

Research Plan

Like other counties across the country, Santa Cruz County, California is confronting twin epidemics of obesity and diabetes. A 2001 California Health Interview Survey estimates that 4 percent of the County's adult population (or approximately 11,000 people) has diabetes. Nationally, at least one undiagnosed case of diabetes exists in the community for every two diagnosed cases. Given this additional pool of likely cases, as well as the prevalence of risk factors for this disease (obesity and lack of physical activity), the true number of patients with diabetes is certainly higher – and is likely to continue to climb.

Santa Cruz County also includes a large Latino population that is at particular risk for this disease: across California, 17.9% of Latino adults between the ages of 50 and 64 reported that they had diabetes (over twice the rate for whites in this age group, which was 8.3%).¹ According to 2000 Census data, 28% of the County's population is of Latino origin. In the southern part of the County, especially within and around the city of Watsonville, the proportion approaches 70%. As in the rest of California, Santa Cruz County's Latino population is the fastest-growing ethnic group, growing by nearly a third between 1990 and 2000 alone.

Diabetes is a chronic illness whose acute and long-term complications can be managed and even avoided altogether through a combination of appropriate medical care and self-management. These complications – vision damage, kidney failure, loss of limbs, strokes, and heart attacks – are both costly (\$17.9 billion per year in California alone) and exceptionally painful and debilitating.

Ideally, the steady increases in diabetes prevalence eventually will be reversed through primary prevention, as physical activity and dietary changes drastically reduce risk factors for diabetes. While this is a compelling goal, even the rosier scenarios make this a long-term prospect. (For example, the Centers for Disease Control and Prevention estimates that the number of people with diabetes in California will double by 2020.²) In the meantime, the thousands of Santa Cruz County residents who already have diabetes – and those who will be diagnosed with the disease in the near future – will be entering a system of care that has an unacceptably high degree of variation.

Consistency is the key to effective diabetes care. Consistency is required from both health care organizations (whose physicians and office staff must closely monitor a number of key indicators) and from patients themselves (who must adhere to regimens that typically involve frequent glucose monitoring, medication, periodic exams, and, hardest of all, lifestyle changes in diet and physical activity).

Unfortunately, despite the best intentions of everyone involved, this consistency is hard to come by. In a short office visit, a health care team would ideally explore at

¹ Diamant AL, Babey SH, Brown ER, Chawla N. *Diabetes in California: Nearly 1.5 Million Diagnosed and 2 Million More at Risk*. UCLA Center for Health Policy Research Policy Brief, 4/03.

² CDC. *The Burden of Diabetes in California*.

least 10 indicators to gauge whether a patient's diabetes is under control. Prompts – on paper or on a computer screen – can and do help, but only to the extent that the information they use is both comprehensive and timely (and, of course, to the extent that these data are actually used at or near the point of care). Even when these data *are* used, if a patient moves from one practice to another (because of changes in insurance coverage, for example), much of that important history – and the trends it represents – can be lost, or at least delayed.

Technology has the potential to elevate the standard of diabetes care by making consistent care routine. Within a medical practice, technology makes it possible for disparate information about a patient's diabetes – glucose control, cholesterol control, hypertension, medication, foot and retinal exams – to be available in one place, drawing from multiple sources (such as laboratory, claims, and pharmacy data). Technology makes it possible for office staff to quickly identify patients overdue for periodic exams and make sure they are scheduled for these appointments. Technology can even provide alerts for particular situations, based on algorithms that notice, for example, an HbA1c test result outside the acceptable range, or a lengthy interval between eye exams.

In Santa Cruz County, several different health care organizations – private, not-for-profit, and public – have taken similar steps to assemble relevant, patient-specific diabetes information within their own practices, using a combination of paper and electronic data gathering. This is useful and necessary (hence the parallel efforts), but, we jointly decided, not enough. As described below, we are proposing a unique partnership among the County's providers of diabetes care to share data on diabetes via an interactive, Web-based diabetes registry: the Santa Cruz County Diabetes Mellitus Registry, or DMR. Our goal is to use this tool to elevate the standard of diabetes care within individual practices, and across practices.

We recognize that many other factors affect diabetes care and outcomes, including access to health care, individual behavior, and primary prevention. Other County-wide efforts are underway in these realms. In this project, we focus on a central piece of the puzzle: using technology and collaboration to make sure that existing information is used to the fullest advantage and that opportunities for better diabetes care are not lost.

Santa Cruz County is an ideal venue for this project for a number of reasons (all described in greater detail below), but chief among these is the track record of successful collaboration and partnership among the County's health care providers and sectors over the past three decades. This track record is one of the reasons that members of our team were one of 15 communities asked by the Institute of Medicine to share our collaborative experience with policy makers at the IOM's national *Bridging the Quality Chasm* Summit in January 2004.

Without the crucial pre-requisite of successful collaboration, we could not even propose the sharing of data and expertise envisioned in this proposal. In doing so – and in launching a successful community-wide registry – we hope to demonstrate to others that such an effort is not only possible, but worthwhile for physicians and patients alike.

I. Partnerships

Description

Participating Organizations

The applicant for this effort is the Pajaro Valley Community Health Trust – a conversion foundation established in 1998 through the sale of Watsonville Community Hospital in southern Santa Cruz County to Community Health Systems (a for-profit health care corporation). Since its inception, the Trust has supported a variety of local efforts to improve the health and quality of life of residents of the Pajaro Valley and has a particular interest in preventing diabetes and its complications. As an important community health resource, the Trust is well-suited to serve as the fiscal steward and convener for a consortium of public, private, and non-profit partners sharing the goal of elevating the standard of diabetes care in our community.

The Trust is joined in this effort by public and private partners sharing an interest in applied information technology and elevated standards of diabetes care. They include:

- Physicians Medical Group (PMG) of Santa Cruz – a for-profit medical group of 200 physicians whose staff developed the interactive diabetes registry software (donated to this effort) and whose Medical Director will serve as Principal Investigator/Project Director.
- Santa Cruz County's Health Services Agency (HSA) – houses the County's public health department and serves as lead agency for the County's Healthy Communities Access Program (HCAP) funding, including implementation of County-wide MIS/IT upgrades.
- Central Coast Alliance for Health (the Alliance) – a County Operated Health System providing care for 85,000 Medicaid patients in Santa Cruz and neighboring Monterey County. The Alliance has succeeded in its goals of controlling costs and increasing access to health care for low-income residents. For several years running, the Alliance's Healthplan and Employer Data and Information Set (HEDIS) scores measuring local access to preventive services have been among the best in California.
- Santa Cruz Medical Foundation (SCMF) – a local not-for-profit group of 120 physicians, founded 50 years ago and now a Sutter Health affiliate. SCMF provides care to half of the County's Medicare population and served 80,000 patients in 2002.
- Regional Diabetes Collaborative (RDC) – Convened by the Trust in 2002, the RDC includes 40 organizations from Santa Cruz, San Benito, and

Monterey counties. The RDC's mission is to support, promote, and coordinate efforts to prevent and manage diabetes in this tri-county region.

- Safety Net Clinics Coalition – Santa Cruz County's network of Safety Net clinics recently has transitioned from an informal group to a more formal coalition. This group includes the County's two public health clinics as well as Salud Para la Gente (a combined Community Health and Migrant Health Center); Planned Parenthood; Santa Cruz Women's Health Center; Dientes! Community Dental Clinic; Dominican Hospital Pediatric and Perinatal Clinics; Cabrillo Student Health Center; and the Diabetes Health Center.
- Health Improvement Partnership Council (HIPC) – a steering committee formed through the County's initial HCAP grant, whose membership includes the County's hospitals, private medical groups, Safety Net clinics, local philanthropies, and medical society.
- Cabrillo College – a local community college actively involved in the County's Health Careers Partnership (a group working to expand the health care workforce by bolstering the educational pipeline, its own Allied Health programs, and links to local employers) and a leader in computer education.

