

The National Firefighter Registry (NFR)

NIOSH Board of Scientific Counselors Meeting
August 4, 2020

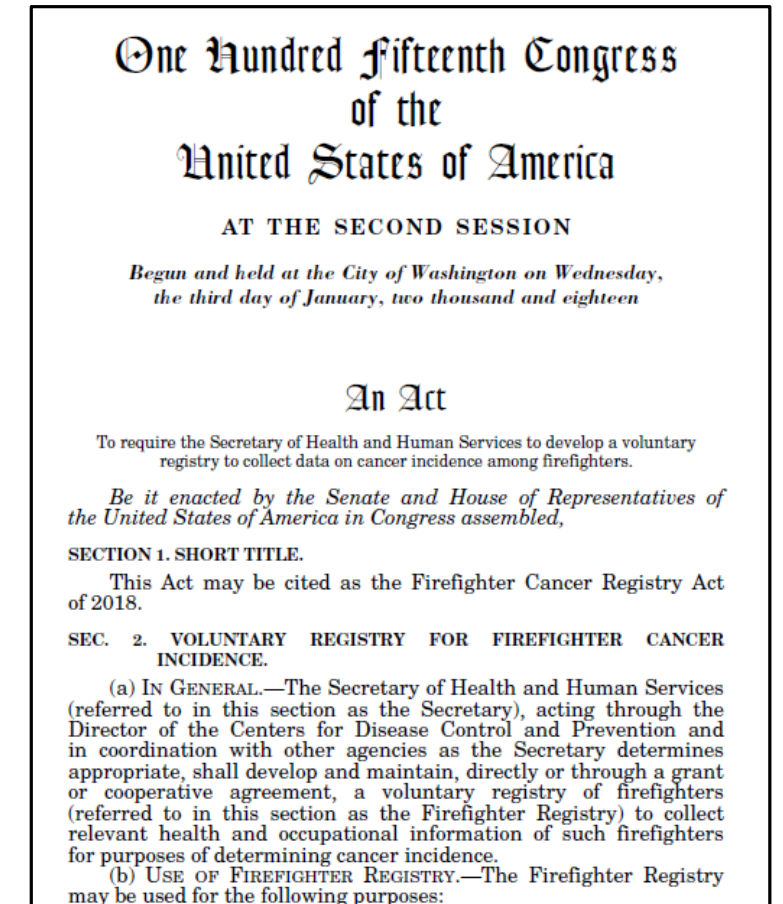
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NFR National
Firefighter
Registry

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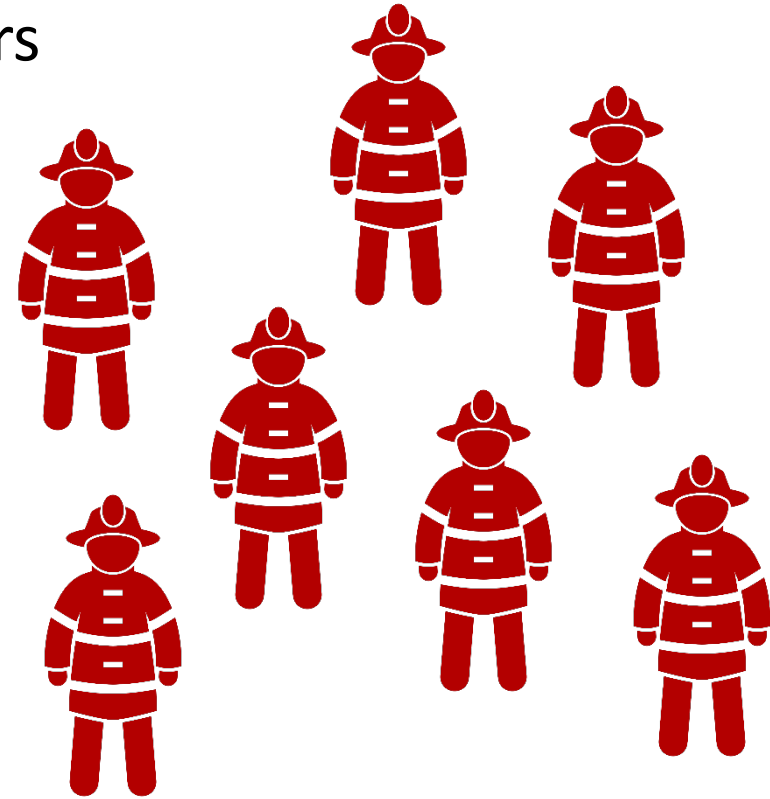
Why is the NFR being created?

- 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 that combine exposure and cancer information for studying the link in firefighters.
- Goal to track firefighters' cancer risk over time to better understand the link between workplace exposures and cancer.



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
 - Fire investigators
- Goal is to enroll 200,000+



Protocol Objectives

Develop a voluntary registry of firefighters to collect health and occupational information for determining cancer incidence and risk factors

- 1. Collect self-reported information** on workplace and personal characteristics through an online web portal
- 2. Obtain records** from fire departments or agencies to track trends and patterns of exposure
- 3. Link with health information databases**, including population-based cancer registries and the National Death Index to detect cancers and deaths

NFR Participants

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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)];
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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

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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

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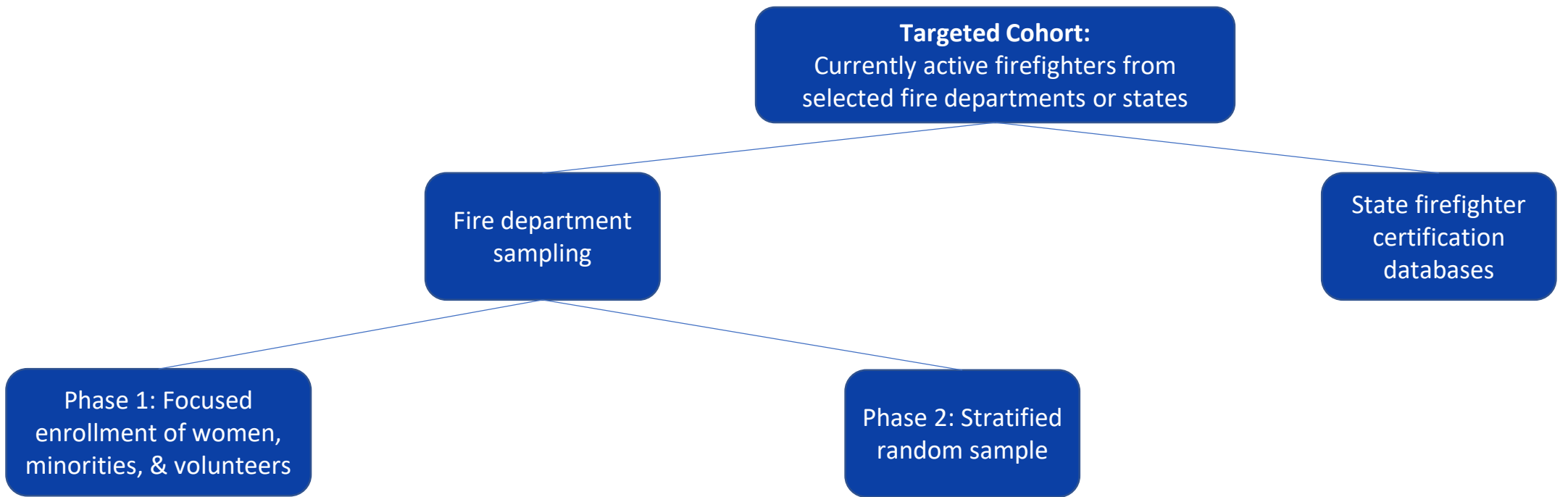
Web portal enrollment

