, nurse, etc." then that's one option. If they want to wait for a list, the list would be like this: "Nurse. Nurse practitioner. Nurse midwife. Midwife. (Mumble) nurse. Physician assistant. Pharmacist. Acupuncturist. Chiropractor. Herbalist. Herbal healer. Natural—I don't know how to pronounce that. Naturalpath. Homeopath. Spiritualist. Other kind of healer. Don't know. Refuse."

(Laughter)

NA4 Medicine man or bartender.

(Laughter)

NA1 But are these questions going to be asked just to the Native Americans or are these asked for everybody.

F Everybody.

NA1 Because I was basically looking at the Native American part of it. I'm not looking at the overall.

F So do you think we need to add or include somebody that hasn't been mentioned.

(Click)

NA1 Those are good, but I didn't hear anything about an Indian health clinic, you know clinic.

F Yeah, this is the health professional. So it'll just be the person. Like, nurse, midwife, physician assistant, pharmacist, chiropractor, herbalist, spiritualist, other kind of healer, don't know.

NA1 Not the ones I know from the health clinic.

NA2 You can see the doctor or they give you a nurse practitioner. So when you go to your appointment, you don't know exactly whom you're going to see at the clinic.

F You mentioned medicine man or bartender. But did you think that if we include medicine man or medicine person, then that way, would that add, do you think we should add that?

NA4 (inaudible)

NA2 You don't think that would offend anybody?

NA1 Yeah, (mumble).

NA3 Well, they don't really read it all, they just kind of wait for the people to...

NA2 Because the spiritual one I think would fall under medicine man.

NA1 Yeah, spiritual leader.

F Spiritualist? Okay.

NA2 Yeah, that would fall under medicine man. Because they might think it was a mockery.

(click)

F Yeah, they would do the list only if the person wasn't sure. Okay, the next one is where people go to for help when they're sick. Again, do we need to add or is this question health person or provider did you talk to?" (Click) The assumption that the previous question they (mumble) to a certain place for health care. A certain person the last time you went to a place to receive health care for something. So the question would be, "What kind of health person or provider did you see or talk

NA1 The question before, just if they answered doctor or nurse, then that would answer that question right there.

NA2 Or Indian health care clinic.

NA1 So you're doubling up your questions.

F So you want to combine the questions when they're very similar.

NA1 Because they're very similar from the one you just asked.

NA2 Are you repeating yourself?

NA1 Because that's what it sounds like, that you just repeated yourself.

NA4 (inaudible)

F And then mostly behind this question, they want to make sure they have all of the options from the list. The nurse, nurse practitioner, physician assistant, pharmacist, spiritualist. So that list is comprehensive you think or do we need to add more.

NA1 Uh-uh. That's long as it is.

NA4 Yeah.

NA2 Because some people, when they get diagnosed for something, they go to the roundhouse, or the sweat lounge. (Mumble)

NA1 So that's the spiritual.

F This next one is where people go when they're sick. (Click) We're kind of doing it (mumble). It's not the way the question is laid out. They're kind of more back and forth. This question then would ask where you go most often and it goes like this: "What kind of place do you go most often? The office of a doctor or some other kind of health professional or clinic or health center, an emergency room, or some other place." And then it gives you the list. "Office of a medical doctor. Office of some kind of other health professional. Clinic or health center. Emergency room. Some other place. Doesn't go to one place most often. Don't know. Refuse."

(Click)

NA2 I would say, I just told you I go to the clinic. Or I don't see the doctor. I just (mumble)

NA1 I think those answers are kind of real wordy. Real wordy. You can go to a doctor's office, the hospital, and the clinic. You know, what kind of clinic? They have those little med clinics now; they have the Indian clinics, what kind of clinic? You know, the clinic—you know?

F Keep it short?

NA1 Yeah, just keep it short, because when you're reading all that (click) To me, it's not interesting.

NA2 Or do it in order—I go to the doctor, then I go to the hospital, then I go to the clinic.

NA1 Yeah, see. I got a doctor. He's one I picked. Then I go to the clinic to see the doctor.

NA2 Then this month I had insurance, and I went to this one. The next month I had no insurance so I had to go to the health clinic.

NA1 But yeah, they're wordy. You just go to the hospital, you go to the doctor's office, and you go to the clinic.

NA2 Just go to the doctor, and if I need to, in an emergency, I go to the emergency room at the hospital.

F So keep it short, keep it concise.

NA1 Short and simple.

F Here's another one that's related to that. "And what other kind of health professional is it? Is it the office of a chiropractor, an herbalist, a healer, a doctor or nurse, or some other person?" And then it gives you a list of 13 answers.

NA1 And does it say, "What kind of doctor did you go to?"

