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FIRST MEETING

NATIONAL FIREFIGHTER REGISTRY (NFRS) SUBCOMMITTEE MEETING

May 15, 2020

The verbatim transcript of the

Meeting of the National Firefighter Registry

Subcommittee Meeting held on
May 15, 2020, 10:00 a.m.

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PARTICIPANTS

(alphabetically)

SHAWN BRIMHALL - MEMBER
CHUCK BUSHEY - MEMBER
DENNIS DEAPEN, DrPH – MEMBER
JOHN HOWARD, MD - DIRECTOR
SARA JAHNKE, PhD - MEMBER
BETSY KOHLER - MEMBER
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VIRGINIA WEAVER, PhD - MEMBER
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DR. MIRIAM SIEGEL
MS. ANDREA WILKINSON
MR. WILLIAM WEPSALA

INTRODUCTION, MEETING LOGISTICS

DR. MIDDENDORF: Okay, it's ten o'clock by my clock, so I think we ought to go ahead and start. Good morning. This is Paul Middendorf and I am the designated federal official for the National Firefighter Registry Subcommittee of the NIOSH Board of Scientific Counselors, and I want to extend a warm welcome to each of the subcommittee members and the (ECD @ 00:01:11) members and—and somebody needs to mute, and you probably want to turn off your computer speakers.

But I do want to welcome each of the subcommittee members and members of the public who have decided to join us. Thank you for being here.

I have a number of administrative issues that I have to deal with on the front end of our meeting today. First, wherever you are, I hope you are staying safe. And I will also ask you to make sure that you know how to exit safely from wherever you are in case of an emergency.

As I just mentioned, this is a subcommittee of the NIOSH Board of Scientific Counselors, and as such, it is subject to all the rules and regulations of the Federal Advisory Committee Act, so we will be following those for this meeting. As part of those procedures, we have to develop minutes for our meetings, and what we've decided to do for this meeting is that we will be recording and developing a verbatim transcript which will be posted on the subcommittee's website, and I want to make sure everyone is aware of that before we get into this.

I was hoping to turn this over to Dr. Howard—he had a few words he wanted to say to us—but I don't see him on the list. Dr. Howard, if you happen to be there…

DR. HOWARD: Yes, I am here.

DR. MIDDENDORF: Oh, okay. Great.

WELCOME

DR. HOWARD: Okay, well, thank you very much, Paul, appreciate it, and welcome, everybody. These virtual meetings are always a challenge, so we all have to have patience as we go through this, but you know, we've had a couple of successful ones, including our last BSC meeting, which was remarkably successful. So, we're getting good at this.

I want to thank all the subcommittee members, especially Grace and Pat for cochairing this very important subcommittee on the Firefighter Registry. I want to thank all of the folks that are on the line that have an interest in the Firefighter Cancer Registry. We really appreciate all your interest, and you know, I think we're all united in the purpose of the registry, which is to protect firefighters and give them knowledge, increase their knowledge about how to best prevent work-

related diseases that are part of the fire service.
And I certainly think that we have an extensive charge to the Board, a number of very specific issues that we'll hear about during the day from the folks in the program. I wanted to thank all the folks in the program, who have worked really, really hard since this legislation was passed, to bring us to this point. I also want to thank Paul and Emily and others that have been working very hard to put our subcommittee together. It's an important purpose that we're all gathered for, and I wish you a wonderful meeting, look forward to all the outputs that you generate from this meeting.
So thank you, Paul.

SUBCOMMITTEE AND NIOSH NFR TEAM INTRODUCTIONS

DR. MIDDENDORF: Thank you, Dr. Howard. I'll leave discussion of our agenda up to Pat and Grace when we get to that point, but I do want to mention that we have public comments scheduled to begin at 11:15 this morning but no one has signed up to provide public comments so we'll move directly into discussion of the protocol at that time.
The next thing I need to do is to do a roll call. That's one of the things that's required under FACA is that we have to do a roll call and we have to make sure that we have a quorum. So, when I call out your name, please come off mute and indicate your presence for the record. Forgive me if I happen to butcher your name. If I do that, please let me know how to pronounce it so I can say it correctly going forward. For this first roll call, I also need to state whether or not there have been any changes in your employment or interests that would affect your conflict of interest status since you filed the OGE-450 form about a month or so ago. I don't expect that there will be much but if there is, we need to be aware of it.
Also, since this is our first time sort of together, I'll ask each of our members to briefly introduce themselves. Please mute and turn off your speakers, please. Thank you.
I will ask each of our members to briefly introduce themselves and say a few words about themselves. I do want you to keep it pointed and brief so we can be sure to accomplish our primary goals of giving good advice and information to the program on how to develop a registry that can (inaudible @ 00:06:33) firefighters.
I'd also mention, members, if you have to leave at any point, make sure you let me know, and also let me know when you return. That's to make sure that we always have a quorum. And a quorum for the subcommittee is eight.
So with that, I'll go ahead and start, and we'll do it in alphabetical order. Shawn Brimhall.

MR. BRIMHALL: Yes, Shawn Brimhall. I'm here. No change in any of my employments that I've been told of. I'm the fire protection specialist at the State of New York's Division

of Homeland Security Office of Fire Prevention. I work predominantly in training and education. I'm also the state's lead advocate for the Everybody Goes Home Program for Fallen Firefighters, and I am also the CAST, which is the local Assistant State Team for line of duty deaths in New York. So, one job for Fallen Firefighters tries to put the other one out of service. I'm also a 38-year member of the Fire Service. I'm assistant chief with my local fire department, and we're expecting a lot of storms today so if I get to hear, I will let you know, but I will take (inaudible @ 00:07:45).

DR. MIDDENDORF: Thanks, Shawn. Charles Bushey.
Okay, I see that you've checked in, but we're not hearing you if you're talking, Chuck. Okay, we'll come back to Chuck. Dennis Deapen.

DR. DEAPEN: Hello, can you hear me?

DR. MIDDENDORF: Yes. Is this Dennis? Is this Dennis?

DR. DEAPEN: Yes, this is Dennis. I'm at the University of Southern California. I direct the SEER Cancer Registry for Los Angeles County, and have created a few cancer registries over my experience, and I'm glad to be here.

DR. MIDDENDORF: Dennis, has there been any change in your conflict of interest?

DR. DEAPEN: No, no change.

DR. MIDDENDORF: Thank you. Bryan Frieders.
Okay, how about Sara Jahnke?

DR. JAHNKE: I'm here. can you hear me?

DR. MIDDENDORF: Yes, we can.

DR. JAHNKE: Okay, Sara Jahnke, Director of the Center for Fire, Rescue & EMS Health Research. No change in employment, and really thrilled to be on this and think everything I've received so far has been fantastic. But been doing firefighter health research for a little over a decade.

DR. MIDDENDORF: Thank you, Sara. Betsy Kohler.

MS. KOHLER: Hi, I'm Betsy Kohler, I'm the Executive Director of the North American Association of Central Cancer Registries, working with all the cancer registries in the US and Canada. And no change in my employments either.

DR. MIDDENDORF: Okay, thank you. Grace LeMasters.

DR. LEMASTERS: Hello, I'm here. I am an occupational epidemiologist at the University of Cincinnati College of Medicine. There has been no change in my employment status, and I am very thrilled to be the cochair of this very important meeting. Thanks, everybody.

DR. MIDDENDORF: Thank you, Grace. Barbara Materna.

MS. NOVICKI: Paul, Barbara is having a little bit of trouble with audio. We're troubleshooting in the chat. But Chuck Bushey is on now.

DR. MIDDENDORF: Okay. We'll jump back to Chuck then, and hopefully Barbara can get her audio figured out. So, Chuck?

MR. BUSHEY: Morning, everyone. No change in my status. Past President of the International Association of Wildland Fire, mostly involved now with our European cohorts, and on the Western Region of the National Wildland Fire Cohesive Strategy. Keeping busy. Been busy in fire for fifty years now. Thanks.

DR. MIDDENDORF: Okay. Chuck, has there been any change in your conflict of interest status?

MR. BUSHEY: None at all, no.

DR. MIDDENDORF: Okay, thank you. Barbara.

DR. MATERNA: Yes, I'm in now. Can you hear me?

DR. MIDDENDORF: Great. Yes, we can hear you.

DR. MATERNA: Okay, great. I am at the California Department of Public Health, where I lead the Occupational Health Branch, and I'm an industrial hygienist by background, and I've had no changes in my interests.

DR. MIDDENDORF: Okay, thank you, Barbara. Brian McQueen.
Brian, if you're speaking, we can't hear you. Okay, we're going to go on to Richard Miller. Richard Miller.

MR. MILLER: Richard Miller with the International Association of Fire Chiefs, retired firefighter captain from the City of Fairfax in Virginia. No change in my status. I'm extremely honored to be participating with this group. I work in the research center for the International Chiefs on health and safety topics. Thank you.

DR. MIDDENDORF: Thank you, Richard. Pat Morrison.

MR. MORRISON: Good morning, everyone. This is Pat Morrison. I'm with the International Association of Fire Fighters. I'm Assistant to the General President for health and safety. Prior to that, I was with Fairfax County Fire and Rescue and spent my career in the fire service. I have no changes in my employment, no conflicts, additional conflicts at all. And I just want to say thank you for allowing this, for me to participate and really, I'm really pleased and excited to be working with Grace, who I consider one of the pioneers in firefighter cancer, and moving forward, this is going to be an incredible project, and I'm pleased to be part of it. So, thank you, Paul.

DR. MIDDENDORF: Thank you, Pat. Virginia Weaver.

DR. WEAVER: Good morning. I'm an Associate Professor at Johns Hopkins University in the School of Public Health. I am now in a part-time capacity, and my role here is that I've been an occupational medicine consultant for the IAFF, the International Association of Fire Fighters, for many years. I have no change in my status, and I'm excited to be a part of this.

DR. MIDDENDORF: Thank you very much, Virginia. Regina Wilson.

MS. WILSON: Good morning, everyone. My name is Regina Wilson. I am an active duty firefighter. I have 21 years on the FDNY and I am the past president of the United Women Firefighters Association as well as the local society, the African American society group of the FDNY.

DR. MIDDENDORF: Thank you, Regina. We're going to go back and check on the Brians, that seems to the issue, the Brians, either can't get in or they're having difficulty speaking. Bryan Frieders?
Okay. Brian McQueen? Again I see him checked in but he's not speaking. Ah, he says he's on. I see in the chat box. Okay, Brian, we'll mark you as here. If we can find a way to get audio to you, we'll ask you to introduce yourself.
Okay, let's see, that's one, two, three, four, five, six, seven, eight, nine, ten, eleven, twelve members present. That's definitely a quorum. So, let's move on. What I'd like to do next is have the NIOSH program team members introduce themselves, as well as the ad hoc consultants that the program team has invited. So, Kenny, if you want to take it.

DR. FENT: Sure. Can everybody hear me?

DR. MIDDENDORF: Yes.

DR. FENT: Great. So, my name is Kenny Fent. I'm a research industrial hygienist at NIOSH. I've been working at NIOSH for ten years now, and have been doing firefighter chemical exposure research over that time period. Right now, I'm team lead for the National Firefighter Registry, and I'm excited to introduce my team members, so starting with Miriam.

DR. SIEGEL: Hi, my name is Miriam Siegel. I'm an epidemiologist at NIOSH. I've been with NIOSH since 2017, and now I'm leading the epidemiology component of the National Firefighter Registry.

MR. MAYER: Hi, I'm Alex Mayer, health scientist from the National Firefighter Registry team. I've been with NIOSH since 2017.

MS. WILKINSON: Good morning, this is Andrea Wilkinson, I am a health scientist for the National Firefighter Registry. I've been involved in first responder healthcare and research for the past several years. My background involves cardiovascular physiology in both clinical and laboratory settings, and I just joined NIOSH in the last year. Prior to that, I was working as the project manager in the First Responder Health and Safety Lab at Skidmore College.

MR. WEPSALA: Good morning, this is Will Wepsala. I am a health communications specialist for the National Firefighter Registry, and I'm going to be doing outreach for the NFR, and I have been with NIOSH for four months.

MS. RAUDABAUGH: And I am Jill Raudabaugh, I am the data science team lead in the branch of the Firefighter Registry. I have been supporting health science research for most of my career, with NIOSH for at least ten years as a consultant, but a federal employee now. And just an honor to be on the NFR team.

DR. FENT: And Paul, did you want us to go to John Brasko next?

DR. MIDDENDORF: Yes, let's do that.

MR. BRASKO: Thank you, this is John Brasko. I am currently employed at the United States Fire Administration in our National Fire Data Center as a researcher. Right now, my

main work is in COVID-19, but also I have done some things with cancer. About 30 years of Fire Service experience in the volunteer and combination department as chief. Also worked with the New Jersey Division of Fire Safety where I did firefighter safety and health, as well as serious injury and fatality investigations. And currently, like I say, I'm at the US Fire Administration and I'm also a cancer survivor firefighter.

DR. FENT: And is Shane Greer on?

MR. GREER: Good morning, Kenny, I am. So, good morning, everybody, Shane Greer. I am currently the Assistant Fire Director for Risk Management in the United States Fire Service, Rocky Mountain Region. I'm also a qualified Type 1 incident commander and I've been working in wildland fire for 34 years now. I've also been working with NIOSH for the last several years and known Kenny for a few years and others working on the long-term health effects study of wildland firefighters. Good morning.

DR. MIDDENDORF: Okay, thank you all very much. Let's try this one more time. Brian McQueen, are you on and—I know you're on. Can you speak? Can you get through I guess is the question I'm really trying to ask?

Okay, we're still not hearing anything. Emily, I notice on my screen, Brian looks like, there's a telephone icon. I don't know if that means anything but I'd just point that out. Okay.

I think we need to move on to the next part of our schedule, and for that I'd like to turn it over to Grace and Pat, our cochairs.

AGENDA AND ANNOUNCEMENTS

MR. MORRISON: Grace, why don't you lead?

DR. LEMASTERS: Okay, well, Pat and I would like to also welcome you to our first National Firefighter Registry subcommittee, and to thank you for the work that you've already done in preparing for this meeting, including reviewing the proposal and all the appendices including the questionnaire, and providing comments regarding the proposal, which we'll be discussing in more detail today.

As you can see on the agenda, we will be starting with the NIOSH team, with Kenny presenting opening remarks and then Miriam giving us a protocol overview.

At 11:15, you see that we have public comments, and if there are none, we will continue on to addressing the questions that we were all sent, to bring—highlight and to bring forth that NIOSH in particular wanted assistance with, and then a couple more from Pat and I.

Then there will be time for our lunch break and if it's okay with everyone, we might limit it to one half-hour instead of an hour, as presumably we're all fairly close to food, working from home.

Then we'll continue on with a discussion of the project proposal, and then the questionnaire, a presentation by Andrea regarding the enrollment questionnaire, and then our own discussion about any issues we might have with this questionnaire.
I would just say that, in terms of announcements, again, I would remind everybody, if they would like to make a comment or have a question, to use your raise hand that you'll see at the top of the computer. You'll see a hand that's open. Just click on that. Or, the other option would be to write something in the chat box but we'd prefer you to use the raise hand first if you can.
Remember to keep your phone muted unless you are speaking. And I would just remind everybody, again, that this is being recorded. All of our comments will be recorded, and at the end of the—our next step will be to provide recommendations to the BSC committee, which we will be having a meeting July 14 to review these recommendations from the report.
Pat, do you have anything to add?

MR. MORRISON: No, thank you. I think, Grace, you did a nice job on just the overview and again, Grace and I are both really pleased of the people we do have on here. We have some really leading experts around the country. This is probably the most anticipated registry that I know of in my career in the Fire Services. Every firefighter out there is looking at this and waiting for this to be rolled out.
So the role that everybody has here is extremely important, and we have a shot to getting it right, and today is really to clean up anything that we feel might be necessarily not what we want to do as the direction. So, there's going to be a lot of questions, and I look forward to the participation, and Grace and I both do.
So thank you and Grace, I think we can turn it back to the program directors.

DR. LEMASTERS: Yes, I agree. Kenneth, Kenny?

TEAM LEAD OPENING REMARKS

DR. FENT: All right. So, Emily—oh, I see I have control now.
Well, good morning, everybody, and thank you for taking time out of your very busy schedules to meet with us. And we know that everybody who is involved in this committee has, you know, expertise and experience that we think is extremely valuable to what we're trying to accomplish.
I know that many of you are probably directly involved in COVID-19, and as are many of us that are part of the program. COVID-19 of course is a very serious and important issue, but occupational cancer is also a very serious issue, and it's something that NIOSH is committed to addressing in workers in general, but in firefighters as well.
So the National Firefighter Registry is still a work in progress, as you all know. We have been working very diligently over the last, actually, over a year. We

have a protocol that I think everybody on our committee has seen, and that's really the purpose of why we're here today.

So for my talk, I just want to really give a brief introduction and some background information about the National Firefighter Registry and what we're hoping to accomplish.

So the National Firefighter Registry is being created because of legislation. The Firefighter Cancer Registry Act of 2018 was signed by the President back in 2019, and really the motivation behind the Act is that, while studies have shown that there's an increased risk of cancer, some types of cancer, in firefighters, there is still a lot of questions that remain.

Most of the studies that have been done to date have been limited by small numbers of women and minorities, or have generally lacked information on volunteer firefighters. Also, many of the studies involved firefighters that were employed decades ago and, as you're well aware, the Fire Service has really changed, especially over the last ten years.

So the bottom line is no national data sources exist that combine firefighters' exposures and cancer outcomes. That's really important if you want to study cancer risk in the Fire Service.

And so the goal of the NFR is to track firefighters' cancer risk over time so that we can better understand that link between their unique workplace exposures and cancer outcomes.

So we want the National Firefighter Registry to be inclusive. We really want it to be open to all firefighters regardless of their position, regardless if they're active or retired, and also regardless if they have cancer. There is a misunderstanding out there in the Fire Service and even in the scientific community that you have to have cancer to register, and that's not what this is. This is really an occupational registry or an exposure registry. And you know, we're especially interested in recruiting minority, female and volunteer firefighters which are specifically called out in the Act, but we're also interested in all the subspecialties of the Fire Service like instructors and wildland firefighters and fire cause investigators among other groups, and many of those groups have not been studied at all with respect to cancer.

Our goal is to try to enroll 200,000 firefighters. That is an ambitious goal, but we also think it's achievable and, if we're successful, we think we'll have enough power to really look at some of the different types of cancer and make comparisons among firefighters within this population.

So we want the registration process to be as simple as possible, but we also want it to be extremely secure. So, we are in the process of developing a web portal that any firefighter in the country can go to to register. It will involve two-factor authentication. I'm sure many of you are familiar with that type of login where you

might enter an email and then a phone number, and you might get a text message to authenticate yourself.

This is a voluntary registry, so it will require informed consent, and then we want to also collect some basic information from the firefighters at the time of the registration including demographics, their work history and exposures, use of control measure over time, and also other important risk factors and confounders for cancer.

We're also interested in doing follow-up questionnaires so that we can longitudinally evaluate some of those risk factors over time in this population.

And then as I said, we want the information we collect to be protected, and we're going to protect that information in accordance with strict federal privacy laws, and we'll talk more about how we're going to do that in the later slides.

So we realize that the last thing that a firefighter wants to do if they are diagnosed with cancer is to report their cancer to a federal agency. I think that's the last thing anybody wants to do if they develop cancer. And so we want to try to collect as much information from the firefighters so that we can link to state cancer registries. So, cancer is a reportable illness in the United States and so anywhere, in any state where you have a cancer diagnosis, that diagnosis is reported to the state cancer registry. And so we'll be able to link the firefighters in the registry to those state cancer registries, and then that information can be used to determine cancer incidence.

We are also interested in linking to the National Death Index for any firefighters in the registry who die, which provides information on cause of death, and that can be used to determine cancer mortality.

So some of the questions that we think the NFR will be able to address, of course the most obvious is how much cancer and the different types of cancer among firefighters and how that compares to the general population. But we're also interested in some internal comparisons. How does cancer differ among different groups of firefighters, with the use of control interventions which have been increasing over time in the Fire Service, how does cancer risk vary geographically, and then, importantly, how does cancer risk vary with increasing exposures? And that would include those major events that we hear a lot from the Fire Service, those, you know, industrial fires or natural disasters, whatever they might be.

And then also, we'll be able to gather some information on workplace practices, which is also valuable to the Fire Service. What practices are currently in place in the Fire Service and how have those changed over time?

So the last thing that we want to do is to work in a little bubble so, as we do develop results and recommendations, we'll publish those in peer-reviewed journal articles but we also want to make sure we get the information out to the

Fire Service and our stakeholders and people who can actually make some positive changes in the Fire Service with that information.

And then we're also required through the Act to be able to share the data that we collect with external researchers, and so we're in the process of developing a mechanism to be able to do that, to share the deidentified data with researchers.

We do think the findings will have the potential to inform interventions and training, various practices and policies, possibly even cancer screening programs in the Fire Service. But also, we think that the registry also has an opportunity to just raise awareness among firefighters of cancer and cancer risk factors. If we are able to register 200,000 firefighters or more, that's a large percentage of the Fire Service that we will have contact with, and we can share all the current evidence, scientific publications and evidence that's out there, with the Fire Service.

And our long-term goal, really of anything that we do at NIOSH, is prevention, right. So, our long-term goal is to try to reduce occupational cancer for firefighters.

So this last slide is really just to give you a very brief overview of our timeline, where we're at right now. You know, the first year of funding was 2019 but that was really just to get our bearings, you know, hire our staff and do some basic research on how to do this kind of registry.

And now, here we are in 2020, and we really are starting to make some significant progress on establishing the registry, and of course an important part of that is our protocol.

Between 2021 and 2023, we hope to start recruiting and enrolling firefighters, and collecting information through that enrollment questionnaire, but also through records that we think we can get through fire departments, incident records or exposure tracking data from firefighters. And that is an ongoing enrollment, so that will continue past 2023.

And then 2024 and beyond is when we hope to start disseminating some of those initial findings.

I do want to mention that because cancer does have a long latency period, and because the registry is going to be a prospective project, it will take a number of years before there are enough cancer diagnoses to draw some conclusions about those cancer risks, but we do think that we'll be able to publish some initial findings even before then.

And at this point, I will turn it over to Dr. Miriam Siegel, and she'll tell you more about the details of our protocol and design.

DR. SIEGEL: Okay, this is Miriam. Grace, were you going to revisit some of the questions about the design prior to this section or should I go ahead?

DR. LEMASTERS: No, why don't you go ahead and provide an overview, as you had planned to do,

and then we will get to the questions after that?

DR. SIEGEL: Okay, that sounds good. That works for me.

DR. LEMASTERS: Is that all right?

DR. SIEGEL: Yes, no problem.

DR. LEMASTERS: Okay.

DR. SIEGEL: So I'm Miriam Siegel and I'm going to give an overview about the protocol itself and the design that we have proposed.

As Kenny mentioned, the main goal of the NFR is to develop a voluntary registry of firefighters to collect health and occupational information for determining cancer incidence and risk factors.

In the protocol, we outlined three primary objectives for accomplishing this. One, collect self-reported information on workplace and personal characteristics through an online web portal. Two, obtain records from fire departments or agencies to track trends and patterns of exposure. And three, link with health information databases including population-based cancer registries and the National Death Index, to detect cancers and deaths.

So I'm now going to discuss how we plan to carry out these objectives. And I don't believe I have control over the slides yet.

MS. NOVICKI: You do, Miriam, you should see little arrows in the bottom left-hand corner.

DR. SIEGEL: Okay, give me one second. Oh, here we go. I had to scroll down. All right, no problem.

So I'm going to start off with our proposed plan for recruiting firefighters. We're proposing two subgroups of the NFR population: a targeted cohort and an open cohort.

The targeted cohort will be a sample of currently active firefighters from selected fire departments or states. We'll partly be able to use the targeted cohort to focus efforts on groups specified in the Act, including women, minorities and volunteers. This subgroup will register through the web portal and will also contribute incident record information that we obtain from the departments, states or other record systems.

The open cohort will include any members of the US Fire Service, including active, former and retired members, both paid and volunteer. All members of the open cohort will register through that same web portal.

