NCIN
national cancer intelligence network
Using information to improve quality & choice

What is the NCIN?

Dr Mick Peake

Clinical Lead, NCIN

www.ncin.org.uk

NCRI
National Cancer Research Institute

NCIN
national cancer
intelligence network

Using information to improve quality & choice

Goal for NCIN: "To develop the best cancer information service of any large country in the world – by 2012"

www.ncin.org.uk

NCRI
National
Cancer
Research
Institute

NCIN Partners

NCIN
national cancer
intelligence network

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breakthrough
breast cancer

CANCER RESEARCH UK

ecric
Fighting cancer with information

DH Department of Health

NHS
The Information Centre
for health and social care

LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE
UNIVERSITY OF LONDON

WE ARE MACMILLAN.
CANCER SUPPORT

MRC Medical Research Council

NHS
National Cancer Action Team

Office for National Statistics

NATCANSAT
The National Cancer Services Analysis Team

oncore UK

O C I U
OXFORD CANCER INTELLIGENCE UNIT

NHS
National Services Scotland

NHS
Northern and Yorkshire
Cancer Registry and Information Service

NWCIS
North West Cancer Intelligence Service

KING'S College LONDON

abpi

NHS

DH Department of Health

SOUTH WEST PUBLIC HEALTH OBSERVATORY

Trent NHS
Cancer Registry

NHS

West Midlands
Cancer Intelligence Unit

Cancer Screening Programmes

NCRI
National Cancer Research Institute

Using information to improve quality & choice

NCRI Members

NCIN
national cancer
intelligence network

abpi

AICR
FUNDING THE FIGHT AGAINST CANCER

bbsrc

breakthrough
breast cancer

breast cancer CAMPAIGN
researching the cure

CANCER RESEARCH UK

DH Department of Health

E·S·R·C
ECONOMIC & SOCIAL RESEARCH COUNCIL

LEUKAEMIA RESEARCH
HODGKIN'S | LYMPHOMA | MYELOMA

LUDWIG INSTITUTE FOR CANCER RESEARCH

WE ARE MACMILLAN. CANCER SUPPORT

Marie Curie Cancer Care
Devoted to Life

Fighting Britain's biggest childhood cancer
CHILDREN with LEUKAEMIA
Registered Charity No. 298405. Inaugurated in 1988 by Diana, Princess of Wales in memory of Jean and Paul O'Gorman

THE ROY CASTLE LUNG CANCER FOUNDATION

MRC Medical Research Council

r&d office

CHIEF SCIENTIST OFFICE

tenovus
the cancer charity

Llywodraeth Cynulliad Cymru
Welsh Assembly Government

wellcome trust

yorkshire cancer research

NCRI
National Cancer Research Institute

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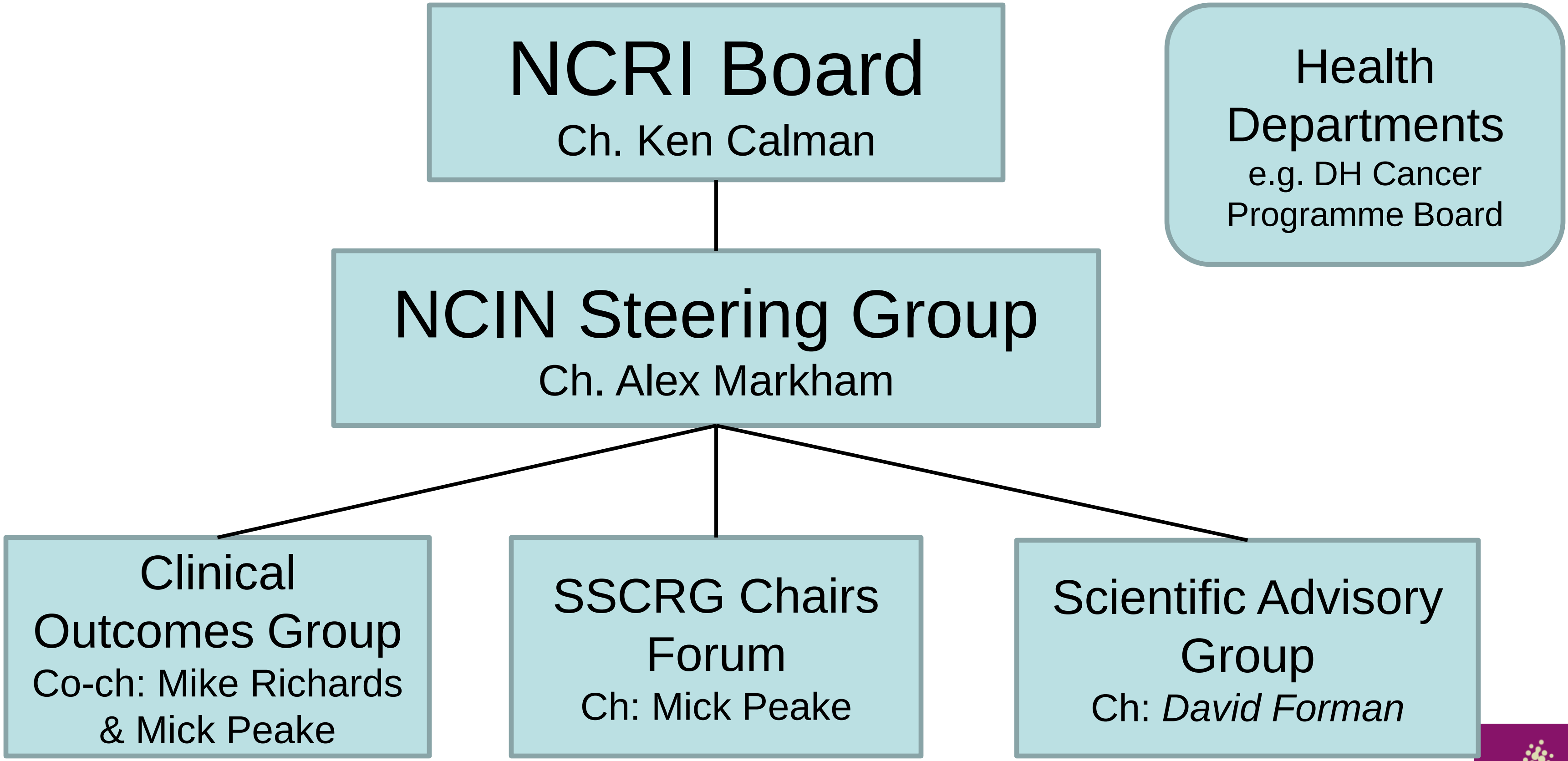
NCIN Governance



NCRI Board
Ch. Ken Calman

Health Departments
e.g. DH Cancer Programme Board

NCIN Steering Group
Ch. Alex Markham

Clinical Outcomes Group
Co-ch: Mike Richards & Mick Peake

SSCRG Chairs Forum
Ch: Mick Peake

Scientific Advisory Group
Ch: *David Forman*

NCIN core objectives

NCIN
national cancer intelligence network

- 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 (including lymphoma)
- Head & Neck (including thyroid)
- Lung (including mesothelioma)
- Bone & soft tissue Sarcoma
- Skin (including non-melanoma)
- Upper GI (including Hepato-biliary)
- Urology (all 4 sub-types)

Main issues for SSCRGs

- Development of a work programme (linked to national priorities)
- Support for data set development
- Identification of main clinical indicators
- Supporting the development of Peer Review measures
- Advising on co-morbidity/radiology etc.
- Improving staging (engaging pathologists)
- Promoting clinical (and public) engagement
- Advising on reporting
- Making the most of links with the research community
- Supporting the use of data to change clinical practice
- Advising on care pathways (Map of Medicine)

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Other workstreams

- Pathology
- Radiology
- Radiotherapy (NRIG)
- Chemotherapy (NCIG)
- Co-morbidity – C-M Advisory Group

Coordinated National Data Management

NCIN national cancer intelligence network

- Linked National Cancer Data Repository (NCDR)
  - ONS Registration record
  - Extended registry records (staging, treatments)
  - Hospital Episodes (IP)
  - Covers England only
- GPRD (controlled linkage)
- To Follow:
  - HES OP
  - National audit data
  - Cancer Waiting Times (referral data, recurrence)
  - Radiotherapy (mandated from April 2009)
  - HES A&E

National Cancer Data Repository (NCDR)

