ABSTRACT: Registry: Its Use In Real-World Data Collection

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Objective:

To understand how registries are being utilized in current post-marketing research.

Methods:

A targeted search was conducted in MEDLINE to identify all original research published in 2013 reporting results from registries. The search was restricted to English language publications. Abstracts of relevant citations were reviewed to obtain the country of study, therapeutic area and registry design. A supplementary search of registries listed on clinicaltrials.gov was conducted to estimate the number of registries currently ongoing.

Results:

The search returned 136 citations, containing 128 citations reporting results from 116 unique registries. Amongst the 116 registries, n=43 (37.1%) were conducted in Europe, n=40 (34.5%) in the United States, n=25 (19.8%) in Asia–Pacific and n=5 (4.3%) multi-nationally. Most registries were studies in cardiology (n=76 [65.5%]), and n=9 (7.8%) unique registries were devoted to the study of pediatric patient populations. 21.6% of the registries were designed to investigate the safety of a medical device or pharmaceutical agent, and another n=34 (29.3%) aimed to evaluate clinical outcomes of surgical interventions.
According to clinicaltrials.gov, there are 747 registry studies that are currently in active recruiting, or planning status. At the time of this review, 410 registries are active in North America and 247 in Europe.

**Conclusions:**

The purpose of the present review was not to perform an exhaustive summary of all registries but to gain a snapshot of what has been published in a given, recent year. Results of this review confirm that different registry designs are being used in real-world data collection to meet specific research objectives, be it safety monitoring, understanding disease natural history or long-term clinical outcome evaluation. Further analysis into the study characteristics will be presented to guide stakeholders in choosing appropriate registry designs.