The Health Services Agency, Alliance, and Safety Net providers joined forces two years ago with the County's three hospitals, the County Medical Society, two local philanthropies (including the Pajaro Valley Community Health Trust), a Health Care Outreach Coalition (representing 20 agencies and 40 programs), and the County's social services agency to apply successfully for funding through HRSA's Healthy Communities Access Program (HCAP).

The CAP funding, now in its second of three years, has strengthened collaboration among these entities in two ways that are crucial to the success of our proposed diabetes registry. The first is the formation of a County-wide planning group – the Health Improvement Partnership Council, or HIPC (described above) – that engages each of the entities listed above in the coordinated pursuit of common goals. This group has not only linked the different private, public, and nonprofit providers in our community to address their original common issue – the problem of the uninsured – with a model program for universal coverage for children, but also has tackled a number of other issues (including, for example, case management for frequent Emergency Department users and seminars on pain management for area providers). The members of this group, acting through the Trust as its formal fiscal representative, are joining forces again to implement the proposed diabetes registry.

The second important influence of HCAP funding is the upgrading of health information technology, primarily by establishing a common clinical messaging system, practice management system, and eventually, Electronic Medical Records (EMRs). The

clinical messaging system is also used by many of the County’s physician medical groups and all three hospitals.

The combination of an interest in innovation and technology, a collaborative spirit, an infrastructure to support it, and a track record of successful collective effort suggests that we have overcome the most difficult implementation obstacles for this type of project already. Technical and other challenges certainly lie ahead, but we are confident that they can be overcome and that our partnership can move to another level of collective accomplishment by implementing the diabetes registry described below.

Roles in the Partnership

The Pajaro Valley Community Health Trust will serve as the lead fiscal agency and convener for the diabetes registry partnership. Physician Medical Group’s Medical Director, Dr. Wells Shoemaker, will lead the project as Principal Investigator. The other health organizations – the Alliance, HSA, Santa Cruz Medical Foundation, Regional Diabetes Collaborative, the Safety Net Clinics Coalition, and HIPC – will encourage adoption of the registry within their practices and will identify champions for each practice. Cabrillo College staff will conduct a needs assessment early in the project and both design and conduct customized training for physicians, medical office managers, medical assistants, and other potential users of the registry.

Contributions of Resources

Each organization’s specific contributions are detailed in the chart below. Letters of support from each organization are provided in Appendix A.

Organization	Contributions
Pajaro Valley Community Health Trust	<ul style="list-style-type: none"> • Administrative stewardship
Physicians Medical Group	<ul style="list-style-type: none"> • Diabetes registry software • PI • Physician participation
Alliance Santa Cruz Medical Foundation HSA Safety Net Clinic Coalition Regional Diabetes Collaborative Health Improvement Partnership	<ul style="list-style-type: none"> • Champion project with physicians and staff • Participate in pilot training and implementation • Nominate committee members for Steering, Clinical, IT, and Medical Office committees
Cabrillo College	<ul style="list-style-type: none"> • Conduct training needs assessment • Design and conduct customized training

Current/Proposed Infrastructure Supporting Partnership

Existing and Planned Information Systems

Like those in other counties, the health care community in Santa Cruz County reflects a range of health information technology (HIT) capacity. Overall, as described below, the last several years have seen a surge of activity – both in terms of general upgrading of IT capacity, as well as movement toward standardization that would allow more efficient sharing of data in consistent formats. However, as is often the case, this general progress has been far from universal. Some individual physicians still resist any type of automation of their practices and not only do not use computers, but do not have them in their offices. Some have computers, but no Internet connection. In other cases, the interest is there, but busy physicians and office staff are unable to create the organizational space and time for training and upgrades.

Through this proposed registry project, we hope to address both ends of the HIT spectrum, as well as the many points in between: those “early adopters” eager and willing to try new technology, those who see some potential but are too busy to learn and invest in something new, those who are resigned to new technology as a necessary evil, and even those who would be pleased if computer hardware and software magically disappeared from their daily lives. Our vision is that this diabetes registry, already operational in one provider organization, can be expanded in phases to include a significant portion of the County’s providers and patients. By helping physicians and offices standardize diabetes care, thus improving outcomes, we hope to demonstrate to everyone involved the tremendous potential of HIT to yield both efficiencies and better health outcomes.

It is important to note that the registry’s success does not depend on full participation. We expect that within each practice, the registry will be used to different degrees – and, in some cases, not at all. At the most intensive (and useful) level, physicians will use the registry at the point of care, acting on prompts and entering new information. If physicians choose not to use the registry in this way, office staff may print out a summary of test results and other relevant information, creating a paper version of the screen. Office staff also may prepare lists of patients overdue for particular exams or tests, and make a more concerted effort than they would otherwise to make appointments for those patients. At an administrative/managerial level, compliance with standards of diabetes care could be assessed for individual doctors.

Currently, many private physician providers and Safety Net clinics use a Web-based clinical messaging system, Axolotl/Elysium, developed in 1995 by a Santa Cruz physician. Axolotl/Elysium, which follows an HL7 protocol, captures clinical data at the source (i.e., laboratory, radiology, transcription). A County-wide Master Patient Index generates unique identifiers (after searching for matches by patient name, sex, birth date, medical record number, and social security number), which are then delivered via the web to physician workgroups. The clinical data are stored by patient, allowing patient-specific data from multiple sources to be viewed electronically across the

County. Since the clinical data include field-specific values, the system also can be used to extract data elements for clinical or population management purposes.

PMG, the original developer of the diabetes registry at the center of this project, has been actively promoting the use of HIT and building an infrastructure to support it for the past decade. PMG uses Elysium to exchange clinical data and is now in the process of standardizing a true Electronic Medical Record (EMR) system (Practice Partner) that works with Elysium. PMG physicians are connected to the Internet (over 90% via DSL) and 48 of PMG's 65 primary care providers use an electronic prescription writer.

Two hospitals also report electronic lab results, physician transcriptions, radiology reports, and inpatient admission and discharge summaries to the Elysium system. The dominant local independent laboratory, Quest, reports results to the system as well. In June 2003, the County's public health and Safety Net community clinics began using Axolotl/Elysium's clinical messaging feature as part of a broader effort to acquire common practice management and electronic medical record (EMR) capacity. Approximately 80% of the County's residents are indexed by this clinical data system.

Although the system is not currently designed to bill payers or purchasers, it is capable of receiving and populating patient demographic and insurance information into the community patient index.

Planned HIT efforts. With HCAP funding from HRSA, the Safety Net clinics are acquiring EPIC for electronic medical records and practice management, by joining the Oregon Community Health Information Network (OCHIN). As described below, this change will make it possible to obtain more encounter data on the diabetes care of uninsured patients seen in Safety Net clinics. As a Sutter affiliate, SCMF also is moving to EPIC within the next 2 years.

Overall, HIT progress – despite some fits and starts – is moving in the right direction in Santa Cruz County: more infrastructure, more standardized data formats, a greater proportion of physicians “online” every year, and, most important, HIT champions within each organization, working together. The proposed County-wide diabetes registry is just one example of this.

One long-term outcome of all these efforts is a County-wide HIT group, meeting regularly (initially to design and implement this registry, but expanding its scope over time) to support HIT development that helps each organization fulfill its individual health care goals, while contributing to better community-level data at the same time.

