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 SUBCOMMITEE

FIFTH MEETING
HYBRID IN-PERSON AND ONLINE, OPEN TO THE PUBLIC
JUNE 13, 2022

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Summary Proceedings

The fifth meeting of the National Institute for Occupational Safety and Health Board of Scientific Counselors (BSC) National Firefighter Registry (NFRS) Subcommittee Meeting was convened on Tuesday, June 13, 2023. Members had the option to attend in-person at NIOSH's Washington DC offices or online via Zoom. The NFRS met in open session in accordance with the Privacy Act and the Federal Advisory Committee Act (FACA).

Attendees

Mr. Shawn Brimhall - Member
Dr. Eric Durbin – Member
Dr. Kenneth Fent
Dr. Manuel Foneseca – Member
Mr. Tom Harbour - Member
Dr. Sara Jahnke, PhD - Member
Ms. Betsy Kohler - Member
Dr. Grace LeMasters, PhD – Co-Chair
Ms. Sarah Lee
Dr. Barbara Materna, PhD - Member
Mr. Alex Mayer
Dr. Steven Moffatt – Member
Mr. Patrick Morrison – Co-chair
Ms. Emily Novicki – Designated Federal Officer
Dr. Miriam Siegel
Dr. Demond Simmons - Member
Mr. Victor Stagnaro - Member

Welcome and Meeting Logistics

Ms. Novicki called to order the open session of the fourth meeting of the NIOSH BSC-NFRS at 9:00 a.m. Eastern Time (ET) on Tuesday, June 13, 2023. A roll call of all NFRS members confirmed that a quorum was present. The roll was also called following each break to ensure that quorum was maintained. Quorum was maintained throughout the day. No conflicts of interest were declared. Members of the public were notified that they would remain in listen-only mode until the public comment period.

Announcements, Introduction, and Agenda

Dr. LeMasters and **Mr. Morrison** welcomed everyone and acknowledged the three new members: Dr. Manuel (Manny) Fonseca, Ms. Sarah Lee, and Dr. Demond Simmons. Dr. LeMasters invited them to briefly introduce themselves.

Dr. Fonseca has been the in the fire service for over 44 years. He began his career as a volunteer firefighter and then worked at the Nashville fire department for 30 years as a career firefighter. He's been an advocate for cancer awareness because he had stage 4 thyroid cancer late in his career which forced his retirement. He's been an advocate for Hispanic firefighters. He's also worked with Black professional firefighters and women firefighters to make sure that there is equal representation in the fire service.

Dr. Simmons is a 26-year member of the fire service currently serving for the Oakland Fire Department. He's a strong proponent of all things safety as it relates to professional firefighters, not only during their career, but equally important, post-career.

Ms. Lee is the CEO of the National Volunteer Fire Council. She's been with this organization for nearly 17 years. Ms. Lee comes from a fire service family. Her dad, brother, mom, husband, and stepson are all in the fire service. Her husband is a cancer survivor as well. He had had cancer about 13 years ago, and the effects of radiation have caught up with him.

Dr. LeMasters also invited **Dr. Eric Durbin** to introduce himself. He is the director of the Kentucky Cancer Registry, a population-based registry in the State of Kentucky. He is also the also a faculty member in the University of Kentucky College of Medicine and serves their cancer center as the director of an informatics core. He has a particular interest in in this work. His father was a firefighter for 29 years and was diagnosed with throat cancer around December 2022. His father has just gone through chemotherapy and radiation and is now considered cancer-free. He described the treatment as "brutal" and shared that his dad is trying to regain normalcy.

Dr. LeMasters and **Mr. Morrison** both stressed the importance of today's meeting and the significance of the National Firefighter Registry for Cancer. They turned it over to Dr. Kenneth (Kenny) Fent for the first presentation.

Overview of Project Background, National Launch, and Current Status

Dr. Fent welcomed the NFRS members and thanked them for taking time out of their busy schedules to attend the meeting and provide advice. He shared that he would give a progress report about the National Firefighter Registry for Cancer and started by introducing the NFR team:

- Lead epidemiologist Miriam Siegel
- Health scientist Alex Mayer
- Health scientist Andrea Wilkinson (currently on maternity leave)
- Health communications specialist Jennifer Tyrawski
- Health communications specialist Greg Hartle,
- Public health advisor Jasmine Nelson
- Fire service subject matter expert Rob Saunders
- Industrial hygienist/Epidemiologist (support) Catherine Beaucham
- Engineer (support) Barb Alexander
- Data scientist (support) Karl Sieber

One thing that you'll notice right away is that our team has grown quite a bit. We have gotten a lot of support from other branches within our division. It has been a helpful thing to have over the last year.

We've also gotten support outside our division. The NIOSH Office of the Director (OD) Information Technology unit has been instrumental in developing the enrollment web portal. Our OD Communications Office has been helpful with the press releases and news interviews, and everything we're doing to get the message out about the NFR. We also have an outstanding contractor, RTI International, who is leading our communications effort. They have been developing great materials and helping us to attend conferences and do a lot of other things get the message out. Then we have fire service subject matter expert (SME) contractors, who are also helping us to disseminate the information to specific groups of firefighters.

There have been some important things that have happened in the fire service over the last several months. These events are raising awareness within the fire service about exposures and potential long-term health implications. The East Palestine, Ohio train derailment got a lot of media attention. This was a major disaster in the state of Ohio, where the NFR team lives. Another event is the Richmond, Indiana, plastics recycling fire. This was a large event that lasted a long time and had unique exposures. And, of course, wildland/urban interface fires that are still happening across the United States, and especially in the western United States.

Many of you at this point have heard of per- and polyfluoroalkyl substances or PFAS. That's of great concern in the fire service because they are components of aqueous film forming films. They are being removed from many types of foams, but they're still present in other types of foams, like Class B foams. Then there's even PFAS that's been found in turnout gear.

Finally, lithium-ion battery fires are becoming quite common, especially in New York City. New York City is averaging about one of those fires per day and expectation is that those fires will become more common in

other areas of the United States. We really don't understand what the toxicity is of those unique exposures for firefighters.

I bring all this up because we've heard from firefighters across the country that they're concerned about these exposures, and that they're interested in how the NFR can help better understand the long-term health implications from some of those unique exposures.

Many of you are probably familiar with this at this point, but the International Agency for Research on Cancer (IARC), which is part of the World Health Organization, recently re-evaluated the occupation of firefighting. Back in 2010 they had evaluated the occupation of firefighting for its carcinogenicity and classified it as a group 2B possible carcinogen. Just last summer they brought together all the experts throughout the world to look at the current scientific evidence. I had the privilege of serving on that committee.

That committee reclassified firefighting as a group 1 known human carcinogen, based on sufficient evidence of two types of cancer (mesothelioma and bladder cancer) in firefighters. The committee also found limited evidence for five other cancers in firefighters: colon, prostate, testicular, melanoma of the skin, and non-Hodgkin lymphoma. Limited evidence is really a bit of a misnomer. There's actually very strong evidence that there's an increased risk of those cancers in firefighters. They just couldn't rule out other causes.

The committee also looked at biological mechanisms that may lead to cancer. There are 10 different biological mechanisms that they consider, and they found strong evidence for 5 biological mechanisms. The chair of that subgroup of the committee believes that this is the only agent that's ever had 5 mechanisms with strong evidence. The fact that we're seeing higher risk of certain types of cancer, coupled with the fact that firefighters are exposed to various known carcinogens (including combustion byproducts like benzene, diesel exhaust, building materials like asbestos, other chemicals, and even shift work) really provides very compelling evidence that firefighters have an increased risk of at least certain types of cancer.

The committee did not differentiate between the different types of firefighters, so they grouped structural and wildland together in this evaluation. However, that was mainly because there wasn't enough data to differentiate between the different types.

I think that although IARC puts to rest the question whether there's an increased risk of certain types of cancer, there are still a lot of questions about firefighters' risk of cancer. We still don't fully understand what the cancer risk is for volunteer firefighters. In the United States volunteer firefighters make up the majority of the fire service, over 65%. We don't understand what the cancer risk is for subspecialties of the fire service, such as fire cause investigators, instructors, and wildland firefighters. We don't understand how the cancer risk varies by demographic groups, between women and men, and among minority groups. There needs to be more research on that.

Other outstanding questions include:

- How does firefighters' cancer risk vary regionally?
- How does it differ between urban and rural departments?

- How prevalent are rare forms of cancer among firefighters? (To be able to study rare forms of cancer, you need a large and diverse cohort that you can follow over a long period of time just to be able to detect enough of those cancers.)
- How does the cancer risk change with increasing exposures? (That includes major events. Is it the cumulative exposures over a work history? Or do some of these major events contribute in a unique way to cancer risk?)
- What other occupational and non-occupational risk factors may contribute?
- Are there other chronic illnesses that are elevated in firefighters?

To be able to answer these questions, we really do need that large, diverse cohort that we can follow over time. That's where the National Firefighter Registry for Cancer comes into play.

The NFR for Cancer came about through an act of legislation, the Firefighter Cancer Registry Act of 2018. It mandated that CDC/NIOSH develop and maintain a voluntary registry of firefighters that collects relevant health and occupational information for purposes of determining cancer incidence. Our mission is to generate detailed knowledge about cancer and the fire service through a voluntary registry that reflects our nation's diverse firefighters, and then to take that information and provide it back to the fire service and public health communities so that they can do something to reduce that cancer in firefighters. Our ultimate goal is to reduce cancer in firefighters.

Our goal is to enroll 200,000 firefighters over the next several years. We want to enroll a diverse group of firefighters, with different job categories and different demographics. And our specific aims are to:

- Collect self-reported information on workplace and personal characteristics through a secure web portal.
- Obtain records from fire departments or agencies to track the trends and patterns of exposure so we can look at some of those exposure and response relationships.
- Link with health information databases, including state cancer registries and the National Death Index, so we can look at cancer diagnoses and deaths.

We have been very busy over the last year, and we've made a lot of progress:

- We finishing touches on the enrollment questionnaire, and we actually provided an updated questionnaire via our protocol on the NFRS web page. We have gotten requests from other researchers who want to see the questions that we're asking and we're happy to share that.
- We also finalized the assurance of confidentiality which provides the highest level of protection for the data that we're collecting. It basically means that we can't provide data to anybody outside of NFR programs even under court order.
- We also updated our website, which will be covered in more detail later.
- We obtained written support from several fire service organizations, many represented here in this room.
- We performed user acceptance testing of the web portal internally.

- We also conducted what we call soft roll out or pilot testing of the web portal with firefighters from 7 different fire departments across the United States.
- We created and staffed an NFR Help Desk.
- We rolled out our communications plan.

But most importantly, we launched the NFR nationally.

The **subcommittee members** gave a round of applause.

Dr. Fent next discussed the updated website, www.cdc.gov/nfr. One thing you might notice right away is that we're calling it the National Firefighter Registry for Cancer or NFR for Cancer. We heard from a handful of our stakeholders that they really wanted cancer to be front and center for this initiative, so we made a subtle change. We'll keep the logo the way it is, but when we first introduce our program, we will be calling it NFR for Cancer.

The other thing that you'll notice right off the bat is that we have a "Join now" button, which takes firefighters directly to our web portal at https://nfr.cdc.gov/. We have several topic pages that provide information about the NFR, how the NFR works, FAQs, videos, and communication materials. We have a link to our NFR newsletter, which provides our latest newsletter as well as a way to subscribe to the newsletter.

There's a section for publications. Any publications that come about through the NFR will course go on that tab. But we also have publications related to firefighter health and safety that we've already posted.

And then we have a supporting organizations box as well. When you click, that takes you to a page with links to all the letters of support that we've gotten from fire service organizations across the country. You'll see International Association of Fire Fighters, National Volunteer Fire Council, the Urban Fire Forum of the Metropolitan Fire Chiefs. Right there you have labor, management, and volunteer firefighters represented, and many other organizations. We're adding to this as we speak. Getting written support from our partners is critical, to give us credibility and show that we are in this together.

Towards the end of calendar year 2022, we were busy putting the finishing touches on the web portal. We did a lot internal quality assurance testing, making sure that we could validate data that was entered, and then fine tuning the web portal. That carried us to the end of 2022, and then at the beginning of 2023, we pushed the web portal to production, making the enrollment system live.

Then we conducted a soft roll out or pilot testing with firefighters at seven fire departments. We are extremely grateful for these fire departments. Their firefighters gave their time to help us, to make sure that the system was operating optimally. They identified some glitches that we were able to fix. We also made subtle changes to some of the wording of the questions based on their feedback as well. I think because of that, the system is operating even better today. Again, we're very grateful for these fire departments and the fire leadership.

We also attended the Fire Department Safety Officers Association Conference in Florida in January. While we were there, we enrolled firefighters. These were a lot of leaders in the fire service, in many cases with very

lengthy work histories that had to be entered. This provided another opportunity to learn how we can make enrollment work better for the fire service.

We implemented some final changes to the enrollment web portal, and then pushed that version to production in April 2023. That is the version we used for our official launch. We notified our fire service partners through our newsletter on April 13. I imagine for many of you here today, that's probably how you first learned that we were getting ready to launch. On April 17, we put out a press release and a social media campaign notifying the rest of the fire service and the general public. And then on April 27 we made a big announcement at the largest firefighter conference in the country FDIC (formerly known as the Fire Department Instructors Conference) in Indianapolis.

We recognize that no matter what, no matter how good you make a system, you still need to be able to provide support. Some firefighters are more tech savvy than others. Our web portal works on mobile, tablet, and computer, but there are a lot of different devices being used and different browsers. There are all these factors, so we understood how important it was to have a help desk. The NFR help desk is being staffed through a contract during business hours; initially it was staffed over the weekend too. They can take phone calls, voice mail, and emails, and they respond within 24 hours. They did get some phone calls when we first launched that they were able to help with.

We also developed an enrollment tip sheet that I'll discuss a bit later. It provides some tips on how to enroll. It’s a great resource that's available from our web portal landing page.

Our big announcement was at FDIC during the opening ceremony on April 27. I don't know how many people have been to FDIC, but it's a huge conference. There were thousands attending in-person. There were thousands attending virtually. I was joined on stage by representatives of International Association of Fire Fighters (IAFF), which is the firefighter’s union; the Firefighter Cancer Support Network (FCSN); the National Fallen Firefighters Foundation (NFFF); and FDIC. NFRS member Victor Stagnaro was on stage as well.

This was a great way to let many people in the fire service know that we were live and enrolling. We also had an exhibit booth at the conference, and we were able to collect over 300 emails. We distributed thousands of materials, and well over 2,000 people accessed the web portal during the week of FDIC. I think this was a great kickoff, a great way to get interest and draw attention in the NFR.

