ATTACHMENT B: Protocol CDC/NCEZID/HCSO Evaluation of Emergency Preparedness Materials for Limited English Proficient Spanish-Speakers (Focus Group)

Valerie R. Johnson, MPH, CHES Ann McCorquodale Burkhardt, MA Laura Ann Smith, MA Caitlyn Lutfy, MPH Centers for Disease Control and Prevention

Kristin A. Mattson, MPH, CHES Ben Wilburn, BA Oak Ridge Institute for Science and Education, Oak Ridge Associated Universities

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Background and Overview

The potential use of anthrax as a weapon by bioterrorists is considered a very real threat in the United States. Therefore, a multitude of federal agencies, including CDC, have ramped up activities to prepare for such an event. In 2010, the Health Communication Science Office (HCSO) within CDC's National Center for Emerging and Zoonotic Infectious Diseases (CDC/NCEZID) received a request from the CDC Anthrax Management Team (AMT) to coordinate efforts to develop and test communication messages and materials to inform the public about anthrax and actions to take in the event that bioterrorists attacked the United States using anthrax. The AMT is a CDC-wide working group established to help strengthen U.S. preparedness in the event of an anthrax attack, and CDC/NCEZID plays a major role in these preparedness activities.

The AMT's Health Communication Team assessed existing CDC anthrax materials and found much of the print and web information was outdated, inconsistent, and incomplete. The AMT identified risk communication as a top priority in CDC's anthrax preparedness activities and encouraged the Health Communication Team to respond to the information needs of the U.S. population by developing clear and relevant materials on anthrax and preparedness for a potential anthrax attack. Specifically, the AMT asked the Health Communication Team to work with the various centers, institutes, and offices within CDC and at other federal agencies to develop, test, and clear materials essential to providing the public with the necessary information to increase the chances for survival in the event that bioterrorists attacked the United States using anthrax. The AMT urged the Health Communication Team to develop an array of print, web, and other electronic materials that could be pulled "off the shelf" and disseminated rapidly should an attack occur. Further, the AMT noted the need for public education messages to be provided in the most common languages spoken by people in the United States who have limited proficiency in English, of which Spanish is the most common.

Of the 40.3 million Spanish-speakers currently in the United States, 41% are limited English proficient (LEP), meaning they speak English "less than very well" (U.S. Census Bureau, 2010). LEP individuals represent very diverse populations in terms of countries of origin, socioeconomic and cultural characteristics, migration status, language proficiency, health status, and other demographic factors. The primary challenges LEPs face are associated particularly with communication barriers (e.g., language and literacy) and isolation (cultural, geographic, and social). For these reasons, LEP populations are considered "at-risk populations," as defined by the Pandemic and All-Hazards Preparedness Act, because they "have needs that are not fully addressed by traditional service providers or who feel they cannot comfortably or safely use the standard resources offered during preparedness, response, and recovery efforts." [1].

Public health emergencies are stressful events that impair people's ability to understand information and take action. In such situations, the use of public health messages in clear, easy-to-understand language increases the chances of people understanding public health officials' advice and acting appropriately in response to that information. Therefore, the AMT Health Communication Team is tasked with developing anthrax materials written in plain language (English), which are translatable to other languages for people in the United States who have

limited proficiency in English. These materials will be revised and formatted to enhance readability in those other languages and revised to incorporate graphics that are culturally appropriate and facilitate message comprehension for people with limited English proficiency. After the creation and translation of these materials into other languages, testing and revisions will ensure the materials are culturally appropriate and that the targeted audiences can understand and act on the information in the event of an anthrax attack.

The purpose of this information collection is to field test the anthrax emergency preparedness and risk communication materials. CDC/NCEZID/HCSO seeks approval to test the materials with members of the populations who will benefit from the materials. These materials have been developed to inform the public of appropriate actions to take in the event of an anthrax emergency. Focus group discussions conducted with LEP individuals from Spanish-speaking communities will inform the refinement of these materials and the development of additional materials. The goal of these efforts is to better reach LEP populations by producing culturally and linguistically appropriate emergency preparedness and risk communication materials about anthrax.

