

# Cancer Registry

Population-based quality of life  
research using the cancer registry

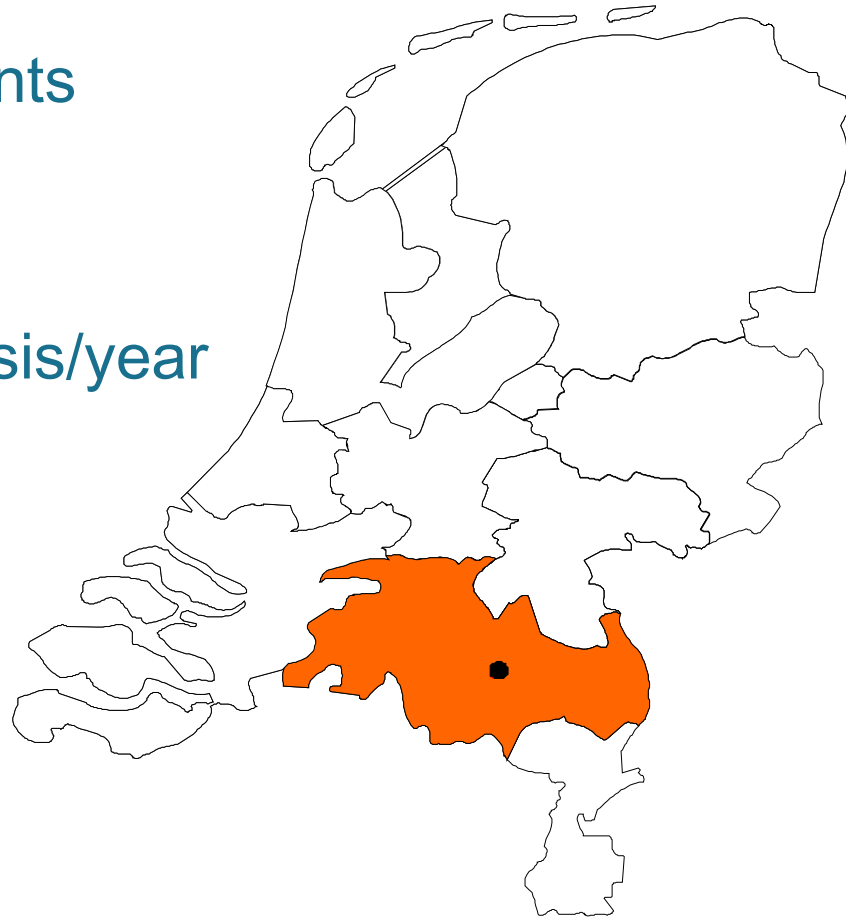
Lonneke van de Poll-Franse

Professor of Cancer Epidemiology and Survivorship



# Eindhoven Cancer Registry

- Area of 2,4 million inhabitants
- 10 hospitals
- 2 radiotherapy institutes
- 20.000 new cancer diagnosis/year (including BCC)
- Part of Netherlands CR
- 100% coverage

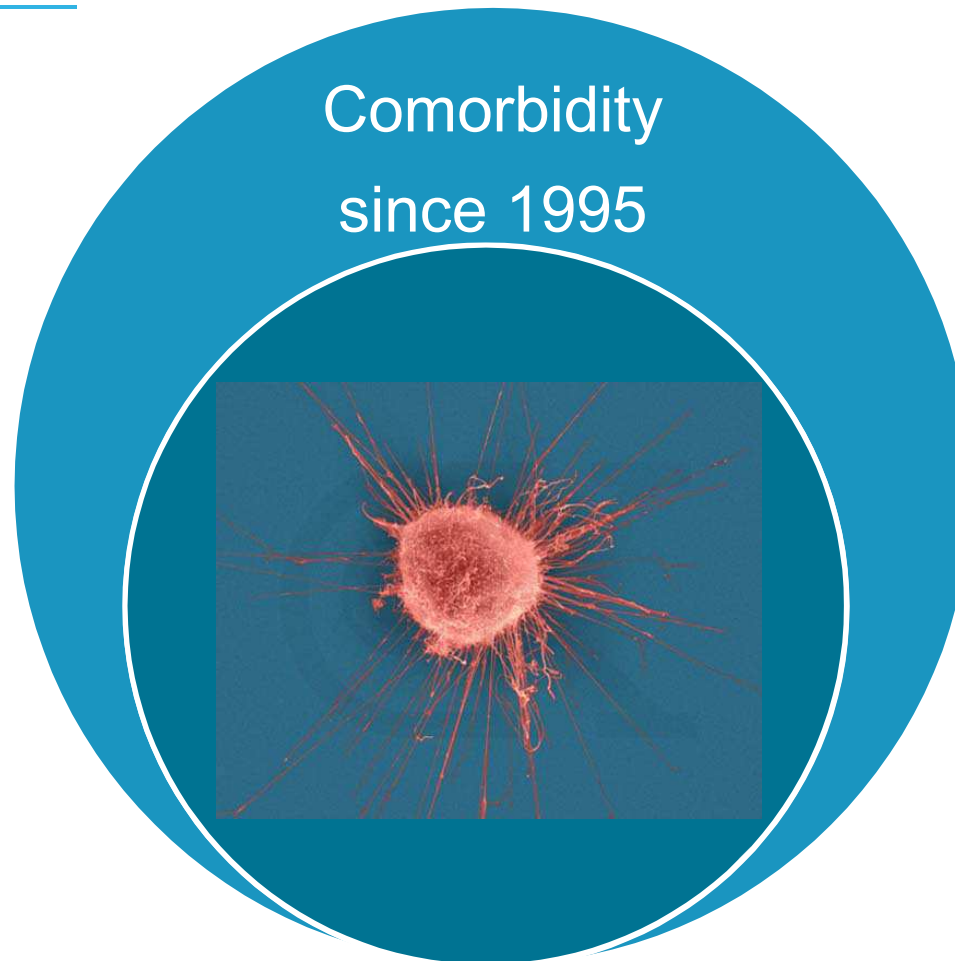


# Eindhoven Cancer Registry

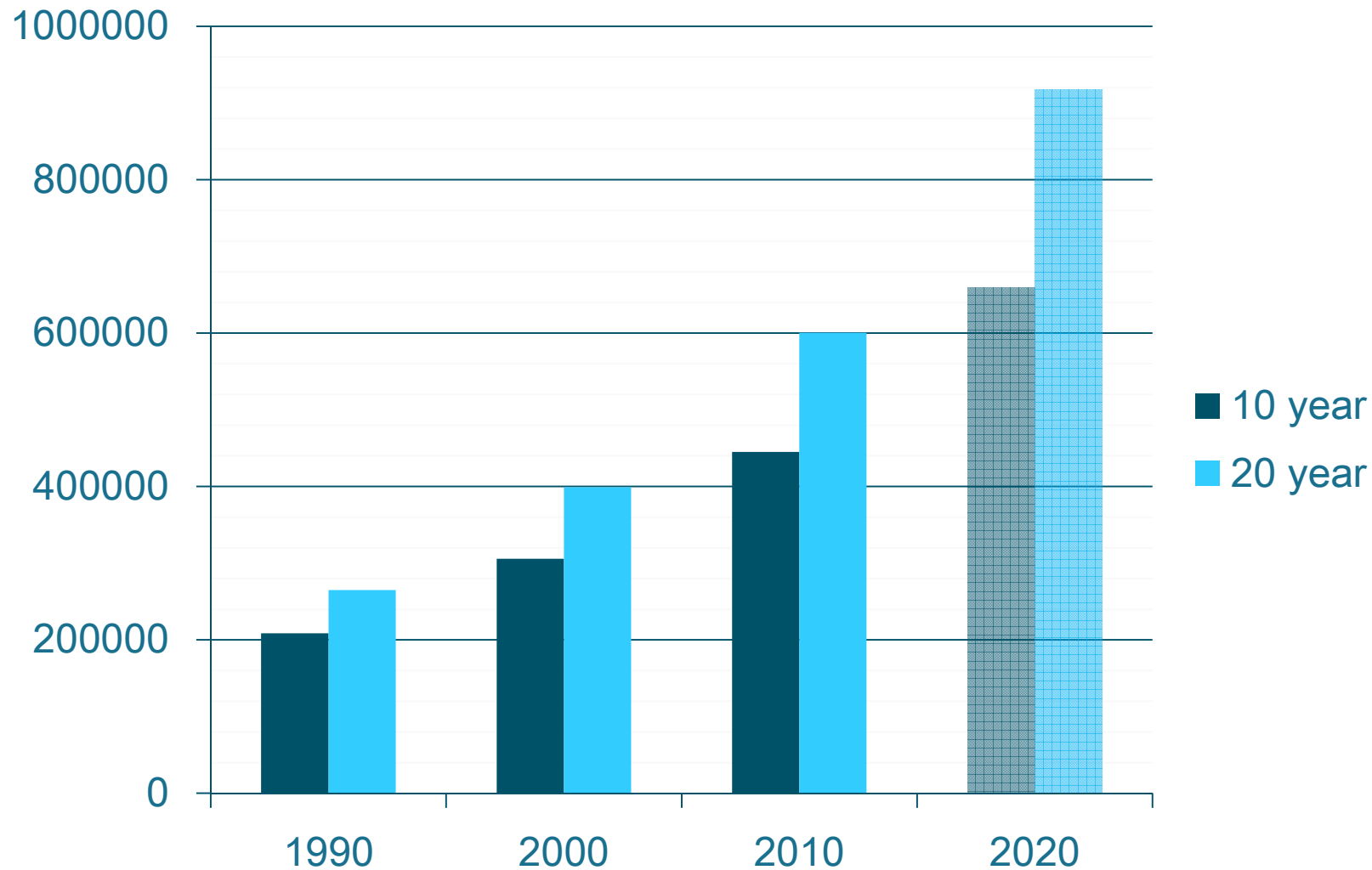
since 1955

- Comorbidity since 1995  
(Charlson Index)

- Tumor stage, grade
- Treatment
  - surgery
  - radiotherapy
  - systemic therapy
- Sex, age, SES
- Survival



# Absolute prevalence in NL



Source: 'Cancer in the Netherlands to 2020' Dutch Cancer Society / Eindhoven Cancer Registry



# Cancer survivors

- Today: 600.000 cancer survivors in the Netherlands, 2 million in the UK and 12 million survivors in US
- Cured?
- Living with cancer as a chronic disease?
- Long term/late effects of cancer treatment?
- Psychosocial needs?

→ How are cancer patients doing in the long run?

# Survival and Quality of Life

What is the value of routine pelvic lymphadenectomy in early stage endometrial cancer?





