The role of primary care in cancer control; lessons for healthcare policy

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Overview

- Cancer control: why consider primary care?
- Primary prevention
- Screening
- Early diagnosis
- Management and survivorship
- Cancer policy
- Conclusions
Cancer control: why consider primary care?

- Primary care is central to health care reform internationally

- International evidence linking more-developed primary care with better health outcomes (Starfield et al)

- Trend towards primary-care based management of chronic diseases (away from hospital-based services)
Primary care – some key features

- directly accessible, first contact care for unselected health problems
- offers preventive, diagnostic, curative, rehabilitative and palliative services
- holistic approach
- key role in management of multi-morbidity
- emphasises co-ordination and continuity of care
Primary care and the Cancer Control Continuum

- Prevention
- Screening
- Diagnosis
- Treatment
- Follow-up/Survivorship Care
- End of life Care
Multi-morbidity in Scotland

- majority of over-65s have 2 or more conditions
- majority of over-75s have 3 or more conditions
International Cancer Benchmarking partnership: Survival data
Overview

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Smoking and primary care

Regular review

Effectiveness of interventions to help people stop smoking: findings from the Cochrane Library

Tim Lancaster, Lindsay Stead, Chris Silagy, Amanda Sowden for the Cochrane Tobacco Addiction Review Group
Alcohol and primary care

Effectiveness of brief alcohol interventions in primary care populations

Eileen Kaner, Heather Dickinson, Fiona Beyer et al.
Diet and obesity

Evidence for effectiveness of primary care interventions is variable – stronger for patients at high risk of chronic diseases especially where moderate to high intensity interventions used.
Role of primary care organisations in primary prevention

- to coordinate and broker a network of referral services to support behaviour change based on standards and quality assurance
- other key roles of primary care include the support of practices to monitor and improve their performance in providing preventive care
Primary prevention and GPs

- Australians visit a GP five times per year
- Patients expect to receive information and assistance regarding preventive health issues from their primary care providers
- Yet few primary care encounters in Australia involve risk-factor assessment and intervention.

In 2005–06:

- 34.6% of general practice encounters were with overweight patients (22.2% being obese)
- 25.9% with those who drank alcohol at risky levels
- 17.1% with daily smokers
- less than one in five patients are routinely asked about their drinking
- two-thirds are asked about their smoking
- only up to a third are asked about exercise and physical activity
- about 15-30% of patients get some form of dietary advice

Centre for Primary Health Care and Equity, UNSW
Guidelines for preventive activities in general practice

8th edition
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Engagement of primary care in cancer screening

- Direct involvement
  - identification and recruitment
  - provision of testing
  - co-ordination of follow-up

- Complementary roles, with centralised programme
  - sharing of tasks
  - endorsement of screening invitations
The role of primary care in UK colorectal screening

- Relatively peripheral in organisational terms – no direct role in recruitment, investigations or co-ordination of follow-up

- Yet..
  - there are substantial disparities in uptake
  - evidence (albeit limited) that primary care can reduce inequalities in screening uptake
  - many of the strategies to address uptake articulated by BCSP involve primary care
Primary care endorsement letter and a patient leaflet to improve participation in colorectal cancer screening: results of a factorial randomised trial

- Endorsement improves uptake by 5 to 6%
- Varying levels/types of endorsement
- Can complement other simple interventions such as patient leaflet
Primary care involvement

- GP time is costly – while there are some enthusiasts, most ‘extra’ GP activity in UK now linked to payments

- Interventions involving significant burden on primary care unlikely to be cost-effective

- Letters of invitation – GP endorsement:
  - include line mentioning GP in standard invitation letter
  - personalised note from GP
  - use of GP letterhead
A range of GP attitudes

- enthusiasm
- ignorance
- engagement
- indifference
- resentment
- desire for more involvement (e.g., feedback on screening outcomes)
Improving CRC screening uptake: potential roles for primary care

- Some evidence that primary care can improve uptake – largely from North America
- Endorsement of invitations
- ‘Local Champion’ role
- More extensive feedback on their patients’ participation
- Primary care-based facilitators
- Practice-based promotion of FOBT screening
Qualitative survey: UK Pilot

- “I left it there for a while, but just didn’t do it and eventually threw it away...it seemed a bit complicated, a bit unpleasant, I couldn’t really be bothered”

- “My partner gives me hassle, she definitely thinks I should do it...actually she thinks I did it the second time, I didn’t actually tell lies, I just didn’t tell her that I hadn’t done it”

- “The tests come by remote, there’s no GP involvement. With this type of screening you don’t have to commit to anybody to do it, it arrives in the post, nobody follows it up to ask why you haven’t done it”
Issues amongst South Asian invitees

Shame and embarrassment:

- once a person is diagnosed with cancer other people get scared as well and start hating him. That is why a person is afraid of taking this screening so that he should not be hated by his family. (Male, Urdu)

