Can Data Be Automatically Transferred from Pediatric Hospitals to the Swiss Childhood Cancer Registry?

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Background

Childhood cancer registration in Switzerland relies on manual data collection at hospitals and the Childhood Cancer Registry (ChCR)

Aims

Develop automated dataflows between hospitals and ChCR to lower manual workload and improve data quality by:

- Assessing the data quality in the clinical information system (CIS) of nine Swiss pediatric hospitals (Figure 1)
- Manually reviewing records of patients not registered in the ChCR (Figure 2)

Methods

- IT collaborators identified eligible patients in their CIS with **ICD-10 codes** that should be reported to the ChCR
- **Study period**: 2017–2023
- **Eligible population**:
  - Diagnosed with childhood cancer (ICD-10 code reportable to ChCR)
  - <20 years at time of diagnosis
  - In- and outpatients
  - Resident in Switzerland at time of diagnosis
- **Data linkage**: via the personal social security number or using name, sex, and date of birth information
- **Manual records review** to determine true missed cases from the ChCR *vs.* ineligible cases to be registered (Figure 2)

Results

- None of the hospitals had entered **structurally** "date of diagnosis" or "residency abroad at diagnosis" in their CIS
- **8–53%** of the "identified eligible" patients based on ICD-10 codes within hospitals are not registered in the ChCR (Figure 1)
- **95%** of "identified eligible" patients **were ineligible** (Figure 2) after manual review

Conclusions/Implications

- Automated data transfer has substantial potential, but critical challenges exist:
  - **Updating ICD-10 codes** in CIS is essential after ruling out a neoplastic or reportable diagnosis
  - recording of the **date of diagnosis**
  - recording of **residency status** at diagnosis

