

The National Firefighter Registry for Cancer
(0920-1348, exp. 9/30/2024)

Request for Office of Management and Budget (OMB) Review and Approval
for a Federally Sponsored Data Collection

Revision

Part A

Program Official/Contact

Kenneth Fent, PhD, CIH
Team Lead, Research Industrial Hygienist
National Institute for Occupational Safety and Health
Centers for Disease Control and Prevention
P: 513-841-4569
F: 513-841-4486
Kif5@cdc.gov

March 21, 2024

TABLE OF CONTENTS

A. JUSTIFICATION.....	4
A1. <i>Circumstances Making the Collection of Information Necessary</i>	4
A3. <i>Use of Improved Information Technology and Burden Reduction</i>	5
A4. <i>Efforts to Identify Duplication and Use of Similar Information</i>	6
A5. <i>Impact on Small Businesses or Other Small Entities</i>	6
A6. <i>Consequences of Collecting the Information Less Frequently</i>	6
A7. <i>Special Circumstances Relating to the Guidelines of 5 CFR 1320.5</i>	7
A8. <i>A Comments in Response to the FRN and Efforts to Consult Outside the Agency</i>	7
A9. <i>Explanation of any Payment or Gift to Respondents</i>	8
A10. <i>Protection of the Privacy and Confidentiality of Information Provided by Respondent</i>	8
A11. <i>Institutional Review Board (IRB) and Justification for Sensitive Questions</i>	10
A13. <i>Estimates of Other Total Annual Cost Burden to Respondents and Record Keepers</i>	12
A14. <i>Annualized Cost to the Federal Government</i>	12
A15. <i>Explanation for Program Changes or Adjustments</i>	13
A16. <i>Plans for Tabulation and Publication and Project Time Schedule</i>	13
A17. <i>Reason(s) Display of OMB Expiration Date is Inappropriate</i>	14
A18. <i>Exceptions to Certification for Paperwork Reduction Act Submission</i>	15
REFERENCES.....	15

ATTACHMENTS

1. Authorizing Legislation
2. 60-Day Federal Register Notice
- 2a. Public Comment from Oncology Nursing Society
- 2b. Public Comment from Individual
3. Protocol
 - 3a. Informed Consent
 - 3b. User Profile
 - 3c. Enrollment Questionnaire
4. Promotional Materials
 - 4a. Invitation to Participate
 - 4b. Frequently Asked Questions
 - 4c. Brochure
5. Request for Information 2019
6. Privacy Impact Assessment
7. Assurance of Confidentiality
8. Non-Research Determination
9. Records Request Email

JUSTIFICATION SUMMARY

Goal of the project: The main goal of the National Firefighter Registry for Cancer (NFR), according to the Firefighter Cancer Registry Act of 2018, is, “to develop and maintain...a voluntary registry of firefighters to collect relevant health and occupational information of such firefighters for purposes of determining cancer incidence.”

Intended use of the resulting data: Results from the NFR will provide information for decision makers within the fire service and medical or public health community to devise and implement policies and procedures to lessen cancer risk and/or improve early detection of cancer among firefighters.

Methods to be used to collect: The NFR is utilizing an ambidirectional, open cohort design with data collection through a secure web portal.

The subpopulation to be studied: U.S. firefighters

How the data will be analyzed: Statistical analyses will be conducted in order to answer several questions related to descriptive characteristics of the current U.S. firefighting workforce; how the risk of cancer and mortality (i.e., health outcomes) in firefighters compares to the general U.S. population; if cancer risk changes with increasing firefighter exposures or other risk factors; and how cancer risk and risk factors vary by subgroups of firefighters.

A. JUSTIFICATION

A1. Circumstances Making the Collection of Information Necessary

This proposal is a revision and renewal request of information collection #0920-1348 to continue work in accordance with the Firefighter Cancer Registry Act of 2018, which has funding of \$5,500,000 for fiscal year 2024. Three additional years of OMB approval are being requested.