You're probably curious what our current numbers are. Keep in mind that again the big launch happened at towards the end of April. It's been about six weeks since then, and we have over 5,200 who have consented and have started the enrollment process. Over 3,600 have completed the enrollment questionnaire. That's a good start, but our goal is to enroll 200,000 firefighters over the next several years. We have a whole lot of work still to do if we want to achieve those registration numbers.

In terms of future work

- Targeted enrollment - We're interested in working directly with fire departments through our targeted enrollment and we will discuss that later today as a separate presentation.

- Messaging and marketing - We also are developing specific marketing and messaging materials that we'll discuss in a later presentation as well.
- Follow-up questionnaires - We want to develop at least the first follow-up questionnaire, which we really want to hear from you as our advisory committee about that later today.
- Dashboards - We want to provide summary statistics to the fire service, to those who have registered, as well as the public so we're looking at building some dashboards with data visualizations.
- Data ingestion – We also want to be able to ingest data. We're looking at how we can pull in incident records and exposure tracking data.
- Data linkages - We're starting the process of data linkages with population-based cancer registries and the National Death Index
- Collaborations with other researchers
- Data sharing - We're required to make the de-identified data publicly available.

In terms of the dashboards or the data visualization, we're in the process of acquiring some additional data science support. We want to provide near real-time figures and plots, including personal dashboards for firefighters who have registered, and public-facing dashboards for those who are interested (for example, fire service leadership). Pubic-facing dashboards would only have aggregated data to maintain privacy, but some of the things that we could do is show the distribution of participation by career status, geographic region, number of years working, and then demographics as well. We could also provide some summary statistics on control interventions or National Fire Protection Association (NFPA) physical. There are a lot of things the fire service would have great interest in, and we don't have to wait a long time to start getting some of that information out. This slide has an example of a heat map that we could potentially do, showing participation rates across the United States.

For collecting incident and exposure records, we plan to start with fire departments. We've had some conversations already with fire chiefs at these departments. Many fire departments have records management systems that they're using. We've also had some conversations with vendors about what it would look like to be able to get information directly from the vendors, with, of course, permission from the fire departments, and with consent from our participants.

Bigger picture, the US Fire Administration (USFA), which manages the National Fire Incident Reporting System, is in the process of modernizing and replacing that system. It will be replaced with the National Emergency Reporting Incident System, which is intended to be a more responsive system that will be less burdensome on fire departments. It will provide data closer to real-time to USFA. I think there's a real opportunity for us to partner and work closely with them, to be able to get those incident records, and lessen the burden on fire departments. We also know that some firefighters are tracking their exposures through systems on the market, and it stands to reason that if you register with the NFR that you would also be interested in sharing that data. We're also working with those systems out in the market to see what that process looks like and trying to pull that data in as well.

Turning to health outcome linkages, this one is important. To do our job with the National Firefighter Registry, we have to be able to match to the state cancer registries, and there are 50 state cancer registries. There are also territories that have cancer registries. This is a very big lift.

Right now, the way it works is you have to apply to all 50 state cancer registries separately. The North American Association of Central Cancer Registries is developing the Virtual Pooled Registry Cancer Linkage System (VPR-CLS). They're trying to streamline the process so you would have one or just a couple of different applications that would apply across all 50 state cancer registries. We want to try to leverage that relationship as much as we can and then actually start piloting some of the linkages. It's early now, only 5,000 people have registered, but we can start to pilot some of the linkages and see how successful we are at matching to cancer diagnoses. We can also compare self-reported cancer diagnoses with the ICD-10 codes (meaning the cancer diagnosis that are reported to the states). There are a lot of data quality analyses that we can do soon and we're looking to start that process as well.

Another future item is data sharing. We are required to make the data available to external researchers. The way that we believe will be doing this is through the National Center for Health Statistics (also part of CDC). They manage research data centers and have a secure way to share de-identified data. External researchers can apply to the research data center and be given access to the data in a secure location, in a way that's consistent with our assurance of confidentiality.

Finally, our future work will involve collaborations. We know that there are many great academic researchers out there who already have relationships with fire departments across the country. Some of these research programs are collecting biomarkers of exposure and biomarkers of effect. They are following firefighters already at their place of work. I think there's a real opportunity to work with these external researchers. We could provide that long-term health outcome follow-up. Academic researchers would have the shorter-term exposure monitoring, and then we would have the long-term follow-up. We're seriously exploring this right now and trying to figure out how we can make that work.

Dr. **LeMasters** and **Mr. Morrison** thanked Dr. Fent for the presentation. There were no questions from the subcommittee.

Strategies for Targeted Enrollment

Dr. Siegel and **Mr. Mayer** led this presentation to revisit some of the more detailed scientific methods steps that the subcommittee has not discussed for a couple of years. **Dr. Siegel** started with a recap of the protocol.

In our protocol, we've planned for multiple enrollment strategies to maximize the scientific rigor of our NFR sample. The first step, that Dr. Fent already mentioned is underway, is our largest: open enrollment. This is largely a non-probability sample, meaning that this enrollment strategy is going to work best through word of mouth and communication to the fire service across the country, visiting at fire service conferences. Any current, former, or retired firefighter who wants to enroll can do so.

Open enrollment will be beneficial for a diverse sample, but it may not be generalizable. It's going to be prone to selection bias, meaning that there are going to be groups that, for whatever reason, don't hear about the NFR or are less motivated to join the NFR. Some groups will join in larger numbers because they are more driven to join the NFR.

With that limitation in mind, we've also devised plans to do a more active targeted enrollment. This will form our more generalizable prospective cohort for calculating incidence rates going forward. This is a sampling designed to recruit active firefighters from selected fire departments that we identify to work with, based on an example sampling plan that we identified in the protocol. We also want to focus on departments that have larger representations of women, non-white firefighters, and volunteers to hone in on cancer and cancer risk factors in those groups. Originally, we planned to access fire department records with those departments and leverage that closer relationship we develop with those departments through the targeted enrollment process.

Now this was the design we went through originally in our first NFRS meeting, and it's also available in the protocol. I won't go through the whole design in-depth, but this is just to give you an idea of how the targeted enrollment and the open enrollment will work. Both the open enrollment and targeted cohorts wind up at the same place, with the cancer registry linkages and other health outcome database linkages. We will continue to engage and administer follow-up questionnaires with everyone that's enrolled regardless of the enrollment route. All firefighters will have this same experience. They'll register through the same route, and we will treat the data the same in that we will be linking with cancer registries to be able to monitor cancer long-term.

Now I do want to go a little bit more in depth about the targeted enrollment plan itself. We did have an original design and I'd like to let you know how those plans have changed somewhat. Again, for the targeted enrollment, we will work fire departments that we've selected across the country to get some diversity in fire departments and some variability in demographic and geographic characteristics. We had originally planned to obtain rosters of all active personnel from those fire departments, and we would contact firefighters from those rosters ourselves. We planned to send active invitations to enroll to all staff, using that contact information from the roster. The roster information that we had planned to obtain has been pared down after consultation with legal staff at CDC.

The roster information we planned to obtain from fire departments for contacting those firefighters included name, fire department, email, address, phone number, and residential address. And then we were going to track participation rates on an individual level using that information and those limited identifiers through a roster-to-NFR database linkage.

That the original plan to obtain incident records through the targeted enrollment has also somewhat shifted because of that same legal consultation. We learned we could only obtain incident records from the fire department for firefighters that consented to be in the NFR. In contrast, the original plan was to obtain incident records on *all* firefighters on the roster, and then only use records for those who consented.

Mr. Mayer took the floor to share lessons learned from planning the targeted enrollment.

We're open for enrollment now, so we needed to get started on the targeted enrollment. We decided to reach out to some fire departments from across the country to get some feedback on the targeted enrollment. We also wanted to learn what they think about this process that we've outlined over the past few months.

Dr. Seigel and I met with a few fire departments from across the country and gave them a presentation to talk them through the process. We covered what records we're going be requesting, what variables specifically within the roster will be requesting, and then the incident and employment records as well. We got helpful feedback from the departments where there was a lot of hesitancy and/or inability to share these roster records. Some departments were worried about sharing all the variables. Other departments really pushed back on the residential address specifically, but it just depended on the department that we talked to. Overall, there were a lot of privacy and legal concerns for many of the departments that we talked to.

Some departments are more positive about sharing the records and thought that it was something that could be done. It really depended on the culture, and the geographic location of those departments. We found that departments on the western side of the country were more willing to share that information. Those on the east coast and middle of the country were pushing back on the idea of sharing those records.

As you can imagine, that could potentially bias our sample if we're only including the departments from a specific geographic location, if they can't share those records in the way that we have it currently designed. Regardless of which avenue we go, this is going to require heavy proactive messaging and education both from us to the department leadership and then from the department leadership to their individual firefighters at their department.

We also talked through the incident and employment records for those that consent to participate. We heard a lot of pushback specifically on the incident records. It was less of a legal or privacy concern and more of a logistical issue. The fire departments really didn't understand how they would be able to parse out the individuals who have consented and share only those incident records versus everybody else. Interestingly, most of them are actually okay with the employment records, which I thought may be a bit more sensitive. They thought those records would be easy to pool and share, especially because the firefighters will have consented to share that information.

Overall, on every call, it organically came up that each department preferred having their leadership disseminate the invitations. I don't think Dr. Siegel or I ever brought that up as an option, but every department thought it would be a much easier way of getting the invitations out. There was a belief that participation would be much higher if the messaging was from the department. There were also concerns from a couple of departments that emails from NIOSH might be distrusted. Or, more often, we heard that they might just be disregarded, especially if this is the first time a firefighter has heard of the NFR. They may just not respond to it.

In part because of some of these issues that we heard during this feedback process, Dr. Siegel and I went back to the drawing board over the past couple of months and came up with this alternative design. I'm really taking what the fire departments gave us and putting it to practice. Our plan potentially would be to develop

a recruitment procedure for department leadership where we would develop the initial and follow up emails that they could send to their own rosters. This would be something we would develop standard language for, to be used in every department in the targeted enrollment.

Another important factor for this to work would be to obtain the workforce count or denominator from the departments. We'd also be requesting demographic denominators, so we could calculate stratified participation rates. Essentially for this to work, NIOSH would try to estimate participation rates using the reported affiliations in the NFR web portal. Every firefighter, when they go through the enrollment portal, enters which fire department(s) they're working at in the self-reported questionnaire. For instance, every firefighter who registers and works at Orange County Fire Authority in California will self-report that they work at that department.

If we obtain a total denominator from Orange County, and then get specific demographics broken out, we can calculate some rough participation rates using our self-reported information and comparing that with the denominators that they provide. This will be a feedback loop with the departments, where we'll continue communication with them to facilitate the reminders to enroll, the same as we were planning on doing, if we were sending out the emails ourselves.

Additionally, we hope that the incident and employment records may still work the same way we have it in the original design, if feasible. As Dr. Fent mentioned, we have explored options working potentially with software companies, software vendors, and USFA. We're interested in any avenues we can explore to reduce the burden on the fire departments themselves, and potentially leverage those existing relationships where we can pull the data and reduce the burden on the fire department. Of course, we'll get that their consent to work with records management software companies.

Dr. Siegel returned to want to walk through some of the pros and cons and limitations that come with the original and alternative designs. There certainly are pros and cons to both options.

Original Design - Pros

As a reminder, the original design is obtaining roster information for all firefighters active at a fire department, and NIOSH sends the invitations for those firefighters to enroll, using that contact information. One pro for that method is that it has a consistent method of recruitment across each of the targeted fire departments participating and engaging with us. We'll be able to employ a standardized method of recruitment that we know is in our control and we know they're getting the same consistent messaging. Every single firefighter at every single fire department we're working with through this enrollment method would get the same messaging.

It would also be the most accurate way to monitor participation rates, including over time. We would be monitoring participation rates at the individual level, using those contact information identifiers to see who specifically enrolled. We'd also get accurate denominator numbers because we've got that list of individuals on the roster. Over time, as we update roster lists and people enroll (as they join the department, or decide to enroll), we can monitor those exact participation rates more easily throughout time. If those fire departments can work with us through that more detailed sharing of roster information, they'd likely be able

to provide that information on incident and employment records more easily or more willingly as well. Although, as Mr. Mayer mentioned, there is difficulty in possibly being able to parse out incident records for individuals that consented versus didn't consent to be in the NFR.

Original Design - Cons

Now for cons of the original design, it's going to be more time and resource intensive. It will be a heavier lift on the department end because of that sharing of records and administrative process, and probably some legal process as well. It's more work on NIOSH's end with crafting those standard emails and sending them. It also requires identifying the best IT resources for sending those communications, managing those records that come from the roster, and linking that with the NFR database. It would involve more time, personnel, and IT support on our end.

As Mr. Mayer mentioned, this original design will limit or bias the departments that are willing to or can participate in targeted enrollment. They need the IT support. They need the legal support, and they need the political support across their workforce to be able to participate on this level. Just through our informational calls with a couple of different fire departments, we've already seen some geographic diversity in willingness and ability. There's also some skepticism that the fire departments were worried about. They anticipated their workforce expressing some concerns over sharing detailed information. Like Mr. Mayer mentioned, residential address was one of those sticking points, as well as possible skepticism from the union or the leadership at fire departments. It would require a lot of heavy upfront messaging from the fire department beforehand. That said, heavy involvement and messaging from fire department leadership would be required regardless of which method is being employed.

The final con is potential issues with monitoring participation rates on that individual level because of the limited information we were allowed to collect from rosters. Email addresses might not match. For example, a fire department might have a certain email on file for that firefighter, and then the firefighter enrolls in the NFR using a different email address. In fact, we encourage firefighters to enroll using a personal email address so they can continue to be engaged over time. Similarly, information on residential address or zip code might not match. This could be the case for a lot of people.

Alternative Design - Pros

The alternative design we're proposing will involve having the fire department leadership send that active recruitment invitation and communication material to their workforce. NIOSH would estimate participation rates using: 1) aggregate numbers of people that report an active affiliation with that fire department in the NFR and 2) the workforce counts that the fire department leadership report to us. This will be less time and resource intensive for all parties involved because there's less exchange of individual level records that would need to be pulled, shared, and managed. More departments will be willing or logistically able to participate, which will result in likely a less biased sample of fire departments.

Another pro is that departments will play a more active role in the recruitment method which the fire departments we spoke with were largely in favor of. The fire department has more trust according to the fire

departments we spoke with than NIOSH might necessarily have. They were confident that it would result in better participation among their fire departments.

Alternative Design - Cons

Now some of the cons that come with the alternative design. NIOSH would have less control over those recruitment methods, which could fall on both ends of the scale related to assertiveness. Fire department leadership at some departments might be more engaged and have the time and the willingness to really drive those invitations and be very assertive about it. Whereas other department leadership might not have the time, or the ability logistically, or for whatever reason is not as active in driving up participation among their workforce.

