



National Firefighter Registry Subcommittee Meeting

July 14, 2020

NFR National
Firefighter
Registry

Timeline [2020]

- **March 20:** Draft protocol sent to NFRS members
- **May 6:** Comments on draft protocol due to DFO
- **May 8:** Comments compiled and provided to Subcommittee
- **May 15:** NFRS meeting to discuss draft protocol
- **June 4 :** Report drafted by co-chairs sent to NFRS members
- **June 19:** Comments on draft report due to DFO
- **June 21:** Compiled Subcommittee comments provided to co-chairs
- **June 25:** Revised draft report sent to NFRS members
- **July 14:** NFRS meeting to approve report for BSC deliberation
- **August 4:** Special BSC meeting to review and finalize report and recommendations for NIOSH and NFR program



Recommendation 1

Because of the importance of obtaining SSN for the National Death Index and the cancer registries, it is recommended that NIOSH should pilot test with several individuals to learn the most compelling approach for explaining the purpose of both the Assurance of Confidentiality and the rationale for requesting the SSN.

Also, NIOSH may want to explore exactly what will be lost if only the last four digits are gathered, especially when they have other identifiers such as date of birth.

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.

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 suggested 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.