NCIN



 The National Cancer Intelligence Network (NCIN) was launched in June 2008 to bring together cancer registries, clinical champions, health service researchers and a range of other interested parties (including the Office for National Statistics; National Clinical Audit Support Programme; NHS Information Centre) under the auspices of the NCRI



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



NCIN Partnership



Research Institute



<u>Chris Carrigan</u> Head NCIN Coordinating Teamhcer <u>Di Riley</u> Associate Director - Clinical Outcomes

Di Riley David Forman Analysis and Information Lead Lead Clinician Mick Peake **CR UK Graduate Trainee** Martine Bomb Michael Chapman **Programme Manager (NCRI)** Nicky Coombes Analysis Programme Manager SSCRG administrator and PA Linda Dutton to Di Riley Lucy Elliss-Brookes (On secondment from ASWCS) Catrina Jordan **NCRN** Sue Knights **Cancer Peer Review** Jon Shelton Information Analyst Alison Stone PA to Chris Carrigan Administration Trish Watts Kath Yates Electronic Cancer Information Tools



NCIN Goal



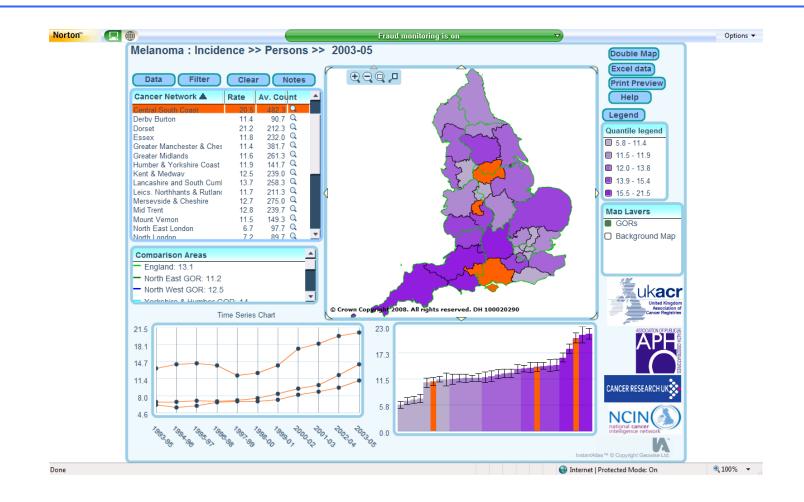
Why?

- 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

National Cancer Research Institute

National Cancer e-Atlas







THOUSANDS OF OLDER PEOPLE DYING PREMATURELY FROM CANCER, SAY RESEARCHERS



- As many as 15,000 people over 75 could be dying prematurely from cancer each year in the UK, according to research presented today at the National Cancer Intelligence Network (NCIN) conference.
- These premature deaths could be prevented if cancer mortality rates in the UK dropped to match countries in Europe and America which have the lowest rates.



Improve Commissioning







Institute

😜 Internet | Protected Mode: On





Driving up the quality of care



Improve Outcomes



Low Graphics Accessi	sility help	Search	Explore the BBC
NEWS	BBC NEWS CHANNEL		and the second s
News Front Page	Page last updated at 00:03 GMT, Thursd	ay, 5 June 2008 01:03 UK	
World	🖾 E-mail this to a friend 🛛 🔒	Printable version	
ик			
England	Rectal surgeons u	ising 'wrong op'	
Northern Ireland			
Scotland	Claims that many rectal cancer patients receive an		SEE ALSO
Wales	"inappropriate" operation have		Why is the UK lagging on cancer?
Business	been rejected by surgeons.		21 Aug 07 Health
Politics	Leeds University researchers said	A MILL MILL	 Fat hormone 'boosts colon cancer'
Health	hospital data showed the APE		07 Apr 07 Health
Medical notes	operation, which leaves patients		Trial slashes bowel cancer risk
Education	with a permanent colostomy, was		09 Oct 06 Health
Science/Nature	being used too often.		RELATED INTERNET LINKS
Technology	In the journal Gut, they said	Surgery can leave a patient needing a	• Gut
Entertainment	introducing official targets would	colostomy	 Association of Coloproctology of Great Britain
Also in the news	cut it further.		and Ireland
Video and Audio	However, leading colorectal surgeo	ns said it remained the best option	 Cancer Research UK
VIGEO ANG AGOIO	for many - and targets would harm	가장 방법은 정말 것 같은 것이다. 한 것이라는 것 같은 것은 것 같은 것이라. 이가 가지 않아야 하는 것이 같이 많이	The BBC is not responsible for the content of external
Have Your Say	Every year in the LIK approximately	/ 13,000 people are diagnosed with	internet sites
Magazine	rectal cancer, and 5,000 die from t	S 80 N N N R	TOP HEALTH STORIES
In Pictures			 Birth defect test guru knighted
Country Profiles	Although radiotherapy and	66 What this does is serve	 Study cracks amoeba attack tactic

Using information to improve quality & choice

National Cancer Research Institute



How will these data be collected?





