

# National Firefighter Registry (NFR) for Cancer: Overview & Update

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**NATIONAL  
FIREFIGHTER  
REGISTRY  
*for Cancer***

Understanding &  
Reducing Cancer

NFR Subcommittee Meeting

August 22, 2024

# Outline

- Expansion of the NFR Program
- Goals
- Priorities
- Strategies



**NATIONAL  
FIREFIGHTER  
REGISTRY**  
Understanding & Preventing Cancer

# STAND TOGETHER

Join your brothers and sisters in a new effort to understand and reduce cancer. Together, we can have a lasting impact on the fire service.

 JOIN THE NATIONAL FIREFIGHTER  
REGISTRY FOR CANCER

**NFR.CDC.GOV**

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## **NFR Mission**

**To generate detailed knowledge about cancer in the fire service through a voluntary registry of our nation's diverse firefighters.**

## **NFR Vision**

**To equip the fire service and public health communities with the knowledge they need to reduce cancer in firefighters.**



# Enhancement of the NFR program

- **NIOSH is in the process of enhancing the NFR Program**
- **Created two teams:**
  - Epidemiology and Exposure Evaluation (3E) Team
  - Investigations, Communications, and Translation (ICT) Team
- **Current positions in the NFR include:**
  - Epidemiologists, industrial hygienists, health scientists, medical officer, health communication specialists, technical information and program specialists (with fire service backgrounds), informaticist, and statistician

# Epidemiology & Exposure Evaluation Team

- **Focused on:**
  - Recruiting and enrolling\*
  - Primary data collection (i.e., NFR web portal), including targeted enrollment of firefighters
  - Data ingestion from other sources (e.g., exposure trackers, departments, agencies)
  - Matching to population-based cancer registries
  - Analyzing and reporting exposure and health outcome data
  - Developing new survey instruments
  - Other firefighter research (non-NFR funding)

\* Priority for both teams

# Investigations, Translations, & Communications Team

- **Focused on:**
  - Recruiting and enrolling\*
  - Developing professional relationships with fire service, health, and scientific organizations
  - Developing, refining, and implementing the communications plan
  - Supporting firefighters with the enrollment process (e.g., Help Desk, email box, etc.)
  - Reaching out to fire departments involved in major events or disasters
  - Translating research into practical recommendations
  - Sharing information on cancer screening and healthy behavior guidelines
  - Investigating medical-related fatalities (non-NFR funding)

\* Priority for both teams

# Organizational goals

- **Goal 1:** Enroll 200,000+ firefighters from diverse backgrounds
- **Goal 2:** Monitor cancer outcomes and risk factors
- **Goal 3:** Characterize firefighters' exposures
- **Goal 4:** Provide data and recommendations to lower cancer and other health risks

# Key priorities

- **Priority 1:** Maximize enrollment in the NFR through a variety of measures including among groups of firefighters who have been historically under-represented in research
- **Priority 2:** Maintain a user-friendly system to register firefighters, and securely collect and protect the data
- **Priority 3:** Increase scientific understanding of firefighters' risk of cancer, carcinogenic exposures, and other modifiable risk factors
- **Priority 4:** Enact positive change in the fire service through delivery of evidence-based recommendations



# Strategies

- **Strategy 1:** Implement multi-pronged approach to increase participation in the NFR
- **Strategy 2:** Improve the user experience by refining and adding features to the NFR web portal
- **Strategy 3:** Develop partnerships and procedures for data linkages and ingesting data from other sources
- **Strategy 4:** Implement ways to share data and communicate research results and recommendations

# Strategy 1: Implement multi-pronged approach to increase participation in the NFR

- Targeted enrollment of firefighters (next presentation)
- (Fire) Program Specialists – field-based support staff
- Firefighter subject matter experts (contracts/agreements)
  - Connect with specific firefighter populations and advocacy groups, including women, racial/ethnic minority groups, volunteers, and wildland firefighters
- Outreach to scientific, health, and medical communities
  - Firefighter Cancer Support Network
  - American College of Occupational and Environmental Medicine
  - North American Association of Central Cancer Registries
- Expanded communications plan, products, dissemination, techniques (later presentation)

