



Standards of care for children with cancer
Jolanta Kwasniewska's Foundation
"Communication without Barriers"

Warsaw 14th October 2009

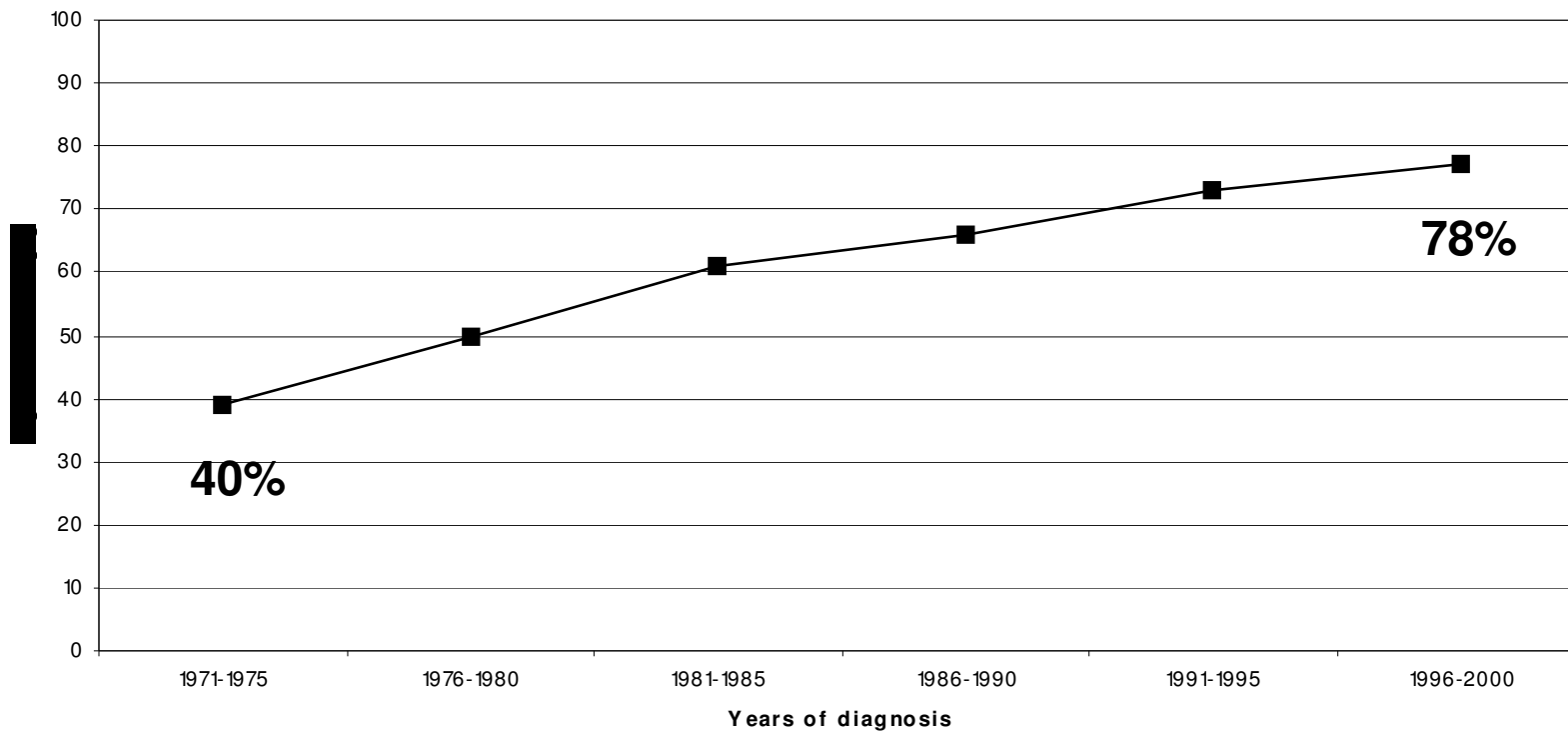
**Interpreting variations in
Childhood Cancer survival
in Europe**

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Royal Marsden Hospital & Institute for Cancer Research,
London, UK**



Survival from childhood cancer is good and continues to improve



5 yr survival all childhood cancers diagnosed in Great Britain, 1971-2000,

How has this been achieved?

- Multidisciplinary approach to diagnosis and care
- National and multi-national co-operation
- Inclusion of majority of newly diagnosed children in clinical trials

