

# IMPROVING THE USABILITY AND UTILIZATION OF CANCER REGISTRY DATA: THE NEED TO IDENTIFY A CORE DATA SET

Iris Zachary

Dr. Suzanne Austin Boren, Dissertation Supervisor

## ABSTRACT

Cancer registries in the US and Canada have a long history of data standards and data collection that have developed from a minimal dataset to the standard dataset that is used now. Central Cancer Registries (CCRs) are good resources for cancer data, but are often underutilized. CCRs are recognized for high quality data standards by the Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR) or the National Cancer Institute (NCI) Surveillance, Epidemiology, and End Results (SEER) Program and receive certification from the North American Association of Central Registries (NAACCR). Each year, there are many changes to the data that are collected in the cancer registry field. The changes in the data collection process cause interference and decrease in quality of data fields, but also delays in the timely collection of cancer registry data. The objective of this study is to identify what essentially needs to be collected and what can be collected optionally in a cancer registry. The goal is a robust dataset that can be used for other disease registries, cancer data surveillance, public health, and research. CCRs and Cancer Centers (CR) were surveyed to identify and describe the data items that are collected and needed to achieve a dataset that can serve cancer surveillance and research. The surveys were analyzed to identify overlaps of common and special interests, as well as barriers. The results showed that cancer registries have data available, but need to look at the timely release of a core dataset for use in cancer surveillance and research. The surveys also evaluated the barriers to data use from cancer registries and barriers for data use of collected datasets to identify the initial data request process. Data in the cancer registry are in a format that can easily be adopted by public health, surveillance, and research.