

The National Firefighter Registry (NFR)

National Firefighter Registry Subcommittee Meeting
May 15, 2020

NFR National
Firefighter
Registry

This information is distributed solely for the purpose of pre dissemination peer review under applicable information quality guidelines. It has not been formally disseminated by National Institute for Occupational Safety and Health (NIOSH), Centers for Disease Control and Prevention (CDC). It does not represent and should not be construed to represent any agency determination or policy.

National Firefighter Registry

Understanding and Preventing Cancer

Coming soon...



LEARN MORE AT: www.cdc.gov/NFR

Introduction & Background

Dr. Kenny Fent

Why is the NFR being created?

- The Firefighter Cancer Registry Act of 2018
- Previous studies, including a study by NIOSH, indicate that firefighters are at higher risk of cancer.
- Studies are limited by small numbers of women and minorities, and a lack of data on volunteers.
- No national data sources exist that combine exposure and cancer information with which to study the link in firefighters.
- NFR goal is to track firefighters' cancer risk over time to better understand the link between workplace exposures and cancer.

One Hundred Fifteenth Congress
of the
United States of America

AT THE SECOND SESSION

*Began and held at the City of Washington on Wednesday,
the third day of January, two thousand and eighteen*

An Act

To require the Secretary of Health and Human Services to develop a voluntary registry to collect data on cancer incidence among firefighters.

*Be it enacted by the Senate and House of Representatives of
the United States of America in Congress assembled,*

SECTION 1. SHORT TITLE.

This Act may be cited as the Firefighter Cancer Registry Act of 2018.

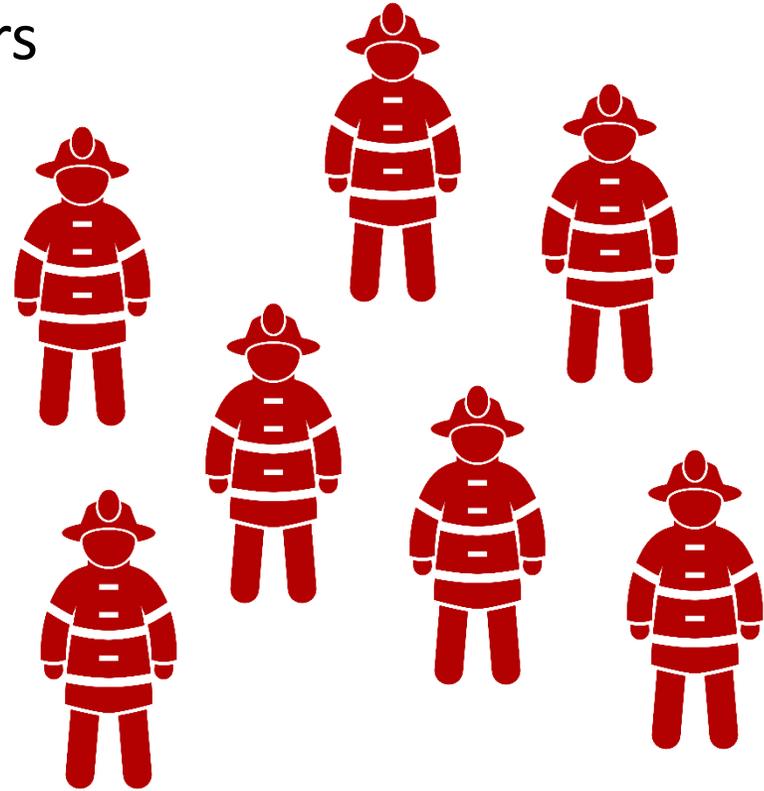
SEC. 2. VOLUNTARY REGISTRY FOR FIREFIGHTER CANCER INCIDENCE.

(a) IN GENERAL.—The Secretary of Health and Human Services (referred to in this section as the Secretary), acting through the Director of the Centers for Disease Control and Prevention and in coordination with other agencies as the Secretary determines appropriate, shall develop and maintain, directly or through a grant or cooperative agreement, a voluntary registry of firefighters (referred to in this section as the Firefighter Registry) to collect relevant health and occupational information of such firefighters for purposes of determining cancer incidence.

(b) USE OF FIREFIGHTER REGISTRY.—The Firefighter Registry may be used for the following purposes:

Who will be included?

- The NFR will represent ALL firefighters, not just those with cancer
- Minority, female, and volunteer firefighters
- Also interested in sub-specialties like:
 - Instructors
 - Wildland firefighters
 - Arson investigators
- Goal is to enroll 200,000+



What will registration look like?

- Registration web-portal under development:
 - Secure (two-factor authentication)
 - Require informed consent
- Collected information will include:
 - Demographics (name, age, sex, etc.)
 - Work history / exposures
 - Use of control measures
 - Other risk factors
- Important, voluntary follow-up questionnaires
- **Personal information will be kept in accordance with strict Federal privacy laws**



How will cancer risk be determined?

- Link participants to state/federal records using individual identifiers over time
 - State cancer registries
 - Databases of all cancer diagnoses
 - NFR participants won't need to contact NIOSH if they develop cancer
 - Used to determine cancer incidence
 - National Death Index
 - National database of deaths and causes of deaths
 - Used to determine cancer mortality



What will the NFR address?

- How much cancer/what types of cancers among firefighters?
- How does cancer risk vary:
 - Among different groups of firefighters
 - With use of control interventions
 - Geographically
 - With increasing exposures, including major events
- What are the current workplace practices being employed?



What will happen with the findings?

- Disseminate findings
 - Scientific & trade publications
 - Communications to the fire service, policy-makers, and the public
 - De-identified (i.e., maintaining privacy) data available for researchers
- Findings will inform:
 - Interventions, training, practices, and policies
 - Awareness among firefighters, fire departments & agencies, policy-makers, professional associations, healthcare providers, friends and family
- Reducing occupational cancer for firefighters is the long-term goal of the NFR

NFR National Firefighter Registry Timeline

Establish the National Firefighter Registry



Collect data



Recruit and enroll firefighters



Analyze and disseminate results



2020

2021-2023

2024+

Protocol & Design

Dr. Miriam Siegel

Recruitment

NFR Participants

```
graph TD; A[NFR Participants] --> B[Targeted Cohort: Currently active firefighters from selected fire departments or states]; A --> C[Open Cohort: Any members of the U.S. fire service, including active, former, and retired members, who have ever been an active firefighter (paid or volunteer)];
```

Targeted Cohort:
Currently active firefighters from selected fire departments or states

Web portal enrollment
Incident records collection

Open Cohort:

Any members of the U.S. fire service, including active, former, and retired members, who have ever been an active firefighter (paid or volunteer)

Web portal enrollment

NFR Participants

Web portal
enrollment

Incident
records
collection

Targeted Cohort:

Currently active firefighters from selected fire departments or states

Open Cohort:

Any members of the U.S. fire service, including active, former, and retired members, who have ever been an active firefighter (paid or volunteer)

Web portal
enrollment

- Provides the population at risk required for assessing cancer incidence rates
- Reduces selection/participation bias
- Additional exposure information from department records
- Ability to assess response characteristics and comparisons with Open Cohort
- Most cost/labor/time-intensive
- Excludes non-structural, non-active firefighters

NFR Participants

Targeted Cohort:

Currently active firefighters from selected fire departments or states

Web portal enrollment

Incident records collection

- Provides the population at risk required for assessing cancer incidence rates
- Reduces selection/participation bias
- Additional exposure information from department records
- Ability to assess response characteristics and comparisons with Open Cohort
- Most cost/labor/time-intensive
- Excludes non-structural, non-active firefighters

Open Cohort:

Any members of the U.S. fire service, including active, former, and retired members, who have ever been an active firefighter (paid or volunteer)

