UICC global cancer control

A MEMBERSHIP ORGANISATION
FIGHTING CANCER TOGETHER

DKG
KREBSGESELLSCHAFT

Initiative-
European Round Table Meetings

22. Informationstagung Tumordokumentation der klinischen und epidemiologischen Krebsregister

Dr. Ulrike Helbig MBA

Krebs – ein zunehmend gesellschaftliches Problem

- Die Zahl der Neuerkrankten wird in den nächsten zwei Dekaden in Europa von 3,6 auf 4,3 Millionen steigen, das bedeutet zusätzlich 716 000 jährlich.

- Die Zahl der Patienten, die mit Krebs leben, steigt entsprechend steiler an - Krebs wird die chronische Erkrankung Nummer 1.

- Global sterben 23 000 Patienten pro Tag an Krebs.

- Zu Zeit sind Gesundheitsversorgung, Prävention und Forschung nicht in der Lage, dieses Problem auszutarieren.

Gesundheitsausgaben rund um Krebs in der EU

- €35.7 Milliarden in 1995
- €83.2 Milliarden in 2014

Drugs:

- €7.6 Milliarden in 2005
- €19.1 Milliarden in 2014

B. Jönsson

9/10 drugs are failing registration

Costs for one approved drug

800 million USD

Comprehensive Cancer Care Netzwerke in Deutschland

Deutschland

- Bevölkerung: 81 Millionen
- Föderaler Staat mit 16 Bundesländern

Bundesministerium
für Gesundheit

Nationaler Krebsplan

Handlungsfelder, Ziele
und Umsetzungsempfehlungen

www.bundesgesundheitsministerium.de

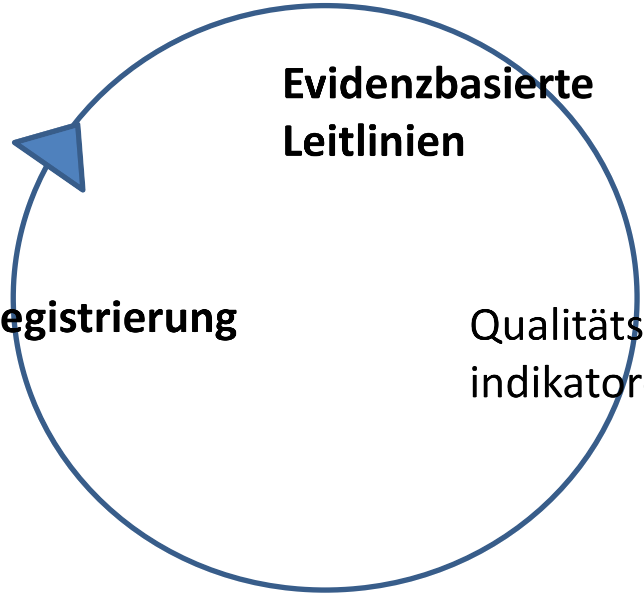
Deutsche Krebshilfe

DKG

ADT

Onkologen im niedergelassenen Bereich

Ca.620 Onkologen
Ca.320 onkologische Urologen
Ca. 140 onkologische Gynaekologen

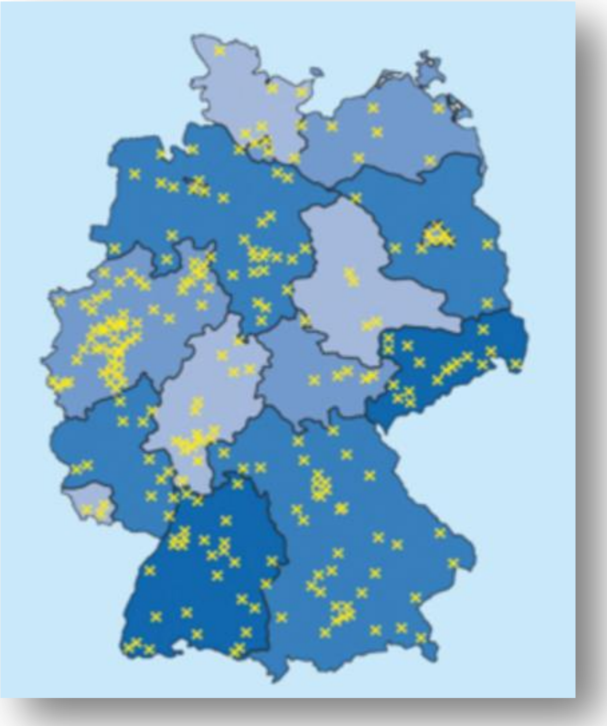


Evidenzbasierte Leitlinien

Qualitäts-indikatoren

Zertifizierte Zentren

Krebsregistrierung



Krebsversorgung in Europa

Inhalte National Cancer Control Plans:

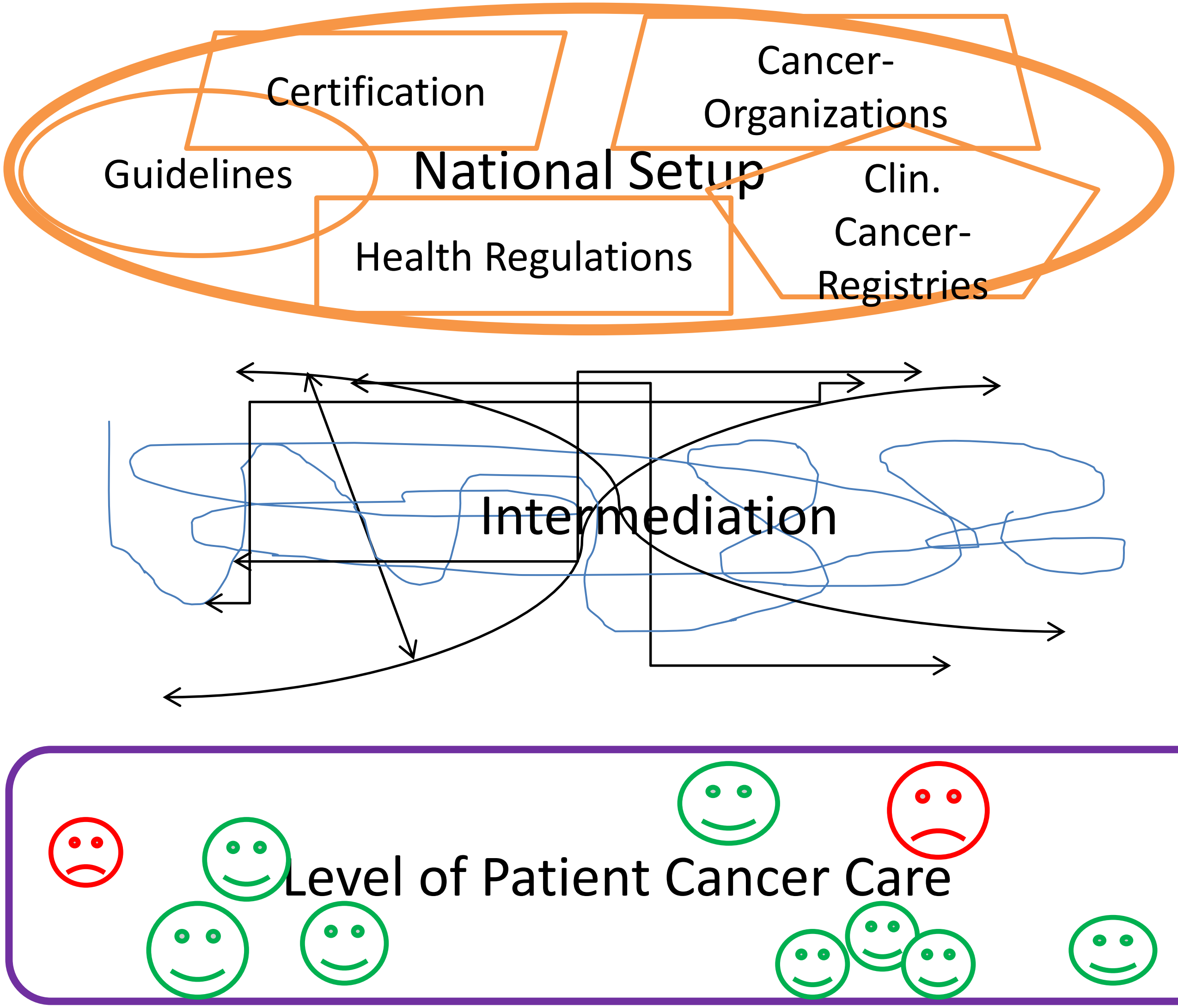
- Registrierung
- Öffentliche Gesundheitskommunikation
- Prävention
- Früherkennung
- Integrative Krebsversorgung
- Quality of Care
- Krebsforschung

