

Cancer Registry in Germany: The Munich Experience

Jutta Engel Munich Cancer Registry (MCR)



1st International Congress of Breast Disease Centers, Paris 28. & 29. January 2011

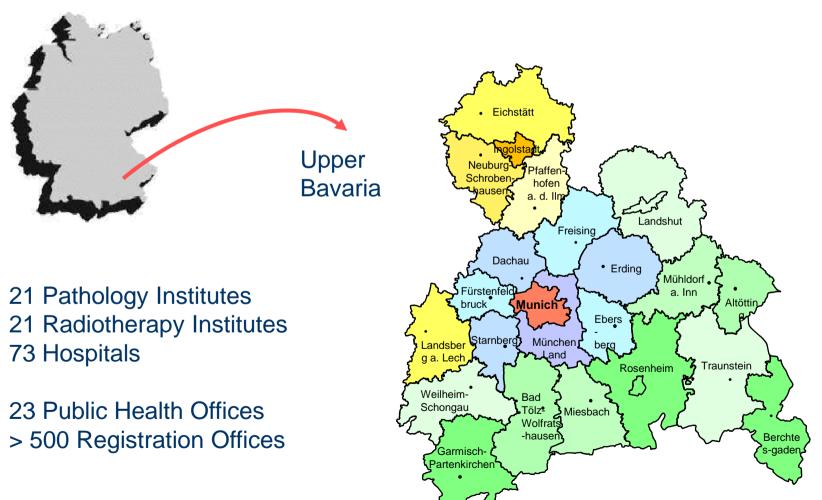
Catchment area: 4.5 million people

1st Int. Congress of Breast Disease Centers Session 14: Survivorship & Follow-up Cancer Registry in Germany: The Munich experience



Munich Cancer Registry: 12 Certified Breast Centers 11 by DKG/DGS (German Cancer/Senology Society)

 $3 \,$ by EUSOMA





Value of Cancer Registries for Breast Disease Centers, Clinics / Ambulatory Sector, Scientific Community

- 1. Health Care during Course of Disease and Infrastructure for Support of Health Care
- 2. Feedback Systems, Quality Management, Benchmarking

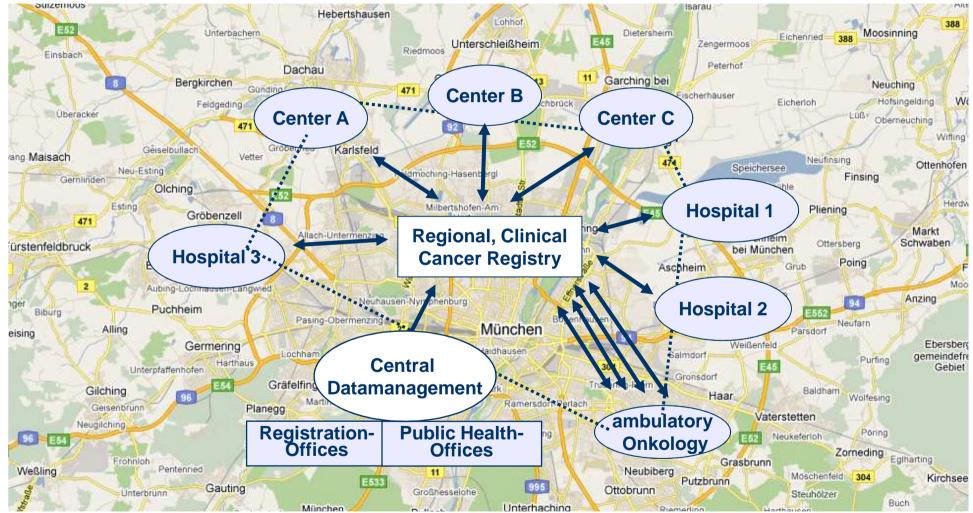
3. Health Care Research

Infrastructure for Support of Health Care

1st Int. Congress of Breast Disease Centers Session 14: Survivorship & Follow-up Cancer Registry in Germany: The Munich experience