- a lot of people have worries that if I had cancer just say if people find out about it my three daughters’ futures because of hereditary some people will be scared that my son and daughter will suffer (Male, Gujarati)
The UK programme – potential impact on primary care

- Practice of 10,000 patients:
  - 2,500 patients aged 50 to 74
  - 50 positive tests every two years
  - 1 positive test every two weeks

- Information needs: telephone and consultations
- Co-ordination of process
Overview

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# Primary care cancer epidemiology

<table>
<thead>
<tr>
<th></th>
<th>Individual GP</th>
<th>Group Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>(population)</td>
<td>(1,600)</td>
<td>(10,000)</td>
</tr>
<tr>
<td>New cases p.a</td>
<td>7-8</td>
<td>50</td>
</tr>
<tr>
<td>Patients with cancer diagnosis</td>
<td>30-40</td>
<td>200</td>
</tr>
<tr>
<td>Deaths from cancer p.a</td>
<td>4</td>
<td>25</td>
</tr>
<tr>
<td>Home deaths from cancer</td>
<td>1</td>
<td>6</td>
</tr>
</tbody>
</table>
National Awareness and Early Diagnosis Initiative – key elements

- Achieving early diagnosis by public and patients
  - Raising awareness of cancer, symptoms, importance of early presentation
  - Reducing barriers to early presentation (fear, difficulty accessing GP)
  - Reducing barriers to screening

- Optimising clinical practice and systems
  - Raising awareness of cancer symptoms amongst GPs and other health workers
  - Promoting optimal referral by GPs
  - Optimal screening services

- Improving GP access to diagnostics eg ultrasound, MRI, colonoscopy

- Research, evaluation and monitoring
To achieve goals in early diagnosis, different interventions are needed across the pathway to influence different groups at different stages.
Major sources of data

- **RCGP Audit of Cancer Diagnosis**
  - 20 / 28 Cancer Networks in England
  - 1170 / 8245 practices, 18,879 cancer patients

- **NCIN Routes to Diagnosis**
  - All patients diagnosed in year*
  - I/P, O/P, Screening, CWT

- **National Cancer Patient Survey**
  - 67,000 patients

- **International Cancer Benchmarking Partnership**
Barriers to symptomatic presentation

Unpublished findings from ICBP Module 2: Data for England only
Public communication: CR-UK campaign

- **Primary objective:**
  - To tackle people’s fear of cancer and encourage them to confront it by reinforcing the benefits of early diagnosis

- **Secondary objectives:**
  - To tackle people’s reluctance to visit their GP
  - To raise awareness of signs and symptoms of cancer
  - To build brand leadership in early diagnosis
  - To strengthen public engagement with CR-UK
Raising awareness of cancer symptoms

If you’ve had blood in your poo or looser poo for 3 weeks, your doctor wants to know.

Chances are it’s nothing to worry about, but it could be the early signs of bowel cancer, so tell your doctor. Finding it early makes it more treatable and could save your life.
Lung cancer – cough campaign

If you’ve been coughing for 3 weeks, it might not be ‘only a cough’, so tell your doctor.
## Awareness raising – impact on primary care

<table>
<thead>
<tr>
<th></th>
<th><strong>Bowel (Jan – March 2011)</strong></th>
<th><strong>Lung (Oct – Nov 2011)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Duration</strong></td>
<td>7 wks; longer lead time</td>
<td>5 wks; shorter lead time</td>
</tr>
</tbody>
</table>
| **Weight (OTS= Opportunities to see)** | • Reach; 88% EofE and 90% SW  
• OTS; 13.1 EofE and 14 SW | • Reach; 94.5%  
• OTS; 9.1 |
| **Awareness**        | • Recognition 75%  
• Support 96% public, 89% GPs  
• Significant increase in recall of symptoms | • Recognition 70%  
• Support 94% public, 87% GPs  
• Significant increase in recall of symptoms |
| **Attendance at Primary Care** | Based on 74 practices:  
• 3 most relevant read codes  
51.6% increase  
• Variation from 58 additional visits to 13 fewer visits; 1 extra visit per practice per week  
• Overall 30-49 yrs highest increase (55%), the target group saw a 46% increase. Varied across areas | Based on 35 practices:  
• Most relevant read codes – 23% increase  
• Variation as an example, 92 more visits in one practice and 51 fewer in another; 2.4 extra visits per practice per week  
• Attendances increased from 30 yrs and tailed off at 85 highest impact 55-59 yrs |
Supporting primary care

- Practice visits supported by GP practice profile discussions
- Use of Risk Assessment Tools (7 networks; 165 practices; over 600 GPs)
- Significant Event Audit
- Improved access to diagnostics
Key ‘Intervals’ in cancer diagnosis

RCGP Audit:

- Interval in primary care
  - <1 month for roughly 67% patients,
  - <2 months for 74%

- Interval in secondary care
  - <1 month for roughly 74% patients,
  - <2 months for 83%

- 76% of patients referred after two or less visits
Saw GP no more than twice before referral to hospital

