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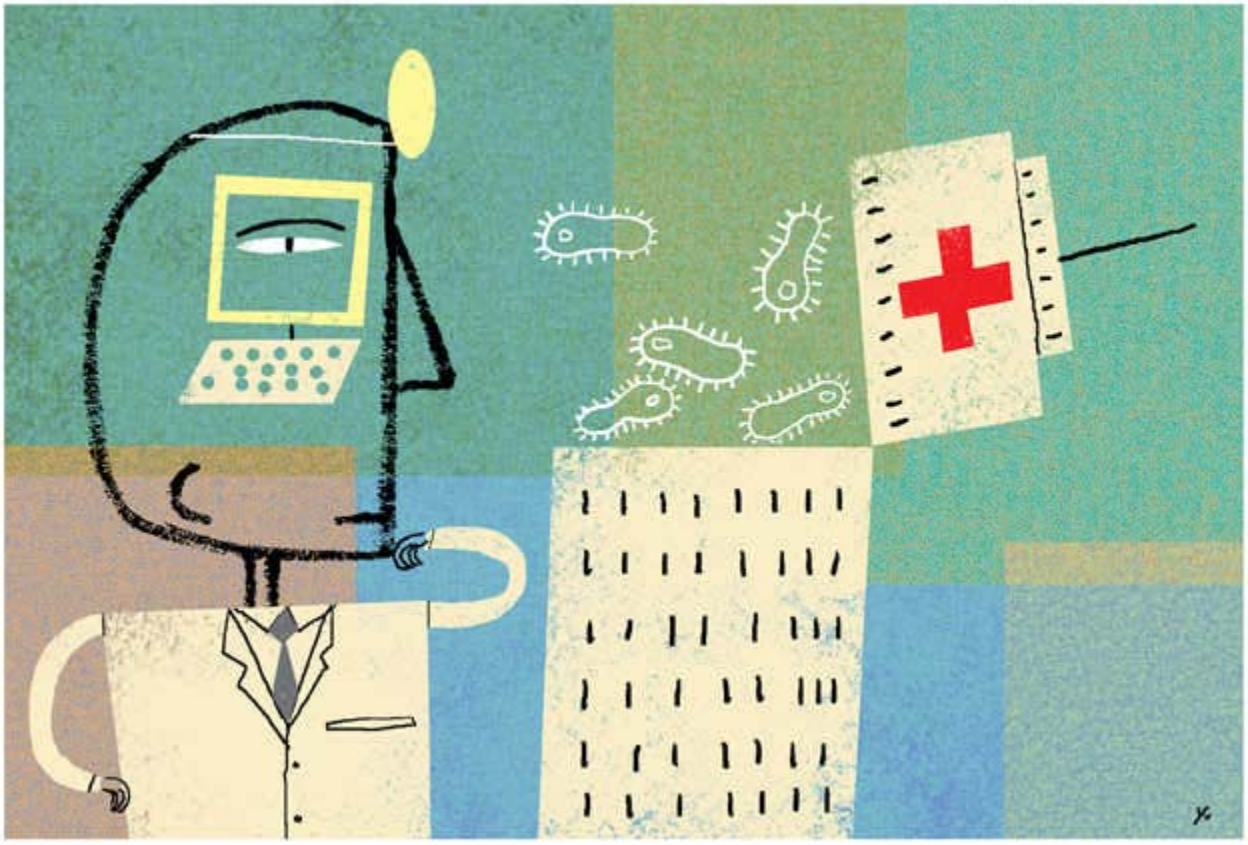

Using Computerized Registries in Chronic Disease Care

Prepared by First Consulting Group
February 2004

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Prepared for:

California HealthCare Foundation

Prepared by:

First Consulting Group

Author:

Jane Metzger

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About the Author

First Consulting Group is a leading provider of consulting, technology, and outsourcing services for health care, pharmaceutical, and other life sciences organizations in North America and Europe. More information about FCG is available at: **www.fcg.com**.

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, our goal is to ensure that all Californians have access to affordable, quality health care.

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Executive Summary

Chronic conditions are the major cause of illness, disability, and death in the United States, despite the fact that much is known about how to prevent chronic disease and delay or avoid many related complications. A systematic and comprehensive approach to caring for patients with chronic disease has been shown to improve the quality of chronic care delivery. This approach includes a range of interventions, such as case management, physician feedback, clinical information systems to track patient care, adoption of clinical practice guidelines, and a focus on patient self-management skills.

A disease registry is one type of clinical information system that is effective in supporting new models for delivering chronic care. By tracking patient information, a disease registry helps physicians and other members of the care team to identify and reach out to patients with gaps in care. It also prompts them to ensure that appropriate and timely care is provided during patient visits.

The first disease registries were developed in the 1980s at Group Health of Puget Sound and Lovelace Health System. Evidence of gaps in care for patients with chronic disease, combined with growing evidence that a more systematic approach improves outcomes, has led a growing number of provider organizations to adopt disease registries as a primary tool for improving chronic care. New programs, such as the Pay-for-Performance initiative in California, are also increasing the interest in and adoption of disease registries.

This report provides an introduction to the function and use of computerized disease registries, one option for improving patient information management. It is intended to help physicians, clinics, and medical groups get started in their own assessment of computerized tools to improve the management of patients with chronic diseases.

The disease registries discussed in this report are computer applications used to capture, manage, and provide information on specific conditions to support organized care management of patients with chronic disease. They provide physicians with three types of reports:

- *Printed patient reports* at the point of care provide information on specific conditions and prompt provider teams to conduct appropriate assessments, deliver recommended interventions, and capture information to update patient records.
- *Registry-generated exception reports* identify patients who are overdue for care or are not meeting management goals, and include important patient information—such as last visit and test dates—to develop an appropriate outreach strategy for each patient.
- *Aggregate reports* provide information about how well individual care teams and the overall provider organization are doing in delivering recommended care to the patient population.

Computerized registries generally require a database to store integrated patient information, as well as a software application that can sort the information into different views and reports as described above. This ability to provide multiple views of patient information makes computerized registries a more powerful tool for population management than the paper-based registries often used to track conditions such as cancer. Registries generally manage a much smaller amount of patient information than electronic medical records (EMRs), and focus on selected information relevant to one or more chronic diseases. Some EMRs for the physician practice also include registry functions for population management. This report focuses on stand-alone disease registries that are not integrated into an EMR.

There is no standard design for disease registries in use today, but the following list of characteristics help to differentiate one registry from another.

- **Source of registry application:** Software applications can be developed locally, purchased from a vendor, or obtained from one of several organizations offering registry applications for free (public domain).
- **Sponsorship:** A registry can be provided by the local medical practice or medical group, a quality improvement organization or clinic consortium, an independent practice association (IPA) or health plan, the federal government, or another organization such as a pharmaceutical company.
- **Technology hosting:** The software application and database can reside on a PC or networked server at the provider organization, or can be hosted by a commercial vendor or other external sponsor (where the data and software program reside) and are accessed over the Internet or private network.
- **Single or multiple condition:** A registry can manage a single disease or multiple conditions.
- **Stand-alone or integrated into an EMR:** A registry can be a separate application or part of a comprehensive electronic medical record.
- **Source(s) of patient information:** Data can be entered manually or through electronic feeds from sources such as practice management systems, claims systems, laboratory or pharmacy systems, or EMRs.
- **Configurability:** A software application can be pre-configured with data elements and pre-programmed with reports that cannot be modified, or it can be modified to collect

additional data or to provide reports specific to the care management goals of the provider organization.

Successful implementation of a disease registry requires physicians and medical groups to consider several important issues:

Select the registry that will support the chronic conditions of interest and track the desired care interventions. Each physician practice or medical group decides which conditions to tackle and which disease management guidelines to adopt. These decisions in turn define the information that should be collected in the disease registry. The design, configurability, and scalability of the registry application also need to support the way the practice expects to deliver chronic care over time.

Choose a suitable registry application that fits within technical and financial constraints. Physician practices and medical groups already planning to acquire an EMR should consider selecting a product that includes the functions of a disease registry, or one that can easily interface with a disease registry. A number of disease registry application options are available, either at no cost or a lower cost than an EMR. The technology for a stand-alone disease registry is fairly simple—involving one or more computer desktops and connection to the Internet or private network. Applications can be hosted locally on a PC or networked server or managed by a sponsor or vendor at another location. It is important to consider the pros and cons of maintaining patient information in a database under local control or of taking advantage of remote hosting, which requires less technical expertise. Regardless of where patient data reside, it is important to take appropriate measures to protect the security of patient information.

Ensure up-to-date, complete, and accurate patient information. Because of the burden of manual data entry, electronic feeds of data from practice management, laboratory, claims systems, or EMRs are highly desirable. Careful attention to the quality of the data is needed, regardless of the source of registry information. When data from external systems are used, daily feeds and successful patient matching are required. Even with electronic data feeds, local care teams must maintain patient lists and manually record data that are unavailable in electronic formats, as well as information on patient services obtained elsewhere and reasons for non-compliance with targeted interventions and services.

Integrate registry use into the workflow of the clinic or practice. Using a registry requires care teams to rethink how they prepare for and conduct patient visits, create new processes for following up with patients, and produce and distribute feedback reports. Practices and larger organizations profiled in this study all reported that successful transition to new processes is hard work. Each had at least one individual overseeing the registry and process elements of chronic disease management. A physician executive or clinical leader is also important for building and sustaining the program.

Physician practices starting work on a more systematic approach to chronic disease care can obtain information about disease registries and how they are used by participating in chronic disease collaboratives and attending conferences offered by groups such as Group Health of Puget Sound, the Institute for Health Care Improvement, and an increasing number of regional and state quality improvement organizations. Community health clinics also have access to a number of programs and publications offered by the Health Resources and Services Administration's Bureau of Primary Health Care.

I. Background

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.[1] The Institute of Medicine (IOM) singled out four chronic conditions—asthma, hypertension, diabetes, and coronary heart disease—among 20 priority areas for improving quality of care.[2]

There is growing interest in a more systematic approach to managing patients with chronic disease. This interest is due to a growing awareness of the large gap that exists in delivering care that can prevent or delay many of the complications of chronic disease. McGlynn et al. recently assessed gaps in care in a random sample of 6,712 adults in 12 different metropolitan areas. Patients with chronic disease received only 56 percent of recommended care; those with diabetes received only 45 percent of care known to reduce costly and debilitating complications.[3]

New comprehensive approaches for chronic disease care – incorporating a variety of interventions such as case management, physician feedback, clinical information systems such as disease registries, adoption of clinical practice guidelines, and a focus on patient self-management skills—were first developed at Group Health of Puget Sound in Washington and Lovelace Health System in New Mexico many years ago. Elements of this model have begun to spread more broadly to physician organizations thanks to nearly 10 years of programs organized by the MacColl Institute (www.improvingchroniccare.org), as well as other groups such as the Institute for Health Care Improvement (IHI) (www.IHI.org), the Institute for Clinical Systems Integration (ICSI) (www.icsi.org), and the Bureau of Primary Health Care, under the Health Resources and Services Administration (HRSA) (www.healthdisparities.net).

These comprehensive approaches to chronic care can be very effective at managing chronic disease.[4,5] According to one review,[5] 32 of 39 studies of interventions based on the model showed improvement in at least one process or outcome measure for diabetic patients; 18 of 27 studies involving three different chronic conditions also demonstrated lower health care costs and/or lower utilization of services. In *Crossing the Quality Chasm,* the Institute of Medicine IOM concluded, "The cur-

rent delivery system responds primarily to acute and urgent health care problems, emphasizing diagnosis, ruling out serious conditions, and relieving symptoms. 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."[6]

The IOM also emphasized the importance of "good information about patients and their care to improve outcomes." 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 multiple views of the information to support chronic care, including reminders during encounters, lists of patients needing follow-up, and reports providing feedback to physicians about how well their patients are doing. A growing number of clinics and physician organizations have adopted a computerized disease registry or an electronic medical record to provide this information support. Registries are usually focused on the information needed for specific chronic care conditions. Though cheaper and easier to implement than an electronic medical record, registries are a less comprehensive clinical system.

Physician organizations using disease registries

	Percent
Diabetes	40.3
Asthma	31.2
Congestive Health Failure	34.8
Depression	15.7

Survey of 1,040 physician organizations by Casolino et al.[7]

The IOM and others have identified numerous barriers to widespread adoption of new models for chronic care.[6, 8] A fundamental barrier is the lack of financial incentives for physicians to change practice to treat patients with chronic disease proactively. Recently large-scale demonstration projects have been launched to experiment with financial incentives:

- **Integrated Healthcare Association Pay-for-Performance**—a statewide effort of seven health plans in California to use common performance measures for health maintenance organization (HMO) members and to pay quality bonuses to physician groups based on that performance (www.iha.org).
- **The Physician Group Practice Demonstration**—a 3-year project of the Centers for Medicare and Medicaid Services (CMS) to pay physician fees for Medicare patients by using a bonus pool derived from savings achieved through improvements in care. (www.cms.hhs.gov).

These programs, combined with the expectation that the pay-for-performance model is likely to spread, are accelerating the incorporation of computerized tools such as disease registries into patient care.

Purpose of the Report

This report provides an introduction to the function and use of computerized disease registries, one option for improving patient information management. It is intended to help physicians, clinics, and medical groups get started in their own assessment of computerized tools to improve the management of patients with chronic diseases.

Practical information about the registries available today and how physician practices are integrating registries into regular workflow was obtained through attendance at collaborative learning sessions, discussions with registry pioneers, and interviews with current users in many different practice settings (see Appendix A). This report provides general information about disease registries and suggestions for getting started.

II. Introduction to Disease Registries

REGISTRIES FOR CHRONIC DISEASE MANAGEMENT are not new. In the late 1980s, Group Health of Puget Sound built one of the first registries—called a "clinically related information system"—regarded today as the pioneering effort in demonstrating the feasibility and value of using technology to track condition-specific information for use in primary care.[10] As disease registries have been adopted more widely, their definition and function have evolved along with a better understanding of how to manage a population of patients with chronic disease.

