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# The stage for childhood cancers: the JARC pilot study

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Pilot Study Working Group

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- WP of epidemiology, task on data quality in population based cancer registries
- Stage in childhood cancers (Toronto guidelines)

# Childhood cancers (0-14 years of age)

## Background

- Rare ( < 1 % all malignant cancers)
- Classified differently to adult cancers (ICCC-3)
- Uses different staging systems to adult cancer

## Aims

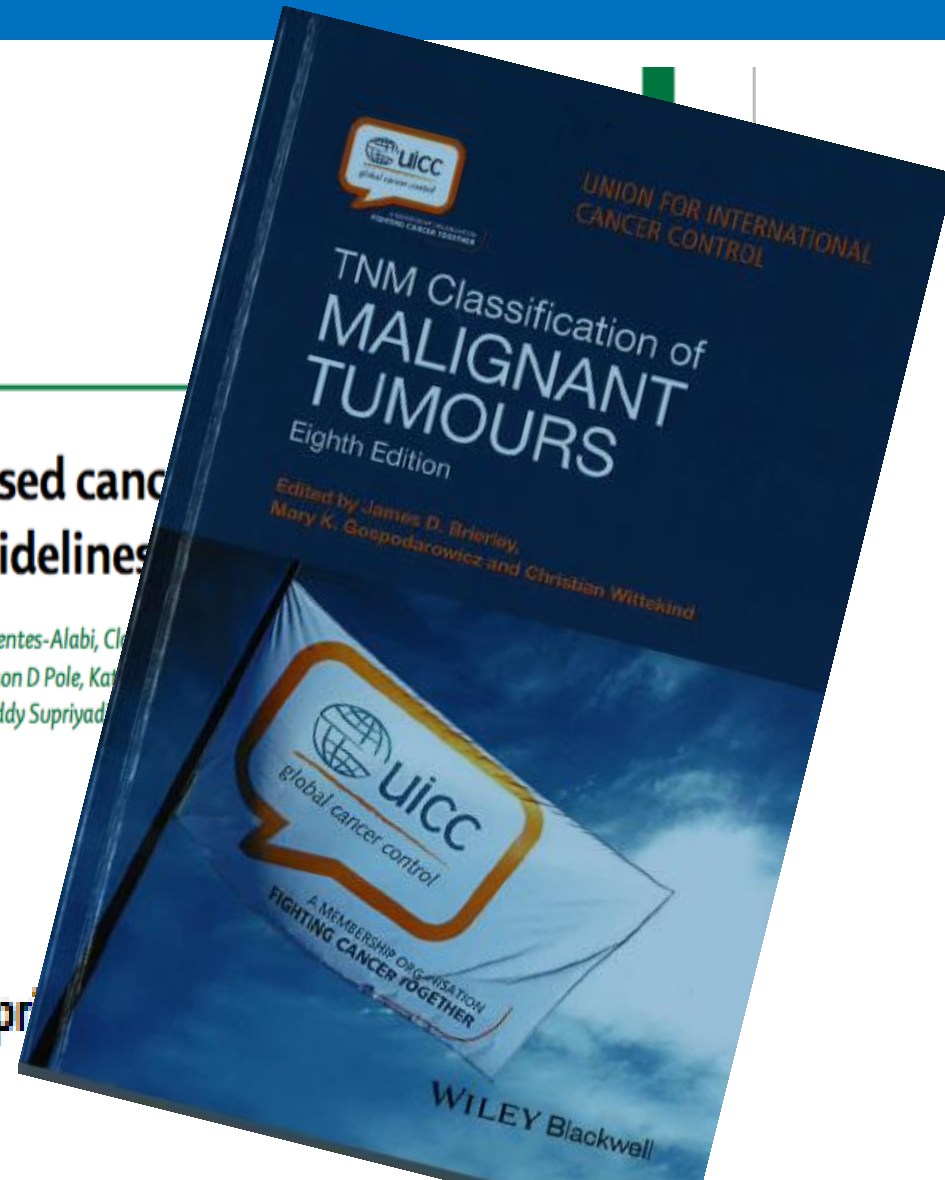
- Can Toronto guidelines be adopted by the European registries?