## Strategy 2: Improve the user experience by refining and adding features to the NFR web portal

- Participants now receive an NFR participant number
  - Available in the user profile
  - Provided in reminder and thank you emails and/or text messages
- Work history section (and other sections of the questionnaire) are now editable after saving but before submitting
  - Only the user profile is editable after submitting the questionnaire
- Exploring best ways to implement follow-up questions for the collection of longitudinal information
- Exploring the development of public and personal data dashboards

## Strategy 3: Develop partnerships and procedures for data linkages and integrating data from other sources

- Planning the process for cancer registry data linkages for NFR participants
- Developing data use agreements and processes for receiving firefighter exposure tracking data
- Providing input on the U.S. Fire Administration – National Emergency Response Incident System (NERIS) in development
- Exploring potential collaborations with ongoing fire service research studies (e.g., Fire Fighter Cancer Cohort Study)
- Note: *NFR participant number provides reliable matching of external exposure data to NFR records*

## Strategy 4: Implement ways to share data and communicate research results and recommendations

***Vision: To equip the fire service and public health communities with the knowledge they need to reduce cancer and other chronic diseases or health effects in firefighters.***

- Continue to explore opportunities to develop exposure reduction training content (e.g., Underwriters Laboratories Fire Safety Academy)
- Continue to use push notifications to send helpful information to NFR participants (email or text message)
- Explore use of dashboards to reinforce best practices
- Pursue Research Data Center for sharing de-identified data
- Plan and develop peer-reviewed publications and reports

# Summary Data Review

**Alex Mayer, MPH**  
**Health Scientist**

NFR Subcommittee Meeting  
August 22, 2024

# Recap of recruitment efforts

- **Began registering firefighters in January 2023**
  - Piloted NFR enrollment with departments and fire service leaders from January-March 2023
- **Kicked off NFR registration at FDIC in April 2023**
- **Current registration numbers are through our open (passive) enrollment**
  - Social media efforts, conferences and meetings, Gold Helmet Campaign, external partner promotion
- **In addition to continuing open enrollment, targeted enrollment started in July 2024**

