

Developing Multicenter Registries to Advance Quality Science



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KEYWORDS

- Clinical registry • Patient registry • Quality science • Clinical database
- Quality improvement • Multicenter

KEY POINTS

- Multicenter registries, both national and international, use observational study methods to collect data that can be used to inform members on the ideal structure, process, or outcome of a measured entity.
- The data from multicenter registries can be used as an observational tool by itself or it can serve as a platform for framing research studies, clinical trials, or quality improvement projects.
- Clinical registries can be used to achieve the 6 improvement goals in health care (care that is safe, effective, patient centered, timely, efficient, and equitable) described by the Institute of Medicine.
- Registries have the unique advantage of garnering much data quickly and are especially helpful for niche populations or low-prevalence diseases.

WHY REGISTRIES?

The gold standard for generating new medical knowledge has historically been the randomized controlled trial, but not all research questions are amenable to such methodology. Although clinical trials provide important sources of new knowledge, they may fail to yield comprehensive data sets that accurately reflect entire populations because patients may or may not meet the inclusion criteria for participation. Furthermore, results from these studies can take years before being translated into clinical use.^{1,2} There are other valid approaches to gathering new knowledge, however. For example, quality improvement (QI) science has recently advanced the use of

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Plan-Do-Study-Act cycles in which the provider can quickly gather a significant amount of information on a topic by considering an intervention, testing the intervention for a short time, and analyzing the result, which then forms the basis for subsequent interventions. Clinical registries have also been used as valuable tools to answer questions that might not lend themselves to formal research studies because of cost, time, and/or ethical reasons. There are several benefits to the clinical registry as an information repository tool, ultimately lending itself to acquisition of new knowledge. Multicenter registries may be required to garner sufficient patient data for rare conditions or diseases. This article reviews the design, implementation, interpretation, and outcomes associated with patient registries and ends with some well-established examples.

Definition and Design

A *patient registry* is 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, condition, or exposure and that serves one or more predetermined scientific, clinical, or policy purposes. The *patient registry database* describes a file (or files) derived from the registry.³

Many factors must be considered before a clinical registry can be formed. Key steps that should be included in the formation of a registry are as follows:

Why form a registry

- Define the purpose.
- Determine whether a registry is an appropriate means for addressing the purpose.

Who should be involved

- Identify the stakeholders.
- Assess the feasibility of forming the registry and secure funding.

What is needed

- Define the scope and target population.
- Plan for what data will be collected and how it will be collected.

How will it be maintained

- Plan for registry governance and oversight.^{3,4}

There is an increasing global trend to use registry data to inform decision-making in health care.⁴ Possible uses include, but are not limited to, the following^{2,5–8}:

- Patient recruitment: Recruit patients for clinical trials.
- Knowledge dissemination: Distribute information on new therapies, best practices, and safety issues.
- Clinical epidemiology: Learn about population behavior patterns and their association with disease development.
- Clinical effectiveness: Develop therapeutics and assess the effects.
- Drive research: Develop research hypotheses.
- Quality and outcomes improvement: Improve and monitor the quality of health care.
- Define clinical excellence: Study best practices in care or treatment.
- Public health planning: Register the causes of disease to illustrate the need for a prevention program.

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