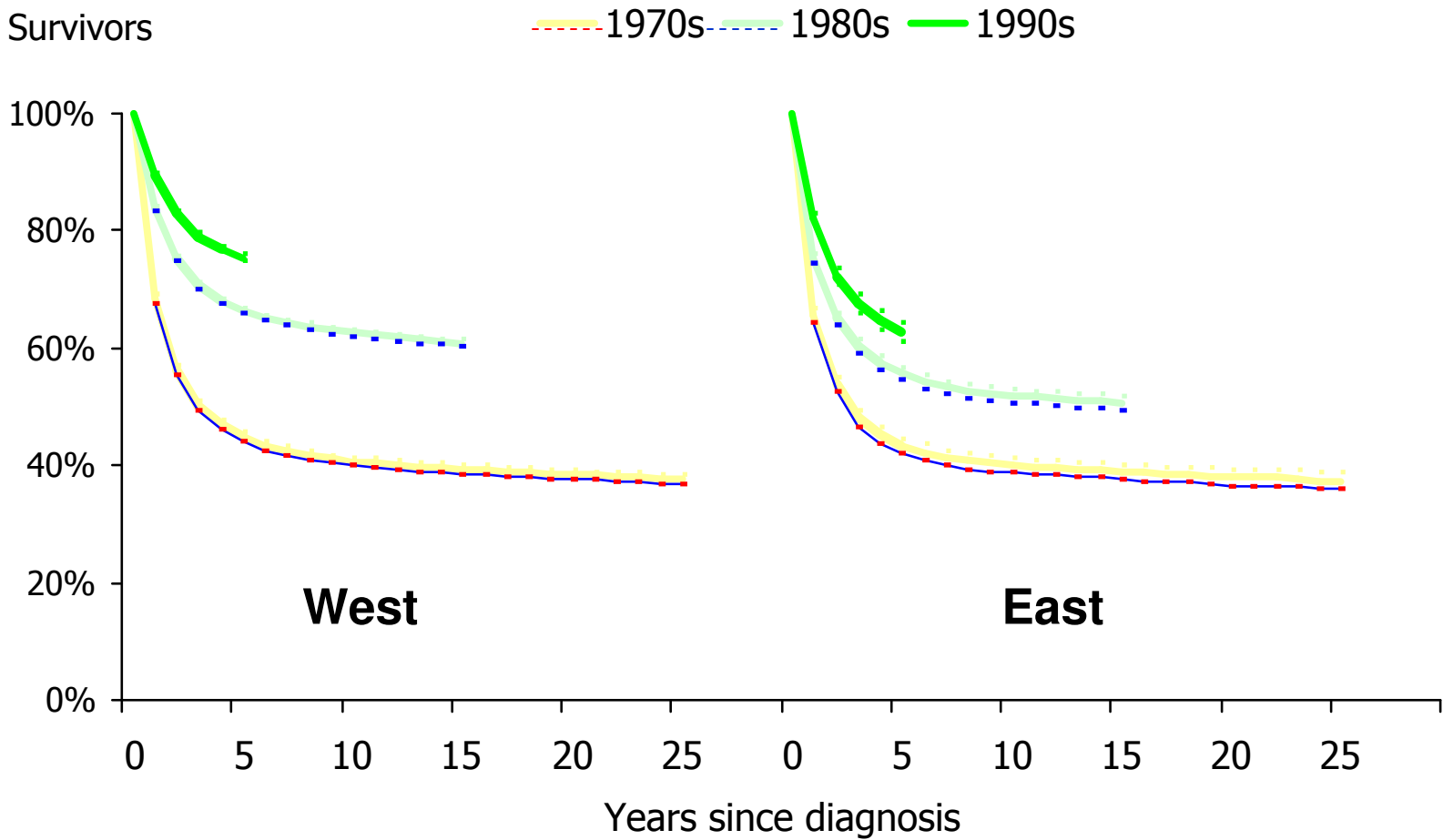
Role of clinical trials in improving outcomes

- Provide detailed protocols for delivery of complex care
- Access to expert multi-disciplinary reference group by tumour type
- Platform for testing new drugs & new approaches to treatment
- Define the 'best standard of care' and continually seek to improve it

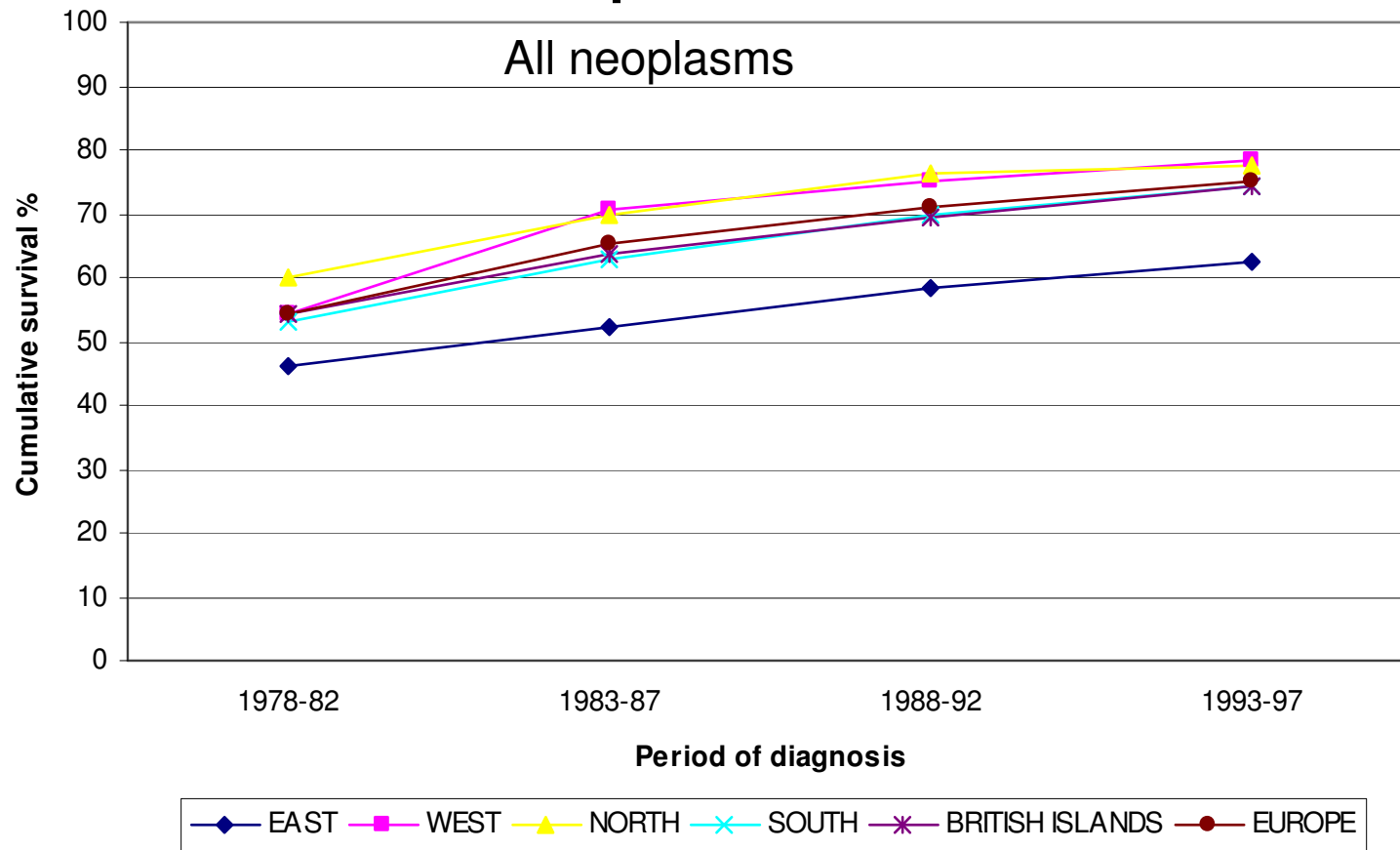
Childhood cancer survival rates vary across Europe



5 yr survival for children with cancer in Europe



Trends in survival after childhood cancer in Europe, 1978-97



Five-year actuarial cumulative survival for all childhood cancers, by European region and period of diagnosis, the ACCIS project
Magnani *et al*, 2006, *Eur J Cancer* **42**:1981-2005.