# Toronto stage guidelines

## Paediatric cancer stage in population-based cancer registries: the Toronto consensus principles and guidelines

Sumit Gupta, Joanne F Aitken, Ute Bartels, James Brierley, Mae Dolendo, Paola Friedrich, Soad Fuentes-Alabi, Clive Harwood, Mary Gospodarowicz, Thomas Gross, Scott C Howard, Elizabeth Molyneux, Florencia Moreno, Jason D Pole, Kathleen A Ryan, Lynn A G Ries, Carlos Rodriguez-Galindo, Hee Young Shin, Eva Steliarova-Foucher, Lillian Sung, Eddy Supriyadi, Julie Torode, Tushar Vora, Tezer Kutluk, A Lindsay Frazier

[www.thelancet.com/oncology](http://www.thelancet.com/oncology) Vol 17 April 2016





Pilot study for neuroblastoma e Wilms tumours



# Registries, countries, period, cases

## REGISTRIES

Belgium  
Denmark  
France  
Greece  
Hungary  
Italy (7)  
Malta  
Norway  
Portugal (1)  
Slovakia  
Slovenia  
Spain (5)  
Switzerland

## CASES

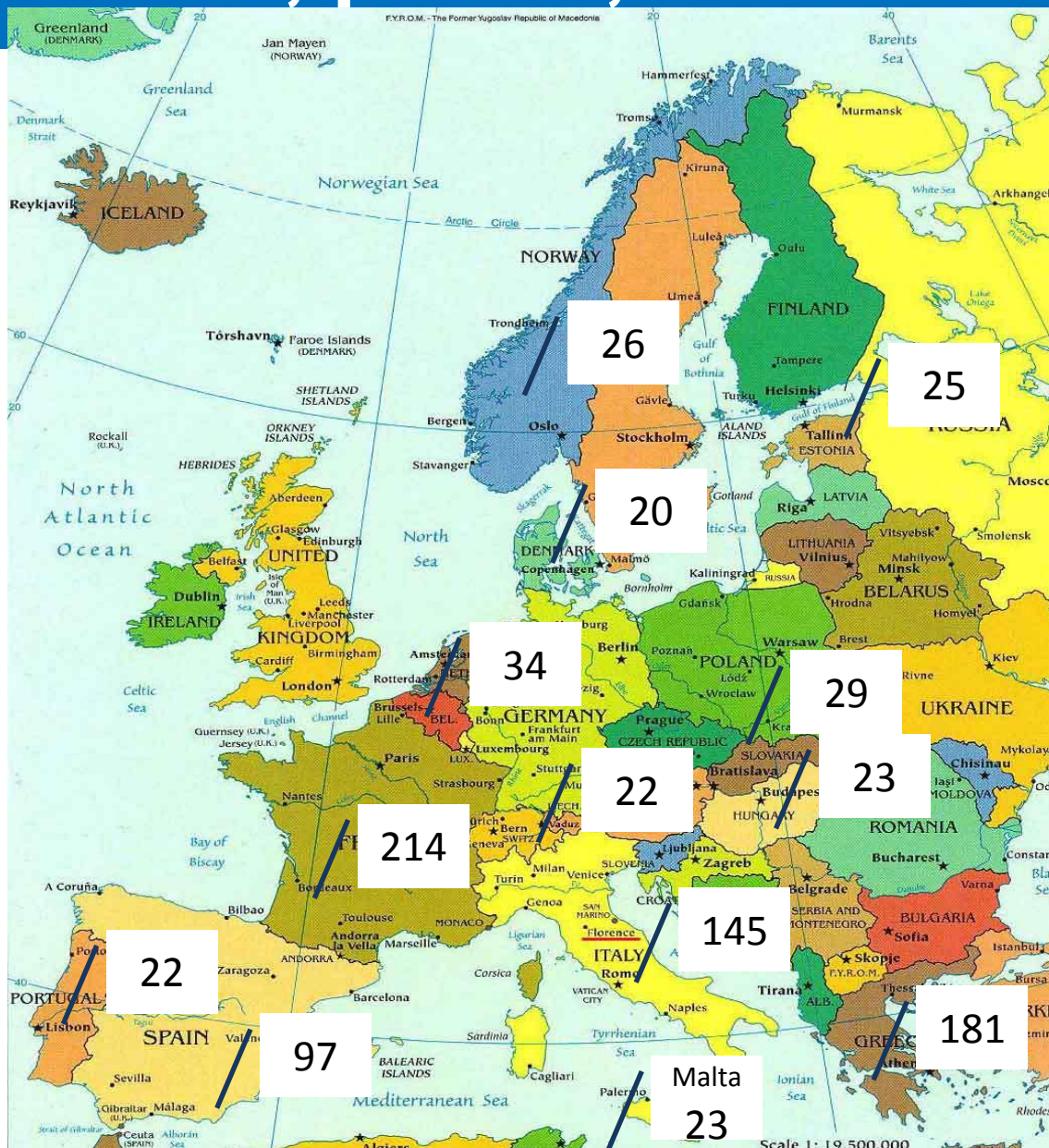
Neuroblastoma = 499

