HOW DISEASE REGISTRIES SUPPORT CHRONIC DISEASE CARE

401 – INTRODUCTION TO THE AMERICAN HEALTHCARE SYSTEM

RESEARCH TERM PAPER

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INTRODUCTION

Due to an aging population, there are a number of individuals who are requiring more long term care. There is an urgency to address this issue and modernize the tools clinicians use to serve these individuals. In 2005 a survey was conducted that indicated only 56% of recommended care is being provided to patients who have been diagnosed with a chronic disease in the United States. A study using data from 1999 – 2000 indicated that 37% of diagnosed diabetic patients achieve HbA1c levels of 7% or less. Worse, the statistics also show that similar numbers appear in other studies of chronic diseases. One approach to dealing with this important issue is the implementation of the Chronic Care Model. Disease Registries are an integral part of the Chronic Care Model and will be the main focus of this paper.¹

WHAT IS CHRONIC CARE?

The basic premise of the Chronic Care Model is a set of principles focusing on improving the quality of patient care by putting in place fundamental infrastructure components that force new patient care to be proactive in nature. The components of the Chronic Care Model are not rigid and can be changed to address any challenges that different organizations may encounter. These components consist of the following concepts: improved delivery and system design, strengthened patient-provider relationships, implementation of decision support systems, deeper involvement of information systems, more leverage of community resources, and a more structured and involved healthcare organization. Disease Registries are part of the deeper involvement of information systems. Research has begun to show that the integration of these Registries has improved patient care for patients with chronic diseases.²

WHAT ARE REGISTRIES?

A Disease Registry is a database that collects information and data about a defined group of people sharing a common disease. The information collected in these databases varies but is usually restricted to a set of key clinical indicators centered on specific conditions related to

chronic diseases. They are most commonly used to capture, manage and report on patient information and conditions of chronic diseases. Disease Registries serve as repositories of recommended clinical interventions that help clinicians act in a more proactive manner, take a more consistent approach, and recognize problems more quickly. If implemented, utilized and maintained effectively and correctly, these Disease Registries can help to improve clinical processes and outcomes for patients the registry is collecting the data for and about. The overarching idea of Disease Registries is to address patient care and disease treatment in a more proactive manner than in a reactive manner.²

As with any technology, there are pros and cons to the idea of Registries. The evident pros to Electronic Disease Registries include a number of items. One of these advantages is patient information exchange – the ability to link with other clinical systems to access other relevant data such as patient medical histories, risk profiles, current treatments patients are receiving, and patient test results. Another advantage is the ability to issue reminders to clinical staff of patient needs. And a final advantage is that of evaluation of practices with comparison data reports. Disease Registries have a couple of cons as well. One con is that new patients being added to a Registry can temper results of population reporting being conducted. Another con is that it can be difficult to measure whether the implementation of a Registry is actually the cause of a patients’ treatment success or whether that success is due to other aspects of the disease management. Though there are cons to Disease Registries, the pros far outweigh the cons.²

**HISTORY**

Disease Registries have been documented since the first decade of this century in the form of a Cancer Registry. In 1906, European countries required physicians to report all observed cancer cases within one year. This objective failed due to a high number of missing reports and the inability to cross reference data from registry to registry. From 1926 – 1937, four permanent registries systems were implemented in Hamburg (1926), Mecklenburg (1937), Massachusetts (1927), and Connecticut (1935). The Hamburg and Mecklenburg registries were later discontinued during the Second World War. These four registries were considered a success.
because by the 1940s, they had solved the majority of technical problems such as merging data from different data sources, the use of classifications, and the use of important indicators. By the late 1940s, linkages between registries were made possible. In 1950, the World Health Organization created subcommittees on the registrations of cancer cases. This initiative prompted foreign countries to join the registry campaign. In the 1960s, the first world-wide analysis appeared which was called the “cancer incidence in five continents.” The result of this initiative is a publication that appears every 5 years distributed by UICC, IARC, an IACR that contains data on cancer registries. By 1997, the 7th update was published. By the 1960s, there were 32 documented registries in 24 countries that served about 3% of the world’s population. By 1990, 143 registries exist in 55 countries that server about 9% of the population. Clearly, Registries have had an impact in the medical world and are here to stay.³

**WHAT DO REGISTRIES DO?**

Disease Registries collect data that is focused on attributes such as symptoms of the disease, laboratory test results, general statistics, and treatment options and alternatives. Although Disease Registries may include personal patient information, it is important to remember that Disease Registries are not Electronic Medical Records. There are a number of ways in which Disease Registries can be used. They can be used to explore how registries help coordinate and deliver quality care, identify patients with gaps in their care, help facilitate communication with patients, help clinical staff by utilizing alert features and to help identify issues that cause sub-optimal care at the organization level. This paper aims to focus on how Disease Registries support Chronic Disease Care by looking into how they promote physician and patient follow-up, how evidence-based guidelines are embedded into daily clinical practices, indentifying subpopulations and collecting data on relevant clinical indicators, and monitoring performance of the clinical team and care system as a whole.⁴

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One way a Disease Registry can support Chronic Disease Care is by ensuring that regular follow-up visits, appointments, and tests are scheduled and adhered to by the physicians and supporting care team. One way this is accomplished is with the use of a Clinical Care Guideline Worksheet. These worksheets are typically begun at the point of care and are attached to a patient chart. These worksheets serve as a guide to remind the physician and patient of important tasks that need attention. The worksheets will aid clinical staff in receiving reminders on making follow-up appointments with patients and ensure that missed or skipped appointments are rescheduled. Clinical Care Guideline Worksheets also promote the initiative of preventative medicine by allowing for test and screening prompts to appear reminding the clinical staff to follow through with these assessments. The Clinical Care Guideline Worksheets are also useful to the patient to remind them of appointments they need to schedule or attend as well as prompting what education the patient should know about their disease. The Registry can also act as a place for clinical staff to store information about the patient's needs, such as what regular tests are recommended, the results of those tests, recommended treatment plans, or any special details about a patient. They can also be useful when tracking what information a patient has received or needs to receive relating to education about their disease, such as what material has been distributed and if any new information has come out recently about the disease the patient can be updated on. All of these items, the Clinical Care Guidelines, reminders, and patient needs awareness are all things that contribute to ensuring that a Registry promotes follow-up and complete care by both the clinical staff and the patient.4

