

Disease Registry Issue Brief

June 2010

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Executive Summary

Chronic diseases, including heart disease, cancer, and diabetes, account for seven out of every 10 deaths and affect the quality of life for tens of thousands of Iowans. In 2007, chronic diseases accounted for 68% of all deaths in Iowa. A systematic and comprehensive approach to caring for patients with chronic diseases has been shown to improve the quality of chronic care delivery.

A disease registry can be an effective tool for providing this systematic and comprehensive care, and provides an introduction for many providers about how to effectively integrate and use health information technology in care settings. It is a cornerstone to effectively implement the medical home model and is crucial in the management of patients with chronic diseases. When using a disease registry, providers are able to track their patients individually and by population subset, which allows them to provide proactive care and treatment to individual patients or groups of similar patients.

Iowa's Health Care Reform legislation, [House File 2539](#), has tasked the Iowa Department of Public Health (IDPH) with coordinating the activities of several key advisory councils charged with making recommendations to improve the health of Iowans. This issue brief on disease registries was collaboratively developed by Iowa's Prevention and Chronic Care Management Advisory Council, Medical Home System Advisory Council, and Electronic Health Information Advisory Council. The issue brief is targeted toward providers, payers, policy makers, and other stakeholders to summarize the definition of a disease registry and describes how registries and registry tools interrelate with electronic health records. The issue brief also provides improvement strategies and recommendations for promoting clinic-based and population-based registries to improve quality of care delivery.

Definition of a Disease Registry

A disease registry is a database that contains information about people diagnosed with specific types of diseases. The registry collects information that can be used for capturing, managing, and organizing specific information for a population of patients. Disease registries are either clinical-based or population-based.

Clinic-Based Registry

A clinical-based disease registry contains data on patients with a specific type of disease diagnosed and treated at a practice, which allows care team members to proactively manage patients with chronic diseases.

Population-Based Registry

A population-based disease registry contains and tracks records for people diagnosed with a specific type of disease who reside within a defined geographic region (i.e., a community, city, or statewide).

Benefits of a Registry

A disease registry is a powerful tool that can drive significant practice change and improve the health of the patients being served. They offer the provider, patient, and community a variety of benefits. Disease registries:

- enable the provider to ensure that all their patients are getting proper care
- track the progress of high-risk patients
- identify the need for follow-up services
- increase quality of care and improve patient outcomes
- empower patients to take an active role in their treatment
- coordinate care and identify gaps
- increase public awareness and prevent chronic diseases
- support the [Chronic Care Model](#) and [Medical Home Model](#)
- incorporate consensus guidelines for disease management
- determine best practices and support evidence-based care

“The registry is the cornerstone of chronic disease management and the Chronic Care Model.”

- ACT report

Considerations

Iowa should carefully weigh the following factors when developing a statewide chronic disease registry:

- ability to interface with Electronic Health Records (EHRs) - pending legislation from the U.S. Department of Health and Human Services will likely require registry functionality within EHR systems as part of the EHR certification process
- incentives for providers to purchase and use a registry tool
- funding for a statewide registry (e.g., costs to develop interoperability standards for vocabularies, data elements, datasets and an interface with the statewide health information exchange; and the resources to analyze the information and make actionable recommendations)
- where the statewide registry will be housed and managed
- sustainability issues maintenance and adapting to future needs
- legal issues of confidentiality and who has access to the data
- communication and outreach to educate providers about registries and EHRs

Electronic Health Records and Registry Tools

Nationally and throughout Iowa, providers are being encouraged to adopt electronic health records (EHR). EHRs are used to store patient information electronically, rather than relying on traditional paper records. EHRs are necessary to enable the electronic exchange of information (e.g., through a secure statewide health information exchange). EHRs can support improvements in quality of care, patient safety, and care coordination. Registry tools generally manage a much smaller amount of patient information than an EHR and may be easier to use when managing information for a targeted group of patients. Some EHRs have a registry function and for those that do not, software can be used to connect registries and EHRs. This provides the benefits of EHRs and registries while eliminating the need to enter data more than once (e.g., in the EHR and in the registry).

Recommendations

- **Iowa should promote clinical registries and a population-based chronic disease registry capable of measuring multiple health conditions or services. The registry tools should be integrated with EHRs and have ease of use and multiple applications for disease reporting and population management.**
- **Build the statewide chronic disease registry incrementally by selecting a small number of high priority diseases initially, and accommodating additional diseases in the future.**
- **Pursue national standards for chronic disease reporting measures such as [National Committee for Quality Assurance \(NCQA\)](#) or [Physician Quality Reporting Initiative \(PQRI\)](#)**
- **Determine best practices for use of population based information obtained from the registry that will encourage prevention, intervention, and evaluation of chronic diseases.**