The targeted cohort will provide the population at risk required for assessing cancer incidence rates. Because of the eligibility criteria implemented for this group, we expect reduced selection and participation bias. We'll also obtain some incident and department-level information for this subgroup to serve as exposure data that complements self-reported information obtained in the web portal. We'll be able to assess response characteristics of the open cohort using information from the targeted cohort as comparison. Obtaining the targeted cohort will be

relatively cost- and labor-intensive, however, and because of cancer's long latency period, it may take some time to detect robust estimates of cancer risk.
The open cohort involves a non-probability sample for which all current and former firefighters are eligible. It's the best method for recruiting a very large and inclusive sample that is diverse by firefighting characteristics. Recruitment for the open cohort will be much less resource-intensive than the targeted cohort. The open cohort's large and diverse sample will allow for many earlier analyses, but because there are no exclusion criteria, the open cohort is subject to selection bias. For example, firefighters that have had cancer may be more likely to participate. Additionally, the exposure information for a majority of this subgroup will be limited to self-report.
We've proposed methods for recruiting firefighters into both subgroups of the NFR. Our sampling design for the targeted cohort will involve a combination of two sampling frames: selecting fire departments, and selecting states that require regular recertification or documented training of all practicing firefighters in that state. Both sampling frames offer comprehensive rosters of current firefighters from which we can recruit. Only a handful of states require recertification of all firefighters, and we may be open to include any of their rosters for active NFR recruitment. But because there are roughly 25,000 fire departments in the US, we need to have a strategy for which departments we invite to participate.
This sampling strategy will need to ensure adequate representation from female, minority and volunteer firefighters, which is the reason for Phase 1 of the proposed sampling design. But the samples should also be diverse geographically and by department characteristics to maximize generalizability of the findings, which is the reason for a stratified random sample in Phase 2 of the proposed design.
In Phase 1, we will consult with stakeholder groups, as well as data on workforce demographics such as those available from NFPA, USFA and individual fire department statistics, to identify departments with large numbers of women and racial/ethnic minorities. We will also work with stakeholder groups to identify departments with a large volunteer workforce from all four regions of the US. We chose four large geographic strata because identifying large volunteer departments that are willing to participate may be challenging in nine smaller geographic divisions.
In the Phase 2 stratified random sample, we will select departments from nine geographic divisions of the US defined by the Census Bureau. Within each of these regions, we will first select career departments with at least 100 fire personnel that are both large and small, based on a threshold of 100,000 population served. Second, we will select volunteer departments without size restrictions from each geographic division.

We used estimates for a hypothetical cancer incidence analysis, informed by results of the Three City study to estimate minimum sample sizes necessary for the targeted cohort. These minimum sample size benchmarks require at least 1,000 women, 6,500 nonwhite firefighters, and 5,000 volunteer firefighters at baseline, to detect elevations in breast cancer or all cancers in comparison to the general population after 30 years of follow-up.

Assuming roughly 50% participation at departments, we estimate that we would need approximately 135 individual departments to participate in the targeted cohort to achieve these benchmarks. However, if one or more states contribute their certification rosters, we can reach these sample size benchmarks with less individual departments. But department participation is critical for assessing incident records from a majority of those in the targeted cohort.

We will strive for a much larger sample size than these benchmarks to the extent possible, as larger sample sizes will be needed to examine more granular subgroups and cancers.

The open cohort will involve firefighters from a wider net, and will likely include many more firefighters than in the targeted cohort. The open cohort presents a great opportunity for enrollment of members from wildland, instructor, arson investigation, airport rescue, federal and other sectors. All participants will consent and enroll through the web portal just like the targeted cohort.

If there are groups of the targeted cohort—if there are groups of the open cohort that have high participation from active rosters, we may analyze them as part of the targeted cohort and potentially request incident records. For example, if a large department that wasn't selected as part of the targeted cohort has high participation in the open cohort, we could combine information from these members to those from the targeted cohort since selection bias may be limited.

We anticipate recruiting firefighters into the open cohort by disseminating materials through departments, stakeholder groups and online communications. We will also be presenting at professional meetings and planning visits at some meetings where firefighters can obtain information and enroll on the spot.

Now onto the enrollment process itself. Individual enrollment into the NFR for firefighters both in the targeted cohort and the open cohort will involve providing consent, in addition to self-reported exposure, demographic and lifestyle information in the online web portal.

NIOSH will be able to use the information voluntarily provided by participants who enrolled to carry out the other objectives necessary for monitoring cancer incidence and risk factors. These include periodically linking with state cancer registries and vital status databases to detect new cancers or deaths, administering follow-up questionnaires to participants through the web portal for more detail on workplace or risk factor information longitudinally, connecting

continued engagement to keep participants informed and their information up-to-date, and potentially collecting additional exposure data from employment records and/or exposure tracking platforms when applicable.

To enroll as part of the open cohort, an individual firefighter will make an account, provide consent, and complete the questionnaire in the web portal.

The process for enrolling individuals in the targeted cohort will be a little more complex. First, selected departments or states will provide NIOSH with contact information for their entire active roster. NIOSH will also request department incident records dating back to at least 2010 and preferably older when available. The rosters and incident records don't need to be sent together, but the rosters are critical for the next step.

Using this contact information for active rosters, NIOSH will assess if individual firefighters have already enrolled on their own; otherwise, NIOSH will contact individuals to invite them to enroll.

Contacted firefighters will either consent and enroll through the web portal, or they will be unresponsive or choose not to consent. In the latter case, NIOSH will not use any of their individual information and they will not be included in the National Firefighter Registry.

This process will be repeated for the targeted cohort every few years to obtain the updated incident records and to recruit new firefighters since the last date records and rosters were shared. We anticipate enrollment being continuous for the open cohort.

There are some potential limitations to the proposed design. The generalizability of the NFR may be impacted by participation bias, especially if participants are more likely to have had cancer or associated risk factors, as well as small sample sizes, particularly for rare cancers or specific firefighter subgroups.

There will be some considerations for NFR analyses. Exposure response analyses will be affected by record availability for example. Self-reported exposures and behaviors may be subject to information or recall errors that affect accuracy. Healthy worker biases will also need to be considered, as firefighters are, in general, a more healthy population than the general population and firefighters that are eligible to participate in the NFR must still be alive or, in the case of the targeted cohort, still in active duty, which means we won't be able to capture firefighters that may be most effective—affected.

Lastly, because of cancer's long latency, it may take some time to detect robust estimates of cancer risk. Regardless, we hope to develop a platform that allows Fire Service and scientific communities alike to better understand the burden of cancer among firefighters, and inform methods for reducing cancer in the Fire Service. Okay.

DR. LEMASTERS: Thank you very much. That was very comprehensive and clarifying from the

proposal, and provided us with a lot of important information. So, thanks very much, Miriam.

I guess we have another speaker, Alex Mayer on data sharing.

MR. MAYER: Yes, thanks, Grace. Any questions before I move on? All right, I'll go ahead and get started.

Hello, my name is Alex Mayer, health scientist on the National Firefighter Registry team. Today I will be discussing the data sharing aspect of the National Firefighter Registry.

I would like to start by reviewing the Firefighter Cancer Registry Act of 2018. Specifically, the Act stipulates that NIOSH must ensure that information and analysis in the Firefighter Registry are available to the public, including researchers, firefighters and National Fire Service organizations. This means we are required to make data publicly available.

The law goes on to say that NIOSH must protect personal privacy to the extent required by applicable federal and state privacy laws. This means we are required to protect firefighters' privacy.

These are two of the things we are trying to balance when making decisions regarding data sharing. When we couple these requirements with the fact that we also need to obtain Social Security numbers from firefighters to match with the cancer registries, we realize that a strong statement of confidentiality is required. To sufficiently address these conditions, the NFR team has decided to obtain an assurance of confidentiality or AOC. An AOC is the highest level of protection allowed by the federal government and will allow us to assure participants, fire departments and other institutions like state cancer registries that NIOSH will protect the confidentiality of the data collected.

As outlined in the protocol, we have identified three uses for data. The first use is the main goal of the NFR, which is to monitor trends in cancer incidence among the US Fire Service. The second use includes any secondary purposes related to noncancer—excuse me one sec—noncancer research aims. Examples of noncancer research aims could include examining reproductive or cardiovascular health among the Fire Service. The third use is approved secondary research purposes proposed by external investigators and collaborators.

In order to allow external researchers to analyze NFR data, however, we need to come up with a data sharing mechanism. We know this is an important issue, and are currently developing a plan for sharing data. One option could be a research data center or RDC, which is a federal data center responsible for protecting the confidentiality of survey respondents while providing access to the restricted use of data for statistical purposes. This is something NIOSH has used previously when sharing sensitive data with external researchers. It's worked well for us and is something that we'll definitely consider for the NFR.

If we go this route, a proposal to the RDC will be made by external researchers. The proposal will be reviewed by the RDC, NIOSH and any state cancer registry mentioned in the proposal. If it's approved by all parties, the appropriate data file will be provided to the RDC for analysis. Again, this is something that NIOSH is considering to fulfill data sharing obligations.

Lastly, we would also like to make it possible for external researchers to contact participants from the NFR to solicit their interest in an outside study. In order for this to happen, external researchers will be required to make a proposal to NIOSH. NIOSH will then be responsible for reviewing and approving of all requests. Once NIOSH has approved the proposal, the NFR program will be responsible for re-contacting participants who said they were interested in follow-up studies to solicit their interest in participation. Once the participant shows interest, the NFR will connect the participant with the primary investigator for the new study.

And now I'd like to pass is on to Will Wepsala.

DR. LEMASTERS: Before we move on, if there's any of the committee members have any immediate questions for, regarding the data sharing? I don't see any as I'm scanning down here. I just had one brief one, Alex.

MR. MAYER: Sure.

DR. LEMASTERS: In the informed consent, did you—is it mentioned or will you be mentioning that these data may be shared with outside investigators?

MR. MAYER: Yes, we will—

DR. LEMASTERS: Is that part of your consent? I don't recall.

MR. MAYER: We will be including that in the informed consent, yes.

DR. LEMASTERS: Okay, very good then. Anybody else have a question? All right, thank you very much for sharing that with us. Next we have a communication plan.

MR. WEPSALA: Yes, thank you.

DR. LEMASTERS: Will.

MR. WEPSALA: Again—thank you. Again, this is Will Wepsala, health communications specialist for the National Firefighter Registry and leading the outreach. I'm going to talk about the communication plan we have set up for the NFR.

We have a number of communication goals. First and foremost is raising awareness of the NFR. We want to get the word out, and we want to put it on firefighters' radar to know that we're getting ready to set it up, and then once it's started, to let them know that we are running it.

And as part of that, we also want to clarify the scope of the NFR. As Kenny mentioned, there have been some misconceptions, one of which would be that you have to have cancer to sign up, or that you have to be an active firefighter. And we hope that clarifying the scope will also highlight the need for the NFR. We want to show firefighters the benefits of a better understanding of cancer in the

Fire Service, could possibly lead to some better protections.
And ultimately, we want to encourage firefighters to sign up. This is the ultimate goal of the NFR and that's going to help the success of the project.
We also want to encourage firefighters to share information with each other. We know that firefighters use social media and are engaged with it, so we want to encourage conversation within the community that could lead to more of them signing up for it.
And we have a number of communication tools to meet those goals. One of the first is focus groups and online surveys. We were planning to do focus groups in person, to speak to firefighters to test messaging and see what it is that they are looking for, but given the COVID-19 situation, that is unlikely to go forward as in-person groups so we are now exploring the option of doing online focus groups or surveys.
We're also going to be using social media. As I mentioned before, we know that firefighters are active and engaged on social media, so we'll be using dedicated channels or using currently existing CDC/NIOSH channels to get the word out.
We'll also be doing publications, one of which would be a brochure that we can hand out at conferences or other events, and that we could also send to interested fire departments.
We'll also be doing videos. Currently we're working on an introductory video to introduce the program that we can share on social media, and also hopefully could use at different events that we attend or, if we can't attend, have it in lieu of attendance. And we'll be attending conferences. Again, with the situation with COVID-19, we understand that in-person conferences probably won't be happening any time quickly but you know, as the project moves on, we'll continue to explore that and do what we can with what is available.
We also have started a quarterly newsletter that's available and you can sign up for that on our webpage. We have, as I have listed below, we have a webpage for the National Firefighter Registry which has information including the signup for the quarterly newsletter, as well as a website for this subcommittee which will have all of the meeting information as well.
And I'm not sure, Emily, am I sharing my screen right now? I was going to show the website. Oh, there it is.

MS. NOVICKI: Yes, go ahead now.

MR. WEPSALA: Okay, is that working? So, here is the National Firefighter Registry website and as you can see, you can subscribe to the quarterly newsletter here, just drop in the email address and that will work. And then for the subcommittee, we also have this website active. And if you go down, we have the charge but also, importantly, we will update this information for meeting details as the meetings move forward. So, we'll have the agendas and the time and the information for

calling in.

All right. Thank you, I need to—okay. All right, thank you, Emily, and that's—we're finished. Next I'll hand it over to—or we'll be doing this. Oh, and Grace, I'll hand it back to you, Grace. Thank you.

DR. LEMASTERS: Okay, thank you. I don't think we get to the enrollment questionnaire till later in the day, but thank you for sharing that information and plan that you have put forth. I'm sure COVID-19 has caused you to rethink a lot of different approaches than what was originally planned, so that can certainly be a challenge, but maybe can also be an asset where you're communicating multiple things perhaps.

I think we're ready—we're a little ahead of schedule, which is a good thing as we have a lot to cover today. So, we can begin with the public comments, if there are any. Paul, do we have any public comments?

DR. MIDDENDORF: No, no one signed up to give any public comments so we can move on.

MS. NOVICKI: Excuse me, it does look like Regina Wilson has raised her hand.

DR. LEMASTERS: Okay, let's—thank you for keeping an eye on this. This line is so long. Yes, Regina?

MS. WILSON: I have a question for the last speaker in reference to, I guess, the enrollment process. When doing outreach, have you considered finding out if the departments will allow you to put up posters around the firehouses to let them know that the registry is happening? And also what we have in the department here is something called Diamond Plate, which we use as an educational tool in order for us to go online and download videos and look at classes, and do certain things within our kitchen in the firehouse. Is there ways that you could see if the department would allow you to get your videos placed inside of the firehouses or have them consider, since you might have a problem especially with the COVID, is to see if they could talk about this as a part of their daily drills so that they can get the word out and trying to enroll people within the different firehouses?

MR. WEPSALA: Great, thank you for the question, Regina. I don't think that we have considered putting up posters in fire departments but that would be an excellent resource, especially given our current limited capacity for doing outreach. So, I think that definitely we'll follow up with that and explore that possibility.

And in terms of the Diamond Plate or other educational tools for sharing the videos, as well, I was not aware of that but that's definitely something that we'll look into, especially as we have those products ready to go and share. So, I appreciate that, and I will follow up on that. Thank you.

DR. FENT: And just—this is Kenny, just to piggyback on that—we have talked with some of the training directors of fire academies throughout the United States, and there appears to be some interest with new recruits, providing some information to the new recruits that are coming through the training academy. So, similar to that, as another option to get the word out.

DR. LEMASTERS: I think we have another hand raised, with Judith Graber. Judith, did you have a comment? I think she took her hand down. Don't be shy.

DR. MIDDENDORF: Grace, do you want to play out—

DR. GRABER: Can you hear me?

DR. LEMASTERS: Yes, we can hear you.

DR. GRABER: Can you hear me? Sorry, it took me a minute to find my microphone. This is Judith Graber from Rutgers. Thank you. And I also thought of Brian McQueen on my comment that I would really encourage you to be thinking about different strategies for volunteer firefighters, who are not always spending time at the firehouse. What we've heard from the fire chiefs of volunteer companies we've been talking to is that they are happy to do outreach for the NFR, and so thinking of ways to get information to them just, so those outreach facilitators I think is something to keep in mind.

MR. WEPSALA: Okay, great. Thank you for that comment.

DR. GRABER: Thank you.

MR. WEPSALA: We will definitely keep that in mind for reaching out to volunteer firefighters. Thank you.

MR. MORRISON: Hey Grace, this is Pat. Will, thank you so much for that. That communication plan seems to be extremely robust, and I really like it. I think even the last comment, I kind of want to tie in just a question. You said you were going to do focus groups or surveys. In your focus group, and let's just say you do an online focus group, how many would you use in a focus group at one time?

MR. WEPSALA: Thank you for the question, Pat. We've been working with a contractor, and their initial plan was to do focus groups at large conferences, and I think that the original plan had been to do around ten to twelve at a time. So, as we move forward, clearly there won't be any large in-person conferences coming up any time—we were hoping to do them this summer actually—but so as we explore the online focus groups, we understand there is some capacity to do that, or else online surveys. I think that we will probably, again, aim for the ten to twelve range of participants. Thanks.

MR. MORRISON: Yes, I think that's still, I think in this case here, it will still be really possible to do some online focus groups, especially in the world that we're in right now, it would better to—since everybody is online. And I think it gives the company that we're looking at, which I am really pleased to hear that you have some outside consultants coming in and looking and asking those questions, because I think in the group, especially in some of these populations, and even the volunteer population, the question that was just asked is really important to understand some of their environment, which is different in a lot of cases, and communication. And I think we would be very surprised as to how they do communicate in some areas, and using the best medium is going to be important

for those, and especially for those populations that we're going to have to target, not the open but the targeted too, so that's going to be important. So, thank you for that.

That's it, Grace, I'm going to turn it back to you.

DR. MIDDENDORF: Grace and Pat, this is Paul. Did you want to move into the communication questions now that the program had?

DR. LEMASTERS: Yes, we do, but I do see a comment from Lauren Barton and Brian McQueen. Lauren Barton says, "Why are volunteers part of the targeted cohort instead of the open cohort?" Can someone address that?

DR. SIEGEL: Sure, this is Miriam, I can take that question. They're actually going to be eligible for both cohorts. For the open cohort, any volunteer or any member, current or former, of the Fire Service is eligible to participate. So, if a volunteer firefighter is interested, we encourage them to just go ahead and sign up in the web portal once it's up and running. The targeted cohort will involve a little more assertive work on our side where we are identifying fire departments or states, both volunteer and paid firefighters to participate. Is that clear? Does that answer the question at all?

DR. LEMASTERS: Okay, thank you.

DR. FENT: And I can just follow up with that a little bit. You know, everybody would be enrolled through the same process. So, the web portal will be the way that we register any firefighter regardless if it's open enrollment or the targeted enrollment. And because of that, if firefighters are really gung ho and they want to register, there's no reason for them not to register. So, if you had a bunch of firefighters in a department and they ended up being, that department ended up being in our targeted cohort, that's okay because we'll know once we start working with that department, oh, that those firefighters have already registered, and we're still getting the same information that we would need to get from them.

DR. LEMASTERS: Good. We have hands up but there was a comment from Brian McQueen first. It says, "Communicating this is crucial and we can assist at the NVFC." Do you have any comment to that?

DR. SIEGEL: I would just say thanks, Brian. We will definitely be taking you up on that offer for getting this message out to our volunteers because that's certainly a hurdle that we are anticipating is getting in touch with so many of them…so thank you.

DR. MIDDENDORF: And Grace, let me ask Brian. Brian, are you able to be heard in the meeting now? We did some things to try to help him but apparently not, so okay. Sorry, Grace, go ahead.

DR. LEMASTERS: Oh, that's fine. I see three hands. We'll go with Judy Graber. Can you tell us your question please?

DR. GRABER: Oh apologies, my apologies. No, that was just my hand from the last time. I'll take it down. Thank you.

DR. LEMASTERS: Oh, okay. And how about Betsy Kohler?

MS. KOHLER: Hi, I had a question about study design and the targeted populations. I see that we're going to have a special outreach to women. I was wondering if there was any consideration to outreach to firefighters who began or had exposures at a young age, as teens in some of the cadet programs, and other methods? Because their exposures may have different effects biologically than in adults, and I was wondering if there was any planned targeted outreach to young people.

DR. SIEGEL: Yes, this is Miriam. We are absolutely interested in participation from young people, not only those that started their career young and have exposures that may have occurred quite a while ago when they were younger. We're hoping to ascertain information on that, as well as firefighters that are young now and just entering their careers, and we'll hope to follow up their exposures that are occurring now as well as in the future. And we are also hoping to collect information on any major incidents of large exposures that could have occurred, and I think one of our discussion points later on might relate to the best methods for us to obtain some of that exposure information and conducting that exposure assessment. But absolutely, we'll be interested in firefighters that were exposed all throughout their lives, and certainly we recognize that exposures that happened when they were younger might be most influential in cancer development.

DR. LEMASTERS: Okay, thank you very much, and I see, Betsy, if you want to take your hand down, and that will leave one hand remaining. Regina Wilson please?

MS. WILSON: Okay. Just two things, one, going back to the enrollment and the posters, I think it has to do a little bit with enrollment and probably recruitment too. Has there been any thought to if you decide to place posters up, which I think might be a good thing for people coming in and out of tours and shifts, and getting into the firehouse and you know, may only be there for a limited amount of time but haven't had an opportunity to hear about the program, to possibly have like a Scantron on the posters so that they can just scan it on their phone and take it with them when they go, and it'll have a link to the website, from the poster?

MR. WEPSALA: Sure, thank you, Regina. That's another great question. We had discussed using a QR code/Scantron for linking to the web portal once that goes, and certainly as we explore the poster route, we could talk about putting that onto the poster once it's ready. But definitely I think that the poster idea is excellent and as we find people coming in and out, it would be a great way to get those people. So, thank you.

MS. WILSON: Okay, and also I just wanted to know, is there a specific face of an outreach team that is going to talk about the enrollment or the rollout of this plan? And if so, is that group diverse?

DR. FENT: This is Kenny. I can take that one. So, we're actually in the process right now of

developing our outreach team, if you will. We're looking at having conference booths and other things set up where we can enroll firefighters at those largely attended conferences or other events. And one aspect of that that is very important is having staffers at those booths, or spokespeople, who are diverse. And so that's actually something that we are actively pursuing. We want to make sure that—and not just at those conference booths, but in a lot of the promotional materials. We're trying to select photographs and other things that really represent the diversity that is within the fire service, so that is a very important part of what we're doing.

DR. LEMASTERS: Okay, thank you, Kenny. Regina, would you mind lowering your hand so we don't get confused? I think we're ready to go to, Paul, the questions that the program would like input from the committee, some critical input from the committee. And we decided to do that during this initial session of public comment. So, if someone can bring up those questions that the program had—and then the co-chairs had a couple of questions, two or three questions also, of overarching issues.

DR. MIDDENDORF: So Emily, would you be able to forward the slides to that section?

DR. LEMASTERS: Okay, thank you.

DR. MIDDENDORF: We will come back to the questionnaire section when Andrea does her presentation.

DR. LEMASTERS: Right.

DR. MIDDENDORF: There we go.

DR. LEMASTERS: There we go. And Pat, you were going to lead off this communication and enrollment issues, and we hope all the firefighters that are on this committee can really help us with, and help NIOSH with answering some of these questions.

MR. MORRISON: Thank you, Grace. We can start with this. We started that conversation. I think that's why Paul was saying, the first one, the question that we had and would like—what are the most effective routes for communicating the enrollment process, data security and confidentiality, and why the NFR program needs access to certain types of records?

So what we'd like here, if you can, and even the non-firefighters, if you want to participate in this—we started doing this in some of the earlier presentations we had to clear up a couple of things. And then, I think Will did a nice presentation on the communicating. But I think for the fire service, and what's going to be important for us in communicating this out, two things that are really going to—I think, data security and confidentiality; I think that was addressed a little bit, but we can talk a little bit more about that.

And then the records, the type of records, that we're going to need. And those were those records, those call runs, the exposure records; we could sit here for another hour and talk about the individual firefighters that are capturing their own

exposure. Fire departments should have exposure protocols when they're using different types of systems software apps to make sure they record that.
So if you have some questions, just so we can continue that communication line that we had a little bit earlier, are there bridges or are there things that we're going to have, hurdles, that we might not have seen or we're going to stumble over, that sometimes you get out there and you think you've got the best plan, and all of a sudden there's a barrier there? That's a little bit of that we want to talk about. What are some of those barriers, and how do we get over those barriers? If anybody has a question on, or if anybody has concerns about that first question, go ahead and start to get in the queue. Just raise your hand, and we'll start taking some of those. For NIOSH, and I'll turn it over to Kenny here in just a little bit, too. Kenny, do you want to expound on that? We don't see anybody in the queue just yet, but we'll do that. Can you just expound on that a little bit, Kenny?

DR. FENT: Yes. Happy to. I think one of the big barriers that we see, and that we've heard from our stakeholders, is because it's necessary for us to collect Social Security numbers. How do we communicate why that's important? We know that firefighters may have some hesitancy of providing that information, but it's critical—I think many of the folks on this call can understand why we need that. That's really the only way that we can accurately link firefighters to those state cancer registries or the national death index. It's the only way we can really do what we're required to do under the legislation. But it's a potential barrier for enrolling firefighters.
So how do we communicate the need for that information? How do we communicate—we're going to be obtaining an assurance of confidentiality, which is the highest level of security that any surveillance project can have. How do we communicate that your information is going to be protected to that very, very high level? Those are some of the communication kinds of questions that we have, and it would be great to hear from the fire service what your thoughts around those.