Available online at [www.sciencedirect.com](http://www.sciencedirect.com)

SCIENCE @ DIRECT®

EJSO

EJSO 32 (2006) 450–454

## Routine pelvic lymphadenectomy in apparent

L.D. Zuurendonk<sup>a,†</sup>, R.A. Smit<sup>b</sup>

K.A.J. de Winter<sup>c</sup>

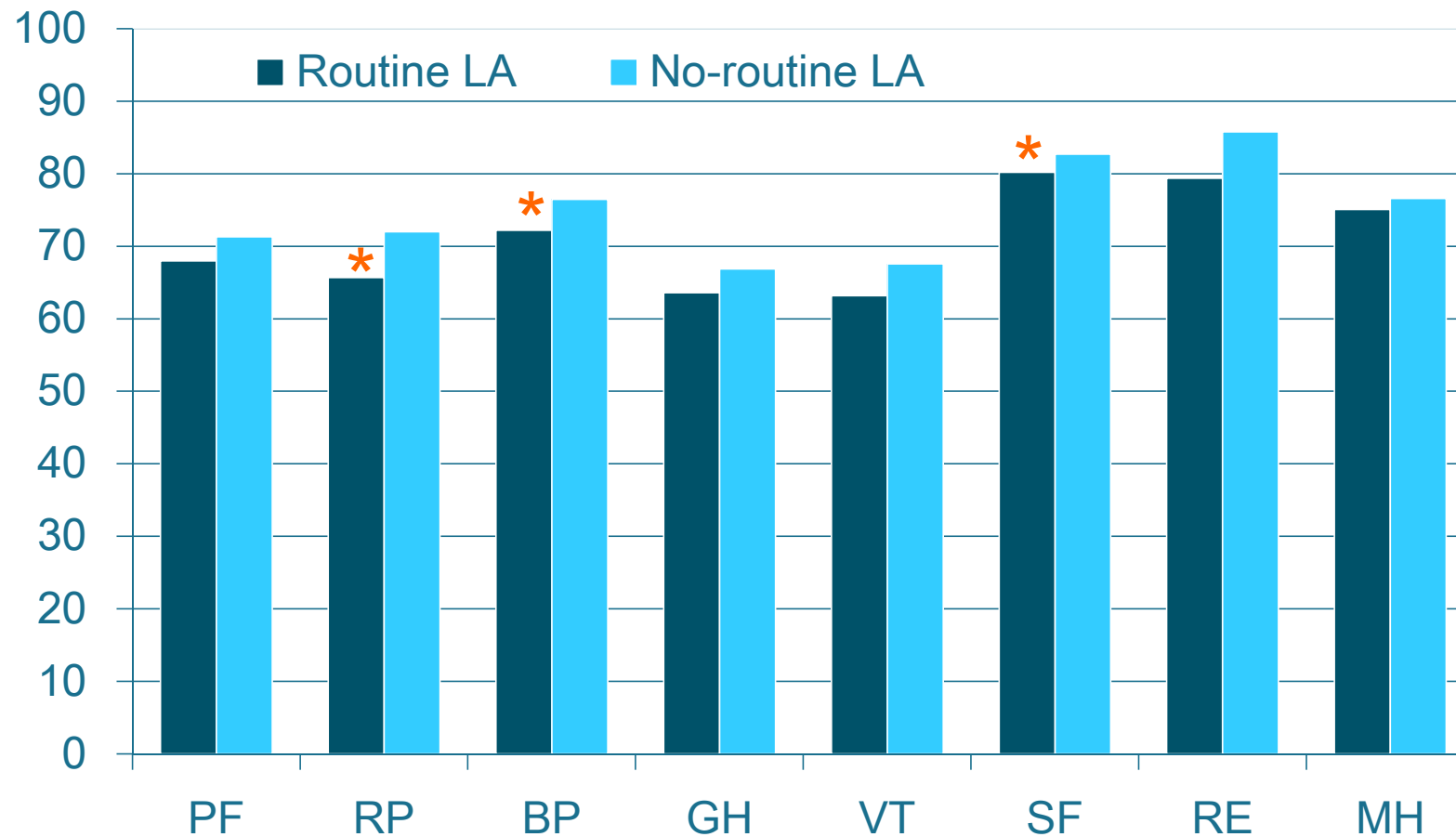
<sup>a</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>b</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>c</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>d</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>e</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>f</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>g</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>h</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>i</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>j</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>k</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>l</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>m</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>n</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>o</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>p</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>q</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>r</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>s</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>t</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>u</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>v</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>w</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>x</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>y</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands  
<sup>z</sup>Department of Gynaecology, St Elisabeth Hospital Tilburg, Tilburg, The Netherlands

Accepted 9 February 2006  
Available online 20 March 2006

No Survival advantage!

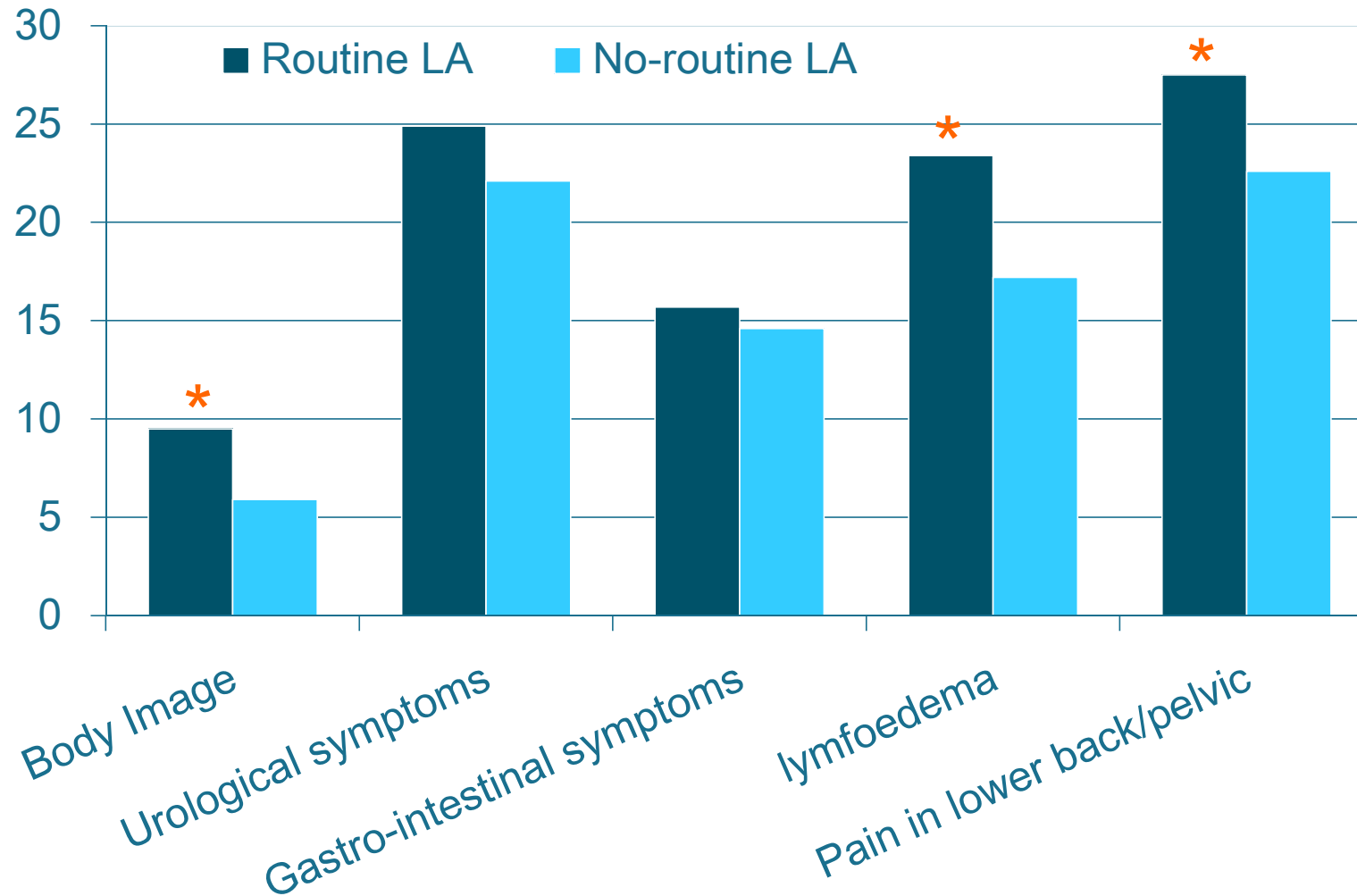
KZ

# QoL after lymphadenectomy in endometrial cancer stage I-II





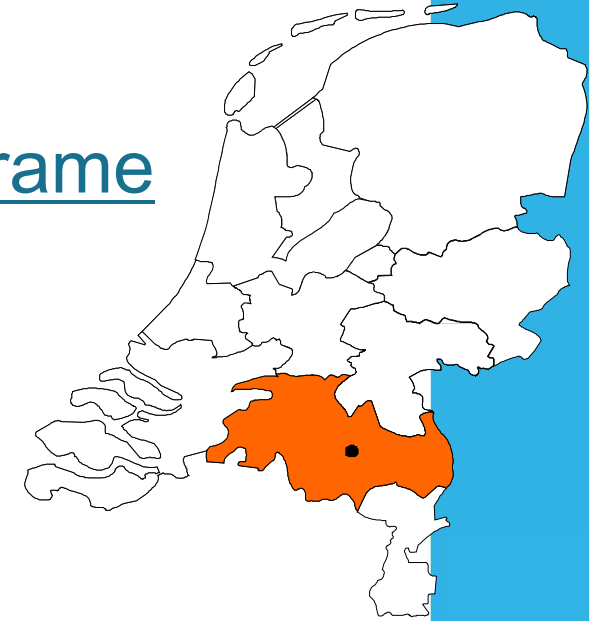
# Cancer specific symptoms



# Methods: Patient selection

## Eindhoven Cancer Registry sampling frame

- Patient characteristics
- Tumor characteristics
- Treatment
- Alive? (linkage municipal registry)
- Longitudinal assessment :
  - Lifestyle and PRO



Questionnaire  
sample



# Methods: Questionnaire

- Socio-demografic, lifestyle
- Cancer specific quality of life (EORTC-QLQ C30)
- Disease specific quality of life (EORTC- modules)
- Anxiety, depression (HADS)
- Fatigue
- Information provision
- Return to work
- Insurance/Mortgage problems

### Home

[Home](#)
[Wat doen we?](#)
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[Wie doen mee?](#)
[Resultaten onderzoek](#)

### Over Profiel

Profiel is wetenschappelijk onderzoek naar kwaliteit van leven bij mensen die kanker hebben of hebben gehad. Hiervoor werken onderzoekers van het Integraal Kankercentrum Zuid (IKZ) in Eindhoven en de Universiteit van Tilburg (UvT) samen met medisch specialisten van ziekenhuizen in Noord-Brabant en Limburg.

