

Grant Final Report

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**Santa Cruz County, CA Diabetes
Mellitus Registry**

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Abstract

Purpose: This project was built on a history of productive collaboration among Santa Cruz County's public and private healthcare providers for the purpose of operating a community-wide diabetes registry. The original aims were to:

- Build a collaborative to support the spread of best practices in chronic care management starting with diabetes;
- Implement a widely adopted point of care electronic registry tool;
- Reduce complications for persons with diabetes;
- Reduce disparities in diabetes care;
- Demonstrate the business case to sustain a community-wide registry

Scope: Project scope included developing the governance structure for the Community Chronic Care Network and implementing a community-wide diabetes registry.

Methods: The method for developing the registry was to extend existing software developed by a local physician group to as many providers as possible and to obtain data from multiple sources including electronic medical records.

Results: Lessons learned regarding the challenges of registry development, adoption and sustainability led to changes in strategy for collaborative improvement of chronic care. Current aims are to support community-wide adoption of electronic medical records with disease registry capability and to wait for a future opportunity to exchange data for a community-wide registry.

Key Words: Diabetes, Registry, Collaboration, Adoption, Sustainability

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Final Report

Purpose

The mission of the Community Chronic Care Network (CCCN) is to ensure that all people with chronic conditions in Santa Cruz County receive consistent and continually improving medical support by employing modern electronic tools and sharing clinical practice innovations among our diverse providers of care.

CCCN received grant funding from the Agency for Healthcare Research and Quality for the period from October 2004 to September 2007 to implement an electronic registry tool for diabetes care in support of this mission. The objectives of the CCCN during this 3-year grant period were:

1. **Collaboration:** Build upon the existing, maturing collaborations of healthcare providers in Santa Cruz County to support the sharing, adoption, and spread of best practices in chronic care management starting with diabetes care. The supporting collaborations include the Health Improvement Partnership and the Regional Diabetes Collaborative.
2. **Adoption:** Promulgate and apply nationally approved diabetes care guidelines through a widely deployed point of service electronic registry tool and support and coordinate with the development of electronic health records in Santa Cruz County.
3. **Decrease Complications:** Reduce the incidence of complications for persons with diabetes in Santa Cruz County along with the suffering that accompanies these complications.
4. **Equity:** Reduce and eventually eliminate disparities in diabetes care in Santa Cruz County through clinical practice innovation, patient activation, cultural responsiveness, and use of community resources across all sites of care.
5. **Sustainability:** Demonstrate overall economic savings to parallel improved clinical outcomes to create a business case to preserve and extend the use of modern electronic practice supports for the diversely funded local healthcare systems.

Scope

Background

In 1993, the National Institute of Diabetes and Digestive and Kidney Diseases of the National Institute of Health published results from the 10-year Diabetes Control and

Complications Trial (DCCT) that demonstrated that keeping blood glucose levels as close to normal as possible slows the onset of complications of diabetes.¹

Since the publication of the DCCT results, numerous studies have provided evidence of improved outcomes for people with diabetes from regular foot, dental, and eye exams, as well as depression management, regular testing of microalbuminuria, blood lipids, self-glucose monitoring, medical nutrition therapy, physical activity, aspirin therapy and smoking cessation.

Based on this research, the Professional Practice Committees of the American Diabetes Association (ADA) published Clinical Practice Recommendations in 2003.² The California Diabetes Prevention & Control Program and the Diabetes Coalition of California also published Basic Guidelines for Diabetes Care in 2003, which were updated in 2005.³

Despite the expansion of medical research and development of evidence-based guidelines, a committee of experts from the Institute of Medicine found that the health care system frequently failed to translate this knowledge into practice. In 2001, the Institute of Medicine (IOM) published a call for action to address what was called the “quality chasm” in health care.⁴ A 2003 survey conducted by Rand Health reported that people with diabetes received only 45% of the care prescribed by national guidelines. For example, only 14% of people with diabetes had the prescribed annual eye exam.⁵

In 2004, the IOM convened a Crossing the Quality Chasm Summit. Representatives of 15 innovative communities from across the country, including Santa Cruz County, met with national leaders and organizations to identify strategies for achieving high-quality care for five chronic diseases including diabetes.⁶ Research presented at the conference demonstrated that a diabetes registry improves provider performance to standards. The Santa Cruz County delegation returned home and advocated for the concept of a community-wide diabetes registry as a strategy for community quality improvement. This led to a successful proposal for such a registry to the Agency for Healthcare Research and Quality’s Transitioning Healthcare Quality Through Information Technology program.

Context

The context in which this research was conducted was important to our analysis of the outcomes, as well as for other communities evaluating a community-wide registry for quality improvement. The following discussion of the Santa Cruz County context is organized by the five project aims—collaboration, adoption, decrease complications, equity, and sustainability.