Krebsversorgung in Europa

Vorhandene Unterschiede in den verschiedenen Europäischen Ländern

- Cancer-Burden
- Struktur
- Strategie
- Versorgung/ Resources

Improving Cancer Care in Europe- 1st ERTM, Germany



1. ERTM, Germany, 2014

Improving Cancer Care in Europe - Share best practice and learn which institutional structures are beneficial and why?

1.) Which structures are necessary on a national level to be able to define and develop a strategic approach to quality in cancer care?

2.) Which criteria are necessary / important to implement the defined strategy for cancer care?

3.) What is necessary to measure quality cancer care in your system?

2. ERTM, Germany, 2015

Improving structural development in oncology – transformation of theoretical health care standards and knowledge into a practical approach

1.) Which strategies of communication between clinical cancer registries and cancer centres are needed to improve quality of care?

2.) Which procedures and communication networks are essential in cancer centers to guarantee optimal interdisciplinary, multi-professional patient care?

3.) What is necessary to include the patient perspective into structural development of cancer care networks?

3. ERTM, Germany, 2016

Current developments in cancer care: including the patient perspective

1.) How much transparency is needed in patient care, how can it be implemented?

2.) How does the cancer care system react on gain of knowledge, how fast can standardized reactions be implemented on basis of patient needs?

3.) How does a benchmark for decision making in partnership with the patient need to be defined?

4. ERTM, Germany, 2017

Quality control and improvement of cancer care – what is needed

1.) How does the data flow need to be described?

2.) How do communication processes between institutions need to be described?

3.) How does result-communication need to be described?

Dutch Cancer Society

Mission:

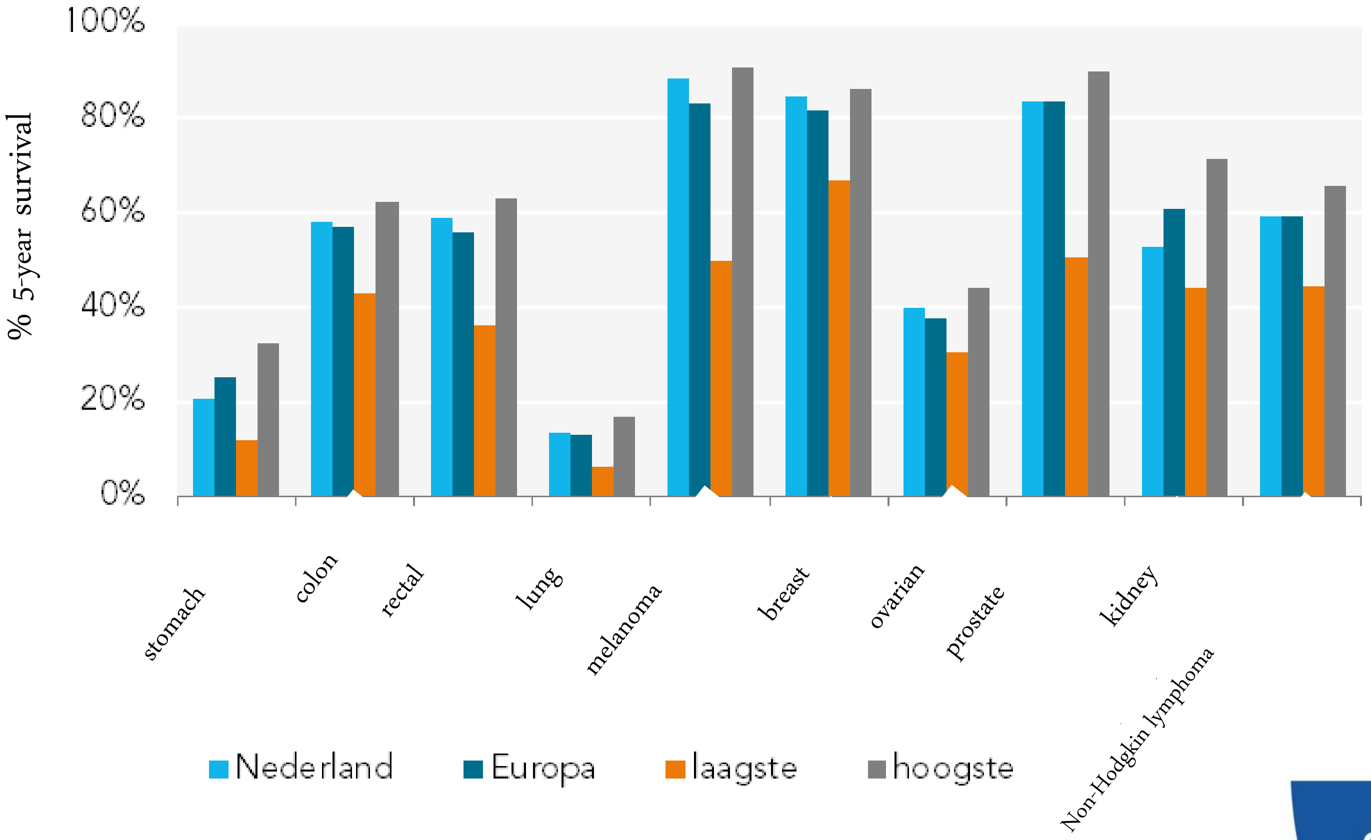
- Reduce cancer rates as soon as possible, and get it under control. We are here to help people living with cancer and those who share their lives.

