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THE US DEPARTMENT OF HEALTH AND HUMAN SERVICES  
CENTERS FOR DISEASE CONTROL AND PREVENTION

NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY AND  
HEALTH (NIOSH)

BOARD OF SCIENTIFIC COUNSELORS (BSC)  
NATIONAL FIREFIGHTER REGSITRY SUBCOMMITTEE

FOURTH MEETING  
VIRTUAL ON ZOOM, OPEN TO THE PUBLIC  
AUGUST 13, 2021

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## Summary Proceedings

The Fourth meeting of the National Institute for Occupational Safety and Health Board of Scientific Counselors (BSC) National Firefighter Registry (NFRS) Subcommittee Meeting was convened on Friday, August 13, 2021 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

Chuck Bushey - Member

Eric Crafter

Dennis Deapen, DrPH – Member

Kenneth R. Fent, PhD

Bryan Frieders - Member

Sara Jahnke, PhD - Member

Betsy Kohler - Member

Grace LeMasters, PhD

Mike Loudermilk

Barbara Materna, PhD - Member

Richard Miller - Member

Emily Novicki – Designated Federal Officer

Steven Moffatt, DrPH - Member

Patrick Morrison - Member

Brian McQueen - Member

Miriam Siegel, DrPH

Donna Spillane

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 Daylight Time (EDT) on Friday, August 13, 2021. A roll call of all BSC members confirmed that a quorum was present. The roll was also called following each break and lunch to ensure that quorum was maintained. Quorum was maintained throughout the day. A list of meetings is appended to the end of this document as attachment A. No conflicts of interest (COIs) 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 her Co-chair, Mr. Patrick Morrison. She stated there were two presentations on the agenda and asked that questions be held until the end of the presentation. Mr. Morrison explained that the most critical thing to during the meeting was to really listen closely to the presentations and try to understand the process needed to get firefighters registered and to be able to provide feedback to NIOSH to help them make the best decision to get the registry up and running.

## Overview of Project Background and Status

**Dr. Kenny Fent** gave a brief update of the progress that has been made over the last year. He stated that the NFR came about through an act of legislation, the Firefighter Cancer Registry Act of 2018, and that the Act mandated that CDC/NIOSH develop and maintain a voluntary registry of firefighters to collect relevant health and occupational information for purposes of determining cancer incidence. So, the goal of the NFR is to track cancer and risk factors over time, to better understand the link between workplace exposures and cancer.

Dr. Fent also said that since we last met, we have established our mission and vision statements and that our vision really is focused on getting the data and findings into the hands of the Fire Service and others, to help them reduce cancer risk among firefighters. But of course, we have got to get this up and running. He also stated that our protocol, which was developed with input and guidance from the NFR Subcommittee, provided our overarching objectives for this project, which includes collecting self-reported information on workplace and other factors through an online portal; obtaining records from fire departments or agencies to track trends and patterns of exposure; and linking with health information databases, which includes state cancer registries and the National Death Index, to monitor cancers and death.

Dr. Fent also mentioned the recently approved logo and drew attention to the lavender ribbon on the helmet. He said that the color of ribbon denotes all types of cancer. He further stated how important it is to note that all firefighters, not just those with cancer, will be strongly encouraged to join the NFR. The NFR is more of an exposure registry than a cancer registry and it is essential that we get many firefighters, with and without cancer, to register if we want to understand the differences between firefighters who do and do not develop cancer. Also, firefighters' participation in the NFR is entirely voluntary, but we do hope to enroll 200,000 firefighters or more, and with a recruitment emphasis on women, minorities, and volunteer

firefighters that are specifically called out in the Act. We are also interested in various subspecialties of the Fire Service such as instructors, wildland firefighters and fire investigators.

There will be two enrollment routes that are part of the NFR. The Open Cohort will be a non-probability sample in which any firefighter, active, former or retired would be eligible. This enrollment route is beneficial for recruiting a large and diverse sample of firefighters, but it may not be generalizable.

The Targeted Cohort will be a prospective cohort of active structural firefighters that would be recruited from rosters from select fire departments or state agencies. This targeted enrollment would allow us to select firefighters throughout the country from geographically diverse departments of various sizes and may be less susceptible to selection bias than the Open Cohort.

The way in which firefighters will enroll is still under development. This is taking a long time because data security is our top priority, and there are several new federal data security requirements that we have to comply with, so it is absolutely critical to get this right the first time. Even though it is still being developed, we do plan for enrollment to involve informed consent, user profile, personal information, and then an enrollment questionnaire that would collect information about demographics, work history, lifestyle, and other important factors for understanding cancer.

We estimate that enrollment will take about 30 to 45 minutes, where newer firefighters will be on the low end of that estimate, and more experienced firefighters would be on the higher end of that estimate and that is simply because they will have more work history experiences to report.

We also want to make sure that firefighters can log out and back in and be able to pick up where they left off, because we know that they could get a call or have other competing activities that would take them away from the registration.

We are also interested in capturing data from other sources, to better understand firefighters' exposures, including fire department incident records or exposure tracking information. We recognize that if firefighters are going to go through the trouble of tracking their own work-related exposures, it stands to reason that they would want to be able to provide that information to the NFR. We will hear more about the enrollment system from our IT Director, Mike Loudermilk. I just want to let everybody know that we are working diligently on this system, and these things do take time to do correctly and securely, as well as require a lot of resources to make it happen.

We understand and appreciate that if a firefighter is diagnosed with cancer, the last thing on their mind is to report that cancer to NIOSH. So instead, cancer information will be determined periodically by linking to state cancer registries to determine cancer incidence, and to the National Death Index to determine cancer mortality. The North American Association of Central Cancer Registries' new Virtual Pooled Registry will also be a useful asset for making those linkages.

The last time we met we discussed the importance of collecting Social Security numbers for these linkages, and we are currently in the process of obtaining approval to collect and store SSN.

The web portal is the common denominator, if you will, among all the NFR participants. But we are also interested in department records and exposure tracking information. All that data will be funneled into a secure exposure database that is later linked to health outcome databases, namely the state cancer registries and the National Death Index.

The Firefighter Cancer Registry Act states that we should ensure information in the NFR is publicly available, while also protecting the personal privacy of participants. So, we are in the process of obtaining an Assurance of Confidentiality or AoC, which is the highest level of protection allowed by the federal government for this type of data. It will assure participants, fire departments and other institutions, like state cancer registries, that NIOSH will protect the confidentiality of the NFR data. We are also pursuing secure mechanisms to make data available to external researchers via the use of research data centers, which are federal data warehouses responsible for protecting the confidentiality of participants while providing access to restricted use data for analyses.

There are some potential limitations that should be considered in designing the NFR. The generalizability of the NFR may be impacted by participation bias, especially if participants are more likely to have had cancer or associated risk factors. So, participation bias is also an important consideration in the design of the enrollment system as the steps required for registration could also affect participation rates across the Fire Service and may impact certain groups of firefighters more than others. This could affect both participants in the open and targeted cohorts. Small sample sizes could also affect our ability to investigate rare forms of cancer, or specific firefighter groups.

There are other limitations that relate to the analysis of the NFR data. For example, exposure response analyses will be affected by record availability. Self-reported exposures and behaviors may be subject to recall bias that could affect the accuracy of that information. Healthy worker effect will also need to be considered, as firefighters are generally healthier than the general population and firefighters that are eligible to participate in a targeted cohort still have to be in active-duty status, which means we would not be able to enroll firefighters that might be most affected, like those who already have cancer.

In closing, Dr. Fent said that because of cancer's long latency period, it will take time to detect robust estimates of cancer risk. However, in spite of all those challenges, what we're trying to do here really has never been done for first responders. It is rare to do this for any occupational group and we hope to develop a platform that allows the Fire Service and scientific communities to be able to better understand the burden of cancer among firefighters, and also inform of ways of reducing cancer in the Fire Service. We have made a lot of progress over the last year and we are especially thankful to the NFR Subcommittee for their careful review of our draft protocol, consent form, and enrollment questionnaire. All of those have been updated based on the comments we received and have been posted to the web. We also submitted our questionnaire for the Office of Management and Budget review, and we just got comments back last week on that. Again, we drafted an Assurance of Confidentiality, and that has been submitted for CDC's review. We are applying for the approval to collect and store SSNs, and we are still, as a team, discussing whether we want to collect full SSN versus partial SSN.

We have begun planning the development of the NFR enrollment system or web portal, and that is the main topic of today's meeting. We will hear a lot more about this possible enrollment system from our IT Director, Mike Loudermilk, and others. We need to make some important decisions about this system, and we hope you will help us evaluate the pros and cons of those decisions. With the NFR Subcommittee's guidance, we are cautiously optimistic that we will be able to have a system in place, tested and ready to register firefighters some time in 2022, and then when enrollment does open, we will work closely with everybody here including all the Fire Service stakeholders, to notify firefighters across the country about this opportunity. So, thank you for your attention and for all your guidance over the last few years.

## NFR System Design and Use Cases

### Presentation

**Mr. Michael Loudermilk**, Associate Director for IT at CDC/NIOSH, introduced himself and thanked the committee for giving him the opportunity to present information regarding the technology, security, compliance, and risk management relative to the National Firefighter Registry. He said how thrilled he was to be working at NIOSH and went on to give some facts about himself. The following information was given by Mr. Loudermilk:

I have spent about 25 years working in the information management sphere around sensitive data dealing with these kinds of regulations and protections. I also have a father who died of mesothelioma due to that exposure, so I very much understand personally. I came to NIOSH to work on programs like this and I am very excited to be able to help provide this kind of enhancement, knowledge, and the benefits this program will offer.

Today's agenda begins with a high-level review of identity management and privacy compliance for the NFR solution. I'll then discuss various considerations regarding NFR responder account creation and protection. Donna Spillane will then overview the steps involved with setting up a basis account versus an identity proof account so you can get a feel for the user experience. Eric Crafter is then going to review some sample registry participant profiles for your consideration, and then finally, Donna will outline our planned path forward with the NFR project, including general timeframes.

