

NCIN

national cancer
intelligence network



Using information to improve quality & choice

HEAD AND NECK TSSG CLINICAL LEADS MEETING 26TH NOVEMBER 2009

NHS

The
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for health and social care

www.ncin.org.uk



NCRI
National
Cancer
Research
Institute

WELCOME AND OUTLINE FOR THE DAY

Richard Wight
NCIN Head and Neck TSSG Chair
DAHNO Project Chair



HOUSEKEEPING



WHAT DOES CANCER INTELLIGENCE MEAN TO YOU ?



The
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Questions?

- Are we agreed cancer intelligence has a significant role to play in improving cancer care and outcome?
- What should be routinely collected, collated and audited?
- If so how do we usefully translate these findings into changes at the MDT/clinical level?

AIMS OF DAY 1

- To examine Cancer Intelligence in head and neck cancer
 - The why
 - The what
 - The how and when
 - The application of, to improve care and outcome
 - DAHNO 4th Annual Report
 - Priorities from NCIN Head and Neck SSCRG
 - What further work needs to be done?
 - Comorbidity
 - Data items

AIMS OF DAY 2

- To consider Head + Neck cancer MDT' s and the impact on and their role in :-
 - Going Further on cancer waits
 - MDT Development
 - Peer Review and clinical indicators
 - Using audit information to influence change

Request

- To actively contribute to the days sessions and the future cancer intelligence agenda
- Not to only promote a personal view but a wider MDT perspective
- To feedback to your MDT the key topics /issues arising
- To enjoy the day!!!

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NCIN –who are we?

www.ncin.org.uk

“Quite simply, we want to have the
best cancer information service
in the world by 2012”

Mike Richards
Britain against Cancer
Dec 2007

“The best cancer information service in the world”



- Build on current strengths of UK cancer registry system
- Collection of defined datasets on all cancer patients to be mandated through the national model contract. PCTs will be responsible for ensuring that this information is collected by MDTs and sent to cancer registries
- A new National Cancer Intelligence Network is being established to bring together relevant stakeholders and to act as a repository of cancer data.

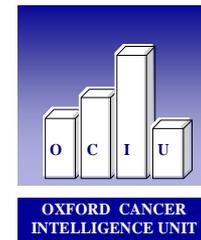
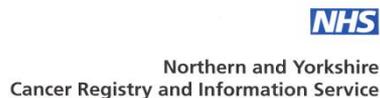
Cancer Reform Strategy 2007

NCRI Partners



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NCIN Collaborators



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The people

- Mick Peake
- Di Riley
- SSCRG's-Chairs and membership
- The important people in the background
- The whole cancer community

NCIN Governance



- Part of the NCRI Initiative
- NCRI Board
- NCIN Steering Group
- NCIN Coordinating Team
- Clinical Reference Groups
- Scientific Advisory Group

NCIN Goal



Why?

- To provide feedback on performance to clinical teams
- To promote stronger commissioning
- To provide informed choice for patients
- To provide a unique opportunity for health services research

i.e. To improve outcomes

NCIN Core Objectives



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

Early outputs....



- Short term survival
- Prevalence
 - By Network
 - By PCT
- International
 - Focused analyses

