

# The role of Swiss cancer registries in health services research

**Volker Arndt, MD, MPH**  
National Institute for Cancer  
Epidemiology and Registration (NICER)  
Zurich

# Outline

- Cancer registration in CH
- Which data are collected in cantonal cancer registries (CCRs)?
- Examples how CCRs had been involved in health service research
- Perspectives with the new law

# Health services research

(health systems research / health policy and systems research)

examines

- how people get access to health care practitioners and health care services,
- how much care costs, and
- what happens to patients as a result of this care

- 
- Social factors
  - Health policy
  - Financing systems
  - Organizational structures /processes
  - Medical technology
  - Personal behaviours

- Access to health care
- Quality and cost of health care
- Quantity and quality of life

# Historically, cancer registries collected data on occurrence of cancer

## Essential variables

- Personal identification.
- Sex.
- Date of birth.
- Address (usual residence).
- Ethnic group (when the population consists of two or more groups).
- **Incidence date.**
- **Most valid basis of diagnosis**
- **Topography (site) of primary cancer.**
- **Tumour morphology (histology).**
- **Tumour behaviour (benign, uncertain, *in situ* or malignant).**
- Source of information.

## Recommended variables

- Date of last contact.
- Status at last contact.
- Stage or extent of disease at diagnosis.
- Initial treatment.

# Cancer Registries – 2 Worlds ?

## Population-based “epidemiological” cancer registries

- Collect data **in well defined populations**
- Collecting case reports **from different sources** (treatment facilities, clinicians and pathologists, and death certificates).
- Historically focus on monitoring of incidence, mortality and survival
- Lack of detailed clinical data (molecular subtyping, therapy)

## Hospital cancer registries

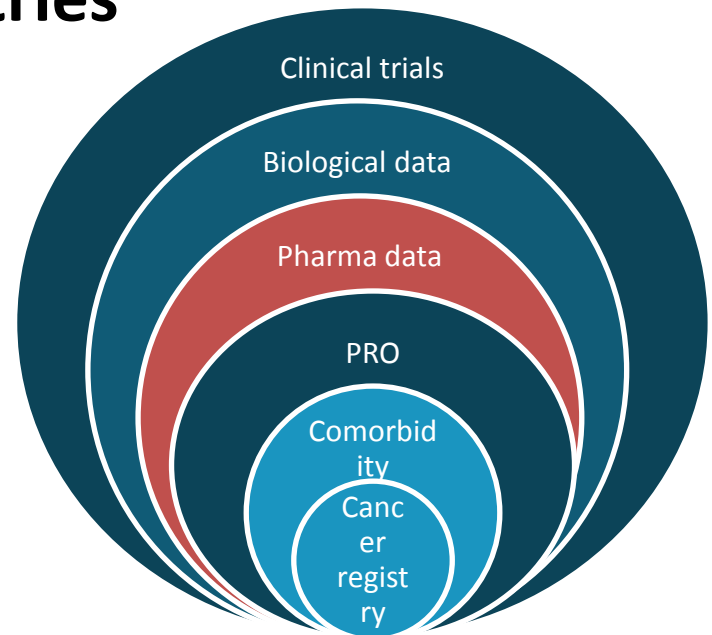
- aim to monitor cancer therapy **in a hospital (or a net of hospitals)**.
- collect **detailed data about diagnosis and therapy**.
- **inform and support health care provider** by planning therapies and generating reminders
- No clearly defined source population (denominator)
- Follow-up ?
- Usually restricted to single institution (not population-based)
- Representativeness?

# Evolution of population-based cancer registration

- Cancer registration is not an end in itself and its tasks are adapted to the needs.
- In recent years, expansion to
  - Aspects of cancer prevention, treatment and care.
  - Evaluation of cancer care
  - Provide information to planning of services.