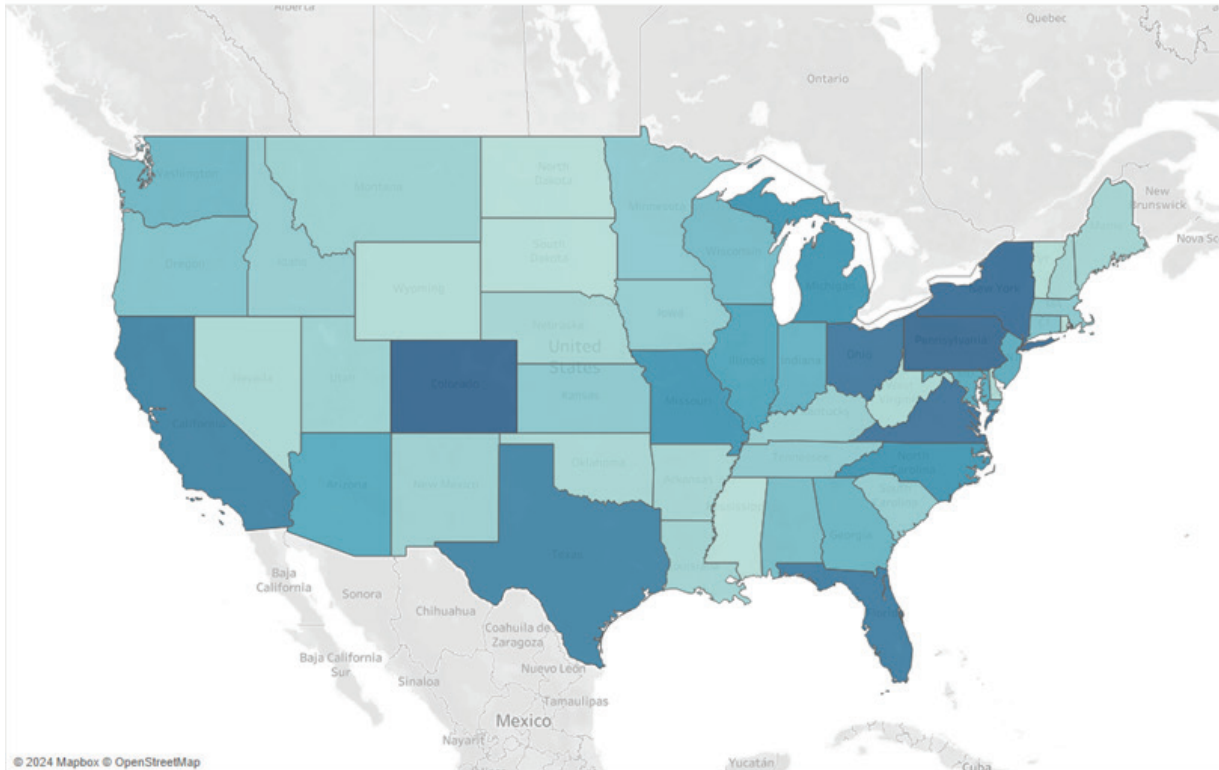
# Additional considerations

- **All data are preliminary**
  - Numbers were pulled on 7/30/2024
- **Only includes self-reported NFR questionnaire data**
  - Will be linking with population-based cancer registries and other informational databases in the future
- **Self-reported cancer estimates do not indicate national prevalence of firefighter cancer**
- **Because not all participants completed the entire questionnaire, denominators vary**



# Map of Enrolled Firefighters

Participation Choropleth



- Participation largely aligns with state populations
- Recruitment efforts could prioritize populated states with relatively low participation
- Southeast and Northwest underrepresented

# Preliminary data

- **Over 15,000 firefighters have consented to participate in the NFR**
  - Over 13,700 have provided key demographic information
- **Over 70% of firefighters completed enrollment**
  - Completion rate has been increasing over time
- **Firefighters have enrolled from all 50 states and Washington D.C, as well as 2 US territories**
- **2,000+ firefighters self-report a history of cancer\***

\* Note, this is not an estimate of national firefighter cancer prevalence

# Preliminary data

- **Over 9% of NFR participants are women**
  - National Fire Protection Association (NFPA)<sup>1</sup> reports that 9% of the U.S. fire service are women (career & volunteer)
- **85% of NFR participants are active firefighters, of which 20% are volunteer**
  - Over 60% of the U.S. fire service is volunteer<sup>1</sup>
- **Over 90% of NFR participants are white, Non-Hispanic**
  - Bureau of Labor Statistics (BLS)<sup>2</sup> reports that the career fire service is ~88% White, ~17% is Hispanic
- **Almost 20% of NFR participants are wildland firefighters**

1 NFPA US Fire Department Profile 2020

2 Employed persons by detailed occupation, sex, race, and Hispanic or Latino ethnicity : U.S. Bureau of Labor Statistics (bls.gov)

# What the preliminary data tell us

- **Open cohort enrollment has been successful with:**
  - Female firefighters
  - Wildland firefighters
  - Structural, career firefighters
  - Firefighters with and without cancer
- **Focus areas for growth:**
  - Firefighters from racial/ethnic minority groups
  - Volunteer firefighters

# Future directions

- **Develop a public-facing dashboard**
- **Track participation of subgroups**
  - May inform recruitment efforts
- **Describe the use of control interventions among NFR participants**
- **Cross-sectional analyses of self-reported cancer and associated risk factors**
- **Begin process for cancer registry linkages (and pilot the process)**

