

# BRIEF REPORT: The Prevalence and Use of Chronic Disease Registries in Physician Organizations

## A National Survey

Julie Schmitt diel, PhD,<sup>1</sup> Thomas Bodenheimer, MD,<sup>2</sup> Neil A. Solomon, MD,<sup>3</sup>  
Robin R. Gillies, PhD,<sup>4</sup> Stephen M. Shortell, PhD<sup>4</sup>

<sup>1</sup>Kaiser Permanente Northern California Division of Research, Oakland, CA, USA; <sup>2</sup>University of California at San Francisco, San Francisco, Calif, USA; <sup>3</sup>NAS Consulting, San Francisco, CA, USA; <sup>4</sup>University of California at Berkeley, School of Public Health, Berkeley, Calif, USA.

**OBJECTIVE:** Disease registries are lists of patients with a particular chronic illness, including clinical information, to improve the care of individuals and populations. The objective of this study was to determine the prevalence of disease registries in physician organizations and the extent to which they are used to improve care.

**DESIGN:** A cross-sectional national telephone survey with a response rate of 70%.

**SETTING:** All physician organizations in the United States with 20 physicians or more.

**PARTICIPANTS:** Chief executive officers, presidents, or medical directors of 1040 physician organizations.

**INTERVENTIONS:** None.

**MEASUREMENTS AND MAIN RESULTS:** Forty-seven percent of organizations reported having a registry for at least 1 chronic illness, with diabetes registries being the most common. Half (51%) of the registries were not linked to clinical data. Organizations with at least 1 registry were more likely to have implemented other chronic care improvements ( $P < .0001$ ). Factors associated with the presence of registries in physician organizations include external incentives for quality and extent of information technology capabilities.

**CONCLUSIONS:** Disease registries are not utilized by half of physician organizations. This finding is disturbing because registries have the potential to catalyze needed improvement in chronic care management.

**KEY WORDS:** disease registries; physician organizations; chronic illness.  
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A recent survey found that only 56% of recommended care is being provided for patients with chronic illness in the United States.<sup>1</sup> Data from 1999 to 2000 indicate that 37% of people with diabetes achieve an HbA1c level less than 7.0%,<sup>2</sup> and similar statistics can be found for other chronic conditions.<sup>3,4</sup>

A growing literature demonstrates that certain care management processes (CMPs) can improve the quality of care for several chronic conditions.<sup>5-9</sup> These CMPs include case management, use of guidelines, clinician and patient reminder systems, performance feedback to individual physicians, patient self-management support, and disease registries. Wagner and associates have proposed a Chronic Care Model that combin-

es CMPs into an effective guide for chronic care improvement.<sup>10,11</sup>

Disease registries are a particularly important CMP. A disease registry is a computer application "used to capture, manage, and provide information on specific conditions to support organized care management of patients with chronic disease."<sup>12</sup> Registries can be used in at least five different ways: (1) to generate performance feedback reports to physicians on patient levels of HbA1c and other clinical endpoints; (2) to provide physicians with "exception reports" that identify patients who are not receiving care according to practice guidelines or who remain out of therapeutic range; (3) to create point-of-care clinician reminders that summarize a patient's care management tasks and identify which tasks are due; (4) to generate reminder notices to be sent to patients when care management tasks are due; and (5) to create "high-risk lists" showing which patients require more intensive management. Performance feedback to physicians has been shown to improve practice,<sup>5,13</sup> while registries linked with patient reminders are associated with lower patient HbA1c levels than registries alone.<sup>14</sup>

Numerous studies suggest that chronic disease registries, if utilized in 1 or more of these ways, can improve clinical processes and outcomes for patients with diabetes.<sup>14-18</sup> But while registries are a vital component of CMPs, the extent to which registries are utilized by organizations caring for patients with chronic illness is unknown. This study is the first attempt to estimate the prevalence of registries in physician organizations in the United States. The study also investigates whether a physician organization with chronic disease registries is more likely to utilize other CMPs. It also explores which characteristics of physician organizations are associated with the adoption of a chronic disease registry.

## METHODS

### Data Source

Data for this study were obtained from the National Study of Physician Organizations (NSPO). This telephone survey, conducted from September 2000 to September 2001, measured the organizational characteristics and CMPs among all U.S. medical groups and Independent Practice Associations (IPAs) with 20 or more physicians. The response rate of the 1,590 physician organizations in the census was 70%, resulting in a study population of 1,104. Sixty-four were deleted from the analysis because they did not treat any of the 4

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Address correspondence and reprint requests to Dr. Bodenheimer: University of California at San Francisco, Department of Family and Community Medicine, Building 80-83, San Francisco General Hospital, 1001 Potrero Avenue, San Francisco CA 94110 (e-mail: Tbodenheimer@medsch.ucsf.edu).