Director and Project Team

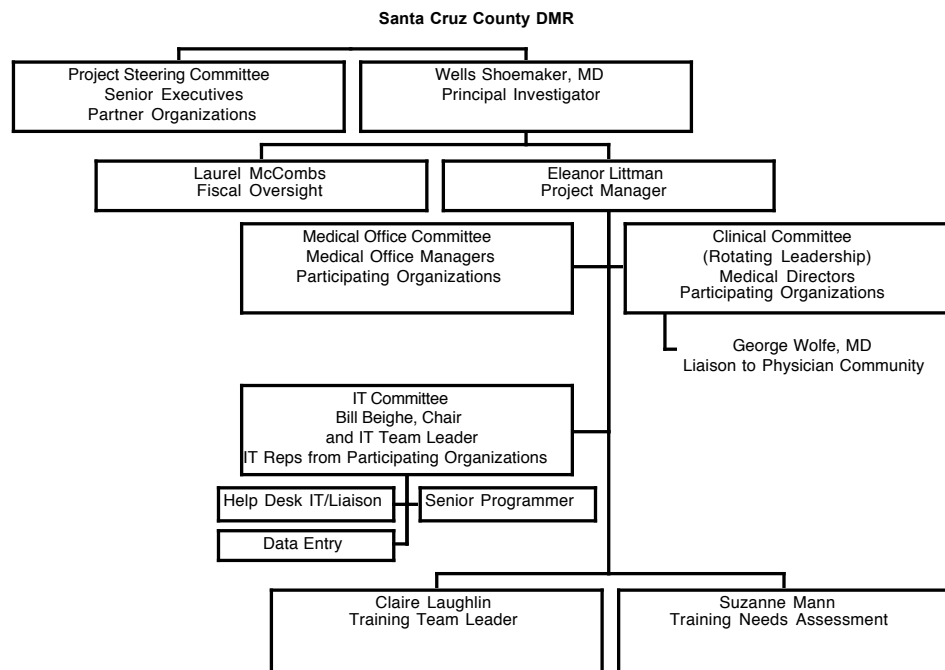
An organizational chart showing the relationships among project team members is provided on the next page. The team includes the following people and organizations:

- Wells Shoemaker, PMG, Principal Investigator.
- Eleanor Littman, Deputy Project Manager

- Laurel McCombs, PVCHT, Administrative Oversight
- An overall project steering committee, made up of representatives of each participating organization (PMG, SCMF, Alliance, Safety Net clinics, HSA, Cabrillo, Medical Society)
- Suzanne Mann, Cabrillo College, Needs Assessment Design/Implementation
- Claire Laughlin, Cabrillo College, Training Design/Delivery and Evaluation
- George Wolfe, Retired Health Officer, Liaison to physicians to promote the registry and training associated with it
- A three-person IT team, made up of a lead programmer, a help desk/technical assistance staff member (who also will serve as the technical liaison to his or her counterpart in each participating organization), and a part-time data entry staff member (to handle any non-electronic submissions of data). The team will report to Bill Beighe, who will supervise their work, assign specific programming or other IT tasks to consultants if necessary, and lead the project’s IT committee (see below).
- Three topic-specific committees, to address and resolve issues brought forward by the project steering committee and/or project managers: one for IT issues, one for clinical issues pertaining to physicians, and one for medical assistants and medical office managers.

II. Proposed Implementation Effort

The chart below shows how different individuals and committees relate to one another and contribute to project goals.



Description of the Project Director

Wells Shoemaker, MD will serve as the Principal Investigator and Project Director. His responsibilities will include general oversight of the project, working closely with the fiscal steward at the Pajaro Valley Community Health Trust and with the Project Manager, Eleanor Littman.

Dr. Shoemaker has been closely involved in the PMG diabetes registry's development and has been a champion of its use within the organization. He first became interested in the potential of such a system after reviewing the medical records of Medi-Cal (California Medicaid) managed care patients who had experienced heart attacks, strokes, and limb amputations or had died prematurely of heart disease. In all these categories, many of the patients had not been seen by their primary care physicians for months – and in many cases, for years. He and his colleagues realized that technology could help physicians and medical office staff improve the standard of care – and, more importantly, health outcomes – for chronic disease patients by helping them monitor key indicators more closely and intervene more effectively, before disease progression occurred.

Dr. Shoemaker is a member of the 2002-2004 cohort of the California Healthcare Foundation leadership fellowship. (Two other project participants – Dr. Barbara Palla and Dr. Larry DeGhetaldi, representing the Alliance and Santa Cruz Medical Foundation, respectively, also are fellows of the program.) As a core component of this intensive program, each fellow chooses a major health improvement project. Dr. Shoemaker chose the creation, testing, deployment, and subsequent measurement of the diabetes point of care program for the defined population of 35,000 patients at PMG. This formal project involves continual feedback from peers and from CHCF health care faculty and UCLA Anderson School business faculty. The oversight emphasizes project design, managerial challenges, adaptation to change, credible metrics, and business case definition. This project led to the development of the registry that Dr. Shoemaker and PMG are now making available to the County's other diabetes care providers.

Dr. Shoemaker brings a rich combination of clinical, administrative, and research experience to this role. He not only has practiced primary care pediatrics in many different settings (including public health, community clinic, large integrated systems, and small private sector settings), but also has participated in many regional health planning activities in Santa Cruz County and is a skilled and respected administrator, with a particular interest in population-based quality improvement and access to care issues. Dr. Shoemaker's interest in practice redesign using IT methods has led to opportunities to participate as a panelist/speaker in conferences in early 2004 for the Institute of Medicine Chronic Care Summit IT section, California Diabetes CQI program, the Lumetra DOQ-IT (Doctor Office Quality Improvement Through Technology) planning forum, and the National Business Group on Health national meeting.

Because of these many relevant skills, his interest in the project, and his familiarity with the individuals and organizations that will be participating in the County-wide registry, the planning group for this grant unanimously selected Dr. Shoemaker to

serve as Principal Investigator. He will serve in this role throughout the project and is interested in expanding the model to other chronic diseases in the future.

Dr. Shoemaker will be assisted by two deputies for day-to-day project administration: a project manager, Eleanor Littman, and a fiscal manager, Laurel McCombs. As project manager, Ms. Littman will be responsible for coordinating project deadlines, making sure the committees receive and resolve issues (clinical, technical, or training) raised by individual organizations, and generally ensuring that information flows smoothly to and from Dr. Shoemaker, the steering committee members, project partners, and project staff. Ms. Littman is a Registered Nurse with over 25 years of experience in health care, including strategic planning and management experience across the continuum of care. She has spent the past decade involved in health planning, preparing certificates of need and analytical studies for regulatory agencies, health care providers, and community-based organizations. She brings to the project seasoned leadership experience in health maintenance organizations, including implementing management programs for chronic conditions with multidisciplinary teams. She also has implemented automated clinical information systems for monitoring outcomes in home health and outpatient settings.

Laurel McCombs will provide fiscal stewardship for the project at the Pajaro Valley Community Health Trust. Working with the PI, the Project Manager, and the steering committee, Ms. McCombs will ensure that the project's budget is on track with project milestones and that resources flow smoothly to each project component as the project moves through each phase.

Project Steering Committee

The project's steering committee will include representatives of each of the organizations listed above (Pajaro Valley Community Health Trust, Physicians Medical Group, Santa Cruz Medical Foundation, Alliance, Health Services Agency, Safety Net Clinic Coalition, Regional Diabetes Collaborative, Health Improvement Partnership, and Cabrillo College). The steering committee will ensure that each organization's individual data and practice protocols are respected, while also providing a forum for rapid discussion and resolution of project issues that affect all the participating organizations. For example, early steering committee agenda items will include the implications of preserving familiar "dashboards" of diabetes indicators in each institution, while contributing a shared list of data elements to the registry. (Currently, each institution's dashboard collects overlapping but not identical information, and each produces different screens and products.) Likewise, the steering committee would be the likely venue for discussions and decisions about registry identifiers for patient records, whether and when to migrate the server and programming to another location, and other major decisions that affect the project overall.

