

**Cognitive Interview Evaluation of the
2008 Oral Health Supplement for the
National Health Interview Survey:**
Results of interviews conducted March 20 – April 4, 2007

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1. Introduction

This report documents cognitive testing results on the 2008 oral health supplement of the National Health Interview Survey (NHIS). The supplement is sponsored by the National Institute of Dental and Craniofacial Research, National Institutes of Health. Testing took place in two rounds between March 20 and April 4, 2007.

Questions in the oral health supplement will be located in both the sample adult section of the NHIS and the sample child section. Sample adult questions focus primarily on symptoms (of teeth, gums, and mouth), access to dental care, and oral cancer screening. Questions in the sample child section (administered by proxy to the sample adult) are similar to the adult section, but exclude questions on cancer screening.

The majority of this report is dedicated to presenting a question-by-question analysis of the validity of the oral health questions. Emphasis is placed on items that have the potential to generate response error, that is, they may not capture the information they were designed to measure. The discussion of these questions includes descriptions of how respondents interpreted question intent and explanations of why and how questions presented problems for respondents. Comments are included for most questions, however, some items were unable to be tested. For example, because no respondents reported ever having received an oral cancer screening, they skipped out of questions on their experience with the exam. Similarly, those who reported no problems with their children's oral health (a majority of the respondents) were skipped past some of the child questions. Because testing took place in two rounds, analysis of the original question is presented first, followed by a rationale for question modification and, where appropriate, results of the second round of testing on the revised questions.¹

The next section briefly describes the qualitative methodology of cognitive interviewing, including the procedures for sampling interview respondents and the interview technique itself. The third section of the report presents a summary of general findings followed by the more detailed question-by-question analysis.

¹ The first version of the full instrument tested in round 1 can be found in Appendix A. The second version tested in round 2 is in Appendix B.

2. Methodology

Cognitive interviewing, as a qualitative methodology, offers the ability to understand the interpretive process behind answers to survey questions. Different types of interviewing techniques exist. Respondent narrative and intensive follow-up verbal probing were the primary cognitive interviewing methods used for the project. With these techniques, interviewers administer the survey question, obtain an answer, then probe the participant for information relevant to their responses. Respondent narrative yields rich and detailed information on how respondents answered the question, what they were thinking when answering, and how they interpreted the meaning of the question. Shedding light on the question-response process, this information allows the analyst to determine which stage in the process of answering a survey question – comprehension, retrieval, judgment, or response – the respondent had difficulty with, if any. The appropriateness of response categories can also be evaluated with this procedure, as can the ability of participants to draw upon their own experiences and knowledge to answer the questions effectively. Because the intensive interviewing method provides extensive detail on the question-response process, not only does it allow the interviewer to identify *which* questions and/or response categories are problematic, it also shows *why and how* questions are problematic, leading to informed strategies for improving question design and minimizing response error.

Sampling and Respondent Demographics

Testing took place in the National Center for Health Statistics (NCHS) Questionnaire Design Research Laboratory (QDRL). We conducted a total of 20 interviews, 10 in the first round and 10 in the second. Respondents were selected with a purposive sample in mind. We were interested in people with both cosmetic and physical dental problems, people with no teeth at all, and people with children under 18 (including infants). Demographic diversity among respondents was also sought. The demographic breakdown of respondents appears in Table 1.

A newspaper advertisement in the Express, a free commuter newspaper, did a good job of identifying the participants we needed and most respondents were recruited this way. However, a couple respondents were drawn from the QDRL database of respondents who have participated in previous studies. Prior to participation, respondents were screened over the telephone in order to identify key demographics such as age, educational attainment, and income level, as well as the extent and nature of their dental problems for both themselves and their children.

At the time of the interview, respondents filled out paperwork whereby they agreed to the interview being video- and audio-taped. The interviewer then explained the purpose of NCHS, described the survey, and told respondents the manner in which the interview would be conducted. After these introductory remarks, interviewers began by administering the survey questions. Once the survey responses were obtained, the interviewer elicited respondent narratives outlining their oral health histories. This was followed by question-specific probes designed to reveal respondents' interpretation of the question and the ease with which they chose a response category. Through both the respondent narrative and follow-up probes, interviewers were able to ascertain whether or not and why a response error had occurred. Interviews were designed to last 60 minutes and a \$40 token of appreciation was given to participants.

Table 1: Demographic summary of respondents in total and for each version of the instrument

	<u>Version 1</u> (n=10)	<u>Version 2</u> (n=10)	<u>Total (%)</u> (N=20)
<u>Has Children</u>			
Yes	9	3	12 (60%)
No	1	7	8 (40%)
<u>Gender</u>			
Female	6	7	13 (65%)
Male	4	3	7 (35%)
<u>Race/Ethnicity</u>			
NH-White	0	2	2 (10%)
NH-Black	10	6	16 (80%)
Asian Indian	0	1	1 (5%)
American Indian	0	1	1 (5%)
<u>Education</u>			
HS or less	6	3	9 (45%)
More than HS	4	7	11 (55%)
<u>Income</u>			
Under 20,000	7	4	11 (55%)
20,000 & Over	3	5	8 (40%)
Don't Know	0	1	1 (5%)

3. Results

General Findings

Like all survey questions, answers to these questions are, in many respects, a function of a respondent's social location. That is, people's cultural and social experiences condition the way they understand and respond to stimuli. Socioeconomic status (SES) frames much of our experience and is a significant predictor of many social outcomes. We found that respondents with lower formal education had more difficulty responding to some of the survey questions than those with higher levels of education. Some of the difficulties observed in the first round of testing were not as pronounced in the second round (see question AOH.060 in the question-by-question analysis), even when no modifications were made to the question. Table 1 shows that the second round of testing had a greater proportion of respondents with more than a high school education. As a result, the lack of response error in the second round is partially a function of educational attainment.

Another problem that manifested itself in some of the items relates to a false dichotomy made in both wording and structure. Some questions operate as though people either have all their natural teeth or have none. This assumption is very subtly embedded in some questions, but the struggles of those with only a few teeth made it apparent. In order to answer a question, respondents with only a few natural teeth mentally placed themselves into a category of either having teeth or not having teeth. However, sometimes the category they placed themselves into (which was influenced by their interpretation of the question) did not allow them to express the reality of their experiences when actually answering the survey question. This resulted in unintended question interpretation and response error.

A good example of this is question ACN.451 “Have you lost all of your upper and lower natural, permanent teeth?” This question was most problematic for those who had lost many, but not all of their natural teeth. One person in the second round of testing responded by saying, “yes, except two” and, despite a repeat of the question and probing by the interviewer, this subject never decided to change his answer to no. He had very clearly placed himself in the category of having no teeth at all, yet this categorization made answering the next question difficult. In AOH.050 (During the past 6 months have you had any of the following problems?), he answered “yes” to the first item (toothache/sensitive teeth) even though probing revealed his teeth didn’t ache. What bothered him were his gums (from chewing on them and from his dentures). He interpreted that first item as “is your mouth sensitive?” Realizing on some level the incongruence between his experience, his response, and the assumption of the question, he points out, “those questions are based on that you have teeth.” However, for the fourth item on this list (broken or missing teeth) he switches the categorization of himself from a person with no teeth to a person with teeth and answers “no.” When asked why he answered “no” (considering he’s missing almost all of his teeth), he explains that he was focusing on the two teeth he had, saying they weren’t broken.

The process of establishing the status of respondents’ teeth should take into account the fact that people missing many but not all teeth will define themselves differently depending on the question being asked. If they believe the intent of the question is to ascertain the problems they have with the functioning of their mouth, for example eating, it’s reasonable that they will classify themselves as not having any teeth when answering the question. On the other hand, if they think the question is asking something specific about the teeth they do have, they will place themselves in the category of having teeth and answer the question on that basis.

In sum, the problem with working from a simple dichotomy (as question ACN.451 does) is that it forces those with some teeth to place themselves into either the all or nothing categories, neither of which truly reflect their situation when answering the questions.

Question-By-Question Analysis

This section is dedicated to an individual review of findings for each question tested. Each item contains an analysis of the response process followed by recommendations for question improvement.

ROUND 1 INSTRUMENT:

Sample Adult

AOH.010 How would you describe the condition of your mouth and teeth? Would you say very good, good, fair or poor? **[NOTE: question includes people who have no teeth, have false teeth and dentures]**

- (1) Very good
- (2) Good

- (3) Fair
- (4) Poor

Analysis: Because this question is less fact-based and more opinion oriented, the language of response error is inadequate. However, respondents had interesting interpretations of the question and went through different judgment processes in order to answer it. Some respondents used the physical health of their mouth as the criteria for answering the question. For example, nine respondents answered “poor” to the question because they either had no teeth, were missing many teeth, or had other ailments such as TMJ, missing crowns, tooth pain, and loose teeth. One person answered “fair” because “I have one cavity and a lot of fillings...and I have teeth missing.”

However, other participants with similar conditions did not judge their mouth to be poor because they used different criteria to arrive at their answer. One respondent with no teeth answered “good” because he’s happy with his dentures and feels as though he receives “good treatment” from his dentist. Similarly, another respondent with many mouth troubles (such as having many root canals, veneers, 2 bridges, missing teeth & dentist-diagnosed dry mouth) answers good “only because I go so often...he [the dentist] keeps up with them.” These respondents have frequent access to dental care, and based their answer on that fact.