> *"Health care teams that have access to a registry can call in patients with specific needs, deliver planned care, receive feedback on their performance, and implement reminder systems."* Wagner et al.[9]

Definition and Functions

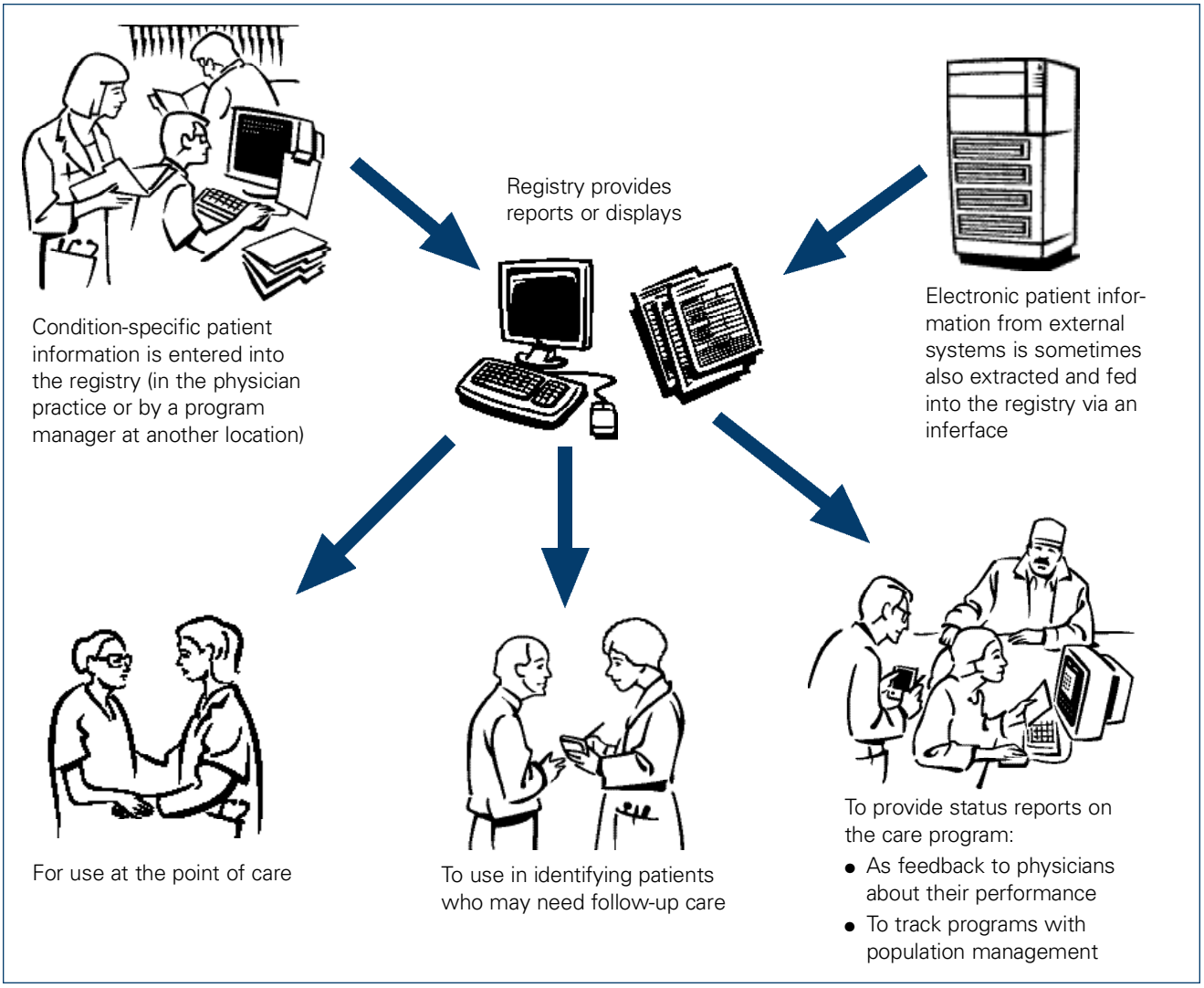
A computerized disease registry is a software application for capturing, managing, and providing access to condition-specific information for a list of patients to support organized clinical care.

Disease registries generally supplement rather than replace individual patient medical records and should support providers in the treatment setting. They help assure that data are complete, readily available, and arranged to make it easier for care teams to deliver appropriate care and follow-up to each patient. The different views and patient lists that a computerized registry can provide are a big advantage over paper-based registries, long used in health care to track information for patients with certain conditions (e.g., tumor registry).

Registries differ from electronic medical records (EMRs) in that they manage only selected information relevant to one or more chronic diseases rather than more comprehensive information about patient problems, health history, and care. Additionally, disease registries are designed to manage up-to-date lists of chronic disease patients so they can be tracked effectively. EMRs were designed primarily to support providers at the point of care, not necessarily to manage patient lists as needed for the ongoing management of a population of patients.

The basic functions of a disease registry are depicted in Figure 1.

Figure 1. Basic Functions of a Disease Registry



As shown, the major function of a disease registry is to provide multiple views of information about a list of patients for use in three situations:

- **At the point of care,** to provide patient-specific information (e.g., lab results, medication lists) and advice to support decision making (typically a report or display called a visit planner or patient profile and often including specific treatment recommendations),
- **Between visits,** for use in identifying patients with apparent gaps in care (patient lists, called exception or outreach reports), and
- **Periodically,** to provide status reports showing aggregate information about the patient population for use in gauging progress and continually improving care delivery (population reports).

Delivering these functions requires that the registry manage patient information in a database and include an application that can deliver multiple views of that information.

How a Registry Supports Chronic Disease Care

A registry provides critical information for the management of individual patient conditions. The basic registry functions described below are typically available in all disease registries; advanced functions are found in more complex designs.

Table 1. Basic and Advance Functions of Disease Registries

	Registry Functions	
Elements of Chronic Care Management*	**Basic**	**Advanced**
Ensure regular follow-up by the care team	• Track desired intervals for next visit, test, or contact based on care guideline. • Allow clinicians to record patient-specific interval for next visit or intervention. • Provide patient lists sorted according to overdue status (e.g., no HbA1c during last 6 months) or patient status according to management control (e.g., HbA1c>8.0 or personal goal). • Provide outreach or exception lists for each physician or care team.	• Provide telephone call lists and/or mailing labels and patient reminder letters for follow-up. • Display next appointment date for patients on outreach or exception lists.
Embed evidence-based guidelines into daily clinical practice	• Incorporate information about care management guidelines into reports and displays for care teams.	• Include prompts to recommend changes in patient care plan using guideline-based algorithms and patient-specific information.
Integrate specialist expertise and primary care	• Incorporate care guidelines for primary care with input from relevant specialists.	• Incorporate information about decision criteria for patient referral to specialist in patient displays and reports for care teams. • Include prompts recommending referrals for specific patients using guideline-based algorithms and patient-specific information.
Provide timely reminders for providers and patients	• Track desired intervals for next visit, test, or contact based on care guideline. • Allow clinicians to record patient-specific interval for next visit or intervention. • Include information about due date for visits and other interventions in patient reports and displays.	• Send email notification to physicians or care team when registry patients are seen in emergency department.
Identify relevant subpopulations for care	• Track information for identified subpopulations of patients with a designated chronic condition. • Manage the list of active and engaged patients for each PCP and care team.	• Assist with identification of new patients with a chronic condition by reviewing electronic information in external systems. • Stratify patients according to severity of condition.

*Improving Chronic Illness Care, www.improvingchroniccare.org

Table 1. Basic and Advance Functions of Disease Registries (continued)

Elements of Chronic Care Management*	Registry Functions	
	Basic	Advanced
Facilitate individual patient care planning	• Provide a condition-specific view of current patient status and progress.	• Recommend changes in patient care plan using guideline-based algorithms and patient-specific information.
Share information with patients and providers to coordinate care	• Patient information available to all members of the primary care team. • Record patient self-management plan for subsequent access by care team.	• Patient information available to case managers, specialists, and others involved in care. • Patient version available from registry including information on status, care plan, and self-management plan.
Monitor performance of practice team and care system	• Provide population reports for lists of patients and user-specified conditions of management control (e.g., HbA1c < 8) or guideline compliance status (e.g., two HbA1c tests in past year). • Provide tabular analysis of trends in any of the above. • Provide population reports for individual physicians and care teams, clinics, and medical groups. • Provide peer comparison reports for individual physicians and care teams and clinics.	• Provide graphic displays of trends in user-specified conditions of management control and guideline compliance in population reports.

*Improving Chronic Illness Care, www.improvingchroniccare.org

Types of Registries

There is no standard design or technology for disease registries. The following list of characteristics describes the differences in registry applications and the options available for new users.

Table 2. Differentiating Characteristics of Patient Registries

Types of Registries		
Characteristic	**Description of Possibilities**	**Explanation**
Source of Registry Application	• Homegrown (designed and programmed locally) • Commercial registry product • Open source or public domain (available free of charge from a government agency or other source)	Early registries were homegrown. Today they are also available for purchase or free access (sometimes only to participants in a particular program).
Sponsorship	• Local practice, medical group, or health system • Independent practice association (IPA) or health plan • Government agencies • Other group, e.g., pharmaceutical company	In additional to obtaining a registry on their own, physicians and medical groups can obtain registry software from other organizations that are also interested in improving chronic disease management.
Technology Hosting	• Registry application and database reside on a PC or network server at the provider organization. • Registry application and database are hosted by a commercial vendor or other external sponsor (e.g., IPA, health plan) at another location.	Remote access (via the Internet, a private network, or dial-up) has made registries more feasible in provider sites lacking IT infrastructure and management skills, but raise the need to address security concerns.
Single or Multiple Condition	• Single disease, such as diabetes or asthma • Multiple conditions with integrated reports for patients with multiple diseases	When separate disease-focused registries are used in the same patient population, separate displays and reports need to be consulted to manage any patient with multiple conditions; duplicate entry may be required for information such as weight and blood pressure.
Stand-alone Integrated into an EMR	• Separate application from EMR • Registry functions and displays part of EMR used in the practice	When an EMR is being used, ideally the care team consults one electronic source of condition-specific patient information and reminders; however, not all EMRs incorporate registry capabilities.
Source(s) of Patient Information	• Manual entry • Electronic feeds from practice management, claims, laboratory, pharmacy, or EMR systems or data warehouses • A combination of manual and electronic data	The more registry information obtained electronically from other systems, the lower the burden of manual data entry. Electronic feeds avoid possible transcription errors and often make it feasible to track a more comprehensive data set.

Table 2. Differentiating Characteristics of Patient Registries (continued)

Types of Registries		
Characteristic	**Description of Possibilities**	**Explanation**
Configurability	• Pre-configured with data elements to track for one or multiple conditions • Configurable to specific care management goals of provider organization (data elements, recommended time intervals, algorithms for patient-specific recommendations)	A configurable registry program permits the practice to change the data sets and visit planner to match the care management targets of the local program and to respond more quickly to changes in clinical knowledge. Ad hoc reporting permits the practice to design its own outreach and population reports.

III. Using Disease Registries

"The process of organized care is humbling. It is relatively easy to collect the registry data, much more difficult to act on it."

Dr. Charles M. Kilo
Greenfield Health
Portland, OR

"If a productive patient-clinician interaction is at the heart of a good visit, then information is the life blood flowing through that interaction."

Michael Hindmarsh
Improving Chronic Illness Care
Group Health of Puget Sound

To be effective, a disease registry must be an active tool used routinely by those within the practice (and possibly within the larger organization) who care for patients with chronic disease. The discussion below reviews how disease registries have typically been incorporated into three processes: treating patients, providing outreach to patients between visits, and assessing the effectiveness of a practice's efforts to deliver quality care.

Point of Care

When the patient is meeting with the physician, disease registries provide easy access to complete, relevant patient information through a printed patient report, sometimes known as a visit planner or patient profile. The report presents a snapshot of the patient's condition, both reminding the care team that the patient has one or more chronic conditions and saving them the time of searching for condition-specific information in the patient's medical record.[11, 12]

Many registries in use today provide further support by integrating clinical guideline-based prompts into the patient report or profile, such as:

- Guideline-based intervals for assessment, testing, and referrals (e.g., HbA1c every six months);
- Interventions that are overdue according to clinical guidelines; or
- Text from the guideline about recommended intervals for care or treatment.

More advanced, rules-based prompting incorporates patient-specific information and is able to generate customized care recommendations, such as:

- "Consider an ACE inhibitor or ARB with evidence of renal disease," where the diabetes patient has a co-morbid condition; or
- "Recommend next HbA1c testing at 90 days because patient is not at goal for glucose control," where a patient's health is falling short of the desired outcome.

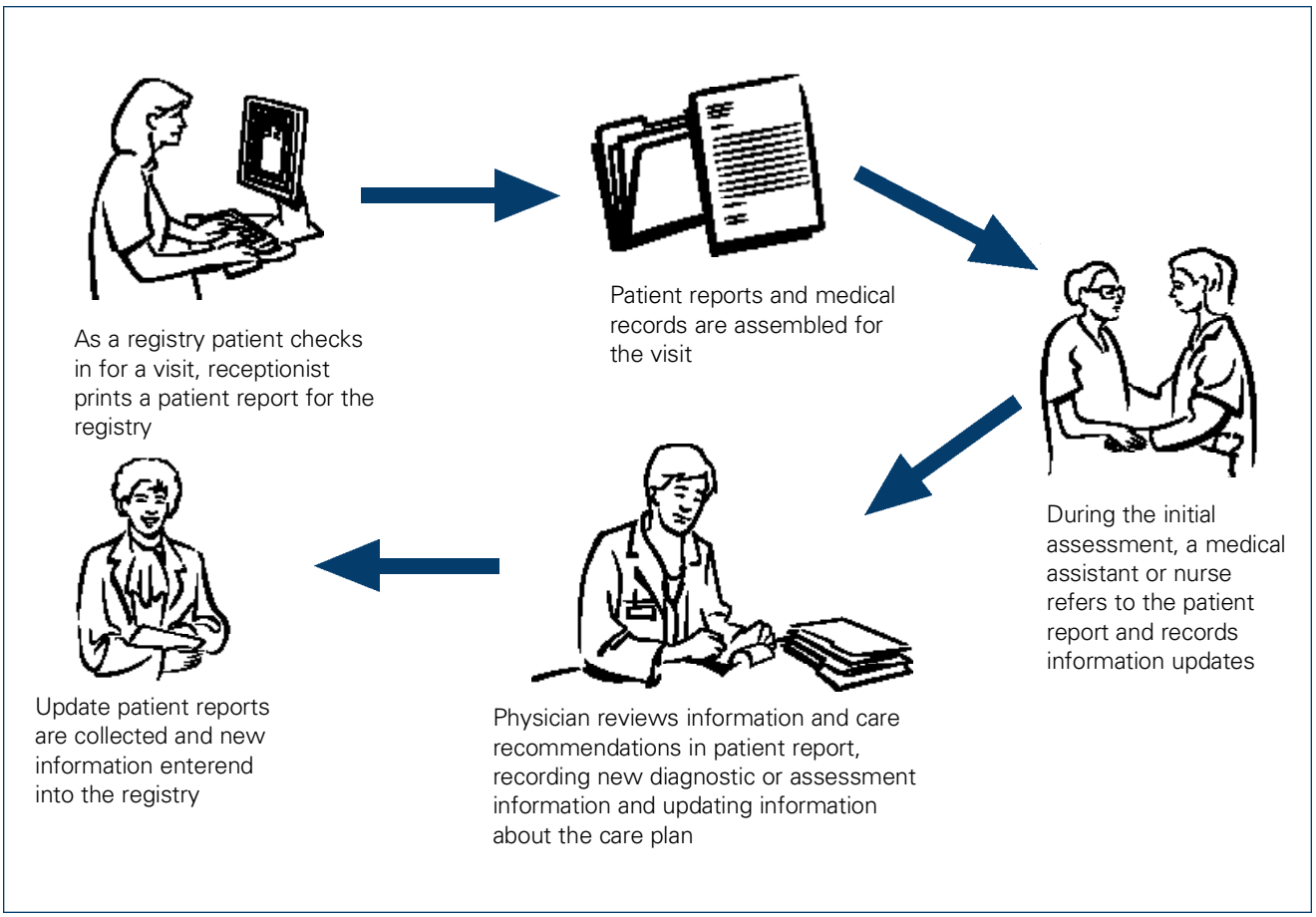
The patient report also records updates to patient information tracked in the registry for subsequent data entry. Some registry applications rely almost exclusively on information available from other electronic systems to minimize the time devoted to these tasks.