The President of the United States signed the Firefighter Cancer Registry Act of 2018 in July 2018, authorizing the Secretary of Health and Human Services (HHS) to develop a voluntary registry to collect data on cancer incidence among firefighters [H.R. 931, Firefighter Cancer Registry Act of 2018]. On October 23, 2019, the Secretary of HHS delegated authority for the Registry to the Director of the National Institute for Occupational Safety and Health (NIOSH).

According to the Act, NIOSH is required to “improve data collection and data coordination activities related to the nationwide monitoring of the incidence of cancer among firefighters” and “to collect, consolidate, and maintain, epidemiological information and analyses related to cancer incidence and trends among volunteer, paid-on-call and career firefighters” [Sec. 2 (b)]. NIOSH is authorized to collect individual cancer risk factors and occupational history, basic demographic information, status of the firefighter as either volunteer, paid-on-call, or career firefighter, total number of years of firefighting, approximate number or estimate of fire incidents, and other medical information and health history [Sec. 2 (c)]. This information will be collected to evaluate how the data relates to cancer risk among firefighters.

Few state cancer registries collect occupational information, and those that do are often vague and incomplete (Freeman, et al. 2017). One study found that roughly half of career firefighters in Florida with a cancer diagnosis were missing an occupation classification in the cancer registry, and only 17% were classified as a firefighter in the cancer registry (McClure et al., 2019). The requested data collection will help bridge this gap by developing a secure/encrypted database or registry of U.S. firefighters, along with other information outlined above, that can be matched to state cancer registries throughout the United States.

Analyses of demographic subgroups in the fire service have been underpowered because study samples have consisted of predominantly white male populations. Because roughly 20% of career firefighters are non-white, and almost 5% of career firefighters are women (and 10% of volunteer firefighters are women) [US BLS/NFPA report], previous findings from firefighter cancer studies are not necessarily representative of the entire firefighter workforce. In addition to open enrollment, a targeted cohort is being recruited that is oversampling for women and minorities.

A2. Purpose and Use of the Information Collection

The purpose of this information collection is for general purpose statistics to be gathered from a registry of U.S. firefighters with the intent to monitor cancer incidence and risk factors among the U.S. fire service. The information collected is the basis for the National Firefighter Registry for Cancer (NFR). NIOSH has an ambitious goal of enrolling $\geq 200,000$ firefighters in the NFR. This will result in a vast dataset of information that will be used to increase our understanding of firefighter exposures, work behaviors, cancer diagnoses, and other relevant risk factors. At the time of this document, over 12,000 firefighters have been enrolled into the NFR.

Without this data collection, NIOSH is unable to meet the requirements of The Firefighter Cancer Registry Act of 2018, specifically with respect to Sec. 2(b)(2), “To collect, consolidate, and maintain... epidemiological information and analyses related to cancer incidence and trends among firefighters.” Currently, most state cancer registries are not able to accurately capture occupation, specifically when pertaining to first responders due to their unique occupational models; thus, making it difficult to estimate the number of firefighters with a cancer diagnosis. The information being collected for the NFR is helping to bridge this gap and allow investigators to better understand how occupational risk factors (and other risk factors) relate to cancer in firefighters.

NFR information will be used in concert with other sources of information. The information collected for the NFR will be linked with records from state cancer registries and the National Death Index to monitor cancer incidence and mortality. The collected information will help answer questions related to descriptive characteristics of the current U.S. firefighting workforce; how the risk of cancer and mortality (i.e., health outcomes) in firefighters compares to the general U.S. population; if cancer risk changes with increasing firefighter exposures, other risk factors, or by adoption of control measures; and how cancer risk and risk factors vary by subgroups of firefighters.

NIOSH will recruit participants using a stratified random design to select a representative sample of career and volunteer firefighters from across the country, while over-sampling for women and minorities. In addition to this Targeted Cohort, all firefighters in the United States (18 years of age or older) will have the opportunity to register. These firefighters will make up the Open Cohort. Both cohorts, which make up the NFR sample, complete the informed consent, user profile, and enrollment questionnaire using a secure web portal. The web portal is accessible to anyone with internet access and minimizes the burden on the firefighter by utilizing skip patterns and auto-populating fields according to previous responses.

