DOI: 10.1377/hlthaff.2011.0762 HEALTH AFFAIRS 5 31, NO. 1 (2012): 220–227 ©2011 Project HOPE— The People-to-People Health Foundation, Inc. By Stefan Larsson, Peter Lawyer, Göran Garellick, Bertil Lindahl, and Mats Lundström

# Use Of 13 Disease Registries In 5 Countries Demonstrates The Potential To Use Outcome Data To Improve Health Care's Value

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ABSTRACT As health care systems worldwide struggle with rising costs, a consensus is emerging to refocus reform efforts on value, as determined by the evaluation of patient outcomes relative to costs. One method of using outcome data to improve health care value is the disease registry. An international study of thirteen registries in five countries (Australia, Denmark, Sweden, the United Kingdom, and the United States) suggests that by making outcome data transparent to both practitioners and the public, well-managed registries enable medical professionals to engage in continuous learning and to identify and share best clinical practices. The apparent result: improved health outcomes, often at lower cost. For example, we calculate that if the United States had a registry for hip replacement surgery comparable to one in Sweden that enabled reductions in the rates at which these surgeries are performed a second time to replace or repair hip prostheses, the United States would avoid \$2 billion of an expected \$24 billion in total costs for these surgeries in 2015.

onventional cost controls have largely failed to rein in increases in health care spending. In response, policy makers have recommended improving value by weighing patient outcomes against treatment costs. According to the Institute of Medicine, "a variety of strategies are beginning to be employed throughout the health system to address the central issue of value, with the goal of improving the net ratio of benefits obtained per dollar spent on health care."

One approach has already shown great potential to improve the quality of care: patient registries that track outcomes in a population of patients who have the same diagnosis (for example, acute myocardial infarction) or who have undergone the same medical procedure (for example, cataract surgery). For reasons of simplicity (and to distinguish these registries from other types of registries, such as those tracking exposure to a

drug or use of a medical device), we refer to them as *disease registries*.

Most discussions of disease registries portray them primarily as repositories of data useful for outcome research. A much-cited handbook published by the Agency for Healthcare Research and Quality describes a registry as "an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease [or] condition."<sup>2</sup>

This description is accurate as far as it goes, but we take a broader view. We see disease registries not only as systems for the collection and analysis of data on health outcomes but also as important institutional catalysts for efforts to improve those outcomes over time.

By identifying variations in outcomes within a population, registries make it possible to benchmark and assess comparative performance at the level of a particular clinic or health system, as well as at the regional, national, or even international level. In-depth analysis of the causes behind variations in performance can lead to the identification of best practices. Active dissemination of those best practices and support to enable their adoption reduce variations in clinical practice over time.

Systematic quality improvement of this type, we believe, can also have the positive side effect of lowering total health care costs for a given condition. What's more, by putting the responsibility for improved quality squarely in the hands of physicians and other health care practitioners, registries organize and engage the medical community around the common goal of better health care value.

# **Background**

Sweden has been an international pacesetter in the establishment of disease registries. The country's nearly ninety government-supported registries, many of them established by the medical societies of the relevant specialty, cover more than 25 percent of total national health expenditures. And many registries have been in place long enough to provide meaningful longitudinal data.

In 2009 a group of commercial and academic health care leaders in Sweden asked the lead author of this article to evaluate the opportunities and costs involved in expanding the registry model to include other conditions. The study concluded that by investing \$70 million annually in disease registries, data analysis resources, and information technology infrastructure, Sweden could reduce its annual growth in health care spending from an estimated 4.7 percent to 4.1 percent. The estimated cumulative return totaled more than \$7 billion in reduced direct health care costs over ten years.<sup>3</sup>

Since then the Swedish government has made the expansion of Sweden's network of registries a national priority and has committed to increasing its direct financial support for registries nearly fivefold—from \$10 million to \$45 million per year—by 2013.<sup>4</sup>

Encouraged by the findings of the initial study, in 2010 we expanded our research to include the impact of disease registries in other countries.