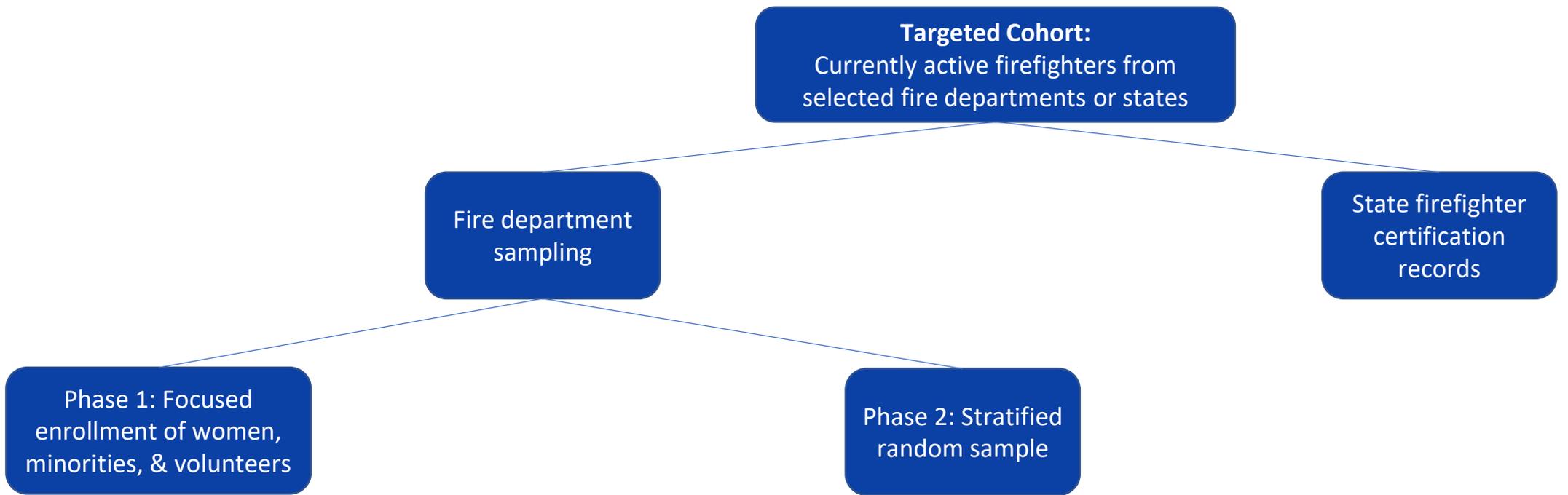
Web portal enrollment

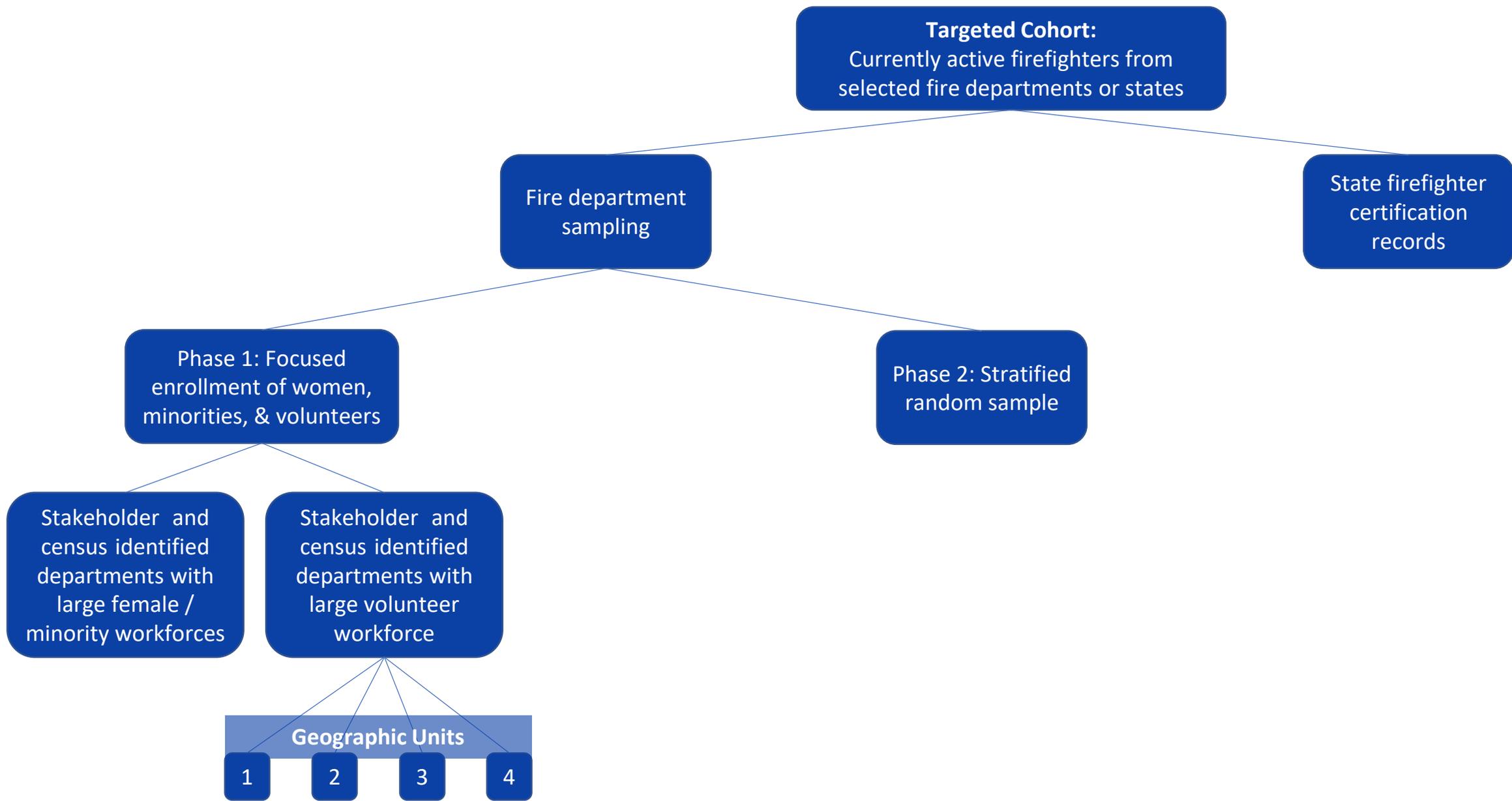
- Non-probability sample for which all firefighters are eligible
- Best method for recruiting a large, diverse, & inclusive sample
- Less cost/labor/time-intensive
- Opportunity for earlier analyses internal to sample (e.g., descriptive, cross-sectional, case-control)
- Subject to selection/participation bias
- Limited to self-reported exposure information

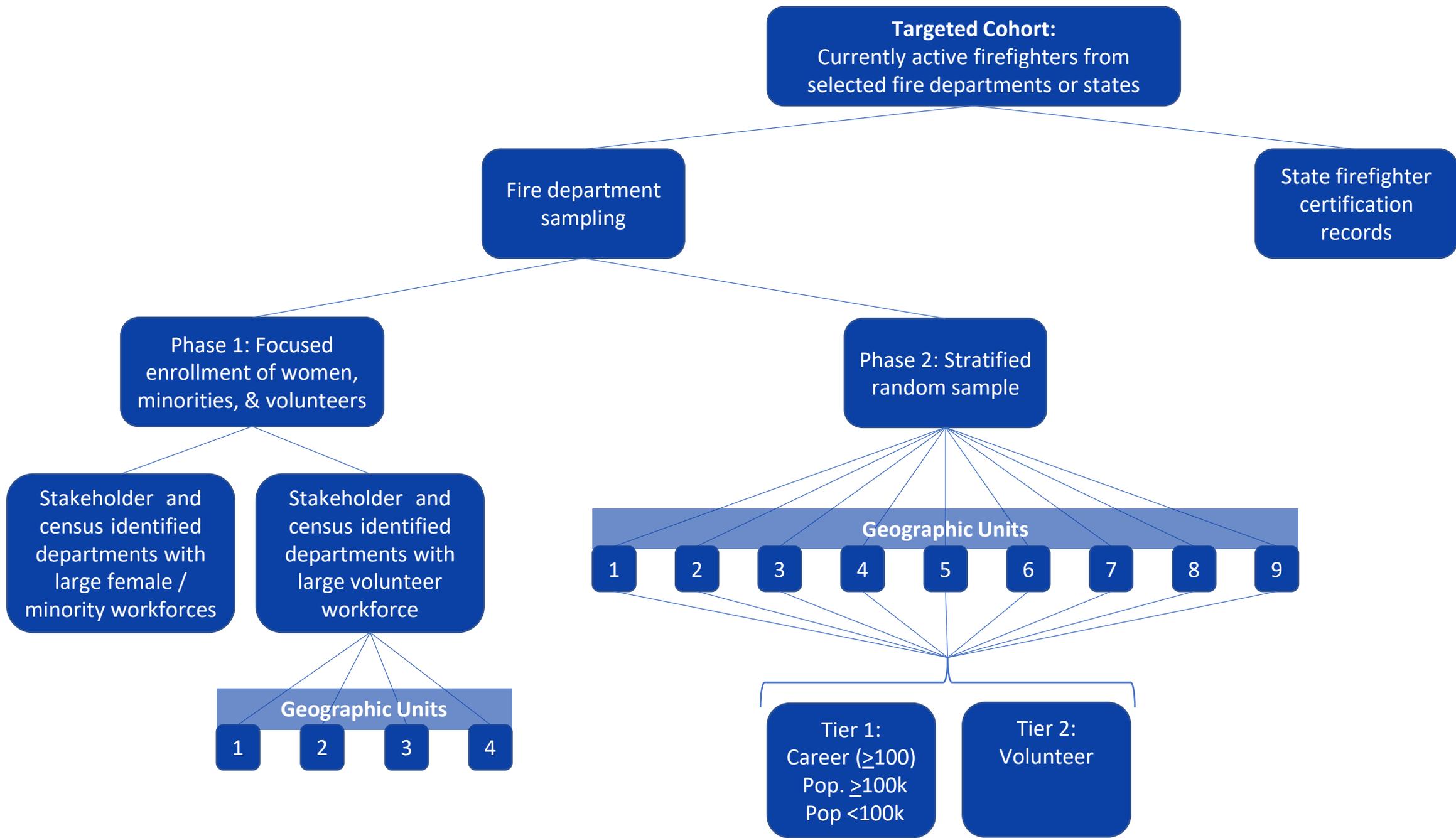
Targeted Cohort:
Currently active firefighters from
selected fire departments or states