This project supports CDC's mission of creating the information and tools that people and communities need to protect their health through prevention of disease and preparedness for new health threats. This project also supports CDC's goal of working with partners to enhance prevention, to implement prevention strategies, and to foster safe and healthful environments. Providing access to potentially lifesaving information on anthrax to a broad base of people in the United States—including people with limited proficiency in English—also supports CDC's vision for the 21st century of health protection and health equity.

Goals and Objectives

This is a one-time information collection. The overall goal of the focus group discussions is to better reach LEP populations by producing culturally and linguistically appropriate emergency preparedness and risk communication materials about anthrax. Approval is sought to conduct information-gathering focus groups in order to test newly-developed materials with members of the target audience. The results of field testing will provide recommendations for improving and finalizing the materials, which will ultimately result in better outreach to LEP Spanish-speaking populations by the AMT, NCEZID, and other centers, institutes, and offices at CDC. These outcomes are aligned with the broader missions of NCEZID and CDC.

Objectives include the following:

- Determine whether participants can understand the messages intended in the materials.
- Evaluate the extent to which messages and visuals are relevant, culturally appropriate, comprehensible, credible, and appealing, and the extent to which they would motivate desired actions during an emergency.
- Inform the AMT Health Communication Team on the best practices for communicating important emergency preparedness information to LEP populations.

• Identify additional knowledge gaps and modalities for disseminating emergency preparedness and risk communication materials for LEP populations.

Target Audience

CDC has focused on increasing knowledge and responding to the emergency preparedness and risk communication needs of the LEP population. This group was selected because of the need for anthrax emergency preparedness and risk communication messages in Spanish, the language most commonly spoken by LEP individuals in the United Sates. Three audience segments will be recruited for the focus groups: parents/expectant parents (with children 12 years of age and younger), adults 40-59 years of age, and adults 60 years of age and older.

Methods of Data Collection

Table 1:

The Oak Ridge Institute for Science and Education (ORISE), managed by Oak Ridge Associated Universities (ORAU) for the Department of Energy (DOE), will provide technical assistance in conducting the focus groups and analyzing the findings. The anthrax communication materials, which have been adapted for these populations, will be used as a point of discussion during the focus groups to assess (1) whether the materials are culturally and linguistically appropriate for the population, (2) whether important messages are clear and effective, and (3) which messages would motivate the populations to take action.

The focus group discussions will last no longer than two hours and will be semi-structured conversations. The data collection tool includes 16 total semi-structured, open-ended response questions with semi-structured, open-ended probes (see Attachment C: Discussion Guide).

Information will be collected from 150 LEP Spanish-speaking respondents in 15 focus group discussions with a maximum of 10 participants in each. Twelve focus groups will be conducted in two major metropolitan cities with large Hispanic populations, (e.g., San Diego, California, and Miami, Florida). Two focus groups will be conducted with each of the three audience segments in each location, for a total of six focus groups in each major metropolitan city. Three focus groups will be conducted in the Knoxville, Tennessee, area. This includes one focus group per each of the three audience segments. Table 1 illustrates the focus group design.

Audience Segment	Major Metropolitan City 1	Major Metropolitan City 2	Knoxville, Tennessee, area	Totals
LEP Spanish- speaking parents/expectant parents (with children 12 years of age and younger)	2 Groups (10 participants per group)	2 Groups (10 participants per group)	1 Group (10 participants per group)	5 Groups (50 participants)
LEP Spanish- speaking adults 40-59 years of age	2 Groups (10 participants per group)	2 Groups (10 participants per group)	1 Group (10 participants per group)	5 Groups (50 participants)
LEP Spanish- speaking adults 60 years of age and older	2 Groups (10 participants per group)	2 Groups (10 participants per group)	1 Group (10 participants per group)	5 Groups (50 participants)
Totals	6 Groups (60 participants)	6 Groups (60 participants)	3 Groups (30 participants)	15 Groups (150 participants)

Focus Group Design

A moderator will guide the discussions, using a discussion guide comprised of key topics and probing questions (see Attachment C). The focus groups will be conducted in Spanish. The

discussions will be audio-recorded and transcripts will be prepared from these recordings. Additionally, focus groups will be video-streamed via Focus Vision or equivalent means, for viewing by CDC team members at other locations. No videotaping will be conducted.

