The National Firefighter Registry (NFR)

NIOSH Board of Scientific Counselors Meeting
August 4, 2020
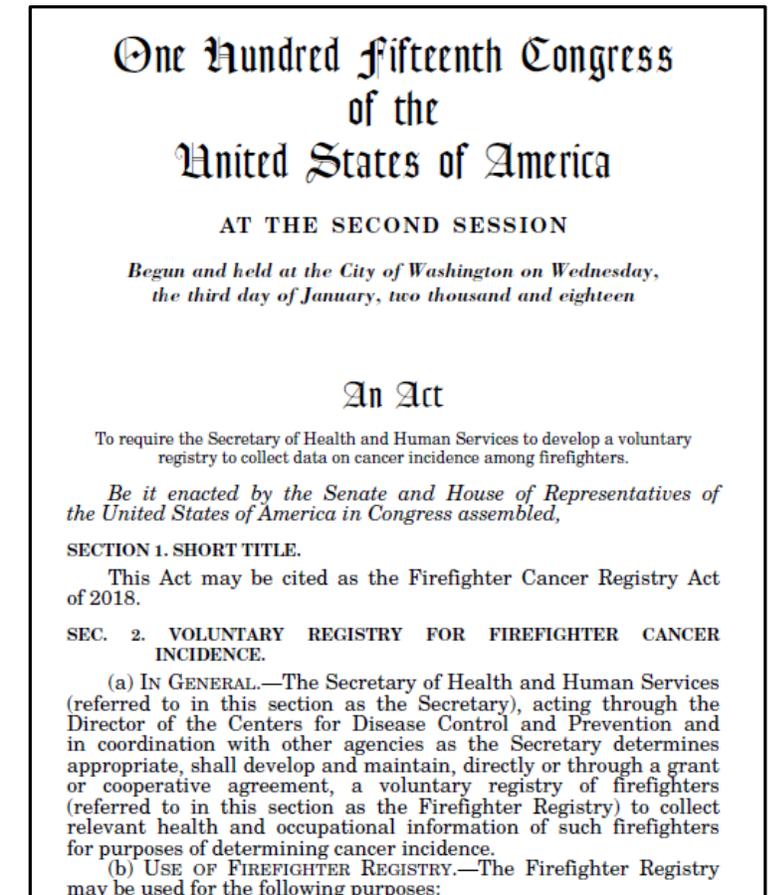
Miriam Siegel, DrPH

NFR Lead Epidemiologist

# NFR
National Firefighter Registry

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.

One Hundred Fifteenth Congress
of the
United States of America

AT THE SECOND SESSION

Begun 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

  - Fire investigators

- Goal is to enroll 200,000+
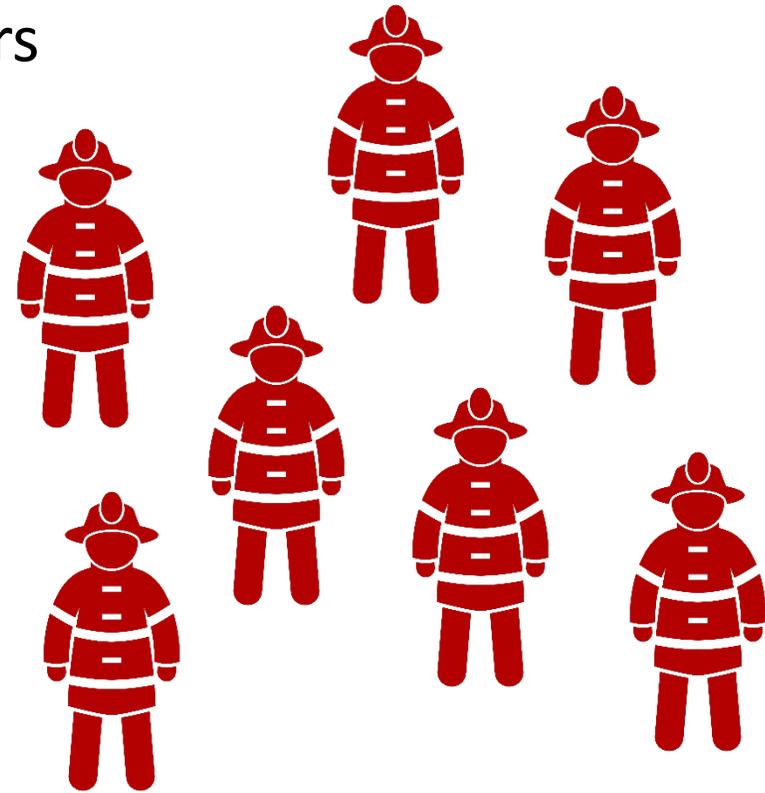
Protocol Objectives

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 on 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

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

- 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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Open Cohort:
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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 selected fire departments or states