Fire department
sampling

State firefighter
certification
records





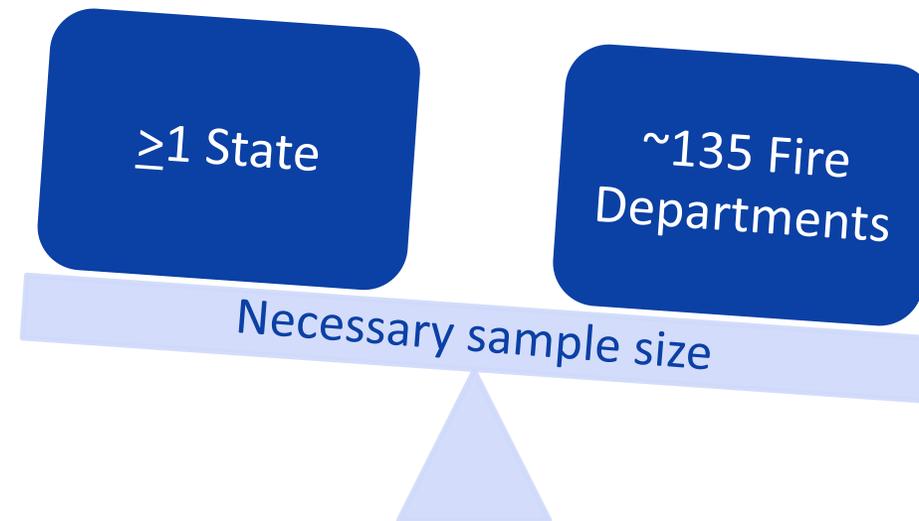


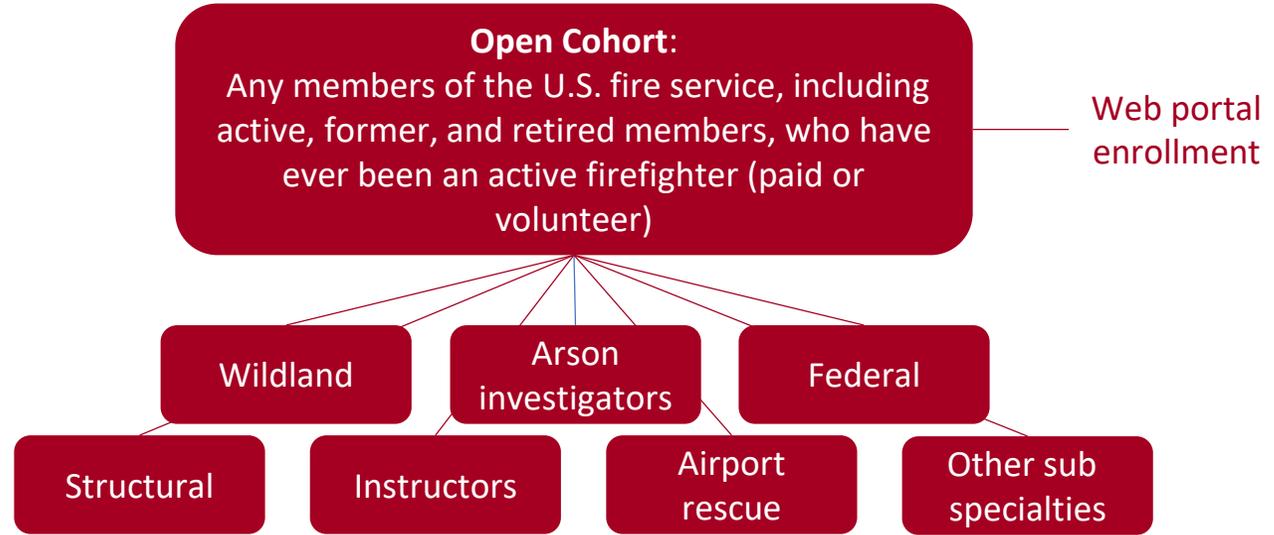
Targeted Cohort Sample Size Estimates

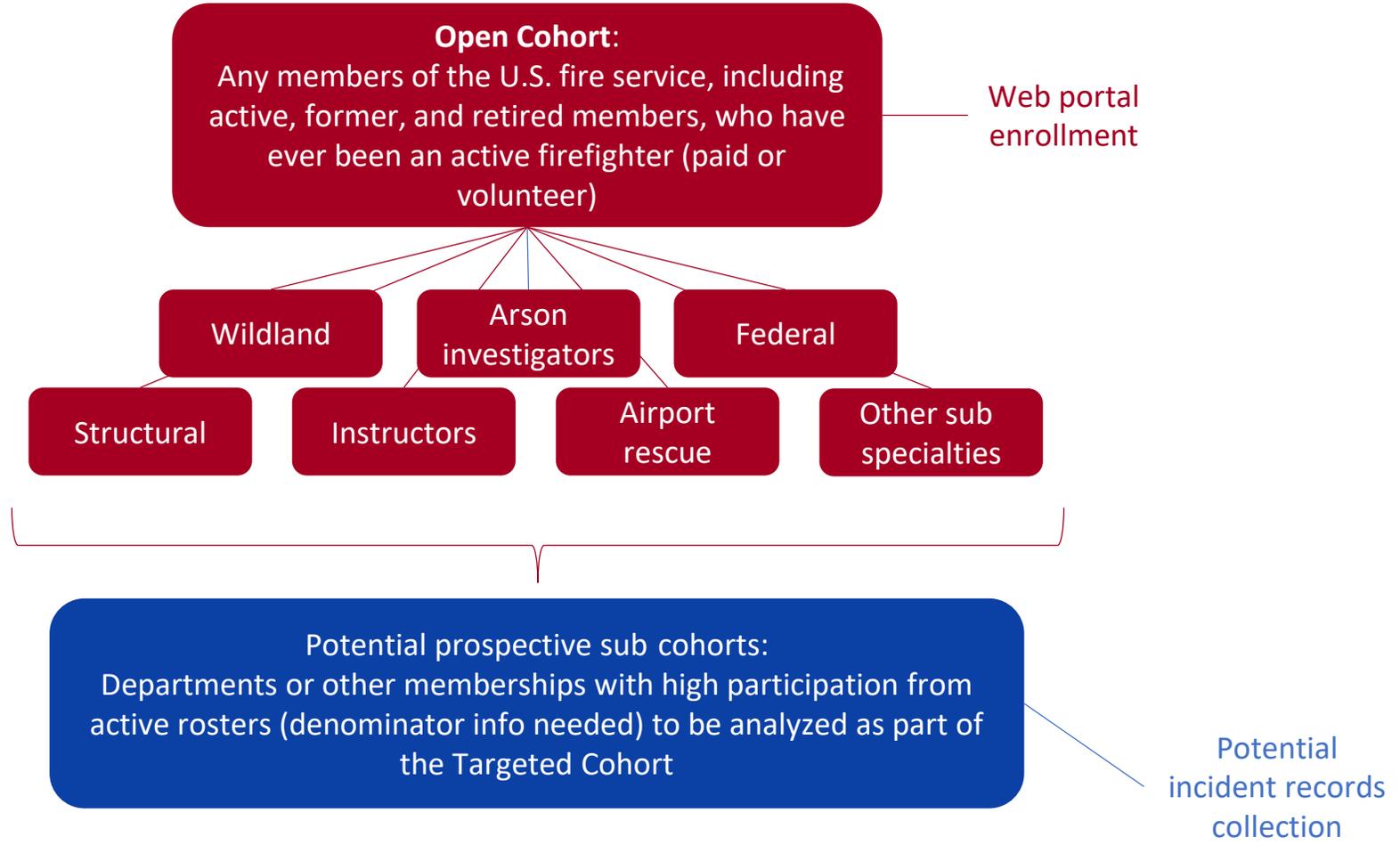
Minimum benchmarks:

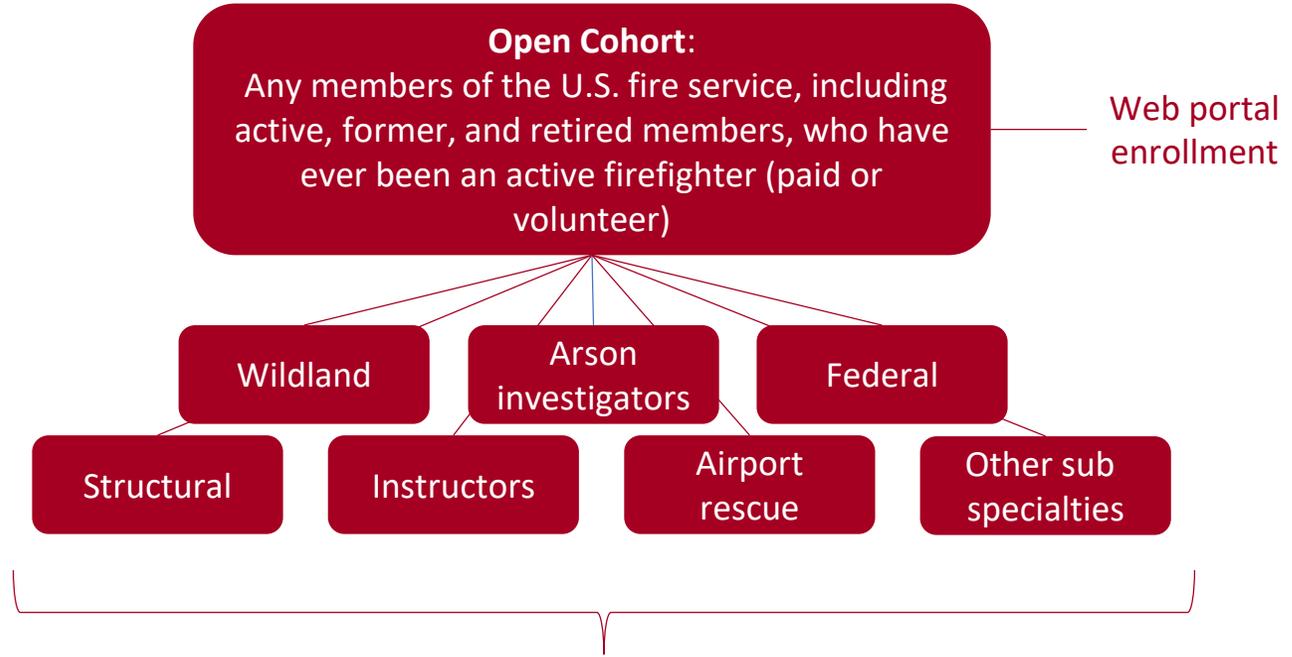
$\geq 1,000$ women; $\geq 6,500$ non-white firefighters; $\geq 5,000$ volunteers

to detect elevations in breast or all cancers in comparison to the general population (SIRs)









Potential prospective sub cohorts:
Departments or other memberships with high participation from active rosters (denominator info needed) to be analyzed as part of the Targeted Cohort