Geographical comparisons of childhood cancer survival

- Need access to high quality population based cancer registries
 - Extremely valuable tool for monitoring outcomes and health service planning at national level
- Variation in national laws (links to mortality data), systems and resources creates potential for 'significant' biases that must be considered in interpretation of any comparisons of different registry datasets.

Population based comparisons of childhood cancer survival

Databases/projects:

- EUROCARE-2, -3 & -4
- ACCIS (Automated Childhood Cancer Information System) project
- SEER programme, USA

ACCIS

Automated Childhood Cancer Information System, IARC, Lyon

European Journal of Cancer

Special Issue

Cancer in Children and Adolescents in Europe

Guest Editors

Eva Steliarova-Foucher, Jan Willem Coebergh,
Peter Kaatsch, Kathy Pritchard-Jones, Charles Stiller



*Three Children in Chalk Farm by Henry Grant. © Museum of London.
Reproduced with permission from the Museum of London*



2006



0959-8049(200609)42:13;1-F

Amsterdam • Boston • Jena • London • New York • Oxford • Paris • Philadelphia • San Diego • St Louis

- ◆ ~80 population-based cancer registries
- ◆ 35 European countries (25 member states)
- ◆ 140,000 childhood cancer cases aged <15 years
- ◆ Diagnosed in 1970s-1990s
- ◆ 1172 million person-years

Summary tables on incidence and survival by country and by tumour type

<http://www-dep.iarc.fr/accis.htm>

New data exchange and analysis planned



EUROpean CANcer REGistry-based study of cancer patients' survival and care

EUROCARE 1	1978-84
EUROCARE 2	1985-89
EUROCARE 3	1990-94
EUROCARE 4	1995-02
<i>EUROCARE 5</i>	<i>2000-04</i>

EUROPEAN JOURNAL OF CANCER 45 (2009) 992–1005



available at www.sciencedirect.com



journal homepage: www.ejconline.com



Survival of European children and young adults with cancer diagnosed 1995–2002

Gemma Gatta^{a,*}, Giulia Zigon^a, Riccardo Capocaccia^b, Jan Willem Coebergh^c, Emmanuel Desandes^d, Peter Kaatsch^e, Guido Pastore^f, Rafael Peris-Bonet^g, Charles A. Stiller^h, the EUROCARE Working Group

EUROCARE 4 EJC (2009) 45:992-2005

Focuses on most recently diagnosed cohort but note change in countries included in 'East' region

Potential factors affecting data quality and comparability

- Completeness of registration
 - No. of sources/case, access to personal data/hospital records etc
- Accuracy of registration
 - Histologically verified v death certificate only
 - Coding used (e.g. benign v malignant brain tumours)
- Completeness of follow up
 - Links to national mortality databases v clinical
 - Regional versus complete national coverage

Study	EUROCARE -2	EUROCARE -3	EUROCARE -4	ACCIS
Analysis	Survival	Survival	Survival	Incidence & survival
Dates	1978-1992	1990-1994	1995-2002	1978-1997
No. Cases	45,000	24,620	40,392	88,465
No. registries	34	45	83	62 (78)
No. Countries	17	20	23	19
National coverage	10	10	10	10
Microscopic diagnosis	91.8%	91.8%	95.5%	97%
FU >5 yrs	93.4% (living pts only)	93.1% (living pts only)	97.4% (living pts only)	99% (E & W) 33% (Germany)
Lost To FU	2%	1.1%	1.1%	<1% (as above)

