

4th International Congress of Breast Disease Centers

Role of Cancer Registries and Data Banking in Quality Control of Breast Cancer Care

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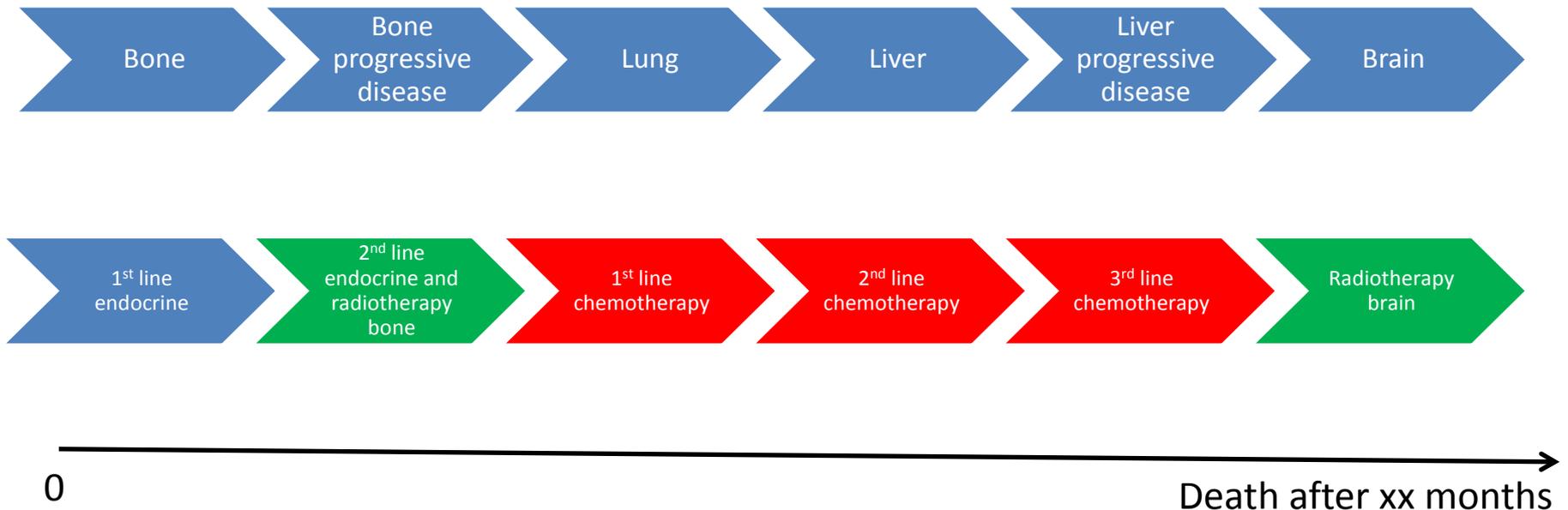
Outline

- Contents of a cancer registry database
- What makes a good quality indicator?
- Dutch Breast Cancer Audit
 - How to interpret inter-hospital variation?
 - Added value of benchmarking ?
- Recommendations for Cancer Registries to serve as a quality tool

Contents of a database: from basic to extended (plus)

Contents of database	Patterns of care primary tumour	Prognosis	Patterns of care relapse	HTA
Primary tumour: mode of detection, size, nodal status, grade, ER, PR, HER2, surgery, radiotherapy, endocrine-/chemotherapy, targeted treatment	+	+	+	+
Tumour relapse, base: first site(s) involved, first treatment, death		+	+	+
Tumour relapse, extended: all site(s) involved, ER, PR, HER2, all treatments (drugs, dose (reductions?), response),			+	+
Tumour relapse, extended plus:??? imaging, laboratory testing, pathology/cytology, hospital visits, hospital admissions (reasons), other health care consumption, including all costs				+
Patient-reported outcomes		+		+

Recognizing the complexity of documenting the clinical course of metastasized breast cancer.



Patient-reported outcomes

- Health-related quality of care
 - Cosmesis
 - Fatigue
 - Anxiety / depression
- Health care utilization
- Health behaviours
 - smoking, alcohol, preventing obesity
 - physical activity, mindfulness etc.)
- Information provision Etc.

Patient reported outcomes registry

- www.profilesregistry.nl



The screenshot shows the homepage of the Profiles Registry. The word "profiles" is displayed in a large, lowercase font with a color gradient from grey to green to blue. Below the logo is a teal navigation bar with the following links: Home, About Profiles Registry, Organization, Proposals, Dataarchive, and Contact. The main content area has a light yellow background and features the heading "The PROFILES registry" in bold. Below this heading is a paragraph describing the registry's purpose and a link to "read more". At the bottom of the content area, there is a short paragraph mentioning a publication in the European Journal of Cancer from May 2011, with a link to "View the paper on pubmed".

