

Transforming Data into Action

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Transforming Data into Action

Overview of this talk

- Goals of NCIN
- Rationale for establishing NCIN within NCRI
- Recent progress
- Looking forwards





NCIN Goal (1)

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

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 Goal (2)

Is this achievable?

Yes: We have the fundamental building blocks

Yes: We have the support of all the essential

partners

Yes: We have the mandate to collect the missing

information we need



Rationale for establishing NCIN within NCRI



- NCRI is UK wide
- NCRI already brings together many of the necessary partners
- NCRI commands confidence
- NCRI provides opportunities for research (e.g. alongside NCRN)



Key building blocks

(A perspective from England)



- Cancer registries
 - Comprehensive information on incidence, mortality, survival
- Hospital Episode Statistics
 - Activity data and lengths of stay in the NHS
- National Screening Programmes
 - Coverage, QA measures, outcomes
- Cancer Waiting Times
 - 2ww, 31 day and 62 day targets
- Peer Review
 - Quality measures on >2000 teams and services
- Programme Budgeting
 - Expenditure on cancer by PCT



NCIN national cancer intelligence network

The Partnership (1)

















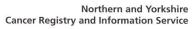


































The Partnership (2)































Council















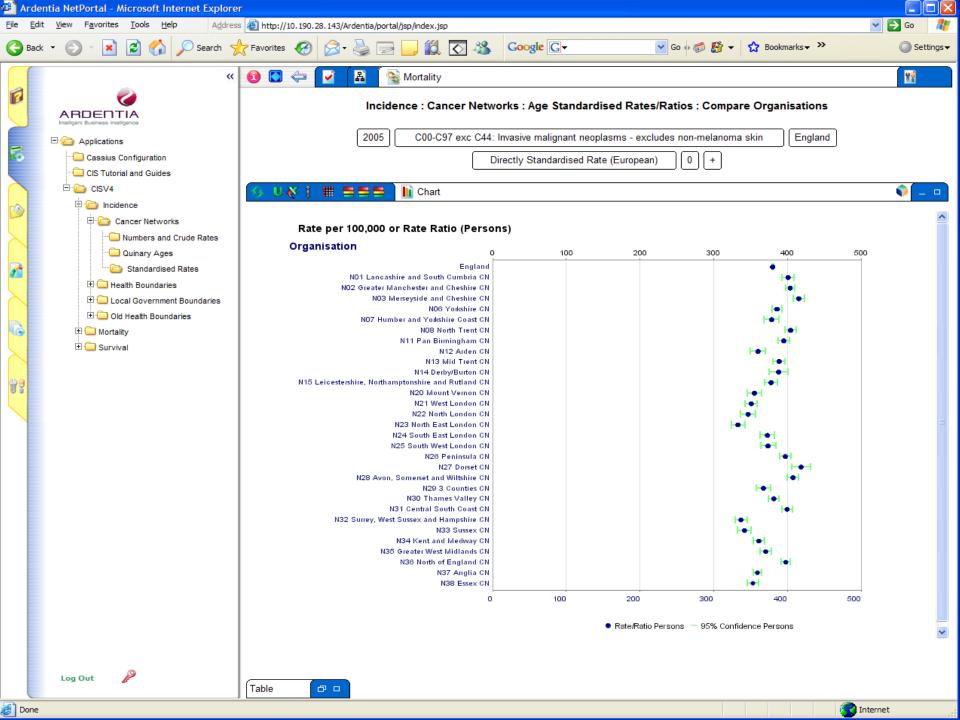


Recent Progress on Cancer Intelligence



- Cancer registries working together
 - National Cancer Information System (CIS)
- Data fusion
 - Bringing together large complementary datasets e.g. cancer registries and HES (1+1>2)
- Cancer Commissioning Toolkit