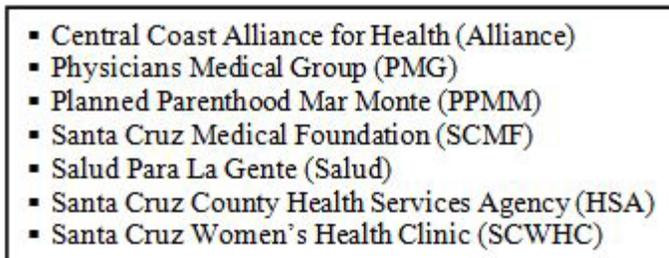
Context: Collaboration. The Santa Cruz County Diabetes Mellitus Registry Project operated in a context of productive collaboration among the County’s public, private, and not-for-profit healthcare leaders. The Health Improvement Partnership of Santa Cruz County (HIP), a nonprofit coalition of public and private health care leaders, was launched in 2002 and incorporated in 2005. Over the last five years, HIP’s members have focused on increasing access to care and building stronger local health care systems including support for the expansion of health information technology and chronic care management. HIP’s Safety Net Clinic Coalition (SNCC) unites community clinics to work on increasing access for the County’s low-income, uninsured population. HIP, along with SNCC, has served as an incubator for a variety of collaborative programs that would have been beyond the scope of any single County health care organization or leader. In 2005, HIP became the legal entity for the community-wide diabetes registry.

The Regional Diabetes Collaborative (RDC) was convened by the Pajaro Valley Community Health Trust in 2002. The RDC includes 40 organizations from Santa Cruz, and neighboring San Benito and Monterey counties. The RDC's mission is to support, promote, and coordinate efforts to prevent and manage diabetes in the tri-county region. Since 2005 the RDC has sponsored an annual provider forum on best practices in diabetes care, including the effectiveness of registries in diabetes management.

The culture of collaboration in Santa Cruz County has thrived despite the competition among healthcare providers. There are three hospitals in Santa Cruz County-- two with complete acute care services and the third a maternity and short-stay hospital. Two of the hospitals are non-profit and one is for profit. There are also two competing medical groups – Physicians Medical Group of Santa Cruz County (PMG), an IPA; and Santa Cruz Medical Foundation (SCMF), an affiliate of Sutter Health. In 2007, another physician group, Dominican Medical Foundation, an affiliate of Catholic Healthcare West, was organized in Santa Cruz County.

The healthcare providers that participated in this project are shown in the figure below. They include the two competing medical groups (PMG/SCMF), the County Health Department (HSA), three community health centers (PPMM/Salud/SCWHC), and the County's Medicaid HMO (Alliance). In addition, partners in this project included the local community college (Cabrillo College) and a local philanthropy (Pajaro Valley Community Health Trust), along with the collaborative organizations noted above--HIP and RDC.

Figure 1.

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- Central Coast Alliance for Health (Alliance)
 - Physicians Medical Group (PMG)
 - Planned Parenthood Mar Monte (PPMM)
 - Santa Cruz Medical Foundation (SCMF)
 - Salud Para La Gente (Salud)
 - Santa Cruz County Health Services Agency (HSA)
 - Santa Cruz Women's Health Clinic (SCWHC)

Wells Shoemaker, MD, served as the Principal Investigator for the project from September 2004 to December 2006. As PMG Medical Director, Dr. Shoemaker was closely involved in the PMG diabetes registry's development and was a champion of its use within the organization. Dr. Shoemaker was also a key player in developing collaboration among competing healthcare organizations in Santa Cruz County and a highly effective spokesperson for the chronic care model and of the value of information technology in support of practice redesign at both the local and state level. In 2006 Dr. Shoemaker took a statewide position in quality improvement as the Medical Director of the California Association of Physician Groups and resigned his role as Principal Investigator for this project.

- Central Coast Alliance for Health (Alliance)
- Physicians Medical Group (PMG)
- Planned Parenthood Mar Monte (PPMM)

- Santa Cruz Medical Foundation (SCMF)
- Salud Para La Gente (Salud)
- Santa Cruz County Health Services Agency (HSA)
- Santa Cruz Women's Health Clinic (SCWHC)

Context: Adoption. Santa Cruz County has a well-earned reputation for leadership in the adoption of health information technology. In 1995 PMG partnered with Axolotl/Elysium to develop a prototype clinical messaging system. Today more than 50% of Santa Cruz County providers, including safety net clinics, receive lab data via the Elysium clinical messaging system.

The PMG diabetes registry at the center of this project was another example of early adoption of health information technology. The registry was Web-based and interactive, captured data electronically and stored it on a Microsoft SQL server. The registry's database was populated electronically from three sources: claims data from encounters, laboratory data, and pharmacy data. For PMG HMO patients, manual data entry was limited. In most cases, the only fields requiring data entry during or after a visit were a patient's weight and blood pressure, referrals, and specific actions taken during the visit. The registry produced several products that could be used by a physician at the point of contact with a patient, and by physicians and office staff reviewing a patient population as a whole. Because the PMG diabetes registry only included patients with HMO coverage, a barrier to physician adoption was that patients who were not currently enrolled in a PMG HMO plan were not in the active registry. Overcoming this adoption barrier was one of the incentives for PMG to participate in developing a community-wide registry which could include patient information from all payors, including Medicare.