profiles

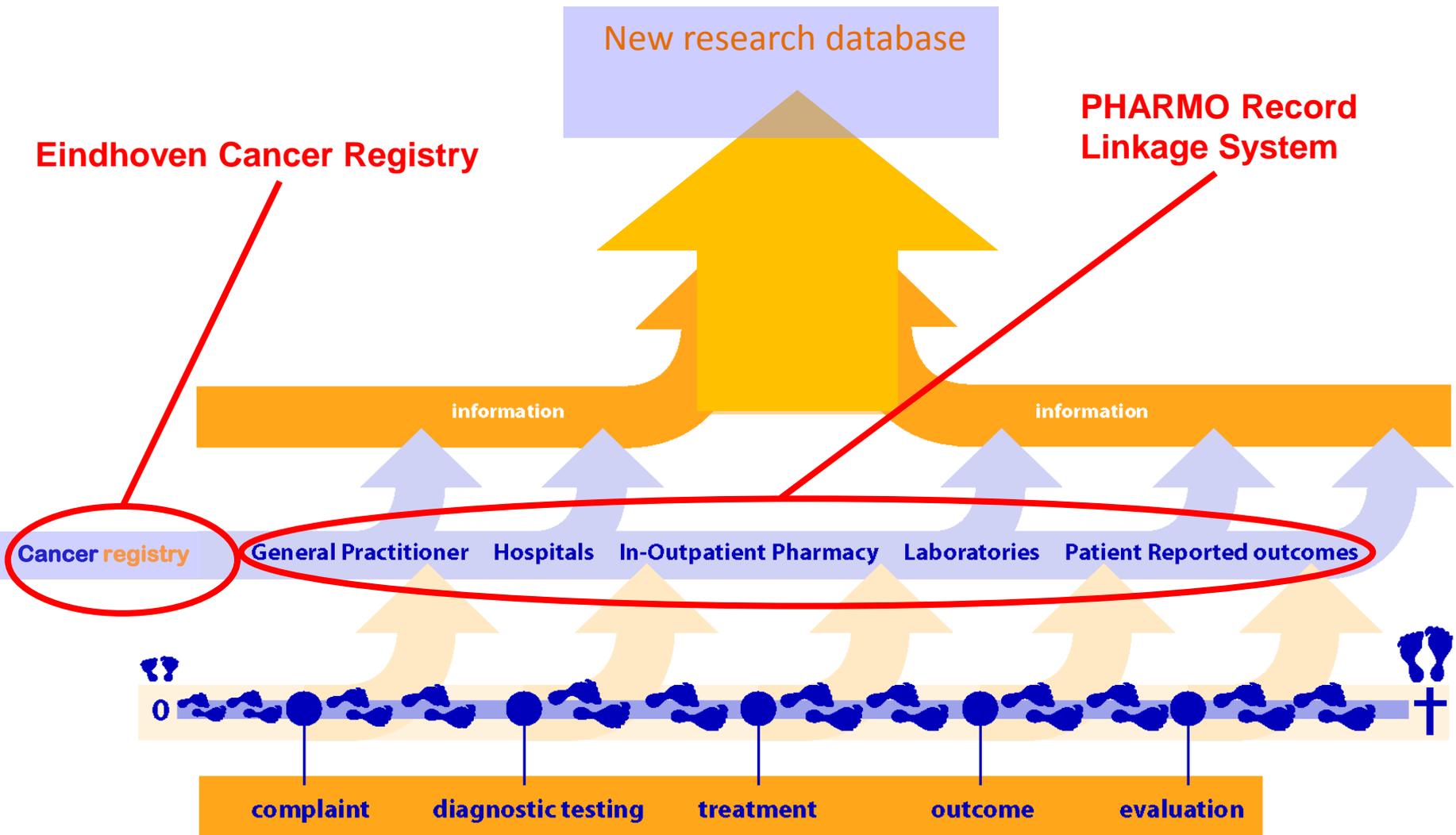
[Home](#) [About Profiles Registry](#) [Organization](#) [Proposals](#) [Dataarchive](#) [Contact](#)

The PROFILES registry

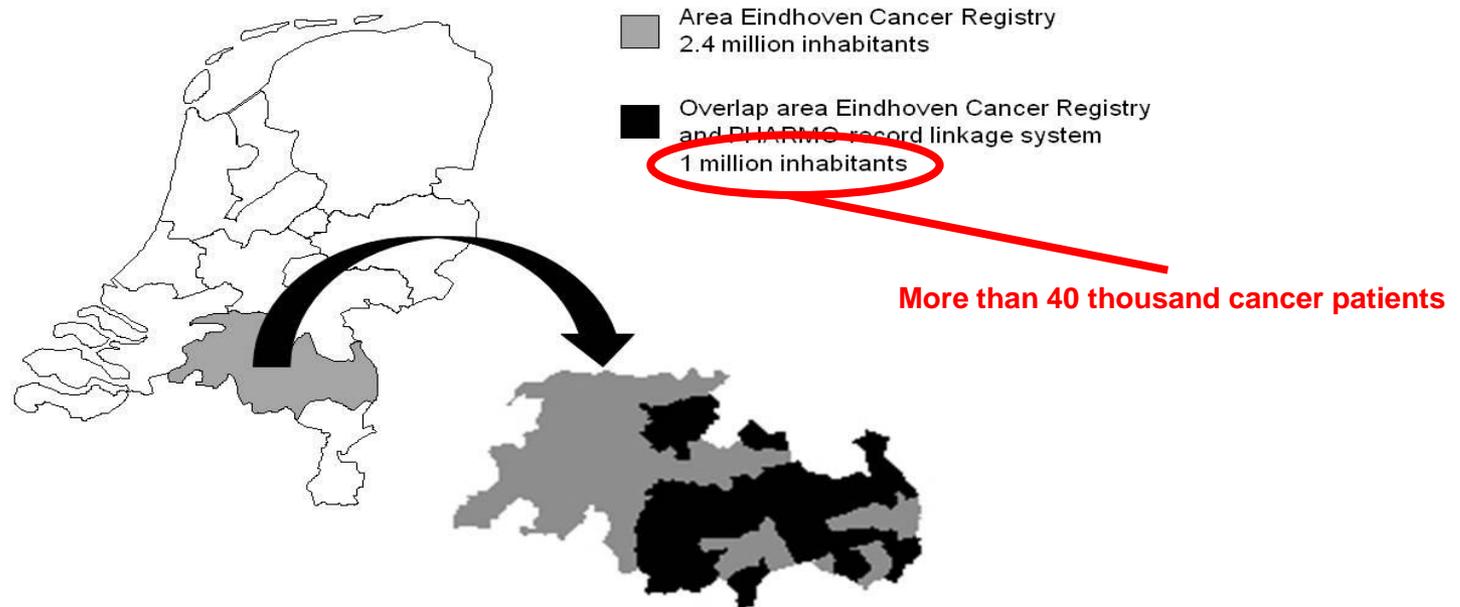
'Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship (PROFILES)' is a registry for the study of the physical and psychosocial impact of cancer and its treatment from a dynamic, growing population-based cohort of both short and long-term cancer survivors. Researchers from the Comprehensive Cancer Centre South in Eindhoven and Tilburg University in Tilburg, The Netherlands, work together with medical specialists from the local hospitals in order to setup different PROFILES studies, collect the necessary data, and present the results in scientific journals and (inter)national conferences. ([read more](#))

Scope, rationale and design of PROFILES were published in the European Journal of Cancer, May 2011:
The Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship registry: Scope, rationale and design of an infrastructure for the study of physical and psychosocial outcomes in cancer survivorship cohorts. [View the paper on pubmed.](#)

Creating a new research database with data from various data sources (CR as sampling frame)



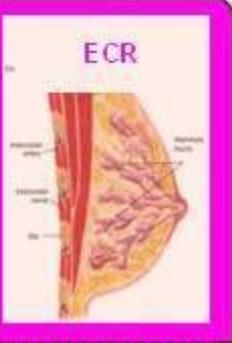
Linkage of Eindhoven Cancer Registry to PHARMO Record Linkage System