Potential incident records collection

Recruitment Strategies



Enrollment

1.a

TARGETED COHORT

Current firefighters from selected fire depts or state certification records

NFR Enrollment

Primary source of self-reported exposure information

1.b

OPEN COHORT

Any current/former members of the U.S. fire service



1.a

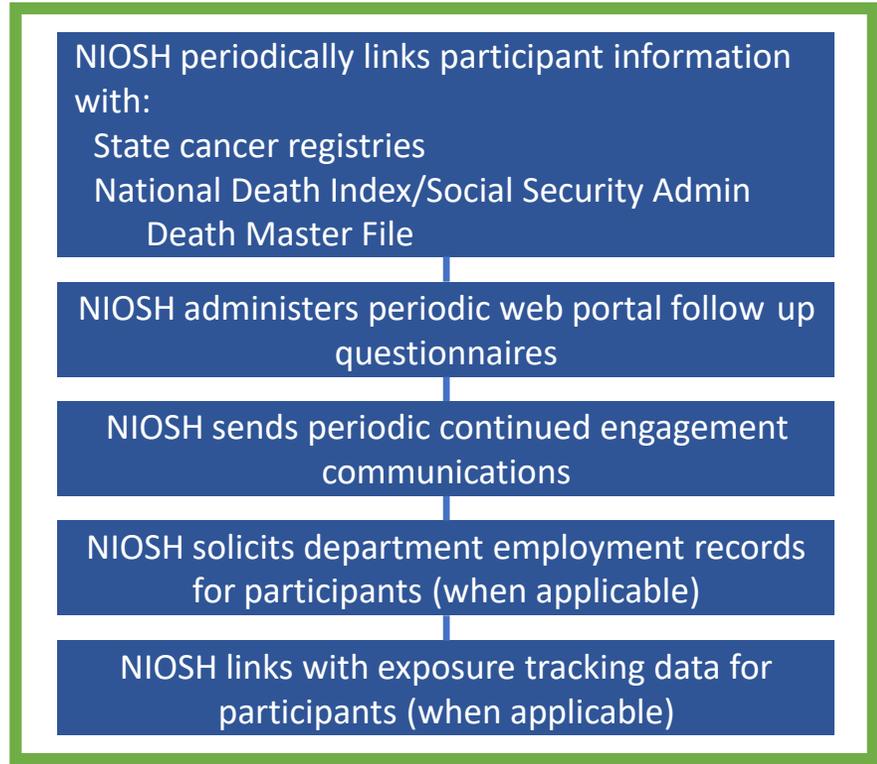
TARGETED COHORT
Current firefighters from selected fire depts or state certification records

NFR Enrollment
Primary source of self-reported exposure information

1.b

OPEN COHORT
Any current/former members of the U.S. fire service

End results of participation



1.a

TARGETED COHORT

Current firefighters from selected fire depts or state certification records

1.b

OPEN COHORT

Any current/former members of the U.S. fire service

2.c

Individual FFs consent & enroll through web portal

5.a

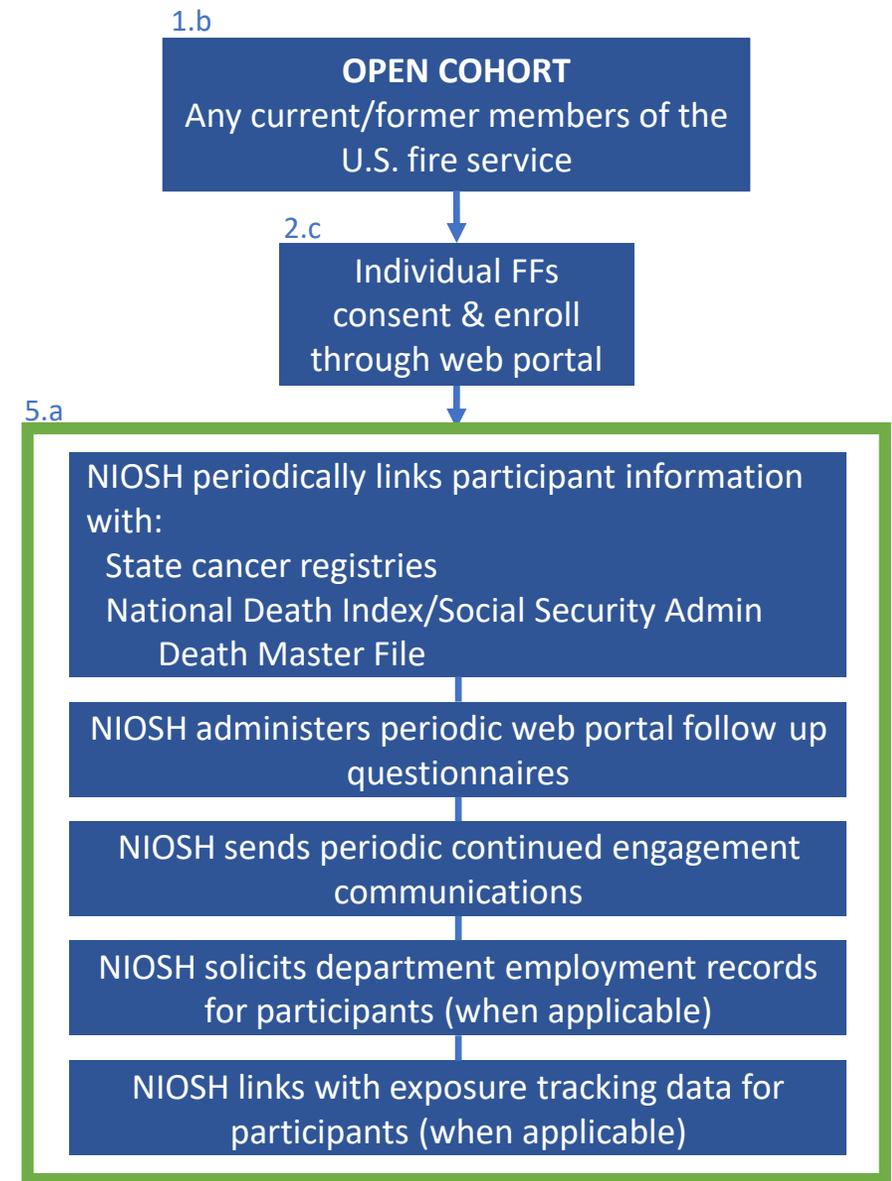
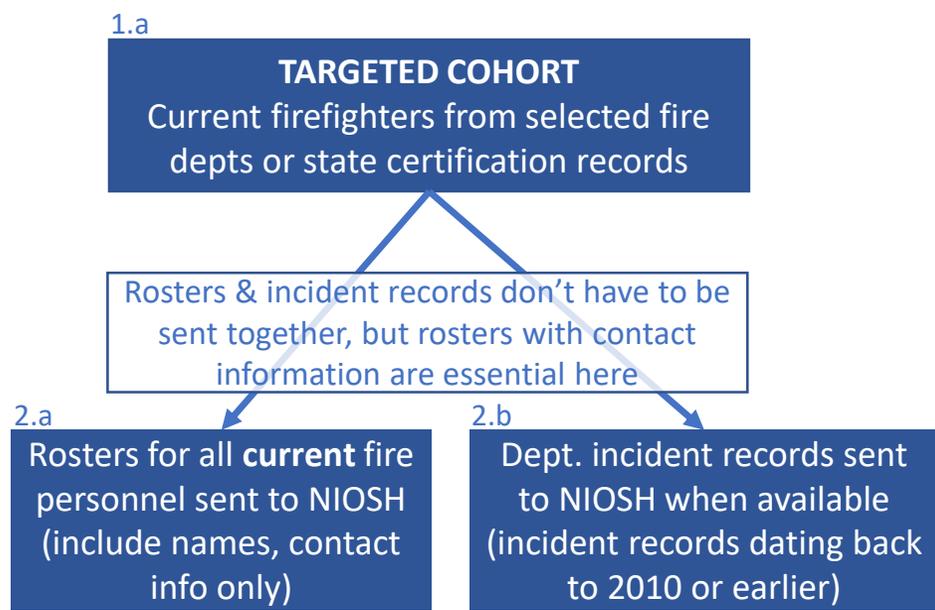
NIOSH periodically links participant information with:
State cancer registries
National Death Index/Social Security Admin Death Master File