Although the support for early adoption of health information technology helped recruit organizations to participate in this project; it also meant that many providers adopted EMRs during this period which became a barrier to adoption of a point-of-care registry. During the three years of this project the adoption of electronic medical records by physicians in Santa Cruz County increased from 9% in 2004 to 46% in 2007. This dramatic increase is primarily due to the implementation of EpicCare EMR by the Sutter/Santa Cruz Medical Foundation and at the Santa Cruz County Clinics. The County Clinics implemented EpicCare as a member of the Oregon Community Health Information Network (OCHIN) and were among the first safety net clinics in California to successfully implement an EMR. The growth of EMRs in Santa Cruz County parallels that of EMR adoption in California during this period. A recent study by the California HealthCare Foundation found that 37% of individual physicians in California used electronic health records in 2007, primarily driven by EMR adoption in large medical groups such as Kaiser Permanente and Sutter affiliates. This is higher than the national average EMR adoption of 28%.⁷

Context: Decrease Complications. As noted above, another important element of the context of this project was the commitment to improving the quality of diabetes care in our community. This commitment is based on the high incidence of diabetes in Santa Cruz County. In the 2007, Santa Cruz County Community Assessment Project (CAP) telephone survey 4.5%

of respondents indicated that they had been told by a doctor that they have diabetes.⁸ In 2007, the Centers for Disease Control did Systems Dynamics modeling for Santa Cruz County and projected that an additional 3% of the population has undiagnosed diabetes.⁹ Applying these percentages to the 200,000 adults living in the County means that there are approximately 15,000 County residents with diabetes.

During the 3-year project, there was also a growing consensus in the provider community that a diabetes registry improves provider performance and would therefore result in a decrease in the development of complications of the disease. The PMG registry findings illustrated in Table 1 were a major factor in building this consensus.

Table 1. Comparative performance of PMG physicians using registry, 2003-05

Registry	% of Persons w/Diabetes: A1c 2/yr	% of Persons w/Diabetes:A1c < 7.0	% of Persons w/Diabetes: LDL 1/yr	% of Persons w/Diabetes: LDL < 130	% of Persons w/Diabetes: SBP < 130	% of Persons w/Diabetes: Retinal exam/yr
Users	59%	60%	83%	74%	74%	64%
Non-Users	26%	54%	56%	42%	NA	29%

Another factor in the clinical context of this project was the Breakthroughs in Chronic Care Program. The California Breakthroughs series is sponsored by a collaborative of purchasers, payors, medical groups, and pharmacy companies which set an ambitious statewide target in chronic care improvement, with an initial focus on diabetes and vascular disease. Both Santa Cruz County private medical groups, PMG and SCMF, participated in the diabetes initiative, the only locality in California in which competing medical groups both participated. Participants implemented intensive PDSA cycles to improve care and reported registry-type data on a monthly basis. The PMG registry was shared as a best practice in improving provider performance in diabetes care.

The Alliance also contributes to the association of registry reports with improved patient outcomes. For several years, the Alliance has produced a quarterly registry-type diabetes report for primary care providers. The report included a list of members who are overdue for diabetes screening exams. The Alliance has excelled in statewide measures of patient outcomes and utilization for several years. For 2006, the Alliance received the Gold Certificate for Quality for outstanding performance in Healthcare Effectiveness Data and Information Set (HEDIS) measures and was recognized as the top health plan in the state for high quality preventive and chronic disease health services. In 2007, the Alliance added a Quality Based Incentive program, rewarding primary care providers for high performance on HEDIS measures including HbA1c and LDL screening.

Context: Equity. The objective of achieving equity in diabetes health is another important factor in understanding the context of this project. It is recognized that there are significant ethnic and therefore geographic differences in the prevalence of diabetes in Santa Cruz County. According to 2000 Census data, 28% of the County’s population is of Latino origin, a population with a higher prevalence of diabetes than the general population. In the southern part of the County, especially within and around the city of Watsonville, the Latino population approaches 70%. An over-sample of the 2007 CAP survey commissioned by the Pajaro Valley Community Health Trust revealed a significant difference in the prevalence of diabetes in Pajaro Valley (South Santa Cruz and North Monterey counties) of 8% as compared to 3% for the rest of the

county. Nineteen percent of Pajaro Valley respondents also reported that they did not have a regular source of healthcare as compared to 9% in the remainder of the county, confirming a critical disparity in chronic care management.

The mission of the Pajaro Valley Community Health Trust is to improve the health status of residents of the Pajaro Valley and to reduce these inequities. This was the motivation for the Trust to be the applicant for the AHRQ grant and to include public and private safety net providers as well as the private medical groups. Among the safety net providers, a special focus was to implement the registry at Salud Para La Gente (Salud), the largest community health center in the County caring for an estimated 2,000 persons with diabetes.

Context: Sustainable. The history of collaboration in Santa Cruz County also includes sustaining successful collaborative projects. The two major examples are the County's Healthy Kids program and Project Connect. Healthy Kids began in 2004 with private grant funding to increase enrollment in Medicaid and Healthy Families insurance program and cover uninsured children not eligible for these public programs. The program which includes an internet based eligibility system, has increased insurance coverage for children in Santa Cruz County to 98%. Healthy Kids is sustained with a combination of private and public funding. Project Connect, an intensive case management program for frequent users of emergency services, was also initiated with grant funding and has been sustained beyond the 2003 to 2007 grant period. Project Connect is sustained with a combination of public funding, reimbursement and provider fees based on its demonstrated effectiveness in decreasing emergency room use.

Methods

Study Design

As noted above, the method for developing the registry was to extend existing software developed by a local physician group to as many providers as possible and to obtain data from multiple sources, including electronic medical records. The original Study Design was divided into three phases: 1) add safety net early adopters to PMG users; 2) add other safety net and private offices; and 3) document outcomes of registry for sustainability. This Study Design did not anticipate the complexity of organizing the governance and legal structure for the registry; nor did it foresee the amount of software development required to deploy a secure registry across legal entities and to meet the needs of a variety of users including safety net providers.