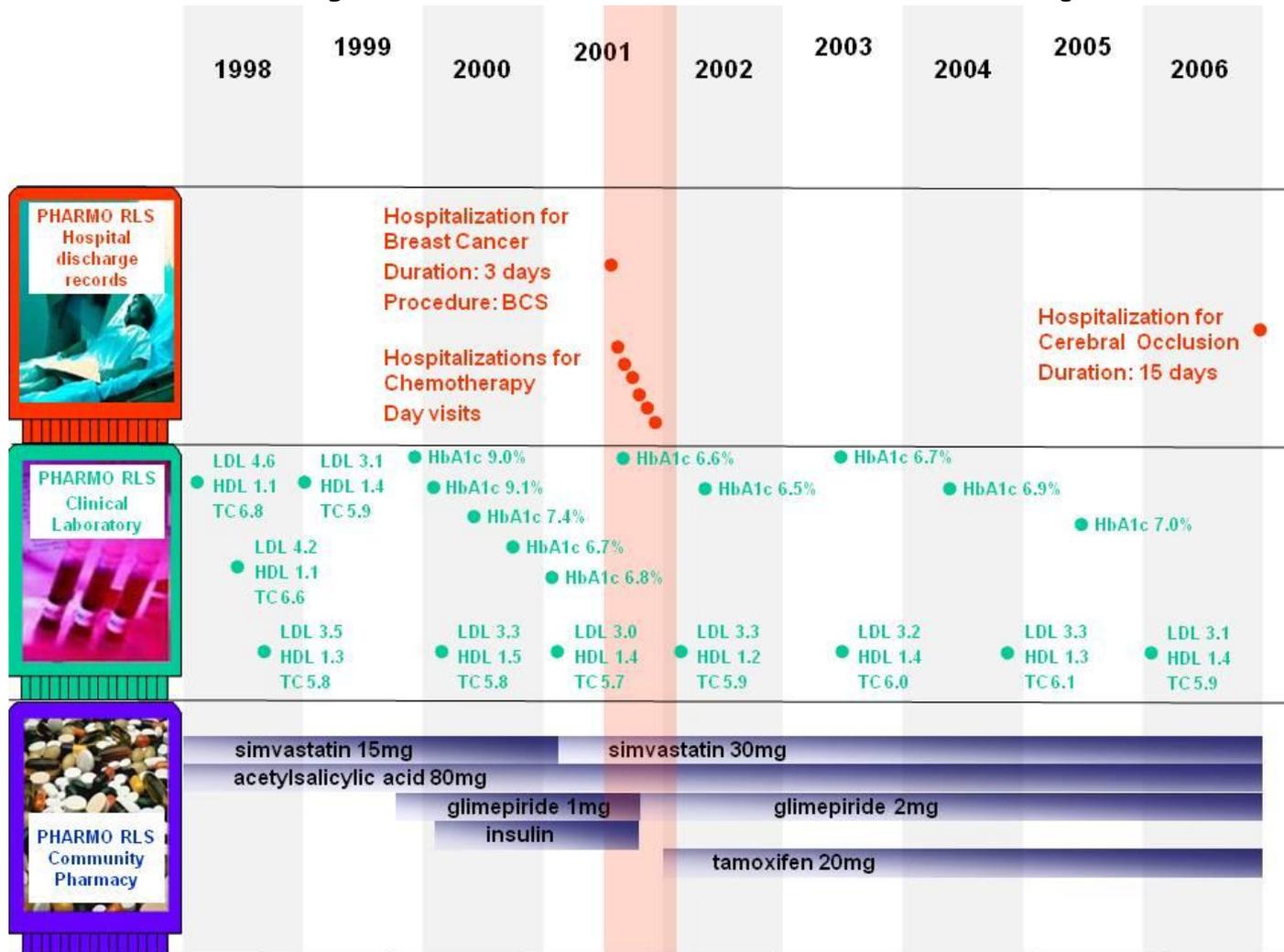
Of cancer patients living in the overlap area, data were linked using probabilistic linkage*

* van Herk-Sukel MP, van de Poll-Franse LV, Lemmens VEPP et al. New opportunities for drug outcomes research in cancer patients: The linkage of the Eindhoven Cancer Registry and the PHARMO Record Linkage System. Eur J Cancer 2010; 46: 395-404.

Demonstration of information: A fictitious 53 year old breast cancer patient

2001	July	August	September	October	November	December	January
 <p>ECR</p>	<ul style="list-style-type: none"> ● Diagnosis: Cancer in left breast Stage IIA: Tumor size 1-2 cm, Node + ER+ and PR+ ● Initial treatment: Breast conserving surgery and Radiotherapy Chemotherapy and Endocrine therapy 						
	 <p>PHARMO Hospital Pharmacy</p>	<ul style="list-style-type: none"> ● morphine ● paracetamol ● heparin 	<ul style="list-style-type: none"> ● CMF 	<ul style="list-style-type: none"> ● CMF ● granisetron 	<ul style="list-style-type: none"> ● CMF 	<ul style="list-style-type: none"> ● CMF 	<ul style="list-style-type: none"> ● CMF

Demonstration of information (c'ntd): A fictitious 53 year old breast cancer patient



Half of breast cancer patients discontinue tamoxifen and any endocrine treatment before the end of the recommended treatment period of 5 years: a population-based analysis

Myrthe P. P. van Herk-Sukel · Lonneke V. van de Poll-Franse ·
Adri C. Voogd · Grard A. P. Nieuwenhuijzen ·
Jan Willem W. Coebergh · Ron M. C. Herings

The Breast Journal

ORIGINAL ARTICLE

Major Changes in Chemotherapy Regimens Administered to Breast Cancer Patients During 2000–2008 in the Netherlands

Myrthe P.P. van Herk-Sukel, PhD,* Lonneke V. van de Poll-Franse, PhD,^{†,‡}
Geert-Jan Creemers, MD, PhD,[§] Valery E.P.P. Lemmens, PhD,^{†,¶}
Paul D. van der Linden, PhD,** Ron M.C. Herings, PhD,^{*,††}
Jan Willem W. Coebergh, MD, PhD,^{†,¶} and Adri C. Voogd, PhD^{†,‡‡}