Interdisciplinary (multidisciplinary) and Intersectoral (inpatient/outpatient) Health Care



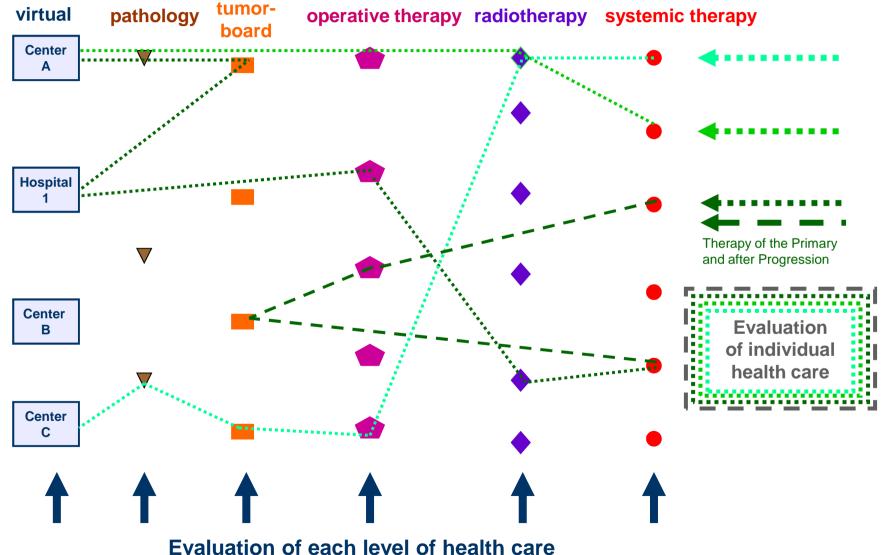
... accompanying the health care delivery for individual patients over years or decades



Infrastructure for Support of Health Care



Levels of health care, Stream of patients and Quality assurance





Value of Cancer Registries for Breast Disease Centers, Clinics / Ambulatory Sector, Scientific Community

- 1. Health Care during Course of Disease and Infrastructure for Support of Health Care
- 2. Feedback Systems, Quality Management, Benchmarking

3. Health Care Research



Access to aggregated data (Examples)

Evaluation of cohorts of patients that received any therapy in a center / hospital ...

Primary therapy: Operated in the center and adjuvant therapy in the center Operated in the center and adjuvant therapy outside Operated outside and adjuvant therapy in the center Therapy of relapse after "own" primary therapy Therapy of relapse after "outside" primary therapy Therapy of relapse outside after "own" primary therapy

Therapy during follow-up: Therapy of recurrences ... Therapy of metastases ...

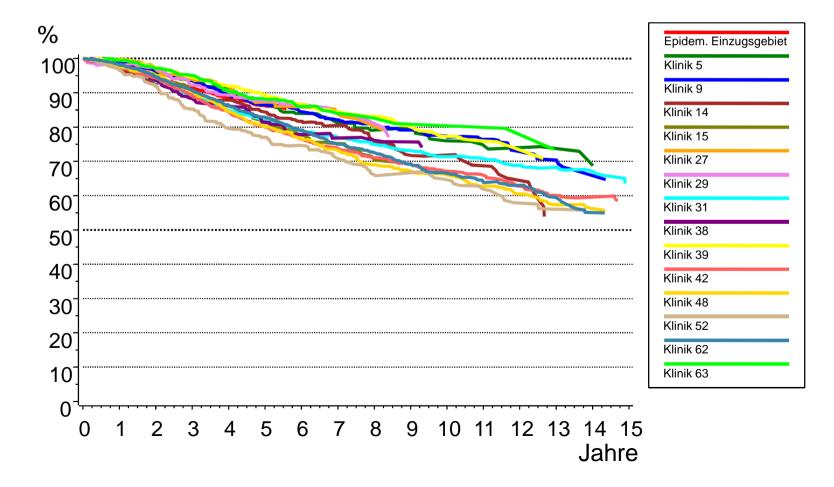
At the end is the demand for the meticulous documentation of all patients in order to adequately classifying cohorts.

