

## PROJECT OVERVIEW

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### **Pre-Testing “Take Charge of Your Sexual Health: What you need to know about preventive services”**

## PROJECT OVERVIEW

### Title

Pre-Testing “Take Charge of Your Sexual Health: What you need to know about preventive services” with the Hispanic Community

### Protocol Summary

The National Coalition for Sexual Health (NCSH), funded through a cooperative agreement from the Centers for Disease Control and Prevention, is conducting this study. The NCSH aims to improve sexual health and well-being by encouraging sustained and productive conversations about sexual health and by promoting high quality sexual health information and health care services.

There is a lack of consolidated information about the many recommended preventive sexual health services that can protect and improve sexual health and well-being. The public also lacks access to information about other actions they can take to achieve good sexual health, and about how to find and talk with a health care provider about this topic.

As a result, the majority of the U.S. population is not getting recommended preventive sexual health services that can help prevent male and female cancers, infertility and sterility, pelvic pain, unintended pregnancies, and other conditions. Among all Americans, the uptake of these services is low. For example, among Hispanics, 53% of girls and 72% of boys did not receive the three-dose HPV vaccine; 63% of sexually active Hispanic girls (ages 15-21) were not screened for chlamydia; and over half of Hispanics have never been screened for HIV.

To educate the public about sexual health and recommended preventive services, the NCSH created a guide, “Take Charge of Your Sexual Health: What you need to know about preventive services,” (hereafter referred to as the “Guide”; see *English Sexual Health Guide: Att 4* and *Spanish Sexual Health Guide: Att 2*), which includes five action steps to good sexual health, recommended preventive sexual health services for men and women, tips on how to find and talk with health care providers, and links to available resources.

To reach the large and growing Hispanic community of 54 million people, which now constitutes 17.1% of the U.S. population, the Guide was culturally adapted and translated into Spanish. This translation is

particularly important for the 15.7 million Hispanics who are not proficient in English. The NCSH convened a group of experts from leading Hispanic health organizations to advise on the cultural adaptation and translation of the Guide, and contracted with a leading translation company.

To help ensure that the Guide is clear, relevant, and appealing to the target audience of Spanish-language dominant Hispanics, it is important to conduct pre-testing. Specifically, the pre-testing will explore overall effectiveness of the translation, and the usefulness, relevance, clarity, appeal, and format of the guide. The *Focus Group Moderator Guide (Att3)* will also ask participants how they would prefer to access this Guide, e.g. through a web-based format and/or print materials.

The project will include four small group discussions led by Spanish-speaking Hispanic male and female moderators, using a (*Att5*) *English Spanish Discussion Guide*. Participants will include Hispanic men and women, ages 18-39, who are Spanish-language dominant. In total, approximately 16 individuals will participate in these discussions.

Based on the results, the NCSH will modify the Guide, as needed, to improve its effectiveness and will determine the best format(s) for making the Guide available to this target audience. Then final Guide will be promoted to Hispanics nationwide through media outreach and NCSH member organizations.

### **Investigators, Collaborators, and Roles**

Penny Loosier, PhD, MPH, DSTDP, CDC

Role: Cooperative Agreement Project Officer

Responsibilities: Oversight of cooperative agreement

Susan Gilbert, MPA, Co-Director, National Coalition for Sexual Health, Altarum Institute.

Role: Study Director

Responsibilities: Development of study design and protocol

Alyson Kristensen, MPH, Co-Director, National Coalition for Sexual Health, Altarum Institute.

Role: Study Co-Director

Responsibilities: Development of study design and protocol

Maureen Michaels, President, Michaels Opinion Research, Inc.

Role: Study Co-Director

Responsibilities: Conduct the study, recruit and train moderators, supervise participant recruitment, analyze results

### **Funding Source**

The source of funding for this project is the CDC Cooperative Agreement (CDC-RFA-PS11-1112) that was awarded to the Altarum Institute.

## **INTRODUCTION**

### **Current State of Knowledge**

There is a lack of information for Americans, including the Spanish-speaking public, about the many recommended preventive sexual health services that can protect and improve sexual health and well-being. The public also lacks access to information about other actions they can take to achieve good sexual health, and how to talk with health care providers about sexual health.

In response, the NCSH created a guide and website, “Take Charge of Your Sexual Health: What you need to know about preventive services,” (hereafter referred to as the “Guide”). The Guide provides a single point of access to information about a wide range of preventive sexual health services and resources relating to sexual health, including practical tools for use during visits to health care providers.