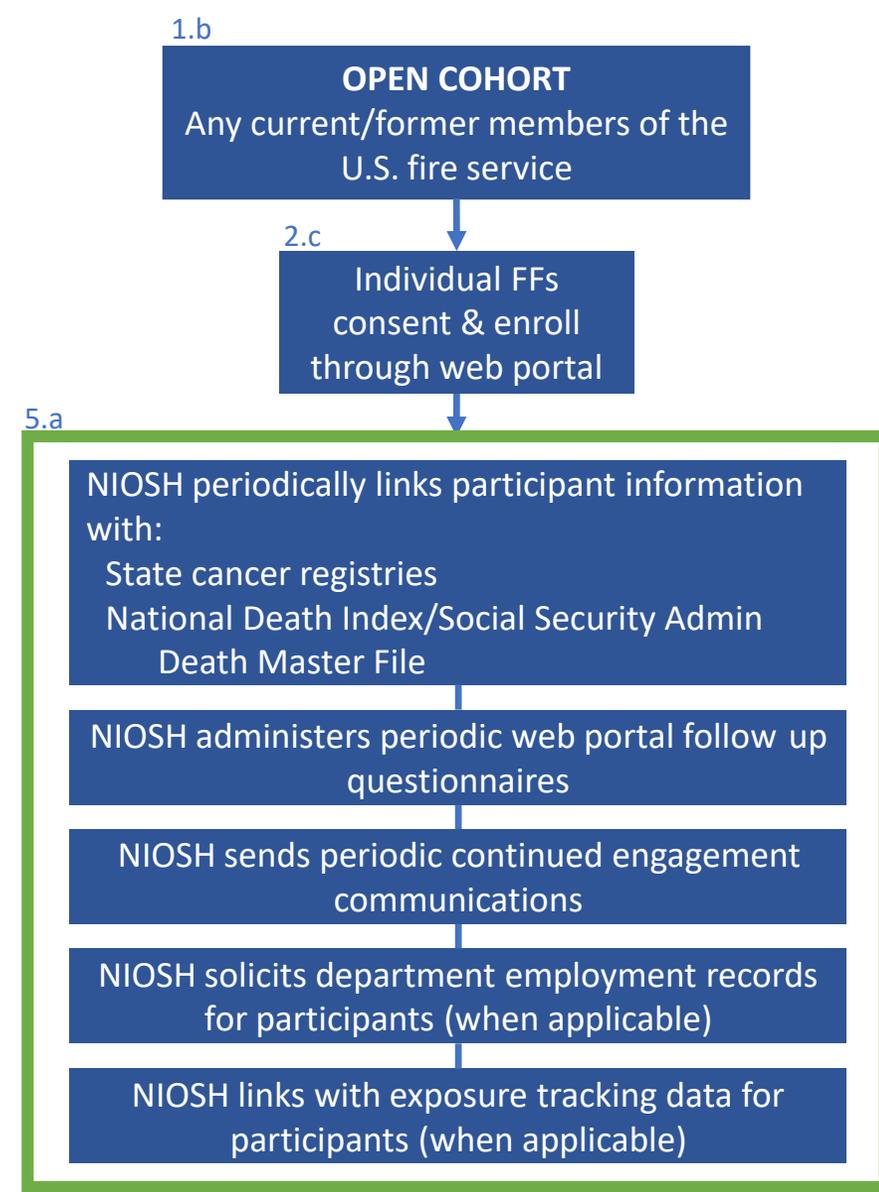
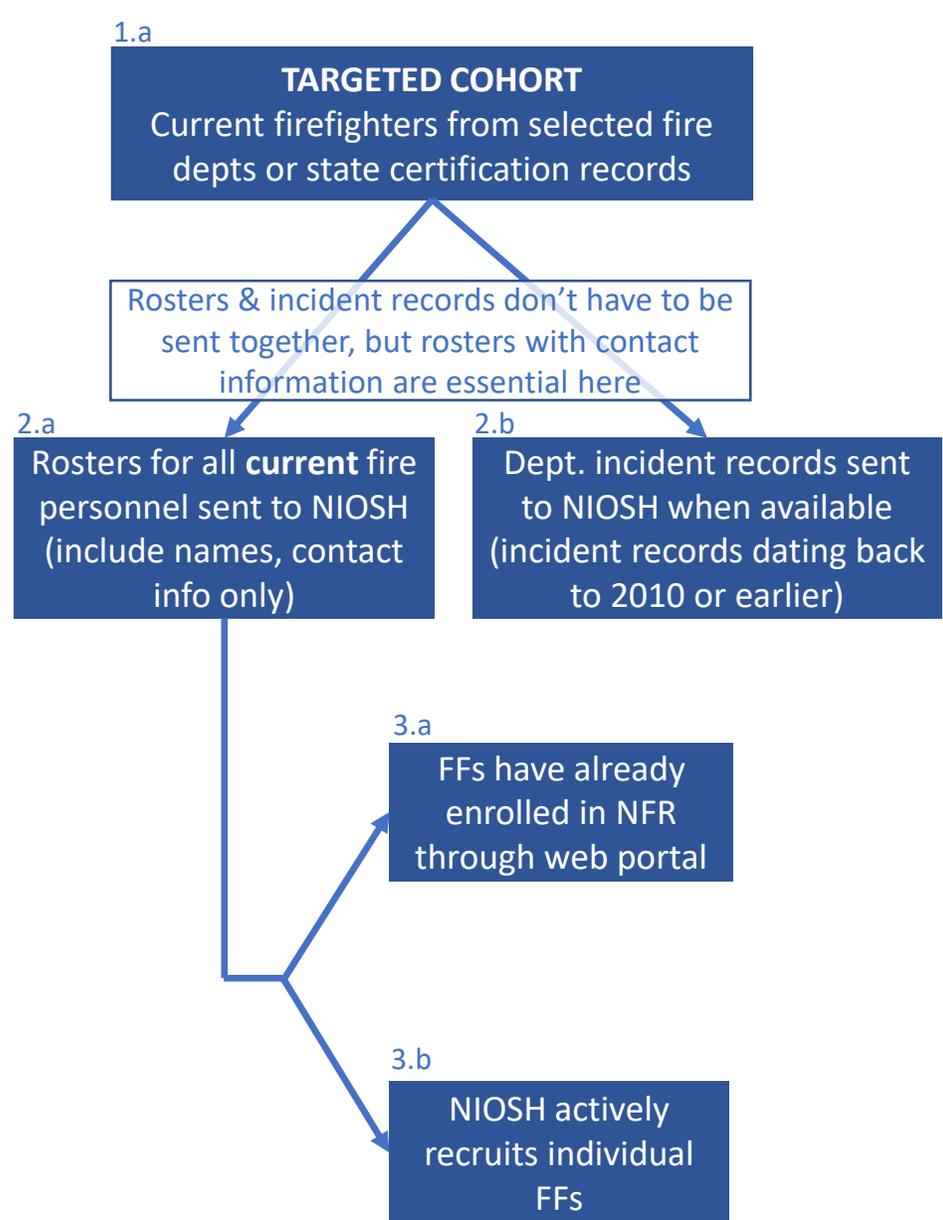
NIOSH administers periodic web portal follow up questionnaires

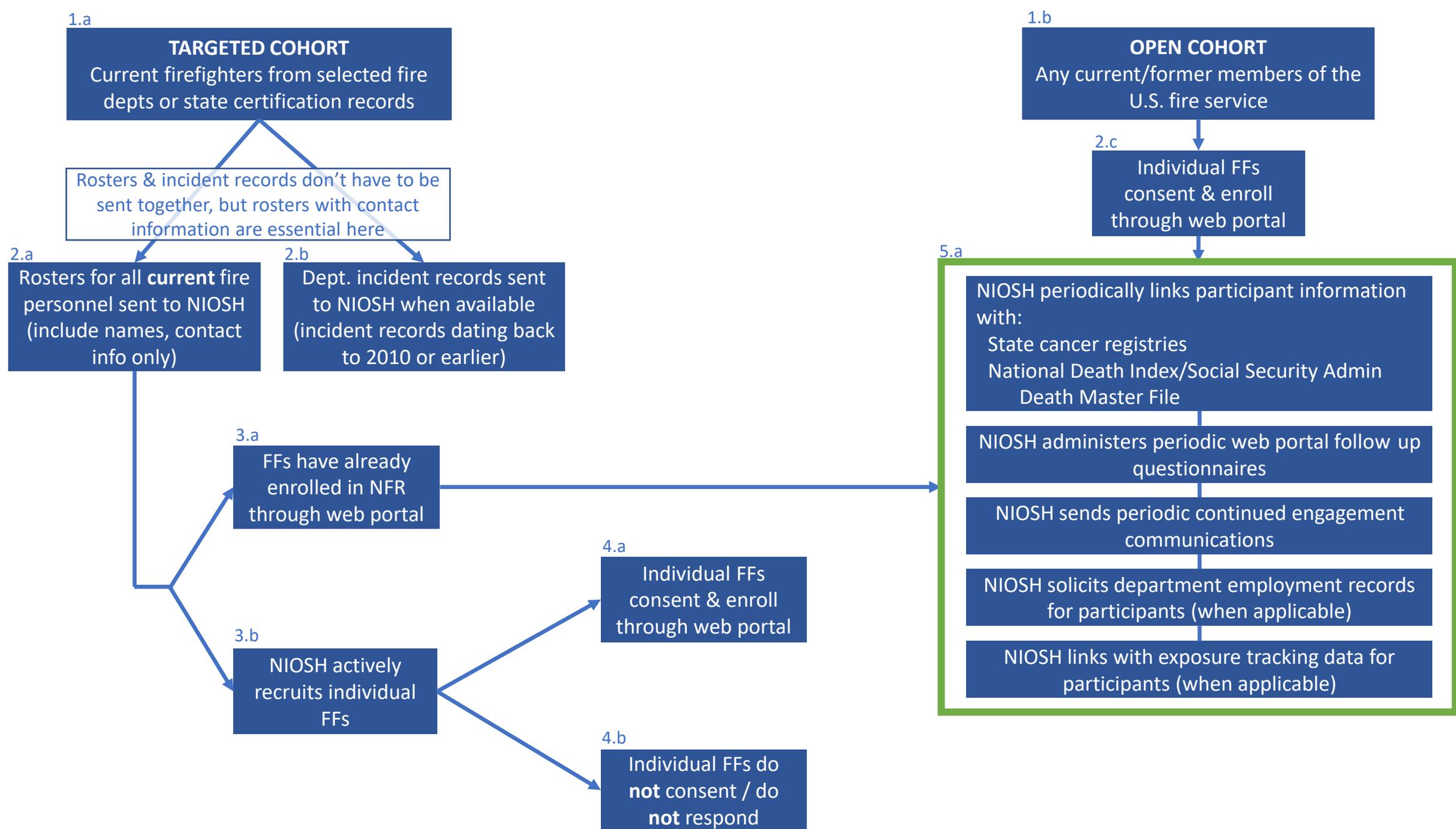
NIOSH sends periodic continued engagement communications

