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Role of the cancer registry in clinical cancer control

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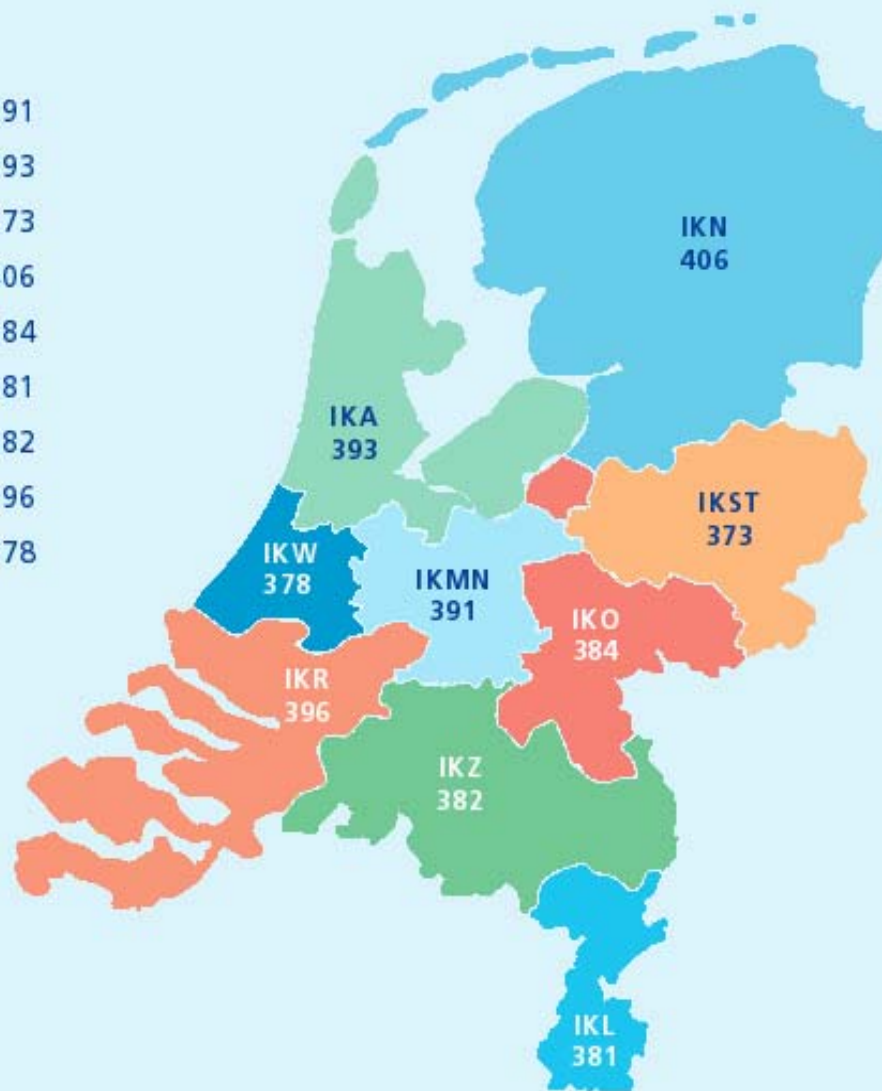


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Figure 2 **Incidence of all cancer sites (ESR) male plus female**