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
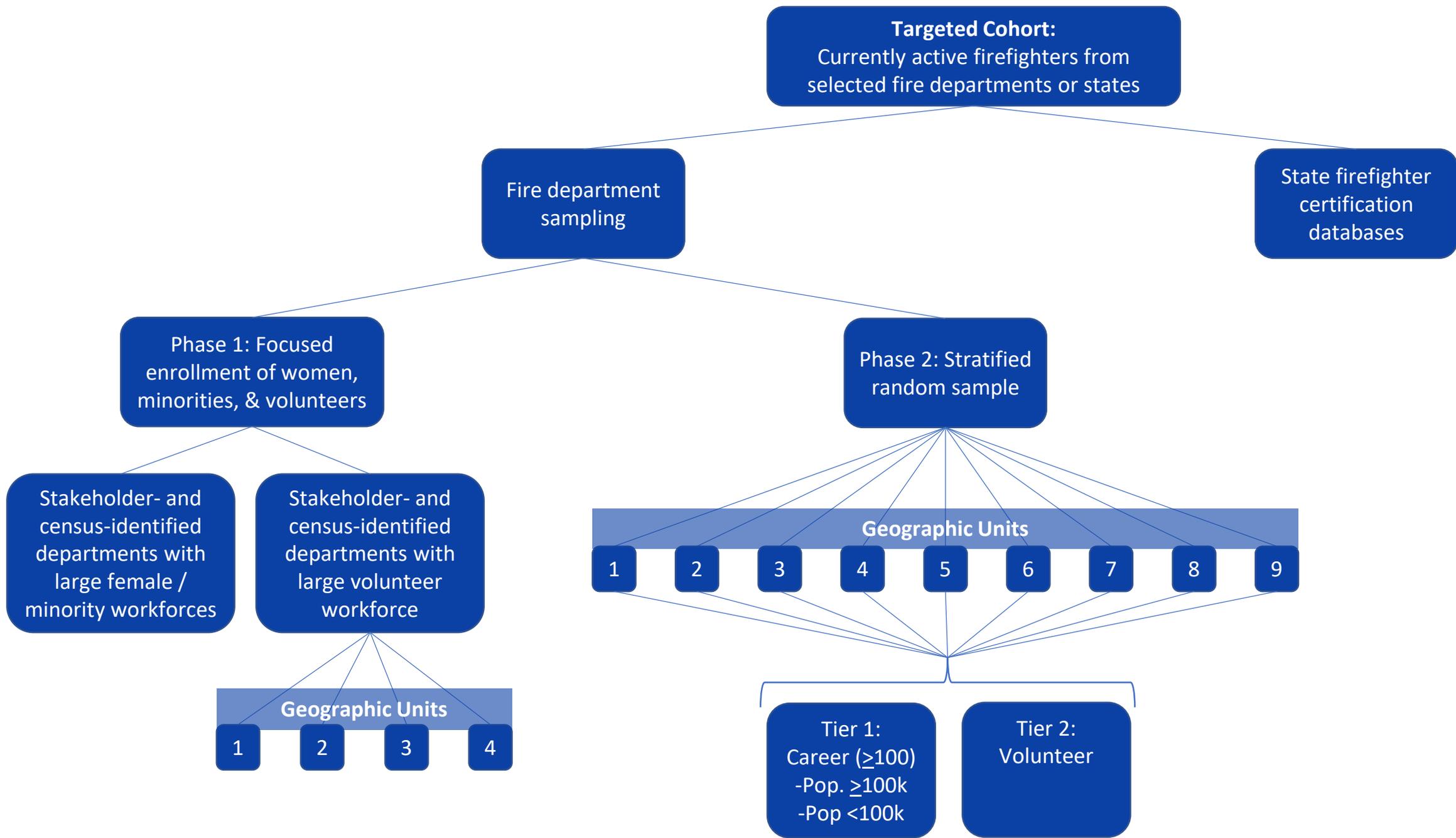
Targeted Cohort Sample Size Estimates

Minimum benchmarks:

≥1,000 women; ≥6,500 non-white firefighters; ≥5,000 volunteers

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

≥1 State

~135 Fire Departments

Necessary sample size

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Web portal enrollment

- Wildland
- Fire investigators
- Federal
- Structural
- Instructors
- Airport rescue
- Other sub-specialties

