

Mammography screening and cancer registration in Tyrol/Austria

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- Evaluation of Mammography Screening Project in Tyrol/Austria → MST

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- Conclusions

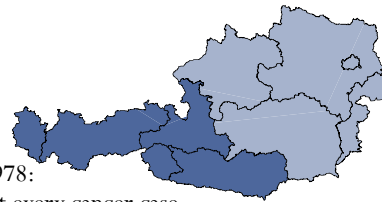
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Cancer registration in Austria

- **Nationwide/regional registries**
 - Nationwide cancer registry run by Stat. AU since 1969
 - Regional registries in states of
 - Vorarlberg: 1981
 - Salzburg: 1985
 - Tyrol: 1986
 - Carinthia: 1988
- **Legal basis**
 - Österr. Krebsstatistikgesetz 1969/1978: **obligation** for hospital to document every cancer case
 - Individual solution for every regional registry



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TRT: Basics, Aims

- **TRT is an epidemiological registry**
 - No follow up data (except life status)
 - No detailed clinical data up to now
- **Aim of TRT: register ALL cancer cases in population of Tyrol and analyse by**
 - Incidence, mortality
 - Survival
 - Secular time trend
 - Geographical distribution

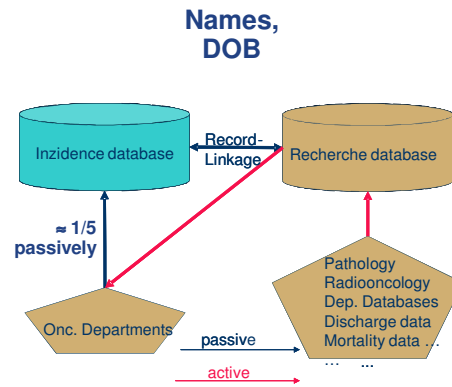
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Data flow

- **Passive**
 - Wait for report by clinicians (according to obligation by law)
- **Active**
 - Use all available data sources
 - Pathology system
 - Department systems
 - Radiooncology
 - ...
 - Trace back and register actively all cases not already in incidence database actively



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Numbers

- Number patients: $\approx 92\,500$
- Number cancers (invasive and in situ): $\approx 104\,000$
- Proportion of patients with multiple cancer: 10.6%
 - However: definition of multiple cancer (international rules)

→ Examples of Analyses

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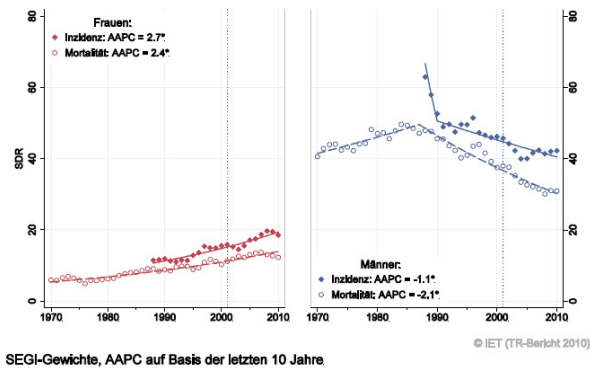
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Analysis: time trend

- Routine report: lung cancer

Abbildung 67: Zeitliche Entwicklung altersstandardisierte Rate Lungenkarzinom



7 Oberaigner, Mühlböck, Harrasser: TRT-Report. Innsbruck 2013.
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Analysis: time trend

- Time trend of prostate cancer mortality

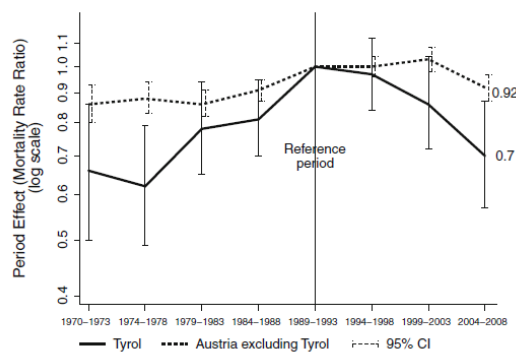


Fig. 2 Prostate cancer mortality in Tyrol and in Austria excluding Tyrol for years of death 1970–2008, age 60+: estimated period effects