To culturally adapt and translate the Guide for the Hispanic community, the NCSH convened a group of consultants from Hispanic health organizations. These experts are providing guidance to help ensure that the Guide will be relevant, appealing, and understandable to the Spanish-speaking population.

Hispanics are a significant, and growing part of the U.S. population. According to the U.S. Census Bureau, 54 million Hispanics -- comprising 17.1% of the total population -- were living in the United States in 2013. Approximately one-third is not proficient in English, totaling 15.7 million Hispanics. At the same time, 73% speak Spanish at home, and might prefer Spanish-language materials. To reach many members of this community with vital sexual health information, it is important to make culturally relevant materials available in Spanish.

### **Justification for the Pre-Testing**

By nearly every measure, the state of sexual health in the United States is poor. Each year, there are an estimated 20 million new cases of sexually transmitted infections (STIs), and up to 110 million cases overall. Approximately 50,000 people are newly infected with HIV annually, and nearly everyone will contract the HPV virus at some point in their lives, which can cause certain male and female cancers. And, there are an estimated 3.4 million unintended pregnancies annually.

The majority of Americans are not getting recommended preventive sexual health services that can help prevent male and female cancers, infertility and sterility, pelvic pain, unintended pregnancies, liver disease, and other health conditions. Among all Americans, including the Hispanic community, uptake of most preventive sexual health services is low. For example,

- In 2013, 53% of Hispanic girls and 72% of Hispanic boys did not receive all three doses of the HPV vaccine, the only cancer-prevention vaccine available.
- 63% of sexually active Hispanic females (ages 15-21) were not screened annually for chlamydia, which, when left undiagnosed and untreated, is a leading cause of preventable infertility.
- Over half (54%) of Hispanics have never been tested for HIV, even though it is recommended that all sexually active people be tested at least once.
- While Hispanic women have the highest cervical cancer rate of all racial/ethnic groups, 23% have not had a pap smear within past three years.

Under the Affordable Care Act (ACA), these services, which are recommended by the Centers for Disease Control and Prevention and the U.S. Preventive Services Task Force, are now available at no cost to insured individuals. For those without insurance, free or low cost services are often available through community health centers or local public health clinics.

To educate Spanish-speaking Americans about sexual health and recommended preventive services, the NCSH culturally-adapted and translated the Guide into Spanish, which aims to:

- 1) Educate men and women of all ages about sexual health and the preventive services they need,
- 2) Empower and motivate them to take control of their sexual health and obtain recommended services, and

3) Help them find and communicate with health care providers about these topics and other issues affecting their sexual health.

The Guide includes five action steps to good sexual health, information on recommended preventive sexual health services for men and women, tips on how to talk with your provider about sexual health, and links to available sexual health resources.

The pre-testing will be conducted with the Spanish-speaking population to test the clarity, relevance, and appeal of the Guide. The testing will also assess the overall effectiveness of the translation, and the preferences relating to some specific word choices and phrases in Spanish. Based on public feedback, the Guide will be modified, as needed, to improve the overall quality and usefulness of this resource.

### **Intended/Potential Use**

The final Guide will be made available to the public for free in a web-based format and/or a print format. The guide and website will be promoted to the public through national media outreach and through NCSH member organizations and their chapters.

### **Message Testing Designs/Locations**

The qualitative discussions will be held in San Diego, California at a professional focus group facility. The moderators will be Hispanic and will conduct the groups in Spanish, using the (**Att5**) English Spanish Discussion Guide.

### **Objectives**

The primary objective of this project is to test the clarity, relevance, and appeal of the Guide among Spanish-language dominant Americans. Participants will provide feedback on content, language, and format. Based on their input, the guide will be modified, as needed, to increase its effectiveness.

### **Hypotheses or Questions**

The project seeks to explore whether consumer reactions to the Guide vary based on gender, age, country of origin, and relationship status, and whether there are common messages and content that resonate with a wide audience.

### **General Approach**

The approach used will be exploratory, and will focus specifically on pre-testing the clarity, relevance, appeal and format of this draft Guide.

### **PROCEDURES/METHODS: Materials Testing Design**

**Overview:** Four “triad” discussion groups will be conducted with approximately four participants in each group. These small groups, which will be about 90 minutes in length, will allow for rich, meaningful participation of all members. Prior to the start of the groups, the participants will read the guide, which will require about 20 minutes.

The discussion groups will be held in San Diego, California at a professional focus group facility. Participants will be screened and selected by professional recruiters using an established screening questionnaire.

At the conclusion of the study, each participant will receive a \$75 token of appreciation. This token aligns with the guidance provided on pages 19-20 of the CDC/ATSDR Information Collection Request Procedures guidelines.

