

Update on National Firefighter Registry (NFR)

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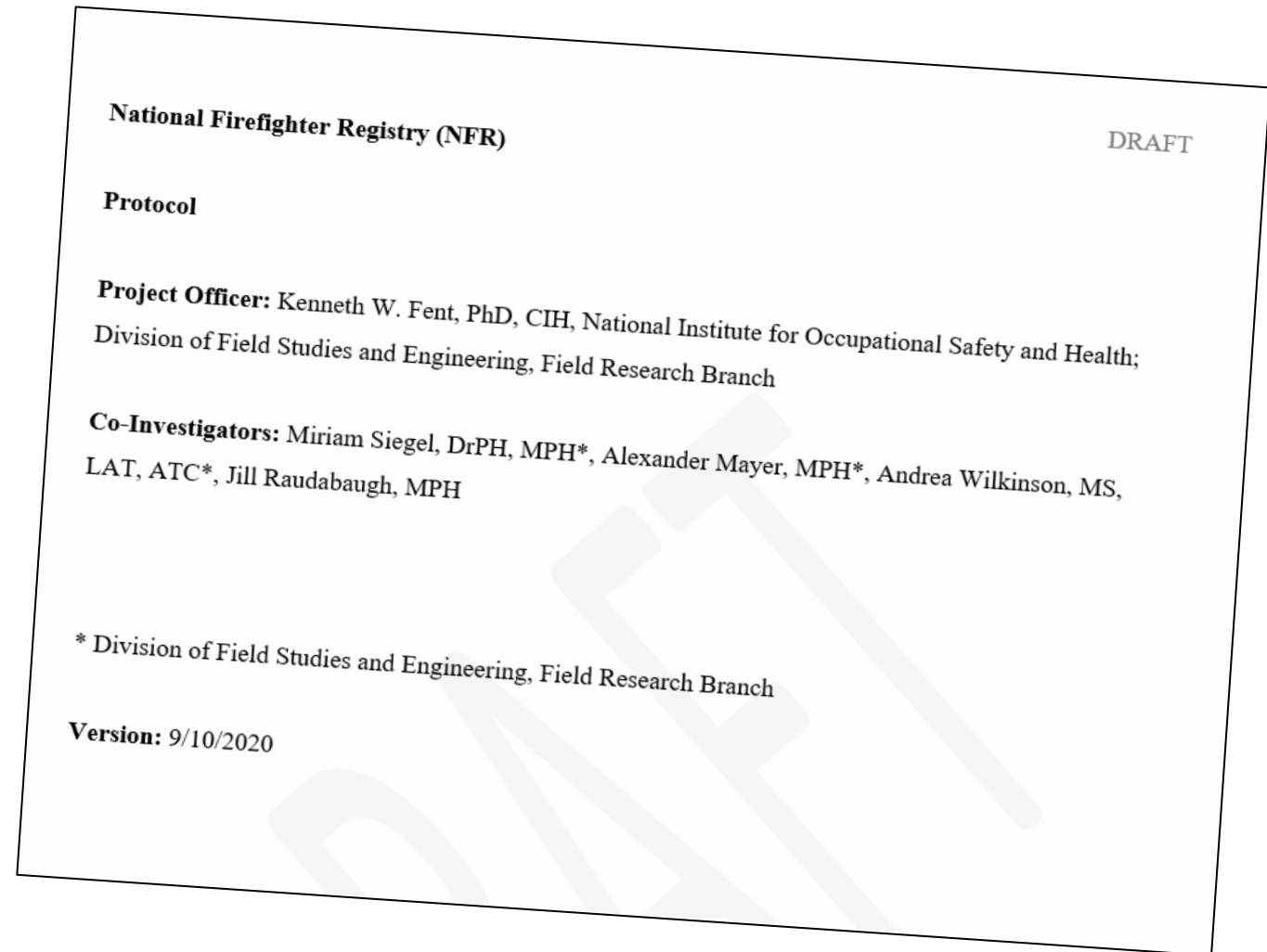
The findings and conclusions in this presentation are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention, National Institute for Occupational Safety and Health.

