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CENTERS FOR DISEASE CONTROL AND PREVENTION

NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY AND
HEALTH (NIOSH)
BOARD OF SCIENTIFIC COUNSELORS (BSC)
NATIONAL FIREFIGHTER REGISTRY SUBCOMMITTEE

SIXTH MEETING
HYBRID IN-PERSON AND ONLINE, OPEN TO THE PUBLIC
AUGUST 22, 2024

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Summary Proceedings

The sixth meeting of the National Institute for Occupational Safety and Health Board of Scientific Counselors (BSC) National Firefighter Registry (NFRS) Subcommittee Meeting was convened on Thursday, August 22, 2024. Members had the option to attend in-person at NIOSH's Cincinnati, OH 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

NFRS Members:

Dr. Eric Durbin
Dr. Judith Graber- Co-Chair
Mr. Tom Harbour
Dr. Gavin Horn- Co-Chair
Ms. Sara Lee
Dr. Bozena Morawski
Ms. Brook Pittinger
Ms. Miyoko Sasakura
Dr. Desmon Simmons
Mr. Victor Stagnaro
Chief Matthew Tobia

NIOSH Team:

Mr. Brent Cameron
CDR. Kevin L. Dunn
Dr. Kenneth Fent
Mr. Alex Mayer
Mr. Micah Niemeier-Walsh
Ms. Kandyce Reeves- Designated Federal Officer
Mr. Kenneth Schroeder
Dr. Miriam Siegel
Ms. Andrea Wilkinson

Welcome and Meeting Logistics

Ms. Reeves called to order the open session of the sixth meeting of the NIOSH BSC-NFRS at 9:00 a.m. Eastern Time (ET) on Thursday, August 22, 2024. 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.

Ms. Reeves thanked past co-chairs, Dr. Grace LeMasters and Mr. Patrick Morrison, for their service to the subcommittee and welcomed new co-chairs, Dr. Gavin Horn and Dr. Judith Graber. Ms. Reeves welcomed new members Miyoko Sasakura, Brook Pittinger, Chief Matthew Tobia and Dr. Bozena Morawski and announced Dr. Manuel Fonseca's resignation from the subcommittee to accept a position with the NFR team.

Announcements, Introduction, and Agenda

Dr. Horn thanked everyone for the opportunity to join the subcommittee and work with everyone at the meeting. He mentioned that he has worked with firefighters for over twenty years and knows several of the attendees. He then mentioned the packed agenda for the day and encouraged subcommittee members to be active in the discussion to provide the NFR team with as much feedback as they can. He acknowledged the broad group of members, from fire service to cancer registry groups, and asked that everyone try to spell out acronyms as much as possible. He then turned it over to Dr. Graber.

Dr. Graber thanked the room for the opportunity to be here and commended the NFR on putting together a panel with such varied expertise. She also discussed logistics and encouraged in person and online participants to raise their hand if they want to speak.

Dr. Horn asked the NFR team if there is anything from the NFR that they would like to bring forward at the beginning of this meeting for us to be thinking about or questioning outside of what is on the agenda, on the slides that you all shared earlier, so we can have that in the back of our head as you're presenting all this work?

Dr. Fent stated that a lot of it will be in the presentation materials. He then took a moment to thank everyone who organized the meeting, including Andrea Wilkinson, Kandyce Reeves, etc.

Overview and Update and Summary Data Review

Dr. Fent introduced himself as the manager of the National Firefighter Registry for Cancer Program and one of two team leads. He mentions that the second team lead, Commander Kevin Dunn, would give a presentation later in the day. He then began his presentation on how they are expanding the NFR program, and then the goals, the priorities, and the strategies that we hope to use over the next year to really hit those goals and priorities:

This is a little bit of a refresher for some of you, but for others, this may be the first time you've seen our mission and vision statement. Our mission is to generate detailed knowledge about cancer in the fire service through a voluntary registry that reflects our nation's diverse firefighters. And our NFR vision is to then equip the fire service and public health communities with the knowledge they need to reduce cancer in firefighters. The ultimate goal is to reduce the risk of cancer for the fire service.

Over the last eight months or so, NIOSH has really focused on trying to build the NFR program and enhance the NFR program, and we've created two teams. We now have an Epidemiology and Exposure Evaluation

team or what we like to call the 3E team; and then we have an Investigations, Communications, and Translation team or what we call ICT team. And our current positions scattered through these two teams includes epidemiologists, industrial hygienists, health scientists, one medical officer, health communication specialists, technical information and program specialists, importantly, with fire service backgrounds, an informaticist, and a statistician.

The 3E team is really focused on recruiting and enrolling. That is also a priority across all members in both teams. The 3E team is also focused on the primary data collection, which is right now the NFR web portal, including targeted enrollment of firefighters, and we will hear more about that today. We're also focused on data ingestion from other sources, so this would include exposure trackers, information on incidents from departments and agencies. We're also interested and focused on matching to population-based cancer registries. This is something we hope to get started here very soon. Analyzing and reporting exposures and health outcome data. Developing new survey instruments, so the idea of a follow-up survey. And, of course, other firefighter research that we are actively involved in. Now, the other firefighter research we do is not NFR-funded, so it does require additional funding to carry out that research.

The ICT team is, again, focused on recruiting and enrolling, as well as developing those professional relationships with the fire service, with health, public health and other organizations, scientific organizations. We really believe that developing, strengthening, activating our partnerships is going to be really critical for the NFR. We are also developing, refining, and implementing our communications plan. So that is constantly being updated and refreshed. We'll talk more about that today. We are supporting firefighters with the enrollment process, so we do have a help desk. We also have an email box. We get emails every day that come to that email box, and we try respond to those within 24 hours. We are also interested in reaching out to fire departments that are involved in major events or disasters. So an example of this is the Maui County Fire Department after the wildfires in August of 2023. We went out soon after that. That was a broad deployment but part of that was introducing the NFR to the firefighters. We are also translating research into practical recommendations. So again, consistent with our vision, we want to take the knowledge that we gain and give it back to the fire service and public health communities so that they can do something positive with that information. Related to that as well, cancer screening is very important, and we believe we have an opportunity to share information on cancer screening and other best practices related to exposure prevention and healthy behaviors. And then we are also, within this team, investigating medical-related fatalities as part of the Firefighter Fatality Investigation Program. Again, this is not NFR-funded, so this is a separate project but it falls under this team.

In terms of our organization goals:

- We've had and we maintain the ambitious goal of enrolling 200,000 firefighters from diverse backgrounds. We have a long way to go to get there but we are maintaining that goal.
- Our second goal is to, of course, monitor cancer outcomes and risk factors. It's really the main focus of the NFR.
- Our third goal is to characterize firefighters' exposures through self-reported information but also hopefully ingesting data from external sources.
- And then our fourth goal is to provide data and recommendations to lower cancer and other health risks in the fire service. You'll see a lot of things being repeated and reinforced as I go through this.

Our key priorities match up pretty well with our goals:

- Our first priority is to maximize enrollment in the NFR through a variety of measures, including among firefighters who have been understudied in research. This includes racial and ethnic minority groups. This includes women. This includes volunteer firefighters, wildland firefighters and so on.
- Our second priority is to maintain a user-friendly system to register firefighters, and securely collect and protect the data. That is basically our NFR enrollment system and database.
- Our third priority is to increase the scientific understanding of firefighters' risk of cancer, their carcinogenic exposures, and other modifiable risk factors. A lot of that, again, is the self-reported information that we're collecting through the online enrollment system.
- And our fourth priority is to enact positive change in the fire service through a delivery of evidence-based recommendations consistent with our vision of enacting change in the fire service.

We have four strategies to fulfil these priorities:

- Our first strategy is to implement a multipronged approach to increase participation in the NFR, and we will hear more about that later today.
- Our second strategy is to improve the user experience by refining and adding features to the NFR web portal. So that's an area that we are actively pursuing and constantly looking at ways we can improve the user experience of the enrollment system.
- The third strategy is to develop partnerships and procedures for data linkages and ingesting data from other sources.
- And our fourth strategy is to implement ways to share data and communicate the results and recommendations. Now I'm going to go through each of these strategies and talk about how we think we can achieve the goals that we're trying to achieve.

Again, our first strategy is the multipronged approach to increase participation in the NFR. A big part of that strategy is the targeted enrollment process. We will hear about that a few presentations later. We are bringing in fire program specialists. These are field-based support staff that have experience in the fire service. We'll hear more about the program specialists from Commander Dunn. We also have firefighter subject matter experts. These are individuals that we either have contracts or agreements with, and they can help us connect to specific firefighter populations and advocacy groups, including those hard-to-reach groups that I already mentioned. We are also doing outreach to our scientific health and medical communities. This is a priority in the next year to try to develop new partnerships and strengthen partnerships. We've listed some of the medical associations that we hope to reach out to, and the North American Association of Central Cancer Registries is the governing body when it comes to state cancer registries. And then we want to expand our communications plan, products, dissemination, and techniques, and we'll hear more about that a bit later today.

Our second strategy is to improve the user experience of the NFR web portal. Participants now receive an NFR participant number that's available in their user profile. They also will get a reminder email or a text message that includes their participant number. We will reach out to individuals who were sort of the early adopters and already registered months ago, to let them know that they have an NFR participant number and share that number with them. If anybody in the audience who has gone through the enrollment process, you would probably agree that the work history section is the most complicated part of the enrollment process. We have made an update that makes the work history section editable now. After you save, or even if you log out and log back in, you will be able to now see what you entered in the work history section and you can update it.

We are in the process of trying to do similar improvements throughout the web portal but, as of now, the work history section is editable. Once you submit your survey, you can still go in and update your user profile. So that is editable after submitting the questionnaire. And then we are currently exploring the best ways to implement follow-up questions for the collection of longitudinal information. It's important with a prospective cohort that we can collect longitudinal information, but we also are sensitive to the fact that it needs to be short, to the point, again focused on making it a good user experience. And then we are currently exploring the development of public and personal dashboards. We believe this is important. Firefighters have given us some information about themselves. We want to make sure that we're being good stewards of that data and making summary data available to the public.

Our third strategy is to develop partnerships and procedures for data linkages and ingesting data from other sources. We are in the process of planning for the cancer registry data linkages for the NFR participants, where we would leverage the North American Association of Central Cancer Registries (NAACCR), virtual poll registry, and do some pilot linkages with a few states. We're hoping to get that started here in the next year or so. We are also developing data use agreements and processes to receive firefighter exposure tracking data. So this is ongoing. We're making good progress but there are several exposure tracking programs out there so we want to try to ingest that, match it with our NFR participants. We are also providing input on the U.S. Fire Administration's National Emergency Response Incident System (NERIS). That's in development. I am a member of the advisory group that's working on that. We are also exploring potential collaborations with other fire service research studies such as the Fire Fighter Cancer Cohort Study. So again, it's really important. Fire Fighter Cancer Cohort Study or FFCCS is another nationally focused study of firefighters. If we can combine the data together, it makes it that much more powerful and we can learn that much more about firefighters' exposures and risk of cancer. It's important to note that part of the reason we are providing an NFR participant number now is to help do this. So once a firefighter gets a participant number, they can then provide that with these other programs and give their permission to share the data with us, and now that NFR participant number provides a reliable way of linking it back to the NFR database.

Our fourth strategy is to implement ways to share data and communicate research results and recommendations. Again, this is consistent with our vision. Our ultimate goal is to try to reduce firefighters' risk of cancer. We are already involved in this in many ways. We have, for example, developed an exposure reduction training course with Underwriters Laboratories' Fire Safety Academy. We are exploring trying to do something similar with the USFA National Fire Academy. But that's a nice way to try to get information out about best practices and different ways that firefighters can reduce their exposures.

We have started doing push notifications to our NFR participants that can be used to provide information on the current results about the NFR but also, again, recommendations, public health messages, other things that may be useful to the participants.

The dashboards in development may also be used to reinforce best practices. So if you're a firefighter and you see how you answered these questions when it comes to exposure reduction controls, that can be sort of a wakeup call, we think, for firefighters.

We are pursuing a research data center for sharing deidentified data. This would be managed through the National Center for Health Statistics. We have begun the process. All these things take a long time, this is the federal government, but we have started the process getting going.

And then of course we're a scientific organization. We are always interested in pursuing peer-reviewed publications and reports, and we will of course continue to do that. As we mentioned before, cancer has a long latency period so when it comes to the cancer risk analyses, those will take a bit longer. But there is a lot of data that we can start looking at now and start at least publishing some reports about that data.

Okay. With that, I'm going to turn it over to Alex Mayer, our health scientist, and he's going to give you an overview. I think what many of you guys are interested in is what does our data look like today. So, Alex.

Mr. Mayer introduced himself as a health scientist that has been working on the National Firefighter Registry for Cancer since its inception back in 2019. He then began his presentation of a brief overview of some of the data that has been collected thus far:

I want to start with just a recap of our recruitment efforts. We began registering firefighters in January of 2023, and that was actually through our pilot of the NFR enrollment system. We piloted the NFR enrollment system with seven fire departments and various fire service leaders from across the country, and this took place for about three months at the beginning of last year. And that was really helpful because we got information from firefighters about the enrollment process, and we made some tweaks to the system before we made it available nationally. But as part of that pilot, those firefighters that did enroll, or that did participate in the pilot, were effectively enrolled into the NFR. So that was our first group who enrolled, and that was about 500 firefighters.

Then we kicked off our official enrollment at FDIC in April of 2023, and that was with Kenny and Chief Rhodes and others at FDIC on the big stage. Very well-received. We had a lot of folks register that day and subsequently over the next couple of weeks, and we really tried to keep that momentum going after FDIC.

But I do want to mention, our current registration numbers are all through our open or passive enrollment, and this includes our social media efforts, as well as conferences and meetings. You know, it's not just FDIC. I think Kevin's going to cover this later, but I want to say we went to 18 to 20 conferences over the past year and a half. We also rolled out our Gold Helmet campaign, which is a system, a way for us to communicate with fire departments and try to get them excited about the NFR. So if more than 50% of a fire department, or over 300 firefighters for larger fire departments, enroll in the NFR and we can confirm that in the database, we'll actually list that department on our website. And I think Kevin may talk about that as well.

And lastly, we've had a lot of external partner promotion, including folks like yourselves who spread the word about the NFR, included slides in your presentations. You know, that's been really helpful in getting the word out as well.

And in addition to continuing the open enrollment, we did start the targeted enrollment last month, and Miriam will talk more about that later. But we really hope that these two enrollment methods will really increase the numbers for the NFR because, like Kenny mentioned, the main focus right now is really trying to drive up our numbers and get firefighters registered from across the country.

Just a few other additional considerations before we get into the data. I did want to mention, all data are preliminary and this hasn't been peer-reviewed or ready for publication, but we did want to share the data that we have thus far. These numbers were pulled on July 30, 2024. I did check a couple of days ago, and I

think we've had 600 or 700 firefighters enrolled since then. So these numbers are a little lower than where we're at now but still a good understanding of where we're at.

I also wanted to mention this is only self-reported NFR questionnaire data. As Kenny mentioned, in the future we'll be linking with population-based cancer registries and other informational databases, but right now we just have the self-reported information that the NFR—or that the firefighters put in the system.

This is important to note, kind of a disclaimer. The self-reported cancer estimates that we have here do not estimate a national prevalence of firefighter cancer. And because not all the participants complete the entire questionnaire, our denominators may vary based on the question that we're asking. So, for instance, the number of firefighters who've completed consent is higher than the number of firefighters who've made it to the lifestyle section which is the last section of the questionnaire.

Okay, so getting into a little bit of the data here. This is a map of enrolled firefighters from across the country. And as you can see, the participation largely aligns with state populations. Specifically, we see California, Texas, Florida, Ohio, Pennsylvania, and New York all have a lot of firefighters registered so far. And that sort of makes sense; those are all states that have higher populations. The exception is looking at Colorado and Virginia, and those two have had a lot of grassroots efforts where individual fire departments have been really excited about the NFR and have gotten folks registered. So that's a good example of, maybe, we could talk with them about how they're getting the word out.

But also, looking at this, how can we use this information to help recruitment? One idea is looking at states, the populated states that have relatively low participation, and specifically looking at like California and Texas and Florida. While they have had a lot of folks registered so far, they're still below what Pennsylvania has and they have much higher population. So that's a potential area we could hit where we know there are a lot of firefighters, and potentially drive up our numbers. Additionally, the Southeast Corridor and the Northwest Corridor are currently underrepresented, so just another area we could potentially hit.

And then as far as how many firefighters have enrolled so far, we have over 15,000 firefighters that have consented to participate in the NFR. Of those, over 13,700 have provided key demographic information, and this is really important because this is the information we're going to be using to link with state cancer registries in the future. Additionally, we've had over 70% of firefighters complete enrollment. And we started tracking this in June or July of last year, and that number was actually closer to 65-66% had completed enrollment, so we are seeing an increase in the number of firefighters who complete enrollment. This is just evidence that our reminder emails and text messages do appear to be working and a lot of folks are coming back and completing registration. You know, it says "over 70%." I think it's closer to like 73% to 75%. So, a fairly significant increase from where we were last year.

