

Workshop:

New data, New methods, New uses for Cancer Registries

>The Swiss Experience

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ANNUAL CONGRESS of the GRELL

“Group for Epidemiology and Cancer Registration in Latin Language Countries”

29.-31.5.2019

Torre do Tombo Lisboa

Contents

- NEW **Federal Law** on Cancer registration
- NICER/**NCC** → NICER/**NKRS-ONEC-SNRT**
- NEW **Data**: Stage and Treatment
- NEW **Methods**: APC Modeling
- NEW **Uses**: Cost efficiency of LDCT LC-screening

**March 2016: Cancer Registration Law
«Krebsregistrierungsgesetz» (KRG)**

**April 2018: Cancer Registration Ordinance
«Krebsregistrierungsverordnung» (KRV)**

Entering into force: 1.1.2020

What is new?

Swiss-wide, mandatory reporting by hospitals and physicians

Uniform legislation on top of cantonal regulations

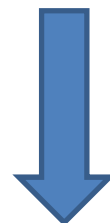
Unique patient ID number (AHVN13)

Veto right for patients uniformly regulated

1st treatment complex: goal, outcome, progression/recurrence

Predispositions, Comorbidities

Top-down federal law
2019: NICER NKRS-ONEC-SNRT

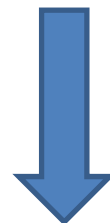


Complete, high quality, comparable population-based data for cancer monitoring, evaluation of prevention and screening measures, quality of diagnosis and treatment, supporting public health resource planning and basic research.



2007: NICER Coordination Centre
1977: VSKR
Bottom-up cooperation of cantonal CRs

Sources are obliged to submit data to CRs



Complete, high quality, comparable population-based data for cancer monitoring, evaluation of prevention and screening measures, quality of diagnosis and treatment, supporting public health resource planning and basic research.



**CRs have permission to actively collect
and abstract data from sources**

NICER Background & Legal Basis

1.1.2019: commissioned with federal role of
NKRS-ONEC-SNRT

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 (FOPH)

Swiss Cancer Research (KFS)

NICER Vision & Mission

Harmonizes the work of the cantonal cancer registries

Provides **quality assurance**

Aggregates cancer data

Analyses the data on a national level

Promotes epidemiological cancer **research**

NKRS-ONEC-SNRT: MAIN Responsibilities

- Data Dictionaries (full revision): with CRs
- National Coding Handbook (1st edition): with CRs
- New Concepts of Cancer Monitoring and Public Health Reporting: with FOPH, FSO
- Information campaigns: patients, data providers
- Cancer Registration Software: with FOPH, FOIT*, CRs

NICER: MAIN TASKS 2019

- Training Days for Coders
- Hosting online platform for knowledge exchange and finding national consensus
- Annual data quality check + quality feedback
- Cancer Monitoring (with Federal Statistical Office, FSO)
- Publications/Reports (Data quality, Epidemiology, etc)

Results of the survey on practices and conditions of registration among 14 Swiss cancer registries

2018

Francesco Galli

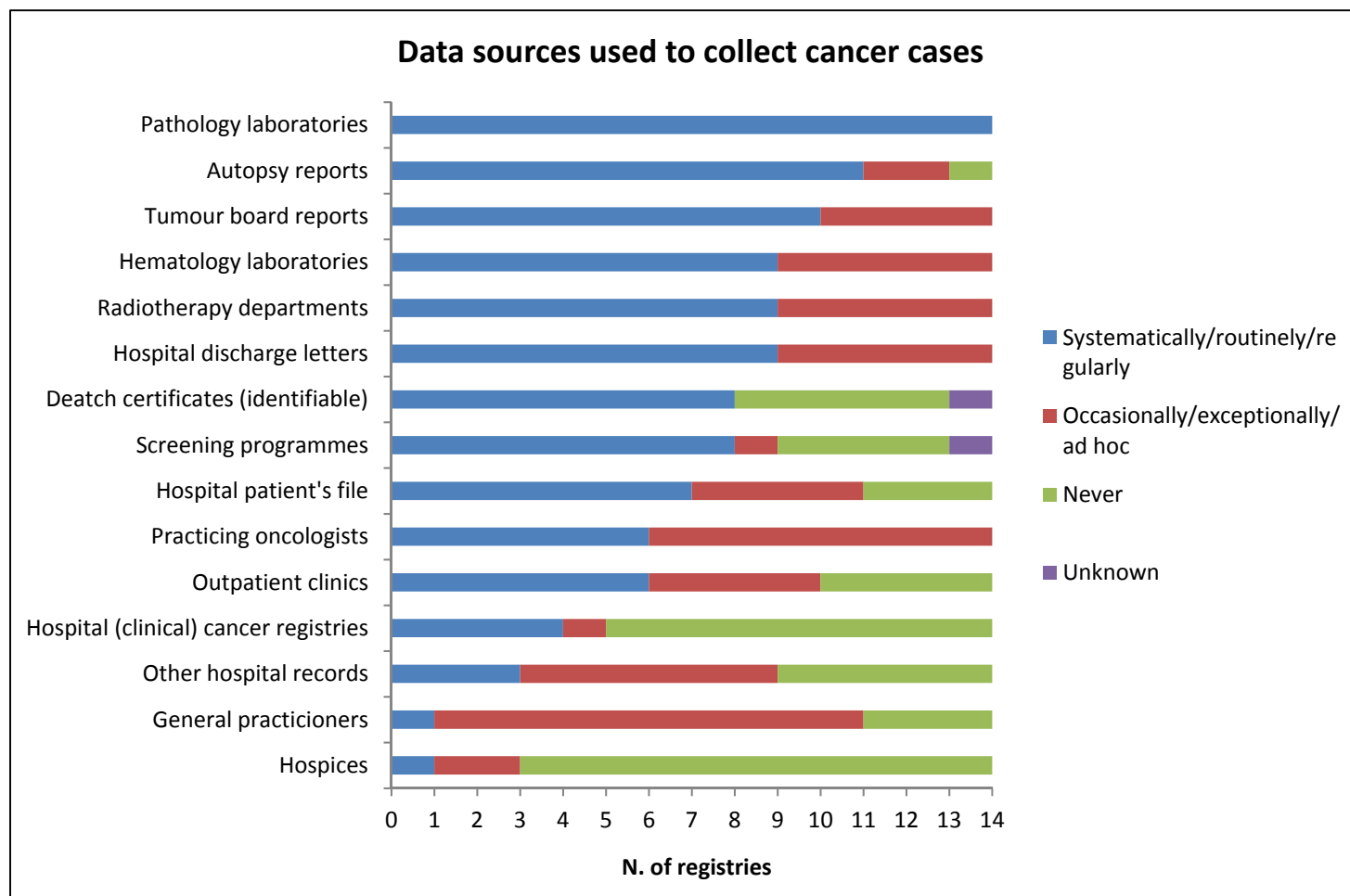
Conditions – legal basis

Cancer registration is not compulsory (except two cantons). Patients have a veto privilege against registration (except six cantons).