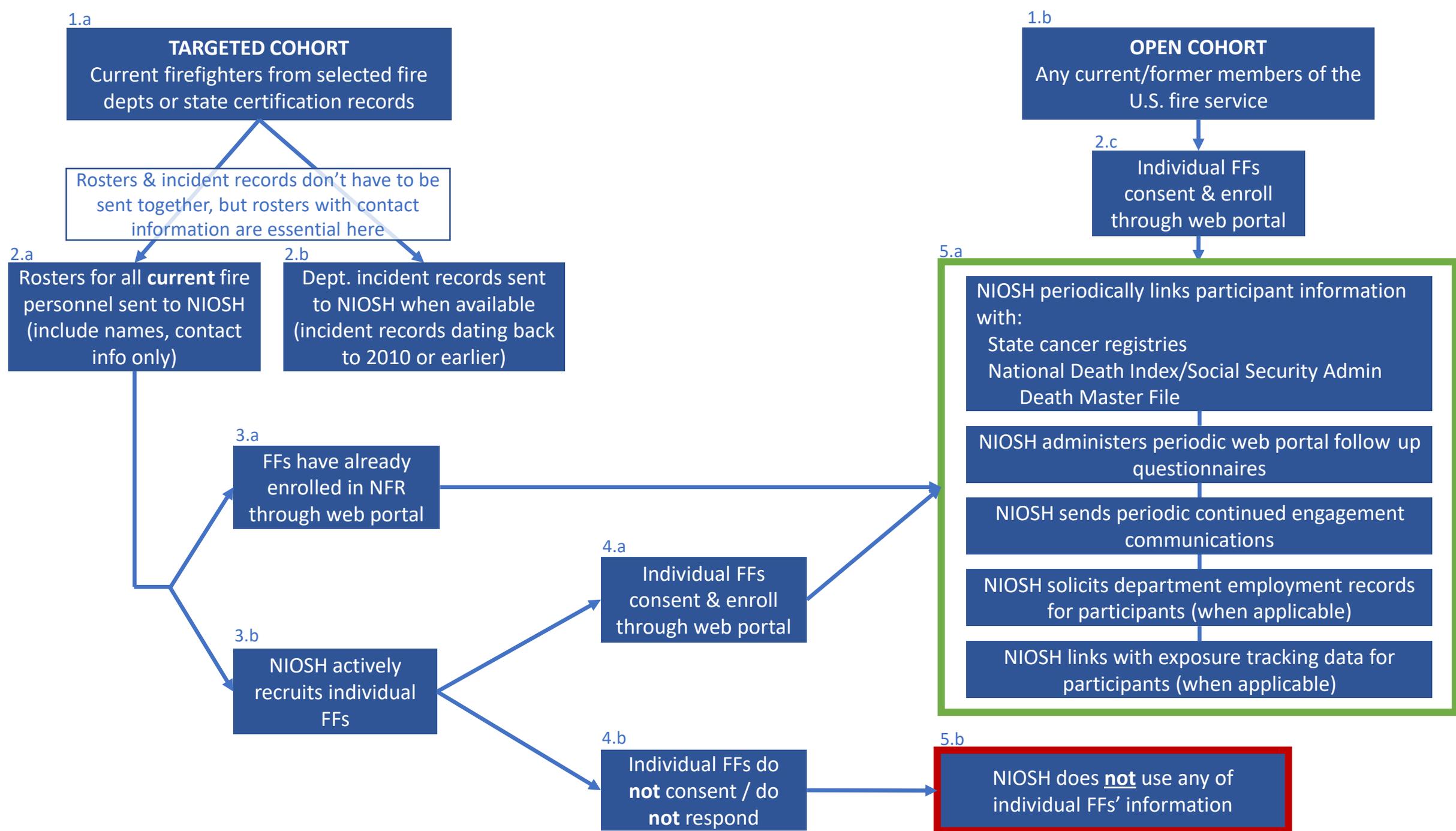
NIOSH solicits department employment records for participants (when applicable)

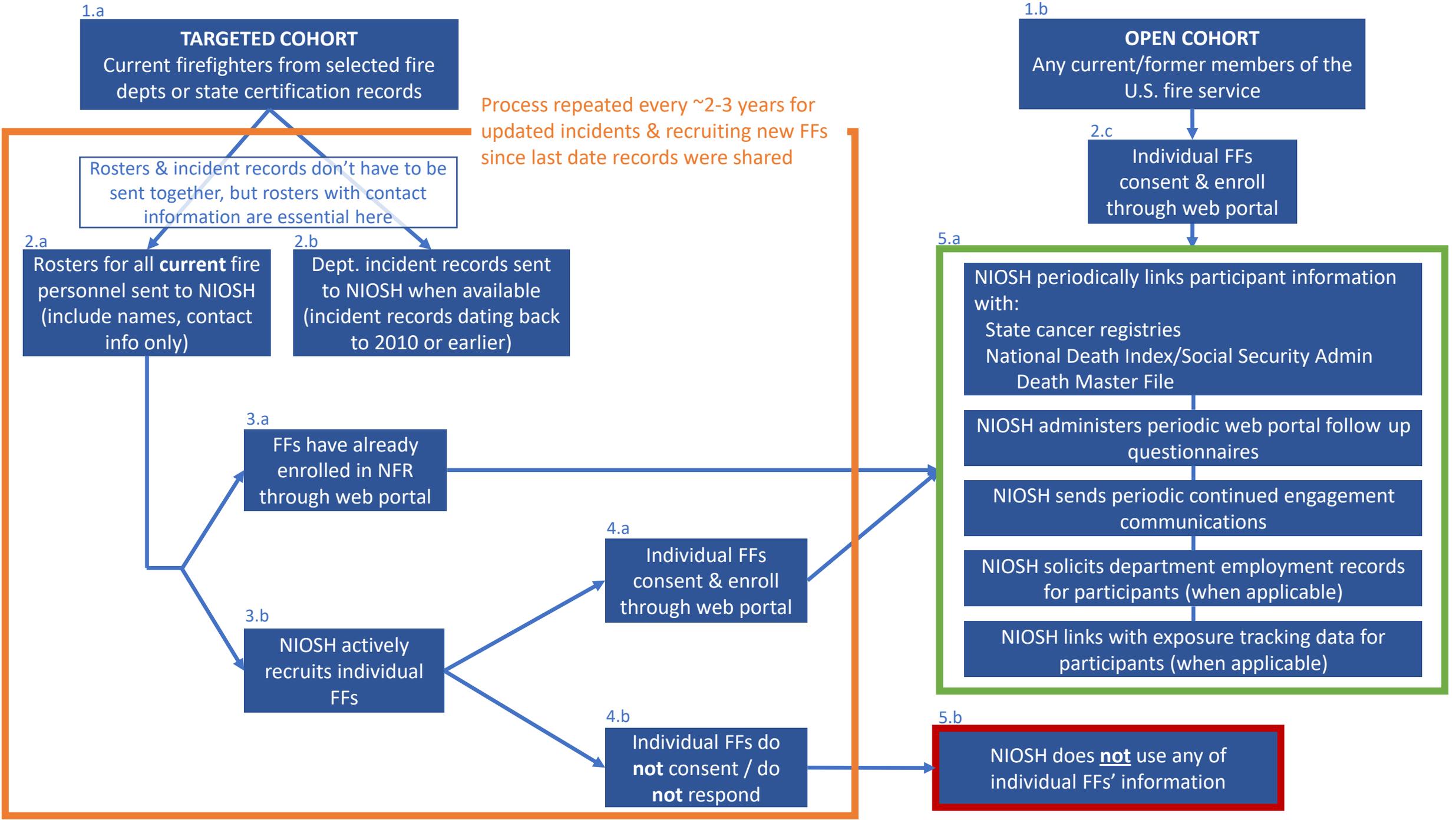
NIOSH links with exposure tracking data for participants (when applicable)











Potential Limitations & Considerations

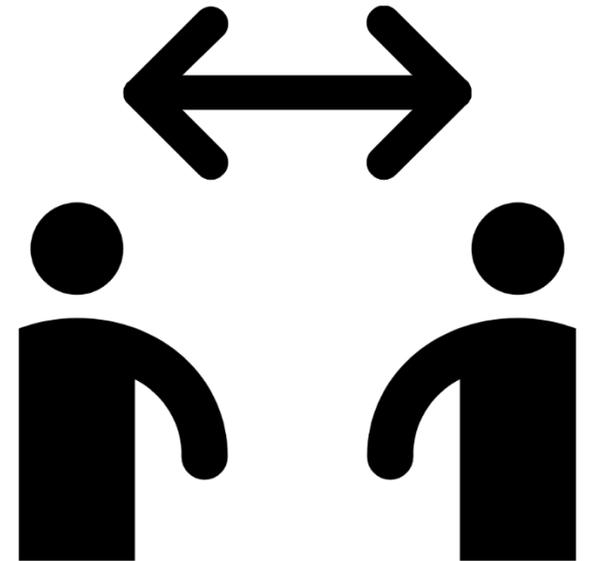
- Generalizability may be impacted by:
 - Participation bias
 - Small sample sizes (e.g., rare cancer, small subgroups, etc.)
- Analyses may be affected by:
 - Record availability
 - Self-report of past exposures
 - Healthy worker bias
 - Long latency of cancer

Data Sharing

Alex Mayer

Review the Law

- Firefighter Cancer Registry Act of 2018 stipulates NIOSH:
 - Make data publicly available
 - Protect firefighters' privacy
- Obtain an Assurance of Confidentiality (AoC)
 - An AoC is the highest level of protection allowed by the federal government
 - Protects individuals and institutions



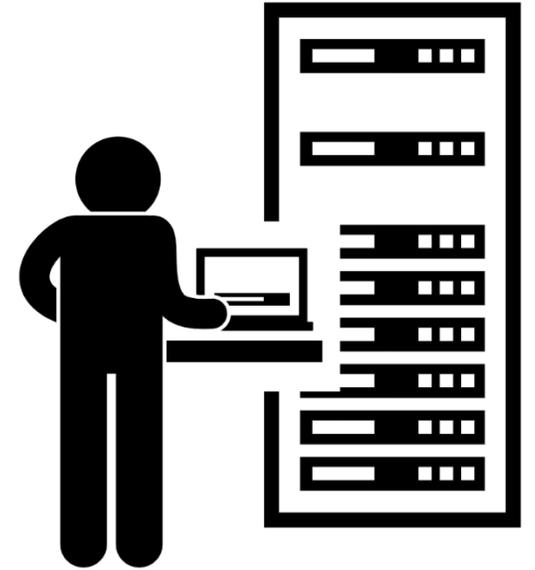
Assurance of Confidentiality (AoC)