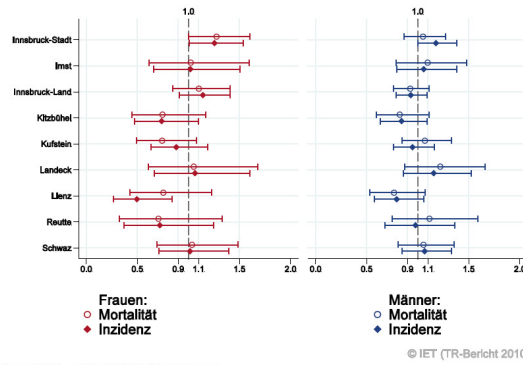
8 Oberaigner et al: Am J Epid 20006, Int J PH 2011
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Analysis: geographical distribution

- Routine report

Abbildung 70: Bezirksverteilung *Lungenkarzinom* 2006–2010, SIR/SMR mit 99%-Konfidenzintervall



Basis: 2006 - 2010, 99%-Konfidenzintervall

© IET (TR-Bericht 2010)

9 Oberaigner, Mühlböck, Harrasser: TRT-Report. Innsbruck 2013.

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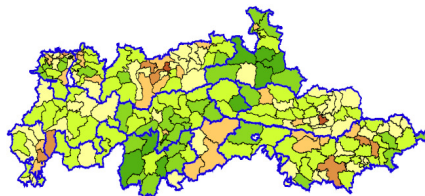


Analysis: geographical situation

- Cancer mapping in alpine regions 2001-2005
→ smoothed maps

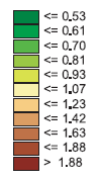
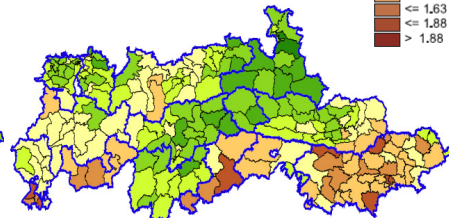
Lung cancer females

Fig. 23: Bronchus, Lung – Incidence – Smoothed Map - Females



Lung cancer males

Fig. 25: Bronchus, Lung – Incidence – Smoothed Map - Males



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Oberaigner, Vittadello. Cancer Mapping in Alpine Regions. 2012.

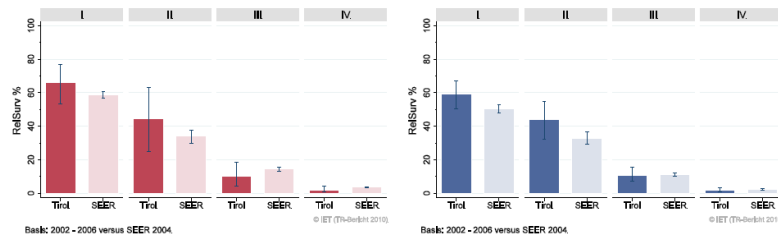
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Analysis: Survival

- Routine report: Lung cancer

Nach Stadien:



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Oberaigner, Mühlböck, Harrasser: TRT-Report. Innsbruck 2013.

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Analysis: Survival

- Survival of cancer patients by gender

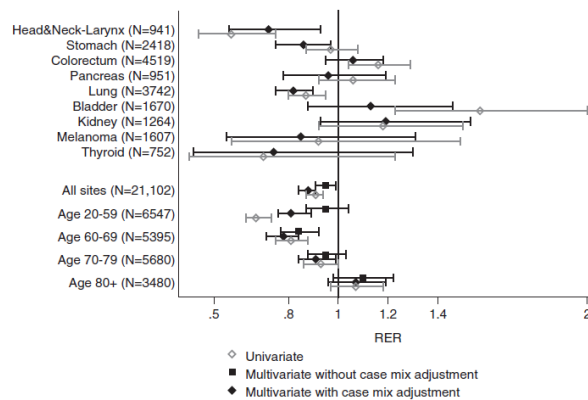


Figure 1 Gender effects for solid cancer sites and all sites combined by age class: gender RER with 95% CIs. RER estimates are shown for women compared to men as the reference group

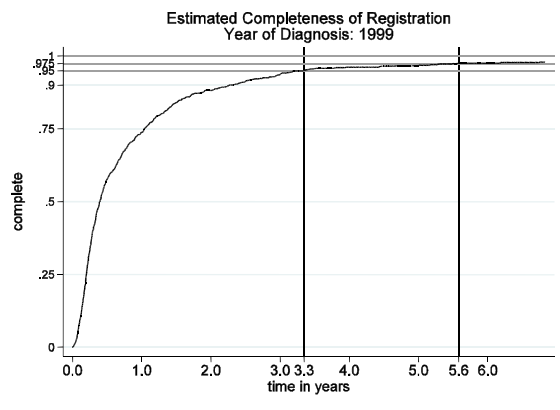
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Oberaigner, Siebert: Eur J PH 2011.

