

Summer 2011
Issue 2

ICBP Newsletter



Welcome from the editor

Welcome to the second issue of the ICBP newsletter.

In the last issue we focused on Research Module 1: Epidemiology. We are pleased to announce that since the last edition, Michel Coleman and his team at the London School of Hygiene and Tropical Medicine have made good progress analysing data on stage and treatment from partner jurisdictions. These will feed into the next ICBP Module 1 publications, exploring the impact of stage at diagnosis and access to treatment by surgery, radiotherapy and chemotherapy on the observed survival differences between partners.

In this issue we focus on Module 2, the research module looking at population awareness and beliefs about cancer. It is an exciting time for this research module; fieldwork has already started using the 'ABC' instrument.

We also put the spotlight on two Programme Board members and introduce you to the Programme Management team.

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Focus on Module 2: Population awareness, attitudes and beliefs about cancer

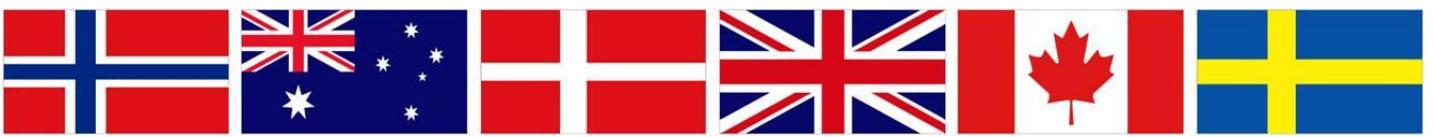
People with low cancer awareness and negative beliefs about cancer outcomes may be more likely to delay seeking medical help for suspicious symptoms, which may, in turn, lead to more advanced stage at diagnosis and poorer survival.

Module 2 will provide the first robust international comparison of population awareness and beliefs in

“Module 2 will provide the first robust international comparison of population awareness and beliefs in cancer...”

cancer, aiming to test the hypothesis that differences in levels of cancer awareness and beliefs contribute to international differences in cancer survival.

As well as investigating the role of awareness and beliefs in cancer survival, the Module 2 results will also identify potential targets for interventions to address low cancer awareness and negative beliefs.



Focus on Module 2: population awareness, attitudes and beliefs about cancer

The ABC Measure

An international collaboration of scientists from each ICBP jurisdiction, led by the Module 2 chairs Amanda Ramirez (King's College London) and Jane Wardle (University College London), has developed the Awareness and Beliefs about Cancer measure (ABC) to be used in surveys in each jurisdiction. After developing and validating the ABC in UK English, drawing on existing survey instruments from the UK, Canada, Victoria and New South Wales, the ABC went through an intensive process of international harmonisation.

In Brief: ABC validation and international harmonisation

This process included:

- Cognitive interviewing
- Test-retest reliability testing
- Content validity assessment
- Local translation/adaptation, piloting and cognitive interviewing
- Assessment of equivalence of meaning by bilingual panels

Q&A with Amanda Ramirez, co-chair of the Module 2 central team.

'How was the Awareness and Beliefs about Cancer Measure developed?'

The ABC measure was built through the close collaborative working between the international partners. We have developed different versions for each country, adopting a robust approach to ensure local relevance and equivalence of cultural and

linguistic meaning. This has been scientifically challenging work, given the culturally and personally sensitive nature of some of the items on beliefs about cancer prognosis and early presentation with cancer symptoms.

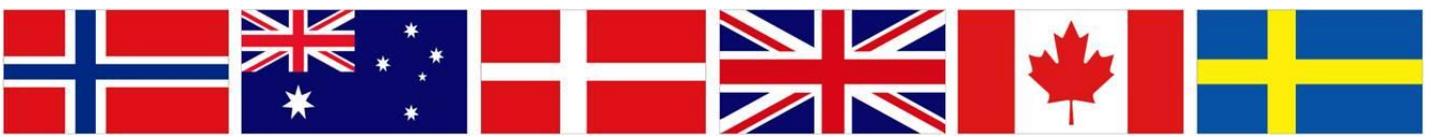
“One possible explanation for the major international differences in cancer survival identified by the ICBP is that people in the UK and Denmark have lower cancer awareness and more negative beliefs about cancer”

'What are you hoping that Module 2 can do for England?'

One possible explanation for the major international differences in cancer survival identified by the ICBP is that people in the UK and Denmark have lower cancer awareness and more negative beliefs about cancer, leading to delayed presentation and worse survival. Module 2 results will provide unique evidence of differences in cancer awareness and beliefs across the participating countries and suggest if we should be focussing resource on interventions to improve cancer awareness and address negative beliefs in England.