All of you are aware of the growing risks and threats to online systems and database on the web. Over the past six months, we've observed a situation where more than half of the federal agencies were severely compromised by a single malicious code exploit. And you may also know, or not know, that on the dark web, there are about 400 million individual account data, email, user ID/password combinations. Every time somebody gets hacked, all the hackers collaborate and put all that data together so that they can keep hacking better with all that information that's exploited. So, the federal regulations exist to protect information systems and the associated users from identity theft or exploiting their personal data for nefarious activities.

Now, bringing this in specific to NFR, a collection of first responder PII not only provides the general identity theft risks, but it also—there are greater risks associated with first responder roles and facility access that's

actually classified as a risk under national security. In addition, compromised personal health information is actually worth more than 30 times the value of financial-based PII because the health insurance system is not as effective at mitigating fraud as the banks and finance system are. So, there is a huge black market for personal health information that is actively exploited in the wild today.

I don't believe it's going to be useful to dive into details of federal security and compliance requirements in this forum, but I wanted you to know that there are varying depths of rules and controls that exist and are mapped into a system based on the risk associated with that system. So, going forward, the functionality that we choose to include carries with it the impact of those requirements based on what we choose to have it do. And often, the complexities associated with these compliance rules and overheads are seen as a burden by users and program owners alike. You don't know anyone that likes compliance and overheads, right? But the reality is, these rules, all this work and sophistication in compliance, it exists to protect the users and their information. The NFR participants should expect no greater risk in regard to identity theft or insurance fraud as a result of participating in this program.

So not only must we protect information associated with the NFR project, but we must also protect identities themselves based on the level of access to sensitive data. Now, most of our protections can be hidden from the NFR participants, all of you, and even our own program people, because we apply that stuff through behind-the-scenes tools and controls that provide overwatch to all that activity, and no one other than the tech people know that it's going on. NIOSH has many use cases where sensitive data is collected from workers and analyzed for opportunities to enhance worker health and safety. How NIOSH meets federal requirements for data security and systems compliance is not really relevant to the NFR user community because we do all that in the background. And just knowing that it's happening is really all you care about.

But there is a key functionality that's on the table related to the Firefighter Registry that impacts the user experience. If a firefighter were to come to a website and complete an NFR survey, regardless of how sensitive or in-depth the questions were, and once that information is entered on the screen, the system can quickly sweep the data away from the internet and put it into a highly secure data vault where that information can be protected. And CDC and NIOSH scientists and researchers can access that data from within that protected bubble to do their analysis, trending, and statistical work. However, the gamechanger is if the Registry provides participants the ability to come back later with account credentials to recall that sensitive personal or health data, significantly, risks are introduced to the system. Because not only must the NFR system protect information from risks like malicious code or brute force user ID/password attacks that go on constantly on the internet, but we also must protect from risks and expect that our participants are going to have their identities and credentials compromised from other stuff that they're doing on the internet. So, I previously referenced that database on the dark web with over 400 million email password combinations. You know, users often leverage the same passwords and email associations for online access, and this threat, combined with the growing level of cell phone spoofing and SIM card fraud, drives the need for specialized risk mitigation to protect NFR users.

Consider the negative implications to future worker safety programs if personal health information was exfiltrated from a participant, program participant like this, even if the core failure resulted from some other system, and user—the compromise came from the user using the credentials in a different system.

I used to be an employee at the Department of Treasury, and one of the most significant cases like this that happened there were about 800,000 US tax records were exploited by nefarious actors—happened because the credentials that the US consumer set up to use in the IRS system were the same as the email and password they used in some other system. And that other system, whether it was a restaurant or online store like a retailer, once that database got compromised, the malicious actors are really smart. They'll go out and try to use that combination anywhere. And they were able to actually exfiltrate lots of detailed tax information, pretty much everything that was on the tax form, for those people who had their credentials stolen somewhere else.

It is really important for this Board to understand that risk, because that might—that happens a lot in the industry, and a lot of the things, when you hear about systems being compromised in the news, and most people assume that it was that system that failed. But often, it's not, that's not the case. The credentials for that system happened to match the same credentials the user was using somewhere else, and that failed. So, when designing systems like the NFR, features that improve research and overall value often require enhanced controls to mitigate risk and better protect the participants.

The content we are sharing today is intended to drive your analysis and input for the best balance of functionality, controls, user experience, and ultimate program benefit to the firefighters. The analysis of the benefits versus the user burden—which is, you know, sometimes burden is just perceived complexities—should be based on the typical firefighter's perspective and the potential difficulties in communicating security measures. If this program was for IT workers, for example, you might come up with a different answer because you could reasonably expect all the IT workers to understand and have some perspective on everything I've said so far. Firefighters are going to have very limited, if any, perspective on the topics I've discussed so far, and I believe either extreme is really undesirable for this program. Having an NFR program with maximum data functionality that is so overly burdensome and tremendously suppresses participation will not maximize the program input. But likewise, maximizing the response at the expense of all functionality or most functionality won't give you a strong program impact either, because some firefighters are going to have outlier perspective and comfort levels with online systems.

So, as previously stated, functionality of the NFR system to offer participant profiles and the ability to retrieve sensitive data increases the compliance controls that we would have to implement on the NFR system. And when considering an approach, I recommend that you think long-term. Changing the design of the participant's account management in the future, it can be done, but it would be complex and somewhat expensive. And depending on the value in updating and enhancing data over time, and I think, you know, the ability for the participant, the registrant, to come back and update and augment information over time, what is that value and how significant is that value? And so modern websites, good ones at least, provide a hierarchical thematic access to information. And users, today, expect direct categorical access to information versus linear, old-school many-page surveys. And we need to consider that being in the design as well, and

how that will get implemented in the profiles that Eric will be reviewing shortly. Modular, categorized and directly accessible surveys, and survey data in an and directly accessible surveys, and survey data in an easy-to-use library, will provide long-term flexibility to enhance data capture needs.

So, now I want to try and help translate all the content I have covered so far into some simple, tangible scenarios for the NFR. These following scenarios are not the only prospective options for the NFR, but I believe these scenarios provide a good example of distinct levels of functionality that is possible within the NFR system.

The first scenario would be a full registration scenario, where there would be no limit on the data retrieval or updating. Under this scenario, the participant would have a very robust profile that includes employment and health history. The participant can view and update previously submitted data, and in this scenario, the participant would be subject to account creation, identity proofing and a more rigorous management of the account that would be in line with the ability to go back and retrieve that information, so that we are doing everything we can to mitigate an accidental release or hijacking, if you will, of that account.

The next scenario is what we will call a light registration scenario, where there is no sensitive health information that can be retrieved by the user. This profile would include less sensitive health identifiers and no ability of the participant to recall a survey response. It still requires them to set up an account, but it would be something more typical of what a user would experience when creating a lightweight account. For example, here is an email, here is my name, and here is a password.

The last scenario has no registration or profile at all, driving users to the Registry on a quick, lightweight way to just capture the data in a one-pass format. It functions like a web-based survey. It still can be hierarchical and easier to use than the linear thing I described earlier, but the user can put that data in, the data gets swept away into that data vault that I talked about, and it is very easy, lightweight, because the public can't ever go back and pull that out. There is no exfiltration option for data. It is one-way data movement.

Now, I would like to overview one specific security tactic that may impact the NFR participant user experience based on the functionality selected. Identity proofing is a tactic that is used to establish the uniqueness and the validity of an individual's identity. And this is accomplished through an automated digital validation of a participant's state-issued ID and personal records. I find this experience to be similar in depositing an online check. Donna is going to walk you through a scenario so that you can kind of get a feeling for what this user experience would be like, but if you have deposited a check online before with your cell phone, it works very similar as you take a photo of the check.

Federal systems rated moderate that enable retrieval of sensitive information require Identity Assurance (IAL2), and the identify-proofing mitigates risk of account compromise, spoofing or hijacking that would expose sensitive data. As stated earlier, this control is to protect the participant's sensitive data.

Being in the IT profession, I personally am dubious when there is an online system that wants sensitive data without protections like this. I also understand that my specialized perspective is unique, and that general users won't reasonably understand the nuances of these protections.

This slide helps illustrate specific data that could be retrieved by NFR participants in hypothetical options 1, 2 or 3 that we've just described.

In Option 1, the full proof, compliant, full-service option, participants could retrieve any of the previously submitted data, the less sensitive basic registration data as well as the more sensitive data in red. And it requires the identity proofing because that extra step means that it is so much harder to compromise that account. It is very difficult to hijack that account, even if you lose your email and password and someone else has time to come in and get it, without the PIN. Now to reset that account you would need to re-proof your identity, which is a good thing to prevent that account hijacking.

Option 2 does not require identity proofing because the sensitive data would not be retrievable in that sort of account setup - that would be the more basic. You would enter your email, your password and your name and we would tie the information to your profile. It would be the green information, the basic information to tether the user to the account.

And then Option 3 is just no account at all, running the Registry essentially as a survey portfolio and allowing users to come in, going through questions, and completing that information, and then having it immediately swept away into that data vault where the firefighter could never come back in and access that information. However, we would still have it for all the scientific purposes that we'll plan.

I'd like to now introduce Donna Spillane, who's going to provide you with a high-level walkthrough of the account creation setup, and to give you an idea of the user experience associated with the functional options.

**Ms. Donna Spillane:** Good afternoon. As Mike said, I am Donna Spillane. I am the Technical Project Manager assigned to this project. I am going to go through pretty quickly because from what I understand, I think most of you have already gone in to set up a creation of a login.gov account, which is pretty basic, as a lot of the other ones are. You know, your email, obviously developing a secure password, you've got a couple of authentication methods, whichever one you're more comfortable with, make sure you have got these, and then we click on here to create an account.

Now I'll go through the actual steps to create an account. Your email address and then always accept this message to say you accept the rules of engagement or rules of use. They will then send you an email. You go ahead and do that and click on that. At this time, you can close this window because you're not going to need to go back to here again. When you click on your email, you're going to go back here. It is going to ask you to create that strong password, and it will show you along here how strong your password really is. It gives you a few tips that you can use along with that. If you want to cancel, you can cancel.

Next is the authentication method set up. This is for two-factor authentication. You have several different options to choose from. From this, they are going to send you a security code via text, or a phone call, whichever is easier for you. I have selected text message. I click here and it will send me the code. I will put in that code, and then we will go from here to "Let's get started".