Nephroblastoma = 387

*complete incidence, at least 10 consecutive  
cases per tumour*

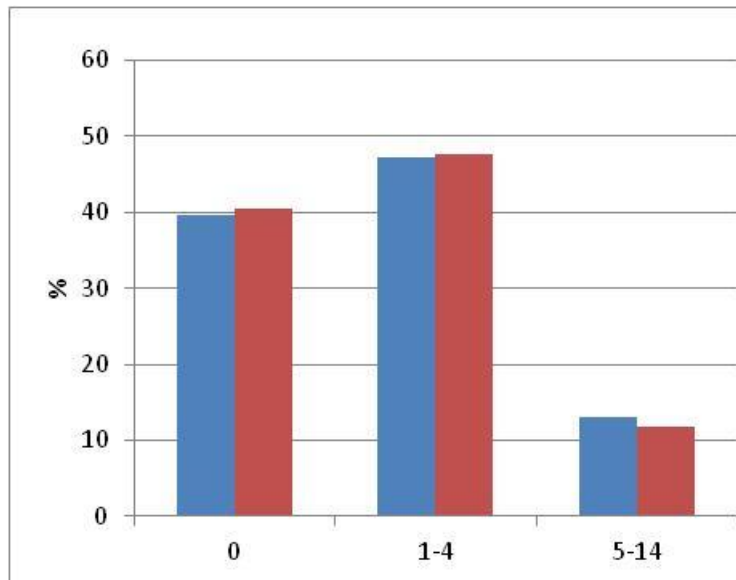
## PERIOD OF DIAGNOSIS

2002-2015

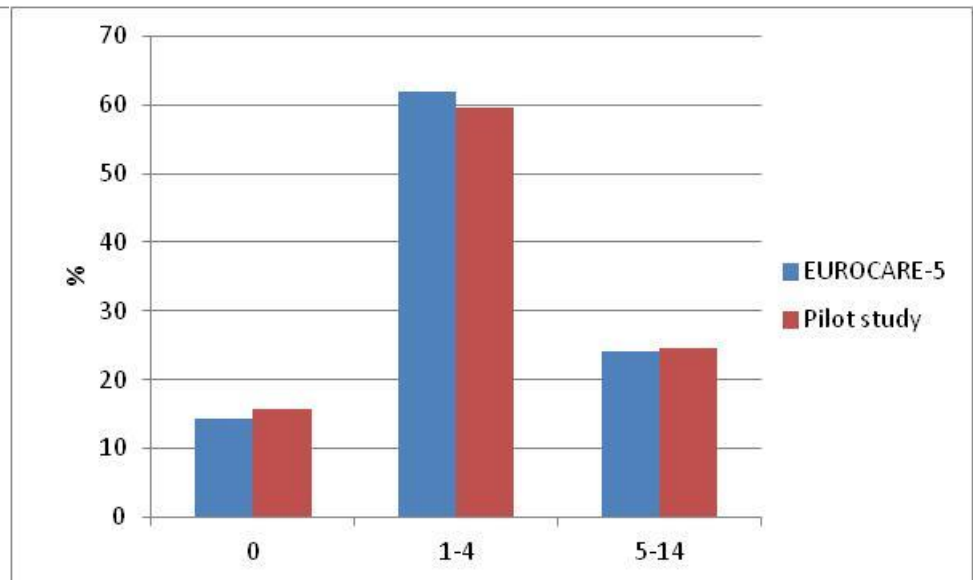


# Sample, age (% distribution)

## NEUROBLASTOMA



## WILMS



red= pilot study  
blue= from EUROCORE-5

**Toronto stage, collected : 97%**



# Toronto stage, age NEUROBLASTOMA

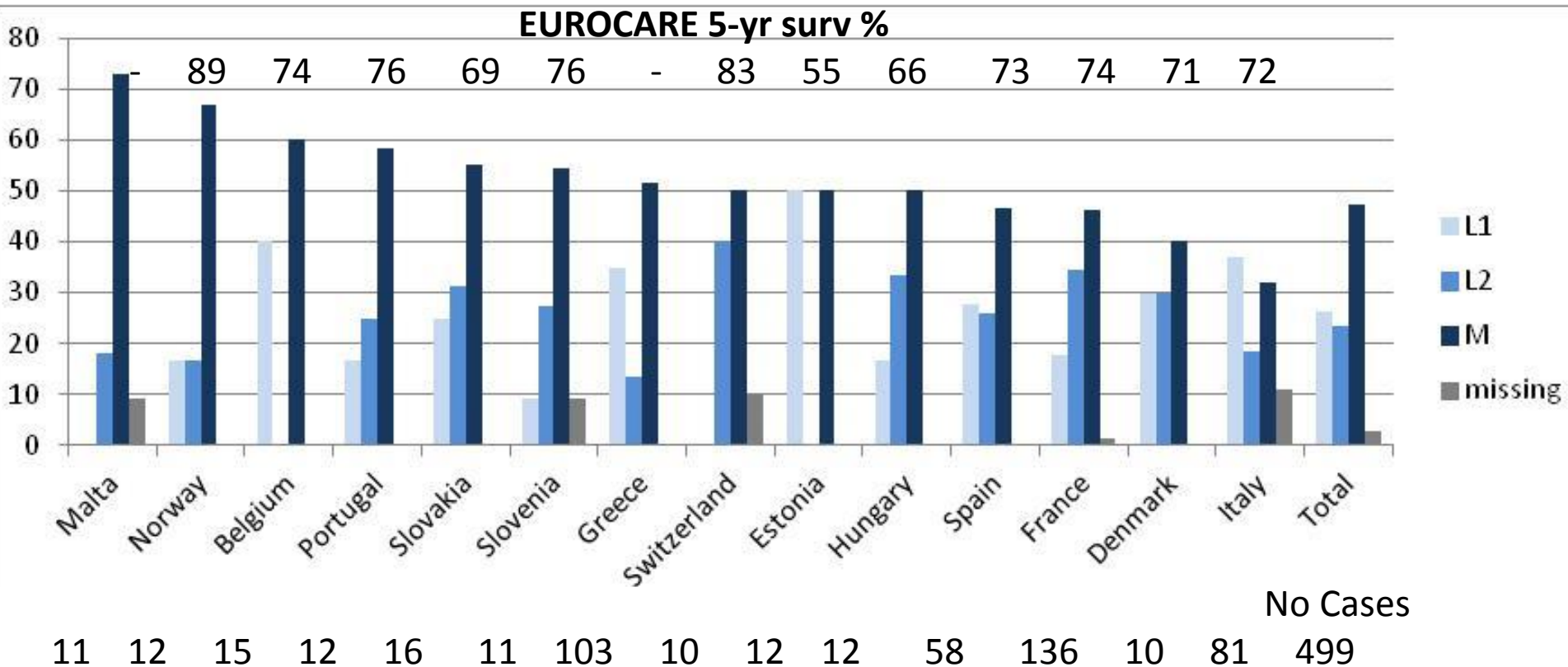
NEUROBLASTOMA			
age	<1	1-4	5-14
% 5-yr surv	91	59	53