Fieldwork

Global market research provider Ipsos MORI are currently carrying out fieldwork in nearly 16,000 men and women aged 50+ in Canada, Australia



Focus on Module 2: population awareness, attitudes and beliefs about cancer

(Victoria and New South Wales), Denmark and the UK (England, Northern Ireland and Wales), using computer-assisted telephone interviews. Fieldwork in Sweden and Norway will start in mid-August, after the Scandinavian holiday season.

Data will be collected in all jurisdictions on the core ABC questions, which include:

- awareness of symptoms and the increase in risk of cancer with age
- physical and emotional barriers to symptomatic presentation
- beliefs that could lead to delayed presentation of symptoms, such as fear and fatalism

Some jurisdictions will also collect data using one or more of the three optional additional ABC modules (awareness of cancer risk factors; awareness and beliefs about cancer screening; awareness and beliefs about ovarian cancer). Some jurisdictions will also survey younger people (age 35-49 years).

Q&A with Magdalena Lagerlund
international collaborator from Sweden.

What have been the highlights and challenges in Module 2 so far?

“ Developing and translating the questionnaire into Swedish (in our case) has been a challenging and very involved process, working in collaboration with professional translators to find wordings sensitive to the cultural, linguistic and health care context, and making sure to maintain comparability with data

collected in the other countries.

The market research provider, Ipsos MORI, has been very professional, helpful and accommodating, when coordinating and juggling all the different aspects of the data collection, with countries being at different stages in the process, and in different time zones.

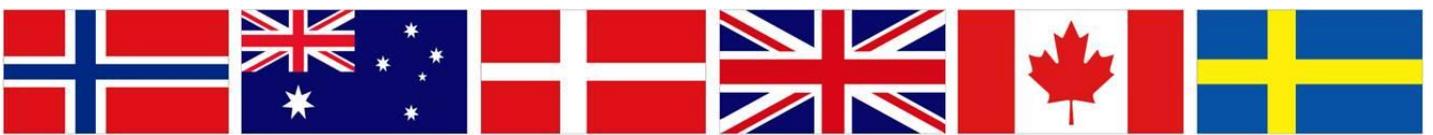
Furthermore, the competent lead of the central team has made this work experience truly enjoyable.”

Where next for Module 2?

Progress in the study will be presented at the National Cancer Research Institute (NCRI) [www.ncri.org.uk/] conference in November. The Module 2 Working Group will then go on to analyse the data and submit scientific papers for publication in peer-reviewed journals.