# Cancer registries are becoming

- **Clinical-epidemiological registries**  
e.g. Germany (collection of > 100 items)
- **Comprehensive cancer registries**  
e.g. Netherlands
- **Cross-linkage data bases**  
e.g. Scandinavian countries

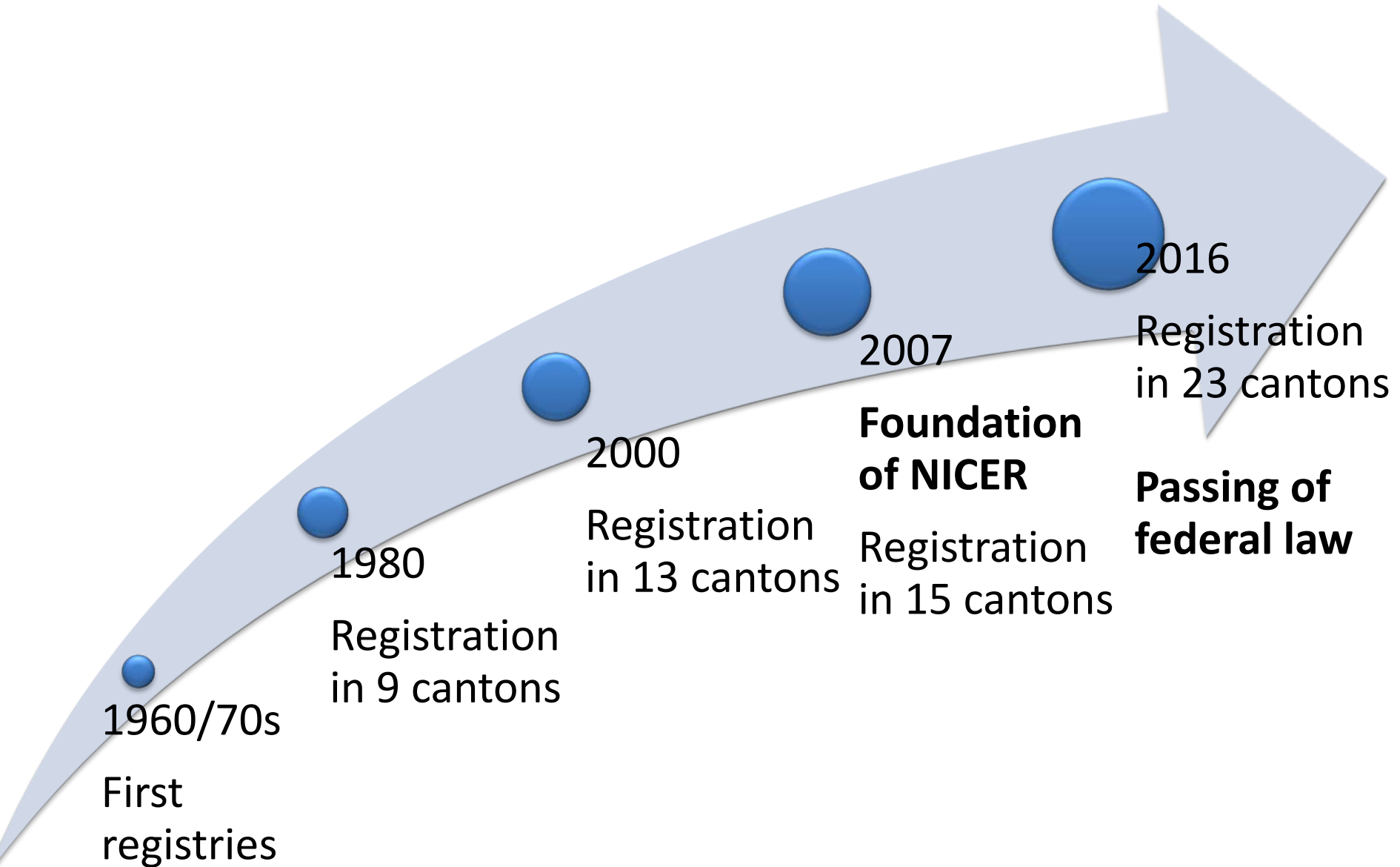


# Cancer registration in Switzerland

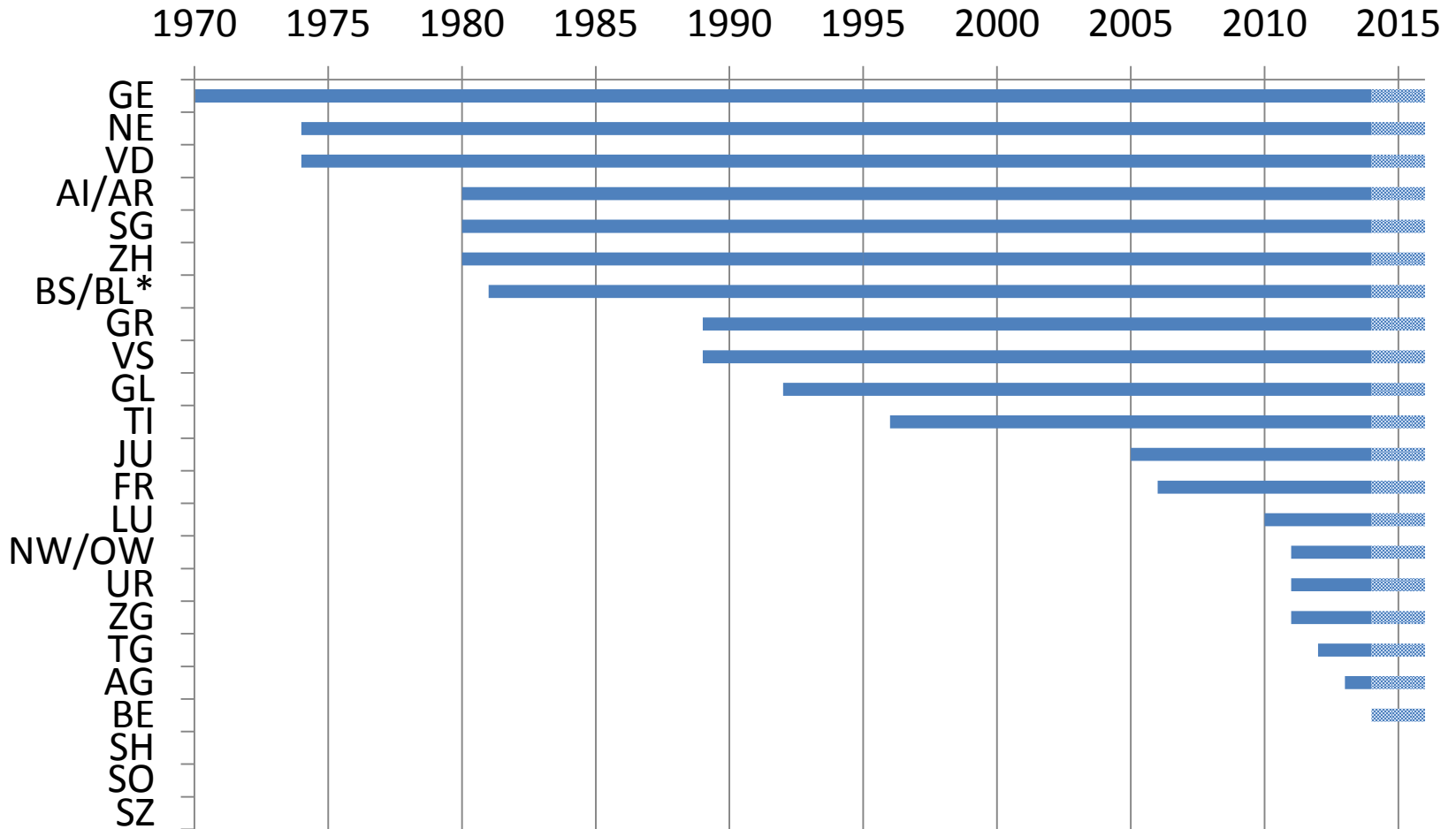
- Follows international recommendations for data collection procedures and contents.
- Organised at the cantonal level (according to cantonal law).
- CCRs maintain links with all hospitals and pathology laboratories in their catchment area.
- Matching with civil registry offices
  - to approve cantonal residence
  - to check the vital status
- Data of patients residing in other cantons will be forwarded to the competent registry.
- (Mostly) voluntary reporting of cancer cases by physicians
- Patients have right to object registration