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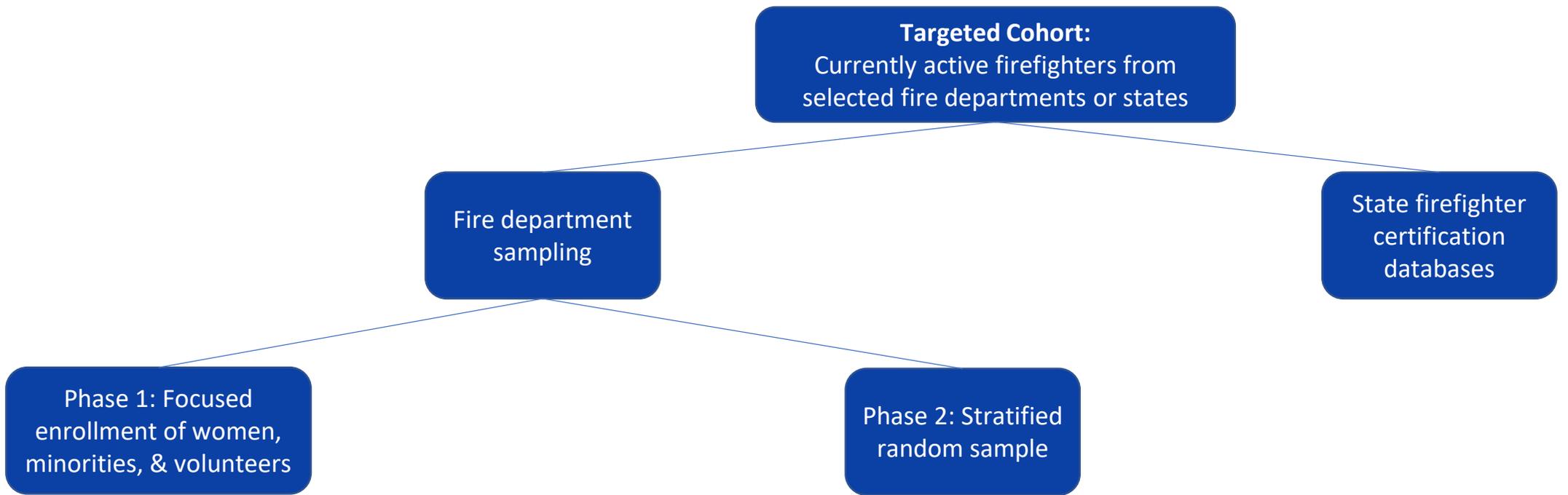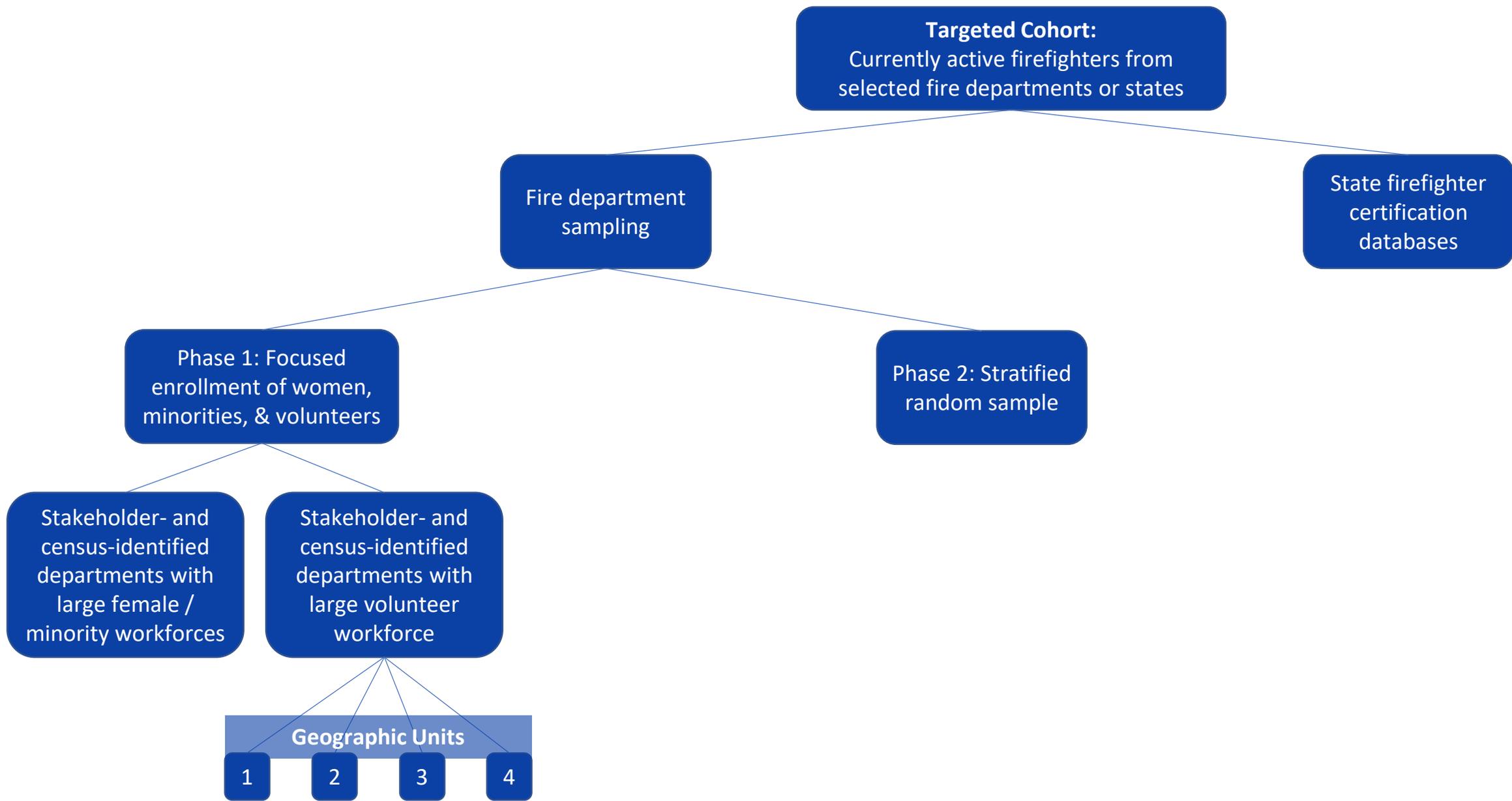
Web portal enrollment

Wildland

Fire investigators

Federal

Structural

Instructors

Airport rescue

Other sub-specialties

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

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

NFR Enrollment
Primary source of self-reported exposure information

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 databases

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

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

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1.b

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2.c

Individual FFs consent & enroll through web portal

5.a

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Rosters & incident records don't have to be sent together, but rosters with contact information are essential here

