The Cancer Registry: what to know?

Belgian Cancer Registry

International Congress of Breast Disease Centers,
Paris, 28-29 January 2011

www.kankerregister.org | www.registreducancer.org

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Overview

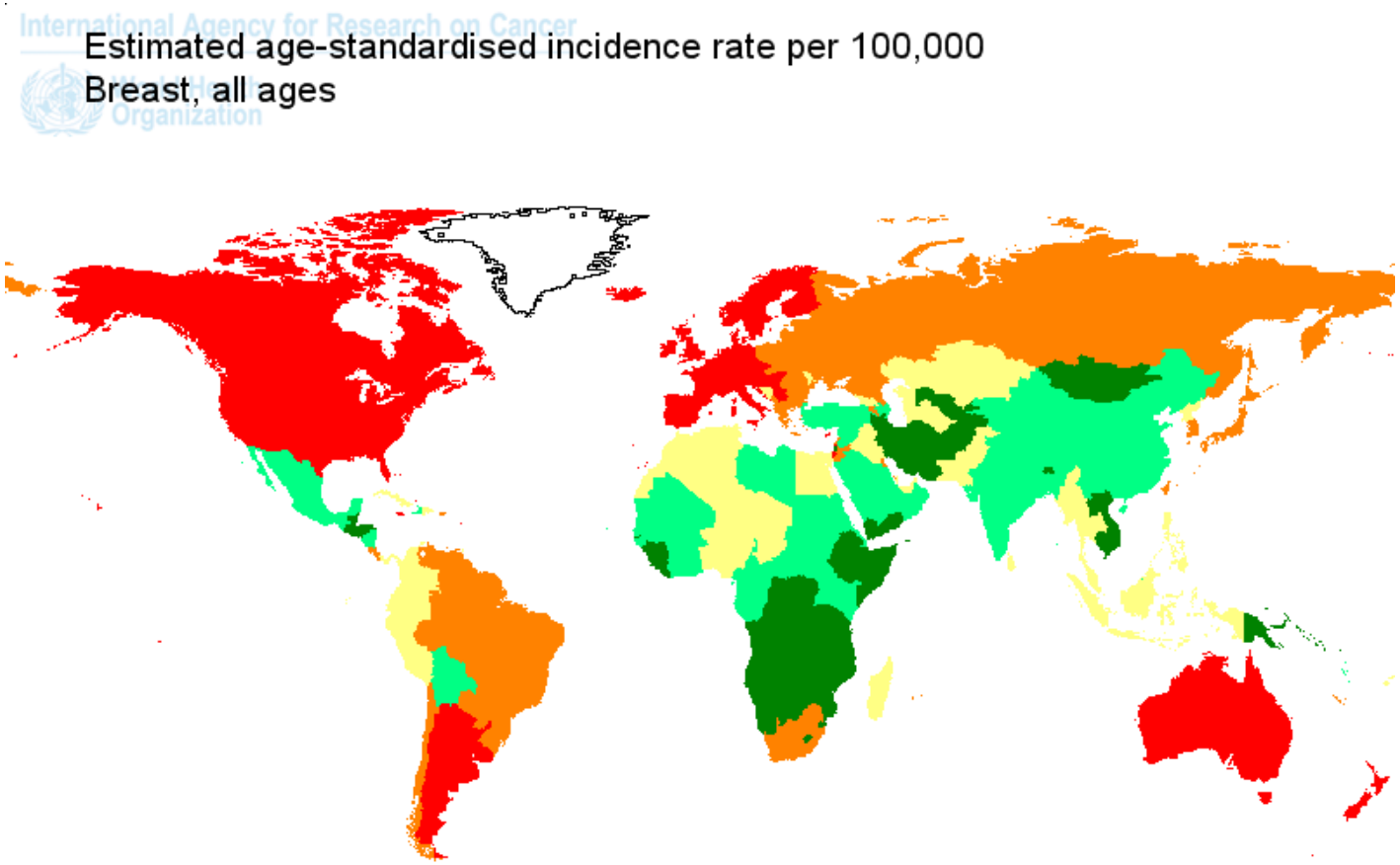
- Introduction
- The Role of the Cancer Registry
  - Incidence
  - Survival
  - Quality of Care and quality indicators
    - examples
- Need for standardization
- Conclusion

The role of the Cancer Registry

- Collection and analysis of data
  - Population based (vs hospital based)