- Uses for data:
 1. Monitor trends in cancer incidence among the U.S. fire service
 2. Secondary purposes related to non-cancer research aims
 3. Approved secondary research purposes proposed by external investigators and collaborators



Data sharing

- Developing a plan for sharing data
- One option: Research Data Center (RDC)
 - A proposal to the RDC
 - Reviewed by the RDC, NIOSH, and state cancer registries
 - (If approved) the appropriate data files will be provided to the RDC for analysis



Re-contacting participants

- External researchers can solicit NFR participants for their interest in an outside study
- NIOSH will review and approve requests
- Once NIOSH has approved the proposal, the NFR program will be responsible for re-contacting participants



Communication Plan

Will Wepsala

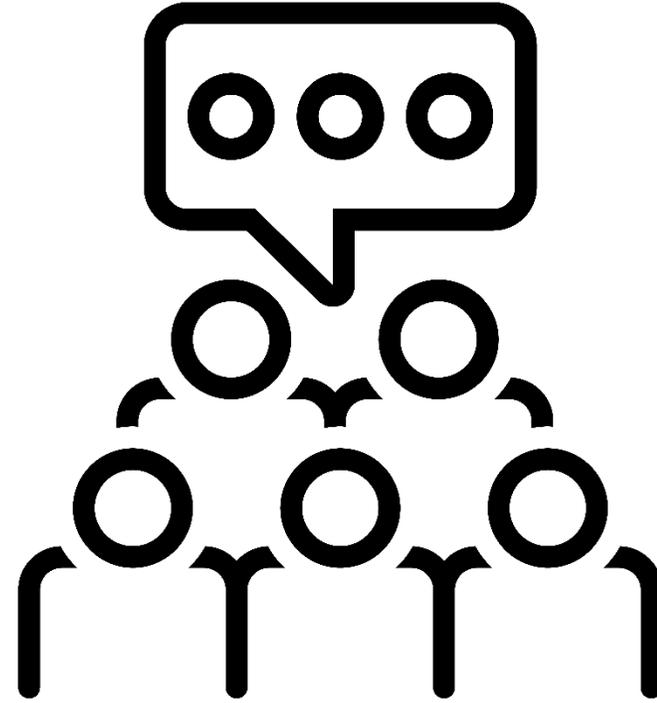
Communication Goals

- Raise awareness of the NFR
- Clarify the scope of the NFR
- Highlight the need for the NFR
- Encourage firefighters to sign up
- Encourage firefighters to share information with each other



Communication Tools

- Focus groups and/or online surveys
- Social media
- Publications
- Videos
- Conferences
- Newsletter
- NFR Website: www.cdc.gov/NFR
- NFRS Website: <https://www.cdc.gov/niosh/bsc/nfrs/default.html>



Enrollment Questionnaire

Andrea Wilkinson

Goals

- Enroll 200,000 firefighters from diverse sample
- Balance brevity with scientific reasoning
- Simple process
- Easily accessible
 - mobile and desktop version
- Secure format
 - Multifactor authentication
- Relevant to all firefighters
 - Current, retired, specialty groups

Enrollment Process

- Step 1
 - Create login.gov account
- Step 2
 - Review and sign informed consent
- Step 3
 - Create user profile
- Step 4
 - Complete enrollment questionnaire



Sign in

Email address

Password

Show password

Next

If this is your first time on login.gov, you'll need to click "Create Account"

[Security Practices and Privacy Act Statement](#)

[Forgot your password?](#) | [Create account](#)

Secure your account

login.gov makes sure you can access your account by adding a second layer of security.

Select an option to secure your account:

Text message / SMS

Get your security code via text message / SMS

Phone call

Get your security code via phone call

Authentication application

Set up an authentication application to get your security code without providing a phone number

Security key

Use a security key to secure your account

Government employees

Use your PIV/CAC card to secure your account

Backup Codes

Receive a pre-generated list of security codes to use when signing in

Continue

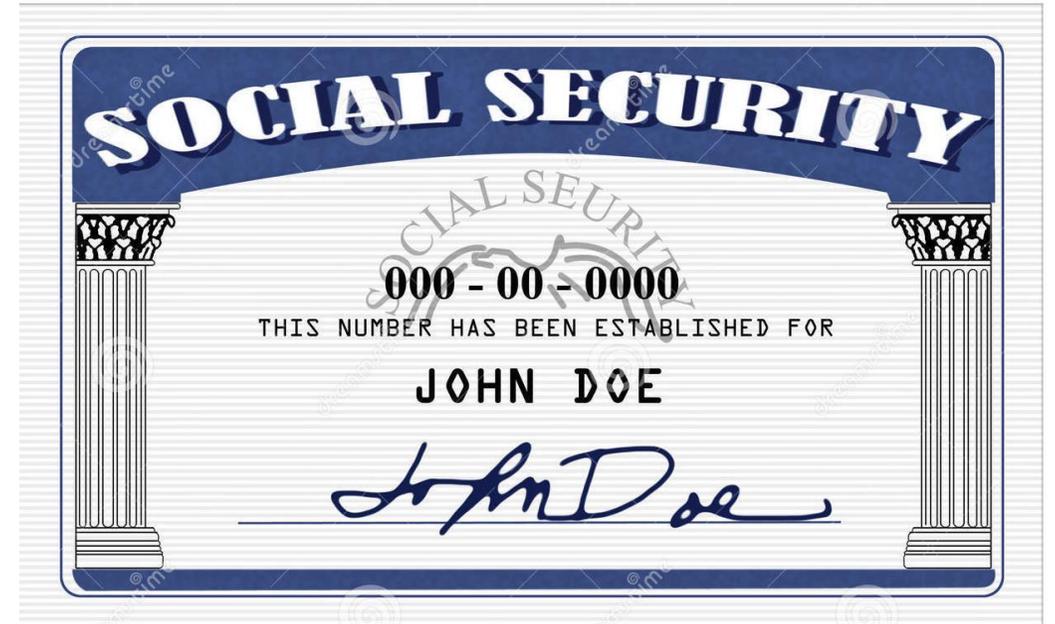
Questionnaire Arrangement

- User Profile
 - Basic demographics
 - Some skip patterns and auto-populated fields will come from this information
 - e.g., Male vs female reproductive history questions and employment history
 - Can be easily updated over time to adjust employment status, address, etc.
 - Will lead directly into enrollment questionnaire



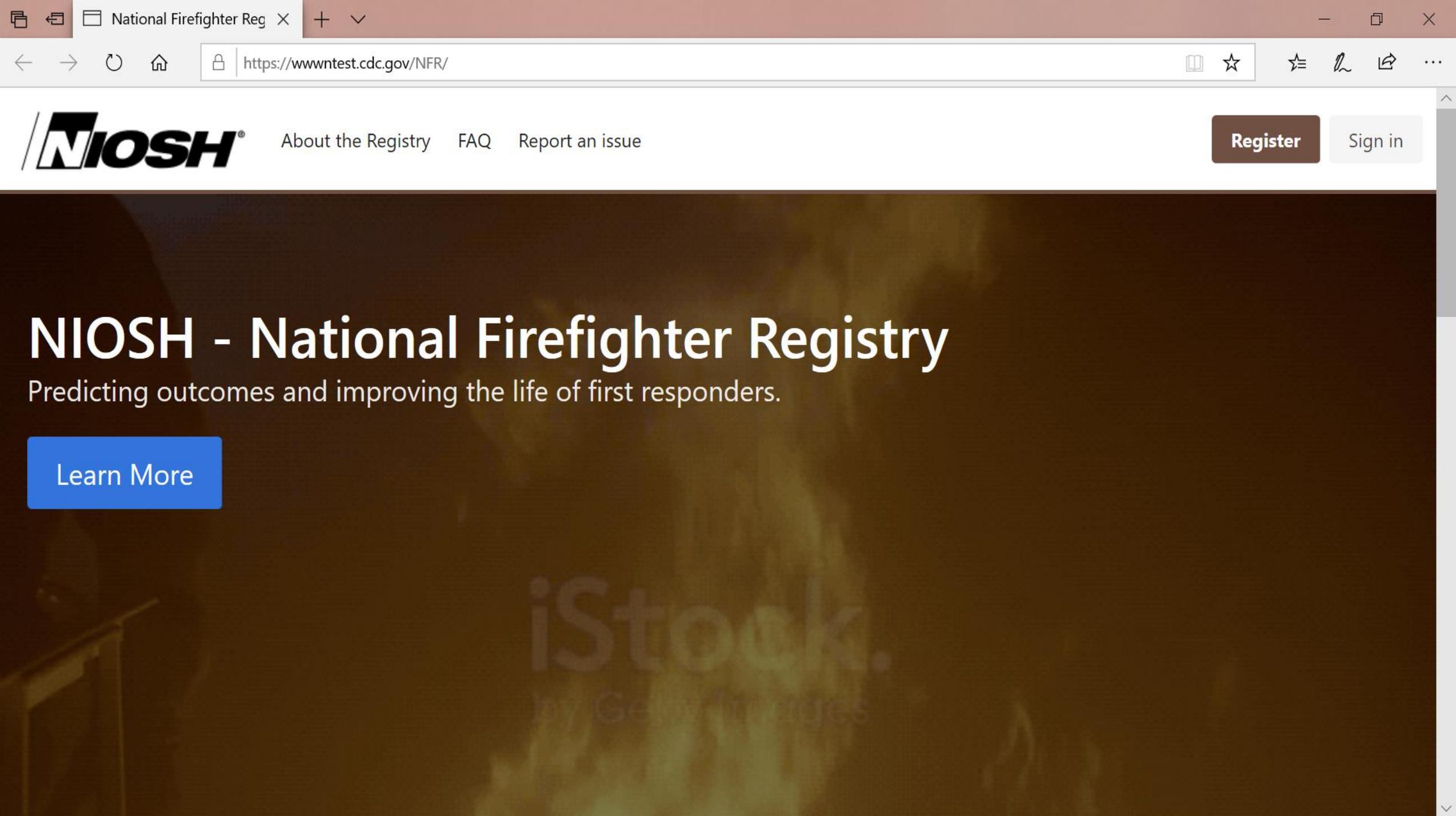
Identity Verification

- Social security number
 - Why do we need this?
 - Cancer registry & vital status matching
 - Appropriate timing within questionnaire to ask for SSN?
 - Link with “why are we asking this”
 - Pop-up at end reiterating the importance of gathering SSN



Pilot Testing & Reviews

- 10 fire service professionals from various ranks and backgrounds
 - Average completion time for enrollment questionnaire ~12 minutes
- Questionnaire reviewed by three physicians, two survey methodologists, and numerous epidemiologists
- Feedback
 - Largely positive
 - Incorporated language and organization suggestions
 - e.g., language changes to make questions more relevant to specific groups of firefighters, reordering of questions, grouping of response options, etc.