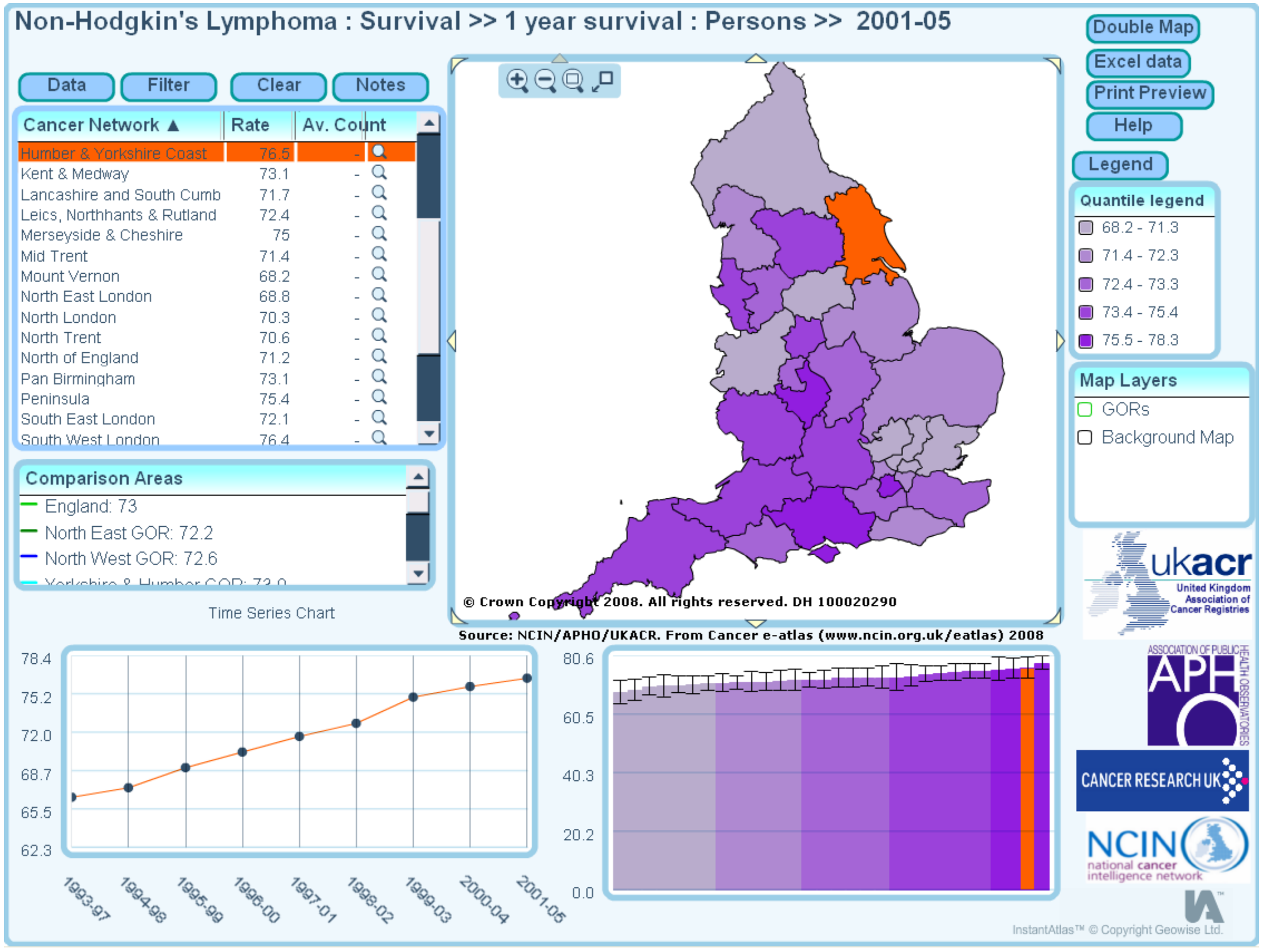
- Currently contains:
  - ONS up to 2006 (8m+)
  - Registries up to 2006, incl stage & treat (8m+)
  - HES up to 2008 (35m+)
  - GPRD linkage complete
- Being updated for
  - Registrations up to 2007
  - NCASP data (lung, colorectal, H&N)
  - HES outpatients
  - Radiotherapy data to follow 2010

Expert analyses

- Cancer eAtlas: - launched July 2008 www.ncin.org.uk/eatlas
  - Large and varied interest
  - International recognition
- Reports on:
  - UK incidence & mortality
  - One year survival
  - Deprivation
  - Prevalence
  - Ethnicity
  - Male cancers
  - Cancer in the Elderly
  - *Surgery (due out Q1 2010)*
- Microsites

National Cancer e-Atlas

www.ncin.org.uk/eatlas



Non-Hodgkin's Lymphoma : Survival >> 1 year survival : Persons >> 2001-05

Cancer Network ▲	Rate	Av. Count
Humber & Yorkshire Coast	76.5	-
Kent & Medway	73.1	-
Lancashire and South Cumb	71.7	-
Leics, Northhants & Rutland	72.4	-
Merseyside & Cheshire	75	-
Mid Trent	71.4	-
Mount Vernon	68.2	-
North East London	68.8	-
North London	70.3	-
North Trent	70.6	-
North of England	71.2	-
Pan Birmingham	73.1	-
Peninsula	75.4	-
South East London	72.1	-
South West London	76.4	-

Comparison Areas

England: 73
North East GOR: 72.2
North West GOR: 72.6

Quantile legend

- ▨ 68.2 - 71.3
- ▨ 71.4 - 72.3
- ▨ 72.4 - 73.3
- ▨ 73.4 - 75.4
- ▨ 75.5 - 78.3

Map Layers

☐ GORs
☐ Background Map

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Source: NCIN/APHO/UKACR. From Cancer e-atlas (www.ncin.org.uk/eatlas) 2008

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Data
Filter
Clear
Notes
Double Map
Excel data
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Help
Legend
Time Series Chart
78.4
75.2
72.0
68.7
65.5
62.3
1993-97
1994-98
1995-99
1996-00
1997-01
1998-02
1999-03
2000-04
2001-05
80.6
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40.3
20.2
0.0

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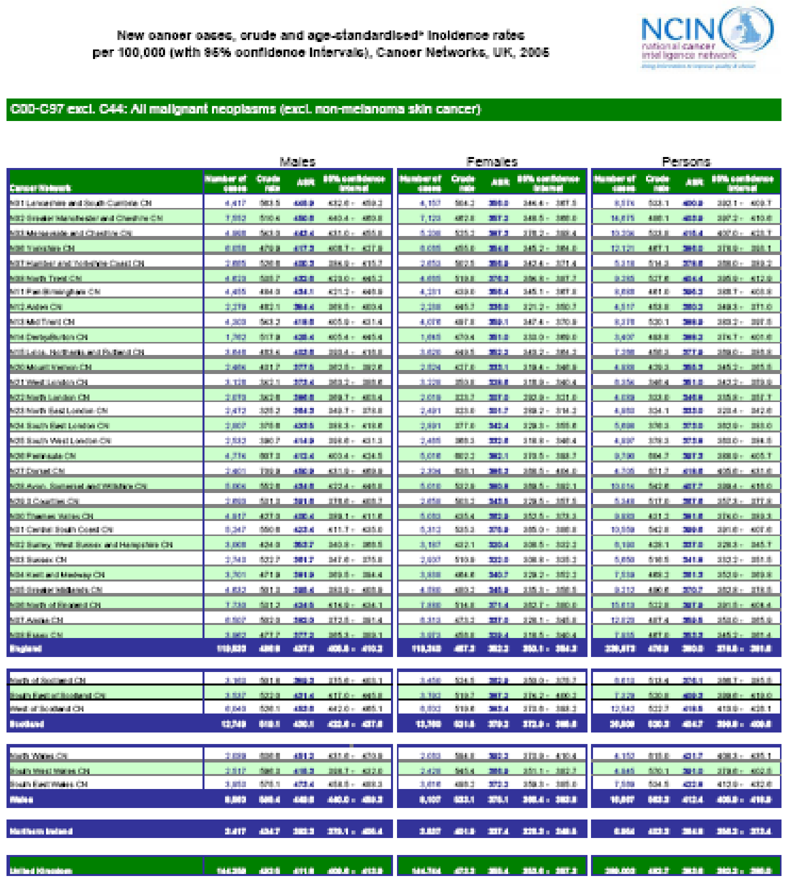
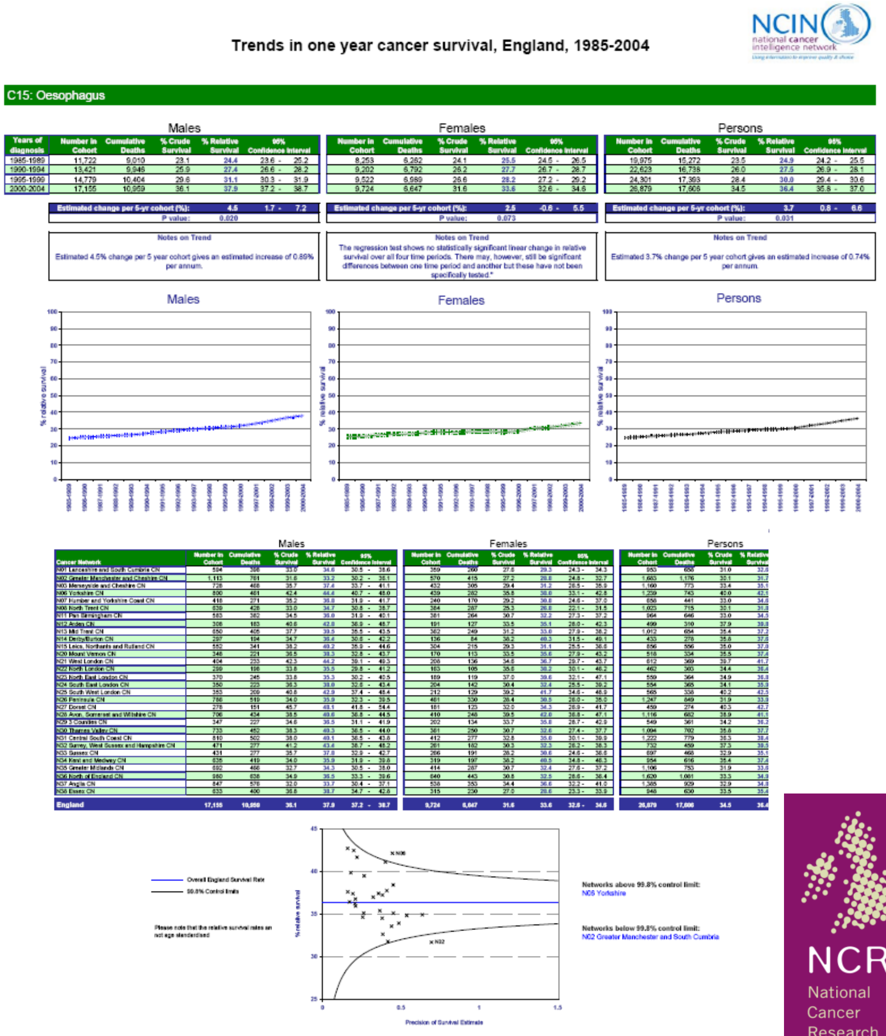
NCIN:
Incidence and mortality



