

The National Firefighter Registry

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NIOSH Board of Scientific Counselors
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The National Firefighter Registry Program

Registry Team

- Kenny Fent, PhD: Team Lead and Research Industrial Hygienist
- Miriam Siegel, DrPH: Lead Epidemiologist
- Alex Mayer, MPH: Health Scientist
- Health Scientist (Vacant)
- Health Communications Specialist (Vacant)
- Statistician (Vacant)

Other Key Personnel

- Beth Whelan, PhD: IWSB Branch Chief
- Jill Raudabaugh, MPH: IWSB Data Science Team Lead

Why is the Registry being created?

- The Firefighter Cancer Registry Act of 2018
- Previous studies, including a study completed by NIOSH, indicate that career firefighters are at higher risk of cancer.
- Studies are limited by the inclusion of small numbers of women and minorities, and a lack of data on volunteer firefighters.
- Goal is to track firefighters' cancer risk over time to better understand the link between workplace exposures and cancer.

H. R. 931

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:

(1) To improve data collection and data coordination activities related to the nationwide monitoring of the incidence of cancer among firefighters.

(2) To collect, consolidate, and maintain, consistent with subsection (g), epidemiological information and analyses related to cancer incidence and trends among firefighters.

(c) **RELEVANT DATA.**—

(1) **DATA COLLECTION.**—In carrying out the voluntary data collection for purposes of inclusion under the Firefighter Registry, the Secretary may collect the following:

(A) Information, as determined by the Secretary under subsection (d)(1), of volunteer, paid-on-call, and career firefighters, independent of cancer status or diagnosis.

(B) Individual risk factors and occupational history of firefighters.

(C) Information, if available, related to—

(i) basic demographic information, including—
(I) the age of the firefighter involved during the relevant dates of occupation as a firefighter; and

(II) the age of cancer diagnosis;

What will the Registry address?

- Firefighters have increased risk of certain cancers, but questions remain:
- What is the cancer risk for:
 - Minority Firefighters? Female Firefighters? Volunteers?
- How does cancer risk vary
 - Among more recent firefighters (with increasing synthetic materials in buildings)
 - With adoption of control interventions
 - Consistent use of SCBA, decontamination measures, laundering, hood exchange programs, etc.
 - Geographically
 - With increasing exposures



Who will be included?

- The Firefighter Registry will include ALL firefighters, not just those with a cancer diagnosis.
- Minority Firefighters
- Female Firefighters
- Volunteer Firefighters
- Also interested in sub-specialties like:
 - Instructors, wildland firefighters, and arson investigators
- Goal is to enroll 200K



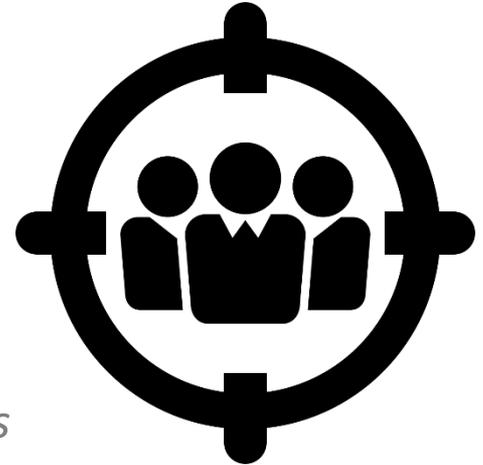
How will Registry data be collected and used?

- The records of participants will be linked with data from state cancer registries to obtain diagnosis information.
- We will collect information on possible confounders and other variables of interest.
- We will also collect work history and exposure records to explore dose-response relationships.
- Findings will be disseminated via scientific publications and communications to the public.
- Data will be made available to researchers while maintaining privacy.

Possible enrollment approaches

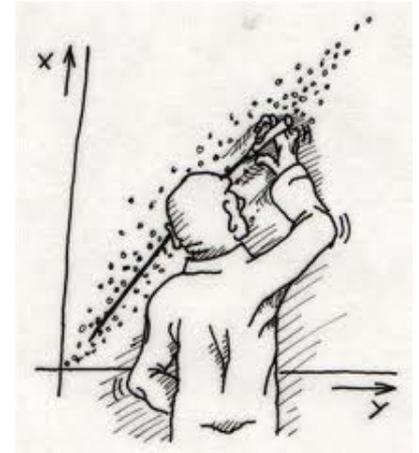
1. Open Enrollment Through Web-Portal
 - A. All firefighters would be able to participate
 - B. May not be representative of the firefighter population
2. Organization-Level Sampling
 - A. Recruit participants through professional associations (IAFF, NVFC, etc.)
 - B. Should be able to reach various groups of firefighters
3. Fire Department-Level Sampling
 - A. Most time and resource intensive approach
 - B. Sample representative of the firefighter population
 - C. Access to fire-department records

NOTE: *We may include aspects of all 3 sampling approaches*



The Registry will address knowledge gaps by...