*PHARMO Institute for Drug Outcomes Research, Utrecht, The Netherlands; [†]Eindhoven Cancer Registry, Comprehensive Cancer Center South, Eindhoven, The Netherlands; [‡]Center of Research on Psychology in Somatic Diseases (CoRPS), Tilburg University, Tilburg, The Netherlands; [§]Department of Oncology, Catharina Hospital, Eindhoven, The Netherlands; [¶]Department of Public Health, Erasmus University Medical Centre, Rotterdam, The Netherlands; **Hospital pharmacy, Tergooi Hospital, Blaricum, The Netherlands; ^{††}Department of Medical Informatics, Erasmus University Medical Centre, Rotterdam, The Netherlands; and ^{‡‡}Department of Epidemiology, Maastricht University, Maastricht, The Netherlands

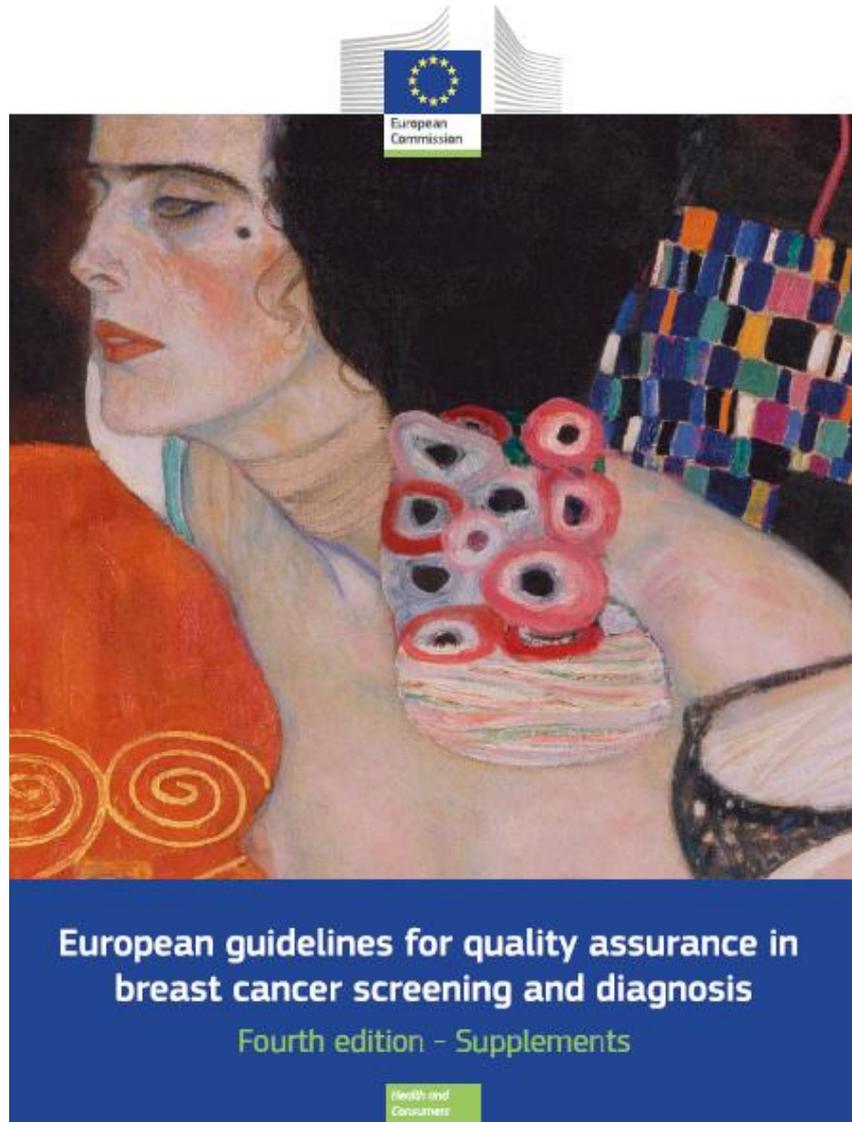
Breast J. 2013 Jul-Aug;19(4):394-401.

What makes a good quality indicator?

- Importance
- Scientific acceptability
 - reliable and valid
- Feasibility
 - readily available
- Usability = easy to
 - understand,
 - apply



Initiatives to define quality indicators and standards



Dutch Breast Cancer Audit (DBCA): > 25,000 patients

- Involved disciplines:
 - radiology
 - pathology
 - surgery
 - radiotherapy
 - medical oncology
 - plastic surgery
- Collaborative effort of:
 - National Breast Cancer Group (NABON),
 - Dutch Institute for Clinical Auditing,
 - Netherlands Cancer Registry,
 - Patient support organization.
- Participation rate: 98 % (89 out of 99 hospitals)
 - **Recorded in 2011: 12,000 pts; 2012: 14,000 pts**

Patients

- Participation in NABON Breast Cancer Audit
- Participation in clinical studies

Diagnosis

- Use of BI-RADS classification in radiological reports
- Percentage of patients discussed in a multidisciplinary team before start of treatment

Neo- adjuvant

- Neo-adjuvant treatment in T4 breast cancer
- Percentage of patients with neo-adjuvant treatment seen by radiation oncologist start of treatment
- Waiting time between diagnosis and start of neo-adjuvant chemotherapy

Surgery

- Waiting time between diagnosis and first surgery (including direct breast reconstruction)
- Irradical excision after first breast-conservative procedure for invasive breast cancer
- Irradical excision after first breast-conservative procedure for DCIS
- Axillary dissection in patients with pN0 breast cancer
- Percentage of patients dicussed in a multidisciplinary team after surgery

Pathology

- Standardized pathology report available
- Percentage of patients with HER2 positive breast cancer
- Percentage of patients with estrogen receptor positive breast cancer
- Percentage of patients with HER2 positive breast cancer