2.a
Rosters for all **current** fire personnel sent to NIOSH (include names, contact info only)

2.b
Dept. incident records sent to NIOSH when available (incident records dating back to 2010, preferably earlier)

1.b

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FFs have already enrolled in NFR through web portal

3.b
NIOSH actively recruits individual FFs

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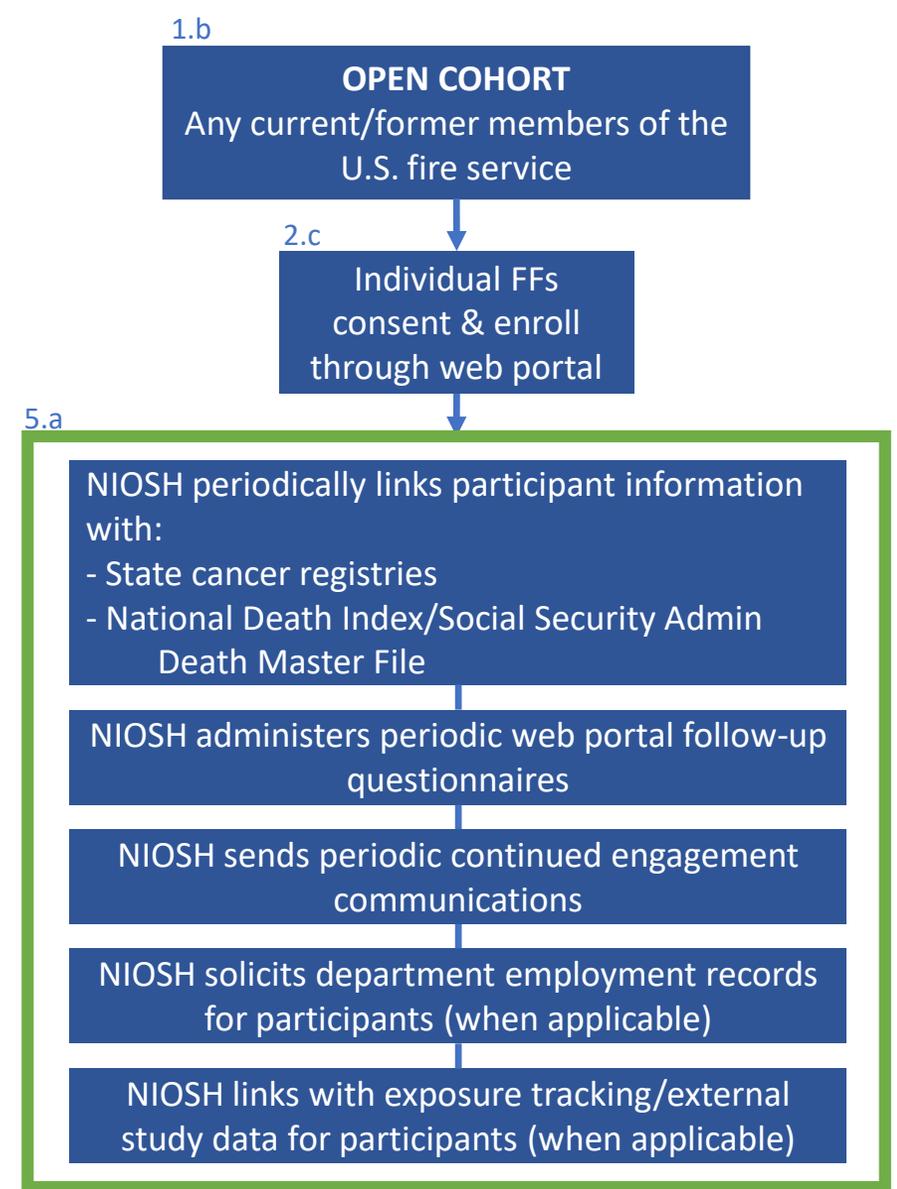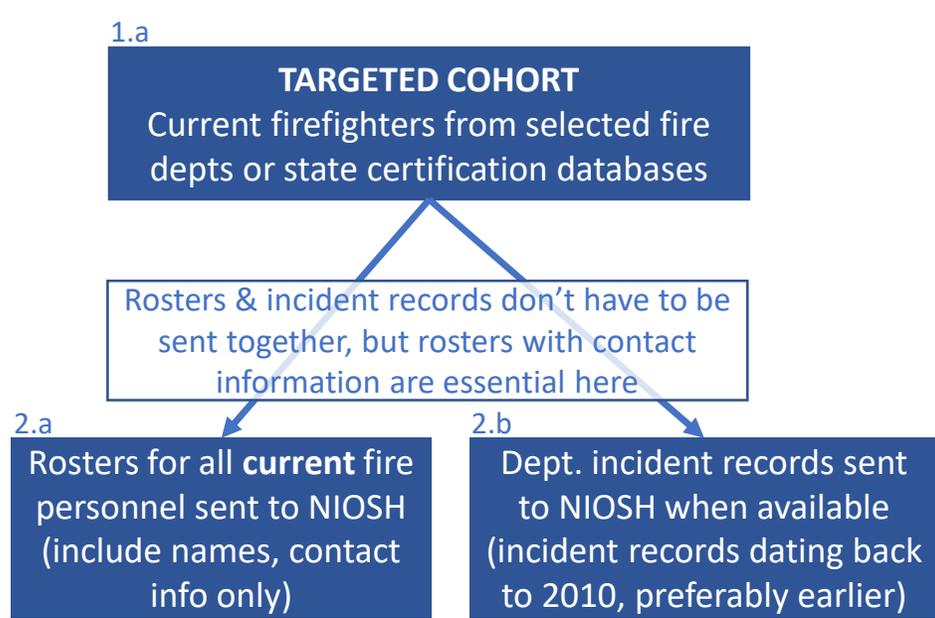
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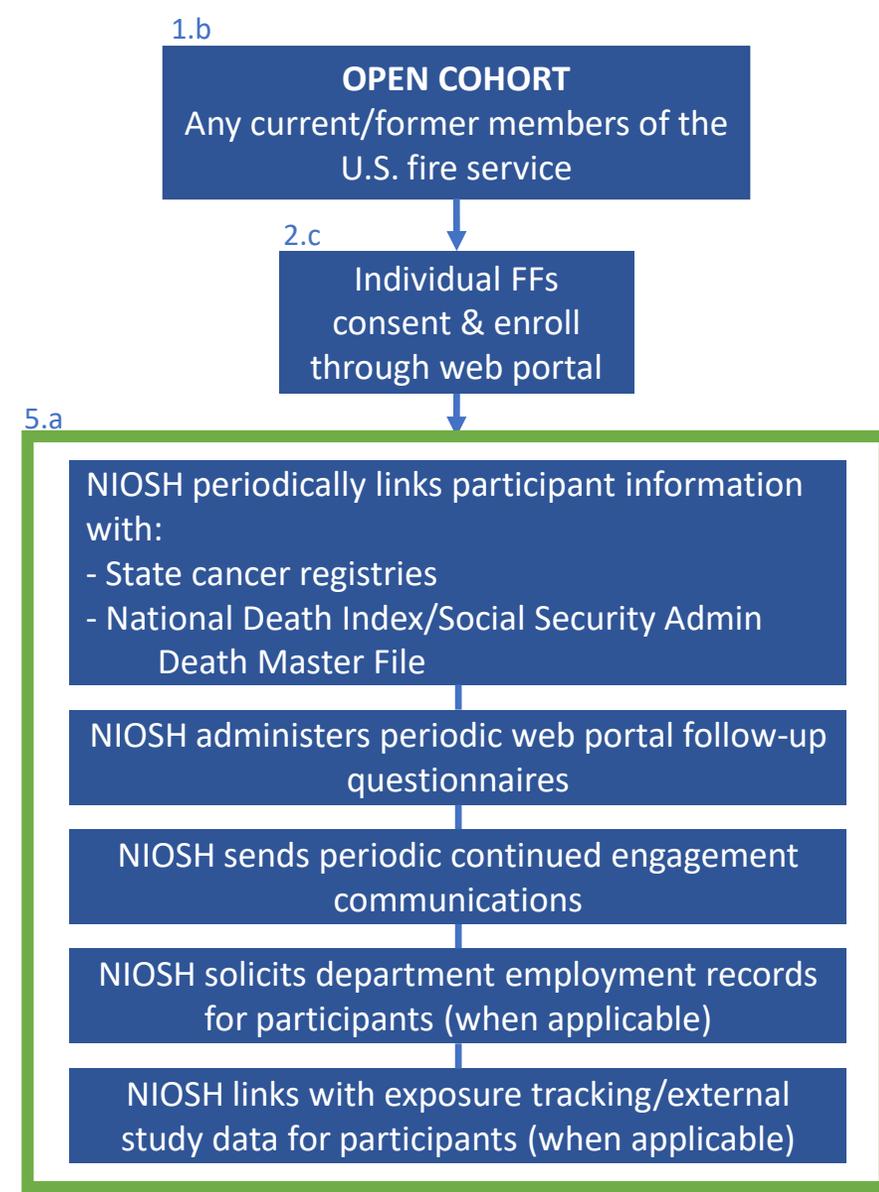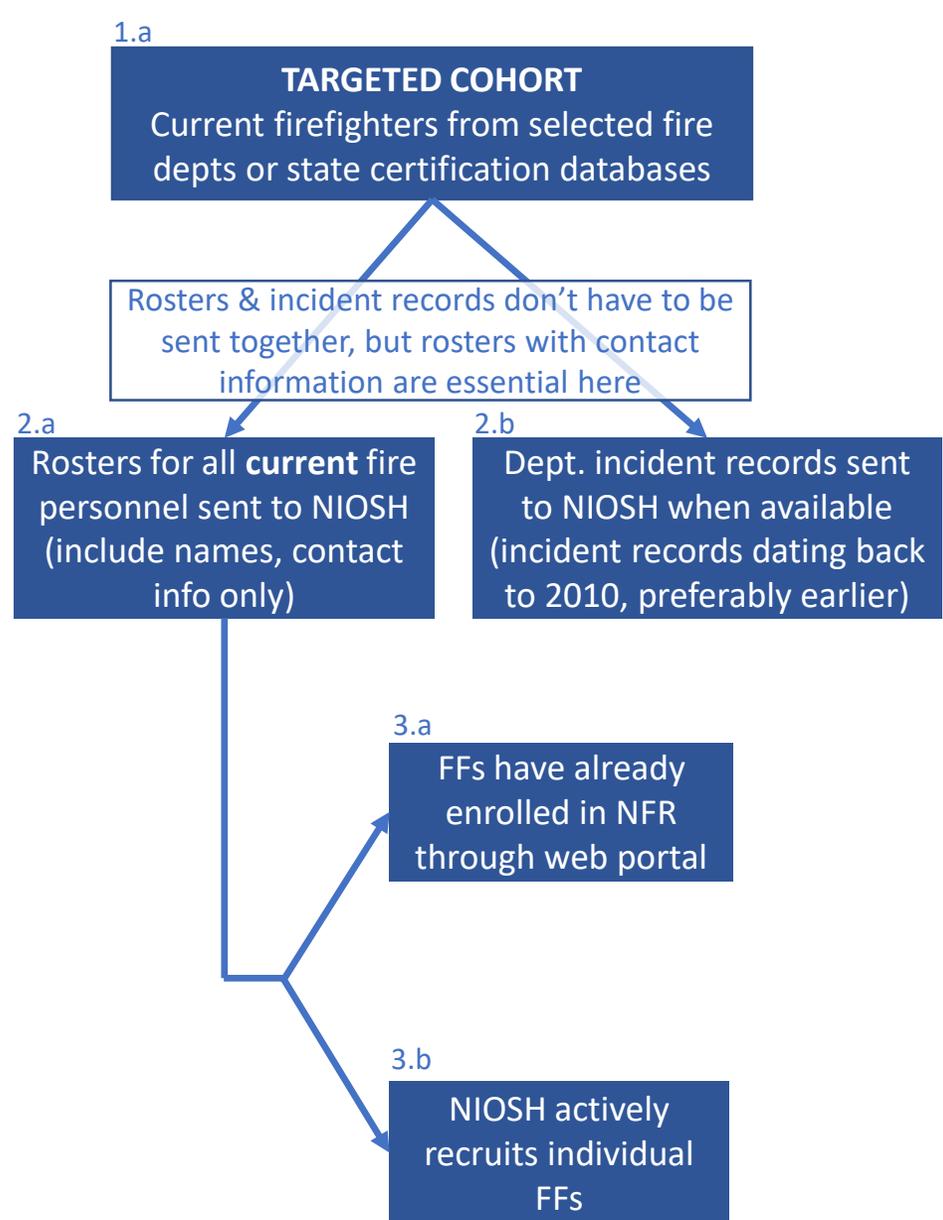- National Death Index/Social Security Admin Death Master File

