

National Firefighter Registry Subcommittee (NFRS) Report on the National Firefighter Registry Draft Protocol

Response to NFRS Report dated 08/04/2020

Memo 10/16/2020

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RECOMMENDATIONS		
1	<p>“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.” (pg. 3 of the NFRS Report on the National Firefighter Registry Draft Protocol)</p>	<p>Following NFRS recommendations, the NFR team conducted four focus groups with firefighters and professional organization leadership to inquire about the collection of SSNs, among other topics. This information will inform the development of promotional materials that will specifically cover the importance of collecting SSNs as part of the NFR. Details about this process are now described in the protocol under Objective 1.</p> <p>Previously, the NFR team held multiple conversations with stakeholders, firefighters, and cancer researchers at meetings and conferences (e.g., 2019 Miami Cancer Symposium) to discuss the collection of Social Security Numbers (SSNs) and best ways to convey the security aspect of this project to participants. The language used in the enrollment questionnaire and informed consent document has since been reviewed by multiple firefighters, researchers, and external stakeholders.</p>
2	<p>“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</p>	<p>The Virtual Pooled Registry (VPR) will be an important tool for conducting cancer linkages. As recommended, we now emphasize the VPR in the protocol (under Objective 3).</p>

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	<p>and on-going, to facilitate future easy access to the state cancer registry data.” (pg. 4 of the NFRS Report on the National Firefighter Registry Draft Protocol)</p>	<p>We have established several connections with North American Association of Central Cancer Registries (NAACCR), including the project coordinator for the VPR, and with staff from individual state cancer registries that have expressed support and offered assistance (e.g., to pilot test linkages, etc.). We will continue raising awareness about the NFR among the state cancer registry community through meetings and presentations, such as a NAACCR webinar this year (2020). We will also continue our discussions with team members from other CDC projects that have/are currently linking with U.S. state cancer registries to assess lessons learned and better understand the process. Because of the complexities and challenges associated with linking with state cancer registries nationwide, we are planning to invest adequate resources for this process.</p>
3	<p>“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</p>	<p>Following NFRS recommendations, the NFR team held a virtual meeting with 3 fire service experts to discuss the options for capturing more detailed work history, exposure, and protective practices in order to select an approach that will capture both the desired level of detail while being mindful of the time burden. We updated the questionnaire to reflect the suggestions from these subject matter experts and the Subcommittee. We now ask for a more detailed work history with exposure questions tied to each job title at each department in which a participant has worked. Additionally, we now also ask the year that protective practices, such as wearing respiratory</p>

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	<p>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.” (pg. 4-5 of the NFRS Report on the National Firefighter Registry Draft Protocol)</p>	<p>protection, were implemented (see Work and Exposure History section of the questionnaire). Finally, we added an additional question to capture history of smoke exposure injuries that have required medical attention, per the Subcommittee’s recommendations.</p> <p>Additionally, multiple firefighters from various backgrounds have reviewed and/or piloted several drafts of the questionnaire during its development. Given the input received from over 30 firefighters, fire service experts, and researchers, we do not believe a formal pilot study of the two different exposure assessment approaches is necessary.</p>
ADDITIONAL SUGGESTIONS		
4	<p>“A question by some committee members was the feasibility of including sufficient wildland firefighters in the open cohort approach to ensure reliability of findings.” (pg. 2 of the NFRS Report on the National Firefighter Registry Draft Protocol)</p>	<p>We added language to the Stakeholder Participation section of the protocol about disseminating recruitment materials to relevant stakeholders like the International Association of Wildland Fire (IAWF). We plan to develop communication materials geared toward specific firefighter populations, including wildland firefighters. We continue to work closely with relevant stakeholders in order to maximize potential response of wildland firefighters in the Open Cohort.</p>
5	<p>“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.</p>	<p>We have modified the language in the protocol to allow for flexibility in recruiting for the Targeted Cohort if we need to select departments based on incident record availability (see Targeted Cohort: Selected Fire Departments section of the protocol).</p>

