

The NCIN's Site-Specific Clinical Reference Groups (SSCRGs) and Cancer 52

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NCIN core objectives

- Promoting efficient and effective data collection throughout the cancer journey
- Providing a common national repository for cancer datasets
- Producing expert analyses, based on robust methodologies, to monitor patterns of cancer care
- Exploiting information to drive improvements in standards of cancer care and clinical outcomes
- Enabling use of cancer information to support audit and research programmes

Site-Specific Clinical Reference Groups

- **Brain/CNS**
- **Breast**
- **Children, Teenage & Young Adults**
- **Colo-rectal**
- **Gynaecological cancers**
- **Haematological cancers**
- **Head & Neck**
- **Lung**
- **Bone & soft tissue Sarcoma**
- **Skin (including non-melanoma)**
- **Upper GI (including Hepato-biliary)**
- **Urology (all 4 sub-types)**

'Cross-cutting' Groups

- **Radiotherapy**
 - collection and use of RT data
- **Chemotherapy**
 - development and implementation of dataset
- **Pathology** (with RCPATH)
 - datasets
- **Radiology**: Joint RCR/NCIN working party
 - proforma-based (codable) reporting (diagnosis/stage)
 - extraction of data from RIS systems
- **Co-morbidity**
- **National Cancer Staging Panel**
- **(Health Economics)**

Site-Specific Clinical Reference Groups

- In place since late 2008
- Very varied 'starting points' (e.g. Lung vs CNS tumours)
- Opinion leaders chosen as chairs
- Multi-disciplinary clinical membership
- Lay (patient) and voluntary sector members
- Strong links with professional bodies & National Cancer Research Institute Clinical Study Groups
- Work closely with a lead Cancer Registry
- Chairs' Forum meets twice a year
- Each holds annual workshops with Cancer Network SSG chairs

Site-Specific Clinical Reference Groups

- **Examples of work to date:**
 - Annual work programmes
 - General site-specific clinical advice
 - National Cancer Dataset
 - Review of National Cancer Data Repository
 - Production of 'data briefings'
 - Supporting Peer Review (Clinical Lines of Enquiry)
 - Supporting Map of Medicine
 - Links with National Cancer Audits
 - Feeding into NICE guideline development and Quality Standards programme
 - Development of Service Profiles

Cancer 52 members of NCIN SSCRGs

SSCRG	Ca 52 member
Children, Teenagers & Young Adults	Teenage Cancer Trust CLIC Sargent
Central Nervous System	Brain Tumour UK Brain Tumour Research Campaign
Gynaecology	Target Ovarian cancer Jo's Trust
Haematology	Myeloma UK The Lymphoma Association
Sarcoma	Sarcoma UK, Bone Cancer Research Trust
Thyroid	AMEND Butterfly Thyroid Cancers Trust
Upper GI	Pancreatic Cancer UK Oesophageal Patients Association
Urology	Orchid Cancer Appeal

Site-Specific Clinical Reference Groups

- Brain/CNS
- Breast **Angiosarcoma**
- Children, Teenage & Young Adults
- Colo-rectal
- Gynaecological cancers
- Haematological cancers (including lymphoma)
- Head & Neck **Thyroid**
- Lung **Mesothelioma**
- Bone & soft tissue Sarcoma
- Skin (including non-melanoma)
- Upper GI **GIST** **Hepato-biliary**
- Urology (all 4 sub-types) **Penile & testicular**

Some relevant NCIN 'data briefings' - 1

- **Soft tissue sarcomas – Incidence & Survival**
- **Bone sarcomas – incidence and survival**
- **Incidence of sarcomas of the facial skeleton**
- **Co-morbidities of bone sarcoma patients**
- **Survival of Children, Teenagers and Young Adults with Cancer in England**
- **Second cancers amongst survivors of teenager and young adult cancers**
- **Gender differences in survival among Teenagers and Young Adults with cancer in England**
- **Place of death for Children, Teenagers and Young Adults with cancer in England**

Some relevant NCIN 'data briefings' - 2

- **Cervical cancer incidence and screening coverage**
- **A national profile of Ovarian cancer in England**
- **Potentially HPV related head and neck cancers**
- **Oral cavity cancers**
- **Malignant pleural mesothelioma**
- **Where do patients with blood cancers die?**
- **Cancer of Unknown Primary**
- **Understanding outcomes in leukaemia; why grouping different cancers is misleading**
- **Rare skin cancers in England**