The significance of documentation and a reasonable evaluation is often highly underestimated.



Munich Cancer Registry Breast Cancer since 1988, n = 26.323

Relative Survival – Comparisons between Clinics (Benchmarking)





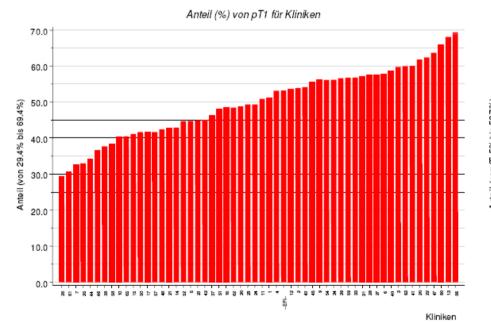
Munich Cancer Registry Breast Cancer since 1988, n = 26.323

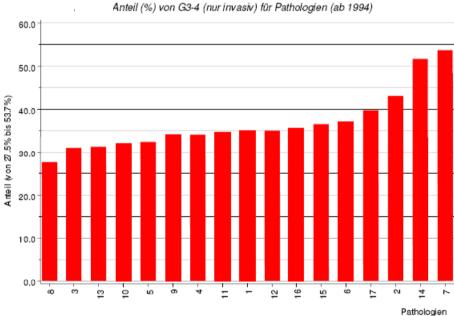
Comparisons between Clinics and between Pathology Institutes

Proportion – % pT1 (Clinics)

(29,4 - 69,4%)









Munich Cancer Registry Breast Cancer since 1988, n = 11.622

Multivariate Analysis: Cox – Model

| Anzahl der Patienten in der Analyse: n = 1 davon verstorben: n = 2305 | | | | Relative Risk (RR) for classic prognostic factors | | | Relative Risk (RR) for each single clinic | | | |
|--|--|------------------------------|--|---|-----------|------------------------------|---|--|-----------|-----------------------------|
| | | Relatives Risiko (RR) | 197.00.0 | Confidenz- all des RR | | Kliniken | Relatives Risiko (RR) | 95%-Konfidenz- intervall des RR | | Clinics: |
| Aiter | < 50 Jahre 50-69 Jahre >= 70 Jahre | 1,00 1,09 2,76 | 144 C 14 | ferenz - 1,22 - 3,11 | p<0,0001* | K0 K5 K9 | 0,87 0,82 0,79 | 0,74 - 1,03 0,63 - 1,07 0,63 - 1,01 | p<0,1469* | p=0,1469 not significant |
| pT-Kategorie | pT1 pT2 pT3 pT4 | 1,00 1,51 2,16 2,91 | | ferenz - 1,67 - 2,57 - 3,38 | p≤0,0001* | K 14 K 15 K 16 K 27 | 0,85 1,11 1,09 0,76 | 0,69 - 1,04 0,87 - 1,42 0,81 - 1,48 0,52 - 1,09 | | |
| pN-Kategorie | pN0/X pN positiv | 1,00 1,89 | 1. Contraction (1997) | ferenz | p<0,0001 | K 29 K 31 | 0,82 | 0,57 - 1,18 Referenz | | |
| Grading | G1/2 G3 | 1,00 1,43 | Re | ferenz - 1,57 | | K 38 K 39 | 0,89 0,81 | 0,66 - 1,19 0,69 - 0,94 | | |
| Hormonrezeptor- Status | HR positiv HR negativ | 1,00 1,59 | Re | ferenz - 1,76 | p<0,0001 | K 42 K 48 | 0,80 0,88 | 0,68 - 0,95 0,67 - 1,15 | | |
| Radiatic | nein ja | 1,00 0,73 | | ferenz - 0,80 | p<0,0001 | K 52 K 54 K 62 | 0,98 0,89 0,84 | 0,78 - 1,22 0,64 - 1,23 0,71 - 1,00 | | |

