International Cancer Benchmarking Partnership (ICBP) policy impacts

Professor David Currow FAHMS
Chief Executive Officer, Cancer Institute NSW. Chief Cancer Officer, NSW.
Deputy ICBP Chair
ICBP impact – policy reach

What is the ‘burning platform’?

There appeared to be wide disparities in cancer outcomes despite:
- similar philosophies underpinning the provision of *health care*;
- similar structures delivering *health care*;
- comparable investment in *health care* as a proportion of gross domestic product (GDP);
- similar levels of training and education for the *health workforce*;
- comparable educational / literacy levels across the *community*; and
- largely comparable processes for *registering cancers* and death at a whole-of-population level?
ICBP impact – policy reach

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There appeared to be wide disparities in cancer outcomes despite:
- similar philosophies underpinning the provision of health care;
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- comparable educational literacy levels across the community; and
- largely comparable processes for registering cancers and death at a whole-of-population level?
PHASE 1

- International cancer survival benchmark (patients diagnosed 1995-2007) for 4 cancer types
- Public awareness, beliefs and attitudes to cancer
- Role of primary care practitioners in diagnosis
- Measuring time intervals from symptoms to diagnosis and treatment
- Exploring factors that may impact short term survival

PHASE 2

- International cancer survival benchmark (patients diagnosed 1995-2014) for 8 cancer types
- Access to diagnostic and post-diagnostic tests
- Access to optimal treatments
- Cancer patient pathways
- Organisation and structure of health systems
What key variations were found?

Community attitudes to, and knowledge about cancers (and therefore how to respond to symptoms)

Primary care: access to, and uptake of diagnostic investigations
Barriers to symptomatic presentation: “Would any of these put you off going to the doctor with a symptom that might be serious?”

- **I would be too embarrassed**
  - UK: 20%
  - Denmark: 10%
  - Norway: 15%
  - Sweden: 25%
  - Australia: 20%
  - Canada: 30%

- **I would be worried about wasting the doctor's time**
  - UK: 35%
  - Denmark: 25%
  - Norway: 15%
  - Sweden: 10%
  - Australia: 20%
  - Canada: 40%

- **I would be worried about what a doctor might find**
  - UK: 30%
  - Denmark: 25%
  - Norway: 15%
  - Sweden: 20%
  - Australia: 15%
  - Canada: 40%

- **I am too busy to make time to go to the doctor**
  - UK: 25%
  - Denmark: 20%
  - Norway: 15%
  - Sweden: 15%
  - Australia: 20%
  - Canada: 35%
ICBP impact – policy reach

What key variations were found?

Community attitudes to, and knowledge about cancers (and therefore how to respond to symptoms)

Primary care: access to, and uptake of diagnostic investigations

Directly amenable to change
The partnership has provided evidence for:

- Cancer plans in **Norway, Australia (New South Wales, Victoria) and the UK (Scotland and England)**.
- Identifying priorities for new cancer control initiatives in **Canada**, such as establishing a Rapid Access Clinic for lung cancer in **Alberta**.
- Public awareness campaigns in **Denmark**, targeting specific sections of the population, addressing barriers to seeing a health professional in **England** and **Scotland**.
- Initiatives in **England, Scotland** and **Wales** aiming to improve access to diagnostics and exploring innovative diagnostic referral pathways.
- The relevance of **Danish** reforms to cancer diagnostic pathways aimed at diagnosing cancers earlier.
- Engagement exercises with GPs in **Manitoba** about barriers to accessing diagnostics, including urban/rural issues.
- Projects to improve cancer data completeness and availability in **NSW, Ontario, England** and **Wales**.
Australia

New South Wales

• Underpinned projects improving cancer data completeness and availability.
• Improved cancer registry practices based on findings from the partnership.
• Insights informed the choice of cancers with special emphasis in the New South Wales cancer plan, starting 2016.

Victoria

• Informed the Victorian Cancer Plan (2016-2020).
• Prompted a review of ovarian cancer treatment practices and supported state-wide implementation of an ovarian cancer optimal care pathway.
• Prompted a review of cancer registration process.
Canada

Ontario

• Underpinned projects improving cancer data completeness and availability.
• Further analyses have validated findings using administrative data and deepened understanding.
• Provided local evidence to the Cancer Care Ontario Clinical Council which develops cancer system strategy and the provincial cancer plan.