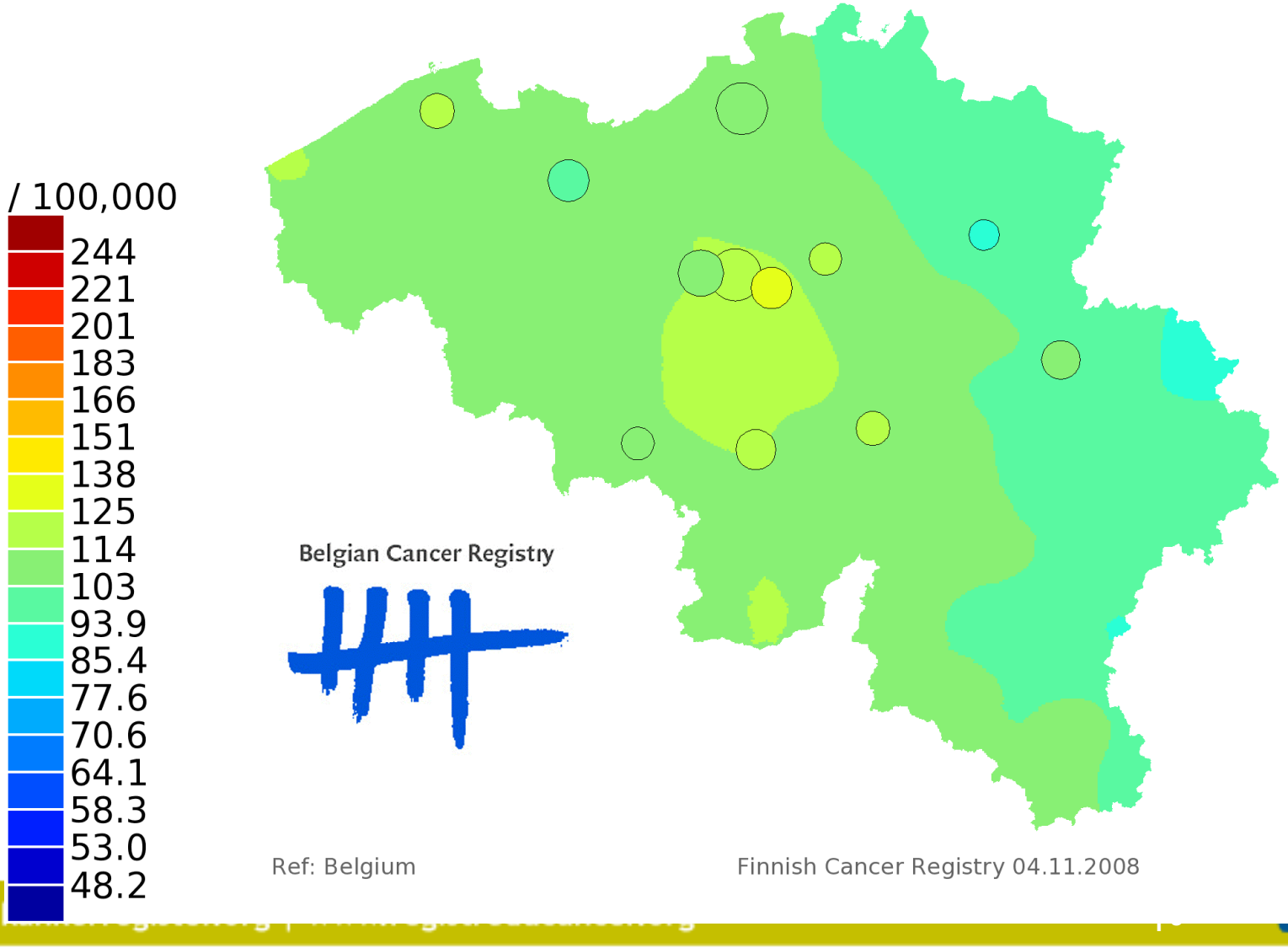
- Cancer Incidence
  - Description of the cancer burden
  - Comparison
  - Predictions
  - Monitoring (sex, age, geography, time, stage, socio-economic)

Cancer Incidence: geography



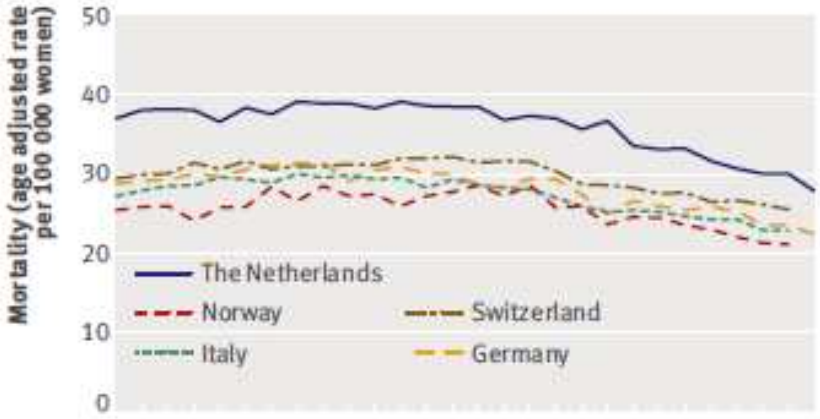
2008

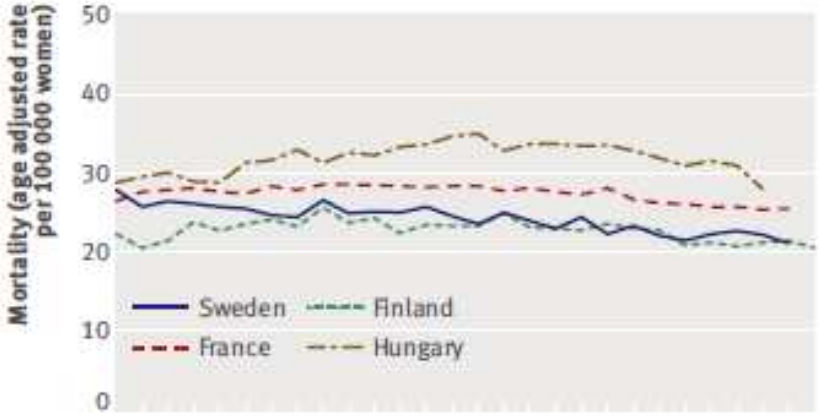
Incidence of Breast Cancer
Belgium, Females, 2004-2005