Another area of less control is information quality. If we go this direction, NIOSH can craft any kind of messaging or emails that we want the fire departments to send. Of course, department input would be welcomed in crafting that messaging. There could still be some information that might not be necessarily accurate or updated that gets reported as well if NIOSH is not conveying that directly to potential participants.

This method of also comes with less rigorous participation rate tracking, especially over time, because we'll be relying on aggregate counts of the workforce and aggregate numbers of participants in the NFR database. It's going to be more difficult if we're not able to monitor rates on a one-to-one basis.

We also anticipate higher difficulty in obtaining incident and employment records through this method, because we won't already have that administrative pathway setup as we would have if we obtained roster records. Originally, we had suggested possibly doing targeted enrollment through states, but this method would make it virtually impossible or very complicated to do targeted recruitment with states. There would also be issues with tracking because it'd be much more difficult to parse those people out on an aggregate level from the NFR database. A lot of national federal fighters live in a state, but they work at the federal level. It's hard to match the aggregate numbers of people that are affiliated with a state versus a federal affiliation, for example, and then getting those state denominators. It's just a lot more complicated.

I've lined up a summary of those pros and cons here for the original and alternative design. We'd love to hear your feedback about these pros and cons and any of those we didn't think of. Thank you.

Strategies for Targeted Enrollment Discussion

Dr. LeMasters invited the members to provide their thoughts.

Dr. Materna: Do you have to pick one or the other? Or if you got rosters voluntarily provided by some, can you do a hybrid?

Dr. Siegel: That's an interesting suggestion. Something to discuss would be that it complicates the participation rates that we're able to calculate and report to track the success of our communication campaign or to try to measure selection bias. It would really complicate the long-term tracking of information.

Mr. Mayer: It would almost add a third bucket. We'd have the open enrollment, the targeted enrollment where we have the rosters, and then the targeted enrollment where we don't have the rosters. It's certainly something we could explore.

Dr. Siegel: It's almost another source of bias, differentiating between those departments that have rosters versus didn't. It would just be a lot more to keep track of, but it's certainly something we can discuss more.

Dr. Materna: From my experience of interacting with the California Fire Agency, in my role of working at the public health department, I have a gotten a lot of this pushback. I've experienced numerous times this reluctance to give a roster of people so we could do outreach on public health issues. I think you're already hearing that it's not often going to work. And then also my experience during COVID over the last 3 years of that resistance from the worker level possibly of public health, and their methods and CDC distrust. It's going to be a double whammy from the other side.

My opinion is: you're more likely to be successful at recruitment with the alternative design. I'm wondering also, in addition to having the invitation come from fire management, is there a role for the unions so that the workers can be getting messaging from both sides. They'll hear that union thinks this is important too, and really wants to encourage your participation. That could help offset any potential distrust of management or pressure that management is making them do this.

Mr. Mayer: That's a great question. A few of the departments invited their union on those calls. We should have mentioned that the unions were present for a couple of the fire departments, and they had the same thoughts. They said it would be great if messaging came from both the fire departments and the unions together. We'll definitely leverage that where unions are present for a fire department.

Dr. Siegel: That's a great suggestion, and that can be incorporated as well into our communication package. We can also develop options for the union too.

Dr. Moffatt: Working with the fire service over the past 25 or 30 years, I really think that the alternative design is probably going to be the most successful. In in my experience, in the research we do here in Indiana, we've used more of a collaborative approach, really led by labor and administration. I think it reduces the anxiety, as you've noted out in the pros, but I think also it allows for the department to own this initiative, and to be a champion. All of us know that when we try to do projects, you really need to have a significant amount of buy-in, and also a champion - the face of the program or face of the initiative.

In many agencies across where I've worked in Indiana, we have varying departments, where there are major champions for this kind of work. I think that identifying those champions leads to greater participation and consistent messaging as well as trust. This is very hard work, as you know, trying to overcome potential concerns or anxiety about how the information is going to be used. I applaud the efforts that you're doing in trying to address these concerns.

One of the thoughts that I had, are just a couple of concepts. Have they been considered? And if so, what were the thoughts regarding that?

One of the most significant times to capture the potential interest of a firefighter, or even or a department and a firefighter, is the academy. Every year there are probably 20,000 new positions for new firefighters, “probies”, if you will. Could there be a lane for messaging NFR participation in the academy? A lot of the Gen Z firefighters are very receptive to this kind of concept. I think they're more concerned about health effects. What I've seen is that sometimes, as the new firefighters get into a department, there can be a level of potential cynicism where they don't want to stand out. They don't want to be seen as different, and maybe doing this in the Academy can increase participation.

The second thought is, has there been any thought about marrying this process of recruitment at the time of the firefighter’s annual physical evaluation? Whether it's a limited NFPA exam, or a more definitive NFPA exam, or a Wellness-Fitness Initiative (WFI) exam. The provider of the evaluation can provide information and answer questions that are messaged by NIOSH and the department, and approved by the department. It would allow the provider or the program doing the NFPA exam to at least at least makes it available to the firefighter. It also allows for additional time to answer questions.

This is very hard work, and but it's good work, and it's important work, because 20 years from now, or a generation from now is when we want to be able to reflect and understand this issue of cancer in the fire service.

Dr. Fonseca: For me, it’s the original design. I think there's a couple things here my 44 years of experience telling me that every morning conspiracy theories develop at the kitchen table. They solve the world, and then they leave, and then they go back the next shift to do it again. When you have the alternative design and you let leadership - you have dinosaurs in the fire department. They will not allow you to progress because it didn't happen to them. It didn't happen anywhere. My thought is the original design.

Here's some of the things that my experience has also led me to think. We cannot start at the level of the fire department. We’ve got to start at the governor, and the governor needs to set the message out. I'll explain why this is very critical. The governor works closely with the State Fire Marshal’s Office, who also works with the legislative process, which decides line of duty injuries, the bills, the laws, who's eligible for cancer lung bills, etc.

When the governor mandates, or proposes, that we learn more about cancer within the fire service, the State Fire Marshal has a duty to act. That’s also passed to the fire chiefs who now have a mandate from a senior authority saying, “Could this impact how we look at firefighters in the future?” When lung and heart bills came out, everybody was part of the process, because everybody knew that it could happen. Now, cancer is very prevalent. If we raise the hands here, everybody knows someone who has cancer or had cancer. Now we need to make sure that they understand that if tomorrow a law was passed, that they're part of the process.

The governor needs to work with the State Fire Marshal, who needs to work with the fire chief, who needs to work with the subordinates. This way we have consistency in leadership. Even though you have dinosaurs, as I call them, because anybody who's been around the far Service knows that you'll find out that people are going to be more receptive. They're going say to you, we might not agree with it, because we have our own conspiracy theories that have developed in the kitchen table during breakfast. However, in time people

change their mind, and that is very common. Everybody has a conspiracy until more facts develop. People change, and then they go, “You gotta sign up. It happened to me,” and the word gets out.

We have to be controlling. If not, you're going to have a hodgepodge of information. It's not going to be accurate information. As they say in data: garbage in, garbage out. You're not going to get what you want.

Dr. Durbin: I have a couple of just basic questions for my own information. How many firefighters are there nationally? Do we know the number?

Several members: No one knows the actual number.

Dr. Siegel: It’s over 1 million.

Dr. Durbin: Do know how many fire departments exist?

Mr. Mayer: It’s about 30,000. But again no one knows the actual number.

Dr. Durbin: And are all of those known to NIOSH? Is there some registration process?

Mr. Mayer: We have a comprehensive list we got from USFA and we cross-referenced that with a list from NFPA. We have about 28,000 included in the web portal currently. We have gotten messages that a specific department isn't included, or that some federal agencies weren't originally included.

Dr. Durbin: There are probably some county volunteer departments that are probably a little bit harder to find.

Dr. Siegel: Correct.

Dr. Fonseca: Some of them open and close too, so you’d never know the actual number.

Dr. Durbin: I have some concerns with the consented approach to this. I don't know that we'll ever reach a point where you'll have group of firefighters that is truly representative of the country. That's a fundamental challenge with a consent approach. I understand why you need a consent approach, and I'm certain there's a fair amount of distrust of the government and sharing personal information with the government. Alternatively, maybe something to be considered would be working a little more closely with your central cancer registries.

Central cancer registries are mandated by state law. There's no consent process, and they already are holding the identifiers of all cancer patients within every state. One of challenges we have in the cancer register is that we don't have good occupational information. We don't know who's retired firefighter, for example. Conceivably I could see leveraging, at least for the firefighters who end up with cancer, the central cancer registries. Of course, it's not going address a cohort moving forward, and probably wouldn't address being able to identify incident exposures and that sort of thing. But if cancer registries could actually identify the firefighters, and there might be a number of mechanisms to approach that, then you can actually be approaching more population-based data on the actual incidence of cancer within that population.

I think there could be some challenges here, but what about getting those rosters to the state cancer registries. They would hold that data. They're already holding the identifiers for those patients. They could protect that and only release deidentified data to the national firefighter registry. That way you eliminate the big government, the federal government, having access to those identifiers.

It may be worth exploring our ability to even identify firefighters within existing registries. There are groups that that assimilate information. In some ways it's kind of scary. There's a group called LexisNexis, and they seem to have every bit of information about all of us. It's really quite amazing, and it's not really controlled. I'm just wondering out loud does LexisNexis know who's a firefighter and who isn't?

Also, getting to the suggestion of going through governors, I could see a state mandate of reporting rosters to the state cancer registries. It conceivably could be more effective at identifying the firefighters who do end up getting diagnosed with cancer.

Mr. Harbour: I'm a wildland fire guy. It sounds like you're trying to solve a division problem where you don't know the numerator and the dominator but you're trying to find an answer. But do you have some idea? I saw that you wanted 200,000 people in a registry, obviously with a diversity of representation. And we've got 3,650 enrolled so far. But is there a number that allows you to have statistically and scientifically sound information? Do you have any idea based on whether it's 20,000 or 40,000 departments? Three-quarters of a million or two million firefighters? Do you have any idea what a minimum number would be, and is that 200,000 that you talked about? Or do you not even know yet what that that number might be? Because if you had an idea of that number, I think a proposal about leveraging the existing state registries also appears to me to be favorable. At least from the wild land perspective, you'd be able to include some of the folks not at the federal wildland level, but at the state wildland.

The question is somewhere between 3,650 and 200,000, do you have an idea about that number? And I bet you do because you work with it statistics all the time. I haven't seen a pro or a con about what gets you closer to that number in these approaches. I'd be interested in feedback on what gets you closer to that.

Dr. LeMasters: I believe the question is: how many departments do you think you will need to participate to get to your targeted number? The whole study is for 200,000, but what part of that was supposed to be targeted versus just volunteer? And of the targeted, how many departments would it take to get to that?

Dr. Siegel: The 200,000 is more of a lofty goal. That was put together more for encouraging participation and messaging purposes. We've put together a rough sample size calculation for our protocol, but really the sample size numbers depend on what we're analyzing and what kind of analysis we're doing. The NFR is a surveillance system, so there's no specific research question that's been identified. It's going to be leveraged to analyze a bunch of different research questions and monitor current rates of a health condition or a workplace practice. The sample size will depend on what the research question is or what the analysis we'll be conducting is.

For sample size calculation purposes, in the protocol we took an analysis similar the one done for the NIOSH cancer incident study, published in 2014 by Doug Daniels and others at NIOSH, and partners. We found that to be able to detect significant differences in cancer incidence for several specified cancers among specific

groups such as firefighters overall, non-white firefighters, and female firefighters, we need roughly a minimum of 5,000 firefighters for that specific group. We're going need to recruit *a lot* more firefighters overall to be able to get groups 5,000 or larger, to be able to analyze them as their own individual level.

The number of fire departments that need to participate in the targeted enrollment will depend largely on the participation rates we're seeing in those departments. It's not necessarily a question we can answer. But again, in the protocol we put together some very rough, ballpark numbers. We assumed a participation rate of roughly 50% and aimed to recruit up to 100 departments to participate. Again, it'll depend on participation rates, and what kind of analyses we're hoping to do at different times.

Mr. Harbour: So that answer leads me to believe that, given fundamental belief that both approaches, the alternative design and the original design, are going to meet those sample size requirements, it's just how we how we get there.

Dr. Fonseco: I have a question on the sample sizes. Do we have enough Hispanics within careers or volunteers that can create the sample size needed? The number of Hispanics within the fire service is less than 1%. Is your sample size going to be sufficient to study Latino males or Latino females? Also women. We see an increase in the number of women in the fire service, but we still don't see a lot of women in the firefighting. We see them in other specialties that are part of the fire department, but they're not directly within firefighting.

Dr. Siegel: It depends on what the question we're trying to answer. And then I'd also like to take a moment and do my due diligence as an epidemiologist, to de-emphasize statistical significance. Sample size calculations are done to try and determine what numbers are necessary to see a statistically significant difference in an estimate. As scientists and epidemiologists, we don't want to always focus on statistical significance in being able to interpret estimates. The sample size calculations are done to get a rough goal in what we want to achieve, but we don't necessarily need to depend on them to do any specific analysis.

Mr. Harbour: That's a fascinating question. For example, in the wildland specialty Hispanic males are technically overrepresented, but not Hispanic females. If you were successful in recruiting those folks in that specialty, you could begin answer the diversity question. Not for my blue shirt friends, the structural folks, but in the wildland world we have a different demographic makeup than the remainder of the fire service.

Ms. Lee: The things that popped up to me from a volunteer perspective is, I kind of like the alternative design and going through the fire chief. I don't think a lot of volunteer departments are always plugged in to the national level, or even the state level, so coming through their department might be a better way to reach them.

Some of the conversation has raised questions for me like, does LexisNexis know who is a firefighter? Well, they might know who is a plumber or who is a doctor, but what if they're a volunteer firefighter? Does it know that? And same with some of the death stats out there too. Do we know if people who died from cancer were volunteer firefighters?

Tying it into the annual physical - I know a lot of volunteer departments don't have funds for the annual physical. Even some career departments don't offer them. I like the concept, and I'd love for all volunteers to have that to tie it in. I just don't know if that's a feasible way to go about it.

At least from the volunteer side, I think we're going need to approach them from many levels. It could be our association; it could be their state firefighter association. It could be the governor that's talking about the necessity for this, and certainly their own leadership in their department, too.

Mr. Stagnaro: I agree with Dr. Materna and some of the other comments that are made. Certainly, the union and leadership component of it, I think that's vital. I like Dr. Materna's idea of a hybrid. I think it will address some of the bias issues if you target the bias components along with leaning towards that alternative design. That way, you can address some of the cons and get the numbers that you're trying to achieve.