Figure 2 describes the use of a registry in a setting that is not fully automated. From a sticker on the patient's chart, the receptionist notes that the patient is on a registry, requests a printed patient report or flow sheet, and attaches it to the patient's chart. Registry patients might also be identified in the scheduling application used at the front desk, and, in some practices, the patient record is printed and filed in the medical record at the *conclusion* of each visit (to be referenced the next time) rather than printing a new one when the patient checks in.

The care team coordinates tasks to deliver services and update the patient report as required. Medical assistants and nurses use the registry report as they interview the patient, take and record vital signs, and order necessary services according to protocols for standing orders. Physicians can use the report for several purposes, including to:

- Communicate with care team members about new services to arrange before the patient leaves;
- Indicate to the receptionist when the next follow-up visit should be scheduled;
- Serve as the encounter note to be filed in the patient's medical record; and
- Record updates to patient information for entry into the registry.

Figure 2. Typical Workflow for Use of a Stand-alone Disease Registry at the Point-of-Care



Usually patient reports are collected for batch entry by a designated individual in the practice or at a central location, although sometimes a member of the care team performs this task.

Examples at the Point of Care

Figure 3 (see page 37) shows a visit planner from a locally developed ("homegrown") registry and used at Quello Clinic, an independent family practice medical group in six clinics (including urgent care) around Minneapolis-St. Paul, Minnesota. The visit planner integrates data for four diseases tracked by the registry—coronary artery disease, hypertension, congestive heart failure, and diabetes. Each patient's chronic diseases are indicated, and the bottom of the form only applies to patients with diabetes. Laboratory test results and dates are fed electronically into the registry. All other information is entered manually.

Figure 4 (see page 38) shows an example of the paper visit planner used at Center Jersey Physician Network, an independent practice association (IPA) with 40 primary care physicians in 10 different sites. The source is PatientPlanner™ (from DocSite, a commercial vendor), which is used to manage asthma and diabetes.

The medical director has set up the registry to track the specific interventions and intervals established by physician committees in the IPA. The example shown for diabetes provides a graphic display of the two major clinical indicators—blood glucose control and cholesterol level. Several areas of the form are designed for recording updates to key information, including entries that can be recorded in "today's action" or "today's answer." Due dates for interventions are calculated based on the service date recorded in the registry, or physicians can designate a patient-specific interval for particular interventions.

The visit planner shown in Figure 5 (see page 39) was locally developed by Physicians Medical Group, a 200-physician IPA in Santa Cruz, California. Electronic feeds from a practice management system, local laboratories, and health plan pharmacy claims are combined with manually entered information. The inclusion of information from pharmacy claims lets a physician determine whether or not prescriptions were actually filled. Customized patient recommendations are also incorporated, indicating, for example, the need for a retinal examination.

For the most part, care teams use paper copies of the patient profile, although they also have online access to the registry application. From the online view, providers can access clinical algorithms for recommendations generated by the software application and are able to send a copy of the visit planner to any referral physician involved in the patient's care.

A screen display from a registry integrated into an EMR is shown in Figure 6 (see page 40). At PeaceHealth, physicians and care managers use an EMR for prescription writing, documentation, and the management of lab results. The EMR now includes a diabetes registry jointly developed by PeaceHealth and IDX. Paper medical records are rarely used, and most care teams use this online version during diabetes wellness visits, although a printed version is also available. Care teams view a flow sheet display, including a time series view of the data tracked for diabetes care.

Much of the information needed for the registry—demographics, problem list, laboratory results, and prescription orders—is available from orders and documentation entered routinely into the EMR. Nurses and medical assistants, as well as physicians, enter additional information required in the diabetes registry, such as documentation of a foot exam or patient use of aspirin. For each data element, an extension screen structures the entry appropriately, as shown in (a) for a "yes/no" entry and in (b) for a year.

Outreach to Patients

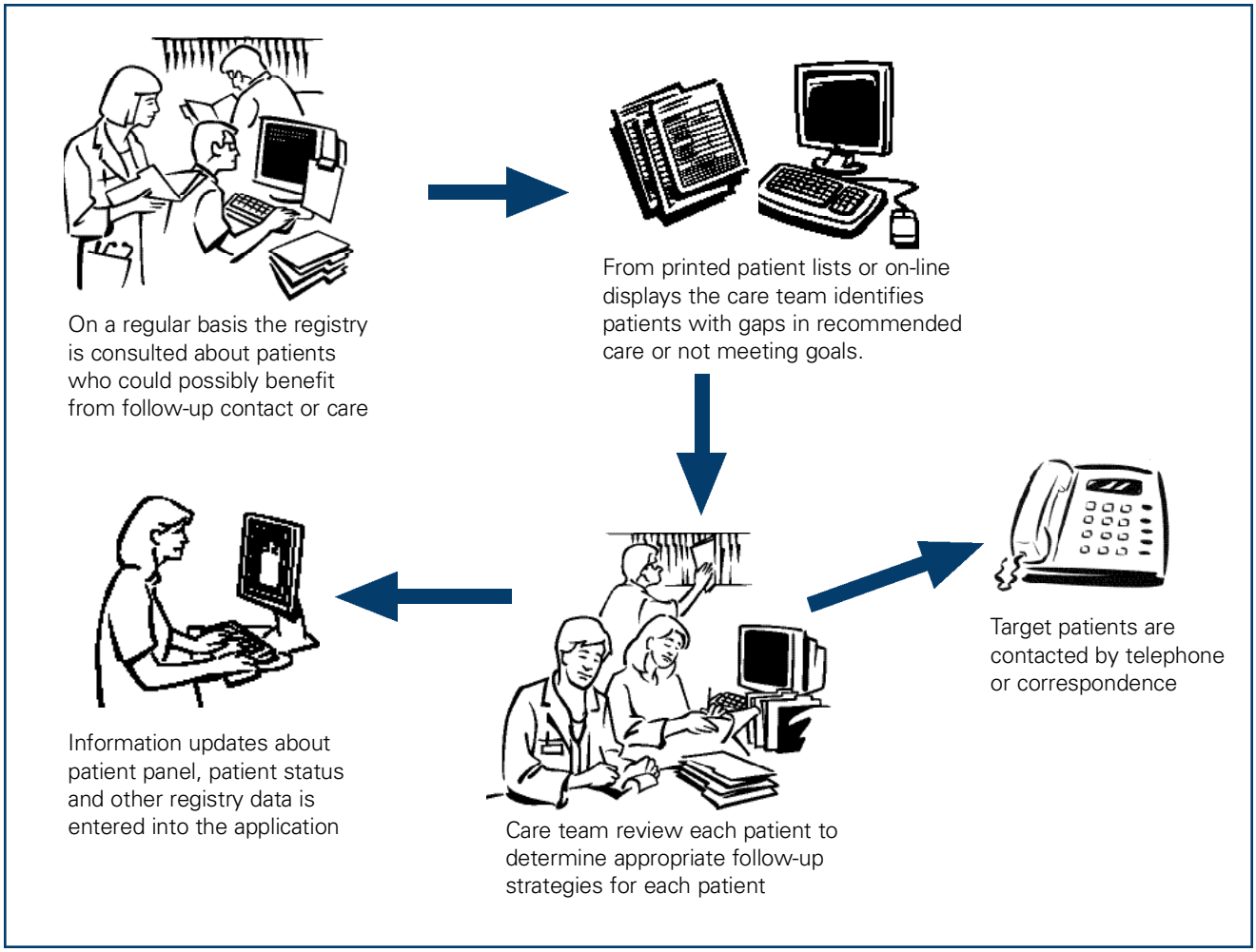
Tracking patients *between* visits to identify those who could benefit from follow-up care is almost impossible without a registry (or EMR incorporating a registry).

> *"The availability of a list of all patients and a few other key data elements presents opportunities to remind patients and physicians of needed follow-up or preventive services."* Wagner et al.[13]

The typical workflow in Figure 7 begins with a care team member reviewing a printed patient list or sitting at a computer terminal to view that information online.

Patient lists or displays can be requested for patients with different types of care deficiencies. The richer the registry's data set, the greater the possibilities for examining subgroups of patients. Most registries include standard reports and permit users to create patient lists for specific date ranges and interventions or status indicators.

Figure 7. Typical Workflow for Use of a Disease Registry to Identify Patients for Outreach



Examples of Types of Registry Exception or Outreach Reports for Groups of Diabetes Patients
Last visit more than xx days ago
Last HbA1c value over xx.x
No HbA1c value last xx days
No self-management goal last xx days
No retinal exam last xx months
No pneumovax in last xx years
Gap in medication refills > xx days

Care teams can use patient lists and other information such as future appointments already booked in the scheduling system to develop an outreach strategy for each patient. The next step is to contact targeted patients by telephone or correspondence. Some registries incorporate patient contact information in outreach or exception lists, others can produce telephone calls lists or mailing labels.

During the outreach process, care teams often become aware of problems with registry information—such as finding that the patient has moved or has a different primary provider, or discovering that the latest test information is missing in the registry. Care team members either enter updated information directly or communicate the changes to a designated person (or registry manager) via paper, telephone, or fax.

Effective implementation requires carving out sufficient time to review patient lists on a regular basis. Because the outreach process is new, the transition to integrate it into the practice routine often is more difficult than the changes in procedures around patient encounters.

Patient lists for outreach purposes are designed to allow care teams to examine different subgroups of patients with possible gaps in care. Registry applications support this function in several different ways.

"We have tried many approaches to institutionalizing outreach as a monthly activity:

- *First we sent exception lists directly to physicians with limited success.*
- *Next we sent them to clinic managers. Several were motivated to take action, but overall this wasn't successful either.*
- *We then managed to designate someone in each practice as a disease management specialist, with 2 hours allocated for each physician. The individual sat down with physicians to discuss patient lists and assisted in contacting patients. This worked reasonably well, but was hard to sustain due to severe cost pressure recently.*
- *Now we offer the assistance of a central resource person to help practices with any aspect of outreach. This is not quite as effective as the specialist role.*

Eventually we have to work toward each care team totally owning this process. That is logically where the responsibility lies and how to get the best results."

Randi Burnham, N.P., team leader,
Clinical Services, Bellin Medical Group
Green Bay, WI

Examples: Outreach

The outreach reports from a locally developed registry at Cambridge Health Alliance (CHA), a regional public health system in Massachusetts, can be viewed online by authorized users. Figure 8 (see page 41) shows one of several possible displays focused on patients with asthma.

Following the summary of registry patients on long-time control medications are lists of the actual patients. By clicking on any one of these displayed names, users can access a patient summary to help them as they consider possible outreach strategies. The CHA disease registry is populated with data from the hospital information system and permits users to access appointment information from any patient record in the registry application. This feature makes it much easier to to focus outreach efforts appropriately by determining which patients already have upcoming appointments.

Other reports available from the asthma registry show patients who were hospitalized or had a visit to the emergency room in the past year, including the reason for the hospitalization or emergency care. Another view shows the panel of patients by severity or without a recorded asthma action plan.

A different style of outreach report shown in Figure 9 (see page 42) is from the registry used by 13 primary care practices at Thedacare in northeastern Wisconsin. One designated person in each practice prints and distributes patient lists to care teams on a monthly basis. The registry tracks NCQA-recommended services and interventions for chronic disease and preventive care. Some of the tracked data are obtained electronically from claims processed by Touchpoint, a health plan partially owned by Thedacare. For patients with other insurance, care teams or disease management specialists in each practice enter missing information directly into the registry. In Figure 9, the source of data is noted, i.e., from claims or manual entry. The column "new pt" is for verifying that a new registry patient identified from claims information is indeed a panel patient and has diabetes. Above each data column in the report, prompts such as "2 per year" remind the care team of recommended intervals for interventions and services.

Population Reporting

A disease registry can also produce population reports with different views of aggregate information about the process and outcomes of care management. Registry applications typically offer a number of pre-configured that users can request for specific patient population(s) and/or date ranges.

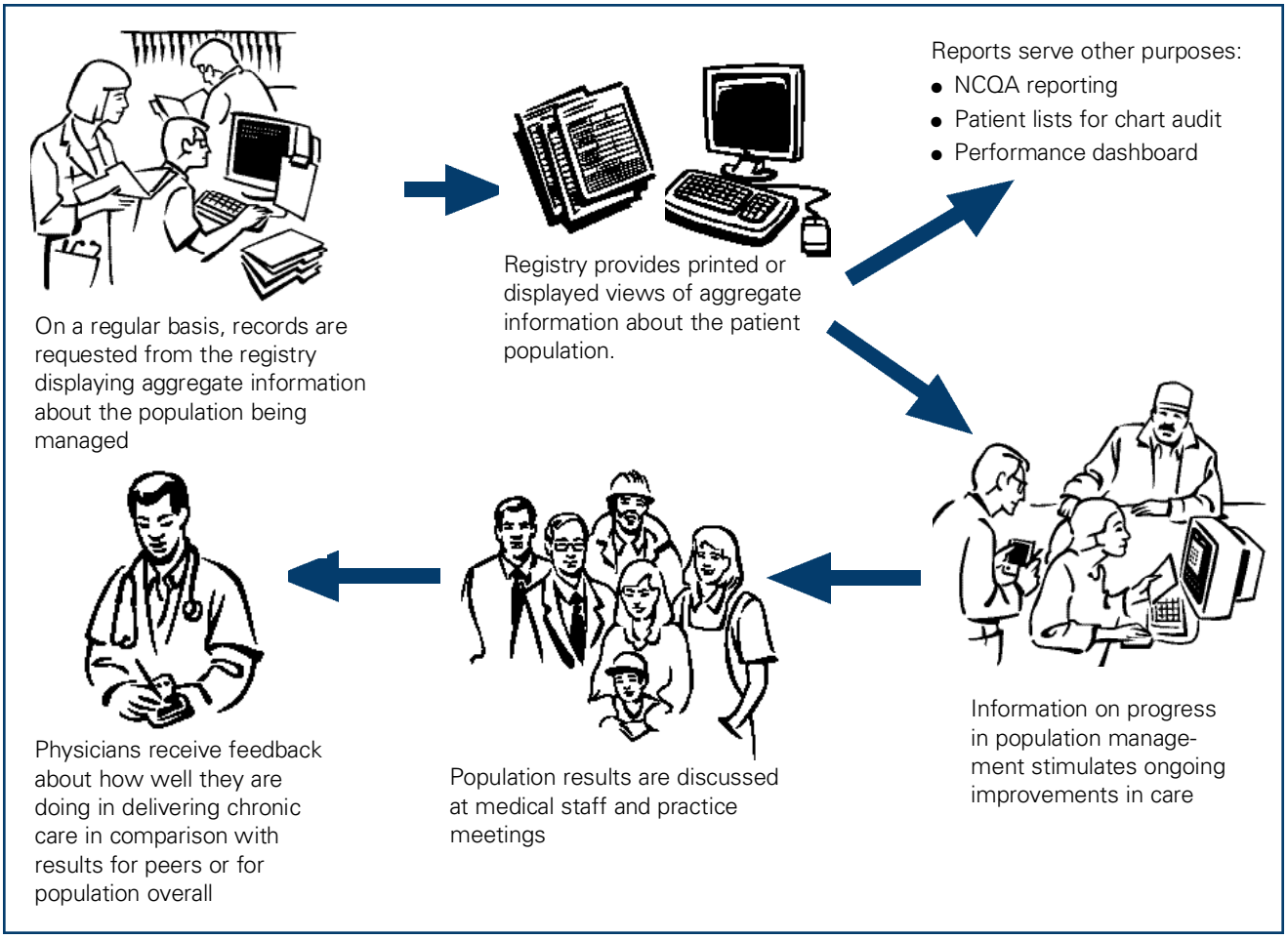
Two primary uses of population reports are shown in Figure 10: feedback to physicians about the status of their own patients and reports to the entire provider organization about the patient populations under its care.