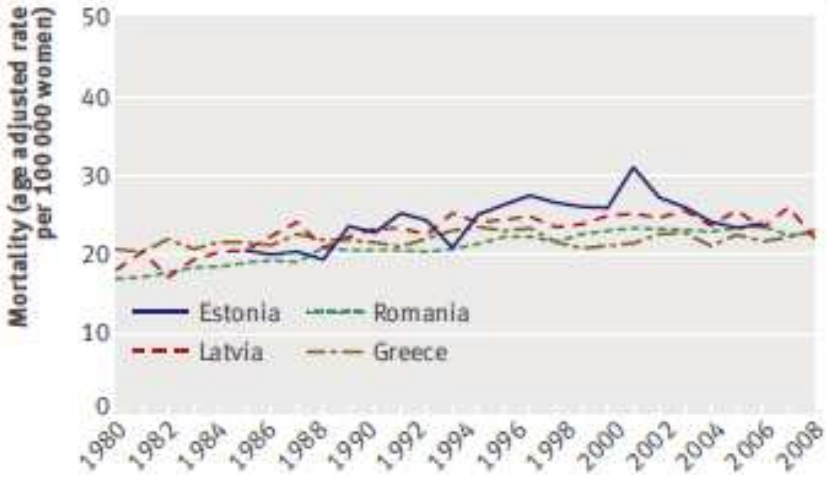


Ref: Belgium

Finnish Cancer Registry 04.11.2008





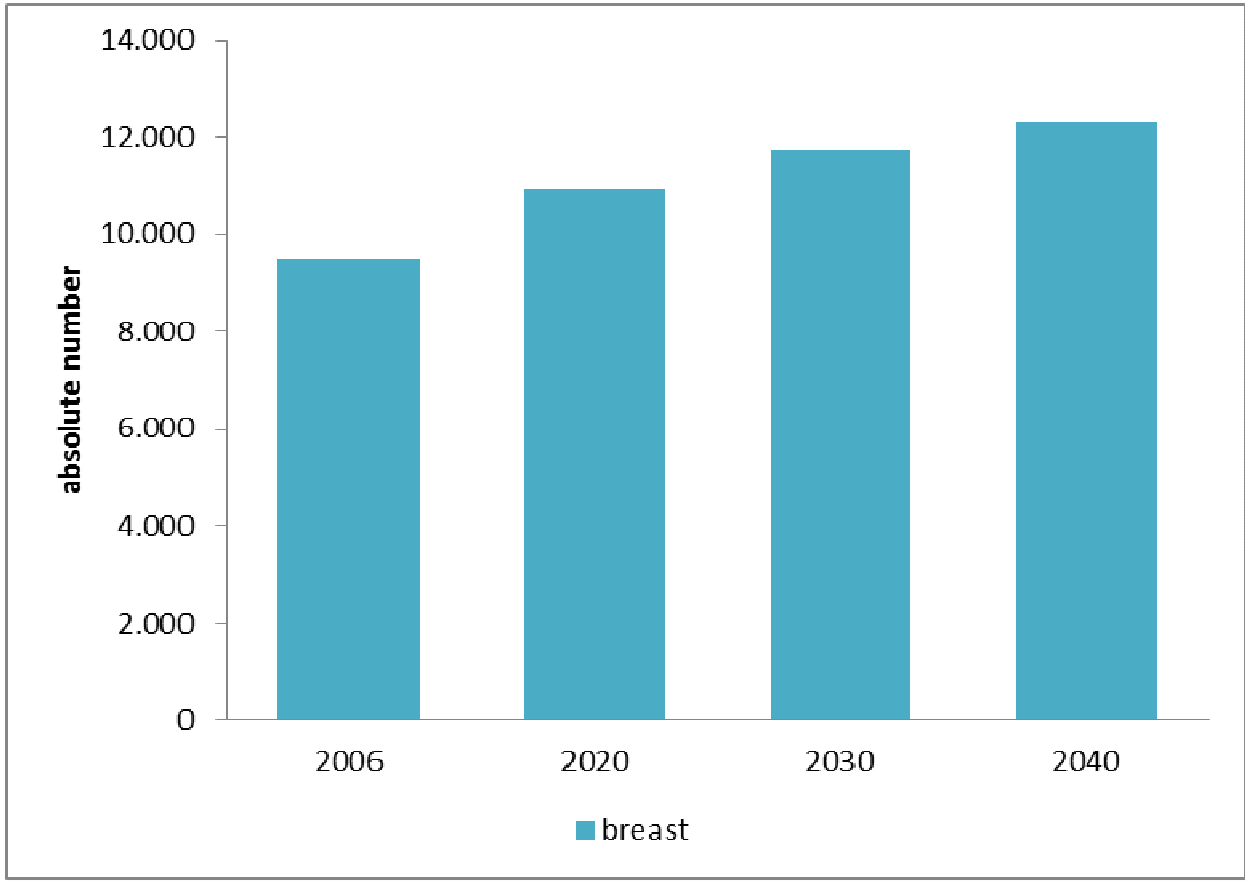


Autier Ph et al, BMJ 2010; 341:c3620

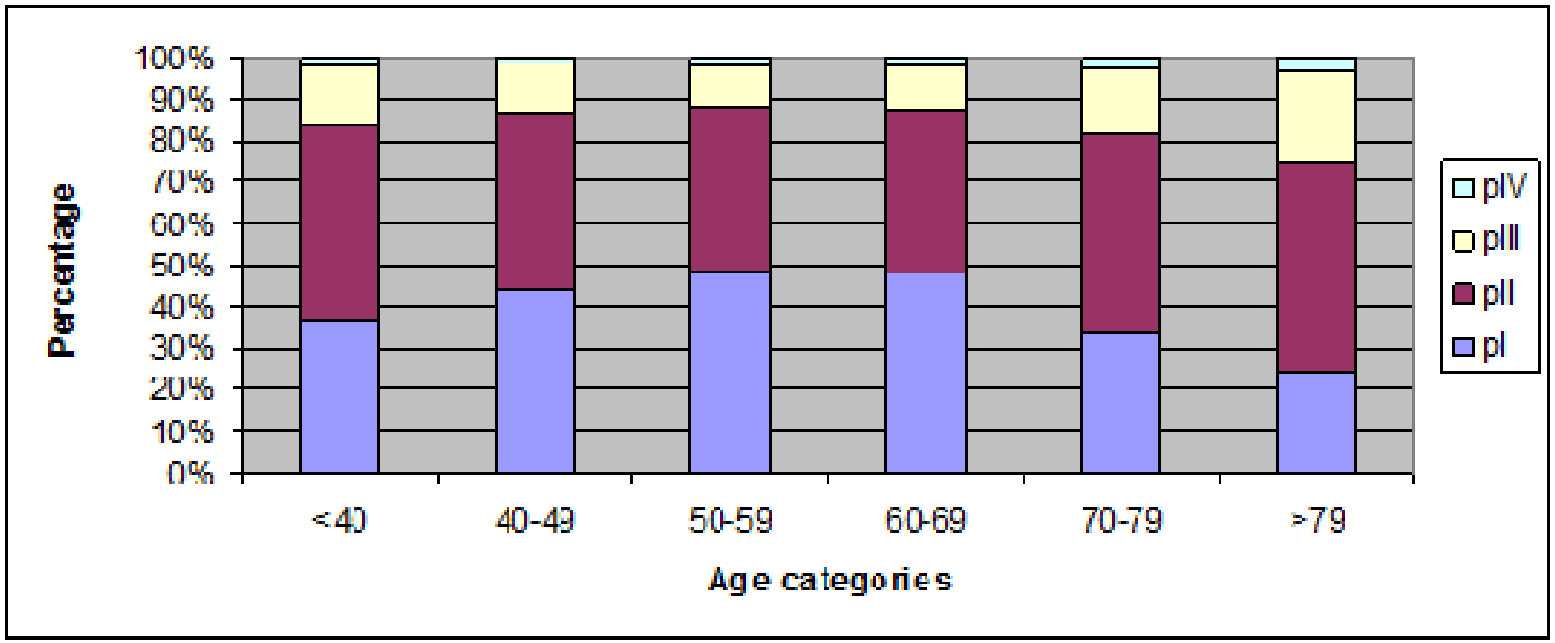
Disparities in breast cancer mortality trends between 30 European countries: retrospective trend analysis of WHO mortality database