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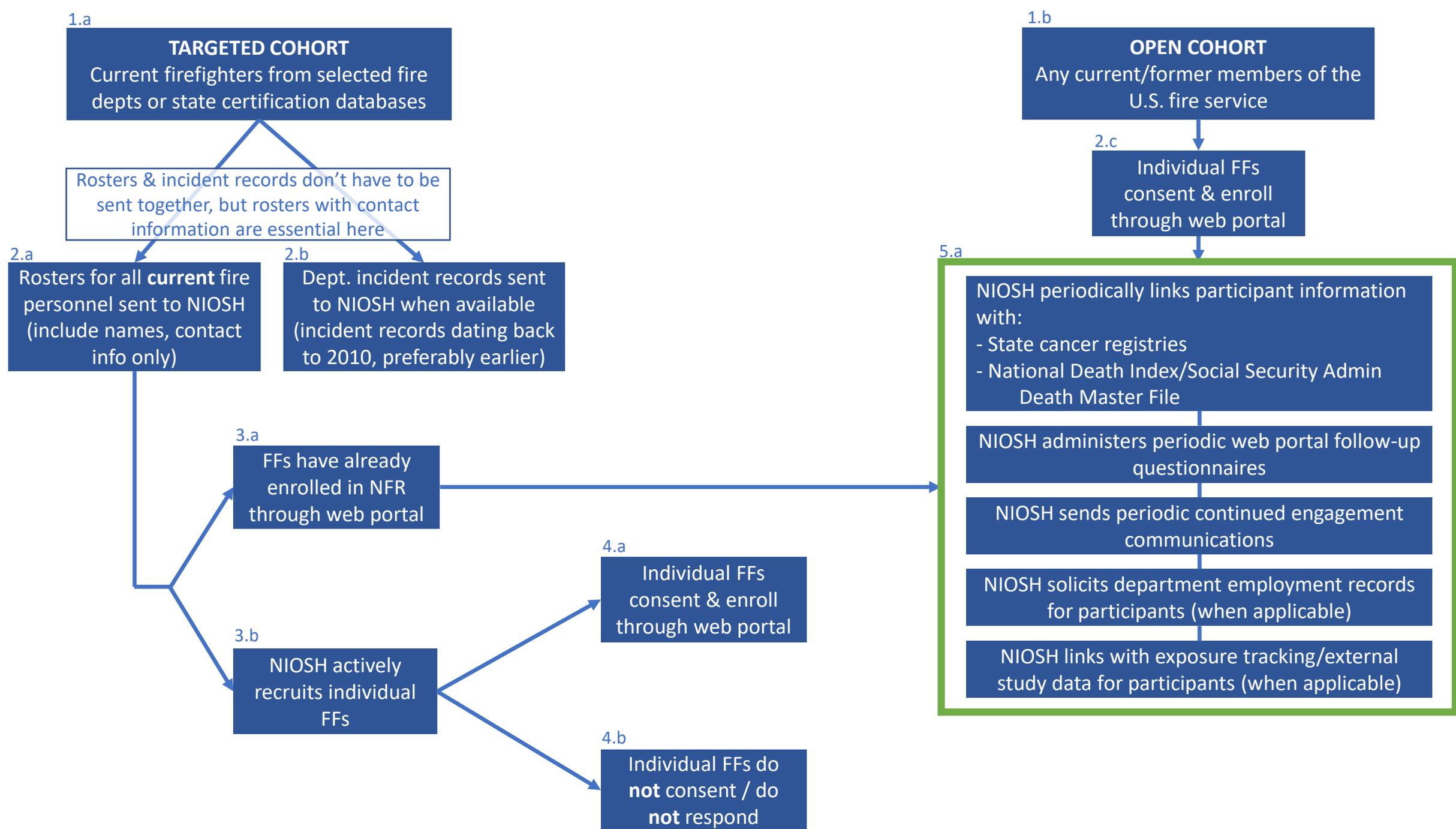
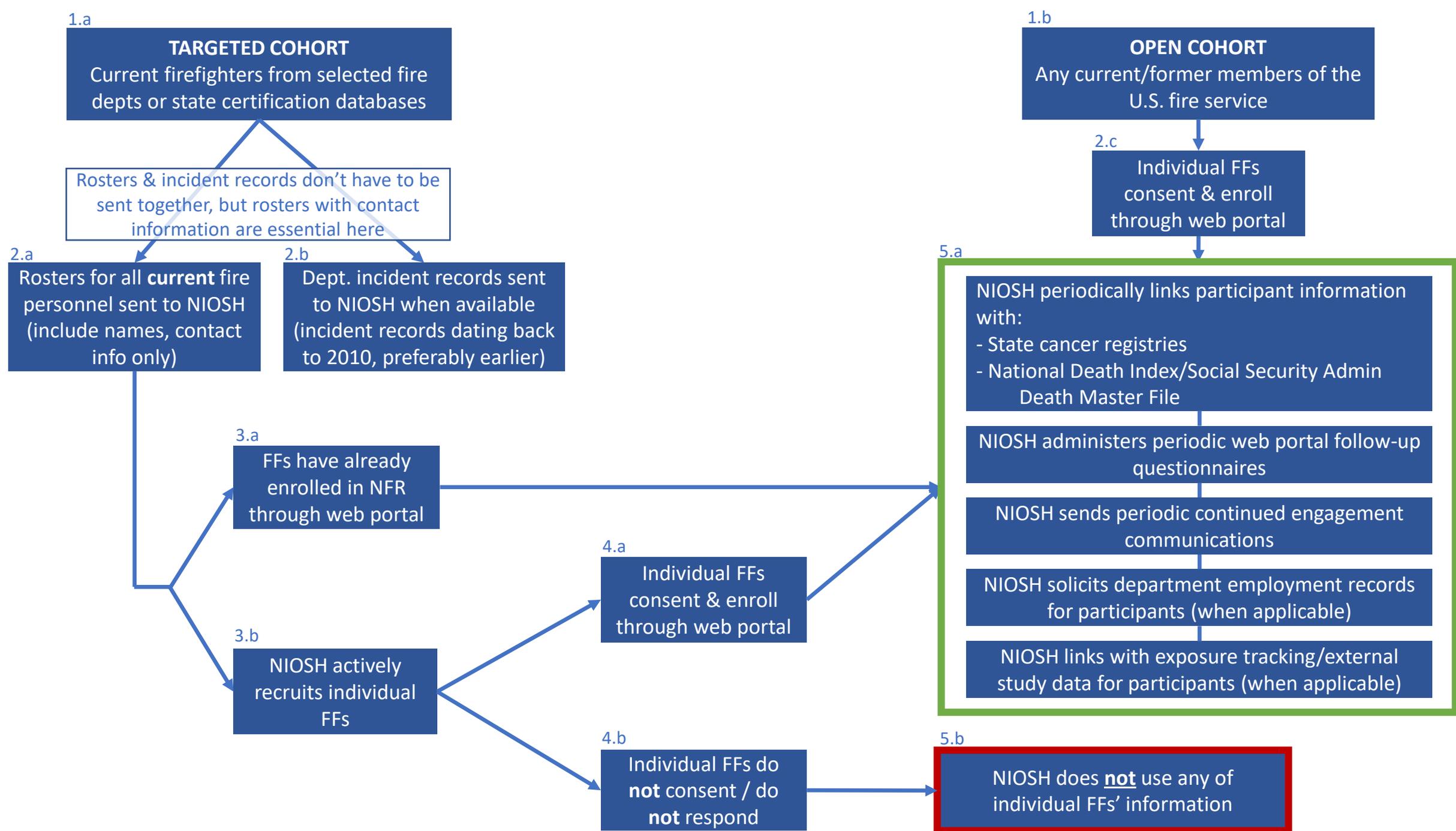NIOSH sends periodic continued engagement communications