New cancer cases, crude and age-standardised* incidence rates per 100,000 (with 95% confidence intervals), Cancer Networks, UK, 2006

C00-C97 excl. C44: All malignant neoplasms (excl. non-melanoma skin cancer)



Trends in one year cancer survival, England, 1985-2004

C15: Oesophagus

Males

Years of diagnosis	Number in Cohort	Cumulative Deaths	% Crude Survival	% Relative Survival	95% Confidence Interval
1985-1989	11,722	9,010	23.1	24.4	23.6 - 25.2
1990-1994	13,421	9,946	25.9	27.4	26.6 - 28.2
1995-1999	14,779	10,404	29.6	31.1	30.3 - 31.9
2000-2004	17,155	10,959	36.1	37.9	37.2 - 38.7

Estimated change per 5-yr cohort (%): 4.5 1.7 - 7.2

P value: 0.020

Notes on Trend

Estimated 4.5% change per 5 year cohort gives an estimated increase of 0.89% per annum.

Females

Years of diagnosis	Number in Cohort	Cumulative Deaths	% Crude Survival	% Relative Survival	95% Confidence Interval
1985-1989	8,253	6,262	24.1	25.5	24.5 - 26.5
1990-1994	9,202	6,792	26.2	27.7	26.7 - 28.7
1995-1999	9,522	6,989	26.6	28.2	27.2 - 29.2
2000-2004	9,724	6,647	31.6	33.6	32.6 - 34.6

Estimated change per 5-yr cohort (%): 2.5 -0.6 - 5.5

P value: 0.073

Notes on Trend

The regression test shows no statistically significant linear change in relative survival over all four time periods. There may, however, still be significant differences between one time period and another but these have not been specifically tested.*

Persons

Years of diagnosis	Number in Cohort	Cumulative Deaths	% Crude Survival	% Relative Survival	95% Confidence Interval
1985-1989	19,975	15,272	23.5	24.9	24.2 - 25.5
1990-1994	22,623	16,738	26.0	27.5	26.9 - 28.1
1995-1999	24,301	17,393	28.4	30.0	29.4 - 30.6
2000-2004	26,879	17,606	34.5	36.4	35.8 - 37.0

Estimated change per 5-yr cohort (%): 3.7 0.8 - 6.6

P value: 0.031

Notes on Trend

Estimated 3.7% change per 5 year cohort gives an estimated increase of 0.74% per annum.

Please note that the relative survival rates are not age standardised

Networks above 99.8% control limit:
N06 Yorkshire

Networks below 99.8% control limit:
N02 Greater Manchester and South Cumbria

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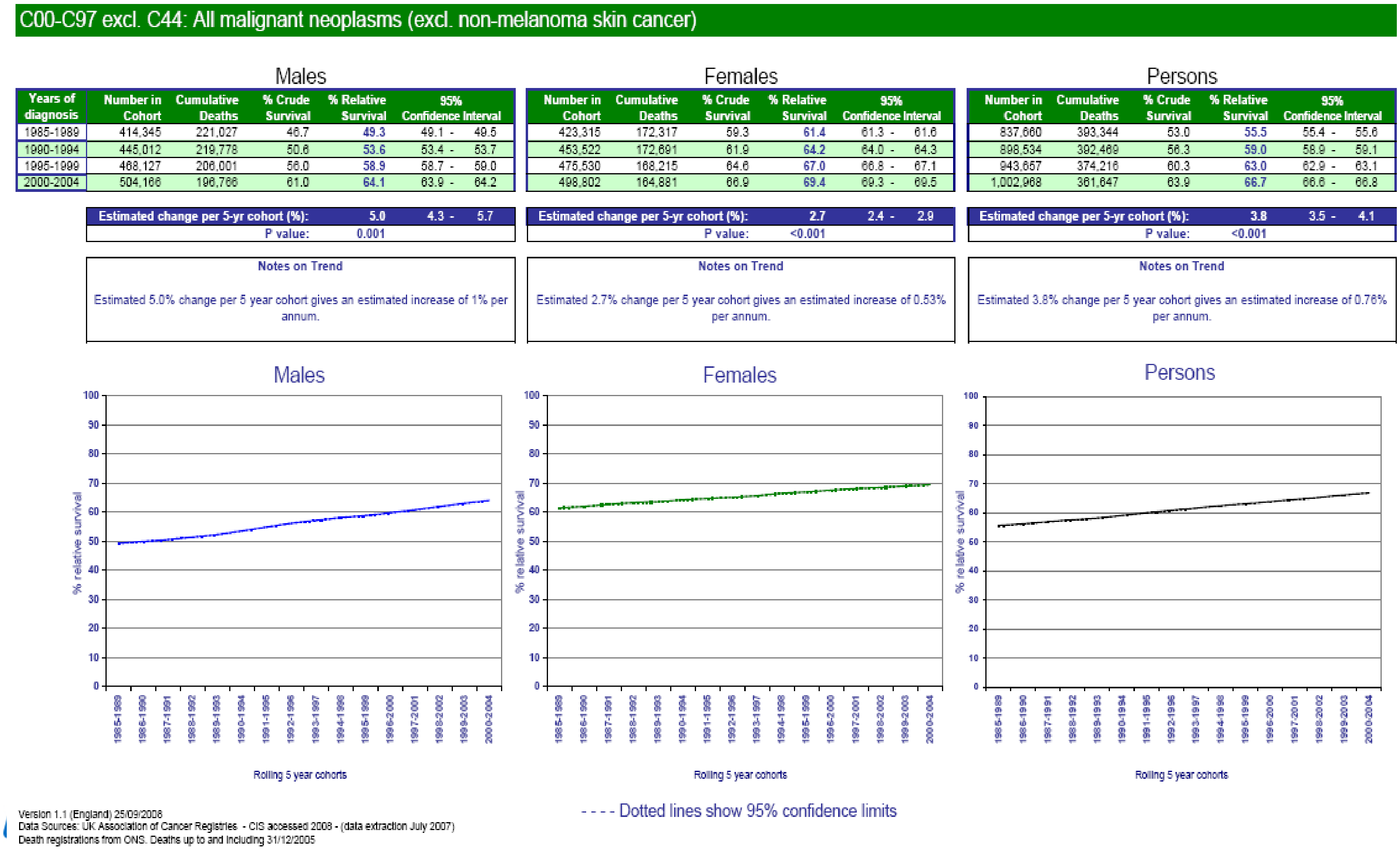
Trends in 1 year survival: England 1985-2004



C00-C97 excl. C44: All malignant neoplasms (excl. non-melanoma skin cancer)

Males

Years of diagnosis	Number in Cohort	Cumulative Deaths	% Crude Survival	% Relative Survival	95% Confidence Interval
1985-1989	414,345	221,027	46.7	49.3	49.1 - 49.5
1990-1994	445,012	219,778	50.6	53.6	53.4 - 53.7
1995-1999	468,127	206,001	56.0	58.9	58.7 - 59.0
2000-2004	504,166	196,766	61.0	64.1	63.9 - 64.2

Estimated change per 5-yr cohort (%):	5.0	4.3 - 5.7
P value:	0.001	

Notes on Trend

Estimated 5.0% change per 5 year cohort gives an estimated increase of 1% per annum.