Goal:

- Less cancer, more cure and a better quality of life for cancer patients

Cancer survival in The Netherlands compared to other European countries

5-year age-standardised relative survival for adult patients with cancer, diagnosed 2000–2007



Source: EUROCARE-5 Lancet Oncology 2013, and report 'Kankerzorg in Beeld', IKNL

DUTCH CANCER SOCIETY

Cancer in Iceland

- Over 50% of cancers are diagnosed after the age of 65 years.
- Cancer causes 28% of all deaths in Iceland.
- One of three Icelanders.....

Infrastructure primary care

- Public health care system with primary health care centers geographically distributed and with local responsibilities.

The Swedish approach

- Regional coordinated cancer centres were established at six geographic areas 1974 - the oncologic university clinics got the mission to coordinate the cancer care
- Regional clinical guidelines with referral recommendations were implemented
- Clinical cancer registries were linked to the regional cancer registries – population based clinical registries
- Regional cancer registries report to the central Swedish Cancer Registry
- University clinics and academic institutions were under a single leadership

A successful development

- At that time, no economic problems – all could agree, no competition
- Clinical guidelines for multidisciplinary cancer care were developed for main tumour diseases
- Adherence to clinical guidelines was assessed
- Recommended referral pathways were respected
- Psychooncology was implemented
- Early detection recommendations were disseminated
- Clinical trials activity was structured in several geographic areas
- Epidemiological research expanded

Spanish NHS Cancer Strategy

Decision of the *Consejo Interterritorial of NHS* 2006:

- Updated in 2010 and this year (2105), a new cancer strategy for the next four years is under discussion
- Scientific Board with advisors from scientific societies, patient groups and representatives of all regions
- From prevention to palliative care: Aims essentially to coordinate the activities of regions and to promote cancer plans in the regions that at the time may not have one
- Based on the experience of the regional cancer plans: Catalonia (2001), Andalusia (2004), Valencia (2005), Castilla-Leon (2005)

Spanish NHS Cancer Strategy

- Consensus based approach to the objectives and targets in Cancer Strategy among all stakeholders (regions, Ministry, scientific societies and patient groups)
- Evidence as input to policy making but not the only matter:
  - Policy discussions about budgetary impact
  - Values at stake different according to region and scientific societies.
  - Equity of access as the central issue for policy discussion, but focused on access to new drugs
  - Centres of reference at national level with specific budget for these procedures at central level, but eliminated three years ago: problems of referral of patients
  - Regionalised strategies for centralising specific procedures limited to one region, but others with interest. Innovation role of some regions worthy of mention