Other subjects used the functioning of their mouth as the judgment criteria for this question. Two people were thinking of their ability to eat when answering this question. One respondent answered “good” because even though she can’t eat certain foods, she can eat almost anything. The other respondent answered “fair” because her broken and missing teeth have a direct impact on almost everything she eats. However, she did not answer “poor” because she knows there are people worse off than her and because she can still get her eating problems corrected. The emphasis of their answers is on their ability to eat, not on the fact that they are missing teeth per se.

Finally, other people arrived at their answer by thinking of cosmetic issues. One participant reported “fair,” *not* because she had toothaches and bleeding gums (which she reported later), but because she has a gap between her two front teeth. Another respondent with broken teeth, loose fillings and sensitive teeth also answered “fair” because her teeth aren’t “perfectly straight and white” – she was not thinking of the afore mentioned problems. Similarly, one subject answered “good” because people compliment him on his smile and teeth, even though he also reports having sensitive teeth, missing teeth, and missing fillings.

Recommendation: Analysts should understand that the question doesn’t capture the same information for all respondents, probably because it asks them to describe the “condition” of their mouth, which can be (and is) interpreted many ways. People use different criteria to make judgments about the condition of their mouth. Their answer to the question can reflect not only the health of their mouth, but also things such as access to health care and the cosmetic appearance of their mouth, irrespective of medical conditions. If the underlying construct is medical health, then perhaps the word “condition” should be replaced with something more direct, such as “How would you describe the health of your mouth and teeth?”

AOH.020 **SHOW HAND CARD A.** Which one of the following statements BEST describes your approach to dental care?

- (1) I never go to a dentist
- (2) I go to a dentist when I have a problem or when I need to get something fixed
- (3) I go to a dentist occasionally whether or not I have a problem
- (4) I go to a dentist regularly

Analysis: This question was problematic to the extent that the intent of the question is relayed primarily (though not exclusively) through the response options. This means respondents have to wait to hear these options before understanding what, exactly, is being asked of them. That can put unnecessary demands on active memory. Additionally, the intent communicated by the options is not entirely clear. They suggest both purpose of dental visit (check-up vs. problem) and regularity of visit, both of which rest on actual behavior. Yet the word “approach” in the question implies it’s asking about a general philosophy toward dental care, not actual behavior. Essentially, there are multiple contradictions in the question that respondents must sift through before providing an answer. As a result, answers were not comparable.

These problems between the question stem and response options created response difficulties for six of the respondents in the first round, and resulted in response error for at least four of them. Some respondents answered based on their beliefs of how often they visit the dentist, disregarding their actual visits. For example, two respondents answered #1 (never go to dentist) when they actually visited a dentist a few months ago to have a problem corrected (extraction & root canal). The second option would have been more appropriate, but they chose the first option because they do not see themselves as people who go to the dentist for regular checkups. Several other respondents answered #3 (visit occasionally, regardless of problem) when they visit the dentist twice a year. They didn’t answer #4 (regularly) because their focus was on purpose of visit – they visit whether or not they have a problem.

Recommendation: The underlying construct of this question needs to be more fully developed and directly communicated. However, because this was a low-priority item for sponsors, the question was dropped in the second round.

AOH.030 I am going to read you a list of reasons people get dental care. Please tell me how many hours of work you have missed in the past 6 months for each one.

Number of hours

(1) For checkups or cleanings _____

Analysis: No response error detected for this item, although only four respondents answered the question. (The others weren’t working (or in school).)

Recommendation: None.

(2) For orthodontic treatment _____

Analysis: Three of the four respondents tested didn’t know what orthodontic treatment was.

Recommendation: This term needs to be defined.

(3) For emergency or immediate dental treatment _____

Analysis: Response error was detected for one respondent. He went to the dentist for a bad toothache which turned out to be abscessed, but didn’t see this as emergency treatment. Another respondent with a toothache answered in days, not hours, simply saying he called in sick for the whole day and visited the dentist.

Recommendation: Respondents may not understand what qualifies as emergency treatment – for example one respondent included a visit prompted by a toothache while the other didn’t. It may need some brief

definition. Also, since some people are likely to have taken the day off from work to see the dentist, they may need prompting to answer in hours.

(4) For a specific problem other than orthodontic treatment or emergency treatment _____

Analysis: Error was detected for one respondent who went to the dentist for a toothache. This should probably have been captured in the previous category for emergency treatment.

Recommendation: Drop this category. It may be a difficult for respondents to understand what should be included.

(5) For tooth whitening or other cosmetic work _____

Analysis: No problems.

Recommendation: None.

(6) For taking someone else to a dental appointment _____

Analysis: One respondent had a telescoping issue. She reports taking her son to the dentist, but remembers it was before school started, which likely puts it outside of the 6 month timeframe. Another respondent answered in terms of days missed from work, not hours.

Recommendation: Since some people are likely to remember this as simply having taken the day off from work, they may need prompting to answer in hours. It's also inevitable that some telescoping will occur, but it didn't seem highly problematic for this question overall.

AOH.040 Does the condition of your teeth, mouth, or dentures cause you to have problems with any of the following. Please say yes or no to each.

- | | | |
|---|-----|----|
| (1) Eating or chewing certain types of food | yes | no |
| (2) Smiling or talking to people | yes | no |
| (3) Doing work or learning | yes | no |
| (4) Sleeping | yes | no |

Analysis: One respondent answered "no" to toothache because even though she's had one in the past, she does not currently have a toothache. This suggests a timeframe should be included. Also, two people answered "no" to problems sleeping, even though they later mentioned having trouble (several times a week for one person and every night for another). And finally, two people have dentures, but did not consider them when answering this question. They answered based on not having them in their mouth. However, the question specifically asks about problem with dentures.

Recommendation: Because this was a low-priority item for sponsors, and the information it's intended to capture is addressed elsewhere in the instrument, they decided to drop it for the second round.

AOH.050 DURING THE PAST 12 MONTHS, how often have you been self-conscious or embarrassed because of your teeth, mouth or dentures? Would you say often, sometimes, rarely or never?

- (1) Often
- (2) Sometimes
- (3) Rarely
- (4) Never

Analysis: This question overall didn't pose many problem for respondents in either round. Many people answered this question based on the cosmetic appearance of their mouth (though a couple considered the physical condition independent of the medical condition). However, note that one person answered "sometimes" because she is embarrassed by her fear of the dentist – not of her mouth – and the fact that she never goes. Another person had a difficult time with the categories because she was not answering how frequently she feels embarrassed, she was answering how deeply she feels embarrassed. She kept using the word "a lot" because her feelings of embarrassment are intense.

Recommendation: Not enough systematic difficulty was found to suggest revisions to the question.

AOH.060 Do you think the condition of your mouth and teeth is better than, the same as or not as good as other people your age?

- (1) Better
- (2) Same
- (3) Not as good

Analysis: In the first round this question had to be repeated for four respondents, not because it was conceptually difficult, but because embedding the responses in the question requires more from active memory. Once they heard it again, they were able to answer. No one in the second round needed the question repeated, but the educational level was higher in general for people in the second round, so they may be more accustomed to thinking in this manner.

Second, not everyone used their age group as the reference category. A couple respondents were thinking in general of the people they know, like friends and family.

Third, the judgments people make here are based not only on physical health. Again, the word "condition" leaves room for multiple interpretations (see AOH.010). Subjects used criteria such as cosmetic appearance, access to dental care providers, and oral hygiene habits to form the basis of their answers.

Recommendation: To make the question straightforward for those with all levels of educational attainment, consider detaching the response options from the question. The reference group participants used to compare themselves didn't matter much to sponsors. However, it should be recognized that the same information is not being captured for all respondents. Finally, the word "condition" was open to different interpretations and, depending on the intent of the question, could be replaced with "health."

AOH.070 Do you think you are at a disadvantage in work or social situations because of how your teeth or mouth looks?

- (1) Yes
- (2) No

Analysis: In the first round, two respondents had difficulty with this question. One person said it varied depending upon if he's wearing his dentures and another person wasn't sure and couldn't say either yes or

no. The answer was more like “sometimes.” For others who answered “yes,” embarrassment factored into their answer. For example, one person said he tended to be self-conscious in social situations and another person feels so embarrassed she won’t smile for pictures.

Recommendation: Because it was a low priority for the sponsor, this question was dropped in the second round.

ACN.451 Have you lost all of your upper and lower natural (permanent) teeth?

- (1) Yes (**go to AOH.090**)
- (2) No (next question)

Analysis: This question isn’t part of the oral health supplement (it’s on the core questionnaire), but seven respondents had response difficulties. Three people were thinking of baby teeth, with one subject explicitly stating that “natural teeth” might mean baby teeth.

Five respondents with missing teeth had some trouble deciphering what the question was asking. Because they were missing at least *some* teeth, they wondered if this is where they should report that fact. For example, one participant’s first response to the question was “yes, except two.” Even when the question was re-read for clarification, he still said yes, explaining that the majority of his teeth are missing. In effect, he defines himself as a person who has no teeth, as a person with dentures. Another person had to think about it because she has veneers on the front and argued that, because she has very little of her own natural teeth left behind the veneers, they don’t count as her own teeth.

Recommendation: None. Because this question is part of the core questionnaire, there are no plans to modify the wording. However, it is noteworthy that people missing some but not all of their teeth struggled most with this question. Estimates from this question are likely to be biased.

AOH.080 DURING THE PAST 6 MONTHS, have you had any of the following problems? Please say yes or no to each.