- Being open to all firefighters (active and retired) regardless of current health status
- Being representative of the general U.S. Fire Service
- Being inclusive of understudied groups of firefighters
- Estimating exposures via work-history records
- Collecting information on other cancer risk factors
- Linking to state cancer registries and National Death Index

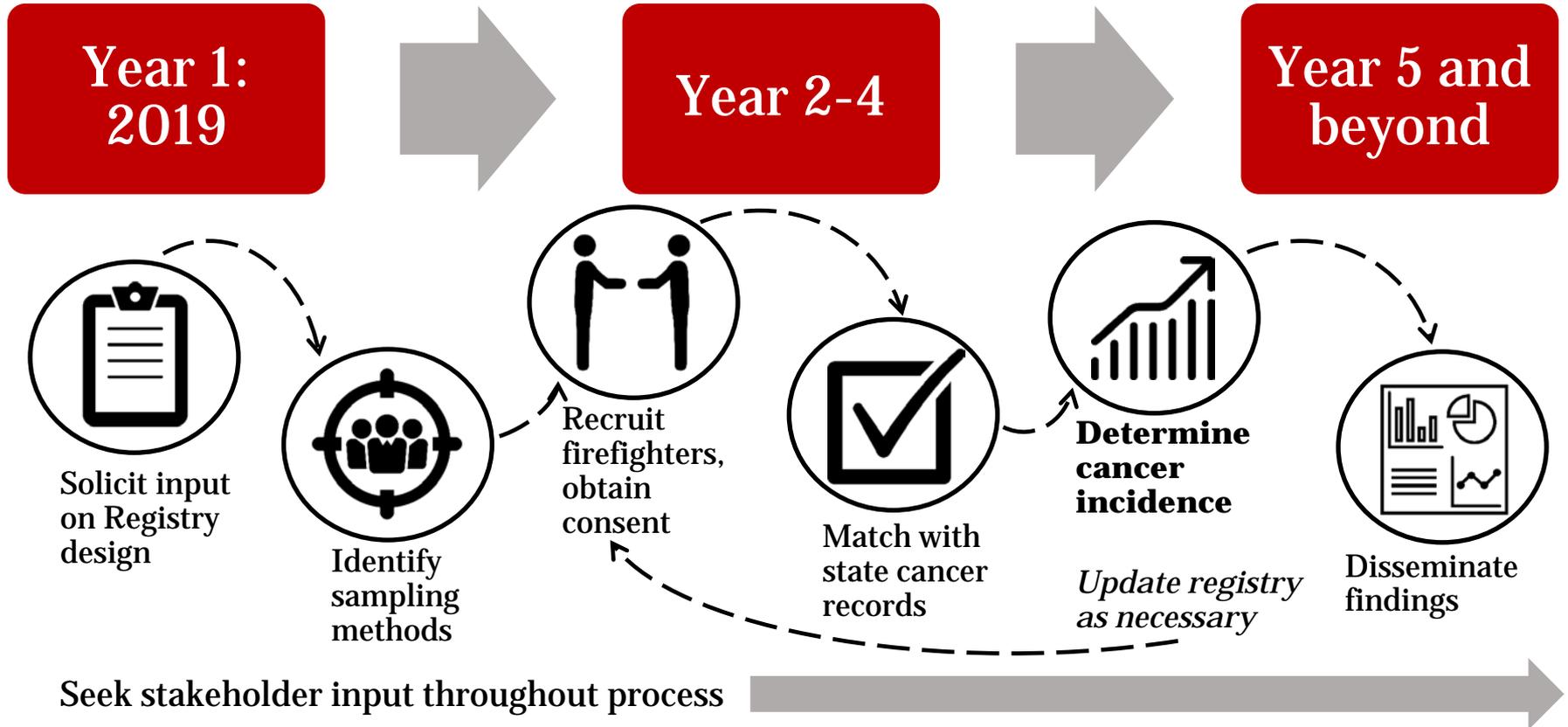


Registry activities in progress

- Budget
 - FY19 funding: \$1 million
 - Future years: \$2.5 million/year (authorized but not appropriated)
- Hiring Registry team
- Meeting with key stakeholders
- Request for Information (RFI) in Federal Register
 - <https://www.federalregister.gov/documents/2019/03/28/2019-05971/national-firefighter-registry-request-for-information>
 - To obtain input on maximizing participation in the Registry