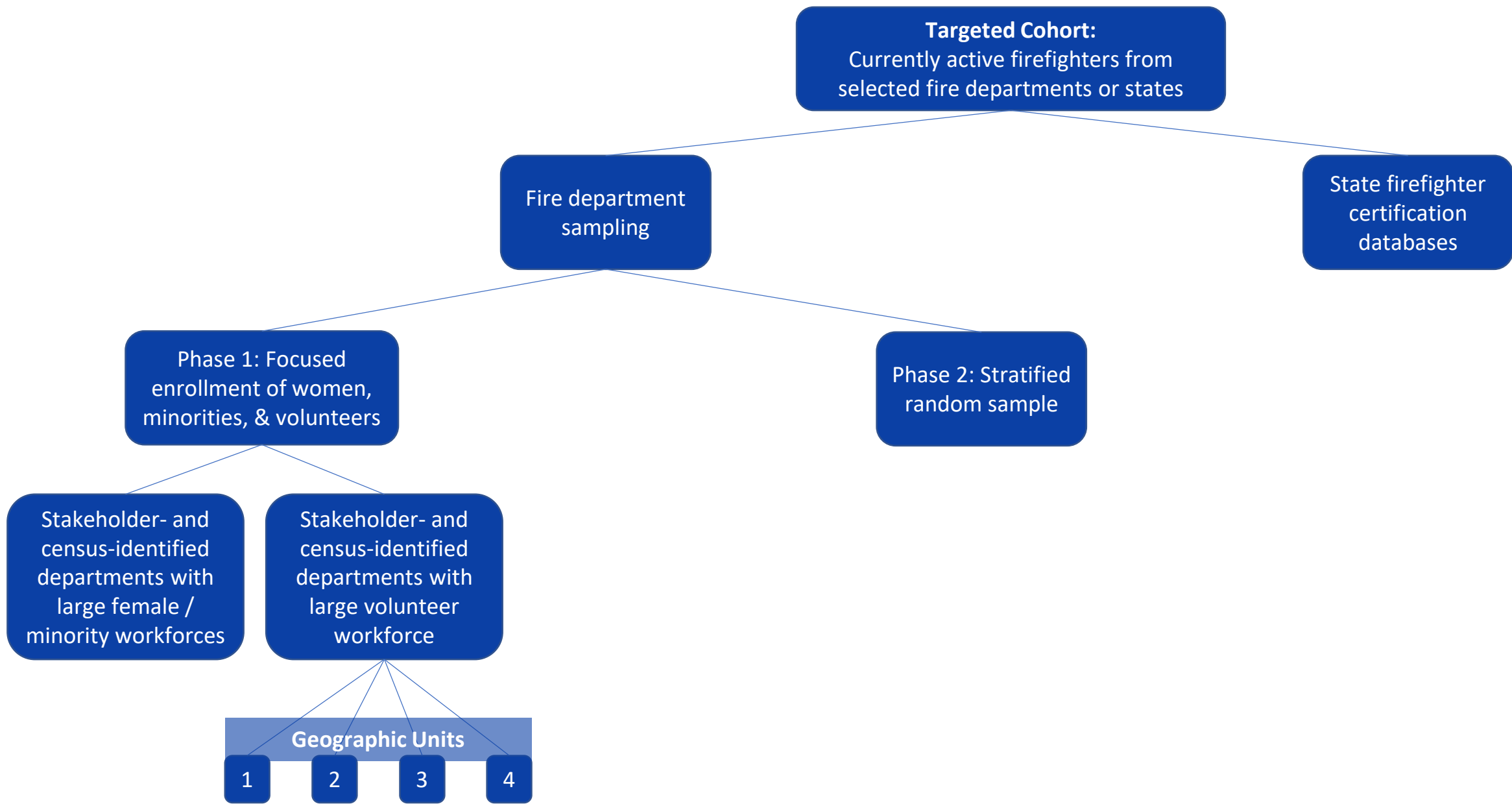
- Non-probability sample for which all firefighters are eligible
- Best method for recruiting a large, diverse, & inclusive sample
- Less cost/labor/time-intensive
- Opportunity for earlier analyses internal to sample (e.g., descriptive, cross-sectional, case-control)
- Subject to selection/participation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

