

**Report of the National Firefighter Registry Subcommittee, as approved by the NIOSH Board of Scientific Counselors:
Review, Advice, and Recommendations for the Registry Protocol and Questionnaire**

History: The National Firefighter Registry (NFR) and the NFR Subcommittee (NFRS) was established based on the Firefighter Cancer Registry Act of 2018 passed by Congress. The National Institute for Occupational Safety and Health (NIOSH) was directed to create a voluntary registry of U.S. firefighters for the purpose of monitoring cancer incidence and risk factors among the U.S. fire service. The NFRS was asked to review the protocol and Appendices A-F and provide written comments. Prior to the subcommittee meeting, the NFRS provided over 12 pages of written comments to the NIOSH team (Attachment 1). Many, but not all, of the written comments were discussed at the subcommittee meeting on May 15, 2020. Hence, it is advised that the NIOSH team review all the provided comments and make changes to the protocol and appendices as they deem appropriate.

Meeting overview and follow-up: The NFRS held a virtual meeting (due to the pandemic) with the NIOSH Team on May 15, 2020, to provide advice and recommendations regarding the NFR protocol. Attachment 2 provides the list of those attending the meeting. In addition, the NIOSH team requested input on six overarching questions, and the co-chairs added three for additional considerations (Attachment 3). These questions included issues related to communication and enrollment of participants, estimating lifetime exposures, use of protective equipment, cancer risk factors, possible additional information needed for linking with state and territorial cancer registries, pilot testing elements of the protocol, approach to implementing recruitment of the targeted and open cohort and expectation for meeting the recruitment goals. A 94-page transcript of the meeting was provided to the co-chairs. The charge to the Co-chairs was to review and condense the meeting transcript to the most salient issues, prepare a report and draft relevant advice and recommendations. The recommendations require formal approval by the NFRS. After review and final approval of the report by the NFRS, the NIOSH Board of Scientific Counselors (BSC) will review and discuss it in an open meeting and decide what to send forward to NIOSH.

Progress of the NFR: The NIOSH Team presented an update on the progress of the NFR, project protocol overview, and the enrollment questionnaire. This progress includes establishing the NFRS, preparing a draft of the protocol, preparing a participant population recruitment design and flowchart, informational and promotional materials, providing a list of stakeholders, an informed consent document, and development of a user profile questionnaire and an enrollment questionnaire. The assurance of confidentiality form is currently under development. The NFRS was quite impressed with the progress made by the NIOSH team as well as the overall study design and approach.

Overall Study Approach: The protocol is a comprehensive and elegant design that includes both a targeted and an open cohort. The targeted cohort is a prospective cohort with continuous enrollment obtained from two sampling frames. The sampling frames are either specific firefighter departments or state firefighter certificate databases. The open cohort involves a non-probability sampling design and is open to active, former, or retired firefighters who have ever been an active firefighter. The open cohort is designed to recruit large representation from sub-specialties. The NFRS felt that there has been excellent progress by the NIOSH Team, and their projected timelines were feasible. The plan is to begin enrollment by 2021. However, it will likely take some start-up period to reach the targeted goal of ~40,000 participants per year. A question by some committee members was the feasibility of including sufficient wildland firefighters in the open cohort approach to ensure reliability of findings.

Department eligibility requirements, communicating to targeted fire departments, overcoming participation barriers and increasing enrollment: One consideration in requesting records from fire departments is that information may be protected by The Family Education Rights Protection Act (FERPA), and some states such as New York are very restrictive. Fire chiefs may have privacy concerns and be very reluctant to provide information pertaining to their firefighters. Plus, departmental leadership frequently changes, and it is unknown if records are maintained in any consistent manner. Hence, eligibility requirements may therefore be too restrictive and decrease the number of participating departments. It is suggested that the NIOSH team explore the restrictions that may be applied to their requests to anticipate the degree of resistance and non-compliance that may occur.

At the department level it will be important to identify “key opinion” leaders in each department to explain the importance of the NFR and encourage participation of the individual firefighters. A webinar for the targeted departments was suggested, and these individuals could then encourage their department to participate.

