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NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY AND
HEALTH (NIOSH)

BOARD OF SCIENTIFIC COUNSELORS (BSC)
NATIONAL FIREFIGHTER REGISTRY SUBCOMMITTEE

FOURTH MEETING
VIRTUAL ON ZOOM, OPEN TO THE PUBLIC
SEPTEMBER 6, 2022

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Summary Proceedings

The fifth meeting of the National Institute for Occupational Safety and Health Board of Scientific Counselors (BSC) National Firefighter Registry (NFRS) Subcommittee Meeting was convened on Tuesday, September 6, 2022 via Zoom. The NFRS met in open session in accordance with the Privacy Act and the Federal Advisory Committee Act (FACA).

Attendees

Shawn Brimhall - Member

Dennis Deapen, DrPH – Member

Kenneth R. Fent, PhD

Bryan Frieders – Member

Tom Harbour - Member

Sara Jahnke, PhD - Member

Betsy Kohler - Member

Grace LeMasters, PhD – Co-Chair

Michael Loudermilk

Barbara Materna, PhD - Member

Alex Mayer

Emily Novicki – Designated Federal Officer

Patrick Morrison – Co-chair

Miriam Siegel, DrPH

Victor Stagnaro - Member

Andrea Wilkinson

Regina Wilson - Member

Welcome and Meeting Logistics

Ms. Novicki called to order the open session of the fourth meeting of the NIOSH BSC-NFRS at 1:00 p.m. Eastern Time (ET) on Tuesday, September 6, 2022. A roll call of all NFRS members confirmed that a quorum was present. The roll was also called following the break to ensure that quorum was maintained. Quorum

was maintained throughout the day. No conflicts of interest were declared. Members of the public were notified that they would remain in listen-only mode until the public comment period.

Announcements, Introduction, and Agenda

Dr. LeMasters welcomed everyone and acknowledged the three new members: Tom Harbour, Victor Stagnaro, and Eric Durbin. She reminded the group that they had three questions to consider during the meeting:

1. What improvements should be considered to enhance the user experience of the enrollment system? (Please note that the questions are final, but the NFR team can make tweaks to make it easier to navigate and use the enrollment system).
2. What is the best way to get information about the NFR into the hands of the fire service?
3. How can NIOSH best build trust with departments to encourage participation in both open enrollment and targeted enrollment where records may be requested?

Mr. Morrison agreed this was the task at hand.

Overview of Project Background and Status

Dr. Fent welcomed the NFRS group and shared that he would provide an update on the National Firefighter Registry. He started by introducing the NFR team:

- Lead epidemiologist Miriam Siegel
- Health scientist Alex Mayer
- Health scientist Andrea Wilkinson
- Health communications specialist Greg Hartle, who splits his time between the NFR and the Field Research Branch
- Public health advisor Jasmine Nelson, who also splits her time between the NFR and the Field Research Branch

To say that this is a team effort is a huge understatement. The NFR team has worked diligently, thoughtfully, and very hard to get where they are today. Dr. Fent was excited to provide a status report to everybody on the call.

Dr Fent started by quickly mentioning the recent IARC evaluation. In 2010, the International Agency for Research on Cancer (IARC) classified firefighting as a Group 2B possible carcinogen. Just this summer, IARC completed their reevaluation of the carcinogenicity of the occupation of firefighting, and Dr. Fent had the privilege of serving on the IARC working group. It reached a new consensus evaluation classifying firefighting as a Group 1 known human carcinogen, based on sufficient evidence of mesothelioma and bladder cancer. The working group also found limited evidence of five other cancers, and strong evidence of five key characteristics of carcinogens among exposed firefighters. These findings, coupled with the fact that

firefighters are exposed to numerous chemical carcinogens, night shift work, and UV radiation strengthens the evidence of firefighting and cancer, at least for some types of cancer.

There are still several questions that remain, and these questions are difficult to answer unless you have a large and diverse cohort that you can follow over a long period of time. These questions include:

- What is the cancer risk for volunteer firefighters?
- What is the cancer risk for all the subspecialties of the fire service?
- How does cancer risk vary for different demographic groups?
- How does the cancer risk vary regionally across the U.S. Fire Service?
- How prevalent are rare forms of cancer among firefighters? (Remember, IARC found that seven cancers had sufficient or limited evidence out of about 30 to 40 primary cancers.)
- How does the cancer risk change with increasing exposures, including major events?
- What other occupational or nonoccupational risk factors contribute to cancer risk among firefighters?
- To what extent do different control interventions and workplace practices reduce the risk of cancer? (There have been a lot of changes in the fire service just within the last ten years.)
- And are there other chronic illnesses that are elevated in firefighters?

The National Firefighter Registry should be able to answer many of these questions, and its mission is to generate detailed knowledge about cancer in the fire service through a voluntary registry that reflects our nation's diverse firefighters. The vision is to equip the fire service and public health communities with the knowledge they need to reduce cancer in firefighters.

Lastly, with input and guidance from the NFRS, the team came up with four primary components of the NFR:

1. Collect self-reported information on workplace and personal characteristics through a secure web portal.
2. Obtain records from fire departments or agencies to track trends and patterns of exposure.
3. Link with health information databases, including state cancer registries and the National Death Index, to detect both cancers and deaths.
4. Make de-identified data available for external researchers.

Dr. Fent also reminded everyone of the enrollment design. There will be two enrollment routes as part of the NFR. The open cohort will be a non-probability sample for which any firefighters—active, former, or retired—are eligible. This enrollment route is beneficial for recruiting a large and diverse sample, but it may not be generalizable. The targeted cohort will be a prospective cohort of active structural firefighters recruited from rosters from select fire departments or state agencies. The targeted enrollment allows them to select firefighters throughout the country, from geographically diverse departments of various sizes, and is less susceptible to selection bias than the open cohort. This design will allow them to focus on enrollment of women, minorities, and volunteers, and to access incident records for more detailed exposure information.

The web portal, or online enrollment system, can be thought of as the starting line in the NFR process to better understand cancer among firefighters. The web portal allows NIOSH to collect self-reported information from firefighters such as demographics, work history, use of controls, and other occupational and non-occupational factors. NIOSH will also request incident records from some fire departments, and participants will have an opportunity to take follow-up surveys, which will capture longitudinal information from firefighters about their jobs and other factors.

The next steps will involve matching to state cancer registries and the National Death Index, followed by data analyses. That is when the NFR team can really start to put the data to use, to find answers to some of the more difficult questions that remain such as the relationship between exposure and cancer, the impact of controls, and differences in cancer risk by job or specific demographic categories.

What has the NFR team been up to? Over the last year since the NFRS last met, they have been busy developing the enrollment system or web portal. They have also been fine-tuning the enrollment questionnaire, obtaining an Assurance of Confidentiality, updating the protocol, establishing relationships, keeping the fire service informed, and developing communication materials.

For the web portal, they started out by developing the business needs, use cases, and requirements. Based on the feedback members provided during the August 2021 NFRS meeting, the NFR team chose to pursue a system that incorporates multi-factor authentication but not identity proofing. This decision dictated much of the design, including building a simpler user profile that includes editable information such as name, address, phone number, and current work status.

The enrollment questionnaire was designed to capture information in a one-way fashion. Once the questions are answered and the participant clicks save and continue, the information will be uploaded to a secure database and will not be retrievable or editable. The result is a very secure system where question responses are quickly protected. The NFR team also decided to only collect the last four digits of social security number. They believe that this was the best balance of collecting information necessary for data linkages such as with state cancer registries, while alleviating some of the concerns that firefighters have about their personal information.

The NFR team then worked with the development team to implement all the requirements, including the enrollment questionnaire. The development team built and released wireframes, which are visual mockups of how each page will look. The NFR team tested the prototype system, provided feedback, and then the development team made changes as necessary. This was repeated using agile development principles.

After several development cycles, the web portal was posted to a test site with integration to the multi-factor authentication service Login.gov. This allowed the NFR team to conduct external testing with University of Cincinnati students, Loveland-Symmes Fire Department firefighters, and other firefighters and officers. At the present time, the development team is making the remaining edits and improvements based on all this testing. All the security and compliance testing and documentation is also being finalized. The NFR team is also in the process of setting up a helpdesk, an 1-800 phone number, and an email with process flows for handling questions or concerns from participants. Once all the boxes have been checked, the NFR team will

post the web portal to the production site, which will make the NFR enrollment system live for all intents and purposes. They are very close to doing that.

As the NFR team developed the web portal, the enrollment questionnaire was implemented in a way to take advantage of skip patterns and other logic to improve the user experience. For example, firefighters will be able to search for their fire department by entering their state and then starting to type the name of the department. The department will then auto-populate.