Both reports provide a check on the actual progress made towards delivering recommended care. Physician feedback reports often include peer comparison data. Population reports often compare results for different practices and clinics, as well as show annual trends as a gauge of progress in the overall program.

> *"Distributing feedback reports did make a difference, especially with physicians who are low performers."*
>
> Sherry Catlin, M.D., medical director
> Florence Clinic, PeaceHealth

Often medical directors ensure that population management results are a regular agenda item at medical staff and practice/clinic meetings. Some larger organizations include results as one component of a regular performance report, which tracks a set of quality indicators (sometimes called a scorecard or dashboard).

Figure 10. Typical Workflow for Use of Population Reporting from a Disease Registry



"Part of the cultural change is realizing that the tasks of organized care management are constant and ongoing. Care teams are energized when they first get care organized in this way. After that the leadership of our medical director and feedback reporting become important to keep up the momentum and the energy."

Terry Murray, guidelines manager, Quello Clinic

Reports are also used by committees in the practice or larger organization that are responsible for continually improving care. These reports can lead to changes in the approach to delivering a particular intervention (such as setting patient self-management goals) or targeting specific care teams or practices for hands-on coaching or assistance with the care model.

Reports about patient populations come in many different formats, suited to different audiences and purposes.

Examples: Population Reporting

At Intermountain Health Care, regional medical directors periodically distribute printed feedback reports to the 500-physician medical group. Physicians and medical directors can also view population reports online over the intranet. Figure 11 (see page 43) shows an online view of trends in delivering recommended diabetes interventions for a physician's patient panel. Results for the physician (blue) are compared with those for the region (green) and health system as a whole (red). Other views of physician-level population reports include a provider detail report with a drill-down view to patient lists.

Figure 12 (see page 44) shows one type of population report available from CVDEMS, "freeware" developed for organizations participating in chronic disease management programs of the Bureau of Primary Health Care, HRSA/HHS. The registry application will segment this report for patients with diabetes or cardiovascular disease by clinic, by provider, or for the entire organization using the registry. The example shown is for diabetes. The three sections of the report provide a demographic breakdown of the population, visit-related information tracked in the registry, and then aggregated laboratory results. Users designate the desired date range when requesting reports.

Figure 13 (see page 45) comes from the diabetes management program in the Family Practice Center, a resident-staffed clinic at Sutter Medical Center of Santa Rosa. From CVDEMS, the registry application used for diabetes management, the program director exports data into a standard spreadsheet program and produces trend reports. The graphs include information about clinical goals, results for different subgroups of patients, and annotations showing when changes were instituted in diabetes care at the clinic.

IV. Considerations in Getting Started

EMR Investment Plans in Physician Practices

Already invested	31.6 %
Within 12 months	14.5%
Within the next 24 months	27.7%
Not in the foreseeable future	26.1%

National Survey of physician executives in 2002[14]

Choosing between a Registry and an EMR with Registry Functions

Since many physician practices plan to invest in EMRs at some point, physicians considering their options often review the tradeoffs involved in adopting a registry or EMR. Registries are cheaper to obtain and operate, but EMRs offer a greater range of functions and potential value.

When considering the purchase of an EMR, cost is always the major issue—not just the cost of acquiring the system, but also of implementing and maintaining it. In practices that can afford an EMR, it is important to verify that products being considered support registry functions. Two functions that are critical to maintaining the patient list and to capturing specific data elements are most likely to be missing.

Critical Registry Functions for EMR

Function	Explanation
Maintain patient list for purposes of ongoing disease management	Needed to identify active, engaged, and condition-appropriate patients for outreach and disease management program monitoring. Many EMR designs rely on patient problem lists.
Capture the specific information needed to track patient status and care for chronic disease management	Few EMR applications include fully structured notes in the product design or use. In the absence of these, mechanisms are needed for capturing coded information (to facilitate analysis) used to track patient status and care. Examples include family history and other risk factors, self-assessment scores, patient compliance with self-management practices, delivery of patient counseling, and services received elsewhere.

For more information about EMRs, refer to *Electronic Medical Records: A Buyer's Guide for Small Physician Practices.*

Choosing a Registry Application

Physician practices have several different options for obtaining disease registry software:

Build a registry from scratch. Several practices and health systems using registries today have developed their own applica-

tions; many have advanced features and are either stand-alone or integrated into a clinical system. User-developed registries are appealing because the builder retains complete control over functionality and can ensure that it meets local needs. On the other hand, development and ongoing maintenance require internal skills in programming and database management.

Download 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. Two examples of public domain registries are CDEMS (Chronic Disease Electronic Management Systems) and the Cardiovascular and Diabetes Electronic Management System (CVDEMS). The majority of the products were developed by agencies of the federal government or quality improvement organizations (QIOs) in various states. The tools are primarily simple, Microsoft Access-based, without sophisticated architecture or in-depth functionality. They are generally limited in the number of users and in the amount of data that can be used and stored efficiently. Their greatest advantage is that they are free and are relatively easy to use, although the physician practice may need a software license (for Microsoft Access).

Purchase commercial registry software. A small number of vendors sell private, stand-alone registry software. Commercial software often has a more sophisticated and scalable architecture; a large number of users can enter or view data simultaneously and the databases accommodate multiple conditions and are optimized for large amounts of data. Disadvantages of private software include the cost, customization options (sometimes involving additional cost), and the possible instability of the vendor. The cost of commercial products varies considerably and companies use a variety of pricing models, but they often range at $500 to 600 per user, per year.

Use a registry offered by a health plan, pharmaceutical company, or other external sponsor. Registry applications may be offered—for free or at a nominal price—by organizations with a common interest in improving chronic care, or whose business model is to provide registry services by hosting data. In these cases, where the application and database are hosted, how data and data access are managed, the adequacy of provisions for security and patient privacy, as well as other requirements for HIPAA, are important concerns. For some providers, it is important to retain all patient data in a database under local management. Others view remote hosting as a better fit with local skills and resources and feel comfortable that the data will be protected.

The registry's cost, installation and management complexity, and fit with the organization's processes for chronic disease management are all major considerations in choosing the right application. A companion report, *Chronic Disease Registries: A Product Review,*[15] details the characteristics of registry applications available today.

Costs to Consider

The monetary costs of implementing a disease registry are relatively low. The more substantial costs are in labor to manage and maintain the system and are more difficult to estimate.

Most registries are hosted locally in the physician practice on a PC or networked server, or they are hosted remotely and accessed over a high-speed line or via dial-up connection. Physician practices need one or more computer desktops and an Internet or intranet connection, both of which most practices already have.

Registry applications themselves can also be obtained without any financial outlay, either by using public domain software such as CVDEMS (although a license to Microsoft Access or other database application may be required) or obtaining it from a parent organization (IPA, health system) or other sponsor. Local programming of a registry is often carried out through the skill and motivation of internal staff member(s), rather than through hiring external resources. At Physicians Medical Group of Santa Cruz, the

Computer desktops in physician practices:

Reception/front office	92% of practices
Back office/billing area	89%
Administration	84%
Physician offices	82%

Type of Internet connection:

T-1	45% of practices
DSL	36%
Dial-up	13%
Cable Modem	12%
Other	3%

HIMSS/AstraZeneca Survey[16]

approximately $100,000 programming effort was largely funded through grants. In some larger organizations, the resources of the corporate IS Department can be focused on this effort.

Costs of commercial registries typically vary with practice size and support services included in the agreement, but are generally lower than costs of EMR products. For example, a Patient Planner™ from DocSite can be obtained for about $500 per physician, per year.

The "soft" costs of setting up and managing a registry, however, can be substantial and should be considered before committing to using the tool. A significant amount of labor is required to enter and update patient data, generate patient lists, conduct outreach programs, and generally maintain the registry. For the most part, tasks related to the registry are absorbed by existing staff. The challenge is to find enough time in the busy environment of a primary care practice to accomplish the necessary work.

"I wish I could get more people to do a registry. It works and it isn't expensive. We developed our own and have reorganized work rather than added staff."

Terry Murray, guidelines manager, Quello Clinic

The Registry Data Set

The data collected in a disease registry depends upon what care interventions care teams want to deliver and the data needed to track delivery to their patients. Guidelines for disease and wellness management are available today from numerous credible sources including the Agency for Healthcare Research and Quality (www.guidelines.gov), Institute for Clinical Systems Integration, the American Diabetes Association,

Table 3. Possible Sources of Disease Registry Data: Specific Example of the Integrated Healthcare Association Pay-for-Performance Measures for Asthma and Diabetes Management

		Measures and Sources		
Measure	**Claims/Practice Management**	**Pharmacy/ Medication Claims**	**Laboratory**	**EMR/ Manual Entry**
Asthma				
Patients with persistent asthma receiving dispensed inhaled corticosteroids (three age groups)	Patient demographics (age) and insurer	Prescription for inhaled corticosteroids		Severity of disease (intermittent or persistent)
Diabetes				
Patients with Type 1 or 2 with evidence of HbA1c screening (18-75 years)	Patient demographics (age) and insurer, date of HbA1c test	Patients on insulin or oral hypoglycemic	Date of HbA1c test	

and others. Clinical committees typically use these as their starting point for determining the care recommendations for their medical group or health system, which in turn help define the desirable information set for the registry.

"We have gotten pretty good at making progress in small steps, rather than boiling the ocean with the ideal, mega-list of data to track. With diabetes, we started with 8-10 data elements."

John Haughom, M.D., senior vice president
Healthcare Improvement, PeaceHealth

"We've learned the importance of including staff who will ultimately be responsible for entering registry information in coming up with the data elements to be tracked. That's the ideal time for a reality check."

Irina Gruben, quality data analyst
Cambridge Hospital Alliance

Oftentimes, clinical committees responsible for disease management programs wish to track a larger data set than is practicable because having more data always seems better. In the end, the

Table 4. Possible Sources of Disease Registry Data for the Diabetes Quality Improvement Project

	Measures and Sources			
Measure	**Claims/Practice Management**	**Pharmacy/ Medication Claims**	**Laboratory**	**EMR/ Manual Entry**
HbA1c testing (at least one per year)			HbA1c+	
Highest risk HbA1c level (>9.5) and glyco-hemoglobin control distribution			HbA1c*	
Monitoring for nephropathy (screening within last 2 years under stated conditions)		Patient on insulin	Screening test for microalbuminuria* (four possible) HbA1c +	Patient on insulin, documentation of assessment of nephropathy
Lipid profile (last 2 years) and LDL-cholesterol control (<130 mg/dL); lipid control distribution	LDL-C+		LDL-C*	
Hypertension control (<140/90) and blood pressure distribution				Blood pressure
Eye exam (dilated, in the past year under stated conditions based on HbA1c)	Eye exam+ (CPT)	Patient on insulin	HbA1c*	Documentation of eye exam/ retinopathy (Y/N) and assessment date
Comprehensive foot exam (protective sensation, vascular status, visual inspection)				Documentation of exam components

*Date and value.
+Date

ideal data set is usually scaled back to be more realistic. In addition, once core data elements are fully implemented, it is usually possible to add additional elements once care improvements have been made and the entire care team understands (and agrees with) the importance of using a registry.

Sample data sets and possible data sources are shown below for the pay-for-performance measurement sets for asthma and diabetes from the Integrated Healthcare Association.[17] These data elements constitute the information needed to participate in the pay-for-performance program.

As shown in Table 4, more comprehensive data would be required to be in accordance with the

Table 5. Possible Sources of Disease Registry Data Needed for Selected Guidelines for Hypertension Management from JNC7

	Measures and Sources			
Guidelines*	**Claims/Practice Management**	**Pharmacy/ Medication Claims**	**Laboratory**	**EMR/ Manual Entry**
Recommend lifestyle modification if systolic BP ≥120 mmHg or diastolic BP ≥80 mmHg	Demographics (age)			Blood pressure, lifestyle modification counseling
Thiazide-type diuretic if systolic BP = 140-159 mmHg or diastolic BP = 90-99 mmHg	Demographics (age)	Thiazide-type medication dispensed		Blood pressure
Two-drug combination if systolic BP ≥160 mmHg or diastolic BP ≥100 mmHg	Demographics (age)	Thiazide-type diuretic and ACEI or ARB or BB or CCB dispensed		Lifestyle modification counseling
If systolic BP ≥140 mmHg or diastolic BP ≥90 mmHg and other cardiovascular risk factors, treat with recommended drug classes		Thiazide-type diuretic, ACEI, ARB, BB, or AldoANT dispensed (appropriate to indication)		Blood pressure, heart failure, post-MI, high coronary disease risk, diabetes, chronic kidney disease
Creatinine, HDL, LDL, microalbumin, and total cholesterol if systolic BP ≥140 mmHg or diastolic BP ≥90 mmHg	Laboratory tests performed+		Laboratory tests performed+	Blood pressure
With HTN and diabetes or renal disease, treat to <130/80 mmHg	Coding on claims			Problem list, blood pressure

*For adults

Note: EMR would likely also include information on medications prescribed and laboratory tests performed, but not necessarily test results or what was dispensed.

ACEI = Ace Inhibitor. ARB = Angiotensin Receptor Blocker. BB = Beta Blocker. CCB = Calcium Channel Blocker. AldoANT = Aldosterone Antagonist.

performance and outcome measures recommended by the ADA/NCQA for the Diabetes Quality Improvement Project[18] (www.ncqa.org/DPRP/).

