Clinical registry

A clinical registry is a systematic collection of data about patients who share a particular condition, treatment, or procedure. It is used to track outcomes, improve care, and support research.

 Key Features of a Clinical Registry: Patient-Centered: Collects detailed information on patients with a specific disease, treatment, or device (e.g., epilepsy patients treated with DBS).

Standardized Data Collection: Uses uniform protocols to collect data at defined time points (e.g., pre-treatment, 6 months, 12 months).

Longitudinal Design: Follows patients over time to monitor outcomes, complications, or quality of life changes.

Real-World Setting: Unlike clinical trials, registries reflect real-world clinical practice, including a broader range of patients.

Quality Improvement Tool: Often used by clinicians and institutions to assess and improve the quality and safety of care.

Supports Research: Helps generate hypotheses, identify trends, and evaluate effectiveness and safety in large, diverse populations.

The importance of clinical registries in neurosurgery: is it time for a European registry? 1)

A patient registry collects information about patients who are affected by a particular condition.

As opposed to clinical trials, which provide evidence from controlled experiments, a patient registry provides medical evidence derived from routine clinical practice 2) 3)

When planning a clinical trial, it is very important that eligible patients can be found and contacted quickly. The best way for this to happen is through a database or “registry” that contains all the information that researchers will need.

In 2013, Sarnthein et al., have installed a patient registry focused on cranial neurosurgery. Surgeries are characterized by indication, treatment, location and other specific neurosurgical parameters. Preoperative state and postoperative outcome are recorded prospectively using neurological and sociological scales. Complications are graded by their severity in a therapy-oriented complication score system (Clavien-Dindo-Grading system, CDG). Results are presented at the monthly clinical staff meeting.

Data acquisition compatible with the clinic workflow permitted to include all eligible patients into the registry. Until December 2015, we have registered 2880 patients that were treated in 3959 surgeries and 8528 consultations. Since the registry is fully operational (August 2014), we have registered 325 complications on 1341 patient discharge forms (24%). In 64% of these complications, no or only pharmacological treatment was required. At discharge, there was a clear correlation of the severity of the complication and the Karnofsky Performance Status (KPS, ρ = -0.3, slope -6 KPS percentage points per increment of CDG) and the length of stay (ρ = 0.4, slope 1.5 days per increment of CDG).

While the therapy-oriented complication scores correlate reasonably well with outcome and length of stay, they do not account for new deficits that cannot be treated. Outcome grading and complication severity grading thus serve a complimentary purpose. Overall, the registry serves to streamline and to complete information flow in the clinic, to identify complication rates and trends early for the internal quality monitoring and communication with patients. Conversely, the registry influences clinical practice in that it demands rigorous documentation and standard operating procedures [4].

[1] Zaed I, Servadei F. Letter to the Editor. The importance of clinical registries in neurosurgery: is it time for a European registry? J Neurosurg. 2022 Feb 18:1-2. doi: 10.3171/2022.1.JNS22133. Epub ahead of print. PMID: 35180703.

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[3] Gliklich R, Dreyer N, Leavy M. Registries for Evaluating Patient Outcomes: A User's Guide. 3rd ed. Rockville, MD: Agency for Healthcare Research and Quality; 2014.

[4] Sarnthein J, Stieglitz L, Clavien PA, Regli L. A Patient Registry to Improve Patient Safety: Recording General Neurosurgery Complications. PLoS One. 2016 Sep 26;11(9):e0163154. doi: 10.1371/journal.pone.0163154. eCollection 2016. PubMed PMID: 27669157.