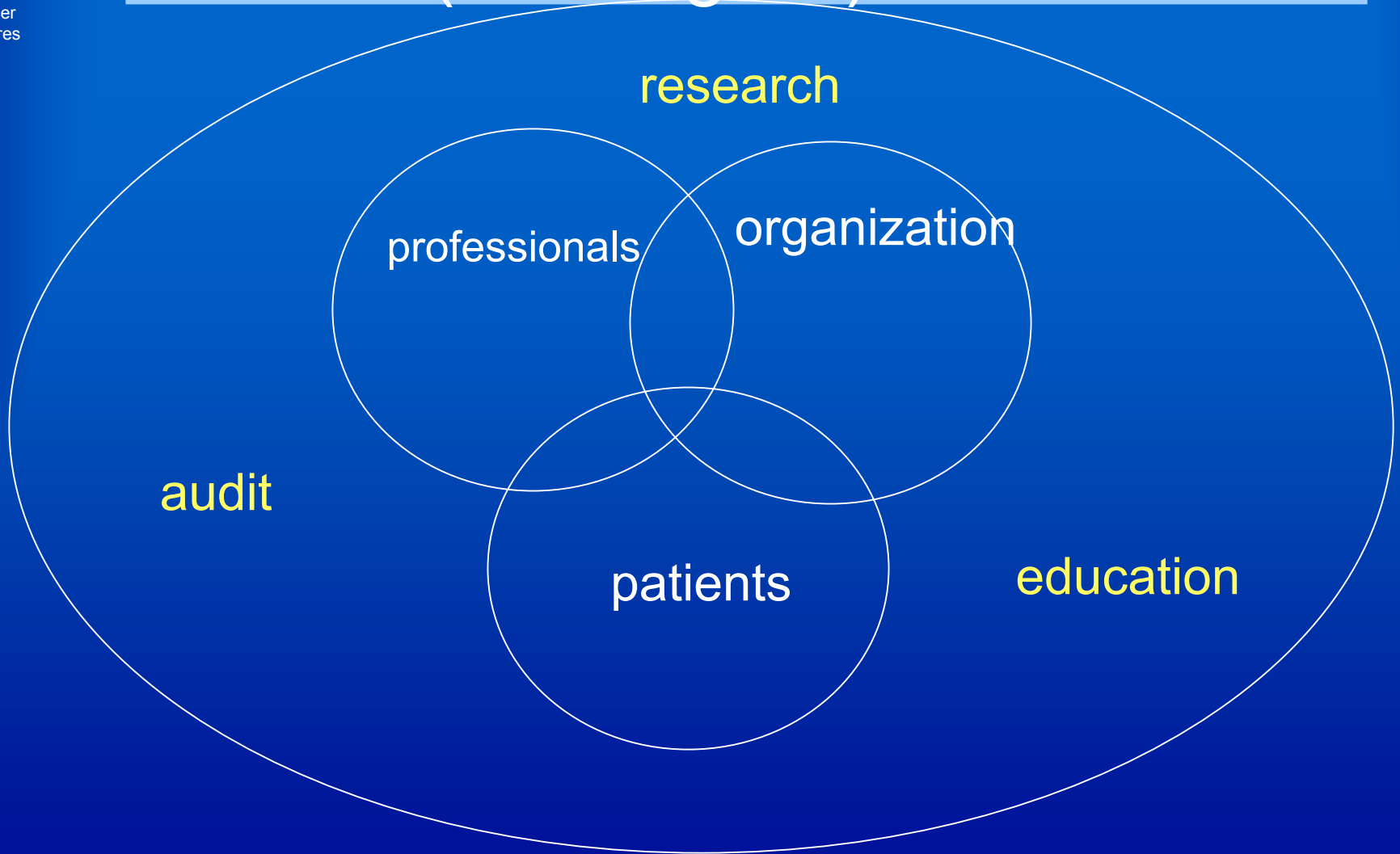
| | | |
|------|---|-----|
| IKMN | – | 391 |
| IKA | – | 393 |
| IKST | – | 373 |
| IKN | – | 406 |
| IKO | – | 384 |
| IKL | – | 381 |
| IKZ | – | 382 |
| IKR | – | 396 |
| IKW | – | 378 |