Philippe Autier, group head and research director,[1,2] Mathieu Boniol, biostatistician and senior researcher,[1,2] Carlo LaVecchia, professor,[3] Lars Vatten, professor,[4] Anna Gavin, director of Northern Ireland Cancer Registry,[5] Clarisse Héry, researcher,[1] Mary Heanue, senior researcher[1]

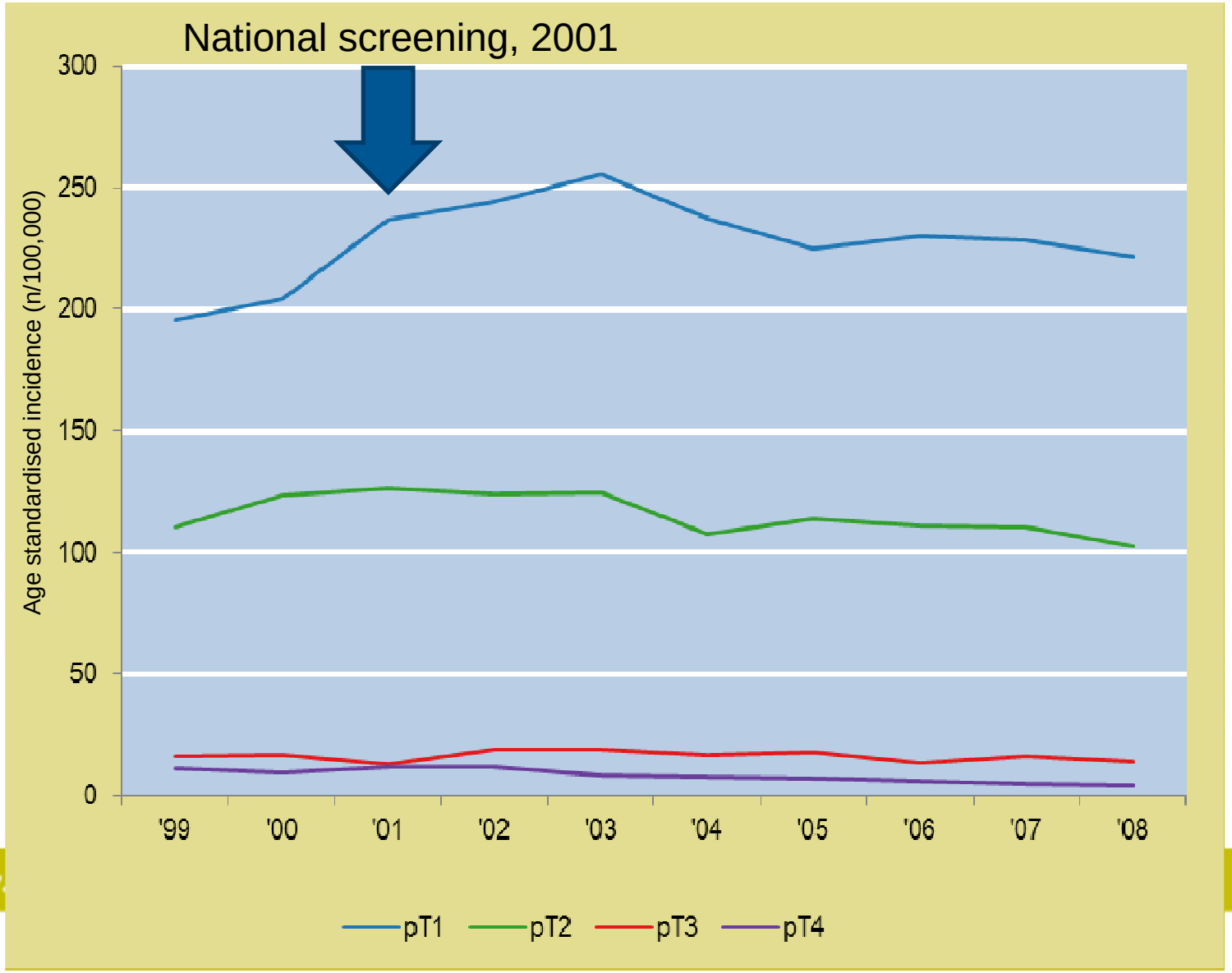
Breast cancer: absolute number prediction Belgium, 2006-2040