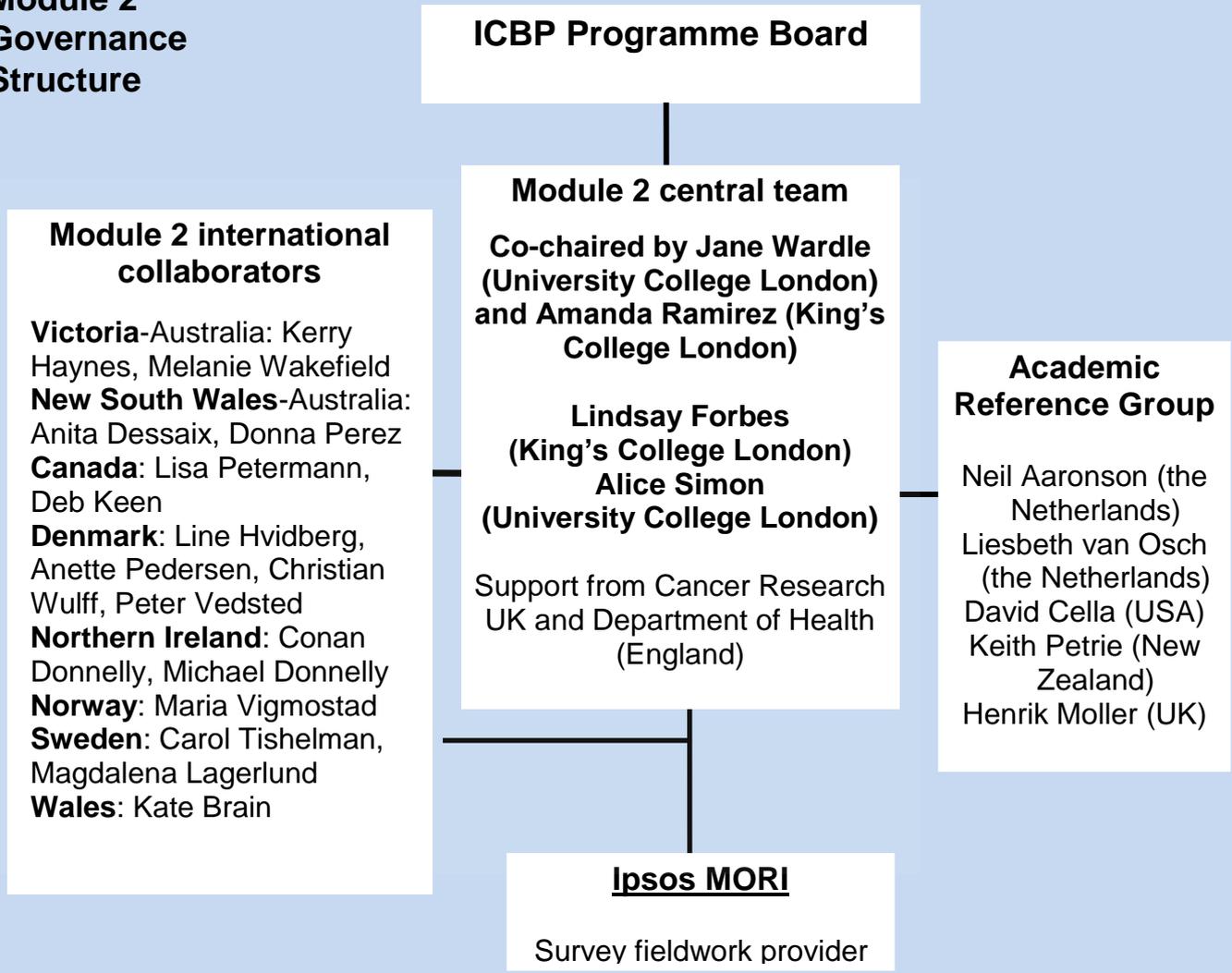
Module 2 governance structure

Overseen by the ICBP Programme Board, a central team leads Module 2, collaborating closely with a group of international collaborators (outlined overleaf). An independent academic reference group provides peer review on methodology, analyses and conclusions. The central team manages Ipsos MORI, the appointed providers of Module 2 fieldwork.



Focus on Module 2: population awareness, attitudes and beliefs about cancer

Module 2 Governance Structure



Spotlight on Gunilla Gunnarsson

Dr Gunilla Gunnarsson – Coordinator of Cancer Strategy
Department of Health and Social Care, Swedish Association of Local Authorities and Regions (SALAR) & ICBP
Programme Board Member, Sweden



Gunilla is a physician with a focus on radiation oncology. She has been the head of the department of oncology in **Jönköping** as well as heading the Surgery, Urology and Oncology Centre for **Östergötland** County. She has been seconded to SALAR from April 2010 – late 2012 to coordinate SALAR's projects and activities arising from the national cancer strategy.



Spotlight on Gunilla Gunnarsson

Swedish Association of Local Authorities and Regions

SALAR represents the governmental, professional and employer-related interests of Sweden's 17 county councils and 4 regions.

SALAR strives to promote and strengthen local self-government and the development of regional and local democracy. The operations of the Association are financed by the fees paid annually by members according to their tax base.

Swedish Cancer Plan

In 2007, the Swedish government established a 'Commission of Inquiry' with a remit to present proposals for a national cancer strategy. The report: 'A national cancer strategy for the future' was completed in 2009.

Following on from this report, the Ministry of Health and Social Affairs has initiated several projects with

the aim of achieving better survival and quality of life for cancer patients. Two agreements regarding implementation of the strategy have already been made between the government and SALAR. Being a partner in the ICBP forms part of these projects designed to achieve better cancer outcomes for Sweden. Other projects include:

- early detection through effective screening programmes
- patient-focused care processes
- national coordination in respect of uncommon cancers
- work on national clinical guidelines

Another result of the national cancer strategy is that six regional cancer centers are opening this year. Their tasks include drawing up regional strategies for the sharing of responsibilities and the structuring of cancer care as well as knowledge transfers between research and care.