Implementing this logic, however, resulted in some changes to the questionnaire. A few other issues such as needing additional response options were identified during testing. As a result, the NFR had to update the enrollment questionnaire accordingly. They submitted these changes to the Office of Management and Budget (OMB) Paperwork Reduction Act department and obtained approval from OMB on July 19, 2022.

An Assurance of Confidentiality (AoC) provides the highest level of protection for public health surveillance data. The NFR team drafted an AoC, which includes details regarding the protection of individual identifiers, as well as details on the mechanism for sharing de-identified data with external researchers through research data centers. Several layers of review were required, including review by the CDC Office of General Counsel, in which an attorney carefully considered the language in the Firefighter Cancer Registry Act of 2018. After several back-and-forth reviews and edits, and some changes to the consent form, they obtained final approval on July 25, 2022.

With the advances made over the last year, the draft protocol from October 29, 2020 needed updating. The NFR team has made all the required updates and posted the new protocol on the NFRS website. This new protocol incorporates changes to the consent form, user profile, and enrollment questionnaire. It includes updated security and compliance information. It includes updated data sharing details as reflected in the AoC, and it includes clear communications materials to date.

To elevate all this hard work, it's essential that the NFR team develop and foster relationships with firefighters. They have reached out to several fire departments across eight states, who have expressed interest in helping test the NFR web portal once it goes to the production site. They've also attended and/or presented at numerous conferences over the last year, including the FDIC, the largest firefighter conference in the country. They set up their very first NFR exhibit booth at this conference, and also had a booth at the Fire Rescue International conference in San Antonio just a few weeks ago.

The NFR team fully recognizes the importance of developing materials to promote the NFR to firefighters of all different backgrounds. Early last year, they conducted focus groups with several diverse groups of firefighters. These focus groups were intended to identify messages that resonated with the fire service, and resulted in some recommended messages, including: "Stand together. Join the NFR."; "Answer the call. Join your brothers and sisters in a new effort to understand and reduce cancer."; and "Let's leave the fire service better than we found it. Join the NFR." Images were also tested with focus groups, which helps the communications team in collecting photos and other images for the communications products, including from Fairfax Fire Department in Virginia, and Hanover Park Fire Department in Illinois.

Some of the products that have been produced so far include a quarterly newsletter, which has almost 1,500 subscribers; an NFR brochure; a fact sheet; two explanatory videos; conference booth materials and handouts including very popular carabiners with the NFR logo. Other products in development including social media images and messages, posters and ads, a roll call announcement, and videos including “How will the NFR protect my data” and a video including firefighter testimonials.

The ultimate goal of the NFR is to reduce cancer risk in firefighters. The team has a long history of working with Underwriters’ Laboratories Fire Safety Research Institute, which manages the Fire Safety Academy (FSA). FSA provides free evidence-based training to firefighters, and currently has over 70,000 accounts and growing. The NFR team recently provided presentation content for an FSA course on comprehensive cancer prevention strategies for the fire service. The course is focused on exposure control measures available in the fire service based on the hierarchy of controls. The course also includes a module at the end about the NFR. The NFR team believes that firefighters who are likely to take this course may also be interested in the NFR. They also hope to do even more with the FSA and other firefighter training academies around the country.

Dr. Fent concluded by asking if there were any questions, but the board members did not have any. Dr. LeMasters complimented the NFR team on their progress.

Demonstration of NFR Enrollment System

Dr. Fent introduced Alex Mayer, who worked diligently with the development team in building and testing the web portal. Mr. Mayer presented a recording of the demo. The team chose to make a recording just in case they had connection difficulties. Mr. Mayer also had the live web portal open and could access that to answer questions from NFRS members.

Mr. Mayer let the group know that he would pause periodically to answer questions. He started with a brief overview of the landing page. This is where firefighters will be taken when they go to nfr.cdc.gov. The URL up at the top of the page is actually nfrtest.cdc.gov, their test environment. This isn't the final production environment where firefighters will be when they enroll in the system. However, everything will look and feel the same in a production environment.

On the landing page, there are some directions for the firefighters at the top after the welcome message, where they need to confirm their eligibility and then select Login.gov to create an account or sign in. A user must agree that they're at least 18 years of age, and they also must agree that they have served or are currently serving as a U.S. firefighter. After checking second checkbox, the “Next” button is now clickable. If the check box is unselected, the “Next” button is grayed out. That functionality is built in to keep the user moving in the right direction. The landing page also has a link to the NFR webpage. If a firefighter comes to the web portal and isn't quite sure they want to enroll, they can select this link and go to the web page to learn more about the NFR.

Next, the user will through to Login.gov and start the registration process. The Login.gov system has a test, or sandbox environment, as well and that is what was shown in this demonstration. The Login.gov landing page for users will have less text and look more official. There are fields for email address and password, and

there'll also be a sign-in for firefighters that have already created a Login.gov account. There will also be a Create an Account option for those who haven't. Mr. Mayer expects that the majority of firefighters will not have a Login.gov account.

Mr. Mayer created an account to show the process. Users put in their email and then select their email language preference and agree to the Login.gov rules of use. Login.gov will then send an email to their email address to authenticate. He moved over to his inbox to confirm his email address, and then was redirected back to Login.gov here where he created a password.

Next, users select an authentication method, and the NFR team recommends using the text or voice message. This is based on trial and error, after creating a few accounts with testers in the past. If users select text or voice message, they'll get a six-digit one-time code to their phone, and they will be able to enter that code into the webpage to continue. Usually, it takes five to ten seconds for the code to come through. After submitting the code into the web form, the page shows the phone was successfully added to the account as an authentication method. Users can also choose to add another authentication method, but it's not required.

This marked the end of the Login.gov process, so Mr. Mayer paused for questions.

Dr. LeMasters asked for clarification about the text authentication process and Mr. Mayer explained that it was a one-time code, separate from the password that is used every time. Dr. LeMasters also commented that there were many options for authentication and that sometimes too many choices can be as confusing as not enough choices. Users may experience anxiety when choosing a method of authentication.

Mr. Mayer said there were five or six options that Login.gov offers out of the box. He was not sure if the NFR team had control over which of those options are offered. They have been encouraging testers to use the text message authenticator.

Dr. Fent added that one of the authentication methods is face ID or other biometrics. For many people who have that feature on their phones, that's probably going to be one of the easier options. Fortunately and unfortunately, Login.gov is run by the General Services Administration, so the NFR team doesn't have much control over how it looks for participants. However, the NFR team can provide helpful language to guide users. He felt a lot of this is going to come down to explaining it to the firefighter so that they don't get tripped up in the login process.

Dr. Materna shared that she had a similar reaction when she saw that that long screen with all the different methods and then heard that the NFR team recommends text authentication. This is probably one of the more common forms that you have to do with your bank and everything else. But it sounds like that screen isn't changeable. She suggested putting the recommended method on top or making it easy to choose so users don't have to read all the rest of them. She acknowledged that her idea may not be possible.

Dr. Fent pointed out that the problem is text message is not as secure as biometrics. Login.gov would probably say their preferred option is using face ID or fingerprint. He wasn't sure that that the NFR team can put text directing users to use text messaging on the Login.gov landing page, but when they work with fire

departments, they could let firefighters know that it's probably the easiest one to do. Dr. Fent continued that they have done some testing with actual firefighters and some of the older firefighters in particular have gotten tripped up on the Login.gov process. NIOSH could provide a job aid to walk them through the process, and then as more and more firefighters actually do this, they'll get over that learning curve and be able to help each other. He agreed that it is kind of confusing, but it's how Login.gov works.

Mr. Mayer continued the demonstration, back at the NFR web portal. A popup box lets users know that to enroll, they'll have to complete the consent form, the user profile, and the questionnaire. Then he continued and opened the web portal.

The user is taken to the landing page for the consent form. There is a progress bar on the left showing the informed consent, user profile, and the questionnaire. They also have the OMB language posted at the top, and on the right, there is a little question mark where a user can click and reach out to the helpdesk, either by phone or email, if they're interested in talking to somebody about a question they may have about the system.

The informed consent uses the standard NIOSH template, and at the bottom there are two options for firefighters on whether they want to participate. The first is "You understand what is required and agree to participate in the NFR," and the second is that "You do not agree to participate in the NFR." If the user says they don't want to participate, the page will ask them if they'd like to learn more about the NFR, and then a popup box goes over some of the information on why it would be great if they would participate. If they want to learn more information, the page has a link to a video where they can learn more. If the user agrees to participate, they go ahead and put their first and last name in.

Users also have the option to receive an email copy of the NFR informed consent, and for that the email used for Login.gov is automatically populated. Users also have the option to download the consent form to their local drive. Then users click the "Begin" button to move on to the user profile.

The user profile page is similar to the informed consent page. It has the same progress bar. The question mark is still present, along with the OMB language. Here, first and last name was taken from the informed consent and brought over. Users can also put in information if they have another name or if they're known by another name. Then they enter current residential address and move down to the email. The email address, again, was taken from the Login.gov email on file. The system asks users, "Would you like to provide another email address that would be used to contact you if we cannot reach you at this primary email address?"