#### Doel

Het doel van Profiel is om meer te weten te komen over de gevolgen van kanker voor het leven van mensen die kanker hebben of hebben gehad. De resultaten van het onderzoek dragen bij aan een betere (na)zorg voor patiënten.

#### Sinds 2004

Profiel komt voort uit een langer lopende onderzoekslijn naar kwaliteit van leven in de regio Zuid-Nederland. Sinds 2004 is er bij meer dan 8000 (ex-)kankerpatiënten onderzoek gedaan naar de late gevolgen van kanker, zorggebruik, en maatschappelijke implicaties.

#### Resultaten

De resultaten van deze onderzoeken worden besproken met medisch specialisten uit de regio. Bovendien worden de resultaten gepubliceerd in (inter-)nationale tijdschriften. Tevens worden presentaties gehouden op (inter-)nationale congressen en workshops georganiseerd waarin de resultaten besproken worden.

Lees meer over [wie we zijn](#), [wat we doen](#) en [wie mee doen](#).

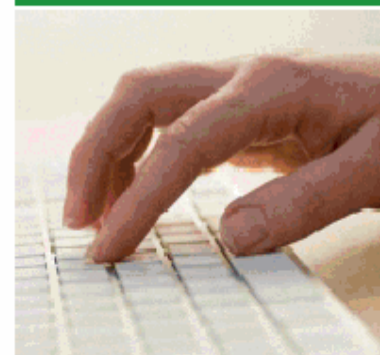
\* Profiel is de vertaling van PROFILES dat staat voor Patient Reported Outcomes Following Initial treatment and Long term Survivorship

### Nieuws



#### 10 Jaar na Hodgkin Lymfoom: betere kwaliteit van leven

EINDHOVEN – Patiënten bij wie 10 tot 15 jaar geleden de diagnose Hodgkin lymfoom is vastgesteld hebben een betere kwaliteit van leven dan patiënten bij wie 5 tot 9 jaar geleden de diagnose Hodgkin lymfoom is vastgesteld. Beide

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# PROFILES Registry

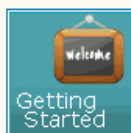
- Patient Reported Outcomes Following Initial treatment and Long-term Evaluation of Survivorship \*
- Infrastructure for data collection: web-based and paper
- Longitudinal survey data linked to cancer registry data
- Normative data available for 2000 Dutch persons\*
- [www.profielstudie.nl](http://www.profielstudie.nl) for patients
- [www.profilesregistry.nl](http://www.profilesregistry.nl) for researchers (free access to data for academic users)

\* Van de Poll-Franse, Eur J Cancer 2011

## Data Archive Homepage

Please select one of the following links to start accessing the Profiles Registry data and metadata.

To download data you have to be logged in. If you do not have a user account yet, click [here](#) to apply for one.



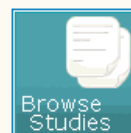
### Getting Started

Information about the Data Archive for first time users.



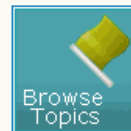
### Login

Login to download datasets. No account yet? Click [here](#).



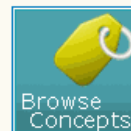
### Browse Studies

View all studies.



### Browse Topics

View all studies and publications by topic.



### Browse Concepts

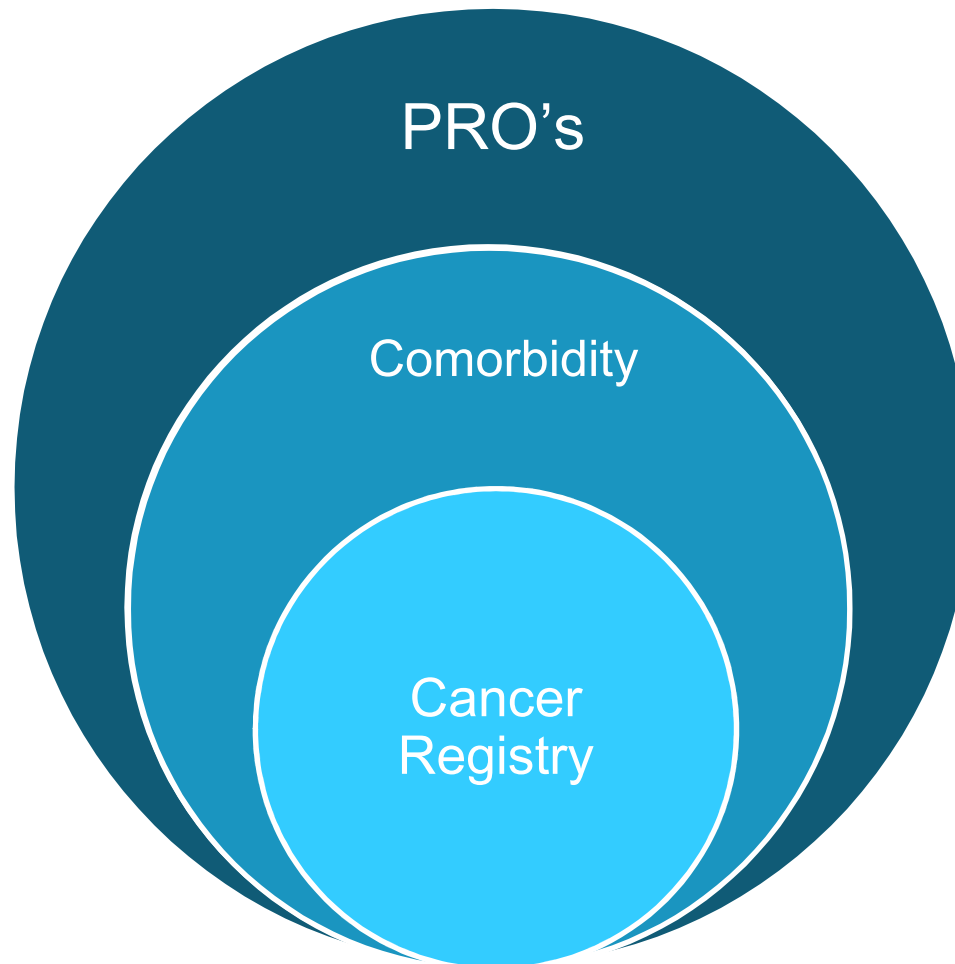
View the concepts used in Profiles Registry.

# Eindhoven Cancer Registry

since 1955

Patient Reported  
Outcomes since 2004

Longitudinal  
assessment of  
lifestyle and PRO's



# Quality of life studies ECR region

Tumor	Year of diagnosis	N patients
Prostate	1994-2009	1400
Breast	1993-2003	500
Colorectal	1998-2010	7000
Lymphoma	1989-2010	3500
Endometrial & Ovarian	1994-2012	1700
Thyroid	1990-2008	500
Melanoma	1998-2007	800
<b>Total</b>		<b>15.400</b>



# Chemotherapy-induced neuropathy

- CRC survivors face continuing problems like chemotherapy-induced peripheral neuropathy (CIPN)
- Questionnaire (EORTC QLQ-CIPN20) was completed by 1648 CRC survivors (83% response rate)

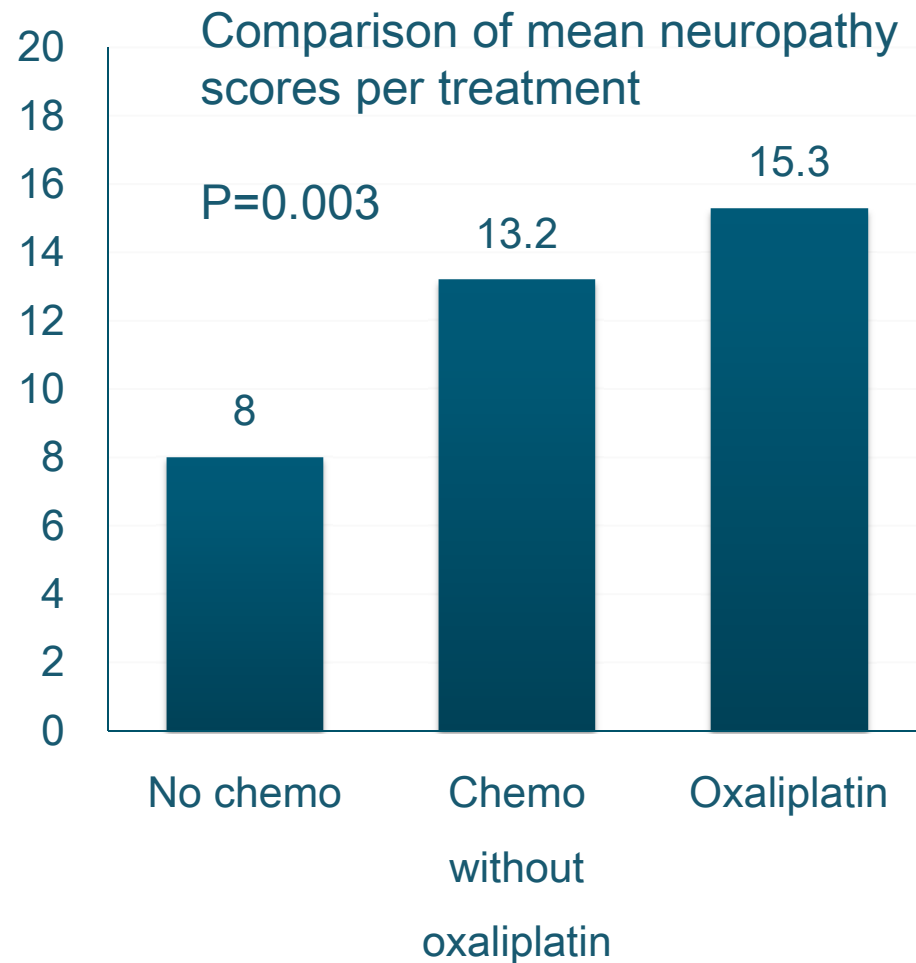
## Patient characteristics:

- Mean age 69 years, on average 6 years after diagnosis
- 31% (n=500) was treated with chemotherapy