# NFRS Discussion Questions

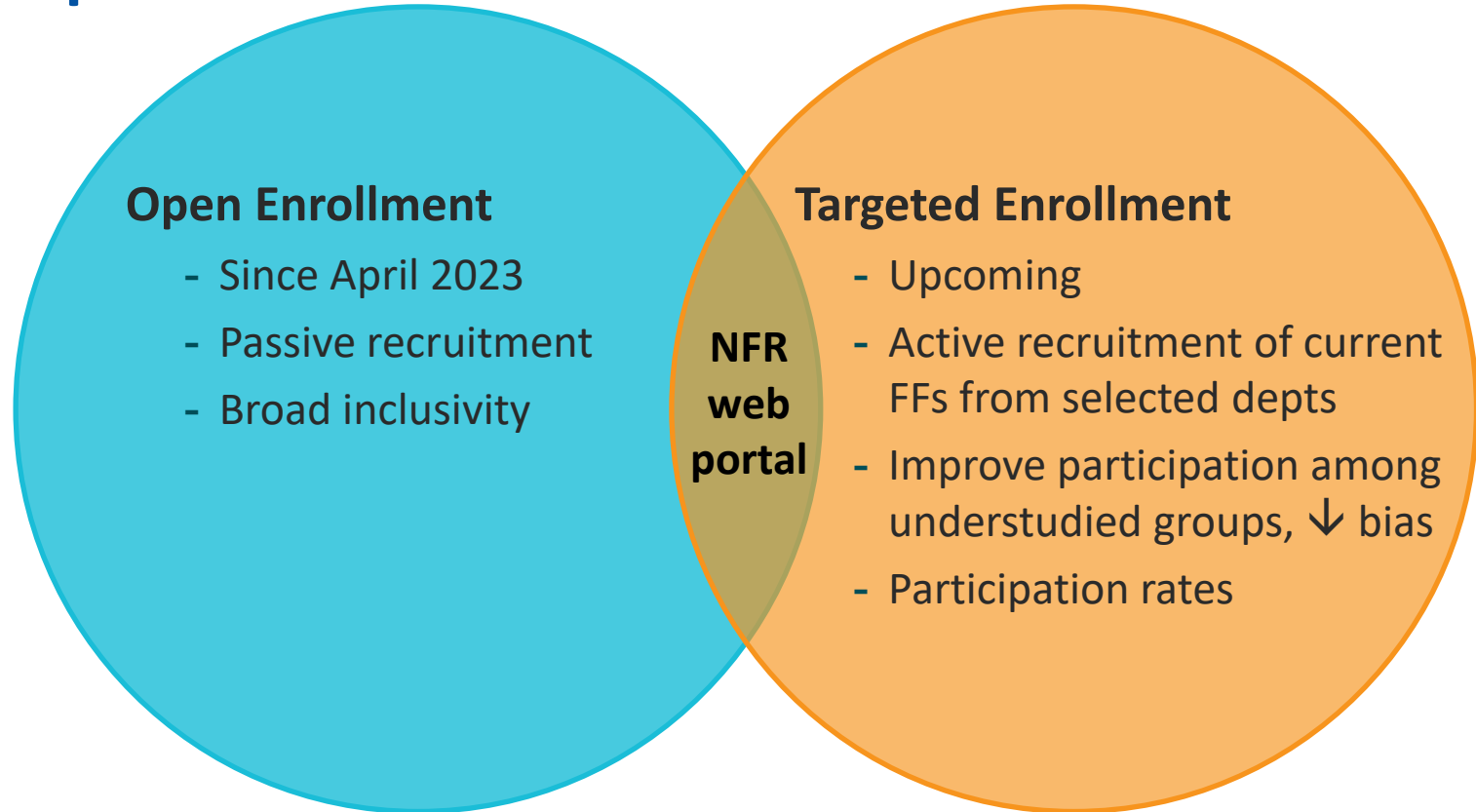
- 1. What kind of summary data will best inform the fire service and public health professionals in the immediate future?**
- 2. What ways do you envision NFR data being used by external researchers or through research collaborations?**

# Targeted Enrollment Activities

**Miriam Siegel, DrPH, MPH**  
**Research Epidemiologist**

NFR Subcommittee Meeting  
August 22, 2024

# Recap of enrollment routes





# Groundwork for Targeted Enrollment

## 2023 NFRS feedback

- NIOSH obtain and recruit from roster records versus work through dept leadership
- Pros and cons to each process
- Acting through leadership determined likely to:
  - Reduce admin burden → Increase dept participation
  - Build more trust → Increase FF participation
- Possible roster & incident records in the future

# Groundwork for Targeted Enrollment, cont.

## **FY 2024 contract: Development and Testing of Methods to Enroll Firefighters**

### - Contract Task #2: Targeted enrollment process

- Obtain voluntary commitments from targeted departments to participate in the NFR.
- Document progress in customer relationship management software.
- Commitments include expectations that:
  - Depts will provide some level of roster information or aggregate workforce counts.
  - Dept leadership will encourage participation according to the guidelines provided by the contractor.
- 20+ depts in base period (24 mo); 10+ depts in two option years each.