23 of 26 cantons register cancer

Canton	Mandatory reporting to cancer registry	Patient has veto privilege
A		•
B		•
C		•
D		•
E		
F		
G		
H		
I		•
J		•
K		•
L		•
M	•	•
N		•
O		•
P		
Q	•	•
R		•
S		
T		•
U		•
V		•
W		•

Conditions – access to data sources



Conditions

- **Active vital status follow-up**

Online connection with inhabitant control	N. cantons
No	9
Yes, only for single requests	5
Yes, batch mode possible	9
Total	23

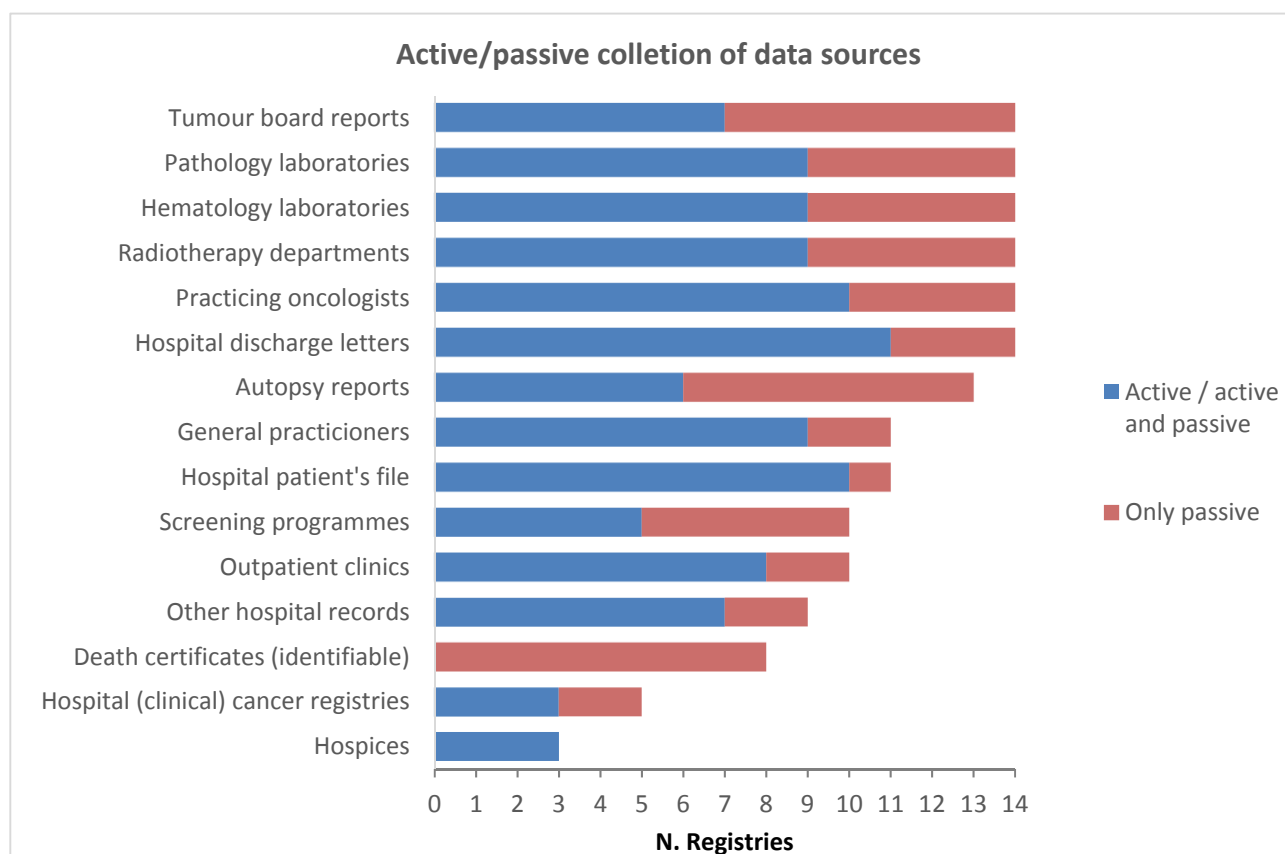
- **Passive vital status follow-up**

Variables used to match
registry records with
date and cause of
death data

Canton	Date of birth	Date of death	Sex	Community code	Cancer diagnosis	Full name	Marital status	Nationality	Address	ZIP code	Doctor's name	Total
A												0
D	•	•		•								3
E	•		•			•						3
F	•		•			•						3
R	•	•									•	3
G	•	•				•			•			4
H	•	•	•	•								4
T	•		•		•					•		4
U	•	•	•	•								4
B	•	•	•	•	•							5
C	•	•	•	•	•							5
I	•	•	•	•	•							5
J	•	•	•	•	•							5
K	•	•	•	•	•							5
L	•	•	•	•	•							5
M	•	•	•	•	•							5
N	•	•	•	•	•							5
O	•	•	•	•	•							5
P	•	•	•	•	•							5
Q	•	•	•	•	•							5
S	•	•	•	•	•							5
V	•	•	•	•	•		•	•				7
W	•	•	•	•	•		•	•				7
Total	22	19	19	17	15	3	2	2	1	1	1	

Practices – data collection

Active/passive collection: main data sources



Practices – data collection

Conditions – missed data

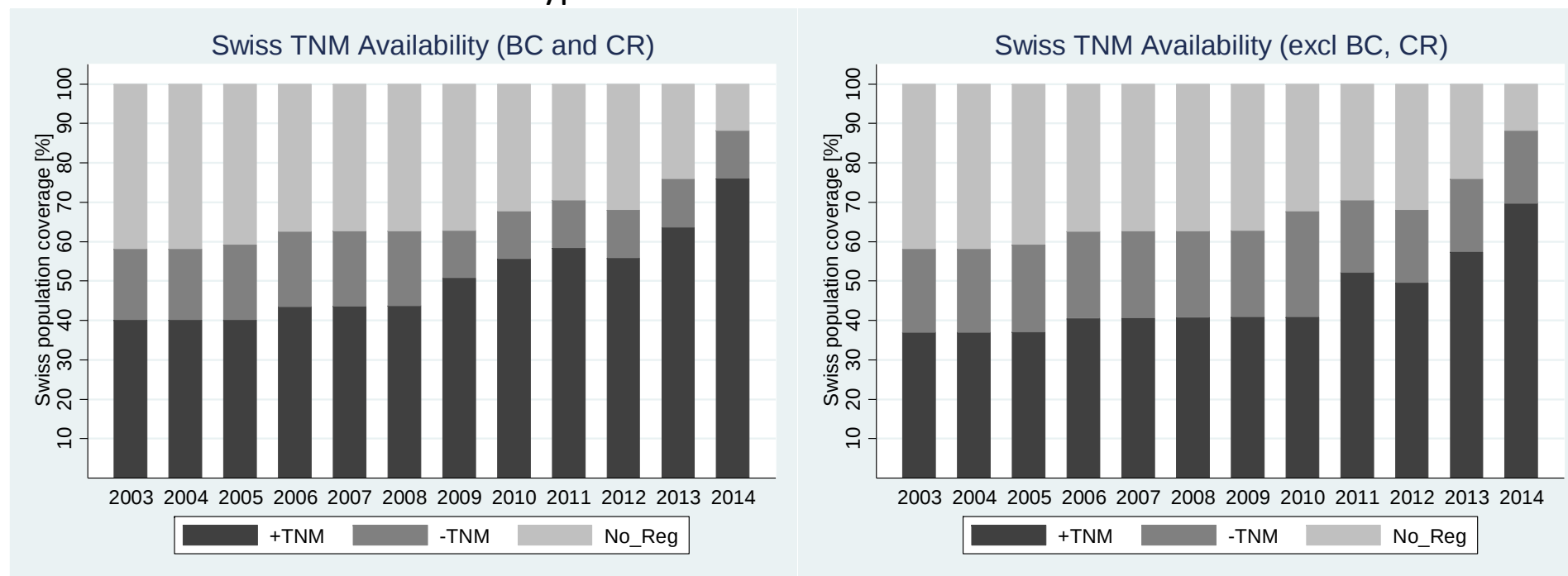
Registry	% cases missed because diagnosed or treated outside registry's catchment area	% cases missed because of problems accessing data sources	% total cases missed
F	2	0	2
I	2	0	2
N	1	1	2
D	2	1	3
K	1.5	1.5	3
B	2	2	4
L	2	2	4
G	2.5	2.5	5
J	5	1	6
H	3.5	4	7.5
C	5	5	10
M	5	5	10
A	7.5	10	17.5
E	unknown	unknown	unknown
Average	3.2	2.7	5.9