As shown in Table 2 below, Phase I of the original study design was revised to add tasks related to developing the governance structure for the registry including negotiating memorandums of understanding among the partner organizations; selecting HIP as the legal entity to operate the registry; and securing liability insurance. In addition, with input from the Clinical and IT Committees and legal counsel, agreements were developed for provider offices/clinics using the registry at point of care, and for data from health plans, laboratories, and other potential sources. To start registry development, a pilot project was initiated to begin the transfer of authorized Alliance patient data into the PMG registry.

In addition to the unanticipated legal and governance tasks, the needs assessment of the safety net providers and the organization of the Clinical and IT committees identified the need

for further software development. The PMG registry required modification to meet the privacy and security requirements of the participating organizations as well as to adopt the registry forms to reflect the work flow needs of potential users, including safety net providers.

Phase II of the project became the development and launch of the community-wide registry.

These tasks were not completed until summer, 2006, in the second half of the three-year project. At that time, both SCMF and the HSA were in the middle of implementing EpicCare EMR, and decided not to participate as point of care registry users. In addition, the largest group of physician users of the PMG registry was implementing their own chronic disease management software using Elysium/Axolotl and decided not to make the transition from the PMG registry to the new community-wide registry. It is important to note that all of these providers continued to commit to providing data into the community-wide registry; but choose not to use the registry point of care. When the registry was implemented in May 2006 the community registry included 4,187 patients and grew to 5,014 by February 2007.

In Phase III of the project, the Steering Committee evaluated whether the initial methodology of expanding the PMG diabetes registry to a community-wide registry would lead to a sustainable product by the end of the 3-year project. This evaluation included an outside technical assessment; a stakeholder survey of the elements required for sustaining the registry; and a survey of registry users to determine barriers to adoption. These activities led to a decision to assess the feasibility of implementing Solutions, a comprehensive disease management software product developed by the Palo Alto Medical Foundation (PAMF), the parent organization of the SCMF. The assessment included the software development needed to implement Solutions as an external product in all settings, and determining the readiness of the safety net providers, principally Salud, to implement comprehensive disease management software. Following these assessments the decision was made that it was premature to develop a community-wide registry until the plans for EMR implementation were completed. The community-wide goal shifted to supporting successful adoption of EMRs with disease registry functions by all providers including safety net clinics. And at the same time to take advantage of the opportunity to develop a comprehensive registry for population health afforded by the widespread EMR adoption.

Table 2. Original & revised Diabetes Registry study design, 2004 – 2007

Original Study Design	Revised Study Design
<p>Phase I: First Wave Expansion</p> <ul style="list-style-type: none"> ● Create the project structure including the three project committees (clinical, IT, and medical office managers) and recruit staff. ● Conduct a needs assessment for key users (physicians and medical office managers) to determine their computer skills and interest. ● Bring the Alliance data into new registry. ● Train PMG and Safety Net physicians and office staff on new registry. 	<p>Phase 1: Development of Organization</p> <ul style="list-style-type: none"> ● Create the project structure including the three project committees (steering, clinical, & IT) and recruit staff. ● Conduct a needs assessment of safety net providers on readiness, requirements for use, and training needs. ● Bring the Alliance data into PMG registry. ● Develop governance structure and legal documents including user agreements. ● Define requirements for community-wide adoption and use by safety net providers.

Table 2. Original & revised Diabetes Registry study design, 2004 – 2007 (continued)

Original Study Design	Revised Study Design
<p>Phase II: Second Wave of Expansion</p> <ul style="list-style-type: none"> ● Develop and evaluate several different curricula to meet varying training needs identified in needs assessment ● Market and promote the registry to non-users based on experience of 1st wave users ● Evaluate whether to move server from PMG to neutral location ● Add the next wave of participating organizations: SCMF, private providers, and any Safety Net clinics that did not join the registry during Phase I 	<p>Phase II: Deployment of Registry</p> <ul style="list-style-type: none"> ● Execute legal agreements with data sources and users ● Bring Alliance and lab data into registry. ● Develop registry software including user interface to meet requirements of community-wide implementation and safety net adoption. ● Test new software and training curriculum at initial PMG physician site ● Close PMG registry; launch new registry for six PMG offices & one safety net clinic
<p>Phase III: Consolidate & Study</p> <ul style="list-style-type: none"> ● Offer training and support to participating organizations as needed ● Add organizations and data to reach critical mass ● Document and disseminate findings on community-wide diabetes incidence, patient outcomes, and improvements in care 	<p>Phase III: Sustain Collaboration</p> <ul style="list-style-type: none"> ● Contract for outside assessment of suitability of the technical approach to achieving a community-wide registry ● Assess stakeholder requirements to sustain community-wide registry beyond grant period ● Hire technology project manager ● Assess user requirements for expanded adoption ● Discontinue point of care tool and provide quarterly registry reports to current users ● Evaluate feasibility of expanding beyond diabetes and implementing Solutions software including achievability for and readiness of safety net providers ● Evaluate lessons learned and develop strategy for building sustainable registry

Data Collection/Measures

The Evaluation Plan for the original study design identified data sources, presented data collection tools including surveys, and set outcome targets in each of the five project aims: collaboration; adoption; decrease complications; equity; and sustainability. As discussed above, the change in the study design focused the project on the first two aims—collaboration and adoption. Stakeholder and user surveys were added to expand the evaluation data in these two areas. An outside Technology Assessment and facilitated Lessons Learned Steering committee meetings contributed to the richness of the results of this project and are presented in the next section of this report.