Another way Disease Registries support Chronic Disease Care is by embedding evidence-based guidelines into daily clinical routines. Patient care guidelines can be created, managed and tracked in the registry and later displayed for the clinical teams to reference as different treatment scenarios arise with a particular patient. There are also a number of reports that a registry can generate that clinical staff can use to aid in chronic care treatment. Patient Performance Feedback Reports can also be created so that clinical staff can monitor patient test results; for example, a physician may want to see the results of a patient’s blood glucose levels for the past 9 months. Registries are also capable of creating High Risk Reports that show
clinical staff which patients might require more intensive treatment management or which
patient's may need a less intensive treatment plan. Exception Reports are also available that
show the clinical staff which patients are not receiving appropriate care that does not follow the
guidelines outlined in the Clinical Care Guideline Worksheet. If the Exception Report indicates
that a patient is missing an important aspect of treatment, the Registry can recommend changing
the course of treatment for the patient. With evidence-based data being collected and the data at
the finger-tips of clinicians, treatment of Chronic Disease Care patients is more thoroughly
managed and the clinical staff can give the best care possible.\textsuperscript{4}

Identification of relevant subpopulations is another way Disease Registries can support
Chronic Disease Care. The basic premise is that the subpopulations are comprised of
information about a specific disease. This is a useful concept in that clinical indicator data about
disease specific subpopulations can be collected and tracked in the registry. Clinical indicators
might come in the form of test results and/or disease symptoms a patient might be displaying.
These clinical indicators are very specific to the disease registry. For instance, a diabetic
patient's HbA1C levels might be tracked and reported on in a Diabetic Registry while a stroke
patient's Systolic/Diastolic blood pressure test results might be tracked in a separate Stroke
Registry. Symptoms of chronic diseases are tracked in these registries much the same way tests
are tracked and reported on. The subpopulation idea is also key in that it assists with
management of active patients. This concept allows for the clinical teams to more efficiently
treat the patient by strategically planning their care based on the severity of their condition.
Patient management can also help identify new patients in external systems and suggest they be
added to the registry if their condition matches specific criteria.\textsuperscript{4}

One final way Disease Registries can support Chronic Disease Care is with the concept of
monitoring performance of practice teams and the overall care system. Using population reports,
Registries can show how the clinical staff is complying with specific care guidelines and how
various groups of patients are reacting to treatment. Population reports can also help trend user-
specific conditions of management control. If these report results indicate that there are too many
patients assigned to one clinician, then this is indicative of the care system not having appropriate
resources to deliver quality care. If the reports show there are areas in the clinical workflow that stall other areas of care, then the report is pin-pointing areas of bottlenecks in the care process that should be addressed and rectified if at all possible. If the organization is seeing double data on a number of different reports, then this might be a sign of clinical staff duplicating work tasks which should also be addressed. Having access to these types of reports can help the practice teams be more efficient with treatment of patients and can also help the health system be more resourceful in their workflow processes.4

BUILDING A REGISTRY

Once the decision has been made that a Disease Registry is indeed appropriate for a chronic disease at a clinical facility, the project should follow a development plan that includes planning, design, implementation, maintenance, and support stages. It must be remembered that there is no “one-size-fits-all” model for Disease Registries. There are three fundamental issues that should be kept in mind to ensure implementation is a success. First, there must be full rational and full buy-in from all stakeholders who will be affected with the implementation of the registry. Secondly, comprehensive definitions of responsibilities during the implementation and ongoing maintenance should be defined for all parties involved so that everyone is clear on what their role entails and who to go to with specific questions. Finally, appropriate initial and on-going training should be scheduled, and support for staff who will be utilizing the registry should be identified and trained. Though these three ideas are crucial to a successful implementation of a Disease Registry, below is a list of additional concepts that should be kept in mind when building a Registry:1

- Be sure the Registry is supporting the intended target of users.
- Define what methods will be used to collect and enter the data.
- Define an appropriate timeline for the implementation.
- Define what key indicators are important to collect data on.
- Select software that is capable of connecting to other computer systems in an effort to capture needed data from an already existing system.
- Work with the internal technical teams to ensure the registry is updated and is on a proper maintenance schedule.
- Review the data on a scheduled basis to ensure the data is accurate and consistent. If the data is of poor quality, providers will have little trust in the Registry.
- Evaluate how the use of the Registry will impact current workflow and address issues that seem apparent and be flexible as workflows need to be changed.
- Define how the success of the Registry will be evaluated.¹

**EXAMPLE REGISTRIES**

There are a number of different registries in use today. In most cases, major diseases such as Alzheimer's and Cancer diseases are typically the most prominent. The following will specifically discuss Diabetes Registries, AIDS Registries, Cancer Registries, and Asthma Registries.

**Diabetes Registries**

There are 1 million Americans newly diagnosed with diabetes mellitus each year by primary care physicians.⁵ The number of people with diabetes in the U.S has quadrupled from 1980 to 2007 and the numbers continue to rise. There are 23.6 million people affected by this chronic disease which is nearly 8% of the population. Diabetes is the sixth leading cause of death in the U.S and is the leading cause of adult blindness, lower-limb amputation, kidney disease, and nerve damage.⁶ The estimated cost of care for patients with diabetes is $174 billion annually. There are evidence-based ambulatory guidelines developed for diabetic care that include management of glucose level, lipid levels, and blood pressure.⁵ The number of people affected by diabetes is expected to rise substantially with estimated projections of 48.3 million people newly diagnosed by the year 2050.⁶

**EHRs with Integrated Disease Registry**

There have been many quality improvement projects aimed at improving chronic care management in patients. Amongst these, health information technology has been implemented at some clinics to improve routine clinical practice settings by utilizing an EHR to achieve

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American Diabetes Association (ADA) established clinical goals. There have been critical success factors identified for successful EHR implementation for chronic disease management. This consisted of the use of an EHR system with integrated disease registries. The disease registries within the EHR would facilitate pre-visit identification of disease specific targeted patient groups for specific services. A team at the Center for Clinical Translational Research instituted critical success factors which included clear explanation of purpose and importance of EHR as it related to diabetic care management and system wide education to providers on ADA guidelines. The team implemented an EHR system which transformed the organization’s approach to managing patients with complex chronic medical conditions. The EHR system was customized to have the ability to generate electronically the following components for diabetes disease management: disease registry to identify patients with diabetes, diabetes management module for point-of-care provider alerting, electronic forms for documentation of foot and eye examinations, patient report cards with individualized patient results based on clinic encounters, and provider patient panel reports used for benchmarking performance.6