MR. MORRISON: I guess firefighters are never shy at other points of the time, but I think right now, we have –

DR. LEMASTERS: We have three hands up.

MR. MORRISON: Okay, I'm sorry. I'm not seeing those on my screen. Grace, do you want to call on those hands?

DR. LEMASTERS: Yes. Regina Wilson, Richard Miller, and Sara Jahnke. Those three.

MR. MORRISON: Got it. It didn't come down. I see that long list. So, Regina, go ahead, you start, and then we'll go with Richard, and then we'll go with Sara. So, go ahead, Regina.

MS. WILSON: Okay, so I guess the first question was some of the most effective routes for

communicating the enrollment process. I know that you had on there social media. I just encourage you to use all forms of social media, definitely IG because that's what a lot of people are using now. And I know with Facebook, sometimes they have, if they see that there's an interest that you have, you will have pop-ups, and I think the pop-ups of the registry, if we can get that somehow to come up on the IG and Facebook, and all those other media outlets to remind them that this registry is here, because they might forget about the registry. But if it keeps popping up on their timeline, they have no choice but to see it.

Also, I think texting is a good route, because not a lot of people read their emails anymore. So, if there are text messages that could go out to everybody, it might be useful and helpful as a part of the registry portion of it, or if there's anybody that has questions or are interested. And I think one of the most valuable pieces is for you to try to get to the level of the affinity groups and these chapters out here that have organizations, especially getting buy-in from women's groups and people of color. I know this is going to be a hard sell because this is a federal-based survey, and dealing with Social Security numbers and trusting the federal government with information and getting that out—if you get buy-in from these affinity groups to help you to push this message and to relay to them more on health and safety, and I think that leaving in the protocols, seeing the importance of participating in their own health, and their own wellbeing and being a part of that process, that has to be a real key point in order for firefighters to see any validity to it. You have to explain to them how they will be able to participate, and in the long run, how it would help them because there is a lot of uncertainty with dealing with this survey.

So I would get to the level of affinity groups, and I would try to even get down to the level of social groups, you know, football clubs, boxing team, all of them, that they have gatherings and friends to pass the word on, and recruiting some of those people within those groups to be the bullhorn for you to help get the message put across. So, I think those things may be a little bit useful.

MR. MORRISON: Regina, thank you for that. And I think that is extremely important information, and especially for those that are not part of the fire service in general, affinity organizations that represent minorities in, and in a lot of cases, around the country—really, that's where those members will go to try to get the information. And when we send this information out, sometimes we call it sort of a cold call information; we're putting it out; it doesn't mean that those members are going to accept it. But if the trusted servants and the officers of those groups send it out and personalize it from their point, and we can probably assist with putting some boilerplate language down there and really looking at it, it goes a lot longer for people to trust that.

And I agree with you completely about what even Kenny said about the Social

Security numbers. We've all heard about that out there and having that breached or something breaching on that. So, that's just an excellent, excellent point. Thank you for that.

Let's go to Richard.

MR. MILLER: Thanks, Pat. Thanks to the previous speaker, Regina, I think you've captured my comments. And I think if we capture the information to clearly articulate the security and confidentiality but the importance of the project, that the fire service and members, both career and volunteers, will realize the importance of this. And they will adapt and buy into why they need to provide their Social Security number. So, to Kenny's original explanation of why they need this—I think if we can concisely describe the importance of this and why they have to have that unique characteristic of the Social Security number, the importance of how to track individuals, I think is the best methodology to do this. I think that will lead to the best results of being able to have this whole index work appropriately.

With respect to the communications and enrollment, as we commented more than a year ago as the process was starting, I think the buy-in is going to be pretty successful if we deliver the first series of messages openly and outward through the fire service. And I do think all of these various methods will be the best methodology to get that out there, and certainly, as Regina just said, the affinity groups, the smaller, unique groups, are going to be that best method of myself telling a friend, or my neighbor who literally is a firefighter, "Hey, have you signed up yet?" and getting your friend the firefighter to sign up, who may not be in the same fire department, but it's explaining the importance. It needs to be literally granular, one-on-one with your other firefighter to tell them why it's so important to go sign up.

And even if you're retired, or if it's a brand new recruit firefighter who totally gets why they need to track their history to the older retired firefighter at the yearly picnic—"Hey, let me show you how to sign up" kind of thing—it needs to be done on that one-on-one basis, and through all different methods. So, I fully endorse all of the methodologies. And I think no matter where you sit in whatever organization, it's everybody's responsibility to do their part, to step up and just take that step to help everybody do this. And it's just going to take right off, regardless of what efforts we put forward. So, thank you. That's all I've got, Pat. Thanks.

MR. MORRISON: Thank you, Richard. That was really excellent. I think that for NIOSH, the words that I really honed in on was that concise and taking the point that Kenny said and why is it so important, but we have to put that down as concise information per our group that processes the information much differently than researchers that don't have the same understanding. But getting that, I think it's important, you had some great comments.

Sara, do you want to comment?

DR. JAHNKE: Yes, I was just going to say thank you to the folks who talked before me. But I want to add a little bit to that. I think we need to hit head on that we're going to be going to asking for Social Security numbers and explaining why, whether it's in articles focused on that or columns focused in the trade magazines. I think the worst-case scenario would be people get on to register and get to the very end and realize their Social Security number is there and feeling uncomfortable with it. I think it should be headline in all the magazines, that it will be asking for your Social Security number and give the reasons why and explain all that information. I love the idea of some key opinion leaders, I think within the departments, where the department-level recruitment; getting those folks on board, whether it's health and wellness or those informal key opinion leaders, I think is really important. And I wonder if there would be a way to set up, both for the departments that are selected, and for the general recruitment, online trainings where you could give people the talking points, or at least give them the "Here's the pieces that you need to know when you're talking to folks about this," or a webinar where you just educate and then use those people to go out and get more folks on board.

And then I think another piece of information that will help ease people's concern about this is if they realize that if they get cancer, it will go into a cancer registry anyway. So, that's not something that will only happen if they were in this registry; but if they know that that information is out there and they are just giving permission for it to be pulled in to this registry as well, I think that might ease some concerns. I think that a lot of folks don't know or aren't aware that that information is already being tracked. So, I would anticipate that if they knew that, they would feel a little bit more comfortable sharing.

MR. MORRISON: Thank you, Sara. I'm going to turn this, because you had a couple of things there that were really talking points, I think, that were very interesting. We're going to need that.

Kenny, does anybody from your staff want to comment? Sara had a couple of things there that she was asking, and maybe she was even suggesting. Does anybody from your staff want to comment on her suggestions? And then when they do, after that, we're going to go to Grace, and then Barbara. We have two more hands up.

MR. WEPSALA: Sure, thanks. This is Will. I just wanted to go back and talk about in reference specifically to the social media. Definitely, we are going to prioritize that; we're actually in the process of developing a social media plan which will include about a year's worth of posts. Part of doing the online surveys and the focus groups was in order to take some of those messages and test them out, and then see what works and what doesn't, and then we can tailor any other messages to meet those discoveries. And so, we're using that right now, and that's going to be one

of our priorities. It's definitely great to hear that that's going to be effective or should be effective. And we will continue to work and prioritize that.

DR. FENT: And I'll just piggyback on what Sara said, some of her points which I think are wonderful. I think I agree with those points. I think, like Sara said, we don't want to hide the fact that we need to collect Social Security numbers, and I think it's a great suggestion to start putting some articles or other messages out ahead of the registry that that is going to be part of it, and why it's part of it.

I also like the point that Sara made about your cancers are already reported to the state, and this is just a way to then link it to your occupation. And then I think the idea of having champions within the fire service, we have heard that from a variety of stakeholders, and we are completely behind that. I think we want to try to find those individuals, highly respected individuals, within the different departments or organizations and really partner with them to be able to get that messaging out through those so-called champions.

MR. MORRISON: All right, thanks Kenny. And then I'm going to turn the next question—I've got the line up; I've got Grace, Barbara, Shawn, and I think Chuck has put his hand up. So, once we do answer questions, I see Betsy just has one up there too. I am going to call on Grace now. And Grace, before I get your question, or your comment on this, how long do we have for this section here? I want to make sure that we're not—it's all very important on this communication, and we're going to show things that are extremely important, but within our sections, and I could even ask Paul, how much time do we have, do you think, that we have to allot for these remaining questions that we have?

DR. LEMASTERS: Well, I think we're covering questions one and two right now. So, the third one, the eligibility criteria, will be one left after we get through these comments. So, lunch break is at 12 or 12:30; we can make it at either time. So, I think we have the time to continue with this. I think it's so important that we get this input. So, if we don't take our lunch until 12:30, if everybody is okay with that, and come back at one. I think we'll get through all these. So, I would take maybe ten more minutes, perhaps for number three.

MR. MORRISON: Did you have a comment, Grace, on top of that?

DR. LEMASTERS: Well, I had more of a question to NIOSH. If you have the date of birth, the name, and the last four digits of the Social Security number, do you really need the whole Social Security number to access NDI and cancer registry?

DR. SIEGEL: This is Miriam. So, for NDI, yes, because we have learned that to access NDI information you can put in the full Social Security number or you can't put in any Social Security number. So, it's all or none for NDI. And for the cancer registries, we have learned that for a majority of them, you can link with last four and date of birth and those identifiers, but it's never going to be as good as having full Social Security number, especially given the expected errors you can expect with

mistyping Social Security digits, or date of birth, or anything like that. I can let some of the cancer researchers on the call answer a little bit more in depth, but we have learned that it's full Social Security number that's going to be most important.

We have also learned that when it comes to name and firefighters in certain geographical areas, you can expect actually quite a bit of them to have the same name, because it is a legacy occupation. And so you'll have people in the same family with the same name that have careers within the same department. So, there are a lot of challenges with identifying people in this population.

DR. LEMASTERS: Yes, with the NDI, if you don't have the Social Security number, you can usually use, as I recall, name, date of birth, and place of death, right? Is that not correct?

DR. SIEGEL: Yes, I believe you can still use those identifiers. But they will be missing field for Social Security number, so you might get a lot of false matches or mismatches.

DR. LEMASTERS: Yes, I know ideally, it would be nice to have. But I'm wondering if you're gathering enough information, that you can go to plan B if you don't get it.

DR. SIEGEL: Right. We certain plan to have a plan B. As it is right now in the questionnaire, we may even be willing able to accept the last four or none at all, but the less information you get, you're aware the match accuracy is going to decrease. But we are willing to work with what we're able to get, and we're shooting for the moon with it.

DR. LEMASTERS: Thank you.

MR. MORRISON: Thanks Grace. Barbara, you're up.

DR. MATERNA: Okay. So, my question or comment is more related to the data security and confidentiality promises. And so I know in the materials you say we are getting an assurance of confidentiality, and this is the highest level, but I suspect that terminology is going to be really mysterious and hard to explain to people what that means. So, I think whatever language you have around that, people are going to want to know, "What is this?" and "Who decides this?" and "What does this really protect me from?" So what your language and explanation around that, I would just recommend pilot testing with a lot of people to see if it's convincing, and what's the best way to get across that kind of terminology that will be very unfamiliar.

MR. MORRISON: Go ahead, Ken.

DR. FENT: That's a great suggestion to pilot test the language. We'll definitely do that.

MR. MORRISON: The other thing, too, we might want to do, and I think we talked about it earlier, but even a section on the website FAQs that almost ask the question like a firefighter would ask it and then the answer in some cases, where they can get a little bit more comfortable with what that is, because I agree with what Barbara said. That's going to be interesting, but that's a great suggestion on that.

I think the next one I have is Shawn. Shawn, are you still up for a question? And if

you could take your hands down if you've done that.

MR. BRIMHALL: Yes, I did. I commented online and agreed with the comment that somebody made that it's the way this is going to go. There's a lot of national, state, and local organizations that we all have or know of that also we can push the message to because they have their social media platforms, their pertinent platforms, their organizational meetings that they could push our comments to. And a lot of times they are looking for things to add to their monthly newsletters and stuff, and this certainly is, I think, something that they are going to grab right onto.

MR. MORRISON: Okay, thank you, Shawn, appreciate that. Next we have—Chuck, you had your hand up, and I know it went down. Do you still have a comment? Did not. Let's go to Betsy.

MS. KOHLER: Hi. I was just going to say that when you go to crafting the language about the Social Security number, we would be happy to participate in that, maybe gather some more information from our registries about a deeper dive into rationale and that sort of thing. We can provide you more background.

DR. LEMASTERS: That would be really great, Betsy. We appreciate that.

MS. KOHLER: Sure.

MR. MORRISON: Judith? Do you have a question?

DR. GRABER: Yes, I would just like to comment to follow up on what Grace had been saying. What we do hear is that volunteer firefighters would be comfortable giving the last four. And I understand why that is not sufficient for a lot of the work you'll be doing. But maybe it's a platform to jump from; why we're asking for more than the last four, and what that does and doesn't do. I think that might be really helpful.

MR. MORRISON: Okay, thank you for that. And let me go to Dennis—

[Background noise.]

DR. DEAPEN: I think we have a couple of—

MR. MORRISON: Yes, Dennis, you might want to turn off your computer. Yes.

DR. DEAPEN: Can you hear me?

MR. MORRISON: We can, we're just getting an echo, that's all. Are you on your computer or on your phone?

DR. DEAPEN: I'm on my computer. I can join on the phone if that works better.

MR. MORRISON: I'll turn that over to Paul. What would you recommend for Dennis?

DR. MIDDENDORF: Can you turn off your speakers temporarily?

DR. DEAPEN: So my speakers are off; can you still hear me?

DR. LEMASTERS: I think we're going to have to move to question two regarding firefighting certificates in the next minute or so.

MR. MORRISON: Okay. Dennis, I think he put his hand down. So, I think he might be calling in. Regina, I know you're still up. Regina, did you want to just add a comment quickly on what we just did, and then we're going to move to question number three.

MS. WILSON: Yes, I just had a question, especially regarding communication. I just wanted to

find out is there money for TV ads in those targeted areas that we're reaching out to? Also, to have someone go through local radio stations; I know, especially in the minority communities, radio station interviews are pretty good to do outreach. And if you know any popular podcasts that might be able to have interviews in reference to the registries, I think that might help.

DR. FENT: I think we're certainly open to opportunities in like that. I'm not sure we have funding to have TV ads or anything that we have to put forward money. But if news stations, or radio stations, or podcasts were to reach out to us—we certainly are aware of some of the existing podcasts and webinars through the fire service, so we would explore using that for outreach.
And then also we're exploring Google promoted ads and those kinds of targeted outreach, which don't necessarily cost a lot, but have a big impact.

MS. WILSON: Right, but don't just stick to fire-related podcasts, because you want to try and go to those targeted podcasts where you have those underrepresented groups that you are looking for that people go to and listen to all the time. So, it might be good to research some of those popular podcasts that a lot of firefighters listen to that might not be firefighter-related all the way. It might be a health podcast, or anything that is a popular podcast that fire service people. I could probably try and find some myself.

DR. FENT: That's a very good suggestion.

MR. MORRISON: Okay, we're going to move along here a little bit. Miriam, just quickly, there was a question that Dennis couldn't get in, but he did write it. I could read it for you in just a little bit in the comments. I don't know if you're reading it, but he asked, "Just confirming information on Social Security numbers with linkage on the NDI and cancer registries. Last four works okay; full Social Security number works better, as linkage software has been optimized to address data entry errors." Miriam, did you want to comment on that?

DR. SIEGEL: No comment, that's great information. Thank you, Dennis.

MR. MORRISON: Yes, pretty factual there.
Okay, the last question here, I think, unless I'm missing something up front. I know there was, on the second question, part two, what is the best process for recruiting states that require firefighter certifications? And there were a lot of ways that you can go about that. The states that did require that, they usually have the state central point that you can actually use, and we can actually get that information out through that point. That's going to be very interesting. We can kind of go through those states that we have, because there were a lot of states that had that requirement.
The last question here is, "Should NIOSH implement eligibility criteria for fire departments' sampling frames?" That question has a couple items to it. One is do we want to recruit fire departments that can get us the information, the most

important part of this thing is going to be that exposure/relationship with the firefighters. How many calls, what was he exposed to—and being able to have that information and access to that information will help out a lot.
Kenny, do you want to quickly just clarify that just a little bit more? And we'll open it up for questions.

DR. FENT: Sure. Our understanding is that fire departments are required to fill out incident records for the runs that they make. But that's not exactly a consistent process throughout the country. And so what we're especially interested in, just like Pat said, is incident record data that can be tied back to individuals. So, through the National Fire Incident Reporting System, NFIRS, there is a personnel module, which I think is optional. But if there are fire departments that have been completing that module on a regular basis, especially over the last ten years or so, those are the kinds of departments that we would be very interested in working with. It would certainly lessen the burden, not just on us, but also on them to be able to get that information and be able to tie it back to the firefighters who register.
So that's one type of criteria we would consider. The only problem is if you develop eligibility criteria like that, the number of departments shrinks, and also you may be getting more progressive departments that may have greater exposure controls in place, for example. So, those are the kinds of the criteria that we're thinking about, but we would certainly like to hear from our stakeholders if there are others or what potential drawbacks there might be for introducing eligibility criteria.

DR. SIEGEL: And just to add on to that, do we want to have criteria in place, related to those incident records, A, do we want to make sure that those departments can give us incident records, or are we still going to include departments that are unable to give us incident records, but can still give us contact information for their entire rosters? And if we do want incident records, do we just want to limit it to those that can only give electronic incident records versus hard copy paper records? Are there any restrictions that we want to put in place to maximize the efficiency of the targeted cohort, but possibly at the expense of some selection bias in which departments are eligible to participate.

MR. MORRISON: Than you, Miriam. That does clarify it a little bit. I've got Shawn is up. Barbara, your hand is still up. Did you have a question that I didn't get to you with, or did you just not take your hand down? Okay, thank you. Shawn, go ahead.

MR. BRIMHALL: Okay, two comments. The first one is relating to eligibility criteria. One of the things in the questionnaire is asking does your department give you an NFPA-1582 physical. I found this quite interesting. I was at one of the Fall Firefighters Cardiac Summit a few years ago in Washington. We had some representation at one of the larger metro Florida fire departments. And the representatives were

saying that their department does not do any fire department physical. And I was quite taken aback by that. It comes to me now that it's been so long since they've not done physicals; there was pushback on both the administration side, because of cost, and of pushback on the firefighters' side because they're afraid it's going to be used as a punitive measure against them to get a physical. "Kenny Fent, I'm sending you in for a physical. We find out that you've got some underlying medical condition that doesn't let you be qualified, now I get to mess with that Kenny Fent guy." Kenny, I don't know you, I'm just using your name as out there. I was going to use Brian McQueen, but I don't want to abuse him. So, there's that.

And then the other thing that might come into play with getting some records and some information here is for your training facilities, the records might be FERPA protected. The Family Education Rights Protection Act, or whatever; I know that as the state of New York, we are very restrictive at who we're allowed to release somebody's training records to because of what it says. So, I don't know if that's been a thought process yet, but that's at least something to take into consideration.

MR. MORRISON: All right. Thank you, Shawn, for those comments there. I don't know if—did the team want to comment back on this, or are we just taking this?

DR. SIEGEL: Just thank you, Shawn, for the—I don't think we had considered FERPA being an issue. But it's a good thing for us to explore. Thanks.

MR. MORRISON: Thanks, Shawn. Brian, you're up.

MR. MCQUEEN: Thanks, can you hear me now?

MR. MORRISON: We can hear you.

MR. MCQUEEN: All right, outstanding. Back to a little bit about what Shawn said—I am not sure if you are familiar with this, but probably over the last three years, the state of New York, the Firemen's Association of the State of New York, and Northwell Health, Dr. Jacqueline Moline, also tried to do a cancer study. And we hit a snag with a lot of fire chiefs that did not want to provide that information, any information, pertaining to their firefighters. We tried everything. We even tried to go in and help them and either authority-having jurisdiction wouldn't release them, or the fire chiefs wouldn't release them. So, it may be an uphill battle for us, but it's something that we definitely need to address.

DR. FENT: Brian, can I ask a question? This is Kenny. Was it because of the burden to provide that information, or was it more of a privacy issue that they didn't want to provide that information?

MR. MCQUEEN: I think it was a little bit of both. I think sometimes, with the volunteer fire departments here in New York City, and Shawn could probably back me up this, we go through changes in our leadership quite often. And sometimes there's not records that have been saved. So, there are just not records there. And there's

also fire chiefs in there that just don't want to do it. They don't want to go back and give that privacy information out. I've had people come up and tell me, "I am not going to give that information. It is not for you to understand." Whether they're afraid, or what they're afraid of, and I'm not sure whether this pandemic is even going to cause more of a harm.

DR. FENT: All right. I was just going to say that I don't know if we get to this in the later slides or not, but we are exploring the opportunity to be able to get some of the information directly from vendors. So, like the incident record management software companies that are out there—some of them have expressed interest in working with us directly, where if they have permission from the department, whatever the department is, to share that information, they could pull those records for that department and provide them to us, which would certainly lessen the burden quite dramatically on the fire department. But that doesn't get over the issue of there may be privacy concerns or other reasons that they don't want to share that information.

And I think we understand that that's a potential limitation, especially with volunteer departments, which when Miriam went over our design, that's why we're primarily focused on some of the larger volunteer departments, at least initially, in the targeted cohort, because we think that they may be a little better organized, and have better record keeping. But certainly, that's no guarantee even that those larger departments would have good records and be willing to provide them.

MR. MORRISON: Thanks, Kenny. We have one more, and then we're going to, I'm going to turn it back to Grace, because we've gone over our allotted time for this section. But Sara, do you want to close this section out?

DR. JAHNKE: I was just going to say that if we, at first, can't get from departments for privacy reasons or whatever, as long as they can tell you the number of personnel that they have, could they do the recruiting if they're not comfortable sharing the emails with you? So send out to their firefighters, and you would know that they have 200 of their 300, but just have them do recruitments on their end with their contacts.

DR. SIEGEL: You know, I think we're interested in what you all think about that, because that's come up a few times. We have also heard in some discussions that some of the state-promoted studies that have been conducted in the past have not been successful because fire departments are not necessarily willing to participate in these state-promoted studies. It could potentially be the same coming from the department or other agencies that are doing the recruitment.

Our thought processing was that as long as the recruitment comes from NIOSH, it will come in a standard way across all departments. And all recruitment that's done, which will be good for response, but also, that we can rely on our name

and our reputation in being the ones that are conducting the recruitment. But we're certainly open to discussion on that.

MR. MORRISON: All right. I'm going to go ahead and turn this back over. If you do have your hands raised, can you lower them? I think Brian and Shawn, I think you asked questions, unless you had an additional follow up question; if not, just lower your hands so when Grace takes over—and Grace, I don't, we're at 11:55, so I'll let you make the call on this, where you want to go from here. So, anyway, thank you from everybody on that communications and enrollment issues. I think we got a lot of really, really helpful information.

Grace, it's all yours.

DR. FENT: Grace, you may be muted, if you're talking.

DR. LEMASTERS: Yeah, I've been talking muted. Thank you. I want to thank everybody for their input, and we had a great discussion from lots of you who are on the front lines in those situations. We have science issues; question four and five, I think we should leave until after we hear from Andrea Wilkinson regarding the enrollment questionnaire. I think they directly relate to what's being asked in those questionnaires.

So can we put those aside until later and go on to question six? And maybe a couple of the ones on the next page, and then take our break at 12:30. Can everybody wait until 12:30 to eat, 12:30 to 1:00? We're kind of on a roll, and I'd like to keep it going if possible. I'm not hearing any nos.

MR. MORRISON: That sound good.

DR. LEMASTERS: Okay. Then let's drop down to question six. Are any crucial details missing from the protocol or consent form that would be needed for linking with population-based (i.e. state and territorial) cancer registries? And then the second part: how soon after initial enrollment should NIOSH seek to conduct cancer registry linkages nationally?

And for these two questions, I would first call upon Dennis or Betsy to both respond to those questions since they are our cancer registry experts, and then anyone else that would like to add.

MS. KOHLER: Dennis, do you want to go first?

DR. LEMASTERS: Betsy, go ahead.

MS. KOHLER: Okay, I'll go. It sounds like he's still incommunicado or whatever. So, missing from the consent form –

DR. DEAPEN: -- Dennis, can you hear me?

MS. KOHLER: There we go. Go ahead, Dennis. We hear you fine.

DR. DEAPEN: I just joined on the phone. So, in terms of cancer registry involvement—are we looking at question number five?

DR. LEMASTERS: No, number six.