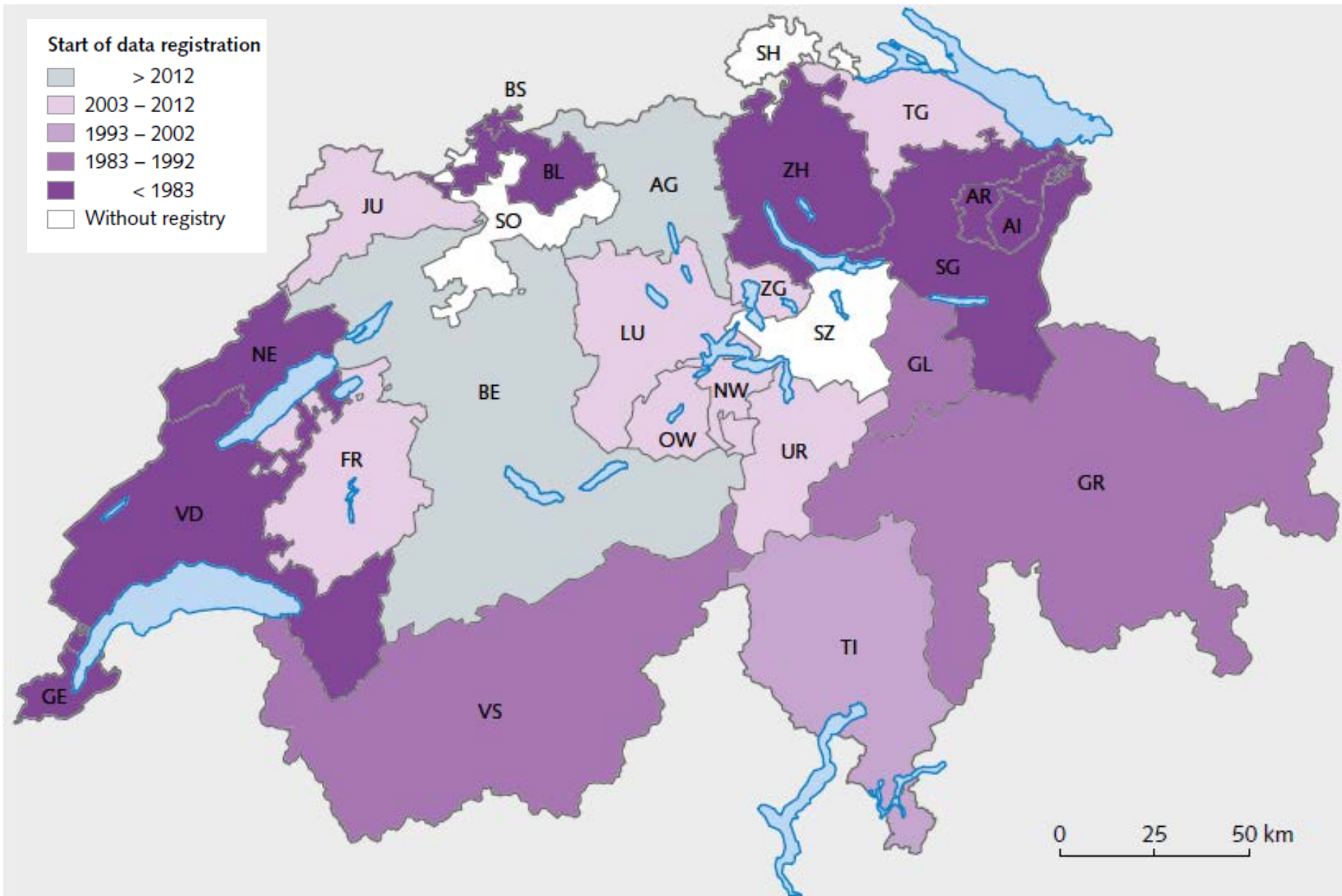
# Development of cancer registration in CH



# ...by canton



# Current status of cancer registration (2016)



# National Institute for Cancer Epidemiology & Registration

- Independent foundation
- Established in 2007 by **Oncosuisse** and the **Swiss Association of Cancer Registries**
- Associated with the University of Zurich
- Funding:
  - Swiss Federal Office of Public Health (BAG)
  - Swiss Cancer Research (KFS)

# Mission

- Act as national coordination centre
- Harmonize the work of the cantonal cancer registries
- Aggregate cancer data
- Provide quality assurance
- Analyse the data on a national level
- Promote epidemiological cancer research

# Cancer Registration and Research

Epidemiologic  
surveillance

Aetiology

Impact of preventive  
interventions

Early diagnosis and  
mass screening  
(secondary prevention)

Evaluation of cancer  
care including outcome  
research  
(effectiveness), pattern  
and quality of care

Economic evaluation  
and planning of cancer  
care policies

Prognosis, risk of  
secondary cancer,  
quality of life and other  
survivorship issues

Registry  
methodology

...