We also will form three committees to pursue each of the key streams of activity anticipated for a County-wide diabetes registry:

- A **clinical** committee, made up of the medical directors of participating institutions, some individual physicians, and a representative of the County's Medical Society. This committee, initially led by Dr. Barbara Palla (Medical

Director of the Central Coast Alliance for Health) and subsequently by a rotating leadership from each clinical group, will help promote the registry and its use with peers within their respective practices. Since the algorithms used by the registry are based on state and national diabetes care standards, we do not anticipate deliberations about the data elements or prompts generated by the registry program. However, as discussed below, the collection and dissemination of patient-specific data is in many ways the more straightforward part of the challenge. Using the data in constructive ways – to standardize care across and within organizations – is far more difficult. The clinical group will tackle this sensitive and difficult issue with the assistance of Dr. George Wolfe, the County's former health officer, whose strong ties to the physician community will help him serve as the liaison to County physicians. The group also will provide advice on how best to conduct the needs assessment and training within each participating institution and help identify physician champions to support the registry's implementation.

- A **medical office** committee, initially including the medical office managers from each participating medical group and medical assistants. This committee will make suggestions about the training of medical office staff, participate in pilot tests, and provide feedback on how the registry can improve general office work flow. The medical office committee is critical to the project's success. Without their buy-in and support, it is unlikely that the registry – even if it is widely in place – will be used to maximum benefit.
- An **IT** committee, made up of IT/MIS representatives from each participating organization. This group will be a central IT resource to all participating organizations, resolving technical issues in a standardized way and making sure that the various systems are compatible. The group will be chaired by Bill Beighe, who supervised the development and deployment of the registry at PMG and is skilled at translating between the worlds of clinical care and IT. Mr. Beighe will track IT issues brought to the committee by members, work with them and with consultants (if necessary) to develop workable solutions, report progress to the PI, and supervise the project-specific IT staff (a programmer, help desk/liaison staff member, and data entry staff member to handle a small but important volume of non-electronic data submissions to populate the registry). Mr. Beighe and his fellow committee members will make sure that technical issues are resolved quickly and that IT lessons learned in one organization are shared with each participating organization. Looking ahead, this group also will form the nucleus of a planning team to develop a County-wide Health Information Exchange.

Other Key Personnel and Their Duties

A senior programmer will manage the server and database functions, including programming required for interfaces between each organization and the central registry. He or she will be assisted by a customer service staff member who will attend all the training sessions, be on-site for each pilot test and system implementation as it occurs, and generally serve as a liaison and technical problem-solver for each organization. A

third part-time staff member will be available to manage the flow of non-electronic data into the registry – an important option for some offices. These individuals will report to the IT Team Leader, Bill Beighe.

The training components will be led by Claire Laughlin of Cabrillo College, working with Suzanne Mann. This will include designing a training needs assessment, developing customized workshops, exploring the inclusion of registry training in Cabrillo College's existing training for medical assistants, incorporating new information into ongoing training as needed, and working closely with the other committees to offer useful training and technical assistance to different audiences. In addition, the Cabrillo team will be responsible for evaluating the training.

Issues and Resolution

An IT project that involves multiple organizations, each with their own IT systems, communicating with one another on an unprecedented scale? Inevitably, some issues are bound to arise – both anticipated and unanticipated. Those we have anticipated are described below, along with possible solutions.

Physician and office adoption of new IT. Even within PMG, where the registry was initially developed and launched in 2003, physician adoption of the new software tool is far from universal. In every setting, we anticipate a range of responses, from early and enthusiastic adopters to those actively resisting the use of this tool. Fortunately, the project's success does not depend on full physician participation. Nevertheless, one of our goals is to convince as many as possible to give the tool a fair trial. Even if physicians themselves do not use the registry to enhance point-of-care interaction with patients, they can still encourage office staff to use the registry in other ways – such as generating lists of patients who should make appointments for needed exams or tests. For all these reasons – their own use, and setting the tone for an office overall – initial and sustained contact with physicians will be critical. We have paid particular attention to this in our project, devoting resources to a thorough needs assessment, a variety of customized training products to meet those needs, and a physician liaison to the medical community. Some organizations also may be able to offer incentives to physicians, as PMG does.

Finding a neutral home for the registry. The organizations joining together to create the Santa Cruz County DMR have a track record of collaboration, but this effort requires a new level of trust and commitment – particularly for the organizations that otherwise compete for patients (SCMF and PMG). Sharing patient data between competitors is an issue for physicians and for organizational leaders. To remove this potential (but not fatal) obstacle, we have planned a phased implementation. In the first phase, the registry's database will be populated by the records of a Medicaid HMO (the Alliance) and insured patients of the County's Safety Net clinics (including the County's two public health clinics). This first phase will allow the server and programming staff to remain at PMG, where the registry was first developed, while we test the addition of other organizations' patient records, develop interfaces and any other programming required to adjust data streams, conduct our initial needs assessment, and fine-tune training and technical assistance protocols. In effect, the first wave of additions will

function as a pilot test. We expect the first phase to take approximately one year (of the 3-year project).

At that juncture, if moving the server and programming/help desk functions out of PMG to a neutral location remains an issue for SCMF and private providers, the project steering committee will consider several options. These include transferring these functions to an existing neutral location (either the Pajaro Valley Community Health Trust, the Alliance, or the County's Health Services Agency) or subcontracting the service to a qualified vendor. (In fact, a transfer would involve some hybrid of these options, since neither the Pajaro Valley Community Health Trust nor the Health Services Agency currently has the IT capacity to take this on, and would likely hire programmers and others to do so as contractors to these agencies.)

We have chosen not to transfer the server and programming staff at the outset because it is not an issue for the Alliance and Safety Net clinics, who would be ideal "first-wave" candidates in any case. Since PMG developed and currently maintains the registry, it made sense to leave it in its current home for the project's initial phase. If it becomes necessary to move these functions, PMG has no objections to doing so and its senior programmer is willing to train his replacement and provide *ad hoc* technical help as needed.

Building interfaces to stream data into and out of the registry. In many cases, the interfaces between an organization and the registry will be relatively straightforward. For the health care organizations using Elysium, mapping of data elements back and forth should be minimal. For those that do not use Elysium but do use electronic reporting (837s for claims/encounter data; HL7 formats for laboratory data), the process may be slightly less centralized, but still a feasible programming task. The issue becomes complex for organizations that interact with multiple vendors (such as private physicians dealing with many different laboratories) or for those who are not yet within the health IT fold.

We have addressed this issue in several ways. First, an initial needs assessment will explore the IT infrastructure and overall IT capacity/interest among individual physicians and medical office managers in each organization. This, in turn, will help us customize training through a combination of workshops and more intensive individual "hand-holding" sessions. Part of the assessment will address current data sources and formats, so that we will have an early and accurate picture of which organizations may require more intensive programming assistance to join the registry.

Secondly, we have included both programming and "help desk"/liaison functions within our project team to deal with this issue. The project's IT team will be augmented in two ways: by a committee that includes senior-level IT representation from each participating organization (capable of making decisions and directing or re-directing resources, as needed) and by in-house IT teams. The in-house teams will be important, because they will be the first to receive requests for assistance and will have to determine whether technical glitches relate to the new registry linkages, or to existing systems (such as computer crashes, Internet connections, and the like).