Each recorded discussion will be transcribed into Spanish and then translated into English for analysis. Analysis will begin after the first focus group discussion has been transcribed and translated. A final summary report will be provided by ORISE/ORAU to CDC.

Recruitment

Venue-based recruitment will take place through community-based organizations (CBOs) offering services for LEP Spanish-speaking populations. Purposive sampling will also be used to recruit participants using contacts at the CBOs.

A screening tool will be used in order to ensure appropriate recruitment (see Attachment D: Participant Screener). Participants will be contacted and recruited by the CBOs serving these populations through their routine work. Respondents will be contacted in advance, either in person or through a phone call. The recruiter will verbally ask each respondent the questions on the screening document. Recruiters will collect some personal contact information (e.g., name, phone number) to secure the groups. Recruiters will never share this information with the researchers. All personal information collected to schedule the groups will be shredded immediately after the focus group discussions take place.

It is estimated that twice the number of respondents needed must be screened in order to yield the desired number of respondents; therefore a total of 300 respondents will be contacted in order to recruit 150 LEP Spanish-speakers, yielding 15 focus group discussions with a maximum of 10 participants in each group. Three different audience segments will be recruited: parents/expectant parents (with children 12 years of age and younger), adults 40-59 years of age, and adults 60 years of age and older.

Age	All participants will be at least 18 years of age.		
Location	All participants should be living in the United States during the data		
LOCATION	collection period.		
Language	All participants should be LEP Spanish-speakers.		
	Recruitment will aim to have a mix of genders in the focus groups,		
Gender	although we can expect to recruit more women than men in this		
	specific population.		
Country of	Participants should represent the share of Spanish-speaking LEP		
birth	populations in the United States.		
Education	No education criteria.		
Employment	No employment criteria.		
Race	No criteria regarding race.		

Participant Selection Criteria

Explanation of Any Payment or Gift to Respondents

Consistent with commercial practice for highly select participants who are not executives or highly paid professionals, participants will receive an honorarium for their participation in the two-hour focus group discussion. CDC/NCEZID/HCSO will not directly provide an incentive to respondents. ORISE/ORAU will provide \$75 per participant to be distributed to partner agencies that assist with the recruitment. The partner agencies will use this to provide \$75 worth of incentives, such as public transportation cards or gift cards for basic supplies, to each participant. The level of incentive payment was determined after Institutional Review Board consultation and discussion with trained focus group moderators who have conducted similar focus groups. The level is consistent with the rate provided by partner organizations for other focus groups of this kind.

Message exploration is a marketing technique commonly used by various commercial, government, and not-for-profit entities; it is standard practice to provide incentives to recruit participants for these message exploration activities. Most focus groups and roundtable discussions have shown that monetary incentives paid directly to the participant are the most effective in compensating participants [2]. Additionally, because of the limited monetary value of the incentive proposed, it is unlikely to induce someone to participate against their better judgment.

Consent Procedure

Before the focus group introductions begin, the moderator will inform each participant that the session is being audio-recorded and live video-streamed. The Participant Information Sheet (see Attachment E) will be distributed to participants at the beginning of the session. It includes details about the focus group sessions, precautions to secure the data, a statement on the audio-recording and live video-streaming process, and details of focus group benefits and risks. Moderators will read aloud the information provided in the written description to ensure that all information is accurately communicated to participants. Participants will be given time to review the document after it is read aloud and ask questions.

At the end of the introduction to the discussion and a brief introduction of participants (participants will reveal only their first names and will be permitted to use pseudonyms; they will also be reminded again that the discussion is private and data will be kept secure), the moderator will ask if participants have any questions and respond to those queries. Informed consent will be secured verbally in the group setting after participants have had the opportunity to review the participant information sheet. Consent will be obtained verbally to avoid drawing attention to any participants who may be illiterate or unable to provide their signature.

Participants who do not wish to be recorded will be thanked for attending and told that that audio-recording is necessary, so they are free to leave if they do not want to participate. These participants will be given an honorarium, as promised, and informed that they are welcome to return to the discussion, which is being recorded, if desired.

Privacy and Confidentiality

The Privacy Act does not apply, because only first names may be used during the focus groups and these first names will be removed from any collected data prior to receipt by CDC. The proposed data collection will have little or no effect on the respondent's privacy.