Based on inventory of Eurocourse:

160 ‘certified’ cancer registries (CRs) in Europe

General cancer registries: N=140 (15-20% national, 75-80% regional)

- **All sites** → dozens of studies of:
  - Incidence by subsite & subtype (ICD-O 3)
  - Survival, often with stage at diagnosis
- Good assessment of multiple tumours
- Sampling frames for in-depth work
- Linked to many other cohorts
  - Including cohorts of radiotherapy patients

Specialised cancer registries (tumor, tract or age) national/regional

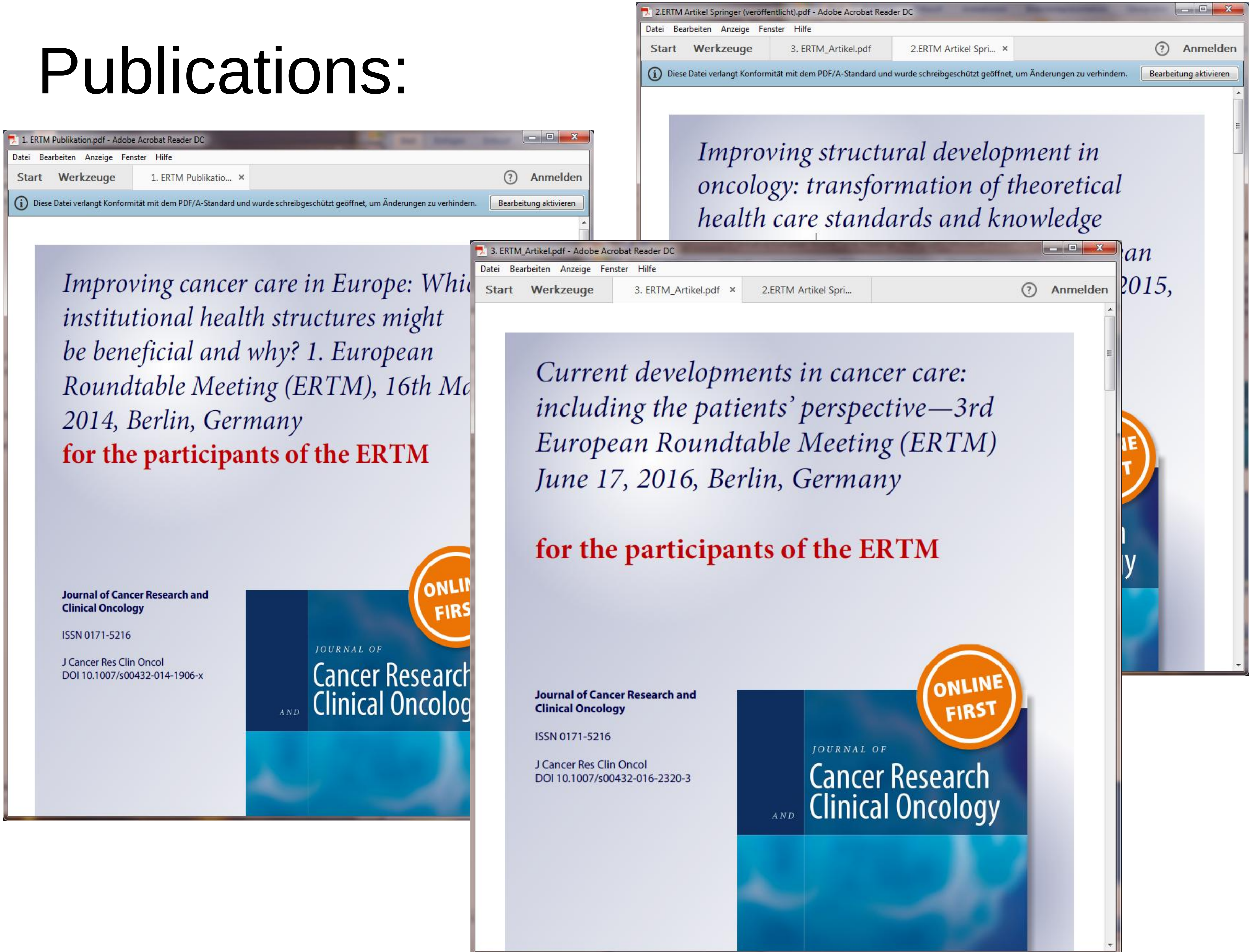
- About 20 isolated
  - Many more, part of a general CR registry
  - Also called: clinical CR
  - About 10 childhood CRs
- Often with (too !!) much unused clinical data
  - useful support to clinical oncology
  - especially elderly, side effects