Dr. Simmons: Going off some of the comments that both Mr. Stagnaro and Dr. Fonseca had, the hybrid method would probably be best. Regardless of which method we go with if you look at con number 3 on the original design side [skepticism from department leadership and/or workforce], it's important that we develop employee strategies to build relationships among department leadership, the union, as well as this particular working group. If those strategies are effective, then in terms of numbers, and what we're seeking to accomplish will come forward.

Dr. Materna: I had one additional suggestion in dealing with these departments that you're trying to target for targeted enrollment. You're going to launch soon, whatever this approach is, but then, my understanding is that you want to try to get all the new firefighters who come to those departments because you're going to stick with these departments for a long time. Is there some way, even initially, you can also get their agreement to include an invitation to join the registry in every new employee packet? Some official way that from now forward you're going keep getting these invitations issued. That that could be helpful.

Also, to address the concern over what information departments are disseminating, get their agreement upfront to blind copy you. I assume they are going to do email blasts to their official email addresses, although you probably want to make sure that all their employees get email addresses. I don't know how it works these days, but if you could get a bcc so that you see every message that goes out, you at least would be able to track often they're being sent. I'm assuming you're going ask them to send it once and then a certain number of follow-ups, because nobody ever responds to the first email. But you're going to want to get feedback on what they are actually sending.

Dr. Moffat: With Doug Daniels and his group looking at San Francisco, Chicago, and Philadelphia, has there been any targeted discussion with those agencies since? Obviously, they've led the science recently with regard to a greater understanding of cancer in the fire service. My understanding is that New York has also joined that particular group. Has there been a targeted approach to these larger agencies for participation? Obviously, those numbers can be large as well.

Dr. Siegel: We haven't selected which departments we plan to formally approach for our targeted enrollment method. However, we recognize that those departments display a lot of the characteristics that we want to prioritize for this enrollment method - the number of female firefighters on roster, for example. You

mentioned the size of those departments and we want to leverage resources by pursuing some departments that will contribute a larger sample size so we can get to our goal numbers faster. So those are great suggestions. We've already been kind of informally discussing some of the departments we might want to approach initially.

Dr. LeMasters: It seems like this situation would be ideal to pilot test before you really pick one and launch. You could pilot test the approaches in two or three departments, going both ways, and then see what the response is. For example, if you go with NIOSH taking the lead and reaching out, and you get a very poor response, then you'll know to go with the departments taking the lead. Without a pilot test it's almost like shooting blind. Which way is better? It's based on a lot of assumptions but very little data.

My recommendation would be that this would be the ideal time, before you launch a whole campaign, to pilot test the two approaches. I think you'll learn a whole lot on the pilot test. I've done pilot tests before and they do take time, and they do set you back a little bit, but they are well worth the time because of what you're going to learn. That would be my primary recommendation. Both these methods, as you have perfectly outlined, have pros and cons. And the only way you'll know which is going work well is to test it out a little bit.

Mr. Stagnaro: I'm not sure if I'm jumping ahead to the messaging and marketing. I was thinking the same thing with reaching out to Chicago, San Francisco, and Philadelphia. They've already got something invested and may be willing to participate.

I think it's less of the original design or alternative design, but the method by which you achieve that. If you look at the Firefighter Cancer Support Network, they have cancer survivors that are out there doing training. Are there thoughts on how you will deliver this message? Are you going to utilize those types of resources to get the message out?

I know USFA is very on board with the registry. Is there an opportunity to provide training or coursework? They're getting people from all over the country. We're headquartered at the USFA, we could put up a kiosk and promote. Again, I might be getting into the messaging and marketing component a little bit.

Dr. Siegel: It reminds me to plug that the targeted enrollment method is not the only way that we want fire departments to get their entire workforce to participate. Just because we don't approach a department to join through our targeted enrollment method doesn't mean that if we get a 100% participation at this other department it won't be helpful. As I said at the beginning, we'll be using everyone's data in the same way. Everyone enrolls the same way. If a department goes out of their way to encourage participation on their own, that's fantastic.

Dr. Fent will get into this in his presentation, but we'll have marketing material and messaging that fire departments can use on their own independently online and material that they can use to educate their workforce.

In our protocol we also describe a little bit about including fire departments with high participation in what we consider to be our targeted cohort, and then use those numbers to better inform our prospective cancer incidence calculations.

Dr. Fonseca: Have you talked with the International City/County Managers Association? Small departments look to the city managers for guidance, especially volunteer departments. I was a volunteer in the Nashville Department, and the fire chief worked on the sewer lines. He made the calls only after he had left the sewer lines. They look for guidance from city managers, so I don't know if that's a venue that needs to be talked to. They need to understand exactly what's going on, because a lot of the fire departments might not understand it. They understand the word "cancer," but do not understand the implication of the registry. City managers, who also talk to the city attorney, which are just one or two blocks from fire departments.

Ms. Lee: I think I just have more questions. Were any volunteers included in the soft launch? Did you get any feedback from volunteer departments on providing those rosters and the data that you're looking for? Did they have that capability? Were they able to provide it?

Dr. Siegel: The soft rollout wasn't discussing this method, although we did have a couple of combination departments represented. The soft rollout was testing the enrollment process and the enrollment system. Alex and I did speak with some volunteer leadership in our initial calls, where we solicited the input that we presented today. As we anticipated for those volunteer departments, as you raised earlier too, the challenges are a little more unique.

Ms. Lee: That's why I was wondering, too, when Grace suggested doing a pilot of each one. I know that takes extra time, and I don't know what your timeline is. If I were running the operational side of this, I would probably go, "I don't have time!"

It would be interesting to see the capabilities of volunteer departments. There are plenty of volunteer departments that are well organized and have HR systems. And then there's your rural departments that don't have these systems in place, that are not as well organized, that don't even have gear to respond, but should be participating because, as you said, the majority of volunteers in the U.S. are volunteers.

So again, just my thoughts on that volunteer piece, thinking about what we can do to help get them engaged, and enrolled and participating in this too, no matter which method you go with.

Dr. LeMasters: I just had one more comment. Sometimes, once you get two or three departments willing to participate - maybe you don't need the residential address from them, and that could be obtained when they're giving information at the site – you could then use that to leverage more participation, almost like a competition. It's like you have a thermometer, and you're raising your thermometer, and how many targeted companies will participate?

What you would say is, we've got four departments in Ohio and six in Indiana. Once they see other fire departments going ahead with it, I think you'll see a dramatic increase in comfort level. Once it's done and people have been successful with it, others will join in. That's why I'm sort of leaning toward the original design.

Mr. Harbour: We we've talked a lot about the macro or departmental level. Let me tell you my experience. I would bet it's replicated thousands of times. I called a few wildland colleagues and said “Hey, have you heard about the NFR? No? Are you near your computer?” It hasn't been easy. The few guys I've called, the response has been “Oh, this is going to take some time, and I gotta go mow the yard or do the dishes or whatever.” I don't know if they’re going to get back to it.

Once you get into the enrollment process, it's a big deal to take the time to run through and get everything set. That's just based on a dozen or so guys I've talked to. Each method is dependent you making sure that once you get the department city manager, governor, and everybody else to say, “Do it,” making sure that the individual firefighter completes enrollment.

Some guys have done it, and said, “Boy, that took more time than what I thought.” Or “I got to this part and I was going to have to think about how to do that so I stopped.”

Dr. Moffat: I want to respond to a comment that Dr. Fonseca made a little while ago. Each state has an association of cities and towns, and oftentimes those individuals can bring back information to fire departments that may be beneficial or seen as positive. In Indiana it's a pretty good relationship. In other states it may or may not be a good relationship, but it's still another avenue to give information and provide the opportunity. It could potentially lead to some dialogue with departments that may be smaller or may not be as connected as other departments. But again, it depends upon the view of departments within a state with regard to those agencies coming to them with ideas or opportunities.

Dr. Materna: I want to follow-up on what Mr. Harbour was saying. This maybe be something you’ve discussed with some of the departments that we're aiming to target or using us to gather information. If you went with the alternative where management is sending out the invitations, are they willing to make it clear that this could be done on work time, or even in groups? Let's all sit down and enjoy at the same time, while we're in for training and sitting at computers, or something like that. It might help.

Dr. Fent: One of the things that we're exploring is identifying retired firefighters who can help us make connections with fire departments that are part of the targeted enrollment, and even some other large departments that we know are important for gaining trust in the fire service. Those retired firefighters would meet with the fire departments and help firefighters enroll, walking them through the process, maybe providing a presentation.

And, like you said Dr. Materna, having work time to enroll. A lot of fire departments, especially structural fire departments, they have an hour training every week, or something like that. There's an opportunity, I think, to fit into their model and help their firefighters enroll.

I think you all are making excellent points. There's a large group of the fire service that will go and enroll, and even though it takes 30 minutes, they'll go through the process. But there's an even larger proportion in this sort of movable middle. They need a little bit of help and we want to be able to provide that.

Dr. Fonseca: Is there money to help the retired firefighters for the travel expenses?

Dr. Fent: We would do this through a contract mechanism.

Mr. Morrison: I think there's been some robust conversation that has highlighted a lot of areas. And this is not easy. If it was easy, we wouldn't have this meeting here today. I think departments would be willing to sign on. We have to get labor, management, volunteers, all the people that have a buy in, to work together, to make sure that we send a message about why this is important.

I do feel that in the fire service this is probably the most talked about item that I've ever heard, right now. We're at a good point. We don't have to convince anybody that firefighters are getting cancer at alarming rates. That's already done. That's out there, so we have that advantage for us.

Of the two choices, I like the alternative. When I look at that, having more departments involved, having a little bit more skin in the game, as they call it, with the fire departments, I like that. Maybe there's a hybrid. Maybe we have to take something over, but I think it's our responsibility as the national organizations, all of them here to today, to take part in this. A lot of times we send out joint communications between all these organizations, and we could deploy that same method with the with the department strategy.

This is probably some of the most important work that we could possibly do. It's not going to be easy. I think there's an avenue. I love that you did come up with an alternative, and there's going to be more discussion. I think we're headed in the right direction.

Mr. Harbour: Let me follow up because think Mr. Morrison made an important point. This is what I've heard specifically and individually from the wildland fire folks. Firefighters grouse about everything. You can give them free food, and they grouse. When my buddies have called me back, said, "This more complicated than what I thought it would be," at least from my small samples, there have been people who will stay on the line. And more importantly, you don't have to talk much with folks. I say, "You know, if you got that far, go ahead and get it done because you're going be helping fellow firefighters." I haven't heard anybody of my small sample size say they're not going to do it once they start. I've heard everybody say, "Well, it's more complicated than what I thought, it's more time than what I thought, but I'm going to go ahead and do it."

Dr. LeMasters: Just a question on the alternative design. When you say under pros "less time and resource intensive," who's that for? It seems like it's *more* resource and time intensive for the fire departments but *less* so for NIOSH. Is that right?

Dr. Siegel: I would say it's for the fire department *and* NIOSH, because it's less individual level data that needs to be transferred. There's a communication aspect. There's also the management of that individual level roster data, and linking that roster data on a one-to-one level with the NFR database as well. On the NIOSH side most of the leg work will be on the IT and data science support side.

Mr. Mayer: For the fire department, the support will be on the IT side as well. We will need to be able to talk with their IT personnel about sharing the roster information, and they'll have to figure out what system we can share records through securely. There'll be a significant lift with our original proposal as opposed to just sending out emails with the alternative.

Dr. LeMasters: You think the original is more intensive for the individual fire departments than the alternative design. Is that correct?

Dr. Siegel: Correct. I can see your thought process here because the alternative design will require that heavy messaging to come from the fire departments.

Dr LeMasters: Right.

Dr. Siegel: In the initial calls that Mr. Mayer and I had with these departments, they were saying, even with the original design, "We will have to have heavy communication on our end with our workforce to let them know this is coming, this is what this is, and you can trust it. We'd like to remind you again and again." Either way the departments expressed that they would have to heavily be involved on the communication end.

Dr. LeMasters: But then you will be reliant on the far departments, following up with the second email or the third email right to their workers. They could do it verbally when they see them in the building. You won't know. It seems like a lot is relying on them to follow through the exact way you want them to, correct?

Dr. Siegel: Correct, and that's exactly why we listed that as one of the cons for the alternate method. We also discussed incorporating a feedback loop once we're able to estimate some participation rates with the fire department. We could communicate that the participation rates are lower than we'd expect and suggest another round of reminder emails. We would develop reminders on our end to try and make it as standardized and easy as possible to limit the burden for the fire department. We can report back once we start getting some comparatively good participation rates from that department as well.

Dr. LeMasters: Some of the fire departments are reluctant to give up certain information, and maybe there's some negotiation you can do, if you do the original design. Maybe if they don't want to give residential addresses, maybe that's not key. Maybe you could gather that another way. But I'm just concerned that that you don't have any control. You could message that the fire department is 100% behind your participation in this and involve them that way. A letter from each fire chief attached to your email, saying we strongly support this study, and we hope you will participate in the next five days. I would give them very limited time, not someday, but in the next five days you will complete this.

I truly think that taking the time out to pilot both approaches with just maybe two departments is worth it. Then you could say, well, now we know that it's best to do the alternative design, because the original design we didn't get the participation rates we wanted, or vice versa. You would have real data to go back to the departments and say, we know, we have tested this out, can we go ahead with this?

Dr. Simmons: I would agree with Dr. LeMasters, with the modification of expanding it out to maybe four to six fire departments.

Dr. Moffat: Adding on to what Dr. Simmons is saying, if you do two pilot sites, geographical issues will emerge. I think if you're able to get some geographical component to the piloting, if you're able to do that, I think that would be important.

Public Comment

There were no written or oral public comments.

Marketing and Messaging

Dr. Fent led this presentation.

We've had a great discussion so far today. Thank you, everybody, for providing inputs and advice. I think there were some questions earlier that hopefully I'll be able to answer in this section of the presentation.

I want to introduce our key personnel that are devoted to this effort. We have our health communications specialists at NIOSH: Jennifer Tyrawski, Greg Hartle, and Jasmine Nelson. I mentioned previously our communications contractor, RTI International. They've really been instrumental in developing some of the materials, as well as helping us staff conference booths and the help desk. They've done a lot of great work for us that you'll see here in just a minute.

I mentioned earlier today that our announcement to our partners went out via our newsletter on April 13. We have close to 2,000 subscribers for our quarterly newsletter right now. That was the way a lot of people learned that we were getting ready to launch nationwide. Then we put out our press release on April 17. The White House even added a couple of sentences to our press release, which got a lot of notice from the media and general public. We got a lot of questions and even some news interviews. Then, of course, we made our big announcement at FDIC. I was joined on stage by representatives from a lot of the major organizations. This information was repeated in NIOSH eNews, which is NIOSH's newsletter. That that went out on May 1. These efforts to notify the fire service were very effective, and we saw the biggest increase in terms of folks accessing the web portal over that period of time.

