

## **Cancer Intelligence: A vision for the future**

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## **Cancer Intelligence: A vision for the future**

- Where have we come from?
- Current strengths and weaknesses
- Future direction
- Immediate priorities for 2011/12

## Cancer Intelligence: The Past



- We are building on firm foundations
  - Longstanding comprehensive cancer registration (unlike Germany, France, Spain, Italy)
  - A national health service which collects a great deal of administrative data (e.g. hospital episode statistics)
  - Information on quality of services (peer review)
  - Information on patients' experience of care (large surveys in 2000 and 2010)

## Cancer Intelligence: More Recently (1)



- Improvements in timeliness and quality of cancer registration
- Collection of new datasets (e.g. cancer waits and radiotherapy)
- National cancer audits – with over 90% case ascertainment for lung, bowel and head and neck cancer
- Linkage of datasets (e.g. registries and HES, allowing analyses that were not previously possible)
- Establishment of NCIN – bringing together expertise from across the country
- Development of new “outputs” e.g. consortium profiles, GP practice profiles. Cancer commissioning toolkit

## Cancer Intelligence: More Recently (2)



- Landmark publications
  - Routes to diagnosis and emergency presentations (NCIN): Recent research is now informing policy
  - Major resection rates for different cancers (NCIN)
  - 30 day mortality following colorectal cancer surgery (NCIN/NYCRIS)
  - International survival comparisons (ICBP) – influencing policy
  - Inequalities (e.g. men and cancer: ethnicity)
    - influencing National Cancer Equalities Initiative

## Current Cancer Intelligence: Weaknesses (1)



- Cancer registration – Completeness and timeliness can be improved further: a small proportion of cases are still being missed
- Staging: Information on staging is only currently available at a national level for around 40% of cases. Staging is vital for monitoring progress on early diagnosis and for case mix adjustment of survival analyses
- Pathology is poorly/variably recorded
- Imaging: We know very little about utilisation rates of imaging procedures (or about results of imaging)
- Chemotherapy: We know very little at a national level

## Current Cancer Intelligence: Weaknesses (2)



- We have only just started linking with primary care datasets – despite the fact that all GP surgeries have IT systems
- We know little about:
  - Comorbidity and performance status at diagnosis
  - Late effects of cancer
  - Quality of life of cancer survivors
  - Recurrences/metastatic disease
- Some of the IT systems in use (e.g. to support cancer screening) are no longer fit for practise

## Cancer Intelligence: Increasing Demands



- Demands for cancer intelligence have increased markedly for:
  - Planning services (nationally and locally)
  - Monitoring service delivery
  - The “information revolution” – “No decision about me, without me”
  - The focus on “outcomes not process targets” – and the public health and NHS Outcomes Framework

## The Information Revolution and Cancer



- How would you choose a hospital if you thought that you or a family member might have cancer? Would you:
  - Rely on your GP?
  - Go to your local hospital?
  - Phone a friend?
  - Try to find data on performance? If so, how?

## Focus on Outcomes



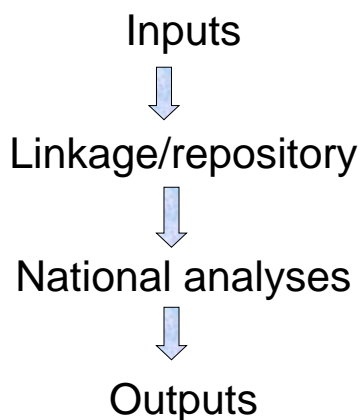
- Cancer spans public health and the NHS. We therefore need to consider both outcomes frameworks
- Public health
  - **Domain 1:** Health protection (e.g. HPV vaccination)
  - **Domain 3:** Healthy lifestyles (e.g. smoking, alcohol, obesity and physical inactivity all impact on cancer)
  - **Domain 4:** Screening (cervix, breast and bowel)
  - **Domain 5:** preventing people dying prematurely

## Focus on Outcomes

Cancer maps well to the NHS Outcomes Framework

- **Domain 1: Reducing premature mortality rates**  
e.g. mortality from cancer by age; 1 and 5 year survival
- **Domain 2: Enhancing quality of life for people with long term conditions**
  - we will develop PROM surveys for cancer survivors
- **Domain 3: Recovery from episodes of ill health**  
e.g. recovery after cancer surgery
- **Domain 4: Ensuring people have a positive experience of care**  
e.g. annual cancer patient experience surveys and surveys of bereaved relatives
- **Domain 5: Protecting people from harm**  
e.g. 30 day mortality after cancer surgery or chemotherapy

## Cancer Intelligence: Future Direction



## Cancer Intelligence: Future Direction (2)

### 1. Inputs

- We should use systems which support direct clinical care, wherever possible e.g.
  - GP IT systems
  - Hospital cancer management systems (e.g. Somerset, Infloflex, e-MDT, Dendrite)
  - E prescribing
  - Radiotherapy (RTDS)
  - Pathology (synoptic/template-based)
  - Imaging
- We should then supplement with information from administrative databases
  - Cancer waits
  - PAS/HES
  - ONS
- Only then should we collect additional data locally where necessary (National Clinical Audits)

## Cancer Intelligence: Future Direction (3)

### 2. Linkage: single repository

- Single “black box”
- Standardise inputs
- Bring all registries up to the standard of the best in terms of timeliness and completeness (e.g. staging)

## Cancer Intelligence: Future Direction (4)



### 3. National analyses

- Maintain decentralised model – i.e. different registries taking the lead on different cancers and/or aspects of cancer care
- Support a mixed economy of analyses:
  - Commissioned analyses e.g. by DH, PHE, NHS Commissioning Board and charities)
  - Investigator-led research (e.g. Funded by NCRI partners)

## Cancer Intelligence: Future Direction (5)



### 4. Outputs

- National reports – preferably in peer reviewed journals to ensure credibility
- National monitoring of progress on specific initiatives (e.g. NAEDI)
- Local reports or “profiles”
  - Consortia
  - GP practices
  - MDTs and services

## Priorities for 2011/12 (1)

1. Inputs
  - Diagnostics dataset (imaging)
  - Routine collection of data on emergency presentations
  - Chemotherapy dataset
  - Cancer outcomes dataset
  - Secondary breast cancer pilot
  - PROMs pilots
2. Linkage/registration
  - Complete 'rapid' review of cancer registration
  - Continue registry modernisation programme

## Priorities for 2011/12 (2)

3. National analyses
  - Routes to diagnosis: 2006-8
  - 30 day mortality: extend beyond colorectal
  - Survivorship: Natural histories
  - Admissions, bed days, length of stay (update)
  - Major treatment rates (surgery + RT)
  - Survival after radiotherapy
4. International analyses
  - ICBP: staging and treatment comparisons
  - Survey of public awareness and beliefs
  - Survey of GP attitudes, beliefs and behaviours

## Priorities for 2011/12 (3)

### 5. Local outputs

- Consortia profiles
- GP Practice profiles
- Service profiles (MDT/Trust)

## Summary

- We have made a lot of progress on cancer intelligence
- Further improvements will help to drive quality and productivity of cancer services, thereby improving outcomes
- We still have some way to go before we can say we have the best cancer intelligence service in the world – but it is achievable!