For some disease management guidelines, critical patient information includes vital signs and other observations recorded electronically only in an EMR. Table 5 lists selected guidelines for hypertension management from the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure.[19] This type of information almost always has to be entered manually into a disease registry.

Automating Data Entry into a Disease Registry

Because manual data entry into the registry places a burden on local practices and care teams, electronic sources of patient information are highly desirable. However, several factors make downloading electronic information from external systems and integrating it into a disease registry difficult:

- There are currently no processes or procedures that enable provider organizations, health plans, and laboratories to exchange data in a smooth, consistent, and efficient way. Agreements about how and when data will be exchanged must be negotiated, and even then data may not be delivered in a timely manner.
- The lack of uniform standards for the format and coding of laboratory and pharmacy data significantly complicates the process of integrating the data from multiple systems. Either the provider organization must build an electronic interface that converts the various formats and coding schemes into one, or this conversion process must be done manually and on an ongoing basis.
- Correctly matching data to a specific patient is also difficult because unique patient identification numbers do not exist. Most data sources (e.g., laboratory and pharmacy systems) use patient identification numbers that can not be tracked outside of the sponsor organization and/or are internally inconsistent. Error rates in the electronic matching process can be substantial and significant manual matching is required to ensure data integrity.

Ultimately, the possibilities for feeding electronic data into a registry depend upon local systems, technical features of feeder systems and the registry application, the availability of necessary technical skills to develop and manage interfaces between systems, and, in many cases, the willingness of other organizations—such as a local hospital or commercial laboratory—to collaborate in the effort. Automation is more feasible in larger organizations that operate clinical laboratories and/or have resident IT specialists than in the typical, small primary care practice. In smaller practices with electronic data feeds to the registry and without the resources of an IS staff, at least one individual is required with enough technical savvy to manage interfaces and uploading of data files

> *"Getting the cooperation of commercial laboratories to feed us electronic test results for our registry was surprisingly difficult, given that this is clearly the right thing to do. In the end, I appealed to local employers who fully supported the use of our registry as a tool to deliver better patient outcomes."*
>
> Dr. Jim Barr, medical director
> Central Jersey Physician Network

Identifying Patients to Track in the Disease Registry

Identifying all of the patients with a chronic disease is itself a major task when physician practices first set up patient registries. Practice management or claims systems can provide a list of candidates based on ICD-9 coding for patient encounters as a starting point. Other external systems can also provide initial lists of patients with the targeted conditions, as shown in Table 6.

> *"One value of the registry is that many physicians don't grasp the enormity of their chronic disease population."*
>
> Evan Steffens, R.N., M.S., quality manager
> Primary Care Networks
> Premier Health Partners

Searching claims or practice management systems for patients with two encounters with the target diagnosis in the past year helps to narrow down the search from a claims or practice management system. However, the physician or care team ultimately needs to verify that each registry patient is a current patient of the practice and actually has the condition in question because coding for billing is imprecise and subject to error.

Two different approaches can be taken to populating the data fields in a registry:

- Identify potential registry patients in advance. Verify patient status and build the registry record based on information obtained at the patient's first visit.
- Identify potential registry patients in advance and pre-populate their records by pulling information from medical records or downloading information from electronic feeds. Verify patient's status and update relevant information at the patient's first visit.

The second option speeds up the availability of registry support to patient care. However, both require personnel resources in scarce supply in most physician practices.

Table 6. Data Available in External Systems for Use in Identifying Patient Candidates for a Disease Registry

Data from an External System			
Claims/Practice Management	**Pharmacy/ Medication Claims**	**Laboratory**	**EMR/ Manual Entry**
ICD-9 code(s)	Prescription for medication typically used to manage condition (e.g., insulin or oral hypoglycemic for diabetes, inhaled corticosteroids for asthma, specified antihypertensive medications for hypertension)	Results of indicator laboratory test (e.g., HbA1c for diabetes)	Problem list documented vital signs (e.g., blood pressure)

Ensuring Data Quality

"Inaccurate patient rosters and wrong data will kill a registry in no time, and we think coding is the greatest source of error. So we involve the physician practices in keeping both correct."

Wells Shoemaker, M.D.
Physician's Medical Group of Santa Cruz

Patient information in registries must be up-to-date and complete if physicians and other members of the care team are to rely upon the data. A clean patient list is essential for both outreach and feedback reporting. Patients move, change primary care physicians, or die, and others do not wish to receive reminders about their care. Unless the records for these patients are changed to an inactive status, the care team stands to waste time (and possibly annoy patients and families) in outreach, and registry population reports present an inaccurate picture of the actual patient population. Regardless of whether manual data, electronic feeds, or a combination are used in the registry, careful attention must be paid to data quality.

In order to ensure data quality, organizations set up specific processes for managing the information and reviewing the data from electronic sources. In some practices, a nurse or medical assistant reviews the registry visit planner before each patient visit, noting information updates from recent laboratory tests or consult reports available in the medical record. Ancillary providers also query the patient for updates as they take vital signs and provide other pre-visit services. Some registry software applications provide lists of patients with missing data. Care team meetings to strategize about patient outreach also provide a natural opportunity to identify and address information gaps. Ultimately, the care team is responsible for the accuracy of information on every registry patient.

The most common approach to correcting data is for care team members to submit updates via telephone or fax to a central registry manager or to enter data locally into a patient status or data field in the patient's record. When electronic data are used, daily feeds are important to keeping laboratory results, in particular, up to date. In registries that are integrated into larger clinical systems, real-time updates are possible. Whenever data from an external system are employed, patient matching algorithms need to ensure that the information ends up in the right patient record in the registry. Patient matching is easier with internal systems such as practice management software that is locally managed than with commercial laboratories. Commercial labs may carry only a minimal set of patient-identifying information in each result report and manual entry of patient-identifying information in the laboratory can be a source of additional errors.

Implementation

"Just grafting a registry onto the clinic doesn't work. You have to change how work flows and care is delivered."

Sean Gaskie, M.D., Family Practice Center
Sutter Medical Center of Santa Rosa

Once the physician practice or medical group has decided to use a disease registry and has selected the application, attention turns to the tasks of implementation. Using a registry requires rethinking how care teams prepare for and conduct patient visits; it also requires the creation of new processes for following up with patients and producing and distributing feedback reports. Change is always difficult, especially in an extremely busy work environment like the primary care practice or community health center. Decisions about new roles and new processes must be group decisions because every physician needs to support the new approach to sustain the change.

In organizations of all sizes, someone with influence must be designated to oversee the registry and its use. Often a lead physician or chief medical officer wears this hat, assisted in larger organizations by a small staff of nurse facilitators. Nonphysicians are key participants, because receptionists and every member of the care team plays a role, often a bigger role than the physicians. Both at Thedacare and Bellin Medical Group, a nurse or administrator in each practice has time dedicated each week to run registry patient lists and work with care teams on outreach.

Many physician practices obtain information about the practical aspects of rethinking their care model for chronic disease and integrating the registry into work flow through conferences or working with other organizations in a chronic disease collaborative. Groups such as the Bureau of Primary Health Care, MacColl Institute of Healthcare Innovation at Group Health of Puget Sound, and local and regional quality improvement organizations offer programs that focus on chronic care. Community health centers can participate in programs sponsored by the Bureau of Primary Health Care, HRSA. Physician practices in California now also have access to programs to help them prepare for the Integrated Healthcare Association's Pay-for-Performance program [www.iha.org].

"The DCQI process infused us with fresh energy in 2001 with access to encouraging, smart people, and an expanded sense of the possible."

Wells Shoemaker, M.D., medical director
Physicians Medical Group of Santa Cruz

The Bureau of Primary Health Care offers one training manual on the general topic of chronic care and three others on asthma, depression, and diabetes management (www.healthdisparities.net/training_manuals_and_tools.html). Another manual on cardiovascular disease is in preparation.

Appendix A: Interviewees from Provider Organizations

Bellin Medical Group
Green Bay, WI

Randi Burnham
Team Leader
Clinical Services

Cambridge Health Alliance
Cambridge, MA

Irina Gruben
Quality Data Analyst II

Astrid Lambert
Quality Systems Manager

Kristin Wagner
Clinical Nurse Specialist, Mental Health

Dr. Hilary Worthen
Director, Clinical Informatics

Central Jersey Physician Network
Central New Jersey

Dr. Jim Barr
Medical Director

Deer Lakes Medical Association
Pittsburgh, PA

Dr. Joel Diamond
Medical Director

Family Practice Center
Sutter Medical Center, Santa Rosa
Santa Rosa, CA

Dr. Sean Gaskie
Director of Special Programs

Greenfield Health System
Portland, OR

Dr. Charles M. Kilo
Internist

Ideal Health of Brighton
Rochester, NY

Dr. Gordon Moore
Internist

Intermountain Health Care
Salt Lake City, UT

Dale Hale
Senior Outcome Analyst, Primary Care
IHC Institute for Health Care Delivery and Research

Ilene Tippets
Program Development/Implementation Facilitator
Primary Care Clinical Program

Luther Midelfort
Westcentral Wisconsin

Dennis Pope
Vice President, Administration

Peace Health
Alaska, Washington, and Oregon

John Haughom, M.D.
Senior Vice President, Health Care Improvement

Sherry Catlin, D.O.
Medical Director, Florence Clinic

Physicians Medical Group, Santa Cruz
Santa Cruz, CA

Dr. Wells Shoemaker
Medical Director

Prairie Community Health
Isabel, SD

David Rollason, P.A.-C.

Primary Care Networks, Premier Health Partners
Dayton, OH

Evan Steffens, R.N., M.S.
Quality Manager

Quello Clinic
Minneapolis-St. Paul, Minnesota

Terry Murray, M.Ed.
Guidelines Manager

Redwood Community Health Coalition
Sonoma, Napa, Yolo, and Marine Counties
Northern California

Adrianne Bowes, R.N., C.P.H.Q.
Director of QI Programs

Cathy Frey
Health Policy and Resource Director

Anthony Stever
Chief Information Officer

Thedacare
Northeast Wisconsin

Sherry Clarke, R.N.
Clinical Quality Consultant
Disease Management and Prevention
Thedacare Physician Services

Appendix B: Profiles of Organizations Using Patient Registries

				Use		
Organization*	**Registry Software**	**Data Sources**	**Patient Conditions Tracked**	**Point of Care**	**Outreach**	**Program Monitoring**
Bellin Medical Group, northeastern WI —18 clinics	Homegrown Hosted on network server Accessed over intranet	Manual entry Electronic: HIS, Health plan claims	Diabetes Coronary artery disease Hypertension Preventive services		✔	✔
Cambridge Health Alliance, Cambridge, MA —12 primary care clinics	Homegrown Hosted on network server Accessed over intranet (clinics) or via dial-in (school nurses)	Manual entry Electronic: HIS	Adult diabetes,++ pediatric asthma++ Depression++	✔	✔	✔
Central Jersey Physician Network (IPA) —16 practices	PatientPlanner™ from DocSite Hosted on central server Accessed from practices over high-speed line	Manual entry Electronic: laboratories	Diabetes, asthma	✔	✔	✔
Deer Lakes Medical Association, Pittsburgh, PA— four practice sites	SMART™ Registry (Health Dialog) from Highmark, accessed via CD-ROM	Manual entry; health plan claims	Asthma Coronary artery disease Congestive heart failure Chronic obstructive pulmonary disease Diabetes		✔	✔
Family Practice Center, Sutter Medical Center, Santa Rosa, CA— resident-staffed clinic	CVDEMS Hosted on network server Accessed over intranet	Manual entry	Diabetes	✔	✔	✔

* Number of clinics/practices using disease registry.
\+ Not all practices/clinics use registry at point of care.
++ Separate registries.
§ EMR used at the point of care.

Appendix B: (continued)

Organization*	Registry Software	Data Sources	Patient Conditions Tracked	Use		
				Point of Care	Outreach	Program Monitoring
Greenfield Health, Portland, OR—one clinic	Homegrown Hosted on local PC	Electronic: EMR	Preventive care, diabetes, hypertension, CAD/MI, hypothyroidism, osteoporosis	§	✔	✔
Ideal Health of Brighton, Rochester NY—solo internal medicine practice	PatientPlanner™ from DocSite Hosted on local PC	Manual entry	Diabetes, asthma	§	✔	✔
Intermountain Health Care, UT—500 physicians	Homegrown Hosted on network server Accessed over intranet in clinics	Manual entry Electronic: health plan claims, Laboratory manual entry	Diabetes Congestive heart failure Asthma Otitis	§✔	✔	✔
Luther Midelfort—west-central WI—being rolled out	PatientPlanner™ from DocSite Hosted on central server Accessed from practices over high-speed lines	Electronic: laboratory, practice management system	Diabetes Congestive heart failure Prevention	✔	✔	✔
Peace Health, health system in AL, WA, OR—200 employed physicians	Integrated into EMR (co-developed with IDX)	Electronic: EMR	Diabetes	✔	✔	✔
Physicians Medical Group of Santa Cruz, CA—being rolled out	Homegrown Hosted on network server Accessed via Elysium clinical messaging system	Manual entry Electronic: laboratory (Elysium), practice management system, pharmacy claims	Diabetes	✔	✔	✔
Prairie Community Health, Isabel, SD—two small rural clinics	PECS Hosted on network server at each site Accessed on network PC	Manual entry	Diabetes, asthma	✔	✔	✔

* Number of clinics/practices using disease registry.
\+ Not all practices/clinics use registry at point of care.
++ Separate registries.
§ EMR used at the point of care.

Appendix B: (continued)

				Use		
Organization*	**Registry Software**	**Data Sources**	**Patient Conditions Tracke**	**Point of Care**	**Outreach**	**Program Monitoring**
Primary Care Networks of Premier Health Partners—36 primary care practices	PreCare, add-on module to Vitalworks practice management system Hosted on network server Accessed over intranet	Manual entry Electronic: practice management system	Preventive care, diabetes, hypertension, heart disease	+✔	✔	✔
Quello Clinic, Bloomington MN—six family practice clinics	Homegrown Hosted on network server Accessed over intranet	Manual entry Electronic: laboratory	Diabetes, coronary artery disease, congestive heart failure, hypertension	✔	✔	✔
Redwood Community Health Coalition, Santa Rosa, CA—12 community health centers	CVDEMS Hosted locally on PC at each site Some clinics have local network	Manual entry	Diabetes, prevention of diabetes and heart disease++	+✔	✔	✔
Thedacare, northeast WI, 21 primary care practices	Homegrown Hosted in corporate IS Accessed in practices over intranet	Manual entry Electronic: claims, laboratory	Diabetes, coronary artery disease, Prevention	✔	✔	✔

* Number of clinics/practices using disease registry.
\+ Not all practices/clinics use registry at point of care.
++ Separate registries.
§ EMR used at the point of care.