Benefits of Integrated Diabetic Disease Registry

The technology component of the diabetes disease management program developed by the Center for Clinical Translational Research was tailored to change workflow process and reflect real office situations of primary care physicians. At the office level the critical success factors could include changes to the office workflow to improve the integration of services for diabetes patients. The EHR integrated diabetes specific components of the system were designed to be point of care focused, administrative components enhanced patient care and incited providers, included a diabetes patient report card, diabetes patient disease registry, real-time clinical guideline support, and comparative patient panel reports for providers. As shown in Figure 1, an electronic form can be utilized to register a patient in the diabetic registry and is a useful tool to capture diabetes related data. Through a diabetes disease registry link as shown in Figure 2, patients could be identified prior to their office visit to enable staff to preprint patient diabetes care summary sheets for providers.6 Also, as Figure 3 shows, patients would be given
patient report cards to help them understand how they are doing in terms of managing their diabetes. These are all useful tools that could be used by patients and providers to assist in managing diabetes.

Figure 1: EHR screen shot for diabetes registry electronic form for PCP provider.
Figure 2: EHR screen shot of Point-of-care diabetes management module.  

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Your Goals</th>
<th>“A-B-C’s”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor Diabetes Control</td>
<td>HbA1c goal is less than 7.0%</td>
<td>A is for “A1c”</td>
</tr>
<tr>
<td>High Blood Pressure</td>
<td>Your blood pressure checked at every office visit.</td>
<td>B is for “Blood Pressure”</td>
</tr>
<tr>
<td>High Cholesterol</td>
<td>Healthy diet and lifestyle help keep your blood pressure and diabetes under control.</td>
<td>C is for “Cholesterol”</td>
</tr>
<tr>
<td>Poor Diet and Obesity</td>
<td>Total cholesterol less than 200</td>
<td>D is for “Diet”</td>
</tr>
<tr>
<td>Unrecognized Diabetic Eye Disease</td>
<td>Healthy heart</td>
<td>E is for “Eyes”</td>
</tr>
<tr>
<td>Unrecognized diabetic foot disease</td>
<td>Healthy heart</td>
<td>F is for “Feet”</td>
</tr>
<tr>
<td>Lack of physical activity</td>
<td>Healthy heart</td>
<td>G is for “Get Active”</td>
</tr>
<tr>
<td>Unrecognized risk of heart disease and stroke</td>
<td>Healthy heart</td>
<td>H is for “Heart and Stroke”</td>
</tr>
<tr>
<td>Influenza Vaccination</td>
<td>Healthy heart</td>
<td>I is for “Immunizations”</td>
</tr>
<tr>
<td>Unrecognized diabetic kidney disease</td>
<td>Healthy heart</td>
<td>J, K is for “Kidneys”</td>
</tr>
</tbody>
</table>

![Diabetes Management Module: Alerts for Providers](image)

Figure 3: Point-of-care printed report card for diabetes.  

Name:  
Date:  

- **A** is for “A1c”  
  - Normal fasting glucose is less than 100 mg/dL.  
  - Normal postprandial glucose is less than 140 mg/dL.  
  - You should get your A1c checked every 3 to 6 months.  

- **B** is for “Blood Pressure”  
  - Your blood pressure checked at every office visit.  

- **C** is for “Cholesterol”  
  - Total cholesterol less than 200  
  - Healthy heart  

- **D** is for “Diet”  
  - Healthy eating and lifestyle help keep your blood pressure and diabetes under control.  

- **E** is for “Eyes”  
  - Healthy heart  

- **F** is for “Feet”  
  - Healthy heart  

- **G** is for “Get Active”  
  - Healthy heart  

- **H** is for “Heart and Stroke”  
  - Healthy heart  

- **I** is for “Immunizations”  
  - Healthy heart  

- **J, K** is for “Kidneys”  
  - Healthy heart  

TARGET DIABETES  
Focus on your future.
The CDEMS is a disease registry currently used in Washington State that assists in collecting nephropathy screening and intermediate health outcomes. CDEMS is a free Microsoft Access database application developed by the Washington State Diabetes Prevention and Control Program in 2002. CDEMS was designed to help providers, clinic managers, and other health care staff members track the care of patients with chronic health conditions. This database stores individual patient demographic information, visit dates, vital signs, medications, diagnoses, services, laboratory results, and custom notes in 7 main data tables. There are data entry screens such as the patient information record and New Visit form as shown in Figure 4. These screens are used to populate the main tables in the database.  

This disease registry is the only source of state-specific data available to monitor nephropathy screening, lab screenings, and blood pressure values for a large patient population with diabetes. The consolidated data from all Washington clinics using CDEMS covered about 13% of all state residents with diabetes in 2004. The data from CDEMS is used to measure the

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status of patients in terms of meeting state and national objectives for diabetes, to provide aggregate comparison data for individual clinics using CDEMS, and to determine the feasibility of combining and using clinic data for ongoing diabetes surveillance and evaluation efforts in Washington. The CDEMS was created as a proactive approach that offers proven strategies to help primary care practice teams manage care for people with chronic diseases.\(^7\)

**AIDS Registries**

As care evolves, the methods used and the scope of the data collected by disease registries must also evolve. Diseases that were once considered a death sentence are now manageable as chronic diseases. Patients are no longer receiving acute care for their disease in its end-stage, comfort before death, but are now living with their disease and require longer periods of care. People are now living longer because medical science has evolved and treatments are now available that are impeding and thankfully in some cases, arresting the diseases progress. However, disease registries that were created to track a disease in its end-stage are no longer gathering adequate data. As a result the agencies that use this data are not able to accurately evaluate the performance of current programs, allocate resources, and infection rates. These registries must evolve to monitor a disease at an earlier stage to increase the amount of data collected to be able to continue to focus public health efforts on the continued survivability of the disease.

The registries used to track human immunodeficiency virus (HIV) and incidences of acquired immunodeficiency syndrome (AIDS) are a perfect example of a registry that has evolved in response to changing disease dynamics. As early as 1981, states had begun conducting AIDS surveillance; these early registries only tracked incidences of AIDS, the end-stage of an HIV infection. Consequently, only a subset of individuals infected with HIV were actually being tracked. However, at the time, this data did prove to be sufficient to identify the behaviors associated with the spread of the virus, track its spread, develop treatment guidelines and inform public health organizations where to focus their efforts to work on controlling the spread of the disease. It was not until 1996 that the first drop in AIDS incidences and AIDS deaths were
reported. This decline has been attributed to the early use of combination antiviral therapy. Some states had already begun to track the incidences of HIV, but with the decreasing cases of AIDS, registry data no longer could be used to accurately predict trends in HIV transmission and it did not represent the need for services.