Females

Years of diagnosis	Number in Cohort	Cumulative Deaths	% Crude Survival	% Relative Survival	95% Confidence Interval
1985-1989	423,315	172,317	59.3	61.4	61.3 - 61.6
1990-1994	453,522	172,691	61.9	64.2	64.0 - 64.3
1995-1999	475,530	168,215	64.6	67.0	66.8 - 67.1
2000-2004	498,802	164,881	66.9	69.4	69.3 - 69.5

Estimated change per 5-yr cohort (%):	2.7	2.4 - 2.9
P value:	<0.001	

Notes on Trend

Estimated 2.7% change per 5 year cohort gives an estimated increase of 0.53% per annum.

Persons

Years of diagnosis	Number in Cohort	Cumulative Deaths	% Crude Survival	% Relative Survival	95% Confidence Interval
1985-1989	837,660	393,344	53.0	55.5	55.4 - 55.6
1990-1994	898,534	392,469	56.3	59.0	58.9 - 59.1
1995-1999	943,657	374,216	60.3	63.0	62.9 - 63.1
2000-2004	1,002,968	361,647	63.9	66.7	66.6 - 66.8

Estimated change per 5-yr cohort (%):	3.8	3.5 - 4.1
P value:	<0.001	

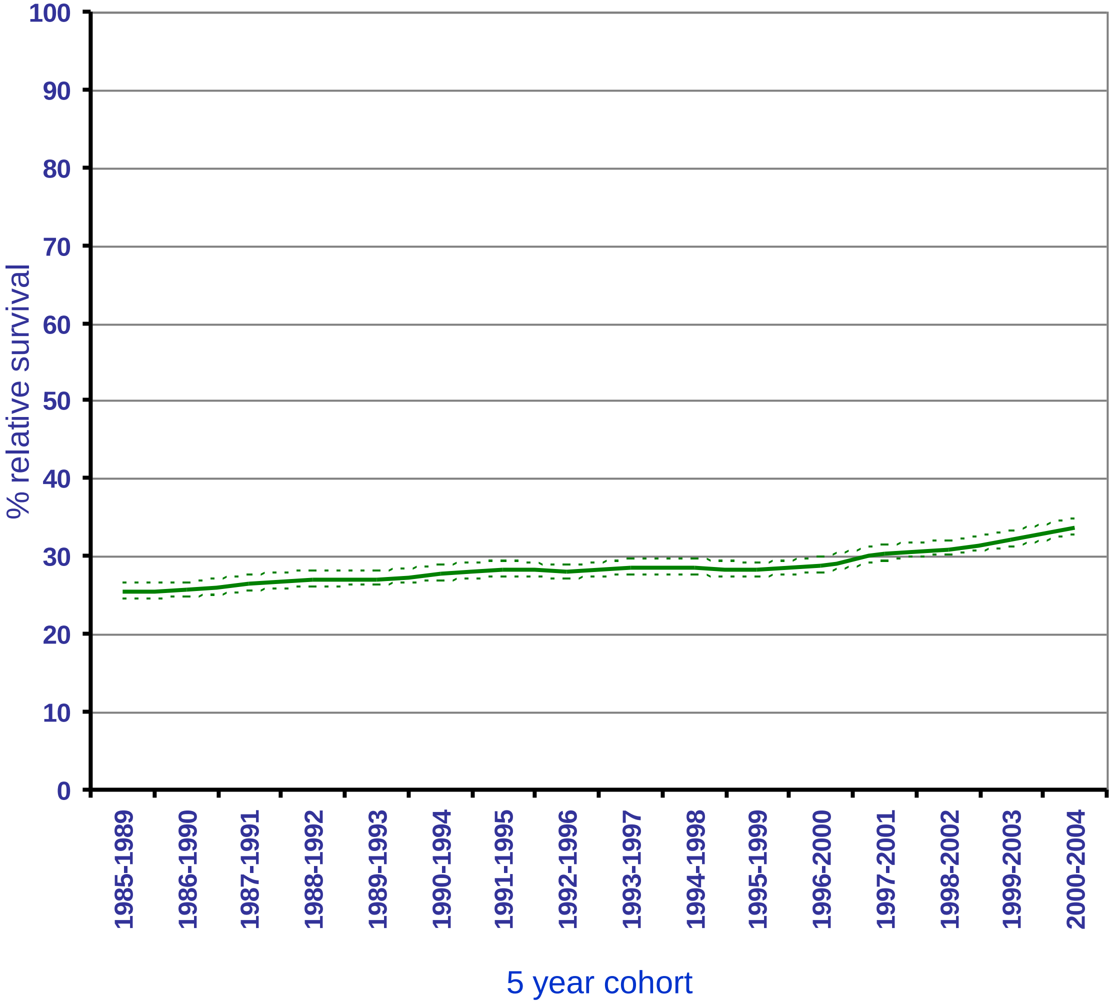
Notes on Trend

Estimated 3.8% change per 5 year cohort gives an estimated increase of 0.76% per annum.

- - - - Dotted lines show 95% confidence limits

Version 1.1 (England) 25/09/2008
Data Sources: UK Association of Cancer Registries - CIS accessed 2008 - (data extraction July 2007)
Death registrations from ONS. Deaths up to and including 31/12/2005

C15: Oesophagus
Trends in 1yr survival



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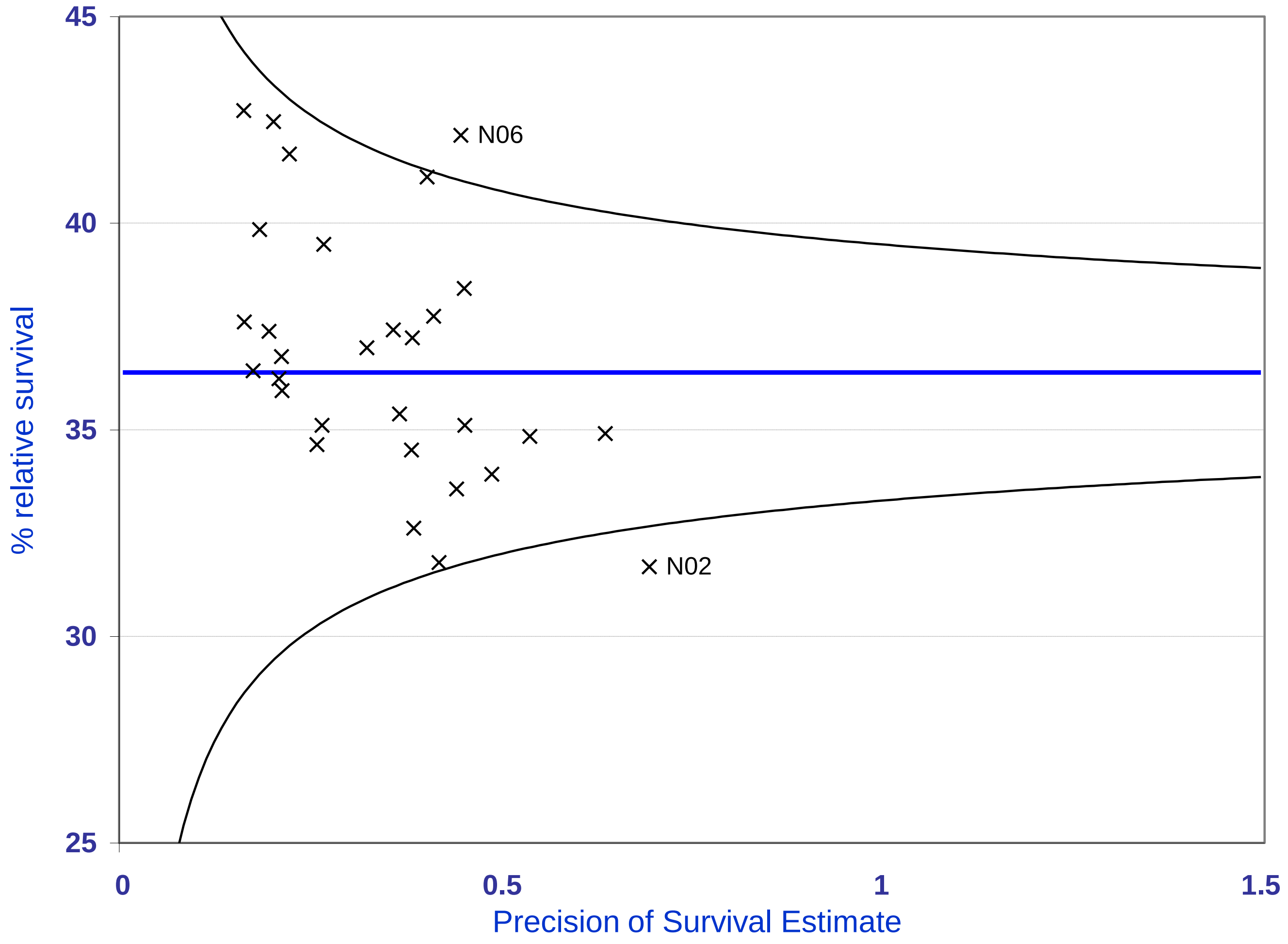
C15: Oesophagus 2005 by Cancer Network



