Welcome to the spring edition of the ICBP newsletter.

In this issue we focus on the scientific publications arising from the ICBP, as well as shining a ‘Spotlight’ on some of the authors. We also catch-up with ICBP board member Todd Harper from Victoria, Australia.

On behalf of all of the ICBP collaborators we would also like to take this opportunity to extend a warm welcome to Scotland who join the partnership for Module 4.

It is an exciting time for the partnership with 8 papers already published and more expected through 2013 and 2014.

Module 1, the core benchmarking module of the ICBP, has delivered five papers to date:

- an overview of cancer survival in six ICBP countries,
- three separate papers that analyse cancer survival by stage at diagnosis in three different cancer types
- a description of a novel way of comparing data on stage at diagnosis.

You can read in-depth summaries of these papers on pages 2-3.

The Module 2 team recently produced 2 papers:

- an international comparison of population awareness and beliefs about cancer across the 6 ICBP countries
- a description of the development of the research tool, ‘the Awareness and Beliefs about Cancer measure’

Read summaries of these findings on pages 4-5.

Before looking at the new findings let’s look back at the first ICBP paper published in 2011.

Module I of the ICBP early on delivered a key aim: the production of robust and comparable analyses of cancer epidemiology data between all of the ICBP partners.

The first paper from the ICBP, published in the Lancet, compared survival from colorectal, lung, breast and ovarian cancers for patients diagnosed between 1995 and 2007 between six countries. It showed that survival has continued to improve for each cancer in all six countries, but generally remains higher in Australia, Canada, and Sweden, intermediate in Norway, and lower in Denmark and the UK.

There are many hypotheses as to why cancer survival gaps exist internationally. These include, later stage at diagnosis, differences in treatment, delay in seeking treatment or referrals, and differences in attitudes and beliefs to cancer. The ICBP was tasked to discover which factors, created or influenced the observed cancer survival differences.

This newsletter focuses on what the ICBP has discovered so far.

How To Reconcile Stage Data for International Analysis

Internationally there a number of different ways of defining and recording stage, meaning that comparing stage data internationally is very challenging. This paper describes the development of a novel method which can be used to compare stage data recorded in different countries in different ways. The development of this method was essential for the fulfilment of Module 1’s aims as it enabled the Module 1 team to conduct analyses of cancer survival by stage. The team looked at ovarian, lung, breast and colorectal cancers.

An international stage classification system, the Tumour, Node, Metastasis (TNM) classification, exists already and is widely, but not exclusively, used. The algorithm that the Module 1 central team developed allows the conversion of stage data classified using TNM, Dukes’ and FIGO (the latter of which are classification systems specifically for colorectal and ovarian cancer, respectively) to a “localised, regional, distant” categorisation system: SEER (the Surveillance, Epidemiology and End Results) system. This algorithm is valuable for future international studies using cancer stage data.

The paper highlights the need for a single staging system that will be adhered to worldwide – so in the future when stage data is recorded it will be consistent and comparable internationally. This will allow international comparative research using stage data to be more straightforward and robust.


Cancer Survival by Stage at Diagnosis: a round-up of three population-based studies

Background

The Module 1 central team compared survival rates in different ICBP countries by the point, or ‘stage’, at which an individual is diagnosed with cancer. The team investigated what proportion of people were diagnosed at an early or at a more advanced stage of disease in each country. From this the team worked out each jurisdiction’s stage distribution. Papers on ovary, breast and lung cancer survival by stage have already been published, the paper on colorectal is imminent.

The international survival differences outlined in the Lancet paper could be due to a number of reasons. The papers summarised below specifically investigate the role stage at diagnosis could be playing, and point to other possible explanations for the survival differences. Each paper included analysis of SEER and TNM stage classification systems, this was to ensure all countries could be included in the analysis.

Stage at Diagnosis and Ovarian Cancer Survival

Stage Distribution

⇒ The proportion of those diagnosed early (stage I) was similar in Canada, Denmark and Norway (20-23%) - but this proportion was higher in the UK (33%).
⇒ In Canada and Norway, countries with similar stage distributions, nearly half of all women in were diagnosed at stage III.
⇒ Denmark had a very high proportion of women diagnosed at stage IV, but the lowest proportion diagnosed at stage III.
⇒ Sweden was not included in the ovarian analysis but was for lung and breast.
⇒ The UK had the highest proportion of missing stage data.