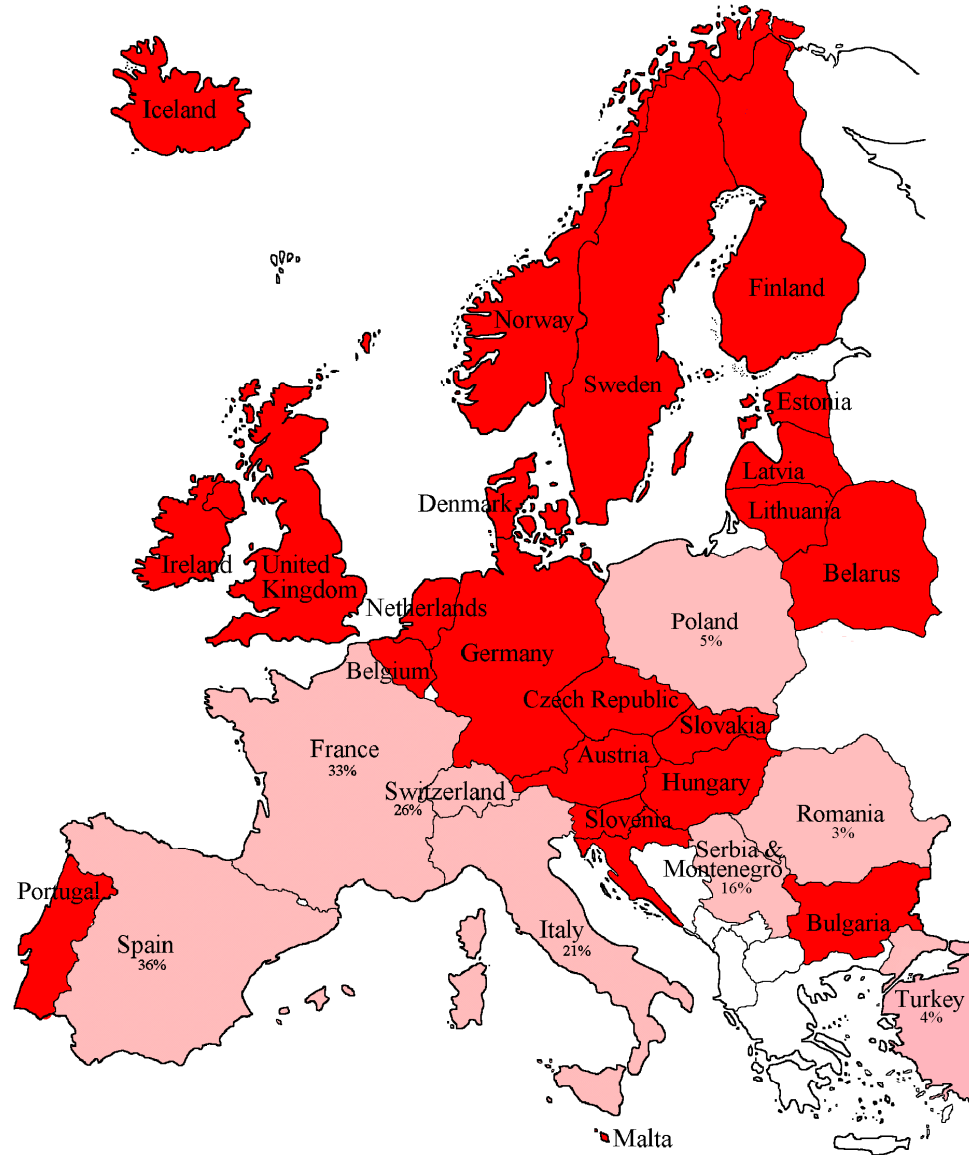
EJC, 2001

Annals Oncol, 2003

EJC, 2009

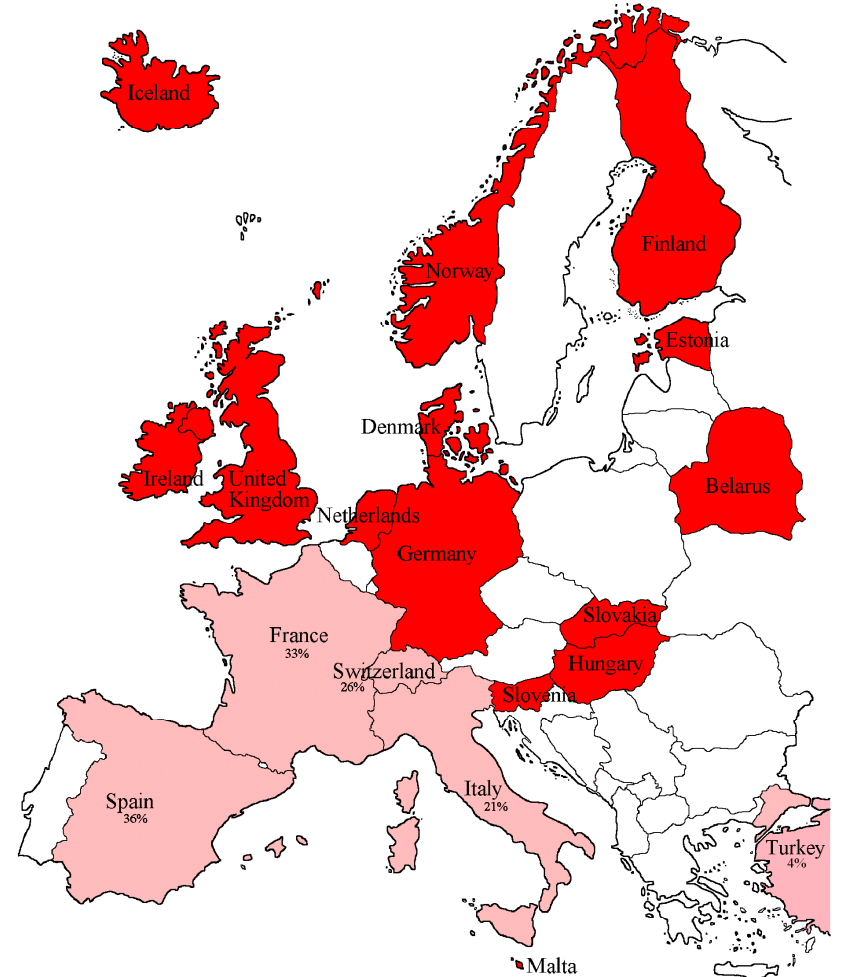
EJC, 2006

Countries included in the ACCIS database



■ Complete coverage
■ Regional coverage (% of national population)
 Not shown: Canary Islands (Spain)