The first thing you're going to do - this is obviously required if you're going to be re-accessing your sensitive health information. The first step is obviously not for that. Basically, you are clicking the box that is letting login.gov keep, ensure your personal information, which would be for the firefighter.

The next section shows you how you will upload your state-issued ID. I have had to do this for a couple of other websites, which is pretty easy. If I can do it, I think most people can. I think it is easier than depositing a check. Let me put it that way. Anyway, it will take a photo on your mobile phone, and usually the mobile phone will let you know when it is not a good picture and click it itself. Then you will take a photo, with your phone. You then enter your phone number and click on "Continue".

These are basically the screen popups that you are getting on your phone. This is how it would look on your phone, and then after it is done, front and back, it is secure, confirmed that these are clear images. Like I said, it is a lot easier than making a check deposit. As soon as it is done processing your images, they will tell you verified state ID, and you will switch back to your computer and finish verifying your ID.

At that point, you are going to enter your SSN. You are going to verify all your information to make sure that it is correct. Enter a phone number that has a name that is associated with this, (with your phone bill is what they're really asking for), if not it will kick you out. As soon as you do that, you will hit "Continue." It will show you have encrypted your verified data. It will give you a personal code, and it wants you to save that so that you have that, probably in a very secure place where no one else will get to. You can also print it, that helps, or download it. You will click on "Continue" and then the process is basically completed.

These are some examples of the NFR profiles, and I am going to go ahead and turn this over to Eric Crafter, who can explain this a little bit more for you.

**Mr. Eric Crafter:** Good afternoon, everyone. I am Eric Crafter, and I've been working on the requirements, engineering part of the NFR project, with Donna and Mike. I'm going to briefly run through a sample profile, so for the options 1, 2, 3 that we previously mentioned on the slides. My slides will focus on options 1 and 2 because they deal with the profile. Option 3, since it does not involve a profile, there is really nothing exciting to show you there. I just wanted to point that out. I'm not overlooking Option 3. There is just nothing exciting to show you from a profile perspective.

For the profile, for ease of use, we were thinking about segmenting them in terms of personal information, employment information and health information. That's kind of how they are aligned in the protocol document, and so we would expect the system to do something very similar. And then the orange highlights that you will see in a few of the slides, those orange highlights just mean that that information that's highlighted in orange, that if we were to include that information in a profile account, that it would have to be identity proofed or we would have to move that information later on to the survey portion of the Registry.

What you see here, think of this as just a blueprint, a very basic idea for the purposes of discussion, of what screens would look like. I can assure you, even though we don't have the system built yet, that your NFR system will look a hundred times better than this. It will be richer and fuller. These are just basic blueprint diagrams just to facilitate our conversation.

The user profile would start with the personal info—name, have you used another name, and your address. The information highlighted in orange would be the identity proofable—making up my own word—information that we would have to make sure that we identity proof. And that would be the data for country of birth and things like that. We would continue by gathering your email address and phone number, basic stuff that most people are probably used to providing. And then we would also gather a little bit of employment info about whether you were full- or part-time.

If we were only looking at Option 2, everything we've seen up to this point would be included in Option 2. Everything from this point forward, you can see highlighted in orange, so this would be information that would have to be identity proofed, or otherwise moved to the survey portion.

This where we would get into more detailed employment information: your level, your job title, things that obviously we would want to make sure that are identity proofed and secured. And then certainly here, as we change from employment information into the first questions about health info, asking about a cancer diagnosis would be something that would have to be identity proofed. Based on if the user selected yes, that there is a cancer diagnosis, then follow-up questions in more detail would be asked, like the types of cancer, age at the diagnosis, and things like that. There has been some mention of Social Security number. Here, we would also ask about Social Security number, and this information is being asked at this point. Social Security Number was mentioned earlier. That was on the login.gov side. Social Security number here would be the first use for the Registry itself. So that's why you are seeing it twice in the presentation.

After we ask all of that profile type information, no matter which option chosen—Option 1, 2 or 3—again it's where you would get into what I would call the heart of the Registry where the really detailed questions and detailed attributes about the specifics of your exposure, the specifics of the cancer diagnosis would be asked, so there are a lot more questions than what you see here. No matter the option chosen, 1, 2 or 3, all of those options would lead you to the beginning of the survey. And of course, throughout this whole process, our idea would be to make this as user-friendly as possible, with all of the latest usability options that are available to us, to make it as easy as possible to the participants.

**Ms. Spillane** then took over the presentation shared a high-level timeline. We started with our business needs analysis - just some use case stories, some use stories, and also wireframes that Eric and the team have been working on. We are in the process of finalizing that, and then also clarifying some requirements, and nailing down with the team specifically where we're going from here. After that is completed, we will turn it over for requirements to engineering, where the engineering team is going to get involved, understand what the requirements are. They're going to talk to the team, obviously, to get some additional information. In February of 2022 the engineers will come back with some solutions, take a look at it and based upon what the requirements are, what is the best solution that we see, that would give you the security, obviously the ease of use and everything else that you're asking for in this. And then, along with that, we look to start implementation in July of next year. This is subject to change at any time. I'm sure most of you have worked on projects where you just never know what you're going to run into. This is at a very, very high level.

At this point, **Ms. Novicki** stated that there was only five minutes to go before the time for public comment, and that we need to pause at exactly two o'clock for public comment the presenters would only be able to take maybe one or two questions about the process.

## Discussion

**Dr. Moffatt** asked if there is the ability for someone to do a light registration to get into the system and then upgrade it to a full registration in the future?

**Mr. Loudermilk** responded that one of the considerations is that we offer tiered participation into the NFR, into the Registry, and that we could allow an individual to sign up with light registration and/or full registration, and then transition it at a future date. There would be some complexity with that approach, but it may be the best approach that's a win-win for the firefighter community and the research community.

**Dr. Moffatt** said he knew that oftentimes permission or participation is situational, and that in some instances in our experience, they may change their mind as they hear from other peers or for other types of issues that may occur after they sign up as a light registrant. He said he thinks that the option to upgrade could be helpful for more participation and more data but he understands the complexity, so it is just a comment.

**Dr. Sarah Jahnke** had a question regarding the matching of the name with a phone number attached. She wanted to know what percent of people would not be approved at that point in the process, and who would have to do additional work to get registered if they do the identity proofing?

**Mr. Loudermilk** responded that there are some statistics from login.gov that are overall averages, and then when you dig into specific programs, can range between 50 and 80 percent. He said that until we did a test in the community, it's would be difficult to understand what that actually would be, but that 50 to 80 percent is a really big range.

**Dr. Jahnke** replied that from her scientific side she would love to do identity proofing, but she thought that we needed to think from the practical side. She said there would be some percent of folks that would not follow up with that and wondered if we would have issues with generalizability. Her guess was that people who are not proofed would not happen at random. But I think we can discuss that later. But that's really useful, thank you.

**Ms. Novicki** then informed the members that there was one more minute before going to public comments and she wanted to know if Dr. Fent had any comment to add since she knew that he has had conversations with the login.gov staff.

**Dr. Fent** said that he has heard similar things to what Mr. Loudermilk had heard in terms of a failure rate of around 30 percent based on general population statistics that they have. His understanding was that if there is a failure, they would use snail mail to confirm identity through that route.

## Discussion of Registration Options

Discussion registration options occurred before and after the public comment period.

**Dr. Fent:** I was just going to try to do my best to clarify these three options. So, the full registration option would require identity proofing, so that's the demo that Donna provided. And after having done identity proofing, basically what that means is that all the data that is entered as part of the registration process would be able to be retrieved and edited as part of that user profile. Now, not all the data that we're talking about collecting do we intend to make retrievable or editable, but there would be no limitations on that. The second option, the light registration option, would not require identity proofing. It would require the multi-factor authentication that I think a lot of people are familiar with. But the only drawback to that is that certain information would not be able to be edited or retrieved, so would not be part of that user profile. But we could still collect it through the enrollment questionnaire. And so, you know, we could go back to that slide if we wanted to, that listed those variables. And then that third option is just basically, you know, web-based surveys, no accounts, very, very simple option, but there are some drawbacks to that as well that the Committee might want to discuss. But I think those first two options are the ones that our project team is really considering at this time.

**Dr. LeMasters** stated, before we go on break, I would just like the NIOSH team to think about a question that I have had, and that is: Do you have any idea, or could you discern, how many people, how many firefighters are going to really want to go back to the profile and change it or update it? I would imagine that's not going to be a whole lot of folks. But I was wondering if you've done any questions, or piloting of that particular question because I think it's imperative. If not a lot of people are going to want to access the information they supplied on the first round, then when you contact them again, you'll just be collecting new information, or give them a chance to change something, if they want to, on the old.

At this point the meeting was adjourned for 15 minutes from 2:15 to 2:30.

After the break **Ms. Novicki** confirmed the quorum and the meeting resumed. She also reminded the members of the public that they were in observation role and that this time would be reserved for the Board members to ask questions and discuss the pros and cons of the different approaches. She then turned the discussion over to Mr. Patrick Morrison.

**Mr. Morrison** began by thanking everyone and stating that the discussion would now be turned over the Subcommittee group. He said that this issue really has hit the Fire Service as a high-profile area of discussion that we really need to give our best input in so they can have the decisions. However, before getting started, he asked Dr. Kent to pick up where he left off at break by going over the three options because he thought that would be important to everyone.

**Dr. Fent:** Option Number 1 would be where identity proofing and multifactor authentication would be required. Firefighters who have done that would then have no limits on the data that they could retrieve and edit. That would primarily be done through the user profile. We could include more data elements as part of their user profile that they could see and edit. For Option Number 2, there would not be identity proofing.

There would still be multifactor authentication. Once they have signed in, certain information could not be retrieved and edited by the firefighters as part of their user profile. We can still collect all the information we want to collect as part of the enrollment questionnaire. And then that third option is just basically no user account, so there would just be web surveys. And, again, our project team is primarily focused on those first two options. Certainly, we are happy to hear your comments about Option Number 3.

One other thing I just want to mention because it might be a little confusing. Donna, our contractor, went through what identity proofing would look like after multifactor authentication and, as part of that, is taking a photo of the driver's license and entering the full Social Security number, as well as other elements. But just because entering full SSN is part of that does not give us access to that SSN so we would still have to ask for SSN, whether we ask for full or partial as part of the registration process. So, I just didn't want that to be confused by the presentation. Questions about that?

