

What is a Clinical Data Registry?

A clinical data registry records information about the health status of patients and the health care they receive over varying periods of time. Clinical data registries typically focus on patients who share a common reason for needing health care. They allow health care professionals and others to see what treatments are available, and how patients with different characteristics respond to various treatments. This information can be used to inform patients and their health care professionals as they decide the best course of treatment and to improve care for patients in the future. Information from registries may also be used to compare the performance of healthcare providers with regard to their outcomes and resource use.

How does a clinical data registry work?

There are many types of clinical data registries including those that focus on a disease or condition (e.g., cystic fibrosis), a procedure (e.g., coronary artery bypass grafting surgery) or to track the performance of a device (e.g. artificial joint). A clinical data registry begins by defining a patient population, and then recruits health care professionals who will submit data on a representative sample of these patients. For each patient population, a variety of treatments may be available. By studying many aspects of the populations patterns associated with particular outcomes can be identified. Since all of the factors that might have an impact on outcomes are not necessarily known at the time of data collection, data can be stored for use at a later time to evaluate previously unrecognized associations.

How does a registry actually collect data?

Patients often receive care from different organizations over time. Each time a patient participating in a registry sees their health care professional or is admitted to a hospital, detailed data are recorded about their health status and the care received. Health care professionals then send encrypted data about the patients to the clinical data registry through a highly secure web portal or from their electronic health record. As data enters the clinical data registry, quality checks are performed to ensure the correctness and completeness of the data. If something is missing or outside of the expected range, registry staff contact the submitting health care professional asking them to review and verify the data.

What is the value of clinical data registries?

Clinical data registries provide information to health care professionals to improve the quality and safety of the care they provide to their patients. For example, the use of evidence-based practice guidelines can be evaluated by asking questions like, “How many patients are receiving recommended treatment(s)?” In addition, information from clinical data registries is used to compare the effectiveness of different treatments for the same disease or condition, to evaluate different approaches to a procedure and to monitor the safety of implanted devices. The information from clinical data registries is also used to support health care education, accreditation and certification. Finally, information from clinical data registries is increasingly used to ensure that payment is adjusted based on the quality of care provided and to give patients the information they need to make better choices.