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chronic illnesses (diabetes, asthma, congestive heart failure, and diabetes) studied by the NSPO, leaving a study population of 1,040 physician organizations. Further information about the survey development, content, and nonrespondents is available elsewhere.<sup>19</sup>

## Measures

Interviewers assessed each physician organization's use of registries with four "yes/no" questions, asking whether the physician organization maintains a registry or list of patients with asthma, congestive heart failure (CHF), depression, or diabetes. Physician organizations answering "Yes" to the question of "registry or list" were coded as having a registry. These registries could be electronic and interactive, or potentially be maintained through manual chart review and data entry.

The physician organizations were asked whether they were able to feed back information on patients with chronic illness to physicians, and were given a more detailed series of 7 questions about their ability to feed back information on: use of anti-inflammatory medications for asthma patients; use of ace inhibitors and hospitalizations for CHF patients; glycohemoglobin monitoring, nephropathy prevention, ophthalmology visits, and hospitalizations for diabetes patients. Physician organizations were also asked how long it would take to generate reports on patients with diabetes, and whether they utilized patient-level reminders for eye exams for patients with diabetes.

Six questions determined whether the physician organization had external incentives to improve their quality of care. These included 4 questions regarding whether they were required to report patient satisfaction results, quality improvement project results, outcomes data, or Health Plan Employer Data and Information Set (HEDIS) data to any outside organization; and 2 questions as to whether they received income or public recognition for scoring well on quality measures.

Each physician organization's clinical information technology (IT) capabilities were assessed with 6 questions asking whether they had electronic data systems containing: a standardized problem list; prescribed medications; progress notes; medication-ordering reminders and/or drug interaction information; lab results; and/or pathology results.

## Statistical Analysis

Chi-square tests and *t*-test difference of means tests were used to examine the bivariate differences in registry use in medical groups versus IPAs, and in care management practices between organizations that had registries and those that did not. A multivariate logistic regression was used to examine the predictors of registry use.

Four out of 6 external incentive questions regarding reporting to outside organizations were combined into an index ranging from 0 to 4. The 6 questions regarding the electronic data systems were combined into an index ranging from 0 to 6. All analyses were performed using SAS version 8.2.

## RESULTS

Table 1 describes the level of registry use within physician organizations. Diabetes registry use was the most common, while depression registry use was the least. The medical groups in this study were asked whether their registries were

Table 1. Registry Use in Physician Organizations

	All Physician Organizations (n=1040)	Medical Groups (n=693)	IPAs (n=347)
Presence of any registry—n (%)	493 (47.4)	326 (47.0)	167 (48.1)
Asthma registry—n (%)	304 (31.2)	176 (27.8)	128 (37.7) <sup>†</sup>
CHF registry—n (%)	339 (34.8)	207 (32.5)	132 (39.2)*
Depression registry—n (%)	143 (15.7)	90 (15.1)	53 (16.9)
Diabetes registry—n (%)	398 (40.3)	260 (40.3)	138 (40.4)
Number of registries—mean (SD) (range =0 to 4)	1.1 (1.4)	1.0 (1.4)	1.3 (1.5)*
Number of registries among organizations with at least 1 registry—mean (SD)	2.4 (1.1)	2.2 (1.2)	2.7 (1.0) <sup>‡</sup>

Note: Disease-specific registry percentages calculated from the total number of physician organizations treating disease. N=973 treat asthma; 975 treat CHF; 909 treat depression; 987 treat diabetes.

\*P<.05. †P<.01. ‡P<.001.

CHF, congestive heart failure.

linked to clinical data; 51% said that they were not (data not shown). Table 2 shows that organizations with registries are significantly more likely to perform feedback and reminder-related CMPs than those without. Multivariate logistic regression analysis found that predictors of whether a physician organization had at least 1 chronic disease registry included the external reporting index, receiving public recognition for quality, and IT capabilities (Table 3).

## DISCUSSION

This study found that only 47% of physician organizations with 20 or more physicians reported having at least 1 chronic disease registry (Table 1). In addition, many organizations reported that these registries were not linked to clinical data, suggesting that the registries are not in active use. Given that studies show that chronic disease registries, when fully utilized, appear to be associated with better clinical processes and outcomes,<sup>14-18</sup> the lack of active registries among most physician organizations indicates a problem that needs attention. In this study, organizations with registries are more likely to provide feedback to physicians about their quality of care and to have patient reminder systems (Table 2). Since these CMPs are associated with better care processes and outcomes,<sup>5,13-14</sup> enabling the building and use of registries in physician organizations may have the potential to improve chronic care management overall.

Both computerized IT and external incentives predict the use of disease registries (Table 3). A movement is growing in the United States for physician organizations to publicly report quality indicators, to receive rewards for improving quality, and invest in IT systems.<sup>19</sup> Physician organizations in this study that have greater IT and greater incentives for quality are far more likely to have disease registries, lending support to proponents of these initiatives.