Some relevant NCIN 'data briefings' - 3

- Is pancreatic carcinoma in the young becoming more common?
- Geographic variation in primary liver & gall bladder cancers
- Trends in incidence of primary liver cancer subtypes
- Incidence of stomach cancer in England, 1998-2007
- Incidence of oesophageal cancer in England, 1998-2007
- Rare bladder cancers
- Differentiated Teratoma of the Testis
- CNS Tumour – developing a tumour registry
- Malignant tumours of the vertebral column, sacrum, coccyx and base of skull: estimating the annual incidence in England



Differentiated Teratoma of the Testis

NCIN Data Briefing

Background and method

There has been a recent recommendation by the NCIN Urology Site Specific Clinical Reference Group (SSCRG) to the UK Association of Cancer Registries (UKACR) to code differentiated teratoma of the testis as a malignant tumour (sarcoma). This recommendation has not been accepted by UKACR because it conflicts with the coding rules in International Classification of Disease (ICD) O3. UKACR have proposed instead to try to influence the coding of testicular tumours in ICD-O4. In the meantime, NCIN have agreed to ensure all testicular tumours are registered to allow analyses reflecting the views of the SSCRG. This data briefing examines the epidemiology of the main types of testicular tumours, and considers the likely impact of such a change in coding. To ensure that all relevant tumours were identified, the following ICD-O3 codes were used: '562: Malignant neoplasms of the testis', '562.6: Germinalis in site of other and unspecified male genital organ' and '562.8: Neoplasms of uncertain or unknown behaviour of testis'.

Results

The proportion of testicular tumours (562, 562.6 and 562.8) registered with a morphology code of 'teratoma, malignant, not otherwise specified (NOS)', which includes differentiated teratomas, decreased over the period studied, from 28% of testicular tumours in 1990 to 7% in 2006. Testes tumours coded as testicular tumours in 2006 (51%), and have been increasing in proportion since 1990. The age-specific rates increased from less than 1% in 1990 to 14% in 2006. Investigation of coding of these tumours is required to understand these changes in detail.

If the statistics in future

most common histological types of testicular

ICD-O3 Code OBT

ICD-O3 Code OBT

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KEY MESSAGE:
Differentiated teratomata account for about 7% of the total of both malignant and benign tumours of the testis. Registering them as malignant will increase the number of testicular cancers in England by about 150 each year.

Is pancreatic cancer becoming more common in the young?

NCIN Data Briefing

Background

There is a concern that the incidence of pancreatic cancer in patients under 50 might be increasing. As these groups are often considered at low risk of pancreatic cancer the concern was that a cohort of adults might be at higher risk and that they might be receiving a late diagnosis and therefore not receiving timely treatment. This briefing investigates whether the incidence of pancreatic cancer is increasing in the younger age groups.

Results

There were 53,265 patients diagnosed with pancreatic cancer in England between 1990 and 2006. 431 patients were aged between 20 and 34, which equated to an average of 23 cases per year for those in their 20s and an average of 165 cases per year for those in their 30s and an average of 165 cases per year for those in their 40s. The age-specific incidence of pancreatic cancer increased with age and was highest in patients aged 40-49. The

Age group	1990-2005		2006-2007	
	Cases	(%)	Cases	(%)
<15	4	(0.0)	4	(0.0)
15-19	22	(0.0)	21	(0.0)
20-24	22	(0.0)	21	(0.0)
25-29	22	(0.0)	21	(0.0)
30-34	22	(0.0)	21	(0.0)
35-39	22	(0.0)	21	(0.0)
40-44	22	(0.0)	21	(0.0)
45-49	22	(0.0)	21	(0.0)
50-54	22	(0.0)	21	(0.0)
55-59	22	(0.0)	21	(0.0)
60-64	22	(0.0)	21	(0.0)
65-69	22	(0.0)	21	(0.0)
70-74	22	(0.0)	21	(0.0)
75-79	22	(0.0)	21	(0.0)
80-84	22	(0.0)	21	(0.0)
85-89	22	(0.0)	21	(0.0)
90-94	22	(0.0)	21	(0.0)
95-99	22	(0.0)	21	(0.0)

51 data briefings to date:
of which 26 on aspects of less common or rare cancers

Using information to improve quality and choice

Using information to improve quality and choice

Cancer 52 questionnaire on 'Missing Cancers'

