What do we learn from the Swiss Childhood Cancer Survivor Study?
Late effects and outcomes

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Increased survival

Period of diagnosis

- 2005-2014
- 1995-2004
- 1985-1994
- 1976-1984

Years since diagnosis
Aims of the Swiss Childhood Cancer Survivors Study (SCCSS)

- Determine the incidence of late effects of cancer and treatments
- Study associations between adverse outcomes and prospectively collected risk factors
- Describe the current health-care use and medical follow-up in survivors
- Describe health-related behaviours and their determinants
METHODS
A COHORT STUDY
The SCCSS Cohort

The Swiss Childhood Cancer Registry (SCCR)
Inclusion Criteria
- Malignant solid tumours,
  Leukaemia and lymphomas,
  CNS tumours (including benign)
  Langerhans cell and other Histiocytoses
- Age at diagnosis 0-20 years
- Resident in Switzerland or Liechtenstein or are treated in Switzerland

SCCSS 1\textsuperscript{st} Follow-up

SCCSS 2\textsuperscript{nd} Follow-up
The SCCSS Cohort

The Swiss Childhood Cancer Registry (SCCR)

The Swiss Childhood Cancer Survivor Study (SCCSS), Baseline
Eligibility criteria
• Swiss resident at diagnosis
• >5 years past diagnosis
• Alive (for survey)

SCCSS 2\textsuperscript{nd} Follow-up
The SCCSS Cohort

The Swiss Childhood Cancer Registry (SCCR)

The Swiss Childhood Cancer Survivor Study (SCCSS), Baseline

SCCSS 1\textsuperscript{st} Follow-up
Eligibility criteria
- Participated in baseline survey
- Diagnosed after 1990
- Age at diagnosis ≤ 16 years
- Aged 18+ years at study

Focus on follow-up care
The SCCSS population-based cohort

The Swiss Childhood Cancer Registry (SCCR)

The Swiss Childhood Cancer Survivor Study (SCCSS), Baseline

SCCSS 1st Follow-up

SCCSS 2nd Follow-up
Eligibility criteria:
• Same as baseline (including new survivors)
SCCSS Procedure

- Address update through communities
- Sending out information letters from former treating clinic
SCCSS Procedure

- Address update through communities
- Sending out information letters from former treating clinic
- Sending out questionnaire
Questionnaires

- 2 groups:
  - Survivors
  - Siblings

- 4 Age groups:
  - Adults (≥20 years)
  - Adolescents (16-19 years)
  - Children (8-15 years)
  - Children (5-7 years)

- 3 languages:
  - German
  - French
  - Italien

24 different questionnaires
SCCSS Procedure

• Address update through communities
• Sending out information letters from former treating clinic
• Sending out questionnaire
• One postal reminder
• Telephone reminder
Participation

The Swiss Childhood Cancer Registry (SCCR)

The SCCSS, Baseline
Participants N= 2222 (response rate 76%)

SCCSS 1\textsuperscript{st} Follow-up
Participants N= 324 (response rate 45%)

SCCSS 2\textsuperscript{nd} Follow-up
Eligible N=1211, Participants until Sept 2016 N=208
Comparison samples

• Siblings
• Swiss Health Survey 2007 or 2012
• Other general population samples
  – SMASH (Swiss Multicenter Adolescent Survey)
• Standardized questionnaires
FINDINGS OF THE SWISS CHILDHOOD CANCER SURVIVOR STUDY
PSYCHOLOGICAL DISTRESS
Psychological distress in adult survivors

- Included: 987 survivors (20+ years at study)
- Brief Symptom Inventory (BSI)

Overall psychological distress

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological distress</td>
<td>24.6%</td>
<td>18.3%</td>
<td>28.1%</td>
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</tbody>
</table>
BSI GSI: Brief Symptom Inventory Global Severity Index

Michel, JCO 2010
Psychological distress in adolescent survivors

- Included: 407 survivors (16-20 years at study)
- Brief Symptom Inventory – 18 (BSI-18)
Mental health-care utilization in adolescent and adult survivors

- Included: 1602 survivors and 703 siblings (16+ years at study)
- Brief Symptom Inventory – 18 (BSI-18)

% of distressed participants attending psychological care

- Survivors: 34%
- Siblings: 24%
QUALITY OF LIFE
Health-related quality of life in survivors of childhood cancer

- Included: 1593 survivors and 695 siblings (16+ years at study)
- SF-36
Comparison of T-scores of the eight SF-36 subscales and the two summary scores in survivors and siblings

Rueegg, J Cancer Surviv 2013
Mean differences comparing survivors with and without chronic health problems
Health-related quality of life in young survivors

- Included: 425 survivors (5-16 years at study)
- KIDSCREEN-27 for parent and for children
The proportion of survivors with a HRQoL score ≤45

<table>
<thead>
<tr>
<th>Category</th>
<th>Self-reported</th>
<th>Parent-reported</th>
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<tbody>
<tr>
<td>Physical well-being</td>
<td>32%</td>
<td>45%</td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>29%</td>
<td>36%</td>
</tr>
<tr>
<td>Autonomy and parents</td>
<td>27%</td>
<td>29%</td>
</tr>
<tr>
<td>Peers and social support</td>
<td>25%</td>
<td>30%</td>
</tr>
<tr>
<td>School environment</td>
<td>24%</td>
<td>27%</td>
</tr>
</tbody>
</table>

Wengenroth, Qual Life Res 2015
LONG-TERM FOLLOW-UP CARE
Preferences for long-term follow-up care

- Included: 314 survivors (18+ years at study)
- SCCSS Follow-up 1
  - Survey on preferences for follow-up care
Preferences for different models of follow-up care among attenders and non-attenders to follow-up

Preferred place of follow-up

Where would you like to go for follow-up?

- Children's hospital
- Adult hospital
- General practitioner
- Specialised late effects clinic
What do we learn from the Swiss Childhood Cancer Survivor Study?


Learning a lot is not enough.....

We need to translate into practice
Collaborations

• Swiss Paediatric Oncology Group
• International collaborations
  – PanCare
  – PanCareSurFup
  – PanCareLIFE
• Guidelines development
  International Guideline Harmonization Group ([www.ighg.org](http://www.ighg.org))
  – Ototoxicity
  – Mental health
  – Models of care
  – Transition
Swiss Paediatric Oncology Group (SPOG)
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THANK YOU

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krebsliga schweiz

Stiftung zur Krebsbekämpfung
Fondation pour la lutte contre le cancer
Fondazione per la lotta contro il cancro

Swiss National Science Foundation

innova

Helsana

HIN

Foundation
National Institute
for Cancer Epidemiology
and Registration

winterthur

FINANZIELLE SICHERHEIT

Celgene

Switzerland