THE INTERNATIONAL CANCER BENCHMARKING PARTNERSHIP: GLOBAL LEARNING FROM OUR RESULTS

Harpal Kumar, Chief Executive, Cancer Research UK

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Outline of session

• **Introduction to the ICBP** - Harpal Kumar, Cancer Research UK (United Kingdom)

• **International comparisons of survival, stage and treatment** - Heather Bryant, Canadian Partnership Against Cancer (Canada)

• **International comparisons of population awareness, attitudes and beliefs about cancer** - Peter Vedsted, Aarhus University (Denmark)

• **Primary care: systems and practitioners** - Jane Young, University of Sydney (Australia)

• **International comparison of routes to diagnosis and possible reasons for delay** - Victoria White, Cancer Council Victoria (Australia) & David Weller, University of Edinburgh (United Kingdom)

• **What can we learn from international comparisons of data linkage?** - Jem Rashbass, Public Health England (United Kingdom)

• **A look to the future** - Sara Hiom, Cancer Research UK (United Kingdom)
What is the ICBP?

- An international collaboration involving clinicians, policy makers, researchers and cancer data experts
- Investigating survival differences and factors that could affect these
- A unique perspective that helps pinpoint how cancer pathways might be improved
- Producing evidence that informs policy across the jurisdictions – 11 high quality peer reviewed papers and more in the pipeline
Who is involved?

13 jurisdictions in 6 countries across 3 continents

- CANADA
  - Alberta
  - British Columbia
  - Manitoba
  - Ontario

- UK
  - England
  - Northern Ireland
  - Scotland
  - Wales

- SCANDINAVIA
  - Denmark
  - Norway
  - Sweden

- AUSTRALIA
  - New South Wales
  - Victoria
Which cancers are we studying?

4 cancers

breast  colorectal  lung  ovarian
What factors are we investigating?

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; plus co-morbidities and early deaths (with an initial focus on lung cancer)
Module 1 - findings and impact

Dr Heather Bryant
VP Cancer Control
Canadian Partnership Against Cancer
Toronto, Canada
Module 1 – survival differences

Core benchmarking

- 2.4 million breast, colorectal, lung and ovarian cancer patients across 6 countries, diagnosed between 1995-2007
- Follow up to end 2007
Survival differences – 5 year relative survival

Survival differences – 1 year relative survival

Colorectal Cancer 1yr Relative Survival

Breast Cancer 1yr Relative Survival

Lung Cancer 1yr Relative Survival

Ovarian Cancer 1yr Relative Survival

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

- All parts of the patient pathway are important
- Earlier diagnosis is a means to achieving greater access to optimal treatments
- The quality of the treatment is also important
Evidence to help identify priorities:

- **England**: new evidence for 2011 cancer plan update confirming the ‘survival gap’
- **Wales**: catalyst for improving data completeness
- **Canada**: informed priorities for new initiatives
- **Victoria**: follow up analysis for ovarian cancer
- **NSW, Ontario, England**: underpins ongoing projects improving cancer data availability
Module 2 - findings and impact

Professor Peter Vedsted
Research Centre for Cancer Diagnosis in Primary Care - CaP
Aarhus University
Denmark

Funding: Danish Cancer Society and Novo Nordisk foundation
The diagnostic funnel – what is normal?

2,000 people in a year

280-380 with rectal bleeding within a year

The patient interval

14-30 seek care

1 colon cancer

Inspired by: McAvoy BR. MJA.
Critical time intervals for cancer

Hypothesis
People with low cancer awareness and negative beliefs about cancer outcomes may be more likely to delay seeking medical help for suspicious symptoms

Population awareness and beliefs

Hypothesis:
- People in **DK** and **UK** would have lower cancer awareness and more negative beliefs about cancer than people in **Australia, Canada, Norway, Sweden**

Measure:
- Awareness and Beliefs about Cancer (ABC) measure

Method:
- Population-based surveys of men and women aged 50+ using computer assisted telephone interviews

When:
- 19,079 interviews completed across 12 jurisdictions in 2011
Awareness of symptoms
Number of symptoms recognised out of 11 (95% CI)
Barriers to presentation

Likelihood of: ‘Agree that I would be worried about wasting the doctor’s time’
Beliefs about cancer

Likelihood of: ‘Agree that many people with cancer can expect to continue with normal activities and responsibilities’

Fatalism and cancer

Likelihood of: ‘Agree that cancer can often be cured’

UK  Den  Nor  Can  Aus  Swe

Awareness and beliefs

• **Social gradient** – deprived people more often have:
  – Negative beliefs
  – Lower awareness

• Awareness of signs of melanoma higher in **Denmark** and **N Ireland** vs **Sweden** and **Norway**

• **Seeing the doctor** for symptoms that might be serious:
  – People in **UK** more **worried & embarrassed** than elsewhere
Impacts of Module 2