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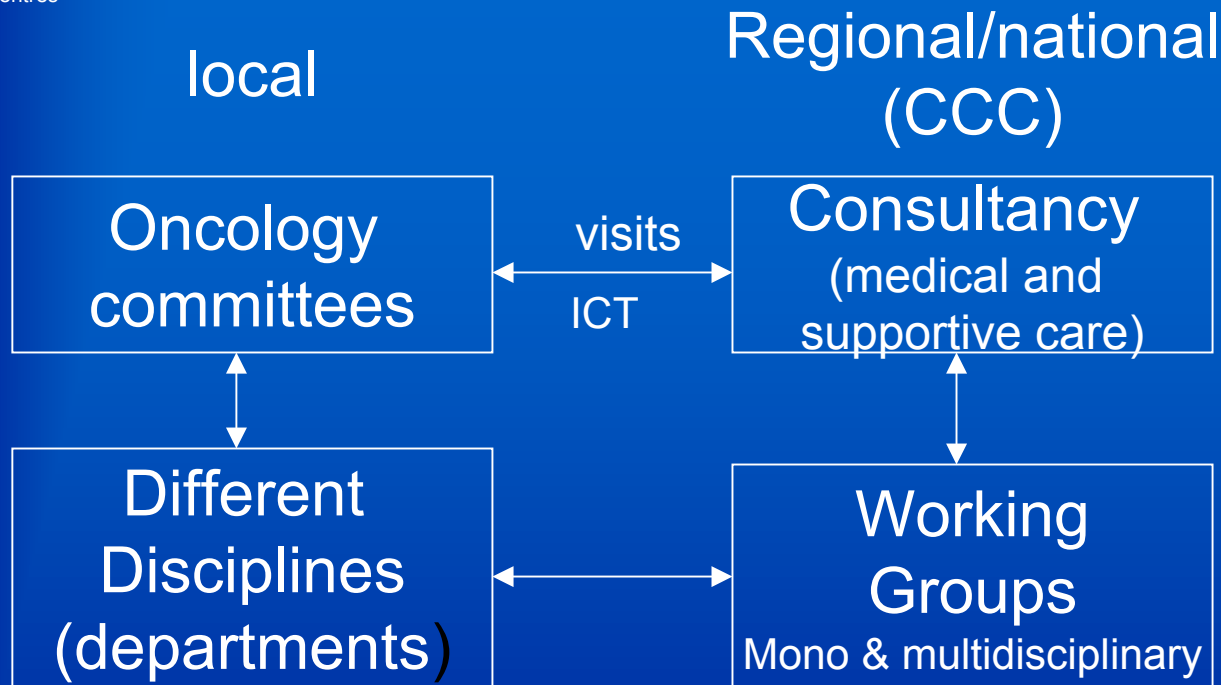
Elements of a quality system for (oncological) care





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Professionals



- symposia
- conferences
- training programs
- information material for
 - .patients
 - .health care givers
- guidelines:**
 - evidence –based
- revalidation program
- palliative care structure
- studies, trials**



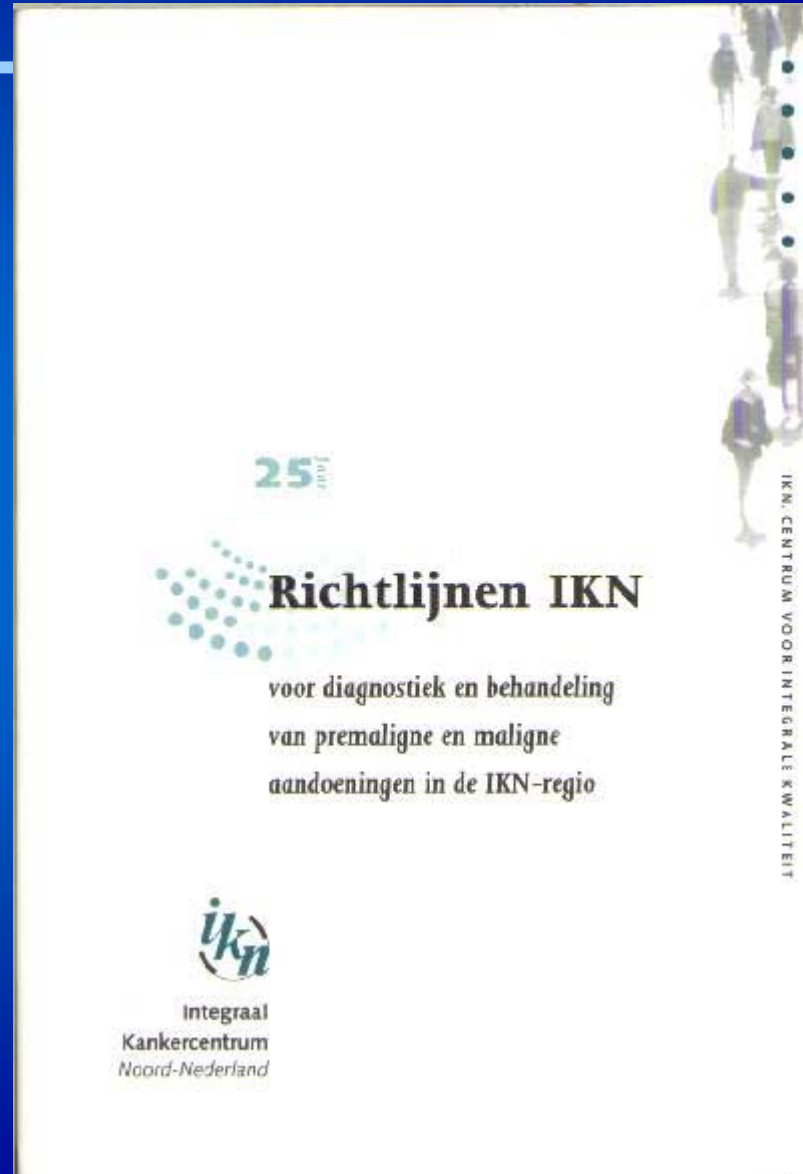
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guidelines