Alberta

• Provided evidence to support the establishment of a Rapid Access Clinic for lung cancer.
Canada

Manitoba

• Prompted a programme of research into ovarian cancer.

• Increased engagement within the primary care community on topics related to cancer, particularly differences in referral to specialists.

• Confirmed evidence underpinning Manitoba’s ‘InSixty’ initiative aimed at reducing the time cancer is first suspected to the time it is treated to 60 days or less.

• Provided a patient voice to the local cancer patient journey initiative, hearing how patients describe their successes and challenges with the system.
Impact – jurisdiction specific

United Kingdom

England

• Provided new evidence for cancer plans and identified priorities for new initiatives.
• Confirmed evidence underpinning public awareness campaigns.
• Contributed evidence for the ACE (accelerate, coordinate, evaluate) programme, exploring innovative diagnostic referral pathways.
• Underpinned projects improving cancer data completeness and availability.
Impact – jurisdiction specific

United Kingdom

Wales

• Prompted a lung cancer initiative to improve outcomes by taking a cross pathway approach.

• Led to a study tour to Denmark to learn more about improvements in access to diagnostics which provided additional evidence to establish pilots to improve diagnosis in Wales.

• Ovarian cancer awareness evidence in Wales contributed to the development of the equivalent English regional ‘Be Clear on Cancer’ campaign.

Northern Ireland

• Developed a mechanism for the cancer registry to receive data on comorbidities that have caused hospital admissions for cancer patients.

• Provided insights for public awareness campaigns.
Scandinavia

Sweden

Provided evidence towards a major effort to reduce waiting times, with additional funding from the national government.

Provided a stimulus for a continuous focus on improvement around breast cancer and led to the development of a colorectal cancer patient reported experience questionnaire.

Provided insights which initiated discussion about public awareness campaigns.

Contributed to a renewed assessment of data quality in the Swedish cancer register, in particular around death certificate only cases.
Scandinavia

Norway

Supported more user-oriented cancer care, improving diagnostic capacity and early cancer prevention as part of the Norwegian Cancer Plan (2013-2017).

Confirmed evidence from the Norwegian Board of Health Supervision that late diagnosis is a key issue in cancer care in Norway.

Provided new evidence of the need for improved and targeted initiatives to enhance public awareness about melanoma.
Scandinavia

Denmark

Provided evidence about stage registration and stage at treatment which underpinned a focus on earlier and faster cancer diagnosis. This is a shared priority for politicians, policymakers, clinicians and patient advocates.

Provided insights for public awareness campaigns and highlighted the impact of social inequalities.

Provided evidence for initiatives in the third and fourth national cancer action plans.

Provided evidence to support the Danish 3-legged strategy highlighting that primary care practitioners need better and faster access to investigations.
Common themes across jurisdictions:

For cancer service delivery:
- directly informing priorities for cancer service plans
- better understanding of public awareness / literacy
- providing in-depth benchmarking of processes
- excellent data to influence funding decisions

For cancer control:
- opportunities to improve cancer registration
ICBP is a natural experiment from which we can all learn.

The systems which deliver cancer today are arguably the most important factors in improving cancer outcomes in the near future.
Presented at over 15 conferences globally

**Module 1: Data**
- **Colorectal stage data:** over 310,000 patients
- **Breast stage data:** over 250,000 patients
- **Lung stage data:** over 57,000 patients
- **Ovarian stage data:** over 20,000 patients

**Module 2:**
- Over 19,000 people over the age of 50

**Module 3:**
- Over 2,700 PCPs surveyed

**Module 4:**
- Over 22,000 surveys returned (so far)

**Impact in numbers**
- Over 1,600 citations for papers referencing ICBP
- Over 250 citations for centrally funded papers
- Over 150 collaborators in 13 jurisdictions
- Over 35 organisations/funders
- Presented at over 15 conferences globally
- Over 2.4 million adults
- Over 2,470,000 PCPs surveyed
- Over 1,600,000 patients
• Pioneered a range of methods and research tools to enable robust and unique international comparisons

• Published 13 quality peer reviewed papers

• Figures from the survival benchmark quoted in conference presentations globally; used as part of the rationale for many investigative research studies