We've also had firefighters enroll from all 50 states as well as Washington D.C. and two U.S. territories. And lastly, we've had 2,000 firefighters who self-report a history of cancer. This is important because for the NFR to be successful, we need both firefighters with and without cancer to enroll, and that was a health communication point that we tried to get out there. It does look like it's working and we're getting a nice mix of both firefighters with and without cancer registering.

Next, we wanted to cover who is enrolling in the NFR, and the Firefighter Cancer Registry Act of 2018, as Kenny mentioned earlier, mentioned women, racial and ethnic minorities, and volunteer firefighters as groups for us to hit in the enrollment process.

So, looking at how many firefighters have enrolled in the NFR that are women, we have over 9% of NFR participants are women. And when we compare that with the National Fire Protection Agency or NFPA report from 2020, they reported that 9% of the U.S. Fire Service are women. So this is evidence that we're doing a pretty good job of reaching women so far with our open cohort enrollment.

Next, we have 85% of NFR participants are active firefighters, and this means 15% are either retired or have left the fire service. Of that 85%, about 20% are volunteer firefighters, and the NFPA report, the same one, had over 60% of the fire service as volunteer. This is an example of somewhere where we could focus in the future.

Additionally, looking at racial and ethnic minority groups, over 90% of the NFR participants are White and non-Hispanic, and NFPA doesn't report race and ethnicity but the Bureau of Labor Statistics does have data for career fire service and that's at 88% White and 17% Hispanic. So again, this is another area where we can focus in the future.

And lastly, while not called out in the Act, wildland firefighters are very important to the success of the NFR long term. And I'm happy to report that almost 20% of NFR participants are wildland firefighters. We don't have an official number to compare to for wildland firefighters but they don't make up 20% of the fire service. So we're doing a pretty good job with hitting them, so kudos to all the folks who communicated to wildland firefighters and gotten the word out.

Okay, so what does the preliminary data tell us? So, overall, we have been really successful for the open cohort enrollment, hitting female firefighters as well as wildland and structural career firefighters. We've also been successful in communicating with firefighters with and without cancer. And focus areas for growth, we've had firefighters from racial and ethnic minority groups, as well as volunteer firefighters.

So, future directions for us to hit. We do want to, as Kenny mentioned, develop a public-facing data dashboard. We also want to track participation of subgroups, and that's something that I think we're already doing with our work here. You know, we're trying to not only use that information to help inform recruitment efforts in the future. Additionally, we want to describe the use of control interventions among NFR participants, and I think this is information that the fire service is really interested in. So, you know, how many firefighters or how many NFR participants are laundering their gear currently? I think that's information that the fire service would be interested in seeing. Next, looking at cross-sectional analyses of the self-reported cancer and associated risk factors. I think that's something that will be important as well. And lastly, we're beginning the process of cancer registry linkages, and Kenny mentioned that earlier, but we're hoping to pilot that process over the next couple of years.

And I think that's it but happy to answer any questions or are we going to go right into the discussion?

Committee Feedback and Discussion on NFR Overview and Update and Summary Data Overview

Dr. Graber and Dr. Horn facilitated the Subcommittee's discussion of the first two presentations.

Dr. Graber: Great, and we'd like to just step back and frame this discussion a little bit. So the first question is: what kind of summary data will best inform the fire service and public health professionals in the immediate future? Just to remind the panel that we'll be talking about enrollment in the afternoon session, so let's really stay focused on data needs. And as an epidemiologist, when I think about what data, I really want to think about what are we going to be using it for. So I'd like the panel to really think about that and think about the different audience. We have fire service, we have public health professionals, and I'd also add, we have the NFR. What data can they use and put out there to both help with enrollment and usefully give back data, all right? So I think those are the audiences and the way we should be thinking, in my mind as an epidemiologist, to provide feedback. Gavin?

Dr. Horn: No, I think you nailed it. What she said.

Dr. Graber: So any thoughts from the committee? We will call on you. Dr. Simmons, what do you think?

Dr. Simmons: Well, as it relates to question number 1 and summary data, and it was kind of briefly mentioned in regards to the subgroups where we are lacking, hopefully later on we'll talk more about strategies to increase those numbers. Obviously the summary data/dashboard will give us a good indicator whether or not we are reaching those targeted numbers.

Dr. Graber: Thank you. Anybody else? Chief Tobia?

Chief Tobia: So, the data unto itself is certainly valuable for researchers and from a research perspective but one of the things that may drive increased participation is what does this mean for me and/or for the broader fire service. One of the things that I think is going to be important going forward is that this becomes the basis of validating other data that already shows that there's a higher incidence of cancer among firefighters. If the data isn't yet showing that, I would be concerned about what the messaging would be around that. But certainly, the flip side of the positive message of that would be the "why" of this program related to what are experiences so far. The fire service asked for this. Congress responded. So, looking for ways to continue to message that I think is going to be important going forward.

Dr. Horn: Chief, how would you use the data? I mean, is this something that would be beneficial for you in terms of program development, in terms of getting funding for something, motivating the team members that you have? Or what is the best way that you could actually take that and make some change or implement something within your fire department?

Chief Tobia: Yes, so I think that's a great question and I think that if I can deliver the message by talking about participation and what the impact is going to be and what it means not only for current firefighters but future firefighters, I think that helps build the case a little bit better for taking the time to participate. You know, I don't think it's a difficult sell, to be honest with you. For the end user it's what is the ease of enrolling and then what is the ongoing benefit to me. The data I think points to a need for more engagement, and I would

take this and say this is a great start. This is where we are right now. This is where we want to be, and how do we best close that gap, and how do we generate energy around getting to that tipping point of making it popular to participate in the program.

Dr. Horn: So, for both Chief Simmons and Tobia, we've heard from both presentations about a dashboard in terms of having a public facing breakdown of the information available and data that's available. Is that something that could help along these lines, both in terms of a targeted enrollment or helping to get that information back to your local? Is there any feedback you might be able to provide to the team around that, or the value of that for your perspectives?

Chief Tobia: This is Matt. I would just offer that I have come to the realization that the current generation, and of course we're dealing with five different generations of firefighters, right? In the volunteer world, we have literally responders who are in their seventies and eighties all the way down to the youngest generation of what we would call new entrants into the system. And what I have come to the realization is that whatever we do, if we are looking with an eye towards the future, that we have kids today who are literally—and I know this is going to sound odd for some people—but my 21-year-old son just literally purchased a home on his phone. He did the entire transaction on his phone. And so, anything that we do should be with an eye towards optimizing sharing of information, either app-based or on a dashboard, that is accessible from a mobile computing device, what most people are calling their phones but is basically a mobile computing device. So, I would just look towards that in terms of what the end user experience is going to be and how easy it is for them to access that data, and then what it means for them. Thank you.

Dr. Simmons: Exactly, and yes, extending off that comment and as it relates to dashboards, so dashboards are great. They're very informative. But, however, as the end user/educator, what do those numbers mean in terms of—and how do we get our fire service personnel to behave in a manner that will reduce the likelihood of them contracting occupational cancers? So hopefully when we talk about dashboards more, we talk about how we can give meaning to them, especially for the end user as they go back to educate the men and women in their organization.

Dr. Graber: I think that's a terrific point. Could you speak a little more about what that might look like, or others on the panel want to speak a little more about what that might look like?

Ms. Sasakura: This is Miyoko. I'm wondering if, with the data that we have now, could we collate some of that information to show, okay, so this is the demographic and this is the sort of cancer trends we're seeing? And that way then we can target some of the outreach that we have for recruitment if we're seeing, you know, women with more of this type of cancer just with the information we've gathered. Could we then say hey, if you can, talk to some of your other female firefighters, we can gather more information about this and have a better understanding of what this means as far as what exposure is leading to this. Like as a researcher, as an industrial hygienist, I do want to get back into what exposure is leading to this cancer, instead of just seeing like this demographic has this cancer incidence. And then be able to then create best practices if possible. So, I wonder if in the immediate future, if we are able to, I don't know if we have enough information to create anything like that yet, but if we can maybe that can help with some of the outreach efforts.

Dr. Simmons: Exactly, thank you.

Dr. Graber: Dr. Durbin, would you like to comment on that or would you like me to comment on it?

Dr. Durbin: I'm sorry, comment specifically on what? I actually have a question myself.

Dr. Graber: Okay, let me comment. So, and I'd also defer to the NFR on this, but I think looking at the long-term goals for the data and how we can get there is really important, and I think that is the essence of your question. How do we really engage the fire service around this question of what cancer and what exposures are linked in the fire service.

I think that it's early. I think that as Alex Mayer said, the information that we have on self-reported cancer unfortunately can't be used to give us rates in the fire service, and therefore it can't be used to really understand yet these relationships. Those golden data are going to come from that all-important linkage with the cancer registries, because then we'll really understand what the true distribution of these cancers are in firefighters. And I think we are all so excited that the NFR is going to be moving towards that quickly. Do you all, the NFR, want to add anything to that at this point?

Dr. Siegel: I'll just say I think that was a really great summary. You know, the data we have right now, while we have over 2,000 self-reported cases of cancer, it's like Alex mentioned, we've got great variation in firefighting, firefighters that have signed up with a history of cancer and without a history of cancer. We recognize that there's a lot of variation within that 2,000 of the types of cancers that they've been diagnosed with, the timing of those cancers. Some of these cancers might have occurred before a fire service history began. So, there's a lot of scientific considerations that are going to go into how we approach these analyses, especially the earlier analyses where all we have is data to do cross-sectional analyses.

And so, what's really going to be most informative and have the greatest level of detail is when we start getting cancer registry linkages completed and getting that data in, we'll have data that's more specific about the diagnoses, about the treatments, about the outcomes, through collaboration with those state cancer registries. And so over time, as the pool of new cancer diagnoses grow and the level of detail we have from data comes in, the amounts of information from those cancer analyses will become a lot more informative over time.

Dr. Graber: And so I think that, getting back to this question of the data we have and where we have, it's really exciting that enrollment is ongoing and moving. And I think the last speaker, you did speak about some of this exposure data and maybe, given your expertise, you'd like to talk about what you might think would be exciting for the fire service right now to see, or maybe others would like to talk to that. Or other questions?

Dr. Durbin: Yes, so actually, if I may, I'd like to actually look forward to the linkage with—I'm Eric Durbin, director of the Kentucky Cancer Registry and I'm also the president-elect of the North American Association of Central Cancer Registries. So, I'm eagerly anticipating this linkage opportunity, and you've actually already done a nice summary of what we're going to get from that. Well, I actually know for a fact, the type of cancer, the diagnosis dates, and a ton of information that will be very important to analyze the cancer incidence within this population. So, in anticipation of the linkage, what will make that more successful will be, to the extent that you actually have good linkage identifiers for the participants, and so that's actually my question. So, to what extent are participants providing first name, middle name, last name, date of birth? Are you collecting Social Security Number and those sorts of variables? Because that will strengthen our ability in the cancer registry to actually come back with a confirmed linkage, at which point we could provide specific details about each cancer diagnosis that has been recorded in our cancer registries.

Mr. Mayer: Yes, that's a great question. So, of the folks who have made it to the demographic section of the questionnaire, about 97% of folks are providing that information, and that includes partial Social Security Number as well as date of birth, sex assigned at birth, first and last name, and residential address.

Dr. Durbin: That's fantastic.

Dr. Siegel: And I'll also add, we've been really impressed with that, and I think it also demonstrates some of the trust that this population has with NIOSH, and we've been doing a really great job in our messaging. And I'll add one other kind of more exploratory piece of information we built in with our feedback from our former committee member Betsy Kohler. When someone self-reports a previous diagnosis of cancer, we collect the approximate year of diagnosis as well as the state the diagnosis was made. So that might help with piloting some manual reviews or other data cleaning or other data quality analyses as well.

Dr. Morawski: Hi, this is Bozena Morawski. I am an epidemiologist and a co-principal investigator at the Idaho Cancer Registry, and also a member of the board for the North American Association of Central Cancer Registries. I had a question about residential history in relation to this conversation around identifiers and linking between the Virtual Pooled Registry and the NFR. Do you have the capability or the mandate, as it were, to establish residential histories for the population that you're collecting these identifiers on?

Mr. Mayer: Yes, that's a great question too. So currently, residential address is in the user profile section of our questionnaire, or of our web portal, and that means that firefighters can come back and update that information and then we will keep track of that long-term. So, we will have a residential address history moving forward. We are not capturing that information going back in time, so we currently are just asking for the current residential address history and then, for future follow-up questionnaires when we're reaching out, they can update their residential address moving forward.

Dr. Morawski: That's great to hear that you will be collecting that information over time. You may be aware, but from a Central Cancer Registry perspective, we do have the ability to look at residential history through some proprietary products such as LexisNexis, and I don't know if the NFR has explored that, but it might be a useful tool if that were available to you.

Dr. Graber: And they are all nodding. Do you want to comment?

Dr. Fent: That's a good suggestion. This question, question number 1, I think we're really wanting to know in the immediate future. I mean, this is a good discussion, an important discussion about the data linkages to the state cancer registries, but we do have, I think, really powerful data on, how many responses they've been, different types of fires, exposure controls, annual physicals. So, there's a lot of information that we're collecting that could be of value. I would be interested in hearing from the fire service or from some of our public health folks, to hear if it makes sense to try to get summary data out on those factors sooner than later?

Dr. Simmons: Yes. Demond Simmons again. And keeping with that theme of data—and I understand we got a diverse type of stakeholders here and data's important to our researchers and medical community—but to the end users on the fire side, my question is what would that data mean to them and, more importantly, how do we expect fire service personnel to use that data as it relates to personnel in their organization?

Dr. Horn: So, Demond, you're suggesting not just having a bunch of graphs and charts on a dashboard but something that can help to translate that and make that more relevant to the local firefighters?

Dr. Simmons: Exactly, yes. Operationalize that data so that it has some meaning to the end users or the practitioners I should say.

Dr. Graber: So for example—

Dr. Simmons: Because you know, so a bunch of dashboards with a bunch of graphs and numbers to a training chief or a fire chief or to a firefighter doesn't really provide a bunch of utility.

Dr. Graber: So in my work, one of the things we use with some of our data from volunteer firefighters is we try to provide data back that is as local as possible. The two big domains that I see that the NFR might be able to kind of divide their data to make it more useful would be these subgroups and regional locality. Is that what you're thinking and are there other ways that they can think about parsing their data to make it useful? And the question is for you and of course anybody else.

Dr. Simmons: Yes. That's one possibility. Thank you.

Ms. Lee: This is Sara with the National Volunteer Fire Council. I do think this data will be especially helpful for volunteer departments, especially if we can parse it out and make it relevant to them locally, the types of calls and exposures that they're experiencing. And I think one way that it will be really helpful is in helping them identify where their funding should go. A lot of volunteer departments are working on very limited funding, so prioritizing a certain type of PPE that is going to protect them from what they are seeing in their area, where they need to focus their funding.

Secondly, I think that data is going to help explain to them the why, and I know this was touched on earlier, I think it was Demond that mentioned it—but talking about why they should enroll in this and why they should participate, and why this is important to them. Because this, firefighting is not their full-time job, so that may not be how they identify as or see themselves when they think about their career. But it is a career for them too. It's a whole entire side job that is taking just as much work almost as a full-time paid job. So, using that data to explain to them why this is important, how it affects them, the risks that they face, and then how they can combat those risks I think is really important.

Dr. Horn: So one thing that I think, Kenny, you mentioned sitting on the NERIS board to help guide that. And I think, going back to getting the information to be local, that's a great way to do it. That's one of the plans of NERIS is to get all the information about fire incidents and help the local decision-makers put that into play. So, can you talk a little bit about how this could go both ways? You can get the information from NERIS in terms of incidents but then also, is this a way that you can feed it back locally and get that data out to those fire department locally and use it once that comes online later this year?

Dr. Fent: Yes, so NERIS is just getting started. My understanding is there's kind of like a phase one and a phase two. Gavin, you might know more about this. Phase one I think is going to be more at sort of a department-level information of the incident. Phase two hopefully will get to more of the individual level, at least that's the hope. So phase one, the trouble is, we have to be able to link the information back to the individuals. So, I don't know if we're going to be able to do that right away, but ultimately the goal is to kind of get it to where

we could at least have, at an individual level, information on the types of responses that they attended, maybe even duration at the response for those individuals.

Again, with the NFR participant number, they could provide that to the system and that would be a way of linking it back to the NFR. And then that would provide tremendously helpful data to be able to look longitudinally at exposure history in the fire service. Now you're tying that exposure history with the information in the NFR, which hopefully will also be longitudinal, and we can look at things like protective practices, exposure reduction controls, and NFPA physicals, all sorts of things. So, it just makes the data go even further. I think that is ultimately the gold standard that we want to achieve. And the nice thing is they'd be two federal data systems.

