

Lessons Learned from International Surveillance and Registries



Europe/Germany



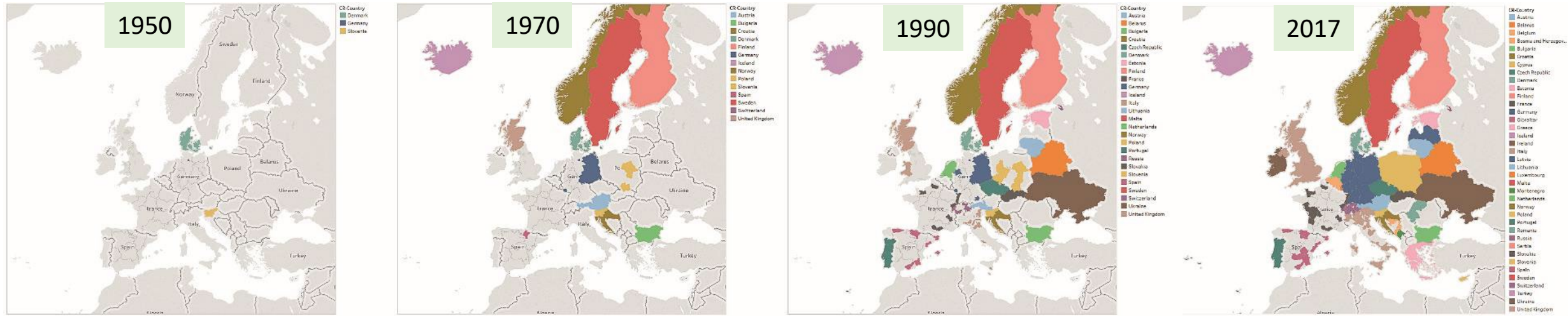
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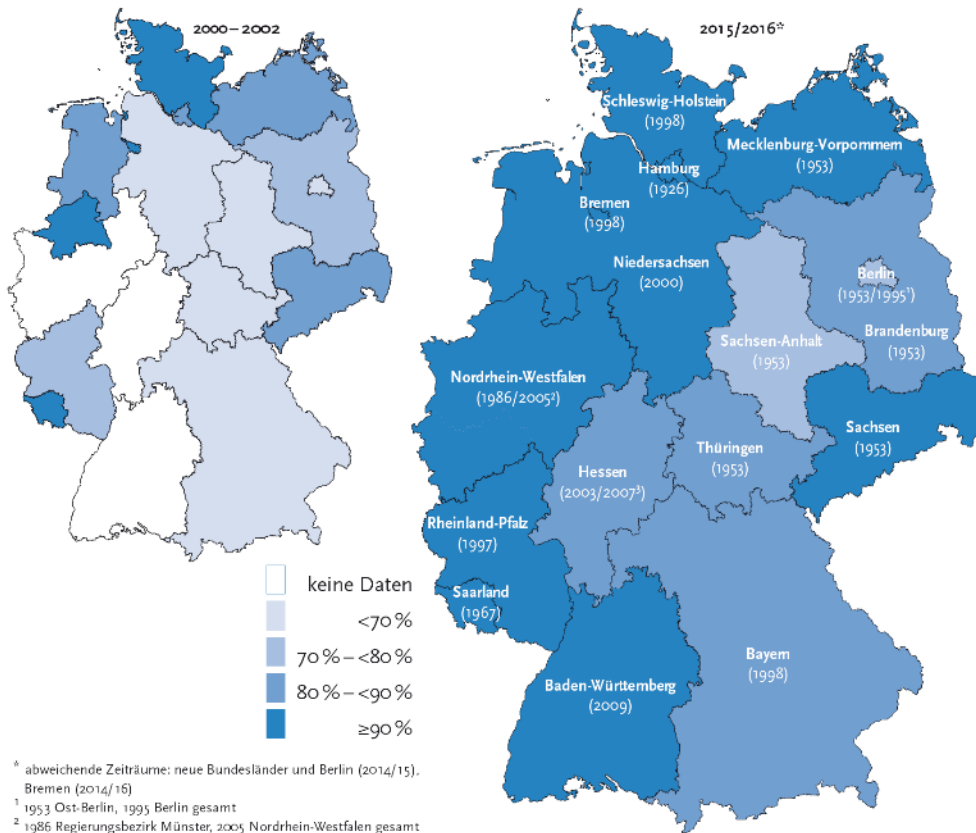
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Timeline of cancer registration in Europe