Countries included in the ACCIS comparative studies



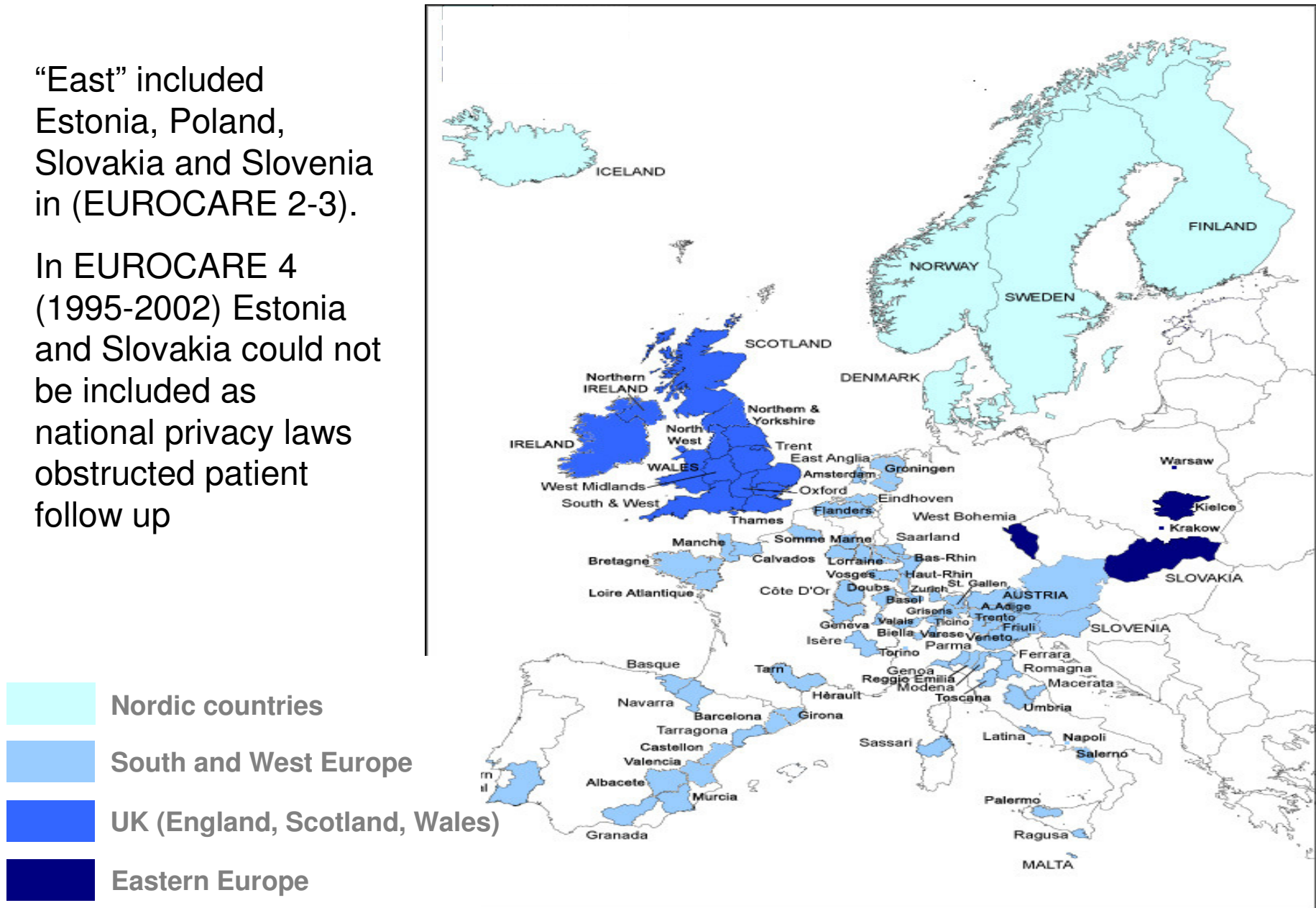
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■ Regional coverage (% of national population)
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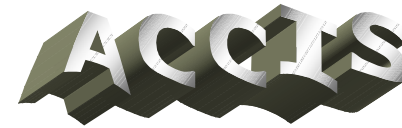
“East” included Estonia, Belarus, Hungary, Slovakia

EUROCARE-4 GEOGRAPHIC COVERAGE

“East” included Estonia, Poland, Slovakia and Slovenia in (EUROCARE 2-3).

In EUROCARE 4 (1995-2002) Estonia and Slovakia could not be included as national privacy laws obstructed patient follow up