Mols, J Clin Oncol 2013

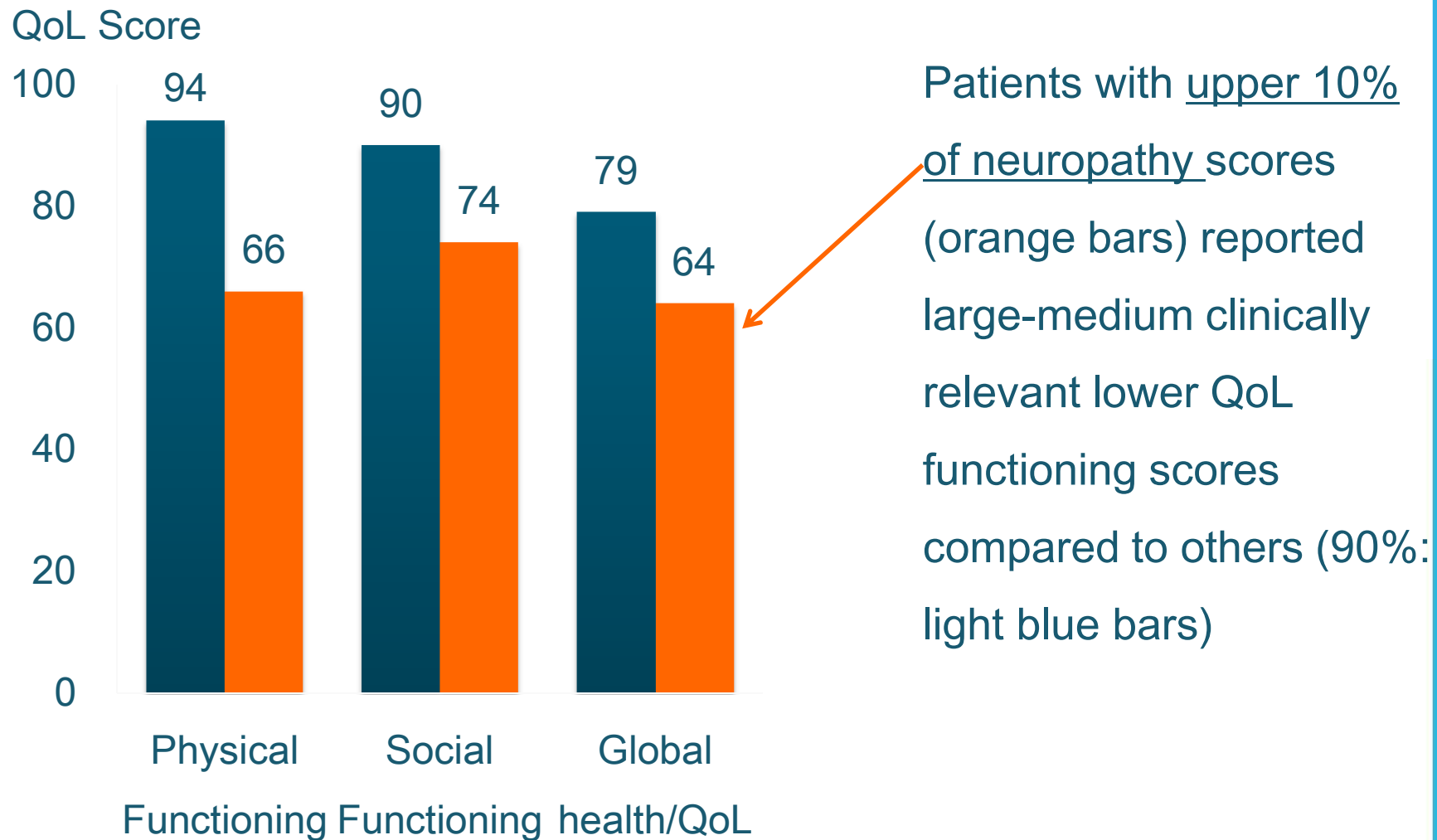
# Chemotherapy-induced sensory neuropathy



NB: 1 in 3 patients (!) treated with oxaliplatin reports tingling, painful hands or feet- up to 10 years after diagnosis

Mols, J Clin Oncol 2013

# Chemotherapy-induced sensory neuropathy

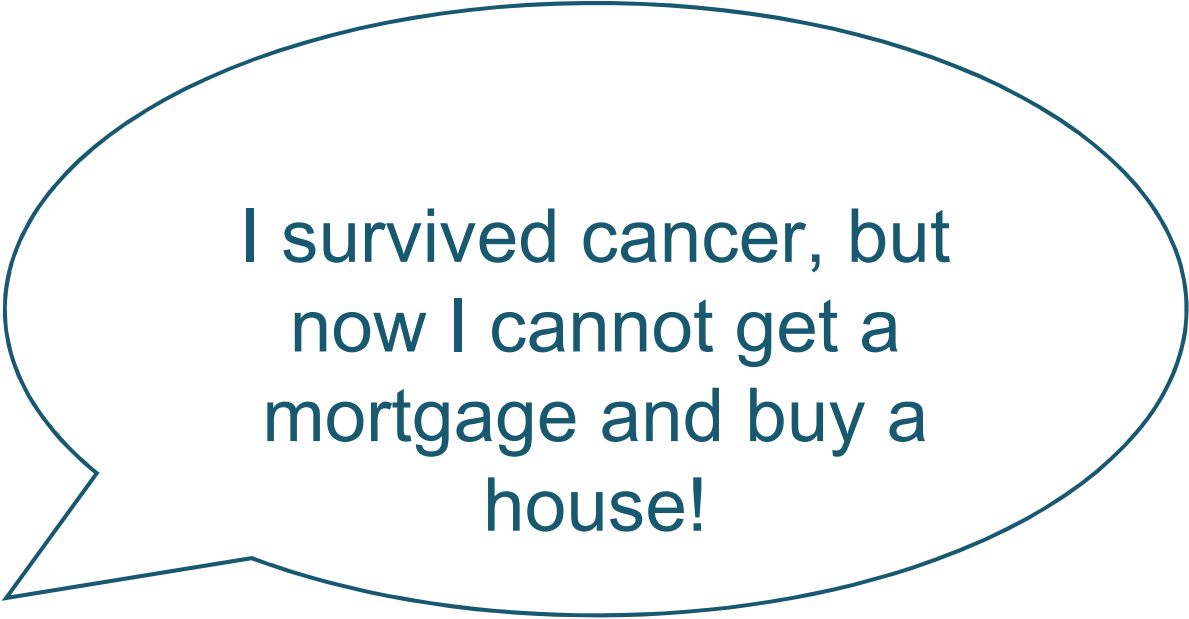


Mols, J Clin Oncol 2013

# Clinical implications

- No well-accepted proven therapy to alleviate or prevent CIPN
- Who are those patient who develop CIPN?
- But also: Bring QoL into the discussion when evaluating the added value of oxaliplatin in adjuvant setting (current stage II/III disease)?!?!
- Overall survival vs. long-term symptoms & quality of life

# Patient reactions on questionnaires



I survived cancer, but  
now I cannot get a  
mortgage and buy a  
house!

Available at [www.sciencedirect.com](http://www.sciencedirect.com)

SciVerse ScienceDirect

journal homepage:



## Socio-economic implications of cancer survivorship: Results from the PROFILES registry

Floortje Mols <sup>a,b,\*</sup>, Melissa S.Y. Thong <sup>a,b</sup>, Pauline Vissers <sup>a,b</sup>, Tamar Nijsten <sup>c</sup>,  
Lonneke V. van de Poll-Franse <sup>a,b</sup>

<sup>a</sup> CoRPS – Center of Research on Psychology in Somatic diseases, Department of Medical Psychology and Neuropsychology, Tilburg University, The Netherlands

<sup>b</sup> Comprehensive Cancer Centre South, Eindhoven Cancer Registry, Eindhoven, The Netherlands

<sup>c</sup> Department of Dermatology, Erasmus Medical Centre Rotterdam, Rotterdam, The Netherlands

### ARTICLE INFO

#### Article history:

Available online xxxx

#### Keywords:

Cancer

Life insurance

Mortgage

Health care insurance

Work

### ABSTRACT

**Introduction:** The goal of this large population-based study was to examine the socio-economic implications of cancer survivorship.

**Methods:** Individuals alive and diagnosed with colorectal cancer and melanoma between 1998 and 2007 or Hodgkin lymphoma, non-Hodgkin lymphoma or multiple myeloma between 1999 and 2008 as registered in the Eindhoven Cancer Registry received a questionnaire on work changes and problems with obtaining a new (or extended) health care insurance, life insurance or a home loan; 70% ( $n = 2892$ ) responded.

**Results:** Results showed that 28% of all cancer patients experienced changes in their work situation after cancer. Most of them switched to part-time work or stopped working

# Socio-economic implications

- N=2892 cancer survivors (colorectal cancer, melanoma, lymphoma)
- Mean years since diagnosis: 4,5 years
- 70% response rate
- 557 patients tried to get a mortgage (home loan)
  - 53 (10%) experienced problems
  - 35/107 (33%) patients <50 experienced problems
- 586 patients tried to obtain a life insurance
  - 119 (20%) experienced problems
  - 64 /109 (59%) patients <50 experienced problems

\* Mols, Eur J Cancer 2011



# Reported in the press

vk.nl

de site van de Volkskrant

NIEUWS OPINIE CULTUUR SPORT **ECONOMIE** REIZEN

VKSHOP SERVICE

## 'No mortgage or insurance after cancer'

Maud Effting - 31/12/11, 09:36



Spreek- en behandelkamer van het VUmc Cancer Center, © ANP

**Bijna 60 procent van de ex-kankerpatiënten wordt financieel gezien nog jarenlang door hun ziekte achtervolgd: ze krijgen moeilijker verzekeringen en hypotheek.**

Jonge mensen die genezen zijn van kanker hebben grote problemen om een levensverzekering of een hypotheek te krijgen. Vaak worden ze geweigerd of moeten ze een fors hogere premie betalen, ook als de ziekte al langer geleden

[MEER OVER](#)

[Kanker](#) [Gezondheid](#) [Banken en verzekeringen](#)

KZ



# Reported in the press

- Picked up by many news-papers and 8 o'clock (prime time) evening news item
- National discussion
- Reaction from 'Netherlands Federation for Cancer Patient Organisations' (NFK)
- Reaction from 'Association of Insurance Companies'

wo 25 jan 2012, 08:35

## Support for cancer survivor

AMSTERDAM - De Nederlandse Federatie van Kankerpatiëntenorganisaties (NFK) en het Verbond van Verzekeraars gaan hun krachten bundelen om een einde te maken aan de discriminatie van ex-kankerpatiënten die een hypotheek of levensverzekering willen afsluiten.