If the user is interested in receiving notifications about the NFR, they can select their preferred method, email or text messages. The system has an email verification as well the ability to opt in for text messages. For text messages, similar to Login.gov, users will get a one-time code to verify their number.

Users save and continue, and then move on to the work information aspect of the user profile. This asks about their current work status in the fire service. Users can check multiple options, for example if they were a full-time firefighter and also a volunteer. The user is able to review their information for accuracy before submitting the user profile. At this time, the user can look back make sure everything looks correct. If they notice any issues, they can click the "Go Back" button and go back.

Dr. LeMasters asked to go back to the informed consent page. She pointed out the font is small, and difficult for an older person like herself to read. She recommended making the font bigger for older firefighters. It would also help to use darker font.

She noticed that the page required a lot of reading, and in the studies she's done, men, and older men in particular, do not want to read that much. Many people don't want to read that much. She asked whether it would be possible to break it down into pieces or whether it had to be presented in one chunk.

Mr. Mayer responded that it needs to be in one chunk to meet the requirements of the NIOSH informed consent template. However, they could look at the font size and other things to make it easier to read. He added that they did have to make this compatible for cell phones, tablets, and desktops. Maybe on the desktop it looks a little smaller, but it might be a lot bigger on a phone or tablet.

Dr. Fent pointed out that users can also use the zoom feature on their browser to make the font bigger.

Dr. Materna added that it may also be blurrier because the group is looking at a video that's paused rather than the actual page.

Mr. Mayer demonstrated that if a user has their desktop zoom set to a higher zoom number—150 or 125—it might be easier to read.

Dr. LeMasters commented that it would be much, much better. If users are going to get all this verbiage to begin with, right off the bat, at least you want to make it not a strain to read it.

Dr. Fent added that the idea behind the “key information” section is that it's the most important takeaway of the consent form. The NFR team would like users to read the whole thing but, if they could at least read and digest the key information section, that would go a long way.

Dr. LeMasters asked if the text of the consent form was set in stone.

Dr. Fent said it was definitely in stone. They've had many back-and-forth reviews on the consent form.

Dr. LeMasters suggested in that case to make the font size more reasonable. Users may not think about adjusting their own font to make it bigger or smaller, or if they're on their phone that's harder to do.

Dr. Fent noted that on the phone it actually will be a larger font. It should be automatic, unless the user has a really tiny phone. It's going to scale larger on the phone. It's going to look different on the phone because, for example, you won't see the progress bar. Users will just see the text and be able to scroll through on the phone.

Dr. LeMasters then suggested making the progress bar on the left smaller.

Dr. Materna agreed and suggested that if the progress bar was smaller the paragraphs wouldn't look so big.

Dr. Stagnaro suggested adding an infographic or a picture so it wouldn't be a lot of words just screaming at the reader. Firefighters love pictures.

Dr. Materna built on that idea, saying the NFR team could add little pictures in the progress bar underneath each of the steps, just tiny pictures for visual interest.

Dr. LeMasters noticed that **Mr. Loudermilk** had put a comment in the chat that font size is dependent on a person's computer settings.

Dr. Fent explained that Mr. Loudermilk is the NIOSH IT director. He agreed that yes, some of the scalability is, unfortunately, out of their control because it's dependent on the user's browser and computer settings. However, he felt a lot of this comes down to communication. Similar to Login.gov, the NFR team is going to have to do a bit of messaging and make sure they can clarify some of those issues when they encounter them.

They are also planning to do testing of the system once it's live, with actual firefighters. At that time, the NFR team will hear directly from firefighters about some of these roadblocks that they might encounter and can develop materials to help them.

Dr LeMasters noted that someone asked in the chat whether this has to meet 508 accessibility requirements.

Dr. Fent said yes, it does have to meet 508 requirements. The NFR team has done initial testing, and it's meeting a lot of the requirements but there's a little bit more work to do. One of the things that they're looking at doing is providing a service for people with a visual disability, where they could call somebody who would help register them over the phone. That's not going to be the main way for firefighters to enroll though. The NFR team doesn't want it to be an option for everybody, but for people with a disability, they're looking to make that an option.

Dr. LeMasters reiterated her suggestion to make the font darker so it would be easier to read.

Mr. Mayer continued with the demonstration with the enrollment questionnaire. This part is set up similarly to the first two pages (the informed consent and user profile). The question mark up is still at the top right, but the progress bar has been updated to add the different sections of the questionnaire. And there are some options: another banner looking at their user profile, if they want to update information, the frequently asked questions if they have any questions about the project, and they can also log out.

First is the demographics section. The only required fields in the enrollment questionnaire are birth date and sex assigned at birth. The social security language is further down. It's important to capture the last four digits. The system has some information for the firefighter, explaining why it's so important. There's also a little "More Information" bubble that they can click with more information on why social security numbers are so important.

After the user submits that first page, there's a popup box letting them know that after they submit responses in the enrollment questionnaire, changes cannot be made. Once they hit save and continue, they cannot go back and change questions that have already been answered. However, they can go back and answer unfinished questions.

Next, is the work and exposure section. One question is about the total amount of time you have worked in the fire service. Next, is what year you first start working as a firefighter, and how many fire departments. The system prompts the user to provide more details about their time in these departments by creating a record for each one. It instructs the user to start with the most recent department and end with the first department they worked for. Users start typing and it provides suggested matches. The system has about 27,000 fire departments in a database for this search function, and that list was cross-referenced by data provided by the U.S. Fire Administration and National Fire Protection Association.

Fire department information is now populated. The system asks for the approximate year they started, and then users either check a box saying they're currently working in that position or enter in the year they stopped working in that position. The reason users are asked this twice is if firefighters are promoted during their time in a position. If a person changed roles, the NFR team may want to capture that information, and what the different exposures might be for these different positions.

Next, is a list of fires and hazmat incidents; users check all that apply. For each option selected, users are asked to estimate the average number of responses in each type, and it's per-year. When they hit the save button, a pop up will inform users that once they hit save, they cannot make any changes. At that point, users can go back and look at all the information that they entered, make sure everything looks right, and then save the record. Now that information has been logged to the database and it is saved.

This process is repeated for each fire department. At the end, if the user has any other departments to add, if they forgot something, they could also click the "Create Record" button and input more information about other departments they've worked at.

Mr. Mayer then paused for questions.

Dr. LeMasters asked if everybody knew their employee ID. Is it like a social security number for firefighters?

Dr. Fent replied that it depends on the department. During pilot testing several of the firefighters did not know their employee ID. But in some career departments, they will. Nearly all questions are an optional field but if it's possible to capture that data, the NFR team would love to have it because it will help with linkages, especially linking to incident records from the fire department.

Dr. LeMasters suggested advertising to firefighters that it would be helpful to know your employee ID and dates of working at the various stations before starting enrollment.

Dr. Fent said that this actually came up when they were working on the Fire Safety Academy course. There's a module within that course on the NFR. Part of that is to give people a heads-up, like these are some of the questions you're going to see so if you can gather that information ahead of time, it'll help you walk through this process. The more that the NFR team can do that, especially with fire academies or fire departments that are part of the targeted enrollment, the more it will help the participants not get tripped up.

Mr. Mayer added that they plan to add something to the NFR web page as well in the future. If people come to the web page to learn more about the NFR, they can read that during enrollment, it would help to have your work history and your employee ID readily available.

Dr. LeMasters added that in her studies, if a firefighter didn't know the exact date, she would encourage them to give their best guess. She noticed that the screen did say approximate date, and that was good. But going further and saying your best guess would be helpful. She asked where they might be able to put a note about best guess. It's preferable to have a best guess over blank fields.

Mr. Mayer thought they might be able to add a little question mark or something next to that question and it would be a popup. If someone's like, "I don't remember exactly," they can click that and see oh, okay, they just want the best guess.

Ms. Wilson commented on the ID number. She didn't think giving a firefighter ID number is a hard thing to do. Most of the time, if people are still getting paystubs or they have to go online to put in their city hours or to put down how much time that they have to get paid for, or time that they've probably used on the volunteer side, the numbers are marked on most of the things that you are connecting yourself to. She felt that it would definitely help if you're dealing with a particular department, to use their registration number or their ID number, to be able to connect with them. It's not a hard thing for firefighters to get.

Mr. Mayer thanked Ms. Wilson for her comments. He reiterated that the NFR team must effectively communicate with the firefighters before they come to enroll that they might need that number.

A **member of the public** interjected with a comment but was notified that this time was for the board members to discuss and provide advice to NIOSH. If they wanted to provide comment, they could sign up for one of the three public comment slots. The person chose not to.