Dr. Horn: Right.

Dr. Fent: So I think we would love to get there. I don't think we're going to be there quickly but that is where we want to go to.

Dr. Horn: You can see that eventually helping to drive some of the enrollment in the future. Obviously, this could be years away but if someone sees that their information gets automatically updated because it's entered into NERIS, in the near-real time, then they could see their own individual profile changing potentially, and the department and national profile changing, others will start to notice that and generate interest as it continues to grow. So, I think that could be a really incredible linkage that could help grow your dashboard and an individual dashboard in a sense.

Dr. Graber: Great. I just want to circle back. Kenny, you were talking about the data use, and we've spent a lot of time talking about fire service use, and I think there's a lot more there, but I want to make sure that we also have time to talk about how public health professionals may use these data. Commissioner Pittinger, would you like to comment?

Ms. Pittinger: Sure. So, a couple of things. I do think looking at barriers is important for why people are not going to respond—are not going to submit or provide information. So, I don't know if there's a way to manipulate the data to look at you might not want to respond but actually this is what it does. So, I do think making sure the barriers are eliminated should be an important or a key component of this.

I agree fully with looking at what the fire service needs. I know in Virginia several years ago, we had a huge push to expand our line of duty benefits, and it was very difficult with the data that we had at the time to kind of show the linkage and the causality between the two. I think everyone agreed within the legislature, yes, we wanted to do it. We had a very narrow scope. Obviously with the cost, looking at the Association of Counties and Municipal Leagues that didn't want to spend too much money. So, I think understanding the "what" of the fire services and "why"—what the data can do for that. I also think the plain language is incredibly important, so making sure that it's presented in such a way that anyone can pick it up.

And then I think looking too at the behavioral changes that we're trying to effect within the community. Is it better decontamination practices? Is it adjusting curriculums, modifying curriculums on the front end so that when they're coming into the fire services, you're actually getting this information before it's too late or you've been in 5 and 10+ years. So, I think those components would be incredibly important just with the data and the data sharing.

Oh, and sorry, one more thing. I do think teaching people how to use it, so some type of tutorial that explains how to use it and how to manipulate it would be helpful. I think sometimes data can be a little overwhelming if you're not used to working in the world of data. So, I think quick and easy, fun—not fun but you know, light—tutorials of how to use data is important.

Dr. Graber: And I would just add to that, as a researcher, things that are easily downloadable. You know when you're writing reports or you're writing grants, and fire departments when they're trying to get their AFG grants, to get easily accessible data that may be actually useful.

Mr. Stagnaro: Yes, this is Victor Stagnaro. So, I think a lot of the things have already been discussed, and some of the things are already in play such as the types of cancer that firefighters are getting, but I realize that some of that data is still not—we're not able to utilize it. The summary groups that were talked about goes back to the vision of NFR. The maps of the registrants, I think there's value in demonstrating that in a dashboard so it will motivate people to try to get them to go and register. I would also add, anything that's related to reduction, right. So, I think Chief Tobia talked about the why. As a new firefighter or a seasoned firefighter, I want to know what this cancer I'm going to be exposed to or potentially could get. How do I reduce it? And then what do I need to tell my doctor as far as screenings? So, I think any data there that could be utilized to really make a difference for me would be helpful.

Dr. Graber: I'd just like to add to that also, not to forget the behavioral data. You know, cancer is a cumulation of risks and wherever we can stop those risks is really important. So, if you have behavioral data on cancer risks—tobacco, or alcohol, as you do, exercise—also really important to feed back those risk factors very considerably we've seen in our data across departments and they have and it is part of the fire service maintaining health in our members.

Dr. Graber: Oh, thank you. Chief Tobia.

Chief Tobia: Yes, just if I could please, I just wanted to go back to a comment earlier, and I just want to go back to the foundational design. I'm brand new to this group so I admit that I am absolutely in a learning curve position, but one of the things that I think we're really focused on is trying to increase our numbers, right, and reach those groups that will ultimately lead to the data that we're looking for. And I think I would be remiss if I didn't highlight the fact that the overall majority of firefighters in the United States don't operate in the world of a desktop computer or even necessarily a laptop computer. There are fire departments in the United States that don't have internet access for example, in very remote areas or rural areas, even with broadband opportunities. Although the incidence of cancer may be lower in those areas just by population and the exposure issues, very large recruit academies, a 300-person recruit academy, doesn't necessarily have 300 computing devices to allow an entire recruit class to register concurrently for the purposes of doing long-term tracking of those personnel. I could very easily see the major metropolitan areas being willing to add all of their recruit classes or take time in their recruit classes to register new entrants into the fire service. But the mechanism for doing that needs to be easy and fast, and I say that in the context of, again, going back to an optimized mobile application and even a National Firefighter Registry app, which I think could dramatically increase the numbers. I think also the ease with which, or the number of fields that obviously need to be completed, you know, I'm at the very far end of my fire service journey and so the amount of time that it took me to register was longer than perhaps a new entrant into the fire service.

So I would just highlight that, in the discussion that we're having around data and the value of it, that the more efforts that we might be able to concurrently put in on the front end of getting people into the system will yield dramatically measurable benefits for the researchers on the other end. I'm at the practitioner end not at the researcher end. I would just offer those comments as something that I think could dramatically help us on this journey. Thank you.

Dr. Horn: Great point. Yes, Kenny actually has a response to that I believe.

Dr. Fent: I was going to ask Chief Tobia a follow-up question. For these recruit classes, I completely agree that it needs to be mobile-friendly. Our web portal is a mobile-friendly system. Now, I'll confess that it's not perfect, but it is mobile-friendly. What would be the ideal length? If we're trying to get an entire recruit class through the enrollment process and, like you said, it took you, a long time because of your work history. Now, new recruits would have, a much shorter work history to report. But what would be the ideal length of time in your mind?

Chief Tobia: Yes, so that's a great question, and I don't necessarily—like my lived experience may be different than other recruit academy leaders but if we told them upfront that they needed to budget 10-15 minutes to explain it and then 15 minutes to complete it, that's a 30-minute block of time. If for, example, they had an hour lunch, that they could cut that lunch down to 30 minutes and for 30 minutes, we're going to spend 15 minutes talking about firefighter cancer and then we're going to do 15 minutes of you all are going to register for this. Now I realize it's a voluntary program but I also, within this room, I'm going to say that, when you direct recruits to do something, they will more likely participate. And even in volunteer firefighter training programs, if we partnered, for example, with the National Association of Fire Training Directors and a wide array of folks to push this registry process, that we could make a lot of inroads I think. And if we budgeted that amount of time, 15 to explain the program, why is it important to you, why are these numbers so critical, why is participating so important, and then 15 minutes to complete it, I think that that's perfectly doable if we explain the why. I think you have an average of five seconds to capture someone's attention before they slide onto the next topic. They'll stay with the topic if they believe that there's a value added for them. So that's what I would offer.

Dr. Durbin: If I can comment really quick just to validate something that Chief Tobia mentioned. I was with Jim Keiken from University of Illinois this past week. Dr. Masoud goes in, spends 30 minutes with her students and promotes the Registry and tries to get them to register. So about 30 minutes was about what they're spending at University of Illinois.

Dr. Horn: And we're getting close to the end of this. Actually, wait, we've got three minutes left, is that right?

Ms. Reeves: Yes.

Dr. Horn: But just want to have one quick additional question to Chief Harbour because this is summary data, we've talked a lot about structural firefighters, but what would be valuable, if you could make a few quick comments in the next couple of minutes about what we could do to help inform the wildland fire service. It's great that we have such a large initial enrollment but is there anything you can provide there that might help support that group in particular?

Mr. Harbour: Two things that are a challenge. There've always been a couple of things that are a challenge for wildland folks. One is the fundamental that still a lot of folks who predominantly do wildland are still making this transition to be accepted as firefighters in America. They have been told for over a hundred years that they have some other duties. So, engaging them in a system that is entitled a firefighter registry takes some effort, and I'm really pleased to see what we've done with the wildland folks.

When you then get into the work history component of the Registry, we've always had a challenge with wildland folks because we see our history associated perhaps, well, in one old man's case, with hundreds of events. Not a 9/11, so to speak, but with hundreds of events that take two weeks to a month out of our lives. I hear from folks, that the work history continues to be a challenge and we tell them to just suck it up and do what you can, improvise and adapt.

I think the question that's been hit on here about how this benefits a wildland firefighter, how this benefits any wildland firefighter, any firefighter, is particularly important because heretofore, these first few years of operation, at least for me, the question about why should I invest even a half an hour or an hour of my time has largely been based on the fact that it's an altruistic measure of service, that you get into the fire service to help people. Here's a chance to help your sisters and brothers in the fire service. I can't remember if there's an FAQ or not but perhaps something that's focused more selfishly on why this helps me, might help. Because like I said, I'm so tickled we've been successful in wildland, but it may be that we can develop something that not only focuses on the service component of entering your information but also begins to speak of what I've heard folks that manage these cancer registries say about this is how it could help.

Dr. Graber: And that's such a great note to end on because I think, at the risk of trying to summarize what we've heard, is the data need to be meaningful at the local and fire service sector level. They need to be useful and accessible and really understandable being key. And again, the whole fire service (inaudible @ 01:15:59). And I believe it's time to move on.

Ms. Reeves: Yes, thank you. Great discussion. We're going to move on to our next two presentations. I just want to point out that the discussion for these two presentations is after lunch, so I want to encourage our members to please take notes of any of your thoughts during these presentations, and we'll get into that discussion after lunch.

We'll take a five-minute bio break and get back to the presentation right after that. After the bio break, I will be taking roll again so just know that we need time for roll. Thank you.

Targeted Enrollment Activities

Dr. Siegel introduced herself as the lead epidemiologist on the National Firefighter Registry for Cancer since its inception back in 2019. She then began her presentation of targeted enrollment activities of the NFR:

Over the past few years, in most of our presentations, you've heard our design and plans, and we also had a really rich conversation last subcommittee meeting about our different two enrollment methods. Kenny this morning talked about one of the strategies being a multipronged approach to increase participation, and this is one of our methods that we're using to create those multipronged approaches about increasing participation.

Since kicking off national enrollment and recruitment in April 2023, we've been using our open enrollment method, and that's just a very wide net we're casting. I mean, you've heard and seen in the consent form, any firefighter is welcome to join the NFR—former, retired, current firefighters of any subspecialty, so long as they are at least 18 years of age and served in the U.S. Fire Service at any point in time. So, through open enrollment, we're mainly employing passive recruitment methods, which is sometimes referred to as convenience sampling, word-of-mouth sampling. We're using our really, really varied communication campaign. We've got factsheets. We've got videos. We've got our stakeholder interviews. We've got posters, all sorts of communication material that is posted online. It's actually really great and easy to download communication resources online. We're hitting up conferences. We're outreaching certain departments. So just kind of all over the place, trying to hit a very wide and diverse sample of the fire service. It includes really broad catchment.

However, with that comes an expected level of what's called selection bias, meaning some groups of the fire service are going to be more likely to be self-motivated to enroll than others. You know, you can imagine that the type of firefighters that attend conferences are inherently different than those that maybe are less resourced or smaller departments more rural areas of the country that might not be going to conferences. We heard just a few minutes ago about some departments that might not have readily access to electronics or the internet, the ability to download and print some of our communication resources. And of course, the concern that we always hear in epidemiology, people with an adverse health history or people that have a previous diagnosis of cancer might be more likely or more motivated to join. And all of this culminates to lead to a certain level of selection bias.

So one of our tools we're using to offset some of that selection bias is targeted enrollment, where we're selecting departments that we know to be diverse, either large numbers of women, or racially and ethnically diverse, volunteer departments, areas where we expect participation to be lower among some of these understudied but high-priority groups of firefighters, to conduct active recruitment in which we work with the fire department. I'll revisit the discussion we had last subcommittee meeting—but we work with the fire department to recruit everyone on roster, and we obtain information about their workforce denominator estimates, stratify denominator estimates by different demographic groups, so we can monitor and measure those participation rates to inform how we're doing. And that information can actually improve our recruitment methods not just for targeted enrollment but also open enrollment as well. So like I said, the overarching goal of this targeted enrollment is to improve participation rates among understudied groups, and reduce selection bias.

So, last year at our NFRS meeting, we had a really rich conversation about the best way to go about implementing the targeted enrollment. The discussion kind of really centered around asking fire departments for their full roster information with contacts for all firefighters that work at that fire department, versus working through fire department leadership to kind of disseminate that communication material. And we had a really great conversation about the pros and cons to each of these processes, and we really determined that acting through the leadership would reduce the most administrative burden and therefore make it more feasible for more departments to participate, as well as building more trust with those departments by collaborating with the fire department leadership, thereby increasing firefighter participation.

I think I also forgot to mention, the targeted enrollment includes currently active firefighters from structural departments. It's a little more exclusive but firefighters participate the exact same way regardless of enrollment route. So, it looks the exact same. They sign up through the web portal, provide the exact same information. And so we get that rich level of detail for everyone regardless of which way they find out or enroll through the NFR. And then we've left the door open, following the conversation last year, for working with departments to obtain department-level records in the future.

And so this year, we've actually started executing fiscal year '24 contract for developing and testing methods to enroll firefighters, and one of those tasks specifically relates to the targeted enrollment process. And the different components of that contract task are to obtain voluntary commitments from targeted departments to participate in the NFR, document the process every step of the targeted way in customer relationship management software, which is really important because we're really emphasizing trying to do this in as standardized of a way as possible across all departments to minimize, again, that selection bias. And the commitments include expectations that the departments will provide some level of roster information or aggregate workforce counts for us to be able to monitor those participation rates, and that department leadership will encourage participation according to those standardized guidelines provided by the contractors. We're shooting for enrolling an estimated 20 departments in the 24-month base period through this method, and then around 10 departments in each of the two option years that we may continue this contract.

So, these are the components of the targeted enrollment process:

- First, fire department interest is obtained. Again, just like individual participation is voluntary, so is fire department participation in the targeted enrollment process. The contractors and NIOSH identify contacts, get their contact information, and provide preliminary information about the NFR, and then we obtain letters of support from the department.
- And we do the same with any applicable local unions that work with the fire departments in those areas.
- And then the process of onboarding is to have in-person meetings and obtain that workforce data. I have that highlighted here because I'm going to go over that a little in detail in the next slide; discuss our playbook, which provides those standardized steps we expect each of the departments to follow; and scheduling the meetings and the steps where recruitment is actually being implemented.
- And again, following that playbook is the essence of carrying out targeted enrollment among each of these departments.

So, this is the workforce information we're obtaining from fire department leadership to serve as denominator data when we're calculating those participation rates. We are getting the overall workforce information, the overall workforce count of currently active firefighters. But we're also interested in total numbers when it's available by different job status like career and volunteer versus, and paid per call, those two denominators; women and men; and then different racial and ethnic breakdowns.

And so, the playbook for participating department leadership that we developed, it serves to promote rigorous and standardized recruitment methods among leadership from participating departments. And this here is just a little snapshot from the playbook that's disseminated to department leadership to kind of show them how this will work, and the purpose of targeted enrollment, and the importance of following the playbook in detail. I can read it here. It says: The following targeted enrollment playbook guides fire department leadership through the process of recruiting their firefighters to participate in the NFR. It provides instructions that outline

the required steps and materials for promoting NFR enrollment. The playbook ensures that all departments involved follow the same steps, which is important for scientific integrity. It simplifies the recruitment process, making it more efficient and effective. And it provides answers to common questions and issues that may arise throughout the process that department leadership can help resolve.

And these are the different steps. There's seven steps, and they're spaced out across a timeline for departments to follow in collaboration with our contractor and NIOSH.

- First, the department leadership sends an initial recruitment email. NIOSH has developed that email so all leadership are providing the same information, worded the same, to all firefighters.
- And then there's the step for any applicable union reps to do the same.
- Leadership then designates a one-week period for firefighters to enroll on-shift, and we also have a roll call announcement that we've had available for a couple of years now that fire departments will have read at the fire stations to increase participation.
- There's a first reminder email that goes out in the fourth step.
- Then in the fifth step, we also have a second reminder email that again we wrote and included in the playbook so everyone's following the same standardized process.
- In the sixth step, we actually provide a feedback loop on participation rates to department leadership to kind of inform the next steps taken from there. If it's less than 50%, then we'll offer in-person support to the fire department.
- And then there's one final email reminder that can go out and again, that is provided in the playbook.

And then I just want to emphasize that even though we've got these separate enrollment routes, a lot of the firefighters from both routes, in addition to enrolling the exact same way, they're going to see a lot of the exact same communication material as well. A lot of them will see us at conferences. A lot of them will receive word-of-mouth and social media posts. They'll see a lot of this hopefully before we even approach their department for targeted enrollment involvement. So, the playbook includes our roll call announcements, posters, factsheets, tip sheet, and directs to the website.