Contractual issues. A more complex issue is that of dealing with third parties, such as laboratories. For organizations that contract with a particular laboratory, for

example, there is no issue: the organization requests that HL7 data for particular patients and test results be sent to the registry, in addition to the ordering physician. However, there are two situations where this becomes complicated. The first is for laboratory tests that are linked to a patient in the registry, but for one reason or another are not performed by the health care organization's contracted laboratory. (This may be the situation, for example, with a portion of the Alliance's HbA1c test results, which appear to be related to dialysis patients who receive HbA1c tests as part of their dialysis, rather than through the contracted laboratory.) One of the project staff's early tasks will be to identify these "out-of-project" data items and figure out how to obtain them – by systematically identifying barriers and negotiating exceptions or changes to existing arrangements. It is important to note that Santa Cruz County's registry partners are not addressing this issue alone; statewide efforts (particularly by the California HealthCare Foundation and California Association of Physician Groups) are working on standardization of laboratory data, in particular through contractual language, so that each County will not be reinventing the wheel as HIT systems expand.

Unique identifiers. A problem for all health IT systems is that of duplicate records for the same patient. Identical names and birth dates, transposed letters and numbers, and deliberate multiple identities (for example, by patients shopping for painkillers from multiple providers) all wreak havoc with registries and other data collection efforts. The Alliance uses a set of algorithms that conduct an initial cleaning function on duplicate names, checking for obvious errors and possible matches. Using this system, up to 98 percent of duplicates can be matched with an existing record, but the remainder must be manually screened. Once the registry expands beyond PMG and its existing patient identifiers, the project steering committee and registry team will have to develop standards for registry identifiers and protocols. The team will have to create not only protocols but a single, consistent point of resolution for duplicates that cannot be resolved through automated or manual checking.

Incomplete data on some patient populations. Some of the patients most at risk for diabetes are also those least likely to be captured in the registry because they lack any type of health care coverage. As a result, if they pay a sliding scale fee or nothing at all, they would not generate the encounter/claims data that will largely populate the database fields. By late 2004 or early 2005, uninsured patients seen in the County's Safety Net clinics (particularly the Women's Health Center, Salud Para La Gente, and the County's two public health clinics) will have clinical data recorded as these clinics adopt the EPIC practice management software.

Another population whose data would not initially be captured is Medicare patients. The project's PI, Dr. Shoemaker, is currently working with Lumetra (a quality improvement organization for Medicare) on this issue and expects resolution within the next year that would allow claims/encounter and laboratory data on these patients to be available to the registry.

EMR/Registry Overlap. Since the registry and EMR systems (particularly EPIC) are being implemented in tandem, there is some concern that a full EMR, once implemented, would make the registry redundant. The registry partners have agreed that the registry will be useful regardless of the speed or thoroughness with which EPIC or other EMRs are implemented. First, the various EMRs are only useful to the degree

that there is portability of data among them. The registry allows this portability to occur quickly – a boon not only to the many patients moving among health plans, but also to the health care providers and systems trying to track and treat them. In addition, the relationships and trust forged through the registry project will make it much easier to expand the registry concept to other diseases in the future, and/or to draw data directly from EMRs. Our conclusion is that the problem of diabetes is severe enough to warrant immediate action, and that the registry’s benefits will extend beyond diabetes – both to broader HIT efforts and to monitoring other diseases and conditions.

Description of Project Implementation

In this section, we describe the current registry and our plans to expand it beyond PMG to include other providers and their patients.

Diabetes, like other chronic conditions, can be treated effectively with what the Institute of Medicine describes as a systematic approach – one that “emphasizes self-management, care planning with a multidisciplinary team, and ongoing assessment and follow-up.”³ Disease registries take advantage of information technology to capture, sort, and report disease-specific data that make this type of systematic approach possible. This project takes an existing diabetes registry developed by PMG in Santa Cruz and, through a public-private partnership, uses the PMG registry as the basis for a uniform, Web-based community-wide diabetes registry. Because, as noted above, it was developed as a fellowship project for the California Diabetes Continuous Quality Improvement (CQI) and Health Care Reporting Initiative, the registry has been subjected to intensive review and revision by state and national experts – in addition to its real-world launch within PMG in 2003.

As information technology has become more sophisticated and accessible, registries like this one have become more common in many health care settings. In fact, a 2003 survey of 1,040 physician organizations found that 40.3% had diabetes registries in place.⁴ Although registries themselves are not unique, the proposed effort in Santa Cruz County differs from conventional registries in several important ways.

First, because of the collaborative relationships already in place among Santa Cruz County’s public, private, and non-profit health sectors, the potential exists for a truly comprehensive registry that would capture (and share) data on County diabetes patients, no matter where they seek care. (A relatively small and contained geographic area helps as well.) We believe that the registry we have proposed – and the collaborative project team sponsoring it – are unique, crossing organizational and sector boundaries. Finally, because the registry

“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.”

*California HealthCare Foundation
Using Computerized Registries in
Chronic Disease Care
February 2004*

³ Institute of Medicine. 2003. *Crossing the Quality Chasm*. Washington, DC: National Academy Press.

⁴ Casolino L. et al. 2003. External Incentives, Information Technology, and Organized Processes to Improve Health Care Quality for Patients with Chronic Diseases,” *JAMA* 289(4):434-441.

is Web-based and interactive, it can offer real-time, interactive data for physicians, medical office staff, and patients. This is a relatively sophisticated, state-of-the-art IT product, but it also is designed to be useful at several levels. For example, if some physicians within a practice use the registry as part of an essentially paperless office, they will get the most out of it. But if other physicians in the same practice are uncomfortable with point-of-care interaction with the database, they can still benefit from it. Their office staff, for example, could print the relevant information for them; likewise, office staff could generate lists of patients overdue for foot or eye exams.

Overview of the Santa Cruz County Diabetes Mellitus Registry (DMR)

The registry, which was originally developed by PMG and is being donated to this project, is currently housed at PMG on a Microsoft SQL server. Approximately 200 physicians are part of PMG. Although almost all these physicians interact with some diabetic patients, those with the greatest numbers and concentrations are 45 internal medicine and family practice physicians, each treating between 10 and 80 diabetic patients.

Once a PMG physician's patient receives a diabetes diagnosis, he or she automatically becomes part of the diabetes registry. The registry's database is populated electronically from three sources: claims data from encounters (e.g., a visit to a podiatrist), laboratory data (e.g., for HbA1c tests), and pharmacy data (e.g., a Metformin prescription). These types of data are collected in HIPAA-compliant electronic formats (837 for claims/encounter data; HL7 formats for laboratory data) to minimize data entry requirements. However, the registry could accommodate practices/offices that prefer to use File Transfer Protocols (FTPs) or other data formats (e.g., digital images and/or faxes).

At PMG, manual data entry is limited. In most cases, the only fields requiring data entry during or after a visit are a patient's weight and blood pressure, referrals, and specific actions taken during the visit (such as a flu shot). These can be entered at the time of the visit or afterwards, either by the physician him/herself or by office staff.

Using a combination of electronically and manually entered data, the registry produces several products that can be used by a physician at the point of contact with a patient, by physicians and office staff reviewing a patient population as a whole, and by administrators tracking aggregate performance in achieving diabetes care goals. Examples of each type of report, as they would appear on a computer screen, are provided in Appendix B.