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	<p>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.” (pg. 2 of the NFRS Report on the National Firefighter Registry Draft Protocol)</p>	<p>We will assess the level of resistance and/or non-compliance from selected departments to providing incident records (for reasons such as restrictions under the Family Educational Rights and Privacy Act [FERPA] or other legal or administrative barriers) during early Targeted Cohort enrollment. We will not consider department eligibility criteria for the Targeted Cohort based on the ability to provide incident records unless the level of resistance/non-compliance affects the ability to obtain a meaningful amount of incident records for this cohort. Such eligibility criteria would likely exclude many departments that are different from those that would be included across a variety of characteristics, which would likely introduce bias into the Targeted Cohort.</p>
6	<p>“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.” (pg. 2 of the NFRS Report on the National Firefighter Registry Draft Protocol)</p>	<p>We added a sentence in the Targeted Cohort section to clarify that we will identify primary points of contact for all NFR-related matters at selected departments. We are cultivating these relationships with several fire departments around the country, and we are also using customer relationship management software to identify contacts at each fire department and to maintain a directory of these key opinion leaders. As we proceed with the NFR we will contact these leaders to help spread the word about the NFR and keep stakeholders informed and involved. We will use newsletters, webinars, and similar events to keep the fire departments engaged, and we anticipate virtual events to be a successful</p>

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		mechanism as people are becoming more accustomed to them.
7	<p>“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.” (pg. 2 of the NFRS Report on the National Firefighter Registry Draft Protocol)</p>	<p>The NFR Team plans to develop promotional materials to communicate the importance of collecting SSNs as part of the NFR and the data protections that will be in place. We held four virtual focus groups with firefighters to gauge how they respond to different explanations for collecting SSNs, which will inform the development of these promotional materials. These details have been added to the protocol under Objective 1. We also added more language in the informed consent explaining our data sharing process where we specifically state that no directly identifiable data will be shared with external researchers. The language explaining the importance of collecting SSNs and how the Assurance of Confidentiality (AoC) protects firefighters’ data in the informed consent and enrollment questionnaire has been reviewed by firefighters, fire service experts, researchers, and health communication specialists, and we continue to enhance it as necessary.</p>
8	<p>“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.” (pg. 3 of the NFRS Report on the National Firefighter Registry Draft Protocol)</p>	<p>We have updated promotional materials to convey to potential enrollees that their extended participation will benefit future firefighters by increasing the knowledge about cancer in the fire service. As we continue to develop promotional materials and engage with the fire service, we will keep this message consistent. We also plan to develop videos</p>

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		that include highly respected firefighters lending their support to the NFR.
9	<p>“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.” (pg. 3 of the NFRS Report on the National Firefighter Registry Draft Protocol)</p>	<p>We are developing a promotional campaign that will include social media, outreach at conferences, and our quarterly newsletter, among other communication channels. Regarding the specific recommendations, we will be developing a social media plan that will include Facebook, Instagram, and Twitter. We will also be preparing a toolkit that we will share with fire service affinity organizations so they can promote the NFR to their members on their social media channels. This will be in addition to reaching out to them to discuss outreach in other formats, such as attending conferences and meetings. We plan to secure Google ads and paid promotional posts on social media that will target potential participants. We are also exploring the use of text messages to maintain communication with participants, as we agree that firefighters are more likely to respond to these as opposed to emails. We will explore further promotional opportunities such as radio interviews and podcasts by NFR spokespersons who will be identified as part of the promotional campaign. Lastly, we will also continue holding conference calls with agencies like IAWF and IAFF to discuss recruitment strategies and disseminate promotional materials. Some details about the promotional campaign have now been added to the protocol.</p>