* Simultan-Test n.s. nicht signifikant bei alpha=0,05

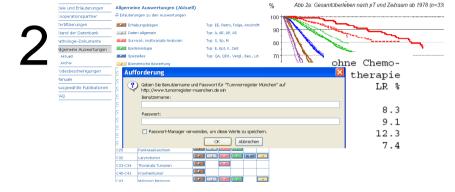
1st Int. Congress of Breast Disease Centers Session 14: Survivorship & Follow-up Cancer Registry in Germany: The Munich experience



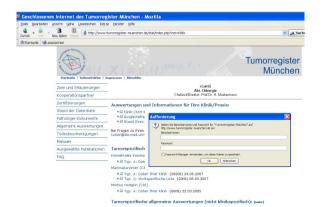
| Datei Bearbeiten Ansicht Gehe Lesezei | chen Extras Een | ster Hilfe | | | | | | | |
|--|--|------------------------|---------------------------------|-------------|--|--|--|--|--|
| 🔹 🔹 📚 🛛 🕄 🚳 👪 🚲 | 🔹 🔌 🧃 🧃 🎉 http://www.tumorregister-muenchen.de/facts/specific_analysis.html 👻 🙇 Suchen | | | | | | | | |
| Startseite Lesezeichen & mozilia.org . | 🗶 mozilisZine 🏒 m | azdev.org | | | | | | | |
| with Minney | | | | | | | | | |
| (m 3 | | | | | | | | | |
| : (tot : | | | Tun | norregister | | | | | |
| E To alt | | | | München | | | | | |
| Suches D | | Impreceum Login | | Mulichen | | | | | |
| suchet | some (montage | 1 mprocessi 1 copin | | | | | | | |
| Aufgaben und Struktur | Tumorspezifi | ische Auswertungen | | | | | | | |
| Einzugsgebiet | Inzugsgebiet (Ergebnisse, Prognosen, Progressionen) | | | | | | | | |
| Kooperationspartner | Basissta | ^ | | | | | | | |
| Historie | 💴 Überleben | | | | | | | | |
| Mitarbeiter | Spezielle | e Auswertungen | D Erläuterungen zu den Tabellen | | | | | | |
| Daten | C00-C97 | Alle Tumoren | | | | | | | |
| Inzidenztabellen | C00-C14 | HNO-Tumoren | | | | | | | |
| Mortalitätstabellen | C00 | Lippentumor | | | | | | | |
| Tumorspez. Auswertungen | C01 | Zungengrund | | | | | | | |
| Versorgungsforschung | C02-06 | Mundhöhlentumor | | | | | | | |
| Ausgewählte Literatur | 002 00 | Zunge ohne Zungengrund | | | | | | | |
| Jahresberichte | C04 | Mundboden | | | | | | | |
| Glossar | | | | | | | | | |
| | C05 | Gaumentumor | | | | | | | |
| | C07-C08 | Speicheldrüsentumor | | | | | | | |
| | C09-C14 | Pharymokarzinom | | | | | | | |
| | C09 | Tonsilenkarzinom | | | | | | | |
| | C09-10 | Oropharynx | | | | | | | |
| | 011 | Nacoobanovtumor | | | | | | | |