Measures—collaboration. A primary measure of whether this project was successful in building collaboration to support improvements in chronic care was to track attendance at the bi-monthly meetings of the Steering, Clinical and IT Committees by each of the healthcare organizations participating in the project. Members of each of these committees were selected to represent all sectors including the two private medical groups, the public sector, local philanthropy, safety net providers and the local health plan. The Steering Committee set a target of 80% average annual attendance for each of the three years of the project as a proxy for continuing commitment to the collaborative mission.

In October 2004 the Project Manager conducted baseline interviews with the stakeholders of the CCCN including the executive leadership of the partner organizations and the leaders of the CCCN Clinical and IT Committees. Each stakeholder was asked why their organization agreed

to participate in the collaboration; their vision of the best outcome; and their concerns about pitfalls and negative impacts. In October 2005 and February 2007, the Project Manager repeated these stakeholder interviews using a survey form based on the baseline interviews. In addition to open-ended questions, stakeholders were asked to rate their satisfaction with the progress of the CCCN on a scale of 1 (extremely dissatisfied) to 5 (extremely satisfied) including the commitment to sustaining the CCCN after the grant period. The Steering Committee set a target of 4/5 for overall satisfaction with the progress of the project including sustainability.

In October 2006, the Program and Grants Manager for the Trust met individually with ten key project and community stakeholders to define actual sustainability options. Respondents represented various public and private partners including several members of the CCCN Steering Committee, two independent physicians, and a community clinic. Survey respondents were asked to rate the value of various registry features to their organizations and assess their willingness to pay for each feature.

Two Steering Committee meetings held in September and October 2007 to discuss lessons learned by the organizations participating in this project provided a final opportunity for data collection regarding collaboration. These meetings were facilitated by consultants Peter Gaarn along with David Sibbet of Grove (graphic process) Consultants International. These meetings added a broader perspective to the findings and conclusions of the project evaluation, and provide valuable insights for other communities embarking on community-wide health information technology initiatives.

Measures—adoption. Another important set of measures of this project was adoption of the registry. Participants in registry training completed pre- and post-tests which included an assessment of their technical skills and understanding of how to incorporate the electronic diabetes registry into the clinic/office workflow. These tools were used to evaluate and revise the training materials and format as well to gauge provider satisfaction with the registry.

After implementation of the registry, monthly utilization statistics were reported to the Steering, Clinical and IT Committees to measure adoption of the registry. Adoption metrics included percentage of primary care offices/clinics that participated in training on the point of care tools as well as the use of the point of care and action report features of the registry. For data analysis, the utilization statistics classified point of care users into 3 categories: 1) Viewers are primary care providers/clinics who used the electronic registry and added point of care data for less than 25% of their registry patients; 2) Basic Users used the electronic registry on a limited basis and added point of care data for greater than 25% and less than 75% of their registry patients; and 3) Strivers who actively used the registry and added point of care data for greater than 75% of their registry patients. The target for adoption were that 90% of registry patients would be cared for in offices/clinics that had received registry training and that 60% of registry patients would be cared for in Striver offices/clinics.

Although not part of the original research design, the Steering Committee made a request to AHRQ for an outside consultant to complete a technical audit of the registry software to assess the suitability of the project's technical approach in achieving the project's specific objectives, as well as to better understand whether the software design contributed to the delays in the project's implementation. This technical assessment conducted by Sujansky and Associates in August 2006, included interviews with 13 project participants, a demonstration of the registry application, and review of 20 documents related to the goals, techniques, processes, policies and legal agreements of the project.

In January 2007, the User Interface Consultant added another source of data for this project, surveying six of the seven clinic/sites that were using the registry. The survey compiled quantitative and qualitative data on the value and usability of the registry; as well as exploring work flow issues and the clinic/offices readiness for a transition to electronic practice management.

Limitations

The delayed implementation and low adoption of the diabetes registry was a major limitation to completing the original research measures of this project. The patient outcome measures of decreasing complications, equity and sustainability that were included in the Evaluation Plan could not be calculated because they required 12-months of registry use and more widespread deployment of the registry than was achieved in this project.

Results

At the end of this project, the goal of healthcare leaders in Santa Cruz County remains to ensure that all people with chronic conditions in Santa Cruz County receive consistent and continually improving medical support by employing modern electronic tools and sharing clinical practice innovations among our diverse providers of care. The results of this Transforming Healthcare Quality Through Information Technology project are informing our aims and strategies in support of the mission of improving the quality of healthcare throughout our community with the support of health information technology. This section of our Final Report presents our principal findings, specific outcomes from our research studies, and conclusions in reference to our five project aims.

Principal Findings

1. **Collaboration:** Community-wide programs of quality and health information technology can build collaboration among healthcare organizations including among staff and providers as well as leadership. Community-wide quality and technology programs are complex, resource-intensive and involve risks especially in a competitive healthcare environment. Collaborative programs in quality and health information technology should begin with an analysis of the costs, risks and benefits for each of the participating organizations.
2. **Adoption:** Successful adoption of community-wide health information technology requires the commitment of leadership of each participating organization as well as support from providers and staff. The commitment includes recognizing successful adoption of health care technology must begin with the assessment of workflow and support for workflow changes if indicated.

