National Clinical Audit & core datasets to improve standards of cancer care in the NHS

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Using information to improve quality & choice
COLORECTAL CANCER 5 YR R.S.

LUNG CANCER 5 YR R.S.

BREAST CANCER 5 YR R.S.

OVARIAN CANCER 5 YR R.S.

Coleman MP et al, Lancet 2001;377:127-37
6ix – LUNG CANCER SURVIVAL

Five year relative survival rates of persons aged 15–99 who were diagnosed with lung cancer during the periods 1991–1993

Source: Office for National Statistics
The National Lung Cancer Audit (LUCADA)
Possible explanations for poor UK cancer survival outcomes

• Late diagnosis
  – lack of public awareness of symptoms
  – ‘cultural’ attitudes
  – primary care as ‘gatekeeper’
  – less good access to diagnostics

• Inferior specialist services
  – availability of specialist clinicians
  – access to treatment (e.g. high-cost, drugs; advanced radiotherapy techniques, etc.)

• Statistical artefacts

• Patient characteristics
  – high rate of co-morbidities
  – different disease biology (population genetic differences)
Potential Ways of Reducing Lung Cancer Mortality

• Prevention - Reducing smoking levels
• Early diagnosis - Including Screening
• Discovery of new treatment modalities
• Provision of optimal treatment for every patient – improving service standards
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Over-arching principle

“Deriving clinical process and outcome data of sufficient quality and relevance to drive up standards in clinical practice and outcomes for patients”
National Lung Cancer Audit: early history

- **1995 -1998**: Royal College of Physicians ‘snapshot’ audit; securing professional ‘buy in’
- **1999**: RCP publication of: ‘Lung Cancer: A Core Data Set’
- **1999**: Search for funding of national programme
- **2000**: Multi-professional Lung Cancer Clinical Reference Group established
- **2000/2003**: Development of software & operating procedures (confidentiality, security, etc.)
- **2003**: Funding secured from DH (‘NCAPOP’ budget)
- **2004**: First data from ‘early adopter’ sites
Time from Bronchoscopy to Surgery

Source: Peake et al. Royal College of Physicians 1999
National Lung Cancer Audit: early history

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Lung Cancer - A Core Dataset (1999)

• Developed by a multi-disciplinary group
• Starting point: “what questions would we need to answer to be able to identify changes in practice that would have the greatest impact on patient outcomes (survival)?’
• Need to know, not nice to know
• All data fields had:
  – purpose, definition, source & how they would be used in analysis
‘Headline’ Reports

• Number of cases recorded by place first seen as a proportion of the estimated lung cancer population served
• % of patients in whom a tissue diagnosis has been established
• % of patients reviewed by an MDT
• % of patients who undergo surgical resection
• % of patients who have any active cancer treatment
• % of patients with Small Cell Lung Cancer receiving chemotherapy
• % of stage IIIB/IV Non Small Cell Lung Cancer patients receiving chemotherapy
• % of patients being seen by a lung cancer nurse specialist
‘Headline’ Reports

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National Lung Cancer Audit
Potential outcome measures

- Survival: 5 years, 1 year, 1 month?
- Peri-treatment death (e.g. 30 day mortality)
- Patient Reported Outcomes: QOL, Pain, Breathlessness etc.
- Hospitalisation (episodes, length of stay)
- Late effects of treatment
- Experience of care
- Place of death
National Lung Cancer Audit
Patient numbers: 2009

UK Total Cases
37,343

England
30,135

Wales
1973

Scotland
4379

N Ireland
819

Jersey
37

100% of all hospital trusts
>98% expected incident cases
Case breakdown (England)

Total cases 30,135

Lung Cancer
28,619
M:F ratio 1.28:1

Mesothelioma
1516
M:F ratio 5.2:1

Small Cell Lung Cancer
3209 (11.2%)

Confirmed NSCLC
17,056 (60%)

Clinical Diagnosis alone
6506 (22.7%)

‘Other’ (carcinoid, etc.)
1748 (6.1%)
### National Lung Cancer Audit (England)
#### Case ascertainment and data completeness