Regional: www.ikn.nl

National: www.oncoline.nl

Or: www.ikc.nl





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Organization

- Includes
- Structure f.e.
 - structured multidisciplinary consultation for selected cases of cancer patients
 - Structured transfer of information given to the patient between the professionals
- Proces f.e.
 - waiting time between professionals
- Organization f.e.
 - Management of oncological care



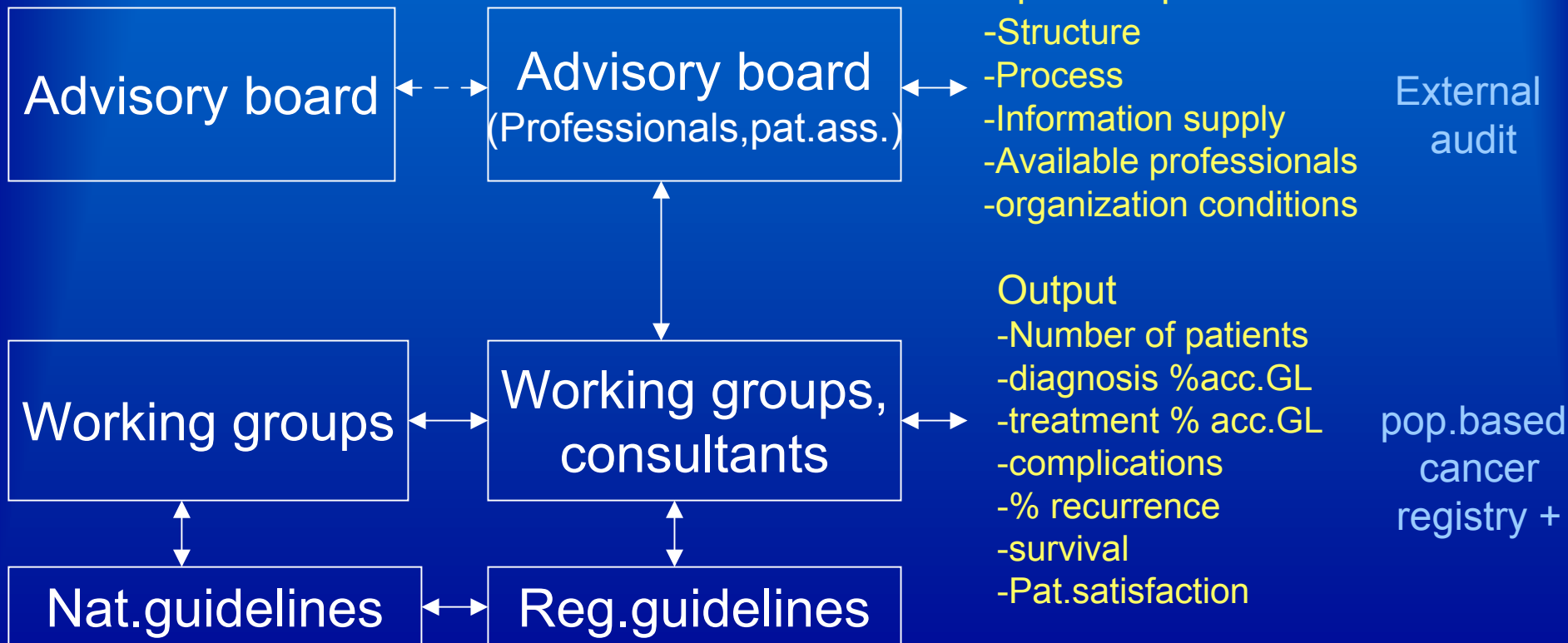
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Measurement tools

