

Attachment 7. Assurance of Confidentiality

**ASSURANCE OF CONFIDENTIALITY
THE NATIONAL FIREFIGHTER REGISTRY (NFR) DATA
FIELD RESEARCH BRANCH (FRB)
DIVISION OF FIELD STUDIES AND ENGINEERING (DFSE)
NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY AND HEALTH (NIOSH)
CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)
2025**

The Secretary of Health and Human Services (HHS) delegated authority to the National Institute for Occupational Safety and Health (NIOSH) of the Centers for Disease Control and Prevention (CDC) to collect health and occupational information for the purpose of monitoring and evaluating the cancer incidence among firefighters in the United States and its territories as outlined in the Firefighter Cancer Registry Act of 2018. The National Firefighter Registry (NFR) data will be used by scientists within CDC/NIOSH to monitor cancer incidence among firefighters and evaluate relationships between occupational and other characteristics and cancer. The data can also be analyzed by CDC/NIOSH scientists for other public health purposes. Data will be provided in a de-identified format for sharing with the public including external researchers, as appropriate.

The Division of Field Studies and Engineering (DFSE), National Institute for Occupational Safety and Health (NIOSH) has received a 308(d) Assurance of Confidentiality for National Firefighter Registry (NFR) data in order to protect the sensitive nature of these records which include direct (social security number (SSN), date of birth (DOB), and first and last name) and indirect (sex, age, race/ethnicity, marital status, employer (name of fire department), employee ID, current and past job titles (e.g., firefighter, company officer, fire chief, etc.), and hire date) identifiers obtained through an enrollment questionnaire. The NFR team will also use firefighters' direct identifiers to link with population-based (e.g., state) cancer registries, the National Death Index (NDI), and other information databases for the purposes of determining cancer and health status, cancer diagnosis information, vital status, and cause of death. CDC/NIOSH will also request roster information from fire departments and state agencies to provide NIOSH with a list of individuals to be contacted to participate in the NFR and for tracking participation. The NFR team could also collect incident and employment records from fire departments or agencies that maintain these records for firefighters who consent to participate in the NFR. Lastly, participating firefighters can also request that exposure tracking software programs release their exposure tracking data for inclusion in NFR analyses to better understand firefighters' exposure profile.

Given that this data collection may include sensitive information that is identifiable or potentially identifiable for individuals, NIOSH has requested and received authorization under Section 308(d) of the Public Health Service Act, (42 U.S.C. 242 m (d)) to assure the confidentiality of NFR data by protecting: identifiable data obtained from individual firefighters participating in the NFR; firefighters' identifiable information provided by other institutions (e.g., fire departments, population-based cancer registries, exposure tracking programs); and the identifying information of fire departments in order to maximize participation from fire departments that are helping with recruitment or providing information to the NFR for consenting firefighters.

Identifiable information collected will be kept confidential and, aside from CDC/NIOSH or other federal employees assigned to the project, government contractors, visiting scientists, cooperative agreement partners, guest researchers, and fellows and trainees, third parties will be restricted from accessing this data. These individuals who handle the identifiable information will be required to adhere to a security and confidentiality protocol, participate in annual security training, and sign a 308(d) Nondisclosure Agreement and 308(d) Confidentiality Pledge. Institutions that house cancer registries and other information databases will be given

access to select identifiable data for data linkage purposes (i.e., so CDC/NIOSH can acquire cancer diagnosis, health, and vital status records). Those institutions will not be using NFR data for public health purposes, nor will they receive any data beyond those needed for making successful data linkages for sharing with CDC/NIOSH. De-identified NFR data will only be accessible to external researchers through a Research Data Center (RDC). All requests for de-identified NFR data files from outside parties must be made through a proposal to the RDC as outlined in Section D. Confidentiality Security Statement.

The voluntarily provided information collected by CDC/NIOSH as part of this activity that would permit identification of individuals or institutions (firefighters and fire departments) is collected and maintained under Sections 304 and 306 of the Public Health Service (PHS) Act (42 U.S.C. Sections 242b, 242k) with an assurance that it will be held in strict confidence in accordance with Section 308(d) of the PHS Act (42 U.S.C. Section 242m(d)). Such data will be used only for the purposes stated in this Assurance, and it will not otherwise be disclosed or released without the consent of the firefighters who provided information to the NFR and parties who were given this Assurance.

No information collected through the activities outlined in this Assurance that could be used to identify any individual on whom a record is maintained, either directly or indirectly, will be made available to anyone as set out in this Assurance. In particular, such information will not be disclosed to: the public; family members; parties involved in civil, criminal, or administrative litigation, or for commercial purposes; to agencies of the federal, state, local tribal, or territorial government including Congress, unless as described herein. This protection lasts forever, even after death.