(Laughter)

NA1 "Health doctor?" You know? "One for my back?"

NA2 My back. I had to go to a chiropractor today. Then I had a diabetic session.

NA1 Real simple. Because if it's real wordy and it's real long

NA2 It gets too personal.

NA1 The people just aren't going to want to do it.

NA2 Maybe there are some people out there who will have patience and will be able to answer all these questions.

NA1 Maybe.

NA2 But the majority of them, that I've dealt with before and I've talked to, they're just like "click." Then you have to put them on a screen to call them back again. "Who is it? Oh

NA1 Because just at the beginning when you said, 30 to 40 minutes, I know you're going to lose a lot of people right there. That's (mumble)

NA2 Oh, I have an appointment.

NA1 If you just say, I have a survey I want you to answer a few questions, take a few minutes of your time, and just kind of break it down like that, but when you pull out those minutes, it's like—

NA2 "Can you call me back?"

NA1 Really.

NA2 Then the ones that have caller ID just won't answer. And every Indian has a caller ID.

(Laughter)

F Yeah, the caller ID is someone in the family. "Tell them I'm not here."

(Inaudible comments)

F Okay, so keep it short, keep it simple and as much as possible, limit the number of questions.

NA1 Combine it. Cut it down.

NA2 You could combine, what, three of those questions in one, three or four questions into one question.

F There is a series of questions related to insurance programs like AFDC, TNF, and WIC. Will people understand the acronyms?

NA2 Yeah.

F Or will they need them spelled out?

NA1 No, the majority of them probably know.

NA2 The ones who are on it will know what it is. The ones that aren't on it, then you if you're not familiar with these, you've never been on these.

F So if they ask a question like, "Are you currently receiving AFDC, TNF, or Cal

NA2 They'll know.

F —people will be able to understand.

NA1 Tana. TNF, Tana.

F Okay.

NA1 Good question. Easy, simple. See, I like that one.

NA2 Woohoo.

F Keep that one, huh. Okay, these next couple of questions is related to delaying or not getting prescription medicine or treatment. So it's a delay in going to the doctor or getting a prescription. So here's what the question will read like: "What was the reason or reasons you delayed getting or did not get the prescription or medicine?"

NA2 No insurance.

F So that would be one of the answers.

NA2 Really bad.

F —it's late, somebody gets taken away from us. Okay. That last question was about getting prescription medicine. The other question is about getting tests or some kind of treatment. So the question would read, "What was the reason or reasons you delayed getting or did not get the test or treatment?"

NA3 (inaudible response)

F Again, you would want the opportunity—someone answering this question, we should just let him or her give us answers, not read him or her to them.

NA1 Uh huh.

F Okay. We shouldn't probe them unless they ask.

NA1 Right.

NA2 Uh-huh.

NA1 Yeah, "They didn't go to any doctors." That's what my mother used to say.

F These next questions are related to where the person lives. You tell me if these are too intrusive or too personal. "What is your zip code?" Would that be okay to ask?

NA1 Uh-huh.

NA2 Uh-huh.

F “We don’t need to know your house address, just the name of the street you live on. What is the name of your street?” Would that be okay to ask?

NA1 Umm. They’re not that way.

F How would you—?

NA1 That’s—You know, I think you only do that in LA or San Diego.

NA2 Like on a reservation or a ranch (mumble).

F (mumble)

NA1 Uphill.

NA2 Yeah, past the willow tree.

(Laughter)

F (mumble)

NA2 I have a name on my tree.

F Streets, what are those?

NA2 I don’t have a street, I have a road.

F Then this one would probably be, what is the name of the street down the corner from—that crosses your street.

NA1 The tree.

(Laughter)

F Okay, these next couples of questions are about emotional problems and mental health. You respond whether or not they’re too sensitive or if they can be asked in a way that they wouldn’t be a problem. Just listen to this and let me know if it would be too
weeks, did you do less than you would have liked
because of any kind of emotional problems?” Would that be an okay question to ask?

NA1 Nope.

NA2 No.

NA1 Why would they want to know about my emotional problems? No, that wouldn’t

NA2 You can (mumble).

F So maybe to do an introduction some way—

NA1 Something. You know, did you have any stress that caused any emotional, you know...

NA2 Did you have a bad week? Was there anything going on maybe that stopped you from doing your normal routine?

NA1 Yeah.

F That made you do less than what you would do.

NA1 Somebody with a negative attitude, and you ask them that question, they're going to you think I've got emotional problems?" You know, instead of you just saying, was there any kind of stress that caused any kind of emotional problems that hindered you.

NA3 A little intro might help.

NA1 Something. Because that right there—

NA3 —jump into.

NA1 Because they're like, is that man saying, I have emotional problems?

NA2 Who do you think you are?

F So that is kind of insensitive?