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EUROCare-5 survival [Lancet Oncology, 2013]

# Toronto stage , by country

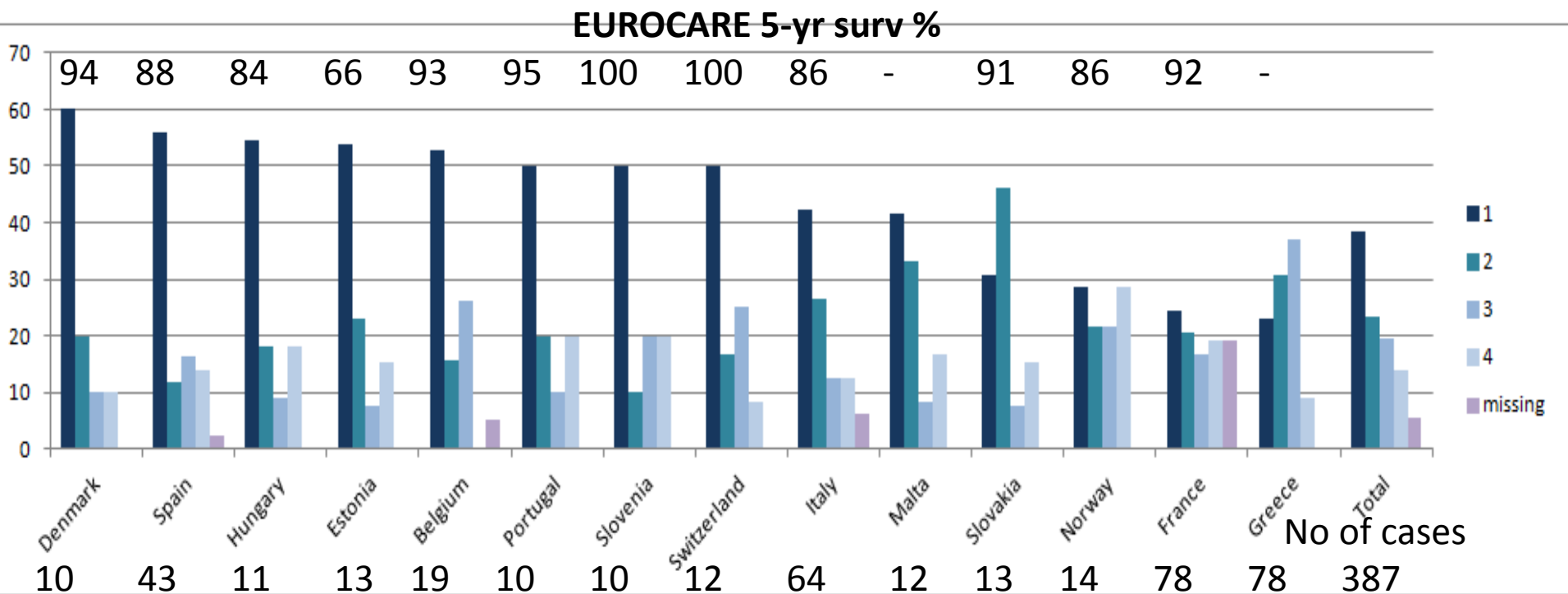
## NEUROBLASTOMA



EUROCARE 5-year survival : from 89% in Norway to 55% in Estonia

# Toronto stage , by country

## NEPHROBLASTOMA



EUROCARE 5-year survival : from 100% in Switzerland and Slovenia to 66% in Estonia