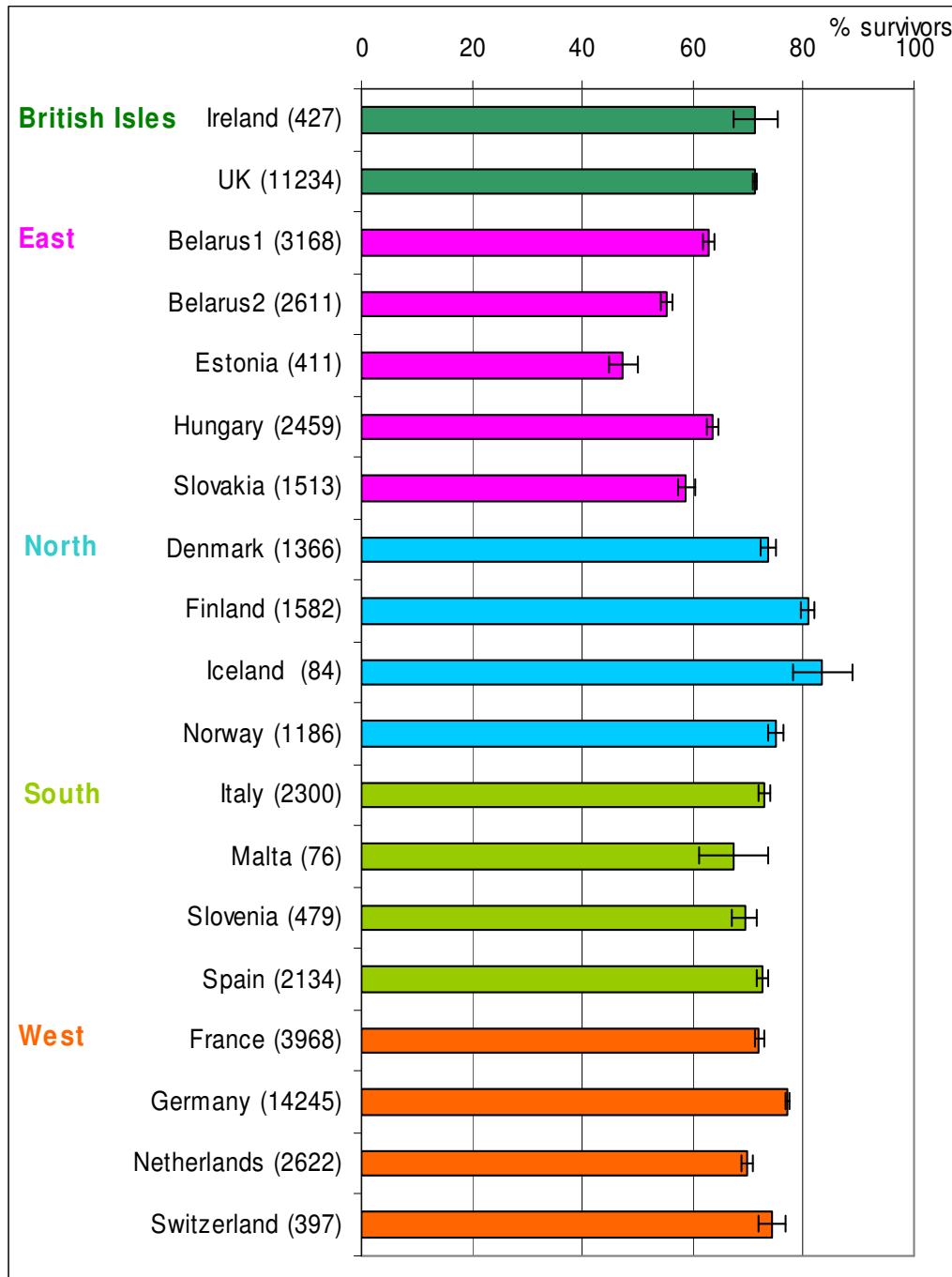


5yr actuarial population based survival of children aged 0-14 yrs, diagnosed 1988-97

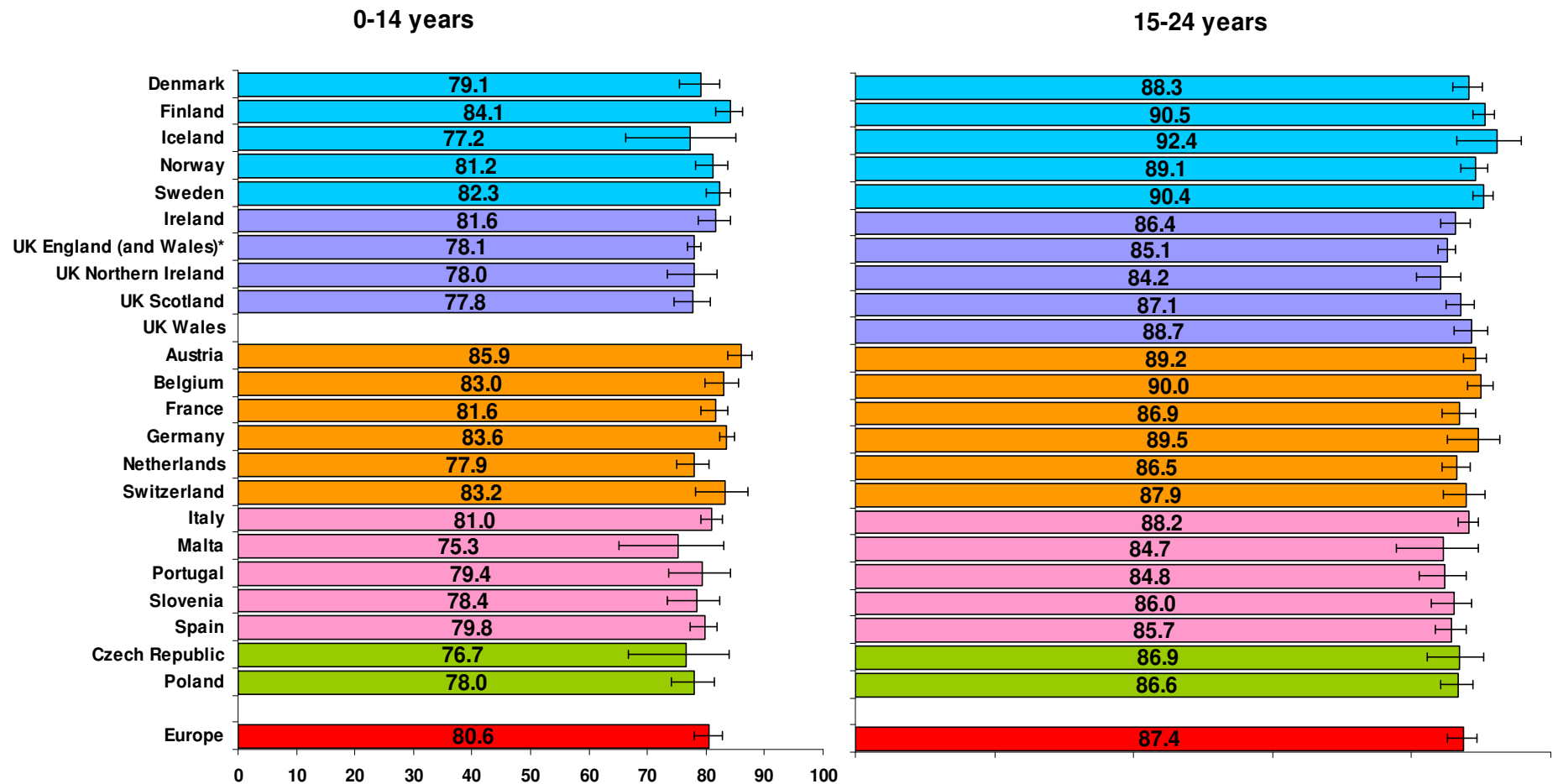
European average 72%

Pritchard-Jones *et al*, Cancer in children and adolescents in Europe: developments over 20 yrs and future challenges,

EJC (2006) 42:2183-2190



5-year survival for all cancer combined in European children and adolescents/young adults (1995-2002)