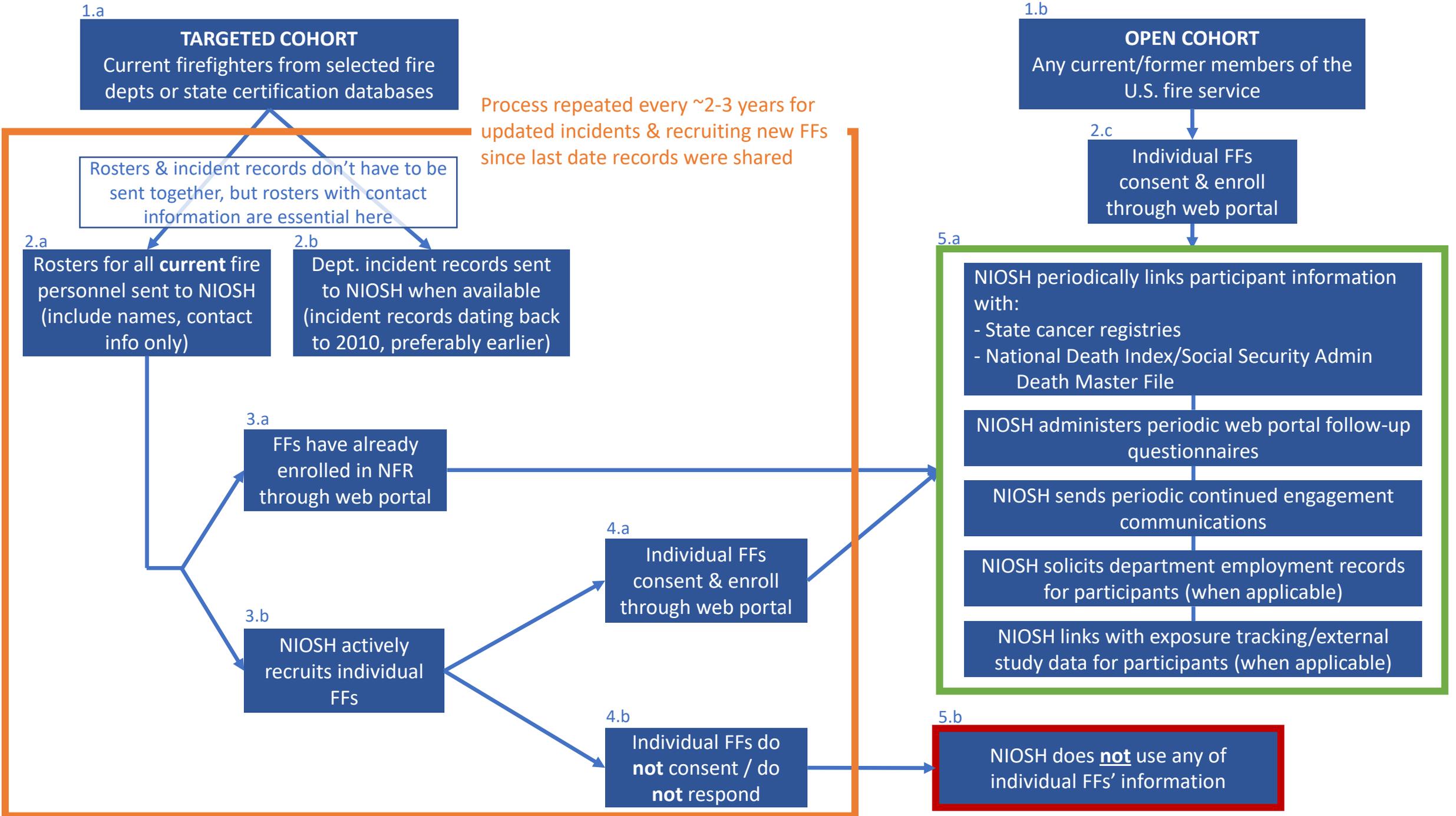NIOSH solicits department employment records for participants (when applicable)