# Sources

Administrative, pathological reports, clinical records, other

source	neuroblastoma	Wilms
	%	%
clinical record *	93	70
pathological report.*	94	87
*alone or together with the other sources		

# Examinations to define T and M by registrars

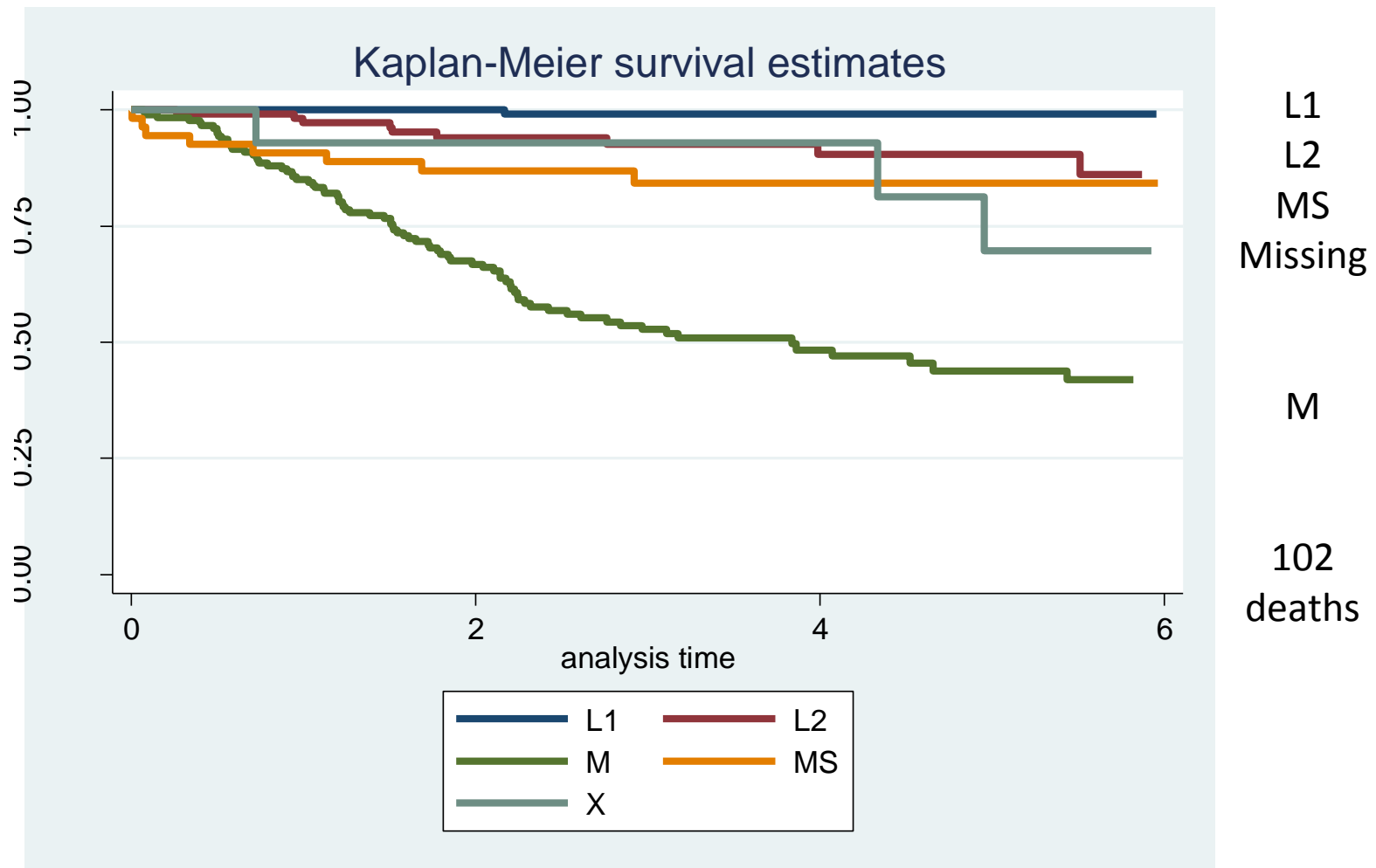
		T	M
		%	%
neuroblastoma	one	11	32
	two	54	36
	three	27	26
Wilms			
	one	7	48
	two	58	6
	three		
		25	4