- | | | |
|--------------------------------------|-----|----|
| (1) A toothache | yes | no |
| (2) Sensitive teeth | yes | no |
| (3) Bleeding gums | yes | no |
| (4) Gum disease | yes | no |
| (5) Crooked teeth | yes | no |
| (6) Broken teeth | yes | no |
| (7) Stained or discolored teeth | yes | no |
| (8) Missing teeth | yes | no |
| (9) Loose teeth not due to an injury | yes | no |
| (10) Teeth that need to be pulled | yes | no |
| (11) Decayed teeth or cavities | yes | no |
| (12) Broken or missing fillings | yes | no |

Analysis: Several response difficulties are identified with this question. First, the category “teeth that need to be pulled” assumes the respondent knows what treatment is necessary. As a result, one respondent vacillated between yes and no because she wasn’t sure if her tooth needed to be pulled or needed a crown. Second, “decayed teeth” and “gum disease” assumes the respondent has a diagnosis of a problem. This is not always the case. One person answered yes to cavities because this was the only explanation she had for why her tooth was hurting. (Others wouldn’t make that assumption, saying things

like, “I don’t know if my teeth are decayed or not.”) Two other people weren’t sure about having gum disease. Their gums bleed sometimes, but a dentist has never told them they have gum disease so they weren’t certain. Third, a person with missing teeth didn’t know what qualified as a missing tooth. He has broken teeth that are essentially useless for chewing, so he counted them as missing. Finally, one tooth can have many problems and respondents tended to report all the symptoms of a single tooth, although two respondents debated whether they should do that or not. This makes sense considering this question takes the symptom/problem as the unit of analysis and not the tooth itself.

Recommendation: Diagnosis and treatment categories (#4, #10 and #11) were deleted in the second round of testing. Also, broken teeth and missing teeth were combined into one category as were toothache and sensitive teeth. This shortened the list and eliminated some of the more problematic categories.

In the second round we found a problem with only one person who is missing all but two teeth and sees himself as a person with dentures. He answered “yes” to toothache/sensitive teeth because his mouth is sensitive sometimes when he has to chew food on his gums. He interpreted the question as “is your mouth sensitive?” On the other hand, he answered “no” to broken/missing teeth saying that the two teeth he had weren’t broken. Yet he was clearly missing many teeth. This vacillation is likely due to the fact that he doesn’t know how these questions are asking him to report answers in light of the status of his teeth (i.e., missing some but not all). For one item (toothache/sensitive teeth) he places himself in the “no teeth” category and in the other item (broken/missing teeth) he places himself in the “has teeth” category, yet neither situation fits his experience. The result is response error. Perhaps a better screening question for people missing many (but not all) teeth should appear prior to this question.

AOH.090 DURING THE PAST 6 MONTHS, have you had any of the following problems? Please say yes or no to each.

(1) Face pain	yes	no
(2) Pain in your jaw joint	yes	no
(3) Sores in your mouth	yes	no
(4) Difficulty chewing	yes	no
(5) Difficulty tasting or swallowing	yes	no
(6) Bad breath	yes	no
(7) Dry mouth	yes	no
(8) Problems with your dentures or plates	yes	no
(9) Some other pain in your mouth	yes	no

Analysis: Many of these categories created response difficulties. First, several respondents weren’t sure what “face pain” meant, asking “Where? Where in my face?” Similarly, “some other pain” was too vague and sometimes captured pain already reported. For example, one respondent answered yes thinking of the cavity he reported in the previous question, and others said yes because of pain caused by dentures (rather than reporting it in the “problems with you dentures or plates” item). In fact, in several instance respondents report multiple symptoms for the same tooth.

Some categories don’t make clear whether or not the symptom has to originate with a dental problem. The “difficulty tasting/swallowing” category is one example. One person has a problem with her esophagus due to chronic sinus drainage, which makes it difficult to swallow. She answered yes to the question but wondered if she should have. Another respondent takes medication for her diabetes. The side effect is dry mouth so she answered yes to the question.

Finally, one person who has dentures, but never wears them because they're uncomfortable, reported "no" to "problems with your dentures." She answered no because "I stopped wearing them a year ago." Is this response error? One could argue yes; she should wear them but doesn't because they're a problem. On the other hand, how can she have a problem with something she doesn't use?

Recommendation: The list was shortened by both deleting four categories. Face pain, difficulty tasting/swallowing, problem with dentures and some other pain were eliminated. Additionally, the phrase "that lasted more than a day" was added to the end of the sentence to indicate a certain level of seriousness for the symptom.

Despite the changes, some problems remained in the second round of testing. Some subjects included symptoms that, by their own admission, weren't serious. Two respondents said yes to bad breath and two said yes to dry mouth, when probing revealed the symptoms did not last for more than a day. Instead, normal situations were described, such as having bad breath in the morning or after drinking coffee, or having dry mouth "every once in a while" but "not everyday."

Moreover, some respondents were still unclear over whether or not to include symptoms caused by non-dental issues. Two people reported yes to bad breath. One respondent believe it to be caused by post-nasal drip and another thought it caused by certain medications she was taking (Paxil). But neither knew for certain. Perhaps the question could read, "...have you had any of the following dental problems that lasted more than a day?"

[For each "yes" to AOH.80 and AOH.090, ask:]

AOH.100 How bothersome is your (fill problem from AOH.080 and AOH.090)? Would you say very bothersome, somewhat bothersome, or not very bothersome?

- (1) very bothersome
- (2) somewhat bothersome
- (3) not very bothersome

Analysis: Respondents generally had no problem indicating how bothered they were by the problems they reported in previous questions. However, this was very tedious for subjects who logged multiple problems. Moreover, to the extent that many reported problems were symptoms of the same tooth, the question was also repetitive.

Recommendation: Because it added substantial administration time to the module and was not critical to supplement sponsors, this item was dropped from the second round of testing.

**[IF ALL RESPONSES = "not very bothered" GO TO DOC.010;
OTHERWISE for each "very bothersome" or "somewhat bothersome" response AOH.100, ASK:]**

AOH.110 Did you try any of these treatments for your (fill very bothersome or somewhat bothersome problem from AOH.90 and AOH.100). Please say yes or no to each.

- | | | |
|--|-----|----|
| (1) saw a dentist | yes | no |
| (2) took medication, or used topical treatment | yes | no |
| (3) asked a friend or family member for advice | yes | no |
| (4) saw a physician | yes | no |
| (5) some other treatment | yes | no |

Analysis: Several categories created problems here. The main problem was the distinction between dentist and doctor. Several respondents answered yes to both when referring to the same person.

A second problem is that the category “some other treatment” captured a variety of methods, some of which were not so much bona fide treatments as strategies used to minimize symptoms (such as chewing on the opposite side of the mouth during a toothache). Other participants included home remedies over medical treatment (such as gargling with salt water upon the recommendation of a family member).

Recommendation: Because primary interest lies with capturing access to a health care provider, this question was eliminated and replaced by two, one that asks if the respondent saw a dentist and another that asks if they saw a physician.

In the second round, AOH.070 (“During the past 6 months did you see a dentist for any of the problems with your mouth or teeth?”) posed no difficulties for participants, and no response error was detected. However, response error did occur for two subjects in AOH.080 (“During the past 6 months did you see a medical doctor for any of the problems with your mouth or teeth?”). One person included a visit to her OB/GYN (just to be sure, the interviewer confirmed that the visit was not related to dental issues) and another person excluded a visit to her general practitioner for a problem with thrush, which was treated with antibiotics. She excluded this visit to the doctor because she didn’t view her symptoms as dental symptoms – that’s why she visited a doctor and not a dentist in the first place. This is a problematic pattern for people with unfamiliar physical symptoms or ailments. They may not define the problem as a dental problem.

Consider combining these two questions into one: “During the past 6 months, did you see a dentist or a doctor for any of the problems with your mouth or teeth?” If yes, “Which one?”

[If NO to “saw a dentist” or “saw a physician” ask AOH.120; OTHERWISE GO TO AOH.115:]

AOH.120 **SHOW HANDCARD B.** Which ONE of these is the main reason you didn’t see a dentist for your (fill very bothersome or somewhat bothersome problem from AOH.90 and AOH.100)?

- | | |
|--|---|
| (1) Didn’t think it was important | (7) Afraid of dentists |
| (2) The problem went away | (8) Waiting for an appointment |
| (3) Had no time to go | (9) Don’t think a dentist can fix the problem |
| (4) Couldn’t afford to see a dentist/ no insurance | (10) Took medication for it |
| (5) Transportation problems | (11) Other |
| (6) No dentist available | |

Analysis: The question didn’t pose any particular problem for respondents. Although some mentioned more than one reason, they were able to narrow it down to one with little difficulty.

Recommendation: None. However, it was decided that hand cards couldn’t be used (due to the number of NHIS interviews conducted via telephone), so the question was changed to a yes/no format for each reason.

The second round of testing produced response error for one respondent. She answered “yes” to no insurance and “no” to couldn’t afford treatment. Because she explained that she hasn’t gone to the dentist

because she doesn't have insurance, the interviewer asked why she didn't answer "yes" to couldn't afford treatments. She said she would have to have dental insurance in order to even consider going to a dentist, otherwise she wouldn't go unless it was an emergency. When growing up, her family always had insurance, so her orientation is that you only go to the dentist if you have insurance. This may be an unusual situation; however, the connection between affording a dentist and having health insurance is likely to confound estimates.

AOH.115 Did you delay or were you unable to treat your (fill: very bothersome or somewhat bothersome problem from AOH.80 and AOH.90) for any of these reasons? Please say yes or no to each.