- Over 180 population-based cancer registries (PBCRs) within 41 out of 47 European countries (as of 2024)
- One third of the population in Europe is not yet covered by PBCRs
- National coverage, timeliness, and range of registered items as well as data sources and pathways differ
- Harmonization is key task of the European Network of Cancer Registries (ENCR)
- 2024: EU Grant (13 Mio EUR) to support quality improvement of cancer registry data

Cancer registration in Germany 2000-...



- 1990s: Only few CRs existed
- 1995-1995: Federal **Cancer Registry Act (KRG)**
- 2009: Federal Cancer Registry **Data Act (BKRG)**
- 2013: Early Cancer Detection and Registry Act (KFRG) => **Quality Assurance through Clinical Cancer Registries**
- 2021: Law on **access to cancer registry data (KRDaZuG)** vom 18. August 2021
- 2022: Call (BMG) Merging and intelligently utilizing cancer registry data: Innovative projects using artificial intelligence
- 2024 Health Data Utilisation Act (GDNG)

15 federal, 1 children and 1 national cancer registry



Population-based clinical cancer registration in Germany

Key characteristics

- **Comprehensive data catalogue (130+ items)**
 - Stage and date at **diagnosis**, histology...
 - Detailed **treatment** data (incl. treatment beyond primary treatment)
 - **Recurrence** and progression
 - **Genetic** data
 - Date and cause of **death**, **out-migration**
- **Mandatory** reporting for **all health care providers** (PCPs, hospitals) involved in **cancer care** (except rehab)
- Reporting based on **EHR/interfaces** or **manual** data entry
- **Patients' consent** only required for storing patient's name and address
(=> enables contacting for further research, e.g. in death surveys, PROs...)
- Record **linkage** via pseudonym
- Data **exchange** across states
- **Financial reimbursement** for clinicians (~5-20 EUR (\$) per notification)
- 90% of all **costs covered** by **health insurance** (statutory and private)



Oncological basic dataset (oBDS 3.0) 130 items

Basic dataset	Data fields (approx. 130)
Personal data	Health insurance number, name, address, date of birth, gender
Details of the reporting centre	Institution, name, address
Tumour diagnosis	ICD-10, ICD-O localisation, diagnosis date, diagnosis confirmation, site
Histology	ICD-O morphology, grading, Number of lymph nodes examined and affected
Tumour classification	TNM and other classifications
Genetic variant	Type
Residual status	After surgery and overall assessment
Performance status	ECOG (at diagnosis)
Surgery	Date, intention, OPS coding, complications
Radiotherapy	Date, Intention, position for surgery, target area, start, end, dose, boost, complications (CTCAE)
Systemic therapy	Date, intention, position for surgery, type of therapy (including active surveillance), protocol, substance, start, end
Tumour board meetings	Date, type
Follow-up	date, overall assessment of tumour, lymph nodes and metastases
Death	Date, cause of death