NA1 Right.

NA2 Emotionally distraught.

NA1 I am now. No. (laughs)

F Here's another question related to that idea. "During the past four weeks, did you not do your work or other activities as well as usual because of emotional problems such as feeling depressed or anxious?" Does it sound like the same question?

NA1 Yeah, read it one more time for me.

F Okay. "During the past four weeks, did you not do your work or other activities as well as usual because of emotional problems such as feeling depressed or anxious?"

NA1 Hmm. (click) The first part. In the past four weeks, did you not—

F Do your work.

NA1 Do your work. That's not even right.

(Laughter)

NA1 You know what I mean? In the past—

NA2 In the past month, was there anything that stopped you from—

NA1 Doing normal routine.

NA2 Doing normal activities such as something emotional.

NA4 (inaudible response)

NA1 It's just that four weeks.

NA4 In the last month, did you do anything?

(Laughter)

NA3 What week are we on now?

NA2 This month instead of four weeks. And then try to simplify it.

NA1 And then take that work—read it.

F "During the past four weeks, did you not do your work—"?

NA1 That. That has to go.

NA4 (inaudible response)

F Reading it is kind of difficult too.

(Laughter)

NA4 In the past month, did you do any work?

NA2 No.

F And I think sometimes, when you hear double negatives—

NA1 Yeah, like the one you read right before that, that's the negative and this one to follow it is like a negative. "Now they're saying I don't work?" You know? Who's telling them?

NA2 I'm emotional, I can't work.

NA1 It's like they're recorded or something.

NA2 They're watching me. How'd you get my number?

NA1 Who told you to call me? Probably think someone's watching them, getting ready to take their kids. You know? It's true. Because they think I have some kind of emotional thing and I'm not going to work because of it. So they're going to pull my kids away from me. That's exactly what they're going to think.

NA2 That is true.

NA4 (inaudible response)

NA1 Just like that. On the reservation, they don't be caring about people be thinking that this is something that's going to get them.

(Murmurs of agreement)

F Here's another question that's kind of related to that idea. "During the past four there are several questions that ask that, this one question says, "Did you feel

(Click)

F Up above, during the past four weeks, have you felt this way? This one would be, "During the past four weeks, did you feel downhearted and sad?"

(Click)

NA1 Does it have to be four weeks? Does it have to be a month? Could it just be, "Have you recently felt, you know, heavy hearted or down?" Does it have to be a month or weeks? I mean, because it's like, when you keep hearing that, have you recently felt down or sad about something? You know, something nice, not—you know what I

- mean? Because if the person is down and not feeling good, you don't want to ask them, have you been downhearted in the last four weeks, you know?
- NA2 Why do you keep saying four weeks?
- NA1 Yeah, who counts weeks when you're sad and your heart hurts? I mean, nobody counts weeks.
- NA2 Sounds like a country song.
- NA1 Yeah.
- F And downhearted? Do you understand what they mean when they say that?
- NA2 Depends what (mumble) you're asking for. They're like, what's downhearted mean?
- F (click) for adults, though.
- NA1 Kind of sad, little bit torn, or something. Downhearted—yeah, you better get another word for downhearted.
- NA2 Because you have young adults.
- F (mumble)
- NA1 Well, kind of sad and just kind of lonely.
- NA3 Lonely.
- F Do you think that if it were worded say, "Have you felt downhearted or sad?" And then
ost of the time, some of the time, a little of the time, not at all,
don't know, refuse." Like when you were mentioning, some of the answers should be a,
b, c.
- NA1 Well, if they answer that, you know, and you ask them, have they been downhearted and sad, they're going to say, yeah, I have been or no, I haven't. That's when you guys can come in and say, has it been recently, or you know, within the last couple of months. That's when you guys come in. They're already opening up and letting you know they are sad and heavy-hearted, so they're opening up the door for you to ask them, well, is this recently, within the last few weeks, and has it caused any problems with your work, or whatever. You know, like those—questions need to be combined so they can just flow together. Because it's just too many one questions where a couple of them could be put together, ask the same, and shrink that survey.
- NA2 Because once they, like how you were saying, you could add that one, then well, has it prevented from going to work or like that. Kind of subtle, rather than.

F (mumble) Here's another one related to that. "During the past four weeks, how much of the time has your physical health or emotional problems interfered with your social activities like visiting with friends or relatives?"

(Inaudible comments)

F Any other feedback on that?

NA1 They should just come straight out and ask the question, you know? Has it depressed you that bad that you're, you know, are you by yourself, have you been by yourself; have to talked to friends about it. Because obviously if they talked to friends about it, they wouldn't be depressed. If they stayed at home, by their self, they wouldn't be depressed. Oh, I don't know. Common sense.