- *“MPN’s? And some specific sub-types of the more common cancers.*
- *CUP does not fit that list*
- *Myelodysplastic syndromes*
- *Neuroendocrine Cancers” etc.....*

Some cancers without current SSCRG 'homes'

- **Cancer of Unknown Primary (CUP)**
- **Multiple Neuro-endocrine tumours (MEN syndrome)**
- **Adrenal tumours**
- **MPN (Myeloproliferative Neoplasms) :Many of these conditions are best considered 'pre-malignant' rather than true cancer and are not currently systematically collected by cancer registries – now being considered.**
- **Cutaneous, gastric and gynaecological sarcomas**

Head and neck cancers

2011-12 outputs

Radiotherapy travel times and distances

- Between 2006-2008, 92.4% of patients with head and neck cancers lived within 45 minutes of a radiotherapy centre as recommended by the National Radiotherapy Advisory Group.
- The percentage of patients living within 45 minutes varied by cancer network with a range from 65% to 100%. Average travel distances by network varied from 3.7 miles to 26 miles.
- Since 2008, a number of additional radiotherapy centres have been established to reduce the travel times in areas that were less well served.

Head and neck cancers

2011-12 outputs

Potentially HPV-related head and neck cancers

- The incidence of potentially HPV-related H&N squamous cell cancers (SCCs) increased between 1990 and 2008 - particularly in males.
- Patients with potentially HPV-related SCCs are on average younger than those with other non-HPV-related H&N cancers.
- The risk of developing a potentially HPV-related SCC is higher among people born after 1940 than those born in earlier decades.

Head and neck cancers

2011-12 outputs

- % of major surgical resections varies by cancer site – between 42.1% (hypopharynx) and 71.4% (oral cavity);
- Lower resection rate in males -for all H&N cancers significantly lower for males (46.7%) than for females (51.7%);
- Clear decreasing trend with age - with patients aged 80 years or over having lowest percentages
- Less marked decreasing trend with deprivation status – except for laryngeal cancer in males which shows the opposite trend
- Significant variation by cancer network-not explained by differences in age structure

Head and neck cancers 2011-12 outputs

Major surgical resections in England: head and neck cancers

Questions for 'outlier' cancer networks

- Is there a well functioning H&N MDT and are all relevant patients discussed?
- Are all appropriate treatment modalities available, accessible and offered to patients?
- Are there any variations in case mix (stage, co-morbidities, performance status) that might explain higher/lower resection rates?

NCIN - commissioned Haematological Malignancies Report

Haematological malignancies & cancer registration in England
(2004-2008)

Quality appraisal comparing data from the National Cancer Data
Repository (NCDR) with the population-based Haematological
Malignancy Research Network (HMRN)