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

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

Year	Males					Females					Persons				
	Number in Cohort	Cumulative Deaths	Crude Rate	Relative Survival	95% Confidence Interval	Number in Cohort	Cumulative Deaths	Crude Rate	Relative Survival	95% Confidence Interval	Number in Cohort	Cumulative Deaths	Crude Rate	Relative Survival	95% Confidence Interval
1985-1989	474,863	221,027	47.3	53.8	51.6 - 56.0	420,315	172,517	41.3	61.4	61.3 - 61.6	895,178	393,544	43.9	57.6	57.4 - 58.0
1988-1990	478,825	220,757	47.3	58.9	58.7 - 59.1	430,131	172,874	40.8	61.9	61.8 - 62.1	908,956	393,631	43.8	60.1	59.9 - 60.2
1991-1993	428,274	220,455	51.5	62.6	62.5 - 62.7	420,529	172,093	40.7	62.1	62.0 - 62.2	848,753	392,548	46.4	62.4	62.3 - 62.5
1998-1999	430,747	220,003	48.7	61.8	61.8 - 61.8	445,934	175,463	41.1	63.1	63.1 - 63.1	876,681	395,466	45.0	61.9	61.9 - 61.9
1999-1999	438,648	221,846	49.4	62.3	62.3 - 62.4	451,027	174,564	41.5	63.6	63.6 - 63.7	889,675	396,410	45.5	63.1	63.1 - 63.2
1999-1994	440,022	219,719	50.6	61.6	61.6 - 61.6	453,529	173,891	40.9	64.1	64.1 - 64.1	906,551	393,610	43.9	63.9	63.9 - 64.0
1991-1995	448,383	219,314	51.3	64.9	64.7 - 65.1	446,074	173,543	42.4	64.7	64.6 - 64.8	894,457	392,857	47.2	64.9	64.8 - 65.0
1996-1998	450,668	219,407	52.5	65.1	65.0 - 65.2	460,134	174,275	42.9	65.1	65.0 - 65.2	910,802	393,682	46.7	65.0	65.0 - 65.1
1993-1997	450,786	219,026	54.2	67.2	67.1 - 67.4	463,513	170,363	43.3	65.0	65.0 - 65.1	914,299	390,389	48.8	65.0	65.0 - 65.1
1994-1998	450,837	207,406	55.2	68.1	68.0 - 68.3	468,898	169,075	42.1	66.0	66.0 - 66.1	919,735	386,481	49.1	65.0	65.0 - 65.1
1995-1999	458,127	208,001	58.0	68.9	68.7 - 69.0	475,530	169,215	44.6	67.0	66.9 - 67.1	933,657	377,216	54.8	67.0	67.0 - 67.1
1998-1999	460,327	207,406	58.0	68.9	68.8 - 69.0	482,928	167,327	45.7	67.0	67.0 - 67.1	943,255	374,733	54.8	67.0	67.0 - 67.1
1998-2000	470,743	205,660	58.0	69.8	69.8 - 69.9	482,928	167,327	45.7	67.0	67.0 - 67.1	953,671	372,987	54.8	67.0	67.0 - 67.1

New cancer cases/deaths, crude and age-standardised incidence/mortality rates per 100,000 (with 95% confidence intervals), Cancer Networks, England, 2005

C00-C97 excl. C44: All malignant neoplasms (excl. non-melanoma skin cancer) - Teenage and young adults (15-24yrs)