**Study Timeline:** The following table provides the estimated timeline for project activities.

<b>Activity</b>	<b>Time Schedule</b>
Participant recruitment	3 weeks after determination
Conduct triad groups	4 weeks after determination
Analyze discussion groups and prepare report	7 weeks after determination

## **PROCEDURES/METHODS: Population**

**Population:** Hispanic men and women, who are Spanish-language dominant, ages 18 – 39.

### **Participant inclusion criteria:**

General inclusion criteria for all participants:

- All participants will speak Spanish at home, watch and listen to Spanish-language entertainment.
- When completing official forms, they will choose to use Spanish-language forms, rather than English-language forms.
- Some or all individuals will be Internet users and users of Spanish-language websites.

Specifically, four groups will be conducted as follows:

- One group with women (ages 18-39) who were born and/or raised in Mexico or to Mexican parents.
- One group with women (ages 18-39) who were born and/or raised in Central America or to parents from this region.
- One group with men (ages 18-39) who were born and/or raised in Mexico or to Mexican parents.
- One group with men (ages 18-39) who were born and/or raised in Central American or to parents from this region.

**Participant exclusion criteria:** Participants may not be under the age of 18. Since the sexual health needs and issues of younger adolescents would differ markedly from those of young adult and adult participants, their inclusion would not be advisable. Participants may not be over the age of 39. The 18-39 year-old age group was selected as the study population since this age group bears the largest burden of poor sexual health, many of the preventive services are recommended for them, and resources for this study are limited.

Participants may not work in the following industries: advertising or public relations, market research, news media, healthcare, or public health. They may not be attending school or training for the health care or public health field.

**Justification of any sub-segments exclusion:** Non-Hispanics and Hispanics who are not Spanish-language dominant are excluded from this study. The Guide is being culturally adapted and translated to reach Hispanic, Spanish-language dominant individuals.

**Estimated number of participants:** Each group will contain approximately three to four participants. In total, the triads will include approximately 16 individuals.

**Sampling:** Sample size and statistical reliability are not applicable because the pre-testing of materials is qualitative and directional.

**Translation:** Translation of existing materials into Spanish was done by the Magnum Group, Inc. The translation was produced based on a culturally adapted English version of the English-language materials and approved by a select group of bilingual leaders of Latino organizations who are familiar with the topic. The Spanish translation was verified by the same group who had access to the English source and Spanish translation during the review process.

**Enrollment:** Respondents will be recruited by outreach to and referrals from residents of San Diego, CA, who have already been recruited through phone calls or online methods to be included in a database of people who are willing to participate in public opinion and market research projects.

Approximately 20 individuals will be contacted by phone, and screened for eligibility and interest in this particular project by professional recruiters using a Spanish-language screening questionnaire (See **Att 1** for *Screener* in Spanish and English). The conversations will be conducted in Spanish. For each individual who agrees to participate, the recruiter will record his/her name and contact phone number, but that information is not accessible to any individuals other than the recruiter. To help ensure maximum participation rates, each participant will receive a reminder call the day before and/or day of the scheduled group.

**Description of risks and benefits to participants:** This message testing project involves no more than minimal risk to participants. Participants will be asked to provide their opinions relating to draft materials. Participants are advised by the interviewer/moderator that they do not have to answer questions that they do not want to answer, and that they may stop at any time. They will not be asked to discuss their personal behaviors. At most, participation in this discussion might cause participants to think more about their own health and behavior. It might also help to educate participants about the benefits of good sexual health and recommended preventive sexual health services.

**Consent:** Participants will be asked for verbal consent prior to participation. Given the minimal risk to participants, documented informed consent will not be sought. All participants will be notified of their right to discontinue participation at any time and for any reason.

**Remuneration:** When participants are being recruited, they will be informed that they will receive a token of appreciation of \$75. Participants will devote about 85 to 90 minutes to the group discussion, and about 20 minutes to read the guide for an approximate burden time of 110 minutes..

*Justification for token of appreciation.* Both the focus group research subjects and the subject matter being investigated in this project present particular challenges in ensuring adequate recruitment and participation.

1. For this pre-testing, focus group participants will be strictly Spanish-only or Spanish-dominant individuals under the age of 40. Sessions will be conducted with immigrant and

first-generation women and men who were born or whose parents were and/or raised in Mexico or Central America, a cohort considered to be among the most difficult to reach populations in the U.S.