Q & A with Gunilla Gunnarsson

Q. What are you hoping the ICBP can do for Sweden?

Even if Sweden has satisfactory survival results for several cancer types, Swedish medical care can be improved further. We hope, together with other participants, to understand why there are differences in survival rates between countries and to learn from other participants how to become even better. The scope of ICBP's work is ambitious. The collecting and processing of data has so far been structured and reassuring to the extent that the results can be relied upon. The work also provides us with an international network whereby thoughts and ideas concerning cancer care can be shared. Sweden's national cancer strategy was proposed in 2009 and we are in the starting phase of implementation. We hope to be able to learn from other countries that have worked longer in this way and also in respect of introducing further cancer plans.

Q. What was your motivation for joining the ICBP?

The motivation of SALAR and the government was that ICBP would offer good opportunities for learning through participating in an extensive international partnership with comparable health care systems in other countries. The results are expected to constitute a foundation for the continuing work of improvement at different levels of the Swedish health care system for the benefit of cancer sufferers.



Spotlight on Anna Gavin



Dr Anna Gavin, founding Director of Northern Ireland Cancer Registry, Senior Lecturer, Centre for Public Health, Queen's University Belfast & ICBP Programme Board Member, Northern Ireland

Anna is the Director of Northern Ireland Cancer Registry and also holds the position of part-time joint national lead for analysis and information at the UK National Cancer Intelligence Network (NCIN). Anna is medically qualified and trained in public health.

She is particularly interested in disease prevention and earlier diagnosis of cancer. As chair of Action on Smoking and Cancer in Northern Ireland she leads a multisectoral team on prevention of tobacco use. She has also led a multiagency group promoting care in the sun and early detection of skin cancers. She is a member of the European Network of Cancer Registry steering group.

"We saw this as an exciting opportunity to learn more about our patient's cancer journey through a standardised methodology and analysis developed by internationally recognised experts."

Northern Ireland Cancer Plan

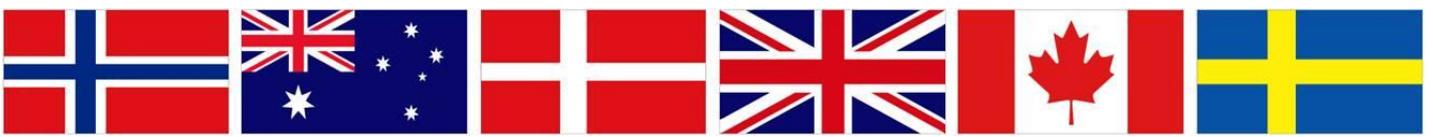
The last cancer plan in Northern Ireland was developed in 1996. It introduced the concept of a cancer centre and four cancer units which would centralise services and see patients treated in centers of excellence, clinicians working in multidisciplinary teams, identification of clinicians as experts in cancer areas, investment in oncology services and palliative care and enhanced communication to the patient and among clinicians including primary care.

The implementation of the cancer plan is monitored on an ongoing basis by the N. Ireland Cancer Registry.

In 2008, cancer waiting times were introduced with targets of 31 days from referral to diagnosis and 62 days from referral to treatment with primary care

clinicians able to red flag suspect cancer cases. 2008 also saw the development and introduction of a regional web based cancer information system, the Cancer Patient Pathway System (CaPPs). This monitors patient progress from referral through diagnosis, staging, treatment and outcome. It is used to manage the multidisciplinary team meeting and the upload of data to national audits. It facilitates communication between professionals including primary care while providing an electronic patient record.

There is a strong emphasis on prevention especially regarding tobacco and care in the sun. Cervical screening was re-organised in 1989 and is now a population based call and recall system. Population based breast screening was introduced in 1993 and bowel cancer screening in 2010.



Spotlight on Anna Gavin

Q & A with Anna Gavin

Q. How does your role as Director of the Northern Ireland Cancer Registry fit into the Northern Ireland cancer system?

The Northern Ireland Cancer Registry, at Queen's University of Belfast, is funded by the Public Health Agency. We work closely with clinicians, services managers, the Department of Health, cancer charities, patients groups and researchers to improve the care and outcome of cancer patients.

The Registry provides routine incidence, survival and prevalence data and has developed unique population level datasets on prostate specific antigen (PSA), colorectal polyps and Barrett's Oesophagus. These are the basis of research projects. We also developed the prototype for the electronic Cancer Patients Pathway System for

Northern Ireland which includes an electronic cancer staging tool. Cancer services are monitored five yearly through registry based clinical audits.

What is your motivation for joining the ICBP?

We saw this as an exciting opportunity to learn more about our patients' cancer journeys through a standardised methodology and analysis developed by internationally recognised experts. The information will hopefully point to areas where we can work to improve cancer survival in our own population. We expect to learn from others while contributing to the study organisation, design and interpretation of results. It will help us to raise the profile of cancer locally and add scientific rigor to policy decisions while meeting local targets.