Final Report
June 2012

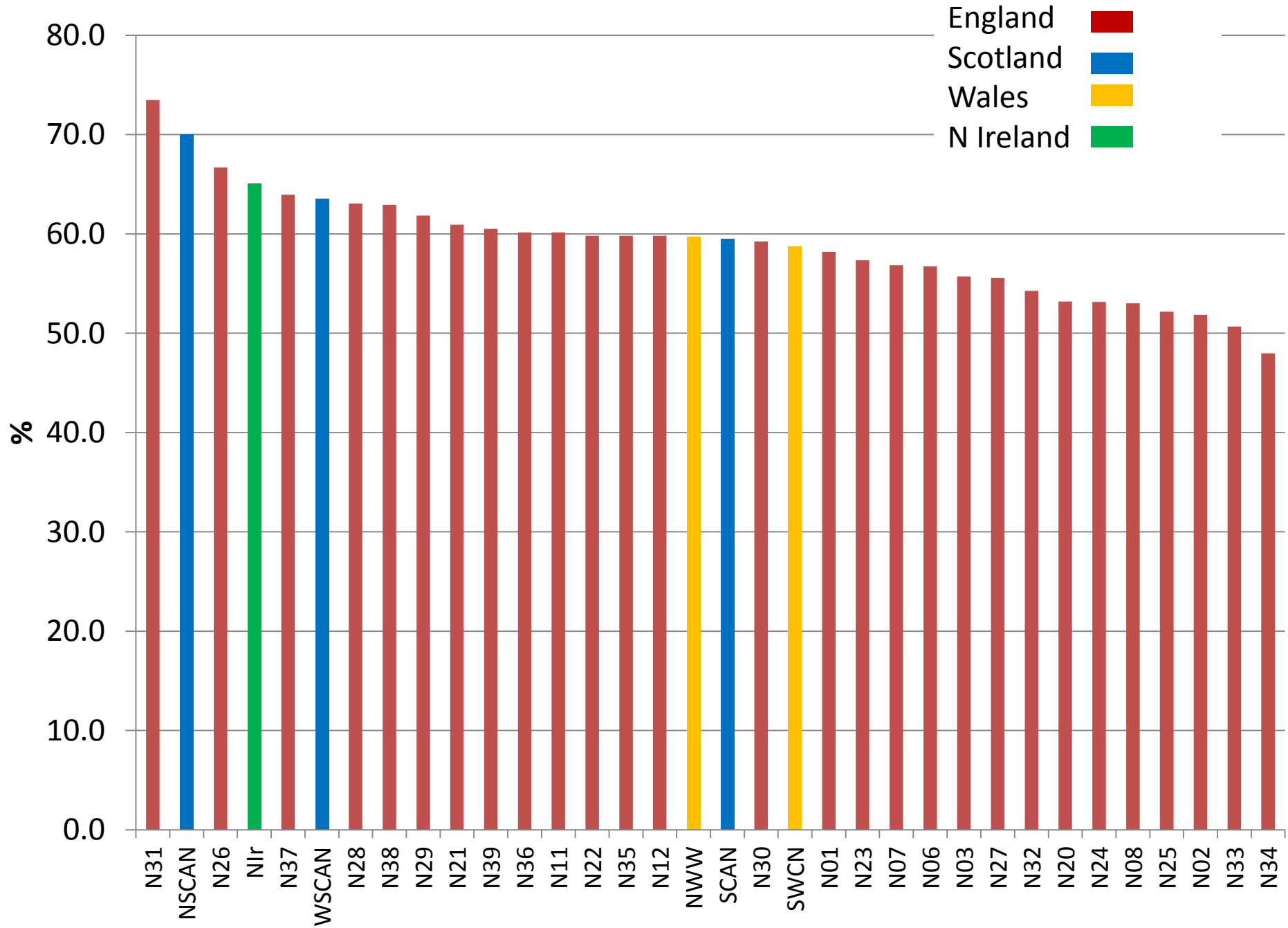
2012-2013 work programme: examples of less common cancer projects

- Incidence of retroperitoneal sarcomas
- Epidemiology of sarcomas– incidence & survival
- Detailed study of penile cancers
- Kidney cancer survival by morphological type
- Trends in one year survival in upper GI cancers
- Routes to diagnosis & short term survival in childhood cancers
- Profile of uterine cancer
- Creation of Head & Neck cancer hub
- Short term ovarian cancer mortality
- Use of Radiotherapy in haematological cancers

