Success Story

Name of the NPCR Program:

Missouri Cancer Registry and Research Center (MCR-ARC)

Title of the Initiative, project or type of data use:

Special Project #3: From EHRs to MCR
Improving Cancer Reporting Utilizing Electronic Health Records

General timeframe during which the initiative/project/data use occurred:

1 December 2010 – 30 September 2013 (ARRA funding); ongoing (funding TBD)

Statement of public health issue, concern or problem:

Complete and high quality cancer case (incidence) reporting has, until recently, relied on hospital registries. Due to changes in medical practice and health care delivery, an increasing number of cancer cases are being diagnosed and treated outside the hospital setting, leading to under-reporting of certain sites/types of cancer (e.g., melanoma skin cancer, prostate cancer, *in situ* and localized breast and colorectal cancer, leukemia and lymphoma). Greater involvement of non-hospital sources is essential or case completeness and data quality will suffer. However, obtaining non-hospital cases can be time-consuming and expensive. Many central cancer registries (CCRs) funded by CDC's National Program of Cancer Registries (NPCR) struggle to obtain cases from clinics/physician offices (C/POs), freestanding cancer treatment centers and small caseload hospitals without cancer registries. A cost-effective mechanism for obtaining cases from such facilities is needed.

Evidence that the use of registry data was effective in addressing the issue, concern or problem:

In December 2010, MCR-ARC was one of two NPCR-funded CCRs to receive American Recovery and Reinvestment Act (ARRA) funding via a subcontract with ICF Macro to conduct a special project in support of CDC Contract 200-2008-27957/Order 0008, "RECOVERY ACT – Enhancing Cancer Registry Data for Comparative Effectiveness". The primary objective of this project is for MCR-ARC to implement electronic reporting from primary care physicians and targeted specialists, that is, to import data directly from C/PO electronic health records (EHRs) to MCR-ARC.

As part of their application for funding, MCR-ARC had received a commitment from a large freestanding clinic in the Northeast region of Missouri to participate in the project. In November 2011, the MCR-ARC Director, the SP#3 Coordinator, MCR Operations Manager and a System Support Analyst met with C/PO management and IT staff on site as well as a certified tumor registrar (CTR) employed by a nearby hospital. Hannibal Clinic and MCR-ARC staff worked together to create a file and transmit data extracted from the clinic's EHR to MCR-ACR. SP#3 and MCR staff reviewed the data; they made recommendations to edit some data elements and include additional elements before resubmitting the EHR file for review by MCR-ARC staff. This somewhat unorthodox approach was taken because clinic administrators

wanted to know the number and type of cases not being submitted to MCR (cases referred to the nearby hospital were reported to MCR by the hospital's CTR); MCR staff were equally interested in the results. MCR staff wanted to know how many cases were currently being missed and estimate the increase in workload; Hannibal Clinic staff wanted to know whether the clinic would benefit from hiring a CTR to abstract these cases rather than sending EHR data directly to the CCR. A decision has yet to be reached.

Beginning in January 2012, MCR-ARC staff conducted several site visits with potential partners identified by the Missouri Health Information Technology (MO HIT) Assistance Center, Missouri's HIT Extension Center, as already having selected EHRs as part of Meaningful Use (MU) Stage 1 requirements. In some cases, the sites had already implemented the use of their EHR while others were in the planning stages of implementation. Over the course of the site visits, MCR-ARC recruited five additional C/POs, two Critical Access Hospitals (CAHs) and one urologist to participate in the project. The participating sites have eight different EHR vendors, including one independently-created EHR.

Near the end of January 2012, MCR-ARC received their first test data from one of the recruited C/POs, Citizens Memorial Clinic. Test data were reviewed by MCR-ARC staff and sent to CDC for further review and analysis. A report detailing the data elements and where they resided in the EHR report templates was shared with MCR-ARC. Also included in the report were recommendations for the C/PO's EHR vendor.

During April 2012, another CAH was visited and recruited to participate in the project. At the time of the visit they were just beginning to implement their EHR and looked forward to working with MCR-ARC in the project.

In addition to the CAH recruitment in April, a Urology C/PO that includes eight urologists participated in a site visit with MCR-ARC. One urologist that has created his own MU compliant EHR software agreed to participate in the project. Several visits, e-mails and phone conversations have been conducted between the urologist and MCR-ARC staff; currently, the programmer of the EHR software is working on adopting the recommended changes to the software. Once these changes are complete, a test data file will be submitted to MCR-ARC.

Citizens Memorial was approached in May 2012 to submit "live" cancer diagnosis data to MCR-ARC to review and analyze as the test data was earlier in the year. These reports were sent to CDC for analysis and a recommendation report was received in July 2012 from CDC staff. Plans for collaboration between MCR-ACR and CDC staff to work with Citizens' vendor, Meditech, began in August 2012.

The MCR-ARC Software Support Analyst is also working with CDC staff as a beta tester of their eMaRC Plus software enhancements. Recommendations on these enhancements have begun and will continue until the software release.

Implications regarding this successful use of cancer registry data:

Among the uses of cancer incidence data are to:

- Provide annual cancer incidence rates;
- Look at trends in cancer incidence by stage at diagnosis, age, race/ethnicity, etc.;
- Study the burden of cancer in defined populations with a goal of reducing disparities;
- Conduct epidemiological and clinical research studies;
- Disseminate information for planning and early detection programs;
- Respond to state and local questions and concerns about possible excess cancer; and
- Provide information to legislators, health professionals and the public.

As stated above, changes in medical practice and health care delivery necessitate obtaining data from non-hospital sources and small caseload hospitals without cancer registries; otherwise, high quality, complete and timely data will not be available to users.

Between December 2010 and the present, MCR-ARC has demonstrated that C/PO EHRs can be used to bring cancer incidence data into the CCR, data that can be used to identify previously unreported cases or provide additional information on cases already in the CCR database. The implications for MCR-ARC are that a more cost-effective means of obtaining data previously not captured or captured at greater expense is available and appears to be feasible. The implication for other CCRs is that they, too, can obtain needed data from C/PO EHRs, assuming that funding, qualified staff and technical support are available. If CCRs succeed in this endeavor, public health surveillance will benefit by having more complete and timely data.

A number of challenges remain, including secure transmission of EHR reports from practices to CCRs. A mode of transmission beneficial to all participating sites has not been decided upon but current modes are Web Plus and secure FTP (File Transfer Protocol). Other challenges are the differences between vendors and the required data elements MCR-ARC would like included in the EHR reports. The variety of programming formats among vendors and the possible adoption of the CDC-recommended CDA message formatting have slowed the progress in vendor changes. With Stage 2 of MU on the horizon, MCR-ARC is confident EHR vendors will become more amenable to the implementation of CDA guidelines/standards.

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MCR-ARC is a NAACCR Gold-certified Registry