

## **Development of the “HIV Pre-Test Information Comprehension” Questionnaire**

### **Introduction**

This paper describes in detail the process of creating and assessing the “HIV pre-test information comprehension” questionnaire used in the pilot trial described in the accompanying paper. The goal of this paper is to outline the background research, development steps, and assessment procedures involved in the questionnaire development as well as successes and lessons learned to create and evaluate the questionnaire.

### **Background Research**

We first searched for and reviewed prior studies on and previously used questionnaires about HIV and HIV testing knowledge in many different settings. We hoped to use questions from these prior questionnaires in their present form or as modified for the needs of this study. Table 1 summarizes the types of searches conducted and the yields of those searches. The review of the questionnaires and studies included an examination of the quality of the questions, the rigor of the survey development, the format of the questions and responses, the survey administration techniques, the populations studied, the purposes for conducting the study, and the study results.

### **Questionnaire Development**

The development of the questionnaire proceeded in three main phases: (1) question selection, composition, and refinement; (2) initial pilot testing; and (3) cognitive-based assessments of questions through intensive patient interviews.

### Question selection, composition, and refinement

Using the results of our review of prior studies and questionnaires located in the background research, we first outlined the goals for the questionnaire, considered which possible topics could be included, and decided upon a format for the questionnaire (Table 2). Because the questions would be delivered orally to the respondent, we determined that the best format of the questions and responses was for the question to be in the form of a statement and the responses to be “true”, “false”, and “don’t know”. We reasoned that short statements would be easier for the respondent to comprehend and that uniform responses would help the respondent focus on the statements and not try to choose from a varying list of response options. Further, short statements would be easier and quicker to deliver orally.

Next, we generated lists of potential questions for the questionnaire using questions located during the background research. There were no available questions that directly compared video or other alternative methods of HIV pre-test information delivery. Few surveys had questions on HIV testing. As a result, we primarily considered questions from surveys that assessed HIV and AIDS knowledge.<sup>9-15</sup>

For questions that could potentially be adapted, we revised their form and content. These adjustments included changing the form of the question or response; updating the content of the questions to reflect current understanding of HIV or other topics; reducing the questions to single rather than multiple parts; paring down the question stem or response for brevity; reformatting the question or responses; and adjusting the language, vocabulary or syntax to improve participant comprehension of the question. If there were no suitable questions for a given topic, we composed new questions.

Once we formed the list of potential questions, we critically reviewed and revised them to ensure that the content was correct and complete; the grammar, syntax, and comprehension level were appropriate; they could be delivered orally and comprehended readily in that form; they were applicable to the study goals; and they were devoid of problems common to many survey questions (were not value-laden, did not contain jargon or slang, were not double-barreled in content, did not have double-negatives, etc.). We administered the questions to colleagues and staff members and further revised them based upon their comments and our observations.

### Initial pilot testing

After forming draft questions for the “HIV pre-test information comprehension” questionnaire, we conducted an initial pilot test of the instrument. The overall goals of the initial pilot testing were to: (1) identify problems in the wording of the questions or responses, (2) gauge the reactions participants had to our questions, (3) determine the length of time it took to deliver the survey, (4) estimate the number of patients who might complete the questionnaires, and (5) uncover any topics that we were failing to address.

The primary goal was to find questions that could assess participant understanding of the pre-test information they received (video vs. in-person discussion). To that end, in the initial pilot testing, we intended to eliminate questions that were not good discriminators of participant knowledge. Modifying the suggestions of Carey, et al., we decided to eliminate questions that were answered correctly by fewer than 20% or greater than 80% of the respondents.<sup>11, 12</sup> We planned to have at least 25 questions in the final version to balance the need for statistical stability in our analyses (more questions) with participant tolerance (fewer questions) and to have approximately four to five questions within each of the five categories outlined in Table 2.

*Methods and conduct of initial pilot testing*

The pilot testing proceeded in three iterations. Each iteration consisted of presenting the draft questionnaires to a group of ten participants. After each iteration, the questions were modified as needed. Some questions were revised, others eliminated, and new ones were written to create a new version of the questionnaires before the start of the next iteration. The worst performing questions were eliminated (those answered by greater than 80% or fewer than 20% of the participants). The stem of the true and false questions for this questionnaire were adjusted after each iteration so that there would be a balance between the number of questions for which true and false were the correct responses. For example, the stem for a question for which the correct response was “true” would be changed so that the correct response would be “false.” The sequence of questions for this questionnaire was also randomly re-ordered after each iteration with the assistance of a random number sequence generator available at [www.random.org](http://www.random.org) (Trinity College, Dublin, Ireland).