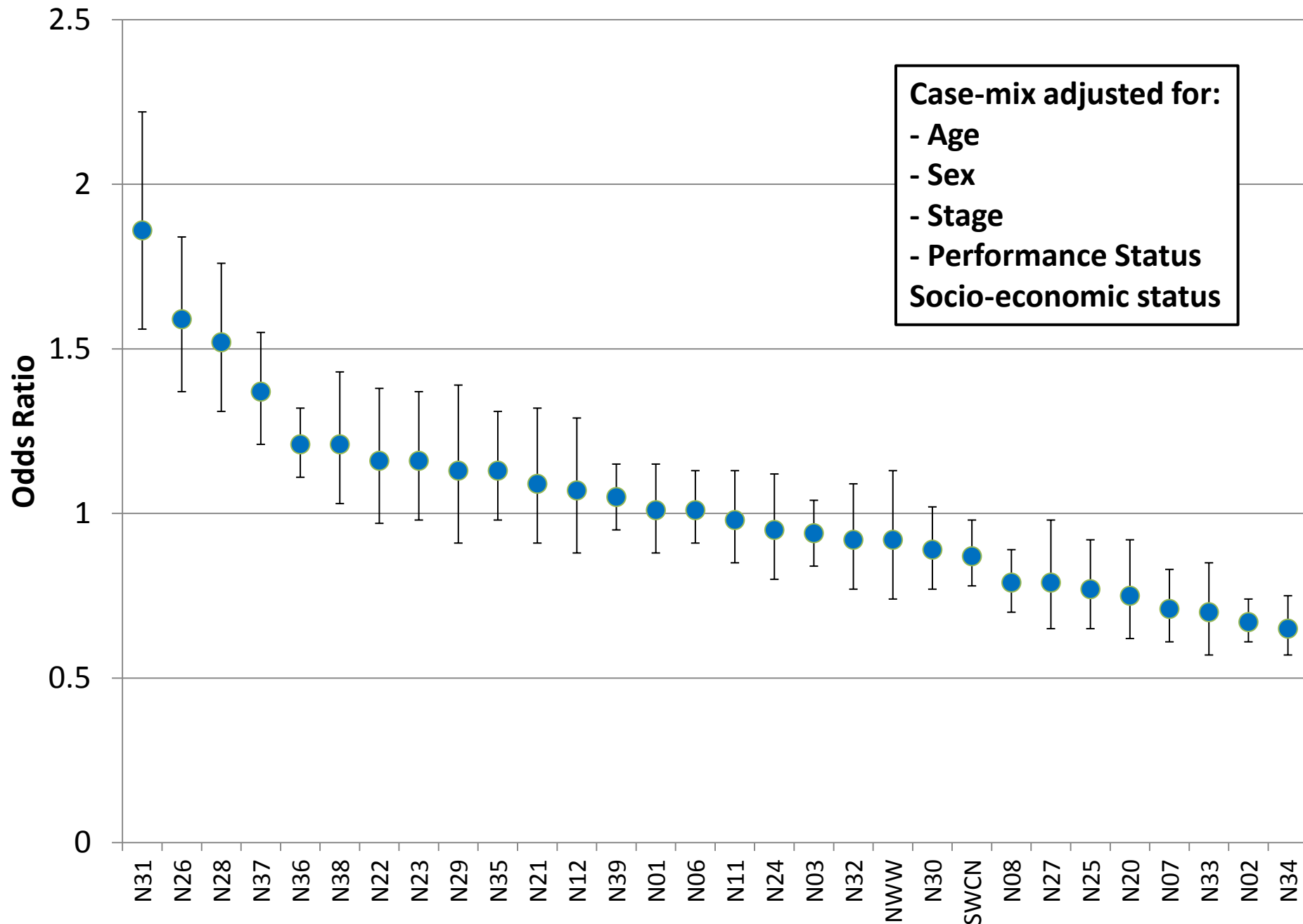
The National Lung Cancer Audit

www.ic.nhs.uk

Active Treatment Rate (%)



Active Treatment Rate (England & Wales only)





Our cancer shame: Survival rates in UK are the worst among leading nations

By JENNY HOPE

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Lung cancer lottery

By JANE SYMONS

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





IT is the most deadly cancer in the UK – and your chance of surviving it could be wrecked by GEOGRAPHY.

HOW THE TREATMENTS COMPARE







BREAST

	1-yr survival	5-yr survival
 Australia	96.7%	88.1%
 Canada	96.3%	86.3%
 Denmark	95.0%	82.4%
 Norway	96.6%	85.5%
 Sweden	98.0%	88.5%
 UK	94.2%	81.6%







BOWEL

	1-yr survival	5-yr survival
 Australia	84.9%	65.9%
 Canada	83.5%	63.7%
 Denmark	77.7%	55.8%
 Norway	82.4%	62.0%
 Sweden	83.8%	62.6%
 UK	74.7%	53.6%

OVARIAN

	1-yr survival	5-yr survival
 Australia	73.5%	37.5%
 Canada	75.2%	41.9%
 Denmark	70.6%	36.1%
 Norway	75.2%	39.7%
 Sweden	n/a	n/a
 UK	65.0%	36.4%

LUNG

	1-yr survival	5-yr survival
 Australia	42.8%	17.0%
 Canada	43.1%	18.4%
 Denmark	34.9%	10.9%
 Norway	39.2%	14.4%
 Sweden	43.6%	16.3%
 UK	29.7%	8.8%