The intent of the NFR is to be generalizable to the U.S. Fire Service, however there may be potential biases that affect our results. NIOSH will have the ability to identify potential biases affecting the NFR sample by comparing the demographics and characteristics of NFR participants to those of the U.S. firefighter workforce that are provided by NFPA, USFA, and BLS (NFPA, 2015-2017), as well as comparing the Open Cohort and Targeted Cohort. Additionally, with roster counts and demographics information provided by fire departments selected in the Targeted Cohort serving as denominator estimates, NIOSH will be able to evaluate characteristics of response and non-response. Cancer rates in firefighters will be compared to the U.S. general population (controlling for demographics and potential confounders). In addition, internal comparisons among firefighters will be utilized in the analysis because that is the most direct way to achieve partial control for the healthy worker selection effect and to explore exposure-response relationships.

The NFR officially opened for firefighter registrations in April 2023. To date, over 12,000 firefighters have enrolled. The purpose for continuing to collect information is twofold; first to continue to fulfill the congressional mandate and secondly to have enough demographic diversity to study specific issues related to cancer and firefighters.

A3. Use of Improved Information Technology and Burden Reduction

All information for the NFR is gathered electronically. The informed consent, user profile, and enrollment questionnaire are available to all interested participants via a designated, secure web portal developed by NIOSH (<https://nfr.cdc.gov/>). The questionnaire has been reviewed by subject matter experts who understand the importance of and are mindful to burden reduction of respondents. The

subject matter experts (survey methodologist, public health scientists, and U.S. firefighters) have assisted with prioritization of information requested in the enrollment questionnaire to ensure that the vital information is being captured without any additional burden.

The web portal meets all requirements of the Federal Information Security Management Act of 2002. Firefighters access the web portal through the dedicated NFR website (www.cdc.gov/niosh/firefighters/registry.html). This website includes frequently asked questions (FAQs) (Attachment 4b) and other important background information about the NFR. After reviewing the NFR website, if firefighters are interested in enrolling in the registry, they click the “Join Now” icon. This will take them to the secure web portal, which has multi-factored authentication (MFA) through login.gov. After creating an account through login.gov, the participant will have the opportunity to complete the NFR informed consent, user profile, and enrollment questionnaire (in that order).

The NFR enrollment questionnaire (Attachment 3c) has been reviewed by a survey methodologist to ensure quality and proper organization of questions. Skip patterns and auto-population of choices based on participant responses are built into the questionnaire to minimize the burden to the participants. Additionally, the questionnaire has preprogrammed dropdown menus for capturing information such as place of employment and various demographics. 100% electronic submission participation is utilized. At this time, alternative methods for enrolling in the NFR are not offered. NIOSH has chosen to use the web portal for enrollment to make the process convenient, scalable, and uniform for all participants.

Once available, de-identified data and summary results will be accessible to the public as dictated by the Act, through a federal data research center.

A4. Efforts to Identify Duplication and Use of Similar Information

The Firefighter Cancer Registry Act of 2018 (Attachment 1) was signed with the purpose of developing a voluntary registry to collect data on cancer incidence among firefighters. This Act was created because this type of information is not currently available for the U.S. firefighter population. Previous data collection is limited and prior studies lacked sufficient power to examine cancer risk in subgroups of the fire service like minority firefighters. The Firefighter Cancer Registry Act of 2018 stipulates the NFR be a voluntary registry of firefighters, so all participants are required to complete an informed consent form during registration. With this stipulation, there are no practical alternatives available to NIOSH to register firefighters. The NFR team has conducted literature reviews, database searches, and contacted state cancer registries to ensure that this information has not been previously recorded.