• Completed the first international comparisons of:
  ➢ Cancer survival and stage at diagnosis using routine data
  ➢ Cancer survival and public awareness, attitudes and beliefs (at this scale)
  ➢ Cancer survival and primary care referral behaviour and health system
Impact - additional analyses
<table>
<thead>
<tr>
<th>Country</th>
<th>Region</th>
<th>Description</th>
</tr>
</thead>
</table>
| Australia  | New South Wales | - Underpinned projects improving cancer data completeness and availability.  
                        - Improved cancer registry practices based on findings from the partnership.  
                        - Insights informed the choice of cancers with special emphasis in the state-wide cancer plan, starting 1 July 2016. |
                        - Led to the examination of Victorian ovarian cancer treatment practices and the cancer registration process, and supported work on implementation of an ovarian cancer optimal care pathway state-wide. |
### Awareness that cancer risk increases with age

<table>
<thead>
<tr>
<th>Country</th>
<th>0%</th>
<th>10%</th>
<th>20%</th>
<th>30%</th>
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<tbody>
<tr>
<td>Sweden</td>
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<td>Norway</td>
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<td>Denmark</td>
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<td>Australia</td>
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<tr>
<td>Canada</td>
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Proportion of respondents who said that 70-year-olds are most likely to be diagnosed with cancer (rather than 50-year-olds, 60-year-olds or people of any age).

### Country focus: Australia (Victoria, New South Wales)

- Australian PCPs reported the highest access to blood tests and whole body imaging (CTs, X-rays and ultrasounds) compared to other jurisdictions.\(^{15}\)
- Victorian PCPs reported higher access to investigations than PCPs in New South Wales.\(^{15}\)
- Australian PCPs reported the shortest waiting times for tests and results, and total waiting times for imaging tests (X-rays, CT, MRI and ultrasound tests) compared to all other jurisdictions.\(^{15}\)
- Average wait times in New South Wales were marginally better compared to Victoria for imaging waiting times. Victoria reported shorter endoscopy waiting times.\(^{15}\)

#### Barriers to symptomatic presentation: “Would any of these put you off going to the doctor with a symptom that might be serious?”

1. **I would be too embarrassed**

2. **I would be worried about wasting the doctor’s time**

3. **I would be worried about what a doctor might find**

4. **I am too busy to make time to go to the doctor**
THE INTERNATIONAL CANCER BENCHMARKING PARTNERSHIP - IMPACT ON POLICY AND PRACTICE

Sara Hiom
Director for Early Diagnosis, Cancer Research UK
NCIN Outcomes Conference, 10th June 2014, Birmingham
What is the ICBP?

- An international collaboration involving policy, research, cancer registry and clinical professionals

- Investigating survival differences, and factors that could affect these differences

- A unique perspective that helps pinpoint how cancer pathways might be improved

- Producing evidence that informs policy across the jurisdictions
13 jurisdictions in 6 countries

Who is involved?

Sweden
Norway
Denmark
Ontario
Manitoba
Alberta
British Columbia
Scotland
N. Ireland
Wales
England
New South Wales
Victoria
What are we looking at?

4 cancers - breast, lung, colorectal and ovarian

5 related modules

**Module 1:** Epidemiological benchmarking study

**Module 2:** Public awareness, attitudes and beliefs

**Module 3:** The role of primary care and healthcare systems

**Module 4:** Variation in patient, diagnostic and treatment time intervals and routes to diagnosis

**Module 5:** Data comparability and early deaths (with an initial focus on co-morbidity for lung cancer)
Hypothesis

- Differences in stage at diagnosis and treatment contribute to international variation in cancer survival

Key Findings

- Cancer survival improved overall between 1995-2007 in all jurisdictions but remains lowest in UK & Denmark
- UK has worst stage distribution for colorectal and lung cancer in particular
- Survival within stage is lower for all four cancers, especially later stages
Module 1 – novel comparison method

For the first time - developed a peer reviewed method for international comparisons of stage at diagnosis
Module 1 – survival by stage at diagnosis
### Module 1 - survival and stage

<table>
<thead>
<tr>
<th>Paper</th>
<th>Stage distribution</th>
<th>Stage specific survival</th>
<th>Possible reasons for differences</th>
<th>Impact of our understanding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>Favourable - more women in the UK diagnosed at an early stage</td>
<td>Low for stages 3 and 4</td>
<td>The quality of and/or access to treatment</td>
<td>All parts of the patient pathway are important</td>
</tr>
<tr>
<td>Ovary</td>
<td>Favourable - more women in the UK diagnosed at an early stage</td>
<td>Poor survival at stages 2, 3 and 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colon/rectal</td>
<td>Mixed distribution fewer stage A and D but the most B and C</td>
<td>Typical for stages A/B Dukes Lower for stages C/D</td>
<td>Poorer treatment or access to treatment for late stage colorectal cancer is likely to be contributing to our low survival rates, and relatively few earliest stage at diagnosis.</td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>NSCLC had a slightly adverse stage distribution</td>
<td>Significantly lower in early stages. Lower in later stages but to a lesser extent</td>
<td>• Partly explained by late diagnosis • Treatment or access to treatment</td>
<td></td>
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</tbody>
</table>
Shift in how we think about international comparisons and useful evidence to help identify priorities