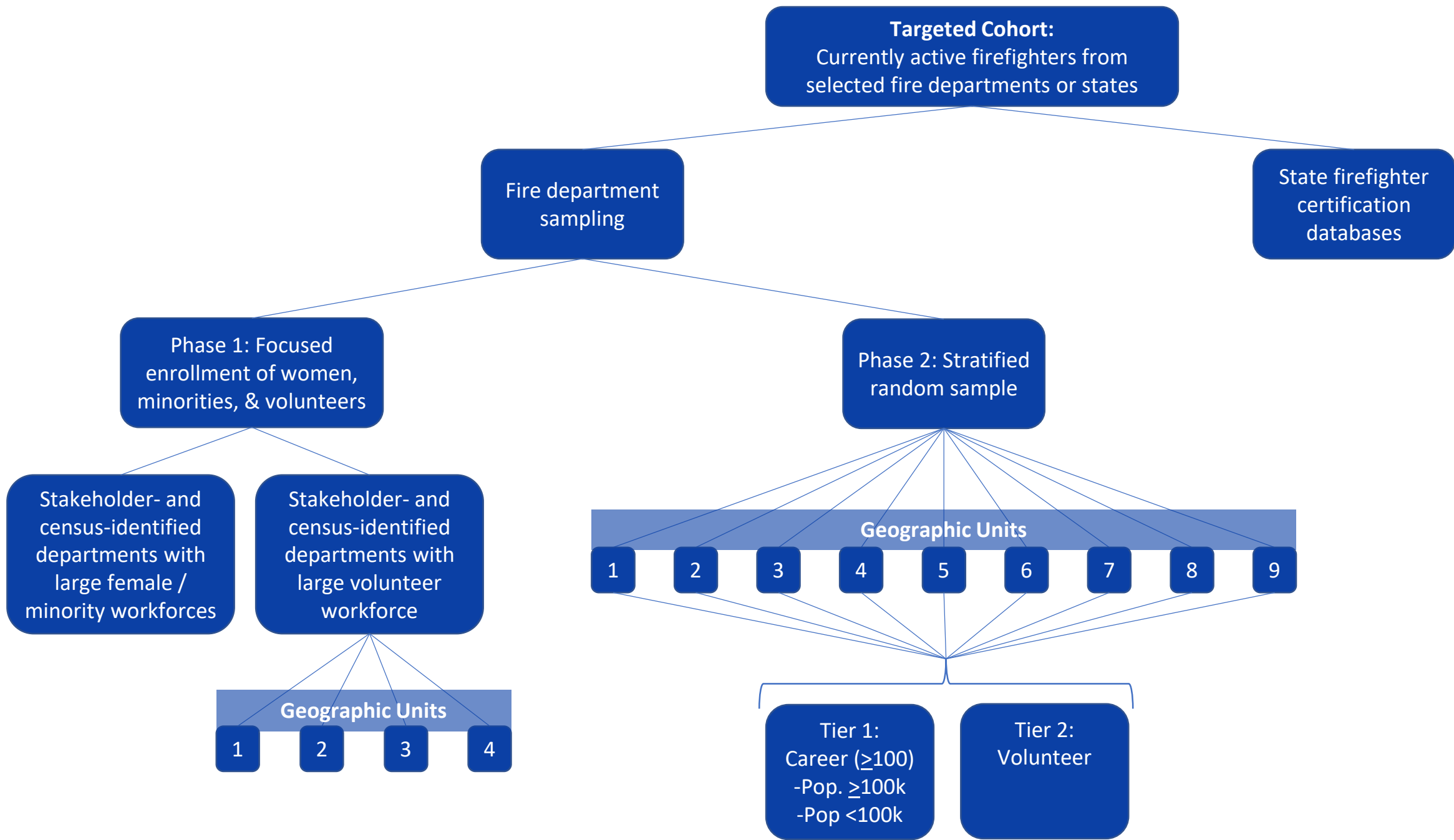
Targeted Cohort:
Currently active firefighters from
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Fire department
sampling

State firefighter
certification
databases







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Fire department sampling

State firefighter certification databases

Phase 1: Focused enrollment of women, minorities, & volunteers

Phase 2: Stratified random sample

Stakeholder- and census-identified departments with large female / minority workforces