2. Although no effort will be made to determine participants' legal residency, it has been the experience of Michaels Research that conducting research with this population (specifically, communications research for the H1N1 Vaccine Information Sheet and with at-risk populations for the NIAID HIV Vaccine Education Initiative (NHVREI)) that anxiety about participating in research of any kind is a significant challenge to the successful recruitment of participants.
3. Additionally, we know from prior recruitment efforts of this socio-economic population that the challenges of childcare, access to reliable public transportation and family issues present additional burdens that affect respondents' willingness to participate in the study.
4. Our prior experience with this population also revealed that the ability to participate in focus groups extends beyond respondents themselves. Many who initially agree to participate will be reliant on others (i.e., family members, friends) to facilitate their participation by providing "moral support," companionship and transportation before and after the focus group session.
5. Finally, the subject matter of the research—reactions to a Spanish-language version of a sexual health care guide—itself produces reluctance to participate in a group discussion with others of similar cultural or social backgrounds.

We believe a \$75 cash token of appreciation will be sufficient to encourage participation. We do not view this token as a reward, honorarium, or compensation. It is a token of appreciation that serves as a stimulus to attend the session and to overcome possible bias in the research findings should potential participants be excluded because of apprehension about the research topic, lower socio-economic status or other barriers.

## **PROCEDURES/METHODS: Variables/Interventions**

Two professional, Spanish-speaking moderators will lead the group discussions based on the discussion guide (See **Att5 English Spanish Discussion Guide**). A female moderator will lead the groups with women, and a male moderator will lead the groups with men. The groups will be conducted in Spanish.

Prior to the small group discussions, the participants will be given a quiet place to read the Spanish-language version of the Guide on their own (See **Att2 Spanish Sexual Health Guide** that participants will read). As they are reading, the participants will be asked to highlight any areas that stand out to them or that are confusing. (For reference, see **Att6 Comparison English/ Spanish Guide** for a side-by-side comparison of both the English and Spanish version of the Guide).

The moderators will start the group discussion by asking participants to write down three to five pieces of information that they recall reading in the guide. Then, the moderator will ask participants if they think the information in the guide is useful and relevant. Next, each participant will be asked to describe what he or she wrote down at the beginning of the session. This will be followed by overall questions about whether the guide is easy to understand; if anything is confusing; if anything is offensive; and if the format and length of the guide are appealing.

After this general discussion, the moderator will ask a series of questions relating to each section of guide, which includes: Sexual Health and How to Achieve It; What are Preventive Sexual Health Services and Where Can I Get Them?; What to Look for in a Sexual Health Professional; What Sexual Health Services Do Women Need?; What Sexual Health Services do Men Need?; What Types of Health Care Providers Address Sexual Health?; Talking with Your Health Professional About Sexual Health; and, Where to Learn More.

The moderator will explore which information is most interesting, is new, and if anything is hard to understand, confusing, or offensive. The moderator will also seek opinions on a few different options for word choices to describe sexual health services and other content in Spanish.

In conclusion, the moderators will ask participants how they would prefer to access this Guide, e.g. through a web-based format and/or print materials. Participants will also be asked if they have any suggestions for improving the guide.

### **PROCEDURES/METHODS: Data Handling and Analysis**

The groups will be held at a professional focus group facility. All sessions will have a simultaneous translation into English, and the original Spanish discussion and the English interpretation will both be audiotaped. The Study Director and a representative from NCSH/Altarum will observe the groups through a one-way mirror.

Descriptive, qualitative data will be collected through this study. Analysis will involve a thorough review of the audiotapes, and identification of major and minor themes for each area that is explored in the study.

Through this analysis, we will identify overall perceptions of the guide, including its usefulness and relevance, any content that is confusing, offensive, or missing, and suggestions for improvement. We will also summarize feedback on the format and length of the guide, and the best channels for making this guide accessible to the public (e.g. website, print). We will also identify any specific words or phrases that are not appealing or understandable.

A summary of the findings, including verbatim quotes, will be produced. Based on this analysis, the Guide will be modified, as needed, to help ensure greatest appeal and relevance to the audience.

**Data management:** The audiotapes will be kept in a locked cabinet. No one outside of the project will listen to the recordings. The names of participants will not be included in the recording or report. The recordings will be destroyed within 12 months from date of pre-testing. The participants' names and contact information will be kept in a sealed envelope in a secure location and will be destroyed within 12 months from date of pre-testing.

**Limitations:** These interviews are exploratory and highly qualitative by design. They elicit information about factors that may influence or be indicative of attitudes or knowledge. Because so few individuals participate, however, it cannot be assumed that the information revealed is definitive or representative of the population as a whole.

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