A DAY IN THE LIFE OF A SURVEY QUESTIONNAIRE

Dr. Ramirez: First, I want to tell you that I never agreed to acting in a skit as part of my job description! Nevertheless, today I will be your narrator for our skit entitled "A Day in the Life of a Survey Questionnaire." (The job of a researcher is anything but predictable or mundane!)

CAST IS FROZEN IN PLACE AROUND A MEETING TABLE. TIME ON PRETEND CLOCK SAYS 8:30am. (Staff person silently carries clock sign across the "stage")

Dr. Ramirez: Good afternoon everyone, I know most of you but I see there are a few unfamiliar faces. My name is Dr. Amelie Ramirez and I am the Director of the IHPR and PI for this project, Redes En Accion. Today's meeting is to finalize our patient-navigation survey.

Dr. Ramirez: Now, for some of you, it may be difficult to think of a research survey as stimulating let alone entertaining! Of course everyone knows that surveys are important to find out how common certain behaviors or beliefs are in particular populations; and they're invaluable for evaluation. But for many people, their view of surveys is, "Just show me the data....tell me the conclusions of your study but don't bother me with the details of how you got it".

Dr. Ramirez: We hope to show you today that, as a researcher, every word, every number, indeed every dot, dash and semi-colon in a survey questionnaire is precious. Because these symbols on the page hold the potential to unlock secrets, to answer complex questions, to prove our hypotheses.....and maybe, if EVERYTHING goes as planned, to ultimately save lives.

Dr. Ramirez: But please keep the following in mind. While the scene you are about to see is based on real facts and real people, not only are these not professional actors, but when these people are in the heat of survey battle, they can behave very *Unprofessionally*. (To make matters worse, this skit has not been rehearsed).

Dr. Ramirez: Also, it is not an exaggeration to say that these meetings go on for 5 to 8 hours at a time; and there may be a dozen or more such meetings in the development of single survey instrument.

Dr. Ramirez: To provide you with a little more context, the process for developing a questionnaire involves months of work beginning with identifying the main topics to

be measured such as beliefs and attitudes about cancer screening; then a thorough review of the literature is done to see what questions have already been studied on this topic. Measures are then selected that have been validated in prior research.

Dr. Ramirez: For questions where there are no prior measures, focus groups and individual interviews are conducted and extensively analyzed to identify appropriate ways to ask the question. Then there is pretesting, pretesting and more pretesting, followed by translations, extensive rewriting and more pretesting. And throughout, there are meetings, meeting, and more meetings.

Becky: And now, I welcome you to the premier showing of "A Day in the Life of a Survey Questionnaire". The location is a conference room at the University of California, San Francisco. The time is [**hold up "clock"**] 8:30 am.

Dr. Ramirez: Ok gang. This is our last meeting before this survey goes into pre-testing. We started with 782 items, all of which were considered of absolute vital importance to someone here. If we include all of them, I estimate that it will take respondents over 5 hours on the phone to answer this survey.

We can only ask 120 questions. In 6 hours, we have cut exactly 7. I KNOW how fond you are of each and every item. BUT IF WE DON'T MAKE THESE CUTS, THERE WILL BE NO SURVEY AT ALL.

Kip: Ok. We all know we need to make the cuts. I'm in favor of cutting most of the sections in half.

Cindy: I agree. But it's really important that we preserve the questions on Columbian culture because the data available on this ethnic population is scarce. This ethnic group is increasing in the US and we need to better understand their health behaviors in the context of their culture. We will be making a major contribution by generating more data on this population.

Exito! Participant #1: I understand how important that is. But do you think it will be appropriate to ask Mexican-American's if they eat Bandeja Paisa? And how often they go back to Columbia to visit their family? Some of these questions just don't apply to all the different Latino ethnic groups!

We know that what really applies to all the populations we're studying are the questions about discrimination in the health care system.....

cast freezes while Becky says

Becky: Now you know the first great dilemma in surveying diverse populations is? What is most important for one group may be totally irrelevant to another.

BACK TO CAST

Kip: Ok. Maybe we can compromise. How about if we ask those 47 important Columbian culture questions only of people who self-identify as Columbian and skip them for everyone else?

Exito! Participant #2: That sounds like a REALLY bad idea! As the statistician on this team, I will resign if you have any skip patterns like that. Your numbers won't be big enough to analyze anything, and the whole thing will be a big waste of time.

CAST FREEZES.

Becky: Sometimes our methods really get in the way of what we want to know. But this is a creative group. They will figure it out.

BACK TO CAST

Dr. Ramirez: Let's come back to that later. Now I'd like to discuss a new concept that we have the opportunity to explore for the first time with these different Latino ethnic groups. It's called willingness to pay. We will ask participants how much they would be willing to pay for a cancer screening test if they had to use their own money instead of insurance or using programs that provide free screening. We ask them a whole range of prices and see what they select. This is a new way of actually quantifying how valuable cancer screening test are to them.

Cindy: Well, I'm sorry to say that you just can't ask these questions of patients at a public hospital. They are very low income, many have little education and some are undocumented. They don't have ANY money to pay. If you ask them this, they will think that they DO have to pay and we may actually frighten them away from screening.

