The International Cancer Benchmarking Partnership (ICBP) was established out of a mutual desire among our partners to deliver world class cancer services in each country to ensure the best possible outcomes for patients.

By learning from the experience of others, sharing ideas, comparing outcomes and good practice it is possible to identify and build a strong case for how cancer services can be improved.

The ICBP is the first international collaboration of its kind: it seeks to understand how cancer survival varies between jurisdictions, as well as what could be contributing to international differences. The partnership is providing strong evidence on a range of possible factors from public awareness and early diagnosis, to access to treatments, comorbidities and health system factors.

International comparisons are complex and require careful consideration and planning. The ICBP has pioneered new methodologies for quantifying and comparing these factors between partners to deliver robust findings.

To date, 11 high quality peer reviewed papers have been published - even more are in the pipeline. These papers have included an international cancer survival benchmark and the first international comparison of cancer survival and stage at diagnosis.

Our insights and understanding are aimed at helping all partners improve cancer outcomes by optimising cancer policies and services. New evidence from the ICBP has already been used to:

- Inform policy developments, to advocate for service planning and enhancements.
- Lead efforts to improve the completeness and comparability of routinely collected cancer data.
- Support the continued need for public awareness campaigns for cancer.

Since its launch in 2009 the partnership has gone from strength to strength. I look forward to the continued progress of the ICBP which is unique in its aim to understand why variation in cancer survival exists and providing insights for policy and practice to improve cancer survival. These insights are relevant for our partners and potentially more broadly.

Sincerely

Mike Richards
Chief Inspector for Hospitals
Care Quality Commission (UK)
The partnership is the first of its kind, seeking to understand not only how cancer survival varies between jurisdictions, but crucially, what could be driving these differences. It generates insight and understanding that will help all partners improve cancer outcomes by optimising cancer policies and services. These findings are also potentially relevant for other countries.

Each of our partners has up to date, long-established and high quality population-based cancer registry data, comparable levels of spending on health and universal access to health care. The ICBP is able to explore issues with great granularity to provide relevant insights for policy, by undertaking focused analyses, using a range of methodologies and approaches involving a small number of similar partners. The ICBP framework can serve as a model for conducting international benchmarking of other health policy topics.1

The ICBP research is predominantly focused on four cancer types: breast, colorectal, and lung cancer - common cancers that contribute a large share of the burden of cancer disease in developed countries - and ovarian cancer, a less common cancer with a complex diagnostic pathway.

The current ICBP programme is made up of five research modules, each looking at different aspects of the cancer pathway to identify possible reasons for international differences.

- Module 1 - Core cancer survival benchmarking
- Module 2 - Public awareness, beliefs and attitudes to cancer
- Module 3 - The role of primary care doctors and health systems in diagnosing cancer
- Module 4 - Measuring time intervals and pathways from symptom(s) to diagnosis and treatment
- Module 5 - Exploring the impact of comorbidities on short term outcomes

We joined the ICBP because we see the potential for accelerating continued improvement in cancer outcomes if we work with partners beyond our own borders to identify issues of common concern, and to work together to devise strategies to address these.

Dr Heather Bryant
Vice President, Cancer Control, Canadian Partnership Against Cancer, Canada
International Cancer Benchmarking Partnership

**Showcasing our findings and impacts**

The deficiencies in the stage data have highlighted the urgent need for a new global consensus for clinicians and cancer registries everywhere to use a single staging system, such as the Tumour, Nodes, Metastasis (TNM) classification, so that international monitoring of cancer outcomes can be done faster and more reliably in future.

Dr Sarah Walters
Lecturer, Cancer Research UK Cancer Survival Group, London School of Hygiene and Tropical Medicine, United Kingdom

"The team produced the first international comparisons of stage at diagnosis and cancer survival, using routinely collected data. The findings highlight that early diagnosis and optimal access to treatment are two factors, amongst others, likely contributing to international differences."

Module 1. Core cancer survival benchmarking

The team led by Professor Michel Coleman at the London School of Hygiene and Tropical Medicine, UK produced the survival comparisons that underpin the ICBP. They compared survival data from breast, colorectal, lung and ovarian cancer patients, diagnosed between 1995-2007, in all ICBP jurisdictions.

The findings show that relative cancer survival has improved in all countries but that differences remain.

Survival is higher in Australia, Canada, and Sweden, intermediate in Norway and lower in Denmark and the UK (England, Northern Ireland and Wales). The survival 'gap' between the best performing countries and the lowest remains largely unchanged – except for breast cancer, where the UK is narrowing the gap. The patterns were consistent with later stage at diagnosis or differences in treatment, particularly in Denmark and the UK, and in older patients (those aged 65 or over).

These findings have underpinned cancer plans and policies in a number of partner jurisdictions, including England, Wales and Canada to improve cancer outcomes.