• **England**: new evidence for IOSC 2011 confirming the ‘survival gap’
• **Wales**: catalyst for improving data completeness
• **Canada**: informed priorities for new initiatives
• **Victoria**: follow up analysis for ovarian cancer
Module 2 – awareness & beliefs

Hypothesis

• Lower survival rates in Denmark and UK are explained in part by lower cancer awareness and more negative beliefs about cancer

Headline findings

Not supported - in all jurisdictions

• Generally positive attitudes and beliefs about cancer in all jurisdictions
• Low awareness of increasing risk with age

But, in the UK
• More likely to identify barriers to seeing their GP
Module 2 – impacts

- Awareness and beliefs about cancer are not likely to be impacting on international survival differences.

- Findings echo responses to the Cancer Awareness Measure (CAM) survey and put these in an international context.

- The new Attitude and Beliefs about Cancer (ABC) tool, based on the CAM is being adapted and used by other researchers.

- **England**: Confirm key messages in Be Clear on Cancer – targeting older patients, call to ‘go see your GP’ or ‘tell your doctor’.

- **Canada**: survey extended to all provinces.
Module 3 – the role of primary care

Hypothesis
• Differences in primary care systems may lead to delays and result in advanced stage at diagnosis, which in turn is associated with poor outcomes

Progress
• 2,795 GPs responses to online survey and analysis complete in 11 jurisdictions
• 3 papers close to publication
Latest (unpublished) international data suggests that GPs in England:

- Are less likely to send a patient for tests or to refer them at their first consultation
- Report having among the lowest access to specialist advice
- Tend to feel more strongly about protecting their patients from over investigation, and preventing a secondary care overload
Module 3 – impacts

• First suggestion of primary care factors that might explain survival differences

• Adds to evidence on system differences

• Opportunity to learn from other jurisdictions, eg Denmark – multi-disciplinary diagnostic centres, rapid (48h) diagnosis

• Contributed to evidence base in policy briefings in devolved countries which have led on to
  • England: explore innovative diagnostic referral pathways to allow GPs to act sooner
  • Wales: helped galvanise support for a new lung cancer initiative
  • Northern Ireland: catalyst for new awareness campaigns
Module 4 – patient, GP and specialist intervals

Hypothesis
• Lengthened patient, diagnostic and treatment intervals are associated with poorer outcomes

Innovative method
• Unique three pronged survey - patients, their GP and specialist
• Will develop a full picture across the cancer pathway in 10 jurisdictions

Progress
• Data collection extended to December 2014

Anticipated impact
• Focus in on areas with longest interval
• Relationship between interval length and survival
Module 5.1 – data quality simulation

Hypothesis

• Variations in cancer registry practices affect the comparability of key data used in cancer survival analyses

Method

• Report on variation based on interviews with cancer registry teams
• An online simulation model to enable jurisdictions to quantify the impact of these differences on cancer survival

Progress

• Australia, Canada, UK and Norway confirmed
• Simulation model underdevelopment

Anticipated impact

• Help to harmonise international data collections to enable comparison
• Links to initiatives to improve data quality and to standardise data collection for international analyses
Module 5.2 – ‘early deaths’ and co-morbidity

Hypothesis
• Deaths within a year of diagnosis are observed in jurisdictions with higher levels of co-morbidities

Method
• Electronic data linkage – registry, hospital, outpatient
• Not to our knowledge previously attempted, begin with lung cancer

Progress
• Australia, Canada, UK and Norway confirmed
• Ethical and information governance issues being addressed

Anticipated impact
• Extend analysis to other cancer types
• Understand better what could be contributing to poor 1-yr survival
Where next?