<table>
<thead>
<tr>
<th></th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of hospital trusts submitting data</td>
<td>77</td>
<td>93</td>
<td>96.5</td>
<td>98.1</td>
<td>100</td>
</tr>
<tr>
<td>Number of cases</td>
<td>10,920</td>
<td>16,922</td>
<td>20,639</td>
<td>27,818</td>
<td>30,135</td>
</tr>
<tr>
<td>Case ascertainment (%)</td>
<td>40</td>
<td>66</td>
<td>75</td>
<td>92</td>
<td>&gt;97</td>
</tr>
<tr>
<td>Data completeness (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage</td>
<td>51</td>
<td>55</td>
<td>70</td>
<td>77</td>
<td>81</td>
</tr>
<tr>
<td>Performance status</td>
<td>66</td>
<td>77</td>
<td>80</td>
<td>87</td>
<td>78</td>
</tr>
<tr>
<td>Treatment</td>
<td>66</td>
<td>72</td>
<td>79</td>
<td>82</td>
<td>89</td>
</tr>
</tbody>
</table>
Cancer network variation (2009)
Active Treatment Rate (%)
Surgical resection rate - all lung cancer cases (%)
% of small cell cases receiving chemotherapy

Cancer Network in rank order
## Small cell chemotherapy by NCRN trial entry status (England 2004 -2008)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Low trial centre &lt;5%</th>
<th>High trial centre &gt;5%</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>5321</td>
<td>2524</td>
<td></td>
</tr>
<tr>
<td>Median age(yrs)</td>
<td>69</td>
<td>69</td>
<td></td>
</tr>
<tr>
<td>Limited stage</td>
<td>16%</td>
<td>17%</td>
<td></td>
</tr>
<tr>
<td>Extensive stage</td>
<td>33%</td>
<td>42%</td>
<td></td>
</tr>
<tr>
<td>Unknown stage</td>
<td>51%</td>
<td>41%</td>
<td></td>
</tr>
<tr>
<td>% PS 0 &amp; 1</td>
<td>36%</td>
<td>37%</td>
<td></td>
</tr>
<tr>
<td>Adjusted odds ratio for chemotherapy*</td>
<td>1.00</td>
<td>1.42</td>
<td>P = 0.017</td>
</tr>
</tbody>
</table>

*adjusted for sex, age, PS, stage, deprivation index and Charlson co-morbidity index

Source: Rich et al; Br J Cancer 2011 (in press)
Odds Ratio for Histological Confirmation by Network (2009)

(England & Wales)

Adjusted for: Age, sex, stage, performance status and deprivation index

Odds Ratio

Cancer Network in rank order
Adjusted for: Age, stage, sex, performance status and deprivation index
Odds ratio for surgery (all cases) by network 2009

Adjusted for: Age, stage, sex, performance status and deprivation index
Case-mix-adjusted mortality 2009

Adjusted for: Age, stage, sex, performance status and deprivation index
Feedback to trusts and networks

- On-line ‘real time’ reporting
- Quarterly reports to cancer networks about data completeness
- Annual reports (headline and case-mix adjusted)
- On-line interactive spreadsheets (data packs)
- Email, phone and face-to-face meetings with trusts and networks
- Annual ‘Local Action Plans’
- Frequent presentations at major meetings
# National Lung Cancer Audit (England)
## Headline indicators over time

