Forum medizinische Register Schweiz

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SwissPedHealth – Pediatric Personalized Research Network Switzerland – a Joint Pediatric National Data Stream

Kurzbeschreibung

Background and Rationale: Annually in Switzerland, over 85,000 children are born and over 100,000 children require admission as inpatients to hospitals. Many more are seen as outpatients. Due to the unique epidemiology, developmental changes, and high vulnerability of children, there is an urgent need to continuously improve health care based on pediatric data. The digital transformation and the availability of electronically stored clinical routine data allows the opportunity to shape a data-driven, agile health care system by collecting data in the national pediatric data stream (NDS) SwissPedHealth. Methods: SwissPedHealth is a registry collecting routine clinical data from pediatric hospitals in Switzerland through the Swiss Personalized Health Network (SPHN) infrastructure. By applying re-usable and expandable informatics, logistical, governance, and regulatory resources in close collaboration with the clinical data warehouses (CDWs), Biomedical Information Technology (BioMedIT), SwissPedHealth provides interoperable, standardized, quality-controlled data which can be requested by researchers. The multi-site, multidisciplinary Steering Committee of SwissPedHealth, representing all partner sites and disciplines (both SPHN and Personalized Health Related Technologies; PHRT) lead the whole consortium. The governance structure and the Ethical, Legal and Social Implication (ELSI) documents in SwissPedHealth are build upon existing agreements and infrastructures developed in national pediatric collaborative studies through the Swiss Research Network of Clinical Pediatric Hubs (SwissPedNet) and SPHN templates to provide an overarching regulatory and legal framework for health-related pediatric data use in Switzerland. Aim: SwissPedHealth integrates clinical routine data, federal administrative data, and research data across Swiss hospitals in an interoperable, standardized, quality-controlled way ready for research and quality control.

Weitere Informationen

Fachrichtung	Kinder- und Jugendmedizin
Registertyp	Klinisch

Datenarten	Soziodemographie, Krankheit/ Diagnose, Intervention/Therapie, Risiken/ Gesundheitsrelevante Bedingungen, Andere: Surveillance
Status	Aktiv, seit 2017
Population	Neonates, infants, children and adolescents with clinical routine data in Swiss hospitals participating in the SwissPedHealth national data stream
Periodizität	Periodisch, Every 6 to 12 months
Geografische Abdeckung	National, Up to now, clinical routine data of children cared in Children`s Hospitals participating in SwissPedHealth (Berne, Basel, Geneva, Lausanne, Zurich) are collected. The Children Hospitals Lucerne and St. Gallen are onboarded.
Trägerschaft	Spitäler, Universitäten, Andere: Consortium SwissPedHealth, SPHN
Finanzierung	Öffentlich
Schnittstellen	In development (e.g. Swiss Childhood Cancer Registry) Weitere Schnittstellen In development (e.g. Federal Office of Public Health)
Datenerfassung	In digitaler Form (Computer-unterstützte Dateneingabe), Clinical electronic information system (Information will be transferred according to SPHN rules based on the FAIR principles and the SPHN RDF schema to the SwissPedHealth BioMedIT B space)
Teilnahmepflicht	Nein
Teilnahmemöglichkeit	Ja, unter bestimmten Voraussetzungen : For further details please contact pfz@ukbb.ch.
Einwilligung Patienten	Ja
Personenbezug	Pseudonymisiert (indirekter Personenbezug via Code)
Datenschutz	According to SPHN obligations
Datenzugang	Ja, Please contact pfz@ukbb.ch for further details and requirements (e.g. relevant regulatory, ethical and governance documents).
Qualitätssicherung	According to SPHN obligations
Berichterstattung	Ja, wissenschaftliche Publikationen

Betreiberinstitution

Pediatric Research Centre Basel, University Children`s Hospital Basel
Spitalstrasse 33
4031 Basel

Kontaktperson	Julia Bielicki
E-Mail:	pfz@ukbb.ch
Tel.	0041797275279
Website	https://www.ukbb.ch/pfz

https://www.swisspedhealth.ch/