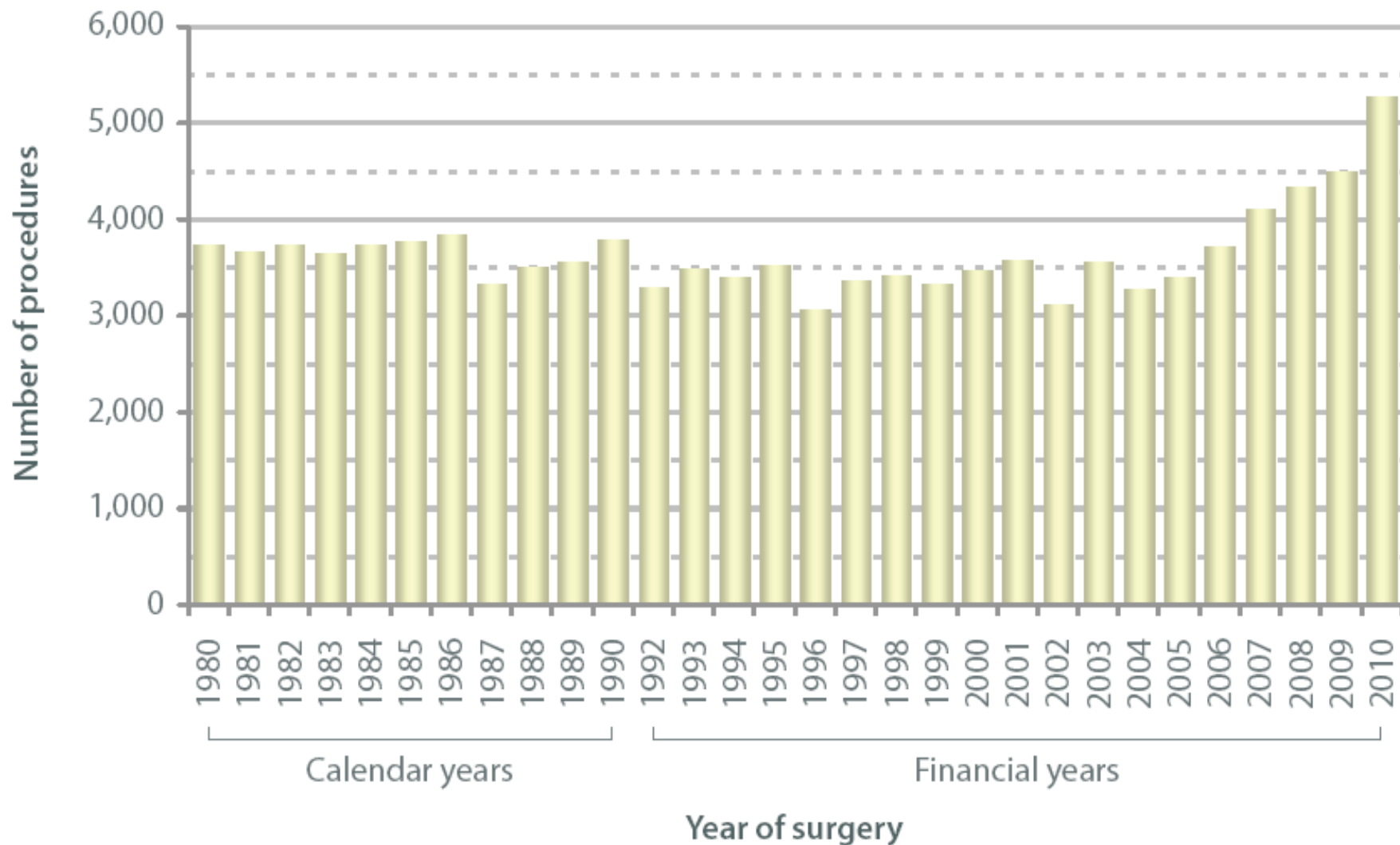
National Lung Cancer Audit

Headline indicators over time

	2005	2006	2007	2008	2009	2010	2011
Case ascertainment (%)	40	66	75	92	>97	~100	>100
% discussed at MDT	79	84.3	86.8	88.6	93.8	96.1	96.2
Tissue confirmation rate (%)	68	66	65	66.7	75.9	76.5	76.9
Overall surgical resection rate (%)	9	9.4	10.3	11.2	13.9	13.9	14.7
Resection rate: confirmed NSCLC (%)	13.8	14.3	15.2	16.0	18.4	18.3	20.1
Active treatment rate (%)	45	50	52	54	59.2	58	60.1
Small Cell chemotherapy rate (%)	57.7	61.7	64.5	63.0	65.4	65	67.9