The team produced the first international comparisons of stage at diagnosis and cancer survival, using routinely collected data. The findings highlight that early diagnosis and optimal access to treatment are two factors, amongst others, likely contributing to international differences.

**Breast cancer 5-year survival changes, 1995-1999 vs 2005-2007**

- **Sweden**: 70% vs 70%
- **Australia**: 66% vs 66%
- **Canada**: 68% vs 68%
- **Norway**: 68% vs 68%
- **Denmark**: 66% vs 66%
- **UK**: 70% vs 70%

*Including England, Northern Ireland and Wales*

**Bowel cancer 5-year survival changes, 1995-1999 vs 2005-2007**

- **Australia**: 50% vs 50%
- **Canada**: 50% vs 50%
- **Sweden**: 50% vs 50%
- **Norway**: 55% vs 55%
- **Denmark**: 50% vs 50%
- **UK**: 50% vs 50%

**Lung cancer 5-year survival changes, 1995-1999 vs 2005-2007**

- **Canada**: 5% vs 5%
- **Australia**: 10% vs 10%
- **Sweden**: 13% vs 13%
- **Norway**: 15% vs 15%
- **Denmark**: 12% vs 12%
- **UK**: 10% vs 10%

**Ovarian cancer 5-year survival changes, 1995-1999 vs 2005-2007**

- **Canada**: 25% vs 25%
- **Norway**: 30% vs 30%
- **Australia**: 35% vs 35%
- **UK**: 40% vs 40%
- **Denmark**: 45% vs 45%

The findings also highlight the importance of having consistent and high quality data on stage at diagnosis to enable further insights to be generated – this has been a catalyst to improving and standardising timely collection of data, such as stage at diagnosis, in a number of jurisdictions, including Wales, and reinforced the importance of such efforts already underway elsewhere, including in England, Ontario and New South Wales, to improve data quality.

Dr Jane Hanson
Head of Cancer National Specialist Advisory Group Core Team and Lead Advisor for Cancer, Public Health Wales, United Kingdom

"These findings have fed into a major effort to improve recording of stage at diagnosis and radiotherapy data. Recording the stage at which cancer is diagnosed is now a national performance measure. Wales is also now implementing the radiotherapy dataset to support benchmarking of services across the UK."

ICBP is a terrific platform for international comparisons. In Ontario we need to know how we stack up so we can learn and apply these lessons to strengthen our own cancer system.

Dr Linda Rabeneck
Vice President, Prevention and Cancer Control, Cancer Care Ontario, Canada

Internationally there are a number of different ways of defining and recording stage. So to explore the impact of different stage at diagnosis and survival by stage, the team developed a novel algorithm that enables researchers to reconcile different ways of defining and recording stage data into a single system.

"The team produced the first international comparisons of stage at diagnosis and cancer survival, using routinely collected data. The findings highlight that early diagnosis and optimal access to treatment are two factors, amongst others, likely contributing to international differences."

ICBP is a terrific platform for international comparisons. In Ontario we need to know how we stack up so we can learn and apply these lessons to strengthen our own cancer system.

Dr Linda Rabeneck
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ICBP is a terrific platform for international comparisons. In Ontario we need to know how we stack up so we can learn and apply these lessons to strengthen our own cancer system.

Dr Linda Rabeneck
Vice President, Prevention and Cancer Control, Cancer Care Ontario, Canada
Module 2. Public awareness, beliefs and attitudes to cancer

People with low cancer awareness and negative beliefs about cancer outcomes may be more likely to delay seeking medical help for suspicious symptoms. In turn this may lead to more advanced stage at diagnosis and poorer survival.

To investigate this hypothesis, a team led by Professor Amanda Ramirez (King’s College London, UK) and Professor Jane Wardle (University College London, UK) undertook a large international survey of members of the general public, involving over 19,000 men and women aged 50 years or over.

The survey, based on the validated and standardised ABC (Awareness and Beliefs about Cancer) instrument asked respondents questions exploring:

- Their knowledge of what increases the risk of cancer.
- Whether they thought specific symptoms could be caused by cancer.
- How likely they would be to visit the doctor with a symptom that might be serious, and what might put them off.
- Their beliefs about the chances of surviving cancer.

Overall the research suggests that awareness and beliefs about cancer are unlikely to explain international survival differences but may form part of a more complex picture. More research is needed to understand further and address the potential barriers to help seeking.

The survey results also indicate that in all countries there is low awareness that cancer risk increases with age.

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<th>Awareness that cancer risk increases with age</th>
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<td>5%</td>
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<td>Sweden</td>
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Proportion of respondents who said that 70-year olds are most likely to be diagnosed with cancer (rather than 30-year olds, 50-year olds or people of any age).