Oncological basic dataset - Extensions

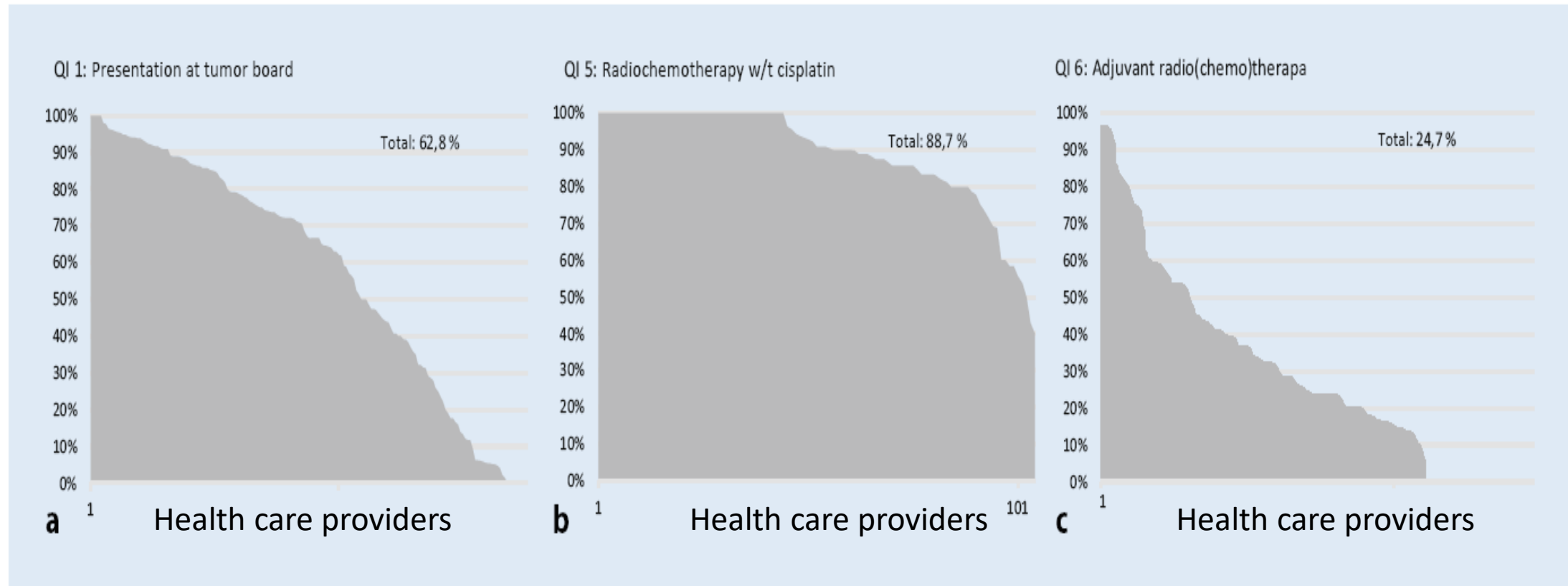
Tumor-specific modules	Specific content
Breast cancer	10 variables
Prostate cancer	10 variables
Colorectal cancer	12 variables
Melanoma of the skin	4 variables

In development

- Late and long-term effects
- PROs

Applications (examples):