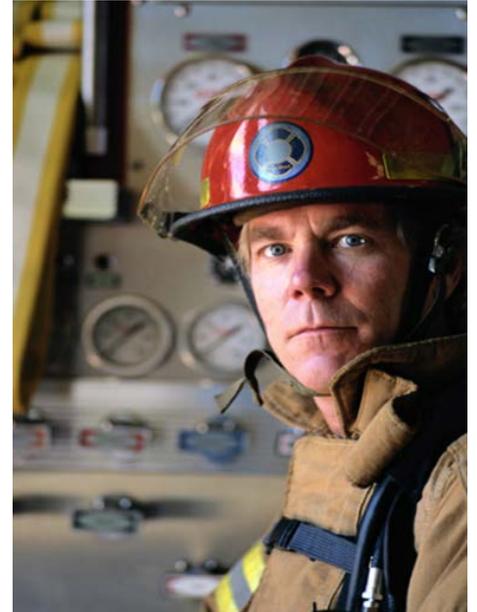


National Firefighter Registry Timeline



Important considerations

- Communicating that the Registry is NOT just for firefighters with cancer
 - Working closely with stakeholders on messaging
 - Strategic roll out communications plan
- Developing secure open-enrollment web portal
 - Exploring ATSDR ALS Registry as a model
 - Make the process of registering as simple as possible
- Enrolling fire departments
 - Accessing employment records and incident information
 - E-records vs. paper records
- Updating the Registry periodically
 - How do we re-contact participants?
 - How do we efficiently link to state cancer registries?



Potential opportunities: Exposure data



- Linking with National Fire Operations Reporting System (NFORS) Exposure Reporting
 - Self-reported exposure and incident information through mobile platforms
 - Links with computer-aided dispatch data for some departments
 - More robust response activity records compared to incident records
 - More refined dose-response analyses

Potential opportunities: Cancer registries

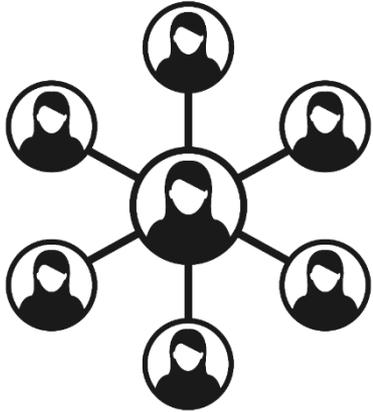
State	Two levels of approval	Pediatric special requirements	Fee	Time frame (months)	Sponsorship required	Human subjects protection training required	Patient contact studies allowed	Physician/patient authorization by cancer registry	Physician notification/patient authorization by cancer registry	Physician/patient authorization by researcher	Limit on number of studies	Level of complexity
New Hampshire	<ul style="list-style-type: none"> Committee Cancer registry IRB 	Yes	No	<2	No	No	Yes	Not applicable	Not applicable	Physician	No	More
New Jersey	<ul style="list-style-type: none"> Committee Cancer registry IRB 	No	Yes	Varies	No	Yes	Yes	Patient	Not applicable	Not applicable	No	Middle
New Mexico	<ul style="list-style-type: none"> Cancer registry director Cancer registry IRB 	No	Yes	Varies	Yes	Yes	Yes	Physician and patient	Physician and patient	Not applicable	No	More

Currently, researchers must approach each state separately

Virtual Pooled Registry Cancer Linkage System

- North American Association of Cancer Registries / National Cancer Institute
- Phase 1: Aggregate case counts
 - 45 registries, 87% of U.S. population
- Phase 2: Central IRB and standardized linkages (late 2019)
 - Survey indicated 14 early adopters
 - Standardized templates available for non-participants

Data sharing



- Making data available to outside researchers
 - “...information and analysis in the Firefighter Registry are available, as appropriate, to the public, including researchers, firefighters, and national fire service organizations”
 - Develop a data access system that maintains privacy
 - Potential processes for approving studies
 - Data may be useful for biomarker studies or exploratory analysis of survey data

Important milestones (through Y2)

1. Set goals and timeline
2. Develop protocol, informed consent, survey(s) and obtain IRB approval
3. Obtain OMB clearance for survey(s)
4. Develop web-portal for enrollment
5. Develop secure database
6. Roll-out communications plan
7. Begin registering firefighters
8. Identify representative fire departments for enrollment
9. Obtain employment and incident records



More information

- Website: <https://www.cdc.gov/niosh/firefighters/health.html>
- Registry email address: FFRegistry@cdc.gov
- RFI: <https://www.federalregister.gov/documents/2019/03/28/2019-05971/national-firefighter-registry-request-for-information>

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Discussion topics

- Any concerns with the proposed enrollment approaches?
- What are some ways to maximize firefighter participation in the Registry (especially among volunteer, female, and minority firefighters)?
- Which under-represented or under-studied groups of firefighters should be included in the Registry?
- What criteria should be used in selecting fire departments for participation?
- What are some potential barriers with updating the registry?
- Other concerns or opportunities we should be aware of?

National Firefighter Registry

to Better Understand Firefighters' Risk of Cancer

Stay Tuned...



cdc.gov/niosh/firefighters/health.html