NA2 But I think the lonely part, have you been lonely—they're going to be like, well, why are you asking me that? Especially if it's a man asking a woman, are you lonely? What kind of—who are you? Where are you from again?

NA1 Is this an Internet service?

(Laughter)

F Well, to follow up on that concept, here's another question. "During the past 12 months, did you think you needed help for emotional or mental health problems, such as feeling blue, anxious, sad, or nervous?"

NA2 (inaudible)

NA1 Why would they want to seek help when everybody would know about it?

(Click)

NA2 (mumble) a lot of Indian people don't want no one to know. You know. You can send them to counselors, you can send them to, and they keep it to themselves. And they're (mumble). They solve problems within their family—

NA1 In their community.

NA2 —not going to some white person asking for help when it's just not going to happen.

NA1 And the majority of the time, like we said earlier, people doesn't go to doctors just because they got a little pain. They go to the doctor when they can't see no more, when they can't walk no more, when their breathing is heavy. That's when native people go to the doctor. When they've got a pain in their arm and it hurts. They've learned to suffer through all these years; they've learned to suffer with little pain.

F Malignancy.

NA1 Malignancy, meaning, and then say what it means, after you say the word. Because they definitely know what the cancers are.

F Another one related to that (mumble). "Have you ever had a sigmoidoscopy, a colonoscopy, a (inaudible) done by a doctor looking for signs of cancer or other problems in your colon?" If needed, then the person would say

NA1 Have you ever had a colon cancer test? That's it. They're not going to understand that

(Laughter and inaudible comments)

F Okay, good. Because they would explain it if necessary. It says, if needed, say, the sigmoidoscopy—

NA1 Well, I'm sure that everyone knows what the colon cancer test is, female and male.

F Actually, they only ask them if they're over 40.

F Okay, over 40, they would go to that one.

F (inaudible comment)

NA1 Did you do the questions?

F (inaudible comment)

F We'll move on then, about blood. These ones are about blood and for example, blood in stools. "What is one most important reason why you have never not had one of these exams in the last 10 years?" That would be

F (inaudible comment)

F How do you feel about questions involving blood? So here's the questions: "The following questions are about the blood stool or called blood tests, a test to determine if you have blood in your stool or bowel movement. The blood stool test can be done at home using a kit. You smear a small amount of stool on cards at home and send the cards back to the doctor or lab. Have you ever done a blood stool test using a home test kit?"

NA2 Detailed.

F Too detailed?

NA2 Well, have you ever had a test, or have you ever done this—

F A blood stool test.

NA2 Because everyone knows what a blood stool test is.

NA1 And if they don't, you can explain.

NA2 Then you can explain.

NA3 Don't go into it.

F Don't go into it. Okay, explain if necessary.

NA1 See a lot of questions like this, they can be answered yes or no. And it'd be like, have you had a cancer test, have you had that test.

NA2 No, no, yes, no.

NA1 then you won't be depending anybody, you know. Asking them when was the last time and how come they did—

NA2 “Why do they want to know about my stool?”

NA1 It's not personal, it's just a yes/no question.

F A related question would be, “How many blood stool tests have you done in the past

NA1 And that's if they've done it.

NA2 If they have done it.

F Right.

NA2 If they haven't, then you don't need to go there.

F Okay, and the final one on that would be, “When did you do your most recent home

NA2 If they answered yes.

F Give me your feedback on the categories that we have and let me know if this would be understandable or would be okay. The question is, “When did you do your most recent home blood stool test? Was it 1) a year ago or less, 2) more than a year ago but not more than two years ago, 3) more than two years ago but not more than 3 years ago, or more than three years ago, but not more than five years ago.”

NA4 (inaudible comment)

NA1 You should just go like this—6 months to a year, one month to two, one to two years, like that. Or 2-4 years.

F So leaves out the “but not more than.”

NA1 Yup.

F So that's kind of unnecessary.

NA2 Doing a bit too much.

- F Okay, moving along. The next questions I'll be reading are about violence and accidents. Are the questions clear and will respondents think the questions are only about legal (mumble).
- NA2 Huh?
- F Legal (mumble). Okay, the lead-up question would be, "What was the cause of the most serious injury," and then they have a list. "Where were you when the injury happened? Home, etc." And then this question is the feedback we want: "Was a gun, knife, or other weapon or other weapon used when this injury occurred?" Is that clear?
- NA1 You're not going to get an answer.
- NA2 You won't.
- F That's only for people that were seriously injured. It's only for certain people who are seriously injured.
- NA1 Somebody that had got shot and—
- F —or seriously injured. Then they ask, was a gun, knife, or other. So not everybody's asked that.
- NA1 Well, if somebody got injured, they probably would tell you what it was.
- NA4 (mumble) car.
- F Keeping along that same line, the follow-up question would be, "Do you keep any kind of gun in your home, car or garage?"
- NA2 No.
- NA3 No.
- NA1 Check that question.
- F What's that one?
- F C6.
- F They wouldn't answer it?
- NA1 Nope.
- F "Do you keep any kind of gun in your home,
- NA1 Along with the one.