Continue delivering
- Ongoing research studies
- Support an infrastructure for an international network of policy, cancer registry, research and clinical professionals

Build an ICBP legacy
- Maximize the use of existing datasets, survey tools and methodologies
- Feed evidence into policy and practice and harmonise processes

ICBP ‘Phase 2’
- New research questions
- Other cancer sites?
- CRUK central coordination and methodology peer review
- Expand the partnership – new partners?
The ICBP is a partnership which involves many collaborators and funders. These include:
Thank you

Any questions?

www.icbp.org.uk
Improving Cancer Outcomes

International Cancer Benchmarking Project
1995-2007

• NSW, Victoria, Scandinavia (less Finland), United Kingdom (less Scotland) and the 4 largest provinces in Canada

• One single analysis

Improving Cancer Outcomes

International Cancer Benchmarking Project
2005-2007 - 5 year (relative) survival

• Colorectal  66.4%  (#1)  (52.3-66.4)
• Lung       17.6%  (#4)  (8.8-20.1)
• Breast     87.8%  (#4)  (81.0-89.1)
• Ovarian    39.9%  (#4)  (36.1-44.1)

International Cancer Benchmarking Program
Background

- Evidence of variations in cancer survival between different European countries
- EUROCARE 4: EUROpean CAncer REgistry based study on survival and CARE of cancer patients
  - ~ 3 million cancer cases in adults 1995-1999
  - 82 cancer registries
  - 32 European countries
  - Cohort followed until December 2003
  - Relative survival by cancer type and country
EUROCARE 4 Results

- Rectal cancer: 5-year age-standardised relative survival

- Marked differences between countries:
  - Switzerland 61%
  - England 52%
  - Poland 39%

Sant et al, Eu J Cancer 2009

- Outcomes for patients in UK consistently worse than for those in other similar countries
Reasons for disparities in outcomes

• Why does cancer survival vary between countries/jurisdictions?
  • Differences between patients (e.g., comorbidities, socioeconomic and behavioural factors)?
  • Differences in stage at diagnosis?
  • Different care processes (diagnostic and treatment pathways)?
  • Different health care systems? Primary care, secondary and tertiary care

• ICBP formed to try to answer these questions.
ICBP - Overview

• International partnership of clinicians, academics and policy makers

• Countries/jurisdictions selection criteria:
  • Broadly comparable wealth
  • Offer universal access to health care
  • Have long-standing, high quality, population-based cancer and death registration
ICBP members

• 12 jurisdictions in 6 countries across 3 continents:
  • Australia (New South Wales, Victoria)
  • Canada (Alberta, British Columbia, Manitoba, Ontario)
  • Denmark
  • Norway
  • Sweden
  • United Kingdom (England, Northern Ireland, Wales)
ICBP - scope

- The ICBP research focuses on 4 cancers:
  - Three common cancers where there are significant international differences in survival:
    - Breast
    - Colorectal
    - Lung
  - One less common cancer with a complex diagnostic pathway and large variations in survival between jurisdictions:
    - Ovarian
ICBP - Overview

The 5 ICBP research modules

• Module 1: Epidemiology
• Module 2: Population awareness and beliefs
• Module 3: Beliefs, behaviours and systems in primary care
• Module 4: Root cause of diagnosis and treatment delays
• Module 5: Treatment, co-morbidities and other factors
Module 1: international comparisons of cancer survival

Between 1995 and 2007 cancer survival improved for breast, bowel, lung and ovarian cancer in all jurisdictions.

But ... persistently

- higher in Australia, Canada, Sweden
- intermediate in Norway
- lower Denmark, England, Northern Ireland, Wales

Gap narrowed over time for breast cancer but less so or not at all for other cancers.
Module 1: international comparisons of cancer survival

Bowel cancer - 3 measures of relative survival

- Australian registries
- Swedish regions
- Canadian registries
- Norway
- Denmark
- UK (excluding Scotland)

Relative Survival

1 year
5 years
Conditional 5-year
Module 3: Beliefs, behaviours and systems in primary care

• To explore how different primary care systems impact on differences in cancer outcomes

• Specifically, to assess differences in GPs’ behaviours, skills, knowledge, incentives and practice administration factors

• Two components:
  • GP survey
  • System mapping exercise
Module 3: GP survey

• Random sample of 200 GPs in each jurisdiction

• Questionnaire will assess:
  • Access to investigations and referrals
  • Ease of obtaining specialist advice/referral
  • Practice administration
    • Length of routine appts
    • Process for booking and following up missed follow up appts
    • Process for following up /avoiding missing test results
  • Self-reported management of patients presenting with possible symptoms of cancer (case vignettes)
Module 4: Patient cohort