In 1993, the CDC working with public health and community groups, proposed a study aimed at researching the implications of changing the case definition to include tracking HIV at all stages of infection and moving to a name based system. This change would include the tracking of newly diagnosed infections as well as those who have acquired or are dying from AIDS. A name based system would allow for the removal of duplicated records and standardization improves reporting. A name based system would also allow for cross referencing other registries for diseases that commonly have co-morbidity with an HIV infection, Tuberculosis for example. TB is actually the number one killer of individuals infected with HIV. By 1997 twenty-six states required case surveillance for all HIV cases, however those states only accounted for 24 percent of the AIDS cases reported to the CDC. As of 2008, all fifty states and territories include case surveillance for all HIV cases.

**Cancer Registries**

Cancer is the second leading cause of death among Americans. Each year, cancer costs the American nation an estimated $107 billion in health care expenditures and lost productivity from illness and death. Cancer registries collect accurate and complete cancer-related data that can be used for cancer control and epidemiological research, public health program planning, and

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patient care improvement. Cancer registries in North America have nearly 70 years of history. Most registries started for a specific reason or set of reasons. For example, concern about the cancer burden in a specific area may lead to the creation of the registry. Often legislatures pass reporting legislation in response to some specific concerns.

Federal agencies such as the Surveillance, Epidemiology, and End results (SEER) program of the U.S. National Cancer Institute (NCI) and the National Program of Cancer Registries (NPCR) of the Centers for Disease Control and Prevention (CDC) are important sources of funding for cancer registries. They also promote standards for data collection and reporting.\textsuperscript{12}

There are three major types of cancer registries including:

- Population-based cancer registries (sometimes referred to as central registries)
- Hospital-based
- Special cancer registries.

**Population-Based Cancer Registries**

Population-based registries record all new cases in a defined population (most frequently at a state level). The common types of data collected under central registries include patient identification, demographic descriptors, hospital-specific identifiers, other confidential information (physicians), cancer identification, stage-prognostic factors, treatment, text and narrative support, follow-up/recurrence/death, administrative record ID, edit overrides, and state-specific items.

Generally the objectives of the central cancer registries are defined at the state level and concern one or several of the following:

- Cancer prevention
- Early detection
- Serve as central registry for hospitals
- Incidence surveillance/cancer rates and trends
- Cluster analysis
- Population-related research
- Mortality rate surveillance
- Patient patterns of care and outcomes
- Evaluation of control efforts
- Etiologic research (the research on the causes of diseases or pathologies)\textsuperscript{12}

**Hospital-Based Cancer Registries**
In comparison to the population-based cancer registry, the data collected by the hospital-based registries services a more narrow range of purposes. Hospital-based registries collect data on all patients diagnosed and/or treated for cancer at a particular facility. Hospital-based registries can be a single hospital registry or a multi-institution registries.

Single intuition registries are aimed at improving patient care by medical audit-type evaluation of outcomes, are also used for physician education, as a source of data for some research, and for some facility utilization as well as for case management. The primary goal of collective registries (multi-institution registries) is to improve patient care by supporting registries with common standards and pooled data as well as for case management.13

**Special Cancer Registries**

There are also special cancer specific registries that exist. These registries were established to collect data on a particular type of cancer. For example, the Gilda Radner Familial Ovarian Cancer Registry is a special cancer registry that collects cancer information from the families with two or more relatives having ovarian cancer. Other special cancer registries relate to brain tumors, colorectal cancer, or lung cancer.13

**Cancer Screening Programs**

Cancer screening programs analyze data from cancer registries. Estimates of premature deaths that could have been avoided through screening in 2009 vary from 3% to 35%, depending on a variety of assumptions. Beyond the potential for avoiding death, screening may reduce cancer morbidity since treatment for earlier-stage cancers is often less aggressive that that for more advanced-stage cancer.14 For nearly all cancers treatment options and survival rates are related to stage. On this basis it is assumed that early detection of cancer at an earlier stage may yield to better outcomes.

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The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute gather cancer incidence data from 11 geographic areas, covering approximately 14% of the U.S. population. This population-based data of long duration (1973-present) are a unique and important resource in monitoring stage-related survival and cancer risk factors. The preventative health registry will include all patients including healthy ones. The Visit planners functionality of the registry will remind physicians to order preventative interventions such as a mammogram or colonoscopy based on a patient’s risk factors such as age or gender.

Cancer Surveillance Systems - Evaluation of Cancer Control Efforts

Cancer surveillance systems are also related to cancer registries. Data in population-based cancer surveillance systems are used to assess the effectiveness of cancer control efforts in different jurisdictions and help stakeholders in cancer control identify areas in which increased efforts are needed. For example, the report by Minnesota Department of Health assesses the effectiveness of cervical cancer control in Minnesota using the Minnesota Cancer Surveillance system and provides recommendations for improvements.

Some of the key report findings:

- The incidence of invasive cervical cancer and mortality from this disease are significantly lower that in the U.S. as a whole.
- About 35 Minnesota women out of 175 diagnosed each year die. The burden of cervical cancer is greater than indicated by its frequency relative to other cancers because over half of the women are less than 45 years of age when diagnosed. Every invasive cervical cancer represents one of three failures: a failure to screen, a failure to detect abnormalities when screened, or a failure to adequately follow-up on detected abnormalities.
- The report highlights the race/ethnic disparities in cervical cancer occurrence in Minnesota that are caused primarily due to less effective screening among women of color.
- There geographical disparities in cervical cancer screening among women in rural areas compare to women living in the seven-county Metro Area.
- The report emphasizes the importance of Pap testing and a need for increasing utilization of Pap testing in underserved communities as well as the need for education efforts that are needed to assure that vaccines are available to and accepted by these same communities.

Cancer Decision Support Navigator

A web based Cancer Decision Support Navigator can be a part of cancer registries as well. Diagnosing cancer can be a difficult task. Patients come to their Family Doctor with symptoms and worries. When cancer is a possible cause of these worrisome troubles, it becomes the primary physicians’ responsibility to know the right steps to make along the path towards diagnosis. Without easy access to current diagnostic process information, the physician may elect to send the patient to a cancer specialist simply to initiate the diagnostic procedure. The visit to the cancer specialist is often incomplete because tests important in confirming the diagnosis are performed after the specialist visit. Diagnosis is delayed, treatment is delayed.