# **Study Data And Limitations**

Our international study had three goals: to document changes in health outcomes in patient populations covered by disease registries; to identify the role, if any, that registries played in these changes; and to quantify (where data were available) the cost savings made possible by those

improvements in the form of avoided health care costs

countries and across six major medical conditions or procedures. Although many of the registries were located in Sweden, the majority were in Australia, Denmark, the United Kingdom, and the United States. In addition to analyzing both published and unpublished registry data, we also interviewed thirty-two health care professionals—registry experts, physicians who used registry data, and health care policy makers—to learn how registries function and to identify any mechanisms by which they are able to influence clinical practice.

For a list of registries and disease areas studied, experts interviewed, and additional case studies, see the online Appendix.<sup>5</sup>

**LIMITATIONS** Our study was based on interviews, observation, and analysis of published and unpublished data. Because we did not conduct a randomized controlled study, we cannot conclusively demonstrate a causal connection between the existence of registries and improvement in health outcomes. In the examples we cite below, outcomes improved following the implementation of registries and quality improvement efforts that capitalized on registry-derived data. However, we cannot rule out the possibility that trends unrelated to registry use played a role in the etiology of the observed improvements.

Finally, because of the difficulty of finding consistent cross-national data on outcomes and costs, our estimates of costs avoided should be applied only with caution.

# **Study Results**

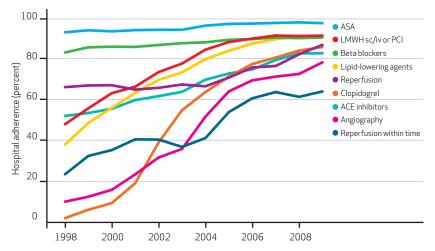
Our study produced three categories of findings: evidence of improved health outcomes associated with registries, documentation of how registries may have helped achieve these outcomes, and estimates of costs avoided as a result of registry-associated improvements.

IMPROVED HEALTH OUTCOMES We identified many instances where the existence of registries was associated with major improvements in health outcomes. Such associations do not prove causality. However, when we looked closely at how the disease registries we studied operate, we found many indications that they played an active—in some cases, a leading—role in encouraging changes in clinical practice that led to improved health outcomes.

This has been the case, for example, in the area of acute myocardial infarction. Sweden's Register of Information and Knowledge about Swedish Heart Intensive-Care Admissions was established in 1991. Since 2009 it has been part of

#### EXHIBIT 1

# Hospitals' Adherence To Swedish National Guidelines For Treating Acute Myocardical Infarction, 1998–2009

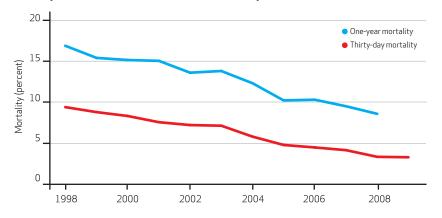


**SOURCES** (1) Carlhed R, Bojestig M, Wallentin L, Lindström G, Peterson A, Aberg C, et al. Improved adherence to Swedish national guidelines for acute myocardial infarction: the Quality Improvement in Coronary Care (QUICC) study. Am Heart J. 2006;152(6):1175–81. (2) Swedeheart data set; Register of Information and Knowledge about Swedish Heart Intensive Care Admissions annual reports, 1998–2009. (3) Interview by Boston Consulting Group research team of Tomas Jernberg, director, Register of Information and Knowledge about Swedish Heart Intensive Care Admissions, Stockholm, 2010 Oct 20. (4) Interview by Boston Consulting Group research team of Bertil Lindahl, director, Uppsala Clinical Research Center, Uppsala University, Uppsala, 2010 Nov 2. **NOTES** ASA is acetylsalicylic acid, or aspirin. LMWH sc/iv refers to the administration of low-molecular-weight heparin (either subcutaneously or intravenously). PCI is percutaneous coronary intervention, or angioplasty. ACE refers to angiotensin-converting enzyme inhibitors (heart medications that widen or dilate blood vessels to improve the amount of blood the heart pumps and lower blood pressure). Reperfusion is the restoration of blood flow to an organ or tissue (for example, after a heart attack, an immediate goal is to quickly open blocked arteries and reperfuse the heart muscles). "Reperfusion within time" refers to reperfusion treatment initiated within the time recommended by treatment guidelines.