Looking at our webpage again, what I want talk about now is our videos and communication materials that are on our website. When you click the box that says "video and communication materials," it takes you to a page that provides all our materials. We want to make them publicly available for our fire service partners to be able to use. One of the first resources that I want to draw your attention to is the NFR promotion toolkit. This is a pdf and it's basically a one-stop shop for all the different ways that our fire service partners can notify firefighters about the NFR and why it's important. This page also provides links to the different materials that have been developed: posters, videos, enrollment tip sheet, palm cards, social media graphics and QR codes. All of that is available directly from this partner promotion kit. This is a great resource to share digitally and has been one of the most downloaded materials that we produced.

We also have some great videos that have been developed for the NFR, all available on our website. A couple of these videos have been, I think, well received. Our partners have commonly shown the How does the NFR Work? video. It's animated video that explains the process of how the NFR works and how we match to state cancer registries. We also produced a testimonial compilation video that provides perspectives from different fire service leaders about why the NFR is important to them. A lot of times our partners are showing these videos to really hammer home why the NFR is important. We also have individual videos that provide perspectives from different fire service groups: fire chief, cancer support, fire investigators, female

firefighters, Latino firefighters, nonwhite firefighters, and then wildland firefighters. All the videos are on Youtube, so they're very easy to share.

We developed a handful of fact sheets. We have:

- General FAQ (frequently asked questions)
- How do I sign up for the NFR?, which is an enrollment tip sheet
- Roll call announcement, which is intended for fire leadership to be able to quickly explain the purpose of the NFR to their firefighters.

We also have promotional posters that we've developed. Some posters feature artwork by Paul Combs, a well-respected artist in the fire service. He's produced the different graphics for us, which work well for social media. He's producing more over the coming months for us. And then we have posters for wildland firefighters as well that include images of wildland firefighters.

We also have:

- Palm cards, which are mainly handed out at conferences. They're very short and work well as bookmarks.
- Social media graphics that are free to download and use by our partners.
- Badges (i.e. website graphics) that partners can use to show they are supportive of the NFR. One of them says, "Proud supporter." The other one has the QR code. These are free for partners to download and put on their websites.

This is all great, but we really need to get it into the hands of our partners to make the biggest impact. We held a partner promotion call on May 10 that was attended by over 30 fire service leaders across the nation. We were able to share these resources with them. Then we brainstormed with these partners on other ideas of how we can reach different groups of firefighters, including some of the harder to reach groups.

Now let's talk about some of the existing partnerships that we have and how those partners are messaging this to their members. Underwriters Laboratories has the fire safety academy, which is an online training academy for firefighters with over 90,000 registered students. They've committed to providing information about the NFR to all their students. Anytime a student goes through a course, at the end of that course they will get a pop-up box that tells them about the NFR. We also worked with Underwriters Laboratories to develop a cancer prevention course. At the end of that course, our module talks about the NFR, how it works and why it's important. I haven't checked with them yet about how successful that's been. But hopefully, we get a lot of students that take that course as well.

The Loveland-Symmes Fire Department is a fire department just outside Cincinnati, Ohio. They have placed the NFR logo and NFR illustrations on their air management resource trailer. The fire chief is taking that trailer around to other local departments that they do mutual aid with. He is using it as an opportunity to share information about the NFR, including posters and palm cards. That's a great way that a really invested fire department can spread the word to local agencies around them.

Th North American Fire Training Directors collectively train a million firefighters every year. These are the state training academies, and several have expressed interest in sharing information about the NFR with their students and have already started to do so. We have the potential to reach firefighters as they're coming through Academy, which came up earlier today. That's powerful in terms of research if we can get them as they begin their career.

And then working with our partners in terms of amplifying the message on their social media accounts. We're coordinating with numerous partners on that. We can plan to continue to do that over the next 12+ months.

I want to share some of the social media posts that went out around the time of our nationwide launch. The Underwriters Laboratory Fire Safety Research Institute put out a really great post for us. The National Volunteer Fire Council put out a post using one of the images that is available on our website. At FDIC, after we made our big announcement, the Firefighter Cancer Support Network put out a post and used some photographs from that announcement at FDIC. We've got these great helmet stickers, and the director of FDIC put out a post showing that he had enrolled in the NFR and held up his helmet sticker in the photo. International Association of Firefighters has put out a lot of great social media posts for us, USFA as well.

I want to mention that the US Department of Labor is required by law to notify any federal firefighters who have cancer claims about the opportunity to enroll in the NFR. They have started doing that, and they also have messaging on their website about how they're supporting the firefighter registry.

The USFA has been supportive of the NFR. The U.S. Fire Administrator herself was one of the early adopters, and one of the first to register and then put out social media about her experience. USFA has more information on their website that that they're sharing as well.

Following that press release, we got a lot of attention from interviews with news organizations as well as podcasts. We've recorded podcasts with NFPA, USFA, Fire Engineering, and National Fire Radio. We've done a handful of local news interviews as well.

We're also attending conferences. It's important that we are where the firefighters are. We're trying to attend conferences of different sizes across the country, and with different audiences as well. We had a large booth at FDIC, and we're doing similar smaller booths or even tables at some of the smaller conferences. We're also utilizing our firefighter subject matter expert (SME) contractors because we just can't be everywhere at the same time. Our firefighter SMEs have been helping us attend some of the smaller, more local meetings on behalf of NFR program, which helps us to reach different groups of firefighters, including women, minorities, and volunteers. These groups are specifically called out in the legislation that established the NFR. Wildland firefighters, and some of the local firefighter unions have their own meetings or regional meetings, so we're trying to attend those as much as we can.

Discussion questions:

- Who are we missing in our marketing?
- How do you feel our initial launch is going?
    - What could be improved?

- Do you think our current messaging is effective?
    - How could our messaging be refined?

Marketing and Messaging Discussion

Dr. LeMasters: Thank you for that presentation. It looks like you have covered the waterfront from my perspective. It's an amazing launch, and you've touched base with a lot of groups. I think your current messaging is very effective, but I would like to hear from the rest of the committee. They may have ideas about other groups to approach or marketing approach that might work with firefighters, especially those of you who are firefighters.

Ms. Lee: I personally think you guys have done a fabulous job with the marketing, and the materials are helpful. You've been great at outreach. For your subject matter experts out in the field – we've had Rick Markley come to our own conference and talk about it. We even did a challenge at our own conference to get our board to sign up for it and offered a gift card to somebody who signed up for it while they were there.

I would say, reaching out to the state fire associations and getting them on board would be beneficial. They tend to carry a lot of weight within their state. That's another way to get the word out to the local level, which is not always easy to reach. We have a link to many of them, that represent volunteers on our side.

There's also the Chiefs Association. I think that would be a good group to add to the mix if we can.

Dr. Fonseca: One of the things that I found that in my experience works is having an ambassador for each state - someone that people know in their state. There's always one person or two that are usually well known around the state with all this associations. This person is trusted and is vital to providing a lot of information. So I'd know who to go to in this state if I have questions. I usually have their phone number and they're able to provide me more and more information this way. You have subject matter experts, but I don't know who they, I don't know their schedule. I don't have their contact information, so tracking them down becomes hard. But someone that works within that state organization, someone that's well known for each state. In Tennessee, I know who to go to. In Florida, I don't know anybody yet. It would help if you had a contact for each state, someone that can say, let me tell you about it, and this is why it's important. They can provide all the links to the NFR. It's another voice.

Dr. Fent: How do we identify those folks within each state?

Dr. Fonseca: The state Fire Marshal is the key to everything. Everybody knows the state Fire Marshal. All the state associations, local fire chiefs, Middle Tennessee Fire Association, they all know the state Fire Marshal. That person can provide information that can spread. That's who you want to approach. They know who can be ambassador and how they can disseminate information on a state level pretty fast, faster than I would ever, or you, or anybody. No offense to anybody here, but they have everybody's phone numbers.

Ms. Lee: Can you share the list of the subject matter experts? We know Rick Markley. It might be helpful, like if your association has a link with one, and you can come out. Or if we know of a conference and we know one of them lives near it. We can help make those connections.

Dr. Fent: We can share that through email, absolutely.

Dr. Materna: These are more questions. I'm wondering if you've thought about these. In addition to active firefighters, you're also interested in including retirees, right? Have you pursued public employee retirement systems, or anything like that? They usually have newsletters and things like that. The other one I think of is, where the cancer claimants go to, which is the workers comp industry.

Dr. Fent: Those are great suggestions.

Dr. LeMasters: Retired firefighters would be key, because they are the ones who were in earlier and have had the 20- 30 year latency required to develop cancer. Is there a retired firefighters association? Does anybody know?

Mr. Brimhall: Typically, a lot of the local IFF chapters [local unions] have some retiree connections. That's probably the most I would be aware of.

Mr. Mayer: We did pick up from some of the departments that we talked to, that their retirees are very involved as well. During our discussion, they mentioned that they would also try to get in touch with their retirees directly.

Dr. LeMasters: This would be a prime group to outreach, to and get on board for this study. Maybe the most difficult one, because of the portal and some of the difficulty with maneuvering through computer systems.

Mr. Brimhall: We kind of hit on it already, but it's the champions that we need that are maybe already doing something and getting that ear to the ground. Maybe it's saying, "Hey, who's already out there doing something on their own? Who's already the guy that's out there talking about his own history, his journey that he's been through already?" And who have *they* made connections with, as another avenue to get the word out.

We've hit on most of the organizations. Consider mayors. I've heard City Managers Associations, County Managers Associations in New York. We're fire commissioner-based for most of our volunteer-based departments. [Inaudible] You hit on the fire marshals, you hit on the fire training directors, we hit most everybody.

Maybe it's asking somebody, like, "Okay, Sarah, which meetings are you putting your people at from the National Volunteer Fire Council? Victor, which meetings are you sending your people to as the National Fallen Firefighters Association?" Are we hitting these same ones? Is this something you could co-locate, co-do, co-message at same time.

One of our silly points from the [inaudible] when it first came out that was misunderstood, is well, you're the seatbelt guys. You're the guys trying to get me to wear my seatbelt in fire trucks. That was the wrong messaging to get out. We don't want the wrong messaging to get out here.

One the things I saw on Facebook most recently was the NFR symbol and it said, “for cancer” and “for cancer” was jumping off the screen. And I'm not a Facebook person, I only get on because my grandkids get on. It seemed like the cancer portion of it jumped out more than just a national firefighter registry up there. I don't know that was the right thing. It caught my eye, because, of course, it's my eye, but I don't know if it would deter somebody else to say, “Well, I don't have cancer. I don't need to pay attention to that.”

Dr. Fent: That is one of the misunderstandings, firefighters thinking that you must have cancer to enroll. That is one of one of the things we're really trying to be careful about in our messaging.

Mr. Stagnaro: Thanks for the plug and my apologies, I don't think we've done enough to promote it from the NFFF side. If you're trying to get the fire chiefs to roll this out in their departments, if you’re going that route, it would be helpful to teach them how to roll it out. We're not marketers. I look on the website and I'm overwhelmed with the amount of information that's there, which is great. But maybe a step by step, “this is how to do it,” because I just get overwhelmed with all the information. I don't even know where to start. That would be a way to maybe help get the word out.

Dr. Fent: We have the promotion toolkit, which is for our partners - the big organizations. One idea we’ve had is to produce something like that for fire chiefs where it's like you said, a step-by-step guide. Step one, find a champion in your department. Step two, send out an email, etc. I think that's a great idea and something we could do.

Mr. Harbour: You reminded us about the procedural requirements associated with the Federal Advisory Committee Act (FACA). I heard you'll share the SME list. Are there any procedural requirements that we have to be aware of as we interact with the SME? In other words, I could see myself looking at the list of SMEs. If I see somebody I know, I’m likely to just pick up the phone and call them. Are there any procedural requirements that we on the advisory subcommittee should be aware of when we're interacting with SMEs?

Ms. Novicki: No, long as you're interacting with them in your other capacity, so not as a member, but in your main role. The big thing is that I must be the one to send you the email, which we can do no problem. Beyond that, then you just don't want to be collaboratively, as a group, interacting with those folks. If you personally are like, “Oh, I know him. I'm going call him,” you're all good.

Mr. Harbour: Can I say, “Hey, you should talk to Victor, or you should talk to Manny?”

Ms. Novicki: That's still okay, since you're doing it in your personal capacity or as part of your “day job.”

Mr. Harbour: Okay, and then Dr. Fent, I hope there's enough energy or a “kick” in the fall, because for wildland folks, now and for the next 3 months, it not the time we're going to be able to convince some of them to open up a laptop and spend an hour or half an hour to enroll. The fall will be the time period for wildland.

Dr. Fent: Right. I didn't talk about this in my presentation, but we have heard from wildland firefighters that they're struggling a little bit with certain components of the web portal. I think a lot of you understand we had to make it work for structural *and* for wildland. And so yes, there are some questions that our wild and firefighters are like, “I don't know how to answer. This is for structural,” and vice versa. One thing we're

wanting to do is to update our enrollment tip sheet and include some specific tips for wildland firefighters to help them with those sticking points.

Mr. Harbour: There's a small group of us that almost did exclusively wildland, but what's the NFPA stat? 84% of all departments in America have some component of wildland. You've got to figure out a sweet spot for all.

Mr. Stagnaro: If I wanted to reach out to an SME to speak, does that go through you, Ms. Novicki, or can I go directly to an SME and say, "We're hosting an event, would you come in?" If I'm hosting an event, how do I request a speaker or presentation.?

Ms. Novicki: You do not need to go through me. Dr. Fent, I'm not sure what the terms of the contract are and how you want the process to work.

Dr. Fent: We'll provide the list of our SMEs. I think a lot of you will know them and you're welcome to reach out to them. And then we would have to work it out internally how to support it.

Ms. Lee: Hopefully they will know the terms of their contract.

Dr. Fonseca: What about my local fire department? I cannot go and talk to them and ask them to join?

Dr. Fent: I think you're more than welcome, because again, that's your official capacity, not on the NFRS. That's you doing what you want to do individually.

Dr. Siegel: As an individual, as opposed to a member of the NFRS, just in your regular affiliations, you can do whatever you want to support. You can reach out to us with questions and suggestions, you can spread the message as far and wide as you're able to.

Dr. Fent: I agree.

Ms. Novicki: Where the FACA comes in is when we start doing things as a group and reaching consensus. If you're acting individually, you're good. It's if several of you got together that we could have a little bit more of a challenge.

Ms. Lee: I was just thinking that cancer survivors are probably some of your best advocates. We have Brian McQueen, who was on this Subcommittee, who is able to make almost every one of our meetings or events. We make sure we give him a space and I think his passion really shines through for why this is important. If you can tap into those people, they'll be likely to want to share the story, and they can also share why this is important. Because you're helping people like them in the future.

And that was one thing that maybe I saw was missing from the current messaging is, "Why should I do this? How does this help me?" It helps you because you're helping your fire service family, wildland and otherwise, in the future.

