

Connecting Cancer Data to Clinical Outcomes Intelligence

Prof David Forman

Lead on Information and Analysis

NCIN

Core Objective #3:

Producing expert analyses, based on robust methodologies, to monitor patterns of cancer care

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

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Using information to improve quality & choice

NCIN
national cancer
intelligence network

[illegible]

Mortality	Males				Females				Persons			
	Number of deaths	Crude rate	95% confidence interval	Age-adjusted rate	Number of deaths	Crude rate	95% confidence interval	Age-adjusted rate	Number of deaths	Crude rate	95% confidence interval	Age-adjusted rate
Cardiovascular diseases and chronic CHD	7	4.0	2.7 - 5.2	3.1	4	2.9	2.0 - 3.8	2.4	11	5.4	4.3 - 6.5	4.8
Stroke	2	1.0	0.5 - 1.5	0.8	2	1.5	0.8 - 2.2	1.1	4	2.0	1.2 - 2.8	1.6
Nonfatal myocardial infarction	2	1.0	0.5 - 1.5	0.8	2	1.5	0.8 - 2.2	1.1	4	2.0	1.2 - 2.8	1.6
Nonfatal stroke	2	1.0	0.5 - 1.5	0.8	2	1.5	0.8 - 2.2	1.1	4	2.0	1.2 - 2.8	1.6
Nonfatal heart failure	2	1.0	0.5 - 1.5	0.8	2	1.5	0.8 - 2.2	1.1	4	2.0	1.2 - 2.8	1.6
Nonfatal heart failure with pulmonary congestion	2	1.0	0.5 - 1.5	0.8	2	1.5	0.8 - 2.2	1.1	4	2.0	1.2 - 2.8	1.6
Nonfatal heart failure without pulmonary congestion	2	1.0	0.5 - 1.5	0.8	2	1.5	0.8 - 2.2	1.1	4	2.0	1.2 - 2.8	1.6
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Nonfatal heart failure with pulmonary congestion												

Version 1 (Draft) 06/06/2008
Data Source: UK Association of Cancer Registries - CIS accessed 2008 - (data extraction July 2007)
Death registrations from ONS. Deaths up to and including 31/12/2005

NCIN
national cancer
intelligence network

Year	Males						Females						Persons					
	Number	In Cumulative	Crude Rate	Relative	95% Confidence Interval		Number	In Cumulative	Crude Rate	Relative	95% Confidence Interval		Number	In Cumulative	Crude Rate	Relative	95% Confidence Interval	
1985-1990	414,207	2,157,677	45.5	47.5	43.5		429,315	2,311,131	59.3	61.8	56.8		843,522	4,468,808	53.3	54.7	52.0	
1986-1990	418,925	2,207,757	47.3	49.8	45.7	50.1	435,131	2,372,854	60.8	61.8	62.1		854,056	4,580,611	55.6	56.1	55.9	56.2
1987-1990	423,642	2,258,899	49.1	51.6	47.0	53.2	440,948	2,423,572	62.6	63.6	63.9		864,590	4,682,471	57.9	58.4	58.1	58.4
1988-1990	428,357	2,309,256	50.9	53.4	47.5	56.3	446,765	2,474,289	64.4	65.4	65.7		875,122	4,781,745	60.2	60.7	60.4	60.7
1989-1990	433,072	2,359,613	52.7	55.2	49.3	58.1	452,582	2,525,006	66.2	67.2	67.5		885,654	4,881,001	62.5	63.0	62.7	63.0
1990-1995	438,788	2,410,401	54.7	57.1	51.3	61.5	458,398	2,575,723	68.1	69.1	69.4		897,186	4,982,124	65.4	65.9	65.6	65.9
1991-1995	443,503	2,461,188	56.7	59.1	53.3	63.5	464,213	2,626,440	70.0	71.0	71.3		907,716	5,083,624	67.7	68.2	67.9	68.2
1992-1995	448,218	2,511,976	58.7	61.1	55.3	66.5	470,028	2,677,157	71.9	72.9	73.2		918,246	5,184,131	69.8	70.3	70.0	70.3
1993-1995	452,933	2,562,763	60.7	63.1	57.3	68.5	475,843	2,727,874	73.8	74.8	75.1		928,776	5,284,638	71.8	72.3	72.0	72.3
1994-1995	457,648	2,613,551	62.7	65.1	59.3	70.5	481,658	2,778,591	75.7	76.7	77.0		939,306	5,385,145	73.8	74.3	74.0	74.3
1995-1997	462,363	2,664,339	64.7	67.1	61.3	72.5	487,473	2,829,308	77.6	78.6	78.9		949,836	5,485,653	75.7	76.2	75.9	76.2
1996-1998	467,078	2,715,127	66.7	69.1	63.3	74.5	493,288	2,879,825	79.5	80.5	80.8		960,366	5,586,160	77.6	78.1	77.8	78.1
1997-1999	471,793	2,765,915	68.7	71.1	65.3	76.7	499,103	2,930,342	81.4	82.4	82.7		970,896	5,686,667	79.6	80.1	79.8	80.1
1998-2000	476,508	2,816,703	70.7	73.1	67.3	78.9	504,918	2,980,859	83.3	84.3	84.6		981,426	5,787,172	81.5	82.0	81.7	82.0
1999-2001	481,223	2,867,491	72.7	75.1	69.3	80.9	510,733	3,031,376	85.2	86.2	86.5		991,956	5,887,679	83.5	84.0	83.7	84.0
2000-2001	485,938	2,918,279	74.7	77.1	71.3	82.9	516,548	3,081,893	87.1	88.1	88.4		1,002,486	5,988,182	85.5	86.0	85.7	86.0
2001-2003	490,653	2,969,067	76.7	79.1	73.3	84.9	522,363	3,132,410	89.0	90.0	90.3		1,013,016	6,088,692	87.5	88.0	87.7	88.0
2002-2003	495,368	3,019,855	78.7	81.1	75.3	86.9	528,178	3,182,927	90.9	91.9	92.2		1,023,546	6,189,199	89.4	90.0	89.7	90.0
2003-2004	500,083	3,070,643	80.7	83.1	77.3	88.9	534,000	3,233,444	92.8	93.8	94.1		1,034,083	6,289,703	91.4	92.0	91.7	