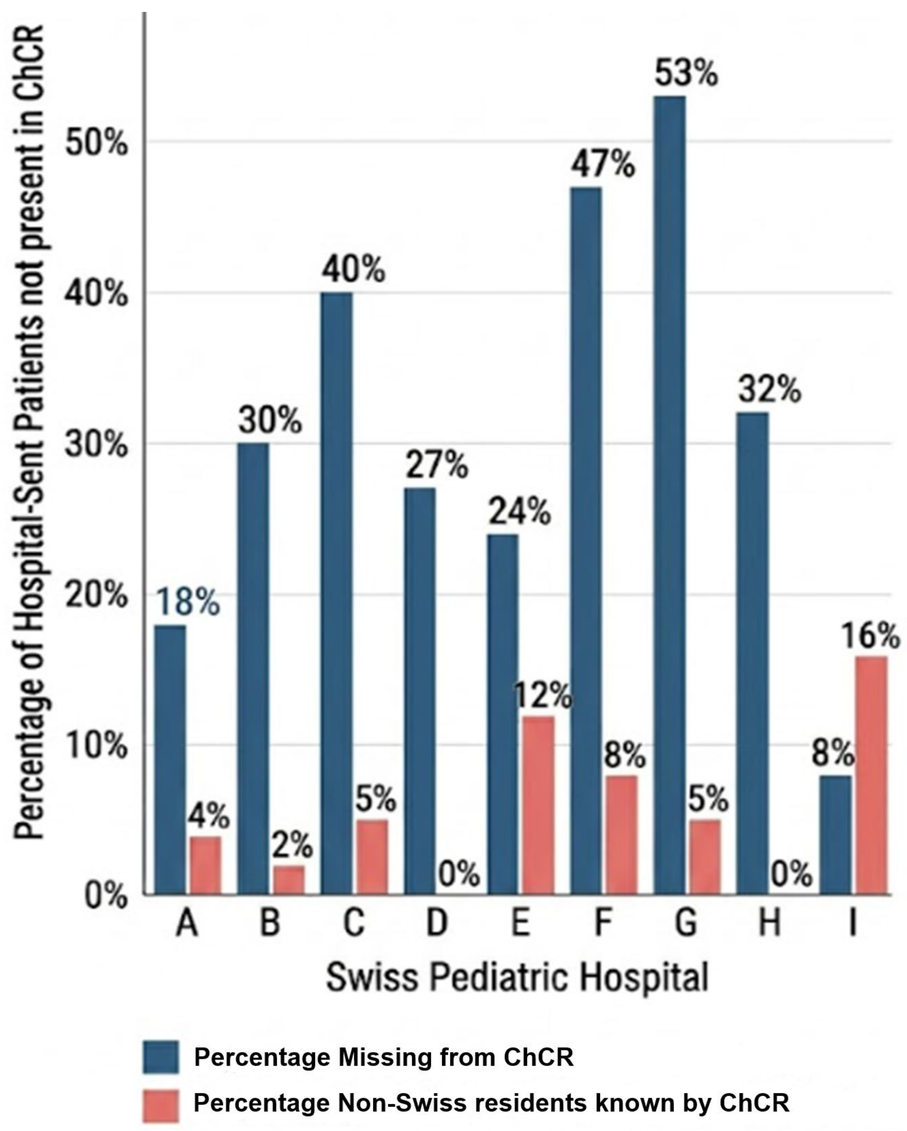

Figure 1. Discrepancies between percentage of patients sent by pediatric hospital CIS and the percentage not registered in the Childhood Cancer Registry (ChCR) data

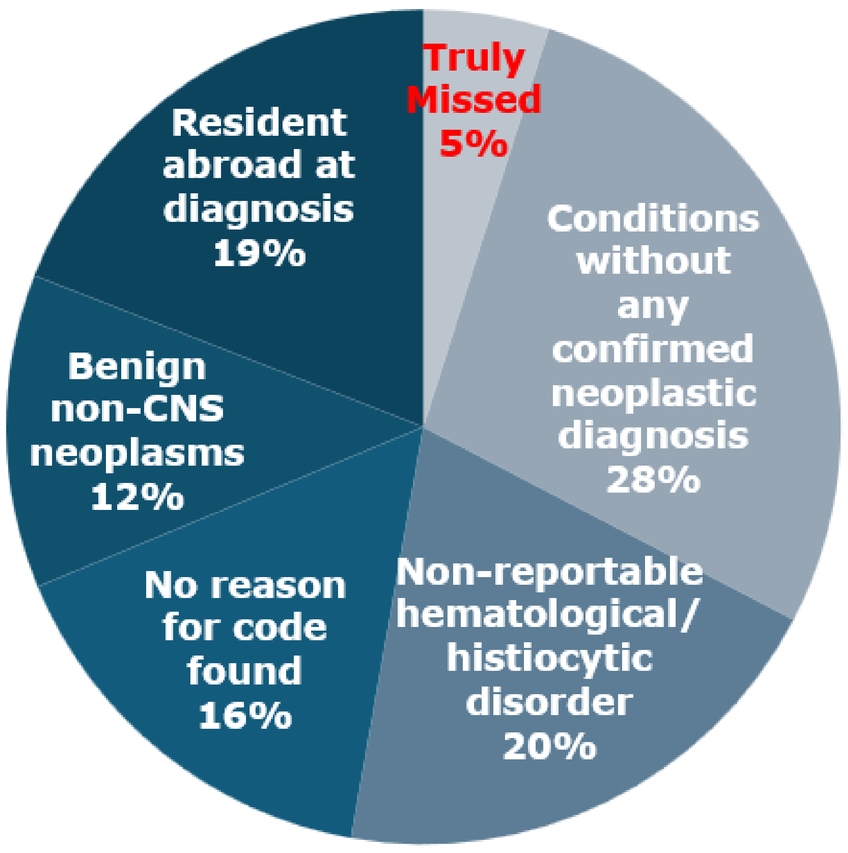

Figure 2. Manual review of all identified patient records for hospitals A, D & H

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