Dr. Durbin: Reducing risk for future firefighters is a key thing, I think, as well.

Mr. Harbour: In the context of what you've seen so far, I haven't detected alarm, but, on the other hand, if you need to tell me, we are stuck in swamp water with how we're doing so far. You just need to be blunt with me. Do have any sense of how we're doing?

Dr. Fent: What we're doing is uncharted territory. This is pretty unique in the federal government. We have registries that have been done before, but not to this scale. Especially because it's a voluntary registry, it's a bit hard to know how well we're doing. I think it's still early. That said, where we know we're doing really well, is we have the support of the fire service across the board, which is outstanding. I think our promotional materials are some of the best that have ever been produced at NIOSH.

Dr. Siegel: And at CDC. We've had other parts of CDC reach out to discuss our materials.

Mr. Harbour: I think almost everybody has said this kind of been easy. And it's easy until you get into the details of how do I answer this question? But it's an easy, "Yeah, I want to do this." "Yeah, I saw something from my association or was talking to a guy." That's easy. We're really rolling it on that part. Well known message, well distributed, well supported. I'm really pleased about it.

Dr. Brimhall: Remember the time is now to get on agendas for 2024. You can't be trying to show up with somebody's conference that's happening later this summer. You want the marketing - you want them to have the advantage to promote you, your message, that you're coming to their conference. Start looking at 2024 beyond and make it continuous.

You had that booth for FDIC, which was nice and huge, but the but reality is, you're going downsize that right? But you still need that presence. You're still going to want the data to go in. People knowing that you're still out there is good, and that you still need that feedback.

[The Subcommittee adjourned for lunch and resumed the conversation afterwards.]

Dr. Fent: I wanted to start out with returning to a suggestion from earlier today about trying to connect with occupational physicians. That's a way to reach firefighters when they're getting their annual physicals, for example. I'm curious if there are any ideas from the advisory committee about how we do that? How do we connect with who occupational doctors or medical professionals that are administrative.

Mr. Harbour: Is there a national organization?

Dr. LeMasters: There's ACOM – American College of Occupational Medicine

Dr. Moffatt: I might add also, with regard to NFPA, they have the ability to put information out from that standpoint. But I do think ACOM has a public safety medical division. That information could be put out there, or at least made available there.

Dr. Harbour: On the federal wildland fire side, you met with Cali. But Dr. Jennifer Symonds from the U.S. Forest Service is the medical officer for the west forest service and their 12,000 firefighters. I'll be happy to make those introductions.

Dr. Materna: I was just going add the American Association of Occupational Health Nurses (AAOHN), because some departments may use nurse practitioners.

Dr. Simmons: Yes, I was going back to original course. I was going to say, work indirectly through fire chiefs and make contact with those specific medical directors for each department or organization.

Dr. Fent: So that could be added to as a step, in the stepwise approach with fire chiefs?

Dr. Simmons: Exactly.

Mr. Stagnaro: I want to follow up on Steve Moffat's comment about the NFPA – reaching out to the 1500 NFP groups. They would be able to penetrate a lot of those occupational medicine folks.

Mr. Brimhall: And you could reach out to the cancer treatment centers too. As part of their investigation, aren't they determining what somebody's occupation was when they're treating somebody? They determine whether you're a firefighter: volunteer, career, somewhere. They could say, "The NFR is here. Maybe you want to share your information with them at the same time you're being treated by us."

Dr. Fent: Is there anybody else that we're missing in terms of our marketing and outreach?

Dr. Fonseca: We were talking at lunch about social media, and it's good that we use the national partners. But how effective could we be if we had a company that can target specific zip code. Specific areas. Just like the other companies do, because if I'm not involved in the National Volunteer Fire Council social media, I'm going to miss out on stuff. But sometimes people just seeing messages around can help.

Dr. Fent: There are Google-promoted ads and things like that you can do. I think we are doing some of that through our communications contractor, but always there's room for improvement right? I agree with you - if you're a firefighter who's not connected with the professional organizations, how are you going to hear about it? We've got to figure out a way to reach those harder to reach groups.

Dr. Fonseca: Especially in rural areas where there are limited capabilities for internet. Where my daughter lives, she has a nice house, brand new, beautiful. But she has to use a hot spot just to get cable and internet. It becomes very difficult. Even in Tennessee, the governor is pushing to get more internet into rural areas where they don't have it, or they don't have enough power to get access to information.

The second part to me was the language. There is a basic assumption here of English, but I go to Texas and a lot of those firefighters don't even speak English. They just speak Spanish because they're predominantly near the borders. And those guys do not communicate in English, only in Spanish. Are we missing them? I learned this when I was on committee with the White House for COVID, and we were targeting Hispanic communities. We were visiting those border communities and the one language was Spanish, but everything was coming in English, so it was ignored.

Dr. Fent: Taking some of our communication materials and translating into Spanish, is probably a good idea.

Dr. Fonseca: In other areas of the country, you'll find out there's other languages, like Arabic, that are very prominent. Farsi, Persian. There are a lot of languages that we have not addressed, that in certain regions of the country, we are seeing more and more firefighters with those languages. This is what I've learned from COVID, just listening to people who think about that.

Mr. Brimhall: We have a very strong population of firefighters in couple of counties that need testing in Yiddish. We just breached the Spanish one.

Dr. Fonseca: We can start with just basic Spanish, a common language. Languages that are more prominent in certain counties.

Dr. Durbin: I don't know if fire science programs, academic programs maybe have a connected community.

Dr. Fonseca: FESHE [Fire and Emergency Services Higher Education] does that, don't they?

Mr. Stagnaro: FESHE is through the U.S. Fire Administration.

Dr. Simmons: I would also say, each state has the Fire Science Technology Directions Association. That's another good avenue.

Dr. Fonseca: The state fire academy, each state has their own.

Dr. Stagnaro: The training directors, too.

Dr. Fent: The one group that we have considered but haven't talked about yet is the spouses of firefighters. But how do you reach spouses of firefighters? I don't know that they have organizations. Maybe they do.

Ms. Lee: Facebook groups.

Mr. Stagnaro: I think Denver has a group called Better Halves. I think there are individual groups that are out there.

Dr. Simmons: I would imagine a volunteer group may have a women's auxiliary captain.

Dr. Fonseca: Yes, like Box 55 or all these associations that help firefighters during large events. They are composed of volunteers. A lot of them are spouses and retired personnel.

Dr. Fent: These are organizations that help during major events?

Dr. Fonseca: They'll bring water, food. Sometimes they'll do blood pressure checks. They do everything. There is a there's a big organization, a box association. I can find that later. But they do show up. A lot of cities have them, and they're very highly respected by the fire service. When it's 20 below 0°, a cup of coffee does good.

Dr. LeMasters: Well, I think we got a lot of good suggestions here as a follow-up to your presentation of what else can we do in messaging and marketing. And I hope that's helpful. I think by adding some of these things

to your already fairly complete messaging, it should be able to reach a good proportion. I think the doing it in Spanish, it would be very helpful. That's an especially important one.

Follow-Up Questionnaires

Dr. Siegel led this presentation.

I'm going to revisit something that's actually exciting to talk about now, because it means we really are at the next stage of the NFR. We've completed everything for the enrollment questionnaire and now we've got our sights set on the future, and one of those future elements relates to follow-up questionnaires.

We're just beginning to start to think about this. We welcome any and all input. I've got some discussion questions at the end that we can use to guide our discussion, but this is just the beginning stages of thinking about what we'll administer, what information we'll obtain and how we're going to do it. Keep that in mind as I go through the presentation.

The purpose of the follow-up questionnaires will be twofold. The first is to add to our current knowledge base on topics that we were unable to dive into, or ask about at all, in the enrollment questionnaire. We informally refer to these as "specialty topics." Now, this can be anything, including:

- Major events - More detailed information about major events or specific events
- Health topics - Special health topics, comorbidities, or health behaviors or health behaviors
- Topics for specific groups – Groups of firefighters, groups with certain demographic characteristics, or groups that have reported some kind of cancer or health condition.
- Emerging topics – We would identify these through consultation with other scientists or fire service leaders.

The second purpose is to collect *self-reported* longitudinal information, which is changes in exposure over time. I emphasize self-reported here because we plan to leverage other measures of exposure records (such as incident records, exposure tracking records, and employment records) over time to be able to collect that records-based exposure information prospectively. You heard little bit about that earlier.

The limitation of these follow-up questionnaires is that we are unsure about or expect low participation. Engagement in any of these questionnaires is voluntary. Most of you are already familiar with the fact that firefighters have struggled a little bit, or they've expressed concern over, the length of the enrollment questionnaire. While we want to develop promotional material for follow-up questionnaires, we don't necessarily expect participation to be as high as we might like for these follow-up questioners. Certainly not all the follow-up questionnaires. We also have heard some messaging from some areas that the NFR registration is one and done. You sign up, and then you never have to touch it again. That kind of mentality is problematic for expecting participation in follow-up questionnaires.

And then I just want to note that obtaining our detailed and accurate information on long term cancer diagnoses is going to be through our state cancer registry linkages. We are not depending on follow-up questionnaire participation to get information on cancer diagnosis.

The example topics that we've talked about over the years for follow-up questionnaires fall into different themes:

- Longitudinal or changes in work information
    - Department/position/work - How has your department affiliation, position, or work status changed?
    - Protective practices - Have your protective practices changed since you last participated, or in the last year?
    - Incident response estimates - How have your responses to different incidents changed?
- Lifestyle
    - Smoking detail/changes - Maybe more in-depth questions about smoking or chewing tobacco, or other lifestyle behaviors that might change over time or where more information would be useful.
    - Alcohol use detail/changes – Similar to tobacco use
    - Diet - We weren't even able to touch on diet in the enrollment questionnaire. The subject matter experts we consulted with suggest a more comprehensive approach to assessing diet, which we didn't have room for in our already in long enrollment questionnaire.
- Health/comorbidities- Health outcomes that may act in conjunction with or somehow be related to cancer.
    - Reproductive
    - Behavioral/mental
    - Attitudes, beliefs, perceptions - related to some health outcomes and health behaviors.
- Subspecialities
    - Wildland, Wildland/Urban Interface
    - Women
    - Volunteers
    - Major events

Questionnaire administration has yet to be designed. How are we going get the word out about these follow-up questionnaires? Will it look like sending email notifications with a link to a single follow-up questionnaire to all the participants in the NFR? Or will it look like a page in the NFR system of any available modules that we've created, that participants can go in and complete at their convenience. We can make announcements about available follow-up opportunities in our newsletters.

Some of the longitudinal information that we can collect comes from changes in in the limited information we collect in the user profile. When we remind participants over time, like “Hey, why don't you go ahead and just update your current work affiliation and your user profile?” That's a simple way for us to collect some limited information longitudinally.

I would like to note that only *eligible participants* will be qualified to fill out some of our specialty topics. The questionnaire frequency will vary. If we've got a questionnaire that's just for women, and then one that's available to all NFR participants, then some groups of firefighters are going to be eligible for multiple questionnaires, whereas some might not see a follow-up questionnaire that they're eligible to complete for some time.

Another aspect is the timing of administration of the questionnaires, as well how we obtain the information. Will it be best to base it on calendar time? If someone enrolls at the end of 2023, and then we've got a questionnaire ready to go in spring of 2024, should we wait until that person's been enrolled for a year? Do we go off calendar time, regardless of when they last submitted a questionnaire? Some other approach? Should it vary questionnaire to questionnaire? That'll be something we have to consider for the deployment of follow-up questionnaires as well.

We'll have contact information that participants provided us in at enrollment. This will be the email that they use to enroll in the NFR, as well as an alternative email for participants that chose to provide us with one. We'll possibly also have cell phone numbers for text messages if there's a way to leverage that information down the road. Cell phone number was also a voluntary field in the NFR enrollment questionnaire.

With that, we'd love to hear your input on all things related to follow up questionnaires. These are some questions to guide the discussion.

1. What is the ideal time length and frequency for follow-up questionnaires?
2. What topics should be prioritized? (Considering likely loss to follow-up and survey brevity, how to prioritize questions on *self-reported* longitudinal information/changes in exposure over time versus "specialty" information?)
3. What is the best format and timeline for questionnaire administration?

We might want to start with the ideal time length and frequency for follow-up questionnaires.

Follow-Up Questionnaires Discussion

Dr. LeMasters: You suggested we start with number 3, I believe. What is the best format and timeline for questionnaire administration? I think anything less than a year would be too soon. What do the rest of you think? Would one year be enough? 2 years?

Dr. Simmons: I would go with that year mark. Anything longer than that you'll lose influence, and anything shorter than that, folks will feel like they're being inconvenienced and will be less likely to complete the follow-up.

Dr. Siegel: Can I interrupt for a second and clarify? I'm sorry. Are we talking about the frequency of follow-up questionnaires?

Dr. LeMasters: We're talking about your question – format and timeline for questionnaire administration.

Oh, well, yes, I guess we're on number 1. What is the ideal time, length, and frequency for follow-up questionnaires? Sorry about that. I didn't know if I was on 1 or 3.

Dr. Siegel: That's okay!

Dr. LeMasters: For the ideal time length and frequency, less than a year is probably too short. But, as someone else has said, but one year might be good. After one year they may forget about you.

Dr. Moffat: Everyone deals with the issues with regard to people filling out questionnaires. I always feel that a year just seems to be too soon. I think that you could potentially fatigue people, especially dependent upon how long the questionnaire is. I guess it depends upon how long do we envision the follow-up questionnaire to be?

I've been involved in projects where people will actually fall out of participation just because here comes this questionnaire again, and I don't want to do it again. And it seems to happen at that year mark. Being sensitive to the length of the questionnaire, and if it's over a certain number of questions, or takes longer than 30 to 40 min to complete, I wonder if there's any potential for fatigue, and people dropping out. That's my only concern with regard to doing it on an annual basis. What's the difference between a year or two years? I tend to more think more in a timeframe of two years, but I'm open, considering how long the questionnaire is, and how long it takes.

Dr. LeMasters: It might help if it's tied with providing some results, so you're not just asking them to complete a survey, but you're giving them some information about who has participated. What parts of the country? What's your total number?

I think it should be that you are giving them something when you are asking them for something. Maybe at the same time, but to what did the rest of you think?

Dr. Fonseca: For me, we base everything on a one year span: anniversaries, jobs, and fun things that happen once a year, like New Year's Day. That's why we celebrate everything within the year span. We tend to remember everything that we've done during that year, so doing it within one year is always good.

