1. **Why is this study being done?**

   The purpose of this study is to determine how many members of the Volunteer Fire Service in New York State have developed cancer and died from cancer or other causes over the past few decades. In addition to supporting presumptive cancer legislation to protect volunteer firefighters who develop cancer in the line of duty, this information will be invaluable for prevention and treatment programs that benefit firefighters. Your participation is voluntary, but a large study with input from every fire department will have the greatest impact on getting you and your fellow firefighters the programs you deserve.

2. **Data Security: Will our department's information be safe?**

   YES! Information from fire departments will be collected by a secure web-based application called REDCap (Research Electronic Data Capture) and will be stored on secure Northwell Health servers. *REDCap is a HIPAA compliant website* used by many universities and hospitals to protect research information. **ONLY the members of the Firefighter Cancer Study team** have been granted access to the information sent through REDCap. We will take **EVERY** precaution to keep the information as secure as possible. (refer to the last page for more information about REDCap Security)

3. **Why won't individual firefighters be contacted?**

   Fire departments are being asked to collect the information on behalf of their firefighters and send them to the **Firefighter Cancer Study team**. The study team will **NOT** have any direct contact with individual firefighters or their families. *No individual or fire department will be asked for information about which firefighters got cancers or died*. The study team needs to get that information directly from agencies that have complete and accurate information about cancer diagnoses (see #4).

4. **How will the study find out which firefighters have cancer?**

   Cancer diagnoses for individual firefighters will be obtained directly from the NYS Cancer Registry which the New York State Department of Health uses to record every cancer in NYS residents. The NYS Cancer Registry will match the names and other information you provide to identify which members had cancer. *Your fire department does not need to indicate any cancer diagnoses or any other medical information, only the demographic information we request*.

5. **Are you asking for our members' Social Security Numbers?**

   NO! We will **NOT** ask for Social Security Numbers.

6. **What information is our department required to send?**

   Your department will be asked to enter the following information in the data collection forms in REDCap:

   a. Fire Department Information - general information about your department, Incident Type Report Summaries (the information that your department would report to NFIRS) for 2012-2016, and information for the department's contact person

   b. Personnel Information Files - basic demographic information for all past (inactive, exempt, and deceased) and present members of your fire department

7. **How will we send you our fire department's information?**

   If you agree to participate in this study, you will be asked to provide the study team with a *single email address for your department*. The "contact person" who will provide the information for your department must have access to this email address. The link for the data collection forms will be sent in an email from ffcancerstudy@northwell.edu with the subject line: **"Northwell Health Firefighter Cancer Study."** *The email will contain instructions and the link for completing the data collection forms*.

   There will be two options for uploading information:
   a. You can upload files from programs you have on your department computers that you use to manage rosters for your fire department.
   b. You can download the study's Excel spreadsheet to enter the information about your firefighters and then upload the Excel file.

8. **What types of files with our department's information can we upload?**

   You can upload *any type of file* you have**. If possible, please include all your information in a single file; however, you are able to upload up to 5 files on the data collection form. If you have more than 5 files, please contact Gina or Vincenza (see question 15 for contact information).

   ***We can also provide step-by-step instructions for downloading your files for some of the common personnel tracking/records management software systems upon request.*

9. **Do we need to submit all the information at one time? Can we start the forms and return later?**

   You can save the forms with the information you've entered at any time and return later. You will receive an access code to use when you return to the forms. *Please save a copy of the code*. If you lose the code, contact the Project Coordinator, garena@northwell.edu, to retrieve it. You may hit "save & return later" as many times as necessary; however, *once you hit "submit" for a survey, you will no longer be able to return to it*. Therefore, please make sure you've completed everything before you hit submit.

10. **Our department doesn't use a computer program or have electronic records of our rosters. How else can we send you the information?**

    The study team's goal is to provide the simplest method for you to participate in this study. Please contact the team and they will be happy to work with you to find alternatives.

11. **What if we can't provide all the requested information?**

    Some of the information is required because it ensures the best match to the NYS Cancer Registry; the data collection form shows which information is required. However, the study team can work with any amount of information you can provide. The more information you provide, the more data the study team will have to conduct a proper research study.