At the point of care, a physician fully using the system would be able to pull up a profile for each patient. The profile, populated as described above, lists all available data on the following fields:

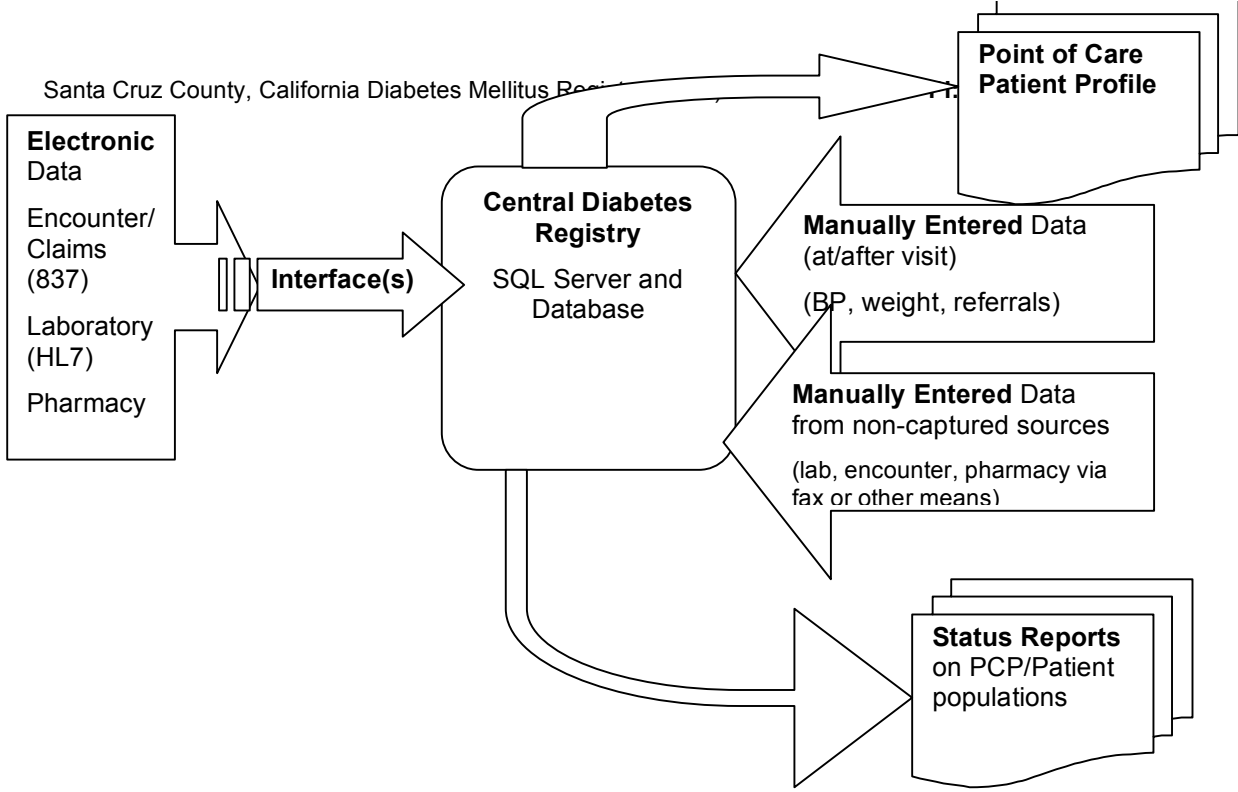
Registry Field	Data Source
Primary Care Provider (PCP)	Automatic
Office Visit Date	Automatic
Blood pressure and weight at visit	Entered by physician or staff
Diabetes Type and Year of Diagnosis – automatic	Automatic (after initial assessment)

Registry Field	Data Source
Co-morbidities (CAD, PVD, Foot ulceration/amputation, TIA/Stroke/CVD, peripheral neuropathy, hypertension, renal failure/proteinuria, retinal disease)	Automatic (after initial assessment)
Hypertension control and medications	Entered by physician or staff
Glucose Control	Laboratory results for glucose and HbA1c tests
Cholesterol Control	Laboratory results for TC, LDL, TG, and HDL
Microalbuminuria	Laboratory results
Medications: aspirin, Ace inhibitor, beta blockers	Pharmacy data
Exams: foot exam, retinal exam	Claims/encounter data (837)
Other information: tobacco use, referrals to self-management classes, other referrals, flu shot	Entered by physician/staff
Pharmacy Data – drug name, class, Rx duration, last filled, % usage, and prescribing provider	Pharmacy data

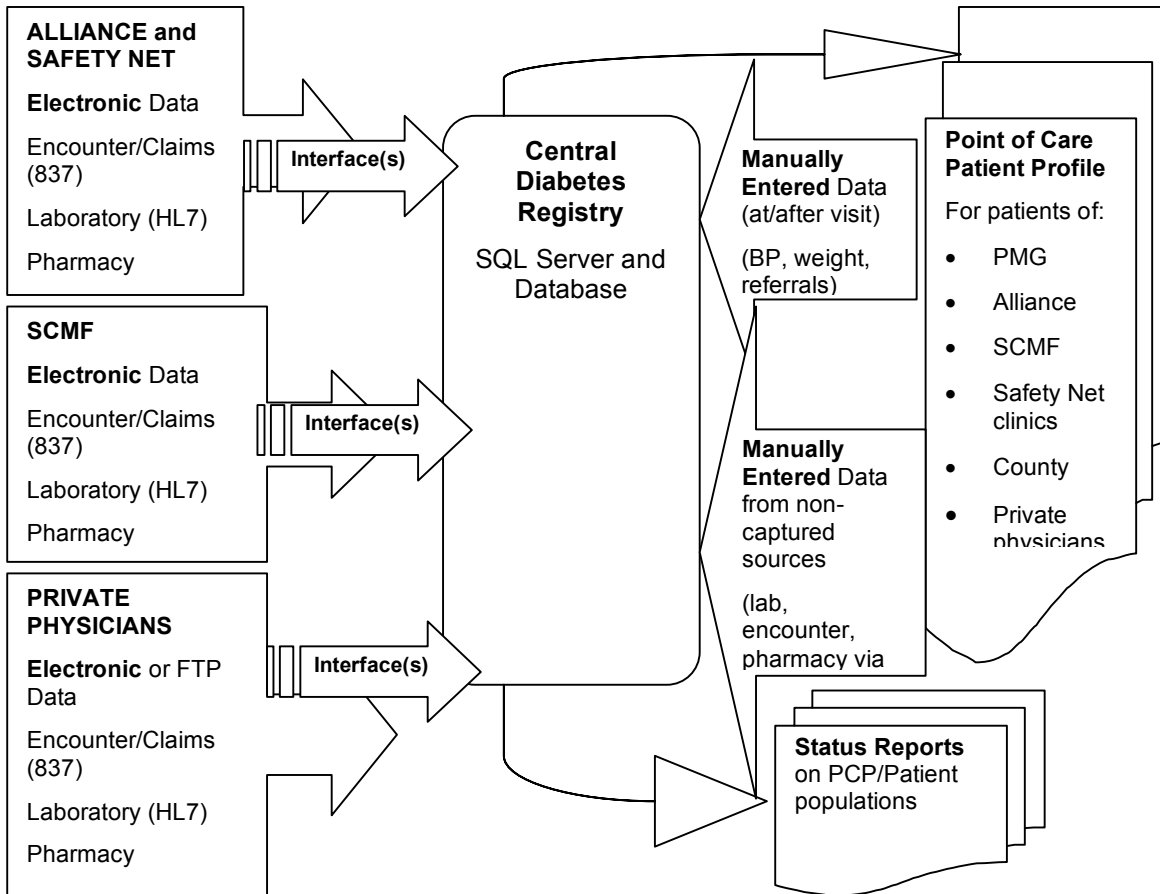
Moving a step further, the registry includes algorithms (based on recently developed state and national diabetes care standards) that interpret the data and present prompts for needed actions. For example, depending on a patient's HbA1c test result (above or below 7.0) and when it was last obtained (within a year or not for those at or below 7.0; within 3 months or not for those over 7.0), the action alert would prompt a physician to obtain an HbA1c test during the visit, and recommend quarterly or annual tests (as appropriate). (A list of the logic behind each item is also provided in Appendix B.)

The registry also allows physicians (and/or medical office managers) to print lists of patients according to different characteristics, such as those whose HbA1c test result is greater this year than last, those with particularly high HbA1c test results (and when they were last seen), and/or those whose last visit was over a year ago (and thus overdue). Examples of these types of lists also are provided in Appendix B.

