Using Data and Surveillance to Drive Cancer Genetics Activities in Michigan

“Cancer is one of the leading causes of death in Michigan. With appropriate or increased screening, some of these cancers could be treated more successfully or completely prevented.”

—Michigan Genetics Connection Cancer web page

Cancer claimed more than 20,000 Michigan lives in 2009. Since family history is the single strongest risk factor for many cancers, improving how providers gather family history and identify at-risk patients offers important opportunities to move the dial with cancer prevention and management. The Michigan Department of Community Health’s (MDCH) Genomics Program, with support from a three-year cooperative agreement from the CDC’s Office of Public Health Genomics and supplemental funding from the CDC’s Division of Cancer Prevention and Control, focuses its efforts and resources on identifying cancer genomics best practices through surveillance, education, and policy change.

Underlying Michigan’s cancer genetics activities are surveillance data; not only does surveillance highlight public health problems and gaps, but the cancer genomics program and its internal and external partners rely on it to develop solutions and evaluate the impact of those interventions on public health practice and health outcomes. According to Jenna McLosky, cancer genomics education coordinator at the MDCH, “We use surveillance data to drive everything we do.”

Using Data to Drive Provider Education Efforts

When an extensive review of medical charts revealed that the majority of healthcare providers were gathering incomplete family history information from patients, the cancer genetics staff developed a systematic approach for addressing the problem. Between 2005 and 2007, a Michigan health plan volunteered to review nearly 700 primary care provider charts to assess provider documentation and collection of family history. Although most providers were documenting some family history, 98 percent of the charts did not document the age of onset or diagnosis for the family member—a key factor used to assess patient risk. As a result, the family history offered an incomplete picture of the patient’s risk, which is a serious problem because it impacts whether a provider refers the patient for further assessment or counseling.

Through provider interviews and focus groups, the MDCH learned that providers felt uncomfortable in their ability to identify high-risk family history and uncertain about where to refer these patients. Among their biggest challenges is time, McLosky says—the amount of time they have to interact with their patients and keep up on issues. Primary care providers have just two and a half minutes, on average, to discuss family history with their patients. “These are rare conditions and there’s a lot to know,” McLosky says. “The genetics world is expanding so rapidly that general practitioners can’t keep up with that amount of information.”

Armed with this knowledge, the cancer genetics team, led by Debra Duquette, adult genetics and genomics coordinator at the MDCH, set out to develop a solution that would help providers quickly and
routinely incorporate cancer risk assessment guidelines into their daily practice. “A few years ago, I was thinking about what doctors could do to collect age of onset and I thought about the pregnancy wheel and how it was something that docs put in their pocket and use on a daily basis,” Duquette said. After a lot of trial and error and focus groups with healthcare providers, which they used to refine their design and complex algorithms, the cancer genetics team finished the Cancer Family History Guide, a hand-held, color-coded wheel, in 2010. The pocket tool helps providers identify who is at risk, determine the level of risk, and ensure proper screening. The primary goal of the tool, according to McLosky, “was to make it useable for primary care physicians who only have very limited time for patient visits.”

The tool works because it is simple and useable, and, most importantly, based on clinical guidelines for identifying patients at risk for hereditary breast, ovarian, colorectal, and uterine cancers. Providers like the wheel, McLosky says, “because it’s something that they can use quickly in clinic.”

The wheel has been a huge success. Other state health departments have requested the wheel by the hundreds, as well as universities, health plans, and community-based organizations. “People like them because of their simplicity,” McLosky says. “Once you know how to use it once, you will know it forever.”

Although the pocket wheel is a promising educational strategy, Duquette says that evaluating its impact on clinical practice is important, which the cancer genomics team will do through ongoing data analysis. “With provider education, it’s hard to know if it truly changed provider habits and practice,” Duquette says. In other words, getting the tool into providers’ hands is only a first step; ensuring that they use it correctly and consistently to assess their patient’s risk levels and needs for further genetic counseling and evaluation is the ultimate goal. “You hear from providers that they use it in clinic,” Duquette said, “but I would like to know that it’s truly getting high-risk people where they need to be and saving healthcare dollars.”

The cancer genetics team uses surveillance data to drive other provider education activities aimed at increasing appropriate screening and testing. For example, the team works with the state cancer registry staff to disseminate information to providers throughout the state. The cancer registry identifies individuals at risk for inherited cancers and sends a packet of information with the number of patients, along with national guidelines and resources, to each healthcare facility in Michigan. According to Duquette, “This is the first time that any of these local cancer registries [at hospitals and universities] have ever seen anything come back from the state” about their specific local data.