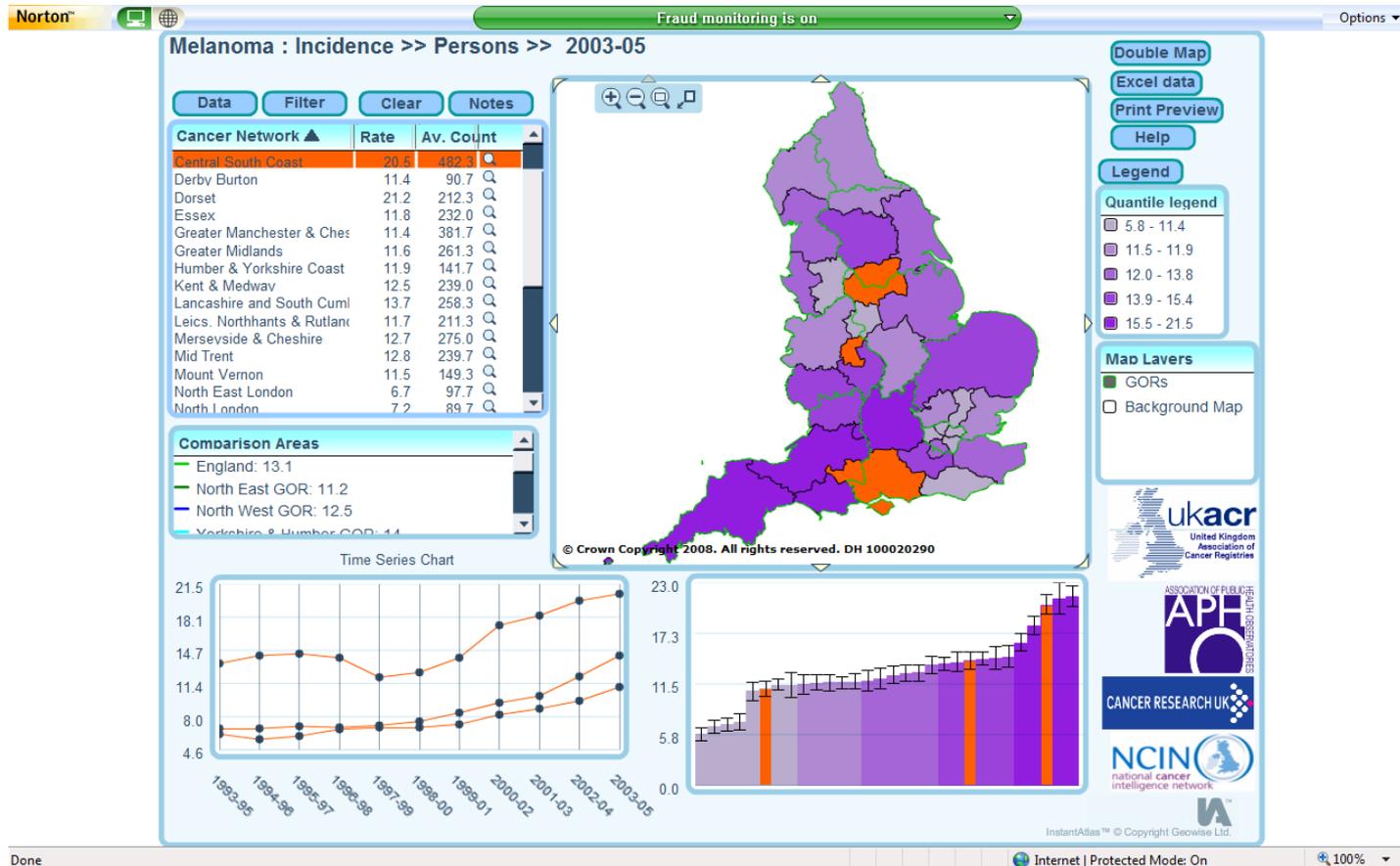
Cancer Network	Males			Females			Persons		
	Number of cases	Crude rate	95% confidence interval	Number of cases	Crude rate	95% confidence interval	Number of cases	Crude rate	95% confidence interval
150 Leukaemia and Soft Cell Carcinoma CN	11	30.9	13.8 - 59.8	20	21.6	21.1 - 22.0	31	26.2	24.8 - 27.7
152 Oesophagus, Mouth and Pharynx Carcinoma CN	1	28.2	0.0 - 100.0	0	0.0	0.0 - 0.0	1	28.2	0.0 - 100.0
153 Colorectal and Endometrial Carcinoma CN	38	27.8	26.8 - 28.7	39	27.8	27.2 - 28.2	77	27.8	27.4 - 28.2
154 Prostate Carcinoma CN	1	27.2	0.0 - 100.0	0	0.0	0.0 - 0.0	1	27.2	0.0 - 100.0
155 Lung and Bronchus Carcinoma CN	30	30.1	27.8 - 32.4	20	26.1	24.6 - 27.6	50	28.1	26.6 - 29.6
156 Breast Carcinoma CN	30	29.8	28.0 - 31.6	21	28.2	26.5 - 29.9	51	29.0	28.1 - 29.9
157 Pancreatic Carcinoma CN	10	24.4	18.8 - 30.0	43	23.7	22.2 - 25.1	53	24.1	23.4 - 24.8
158 Stomach Carcinoma CN	1	24.4	0.0 - 100.0	0	0.0	0.0 - 0.0	1	24.4	0.0 - 100.0
159 Testis Carcinoma CN	10	23.8	18.8 - 28.7	39	24.7	22.7 - 26.7	49	24.3	23.1 - 25.7
160 Kidney Carcinoma CN	1	23.8	0.0 - 100.0	0	0.0	0.0 - 0.0	1	23.8	0.0 - 100.0
161 Liver, Gallbladder and Biliary Carcinoma CN	10	24.4	20.6 - 28.2	11	26.6	24.8 - 28.4	21	25.5	23.8 - 27.2
162 Heart Carcinoma CN	10	24.4	20.6 - 28.2	11	26.6	24.8 - 28.4	21	25.5	23.8 - 27.2
163 Thyroid Carcinoma CN	10	24.4	20.6 - 28.2	11	26.6	24.8 - 28.4	21	25.5	23.8 - 27.2
164 Bladder Carcinoma CN	10	24.4	20.6 - 28.2	11	26.6	24.8 - 28.4	21	25.5	23.8 - 27.2
165 Cervix Carcinoma CN	10	24.4	20.6 - 28.2	11	26.6	24.8 - 28.4	21	25.5	23.8 - 27.2
166 Uterus Carcinoma CN	10	24.4	20.6 - 28.2	11	26.6	24.8 - 28.4	21	25.5	23.8 - 27.2
167 Ovary Carcinoma CN	10	24.4	20.6 - 28.2	11	26.6	24.8 - 28.4	21	25.5	23.8 - 27.2
168 Endometrial Carcinoma CN	10	24.4	20.6 - 28.2	11	26.6	24.8 - 28.4	21	25.5	23.8 - 27.2
169 Skin Carcinoma CN	10	24.4	20.6 - 28.2	11	26.6	24.8 - 28.4	21	25.5	23.8 - 27.2
170 Unknown Carcinoma CN	10	24.4	20.6 - 28.2	11	26.6	24.8 - 28.4	21	25.5	23.8 - 27.2
Total	601	28.0	27.4 - 28.6	710	27.0	26.6 - 27.4	1,311	27.5	27.1 - 27.9