European average 80.6%

EUROCORE 4, EJC (2009) 45:992-1005

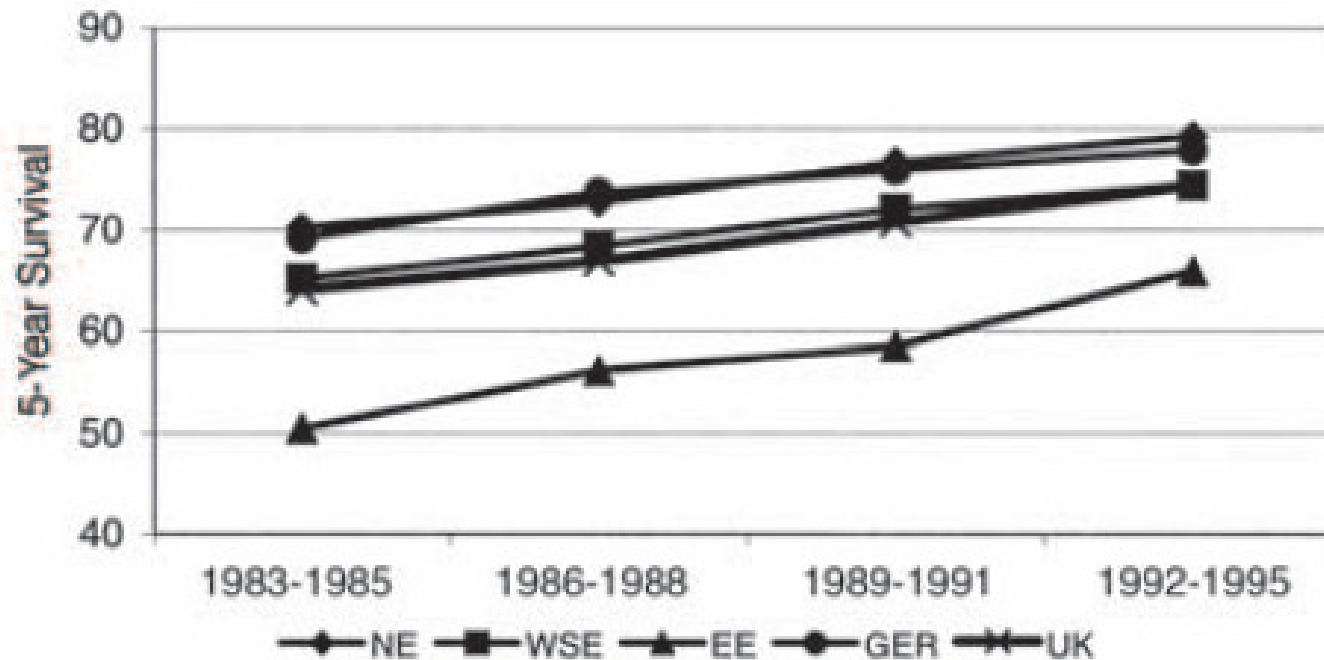
Potential confounding factors:

- Quality of reporting:
 - No. of sources/case
 - Proportion with histological confirmation or death certificate only
- Accuracy of tumour classification
- Completeness of follow up
 - Migration
 - Overzealous interpretation of confidentiality and lack of links to national mortality data
- Multiple 'post hoc' analyses can give rise to individual 'significant differences' by chance
- Changes in registries eligible for comparison

*What can we learn from geographical comparisons of childhood cancer survival?
K Pritchard-Jones & C Stiller on behalf of CCLG, Brit J Cancer (2007) 96:1493-7*

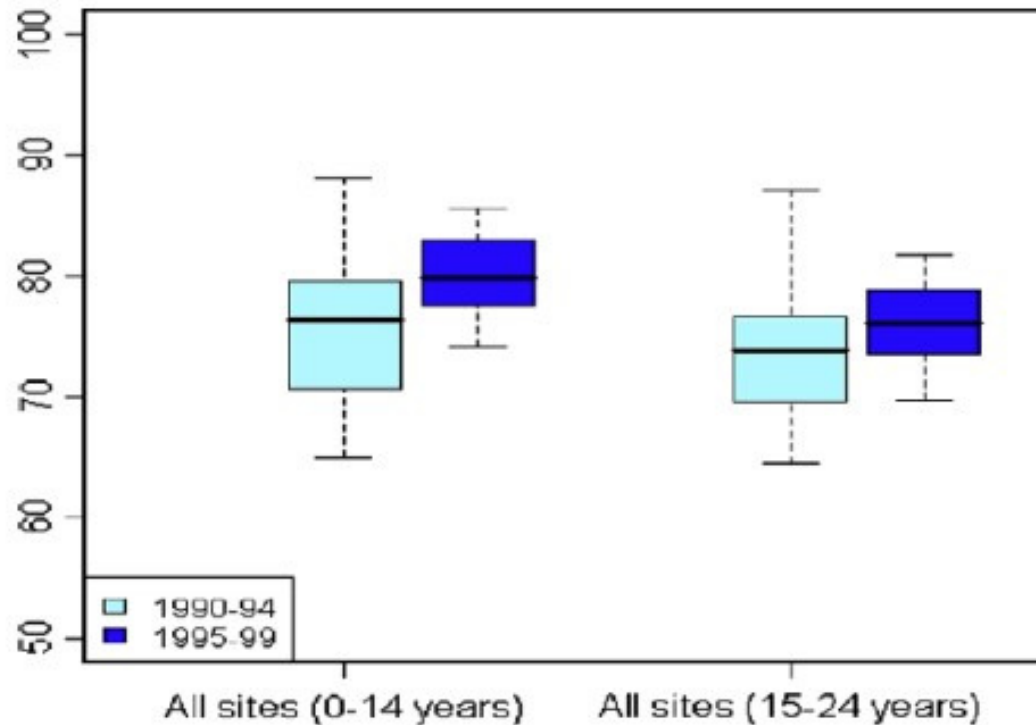
Five-year survival trend for all childhood tumours, 1983 to 1994, Eurocare

Gatta et al, JCO, 23: 3742, 2005



Period of Diagnosis	NE	WSE	EE	UK	GER
1983-1985	70.2	65.2	50.5	64.1	69.2
1986-1988	72.8	68.4	56.2	66.9	73.7
1989-1991	76.7	72.1	58.6	70.8	76.0
1992-1995	79.2	74.5	65.9	74.4	77.9

Inter-country variation in survival is decreasing during 1990s



Changes in 5-year country-specific* survival for all cancers combined in European children (0-14years) and adolescents/young adults (15-24years) diagnosed between 1990-1994 to compared to 1995-1999. EURO CARE 4

*only for countries whose registries contributed data for both periods.