Swedeheart, Sweden's national registry for acute coronary care. Between 1998 and 2009, Swedish hospitals greatly improved their adherence to nine interventions recommended by the Euro-

## EXHIBIT 2

# Mortality Rates For Swedish Patients With Acute Myocardical Infarction, 1998-2009



sources See Exhibit 1.

pean Society of Cardiology (Exhibit 1), decreasing the average thirty-day mortality rate for patients who had an acute heart attack by 65 percent and the one-year mortality rate by 49 percent<sup>6</sup> (Exhibit 2).

THE ROLE OF REGISTRIES What role did the Swedish heart attack registry play in this improvement? The registry collects comprehensive data from all seventy-four of the nation's major hospitals and covers approximately 80 percent of the patients in Sweden who suffer a heart attack. In addition to tracking well-accepted clinical-outcome standards such as thirty-day and one-year mortality rates, the registry also monitors adherence to proven process metrics such as the European guidelines.

But the registry does not simply collect these data. It has also made them transparent—initially to health care practitioners and later, after the data collection process and outcome metrics were fully vetted, to the public at large. This data transparency has had a demonstrated impact on the rate of clinical improvement.

In 2005 the registry created a quality index that tracked how well the nation's hospitals were complying with clinical guidelines. At first the registry published only aggregate data at the regional level. In late 2006, however, it decided to make public both the index scores and the actual patient survival rates for each of the country's seventy-four hospitals.

A review of the results shows a dramatic change after public disclosure (Exhibit 3). From 2005 through 2007 the average hospital quality index score improved at a compound annual growth rate of 13 percent. However, the hospitals whose scores were below the average improved by only 7 percent, indicating a widening quality gap between above-average and below-average hospitals. From 2007 through 2009, the period after all of the data were made public, the average annual rate of improvement grew to 22 percent for the period. But below-average performers improved to 40 percent per year, decisively narrowing the gap.

Karlstad Hospital, located in central Sweden, illustrates how data transparency can inspire clinical engagement, tighten focus on a clear goal, and in the process transform care. In 2005 Karlstad had one of the lowest scores on the quality index. In response, the hospital reorganized the total care cycle and improved its adherence to clinical guidelines, raising its rank to forty-third out of Sweden's seventy-four hospitals by 2007. Once the performance data became public, Karlstad boosted its ranking to twenty-second, cut its thirty-day mortality rate from 9 percent to 4 percent, and improved its one-year mortality rate from 13.5 percent to

# 5.2 percent—well below the national average.

In effect, Sweden's registry for acute coronary care has become a key resource and partner in the efforts of Swedish cardiologists to improve health outcomes. Registry staff and clinical researchers who have been engaged in registry work have even participated in hospitals' quality improvement initiatives, whose impact has been demonstrated to improve clinical outcomes significantly.<sup>7</sup>

Many Swedish cardiologists fully acknowledge the registry's role. Swedeheart conducts an annual survey of the physicians and nurses who are the formal contacts for the registry at Sweden's hospitals. In 2010 the survey received 124 responses (a response rate of 88.5 percent). Ninety-two percent of the responding physicians and 89 percent of the responding nurses either strongly agreed or partly agreed that "the registry helps us identify areas where we need to improve." And 93 percent of physicians and a striking 99 percent of nurses either strongly agreed or partly agreed with the statement: "I believe that the registry is useful to our work improving the quality of health care."

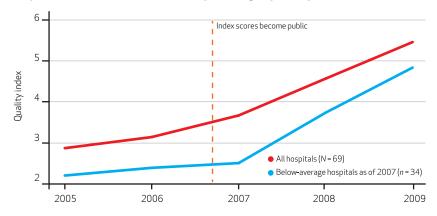
Our research identified three organizational characteristics that allowed disease registries to effectively promote continuous improvement of clinical practice and health outcomes.