DR. DEAPEN: Number six. Okay, thank you. So, in terms of the consent form, I haven't looked

at the actual language, but it's typically quite straightforward in terms of what the IRB expects, and is fairly simple, I think, to communicate, and so this is very commonly done. I think there are many cancer epidemiology cohorts that link with cancer registries and it's just a very straightforward and common practice. So, I would be happy to look at language and proposed language and see if there's any recommendations that I would have.

In terms of how soon after initial enrollment, if you're conducting linkages, I'll take a minute just to talk about an opportunity that Betsy and I and others have created in the last few years that is really going to be transformative in our ability to link with cancer registries for this cohort.

So up to about a couple years ago, every state cancer registry is separate. And they hold on to their patient identifier data exclusively. Even if they share data with national organizations like NCI or CDC, they don't share their identifiers, so linkages cannot occur on a national level. And that fact has resulted in an impact that no cancer epidemiology cohort has ever successfully linked with all of the country, all fifty cancer registries. Because it's just too burdensome; they all have separate approval processes, and many of them have two; they have one for the registry and one for the IRB.

I have conducted two studies where I have attempted to do that, and it takes years to attempt to get those approvals. So, that's been a huge barrier, and it's also very expensive. And what NAACCR, the organization that Betsy represents, has created is a virtual national cancer registry called the Virtual Pooled Registry. And the states have agreed to a single point of access where a data file license and national firefighters registry can be submitted with identifiers. And it's submitted through a secure mechanism to each cancer registry, and then we can provide software to each of those cancer registers identically to link with the cancer registries.

And the study investigators, in this case NIOSH, would receive back initially just a report of the number of matches that occurred; so no identifiers, just counts. And then the investigator, or in this case, NIOSH, can negotiate with the states to receive the actual patient identifiers and the tumor information. That is really going to facilitate this registry going forward.

And to answer the specific question about how (inaudible @ 02:03:11) the enrollment, a question that I had in my mind that had been on this meeting today is do you envision any retrospective aspect to this, because it's challenging methodologically. It's potentially a missed opportunity. Certainly, we would expect to enroll firefighters that have decades of experience and exposure. And the entire nation has been covered by these state-based cancer registries since 1995. We can at least go back to 1995 in terms of retrospective linkage. And it's only going to stop right there, and just ask them if there's any consideration as to

retrospective aspects to these incidences.

DR. SIEGEL: Dennis, that's a really great question. And that's a topic that we've gone back and forth with quite a bit, and originally we were planning for a retrospective component of this. But the sticky part is that because this is 100 percent voluntary, we can't include anyone in the registry that does not provide their okay to be in the registry. And so if we had a retrospective component, we'd have to include firefighters that have since deceased to get that entire population at risk going back in time. And because they are not able to provide the consent to be in the registry, we're not able to have that retrospective component.

DR. DEAPEN: I think IRB can accommodate for deceased members. I'm not an expert on that. But if that hasn't been explored with an IRB expert, I think that's a question that should be asked, because I'm not sure that that is prohibitive.

I think there are studies that in fact have been allowed to link deceased participants without their consent, obviously.

DR. SIEGEL: We agree, absolutely, there's been really great retrospective analyses that have been done in that way, but it's actually not a human ethics problem. It's an issue with some of the language in the law itself in the way that it's interpreted with the world "voluntary" that restricts our ability to do that.

DR. DEAPEN: I understand. That being the case, is there any scientific or public health merit in retrospectively linking those who do provide consent?

DR. LEMASTERS: I would agree. I think that that's a good opportunity there. And also, what about the potential of using next of kin consent? You're going to be enrolling firefighters who have a history of cancer, that currently are cancer survivors. I would think that we would want to go back in time and verify that diagnosis.

DR. SIEGEL: And certainly for the open cohort, former and retired firefighters are encouraged to participate. So, we're absolutely going to get firefighters in that route that may not be current firefighters, and they may have had cancers in the past, and we definitely want to document that, and be able to do some analyses with that. But as far as the targeted cohort goes in calculating cancer risk, right now the design only includes that prospective of only active firefighters participating.

DR. DEAPEN: One more comment. Again, whatever the legislation requires, obviously, must be respected. But one thing I didn't mention in our introductions—I have done research in partnership with NIOSH in the past where I linked, where I searched the California Cancer Registry that I'm part of for the cancer patterns of firefighters and have published those results.

And so again from an IRB point of view, I have been able to obtain California IRB consent to perform linkage studies without patient consent, where there's no patient contact, without study consent. So, there are ways to do this; again, if it's not allowed, or if it's not acceptable for this cohort, I understand that. But that having been said, we now have 20 years of national cancer, wholly identified

cancer registry data. And if there's any way that it's valuable and possible to go retrospective, that would be an opportunity.
So to get back to your question, going forward, if prospective is the only option, for that reason, these are not new—some cohorts are created upon exposure; a patient receives an implant device or something like that, so their exposure begins on that date. Here we have decades of exposure, for (consents @ 02:09:18). And so I would, I'm interested in Betsy's comment, but I would advocate for an as early as possible linkage to really set a baseline. I would expect quite a yield of cancer linkages early on, for that reason: that you've got the entire age range and exposure range for this cohort.

DR. SIEGEL: And just to jump in, Dennis, I think one of the projects you might be referring to is the California case control study. And we're very open to this kind of design with anyone that participates in the registry being able to link, no matter when they started their career, be it current firefighters, or past firefighters, if they have volunteered to be in the registry, we are absolutely open to linking with cancer registries and doing that kind of analysis. That would be no problem.

DR. DEAPEN: Good, good.

DR. LEMASTERS: Okay. I think we've covered that. Oh, is there another comment?

MS. KOHLER: Yes, this is Betsy. Just going back to the protocol on consent issues. I think Dennis and I can take a deeper look at the consent form later. But two things that come to my mind is that there is an explicit consent in there that the individual agrees to linking with cancer registries and potentially other data sources, and that I think that if there's a clause in there that addresses re-release of de-identified data to other researchers, that would go a long way with the cancer registries to support this project.

DR. LEMASTERS: Can someone on NIOSH address that? Is there an explicit consent form in this? I thought there was, right?

DR. FENT: Yes. Both of those components are part of the consent form.

MS. KOHLER: Great.

DR. LEMASTERS: Any final comments before we move to the next slide?

MS. KOHLER: I just have one quick question. When will enrollment begin, and when do we expect it to potentially end?

DR. FENT: So our goal right now is for enrollment to begin in the spring of 2021, give or take a few months on either end. And then in terms of how long, I think we're looking at continuous enrollment. So, we're certainly focused on this first couple of years of trying to get as many firefighters enrolled as possible, but there would be—as long as we were continue to be funded, we would have continuous enrollment.

MS. KOHLER: So that would line up nicely with our Virtual Pooled Registry project and being able to accept studies, after 2021.

DR. FENT: Great. We're very interested in that. I know Miriam has been talking with folks,

probably you as well, about the opportunity to use that virtual pooled registry.

DR. LEMASTERS: So if I understand what's been said, it could take—I think Dennis said this—it could take quite a while to get approval from the cancer registries before you can start with gathering the information. So, does that mean that NIOSH should try to start going to all these state cancer registries and seek approval now?

MS. KOHLER: No, the process that we're developing right now really streamlines that whole process. We've developed templated data agreements and data sharing agreements. We're moving towards a centralized IRB. So, I think what Dennis was focusing on was the difficulty in the past that we've had, and we're really working on trying to streamline that process. But I think we can start having discussions on when to start the process, and some more guidance on how to help you through it.

DR. DEAPEN: I'm sorry if I wasn't clear. Betsy is exactly right. The past is the experience that was so frustrating. It would take years to get these approvals. Our current approach in the last year or two has resulted in the large majority of states approving this within weeks, and providing the linkage within weeks of initial request. So, it's really transformed that landscape.

DR. LEMASTERS: Okay, thank you for clarifying that. This is Grace. I think we need to move on to the next slide. And I think we can get through the next slide. There were some additional overarching questions by the co-chair, and these are probably pretty short, but I think important to give us a framework.

And the first question was: there was no mention of pilot testing either as a section of the approach, such as recruitment, or the questionnaire. Are there plans for pilot testing? I know you pilot-tested the enrollment questionnaire with ten people, but how about the work history questionnaire, and the recruitment process?

DR. FENT: So I will take a stab at answering this, but Jill Raudabaugh, who is our IT team lead, may also want to chime in here. But we are interested in doing pilot testing. I apologize that it wasn't part of the protocol. But you know, a sort of soft opening is what we're looking at. So, once we have the web portal up and running and approved, and possibly working with a couple large departments, or maybe even one particular state with their firefighters, just to make sure everything is working properly. And then of course, there is still going to be focus groups and other things that we're going to do, even before we go live to test out the different collection instruments.

But Jill, I don't know if you want to say any more about that.

MS. RAUDABAUGH: Just that it is going to be tactically possible, and it's something that we are going to want to do that from a tactical perspective to make sure that we can handle the load and we'd be working with the technical people in Atlanta that run the servers to see how if we will allow perhaps certainly a few at a time, and then maybe

targets from departments and just kind of scale up from there. We will work closely, I think, with the communications team and the team at large to not just broadcast immediately, "Hey, it's available." We'll work slowly at first to test the site and make sure we're on solid footing.

DR. LEMASTERS: Okay, so the answer is yes. There are plans for pilot testing in most aspects, correct?

MS. RAUDABAUGH: Correct.

DR. LEMASTERS: And that goes into number eight; has there been a decision regarding implementing the targeted or open cohorts simultaneously or consecutively?

DR. SIEGEL: I think that's just going to kind of naturally work out that the open cohort will begin first, because open cohort enrollment will begin as soon as the web portal is up and running. And it will also work well as we start to pilot and everything. It will take a little bit longer to identify the departments that we select for the targeted cohort, as well as getting everything squared away in terms of their willingness to participate and share records and everything. And so it will naturally work out that the open cohort enrollment will begin first, but that enrollment will be ongoing, so as soon as targeted cohort enrollment begins, then they will be happening concurrently.

DR. LEMASTERS: Okay, thank you. That seems reasonable. And the third question from the co-chair was are there data indicating that you will be able to recruit 40,000 firefighters per year? And do you have any idea of what the expected split will be between the targeted and open cohort?

DR. SIEGEL: Well the expected split—ultimately, our ambitious goal that we're shooting for is 200,000 overall. The targeted cohort with our minimum sample size benchmarks, we're shooting for 25,000 to 30,000 firefighters at baseline. That will continue to grow as we do those updates with those departments every few years. And then the open cohort, we were hoping, can be potentially three to four the times the size of the targeted cohort, just encouraging firefighters all across the country to participate.

DR. LEMASTERS: Do you think you can get this per year? That was the question. Forty thousand per year?

DR. SIEGEL: I'm not sure of the answer to that right now.

DR. LEMASTERS: Okay.

DR. FENT: We're optimistic, Grace, that we can do that.

DR. LEMASTERS: Okay. Optimism in research is always good. Does anybody else on the committee have any comments regarding these three questions? Okay, I don't see any hands raised.

So we are—here's the plan. We're at almost 12:11. Let's return in 30 minutes. That will be 12:45, and at that point, we will start to go through all the comments. You all got a copy of the comments of the committee regarding the proposal. And

we will go through the ones—we won't go through the editorial ones. We know you all can decide if you like our editorial comments or not. But we will just try to hit the sections that are more strategic in relationship to the approach.
And then after that, the protocol discussion can continue until 3:30. We will get to hear about the enrollment questionnaire. And then we'll go back to those two questions that you all proposed about exposure history. Is that satisfactory with everybody? Pat, and everybody else?

MR. MORRISON: Yes, Grace. That works.

DR. FENT: Grace, I am wondering if it might make more sense to do Andrea's presentation after lunch, so that we can at least talk about the enrollment questionnaire. I think some of the questions or comments that we received on our protocol pertain to that? And that might be the best way forward, and then we can really jump into the discussion.

DR. LEMASTERS: Okay. That sounds perfect. So, if everybody else is in agreement, when we come back after lunch, thirty minutes, that's 12:45, Andrea, if you're ready, we'll start with your presentation. And then the rest of the afternoon will be in regard to the protocol as well as the questionnaire. Is everybody okay with that?

DR. MIDDENDORF: I will just remind you, Grace, that we will have to do a roll call when everybody comes back. And at that point, I will ask Brian McQueen to introduce himself, since it sounds as though his speakers and microphone are now working, and we hadn't had a chance to hear from him.

DR. LEMASTERS: Okay. He could introduce himself now if he'd like. Would you like to introduce yourself now?

MR. MCQUEEN: Sure, I can do that. Not a problem. I'm a retired school administrator. I sit on the National Volunteer Fire Council's executive committee, and also their chairman of their cancer committee. I am a retired director of the Firemen's Association of the State of New York, a 41-year active member of the Whitesboro Volunteer Fire Department as their past chief, current training officer, and I'm an occupational cancer survivor. So, I'm glad to be on here and it's great to see such a great turnout and some positive communication going back and forth. So, thank you for the opportunity.

DR. LEMASTERS: Well, I'm glad we were able to get you up and running with us. Thank you all, have a good lunch break. I will see you in 30 minutes.

MR. MORRISON: Thank you.

DR. LEMASTERS: Bye, everybody.

[Lunch.]

DISCUSSION OF DRAFT PROJECT PROTOCOL

DR. MIDDENDORF: Okay, it's about 12:50. How about if we go ahead and start again? So I'll start in on the roll call again. We'll do it in alphabetical order. Shawn Brimhall? Shawn,

	are you there? Okay, I'll come back. Chuck Bushey? Chuck? Okay. Dennis, are you there?
DR. DEAPEN:	I'm here.
DR. MIDDENDORF:	Thank you. Bryan Frieders? Okay. Sara Jahnke?
DR. JAHNKE:	I'm here. And I did talk to Bryan and he is arranging his mom's funeral this morning.
DR. MIDDENDORF:	Okay, thank you for letting us know. Betsy, Betsy Kohler?
MS. KOHLER:	I'm here.
DR. MIDDENDORF:	Grace LeMasters?
DR. LEMASTERS:	I'm here.
DR. MIDDENDORF:	Barbara Materna?
DR. MATERNA:	I'm here.
DR. MIDDENDORF:	Brian McQueen? Okay. I don't know if you're not back at your desk or if we're having trouble with the audio again. I'll come back to you, Brian. Richard Miller?
MR. MILLER:	I'm here.
MR. MCQUEEN:	Brian McQueen, John.
DR. MIDDENDORF:	Thank you, Brian. Pat Morrison?
MR. MORRISON:	I'm here.
DR. MIDDENDORF:	Virginia Weaver?
DR. WEAVER:	I'm here.
DR. MIDDENDORF:	Regina Wilson.
MS. WILSON:	Here.
DR. MIDDENDORF:	Okay, heading back to the top of the list, Shawn Brimhall? Okay. Chuck Bushey?
MR. BUSHEY:	Here.
DR. MIDDENDORF:	Okay. By my count, that's—one, two, three, four, five, six, seven, eight, nine, ten, eleven—eleven people present and we do have a quorum. So, Grace, if you want to take it away.
DR. LEMASTERS:	Okay. And just double-checking, is John Brasko here, is Shane Greer here?
MR. GREER:	Shane's here.
DR. LEMASTERS:	Who, who's here?
MR. GREER:	Shane Greer, I'm on.
DR. LEMASTERS:	Oh, okay, Shane, how about John? No? Well, I just wanted to say upfront that both Shane and John are federal employees and are on the ad hoc committee, but Pat and I really want to give you carte blanche opportunities to say or comment on anything that comes up.
DR. MIDDENDORF:	Okay, I'm sorry; we can't do that, Grace.
DR. LEMASTERS:	Oh, we can't do that?
DR. MIDDENDORF:	The FACA rules, we can't do that. If we have questions that we think they might have substantial input on, we can certainly ask them. But we can't just give them

carte blanche.

DR. LEMASTERS: Well, can they raise their hands?

DR. MIDDENDORF: Sure.

DR. LEMASTERS: They can raise their hands or they can't?

DR. MIDDENDORF: Sure.

DR. LEMASTERS: Okay, good.

DR. MIDDENDORF: Yes.

DR. LEMASTERS: Well, I didn't want to leave you two out and so if you can raise your hands, then that's great. I was afraid we overlooked the two federal employees who are on the ad hoc consulting with us, so great.

Okay, everybody I know that we've been pushing hard. We have a lot to cover during this afternoon, so bear with us. We're trying to get through a lot of material. The idea is, if we're able to get through the material, we won't need to have to have a follow-up meeting in the near future. And I think, the way things are lining up, we're doing an exceptional job and all your input has been exceptional. I would like to make sure that everybody has with them the comments on the National Firefighter Registry Protocol Version 3/18/2020 because that is what we're going to be using to go through our protocol discussion. So, Paul sent you that and I hope everybody has that in front of them so they can refer to it because that's going to be pretty critical. And if not, maybe you can get it printed out or on a separate screen before we begin that process. So I think we're ready to hear about the Draft Enrollment Questionnaire, Andrea Wilkinson.

MS. WILKINSON: Great, thank you. And, Emily, if you can just go ahead and give me presenter rights, please? Well, I hope you all had a good lunch. We would just like to take a couple of minutes to provide you with an overview of the enrollment process and the questionnaire that we have proposed for the National Firefighter Registry. So, as you know, we have several overarching goals for the Registry. In order to accomplish these goals, we realize that we need to have a simple and concise, yet meaningful questionnaire experience. It is important to us that we are as minimally burdensome on our participants as possible. So, as such, we plan to have the enrollment questionnaire be accessible on any type of device such as a computer, tablet, or cell phone, and we are being very mindful of the time that it will take for completion. As you know, security is also a very high priority for this project team, which is why we have sought out highly-skilled IT and data security experts to assist with this portion of the project. We'll talk more about that momentarily. And, finally, we want to ensure that our enrollment questionnaire is relevant to *all* firefighters, whether they are currently working in the field, retired, wildland, structural, anything in between. We want to provide an appropriate questionnaire for each of them.

This slide outlines the proposed process that a firefighter will go through to enroll in the National Firefighter Registry. First, the firefighter will create a login.gov account. Secondly, they will read and electronically sign an informed consent. The user will have the option to print this page for their records if they so desire. The third step is to create a user profile that consists of basic demographic information. And lastly, the firefighter will complete the enrollment questionnaire. We expect that this process will take no more than 30 minutes.

This is a screenshot of the login.gov's website where firefighters will be directed to go to create their account. This method was chosen due to the high security requirements. As you can see on the right side of your screen, the participant will be prompted to select a method of contact to complete the multifactor authentication process. The process is very quick and can be completed in just a couple of minutes. Once the participant has completed their login.gov account creation, they will be redirected back to the enrollment website. At this point, the firefighter is ready to complete their user profile. This brief section will collect basic demographics and current employment information. This section of the questionnaire can be easily accessed by the participant and updated as changes occur in things such as employment or contact information. Information provided here in the user profile will be used to auto-populate fields and to generate skip patterns throughout the questionnaire. For example, the participant's response to the gender field will determine what reproductive history questions that individual will see.

And we've talked briefly about this but just taking it from another lens, this, again, is a very important piece of information for the NFR to gather the social security number. And because firefighting is a known legacy occupation, therefore many firefighters carry the same or similar name, geographic location and, in some cases, even work for the same department as a relative. We need to collect the social security number to ensure that we have those correct identities for cancer registry and vital status matching. We have spent a great deal of time exploring options and weighing the pros and cons of placement of this question. Currently, it comes at the end of the questionnaire; however, this is something that we are certainly open to discussion. Next to the question there will be an icon that reads "Why are we asking this?" When participants click to find out more information regarding this request and they will also find out how we will use that information. Should a participant leave the SSN field blank, they will be prompted with a popup box explaining the importance of gathering this information and asking if they would reconsider providing the full or at least a partial SSN. Participants would then be able to input their SSN or click the decline option.

Throughout various iterations of the enrollment questionnaire, we have asked numerous individuals, internally and externally, to pilot the questionnaire and

provide feedback. Of the ten fire service professionals who completed a pilot questionnaire, the average time for completion was approximately 12 minutes. This time did not include the time that it would take to create the account or to review the informed consent. Additionally, we had multiple physicians, two survey methodologists, and numerous epidemiologists review the questionnaire. Feedback from reviewers was largely positive and we have incorporated the majority of their suggestions into the current version of the enrollment questionnaire. Our contract team, working under the direction of Jill Raudabaugh, has created a mock web portal to simulate what the enrollment questionnaire will look like in web form. The next few slides will give you an idea of the website development. The homepage that you see here will provide links to find out more about the Registry, frequently-asked questions, and a quick start to enroll. If firefighters don't have any questions or want to read any of the background information, they can simply click "Get started" and begin the account creation process.

Here you see pictures of four different screens that outline the steps that the participant will encounter while navigating the enrollment process. So, it's very simple and self-explanatory. Following account creation, firefighters will be directed to the informed consent document which they will read and either decide to electronically sign and continue on to the enrollment questionnaire, or they can decline and go no further in the process. Users will be given the option at this point to print the document.

[Background noise.]

DR. MIDDENDORF: Can we have everybody mute their phones, please?

MS. WILKINSON: Following the informed consent, we will move on to the user profile. This is a screenshot of an example of what the user profile may look like. As a reminder, this is the section that participants can revisit to update pertinent information as it may change such as phone number or fire department. The following sections, as seen here, are all sections of the enrollment questionnaire that flow directly from one to the next. As you can see at the end of the questionnaire, participants will have a free-text area in which they can provide any additional information or feedback to the project team. Following the submission of the enrollment questionnaire, that participant will be thanked and given the option to view additional resources.

The project team understands that it is unrealistic to gather all of the desired variables in one questionnaire; thus, the version you are seeing is in draft form. We have narrowed this down from a very large pool of questions based on our expert reviews. Although we realize that response rates will vary, it is also our intention to conduct brief, periodic follow-up questionnaires to targeted cohorts. And finally, we are also exploring the option of developing a questionnaire for fire

department leadership to better understand how PPE use and other control measures have changed over time. We think that these departmental questionnaires, coupled with detailed work histories and incident records, can be valuable in developing exposure estimates for these targeted cohorts.
Thank you so much for your time. I'd now like to turn things back over our co-chairs for discussion.

DR. LEMASTERS: Okay, thank you very much, Andrea. Pat, do you want to lead the discussion on any follow-up questions regarding this presentation?

MR. MORRISON: Sure. Do we have anybody out there that would like at this time to talk about that whole process? It seemed to be pretty straightforward. I'll just start real quick, just one question on that: very well done, very (inaudible @ 00:13:59) some people that's probably two minutes longer than a typical firefighter's attention span. But that's all right, we'll take that. The follow-up that you're going to be reaching back, are we going to be talking about that later? I mean did we talk a little bit—I might have been multitasking here, but getting that information on a regular basis, have we talked about that here yet?

MS. WILKINSON: We haven't discussed it too much. Just to kind of give you an idea of some of our thoughts, based on responses or demographics, we may reach out to certain individuals. For example, we may have follow-up questions just for female firefighters. And as part of the enrollment process, we are asking permission to contact them over time and if they would allow things like text messaging so we could reach out with a text or an email saying, "Hey, there's a quick, five-minute follow-up survey or a five-question that the NFR would like to ask you." And we hope that they are very brief and we're not exactly sure what all of those will be yet. We kind of want to see what the responses are who our population may be. And I'm actually going to have Miriam jump in here with a little more information on that as well.

DR. SIEGEL: One of the important reasons that we're going to be doing follow-up questionnaires is so we can follow the characteristics of the firefighters' work exposures and lifestyles longitudinally, because we'll need to get this information going in the future because obviously it doesn't stay the same. They go on more incident runs, their job characteristics could change, their lifestyle characteristics can change, and this is all going to be really important to gather to be able to analyze their changing risks for cancer prospectively. So, some of those questionnaires, while they might have a different topic of interest, some of them will go into more detail about specific topics and some of them are just going to be updating some of the basic information we want to know about their job characteristics over time.

MR. MORRISON: Okay. And that will be all done by electronic means?

DR. SIEGEL: Yes, it'll be through the same web portal, unless it's information we're getting

updated from the departments, in which case they'll come from the department records and possibly department surveys.

MR. MORRISON: Okay, all right, thank you. Grace, do you have a comment?

DR. LEMASTERS: Yes. My comment, I wasn't clear about why there is a user profile questionnaire and then the actual registry questionnaire. Do we need to have two separate instruments? Couldn't they be combined into one?