- Breast: 92%
- Colorectal / Lower Gastro: 70%
- Lung: 66%
- Prostate: 77%
- Brain / CNS: 65%
- Gynaecological: 71%
- Haematological: 75%
- Head & Neck: 62%
- Sarcoma: 60%
- Skin: 90%
- Upper Gastro: 67%
- Urological: 81%
- Other: 59%

Source: National Cancer Patient Experience Survey 2010
## GP Practice Profiles

### Cancer Indicators in [X4332] Dr Smith’s Surgery, Another PCT (5XX)

These profiles provide comparative information for benchmarking and reviewing variations at a General Practice level. They are intended to help primary care think about clinical practice and service delivery in cancer and, in particular, early detection and diagnosis. They are not for the purpose of performance management and there are no ‘right or wrong’ answers.

| Practice population (2008/09) | 10,121 |
| PCT population (all practices) | 198,967 |

### Domain

<table>
<thead>
<tr>
<th>Domain</th>
<th>Indicator (Rate or Proportion in brackets)</th>
<th>Practice indicator value</th>
<th>Practice indicator rate or proportion</th>
<th>Lower 95% confidence limit</th>
<th>Upper 95% confidence limit</th>
<th>PCT mean</th>
<th>England mean</th>
<th>Lowest practice</th>
<th>Range</th>
<th>Highest practice</th>
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<tbody>
<tr>
<td>Demographics</td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td></td>
<td>Practice Population aged 65+ (% of population in this practice aged 65+)</td>
<td>1493</td>
<td>14.8%</td>
<td>14.1%</td>
<td>15.5%</td>
<td>17.0%</td>
<td>15.6%</td>
<td>10.1%</td>
<td>24.7%</td>
<td>32.8%</td>
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<tr>
<td></td>
<td>Socio-economic deprivation, “Quintile 1 = affluent (% of population income deprived)</td>
<td>Quintile 4</td>
<td>19.6%</td>
<td>18.8%</td>
<td>20.4%</td>
<td>19.7%</td>
<td>15.9%</td>
<td>10.2%</td>
<td>32.8%</td>
<td>47.4%</td>
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<tr>
<td></td>
<td>New cancer cases (Crude incidence rate: new cases per 100,000 population)</td>
<td>51</td>
<td>504</td>
<td>375</td>
<td>663</td>
<td>654</td>
<td>504</td>
<td>235</td>
<td>973</td>
<td>1235</td>
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<tr>
<td></td>
<td>Cancer deaths (Crude mortality rate: deaths per 100,000 population)</td>
<td>26</td>
<td>257</td>
<td>168</td>
<td>376</td>
<td>278</td>
<td>236</td>
<td>66</td>
<td>503</td>
<td>580</td>
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<tr>
<td></td>
<td>Prevalent cancer cases (% of practice population on practice cancer register)</td>
<td>158</td>
<td>162</td>
<td>168</td>
<td>167</td>
<td>1417</td>
<td>1610</td>
<td>2599</td>
<td>2599</td>
<td>2599</td>
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<tr>
<td></td>
<td>Females, 50-70, screened for breast cancer in last 36 months (3-year coverage, %)</td>
<td>837</td>
<td>706</td>
<td>674</td>
<td>726</td>
<td>715</td>
<td>718</td>
<td>49.7%</td>
<td>79.6%</td>
<td>79.6%</td>
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<tr>
<td></td>
<td>Females, 50-70, screened for breast cancer within 6 months of invitation (Uptake, %)</td>
<td>13</td>
<td>25.9%</td>
<td>17.6%</td>
<td>43.4%</td>
<td>65.4%</td>
<td>74.8%</td>
<td>0.0%</td>
<td>77.4%</td>
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<tr>
<td></td>
<td>Females, 25-64, attending cervical screening within target period (3.5 or 5.5 year coverage, %)</td>
<td>1954</td>
<td>60.2%</td>
<td>78.6%</td>
<td>81.8%</td>
<td>79.3%</td>
<td>75.4%</td>
<td>65.0%</td>
<td>88.5%</td>
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<tr>
<td></td>
<td>Persons, 50-69, screened for bowel cancer in last 30 months (2.5 year coverage, %)</td>
<td>541</td>
<td>54.6%</td>
<td>51.7%</td>
<td>57.9%</td>
<td>51.6%</td>
<td>40.2%</td>
<td>35.3%</td>
<td>59.0%</td>
<td>59.0%</td>
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<tr>
<td></td>
<td>Persons, 50-69, screened for bowel cancer within 6 months of invitation (Uptake, %)</td>
<td>232</td>
<td>60.2%</td>
<td>55.5%</td>
<td>64.5%</td>
<td>56.2%</td>
<td>55.1%</td>
<td>40.4%</td>
<td>64.8%</td>
<td>64.8%</td>
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<tr>
<td></td>
<td>Two-week waits (Number per 100,000 population)</td>
<td>162</td>
<td>1601</td>
<td>1364</td>
<td>1867</td>
<td>1417</td>
<td>1610</td>