New Data

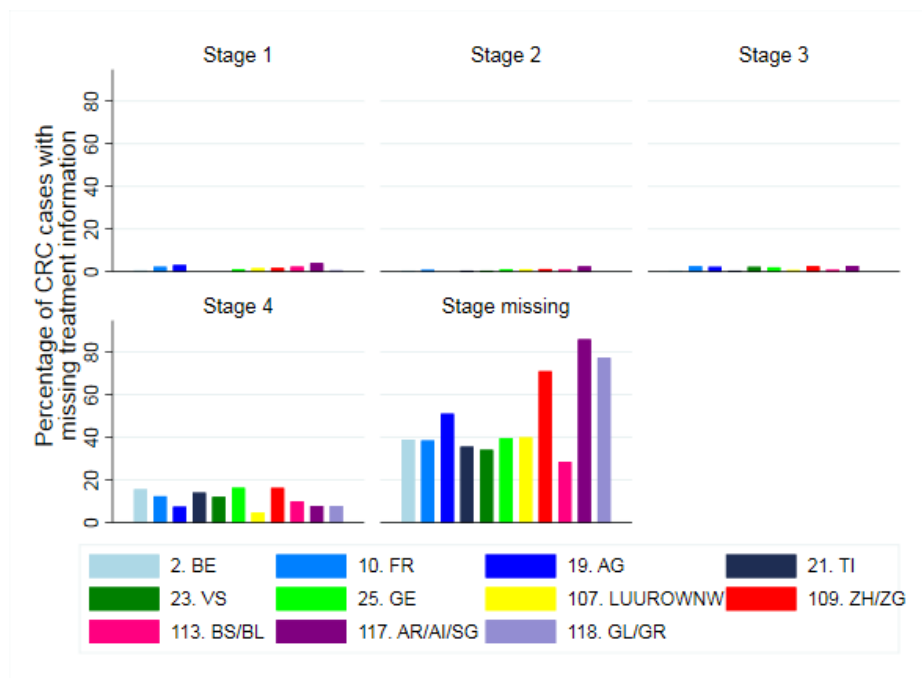
(... for routine cancer reporting)

Increasing % Cases with Information on Stage

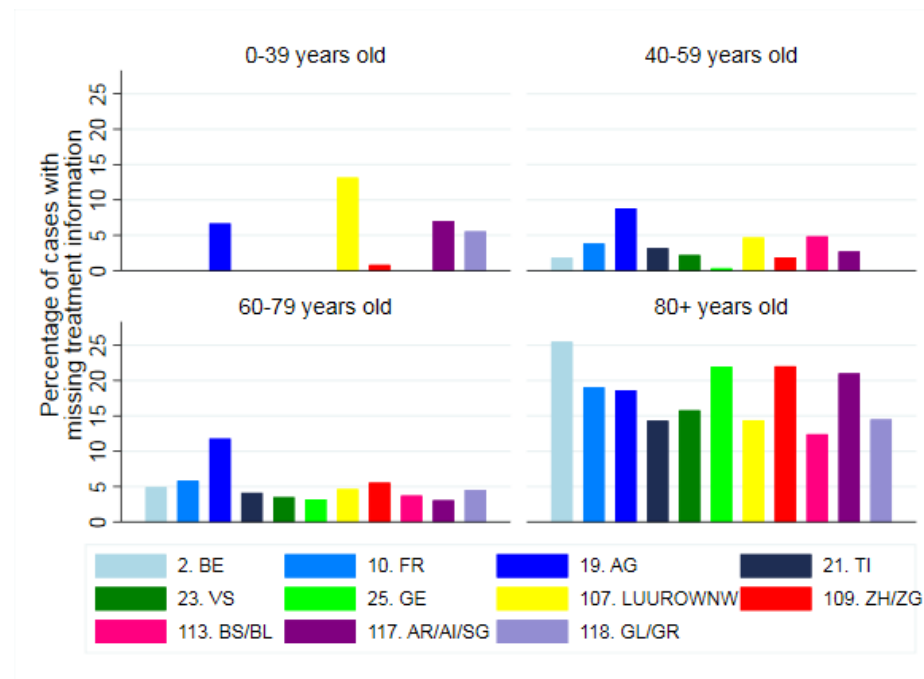
Past focal cancer types



Treatment data availability



Bar graph of the percentage of CRC cases with missing treatment information per stage and per registry.