[About the Registry](#) [FAQ](#) [Report an issue](#)

[Register](#)

[Sign in](#)

NIOSH - National Firefighter Registry

Predicting outcomes and improving the life of first responders.

[Learn More](#)

iStock
by Getty Images

Introducing the National Firefighter Registry



Improve data collection, track, and predict the incidence of cancer among firefighters nationwide.



Develop reliable methods for estimating the number and type of fire incidents attended by a firefighter.



Examine cancer risk among recent firefighters exposed to burning of synthetic materials present in newer structures

Get Started

STEP 1 of 4

Enter your email address

Email

 bill@murray.com

Sign Up

STEP 2 of 4

Confirm Your Email Address

An email was sent to confirm your account. To continue, please check your email.

An email will be sent to the user asking them to confirm their account/email address.

[Click here to simulate clicking confirm in the email](#)

STEP 3 of 4

Set a Password

Your account has been successfully confirmed. Please set a password.

Password

 ●●●●●●●●

Confirm Password

 ●●●●●●●●

Set Password



Your password has been set.

Register / Enroll

National Firefighter Registry Consent Form

Key information (Short Summary): The National Firefighter Registry (NFR) is a voluntary registry created to evaluate cancer trends in U.S. firefighters. Any firefighter can register regardless of health status. You can register in the NFR in about 20 minutes by completing this consent document and enrollment questionnaire.

The NFR tracks the health of its participants. If you are diagnosed with cancer, your cancer will be reported to the cancer registry in the state or territory where you were diagnosed. The National Institute for Occupational Safety and Health (NIOSH) will match the information you provide in the NFR with this diagnosis information. NIOSH may also collect information about your work history from your fire department(s) to estimate your exposures. All your personal information will be kept confidential and protected to the fullest extent allowed by law. The goal of the NFR is to understand and prevent cancer in the U.S. fire service.

Who is conducting the Registry?

The NFR tracks the health of its participants. If you are diagnosed with cancer, your cancer will be reported to the cancer registry in the state where the diagnosis was made. The National Institute for Occupational Safety and Health (NIOSH) will match the information you provide in the NFR with this diagnosis information. NIOSH may also collect information about your work history from your fire department(s) to estimate your exposures. All your personal information will be kept confidential and protected to the fullest extent allowed by law. Our goal is for this information to help understand and prevent cancer in the U.S. fire service.

What is the purpose of the Registry?

The National Firefighter Registry (NFR) aims to better understand the link between firefighting and cancer in the United States.

Who is eligible for the Registry?

All current and former firefighters in the United States are eligible for the NFR. This includes career, volunteer, and part-time firefighters.

Is my participation voluntary?

The NFR is voluntary. No one can force you to register.

What is expected of me?

After signing this consent document, you will be asked to complete a user profile and an enrollment questionnaire focusing on demographics, work history, exposures, current health status, and other risk factors for cancer. It is critical to understand the link between firefighting and cancer. Once you have registered, NIOSH will be able to track your cancer status. If you are diagnosed with cancer, you give NIOSH permission to access any potential cancer diagnosis information from these cancer registries. NIOSH will also send you follow-up questionnaires asking for additional details on your health or work as a firefighter to help understand the relationship between firefighting and health status over time. We will not send more than one questionnaire to learn more about your fire exposures. This will not require any action from you. If you are current or former firefighter, this will help us understand how your exposures relate to cancer risk.

What is the time commitment?

You should be able to read and complete this consent document and the initial questionnaire in 20 minutes or less. You can complete the questionnaire in one sitting, you can log off and finish it later. Once you finish, you are officially registered. We will track cancer diagnoses over a long period of time. To do this, we will send you follow-up questionnaires over the time.

Are there direct benefits to me?

There are no direct benefits from participating in the NFR. Findings from the NFR may increase scientific understanding of firefighting and its relationship to cancer risk.

Are there risks associated with participating in the Registry?

You may experience stress from participating in a study focused on cancer. If you are uncomfortable answering a questionnaire at any time, you can stop. While there is always a risk that data could be accidentally released, we will minimize this privacy risk by separating your identifiable information from your questionnaire responses or exposure data, and assigning unique identifiers to each.

Will my personal information be kept private?

Information or documents that can be used to identify you are considered identifiable information. NIOSH will protect your identifiable information with an **Assurance of Confidentiality (AOC)**, which is the highest level of protection available. The AOC protects your identifiable information from being shared with any external parties without your written permission.

- NIOSH cannot give your identifiable information to your employer or insurance company
- NIOSH cannot be forced to share your identifiable information for a lawsuit.
- NIOSH cannot release your identifiable information for use as evidence even if there is a court subpoena.

What if I'm injured or harmed?

Injury or harm as a result of participating in the NFR is unlikely. If harmed through negligence of a NIOSH employee or contractor, you may be able to file a claim with that contractor.

Will I or anyone else receive study results?

Analysis of the NFR data will result in scientific papers and reports. The papers and reports will summarize our findings and will never identify you or any other individual. These papers and reports will be provided to fire service organizations and departments. NIOSH will also post any papers and reports on its [website](#) and make them available to NFR participants through their communication channels. NIOSH will also make the data we collect available to outside researchers, this data will not identify you. We will not release your individual data or study results to anyone without written permission.

Who can I talk to if I have more questions?

Answers to frequently asked questions (FAQs) about the NFR are available at the [NFR Resource Page](#). For additional questions, contact the NFR team at NFRRegistry@cdc.gov.

- NIOSH cannot give your identifiable information to your employer or insurance company
- NIOSH cannot be forced to share your identifiable information for a lawsuit.
- NIOSH cannot release your identifiable information for use as evidence even if there is a court subpoena

What if I'm injured or harmed?

Injury or harm as a result of participating in the NFR is unlikely. If harmed through negligence of a NIOSH employee, you might obtain compensation under Federal Law. If a NIOSH contractor is negligent, you can file a claim with that contractor.

Will I or anyone else receive study results?

Analysis of the NFR data will result in scientific papers and reports. The papers and reports will summarize our findings and will never identify you or any other individual. These papers and reports will be provided to fire service organizations and departments. NIOSH will also post any papers and reports on its [website](#) and make them available to NFR participants through their communication channels. NIOSH will also make the data we collect available to outside researchers, this data will not identify you. We will not release your individual data or study results to anyone without written permission.

Who can I talk to if I have more questions?

Answers to frequently asked questions (FAQs) about the NFR are available at the [NFR Resource Page](#). For additional questions, contact the NFR team at NFRRegistry@cdc.gov.

I prefer not to participate

I Agree

I prefer not to participate

I Agree



1 Personal Information

First Name

Middle Name

Last Name

Employee ID / Departmental Identification

Email

Phone

Street Address

City

State

Zip

Date of Birth

City of Birth

State of Birth

What is your height?

What is your current weight (lbs)?

2 Fire Service

3 Work History

4 Current Role

5 Health Information

6 Identity

7 Final Thoughts

Is there anything else you would like us to know?



Finish

✓ Thank you!

We sincerely thank you for participating in this important project. Your registration has been submitted to the National Firefighter Registry. Gathering this information is the first step in understanding and preventing cancer in the U.S. fire service.

[Get Started](#)



UNDER
DEVELOPMENT

Questionnaire Discussion



Questions for Input

Dr. Paul Middendorf

The Program Would Like Input on These Questions

I. Communication and Enrollment Issues

1. 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?
2. What are the barriers to participation and what can NIOSH do to increase participation? What is the best process for recruiting states that require firefighter certifications?
3. Should NIOSH implement eligibility criteria for the fire department sampling frame?

II. Science Issues

4. What is the best way to estimate lifetime exposures and changes in implementation of controls over time as a firefighter? What role should follow-on or repeat questionnaires, or department-level surveys, play in this data collection?
5. What other important variables related to cancer risk should be collected as part of the enrollment process and what should be included in follow-on surveys (e.g., lifestyle factors and secondary jobs)? *Please keep in mind we would like to limit the time burden on participating firefighters for the initial enrollment process to 30 minutes or less.*
6. 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? How soon after initial enrollment should NIOSH seek to conduct cancer registry linkages nationally?

Additional Questions Identified by the Co-Chairs

7. There was no mention of pilot testing either section of the approach such as recruitment or the questionnaire; are there plans for pilot testing?
8. Has there been a decision regarding implementing the targeted or open cohorts simultaneously or consecutively?
9. Are there data indicating that you will be able to recruit ~40,000 FF/year, and what is the expected split between the targeted and open cohorts?

Thank you!

Website: www.cdc.gov/NFR

Email: NFRRegistry@cdc.gov

For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