**Mr. Morrison** thanked Dr. Fent and said he really wanted to open it up to the Committee. He asked Ms. Novicki for assistance in tracking the raised hands in the chat and noted that Dr. Materna already had her hands raised.

**Dr. Materna** said, as I understand it, only Option 1 allows someone to edit their survey data if they realize they made a mistake or something. And I don't personally think there's a high likelihood that a lot of people are going to be thinking, oh, I responded in this way, that wasn't quite right, I need to go back in. But my question is, from the researchers' side, when they find inconsistencies in the survey data that are obvious clearly errors or inconsistencies, will there be a way for them to contact the participants to clarify—outside of this whole system—to clarify or correct errors in the data?

**Dr. Fent** responded: So, I'm going to attempt to answer that but then I think Miriam Siegel, our lead epidemiologist, may want to jump in as well. I didn't talk much about this during my presentation, but we do plan to do follow-up questionnaires periodically like once a year with the firefighters. So that's an opportunity. If there are certain questions where we're getting maybe conflicting results or it's just confusing the kind of data we're getting, we could try to obtain new information or corrected information as part of those follow-up questionnaires. Maybe it's a wording problem or whatever, so we would reword the question. But with Option 2, if you don't have identity proofing, we wouldn't be able to share their previous answer if it's part of that sensitive health information that's protected, if that makes sense. So, an example of that would be like self-reported cancer diagnosis information, we wouldn't be able to say, "Hey, you said you had bladder cancer, is that really what you had?" We wouldn't be able to do that unless we had done the identity proofing.

**Dr. Siegel:** Just to add on to that, the survey, according to our protocol, was never going to be anything that they would be able to re-access again. It was a one-time survey at enrollment. The user profile is kind of the content that's being discussed at its core here. And so, with the full registration, participants would be able to see what they entered in previously in the user profile and they'd be able to update it if anything has changed. But with the light registration, if there are certain fields such as current department that are deemed to require identity proofing but we opt not to do identity proofing, those are fields that'll have to be moved to the survey, so they won't be able to see what they provided to us previously. In which case the

next time they go to fill out that information, the next time we solicit that information in another survey or in a user profile update and they can't see what they previously gave us, it is possible that there will be information that is inconsistent with the information they previously gave us. In which case there would need to be a plan to reconcile that information, but those would only be for a select few fields that had to be moved from the user profile to a survey.

**Mr. Morrison** thanked Dr. Siegel and called on Mr. Shawn Brimhall.

**Mr. Brimhall** thanked Mr. Morrison and stated: Just to bring something to your attention too, there's a very small element on the volunteer Fire Service in New York that are Mennonites and Amish. So, the Amish wouldn't even have a driver's license, some of the Mennonites do, but none of them are going to have any sort of electronic device to be able to participate in that. And we do have, in our rural areas—the Finger Lakes, along the Mohawk Valley area out in Western New York — some very large contingents that are members of the Fire Service where the Fire Service actually takes routes to the scenes to go by the farms to grab these guys on the way there. So just for consideration, that's somebody that we are probably going to miss out on and those would be highly more likely for respiratory issues because they can't wear the air packs. They are exterior firefighters and are workhorses and still members of the Fire Service.

**Mr. Morrison** thanked Mr. Brimhall for bringing up that very interesting perspective. He then called on Dr. Moffatt.

**Dr. Moffatt** started by saying: Just as a new member to this committee, I'm very excited to be a participant. I think the amount of work that has been done developmentally, with where we are at right now, I think is substantial. And I just really commend the committee for their dedication and their passion for what they're doing. I just had a quick comment that, in experience with the Fire Service over many years, one of the most impactful things in a fire department is a colleague of theirs that develops a cancer that then really brings it home to that particular department. And in those instances, there's almost a rally cry to be more aggressive with regard to addressing these issues of cancer - it becomes very personal at that moment. And I think sometimes there's an opportunity to capture individuals who do want to do more than what they're currently doing or, in the circumstance where they might want to move from a light registration to a full registration, that that might be an opportunity for them. I have seen it happen in a lot of different situations with a lot of agencies. So being new, not really having the background with regard to how all of this is developed, again, as a newbie, I just may be not understanding the full concept. So, thank you, I appreciate it.

**Mr. Morrison** thanked Dr. Moffatt and called on Dr. Jahnke to comment.

**Dr. Jahnke** responded: I think if we could give both options, although I would argue that you're still probably going to have a little bit of a bias of the people who go for the full registration. Honestly, I think if we don't have the light registration as the primary option, I think we're just kind of shooting ourselves in the foot. I think that the selection bias will be so significant that I just think that the data we get will be pretty much useless because we'll only get the people who are so invested that they were willing to go to that level.

**Mr. Morrison** responded: Yes, no, and I agree, Sara. I was looking at that and I really like what Dr. Moffatt was saying because I didn't realize it. And Mike did a nice job in his presentation giving us the platform and

that that was a possibility. I think when we start off and kick off, that having two—light registration, full registration—options will confuse a lot of firefighters right from the get-go. That's just a suggestion that the light registration would be the primary and then later on, perhaps, if somebody wanted, to once we get the people. But this is a registry, so our primary goal right now is to get people to register. That is going to be a challenge, but I think we are getting to that place. But thank you, Sara.

**Mr. Morrison** then called on Mr. Bryan Frieders and asked him to share his opinion about this option. Mr. Morrison also went on to say that Mr. Frieders has done a lot of work for the Firefighter Cancer Support Network and that he has a lot of information and has been around for a long time dealing with this topic.

**Mr. Frieders** thanked Mr. Morrison and said: I appreciate my colleagues' comments because I think they're spot-on. Look, I don't want to make this so simplistic, but I have got to tell you that the more complicated this becomes, no one's going to do it. We already have an uphill battle in trying to get people's information. If we make it more complex, it's going to turn everybody off and no one's going to do it. That's just the reality of firefighters. The people that are going to really be engaged in this are the ones that have been impacted, the survivors, those that have had it happen to their organization or someone close to them. They are the ones that are going to pay attention. But unless we pull, in some capacity, on the heartstrings of those involved, we are not going to get the enrollment. And then add to that a level of complexity for the sake of adequate data mark points or whatever other standards we need to be. I just fear that we are not going to have the motivation to do this, and firefighters aren't going to do it. It will be the latest, greatest thing and then it will kind of disappear. And I just would hate to see that happen. So, I think the message that we have to craft is one of simplicity, user friendliness, and then go back later and see if we need to clean it up somehow. And, again, just my opinion; being in the Fire Service for 30 years, I just know firefighters and we will get a great response from those that have been impacted by cancer, but the majority of people—and including the volunteer groups—probably are not going to be as robust of responders.

**Mr. Morrison** thanked Mr. Frieders and then called on Regina Wilson who not available. He then called on Dr. Betsy Kohler saying she is the Executive Director of North American Association of Central Cancer Registries and asked her opinion because he thinks she has a lot of experience already in registries and getting that information and getting people registered.

**Ms Kohler** responded: Yes, I am. But cancer registries are not voluntary registries, so data is collected through medical records and we have access to most of the personal identifiers and sensitive data that are required here and there is no sort of authentication that is necessary. The thing that I would comment on is that for matching later on, with either the National Death Index or the cancer registries, the Social Security number is key. It is one of the identifiers that we use. It's not the only one. But it greatly improves our results in being able to identify matches between the firefighters and cancer cases that occur in the registries.

**Mr. Morrison** thanked Dr. Kohler and said that, last part was important. We had a lot of discussion on that, and I think there was a lot of trying to match those registries, how important the Social Security number is. And we had a lot of discussion internally at our organization about that there too. So, I appreciate that too.

**Mr. Morrison** then called on Mr. Richard Miller, who is with the International Association of Fire Chiefs.

**Mr. Miller** thanked Mr. Morrison and said: So, as we look at the three options and potentially blending of two to allow for the greatest participation and the ease of registration, it is only the full registration, the Cadillac of this process that gets us to all the information that we need to do the proper research and documentation moving forward. Or can we exist at the light registration and utilize the survey component to gather additional background information? So, as I looked at all these different options and spoke with lots of different Fire Service members, one of the questions that they came back with was, "What do I get out of this if I register? What does the end-user Fire Service member gain? And will I be able to retrieve my data?" Well, that only comes if we have the full registration, not the lesser amount. Because then they are able to go in and get their specific information and continue to update that, continue to update those exposures.

Knowing our target cohorts 200,000-or-so members across the Fire Service and that we are going to be specifically targeting those fire departments and then members, is that the group perhaps we go to the full registration for and then look to go to a lesser, to more ease of data collection with the majority of the Fire Service? And to Chief Brimhall from New York, it is a very interesting dilemma, but I don't think it is unique to that society. I think probably there are a lot of people that are not focused on electronic usage of systems, so how are we going to reach out to them? So that is a critical piece I think that we need to talk about a system. But, again, I think this all boils down to marketing and how best we can do the outreach efforts from all the Fire Service groups and the researcher groups showing a united activity for the betterment of gaining all the information.

**Dr. Fent** responded to Mr. Miller's question about being able the ability to collect data needed for the science under the light registration option: we would still be able to collect that data. So here we have the list of the variables that we were planning to include as part of the user profile. And those ones that are listed in red here could only be part of the user profile if we did identity proofing. But what that actually means, under Option 2, is that all those questions then get moved to the enrollment questionnaire, which, once you complete that questionnaire, it gets swept up into our secure database. So, we are still collecting all the variables that we need to do the science. Now, there are some other sacrifices and you mentioned one of those being that some firefighters may want to be able to retrieve the data that they've entered maybe years down the road. And some of that information unfortunately would not be able to be released under this account-based system. There may be other ways of doing that. It could be a question for Mike Loudermilk if he is still on. But in terms of accessing that information through the account, that could only be done if we had done identity proofing. But again, to answer your question, we can still collect all the information that we had intended to collect.

**Dr. LeMasters** had a follow-up question. Wouldn't you be collecting some of these data twice? I mean one in the identity proofing and then again in the questionnaire, like current department, employee ID, start and stop working, job title. Isn't that being already collected in the questionnaire? So why would we even need to do it initially.