NA2 Well, if you really want to know...

(Laughter)

NA1 No way, they're not going to answer it.

F A follow-up to that would be, "Have you received any kind of formal training on how to

NA2 (mumble)

NA1 (mumble) read that one again.

F If you had answered yes to that last question, do you keep any kind of gun in your home?

NA1 I think that should be checked, but the first question before that that said, were you injured by a gun, knife, or I forget what the other one was, and then this question, if they said they were shot, then—

NA2 Then you do that question.

F Then you (mumble).

NA1 Especially with a gunshot wound. But now with a knife or the other question there, where do you store them, that should be gone.

NA2 That's not going to be answered. Not by Indian people anyway.

NA1 Wouldn't be answered.

NA2 Well, let me go check my shed. My basement.

F If someone answered question C6 that was, "Do you keep any kind of gun in your home, car or garage?" If they answered yes, then they would answer C7, which was, "Have you received any kind of formal training on how to use and store these guns?" Then the next one would be, "How many of these guns are handguns?"

NA1 Wouldn't answer.

F What about this one. During the past 12 months, have you been the victim of a crime in which a gun was used?"

NA1 That should be in front of the first question.

NA2 That should be the whole question in front of—

NA4 In front of—

NA2 Then, once you get that opened up—

(Tape flipped)

F This next couple of questions is about sexual orientation. You let me know if they're too sensitive. And one is, "Are you gay or bisexual?" And if it's a female that would be answering the question, lesbian. So, "Are you gay, lesbian, or bisexual?"

NA1 It's, "Are you gay?" Kind of fits the whole category. But they aren't going to answer that anyway.

F They won't?

NA1 Nope.

F Then the flip side of that would be, if a male answers "gay" or a female answers "lesbian," then they would ask, "Is that gay male/lesbian female (mumble)?"

NA2 No.

NA1 They aren't going to answer that question.

NA2 There are some gay people that are real proud of it so you might get an answer.

F That's only if they say yes to that first one. If they say yes to the first one, they ask them,

NA1 That sounds better. Instead of, "Are you gay, lesbian, bisexual?"

(Laughter)

NA2 Going on and on and on.

NA1 Yeah.

NA2 In the past four weeks.

(Laughter)

NA1 Yeah, they need to be put back in order because those ones probably should follow, before that, the ones about heavyhearted and stuff.

(Laughter)

NA1 You know, order (mumble).

NA1 Just periods or moon.

F Not menstrual cycle. So you don't need menstrual cycle.

NA1 No.

F Do some people call it moons?

NA2 Yes. Moon.

F Oh, the moon.

NA2 Not moons.

F Got it. "How many children have you given birth to?" If needed, the person would say, "Count only those that were brought born alive." They would either say none or the number. Is that clear?

(Murmurs of approval)

F "Have you ever had a Pap smear test?" And if needed, they would tell you what that was. Do you think most women would know what a Pap smear test was?

NA2 Yes.

NA1 Maybe. You might have to explain it.

F The lady would say, “A Pap smear is a routine test for women in which the doctor examines the cervix during exam and takes a cell sample from the cervix with a small stick or brush and sends it to the lab.” Any other words you would use?

NA1 (mumble)

NA2 Did you get a check-up?

NA1 Yeah, did you get a check-up?

F As far as a Pap smear—

NA1 (mumble)

NA2 “Is that an STD test?”

F So maybe clarify—

NA2 Which one is it?

F So clarify that it’s not an STD test. Cancer. This is for people who are over 40 and not pregnant. You guys probably aren’t over 40, but just listen to it. “Regarding the change of life or menopause, which of the following apply to you.” So if you were over 40, they would read you these. “I am still having periods and have not started menopause. My periods have become irregular or stopped because of menopause. I have stopped having periods for medical or surgical reasons. I have never had periods. Don’t know

NA1 Pretty clear and long.

NA2 Yeah, it was really long.

NA1 Read it.

F “Regarding the change of life or menopause, which of the following apply to you.”

NA1 Right there. Regarding the change of life.

F What about it? You don’t like change of life?

NA2 Yeah.

NA1 No.

F They say, “or menopause.”

NA2 The majority of people that I know that are going through it or have gone through it, already passed it, they just call it the change. “I’ve gone through the change.”

NA1 Change of life.

F So maybe use change.

NA1 The change of life.