Males

Year	% relative survival
1985-1989	49
1990-1994	50
1995-1999	51
2000-2004	52
2005-2009	53
2010-2014	54
2015-2019	55
2020-2024	56

Females

Year	% relative survival
1985-1989	60
1990-1994	61
1995-1999	62
2000-2004	63
2005-2009	64
2010-2014	65
2015-2019	66
2020-2024	67

Persons

Year	% relative survival
1985-1989	55
1990-1994	56
1995-1999	57
2000-2004	58
2005-2009	59
2010-2014	60
2015-2019	61
2020-2024	62

--- Dotted lines show 95% confidence limits

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Year one outputs-examples

- A national Cancer E-Atlas providing the most recent incidence, mortality and survival figures by locality (in collaboration with UKACR and APHO)
- An electronic toolkit, bringing together information on cancer to enable the benchmarking of services and to inform commissioning (in collaboration with the Cancer Action Team)
- A national analysis of cancer incidence and mortality by deprivation
- An estimation of the number of cancer survivors (in collaboration with Macmillan Cancer Support and Thames CR)
- Reports on cancer incidence in relation to ethnicity and among teenagers and young adults (in collaboration with Cancer Research UK and NWCIS)
- An evaluation of the potential for following up patients who have been in clinical trials over long periods (in collaboration with the NCRN)

Publication policy

- Analyses of topics not previously available (e.g. ethnicity, prevalence, trial demographics)
- Avoid duplication of existing outputs (e.g. CRUK Statistics)
- User friendly and readily accessible
- Professional and public dissemination
- Collaborative basis
- Encourage employment of state of art methodologies for analysis
- Ambition for full UK coverage

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the guardian

Hospital surgery death rates to be made public

- UK first in world to publish data
- Major variations will be exposed

John Carvel
Social affairs editor

The government is preparing to publish for the first time the death rates of patients undergoing major surgery at NHS hospitals in England, the Guardian has learned.

The move will expose alarming variations in the mortality rates of NHS trusts carrying out commonplace procedures, including hip and knee replacements and surgery of the oesophagus and abdominal aorta, the main blood vessel.

It will be the first time anywhere in the world that a government has systematically exposed the work of rival hospital teams, giving patients an opportunity to choose to be treated where their lives are least at risk.

The data, which is to be put up on the NHS Choices website during the summer, is expected to reveal a disproportionately high death rate in hospitals carrying out fewer operations, where the surgeons have less opportunity to hone their skills.

Ministers think publication of the figures will drive up standards by forcing trusts to improve performance or withdraw from medical specialties at which they do not excel.