Some population-based (i.e., state) cancer registries collect occupational information, but it is often vague and incomplete (Freeman, et al. 2017) because patient information related to work history is often not obtained in the healthcare setting. Among firefighters specifically, one study found that roughly half of career firefighters in Florida with a cancer diagnosis were missing an occupation classification in the cancer registry, and only 17% were classified as a firefighter in the cancer registry (McClure et al., 2019). This estimate would likely be much smaller for former or retired firefighters, or volunteers working a non-firefighting job at the time of cancer diagnosis, since the extent of occupational information ascertained may relate only to current job. Therefore, there is not enough accurate information available from state cancer registries alone to produce comprehensive estimates of cancer burden and risk factors among the fire service nationally. Additionally, the NFR’s proposed method (Attachment 3c) will allow for more extensive information to be obtained regarding work and exposure history, demographics, co-morbidities, lifestyle factors, and other covariates. This information

will be linked with records from state cancer registries, NDI, and other information databases to monitor cancer diagnoses and mortality and improve our knowledge about cancer risks for U.S. firefighters, especially those linked to workplace exposures.

The information gathering of the NFR is imperative to fulfill the federal mandate which provides clear instruction on the information and population on which to focus; no similar data is currently available to fulfill this task.

A5. Impact on Small Businesses or Other Small Entities

This data collection will not involve small businesses. Firefighters will likely complete the informed consent, user profile, and enrollment questionnaire while at their respective fire departments or outside of work.

A6. Consequences of Collecting the Information Less Frequently

The respondents are only required to fill out the enrollment questionnaire (Attachment 3c) once. It is NIOSH's intent to minimize the burden of respondents and therefore the informed consent is located on the same web portal as the enrollment questionnaire. Respondents may opt to return to the web portal to update their personal information in their user profile, including full name, mailing address, email address, mobile number, and work status. It is not anticipated that respondents will update this information more than once per year.

In order to fulfill the charge given to NIOSH to “develop and maintain... a voluntary registry of firefighters to collect relevant health and occupational information of such firefighters for purposes of determining cancer incidence” NIOSH must, at a minimum, collect the requested information one time from each respondent.

A7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5

This request fully complies with the regulation 5 CFR 1320.5

A8. Comments in Response to the FRN and Efforts to Consult Outside the Agency

Part A: PUBLIC NOTICE

A 60-day Federal Register Notice was published in the *Federal Register* on March 22, 2024, vol. 89 No. 57, pp. 20478 (Attachment 2). CDC received 2 non-substantive comments (Attachment 2a and Attachment 2b) and replied with a standard CDC response.

Part B: CONSULTATION

The individuals listed below (Table A.8.1) were consulted to obtain their expert views on availability of data, clarity of instructions, recruitment tactics, and survey content. Additionally, the NFR holds regular meetings with a federal advisory subcommittee who report to the NIOSH Board of Scientific Counselors. Details about these meetings can be found at <https://www.cdc.gov/niosh/bsc/nfrs>.

Table A.8.1 External Consultations

External Consultations

Affiliation	Role
Tucson Fire Department	Subject Matter Expert
Hanover Park Fire Department	Subject Matter Expert
Firefighter Safety Research Institute, Underwriters Laboratories	Subject Matter Expert, firefighting and research
Center for Fire, Rescue & EMS Health Research	Survey development & fire service expert
DOL/OSHA, Directorate of Standards and Guidance	OSHA consultant
NIOSH	Epidemiology, cancer subject matter expert
Harrisonburg Fire Department	Fire service subject matter expert
Sarasota Fire Department	Fire service subject matter expert
University of Arizona	Research subject matter expert
University of Miami	Cancer research expert
Rutgers University	Volunteer firefighter and research subject matter expert
University of Miami	Researcher, subject matter expert
Oak Ridge Associated Universities	Subject matter expert