And then I'll also mention that departments participating in targeted enrollment are also eligible for our Gold Helmet Department distinction, where they're recognized for enrolling 50% or more of their firefighters or more than 300 of their firefighters into the NFR. And then departments not participating in targeted enrollment are also eligible for this distinction as well.

So, status of targeted enrollment as of last month. Again, this is a very new process. It involves a lot more resources and carefully thought-out design than the larger efforts. We first selected an initial list of 30 departments to approach to see if they're interested in participating. This initial list was identified using previously obtained estimates from NFPA, who have some limited information on the number of women at fire departments, and we also did some cross-checking of estimates from some individual large departments to make sure the numbers we had were accurate. So, we identified a list of 30 departments with large numbers of women, and this list also comprises a lot of geographic and community demographic diversity, as well as both career, volunteer, and combination departments as well. So already, we have 18 fire departments and 18 local unions that have expressed interest. Currently, 2 departments are in the onboarding stages, and 1 department is actively executing recruitment within their department, and this is a very large department in the South with a lot of demographic and racial diversity as well.

So, some of the challenges that have come up are issues with timing and schedules of the department leadership and the department's workload. We're hearing a lot of support from departments but there might be slow uptake from other authorities within the department or within the local government or regional area. Potential lack of standardized recruitment—we talked about this a lot last year because we're acting through the department, because it's the most feasible, we're still prone to some differences in how recruitment is conducted within departments, and this can contribute to some of those selection bias issues that I mentioned and differences in just participation success across departments. And then, eventually, we anticipate potential challenges with monitoring exact participation rates, like cross-referencing the numerators from the NFR database with denominator information from the department because, again, our denominators are aggregate, which means we don't have individual-level information. And the workforce changes over time at these departments as well, so as recruitment picks up over time, especially if it's slower and it happens over months and months and months, there might be changes in the workforce that affect the potential denominator make-up of that department.

So, we'll continue initiating the process with the current list of departments and tracking progress, also tracking obstacles and challenges like we discussed before. That's going to be really important. That's an important part of this activity. Evaluating the need for and characteristics of future lists of fire departments. Our protocol talks about selecting lists, working through stakeholders to identify volunteer departments to work with, departments that are diverse racially and ethnically if this initial list does not hit those groups as we would want it to. And then using participation rates to inform recruitment and communication strategies for all aspects of the NFR, not just targeted enrollment.

And with that, I'll pass it on to Kevin.

Public Comments

There were no written or oral public comments.

Outreach Efforts and Recruiting

CDR. Dunn introduced himself as an industrial hygienist who has recently joined the NFR during the efforts to expand earlier this year. He then began his presentation on new and ongoing efforts for outreach, communication and recruiting:

Just a recap of the foundational work, and I think everybody's going to realize that we have so much overlap in all of our presentations because everything is integral to everything else. We're very dependent upon each other and we're really trying to work hard together to make sure all the goals are met in a seamless fashion. So, you will see a little bit of overlap but please bear with us.

As we mentioned, open enrollment—or as Miriam said, passive enrollment here for the last year—has been going very well. It's been a big effort. It's only passive from the outside; from the inside, it seems very active indeed. We've had about 25 print and digital products, 3 campaign toolkits, monthly social media posts,

website content, videos, things of that nature. Alex was right, we did attend 18 conferences, many with our communications contractors, to set up exhibit booths, pass out materials, and enroll people in person. And we also work on things like our quarterly newsletter, which is actually the highest open rate for any CDC newsletter at over 50%. So, we've done a lot of things in this, quote/unquote, "passive" time that we feel is really great foundational work to get us out into more active recruiting and engagement with firefighters where they live, on a granular level. While it's deemed passive, it was very active, and it really set a good foundation for us moving forward.

So, one of the things Kenny mentioned that we're really going to try to play on from our early work is the importance of partnership. And not only are we going to have all the partnerships that we have, we're going to try to really work to activate those partnerships.

We have gained 21 letters of support from different organizations, fire service interest organizations and cancer support networks, and we're really going to move this year to try to make sure that those active partners are going to be helping disseminate our message from their communication channels so that the firefighters and their members are going to be receiving this from a trusted source and kind of an endorsed source, and maybe that will help lower some of the barriers for joining and some of the barriers for participating.

Some of the more recognized partners are the IAFF of course, the International Association of Fire Fighters, International Association of Fire Chiefs, and the National Volunteer Fire Council, but we're trying to reach out to as many different organizations as we can to really improve our messaging from trusted resources. Other types of groups such as the Firefighter Cancer Support Network are really critical in this messaging as well, to not only hit the fire service specifically but also the members of the fire service families who may be really getting more community from those groups. And those times were really critical, especially in January, which is Firefighter Cancer Awareness Month.

This is a great demonstration of how we were able to utilize one of our partnerships. At FDIC last year, during the opening meeting, the very first thing that happened right after the video from Ed Kelly, was Kenny had the opportunity to take the stage as part of a group of 15 different leadership members of fire service organizations. And the whole presentation ended with Kenny giving a good, heartfelt communication about the NFR, why you should join the NFR, and an opportunity to do so. You can see on the right, we have all of our partnerships listed up on the big screen for everyone in the hall to see, and the presentation ended with the presentation of our QR code that will take you directly to the NFR web portal so you could start registering right there if you wanted to.

Speaking to the clear and precise instructions, I think we do have to put together a how to use a QR code infographic for some of our firefighters, but we did see a really nice increase right after this presentation in our enrollment. So, it spoke to people, it reached people, and that's what we'd like to do with more of our partnerships this year.

Also, we want to try to have not only our efforts in these types of communication products but our partners, using their channels of these same types of communications, write email blasts. We've had the opportunity to work with several different specific email lists, the Secret List with Billy Goldfeder, the Firefighter Fatality Investigation and Prevention Program which is a NIOSH program that now rests in the same area as the NFR so

we're able to use their lists, and CRACKYL magazine. We've put a couple of email blasts out with these different areas. As you can see, that's over 300,000 names on these different listservs that we were able to reach.

Focused ads and article space—we're going to continue these efforts. We've been running regular ads in Fire Engineering and their suite of magazines, CRACKYL magazine as we said, and the NVFC Firefighter Strong is an area we're hoping to do a little more work in this year.

And, as has been mentioned a couple of times, push notifications. We did use the push notification to alert people about the Gold Helmet program. That actually went to people already registered, so you would wonder why that increases enrollment, but the chiefs or the leadership or the individuals in those different firehouses actually started going around and saying hey, are we enrolled? Do we have enough to get this? If not, why don't you guys come on, get on the bus and join with us? And we've had a really good response from this effort. Ten firehouses so far have qualified for the Gold Helmet distinction in I think it's been about three months that we've had it out, and we get many, many requests every week for hey, can you check our department and see if we are, see if we qualify for the Gold Helmet. So, it's been a great, a great proving ground or initial effort to show how our push notifications can work and bring in other registrants from the pool of registrants we already have.

And then we did change our messaging this year, which is going to show in the next slide, for changing the call to action and, once again, lowering barriers to joining, lowering that initial step to go ahead and join the NFR. So, this is a nice graph. This is kind of showing our enrollment numbers by month since we opened in early 2023. You'll see the initial spike at FDIC in 2023 was of course our biggest spike. That's because all of the early adopters, people who had been hearing about it, waiting for it, jumped right on right then and made things happen. So, a very big spike, a nice interest, and shows everybody was interested.

But since then, you can see we really have to push out momentum products to keep the enrollment going and to keep people hearing about us and connecting with us. So, Fire-Rescue International was a good conference in August of last year. You can see a couple of CRACKYL eblasts that came out. But the FDIC in 2024, we really changed our messaging. Our initial messaging has been it takes about 30 minutes, and while that's true, it's not the greatest way to get somebody's mindset for doing this because your initial thought is if I don't have 30 minutes to do this, I shouldn't start it right now. Maybe I'll get to it later. So, we've changed and it's absolutely true that you can get started in about five minutes.

If you go into the Registry, you fill out your first couple of sections, get your participation number, put in your demographics, that can take five, six, seven minutes. Well, for me and my big thumbs it takes a little longer but for many people, they can do it very, very quickly. And then once you've started into this process, you know you can leave and you can come back as many times as you need to finish that occupational history, which is very important. But you also are automatically going to get up to four different email reminders to come back in and get it. So, once we have you in our system, we can continually communicate with you and ask you to continue and give you the opportunity to come back as you have time. And as Alex said, this has proven to be really effective. I think our registrations are actually going up since we've made this, as the graph shows, but we're getting a better completion percentage because people don't get frustrated partway through the process and leave, or run out of time and leave. So, it's been really effective and we've enjoyed that. But we're looking for all types of other ways lower the barrier for entry.

One of the things that we have heard and we have really listened to and responded to we're not actually reaching firefighters on the ground, where they live, where they work. Our conferencing is very important. We need the support of all of our partners and we need to maintain those relationships, but we also need to reach the people who aren't going to conferences or who don't have, as you said, the funding to maybe do all of those different things.

Reaching people on the ground where they live is going to be a big focus this year. To do that, we've brought on fire program specialists. They are working right now on coming through the HR system, which in the government is an adventure of itself, but they are coming through. We have a couple onboard now and a few more coming soon. These program specialists are widely geographically dispersed. We have representation in Washington State, Texas, Florida, Kentucky, and Indiana. And of course, we have the entire NFR program to be able to support these other needs if they should have needs for us for support in the field. And they all have fire and emergency response backgrounds. So, some of the credentials that we have on our program are National Fire Academy and National Fire Protection Association leadership, National Association of Hispanic Firefighters leadership. We have local and regional IAFF union, former leadership. So all with fire experience, all know the culture, all can do communications, and really help us to, like I said, connect on a granular level where firefighter live.

We've made some connections and made some requests for information from groups like IAFF and NVFC so that we can understand the structures of those organizations, understand the best way to communicate with these groups all the way down to their local firehouses, and then we can use that information to enable our fire program specialists to go out and make those connections. And those connections may be simply a communication, "Have you heard of the NFR? If not, here we are and this is what we'd like to do." And we could also do a video presentation if you need or if you have a nice meeting coming up, we can come in person and give you a good overview of the NFR and tell you why it's important. So, we have a lot of different, like I said, boots on the ground type of efforts that we're going to be expanding this year.

Also, the community-based efforts, I think we can work with a lot of different organizations who firefighters participate with, maybe join with and help spread just through the community of some of these areas. And this could be very good for reaching those underserved or under researched populations, looking for groups that may have an overlap and talking with them, and trying to find a way to connect with firefighters of different needs in the underserved populations or under researched populations.

Some other new efforts we've been doing. This is falling right in line with activation of partnerships. We just produced a "Dispelling Myths of the NFR" blog with IAFF. The blog should be coming out very soon, but basically, they submitted to us a list of questions that they commonly get from their membership, and we were able to answer all those questions, and those answers will be delivered to the membership from a trusted source.

A Speakers' Bureau—I think this one's going to be really important for us on that granular level. Of course, we don't have enough people and funding to travel to every fire department in the country. However, if we get requests for information or requests for a speaker, we can put together several different small 15-20 minute type of conversational talks to really engage a firefighter, let them know what's going on at their meeting house or the union hall, and then stay on for a bit after that to answer questions. And this would all be a great virtual tool. Our fire program specialists can do this, all of the NFR members can do this, so we can kind of

share the burden and be very responsive to different requests for information that we get. Of course we will be selective and make sure we have the right people talking to the right audiences, but it's going to be a big team effort and we're all pretty excited about it.

Exploring new and innovative delivery mechanisms. At firefighter memorials and museums, we're actually talking with the 9/11 Memorial right now and trying to find out how we can get our information in those types of settings for people who come and are obviously very invested in the fire service or even in the cause, and maybe they will spread our information to a friend that in the fire service.

The next point we were trying to make is the focused events on specific audiences. This is being called out and we understand the need to try to really reach these people. I know that Miriam has a lot of plans in targeted enrollment to try to make sure that this happens, but we're also going to try and do it in the more open and active recruitment setting. We just actually completed the exhibit at the International Association of Black Professional Firefighters convention. We are attending the Women in Fire conference in San Diego here in just a few months, or next month actually. Time flies. And we're going to start trying to reach out with the medical organizations. The American Occupational Health Conference is one conference that we're going to do next month—or next year, I should say—as well as exploring the opportunity to work with cancer consortiums, state cancer consortiums who are starting to do a lot of pre-screening for firefighters, and we're talking to several different states' consortiums to see if we can blend our materials in with their materials and perhaps enroll people at that time, while they're having this procedure and this screening for their interests in cancer.

And then finally, we're really taking the opportunity to engage with federal firefighters at this point. We are working with the Defense Health Agency and the Undersecretary for Defense Office. In the last two weeks, I've had the opportunity to speak with the occupational medicine and medical leaders for the DOD. They run all of the DOD occupational health clinics and are very interested in distributing our materials and getting people enrolled. The DOD has several different firefighter cancer awareness initiatives going on, including PFAS studies and different screenings and things of that nature, so we're going to try to work in with their networks. Also, the DOD Fire & Emergency Services Working Group, last week I got to go to Virginia and speak to firefighters in each branch of the service, and they were very interested in dispersing our information. They were very interested in this cause, and actually the next day, we were in the Navy Fire & Emergency Services Working Group newsletter. So, it worked out great. It turned out to be a little immediate validation. We're also working with the Homeland Security Total Workforce Protection Directorate, the Office of Homeland Security. They are in charge of all U.S. Coast Guard, NOAA, and FEMA firefighters so they're very interested in having that population enrolled.

And finally, we are working with the Department of Interior and all the departments within the Department of Interior, the U.S. Forest Service, etc., to really try to make some strides and solutions to lower the barrier for wildland firefighters to join the NFR. We recognize that wildland firefighters' experiences are different than in structural firefighters, and while we can't make our questionnaire one-size-fits-all, we do have a working group with the DOI leadership and also DOD wildland firefighter leadership to try to develop some tools to help make our questionnaire make more sense to wildland firefighters. We're going to use that working group eventually to create a follow-back or a different product to really try to capture the exact events for wildland firefighters but we need them all to understand you'll have to join now so we have your participant number and we can

bring you back to get more specific information to your service. So, we're working with DOI leadership, DOD leadership, and really trying to reach that group and speak in their own language.

So where do we go from here? We're going to continue to expand our open enrollment efforts as we said, increase engagement with the underrepresented groups, activation of our current partnerships, use of data analysis of the current enrollment to guide recruiting efforts. As Alex said, maybe we can identify which geographic areas we really need to hit more and who needs more support in what areas? Engage at a more local and regional level with our fire program specialists. And then continually refine our marketing products and methods based on the feedback that we're already receiving.

So we're always, so the last bullet, receiving new suggestions and really enjoyed those types of interactions. So, from that, we can discuss some of the open discussion questions if everybody's ready now.

Committee Feedback and Discussion on Targeted Enrollment Activities and Outreach Marketing

Before lunch, the committee discussed and provided feedback on the NFR targeted enrollment activities and outreach marketing:

Dr. Simmons: Yes, I'm Demond Simmons. Just a couple of comments and some suggestions. I think it's probably safe to say that because we are the same types, same individuals who attend FRI and FDIC year in and year out, we probably have peaked out in terms of recruiting new folks. So, I would offer two suggestions. One, collaborating with IFSTA. They do have a large target audience throughout the various periodical manuals. And then number two, the various community college firetech directors across the United States is another possible avenue for sharing information about the program and potentially recruiting folks into the Registry.

Dr. Graber: Thank you, that's a great comment. Let's continue on this, which is that first question: What are some ideas for boosting the overall enrollment in the NFR? So, let's really use this 15 minutes for that if we can...

Dr. Morawski: I'm not sure what the federal rules are but podcasts seem to be popular, and I think that's more of maybe the younger generation that might be interested. So, social media, I'm not sure what avenues you are allowed to utilize, what restrictions are in place. And then I know a lot of the educational programs like the EFO program through the USFA, they all have to do the Capstone research projects. So, I'm not sure if you could reach out to them and say hey, we have this great data, we would love for your students if they would like to leverage it to use this as one of their Capstone research projects. Particularly, at the USFA they track fire fatalities. Most of them are (inaudible)-related, not as much cancer-related, but I do think there could be a potential partnership there with kind of how the tracking and the data is utilized.

CDR. Dunn: Thank you, and I was remiss in mentioning, and we are doing social media ads, both through organic and paid channels. We are also offering to provide social media messaging to our partners so that they may spread it through their channels. And podcasts, we've done several of them so far. We hope to add that to the Speakers' Bureau type of product that we can put out. Great suggestions, thank you.