Cancer Network	Males			Females			Persons		
	Number of deaths	Crude rate	95% confidence interval	Number of deaths	Crude rate	95% confidence interval	Number of deaths	Crude rate	95% confidence interval
150 Leukaemia and Soft Cell Carcinoma CN	1	2.9	0.0 - 13.9	0	0.0	0.0 - 0.0	1	2.9	0.0 - 13.9
152 Oesophagus, Mouth and Pharynx Carcinoma CN	1	2.9	0.0 - 13.9	0	0.0	0.0 - 0.0	1	2.9	0.0 - 13.9
153 Colorectal and Endometrial Carcinoma CN	1	2.9	0.0 - 13.9	0	0.0	0.0 - 0.0	1	2.9	0.0 - 13.9
154 Prostate Carcinoma CN	1	2.9	0.0 - 13.9	0	0.0	0.0 - 0.0	1	2.9	0.0 - 13.9
155 Lung and Bronchus Carcinoma CN	3	4.6	0.0 - 10.7	1	1.8	0.0 - 4.4	4	3.1	0.1 - 8.7
156 Breast Carcinoma CN	1	4.6	0.0 - 10.7	0	0.0	0.0 - 0.0	1	4.6	0.0 - 10.7
157 Pancreatic Carcinoma CN	3	3.7	0.6 - 7.6	4	3.7	2.0 - 5.4	7	3.7	1.4 - 6.0
158 Stomach Carcinoma CN	1	4.6	0.0 - 10.7	0	0.0	0.0 - 0.0	1	4.6	0.0 - 10.7
159 Testis Carcinoma CN	4	3.8	0.1 - 7.2	3	2.8	0.8 - 5.1	7	3.3	0.8 - 5.6
160 Kidney Carcinoma CN	4	3.8	0.1 - 7.2	3	2.8	0.8 - 5.1	7	3.3	0.8 - 5.6
161 Liver, Gallbladder and Biliary Carcinoma CN	5	4.8	0.8 - 8.6	9	3.8	1.8 - 5.8	14	5.2	3.1 - 7.2
162 Heart Carcinoma CN	5	4.8	0.8 - 8.6	9	3.8	1.8 - 5.8	14	5.2	3.1 - 7.2
163 Thyroid Carcinoma CN	5	4.8	0.8 - 8.6	9	3.8	1.8 - 5.8	14	5.2	3.1 - 7.2
164 Bladder Carcinoma CN	5	4.8	0.8 - 8.6	9	3.8	1.8 - 5.8	14	5.2	3.1 - 7.2
165 Cervix Carcinoma CN	5	4.8	0.8 - 8.6	9	3.8	1.8 - 5.8	14	5.2	3.1 - 7.2
166 Uterus Carcinoma CN	5	4.8	0.8 - 8.6	9	3.8	1.8 - 5.8	14	5.2	3.1 - 7.2
167 Ovary Carcinoma CN	5	4.8	0.8 - 8.6	9	3.8	1.8 - 5.8	14	5.2	3.1 - 7.2
168 Endometrial Carcinoma CN	5	4.8	0.8 - 8.6	9	3.8	1.8 - 5.8	14	5.2	3.1 - 7.2
169 Skin Carcinoma CN	5	4.8	0.8 - 8.6	9	3.8	1.8 - 5.8	14	5.2	3.1 - 7.2
170 Unknown Carcinoma CN	5	4.8	0.8 - 8.6	9	3.8	1.8 - 5.8	14	5.2	3.1 - 7.2
Total	40	4.8	4.3 - 5.3	40	3.8	3.1 - 4.5	80	4.3	3.7 - 4.9