**Dr. Fent** replied yes, it could be collected as part of the questionnaire or it could be collected as part of the user profile.

**Dr. LeMasters** responded: But isn't it being collected as part of the questionnaire, definitely?

**Dr. Fent** said: Right. Yes, if you look at our protocol the questions would still be part of the enrollment questionnaire, but it would be auto-populated from the user profile. So, they wouldn't have to answer it twice per se, it would be auto-populated if they had already answered it. The reason to include it as part of the user profile in addition to the enrollment questionnaire is because the user profile is something they can see, access, and edit. So, these were variables that we know will change - not all of them, but most of them could change over time, which is why it was initially listed as part of the user profile. Did that answer your question, Grace?

**Dr. LeMasters** asked: So how would you auto-populate something without knowing where to put it? I don't see how that would even work. Okay, that's one issue. And the other thing, you also are asking county, city, and state of birth. I don't know what *county* I was born in. It's in Michigan somewhere, but I wouldn't be able to answer that. And I was wondering why you need that county, city, and state of birth. I think particularly in the enrollment, we want to limit as much as possible what we're asking individuals to provide.

**Dr. Fent** shared that it is actually *country*. It is country, the city, date of birth. But, yes, I mean you make a good point. A lot of this information can just as easily be part of the enrollment questionnaire. It's not difficult to move it from the user profile to the enrollment questionnaire. The only sacrifice that we're making is—we know, for example, that current departments and job title, some of those things are going to change and it would be nice to be able to have that as part of the user profile because then they could see like, oh, I no longer work at that department, I now work at this department, and they can more easily update that information. But we could also get that information updated through the follow-up questionnaires.

**Mr. Loudermilk** said: I wanted to make one clarification based on Richard's comment. I think one of the points that was brought up was around burden or reusability and simplicity of capturing the information. And I wanted to clarify from a technology standpoint that the line between what's a user profile and what's a survey is rather arbitrary, and that the committee should consider the data that's being collected from the firefighter is just a hierarchy of information. And I think the way the profile was considered is that that would be close available data associated with the registration and that survey data would be a deeper level of information. And any of it could be retrievable. It would really be a decision around the system functionality as people can retrieve the profile, the top-level survey data, all their survey data, survey data from the last survey, any survey. There is no technical limitation to those functionalities.

What I would encourage you to envision over time is what is really going to be the least burdensome to the firefighter. The concept of an annual redo of the survey was mentioned before, but if I was a firefighter getting that full survey on an annual basis without access to the information that had already been filled out, that would seem kind of burdensome. Whereas, if I am getting prompted once a year to go in and update any information that I have -whether it is in my profile or somewhere in the survey - and it is really simple to go in and make changes - like where I'm working and I'm not a volunteer, I'm full time now, any of those kinds of pieces – it is a possibility in the technology in Option 1 that they could recall any of that information. And we are really looking for, as part of the functional engineering here, for you to tell us what in the end is the least burdensome to the firefighter.

**Dr. LeMasters** said: But when you say I filled this out in 2022 and then you came back to me in 2024 and asked me, "Since June of 2022, what department have you been working for?" and so forth, you wouldn't – surely, you're not planning to ask them all the jobs all over again?

**Mr. Loudermilk:** It is pretty easy now in user interfaces to sort of combine current and historical data, right? So, the way I would expect that to play out would be instead of asking them any specific questions, say, "Please come in and update your information." And they can see what's been there in the past - whether it was one, two, or five jobs, if that was the particular field that they were looking at - and they could add a new one. And the newest one would go to the top. You see? They could view as much of that or as little of that history. None of that is a barrier technologically. It really is up to you guys in how much of that information. It sounds like some firefighters would want to go look at that information if that's a value proposition. So, I'm trying to just be as clear as possible as to what is or is not a technical barrier versus really more what's a functional decision that you have to make.

**Ms. Novicki** said she would like to turn it over to Dr. Siegel to comment as the lead epidemiologist.

**Dr. Siegel said:** I just wanted to jump in and clarify. I think one of Mike's points wasn't exactly accurate. For the enrollment questionnaire, the thing that distinguishes the user profile from the enrollment questionnaire is not depth of information. It is ability to re-access information. So, in our protocol it specifies that the questionnaire is something they will fill out one time and they will not be able to re-access it in the future. The intent behind the user profile is that folks will be able to log back into the account and see their user profile and update that information. So, we can capture changes in current department. For example, like Mike mentioned historical information; if we decide to move some of these fields from the user profile to the survey that would make it so they cannot re-access that information. And I hope that clarifies that point a little bit better.

**Dr. Fent** commented: And also, if I may, we do not intend to reissue the same survey over time. So, the follow-up questionnaires will be - I mean there may be some longitudinal information we want to collect, but it's going to be a much shorter questionnaire. We haven't developed the follow-up questionnaires yet, but I think our goal would be to try to make them 10 minute or shorter. So, it's not going to be the same questionnaire over and over again. That would not be an ideal situation.

**Mr. Morrison** pointed out there were four people in the queue and gave the floor to Dr. Deapen.

**Dr. Deapen:** Thank you. Returning to the identity proofing discussion, as an epidemiologist, I always want more data. And I've conducted many, many surveys, as well as directed a population-based cancer registry. And there's a clear tension between the burden, including how much data you're collecting and its sensitivity, and the participation rate. The greater the burden, the longer the interview, the more sensitive the questions, the lower your participation rate. And hearing this discussion today, I am leaning towards reducing the burden to maximize participation rate. A deep dive on an unrepresentative and small subset of firefighters I think will be less valuable than a broader inclusion. And the other experience that I want to add, in many areas of my experience, is building trust over time. And so, I would expect especially from what I've heard, there to be skepticism and concern about the government and what this is and what's going to

happen to my information. But with confidence-building over time, that would spread word of mouth among firefighters, as well as encourage ongoing participation. So, I'm leaning away from even offering Option 1 partly because just the complexity. We would have to start with this thorough discussion of the pros and cons of why we have two options. And right there we've added to the burden. So, thanks for the opportunity to comment.

**Mr. Morrison** thanked Dr. Deapen and turned to Ms. Kohler.

**Ms. Kohler:** Yes, I was just going to comment on this user profile piece in saying cancer diagnosis, I don't think you'd want the participants changing that over time. You want to get that information from the matching done with the registries. So, I would not like to see that as an option that someone could change unless you can track that really well, if it has been changed.

**Mr. Morrison** thanked Ms. Kohler and gave the floor to Dr. Moffatt.

**Dr. Moffatt:** Yes, thank you. Maybe I'm just asking a question. For the registry, is the intent to register as many people as we can and do the initial survey and then do data collection and outside databases for an occurrence of cancer? Since we are not doing a follow-up survey, we are just doing an initial survey, is that what we're doing here, or are they being surveyed every so often to report new incidents of cancer? It is just a clarifying question. I apologize if I don't understand the structure.

**Dr. Siegel:** I can answer that. So, follow-up for our main outcomes, which is cancer incidents, and potentially mortality too. The gold standard, as Betsy just mentioned, for cancer incidents information is from the state cancer registries. So, we're primarily going to be doing follow-up of these health outcomes through data linkages. Now, there are other important health and covariate information that, because we were trying to make the enrollment survey as meaningful but as concise as possible, will be interesting and important to collect through follow-up questionnaires, as well as updating exposure information and work information in follow-up questionnaires as well. So, health outcome follow-up primarily through data linkages but other lifestyle covariate, health, and work information, currently and prospectively, in the future will occur through follow-up questionnaires primarily.

**Dr. Moffatt:** Thank you, Miriam. That really helps me to understand. I really get now that there's a downstream data linkage process with the potential for follow-up of those particular firefighters who have developed cancer and being able to get additional information. I have one comment with regard to repetitive surveys in that with the Fire Service we have to do OSHA clearances questionnaires every year, and what we've done is to be able to provide or serve up that questionnaire from their prior visit then they're able to review it and make any edits to that particular document that have been changes. So, the time taken for reviewing the questionnaire is much less on the basis of that and we still keep an annual copy of each of those individual responses. So, thank you.

**Mr. Morrison:** Thanks, Dr. Moffatt, I appreciate that. I'd like to just turn back to Barbara. You've had a couple things on the chat that you did, and I think Emily provided some of the answers. Is there anything else you want to say to the group about your question on the chat?

**Dr. Materna:** Sure. My question was about work status, because I'm looking at the green things are the things people could go in and change. And so, I asked, what was the actual question, "Employed, yes or no," something basic like that. But Emily filled in that the question is actually "What is your current work status in the Fire Service?" And there are all these options: full-time paid, part-time paid, volunteer, seasonal, paid on-call, retired/in what year did you retire, no longer working, out on long-term disability, other. So, there's a lot of information. So, what I'm concluding is that for Option 2, participants who are enrolled could go back in and change information related to their work status, as well as their contact information. And so, to me, that seems useful and probably enough. And I tend to agree with all the previous commenters who are saying if you pose this identity proofing and all that entails - which, to me, seems like you have to sit at a computer and have a smartphone that can take a picture and all that stuff - that that's going to be found to be too burdensome. And giving all that information right before you're even enrolled and invested in the survey might be off-putting to some people who don't really want to share that much information with the government. So, I guess if I have all that right, I guess personally I would lean towards going with 2.

**Mr. Morrison** thanked Dr. Materna and called on Mr. Bushey.

**Mr. Bushey:** From the wildland standpoint, they're human just like all the other firefighters. So, there's going to be within a small group that are going to be resistant to any sort of what they might consider to be excess intrusion into personal information. But I think that the vast majority of wildland firefighters are very tech-savvy and won't have any problem with this at all. The main problem is at that that particular subsection of the Fire Service tends to be very transient and will change one to another every other year, or only spend a few years in before they go on to a more permanent career. The vast majority are seasonal. But that's a very small subsection of what you're looking at here. Overall, the goal of picking at least 200,000 participants out of the large mass of the population of firefighters, I don't think that's going to be that much of a problem, personally.

**Mr. Morrison:** Yes, that's our thought too. We don't know yet. Somebody had mentioned earlier, it's going to be our marketing strategy. This conversation is extremely important for us to do this right. If we don't get this right - you only get one chance sometimes to put this out there and if we have to keep changing, it's not going to work. Chuck, did you have something else?