Stakeholder- and census-identified departments with large volunteer workforce

Geographic Units
1 2 3 4 5 6 7 8 9

Geographic Units
1 2 3 4

Tier 1: Career (≥100)
-Pop. ≥100k
-Pop <100k

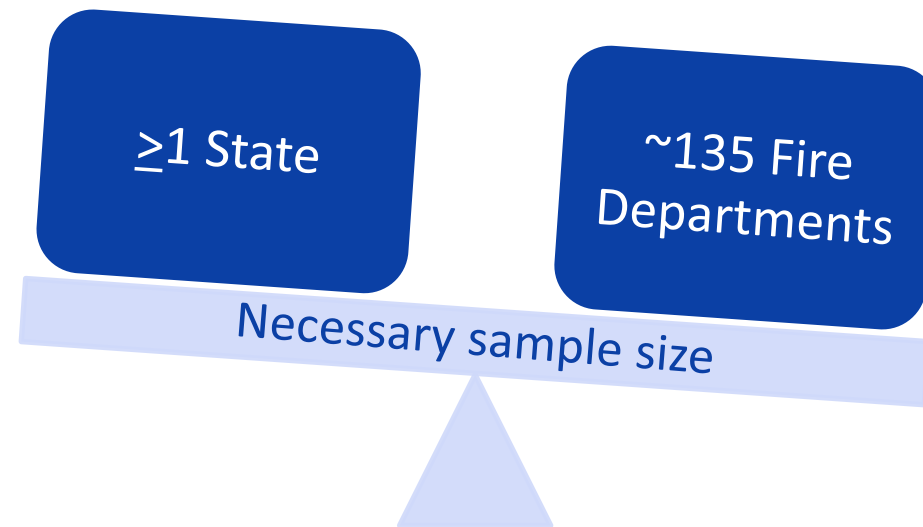
Tier 2: Volunteer

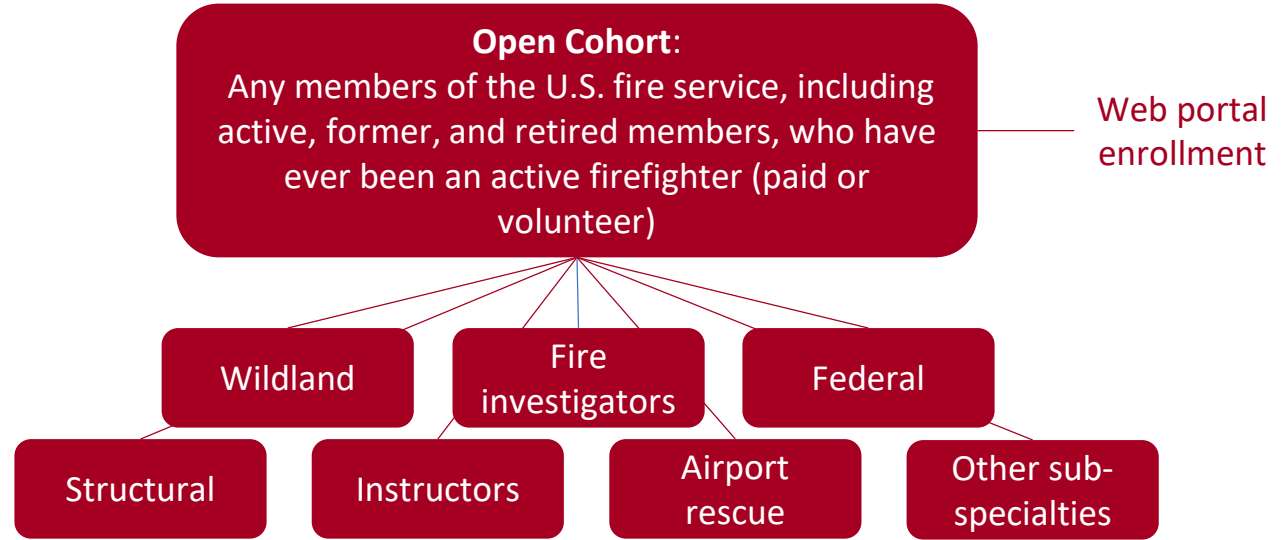
Targeted Cohort Sample Size Estimates

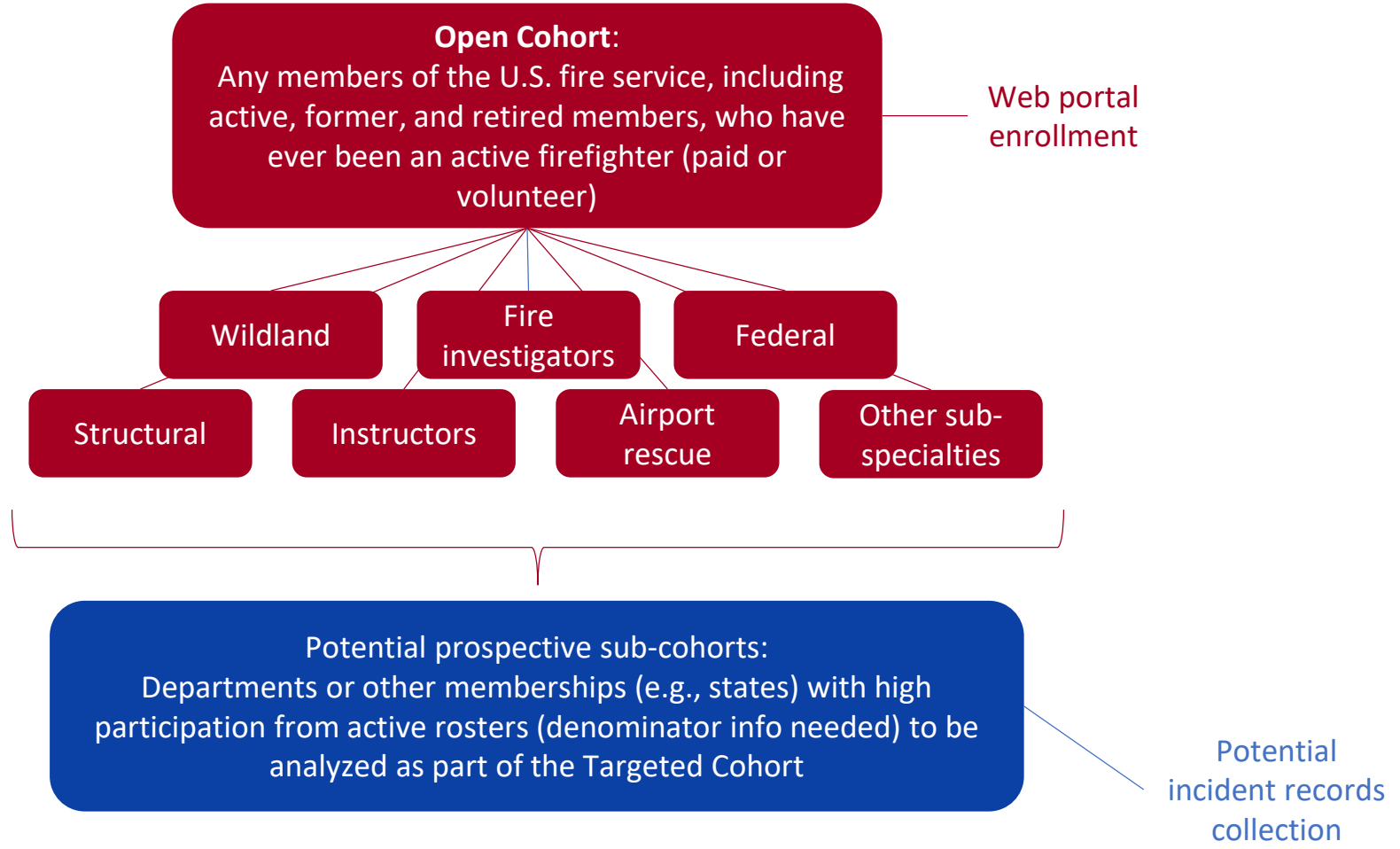
Minimum benchmarks:

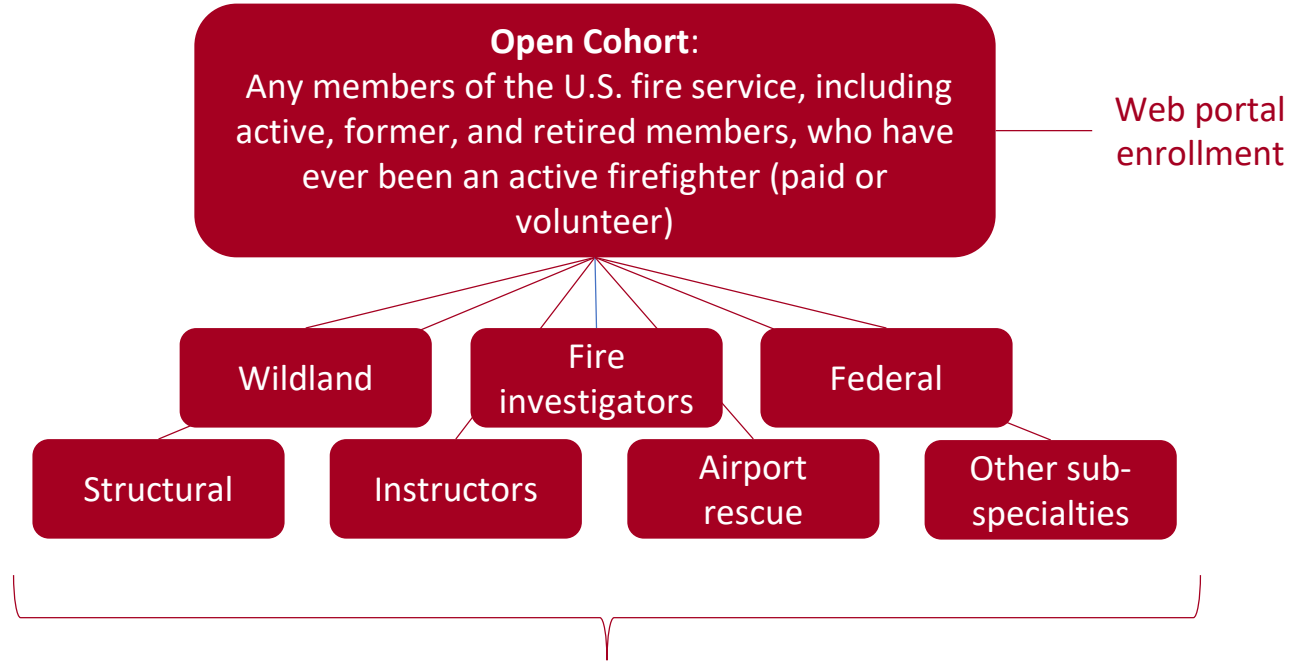
$\geq 1,000$ women; $\geq 6,500$ non-white firefighters; $\geq 5,000$ volunteers