A solution to this situation can be a Care Map presented via a web portal in the form of a Cancer Decision Support Navigator. The electronic map provides the practitioner with a framework for stepping towards a completed disease specific diagnostic work-up in preparing the patient for referral to the appropriate cancer care specialist.

The Navigator reminds physicians of what questions to ask, what tests to perform, what “next steps” to take to complete the diagnostic work-up. The information driving the Cancer Decision Support Navigator will be evidence supported and endorsed by trusted sources and available in real time. The final step in the process is to create an online referral process to a cancer specialist. Access to the Internet is all that would be required to have to use this web-based guidance system. The Navigator can be administered by a hospital or system of hospitals. It can be supported by evidence from hospital registries and configured to use hospital specific guidelines and referral processes.

Asthma Registries

“Asthma is a chronic inflammatory disorder of the airways characterized by episodic and reversible symptoms of airflow limitation.” It is estimated over fourteen million people in the United States are affected by this disease and overall costs related to asthma exceed $11 billion.

\[^{16}\text{Author unknown, year unknown. “Smoothing the Way to Diagnosis: Creating a Web Based Cancer Decision Support Navigator”}\]

\[^{17}\text{Patel, P. H., C. Welsh, et al. (2004). "Improved asthma outcomes using a coordinated care approach in a large medical group." Dis Manag 7(2): 102-111.}\]
billion. This is a condition that affects all age groups, genders and races. The number of people in the US affected by asthma is growing and costs of treatments are increasing.

The steps for proper control of asthma are well documented and include having the correct diagnoses, properly classified severity, appropriate medications, documented treatment plans, and clear crisis management plans. Although the steps in treatment of asthma are well known, a number of studies suggest that many aspects of asthma care are not adequate and care improvement initiatives have mixed results. That is often attributed to the barriers that are organizational in nature and for this reason asthma is a frequent target of chronic care management initiatives. However there are not too many studies that suggest significant success in implementing a broad chronic care management program for asthma.

One initiative that has documented positive results is the implementation of the comprehensive asthma management program undertaken in 1999 by the Advocate Health Centers, a large medical group in the Chicago area. The goal of this program was to improve quality of life of its asthma patients, reduce complications due to the disease, and increase patient satisfaction. A multidisciplinary team of dedicated clinical and non-clinical resources was formed to implement the initiative. This task force worked on several objectives. One of the objectives was to improve provider knowledge about evidence-based treatments. Another objective was to improve patients’ skills in self-managing their condition. The third objective was to create and implement a population-based chronic disease management model.

The new approach addressed the entire population of patients and it replaced the often taken approach of targeting repeatedly hospitalized asthma patients. The expectation was that this change would provide a better insight on treatment failures. In order to support the population-based approach a new asthma patient registry was created. The data already available in the organization was used to build the registry. The data was filtered using predefined selection criteria required to support the population-based model. The registry was used to identify targeted patient groups and create contact lists for follow-ups, surveys, educational information, and
seasonal flu shots. All treatments, outcomes, home treatment plans, and survey responses were recorded and analyzed.\textsuperscript{17}

The study suggests that the initiative at Advocate Health Centers to implement a comprehensive chronic disease management model for asthma patients achieved a number of its improvement goals. Most notably the number of emergency department visits and hospitalizations due to asthma decreased by 41% and 54% respectively, the number of correct diagnoses improved, patient education and the number of written home care plans had significant increases. The two diagrams below (Figure 5 & Figure 6) show the summary of the results.\textsuperscript{17}

\begin{table}
\centering
\begin{tabular}{|l|c|c|c|c|c|c|}
\hline
Documentation of process measure & Baseline & Post program & Odds ratio & 95\% CI & p value \\
& (n = 451), & (n = 427), & & & \\
& \% yes & \% yes & & & \\
\hline
Asthma diagnosis & 83.3 & 98.6 & 13.94 & 6.3–35.7 & <0.001 \\
Patient education & 15.7 & 26.1 & 1.89 & 1.4–2.7 & <0.001 \\
Influenza vaccine & 24.2 & 15.0 & 0.56 & 0.4–0.8 & <0.001 \\
Owns peak flow meter & 16.3 & 14.5 & 0.87 & 0.6–1.3 & NS \\
Uses peak flow meter\textsuperscript{a} & 29.2 & 19.6 & 0.59 & 0.3–1.1 & NS \\
Smoking cessation advice given\textsuperscript{b} & 27.7 & 23.8 & 0.81 & 0.4–1.6 & NS \\
Home action plan & 11.1 & 25.4 & 2.72 & 1.8–4.1 & <0.001 \\
\hline
\end{tabular}
\caption{Processes of care as assessed by chart audits of asthma patients at baseline and post program.\textsuperscript{17}}
\end{table}

\begin{figure}
\centering
\includegraphics{figure5.png}
\caption{Processes of care as assessed by chart audits of asthma patients at baseline and post program.\textsuperscript{17}}
\end{figure}

\begin{figure}
\centering
\includegraphics{figure6.png}
\caption{Asthma-specific emergency department (UD) visits and hospitalizations among persons with asthma at baseline and post-program.\textsuperscript{17}}
\end{figure}
The results indicate that the key to success in implementing a chronic care model is a comprehensive approach that combines changes to case management practices with the right patient and provider education, and the involvement of the entire organization rather than clinical staff only. The sustainability of this model proved to be a success as well as the rates of emergency department visits and hospitalizations stayed at the reduced levels. One of the major enablers of the significant improvement is the creation and use of a well defined patient registry.

**Special Examples**

In some cases there is a need for very specific kinds of Registries. This is usually called for in circumstances of environmental disasters or when special groups of people are identified. The following will discuss special registry scenarios including: the World Trade Asthma Registry, Registries for Clinical Trials, and Childhood Immunization Registries.

**World Trade Center Asthma Registry**

In addition to organizational and systemic problems in properly diagnosing asthma, effectively treating it, and enabling patients’ self-management, there are many environmental issues that effect asthma patients. Outdoor and indoor allergens and pollutants seem to have greater effect on children while the effects of the work environment are more significant for adults.\(^{18}\) The prevalence and costs of treating asthma warrant improvements in prevention. Because the environment can have significant impacts on the number of asthma patients, a better management of known environmental problems is needed.