F The change. What about, this one says, “Are you currently using any hormone or replacement supplements prescribed by a medical doctor?” If needed, the supplement (mumble) treatment that gives them more of the female hormone estrogen.

NA2 Yeah, they get hormones, right.

F Right. There are some questions about—“Have you ever had a bone density test?” That’s for ladies over 50 when they get older and have the bones. Is that pretty clear?

NA1 Yeah, bone loss.

F So that one’s okay. That’s all I have for you now. So thanks a lot for your input and your advice. I really appreciate all your—

(Tape ends)

FOCUS GROUP

FOR

NATIVE AMERICAN ADOLESCENTS (TEENAGERS)

MAY 17, 2000

F We will provide you with a \$20 stipend when you’re done. If you feel like you need a break, go ahead and stand up and have a soda. Okay. Well, we’re here today to listen to some survey items that will be in the California Health Interview Survey. It’s going to reach about 50,000 households in California and it will ask questions about health, exercise, diet, and access to health care. ARDAC, along with a team at UCLA, are

looking at survey questions and we're going to help them hopefully simplify, clarify the surveys. And the project is trying to help produce a culturally sensitive and valid survey to help improve the health care for children and adults (CHECK THAT LAST PART). So we're going to be reading some questions to you and also we have some topics that we want your advice on. We'll need your ideas on how we can improve and clarify these questions and again (click) anybody, (click), that's what they're there for, to try (click).

ted. The first part is when an interviewer calls someone at home; this is what they're going to say. Now, just pretend you're listening, and you might want to close your eyes if you want to, you can even put your fingers up to your ears. But this is how it's going to sound. And if any part of it sounds kind of weird or strange or "hmm, that doesn't make sense," let us know and we'll make notes. Okay. "Hello, my name is Jerry. I am calling from a California health interview survey on behalf of the University of California at Los Angeles School of Public Health. We are not selling anything; we are doing a scientific survey with the California Dept. of Health Services and the National Cancer Institute. I understand that you are a guardian parent of (click) so we're calling parents. We understand that Bobby, who is 15, is that correct?" And then they answer, yes. "Bobby has been selected to be interviewed for the adolescent portion of the health survey. It is a telephone interview and should take him/her about 20 minutes to do." So this goes on like that. Now this is where we would be talking to the student. "Hello, Bobby, my name is Jerry. I am calling from the California health interview survey on behalf of the University of California at Los Angeles School of Public Health. We are doing a scientific survey with the California Dept. of Health Services and the National Cancer Institute. We are talking with young people like you so we can use the results to help improve health services all over the state. You were selected by chance for this survey and it is completely voluntary and all of the information you give us will be kept confidential. Your name will not be connected with your answers in the final results. The interview takes about 20 minutes and it is all done over the phone. You can stop the interview at any time and you can skip any questions you want to skip. Would you like to hear some of the topics we ask about? This is a health survey so I'll be asking some personal questions about your health and also questions about your health behaviors like the food you eat, exercise, and about tobacco, alcohol, and drugs, even if you don't use any of those. There are also some questions about safety and violence and sexual behavior questions. Would you like to start this interview now?" And then, "(click) place where you are comfortable to do the interview. If you'd like more information, I can give you the name and telephone number (click)." Okay, so I'm going to ask you, or not ask questions now and get your feedback. And you let me know if it's clear or if it doesn't make sense. So here's the first question and it's on injuries, violence, and guns. "During the past 12 months, were you injured seriously enough that you got medical advice or treatment?" Is that clear? Read it again?

NT1 Read it again.

F If it was clear enough, then that means it doesn't need to be changed. "At any time in the past 12 months, were you injured seriously enough that you got medical advice or treatment?"

NT1 What does it mean by medical advice?

F Medical advice? So that would need to be explained. The answer would be times (???) and the person would answer the question. (Click) That's good, thanks. The next question would be after that, "What was the cause of the most serious injury?" And there's a list. "Motor vehicle occupant injury. Motor vehicle pedestrian accident. Bicycle related. Accidental fall. Swimming, boating, or other near drowning. Fire, burn, or scald. Accidentally hit or cut with an object. Intentional injury by another person. Unintentional injury by another person. Sports related. Other. Don't know or refuse." Is that question clear?

NT2 Uh-huh.

F "Were you injured with a gun, knife, or other weapon?" And if the answer was yes, "What type of weapon was used?" Responses are, "No weapons used. A gun was used. Knife used. Some other weapon used. Don't know." "Where were you when the injury happened?" This is the next question. They give you a list. "Inside at home. Outside at home. At work. At school or a child care center. On the street, highway, or parking lot. At a recreational area like a gym. At a business other than where you work. Other. Don't know. Refuse." There needs to be other places? Home, work, school, day care center. Okay. The question would be, "Do you or anyone else in the household keep any kind of guns in the house, car, or garage?" Clear enough?