- | | | |
|---|-----|----|
| (1) because nothing would help it | yes | no |
| (2) because you couldn't afford treatment | yes | no |
| (3) because you didn't think it was important | yes | no |
| (4) because you didn't have transportation | yes | no |
| (5) because you were afraid to see a dentist | yes | no |

Analysis: The main problem with this question is that it carried a false assumption in the minds of some respondents. It assumes they didn't see a dentist for their problem or that they were unable to treat it. After hearing the question several times, one person was confused and said point blank, "I was able to treat it." Others heard the question as asking them to choose between whether they delayed treatment or were unable to treat the problem. For some who already indicated they were unable to treat the problem (for lack of health insurance), the question was repetitive.

Recommendation: This item wasn't critical to sponsors and was dropped in the second round.

AOH.130 How much did your (fill: very bothersome or somewhat bothersome problem from AOH.80 and AOH.90) interfere with the following activities. Would you say a lot, some, a little or not at all?

- | | ANSWER |
|--|--------|
| (1) Your job (only asked of people who work) | _____ |
| (2) Eating | _____ |
| (3) Sleeping | _____ |
| (4) Social activities such as going out or being with other people | _____ |
| (5) Your usual activities at home | _____ |

Analysis: This question was difficult to administer and difficult for respondents to process due to its structure (they tended to provide their own answer and forget the response categories). It demands a lot from active memory.

Recommendation: In the second round this was changed to a simple yes/no for each category, and rather than ask about each problem separately, respondents were asked to answer for their dental problems in general.

The second round of testing didn't show many difficulties with respondents. However, one subject demonstrated some telescoping by saying "yes" to difficulty eating due to surgery she had back in 1997. (It's unclear, but it seems as though the intention of the question is not to include problems that go that far back.) Another subject reported a false negative answer. She has TMJ and the pain it gives her can interfere with her ability to sleep. However, because the pain medication she takes is effective at

eliminating the pain overnight, she can sleep without trouble and answered “no” to this item. Sponsors might consider rewording the question to something like: “Left untreated, do the problems with your mouth or teeth interfere with any of the following?” (Changing the word “did” to “do” might also improve telescoping rates – “did” implies the question is referring to problems that occurred any time in the past.)

CANCER SCREENING

DOC.010

Have you ever heard of a test or exam for oral or mouth cancer?

- Yes
- No
- Don't recall

Analysis: Not a single respondent in either round answered yes to this question. Only one respondent demonstrated anything close to response error. This respondent actually had cancer in her mouth. It's likely she reported no because she didn't realize she was screened for cancer, only that on one dentist visit he “didn't like what he saw” and ordered follow-up tests that ended up showing a malignancy.

Recommendation: None.

DOC.020

Have you ever had a test {/exam} for oral or mouth cancer in which the doctor or dentist pulls on your tongue, sometimes with gauze wrapped around it, and feels under the tongue and inside the cheeks?

- I think so (GO TO DOC.030)
- Yes (GO TO DOC.030)
- No (GO TO DOC.090)
- Refused
- Don't know, not sure

Analysis: Everyone answered no to this question. Probing revealed no response error.

Recommendation: None.

DOC.030

During your last oral cancer exam, did the doctor or dentist examine your neck?

- Yes
- No

Analysis: Not tested in the first round; everyone screened out.

Recommendation: None. However, in an attempt to see if people were receiving cancer screenings without knowing it, this question was asked of everyone in the second round. The word doctor confused a couple participants who mentioned that doctors (not dentists) have felt their neck before, but not for oral cancer. That exam is usually part of a regular physical evaluation.

DOC.040

When did you have your most recent oral or mouth cancer exam? Was it within the past year, between 1 and 3 years ago, or over 3 years ago?

- Within past year
- Between 1 and 3 years ago
- Over 3 years ago

Analysis: Everyone screened out.

Recommendation: None.

DOC.050

What was the main reason you had for this test/exam? Was it [READ EACH OF THE FOLLOWING...]

- For a specific problem
- Follow-up to a previous oral problem
- Part of a routine physical exam
- Part of a routine dental exam
- Other (specify) _____

Analysis: Everyone screened out.

Recommendation: None.

DOC.070

What type of health care professional examined you when you had your last check-up for oral cancer? Was it a [READ EACH OF THE FOLLOWING....]

- Doctor/physician
- Nurse/nurse practitioner
- Dentist
- Dental Hygienist
- Other (specify) _____

Analysis: Everyone screened out.

Recommendation: None.

DOC.090

SHOW HAND CARD E. What is the most important reason why you have [never had/not had an oral cancer exam in the past few years]?

- No reason/never thought about it/didn't know I should
- Not needed/haven't had any problems
- Put it off/laziness
- Costs too much/no insurance
- Doctor/dentist didn't recommend it
- Don't go to doctors or dentist/don't like
- Other (specify) _____

Analysis: The question didn't pose any particular problem for respondents. Although some mentioned more than one reason, they were able to narrow it down to one with little difficulty.

Recommendation: None. However, it was decided that hand cards couldn't be used (due to the number of NHIS interviews conducted via telephone), so the question was changed in the second round to an open format with the interviewer coding the answer to fit one of these categories. The coding process was not entirely straightforward. Respondents gave answers that encompassed multiple reasons. For example, one subject said she never knew about it (an oral cancer exam) because she never visits the dentist where he would've said she needed this exam. The participant didn't see this as a multiple-reason response. The interviewer had to decipher all the reasons listed in that answer, then tease out the most important one with the respondent. In some cases, it was a judgment call on the part of the interviewer.

Sample Child

COH.010 How would you describe the condition of [child's] mouth and teeth? Would you say very good, good, fair or poor?

- (1) Very good
- (2) Good
- (3) Fair
- (4) Poor

Analysis: Respondents had no trouble answering this question for their child. However, as in the adult question, participants used difference criteria to make an assessment of their child's teeth, and answers aren't entirely comparable.

One interesting perspective comes from a respondent who answered "very good" even though her son has a front tooth that is chipped and, according to the dentist, needs a root canal. Despite that diagnosis, the tooth is not perceived by her son to be problematic. (Her son, 16, refused treatment on it, saying the girls actually liked his chipped tooth). Because the tooth is not problematic for him, it's not problematic for her. The criteria for judging the condition of his mouth is based on others' perceptions of his mouth and teeth.

Cosmetic appearance factored into one other respondent's assessment of her child, but it was combined with a medical health aspect as well. Her toddler fell on the play ground and chipped a front tooth. Because the dentist said it wouldn't create any problems, the respondent judges the condition of her daughter's mouth to be very good – her teeth are white and there are no physical problems in her mouth.

Other respondents combined physical health with an oral hygiene criteria. In fact, using oral hygiene as a criteria to assess the condition of their child's mouth factored more prominently in the judgment process for their children than it did for themselves. Parents evaluated the quality (e.g., whether or not brushing was done well) and quantity (e.g., frequency of brushing) of their children's oral hygiene habits in answering this question, sometimes weighing it against what they knew to be true of their physical health. For example, one respondent answered "good" to the question, commenting that his son is "constantly taking care of his mouth" and that he "brushes all the time – after every meal and before bed." When asked by the interviewer why not "very good," the respondent says that his son also has one or two cavities that haven't been fixed yet.

Recommendation: Like the adult section, the word “condition” in the question leads people to evaluate their child’s mouth by more than just health standards. As a result, parents may answer “good” or “very good” to this question even though their children have physical problems with their teeth. Depending on the intent of the question, the word “condition” could be changed to “health.”

COH.020 **SHOW HAND CARD C.** Which one of the following statements BEST describes your approach to [child’s] dental care?

- (1) [child] never goes to a dentist
- (2) [child] goes to a dentist when [he/she] has a problem or when [he/she] needs to get something fixed
- (3) [child] goes to a dentist occasionally whether or not [he/she] has a problem
- (4) [child] goes to a dentist regularly

Analysis: This question functioned similar to the one in the adult section (AOH.020). Of the seven respondents who answered this question (others skipped out), three had difficulty. One person didn’t see a difference between option 3 and 4. Another person had trouble answering because her daughter’s first appointment is in May – a dental visit routine has not yet been established for her.

Recommendation: This question was low priority and was dropped both here and in the adult section.

COH.030 I am going to read you a list of reasons people get dental care. Please tell me how many hours of school [child] has missed in the past 6 months for each one.

	# OF HOURS
(1) For checkups or cleanings	_____
(2) For fluoride treatments	_____
(3) For sealants	_____
(4) For orthodontic treatment	_____
(5) For emergency or immediate dental treatment	_____
(6) For a specific problem other than orthodontic treatment or emergency treatment	_____
(7) For tooth whitening or other cosmetic work	_____

Analysis: This question had problems similar to it’s counterpart in the adult section. Respondents had difficulty with the vocabulary (specifically the words orthodontic and sealants – no one knew what sealants were), provided answers not in the form of hours (number of times and number of days missed from school were given), and had some trouble with recall (one respondent demonstrated clear error, reporting that her son missed 2 days of school, when probing revealed that those dentist visits actually occurred in August, before school started). Finally, one respondent needed the question read two times in order to figure out what it was asking.

Recommendation: Several categories were dropped after the first round of testing, including fluoride treatments (#2), sealants (#3) and specific problem (#6). Additionally, orthodontic treatment was combined with routine care in number 1, and taking someone else to a dental appointment was added for children 16 and older. Finally, emergency or immediate treatment (#5) was limited to simply emergency treatment. The unit of analysis, hours, was retained with an instruction to interviewers to prompt the respondent for hours if they provide an answer in the form of days.