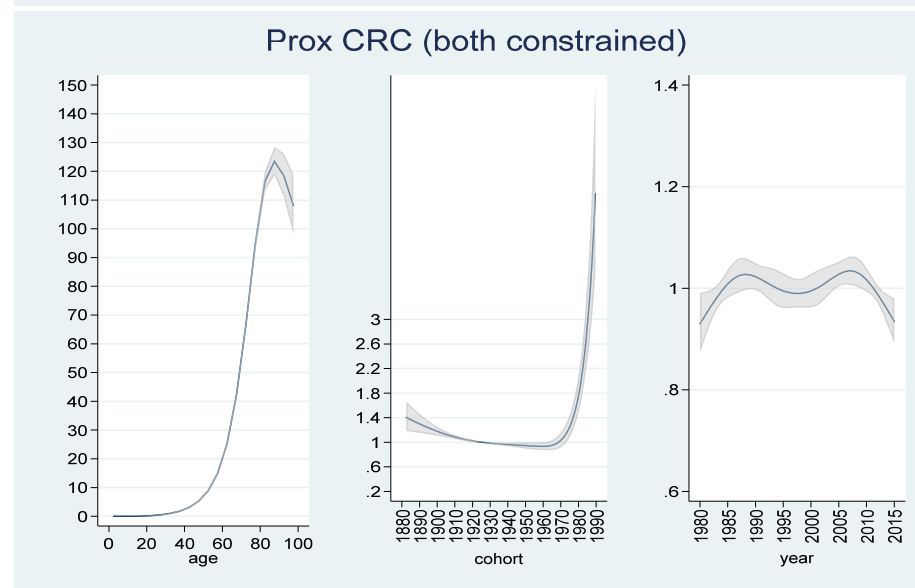
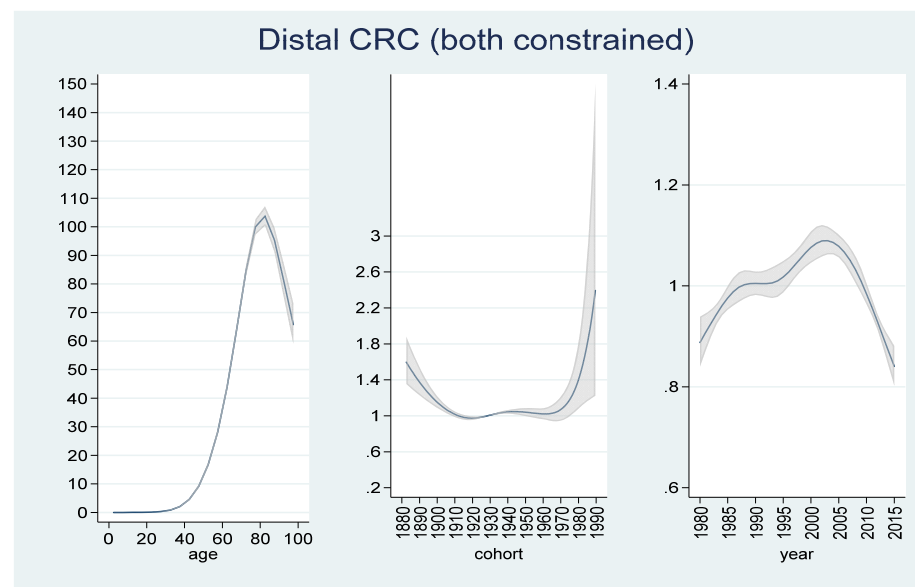
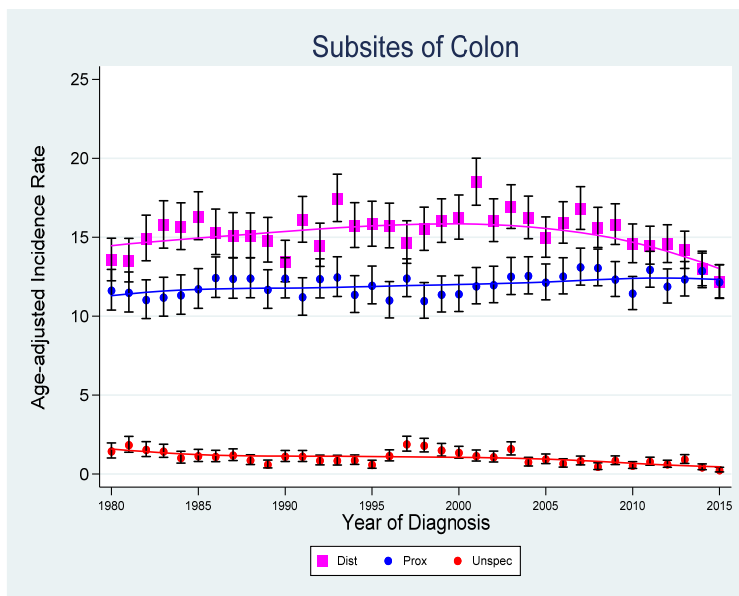
Bar graph of the percentage of CRC cases with missing treatment information per age group and per registry.

New **Methods**

Age-Period-Cohort Modeling

Subsite-specific Colon Cancer Trends

Weighing Cohort vs Period effects



Model	Distal colon BIC	Prox colon BIC
AC	17698	17219
AP	17669	17274
APC	17673	17246

New Uses



LDCT
Lung Cancer Screening

Lung Cancer Screening Model

Objectives of the study

- To model individual complete (birth to death) life histories of people born 1935-1965 **in Switzerland**
- To estimate the **impact of LDCT screening** on the number of lung cancer deaths prevented and on the number of life years gained
- To estimate the **cost per life years gained**
- To explore the impact of **different screening scenarios** on these outcomes

Yuki Tomonaga, Kevin ten Haaf, Thomas Frauenfelder, Malcom Kohler, Roger D. Kouyos, Mohaned Shilaih, Matthias Lorez, Harry J de Koning, Matthias Schwenkglenks, Milo Puhan (2018). Cost-effectiveness of low-dose CT screening for lung cancer in a European country with high prevalence of smoking-A modelling study. *Lung Cancer* **121**, 61-69.