Appendix C: Examples of Computerized Disease Registry Tools

Figure 3: Visit Planner from Disease Registry at Quello Clinic

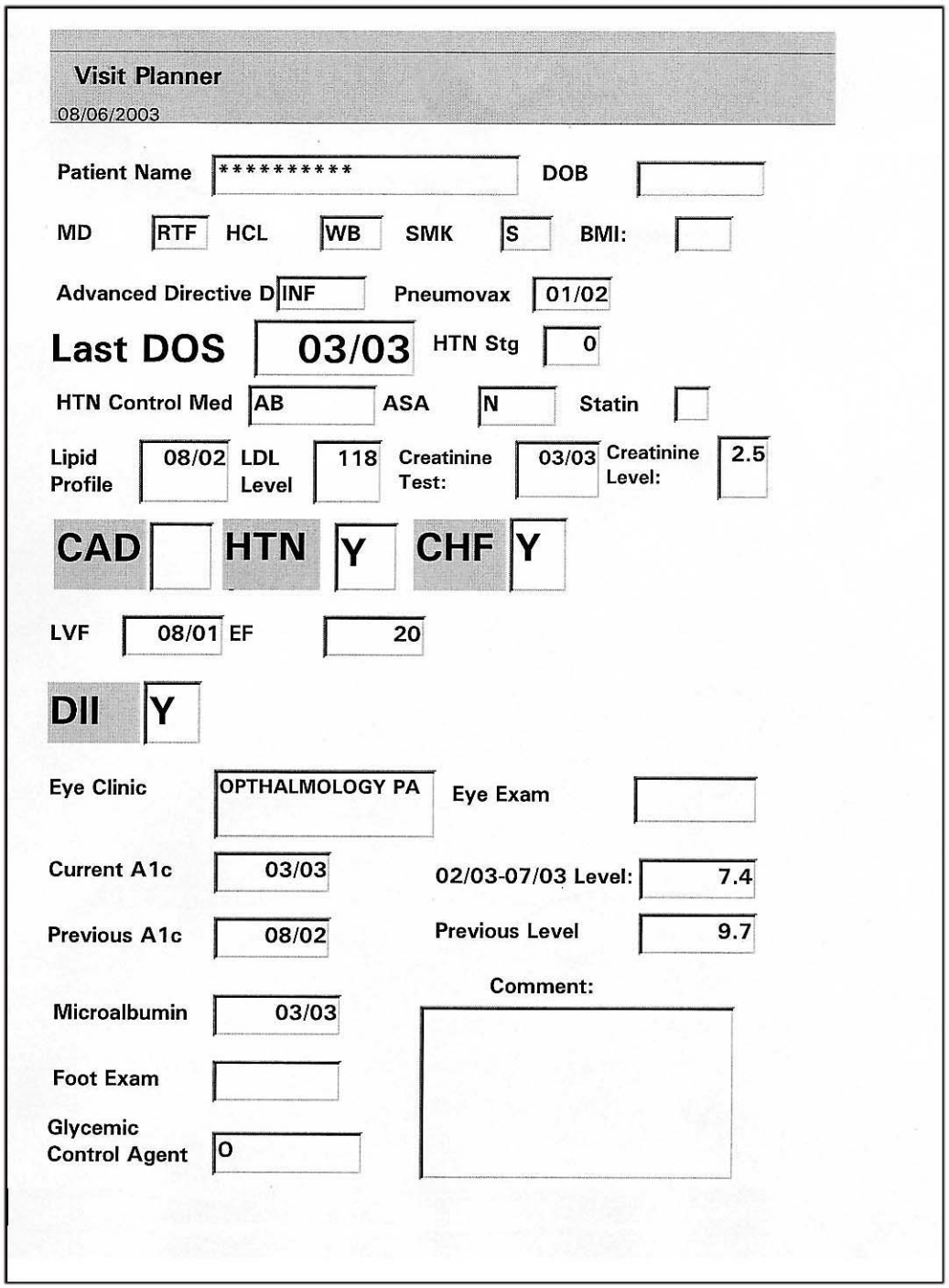
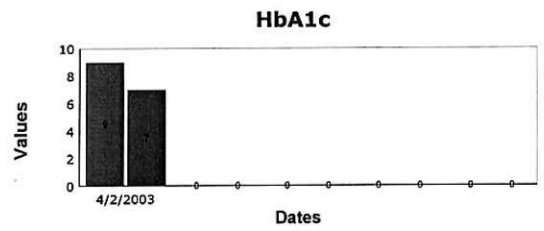


Figure 4: Visit Planner from DocSite Registry Used at Central Jersey Physician Network

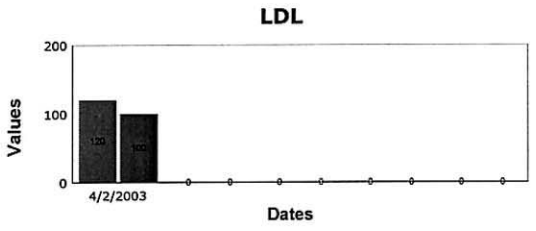
Print Date: 4/11/2003 Page 1 of 1

Date of Visit: ____/____/_____ Provider: _____	**Visit Planner**	**Patient:**Sample Patient **MRN:**
Gender: Female	**DOB:** 03/29/1949	**Conditions:** Diabetes

Medications: **Allergies:**



Left Bar (Blue) = Results | Right Bar (Red) = Goal



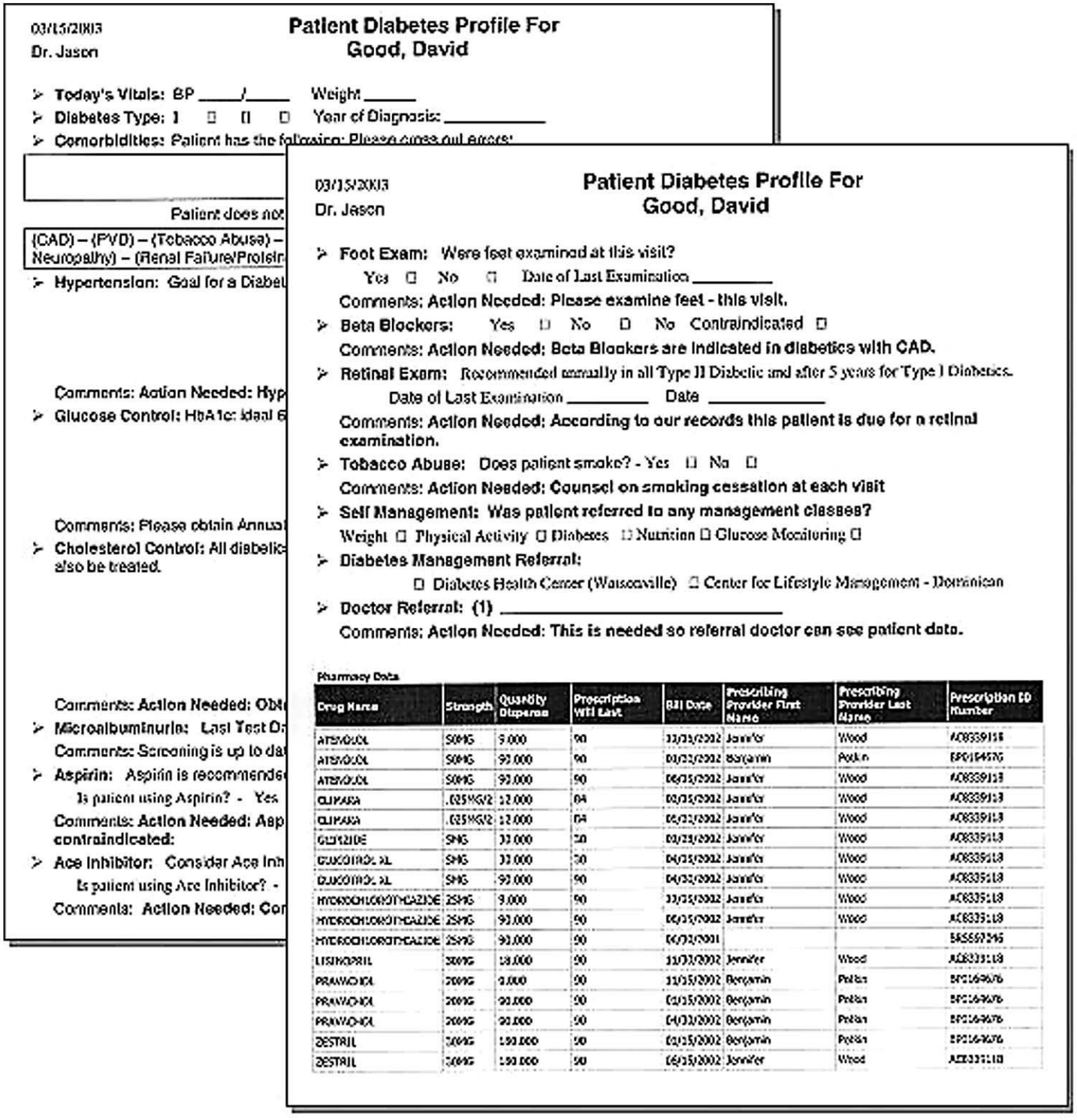
Left Bar (Blue) = Results | Right Bar (Red) = Goal

Enrollment Only	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Height	inches				365	
Vitals	**Today's Action**	**Last Value**	**Date Last**	**Pt. Goal**	**Int. Days**	**Due Date**
Body Mass Index	Calculated			< 25	per visit	
Weight (lb)	lbs				per visit	
BP SBP	mmHg			< 130	per visit	
BP DBP	mmHg			< 85	per visit	
Clinical	**Today's Action**	**Last Value**	**Date Last**	**Pt. Goal**	**Int. Days**	**Due Date**
Eye Exam-Diabetes	Done, Referred				365	
Foot Exam Monofil (LOPS)	Normal, Abnormal				365	
Foot Exam-Routine	Normal, Abnormal, Not Checked				per visit	
Lab	**Today's Action**	**Last Value**	**Date Last**	**Pt. Goal**	**Int. Days**	**Due Date**
Microalbumin	Y, N				365	
HbA1c	%	9	4/2/03	< 7	90	7/1/03
LDL	mg/dL	120	4/2/03	< 100	365	4/1/04

Medication	Today's Answer	Last Value	Date Last	New Med	Status Medication
Insulin	N, Y, CI, N/A				Start, Chg Dose, D/C, Continue,CI,Med AI
Biguanides	N, Y, CI, N/A				Start, Chg Dose, D/C, Continue,CI,Med AI
Biguanide Combinations	N, Y, CI, N/A				Start, Chg Dose, D/C, Continue,CI,Med AI
Glucosidase Inhibitors	N, Y, CI, N/A				Start, Chg Dose, D/C, Continue,CI,Med AI
Sulfonylureas	N, Y, CI, N/A				Start, Chg Dose, D/C, Continue,CI,Med AI
Thiazolidinediones	N, Y, CI, N/A				Start, Chg Dose, D/C, Continue,CI,Med AI
Other Diabetes Meds	N, Y, CI, N/A				Start, Chg Dose, D/C, Continue,CI,Med AI
ARB	N, Y, CI, N/A				Start, Chg Dose, D/C, Continue,CI,Med AI
Beta-blocker for HTN	N, Y, CI, NA				Start, Chg Dose, D/C, Continue,CI,Med AI
Antilipemics	N, Y, CI, NA				Start, Chg Dose, D/C, Continue,CI,Med AI
Aspirin	N, Y, CI, N/A				Start, Chg Dose, D/C, Continue,CI,Med AI
Antidepressants (Non-Specific)	N, Y, CI, N/A				Start, Chg Dose, D/C, Continue,CI,Med AI

Visit Comment:

Figure 5: Patient Diabetes Profile from Disease Registry Used at Physicians Medical Group, Santa Cruz



03/15/2003
Dr. Jason

Patient Diabetes Profile For
Good, David

- **Today's Vitals:** BP _____/_____ Weight _____
- **Diabetes Type:** I ☐ II ☐ Year of Diagnosis: _____
- **Comorbidities:** Patient has the following: Please cross out errors:

Patient does not

(CAD) – (PVD) – (Tobacco Abuse) –
Neuropathy) – (Renal Failure/Protein

- **Hypertension:** Goal for a Diabet

Comments: Action Needed: Hyp

- **Glucose Control:** HbA1c: Ideal 6

Comments: Please obtain Annual

- **Cholesterol Control:** All diabetic
also be treated.

Comments: Action Needed: Obt

- **Microalbuminuria:** Last Test D
Comments: Screening is up to da
- **Aspirin:** Aspirin is recommende
Is patient using Aspirin? - Yes
Comments: Action Needed: Asp
contraindicated:
- **Ace Inhibitor:** Consider Ace Inh
Is patient using Ace Inhibitor? -
Comments: Action Needed: Cor

03/15/2003
Dr. Jason

Patient Diabetes Profile For
Good, David

- **Foot Exam:** Were feet examined at this visit?
Yes ☐ No ☐ Date of Last Examination _____
Comments: Action Needed: Please examine feet - this visit.
- **Beta Blockers:** Yes ☐ No ☐ No Contraindicated ☐
Comments: Action Needed: Beta Blockers are indicated in diabetics with CAD.
- **Retinal Exam:** Recommended annually in all Type II Diabetic and after 5 years for Type I Diabetics.
Date of Last Examination _____ Date _____
Comments: Action Needed: According to our records this patient is due for a retinal examination.
- **Tobacco Abuse:** Does patient smoke? - Yes ☐ No ☐
Comments: Action Needed: Counsel on smoking cessation at each visit
- **Self Management:** Was patient referred to any management classes?
Weight ☐ Physical Activity ☐ Diabetes ☐ Nutrition ☐ Glucose Monitoring ☐
- **Diabetes Management Referral:**
☐ Diabetes Health Center (Watsonville) ☐ Center for Lifestyle Management - Dominican
- **Doctor Referral:** (1) _____
Comments: Action Needed: This is needed so referral doctor can see patient data.