Breast cancer: pStage distribution by age 2001 – 2006, Belgium



Breast cancer incidence by pT category (50-69 years)
Belgium, Flemish region



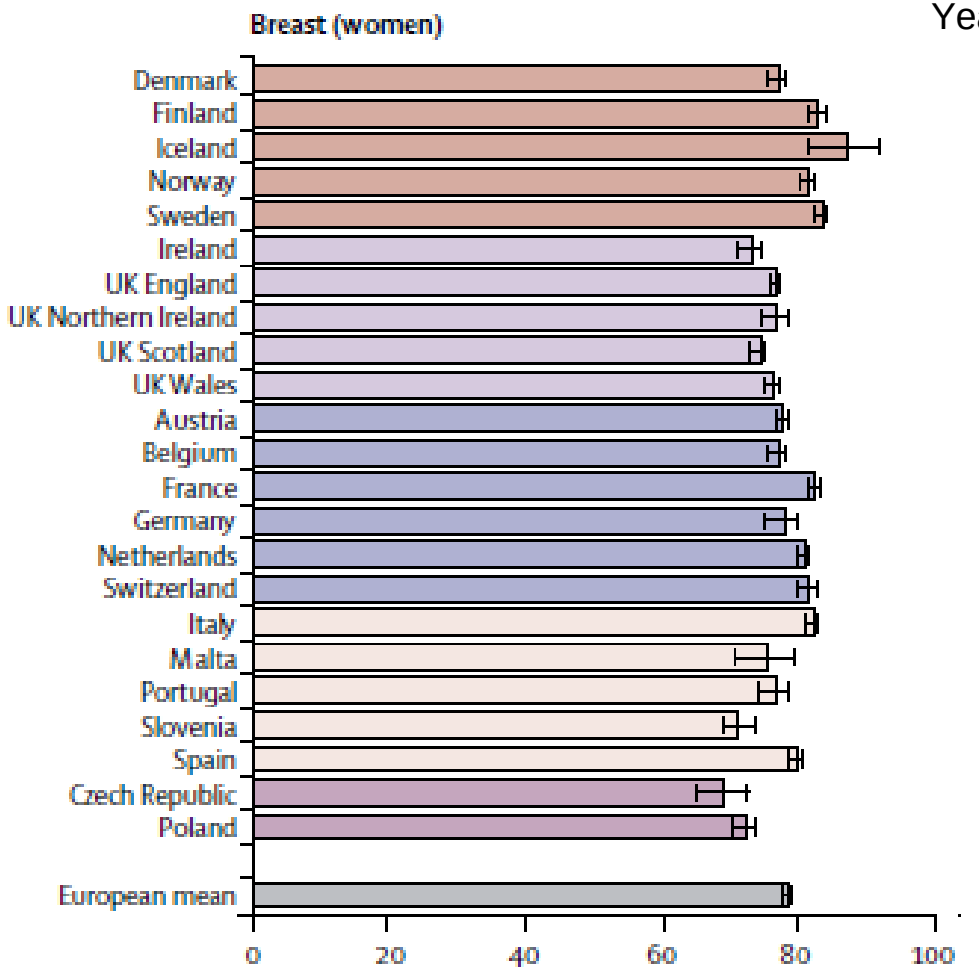
The role of the Cancer Registry (2)

- Collection and analysis of data
  - Population based
- Cancer Incidence
  - Monitoring (sex, age, geography, time, socio-economic, stage)
  - Comparison
  - Predictions

- Survival
  - Access to data on vital status: need for a reliable patient ID
  - Monitoring
  - Comparison