CCC national ↔ CCC regional

norms

tools





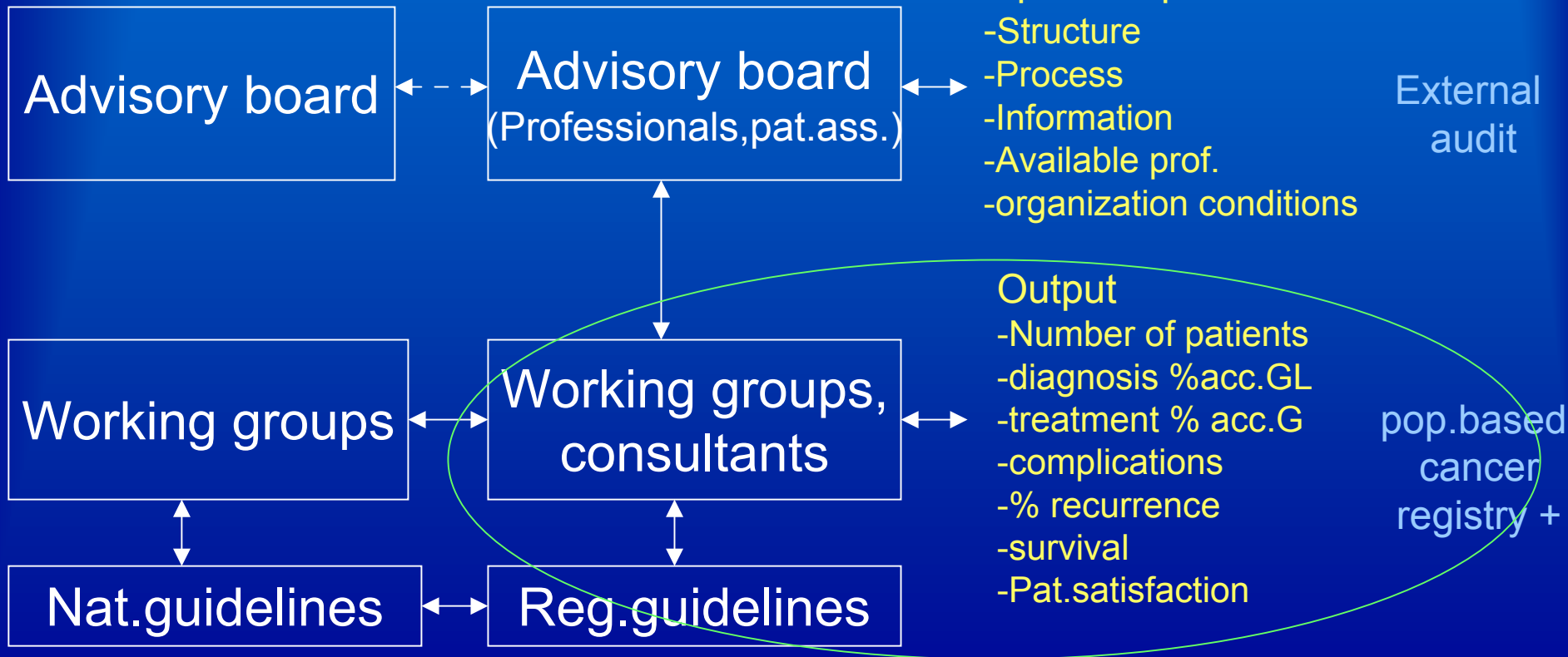
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Measurement tools