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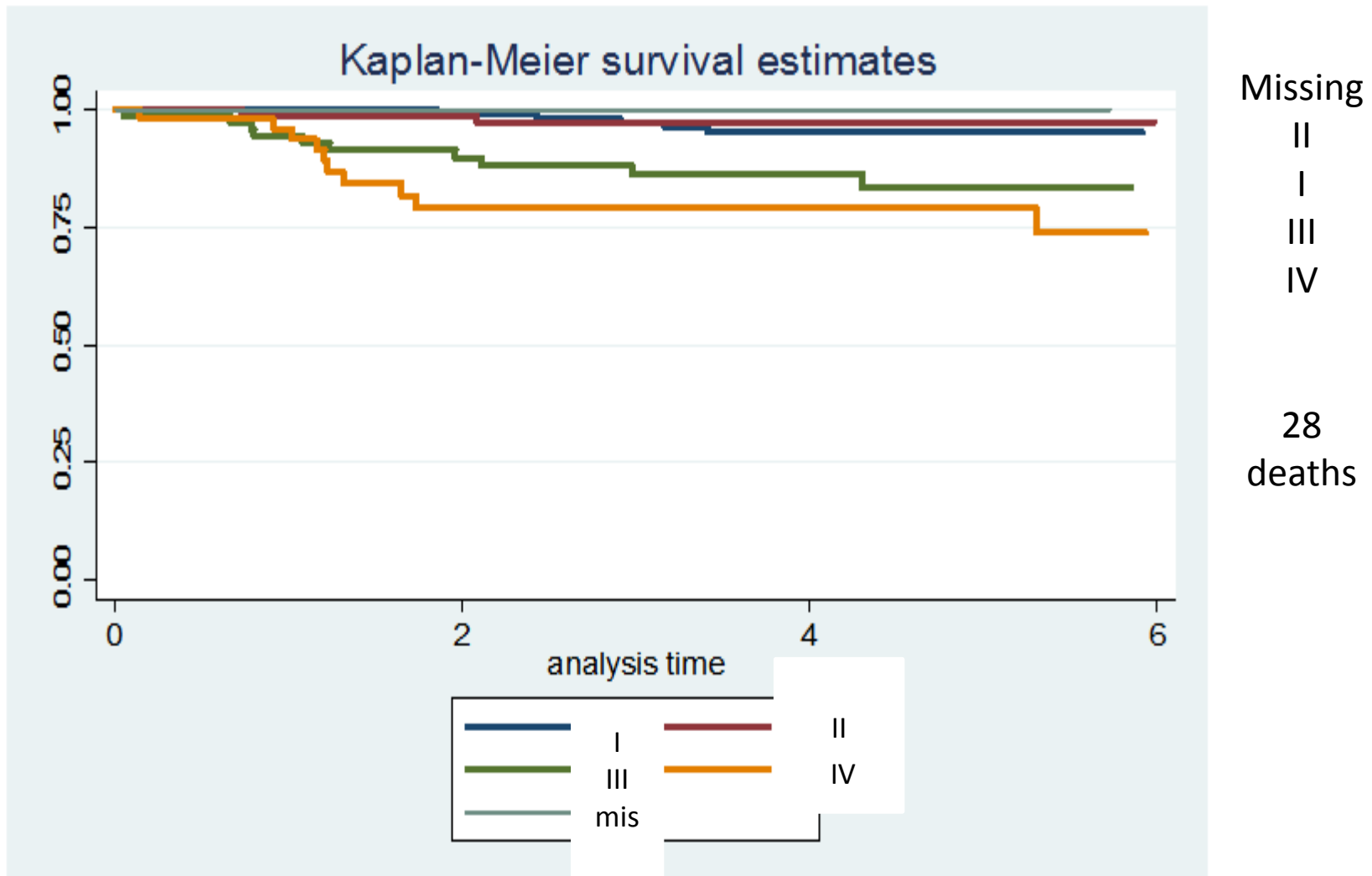
*T : CT scan, MRI, abdominal ultrasound*