All participants will be informed that discussions are private and that their information will be treated in a secure manner and will be protected to the extent allowed by law (see Attachment E: Participant Information Sheet). None of the information being collected is of a personal nature. No identifiers (other than audio-recording and live video-streaming) will be used. First names may be written and used to address participants during the discussion, however, no last names or other identifiers will be written. Participants are free to use a pseudonym if they prefer. All data will be de-identified in transcripts or summary notes, and any information communicated by participants will not be associated with any particular individual's name in any reports or other materials produced by ORISE/ORAU or CDC. No personally identifiable information (PII) will be filed or retrievable by CDC. No additional individually identifiable information is being collected.

Data will be maintained in password protected files to which only project staff from CDC, ORISE/ORAU, and contractors will have access; data will not be disclosed, unless otherwise compelled by law. Any notes, recordings, and other identifying information collected during the focus groups will be destroyed after three years. The live stream video will be archived for one year, password protected, and only ORISE/ORAU research staff on the project will have access.

Estimated Burden Hours and Distribution of Respondents

Table 2:

Type of respondent	Form Name	Number of Respondents	Number of Responses per	Average Burden per Response (in	Total Burden Hours
			Respondent	hours)	
LEP Spanish- speaking parents/expectant parents (with children 12 years of age and younger)	Participant Screener	100	1	10/60	17
LEP Spanish- speaking parents/expectant parents (with children 12 years of age and younger)	Discussion Guide	50	1	2	100
LEP Spanish- speaking adults 40- 59 years of age	Participant Screener	100	1	10/60	17
LEP Spanish- speaking adults 40- 59 years of age	Discussion Guide	50	1	2	100
LEP Spanish- speaking adults 60 years of age and older	Participant Screener	100	1	10/60	17
LEP Spanish- speaking adults 60 years of age and older	Discussion Guide	50	1	2	100
Total					351

Estimated Burden Hours

Table 3:

Distribution of Respondents

		Distributio	ii oi Kesponde			
Audience Segment	Type of Responden t	Major Metropolita n City 1	Major Metropolita n City 2	Knoxville, Tennessee, area	Total Numbe r of Groups	Total Respondent s
LEP Spanish- speaking parents/expectan t parents (with children 12 years of age and younger)	Participant Screener- only	20	20	10	0	50
LEP Spanish- speaking parents/expectan t parents (with children 12 years of age and younger)	Participant Screener and Focus Group	20 (2 groups, 10 participants each)	20 (2 groups, 10 participants each)	10 (1 group, 10 participants)	5	50
LEP Spanish- speaking adults 40-59 years of age	Participant Screener- only	20	20	10	0	50
LEP Spanish- speaking adults 40-59 years of age	Participant Screener and Focus Group	20 (2 groups, 10 participants each)	20 (2 groups, 10 participants each)	10 (1 group, 10 participants)	5	50
LEP Spanish- speaking adults 60 years of age and older	Participant Screener- only	20	20	10	0	50
LEP Spanish- speaking adults 60 years of age and older	Participant Screener and Focus Group	20 (2 groups, 10 participants each)	20 (2 groups, 10 participants each)	10 (1 group, 10 participants)	5	50
Totals					15	300 Respondent s

Project Time Schedule

The Interagency Agreement (IAA) with ORISE/ORAU/DOE ends on 9/19/2014. Therefore, data collection must begin no later than July 2014.

Table 4:

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Activity	Time Schedule
Recruitment of respondents	2 weeks after OMB approval
Data collection	1 month after OMB approval
Complete field work	2 months after OMB approval
Analyses	3 months after OMB approval
Report Recommendations	3.5 months after OMB approval

Project Time Schedule

<u>References</u>

[1] US Census Bureau, 2010. American Community Survey, "Language Spoken at Home by Ability to Speak English for the Population 5 Years and Over." <u>http://factfinder2.census.gov/faces/nav/jsf/pages/index.xhtml</u> (Retrieved 20 Dec 2011).

[2] Singer, E. *The Use of Incentivs to Reduce Nonresponse in Household Surveys*. Survey Methodology Program, University of Michigan. <u>http://www.isr.umich.edu/src/smp/Electronic</u> <u>%20Copies/51-Draft106.pdf</u> (Retrieved 21 Mar 2013).