<td>2599</td>
<td>2599</td>
<td>2599</td>
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<tr>
<td></td>
<td>Two-week waits (Number per 100,000 population, Age standardized)</td>
<td>162</td>
<td>100.9%</td>
<td>85.9%</td>
<td>117.7%</td>
<td>93/0</td>
<td>100.2%</td>
<td>10.5%</td>
<td>158.6%</td>
<td>158.6%</td>
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<tr>
<td></td>
<td>Two-week waits with cancer (Conversion rate: % of all TWW waits with cancer)</td>
<td>24</td>
<td>14.6%</td>
<td>10.2%</td>
<td>21.1%</td>
<td>14.5%</td>
<td>11.2%</td>
<td>5.7%</td>
<td>50.0%</td>
<td>50.0%</td>
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<tr>
<td></td>
<td>Number of new cancer cases treated (% of which are TWW waits with cancer)</td>
<td>48</td>
<td>50.0%</td>
<td>36.4%</td>
<td>63.6%</td>
<td>44.5%</td>
<td>42.9%</td>
<td>12.5%</td>
<td>85.7%</td>
<td>85.7%</td>
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<tr>
<td></td>
<td>Two-week waits with suspected breast cancer (Number per 100,000 population)</td>
<td>47</td>
<td>464</td>
<td>341</td>
<td>618</td>
<td>359</td>
<td>329</td>
<td>0</td>
<td>702</td>
<td>702</td>
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<tr>
<td></td>
<td>Two-week waits with suspected lower GI cancer (Number per 100,000 population)</td>
<td>38</td>
<td>375</td>
<td>266</td>
<td>515</td>
<td>270</td>
<td>251</td>
<td>0</td>
<td>771</td>
<td>771</td>
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<tr>
<td></td>
<td>Two-week waits with suspected lung cancer (Number per 100,000 population)</td>
<td>7</td>
<td>69</td>
<td>28</td>
<td>143</td>
<td>70</td>
<td>66</td>
<td>0</td>
<td>209</td>
<td>209</td>
</tr>
<tr>
<td></td>
<td>Two-week waits with suspected skin cancer (Number per 100,000 population)</td>
<td>10</td>
<td>99</td>
<td>47</td>
<td>182</td>
<td>146</td>
<td>280</td>
<td>0</td>
<td>566</td>
<td>566</td>
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<tr>
<td></td>
<td>In-patient or day-case colonoscopy procedures (Number per 100,000 population)</td>
<td>103</td>
<td>1016</td>
<td>831</td>
<td>1234</td>
<td>677</td>
<td>513</td>
<td>302</td>
<td>1419</td>
<td>1419</td>
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<tr>
<td></td>
<td>In-patient or day-case sigmoidoscopy procedures (Number per 100,000 population)</td>
<td>40</td>
<td>396</td>
<td>262</td>
<td>538</td>
<td>324</td>
<td>360</td>
<td>55</td>
<td>682</td>
<td>682</td>
</tr>
<tr>
<td></td>
<td>In-patient or day-case upper GI endoscopy procedures (Number per 100,000 population)</td>
<td>134</td>
<td>1324</td>
<td>1109</td>
<td>1568</td>
<td>1374</td>
<td>999</td>
<td>729</td>
<td>2385</td>
<td>2385</td>
</tr>
<tr>
<td></td>
<td>Number of emergency admissions with cancer (Number per 100,000 population)</td>
<td>48</td>
<td>474</td>
<td>350</td>
<td>629</td>
<td>583</td>
<td>691</td>
<td>239</td>
<td>1122</td>
<td>1122</td>
</tr>
<tr>
<td></td>
<td>Number of emergency presentations (% of presentations)</td>
<td>4</td>
<td>14.3%</td>
<td>5.7%</td>
<td>31.5%</td>
<td>33.7%</td>
<td>23.7%</td>
<td>12.5%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td></td>
<td>Number of managed referral presentations (% of presentations)</td>
<td>18</td>
<td>64.3%</td>
<td>45.8%</td>
<td>79.3%</td>
<td>46.5%</td>
<td>48.6%</td>
<td>0.0%</td>
<td>87.5%</td>
<td>87.5%</td>
</tr>
<tr>
<td></td>
<td>Number of other presentations (% of presentations)</td>
<td>6</td>
<td>21.4%</td>
<td>10.2%</td>
<td>39.5%</td>
<td>19.4%</td>
<td>27.7%</td>
<td>0.0%</td>
<td>50.0%</td>
<td>50.0%</td>
</tr>
</tbody>
</table>
Cancer Risk Assessment Tools
- Patients with higher risk scores were more likely to be investigated ($p<0.0001$, rank sum test).
- Doctors reported that RATs helped to confirm a need for investigation as well as allowing reassurance when investigation was not needed.
- RATs were seen as helpful by users in assisting with the complex decisions around early cancer diagnosis, especially in cases of unusual presentations.
- Different referral decisions were made as a result of using them than might otherwise have been made.
- Overall, it is likely the GPs’ threshold for investigating for cancer was lowered.
Access to investigations

- Rapid access to investigations would have altered the GP’s management of the patient in 6% of cases.