**Mr. Bushey:** I just agree that marketing of this particular registry, as you say, is going to be key. It's going to have to be a very intense presentation to the entire firefighter service, not only Wildland, to get the word out. I know in Wildland we've got a lot of people out in the field now. Just communicating with the folks that I know, they're aware of the potential cancer problem of this particular effort, they are not aware, very few. So, the rollout is going to have to be very important.

**Mr. Morrison** thanked Mr. Bushey and turned to Mr. Brimhall.

**Mr. Brimhall:** A couple of these survey questions ask for "select all that apply," yet it only looks like we're trying to capture data on one agency. I have some people that fall in the category of being active with three or more agencies like myself currently. I work full time for the state Fire Service. I volunteer as fire chief. And I volunteer with my local Wildland facility, a nature center doing prescribed burns. I've got others of my

employees. We have 500 part-time state fire instructors in New York that are either current or former firefighters. So, they're going to fall into more than one category. Is there going to be an attempt to capture all those different entities or are we just focusing on one?

**Ms. Wilkinson:** Based off of that feedback that you had mentioned early on, it is part of our functional requirements that firefighters would be allowed to enter multiples for any of the departmental employment information. So, if you were to say that "I am both a career and a volunteer," it will give you the spaces to fill in for as many departments as you report. So, it is intended to accommodate all of those.

**Mr Morrison:** Thanks, Andrea, for stepping in and answering that. What I'd like to do is I might have to go around a little bit it, but just think about what NIOSH—and, Emily, you know what? I've called on so many people, but I'm going to call on you again, Emily, to get the information you need. So, Emily, go ahead and present.

**Ms. Novicki:** Yes, yes. So, what I think would be really help to us at NIOSH, and the NFR program staff in particular, is just a little bit more about the pros and cons. I think we've gotten some really helpful pieces of that as we've discussed, but just in helping us really make a final decision, just more about what you see as the pros and cons of Option 1 and then Option 2.

**Mr. Morrison** called on Dr. Janke.

**Dr. Jakhnke:** I think the one pro of the proofing is that we get a lot of data, but I think pretty much everything beyond that is just a con and I think it will severely limit the recruitment and I think it will limit the generalizability of the sample overall. So, I think the list of cons is long with that one. Obviously, the con of Option 2 is that it's going to be a little bit more challenging if people aren't going to be able to get in and look at what they filled out previously. But I think the pro is that it just makes it so much easier. So, I think we're going to get a wider sample. I can tell you every time I try to mention this registry, every time I present anywhere on any topic - which sometimes seems a little bit off-topic on the presentations—but I think this is so important. And when I say the challenge is going to be we need everyone on board because we're going to have to ask for information about Social Security numbers, the look or horror on people's faces. When I explain why, people start to nod, but I just think we're already asking for so much and we're already asking for so much trust that I think if we get/give any more barriers than are absolutely necessary, I think that we're going to lose people before we even get them in. And I put my hand down earlier because I thought Dennis covered everything so beautifully that if we get people bought into this early on, I think we can ask them for 10 minutes of time as we go. So, I think that the pro is really going to be a rich dataset that provides a lot of really good information. And I think this is one of those really instances where being perfect can't be the enemy of the good. And vice versa; I think we really need to think maximizing how we can use the dataset for the best good and not the best perfect. And then I think the best good is really that Option 2.

**Mr. Morrison** thanked Dr. Janke and called on Mr. McQueen from the National Volunteer Fire Council.

**Mr. McQueen:** First of all, I want to let everybody know that the National Volunteer Fire Council fully supports the NFR and what they're doing. However, there are some issues that we ran into here in New York State with collecting of the data. You can have the simplest project you ever want to do but, to some people,

when it comes to putting their name to something, feels that Big Brother is watching them. So, the way that we approach, the way that we go about doing this is very crucial and the way that we all convey a simplistic attitude of this and why we're doing this and the success rate that we're going to get out of this and the belief that we can reduce the issues with cancer and occupational cancer in the Fire Service, the better off we're going to be. I am an occupational cancer survivor. As a matter of fact, I go back for my two-year test on the 26<sup>th</sup> of this month. It's been the worst month of my life, just like every month is when you go back and check. However, if I know that I can make a firefighter's life a lot better by doing this, then I will do that. And I think that's the process we've got to do. We've got to stay upbeat, we've got to stay positive, and we've got to keep moving forward. We cannot let this die.

**Mr. Morrison** thanked Mr. McQueen and called on Mr. Miller.

**Mr. Miller:** Thank you, Pat. So, as we looked at all these various options and knowing the big concern of being the necessary data that's going to meet the needs for the researchers, I'm really looking at Option 2 as probably the more appropriate choice to get us where we need to go to gather the most data. And I think that's the pro of all this. As we talked over this last year and were educated on the need to have the appropriate information for the various registries and for additional research, it provided insight I think for all of us as to why it's important to get all the information, but as we spoke to the user, the Fire Service members, clearly the apprehension to providing that is still there. So Option 2 obviously then rises to the top of being a choice that will allow for the greatest participation and ease of registration in doing that. In looking over the list, though, within the green and red, are there items within that sensitive-data area that are truly sensitive? Is there information in that area that can be moved to the green to be a pro about what's going on? We're asking the work status and where you're at—career, volunteer, part time, not working, retired, whatever—but can we glean information such as the department, which then opens the door to gaining more information further down the road within the research and does that meet the intent of the registry? So, again, obviously the pros are ease of registration, but data is required to do that and we need that data for the research.

**Mr. Morrison** thanked Mr. Miller and called on Mr. Frieders.

**Mr. Frieders:** Yes, it's that same thing everybody else has said, there's no benefit in not getting the data. I mean if we can put together the most robust programs and most robust systems, and if nobody uses it or nobody decides to ever log into it, it's worthless, it's a waste of time. So I echo what Sara said, I echo what Richard said. I think the more simple it is, the more likely we're going to get what we're looking for.

**Mr. Morrison** thanked Mr. Frieders and called on Dr. LeMasters.

**Dr. LeMasters:** I think Richard Miller made a very good point that had crossed my mind too, was that the current department, I mean some of the things in the red, it seems like they could really be moved to the green. The current department, how sensitive is that information? Even things like state of birth. I don't even know how important that is to even ask, but could that be moved to the green section? And I feel like we've had a pretty unanimous input from both our panel members, as well as the letters we've received, as well as the public comments, that we have to make enrollment as easy as possible and Option 1 does not do that.

And I think the committee is suggesting that Option 2 is probably the most user-friendly—besides Option 3, which I guess is not going to even be considered—but Option 2 is the most user-friendly. And just thinking of how much difficulty we've had in getting people vaccinated and regarding their health, even when death may be an option. It makes me think that we've got to really, really make this as simple as possible and that should be pilot-tested before we go to the field that we have, in fact, if we go with Option 2, made Option 2 as simple as possible. And we should try it out—if we didn't want to influence the firefighters by using them to pilot-test it, maybe we could pilot-test it on policemen or some other group that won't be included in this, which I have done. I've pilot-tested things on a similar-but-different group to see how well it was received.

**Ms. Novicki:** Would Mike Loudermilk be able to comment on the issue about the potential for moving variables from red into green? I think the current department one has come up a of couple times.

**Mr. Loudermilk:** There is very limited flexibility in terms of how PII is categorized in sensitivity levels in the federal space. There are hundreds of pages of regulations around what is viable to back into an identity and those classification levels. There may be some ability in the department, like anything that's not truly a PII attribute that's more about that work history, has more flexibility and we certainly will help support the program in trying to make the pallet of the data that would be available in Option 2 as rich as possible. But I didn't want to mislead that a lot of that is just—there are regulations about PII. And that's actually gone in the wrong direction and I've witnessed that change in the past five years as people have gotten more creative about misusing that data, it's become more restricted.

**Mr. Morrison** asked Dr. Materna to share what she wrote in the chat.

**Dr. Materna:** It seems like possible pro of Option 2 is that you could complete your enrollment on either a cellphone or a computer; whereas, it seemed like Option 1 required both because of that thing of taking a picture of your license or whatever it was that was verifying your identity. So, if that's true, then I think it is another pro for Option 2.

And then, just while I'm on, I just feel like we should also consider taking some of those red items and just putting them in a survey. I mean they're already deemed as more sensitive, so it seems like requiring them in the profile—well, I guess that would be my question to NIOSH: what is the advantage to requiring them in the profile versus once you're like, okay, I'm on board, I'm enrolled now, and then you jump into the survey where you expect to be asked a lot of questions? Like country of birth could be considered sensitive, definitely Social Security number. I mean talking about cancer diagnoses right away? Maybe, I don't know.

**Dr. Siegel:** I think that's a great suggestion and in light of some of the IT requirements that we've really delved into since the original design, I think that's why this is up for discussion. And that could be potentially the plan is to move these items to the questionnaire. I think the meat of the discussion—and this has got brought up a couple times now—is that cancer diagnosis, date of birth, state of birth, SSN, those are items that could be considered sensitive or wouldn't change, and that would be a no-brainer to potentially move to the questionnaire. I think the biggest downfall of potentially moving current department and basic information about your current job to the enrollment questionnaire is that they wouldn't be able to re-access that and update that over time if it's considered to be PII.

**Mr. Morrison:** And, Kenny, do you have anything to add to that?

**Dr. Fent:** I just want to thank the committee again. This has been very informative for us. It's good to hear all the different perspectives and you all come with different backgrounds. Obviously, we want to collect the data we need from the scientific side of things and we also want to make sure that we have good participation rates. So, we're trying to wrestle with all of these things. I think that we're certainly going to consider all these options, but it sounds like we're hearing a lot about Option 2 and that's something that I think we can do really good science under that option. The account, having the ability to have firefighters have an account is going to be really important for us because we want to maintain contact and interaction with the participants. We do plan on reaching out to them on a semiregular basis, giving them updates on the Firefighter Registry, letting them know about papers and different publications and things that may apply to their work, and then encouraging them to of course update their user profile or come back in and do a questionnaire. Our plan is to make it a very dynamic kind of system where we have those regular interactions with our firefighters. But we also recognize that there will be a handful of firefighters that will register and we'll never hear from them again. And so that's why that initial enrollment questionnaire, we want to try to collect as much information as we can at the outset. These are all things, I mean we're going to take all this into consideration, everything we heard today, in making our decision and finding a path forward. So, we really appreciate all the feedback that we've gotten.

