AMA | STEPSforward™

# Patient Care Registries

## Proactively Manage Chronic Conditions

**Bruce Bagley, MD**
Senior Advisor, Professional Satisfaction and Practice Sustainability, American Medical Association

## How Will This Toolkit Help Me?

Learning Objectives:

1. Describe a patient care registry and the benefits of implementing a registry in your practice
2. Summarize steps to select the criteria for your registry and build a registry framework
3. Explain how to design practice workflows and train your team to use the registry

# Introduction

A patient care registry is a system to identify and care for patients with chronic conditions, as well as a means of tracking preventive care in your practice. It can be integrated into your practice's electronic health record (EHR), a separate database program, or even a simple spreadsheet that is manually updated. Patient care registries can be extremely useful at the population level for managing common chronic illnesses, such as diabetes or coronary artery disease.
A patient care registry can help your practice track high-risk or high-need patients to ensure that services are delivered to all patients in a timely manner according to **evidence-based medicine (EBM)** guidelines. When optimized, you can use your practice's patient care registry system to create customized planned visit protocols for each patient visit and for outreach between visits.

# Five STEPS to Create a Patient Care Registry for Your Practice:

1. Develop the Criteria for Your Registry
2. Build the Registry Framework
3. Develop Workflows and Train the Team to Use the Registry
4. Put Your Registry Into Action
5. Evaluate and Apply Registry Findings

## 1 Develop the Criteria for Your Registry

Registries take resources, both human and technical, especially during the launch and pilot phases. It is critical to have the entire care team (including non-clinical and support team members) on board to develop and maintain the registry. Take the opportunity to engage your entire practice during the brainstorming session to determine what an effective registry will look like. The entire team can be an integral part of developing the infrastructure of the actual registry. It is important that non-clinical and support team members are familiar with your patient care registry design, as they may be the ones regularly using reports once your registry is up and active.

**To be effective, patient care registries must fulfill 5 criteria:**

1. Include a list of all the patients in the practice with the target condition(s) (eg, diabetes, asthma, hypertension).
2. Show a "snapshot" of the EHR to detail important clinical parameters and identify the gaps in EBM-recommended care.
3. Aggregate the results from all patients in the practice with the specific condition to assess the overall quality of care provided (eg, the percentage of patients with diabetes who have controlled blood pressure).
4. Produce support for outreach and follow-up (eg, for all patients with diabetes who have not had an A1c in 6 months, the registry system suggests an eye exam or diabetes education referral).
5. Integrate clinical quality reporting into the process of care rather than as a separate endeavor.

Ensure you have sufficient support of team members (eg, medical assistant or nurse) to return phone calls, make appointments, update medication lists, and so forth. Ideally, patients should be able to see their own data in

the patient care registry, either provided via an **online portal**, mailed to them before their visit, or given to them at the visit. For any registry system, it is crucial to ensure that patient confidentiality as well as data privacy and security requirements are adequately addressed.

**Registry Brainstorming Guide**
Use this tool to help you and your team develop your registry criteria.
(MS WORD, 52 KB)

Q&A

### What can I monitor with a patient care registry?

Your practice should start with one or more chronic conditions commonly seen in your patient panel that have well-developed EBM guidelines and established clinical performance measures.

Examples include:

- Diabetes
- Hypertension
- Asthma
- Coronary artery disease
- Chronic obstructive pulmonary disease (COPD)
- Attention deficit hyperactivity disorder (ADHD)
- Depression

You could also use a patient care registry to monitor preventive services, such as age-appropriate screenings and **immunizations**, and track **social determinants of health**.

### Can I use a patient care registry for following high-risk or high-need patients?

You can use a single patient care registry system to track and follow up with patients identified as high-risk or high-need. This approach is more patient-centered than a disease-specific registry and can be especially useful to support care managers, care coordinators, and a **care transitions** team as they follow those particular patients in your practice. It is important to collaborate with the care managers of patients who are already receiving other care coordination services in order to integrate the care into your registry. For example, a registry of patients on **opioids** for non-cancer pain will aid in ensuring that the patients have current documented goals of care and (if appropriate) updated opioid registry reviews have been completed.