At this stage the published data will give results for hospital units, not individual surgeons. But Ben Bradshaw, the health minister, has instructed that the NHS Choices website should eventually let patients compare the performance of individual surgeons and GPs, heralding a big switch in the balance of medical power in favour of the patient.

Until recently surgeons resisted the disclosure of mortality rates, arguing that it might discourage them from taking on riskier cases and lead to the loss of lives among patients who could have benefited from treatment.

The surgeons also disputed the accuracy of "hospital episode statistics" submitted by trusts to the Department of Health.

But ministers were impressed by a pioneering experiment by the Society of Cardiothoracic Surgeons, which published the mortality rates of consultants carrying out heart bypass operations.

Since the data was made available two

years ago, the surgeons have taken on more risky cases without any increase in the death rate.

They have acknowledged that they were persuaded to reveal the risk-adjusted mortality rates of individual surgeons after the Guardian lodged 36 applications under the Freedom of Information Act in 2005.

Sir Bruce Keogh, a heart surgeon and former president of the society, was recently appointed medical director of the NHS with responsibility for introducing openness to other branches of medicine.

At a private seminar at the Royal College of Surgeons on Tuesday he made it clear that ministers were no longer prepared to put up with excuses for continued medical secrecy. "There is no going back," he warned representatives of the medical colleges. "The department is not seeking your permission. It is merely seeking your help."

Keogh told the Guardian that the first batch of mortality data would be published "within weeks or months" – at the latest by September.

Disclosure of the mortality data of hospitals will be followed by the publication of a wider range of indicators showing the outcome of treatment across many branches of medicine.

Keogh has asked the medical directors of every hospital and mental health trust in England to send in examples of the performance statistics they use internally to assess the quality of their clinical teams. The department will select about 50 for debate within the medical community.

Once any statistical snags have been ironed out, they will be published on the NHS Choices website, probably during the spring of next year.

Keogh said the desire for openness was being driven by three imperatives for the next stage of NHS reform: health commissioners need better data on the quality of hospitals' performance; doctors need to demonstrate the quality of their work; and patients need information about quality to exercise choice about where to go for treatment.

"We hope to identify a series of

Continued on page 2 »



Ministers believe the publication of the death rate figures of hospitals will drive up standards in NHS trusts in England Photograph: Science Photo Library

Labour cash crisis could bankrupt party leaders

David Hencke
Westminster correspondent

Senior officials in the Labour party, including Gordon Brown, could become personally liable for millions of pounds in debt unless new donors can be found within weeks, the Guardian has learned.

The party has five weeks to find £7.45m to pay off loans to banks and wealthy donors recruited by Lord Levy, Tony Blair's former chief fundraiser, or become insolvent. A further £5.2m will have to be repaid by Christmas – making £13.65m in all. The sum amounts to two-thirds of the party's annual income from donations.

The figures are a conservative estimate as they do not include interest that will also have to be paid. A Labour source said that although the total debt was listed as £17.8m on the Electoral Commission website, the true level, with interest, was nearer to £24m.

The possibility that party officials and members of its national executive committee could become liable is being taken seriously by union leaders, and has been underlined by the decision of equity fund chairman David Pitt-Watson not to accept the post as Labour's general secretary.

Though he was Brown's candidate for the post, he declined the offer after receiving independent legal advice that he would be personally liable for repaying the loans and could be bankrupted if Labour's finances collapsed.

The advice from City solicitors Slaughter and May said unequivocally that leading party officials and members of the NEC would be "jointly and severally" responsible for the party's debt.

The reason is that the Labour party constitution is framed like a local club or society, and has no provision for limiting the liability of its officials or managers.

A Labour source said: "The party's constitution is like a five-a-side football club, or the local cricket club. The big difference is that the most club officials and managers could expect to have to fork out is an unpaid bill for hiring the pitch. In Labour's case, it's tens of millions of pounds."

