

Enhancing epidemiological and health services research on cancer

Harpal Kumar
NCIN Launch
18 June 2008

Together we will beat cancer

The UK is uniquely positioned among larger countries in the world to undertake high quality epidemiological and health services research related to cancer

The UK is uniquely positioned among larger countries in the world to use data intelligently to improve outcomes through better services and to provide useful information to patients

Our strengths in the UK

– the National Health Service



Our strengths in the UK

– population data

- Comprehensive patient level national cancer registration (*unlike France, Italy, Germany or Spain*)

% of national population covered by cancer registration (1998)	
Denmark	100
France	17
Germany	1
Italy	28
Poland	9
Spain	16
UK (Eng, NI, Scot, Wales)	100

Eurocare 4 (2007) Lancet Oncology 8: 773-783

Our strengths in the UK

– clinical data

- Extensive patient-level datasets
 - Hospital Episode Statistics
 - Radiotherapy Episode Statistics
 - Cancer site specific audits e.g. LUCADA
 - Waiting times/referral patterns
- Technological progress enabling sources of data to be linked



Our strengths in the UK

– climate for research

- Relatively favourable ethical framework
- A population that is interested in research (and in participating in clinical trials, epidemiological studies and surveys)



Our strengths in the UK

– research infrastructure

Some of the best cancer research in the world

- High quality epidemiologists and research scientists in registries and academic institutions
- Networks – NCRN and the ECMCs
- High quality sample collections for research studies
- Informatics

But:

- The relevant data for epidemiological and health services research is hard to source
- We cannot track outcomes meaningfully
- Many research studies are small and lack power
- Patients' choices are not sufficiently informed

What is holding us back?

Current Weaknesses

- Significant spend on cancer registration across the UK (£15 million) – but few outputs from this investment
- Collection of data within the NHS is laborious and may be collected or documented more than once
- Data may not be recorded electronically
- Collection of some data is not mandatory, or is incomplete
- Many unlinked datasets
- Linkage between different data sources rarely undertaken (e.g. *cancer registration and hospital episode statistics*)

Research is limited by the availability of data

- Important health service questions are not studied
- Performance is not fully monitored
- We are unable to measure progress against some goals
- Key research questions remain unanswered
- Research is more costly and may take longer to produce answers
- Rapid progress in genetic and molecular research is not fully exploited for the benefit of patients

The solution

- a national cancer intelligence network

- Proposed by the National Cancer Research Institute (NCRI) in June 2006
- Driven in England by the Cancer Reform Strategy 2007 (*2012 goal to have 'simply the best cancer intelligence in the world'*)
- UK wide focus - positioned within the NCRI
- NCRI partners (patients, public, research funders, health professionals, scientists, industry) can 'own' and invest in the National Cancer Intelligence Network (NCIN)

NCIN will bring about a quantum change in the information available to support the delivery of quality cancer services

We know there are important variations between people and across services

We need better data to answer key questions and implement strategies, policy and research

- Variations in cancer incidence and mortality rates across the country and between groups of people
- 1 and 5 year cancer survival, variations between 'rich' and 'poor'
- The ability to deliver the best care in the world but significant variations in delivery and inequity
- Significant variations between patients in response to existing treatments
- Late presentation with symptoms needs to be fully researched and tackled in the UK – patient and doctor delay and variations in the uptake of, and need for, screening

An example of the kind of question we would like to answer

Early onset of breast cancer in British black women (Bowen et al (2008) BJC 98: 277-81)

Supported by Cancer Research UK and Barts & The London Charitable Foundation

Women with breast cancer in East Hackney (Homerton University Hospital)

Median age of diagnosis of black women - 46 years

Median age of diagnosis of white women – 67 years

Black women have a higher frequency of:

- Grade 3 tumours

- Lymph node positive disease

- Negative hormone receptor status and basal-like tumours

No difference in stage at presentation

Black women with small tumours were more than twice as likely to die from their disease.

The contribution of NCIN will be significant and far-reaching

- Clinical outcomes data on cancer patients and cancer services
- The evidence base for policy, planning and commissioning services at local and national level
- Improved services and a reduction in inequity
- The best care for patients right across the UK
- Informed choice for people with cancer
- Answers to key research questions
- Raw data for new research on prevention, early detection and treatment
- The ability to monitor our progress on tackling cancer in the UK

The UK is uniquely positioned among larger countries in the world to undertake high quality epidemiological and health service research related to cancer

The best cancer intelligence in the world will transform our ability to answer key questions and deliver the effective interventions and the best management of patients

The opportunities are huge

There are many challenges to overcome

We must be visionary and ambitious

Together we will beat cancer