### How can I include multiple conditions in my patient care registry?

We recommend you use a system that will enable your practice to have an all-condition, or patient-centered, registry. However, you may want to expand to include multiple conditions in your patient care registry after your practice has had some experience with its systems and workflow when it includes one condition. Once your practice feels more comfortable with these processes, you can then expand the effort over time to other chronic conditions and preventive services, such as patients with **diabetes** and hypertension on appropriate blood pressure medicines like ACEi (angiotensin-converting enzyme inhibitors).

This system should also display all the parameters for a patient with multiple chronic conditions, which helps to identify gaps in EBM-recommended care. Almost all patients in the practice need age-appropriate

screenings and immunizations as part of your preventive medicine strategy. Registries within EHR systems will eventually help track and measure the rates of these services for all patients. Many registries are built outside of EHR systems, so you are not limited to those within EHRs, but you then need to be sure your EHR data is compatible with the outside registry and that all necessary data privacy and security requirements for legal compliance will be in place with any such integration.

### How is a patient care registry different from a national database registry?

Patient care registries differ from national database registries in three fundamental ways:

- Patient care registries are available to the physician and care team during any type of patient encounter to show the current status and highlight gaps in EBM care parameters.
- The patient care registry information is part of the regular office workflow.
- Patient care registries can be designed to feed data into national databases, but the current constructs used by most national database registries limit their ability to feed data in real time.

Most national database registries are designed to collect data, establish useful comparisons, and provide reports back to practices at some regular interval. Comparison data is helpful to evaluate how your practice is doing relative to other practices with similar patient demographics and risk profiles.

## 2 Build the Registry Framework

Survey, assess, and select a patient care registry system that best fits with your current EHR, target patient populations, and practice workflows. Your program should include all the clinical parameters that you rely on to make informed medical decisions. These parameters need to be presented in an organized and complete format, allowing you to focus on those aspects of care that need the most attention. You may consider using a generic registry template within your EHR or developing a custom version with a programmer. Note that working with your EHR vendor to create the registry, as opposed to developing or buying a separate system, may help avoid workflow problems and the need for separate log-ins.

Q&A

### What are some examples of patient care registry systems I could use or purchase?

Many EHRs have modules for a registry function that are either not installed or not turned on. Be sure to check with your EHR vendor and evaluate the registry functionality against the 5 criteria listed in STEP 1. Working with the EHR vendor is generally preferable to building a separate registry, as it will be built into the existing workflow of the EHR that your practice is already familiar with. If a module is not available through your EHR, then stand-alone registries are available for a fee.

The 3 essential components of stand-alone registries include:

- A database—complete with a server, database management software, and management tools—to store patient information
- A data model to organize and integrate information
- Software tools that allow users to sort, manipulate, and create reports from the information

You may purchase each of these components individually to create a stand-alone registry, purchase them as a package, or choose to use a simple spreadsheet. No matter what approach you choose, you should make sure that your patient care registry is fully integrated into your practice workflow.

### What searchable fields do I need to include in the patient care registry program?

Keep it simple. In addition to the usual demographic data to identify and contact the patient, you need to include the clinical parameters you and other care team members would want to know to make an informed decision about care, including **social determinants of health**.

For example, if you are setting up a diabetes registry that would be compatible with the Diabetes Collaborative Registry, you will want searchable fields for:

- Body mass index (BMI)
- HbA1c
- Lipid levels
- Blood pressure
- Blood pressure control (angiotensin-converting enzyme inhibitor/angiotensin II receptor blocker [ACE/ARB] use)
- Kidney function (albumin/creatinine ratio, eGFR, or creatinine)
- Smoking status
- Dates and results of dilated eye exams
- Dates and results of foot exams
- Influenza, pneumococcal, and hepatitis **vaccines**
- Housing status
- Employment status
- Access to nutritious food and safe exercise

Most are the same searchable fields required to calculate most of the clinical performance measures that may need to be reported to payers, CMS, and for maintenance of certification (MOC) part IV activities. Keep in mind that the fields must conform to electronic Clinical Quality Measures (eCQMs) to satisfy federal **value-based** payment reporting.