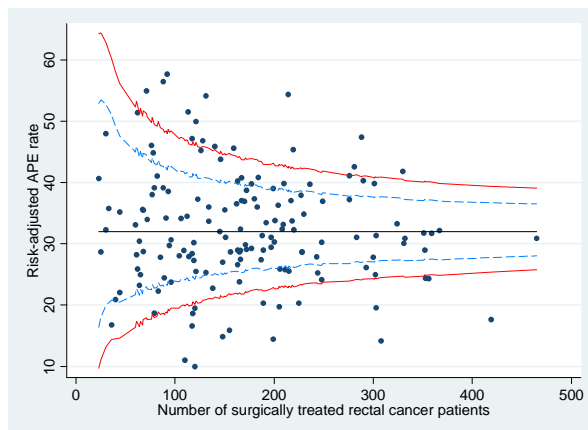
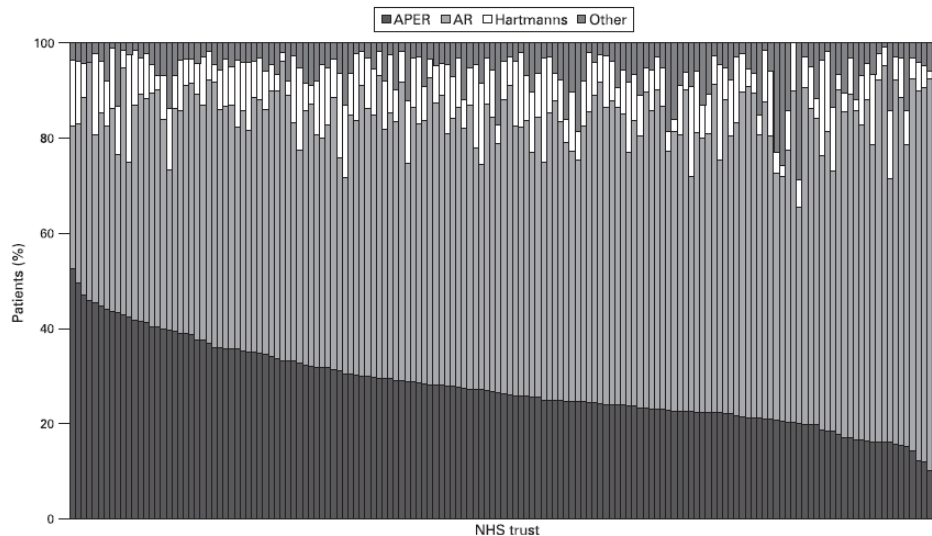
The advice was the sole reason why Pitt-Watson, a committed Labour supporter and former Westminster City councillor, turned down the job this month.

But the revelations inside the party have been enormous. Earlier this month the GMB union's executive decided to

Continued on page 2 »

Unacceptable variation in abdominoperineal excision rates for rectal cancer: time to intervene?

E Morris,^{1,2} P Quirke,² J D Thomas,^{1,2} L Fairley,⁴ B Cottier,³ D Forman^{1,4}



Colorectal cancer intelligence work programme

- Post-operative mortality
- Variation in consultant workload
- Survival in relation to ethnicity
- Impact of PELICAN surgical training
- Hepatic resection for metastases
- Follow-up of RCTs
- Impact of screening programme
- Outpatient attendance patterns
- Linkage with genetic datasets
- Linkage with GPRD
- International care comparisons – Netherlands and France



Supported by NYCRIS & Cancer Research UK
– Bobby Moore Fund Career Development Award

Lead areas for cancer registries:

- Lung – Thames
- Breast – WMCIU
- Colorectal – NYCRIS
- Urology – SWCIS
- CNS – ECRIC
- Gynae – Trent
- Head & Neck – Oxford
- TYAC – NWCIS
- Skin – SWCIS
- Upper GI – Thames
- Sarcoma – WMCIU
- Haematol – NYCRIS
- Children – CCRG

**To be supported by
National Clinical
Reference Groups**

Intelligence in cancer care

Site-specific analyses, at population level, to:

- monitor service delivery and clinical interventions which impact on patient outcomes and/or quality of life
- monitor uptake and demographics of new interventions
- supplement and extend information from clinical trials
- analyse demographics of relatively rare procedures

Dependency on:

- detailed flow of information on stage of disease, comorbidity, RT and CT
- receipt of information in timely manner (close to real time)

Intelligence in cancer care

- Data will be more extensive and more complete than ever previously available
- But based on routine NHS sources not specifically collected for audit/outcomes research
- There will be inaccuracies and data errors
- Case-mix adjustment will be inadequate
- How do we present results professionally and in public domain?

Intelligence in cancer care

- Work with PIAG, Information Centre, NHS Choices, Cancer Networks to maximise open publication of results
- Identification of Trusts and clinicians should become the 'norm'
- Maintain clinician 'buy-in' – advance warning and no surprises
- Importance of robust methodologies and mix of peer review publication and routine reports

Future perspectives:

- Massive potential of data linkages:
 - Service: clinical, primary care, end of life
 - Research: genetic, trials, informatics
- Scope to transform information landscape
 - New linked datasets as research tools
 - Clinical care and outcomes properly monitored for service improvement and patient benefit