• There are differences between countries in awareness, beliefs and barriers
  – But no specific association with cancer survival

• England – confirmed key messages in awareness campaigns, targeting older patients and call to ‘tell your doctor’

• Long term evaluation of awareness campaigns needed
  – But some encouraging findings

Module 3 findings and impact

Professor Jane Young
University of Sydney and Cancer Institute New South Wales, Australia
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

Methods

- Systems mapping exercise
- Online survey of primary care practitioners
Survey of primary care physicians

Hypothesis
That there is a positive correlation between the proportion of PCPs who would investigate symptoms that are suspicious for cancer and cancer survival rates for the given cancer across jurisdictions

Methods
– Online, validated survey
– Questionnaire had two sections:
  • **Direct questions** - practice organisation, access to and timing of investigations
  • **Clinical vignettes** - patients presenting with ‘low but not no-risk’ symptoms, 2-3 stages per vignette
Statistical analysis

• PCPs classified as ‘acting’ when they referred a patient to secondary care or ordered a definitive diagnostic test for the cancer in question

• Definitive tests determined by a panel of experts were:
  – **Colorectal cancer**: colonoscopy or abdominal CT
  – **Lung cancer**: chest X-ray or chest CT
  – **Ovarian cancer**: abdominal CT or abdominal/trans-vaginal ultrasound

• Cumulative proportion of PCPs who acted at each stage of each vignette was calculated
PCP recruitment

- **2,795 respondents** across 11 jurisdictions
  - Australia (NSW, Victoria)
  - Canada (British Columbia, Manitoba, Ontario)
  - United Kingdom (England, Northern Ireland, Wales)
  - Denmark
  - Norway
  - Sweden
Results – logistic regression analysis

• No factors showed consistent association with readiness to investigate
  • PCP characteristics
  • Access to tests
  • Length of time from ordering test to receiving result
Limitations

• Generally poor response rates so respondents may not be representative of their jurisdictions
• Other analyses suggest that respondents are more positive towards cancer care than non-responders
• Do vignettes relate to actual practice?
• Ecological analysis
Conclusions

• Issues are complex
• Some variation in systems, but not related to outcome
• Vignette correlation with outcome looks interesting but does this relate to real life?
• PCPs acted at low levels of risk, but were not necessarily aware of the PPVs of groups of symptoms
Implications for timelier diagnosis

• Solutions will likely differ between jurisdictions:
  – Risk prediction tools for primary care
  – Empowering PCPs towards earlier investigation
  – Reducing barriers to specialist referral
• Likely to require changes in local health policy and systems -
to increase access to investigations, more efficient referral
pathways and redrafting of local referral guidelines
Module 4 – time intervals and routes to diagnosis

Dr Vicki White
Cancer Council Victoria
Australia

Professor David Weller
The University of Edinburgh
United Kingdom
Module 4 – time intervals and routes to diagnosis

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

Innovative method
- Unique three pronged survey – patients, their GP and specialist
- Recruitment through cancer registries
- Will develop a full picture across the cancer pathway in 10 jurisdictions
Module 4 – time intervals and routes to diagnosis

Progress
• Over 8,500 patient responses already received

Anticipated impact
• Focus in on areas with longest interval
• Relationship between interval length and survival
• Details on route to diagnosis and treatment
Module 4 – issues going forward

• Low/differential response rates
• Possible insufficient numbers in some jurisdictions, particularly for ovarian cancer
• Conflicting responses from patient, GP and specialist
• Socio-cultural differences in interpretation of questions
• Interpretation of differences in diagnostic intervals
Module 5 –
Exploring the impact of data quality differences and comorbidities on short term outcomes

Dr Jem Rashbass
Public Health England
United Kingdom
Module 5.1 – data quality

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
Module 5.1 – data quality simulation

Progress

• Simulation model in development

Anticipated impact

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

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
• Lung cancer diagnoses (2009-2012) – as proof of concept
Module 5.2 – ‘early deaths’ and comorbidity

Progress

• **Australia** (Victoria & NSW), **Canada** (Alberta, Manitoba, Ontario), **Denmark**, **UK** (England, N Ireland, Scotland, Wales) and **Norway** taking part

• 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
A look to the future

Sara Hiom
Director of Early Diagnosis and Cancer Intelligence
Cancer Research UK
United Kingdom
A look to the future

Building an ICBP legacy

• Delivering ongoing studies
• Maximising the use of existing datasets, survey tools and methodologies
• Continuing to push forward with challenging projects
• Becoming a stronger voice in making policy and practice recommendations
• Increasing clinical involvement and impact
• Going beyond published literature
A look to the future

Launching ‘Phase 2’

• New research questions
• Other cancer sites?
• Expanding the partnership
The ICBP is a partnership which involves many collaborators and funders. These include:
Thank you

Questions for the panel

www.icbp.org.uk