Background

- NFR subcommittee (NFRS) held first public meeting on May 15, 2020 to discuss protocol
- NFRS drafted a report of recommendations for Dr. Howard that was approved at the July 14, 2020 meeting
- Draft report submitted to NIOSH BSC for review in July 2020
- BSC modified and approved the report during Aug. 4, 2020 meeting
- Final report is publicly available at <https://www.cdc.gov/niosh/bsc/meetings.html>

Report Recommendations

- Final report had 3 main recommendations
- NFR team made edits to the protocol to address these 3 recommendations
- Revised protocol, questionnaire, consent form, and response memo have been submitted for NIOSH review/approval (pending)



Recommendation 1

Because of the importance of obtaining SSN for the National Death Index and the cancer registries, it is recommended that NIOSH should perform targeted stakeholder interviews to learn the most compelling communication approach for explaining why the SSN is needed and how it will be protected, then the communication approach should be pilot tested.

SSN = Social Security Number



Response to Recommendation 1

- Held multiple conversations with firefighters, fire officers, and other stakeholders regarding SSN, confidentiality, and messaging
- Surveyed fire chiefs from around the country about the potential barrier to participation from asking for SSN
- Currently conducting focus group sessions with different groups of firefighters (i.e., career, volunteer, female, and minority firefighters) about the best way to promote the registry, including importance of SSN
- In discussion with International Association of Fire Fighters (IAFF) regarding support for SSN collection
- All of this will inform how we communicate why SSN is important and how it will be protected
 - Plan to add a section on SSN to the NFR webpage

Response to Recommendation 1

- Moved the question regarding collection of SSN to the end of the User Profile
 - We heard from several stakeholders that it is best to be up-front regarding this data element
 - Plain language explanation, “Why we are asking for this” is included
 - By making SSN part of the user profile, a participant could input this information later

Response to Recommendation 1

- We currently ask for full SSN
- If a participant does not provide SSN, then...
 - Pop Up: *“We noticed that you did not include an SSN. Would you consider providing your SSN or at least the last four digits? Although not as reliable as your full SSN, the last four digits of your SSN would increase the likelihood of linking your information to any future cancer diagnosis.”*
- We are considering only asking for last 4 digits of SSN
 - How would this impact our ability to match to state cancer registries or NDI?
 - How would this affect participation rates?

Recommendation 2

Currently changes are underway with NAACCR to facilitate and streamline linkage between research groups and state cancer registries via the Virtual Pooled Registry. NIOSH should begin the groundwork for establishing the framework for linking the firefighter cancer information, both past and on-going, to facilitate future easy access to the state cancer registry data.

NAACCR = North American Association of Central Cancer Registries



Response to Recommendation 2

- Established several connections with NAACCR, including with the project coordinator for the Virtual Pooled Registry
- Raising awareness of the NFR among the state cancer registry community
 - Dr. Siegel gave a presentation on the NFR at a NAACCR Webinar on September 9, 2020
- Have held meetings with other CDC researchers who have successfully linked with multiple state cancer registries
- Plan to devote considerable resources and personnel to linking to state cancer registries
- Updated the protocol to provide even more information about the Virtual Pooled Registry

Recommendation 3

It is recommended that one of two approaches be used to characterize exposure.

- One approach could be the use of strategic questions regarding the approximate year that the individual firefighter started using each protective action such as self-contained breathing apparatus, other respiratory protection during overhaul, types of turn-out gear used, storage and cleaning of turn out gear, showering etc.,
- The second approach would be to ask questions 25, 28-29, 30-35 for each job held.
- Further, it is recommended that both approaches be assessed in a pilot study to determine how much time is added to the total time for collecting information for the enrollment questionnaire. Several subcommittee members felt that 30 minutes or less may be ideal for completing the enrollment questionnaire but that this exposure/protection information was vital for the success of the study. Hence, it is recommended that different versions of the questionnaire be pilot tested to have a better understanding of which approach is more reliable, valid, and acceptable to the participants.