When you have a major event, that is catastrophic - not that you had a house fire, but something like the highway derailment that caused national attention, that you evacuate a town for, that you're exposing your members to ethyl methyl bad stuff out there. Nobody knows what's what the exposure is, but it's something that we need to make sure that they understand that if anything catastrophic happens, we need to document it. In the career departments, every time we have a major catastrophic event that causes exposure, everybody that responded has to fill out an incident report. Why? Because we don't know what's going to happen, whether you grow a third arm, another head. Who knows? Or you die. This is something that we've had, where people were exposed, and the next thing you know, a month later they're taking retirement because they were exposed to something that's horrific, and nobody knew about it.

For me is yearly is good, and the frequency should be with any major event. Now that's unless you're in a area that does two house fires a day, something like that. That's an exposure that needs to be visited, which is all tied to what I think is the call volume of your department. Some cities make 300,000 or 400,000 calls in a year. That's significant compared to a small department that makes maybe 200 calls a year. That tells you about the exposure level that your members are getting. 300,000 calls for a department is probably about a 1,000 calls a day. That's a lot of exposure versus 200, which is maybe one call per day for the whole fire department. Exposure could be minimal. We're not dismissing that, but the call volume is critical for me to understand how I'm dealing with exposure, what I'm dealing with the types of illnesses. I've worked in a 200,000 call department, so we made 20 calls a day, and that was normal.

Mr. Stagnaro: I think for frequency it's no more than a year – a year or longer, to Stephen's comment. Maybe take advantage of Firefighter Cancer Awareness Month. There might be opportunities where, at least it's in the mindset of the firefighter. You just kind of creating a greater awareness along with another marketing campaign that's going on.

As far as the length I think 3 to 5 questions, you can't go beyond that. If you're going do it annually, 3 to 5 questions. More than that, and you're going to lose people.

Dr. Materna: I wanted to ask, what were they told at the beginning, in the initial enrollment? What were they told expect from you about follow-up?

Dr. Siegel: In the consent form? I don't know what the ultimate language was.

Dr. Kent: That there will be periodic, follow-up questionnaires that are optional.

Dr. Materna: I sort of agree with everyone. Once a year, or every 2 years. I totally agree with keeping it *much* shorter than the initial enrollment, and it seems like you would want to prioritize capturing things that could have changed. You'd want to know if they completely left the service or major changes in job. And, I agree, any noteworthy, serious exposures or things they were particularly concerned about. And, as an industrial hygienist, any major changes in the protections used. That's hard to capture in short questions, but particularly use of personal protective equipment, if that changes.

Mr. Harbour: Make sure you think about the motivation for follow up and that frequency too. At least one of my buddies got in, completed the form, and, like 2 months later, got a melanoma diagnosis. Then he was asking, "How do I get back in?" He was really willing at the time to offer information. If there's a way not only to push from your side, but is there a way for the department or the individual that's more motivated all of the sudden to provide information?

Now it's not just an esoteric one of 3,600 or 200,000. "Well, I got diagnosed. I'm going through this right now. I'm anxious to help my brothers and sisters."

Dr. LeMasters: I think that's a good point. But you all are planning to find out about all cancers through the cancer registry and not through the follow-up questionnaires. Is that correct? Cancers will be identified through the registry only?

Dr. Siegel: That's going to be our method for our most comprehensive and dependable cancer diagnosis information. That's not to say we won't collect cancer information in follow-up questionnaires, but the participants are not needed to return and report cancer information to us.

But I think to Mr. Harbour's point, that was just the motivation for this person to contribute more information generally. This relates to the third discussion question as well. One of the format options was to have a page, for example, in the portal there are different modules where you can fill out information when you feel like it. So that's one option for us to consider.

Dr. LeMasters: You mean, let them choose which questions they'd like to answer. Is that what you're saying?

Dr. Siegel: Yes. Some design like that. We've heard some other CDC programs that have a similar format. And I personally just found that interesting.

Dr. Lemasters: The only difficulty, I suppose, is that you wouldn't be collecting the same thing on everybody right? Like you wouldn't be collecting, perhaps protective practices. They might not fill out that work information section unless you require that.

Dr. Siegel: I don't think we can require. I think it would be voluntary, no matter what the format was.

Dr. LeMasters: You could say, fill this out and then pick another. Pick another section of your choosing. I mean, there might be one specific area that you would always want to gather information on like work status change, or incident response. That longitudinal work information to me would be key, and then they might pick something else out to fill out.

Dr. Simmons: I'm going to simply say, looking at the original survey, the follow-up should be based on what could change. And among what could change, what is most important to us moving forward from a strategy, perspective? It's one way of looking at it.

Dr. Kohler: I'm a little concerned that the group is putting a lot of restrictions on themselves, regarding the timing and the number of questions that they're willing to ask the firefighters. I agree with the previous comment that some people may be very willing to share information. I think setting policies, oh, we're only going to contact them once a year or twice a year. I don't think you're really, going to know until you get into this. And I think that individuals who are bothered by frequent requests for information will let you know, and will ask to opt out, or something like that. They'll say, "Don't bother me so much."

I would encourage you not to be too restrictive in your request for information. I like the idea of having the modules available that people can provide as much information as they want, and then you'll have to figure out how to deal with it during the analysis. But I think the more information you ask for, the more you're likely to get.

Dr. Harbour: I'm not epidemiologist, but in a sense, you're biased right now, because those people that have responded, are guys like me and my buddies who had some experience. We've seen somebody go. Even my son, it's like, "Dad, yeah, you know, I'm busy doing a lot of other things." It hadn't hit him like it hit me so

I think I see what you're saying. You're hoping for a sample that's large enough, that's entry level, young people beginning to set history. I would assume these first responders, and maybe this first wave are going to be folks like me who think, “I’ve got to do this” because it's visceral for me. They have that level of commitment to do the questionnaire, and then to do any follow-up.

Dr. Fent: I think it's a very good point, and it's one of the primary drivers behind the targeted enrollment approach because of that bias from open enrollment. When we're considering these follow-up questionnaires, we have to consider that first group that enrolled (open enrollment) and the future group (targeted enrollment) that hopefully won't have as much of that bias.

Dr. Siegel: When we're talking about frequency and timing -this relates to the third discussion question too. Questions 1 and 3 are quite related. When we say one year or 2 years, we'd also really like input on the timing. Are we talking from the last time a participant participated? Or one year in terms of a calendar year? Registration is open to anyone to enroll at any time. Someone might have enrolled in January of 2023, and someone else in December of 2023. Are we going to push questionnaires, for example, a year after they enrolled, or starting in the year 2024?

So just keep that in mind a little bit when we're talking about timing and frequency, because I think we could really use input on that.

Dr. Kohler: I think if you do an open, rolling questionnaire, you're setting yourself up for a nightmare in terms of practicalities of analysis. And I wouldn't do that.

Dr. LeMasters: What would you propose?

Dr. Kohler: Well, if you want to put out a questionnaire at the beginning of January 2024, you send it out to everybody who's eligible. You get the results in, and then you send another one at the appointed time, no matter how long they've been enrolled.

If you know if you're sending out, you know, based on when they enrolled, you'll be sending out the questionnaire in January. And then you'll send more out in February, and then you'll send more out in December, and you'll be waiting a whole year to get any data back. That would be a nightmare to me. Plus, for analysis, you probably want a point in time survey. Asa of this point in time, this was their cancer status, or this was their occupational status. I think it'd be crazy, but computers can do lots of things, or you could handle it.

Dr. Fent: I really like the idea of January, because it's cancer awareness month. And I like the idea from Dr. LeMasters, who said, “Give them something when you go to ask for something.” We could provide some summary statistics, or a dashboard with information that's valuable to them. While we're asking for, “Hey, there's this follow-up questionnaire. It's totally optional. It’s short, and it's during cancer awareness month.” I think there's a lot of benefits to doing it that way.

Dr. Harbour: Much of the early adopter enthusiasm has been based on a pitch that this is for us. Yeah, you guys get to use it, but this is for us. I think you can work with professional communicators, and maybe a January cancer awareness month works to try to maintain this focus. When you think about it, okay, yeah, it's

you, the scientists that are getting use it, but we're not that altruistic. We're not going to spend time for you. We're going to spend time for us. If you can give them something and make it not appear to sterile and disconnected from the folks who spend the time putting the information in.

I think that's part of what has made this resonate so well, so quickly. You have made great presentations, and when you leave the talk is, "Yeah, this seems worthwhile." Mr. Stagnaro said it was good. Dr. Fonseca said it was good. Ms. Lee said it was good too. The firefighters themselves are talking. That's if we're going to get anywhere near the 200,000. You've got to maintain a lot of momentum to make sure they believe that there's benefit to their brothers and sisters in the fire service. You PhD's get to use it. That's cool, but that isn't fundamentally why I'm excited about this.

Dr. Durbin: Personally, annual seems reasonable, and I think it depends on the technology that you use to administrator this. If you do a survey in January to everybody and you've got 4,000 surveys coming in potentially. Whereas if you spread them across the year, the computer has no problem generating an automated email or message to go out. It may change the volume of work for the people that have to contend with this.

Another thing that occurs to me is that I think there's some risk of loss to follow up for people, right? Their phone numbers change, they move, and different things. So, at least for me, personally, I've signed up for a couple of health-related apps. People are developing apps that you install on your mobile device, and it tracks your health issues. One is an exercise program. Have you thought about, implementing an app?

The lift may not be all that difficult, depending on the features that you would have. It would be a way that if the person's phone number changes, you still may have a way to contact them. The app itself can send notification messages conceivably. It could also provide some information that might be of interest to folks like, how many people have enrolled, how many people have reported incidents, or how many have cancer. Something to give him a reason to open it and look at the information there. I don't know to what extent you've thought about that, but maybe there could be an opportunity to think about an app that would stay with the individual and keep them in touch with the you know with the program.

Dr. Seigel: I love that idea. That's something we discussed early on, and had dreams about that, or maybe making the web portal something like that. It's certainly something we could talk about more and bring to our IT group.

Dr. Fent: It would be new territory for us. We have produced apps before at NIOSH that have been successful. This is a little bit different because it's also a data collection instrument.

Dr. Durbin: This is new technology for us too, at my cancer center. But we're looking more into new apps. Younger people are familiar with those and familiar with communicating through apps. Everything has an app now.

Ms. Lee: At first when you were talking about the timing, I thought, of course, we should do this on a rolling basis, depending on their anniversary. But then when you all started talking about maybe doing it January,

you could do a big push in fire service media saying, “Hey, don't forget the surveys are out now.” I think that could actually be a benefit to doing it once a year, at a certain time.

Dr. Siegel, I like your idea of having questions that they could fill out if they wanted to. This could be similar to a profile as a nonprofit. We register with Guide Star, and we can fill out our name and our address, or we can fill out our name and our address, add our 990’s, and talk about our mission. We get a gold star at the end. It's optional. It gives them more information, so that might be something people would be willing to do perhaps.

The other thing I was going to say is, I think it's going be important to also show value in this pretty quickly. Maybe after the first year, what is coming out of the data? What is being done with the data? And I say this because my kids have been enrolled in a study at NIH on adolescent brain development. And it was super exciting at first, and we would go up to Baltimore and they would do this, and I'm like, “Oh, we're helping other kids!” And then, we never really heard what they were doing with it. It was taking a lot of time, and then they want to call with the 20 min questionnaire, and we just kind of dropped out of it. But I think if you keep that value going and show them what is getting out of this, what research is or could be, or is coming down the line with it. I think that'll help keep the motivation going.

Dr. Fent: I think you mentioned it, but as part of the enrollment process you can opt in for text messaging. There is the potential to provide updates via text message. I think sometimes emails get lost. I get thousands of emails a day. But the text message like, “Hey, check out this latest infographic” or something. I think there's a real opportunity there.

Dr. LeMasters: I think text messages should be utilized in some format. I agree with that comment.

We haven't touched on discussion question 2. I'm wondering if we should go to question 2, and then we can come back to 1 and 3 if we would like. I thought we should give some feedback about what topic should be prioritized: longitudinal work information, health/comorbidities, lifestyle, or subspecialty.

Dr. Siegel: And I'll just read this subtext briefly, which is considering likely lost to follow up and survey brevity. How should we prioritize questions on self-reported longitudinal information and changes in exposure versus specialty information. The slide has some sample topics, but this is certainly not even close to the realm of possibilities.

The longitudinal work information is “Type A” of that information. And these other 3 themes fall somewhat into “Type B”, which are specialty topics or new topics that we didn't obtain information on in the enrollment questionnaire.

Dr LeMasters: I guess you're asking, should this be expanded? Are there others that are more important? Which would the committee recommend that you all focus on, correct?

Dr. Siegel: Yes, and where should we begin?

Mr. Stagnaro: The question first, from a science standpoint, or is there something that you're trying to gather? Or you don't know what the question is yet, so you're just determining what we think you should gather.

Dr. Siegel: We know there's all sorts of important topics. We want to get to everything that we can. But guiding the direction of where we begin and where we should go, in terms of which topics, or which changes to prioritize, we want input on.

Mr. Stagnaro: Certainly, the longitudinal work, and the information that's there from the standard point of information that's helpful to you to feed back to the fire service, is obviously pretty vital. And then I would say the reproductive component seems to have a heightened alertness. I would even add, related to the reproductive piece, firefighters with children who have special needs. It could help to determine if there's issues there that could be better studied or should be better studied.

Dr. Fonseca: I'm kind of lost with the longitudinal. What I want to know is, are they directly involved? Directly involved with in the exposure means they're actively working a scene, or they're indirectly working. They're at the scene after the fact, when things are done. They could be office worker. They could still be an inspector, but they only do the paperwork part. They're not directly in there, but they're still considered firefighters. They've been through the academy. They've done everything. The roles are different. People that are directly involved have a higher degree of exposure. That's just known. And then the second part is the people that are indirectly are there are the arson investigators, the people that are looking after the fact. They have those secondary exposures that we don't talk about. That's critical to understand, for me. Once I know that, then I can ask specific questions to those people. I cannot ask someone who's doing the paperwork the same questions as the person on the scene.

Ms. Lee: Or if they're a lifetime member. They're still on the department.

Dr. Fonseca: Yes, they're a lifetime member, but they don't make the calls. They just show up, maybe hand up coffee. They're there! And it's an indirect exposure to smoke around there, or they're next to the people around it. But they're not in the hot sun or the live hazard zones. So that's an important question that we have to think about.

Dr. LeMasters: So your suggestion is to ask specifically what?

Dr. Fonseca: What's your job? Are you directly involved with the exposure or not? Are you fighting the fire, or directly treating the patients, or in the incident? Or do you come in after everybody's gone home, and you're the arson investigator.

Dr. LeMasters: So almost specific job description. What are you actually doing at the fire?

Dr. Fonseca: Right. If you came on an engine, you were directly involved.

Ms. Lee: Or just a question like, "Are you on the fire ground for any reason?"

Dr. Fonseca: That's good.

