

## **CDC and ATSDR Health Message Testing System (OMB No. 0920-0572)**

We would like to submit a request for change to the generic clearance, OMB No. 0920-0572, CDC and ATSDR Health Message Testing System.

This change would add thirteen screening questions to the Demographic Questions portion of the Health Message Testing System Question Bank. The change would not involve changes to the burden hours or any other part of the approved package.

The Division of Vector-borne Infectious Diseases in the National Center for Emerging and Zoonotic Infectious Diseases submitted a request to the Office of the Associate Director for Communication to use the Health Message Testing System for the study, "Lyme Disease Formative Research."

The approved Health Message Testing System Question Bank consists of 367 questions including 41 Demographic Questions; however, these screening questions do not completely address the specific audience segment required for the NCEZID data collection. Thirteen additional questions are required to identify members of the appropriate audience segment to participate in triad focus group discussions.

### **Justification for the Additional Screening Questions**

In 2008, CDC leaders, scientists, and communication professionals from the National Center for Zoonotic, Vector-Borne, and Enteric Diseases (now called the National Center for Emerging and Zoonotic Infectious Diseases) and the Division of Vector-Borne Infectious Diseases (DVBID) (now called the Division of Vector-Borne Diseases) began working together to create a proactive Lyme disease communication plan to clarify CDC's role, accomplishments, and aspirations in the public dialogue about Lyme disease as well as to ensure that CDC is seen as a go-to source for credible information on the prevention and early detection and treatment of Lyme disease.

### **Goals**

The primary goals of this communication plan are to position CDC as a trusted, leading resource on Lyme disease prevention and control and to provide key audiences (the general population, affected population, and clinicians) with accurate and actionable information as well as credible answers to their questions about Lyme disease. This plan is intended to complement tick-borne disease prevention efforts. To date, CDC has not effectively tackled some of the complex and controversial issues around Lyme disease diagnosis and treatment, which may be undermining our effectiveness in tick-borne prevention efforts.

### **Objectives**

A key objective is to develop a comprehensive, proactive communication plan to ensure message clarity and consistency, dissemination of credible information, promotion of key facts related to important issues, and offer an appropriate/rapid-response when

disinformation is widely promoted. To accomplish this, CDC has undertaken several key activities including:

1. **Finding a firm theoretical foundation for developing a communication plan.** CDC reviewed the risk communication literature (both theories and practice principles) to identify which might be most helpful as applied to Lyme disease message framing. Several theories emerged as relevant to the issues at hand including: The Model of Risk Information Seeking and Processing (Griffin, Dunwoody, & Neuwirth, 1999) and Kleinman's (1980) use of explanatory models in understanding illness.
2. **Assessing the current state of the Lyme disease communications environment.** CDC did a landscape audience of news media coverage, reviewed existing materials and messages of CDC and Lyme disease advocacy groups, reviewed position statements from various governmental and non-governmental organizations, and reviewed internet and blog postings about Lyme disease.
3. **Looking for any existing market research about Lyme disease.** CDC looked at available market research databases for any questions that could help to inform audience segmentation and/or developing audience profiles. No relevant items were found so CDC suggested some Lyme disease questions to the Office of the Associate Director for Communication at CDC for placement on Porter Novelli's Healthstyles and Docstyles surveys. Preliminary analysis has been completed.
4. **Interacting with audience members to learn about their experiences with Lyme disease.** CDC hired a contractor (RTI) to begin formative research to explore the public's knowledge, beliefs, and information sources regarding Lyme disease. In the summer of 2010, RTI conducted several focus groups and in-depth interviews. Three audience segments emerged from this work including: (1) persons who were diagnosed with Lyme disease, received appropriate treatment, and who recovered fully; (2) persons who were diagnosed with Lyme disease, received appropriate treatment, and who experienced lingering symptoms; and (3) persons who believe they have "Chronic Lyme Disease." Half of the participants were asked about their experiences with Lyme disease and the other half were asked about the information sources which were useful to them in the course of their disease. Participants provided very rich data on the gaps in information and their needs. Because of the tight timeline for this project, OMB approval for data collection was avoided by asking fewer than nine persons any set of questions (or line of inquiry).
5. **Creating messages that are theoretically sound and responsive to the input from audiences.** RTI has developed "Guiding Principles for Communication on Lyme Disease" that synthesizes findings from the literature review, landscape audit, and exploratory formative research.

**Currently, CDC and RTI are drafting messages for testing with these three unique audience segments.**

This HMTS Change Request would allow us to add questions to the Demographics section so that we can ensure that we recruit and test messages with each identified

audience segment. In addition to the benefits for this particular project, other programs at CDC would be able to recruit persons experiencing infectious or chronic diseases. The addition of screening questions should allow for more effective targeting of message testing and therefore more efficient use of the time of respondents and the resources of the government.

Because of the need to address the complex issues of Lyme disease diagnosis and treatment and develop effective messages for different “experiences” with Lyme disease, it is critical to test proposed messages for three unique audiences: (1) persons who have been diagnosed with Lyme disease, report receiving appropriate treatment, and who recovered fully; (2) persons who have been diagnosed with Lyme disease, report receiving appropriate treatment, and who have experienced or are still experiencing lingering symptoms that they believe may be due to Lyme disease; and (3) persons who believe they have “Chronic Lyme Disease.” In order to ensure that we reach these specific audiences, we are requesting to add the attached screening questions to the Health Message Testing System Question Bank.

Adding these questions to the Health Message Testing System Question Bank will ensure NCEZID programs will be able to maximize their use of the Health Message Testing System OMB clearance for future concept/message testing data collection instruments maximizing the health impact of the information directed at specific audience segments and resulting in optimum benefit for public health.