► COMPREHENSIVE, HIGH-QUALITY DATA: The registries we studied pay a great deal of attention not only to collecting comprehensive data but also to making sure that they are reliable. In addition to the data it collects on heartattack patients, for example, Swedeheart also covers 100 percent of patients undergoing angiography, angioplasty, and other types of cardiac surgery, as well as nearly 100 percent of patients with acute coronary syndrome admitted to hospitals' coronary care units.8 The registry collects baseline data on 106 variables for patients with the syndrome and another 75 variables regarding secondary prevention twelve to fourteen months after the hospital admission. The data are registered online directly by the caregiver.

There are computerized error-checking routines that immediately flag any entries that are outside normal ranges or inconsistent with previous data for a particular patient. In addition, a monitor visits approximately twenty randomly selected hospitals each year to compare data entered into the registry with the information in the medical records of thirty to forty randomly chosen patients. In 2007 this data validation process demonstrated an agreement of 96.1 percent between the information in the registry and that in medical records—an extremely high score, given the inevitability of some human error in data entry.<sup>8</sup>

#### EXHIBIT 3

# Hospital Scores On The Swedish Coronary Care Registry Quality Index, 2005-09



**SOURCES** Register of Information and Knowledge about Swedish Heart Intensive Care Admissions annual reports, 2005–09. **NOTES** See text for an explanation of the index, which was established in 2005 (the start of graphic plotting). Data on individual hospital performance were first made public in the 2006 annual report, as noted by the dashed orange rule. Data on five hospitals were removed because they did not include a complete time series.

A similar commitment to comprehensive and reliable data exists at Sweden's National Cataract Register, which was established in 1992 and is owned by the Swedish Ophthalmological Society. The registry's database includes information about all public eye clinics and ophthalmology departments in Sweden and 98 percent of all eye surgeries performed by private clinics. The database includes more than a million records, representing 95.6 percent of all cataract extractions performed in Sweden since 1992. A study of 574 operations for cataracts at five Swedish clinics demonstrated an agreement between the database and patient records of 95.4 percent. Description

▶ A BIAS TOWARD DATA TRANSPARENCY: Many of the registries we studied were similar to Swedeheart in making their data public at the level of the individual hospital, to encourage benchmarking and accelerate improvements in outcomes. Data transparency at the US Cystic Fibrosis Foundation Patient Registry appears to have played a key role in accelerating the decline of *Pseudomonas* infections in US cystic fibrosis patients.

*Pseudomonas* is one of the most serious and difficult-to-treat hospital-acquired infections and a common complication in cystic fibrosis. Since 1995 the annual incidence of *Pseudomonas* in the 25,000 patients at the 115 certified cystic fibrosis centers covered by the registry has declined by more than 14 percent. But that decline has come in two distinct phases.

Between 1995 and 1999 the drop in *Pseudomonas*-positive sputum cultures was relatively modest—from 60.3 percent to 59.3 percent. A straight extrapolation of this trend line would

have yielded a 57.3 percent positive-culture rate by 2009. However, in 1999 the registry began providing each center with data on its own performance compared to a national benchmark. In 2006 the registry began making these data public.

In addition, the registry established guidelines for new clinical practices that went beyond typical infection control—in particular, daily mechanical airway clearance (removing mucus from the lungs through a variety of mechanical methods, including vibrating vests and manual chest percussion) for all cystic fibrosis patients and routine inhalation of hypertonic saline for all patients older than age six. The decline in the *Pseudomonas* infection rate accelerated dramatically, reaching 51.7 percent by 2009.<sup>11</sup>

▶ ACTIVE ENGAGEMENT WITH THE CLINICAL COMMUNITY: In effect, the registries we studied functioned as a valued community partner. They worked to engage physicians and other clinical staff in the shared task of improving the quality of care and served as a clearinghouse for the dissemination and sharing of best practices.

Perhaps the most dramatic example is the contribution of Sweden's cataract registry to the development of national clinical guidelines for the prevention of postoperative endophthalmitis, a

rare but severely debilitating infection that is among the complications that can occur during cataract surgery.