Ex-patiënte Mireille Canoo werd door de verzekering afgewezen wegens een 'sterk verhoogd overlijdensrisico'.



dat onmogelijk. Een woordvoerder: „De levensverzekering kent geen acceptatieplicht. Dat maakt het anders dan bijvoorbeeld een ziektekostenverzekering. Wij kunnen daar niets aan doen; die ambitie hebben we ook niet.”

Gisteren gingen de partijen voor het eerst met elkaar aan tafel naar aanleiding van schokkende cijfers uit onderzoek van de Universiteit van Tilburg en het Integraal Kankercentrum Zuid: daaruit blijkt dat zes op de tien ex-kankerpatiënten onder de vijftig jaar problemen ondervinden bij het afsluiten van een hypotheek of levensverzekering.

### Eerste stap

„We gaan een eerste stap zetten door het geven van betere voorlichting aan zowel verzekeraars als ex-patiënten”, aldus Laurence Maes, beleidsmedewerker bij het NFK.

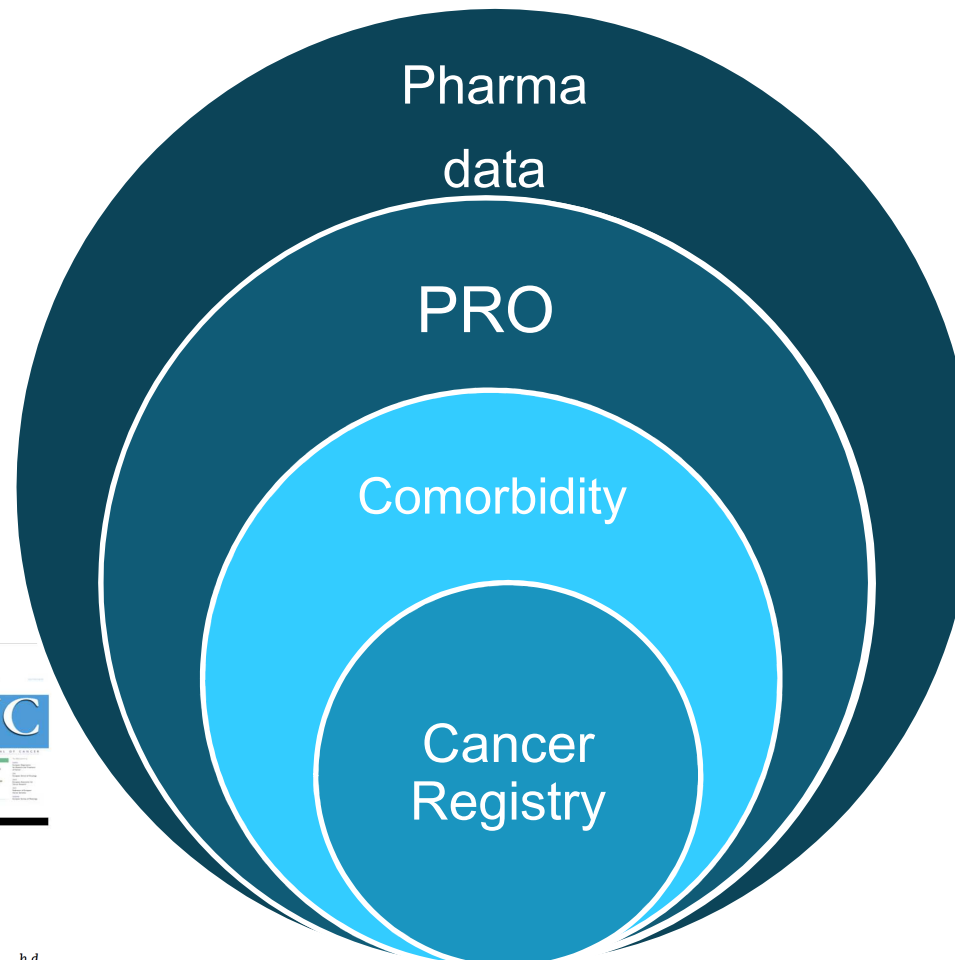
De organisatie ziet het liefst dat verzekeraars die ex-kankerpatiënten weigeren op de vingers worden getikt, maar volgens het Verbond van Verzekeraars is

Patient organisations and Insurance Companies are joining forces to end discrimination of cancer survivors who want to get a mortgage or life insurance

# Eindhoven Cancer Registry since 1955

## PHARMO:

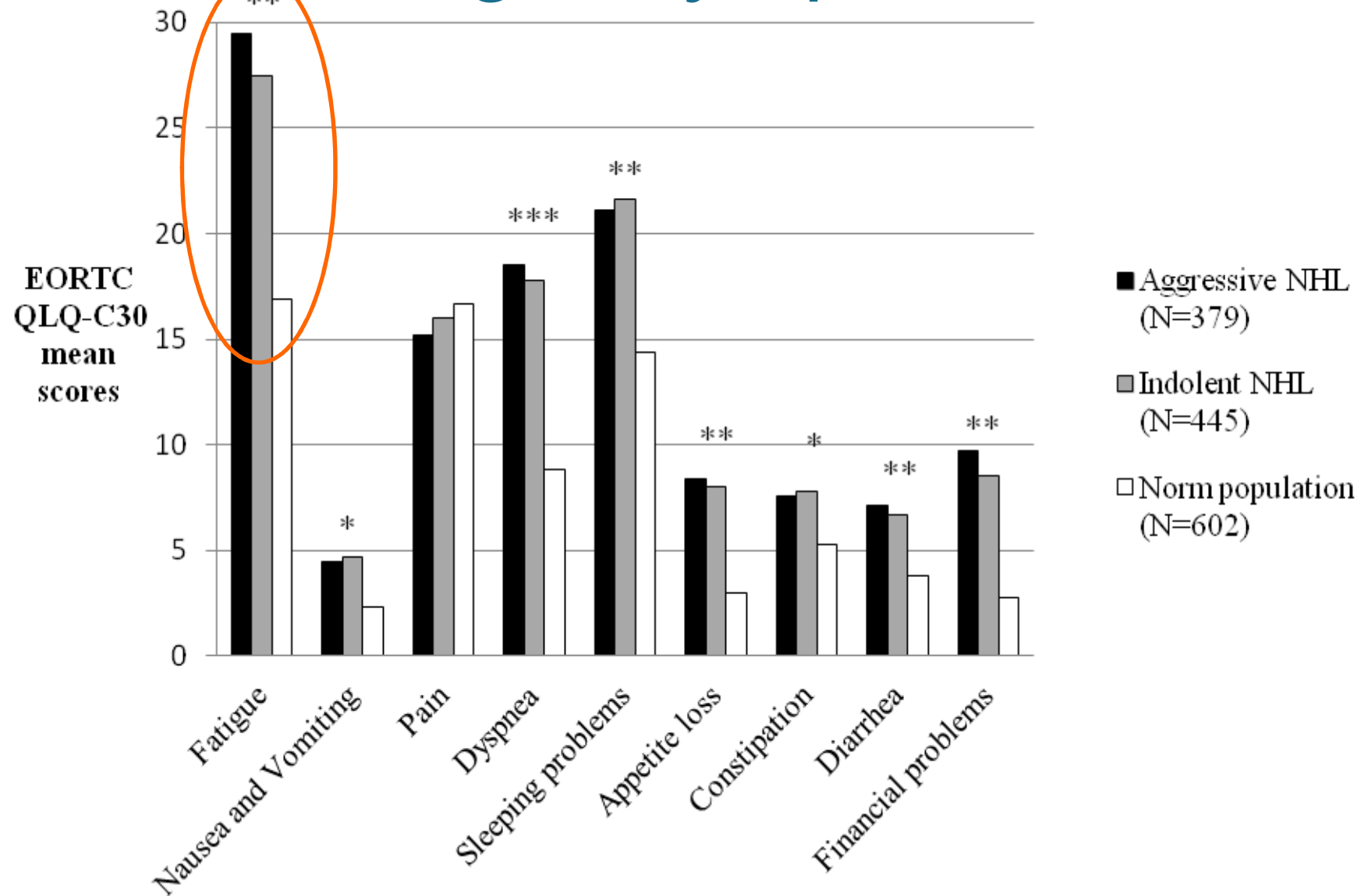
Linkage with  
pharmacy data  
from public and  
hospital  
pharmacies



**New opportunities for drug outcomes research in cancer patients: The linkage of the Eindhoven Cancer Registry and the PHARMO Record Linkage System**

Myrthe P.P. van Herk-Sukel <sup>a,\*</sup>, Lonneke V. van de Poll-Franse <sup>b,c</sup>, Valery E.P.P. Lemmens <sup>b,d</sup>, Gerard Vreugdenhil <sup>e</sup>, Johannes F.M. Pruijt <sup>f</sup>, Jan Willem W. Coebergh <sup>b,d</sup>, Ron M.C. Herings <sup>a,g</sup>

# Non-Hodgkin lymphoma



\* Oerlemans, Haematologica 2012

Health-Related Quality of Life and persisting  
symptoms in relation to (R-)CHOP14  
(R-)CHOP21 among Patients with Diffuse  
Large B-Cell Lymphoma in the Netherlands