Dr. Fent mention that that the job history question was the hardest one to design because firefighters may have multiple different jobs in the same department, or may have worked for several departments. The NFR team tried to do the best they could, but it is going to be the most difficult question on the whole questionnaire.

Mr. Mayer added that the longer a person has worked as a firefighter or the more they've jumped around to different fire departments, the longer it may take to complete the signup for the NFR. For newer firefighters, it may be a lot quicker. For instance, he only put in two departments in the demonstration, just to make sure he was making good use of time.

Mr. Mayer continued the demonstration, picking up in work history. The next question is, "Have you implemented the following practices on a regular basis (most of the time), at any point in your career?" The page shows a list of practices and the option to select yes, no, or N/A for each one. If the user selects yes, they are then asked what year they started regularly doing this practice, or "I've always done this." The practices include:

- Wear SCBA during interior fire attack of a structural/industrial fire
- Wear SCBA during external fire attack of a structural/industrial fire
- Wear SCBA or an air purifying respirator with multi-chemical canister/cartridge during overhaul of a structural/industrial fire
- Wear SCBA or an air purifying respirator with multi-chemical canister/cartridge during vehicle fires

- Wear SCBA, an air purifying respirator with multi-chemical canister/cartridge, or filtering facepiece respirator (example, N95 mask) during brush or vegetation fires
- Wear air purifying respirator with multi-chemical canister/cartridge or filtering facepiece respirator during wildland fire suppression
- Wear SCBA, air purifying respirator with multi-chemical canister/cartridge, or filtering facepiece respiratory (example, N95 mask) while performing or attending fire investigations
- Wear SCBA or air purifying respirator with multi-chemical canister or cartridge when responding to wildland-urban interface fires
- Wear a protective hood during interior fire response
- Conduct preliminary exposure reduction of my PPE (on-scene gross decon of turnout gear)
- Keep used PPE out of passenger compartment of vehicle
- Wash/wipe down equipment (radio, SCBA, tools, etc)
- Wash or clean my hands on-scene before taking in food or drink lean your exposed skin on-scene after a fire response (use skin wipes or other cleansing method)
- Prioritize showering as quickly as possible following fire response (for example, “shower within the hour”)
- Have hood laundered after every or almost every fire response
 - If the answer is no, the system asks how often they launder their hood
- Have turnout gear or other fire-response clothing laundered after every or almost every fire response
 - If the answer is no, the system asks how often they launder their gear

That is the end of this page on work history, so the user will save and submit that information and move on.

The next page starts with a question on service in the armed forces. If the user says yes, there are two additional questions, one on whether they are currently serving and one on if they’ve ever served in a combat war zone. Next, is a question about holding another job while also working in the fire service. If the user says yes, additional questions pop up. It asks, “For your job that overlapped with your fire service career the longest, what kind of work did you do?” The user types in an answer. Then it asks, “What kind of business or industry did you work in?” and again the user types in an answer. Next, it asks what year they started the job and whether they are currently employed in that job.

The next question is “Over your lifetime, have you ever held a non-firefighting job for at least 100 days where you were routinely exposed to smoke, exhaust, or chemicals?” The answer choices are yes, no, or unsure.

Then the user moves on to the next subsection within work exposure, where they are asked to answer a group of questions based on their current or most recent assignment.

- What is your typical shift configuration? (list of options)
- On average, how many calls do you go on per shift? (drop down menu with numbers)
- On average, how many hours of uninterrupted sleep do you get on duty? (drop down menu with numbers)

- On average, how many hours of uninterrupted sleep do you get when not on duty? (drop down menu with numbers)
- Throughout your entire career, have you ever used Aqueous Film Forming Foam (AFFF)? (yes, no or N/A)
 - If yes, there's a follow up question about how many times they've used it.
- Throughout your career, have you ever responded to any major events that you would consider unusual in duration or intensity? (yes, no, unsure)
 - If the user says yes, this function is similar to the work history question where the user has an ability to create a record. To complete a record, the user chooses from a list of event types, then enters how long the event was in days or hours. The final question is whether this was a named event.

The next page is the start of health history section of the enrollment questionnaire. The first question is "How often do you get an NFPA [National Fire Protection Association] occupational or physical exam?", with several answer choices. Second is "How often do you see a healthcare provider for a routine checkup?" again with several answer choices. Then the user selects save and continue.

The next page is the start of a section of questions on cancer. Mr. Mayer mentioned that there are fewer questions in this demonstration because he put age 31 in at the beginning. There are additional cancer screening questions for older individuals, and for females and males specifically. This is why age and sex assigned at birth are required questions earlier in the questionnaire.

In this demonstration, the page starts with "Have you ever been diagnosed with cancer?" If the user says yes, the system brings up a follow-up question about which type of cancer. There is a long list of options and users are asked to choose the primary site, but they can check all that apply if they've had multiple cancers. For each type of cancer that is selected, users are asked to enter their age at diagnosis and which state they were diagnosed in.

The next question is about the comorbidities that an individual may face or may have. This section has a list of conditions like diabetes and high blood pressure, and users select yes or no for each one.

Next, are a series of questions:

- Have you ever experienced an injury resulting in three or more days away from work? (yes or no)
- Have you ever experienced a smoke inhalation injury resulting in the need for medical care? (yes or no)
- Do you have any biological children who have a history of cancer? (yes, no, I do not have any biological children, or unsure if biological children have a history of cancer)
- Do you have a family history of cancer among immediate biological (blood) relatives? (yes, no, or unsure if I have a family history of cancer)
 - If yes, a long list of types of cancers appear and users are asked to select all that apply.

And again, for every page, users can review the information before they move on to the next page but once they select “save and continue,” the information is input into the database and cannot be edited.

The next page has lifestyle questions, which is the last section of the questionnaire. The NFR team included lifestyle behaviors because cancer or other health conditions may be related to a combination of work events and lifestyle choices. This section has questions about physical activity in a typical week, weight or strength training in a typical week, and sunburn history.

Next, is a section on current and past uses for tobacco products. This is a series of questions about current and past smoking of cigarettes; use of smokeless tobacco such as chewing tobacco, snuff or dip; cigars; pipes; and e-vape, vape or e-cigs. For any of these the user says yes to, there are additional questions about the age they started, years used, current and former use.

Next, is a section on alcohol use. Users are asked: in the past 30 days, how many days did you have at least one drink of alcohol—one drink is equivalent to a 12 oz. beer, a 5 oz. glass of a wine, or a shot of liquor. And during those days, how many drinks on average did they consume? They’ll choose a number. And considering all types, how many times did they drink five or more drinks? And again, they’ll choose a number.

And then the last question is an opportunity to give feedback. It’s a free text field for individuals to share anything they would like to about the NFR or their exposure, or anything else.

There’s a thank you message down at the bottom and the user can select the “Submit” button. If they do have questions, they can email the NFR mailbox, which is displayed in large font. When the user selects the “Submit” button, the system provides another notice that if they select “Submit” it will complete the registration process. If they select “Go Back,” they can still make changes to questions on the last page. Once the user submits, they receive another thank you for completing the NRF questionnaire.

Mr. Brimhall had a comment about filling this out as a wildland firefighter. On one page of the enrollment there as a question about wildland versus wildland/urban interface, and then there was a question on a subsequent page about have you gone to a wildland fire, have you gone to a vegetation fire. He thinks this will cause a little bit of confusion for people that don’t necessarily work in that discipline or understand how it applies to suburbia, because isn't the wildland/urban interface suburbia? He suggested spelling out the difference between wildland and vegetation fires for the major event question. Maybe in Cincinnati the career department’s not going to go to any sort of wildland fire but they could go to vegetation fires during the year. Even in New York City you can get a vegetation fire and some of the parks are big enough. He didn’t know that question was being asked in the right way.

Mr. Mayer thanked Mr. Brimhall for that feedback. The NFR team did run this by wildland fire subject matter experts and people who are career structural firefighters, and this was the language agreed upon. That said, he did understand Mr. Brimhall’s point about differentiating between vegetation and wildland specifically for that major event question and thought it was something they could look at for a future version of the questionnaire.

Dr. Siegal added that it's complicated because one questionnaire, one enrollment system has the tricky task of enrolling firefighters from all over the country and all different subspecialties. There might be some slipups, especially when it comes to asking specific information from wildland versus career. She hopes that if there is some confusion, that it won't be too differential and it'll be across the board for firefighters. Most structural firefighters will know what a vegetation fire is. Some of the wildland fire experts the NFR team consulted with were comfortable with this language as well. But the team does acknowledge that there might be some imperfections but again, hopefully those imperfections won't be too differential across participants.

Mr. Mayer added that the NFR team is pilot testing this questionnaire with eight different fire departments including some wildland firefighters. They will get additional feedback on this over the next couple of months as well.

Dr. Fent wondered what Mr. Harbour thought about that language.

