Cancer Intelligence:
A vision for the future

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- 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

Inputs

Linkage/repository

National analyses

Outputs
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)
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)

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!