Nested project 2

## Cancer in children: improving data flows to and from the Swiss Childhood Cancer Registry (ChCR; Responsible: Kuehni).

### Study Overview

The study aims to improve data flows to and from the Swiss Childhood Cancer Registry (ChCR) to enhance cancer registration for children. The ChCR has been assessing cancer incidence, treatment, and survival in children since 1976. Although registration is complete for most children, there is poor registration for those diagnosed at age 16-19 years. Data entry and quality control are manual, leading to delays in registration and duplication of work.

### Study Objectives

1. Link SwissPedData with the ChCR to assess completeness of registration and characterize unregistered patients.
2. Evaluate data quality for key diagnostic information.
3. Assess the feasibility of extracting treatment data from EHRs.
4. Use results to improve both SwissPedData and the ChCR and rationalize data flows.

### Methods

Extract datasets for in- and outpatients diagnosed below age 20 years from 2017 to 2023. Assess which patients are present in one or both datasets and characterize the groups. Compare diagnostic information between CDWs and the ChCR. Pilot automatic extraction of treatment data from EHRs and controlled import into the ChCR.

### Significance

Quality control of SwissPedData with a high-quality external reference standard. Improvement of data collection pathways. Eventually, more efficient cancer registration.

## Original

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Background: The ChCR (www.kinderkrebsregister.ch) assesses cancer incidence, treatment and survival since 1976. Registration is complete (>95%) for children, but poorer for those diagnosed at age 16-19 years. Although the ChCR receives the data from EHRs, data entry and quality control are manual, leading to delays in registration and duplication of work. This problem is common for clinical registries.

Aims: We will link SwissPedData with the ChCR, to: 1) assess completeness of registration and characterize unregistered patients; 2) evaluate data quality for key diagnostic information; 3) assess the feasibility of extracting treatment data (chemotherapy, radiotherapy, surgery) from EHRs; 4) use results to improve both SwissPedData and the ChCR and rationalize data flows.

Methods: Extract datasets for in- and outpatients diagnosed below age 20 years from 2017 to 2023. Assess, which patients are present in one or both datasets, and characterize the groups. Compare diagnostic information (ICD-10, ICD-O3) between CDWs and the ChCR. Pilot automatic extraction of treatment data from EHRs and controlled import into the ChCR, instead of manual entry. We expect +/-2450 incident cancers in collaborating hospitals for this period. All concepts (tumor diagnoses, staging, grading, and drug ATC codes) are already defined by the SPHN.

Significance: Quality control of SwissPedData with a high-quality external reference standard; improvement of data collection pathways; eventually more efficient cancer registration.