Table A.8.1 Consultations within CDC

Consultations within CDC

Name	Title	Affiliation	Phone	Email	Role
Matthew Dahm	Team lead, Exposure Assessment Team	NIOSH	(513) 458-7136	Iwa6@cdc.gov	Environmental health expert reviewer
Robert (Doug) Daniels	Epidemiologist, Health Physicist	NIOSH	(513) 533-8329	rtd2@cdc.gov	Firefighter cancer research expert reviewer
Lynda Douglas	Public Health Advisor	CDC, DDNID	(770) 488-1075	LDouglas@cdc.gov	Public health reviewer
Thomas Hales, MD	Medical Officer	NIOSH	(513) 841-4583	trh1@cdc.gov	Physician reviewer
Kevin Horton, DrPH, MSPH	Branch Chief, SRB	ATSDR	(770) 488-1555	dhorton@cdc.gov	Registry expert reviewer
David Weissman, MD, FCCP	Director, RHD	NIOSH	(304) 285-5749	dqw4@cdc.gov	Occupational health reviewer

A9. Explanation of Any Payment or Gift to Respondents

Respondents do not receive an incentive to participate in the NFR.

A10. Protection of the Privacy and Confidentiality of Information Provided by Respondent

The information in identifiable form (IIF) required for registration into the NFR has been limited to only that needed to confidently link an individual to state cancer registries and National Death Index (NDI). IIF collected from firefighters will include employee ID, last four digits of social security number (SSN), full name, date of birth, sex, and contact information (i.e., email and mailing address, mobile phone number). The last four digits of SSN, if provided, will be very useful to match against state cancer registries. NIOSH may use other identifying information (above) to match to state cancer registries and NDI.

The NIOSH Information Systems Security Officer (ISSO) reviewed this submission and determined that the Privacy Act does apply (Attachment 6). There have been no changes to the Privacy aspects of this package since the previous submission. The following IIF Categories apply to this information collection (Attachments 3b & 3c):”

- Name
- Date of birth
- Last four digits of SSN
- Mailing address
- Phone numbers
- Medical information
- Email address
- Military status
- Employment status

IIF data will be collected and maintained as followed:

- Respondents are only able to enter their information or see previously entered responses after successfully logging in using multi-factor authentication (MFA). Security of user accounts meets requirements outlined in [NIST 800-63-2 levels of assurance \(LOA\)](#).
- Once respondents submit their enrollment questionnaires (Attachment 3c), their responses are uploaded to an on-premise secure and encrypted IT database. Their responses are then cleared from the web portal and can no longer be accessed by them, with the exception of information collected as part of their user profile (Attachment 3b).
- User profile information can be edited, but only after successfully logging in using MFA. Certain IIF fields will be masked on the Graphical User Interface because of the sensitivity of the data. For example, last four digits of SSN will be masked after saving.
- Data is encrypted at rest and in transit following controls listed in NIST Special Publication 800-53, SC-28. Multiple layers of encryption will be implemented on the database.
- Collected data (including questionnaire data, exposure data, and matched cancer data) is stored by unique respondent ID. This unique respondent ID is a universally unique identifier (UUID), assigned by the MFA program.
- Respondents’ IIF (e.g., name, last four digits of SSN, etc.) will be shared with population-based (e.g., state) cancer registries and the National Death Index (NDI) in order to match their NFR profile with cancer diagnoses and identify vital status and cause of death. However, population-based cancer registries and NDI will not keep respondents’ IIF provided to them for matching purposes. The data exchange must meet federal standard of encryption FIPS 140-2, Security Requirements for Cryptographic Modules, according to CSPO Standard for Portable Media and Mobile Device Security.
- IIF data will not be given to external researchers. However, external researchers may have access to indirectly identifiable data (e.g., sex, race, etc.) through a Research Data Center (RDC). External researchers will only be permitted to remove summary data tables from the RDC, which RDC staff will review before releasing to the external researchers to ensure that participants cannot be indirectly identified.
- The following individuals will have access to IIF data: NIOSH employees and on-site contractors operating on CDC network that have been approved for access by NIOSH. Restrictions on internal access and auditing of internal access will be implemented to meet the controls listed in [NIST Special Publication 800-53 \(as amended\)](#), Security and Privacy Controls for Federal Information Systems and Organizations.
- NIOSH will maintain the IIF data according to the NIOSH Records Control Schedule.