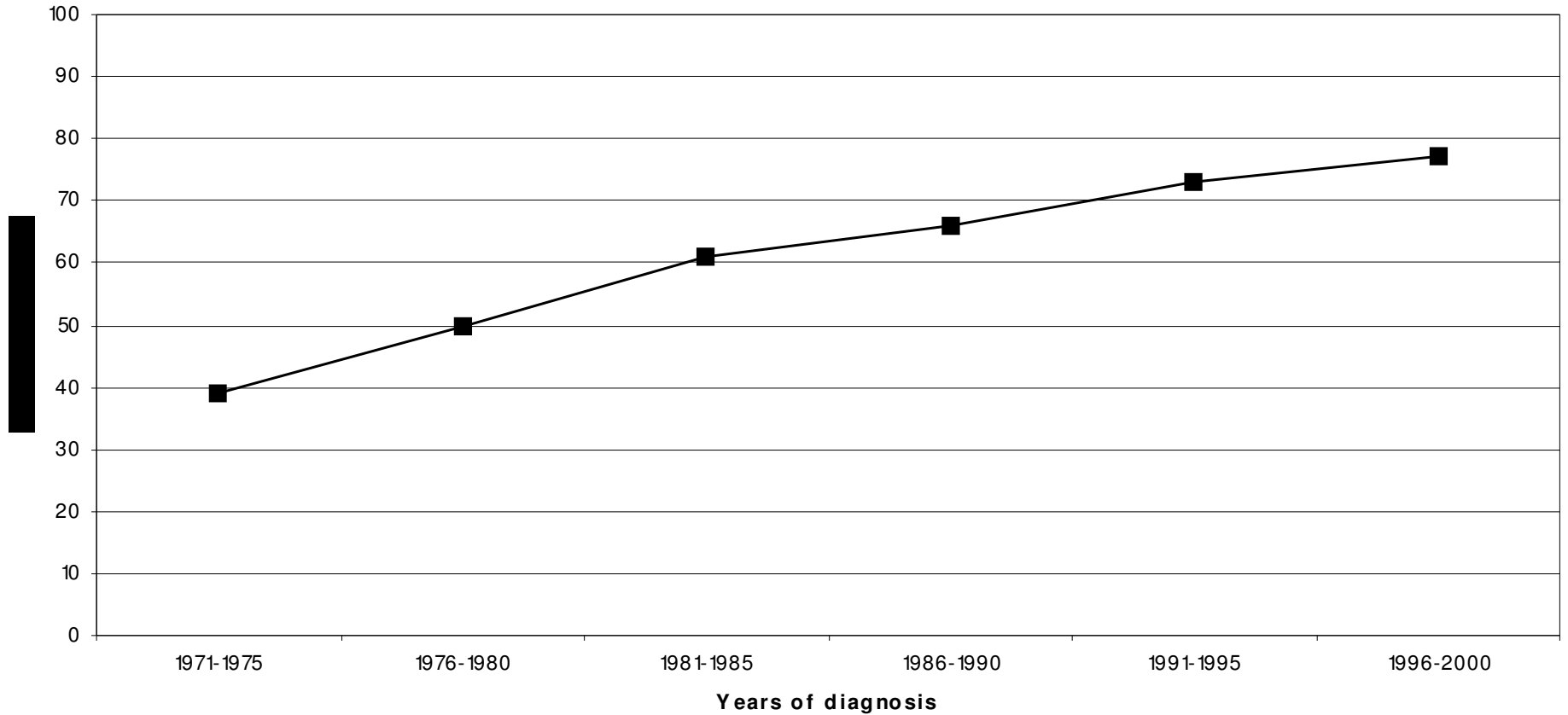
Potential reasons for differences and areas for improvement

- Organisation of care and referral to specialist treatment centres
- Speed of diagnosis and delivery of treatment
- Choice of treatment (is it 'the best'?)
- Availability of clinical trials
- Adherence to protocol recommendations
- Attitude to treatment at relapse

Percentage of children with cancer in Great Britain initially referred to a Children's Cancer & Leukaemia Group (CCLG) centre

Diagnostic groups (ICCC-3)	1988-1995 (ACCIS period)	1996-2000	2001-2002
I Leukaemia	87	93	95
II Lymphoma	86	91	94
III CNS	65	85	85
IV Sympathetic Nervous system	96	98	98
V Retinoblastoma	88	93	91
VI Renal tumours	94	98	99
VII Hepatic tumours	88	90	97
VIII Bone tumours	74	94	92
IX Soft tissue sarcoma	85	90	85
X Germ cell & gonadal	77	82	90
XI Melanoma & other carcinoma	23	36	35
XII Other	11	35	36
All cancers combined (I-XII)	79	88	90

Actuarial 5 year cumulative survival for all childhood cancers diagnosed in Great Britain (England, Wales, Scotland) during the period 1971-2000.



Stiller C (2007) Childhood Cancer in Britain: Incidence, Survival and Mortality, Oxford University Press.

What is needed to reduce inequalities in survival

- All countries should monitor outcomes
 - Population-based cancer registries are the ideal
 - Privacy laws must not impede follow up
- National cancer plans must address the specific needs of children and adolescents with cancer
 - Timely access to multi-disciplinary care
 - Networks of specialist centres with sufficient “critical mass” to diagnose rare diseases and deliver complex multi-disciplinary treatment protocols
 - Should consider access of patients to clinical research

Cancer in children needs special organisation

- Rare - 1 in 600 by age 15 yrs
- 45% of all childhood cancers occur before the age of 5 yrs
- Average family doctor will see 1 case every 20 years
- Special measures are needed to ensure early recognition, rapid referral to appropriately resourced specialist centres

QuickTime™ and a
TIFF (Uncompressed) decompressor
are needed to see this picture.

UK:

2001 National Cancer Plan

2005 IOG for children with cancer

2009 Self assessment of centres

2011 “Accreditation” and full
implementation

www.nice.org.uk



Acknowledgements

- Charles Stiller, Childhood Cancer Research Group, Oxford
- Eva Steliarova-Foucher & ACCIS collaborators
- Gemma Gatta, EURO CARE