

Program Name:**Missouri Cancer Registry and Research Center****Title of Success Story: Collaboration shortens the road to becoming a survival registry****Public Health Problem:**

Cancer remains the second leading cause of death in Missouri as in the nation as a whole. Decreasing cancer-related morbidity and mortality is a goal for many organizations and individuals. It is also a challenge. The Centers for Disease Control and Prevention (CDC) have helped state health departments and other organizations develop and clarify the concept of a comprehensive approach to cancer control. One of the principle components of comprehensive cancer control is the use of scientific data to identify priorities and inform the decision-making process. In 2011, the Missouri Department of Health and Senior Services (DHSS) and the Missouri Cancer Consortium (MCC) produced a report on *The Burden of Cancer in Missouri: A comprehensive analysis and plan, 2010-2015* (<http://health.mo.gov/living/healthcondiseases/chronic/chronicdisease/cancerburdenreport.pdf>). The report provided information about cancer incidence, prevalence and mortality as well as health care utilization. It did not contain information about cancer survivorship. While the Missouri Cancer Registry and Research Center (MCR-ARC) has timely, complete (>95% of expected cases) and accurate incidence data, it lacks complete survival information.

Use of Surveillance:

Surveillance data have many uses. We need both incidence and survival data to:

- measure the impact of programs aimed at improving population health, such as Show Me Healthy Women (SMHW), a free breast and cervical cancer screening program for the state of Missouri funded by CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and the state of Missouri; and
- provide a more complete picture of the cancer control continuum – cancer prevention, early detection, diagnosis, treatment, survivorship and end of life.

Collaboration:

To provide DHSS and MCC with survival data on breast cancer for the next *Burden of Cancer in Missouri* report, MCR-ARC needed to become a survival registry. This would require linkage with the National Death Index (NDI), a centralized database of death record information on file in state vital statistics offices established by the National Center for Health Statistics (NCHS). Through CDC's National Program of Cancer Registries (NPCR), MCR-ARC had access to the National Death Index (NDI), the final part of a multi-step process that begins with review of a state's own vital statistics death file and includes Social Security Death Index (SSDI) linkage. However, MCR-ARC did not have the resources to carry out all aspects of the linkage. Missouri's Comprehensive Cancer Control Program, funded largely by CDC's National Comprehensive Cancer Control Program, received approval to use unobligated funds from Year One of the current DP12-1205 five-year funding cycle to provide additional funding to MCR-ARC to carry out NDI linkage. We will produce a report on breast cancer survival in Missouri and make a presentation to the MCC at its quarterly meeting in July 2014.

Public Health Outcome:

The MCC is a statewide group made up of individual healthcare professionals, healthcare organizations, academic and medical institutions, public health agencies and community-based groups concerned about cancer. For the first time, MCC members will have high-quality data on breast cancer survival in Missouri by the third quarter of 2014. These data will be available through DHSS's website and MCR-ARC's website. Eventually, these data will be included in the next *Burden of Cancer in Missouri* report, which will also be available electronically. Thus, health professionals, legislators, cancer survivors and members of the public will have a more complete picture of breast cancer in Missouri

Lessons Learned:

We have taken the first step to becoming a survival registry. Collaboration was the key to obtaining funding. We consulted with other central registries, adapted procedures when possible and developed guidelines as needed. Manual review is time consuming but critical to quality.

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