- NIOSH will keep all individual identifiable data confidential according to an Assurance of Confidentiality (Attachment 7). An Assurance of Confidentiality (AOC) is a formal confidentiality protection authorized under Section 308(d) of the Public Health Service Act. An AOC protects individuals and institutions involved in either research or non-research (e.g., surveillance), thereby protecting the data provided by respondents involved in both surveillance and research.
- All incidents involving a suspected or confirmed breach of IIF must be reported to OCISO according to the policy titled “OCISO/CDC Standard for Responding to Breaches of Personally Identifiable Information (PII).”
- Respondents are notified of their privacy protections, including the Assurance of Confidentiality (Attachment 7), through the informed consent document (Attachment 3a) that is required to be signed before advancing to the enrollment questionnaire on the web portal.

Collected data (including questionnaire data, exposure data, and matched cancer data) is stored by unique respondent ID. This unique respondent ID is a universally unique identifier (UUID), assigned by login.gov. User accounts are proofed at (LOA3), corresponding to [NIST 800-63-2 levels of assurance \(LOA\)](#). All collected data will be stored in a secure database that meets NIST 800-53, SC-28 PROTECTION OF INFORMATION AT REST standards. Multiple layers of encryption are implemented on the database. Certain IIF fields are masked on the Graphical User Interface because of the sensitivity of the data. For example, last four digits of SSN and month and year of birth are masked after saving.

Identifiable information provided to state cancer registries or the National Death Index will not be kept by those programs. Additionally, NIOSH has obtained an Assurance of Confidentiality (AoC) for all IIF data collected from firefighters, fire departments, and other institutions (e.g., population-based cancer registries) (Attachment 7). All IIF is kept confidential and, aside from NIOSH or other Federal employees assigned to the project, government contractors, visiting scientists, guest researchers, and fellows and trainees, no one is allowed to see or have access to the information.

Data will be kept private to the extent allowed by law.

A11. Institutional Review Board (IRB) and Justification for Sensitive Questions

IRB approval is not required. The development and maintenance of the NFR has been deemed non-research (Attachment 8).

Participation in, and all questions included in the NFR enrollment process are voluntary. The respondents are informed that their responses to all questions are voluntary. Questions 54-57 on the NFR enrollment questionnaire (Attachment 3c) may be considered sensitive information due to the topic of alcohol consumption. The collection of this information is necessary as there is evidence to support alcohol consumption as a risk factor for certain cancers (<https://www.cancer.gov/about-cancer/causes-prevention/risk/alcohol/alcohol-fact-sheet>). The cancers that have been identified as a result of increased alcohol consumption are also of interest in regard to exposure of firefighters. It will be important for the NFR to have this self-reported information in the case of cancer diagnosis and tracking.

Questions 29-44 may also be considered sensitive in nature due to the subject matter of health history and diagnoses. Again, instructions include that participation in any or all parts of the NFR (including individual questions) are voluntary.

It is necessary for the NFR to request respondents’ partial SSN to increase the probability of proper identification of the respondent for matching with state cancer registries. Not having partial SSN would lead to substantially decreased sensitivity and specificity in matching against cancer diagnoses in state cancer registries (i.e., there will likely be false matches or missed matches).

The question that asks for last four digits of SSN (user profile, Attachment 3b) specifically notes: (1) the statute authorizing NIOSH to solicit the SSN; (2) how the SSN will be used; and (3) that providing the SSN is voluntary.

At this time, the National Firefighter Registry (NFR) for Cancer team is requesting to delay in the implementation of changes to the demographic section of the enrollment questionnaire. The team is planning to speak to major fire service organizations and firefighter health and safety researchers to gather input for recommendations to best implement these changes. Previous fire service research projects have experienced participant difficulties with the sensitive nature of asking for participants’ sexual orientation/gender identity, and we would like to receive guidance from fire service and research subject matter experts prior to proceeding. Having time to seek this guidance will help inform our decisions and implementation process.