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









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

Potential incident records collection

Recruitment Strategies



1.a

TARGETED COHORT

Current firefighters from selected fire depts or state certification databases

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

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Primary source of self-reported exposure information

1.b

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

End results of participation

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/external study data for participants (when applicable)

1.a

TARGETED COHORT

Current firefighters from selected fire depts or state certification databases

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

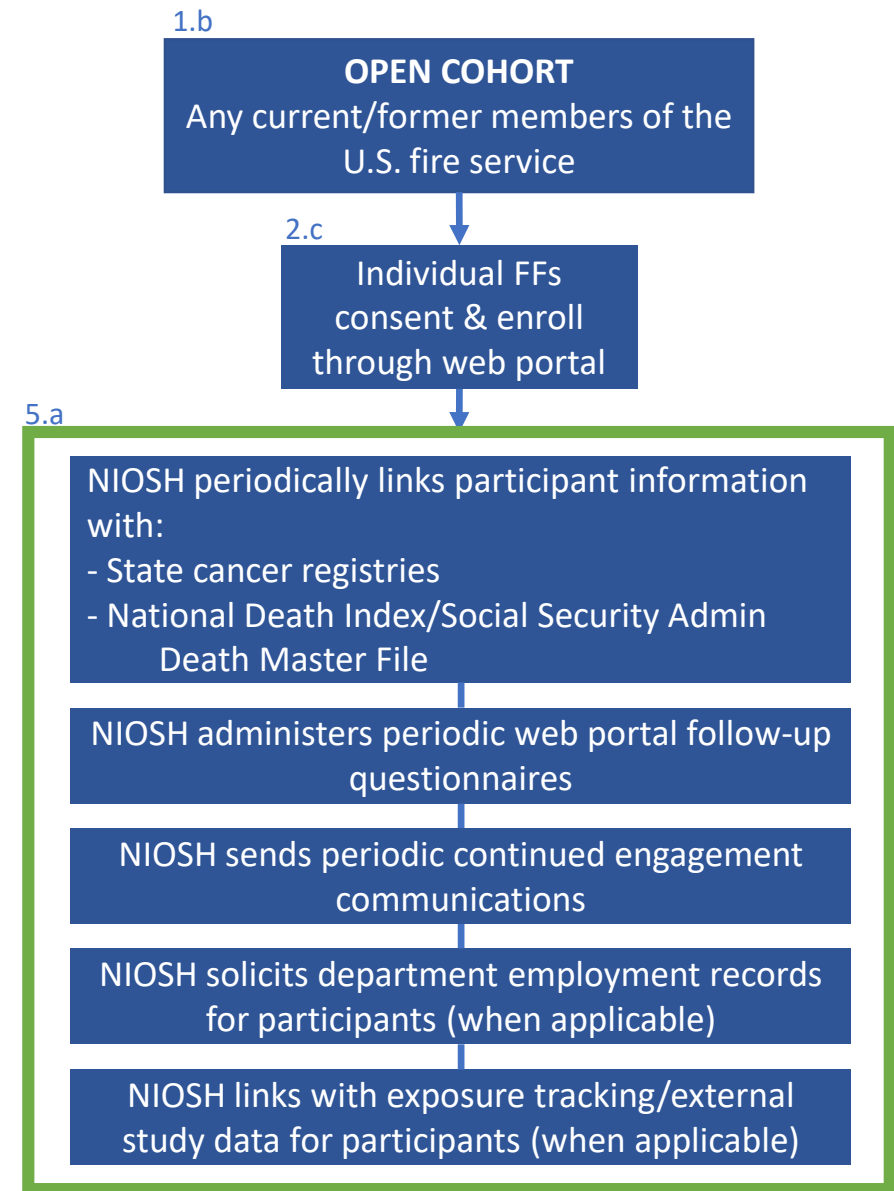
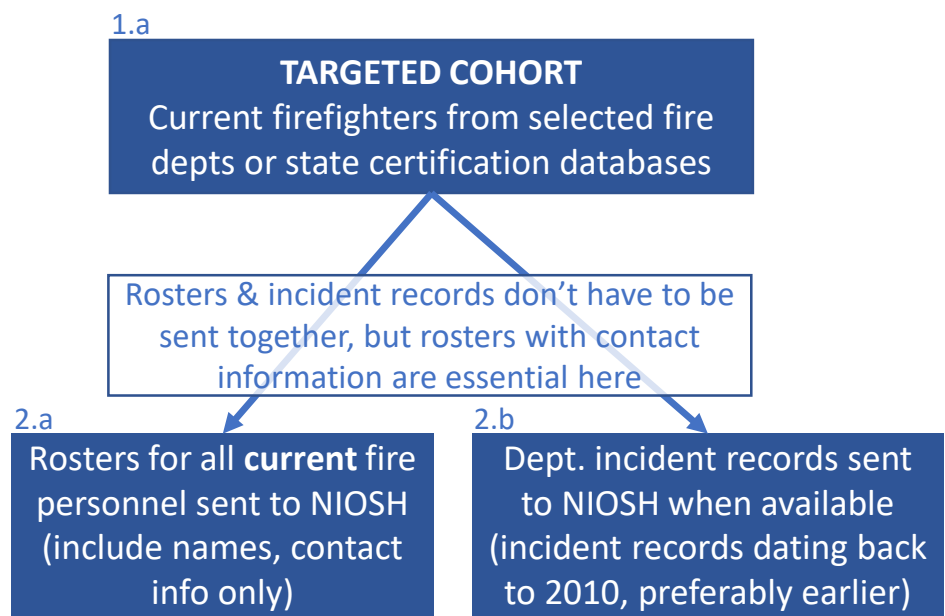
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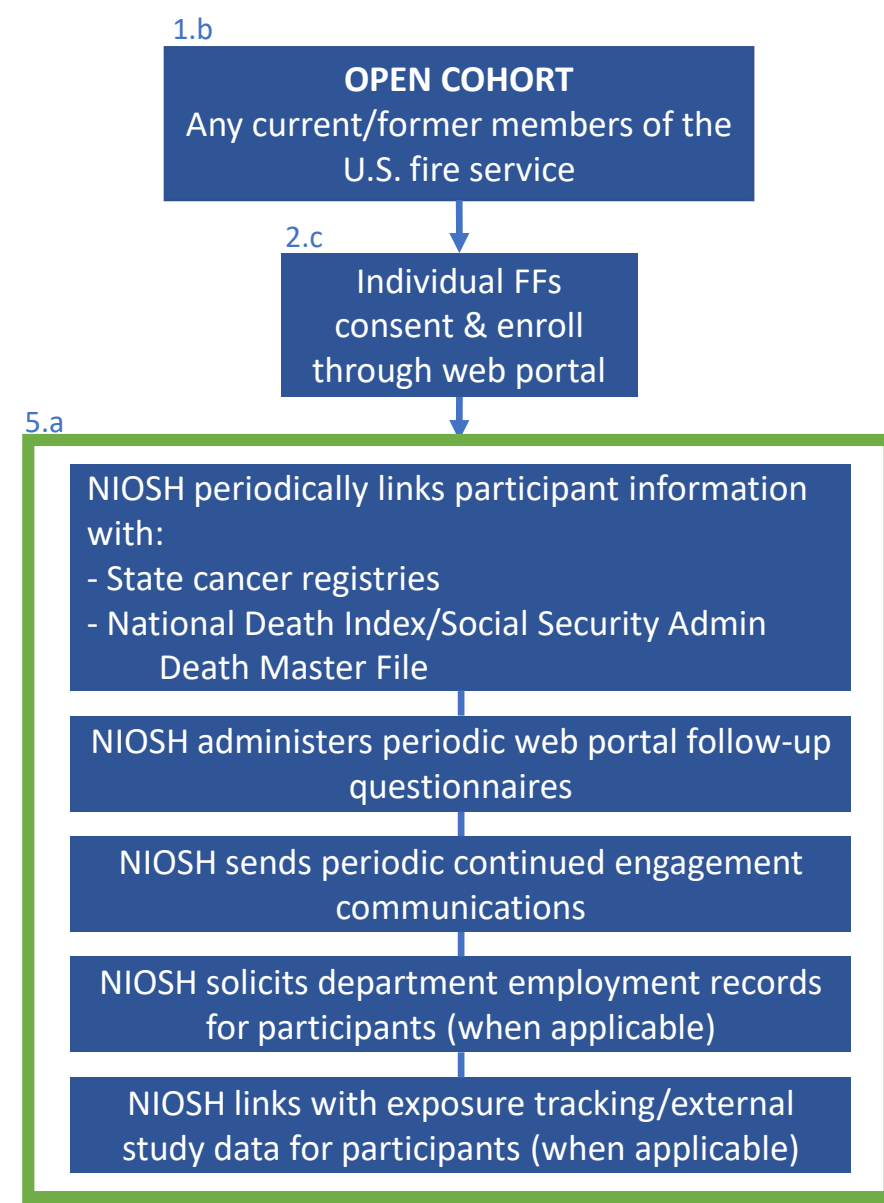
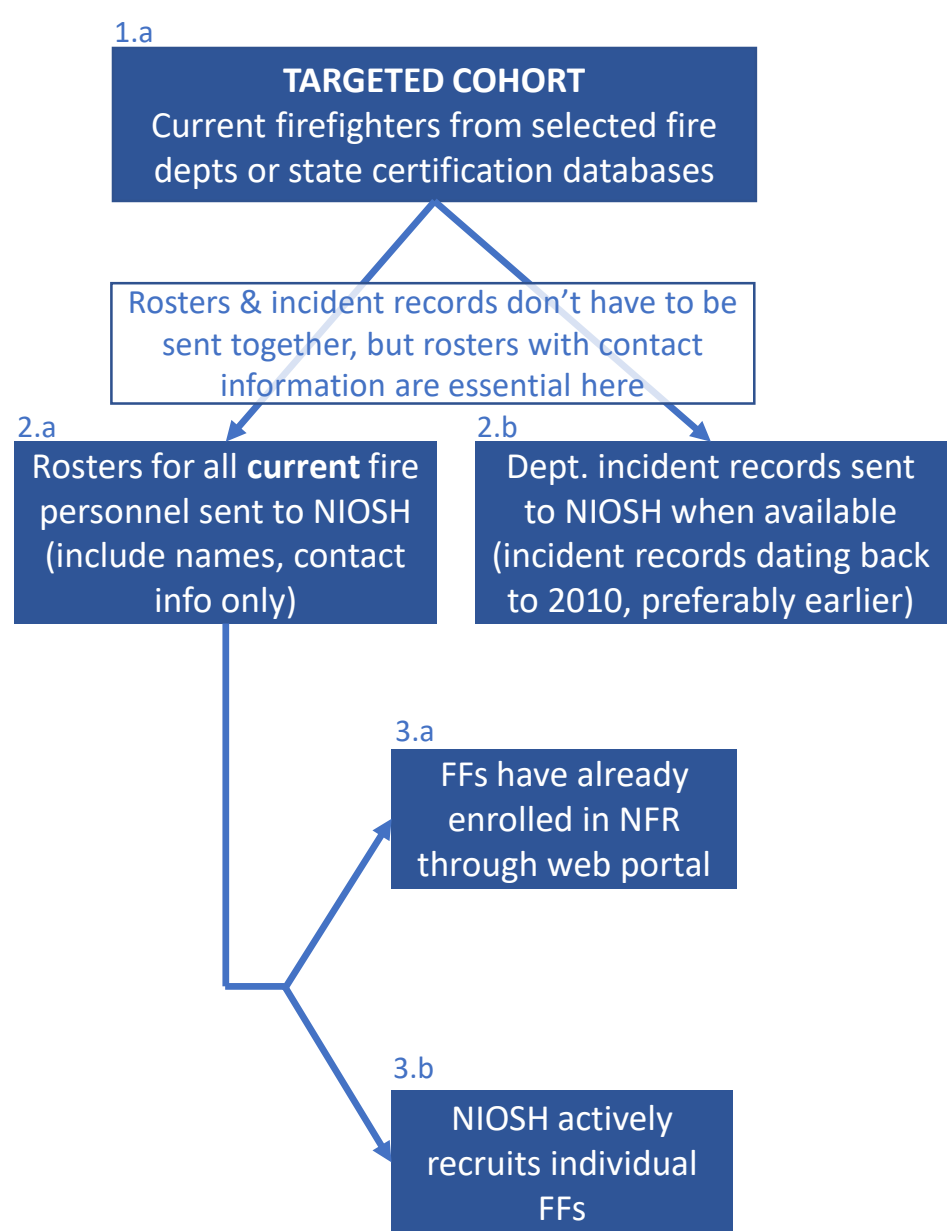
NIOSH administers periodic web portal follow-up questionnaires