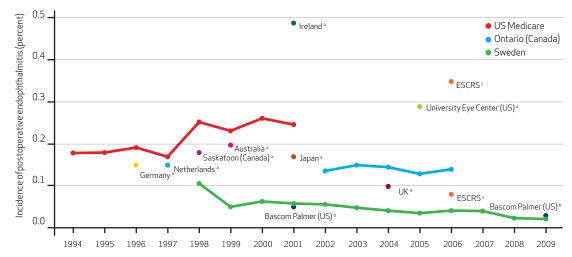
Since postoperative endophthalmitis is so rare, few hospitals or medical centers can develop a large enough reference sample to produce reliable statistics. In 1997, however, Sweden's cataract registry began collecting nationwide data on the condition. Over the next decade the registry identified a series of specific risk factors associated with the condition, as well as best practices that improved outcomes.

Since the registry began tracking the occurrence of postoperative endophthalmitis, the incidence of the condition in Sweden has declined from 0.11 percent of all cataract surgery cases in 1998 to 0.02 percent in 2009. This is by far the lowest national average that we have observed in published data. Today the average Swedish ophthalmology clinic has results on a par with those of the Bascom Palmer Eye Institute in Miami, which has been rated the best ophthalmic hospital in the United States by board-certified ophthalmologists for seven consecutive years in *U.S. News & World Report*'s annual list of "America's Best Hospitals" (Exhibit 4).

**ESTIMATED COST SAVINGS** A core tenet of the total quality movement that has swept through

#### EXHIBIT 4

# Incidence Of Postoperative Endophthalmitis In Cataract Patients, 1994-2009



**SOURCES** (1) Barry P, Seal DV, Gettinby G, Lees F, Peterson M, Revie CW, et al. ESCRS study of prophylaxis of postoperative endophthalmitis after cataract surgery: preliminary report of principal results from a European multicenter study. J Cataract Refract Surg. 2006;32(3):407–10. (2) Note 13 in text. (3) Hatch WV, Cernat G, Wong D, Devenyi R, Bell CM. Risk factors for acute endophthalmitis after cataract surgery: a population-based study. Ophthalmology. 2009;116(3):425–30. (4) West ES, Behrens A, McDonnell PJ, Tielsch JM, Schein OD. The incidence of endophthalmitis after cataract surgery among the U.S. Medicare population increased between 1994 and 2001. Ophthalmology. 2005;112(8):1388–94. (5) Note 14 in text. (6) Notes 9 and 12 in text. Part of a multicenter, multiyear study; dates used in exhibit are the last year of data, not the year of publication. Bascom Palmer Eye Institute has been rated the best US ophthalmic hospital by board-certified ophthalmologists for seven consecutive years in US News & World Report. ESCRS is European Society of Cataract and Refractive Surgeons. The study divided patients into two groups: those receiving cefuroxime (and thus having a lower incidence of postoperative endophthalmitis) and those not receiving cefuroxime (and thus having a higher incidence). This is indicated by the two orange circles for ESCRS.

the manufacturing world in recent decades is that boosting quality often has the beneficial side effect of lowering costs—a principle captured in the expression "quality is free." Despite severe data limitations, we nonetheless found several instances to suggest that this phenomenon may also apply to disease registries.

Total hip arthroplasty, the replacement of a hip joint with a prosthesis, is a common operation. Although generally effective, the procedure fails for some patients, because of either postoperative infection or normal wear on the prosthetic hip. In such cases, a second procedure, known as a "revision," is required to repair or replace the implant. In addition to being disruptive for patients, hip-surgery revisions are expensive, with an average cost in Sweden of about US\$18,500 per operation.