A number of studies were conducted to investigate and assess effects of occupational exposure to adult-onset asthma. “Occupational asthma (OA) has been defined as asthma originating from causes and conditions attributable to a particular occupational environment and not to stimuli encountered outside of the workplace.”\(^{19}\) Estimates of the prevalence of occupational asthma vary by country and region due to different methods being studied, and can go as high as 20% for some high risk occupations. A study conducted in Canada in the early

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1990s suggests that one in three adult-onset asthma cases can be attributed to occupational exposures. A significant number of adult-onset asthma cases are preventable, subject to reducing or eliminating exposure to known high risk substances. Similar studies conducted in other countries, including the US, came to similar conclusions. Because a lot of the data studies and improvement initiatives rely on self reported, asthma patient registries are key enablers as sources for identifying target groups.

Some large environmental impacts are more difficult to control than others. The terrorist attack on the World Trade Center in New York City on September 11 not only killed thousands of people but it also left long term impacts on the health of many more thousands. The most common outcomes of this disaster are asthma and posttraumatic stress. A large number of people had intense or prolonged exposure to heavy dust and smoke that increased the risk of adult-onset asthma. The information about those that were affected in the disaster is kept in a dedicated patient registry. “The World Trade Center Health Registry (WTCHR) is the largest post-disaster registry in U.S. history. The WTCHR is a key public health resource to document the duration and severity of health impacts, guide decisions about medical care and other services, connect individuals to specific services, and inform response planning for future disasters.”

The diagram below (Figure 7) shows the major enrollment groups kept in this WTCHR and how they overlap.

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Almost ten years after the attack The World Trade Center Health Registry is still in use. It will stay as an infrastructure for on-going studies and surveys. The findings based on the data from this registry will continue to help with decisions on chronic disease management and other medical care for its members. This can be seen in Figure 8.

Figure 8  The analysis of data collected between 2001 and 2006 shows a high number of new asthma patients among people with post-disaster exposure within a year following the attack and some decline in the following several years.
Clinical Trial Registries

In the past decade, there has been outrage with reference to the use of some drugs used in clinical trials. Merck’s recall of Vioxx and GlazoSmithKline’s suppression of data related to suicidal tendencies in children when taking Paxil are two prominent examples. With incidents such as these occurring, scientists, medical community members and the public have all advocated for improved conduct of clinical trials and the drug approval process. Registries for clinical trials have successfully gained support to reform this effort.22

One example of a clinical trial registry is that of ClinicalTrials.gov. This registry is web-based and administered by the National Library of Medicine. It was created in response to demands by patient advocacy groups in an effort to have greater access to clinical trial data. Entries in ClinicalTrials.gov provide information about each trial including, but not limited to, a summary of the purpose of the study, recruiting status, eligibility criteria, trial location, study design, and much more. Currently, this registry contains approximately 12,000 clinical studies.22

Another example of a clinical trial registry is the metaRegister of Controlled Trials (mRCT). This registry is a free, online searchable database of Registered Controlled Trials (RCT). It is based in the United Kingdom and administered by BioMed Central. It is intended for people who use evidence from RCTs and are interested in comprehensive knowledge of all evidence on a subject. Entries in mRCT include but are not limited to: title, sponsor, disease or condition being studied, hypothesis and objectives, eligibility, current status of trial, and contact information.22

Childhood Immunization Registries

Childhood immunizations embody a basic health strategy for the prevention of disease in communities worldwide. Registries for childhood immunizations were originally developed in an effort to expand immunization coverage by improving the deliver of immunizations to children. There are 3 specific reasons for the need of developing an immunization registry that include, tracking changes made to recommended immunization schedules, ensuring child immunizations are up to date, and providing a central place to store immunization records. Figure 9 attempts to

show how these immunization registries work by identifying various functions, users, and policy issues.

In 1996, the Robert Wood Johnson Foundation sponsored an initiative called the All Kids Count Childhood Immunization Registry Initiative that identified 13 essential functional standards the registry should include. Later, in 1997, the National Immunization Program of the U.S. Centers for Disease Control and Prevention became involved in the initiative and began to include immunization program managers. The standards have since been revised and shortened to 12 and as of 2001, is now known as the Immunization Registry Minimal Functional Standard.

The following list is what the 12 functions include:

1. Electronically storing data on all NVAC-approved core data elements.

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INTERNATIONAL HEMOPHILIA AND RARE BLOOD DISORDER REGISTRIES

Introduction

Sometimes a disease is so rare that a global population must be used to have a large enough sample to collect useful data. The international Registry of Rare Bleeding Disorders (RBDD) is one such project. It works “to better identify the number of affected individuals throughout the world, define the clinical manifestations and sequelae associated with these disorders, create a network of individuals who care for these patients that are able to share diagnostic and treatment expertise, and provide potential centers where specific products once developed may be utilized in clinical trials.” 95-97% of these diseases are deficiencies of coagulation factors, Hemophilia for example.

As of 2006, only 400 patients have been identified, making this is a very specific disease registry. RBDD’s goals are simple; gather data to measure disease distribution, track drug availability and distribution to ensure areas with high populations of a disease have access to the medications needed and ultimately to become a resource where knowledge can be shared. The
data gathered should spur new research into treatment and diagnoses. See Figure 10 below for a graphical representation of the RBDD model.

![Figure 10 Conceptual Schema of RBDD](image)

**Italy**

Acquired hemophilia is a rare syndrome which is caused by inhibitors of factor VIII and rarely factor IX. This disease is characterized by a sudden onset of bleeding in patients with no family or personal history of bleeding diseases. Acquired hemophilia is seen as a medical emergency and requires prompt treatment and is clinically and financially demanding. In 2001, the Italian Registry for hemophilia was used to analyze data on patients treated with the therapy rFVIIa. The therapy rFVIIa is a systemic haemostatic agent with topical action and is beneficial in a variety of bleeding conditions. The data extracted from the hemophilia registry consists of primary condition, cause of bleeding or its spontaneous occurrence, site, severity evaluated by the hemoglobin level and by transfusion requirements, therapy, selection criteria and results. The analysis of this data from the hemophilia registry concluded that the treatment was safe and that

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rFVIIa carries a low risk of thromboembolism. The use of disease registries such as the Italian Hemophilia Registry allows for analysis of data to improve different areas of chronic disease management.25