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5.b
NIOSH does **not** use any of individual FFs' information

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Process repeated every ~2-3 years for updated incidents & recruiting new FFs since last date records were shared

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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
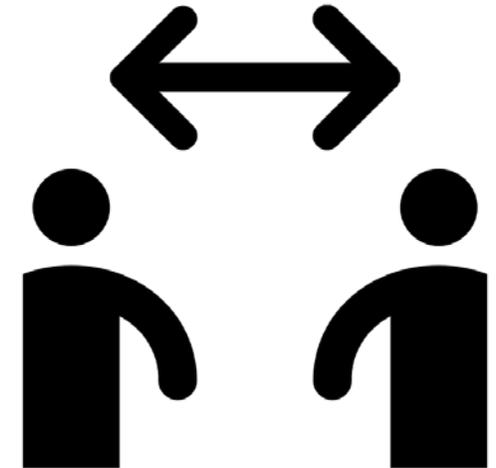
Communication Plan

Focus groups

Publications

Raise awareness

Clarify scope & expectations

Social media

Conferences

Highlight the need

Videos

Encourage firefighters to enroll
& spread the word

Newsletter

www.cdc.gov/NFR

www.cdc.gov/niosh/bsc/nfrs

Thank you!

Website: www.cdc.gov/NFR

Email: NFRegistry@cdc.gov