- Some cancer patients, however, were more likely to have benefited from better access to diagnostics. These included patients with brain, ovary, pancreas, liver and kidney cancer (RCGP).
International comparisons - crude colonoscopy rates per 1,000 in 2010/11
Strategies which may bring about earlier diagnosis:

Awareness raising in the community

Practice profiling/benchmarking

Significant event analyses

Risk assessment tools
Research priority: large scale data linkages

- Cancer Registration
- Hospital Inpatient Activity (HES)
- GP Research Database
- Hospital Outpatients
- Cancer Screening
- Cancer Waiting Times
- Trials, cohorts
Overview

- Cancer control: why consider primary care?
- Primary prevention
- Screening
- Early diagnosis
- Management and survivorship
- Cancer policy
- Conclusions
Acute management of cancer

- Generally minimal involvement of GP but....
  - typically substantial increase in face-to-face contacts compared to patients without cancer
  - significant increases in drug prescriptions and referrals
  - increase in consulting and prescribing relating to psychosocial issues
Follow up - why?

- detect cancer recurrence
- treatment side effects, new cancers
- other co-morbid health conditions
- incorporate on-going therapy (e.g., endocrine treatments)
- quality of life issues
- psychosocial issues
- empowerment/self management
UK RCT of PCP vs Specialist Follow-up

**Setting:**
- two district general hospitals in England

**Participants:**
- 296 women with breast cancer on follow-up through specialist clinics
- 18 month study period

**Randomization:**
- Group 1 – continued specialist follow-up
- Group 2 – follow-up from their own GP
<table>
<thead>
<tr>
<th>Randomized Trial (18 months follow-up)</th>
<th>Trial Group</th>
<th>Difference (95%CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>GP n = 148</td>
<td>Specialist n = 141</td>
</tr>
<tr>
<td>Time to diagnosis of recurrence (days)</td>
<td>22 days</td>
<td>21 days</td>
</tr>
<tr>
<td>Total time with the patient (min)</td>
<td>35.6</td>
<td>20.7</td>
</tr>
<tr>
<td>Cost per patient (£s)</td>
<td>65</td>
<td>195</td>
</tr>
<tr>
<td>Time cost to the patient (min)</td>
<td>53</td>
<td>82</td>
</tr>
</tbody>
</table>

- No difference in health-related quality of life over time
- No difference in anxiety or depression over time
- GP patients more satisfied

*p<0.001

Grunfeld et al BMJ 1996
Randomized Trial of Long-Term Follow-Up for Early-Stage Breast Cancer: A Comparison of Family Physician Versus Specialist Care

Eva Grunfeld, Mark N. Levine, Jim A. Julian, Doug Coyle, Barbara Szechtman, Doug Mirsky, Shalendara Verma, Susan Dent, Carol Sawka, Kathleen I. Pritchard, David Ginsberg, Marjorie Wood, and Tim Whelan
Patients
- Early stage breast cancer
- Completed adjuvant therapy (continued Tamoxifen)
- Disease free
- 9-15 months post-diagnosis

FP Group
- Follow-up by patient’s FP
- Guideline (1 page)
- Refer back to CC if recurrence or new cancer

CC Group
- Follow-up at cancer center
- Usual practice
<table>
<thead>
<tr>
<th>Outcome Event</th>
<th>Family Physician (FP) Group (n=483)</th>
<th>Cancer Centre (CC) Group (n=485)</th>
<th>Risk Difference CC – FP (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of Patients (%)</strong></td>
<td></td>
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<tr>
<td><strong>Recurrence</strong></td>
<td></td>
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</tr>
<tr>
<td>Distant&lt;sup&gt;a&lt;/sup&gt;</td>
<td>54 (11.2%)</td>
<td>64 (13.2%)</td>
<td>2.02% (-2.13, 6.16)</td>
</tr>
<tr>
<td>Local&lt;sup&gt;a&lt;/sup&gt;</td>
<td>36</td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>Contralateral&lt;sup&gt;a&lt;/sup&gt;</td>
<td>11</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td><strong>Death (All Causes)</strong></td>
<td>29 (6.0%)</td>
<td>30 (6.2%)</td>
<td>0.18% (-2.90, 3.26)</td>
</tr>
<tr>
<td><strong>Serious Clinical Events</strong></td>
<td>17 (3.5%)</td>
<td>18 (3.7%)</td>
<td>0.19% (-2.26, 2.65)</td>
</tr>
<tr>
<td>Spinal Cord compression&lt;sup&gt;b&lt;/sup&gt;</td>
<td>0</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Pathological fracture&lt;sup&gt;b&lt;/sup&gt;</td>
<td>3</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Uncontrolled local recurrence&lt;sup&gt;b&lt;/sup&gt;</td>
<td>2</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>KPS ≤ 70&lt;sup&gt;b&lt;/sup&gt;</td>
<td>14</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>Brachial plexopathy&lt;sup&gt;b&lt;/sup&gt;</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Hypercalcemia&lt;sup&gt;b&lt;/sup&gt;</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>
• In Australia ~ 144,000 women living with breast cancer