It wasn't extensively tested because most respondents (seven) in the second round didn't have children, but the only problem detected was that respondents still tended to answer in terms of "number of times" the child missed school. It took some work for the interviewer to arrive at the number of hours, as the respondents had to explain that both times the child missed school she picked him up at 2:00 to take him to the dentist. The interviewer had to ask what time school ended in order to determine that the number of hours missed was two. This could be a problem in the field. Some interviewers will take more care than others to reach the correct answer.

COH.040 Does the condition of [child's] teeth or mouth cause [her/him] to have problems with any of the following. Please say yes or no to each.

- | | | |
|---|-----|----|
| (1) Eating or chewing certain types of food | yes | no |
| (2) Smiling or talking to people | yes | no |
| (3) Learning | yes | no |
| (4) Sleeping | yes | no |

Analysis: Most respondents answered "no" to every item here. However, there is a potential age issue for toddlers. One respondent said yes to eating because her daughter touches her teeth, makes a face, and says "cold" when she's given cold food to eat. The respondent interprets this as teeth sensitivity and draws the conclusion that her daughter has trouble eating certain types of food.

Recommendation: This question makes certain assumptions about what parents can know about young children. However, like it's adult counterpart, it was dropped in the second round of testing.

COH.050 DURING THE PAST 12 MONTHS, how often has [child] been self-conscious or embarrassed because of [her/his] teeth or mouth? Would you say often, sometimes, rarely or never?

- (1) Often
- (2) Sometimes
- (3) Rarely
- (4) Never

Analysis: This question overall didn't pose many problem for respondents. One possible issue is the age of a child. One respondent with a 20 month old laughed at the question, but was able to answer it.

Recommendation: In the second round of testing this question was asked only for children over 5 years old. Of the three respondents tested in the second round, one parent was speculative in answering, and used broad criteria to assess embarrassment. She answered "maybe sometimes," offering that her son has bad breath once in a while, which could cause embarrassment around his friends. She did not say, however, that he ever directly mentioned this to her. No suggestions for change; this phenomenon will always occur when asking a respondent to report on the way someone *else* feels. They may have no knowledge of this. (If this is a low priority item, consider dropping.)

COH.060 Do you think the condition of [child's] mouth and teeth is better than, the same as or not as good as other people [her/his] age?

- (1) Better
- (2) Same
- (3) Not as good

Analysis: Respondents were able to answer this question without difficulty, but used different criteria to determine the “condition” of their child’s mouth. One person used the judgment of her son’s peers as her criteria for answering “better” (even though the dentist has said her son needs root canal on a front tooth). Another participant was thinking of her access to health care and dentists when answering the question: “I would say better than. You’d be surprised at the number of people that...don’t really take their children to the dentist on a regular basis...be it because of lack of insurance, not having time, or not having a family dentist.” Finally, someone else considered the cosmetic appearance of her son’s teeth when she answered “not as good as.” He needs braces on his bottom teeth. This participant is a good example of how the word “condition” encourages shifts in interpretation. She answered “good” to COH.010, where she was thinking of oral hygiene. The condition of his mouth is good because he brushes regularly and she makes sure he takes care of his teeth. However, in this question, her criteria shifts to cosmetic issues when she thinks of the condition of his mouth in relation to other people. (And it makes sense that she would know the condition of other people’s mouth by cosmetic appearance alone.) The reference to other people, combined with the fluidness of the word “condition” caused a shift in interpretation.

Recommendation: As with the adult version of this question (AOH.060) the same information is not being captured for all respondents. The word “condition” is open to different and shifting interpretations and, depending on the intent of the question, could be replaced with the word “health.”

COH.070 Do you think [child] is at a disadvantage in school or social situations because of how [her/his] teeth or mouth looks?

- (1) Yes
- (2) No

Analysis: Every respondent answered no to this question in the first round. No difficulties were detected.

Recommendation: None, but the item was a low priority for the sponsor and dropped from the second round.

COH.080 DURING THE PAST 6 MONTHS, has [child] had any of the following problems. Please say yes or no to each.

- | | | |
|--|-----|----|
| (1) A toothache | yes | no |
| (2) Face pain | yes | no |
| (3) Pain in [her/his] jaw joint | yes | no |
| (4) Sores in [her/his] mouth | yes | no |
| (5) Sensitive teeth | yes | no |
| (6) Bleeding gums | yes | no |
| (7) Crooked teeth | yes | no |
| (8) Broken teeth | yes | no |
| (9) Stained or discolored teeth | yes | no |
| (10) Missing teeth other than losing baby teeth | yes | no |
| (11) Loose teeth not due to an injury or losing baby teeth | yes | no |
| (12) Teeth that need to be pulled | yes | no |
| (13) Decayed teeth or cavities | yes | no |
| (14) Broken or missing fillings | yes | no |
| (15) Bad breath | yes | no |
| (16) Dry mouth | yes | no |

COH.120 **SHOW HANDCARD D** Which ONE of these is the main reason you didn't take [child] to a dentist for [her/his]] (fill very bothersome or somewhat bothersome problem from COH.80)?

- (1) Didn't think it was important
- (2) The problem went away
- (3) Had no time to go
- (4) Couldn't afford to see a dentist/ no insurance
- (5) Transportation problems
- (6) No dentist available
- (7) Afraid of dentists
- (8) Waiting for an appointment
- (9) Don't think a dentist can fix the problem
- (10) Gave [her/him] medication for it
- (11) Other

Analysis: This was not extensively tested.

Recommendation: None. In the second round, this question was changed to a yes/no format to match changes made in the adult counterpart.

COH.115 Did you delay or were you unable to treat [child's] (fill very bothersome or somewhat bothersome problem from COH.80) for any of these reasons. Please say yes or no to each.

- | | | |
|---|-----|----|
| (1) because nothing would help it | yes | no |
| (2) because you couldn't afford treatment | yes | no |
| (3) because you didn't think it was important | yes | no |
| (4) because you didn't have transportation | yes | no |
| (5) because you were afraid for [her/him] | yes | no |
| (6) to see a dentist | yes | no |

Analysis: This was not extensively tested.

Recommendation: Because this was a low priority item for the sponsor, it was deleted in the second round.

COH.130 How much did [child's] (fill very bothersome or somewhat bothersome problem from COH.80) interfere with the following activities. Would you say a lot, some, a little or not at all?

- (1) School
- (2) Work
- (2) Eating
- (3) Sleeping
- (4) Social activities such as going out or being with other people
- (5) [her/his] usual activities at home

Analysis: This was not extensively tested.

Recommendation: None. This was changed to a yes/no format in the second round to match changes made in the adult counterpart.

COH.140 How important do you think it is to keep children under 6 from getting cavities in their baby teeth?

- (1) very important
- (2) somewhat important
- (3) not very important

Analysis: There was very little response variation on this item. Everyone but one subject answered “very important.” And the one person who answered “somewhat important” had a different interpretation of the question. He understood it to be asking how *easy* it is for parents to prevent cavities in baby teeth. He said, “Basically it’s kind of hard sometimes, unless you’re going to be a stickler of a parent not to give kids little treats like candy or gum...things that contain sugar. So it’s somewhat important that you don’t overdo it, but then how do you know what’s too much?”

Recommendation: The lack of response variation suggests that parents know what the “correct” answer to this question is. It might not be a very useful analytical tool. In the second round only three people were tested, with still no response variation – everyone said “very important.”

COH.150 Do you agree or disagree with the following statements?

- (1) Cavities in children under six are not that important because they lose their baby teeth
 - Agree
 - Disagree

Analysis: There was no response variation in this question. Every respondent disagreed. This item might not be a very useful analytical tool.

Recommendation: This item was low priority for the sponsor and was dropped in the second round.

- (2) Cavities in children under six cannot be prevented
 - Agree
 - Disagree

Analysis: There was very little response variation on this item. Everyone but one subject answered “disagree.” The one person who answered otherwise said, “Maybe to be open-minded I would say I agree. Basically, unless you are really a stickler of a parent and keep your child completely away from sugar...along with knowing that most children in that age group don’t brush on a regular basis...you encourage them to, but unless you’re standing right over top of them, they may not.” This answer suggests he knew that the “right” answer was “disagree,” but was willing to admit the logistical difficulties in actually preventing cavities in young children.

Recommendation: This was changed to a yes/no format in the second round, and elicited no response variation. Everyone said yes, cavities can be prevented.

COH.150 Which of these do you think will help to keep young children from getting cavities?
Answer yes or no to each

(1) brushing their teeth	yes	no
(2) not letting them take a bottle to bed	yes	no
(3) not eating or drinking sweeten drinks or foods	yes	no
(4) using toothpaste that has fluoride in it	yes	no
(5) drinking water that has fluoride in it	yes	no
(6) getting regular dental care	yes	no
(7) getting dental sealants	yes	no

Analysis: The main problem with this question is that 8 of the 9 respondents tested in round one did not know what dental sealants were.

Recommendation: Because this was a low priority item for the sponsor, it was dropped in the second round of testing.

QUESTIONS NEW TO ROUND 2 INSTRUMENT

(not already covered in analysis):

Sample Adult

AAU.135 About how long has it been since you last saw or talked to a dentist? Include all types of dentist such as orthodontists, oral surgeons, and all other dental specialists, as well as dental hygienists.