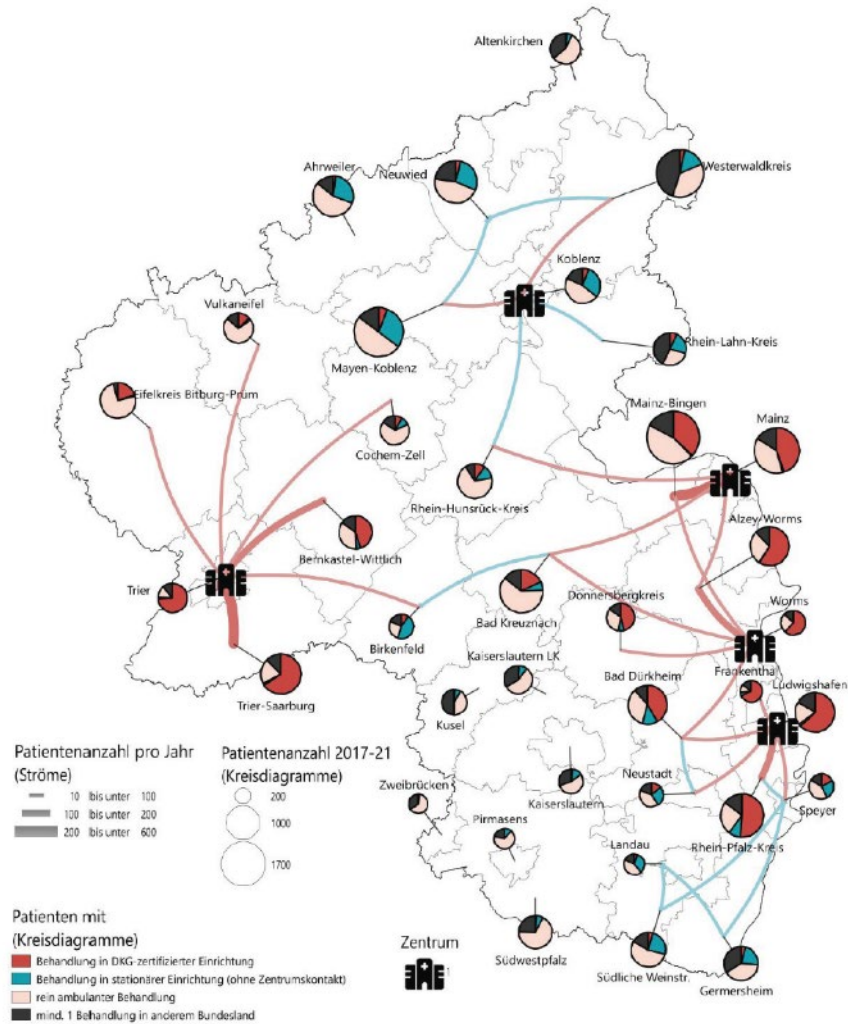
Fulfilment rates of quality indicators in oncological care of cervical cancers



