

INFORMATION SHEET

Risk Tolerance Among Survivors, Providers, and Caregivers of Head and Neck Cancer

Principal Investigator: Matthew C. Miller, MD

This research study is being conducted by the Head and Neck Cancer Alliance and Dr Matthew Miller from the University of Rochester's Department of Otolaryngology Head & Neck Surgery. The purpose of this study is to understand the outcomes and quality of life of patients who have undergone treatment for head and neck cancer in the past.

If you decide to take part in this study, you will be asked to complete 1 survey that will take about 5 minutes to complete. This survey asks about your attitudes and perceptions of risk vs benefit for various treatments for Head & Neck Cancer. We estimate that approximately 200 subjects will take part in this study. The overarching purpose of this survey is to benefit any future patients and help physicians to improve patient care and outcomes.

Some of the survey questions may be upsetting or make you feel uncomfortable. You can skip any of the questions you do not want to answer. This study does not involve collecting any personal or identifiable information about you.

The University of Rochester makes every effort to keep the information collected from you private. In order to do so, all of the information we collect will be stored in a secure manner and only study team members will have access to it. Sometimes, however, researchers need to share information with people that work for the University. If this does happen, we will take precautions to protect the information you have provided. There are no other expected risks. There are also no expected benefits.

You will not be paid for participating in this study. There will be no cost to you to participate in this study. Your participation in this study is completely voluntary. You are free not to participate or to withdraw at any time, for whatever reason. No matter what decision you make, there will be no penalty or loss of benefits to which you are otherwise entitled.

For more information or questions about this research you may call Dr Matthew Miller at 585-758-5700. Please contact the University of Rochester Research Subjects Review Board at 265 Crittenden Blvd., CU 420628, Rochester, NY 14642, Telephone (585) 276-0005 or (877) 449-4441 for the following reasons:

- You wish to talk to someone other than the research staff about your rights as a research subject;
- To voice concerns about the research;
- To provide input concerning the research process;
- In the event the study staff could not be reached