MS. WILKINSON: Grace, that's a wonderful question. It really is one thing. The user may not even realize that we are separating it out. So, when they create the user profile, it really is just the first section of the questionnaire. That is the only piece that users will be able to revisit to edit once they have hit Submit. We don't want them to be able to go back and change answers in the questionnaire itself over the next few years. Just the user profile would be editable. So, I don't think, from the way that our web team, the software developers are putting this together, that the user would have any idea that they are separate things in our book.

DR. LEMASTERS: So where you have full name in the user profile and you have that again under demographics, that's all populated into the demographics automatically?

MS. WILKINSON: Yes, that's correct. So, what they fill out in the user profile will auto-populate. The fire department will also auto-populate. When they tell us in the user profile "I currently work for FDNY," then when they go to their employment history, the first department that will show up will be what they had already inputted, so it would be like FDNY, so they don't have to repeat any of the information.

DR. LEMASTERS: But, okay, I'm still not clear. If I fill out your profile questionnaire, then where you ask me "What job do you hold in this department," then will I start on a different page in the first page of the registry enrollment questionnaire?

MS. WILKINSON: If I'm understanding correctly, I think what you're saying, so the way it will set up is they'll complete their user profile and then immediately it rolls into just the questions that we are gathering and whenever they reach that question for work history, that it would be filled in.

DR. LEMASTERS: Has this been piloted?

MS. WILKINSON: It has in paper format, but not electronically yet. However, it will be.

DR. LEMASTERS: Yes. That could be confusing.

MS. WILKINSON: The development site that we have played around with, they're making it very smart. I don't think it will be confusing to the users because they won't realize that there's any skip patterns being generated.

DR. SIEGEL: Grace, functionally, the user profile will seem just like part of the questionnaire. It'll be one component of the web portal, functionally. The user profile is going to be separate because it reflects your current status and your current contact information, so that's something firefighters can go back to and update to allow us to gather current contact information and current employment status

information. But functionally, it's all going to be one unit within the web portal.

DR. LEMASTERS: Okay, so it'll just be an automatic continuation?

DR. SIEGEL: Correct, exactly.

DR. LEMASTERS: Okay. All right, well, I see other hands up.

MR. MORRISON: Yes, we have Richard. Do you want to go, your comment?

MR. MILLER: Sure, thanks Pat. So, my question's maybe a little complex in the sense of the user profile. So, as I'm entering my information and building my history—and this is going to go all the way down to the last part of data gathering for PPE—I build in my fire department information and I work for Fire Department X, but I'm an instructor at an academy where I'm using PPE from my first fire department in tracking that information. So, as a fire employee of the first fire department, my PPE may have traveled with me. And so the statement was made that we may reach out to leadership to get a history of PPE use. And in reading through the document, it talks about cancer risks related to firefighter exposures. So, the employer may not know the full scope of risks that the gear was used for that employee while he was doing instruction. And that's a pretty common practice I think within the fire service, that instructors take their gear from their department and use it at other facilities or other training sites. So, I'm just a little concerned how that's shaping out and we want to make sure we fully vet that question out appropriately. And then that the firefighter that puts the information in understands that it's not just one set of gear. There may be multiple sets of gear that tracks through that and that they may have multiple employers or volunteer departments that they're participating with or volunteer and career departments and multiple sets of gear that are part of that whole practice and cancer risk that are part of that. So, I'm kind of throwing that out there to just maybe vet that a little more. That's it, Pat.

MS. WILKINSON: Chief Miller, thanks so much, that's a very important point that we certainly would want to consider. Do you have any suggestions for how we could clearly ask that to differentiate? Would it be something such as if they have selected earlier in the questionnaire that they are an instructor that additional PPE questions are asked at that point? Or do you have any other potential suggestions for good implementation of that?

MR. MILLER: Well, first off it's just Captain, and retired. So, a couple things; on the front end—so I'll use myself as an example. My work history is going to represent multiple volunteer fire departments and at least five different employers over a 40+-year career. So, if you're tracking all that information, you're going to need to capture that and the best methodology is through the FDID number which then goes back to NFIRS, because you talked about the data collection component earlier. So, that needs to be built into the system back to the FDID number. And every fire department has a unique FDID number that then can be plugged in as part of

that registration process. And then as part of that questionnaire, you can go through that and you can ask those questions "What fields were you at within that FDID number?" So, if you're at X-Y-Z Fire Department within—my last employer had multiple positions, so you're going to have to have multiple checkboxes to be able to say that you did those job components with that particular employer. And then for the end result of the question, of the data collection such as what are the risks or how is the fire department looking at the cancer risks within the exposures, what are the department workplace practices in understanding the cancer risks associated? Are they doing regular gear cleanings? Are they doing regular standardized NFPA gear swaps? Are they following the standardized ten-year practices of swapping out gear? Are they doing the internals checks every so often within the stations and so forth? Are they practicing the current standardized practices of swapping hoods after every incident? Those kinds of questions need to I think be dove into in today's fire service to ensure that we're gathering all the data to build this bigger picture of the individual.

DR. FENT: This is Kenny. I think these are great points, Richard, that you're making and I think it really highlights why this questionnaire has been such a challenge. Because, like you said, firefighters may work for multiple departments sometimes at the same time. They may be instructors, multiple sets of PPE, all the things that you mentioned. It's been difficult to kind of strike a balance between collecting as much information as we can in the enrollment questionnaire, but also keeping it brief enough that we're not going to lose people during the registration process. And so I think this idea behind having a questionnaire for departments to get a better sense of how their practices and policies have changed over time is one way to sort of get some more information, but not necessarily directly from the firefighter, get it from the department. And that questionnaire has not been developed yet. I think that's something that we would look to do in an amendment to our protocol and certainly working through our committee, this committee, as well as other stakeholders to identify the appropriate questions. So, it sounds like you would have a lot of really good input in that questionnaire, so I think we would definitely draw on that expertise as we move forward.

MR. MILLER: I think it has to be a give and take. On the front end as I'm the user filling out the questionnaire, maybe there needs to be a level of how much information do you want to give out in the sense of participation and continue to drill down? Yes, I want to participate, I want to be able to give you, say, Level 1—that's just an example—and can I get into the system to be able to provide you that? I'm a current firefighter, I'm here today. I started my career yesterday. I want to participate so I want to give you as much as possible to protect myself. I'm a retired firefighter. I'm going to try to give you as much as possible. I've already

survived cancer. I've had limited exposures and that kind of such. I don't have any of my old records. That's the difficult part. Maybe I don't have a health history. Pat and I are fortunate, we come from jurisdictions that do track our history, did have medical records, do have exposure records. So, we can provide not just suppositional reports, but we can provide data that provides that information. So, there's going to be a wide variation of information across the country to build the data that you all need. So, giving a choice up front as you start the process I think will help to build that data. So, you're going to get a varied component. So, I think, like you said, picking the right departments is critical and then matching the employees to within that department are also critical.

MS. WILKINSON: Captain Miller, if I could ask just one follow-up. You mentioned the FDID. Do you believe that that would be a valuable addition in this iteration of the questionnaire where we ask the name of the department and the FDID?

MR. MILLER: I mean I thought that from the start that that was a pretty good way to gather information. I'll ask the two chiefs from New York. That's a pretty valid methodology in New York. Again, there's different systems. But the FDID numbers are standard methodology for all fire departments to register into the NFIRS system. I'll give way to other fire service participants here.

MR. BRIMHALL: Yes, hi, it's Shawn. I concur. We use that as the primary way to track a firefighter's agency and that begins their training record identification which tracks back to their social security number if we have it, or a partial, throughout the years. So, I would agree that that's the best way to do it. And then the only concern I would have is it's not going to be 100 percent accurate for people who have then left an agency and are now a part-time, at-will contract or something instructor for another entity, may to may not have an FDID.

MS. RAUDABAUGH: Hi, this is Jill Raudabaugh, the data person on the NFR team, and currently we're going to be using I think a standard ID. It sounds like the FDID is the standard ID to track stuff. I mean everything behind the scenes of almost all the data points end up being coded in a database. And so I'll definitely be using that FDID. I was envisioning actually a dropdown box that would have the name and then behind the scenes, that FDID and this lookup table would get stored. But my question is people filling out the survey, do they know what their FDID is or are they just going to look for their fire department name and we should be diligent that we store the FDID when they select that name, if you know what I'm asking?

MR. BRIMHALL: This is Shawn again. The name only is an issue. There's two town of Hamlins in the State of New York. There's two towns of Cold Springs in New York. And they're on opposite sides of the state. So, if you call Cold Springs Fire Department, there's two. So, firefighters in New York State to train are accustomed to using and going back to their Fire Department Identify number.

Again, that's how a record is created and stored in our system and it's how we then track and then move them about. As they change agencies, we change their FDID number but historically keep a record of where else they were once registered. So, we would have that in our system in their training record. Shawn Brimhall, I've been a member of six different volunteer fire companies in the State of New York over 38 years. It tracks all six of those departments. So, if you want any six of the FDID numbers, you look in the membership it will show me as an inactive member of those other agencies.

MR. MORRISON: Yes, one of your questions too, would the firefighters know that number? No, most of them would not know that number. But it doesn't mean that we don't—we'll probably have more discussion on this. That was great from Richard and Shawn bringing that up. And I think you guys got some information from that there, too, on how do you do it, a dropdown. And really that's going to be the data people. Are you guys saying does that—is that a big assistance? Does that help us assist, get us—is that something we wish we did upfront? And that's why we're having this discussion. So, if anybody doesn't have any more discussion on that, I know Betsy has a comment.

DR. FENT: This is Kenny. I just have a point of clarification. The Fire Department ID, is that specific to the fire department or specific to the individual?

MR. BRIMHALL: Specific to the fire department. In the State of New York, you can't register for training without knowing what your department ID number is. It's impossible.

DR. FENT: Okay, got it.

MR. BRIMHALL: And going forward, our records management system—which was supposed to be implemented which is now COVID conveniently delayed—requires online registration for all of our local training. So, again, if you don't know it, you're not getting trained.

DR. FENT: Okay, great.

MR. MORRISON: And, Kenny, you could probably follow up with the NFIRS. Like Richard said, they have that number and they use that as a cross-reference number. And they might have the tools developed to say, okay, how do you actually do that when reporting takes place? So that will be interesting there.

DR. FENT: Any other comments on that? We're going to move, if not. Go ahead.

MS. WILKINSON: Can we simply just ask if John Brasko has any ideas? Does USFA have that type of database that would list out all the FDIDs?

MR. BRASKO: Yes, we do. This is John Brasko. We have that database with all that information in it. I'm not one of the NFIRS people, but we have a whole shop that does that. And all the other discussions about NFIRS were correct. We're the ones that I believe issue the NFIRS, the FDID, working with the states. So, we have a lot of that information available. I will talk to our people and see where I can get more information for you.

MS. WILKINSON: That's fantastic, thank you so much.

MR. BRASKO: You're welcome.

MR. MORRISON: I guess the only question we really had, is there any case that we have fire departments that do not have that number?

MR. MILLER: This is Richard. We may run into that with industrial firefighters and maybe some of the military units that are not going to have an FDID number.

MR. MILLER: Okay, we'll have to take that into consideration.

MR. BRIMHALL: Yes, this is Shawn again. I can't speak for other states, but in the State of New York we give them to every government entity, whether or not they're a fire service entity or not. They get a New York State FDID number for of their personnel who may go into our records management system. So, if you're a police officer or you're a harbor department worker, you have a number assigned to your government locale.

MR. MORRISON: Okay. Hey, Betsy, do you want—I know you had your hand up. I'm sorry; we're just getting to you now. Do you have a question, comment?

MS. KOHLER: Well, it's sort of off this topic, but it was back on the user profile section and concept that the individual may go back and change this information over time. Are we really expecting that they might go in and update that between questionnaires? And if that's so, I'm wondering why we might not want to consider putting a cancer diagnosis field in there, "Have you ever been diagnosed with cancer, because somebody might be motivated to go in and update that information," between questionnaires, which would be helpful.

MS. WILKINSON: Yes, thanks for that, Betsy. I think we had tossed around that idea and now that you bring it back up, we'll put that back on the plate as an option to add that into the user profile. In regards to our expectation if they'll return, we really don't think that they would do that unprompted. But whenever we do send the follow-up survey, it may have a tagline that says something like "Has your contact information changed? Has your fire department changed? If so, please update information here." Or maybe in our annual check-in email we ask them to please check that their information is correct. But thank you for that suggestion to add the change in cancer status.

MS. KOHLER: Yes, I think if you're going to prompt, that would be a good thing to have there—

DR. SIEGEL: Betsy, would your suggestion be as simple as "Have you received a cancer diagnosis?" Yes, no. And then potentially state of diagnosis?

MS. KOHLER: Well, I would want to know the site. And actually I do have a comment on the state of diagnosis. The way you have that phrased, we need to redo that. We need to ask not where what state they were diagnosed in, but where they were living at the time. For example, I live in New Jersey. I could go and get diagnosed at Memorial in New York and I would answer "New York" to that and that's not what we're after. We're after the residence.

DR. SIEGEL: Okay, great, that's great feedback.

MR. MORRISON: Excellent. Grace, did you have another comment?

DR. LEMASTERS: I just had a quick question. We're going under the assumption that the questionnaire should only be 30 minutes. But I'm wondering if the firefighters would not be willing to continue a little longer than 30 minutes in order to get a good cumulative work history. I mean is 30 minutes a magic number? I would like to ask all the firefighters on the committee, would 45 minutes work also? I think the questions are interesting enough that it could very well keep them engaged, but I wanted to know what the actual firefighters on this committee thought.

MR. BRIMHALL: This is Shawn. My comment would be that it may need to be revisited by the firefighter who may not have all the data that we're looking for for them to complete all at once. A very common thing with just doing your taxes; all of a sudden you forgot and you didn't get his piece of paper from somewhere and you now got to go back and research that and get that answered. So, I don't think taking the 45 minutes would be too much. I certainly wouldn't want to see anything go beyond that. But attention spans of people just don't last because you're either multitasking or you've got something else going on at the same time that you're trying to do it. So, I don't see it as a big hiccup. I would be concerned if it was to go beyond that.

DR. LEMASTERS: Anybody else?

MS. WILSON: Hi, it's Regina. I think 45 minutes is a long time to keep that interest. Is it possible for you to get as much pertinent information that you can in the 30 minutes and then ask them if they're willing to answer more questions to see if they'll do in a 45? Because I think 45 minutes is a long time.

MS. WILKINSON: This is Andrea. I was just going to add in that, at this point, no firefighter has tested it electronically so we don't have a solid timeline right now. But those that have gone through on paper, it's been averaging 12 minutes so we do think that we are well within our timeframe right now. Of course it's going to be longer for those with a more extensive work history or more health conditions.

MS. KOHLER: The consent form.

MS. WILKINSON: Yes, the consent form, it also depends are they just clicking "I accept" or are they actually reading the document? So I think that the time really may vary depending on the user.

MS. KOHLER: But similar with what Regina says, we have heard quite often from fire service members we've talked to that it needs to be short, short, short. So, I'm really interested to hear what folks on the committee have to say about that because it is a delicate balance from the science side and the survey length and response.

MR. MORRISON: This is Pat. You bring up a very, very valid point there. I mean we've had in the surveys that we have done with the IAFF and a lot of times we all want the

information to be all-encompassing and sometimes it doesn't work out that way for us. We have less people using it because they get to a point and just say, "Hey, I'm just tired of filling this out." Some will be motivated to fill it all out. Some will take that time, but others—and I agree, I wish that we were all into this in a way that I would say that, yes, they'd spend all the time they can, but there is a break point in that. This might be something that I would use. I don't know if we have time for a focus group with firefighters in there. I mean you probably already have done some on paper. The electronic, getting those people to join a focus group and prior to doing that, filling out the electronic format and using that and then just getting some other things from those end users actually going through that process. We can talk about it here, but I think that sometimes it's hard to actually understand every element until you actually do it and see others do it. And I think what Shawn said, there's going to be some information they might not have. If it's complicated work history, if they've moved from place to place, that's going to be a little bit longer. But anyway, anybody else on that?

MR. MAYER: Hi, this is Alex from the registry team. I just wanted to jump in and say firefighters will be automatically logged off if there is no online activity for five minutes, but they can log back in using the multifactor identification and pick up where they left off. So, that's how we have it drafted currently.

MR. MORRISON: That's going to be important for them to pick up where they were.

MR. MILLER: This is Richard Miller. Yes, but will they be able to pick up where they left off?

MR. MAYER: Yes.

DR. LEMASTERS: But why five minutes? I mean one of the comments that was written in this document that the committee put together was that five minutes doesn't even give you hardly time to go to the bathroom and back.

MR. MAYER: I think it's for security purposes, especially since we're having the social security numbers open and their complete work history and health history. So, I think that's where we were coming from with that five-minute cutoff.

MS. RAUDABAUGH: There are actually government regulations that we have to abide by. And I'll double-check with our security officer and the CDC security officer, but I think there's like FISMA controls or whatever that we have to abide by.

DR. LEMASTERS: But the social security number isn't asked until last. They wouldn't have gotten to that. To be perfectly honest, when I am logged off my continuing education courses I have to take, it's so frustrating to have to go back in. And I think we want to decrease that frustration as much as possible. So if we can make it longer than five minutes, or at least alert them if they're away for five minutes, they're screwed. They have to get back on.

MS. RAUDABAUGH: I agree, it is irritating and I will definitely get back to the top security people at CDC and whatever the regulation is we'll make is as long as possible. But we will also be very mindful of trying to have a good user experience if they do come

back to where they left off if they are signed off.

DR. LEMASTERS: Right.

MR. MORRISON: No, I was just saying we'll put a motion sensor on the computer and then when they move, the voice will say, “Hey, you know you're going to have to log back on?” But anyway, Grace, where are we?

DR. LEMASTERS: Well, Pat, I was thinking that since we're on the questionnaire, we should go back to Question Number 4 and 5 of the science issues that the NIOSH team wants us to answer. Could that be pulled up? There we go.

MR. MORRISON: Okay, and before we get to that place—yes, Grace, just one second. Richard, you had your hand up. Was there a comment you wanted? I did not see it.

MR. MILLER: Well, yes, this goes back to being logged off. Is the access going to be mobile adaptive, I guess is my question, to where I could fill out this form on my cell phone?

DR. FENT: Yes.

MS. RAUDABAUGH: Yes, I’m sorry, Kenny. So, geeky people call it responsive design and so we are going to develop an application that will be aware of what device you're using. So, if you're coming in on the Web, it'll kind of format it for the Web and if you're coming in on your phone, it should know and automatically kind of give you something that’s formatted a little bit better for your phone. That was kind of the nature of your question?

MR. MILLER: Yes, no, that’s it. Because knowing the limited capabilities within a lot of fire stations and limited time that you may have to do some of these types of extended surveys, firefighters are more apt to perhaps do these on their smart devices. So, if I can take the device and take the enrollment form on my smart device, then I can sit down and do it anywhere. I could do it in the fire truck if I have to. So, that’s the root of my question. So, then the five minutes and being logged off changes that time parameters somewhat as I can fill out the information anywhere pretty much.

MR. MORRISON: All right, Richard, that’s an excellent question, thank you. I’m going to turn it back over to Grace. Anybody else have any other comments on that? If not, I’m going to turn it back to Grace.

DR. LEMASTERS: Thank you, Pat. For the science issues, Question 4 and 5, I would suggest that if you have Appendix F—Enrollment Questionnaire—handy, you might want to pull that out. And in the overview, Appendix F—which is the questionnaire—I think while we're on the questionnaire for Questions 4 and 5, we'll just deal with any of the other issues that have been brought up. So, if you can have those two documents in front of you, we can go ahead and start with “What is the best way to estimate lifetime exposures and changes in implementation of controls over time as a firefighter?” And the second part of that question is “What role should follow-on or repeat questionnaire or department-level surveys play in this data

collection?" So, for the first part of the questionnaire, "What is the best way to estimate lifetime exposure," I would like to have my hand up, and just begin with my thoughts and then hear from the rest of the committee. I did a sort of practice taking the questionnaire as if I had three jobs—I was in three departments, that is. And what I found that as it is written now, the data that you will have for a whole work history is total duration, Question 16, latency, Question 17, job titles and position like full or part time, if you will not have exposure data or lifetime exposure and so you're not going to be able to estimate lifetime exposures, as I see it, with the questions that you have for all the previous jobs. But if you are able to add—and this is a suggestion of what I would probably do—if you would add for every job—say, like for your first department, because that's the way you're asking them now—if you would ask Question 25 and then 28 to 35, you would get the complete history and exposure history for every job. Now, I'm going to leave out Question 26 and 27 because that's about sleep and the recall on that is not going to be good for all those past jobs, how many hours did they sleep? I think it'd be poor reliability. But I think you could get Question 25 and 28 to 35 for all the jobs without—it took me six, seven minutes to go through three different departmental jobs I pretended to have. Now, that's my thinking. Anybody else? Or any comments from NIOSH, Kenny, anybody?

DR. FENT: Just that we've had some discussions—we got your comments ahead of time, Grace, and we understand the importance of trying to get that exposure history. I think we're struggling quite a bit on how to do that in as streamlined of a way as possible so that it doesn't make the questionnaire too long or burdensome. I mean we do know that there are going to be some firefighters that will have worked for many different departments on many different jobs over a long period of time. I guess I would really like to hear from the fire service stakeholders if they think asking those detailed kinds of questions for each job title would be too much in a questionnaire or if they have ideas on a more streamlined way of trying to capture that information.

DR. LEMASTERS: We have a hand up. Gavin?

DR.. HORN: Hey, guys, can you hear me?

DR. LEMASTERS: Yes, we can.

DR.. HORN: All right, very good, Gavin Horn from UL Firefighter Safety Research Institute. I do think you're going to start getting into quite a bit if you go through this for each individual department asking each one of these questions. But it might also be a way you might be able to look at it from when did an activity begin as opposed to on what department did it begin? We know certain things came online. The use of SCBA; some of the firefighters who've been on departments for 30, 40+ years, maybe they did not have SCBA when they began. So, could it be listed as "When did you begin using SCBA? When did you begin wearing full bunker gear

as opposed to three-quarters?" If we can narrow it down to a set of behavior changes that you're interested in—like showering, like cleaning skin, like doing decon, like regularly washing your gear, all of those sorts of things—maybe you could just ask approximately what year did you begin doing these behaviors? Many of them, SCBA wearing, at least for firefighters nowadays, will have been their entire careers. Others might have been more likely. That can at least get you to what are the kind of behaviors that you might be able to quantify in a short period of time. So, just a thought because I do think it's going to be a whole lot for people, especially to think back throughout their careers.

DR. SIEGEL: Gavin, this is Miriam. So, if we ask when they began a certain protective activity, for example, is it safe to say that, in general, you can assume that since that time that activity has continued; in that meaning that firefighters don't start to not practice a protective behavior, but it's usually consistent from that point on?

DR. HORN: No. I mean I don't think you could assume any of these will be done 100 percent in any case. I think we can start to get a handle on it and get some bounds on when it increased, but these will change significantly and behaviors will change even within an individual response based on the environmental conditions, based on exhaustion during the fire response. So, rarely are you going to get someone who does things every single time. But if you're looking at when a behavior change might have occurred, maybe you could say, "Okay, when did you start, when did it become a common practice?" But I think for brevity, just to say when it was something that became commonplace within that individual or within that department, will allow you to get a handle on it. But it certainly will not give you the percentage of time like you have here with "never," "rarely," "sometimes." So I don't think you'll get that level of granularity, but you might get more responses and a little bit easier analysis with those responses.

DR. SIEGEL: Sure, sure. But kind of what I was asking is, is it safe to assume that that becomes a common practice and doesn't stop being a common practice, in that there's an instance where a firefighter will start doing a protective behavior but then stop completely doing that at a later point in time?

DR. HORN: Yes, I hate to make generalizations. I think that's not a bad assumption that—again, once SCBA has become adopted, it's now become pretty much commonplace. When departments begin doing decon, it continues on quite regularly. So, it would be an assumption, it would be an addition assumption that would have limitations.

DR. SIEGEL: Sure, sure.

DR. HORN: But I think that would be the tradeoff you would make. So, I think that you can largely expect that, but not 100 percent. And, again, I would defer to the rest of the firefighting group as to what their thoughts would be on that.

MR. MORRISON: This is Pat. Thanks, Gavin, for that. That's interesting and the follow-up

question was even more interesting with will firefighting continue to maintain that behavior. A lot of it is going to be department-driven with their guidelines, their SOPs. And it's unfortunate, but some of it has to do with leadership. But over time, what we have seen, when changes have come in, it takes a while for the fire service to get to that fulcrum. But eventually when they do, then things that we did before, all of what you see now, you just don't see that anymore in certain areas. So, there is some consistency. It just takes—it takes time and it takes leadership, and that those things are going to be mandated. So, anybody else on the fire side here that—I don't see any other hands?