Using information to improve quality & choice

Lung Cancer Incidence by deprivation

Cancer incidence by deprivation quintile, England, 1995 - 2004

C33-C34: Trachea, bronchus and lung

Males

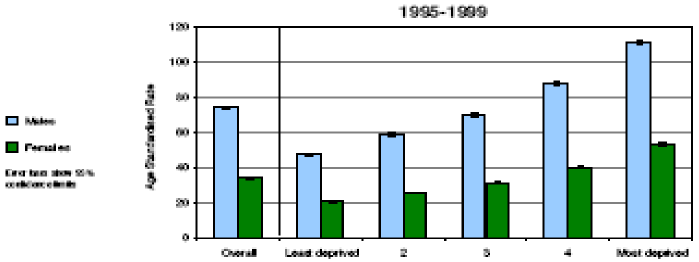
Deprivation Quintile	Number of cases	Crude Rate	ASR	95% Confidence Interval	ASR Ratio	Excess Cases
1995-1999						
Least deprived	12,794	54.9	47.1	46.3 - 47.9	1.0	0
2	17,063	72.6	58.7	57.8 - 59.5	1.2	3,356
3	20,225	86.8	70.1	69.1 - 71.0	1.5	6,623
4	23,793	99.6	87.7	86.6 - 88.8	1.9	11,005
Most deprived	27,443	112.7	110.9	109.6 - 112.2	2.4	15,786
Overall	**101,308**	**85.4**	**74.1**	**73.6 - 74.5**		
2000-2004						
Least deprived	12,544	51.2	41.3	40.6 - 42.1	1.0	0
2	15,820	65.4	49.6	48.8 - 50.4	1.2	2,647
3	18,525	76.3	59.7	58.8 - 60.5	1.4	5,693
4	21,525	88.3	76.3	75.3 - 77.3	1.8	9,866
Most deprived	24,351	99.2	100.6	99.4 - 101.9	2.4	14,346
Overall	**92,865**	**76.1**	**63.7**	**63.3 - 64.1**		

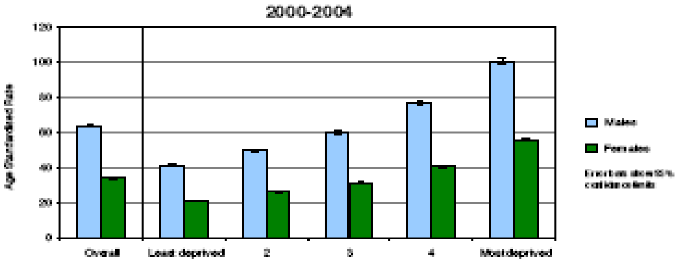
Females

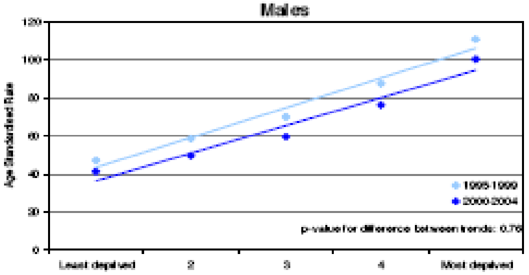
Deprivation Quintile	Number of cases	Crude Rate	ASR	95% Confidence Interval	ASR Ratio	Excess Cases
1995-1999						
Least deprived	7,175	29.5	20.8	20.4 - 21.3	1.0	0
2	9,397	38.1	25.3	24.8 - 25.9	1.2	1,670
3	11,578	46.5	31.0	30.4 - 31.5	1.5	3,786
4	14,122	55.9	40.1	39.5 - 40.8	1.9	6,786
Most deprived	16,733	65.2	53.1	52.3 - 53.9	2.5	10,166
Overall	**59,005**	**47.3**	**33.8**	**33.5 - 34.0**		
2000-2004						
Least deprived	7,691	30.7	20.9	20.5 - 21.4	1.0	0
2	10,290	40.8	26.0	25.5 - 26.5	1.2	2,003
3	12,140	47.8	31.1	30.5 - 31.7	1.5	3,972
4	14,719	57.6	40.7	40.0 - 41.3	1.9	7,143
Most deprived	17,024	66.4	55.9	55.0 - 56.7	2.7	10,647
Overall	**61,864**	**48.8**	**34.0**	**33.8 - 34.3**		

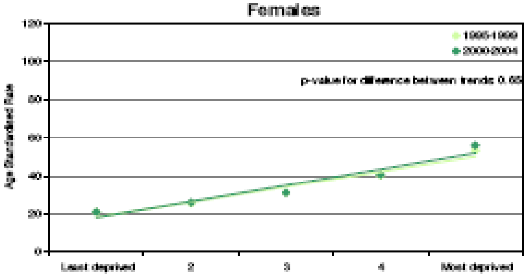
Persons

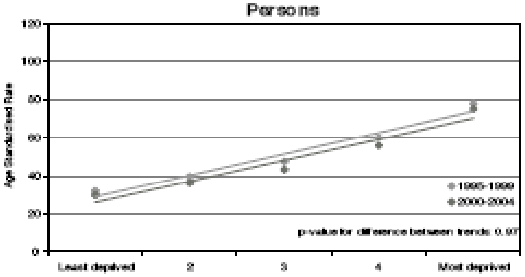
Deprivation Quintile	Number of cases	Crude Rate	ASR	95% Confidence Interval	ASR Ratio	Excess Cases
1995-1999						
Least deprived	19,969	41.9	32.0	31.5 - 32.4	1.0	0
2	26,460	54.9	39.6	39.1 - 40.0	1.2	5,025
3	31,803	66.6	47.5	47.0 - 48.0	1.5	10,409
4	37,915	77.2	60.1	59.5 - 60.7	1.9	17,790
Most deprived	44,176	88.3	77.8	77.1 - 78.6	2.4	25,951
Overall	**160,313**	**65.9**	**50.9**	**50.7 - 51.2**		
2000-2004						
Least deprived	20,235	40.9	29.8	29.4 - 30.3	1.0	0
2	26,210	52.9	36.3	35.8 - 36.7	1.2	4,650
3	30,665	61.7	43.3	42.9 - 43.8	1.5	9,666
4	36,244	72.6	55.8	55.3 - 56.4	1.9	17,006
Most deprived	41,375	82.5	75.2	74.5 - 75.9	2.5	24,993
Overall	**154,729**	**62.2**	**46.9**	**46.6 - 47.1**		











Males

Cohort	Est. Deprivation Gap (Difference in ASR)	95% Confidence Interval	Modelled %Change	P-value for Trend
1995-1999	65.5	46.0 - 85.1	155%	0.002
2000-2004	62.4	37.5 - 87.4	182%	0.004