Mr. Harbour agreed with Dr. Siegal that the problem is that there are a million firefighters in America and maybe thirty, forty, fifty thousand—a very small subset of those—focused on wildland. For the organization he worked at for almost 50 years, the U.S. Forest Service, has over 10,000 firefighters, and they don't consider themselves a fire department. They don't do shift work. They don't have NFPA standard checkups. On the work and exposure portion of the questionnaire, he was scratching his head trying to figure out, at least for many of the federal and state folks that do wildland exclusively, how to work that because he fears they'll get to that portion of the questionnaire and think, "Well, I don't do shift work." And they'll cease the enrollment process. He's less concerned about definitions for wildland and vegetation further on in the questionnaire.

Dr. Fent agreed it was a challenge. When the NFR team was developing the questionnaire, they tried to make it applicable for all the different subspecialties. And they do have some logic built in. For wildland, participants say how many campaign fires they've been on, because it's a different situation. Fires last for weeks. For shift work, there's a response where you can say, "I don't work shifts." They tried to incorporate where you could still have answer options that work for the user's specific work environment.

At this point, the NFR is so close to launching that they can't change the question wording, but it's still valuable to know some potential roadblocks so that they can try to work on educating the fire service or coming up with job aids for different groups of firefighters. And they may want to do something like that for wildland.

Mr. Morrison asked whether it would be too hard to put in "not applicable" in some of these categories?

Dr. Fent said they had to be careful about it.

Mr. Mayer added that they do have not applicable as an option in that Question 15 with all the different interventions.

Dr. LeMasters asked whether the questionnaire needed overweight/obesity questions if it already includes height and weight.

Dr. Seigal responded that it's historical. It asks if you've ever had a diagnosis.

Mr. Morrison asked whether they would be calculating BMI, and **Dr. Siegal** confirmed they would.

Discussion of Enrollment System

Dr. Fent introduced a discussion question: What improvements should be considered to enhance the user experience of the enrollment system? He acknowledged that the group has covered some of this already with the comments provided. He opened an opportunity for additional comments.

Ms. Novicki encouraged those who have not spoken yet to share their thoughts.

Mr. Stagnaro suggesting using a QR codes in education pieces in addition to a link to the registration portal. This is especially valuable at trade shows, where attendees can scan the QR code and then go right into the registration process along with maybe some other educational pieces about it.

Dr. Fent agreed. For the conference exhibit booth, they have QR codes that are printed out. And one of the takeaways that the NFR team would like after launch is if they could get firefighters who are interested to scan that QR code and maybe set up an account at a minimum. And then the team could be there to help them with that Login.gov process and then if they go back to their hotel that night, it'll be easier for them to get back in and complete that questionnaire, which will take a bit longer.

Mr. Stagnaro pointed out that firefighters are not going back to the hotel room that night and logging into the NFR registry. But maybe the following week when they get back.

Dr. Fent said they'll take it. Because the other thing is once you set up an account, if you use your phone, most phones today will remember passwords if you have that option on your phone. You'll have that password and you won't forget it.

Mr. Morrison asked how many tablets they need to sign firefighters up at conferences? It takes 30 to 45 minutes for an individual to go through this.

Dr. Fent responded that they have 13 to 15 tablets right now that they can take out with them. At a lot of these conferences, everybody is so busy, it's unlikely firefighters are going to sit down and actually take the entire survey. Maybe motivated firefighters will, and the team can certainly help them with that. For many firefighters, it'll be that process of setting up the account and then later they can go through the enrollment process. And then again, if the team comes up with a job aid or something that to hand out, that's something firefighters can take back with them to wherever they live. Maybe they can tell their fire department. It probably depends on the meeting though. Some meetings are more training-oriented and they may have a devoted audience for a while and could get a lot of people registered that way.

Dr. LeMasters asked whether the NFR team could give out gifts for people who complete it, like a pair of safety glasses or a hard hat. Can you do that at NIOSH?

Dr. Fent replied that they can't do gifts for people at conferences and not everyone who enrolls, even if they enroll themselves online. It's an incentive. They can do raffles and things like that at conferences as long as everyone who visits the booth is able to enter. They would need to consult their ethics office.

Ms. Novicki pointed out that the NFR rollout and engaging firefighters would be discussed more after the break. For this particular question about the user experience, NFR members have suggested looking at font size, darkening the font, making the left sidebar a little bit smaller, and adding pictures. The group discussed having job aids specifically for wildland firefighters. Is there anything else about that user experience, that filling out the form, any thoughts about that to share?

Dr. LeMasters asked at the end when you're thanking them for participation, are you asking them to come back another year?

Dr. Fent responded that there is a thank you note at the very end and then when participants come back to the dashboard, it thanks them again, and they'll get a thank you email. And if they sign up for text messaging, they get a thank you text message too. They do plan on maintaining contact with firefighters periodically, over time, about every six months or so. They don't want firefighters to just never hear from them again. And as part of that follow-up, about a year later, the NFR team will have a follow-up questionnaire that's available. And that will be available to everybody. Firefighters will get an email or text message or both, saying hey, there's this follow-up questionnaire we would love for you to complete, and they will need to go sign back into the system at that time to complete that questionnaire.

Dr. LeMasters: And to be able to do that, they have to remember their password that they created.

Dr. Fent said that was correct, but if they forget their password, there is a way to reset it. That's where multi-factor authentication is really nice because you use your other authentication service like a text message to make sure that you are who you say you are, and then you'll be able to reset. It'll send a link to your email and you can reset your password with that link.

Mr. Mayer that he tried that recently and it was relatively painless. It was similar to the process for resetting a password for other accounts, like a bank.

Dr. LeMasters asked if they had considered a password that takes the last four digits of your phone number and the middle initial of your name. Something that is almost impossible to forget.

Mr. Mayer said that was an approach for firefighters to consider but NIOSH cannot provide feedback on what type of password they should use, from a security perspective. The users ultimately have to determine their own password.

Dr. Fent added that he strongly recommended using a password manager. But again, if they forget their password, they'll be able to reset it.

Mr. Morrison asked how easy it was to do on a mobile phone. A lot of firefighters would want to fill this out on their mobile phones. Does the system remember where you were the last time you filled it out? If you didn't complete it, will it take you to the place you left off?

Dr. Fent shared that when they did pilot testing with a local fire department in Ohio, about 80% used their phone. He agreed a lot of firefighters will use their phone. The portal functions pretty well on a mobile device, and in some ways it may be better than on computer. Certainly, the login process is better on a mobile device. And Mr. Morrison is correct that if a firefighter can't finish it, and they log out, when they log back in, it will take them where they left off. The team did think about that, and it's important because firefighters get calls or have other commitments. But yes, it'll work well on a mobile platform, on a tablet, or on a computer.

Mr. Morrison then asked if the system prompts participants to fill in blank questions before they move to the next section.

Mr. Mayer said the only questions where it does that are the two required questions: birth date and sex assigned at birth. That's due to the voluntary nature of the questionnaire and registry itself.

Dr. Fent added that if you go back, it will show you which questions have not been answered. Because they'll still be answerable questions, if you will. But yes, because it's optional, the system is not necessarily saying "Hey, you forgot these questions," because the user may have decided not to answer them.

Dr. LeMasters commented that the team has really worked on this questionnaire to make it smooth and relatively easy, and have streamlined it.

Mr. Morrison agreed. The last couple of pages in the demonstration were really straightforward. It was very, very easy to get through. The pace of it seemed to be just about right where you'd want to get through.

Mr. Mayer said it was great to hear. It took about 30 minutes to go through the demonstration, and that's about how long they expect for it to take a firefighter to complete this. Anywhere from 30 to 45 minutes, 45 minutes being where a firefighter puts in a more comprehensive work history.

Dr. Materna put in the chat that she learned from literacy experts that big blocks of bold or outsize text are harder to read so the NFR team might want to make the font start out larger and look darker on the opening in the questionnaire. The enrollment site looks very nice and clear as far as how the questions and answers look, with good use of popups, reminders, etc.

Public Comment

There were no written or oral public comments.

Project Roll-out and Next Steps

Dr. Fent started by saying that for roll-out, the next step will be to get the web portal into production. The web portal application will be hosted at nfr.cdc.gov and have a soft launch this fall. The team will continue to do testing with firefighters all over the country who decide to enroll, who can be thought of as early

adopters. Eight departments from eight states are interested in helping with this testing. Any issues they encounter will be documented and addressed in a future release.

During the soft launch, they will slowly ramp up promotion with a big push in January. They've chose this approach for two reasons. Number one, January is Firefighter Cancer Awareness Month and number two, by slowly building the promotional campaign, they can control the traffic and make sure everything is running smoothly. This also allows for organic distribution across the fire service and it gives the team additional time to develop more communication materials and to coordinate with professional organizations, advocacy groups, and trade magazines, which are all in progress. In the next year the team will also start identifying and reaching out to fire departments to participate in the targeted enrollment.