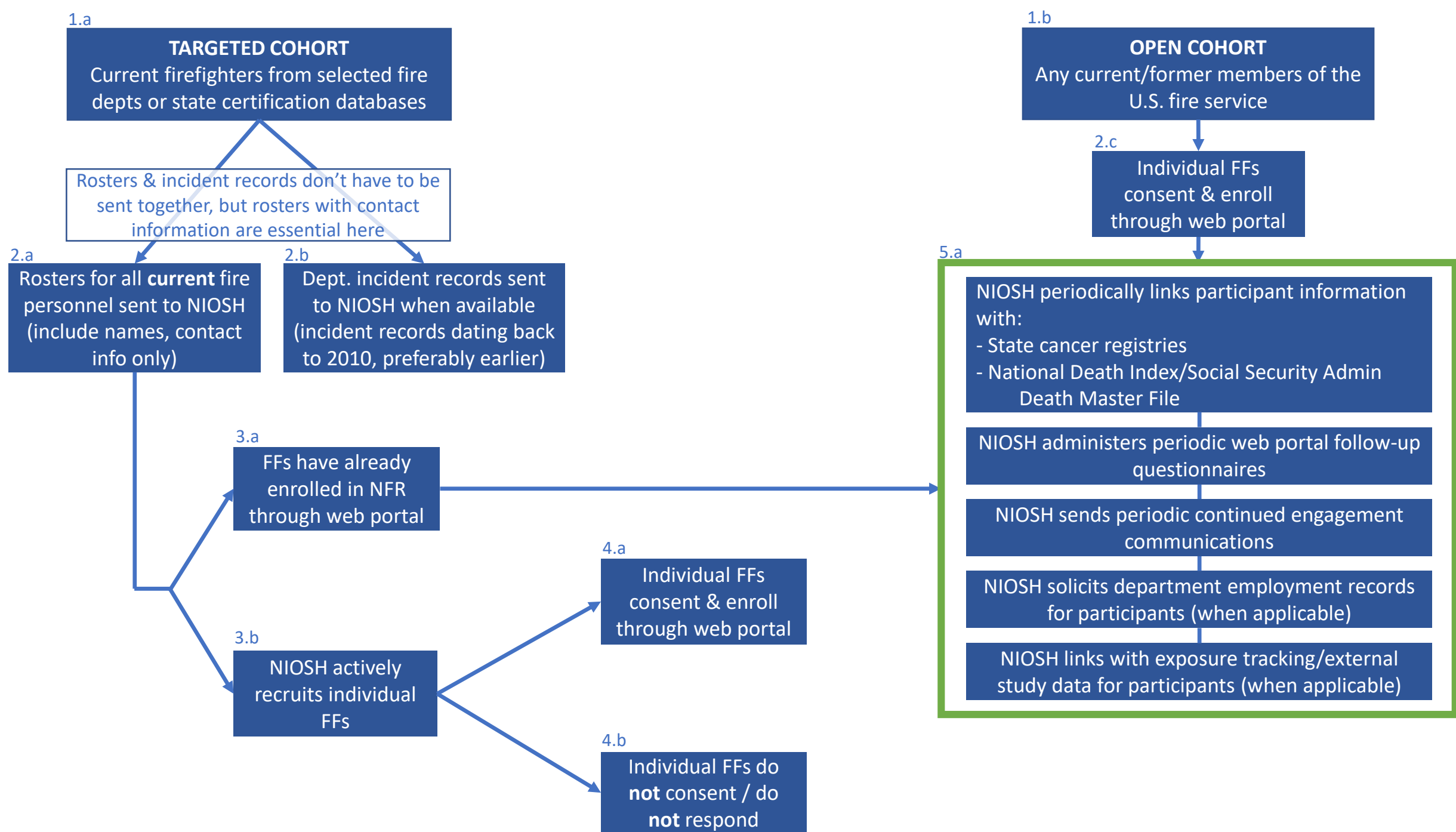
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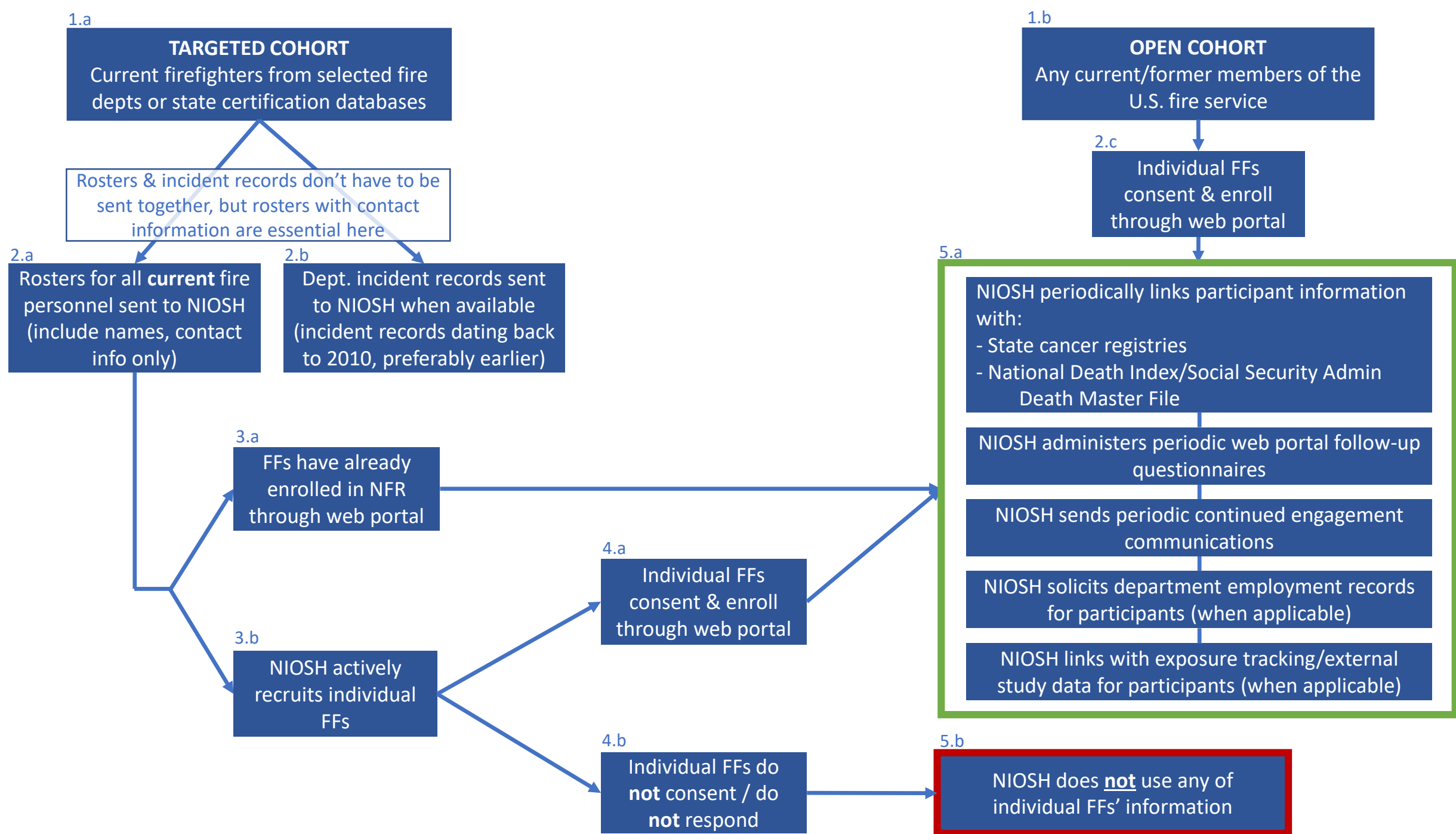
NIOSH solicits department employment records for participants (when applicable)