www.tumorregister-muenchen.de

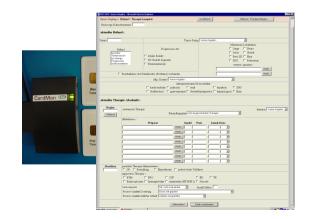
for all



differentiated aggregated analyses for "authorized" interested parties



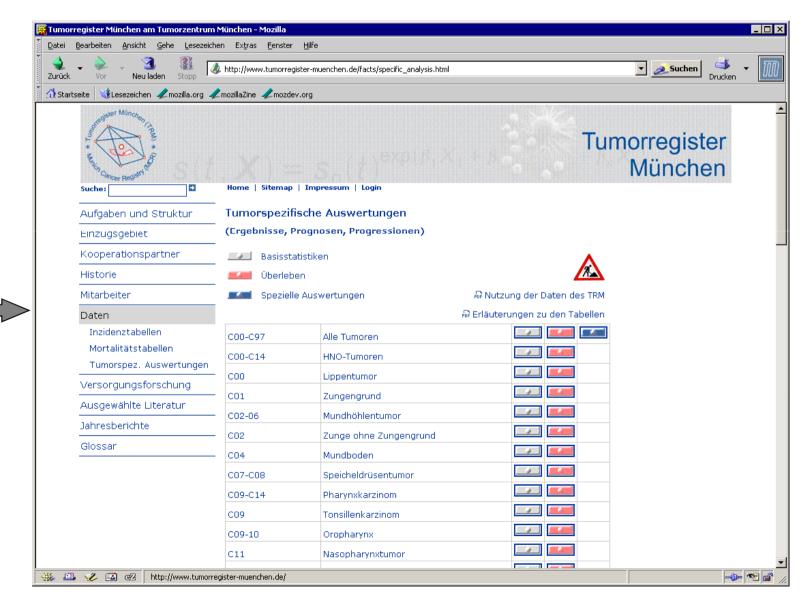
differentiated aggregated analyses + clinic specific analyses for doctors and clinics only



casuistics, queries of data, online documentation for doctors and clinics only



1. Internet (open access): www. tumorregister-muenchen.de



1st Int. Congress of Breast Disease Centers Session 14: Survivorship & Follow-up **Cancer Registry in Germany: The Munich experience**



2./3. Internet (login with password only): www. tumorregister-muenchen.de

| | | | - | | | | | | | | | | | | |
|---------------------------|-----------------------------------|---------------------|-----------|---|--|------------|--------------------------------|----------------|----------|------------------------|---------|-----------------------|---|------|--|
| Ziele und Erläuterungen | Allgemeine Auswertungen (Aktuell) | | | | | | | | | | | | | | |
| Kooperationspartner | 🖟 Erläuterung | gen zu den Auswe | | | | | | | | | | | | | |
| Zertifizierungen | - Erhebungsbögen | | | Тур: Б | EE, Retro, Folge, A | Anschrift | | | | | | | | | |
| Stand der Datenbank | Daten allgemein | | | Тур: А | A, AE, AP, AS | | | | | | | | | | |
| Pathologie-Dokumente | Survival-, multivariate Analysen | | | Тур: 9 | S, Sp, M | | | | | | | | | | |
| Allgemeine Auswertungen | Epidemiologie | | | Тур: Б | E, EpI, K, Zeit. | | | | | | | | | | |
| Aktuell | Spezielles | | | Тур: С | QA, QErl., Vergl., E | Bes., Lit. | | | | | | | | | |
| Archiv | Eiomet | trische Bewertung | | | | | | | | | | | | | |
| Todesbescheinigungen | C00-C97 | Alle Tumoren | | | | |] | | | | | | | | |
| Manuale | C03-C06 | 3-C06 Mundhöhle | | | | | 1 | | | | | | | | |
| Ausgewählte Publikationen | C07-C08 | Speicheldrüse | | | | |] | | | | | | | | |
| FAQ | C09-C10 | Oropharynxkarzino | m | |] | | | | | | | | | | |
| | C11 | Nasopharynxkarzin | iom | | | 6 | | | | | | | | | |
| | C15 | Ösophaguskarzinor | m | | | | | | | | | | | | |
| | C16 | Magenkarzinom | | | | | | | | | | | | | |
| | C18-C20 | Kolorektales Karzin | iom | | | | | | _ | | | | Benchmark | king | |
| | C22 I | Leberkarzinom | | | A: Daten aller Kliniken - Dec 2007 AE: Daten des epid. Einzugsgebiets - Dec 2007 | | | | | | | - | | | |
| | C23-C24 Galienkarzinom | | | | AS: Daten aller Strahlentherapien - Dec 2007 A(Rektum): Daten aller Kliniken - Dec 2007 | | | | | | | | multivariate | | |
| | C25 | Pankreaskarzinom | | | | | | | | | | | Analyses | | |
| | C32 I | Larynxtumor | | | AE(Rektum): Dater A(Kolon): Daten al | | | ets - Dec 2007 | | | | | Analyses | | |
| | C33-C34 | Thorakale Tumoren | 1 | and the second se | · · · · · · · · · · · · · · · · · · · | | pid. Einzugsgebiets - Dec 2007 | | | | | | | | |
| | C18-C20 Kolorektales H | | | irzinom | | | | | | | | | | | |
| | | | | | | - | | | | il Analysen - Mar 2008 | | | | | |
| | C22 | Leberka | arzinom | | | | | M: Multiva | ariate A | nalys | en - Ap | r 2007 | | | |
| | | C18-C20 | Kolorel | ktales Ka | rzinom | | | | | | | | | | |
| | | C22 | Leberk | arzinom | | | | | | | | ogie - Fe - Feb 20 | | | |
| | | , LC18-C5 | . <u></u> | iurektaies | кагинн | | | | | | | Tul Autor | | _ | |
| | | C22 | Let | berkarzino | om | 1 | - | | | | - | | rungen - Dec 2007 er Kliniken - Dec 2007 | | |
| | | C23-C2 | 4 Gal | llenkarzin | om | 1 | - | | | | V: Klir | ikvergle | iche - Dec 2007 | 13 | |