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<td>40</td>
<td>66</td>
<td>75</td>
<td>92</td>
<td>&gt;97</td>
</tr>
<tr>
<td>% discussed at MDT</td>
<td>79</td>
<td>84.3</td>
<td>86.8</td>
<td>88.6</td>
<td>93.8</td>
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<tr>
<td>Tissue confirmation rate (%)</td>
<td>68</td>
<td>66</td>
<td>65</td>
<td>66.7</td>
<td>75.9</td>
</tr>
<tr>
<td>Overall surgical resection rate (%)</td>
<td>9</td>
<td>9.4</td>
<td>10.3</td>
<td>11.2</td>
<td>13.9</td>
</tr>
<tr>
<td>Resection rate: confirmed NSCLC (%)</td>
<td>13.8</td>
<td>14.3</td>
<td>15.2</td>
<td>16.0</td>
<td>18.4</td>
</tr>
<tr>
<td>Active treatment rate (%)</td>
<td>45</td>
<td>50</td>
<td>52</td>
<td>54</td>
<td>59.2</td>
</tr>
<tr>
<td>Small Cell chemotherapy rate (%)</td>
<td>57.7</td>
<td>61.7</td>
<td>64.5</td>
<td>63.0</td>
<td>65.4</td>
</tr>
</tbody>
</table>
## Non-Small Cell Lung Cancer ‘Not Otherwise Specified’ rate (England)

<table>
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<th>Year</th>
<th>NOS Rate</th>
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</thead>
<tbody>
<tr>
<td>2006</td>
<td>36%</td>
</tr>
<tr>
<td>2007</td>
<td>31.8%</td>
</tr>
<tr>
<td>2008</td>
<td>33.6%</td>
</tr>
<tr>
<td>2009</td>
<td>30.28%</td>
</tr>
<tr>
<td>2010*</td>
<td>24.2%*</td>
</tr>
</tbody>
</table>

*Provisional data*
Goal for NCIN: “To develop the best cancer information service of any large country in the world – by 2012”

Mike Richards 2007

www.ncin.org.uk
UK: Cancer data sources

• Cancer Registries (registration not legally mandated) – since late 1960s
• Hospital Episode Statistics – in patient & out patient
• National Cancer Intelligence Network – 2008
  – 12 Site-Specific Clinical Reference Groups with Lead Cancer Registry
• National Cancer Audits:
  – Lung, Colo-rectal, Head & Neck, Upper GI Cancers
• Radiotherapy dataset
• National Cancer Patient Survey
• National Cancer Peer Review

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National Cancer Data Repository (v2008)

Registry-HES linkage: 1985-2008 (England)

- >7.3 million tumour records from Registries
  - c. 30 fields of data
- >49 million hospital in patient episodes
  - c. 150 fields of data

Recently added

- National Cancer Audit data
- Co-morbidity (Charlson Index)
- Radiotherapy Dataset (2009/10)

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Cancer Datasets

- Cancer Registration Dataset – *mandated for several years*
- Going Further on Cancer Waits – Jan 2009
- Radiotherapy – April 2009
- *Chemotherapy (SACT)* – April 2012
- *Cancer Outcomes and Services Dataset* – Autumn 2012
- *(RC Pathology – Professional/Clinical Standards)*
- *(RC Radiology – Professional/Clinical Standards)*
- National Cancer Audit Strategy

*Using information to improve quality & choice*
Resection rate by PCT
2004-6*

*Source: National Cancer Data Repository

N = 77,349

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Mortality hazard ratios for resected patients; England 2004-6 by Government Regional Office

N = 6,900

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Implications: comparing the top quintile PCT with Lower 4:
5420 deaths ‘postponed’ by surgery
146 deaths related to higher resection rates

N = 6,900
30 day mortality data: Colo-rectal cancer surgery

Using information to improve quality & choice
Conclusions

• National Audits can generate high quality population-based data
• A limited ‘core’ dataset can be collected nationally
• There is clear evidence of clinical behaviour change – survival impact awaited!
• Data linkage is creates an enormously powerful resource
• Complementary to RCT data (e.g. elderly, poor performance status, socially deprived, ethnic minorities are included)
• Huge potential for linking to research programmes
• Patient reported outcome measures needed

Using information to improve quality & choice
"In attempting to arrive at the truth I have applied everywhere for information, but in scarcely an instance have I been able to obtain hospital records fit for any purpose of comparison.

If they could be obtained they would enable us to decide many other questions beside the one alluded to.

They would show subscribers how their money was being spent, what amount of good was really being done with it, or whether the money was not doing mischief rather than good."
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Florence Nightingale 1863