Survival

⇒ One year age-standardised survival was lowest for women in the UK, intermediate in Denmark and highest in Canada, Norway and Australia.
⇒ The UK had the lowest overall net survival across each age group (all stages combined).
⇒ Women in Denmark and Australia with early disease (stage I:localised) had lower survival (94-95%) than elsewhere (over 97%).
⇒ Across all of the countries, women aged 70-99 years had lower 1 year survival than women...
Within each stage classification international survival differences were observed. Women in the UK (across all ages) diagnosed at more advanced stages of their disease had significantly lower survival compared to the other countries in the study. This suggests there might be differences in the quality of treatment or access to treatment in the UK in comparison to other countries.


Stage at Diagnosis and Breast Cancer Survival

Stage Distribution

- Denmark had the fewest number of women diagnosed at the earliest stage of the disease.
- The proportion of women diagnosed at early stages of their disease was similar in the UK, Canada, Norway and Sweden.
- Canada and Denmark had high proportions of women being diagnosed at an intermediate stage.
- The UK had the highest proportion of missing stage data (TNM), 25%, compared to 11% in Denmark.

Survival

- One year after diagnosis, survival for women with early-stage disease (TNM Stage I) was close to 100 per cent in all countries.
- For women diagnosed at later-stage disease, international differences were wide.
- For women with the most advanced cancers (TNM Stage IV), one-year survival ranged from 53% in the UK to 67% in Sweden (the best performing country), and three-year survival varied from 28 per cent in the UK to 42% in Sweden, a range of 14% in both cases.
- Australia and Sweden, using the SEER and TNM classification systems respectively, had relatively high survival across all stages of disease.
- Canada and Norway had similar survival for women with early stage disease in comparison to the other countries but those with later stage disease had lower survival than in Australia and Sweden.
- Differences in stage specific survival could be due to differences in treatment or access to treatment.
- Lower overall survival in Denmark is likely to be due to their adverse stage distribution.


Stage at Diagnosis and Lung Cancer Survival

Stage Distribution

- Lung cancer is generally diagnosed at a advanced stage of disease.
- The UK and Denmark had the fewest patients diagnosed at early stages of their non-small cell lung cancer, when compared to other countries. This suggests that late diagnosis may be playing a role in lower survival observed in the UK and Denmark.
- There was a higher proportion of patients diagnosed at an advanced stage of small cell lung cancer in Denmark in comparison to the other countries in the study.
- Sweden and Australia, two of the best performing countries, had the fewest number of people diagnosed at advanced stage using the TNM and SEER classification systems, respectively.
- Canada, Sweden (TNM) and Australia (SEER) had the highest proportion of people diagnosed at an early stage of disease.
- The UK had the highest proportion of stage data (TNM) missing across both lung cancer types, this proportion was also relatively high in Australia (SEER).

Survival

- 1-year net survival from non small cell lung cancer ranged from 30% in the UK to 46% in Sweden.
- Survival was also high in Australia and Canada and was intermediate in Denmark and Norway.
- UK survival figures were amongst the lowest at all stages compared to the other countries. This suggests lung cancer patients in the UK may not be getting the best available treatment, whatever the stage of their disease at diagnosis.
- Survival was lower in the UK for patients diagnosed at later stages. This suggests there might be differences in treatment or access to treatment in the UK compared to other countries.

How To’ measure awareness and beliefs about cancer

This paper describes the development of the Awareness and Beliefs about Cancer or ABC, measure - an internationally validated research measure of cancer knowledge and beliefs. Cancer knowledge and beliefs have been highlighted as possible contributing factors to a delay in symptomatic presentation, which can reduce the number of cancers diagnosed at an early stage and lead to lower survival rates.

This research tool is used in Module 2 ICBP analyses to see if differences in cancer awareness and beliefs between countries contribute to differences in cancer survival. Existing studies of knowledge and beliefs have focused on individual countries, so this tool is important in enabling the measurement and comparison between ICBP countries.

A number of different factors influence how people shape their awareness and beliefs about cancer, including:

♦ variations in cultural attitudes to cancer,
♦ provision of public education about cancer and delivery of health care

These factors were taken into account when developing the instrument as well as making sure questions were culturally sensitive and equivalent across jurisdictions.

The ABC will serve in future as a blueprint for researchers in other countries to study their population’s awareness and beliefs about cancer.


What impact does the development of this instrument have on international cancer research?