**Netherlands**

According to the World Health Organization, hemophilia is a serious and well known condition that affects almost half a million people worldwide. In approximately 70% of hemophilia patients the condition is inherited, and for the remaining 30% it is the result of a spontaneous genetic mutation. Hemophilia patients can have reduced life expectancy, frequent hospitalizations, discomfort or even disability due to the impact on joints, and increased risk of contracting HIV and hepatitis due to treatments based on blood products.26

The treatment of hemophilia has changed dramatically in the late 1960s and 1970s when the new proactive prophylaxis treatment was introduced as an alternative to the reactive treatments that required hospitalization, and a web of National hemophilia treatment centers was created in a number of countries to provide comprehensive care to hemophilia patients. To compare treatments, measure effectiveness, evaluate outcomes and improve healthcare for hemophilia patients, a number of statistics are collected and kept in hemophilia patient registries.27

In the Netherlands, the lists created using patient registries owned by the Netherlands Hemophilia Society and hemophilia treatment centers were used to conduct a series of five nationwide surveys between 1972 and 2001 to measure the medical and social effects of the new treatment and other improvements in care. The structured predefined questionnaires were sent to the patients, or their caretakers in case of children below 12 years of age, included 1567 out of the estimated 1606 hemophilia patients in the Netherlands. The results of this broad study (Figure 11) showed that in the course of thirty years the change in treatments and incremental improvements to care in the Netherlands made significant results. For example, the life

expectancy increased to a level very close to the rest of the population (68), the number of hemorrhages decreased by half or more, length of hospital stay reduced by three quarters, the time off work and school because of hemophilia went down.  

| Table 3. Outcome of treatment presented for patients with severe hemophilia and moderate hemophilia |
|----------------------------------|---------|---------|---------|---------|---------|
| Severe hemophilia, N             |         |         |         |         |         |
| Hemorrhages, median no. per year (range)* |         |         |         |         |         |
| Child, 0-16 y                    | 20 (4-68) | 20 (4-70) | 10 (4-60) | 10 (4-60) | 5 (1-5) |
| Adult, older than 25 y           | 14 (3-70) | 15 (5-100) | 10 (5-60) | 10 (5-60) | 10 (5-75) |
| Hospital admissions*             |         |         |         |         |         |
| Hemorrhila, %                   | 51      | 58      | 25      | 22      | 22      |
| Duration of stay, median no. of days (range) | 28 (3250) | 20 (1-180) | 11 (1-100) | 5 (0-500) | 7 (0-65) |
| Absent from school due to hemophilia, d (range)* |         |         |         |         |         |
| School                          | 30 (0-60) | 15 (0-60) | 4 (0-60) | 2,5 (0-60) | 7 (0-90) |
| Work                            | 15 (0-60) | 22 (0-213) | 7 (0-125) | 8 (0-335) | 5 (0-365) |
| Moderate hemophilia             | 23      | 106     | 175     | 173     | 176     |
| Hemorrhages, median no. per year (range)* |         |         |         |         |         |
| Child, 0-16 y                    | 4 (0-49) | 10 (1-104) | 3 (0-60) | 7 (0-10) | 2 (0-57) |
| Adult, older than 25 y           | 5 (0-59) | 5 (0-100) | 2 (0-49) | 3 (0-92) | 1 (0-71) |
| Hospital admissions*             |         |         |         |         |         |
| Admitted, %                     | 51      | 27      | 23      | 22      | 15      |
| Duration of stay, median no. of days (range) | 17 (2-180) | 10 (1-50) | 7 (1-50) | 5 (0-73) | 6 (3-51) |
| Absent from school due to hemophilia, d (range)* |         |         |         |         |         |
| School                          | 30 (0-60) | 5 (0-60) | 3 (0-60) | 0 (0-15) | 5 (0-20) |
| Work                            | 2 (0-60) | 13 (0-130) | 7 (0-150) | 5 (0-365) | 5 (0-150) |

N indicates the entire population under study.
*Reported for the 1-year previous to the questionnaire.
†Due to hemophilia in patients following full-time day education.
‡Total absence in unemployed people between 15 and 64 years of age.

Figure 11 Example of the results of the treatment outcomes analysis over the period of thirty years.  

After the conclusion of the nationwide survey in 2001, all hemophilia patients in the Netherlands had to be registered in one of the treatment centers throughout the country.  

The Dutch share their experience and results of using hemophilia patient registries for improving medical and social outcomes for hemophilia patients with other countries in the world. In the multinational RODIN study conducted in several European countries, the central registry was located at and managed by the University Medical Center Utrecht, Netherlands. This European Pediatric Network for Hemophilia patients (PedNet) registry is a source for ongoing clinical studies and research of hemophilia among children. It contains a standardized set of data intended to support on going clinical management of young hemophilia patients as well as studies and research geared towards improved safety, efficiency, and quality of treatments.  

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diagram below (Figure 12) shows the role that the PedNet registry plays in collecting the hemophilia patient data and sharing it with treatment centers and researchers.

![Diagram of PedNet data flow](image)

**Figure 12 How PedNet collects data.**

**Canada**

The Canadian Hemophilia Registry (CHR) was formed in 1988 by the Canadian Hemophilia Clinic Directors Group to enumerate the number of individuals with hemophilia A and B. The registry was expanded in 2003 to accommodate a "Von Willebrand" registry, and in 2004 statistics from the Rare Inherited Bleeding Disorders Registry were incorporated.29

The CHR has been designed to serve the interests of patients while overcoming the challenges of sharing data over great distances and protecting patient privacy. It has been used to identify the patient population, plan research projects, identify the scope of viral infections and the cause of deaths, lobby government for resources, and has aided in the fight for compensation for patients with transfusion-transmitted viral infections.30

When the CHR was created it received one time funding. The authorized reporting from CHR was free for many years. Since then the data collection is done thanks to goodwill by many for many years to provide information. In 2008 the registry received $8,000 for data entry.31 Data is

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submitted anonymously by the 24 Canadian hemophilia treatment centers (HTC) and updated annually. Each patient is identified by factor deficiency, date of birth and an "Extra Identifier". CHR assigns this number which remains with the person if transferred to another clinic.

CHR has had a few challenges in the time it has been around. Though the CHR is an anonymous system, it must maintain identities to avoid patient duplication. Another challenge is to maintain accurate status of patients since patients with mild disorders may seldom attend a clinic. Also, a clinic is not always advised when a patient has moved or died. Another challenge is that of privacy. In Canada, each province has its own laws regarding the confidentiality of medical records so that participating clinics have had to make sure they are in compliance with the appropriate legal requirements for their jurisdiction. This has meant that clinics have adopted slightly different procedures regarding consent for sharing anonymous data.