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Estimation of completeness according Bullard method



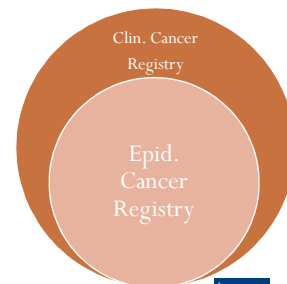
Oberaigner, Siebert: Acta Oncol 2010

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Limits of epidemiological cancer registry

- Completeness: OK
- Validity:
 - Staging: OK (in most entities)
 - Primary therapy (only key facts): OK
 - Clinical Follow Up: Open
- Timeliness: delay of 21 months is very good (gold standard NAACCR)
- Main problem: for many research questions lack of data



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Mammography Screening Program Tyrol (MST)

Aim: Evaluation of MST according EU Guidelines

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History in Tyrol

1990: Start of Spontaneous Mammography Screening

1998: Working Group for Early Breast Cancer Detection for Tyrol

2005: Expert Panel „Mammography Screening“: Design of an organised mammography screening program

June 2007: Start of Pilot Program

June 2008: Complete Rollout

Full Screening Database since June 2007

Evaluation and publication since June 2007 →

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Oberaigner et al: BMC PH Feb 2011, Oberaigner et al: BMC PH Aug 2011

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Characteristics of Tyrol program

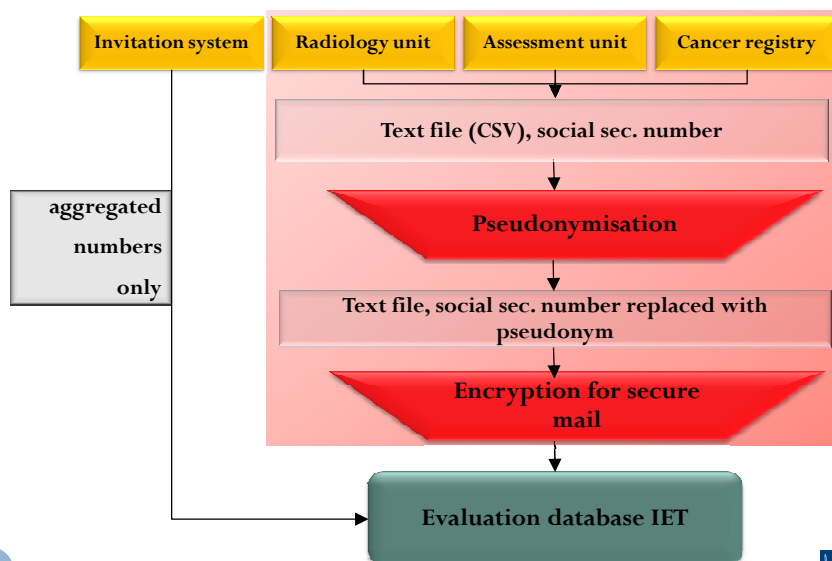
- Smart change of spontaneous screening program
- Target population: all women aged 40-69 with social insurance
- Written personal invitation
- Free choice of appointment
- Screening interval:
 - 40-59: one year
 - 60-69: two years
- Adjunct ultrasound
- No double reading
- No minimum caseload
- 22 screening units (13 private practice)
- 9 assessment units (hospitals)
- Evaluation following EU guidelines

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Data Flow



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Invitation System

(Data from Rollout 1 to 4, not published)

	40-49	50-69
Number invitations	221,316	245,042
Number invited women	73,330	100,060
Coverage of target population	97.8%	
Participation rate (One year)	38.8%	34.8%
Participation rate (Two years)	60.5%	53.1%

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Screening Outcome

(Data from Rollout 1 to 4, not published)