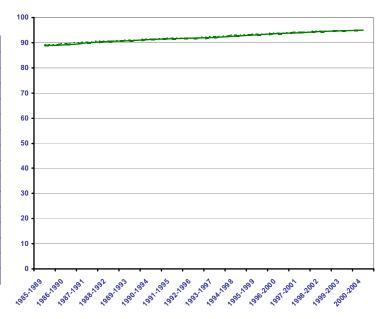




Trends in one year cancer survival, breast cancer, females, England, 1985-2004 (five-year moving average)



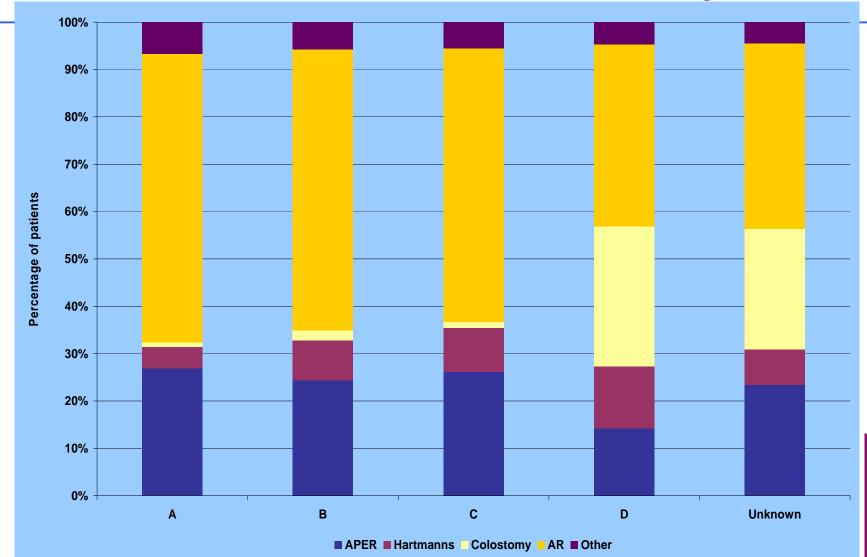
Year	Number in Cohort	Cumulative Deaths	Crude Rate	Relative Survival	95% Confidence Interv	/al
1985-1989	115,172	15,559	86.5	88.9	88.7 - 89.1	
1986-1990	119,114	15,547	86.9	89.3	89.1 - 89.5	5
1987-1991	124,244	15,370	87.6	89.9	89.7 - 90.1	
1988-1992	129,482	15,379	88.1	90.4	90.3 - 90.6	;
1989-1993	133,081	15,422	88.4	90.7	90.6 - 90.9)
1990-1994	135,249	15,064	88.9	91.2	91.0 - 91.4	ļ
1991-1995	137,167	14,890	89.1	91.5	91.3 - 91.7	7
1992-1996	138,737	14,829	89.3	91.7	91.5 - 91.9)
1993-1997	140,591	14,485	89.7	92.1	91.9 - 92.2	<u> </u>
1994-1998	143,894	13,911	90.3	92.7	92.6 - 92.9)
1995-1999	148,009	13,696	90.7	93.1	93.0 - 93.3	}
1996-2000	151,320	13,222	91.3	93.6	93.5 - 93.8	}
1997-2001	153,862	12,835	91.7	94.1	93.9 - 94.2	<u>}</u>
1998-2002	155,571	12,546	91.9	94.4	94.2 - 94.5	5
1999-2003	158,404	12,306	92.2	94.7	94.5 - 94.8	}
2000-2004	160,007	11,947	92.5	95.0	94.8 - 95.1	