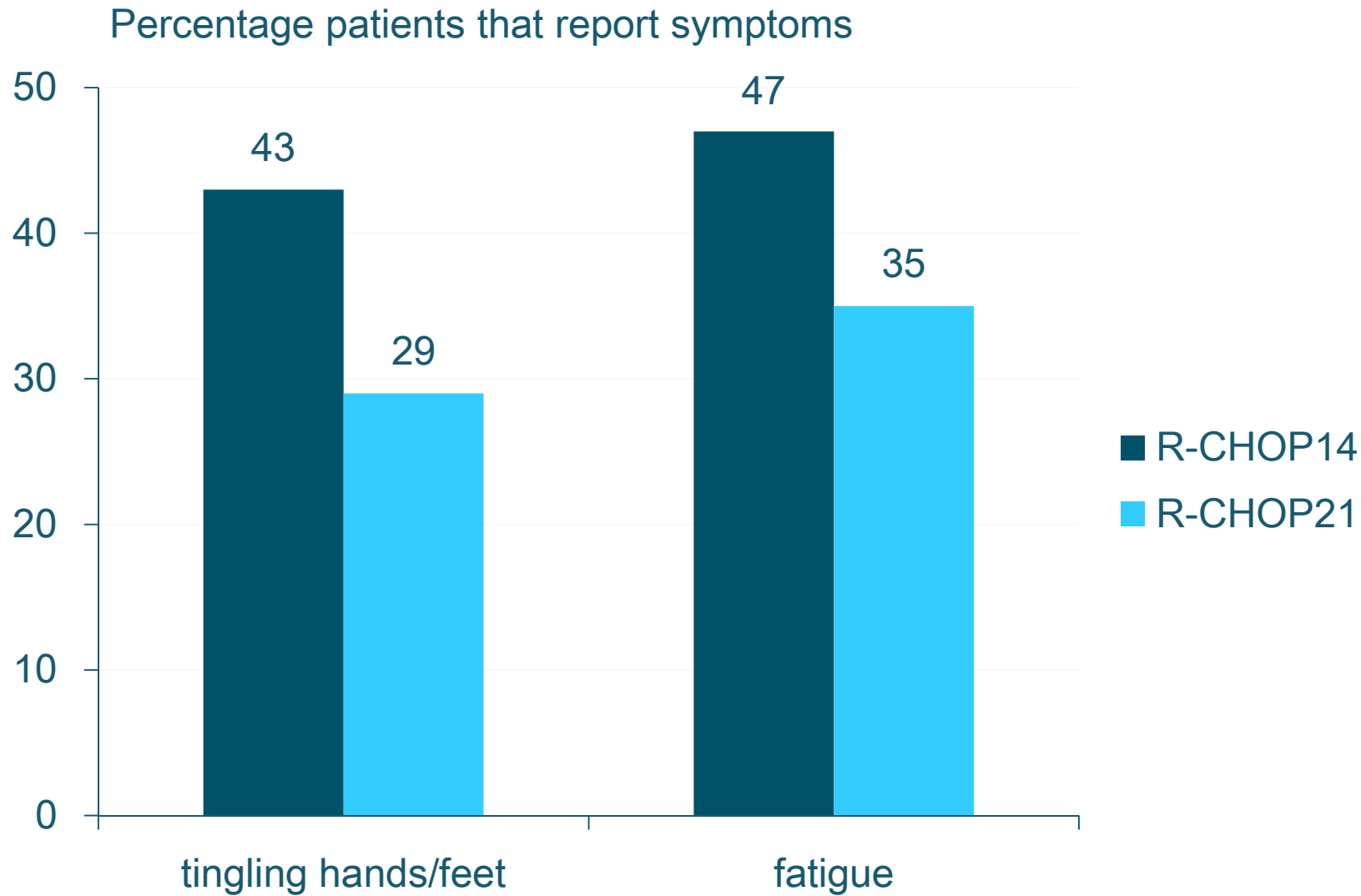
# Patient characteristics

## R-CHOP14 vs. R-CHOP21

In comparison with R-CHOP14 (n=93) patients, R-CHOP21 (n=126) patients are on average:

- A bit older: 67 vs. 61 jaar ( $p < 0.01$ )
- Longer after diagnosis: 2.9 vs. 2.0 jaar ( $p < 0.01$ )
- Better stage distribution: more stage I (44% vs. 16%) en less often stage IV (16% vs. 26%)

# R-CHOP14 vs. R-CHOP21



# Clinical implications

- R-CHOP14 results in almost similar HRQoL scores as compared to R-CHOP21
- BUT... more neuropathy and fatigue
- Recent phase 3 studies showed no improved survival between patients treated with R-CHOP14 vs R-CHOP21\*
- Doctors should pay attention to persisting symptoms: at least 1/3 experiences persisting neuropathy and/or fatigue
- What is the added value of the R-CHOP14 scheme?!?!

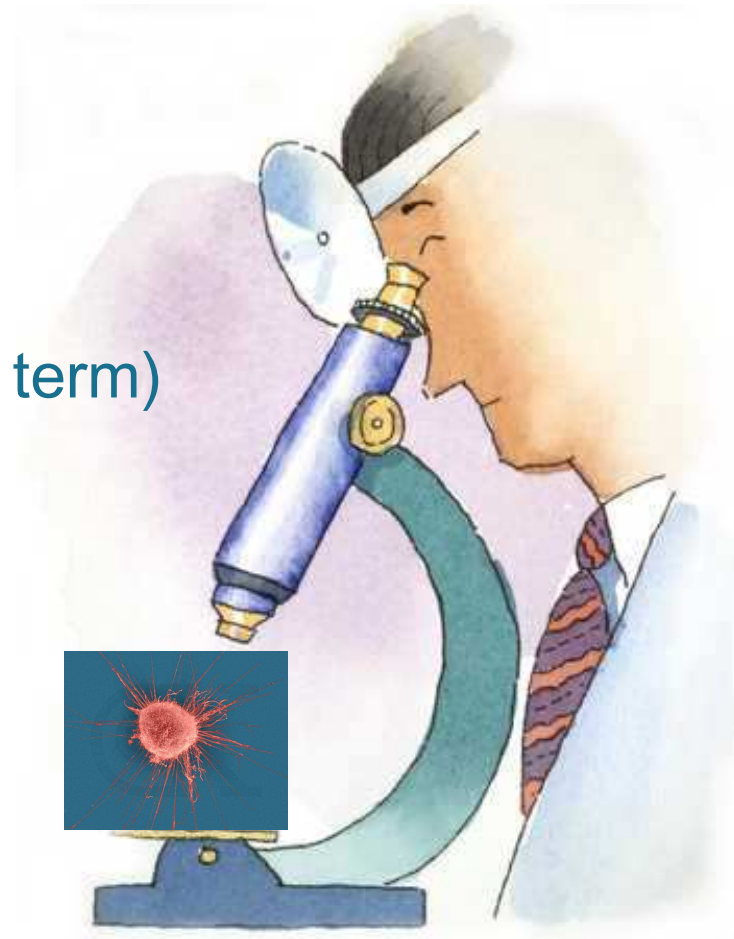
\* Cunningham D et al *Lancet* 2013;381:1817-26.

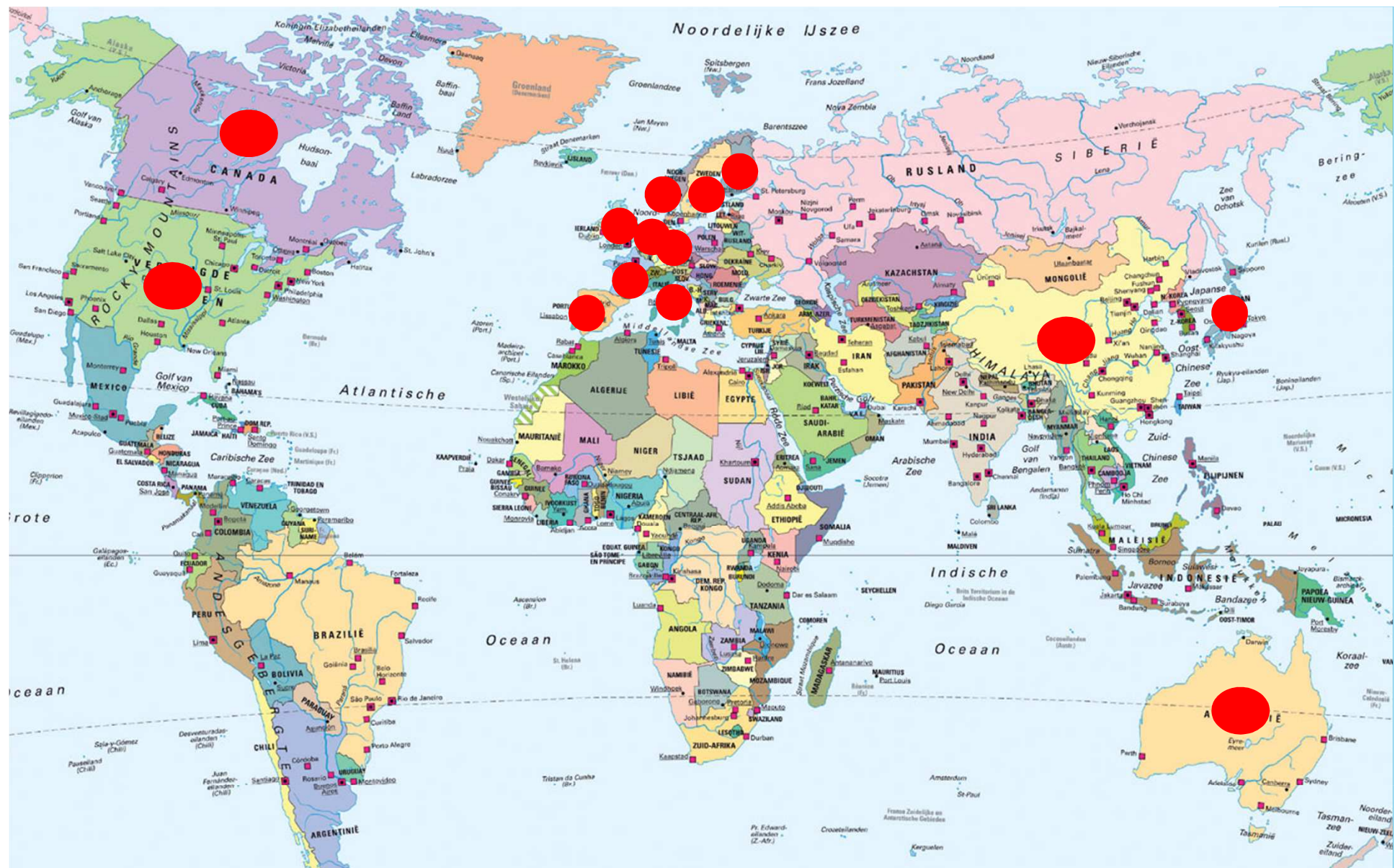
\* Delarue R et al *Lancet Oncol* 2013;14:525-33.



# Cancer registration

- Clinical data from the Cancer registry
  - Comorbidity
  - Patient reported outcomes
- 
- Continuous monitoring of (long term) impact of cancer and (new) therapies





Cancer Registries worldwide become  
Cancer *Patient* Registries

# Population-based cancer registries for patient-reported outcome research: a work-in-progress resource for survivorship studies?