Each packet includes an offer of technical assistance by MDCH staff, which they deliver through lunchtime learning or grand rounds. McLosky describes an interactive approach to educating providers about cancer assessment and management. Using an electronic audience response system, McLosky or another cancer genetics staff member describes a hypothetical case and asks a classroom of providers to choose how they would make decisions about their care. “It’s a ‘Choose Your Own Adventure’ approach to cancer management,” McLosky says. As providers make decisions, she adds, “the outcomes for the hypothetical patient change based on what management path was chosen.” According to McLosky, they
run through the first exercise without the pocket tool and the subsequent exercises with it so that the providers can learn to use the tool to make evidence-based decisions.

**Using Data and Partners to Achieve Policy Goals**

In addition to educating providers, the cancer genomics team also focuses on the policy levers that support or impede appropriate screening and testing. In their 2008 cooperative agreement with the CDC, the MDCH identified two goals that drive their policy development work: increasing what is known about the current status of health insurance policies for breast and ovarian cancer genetic testing and increasing the number of health plans that have policies consistent with United States Preventive Services Task Force (USPSTF) testing guidelines.

As a first step, Duquette says that they needed to know more about what health plans currently covered. The MDCH contracted with one of Michigan’s health plans, Priority Health, to assist with surveying health plans about their insurance policies for genetic testing. According to Duquette, enlisting a health plan “champion” from the private sector was critical: “You’re not getting far without working with people from the health plans.”

Karen Lewis, Michigan’s health plan champion and an employee of Priority Health, worked with MDCH staff to survey all insurers to assess whether they had a policy in place related to genetic testing, and if so, how it compared to the existing national clinical guidelines. Based on her findings, Lewis, McLosky, and Duquette worked with health plans to adapt existing policies or adopt new policies that reflect USPSTF guidelines, and they publicly rewarded plans with model policies.

As an employee in a private plan, Lewis says it was very important to underscore that the model policy not only benefits members’ health but also benefits the health plans: “We are able to show that this is beneficial from a cost standpoint in a good way—it helps providers identify at-risk patients, and it eliminates referrals and testing for those people who don’t have risk factors and shouldn’t get limited resources.” In other words, aligning health plans with best practice guidelines not only improves health for members, it also makes sense financially. “It’s a win-win,” Lewis says.

**Moving Forward**

Now in its third year of a three-year cooperative agreement with the CDC, Michigan’s cancer genomics work is well-established and has laid the foundation for future work in cancer genomics. According to Duquette, data and surveillance will continue to play a central role in defining the program’s goals and strategies, with an emphasis on using the cancer registry to deliver targeted outreach and education to healthcare providers and patients: “It’s important to build bridges with the cancer registry. It’s a source of existing data with genomics written all over it.”

**For more information on Michigan’s public health genomics and partner resources:**

Michigan Department of Community Health
MDCH Public Health Genomics Program
http://www.michigan.gov/mdch/0,1607,7-132-2942_4911_4916_47257--,00.html

MDCH Public Health Genomics Program: Publications and Presentations
http://www.michigan.gov/mdch/0,1607,7-132-2942_4911_4916-171715--,00.html

MDCH Cancer Family History Guide
http://www.michigancancer.org/AboutTheMCC/WhatsNew-CaFamilyHxGuideRisk-AssessTool.cfm

http://www.michigan.gov/mdch/0,1607,7-132-2942_4911_4916-223425--,00.html

Adult Genetics and Chronic Disease Cancer Family History Guide
http://www.migeneticsconnection.org/cancer%20tool.shtml

Michigan Genetics Connection Adult Genetics and Chronic Disease web page
http://www.migeneticsconnection.org/adultgenetics.shtml

Michigan Biotrust for Health
http://www.michigan.gov/mdch/0,1607,7-132-2942_4911_4916_53246-209738--,00.html

Cancer and Your Family History (Michigan Cancer Consortium)
http://www.michigancancer.org/familyhistory.cfm

Michigan Sudden Cardiac Death of the Young Surveillance and Prevention Project
http://www.michigan.gov/mdch/0,1607,7-132-2942_4911_4916_47257-241907--,00.html

Diabetes Genomics Education
http://edmodules.dpacmi.org/

Michigan Cancer Genetics Alliance
http://www.migeneticsconnection.org/cancer/

Genomics and Public Health Case Study

Michigan Association of Health Plans
http://www.mahp.org/