Adjuvant treatment

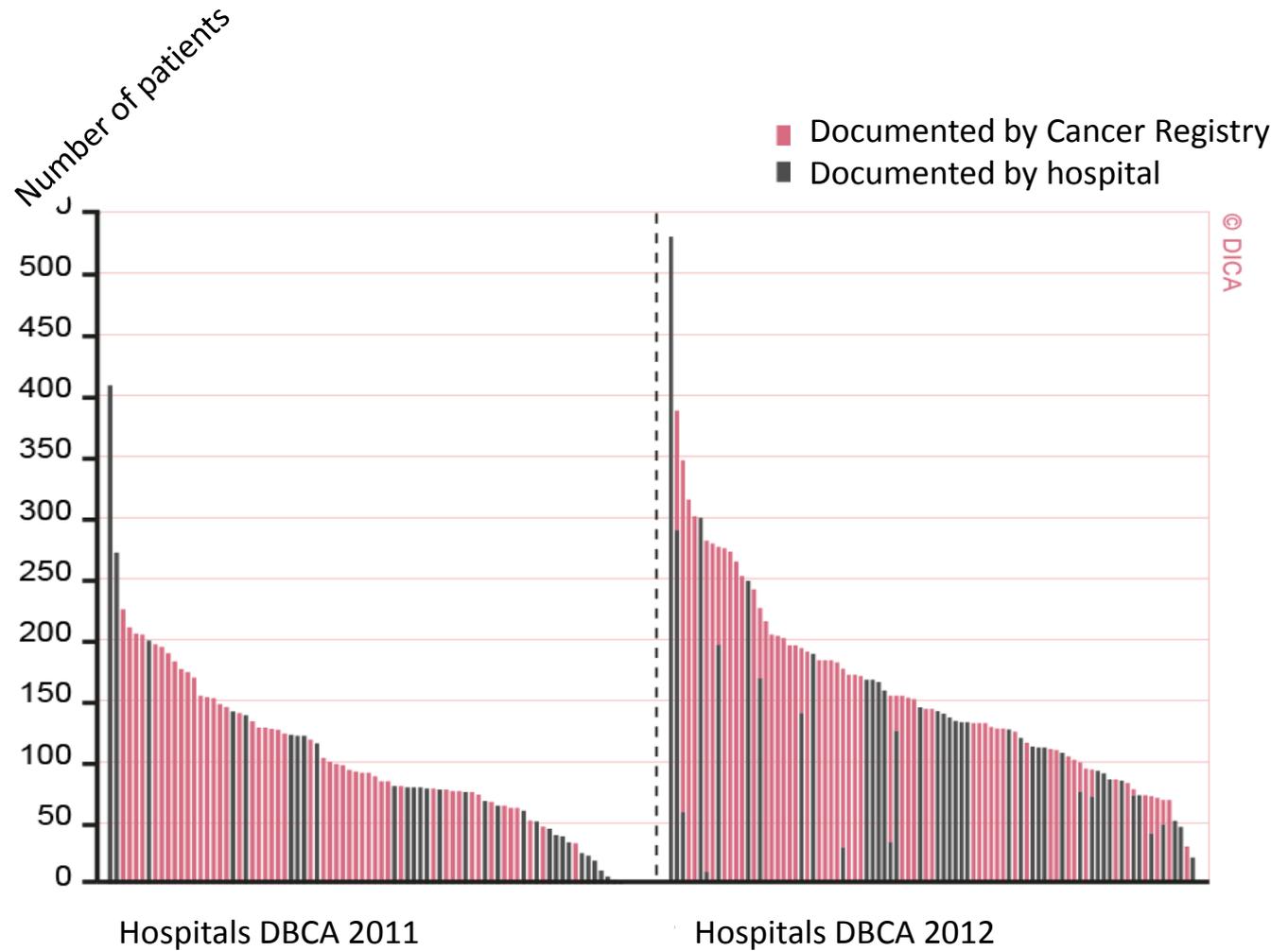
- Adjuvante chemotherapy in early stage breast cancer
- Waiting time between initial treatment and start of chemotherapy
- Percentage of patients with ablative surgery for locally advanced breast cancer receiving chemotherapy
- Percentage of patients receiving radiotherapy folowing conservative surgery for DCIS
- Waiting time between last surgical intervention and start of radiotherapy
- Waiting time between first day of chemotherapy and start of radiotherapy

Follow up

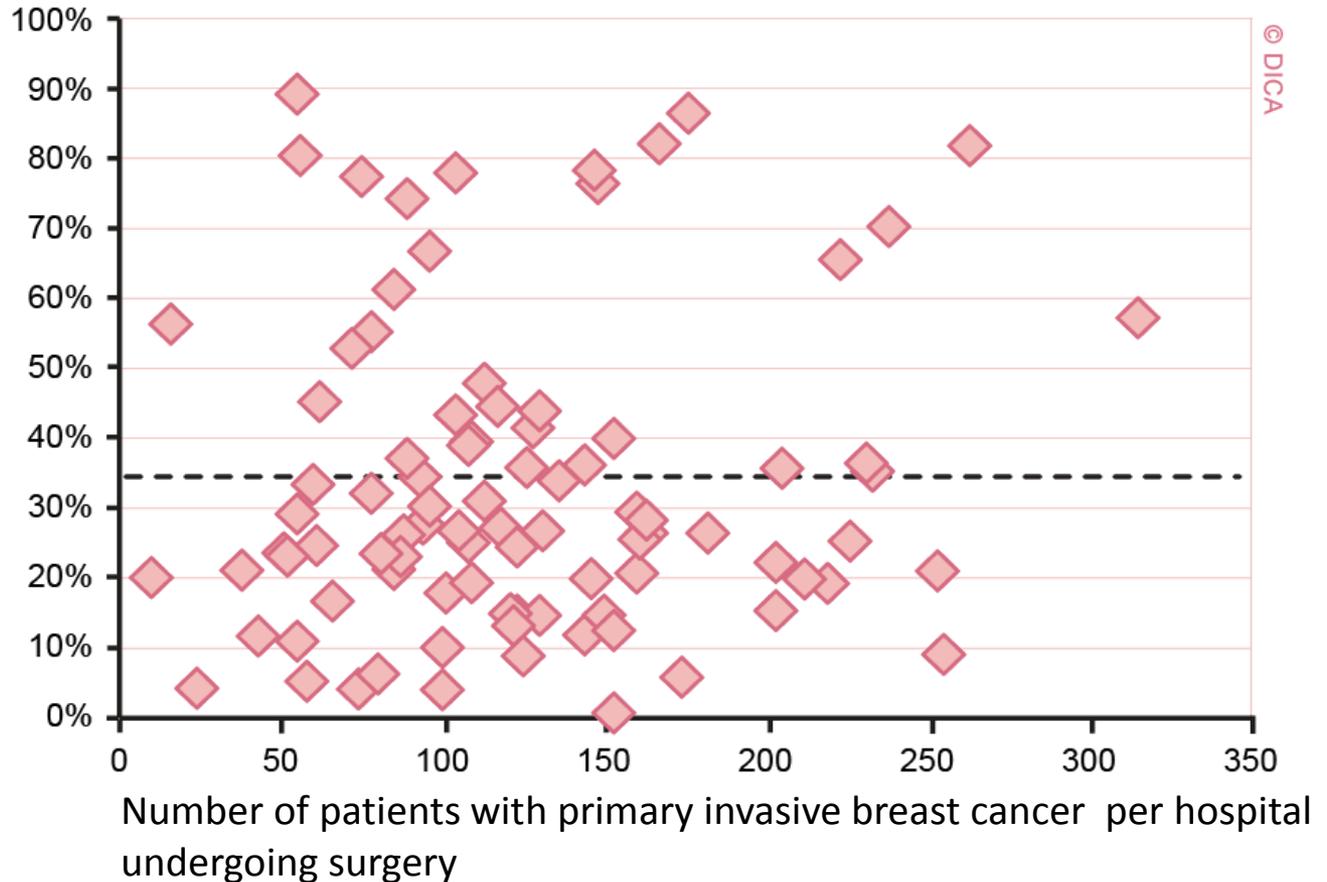
- Percentage of patients with local relapse in ipsilateral breast following breast-conserving treatment
- Percentage of patients with local relapse in chest wall following mastectomy