## *A systematic review*

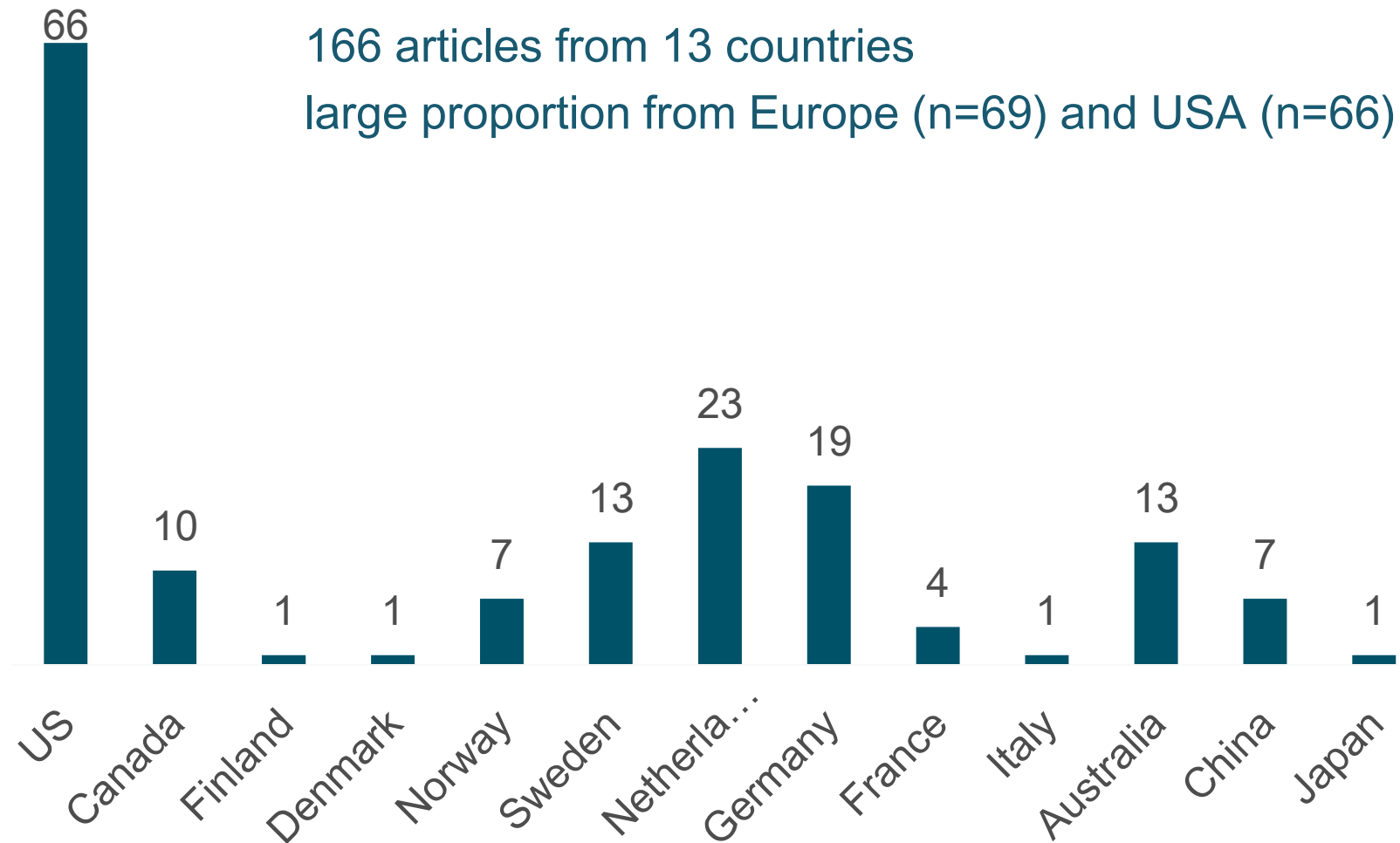
Melissa S.Y. Thong (PhD), Floortje Mols (PhD),  
Kevin D. Stein (PhD), Tenbroeck Smith (MA),  
Jan-Willem W. Coebergh (MD, PhD),  
Lonneke V. van de Poll-Franse (PhD)

\* Cancer Supplement,  
European-American Dialogues on Cancer Survivorship:  
Current Perspectives and Emerging Issues, 1 June 2013

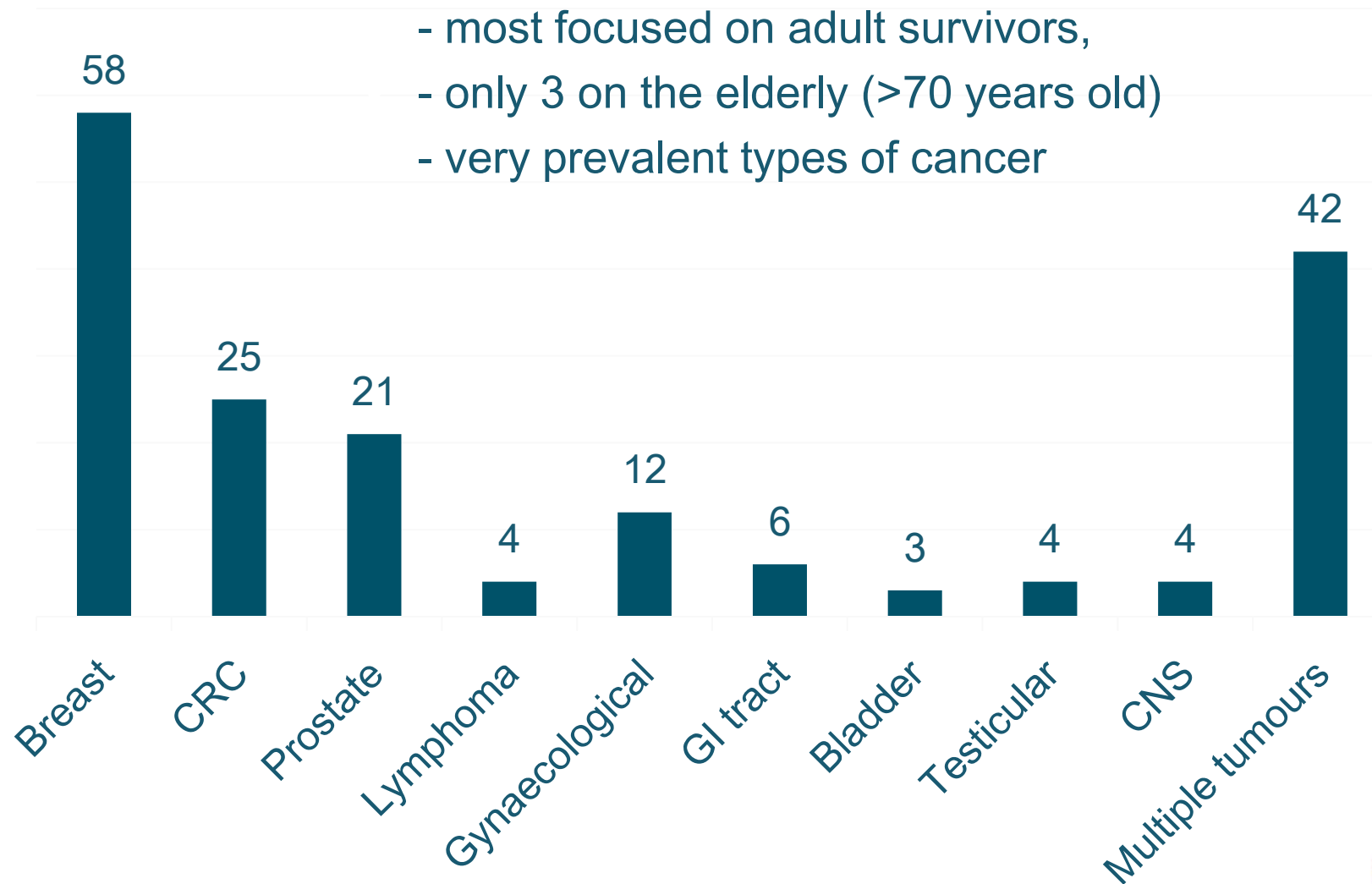
# Advantages of cancer registry based PROs

- inclusion of large numbers of patients/survivors
- information on socio-demographic and clinical characteristics available
- less likely to have problems with referral biases
- better external validity

# Country of study



# Types of tumor



# Conclusion

- PRO studies increasingly use population-based cancer registries
- CRs provide important clinical variables and an excellent sampling frame for identifying sub-groups
- Most studies tend to focus on more prevalent cancers
- Surprisingly few studies focused on PRO of elderly survivors who remain understudied in clinical studies



# Eurocourse meeting WP6

- How can we learn from each other?





# Eurocourse WP6 participants

## Cancer Survivorship Studies

Volker Arndt	German Cancer Research Center, Heidelberg, <a href="#">Germany</a>
Anne-Marie Bouvier	Registre Bourguignon des Cancers Digestifs Dijon, <a href="#">France</a>
Linda Sharp	National Cancer Registry, Cork, <a href="#">Ireland</a>
Penny Wright	University of Leeds, Leeds, <a href="#">UK</a>
Melissa Thong	Eindhoven Cancer Registry &
Floor Mols	Tilburg University, <a href="#">The Netherlands</a>
Lonneke van de Poll	

# Ethical issues in Europe

- Large variation
- In the Netherlands not always ethical approval needed for QoL studies, otherwise central
- Ireland each (!) center (and many centers!)
- UK and France central ethical approval
- Germany, ethical approval from one center as a master/ regional approval

# Participation of patients

- Have patients approached by own treating doctor
- Cross-sectional studies easiest to start with
- Clinicians sometimes more interested in short term outcomes
- Get patients as early as possible, keep track of them: create cohorts!
- Most registries have difficulties to include patients very early (CR usually completed later)
- First patient, later linkage to CR (ePOCS UK\*)