# Targeted Enrollment process

## FD Interest

- Identify contact
- Email & send info
- Conference call
- Letter of support



## Union Interest (if applicable)

- Identify contact
- Email & send info
- Conference call
- Letter of support



## Onboarding

- In person meeting
- Workforce data
- Discuss Playbook
- Scheduling



## Recruitment

- Follow Playbook

# Obtain workforce counts (denominators) from dept leadership

Current firefighting workforce for **Insert Fire Department Name**, stratified by sex, ethnicity, and race

Characteristic	Total number
Active Fire Personnel	
Career	
Volunteer/paid per call	
Total	
Sex assigned at birth	
Women	
Men	
Ethnicity	
Hispanic or Latino	
Not Hispanic or Latino	
Race	
American Indian or Alaskan Native	
Asian	
Black or African American	
Native Hawaiian or Other Pacific Islander	
White	
<b>*Provide the date the workforce data was captured</b>	

# “Playbook” for participating dept leadership

- **Promotes rigorous and standardized recruitment methods among leadership from participating depts**

The following targeted enrollment playbook guides fire department leadership through the process of recruiting their firefighters to participate in the NFR. It provides instructions that outline the required steps and materials for promoting the NFR enrollment within departments participating in the targeted enrollment program. The playbook:

- Simplifies the recruitment process, making it more efficient and effective for fire department leadership
- Provides answers to common questions and issues that may arise
- Ensures that all departments involved in the targeted enrollment follow the same steps, which is important for scientific integrity

# Playbook steps

- 1. Dept leadership sends initial recruitment e-mail (provided) to all FFs**
- 2. Dept's union reps send initial recruitment e-mail (provided) to all FFs**
- 3. Leadership designates a 1-week period for FFs to enroll on-shift; Roll call announcement is read**
- 4. Leadership sends a first reminder e-mail (provided)**
- 5. Leadership sends a second reminder e-mail (provided)**
- 6. Feedback on participation rates provided to dept leadership; If <50%, in-person support can be requested**
- 7. Leadership sends a final reminder e-mail (provided)**

# Playbook resources

- Many communication resources are applied for both Targeted and Open Enrollment to boost overall NFR participation!
  - Roll call announcement, posters, fact sheet, tip sheet, website

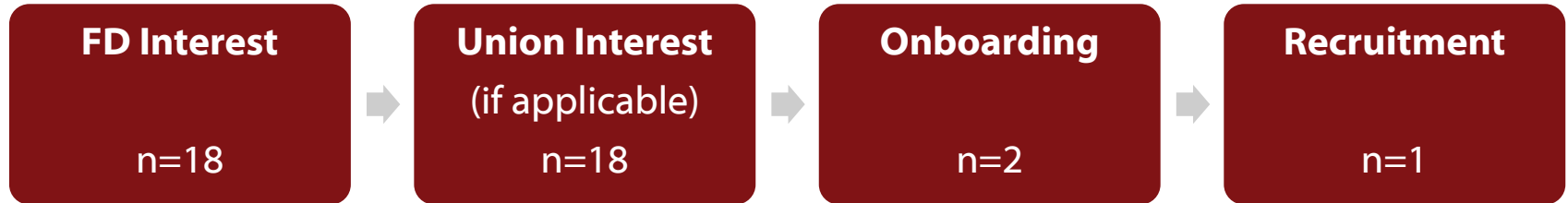


**GOLD HELMET  
DEPARTMENT**

NIOSH is recognizing any U.S. fire department that enrolls 50% or more than 300 of their active firefighters in the National Firefighter Registry (NFR) for Cancer as a Gold Helmet Department.