# Research activities in Swiss CCRs 2010-2015

## **(1) Epidemiologic surveillance**

- **Monitoring time trends** in incidence or mortality (by age and gender) [2, 3, 16-27]
- Monitoring **social class differences** and **migration** [22, 28-30]
- Monitoring **prevalence** [2, 3, 31, 32]
- **Exploring perceived or real environmental threats**

# Research activities in Swiss CCRs 2010-2015

## (2) Assessing new potential risk or prognostic factors

- CRs as **follow-up source** for epidemiologic cohort studies[7-10, 38, 44, 50-54]
- CRs as **baseline source** for epidemiologic cohort studies[30, 38, 39, 44, 49, 51, 53-56]
- CRs as **source of cases** for population-based case-control studies[8, 9, 27-29, 32, 34-37, 40-43, 45-48]
- Cross-sectional or longitudinal studies **of variation in occurrence** (incl. clusters)[15, 16, 18, 20, 33]



# Research activities in Swiss CCRs 2010-2015

## **(3) Evaluation of impact of preventive interventions on populations**

- **Primary prevention:** e.g. smoking cessation and lung cancer risk[19, 20]
- **Secondary prevention:** (side)effects of mass, grey or targeted screening[14, 23, 24, 57-59]
- Evaluate **impact of new diagnostics**[60]

# Research activities in Swiss CCRs 2010-2015

## **(4) Evaluation of cancer care**

- Changing burden of cancer on health services [64-67]
- Treatment pattern and outcome [11, 55, 59, 64, 68-78]
- Assessing patient's preference in care [65-67, 79]
- Monitoring of process indicators and quality of information [68, 70]
- Translational research of prognostic biomarkers [45, 80, 81]
- Host determinants like co-morbidity, family history [7, 37, 39, 70]

# Research activities in Swiss CCRs 2010-2015

## **(5) Survival, quality of life, secondary primaries, recurrences**

- Trends in survival [2, 3, 66, 79-93]
- Quality of life  
[work in progress]
- Risk of secondary cancers and recurrence  
[30, 38, 39, 51, 53, 54, 94-98]

# Research activities in Swiss CCRs 2010-2015

## **(6) Registry methodology**

- Completeness/accuracy of population-based registration and statistics [101, 102]
- Validating classifications (ICD-O, Gleason score etc.) [63, 103]

# Limited research activities

## **Economic evaluation and planning of cancer care policies**

- Scenario planning and resource allocation for specialised care/centres
- Contribution to cost-effectiveness analyses

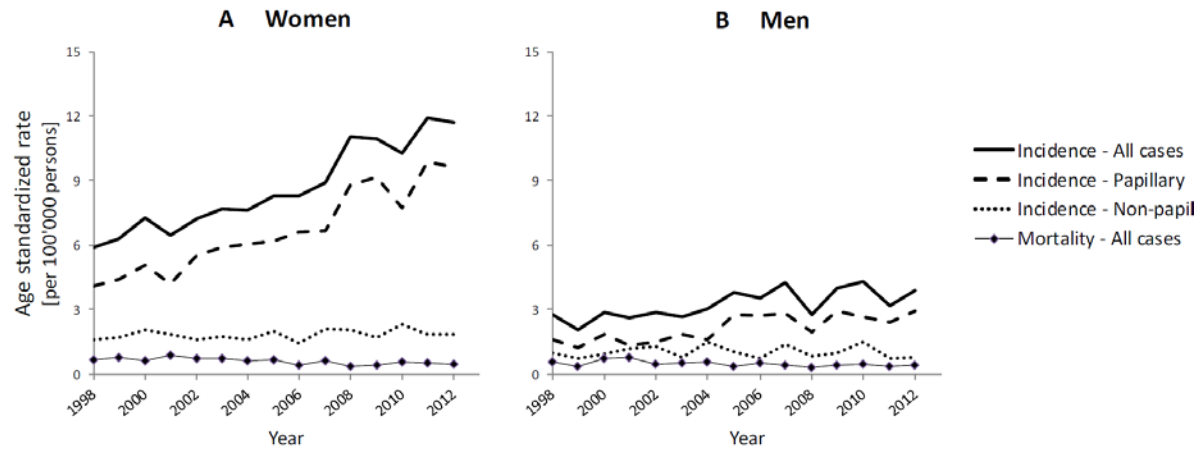
# Examples how cancer registries can provide evidence-based data to improve quality of care