### Who sets up the patient care registry?

Designate a small work group to investigate the available options, the costs, and the functionality. While the entire care team will contribute to the registry, these specific team members will spend the most time working with the system or software. This group may also help design a workflow and formalize the procedures, roles, and responsibilities for using the registry. Data entry should be automated wherever possible, so integration with your EHR is essential to reduce duplication of work. For example, lab test results or blood pressure readings from the EHR should automatically populate on the patient summary page in the registry with a visual cue identifying the result as in or out of range. Some tasks or set-up, such as entering a new patient into the registry, may need manual input.


## Develop Workflows and Train the Team to Use the Registry

Involve the entire care team to keep the patient care registry up to date and complete by developing new workflows or adapting existing workflows to ensure that the data is properly and reliably entered. Establish how the team's clinical and clerical members should use the registry to follow up on gaps in care and **plan for visits** to **close these identified gaps** and provide timely care.

The entire care team should have access to the registry and be able to use protocols and standing orders to identify and address patient care needs. Designated team members, such as physicians, nurses, medical assistants, care managers, or panel managers, should be well trained in executing their role in managing the registry to improve data reliability, consistency of care, and patient outcomes.

Q&A

What kind of training does the team need to make sure patient care registry data is accurate and reliable?

Ideally, the practice should train 2 individuals in registry implementation, maintenance, and daily integration into the workflow. If you are using an EHR-based registry, your vendor should offer training. You may find additional registry training as part of population health and care coordination curriculums. These two "registry specialists" should be responsible for sharing their knowledge with everyone on the practice team. Much of the training will involve educating the care team about where information from the EHR flows into the registry, so that the data is as accurate and complete as possible. There may be some manual tasks in the initial set-up process or when entering a new patient into the registry. For more information about using a registry to improve care, see the AMA STEPS Forward™ toolkit on **panel management**.

How can I incorporate the patient care registry into my existing workflows to maximize impact?

Implementing a patient care registry is just one of many systematic changes you can make to improve practice efficiency and effectiveness. As you consider the design and implementation of your registry, there may be some overlap and synergies in workflows. Other AMA STEPS Forward™ toolkits can help guide how your patient care registry might integrate with or facilitate **pre-visit planning**, **expanded rooming and discharge**, **panel management**, and **risk-stratified care management**. The combination of these approaches with the registry should yield efficient, comprehensive, and effective care for patients with chronic conditions.

## 4 Put Your Registry Into Action

When implementing your new patient care registry, your practice may want to start by focusing on just one patient population, such as your patients with **diabetes**, and limit it even further by identifying an age range (ie, between 40 and 65 years old). Use a phased approach to allow the team to adapt to the patient care registry and the new workflows to manage care between visits.

Although 2 people should be responsible for making sure the registry is working properly and used by all, every care team member should contribute to its maintenance by entering information when missing fields are identified. The more complete the information, the better it works.