For **PMG alone**, the registry can be pictured as follows:



Through this project, we propose adding more health care organizations and their patients to PMG's initial registry, in phases. As each is added, it will replicate the data flow and products depicted for PMG (above):



The Alliance and Safety Net Clinics. The easiest organization and patient population to add will be that of the Alliance. For patients covered by Medicaid, the Alliance will represent significant overlap with the County's Safety Net clinics (Planned Parenthood, Women's Health Center, Salud Para la Gente, and two County public health clinics).

Interest in improving diabetes standards of care and outcomes is high among both the organization's leadership and participating physicians. For example, a recent effort to increase timely eye exams for diabetic patients, using a paper reminder system for physicians, increased the proportion of diabetic patients who were up-to-date on their eye exams from 29 to 60 percent over a 2-year period (2000 – 2002).

The Alliance also offers some practical advantages as an early addition to the registry. The Alliance has developed a similar internal diabetes management program and could both send and receive claims/encounter and laboratory data with minimal adjustments. Alliance patients receive a unique state-generated Client Index Number (CIN) which reduces (but does not eliminate) the problem of duplicate records for the same patient. Eighty-nine percent of Alliance members are assigned to a PCP (with the remaining 11% divided among new patients who have joined in the last month, children enrolled in CCS, and those in long-term care facilities).

As noted in the "Issues and Solutions" section, above, some concerns will have to be addressed as the project moves ahead. The first is that the Alliance's patient population includes not only Santa Cruz County residents, but Monterey County residents as well. (In the near future, members from other California counties may also be added to the Alliance system.) In order for the registry to be useful to the Alliance, it will eventually have to be able to accommodate patients from outside Santa Cruz County – possibly by creating a separate database for this use. Alliance analysts also have recently discovered that a small but significant number of HbA1c tests (900 out of 20,000) are being conducted by laboratories other than the one with which the Alliance currently has a contract – and by one laboratory in particular. Exploring whether this laboratory would provide test results to the database (since it will be providing data for other Santa Cruz County patients) will be an early task for project staff.

Santa Cruz Medical Foundation. A second phase of the project will bring 120 Santa Cruz Medical Foundation (SCMF) physicians and their patients into the registry. This expansion is in some ways the most challenging part of the project, yet it is also what most distinguishes the Santa Cruz County DMR project from other registry efforts. Unlike registries that share data only among physicians and organizations affiliated in some formal way (such as members of the same health plan or publicly funded clinics in a particular geographic area), this registry will pool data from competitors in the health care marketplace. To ensure the registry's neutrality and to increase the chances of full participation by all diabetes care providers, the registry functions – after an incubation period at their current location at PMG – may migrate to a neutral location and staff configuration. Possibilities include the Pajaro Valley Community Health Trust, the County's Health Services Agency, or an outside contractor. Each of these choices has pros and cons (as discussed above); the project's Steering Committee and staff will

have to weigh these factors at this particular juncture and choose a scenario that preserves the registry and maintains the fullest possible level of participation.

Like the Alliance and PMG, SCMF has invested in internal quality improvement efforts for diabetes care, developing a similar in-house registry. In many ways, the SCMF internal system is self-sufficient – receiving similar laboratory data and tracking similar data elements as the PMG registry. However, when new patients transfer into the SCMF, their prior treatment history may be difficult or at least time- and labor-intensive to obtain. Likewise, patients who transfer from SCMF to other providers/plans within the County may move without the carefully collected diabetes data following them in a timely way.

Technically, the SCMF interface may be somewhat more complicated than those for the Alliance and Safety Net clinics (since the others can flow through Elysium) and will require some programming time to select and map individual data elements. The SCMF IT officer and programmer are willing to work with the project through its IT Committee to make this possible, with the endorsement of SCMF's senior management. As noted above, the technical hurdles can be tackled successfully with some programming resources. It is the willingness to participate that is a more formidable obstacle, and one that the planning group for this project already has overcome.

Non-affiliated physicians. Approximately 75 practicing physicians in Santa Cruz County are unaffiliated with any of the organized networks described above. A small number of these, estimated to be between 10 and 15 physicians, is providing mainstream primary care. Most have some relationship with the Alliance.

This group is likely to have the widest variation in IT infrastructure, skills, and enthusiasm. (A needs assessment early in the project will help classify who falls into which category.) In addition, some individual physicians may have contracts with a large number of laboratories and pharmacies, making it more complicated to obtain data in one fell swoop. We plan to incorporate the private physicians in stages as well – starting with those with a combination of interest, IT infrastructure, and existing electronic reporting. The training and technical assistance team will work with others on a case-by-case basis to identify and resolve barriers. The project team is willing to accommodate other formats – such as File Transfer Protocols (FTP) or even digital images and faxes of forms – to encourage participation (at least at first).

Tasks, by Phase

Since a tested, functioning prototype is already in use within PMG – and has generously been made available to the partners pursuing this grant – we have the luxury of beginning this process with costly and time-consuming software development already completed.

To expand the existing registry to the entire County, we anticipate three phases, each lasting approximately one year. During **Phase I**, we will concentrate on three tasks:

- Creating the **project structure** and team. This will involve convening the three project committees (clinical, IT, and medical office managers) and recruiting staff for unfilled positions (Project Manager, Programmer, Help Desk/Liaison).
- Conducting a **needs assessment** for key users (physicians and medical office managers) to determine their computer skills and interest level. The needs assessment phase is critical because it allows us to gather information about the context into which this system will be introduced. We will want more information about the following:

Phase I

- Project structure and team
- Needs assessment
- First wave of expansion: Alliance and some SN clinics

- The work climate: How likely is it that potential users will adopt a new process? How do they feel about new technology? At what level would they anticipate using the registry? What benefits do potential users see in using this system at various levels? What barriers to use do potential users anticipate?
- Technological systems: What systems do potential users currently have in place? Is the current registry compatible on a systems and interface level?
- Current knowledge level: How much do potential users currently know about diabetes and do they see the potential for better care by using this system?
- Technical skills: How proficient are potential users with computers and basic computer skills?
- Who are the potential users? Physicians? Medical Assistants? Front Office Personnel? Registered Nurses? Others?

Specific activities related to the needs assessment include:

- Developing a question bank and piloting the questions for the needs assessment
 - Researching options for survey software
 - Piloting both the on-line assessment and a qualitative assessment
 - Assembling a team for data analysis
 - Planning and implementing a full-scale needs assessment with qualitative component
 - Compiling and reporting results
- Bringing the **Alliance** into the registry. This “first wave” of expansion starts with the easiest addition. An interface will still have to be developed,

requiring programming time from the project and from Alliance staff. This will serve as an initial pilot test of the data flow. In addition, as training is developed in Phase II, PMG and Alliance physicians and office staff will be offered training first.

During **Phase II**, the needs assessment results will be used to develop several different curricula to meet varying training needs. For example, those with high interest and high skill levels may need a brief “nuts-and-bolts” demonstration and some ideas about ways to use the registry results to improve both point-of-care interactions and office work flow. We also have discussed incorporating some information on the registry in classes conducted at Cabrillo College for medical assistants, many of whom are employed locally. Workshops with continuing education credits may also be an option. As these training options are being developed (with input from potential users), we also will develop a marketing plan to educate potential users and build interest in the registry. Each variation of the curriculum will be tested with its intended audience and adjusted based on their feedback. Ultimately, we will create a training plan that addresses the needs of various groups of users and levels of usage. The training will be delivered and evaluated during Phase II as well.