MS. WILSON: Yes, this is Regina. I agree, it has to do with leadership.

MR. MORRISON: Regina, you're breaking up.

MS. WILSON: Okay, sorry.

MR. MORRISON: Your better.

MS. WILSON: It's whatever protocol that the department wants to use and whether or not they're going to implement it, and then it also has to do with the culture of the firehouse. So, if the firefighters see that all the other firefighters are doing it, it becomes a part of what you do every day and what everybody does. And so they follow suit because they don't want to look indifferent. So, it's all about whether or not the departments make it mandated and the officers implement it, and then whether or not the firefighters pick it up, use it, and continue to. So, it's a follow-the-leader kind of job, really.

MR. MORRISON: I agree. I see Virginia. Thank you, Regina. Virginia, your hand's up.

DR. WEAVER: Yes. So, I just wanted to say we've taken lots of histories from firefighters who develop cancer and we go back through what PPE they've used, et cetera. I don't recall ever having someone backslide unless—the potential would be if they change departments in probably a fairly different area, then they might end up being in a setting where they're using less protective behaviors. But I would say that's relatively rare.

DR. SIEGEL: Thank you. And by "area," do you mean geographically or subspecialty?

DR. WEAVER: I would say geographics because I think that once a department starts to put new guidance in place that's going to increase protection, there's a rollout phase and it's adopted over a period of time. But I think that, in general, areas tend to rely on each other. And the big differences we see are in huge geographic areas, rural versus urban, or parts of the country.

MR. MORRISON: Thank you, Virginia. We'll take two more questions on this. I think we have Richard and Shawn.

MR. MILLER: Thanks, Pat, this is Richard. So, one way we could do this as a way to assist the fire community in remembering key dates would be to provide a list of when things changed in the fire service. So, when did the fire service move to making SCBAs mandatory in the sense of wearing them? When did we move to trying to

get the whole fire service to wearing full bunker gear? When did two-in, two-out come on board? When did the fire service try to move to ensuring everybody was wearing fire protection hoods? When did NFPA 1500 come out? When did investigators start to look to wearing respirators during active investigations? So providing some key dates and significant dates for the fire service might help them remember when their fire department began to make that phased change to a positive change of doing more things to protect themselves. And it's just a way to provide them the history of safety culture change that made say, "Oh, yes, I was at this department at this time and that's when we made our change." "NFPA 1500 came out and that's when we started to put that safety change in place." Or, "This is when in 1985 we went to making a change in our PPE and that was a significant change to us doing that." "Oh, that's right after I got diagnosed with this." So those kinds of things will then be a way to trigger some things. So, just a thought, that's my suggestion.

MS. WILKINSON: This is Andrea. I think we'll definitely explore that option. That suggestion was wonderful, thank you.

MR. MORRISON: Thanks, Richard. That was wonderful. Shawn?

MR. BRIMHALL: Yes, I'm just going to say for your legacy firefighters a way to refer to us, because I've been doing this for a while, we're going to have all experienced all those different PPE changes from starting with three-quarter boots and rubber jackets, and orange fireball gloves and plastic helmets, and may or may not have had access to an SCBA, to the evolutions of the bunker gear and hoods and the other changes over the years. So, I don't know how qualitative that's going to be looked at between each agency because some of those changes are agency-driven, some of them are individual-driven. I bought my first pair of bunker pants because I got burned in a fire when the fire came up my rubber—below my jackets above my boots—so that pushed me to pay for my own proactive layer and so there might be some individual answer to that. But looking at some of those things—the type of alarms, number of alarms—when you have this 34-year firefighter or longer, that's a daunting task to imagine. I remember most of the plane crashes I was at because I've been at one. Most of the boat fires I've been at because I've been at probably five. But number of structure fires, number of brush fires, number of car fires, number of dumpster fires, some of those other things, I'm not going to remember them all.

MR. MORRISON: Thanks, Shawn. Barbara, do you have a—go ahead, Kenny.

DR. FENT: I was just going to ask Shawn, do you think that you would know approximately how many structure fires? I mean maybe you wouldn't know exactly when they occurred or details about the individual ones, but would you know approximately how many structure fires you had been to in your career?

MR. BRIMHALL: Probably not. Not really something I would have any reason to remember unless

they were significant, a fatality, arson, multiple building fires at the same time. Because when my career started, I had an arsonist in my area who was burning every barn down in town and we were pretty busy for the first couple years I was a volunteer firefighter. But number, I don't even think if I sat and I tried to think about it for a couple hours I could be a good, accurate number on number of fires. And then the thing for me, too, is anybody who's an instructor, you're doing training fires all the time so you may be able to go back through records and say, okay, I taught this many Firefighter 1s over the years so I would have had—four of the twenty-eight units were fire evolution so those would be potential ones. For arson investigators and fire investigators, they keep very detailed records because they have to by standard of exactly what they do, so they may have a little better grasp on that. But for the average firefighter keeping track, especially if you're in a busy department like Regina down in FDNY—and in case you didn't notice, Regina has an outstanding voice, she does the National Anthem for us at the New York State Firefighters Memorial, just throwing that out there in case you ever want to hear her sing—that's not going to have a chance of remembering them all.

DR.SIEGEL: Can we add a charge question for her to sing for us?

MR. MORRISON: Okay. Barbara, you have a question?

DR. MATERNA: Yes. So, I've been listening to all this discussion about capturing information about respirator use and other PPEs. And I was wondering, so you have Question 28, which I think you could clarify to mean "How often were you exposed to smoke without regard to the use of respiratory protect?" because I think you want to be clear on that; otherwise, people might not call themselves exposed if they were in an SCBA. Or I'm not sure what you're getting at there. That was like a more minor point on clarifying. But I'm looking at Question 29, "How frequently do you or did you wear respiratory protection?" and then you have all the different types of fires and obviously the use of respirators is going to vary with that. But it occurred to me wherever they have used respirators, insert there the question "Approximately what year did you start using this type of respirator?" Anyway, that's just a suggestion. And then my other question is related to 31 or this whole series on PPE. It never asks what PPE that is, so you're not going to have any information on changes and all those other things people mentioned—three-quarter gear, this or that or the other thing—because you have no information about types of PPE anywhere.

DR. LEMASTERS: Okay, I think that's an excellent comment for NIOSH to consider. I think we probably now need to look at the second part of that Question Number 4—unless you think we've answered this already, guys—"What role should follow-up or repeat questionnaires or department-level surveys play in this data collection?"

DR. FENT: Hey, Grace, before we move on to that part of the question, I like the

suggestions. It actually sounds like a lot of people on our committee have a suggestion that it would be good to collect information on when some of these changes and PPE policies took place, which I think those are great suggestions. But I think we also want some idea of how those correlate, then, with the fire responses that the individual's been on. Right now, we have some questions—this is why I was asking Shawn if he could remember how many responses he's been on, but we have questions just like "Estimate the number of these different types of fire responses you've been to in your career." So that gives you sort of a magnitude of the responses, but it gives you no information on when those occurred. And I think, Grace, you had a good point that we really want to know when those responses took place for lagged analysis and then also with respect to changes in PPE policies, because if you had a lot of responses in the Nineties, PPE use was very different than it is today. So, I'm curious if anybody on our committee has any suggestions on how we can better capture some of that time-result information on responses.

MR. MORRISON: Kenny, this is Pat. There's one area. Prior to exposure tracking—and this whole project is probably going to put a lot of good push toward why it's important for firefighters to monitor their exposures. But those exposure apps that we're seeing now that can be tied into the incident reporting, moving forward in some cases is going to be easier I'm hoping because this thing is going to be around for a long time and I think we're going to have to really take a look at that, the firefighter actually reporting their daily exposures and then that actually tracks back to an incident and then you get the number of calls. I believe in what Shawn said, sometimes you have to go back and some people that have been around for a long time, it is difficult to do that. So, I'm interested in hearing what Shawn said, sometimes you worked at busier station for your first 15 years and then you went to a retirement station to kind of settle down and not getting up every minute. So, there's a lot of different variables in that. And then the department, they do some sort of tracking of the pieces of equipment that you were on. You can have that, but there's so many different variables in that. Trying to get our hands around that is going to be important. I think it's going to be critical. How we do that, I'm not too sure. So, I'll listen to some others. Shawn, do you have your hand up on this one?

MR. BRIMHALL: Oh, I might have left it up from before. I'm trying to multitask. I came home to mow my lawn and do my laundry. I'm going from one COVID testing site in Brooklyn to one in New Rochelle for a couple of weeks.

MR. MORRISON: Oh, God.

MR. BRIMHALL: Let me lower my hand here. I think that part of the concern for me with trying to tackle all that stuff and look back is I would have a hard time trying to go back to some other departments to get it because I don't know how much information

they'd had either over the years. I know that maybe the one mindset is when did things start to change and when did you start to change? I could probably timeline that a little easier than I could how many incidents I had in that timeframe. That's just my take.

DR. LEMASTERS: Shawn and Pat, the challenge is that the cancers that are going to occur in the next five, ten years are going to be related to the exposures twenty years ago. I mean the first cancers that we're going to get is going to be about past exposures so it becomes very critical that we try to, as well as possible, find a way to characterize those exposures in the past and the cancers that happen now. The exposures were 20 years ago.

DR. SIEGEL: And to add on to what Grace was saying, the question doesn't need to necessarily result in an accurate estimate because if the firefighters that were working back then were all kind of inaccurately estimating their fire runs kind of across the board, then that still works just as well because we're able to comparatively run these analyses with the same degree of inaccuracy across all those firefighters. So, it's just kind of like a best guesstimate is all we would shoot for, not necessarily the same number that might be reflected by incident records.

MR. MORRISON: I mean it is an estimate and we understand that and you're roughly get—there'll be a variance on that that, if they take some time to think about it, they're going to get—that's going to be an interesting—I know that even in the NIOSH cancer study, the most difficult part was going back and getting the exposure. And that was very difficult. That was the harder part of that whole program and the information we needed. That was probably the most important. So, I know this is just a critically-important question. I know how Grace just put it out and how do you say that this group had this cancer, and the one thing in common was the number of fires they were on. So, it just meant that they had—how much more exposure do you have, and exposure is extremely critical to tying in the link to the cancer. So, with that, do we have anybody else out there that want to—I think this is a really important segment here that we have to take a look at.

MR. HORN: This is Gavin real quick. One other thing we might think about this, as opposed to trying to ask someone what their numbers or estimate their numbers, I mean you're eventually going to chunk this when you do the analysis, correct? So could you just have less than 10, 10 to 50, 50 to 100, and just put it in those—if you have those rough groups or categories or ranges, that would be much more likely for firefighters to be able to remember and say, "Yes, that year, during the war years I ran hundreds per year, but recently we're running 10 per year," or something along those lines that would allow us maybe to do a little bit easier analysis on the back end, but also would maybe prompt the firefighters to put in a range as opposed to trying to get a specific number.

DR. LEMASTERS: Yes, that's not a bad idea to do it into categorical responses probably is easier to recall.

DR. SIEGEL: You know, that's a good suggestion and that's something we've talked about in the past too, and we would certainly willing to discuss further. But the critical information we would need is what those bins, what those ranges should be because right now we have no jumping-off point of the ranges and the distribution of that number of incidents, that quantitative distribution to form those ranges off of. So, it would require a little bit of front-end information gathering, which is certainly possible for members in the fire service. But we wouldn't be able to create those categories as of right now.

DR. LEMASTERS: Would some of us be willing to help with that?

MR. MORRISON: Yes, I think we can get a group together to help with that. That's not an issue. I think we could probably take a look at this and see what's been done before in the past, also on here too. So, it looks like we've got some hands up here. We've got, I think, everybody here. Betsy, did you still have a question? And then Virginia.

MS. KOHLER: Yes, it was just a suggestion on collecting the exposures of potentially having sort of a nested questionnaire where, to the point of the exposures occurring 20 years ago, maybe we could have a special portion of the questionnaire for people who began firefighting more than 20 years ago to collect more detailed exposure history.

MR. MORRISON: That's to the NIOSH staff. Do you guys have any comment on that?

DR. SIEGEL: I think that's a good suggestion and something we can potentially entertain. Once again, it would require us to work out what the threshold would be and what extra details to obtain for which firefighters.

MS. KOHLER: Right. You might be able to ask them if they would be willing to do it as a separate questionnaire or something like that so you could keep the base questionnaire short, but it would give you good exposure data for the analyses now and then collect further exposure data on follow-up questionnaires down the line for the people who have more recent exposures.

MR. MORRISON: Okay, thank you, Betsy.

DR. LEMASTERS: Okay, that was a good idea.

MR. MORRISON: Yes. Virginia?

DR. WEAVER: Yes. I just wanted to say that, again, in my experience, firefighters are much better at remembering unusual fires so they can generally give us a list of industrial fires, very challenging fires, and approximate year that they did that. And that would all be useful information to capture potentially. They can generally indicate that they fought more fires in the past, although sort of a moving target. But I think it would be helpful to have the option for them to select a different range more recently compared to in the past and then pilot testing,

whatever questionnaire you develop a lot to try and figure out what works and what doesn't work.

MR. MORRISON: Thank you on that. Richard?

DR. LEMASTERS: Thank you for that, Virginia. Richard?

MR. MILLER: So I guess the one question would be to put it back into USFA if whether or not we could try to glean any specific information by department from the National Incident Reporting System. And it may have to go back to the individual because it's a global system, because a department would have to make that request of their data by year. So, I'd have to look back and say how many incidents did Fairfax run in the specific year, but then you would have a global total for that year and then I, as an employee, would say, "Okay, I worked in that given year," so you would get a perspective of we ran 500 house fires or 500 incidents that year and I, as an employee, worked one-third of the time on that year and perhaps I was then on that number of incidents. So, from a bigger sense, you would have a very pie-in-the-sky kind of number to look at, so kind of to Gavin's point of looking at big numbers from a historical perspective.

MR. MORRISON: Good suggestion.

DR. LEMASTERS: Okay, thank you. Any final comments, one or two final comments? NIOSH team, do you think you've gotten enough from this now?

DR. FENT: Yes, definitely. This has been a great discussion

DR. LEMASTERS: I think you should feel comfortable calling on the committee for some—if you go categorically, individuals might be able to help you out with that, right, Pat?

MR. MORRISON: No, I think so, yes. I think the thing that we do well is that when we pull it together, Kenny, we can probably get this thing a little bit more fine-tuned on that. I mean I understand all of these questions. And then you start to go backward. Grace just said if you go back 10 to 20 years when they were fighting fire, back then a lot of us, overhaul wasn't something you used SCBA. Today's time you might be on the same amount of calls that somebody was on 10 to 15 years ago. And we talked about this before, but the difference was what was acceptable back then is not acceptable now. And you'll see a different—we should see a variance in that there too. But yes, Grace, we can assist with this in really pulling in on this advisory committee, using it to have more input on this is an option on the table for you, Kenny.

DR. FENT: Great, thanks.

DR. LEMASTERS: Okay. Are you still interested in the question about "What role should follow-on or repeat questionnaires or department-level surveys play in this data collection? Or has that been answered? What is specific the issue?

DR. FENT: I think we can maybe skip it just simply—or not skip it, I think we've heard some guidance on this already. But I will just say that I think some of the points that were made about trying to collect some information from the firefighters on when

PPE changes happened I think is important. I think Regina made a good point that often times what you see at a fire station may not reflect policy. And so I think having that department-level survey is also important because that gives you an idea of policy—having the individual questionnaire gives you an idea of the implementation of the policy. So, I think we're still very much interested in those department-level surveys, as well as repeat questionnaires. But it's a little hard to get into the weeds on it right now because we still have to develop those questionnaires. So, I would kind of kick this down the road a little bit until we have those amendments to the protocol.

DR. LEMASTERS: And the committee can always meet again.

DR. FENT: Right.

DR. LEMASTERS: That's what we're here for, to be of assistance. Let's go to Number 5, then. "What other important variables related to cancer risk should be collected as part of the enrollment process and what should be included in follow-up surveys?" So what's asked now is smoking, exercise, and alcohol use. Would you not want to use those same questions to update?

DR. FENT: I guess that's a question for the committee. We ask some information on smoking and alcohol use. Should we continue to collect those and follow-on surveys? I think it probably makes sense to do that. I know that lifestyle factors certainly change over time. If you look at our questionnaire you'll notice that we don't have any questions on like diet, for example. We went back and forth on that, but the decision was made that—and we consulted some experts in nutrition research—the decision was made that there are just too many questions that you would have to ask to sort of really evaluate that risk factor, so we decided to pull it out of the enrollment questionnaire. But it might be something we would be interested in doing in a follow-on questionnaire. And there may be other—I think we touched on this a little bit in our presentation, but when they want to ask more questions for female firefighters, for example, or other subgroups where they may have specific work environments that we want to learn more about.

DR. SIEGEL: I think what this question is getting at is with any kind of project like this, you can expect a certain degree of loss to follow-up for follow-up questionnaires. So, we just want to make sure we're getting the critical information, again, balancing the scientific needs with the needs for a short and user-friendly survey. So, we want to make sure we're including what we can in the enrollment survey and then that we can get other useful information that can be saved for follow-up surveys as well.

DR. LEMASTERS: Yes. Well, we have three comments from people about this, so let's just start with Richard and go down the line. We have four comments. Richard Miller?

MR. MILLER: Sorry, I got to take my hand down.

DR. LEMASTERS: Oh, okay. Sara?

DR. SIEGEL: Yes, I would just like to say that I think it would be nice in future surveys to ask some sort of question related to stress or behavioral health just because of the role that plays with all the other health behaviors in terms of risk. I did also have a comment on Question 26, 27 as was rereading this, and maybe even 25, that those refer to shiftwork. And I really appreciate your including sleep on this, but for the volunteer fire service they're not necessarily going to be on shift. Their shift's going to be 24/7. So, it might be useful to have a slightly different wording for those questions that fall out like if you're a volunteer firefighter, you get that version of the questions. I just want to throw that out there for the record.

DR. LEMASTERS: So shiftwork if you're one of those firefighters and issues related to stress, right, Sara?

DR. JAHNKE: Correct.

DR. LEMASTERS: Is that what you're suggesting?

DR. JAHNKE: Yes, yes. And there is the information on shiftwork and sleep in Question 26 and 27 on the draft that we have, but it just refers to shift. And I think for the volunteer fire service we'll want to ask questions more generally about average number of sleep not necessarily on and off shift because they would be on shift I guess technically all the time.

DR. LEMASTERS: I think for current jobs, they could certainly get at sleeping very reliable—reliably. And one or two questions about stress is always—stress is always an important question related to cancer development. Thank you, Sara. Barbara?

MS. WILKINSON: Sara, could I just ask a quick follow-up? I know you've done a lot of work with sleep. Do you feel that the questions we're asking are complete enough to give us meaningful information? Because that's another area that we went back and forth on like the nutrition questions where we want to make sure we're asking enough that it means something but not be burdensome. Do you think the questions there will give us useful information?

DR. JAHNKE: I do. I mean obviously I'd like to add three hours' worth of questions on sleep but given that's not possible, I think the questions you have are nice questions.

MS. WILKINSON: Thank you.

DR. LEMASTERS: Barbara?

DR. MATERNA: Thanks. My comment was related to the tobacco products section. Did you consider asking whether they smoke marijuana as well?

MS. WILKINSON: We had one conversation with a firefighter regarding this and they advised us that there would probably be a strong bias on this question as many firefighters might not feel comfortable answering it as it probably goes against their fire department policies. So, we had decided to just eliminate the question.

DR. MATERNA: Okay.

DR. LEMASTERS: Okay. Yes, we have some more. Let's see, Betsy?

MS. KOHLER: Mine has to do with the family history of cancer and we might consider adding

child as a first degree relative in there. And actually I'm thinking that cancer in children of firefighters would be a really interesting subtopic, but if we could get the child, we might be able to use that as a marker.

DR. JAHNKE: Betsy, that's a really interesting point you bring up and we did have some conversations before with some other epidemiologists about adding children as an immediate family member. The challenge was just adding that one item and we're happy to hear your opinion, is interpreting it as a risk factor for cancer for the firefighter themselves versus separating out the potential interpretation of take-home exposures causing the childhood cancer.

MS. KOHLER: Yes, it would be a knotty topic, but it would be very interesting. "Knotty" meaning complicated, not poor behavior.

DR.SIEGEL: Yes, K-N-O-T-T-E, right. Yes, I understood, no problem.

DR. LEMASTERS: Okay, I think that addresses all the comments from the committee. Any final questions or comments from the team? Oh, one more from Betsy: "What about collecting usual occupation for the volunteer firefighters?"

DR. SIEGEL: We do have an item, just a basic industry and occupation item for any non-firefighter jobs worked and we do intend, as follow-on question, potentially getting a more comprehensive external work history.

MS. KOHLER: Great, thanks.

DR. JAHNKE: And this is Sara. Sorry, one more thing on the tobacco use. Would you want to get some type of measure of the amount of use when they used it so you could calculate like past years?

DR. FENT: I think that's a good point and we've kind of gone back and forth on that one too. We'll have to revisit that, Sara.

DR. LEMASTERS: Yes, number of cigarettes smoked was not in here. I think that's a good idea to add that for past years. It's a critical variable. I would agree totally. I'm looking over our whole section of comments on National Firefighter Registry Protocol Version and Appendix F section has pretty much been covered totally in this discussion, so I think we can move on to the comments regarding the rest of the protocol. And some of these may have been answered also. Does everybody have that in front of them? Because I'm going to be referring to Pages 1, 2, 3—

DR. MIDDENDORF: Emily, can you bring that document up?

EMILY: Yes, just give me a moment. I have to convert it to PDF first.

DR. MIDDENDORF: Okay, thanks.

DR. LEMASTERS: While we're waiting for that, in terms of the background and there were a lot of comments that are primarily editorial. But there was one who's question that was brought up a little bit later in this document that also had to do with the comment in the front part and that was "Could you possibly make wildland firefighters one of your targeted groups?" And this goes to NIOSH.

DR. FENT: So I think this is a resource kind of issue where we're trying to prioritize the, I

guess, limited amount of funding that we do have and really target the groups that were specifically called out in the act, which includes female, volunteer firefighters, minority firefighters. And granted there are certainly female firefighters that are part of the wildland fire service. But it's really resource-driven and so that's why we're focusing on structural firefighters initially at least for our targeted cohort. That said, I think we're certainly open to having a more targeted approach for wildland and maybe even other groups, but that I think would be on another down-the-road phase of the project.

DR. LEMASTERS: Comments from the committee? I see two hands raised. Barbara? Betsy?

MS. KOHLER: That's an old one. Yes, I'm trying to get it off.

DR. LEMASTERS: Okay.

DR. WEAVER: This is Virginia. I did have my hand raised.

DR. LEMASTERS: Virginia?

DR. WEAVER: Yes, so I would strongly encourage attention to wildland firefighters to the extent possible. I know resources are incredibly limited for this project, but it's a workforce that I'm increasingly worried about and a lot of others are as well due to the extended fire season that is likely just going to get worse and worse. And the fact that the protective equipment that wildland firefighters have is vastly different than structural firefighters and nowhere near as protective.

DR. SIEGEL: And just to echo what Kenny said, I think we really do hope to have an assertive communication and recruitment strategy for wildland. They'll certainly be encouraged to enroll with heavy representation into the open cohort. The more representation we can get into that open cohort from wildland, the more robust analyses we'll be able to do. And the point is maybe we can develop a separate communication protocol just for the wildland community.

MR. MORRISON: I'd have to agree with what Virginia said. And thank you for that last comment, too, because I think we can get them in that open enrollment. We have a combination of—what's going to be interesting, too, with the urban interface, we have so many firefighters wildland but structural, too, at the same time. And Virginia's right there. I think the increase, it is alarming. And I know in our association with the wildland, we're doing a lot. There's a lot of work going on out there. But I think we will be able to help you and assistant you in really getting that push in the open enrollment so we have enough representation in that special sort of sector there, too. That's going to be important for us.

DR. FENT: And I think it's important to also keep in mind that if we have really good response rate from the wildland firefighting community—for example, US Forest Service or CAL FIRE, whatever the group might be—then they could be part of the targeted enrollment just simply from a high response rate and then we could work with those organizations to get more detailed records.

MR. MORRISON: That's good to know, Kenny, thank you.

DR. LEMASTERS: Any other comments? Barbara, your hand is raised.

DR. MATERNA: Yes, thanks. So, I would just second what everybody said about the rationale for trying to target wildland firefighters for the open cohort. The increasing fire season, the lack of use of respiratory protection in that whole segment of firefighting, and it just reminded me of a thought that I had earlier and I didn't have time to comment. When you ask them about the number of fires over their career, that metric doesn't really translate well for wildland firefighters because they could be on fires that last for weeks rather than individual calls. So, you might think about that.