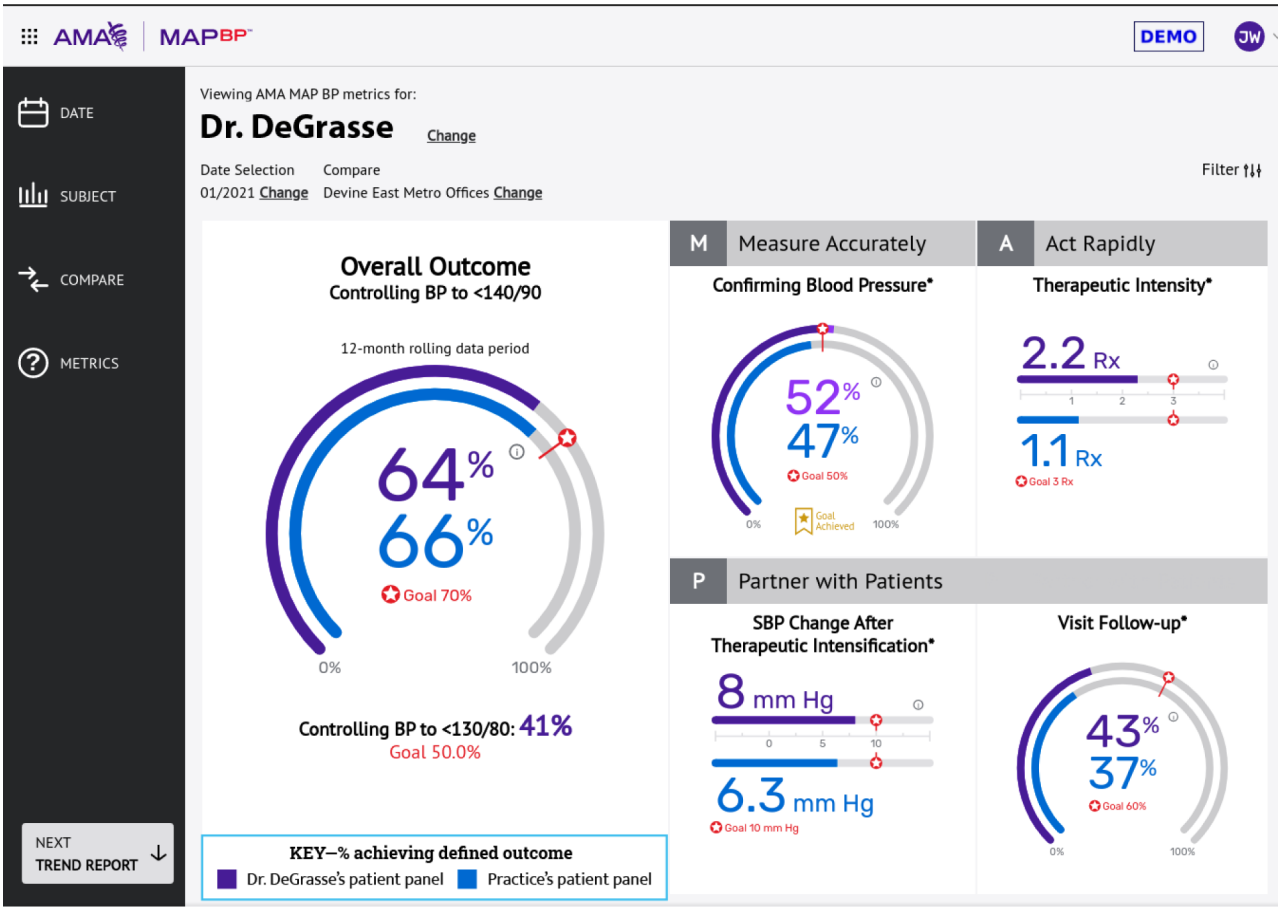
**Consider starting by assembling a list of patients with a specific condition.** All patients who have the specific condition should be added to the patient care registry; as patients come in or as new diagnoses are made, make sure the patients are added or that their profiles are updated. As the registry grows, it will become more useful for monitoring EBM care and facilitating outreach.

You may choose to collect information in a spreadsheet until you have selected a software package or if you do not have an EHR system in your practice, being mindful of data privacy and security legal requirements. Your team may find that it is more comfortable starting with a spreadsheet and then moving to the registry function in the EHR.

**Diabetes Tracking Worksheet**
If your practice is starting out with a spreadsheet as a patient care registry, you can customize this template to suit your practice's unique needs.
(MS XLSX, 18 KB)

Figure 1 shows a typical dashboard to visualize hypertension control for a single physician compared to their practice as a whole.

**Figure 1.**
Hypertension Patient Panel Included in a Sample Patient Care Registry



# 5 Evaluate and Apply Registry Findings

In addition to providing more efficient and effective care for your patients with chronic conditions, registries can help with **quality improvement** efforts. For example, if you learn from the registry that only 50% of your diabetic patients have their blood pressure under control, you could make changes in your treatment approach, **initiate a health coaching program**, or pursue a more active follow-up approach with these patients. You can then use the registry to track whether these process changes improve the percentage of patients whose blood pressure is under control. Depending on the sophistication of your patient care registry, you could generate the following types of reports to improve your practice:

- Patient reports at the time of the visit
- Exception reports to flag patients not meeting management targets
- Progress reports for care team members to measure care delivery
- Population reports to monitor and stratify at-risk patients

**Q&A**

### How do I make sure our patient care registry is adaptable and sustainable to meet ever-changing practice and payer standards?