5-year relative survival: Results Eurocare 4

Years of Diagnosis: 1995-1999



Berrino et al, 2007, The Lancet Oncology

5 year relative survival: Eurocare 3 – Eurocare 4

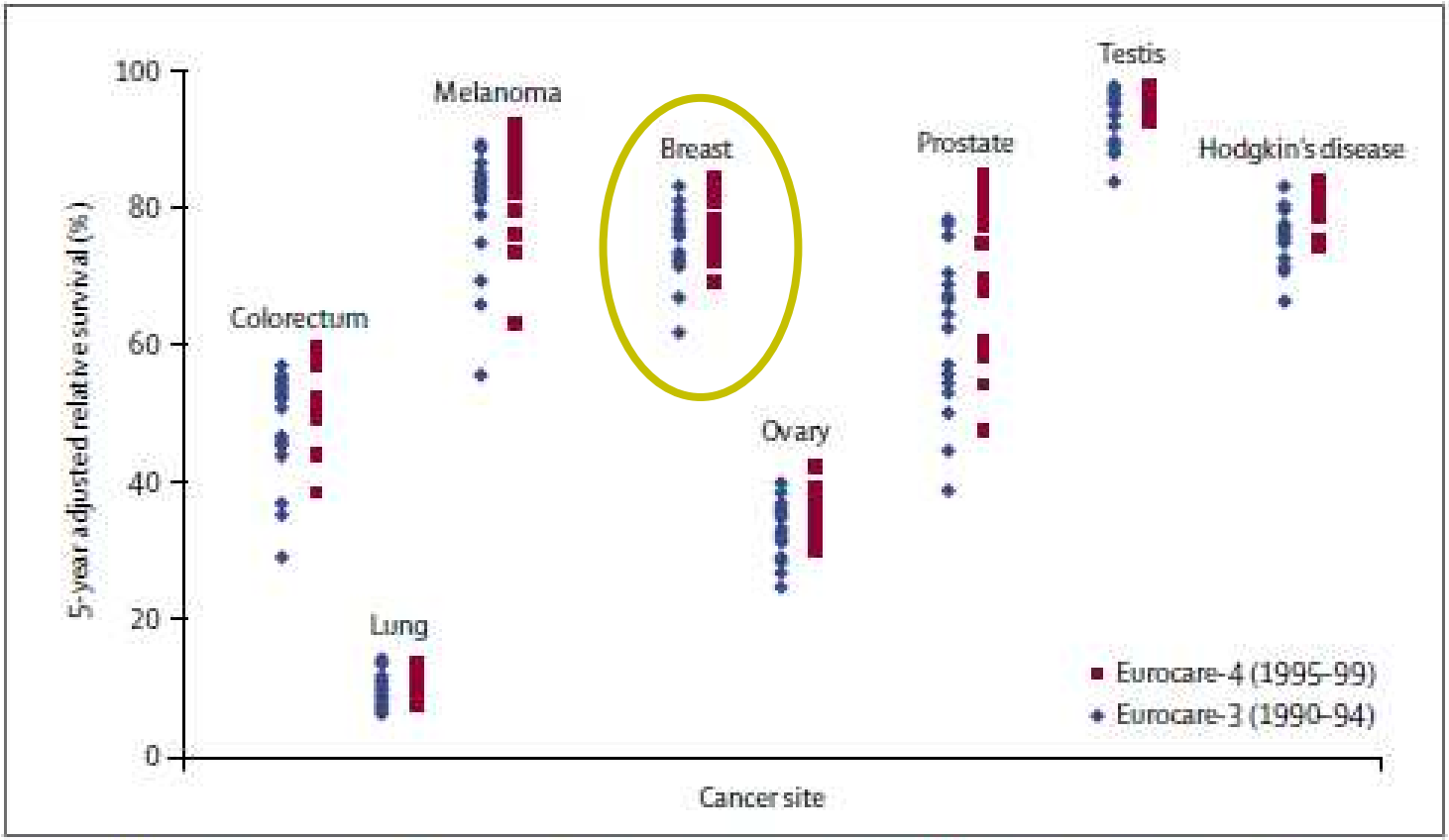


Figure 5: Changes in 5-year age-adjusted relative survival from EUROCARE-3 (1990–94) to EUROCARE-4 (1995–99)

- **Cancer survival in five continents: a worldwide population-based study (CONCORD)**

  Coleman M, Quaresma M, Berrino F et al. and the CONCORD Working Group, The Lancet Oncology, Volume 9, Issue 8, 730 - 756, August 2008

  - breast, colon, rectum, or prostate

The role of the Cancer Registry (2)

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- Survival
  - Monitoring
  - Comparison
  - => outcome parameter => quality of care

Quality of Care

- Definition of good ‘quality’
  - Donabedian, JAMA, Vol 260, 1988
  - “Providing patients with appropriate services in a technically competent manner, with good communication, shared decision-making and cultural sensitivity.” (UMHS)

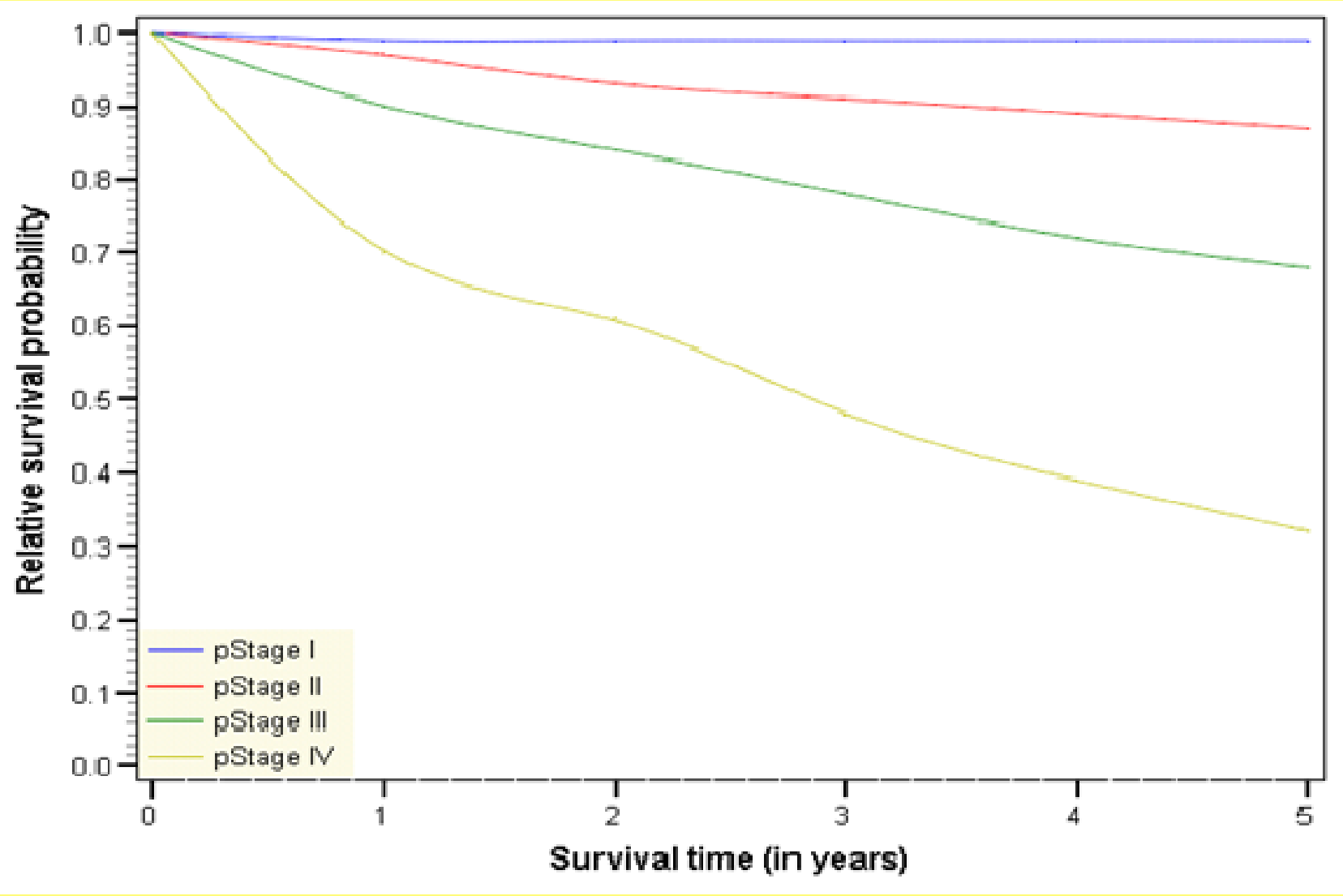
Quality indicators: three categories

- Outcome indicators
  - Denote the effect of care on the health status of the patient and population

- Structure indicators
  - Denote the attributes of the settings in which care occurs
    - E.g. facilities, equipment, money…

- Process indicators
  - Denote what is actually done in giving and receiving care
    - E.g. making a diagnosis, recommending or implementing treatment

5-Year relative survival by pStage, Belgium, 2001-2006



Quality indicators in breast cancer,

KCE report, S. Stordeur, J. Vlayen, L. Van Eycken, Jan 2011, Belgium

Quality indicators: three categories

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- Process indicators
  - Denote what is actually done in giving and receiving care
    - E.g. making a diagnosis, recommending or implementing treatment
    - But….capture more data on diagnosis and treatment!