This study has several limitations. The prevalence of registries is based on the self-reporting of organizational leaders, who may have exaggerated their use of CMPs. However, the relatively low use of registries reported makes this unlikely. A second weakness is the lack of data for physician organizations with fewer than 20 physicians; this survey leaves out many physician organizations that by virtue of their small size are unlikely to have the capability to maintain disease regis-

Table 2. Use of Registry-Related Functions by Presence of Registries

	Any Registry (n=493)	No Registry (n=557)	Ratio of Registry/ No Registry
Provides written feedback reports or data to MDs regarding chronically ill patients—n (%)	249 (51.9)	132 (24.5)	2.1
	<b>Asthma Registry (n=304)</b>	<b>No Asthma Registry (n=669)</b>	
Feedback to MDs or case managers on: Appropriate use of anti-inflammatory medications—n (%)	105 (34.5)	68 (10.2)	3.4
	<b>CHF Registry (n=339)</b>	<b>No CHF Registry (n=636)</b>	
Feedback to MDs/case managers: Use of ace inhibitors—n (%)	169 (49.9)	94 (14.8)	3.4
Hospitalizations for CHF—n (%)	209 (61.7)	146 (23.0)	2.7
	<b>Diabetes Registry (n=398)</b>	<b>No Diabetes Registry (n=589)</b>	
Feedback to MDs/case managers: Appropriate glycohemoglobin Monitoring—n (%)	254 (63.8)	138 (23.4)	2.7
Prevention of nephropathy—n (%)	154 (38.7)	66 (11.2)	3.5
Ophthalmology visits—n (%)	226 (56.8)	138 (23.4)	2.4
Hospitalization for diabetes—n (%)	194 (48.7)	118 (20.0)	2.4
Reminders to patients for retinopathy exams—n (%)	175 (46.1)	90 (16.4)	2.8
Can PO provide reports within 5 d of request on patients with diabetes?—n (%)	307 (78.5)	325 (57.0)	1.4

Note: All differences significant at the  $P < .0001$  level.  
MD, medical director; PO, physician organizations.

tries. The study also does not directly answer the question of how the registries are used in physician organizations. It is likely, but not certain, that physician feedback and reminder systems, which are associated with the presence of registries, are derived from the registry. The data collected by the NSPO do not allow a conclusion on whether the registry itself was used to generate physician feedback and reminders or whether physician organizations implementing registries are more con-

scious of chronic care management and are thus more likely to implement multiple CMPs. While other methods, such as EMR use and manual data collection and entry, may also facilitate these CMP functions, these data help demonstrate that actual registries more fully enable their use.

## CONCLUSION

A central element in the Chronic Care Model is the use of disease registries for individual and population management of chronic conditions; however, this study finds that active registries are relatively uncommon in physician organizations. This is disturbing since registries have the potential to improve chronic care, which, in the U.S., has been repeatedly shown to be inadequate. Policies that may encourage the spread and use of registries may help increase the processes and quality of chronic illness care.

Table 3. Factors Associated with Presence of Any Registry—  
Multivariate Logistic Regression

Independent Variables	Odds Ratio (95% Confidence Interval)
External incentives variables	
Outside reporting index (range 0 to 4)	1.2 <sup>†</sup> (1.1, 1.4)
Income for quality	1.1 (.81, 1.5)
Public recognition for quality	2.2 <sup>†</sup> (1.5, 3.1)
Clinical IT index (range 0 to 6)	1.1 <sup>‡</sup> (1.03, 1.2)
% delegation for hospitalization utilization management	1.008 <sup>†</sup> (1.004, 1.01)
Medical group (vs IPA)	1.5 (.91, 2.4)
Specialty type (multispecialty as referent)	
Specialty only	1.3 (.77, 2.3)
Primary care only	.91 (.57, 1.5)
Size (less than 100 MDs as referent)	
100 to 199 MDs	1.06 (.70, 1.6)
200 or more MDs	1.6 <sup>‡</sup> (1.03, 2.4)
County HMO penetration*	1.005 (.99, 1.01)
Ownership type (MD owned as referent)	
Hospital or HMO owned	1.5 <sup>‡</sup> (1.09, 2.1)
Other owned	1.8 <sup>‡</sup> (1.1, 2.8)
Age of PO	1.005 (.99, 1.01)
Number of different clinic locations	1.00 (.999, 1.001)

C-statistic = .73.

Hosmer and Lemeshow Goodness of Fit Test = 18.0 ( $P = .02$ ).

\*Interstudy data<sup>20</sup>.

<sup>†</sup> $P < .05$ . <sup>‡</sup> $P < .001$ .

IT, information technology; IPA, Independent Practice Association; MD, medical director; PO, physician organizations.

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