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Invited Article

ABC OF CLINICAL REGISTRY

Kanagavel Manickavasagam[1*]

1 Director, Gastropro, Department of General, GI and Minimal Access Surgery, St Isabels Hospital, Chennai 600004

***Correspondence:**
Dr. Kanagavel Manickavasagam,

Clinical Data Registry:

A clinical registry is a computer database that collects information about various health parameters. A clinical registry has been defined as "an organised system that uses observational study methods to collect uniform data to evaluate specific outcomes for a population defined by a specific disease, condition or exposure that serves one or more predefined scientific, clinical or policy purpose"(1). Registries are of various forms and can encompass research, multiple health, treatment and outcome parameters. They may also involve drug and human implant information.

Clinical quality registries complement other approaches including sentinel event reporting, limited adverse occurrence screening, incident reporting, morbidity and mortality review, accreditation, credentialing and patient satisfaction surveys. The other principal registries are disease based and product based.

The essential features of a clinical quality registry include:

1. Collection of an identical set of 'epidemiologically sound' data from 100% of patients
2. Data elements includes both 'process' and 'outcome' measures.
3. Outcome measures to be collected from all subjects at a defined time.
4. Risk adjustment to be undertaken to allow for important differences in patient mix.
5. Ethics approval to be sought from each participating institution to allow for 'opt-out' consent.
6. Data management, sharing and utilization of outcomes need to be predefined.

How does a registry work?

The information is collected by the treating healthcare team and are entered into a secure database that protects privacy. Registries take data privacy and security protocols very seriously and follow health privacy rules and regulations to protect health information. Registry governance is always done by an autonomous body who are not involved in the study group or data contribution team. The outcome analysis is predefined however can be defined at a later time frame based on the interim and ongoing analytical outcomes.

Why are registries so important?

When data about similar diseases, conditions, or treatments are entered into a registry, the information is available for the researchers now and in the future. In short, registries help patients receive the best possible care. They are open ended long-term data repository, quite exhaustive within the selection criterion with diverse data. The purpose of clinical quality registries is fundamentally to improve quality and safety of care.

References:

1. G liklich R, Dreyer NA, Center OD. Registries for Evaluating Patient Outcomes: A User's Guide. Rockville, Maryland: Agency for Healthcare Research and Quality, 2010.