Forum medizinische Register Schweiz

Auszug aus der Register Online-Plattform der FMH-Website (www.fmh.ch > Themen > Qualität / SAQM > Register).

SHR – SWISS HEMOPHILIA REGISTERY

Kurzbeschreibung

The Swiss Hemophilia Registry (SHR) is a registery for medical research and quality assurance in the care of people with hemophilia A (deficiency of coagulation factor VIII), hemophilia B (deficiency of coagulation factor IX) and other severe coagulation factor deficiencies. The SHR aims to ensure high quality data: • on the prevalence of hemophilia A and B, as well as other severe congenital bleeding disorders (geographic distribution, the characteristics and the evolution of the population affected) • on the use prophylactic and therapeutic factor products • on the incidence of the development of inhibitors (antibodies against coagulation factor VIII or IX) in Switzerland that are to be made available for health monitoring allowing rapid investigation in case of suspicion of new contagious agents transmitted by or other rare side effects of coagulation factor products and other hemophilia treatments. The SHR represents a systematic collection of data, i.e. standardized medical documentation that makes data more comparable and thus easier to evaluate in order to answer practice-relevant questions. Hemophilia is a rare disease and the strength of a registry lies in the possibility of long-term observation of the disease and its treatment to draw meaningful conclusions.

Weitere Informationen

Fachrichtung	Hämatologie
Registertyp	Klinisch
Datenarten	Soziodemographie, Krankheit/ Diagnose, Intervention/Therapie, Risiken/ Gesundheitsrelevante Bedingungen
Status	Aktiv, seit 2016
Population	Patients with hemophilia or other inherited bleeding disorders.
Periodizität	Periodisch, Annualy

Geografische Abdeckung	National, All hemophilia centers in Switzerland participate. The few patients treated by general practitioners, who are not attached to a hemophilia center are not enrolled in the registry.
Trägerschaft	Andere: Swiss Hemophilia Network
Finanzierung	Swiss Hemophilia Network
Schnittstellen	
Datenerfassung	In digitaler Form (Computer-unterstützte Dateneingabe), RedCap
Teilnahmepflicht	Nein
Teilnahmemöglichkeit	Ja, unter bestimmten Voraussetzungen : (1) Membership of the SHN (2) approval by the responsible ethics committee
Einwilligung Patienten	Ja
Personenbezug	Pseudonymisiert (indirekter Personenbezug via Code)
Datenschutz	indirect personal reference via code
Datenzugang	Ja, Under specific circumstances via a specific access request form and approval by the SHN Board.
Qualitätssicherung	Annual monitoring of centers
Berichterstattung	Ja, wissenschaftliche Publikationen

Betreiberinstitution

Swiss Hemophilia Network (SHN)
Bahnhofstrasse 55
5001 Aarau

Kontaktperson	Marie Stutz
E-Mail:	contact@swiss-hemophilia-network.ch
Tel.	+41 62 836 20 90
Website	www.swiss-hemophilia-network.ch