*M: Scintigraphy, marrow agobiopsy, x-ray thorax*

# survival, neuroblastoma (n=499)



# survival, Wilms (n=387)





# Comparison with other studies

# Stage, comparison with other studies **MISSING**

Population registries from Argentina, SEER,  
Denmark, UK.

**missing 35% - 21%**



# Australian study on Toronto staging



# Australian study on Toronto staging

Articles

## Assessing the feasibility and validity of the Toronto Childhood Cancer Stage Guidelines: a population-based registry study



Joanne F Aitken, Danny R Youlden, Andrew S Moore, Peter D Baade, Leisa J Ward, Vicky J Thursfield, Patricia C Valery, Adèle C Green, Sumit Gupta, A Lindsay Frazier

### Summary

**Background** Cancer stage at diagnosis is crucial for assessing global efforts to increase awareness of childhood cancer and improve outcomes. However, consistent information on childhood cancer stage is absent from population cancer

*Lancet Child Adolesc Health*  
2018; 2: 173-79



**All Queenslanders, all cancers.**



# Could a registry simply collect stage recorded in the chart by the physician?

## Not in Australia:

- Stage was present in the record in only 39% of cases (*93% could be staged using the Toronto Guidelines*).
- The staging system used was not recorded.
- Staging data were inconsistent – different stages were recorded (different times, different opinions?..)

# Cost of collecting data elements and assigning Toronto stage, Australian study

**average 18 minutes per case**

Personnel	
Average cost per case	€ 20.80

# Discussion

- Toronto guidelines are applicable and should be implemented also for the other childhood cancers
- Training course with test for validation are welcome (ENCR?)
- We hope the Toronto stage could be included in the routine of the majority of European registries
- Involvement of the paediatric oncology community (for example, stage must be reported in the clinical record)
- Further efforts to standardise the stage coding among registries



Proposal: can the next EURO CARE include stage according to the Toronto guidelines?

# thank you

**Belgium:** National (Liesbet Van Eycken, Nancy Van Damme);  
**Denmark:** National Childhood (Filippa Nyboe Norsker, Jeanette Falck Winther)  
**Estonia:** National CR (Keiu Paapsi, Kaire Innos)  
**France:** National Childhood Solid Tumours (BLacour, EDesandes);  
**Greece :** National (Eleni Petridou, );  
**Hungary:** National childhood CR (Jakab Zsuzsanna);  
**Italy:** Agrigento and Trapani (Pina Candela, Tiziana Scuderi),  
Barletta Andria Trani (Enzo Coviello),  
Campania childhood (Francesco Vetrano, Fabio Savoia),  
Catania Siracusa Enna (Marine Castaing),  
Palermo (Francesco Vitale, Rosalba Amodio),  
Pavia (Lorenza Boschetti),  
Varese (Giovanna Tagliabue, Sabrina Fabiano);  
**Malta:** National CR (Dominic Agius);  
**Norway:** National CR (Bernward Zeller, Aina Helen Dahlen);  
**Portugal:** South Portugal (Ana Miranda);  
**Spain:** Basque Country (Arantza Lopez de Munain Marques),  
Girona childhood (Rafael Marcos-Gragera ),  
Granada (Maria Josè Sanchez),  
Murcia (Maria Dolores Chirlaque),  
Navarra (Eva Ardanaz, Marcela del Pilar);  
**Slovakia:** National CR (Chakameh Safaei Diba);  
**Slovenia:** National CR (Zadnik Vesna, Žagar Tina);  
**Switzerland:** Swiss national childhood (Claudia Kühni, Shelah Redmond )