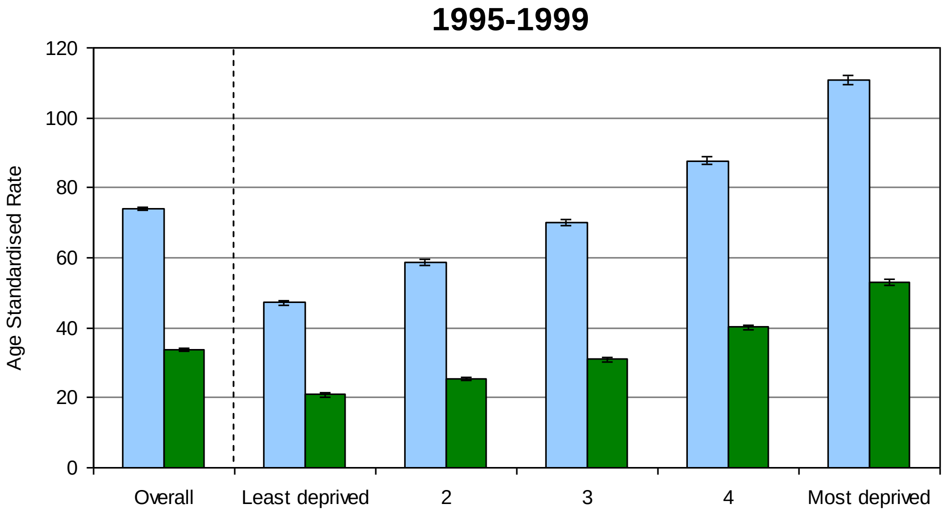
Females

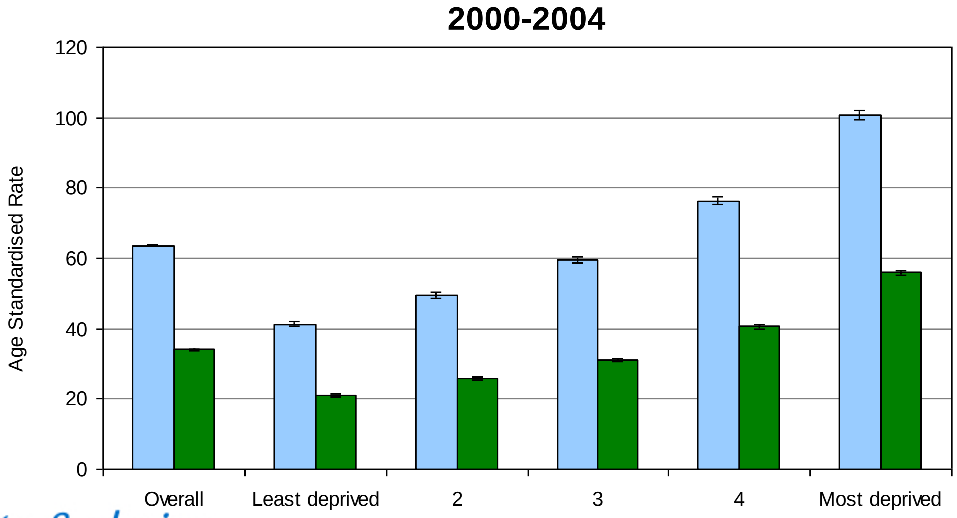
Cohort	Est. Deprivation Gap (Difference in ASR)	95% Confidence Interval	Modelled % Change	P-value for Trend
1995-1999	33.8	20.7 - 46.9	196%	0.004
2000-2004	36.8	20.3 - 53.3	222%	0.008

Persons

Cohort	Est. Deprivation Gap (Difference in ASR)	95% Confidence Interval	Modelled % Change	P-value for Trend
1995-1999	47.4	31.1 - 63.7	171%	0.003
2000-2004	47.7	27.2 - 68.3	198%	0.005

C33-C34: Lung cancer 2000 - 2004 by deprivation



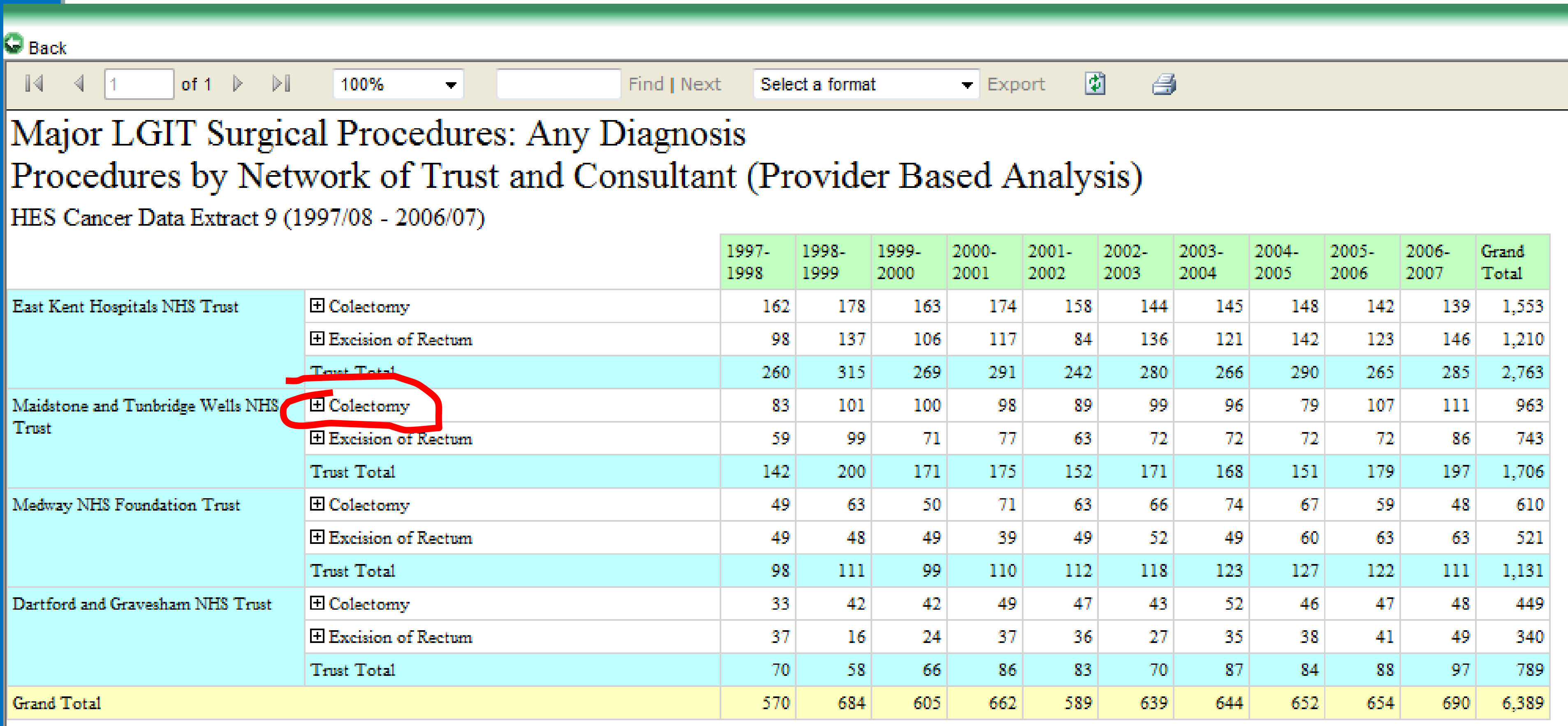


Expert analyses

NCIN
national cancer
intelligence network

- Cancer eAtlas: - launched July 2008 www.ncin.org.uk/eatlas
  - Large and varied interest
  - International recognition
- Reports on:
  - UK incidence & mortality
  - One year survival
  - Deprivation
  - Prevalence
  - Ethnicity
  - Surgical treatment rates ('mid' 2010)
- Microsites

Detailed “Microsites”



Major LGIT Surgical Procedures: Any Diagnosis

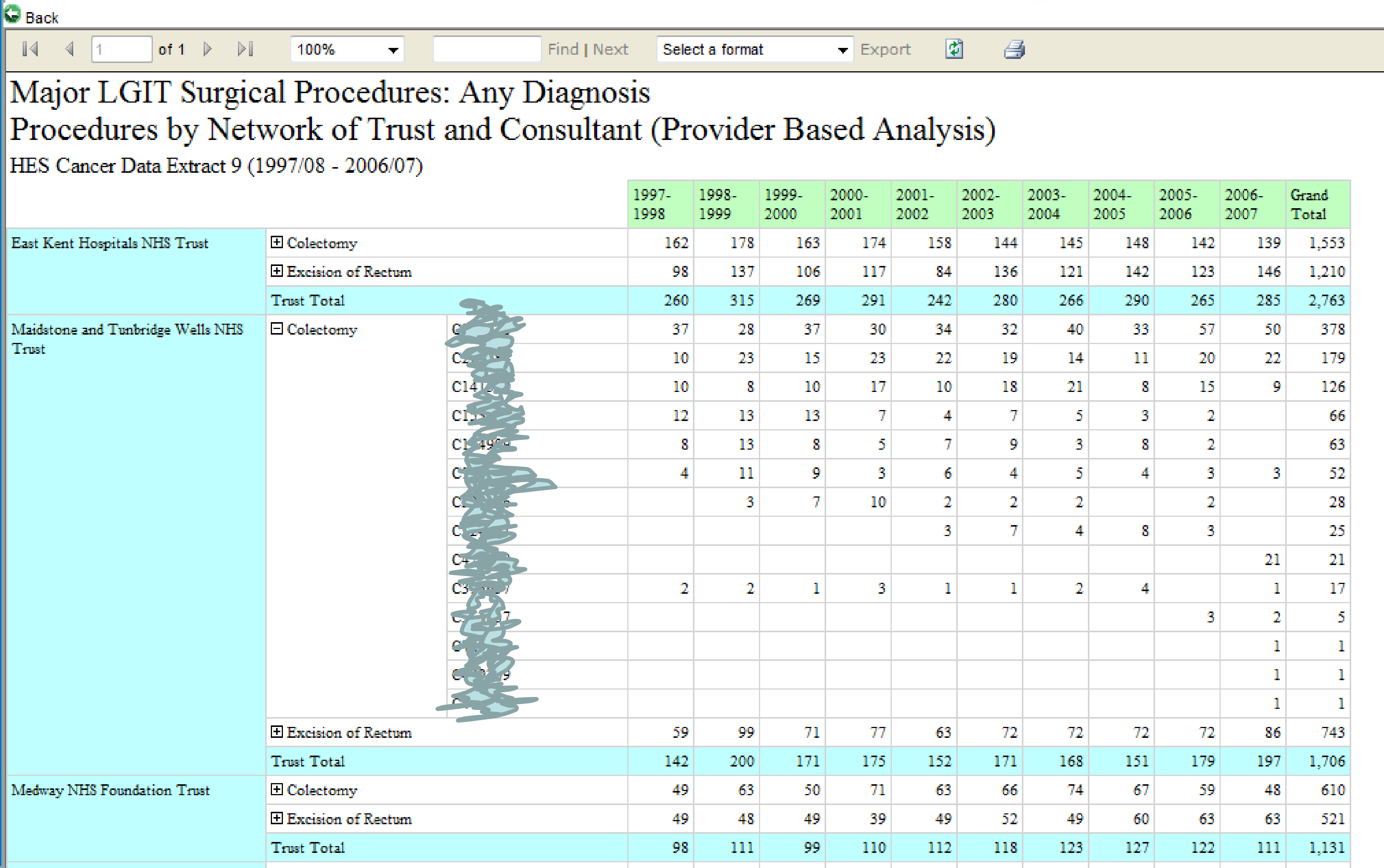
Procedures by Network of Trust and Consultant (Provider Based Analysis)