DR. FENT: Yes, we agree. I don't know if it made it in this version or not, but I think we were trying to adopt that question to get at not a fire response, a campaign fire, knowing that it lasts for days or weeks.

MR. MAYER: Yes, we have it in there currently asking how many days have you spent actively responding to wildland fires specifically for the wildland, rather than...

DR. LEMASTERS: Paul, the document that s been brought up is not the one we're looking for. We're looking for the comments by the committee on the National Firefighter Registry's protocol.

DR. MIDDENDORF: Emily, do you need me to send you the PDF of that?

EMILY: Can you all not see the PDF?

DR. MIDDENDORF: We see a PDF, but it's the protocol, it's not the comments.

EMILY: Oh, I'm sorry. Yes, I will pull that up. I misunderstood your request. Yes, I will do that.

MS. WILKINSON: Could we just ask if—I think Chuck and Shane, if you have any input, I believe we're on, if you have the document, the protocol Page 62 is where we ask the wildland firefighting, we say, "Approximately how many wildland fires have you responded to in your career and then, in total, how many days have you spent actively responding to these fires?" Do either of you have different language or suggestions for how to appropriately ask that question, or anyone else with wildland—

MR. BRASKO: You want to go first, Shane?

MR. GREER: Yes. I finally got my hand to raise on here. I was trying to raise my hand and it kept going away, so I apologize.

DR. LEMASTERS: There you go, Shane.

MR. GREER: Yes, we don't really use this. Oh, okay. I'm used to Teams and Zoom and all kinds of things, but not this. Two things on this wildland firefighter thing and then I'll answer your question. Kenny and I have talked extensively about how to deal with wildland firefighters and there's kind of two components, as you all know. There's people like me. I've never been to a structure fire. I started fighting forest fires in college. As to the number of fires, I've been to almost 1,000 forest fires. How many days? I don't even know. Could we get to that question? Yes,

probably I'm going to have records of most of my stuff. So, my group of people, like from the Forest Service or even a lot in CAL FIRE where they do some structure things, we're a difficult group to get at. Until—jeez, I can't remember—maybe 15 years ago, we weren't even identified in our own HR system as firefighters. We're still actually not in a series of firefighters. There's just a trigger for our retirement that says Shane's a firefighter. So, on top of that, then we have this whole militia thing within the federal government, BLM Forest Service, et cetera. Well, you can be a wildlife biologist, but you're qualified as a firefighter so you come to fires. So, we can't even tell if they are firefighters per se in the system, so getting to them and finding out what their records are and where they were is even more difficult. So, there's that group, or those groups I should say. And then there's like L.A. County or Ventura County or West Metro and Colorado that their structure departments that go to tons of wildfires. So, I agree with Kenny at this point, sort of focus on the structure thing and get at some wildland issues perhaps that way. And wildland do everything in our power in the federal agencies to get the Forest Service, the BLM, et cetera, to voluntarily go into the database and see how many we can get. But it's far more difficult. It's a complex problem that I don't want to waste everybody's time on here. And with those questions, again, to answer that question about number of fires and days, yes, I think for the most part that's a decent enough question because I can tell you. I could look up how many fires I've been to and get close to the days. So, hopefully that was helpful.

MS. WILKINSON: Perfect, that's very helpful, thank you.

MR. BUSHEY: This is Chuck Bushey. I would add that besides what Shane just added there, I spent a couple weeks trying to figure out going through the different groups what the potential population segment was dedicated to wildland. And it's significantly lower, as would be expected, than the structural firefighter community. And there's parts of the wildland community that there are just no numbers on at all and the population tends to be—let me use the term "transient." They work for a couple years in wildland frequently during their college education and then move on to whatever becomes their lifetime career, something other than fire most likely. So, yes, it's a difficult population to get a grip on. The number that I supplied in my comments—129,000—that would be for like one year. And for the federal firefighters, I basically had to go into the budgets to see what was allocated in the federal budgets for the different organizations to come up with numbers. And the another point I would add that one of the frequently-used segments of the firefighter community for us in the last couple decades has been the rural and volunteer fire departments, especially on initial attack and mop-up. And those numbers aren't included in there at all. And maybe the national volunteer firefighter organizations wouldn't be able to get a hold on that. But

when it comes to the PPE, then you have fire departments that only have structural gear and other departments, especially in the West, where they'll have structural gear and wildland gear and depending upon the type of incident will depend upon the type of PPE that they respond in. And that can be highly variable depending upon the budgets for the volunteer and rural fire departments. So, like I say, you can get a wide variety of answers and the exposure and different exposure types can be very significant, I think. Thank you.

DR. LEMASTERS: Well, thank you. Any further comments?

MR. BRIMHALL: Yes, this is Shawn. I'll lower my hand. The other thing with wildland firefighters is they also do a lot of prescribed burning, which they may, if you don't specifically say it, it's not a response, it's a planned activity. We do a lot of them in the greater Capital District area of New York State, believe it or not, because they have an area where they have a natural habitat that they do 600 to 800 acres a year. And then Saratoga National Park, the Battlefield does a lot to keep the look of the park the same as it was during the battle. So, there is that type of activity. Then Nature Conservancy on Long Island is another one that does a lot of prescribed burning to try to keep stuff down. And that would be very similar to your fire instructors where it's not a response fire, it would be a prolonged exposure because you're in a training environment where maybe, even though you're rotating, you may be rotating over three to eight hours a shift doing fire suppression training.

MS. WILKINSON: Thanks for that, Shawn, very good suggestion that we need to add in language on—

MR. BUSHEY: Chuck Bushey again. I would add to that that the prescribed fire comes under a land management activity for most of us rather than a suppression response. And all our language management organizations—or at least the vast majority of them—are actively involved in prescribed fire opportunities, as is the private sector. We use a lot of private contractors that have a wildland background and I run a company involved in that. But also another organization that I haven't heard very much of mentioned here is Department of Defense. They do a tremendous amount of prescribed burning activity, much of it required by a federal law for various species management of frequently rare/endangered or threatened species. And either within their different military organizations are the contractors to the various DoD departments, they do literally hundreds of thousands of acres a year.

DR. LEMASTERS: All right, thank you. So, there are our comments on wildland firefighters and there's quite a bit that this committee is interested in and concerned about. So, I guess we just ask NIOSH to take that under advisement. It's time for our break. We have a 15-minute break now. So, when we come back, it will be what time will it be? I'm on Mountain Time so it'll be, what, 2:45—

MR. MORRISON: 2:55.

DR. LEMASTERS: 2:55? Okay, 2:55. And I think just Pat and I, I'd just like to coordinate a little bit for a minute. The rest can take a break. Emily, could you bring up Page 3? I think that's where we should start. Page 1 and 2 are just editorial comments that mostly have been addressed. And then Pat, if you could read through starting with Proposed Approach. Yes, I'll stop there. And look at what we've already covered and just hit the high points, nothing editorial at that point. And then I'll take over on Page 5 with Objectives and Data Management, Data and Analysis, Data Security, through Page 17. And then I think we'll be done because Appendix A and B had mostly editorial comments that I don't think we need to review. You can check and make sure you agree. Appendix B, same thing. And then we've really discussed the questionnaire pretty much in depth, so we've covered all those issues. Does that sound okay, Pat?

MR. MORRISON: Yes, no, that sounds fine there too. So, I've got Pages 3 and 4 and then going on here to—that would be fine. That sounds good.

DR. LEMASTERS: And half of Page 5.

MR. MORRISON: Oh, go to Page 5? We're not going to do a lot of discussion on this? You're going do Page 5?

DR. LEMASTERS: Yes, I would just say pick out the high points of things that we think are critical, not redundant in what we've already discussed. Some of things have been brought up. You know what I'm meaning, just the high points.

MR. MORRISON: I do, yes.

DR. LEMASTERS: Alrighty.

MR. MORRISON: Okay, we'll do it. I'll see you in a few minutes.

DR. LEMASTERS: Back at 2:55.

MR. MORRISON: Alrighty, bye.

DR. LEMASTERS: Bye-bye.

[Break.]

CONTINUATION OF PROTOCOL DISCUSSION

DR. MIDDENDORF: It's about 2:56 by my clock, so how about if we start up again? I need to do another roll call and, as always, we'll do it alphabetically. Shawn Brimhall?

MR. BRIMHALL: Shawn is on.

DR. MIDDENDORF: Thank you, Shawn. Chuck Bushey?

MR. BUSHEY: Present.

DR. MIDDENDORF: Thank you. Dennis Deapen?

DR. DEAPEN: Here.

DR. MIDDENDORF: Sara Jahnke?

DR. JAHNKE: Here.

DR. MIDDENDORF: Okay, Betsy Kohler?

MS. KOHLER: Here.
DR. MIDDENDORF: Grace LeMasters?
DR. LEMASTERS: Here.
DR. MIDDENDORF: Barbara Materna?
DR. MATERNA: I'm here.
DR. MIDDENDORF: Brian McQueen? Okay, I'm not hearing anything from Brian. I'll come back in a minute. Richard Miller?
MR. MILLER: Richard Miller's here.
DR. MIDDENDORF: Pat Morrison?
MR. MORRISON: Pat Morrison's here.
DR. MIDDENDORF: Virginia Weaver?
DR. WEAVER: Yes, I'm here.
DR. MIDDENDORF: And Regina Wilson?
MS. WILSON: Here.
DR. MIDDENDORF: Thank you. Going back to Brian McQueen, Brian? Okay, not hearing Brian. I'll put something in the chat box that you can respond to when you do get back. But that gives us 11 and that is a quorum, so we can move forward. Grace and Pat, do you want to take it over, then?
MR. MORRISON: Okay. We're going to go and I think that—is Grace on? Did she get on?
DR. LEMASTERS: I'm on, yes.
MR. MORRISON: Okay. Grace, you want me to take it from the Proposed Approach to questions that we have and work down that way?
DR. LEMASTERS: Right. We don't need to cover every one because some of them are just editorial, I think.
MR. MORRISON: Yes.
DR. LEMASTERS: But I think if you can start there, that'd be great.
MR. MORRISON: Okay. Yes, we'll just start. We'll kind of work down. There might be some comments from the NIOSH team on this, too, because some of these are questions. And whether they've taken these and changed that approach, or thinking about changing the approach, what I would like to hear from that team is that did you take any of these recommendations and plug them into the approach? Does that make sense? Hopefully it does.
Anyway, we're going to start on Page 3 of 13, Section 4, Proposed Approach. The first one is Question 12. That's the cohort consideration. This was interesting. This is just the departments that we are recruiting from, number of women that will be recruited from, and they were looking at the sample size and they were looking at if there was another way. Do we have anybody from NIOSH that wants to comment on this real quick?
DR. SIEGEL: Sure, I can comment a little bit on this. Specifically, I think the comment pertains to departments with a large number of women, if I'm in the same comment field

you are. And I think the threshold for that is to be determined. I think we're shooting for selecting some of the departments that have the highest numbers, just sheer numbers of women in the country. And a lot of that's going to be informed by some information that we get from NFPA. I know NFPA conducts a survey where they get information on female workforce from departments. And so we don't want to define a strict number as of now because we don't want to exclude anyone based on which departments are able to participate. It won't be a percent of the workforce because some departments with a high percent of women might be very small departments potentially and we'd rather recruit from departments with large numbers of women for the sake of sample size.

MR. MORRISON: Okay, thank you for that. The next question we're going go, we're going to go down here if anybody has—I don't have on my screen—somebody who can just look at raised hand, if we have raised hands on this going down. But 13, it was a good question. They're saying that basically the incident records for the departments dating back to ten years ago. They were wondering why just ten years, why aren't we going back longer than ten years that will be collected? And everybody on the line here, make sure your phones are muted. I think we have an open line someplace. So, with this, Kenny, do you know what, going back to at least 1/1/10 and is there anything that we need to address on this at all?

DR. SIEGEL: This is Miriam. So, incident records going back to 1/1/10, it's just kind of a benchmark to get departments to communicate that we would like incident records going back at least a decade in time. We chose 2010 because that's kind of a time point where we are hearing that departments made the switch to using electronic records. But where it's feasible, we would absolutely encourage departments to send us older records ideally going back to the start to which their current oldest firefighter started practicing. The farther back the incident records they are able to give us go, the more firefighters we're able to include in any kind of exposure response analyses. So, the 1/1/10 threshold is no definitive point in time.

MR. MORRISON: Okay, thank you, thank you for that. That's good clarification. The recruitment of volunteer firefighters from the department, it's an interesting one. This is from a career department with large volunteer. I mean there's some different—have you guys thought about that being looking at volunteers from rural versus volunteers from the career side? And that would be a combination system where they would have different—those volunteers would definitely have a different exposure in some cases, and equipment and other tools that they're using most likely in comparison with the career staff that's there. Any question on that?

DR. FENT: I think, again, this is kind of a resources issue where our targeted approach will be for those large combination volunteer departments. But we certainly

appreciate that there are differences among volunteer firefighters in more rural areas. And the problem is when we really started to delve into this, a lot of these smaller volunteer departments are very, very small and it's just not practical to try to target them in the targeted cohort. I'll let Miriam say something else about that, but it would be a lot of work to get enough sufficient numbers. Certainly they can register through the open cohort. And I'll let Miriam maybe say something else about that.

DR. SIEGEL: Sure. Just to provide a little bit more detail, Kenny's referring to Phase 1 of the targeted cohort sampling in that we're really going to focus on recruiting the vast majority of our volunteer sample sizes in the targeted cohort by working through stakeholder groups and organizations to identify those other large combination or large volunteer departments with large numbers of volunteer firefighters that will enroll. But then in that second arm, that Phase 2 of the targeted cohort, the Phase 2 sampling strategy, that is where we'll be able to select volunteer departments from all across the country with no restrictions proposed in selecting which volunteer departments are randomly selected to participate in those nine geographic regions.

MR. MORRISON: Got it, thank you on that one there too. So, in Question 15 on this one here that we have, Phase 2, this was the selection and use in the 100,000 population breakpoint on this and I took the question. Do you have a comment on this one, whether this is anything that we wanted to comment on that?

DR. SIEGEL: So the 100,000 population size served, it was somewhat arbitrary but we chose a threshold that we believed might designate, again, a large-versus-smaller department just on the basis of what's going to contribute a larger sample size. So, 100,000 was a threshold we picked as a designation for large versus small, but we are certainly open to entertaining other ideas.

MR. MORRISON: Okay. I don't have the questions. If anybody does have any questions, Grace can kind of watch those.

DR. LEMASTERS: Chuck has a question.

MR. MORRISON: Go ahead, Chuck.

DR. LEMASTERS: Maybe that's an old hand up.

MR. BUSHEY: Yes, that's the old hand, I'll remove it.

DR. LEMASTERS: Okay. And I have a question. And I see Regina and Richard have questions. Regina, would you like to go ahead with your question?

MS. WILSON: Yes, I wanted to find out—and I'm not sure if it was already mentioned or written in here somewhere. Is there any way for us to draw information from the career or volunteer firefighters? Because we have firefighters that are in the FDNY that also volunteer in Long Island, so is there ways that we can probably get information from those two types of people to be able to help the registry?

MS. WILKINSON: Hi, Regina, this is Andrea. Yes, absolutely, and that's something that we are

very interested in. So, when firefighters are completing their enrollment questionnaire, they can add both of the departments that they're working for, career department and as a volunteer, and answer questions regarding each. The one comment that came up earlier that we'll need to consider, though, is PPE changes. So, that's something that we'll go back and look at how we could potentially add that field in. But, yes, absolutely, that'll be really important for us.

DR. LEMASTERS: And Richard?

MR. MILLER: On the population for the department, are we going to be clear that it's the populations served, like not residents and daytime populations in metros surge? You could have a population of residents that's 50,000 or 60,000 but yet the daytime population could be 150,000. So, the population is higher in the daytime and, hence, the risk could be higher.

DR. SIEGEL: I think we were planning on going off information that we have from NFPA about departments, which I believe is department-reported.

MR. MILLER: Yes, so that could be confusing and that's kind of my point.

MR. MORRISON: I understand what you're saying, Richard.

DR. LEMASTERS: Can you elaborate?

MR. MORRISON: It would almost be like Washington, D.C. in the daytime that quadruples almost and then at 6:00 it empties out. Is that what you're saying?

MR. MILLER: Right.

MR. MORRISON: Those working in D.C. are not considered part of the population that come from the metro area. So, that city then triples almost—or quadruples almost, really—with workers coming in, but then they're not counted as the population base for Washington, D.C. It's just the population not served, but population that is the census population, correct, Richard?

MR. MILLER: Yes.

DR. FENT: So I guess a follow-up question from the program would be how do we get information on population served for departments? Does anybody track that kind of data?

MR. MILLER: It's not that difficult to look at. So, when you do census searches you can get your resident population and then you can get your daytime populations, so it's an easy search to pull that up. And since it's only a department question you're trying to pull in I think for those departments, if it's for individual firefighters it'll take a Google search and it's not that difficult to find. But it just depends on where it's going to sit in your calculation.

DR. FENT: Okay.

MR. MORRISON: And we'll go to 16. This is some people from the program, 16 and 17 because these are all sort of program—

DR. LEMASTERS: Oh, Pat?

MR. MORRISON: Yes?

DR. LEMASTERS: I've got a couple of comments still. Regina has her hand up.

MR. MORRISON: Oh, I'm sorry.

DR. LEMASTERS: And myself. Regina's hand just went down. My question has to do with the response of the committee so far. What I hear the committee saying is that how you define the population is very variable in time. Is that correct from all of you that are in the firefighting field, that during the day it might be 150, at night it's 50, so how is the size determined? Is there a table that provides this?

MR. BRIMHALL: Hey, this is Shawn. So, you're going to have the same issue no matter where you are. So, any metro area is going to increase during the day because that's where the people go to work and then the suburban communities decrease during the day because everybody went to the urban communities. So, you need to pick which one it's going to be and then stick with that. So, if it's residency location, then that's good. That's probably census-based.

DR. LEMASTERS: Residency location as who or what?

MR. MORRISON: People that are actually residents of that community. So, they're not coming in—

DR. LEMASTERS: Of that firefighting community?

MR. MORRISON: No, it's the community itself, Grace. It would be like in Cincinnati, if you took the population of Cincinnati, there is a census that's done on a regular basis. It's almost how the state divides some of the funding and money into the areas there. But Cincinnati, how many people come from not Cincinnati but maybe the metro area to work in Cincinnati, that wouldn't be included. The only population that would be included would be the population that is actually on the census. Does anybody else want to clarify that? I couldn't have been that clear, but I'll take it. I should ask Grace. Grace, did we answer your question?

DR. LEMASTERS: No, I'm still confused but if everybody else understands. So, like going back to Cincinnati, the cut with the 100,000, is it by city, the city, that demographic area? So let's say the greater Cincinnati metropolitan area would have more than 100,000 firefighters registered as firefighters in that community? And they might live in Kentucky, but they're working in Cincinnati.

DR. SIEGEL: So this is Miriam. Just to clarify a little bit, our plan with this 100,000 threshold is just strictly for the sampling design just to have a way to identify large and small departments. It's not being used for any kind of analyses. It's just a tool to identify departments of various sizes. And our plan was to use the department registry data that we have from NFPA or USFA, those national sources that collect that information for all departments. And that was just a tool that we had planned to incorporate into our sampling strategy for the target cohort.

DR. LEMASTERS: Well, thank you. Then like is Cincinnati considered one department or multiple departments? I mean I know the individual firehouses in Cincinnati and none of them have 100,000 but all together they probably do.

MR. MAYER: Yes, this is one department, yes.

DR. FENT: We're talking about the size of the community they serve. So, 100,000 is going to be your larger metropolitan areas in general. Under 100,000 might be some of the smaller departments.

DR. LEMASTERS: Okay, okay, That's—

MR. MORRISON: Yes, thank you. It's the community itself, yes. Grace, in NFPA they even have what they call the metro chiefs and those are departments that serve a population of—I think it's over 400,000. They have them kind of based on that. Then they have others based on different populations. But Cincinnati's fire department would be like if, let's say that your community is of 100,000. Then that fire department is serving 100,000 community members. That's what it shows. So, the size of the department is going to vary depending upon a lot of things, but it's all based on community census. How many actually live in Cincinnati, that department then would say that if it was—let's just say it's over 100,000 people and let's say it's 100,000; then that department serves 100,000; population base 100,000.

DR. LEMASTERS: Okay, thank you.

MR. MORRISON: Okay, going to 16, again, I'm going to need some program help on 16 and 17, unless there's any other questions. Sorry, Grace, you're going to have to be my guide. I don't know what I lost on my perimeter here, those raised hands. So, if you see one, just let me know.

DR. LEMASTERS: I keep looking. Yes, I think we're okay to move on.

MR. MORRISON: Okay. Program people, 16 and 17, you guys want to go through that?

DR. SIEGEL: So Number 16, I think I sort of mentioned in the presentation, but the reason we chose four regions for Phase 1 of the selecting volunteer departments is because we recognize that a majority of volunteer departments across the country are more likely to be smaller. So, if we divide the country into more geographic divisions, we're less likely to find large volunteer departments that are able to participate; hence, why we selected fewer, larger regions from which to identify larger volunteer departments in Phase 1. In Phase 2, there are less eligibility criteria based on size for those volunteer departments and that's why we're going with all nine smaller divisions of the US from which to identify career and volunteer departments.

MR. MORRISON: Okay, thank you. And 17 basically is just a comment, they think it's an excellent idea, I don't think we need to talk too much about that. And 18, I think we have talked about 18. Somebody's just recommending the wildland firefighters in a targeted group cohort. We talked about that, the open cohort and a targeted cohort. And Question 19, the program people, do you want to take a stab at that?

MS. WILKINSON: Yes, I think we'll ask our statistician, Steve Bertke, if he will weigh in on this.

DR. BERTKE: Yes. So, again, my name's Steve Bertke and I am the statistician for NIOSH.

I've worked and helped with these sample size calculations. So, for 19, that's the confidence intervals for some of those incident ratios. And for a power calculation, you normally don't have confidence intervals. Confidence intervals come in once when you've collected the data. And just to make a note I think to answer maybe some of the future questions coming up, when we did the sample size calculations, we were sort of thinking in terms of a worst-case scenario. How much could we do or what is the minimal amount of data we think we can reasonably get and what will we be able to see with that? So worst case, we were sort of just broadly saying, okay, how many firefighters would we need after 30 years to be able to detect various some broad cancer groupings; so just keeping that in mind as we go through I think some of these next few questions.

DR. LEMASTERS: Yes, I didn't get my hand up soon enough. My question is this: then your power calculations are done waiting for 30 years to pass before you think you will have sufficient number of cancer to detect in firefighters; is that right?

DR. BERTKE: Enough power, right. It doesn't mean we're only going to study it after 30 years. It just means by the end of 30 years, we should have enough data to detect any increased elevations in cancer. But you can certainly look at them as to 5, 10, 20 years and you may seed something. Again, there's a lot of predicting of what you think. When you do these types of calculations, you have to make some assumptions of what you think you might see. And it's hard to do that, that's why we're collecting this data. We don't know what we're going to see. I don't know if that answers your question.

DR. LEMASTERS: It just seems like a long time to wait for findings.

DR. BERTKE: Again, as you get more data, if we end up collecting more than the 5,000 we should be able to see more, earlier. But these were minimum numbers that we think we need to collect in order to make any confident findings from.

DR. SIEGEL: And, again, this is just related to the cancer incidence analysis calculating the standardized incidence ratios and comparing it with the general population. There's going to be other earlier analyses we can do earlier. Dennis and I talked about some of the possibilities with case control analyses that can be done by linking participants with state cancer registry records earlier on. So, this was one hypothetical analysis that's going to be done with the data and it's really the analysis that'll get at those cancer incidence rates. But there's all sorts of analyses that are going to be able to happen earlier than that. And again, just to reiterate what Steve said, it's a worst-case scenario to define a jumping-off point, but we really do anticipate recruiting more firefighters than is required by this sample size calculation.

DR. LEMASTERS: Okay, thank you.

MR. MORRISON: We've got to go back up, I think. My screen just popped up here.

DR. LEMASTERS: Yes, Number 20.

MR. MORRISON: Yes, Number 20, we have just a couple more questions here in this section. So, Number 20 was interesting in they are stating the non-White in the 6,500 non-White firefighters presumably and then they have the categories in the groups. And then they're asking about the percentage in each group. But if you break this down, they're saying it's going to be much smaller and should be considered.