4. Intranet or Chipcard: Access to database / online documentation

| TRM : Tumorregister München | | | | | | | | |
|--|--|--|--|--|--|--|--|--|
| Datei Bearbeiten Ansicht Favoriten Extras 2 | | | | | | | | |
| and the second | uchen 🧙 Favoriten 🕢 🔗 🕻 🍃 🚍 + 🧾 🕉 | | | | | | | |
| Adresse 🗃 https://localhost/trm/TRM | | 🕑 🛃 Wechseln zu 🛛 Links | | | | | | |
| Tumorregister München | Tumorregister München Haupt-Auswahl | | | | | | | |
| TRM | Einzelanfragen Patienten-Verlauf | Patienten-Listen und Statistiken (Klinik_Nr-, KV_NR-spezifisch) | | | | | | |
| am Tumorzentrum München der medizinischen Fakultäten der Ludwig-Maximilians-Universität | Nachsorge-Kalender-Nr. | Basis-Zahlen | | | | | | |
| und der Technischen Universität e-mai: 📾 | erforderliche Angaben : Kalender-Nr. + Geburtsdatum | Diagnosen pro Jahr | | | | | | |
| zur Haupt-Auswahl Benutzer hoelzel Typ = G Gesamt-Abteilung | mitvollem Namen erforderliche Angaben : Geburtsdatum und Vor-/Zu-Name + Geschlecht, soweit zur Identfikation nötig | ausstehende Ersterhebungen zu Pathobefunden | | | | | | |
| Klinik_Nr 0 | bekannte PAT_ID | ausstehende Ersterhebungen zu DCO-Fällen | | | | | | |
| Identitäts-Wahl für privilegierten Benutzer : | erforderliche Angaben : Pat_ID (des TRM) + Geburtsdatum Namens-Abfragen ohne Dateneingabe | Tumor-spezif. Patienten-Listen | | | | | | |
| KTYP Gesamtkinik ♥ Klinik_Nr KV_Nr Identität setzen | | | | | | | | |
| Fertig | | 🔒 🥞 Lokales Intranet | | | | | | |

Possibility for independent queries of specific cases or listings of patients groups for each clinic (about their own patients only)

... case-based learning is an interactive process ...

