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

Using information to improve quality & choice
NCIN Partnership

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Chris Carrigan  Head NCIN Coordinating Team
Di Riley  Associate Director - Clinical Outcomes
David Forman  Analysis and Information Lead
Mick Peake  Lead Clinician
Martine Bomb  CR UK Graduate Trainee
Michael Chapman  Programme Manager (NCRI)
Nicky Coombes  Analysis Programme Manager
Linda Dutton  SSCRG administrator and PA 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
Trish Watts  Administration
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
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

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Purpose

- Driving up the quality of care
Rectal surgeons using 'wrong op'

Claims that many rectal cancer patients receive an "inappropriate" operation have been rejected by surgeons.

Leeds University researchers said hospital data showed the APE operation, which leaves patients with a permanent colostomy, was being used too often.

In the journal Gut, they said introducing official targets would cut it further.

However, leading colorectal surgeons said it remained the best option for many - and targets would harm care.

Every year in the UK, approximately 13,000 people are diagnosed with rectal cancer, and 5,000 die from the disease.

Although radiotherapy and chemotherapy can be used to...
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

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NCIN Governance

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

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Skin Cancer Clinical Reference Group

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

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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

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

Using information to improve quality & choice
Data is only useful if its accurate and we collect information to explain it.
And how useful are the data we have now in MDTs?

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

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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?
So?

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