- Structure indicators
  - Denote the attributes of the settings in which care occurs
    - Material resources, human resources, organizational structure

How to register/collect data?

- Use existing data bases
  - Hospital based registries: more detailed information on diagnostic, prognostic and treatment related aspects
  - Administrative data bases
    - Reimbursement data (nomenclature) – medical acts
    - Hospital discharge data
  - Linkage! = reliable Patient ID = confidentiality and privacy issues

- Prospective registration
  - Uniform data set
  - Compulsory? Voluntary?
    - Belgium: Royal Decree on Breast Clinics, 26th of April 2007
  - Population based?

- Belgium: national study 2010
- Quality indicators in breast cancer,
  KCE report 150 A, S. Stordeur, J. Vlayen, L. Van Eycken, Jan 2011,

- Literature: selection of quality indicators
  - Definition of 32 quality indicators
    - Existing data bases: 13 indicators measurable
      - Cancer Registry
      - Medical act data base + drugs

    => some examples

Example process indicator (1)

- Proportion of patients who received RT after breast conserving surgery

	Numerator	Denominator	Proportion (%)
2001	2 716	3 302	**82.3**
2002	3 003	3 608	**83.2**
2003	3 525	4 131	**85.3**
2004	3 550	4 039	**87.9**
2005	3 780	4 318	**87.5**
2006	**4 022**	**4 477**	**89.8**

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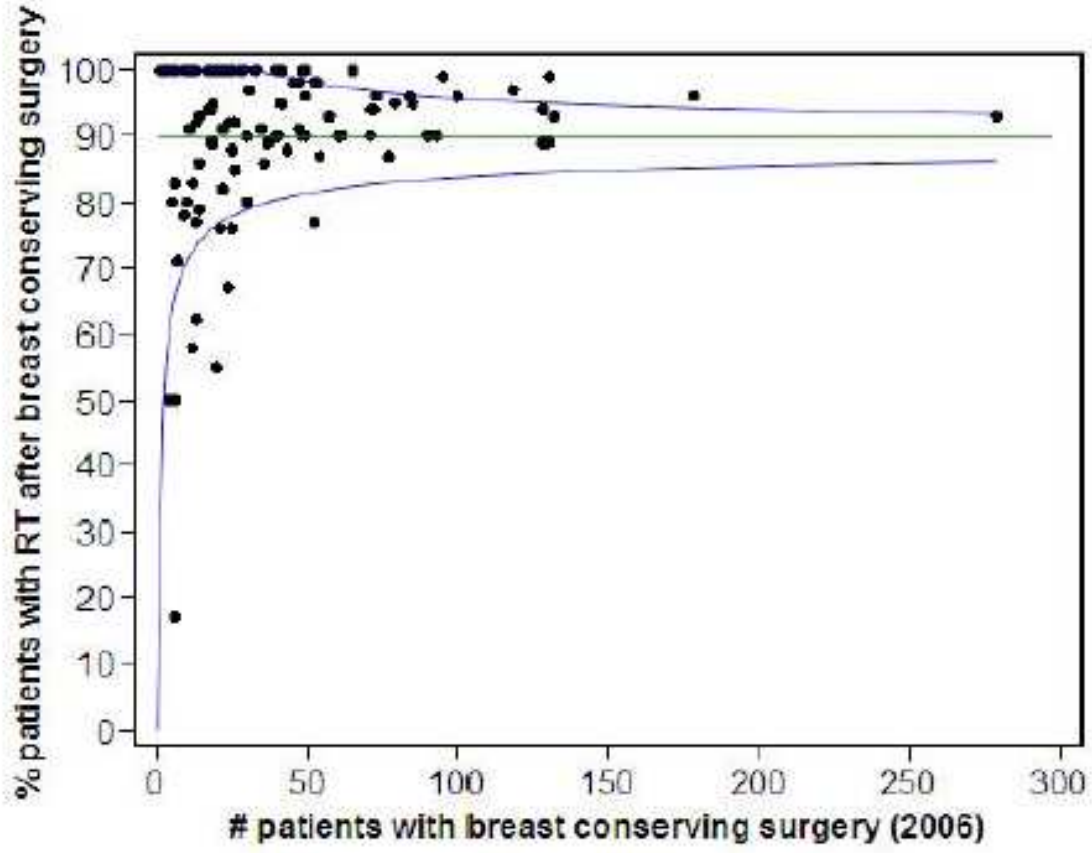
Example process indicator (2)

- Proportion of patients who received RT after breast conserving surgery: analysis per centre (2006)



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Example process indicator (3)

- Proportion of patients with assessment of ER and PR status before any systemic treatment (2001-2006)

	Numerator	Denominator	Proportion (%)
2001	5 935	6 555	90.5
2002	6 367	6 684	95.3
2003	7 130	7 360	96.9
2004	7 042	7 230	97.4
2005	7 629	7 839	97.3
2006	7 807	7 963	98.0
Total	**41 910**	**43 631**	**96.1**

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- Results ER – PR: unknown…
- Result Her-2: unknown…

Quality indicators: three categories

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Example structure (1)

- Proportion of women with breast cancer discussed and treated in a multidisciplinary team setting

  ⇒ measured: proportion of women with breast cancer discussed at the multidisciplinary team meeting

	Numerator	Denominator	Proportion (%)
2003	4 770	7 771	**61.4**
2004	6 285	8 232	**76.3**
2005	6 831	8 942	**76.4**
2006	**7 280**	**9 067**	**80.3**