Lung Cancer Screening Model

Costs and life-years gained vs. no screening

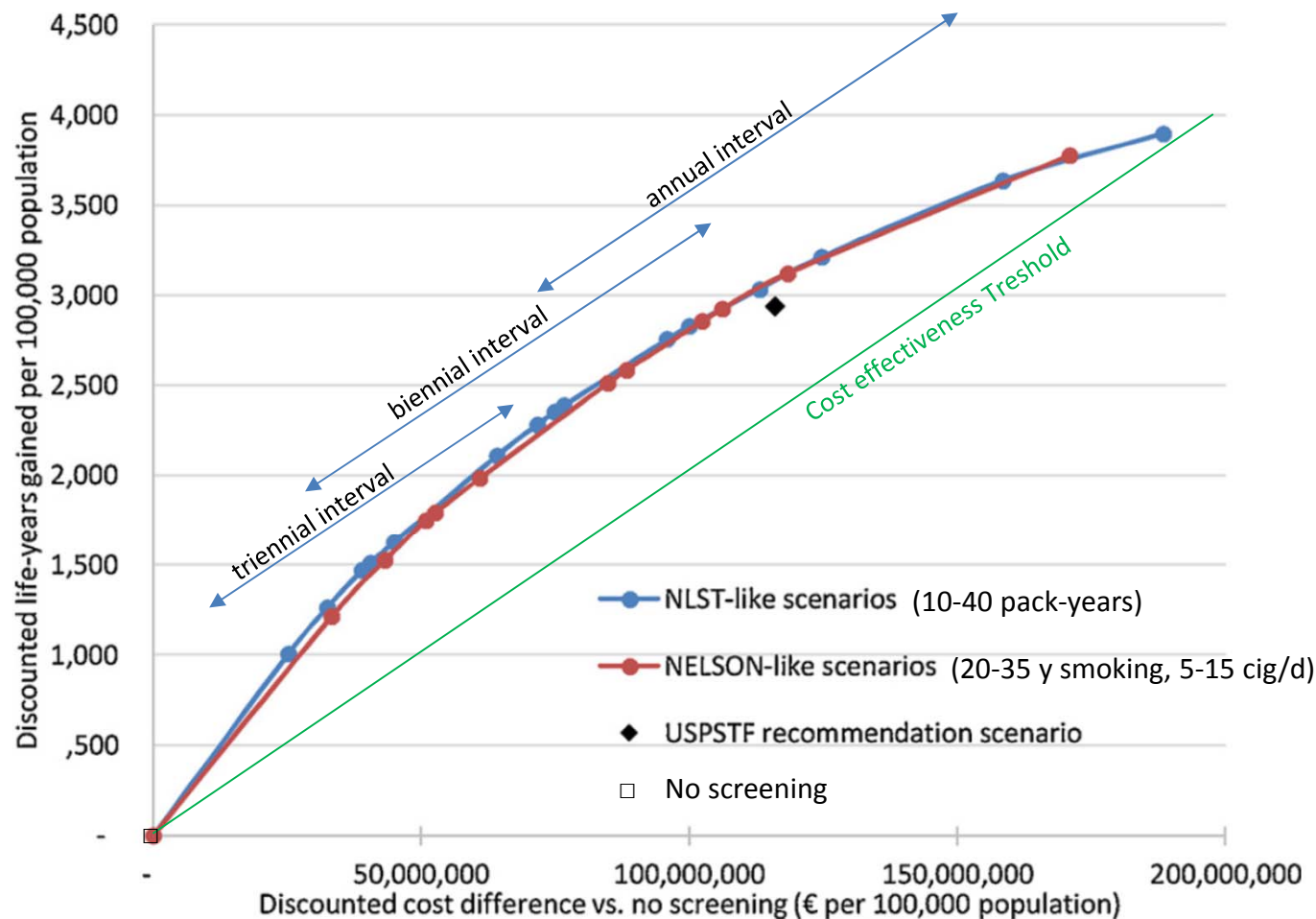


Fig. 2. Costs and life-years gained of the scenarios on the efficiency frontier. Results are presented per 100,000 individuals alive in 2015. (adapted)

Lung Cancer Screening Model

Conclusion of the study

- LDCT screening may be **cost-effective in Switzerland**
- The most cost-effective scenarios **reduced lung cancer mortality by 6-15%** while increasing incidence of lung cancer by 2-6%

But:

- Costs would be considerable: **affordability**
- Cost-effectiveness must be considered in the context of **competing interventions**, particularly smoking cessation

Acknowledgements

Cantonal Cancer Registries

Cancer Data

Francesco Galli (NICER)

Survey of Swiss Registration Practices

Yuki Tomonaga (EBPI University Zurich)