Dr. Fent then shared the [NFR webpage](#) in development, which was published the following day (Sept 7, 2022). This is the main website to learn about the National Firefighter Registry. There will be a link to the web portal from this website when the portal is live. The NFR team reorganize this website to be more user friendly and to answer the big questions from firefighters.

The first page has the NFR logo. It talks about joining the Registry. Web visitors can sign up for updates and receive the NFR quarterly newsletter. Further down there are different boxes that cover about different topics and answer questions. Web visitors can also navigate to these from the left menu.

If you click "[About the NFR](#)", it will take you to a page that tells you a little bit more about what the NFR is: by joining, what you can help us to learn about cancer in the fire service; who can join; who's eligible, which is any firefighter, active or retired; when they hope to launch, which will be in the fall; and how your personal information will be kept confidential. But the piece that many firefighters will probably go to is this video called [National Firefighter Registry](#). Dr. Fent then played the 1:25 minute video, which describes the NFR and encourages firefighters to participate.

Returning to the main NFR webpage, if you select "[How the NFR Works](#)", the text walks through the steps of what it takes to register and how the information is going to be used—the link to state cancer registries, for example—and then how NIOSH is also interested in getting work history details. The page also includes a video [How does the NFR Work?](#), which Dr. Fent played. It's a bit longer, nearly 3 minutes, but is also more descriptive.

The NFR webpage also has a section devoted to "[Frequently Asked Questions](#)" and these accordion-open as you click them. These are common questions from firefighters and partners. The last page is "[Communication Materials](#)." Right now, it has the two videos and a brochure, but in the coming weeks, more materials will be added as they are cleared.

They have a foldable NFR brochure, which they've been handing out at conferences and providing to fire chiefs and other leadership at fire departments. It answers the big questions: what is the NFR and what do they hope to accomplish from it? They also have an NFR Fact Sheet. This is approved for handouts, so they've been handing it out at conferences, but are about to get a pub number. Once they do, they will post it on the website so anybody can download it and use it.

Mr. Mayer added that both the brochure and fact sheet have QR codes, like Mr. Stagnaro mentioned earlier. That's something they'll definitely try to make use of at conferences and at fire departments.

Dr. Fent agreed. Right now, the QR code links to the NFR website, but they'll have a version that links to the web portal once it launches.

Dr. Fent continued with the presentation, showing the quarterly newsletter. It keeps everybody updated on the NFR and, when the registry does launch, everybody on our email list will be the first to know that it's live.

They have other materials in development, including some artwork by Paul Combs. Paul is a famous fire service artist and he's going to be creating some additional artwork in the coming months. This art can be used in social media posts, or could be printed out as posters and hung up in fire departments. And then Paul has also offered to sign/autograph some of these and they could even auction some of these off at conferences.

The team is also developing palm cards to be handed out at conferences. These are very short and to the point, not a lot of verbiage. It's just basically, "Hey, this is out there, here's the QR code, go register when you have a chance." These cards will probably be one of the main giveaways at conferences moving forward. They are also working on a poster that could be used in full-page ads for fire service magazines, or as printed posters that fire departments could use.

There are also videos still in development. The first one is "How Will the NFR Protect My Data?" It's close to being finalized and approved. It'll be a short, one-minute video about data security. And they're also working on firefighter testimonial videos where respected fire service members say what the NFR means to them and why they believe it's important. They are also working with Chief Billy Goldfeder, who is actually the one that helped connect them to Loveland-Symmes Fire Department for pilot testing. Chief Goldfeder manages the "Secret List," which is an email with over 200,000 subscribers, and FirefighterCloseCalls.com. He's one of the respected leaders being interviewed for these videos. The NFR teams look forward to that coming out in the next month or so.

Dr. Fent also shared renderings of their conference exhibit booth materials. Their booth materials allow them to be flexible for any size booth space. They also have several interactive features that are available depending on the space, including a digital memorial or honor wall which allows anybody to pay tribute to somebody that they know who has battled or is battling cancer, a video that is on repeat about the NFR, tablets to sign up for the newsletter or sign up for the NFR when it launches, and QR codes that take people directly to the NFR website or web portal. They also have a step-and-repeat photo wall for the larger booth for social media if people want to take photos.

They have several upcoming conferences that they plan to have a presence at, and they'll have an exhibit booth at least a few of these. Dr. Fent will be presenting at the Urban Fire Forum, which is part of Metro Chiefs. They will have booths at the North American Fire Training Directors Conference and Firehouse Expo. The team is attending National Fallen Firefighter Foundation Life Safety Summit, U.S. Fire Administration meetings, iCHIEFS Symposium in the Sun, International Association of Fire Fighters, Wildland conferences,

Congressional Fire Services Institute, and others. The team is going to be at a lot of these meetings and conferences over the next year and really trying to build awareness and hopefully get firefighters to register.

They also have subcontracts with fire service experts who can connect with specific groups of firefighters and disseminate information, and also review materials as needed. These experts have connections to retirees, career and volunteer firefighters, fire investigators, and wildland firefighters. The NFR team only has four full-time employees, and they can't be at every meeting or event. They hope to utilize these contracts and other existing relationships where possible. They may also consider other contracts or agreements in the future, particularly those that can help them connect with hard-to-reach groups of firefighters.

Discussion of Roll-Out and Next Steps

Dr. Fent shared two discussion questions:

- What is the best way to get this information into the hands of the fire service?
- How can we [NIOSH] best build trust with departments to encourage participation in both open enrollment and targeted enrollment where records may be requested?

Mr. Morrison asked the group to give suggestions. Is there group, a demographic, or somewhere where the NFR needs to refocus their marketing? He also expressed his excitement about the NFR.

Mr. Frieders felt that their partnership [among the National Volunteer Fire Council, Firefighter Cancer Support Network, and International Association of Fire Fighters] for Firefighter Cancer Awareness Month will be prevalent as far as advertising and marketing goes. Collectively, they all really need to make a concerted effort to put this at laser focus in everybody's mind. It's going to be the first campaign for his organization and all the partner agencies. Their whole database is going to get relentless notifications about this. From his standpoint, this will be the widest reach, when everybody is focused on cancer for January. This is just one more opportunity for them to really enhance the preparedness and opportunities that exist with this program to really make it good for the fire service overall. He is 100 percent committed and really appreciates anybody's suggestions or input into adding content for Firefighter Cancer Awareness Month because this year it's going to be really, really good.

Mr. Morrison added that the IAFF has a lot of material on their firefighter cancer prevention month platform, but it's open to other organizations too. The IAFF is really hoping to get Dr. Fent or somebody from his team to do a webinar or to do something during the month of January to engage people.

The IAFF also just finished their convention in Ottawa. They're all excited about IARC. The number one discussion during that whole convention, the one that really reached its peak, was cancer. They asked the delegates for additional funding, so IAFF will have about a half-a-million dollars every year just for cancer research. They're doing a lot of work with universities; they're trying to do some science that they haven't done before. They are still looking at a lot of different projects on cancer.

Dr. Jahnke said she loved the idea of putting the NFR out with the Firefighter Cancer Awareness Month. She suggested that at the end of every single presentation that's done that month, have this be a "this is the

thing you can do." She also recommended reaching out to all the organizations. Women in Fire is aware of what's going on, but she thought it would help to have them push out information to their membership. Dr. Jahnke also suggested talking to the different affinity groups, since the NFR is trying to have higher representation for some groups than the overall fire service. Perhaps their leaders could film a little video saying, "Hey, do this, this is why we're doing it." She includes the NFR in pretty much every presentation she does. She talks about the fact that this is coming and tries to get people excited about it and then tasks them with going out and getting at least 20 other firefighter friends to do this as well.

Dr. Jahnke also felt it was important to be up front with everyone: "Hey, just so you know, the process is a little bit cumbersome up front. You're going to have to give the last four of your social, but it's very secure." She always brings that up as a point as she's talking just because she doesn't want anyone to be surprised and she thinks if we're honest about it up front, it will help. She offered to talk about the NFR to Women in Fire at her next call with them to see if their President would do a message out. She thought most of the groups would be interested or willing to do that.

Ms. Wilson wanted to ditto the last comments that were made. She also recommended reaching out to the affinity groups in order to get buy-in because sometimes—speaking for New York, where she works as a firefighter—if the message is given from the union, it may or may not be a message that is received in the best of lights, especially to the affinity groups of color and women. But the NFR team should definitely reach out to the groups where their members are, especially groups of color and women groups within the respective fire services, and have a conversation with them to be able to talk to their membership.

Ms. Wilson also asked if any of the people who are subcontracted to do events are people of color.