• Aims to investigate routes to diagnosis and time intervals

• Time intervals
  • Patient interval – time from symptom onset to first health professional (HP) contact
  • Diagnostic interval – time from first HP contact to definitive cancer diagnosis
  • Treatment interval – time from definitive diagnosis to start of treatment
  • Total time interval – time from onset of symptoms to start of treatment
Beliefs, behaviours and systems in primary care: NSW findings from the International Cancer Benchmarking Partnership

Jane Young, Claire McAulay, Ingrid Stacey, Megan Varlow, David Currow
Background to ICBP

• Evidence of variations in cancer survival between different European countries

• Example – rectal cancer: 5-year age-standardised relative survival
  • Switzerland 61%
  • England 52%
  • Poland 39%

Sant et al, Eu J Cancer 2009

• ICBP formed to try to answer these questions
• Focus on lung, colorectal, breast and ovarian cancer
ICBP Module 3 aims

• To explore whether differences in primary care systems might explain variations in cancer survival between countries

• In NSW, to investigate GPs’:
  • beliefs about early diagnosis of cancer and their role in the cancer system
  • access to diagnostic tests and specialists in the public and private sectors
  • self reported practices for patients presenting with suspicious symptoms
  • views of resources that could improve the interface between primary and specialist care

• To compare responses for urban and rural GPs
Methods

• Online survey of GPs in
  • UK (England, Wales, Northern Ireland)
  • Scandinavia (Norway, Sweden, Denmark)
  • Canada (British Columbia, Manitoba, Ontario)
  • Australia (Victoria and NSW)

• GPs’ behaviours measured using case scenarios
• GPs’ beliefs and systems measured using direct questions

• Additional questions in NSW and Victoria:
  • access to services in the public and private sectors
  • out-of-pocket expenses for patients
  • influences on referral practices
  • preferences for resources to improve the interface between primary and specialist care
NSW sample and recruitment

• Random sample of GPs identified from a commercial list (AMPCo)
• Stratified by urban or regional/rural location based on ARIA+ classification of practice postcode
• Primer letter, invitation and up to 3 mailed reminders
• GPs were ineligible if:
  • not working primarily in clinical general practice
  • provided locum services only
  • had died, retired, on extended leave
  • no longer in NSW
Response rate

2500 names selected
1250 metro, 1250 rural
(10% not eligible)

2246 eligible

Embedded RCT of response-aiding strategies

273 responses (12.2%)
## Characteristics of respondents

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Rural (N = 140)</th>
<th>Urban (N= 133)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Female</td>
<td>61 (44)</td>
<td>62 (47)</td>
</tr>
<tr>
<td>Age (years)</td>
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<tr>
<td>&lt; 35</td>
<td>14 (10)</td>
<td>13 (10)</td>
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<td>35–44</td>
<td>28 (20)</td>
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<td>45–54</td>
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<tr>
<td>55–64</td>
<td>52 (37)</td>
<td>39 (29)</td>
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<tr>
<td>≥ 65</td>
<td>4 (3)</td>
<td>15 (11)</td>
</tr>
<tr>
<td>GP registrar</td>
<td>10 (7)</td>
<td>8 (6)</td>
</tr>
<tr>
<td>Sole practitioner</td>
<td>13 (9)</td>
<td>21 (16)</td>
</tr>
<tr>
<td>Part time</td>
<td>44 (31)</td>
<td>54 (41)</td>
</tr>
<tr>
<td>Years in general practice</td>
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<td></td>
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<tr>
<td>&lt; 3</td>
<td>11 (8)</td>
<td>8 (6)</td>
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<td>3–5</td>
<td>18 (13)</td>
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<td>6–10</td>
<td>12 (9)</td>
<td>21 (16)</td>
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<tr>
<td>11 +</td>
<td>99 (71)</td>
<td>94 (71)</td>
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Beliefs about timely diagnosis
More timely diagnosis of cancer is important to ensure better outcomes

<table>
<thead>
<tr>
<th></th>
<th>Agree or Strongly agree</th>
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<tbody>
<tr>
<td></td>
<td>Rural (%)</td>
</tr>
<tr>
<td>Colorectal</td>
<td>97</td>
</tr>
<tr>
<td>Melanoma</td>
<td>96</td>
</tr>
<tr>
<td>Breast</td>
<td>94</td>
</tr>
<tr>
<td>Ovarian</td>
<td>89</td>
</tr>
<tr>
<td>Lung</td>
<td>83</td>
</tr>
<tr>
<td>Prostate</td>
<td>51</td>
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## Beliefs about role in cancer system