- 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



NCIN Governance



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



Skin Cancer Clinical Reference Group



- Melanoma
- SCC
- BCC
- Cutaneous Lymphoma
- Probably others eg Merkel



Skin Clinical Reference Group



- Julia Newton-Bishop
 - Dermatologist
 University of Leeds
- John Lear
 - Dermatologist
 Manchester
- Di Riley
 - NCIN Coordinating Team
- Kathy Elliott
 - DOH

- Julia Verne
 - Director SW
 Observatory
- Debbie Beirne
 - Nurse Consultant,
 Leeds Teaching
 Hospitals
- Will Merchant
 - Dermatopathologist
 Leeds Teaching
 Hospitals Trust



Skin Clinical Reference Group



- Pippa Corrie
 - Medical Oncologist
 Addenbrooke's
- Paul Nathan
 - Medical Oncologist Mount
 Vernon Hosp
- Pippa Torstevin
 Consumer
- Vacancy
 - Network lead
- Andrew Jacks

Using information at mologistality declarce

- Barry Powell
 - Surgeon, St George's Hospital
- Dennis Crane
 - Consumer
- Julian Peace
 - Barnsley GP
 representing Primary
 Care and PCDS
- Sean Whitaker
 - Dermatologist Guys a St Thomas's



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



Data is only useful if its accurate and we collect information to explain it



men	Nation	
62.9	United States	60
62	Canada 🚺	58
61.8	Iceland	\$7.7
61.7	Sweden	60.3
61.6	Belgium	53.2
61.1	Finland	55.9
61.1	Switzerland	54.6
59.7	Italy	49.8
59.0	Spain	49.5
58.8	Germany	50.0
58.4	Norway	53.0
58.3	Netherlands	47.1
58.0	Austria	55.4
54.6	Maita 📃	42.3
54.1	Wales	47.9
52.9	Slovenia	36.6
52.7	England	44.8
51.9	Ireland	48.1
51.0	N. Ireland	42.0
49.3	Crech Republic	37.7
48.3	Poland	38.8
48.0	Scotland	40.2

Five-Year Cancer Survival Rates

C Political Calculations 2007



And how useful are the data we have now in MDTs?

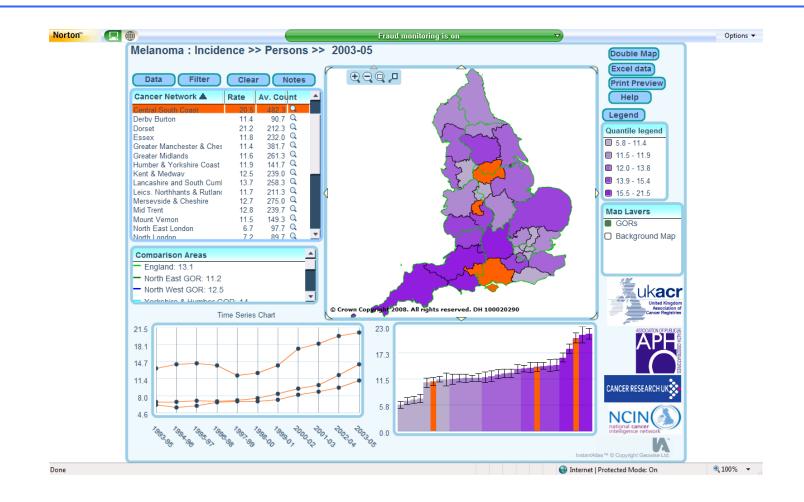


 And are the data we have now open to mis-interpretation?



National Cancer e-Atlas







3 year relative survival for males with melanoma 1999-2003



Merseyside and Cheshire
 - 82.7% (95% CI 78.0, 87.4)

- Yorkshire
 - -93.7% (95% CI 90.7, 96.7)

 Humber and Yorkshire Coast - 83.9% (95% CI 77.2, 90.7)



But want does this mean?



- Do patients present later to GPs in Merseyside?
- Is diagnosis poorer in primary care?
- Is treatment in secondary care poorer?
- Is there something about general health/diet etc in these regions which accounts for variation in outcome?
- Are the data correctly collected?







- Good quality data collection has the power to really improve health
- How can we do it?