Fulfilment rates of quality indicators by type of hospital

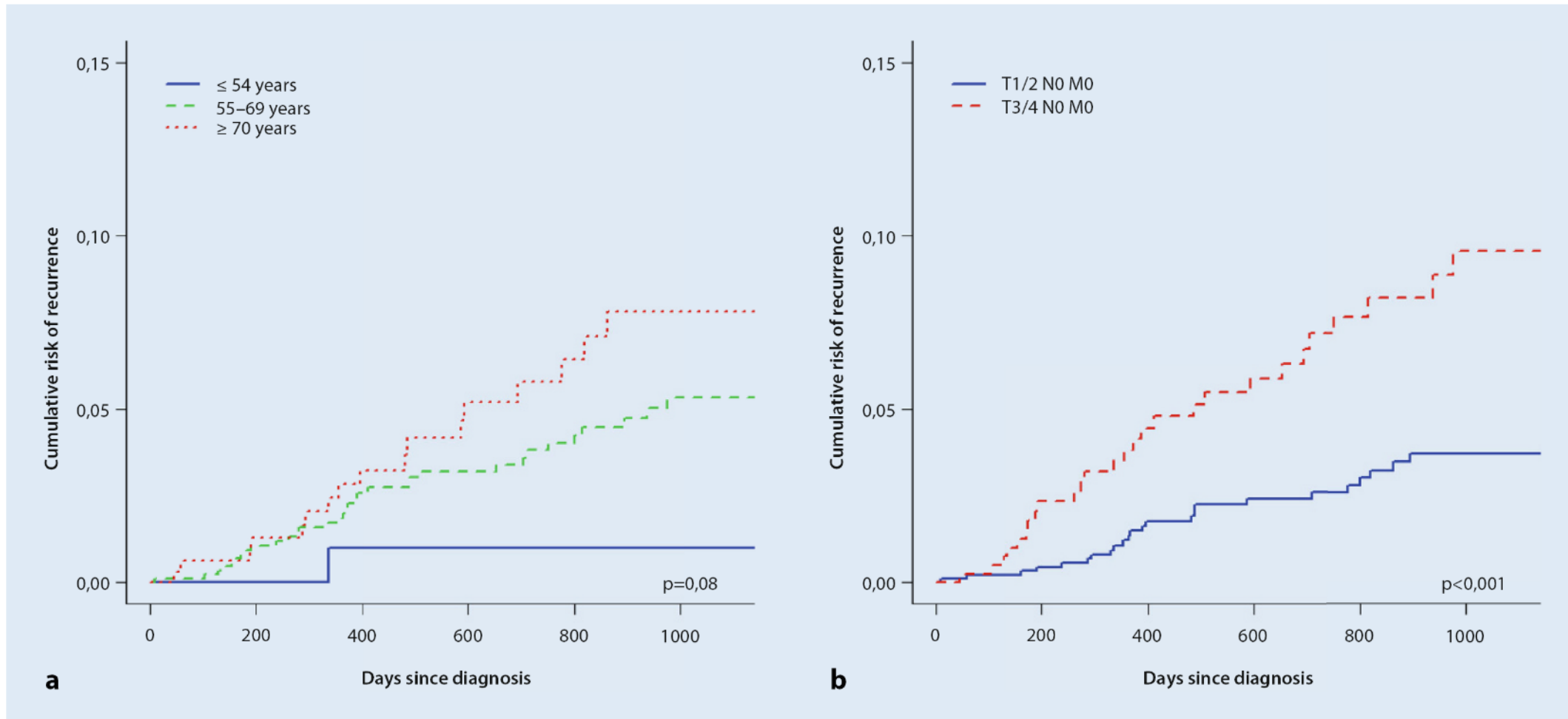
Patient group/quality indicator (QI)	Certified CCC	Other hospitals	p-Value
Breast Cancer			
• X-ray, ultrasound while surgery	97%	92%	< 0,001
• Hormones as first-line therapy in metastatic stage	43%	25%	< 0,001
• Sentinel node biopsy alone	75%	23%	< 0,001
• Radiotherapy after BCT	80%	63%	< 0,001
• Adjuvant endocrine therapy	64%	42%	< 0,001
• Trastuzumab > 1 year	59%	33%	< 0,001
Colorectal Cancer			
• Combination chemotherapy	81%	68%	< 0,001
• Distance to mesorectal fascia reported	52%	46%	0,09
• Good or moderate quality of total mesorectal excision	93%	89%	0,01
• Adjuvant chemotherapy	49%	37%	< 0,001
• Preoperative marking of the stoma position	87%	78%	< 0,001
Lung Cancer			
• Adjuvant chemotherapy with a cisplatin-based combination	51%	35%	< 0,001
• Radio-chemotherapy (NSCLC)	34%	27%	0,03
• Radio-chemotherapy (SCLC)	32%	17%	< 0,001

Patient journeys (State of Rhineland-Palatinate)



- Certified CCCs attract patients
- ...even from neighborhood counties
- ... and to other states

Recurrence in patients with prostate cancer (ICD-10 C61) after radical prostatectomy (R0)



Applications, challenges and outlook



Applications

- Quality of cancer care
- Pattern of care
- Real-world data regarding efficacy of novel treatments.
- Feedback to health care providers
- Public interactive web-sites

Challenges

- Data quality:
 - Completeness?
 - Timeliness?
 - Validity?
- Extra work for health care providers (and registry)
- Extensive plausibilization and harmonization necessary
- Rehab not yet included
- No baseline comorbidity
- Costs

Outlook

Call by MOH (2022): Better use of cancer registry data by AI

1. Merging and validating CR data using AI
2. Analysis of CR data using AI
3. AI-driven completeness checks of therapy data
4. TextMining of pathology reports
5. AI-based biomarker detection
6. AI-supported evidence generation by linking data from clinical cancer registries, health insurances, and hospitals

Health Data Utilisation Act (2024)

- Linkage of CR, HI and other data