**Mr. Morrison:** Kenny, just a real quick question. I think it's something that Grace just stated was about pilot-testing. Are you going to pilot-test this?

**Dr. Fent:** Yes, that's definitely the plan, although Grace's idea around maybe a different occupational group is an interesting one that we might consider. Our plan is to work with maybe a smaller department in Ohio or someplace a little bit more local to pilot it. And then we also have some plans to do usability testing even before we do the piloting, just making sure that we've got that user experience as tight and seamless as we can.

**Mr. Morrison** asked for closing comments and Mr. Brimhall raised his hand.

**Mr. Brimhall:** If we are going to be ready to roll this out next summer, we need to start getting on the agendas to be at the big, national-level Fire Service conferences, both as a booth and as a presentation. Most of these things book out a year or more in advance of their next agenda. I think Fire Expo was in Columbus, Ohio, Kenny, this year, in September? The National Fallen Firefighters is having a workshop just prior to it in Columbus, I know that. But we've got to get on these things ahead of time or we'll be delayed on getting our information out to the Fire Service. Because that's going to be our best exposure is to be at these locations where people can come and talk to us.

**Mr. Morrison:** Thanks, Shawn, I appreciate that. That's definitely something we have to start thinking about. Yes, Dr. Moffat?

**Dr. Moffatt:** Yes, Pat. I'm in the midst of doing a cancer cause of death for a firefighter who was 38 years old that passed away from acute lymphoblastic leukemia. And I just want to thank the work that NIOSH is doing, especially Kenny Fent and Alex Mayer, with regard to the research they're doing with regard to Benzene and

other cancer compounds, as well as the great work that Dr. LeMasters has done with all the history that she brings forth. I just want to thank you all. It makes it easier for me to build a case for this young man's family. He has a widow and two children. And these are the kind of outcomes that we're looking for in these situations and that's when it becomes real for us as physicians to have the data to go back to the state pensions and be able to say that this is a direct occupational disease and to be paid for. So, thank you all, I appreciate it.

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

**Ms. Novicki:** This has been hugely helpful to hear all your input. We appreciate all the Subcommittee members, the members of the public who wrote in written comments ahead of time, and the three folks who shared oral comments with us today. It's been so, so helpful. So as far as next steps, we're going to do detailed meeting minutes which will be public up on the website. And then the registry team will take all this information and figure out next steps.

Kenny will be presenting to the main NIOSH Board of Scientific Counselors this October. We have to funnel everything that happens here up through the main committee. Grace and Pat are both members of the main NIOSH BSC. That's the immediate future. This group will not be meeting again until 2022, but we can continue to provide email updates in the meantime about how things are going. So that's our plan for the moment.

**Dr. LeMasters:** I just wanted to thank everybody for being here today and continued support of this very important work. And a big shout-out to the NIOSH team that has really come a long way; I can remember from our first meeting and the proposal, I've come a long way to getting as closer to actual rollout of this in a year from now, hopefully. So, thank you all, NIOSH, for all of your hard, hard work, both on the exposure side, the epidemiology side, the statistical side, and the bioinformatics side. We appreciate it all. And thank you, Pat, for leading that great discussion.

[Adjourn.]

# Public Comments

## Oral Comments.

**Dr. Judith Graber, Associate Professor at the Rutgers School of Public Health**

I'd like to thank you, thank Dr. Lemasters, Mr. Morrison and the National Firefighter Registry Subcommittee for this opportunity to comment on these important issues that will impact the development, and ultimately the success, of the National Firefighter Registry. I also want to really comment Dr. Fent, Dr. Siegel and the NIOSH team for the extraordinary job they've done designing this important public health surveillance system.

Once operational, the NFR will be a unique resource for obtaining exposure and outcome information that will provide the evidence base to guide primary and secondary prevention strategies to reduce the burden of cancer incidence, disability and death among the women and men of our US Fire Service. However, to do this, the NFR will need to enroll firefighters in a way that represents the complexities of the US Fire Service and the incredible diversity of exposures among our firefighters. Her primary work is with volunteer firefighters. About 67 percent of US firefighters serve as volunteers, and they protect communities that include only about a third of the US population, because they tend to serve in less populated areas than their career counterparts. But the reality is that you do, of course, see volunteers in some very densely populated areas like Piscataway, New Jersey, and you see career firefighters in some very, very rural areas like Maine. So, while volunteer firefighters do the same job as career firefighters, they often do this with less training, protection, and organizational support. By "organizational support", I mean things like annual physicals, health monitoring, having exercise equipment, etc. on site. As well, volunteers tend to serve many, many more years than career firefighters, all adding to the potential for very different and increased firefighting-related exposures, again pointing to this diversity of exposures.

Now, because volunteer firefighters are not typically at the firehouse on shifts, they are really challenging to access. As well, we don't typically have the equivalent of health records or employment records, so they're rarely included in studies of firefighter health, including cancer, making their participation in the NFR so critical.

So, my current research, I am trying to enroll volunteer firefighters into a large national cohort, the Firefighter Cancer Cohort Study. This is extremely challenging, both in terms of engaging these volunteer departments as well as in the response rates for individual firefighters at these departments. And the reasons for this are very complex but they include, again, that volunteer firefighters are not typically on shift, and they have many, many, many demands on their time. So, it is really imperative that we make the NFR as accessible as possible to members of our Fire Service, particularly the volunteers that face these unique challenges, and their difficulty in participating in research and in registries. So as such, it is my opinion that multi-stage validation such as that required for identity proofing will be a significant impediment to firefighters participating in the NFR, particularly to the majority of US firefighters who serve as volunteers. And I want to repeat that. I believe that multi-stage validation such as that required for identity proofing will

be a significant impediment to firefighters participating in the NFR, particularly volunteer firefighters. Further, from my experience, I think it is very likely that identity proofing will disproportionately discourage members of smaller, more rural fire departments from participating. I'd also like to note, on the side, that it's very unclear to me why the firefighter's current department is considered a sensitive data element. To me, it implies that there's an available list that someone could link to of firefighters in different departments. I know of no such resource, especially in volunteer departments.

Finally, I would just like to add that to successfully enroll and retain this under-studied majority of the US Fire Service, the NFR is going to need significant resources targeted at outreach and ongoing communication with fire departments, and it is going to be really, really easy to underestimate the resources needed for this. So, I just want to add for you to consider this, as I'm sure you are, in your long-term planning. So that concludes my comments. Thank you again for the opportunity to comment on the development of this critical public health program.

### **Mr. Derek Urwin, Director of Science and Research at the International Association of Firefighters**

Thank you and good afternoon. My name is Derek Urwin. I am the Director of Science and Research at the International Association of Fire Fighters. I have been a firefighter for fifteen years, serving with Miami-Dade Fire Rescue and the Los Angeles County Fire Department, and I am also a PhD candidate in chemistry at UCLA. You are well aware, I am sure, that the Fire Service relies on teamwork to be effective. But what may be less apparent is that the effectiveness of any crew in the Fire Service is predicated upon trust. Trust that your tailboard partner is always by your side, trust that we will come for one another if trapped in a fire, and trust that my crew would care for my family if I were to die in the line of duty. For the NFR, or any cancer-related research project in the Fire Service to be effective, you have to build that same trust with firefighters, because we see cancer as something that impacts not only us but our families as well. So, while you'd find that most firefighters are eager to participate in research that might put a dent in cancer in the Fire Service, you'll also find that many are hesitant to give personal information, not out of paranoia but because there is often the concern that doing so might impact their ability to provide for their family.

Over years of enrolling firefighters into the Firefighter Cancer Cohort Study for example, I am often asked by prospective research participants if data from the study could cause them to lose their job or prevent them from getting life insurance for their family - again, always coming back to providing for their family. So, in this age of weekly catastrophic data breaches, it's important to recognize that many firefighters will be hesitant or wholly unwilling to provide things like their driver's license or cell phone information - again, not out of paranoia but out of concern that a breach of such information could impact their family financially or worse, could impact their family's safety, as many of us have faced threats of violence in the line of duty.

As outlined in the NFR's engineering requirements review, the full registration option with identity proofing is likely to discourage prospective applicants from enrolling, for the reasons I just mentioned. Prospective research participants are not likely to prioritize the ability to access and update their own information, but they are likely to be discouraged by the prospect of providing information that they deem sensitive, irrespective of the protections that might be in place. The light registration option is far more likely to

achieve the maximum study participation that is crucial to the NFR's success. So, the IAFF asks respectfully that you take these points into consideration as you determine the information required for the NFR enrollment process, in hopes of maximizing firefighter participation in this extremely important project. And thank you for your time.

### **Mr. Frank Leeb, FDNY Deputy Assistant Chief and Chief of the Fire Academy**

Thank you. I appreciate being on here today. So, I respectfully submit the following comments for consideration to the National Firefighter Registry Subcommittee. To begin, I, like most firefighters who understand an increased risk to firefighters, both career and volunteer, greatly appreciate and are humbled by the dedication and efforts of this committee and, frankly, everyone on this call. I join all of you who eagerly await the rollout of this critically important registry. It is vitally important that your registry is easy and quick to join, and that it takes into account the sensitivity of firefighters to give too much personal or identifying information. These must be viewed as significant barriers to firefighters joining this registry. It is in this spirit that I present my comments for consideration.

My comments and potential concerns reside primarily as it relates to barriers to join the Registry. It is all about eliminating barriers to join, just like it is all about eliminating barriers to reduce the cancer risk of our firefighters both in the fire station, on the scene, and elsewhere. If there is too many barriers or hurdles, the average firefighter simply will not join. The enrollment system and data that may be required could greatly impact those willing to enroll. It's important that any system of enrollment does not require a great deal of identifying information, and only takes a limited amount of time to join. Having to enter a driver's license or Social Security number, especially an entire Social Security number, are significant impediments, and will greatly reduce the number of firefighters willing to participate. After all, it is a voluntary registry.