CCC national ↔ CCC regional

norms

tools





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Population-based cancer registry

- Organization: (since 1986)
 - 9 regional registries → one national registry
- Some data:
 - Population:
 - 15.5 million inh. (49% males, 51% females)
 - 450 inh/km²
 - 65 000 new cancer patients/year
- Life expectancy:
 - Males: 74 years
 - Females: 80 years



Population-based cancer registry

- Data collection:

- Sources:

- pathological lab.
 - Hospital discharge diagnosis
 - Radiotherapy institutions
 - Hematological departments



- Medical records

- Abstraction and recording by trained registrars

- Data entry into the PC

- Regional registry ↔ national registry



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Cancer registry and multidisciplinary working groups

- Annually feed back during a meeting of regional data out of the general cancer registry:
 - regional adherence to the guidelines
- Feed back on specific data concerning additional data asked by the WG (documentation/pattern of care studies):
 - Insight information



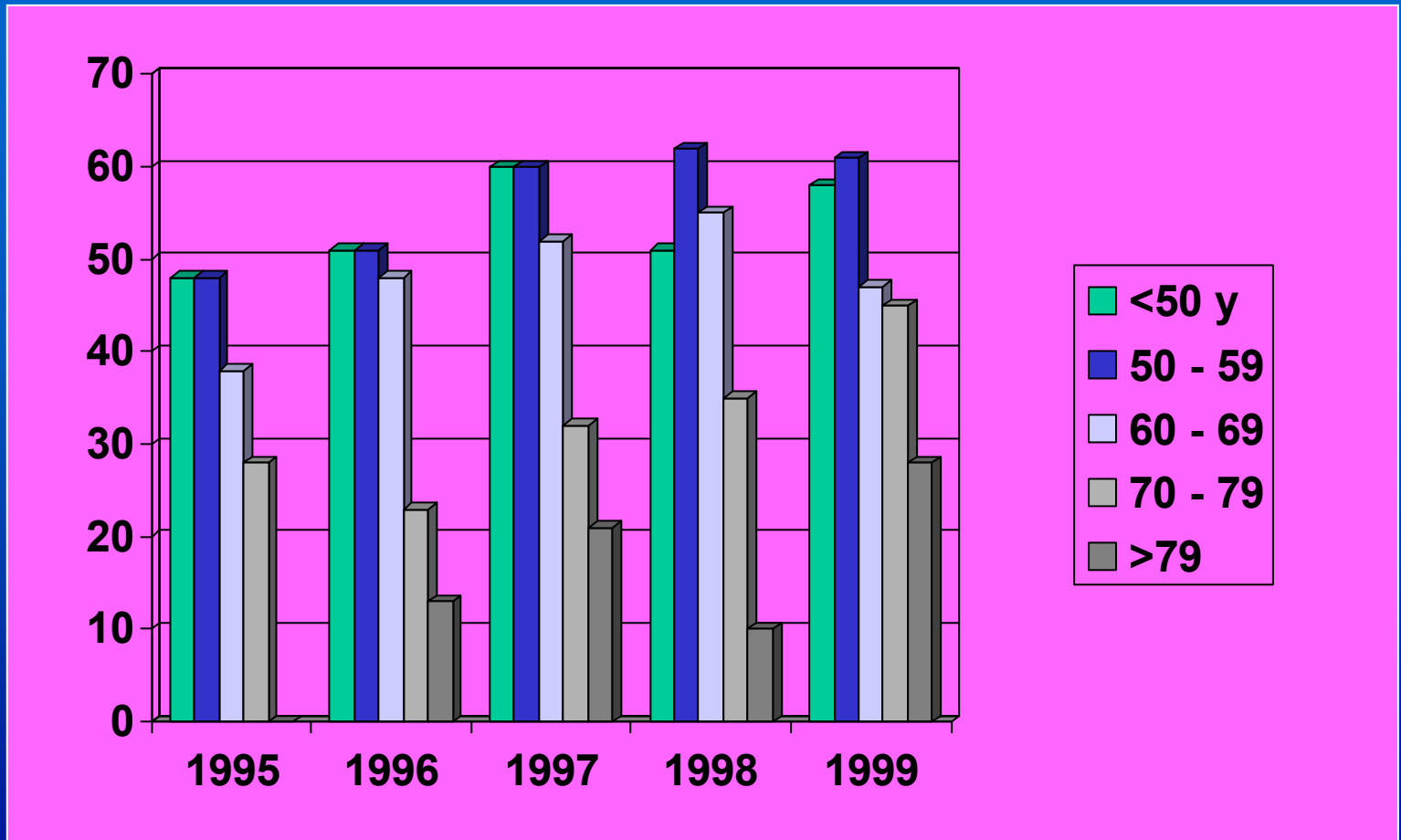
Invasive breast cancer

- GL since 1970's on CCC level
 - GL since 1994:
 - **T1-2, N0-2 :BCT**
 - **No age limit**
- Incidence in NL
 - 1989: 7,894
 - 1998: 10,317
- Screening programme:
 - Starts in 1990, implemented in 1996 on national level (50-69)
 - Since 1996 :70-74 years included
- 1998
 - **T1 N0-2: 50.6% of all diagnosed breast cancers**
 - **T2 N0-2: 40.3 %**
 - T1= <2 cm
 - T2= 2-5 cm



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% BCS + RT for T1 N0-2 breast cancer patients





Compliance to GL

- **Lip cancer** (CCC level)
 - GL: no revision since 1989
 - Incidence WSR: 2,06
 - N=248, 1989-1997
- **Adherence:**
 - Diagnosis: 41%
 - Staging:
 - Physical exam.: 70%
 - Chest X-ray: 26%
 - Treatment: 44%
 - » Int.JQHC 2001
- **Soft tissue sarcoma** of head & neck, upper and lower limbs (CCC level)
 - GL identical 1989-1998
 - Incidence WSR:
 - M:1,17 F 1,24
- **Adherence:**
 - Physical exam.: 78% (93% center-73% district hospital)
 - Radiological exam. Of tumor region: 54% (86 – 41)
 - Lab.exam.: 84% (84-79)
 - » Cancer 2001

Cancer registry and hospitals (1)