Persons



National Cancer e-Atlas



...drive improvements...



...support audit/research...

- Dealing with gaps in currently available data
- Developing partnership working with the existing National Cancer audits amongst others
- Making best use of opportunities

The role of NCIN

- Coordinate implementation of National Contract
- Support MDTs to coordinate data capture
- Oversee MDT training programmes
- Facilitate discussions re: data gaps
 - Staging & co-morbidity
- Support submissions to ISB and ROCR
- Work towards harmonisation of processes
- Strive for data quality and timeliness

HEAD AND NECK SSCRG – membership (1)

- The relevant major colleges and professional groups + **DAHNO CLINICAL REFERENCE GROUP CONJOINED**
- The lead cancer registry **OXFORD**
- Any national audit group (e.g. NCASP) relevant to the tumour site **DAHNO**
- The relevant NCRI Clinical Study Group **H+N**
- Patients (minimum 2 – at least one of whom should ideally be a member of the relevant NCRI CSG) **NCRI PATIENT LIASON GRP**

HEAD AND NECK SSCRG – membership (2)



- The major, relevant voluntary sector groups/charities **NALC/LETS FACE IT**
- The Director from the lead Cancer Network for the tumour site **HUMBER AND YOKSHIRE COAST**
- A member from the ‘national cancer strategic team’ (DH, NCAT, Peer Review Team or NHS Improvement)
- The NCIN core management team.

Main issues for SSCRGs

- Identification of current initiatives
- Support for data set development
- Identification of main clinical indicators
- Advising on co-morbidity
- 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

ACTION PLANNING- INFLUENCING CHANGE

- Look at the information presented as member of the MDT –what actions would you take?
- Look at the information through the eyes of an external reviewer-what actions would you advise ?