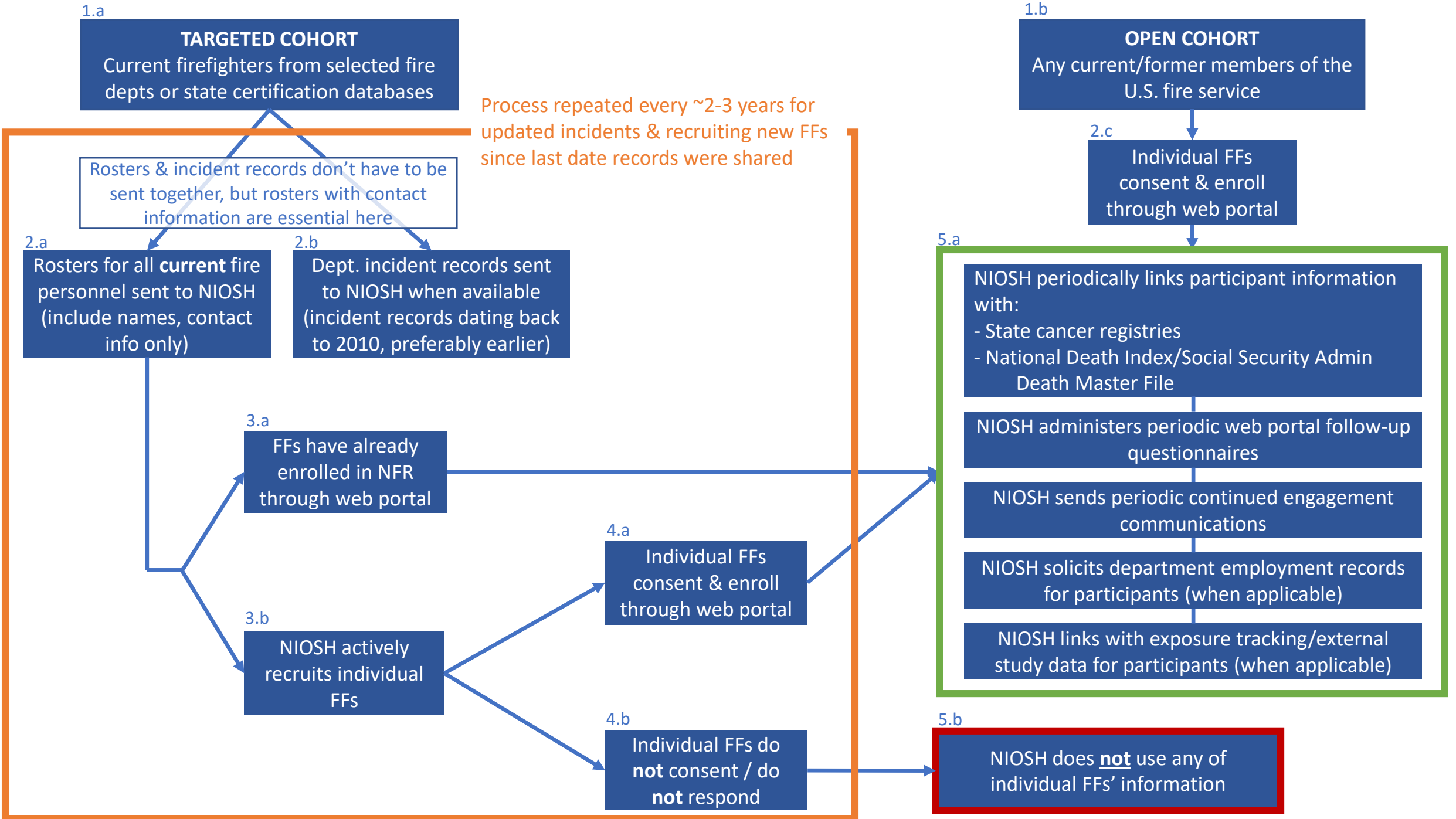
NIOSH links with exposure tracking/external study data for participants (when applicable)











Enrollment Questionnaire/Web Portal

- Balance brevity with scientific reasoning
 - Work/exposure history, demographics, lifestyle, health history
- Simple & easily accessible
 - Mobile and desktop version
- Secure format
 - Multifactor authentication
- Relevant to all firefighters
- Convey privacy (e.g., for SSN collection)
- Platform for important, voluntary follow-up questionnaires

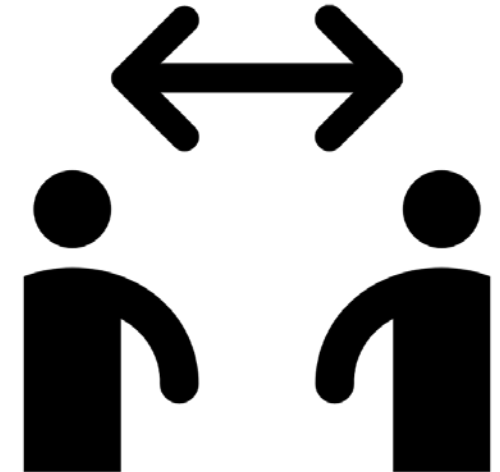
Enrollment Process

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



Assurance of Confidentiality

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



Communication Plan

Focus groups

Raise awareness

Publications

Clarify scope & expectations

Social media

Highlight the need

Conferences

Videos

Encourage firefighters to enroll
& spread the word

Newsletter

www.cdc.gov/NFR

www.cdc.gov/niosh/bsc/nfrs

NFR National Firefighter Registry Timeline

Establish the National Firefighter Registry



Collect data



Recruit and enroll firefighters

Analyze and disseminate results

2020

2021-2023

2024+

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.