- **Quality indicators serve more than one purpose:**
 1. A tool for quality improvement:
 - Internal: not (yet) available at hospital level for 3rd parties
 - » Benchmarking
 - » Team/breast centre: multidisciplinary information to guide improvement
 - External: at the hospital level and accessible for 3rd parties
 - Transparency, comparing hospitals (health insurers)
 - Patients: decision-aids
 - Health insurance companies: contracts
 2. Research: epidemiological (e.g.: trends, patterns of care, prognosis), cost-effectiveness, etc.

Participation in Dutch Breast Cancer Audit: > 25,000 patients



Diagnosis: pre-operative MRI-scan



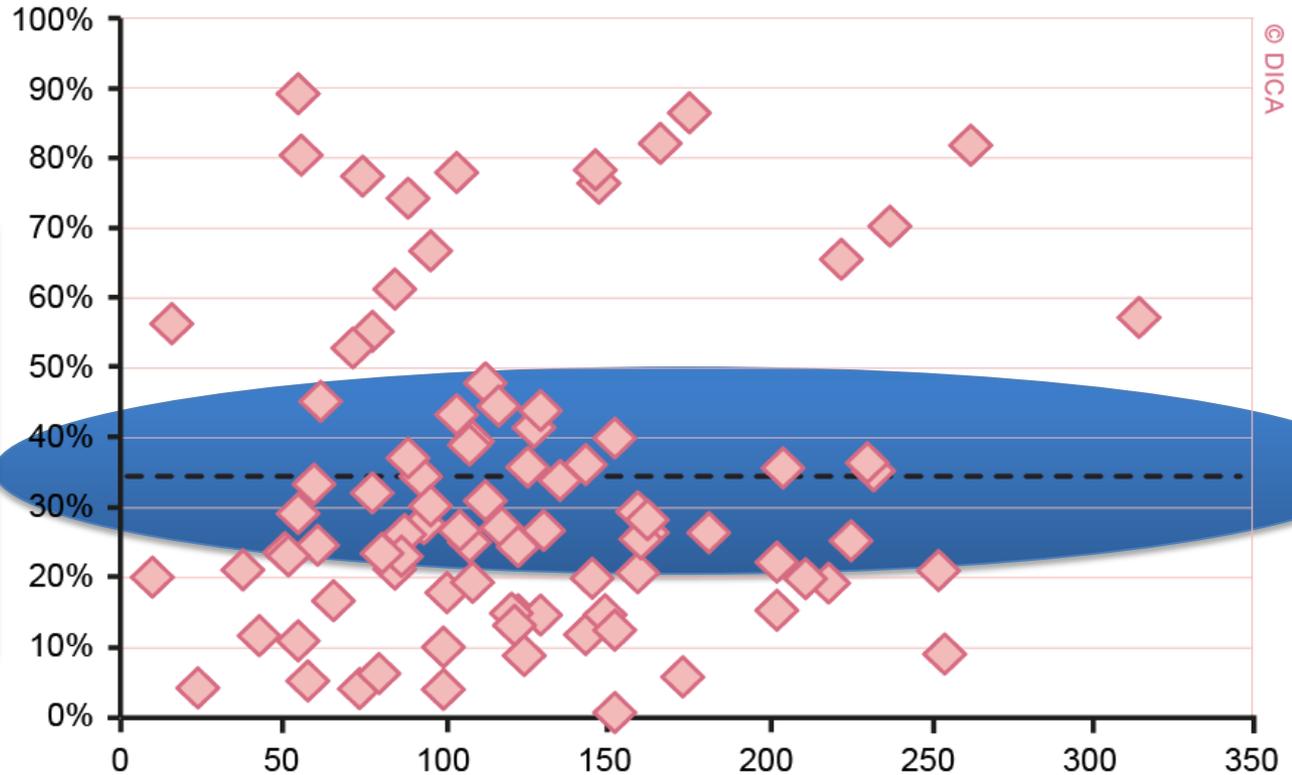
Large inter-hospital variation in use of MRI,
independent of hospital volume

How to interpret these results?

- Large inter-hospital variation may reflect:
 - Specific referral patterns , related to SES
 - True differences in quality of care
 - Lack of scientific evidence
 - Lack of consensus regarding scientific evidence

Diagnosis: pre-operative MRI-scan

Should the average become the standard?