LDCT screening modeling

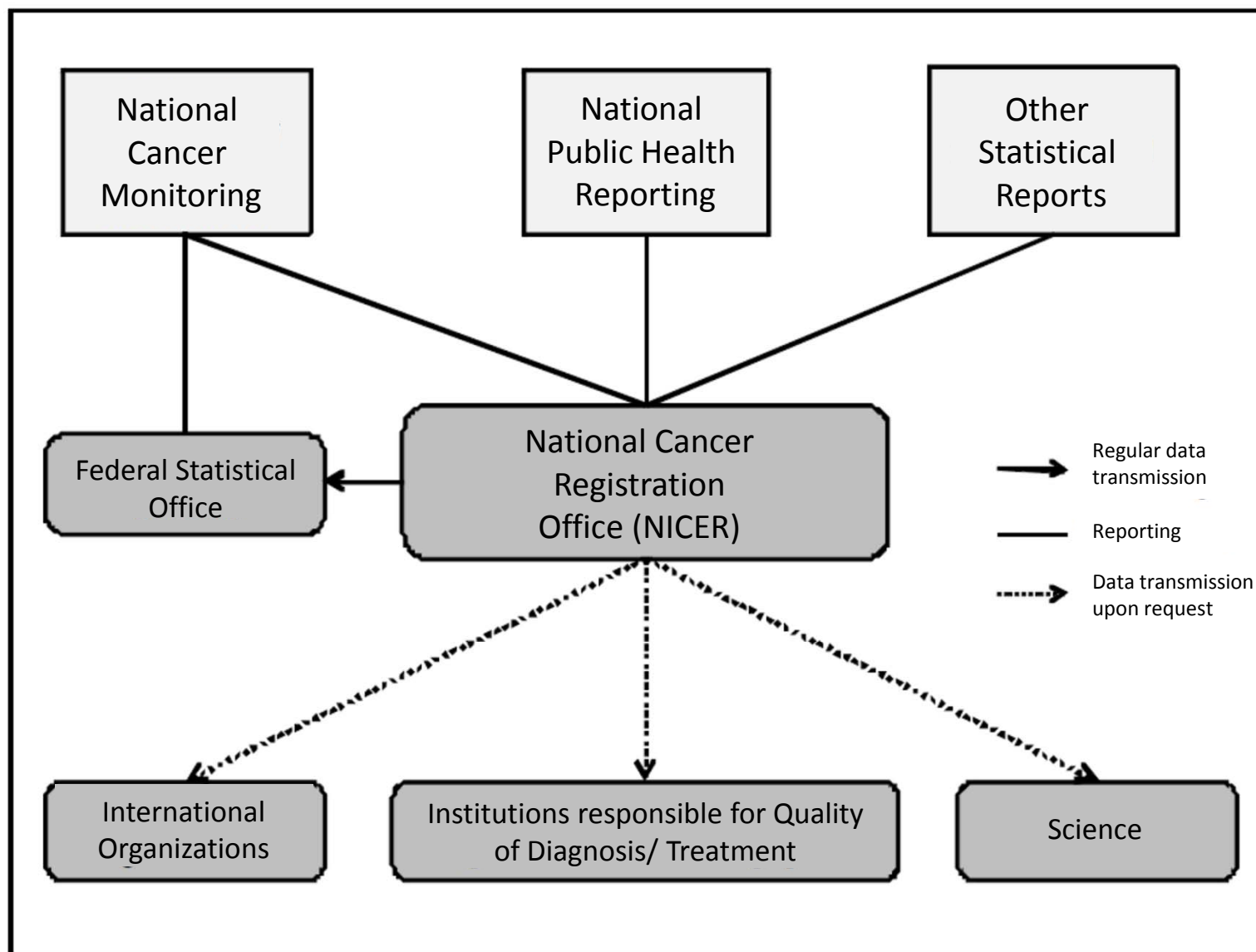
Swiss Federal Office of Public Health

Funding

**Many thanks for
your attention!**

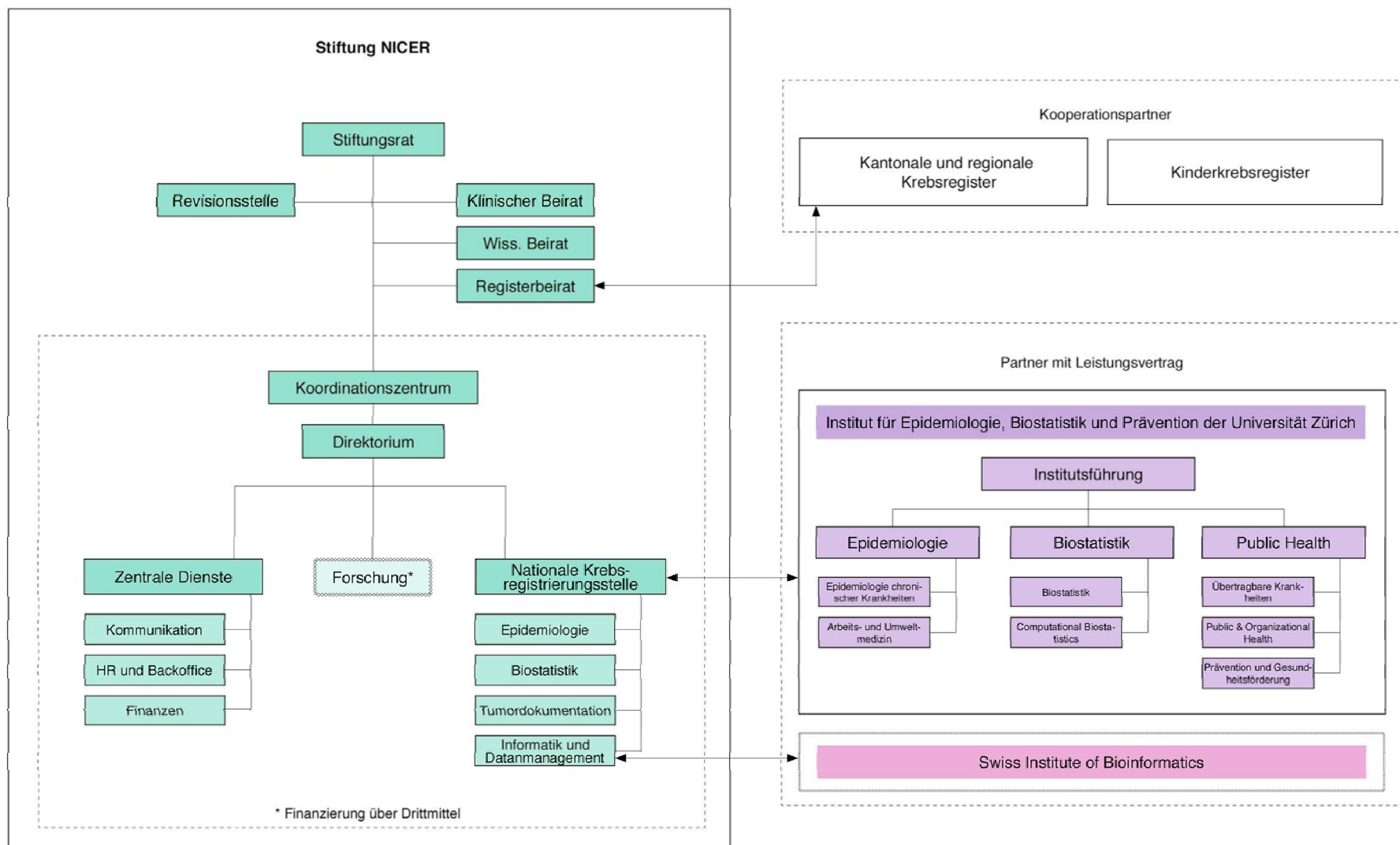
Other slides

Data Transmission and Data reporting

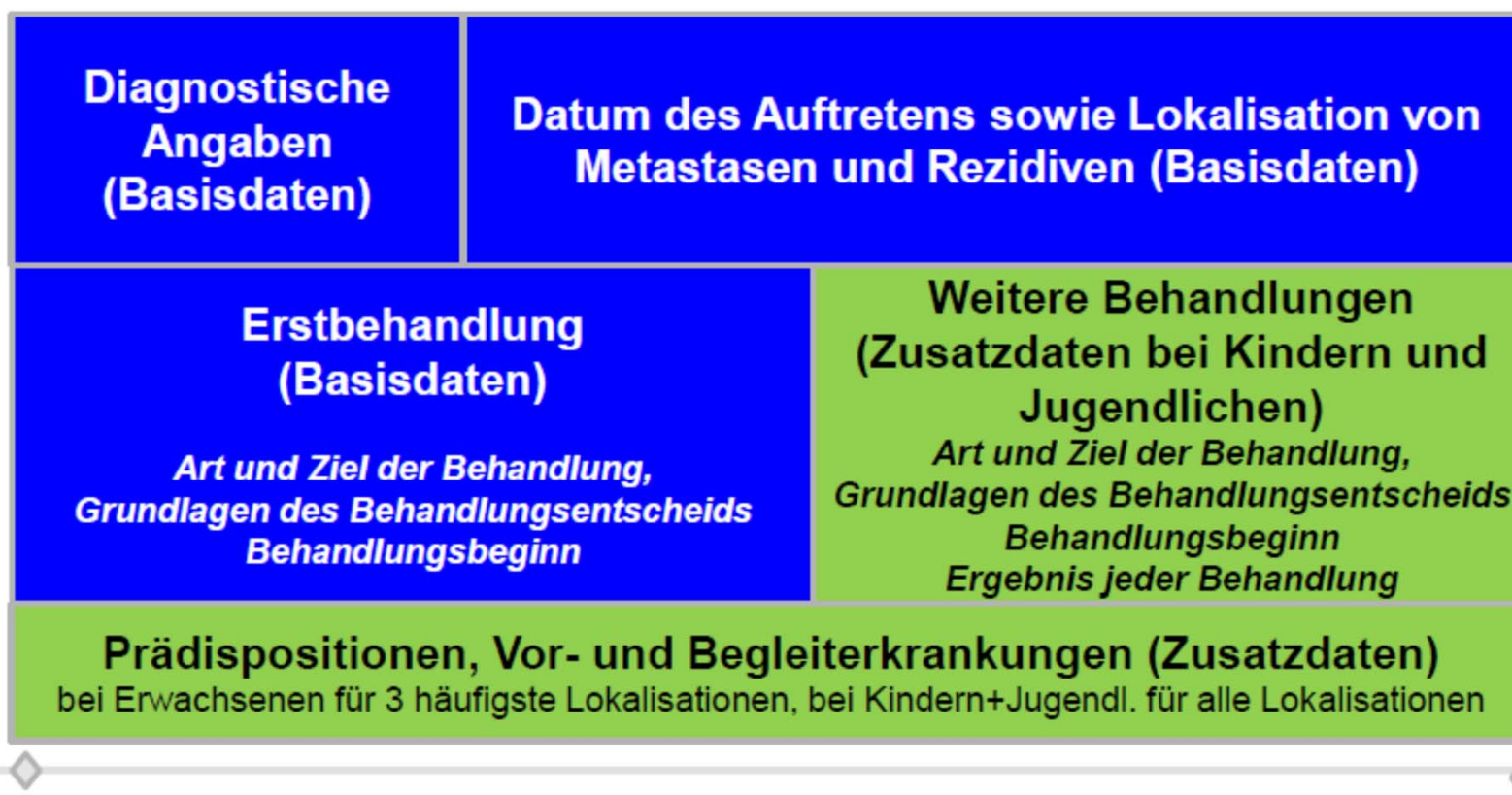


Eidgenössisches Departement des Innern

Bundesamt für Gesundheit



Übersicht über Basis- und Zusatzdaten

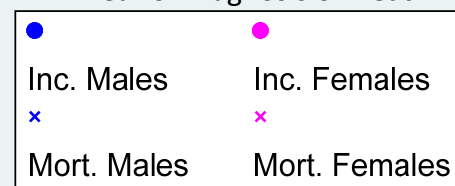
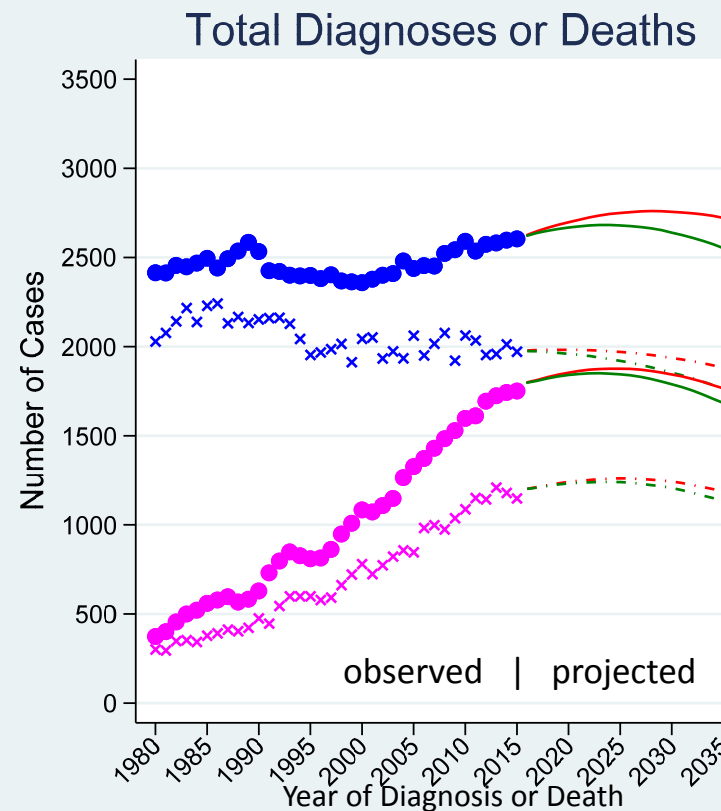
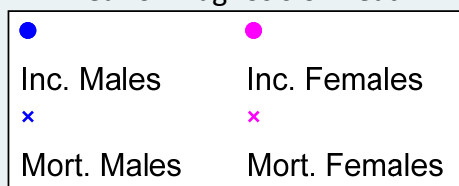
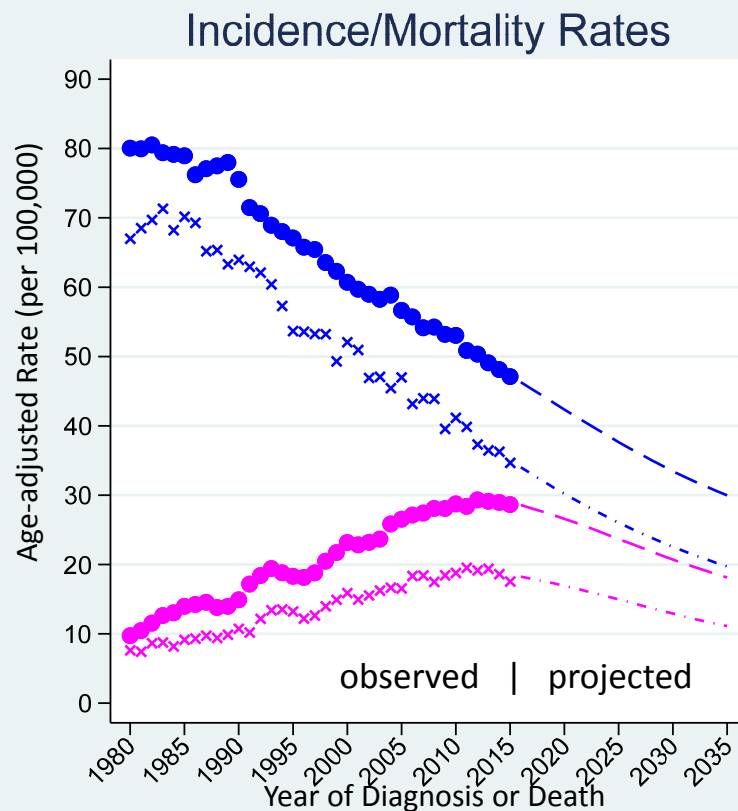


1. Diagnose

Heilung oder Tod

Lung cancer Incidence/Mortality Trends

Projections



Largest Lung Cancer Screening Trials

US NLST (2002-2004) results (2011)¹

- >50,000 smokers; age 55-74, >30 pack-years
- 3 screening rounds at annual intervals (LDCT vs chest x-ray)
- Work-up based on nodule diameter
- 17% reduction in lung cancer deaths (2.5 per 1,000 vs 3.0 per 1,000)

NELSON (2003-2006) results reported at World Conference on Lung Cancer 2018²

- >15,000 smokers; age 50–75, $\geq 15(10)$ cig./day for at least 25(30) years
- 4 screening rounds (1,2,4,6.5 years) (LDCT vs no screen)
- Work-up based on nodule volume and volume doubling
- 26% reduction in lung cancer deaths (in Males)