Each of the three iterations included ten patients, five women and five men, from a convenience sample of ED patients awaiting medical care in the urgent care and the ambulatory care sections of the ED. Patients 18-55-years-old were eligible to participate in the pilot testing if they were not pregnant; not an inmate; not known to be HIV infected; could speak, read, and write in English; were not deaf; or were not critically ill, intoxicated, or presenting to the ED for a psychiatric problem. This and all parts of the study were approved by the hospital institutional review board. Participants received a \$2 gift card to a local pharmacy.

A research assistant (RA) screened medical records of patients awaiting medical care in the ED during 9 a.m. to 5 p.m. weekdays during February 2005. Participants eligible for the study were first administered a semi-scripted in-person discussion with the RA on five topics:

HIV and AIDS, HIV transmission, prevention, testing, and rapid HIV testing. An outline of the points covered in the in-person discussion is provided in the accompanying article. The outline was created by the study authors and is based upon the 2001 CDC recommendations for pre-test information<sup>19</sup> with additional information on rapid HIV testing specific to OraQuick®<sup>20</sup>. The RA was certified by the state to conduct HIV test counseling and underwent approximately twenty hours of training and mock-interviews to practice delivering the in-person discussion prior to conducting the pilot study.

### *Results of initial pilot testing*

The RA approached 42 patients of whom twelve declined to participate. Fifteen of the participants were women and fifteen were men. We presented 28 questions in the first iteration, 32 in the second, and 32 in the third iteration. During the first iteration, we reformatted one question that was poorly worded, eliminated twelve questions from consideration because 90% or more of respondents answered them correctly, and removed another question because it could be answered correctly in different ways depending upon participant interpretation of the question. In the second iteration, we reformatted six poorly worded questions, changed the focus of another question, eliminated four questions because 90% or more of respondents answered them correctly, and removed another question because it could be answered correctly in different ways, depending upon how it was interpreted. In the last iteration, we did not eliminate any questions.

### Cognitive-based assessments of “HIV pre-test information comprehension” questionnaire

The initial pilot testing of the questionnaire did not determine whether or not the participants truly understood the questions or whether they answered the question in the way it

was intended to be answered. We conducted cognitive-based assessments of the questionnaires to address these concerns based upon interviewing techniques suggested by other researchers.<sup>21-</sup>

<sup>23</sup> The overall goals for the cognitive-based assessments were to understand participant thought processes in answering of the questions, obtain their impressions of the questions, discover participant difficulties in understanding the questions or particular words in the questions, identify concerns about the question content and phrasing, and uncover any demographic or cultural-related inappropriateness in the questionnaire

#### *Methods and conduct of cognitive-based assessments*

First, we reviewed our questionnaires and identified what we believed to be concepts, questions, phrases, expressions, and words that might be difficult for participants to understand. Second, we established specific goals for our cognitive-based assessments based upon these identified areas of concern. Third, we composed probe questions that would address these concerns. Examples of the survey questions, the goals, and the corresponding cognitive probes, are provided in Table 3.

For this qualitative analysis, we strove to include a mixture of patients from different demographic groups to obtain a broader range of participant input. We selected patients using a quota system based on demographic characteristics (age, gender, and years of education) that would provide a diversity of participants. The participant exclusion criteria established in the initial pilot testing was also used for the cognitive-based assessments. At the completion of the intensive interviews, participants were provided an envelope with a thank you letter, a \$10 gift card to a local pharmacy, and an educational brochure on HIV and HIV testing that contained a list of HIV testing centers in the area.

Two RAs worked in tandem to conduct the cognitive assessments. One RA read the survey questions from the Tablet PC QDS program and entered the participant responses. The second RA read the cognitive interview questions and recorded the respondents' answers and any observations on paper. In addition to collecting participant verbal responses to the questions, the second RA recorded non-verbal responses to the questions, participant requests for clarifications, pauses in responses, facial responses, and the prefacing of answers.

### *Results of cognitive-based assessments*

The RAs interviewed patients in March 2005. Each interview lasted approximately 35-45 minutes. The final sample included six women and four men; two patients in each of five age groups; three patients who had not completed twelve years of formal education, four who had twelve years of formal education, and three who had more than twelve years of formal education. Two more patients initially agreed to participate, but declined to finish the survey.

Cognitive-based assessments of the questionnaire were enlightening. There were errors in questions that had performed well in the initial pilot study and were presumed to be good discriminators of participant knowledge of HIV pre-test information fundamentals. For example, a question about a link between tattoos and HIV transmission could have been correctly answered as false or true depending upon participant assumptions about the context and purpose of the question. This question was subsequently eliminated from the survey. A question that asked about the ability of bleach to destroy HIV in the context of injection-drug usage was modified based upon participant feedback. Participants had trouble with the statement that bleach "killed" HIV and were more comfortable with the alternative statement of bleach "destroying" HIV. Using the results of cognitive-based assessments, we made several modifications to the questionnaire. The resultant questionnaire is provided in the accompanying article.

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