3. **Decrease Complications:** Improving the quality of care at the community level requires the commitment of leadership of each participating organization as well as support from providers and staff. The commitment includes recognizing successful quality improvement often requires making changes in the organization’s model of patient care.
4. **Equity:** To reduce inequities in healthcare, safety net providers need to participate in community-wide quality and health information technology programs. The readiness, requirements and differences in the public and private safety net clinics, as well as the needs of the uninsured and underinsured, need to be included in the design and implementation of community-wide quality and health information technology programs.
5. **Sustainability:** In addition to providing value to individual provider organizations, community-wide health information technology can have significant value for population health. The case for this public benefit needs to be made to public health agencies, foundations, elected officials, advocacy groups and to the public.

Outcomes

This section of the report summarizes a broad range of outcomes from this project organized by the project aims as well as outcomes from the work on legal and technology added to the Study Design. These outcomes include results of the specific data collection efforts described above, as well as outcomes from other project tasks such as the development of user agreements. Because of the project limitations there was not sufficient data to assess outcomes related to decreasing complications. More detailed information on these outcomes and tools, including a registry prototype, are available on the project website — www.chroniccarenetwork.org.

Outcomes—collaboration. Table 3 shows the percentage of member organizations that participated in bi-monthly Steering, Clinical and IT Committee meetings. The Steering Committee had set an attendance target of 80% of member organizations. Although Steering Committee attendance declined below the 80% target in Years 2 and 3; it still averaged 77% in Year 3. The Clinical Committee consistently had the highest attendance in all years of the project. The IT Committee attendance declined in Year 3 primarily due to the lack of representation of community health centers with only one IT staff representative. Members of the Clinical and IT Committees, many of whom had never met with their counterparts in other organizations, expressed appreciation for the opportunity to work collaboratively on the community-wide registry. The IT Committee continues to meet under the sponsorship of the HSA.

Table 3. Committee meeting attendance by member organizations

Committee	% of Member Orgs. Attending Meetings: Year 1	% of Member Orgs. Attending Meetings: Year 2	% of Member Orgs. Attending Meetings: Year 3
Steering	83%	79%	77%
Clinical	97%	89%	90%
IT	82%	87%	70%

Table 4 summarizes the numeric results from the Stakeholder interviews conducted in Year 2 and Year 3. For this survey, stakeholders were defined as members of the Steering Committee plus the chair of the Clinical and IT Committees. In October 2005 stakeholders said their overall high satisfaction was due to the building of collaboration among diverse organizations including clinical and IT staff. Stakeholders also warned that to sustain high satisfaction, registry implementation needed to be achieved early in Year 2.

Therefore it was not surprising to see the drop in satisfaction from 4.5 to 3.0 in Year 3 reflecting stakeholder frustration with the delayed implementation and low adoption of the registry. Most respondents attributed the low adoption to the internal focus of many organizations on the implementation of electronic medical records and other HIT initiatives. Other stakeholders acknowledged that having a member organization in the role of software vendor complicated the resolution of technology issues. The low scores for the question about whether the project had decreased disparities reflect the particular disappointment of the stakeholders with the lack of registry adoption by safety net clinics.

Table 4. Stakeholder Interviews (scale 1-extremely dissatisfied to 5-extremely satisfied)

Question	October 2005	February 2007
Overall Satisfaction	4.5	3.0
Improved Quality	4.4	3.0
Well Adopted	4.4	3.2
Community Collaboration	4.9	4.3
Decreased Disparities	3.2	3.0
Reduced Barriers to HIT	3.8	3.7

Despite the decline in Steering Committee meeting attendance and satisfaction with the project, in the Lessons Learned meetings stakeholders agreed that there was incredible value added by this project which would be realized in future collaborative projects related to health information exchange.

The outside technical assessment by Sujansky & Associates included findings regarding collaboration.

- The CCCN disease registry is an important project to improve the health care of Santa Cruz County residents with chronic illnesses.
- The project has effectively convened many stakeholders in the Santa Cruz County health care community and focused them on the task of improving chronic disease care through information technology.
- Significant progress has been made in thinking through the many issues related to policies and procedures, the readiness of and barriers to practices' adoption of registry systems, and user-interface requirements of a professional-looking registry application.

Outcomes—adoption. Only seven offices/clinics adopted the point of care registry for office use. This represents less than 10% of primary care providers caring for patients with diabetes in Santa Cruz County and only 14% or 713 of the 5,014 registry patients were seen by

providers who were registry users. Even among this small number only 2 offices/clinics used the registry at the Striver level, again short of the 60% target goal. Table 5 shows this finding and also illustrates the improvement in patient outcomes with active registry use.

Table 5. Comparison of process measures, CCCN Registry Users, March 2007

Office/Clinic	Patients w/ diabetes	% of Patients w/ Diabetes: HbA1c test last year	% of Patients w/ Diabetes: Lipid panel last year	% of Patients w/ Diabetes: Microalbumin last year	% of Patients w/ Diabetes: Eye exam last year
Viewers (n=2)	230	53%	50%	43%	43%
Basic Users (n=3)	282	73%	55%	49%	40%
Strivers (n=2)	201	83%	80%	84%	63%
Total (n=7)	713	71%	62%	59%	48%

To determine the reasons for the low use of the registry among the users, six of the seven user offices/clinics were surveyed in January 2007. On average the respondents were only “somewhat satisfied” with the registry. The main reason for dissatisfaction was the point of care tool which was too many pages and was not organized to match the flow of the patient visit in their office. Respondents stressed that the registry needed “100% data reliability” and that occasional occurrences when patient data “disappeared” undermined their willingness to use the registry. For PMG physicians the fact that they were not compensated for registry use for non-PMG patients was another area of dissatisfaction.