Mr. Harbour: So, continuing to build on that great success you've had with wildland firefighters, remember the U.S. Forest Service, my alma mater, is a department within the U.S. Department of Agriculture. So, while DOI and USDA are separated by almost 500 yards across the Mall, sometimes the barriers are different in Department of the Interior than they are in USDA, and so keep reaching out to the U.S. Forest Service within the USDA. There's a group of wildland firefighters that are associated with states, in particular Oregon Department of Forestry, Washington DNR. There are large numbers of wildland firefighters that respond through the National Association of State Foresters, and if you haven't got that letter of support from NASF, the National Association of State Foresters, I'd be glad to help facilitate reaching out and improving, again, wildland firefighters at the state level. And they're not really seen, you know. When we talk about reaching out through fire departments, they kind of see fire departments differently than what, for example if you work for the Arizona Department of Forestry and Fire Management, you certainly see yourself as a firefighter. You certainly, I hope, would want to be involved in the national registry, but you don't see yourself as any fire department per se. So, whatever I can do to help there, I'd be glad to help.

CDR. Dunn: Thank you very much. We would appreciate, like I said, all of those types of connections and suggestions that we can get. To step back to the U.S. Forest Service, we are in contact with the U.S. Forest Service wildland firefighting leadership, particularly on their safety and health side, and they are actually working now with DOI even though it's a separate entity. They are actually working with DOI and they will be represented in our working group. So, thank you for bringing up that distinction.

Ms. Lee: This is Sara with the National Volunteer Fire Council. We have found—and I know this sounds a little old-school—but in terms of reaching volunteers, actual like hard copy mail has been pretty effective, whether it's a postcard or just a simple mailing. But as was mentioned earlier, there are a lot of volunteer departments that don't even have internet connection. They're in rural areas. So, we've had some luck with that, and I know that's a little added cost over other methods. But we have personally, at the NVFC, found that to be effective.

Dr. Horn: That's a great point. It's amazing how diverse the fire service truly is. Chief Stagnaro then Dr. Durbin?

Mr. Stagnaro: Thank you. So, thank you for the comprehensive efforts on all of that. I think it's been mentioned, but the North American Fire Training Directors, anybody related to training, if there's a way to expand the Gold Helmet component for people who just register people. If I'm a training academy and I register 200 or whatever it is, some sort of expansion and recognition for those folks that are not fire departments may be an opportunity.

I also think we're honoring fewer and fewer trauma deaths but we're increasing the number of firefighters that are honored at the National Memorial. So there needs to be a very strong training component with regards to cancer, and I think if there's job performance requirements and that includes the registration component, whether it's the NFPA Firefighter I/Firefighter II curriculums, those types of things, because those are the things that are the increased number of firefighter fatalities, I think that would be very helpful.

And then if I know of fire departments that might want to sign up to the targeted enrollment, what is the process for me? Who do I put them in contact with? And then just from the NFFF side, we have about 190 advocates across the country. Would love to try to get you connected to them to be able to help that message as well as state fire marshals. You may have already reached out to them, but they are a great resource, have

a lot of connections within the state. And then a question for Tom Harbour, are there not—like there's hotshot associations and those kinds of things too that might be another opportunity. Thank you.

Dr. Horn: Dr. Durbin?

Dr. Durbin: Yes, Eric Durbin. First, I want to congratulate the team on your efforts thus far. Fifteen thousand participants in what, in 15 months of enrollment, that is impressive, and you have already created a worthwhile cohort of participants. You're to be commended for that. So, you're doing something right, and it will be exciting to see these efforts expand and to expand your enrollment. Miriam, I'm very excited about your targeted enrollments. That's fantastic.

When I saw the map of the U.S., it struck me, it's like wouldn't it be nice to have a representative or an advocate—and you just mentioned advocates, and advocates can be very effective in getting people involved—and so to have an advocate lead efforts in each state would be fantastic. Cancer survivors are very effective advocates. I've done some work in childhood cancer, and a survivor is very motivated, and they've gone through the experience and they want to reduce that experience in other individuals. So perhaps recruiting volunteer advocates in each state maybe could be an effective approach as well.

Dr. Horn: Chief Tobia?

Chief Tobia: Thanks very much. Obviously, just to echo, tremendous work so far. Chief Stagnaro mentioned a couple of things that I was going to mention as well. Two things that I do want to bring up. Number one, the NFPA is currently building its sixth needs assessment of the U.S. Fire Service and, interestingly, they are very open to contemplating some questions that are focused on safety, health and wellness, and specifically health and wellness, and I wonder if there might not be an opportunity to partner with them on getting a question or two added into the sixth needs assessment to contemplate just an assessment of efforts thus far, as well as educating around the topic that we're working on today. And if you want a contact for that, I'm more than happy to provide that offline.

And then one of the things that you talk about is leveraging push notifications and I wonder if there isn't a way to initiate an effort to start enrolling people simply on their name and a contact phone number, a cell number, so that push notifications can be sent via text message that they can opt out of if they want to. Start sending push notifications, which allows us to start sending messaging. And then hey, this is how you can enroll in the Registry, right, and this is why it's important. So, I don't know if there is an option for that.

Obviously, on the social media front, you know, X, Instagram and Facebook—and these are all things that I'm sure have been talked about previously—but they're really targeting very different generations of firefighters depending on who we're trying to look at.

But those are just a couple of things, and of course I expect there's already been a significant effort with the Firefighter Cancer Support Network. They do have advocates in just about every state, and it might be an opportunity to leverage their advocacy as part of the ongoing efforts as well. Thanks.

Dr. Horn: Fantastic. We're, at the end, just about to lunch break but before I turn it over to Judith real quick, I want to ask Dr. Durbin if we can quote you on the statement that you made about that enrollment, because it's something that we hear often. Like what is 15,000? That's an important and a large, valuable number and

with your history and background, that's something that could really be beneficial for many more people to hear and understand how hard it is to get to this point, yet the goals are still to be used.

Dr. Durbin: Yes, you can absolutely quote me on that.

Dr. Horn: Fantastic.

Dr. Graber: Great, and just to wrap up, I think this first discussion on the overall enrollment has been really rich. We're going to get to these second two questions after lunch. For the second question, which are additional suggestions for contacting firefighting groups. I want us to think about how heterogeneous some of these groups are, and that there may be different ways to reach different parts of these groups. I think that would be a really helpful discussion. And then also just to note, we will be circling back to that first question from the earlier discussion which was about how researchers can use and collaborate on the data. Any other thoughts, Kevin, or...?

CDR. Dunn: No.

Ms. Reeves: All right, thank you so much. We will now break for lunch, and we will reconvene here at 1 p.m. sharp. Thank you.

After lunch, the committee reconvened to continue discussion and provide feedback on the NFR targeted enrollment activities and outreach marketing:

Dr. Graber: Okay, welcome back, everybody. Right before we left, we were having a really robust discussion about ideas for boosting overall enrollment. So, I think that discussion will continue through our second question, which is additional suggestions for connecting with firefighting groups that we're having trouble reaching. And then I'd just remind you of my kind of prompt before we left, which was these groups are fairly heterogeneous. When we think about volunteer firefighters, they come from some very, very large, well-resourced departments, they come from some very, very, very under resourced, small departments. So, and similarly, women in firefighting, very heterogeneous. There's a lot of heterogeneity. So, let's think about how we can give the NFR ideas for connecting with these subpopulations and how to prioritize those. Remember you'll get called on.

Dr. Horn: If there's no immediate questions, I have one kind of tying back to what we talked about earlier. And I think, Victor, you talked about both NAFTD and state fire marshals. And I noticed on the partners slide that North America—the state fire marshals, NASF?

Dr. Graber: NASFM.

Dr. Horn: NASFM, isn't included. Is that someone that you have reached out to in the past or a connection hadn't been made there? Or is there a way that that can be kind of integrated? Because they do have a lot that I think—and that'll boost overall enrollment—but getting down into some of those more rural areas, much like NAFTD can do through regional training area. So, I think that'll be a great place to look at potential partnerships, unless it's something that just didn't work out in the past. So, Kenny, you got any thoughts on that?

Dr. Fent: Just that we agree. It's a group that we want to develop a partnership and we just haven't yet. So, if you have connections or others have connections to that group—Victor—yes, we would love to get connected. Absolutely.

Mr. Stagnaro: And if I'm correct, you have a component for fire investigators, right? So, I think there's a lot of synergy there to connect, yes, and do that.

Ms. Lee: But I know there's the ID.me program that's federally driven that fire services could go on and then you get the discounts from certain vendors. So I don't know if that captures the essence of a lot of that, the first five minutes campaign, and if it would be possible to partner with them to either, obviously, share the data or at least see if there was a way if they could click a box and it would take them to the registration or if they clicked it, it could potentially just feed into the registration so that you're capturing at least a demographic that's doing some kind of registering.

Dr. Graber: Are there any comments online?

Dr. Simmons: Yes, just a quick follow-up. We were talking about the fire service affinity groups and in particular the International Association of Black Professional Firefighters. Oftentimes, you can best reach a large majority of members by going through the regional directors or chapter presidents to get the word out as it relates to the Registry.

Dr. Fent: Thanks, Demond. That's actually another group that we want to try to develop a partnership with that we have not had, I guess, significant success with just yet. So, thank you.

Dr. Graber: And then I have a question. Have you done any outreach to Tribal fire?

CDR. Dunn: Yes, we have spoken to some representation of the Tribal Indian Health Service and those type of groups. Not getting a big response back. We're also trying to work through Senator Murkowski's group, the Bureau of Indian Affairs, to see if we can get our messaging to come in through that way, or at least make better connections for delivering our messaging. It's an ongoing process and we're working on it.

Dr. Simmons: And also another group, the International Society of Fire Service Instructors. I don't know if you've made contact with them.

Dr. Fent: I'll just keep this microphone on. Yes, so we do have a letter of support from ISFSI. I mean, this is another thing that, just like Kevin talked about, it's great we have the letters of support. We need to take the next step of activating our partnerships, and we have a plan to do that, but it is more than just a letter of support. I mean, that's an important first step, absolutely, and I think we're interested, we love these ideas. We're definitely interested in trying to get a letter of support from the fire marshals, from the International Association of Black Professional Firefighters. I think there's probably organizations that represent Tribal firefighters. So the more that we can learn about these organizations and try to reach out and try to get the letters of support, that's the first step. But then what's the next step? And so, like I said, we're coming up with a plan to do that but definitely we want to activate these partnerships.

Dr. Horn: And that's very clear—

Dr. Simmons: Exactly.

Dr. Horn: Sorry, go ahead. So, places like NAFTD, you have one organization that each state has a training director, and then most of those states then have regional representatives that push down their training to, in some cases very rural, to very populous areas. And so, is there—instead of just them supporting you, ways that can be pushed information to them? Is that an option that...?

CDR. Dunn: Yes, that's much like what we were speaking about with activating the partnerships, getting our messaging delivered through these groups, so it's coming from a trusted source, through all of their structures and down to the most granular level is going to be one of our main focuses this year.

Dr. Horn: And so, the follow-up to that also is part of the trust is also in that logo or the emblem. Are options available for potentially co-branding or something along those lines, so that it comes from NFR but also NAFTD or IAFF or NVFC or whoever else that might be so that they see both logos, that that trust can kind of be shared across them.

CDR. Dunn: Yes, we have some opportunities to do co-branding. They're not as easy as they sound. What might be the more efficient route while we work on those opportunities is to have those groups share the NFR logo in their messaging through their social media, their newsletter, those type of opportunities, and that's what we're pursuing first while we work on the co-branding on the government side. So yes, I think it's a great idea, and trusted delivery of messaging is something we're really looking for.

Dr. Graber: And I hate to put you on the spot but to what degree are you able to have your fire service program people represent these subgroups and have a connection to them?

CDR. Dunn: I'm sorry, can you specify "represent the subgroups"?

Dr. Graber: Yes, so come from women, minority, you know, how is that going in terms of bringing on your fire service, what do they—

CDR. Dunn: Okay, representation in our fire program service—

Dr. Graber: Representation, exactly.

CDR. Dunn: —personnel from these groups. Several of our members of the team that we've just brought on have represented these groups or some of these groups in the past. Others are going to be targeted to make the better, or activate the connection with these groups, and find out where we are missing our opportunities and try to pursue those opportunities. So, it is in mind. We do have representation from a large ethnic and experience diversity in the fire service, of different types of fire service, and different representation in those groups as part of their experience, and we'll work to see what we can do to fully develop those opportunities.

Ms. Reeves: We have a hand online. Miyoko. Miyoko.

Ms. Wilkinson: Miyoko, you have a question—a comment?

Ms. Sasakura: I was wondering if there is such a thing as a QR code that, like when you're at a conference and someone comes up and wants to register could quickly get to the site. I don't see it on the website but that doesn't mean that one doesn't exist.

CDR. Dunn: Yes, nearly all of our communication products have a QR code on them. Those QR codes, depending on the product, will take you to our website or directly to the portal, and you can literally be at a conference or walking down the hallway of your occupational health clinic, scan that QR code, and start registering immediately. So, we do have that in a lot of our different products, and we're always looking for ways to utilize that type of connection in the future.

Mr. Mayer: And we do have downloadable QR codes. So, if you only want a QR code, that's available from our website. Speaking of NAFTD, some of the state training directors, that's what they're doing. They downloaded the QR code, they do a five-minute presentation about the NFR and then at the end, they have the QR code up. Firefighters can go ahead and scan it using their mobile device and get started registering. So that is available, and certainly it's free to download by anybody. So that's, again, thinking about activating our partnerships, that's one way we could do it, try to get that QR code out more readily. There could be opportunities to do more. So would love to hear other ideas about that.

Ms. Lee: This is Sara again with the National Volunteer Fire Council. Probably this isn't a thing to mention to a government agency but incentives are always a great way to get people to do things, especially when it's about a 30-minute process, which can be a significant undertaking. So, I don't know if you guys have the ability to offer incentives and if not, maybe that's something that partners can do, like NVFC could offer free membership or something for people that register within a certain timeframe or something like that. But incentives are a really great way to get people to do something, so I don't know if that's within the capability of CDC/NIOSH or not, but maybe it's in the realm of the partners.

Dr. Graber: So, this is Judith, I agree completely. One of the things we did with our study, and again understanding we're not the federal government, is that we gave our fire departments some, I think it was \$500 when they participated in the study as a recognition of the administrative burden. Now, these were volunteer fire departments. We're in the process of finding out how they used it. But I think you can be very creative in what an incentive is, whether it's a possibility to have somebody attend a national meeting, which was something else we've done with our departments, which especially those under resourced departments really appreciate. And then I think thinking about whether it's at the individual level or the fire department level could be really important.

Dr. Horn: Is it within your ability to provide incentives? Can you comment on that?

Mr. Mayer: So, we would need to consult with the Office of Science to see what we can do. We certainly, in the federal government, we have provided incentives before for studies, so it is within the realm. I think the question becomes can we provide an incentive for every—we already have 15,000 people that have registered. That's through the open enrollment. Perhaps there's some sort of incentive or small token or department thank you item that we could give for the targeted enrollment. So, targeted does require more effort, at least at a department level, so there might be something we could do there. It's a very good suggestion. So, we appreciate it and we can certainly look into it.

CDR. Dunn: Because I love Sara's concept about with the partners, with those who have signed on, if it is something like if you have signed up within this month, you get a free year membership at NVFC or something along those lines. I mean, I think that's a beautiful way of not necessarily co-branding but bringing groups together. And if the partners would be willing to do something like that, I think that could be a really nice way

of incentivizing before going to something that might be more monetary out of the federal government's pocket. So, thanks for that recommendation.

Ms. Reeves: We have a hand online. Dr. Morawski.

Dr. Horn: Dr. Morawski, do you have a hand up?

Dr. Morawski: I do. Yes, thank you. So, the landscape of outreach to firefighting personnel is not my expertise, so I have two thoughts. One I wanted to echo Dr. Durbin's comment earlier about the power of a motivated advocate and volunteer. We've certainly seen that in the cancer space, and I wonder if at the state level, if having a volunteer coordinator and advocate would be helpful.

And then second, I was thinking about, especially in rural areas and thinking about Idaho, the overlap between, for example, EMS and preparedness in the firefighting personnel and if there has been any consideration of reaching out to state bureaus of EMS and preparedness or just other sort of disciplines that have overlap with firefighting personnel. Thanks.

Dr. Fent: Yes, that's a good suggestion as well. I think that's another area. And again, we have, as we mentioned, 21 letters of support but those are the organizations that that come to the top of mind, right? So, some of these other organizations that you guys are mentioning haven't really hit our radar yet. And so, I think the more we learn about those organizations, a lot of these organizations may be more regional or local. I think now, with an expanded program, we have more personnel, we have more bandwidth, the time is right to try to make these connections. So, really appreciate these suggestions.

Dr. Graber: Another thought is whether or not there's a way to work with accreditation. You know, through CFAI. And again, that is just your career departments, I don't know if you're doing that.

Dr. Fent: So, we actually are in fact doing that. Thank you for bringing that up. So CPSE, which runs the CFAI— is that it?