NT2 Clear.

F The question would be, "How many are handguns?" And then underneath is the number and you could answer, "None. Don't know. Or refuse." In response to the question, "Do you or anyone else in the household keep any kind of guns in the house, car or garage," and if they answered yes, then, they go to question #9 and say, "How many are handguns?" They would only answer that question if the answer to the last question was yes. And then if C8 were yes, that question about, "Do you or anyone else in the household keep any kind of guns in the house," then the one after that would be, "Do any

NT2 Yeah.

F And the next one would be, "Who do these working handguns belong to? Mark all that apply." The options are, "Father. Mother. Respondent" which would mean the youth who was on the other end of the line—"Other household member. Parent. Other. Don't know. Refuse." Is that clear? Okay, now we're going to ask some questions related to

emotional feelings and mental health and whether or not they're too personal. I'm going to read an introduction to this series of questions and you let me know if that's enough to move onto the questions or if you think there needs to be something else. So this is what the interviewer would say: "Now I am going to read a list of statements about how you may feel emotionally and about feelings in general. For each statement, I only want you to think about your feelings in the past week including today but not more than a week ago." Does that sound clear? Do you understand that? It's from today and the past seven days. "Tell me how often each of the following things were rarely true, sometimes true, true a lot of the time, or true most of the time." So here is the question. "In the past week, you were bothered by things that usually don't bother you. Was that rarely true, sometimes true, true a lot of the time, or true most of the time?" (Mumble)

(Click)

F (mumble)

(Inaudible comments)

F (Mumble) or just once?

NT2 Probably like one more time.

F Maybe the person needs to (mumble) that slowly.

(Click)

F "You were bothered by things that usually don't bother you. Was that rarely true, sometimes true, true a lot of the time, or true most of the time?" And then the options rarely, sometimes, a lot of the time, most of the time, doesn't know, refuse.

(Click)

F Related to that, "You felt that you could not shake off the blues even with help from your family and your friends. Was that rarely true, sometimes true, true a lot of the time, or true most of the time?"

(Inaudible comments)

NT1 What do you mean when you mention the blues?

(Click)

F The question would be, "You felt that you were just as good as other people." (Click) "In the past week, you felt depressed. Was that rarely true, sometimes true, true a lot of the time, or true most of the time?" (Click) That'd be okay to ask you think? Not too

NT3 Those questions could be together in one.

F So some of these you think can be combined.

NT1 Lonely (inaudible comment).

F You think based on that last question, rewording it so that the question (mumble), that would make more sense?

NT3 Yeah.

F “Have you felt lonely or sad?”

NT1 And the time (mumble).

F And that last question. “You felt life was not worth living.” (Click) Personal, if it was worded differently.

NT2 Yeah.

F From “You felt life was not worth living” to something like, (click). Okay, this question, this next one is about psychological or emotional complex. “In the past 12 months, have you received any psychological or emotional complex?” Is there another way we could ask that?

NT1 That’s kind of confusing.

F Confusing.

NT2 Yes.

NT1 Psychological.

NT3 You could explain what the word means.

NT1 Have you had any (mumble)?

(Click)

F Just to make it more clear, to define psychological. Emotional (mumble) the way that it’s worded?

NT2 Yeah.

F The next group of questions related to sexual orientation activities. So what we’re going to do is ask you, do you think we need to have some kind of introduction to this section and if so, what would that introduction or how can we introduce these questions so the youth on the other end of the phone will be okay, comfortable? This is how it is now. There really isn’t any introduction. “I want to remind you that all of your answers will be kept confidential. The next few questions are about sexual orientation and activity. “Do you feel sexual attracted to boys, girls, both the same, don’t know, refuse.”

(Click)

NT1 Attracted to anybody.

(Click)

NT3 Yeah.

F The next question would be, "Have you ever had sexual intercourse?"

(Inaudible comment)

F If we were going to get a young person to answer that question, would we need to remind them that their answers were confidential?

NT3 Yeah.

F Maybe with each of these questions we should do that, because the next question would be, if that last question they said yes, "How old were you when you had sexual intercourse for the first time?" Okay the way it's asked?

NT3 Yeah.

F Do you think that again, we would need to say (click)? "The time you had sexual intercourse, did you or your partner use any methods to prevent pregnancy or disease?"

(Click)

NT2 Together as one question. Like, (click)

F Would it be easier if those three questions were grouped together.

NT2 Yeah, and then remind them again.