Dr. Fent said no, they don't have anybody of color. They are looking at trying to increase the diversity. The initial intent was to try to identify people who could cover some of the subspecialties like wildland and volunteer firefighters rather than demographic groups. But they are definitely interested in doing that for the different demographic groups as well.

Ms. Wilson said that it was important and especially for buy-in if you have a person of color or women that are part of the team to be able to give that message out, especially knowing that a lot of these conferences are predominantly White male. If NIOSH is trying to get that different perspective to come through to people of color or women that are attending, being able to see someone that looks like them that is giving the message and putting the message across may be something that's helping to be more sellable to that group that we're trying to reach.

She again recommended reaching out to the infinity groups. In New York it's very important to have those conversations with those groups in order to get the biggest bang for your buck, as opposed to letting the union give the message. It might be the same in different areas.

Dr. Fent asked Ms. Wilson if there were specific groups that she would recommend reaching out to?

Ms. Wilson said, yes, absolutely. She can identify all of them in New York and they might need to do that across the country. There's the International Association of Black Professional Firefighters, and she is the first

director of the northeast, so she can provide all of the names for the African American groups on the northeast region side.

The Hispanic Society has an international group as well. They can provide the chapters that they have across the country for the NFR team to reach out to. This may be necessary to reach the ground-workers and the membership and get buy-in because you might not get that if the department gives that message or if the union gives that message. You've got to go to these affinity group heads and get that.

Mr. Morrison expressed support for Ms. Wilson's points. He suggested, when reaching out to these affinity groups, have their leadership or leadership appointing somebody to give that message to their members so it's their board giving that message. It's powerful when head of their organization gives the message. That's going to be the best buy-in, in some cases, because there's a trust factor there.

Mr. Brimhall suggested that, in addition to the partner groups already mentioned, the NFR team consider going to Safety Officers Association, or other smaller meetings with a targeted attendance. Even if it's not worth a booth, the 90-second video could be shown. Or even at something like the FDIC conference, showing the video between presentations. The video could be shown two or three times as people mill in and mill out of a room. That might draw a lot of interest or at least give greater exposure.

Another suggestion was to look into some of the state-level conferences that have a good draw of people. Most states have some sort of a fire chiefs'-type conference or a regional one like New England Chiefs or Harrisburg Fire Show or something that has a pretty good draw across state lines. That would be a good place to have a kiosk. If a person is stuck standing in line to buy a hotdog or switching vendors or going on the floor to look at what's going on, if they see that, maybe it's going to draw their interest to pull it up on their phone right then and there or to look at it further down the road.

Dr. Fent agreed that they could get a bigger bang for their buck at some of the smaller meetings. The NFR team can't be everywhere, but they can send their video to a lot of these places or maybe the subcontractors who'll already be out there can go out and promote the NFR. They're going to try to do a little bit more with those smaller organizations.

And the other thing is that if the early adopters have a good experience, even if there are a few hiccups here or there, if they learn how to navigate through them and they believe in what they're doing, that will go a long way too, because they can go back to their departments or organizations and help other firefighters to enroll. That's something that they really want to try to take advantage of as much as they can.

Mr. Stagnaro agreed these are all really good opportunities. His organization, the National Fallen Firefighters Foundation (NFFF) has a large group of advocates that do training for line-of-duty death prevention programs. If there's messaging that NFFF can feed to them, this would be right up their alley. They love to provide this kind of thing if it's 15 minutes. For recruit schools - and of course everybody's competing for time in a class session - but if NFR can include a 30-minute session or during the lunch break, try get people to register and then have a facilitated process for people to do that. The NFFF could certainly commit to try to do some of those things as well.

Another idea for messaging is a joint statement from all the organizations that are supporting the NFR. If you get the International Association of Fire Chiefs, the IAFF, and other organizations coming together and say, "Hey, this is really important," it'll carry a lot of weight in being able to tell the fire service, "This is something you should do."

Dr. Fent said that on that note, they are looking at adding to the NFR website a section of organizations that are supporting the NFR. They already have several that have written position statements, they're supportive of it, and could list the organizations out. And then the U.S. Fire Administration has even provided some financial support. Having some of those organizations listed out with their logo adds some credibility. It might not be exactly what Mr. Stagnaro was talking about, but it is one way of doing that. But more importantly if they can get some of the leaders of these organizations to speak about the NFR, that will go even further.

One idea they have with FDIC is if they can get Indianapolis Fire Department to be one an early adopter, their chief always gives a talk at FDIC and so they could actually incorporate "Hey, our department was one of the first to enroll in the NFR and we encourage your department to do the same thing." And that's a very large audience at the opening session. Same thing with IAFF and the National Volunteer Fire Council, when their leaders get up and talk about this, I think it really resonates with their membership.

Mr. Morrison thought Bobby Halton would probably even carry some of that message too. He's a pretty big leader for the conference. This is a good suggestion.

Mr. Morrison followed up on Mr. Stagnaro's earlier point about recruit schools and probie [probationary firefighter] classes. Since the NFR is a large research project and will be going for years, is it important to have new firefighters enroll? Will getting new firefighters that are going to be around for 25 years help a project like this?

Dr. Seigel confirmed that it's helpful because a lot of these recruits are early in their career and they haven't been diagnosed with cancer. NIOSH can follow them prospectively. They're going to be a big component of this prospective cohort side of the analyses of the surveillance data. That being said, they also don't have much exposure to report, so it's going to be really important to engage participants over time to get updates on their exposure information and their work history throughout the course of their career.

Dr. Fent added that as part of the North American Fire Training Directors (NAFTD) meeting in a few weeks, that's something they want to talk to the training directors about. How can they encourage some of the new recruits to consider participating? The one advantage is if you're a new recruit, it's actually going to be even quicker to enroll. It shouldn't even take 30 minutes to get through the survey for a new recruit because they don't have the work history to report and that takes the longest time. It will probably be 15 or 20 minutes for somebody like that.

Dr. LeMasters asked, at these conferences where you are going to be attending, are you going to have laptops set up in a room where people can just go in then and register?

Dr. Fent said yes they have tablets and the plan is to always bring them.

Dr. LeMasters followed up and asked whether there will be a room where they know where to go and they can go in and somebody's there to help them in case they have a problem?

Dr. Fent said that the ability to get a room depends on the conference. If it's possible, it's an option they can explore.

Mr. Stagnaro built on Mr. Morrison's earlier point. The NAFTD will capture a lot of the volunteer groups, but another one would be the metro chiefs. And then as a recruit class is onboarding, if it's 20 minutes, say, "Take out your phones, go to this QR code, and go through this process," in trying to capture large groups at one time might be a way to do that.

Mr. Morrison said he was really impressed when he went to Indianapolis for the show and saw the NFR booth for the first time. For a bunch of rookies, the NFR team a really good job. They looked professional, and it was sharp. The booth really invited you into the exhibit and he was really impressed with that.

Dr. Fent thanked Mr. Morrison and added that they hope they're building awareness through the conferences. That's the idea right now because they're not actually registering. But they do have to be strategic. At FDIC they'll try to find an even better location for next year. For some of the conferences, it might be smaller booths, or they might be in the hallway. They're trying to do whatever they can to get the word out that this is available. And they'll try to go to as many conferences as they can, but there is a limit to where they can be and how often they can do it.

Mr. Morrison said they've got twofold here: a captive audience sometimes, but the prevention side of the program has to be part of it too. The NFR has a have a strong message it can give at the same time for about prevention. This is about registering for the Registry and getting it done, but is an opportunity to even tell firefighters that "You have a way of reducing these exposures too."

Dr. Jahnke wanted to add to her earlier comments. In January her organization is partnering with the Fire Department Safety Officers Association for a conference in St. Pete Beach, Florida. The First Responder Center of Excellence will be there. They have a daylong report out on Federal Emergency Management Agency (FEMA) grants, on what's been accomplished so far, called Nerdstock. The NFR can definitely be highlighted there. Dr. Jahnke also said she would ask the keynote speaker, Laurie Moore-Merrell, to highlight it during her speech. The Firefighter Cancer Support Network is part of that as well.

Dr. Materna made a suggestion for an additional way for the NFR team to build their network. Her health department works with the firefighter fatality investigation program in the NIOSH Division of Safety Research over in Morgantown. They might have lists of other groups and other contacts that could supplement this great list that the NFR team is already building.

Dr. Fent said it's something that they have started looking into. It's still a little bit immature, but definitely they will look into that.

Ms. Wilkinson confirmed that she presented to a local Fatality Assessment and Control Evaluation (FACE) group last month in Kentucky.

Mr. Morrison turned the discussion to the second question: How can NIOSH build trust with departments to encourage participation in both open enrollment and targeted enrollment where records—this is really important and "records" should be underlined—may be requested? Exposure records are probably the most important part of this research. And firefighters can report a lot of things that happen to them, but can they give us the exposure information? In the previous NIOSH study, going back to the records was the hardest thing for them to do. It took the most time, the most money.