- | |
|--|
| <p>Phase II</p> <ul style="list-style-type: none"> • Curriculum development • Marketing/promotion • Training delivery and evaluation • Second wave of expansion: SCMF, private physicians, and remaining SN clinics |
|--|

Another Phase II activity will be adding the next wave of participating organizations: SCMF, private providers, and any Safety Net clinics that did not join the registry during Phase I. Depending on the registry’s status at that point, the project’s Steering Committee may elect to move the server and staff to a neutral location (outside PMG) to make it easier for SCMF physicians and other private providers to participate. PMG has no objection to doing this and, because the bulk of the work would be contracted to programmers and help desk staff familiar with the program, it is unlikely to interrupt the registry’s operations.

This second wave of participants is likely to include private physicians and Safety Net clinic providers who have the most doubts and/or resistance about the registry. As a result, they will require more intensive training, visits from the help desk/liaison staff member, and general project support.

Our goal is to have every physician and organization that wants to participate on board by the end of Phase II, with training and support in place.

This schedule will allow us to concentrate on the registry’s functions and potential in **Phase III**. During Phase III, we will continue to offer training and support to new participants, as needed – for we expect that even within participating organizations, some individuals will be too busy or too reluctant to attend training or try the registry when it is first offered. (Indeed, some may never do so, but we hope that number will be small to begin with and will be reduced further through our efforts.)

By the end of Phase III, with a critical mass of participating organizations and individual physicians/offices, we will be able to take the first comprehensive look at diabetes care in our County. As the section on evaluation, below, suggests, we hope to

document not only participation and elevated standards of care, but improved health outcomes for diabetic patients.

If the project succeeds in this way – even if the success occurs in fits and starts and is far from universal – we will have made tremendous progress on several fronts. We hope first and foremost to elevate the standard of diabetes care so that every patient in Santa Cruz County has an equal chance – and a good chance – of receiving care that meets or exceeds state and national standards. We hope, in doing so, to reduce the largely preventable consequences – in terms of both needless suffering and avoidable costs. If we succeed, we may also have some converts along the way to the idea that information technology can actually enhance, rather than hinder, disease management. This will open many doors for our community, potentially expanding this effort to other diseases and building interest in (and commitment to) a community-wide health information exchange.

Phase III

- Continued training events
- Additional expansion, as needed
- Documenting and disseminating results

Future Plans

“It is relatively easy to collect the registry data, much more difficult to act on it.”

As a physician pointed out in the California HealthCare Foundation’s recent report on chronic disease registries, “It is relatively easy to collect the registry data, much more difficult to act on it.”⁵ Our proposed project takes this important distinction into account, especially in terms of sustaining and eventually expanding the registry concept.

For the project’s short-term and long-term success, it will be critical for physicians and health care organizations to see its value. A case will have to be made not only in terms of efficiency, but also in terms of elevated standards of diabetes care. However, it is also worth noting that the registry will still be useful – and can still advance standards of diabetes care in the community – even if it is *not* used to its fullest potential by every practice.

Ideally, physicians will use the full program with the patient present, including entering new information and reacting to the algorithmically driven care prompts. In other cases, action lists generated by the program will enable office staff to help connect patients with needed care, whether the physician uses the system or not. Still others may choose to use the registry as a passive "dashboard indicator," efficiently gathering information and saving some time, but not necessarily using the real-time prompts. Some may use it to create action lists as a generic electronic "tickler file" for reminder/recall without individual patient data. Others may use the system exclusively for overall system performance evaluation, or use this feature in combination with

⁵ First Consulting Group. 2004. *Using Computerized Registries in Chronic Disease Care*. California HealthCare Foundation.

others. We expect this type of variation to occur across organizations and certainly within a practice as well, as individual adoption rates and enthusiasm inevitably will vary.

The registry itself makes tracking many of these variables straightforward. For example, registry “hits” – when physicians or medical office staff access the database – are routinely tracked. Likewise, trends in selected patient outcomes (listed below) can be tracked by physician, office, and medical group – and, ultimately, for the community as a whole.

As noted elsewhere in this application, we anticipate that the registry will be successful not only because it has already undergone a rigorous development process, but also because the leaders of each participating organization are committed to its success. To evaluate the project’s successes (as well as areas from which we can learn during and after the project’s 3-year time frame), we plan to collect the following types of data:

Adoption/participation:

- Participation in training
- % of physicians and offices using registry; trends over time
- Type of use (full, partial, none)

Standards of care:

- % diabetes patients under care of physician/practice using program; trends over time
- % diabetes patients with
 - particular indicators under control or within guidelines
 - Hypertension
 - Glucose control
 - Cholesterol control
 - Microalbuminuria
 - Tobacco abuse
 - Medication (prescriptions and use)
 - Aspirin
 - Ace inhibitor
 - Beta blockers
 - Exams and referrals
 - Foot exam
 - Retinal exam
 - Self management class referral
 - Diabetes educator referrals
 - Flu shots

Health outcomes:

- Hospitalization rates (and days) for heart attacks, stroke, amputations

Long-term Outcome Goals

Based on PMG's experience with the diabetes registry to date, we believe realistic long-term goals include the following:

- Elevating the standard of care for diabetes in Santa Cruz County
- Making an elevated standard of care consistent within organizations and across organizations, so that any Santa Cruz County patient with diabetes has the highest chance of receiving optimum care – regardless of the clinic or provider chosen.
- Reducing the incidence of complications of diabetes (by keeping diabetes under control for more patients) – along with the suffering and costs that accompany these complications.
- Creating a model that can be expanded to manage other chronic diseases.
- Engaging patients in their care in several new ways – by using the technology to customize self-management information (e.g., on diet and exercise) and by creating a patient advisory group to parallel the other committees (clinical, medical office, and IT) envisioned for the current grant.
- Creating a track record of success that will open the door to a truly comprehensive Health Information Exchange.
- Extending a similar systematic approach to primary prevention – detecting and monitoring “pre-diabetic” conditions so that patients do not become part of the diabetes registry in the first place.

The PI, Project Manager, and steering committee will use a combination of registry data (tracking patient indicators as well as physician and office use of the registry), interviews (with leaders of participating organizations), and training evaluations (such questionnaires based on needs assessment parameters, and focus groups of participants) to gauge the project's success in each area.

Achieving these long-term goals will support many of AHRQ's health information technology initiative goals. By prompting physicians and practices to follow standardized guidelines, the registry will help reduce practice variation and the suboptimal care that often accompanies that variation. This, in turn, should yield significant benefits relative to the registry's cost. A centerpiece of our project is customized training designed specifically for physicians (especially reluctant ones) and for medical office staff. The project will help document approaches to both assessing training needs in these populations and to designing and delivering training that makes possible not only the collection of data, but (more importantly) its day-to-day use. Collectively, these features will serve as a model for others willing to collaborate across organizational boundaries to improve diabetes care in their communities.

Appendix A:
Letters of Support

Appendix B:

Sample Diabetes Registry Screens

Appendix C:

Participating Organizations

Santa Cruz County, California Diabetes Mellitus Registry (DMR)

Participating Organizations

Organization	Role/Contributions
Pajaro Valley Community Health Trust	<ul style="list-style-type: none"> • Administrative stewardship/fiscal oversight
Physicians Medical Group	<ul style="list-style-type: none"> • Diabetes registry software • PI • IT staff support • Physician participation
Alliance Santa Cruz Medical Foundation HSA Safety Net Clinic Coalition Regional Diabetes Collaborative Health Improvement Partnership	<ul style="list-style-type: none"> • Champion project with physicians and staff • Participate in pilot training and implementation • Release physicians, medical assistants, office managers for training and endorse participation in needs assessment and evaluation (surveys, focus groups) • Nominate committee members for Steering, Clinical, IT, and Medical Office committees; release staff to participate in committees • Participation in evaluation; dissemination of project results
Cabrillo College	<ul style="list-style-type: none"> • Conduct training needs assessment • Design and conduct customized training • Participate in evaluation of training components