

Attachment A

Background Information

Purpose

In an effort to understand cancer rates in firefighters, the Firefighter Cancer Registry Act of 2018 (42 U.S.C. 280e-5) was passed by Congress and signed into law by President Trump.

The new law requires that CDC/NIOSH develop and maintain a voluntary database of firefighter health and occupational information to improve the nationwide monitoring of cancer rates among firefighters and to make the resulting epidemiological information and analysis publicly available. The National Firefighter Registry (NFR) will be constructed primarily for the purpose of determining cancer incidence and trends among firefighters.

Data submission to the registry will be voluntary. Consequently, to better understand what might drive people to participate or keep them from registering, we must undertake multiple information-gathering sessions with firefighters.

Firefighters are not a monolithic group. Each audience segment has a different understanding of the issues and awareness of the NFR. Their motivation for participating in the NFR may vary considerably. Certain segments of the overall firefighter population, such as minorities and women, have not been included in earlier cancer studies. And the impact of on-the-job exposures and the incidence of cancer may vary by subgroup. For these reasons, we need to reach out to a wide population of firefighters through focus group and informal survey tools to ensure that we know how best to communicate with the full breadth of types of firefighters.

In order to develop an accurate picture of cancer incidence among the firefighting community, the Registry will be designed to collect information on volunteer, paid-on-call, and career firefighters, as well as women and minority firefighters, independent of cancer status or diagnosis.

To successfully carry out the requirements of this legislation, NIOSH plans to begin registering firefighters by the end of 2020. NIOSH is in the process of developing a system to register the various groups of firefighters specifically identified in the Act.

However, each of these groups may have different perceptions of research and cancer and utilize different communication channels and/or respond uniquely to different types of messaging. Hence, it is critical that NIOSH conduct focus groups for the different target audiences to refine message concepts and to test draft materials on the importance of the NFR for clarity, salience, appeal, and persuasiveness.

NIOSH is working with Advanced Technologies and Laboratories International, Inc., in association with the International Public Safety Data Institute (BPA 200-2016-F-89201) to conduct these focus groups. In order to hear from each target population, we need to conduct a total of six focus groups of firefighters, each representing a different audience.

We would also like to develop and use informal survey tools targeting different stakeholder groups. Results from these focus groups and the informal surveys will help NIOSH and the contractor develop targeted health messaging that effectively explains the purpose and importance of the NFR and why individual firefighters should participate.

This research will be designed to increase enrollment, especially among hard-to-reach groups of firefighters, such as volunteer firefighters, and will further improve the ability for researchers to evaluate cancer risk among this critical emergency-responder workforce.

The focus group guide was developed using the CDC's Health Messaging Testing System Message Bank. All survey questions will be taken directly from the same source. The questions concentrate on how much firefighters worry about or are concerned about cancer in their lives and profession. Questions also try to understand what actions they may take to help prevent the disease, including registering for the NFR. We will also examine the obstacles to getting them engaged in the NFR and the best channels of communications to use to connect with them on a regular basis.

Protection of the Privacy and Confidentiality of Information Provided by Respondents

Focus group attendees will be coordinated and selected by firefighter stakeholder groups with the understanding that they will be providing the appropriate diversity in each focus group.

Once 10-12 individuals per focus group have been identified and confirmed, the names of attendees will be documented electronically and saved on an encrypted server. This attendee list will only be used to confirm attendance at the focus group meeting and will then be deleted.

During the focus group, some basic demographic information will be collected via a paper form, with the majority of the questions coming directly from the Health Messaging Testing System Message Bank, (e.g., gender, age, race, type of fire department, geographic location of fire department, and job title), which are necessary to understand communication differences. A few questions about their fire department will also be asked.

All focus group attendees will be told that their responses will be treated in a secure manner and will not be disclosed, unless otherwise compelled by law. The focus group attendees will also be notified that the session is being recorded (audio) for quality assurance and encouraged not to use names. The audio recordings will be stored on an encrypted server and then subsequently used by the contractor to validate the notes taken during the sessions and ensure an accurate analysis of the focus group research. After validating all notes, the focus group administrator will destroy the audio file. The contractor will provide a report of each focus group session to NIOSH, as well as a summary report that analyzes overall findings from all six of the focus groups. The reports will not include any personal identifiable information (PII). Any PII still in the contractor's possession after submitting the reports will be destroyed.

The informal surveys will be conducted using the online platform Survey Monkey with all survey responses sent over a secure, encrypted connection. The survey will not ask for any names or personal information.

NIOSH and its contractors plan to collaborate with stakeholders to distribute the survey. Stakeholders will be provided a survey link and will publicize the survey through their social media channels or via other appropriate means through which they reach firefighters.

The contractor will close the survey if/when responses reach the desired response rate and demographics within 60 days. Alternatively, in the unlikely event that the survey does not achieve the desired response rate within the 60-day timeframe, we will extend the survey for an additional 15 days.

Justification for Sensitive Questions

To reiterate, all questions were developed from the Health Messaging Testing System Message Bank. None of the questions for the focus groups are sensitive in nature. Focus group participants will be informed that they need not answer any question that makes them feel uncomfortable or that they simply do not wish to answer. Our focus group moderators have a long history working with firefighters and are trained to ask questions in a sensitive manner and to handle any subsequent discussion skillfully.

Efforts to Identify Duplication and Use of Similar Information

We have not identified any other CDC message testing information collection with a focus on communicating the importance of the National Firefighter Registry.