Secondly, The NFR enrollment system and database is still undergoing careful monitoring and maintenance after its initial launch in April 2023. Several refinements are ongoing and have required substantial time and resources from the development and technology operations teams. Incorporating additional changes in data schema are likely to impact these ongoing efforts and potentially complicate root-cause analyses and solutions engineering.

Lastly, at this time, nearly 15,000 firefighters have enrolled, many of whom have already provided demographic information based on the original questioning. Incorporation of the OMB-recommended SO/GI and race/ethnicity needs to carefully consider how these questions will be asked among existing participants, as well as new participants, and further incorporated into the existing application and database in way that maintains a high standard of user experience and data integrity. This could require adding these questions to the editable User Profile. However, the NFR application is not currently designed this way. Making design changes would require development wireframes, user acceptance testing in development and pre-production environments, and quality assurance/quality control testing.

For these reasons, the NFR Program is requesting a delay in implementing the current OMB-recommended SO/GI and race/ethnicity questions.

A12. Estimates of Annualized Burden Hours and Costs

Table A.12.1: Estimated Annualized Burden (Hours)

Type of Respondents	Form Name	Number of Respondents	Number of Responses per Respondent	Average Burden per Response (in hours)	Total Burden (in hours)
U.S. Firefighters	Informed Consent	66,666	1	5/60	5,555
U.S. Firefighters	NFR User Profile (web-portal registration)	66,666	1	5/60	5,555

U.S. Firefighters	NFR Enrollment Questionnaire	66,666	1	30/60	33,333
U.S. Firefighters	Records request	34	1	960/60	544
Total					44,987

The NFR enrollment questionnaire was pilot tested by thirteen individuals: eleven firefighters and two research scientists, and numerous firefighters (400+) from 7 fire departments. The completion times for each respondent were recorded and averaged, along with the time that it would take for a thorough review of the informed consent process. In this pilot testing, the average respondent spent approximately 40 minutes completing the entire enrollment process, including informed consent (Attachment 3a, 5 min), user profile (Attachment 3b, 5 min), and questionnaire (Attachment 3c, 30 min).

The NFR team anticipates receiving records (i.e., roster counts and demographic information) from an estimated 34 targeted departments; we anticipate those responding to the request to be firefighters or fire leadership within the respective departments and to take an average of 16 hours to complete. With a goal of enrolling 66,666 firefighters annually, we anticipate total annual burden hours related to the information collection to be approximately 44,987. The summary of this information is provided above in Table A.12.1. Table A.12.2 provides our estimate of the annualized burden costs, which was based on an average hourly wage for firefighters according to The Bureau of Labor Statistics (<https://www.bls.gov/ooh/protective-service/firefighters.htm>).

Table A.12.2: Estimated Annualized Burden Costs

Type of Respondent	Form Name	No. of Respondents	No. of Responses per Respondent	Average Burden per Response (in hours)	Total Burden Hours	Hourly Wage Rate	Total Respondent Costs
U.S. Firefighters	Informed Consent	66,666	1	5/60	5,555	\$24.85	\$138,042
U.S. Firefighters	NFR User Profile (web-portal registration)	66,666	1	5/60	5,555	\$24.85	\$138,042
U.S. Firefighters	NFR Enrollment Questionnaire	66,666	1	30/60	33,333	\$24.85	\$828,325
U.S. Firefighters / Fire Leadership	Records request	34	1	960/60	544	\$24.85	\$13,518
Total		66,700			44,987		1,117,927

A13. Estimates of Other Total Annual Cost Burden to Respondents and Record Keepers

There are no capital or maintenance costs incurred by respondents. There are also no costs or burden to respondents for record keeping. Information requested from fire department leadership (i.e., roster counts) is already being collected and maintained.

A14. Annualized Cost to the Federal Government

To carry out the charge given to NIOSH, Congress authorized funding in the amount of \$2,500,000 for each fiscal year from 2020-2023 (H.R. 931- The Firefighter Cancer Registry Act of 2018) (Attachment 1). The most recent annual funding amount was \$5,500,000 in fiscal year 2024. Two identical Firefighter Cancer Registry Reauthorization Act bills (H.R. 3821 and S. 2119) are currently under consideration in Congress for continued annual funding at the most recent level.