Two issues that are of paramount concern for participation by both fire departments and firefighters are data security and confidentiality. To ensure data security NIOSH will seek to offer an Assurance of Confidentiality (AOC) which is a formal confidentiality protection authorized under Section 308 (d) of the Public Health Service Act. An AOC protects individuals and institutions involved in such activities as research or surveillance that states that no supplied information may be used for any purpose other than the purpose for which it is supplied. Most participants will need a clear and specific explanation of how the AOC protects their privacy. This explanation may be included in the informational and promotional materials, the informed consent documents, and the enrollment questionnaire.

Regardless of having an AOC there likely will be considerable reluctance to provide social security numbers (SSN). Thus, it will be important to explain why the SSN is necessary to track and locate information in the future for accessing information from the cancer registries. The need for SSN should be highlighted in all communications and “headlined” in trade magazines.

It may be time to begin providing information to trade magazines and other sources. It will be important for the firefighter to understand that their cancer information will already be in a registry, and that their SSN will assist in gathering information that is already found on another data source. The last four digits of the SSN would be considerably easier to obtain and less likely to decrease participation. Enrollment will require that individuals understand that their participation will provide an overall benefit to the profession as well as contribution to science. It will be necessary to explain to the firefighters how in the “long run” it will benefit future firefighters and the profession.

- **Recommendation 1:** Because of the importance of obtaining SSN for the National Death Index and the cancer registries, it is recommended that NIOSH should perform targeted stakeholder interviews to learn the most compelling communication approach for explaining why the SSN is needed and how it will be protected, then the communication approach should be pilot tested.

Methods for increasing enrollment should include all forms of social media and especially Instagram and Facebook. It was suggested that the “pop-ups” about the registry will help keep the program on the forefront. Also, it was proposed that text messages could be used (if phone numbers are available) as more people use texts than emails. Outreach to “affinity” organizations such as Women in Fire, International Association of Black Professional Fire Fighters and National Association of Hispanic Firefighters will help to obtain these stakeholders for the NFR. It was suggested that there should be outreach to the officers of these affinity groups, and members of the NFRS could assist with some boilerplate language that firefighters will trust. It should be conveyed that it is everybody’s responsibility to do their part in encouraging each other to participate. Use of radio station interviews and podcasts targeted to various firefighter populations are additional outreach opportunities. It was suggested that researching some of the popular podcasts such as health podcasts might be a good avenue.

Linking with cancer registries: The NIOSH Team requested assistance in understanding: “Are any crucial details missing from the protocol or consent form that would be needed for linking with population-based (state and territorial) cancer registries? How soon after initial enrollment should NIOSH seek to conduct registry linkages nationally?”

The entire nation has been covered by state-based cancer registries since 1995. There was considerable discussion about the recent transformative developments to link individual identifiers with cancer registries. The North American Association of Central Cancer Registries (NAACCR) has created a virtual national cancer registry called the Virtual Pooled Registry. To date, 38 states have agreed to a single point access where a data file can be submitted with identifiers. The file is then submitted through a secure mechanism to link with each state cancer registry. The deliverable to NIOSH will be a report of the number of matches by state that occurred. No personal identifiers will be released in this phase. Then NIOSH can negotiate with the states to receive patient identifiers which are needed for data analysis. It was

reported that it is possible to do minimal risk linkage studies using cancer registries with an IRB approved waiver of consent.

- **Recommendation 2:** Currently changes are underway with NAACCR to facilitate and streamline linkage between research groups and state cancer registries via the Virtual Pooled Registry. NIOSH should begin the groundwork for establishing the framework for linking the firefighter cancer information, both past and on-going, to facilitate future easy access to the state cancer registry data.