- Impact of family history on breast cancer outcome (Ayme, 2014; Bouchardy, 2011):  
RR of contralateral ER<sup>-</sup> BC: 10-50; but only 25% attend genetic counseling!
- Impact of social class on BC mortality: HR 1.7-2.4 (Bouchardy, 2006)
- 150% excess of cardiovascular mortality among node-negative breast cancer patients irradiated for inner-quadrant tumours (Bouchardy, 2010)
- Merits of observational studies if clinical trials are not available (Merglen, 2007: Survival after early PC varied by treatment options)
- Limitations of non-invasive treatment of CIN III tumours (Rapiti, 2012)
- Undertreatment among elderly cancer patients (Bouchardy, 2003):  
Elderly women had more often delayed diagnosis, poorer diagnostic characterisation and suboptimal treatment (not explained by comorbidity)

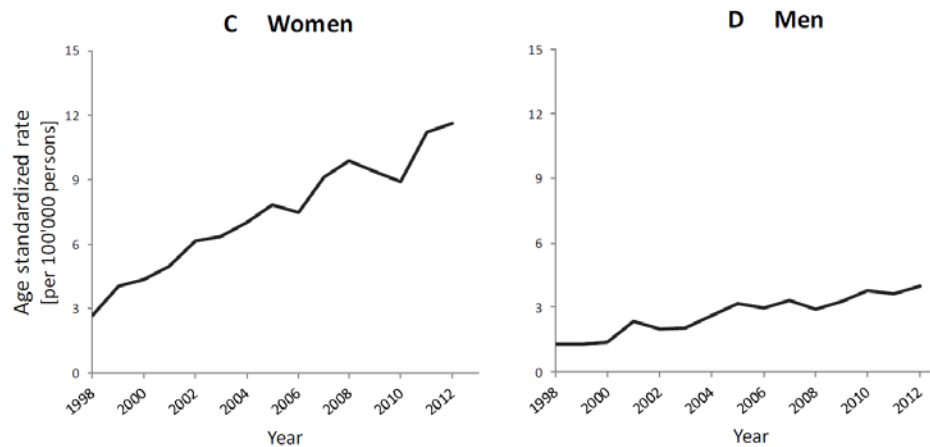
# Trends in thyroid cancer incidence and thyreoectomy

Example for ecological comparison of incidence (CRs) and treatment data (CH Hospital Statistics)

## Thyroid cancer incidence



## Thyroidectomies



# Pattern of Care Studies - Examples

- Breast Cancer
- Prostate Cancer
- Colorectal cancer
- Care during last year of life



# POC - Study Breast Cancer in CH (Silvia Ess et al., 2010ff)

- Multiregional, population-based study
- Including over 4800 BC cases,  
dx in 2003-2005
- 7 cancer registries  
(covering 47% of CH population)
- Grant KLS-01766-08-2005

# Study Questions

- Do variations in the process of care exist among patients with BC in Switzerland?
- Which patient, provider and health system related characteristics are associated with optimal resp. suboptimal care?
- Have standards of care reached the patient?

# Methods

- Retrospective collection of 150 variables
  - Demographic characteristics,
  - Clinical presentation,
  - Co-morbidity,
  - Investigation techniques,
  - Morphology and biological characteristics of the tumor,
  - Stage at diagnosis,
  - Details of planned and effectively delivered local-regional and systemic therapies

# Variation in BC care by region

(after adjustment for age, stage, tumor size)

	Mastectomy in patients with unifocal disease			
	Univariate		Multivariate*	
	OR (95% CI)	p-Value	OR (95% CI)	p-Value
GE	1.0 (Ref)	–	1.0 (Ref)	–
VS	2.6 (1.9–3.6)	<0.01	2.90 (2.1–4.1)	<0.01
TI	2.2 (1.6–2.9)	<0.01	2.0 (1.4–2.8)	<0.01
BA	1.7 (1.2–2.4)	<0.01	1.7 (1.2–2.5)	<0.01
ZH	1.6 (1.1–2.2)	0.02	1.5 (1.0–2.2)	0.04
SGA	2.4 (1.8–3.2)	<0.01	2.3 (1.6–3.1)	<0.01
GG	2.3 (1.5–3.3)	<0.01	2.4 (1.6–3.6)	<0.01