Dr. Graber: CFAI—

Dr. Fent: —accreditation, I always forget what it stands for. Departments that are applying for that accreditation do get points towards accreditation if they're participating, if they can show that they're participating and supporting the NFR. Now, one way that they can do that is through the Gold Helmet Distinction program. So, it's kind of a nice synergy that wasn't necessarily on purpose but yes, so we are.

Dr. Harbour: And also recommended—

Dr. Simmons: And Dr. Fent, if I may add, FireNuggets started off as more so a local training and newsletter, now has a national prominence, so it's another outlet for advertisement and recruitment.

Mr. Harbour: I'd also recommend maybe bring in the 21 supporters together and ask them how they can help push the message, whether it's providing real estate on their websites just for whatever it might be but let them come up with ideas as to how they can support. I'm sure you'll get a lot of synergy with the 21 groups. And then I think the other component of that is if we advertise—and I know it's on the website—how do you become a supporter? And then I think it would create some synergy where other agencies, other organizations, are going to want to be part of that.

Dr. Graber: So I'd like to spend a little time focused on the targeted recruitment if that's okay with everybody. I think what I hear is a couple of things, and I'd like to get, Sara Lee, to get your thoughts on this. I think that the intent is to have it focused on structural firefighters, career and volunteer, but it is very much written for career firefighters, both with the mention of shifts and I know the union is an option but I think that's something to keep in mind. And it's also, because I think there's a bit of a tension between enrolling as many as possible as quickly as possible and getting the breadth of the volunteer service. And I think with targeted enrollment, I'm wondering if there's a way to be creative to get the volunteer, rural volunteer departments. And one thing I was thinking of is maybe doing a targeted mutual aid enrollment where you'd have like an anchor department and then enroll their mutual aid departments, you know as a targeted kind of semi-region. So that was the only one thought that I had about how to try to get that wider representation of these departments that have, you know, 5, 10, 20, even 40 people. That's not who you're looking at for these, for this enrollment. And Sara Lee, I was going to ask you if you had any other thoughts, or if anybody else did, around this aspect of the targeted enrollment.

Ms. Lee: Yes, and I think this is kind of where that incentive concept came from. I mean, we've got so many volunteer departments that don't even have basic needs that they need to have to operate. So, I guess if you're thinking about Maslow's hierarchy of needs, them having the gear and equipment and people to get out the door is going to be a higher priority than registering for this. But if there was something that we can give them in return that helps them meet a need, then I think that will help a lot on the volunteer side.

And I think we have to keep in mind too that they're balancing their day job and their volunteerism and their family life. So, it's not like they're doing it on the job necessarily. They're not going to register during the day maybe when they're working their 9 to 5. So, thinking about how we can be creative in reaching them, offering incentives, and being sensitive to that balance that they are struggling to maintain in their life too. I don't know if that helps but those are just kind of my thoughts and I'll continue to ponder this one as well.

Dr. Siegel: I think those are really great suggestions and like you mentioned, Judith, a lot of the playbook does encourage on-shift enrollment and you know, Sara, you make a really good point about, the scheduling being very different. And at least, you know with career departments, we can suffice that activity of getting the local union support. So, what could a stand-in be for that with these volunteer departments? And on our initial list we've got a few combination departments, so they're going to be easier to leverage some of those career tools and still recruit their volunteer firefighters. But what about these fully volunteer departments? So, I think these are some really great suggestions and considerations.

Ms. Lee: And the state firefighter associations that represent volunteers would be a good ally in this too. Maybe having a sign-up mechanism at their annual conferences would be a way to bring these people in and raise awareness of it. We've tried to raise awareness at our conferences too but at the state level, you are going to get some of those more rural volunteers that are not coming to like the FRI, the FDIC and those bigger shows that are out there.

Dr. Fent: So, I really like the idea of having an anchor department and reaching out to the mutual aid departments. I think we sort of envisioned that as how it would work. I mean, with the targeted enrollment, many of those departments are large, highly respected departments. And so, I think the surrounding departments may look up to them, but the idea of actually asking for it is not something that really has crossed our mind yet. So, I think that's really creative and a good idea.

I think also the Gold Helmet campaign is another way to kind of do that, this idea of competition and if one department in an area of a state has the Gold Helmet Distinction, hopefully other departments will want to follow suit. But again, this idea of actually reaching out to those departments, because otherwise we're just hoping, right? So, I think it's, yes, it's a valid point.

Chief Tobia: So, two quick things. Going back to what Judith said about mutual aid, Illinois in particular has a very well-established mutual aid system called MABAS, Mutual Aid Box Alarm System. So, the state is broken down into different areas where those mutual aid agreements are set up, and they actually have conferences and everything else, and it's extended into some of the surrounding states as well. That'd be a great place where you could start to come because the local departments are represented in each of those MABAS districts, and that can help distribute it down from there. I'm sure other states, some other states have some similar types of things, but Illinois could be a great place to start laying out that concept through MABAS.

The other thing I thought of is what you brought up earlier about the Speakers' Bureau. There are county fire schools almost every week throughout the United States, some in summer, some in winter. Having a Speakers' Bureau who could come out—people are often looking for a 15-minute presentation at the beginning. You have your welcome, you have your keynote, and someone who could spend 10 to 15 minutes, that speaks in a similar accent, that could connect with those people, that Speakers' Bureau could potentially be busy almost every weekend. And again, that drives it down on some of those local, more county- and community-based fire schools. But you need to have those people that can locally understand where those are and get connected into there. But I think it's a great use of what you brought up earlier this morning.

Dr. Graber: I have another question. You know, so much of the fire service is about prevention and community engagement around prevention, and we all know that cancer, fire service-related cancer, impacts so much more than the firefighter. So, I'm wondering how you are thinking about this and the extent to which messaging hits the intersection with the communities.

Dr. Simmons: To your point, communities and the families of the firefighters. And sometimes those family members can be an advocate to get our members to not only join the Registry but also engage in healthy behaviors that prevent a likelihood of contracting occupational cancers.

CDR. Dunn: Yes, thank you. I think that's a really good point and well-taken. A couple of ways we are considering doing that is fraternal order type of things. I know a lot of people are joining those from this type of service. We're looking for regional or national Facebook groups from retired firefighters and firefighter support systems and firefighter families. You know, they have their own support needs and communications that maybe the firefighters aren't necessarily involved in. So yes, we are looking for those but really, I don't know the area. I don't know the people to talk to. So those kind of suggestions coming in will be great from the committee, as well as from our fire program specialists we're just bringing on, who do have a much better understanding of that need in that area, so we can try to develop those relationships. But thank you, it's a great point.

Dr. Graber: Does anybody else on the committee have any thoughts on that?

CDR. Dunn: Victor, if I remember correctly, particularly on the East Coast, there's a lot of alumni groups, right? So like Prince George's County alumni group, I mean that seems to be a relatively common thing out there. Are there ways of connecting to those groups that would be...

Mr. Stagnaro: Yes, I think a lot of—through the IAFF and the locals, you know a lot of the retired groups, those kinds of things as well. Yes.

CDR. Dunn: Okay.

Dr. Graber: I have another idea that might be a little out there but you know, I've been around CDC and public health departments for a long time and there's been such a connection in the last two decades between public health and readiness, and our local health departments have changed the way they work in many ways around that. And I'm wondering how that can be leveraged. You're in CDC, right, and so how those relationships with the local and state health departments that have these emergency response components might be leveraged. And I don't know if you're thinking about that. And it would be also really interesting to hear what our health departments and cancer registry folks think about that.

Dr. Fent: So yes, I mean I think we do work with health departments—NIOSH has a history of working with health departments. We certainly work with health departments. Kevin came from the HHE program. So, they're usually involved, at least from an awareness level, when we do evaluations. A lot of the health departments that we have interacted with, once they hear about the NFR, they're all on board. They get it. They understand it. I think the challenge is do they have a connection to the fire service. Some may have a connection more than others. So, like you said, Judith, I'd love to hear from other people who might be in a public health department to see what they think. I'm just not sure, you know, how fruitful it would be.

Dr. Morawski: This is Bozena Morawski in Idaho again. You know, I think this makes me think of the quote of, "All politics is local and all public health is local," and so you know, in Idaho for example, we have very robust, I think, relationships within the health department with emergency response preparedness. There's internal and external capacity that is leveraged, and then there's also a connection that trickles down eventually to our locals, whether that be the district level or something more granular like a county-based entity. And I think that, again, it's just a question of identifying the right people because I think those relationships do exist and can be leveraged, but I mean, not to state the obvious, I think this is the work that you've been doing for years now, but I think it could potentially be fruitful.

Dr. Durbin: So—Eric Durbin. Just a thought that when we look long term at the Registry, eventually it's going to create opportunities for screening, right, because I think we're going to identify a need for increased screening amongst firefighter personnel. And so, I think that's potentially, typically health departments, that's one of the main areas that they're focused on. So, I think there could be some synergy and opportunities for cooperation, planning for screening programs maybe targeted at firefighters.

Ms. Lee: Yes. I'll just say I think that's also really great and it ties in with the conversation we had this morning about the type of data. That would be great for public health practitioners to see as well is just like descriptive cancer screening rates among fire service personnel as well. So, I think that ties in really nicely.

Dr. Horn: Any other suggestions online for boosting overall enrollment, or suggestions for connecting with firefighting groups?

Chief Tobia: Has there been any effort on industrial fire departments? A lot of industrial firefighters are volunteers in their communities as well.

Dr. Horn: Great point.

Dr. Simmons: And also DOD fire departments as well.

Dr. Fent: DOD, we are actively pursuing that right now.

Dr. Simmons: Okay.

Dr. Fent: Industrial fire, I mean we definitely have questions about industrial firefighting as part of the enrollment questionnaire. As far as identifying those groups, if there is like an association or some professional organization, that would be great to know. But we haven't done that yet.

Participant: One group, you have the ARF working group for airport rescue firefighting.

Participant: Adding to the list.

Chief Tobia: Yes, and that might be helpful from the standpoint of if you're not part of a municipal fire department but you're just an airport, like Baltimore's BWI has its own fire department. It's not associated with Anne Arundel or any of the counties or cities around it.

Dr. Horn: So, we've talked a lot about some of these specific, targeted—I know you're also working on some national media pushes in order to get the information out as broadly as possible. So, I keep looking that way while we're talking. What are the plans for continuing through there? And actually, I know that you've had some plans. We reviewed, say for instance, some artwork from Paul Combs. And for those of you who are outside of the fire service, Paul Combs is a cartoonist, kind of almost like a political cartoonist, who pushes buttons in certain ways that makes people think about issues in the fire service. And so, there's some work that was done with those. Is that something that's going to continue? I have not seen those yet out in the world much. What's the plan for that, or are there other things that are going to be done like that, that can still get the message out broadly in these large magazines or the large presentations at Firehouse, Fire & Engineering, what have you.

Dr. Fent: I'll start and then Kevin can jump in if he needs to. So, we have a big communications campaign that's ongoing that we're constantly updating and refining, and that's about to go into like kind of phase two. So, phase one is building awareness, like you said, at a national level. Now, I will say that when you actually talk to line firefighters, especially in the middle of the country, they have not heard of the NFR. So we're not done building awareness.

I think that we want to use every type of communication we can to reach the fire service. I think some resonate with firefighters from certain groups better than others. I think Paul Combs may resonate very well with the broad fire service, and we are exploring other artwork that he's producing for us. A lot of that would get done through social media or things like that or working through our partners. You know, paid ads. We're looking at doing paid ads. We're putting advertisements in magazines, like Kevin mentioned. Of course we're going to conferences and things like that.

But nothing is off the table. If we can reach a demographic of the fire service that we haven't reached yet, and there's a lot that exist, then we want to do that. We want to be creative. You know, it's really important with a communications campaign that you are maintaining the same messaging throughout, that you're hitting your

branding guidelines and all of those kinds of things. So we have to be cognizant of that, and it takes time. It takes time to get those things developed and cleared and posted. You have to have a dissemination plan that gets approved. But we are very committed to doing it. So again, as the subcommittee if you have ideas on different ways of thinking about different dissemination techniques, different media that the fire service takes in. I know we talked about podcasts. We've done a number of podcasts but there's a lot more out there, I'm certain of it.

So, we are certainly open to those kinds of ideas, and again the plan is to reach every firefighter in the country. I mean, at some point, we want every firefighter in the country, whether they're active or retired, to have heard of the NFR, to know what it is, and we're not even close to being there yet.

Dr. Horn: So, I have what may be another off-the-wall thought. What about police and firefighter pension funds? I mean, they certainly have contact information and they may actually have actionable data. You know, a cancer diagnosis impacts a family financially and so there might be an incentive for a pension fund to be thinking about financial impacts to their members. So that could be an interesting—I notice there is an Ohio police and firefighter organization that was established in 1965, so you guys might be able to reach out to them locally.

Dr. Simmons: Oh, that's a good thought. It's not far out.

Dr. Sigel: Yes, I think that's a great idea. We haven't had any direct communication with any of those agencies, but we actually worked on a research collaboration with the State of Washington looking at their data for firefighter safety and health research. So, we were looking at it from like kind of a data quality, data source lens but as far as communicating with the fire service, I think that's a really great idea.

Dr. Graber: Especially given the multigenerational component of the fire service. I'm just curious. I know that you're—it's both state and territorial. You'd mentioned two territories. Territories seem like they might be really interesting in terms of they're small but if you can get in, you might be able to get quick coverage. I'm curious about what the two territories are and what your plans are to maybe go to Guam.

Mr. Mayer: I know the two territories.

Participant: Tell us the territories.

Mr. Mayer: Yes, the territories are Guam and Puerto Rico, yes.

Dr. Fent: But U.S. Virgin Islands, I think you have a contact with...

CDR. Dunn: Yes. Yes, we are cognizant of the territories and maybe the unique information they could bring. We have been working with some different people in, as Kenny said, U.S. Virgin Islands and Puerto Rico. I haven't gotten to work with Guam yet but I'm interested in doing that. Yes, we're definitely interested in reaching those groups and making sure that they're well-represented in the data and in the Registry.

Dr. Fent: And we agree that it could be very interesting. I mean, if you think about Puerto Rico, I mean my goodness, they've been hit by a number of natural disasters, hurricanes, just in the last five years. So, I think they have potentially unique exposures that we—we truly do not understand major events like that, how it

impacts the cancer risk. So, I think it's an important demographic that we definitely want to reach, and certainly an understudied group.

Dr. Graber: And again, getting back to your larger organization, you certainly have, both American Samoa and NMI have routine outbreak investigations and maybe you can partner with those folks.

Ms. Pittinger: Are you—I don't know the rules—are you guys able to partner with like cancer centers? I mean, I know at that point, the person is being affected, but in Virginia, Richmond, the big one is Massey Cancer Center. I'm not sure if you are allowed to intersect at that level. And then, two, I can't remember the name of the company, they were at FRI several years ago, but they do the screenings. They're a private company and they kind of market themselves so you come in, so I'm not sure if those are organizations you can work with kind of as part of the screening. Maybe the locality can push that you get to register as well.

Dr. Fent: I would love to hear from the committee about this idea. I think we are interested in exploring it further. The idea of potentially collaborating with, like, medical centers. You know, we have heard that there are states that are starting to fund, with state funding, cancer screening of firefighters in the state. I think there might be an opportunity there to collaborate, but I would love to hear from the committee if you have strong feelings about that.

Ms. Pittinger: I like it because it (inaudible) so...

Dr. Graber: So I have a very strong feeling about it. I've never been known to hold back, unfortunately, as it is. But I think as long as the screening is evidence-based, that makes a world of sense. I'm concerned because I've seen non-evidence-based cancer screenings being aggressively marketed to local state fire service organizations, and it concerns me greatly. So, I think as long as you're working in evidence-based screening, I think that's fantastic. But that would be, I think, the major caveat.

Dr. Simmons: I second that.

Dr. Horn: And I think that would be a great service to the fire service itself because there's a lot that may appear to be evidence-based as they're being sold to the fire service, so it's a challenge that I think everyone—it's being asked regularly. What is a screening that we should go after, and which one should we not? And so, I think what would be important then is to what is the mechanism that you would put in place to make sure that it is. What is that threshold it has to clear in order for you all, as NIOSH, to recommend that this is something that should go forward. And maybe you know what that should be, but I've heard a lot of conversations around it but nothing that's been concrete yet that I've heard.

Dr. Graber: And of course it fits so well with your goal of sharing information on cancer screening and health behaviors. So, I think it's a win-win. There's so much misinformation out there, and the degree to which the NFR can help the fire service clarify the exact questions that Gavin was answering I think would be such a win.

Chief Tobia: Yes, I almost envision an NFR seal of approval if that's something you could do. I was just in Inova in Virginia. They were handing out screening kits. I could just take it home, do a swab or whatever it was, and mail it in. And it was for firefighters. If it had the NFR sticker on there, then I'd know this is okay.