Overall the research suggests that awareness and beliefs about cancer are unlikely to explain international survival differences but may form part of a more complex picture. More research is needed to understand further and address the potential barriers to help seeking.

Our findings

This is the first robust international comparison of population awareness and beliefs about cancer. It highlights that there is a similar level of awareness of cancer symptoms and generally positive beliefs about cancer across all countries. On average, respondents in ICBP countries recognised 8 out of 11 cancer symptoms.

The research suggests that people in the UK are more worried and embarrassed about seeing their doctor with a symptom that might be serious compared to those in other countries. This would seem to underscore the importance of calls in public awareness campaigns for cancer to ‘tell your doctor’.

Module 3. The role of primary care doctors and health systems in diagnosing cancer

An international team of academic general practitioners (GPs) led by Dr Peter Rose (Oxford University, UK) has explored the central role of primary care in cancer diagnoses. Nearly 2,800 GPs across 11 ICBP jurisdictions participated in this study and completed a two part validated online survey:

- **Patient scenarios** - respondents indicated how they would manage patients presenting with low risk symptoms that could be indicative of cancer to identify international differences in management.

- **The local health system** - respondents provided information on the health framework they work within, including average length of consultations, direct access to diagnostic tests, waiting times for tests and results and availability of advice from secondary care.

Published results from this study, which will put findings into the context of observed survival differences, are anticipated in 2015.

A key motivation for New South Wales to be part of the ICBP is to understand the areas where our system is already performing strongly - in order to further strengthen it - as well as identifying areas where it is not performing optimally - in order to understand how we can build on this in the future.

Professor David Currow
Chief Cancer Officer and CEO Cancer Institute New South Wales, Australia

Dr Sally Brown and Professor Greg Rubin (University of Durham, UK), working with ‘key informants’ in each jurisdiction, led a health systems ‘mapping’ exercise, to complement the survey findings and provide greater local context.

This research confirmed that there are many common features of the health care systems between partner jurisdictions. However, it identified some subtle differences that merit further research - including understanding differences in the nature of a patient’s contribution to health care costs and the ease with which patients can move freely between primary care providers - to understand whether they have an impact on patient or doctor behaviour and thus possibly contribute to differences in cancer outcomes.
Module 4. Measuring time intervals and pathways from symptoms to diagnosis and treatment

Observed differences in cancer survival may be partly linked to differences in the time intervals between patients noticing a symptom to being diagnosed and to treatment.

Professor Usha Menon (University College London, UK), Professor Peter Vedsted (Aarhus University, Denmark) and Professor David Weller (University of Edinburgh, UK) are leading the study. They are working with an international team of researchers on the first robust international comparison of time intervals and routes to diagnosis to see if these are associated with cancer survival.

This is the first robust international comparison of the time intervals from first symptom(s) until diagnosis and start of treatment for cancer patients. It will include information provided by over 9,000 patients from 10 ICBP jurisdictions.

The study invites over 9,000 newly diagnosed - within three to six months after diagnosis - breast, colorectal, lung and ovarian patients in 10 jurisdictions to take part in a survey, to provide information on areas including:

- Specific time intervals and details of their route to diagnosis and treatment.
- The number of times they saw a health care professional before diagnosis.

For patients who consent to take part in this study, their GP and a specialist care consultant are also surveyed to provide additional information relating to the patient including:

- The nature of any referrals and diagnostic tests carried out.
- General health of patients, including other health conditions (comorbidities).
- Cancer stage.

First insights from this in-depth international comparative analysis are expected in 2015.

Module 5. Exploring the impact of comorbidities on short-term outcomes

The core cancer survival benchmarking study highlighted that observed survival differences might partly be explained by a group of patients who die shortly after diagnosis.

An international team, led by Dr Jem Rashbass (Public Health England, UK), Dr Mick Peake (Public Health England, UK) and Dr Eva Morris (University of Leeds, UK) is exploring this topic, working across two complementary studies:

- Testing the hypothesis that patients who die shortly after diagnosis are more likely to be living with one or more health condition(s) - comorbidity - which affects whether they receive optimal treatment and the chances of surviving their cancer.

  This study is focusing on lung cancer in the first instance and is linking routinely collected data from hospitals, cancer registries and, where available, clinical audits.

- Exploring how differences in cancer registry practices and available data sources between countries might affect international comparisons, particularly the first few months after diagnosis.

  The team have built an online simulation model based on information provided from cancer registry teams in all jurisdictions. This allows users to adjust a number of key fields, including date of diagnosis, tumour site and the proportion of patients diagnosed at different stages, and measure any impact on 1-year cancer survival.

  The aim is to use these findings to identify further opportunities to harmonise and standardise international cancer registry data collection to underpin robust international comparative studies, such as ICBP.