On the positive side, respondents praised the ease of use of the online version of the registry and that it required little or no training. Providers also commented that “patients were more apt to open up and talk about their care when using the registry and showing them the changes in their blood pressure, weight or lab results.” Providers agreed that although the point of care tool was “labor intensive it produced a thorough exam.”

In the last six months of the project, the point of care tool was discontinued and users were given an Excel spreadsheet and quarterly reports with outcome data for individual patients, their office/clinic and a de-identified comparison with other registry users. The purpose of this change was to determine the effectiveness of provider reports in improving patient outcomes as compared to the more expensive point of care tool. Unfortunately registry adoption issues also plagued this work. Most users found the reports were not complete and required a change in office procedure to use effectively. Only one user site decided to continue to use and maintain the patient spreadsheet.

As noted above, an important factor that impacted adoption of the diabetes registry was the rapid adoption of other health information technology in Santa Cruz County from 2004 to 2007, specifically EMRs. Table 6 provides results from a self-reported survey of providers on their implementation of health information technology. Adoption of disease registries is lagging behind EMR implementation and is planned as an add-on to the EMR.

Table 6. Outpatient adoption of health information technology, Santa Cruz County

	% All Providers	% Primary Care	% Specialists
EMR: 2004	9%	19%	2%
EMR: 2007	46%	74%	23%

	% All Providers	% Primary Care	% Specialists
EMR: 2010	62%	92%	35%
Chronic Disease Registry: 2004	8%	16%	2%
Chronic Disease Registry: 2007	15%	31%	2%
Chronic Disease Registry: 2010	28%	49%	10%

Outcomes—equity. In the first year of the project, a Readiness Assessment was done of all safety net clinics in Santa Cruz County. Information was captured on operational and technical readiness. The following are the key outcomes from this work. Because they relate to the success of implementing the registry by the safety net these findings are presented under the equity aim. Many of them apply as well to other settings.

- Critical to define a workflow that does not result in redundancy because clinic schedules are full and office visits are only fifteen minutes.
- PMG registry form needs to be re-designed to meet the workflow and staffing in safety net clinics including use of care managers and educators.
- Large population of self-pay or uninsured who do not have claims data will require manual data entry.
- Need support for data entry and concerned not sustainable beyond project funding.
- Need more diabetes related training for staff as part of registry training.
- Most clinics do not have enough computers and printers and no dedicated IT staff.
- Existing workflow bottlenecks caused by duplication of forms/systems which needs to be addressed before adding another form/function.

Only one safety net provider, Santa Cruz Women’s Health Center, was able to implement the electronic registry. Planned Parenthood and the County Clinics had devoted all of their staff resources to implementation of new integrated practice management and EMR software applications. Salud, which was a particular focus for equity as the largest safety net provider in the County, had a major financial crisis during this period resulting in a complete change in senior management. Compounded by an inefficient workflow, an outdated practice management system, and staffing shortages, Salud decided in 2007 that they were not able to implement the registry during the project period.

Outcomes—sustainability. In the last year of the project interviews with ten key project and community stakeholders were conducted to define sustainability options. The following are the key findings captured during these interviews:

- No business case for the original registry with a focus on the point of care tool. The expansion of EMRs eliminated the point of care value of the registry.

- Limited support for a registry that cannot be expanded beyond diabetes. There is broader support for a registry that could be expanded to all chronic conditions.
- Some interest in action and performance reports, but many providers were already able to obtain this information from other sources.
- Broad support for a community-wide database for population health, but because there is no direct benefit to individual partner organizations, there is no willingness from private providers to provide financial support for this type of registry.

Outcomes—legal. A community-wide registry requires the partners to make multiple decisions in regard to privacy, security and ownership of data, as well policies and procedures for its use. While sometimes contentious, the development of the legal documents in this project was an opportunity to discuss the different policies and procedures of the participating organizations and to develop understanding and trust among IT staff and providers, as well as leadership. The resulting legal agreements included a Memorandum of Understanding among the partner organizations; a User Agreement for the point of care providers; and Policies and Procedures for privacy and security. With the assistance of legal counsel, staff and committee members worked hard to create short and understandable documents which each participant felt they could use to champion the project within their organization and with providers. These legal documents are available for review and download on the project website: www.chroniccarenetwork.org.

The fundamental decision affecting the legal structure of the registry was whether or not to require patient consent prior to adding a patient into the registry (opt in). Because the technology was built to identify and add patients from electronic claims data, the decision was made to restrict access to a registry patient's data to providers with a documented treatment relationship rather than require patient consent. The user agreements encouraged, but not require, providers to include information about the registry in their patient information and consent forms. Patient information sheets were also developed informing patients on their right to opt out of the registry.

The decision not to obtain patient consent prior to adding patients to the registry also complicated the development of data transfer agreements, especially with laboratories. After months of discussion, Quest Diagnostics agreed to send laboratory data without a registry-specific patient consent only if there was an exact match of patient name and date of birth; and that the lab test order listed the name of a provider who had signed a registry user agreement. This resolution further raised the technology requirements of the registry, especially in regard to patient matching. Legal counsel recommended that the test of a treatment relationship be set as high as feasible especially when transferring patient information from one provider organization to another.