• follow-up is mostly carried out in the tertiary setting by a specialist clinician

• *Shared care demonstration project* aims to assess shared care as a model for follow-up care that is safe and effective, and facilitates equity of access to breast cancer care across Australia
## Follow-up of women with early breast cancer

<table>
<thead>
<tr>
<th>Method</th>
<th>Years 1 and 2</th>
<th>Years 3–5</th>
<th>After 5 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>History and examination</td>
<td>Every 3–6 months</td>
<td>Every 6–12 months</td>
<td>Every 12 months</td>
</tr>
<tr>
<td>Mammography of the ipsilateral breast (if breast conserving therapy)</td>
<td>Every 12 months*</td>
<td>Every 12 months</td>
<td>Every 12 months</td>
</tr>
<tr>
<td>and contralateral breast</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chest X-ray</td>
<td>Only if clinically indicated on suspicion of recurrence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bone scan, CT, PET or MRI scans, blood count, biochemistry and tumour markers</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Shared care demonstration project

Aim

To implement and evaluate a model of shared care, between primary and specialist clinicians, for follow-up of women after completion of hospital-based therapy for early breast cancer, consistent with evidence-based guidelines.
Evaluation

Is shared follow-up care acceptable to women, specialists and general practitioners?

Is the cost of delivery comparable to the existing model of care?

Does shared follow-up care support best practice care?
**RECOMMENDED FOLLOW-UP SCHEDULE**

- To be completed and agreed by the specialist and GP at commencement of shared care to document all planned monitoring.
- The standard follow-up schedule recommended by National Breast and Ovarian Cancer Centre is provided below to plan follow-up appointments.

<table>
<thead>
<tr>
<th>Time since diagnosis</th>
<th>Date</th>
<th>Purpose of Visit</th>
<th>Provider Name &amp; Speciality</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Years 1–2</strong></td>
<td></td>
<td>Breast cancer follow-up</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• History and clinical breast examination (CBE) every</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3–6 months, and</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Breast imaging (mammogram and/or ultrasound) every</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>12 months</td>
<td></td>
</tr>
</tbody>
</table>
Strategies identified for recruitment and engagement of GPs:

- Presentations about shared care to Divisions of General Practice (DGP) and individual GPs, delivered by the specialist team;
- Strategies to support the GP deliver shared care e.g. a central contact at hospital sites for GP queries;
- Approaching GPs through existing hospital databases to identify potential providers of shared follow-up care; and
- Individual patients approaching their GP
Best practice follow-up care

- 91% of patients recruited to the project received an individualised follow-up schedule

- For over 80% of follow-up visits the following core actions, as recommended in NBOCC’s clinical practice guidelines, were undertaken:
  - Checking for symptoms and signs of local or regional recurrence
  - Asking about symptoms of distant recurrence
  - Reviewing medications
  - Identifying side-effects of treatment
Components of a shared care model

- Evidence-based clinical practice guidelines

- Information and tools
  - Patient held Shared Care Plan
  - Rapid Request form

- Clinical leadership

- Appropriate infrastructure
  - Accurate and accessible electronic medical records
Aromatase Inhibitors: Anastrozole (Arimidex®), Exemestane (Aromasin®), Letrozole (Femara®)

ESCA: For the treatment of postmenopausal breast cancer

AREAS OF RESPONSIBILITY FOR THE SHARING OF CARE

This shared care agreement outlines suggested ways in which the responsibilities for managing the prescribing of aromatase inhibitors (anastrozole, exemestane and letrozole) for early or advanced postmenopausal breast cancer can be shared between the hospital specialist and general practitioner (GP). GPs are invited to participate. If the GP is not confident to undertake these roles, then he or she is under no obligation to do so. In such an event, the total clinical responsibility for the patient for the diagnosed condition remains with the specialist. If a specialist asks the GP to prescribe this drug, the GP should reply to this request as soon as practicable.

Sharing of care assumes communication between the specialist, GP and patient. The intention to share care should be explained to the patient by the doctor initiating treatment. It is important that patients are consulted about treatment and are in agreement with it. Patients with postmenopausal breast cancer are under regular specialist follow-up, which provides an opportunity to discuss drug therapy.

The doctor who prescribes the medication legally assumes clinical responsibility for the drug and the consequences of its use.