Pharmacy Data

Drug Name	Strength	Quantity Dispense	Prescription Will Last	Bill Date	Prescribing Provider First Name	Prescribing Provider Last Name	Prescription ID Number
ATENOLOL	50MG	9.000	90	03/15/2002	Jennifer	Wood	AC8339118
ATENOLOL	50MG	90.000	90	03/22/2002	Benjamin	Pollin	BP0164676
ATENOLOL	50MG	90.000	90	06/15/2002	Jennifer	Wood	AC8339118
CLIMARA	.025MG/2	12.000	84	03/15/2002	Jennifer	Wood	AC8339118
CLIMARA	.025MG/2	12.000	84	06/22/2002	Jennifer	Wood	AC8339118
GLIPIZIDE	5MG	30.000	30	03/15/2002	Jennifer	Wood	AC8339118
GLUCOTROL XL	5MG	30.000	30	04/15/2002	Jennifer	Wood	AC8339118
GLUCOTROL XL	5MG	90.000	90	04/22/2002	Jennifer	Wood	AC8339118
HYDROCHLOROTHIAZIDE	25MG	9.000	90	03/15/2002	Jennifer	Wood	AC8339118
HYDROCHLOROTHIAZIDE	25MG	90.000	90	06/15/2002	Jennifer	Wood	AC8339118
HYDROCHLOROTHIAZIDE	25MG	90.000	90	04/22/2001			BR5597246
LISINOPRIL	30MG	18.000	90	11/30/2002	Jennifer	Wood	AC8339118
PRAVACHOL	20MG	9.000	90	11/15/2002	Benjamin	Pollin	BP0164676
PRAVACHOL	20MG	90.000	90	01/15/2002	Benjamin	Pollin	BP0164676
PRAVACHOL	20MG	90.000	90	04/22/2002	Benjamin	Pollin	BP0164676
ZESTRIL	30MG	150.000	90	01/15/2002	Benjamin	Pollin	BP0164676
ZESTRIL	30MG	150.000	90	06/15/2002	Jennifer	Wood	AC8339118

Figure 6: Diabetes Flow Sheet Integrated into an Electronic Medical Record

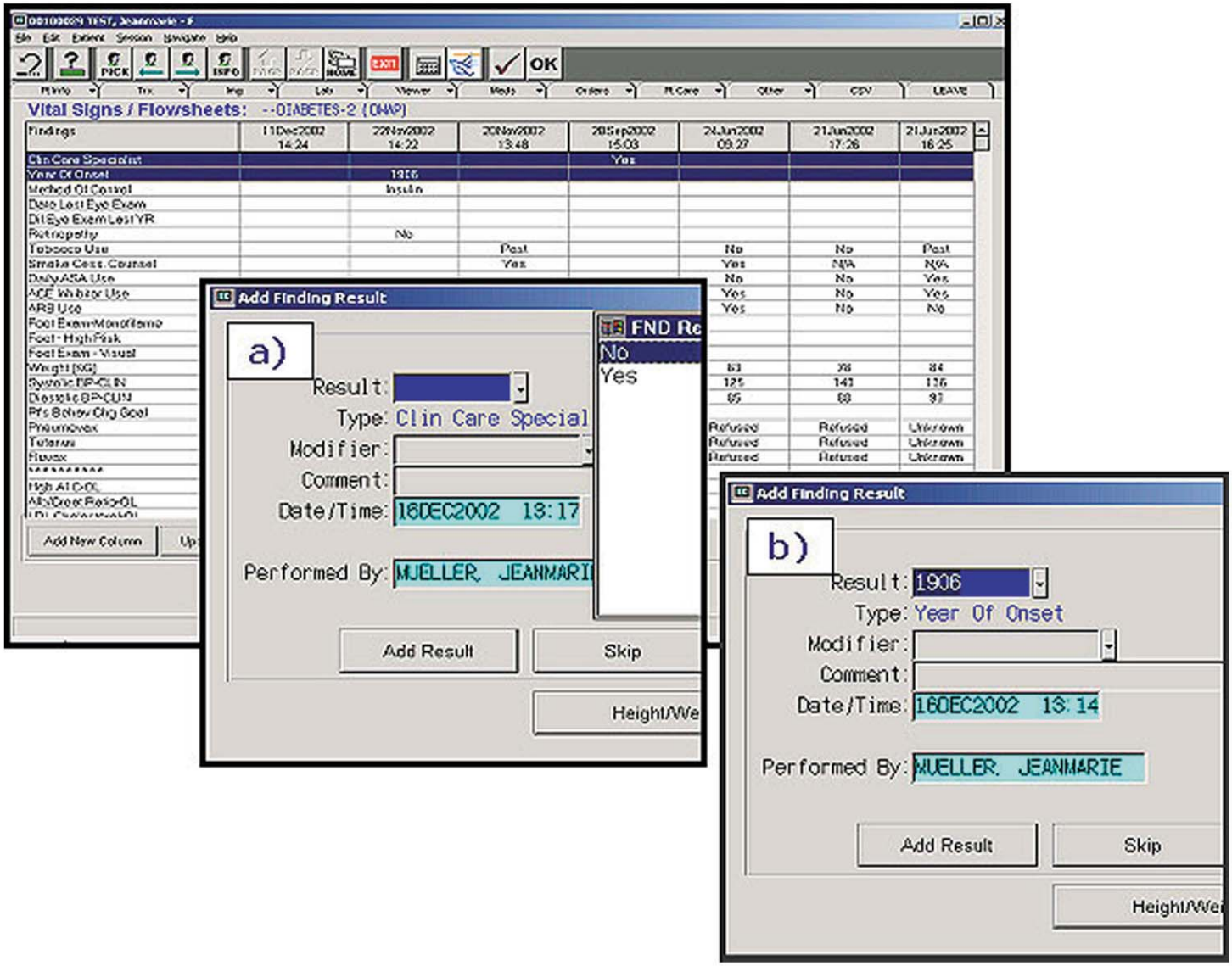


Figure 8: Patient List Display from Asthma Registry at Cambridge Health Alliance

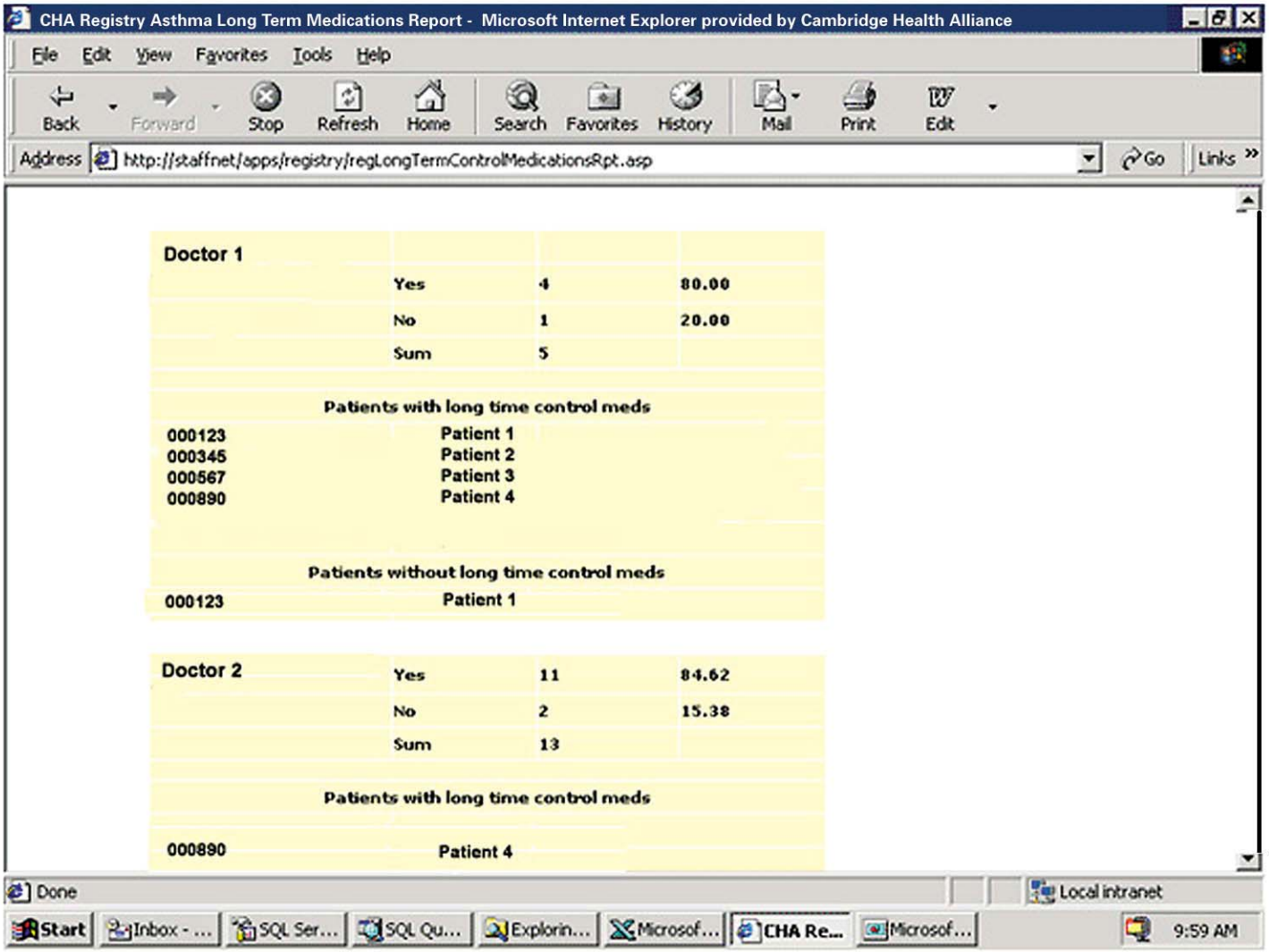
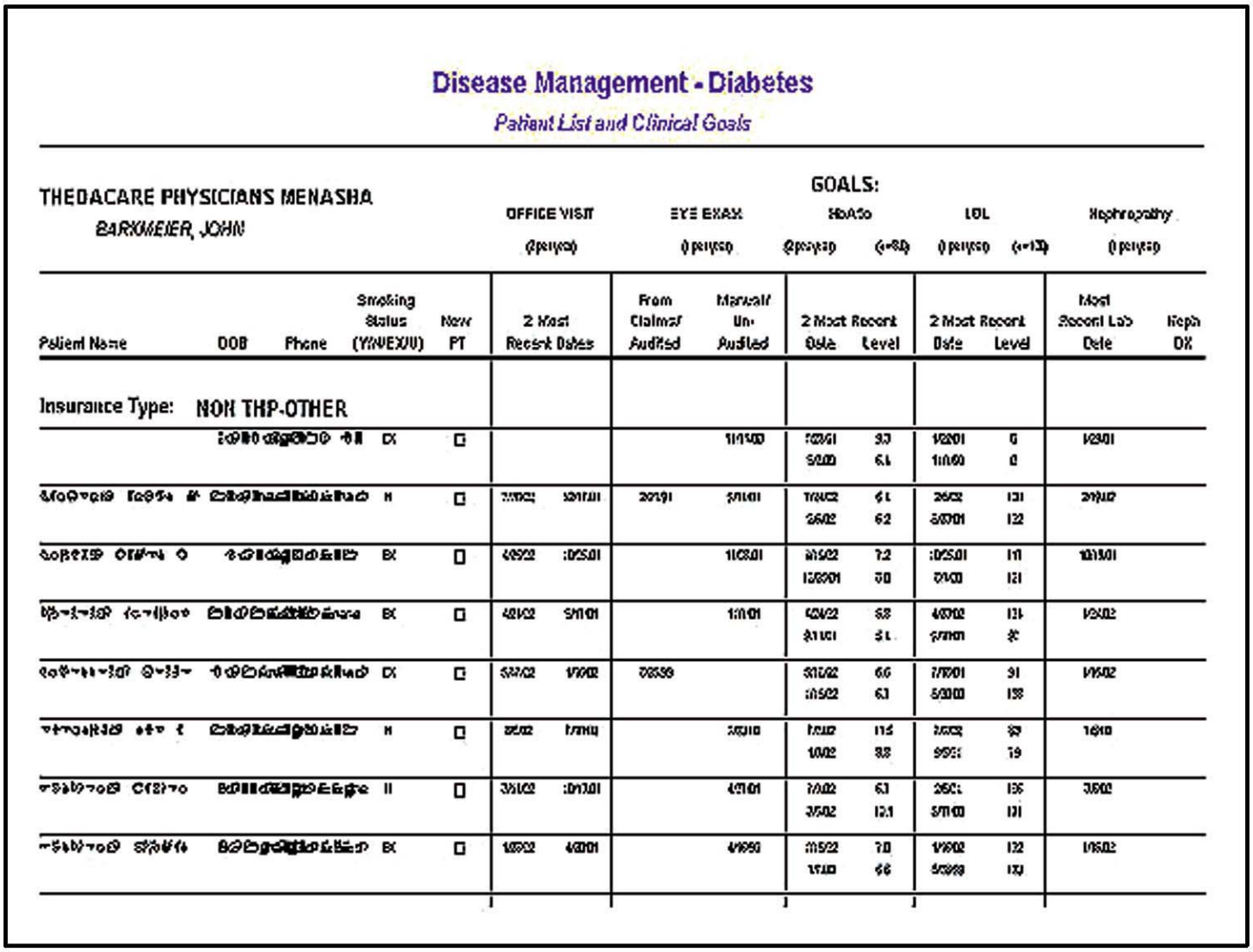


Figure 9: Diabetes Patient List for Registry Used at Thedacare



Disease Management - Diabetes

Patient List and Clinical Goals

THEDACARE PHYSICIANS MENASHA
BARKMEIER, JOHN

Patient Name	DOB	Phone	Smoking Status (Y/N/EX/U)	New PT	OFFICE VISIT (2 per year) 2 Most Recent Dates		EYE EXAM (1 per year) From Claims/ Audited	Manual/ Un-Audited	GOALS: HbA1c (2 per year) 2 Most Recent Date	HbA1c (<=8) Level	LDL (1 per year) 2 Most Recent Date	LDL (<=13) Level	Nephropathy (1 per year) Most Recent Lab Date	Neph DX
Insurance Type: NON THP-OTHER														
[illegible]	[illegible]	[illegible]	EX	☐				11/15/00	[illegible]	9.3	1/22/01	0	1/23/01	
									5/2/00	6.4	11/1/00	0		
[illegible]	[illegible]	[illegible]	N	☐	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	6.1	2/6/02	131	[illegible]	
									2/6/02	6.2	5/8/01	122		
[illegible]	[illegible]	[illegible]	EX	☐	[illegible]	[illegible]		[illegible]	[illegible]	7.2	[illegible]	111	[illegible]	
									[illegible]	5.0	[illegible]	121		
[illegible]	[illegible]	[illegible]	EX	☐	[illegible]	[illegible]		[illegible]	[illegible]	6.8	[illegible]	131	[illegible]	
									[illegible]	5.1	[illegible]	[illegible]		
[illegible]	[illegible]	[illegible]	EX	☐	[illegible]	[illegible]	[illegible]		[illegible]	6.6	[illegible]	91	[illegible]	
									[illegible]	6.1	[illegible]	138		
[illegible]	[illegible]	[illegible]	N	☐	[illegible]	[illegible]		[illegible]	[illegible]	11.5	[illegible]	[illegible]	[illegible]	
									[illegible]	8.8	[illegible]	79		
[illegible]	[illegible]	[illegible]	N	☐	[illegible]	[illegible]		[illegible]	[illegible]	6.1	[illegible]	136	[illegible]	
									[illegible]	12.1	[illegible]	131		
[illegible]	[illegible]	[illegible]	EX	☐	[illegible]	[illegible]		[illegible]	[illegible]	7.0	[illegible]	122	[illegible]	
									[illegible]	6.6	[illegible]	[illegible]		

Figure 11: Online View of Physician Feedback Report from Disease Registry at Intermountain Health Care