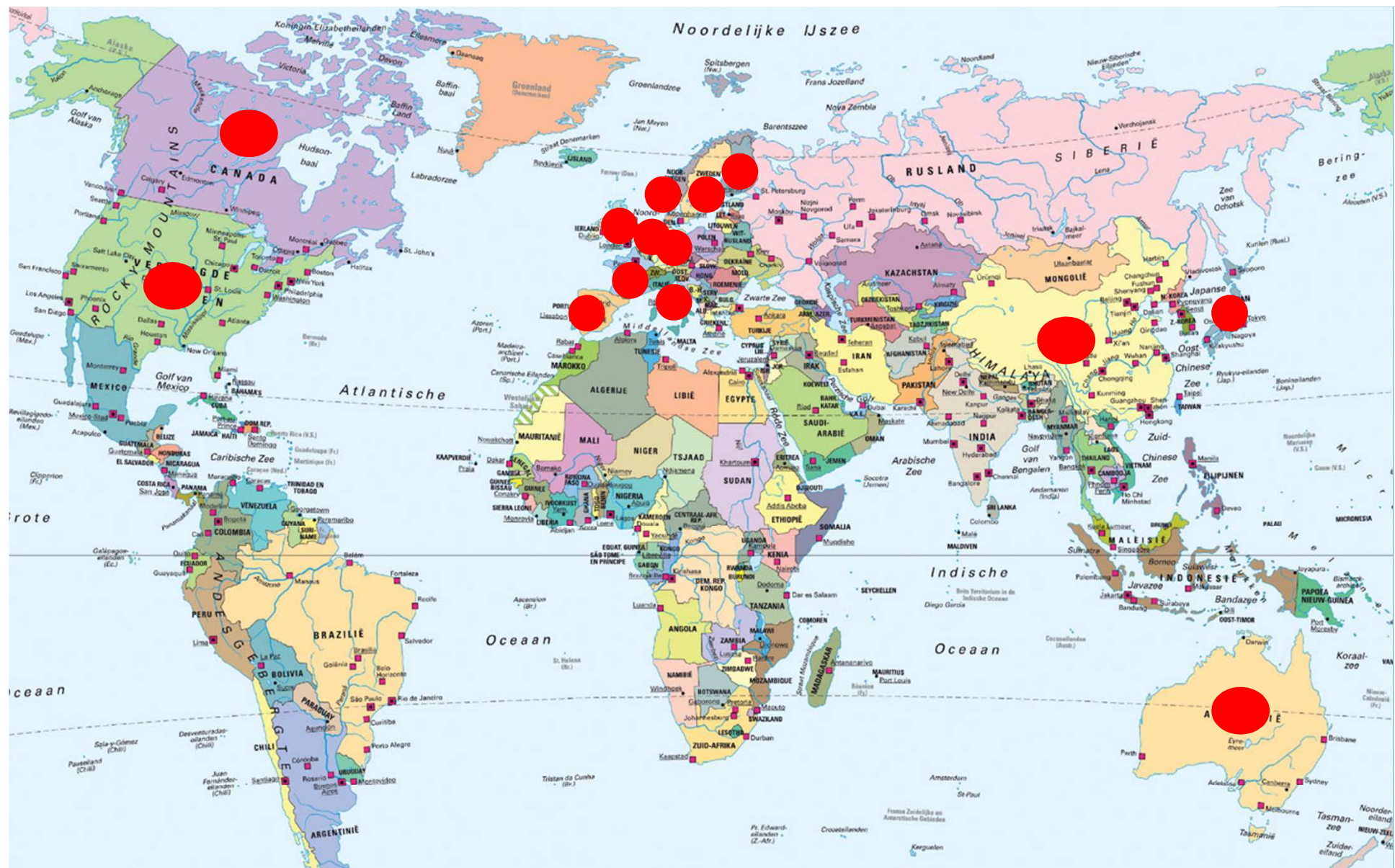
\* Wright, BMC Med Inform Decis Mak. 2011

# Control ('normative') population

- Ideally, each country needs his own population based control group for comparison with (long) term survivors
- Find other groups that do (longitudinal) household or health surveys (economists do European studies)

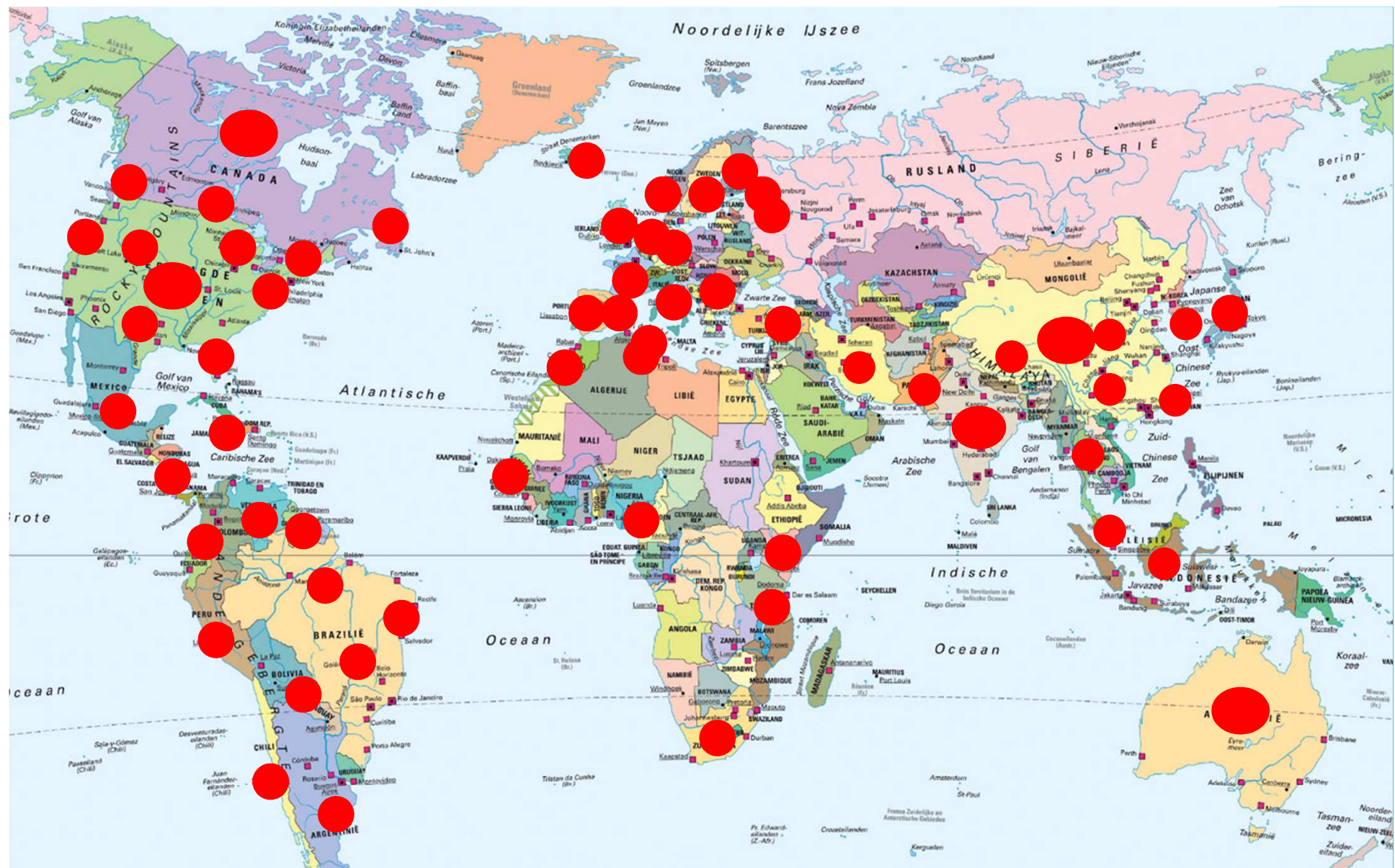
# How to pay for these studies?

- PROs within CR as routine measurement?  
Not feasible in most countries under current legislation
- Measuring patient reported outcomes as 'quality assurance' (Germany)
- Tag it to 'holistic needs assessment' (UK)
- Evaluation quality of care/guidelines (Ireland)
- Cost-effectiveness studies easier funded



Cancer Registries worldwide become  
Cancer *Patient* Registries





Cancer Registries worldwide become  
Cancer *Patient* Registries

# Cancer Registration Registration

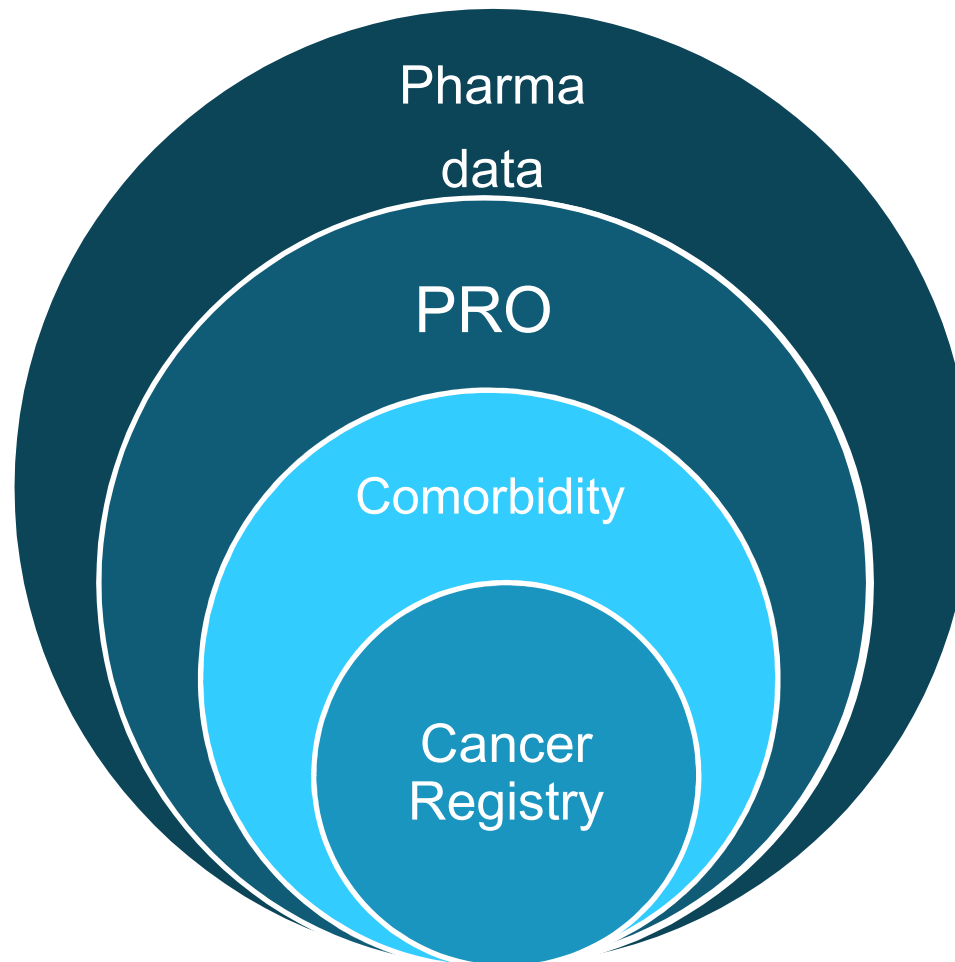
- Continuous monitoring of (long term) impact of cancer and (new) therapies
- Contribute to the discussion on the added value of (new) therapies (for example targeted therapies) in daily clinical practice
- Socio-economic implications of cancer survivorship
- Psychosocial needs of cancer survivors
- Interventions to improve quality of care and QoL of cancer survivors!





# Eindhoven Cancer Registry since 1955

Towards a  
comprehensive  
assessment of  
cancer  
survivorship



[www.profielstudie.nl](http://www.profielstudie.nl)

[www.profilesregistry.nl](http://www.profilesregistry.nl)

[www.ikz.nl](http://www.ikz.nl)