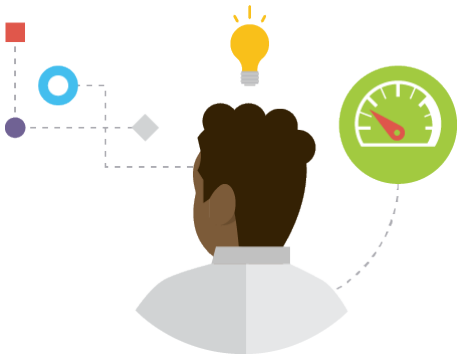
As your practice starts to feel comfortable with the existing registry, let your patient population and practice priorities guide expansion to include another chronic condition. The registry function is basically the same regardless of the sub-population, so adding another common chronic condition (or two) should be easier. If clinical performance measures change or more measures are added by regulators or payers, you will need to actively manage the modifications in the parameters you track or the acceptable ranges that you set in the system.

### Doesn't the patient care registry just add more work for everyone? What is the advantage?

Initially, yes, but your practice may soon see a return on the investment. A well-functioning registry can reduce the amount of digging you have to do to identify what EBM care your patients need.

Some of the advantages of a properly implemented system that meets all 5 criteria may include:

- Less chaotic care for patients and an improved patient experience
- A more even distribution of work across the care team
- A better practice workflow
- Engagement of the entire team because everyone can update and view the registry
- Active participation in patient care by the entire team through the use of standing orders and established protocols
- Elimination of data-gathering activities by the physician during the patient visit
- Clear presentation of clinical parameters that are out of range so that the physician and team can focus on the areas that need the most attention
- Potential revenue capture for pay-for-performance or other **value-based payment models**



# Conclusion

A patient care registry can allow you to be proactive—rather than reactive—in your approach to providing care to patients with chronic conditions, including preventive care. This organized approach to tracking and reporting specific disease measures and management will help you and your practice team reveal opportunities for improvement and the delivery of better and more efficient care to your patients.

Further Reading

**Journal Articles and Other Publications**


- Bagley BA, Mitchell J. Registries made simple. *Fam Pract Manag*. 2011;18(3):11-14. PMID: 21842803. https://www.aafp.org/fpm/2011/0500/p11.html
- Metzger J. Using computerized registries in chronic disease care. California HealthCare Foundation. Updated February 19, 2004. Accessed February 15, 2021. http://www.chcf.org/wp-content/uploads/2017/12/PDF-ComputerizedRegistriesInChronicDisease.pdf
- Registries: powerful tools to track, manage chronic disease. Medical Economics. May 10, 2013. Accessed February 15, 2021. https://www.medicaleconomics.com/health-care-information-technology/registries-powerful-tools-track-manage-chronic-disease
- Ortiz DD. Using a simple patient registry to improve your chronic disease care. *Fam Pract Manag*. 2006;13(4):47-52. https://www.aafp.org/fpm/2006/0400/p47.html
- Centers for Medicare & Medicaid Services. The Physician Quality Reporting System Maintenance of Certification Program Incentive Requirements for 2013. Accessed February 15, 2021. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/PQRS/Downloads/2013-MOC_Qualification_Requirements.pdf
- Centers for Medicare & Medicaid Services. Registry reporting. Updated December 17, 2015. Accessed February 1, 2016. https://wayback.archive-it.org/2744/20160824144659/https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/PQRS/Registry-Reporting.html
- Yang M, Loeb DF, Sprowell AJ, Trinkley KE. Design and Implementation of a depression registry for primary care. *Am J Med Qual*. 2019;34(1):59-66. doi:10.1177/1062860618787056
- Constructing an asthma registry [download]. Improving Chronic Care. Accessed February 15, 2021. http://www.improvingchroniccare.org/downloads/astregis.doc


**Websites**

- Computerized disease registries. Agency for Healthcare Research and Quality. Digital Healthcare Research Archive. February 2015. Accessed February 16, 2021. https://digital.ahrq.gov/key-topics/computerized-disease-registries
- The Diabetes Collaborative Registry®. American College of Cardiology National Cardiovascular Data Registry. Accessed February 15, 2021. https://cvquality.acc.org/NCDR-Home/registries/outpatient-registries/the-diabetes-collaborative-registry
- What is a disease/immunization registry? HealthIT.gov. Reviewed January 15, 2013. Accessed February 15, 2021. https://www.healthit.gov/faq/what-diseaseimmunization-registry


# Article Information

**Disclosure Statement:** Unless noted, all individuals in control of content reported no relevant financial relationships.

**Renewal Date:** 04/24/2021