DR. BERTKE: So just to comment, to answer directly the question, it was sort of a simple rate that we used. And so it implicitly assumed the percent matches the US population, which isn't probably a great assumption. But I don't know that it necessarily means within each group the SIRs will be much smaller. Again, as a group, it sort of represents an average so some subgroups are going to be higher and some are going to be lower. But certainly, yes, we could try to make these numbers a bit more realistic if we have more ideas about how we should break these down. But, really, I don't think it's going to impact the results all that much. These give you good jumping-off points that we're going to need roughly in the thousands, approximately in the five thousands of numbers of firefighters to get started.

MR. MORRISON: Okay. The comment 21, this is an interesting one—thank you—this is an interesting one. I know we have people on here from New York State and it would be interesting because there are a lot of questions on that. Do you want to comment on this one here? Because it seems like that was not correct or information that was on Page 14 was not correct in that paragraph.

MR. BRIMHALL: That was my comment and it was stating that there was a set requirement, a minimum certification needed for firefighter training, and that's not correct. The civil service law for career firefighters in departments of five or more career firefighters, which is a minimum standard and an annual refresher that they must meet. But for volunteers, New York is a home-rule state; there is no requirement for volunteer firefighters to ever take fire training in the State of New York, unfortunately. And as sucky as that sounds, it's the reality of being a home-rule state.

MR. MORRISON: Yes. Thank you for that presentation. From the program, did we correct this?

DR. SIEGEL: That's really good information to know. We have a source of information that lists New York, but again, as we start to approach individual states that are listed in our resource and start conversations with those states, this is the exact kind of information we'll be looking for. So, you just let us know that New York doesn't have this information for all firefighters, just a subset of those career firefighters, and so we may not necessarily be interested in pursuing the state certification route for New York itself.

MR. MORRISON: Okay. And we just want to make sure that we have that same—I mean, it's a good question. It's a question coming out because you might have that same in some other states that we've listed, so we might have to just go back when you

get to that point just to make sure that we don't have—because there's a lot of states that do have state certifications, but then they have individual fire departments within the state that have their own certifications also. Not state, they don't have to be mandated by the state. I think Florida is one where you can get a state certification and have that, but then individual departments either can take that certification or individual departments have their own certification parameters that they use, if that makes any sense.

Funding, 22, well, I'm not going to be around in 30 years so I don't really care—no, I'm just kidding. The funding, do we have enough money for 30 years?

DR. FENT: Well, we have authorized funding for the next I guess three years. This was a five-year-funded project. But we certainly, again, it's important to be optimistic so we're optimistic that we can continue to get funding to do the important linkages and follow-ups that we need to do. So, I would say we're going to have to wait and see. The hardest part of this is assembling the cohort, getting the firefighters to register, which we'll do initially. And then doing those linkages down the road, that could happen with—we could seek out additional funding if we need to on a periodic basis.

MR. MORRISON: Okay. Yes, no, it makes sense. I know what they were doing. They were just extrapolating out on that question and then they were saying that we have up there that we're going to report out in 20, 30 years, are we going to have enough funding for that? So thank you, Kenny. And I know how that goes. That's just the stronger the study, the longer we're going to get the funding for it. Funding is always an issue. It's an issue just to get this thing started. We had to do a lot of political maneuvering to get the money just to start this.

And then really the last question is the open cohort. I thought that we already had answered this with the wildland firefighter and key groups. So, I think you guys did a nice job of already really explaining the open and the targeted, so I don't think there's any questions there. That's just a statement. I think that's already been answered.

And the last one here that I have on my list from my section would be just changing some. I think that's just a list of change that somebody was recommending. So, Grace, that's all we have here in this section, unless somebody's got their hand up or somebody has a question. If not, I'm going to turn it back over to you for objectives.

DR. LEMASTERS: Okay. I'll start with Number 25. It's just a procedural issue. I was wondering would you be able to have a chatroom that the firefighters could go to if they have a question in the process?

DR. FENT: Yes. So, we're definitely open to that option and we're exploring all those options for when we start registering.

DR. LEMASTERS: Okay. Let's see, Number 26, is there a way to make an opting-out of receiving

notifications for follow-up not an option? I guess the issue is there's almost no point in collecting the initial information if they opt out later. And if it can be clear that this is a long-term study and that if you do the questionnaire, you have agreed essentially to continue with the follow-up.

DR. FENT: Yes, I think it's a very good point. I don't know that we've reached the final decision on how they would opt out. We do need to give them the option to opt out, but I think that right now the plan is that as part of the consenting process, they would essentially opt in and receive those follow-on questionnaires. After they receive that first follow-on questionnaire, they could decide at that point if they wanted to opt out. But they would be initially enrolled, that's the approach we were thinking of doing.

DR. LEMASTERS: I guess if there's a way that if they know this is a long-term study and that there will be follow-up questionnaires and, if they're not willing to do that, then they opt out right at the beginning. It would save you a lot of time and energy, if this is a targeted group, in collecting their histories. What do you think?

DR. SIEGEL: I think there's still going to be value for people to enroll, even if they are lost to follow-up for future questionnaires. We'll get valuable information from them at enrollment. And if they're in the targeted cohort or a department that's participating giving incident records prospectively, we'll have that information for them too. So, there's certainly value to them enrolling, even if they are lost to follow-up in the future. But it is an important part for the communication aspect, I think, is making sure to communicate that. It is a commitment to be part of the National Firefighter Registry and to the extent that firefighters are willing to participate, they're going to be benefitting the information that goes into the registry and the interpretations that can be made with the results from the analysis.

DR. LEMASTERS: Right, yes, just really emphasizing that if a—you don't want a lot of lost to follow-up, for sure, because then that really affects the quality of your study. So, if you can really emphasize that in the beginning, it's probably helpful.
Okay, going on to Number 7, the last line, someone wrote here "It would reduce the burden of follow-up questionnaires if they are prepopulated with each firefighter's initial or most recent answered questions during each update." What do you think about that?

MS. RAUDABAUGH: That's certainly possible, if I'm understanding their recommendation correctly. But it's going to work I think very similar to the way a lot of websites where the profile information is always—I think the point of what is in the protocol is that, you know, the (earlier @ 00:36:18) part of that is that we don't want people to come back and resubmit a questionnaire that they've already taken and we've already started doing analysis on the answers. So, to the point that we can have with the website have them come back to where they may have left off before

they actually submit. If that's what this question is about, we can do that.

DR. LEMASTERS: Does anybody on the committee have a follow-up to that? Because I think that's what the question is about, but I can't say for sure. Any comments? No comments?

MS. WILKINSON: I think I would just agree with what Jill was saying and, in addition, that we likely wouldn't be asking redundant questions. Hopefully the follow-ups would be brief and new information.

DR. LEMASTERS: Yes, okay. Next one, Number 28, I think—

MR. MILLER: This is Richard Miller.

DR. MIDDENDORF: People have some comments.

DR. LEMASTERS: Okay, good.

MR. MILLER: I have a question on the follow-up. So, I initially file a report and I agree to participate. And I have a documented asbestos exposure and then nothing happens. Ten years later I am now diagnosed. How do I update that?

DR. SIEGEL: So if you receive a diagnosis of cancer, that's going to be the point of linking with state cancer registries. When you're diagnosed with cancer, it'll be picked up by the state cancer registry.

DR. FENT: So I guess what you're getting at, Richard, is how do you update that you had an exposure to asbestos? Is that your question?

MR. MILLER: I guess there's a couple of scenarios that we could play out here of a diagnosis in this scenario where I've agreed to be a participant and I want to go into this system and update my information.

DR. FENT: Mm-hmm. Update your exposure information? Not necessarily your health information?

MR. MILLER: Correct.

DR. FENT: Okay. I mean it's a good question. And I don't know that we have thought about that. And it's something that we'll take under advisement. I think we'd want to have some more internal discussions about what that would look like.

MS. RAUDABAUGH And technically speaking, it would just be another round of the survey, I would think. So, database-wise, certainly you're going to be able to store that data and also keep a history of what they may have answered in the previous round of a survey.

DR. LEMASTERS: Okay. Is that satisfactory for the committee? If it is, I will move on. Okay, 29, it says, "What is meant by the incident type? Is this referring to house/car/brush types of fires? How will match or use what the firefighter is reporting with the incident report? Date information is difficult to recall so the firefighter may be reporting one date that is different from the records. What variables will be deemed essential to match the information from what the firefighter reports with what is reported at the station? It is not clear in the proposal what will be considered the 'primary' exposure information for the targeted population. Is it

what the firefighter says or what the department says?" I guess is the question.

DR. FENT: I don't think we planned to try to match responses on the questionnaire with information we would get from a department on incident records. They're kind of like two different data sources that we might use for exposure estimations. But I think really for the targeted cohort, the primary source of exposure information is going to be those department incident records. For the open cohort, it would be the questionnaire responses. And because of that, I don't think it's as critical that the incident type that we're getting from the questionnaire matches exactly with NFIRS. But certainly open to other thoughts from the committee on that, especially the fire service stakeholders.

DR. LEMASTERS: My initial thought on the firefighter stakeholder, maybe someone else will jump in here, but if you don't use the firefighter's reported information the same as what you'll have with the open cohort, you'll never be able to combine those two data populations, those two cohorts, in order to do an analysis. The only thing they'll have in common is their own report. The incidents report from the department could be used to validate what the firefighter is saying but I think, at some point, you're going to want to pool the data if you can after you've looked at it and see if it's poolable. You'd have to examine that first. You see what I'm saying?

DR. SIEGEL: Yes, we'll certainly be able to pool information for everyone that enrolls and has that self-reported information. Everyone will be able to pool for that. It also depends on what analysis is being performed. But we would never include participants in exposure response analyses, for example, using department records if we don't have department records for them.

DR. LEMASTERS: Well, yes, that's for sure. Okay, Regina had her hand up. Regina?

MS. WILSON: Yes, I just have a question. And I guess the other people on the fire service can let me know if I'm being too minute with the understanding. I think some firefighters may need to know what you mean by exposure and if you're talking about exposure in reference to time. Because a car fire is exposure, but they might not think of it as that; they may think of exposure is just dealing with structural fires or any chemicals or stuff that might impede—well, with us discussing cancerous things, like I think you need to give some type of references of what you consider them to give—so for of them to be exposed to in order for you to get the information that you need. And then also, I don't know if it was already taken into consideration or discussed that a lot of these fire departments, I know when sometimes I go out on a run my office has to fill out an exposure report for us. So, you'll get a chance to see some of the information, the department will provide it for you, to see some of the incidences we have been exposed to and the frequency of them.

DR. SIEGEL: Okay, yes, those are good comments.

DR. LEMASTERS: Okay. Up to comment Number 30, "Updating vital status every five years seems

like a long timeframe." Is that what it is, five years and then they go on to say, "Every three years will allow you to update the firefighter results and get results out to your stakeholders. Otherwise the firefighter may lose interest if they don't get reports from the registry on a more frequent basis." That's one way I have found of keeping people's interest in a study that's a long-term study is by giving them feedback all the time on the results of the study.

DR. SIEGEL: I think any timeframes we might have given would have been an example. I don't know that we said five years explicitly. A lot of factors will have to be considered into how often we are able to link considering sample size and resources. But regardless, vital status analyses aren't going to be the only analyses that we anticipate doing and we certainly plan to have reports on a wealth of different kind of questions and information readily available and to communicate to the fire service on a frequent basis.

DR. LEMASTERS: So when you get results back, how will you get them? Will you be like emailing the results to all the firefighters that are participating, like, "Hey, these are our first findings, we want you to keep participating, please"? Who's going to get the information? It seems like the actual firefighters need the information too.

DR. FENT: Yes, Grace. We do plan on having regular communications with firefighters in providing any results that we have produced, I guess, and published would be shared with them. We'll have contact information just from the registration process, which would include email and potentially even phone number for text messaging. So, we want to maintain regular communications with them and I guess any publications we produce would be provided to our participants that way.

MR. MAYER: Hey, this is Alex from the team. I just wanted to say in the protocol we mention every six months trying to reach out to the NFR participants. And that's just an example, but we do realize we want to keep them engaged as we move forward.

DR. FENT: Grace, I'm sorry.

DR. LEMASTERS: Go ahead.

DR. FENT: Just a question. That's interesting and I like that. I think not only the participants, but I think that for something like this that's so anticipated, so many firefighters are talking about it in so many different circles. I think that when NIOSH did the original cancer study, Doug Daniels and his team, there was a report. There might be a lot of other documents, but there was just sort of an update. It was almost like a newsletter. And I think you wrote that in your communication. I think that's going to be real, real important. I think a lot of people, they might not be participants, but they're going to be interested in listening that could be future participants in some cases. But to maintain that interest and to keep it, that's the kind of stuff that people are going to be very, very interested in. And I think as we go along, we'll have the information to

supply the fire service as to here's where we are. A lot of times they just want to know, okay, where are we on this? How many people have registered? Those things are going to be real interesting and really easy to kind of produce. But it keeps—like this project, it's alive. There's a lot of work going into it. It's not behind the doors. We're not seeing—we're not waiting five years to come out. And I really think that is going to be important. And those are the kind of publications that we share among fire service organizations: did you see the latest, you know, the report that just came out? So I think that's going to be something that has to be done and done consistently.

MR. MAYER: And we do have our newsletter that we'll be sending out every three months and we'll continue doing that. And you're able to sign up for that through the NFR website.

DR. LEMASTERS: Can you sign up for the newsletter at the time you log in for participating?

MR. MAYER: Yes, that's a good idea. We'll make a note of that. I don't think we have that included yet, but that's a great idea.

DR. LEMASTERS: Yes, I think most people would want the information if they could get it just when they log in to the portal once you have it. Okay, moving on, Potential Approach Limitations. We didn't see anything in the proposal about selecting a little bit of information on those who decline to participate to see if there's any bias in the group that do participate versus the ones that don't end up participating.

DR. SIEGEL: Some of the information we can obtain and I think it's kind of mentioned here is certainly information about the departments where they work. But beyond that, if they don't volunteer to be part of the registry, then we can't collect and retain any information about individuals that don't consent to be part of it, even if it is very basic information for the purposes of analyzing response characteristics, unfortunately.

DR. LEMASTERS: So I guess the people that don't participate are the ones that just don't go to the portal, right? But you have the targeted groups and of the targeted group, you'll know how many people went to the portal and those that did not go to the portal, right?

DR. FENT: This is Kenny. Unfortunately, because of the way the act was written—and we've gotten a legal interpretation from OGC, the Office of General Counsel on this—we can't collect even basic information from the targeted departments on firefighters who don't volunteer to be part of the registry, which is what you really need to do what is being described here. So, that's just unfortunately a limitation because of the legislation.

DR. LEMASTERS: Okay, yes, I thought that might be the case. Thank you, Kenny. Going on with Number 32, Data Security, going into the middle it says, "Also, before going 'live' with the entire questionnaire, I would recommend a beta-test of hundreds of people logging in at the same time to make sure there are no glitches." Are you

able to do that?

MS. RAUDABAUGH This is Jill. There are ways to test the system and load test. We'll be working with our technical team in Atlanta to make sure that we can handle the load for sure. And we'll also be working with communications. Our team will coordinate to make sure that we roll out in a more sustainable way than the mass requirement of login.govs. So, yes, we definitely don't want to repeat that.

DR. LEMASTERS: Okay, thank you. Now, I think we can hop down to Data Analysis. These other issues are just more editorial things. So, Data Analysis, beginning with 36, just the recommendation didn't seem to be anything written in the analysis part of how you're going to compare the data sources from different groups before you pool them as a whole group. "An example is the volunteer firefighter from a career department where versus one that is entirely volunteer. Practices may be very different in the two groups. How will the self-reported exposure data be used compared to the data from the fire departments?" I guess the bottom line is you're getting data from a lot of different sources. Before you can pool everything, you have to see to what extent there's a big difference in them, right?

MS. RAUDABAUGH There's several angles that answer that question. From a data perspective, we're very much trying to wrestle to the ground vocabulary and taxonomy. Part of our contract that we've already had is going over what different data standards there are from different software vendors and NFIRS, and we're like looking at how different categories and coding of data so that when the day comes when we are trying to marry data from data sources, we're using and leveraging data standards to the extent possible. So, that's kind of from that perspective, but I certainly defer to the rest of the team to talk about some of the other nature of this.

DR. SIEGEL: Sure. And from an analytic perspective, we certainly plan to examine and consider differences between different subpopulations before pooling and pooling them where we're confident it's worth pooling them that the results can be interpreted in a reasonable manner. And we plan to do what we can and keep those considerations in mind.

DR. LEMASTERS: Right. Well, I think they have to be thought through. A priority before you begin with the statistical analysis section in maybe a little more detail about what are some of the issues and how will they be compared and defined and when data might or might not be appropriate to pool. I think that's the essence of that comment.

DR. SIEGEL: Sure. I think that we also do have to wait and see what our numbers look like from different subgroups of firefighters. Certainly where subgroups can stand to be analyzed alone, we'd like to do that and do stratified analyses where possible as well.

DR. LEMASTERS: Okay, I would agree with that. I think 38, 39, and 40 are just general comments

or suggestions about preparing tables ahead of time to make sure that you have all the information you want, dummy tables. For example, that's Number 40. So, I think we don't really need to discuss that. And I think that's it. We covered—there's nothing for Human Subjects, Risks and Benefits, Appendix A, Appendix B are mostly editorial comments. I think it's up to you all to decide what you want to use. If you want to cut down the verbiage as we say in Appendix B, Number 42, or not. Appendix C, there was a couple issues about the stakeholders and, maybe to clarify, these are self-identified stakeholders. Otherwise on the next page under comments, "Not sure how you classify 'stakeholders,' IAWF is not listed." So I guess these were self-identified stakeholders, correct?

DR. FENT: Yes, that's correct. And this is an evolving list, so we are more than happy to add different groups to our stakeholder list. We have a roster that we use for communication, so we're more than happy to include IAWF. I actually think it was probably an oversight that they not on that list right now.

DR. LEMASTERS: Okay. Well, yes, I'm sure it is, but it is evolving and growing as you go. I would like to jump down to Appendix D, 52. It says, "Under Number 11, can you make 'findings' available when they update their information each year such as through a link provided at the end of the update?" That's, again, a way of communication. I think we've talked about that, but the more you keep everybody feeling involved in the study, even though you may not contact them again for information for three years but get back to them, "Hey, here we are. This is what we have going on." And we've talked about that, keeping people well-informed will keep them involved in the study more than anything else, I have found.

And I think that does it. We covered Appendix F, the questionnaire in detail, and I think I have most everything crossed off there. So, you can read it at your leisure, but we really went through the questionnaire and issues related to work history and demographics pretty thoroughly. Does anybody on the committee want to bring forth any of these comments, anything else? I guess everybody's worn down. Okay, go ahead, Pat.

MR. MORRISON: No. I said, Grace, I think we've done a good job, given all the material, going through the information. I think I'd like to listen to the program people just to ask them quickly, have we missed anything that you need from the operational side? Because you are the day-to-day on this and we thank you for not only being on here with us, but are there any questions for anybody here on the panel, on the advisory group, or Grace or I, that you would maybe like some clarification? Or you want to just get rid of us and hang up and start your weekend?

DR. FENT: No, I think this has been a very comprehensive review of our protocol. I know that there's a lot to it, so I sincerely appreciate everybody taking the time to really look it over. And I know we've talked about it here today, but hopefully

everybody has a chance to look at it and we appreciate any additional comments that you have. I know Paul is going to talk about the procedures moving forward, but we've received a lot of very valuable information today from everybody on the committee that we're going to take into consideration for sure. I think we'll more than likely be making some changes to the questionnaire. I thought we got a lot of good advice around that. And we look forward to continuing this conversation moving forward. And I guess that's it for me other than just to thank everybody for your time.

DR. LEMASTERS: Anybody else from NIOSH, the team, or the committee? Have any final comments? If not, Paul, I think we're turning it back over to you.

DR. MIDDENDORF: Okay. As Kenny mentioned, I'd like to go over the plan going forward, let everybody know what to expect. Our current plan is for the co-chairs to take the comments that have been provided and the input from this meeting to develop a draft report. In a couple of weeks they'll send that to me and I'll distribute the draft to the subcommittee members. Members can then review and provide comments back to me within a couple of weeks. And they should not share their comments on the draft report directly with the co-chairs or with others on the subcommittee. This is one of the FACA things that we have to comply with. What I'll do then is compile all the comments that I get—can somebody mute themselves, please—I'll compile all the comments and flag them to the co-chairs to update their draft report within another couple of weeks. And then that draft report will be provided to all the subcommittee members and posted to the NFRS website for the public to review and provide comments.

That timeline takes us to the beginning of July and then we're planning on having an open meeting on July 14th with the subcommittee to review the draft report. And the draft can contain specific recommendations. It can just discuss approaches for the program to consider, whatever the subcommittee wants. The intent for the July 14 meeting then is to reach a point where the subcommittee can vote on finalizing the report and/or any of the recommendations that are in it. Whatever is passed at that meeting will then go to the Board of Scientific Counselors. Because the NFRS is a subcommittee, the report doesn't go to NIOSH or the program directly. It has to go to the Board of Scientific Counselors where Grace and Pat, as members of the Board, would present it for discussion in an open meeting of the Board. So, we're looking at a meeting in early to mid-August to handle that. Then when the Board gets it, they could do a number of things. They could vote to accept it as presented and send it to Dr. Howard and the program. They could vote to make changes to the report from the subcommittee and send that to Dr. Howard and the program. It's a low probability, but they could also decide just to table it. I don't think that would do what anybody wants, but it is a possibility. Once the program gets the report, it'll

review it and determine a path forward. The program has to evaluate each of the recommendations and some of them it may adopt, some may be modified, and some may not be able to be accepted. But whatever they decide, they will respond formally and the response will be posted to the docket.

So that is our intended path forward at this point. Are there any questions about that? I don't hear anything so, Pat and Grace, are we ready to adjourn?

MR. MORRISON: I think we are, Grace, I'll turn it over to you. I just from my part, thank you all for spending a good part of your whole day on this, I appreciate it. This is a tough process, but this is what makes the product the kind that we want. And I'm sure the fire service is going to be well-rewarded from all of this and in what you've done. For NIOSH, thank you so much for everything, Kenny, and all your program and all the people that are behind the scenes here. I really appreciate the hard work. There's been a lot of thought and I really like the way that you not only listen, but you've incorporated and you've brought in the fire service into this. We're not separate; we're kind of combined in this. So, I really appreciate all your efforts. We will be seeing each other again. We still have a lot of work to do before this advisory group is dismissed. So, thank you all, I appreciate it. I hope you all have a wonderful weekend. I'll turn it over to Grace for closing comments. Hey, Grace, I think you're on mute. Are you on mute?

DR. LEMASTERS: I was muted. I think you said it well, Pat. We appreciate all the work everyone has done. The committee, reviewing everything and getting comments in, as well as spending the day with us. And the NIOSH team, what an exceptional job you have done. Even though we've raised a lot of issues along the way, it's an amazing survey and study that you are about embark on. And it's complex and it has a lot of moving elements. And though we pointed out some things we thought might be better, I just want to say that most of it is just right on and excellent. And I for one appreciate all the work you've done in preparing the protocol and the questionnaire and all the appendices. It's truly amazing work.

DR. FENT: Thank you, Grace.

DR. MIDDENDORF: Okay. Well, thank you, each and every one of you. On behalf of NIOSH, we greatly appreciate all your effort, your thoughts and your input. And we look forward to continuing the relationship. I guess I adjourn this, then. Thank you all very much.

[Adjourn.]

GLOSSARY

AOHP	Association of Occupational Health Professionals
BSC	Board of Scientific Counselors
CDC	United States Centers for Disease Control and Prevention
COSH	Conference and Exhibition on Occupational Safety and Health
CRA	Cumulative Risk Assessment
DFO	Designated Federal Officer
DSHEFS	Division of Surveillance, Hazard Evaluations, and Field Studies
FACA	Federal Advisory Committee Act
FDID	Fire Department Identification
HELD	Health Effects Laboratory Division
HHS	US Department of Health and Human Services
HRSA	Health Resources and Services Administration
IAWF	International Association of Wildland Fire
IOHA	International Occupational Health Organization
IRB	Institutional Review Board
NACOSH	National Advisory Committee on Occupational Safety and Health
NFIRS	National Fire Incident Reporting System
NFPA	National Fire Protection Association
NFR	National Firefighter Registry
NIH	National Institutes of Health
NIOSH	National Institute for Occupational Safety and Health
NORA	National Occupational Research Agenda
NVFC	National Volunteer Fire Council
OEL	Occupational Exposure Limit
OSHA	Occupational Safety and Health Administration
SCBA	Self-contained breathing apparatus
USFA	United States Fire Administration