(Siesling et al, 2015)

Take home messages for the registry aspect

- Develop programmatic research platform for CRs
  - Get energy from MSc and PhD students
- Multi-regional projects of dedicated registries
  - Within and across country borders
  - Study question-based minimal data on processes and outcomes
- Develop early ‘success’: lightfooted through the swamps
- Step by step: big adventures are vulnerable
- Make it possible that others can join the bandwagon
- Educate your program owner (constantly)

Publications:



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Improving cancer care in Europe: Whi
institutional health structures might
be beneficial and why? 1. European
Roundtable Meeting (ERTM), 16th M
2014, Berlin, Germany

for the participants of the ERTM

Journal of Cancer Research and Clinical Oncology

ISSN 0171-5216

J Cancer Res Clin Oncol
DOI 10.1007/s00432-014-1906-x

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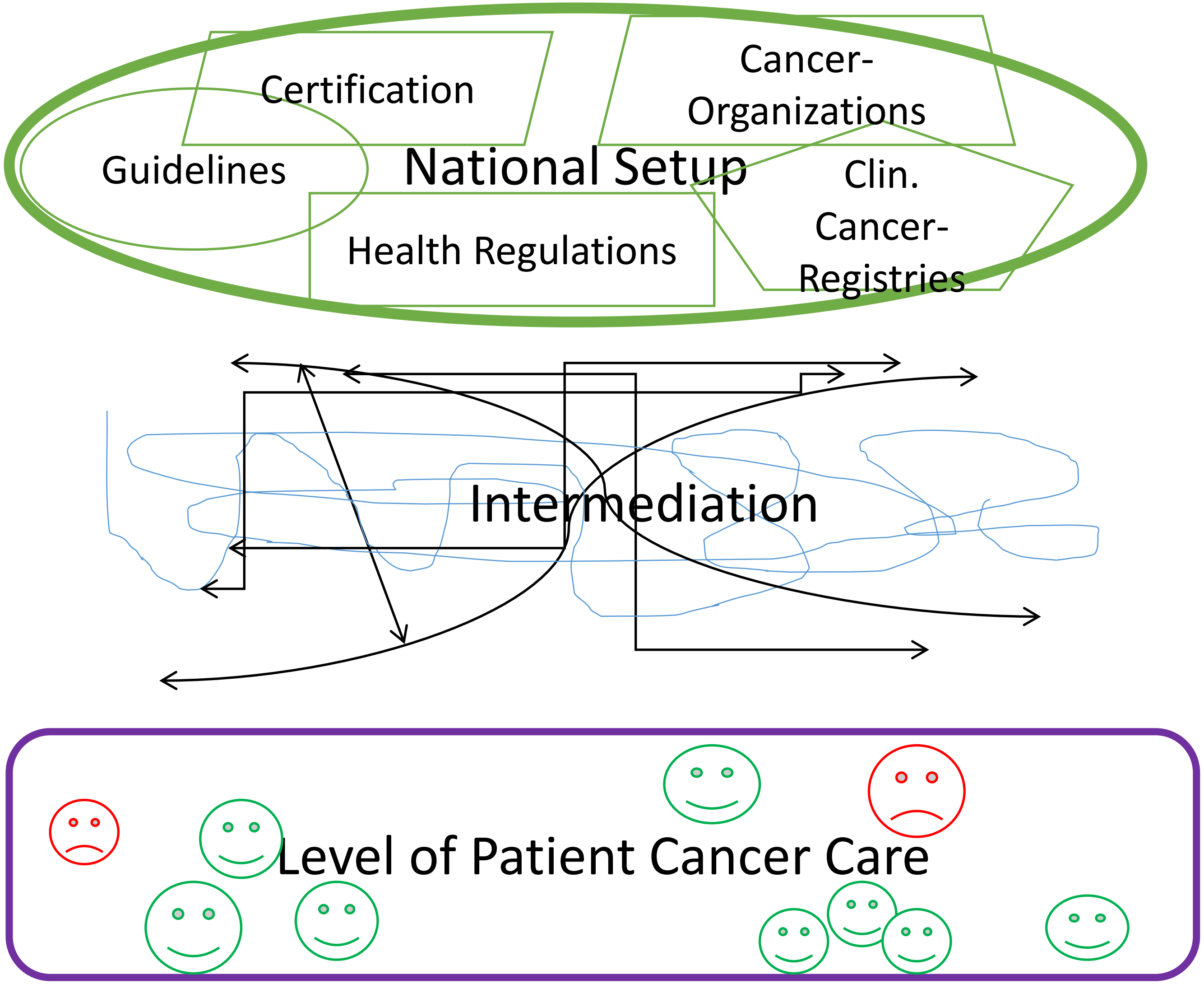