# Status of Targeted Enrollment (as of July 2024)

- **Initial list of 30 departments:** Large numbers of women; geographic & community demographic diversity; career & volunteer





# Challenges

- **Timing, schedules of dept leadership & dept workload**
- **Supportive dept leadership but slow uptake from other authorities**
- **Potential lack of standardized recruitment**
- **Potential challenges with monitoring exact participation rates**
  - Identifying numerators in NFR database
  - Aggregate workforce counts
  - Workforce changes over time

## Next steps

- **Continue initiating process with current list of depts & tracking progress**
- **Track obstacles & challenges**
- **Evaluate the need for and characteristics of future selected depts**
- **Use participation rates to inform recruitment & communication strategies**

# Outreach Efforts & Communication

**CDR Kevin L Dunn, MS, CIH,**

**NFR Investigations, Communications, and Translation Team Lead**

NFR Subcommittee Meeting

August 22, 2024

# Recap of 2023 Foundational Work

# Open enrollment



**“Firefighters will be recruited for the Open Cohort by disseminating informational and promotional materials through stakeholders, membership organizations, social media, and trade literature.” - NFR Protocol 2022**

- **NFR web portal launched in April 2023**
- **In the ensuing year, we primarily used passive marketing techniques to build awareness:**
  - 25 print and digital products, three campaign toolkits, monthly social media posts and advertisements, website content and updates, videos, podcasts
  - Attendance at 18 conferences (many with exhibit booths or scientific presentations)
  - NFR quarterly newsletter – among highest open rate of any CDC newsletter

# Importance of partnerships



- **NFR/NIOSH has obtained 21 letters of support**
- **Partnerships with International Association of Fire Fighters (IAFF), International Association of Fire Chiefs (IAFC), National Volunteer Fire Council (NVFC), and many others**
  - Instrumental in disseminating information about the NFR
- **Official agreement/partnership with Firefighter Cancer Support Network (FCSN)**
  - Share information about NFR through their network, meetings and conferences, and through special initiatives (e.g., Firefighter Cancer Awareness Month)





# Transition to more active marketing

- **Email Blasts**

- Secret List email (>200K members), Firefighter Fatality Investigation Prevention Program alert email (>22K subscribers), CRACKYL magazine eblasts

- **Focused ads/article space**

- Fire engineering (>650K views monthly), CRACKYL magazine, NVFC Firefighter Strong