- a. 6 months or less [GO TO AOH.040, number 1]
- b. More than 6 months [GO TO AOH.040, number 4]

Analysis: New to the second round of testing, this question didn't present many problems for respondents and no response error was detected. However, one person needed to hear the question more than once, saying, "what's the top part of that question?" It's a long definition that caused him to lose track of the original question.

Recommendation: Because it's part of the NHIS core, this question is unlikely to be changed. However, the definition could benefit from being shortened.

AOH.040 I am going to read you a list of reasons people get dental care. Please tell me how many hours of work or school you have you missed in the past 6 months for each one.

[INTERVIEWER: Probe for hours if respondent answers in "days"]

Number of hours

(1) For routine dental or orthodontic care _____

Analysis: Orthodontic care was combined with routine care in the second round. This was only tested on two people in the second round (no one else went to school or work). One person had difficulty with answering in hours ("I just take the day off to go to the dentist") and might have misreported the nature of the visit. One visit was to get fillings replaced that had fallen out. Should this be included in emergency care since it wasn't a routine cleaning?

Recommendation: The interviewer was able to translate her answer into hours, but the problem of classifying a dental visit as routine vs. emergency remains. Maybe something like "routine dental check-up" would convey the idea better.

(2) For emergency dental care _____

Analysis: See comments for previous item. "Emergency care" isn't entirely clear to respondents.

(3) For tooth whitening or other cosmetic procedures _____

Analysis: As in the first round, this item presented no difficulties for respondents.

Recommendation: None.

(4) For taking someone else to a dental appointment _____

Analysis: No problems detected.

Recommendation: None.

AOH.060.010 Does the condition of your mouth or teeth cause you to have problems eating or chewing?

- (1) Yes
- (2) No

Analysis: New to the second round, this question wasn't any more or less difficult for people to answer than the third item in the previous question. One respondent did have to debate saying yes or no because it depends on the type of food she's eating. She ultimately answered "no."

Recommendation: None. Neither method of asking about difficulty eating (AOH.060 vs. AOH.060.010) seemed superior to the other.

Appendix A – First Version of Instrument Tested in First Round

Sample Adult

The first questions are about your oral health, then later I'll ask about [CHILD'S NAME].

AOH.010 How would you describe the condition of your mouth and teeth? Would you say very good, good, fair or poor? [NOTE: question includes people who have no teeth, have false teeth and dentures]

- (1) Very good
- (2) Good
- (3) Fair
- (4) Poor

AOH.020 **SHOW HAND CARD A.** Which one of the following statements BEST describes your approach to dental care?

- (1) I never go to a dentist
- (2) I go to a dentist when I have a problem or when I need to get something fixed
- (3) I go to a dentist occasionally whether or not I have a problem
- (4) I go to a dentist regularly

AOH.030 I am going to read you a list of reasons people get dental care. Please tell me how many hours of work you have missed in the past 6 months for each one.

- | | Number of hours |
|--|-----------------|
| (1) For checkups or cleanings | _____ |
| (2) For orthodontic treatment | _____ |
| (3) For emergency or immediate dental treatment | _____ |
| (4) For a specific problem other than orthodontic treatment or emergency treatment | _____ |
| (5) For tooth whitening or other cosmetic work | _____ |
| (6) For taking someone else to a dental appointment | _____ |

AOH.040 Does the condition of your teeth, mouth, or dentures cause you to have problems with any of the following. Please say yes or no to each.

- | | | |
|---|-----|----|
| (1) Eating or chewing certain types of food | yes | no |
| (2) Smiling or talking to people | yes | no |
| (3) Doing work or learning | yes | no |
| (4) Sleeping | yes | no |

AOH.050 DURING THE PAST 12 MONTHS, how often have you been self-conscious or embarrassed because of your teeth, mouth or dentures? Would you say often, sometimes, rarely or never?

- (1) Often
- (2) Sometimes
- (3) Rarely
- (4) Never

- AOH.060 Do you think the condition of your mouth and teeth is better than, the same as or not as good as other people your age?
- (1) Better
 - (2) Same
 - (3) Not as good
- AOH.070 Do you think you are at a disadvantage in work or social situations because of how your teeth or mouth looks?
- (1) Yes
 - (2) No
- ACN.451 Have you lost all of your upper and lower natural (permanent) teeth?
- (1) Yes (**go to AOH.090**)
 - (2) No (next question)
- AOH.080 DURING THE PAST 6 MONTHS, have you had any of the following problems? Please say yes or no to each.
- | | | |
|--------------------------------------|-----|----|
| (1) A toothache | yes | no |
| (2) Sensitive teeth | yes | no |
| (3) Bleeding gums | yes | no |
| (4) Gum disease | yes | no |
| (5) Crooked teeth | yes | no |
| (6) Broken teeth | yes | no |
| (7) Stained or discolored teeth | yes | no |
| (8) Missing teeth | yes | no |
| (9) Loose teeth not due to an injury | yes | no |
| (10) Teeth that need to be pulled | yes | no |
| (11) Decayed teeth or cavities | yes | no |
| (12) Broken or missing fillings | yes | no |

[ASK ALL RESPONDENTS:]

- AOH.090 DURING THE PAST 6 MONTHS, have you had any of the following problems? Please say yes or no to each.
- | | | |
|---|-----|----|
| (1) Face pain | yes | no |
| (2) Pain in your jaw joint | yes | no |
| (3) Sores in your mouth | yes | no |
| (4) Difficulty chewing | yes | no |
| (5) Difficulty tasting or swallowing | yes | no |
| (6) Bad breath | yes | no |
| (7) Dry mouth | yes | no |
| (8) Problems with your dentures or plates | yes | no |
| (9) Some other pain in your mouth | yes | no |

[For each “yes” to AOH.80 and AOH.090, ask:]

- AOH.100 How bothersome is your (fill problem from AOH.080 and AOH.090)? Would you say very bothersome, somewhat bothersome, or not very bothersome?

- (1) very bothersome
- (2) somewhat bothersome
- (3) not very bothersome

**[IF ALL RESPONSES = “not very bothered” GO TO DOC.010;
OTHERWISE for each “very bothersome” or “somewhat bothersome ” response AOH.100, ASK:]**

AOH.110 Did you try any of these treatments for your (fill very bothersome or somewhat bothersome problem from AOH.90 and AOH.100). Please say yes or no to each.

- | | | |
|--|-----|----|
| (1) saw a dentist | yes | no |
| (2) took medication, or used topical treatment | yes | no |
| (3) asked a friend or family member for advice | yes | no |
| (4) saw a physician | yes | no |
| (5) some other treatment | yes | no |

**[If NO to “saw a dentist” or “saw a physician” ask AOH.120;
OTHERWISE GO TO AOH.115:]**

AOH.120 **SHOW HANDCARD B.** Which ONE of these is the main reason you didn’t see a dentist for your (fill very bothersome or somewhat bothersome problem from AOH.90 and AOH.100)?

- | | |
|---|---|
| (1) Didn’t think it was important | (7) Afraid of dentists |
| (2) The problem went away | (8) Waiting for an appointment |
| (3) Had no time to go | (9) Don’t think a dentist can fix the problem |
| (4) Couldn’t afford to see a dentist/
no insurance | (10) Took medication for it |
| (5) Transportation problems | (11) Other |
| (6) No dentist available | |

AOH.115 Did you delay or were you unable to treat your (fill: very bothersome or somewhat bothersome problem from AOH.80 and AOH.90) for any of these reasons? Please say yes or no to each.

- | | | |
|---|-----|----|
| (1) because nothing would help it | yes | no |
| (2) because you couldn’t afford treatment | yes | no |
| (3) because you didn’t think it was important | yes | no |
| (4) because you didn’t have transportation | yes | no |
| (5) because you were afraid to see a dentist | yes | no |

AOH.130 How much did your (fill: very bothersome or somewhat bothersome problem from AOH.80 and AOH.90) interfere with the following activities. Would you say a lot, some, a little or not at all?

- | | |
|--|--------|
| | ANSWER |
| (1) Your job (only asked of people who work) | _____ |
| (2) Eating | _____ |
| (3) Sleeping | _____ |
| (4) Social activities such as going out or being with other people | _____ |
| (5) Your usual activities at home | _____ |

CANCER SCREENING

[ASK ALL R’s:]

DOC.010

Have you ever heard of a test or exam for oral or mouth cancer?

- Yes
- No
- Don't recall

DOC.020

Have you ever had a test {/exam} for oral or mouth cancer in which the doctor or dentist pulls on your tongue, sometimes with gauze wrapped around it, and feels under the tongue and inside the cheeks?

- I think so (**GO TO DOC.030**)
- Yes (**GO TO DOC.030**)
- No (**GO TO DOC.090**)
- Refused
- Don't know, not sure

DOC.030

During your last oral cancer exam, did the doctor or dentist examine your neck?

- Yes
- No

DOC.040

When did you have your most recent oral or mouth cancer exam? Was it within the past year, between 1 and 3 years ago, or over 3 years ago?

- Within past year
- Between 1 and 3 years ago
- Over 3 years ago

DOC.050

What was the main reason you had for this test/exam? Was it [READ EACH OF THE FOLLOWING...]

- For a specific problem
- Follow-up to a previous oral problem
- Part of a routine physical exam
- Part of a routine dental exam
- Other (specify) _____

DOC.070

What type of health care professional examined you when you had your last check-up for oral cancer? Was it a [READ EACH OF THE FOLLOWING....]