RESPONSIBILITIES and ROLES

<table>
<thead>
<tr>
<th>Specialist responsibilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Ask the GP whether he or she is willing to participate in shared care.</td>
</tr>
<tr>
<td>2. Discuss benefits and side effects of treatment with patient.</td>
</tr>
<tr>
<td>3. Initiate treatment with</td>
</tr>
<tr>
<td>4. Continue to prescribe until GP has agreed to take over prescribing.</td>
</tr>
<tr>
<td>5. Notify GP of review date (at least annually) and give advice on stopping treatment.</td>
</tr>
<tr>
<td>6. Assess need for BMD measurement and advise GP on need for subsequent monitoring and/or treatment for osteoporosis (or arrange BMD measurement if not available to GP).</td>
</tr>
<tr>
<td>7. Have a mechanism in place to receive rapid referral of a patient from the GP in the event of adverse effects or deteriorating clinical condition.</td>
</tr>
<tr>
<td>8. Report adverse events to the CSM and GP.</td>
</tr>
<tr>
<td>9. Ensure clear back up arrangements exists for GPs for advice and support.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>General Practitioner responsibilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Reply to the request for shared care as soon as practicable.</td>
</tr>
<tr>
<td>2. Prescribe aromatase inhibitors (anastrozole, exemestane or letrozole) as per attached guidelines.</td>
</tr>
<tr>
<td>3. Refer promptly to the specialist when any loss of clinical efficacy is suspected (e.g. worsening of disease related symptoms, new symptoms suggestive of disease progression) or intolerance to therapy occurs.</td>
</tr>
<tr>
<td>4. Stop treatment on advice of specialist.</td>
</tr>
<tr>
<td>5. Liaise with specialist about need for osteoporosis monitoring, treatment or prophylaxis.</td>
</tr>
<tr>
<td>6. Report to and seek advice from the specialist on any aspect of patient care that is of concern to the GP and CSM.</td>
</tr>
</tbody>
</table>
Primary care physicians' views of routine follow-up care of cancer survivors.

Del Giudice ME, Grunfeld E, Harvey BJ, Piliotis E, Verma S.
‘the majority of breast cancer patients prefer routine tests and periodic routine visits for 10 years or longer by specialists’
Follow-up of cancer in primary care versus secondary care: systematic review

Ruth A Lewis, Richard D Neal, Nefyn H Williams, Barbara France, Maggie Hendry, Daphne Russell, Dyfrig A Hughes, Ian Russell, Nicholas SA Stuart, David Weller and Clare Wilkinson

Patients’ and healthcare professionals’ views of cancer follow-up: systematic review

Ruth A Lewis, Richard D Neal, Maggie Hendry, Barbara France, Nefyn H Williams, Daphne Russell, Dyfrig A Hughes, Ian Russell, Nicholas SA Stuart, David Weller and Clare Wilkinson
Involvement of primary care in cancer follow-up: potential benefits

- Evidence that strong primary care can lead to better health outcomes in chronic disease management.
- Cancer patients have multiple health needs, and require holistic, co-ordinated care.
- Many primary care practitioners want to have a greater role.
- Many patients want their family doctor to be involved.
- Potentially:
  - Promotes better-integrated care.
  - More cost-effective.
Involvement of primary care in cancer follow-up: caveats

- many cancer patients prefer to stay closely linked to hospitals/specialist services
- many problems experienced by cancer patients require specialised skills
- primary care practitioners often reluctant to take on these kinds of responsibilities
- may not have sufficient access to services needed
- quality of primary care varies widely
Survivorship

‘the period following first diagnosis and treatment and prior to the development of a recurrence of cancer or death’

From Cancer Patient to Cancer Survivor,
Institute of Medicine, USA, 2006
Increasing cancer survival

Five year relative survival, all cancers combined, Australia, 1982-1986 to 2006-2010


Follow-up of breast cancer survivors

Breast cancer five-year survival rates are high for people whose cancer is detected early. They are among the highest five-year survival rates.

Advances in treatment over recent years have reduced psychological and physical morbidity (e.g., through the use of sentinel lymph node biopsy, and breast-conserving surgery versus radical mastectomy) and reduced the risk of recurrence and mortality (e.g., through the use of adjuvant chemotherapy, aromatase inhibitors, tamoxifen and surgical removal of ovaries). Genetic profiling advances may help to further increase the effectiveness of treatment and reduce late effects from treatment. Follow-up includes scheduling regular reviews and ensuring cancer survivors are aware of the risks of late effects associated with their breast cancer treatment.

Five- and 10-year survival (Australia)
In 2004, five-year survival for women with breast cancer was 87.7% and 10-year survival was 79.4%.

Potential issues for survivors
Survivors may experience many different issues after completing treatment: physical, emotional, psychosocial and practical.
Survivorship care ideally addresses all of these issues. The four main aims of care during the survivorship phase, as detailed by the Institute of Medicine’s report (see Hewitt et al. 2006) ‘From cancer patient to cancer survivor: lost in transition’, are:

- surveillance for cancer spread, recurrence or second primary cancers
- coordination between specialists and primary care providers to ensure that all of the survivor’s health needs are met (incl. health promotion, immunisation, screening for cancer and non-cancerous conditions, and the care of concurrent conditions)
- intervention for consequences of cancer and its treatment (e.g., problems such as lymphoedema and sexual dysfunction, symptoms including pain and fatigue, psychological distress experienced by cancer survivors and their caregivers, and concerns related to employment and insurance)
- prevention and detection of new cancers and recurrent cancer.