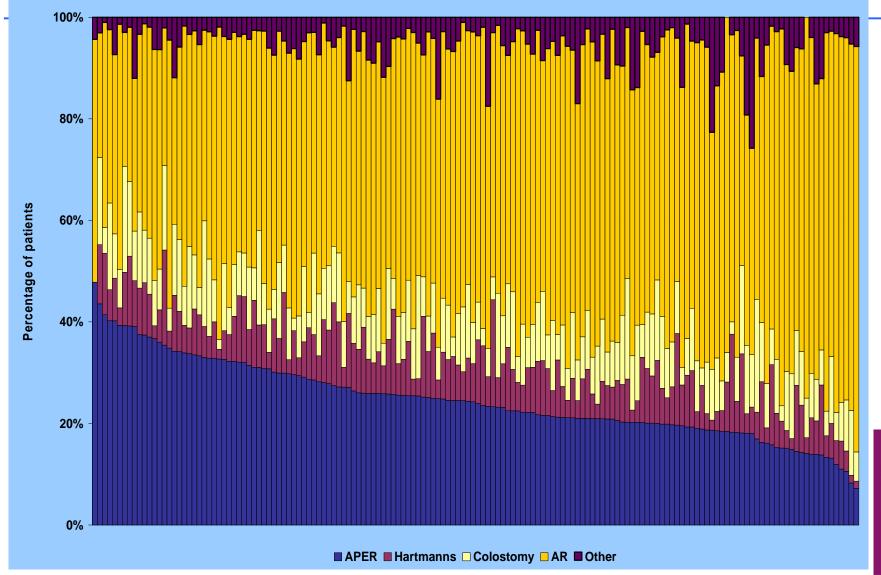
Rectal surgery by Duke's stage NCIN national cancer intelligence network







Rectal surgery by Hospital TrustNCIN national cancer intelligence network





The Cancer Commissioning Toolkit (CCT)



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Welcome to the NHS Cancer Commissioning Toolkit

This site is aimed at supporting World-class Commissioning of cancer services across the NHS by making information on cancer care in England freely available. It includes a range of high-level indicators, as well as a number of links to more detailed information, right across the patient's journey: from prevention and screening through referral and treatment to living with and beyond cancer, as well as end of life care.

All NHS organisations involved in the commissioning of cancer services are encouraged to use this information to benchmark the services they commission against the very best, setting the highest standards of care and improving outcomes for people.

NB: Caution is advised when interpreting high-level metrics in isolation. For example, high relative levels of incidence in cancers may simply reflect the demographic profile of a given entity (e.g. Primary Care Trust); and high levels of cost of cancer services may equally reflect higher cancer incidence; etc. By entering this site you are agreeing to use the information in a responsible manner and are encouraged not to take this information out of context.











The CCT dashboard contains the key cancer metrics

- National target

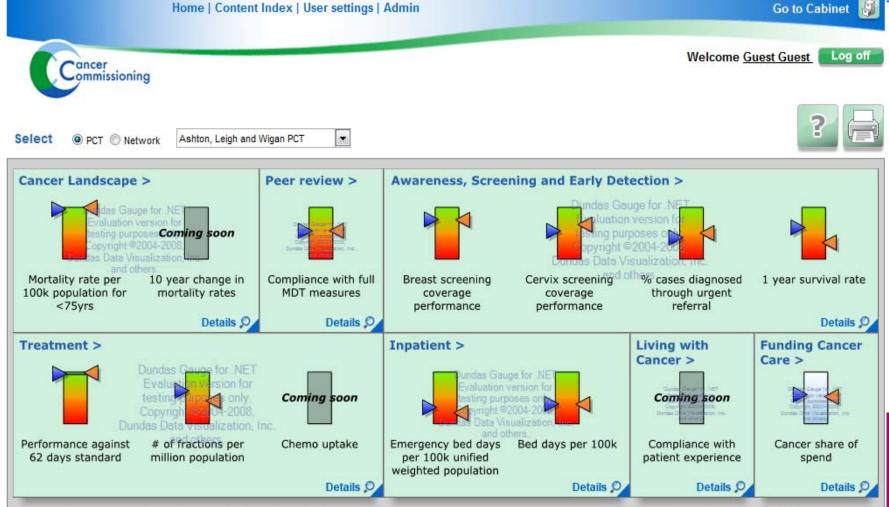
National level

Legend:

Local level



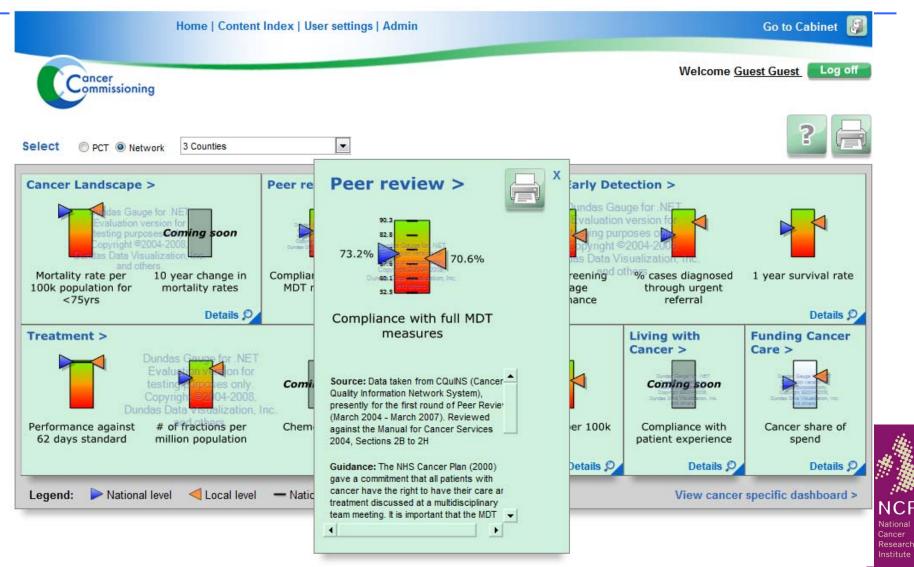
View cancer specific dashboard >





Each metric can be observed in more detail with information on sources and guidance







NCIN: Looking forwards

- Dealing with gaps in currently available data
- Developing partnership working
- Making best use of opportunities



Gaps in currently available data national cancer intelligence network

- Primary Care
- Staging and comorbidity
- Detailed pathology
- Radiotherapy
- Chemotherapy
- Relapse
- Patient reported outcomes
- (Ethnicity)





Looking forwards: Closing the gaps

- Primary Care: GPRD and other systems
- Staging: Mandatory datasets
- Pathology: Recording of RCPath datasets
- Radiotherapy: RES dataset
- Chemotherapy: Chemotherapy dataset
- Relapse: Linkage to Cancer Waiting Times
- Patient Reported Outcomes: ?
- Comorbidity: Linkage to HES



Looking Forwards: Developing the partnership



- Steering Group (Chair: Sir Alex Markham)
- Lead registries for different cancers
- National Clinical Leads
- Developing clear governance arrangements
- Building links with multiple individuals and organisations (National audits, professional societies, researchers etc.)



Looking Forwards: Early products



- Electronic commissioning toolkit
- Analyses of cancers in teenagers and young adults
- Secondary cancers
- Making information available to the public: NHS Choices
- Follow up of patients in clinical trials
- Trends in one year survival rates

(Cancer Reform Strategy: Box 42)



Looking Forwards: Links to CRS initiatives



- National surveys of symptom awareness
- National Audit in Primary Care
- National Cancer Survivorship Initiative
- Cancer Patient Experience Survey Programme
- National Cancer Equality Initiative
- Inpatient Management Programme
- End of Life Care Strategy



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
- Haematology NYCRIS
- Children CCRG

To be supported by National Clinical Reference Groups



Looking Forwards: Cross cutting analyses



- Prevalence: Current and projected
- Ethnicity
- International comparisons
- Health economics
- Outpatient and GP attendances
- Rare cancers



NCIN: Summary



- This launch marks a very important step forward for cancer intelligence
- There is a huge amount to do and it won't always be easy
- But the prize is great: Better information will lead to better outcomes