We hope that providing a validated instrument will encourage other countries to take up and use the measure. In the long term this would make it possible to compare ICBP data with results from other countries. We have already had some interest from researchers in other countries that are looking at using the ABC and replicating our survey method.

What would you say was the trickiest/hardest part of the developing the ABC measure?

A lot of the reliability and validity tests are time consuming and intricate. It was certainly a much larger challenge trying to run these tests across a number of countries. It has been hugely enjoyable working with so many interesting people across the partnership, but inevitably reaching a consensus on the content of the ABC measure was also a difficult task. We think that we have managed to produce a useful and meaningful measure that is relevant for all of the jurisdictions.

What is your motivation for carrying out ICBP research?

The work of the partnership is essential. Understanding the reasons behind international variations in cancer survival will be hugely informative and will enable each jurisdiction to identify areas for improvement.

“IT has been a wonderful opportunity to work with so many amazing people from around the world.”
Do differences in cancer awareness and beliefs between Australia, Canada, Denmark, Norway, Sweden and the UK contribute to differences in cancer survival?

Why this question was asked:
It is hypothesized that countries with populations that have lower cancer awareness and negative beliefs about cancer outcomes may be more likely to delay seeing their doctor about any symptoms they may have. This may lead to more cancers being diagnosed at a later stage and poorer survival.

As described on page 4 the ICBP Module 2 team developed and used a new research tool - the Awareness and Beliefs about Cancer measure - to study the populations awareness and beliefs in 6 countries. More than 19,000 men and women aged 50 and older were interviewed in Australia, Canada, Denmark, Norway, Sweden and the UK – resulting in the first robust international comparison of population awareness and beliefs about cancer.

What they found:
Denmark had the lowest level of barriers to symptomatic presentation, followed by Sweden, Norway, Australia and Canada – and the UK had the highest level of barriers to symptomatic presentation. The UK also reported the lowest awareness that the risk of cancer increases with age. The researchers stated that the number of people in the UK presenting early to their GP with symptoms may rise if public awareness of age-related risk increases and the public’s confidence in approaching their GP with possible cancer symptoms were improved.

Awareness of cancer symptoms was high and beliefs about cancer outcomes were positive for all of the countries populations studied. Differences between the countries were small. All of the countries reported that approximately eight out of eleven cancer symptoms were recognised by members of the public. All of the countries also reported around nine out of ten people thought that “cancer can often be cured” and seven out of ten disagreed with the statement that “a diagnosis with cancer is a death sentence”.

Low one year cancer survival does not seem to be explained solely by poor awareness and negative beliefs about cancer. This paper calls for continued research into why international cancer survival differences exist.


Were you surprised that the findings showed that the pattern of cancer awareness and beliefs does not follow the pattern of one-year survival?
No, because we never expected that cancer awareness and beliefs would be the sole determinant of one year survival in each country. The results can only be fully interpreted once we have gathered evidence about all the possible influences, including organisation of primary care, and access to effective treatments, and so on.

Do you think that the findings will have an impact on cancer policies and services within the ICBP countries?
The UK stood out – people had poor awareness that the risk of cancer increases with age and a high proportion said that not wanting to waste the doctor’s time and embarrassment might stop them going to the doctor with a symptom that might be serious. In the UK, it’s important that we should help people understand better that their risk of cancer increases as they get older, and that we examine what is happening in the interaction between people and their GP practices to make people think that they might be wasting the doctor’s time or feel embarrassed.

“My motivation is to build the evidence about the consequences of poor cancer awareness and negative cancer beliefs, so that policies and interventions to promote early cancer presentation can be evidence based – a subject I am passionate about”

In Denmark, which also has poorer cancer survival, it is likely that the reason is not poor population levels of cancer awareness and negative beliefs. So the explanation for poor population levels of cancer survival in Denmark should be sought elsewhere.

It’s important to remember that the Module 2 findings do not mean that at an individual level, poor cancer awareness and beliefs do not influence cancer. The findings tell us only about the association between average levels of cancer awareness and beliefs and survival.
Spotlight on Programme Board Member—Todd Harper

**Biography**

Todd Harper commenced as Chief Executive Officer of **Cancer Council Victoria** in April 2011, after four years as Chief Executive Officer at the Victorian Health Promotion Foundation (“VicHealth”).

Prior to his role with VicHealth, Todd was the Executive Director of Quit Victoria and the VicHealth Centre for Tobacco Control.