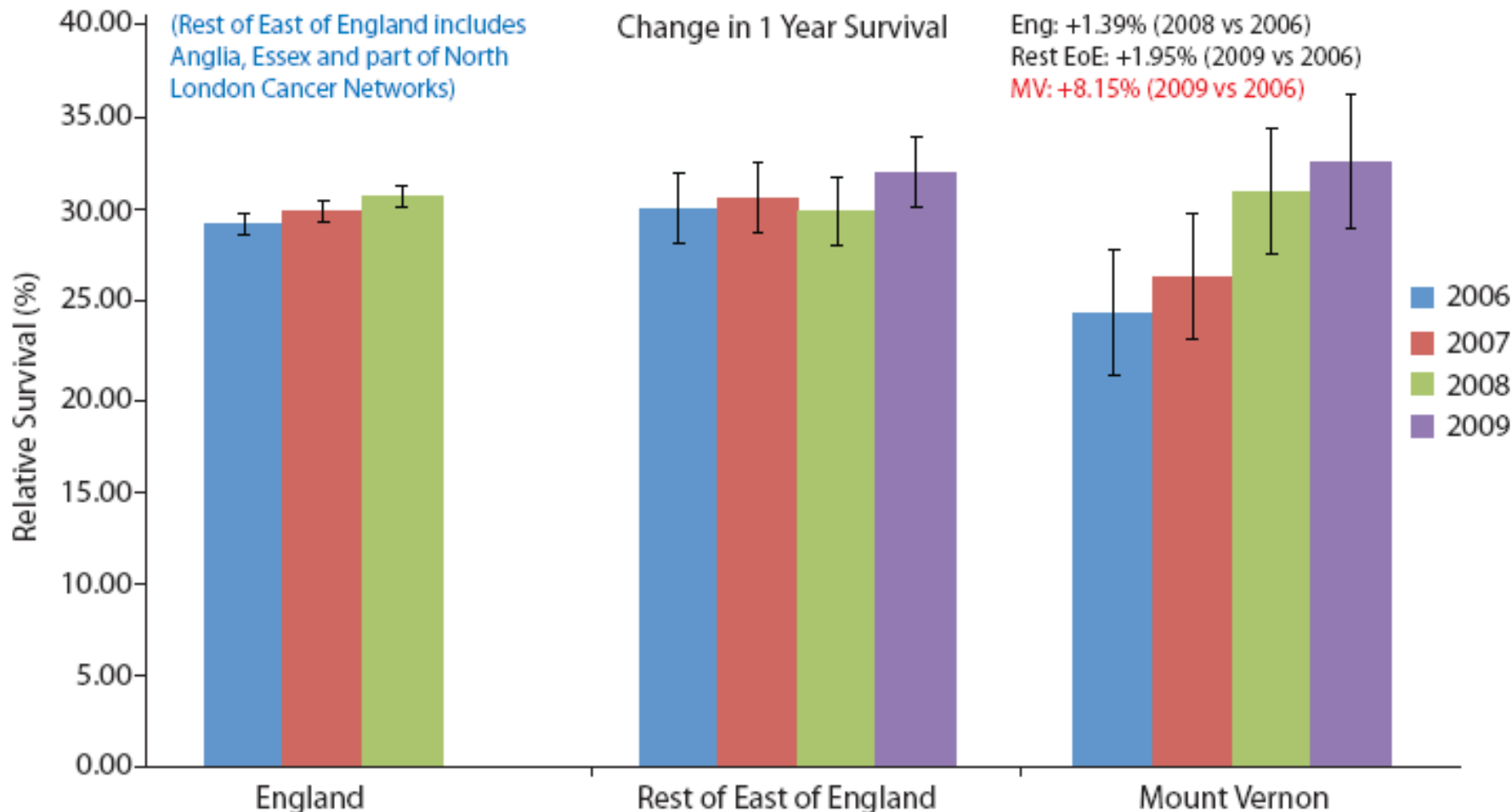
Fig. 1.A.8

Primary lung cancer resections (n=109,388)



Source: R Page, Society of Cardiothoracic Surgeons Audit 2011

Survival improvements in Mount Vernon Cancer Network



Source: Greenberg et al; BTOG, January 2012

Summary

- Low current level of systematic identification of many less common cancers (e.g.CNS tumours, sarcomas, haematological)
- Wider data on stage, treatment etc., even less well developed
- A number of rarer cancers still do not have an SSCRG 'home'
- Significant progress:
 - Multiple data briefings
 - 2012-13 work programme
 - Thyroid cancer sub-group
 - Some Cancer 52 members on SSCRGs
- Resource limitations – need to focus on areas where greatest benefits may come
- There is evidence that good data change clinical practice