Rural Policy Brief

Chronic Disease Management Systems (Registries) in Rural Health Care

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Purpose

Health care quality is being addressed from a variety of policy perspectives. The 2001 Institute of Medicine report, *Crossing the Quality Chasm*, calls for sweeping action involving a five-part strategy for change in the U.S. health care system.[1] This agenda for change includes use of evidence-based approaches to address common conditions, the majority of which are chronic. A Chronic Disease Management System (CDMS), or registry, is a tool that helps providers efficiently collect and analyze patient information to promote quality care for the rural population. CDMSs can provide a technological entry point for the impending use of Electronic Medical Records.

A CDMS is a patient-centered electronic database tool that helps providers diagnose, treat, and manage chronic diseases. The purpose of this brief is to discuss the different types of CDMSs used by a sample of 14 state organizations and 19 local rural clinics in Maine, Nebraska, New Mexico, South Carolina, Washington, and Wisconsin.

As part of a larger study examining the challenges and innovations in implementing disease management programs in rural areas, we conducted interviews with national, state, and local contacts. During interviews, respondents helped us understand the usefulness and functionalities of commonly used CDMSs in rural facilities. Our focus was on the use of CDMSs in the management of diabetes, a disease prevalent in rural populations.

Key Findings

- CDMSs are readily available to rural clinics and are being implemented and maintained by clinic staff with minimal expenditures for technology.

- Use of a standardized system in a collaborative helps provide data comparisons and share costs involved with technical assistance services across the group.

[1]Institute of Medicine, Committee on Health Care in America. (2001). *Crossing the quality chasm: A new health system for the 21st century.* Washington, DC: National Academy Press.

Chronic Disease Management Systems

Health care providers use CDMSs to electronically capture and track specific processes and outcome indicators related to the care of a patient diagnosed with a chronic disease. A highly functional system is capable of the following:[2]

- Providing reminders at the point of care to prompt the care team to deliver recommended care
- Generating exception reports that provide information about patients who are overdue for care or have clinical outcomes that indicate the chronic disease is not being managed effectively
- Providing patients with graphs and charts of critical indicators to motivate and aid in self-management
- Tracking facility-wide and provider performance consistent with evidence-based guidelines
- Measuring the effectiveness of the clinic's disease management program through outcome indicators
- Providing a record of care for communication across interdisciplinary teams and providers
- Interfacing with the information systems of ancillary services such as laboratory and billing

The following CDMSs were being used in rural diabetes management programs according to our interview respondents:

- Diabetes Electronic Management System (DEMS) and Chronic Disease Electronic Management System (CDEMS)
- Patient Electronic Care System (PECS)
- Program-sponsored CDMSs
- Custom CDMSs

Diabetes Electronic Management System and Chronic Disease Electronic Management System

Developed by the Washington State Diabetes Prevention and Control Program and released in 1999, DEMS was designed specifically to manage diabetes. An interview respondent offered the following background on DEMS:

> *"The Department of Health here, the Diabetes Prevention and Control Program, developed the registry that is used by the National Health Disparities Collaboratives for community health centers, and so our state department here developed our own registry, and it continues on today. We have over 40,000 people in the registry. . . . Most of them have diabetes. . . . Over 100 clinics [participate]."*

[2]Simon, J., & Powers, M. (2004). Chronic disease registries: A product review (prepared for California Healthcare Foundation, May 2004). Retrieved January 13, 2005. http://www.chcf.org/documents/chronicdisease/ChronicDiseaseRegistryReview.pdf

The Washington State Diabetes Prevention and Control Program released CDEMS in 2002 as a more flexible outgrowth of the DEMS system that customizes measures and incorporates other chronic diseases such as asthma, cardiovascular disease, and depression.

Both DEMS and CDEMS have the same basic functions, including the following:

- Store demographic information, visit dates and vitals, medications, diagnoses, services, labs, and notes.
- Produce reports of lab histories and graph selected measurements including lab results.
- Interface with selected laboratory systems.
- Generate patient-specific reports that can be used at the point of care to reinforce evidenced-based care.
- Provide reports to support patient self-management.
- Generate additional reports to measure provider and clinic compliance with recommended care indicators.

> DEMS and CDEMS applications are available free of charge and require a PC with a Microsoft Windows 98 or later operating system. Microsoft Access, a database application included in the Microsoft Office Suite, is necessary to run the software, although working knowledge of the program is not required. In addition, users must have Internet access to download program files and upgrades and to receive technical assistance through the program Web site.

Clinics using DEMS or CDEMS benefited from the applications' ease of use and reporting capabilities. Collaborative groups were able to standardize reporting to compare results between facilities. Although it is possible, none of the clinics we spoke with had integrated any other ancillary systems, such as laboratory and billing, with DEMS or CDEMS. A user's group and technical support is provided through the CDEMS Web site.

Users' Perspectives of DEMS

"It [DEMS] is fantastic. I would absolutely hate it if I knew [they] were going to take this away from me."

"The collaborative, this large quality improvement project [requires] that teams have a registry, a way of gathering population-based data. . . . They can choose any registry they want. CDEMS happens to be open source code, which means clinics can do anything they want to it. It's also free, free, free, free, free, and so is the technical assistance, so it makes it attractive."

Patient Electronic Care System

Patient Electronic Care System, or PECS, is a software program developed by the Aristos Group in cooperation with the Bureau of Primary Health Care and the Institute for Healthcare Improvement. The system was originally developed to specifically support the data needs of publicly funded community health centers participating in the National Health Disparities Collaboratives (HDCs). These collaboratives focus on patients with diabetes, cardiovascular disease, asthma, depression, cancer, and preventive service needs. PECS is modeled after the original registries (DEMS, CVDEMS [Cardiovascular and Diabetes Electronic Management System]) used in the beginning years of the collaborative program (see http://www.pecsusers.net/about.asp).

PECS has the same basic functions as DEMS. Unique PECS characteristics include the following:

- Facilities enter data and build reports through the Health Disparities National Reporting Web site (www.HDNR.org).
  - This site is only available for participating facilities with a user name and password.
- Members gain the benefit of being able to access the reporting Web site to compare their results to those of other similar clinics.

> PECS can be run on a stand-alone PC desktop with a Windows 2000 or later operating system. It can also be run through a client/server environment with Windows 98 SE or later, and the server on Windows NT4 sp5 or later and Microsoft SQL Server 7 or later. To access the reporting Web site, facilities must be able to connect to the Internet. At the time of our study, PECS was available free of charge only to clinics involved in an HDC. PECS is now available for purchase through the Aristos Group, Inc.

Respondents in our study indicated that belonging to the collaborative and using PECS is an advantage for chronic disease management programs at federally qualified health centers.

Users' Perspectives of PECS

> *"They [CHCs] do have Internet capabilities and certain programs that will be able to manage the PECS program. There will be some adjustments as far as the computer infrastructure. There are health centers that may have one computer at the front desk, so once they get into the Health Disparities Collaborative, they want the whole team to have e-mail and a computer. So there is some need to expand that."*

"We also align them with this patient registry called PECS. . . . It [PECS] allows you to look at the measures and facilitate it with diabetes. So, for example, it may be that a patient comes into the clinic [who has] been diagnosed with diabetes and . . . the PECS system . . . says, 'Okay, you've got a patient with diabetes. Have they gotten the test for A1C? If they have received that test, did they get a second one within a certain amount of time?' The overarching . . . concept of this entire process of quality improvement or quality management is making sure that you are providing the services that [patients] need."

"Once they get set up, as you know, those registries are wonderful because of the materials they can extract and the way that they can practice . . . they can be so much more proactive. It's very helpful. It's worth all the time and grief in entering data. PECS will do graphs for you, such as all the diabetic patients within the last year or all of the A1Cs."

Program-Sponsored Chronic Disease Management Systems

Membership in a collaborative such as the HDC can help secure hardware, software, and support for technology. Some disease management programs recommend or require a specific CDMS. For example, the HDC requires that participants in their program have a CDMS and strongly recommends PECS. Having a standardized system facilitates sharing knowledge and comparing results against other program participants. Technical assistance through help lines, remote technical assistance, or on-site technical assistance is often provided free of charge for clinics using a program-sponsored CDMS.

The involvement of a quality improvement organization (QIO) in a CDMS varies from state to state. No standard software program is required, recommended, or sponsored. A custom CDMS developed by one state QIO provides uniform data collection for clinics participating in quality improvement efforts. Participants send discs containing quarterly data downloaded from their PCs to the QIO for analysis. Data are compiled into reports that are shared with medical staff and then aggregated for comparison purposes. Use of the system is voluntary, and technical assistance is available with installation, implementation, and maintenance. Limited resources have prevented the QIO from providing the level of assistance desired, and they will no longer be starting clinics on the program.

"In terms of understanding, in the beginning . . . states were each developing their own [registry] and now there is some thought or discussion around adopting one more [registry] uniformly across all places. We, as a QIO, are thinking, do we push these clinics . . . to [use a QIO sponsored product] when in another 12 to 18 months, CMS is going to come down and say[they] have a better tool?"

Other QIOs view their collection of confidential CMS billing data and its subsequent analysis as a tool to determine if facilities and doctors are following specific clinical guidelines for the Medicare population. These data are beneficial for quality improvement guidelines, but the delay in reporting may not actually reflect what is currently happening.

> *"We do not collect that [patient data] directly from clinics. That data is their billing data that's actually submitted to CMS for reimbursement. That data is provided to QIOs to support the process of driving quality."*

> *"Our data is updated quarterly, and we've got about a nine-month lag on the data, like what we have now with data was billed nine months ago. . . . But that's much better than it used to be. . . . It used to be a two-year lag time."*

Asked whether the QIO relays info back to the clinic, one respondent answered as follows:

> *"We do, we definitely do, because we feel like not knowing is an awful thing. You need to know or there's no incentive to do anything if everybody can go merrily through their lives thinking, 'Oh we do great, oh yeah, every one of our patients, diabetic patients, get everything they need. I'm 100% at everything.' So we actually . . . mail a letter out. . . . We have a physician on staff who writes each doc. . . . We do a letter and we enclose each physician's own personal data so they can see that for themselves. . . . If they have any questions about it, they're welcome and invited to call our physician or one of our epidemiologists.*

State physician-hospital organizations (PHOs) also have a stake in sharing data and improving quality within their region. A custom CDMS standardizes their data collection and provides the ability to give feedback to physicians to compare and improve their practices. Group collaboration also promotes cost-sharing of technical and administrative assistance.

> *"The registry is something that is really driven by the PHO. The PHO said, 'We're doing this.' So . . . 95% of the practices are doing it. And we're using that as a way to access the clinical data around participants in our program. . . . Anybody can enroll in different aspects of the diabetes care initiative here, and 95% of the practices are participating in the disease registry, so most of the people are covered."*

One state Medicaid program developed a diabetes disease registry system that uses claims and pharmacy data processed through an algorithm to determine persons who are clinically diagnosed with diabetes. The patient's claims are then examined to identify if certain diabetes quality measures are being met. If not, the practitioner and/or person with diabetes is notified. The system also aggregates data to determine individual facility guideline compliance compared to others in the state.

"What we will be doing is providing actual diabetic and some other chronic diseases expertise, really the latest cutting-edge care, talking to people in the clinics that participate in this initiative as well as providing a web-based registry for them to be able to be more proactive [in] population-based management of their diabetic patients. . . . Hopefully, we can move into other areas of chronic care . . . but our major focus will be . . . diabetic care. We are hoping to provide that to [state-level group] as a service . . . at no cost to them. We are in the planning stage of this."

There's no sense in any practice having six or seven different registries, and the one that we'll be working with them on . . . can . . . integrate . . . most all the chronic diseases. . . . This company [is] headed up by a physician that's actually been working pretty closely with CMS folks . . . to develop a registry that CMS could then hand down to QIOs to hand down to physicians. . . . There's a couple of really good Web-based ones available, and DocSite seems to be an excellent system. We've done a lot of research into it; the cost is minimal, and we feel like we can help pick that up to get a good pilot going."

Custom Chronic Disease Management Systems

Small clinics can successfully build their own CDM, or registry, with spreadsheet and/or database software. Microsoft Office products such as Excel (spreadsheet software) and Access (database software) are popular choices for customized data tracking. Created by staff members who enjoy working with computers and data, applications range from simple to complex. Time consuming chart abstraction can be replaced by flexible data queries that allow for the monitoring and communication of quality improvement activities. Potential drawbacks to a custom registry are the lack of standardization for reporting and the inability to collaborate and benchmark with other facilities.

"The way we track is we have a special form design, and our secretary . . . inputs [the data], and anytime I . . . want to know anything, I just ask her for that printout and . . . I know how many have had their hemoglobin A1C, or where they are with their classes, or whatever. So it's an in-house system that she [the secretary] formatted."

"The diabetes educators also have a registry in the Oracle database, and we created that as well. So they're able to track preimposed hemoglobin A1Cs and how many patients finish the program. There's a limited number [of measures] that they gather, but they're able to look at how many patients at each of the centers are in the diabetes education program and how many haven't been through diabetes management education, and they do outreach to those patients . . . . The only people who handle the educator's registry are the educators, and they fill out a sheet. It's really just like using DEMS. You have your encounter sheet, you make your checkmarks and fill in the info, and then it goes to someone for data entry."

Discussion

Rural clinics are beginning to feel increasing pressure to implement some type of electronic disease management system. Successful implementation, use, and sustainability of simple CDMSs have helped introduce technology into small rural clinics and have positively impacted chronic disease management programs.

Fear about the challenges of integrating data between CDMSs and electronic medical records could negatively influence the adoption rate of CDMSs. Facilities may choose to wait to implement any type of CDMSs in hopes of an all-encompassing system. Unfortunately, this delay could lead to data collection inefficiencies and stall quality improvement efforts that benefit from data accessibility and timely analysis.

> *"We [the state] are trying to implement some electronic medical records. One of our health centers already has Logician and several of the other health centers have decided that they are going to try Nexgen, and it is going to be phased in over a couple of years, so some are in the first phase and some are in the second phase. I think there are a total of eight health centers that will be implementing an electronic medical record in a year and a half to two years. A lot of people were hesitant. They said, 'If we're in the Health Disparities Collaborative and using PECS, then we won't be able to use EMR,' but it will transfer to PECS."*

Finally, it is important to remember that a CDMS is just one component of an effective disease management strategy. Simply implementing an electronic disease management system without changing clinical processes, incorporating interdisciplinary services, and involving the patient will not lead to effective and sustainable change.