- Doctor/physician
- Nurse/nurse practitioner
- Dentist
- Dental Hygienist
- Other (specify) _____

[Ask if DOC.040 –CANCER EXAM – is over 3 years ago OR IF R NEVER HAD CANCER EXAM (DOC.020=NO); OTHERWISE, GO TO NEXT SECTION – SAMPLE CHILD]

DOC.090

SHOW HAND CARD E. What is the most important reason why you have [never had/not had an oral cancer exam in the past few years]?

- ___ No reason/never thought about it/didn't know I should
- ___ Not needed/haven't had any problems
- ___ Put it off/laziness
- ___ Costs too much/no insurance
- ___ Doctor/dentist didn't recommend it
- ___ Don't go to doctors or dentist/don't like
- ___ Other (specify) _____

Sample Child

[IF R HAS A CHILD, ASK:]

Now let's talk about [CHILD].

COH.010 How would you describe the condition of [child's] mouth and teeth? Would you say very good, good, fair or poor?

- (1) Very good
- (2) Good
- (3) Fair
- (4) Poor

COH.020 **SHOW HAND CARD C.** Which one of the following statements BEST describes your approach to [child's] dental care?

- (1) [child] never goes to a dentist
- (2) [child] goes to a dentist when [he/she] has a problem or when [he/she] needs to get something fixed
- (3) [child] goes to a dentist occasionally whether or not [he/she] has a problem
- (4) [child] goes to a dentist regularly

COH.030 I am going to read you a list of reasons people get dental care. Please tell me how many hours of school [child] has missed in the past 6 months for each one.

	NUMBER OF HOURS
(1) For checkups or cleanings	_____
(2) For fluoride treatments	_____
(3) For sealants	_____
(4) For orthodontic treatment	_____
(5) For emergency or immediate dental treatment	_____
(6) For a specific problem other than orthodontic treatment or emergency treatment	_____
(7) For tooth whitening or other cosmetic work	_____

COH.040 Does the condition of [child's] teeth or mouth cause [her/him] to have problems with any of the following. Please say yes or no to each.

(1) Eating or chewing certain types of food	yes	no
(2) Smiling or talking to people	yes	no
(3) Learning	yes	no
(4) Sleeping	yes	no

COH.050 DURING THE PAST 12 MONTHS, how often has [child] been self-conscious or embarrassed because of [her/his] teeth or mouth? Would you say often, sometimes, rarely or never?

- (1) Often
- (2) Sometimes
- (3) Rarely
- (4) Never

COH.060 Do you think the condition of [child's] mouth and teeth is better than, the same as or not as good as other people [her/his] age?

- (1) Better
- (2) Same
- (3) Not as good

COH.070 Do you think [child] is at a disadvantage in school or social situations because of how [her/his] teeth or mouth looks?

- (1) Yes
- (2) No

COH.080 DURING THE PAST 6 MONTHS, has [child] had any of the following problems. Please say yes or no to each.

- | | | |
|--|-----|----|
| (1) A toothache | yes | no |
| (2) Face pain | yes | no |
| (3) Pain in [her/his] jaw joint | yes | no |
| (4) Sores in [her/his] mouth | yes | no |
| (5) Sensitive teeth | yes | no |
| (6) Bleeding gums | yes | no |
| (7) Crooked teeth | yes | no |
| (8) Broken teeth | yes | no |
| (9) Stained or discolored teeth | yes | no |
| (10) Missing teeth other than losing baby teeth | yes | no |
| (11) Loose teeth not due to an injury or losing baby teeth | yes | no |
| (12) Teeth that need to be pulled | yes | no |
| (13) Decayed teeth or cavities | yes | no |
| (14) Broken or missing fillings | yes | no |
| (15) Bad breath | yes | no |
| (16) Dry mouth | yes | no |
| (17) Some other pain in [her/his] mouth | yes | no |

[For each "yes" to COH.080 ask:]

COH.100 How bothersome is [child's] (fill very bothersome or somewhat bothersome problem from COH.80)? Would you say very bothersome, somewhat bothersome, or not very bothersome?

- (1) very bothersome
- (2) somewhat bothersome
- (3) not very bothersome

[For each "very bothersome" or "somewhat bothersome" response in COH.100, ask:]

COH.110 Did you try any of these treatments for [child's] (fill very bothersome or somewhat bothersome problem from COH.80)? Please say yes or no to each.

- (1) took [her/him] to a dentist
- (2) gave [her/him] medication, or used topical treatment

- (3) asked a friend or family member for advice
- (4) took [her/him] to a physician
- (5) some other treatment

[If NO to “took to [her/him] a dentist” or “took [her/him] to a physician” in COH. 110, ask:]

COH.120 **SHOW HANDCARD D** Which ONE of these is the main reason you didn't take [child] to a dentist for [her/his]] (fill very bothersome or somewhat bothersome problem from COH.80)?

- (1) Didn't think it was important
- (2) The problem went away
- (3) Had no time to go
- (4) Couldn't afford to see a dentist/ no insurance
- (5) Transportation problems
- (6) No dentist available
- (7) Afraid of dentists
- (8) Waiting for an appointment
- (9) Don't think a dentist can fix the problem
- (10) Gave [her/him] medication for it
- (11) Other

COH.115 Did you delay or were you unable to treat [child's] (fill very bothersome or somewhat bothersome problem from COH.80) for any of these reasons. Please say yes or no to each.

- | | | |
|---|-----|----|
| (1) because nothing would help it | yes | no |
| (2) because you couldn't afford treatment | yes | no |
| (3) because you didn't think it was important | yes | no |
| (4) because you didn't have transportation | yes | no |
| (5) because you were afraid for [her/him] | yes | no |
| (6) to see a dentist | yes | no |

COH.130 How much did [child's] (fill very bothersome or somewhat bothersome problem from COH.80) interfere with the following activities. Would you say a lot, some, a little or not at all?

- (1) School
- (2) Work
- (2) Eating
- (3) Sleeping
- (4) Social activities such as going out or being with other people
- (5) [her/his] usual activities at home

[ASK ALL R's:]

COH.140 How important do you think it is to keep children under 6 from getting cavities in their baby teeth?

- (1) very important
- (2) somewhat important
- (3) not very important

COH.150 Do you agree or disagree with the following statements?

- (1) Cavities in children under six are not that important because they lose their baby teeth

Agree
Disagree

(2) Cavities in children under six cannot be prevented

Agree

Disagree

COH.150

Which of these do you think will help to keep young children from getting cavities? Answer yes or no to each

- | | | |
|--|-----|----|
| (1) brushing their teeth | yes | no |
| (2) not letting them take a bottle to bed | yes | no |
| (3) not eating or drinking sweeten drinks or foods | yes | no |
| (4) using toothpaste that has fluoride in it | yes | no |
| (5) drinking water that has fluoride in it | yes | no |
| (6) getting regular dental care | yes | no |
| (7) getting dental sealants | yes | no |

HANDCARD A

- 1) I never go to a dentist
- 2) I go to a dentist when I have a problem or when I need to get something fixed
- 3) I go to a dentist occasionally whether or not I have a problem
- 4) I go to a dentist regularly

HANDCARD B

- (1) Didn't think it was important
- (2) The problem went away
- (3) Had no time to go
- (4) Couldn't afford to see a dentist/ no insurance
- (5) Transportation problems
- (6) No dentist available
- (7) Afraid of dentists
- (8) Waiting for an appointment
- (9) Don't think a dentist can fix the problem
- (10) Took medication for it
- (11) Other

HANDCARD C

- 1) [child] never goes to a dentist
- 2) [child] goes to a dentist when [he/she] has a problem or when [he/she] needs to get something fixed
- 3) [child] goes to a dentist occasionally whether or not [he/she] has a problem
- 4) [child] goes to a dentist regularly

HANDCARD D

- (1) Didn't think it was important
- (2) The problem went away
- (3) Had no time to go
- (4) Couldn't afford to see a dentist/ no insurance
- (5) Transportation problems
- (6) No dentist available
- (7) Afraid of dentists
- (8) Waiting for an appointment
- (9) Don't think a dentist can fix the problem
- (10) Gave [her/him] medication for it
- (11) Other

HANDCARD E

- (1) No reason/never thought about it/didn't know I should
- (2) Not needed/haven't had any problems
- (3) Put it off/laziness
- (4) Costs too much/no insurance
- (5) Doctor/dentist didn't recommend it
- (6) Don't go to doctors or dentist/don't like
- (7) Other (specify)

Appendix B – Second Version of Instrument Tested in Second Round (handcards eliminated)

Sample Adult

The first questions are about your oral health, then later I'll ask about [CHILD'S NAME].

AOH.010 How would you describe the condition of your mouth and teeth? Would you say very good, good, fair or poor? [NOTE: question includes people who have no teeth, have false teeth and dentures]

- (1) Very good
- (2) Good
- (3) Fair
- (4) Poor

AOH.020 Would you say the condition of your mouth and teeth is better than, the same as or not as good as other people your age?

- (1) Better
- (2) Same
- (3) Not as good

AOH.030 DURING THE PAST 6 MONTHS, how often have you been self-conscious or embarrassed because of your teeth, mouth or dentures? Would you say often, sometimes, rarely or never?

- (1) Often
- (2) Sometimes
- (3) Rarely
- (4) Never

AAU.135 About how long has it been since you last saw or talked to a dentist? Include all types of dentist such as orthodontists, oral surgeons, and all other dental specialists, as well as dental hygienists.