National Setup

Certification

Cancer-Organizations

Guidelines

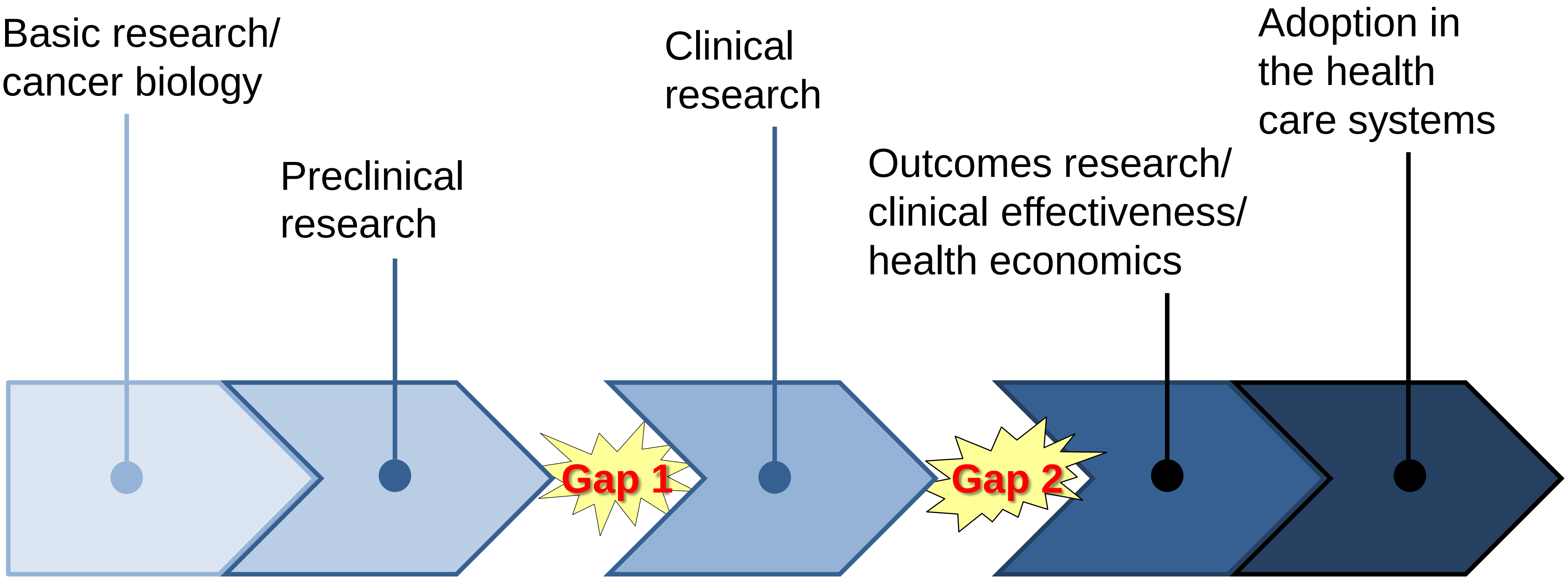
Health Regulations

Clin. Cancer-Registries

Intermediation

Level of Patient Cancer Care

Translational cancer research – a coherent research continuum



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Vielen Dank

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