The evaluation begins with a critical check of conspicuous casuistics.



Value of Cancer Registries for Breast Disease Centers, Clinics / Ambulatory Sector, Scientific Community

- 1. Health Care during Course of Disease and Infrastructure for Support of Health Care
- 2. Feedback Systems, Quality Management, Benchmarking

3. Health Care Research



Formulate and prioritize research questions (Example: Lymph Node Dissection)

- All randomised clinical trials for different solid tumours have not shown any survival benefit of lymph node dissection (LND).
- Gene-expression analyses of the primary tumour allow a prognosis in LN negative and positive cases.
- Gene analyses predict the sites of metastasis.
- ...
- → "Seed and soil" principle seems valid! Cell-characteristics of the primary tumour and the microenvironment are essential for a successful "metastasis".
- The risk of metastasis arises from the primary tumour, not from secondary tumours (like local, regional or distant metastases)!
- A cascade-like progression model seems outdated.

Hypothesis for solid tumours: metastases do not metastasize!



Hypothesis for solid tumours: metastases do not metastasize!

If metastases do not metastasize, then positive lymph nodes, as an example of regional metastases, also do not metastasize and therefore the benefit of LND is questionable. If any LND is questionable then also the sentinel technique is questionable.

The Breast (2006) 15, 451-454



THE BREAST

www.elsevier.com/locate/breast

SHORT REPORT

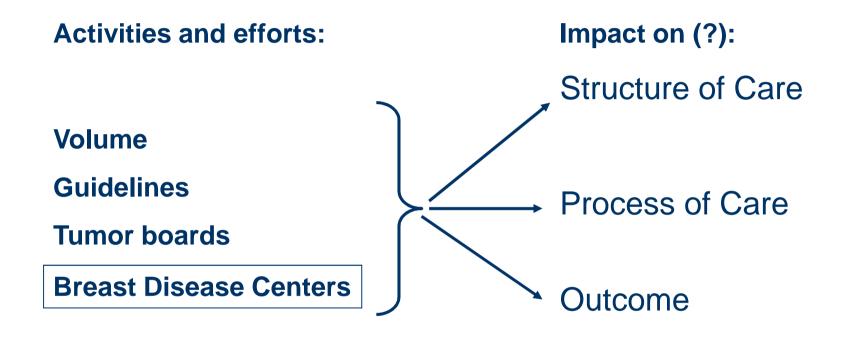
Are we wasting our time with the sentinel technique? Fifteen reasons to stop axilla dissection

J. Engel^{a,*}, A. Lebeau^b, H. Sauer^c, D. Hölzel^a

^aMunich Cancer Registry (MCR) of the Munich Comprehensive Cancer Centre (MCCC), Institute of Medical Informatics, Biometry and Epidemiology (IBE), Clinical Centre of the Ludwig-Maximilians-University, Großhadern, Marchioninistrasse 15, D-81377 Munich, Germany ^bDepartment of Pathology, Ludwig-Maximilians-University, Munich, Germany ^cMedical Clinic III, Clinical Centre of the Ludwig-Maximilians-University, Großhadern, Munich, Germany

1st Int. Congress of Breast Disease Centers Session 14: Survivorship & Follow-up Cancer Registry in Germany: The Munich experience





Several responsibilities of Health Care Research



The role of cancer registries is, among others:

- Cancer registries ...
- ... can manage and contribute valuable data to support the health care delivery system in an increasingly complex network
- ... can provide sensible evaluations regarding quality assessment
- ... can help to formulate and prioritize research questions
- ... can monitor whether activities and efforts (like the establishment of Breast Disease Centers) are implemented into practice and have impact on the outcome.

Thank you very much for your attention! Mercy beaucoup pour votre attention!