During his time at Quit Victoria, Todd was responsible for the development and execution of numerous health promotion campaigns to reduce the incidence of smoking in Australia. He also presented at many national and international conferences and worked with overseas organisations such as the World Health Organization to develop strong and effective tobacco control policies.

Todd has over 18 years’ experience in the health promotion and advocacy field, along with a deep passion for the Cancer Council Victoria’s vital work in research, prevention and support. He is an active sportsperson and an advocate of a healthy lifestyle, cycling to and from work daily, and frequently participating in organised road rides.

A former journalist, Todd has a Bachelor of Economics degree, a graduate diploma in health promotion, and a Masters of Health Economics.

**Cancer Council Victoria**

Cancer Council Victoria is a non-profit organisation involved in cancer research, patient support, cancer prevention and advocacy. We were established in 1936 by the Victorian State Government and have earned a reputation among our peers as a world leader, widely acknowledged as a trusted, independent and skilful advocate for effective cancer control.

One of our best known initiatives is the SunSmart programme, which educates Victorians about the dangers of excessive exposure to UV radiation. This programme is estimated to have prevented more than 100,000 skin cancers in the last 25 years alone. We have also been at the forefront of tobacco control, most recently demonstrated by our strong public support of the Australian Government’s world-leading legislation mandating the plain packaging of cigarettes.

In the research arena, we contribute over $20 million annually to biomedical, epidemiological and behavioural research. One of the highlights of our research program is the work of Professor Don Metcalf, our 1954 Carden Research Fellow, who discovered, isolated and produced agents called Colony Stimulating Factors (CSFs), which are the naturally-occurring regulators of bone marrow growth. His discovery was developed into a clinical treatment which has been used to treat cancer patients since the early 1980s.

**Q&A**

**How does Cancer Council Victoria fit into the Australian cancer plan?**

Throughout our 75 year history, Cancer Council Victoria has had a strong history of collaboration and leadership across many cancer-related fields. As a member of a federal structure, we work with colleagues on national policy including issues such as breast, cervical and bowel screening and plain packaging legislation. We also advocate on issues such as obesity and alcohol policy and run the Victorian Cancer Registry, which reports annually on cancer incidence and mortality. We also advise government and liaise with business to help create strategies to fight cancer. Our strong public profile allows us to maximise our ability to influence the public agenda.

**What was Victoria’s motivation for joining the ICBP?**

The opportunities for Cancer Council Victoria to learn from other jurisdictions and share our knowledge through the ICBP closely align with our strategic key result areas, especially our commitment to build the capacity and the knowledge base for cancer control. We are able to benchmark our survival rates against other jurisdictions, and in doing so, see where Victoria is performing well, and also where there are opportunities for improvement. Sharing of knowledge, understanding the successes and challenges of colleagues, and being open to new ideas were also other motivators for joining the ICBP.
What’s New on ICBP online…?

We have updated the following web pages to give more detail about the research modules and recent ICBP publications:

- Module 1—Epidemiology
- Module 2—Awareness and Beliefs about Cancer
- ICBP Publications

The ICBP team have also produced several blog posts which can be found at the following link, cruk.org/blog, please use ICBP as a search term.

As many of you have expressed interest in the ICBP Linked-In group the forum will be open and accepting members from the Friday 20th April. We look forward to connecting with you on this forum.

A reminder of what the group should be used as:

- A forum where collaborators post ideas and exchange knowledge so that discussion can be facilitated. For example, ICBP members can post relevant research work they are involved with outside of ICBP, which may be of interest to the other collaborators.

- An ‘updates’ platform where collaborators and the Cancer Research UK programme management team can give you the latest news and updates on module progress and paper submissions.

- A ‘networking diary’ – so ICBP collaborators can let the rest of the partnership know which international conferences they are attending. This will not only strengthen the partnership as a whole but facilitate better communication and idea sharing.

What it isn’t:

- A ‘work platform’ where official ICBP work is discussed, for example, changes to questionnaires, ethics approvals, proofreading or any other ‘official’ work.

You can find the ICBP group on the Linked-In (http://www.linkedin.com/groups?gid=4565455&trk=hb_side_g) website. This is a closed group, so people can only join the group or view discussions and posts if we add them as members.

We would like to hear from you with your views and comments about the partnership, and we encourage you to stay in touch via icbp@cancer.org.uk.
The ICBP is a partnership which involves many collaborators and funders. These include: