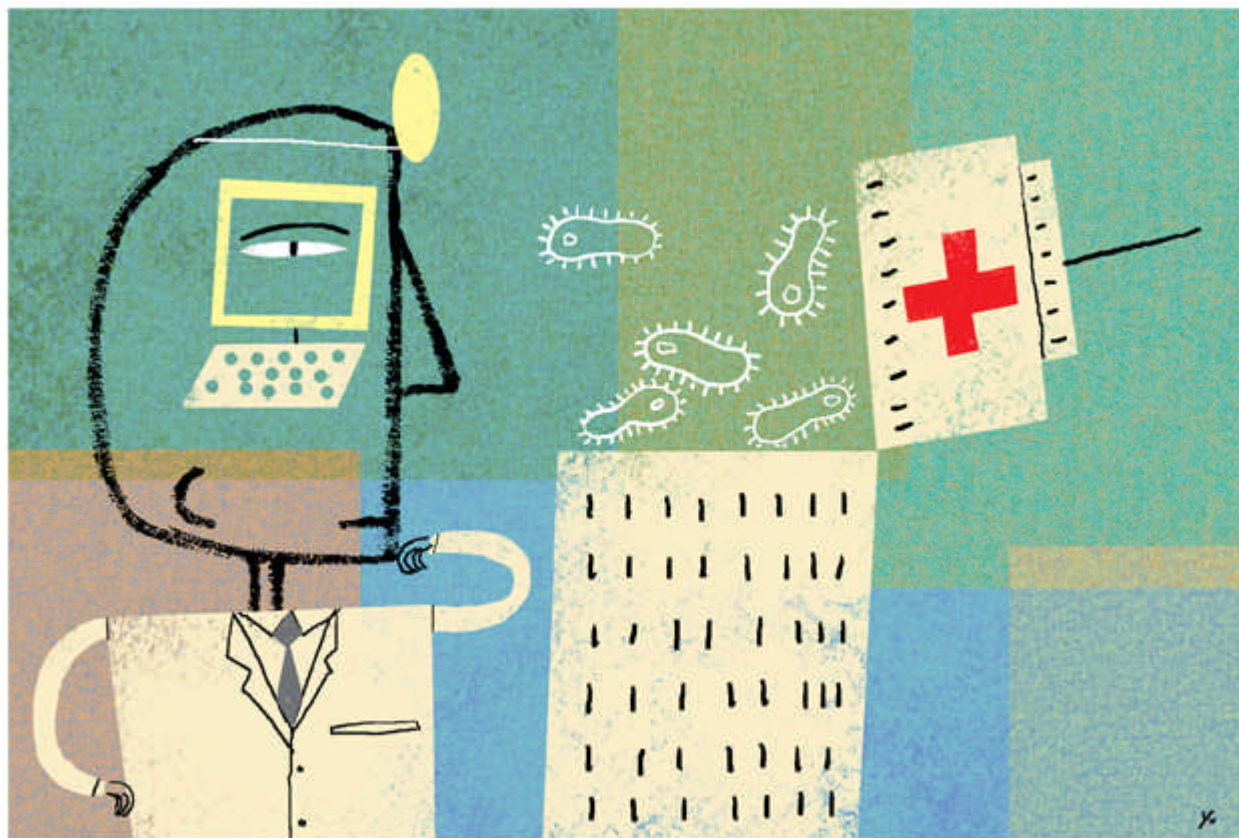




CALIFORNIA  
HEALTH CARE  
FOUNDATION



## Chronic Disease Registries: A Product Review

 **ihealthreports**

Prepared by NAS Consulting Services  
May 2004

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# Chronic Disease Registries: A Product Review

*Prepared for:*

CALIFORNIA HEALTHCARE FOUNDATION

*Prepared by:*

NAS Consulting Services

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## Acknowledgments

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### About the Foundation

The **California HealthCare Foundation**, based in Oakland, is an independent philanthropy committed to improving California's health care delivery and financing systems. Formed in 1996, its goal is to ensure that all Californians have access to affordable, quality health care. For more information, visit us at **[www.chcf.org](http://www.chcf.org)**

This report was produced under the direction of CHCF's Chronic Disease Care Program with support from the Health Information Technology group. The Chronic Disease Care Program seeks to improve the health of Californians by working to assure those with chronic diseases receive care based on the best scientific knowledge. Visit **[www.chcf.org/programs](http://www.chcf.org/programs)** for more information.

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# Executive Summary

CHRONIC DISEASES ARE PLACING A GROWING burden on the health care system in the United States. As a result, provider organizations are seeking new strategies for effectively managing these large and expensive populations. Computerized disease registries are one tool being used to support care management efforts for groups of patients with chronic diseases. These tools capture and track key patient information to assist care team members in proactively managing patients. Specifically, they provide:

- Printed patient reports used at the point of care to communicate condition-specific information and prompt physicians and their teams to deliver recommended care;
- Exception reports to identify patients overdue for care or not meeting management goals; and
- Progress reports to provide information about how well individual providers and overall organizations are doing in delivering recommended care to specific patient populations.

This report evaluates 16 computer registry applications and is intended to assist physician and provider organizations interested in purchasing a registry product. The products are divided into two categories: public domain software and commercial software. Public domain software is the most prevalent type of registry software in use today. The majority of these products are developed by Quality Improvement Organizations (QIOs) in various states, with one of the most widely used products being the Diabetes Electronic Management System (DEMS), and derivative products in the DEMS family. DEMS was initially developed by the Washington State Diabetes Prevention and Control Program (funded by the Centers for Disease Control) and then adapted by the Bureau of Primary Health Care (BPHC) to be used by federally qualified community health centers participating in the national Health Disparities Collaboratives across the country. The most beneficial attribute of the public domain products is the fact that they are free and have been used in a variety of settings.

Five commercial products are also profiled in this report. The major advantages of the commercial software over the public domain tools are a more sophisticated and scalable architecture, tech support (e.g., upgrades and help desk), and more robust

functionality including patient education tools and point-of-care tools such as messaging and reminders. A glossary that defines some of the technical terms used in the report can be found on page 40.

The sixteen products were evaluated along eight key decision-making criteria: Patient vs. disease focus, ease of use, market penetration, customizability, ease of set up, import or interface capability, scalability, and cost. Registry selection depends upon which of these criteria are most critical to the organization. If upfront/purchasing costs is the key consideration, two public products stand out—CDEMS, a more customizable variation of the DEMS product and the Chronic Disease Management System (CDMS), a Web-based registry tool that was developed by the Mountain-Pacific Quality Health Foundation. For organizations able to make a more substantial monetary investment, PatientPlanner by DocSite<sup>SM</sup> rated highly on all criteria. In addition, the Delphi Diabetes Registry rated high and is appropriate for organizations seeking a product specifically tailored for diabetes.

# I. Introduction to Chronic Care<sup>1</sup>

CHRONIC CONDITIONS SUCH AS DIABETES, asthma, and coronary artery disease are the major cause of illness, disability, and death in the United States. In 2000, the medical cost of chronic disease amounted to 75 percent of health care spending.<sup>2</sup> Interest in a more systematic approach to managing patients with chronic disease is being spurred by a growing awareness of the inefficiencies in delivering care to patients with a chronic disease. Appropriate and timely care can prevent chronic disease altogether and delay or avoid many of the complications associated with the diseases.

*In Crossing the Quality Chasm*, the Institute of Medicine (IOM) concluded, “The current delivery system responds primarily to acute and urgent health care problems... Those with chronic conditions are better served by a systematic approach that emphasizes self-management, care planning with a multidisciplinary team, and ongoing assessment and follow-up.”<sup>3</sup> The IOM also emphasized the importance of “good information about patients, their care, and outcomes in order to improve outcomes.”

By tracking key patient information, a disease registry helps physicians and other members of their team identify and reach out to patients who may have gaps in their care. It also reminds them to do the right things during patient visits. Paper registries have been used in the past to track important information about conditions such as cancer. Computerized systems for managing the necessary patient information have the advantage of quickly providing the information necessary to support chronic care, including reminders during encounters, lists of patients needing follow-up, and reports providing feedback to physicians about how well they are doing with their patients. Systems also provide feedback to patients about how well they are self-managing their care.



## **Purpose and Scope of Report**

This report is intended to help physicians, medical groups, and other organizations considering the purchase of an electronic registry application. The report provides an overview of the types of electronic registry products that are publicly and commercially available and describes fifteen of those products in detail. The report outlines a number of decision criteria that are important for purchasers to consider in choosing a product and provides details about which products are best for certain types of organizations.

The focus of this report is stand-alone registry software products. While some electronic medical records and practice management systems are capable of supporting registry functions, those products were not reviewed for this report. In addition, while many organizations choose to build registry software themselves, this type of strategy was not evaluated in depth.

Finally, registry software products typically do not have fully automated data integration capabilities, including the ability to normalize, integrate, and match data from disparate sources. This product review does not evaluate supplementary software databases, patient matching software, and other interface technologies that are necessary to support a fully automated disease registry.

## II. Overview of Computerized Disease Registries

A COMPUTERIZED DISEASE REGISTRY IS ONE TYPE of clinical information system that is effective in supporting organized care management. A registry can assist physicians in three key processes for managing chronic disease:

- **Printed patient reports** used at the point of care communicate condition-specific information and prompt physicians and their teams to conduct appropriate assessments and deliver recommended care.
- **Registry-generated exception reports** identify patients who have missed appointments, are overdue for care or are not meeting management goals. Reports provide information to aid in reaching patients (outreach) and helping them meet goals (compliance).
- **Progress reports** provide information about how well individual care teams and overall provider organizations are doing in delivering recommended care to specific patient populations.
- **Stratified population reports** separate patients into various categories of risk in order to target interventions at the patients with the highest needs.

Computerized registries generally require a database to store integrated patient information and a software application that can sort the information into different views and reports, as described above. One major drawback of current registry software is that most products do not have the capability to normalize, integrate, and match data from disparate electronic sources. Instead, most registry software manages electronic data that has already been integrated, or requires manual data entry.

Registries are different from electronic medical records (EMRs) in that they manage only selected information relevant to one or more chronic diseases, rather than containing more comprehensive information about patient problems, health history and care. Further, the registry is generally not the legal documentation of care provided to the patient.

For more information on disease registries, see *Using Computerized Registries in Chronic Disease Care*. The report provides an overview of the function and use of computerized disease registries and outlines issues for consideration in obtaining registry software and integrating registry products into the routine work of the physician practice. It can be found at [www.chcf.org/topics/view.cfm?itemid=21718](http://www.chcf.org/topics/view.cfm?itemid=21718).

### III. Considerations in Disease Registry Selection

WHICH TYPE OF REGISTRY SOFTWARE TO implement is a decision that must be informed by several factors. It is not uncommon for a provider organization to select a registry product and subsequently find that it is not appropriate for their patient population or does not synchronize with their organization's strategy or capabilities. This can result in expensive and time-consuming registry modifications or may require discarding the registry and implementing another product.

To prevent poor decisions, organizations should carefully weigh the following factors as they choose their registry:

- 1. Overall disease management strategy.** A registry is just one component of a comprehensive disease management strategy. A systematic and comprehensive approach to disease management includes a range of interventions, such as case management, physician feedback, clinical information systems to track patient care, adoption of clinical practice guidelines, outreach to patients who need to come in for care, and a focus on patient self-management skills. Relying on a registry to improve care without changing care-management functions is unrealistic and may lead to disappointment and frustration after registry implementation. The organization should also consider any long-range plans for technical expansion, such as plans to implement an EMR, and how the registry will synchronize with these efforts. For some organizations, registries may be considered a transitional technology until they implement an EMR with full-registry functionality. These organizations should choose the least-costly options in registries with an eye toward the future.
- 2. Direct vs. indirect costs.** The direct, monetary costs of the registry product are not necessarily the most significant costs associated with the product. Setting up and managing a registry requires a substantial labor effort that cannot be minimized. Implementing the system itself will require technical and programming support, possible hardware costs and training personnel how to utilize the registry. In addition, "selling" the registry to frequently independent-minded physician users can be the most labor-intensive portion of implementation. Finally, inputting data into the registry will have varying costs

depending on whether it is manually entered by staff or automatically downloaded through data streams.

**3. Data management.** One of the most significant efforts needed to maintain a registry is collecting, integrating and managing data. Provider organizations must decide which data sets will be incorporated into the registry (i.e., laboratory, pharmacy, encounters), and how the data will actually enter the registry. If data is automatically downloaded, relationships must be formed and cultivated with outside data sources such as laboratories. If data is manually entered, staff must be identified who will consistently enter data into the registry. For registries to be used in a meaningful way, data quality is of utmost importance. Providers expect data to be current, accurate, and useful, and will often reject reports that are perceived to be based on inaccurate data.

**4. Return on investment (ROI).** A careful accounting of project costs is important before acquiring any software, be it public domain or commercial. Costs often overlooked are those related to establishing interfaces with external systems, as well as maintenance, data entry, and the necessary investment in implementation, primarily training and process change. For clinical systems such as chronic disease registries, there are rarely enough financial benefits to offset all the costs. California's "Pay for Performance" initiative may provide an opportunity to recoup some of the investment; however, factoring this into the value proposition requires information about numbers of patients and an estimate of potential incentive payments.

## Registry Types

Provider organizations must weigh each of these approaches carefully when deciding which type of software product to implement. Organizations may choose to build their own registry, download public domain software, or purchase commercial registry software. A brief overview of each registry type follows; however, this product review will focus on facilitating the choice between public domain and commercial registry software products.

## Building a Custom Registry

Many provider organizations choose to build their own registry rather than use existing software tools. These "home grown" registries take a variety of forms. Some groups create registries using Microsoft Access or Microsoft Excel, while others utilize their internal data warehouses to create a registry.

## Major Benefits:

- **Organizational control**—The builder retains complete control over the registry's functionality and data. There is also no risk associated with a potentially unreliable or unresponsive external vendor.
- **Product flexibility**—When the organization is ready to change registry products, data from these solutions can be easily imported into many existing registry software products or into an EMR.
- **Cost**—For those organizations with limited resources, building a custom registry can allow for tighter control of up-front costs. Organizations can be selective about functionality based on internal development resources available.

### Major Obstacles:

- Internal technical capacity—The builder is constrained in upgrading the product by the availability and skill of internal technical resources. For example, organizations that choose to increase the number of chronic conditions managed with registries may find the project requires substantial internal information technology (IT) resources.
- Software limitations—The typical solution relies on a Microsoft Access database and either addresses one chronic condition or multiple conditions in separate registries. It typically includes only a small number of stored queries available to generate reports.
- Duplication of effort—Organizations may be trying to solve data management challenges that have already been addressed and solved by others.
- Data security—Requires local management of data access and mechanism for regular back up.
- Time—Development time will prolong the time to implementation.

### Public Domain Software

Public domain software—which is available for use by the general public without licensing or fees—is the most prevalent type of registry software in use today. The majority of the products were developed by Quality Improvement Organizations (QIOs) in various states. One of the earliest products, the Diabetes Electronic Management System (DEMS), was developed by the CDC-funded Washington State Diabetes Prevention and Control Program. This product's success quickly spread to other organizations and QIOs, who created numerous variations of the original product.

The public domain tools are primarily simple software programs based on Microsoft Access. The tools usually do not have sophisticated architecture or in-depth functionality.

### Major Benefits:

- Cost—The greatest advantage of the public domain tools is that they are free. Many can be downloaded from public Web sites.
- Straightforward technology—The tools are relatively simple to use and do not require a significant information technology infrastructure. Limited support is needed, although many QIOs offer training and support for their software in their own state.
- Community support—Numerous chronic disease collaboratives utilize various public domain tools. Participation in the collaborative provides users with training and other registry support. The DEMS Web site also has an online community for support.
- Product testing—Many of these tools have been thoroughly tested in a provider organization setting. The feedback from these implementations has resulted in products with few bugs and the registry contains many of the features found to be most critical to provider organizations.

### Major Obstacles:

- Manual data entry—Few public domain products have real-time interfaces to lab or encounter systems and therefore have a strong reliance on manual data entry. The ability to import data electronically on a periodic basis is also limited.
- Scalability—Many of the public domain tools are Microsoft Access-based, and, therefore, are limited to 10 concurrent users. This does not apply to the Web-based public domain tools.

- Flexibility—Some public domain products allow for very limited customization of disease management guideline parameters and pre-programmed reports
- Limited support—Many products have been developed for specific users and, while available in public domain, support is usually limited to these target organizations of the developers.

### Commercial Registry Software

A small number of vendors sell private, stand-alone registry software. For-profit entities sell their applications to provider organizations on a per-user or per-patient basis.

#### Major Benefits:

- Scalability—Commercial software often has a more sophisticated and scalable architecture than the public domain programs. A large number of users can enter or view data simultaneously and the databases are optimized for vast amounts of data.
- Enhanced functionality—These products typically have robust functionality, including patient education tools and point of care tools such as messaging or reminders, as well as flexibility to customize guideline parameters, data sets to be tracked, and reports.
- Technical sophistication—Some vendors are equipped to perform services such as building data interfaces and may be more likely to develop Web-based products in the future.

#### Major Obstacles:

- Cost—While the cost of the products varies considerably and the companies use a variety of pricing models, costs range from \$36 per patient per year to \$600 per individual user per year, which may be prohibitive for some organizations.

- Data ownership—Some commercial companies may house the data in their own database or server, with the provider group possibly having limited access to overviews of the data.
- Security—For some providers, it is important to retain all patient data in a database under local management. This may also raise concerns about security, privacy, and other HIPAA issues.
- Vendor stability—There is also real concern about the possible long-term financial stability of some vendors and their products, making it difficult to predict their future availability for support, upgrades, and modifications.
- Lack of testing—Commercial solutions have usually only been implemented in a handful of organizations, so have not yet been extensively market tested.

## IV. Detailed Product Profiles

THIS GUIDE EVALUATES 16 REGISTRY PRODUCTS, which can be divided into two categories: public domain software and commercial software. Each software product reviewed below includes an overview of functionality, strengths and weaknesses, and cost. An overview of the public domain software functionality can be found at Table 2, with commercial software functionality summarized in Table 3.

### Public Domain Products

#### 1. DEMS Product Family

*Overview:* The original Diabetes Electronic Management System (DEMS) product was developed in 1999 by the Washington State Diabetes Prevention and Control Program. A straightforward, Microsoft Access-based tool for tracking and reporting on patients with diabetes, the tool at one time was being used by 65-75 clinics in Washington State and had over 13,000 users.

The success of DEMS resulted in additional QIOs developing their own registry software for other states and government organizations. DEMS is now being phased out because a new version with greater flexibility and functionality has been developed: the Chronic Disease Electronic Management Systems (CDEMS) product. Many created variations of the original DEMS software and are actively promoting and supporting them. An overarching summary of the DEMS product family is provided below, followed by brief descriptions of the product variations. See Table 1 for a comparison of all the DEMS products.

*Functionality:*

- Patient visit note form (See sample form at Figure 1)—  
Used to view and enter data for a given patient. This form can be printed and filed in the chart and accessed during patient encounters. Different layouts are available. Types of information contained on the form are:
  - Demographics
  - Encounter information
  - Conditions
  - Services
  - Labs
  - Medications
  - Patient handout information
  - Custom (free text)

Figure 1. DEMS Patient Visit Note

ID

Last Visit

This Visit

Date mmmddy

Weight (pds)

BP-Sys/Dia

## Diabetes Visit Note

SKCN

version: 1-09-00m

LN	Firstman	FN	Hugo	Age	66	DOB	01/01/34
Address	Lands End		Phone	Sex	M	Type DM	1
PLanguage	English	Ethnicity	White	Meter		Ht	73.1
Insurance	Medicaid	PCP	Spock	DM Dx date		Mig	N
						Homeless	N

Medications	Rx	Add	D/C
Insulin	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sulfonylurea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Glucophage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Glitazones	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prandin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
AG Inhibitor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ACE Inhibitor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lipid agent	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ASA/ Coumadin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
BP Medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinic-Med	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Health Profile	Dx	Add	D/C
Cerebrovascular	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Heart Disease/CAD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hypertension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hyperlipidemia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nephropathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neuropathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
P. Vascular Dis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Retinopathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self monitors BG	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Exercise x/wk	<input type="text" value="0"/>	<input type="checkbox"/>	<input type="checkbox"/>
Smoker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinic-Profile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Refer/Ed	LastDate	PRef	Rcvd Date	Ref	Dec
DM Educ	01/98	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NutEduc	10/99	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Retinal Ex		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Smke Ce	d10/99	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pne Vac	10/99	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Flu Vac	02/98	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dental	d10/99	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
SM Goal.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Foot chk		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Foot Risk (0-3)	<input type="text" value="3"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinic-Care	01/00	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Tests	Last Value	Date	PRef	New Value	Ref
HbA1c	10	1/1/00	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MiA/Cr	35	1/2/00	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Creat	2	1/2/00	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LFT			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chol	190	1/2/00	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Triglyc	167	1/2/00	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HDL	450	1/2/00	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LDL	50	1/2/00	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24hrUP			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cl-Lab	789	1/1/00	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Date	HbA1C
01/01/00	10
10/26/99	10
10/01/98	14.3

Date	Chol
01/02/00	190
10/26/99	300
10/01/98	230

Date	LDL
01/02/00	450
10/26/99	35
10/01/98	56

Date	HDL
01/02/00	450
10/26/99	35
10/01/98	56

Date	Sys	Dia
12-30-99	140	90
12-10-99	160	90
11-23-99	124	89
10-26-99	140	75
10-01-98	150	100

Date	Wt
12/30/99	225
12/10/99	227
11/23/99	220
10/26/99	234
10/01/98	200

Date	Ser Cr
01/02/00	2
10/26/99	3.5
03/01/99	4
10/01/98	1.9
11/01/97	4

NOTE

will stop eating between meal chocolate

Next Visit Date

NEW NOTE (leave blank if no change)

Provider \_\_\_\_\_

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- Reporting—Standard reports are available at both a provider and clinic level. Users knowledgeable in Microsoft Access can write their own queries to create additional reports.
- Manual data entry—Required in most DEMS product family implementations. Data entry can be performed by anyone with access to the database—the physician, another care provider, or front office staff. Rough estimates of data entry times are three-and-a-half minutes to enter a new patient and one minute to enter data from a follow-up visit for an existing patient.<sup>4</sup>
- Import capability—Processes for importing lab data have been set up with some of the major labs in Washington State (LabCorp, Dynacare, Pathology Associates Medical Laboratories, and Quest).<sup>5</sup> Users outside of Washington State may benefit from the lessons learned in these implementations.

*Strengths:* The DEMS product family can be an appropriate option for an organization with limited technical resources to get started. It offers a simple, clean interface, requires little or no training and can be installed in a single day. The product has been extensively tested in a provider organization setting and regularly refined over a three-year period. The patient visit note is a key asset of the product as it provides critical summary information for use at the point of care, as well as longitudinal graphs of labs and vitals.

*Weaknesses:* Despite its success, the DEMS product family has several limitations. Some registries can only be used for a single condition and only a predefined set of information can be captured. Reporting capability is limited, particularly for reports of historical data. Without technical skill or advanced knowledge of Microsoft Access, the user cannot add new fields or modify reports. In addition, as with all Microsoft Access-based solutions, the tool will not scale to serve a large number of

users. Ten concurrent users entering data is the limit in Microsoft Access. As mentioned above, the need to manually enter data into the registry, thereby increasing staff time and the chance of error, is another limitation of DEMS products.

*Cost:* DEMS and CDEMS are free public domain software. The Washington State Diabetes Prevention and Control Program offers limited support to organizations outside the state.

Noted below are the primary differences between DEMS and CDEMS, as well as subsequent versions developed by other entities.

#### *CDEMS (Chronic Disease Electronic Management Systems)*

- Condition tracking—Users can choose which conditions to track and what variables are of interest for each condition. The user can also create and edit drop-down lists for faster data entry. These customizations can be accomplished through user-friendly wizards.
- Reporting—Two types of standards reports are available: Intervention reports that contain lists of patients with certain characteristics or in need of services and summary reports of clinic statistics. Summary reports are generated using a template in which the user can choose the population and parameters of interest. CDEMS also has a report wizard that allows the design of custom queries.
- Web forum—This discussion board provides the opportunity for users to pose questions, share solutions, and discuss issues relating to the DEMS and CDEMS programs.

#### *CVDEMS (Cardiovascular/Diabetes Electronic Management System)*

- Condition tracking—Ability to track cardiovascular disease as well as diabetes.

- Import capability—Data can be imported from DEMS, but the product does not have the capability to import lab or other data.
- Community support—Promoted by the Bureau of Primary Health Care for use by organizations participating in their chronic disease collaboratives. However, BPHC technical support of updating/debugging this product has ended, in favor of the new, improved BPHC registry program—the Patient Electronic Care System, or PECS.

*DEMS Lite (developed by the New Mexico Medical Review Association)*

- Interface—A more streamlined version of DEMS containing only two-thirds of the fields in the original product. The elimination of these fields has resulted in a simplified interface.
- Reporting—Addition of over 20 standard reports.

*OR-DEMS (developed by Oregon’s QIO, OMPRO)*

- Patient visit note—Enhanced version includes availability in English and Spanish, an upgraded provider version with color-coded “grades” for lab results and due dates and diabetes guidelines.
- Support—OMPRO provides support only to organizations participating in the Oregon Diabetes Collaborative.

*PHEMS (Preventive Health Electronic Management System by the Missouri PRO)*

- Preventive services—Expanded ability to track preventive services.
- Automated back-up/restore utility.
- Medication dosages and frequency tracking.
- Reporting—Includes twenty standard reports, all at a clinic or population level. Several new reports added and existing reports updated with new data fields.

**Table 1. Summary of the DEMS Family of Products**

Product	Conditions	Base Product	Key Differences
DEMS	Diabetes	Original product	N/A
CDEMS	Can be customized for any condition	DEMS	Ability to customize for any condition; enhanced reporting capability.
CVDEMS	Diabetes; cardiovascular disease	DEMS	Ability to track cardiovascular disease.
DEMS Lite	Diabetes; immunizations	DEMS	Simplified version of DEMS. One-third fewer data capture fields. Simpler interface. Additional standardized reports. New graph on patient visit summary.
OR-DEMS	Diabetes	DEMS	Added a visit summary for the patient (available in English and Spanish).
PHEMS	Diabetes; cardiovascular disease	CVDEMS	Added a prevention tracking component; added an automated Backup/Restore utility; minor data field additions (dosage and frequencies of medications, Microalbuminaria test); several new reports added and existing reports updated with new data fields.

## 2. Adult Preventive Health Services Software (APHS)

*Overview:* APHS is a Microsoft Access-based registry tool for tracking preventive services for adults, with additional modules specific to women's health and diabetes. It was developed by Qualis, Idaho's QIO.

### *Functionality:*

- Patient data—Patient demographic information, patient history, preventive services, general screening tests and immunizations, and all the major diabetes services can be tracked for a given patient.
- Clinical breast/mammogram case management—Tracks the date and results of the last exam and mammogram, follow up steps, preferred frequency of service, and the date of the next service. The pap case management component captures similar information for pelvic exams and pap smears.
- Decision support—Embedded guidelines suggest service frequency based on the patient's age and gender. Alerts are also provided if the user adds a service that may not be necessary.
- Patient information profile—Summarizes the patient's history, demographics, and services needed. A graphing capability allows the user to generate graphs for viewing lab or vital measurements over time.
- Reporting—A number of standard reports can be run at a provider or facility level. Patient information and history can be imported from a comma delimited text file, if rigid data format requirements are met.

*Strengths:* APHS' strength lies in its ability to capture in-depth information about preventive services. Particularly detailed information can be captured for mammograms and pap smears if necessary. The basic embedded guidelines are also valuable.

*Weaknesses:* This product does not offer the user great flexibility in customizing the system to meet local needs. Guidelines can be overridden but not changed at the organizational level. Modifications or customizations cannot be augmented without advanced knowledge of Microsoft Access. As with many of the DEMS-like products, import capability is limited and may result in most implementations relying primarily on manual data entry. In addition, as with all Microsoft Access-based solutions, the tool will not scale to large number of users.

*Cost:* APHS is free public domain software available through Qualis Health. While the registry is still in use at locations in Washington and Idaho, Qualis Health is no longer actively recruiting new users for the software.

## 3. Chronic Disease Management System (CDMS)

*Overview:* CDMS is a Web-based registry tool that was developed by the Mountain-Pacific Quality Health Foundation (Helena, MT). CDMS can be customized for managing populations with any condition or for tracking preventive services. The Mountain-Pacific QIO hosts the data.

### *Functionality:*

- Patient profile/patient history—Information on chronic diseases, current medications, drug sensitivities, drug allergies, clinical exams, and lab data. The patient history contains graphs of clinical exam results over time.
- Decision support—Embedded guidelines for a variety of chronic diseases (diabetes, atrial fibrillation, heart failure, coronary artery disease, hyperlipidimia, depression, asthma, osteoporosis, and preventive services). Patient due dates for tests and services are calculated based on these guidelines. Providers can

print a list of patients overdue for interventions or access a calendar view of due dates for all patients. Providers also have the ability to modify any of the guidelines for a given patient or their entire panels.

- **Reporting**—Includes reports comparing providers to each other and to national de-identified data (e.g., health information that has been stripped of elements that could identify the individual and a report that tracks the behavioral goals and other indicators required by the American Diabetes Association’s Education Recognition program (the ADA Education Recognition Program assesses whether applicants meet the National Standards for Diabetes Self-Management Education Programs and then endorses those programs). CDMS also has a generic reporting engine in which users without technical skill may define new custom reports by selecting population and indicators of interest.
- **Import capability**—Able to import data from a variety of billing systems (Meditech, IDX, Smart Practice, Medical Manager, Medical ABC). The process entails running “import agents” that extract the data from the billing systems in the appropriate format and import them into CDMS. Auto data-population function can also be performed for select formats.
- **Medicaid call center**—Telephonic outreach capability for Medicaid patients with diabetes, congestive heart failure, and asthma. Call center coordinators create clinical assessments during telephone outreach with patients.

*Strengths:* The scalable, Web-based platform provides considerable advantages over other products. Web-based access gives users the ability to access information from any facility

and eliminates problems associated with connecting multiple clinics. The ability to track multiple conditions in a single product is an additional strength. Embedded guidelines are also valuable. Finally, the product has strong reporting capabilities including a comprehensive set of standard reports and a generic reporting engine.

*Weaknesses:* The robust functionality of CDMS results in greater complexity in setting up and using the system, as well as greater training needs.

*Cost:* CDMS is free public domain software but currently only available in the following states: Montana, Wyoming, Hawaii, Indiana, Kentucky, and Rhode Island.

#### 4. Patient Care Management System

*Overview:* The Patient Care Management System is a Microsoft Access-based diabetes registry tool developed by Metastar, Inc., Wisconsin’s QIO.

##### *Functionality:*

- **Diabetes registry**—Provides the ability to track diabetes provider visits, diabetes lab work, and eye and foot exams.
- **American Diabetes Association recognition**—Adds to the diabetes registry the ability to track educational visits and self-management goals.
- **Preventive services**—Tracks vital signs, preventive labs, immunizations, and other preventive services.
- **Patient visit note**—A one-page summary of clinical and demographic information, for the provider.
- **Reporting**—A variety of population-level standard reports are available along with a limited number of provider and patient spe-

cific reports. The registry also contains the ability to generate reminder letters for patients who have not had a recent visit.

- Import capability—Demographic and lab data can be imported from a comma-delimited text file if rigid data format requirements are met.

*Strengths:* Like the DEMS products, the strength of this tool lies in its simplicity. It can be rapidly implemented and offers a straightforward user interface. The ability to track the data required for the ADA Education Recognition program is an additional strength.

*Weaknesses:* One weakness of the product is that it can only be used for a single condition—diabetes—and only a predefined set of information can be captured. Without technical skill or advanced knowledge of Microsoft Access, the user cannot add new fields or modify reports. The import capability is very limited and may result in most implementations relying on manual data entry. In addition, as with all Microsoft Access-based solutions, the tool will not scale to large number of users. As mentioned above, the need to manually enter data into the registry, thereby increasing staff time and the chance of error, is another limitation of PCMS.

*Cost:* The Patient Care Management System is free public domain software and can be downloaded from [www.metastar.com/professional/pcm\\_form\\_xp.asp](http://www.metastar.com/professional/pcm_form_xp.asp). MetaStar cannot offer support to organizations outside the state of Wisconsin.

## 5. Patient Electronic Care System (PECS2)

*Overview:* PECS2 is an n-tiered SQL server-based registry product that can be used to track clinical data for patients with any chronic disease and is currently tailored for diabetes, asthma, cardiovascular disease, cancer screen-

ing and follow-up, and depression. There are also some elements to support HIV care and prevention. It was developed by The Aristos Group, and until recently was being used exclusively by the Bureau of Primary Health Care collaboratives. It will be available commercially under the PECSYS name on March 31, 2004 (see the PECSYS product description in the Commercial Products section on page 27).

## 6. STEPS Electronic Collection and Analysis Tool (SECAT)

*Overview:* SECAT is a Microsoft Access-based registry tool for tracking preventive services and diabetes indicators. It was developed by the Iowa Foundation for Medical Care and the Illinois Foundation for Quality Health Care.

*Functionality:*

- Diabetes data collection tool and preventive care data collection tool—Used for data entry and maintenance.
- SECAT analysis tool—Case summaries of all relevant patient data, flow sheets showing recent information, and indicator reports displaying trends. Benchmark reports for diabetes indicators show clinic performance relative to national benchmarks in a bar graph format. Performance reports show clinic-level aggregate statistics relative to benchmarks in a table format.
- Data query tool—Enables the generation of customized lists of patients based on user-defined criteria.
- Patient tracking tool—Used to produce patient-specific or generic notification letters and mailing labels.
- Assignment of user rights—Levels of user rights include system administration, data entry, and viewing data only.

- Customization—Administrator can add up to six new fields to the diabetes tool and as many as 10 to the preventive care tool.
- Import capability—Data can be uploaded only if rigid data format requirements are met and a consistent set of patient identifiers is used.

*Strengths:* SECAT is a simple tool that has been well tested within the states of Illinois and Iowa. It has been refined numerous times since its initial release in 2001 based on feedback from over 75 implementations. Its strengths include some ability to customize data fields, fairly robust reporting and querying capability, and the ability to track data for the ADA Education Recognition.

*Weaknesses:* One drawback of the system is the fact that it is limited to diabetes and preventive services. While indicators within these topic areas can be added, the system cannot be customized to track patients with other conditions or, for that matter, multiple conditions of a patient with diabetes. A second weakness of the program is its limited data import capabilities. In addition, as with all Microsoft Access-based solutions, the tool will not scale to large number of users.

*Cost:* SECAT is free public domain software. Limited support is available for organizations outside the states of Illinois or Iowa.

**Table 2. Public Domain Registry Software—Functionality Overview**

Vendor	Conditions	Hosting Model	Security	Data Export/Import	Point of Care Tools	Patient Outreach Tools	Reporting Capabilities
<b>Adult Preventive Health Services Software (APHS)</b>	Preventive services*	Client server software (MS Access based**); database can be stored on a server	N/A	N/A	<ul style="list-style-type: none"> <li>• Patient summary for clinician***</li> <li>• Graphs for patient of lab values over time</li> </ul>	<ul style="list-style-type: none"> <li>• Lists of patients in need of services</li> <li>• Patient reminder letters</li> <li>• Patient data graph for take home use or educational talking point</li> </ul>	Over 25 standard reports including standards-based (HEDIS, DQIP, BCCP) population level reports. Additional queries can be written if users have knowledge of MS Access.
<b>Chronic Disease Electronic Management System (CDEMS)</b>	Can be customized for any condition	Client server software (MS Access based); database can be stored on a PC or local network server	<ul style="list-style-type: none"> <li>• No secure Web access</li> <li>• Visit notes, exception reports contain visible patient identifiers</li> <li>• Access has native tiered security system, plus network security scheme.</li> </ul>	<ul style="list-style-type: none"> <li>• Users can export any data to Word, Excel or statistical packages such as SAS or Stata</li> <li>• Data ownership resides with clinic</li> <li>• Less than 60 seconds input time per patient</li> </ul>	<ul style="list-style-type: none"> <li>• Patient summary for clinician with clinical guidelines</li> </ul>	<ul style="list-style-type: none"> <li>• Lists of patients in need of services</li> <li>• Patient reminder letters</li> </ul>	Set of standard reports; ability to generate custom statistical summary reports. No programming knowledge required.
<b>Chronic Disease Management System (CDMS)</b>	Can be customized for any condition	Web-based; data is hosted by the Mountain QIO	N/A	N/A	<ul style="list-style-type: none"> <li>• Patient summary for clinician</li> <li>• Care planner tool that contains calendar view of when patients are due for services</li> <li>• Progress Notes with automated templates</li> <li>• ePrescribe function with digital authentication</li> </ul>	<ul style="list-style-type: none"> <li>• Lists of patients in need of services</li> <li>• Reminder letters</li> <li>• Patient care plan</li> <li>• Self-management and RN-case management tools for diabetes, congestive heart failure and asthma</li> </ul>	Set of standard reports; reporting tool that allows for user-defined queries. No programming knowledge required. Can also generate reports comparing physicians to each other and to national de-identified data. Intervention and Chronic Condition Reports.
<b>Cardiovascular and Diabetes Electronic Management System (CVDEMS)</b>	Diabetes; cardiovascular disease	Client server software (MS Access based); database can be stored on a server	N/A	N/A	<ul style="list-style-type: none"> <li>• Patient summary for clinic; clinician; all patients</li> <li>• Patient Encounter Note includes graphs for patient over time</li> </ul>	<ul style="list-style-type: none"> <li>• Lists of patients in need of services</li> <li>• Patient reminder letters</li> </ul>	Set of standard reports plus additional queries can be written if users have knowledge of MS Access.

**Table 2. Public Domain Registry Software—Functionality Overview (cont.)**

Vendor	Conditions	Hosting Model	Security	Data Export/Import	Point of Care Tools	Patient Outreach Tools	Reporting Capabilities
Diabetes Electronic Management System (DEMS)	Diabetes	Client server software (MS Access based); database can be stored on a PC or local network server; maximum 10 concurrent users.	<ul style="list-style-type: none"> <li>No secure Web access</li> <li>Visit notes, exception reports contain visible patient identifiers</li> <li>Access has native tiered security system, plus network security scheme.</li> </ul>	<ul style="list-style-type: none"> <li>Users can export any data to Word, Excel or statistical packages such as SAS or Stata</li> <li>Data ownership resides with clinic</li> <li>Less than 60 seconds input time per patient</li> </ul>	<ul style="list-style-type: none"> <li>Patient summary for clinician</li> </ul>	<ul style="list-style-type: none"> <li>Lists of patients in need of services</li> <li>Patient reminder letters</li> </ul>	Set of standard reports plus additional queries can be written if users have knowledge of MS Access.
Diabetes Electronic Management System Lite (DEMS Lite)	Diabetes; immunizations; cardiovascular	Client server software (MS Access based); database can be stored on a PC or network/server; no limitation on number of users.	<ul style="list-style-type: none"> <li>Web access possible</li> <li>Visit notes contain visible patient identifiers</li> <li>Password protected or network security restrictions.</li> </ul>	<ul style="list-style-type: none"> <li>Users can export any data to Word, Excel or statistical packages such as SAS or Stata</li> <li>Data ownership resides with registry users/manager</li> <li>Data input time is 7-10 minutes for new patient; 3-5 minutes for existing patient.</li> </ul>	<ul style="list-style-type: none"> <li>Patient summary for clinician</li> <li>Summary notes for patient in patient friendly language and graphs</li> </ul>	<ul style="list-style-type: none"> <li>Lists of patients in need of services</li> <li>Patient reminder letters</li> </ul>	Set of standard reports plus additional queries can be written if users have knowledge of MS Access.
Oregon Diabetes Electronic Management System (OR-DEMS)	Diabetes	Client server software (MS Access based); database can be stored on a PC or local server.	<ul style="list-style-type: none"> <li>No secure Web access</li> <li>Patient identifiers visible</li> </ul>	<ul style="list-style-type: none"> <li>No export/import capability</li> <li>Data ownership resides with clinic</li> </ul>	<ul style="list-style-type: none"> <li>Patient summary for clinician</li> <li>Summary for patient (available in English and Spanish) containing clinical guidelines and summary data in patient friendly language</li> </ul>	<ul style="list-style-type: none"> <li>Lists of patients in need of services</li> <li>Patient reminder letters</li> </ul>	Set of standard reports plus additional queries can be written if users have knowledge of MS Access.
Patient Care Management System	Diabetes; preventive services	Client server software (MS Access based); database can be stored on a PC or network; maximum 10 concurrent users	<ul style="list-style-type: none"> <li>Access to data controlled by provider.</li> </ul>	<ul style="list-style-type: none"> <li>No export/import capability</li> <li>Data ownership resides with provider/clinic</li> </ul>	<ul style="list-style-type: none"> <li>Patient summary for clinician</li> </ul>	<ul style="list-style-type: none"> <li>Lists of patients in need of services</li> <li>Patient reminder letters</li> </ul>	Set of standard reports plus additional queries can be written if users have knowledge of MS Access.



**Table 2. Public Domain Registry Software—Functionality Overview (cont.)**

Vendor	Conditions	Hosting Model	Security	Data Export/Import	Point of Care Tools	Patient Outreach Tools	Reporting Capabilities
<b>Patient Electronic Care System (PECS2)</b>	Can be used for any disease; currently tailored for diabetes; cardiovascular; depression; asthma; cancer screening and follow-up.	N-tiered with SQL Server	<p>Patient identifiers visible, but PECS database can have all identifiers scrambled, allowing users to view the data without showing patient identifiers. Exports can be made both anonymous and encrypted</p> <ul style="list-style-type: none"> <li>• Provider owns data</li> <li>• Three security levels for data entry</li> </ul>	<ul style="list-style-type: none"> <li>• All patient data can be exported and imported.</li> <li>• Automatic import system</li> <li>• Manual data entry time is 2-5 minutes per patient</li> </ul>	<ul style="list-style-type: none"> <li>• Patient summary for clinician</li> </ul>	<ul style="list-style-type: none"> <li>• Lists of patients in need of services</li> <li>• Patient reminder letters</li> </ul>	Set of standard reports plus customization capability. No programming knowledge required
<b>Preventive Health Electronic Management System (PHEMS)</b>	Diabetes; cardiovascular	Client server software (MS Access based); database can be stored on a server	<ul style="list-style-type: none"> <li>• No secure Web access</li> <li>• Patient identifiers visible</li> </ul>	N/A	<ul style="list-style-type: none"> <li>• Patient summary for clinician</li> </ul>	<ul style="list-style-type: none"> <li>• Lists of patients in need of services</li> <li>• Patient reminder letters</li> </ul>	Set of standard reports plus additional queries can be written if users have knowledge of MS Access.
<b>STEPS Electronic Collection and Analysis Tool (SECAT)</b>	Diabetes; preventive services	Client server software (MS Access based); database can be stored on a server	N/A	N/A	<ul style="list-style-type: none"> <li>• Patient summary for clinician</li> <li>• Graphs for patient of lab values over time</li> <li>• Patient flow-sheets showing recent services</li> </ul>	<ul style="list-style-type: none"> <li>• Lists of patients in need of services</li> <li>• Patient reminder letters</li> </ul>	Set of standard reports plus additional queries can be written if users have knowledge of MS Access.

\* Preventive services include recommended screening tests and immunizations.

\*\* Microsoft Access-based products have a limit of 10 concurrent users.

\*\*\* The patient summaries for clinicians typically include patient demographics, history, and recent services.

## Commercial Software Products

### 7. AmCare™ (by Therapeias Health Management)

*Overview:* The AmCare suite of products offers both disease registry and full case management applications. AmCare is client-server software that can be customized for any chronic condition. The company that developed AmCare, Therapeias Health Management, has been developing case management software for 15 years.

*Functionality:*

- Patient summary—A one-page summary of a patient's vital information.
- Import capability—The AmCare Smart Chart provides an interface to capture a wide range of clinical and administrative data from other data systems. It also features a universal care plan for managing all the patient's conditions in a cohesive way.
- Read-only capability—AmCare Observer allows some users to view but not change patient information.
- Reminder service—AmCare Inbox is a secure messaging alert and reminder service, provided on a subscription basis.
- Reporting—AmCare Query Wizard is a reporting tool that allows users with no technical training to query the AmCare database.
- Data entry—Process is partially automated through interfaces that Therapeias has built—including paper scanning—to a number of data warehouses and legacy systems. A phone gateway also allows secure data entry via a telephone or fax.

*Strengths:* Good option for organizations in need of more detailed patient information and in-depth case management functionality. The ability to use the product for any condition

and its user-driven reporting module are also product strong points. The product offers some unique data entry options including scanning and telephone. In addition, Therapeias can build custom interfaces.

*Weaknesses:* Organizations interested only in disease registry functionality will find AmCare complex. An organization must purchase the complete AmCare suite in order to obtain the registry functionality. In addition, the time needed for vendor customization of the product to the specific needs of organizations may be lengthy (one year in some cases.)

*Cost:* Cost information not available.

### 8. CliniPro® (by NuMedics, Inc.)

*Overview:* CliniPro® is a client-server registry tool primarily tailored for diabetes. The product, developed by NuMedics, Inc., also offers some practice management, electronic medical record (EMR) and other patient management functionality.

*Functionality:*

- Patient chart and medical record—Auto generated clinical notes on predefined templates. Tracks outliers in patient population based on disease-specific risk profile.
- Diabetes management system—Includes clinical, nutritional, physical exercise, and psychosocial data tracking.
- Diabetes education module—Ability to collect data required for the ADA Education Recognition program and NCQA provider recognition; features include patient evaluations, class and individual consultation scheduling, customizable course descriptions, and patient attendance and progress reports.
- Form letter capabilities—Preformatted and customized letter templates that can be merged with patient data.

- Outcomes reports—Number of standard reports at an individual and provider level; contains ability to customize reports with Microsoft Access-like SQL query engine.
- Patient demographics database—Searchable patient database with general demographic information.
- Electronic scheduler—Appointment book feature for scheduling provider appointments or other resource allocations.
- Electronic mail system—Secure communications among members of the care team.
- Import capability—Interfaces to external system via HL7 engine to import and export patient registration, lab, exam, progress notes, and billing information. Includes ability to upload data from 21 different brands of glucose meters, assessment screens to monitor behavioral goals and charts, and graph views to track progress.

*Strengths:* The product is well tested having been implemented in over 120 sites since 1997. Its robust functionality in the area of patient education, in particular the ability to track data required for the ADA Education Recognition program NCQA Provider Recognition and AADE NDEOS and D-Smart reporting electronically, is an asset. The ability to import data via HL-7 interfaces is an additional strength.

*Weaknesses:* Users interested primarily in a registry product may not be ready for or may not need an EMR, scheduling, or messaging capabilities. These features are part of the standard product; organizations interested only in the registry functionality must still purchase the complete product.

*Cost:* Subscriber fees are set on a sliding scale based on the total number of users. For example, the cost for one license starts at \$3,500,

while 100 licenses cost \$122,000 for first year. After year one the organization pays \$629 per license per year. Licenses are for *concurrent* uses so an organization can purchase fewer licenses than the total number of users. The cost of the report writer is \$2,995 and each HL-7 interface costs \$2,995.

## 9. Delphi Diabetes Registry

*Overview:* The Delphi Diabetes Registry™ is offered by Delphi Health Systems in collaboration with the American Diabetes Association. It may be used to apply for ADA Provider Recognition, supports the National Standards for Diabetes Self-Management Education, and in 2004 will be able to support the AHA/NCQA “Heart/Stroke Program.” It can be used in either a client-server or individual workstation environment.

### *Functionality:*

- Patient profile—Provides real-time quality assessment and reporting and creates a comprehensive medical record able to track all aspects of diabetes and cardiac care. Information is summarized in patient and provider profiles that compare clinical results and quality measures for individuals and groups.
- Decision support—Guidelines can be customized at the individual patient or organizational level. These guidelines generate alerts and reminders to notify providers of overdue tests and unusual results or conditions.
- Patient stratification—Contains a predictive “high-risk monitor” that allows the care team to establish the clinical and compliance criteria to identify high-risk patients.
- Patient reminders—Produces patient letters in multiple languages.

- Reporting—Automatically generated provider, health plan, and employer level reports include a comparison to quality standards or other benchmarks. Patient-specific reports include analyses comparing the use of specific medications to changes in results (HbA1c, lipids, blood-pressure, etc.) over any period of time.
- Import capability—Vendor can assist customers in setting up electronic links to import retrospective data, and for periodic updates from other electronic data sources including, lab, practice management, and EMR systems.
- Data ownership—Ownership of data resides with customer, however, Delphi retains rights of de-identified data for benchmarking purposes.

*Strengths:* A strength of this registry is its comprehensive functionality for diabetes and cardiac care. The tool requires minimal training and, due to its simplicity, allows rapid data entry. Additional strengths include support for guideline-driven care and the ability to track and report compliance with quality improvement programs and initiatives.

*Weaknesses:* One weakness of the Delphi Registry is the fact that the registry does not address conditions outside of diabetes and cardiovascular disease. A second weakness is the lack of a customer-driven data import capability. Delphi will, however, work with customers to set up automated links to electronic data feeds.

*Cost:* The cost of the Delphi Diabetes Registry is \$36 per patient per year. Bulk pricing is available, as well as special terms for non-profit organizations and for use in research.

## 10. PatientPlanner (by DocSite<sup>SM</sup>)

Overview: PatientPlanner is an interactive, Web-based registry tool developed and hosted by DocSite<sup>SM</sup>. The tool can be used for any condition and offers a range of customization options.

### *Functionality:*

- Patient encounter form—VisitPlanner lists the patient's conditions, providers, medications and allergies, with associated interventions, and can graph two disease-relevant status indicators over time.
- Decision support—Embedded national standard guidelines for several chronic conditions (among them: asthma, CHF, diabetes, stable coronary disease, post-myocardial infarction, and depression) with the ability to make local guideline modifications and add new conditions without technical intervention. The guidelines are displayed on encounter documents, used to generate alerts, and relied upon in the reporting module.
- Reporting—Report wizard allows users to generate standard or custom reports. The reporting component contains the ability to make comparisons among providers, view an individual's progress over time, or assess a subgroup of patients on certain clinical measures.
- Patient education—Providers can personalize and print relevant educational materials. Also contains a form letter generator.
- Import capability—User interface allows an automatic data import from practice management or other systems. Although the interface will work with standard (HL7) feeds, the data does not have to adhere to a particular format. Using a consistent patient identifier is not a requirement (although it is recommended) as PatientPlanner can match

patient records by name, date of birth, and other demographic information (if available). HL7 and XML interfaces exist for lab interfaces and export, in addition to the administrative import/export capabilities. PatientPlanner has specific, pre-built interface capability to two major lab systems, Labcorp and Quest.

- Data ownership—Data can be housed by DocSite as an “ASP” or hosted locally behind a customer firewall.
- Additional features—Include links to evidence based medicine sites, health status surveys (SF36, SF12), patient satisfaction surveys, and health risk assessments.

*Strengths:* PatientPlanner offers a scalable, Web-based platform that enables deployment across multiple sites. The flexibility to use the product for any chronic condition and to customize the product for local needs are additional strengths. PatientPlanner has a more extensive patient education component than many of its competitors and offers greater support for evidence-based medicine through integration of guidelines. The ability to set patient-specific goals as well as guideline specific goals is another strength. Finally, the company offers full customer support, including the ability to work with customers on automatic import formats and data manipulation.

*Weaknesses:* The main disadvantage of the product is its cost. In addition, some training is required upon initial use to familiarize the user with the numerous screens and functionality options.

*Cost:* The cost of the product for a provider, including support services starts at \$50 per month. Volume discounts are offered for licenses to larger organizations. Additionally,

DocSite can provide hosting services for incremental fees of approximately \$10 per month, per provider. DocSite has an ongoing strategic partnership with GlaxoSmithKline for development, use, and deployment of the product. The most recent update to PatientPlanner was completed in May 2004.

## 11. Patient Electronic Care System (PECSYS)

Overview: PECSYS is an n-tiered SQL server-based registry product that can be used to track clinical data for patients with any chronic disease and is currently tailored for diabetes, asthma, cardiovascular disease, depression, prevention, and cancer screening and follow-up. It was developed by The Aristos Group, Inc. and has been used exclusively within the Bureau of Primary Health Care collaboratives. PECSYS builds on its predecessor PECS2 by adding enhanced point of contact interface, importing and exporting, and reporting capabilities.

### *Functionality:*

- Encounter documents—Contains five different types of encounter documents:
  1. Encounter note—a dynamic form containing demographics, conditions, medications, labs, referrals and education data; it can be customized for a specific patient.
  2. Run charts—shows trends over time for selected items.
  3. Follow up worksheet—a tool for tracking recommended services.
  4. Reminders—a list of clinical services suggested for the patient.
  5. Patient history.
- Patient reminders—Guideline-based reminders that the user can add and customize.

- Reporting—“Registry summary reports” (diabetes, asthma, cardiovascular disease, depression, cancer screening and follow-up) contain aggregate statistics on demographic and visit information, vitals, lab data, referrals, and follow-up for any subset of patients. These reports are not customizable. “Spreadsheet reports” can be customized using a report wizard.
- Import capability—Can import and export any patient data. Imports can be scheduled to run automatically, allowing transparent connection to practice management systems, EMRs and lab data. Exports contain anonymous and encryption functionality.

*Strengths:* PECSYS offers the flexibility to use the product for any chronic condition, using evidence-based guidelines within the framework of the Chronic Care Model. A second strength is that users without technical skill are able to generate some types of additional reports. The product’s automated and manual reminder capabilities are yet another positive aspect. Electronic import and export of data reduces the need for manual data entry.

*Weaknesses:* Added flexibility results in a more complex product that requires additional training.

*Cost:* Cost is \$495 per provider (non-recurring fee).

**Table 3. Commercial Registry Software—Functionality Overview**

Vendor	Conditions	Hosting Model	Security	Data Export/Import	Point of Care Tools	Patient Outreach Tools	Reporting Capabilities
AmCare (Therapeias)	Can be customized for any condition	Client-server software; database can be stored on a server	N/A	N/A	<ul style="list-style-type: none"> <li>• Patient summary for clinician*</li> <li>• Secure messaging system for alerts and reminders</li> <li>• EMR like functionality to capture wide range of clinical and administrative data</li> <li>• Patient care plans</li> </ul>	<ul style="list-style-type: none"> <li>• Lists of patients in need of services</li> <li>• Patient reminder letters</li> </ul>	Set of standard reports plus ability to create new or edit existing reports. No programming knowledge required.
CliniPro (Numedics)	Can be customized for use for any condition	Client-server software; database resides on a local server or network. May also be hosted by outside vendor over secured internet VPN setup. Unlimited simultaneous users allowed.	<ul style="list-style-type: none"> <li>• Can be set up for secure Web access using VPN connection.</li> <li>• For viewing of population data, patient identifiers can be blocked; patient identifier visible for viewing individual patient data.</li> </ul>	<ul style="list-style-type: none"> <li>• Can save de-identified data in Excel or Access format for exporting.</li> <li>• Equipped with HL7 interface to export data to other systems.</li> <li>• Ownership of data resides with customers.</li> </ul>	<ul style="list-style-type: none"> <li>• EMR-like capability to automatically generate clinical notes based on predefined templates</li> <li>• Scheduling system</li> <li>• Secure messaging functionality for team member and patient communication</li> <li>• Ability to upload data from glucose meters</li> <li>• Nutrition assessment and planning for disease management</li> <li>• Patient education tracking and certification</li> </ul>	<ul style="list-style-type: none"> <li>• Lists of patients in need of services</li> <li>• Patient reminder letters customizable in any language (Spanish, German, French, etc.)</li> <li>• Communications with patients via remote access and integrated e-mail system</li> <li>• Secured access for providers and patients for outreach</li> </ul>	Set of standard reports. Limited ability to edit or creating additional reports.  Standard reports to meet HEDIS, DQIP, NDEOS, AADE Dsmart, ADA Education Recognition, NCQA Provider Recognition and CQI Reports.

**Table 3. Commercial Registry Software—Functionality Overview (cont.)**

Vendor	Conditions	Hosting Model	Security	Data Export/Import	Point of Care Tools	Patient Outreach Tools	Reporting Capabilities
Delphi Diabetes Registry (Delphi Health Systems)**	Diabetes; cardiovascular disease in 2004	Client-server software; database can be stored on a server. Can be installed on a single PC or network. Multiple simultaneous users allowed without limitations.	<ul style="list-style-type: none"> <li>No secure Web access</li> <li>Patient identifiers can be shown, or patient data can be extracted and analyzed in “de-identified” format.</li> </ul>	<ul style="list-style-type: none"> <li>Patient and provider data can be imported/exported to/from other digital systems such as EMR or electronic lab feeds.</li> <li>Data ownership resides with customer. Delphi retains rights of de-identified data for benchmarking purposes.</li> </ul>	<ul style="list-style-type: none"> <li>Patient summary for the clinician with embedded guidelines</li> <li>Guideline driven alerts and reminders</li> <li>Identification of high risk patients</li> <li>Patient care plans</li> <li>Automated treatment outcomes analyses</li> <li>Encounter notes and messaging</li> <li>Paper and electronic referrals</li> </ul>	<ul style="list-style-type: none"> <li>Lists of patients in need of services</li> <li>Patient reminder letters (available in multiple languages)</li> <li>Full support of Diabetes Self-Management Education (DSME), including course planning, management, scheduling, and outcomes assessment</li> </ul>	<p>Set of standard reports plus ability to set custom filters to define the population of interest. No programming knowledge required.</p> <p>The software supports the reporting of HEDIS, DQIP, ADA Education Recognition Program data, ADA/NCQA Provider Recognition Program and AHA/NCQA “Heart/Stroke Program.”</p>
PatientPlanner (DocSite)	Can be customized for use for any condition	Web-based; data can be hosted by DocSite or by client. Can also be deployed as stand-alone Access database. Up to 1000 simultaneous users Scalable based on host processor capacity.	<ul style="list-style-type: none"> <li>Can be set up for secure Web access using SSL.</li> </ul>	<ul style="list-style-type: none"> <li>Can export de-identified data to SAS, Excel or as XML.</li> <li>Data can be housed by DocSite as an “ASP” or hosted locally behind a customer firewall.</li> </ul>	<ul style="list-style-type: none"> <li>Patient summary for clinician with embedded guidelines</li> <li>Alerts and reminders based on guidelines; identifies high-risk patients</li> <li>Interacts with Care Manager Views</li> </ul>	<ul style="list-style-type: none"> <li>Lists of patients in need of services</li> <li>Patient reminder letters</li> <li>Ability to customize and print patient educational materials</li> <li>Satisfaction surveys</li> <li>Health risk assessments</li> <li>Health status surveys</li> </ul>	<p>Wizard selection populates set of standard reports plus user has ability to create new or edit existing reports. No programming knowledge required.</p> <p>Software supports HEDIS, DQIP, ADA, Bridges to Excellence, California IHA and CMS DOQIT initiatives.</p> <p>Users can export raw data (identifiable or not) for use in external reporting systems.</p> <p>Supports continuity of care record (CCR) standard.</p>



**Table 3. Commercial Registry Software—Functionality Overview (cont.)**

Vendor	Conditions	Hosting Model	Security	Data Export/Import	Point of Care Tools	Patient Outreach Tools	Reporting Capabilities
Patient Electronic Care System (PECSYS) (the Aristos Group)	Can be customized for use for any condition; currently tailored for asthma, cancer, cardiovascular disease, diabetes, and depression	Client server software (MS Access based); database can be stored on a server	<p>Patient identifiers visible, but PECS database can have all identifiers scrambled, allowing users to view the data without showing patient identifiers.</p> <ul style="list-style-type: none"> <li>• Provider owns data</li> <li>• Three security levels for data entry</li> </ul>	<ul style="list-style-type: none"> <li>• Can import lab, demographic and diagnosis data in predefined ASCII format</li> </ul>	<ul style="list-style-type: none"> <li>• Several types of patient summaries for clinician including an overall summary, run charts showing trends over time, follow up worksheet for tracking recommended services, patient history, and a list of reminders of recommended services</li> </ul>	<ul style="list-style-type: none"> <li>• Lists of patients in need of services</li> <li>• Patient reminder letters</li> </ul>	Set of standard reports plus ability to create new or edit existing reports. No programming knowledge required.

\* The patient summaries for clinicians typically include patient demographics, history, and recent services.

\*\* Delphi plans to expand their platform for additional chronic diseases, starting with CAD in 2004.

### Product Comparisons

Vendors of the registry products profiled in this report were asked to provide data to evaluate their products using eight criteria believed to be key differentiating factors. The criteria and evaluation process are described below.

- **Patient or disease focus:** Ideally, registry products should be organized around patients (“patient focused”) so that reports and displays for patients with multiple conditions are integrated. Organizations relying on registries that focus on a single disease (“disease focused”) may eventually require numerous, separate registries for each chronic disease of interest, often with overlapping patient populations. In addition, disease-focused registries may be limited in their ability to support individual care as they may omit critical information for patients with multiple chronic conditions.
- **Ease of use/user interface:** The user interface should provide a simple, clear way for users to view, enter, and modify information and generate reports. This criterion was evaluated on a three-point scale with one star representing the least user-friendly interface and three stars representing the most user-friendly interface. The interface was evaluated on the simplicity and clarity of its use.
- **Market penetration:** Implementation of a product across a large number of organizations can validate the tool’s utility across organizations. A high market penetration usually means it has undergone numerous revisions to address user needs. This may also increase the likelihood that the product will continue to be offered and supported into the near future. Number of implementations is evaluated on a three-point scale with one star representing a product implemented in

0-10 organizations, two stars for products implemented in 11-50 organizations, and three stars for products implemented in more than 50 organizations.

- **Ability to customize:** Many organizations greatly value the ability to tailor the software to meet local needs. Customization can include the ability to select what conditions are included in the registry, what data fields are tracked for each condition, the ability to alter embedded guidelines, and the ability to generate custom reports without requiring technical skill. This criterion was also evaluated on a three-point scale. Products with one star offer minimal customization ability. Products with three stars offer a wide range of customization options.
- **Ease of set-up/implementation:** Registry products vary by how easy or challenging they are to install and begin using. This criterion was rated on a three-point scale. One star represents a product that both requires a lengthy installation process and at least four hours of user training. Three stars represents the products with a simple set-up process requiring no technical skill and no training other than a user manual to get started.
- **Existing import or interface capability:** Entering data into the registry manually can be the greatest barrier to its use. Organizations may not have the capacity to maintain products that rely heavily or exclusively on manual data entry. The various registry products offer a range of options for alleviating the burden of manual data entry including periodic data import processes and in a few cases live, real-time interfaces to other data sources. This criterion was evaluated on a three-point scale, in which one star represents a product with limited import capability; two stars represents a product

with more sophisticated import processes or a single live interface customized by the vendor; and three stars represents a product with live interfaces to several major data sources.

- **Scalability:** Some registries have constraints on the number of users that can access the system simultaneously. For example, any Microsoft Access-based product can only accommodate ten users at the same time. For larger provider groups or independent practice associations (IPAs), this can be a barrier to registry use, as they may deploy multiple users in widely dispersed provider offices. This criterion was evaluated on a three-point scale in which one star represents a product with limited scalability (10 or less concurrent users) and three stars represent a product with virtually no limits on number of users.
- **Cost:** The price range of the products varies from free, public domain software to upwards of \$600 per user per year. The cost includes only the base product; customization and the building of interfaces may result in additional fees.

See Table 4 for an evaluation of the registry products using the above criteria.

**Table 4. Comparison of Registry Product Along Key Selection Criteria**

Vendor	Patient or Disease Focus	Market Penetration	Ease of Use/ User Interface	Customizability	Data Import or Interface Capability	Ease of Setup/ Implementation	Scalability	Cost
<b>Public Domain Software Products</b>								
<b>1. DEMS Product Family</b>								
Diabetes Electronic Management System (DEMS)	Disease focus (diabetes)	✓✓✓	✓✓✓	✓	✓✓	✓✓✓	✓	Free, public domain software
Chronic Disease Electronic Management System (CDEMS)	Patient focus	✓✓✓	✓✓✓	✓✓✓ • User can create custom reports • User can customize embedded guidelines	✓✓	✓✓✓	✓	Free, public domain software
Cardiovascular and Diabetes Electronic Management System (CVDEMS)	Disease focus (cardiovascular disease, diabetes)	✓✓✓	✓✓✓	✓	✓	✓✓✓	✓	Free, public domain software
Diabetes Electronic Management System Lite (DEMS Lite)	Disease focus (diabetes)	✓✓	✓✓✓	None	✓	✓✓✓	✓	Free, public domain software
Oregon Diabetes Electronic Management System (OR-DEMS)	Disease focus (diabetes)	✓✓	✓✓✓	✓	✓	✓✓✓	✓	Free, public domain software
Preventive Health Electronic Management System (PHEMS)	Disease focus (cardiovascular disease, diabetes)	✓✓	✓✓✓	✓	✓	✓✓✓	✓	Free, public domain software
<b>2. Adult Preventive Health Services Software (APHS)</b>	Disease focus (preventive services)	✓✓	✓✓	✓✓ • User can choose to data fields to track (to a limited extent)	✓	✓✓✓	✓	Free, public domain software

**Key**

- ✓ Indicates the least favorable score on track record, ease of use, customizability, import capability and ease of set up.
- ✓✓ Indicates an intermediate score.
- ✓✓✓ Indicates the most favorable score.

**Table 4. Comparison of Registry Product Along Key Selection Criteria (cont.)**

Vendor	Patient or Disease Focus	Market Penetration	Ease of Use/ User Interface	Customizability	Data Import or Interface Capability	Ease of Setup/ Implementation	Scalability	Cost
3. Chronic Disease Management System (CDMS)	Patient focus	✓✓	✓✓✓	✓✓✓ <ul style="list-style-type: none"> <li>• User can choose conditions of interest</li> <li>• User can choose data fields to track</li> <li>• User can create custom reports</li> </ul>	✓✓	✓✓	✓✓✓	Free, public domain software currently only available in Montana, Wyoming, Hawaii, Indiana, Kentucky and Rhode Island
4. Patient Care Management System	Disease focus (diabetes, preventive services)	✓✓	✓✓	✓	✓	✓✓✓	✓	Free, public domain software
5. Patient Electronic Care System 2 (PECS2)	Can be customized for use for any condition	✓✓✓	✓✓	✓✓✓ <ul style="list-style-type: none"> <li>• User can choose conditions of interest</li> <li>• Customizable reminders</li> <li>• User can create custom reports (to a limited extent)</li> </ul>	✓✓✓	✓✓	✓✓✓	Product is available royalty free only to Federally Qualified Health Centers who have participated in a BPHC sponsored collaborative. For a commercial version see information on PECSYS.
6. STEPS Electronic Collection and Analysis Tool (SECAT)	Disease focus (diabetes, preventive services)	✓✓✓	✓✓✓	✓✓✓ <ul style="list-style-type: none"> <li>• User can choose data fields to track (to a limited extent)</li> <li>• User can create custom reports (to a limited extent)</li> </ul>	✓	✓✓✓	✓	Free, public domain software
<b>Commercial Software Products</b>								
7. AmCare (by Therapeias)	Patient focus	✓*	✓✓	✓✓ <ul style="list-style-type: none"> <li>• User can create custom reports</li> </ul>	✓✓	✓	✓✓✓	Cost information not available

\* AmCare implementations do include some very large organizations.

**Key**

- ✓ Indicates the least favorable score on track record, ease of use, customizability, import capability and ease of set up.
- ✓✓ Indicates an intermediate score.
- ✓✓✓ Indicates the most favorable score.

**Table 4. Comparison of Registry Product Along Key Selection Criteria (cont.)**

Vendor	Patient or Disease Focus	Market Penetration	Ease of Use/ User Interface	Customizability	Data Import or Interface Capability	Ease of Setup/ Implementation	Scalability	Cost
8. Clini-Pro (by Numedics)	Patient focus; set up for diabetes.	✓✓✓	✓✓	✓✓✓ • User can choose data fields to track • User can create custom reports (to a limited extent)	✓✓	✓	✓✓✓	Subscriber fee based on number of users. For 100 users, \$122,000 for first year. \$629/user/year for subsequent years. Licenses are for concurrent uses so organization can purchase fewer than total number of users.
9. Delphi Diabetes Registry	Disease focus (diabetes)	✓✓	✓✓✓	✓✓✓ • User can set custom filters on reports • User customize guidelines and high risk stratification criteria • User can choose data fields to track	✓†	✓✓✓	✓✓✓	\$36 per patient per year
10. Patient Planner (DocSite)	Patient focus	✓✓✓	✓✓✓	✓✓✓ • User can choose conditions of interest • User can customize embedded guidelines • User can create custom reports • User can customize patient educational materials	✓✓✓	✓✓✓	✓✓✓	\$50 per provider per month; volume discounts offered to larger organizations
11. Patient Electronic Care System (PECSYS)	Can be customized for use for any condition	✓✓✓	✓✓	✓✓✓ • User can choose conditions of interest • Customizable reminders • User can create custom reports (to a limited extent)	✓✓✓	✓✓	✓✓✓	Pricing set at \$495 per provider (non-recurring fee).

† The Delphi Registry product does not contain any import function but Delphi Health Systems will import data for client organizations.

**Key**

- ✓ Indicates the least favorable score on track record, ease of use, customizability, import capability and ease of set up.
- ✓✓ Indicates an intermediate score.
- ✓✓✓ Indicates the most favorable score.

## **Narrowing the Choices**

Ultimately, choosing a registry product is highly dependent on which decision criteria are most important to the purchasing organization.

As discussed previously, a disease registry is only one component of a more comprehensive disease management strategy. To effectively manage chronic conditions and provide better care to patients, a registry must be integrated into a program that includes elements such as provider support, use of multi-disciplinary provider teams, and increased patient self-management. A registry can enhance disease management of a population, but is not a disease management program by itself.

# Appendix A. Registry Product Contact Information

Product	Contact Information	Website
Adult Preventive Health Services Software (APHS)	Qualis Health Andrea Sciaudone, RN 10700 Meridian Ave. N., #100 Seattle, WA 98133-9075 Phone: (206) 364-9700 x2030 Toll Free: (800) 949-7536 Fax: (206) 368-2419 TDD: (800) 251-8890	
AmCare (by Therapeias)	Therapeias Health Management 1200 N. College Ave. Claremont, CA 91711 Phone: 909-626-6380	<a href="http://www.therapeias.com">www.therapeias.com</a>
Chronic Disease Electronic Management System (CDEMS)	Washington State Diabetes Prevention and Control Program Dusty Knobel PO Box 47836 Olympia, WA 98502 Phone: 360-236-3738 or 425-3150151 Email: dusty.knobel@doh.wa.gov or dems.cdems@verizon.net	<a href="http://www.cdems.com">www.cdems.com</a>
Chronic Disease Management System (CDMS)	Mountain-Pacific Quality Health Foundation John W. McMahon 3404 Cooney Drive Helena, MT 59602 Phone: 406-443-4020 Email: JMCMAHON.mtpro@sdps.org	<a href="http://www.mpqhf.org/mpqhf_web/cdmsinfo/index.html">www.mpqhf.org/mpqhf_web/cdmsinfo/index.html</a>
Clini-Pro (by Numedics)	Numedics 9400 SW Beaverton-Hillsdale Hwy., Suite 136 Beaverton, OR 97005-4752 Phone: 888-254-6477	<a href="http://www.numedics.com/">www.numedics.com/</a>
Cardiovascular and Diabetes Electronic Management System (CVDEMS)	California Primary Care Association Lisa Kavanaugh 1215 K Street, Suite 700 Sacramento, CA 95814 Phone: 916-440-8170, Ext. 230 Email: lkavanaugh@cpca.org	<a href="http://www.cpga.org/health/dems.htm">www.cpga.org/health/dems.htm</a>
Delphi Diabetes Registry (Delphi Health Systems)	Delphi Health Systems, Inc. Richard G. McGeary 360 Bloomfield Avenue Windsor, CT 06095 Phone: 860-687-4705 Email: rmcgeary@delphihealth.com	<a href="http://www.delphihealth.com/delphi_diabetes_registry.htm">www.delphihealth.com/delphi_diabetes_registry.htm</a>

**Appendix A. Registry Product Contact Information (cont.)**

<b>Product</b>	<b>Contact Information</b>	<b>Website</b>
Diabetes Electronic Management System (DEMS)	Washington State Diabetes Prevention and Control Program Dusty Knobel PO Box 47836 Olympia, WA 98502 Phone: 360-236-3738 or 425-3150151 Email: dusty.knobel@doh.wa.gov or dems.cdems@verizon.net	<a href="http://www.cdems.com">www.cdems.com</a>
Diabetes Electronic Management System Lite (DEMS Lite)	New Mexico Medical Review Association Galina Prilouts kaya P.O. Box 3200 Albuquerque, NM 87190 Phone: 505-998-9765 Email: gprilouts kaya@nmqio.sdps.org	<a href="http://www.nmmra.org/providers/topics_diabetes.html#dems">www.nmmra.org/providers/topics_diabetes.html#dems</a>
Oregon Diabetes Electronic Management System (OR-DEMS)	OMPRO Margene Bortel 2020 SW Fourth Avenue, Suite 520 Portland, OR 97201-4960 Phone: 503-279-0100 Email: mbortel@ompro.org	<a href="http://www.ompro.org/diabcollab/ORDEMS.html">www.ompro.org/diabcollab/ORDEMS.html</a>
Patient Care Management System	Metastar Pam Clemens 2909 Landmark Place Madison, WI 53713 Phone: 608-441-8259 Email: pclemens@metastar.com	<a href="http://www.metastar.com/professional/tools.asp">www.metastar.com/professional/tools.asp</a>
Patient Electronic Care System (PECS)	The Aristos Group Allan Fabrick PO Box 684715 Austin, TX 78768-4715 Phone: 425.483.7346 Email: CustomerService@aristos.com	<a href="http://www.pecs-cis.org/index.htm">www.pecs-cis.org/index.htm</a>
PatientPlanner (DocSite)	DocSite John Haughton 540 Main Street, Suite 1 Winchester, MA 01890 Phone: 781-721-0005 jhmd@docsite.com	<a href="http://www.docsite.com/">www.docsite.com/</a>
Preventive Health Electronic Management System (PHEMS)	Missouri Patient Care Review Foundation Jason Isaacs 3425 Constitution Court, Suite E Jefferson City, Missouri 65109 Phone: 800-735-6776 Ext. 169 Email: jisaacs.mopro@sdps.org	
STEPS Electronic Collection and Analysis Tool (SECAT)	Illinois Foundation for Quality Health Care Sally Balsewich 2625 Butterfield Rd., Suite 102 East Oakbrook, IL 60523 Phone: 1-800-386-6431 ext 5808 Email: SBalsewich.IL1PRO@sdps.org	



## Appendix B. Report Methodology

The authors attempted to identify every type of registry software available in the United States that met basic criteria: Ability to track individual patients and populations; designed to support the care of one or more chronic conditions; implemented in at least one site and currently or soon to be available to other delivery systems; not bundled to, or embedded in, other software programs such as a full-fledged electronic medical record. As part of a larger project, the authors interviewed clinical and technology leaders from 35 representative California provider organizations. The authors asked each organization if it relied on a disease registry, and if so, what software product it used. Individuals from various chronic disease collaboratives (within and outside California) and from the Institute for Healthcare Improvement were also contacted to augment this list. Internet searches were conducted as well.

This process identified 19 registry products. Two were excluded as the registry product was not stand-alone, but represented a component of a larger system or service. A third was excluded because it is an in-house product that cannot be licensed by other organizations.

Thirty- to sixty-minute semi-structured interviews were conducted with the product manager, lead developer, sponsor or champion at the qualifying organizations and companies. In many cases, additional interviews were conducted with users of the product, and draft reports were sent to all of the vendors for accuracy and content review prior to publication. To gather additional product information, copies of the actual software or user manuals were reviewed. The rating criteria were derived in part from an evaluation tool developed as part of a disease collaborative

registry evaluation project conducted by the Centers for Medicaid and Medicare Services, the Improving Chronic Illness Care (ICIC) project, and Qualis Health.

Vendors were sent pre-publication copies of the full report and asked to review for completeness and accuracy. (Note: Not all of the vendors reviewed the document and not all of the suggestions offered were incorporated into the final version.) Judgments in this report were based on comparisons of products and were made by the primary authors. None of the authors of this report has any commercial ties to any of the products reviewed.

## Appendix C: Glossary

### **American Diabetes Association (ADA)**

**Education Recognition program:** The ADA's Education Recognition program identifies quality diabetes self-management education services that meet the National Standards for Diabetes Self-Management Education. One of the requirements of the program is that the organizations track patients' behavioral and other outcomes as part of a continuous quality improvement process to evaluate the effectiveness of the diabetes education services. Compliance with this requirement can be documented in some registry products.

**Client-server software:** This term describes the relationship between two computer programs where one program, the client, makes a service request from another program, the server, which fulfills the request. Although the client server idea can be used by programs within a single computer, it is a more important idea in a network. In a network, the client-server model provides a convenient way to interconnect programs that are distributed efficiently across different locations.<sup>6</sup>

**Data warehouse:** A data warehouse is a repository of some or all an organization's data that is structured in a way that is optimized for querying and analysis. The repository may consolidate data from disparate systems.

**DQIP:** The Diabetes Quality Improvement Project began under the sponsorship of a coalition of public and private entities (including the American Diabetes Association, Foundation for Accountability, Health Care Financing Administration, and the National Committee for Quality Assurance) to evaluate and recommend a set of diabetes-specific performance and outcome

measures with which plans, physicians, clinics, and other health care providers could be compared for the purposes of accountability. For more information on the DQIP measures, see [www.ncqa.org/DPRP/dqip2.htm#rationale](http://www.ncqa.org/DPRP/dqip2.htm#rationale).

**HEDIS®:** The Health Employer Data and Information Set is a set of standardized performance measures designed to ensure that purchasers and consumers have the information they need to reliably compare the performance of managed health care plans. The performance measures in HEDIS are related to many significant public health issues such as cancer, heart disease, smoking, asthma and diabetes. For more information on HEDIS® measures, see [www.ncqa.org/Programs/HEDIS/](http://www.ncqa.org/Programs/HEDIS/).

**HL7:** HL7 is a set of data specifications and standards that enables independent health care applications to exchange clinical and administrative data. For more information see [www.hl7.org](http://www.hl7.org)

**ICD-9 codes:** The International Classification of Diseases, Clinical Modification (ICD-9-CM) is a set of codes used to classify morbidity data from inpatient and outpatient records.<sup>7</sup>

**Interface:** A format and language that enables two independent systems to meet and act on or communicate with each other.<sup>8</sup> For example, an interface may enable registry software to obtain demographic data from a practice management system.

**N-tier:** A software system architecture, with increased flexibility and scalability over previous single and two-tier systems. Using this multi-tier architecture, a user can implement the system through a browser, both in-house and on the Web. This allows for increased network flexibility and easier system maintenance.

**Quality Improvement Organizations (QIOs):** Formerly called Physician Review Organizations, or PROs. Under the direction of the Centers for Medicare and Medicaid Services (CMS), the QIO program consists of a national network of 53 QIOs responsible for each U.S. state, territory, and the District of Columbia. QIOs work with consumers, physicians, hospitals, and other caregivers to refine care delivery systems, particularly among underserved populations. Another role of the program is to safeguard the integrity of the Medicare trust fund by ensuring payment is made only for medically necessary services, and investigating beneficiary complaints about quality of care.

**Sensitivity:** The degree to which the testing process is able to extract true positives, and avoid false-negatives.

**Specificity:** The specificity of a test or process is the proportion of true negatives detected of all those that the test detected as negatives. Specificity describes how accurately a test identifies negatives.

# Endnotes

1. Metzger, J. “A Primer on Disease Registries, Information Technology for Chronic Disease Management,” California HealthCare Foundation, 2004.
2. O’Dell, G. “2002 AHA Environmental Assessment,” Hospitals & Health Networks, 77(10): centerfold, 2003.
3. Institute of Medicine. “*Crossing the Quality Chasm*,” National Academy Press, Washington, D.C., 2001.
4. Data provided by James Byrkit, M.D., at Salem Clinic in Salem, OR, April, 2003.
5. Import processes from LabCorp and Quest should function outside of Washington State although the processes have not been tested. Technical support is required and can be provided to a limited extent by the Washington State Diabetes Prevention and Control Program.
6. Definition from SearchNetworking.com, [http://searchnetworking.techtarget.com/Definition/0,,sid7\\_gci211796,00.html](http://searchnetworking.techtarget.com/Definition/0,,sid7_gci211796,00.html).
7. Definition from the National Center for Health Statistics, <http://www.cdc.gov/nchs/icd9.htm>
8. Definition from Webopedia.com, [www.webopedia.com/TERM/i/interface.html](http://www.webopedia.com/TERM/i/interface.html)