**CHALLENGES**

Disease registries are not without challenges. From a broad perspective there are a number of issues that can plague disease registries no matter how well designed or how efficiently they are administered. The following discussion focuses on leadership challenges, privacy and security challenges, and political challenges that are effecting registries.

**Leadership**

The Chronic Care Model (CCM) provides a conceptual framework for transforming health care for patients with chronic conditions; however, little is known about how to best design and implement its specifics. Changing traditional care patterns is difficult and requires enormous attention and focus, with clear specifications, strong leadership including representation from medical side, and attention to details at both local and central levels of an organization.

Strong leadership, vision, and support of senior leadership in improving quality of chronic disease management is a major predictor of success. Conversely, lack of leadership support, or turnover in leadership are primary predictors of failure. Senior leaders are instrumental in

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33 Ibid
securing resources or removing barriers that may stall quality improvement activities. For example, the development of registries and other computer functions often requires juggling the priorities of information system staff.\textsuperscript{34}

**Privacy and Security**

**HIPAA Privacy Rule**

The U.S. Department of Health and Human Services issued the Standards for Privacy of Individually Identifiable Health Information, also called the Privacy Rule. This Privacy Rule was enacted under HIPAA in 2002 and creates regulations for managing protected health information. Research under HIPAA is defined as a systematic investigation including research development, testing, and evaluation which is designed to develop or contribute to general knowledge. The implementation of HIPAA has changed the way registry data is collected. The Privacy Rule required that consent for a telephone based follow-up questionnaire be obtained by patients. This change caused challenges with obtaining follow-up information for registries since the consent forms would be mailed to patients and some wouldn’t respond since the consent could be viewed and lengthy and confusing. Other challenges caused by the HIPAA Privacy Rule include a decrease in the ability to obtain consent which results in less representative registries of patient populations, potentially biased outcomes, and increased costs.\textsuperscript{35}

**Legal Issues**

Recently there have been public concerns about privacy rights due to technological advances in database storage and management. There is a raised public consciousness about identity theft and genetic discrimination and blurred distinctions between a person, genetic or other bodily material, and personal identifying information. Due to these concerns, standard protocols and efficacy of registry surveillance have been affected. For instance, due to data security concerns and public accountability, the federal Veterans Affairs hospitals withdrew from


participation in state-mandated cancer registries between 2005 and 2007. Challenges to state-mandated cancer registration now face legal questions about its constitutionality. The constitutionality of cancer registration will depend on the value of the data relative to privacy interests and its compatibility with privacy rights.36

**Politics**

There are also political issues that can come into play when dealing with disease registries. In 2008, the US Centers for Disease Control was charged with suppressing information that suggested important health risks for individuals and families living in the Great Lakes Area. Specifically, the CDC’s Agency for Toxic Substances and Disease Registry (ATSDR) was accused of suppressing a report that revealed data that showed potential human health issues such as increased infant mortality rates and cancer in rates. Although the report did no directly substantiate the existence and release of environmental pollutants, the cancellation of the publication on this report was still seen as being suppressed for political concerns within the Bush Administration.37

**Doctor Resistance**

Although patient registries prove to be valuable in improving quality and safety of chronic care they are not universally accepted and implemented throughout the US. Disease registries seem to be predominantly used by larger groups and IPAs, and are more common in California than in the rest of the US.38

The cost of registries is not prohibitive; some solutions on the market are even free. The barriers to adoption seem to be elsewhere. One of the challenges in adopting registries is the limited ability of organizations to create them. The data may be scattered, the resources required for implementing and maintaining a registry database not available, workflow may be lacking.

steps, clinicians may not be on board with using an additional tool, and so on. Some studies suggest that there is little difference in ability to create registries between organizations that implemented EMR and those that did not. However, the use of registries in improving care may be simpler when their implementation and introduction are part of a quality improvement initiative and possibly EMR implementation. A combination of a broader initiative, additional training and financial incentives may be a good start in introducing registries.  

The pay for performance program provides the financial incentive for using registries. Registries store information about services to chronic care patients and because of that they can be used for measuring performance and quality that qualify. In addition, some groups such as “Bridges to Excellence (a national consortium of employers and health plans) and the HMOs in California’s Integrated Healthcare Association (an organization of insurers, employers, physician groups, and other stakeholders) reward practices that use electronic registries.”

One other challenge in adopting registries is the resistance by physicians. There are few reasons for the physicians to not accept registries. In places where EMRs are implemented, if registries are not well integrated with an EMR system the same data has to be entered twice in two different places. This is the reason for some organizations to give advantage to EMR solutions that have built-in integration with registries, but those are rare. Even when the integration between the two systems exist, the details have to be documented in the EMR system in such a way that they can be passed to a registry. This can be a restriction for clinicians. Sometimes, integration is lacking. For example, for diabetes registries to be of high value, they need to be integrated with lab systems to collect and store lab results for their members. Another example would be the registry of discharged patients with particular diagnoses not being integrated with other patient registries that store information about follow up visits. Some physicians are not in favor of such fragmented information. To resolve concerns of data fragmentation, Green Field System in Portland Oregon created a more comprehensive patient registry. This turned out to be a new problem because the registry stores too many conditions.

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and that makes it hard to target patients and reach out to them. In addition to all other issues, some physicians have little trust in completeness and accuracy of reports coming out a registry. In the past there were some errors in these reports and they are used to support pay for performance bonuses.\textsuperscript{38}

None of the organizational challenges and physicians’ concerns related to the creation, implementation and use of registries are unsolvable. The physicians play a key role in fully utilizing registries to improve quality of chronic care and safety of their patients. In order to address their concerns and improve acceptance of registries, the selection of software solutions and their implementations need to be handled with a strong attention and focus on change management. Physicians need to participate actively in introducing a registry into the process in order to reduce risk of low adoption.\textsuperscript{32} More universal acceptance and use of registries in the US would make a significant improvement in quality and safety of chronic care in the US.

**CONCLUSION**

Based on the current state of the healthcare system, it can be expected that chronic care is not a concept that is going away anytime in the near future. With the use of disease registries, chronic care data and information can be better managed helping to manage overall patient care of the chronic disease. Ultimately, the integration of disease registries with chronic care models will help discourage reactive treatment tactics and encourage more proactive treatment plans for patients.