(Click)

F The next one would be, "The last time you had sexual intercourse, did you or your partner use any methods to prevent pregnancy or disease?" So it's understandable that we're asking are they using birth control or (click). "Again, I need to ask you what one or more methods you used. Again, you can tell me what methods you used or if you need a list of methods and you can answer yes or no. Do you want to tell me or do you want me to read from my list?" Understand that? "How many children do you have?" I guess this would be a follow-up if you answered yes to the sexual intercourse. "In the past year, have you received family planning counseling or services?"

(Inaudible comments)

(Click)

F Does the interviewer need to explain what family planning is, family planning counseling?
(Click) This next series of questions, we're going to be talking about alcohol and drug use. What we're going to ask you is to think about what would the interviewer need to say to introduce this or to make you comfortable. (Click) " Ever have more than a few sips of any alcoholic drink like beer, wine, mixed drinks or liquor?"

(Inaudible comments)

(Click)

F So the last question is—

NT1 You could rephrase it like, "Have you ever drank alcohol before?"

NT1 Yes.

F Again, feedback on whether we need to introduce it in a different way or if it's clear or changes. (Click) "If we consider one drink to be a can or bottle of beer, a glass of wine, a shot of liquor, or one mixed drink, on how many days in the past 30 days did you have at least one drink of alcohol?" (Click) Do you think that's when we mention that
we consider one drink to be a can or bottle of beer, a glass of wine, a shot of liquor, or one mixed drink, on how many days in the past three days did you have at least one drink of alcohol?" (Click) Okay. (Click)

NT2 How long ago.

F Follow-up to that question would be, "On how many days in the past 30 days did you have five or more drinks in one day?" (Click) "When you drink alcohol, about how many drinks do you usually have?" (Click) "Have you ever drink a car after you've been
ld be "Yes, no, don't know." (Click) "Do you think you will start to drink alcohol in the next 12 months." After that, they would answer, "Yes, no, don't know." (Click) "Have you ever tried any drugs such as marijuana, cocaine, (mumble) blue or other drugs?" (Click) Maybe something like, this next question is about drug use.

NT3 Yeah.

F (click) the different terms, marijuana, cocaine. (Click) The next one would be, "The next question is only about marijuana. In the past 30 days, about how many days did you smoke marijuana." (Click) "This question is about glue sniffing and aerosols. Just in the past 30 days, on how many days did you sniff glue, breathe the contents of aerosol spray cans or inhale any paints or sprays to get high?" (Click) Okay, this next series of questions are how much your parents know about your alcohol use, sexual behavior, or

tobacco use. Is the wording appropriate, that's what we're asking? And what they'll ask is, "How much do your parents know about your alcohol use, sexual behavior, or tobacco use." And then, the question is, "And about your alcohol use, do they know a lot, a little, know nothing, don't know, refuse."

(Inaudible comments)

F I think so. (Click) So I think that (click) let me ask this first. This is how these questions (mumble). These questions are about how much your parents know about you (click)

NT1 This next question (click)

F Start out with, "How much do your parents or guardians really know about where you go at night? Would you say they know a lot, know a little, or know nothing? How much do they know about what you do with your free time? Would you say they know a lot, know a little, or know nothing? And how about where you are most afternoons after school. Would you say they know a lot, know a little, or know nothing?" And then, "How about your alcohol use? Would you say they know a lot, know a little, or know nothing?" That'd be clear? If they just said, "And about your alcohol use" after those questions? "Your tobacco use?" "Know a lot, know a little, or know no activity. Know a lot, know a little, or know nothing?" (Click) We'll leave it that way where there is no (mumble) "Do your parents know about alcohol use, how much do your parents know about your alcohol use." It should be consistent then they're going to do it from the beginning. Okay, this next question is about stalking. Do teens and other youths in your age groups know about stalking? Know what the term means? The question would be, "Have you ever been stalked by anyone?" Would they understand that?

NT2 Yeah.

F Okay. (Click) Those were all the questions we felt necessary to get feedback from your age group to help us and make sure that would be clear and understandable. Are there comments about the survey?

NT2 (mumble) all three of highlight and us the ones we were (mumble) about so we could read it and put it in. (click) what we think should be done.

F You think this survey should be a written survey instead of—

NT2 It could either be both.

F (click) came up; I wanted to ask (mumble). Before they were unclear how their household number got chosen. And it says something like they were chosen at random. Would you need that explained? At the beginning, it says, something like your number was chosen at random. Some people think people would be afraid they'd know who they were.

NT1 (inaudible comment)

F Would you want that explained up front?

NT2 Yeah.

F What happens is the computer dials a number at random, so they're going to know (mumble).

NT1 Yeah, because they might think this would transmit our information.

F Say, you were selected by chance.

F By chance. It would have gotten (mumble) by chance.

F Say some stranger calls and you were selected by chance for this survey.

F By a computer.

F Randomly selected by a computer. Well, I just want to thank each of you again for taking time out of your schedules.