- **NFR participant push notifications**

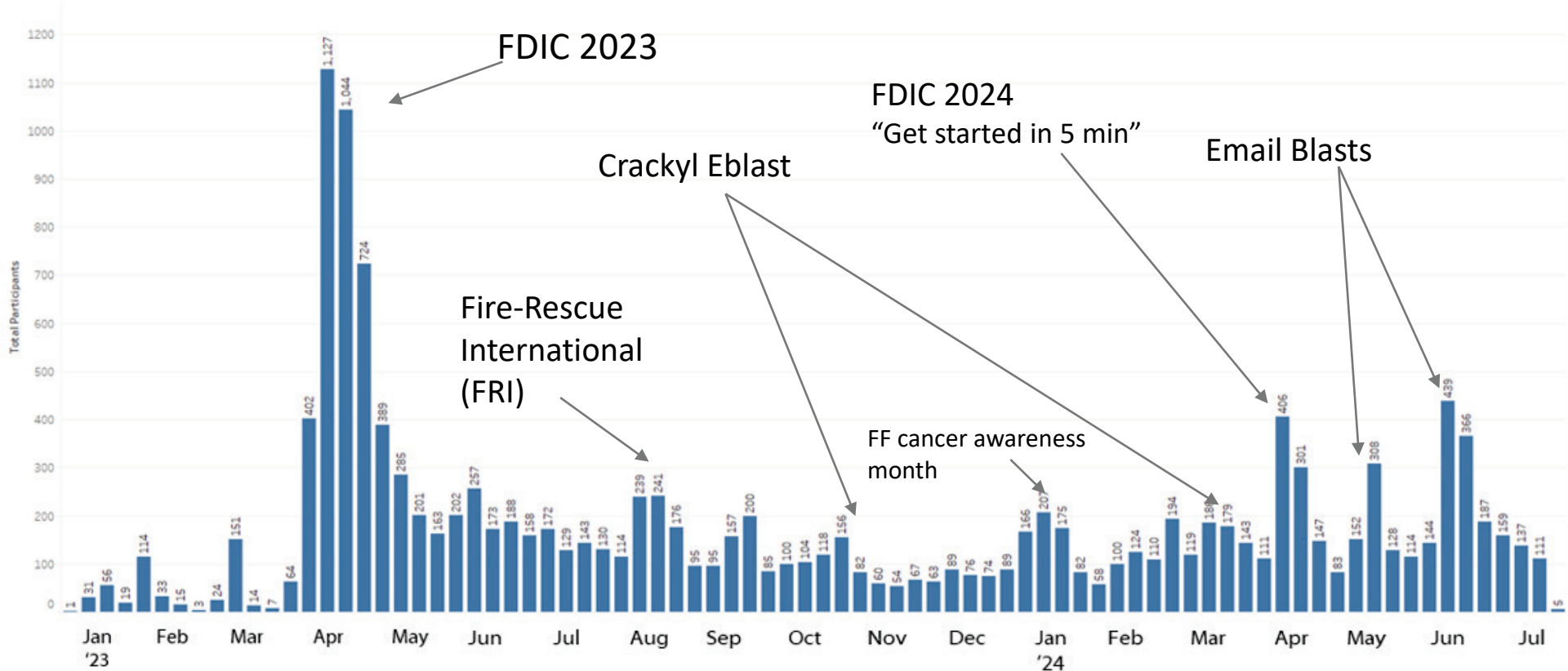
- Gold Helmet initiative was sent via email or text message in June
- So far, 10 departments have requested and received Gold Helmet status.

- **Call to action and messaging to lower barriers – “Get started in 5 min”**

- Effective at conferences where you only have a few minute interaction



Participation By Week



# Boots on the ground



- New (Fire) Program Specialists – onboarding soon
- Geographically dispersed
- Fire service/emergency response backgrounds
- Working with IAFF, NVFC, and others to identify:
  - Regional union districts and points of contact
  - Influential FD locations (career and volunteer) and points of contact
  - Other regional or local fire organizations
- Community-based – will seek to know current issues, concerns, and major events



## Other new efforts

- Producing a “Dispelling Myths of the NFR” Blog with IAFF.
- Speaker Bureau for webinars/virtual presentations.
  - Enable us to be more responsive to requests from invested parties
- Exploring innovative delivery mechanisms
  - e.g., Materials/exhibits about the NFR at firefighter memorials/museums
- Events focused on specific audiences
  - International Association of Black Professional Firefighters Convention (Aug. 2024), Women in Fire Conference (Sep. 2024)
  - Medical organizations: e.g., American Occupational Health Conference (AOHC) 2025

# Engagement with Federal Firefighters



- Defense Health Agency- Occupational Medicine and Medical and Public Health Meeting
- Under Secretary for Defense Office – DOD Fire and Emergency Services Working Group
- Homeland Security Total Workforce Protection Directorate, Office of Health Security Homeland Security
- Department of Interior (DOI) - working group with the DOI to identify obstacles for enrollment of wildland firefighters in health studies

# NFRS Discussion Questions

1. What are some ideas for boosting overall enrollment in the NFR?
2. Are there additional suggestions for connecting with the firefighting groups that we are having trouble reaching?
3. How can we leverage push notifications more? How frequently?

# Where do we go from here?



- Continue and expand open enrollment efforts
- Increase engagement with underrepresented groups
- Use data analysis of current enrollment to guide recruiting efforts
- Engage more at the local or regional level - integrate more with community (e.g., Fire Program Specialists)
- Refine our active marketing products and methods based on feedback and metrics
- Be receptive to new suggestions and opportunities

# Thank you!

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