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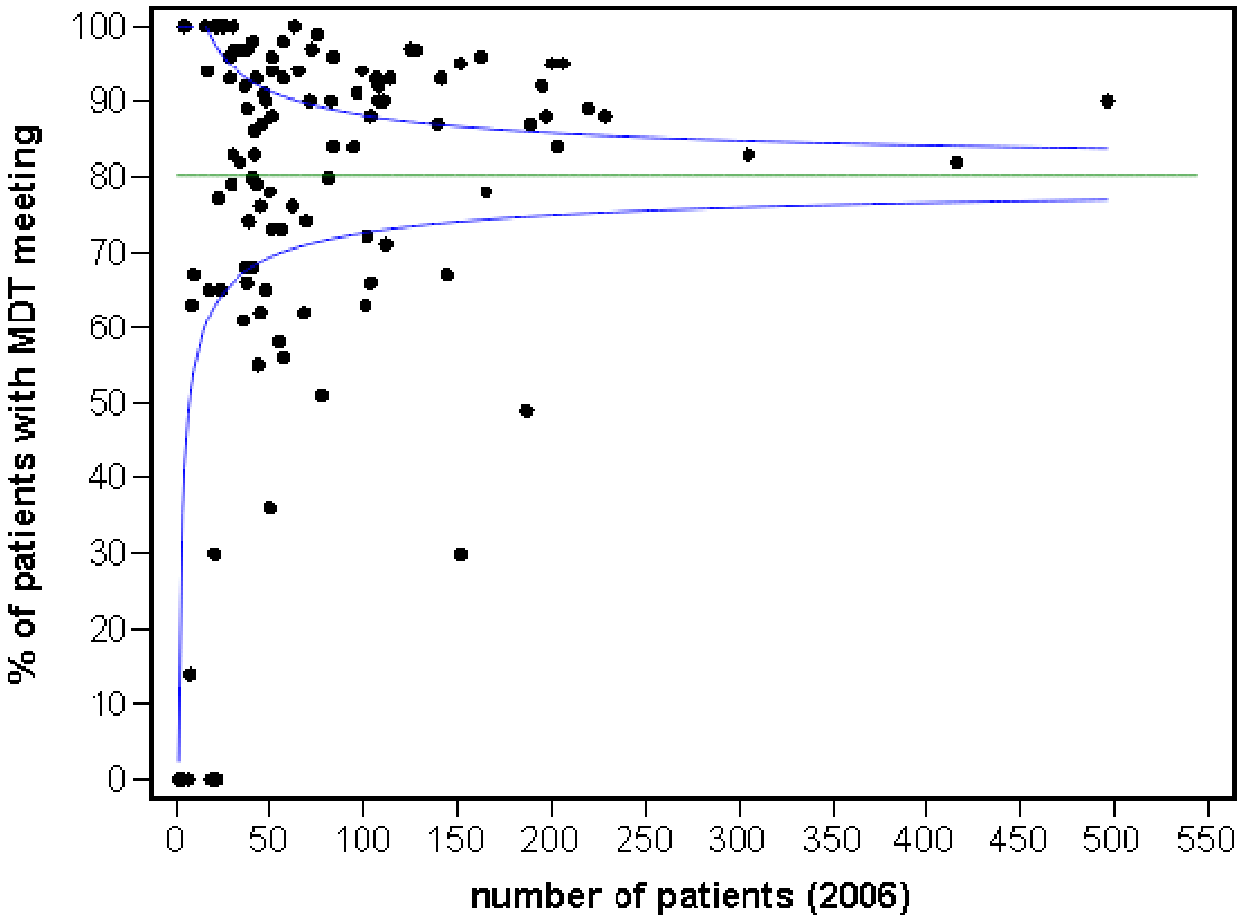
Example structure (2)
Proportion of women with breast cancer discussed at the multidisciplinary team meeting, per centre



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Confidentiality and privacy aspects

- EU directives
- Privacy legislation: national

- “3 level” concept at the Belgian Cancer Registry
  - Patient
  - Treating physician
  - Hospital
    - Although no ‘person’ => privacy legislation, EU directives
    - Different approaches international

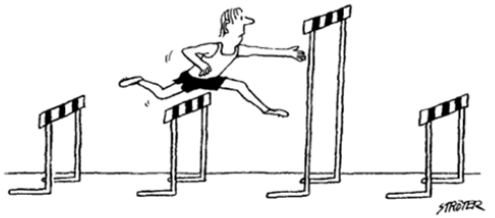
Standardisation

- Why? Comparability, Conformity, Reproducibility…
  - ⇒ Need for standardization:
  - o Improve consistency (reduce variability) in treatment
  - o Monitor the progress of the implementation of a National Cancer Plan
  - o Provide evaluation of the many individual cancer control activities
  - o Evaluate on health care costs

- International comprehensive information data base
  - o Harmonization of registration activities

Standardization
Essentials

  - o Cfr national registries, OECD, Eusoma



Conclusion

- Role of cancer registries => extended
  - Joint venture with treating physicians, epidemiologists, DM, …
  - If possible: make use of existing data bases
    - Beware of possible bias!

- Standardization or defining a set of measures, agreements, conditions and specifications will enable
  - International comprehensive information data base… as an essential component of cancer control efforts
  - Improvement of cancer related decision making
  - And ultimately: improve the quality of care offered to patients with (breast) cancer

Thank you for your attention!

Thank you Sabine Stordeur, Joan Vlayen, France Vrijens,
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Thank you!

Annemie Haelens (4), Kris Henau (3), Karen Vos (2) Liesbet Van Eycken (1) Caroline Androgé (12), Frédéric Calay (14), Céline Degaillier (7), Marie-José Hoovelts (15), Aline Kayumba (8), Sophie Petit (9), Greet Pieters (13), Linda Thibaut (11), Elke Van Vaerenbergh, Kristel Van Damme (5), Martine Verstreken (10), Christel Vervoort (6)