As of May 2024, annual NIOSH personnel and overhead costs are approximately \$2,400,000.

Additional estimated annual expenses for 2024/2025 include:

- Development, monitoring, and maintenance of the data collection system \$500,000
- Data science support (contract): \$250,000
- Communications campaign and help desk support (contract): \$800,000
- Enrollment of firefighters at targeted fire departments throughout the United States (contract): \$900,000
- Travel expenses to meet with fire leadership and other groups to educate, recruit, and enroll participants: \$150,000
- Intergovernment Personnel Act Agreements to assist with education and recruitment of firefighters: \$100,000
- Linkages to population-based cancer registries (possible contract): \$250,000
- Licensing and other IT costs: \$100,000

These costs, along with miscellaneous costs, will total approximately \$5,500,000 per year.

A15. Explanation for Program Changes or Adjustments

Revisions to this collection include an update of the estimated annualized time burden and occupational wage information to reflect current earnings based on the U.S. Bureau of Labor Statistics for 2022 and a more accurate number of respondents based on the first year of project enrollment (updated table below).

Several minor updates have been made to the enrollment questionnaire; these changes are necessary to improve readability and the overall user experience. Specific changes are listed below.

Revisions to the NFR Enrollment Questionnaire:

- Changed the instructions for providing a second email address in the user profile to improve the user experience
- Instructions for question 17 were reworded to improve clarity
- Reduced the number of sub-options under “structural or industrial firefighter” to reduce data redundancy
- Sub-questions for the last question under question 19 (Have turnout gear or other fire-response clothing laundered after every or almost every fire response) were updated to improve clarity
- Options and instructions were changed for question 28 to improve the user experience
- Additional instructions were provided for tobacco-related questions (49-53)

A16. Plans for Tabulation and Publication and Project Time Schedule

The NFR team will conduct periodic statistical analyses on the data in the system. As available, NIOSH will disseminate the results of this project to the fire service, other researchers, and general public through reports, briefings, presentations at professional meetings, and publication of manuscripts in peer-reviewed journals. It is difficult to predict the timeline for publication as results rely on the time it takes for demographic diversity to be achieved in the NFR database.

Table A.16.1

Project Time Schedule	
Activity	Time Schedule
Surveillance Activity	Ongoing data collection (began April 2023)
Summary Reports	Every year after OMB approval
Yearly Evaluation	Every year after OMB approval

A17. Reason(s) Display of OMB Expiration Date is Inappropriate

The display of the OMB expiration date is appropriate.

A18. Exceptions to Certification for Paperwork Reduction Act Submission

There are no exceptions to the certification. These activities comply with the requirements in 5 CFR 1320.9.

REFERENCES

BLS. Employed persons by detailed occupation, sex, race, and Hispanic or Latino ethnicity (2022).
 Daniels, R.D.; Kubale, T.L.; Yiin, J.H.; Dahm, M.M.; Hales, T.R.; Baris, D.; Zahm, S.H.; Beaumont, J.J.; Waters, K.M.; Pinkerton, L.E. Mortality and cancer incidence in a pooled cohort of US firefighters from San Francisco, Chicago and Philadelphia (1950-2009).
 Occup Environ Med, 71 (2014), pp. 388-397
 Freeman, M.; Pollack, L.; Rees, J.; Johnson, C.; Rycroft, R.; Rousseau, D.; Hsieh, M.

Capture and coding of industry and occupation measures: Findings from eight National Program of Cancer Registries states. *Am J Ind Med*, 60 (2017), pp. 689-695

McClure, L.; Koru-Sengul, T.; Hernandez, MN.; Mackinnon, J.; Schaefer-Solle, N.; Caban-Martinez, A.; Lee, D.; Kobetz, E. Availability and accuracy of occupation in cancer registry data among Florida firefighters. *Plos One*, 14 (2019)

NFPA.

U.S. Fire Department Profile (2018)