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- **Pattern of care studies** on regional level :
 - additional data to the registry are registered on request of the professionals by CCC registrars
 - Evaluation on regional and local (hospital) level: **bench marking**
 - Examples: complications of treatment versus patients' volume (rectal surgery, chemotherapy...)

Cancer registry and hospitals (2)



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- Cancer registry as source for special requests:
 - patient satisfaction: results on hospital and professional level versus the regional average
- Planning, development and control:
 - Radiotherapy instruments
 - Capacity of medical specialists
 - PET scans.....

Number of projects in the CCC's (1989-2000)



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| Tumor localization | CR and adherence to GL | CR + and adherence to GL | Others |
|--------------------|------------------------|--------------------------|--------|
| Head & neck | | 2 | 1 |
| Digestive system | 5 | 2 | 3 |
| Lung | | | 1 |
| Soft tissue | 3 | 2 | 2 |
| Melanoma | | 2 | |
| Breast | | 9 | 4 |
| Gynecology | 3 | 4 | 3 |
| Urology | | 2 | 3 |
| Hematology | 2 | 1 | 7 |
| All cancers | | | 4 |



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Conclusions

- 1. A population-based cancer registry including items on staging and initial treatments is of great use with regard to evaluation of implementation of clinical guidelines and clinical cancer control
- 2. More research is needed to better understand the reasons of differences between hospitals in compliance to GL, and to show the relevance of adhere to the GL for the patients



Conclusions

- 3. Improvement of the quality in oncological care requires an additional organization in order to feed back the results to the professionals , on regular basis (guarantee for quality)
- 4. The cancer registry can be used for many purposes, but usually only few are taken into account.



Conclusions

- 5. However the registry must contain data of high quality which the researcher and the user should rely on
- This requires a.o.
 - Well trained personnel and staff
 - Well defined data and an up to date manual
 - a systematic datacontrol on quality and a quality manager