He then invited Dr. Fent or Ms. Novicki to explain further.

Dr. Fent acknowledged that he didn't talk much about this in his updates. He explained that in the targeted cohort, fire departments will be identified and asked to voluntarily participate. The fire department, by participating, would be entering an agreement with NIOSH and would also provide incident records. There's some legwork that is involved to be able to get the incident records over to NIOSH.

It'll probably be a year or so before the NFR team actually starts to try to do this. And there are software vendors; they're called RMS management software vendors, that do this recordkeeping. And those software vendors can help so that all the burden is not on the department. It's also possible that NFR may be updated in the future, but that's even maybe several years down the road. They're trying to do what they can to make it easier on departments, but early on, unfortunately the departments will have to work with their IT folks to try to get NIOSH incident records and then they have to be able to match it back to the participants.

As Mr. Morrison said, this was one of the hardest things that they had to do with the NIOSH three-city study, and those were paper records. Now it's all electronic records and so hopefully that will help streamline the process. But the biggest concern of the NFR team is that they go to a fire department and say, "Hey, are you interested in the NFR?" and I think a lot of departments are going to say, "Yes, we're interested." And then when they mention the incident records, the fire department is going to say, "Well, wait a minute; that sounds like a lot of work." That's the biggest hurdle that the NFR team has to overcome with this ask.

Dr. Siegel added that more immediately than the incident records—which is going to be a very important component long term for building an exposure profile—but more immediately than that, for the targeted cohort the NFR team is going to be requesting rosters from fire departments in order to be able to do a more assertive approach to inviting firefighters to participate. Many of the same challenges they might see with incident records might exist with rosters, but there might also be, especially in the early days, barriers to being granted access to rosters due to a lack of trust. The receipt of rosters for sending individual invitations to register for the NFR is the more immediate concern in terms of reaching out to fire departments.

Mr. Morrison asked a clarifying question. Let's say a fire department says, "I don't want to give you my roster, but what I will do is I'll send out exactly what you would send out." Would that be the same or is that different?

Dr. Seigel said it was slightly different. It'll be helpful for departments that are unable or unwilling to provide rosters to do that. Absolutely, it'll help increase participation. But really the benefit of that targeted cohort is that the NFR team will be able to track participation rates. They can check against the roster, they can match that against the NFR database to see who signed up and calculate those participation rates to get indicator of

potential severity of biases or potential areas of growth and needed attention with our communication and outreach programs.

Mr. Morrison agreed this could have a little pushback. It really is going to be how you explain it to the department and the confidential part of the records and is there anything that they would have to run by their own legal people in their government system.

Mr. Brimhall shared that NIOSH might want to make sure that legal and IT departments of fire departments are okay with them using agency equipment to answer these questions and use their agency emails, because many places will tell you that you can only use agency IT equipment and agency emails for official usage. The other thing is to look at for the targeted cohort departments who's going through an International Standards Institute (ISO) audit or an audit for maybe the NFFF certificate of excellence. These departments will already have gone through that effort to create and gather their records and have them available to share. This would make the records more easily accessible to share with NIOSH.

Mr. Morrison said those were good suggestions. He added that they'll have to take some real thought in this. Departments might be timid on where is this information going to go. A lot of the questions in the survey are about what should be standard operating procedure, but departments might not be doing those things now or didn't do them in the past. Nobody wants to be shown up, so sometimes they'll protect themselves by saying, "Hey, we don't want to air our dirty laundry in here." The NFR team is going to have to convince them that this is not about outing a fire department—this information is only for X, it's not going to end up in a chart that says these are the best fire departments to work in as far as exposures go.

Dr. Siegal agreed. And to add on to that, NIOSH can't use any information for any of the NFR analyses that they publish unless those individuals consent to be part of it. The comprehensive rosters won't be used for any of the NFR analyses that they'll be doing with the participants—as opposed to the participants that consent and register and sign up and complete the profile and questionnaire.

Dr. Jahnke had two suggestions. The first was to work with the Center for Public Safety Excellence. Their departments tend to be progressive and used to handing over data so they might be well organized for that. The second is to reach out to fire departments who have expressed interest in the cohort study that Jeff Burgess started. There are a lot of departments that are interested in participating but there aren't funds to enroll them yet. NIOSH would have to be clear that it's different from the cohort, but it could be something that they could do and get involved in while they're waiting for funds to come through to register for the larger cohort.

Dr. Fent responded that he and Jeff Burgess have talked a few times about they can potentially collaborate. Firefighters that are participating in his cohort study may also be interested in the NFR and there are some advantages if they were to do both.

De LeMasters asked whether there would be any confusion with these two studies going on?

Dr. Fent answered yes, probably. Mr. Mayer is actually involved in that other study.

Mr. Mayer shared that they're working on a one-pager that goes over the similarities and differences between the FFCCS, the Fire Fighter Cancer Cohort Study, and the NFR, just for participants and for fire departments so they can understand what each study or project is offering.

Dr. Fent didn't think it would be a major issue, though, because the FFCCS is smaller. The NFR is much larger, 200,000 participants. But it is something that the NFR team needs to keep on their radar, certainly.

Dr. LeMasters asked how many participants the FFCCS study would enroll.

Mr. Mayer believed they have about 2000 enrolled thus far and they're hoping to enroll up to 10,000 over the next five or ten years. And for that study it's a little bit more involved where they're providing biological samples and doing yearly follow-up questionnaires.

Dr. LeMasters: But they're not linking to state cancer registries. So that is a key difference.

Mr. Mayer confirmed that is correct.

Mr. Morrison added that it's a little bit like the Framingham Heart Study. Over a period of time, going back to the same set participants. That's a different track. But it is kind of confusing. He suggested announcing the NFR as the biggest one and the FFCCs as the small one.

Dr. Fent believes that a lot of people that are participating in FFCCS will be interested in the NFR. It's just a matter of explaining the difference and a lot of them will take advantage of the NFR.

Summary and Wrap-Up, Future Agenda Items, Meeting Dates, Closing Remarks

Ms. Novicki thanked the departing members of the committee, starting with co-chairs Mr. Morrison and Dr. LeMasters. **Dr. Fent** expressed his gratitude for their leadership and input into the NFR. **Dr. LeMasters** and **Mr. Morrison** each reflected on their time on the subcommittee and the importance of this topic.

Ms. Novicki next thanked departing members Mr. Frieders, Mr. McQueen, and Ms. Wilson. **Dr. Fent** thanked each of them personally and highlighted their contributions.

Ms. Novicki covered next steps. The next full BSC meeting will be October 4, 2022 and as part of the procedural requirements, Dr. LeMasters, Mr. Morrison, and Dr. Fent will share about this meeting and the Subcommittee's recommendations. The BSC members will have the opportunity to provide additional input. From there NFR team will move forward with the rollout and incorporate these ideas.

The next meeting will be sometime in 2023. These meeting are timed with NFR decision points so that the advice can be as useful as possible. That's why the meeting dates have shifted a little bit over the years. The subcommittee will come back together in 2023. The topics are undecided but may include the rollout/communications and future surveys.

Glossary

Abbreviation	Definition
AoC	Assurance of Confidentiality
BSC	Board of Scientific Counselors
FACA	Federal Advisory Committee Act
FACE	Fatality Assessment and Control Evaluation
FDIC	Formerly Fire Department Instructors Conference, now known as FDIC
FEMA	Federal Emergency Management Agency
FFCCS	Fire Fighter Cancer Cohort Study
FSA	Fire Safety Academy
IAFF	International Association of Fire Fighters
IARC	International Agency for Research on Cancer
ISO	International Standards Organization
NAFTD	North American Fire Training Directors
NFFF	National Fallen Firefighters Foundation
NFPA	National Fire Protection Association
NFR	National Firefighter Registry
NFRS	National Firefighter Registry Subcommittee
NIOSH	National Institute for Occupational Safety and Health
OMB	Office of Management and Budget

Certification Statement

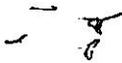
I hereby certify that, to the best of my knowledge and ability, the foregoing minutes of the September 6, 2022, meeting of the National Firefighter Registry Subcommittee of the NIOSH Board of Scientific Counselors, CDC are accurate and complete.

Grace LeMasters
Name

10-11-22
Date

Dr. Grace LeMasters

Co-Chair, National Firefighter Registry Subcommittee of the NIOSH Board of Scientific Counselors



Certification Statement

I hereby certify that, to the best of my knowledge and ability, the foregoing minutes of the September 6, 2022, meeting of the National Firefighter Registry Subcommittee of the NIOSH Board of Scientific Counselors, CDC are accurate and complete.

Mr. Patrick Morrison

Co-Chair, National Firefighter Registry Subcommittee of the NIOSH Board of Scientific Counselors