<table>
<thead>
<tr>
<th>Belief</th>
<th>Agree or strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rural (%)</td>
</tr>
<tr>
<td>I like to wait until I am sure of a diagnosis before referring to a specialist</td>
<td>21</td>
</tr>
<tr>
<td>I am often unclear about when I should refer to a specialist when I suspect cancer</td>
<td>6</td>
</tr>
<tr>
<td>Protecting patients from over-investigation is an important part of my role</td>
<td>44</td>
</tr>
<tr>
<td>Preventing secondary/specialist care cancer services from being overloaded is an important part of my role</td>
<td>44</td>
</tr>
</tbody>
</table>
## Influences on management decisions

<table>
<thead>
<tr>
<th></th>
<th>Agree or strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rural (%)</td>
</tr>
<tr>
<td>Fear of litigation sometimes influences my decisions to order investigations</td>
<td>38</td>
</tr>
<tr>
<td>Fear of litigation sometimes influences my decisions to refer</td>
<td>35</td>
</tr>
<tr>
<td>I sometimes order cancer investigations that I don’t feel are indicated due to patient pressure</td>
<td>36</td>
</tr>
<tr>
<td>I sometimes refer patients due to patient pressure rather than clinical indication</td>
<td>29</td>
</tr>
</tbody>
</table>
Access to specialist advice within 48 hours regarding investigations for suspected cancer

<table>
<thead>
<tr>
<th>Agree or strongly agree</th>
<th>Rural (%)</th>
<th>Urban (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public system</td>
<td>51</td>
<td>51</td>
</tr>
<tr>
<td>Private system</td>
<td>76</td>
<td>89</td>
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</tbody>
</table>
Specialist referral within 48 hours for patient with suspected cancer

<table>
<thead>
<tr>
<th></th>
<th>Agree or strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rural (%)</td>
</tr>
<tr>
<td>Public system</td>
<td>36</td>
</tr>
<tr>
<td>Private system</td>
<td>69</td>
</tr>
</tbody>
</table>
Proportion of GPs reporting direct access to GI diagnostic tests (no specialist referral required)

<table>
<thead>
<tr>
<th></th>
<th>NSW rural</th>
<th>NSW urban</th>
<th>VIC rural</th>
<th>VIC urban</th>
</tr>
</thead>
<tbody>
<tr>
<td>Upper GI endoscopy</td>
<td>21</td>
<td>30</td>
<td>53</td>
<td>9</td>
</tr>
<tr>
<td>Flexible sigmoidoscopy</td>
<td>14</td>
<td>21</td>
<td>29</td>
<td>43</td>
</tr>
<tr>
<td>Colonoscopy</td>
<td>21</td>
<td>31</td>
<td>47</td>
<td>78</td>
</tr>
</tbody>
</table>
# Access to colonoscopy

Proportion of GPs reporting average waiting time of 4 weeks or less:

<table>
<thead>
<tr>
<th></th>
<th>NSW rural</th>
<th>NSW urban</th>
<th>VIC rural</th>
<th>VIC urban</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public system</td>
<td>14</td>
<td>23</td>
<td>24</td>
<td>18</td>
</tr>
<tr>
<td>Private system</td>
<td>79</td>
<td>88</td>
<td>84</td>
<td>96</td>
</tr>
</tbody>
</table>

Proportion of GPs receiving colonoscopy results within 1 week:

<table>
<thead>
<tr>
<th></th>
<th>NSW rural</th>
<th>NSW urban</th>
<th>VIC rural</th>
<th>VIC urban</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>37</td>
<td>40</td>
<td>67</td>
<td>68</td>
</tr>
</tbody>
</table>
Proportion of GPs who can arrange colonoscopy with no out of pocket expenses