Dr. Siegel: And I believe the AFG grant, one of the areas you can apply for, it's permissible to use it for cancer screening. I don't know if they have a list, how they, when they review it at the FEMA level, that says, "Yes, we

like this company,” “No, these are not—these are not evidence-based.” So, I don’t know how they screen the grant applications under AFG but they could potentially give you a lead on what departments or at least companies they’re at least using.

Dr. Fent: Right, and I mean, there’s routine cancer screening, so the U.S. Preventive Services recommends routine screening at certain ages, and that’s easy, right? I mean, we know what the standards are for that. But then there’s advanced cancer screening, right? And there are a lot of products on the market for that. There is advanced cancer screening that is more based on science, but it is still more experimental, right? And so, what if you had an organization—a reputable organization even—that was doing more of a scientific study, looking at some of these advanced cancer screenings, and let’s say they wanted to collaborate? What are your thoughts on that? Again, it would be a study so they would have to communicate that to the firefighters. This is a study. This is more experimental. We want to understand how effective this is. But again, the idea—and I think it’s actually the second discussion question from this morning—this idea of collaborating with external researchers. So, this would be in line with that. Thoughts about that?

Participant: The first thing that kind of pops in my mind I think is the Wingspread report, which I know is a partnership with Johnson and Johnson I believe,—I think they changed their name as Johnson’s or something. So, I don’t know if that could be—I know they meet every so many years and I think it’s every five or ten. They’ve added in firefighter wellness and safety as one of their initiatives and things that they want to study. So, I know that that is heavily funded by Johnson & Sons I think it is now. So, I don’t know if that could be a potential avenue but they’re obviously evidence-based and research as well.

Dr. Durbin: So I’d just like to add, I think that’s an intriguing idea, the intersections in collaboration with cancer centers. So, I also represent the Markey Cancer Center at the University of Kentucky. Most cancer centers have interests in occupational exposures and environmental exposures, and so I could see potentially some nice research opportunities, particularly if this resource could provide potential enrollees into the study. So there actually could be maybe some great opportunities focused around research in this area.

CDR. Dunn: Yes, thank you. I think that’s a really great point. We have spoken with several different cancer centers and cancer consortiums, and we are exploring how we can work with them to kind of develop this dual research goal. But I do think, just as one caveat with all of these different ideas, the bar for us to, quote/unquote “approve” or even appear to approve of any of these types of things it’s very, very high. As much as we want, may want to do something or think it’s the greatest thing in the world, the bar is just very, very high to prove to our chain of command that it’s okay and the federal government can do this without incurring any negative reaction. So, we’re interested in exploring all of these. Some of them are more achievable than others just because of that threshold. So, I just want everybody to keep that in mind.

Dr. Horn: Yes, of course, and you don’t have unlimited funding resources, right, and so there are only so many things that you can pursue. But still, interesting to think about.

Dr. Fent: I do want to say, so some of these research projects we are learning are funded through the National Cancer Institute. So, if that’s the case, that does give it credibility. That’s another federal agency that’s supporting the project. So that’s a little bit of a wrinkle.

Dr. Graber: And I think that’s actually, yes, the bar is high but there’s so much out there that I think that we need that level of credibility, and human subjects protection is really at the base of the bar being so high. And

to me if NIOSH sets the bar then yes, you should collaborate with whoever that collaboration can go forth. You know, I can't see a downside of the NFR—and I'd love to hear the fire service representatives' thoughts on this. You know, it's clear it's research. It's clear that it's experimental. My big concern with a lot of these screening products is false positives and the impact that that has when you're told you might have cancer and you don't, and then you have to go for a lot of testing. And I mean, I work mostly with volunteers in small rural communities, and then what happens next year? Do you have to go back again? So, there's so much unknown here, and I think having that high bar is really what's needed. But again, I'd really like to hear from others, particularly our fire service partners on the panel.

Chief Tobia: This is Matt Tobia. Thanks so much for asking. I'm aware that there are departments who have secured FEMA grant/AFG funding for the Galleri tests and I'm just naming that because I factually know that that's been the case, and there has been apparently a good level of support for that particular test even though it does have limitations obviously around the blood-brain barrier as well as certain other issues. I share the concern around several things related to this, but the fire service is generally very open-armed about participating in research that helps us reduce the risks of cancers and other occupational illnesses. So, in general, my sense would be that the culture of the fire service is generally very supportive. I think that the NFR would just need to be very careful about who that partnership might be with, because less specific tests that are suggestive of the possibility of a cancer developing at some point in the future versus empirical evidence of the existence of mRNA at the cellular level, or noninvasive diagnostic testing that is also suggestive. Those, you know, those noninvasive suggestive tests are much more concerning to me because they produce an extremely high level of anxiety. And I think the departments that have thus far embraced the mRNA test have done so very carefully, with a very solid foundation of occupational medical support for a firefighter if they are given a positive diagnosis, as opposed to just sending them on their way to deal with it on their own. But I think, I think in general, the fire service is very supportive. I would just suggest that we be particularly careful about who we choose to partner with. Thanks.

Dr. Graber: Any other thoughts on this topic? Because while we're generally here, we are on this question that we really didn't address earlier, which are of other kind of research collaboration and ways that this data could be used in a research environment. What are folks' thoughts on that?

Chief Tobia: I'm asking a question. Has there been any discussions about integrating within the 1582 community? You know, there's also a very significant community within the NFPA, National Fire Protection Association, 1582 standard on annual medical evaluations and the possibility of having those entities that are doing 1582, exploring the possibility of sharing deidentified data around their cohort of individuals that they follow. I think there's been some discussions I think in the past within that community about the possibility of sharing that deidentified data, which may help us more effectively identify individuals who would want to sign up for the Registry as well as gain data with regard to the incidence of cancer in the fire service.

Dr. Fent: So, yes, I think we are definitely open to this idea. This is a group, occupational physicians, medical directors of fire departments, this is a group that we really want to get tied into better and hear from them directly. So that's actually one of our priorities over the next year or two. But you're right, I mean at least for career fire departments, hopefully many firefighters are getting their annual physicals. So, they're having that touchpoint. They're a respected professional that could speak to the firefighters, encourage participation in

the NFR, and then perhaps figure out if there is some sort of opportunity to share data. I'm not sure exactly what that would look like; it's medical data. But it's certainly something we could explore.

Dr. Graber: I think the great opportunities in the NFR to be thinking about training the next level of occupational professionals, and I think collaborations with the universities that have occupational training through the ERCs for example, postdocs. There are method issues. You know, you have self-reported cancer and cancer diagnosis, great project. There's just a lot of ways to contribute to the science of occupational health. So, I don't know how much that is on your radar in terms of long-term benefit of this program.

Other thoughts? How about the folks at the cancer registries? Can you think of ways you might want to think about using these data—collaborating with the NFR for your own research or future research?

Dr. Durbin: Well, I think there are tons of opportunities here. So, you already have a cohort of 15,000 participants. In following those patients—or individuals, I'm sorry—over time, huge opportunities there. So, I think there would be a lot of interest. Even in registration, one of our challenges is documenting occupation and industry in the cancer registry. We don't do a good job with that. So maybe there would be some opportunities to conduct some research in this area as well. But lots of opportunities I think.

Dr. Siegel: Yes, Judith and Eric, you both bring up great data quality analyses. That we've also thought about, especially related to cancer registry records. There have been a few studies looking at occupation and industry reporting in several cancer registries, and Florida has actually published some research looking at firefighting occupation in particular in the cancer registry record, which is imperfect to say the least. So, we do have the opportunity to do that in our questionnaire. We also gather information about other occupations held during their fire service career, so comparing both self-reported cancer information but also self-reported occupation and industry information and other health behaviors that might be recorded in a cancer registry. I mean, there's a wealth of opportunities for doing that.

Dr. Graber: And then—and this is probably just because I'm new here, but I hear you talk a lot about cancer incidence. Of course, the other incidence measure is mortality. I assume that you have it in your plans to match with NDI eventually.

Dr. Siegel: Yes. Yes, down the road. Fortunately, I would say a vast majority of our participants are still living today.

Dr. Graber: Yes, good thing. I mean, and one thing that we've found even with trying to do linkages in New Jersey with career firefighters and our retirement system, 24% of firefighters had moved out of state. So, most folks will still be in the U.S. but there will be some migration.

Dr. Siegel: Yes, another issue that is currently a problem, but you know, maybe not in the future once we're planning these designs, is that cancer registries use a linkage method that can allow for linkages with partial information like partial SSN. The current system for linking with NDI for example, doesn't allow for linking on partial SSN. So that's something that could change in the future, or we'll have to leverage other creative measures like Bozena mentioned earlier, gathering information from LexisNexis or other administrative databases. So, as we get closer to anticipating larger cases of decedents, we'll have to start thinking about what opportunities there are for conducting those linkages.

Dr. Graber: And I apologize, NDI is the National Death Index. It's the U.S. Vital Registry's overall deaths in the states and territories.

Dr. Durbin: Thank you.

Dr. Horn: All right, should we come back to this third question here? We touched on how we could possibly leverage push notifications a little bit more. And if you could just refresh, what is the current pace or plan or how do you use the push notifications at this point? And where are you all seeing successes and where do you think you might be able to expand?

Dr. Fent: The only way that we've used the push notifications so far, other than reminders, is for if you log out, you haven't completed the process, you do get a reminder, four emails, and if you opt in for text messaging, you would get four text messages.

Dr. Horn: Okay.

Dr. Fent: Other than that, the only way we've used it so far is to do a push notification for the Gold Helmet campaign. So that went out to all, at that point in time, we were at 13,000 maybe participants back in June. That went out to all 13,000 participants. What's interesting is—and I don't have the numbers, but we saw a sizeable increase in participants getting that push notification and going to our website to learn more about the Gold Helmet campaign. So, it clearly worked. And then after that, we saw an increase in departments applying for the Gold Helmet. So, I think that it demonstrates—and maybe Alex will pull up...

Mr. Mayer: Yes.

Dr. Fent: Okay, great.

Mr. Mayer: Yes, I was just pulling it up. It's right here. This jump was when we sent that push notification. The 308 email blasts, I guess you can't see my mouse so this wasn't super useful. Never mind.

Dr. Fent: It's in June and...

Mr. Mayer: Yes, it's in June.

Dr. Fent: There is a big screen covering it, but yes. Anyway, I think it shows that this can be an effective tool.

Now, how can we use it in the future? Some of the things that we're thinking about doing would be, as I mentioned, once we ensure data quality, once we ensure that all the participants have a participant number assigned in the database, we would be doing a push notification for that and letting them know. We wanted to provide—as a friendly reminder, here's your NFR participant number. So, we'll definitely be doing that. Probably once we get the dashboard up and running, we'll do a push notification to let them know that that's up and running. When we publish reports or papers or anything like that, we would notify the participants. So, anything that comes about because of the NFR, we want to communicate that.

But there could be other opportunities. So again, this idea of what is our vision. Our vision is to reduce firefighters' risk of cancer. So, there could be public health messaging that we could provide. So that's the spirit of that question. How else can we use push notifications without being—we don't want to be a

nuisance, right, so we do have to be careful about that. But anyway, that's what we want to hear from the subcommittee.

Participant: (Inaudible) possible.

Dr. Simmons: No, I agree with that. If nothing else, a once-a-month push notification highlighting best practices or hearing a story from a fire service member across the nation in regards to his or her efforts in terms of keeping themselves safe or overcoming a case of occupational cancer. A testimonial.

Dr. Horn: So, you think about once a month would be an appropriate pace?

Dr. Simmons: Yes, just on and out there. We don't want to, like Dr. Fent mentioned, overdo it. But at the same time, we don't want to have it on the other extreme to where the site becomes stale.

Dr. Horn: Yes.

Mr. Mayer: And we do have the option to send an email or a text message, so it might be a situation where maybe an email on a more routine basis makes sense, and then a text message, a little less frequently. But we do have the control to send either/or. And I did want to mention for push notifications, we'll also be sending reminders for the follow-up questionnaires in the future too, so.

Dr. Graber: I was going to make exactly that point. You know, if they're being sent out regularly and they're engaging people, that'll be great. But if they're being, obviously, sent out regularly and they just get to be something that people don't look at then that's going to really impact your follow-up. So, I think that the important thing is having that follow-up message be different in whatever way it could be.

Dr. Horn: Yes, separating that out between text and email is a great way to do it. It's easy to just have people filter one versus the other.

Participant: I think you could also ask them. You could do a quick three-question survey of how often you want to hear it and what kinds of information do you want.

Dr. Simmons: That's a good suggestion. I just received something today from the Science to the Street [Station], Sara Jahnke, and same type of questions came up in regards to topics and frequency.

Dr. Horn: I think it's the hard point when we say how frequently, it's going to be very different, as we've talked about how broad the fire service is. There are some, I'm sure my father's generation would prefer to have it once a year, whereas my son's generation probably once a day would be just fine. So that option is really, I think, could be powerful.

Dr. Simmons: Yes. So accurate there, Gavin.

Dr. Horn: Any other thoughts? I know it's getting late. It's 2 o'clock here, so we've been talking about this for quite some time, but I think this is the last question that we have for this discussion session before we move to closing out. So, any other thoughts? I don't want to cut anyone off if anyone has some great ideas out there.

Dr. Fent: So just to add to this question, again thinking about the public health mission, what about providing information on cancer screening? For example, if somebody reaches a certain age and we know that they have now aged into certain cancer screening guidelines, what do you think about that?

Dr. Simmons: Yes. No differently than what we do now for prostate cancer.

Participant: Agreed.

Dr. Horn: Yes, absolutely. There are actually some new screening opportunities, particularly in lung cancer. Like historically, you really haven't thought about being able to screen and impact lung cancer, and lung cancer is the leading incident cancer and a leading cause of cancer mortality worldwide. And through low-dose computer topography screening now, low-dose CT scanning. There are opportunities for scanning eligible individuals. That's typically people that have smoked for a number of years, but I would imagine being a firefighter and a history of smoking maybe would increase risk. But the opportunities for screening to identify lung cancer at a much earlier stage, they're much more treatable, survival will be much better. But I think across all cancers, I think using this as a platform to advocate for screening and to facilitate that would be a fantastic objective.

Dr. Graber: And I would add to that to make sure to message around firefighters informing their clinicians, their primary care providers, that they are indeed firefighters. This is really important for the volunteer service but I think it's important across the service. Those that do, are able to get an annual exam don't think then to take that information to their primary care provider, and certainly such a large percentage of our volunteer fire service doesn't get an exam. And initiating those conversations around screening because smoking rates in the fire service are much, much lower than in general population, almost less than 1% for career firefighters and about half of that of volunteer firefighters. So, should some of these folks still be getting lung cancer screening even though they don't meet the recommendation? That's a discussion they should be having with their clinician. But if the primary caretaker, primary care provider, or healthcare provider doesn't know then those discussions don't happen.

Dr. Horn: In some ways, this could be what does the NFR provide to you? I mean, that's a service in some ways that you can provide by sending these reminders for people who may not have those conversations. So, I'm thinking in particular for some of those smaller rural fire departments where they would not have a medical facility or medical director. So, if that is something they could opt in to, that could almost be sold as if you join us in this group, this is a service that we'll provide to you to help you to keep on top of some of these things, and hopefully keep you from having that cancer diagnosis. So, I think you could actually turn that into even a feature for selling enrollment.

All right. It looks like we've gotten to the end of this line of questions. So, our next, next agenda item, Kandyce, is a summary, wrap-up, and future agenda items. Anything you need to prompt us on before we go down that path?

Ms. Reeves: No, you all can go ahead.

Dr. Horn: No?

Ms. Reeves: Yes. And I'll adjourn when you are done.

Dr. Horn: All right.

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

Dr. Graber: So, thoughts from the panel on future agenda items before we summarize up?

Dr. Simmons: I don't know when the next meeting's going to be but just an update on what specific task-level activities are in the works or have been executed since we last met would be great.

Dr. Horn: I guess this would be a great question to get started. It's the first time I've been involved in one of these meetings. So, it would be good to understand what is the ground rules in terms of particularly when is the next meeting. Are we typically going to meet on a six-month basis? What's the plan for the next one?

Ms. Reeves: Yes, so based on the rules, a year from today we have to have a meeting, so not—

Dr. Horn: A year.

Ms. Reeves: So not on the day, so it'll probably be July/August just because it takes a lot of time to get these scheduled. But yes, so within the next year, our next meeting, we have to have it.

Dr. Horn: Okay. So, agenda items for next year. Got it.

Dr. Graber: So, shockingly, I have one. So, part of the power of the NFR is the longitudinal aspect of it and the longitudinal follow-up. I think it's going to be extremely challenging. And I'm sure you have a lot to talk about, your plans for follow-up with enrollees. But to me, as an epidemiologist and a bit of a survey geek, really interested in your plans for leveraging this large cohort and what questions are priorities, how are they priorities? You know, there's so much that could be asked, and of course you can't ask that of everybody. What's the approach and how can the fire service and the panel help with that?