12. **How many years should we go back? Which rosters do we need to submit?**

    The NYS Cancer Registry started recording cancers in 1976; therefore, cancers diagnosed before 1976 can't be used in the linkage. The further back in time you can provide rosters, the better for the study. If you can, submit the information for *every active, inactive, exempt, and deceased firefighter* who served in your department, *starting with the current roster and working back as far as possible*. The study team recognizes the difficulty of this request and will therefore work with any amount of information from your rosters you can provide.

13. Who will have access to the information we provide?

The members of the **Firefighter Cancer Study team** will be the **ONLY** people with access to the information you provide. The information will be stored on secure Northwell Health servers for the study period. There are strict limits on how we can use your information; these limits are enforced by the boards that oversee research at Northwell Health and at the New York State Department of Health. *The study team is obligated to keep the information safe and only use it for the purposes of this study*. The information will NOT be shared with FASNY and will NOT be used for solicitation or any other purpose.

14. What are the risks of participating in this study?

There is a risk of loss of confidentiality of the information collected for this study; while this risk is possible, the highest priority is keeping your information safe. Northwell Health provides research information technology (IT) procedures and training to ensure that the study team does everything it can to keep the information secure, including password protections and log-in restrictions to files and Northwell Health computers. Representatives from Northwell Health's Human Research Protection Program (a group of people that oversee research at Northwell Health) will make sure this study is being done properly.

15. What are the risks of sending information on behalf of our members?

Please consult with your fire district manager or attorney about NY laws governing release of personnel information that may affect your department.

16. Will we get results about our fire department?

You will not receive results about your specific fire department. The study may report cancer rates among firefighters by county, but not for individual municipalities or fire departments.

17. Who do we contact if we have questions?

You can contact any member of the research team with any questions or concerns you have by emailing ffcancerstudy@northwell.edu.

> For questions regarding participation and completing the data collection forms, contact:
> - Project Coordinator: Gina Arena – 516-465-1944 – garena@northwell.edu
> - Research Assistant: Vincenza Caruso – 516-465-3196 – vcaruso2@northwell.edu

> If you have a research-related question or concern, contact:
> - Principal Investigator: Dr. Jacqueline Moline – 516-465-2639 – jmoline@northwell.edu
> - Program Director: Dr. Anne Golden – 516-465-3171 – agolden3@northwell.edu

> For questions regarding protection of research participants or other concerns about this study (refer to Northwell Study ID #16-848), contact:
> - Human Research Protection Program at Northwell Health – 516-465-1910

REDCap Survey and Database Security

To help protect and secure the data stored in REDCap's back end database, the software application employs various methods to protect against malicious users who may attempt to identify and exploit any security vulnerabilities in the system. Such methods will be described here in technical detail.

In REDCap, all incoming data gets intentionally filtered, sanitized, and escaped. This includes all data submitted in an HTTP Post request and all query string data found in every URL while accessing REDCap, among other modes through which user-defined data gets submitted in the application. Server environment variables that are vulnerable to forgery by users are also checked and sanitized. All user submitted data is properly filtered for any possibly harmful markup tags (e.g. <script>) and is then escaped before ever being displayed on a web page within the application. SQL queries sent to the database server from REDCap are all properly escaped before being sent. If any values used in an SQL query originated from user-defined values, they would have already been sanitized beforehand as well, as described above. User-defined data used within SQL queries also have their data type checked to prevent any mismatching of data types (e.g. making sure a number is really a number). These processes of sanitization, filtering, data type checking, and escaping all help to protect against methods of attack, such as Cross-Site Scripting (XSS) and SQL Injection. To specifically protect against Cross-Site Request Forgery (CSRF), which is another method of attack, REDCap utilizes a "nonce" (a secret, user-specific token) on every web form used in the application. The nonce is generated anew on each web page as the user navigates within REDCap during a session.

Many institutions that have installed REDCap have made use of enterprise-level web application security scanners, such as HP Webinspect and Acunetix, to scan and test REDCap's security and its ability to withstand various methods of attack. REDCap has performed very well in such instances. Any partner institution that wishes to scan REDCap using security scanning software is free to do so without the consent of Vanderbilt University or REDCap developers so long as the particular instance of REDCap being scanned is their own and not hosted by another institution. If an institution decides to perform a security scan of REDCap and finds any medium- to high-risk security issues that are directly REDCap related, they are encouraged to contact the REDCap developers at Vanderbilt so that such issues can be addressed. More information is available at https://projectredcap.org/REDCapTechnicalOverview.pdf