Outcomes—technology. An important technology outcome of this project was the finding that extending internal software to other healthcare organizations requires significant software development, time and technology resources. Internal products are developed to work incorporate the organization's patient matching process, data specifications, and are designed to work with and maximize other software and hardware resources. This was one of the findings of

the technical assessment of PMG software by Sujansky & Associates and was a similar finding during the technical due diligence of PAMF's Solutions software.

Sujansky & Associates recommendations for adopting an internal product for community-wide use included:

- The application and data-integration features must be systematically explored and documented, so that the full set of requirements is understood, effectively communicated to the development team, and implemented in a timely manner.
- Expanding internal software tools requires major modification in order to scale the registry to adapt to an increase in the number of patients and users; develop and maintain new and more inclusive data interfaces; and adopt more robust patient-matching techniques.
- Transmitting data to and from a registry and EMRs in formats that both sides can integrate into their own databases is challenging because no standards exist among EMR products for the representation of clinical data. In addition the reporting processes and interfaces that are built will need to be maintained over time requiring ongoing development with associated costs and resources.
- To accomplish this work requires an experienced Technical Project Manager and staff to support the software development as well as a rigorous quality assurance and testing process.

Using an internal product developed by one partner organization for a community-wide registry also complicates the issue of locating the server and selecting an ASP provider. From the technology perspective, the organization that has developed and is modifying the software should serve in this role. However, when the organization is a partner, and a competing healthcare organization, a neutral party is essential to develop the trust needed to build a community-wide patient database. During the development of the project proposal the decision was made to locate the server at PMG during the initial phase of the project and to re-examine this decision once the registry was fully deployed. And although full deployment was not achieved, the issue about the location of the server nagged at the project and made it more challenging to build of trust among the partners. This issue is another drawback to adopting a local internal product for community-wide use.

Lessons Learned

In September and October 2007, the Steering Committee met twice with outside consultants to review the history of the project and to develop common understanding of the Lessons Learned in this project. The discussion in these meetings is integrated into this report, especially in the RESULTS and PRINCIPAL FINDINGS. The following is a summary of the lessons learned in the words of the Steering Committee members.

- Major health care change requires commitment down the line not just at the top.

- Take time to develop a community vision.
- Community should come together and agree on clinical standards & changes in patient care delivery before implement technology tool.
- Know the needs; but focus and narrow the project scope (beware scope creep).
- Create the rigorous business case before funding including return on investment.
- Define requirements for participation, don't discount them to recruit participants.
- Market the vision; do not sell it.
- Do workflow analysis for each site before implementation.
- Keep people at the table with open honest conversation; collaboration is bigger than individual agendas.
- Back away when project doesn't involve everyone.
- Identify winners and losers and how they win and lose and revisit (be comfortable going back knowing good of whole).
- Technical informatics analysis must be on-going.
- Assure quality and access and have a tool to monitor.
- Involve a neutral agency to be the glue, the switchboard.
- Look at the nitty, gritty definition of ownership (grant money not the same as partner commitment).
- Don't be afraid of spending time doing planning.
- Communicate & lay trust on table.
- Commitment & accountability need to go together.
- Create a marketplace for discovering opportunities for collaboration.
- Don't lose track of excellent things that emerge.

Conclusions

The conclusions of the Santa Cruz County community for continuing this collaboration in chronic disease management include:

- Support adoption of diabetes registries by all primary care providers including safety net providers and small unaffiliated private practices.
- Take the opportunity afforded by EMR expansion to develop chronic disease registries for population health including to improve understanding of the prevalence and incidence of diabetes as well as populations at risk for developing diabetes with measures of BMI and pre-diabetes.
- Support other community collaborations working toward improvement in diabetes prevention and treatment including adoption of the chronic care model in all setting of care. These collaborations include HIP's Safety Net Clinic Coalition, the Regional Diabetes Collaborative, and Go For Health! (pediatric obesity).
- Value, use and disseminate the enormous amount of work that was done by all the partner organizations in this project and what was accomplished including spin-off initiatives such as HIT training at the Cabrillo Community College and the clinic-based retinopathy screening program of the Safety Net Clinic Coalition.

Significance

We believe this research on the implementation of a community-wide diabetes registry provides valuable information to other communities with a similar mission to improve the quality of care in their community using information technology. The Steering Committee developed the following checklist for use in our community before launching the next community-wide quality/technology project. We offer this checklist to other communities.

Figure 2.

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|---|
| <ul style="list-style-type: none"><input type="checkbox"/> Develop a specific and shared vision<input type="checkbox"/> Assess needs, evaluate risks & define wins and losses for stakeholders<input type="checkbox"/> Present a business case/ROI to each stakeholder<input type="checkbox"/> Agree on ground rules including an open dialogue on interests<input type="checkbox"/> Set criteria for participation in the project (don't back off)<input type="checkbox"/> Present a clear project plan for review and reporting<input type="checkbox"/> Assign accountability<input type="checkbox"/> Select a lead trusted agency |
|---|

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List of Publications and Products

No published works resulted from this project. Documents including legal agreements and products including the user interface prototype have been published on the project website: www.chroniccarenetwork.org.