Since the founding of the Swedish Hip Arthroplasty Register in 1979, Sweden has reduced its revision burden (the number of surgeries that have to be performed again as a share of total hip arthroplasties in a given year) to 10 percent—one of the lowest national rates in the world. Thirty years of data have helped Swedish hip surgeons identify not only the best clinical practices but also the highest-performing implants (in sharp contrast with other countries, the number of implants used in Sweden is small, with six different types accounting for more than 90 percent of all total hip replacements). Based on registry data, we estimated that Sweden avoided some 7,500 revisions in the decade 2000-09 that would have taken place if Sweden's revision burden had been as high as that of the United States in that decade.17 That represents approximately \$140 million, or \$14 million per year, in avoided costs. The amount is equivalent to about 8 percent of the cost of total hip arthroplasty overall in Sweden during this period.18,19

The US health care system spent \$6 billion on total hip arthroplasty in 2005, and according to one estimate, these costs are expected to rise to \$24 billion by 2015. Based on these assumptions, we estimate that if the US health care system could lower its revision burden by 2015 to Sweden's current level of 10 percent, it would avoid \$2 billion of the expected \$24 billion in total costs. 1

For additional case studies on the economic impact of registries, see the online Appendix.<sup>5</sup>

## Discussion

Our research suggests that disease registries can function as powerful platforms for improving health outcomes, lowering health care costs, and increasing health care value. Yet establishing registries in the United States with the scope and

comprehensiveness of those found in Sweden faces major challenges.

The US health payer system is complex and fragmented, with few common reporting standards and clinical outcome metrics across this system—even within the same specialty. There is no national mechanism to compel providers to report outcomes to disease registries. Nor is there a unique patient identifier that would enable researchers to combine data across different disease states to examine the effect of complex comorbidities.

The widespread adoption of disease registries in the United States faces an additional cultural challenge. Improving clinical outcomes can be considered a competitive advantage. Thus, sharing results and best practices with other providers may well run counter to the interests of individual clinics and physicians.

Despite these obstacles, the United States boasts some outstanding registries, including the Cystic Fibrosis Foundation Patient Registry mentioned above, the American College of Cardiology's CathPCI Registry, and the National Cancer Institute's Surveillance Epidemiology and End Results database. These and other examples suggest that disease registries can succeed in the US health care environment.

For more widespread and systematic use of registries to take hold, however, key stakeholders will need to champion them. Medical professional societies have a central leadership role to play, both in creating uniform standards for data collection and in securing the broad support and participation of practicing clinicians.

The federal government can support registries by creating a legislative and regulatory framework that facilitates their establishment and by providing seed funding to get them up and running. And private-sector players—insurance companies and the manufacturers of drugs and medical devices—should support disease registries because the high-quality data that registries produce would help them focus on genuine innovations to improve clinical outcomes and bend the health care cost curve.

## Conclusion

After decades of struggling to control rising health care costs, it is clear that conventional methods alone will not achieve complete success. There is, however, a promising alternative: improving patient outcomes and focusing on health care value. Disease registries can contribute to this effort by engaging doctors and other clinical professionals in identifying, comparing, and adopting best practices that can both transform care and lower costs.

Some of the material in this article was presented at the 2010 Elsevier FDA-CMS Summit in Washington, D.C., December 10, 2010; at the Physicians' Consortium for Performance

Improvement biannual members' meeting in Washington, D.C., March 11, 2011; and at the 2011 Regulatory Affairs Professionals Society Horizons Conference in Vancouver, British

Columbia, April 7, 2011. The authors acknowledge Jennifer Clawson, Rasmus Nerman, and Robert Howard for their contributions to this article. [Published online December 7, 2011.]

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In this month's Health Affairs, Stefan Larsson and coauthors focus on how thirteen disease registries in five countries have enabled an extensive assembly of outcome data and used the information to improve the value of health care for everything from hip replacements to cardiac care. Sweden, home of four of the authors, has the world's most extensive and longest experience with disease registries and offers a model for "confronting the enormous challenge of improving outcomes while lowering costs," Larsson says.

Larsson is a senior partner and managing director in the Boston Consulting Group's Stockholm office and global leader of the firm's payer and provider practice. He completed his medical training at the Karolinska Institute in Stockholm. He completed part of his graduate studies at Harvard Medical School and ultimately earned his doctorate in pediatric nephrology from Karolinska.



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