Exito! Participant #2: Yes, I am certain that Latinos, who have never heard of such a

way of expressing their value for a medical service, would be confused and maybe even offended by the question.

Exito! Participant #3: Oh yes, I can see this being true for less acculturated Latinos especially.

Exito! Participant #4: Yea, other participants may think this is some kind of trick to get them to pay more too.

CAST FREEZES

Becky: In real life, this debate went on for months, involved numerous focus groups among different Latino ethnic groups, more debate, and finally resulted in a modified version that everyone could work with.

BACK TO CAST

TIME SIGN CHANGES: 12:30PM

Dr. Ramirez: Let's come back to that.

Exito! Participant #1: Do you think we could break for lunch?

Dr. Ramirez: Oh it's only 12:30...can we keep going for another half hour?

Everyone nods reluctantly in agreement

Exito! Participant #2: Let's discuss acculturation. You all know how important this is. People who are recent immigrants have far more problems getting health care, much less understanding of how the system works, and many more myths and misconceptions about cancer screenings and prevention.

As a result, they suffer much more than those who are born in the states. We must be able to identify them and to assess the problems that come with lower levels of acculturation.

Exito! Participant #3: This is definitely true for Mexican-Americans and ______. The problem is how to measure acculturation. The simplest way is to determine how

well they speak English and how long they've lived here.

Exito! Participant #4: It's important for Puerto Rican's too, but it's such a different concept for them because of the strong American influence in Puerto Rico itself. We often say that acculturation to US society actually begins in the Puerto Rico, and most people do speak English, so those questions are not adequate.

By the way....isn't anyone HUNGRY?????

TIME SIGN CHANGES: 4pm

Exito! Participant #3: But does this concept work at all for Mexican-American's, most of who have lived here for generations? Yet for many, they are as disenfranchised as new immigrants, and maybe even more so because of discrimination.

Exito! Participant #5: Even for _____, those questions don't get at how comfortable they are navigating mainstream society. We have to ask some more complex questions than that.

Exito! Participant #2: Here are some items that have been asked in other studies. They try to get at whether or not the person's social circle is confined to their own culture or if they socialize with a broader range of people. For example:

> "Do you prefer going to social gatherings or parties that are: All Latino? More Latino than other racial groups? More racially mixed than Latino?"

Cindy: Well that's fine in principle, but the last time we asked those questions in a survey, people thought we were trying to trick them so we could find out if out if they are racist.

Dr. Ramirez: Acculturation is really a tough one. Maybe we should come back to that. I want to talk about my second favorite question: "Do you think that getting cancer is bad luck?" The point is to measure if people are fatalistic or if they are under the illusion that they have control over their health.

Exito! Participant #1: Many Latinos believe that cancer is bad luck but would be very offended by this question because saying something like this to them might make

them believe we are saying they might get cancer.

Exito! Participant #2: And then they would refuse to answer, resulting in missing data. I just HATE missing data!!!!!!!!!

Exito! Participant #4: Hey, does anyone think that getting cancer is GOOD luck? There must be a better way to get at this important concept.

CAST FREEZES

Becky: For many important health related concepts, there is no known culturally appropriate form of measurement. As a result, these critical issues remain poorly understood.

BACK TO CAST

Dr. Ramirez: Let's come back to that.

Cindy: I'm sure we can all agree on the income questions. These are critical to everyone because we know that people with lower incomes have more health problems, regardless of their language or culture. So we HAVE to be able to measure income to know who is wealthy and who is not.

Exito! Participant #3: Did you know that Latino men will be more likely to tell an interviewer how many sexual partners they've had than to state their income?

Exito! Participant #1: ______ women won't want to talk about either of those subjects.

Dr. Ramirez: Let's come back to that later. For the first time, we have a chance to test constructs of an important behavioral theory in diverse populations, the transtheoretic model. As you know, this model posits that a ratio of a person's favorable to unfavorable attitudes about a behavior can be combined into a score called decisional balance. We expect that over the course of our intervention program, Latinos decisional balance will change, and as it does, they will be more likely to receive preventative screenings.

Ok. The first thing we're going to look at is our questions to women about their attitudes toward receiving ______.

Exito! Participant #5: Excuse me, but there is no direct translation for ______ in Spanish..

Exito! Participant #2: This is a very serious problem. Because if we don't ask the question the same way to everyone, we may not be able to combine data across languages. Then we cannot be sure that the answers are really comparable, in which case we might as well not ask the question at all.

Dr. Ramirez: But the whole point of our survey is to study use cancer prevention screening practices among Latinos!

Dr. Ramirez putting her head down in her arms in total despair

WHOLE CAST IN UNISON: "Let's come back to that!!"

THEN FREEZE

TIME SIGN CHANGES: 6:30PM

Becky: While the problems you've heard are real, I'm happy to report that this talented group of researchers did find ways to address these problems and has developed better questions for multiethnic Latino population surveys. It's not perfect yet....but we're getting there."

Thank you.