- a. 6 months or less [GO TO AOH.040, number 1]
- b. More than 6 months [GO TO AOH.040, number 4]

[ASK AOH.040 IF R GOES TO WORK OR SCHOOL; OTHERWISE GO TO ACN.451]

AOH.040 I am going to read you a list of reasons people get dental care. Please tell me how many hours of work or school you have you missed in the past 6 months for each one. [INTERVIEWER: Probe for hours if respondent answers in "days"]

- | | Number of hours |
|--|------------------------|
| (1) For routine dental or orthodontic care | _____ |
| (2) For emergency dental care | _____ |
| (3) For tooth whitening or other cosmetic procedures | _____ |
| (4) For taking someone else to a dental appointment | _____ |

ACN.451 Have you lost all of your upper and lower natural, permanent teeth?

- (1) Yes [go to AOH.060]
- (2) No

AOH.050 DURING THE PAST 6 MONTHS, have you had any of the following problems? Please say yes or no to each.

- | | | | |
|-----|----------------------------------|-----|----|
| (1) | A toothache or sensitive teeth | yes | no |
| (2) | Bleeding gums | yes | no |
| (3) | Crooked teeth | yes | no |
| (4) | Broken or missing teeth | yes | no |
| (5) | Stained or discolored teeth | yes | no |
| (6) | Loose teeth not due to an injury | yes | no |
| (7) | Broken or missing fillings | yes | no |

[ASK ALL RESPONDENTS:]

AOH.060 DURING THE PAST 6 MONTHS, have you had any of the following problems that lasted more than a day? Please say yes or no to each.

- | | | | |
|-----|------------------------------|-----|----|
| (1) | Pain in your jaw joint | yes | no |
| (2) | Sores in your mouth | yes | no |
| (3) | Difficulty eating or chewing | yes | no |
| (4) | Bad breath | yes | no |
| (5) | Dry mouth | yes | no |

OH.060.010 Does the condition of your mouth or teeth cause you to have problems eating or chewing?

- (1) Yes
- (2) No

[IF NO PROBLEMS, SKIP TO AOH.110, CANCER EXAM; FOR THOSE WITH PROBLEMS, ASK...]

AOH.070 During the past 6 months did you see a dentist for any of the problems with your mouth or teeth?

- Yes
 No

AOH.080 During the past 6 months did you see a medical doctor for any of the problems with your mouth or teeth?

- Yes
 No

[IF NO TO AOH.070, "saw a dentist" ASK:]

AOH.090 DURING THE PAST 6 MONTHS, why didn't you see a dentist for the problems with your mouth or teeth? Please say yes or no to each.

- | | | | |
|-----|--|-----|----|
| (1) | you didn't think it was important | yes | no |
| (2) | the problem went away | yes | no |
| (3) | you couldn't afford treatments | yes | no |
| (4) | you didn't have insurance | yes | no |
| (5) | you didn't have transportation | yes | no |
| (6) | you were afraid to see a dentist | yes | no |
| (7) | you were waiting for an appointment | yes | no |
| (8) | you didn't think a dentist could fix the problem | yes | no |

**[ASK RESPONDENTS WITH TOOTH OR MOUTH PROBLEMS;
OTHERWISE GO TO NEXT SECTION – ORAL CANCER EXAM]**

AOH.100 Did the problems with your mouth or teeth interfere with any of the following. Please say yes or no to each.

- (1) Your job or school
[ASK ONLY IF R WORKS OR GOES TO SCHOOL] yes no
(2) Eating yes no
(3) Sleeping yes no
(4) Social activities such as going out or being with other people yes no
(5) Your usual activities at home yes no

ORAL CANCER EXAM

AOH.110 Have you ever heard of an exam for oral or mouth cancer?

____ Yes
____ No

AOH.120 Have you ever had an exam for oral cancer in which the doctor or dentist pulls on your tongue, sometimes with gauze wrapped around it, and feels under the tongue and inside the cheeks?

____ Yes
____ No

AOH.130 Have you ever had an exam for oral cancer in which the doctor or dentist feels your neck?

____ Yes
____ No

[IF NO TO BOTH AOH.120 AND AOH.130, GO TO AOH.170. IF YES TO EITHER, ASK AOH.140]

AOH.140 When did you have your most recent oral or mouth cancer exam?
Was it within the past year, between 1 and 3 years ago, or over 3 years ago?

____ Within past year
____ Between 1 and 3 years ago
____ Over 3 years ago

[IF CANCER EXAM OVER 3 YEARS AGO, GO TO AOH.170, ELSE ASK AOH.150]

AOH.150 Was your most recent oral cancer exam part of a routine exam or because of a problem you were having?

____ Part of a routine exam
____ For a specific problem

AOH.160 What type of health care professional did your most recent oral cancer exam? check-up for oral cancer?

- Doctor/physician
- Nurse/nurse practitioner
- Dentist (include oral surgeons)
- Dental Hygienist
- Other (specify) _____

[Ask if CANCER EXAM – is over 3 years ago OR IF R NEVER HAD CANCER EXAM; OTHERWISE, GO TO NEXT SECTION – SAMPLE CHILD]

AOH.170 What is the most important reason why you have [never had/not had an oral cancer exam in the past few years]? **[INTERVIEWER: Code open ended response.]**

- No reason/never thought about it/didn't know I should
- Not needed/haven't had any problems
- Put it off/laziness
- Costs too much/no insurance
- Doctor/dentist didn't recommend it
- Don't go to doctors or dentist/don't like
- Other (specify) _____

[GOTO NEXT SECTION – SAMPLE CHILD]

Sample Child

Now let's talk about [CHILD].

COH.010 How would you describe the condition of [CHILD'S] mouth and teeth? Would you say very good, good, fair or poor?

- (1) Very good
- (2) Good
- (3) Fair
- (4) Poor

COH.020 Would you say the condition of [CHILD'S] mouth and teeth is better than, the same as or not as good as other people her or his age?

- (1) Better
- (2) Same
- (3) Not as good

[ASK COH.030 IF CHILD IS OVER 5 YEARS OLD]

COH.030 DURING THE PAST 12 MONTHS, how often was [HE/SHE] self-conscious or embarrassed because of [HIS/HER] teeth or mouth? Would you say often, sometimes, rarely or never?

- (1) Often
- (2) Sometimes
- (3) Rarely
- (4) Never

[ASK ALL:]

CAU.135 About how long has it been since [CHILD] last saw or talked to a dentist? Include all types of dentist such as orthodontists, oral surgeons, and all other dental specialists, as well as dental hygienists.

- (1) 6 months or less [GO TO COH.040, number 1]
- (2) More than 6 months [GO TO COH.040, number 4]

[ASK COH.040 IF CHILD IS OVER 1 YEAR OLD AND GOES TO SCHOOL/DAYCARE]

COH.040 I am going to read you a list of reasons people get dental care. Please tell me how many hours of school [CHILD] has missed in the past 6 months for each one.
[INTERVIEWER: Probe for hours if respondent answers in “days”]

- | | # OF HOURS |
|---|-------------------|
| (1) For routine dental or orthodontic care | _____ |
| (2) For emergency dental care | _____ |
| (3) For tooth whitening or other cosmetic procedures [age 6+] | _____ |
| (4) For taking someone else to a dental appointment [age 16+] | _____ |

COH.050 DURING THE PAST 6 MONTHS, has [CHILD] had any of the following problems. Please say yes or no to each.

- | | | | |
|--|-----|----|--|
| (1) A toothache or sensitive teeth | yes | no | |
| (2) Pain in [her/his] jaw joint | yes | no | |
| (3) Sores in [her/his] mouth | yes | no | |
| (4) Bleeding gums | yes | no | |
| (5) Crooked teeth | yes | no | |
| (6) Broken teeth or missing teeth other than losing baby teeth | yes | no | |
| (7) Stained or discolored teeth | yes | no | |
| (8) Loose teeth not due to an injury or losing baby teeth | yes | no | |
| (9) Decayed teeth or cavities | yes | no | |
| (10) Broken or missing fillings | yes | no | |
| (11) Bad breath | yes | no | |
| (12) Dry mouth | yes | no | |

COH.060 During the past 6 months did [CHILD] see a dentist for any of the problems with [HIS/HER] mouth or teeth?

- _____ Yes
- _____ No

COH.070 During the past 6 months did [CHILD] see a medical doctor for any of the problems with [HIS/HER] mouth or teeth?

_____ Yes
_____ No

[If NO to “took to [her/him] a dentist” COH. 060, ask:]

COH.080 DURING THE PAST 6 MONTHS, why didn't you take [CHILD] to a dentist for the problems with for [HIS/HER] mouth or teeth? Please say yes or no to each.

(1) you didn't think it was important	yes	no
(2) the problem went away	yes	no
(3) you couldn't afford treatments	yes	no
(4) [child] didn't have insurance	yes	no
(5) you didn't have transportation	yes	no
(6) [child] was afraid to see a dentist	yes	no
(7) you were waiting for an appointment	yes	no
(8) you didn't think a dentist could fix the problem	yes	no

COH.090 Did the problems with [CHILD'S] your mouth or teeth interfere with...

(1) School or school activities	yes	no
(2) Work (Age 14+)	yes	no
(3) Eating	yes	no
(4) Sleeping	yes	no
(5) Social activities such as going out or being with other people	yes	no
(6) [Child's] usual activities at home	yes	no

[ASK ALL R's:]

COH.100 Do you think cavities in children under six can be prevented?

(1) yes
(2) no **[END]**

COH.110 How important do you think it is to keep children under 6 from getting cavities in their baby teeth?

(1) very important
(2) somewhat important
(3) not very important