HES Cancer Data Extract 9 (1997/08 - 2006/07)

		1997-1998	1998-1999	1999-2000	2000-2001	2001-2002	2002-2003	2003-2004	2004-2005	2005-2006	2006-2007	Grand Total
East Kent Hospitals NHS Trust	⊞ Colectomy	162	178	163	174	158	144	145	148	142	139	1,553
	⊞ Excision of Rectum	98	137	106	117	84	136	121	142	123	146	1,210
	Trust Total	260	315	269	291	242	280	266	290	265	285	2,763
Maidstone and Tunbridge Wells NHS Trust	⊞ Colectomy	83	101	100	98	89	99	96	79	107	111	963
	⊞ Excision of Rectum	59	99	71	77	63	72	72	72	72	86	743
	Trust Total	142	200	171	175	152	171	168	151	179	197	1,706
Medway NHS Foundation Trust	⊞ Colectomy	49	63	50	71	63	66	74	67	59	48	610
	⊞ Excision of Rectum	49	48	49	39	49	52	49	60	63	63	521
	Trust Total	98	111	99	110	112	118	123	127	122	111	1,131
Dartford and Gravesham NHS Trust	⊞ Colectomy	33	42	42	49	47	43	52	46	47	48	449
	⊞ Excision of Rectum	37	16	24	37	36	27	35	38	41	49	340
	Trust Total	70	58	66	86	83	70	87	84	88	97	789
Grand Total		570	684	605	662	589	639	644	652	654	690	6,389

..with detailed “drill through”

NCIN
national cancer
intelligence network



Major LGIT Surgical Procedures: Any Diagnosis
Procedures by Network of Trust and Consultant (Provider Based Analysis)

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	Trust Total		260	315	269	291	242	280	266	290	265	285	2,763
Maidstone and Tunbridge Wells NHS Trust	⊟ Colectomy	[redacted]	37	28	37	30	34	32	40	33	57	50	378
		[redacted]	10	23	15	23	22	19	14	11	20	22	179
		[redacted]	10	8	10	17	10	18	21	8	15	9	126
		[redacted]	12	13	13	7	4	7	5	3	2		66
		[redacted]	8	13	8	5	7	9	3	8	2		63
		[redacted]	4	11	9	3	6	4	5	4	3	3	52
		[redacted]		3	7	10	2	2	2		2		28
		[redacted]					3	7	4	8	3		25
		[redacted]										21	21
		[redacted]	2	2	1	3	1	1	2	4		1	17
		[redacted]									3	2	5
		[redacted]										1	1
		[redacted]										1	1
		[redacted]										1	1
	⊞ Excision of Rectum		59	99	71	77	63	72	72	72	72	86	743
	Trust Total		142	200	171	175	152	171	168	151	179	197	1,706
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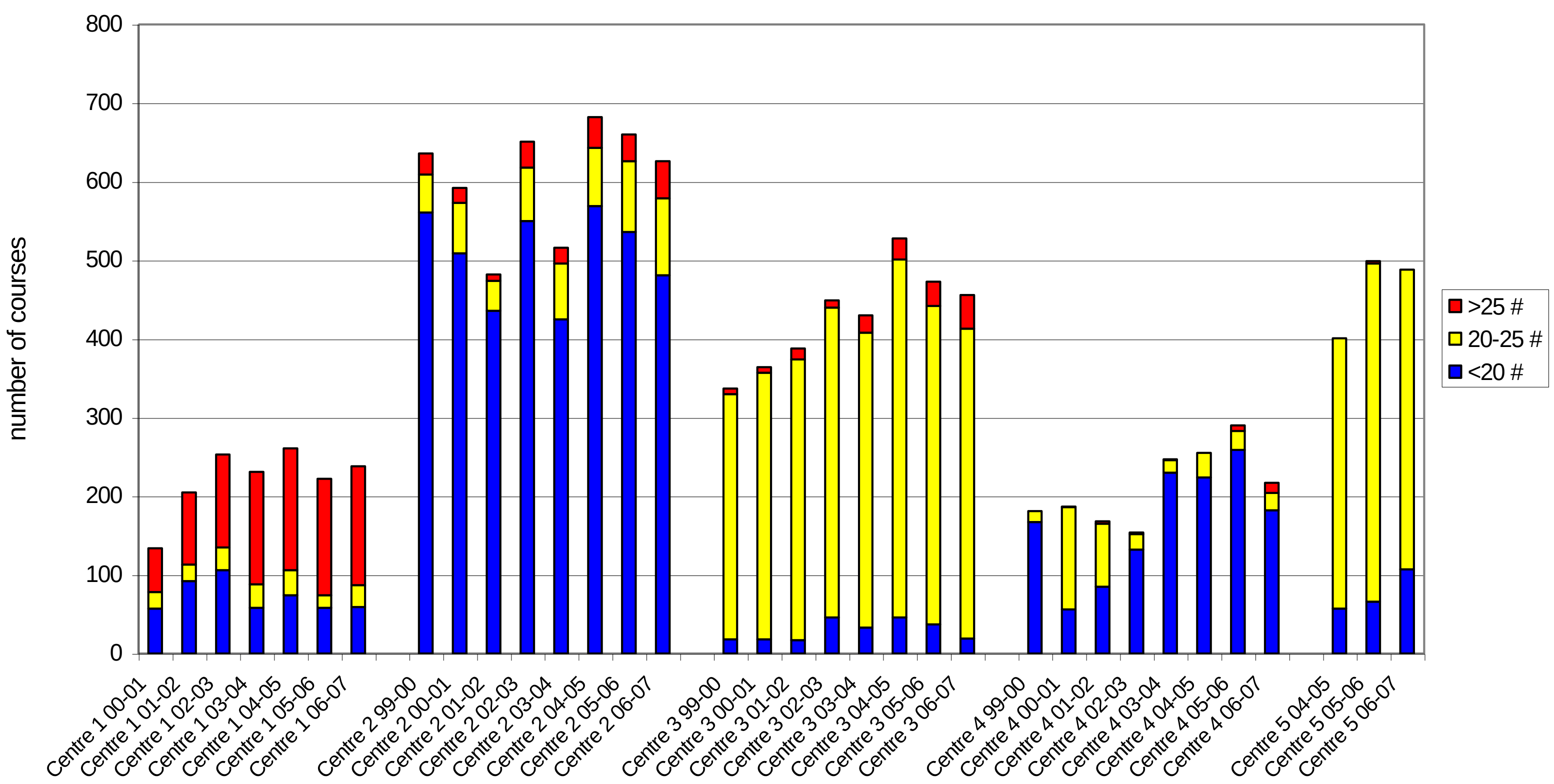
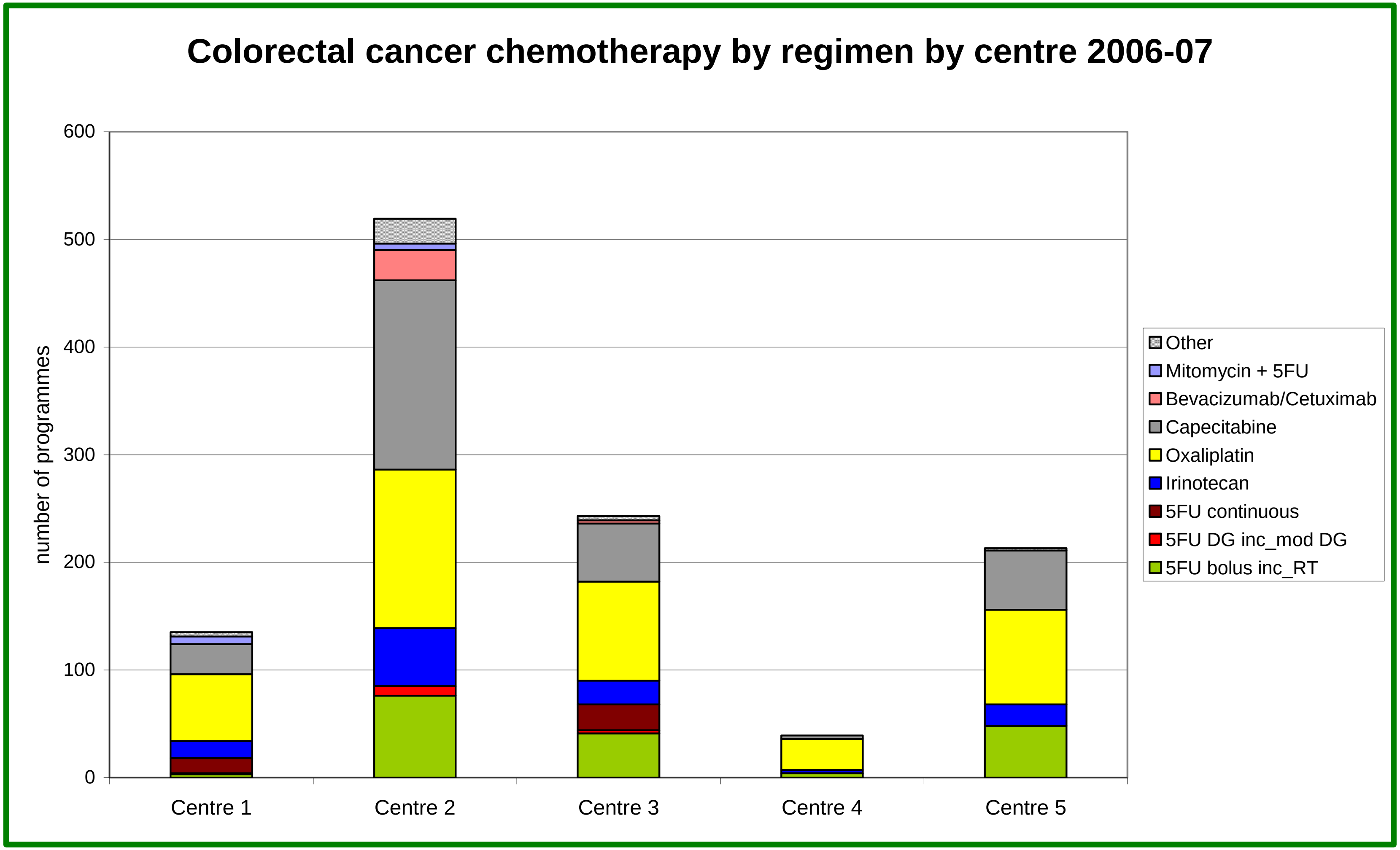
Links with treatment data