Work is underway across both studies and the team anticipate first outputs in 2015.

The ICBP aims to generate insights which will help all partners enhance cancer survival by improving cancer policies and services.

Professor Sir Mike Richards Chair, International Cancer Benchmarking Partnership
The ICBP has successfully laid the foundation for an ongoing international benchmarking partnership. It is now moving forward with an ambitious and robust international research programme that continues to be of relevance for policy and clinical partners.

The partnership will deliver ongoing studies, further analyse the wealth of data already generated over the past few years as well as accelerate its groundbreaking research and evidence.

The ICBP will keep generating a deeper understanding of where action is needed across policy and practice to deliver world class cancer services that lead to the best possible outcomes for cancer patients.

The ICBP has gone from strength to strength since the partnership was formed in 2009, generating insights into reasons for observed cancer survival differences between partner countries and developing novel methodologies and tools for robust international comparisons.

**LOOKING TO THE FUTURE OF THE PARTNERSHIP**

**ICBP GOVERNANCE**

The strategic direction of the partnership is set by an international programme board, chaired by Professor Sir Mike Richards, and comprising senior representatives from all jurisdictions:

- Ole Andersen, Danish Health and Medicines Authority, Copenhagen, Denmark
- Søren Brostrøm, Danish Health and Medicines Authority, Copenhagen, Denmark
- Heather Bryant, Canadian Partnership Against Cancer, Toronto, Canada
- David Currow, Cancer Institute New South Wales, Sydney, Australia
- Dhali Dhaliwal, Cancer Care Manitoba, Winnipeg, Canada
- Sean Duffy, National Clinical Director for Cancer, NHS England, London, UK
- Anna Gavin, Northern Ireland Cancer Registry, Queens University, Belfast, UK
- Gunilla Gunnarsson, Swedish Association of Local Authorities and Regions, Stockholm, Sweden
- Jane Hanson, Welsh Cancer National Specialist Advisory Group, Public Health Wales, Cardiff, UK
- Todd Harper, Cancer Council Victoria, Carlton, Australia
- Stein Kaasa, University Hospital of Trondheim, Trondheim, Norway
- Aileen Keel, Acting Chief Medical Officer, Scottish Government, Edinburgh, UK
- Nicola Quin, Cancer Council Victoria, Carlton, Australia
- Linda Rabeneck, Cancer Care Ontario, Toronto, Canada
- Mike Richards, Care Quality Commission, London, UK
- Michael Sherar, Cancer Care Ontario, Toronto, Canada
- Robert Thomas, Department of Health Victoria, Melbourne, Australia
- Kathryn Whitfield, Department of Health Victoria, Melbourne, Australia

The board also oversees the partnership’s research which in turn is led by academic chairs, working closely with collaborators across all jurisdictions. Academic reference groups and clinical committees provide additional independent input into research proposals and analyses.

Cancer Research UK provides programme management to the partnership. Module 1 was funded by the Department of Health and the National Cancer Action Team as a direct result of the 2007 Cancer Reform Strategy for England. Modules 2-5 are funded in a collaborative model with each participating partner contributing a proportion of the research and management costs.
REFERENCES


10 Rose PW, Hamilton W, Aldersey K et al. 2014. Development of a survey instrument to investigate the primary care factors related to differences in cancer diagnosis between international jurisdictions. BMC Fam Pract, 15:122


The ICBP involves many collaborators and funders. We would like to thank all our partners. These include:

Aarhus University (Denmark)
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Cancer Council Victoria (Australia)
Cancer Institute New South Wales (Australia)
CancerCare Manitoba (Canada)
CancerCare Ontario (Canada)
Canadian Partnership Against Cancer – Partenariat Canadien Contre Le Cancer (Canada)
Cancer Research UK
Grwp Cydgysyltu Gwasanaethau Canser – Cancer Services Co-ordinating Group (UK)
Grwp Cynghori Arbenigol Cenedlaethol Canser – Cancer National Specialist Advisory Group (UK)
Danish Cancer Society (Denmark)
Danish Health and Medicines Authority (Denmark)
Department of Health (UK)
The Eve Appeal (UK)
Prifysgol Bangor – Bangor University (UK)
Guidelines and Audit Implementation Network (GAIN) (UK)
Helsedirektoratetet (Norway)
Kings College London (UK)
London School of Hygiene and Tropical Medicine (UK)
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Northern Ireland Cancer Registry (UK)
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United Kingdom Association of Cancer Registries (UK)
University College London (UK)
The University of Edinburgh (UK)
University of Oxford (UK)
Ymchwil Canser Cymru – Cancer Research Wales (UK)
INTERNATIONAL CANCER BENCHMARKING PARTNERSHIP
SHOWCASING OUR FINDINGS AND IMPACTS

For more information please go to: www.icbp.org.uk

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