Improving Outcomes for Patients with Diabetes Using Joslin Diabetes Center’s Registry and Risk Stratification System

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ABSTRACT
Joslin Diabetes Center’s Registry and Risk Stratification System collects data on key measures of diabetes care and provides diabetes decision support to primary care providers. Specifically, this system identifies high-risk patients in a population, recommends patient-specific interventions based on Joslin’s clinical guidelines, and reports a clinic’s process and quality metrics for benchmarking and regional comparisons. This article describes Joslin’s system and its impact on the quality of diabetes care in the primary care setting.

KEYWORDS
- Diabetes
- Decision support
- Quality of care
- Primary care
- Registry
- Risk
- Interventions
- Informatics

“There are too many cases for the specialist... so we need to teach the patient and others how to care for and manage diabetes.”
- Dr. Elliot P. Joslin, Founder, Joslin Diabetes Center

Caring for patients with diabetes is a challenge to primary care providers in light of the complexity of clinically managing the disease: the existence of complications and co-morbidities; the introduction of new medications, medication classes and delivery mechanisms, such as inhaled insulin; and evolving clinical best practice. This high-intensity and time-consuming care, which is inadequately served by the typical 15- to 20-minute primary care visit, is further challenged by a patient’s need for provider guidance and encouragement in best-practice self-care. With the increasing prevalence of diabetes in the U.S., the challenges that diabetes presents to the primary care setting will continue to proliferate.

Disease Registries and Decision Support
Although primary care providers must be versed in best practices for multiple diseases, it has been proven that changes in best practice are slow to be disseminated into...
Furthermore, providers and clinics have few resources to support their delivery of best-practice care and to assess how they are performing against quality measures. Registries and decision support tools can fill these needs. Disease registries are Web-based systems that are used to record data for patients with a particular diagnosis, such as diabetes. Data elements are typically a subset of what would be found in an electronic medical record, such as general patient data like height, weight and other information; past diagnoses; labs results; details of patient visits; medications; and family history.

Registries can be used in the absence of an EMR, or their functionality may be incorporated as part of an EMR. Using a clinical algorithm to analyze this data and assess patient risk, registries support providers in making care decisions based on established current clinical guidelines.

Identification of high-risk patients in a provider’s panel has many benefits, as described in Figure 1, which is based on a patient’s level of interaction with a provider’s office (x-axis) and the patient’s level of risk (y-axis).

Many studies and articles have been published about registries and decision support in the primary care setting; this article focuses on the specific experience of Joslin Diabetes Center in the creation and implementation of a registry and diabetes decision support based on Joslin’s clinical guidelines.

### Joslin’s Registry and Risk Stratification System

Being a specialty center for the treatment of diabetes, Joslin Diabetes Center sees some of the most complex, and therefore costly, patients in the world. To evaluate the severity of illness for its patients in capitated managed care plans, Joslin developed a system of risk stratification in 2002, using five risk categories as shown in Table 1. Only one of these risk categories, glycemic control, is directly related to diabetes; this is because diabetes is a condition that encompasses many organ systems.

The system assigns each risk category a risk level of low, moderate, high or very high risk. For example, a patient with a history of hypoglycemia who has not been hospitalized or treated in an emergency department and who has an Hba1c in the range of 7 percent to 7.9 percent would receive a moderate risk level for the glycemic control category. Joslin’s risk stratification approach allowed for targeted interventions to improve care in subpopulations of people with diabetes and was also used to select appropriate patients for case management.

Subsequently, this approach was incorporated by Joslin’s disease management team into a Web-based diabetes registry, Joslin’s Registry and Risk Stratification System.

<table>
<thead>
<tr>
<th>Glycemic Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular Disease</td>
</tr>
<tr>
<td>PVD/Peripheral Neuropathy/Feet</td>
</tr>
<tr>
<td>Retinopathy (eye disease)</td>
</tr>
<tr>
<td>Nephropathy (kidney disease)</td>
</tr>
</tbody>
</table>

**Table 1. Clinical Categories.**
FOCUS: Clinical Decision Support/Business Decision Support

Table 2. Joslin Diabetes Center Clinical Guidelines.²

<table>
<thead>
<tr>
<th>Category</th>
<th>Low</th>
<th>Moderate</th>
<th>High</th>
<th>Very High</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glycemic Control</td>
<td>16%</td>
<td>35%</td>
<td>12%</td>
<td>37%</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>4%</td>
<td>31%</td>
<td>45%</td>
<td>19%</td>
</tr>
<tr>
<td>Foot Disease</td>
<td>25%</td>
<td>53%</td>
<td>22%</td>
<td>0%</td>
</tr>
<tr>
<td>Retinopathy</td>
<td>6%</td>
<td>1%</td>
<td>89%</td>
<td>3%</td>
</tr>
<tr>
<td>Nephropathy</td>
<td>18%</td>
<td>74%</td>
<td>5%</td>
<td>3%</td>
</tr>
</tbody>
</table>

Go to Guidelines

Practice Risk Stratification Summary

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Please click on the numbers in the table to obtain a listing of patients for a particular risk level and category. Reminder: Anyone accessing any patient information contained herein is accountable for maintaining the security and confidentiality of those records.

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(RRSS), to address the needs of patients with diabetes outside of the Joslin Clinic in primary care settings. This Web-based system enabled primary care providers and other caregivers to use patient appointments more efficiently and effectively by automatically identifying drivers risk for each patient based on the patient's unique combination of data within the system and recommending patient interventions based on Joslin's practical clinical guidelines. This “to-do list” is comprised of actionable, patient-specific reminders and care recommendations appropriate for use at the point-of-care.

