The Swiss Childhood Cancer Registry
methods and research

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Topics

- History of SCCR
- Patients: inclusion criteria, coverage
- Data sources
- Ethics/consent
- Collaboration with clinicians
- Research
Swiss Childhood Cancer Registry

Short history

- **1976**: founded by clinicians, for study patients
- **1982**: non-study patients added
- **1992**: long-term follow-up begins
- **2004**: registry renewal & collaboration with ISPM Bern
  - registry permission, new database, standardised procedures, recoded diagnoses (ICCC-3)
- **2007**: use of routine data
  - **Patient identification** via multiple sources (prospectively & retrospectively back to 1976)
  - **Follow-up** via population registers and mortality stats
  - **Exposures** from census & Swiss national cohort
- **2007**: Swiss Childhood Cancer Survivor Study
Aims of the Swiss Childhood Cancer Registry

1. Monitoring of cancer in children and adolescents
   — Incidence, time trend, regional differences
   — Outcomes
   — Health care provision, quality control

2. Research on
   — Causes of childhood cancer
   — Therapy (clinical studies)
   — Outcomes
Inclusion criteria

- **all children** (until 15) and **adolescents** (until 20)
- **With ICCC-3- coded diagnoses** (leukaemias, malign solid tumours, CNS tumours) or histiocytosis
- **Resident or treated in Switzerland**
- **Complete (>95%) for children** (until 15), incomplete for adolescents (aged 16-20)
What are the data sources?

- **All 9 Swiss Paediatric Cancer Centres** (Aarau; Basel; Bern; Lausanne; Lucerne; St.Gallen; Ticino; Zurich): *main source, clinical data*

- **Other sources** (hospitals, regional cancer registries, pathology labs): *epidemiological data, completeness*

- **Swiss Routine data** (population registers, mortality & birth statistics, hospital statistics, census, Swiss National cohort): *exposures, outcomes, comparison data*

- **Patient-reported data** (Questionnaires to patients and parents): *lifestyle, morbidity, QOL, …*
Data source

- Questionnaires – Swiss Childhood Cancer Survivor Study
- Birth statistics Perinatal Data
- Swiss National Cohort (SNC) Socio-demographic information, environmental exposures

Purpose

Research
- Aetiological research
- Clinical research
- Outcome research

Results

- Publications, presentations
- Publications, presentations
- Publications, presentations

Monitoring

- Annual reports
- Feed-back for clinicians & hospitals
- Analyses for government bodies
- Exchange with patient groups

Paediatric Cancer Centres
Patient data, Diagnoses, treatments, recurrence, comorbidities, late effects

Population registers
Vital status, current address

Mortality statistics
Causes of death

Hospital episode statistics
Diagnoses

Pathology laboratories
Diagnoses, 2ndary cancers

Regional cancer registries
Diagnoses, 2ndary cancers

Schweizer Kinderkrebsregister
Registre Suisse du Cancer de l’Enfant
Registro Svizzero dei Tumori Pediatrici
Swiss Childhood Cancer Registry
What data are collected?

- **Epidemiological data** (patient, tumor, diagnosis)
- **Clinical data from charts** (comorbidities, treatment (chemo, radio, surgery, studies), clinical course (remission, relapses, change of treatment))
- **Environmental exposures**
- **Follow-up**: Survival, causes of death, 2ndary cancer morbidity, HRQOL, psychosocial
Registry permission from the Swiss Federal Office of Health

- 2004: Sonderbewilligung (informed consent)
- 2007: cancer registry permission (as regional cancer registries). Step out (no written informed consent needed, patients are informed and can opt out (veto)

New law on human research (2014)

- Registry permission confirmed by cantonal ethics committee
- Epidemiological and clinical data collection, linkages and PRO questionnaire
- Informed consent where feasible; opt-out for others
Results – Monitoring
Incidence and survival

300 new cases per year
- 200 kids, 100 ados
- N >9500
- >95% coverage since ~ 1990

Survival, since 1976
Research - Cancer aetiology

Environmental risk factors

Is risk of cancer increased in children growing up:

• Near nuclear power plants?
• Exposed to natural ionising radiation
• Close to highroads?
• In areas with increased population mixing?
Research: Linking the SCCR to the Swiss National Cohort (SNC)

- The SNC includes all Swiss inhabitants (8 mio)
- Obtained by linking census records with birth, mortality and migration statistics
- Linkage the SCCR with the SNC gets additional data:
  - Socio-demographic
  - Parental occupations
  - Environmental exposures
- And a representative comparison group

www.swissnationalcohort.ch
How do we link to routine data?

CH has no national ID & routine statistics are anonymous

We link

- With full names and addresses to:
  - Population registers: address history, vital status, dod, parents
  - Hospital episode statistics (planned)

- With first names, birth address, parent info, dod, place of
  - Birth statistics
  - Mortality statistics

- With all available info
  - Census data, Swiss National cohort
Leukaemia risk in children growing up near a nuclear power plant

- Home address (birth & Dx)
- for cases + population
- Comparing distance to hazards
- Adjust for confounders assessed in census
- No association with NPPs (Spycher, IJE 2011)

Other /ongoing studies:
- No association: radon (Hauri, 2011), broadcast transmitters (Hauri, 2013)
- Increased risk: background gamma radiation (Spycher, in press), highways (submitted), parental exposures to benzene (ongoing), population mixing (ongoing)
Collaborations and feed-back

- **Clinicians (Swiss Paediatric Oncology Group)**
  - Lead the SCCR together with Uni Bern
  - Regular meetings
  - Receive regular and on-demand feed-back on
    - patient numbers, clinical study participation
    - Long-term outcomes
    - patient recruitment for nested studies
  - Are co-authors in publications

- **Governmental bodies obtain:**
  - Fast answers to questions on cancer risk, healthcare planning, quality control etc

- **Patients:**
  - Receive individual data where needed
  - Have access to general results
  - Contribute to funding and political support
The SCCR

- Is a population-based national cancer registry,
- with detailed clinical data,
- linkage to routine data (obtains exposures and allows national cohort studies)
- Continuous long-term follow-up, via
  - Linked routine data for survival and 2nd
  - Questionnaires to patients for morbidity and QOL
- Fast feed-back to patients, doctors & governement
- Contributes to reduce cancer incidence & improve outcomes
Questions?

www.kinderkrebsregister.ch
Funding

- University of Bern
- Swiss Paediatric Oncology Group
- Patient organisations
- Cancer research Switzerland (since 2011)
- Cantons (GDK, since 2010)
- Industry (small contributions)

- If cancer registration law accepted, more governmental funding
Genügen kantonale Krebsregister?

Kantonale Krebsregister

- Bisher nicht in allen Kantonen
- Viele neu – keine Daten aus der Vergangenheit
- registrieren wenig Kinder (0.5% aller Einträge). Keine Expertise & Zeit
- erheben nur minimale Daten (Erkrankungsdatum & Tumor, keine Behandlung oder Langzeitverlauf)
- keine Kontinuität nach Umzug in anderen Kanton
- Bisher keine Publikationen zu Kinderkrebs aus kt. Registern
Incidence, per 100'000
Collected data

- **Epidemiological data** (patient, tumor, diagnosis)
- **Clinical data from charts** (comorbidities, treatment (chemo, radio, surgery, trials), clinical course (remission, relapses, change of treatment))
- **Environmental exposures**
- **Follow-up:** Survival, causes of death, 2ndary cancer morbidity, HRQOL, psychosocial