<table>
<thead>
<tr>
<th></th>
<th>Rural</th>
<th>Urban</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, this is easy to organise</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td>Yes, but with difficulty</td>
<td>51</td>
<td>56</td>
</tr>
<tr>
<td>No</td>
<td>19</td>
<td>18</td>
</tr>
<tr>
<td>Don’t know</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Speciality</td>
<td>Public</td>
<td>Private</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
<td>General surgeon</td>
<td>46</td>
<td>85</td>
</tr>
<tr>
<td>Gastroenterologist</td>
<td>31</td>
<td>68</td>
</tr>
<tr>
<td>Colorectal surgeon</td>
<td>38</td>
<td>69</td>
</tr>
<tr>
<td>Respiratory physician</td>
<td>36</td>
<td>66</td>
</tr>
<tr>
<td>Thoracic surgeon</td>
<td>29</td>
<td>57</td>
</tr>
<tr>
<td>Gynaecologist</td>
<td>46</td>
<td>77</td>
</tr>
<tr>
<td>Gynaecologic oncologist</td>
<td>27</td>
<td>52</td>
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</tbody>
</table>
### GPs’ perceived importance of various factors for selecting a specialist

<table>
<thead>
<tr>
<th>Factor</th>
<th>Rural</th>
<th>Urban</th>
</tr>
</thead>
<tbody>
<tr>
<td>Previous experience referring patients to this specialist</td>
<td>84.3</td>
<td>90.2</td>
</tr>
<tr>
<td>Length of wait for appointment</td>
<td>70</td>
<td>68.4</td>
</tr>
<tr>
<td>Patient preference</td>
<td>49.3</td>
<td>52.6</td>
</tr>
<tr>
<td>Colleague recommendation</td>
<td>52.1</td>
<td>48.9</td>
</tr>
<tr>
<td>Specialist's hospital has good reputation for cancer care</td>
<td>32.1</td>
<td>57.9</td>
</tr>
<tr>
<td>Specialist is member of MDT</td>
<td>33.6</td>
<td>51.1</td>
</tr>
<tr>
<td>Specialists’ relevant cancer caseload</td>
<td>29.3</td>
<td>43.6</td>
</tr>
<tr>
<td>Know specialist personally</td>
<td>32.9</td>
<td>38.3</td>
</tr>
<tr>
<td>Out of pocket costs for patients</td>
<td>32.9</td>
<td>34.6</td>
</tr>
<tr>
<td>Distance patient must travel</td>
<td>33.6</td>
<td>26.3</td>
</tr>
<tr>
<td>Specialist's hospital has good published outcomes/low complication rates for cancer patients</td>
<td>17.1</td>
<td>41.4</td>
</tr>
<tr>
<td>Specialist is in directory of cancer specialists</td>
<td>6.4</td>
<td>19.5</td>
</tr>
<tr>
<td>Specialist is involved in clinical trials</td>
<td>3.6</td>
<td>11.3</td>
</tr>
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</table>
Perceived usefulness of resources for informing about cancer services and referral pathways

<table>
<thead>
<tr>
<th>Factor</th>
<th>Percentage responding “very important”</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rural</td>
</tr>
<tr>
<td>Discussion with colleagues</td>
<td>82</td>
</tr>
<tr>
<td>GP meetings or seminars</td>
<td>60</td>
</tr>
<tr>
<td>Feedback from patients</td>
<td>41</td>
</tr>
<tr>
<td>Mailed brochures or info from hospitals/specialists</td>
<td>36</td>
</tr>
<tr>
<td>GP publications and newsletters</td>
<td>25</td>
</tr>
<tr>
<td>Directory of specialists/services</td>
<td>26</td>
</tr>
<tr>
<td>Internet searches</td>
<td>24</td>
</tr>
<tr>
<td>Cancer Institute NSW CanRefer website</td>
<td>14</td>
</tr>
</tbody>
</table>
Limitations

- Very low response rate
- Participating GPs more positive towards cancer care than non-responders
- Scope of questions limited due to requirements of standardised instrument
Summary

• GPs expressed strong support for timely diagnosis to improve patient outcomes for breast, colorectal and melanoma skin cancer, but less for other cancer types
• Almost half of GPs considered that gatekeeping was an important part of their role
• There were marked differences in access to diagnostic tests and specialist services between urban and regional/rural GPs and for patients in the public and private sectors
• Waiting times were one of the most important factors influencing referral pathways
• These findings can inform future programs to enhance the interface between primary and specialist care and provide a baseline to monitor change
Acknowledgements

- We thank the GPs who participated in the survey, the ICBP Module 3 team who developed the core questionnaire and Sigmer UK who developed and managed the online database.
- The study was funded by the Cancer Institute NSW.
- JY is supported by Academic Leader in Cancer Epidemiology award number 08/EPC/1-01 from the Cancer Institute NSW and CM was employed through this award.
- Paper reporting embedded RCT of financial incentives to improve response rate will be published in *Journal of Clinical Epidemiology* (in press).