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10	"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." (pg. 5 of the NFRS Report on the National Firefighter Registry Draft Protocol)	After discussing the importance of capturing Fire Department IDs (FDID) for department identification, and the possibility that many firefighters won't know their FDID, we are developing a mechanism for recording FDID on the database end of the web portal by linking each specific self-reported department with the appropriate FDID using source data from the U.S. Fire Administration and FireCares.
11	"It was suggested that some type of measure of the amount of use for tobacco products should be added for calculating pack-years." (pg. 5 of the NFRS Report on the National Firefighter Registry Draft Protocol)	We have revised the tobacco items in the questionnaire and now ascertain an intensity metric from which to calculate pack-years for cigarettes; and we also ascertain never/current/former status, age at initiation, duration of use, and age at cessation for all items including cigarettes, cigars, pipes, vape/e-cigarettes, and smokeless tobacco.
12	"The subcommittee felt that for the follow-up questionnaire question(s) on sleep and stress might be added." (pg. 5 of the NFRS Report on the National Firefighter Registry Draft Protocol)	NIOSH scientists that study sleep and related risk factors in relation to health and cancer have advocated for the two current sleep items in the enrollment questionnaire. The enrollment questionnaire also includes questions in the health history section that relate to mental/behavioral health (i.e., previous diagnosis). However, we have noted within our planning documents that we will obtain more detail about sleep and stress (as well as other important factors and health outcomes) in future follow-up questionnaires. We are actively maintaining a list of important topics or questions that could be included in follow-up questionnaires.
13	"In the written comments to NIOSH it was also advised that the questions be asked in order from lower sensitivity to those of	We have adopted this re-ordering for questionnaire items.

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	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.” (pg. 5 of the NFRS Report on the National Firefighter Registry Draft Protocol)	
14	“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.” (pg. 5 of the NFRS Report on the National Firefighter Registry Draft Protocol)	<p>Participants can update all self-reported user profile information, including cancer status. Participants will receive periodic reminders to update their profiles. Information from the original profile and from updates will be saved to follow changes in the information over time.</p> <p>Residence at the time of diagnosis has been corrected in the user profile cancer status item and in other references to the cancer reporting mechanism (e.g., consent form)</p>
15	“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.” (pg. 5 of the NFRS Report on the National Firefighter Registry Draft Protocol)	We have added an additional questionnaire item about the occurrence of cancer in biological children.
16	“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.” (pg. 5 of the NFRS Report on the National Firefighter Registry Draft Protocol)	We are planning a promotional campaign that will use several communication channels to announce the opening of the NFR, including social media, conferences, and the NFR newsletter, among others. This campaign includes leveraging contacts at fire service organizations and unions to help spread the word that the NFR is opening. More details about the promotional campaign have been added to the protocol (see Stakeholder Participation and Advisory Committee section).

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		<p>We will explore options for communicating regular updates on the NFR to its participants. Specifically, we will explore developing a dashboard in the web portal that shows preliminary results or estimates (e.g., overall enrollment), which is now referenced in the protocol (see Follow-Up Questionnaires and Continued Engagement section). Firefighters that enroll will be able to see how many others have already enrolled when they sign up and will also be able to revisit the dashboard to see how the NFR is progressing. We will also explore sending regular updates to participants with enrollment summaries as recommended in the report and when important milestones are met (e.g., 200,000 participants). Relevant NFR or firefighter health and safety publications can also be shared with registered firefighters. These types of communications will serve to keep participants engaged and encourage participants to keep their web portal information up to date and participate in follow-up questionnaires.</p>
17	<p>“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.” (pg. 5-6 of the NFRS Report on the National Firefighter Registry Draft Protocol)</p>	<p>We are developing social media material that is easy to share to one’s own social media as well as send to others.</p> <p>Because all information obtained by the NFR is strictly voluntary, and requires individual consent from all participants, we cannot collect names/contact information in our web portal on other individuals from NFR participants. However, we will strongly</p>

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		encourage participants to share information about the NFR with their colleagues and encourage participation.