Trends in breast cancer radical radiotherapy
(courses divided into fraction groups)

Source: Monica Roche: Oxford Cancer Intelligence Unit

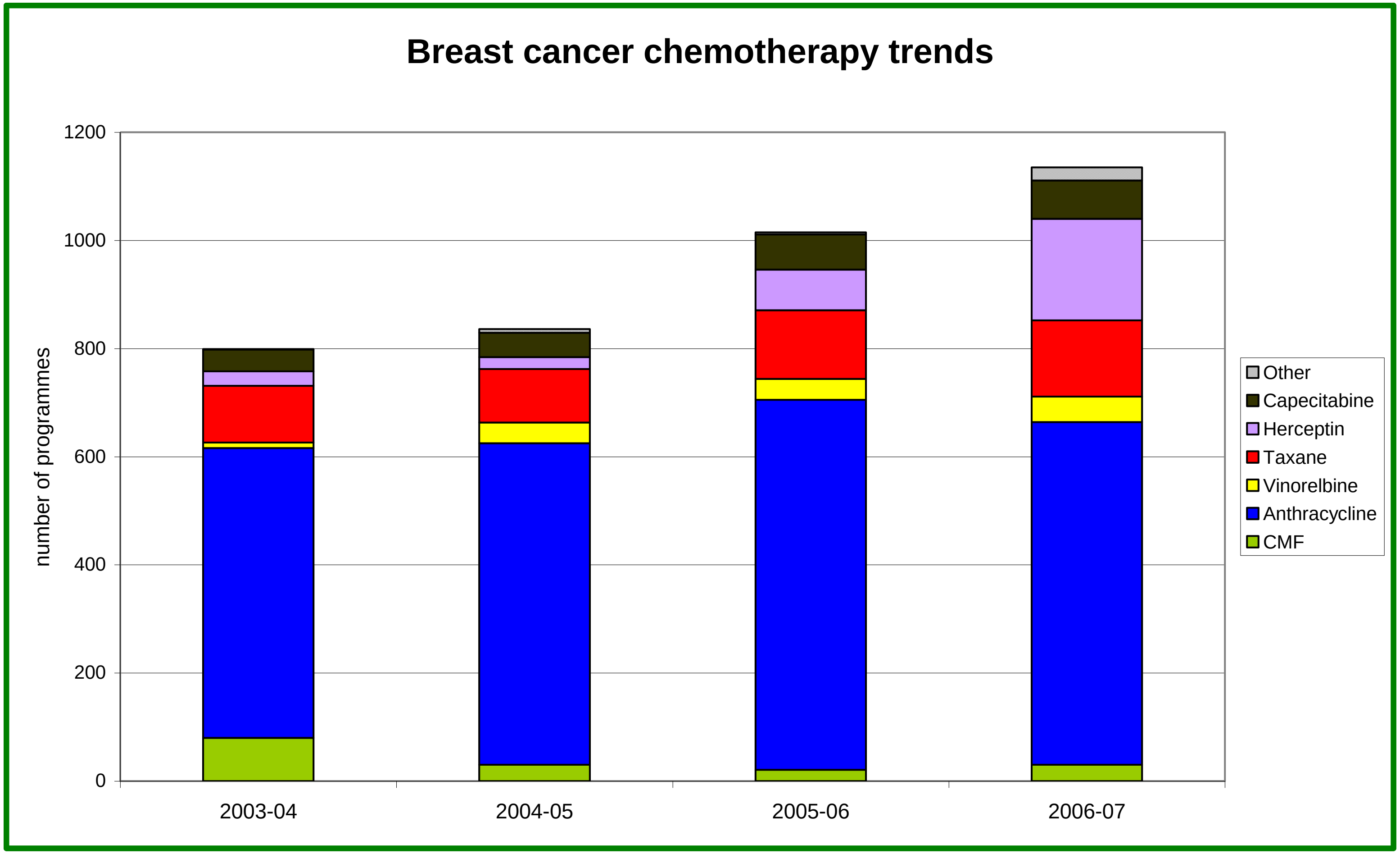
Links with treatment data



Source: Monica Roche: Oxford Cancer Intelligence Unit

Links with treatment data

NCIN
national cancer
intelligence network



Source: Monica Roche: Oxford Cancer Intelligence Unit

NCRI
National
Cancer
Research
Institute

Scientific Advisory Group

- Agree analytical methodologies – including the identification of outliers
- To review the ‘scientific’ content of NCIN reports
- To advise on the commissioning of methodological research
- To advise on Peer Review of analytical and research proposals put to the NCIN
- To liaise with the UKACR and other analytical bodies to, common approaches to the analysis and reporting of results

Drivers for change

- Cancer Peer Review (‘*Clinical Lines of Enquiry*’)
- CQC ‘Annual Health Check’
- Peer pressure
- Voluntary sector pressure
- Cancer Reform Strategy
- DH ‘Quality agenda’ (*Quality Accounts*)
- Commissioning
- National Guidelines
- Patient choice

Drivers for change

- Cancer Peer Review
- CQC ‘Annual Health Check’
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- Voluntary sector pressure
- Cancer Reform Strategy
- DH ‘Quality agenda’
- Commissioning
- National Guidelines
- Patient choice

+ Data

Clinical Outcomes Group

Clinical Outcomes Group: Main purposes

- To provide a strategic link between the NCIN & the National Cancer Action Team
- To oversee & support the development of Peer Review
- To link between those producing data and those responsible for improving the quality of care
- To identify what data is required to support the strategic development of cancer services
- To support’ intelligent commissioning’
- To promote the use of outcome data in service improvement
- To support the implementation of NICE guidance
- To support the development of care pathways

Clinical Outcomes Group: Members

- NCIN
- National Cancer Action Team
- Peer Review Team
- DH Cancer Policy Team
- DH Quality Team
- SHA rep
- Specialist commissioner
- Network Director
- NHS Improvement
- NHS Information Centre
- NICE
- CQC

NCIN

national **cancer**
intelligence network

Using information to improve quality & choice

www.ncin.org.uk

NCRI
National
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Research
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