Swiss Childhood Cancer Registry
- clinical
- population-based
- research-oriented

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Cancer in children

- 2nd cause of death in childhood
- 300 new cases every year
- Tumours, risk factors and treatments differ
Incidence

Alterspezifische Rate, pro 100'000 Kinder

Types of cancers, by age

Key characteristics

1. Clinical

2. Population-based

3. Research-oriented
   • Monitoring
   • Aetiological research
   • Outcome research
1) a registry from and for clinicians
2) population-based representative data

- **All 9 paediatric oncology clinics**: clinical data
  Aarau, Basel, Bern, Geneva, Lausanne, Bellinzona, Lucerne, St Gallen, Zurich

- **Other clinics, cantonal cancer registries, pathology labs**: completeness

- **Swiss routine statistics (FOS)**: exposure, outcomes and source population
  Mortality, birth and hospital statistic, census data

- **Questionnaires**: patient-reported outcomes
3) research-oriented

Research

- Aetiology
- Clinical
- Outcomes

Monitoring

Annual reports & Publications, for
- Public & Authorities
- Physicians
- Patients

Publications, Presentations
- >150 publications
- >30 competitive grants
Monitoring incidence

- Overall stable incidence
- Possible increase in ALL
Do nuclear power plants increase cancer risks in children?
research environmental causes of cancer
research

environmental causes of cancer

- Cancer dx

exposed

not exposed

(N=162,830)

(N=175,929)

1990 Census

Births and immigrants 1991 – 2000

Emigrants

Deaths 1991-2000 (591,979)

Deaths 2001-08 (462,075)

N=6,973,687

N=7,298,010

Environmental causes

Nuclear power plants?

- no association

Environmental causes

highways

- more leukaemia in 0-4 year olds (IRR 1.6; 1.1-2.3)

Spycher et al. *Int J Epidemiol* 2011
**Environmental causes**

**natural background radiation**

<table>
<thead>
<tr>
<th>Outcome</th>
<th>All children HR per mSv (95% CI)</th>
<th>P</th>
<th>Stable place of residence HR per mSv (95% CI)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leukemia</td>
<td>1.036 (0.997, 1.077)</td>
<td>0.075</td>
<td>1.046 (0.999, 1.096)</td>
<td>0.054</td>
</tr>
<tr>
<td>ALL</td>
<td>1.037 (0.990, 1.086)</td>
<td>0.124</td>
<td>1.049 (0.994, 1.107)</td>
<td>0.084</td>
</tr>
</tbody>
</table>

Spycher et al. *Env Health Perspect* 2015
Environmental causes

and?

- Nuclear power plants (publ.)
- Ionising background radiation (publ.)
- Radon gas (publ.)
- Birth and family characteristics (publ.)
- Radio and TV transmitters (publ.)
- Population mixing (publ.)
- Exposure to infections (publ.)
- Mothers exposure to benzene (publ.)
- Highways (publ.)
- Powerlines (ongoing)
- Transformers (ongoing)
- Air pollution (ongoing)
- Clustering (publ., ongoing)
monitoring survival

- Most children in consecutive clinical studies
- 10-year survival now 84%
research

long-term outcomes

- Cancer treatments are harsh and have side effects
- Long-term mortality and chronic diseases increased

Schindler et al. *Int J Cancer* 2016
Long-term outcomes

Questionnaire survey to all 5-yr survivors

- Since 2007, N=2,876, RR 70%
- 3 languages, 3 age groups
- Detailed questions on: health, health care, lifestyle, risk factors, quality of life, social outcomes
- Comparison: siblings, representative population surveys
Long-term outcomes

European collaborations (FP7)

**SAGHE** (2011-2014)
- growth hormone treatments

**PanCareSurFup** (2011-2016)
- cardiovascular diseases, second neoplasms, late mortality, guidelines

**PanCareLIFE** (2013-2018)
- hearing, fertility, quality of life

**Concord 2 und 3** (ongoing)
- survival
Long-term outcomes

Hearing loss

- Platinum chemotherapy & cranial irradiation > irreversible hearing loss: education, social outcomes, QOL

Long-term outcomes

Treatment-related risks

Chemotherapy
Reference: No platinum
- Carboplatin
- Cisplatin
- Both

Radiotherapy
Reference: No cranial radiation
- 1-29 Gray
- 30-49 Gray
- >50 Gray

CSF-shunt
Reference: No CSF-shunt
- CSF-Shunt

BMT
Reference: No BMT
- BMT

Surgery
Reference: No brain surgery
- Brain surgery

Odds ratio with 95%CI adjusted for age at diagnosis and sex

Weiss, Ped Blood Cancer 2016
Long-term outcomes
Validation with medical records

SCCSS – Questionnaire survey

Survivors diagnosed 1990-2005 in a SPOG clinic exposed to ototoxic treatment (n=361)

Hearing outcome from questionnaire

Hearing outcome from medical records

Reports on hearing or original hearing test

Medical records from oncological and ear-nose-throat (ENT) departments
Long-term outcomes
Validation with medical records

S2 Figure. Sensitivity of questionnaire-reports by laterality and severity of hearing loss
*according to medical records

Weiss, Validation of questionnaire-reported hearing with medical records. PLoS ONE; 2017
Health-care

Are follow-up examinations done?

Swiss Childhood Cancer Registry
Ototoxic treatment 2005-13

Medical records, oncology & ENT
Audiograms

- only 40% get recommended tests
- Follow-up study introduces standardized prospective examinations into routine care

Newest KLS application (submitted yesterday):

- **Standardised prospective monitoring**: all patients, all clinics
- **Delphi process** of all paediatric oncologists & audiologists
- **Real life data** from all patients
- Individualized care
- High quality data for research
The Swiss Childhood Cancer Registry

- **Population-based registry**
  - Reliable data on incidence, survival, time trends

- **Clinicians and patients collaborate**
  - Good quality, complete and rich data
  - Implementation of results, change of practice

- **Research program allows to**
  - Identify causes of cancer, preventative measures
  - Investigate late effects of treatments
  - Assess patient-relevant outcomes

Improved health and quality of life
Thanks to
patients, survivors, families, health care staff and sponsors