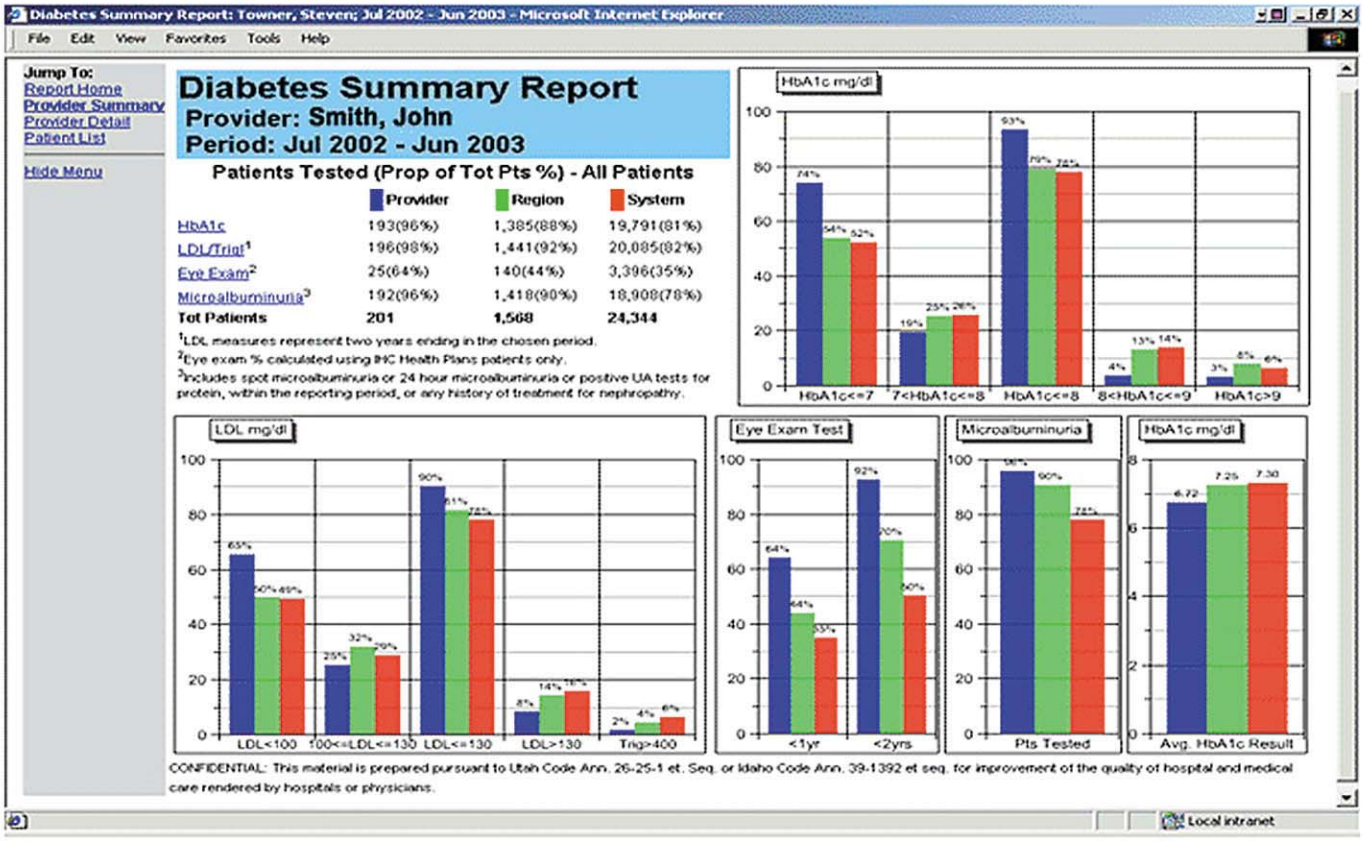


Figure 12: Diabetes Registry Report from CVDEMS (the Cardiovascular and Diabetes Electronic Management System)

Report version: 1.10

Diabetes Registry Report

FPC

Between: 10/15/00 And 10/15/01

DEMOGRAPHICS

1. Patients (type I and type II diabetes)

163	1.88	a. Total registry Avg visits/
25	15.3%	b. Pts w/ 0 visits
104	63.8%	c. Pts w/. 1-2 visits
34	20.9%	d. Pts w/. 3-5 visits
0	0.0%	e. pts w/. 6+ visits

2. Gender

96	58.9%	a. Female
67	41.1%	b. Male
0	0.0%	c. Unspecified

3. Age

1	0.6%	a. Age unspecified
1	0.6%	b. <= 14
34	20.9%	c. 15-44
80	49.1%	d. 45-64
47	28.8%	e. >= 65

4. Ethnicity

38	23.3%	a. White
3	1.8%	b. Black
0	0.0%	c. American Indian
0	0.0%	d. Asian
10	6.1%	e. Hispanic
112	68.7%	f. Other/unspecified

5. Insurance

132		a. Insurance indicated
3	2.3%	b. Commercial
75	56.8%	c. Medicaid
42	31.8%	d. Medicare
0	0.0%	e. Other
12	9.1%	f. None

7. Type of diabetes

5	3.1%	b. Type 1
158	96.9%	c. Type 2

8. Special Populations

1	0.6%	a. Migrant
3	1.8%	b. Homeless

VISIT INFO

9. BMI

99	60.7%	a. BMI calculated
22	22.2%	b. <= 24
23	23.2%	c. 25 - 29
54	54.5%	d. >= 30

VISIT INFO

10. Blood pressure

137	84.0%	a. Patients w/ bp checked
127	69	b. Avg systolic & Avg diastolic
53	38.7%	c. Patients BP >Or= 135/85
42	30.7%	d. Patients BP >Or= 140/90
84	61.3%	d. Patients BP < 135/85

11. Medications

34	20.9%	a. Insulin
64	39.3%	b. Sulfonylurea
80	49.1%	c. Glucophage
44	27.0%	d. Glitazones
2	1.2%	e. Prandin
5	3.1%	f. AG_Inhibitor
76	46.6%	g. ACE inhibitors
56	34.4%	h. Lipid lowering
66	40.5%	i. Aspirin
12	7.4%	j. BP Other

12. Health Profile (number % diagnosed)

8	4.9%	a. CVA
86	52.8%	b. Hypertension
8	4.9%	c. Post MI
7	4.3%	d. Cong. Heart Failure
71	43.6%	e. Hyperlipidemia
28	17.2%	f. Nephropathy
31	19.0%	g. Neuropathy
1	0.6%	h. Periph Vascular
17	10.4%	i. Retinopathy
41	25.2%	j. Depression
20	12.3%	k. Self monitors BG
1	0.6%	l. Physical Activity >3/ wk
31	19.0%	m. Current Smoker

13. Specialty Care Received

35	21.5%	a. Dm Education
3	1.8%	b. Self mgt goal set?
30	18.4%	c. Nutrition
0	0.0%	d. Dental
2	6.5%	e. Smoke Cessation (smkers)
24	14.7%	f. Retinal Exam
0	0.0%	g. Depresssion Screening
0	0.0%	h. Sub Abuse Screening
15	9.2%	i. Pneumonia Vaccination
35	21.5%	j. Flu Vaccination
23	14.1%	k. Foot Check
0	0.0%	l. Foot risk specified?
0		m. Foot risk 0
0		n. Foot risk =1
0		o. Foot risk =2
0		p. Foot risk =3+

TEST INFO

14. HbAlc or Glycosylated Hb

94	57.7%	a. Patients with test
8.0		b. Ave HbAIC
43	45.7%	c. < 7.0
17	18.1%	d. 7.0 to 7.9
7	7.4%	e. 8.0 to 8.9
10	10.6%	f. 9.0 to 9.9
17	18.1%	g. 10+
23	24.5%	h. 9.5+
41	25.2%	i. 2+ Alc 91+dys apart

15. MicroAl/Creatinine Ratio

56	34.4%	a. Patients with test
38	67.9%	b. Normal (<= 30)
18	32.1%	c. Abnormal (> 30)

16. Creatinine

96	58.9%	a. Patients with test
83	86.5%	b. < 1.5
10	10.4%	c. 1.5 - 2.5
4	4.2%	d. > 2.5

17. ALT

89	54.6%	a. Patients with test
41.4		b. Ave ALT

18. AST

86	52.8%	a. Patients with test
24.9		b. Ave AST

LIPID PROFILE

19a. Cholesterol test

80	49.1%	a. With Cholesterol test
208.5		b. Average Cholesterol
36	45.0%	c. Patients >= 200

19b. Triglycerides test

81	49.7%	d. With Triglycerides test
221.8		e. Average Triglycerides
33	40.7%	f. Patients >= 200

19c. HDL test

81	49.7%	g. With HDL test
46.8		h. Average HDL
17.0	21.0%	i. Patients < 35

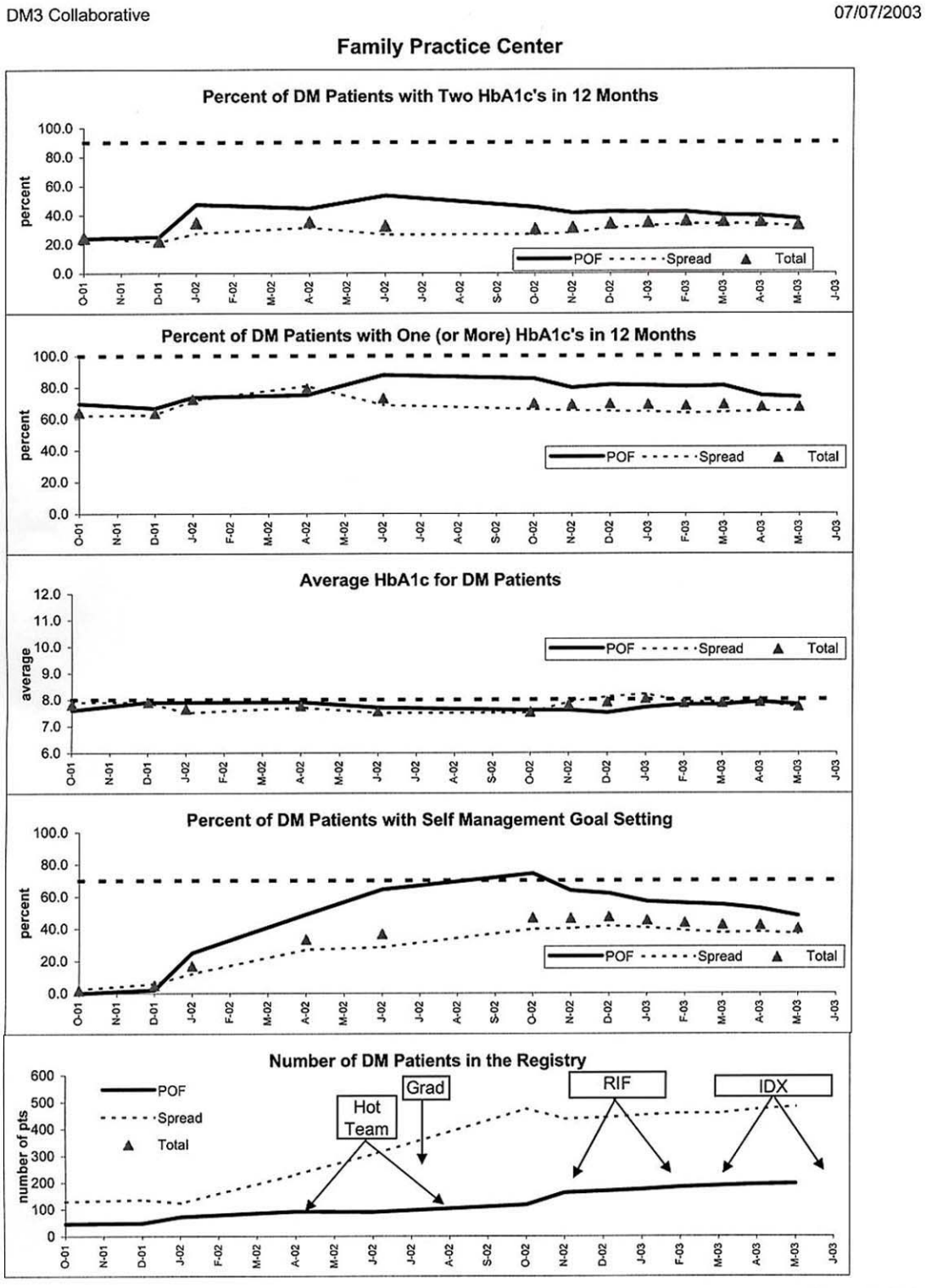
19d. LDL test

80	49.1%	j. With LDL test
118.9		k. Average LDL
30	37.5%	l. Patients < 100
26	32.5%	m. Patients 100 - 129
24	30.0%	n. Patients >= 130
56	70.0%	n. Patients < 130

20. 24 hour Ur Protein

4	2.5%	a. Patients with test
2706.8		b. Ave Urine Protein

Figure 13: Diabetes Program Report Used at Family Practice Center, Sutter Medical Center of Santa Rosa



Appendix D: Glossary

Chronic care model—A systematic approach to managing health care for patients with chronic disease. Developed at Group Health of Puget Sound, the model includes community, health, and delivery system; clinical decision and patient self-management support; and clinical information systems. For more information, access www.improvingchroniccare.org.

Computerized disease registry—A computer application for capturing, managing, and providing access to condition-specific information for a list of patients to support organized care management.

Disease registry—A paper-based or computerized approach to identifying and tracking information about patients with one or more chronic diseases. Disease registries manage a focused set of information relating to the chronic condition(s) of interest.

Electronic medical record (EMR)—A computer application for capturing, managing, and providing access to some or all of the information maintained in paper medical records.

Exception/outreach report—Patient list generated by a computerized disease registry listing patients with care deficiencies according to the disease management guideline in use (e.g., overdue for a recommended test or examination, not at recommended management goal). Disease registries typically include standard pre-designed exception reports, as well as permit users to request reports for any date range and care deficiency of interest.

Intranet—An in-house Web site that serves the employees of the enterprise. Although intranet pages may link to the Internet, an intranet is not a site accessed by the general public.

Networked server—A server in a network that hosts data and applications for multiple users.

Patient report—A disease registry report that presents a snapshot of condition-specific information about a patient. Paper copies are used by the physician and other members of the care team during patient visits and often are used to document information updates to be entered into the registry application. Some registries incorporate prompts about recommended interventions that are due or allow for general care recommendations. May also be called a visit planner.

Population management—Also called population-based management, this approach reorganizes clinical practice and care delivery to deliver effective care interventions systematically to maximize the health outcomes of a defined population. Clinical roles and care delivery are reorganized to be more planned and proactive.

Stand-alone disease registry—A separate computer application from an electronic medical record. Disease registries may also be integrated into the software for an electronic medical record.

Technology hosting—Maintaining computer system data and running the software applications at a third-party site.

Visit planner—A disease registry report presenting a snapshot of condition-specific information about a patient. Paper copies are used by the physician and other members of the care team during patient visits and often used to document information updates to be entered into the registry application. Some registries incorporate prompts about recommended interventions that are due or allow for general care recommendations. May also be called a patient report.

Endnotes

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