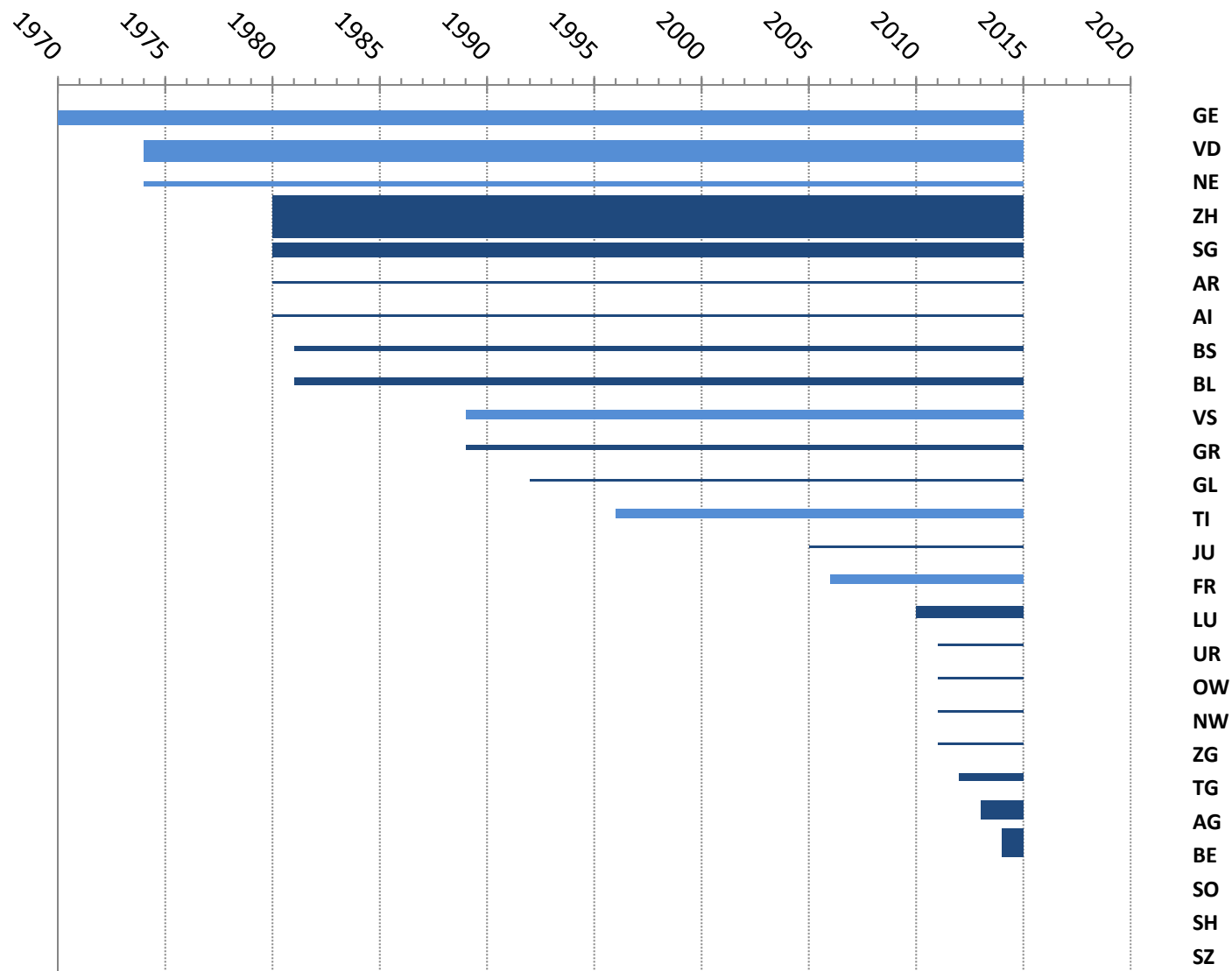
Sources:

1 National Lung Screening Trial Research Team (2011). *N Engl J Med* 4;365(5):395-409

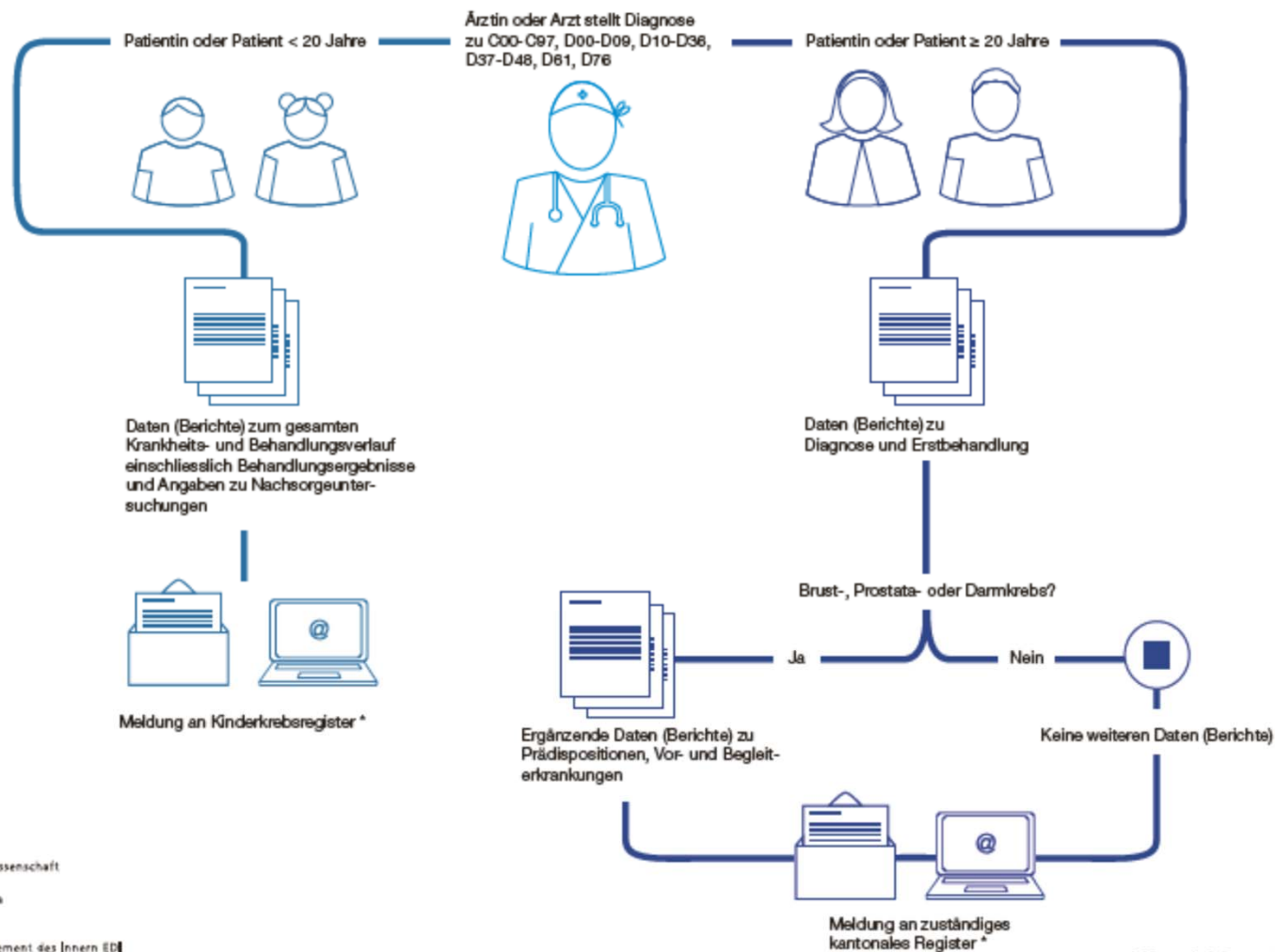
2 WCLC Press Release – Harry De Konning. September 25, 2018

Progression of Cancer Registration in Switzerland

National Cancer Dataset: Situation End_2018



Meldung von Krebserkrankungen nach Krebsregistrierungsgesetz (KRG) ab dem 1. Januar 2020



Effiziente und qualitativ hochstehende Krebsregistrierung
für das nationale Monitoring und die Gesundheitsberichterstattung zu Krebs

Datengebrauch

Nationale Berichterstattung
zu Krebs

Nationale Gesundheits-
berichterstattung zu Krebs

Datenanfragen

Jahresbericht

Harmonisierung

Datenstruktur und
Kodierstandards

Datenqualität und
Feedbacks

Beratung und
Schulungen

Datenmanagement

Entwicklung der
Registrierungssoftware

Widerspruch-
Informationssystem

Innovation und
Automatisierung

Information

Kollaboration mit Partnern

Management, Administration und Finanzen