	Radiation therapy after BCS			
	Univariate		Multivariate*	
	OR (95% CI)	p-Value	OR (95% CI)	p-Value
GE	2.8 (1.9–4.3)	<0.01	3.0 (1.9–4.8)	<0.01
VS	2.2 (1.3–3.6)	<0.01	1.7 (1.0–2.9)	NS (0.06)
TI	1.0 (Ref)	–	1.0 (Ref)	–
BA	1.6 (1.0–2.5)	NS (0.05)	1.6 (0.9–2.7)	NS (0.09)
ZH	2.0 (1.2–3.3)	<0.01	2.1 (1.2–3.6)	0.01
SGA	1.3 (0.9–2.0)	NS (0.13)	1.4 (0.9–2.1)	NS (0.18)
GG	1.6 (1.0–2.8)	NS (0.06)	1.7 (0.9–3.0)	NS (0.10)

	Hormonal therapy in endocrine sensitive disease			
	Univariate		Multivariate*	
	OR (95% CI)	p-Value	OR (95% CI)	p-Value
GE	3.3 (2.3–4.8)	<0.01	3.4 (2.3–5.0)	<0.01
VS	10.5 (4.8–22.9)	<0.01	11.1 (5.0–24.4)	<0.01
TI	1.0 (Ref)	–	1.0 (Ref)	–
BA	1.3 (0.8–1.8)	NS (0.26)	1.3 (0.9–1.9)	NS (0.22)
ZH	7.0 (3.6–13.8)	<0.01	7.5 (3.8–14.8)	<0.01
SGA	2.6 (1.8–3.9)	<0.01	3.0 (2.0–4.5)	<0.01
GG	2.5 (1.5–4.1)	<0.01	2.6 (1.5–4.3)	<0.01

# Frequency and predictors of state-of-the-art care in early breast cancer in Switzerland

1) Operationalisation of „state-of-the-art management of early breast cancer“

Development of a quality score based on surgical and non-surgical items



2) Have standards of care reached the patient?

Distribution of quality score



3) What are independent predictors of optimal care?