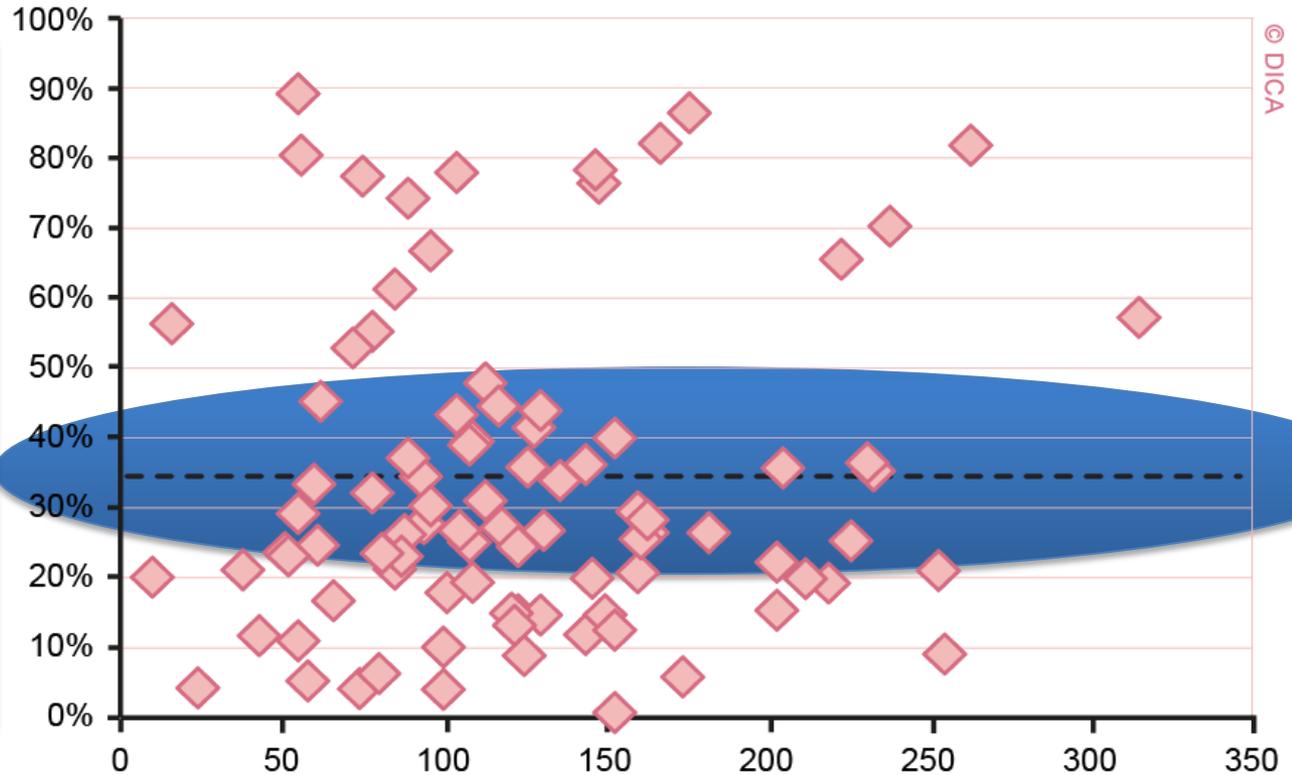


Number of patients with primary invasive breast cancer per hospital undergoing surgery

Large inter-hospital variation in use of MRI, independent of hospital volume

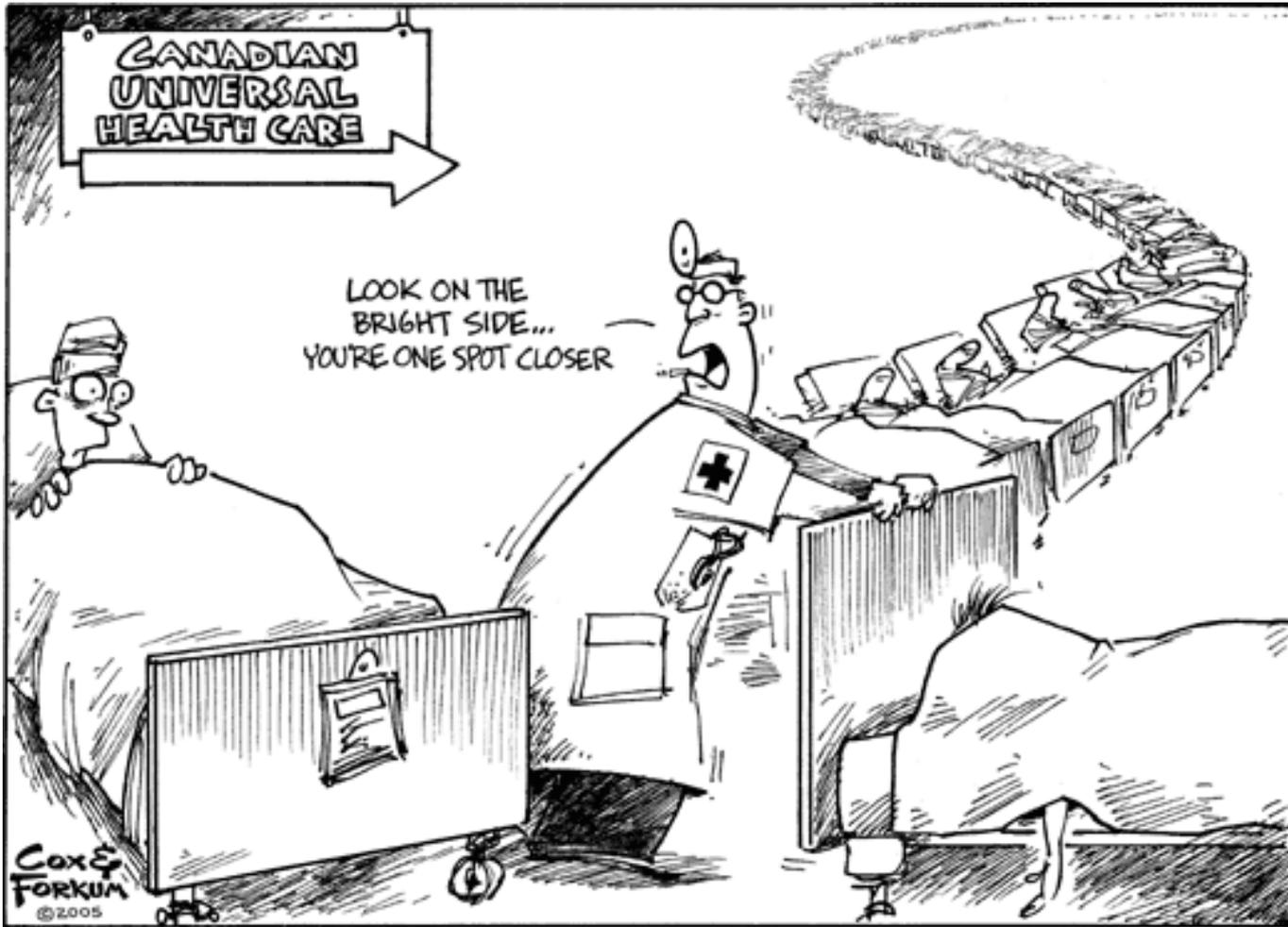
Diagnosis: pre-operative MRI-scan

Or could it be that hospitals with >70% or perhaps those with 10-20% use of MRI have organized their care in the most cost-effective way?