Dr. Horn: I would say specifically, I would love to hear progress on the targeted enrollment. And I think a year is almost a really long time because the amount of time and effort that you all are going to have to put in to that, the boots on the ground, it's a critical piece of this. So, I don't know if there's a way to get maybe an interim update on how that's going somewhere in between, and maybe we can have a conversation, even just by email, about what is working, what is not working, is there any feedback that the committee could provide? Because I think that's going to be really resource-intensive and we should figure out if could help you think through anything that might need to pivot, or just keep on going the way it is.

Ms. Wilkinson: Can I just mention that—just to clarify, the Act requires that we meet once a year, so that's a minimum. So, if the committee feels like there's a reason to meet, we could certainly do a virtual, much easier than an in-person. So if that's something you guys recommend, we can certainly put that on the table. It's just that at minimum, we need to see each other in the next 12 months.

Mr. Mayer: Does it have to be like a full-day meeting, or could it even be a couple of hours if that's the only topic?

Ms. Wilkinson: Yes.

Mr. Mayer: Cool, thanks.

Mr. Stagnaro: So yes, I would also recommend then that as we've provided lots of input and recommendations, recognizing you can't take them all and use them all, but the ones that you can use, how they've been effective. And then how else us as a committee and how other partner organizations can continue to support, I think there would be really good, valuable information to us be able to help educate the masses.

Mr. Harbour: Yes, building on that—that's why he's the brains—at least for me, this first couple of years has been an altruistic pitch to my fellow knuckle-draggers as, you know, get your information in because it's going to help your buddies, the folks that you work with. That's still fairly effective because, as you said, there's thousands, tens of thousands, maybe hundreds of thousands of firefighters that still haven't even heard about the Registry. So that's cool. But just as soon as you all have some, "Here's something we did with that data that's pretty cool, that helped," you know, that would be great to not only say, "Brook, you work with me as a volunteer, go ahead and get in there and put your data in because it's going to help somebody." It'd be pretty cool if you start to have stories about, Victor put his stuff in, I put my stuff in, and it could help you in this way. That would, I think, help a virtuous cycle in the recruitment of people because they begin to not only get the sense of an act of service but an act of benefit to them by participating in the Registry. And maybe that's a long ways off too. I get asked that question relatively frequently about, well, especially for those of my age that have been diagnosed with cancer, then my doctor already report this to the Registry. So why do I need to do this? Well, once again, it's been an act of service. But the more you can give us a few stories about how this is selfishly benefiting the fire service, that'd be cool.

Ms. Reeves: All right, Matt, your hand's up online.

Chief Tobia: Thanks so much. Great meeting today. Great communication. Outstanding stuff. Always an honor to be present. I think for me personally, this is the first Advisory Board meeting that I've been to, and what I'd really like to know for myself is what specifically does the NCR team need from me or expect from me as an Advisory Board member in between the meetings. What specific things can I be doing to help lend voice, energy, effort to promoting this and/or what do you need from me as a member for providing feedback? That would be extraordinarily helpful and that could be done offline, and you can feel free to send me a long list of things that you need.

And then the second thing is if, in fact, we are potentially a year away from meeting again, I would just respectfully ask the team to please energetically explore the possibility of the development of an app because what I think I hear is a desire to have potentially more two-way communication with the fire service, and I think an app that is hosted by a professional company that can provide push notifications, that can send out vignettes of stories, that can, highlight the ongoing value of the NFR can only yield measurable benefits. And again, I think that, for the newest generation of people, an application is going to be an ideal way to get people into, get firefighters into the Registry, and then once they're in the Registry, give them an easy opportunity to update their information as well as send information to them. So, I would just respectfully ask for kind of an energetic effort around at least exploring that and if it can't happen, what the barriers might be. So, thank you.

Ms. Wilkinson: Thanks, Chief. This is Andrea. I think the biggest thing, to address your first question about what the committee can be doing, is be eyes and ears for us. Give us feedback. What are you hearing? The good, the bad, the ugly. We need to know what—if you're hearing from firefighters, maybe you're hearing

nothing, they don't know a thing about it. We need to know that. Maybe they say I'm not participating because there's not an app, as you suggested, and it's too confusing on my phone. Any of that feedback is excellent for us. And just helping to create awareness of what this is. There are still so many myths out there about the NFR being for those diagnosed with cancer, since that's typically what a cancer registry would be, and so that's why we really want to try to differentiate our self from that. So, anything that you as committee members, any conversations that you have where you could kind of help plug it and get feedback and provide that, you can do that either through Kandyce or through the co-chairs.

And speaking of the co-chairs, Gavin and Judith are, whether they know it or not, will actually be representing you as the committee to the next level of—which is the Board of Scientific Counselors. So, they'll be providing kind of a summary of this meeting and recommendations that you all have made, and there will certainly be feedback from that committee that will then come back to this committee and kind of cycle through. So, there will be some ongoing communication regardless of when we meet again, but I think that's the biggest ask is just help be eyes and ears, and keep communication open with us. Anything else?

Chief Tobia: Outstanding. Thank you so much for that feedback. I appreciate it.

Dr. Fent: This is maybe a question for Kandyce but as we do make progress in certain areas, how does it work? Are we allowed to sort of send an email out to everybody on the committee and kind of let them know?

Ms. Wilkinson: Yes.

Dr. Fent: Through Kandyce?

Ms. Wilkinson: Through Kandyce, yes.

Dr. Fent: Yes. Okay, so there you go. I mean, we've heard a lot of great recommendations, suggestions if you will, that we can pursue and then as we make progress, we can actually give updates. So, we don't necessarily have to wait for the next meeting to do that, through Kandyce.

Dr. Durbin: Is there a—obviously we provided, I think, a fair bit of feedback. Some of it is probably, was on your radar, some might not have been. But how will you use this? Will this inform a roadmap that exists? Will this generate a roadmap? Is there a plan to say okay, these are the things that we want to put in place in a certain timeline, or those sorts of things, that they would be worth a feedback and a conversation with us that you heard these things from the committee, these are the things we're going to prioritize, and just make sure that that was the intended thing, the intended feedback? Or how does that work moving forward between now and the next time we get together?

Dr. Fent: So the way this works is—and Andrea, you can maybe speak more eloquently about it—but we are taking notes and we have a transcription service as well, so we take everything that you guys say and we drill it down into action items, and then we determine, just as you guys mentioned, we can probably do something here, maybe not here.

Dr. Durbin: Right.

Dr. Fent: So, we do have a roadmap but this would certainly add to the roadmap, or fine-tune our roadmap. And so definitely, some of these we were planning on doing already but there are some new ideas here that

we're going to add to our plan, and like I said, I think we can probably report back on the progress we're making as we proceed.

Dr. Durbin: Okay, thanks.

Ms. Wilkinson: And just to add to that, with this meeting, it was more of an update and conversational. There is opportunity for future meetings that would be a little more formal, where voting could play into the meeting, in which case—let me give you an example, our very first meeting, a vote was taken on our protocol to approve that and put that forward. And if there are meetings or topics that we feel we need our experts, so the committee members, to vote on this, we'll take that forward and then there'll be a formal report written on that topic as to what the consensus was and what our actions would be going forward. We'll have a meeting summary. We won't have a full-blown report since there's no vote today, but just so you're all aware, for those of you newer on the committee, there's opportunity for a more formal approach as well.

Ms. Reeves: Miyoko, online?

Ms. Sasakura: This is probably coming from a totally ignorant standpoint, but I was wondering, to better answer the what kind of summary data to best inform like the public health professional, is there a way for us to know what the columns are for the data that's being collected? So then, if you're collecting exposure information, what is that exposure information? And so, then we're like, oh, okay, yes. We would like to understand, at a local level, what sort of exposures the firefighters are experiencing, and then we could send out hazard alerts. Or whatever developing and brainstorming research studies that may be a little more localized, but anyway. That's just a question, if that's possible.

Dr. Siegel: Hi Miyoko, that was a great question. This is Miriam Siegel. What we have available right now is our full questionnaire, which was actually updated and posted online to the subcommittee website earlier this year, not with the current meeting material, but we did update that and post it earlier. So that gives a really great idea of the amount and breadth of information we do collect. Now, the variables that we're going to create for analysis from that data are largely yet to be determined, especially as it relates to exposure profile. You know, a lot of it'll depend on sample sizes for different variables, and data quality. But we've already started diving into some of that. But it kind of gives you an idea of the characteristics that we are currently working with in terms of building that information.

Dr. Horn: Other suggestions for agenda items?

Dr. Graber: One suggestion. Overall, I think the questions that were framed today were really helpful. I think the discussion was really rich. Thinking about the question about what data would be useful, it might be helpful, especially for the newer members, to have had a little more kind of data framing there. I think, so maybe just thinking about maybe the onboarding process or the pre-meeting process a little more, we have a very engaged advisory board here, and I think you could give us stuff ahead of time to dig into and give you feedback on.

Dr. Horn: I think one of the things that could be useful—I mean, you mentioned having the roadmap. Could we get a brief on that? Understanding of kind of where we've been, where we're at? You had a pretty large turnover with this group, right? I think we're both new. A lot of the group is new. So, something along those lines to kind of help bring up to speed. And maybe even think about that is as newer groups are coming on, as

more people rotate off and come back on, what are the things that should be provided? We go through a whole lot of the ethics and the financials and all those other pieces, and some of us are pretty familiar with the NFR but I think others might be coming from a very different place and might not have the history. So that onboarding process for the next group that will come through I think could be a very useful thing to start thinking about setting up for the next round.

Mr. Mayer: Yes, I think that's a really great idea. Like the enrollment questionnaire or even our protocol, things like that that we have posted publicly and have shared with NFRS in the past, but for newer folks, I think that's really smart. Thanks.

Dr. Siegel: And our previous PowerPoints.

Mr. Mayer: Yes. And the previous PowerPoints too.

Dr. Fent: Right, I think also having an understanding, a little bit, of the history, right? If you're brand new, you're probably wondering, it's 2024, you got funding in 2019, you know, what took so long? So you know, providing a little bit of an orientation of everything that went into it. It was a tremendous amount of work. We had a pandemic in the middle of it. But I think having a little bit of that background information would probably be helpful too.

Participant: It just happened yesterday, right? Right?

Participant: I think so.

Ms. Reeves: For those online, I have put the subcommittee website in the chat that has all of the previous presentations, protocol, questionnaire, all of that information. And for those in the room, I can email that out to you.

Dr. Horn: Thank you.

Dr. Fent: And I think we've mentioned this before but there are new members. Our enrollment system, we do have a test site, okay. And so, we can share the test site. Anybody can go through the test site. Your information is not kept in the test site, but it allows you to go through the process just as a firefighter would go through the process. So, we can share that with everybody as well. I guess we'll send it to you, Kandyce, and you can share it.

Chief Tobia: Please. That would be deeply appreciated.

Dr. Graber: So it seems like we're sort of getting to a natural end here. Are there any other comments before Gavin and I try to do a summary?

Mr. Harbour: Yes, so I would just like to take this opportunity to thank the team, the NFR team. I think your enrollment numbers speak for themselves. You guys are doing a fantastic job. We appreciate your service to this community.

[Applause.]

Dr. Graber: Yes, and I think that was going to be our first point was that you had brought that up again, and I don't think we can understate how impressive the start you've had is. It can feel like, oh, we're only at less

than 10%, but it is a lot to get that many people enrolled in the amount of time you've done it. And I think, I think I can speak for everybody on the committee to say it's very impressive, and again to thank Kandyce and Andrea for the amazing job you've done in organizing us and keeping us moving forward.

So, some of the things I'd like to reflect back, starting with the data, we talked about accessible, I always like the term "fire service-friendly," and actionable, both in terms of actionable for folks who are receiving the data, how they're going to use it, and then actionable for moving the NFR forward in enrollment and visibility.

You know, I think in terms of collaborations, we talked this morning and this afternoon about the positive role of collaborations with research and other partners, and how it can expand on the promise and the opportunities in the NFR. And then I think this afternoon, we really spoke a lot about how the NFR can expand enrollment, different opportunities for collaboration, leveraging the promises that have been made, as you have talked about quite a bit, how to move those support letters into action, and some of the challenges of the heterogeneity in the groups, and I think some good ideas have come up about how to address that. I do want to repeat the idea of an app, which I think is fantastic if the capacity is there to do it. And then also just investigating things like incentives and other ways to engage different parts of our—of the fire service.

I think those are my main points. Gavin?

Dr. Horn: Yes, I agree. Chief?

Mr. Stagnaro: I told you I was leaving at 14:30, so...

Dr. Horn: Thank you, sir. Appreciate it.

Participants: Thank you.

Mr. Stagnaro: Don't mean to disrupt the (inaudible), so.

Ms. Reeves: Thank you.

Dr. Horn: So I agree with all the points that you've just made. I think one thing that really struck me from what you presented this morning is the different concepts of how to pivot and how to continue to go after the recruitment as the number one instead of just sticking with you're trying to pound your head into a wall with the exact same approach over and over again. I like the continued updates to the ways you might go after certain individuals, the broad base. I think Sara mentioned it earlier, that there are still some very rural fire departments who don't have internet, and in some of the largest states in the nation. I think the app is a great idea but those paper pamphlets, those cardboard cut—whatever you send in the mail are still going to have a huge impact if you want to try to get to some of those rural communities, in particular some of the volunteer rural communities. So, I think we need to continue that broad band approach. Your idea about a Speakers' Bureau I think has some great opportunities to, again, get further and deeper down into those grassroots areas. And that's going to be more intensive in terms of resources, obviously, but that's probably where you'll start getting more of those—at least on the orders of 40, 50 or so at a time.

So, I commend you on continuing to come up with those things, and looking forward to what you learn from those. And that's why I think, particularly with the relatively new group we have here, I do think a six-month update, even if it's just a one-hour virtual meeting, could be very useful to help us to kind of get more on

board and let some of the new members have more understanding of what's going on here, and those updates would be valuable. But thank you for the opportunity of really—enjoyed getting to know many of the folks here, and the fire service is going to benefit from this greatly, I think, not just in the U.S. but around the world will benefit greatly from the work that you all are doing, so.

Any other closing thoughts from those around the table? Anyone else online got something else they'd like to say?

Mr. Harbour: If I may, I would just like to congratulate Captain Ken.

Dr. Horn: Captain Ken.

Mr. Harbour: On his new, on his promotion. Congratulations.

[Applause.]

Dr. Fent: Thank you. Thank you.

Dr. Horn: Online, do we have any other closing thoughts anyone might like to make before we adjourn the meeting? Kandyce?

Ms. Reeves: All right, so on behalf of myself and the NFR team, I would like to thank all of the committee members for being here today. Those of you who traveled, I hope you get home safely, and thank you to those who joined us online. And as a reminder, I am your primary contact to this team so if you have anything you would like to say, any questions, comments, or concerns, please reach out to me and I'll make sure they get the message.

But thank you all so much and we will adjourn the meeting at 2:34 p.m. Eastern. Thank you very much.

Dr. Horn: Thank you.

Ms. Reeves: Have a great day, everyone.

[Adjourn.]

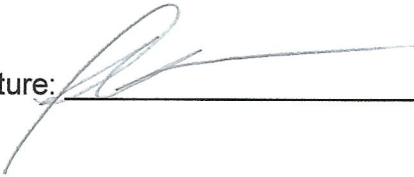
Glossary

| Abbreviation | Definition |
|---------------|---|
| AFG | Assistance to Firefighters Grant |
| BSC | Board of Scientific Counselors |
| CFAI | Commission on Fire Accreditation International |
| DOD | Department of Defense |
| DOI | Department of the Interior |
| ERC | Education and Research Center |
| FACA | Federal Advisory Committee Act |
| FDIC | Fire Department Instructors Conference |
| FEMA | Federal Emergency Management Agency |
| FFCCS | Fire Fighter Cancer Cohort Study |
| FRI | Fire-Rescue International |
| HHE | Health Hazard Evaluation Program |
| IAFC | International Association of Fire Chiefs |
| IAFF | International Association of Fire Fighters |
| IFSTA | International Fire Service Training Association |
| ISFSI | International Society of Fire Service Instructors |
| NAACCR | North American Association of Central Cancer Registries |
| NAFTD | North American Fire Training Directors |
| NASFM | National Association of State Fire Marshals |
| NDI | National Death Index |
| NERIS | National Emergency Response Incident System |
| 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 |

| | |
|-------------|-------------------------------------|
| NMI | Northern Mariana Islands |
| NVFC | National Volunteer Fire Council |
| PFAS | Per- and polyfluoroalkyl substances |
| PPE | Personal protective equipment |
| USFA | United States Fire Administration |

Certification Statement

I hereby certify that, to the best of my knowledge and ability, the foregoing minutes of August 22, 2024, meeting of the National Firefighter Registry of the NIOSH Board of Scientific Counselors, CDC are accurate and complete.

Signature:  Date: 10/24/2024

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