Multivariate analyses

# 1) Operationalisation of „state-of-the-art management of early breast cancer“

## Items used to construct the „State-of-the-art BC care – Score“

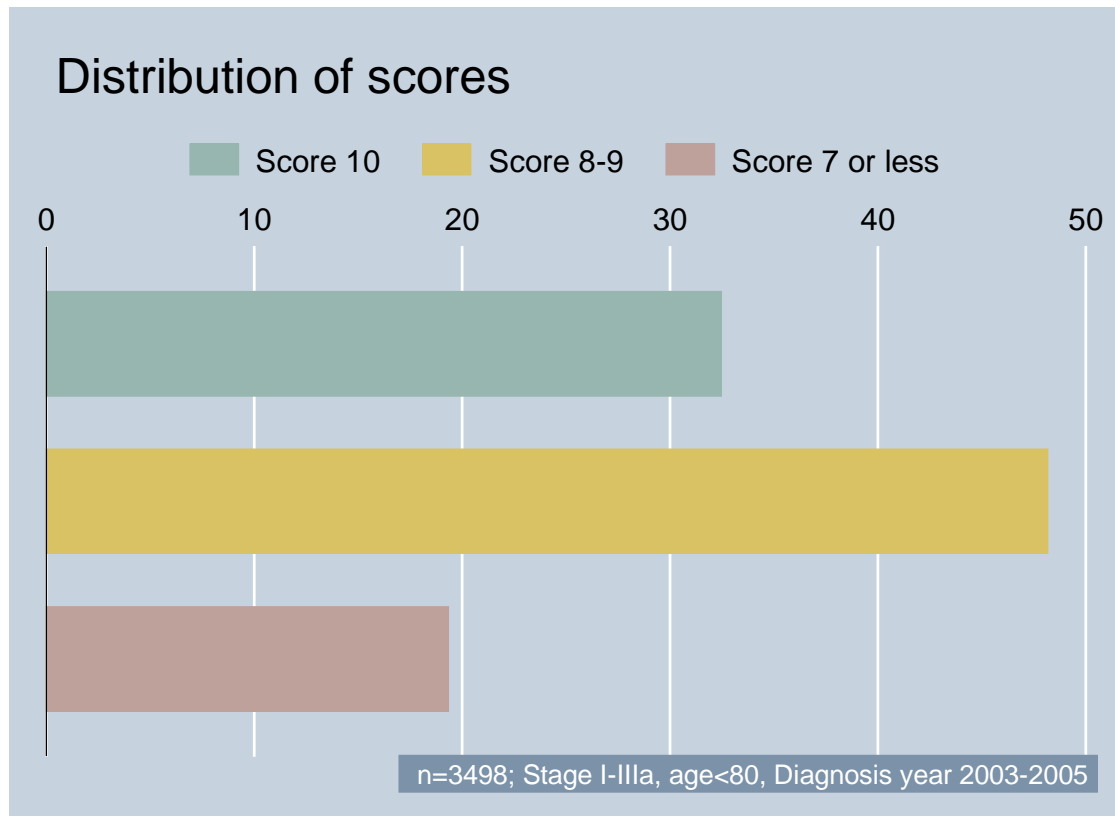
### Surgical items

- Pretreatment diagnostic by FNA or CNB
- $\geq 1$ -mm tumor-free margin after final surgery
- Removal of  $\geq 10$  LN when undergoing AND
- Sentinel node as definitive procedure in pathologically confirmed N0 disease
- One breast surgery for R0

### Nonsurgical items

- Reporting of hormone receptor immunoreactivity, tumor size and grading
- Adjuvant radiotherapy following BCS
- Adjuvant radiotherapy following mastectomy (if indicated)
- Endocrine therapy prescribed (if indicated)
- Chemotherapy prescribed (if indicated)

## 2) Frequency of state-of-the-art care in early breast cancer in Switzerland



### 3) Predictors of state-of-the-art management of early breast cancer in Switzerland

#### **Independent predictors:**

- Treatment by a surgeon with caseload in the upper tercile (OR = 1.43)
- Team involved in clinical research (OR= 1.42)
- Urban/suburban residence (OR=1.47)
- Canton (ORs up to 3)
- Age (for low scores only)

#### **No predictors were:**

- Socioeconomic characteristics such as income, education, nationality
- Stage, grade, receptor status
- Multidisciplinary tumor conference

#### **Conclusions:**

Specialization and involvement in clinical research seem to be key elements for enhancing the quality of early breast cancer management at population level.



# POC - Study Prostate Cancer in CH

- **Start of data collection:**  
January 2016 (ongoing until at least June 2017)
- **Participating CRs:**  
BS/BL, GE, GL/GR, FR, SGA/APP, ZH
- **Study sample:**  
2500 prostate cancer patients diagnosed between 2006 and 2010.
- **Data collection:** patient characteristics, cancer history, screening history, comorbidity status, tumour characteristics, treatment information, complications of treatment, **5-year vital status follow-up**

# SNC-NICER Cancer Epidemiology Study

- **Data source:**  
Linkage of the Swiss National Cohort (SNC) - a census-based cohort combining the 1990 and 2000 census and mortality data up to 2014 - with cancer registry data of the NICER-Cancer Registry Network using probabilistic linkage techniques.
- **Participating registries:**  
GE, FR, NE, TI, VD, VS, ZH
- **Objectives / study question:**  
Socioeconomic and demographic disparities in stage at presentation and survival in cancer patients

# Summary

## Cantonal Cancer Registries contribute to health service research

- Population-based sampling frame
- High completeness (>95% for most sites)
- Large samples
- Provide long-term vital status outcome

## Limitations

- Incomplete or missing information regarding specific clinical data (comorbidity, molecular subtyping, therapy)
- Not all registries routinely collect information regarding progression or recurrence of disease
- Additional data collection is necessary
- Delay in registration (completeness may take up to 2 years)

# Perspectives with the new cancer registration law

- A systematic cancer registration in all cantons
- Mandatory reporting unless veto of patient
- Basic data set contains some clinical data
- Collection of supplementary data possible (details to be determined, e.g. progression, recurrence, quality indicators of treatment?)
- Automatic access to population registry data
- Right of cantonal registries to give feedback to providers