Estimating lifetime exposures and use of protective equipment: The NIOSH Team requested input concerning the best way to estimate lifetime exposures and changes in implementation of controls over time. The concern is balancing time for completing the Enrollment Questionnaire (EQ) with obtaining sufficient data to estimate lifetime exposures. The cancers that are reported in the next ten years will likely be related to exposures that occurred at least 15-20 years previously. As the work history questionnaire is currently designed in the EQ (Appendix F) the past work history from inception of work as a firefighter will obtain total duration of exposure, latency from date of hire to cancer diagnosis, job titles and positions held. However, what is missing from the past work history that is found in the current or most recent job assignment are questions 25 (runs/shift), 28 (frequency of smoke exposure and smoke exposure requiring emergency room evaluation), 29 (frequency of wearing respiratory protection and type), and 30-35 (care of personal protective equipment (PPE), showering, and laundry of PPE). If added these questions will provide the data to estimate lifetime exposures and the availability, use, and care of PPE that assists in defining the extent of personal exposures. A second approach for a more complete past work history would be to ask firefighters when the use of PPE became a common practice. It was stated that much of the use of PPE has to do with culture of individual firehouses and may depend on whether it is mandated. One concern raised was that when a firefighter changed departments the culture in the new department may be entirely different, and the firefighter's behavior might change. The big differences that are seen are between geographic areas, such as rural compared with urban, and these differences must be considered. Also, it was suggested that it would be useful to collect information on when official policies in use of PPE changed. These official changes could be provided to the interviewee as a trigger for recall but may also introduce a recall bias. For the future, an exposure app could be developed that is tied to incident reporting, and the firefighter reporting their daily exposures which is tracked back to an incident.

- **Recommendation 3:** It is recommended that one of two approaches be used to characterize exposure. One approach could be the use of strategic questions regarding the approximate year that the individual firefighter started using each protective action such as self-contained breathing apparatus, other respiratory protection during overhaul, types of turn-out gear used, storage and cleaning of turn out gear, showering etc., The second approach would be to ask questions 25, 28-29, 30-35 for each job held. Further, it is recommended that both approaches be assessed in a pilot study to

determine how much time is added to the total time for collecting information for the enrollment questionnaire. Several subcommittee members felt that 30 minutes or less may be ideal for completing the enrollment questionnaire but that this exposure/protection information was vital for the success of the study. Hence, it is recommended that different versions of the questionnaire be pilot tested to have a better understanding of which approach is more reliable, valid, and acceptable to the participants.

Another important point raised was that fire departments may share the same name and a way to distinguish these would be to capture the Fire Department Identification (FDID). Every fire department has a unique FDID which may be key to understanding how protective gear was handled by the individual fire departments. Knowing the FDID may be especially important when individuals worked at multiple fire departments. The FDID numbers are standard. All fire departments registered with the NFIRS system use the FDID. It is advised that the NIOSH team explore how to incorporate the FDID numbers but understand that individual firefighters may not know their departments FDID.

Assessing cancer outcomes and identifying risk factors: The NIOSH Team asked the NFRS to address “What other important variables related to cancer risk should be collected as part of the enrollment process and what should be included in follow-up surveys”. The subcommittee noted that the key risk factors have been well identified and include use of tobacco products (including cigars, chewing tobacco and snuff), alcohol use, exercise, strength training, use of indoor tanning devices, and having annual medicals. It was suggested that some type of measure of the *amount* of use for tobacco products should be added for calculating pack-years. The subcommittee felt that for the follow-up questionnaire question(s) on sleep and stress might be added. In the written comments to NIOSH it was also advised that the questions be asked in order from lower sensitivity to those of greater sensitivity (e.g. start with exercise first and end with alcohol use). It is also advised that these risk factors be updated during the follow-up evaluations. The question was raised whether the profile questionnaire could be updated with a new cancer diagnosis or exposure information. It was also stated that regarding cancer diagnosis, what is critical is the *residence* where the individual was living at time of cancer diagnosis and not the state where the diagnosis was made. One person mentioned about asking if any of their children had developed cancer which would be related to bringing workplace exposures to the home or possible spermatogenic effects as well as genetic risks.

Communicating findings to participants: The committee felt additional considerations should be given to communicating the start-up of the study as well as on-going communication of the findings. For example, at time of sign-up through the web portal the individual could request to receive regular updates. At least every 6-12 months participants might receive a summary of how many have registered, what regional areas have been included, etc. There could also be an on-going visual as to how far the enrollment has come toward meeting the goal of 200,000 participants, with some figure like a thermometer. The committee wondered if it was possible

for participants to refer other people to the NFR as it is always good for other firefighters to encourage each other. Communication of study findings is the ultimate tool for maintaining interest and follow-up participation.