Number of patients with primary invasive breast cancer per hospital undergoing surgery

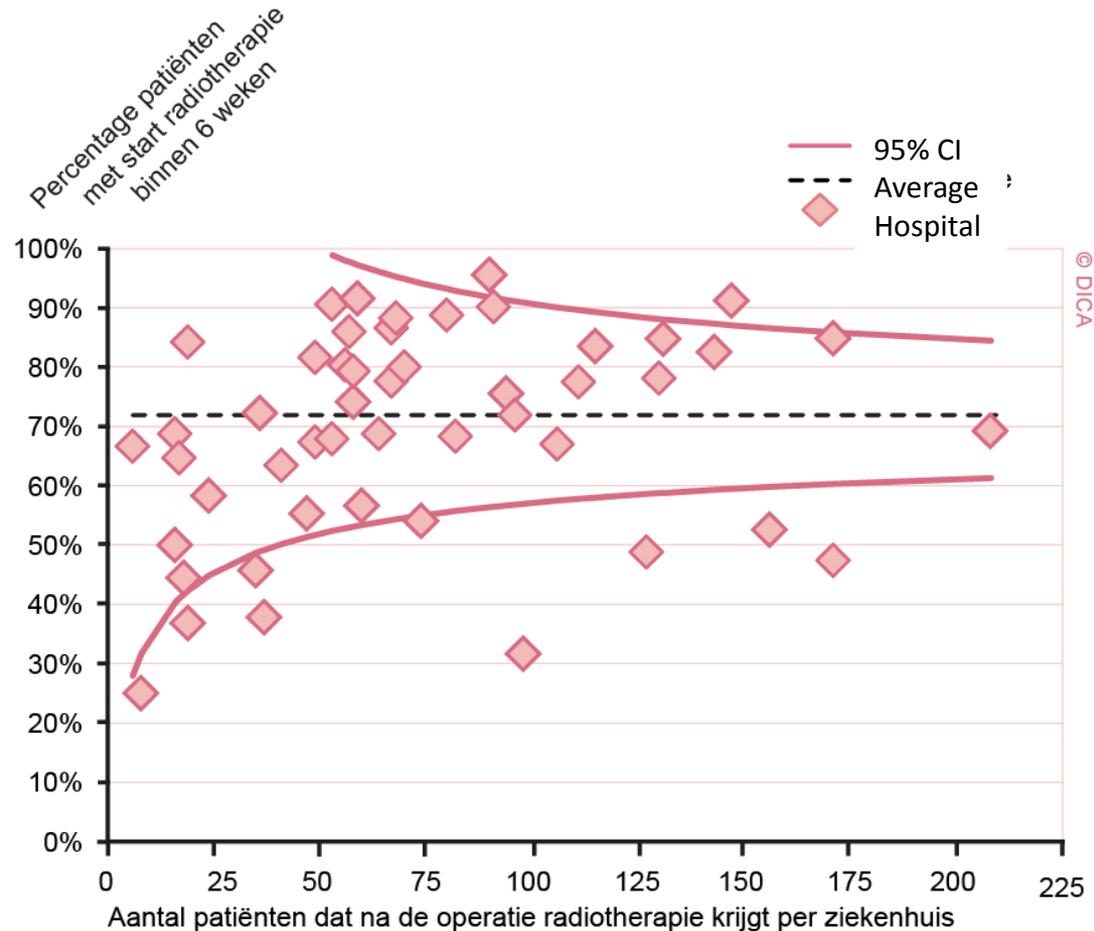
Large inter-hospital variation in use of MRI, independent of hospital volume



www.CoxAndForkum.com

Waiting times

Start of radiotherapy <6 weeks after surgery



Funnelplot of percentage of patients starting with radiotherapy within 6 weeks after the last surgical intervention, according to hospital (2011)

5-year local relapse rate (%)

	no. patients	follow up ^a	no. events	event rate ^d (95% CI)	no. hospitals (%) sign> 5% ^c
breast conserving surgery					
2003	4,159	18,669	93	2.54 % (2.07 - 3.10)	1 (1%)
2004	4,334	19,269	84	2.21 % (1.79 - 2.74)	2 (3%)
2005	4,551	20,541	68	1.68 % (1.33 - 2.13)	0 (0%)
2006	4,598	20,768	61	1.49 % (1.16 - 1.92)	0 (0%)
<i>2003-2006</i>	<i>17,642</i>	<i>79,248</i>	<i>306</i>	<i>1.96 % (1.76 - 2.20)</i>	<i>0 (0%)</i>
mastectomie					
2003	3,646	14,767	106	3.48 % (2.88 - 4.20)	3 (4%)
2004	3,642	14,536	110	3.71 % (3.08 - 4.46)	3 (4%)
2005	3,461	14,133	88	3.03 % (2.46 - 3.72)	2 (3%)
2006	3,601	15,003	84	2.71 % (2.19 - 3.35)	1 (1%)
<i>2003-2006</i>	<i>14,350</i>	<i>58,442</i>	<i>388</i>	<i>3.23 % (2.92 - 3.56)</i>	<i>1 (1%)</i>

^a follow up time in years

^b Kaplan meier estimate

^c based on 95% CI around the target value of 5%

	Hospital X			NL (2011)	NL Q1 2012
Quality Indicator (QI)	Numerator	Nominator	%	%	%
Pathology					
Standardized pathology reporting				82%	89%
Multidisciplinary meeting					
Percentage of patients discussed				90%	94%
Digital report available				80%	88%
Specialties present reported				22%	41%
Diagnostics radiology					
Standardized radiology report				97%	98%
Waiting time ≤ 5 weeks since biopsy					
Until neo-adjuvant chemotherapy				73%	78%
Until first breast surgery				84%	86%
Radicality					
For invasive carcinoma				7%	6%
For DCIS				25%	23%

Added value of benchmarking

Improvements in performance in 2012 versus 2011 are proof for the added value of benchmarking, in which validated quality indicators contribute to growing awareness about what makes good multidisciplinary care, .. **provided that we care about correct interpretation of the figures**



Prerequisites for a Cancer Registry to serve as a successful quality tool

- Participation is obligatory
- Independent and trustful
- Possibility to check correctness of data within multidisciplinary team
- Easy access to data for caregiver
- Data available without much delay
- Flexible (continuous evaluation of usefulness, quality and completeness of items registered)

But also:

- Items registered need to reflect quality of care
- Case mix correction in analyses
- Proper use of standards (margin of error)

Cancer Registries (especially if linked to other data banks) can really contribute to the improvement of breast cancer care!