Practices also used the system's reports to track clinic process and quality metrics for benchmarking and regional comparisons, which facilitates National Committee for
Quality Assurance provider recognition, and to track diabetes education, which facilitates American Diabetes Association Education program recognition.

The system’s algorithm is based on Joslin’s clinical guidelines.2 Joslin’s clinical oversight committee updates the guidelines annually or more frequently as new research dictates or as new medications become available or for other reasons. Table 2 lists Joslin’s clinical guidelines.

RRSS Reports

The System produces five major reports.

The Practice Risk Stratification Summary (Figure 2) indicates the percentages of patients that fall into each risk category at the four levels of severity. By clicking a percentage, the list of patients that compose that percentage appears in a new window. To drill down further, by clicking an individual patient on the list, the provider can see the drivers of risk for that particular patient.

The Risk Stratification Levels report (Figure 3) shows risk data for a particular patient. For each of the five risk categories shown in the first column, the patient’s risk level is shown in column 2. Column 3 describes why the patient was assigned to that risk level. Note that risk is cumulative, so all levels of risk up to the level for which the patient qualifies are described.

The “To Do” List for a patient (Figure 4) shows the

“Registries can be used in the absence of an EMR, or their functionality may be incorporated as part of an EMR.”
patient’s last visit date and recommendations to the provider for the patient’s care, based on Joslin’s clinical guidelines, at this current visit.

There are many graphical trend reports available that show patient data in graph form; Figure 5 is one such example. These reports often are used during visits for patient education purposes.

The Diabetes Performance Measure Summary (Figure 6) enables clinics to take HEDIS3-type quality measures and compare them with a target they have established for their patient population, the initial target column, as well as other clinics (“Other Sites” column) to which they are associated.

Challenges to Using the RRSS

Primary care practices do not have time to incorporate extra processes into their workflow. Most do not have an EMR, computers in the exam room or multiple computers with Internet access, which means that data entry for the RRSS needs to be done manually, and that it would be often difficult for busy practitioners to use the system at point of care.

Figure 4. “To Do” List.

“To Do List

These recommendations should be used as a guide or cues for therapy. Exceptions may be based on professional clinical judgment.


Most recent A1C is above target of 7.0. Consider review of management plan or medication adjustment

Last blood pressure reading above target of 130/80; consider treatment/adjustment if this persists

Most recent LDL cholesterol above target of 100. Consider treatment with lipid-lowering agent or adjustment of dose, unless contraindicated.

Positive repeated urine microalbumin (2 out of the last 3 results over 30). Consider treatment with ACE Inhibitor (unless contraindicated) or ARB, or adjustment of dose.

Consider pneumococcal vaccine: recommendation is once for all patients with diabetes

Return to Risk Stratification Report
The clinics currently using the RRSS have developed workarounds for these challenges. For example, office staff print the to-do list before the visit, and attach it to the front of the patient’s chart, preparing the provider before he or she enters the exam room to provide Joslin quality care. In addition, the RRSS’ data input pages are printed and used as a form by the provider to record the relevant data elements during the patient’s visit. After the visit, the completed forms are given to a clerical assistant to input data into the corresponding RRSS screens.

**RRSS Outcomes**

In addition to its use at Joslin’s Boston Clinic, the risk stratification system that evolved into the RRSS was used for three years at an inner-city practice in Boston that had a high incidence of diabetes. Joslin provided diabetes education to the provider and his patients as well as feedback to the provider on his performance based on RRSS reports.

Outcomes included improvement in mean hemoglobin A1C ($p<0.001$). Because lower A1Cs indicate good diabetes control, a declining A1C indicates improved quality of care and patient self-care. Joslin’s Clinical Guidelines define the target A1C for adults with diabetes of 7 percent. An average reduction of 1 point in mean A1C can translate into a 30 percent reduction of a patient’s risk of developing complications.

Other positive outcomes of reduction of both systolic ($p<0.001$) and diastolic ($p<0.001$) pressure, as well as increased documented foot exams ($p<0.001$). Patients often report that during an office visit, they did not remove shoes,
even though the foot exam is an important component of an office visit for patients with diabetes. If a provider actually is performing a foot exam, it should be documented for payment purposes. Documented foot exams are an easy but important improvement in quality of care.

Other positive outcomes include improved practice outcomes such as statistically significant improvements in the percentage of patients with blood pressure $<130/80$ (p<0.01) and LDL $<100$ mg/dl (p<0.05). Also improved were process outcomes, such as statistically significant improvements in the percentage of patients on angiotensin converting enzyme inhibitors or angiotensin receptor blockers (p<0.001). These include patients who received a microalbumin test once per year (p<0.001); with a positive microalbumin test who were on an ACE or ARB (p<0.001); and with hypertension who were on medications (p<0.001).

**Conclusion**

Outcomes from the use of Joslin’s RRSS in the primary care setting indicate that Joslin’s clinical guidelines embedded into software that both risk-stratifies patient populations and identifies drivers of risk for individual

![Diabetes Performance Measure Summary](image_url)
patients with diabetes can significantly improve quality of care. Furthermore, using data that reports care quality at the clinic level enables providers to assess and improve their performance, compared with benchmarks and subsequently to set care quality goals, both of which are useful in pay-for-performance programs and regional health information organizations. Results similar to Joslin’s have been found with the use of diabetes registries in several other clinical settings, including the Pennsylvania State Diabetes Center and the Mayo Clinic, with the key elements for successful implementation being linkage to clinical guidelines; real-time availability of decision support; ability to provide accurate, usable outcomes reports; ease of use; and acceptance by providers.

About the Authors
Karen Golden Russell, MA, MBA, is responsible for business development and marketing for Joslin’s Strategic Initiatives division.

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References
3. Health Plan Employer Data and Information Set (http://www.ncqa.org/programs/hedis/)