Surveillance for cancer spread, recurrence or second primary cancers

Most recurrences are detected in the five years after diagnosis, although recurrence can occur more than 20 years after the initial diagnosis. For women who have had mastectomy, the majority of recurrences will be detected by clinical examination alone. For women who have had breast-conserving surgery, a significant proportion will be
Quality and Outcome (‘QOF’) indicators

Thames Valley audit: 35 patients had had a review, only 2 could recall it
Adams E, Boulton M, Rose P et al Br J Gen Prac 2011
Survivorship care plans

- Can take many forms but typically include:
  - Guidelines for health care providers
  - Guidelines for patient
  - Information on health care services
  - Educational session for patient
  - Detailed information on treatments, outcomes, and risk of future problems
primary outcome: cancer-related distress at 12 months, assessed by the Impact of Event Scale (IES).
Effective follow up: Testing risk stratified pathways
May 2011
Risk stratification and survivorship: UK pilots

- Risk stratified pathways of care based on:
  - tumour type, treatment and personal circumstances of the individual
- all patients offered a personalised care plan that ‘focuses on their individual needs’
- treatment summary for the patient
- information and education to ‘enable choice and confidence to self manage’
- remote monitoring
- care coordination
- hand held records
National Cancer Survivorship Initiative (NCSI) - Adult Prototype Sites (2011)

1. Hull and East Yorkshire Hospitals NHS Trust
2. Ipswich Hospital NHS Trust
3. Luton and Dunstable Hospital NHS Foundation Trust
4. North Bristol Hospital NHS Trust
5. Guy’s & St Thomas’ NHS Foundation Trust
6. Hillingdon Hospital NHS Trust
7. Brighton and Sussex University Hospitals NHS Trust
Cancer Survivorship in Australia
Overview

- Cancer control: why consider primary care?
- Primary prevention
- Screening
- Early diagnosis
- Management and survivorship
- Cancer policy
- Conclusions
Where am I?

You're 30 metres above the ground in a balloon.

You must be a researcher.

Yes.

How did you know?

Because what you told me is absolutely correct but completely useless.

You must be a policy maker.

Yes, how did you know?

Because you don’t know where you are, you don’t know where you’re going, and now you’re blaming me.

The problem.
Cancer control: evidence translates into policy and practice in unpredictable ways

- Cancer screening programmes
  - Modalities
  - Target groups
  - Programme organisation

- Cancer follow-up strategies
  - Primary care
  - Nurse-led
  - Self-care
The Primary Care Collaborative Cancer Clinical Trials Group

- Should I take low-dose aspirin?
- CHEST Australia: a Phase II randomised controlled trial of a complex intervention to promote consulting with symptoms of cancer
- Applying risk markers to prostate cancer screening
- Timely diagnosis and referral of people with suspected or definite lung cancer: An analysis of current practice and examination of barriers to best practice
The Primary Care Collaborative Cancer Clinical Trials Group

- acupuncture for lymphoedema
- trial of primary care-based follow up for prostate cancer
- rehabilitation and early return to work after cancer
- coordinated, needs-based model of supportive care for lung cancer patients
- functioning of breast and prostate cancer survivors through tailored nutrition and exercise intervention
Overview

- Cancer control: why consider primary care?
- Primary prevention
- Screening
- Early diagnosis
- Management and survivorship
- Cancer policy
- Conclusions
Primary care: why a limited role in cancer?

- Recognised role in:
  - assessing symptoms and diagnosis
  - delivery of some screening programmes
  - palliative care

- Some noteworthy models of primary care involvement, but typically excluded in ‘conventional’ models of cancer care

- Reasons for limited role in many aspects of cancer journey:
  - perception that management of cancer is high technology and hospital-based
  - territorial issues, perceived lack of necessary skills amongst PCPs
  - lack of integration between primary and secondary care services
  - training, education and workforce issues
Why should primary care have a greater role in cancer prevention?

- **Broad-based contribution:**
  - education/awareness raising of cancer symptoms
  - promotion and delivery of screening
  - co-ordinating care for complex needs of individuals with cancer
  - primary prevention
  - management of co-morbidities
  - advocacy re poor housing, poor nutrition, inadequate water supplies

- **Affordability in low-resource settings**
Integrating primary care into cancer control

- National cancer plans need to recognise the potential of primary care in cancer control.
- This recognition needs to translate into practical strategies in areas including:
  - primary prevention
  - screening
  - early diagnosis
- Strategies need to address:
  - financial, organisational and attitudinal constraints
  - significant gaps in research and evidence
Acknowledgements..

- my collaborators
- NCRI
- PC4
- Cancer Australia
- UNSW
- Australian Primary Health Care Research Institute
Thanks for your attention!

David Weller

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