Dr. Durbin: I completely agree. That will be critical to know, whether are they actually being exposed to fire scenes. A secondary occupation might actually be important. Many firefighters, because of the 24 hour shift with couple of days off, they have a second occupation. Maybe they're a welder on their days off.

I certainly think lifestyle and health getting a sense for that. It would be important. BMI for that matter, if there are associations between BMI and cancer. I don't know to what extent you inquire about that. You can't ask everything. You do have to limit and prioritize, but I think behavioral lifestyle factors longitudinally might be important to capture.

Dr. Siegel: Thank you. And we do ask about other jobs in the enrollment questionnaire too, which will be exciting to look at.

Dr. Materna: I agree with what everybody said, that changes in jobs and what they're doing is a priority, so that you know who to drop out as you go to do your analyses. It occurs to me that this follow-up questionnaire could have some limited questions on a topic of interest. It could give you interesting cross-sectional information. To me the one that pops out is the behavioral/mental. There's so much more focus on PTSD and the stress-related aspects of firefighting that there's just so little known about that. You could, from year to year, pick a different topic to focus on and have a little module to it. This is going be such a rich study population for all sorts of things, but those would be my favorites.

Dr. LeMasters: I have a couple of comorbidities that I think might be important in this particular occupation. First is pulmonary disease, like pulmonary fibrosis, or pulmonary disease in general. This could have an influence on how heavily they've been exposed if they have pulmonary issues. The other thing would be nice to know about is coronary heart disease. This is another comorbidity that might be very influential in quality of life for the firefighters. Maybe not necessarily cancer, but certainly quality of life, both pulmonary and coronary heart disease.

Dr. Fent: Dr. Siegel, do we ask about heart disease in the enrollment questionnaire?

Dr. Siegel: We do.

Ms. Novicki: One thing I think you're trying to get at, Dr. Siegel, is the mix of how much of this longitudinal follow-up versus how much of these specialty topics. If the questionnaire must be very short, how much space should be allocated to each? Does anybody have any thoughts about that?

Dr. Siegel: Right, because we know we're not adequately touching on a lot of topics. For example, a lot of risk factors for wildland firefighters, a lot of stuff about wildland jobs. There are topics that we want to make sure to hit with either follow-up questionnaires, or specialty modules in the web portal that we won't have the space to focus on getting routine changes in jobs and work status. It's about striking that balance with limited space and limited follow-up participation.

Dr. LeMasters: Well, one subspecialty I don't see on here is the volunteer firefighter. Wouldn't that be considered a subspecialty?

Dr. Siegel: It's there. But this list is not comprehensive. It's just to start the brainstorming process.

Dr. Lemasters: Got it. Thank you.

Dr. Moffatt: In Indiana we take care of the task force team members that travel out. One of the interesting dynamics with the most recent one, the Surfside condo collapse, is this pummeled concrete exposure. That was significant at Surfside. Has there been any contemplation of categorizing the special events with regard to the types of the exposures that they had? Obviously, Katrina would be different than Surfside. Certainly, World Trade Center. There's a lot being done with World Trade Center. But Surfside popped up as another rather unique type of exposure.

Dr. Siegel: That's a great idea. I mean, we collect some open-ended information about that in the enrollment questionnaire, but I think follow-up questionnaires or follow-up modules are a great opportunity to administer targeted questions to people with a certain response in the enrollment questionnaire. Or, likewise, for all participants to get updated information on special incidents.

Dr. Moffat: It's been an interesting dynamic with regard to the participants. We're doing more aggressive surveillance on those individuals with regard to their exposures. For task force events, many instances can be rather different and unique.

The other comment, and Dr. LeMasters mentioned it with regard to issues of pulmonary fibrosis, along with coronary artery disease, I think also diabetes would be an important one to monitor for as well. Obviously with the underlying concern over cellular information inflammation as predisposition to cancer, or at least a component to cancer in inflammatory types of responses. But again, it depends upon the length of the questionnaire, and how many questions we can ask.

I do like the module piece where other firefighters that have interest can go to those modules and fill them out. it I think it's going be important as time goes on to have an understanding of the frequency of these co-morbid conditions as we enter into situations where people then develop cancer. So what are those co-morbid conditions that are closely associated with those incidences of cancer in the fire service? I think the more information we have on those medical conditions, we're going to glean a lot of important information with regard to relationships.

Dr. LeMasters: Thank you. I think that's a very important point. Would anybody else like to comment on any of the 3 questions?

Dr. Fonseca: My thing is the timing. Earlier someone mentioned January, but are we competing with other organizations that are very big on cancer in January? The American Cancer Society, breast cancer awareness, and all these organizations that push and the community rallies around these big events. There are walks, talks in organizations. Now the fire service takes October for a fire prevention month, week, whatever.

My question is here is which is the best time to get enough information that would help the budgets, so that you can feed Congress more information. If we're if we're lagging behind - things happen all the time in Congress, and money comes in and goes away. Do we need to be in January? Do we need to be in May, June, July? I have no idea, because the more we gather, the more information we have that's relevant and new, the

better it is to report. And that helps support the program and support everything it needs to and helps push the message out.

Dr. Fent: That's it's a good point. In January, there's a lot of messaging about cancer and we could get lost.

Dr. Fonseca: Ours is new. This is not breast cancer awareness. I rally big around it because I've had family members who have died from breast cancer. To me, it's a very important topic. I don't want to think about firefighter cancer. I want to think about protecting the women in my life. You know I have daughters, and a mom. Well, my mom's passed on, but I mean but daughters and aunts. I have all those family members, that I think that are exposed and have a high chance of getting of getting it.

Mr. Stagnaro: I think January's firefighter cancer awareness. It's not cancer awareness broadly. It's very focused on fire. And I would guess, because of all the organizations that are supporting this, they would include messaging for the registry.

My comment, coming back to the specialty topics, came up in a different meeting I was in, but urban search and rescue teams. I don't know if you have hazmat teams and specialty teams within a department. It might be another avenue to focus in on.

Dr. Fent: I wanted to make a point. We've talked about incident records, and that's a way to get information on firefighters' responses over time. Theoretically, that would include major events. Maybe even, depending on what happens with USFA, maybe even length of time at a scene. USFA is modernizing now, and we know how long these things takes. It's going take a couple of years, at least, before that happens.

How much effort should we be putting into trying to collect longitudinal exposure information now, with follow-up questionnaires, knowing that at some point in the future we'll hopefully have a better system, and we'll be collecting that information anyway, through the incident records.

Dr. Durbin: It's a great question, isn't it? As I hear about it, it's there's a lot of discovery that is going on right now. So wouldn't it be good for you guys to make sure you raise your hand and say, "Hey! Are you capturing this kind of information because it would be beneficial for us?" Maybe they already are. Maybe they're not. But so great point about trying to make sure that you contact USFA and are in on the design.

Ms. Stagnaro: Is there a detriment to collecting the data now and then changing the way the data is collected? Does it impact the quality of the data, so that the old data is really not as useful as it was. If that's the case, then I would say yes, probably worth waiting and getting in on the ground level of the USFA process, and then knowing it's going to be really good data forward.

Dr. Fent: This is how I look at it. In the enrollment questionnaire, you sign up for the registry and you report your exposures backwards in time. Then we need a way to be able to track exposures forward in time. Theoretically we'll have a system that USFA is building that can do that. We're in this weird window of time when we're not going have that system. And so perhaps we do need to have these follow up questionnaires that are collecting longitudinal work information, or the next, who knows, four years or so, until USFA gets online and we can move over to that new system. But then, there's pros and cons to that, because it's also going to maybe link to your questionnaire, or we'll have to not collect some information that we want.

Dr. Siegel, you're the epidemiologist, but I don't think you want to be missing a pretty big chunk of work history.

Dr. Siegel: I don't consider one to be a substitute for the other. I think self-reported information would be better collected in a way that leverages the self-reported nature. For example, we ask self-reported job information that someone could tell us, but that incident records wouldn't necessarily show us in the enrollment questionnaire. The same will be true if we collect records from some USFA source down the road. That'll only offer certain types of information, whereas you know, we'll gather self-reported information that's not necessarily the same. I also don't worry too much about gaps in information. It's just it's all information that's helpful. I don't think we're relying on getting updates on changes and exposure information on any routine basis, because we're already expecting follow-up participation to not necessarily be so great. We're not shooting for perfect. We realize it'll be imperfect. Any additional information that we are able to collect would be great.

Mr. Mayer: I want to add that we're not necessarily expecting longitudinal data. That's why we're having this discussion. We'll get some of the specialty information with a smaller population rather than trying to capture longitudinal information for everyone.

Dr. Siegel: Think of the captured audience that we have once we have our NFR sample and think about how many people we might lose even going into a first follow-up. Then over time, that's going to wane even more. Do we want to prioritize asking them, now what's your job title? Okay, now what's your job title? Okay, now what's your job title? Or do we want say, "Oh, while you're in here? Tell us more about this thing that we didn't ask about in the first place." Just balancing that because I realize changes in job history are really, really important, especially for any prospective analyses we'll be doing with longitudinal information. But so is having a captive audience for collecting some of these additional topics.

Not that you all need to have the answers either, but your input even thus far has been really beneficial. I think, going into our conversations, going forward.

Dr. Durbin: One thing to think about in the long run, is that you want to categorize these individuals, right? Put them in certain categories, so you can analyze a person who is exposed many times over many years has this risk of cancer, whereas an individual, whose exposure you may be changed over time. You capture your data at a point in time. In 30 years, when they hit the registry, any identify they've had cancer, how are you going use that? And so I think importantly, you want be able to categorize those individuals based on exposure history over time. I just think those repeating questions maybe would be valuable in the end.

Ms. Lee: I'm sorry. This is probably a dumb question. I'm not a scientist. I don't have a PhD. How do we account for volunteers that have other jobs that might be exposed in other areas? How do we determine if they're cancer is fire related, if it's related to their other job, or something else.

Dr. Siegel: Well, that's not the goal of the NFR to determine whether or not an individual's cancer is caused by any certain factor. But we do try to collect comprehensive information, not just on firefighting, but non-firefighting related factors too. We can point to different risk factors overall that could be associated with the risk of cancer, or that might interact with a firefighting career to affect a risk of cancer. We do have some

questions on other risk factors, like smoking behaviors and other occupations. We have one question on work where they might be exposed to some unique chemicals or exposures as well. All of that is helping build a risk profile that we can use on an aggregate level to point to different risk factors.

Ms. Lee: That makes total sense.

Mr. Mayer: We could potentially ask a follow-up questionnaire to those that mark that they have an exposure and a job that's not firefighting. We could develop a follow-up questionnaire specifically for this. That's another subspecialty topic that we've been considering.

Dr. LeMasters: I'd like to go back to the team. While you still have us here, and we still have the time, have we answer your questions? Have we answered your questions, or would you like us to delve deeper on a topic?

Dr. Fent: I think I think you have given us a lot to think about and have had really great suggestions already. I don't think we expected you to have the answers to all these questions. This is more about getting input. And then we can kind of regroup and try to decide what our next move is.

I also don't know that there is a "right" answer to some of these, like follow-up questionnaires. There are probably 10 different directions you could go, and they could all be fruitful. We'll regroup as a team, and we'll keep you all updated as we proceed.

This has been really valuable. I made several notes, and starred several things that I think we definitely want talk about and potentially implement. You each individually represent your own organizations and hopefully, you can go back to your organizations and talk up the work that we're doing. The more that we can just work within the fire service communities, and the public health and scientific communities, to make sure people understand how important this is, the better. I really do think that for this to be successful, it needs to be a grassroots initiative. You are all invested in it, you're here helping us, you're leaders in your organizations.

We've got to get to the line firefighters, the folks that are going out every day and fighting fires. We've got to reach those folks, and so we all, I think, collectively have our work cut out for us. Over time we'll continue to brainstorm and come up with ideas and figure out how we can collaborate with each other. I think there's a lot more work to do for us and for this committee. And just again, thank you so much for giving up your time to help us think through some of these challenges that we have.

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

Dr. LeMasters: That was a nice wrap up! Thank you for doing the wrap-up for us. I think we are all invested in your program, and it's like pushing a rock up a mountain and you've got it part of it started and going. Just getting to the portal was a big push, and now you have the next phase to continue, and the next phase. You still have a lot of issues and work ahead of you, and I'm glad we have this committee.

Ms. Novicki: For follow-up, you'll hear from me over email with the SME list. From there you can work with Dr. Fent and the rest of the NFR team to discuss contractually how you can work with those folks.

The next meeting will be sometime in 2024. We try and time these meetings with major decisions. We appreciate your flexibility about when to meet so we can try and get the most out of it.

Finally, I want to thank everyone for coming here today, especially Dr. LeMasters and Mr. Morison, who thought they were going get to sail into the sunset and instead we ask them to come back. We super appreciate their help. I don't want to say any premature goodbyes, because we've been having a lot of challenges with committee membership. It's not you all, it's a higher-up issue that we're working through. We may ask some of you to extend a little bit, and we can have those conversations offline.

If this is your last subcommittee meeting, we deeply appreciate you. If it's not, we'll see you next year. Thank you all so much.

[Meeting adjourned]

Glossary

Abbreviation	Definition
CDC	Centers for Disease Control and Prevention
FACA	Federal Advisory Committee Act
FCSN	Firefighter Cancer Support Network
FDIC	Formerly Fire Department Instructors Conference, now known as FDIC
FESHE	Fire and Emergency Services Higher Education
IAFF	International Association of Fire Fighters
IARC	International Agency for Research on Cancer
NFFF	National Fallen Firefighters Foundation
NFPA	National Fire Protection Association
NFR	National Firefighter Registry
NFRS	National Firefighter Registry Subcommittee
NIOSH	National Institute for Occupational Safety and Health
OD	Office of the Director
PFAS	Per- and polyfluoroalkyl substances
SME	Subject matter expert
VPR-CLS	Virtual Pooled Registry Cancer Linkage System
WFI	Wellness-Fitness Initiative
USFA	U.S. Fire Administration

Certification Statement

I hereby certify that, to the best of my knowledge and ability, the foregoing minutes of the June 13, 2023, meeting of the National Firefighter Registry Subcommittee of the NIOSH Board of Scientific Counselors, CDC are accurate and complete.

Grace LeMasters — Name

8-3-23 — Date

Dr. Grace LeMasters
Co-Chair, National Firefighter Registry Subcommittee of the NIOSH Board of Scientific Counselors

Certification Statement

I hereby certify that, to the best of my knowledge and ability, the foregoing minutes of the June 13, 2023, meeting of the National Firefighter Registry Subcommittee of the NIOSH Board of Scientific Counselors, CDC are accurate and complete.

Patrick Morrison

Digitally signed by Patrick Morrison
Date: 2023.08.18 11:28:34 -04'00'

Mr. Patrick Morrison
Co-Chair, National Firefighter Registry Subcommittee of the NIOSH Board of Scientific Counselors