	40-49	50-69
Intermediate screening in six months	1.7%	1.1%
Recall for further Assessment	1.4%	1.2%
Additional ultrasound	82.3%	71.7%

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Assessment Outcome

(Data from Rollout 1 to 4, not published)

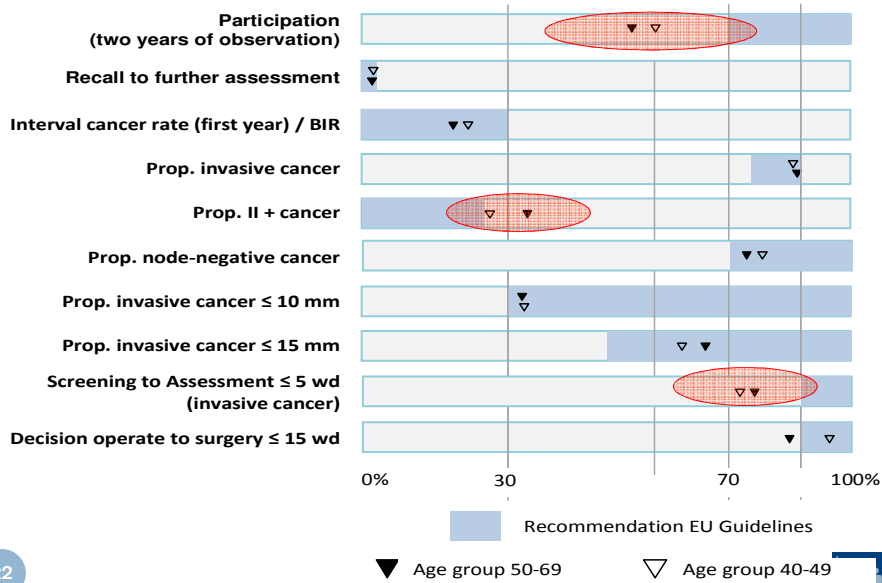
	40-49	50-69
Biopsy rate [1000 screens]	6.9	7.8
Cancer Detection rate [1000 screens]	2.2	4.2
Proportion in situ	12.7%	12.0%
Ratio Screening Detected Cancer Rate / BIR	1.8	2.0
PPV Assessment	15.9	33.5
PPV Biopsy	30.6	52.8

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Selected EU Guidelines (Data from Rollout 1 to 2)



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Discussion: Data privacy, data flow

- **TRT**
 - Identification of patient → very sensitive
→ record linkage must be done very carefully!!
 - Maybe changing in future
 - Att: pseudonymised registry in Germany causes extra costs (≈+30%)
 - Much of documentation done by registry personnel
- **MST**
 - Pseudonymised data
 - Documentation done in radiology units

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Discussion: Data comparability

- **TRT**
 - Few variables
 - Mostly expertise of registry
 - Some problems in staging
 - Well established routines of datachecks (network of cancer registries)
 - Education: mostly registry personnel
- **MST**
 - Few variables
 - Data entry personnel is not directly involved in evaluation
 - Plausibility rules versus few data (redundancy)
 - Education!!

Use of international standards!!

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Discussion: completeness

- **TRT**
 - Completeness of cancer registry is key issue → expertise in registry
 - Bullard method → 97%
- **MST**
 - Completeness in responsibility of radiology units (minimum number per unit/radiologist)
 - Few formal checks

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Discussion: Timeliness

- **TRT**
 - Time lag of 21 months
 - From an international perspective very good (Gold Standard acc. NAACCR)
- **MST**
 - Data ready for quality reports in 4 weeks after end of quarter (of year)
 - Final checks when publication data are fixed, needs much time!!

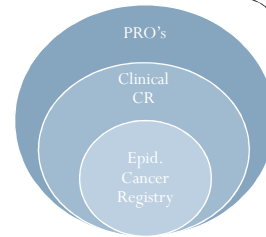
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Conclusions

- Technical problems not really complicated
- Legal and organisational problems relevant, motivation, education
- Use International standards
- Main problem is data quality, mainly if multiple sources (multicenter trials)
- Cancer registry: transition from epidemiological to patient oriented registry (additional costs!!!)
- Mammography system: transition to Austrian wide system with some expected problems



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Thank you for your attention

Looking forward to take your questions

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