Other systems of identification could be used. When I go to training in my volunteer department for example, they use the first two letters of my last name and the last four of my Social Security to identify me, and my ID number. A similar system could be used for the Registry, not having to provide an entire Social Security number. Additionally, I believe it's important that willing fire departments that meet a set of criteria be allowed to vet their members for inclusion. Importantly, these vetted firefighters will not need to submit that additional proof. Their fire department can do that on their behalf. This could be done using a dedicated portal or by submission of a master list or other means of inclusion. Grassroots methods that encourage fire service partnerships with the Registry, while leveraging already-in-place vetting that serve most fire departments, could be beneficial. It is important, and can be expected, that these partner departments will encourage their members to join the Registry, with an eliminating vetting process for firefighters to join. Such a strategy, with the elimination of barriers, will likely increase the number of registrants in a given department.

As both a career and volunteer firefighter, I can speak to both sides. These are significant barriers, regardless. Perhaps a light or a full registration option, or both, should be the method that we go with. I think of the 9/11 Health Registry, and I had to enter a lot of information initially, but I then take yearly surveys that I do while I'm at the fire department on duty. They send out monthly emails with information specific to the health

registries of the members. I do not have the ability to go in and alter my information other than my annual questionnaire that I'm sent to.

The other issue—so with that, that would make it where periodic emails go out, highlighting data. But it could also do subsets for departments that are willing participants, that if they have their members do the questionnaires or fill out information periodically, they could have specific data to their department and their members. That adds an increasing value to some of the stakeholders.

My final point is volunteers are more transient than career firefighters. Although career firefighters may change jobs, they usually stay within the Fire Service. What would be the mechanism to ensure that someone who registers and then leaves the Fire Service in three years is not counted for their life, for their entire life? That concludes my comments. Thank you very much.

## Written Comments

### Gavin Horn

I would like to begin by expressing my appreciation and admiration to the National Firefighter Registry (NFR) team for their leadership and dedication to this important project.

This comment is respectfully submitted for NFR's consideration regarding logon requirements for firefighters to achieve access to the registry. Recruiting firefighters to participate from the diverse departments, districts and agencies (as well as retirees) from across the country will require working through distinct opportunities and challenges, but one of the most significant hurdles is likely the time and complexity needed to recruit and enroll firefighters. While it is critical to relay study risks and benefits as well as ensure data security, if this process becomes overly cumbersome, participation rates are likely to drop quickly. This challenge becomes more prevalent when working with individuals or groups of firefighters who are not as familiar with technology or may not have robust internet infrastructure.

In order to achieve strong participation from a broad representation of the fire service in the NFR, it is important that the sign up and logon processes be made as straightforward with minimal steps, complexity and time commitment as possible while maintaining data security. If this means that individuals' full social security number cannot be collected (in order to maintain security standards), the tradeoff in attracting a broader representation of the fire service may pay off.

Again, thank you for all of the hard work, planning, and preparation by NFR team!

### Tom Harbour

The committee and the public is well aware of the current wildfire situation in the western United States. Over 20,000 firefighters are engaged in work to protect lives and sustain critical natural resources.

While related to the firefighting which occurs in our more populated areas, and which includes firefighting in buildings, hazardous materials operations, rescue, and medical assistance, wildland firefighting is a distinctive component of our national firefighting capacity.

The work is accomplished by women and men who selflessly engage in work for which the risks of cancer are not well understood.

Research by scientists such as Kathleen Navarro, Corey Butler, and Jeff Burgess is beginning to develop information about the risks faced by those who labor in our nations forests, grass lands, and brush fields.

While continuing to focus on firefighters who face specific and urgent questions about cancer in our cities and towns, I urge the committee to continue the quest for answers to questions about those who work in our nations "wildlands".

### **Frank Leeb**

I respectfully submit the following comments for consideration to the National Firefighter Registry Subcommittee. To begin, I like most firefighters who understand the increased cancer risk to firefighters both career and volunteer greatly appreciate and are humbled by the dedication and efforts of this committee. I join all of you who eagerly await the roll out of this critically important registry.

It is vitally important that the registry is easy and quick to join and takes into account the sensitivity of firefighters to giving too much personal or identifying information. These should be viewed as significant barriers to firefighters joining this registry. It is in this spirit that I present my comments for consideration.

My comments and potential concerns reside primarily as it relates to the barriers to join the registry. It is all about eliminating barriers to join.

If there are too many barriers or hurdles, the average firefighter will not join. The enrollment system and data that may be required could greatly impact those willing to enroll. It is important that any system of enrollment does not require a great deal of identifying information and takes only a few minutes to join. (This includes license numbers or social security numbers). Other systems of identification can be used. For example, some large firefighter training schools use the first two letters of your last name and then the last four of your social security number as an id number. A similar system can be used for the registry. (Example Ke1075)

Additionally, I believe it is important that willing fire departments that meet a set of criteria be allowed to vet their members for inclusion. Importantly, these vetted firefighters will not need to submit additional proof that they are a firefighter. This can be done using a dedicated portal or by the submission of a master list or other means of inclusion.

This grass roots method encourages fire service partnerships with the registry while leveraging the already in place vetting that most fire departments have. Importantly, it can be expected that these partner departments will encourage their members to join the registry with an eliminated vetting of the firefighters

to join. Such a strategy with the elimination of barriers will likely increase the number of registries in a given department.

### Derek Urwin

Maximizing participation in the National Firefighter Registry is essential to its mission to track and analyze cancer trends and risk factors among members of the U.S. fire service. To this end, it is essential to simplify the enrollment process and to limit identification requirements to the minimum necessary so that prospective Registry participants feel comfortable and secure in the process.

Thank you for taking the time to consider this comment.

### Jeff Burgess

For the NFR, if the enrollment process for firefighter participants is too burdensome (e.g. identity authentication for website use), then this will severely limit their participation in the study and likely lead to selection bias.

### IAFC/NFPA Metropolitan Fire Chiefs

Submitted a letter as an attachment. The text is below.

IAFC/NFPA Metropolitan  
Fire Chiefs Association  
3257 Beals Branch Road, Louisville, KY 40206. Tel: +1-502-727-0239  
Email: [Rsanders@NFPA.org](mailto:Rsanders@NFPA.org) Website: [www.nfpa.org/metro](http://www.nfpa.org/metro)

The Metropolitan Fire Chiefs Association acknowledges that previous studies, including a study completed by NIOSH, indicating that career firefighters are at higher risk of cancer. The Metro Chiefs further understand that previous studies are limited by the inclusion of small numbers of women and minorities, and a lack of data on volunteer firefighters.

While studies show that firefighters have increased risk of certain cancers, questions remain:

- What is the cancer risk for Minority Firefighters? Female Firefighters? Volunteers?
- How does cancer risk vary among firefighters based on exposures?
- What is the risk among more recently hired firefighters responding in a built environment with increasing synthetic materials?
- Has the risk changed with adoption of control interventions from previous studies?
- Does consistent use of SCBA, decontamination measures, laundering, hood exchange programs make a difference? Do these measures make a difference in differing geographic regions and in differing toxic exposure doses?

Based on the enabling legislation, it is the goal of the NFR to track firefighters' cancer risk over time to better understand the link between workplace exposures and cancer. Therefore, the NFR must have hundreds of thousands of firefighters participate and share their exposure data to ensure sufficient information for ongoing research. Given this high number of participants, the CDC/NIOSH must not introduce barriers that cause firefighters to forego registering in the NFR.

One such barrier is identity proofing. To ask firefighters to provide driver's license and full social security information to be able to register is a path to disaster for the NFR. Through many discussions and conference presentations, we know that firefighters and fire officers are not willing to go through such an exercise to participate in the NFR. It is the strong recommendation of the Metropolitan Fire Chiefs that the registration and personal identifiable information for entry into the registry be no more than a name and date of birth. Keeping the entry simple and minimizing the person's identity information will allow our organization to better advocate for our members to register and lead their firefighters and fire officers to do the same.

Thank you for your consideration.

Respectfully,  
Russell E. Sanders, Executive Secretary

### National Fallen Firefighters Foundation

Submitted a letter as an attachment. The text is below.

August 4, 2021

Docket number CDC-2021-0055; NIOSH-232,  
c/o Sherri Diana, NIOSH Docket Office  
National Institute for Occupational Safety and Health  
1 090 Tusculum Avenue, MS C-34, Cincinnati, Ohio 45226.

Dear National Firefighter Registry Team,

The National Fallen Firefighters Foundation (NFFF) is profoundly aware of the loss and sacrifice of firefighters every day. When a firefighter dies in the line of duty the impact is felt throughout the community, but the families and co-workers of the fallen feel the sense of loss most deeply. The work initially spearheaded by NIOSH and then by so many other researchers is making a difference in firefighter's lives. Because of those efforts the NFFF will have fewer names to add to the National Fallen Firefighters Memorial.

The Firefighter Registry will continue to save lives and will impact future generations with cutting edge information about cancers and how to reduce the instances of firefighter cancers. Furthermore, the research focusing on firefighter cancers will undoubtedly benefit the lives of all Americans.

As you wrestle with questions related to a firefighter's ability to input data into the registry, the NFFF encourages the National Firefighter Registry team to make the process as user friendly as possible. Our own experience with various registration systems, through our Seat Belt Pledge Program or our Fire Hero Learning Network has shown us the simpler the registration process the more people register. We believe the science obtained through the registrants is crucial for the research to valuable in the future. Equally as crucial is to get more firefighters to input their information, even if it means sacrificing the registrant's ability to change data once they have already entered it.

If you would like more clarification on our position or if I can answer any questions for the NFR team please do not hesitate to contact me.

Sincerely,

Chief Ronald Jon Siarnicki

Executive Director

## Certification Statement

I hereby certify that, to the best of my knowledge and ability, the foregoing minutes of the August 13, 2021, meeting of the National Firefighter Registry of the NIOSH Board of Scientific Counselors, CDC are accurate and complete.

Grace LeMasters PhD 9/17/21

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 August 13, 2021, meeting of the National Firefighter Registry 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

## GLOSSARY

<b>Abbreviation</b>	<b>Definition</b>
AoC	Assurance of Confidentiality
FACA	Federal Advisory Committee Act
IAFF	International Association of Fire Fighters
NFR	National Firefighter Registry
NFRS	National Firefighter Registry Subcommittee
PII	Personally identifiable information
SSN	Social Security Number