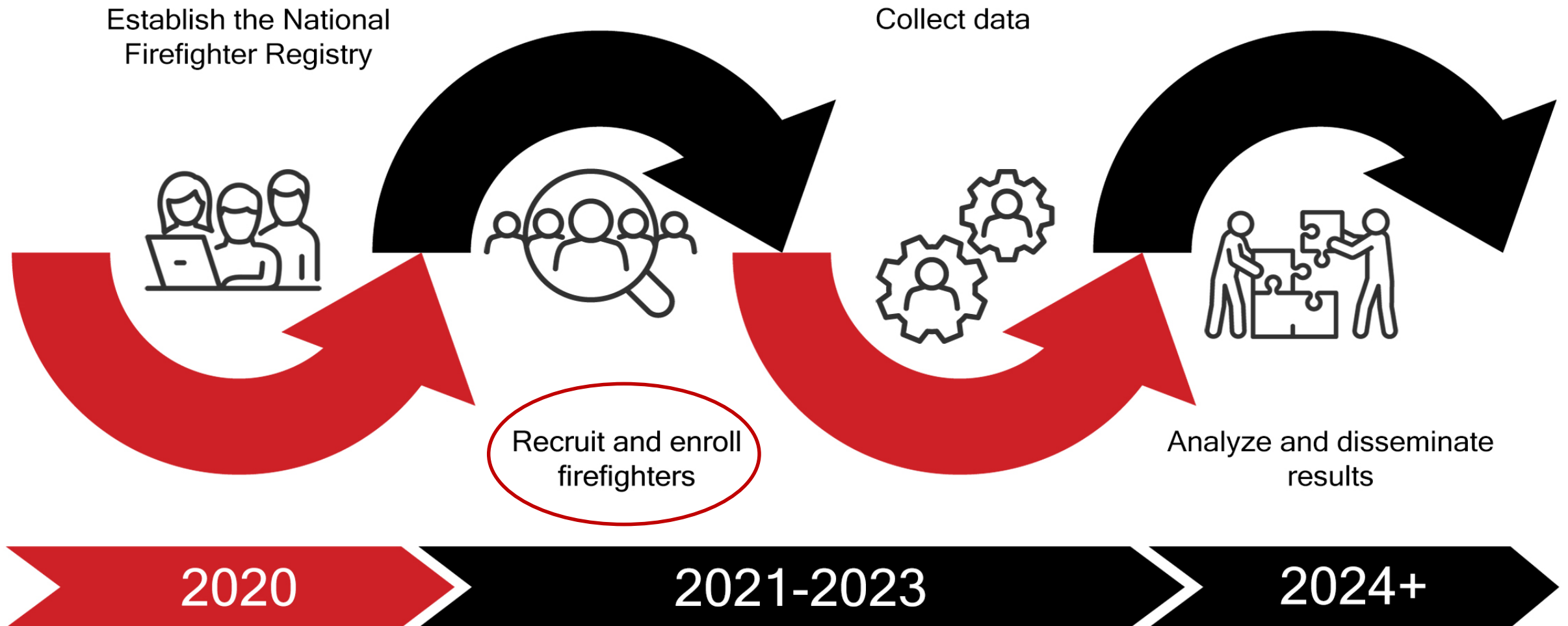
Response to Recommendation 3

- Modified the questionnaire to collect more detailed work history with exposure questions tied to each job title held in each department
- Added questions about the approximate year in which different controls were implemented, such as use of respiratory protection
- Added a question regarding smoke exposure injuries
- Held phone calls and piloted versions of the questionnaire with firefighters and other stakeholders
- Web-based questionnaire will be piloted with several firefighters to evaluate user experience and time burden
- Plan to pilot the entire registration process with small to medium-sized department(s)
 - Pilot testing plans have been added to the protocol

What happens next?

- Post NIOSH-approved updated protocol and response memo to the NFRS/BSC website
- Submit OMB package for enrollment questionnaire
 - 30-day Federal Register Notice
- Submit the Assurance of Confidentiality for CDC approval
- Continue to develop the secure web portal and database
- Implement communications plan, including working with stakeholders to deliver promotional materials
- Pilot the NFR registration process with small to medium sized department(s)
- Launch the NFR (open enrollment)
- Promote NFR at professional conferences, etc. (dedicated booths)
- Begin the targeted enrollment process for selected fire departments

NFR National Firefighter Registry Timeline



For more information:

<https://www.cdc.gov/niosh/firefighters/registry.html>

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