Meet the ICBP Programme Management team

John Butler, ICBP Clinical Advisor

Fellow in Gynaecologic Oncology, St Bartholomew's and Royal Marsden Hospitals, London

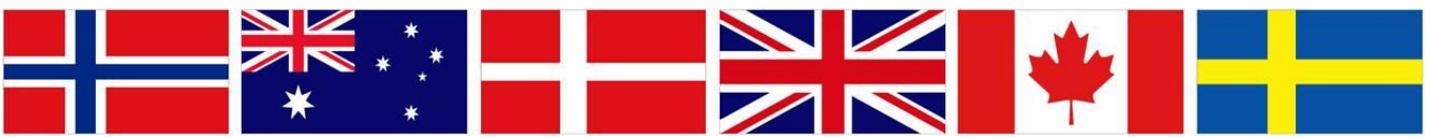
John is completing his specialist surgical training in gynaecological oncology at St Bartholomew's and the Royal Marsden Hospitals in London. In 2009 he was seconded by the Chief Medical Officer of England and appointed as clinical advisor to Professor Sir Bruce Keogh, NHS Medical Director. John spent 18 months with the Department of Health and the majority of this work was with the cancer policy team and the ICBP. He is currently combining his surgical fellowship with his work on the ICBP.

Q What is your role in the ICBP

I have been involved with the programme management of the ICBP from September 2009. I am currently helping support the clinical input into Module 1, and using this to develop the key questions and protocol for Module 5. A key role has been working between the academics, policy makers and clinicians in the ICBP.

Q: What do you hope the ICBP will achieve?

Compared to many areas of cancer research the ICBP can make an enormous difference at a population level for cancer outcomes. I hope that the partnership helps develop and inform evidenced based cancer policy to both close the 'survival gap' and also improve survival in all jurisdictions. I hope that not only will the first 5 modules find funding across the partnership, but that I will see both growth and longevity of the ICBP over the coming years.



Meet the ICBP Programme Management team



The ICBP Programme Management Team (From left to right) Greg Hartwell, Donia Sadik, Martine Bomb, Catherine Foot, Penny Sellers and Kate Aldersey.

Greg Hartwell, Policy Manager

Greg works in the Cancer and End of Life Care team within the Department of Health. As well as working on the ICBP, he covers policy for his team on support for cancer survivors and on cancer prevention and early diagnosis awareness campaigns. He is on the civil service fast-stream graduate scheme.

Kate Aldersey, Programme Manager

Kate has recently joined ICBP, having been seconded from the policy team at Cancer Research UK, where she works on cancer services issues. Kate trained as a doctor and worked in the NHS for four years, giving her working knowledge of the NHS in England. She joins the team on a part time basis, continuing her role as a policy adviser two days per week.

Penny Sellers, Programme Assistant

Penny is in her final year of a two year Corporate and Scientific Services graduate training scheme at Cancer Research UK. As part of this she worked on the United Kingdom Centre of Medical Research and Innovation Programme and the CR-UK Centres team. She holds an MSc from the London School of Hygiene and tropical Medicine (LSHTM) in Control of Infectious Diseases.

Catherine Foot, Programme Director

Catherine works part time as the Programme Director for ICBP. She also works as a Senior Fellow at The King's Fund - a charity that seeks to understand how the health system in England can be improved. Catherine manages a programme of policy research and service evaluation looking in particular at quality measurement and reporting, including some recent work into the quality of diagnosis and referral in general practice in England. She was previously Head of Policy at Cancer Research UK and was seconded to the Department of Health to help draft the 2007 Cancer Reform Strategy. She has a Master's in Public Policy.

Martine Bomb, Programme Manager

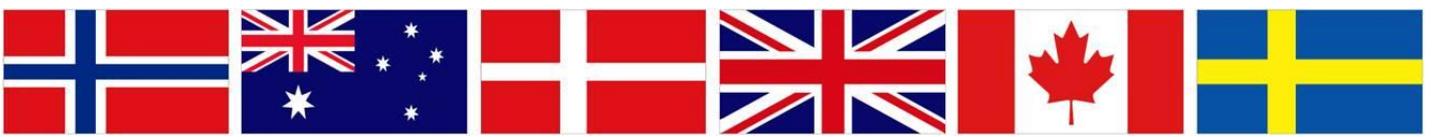
Martine completed a two year Corporate and Scientific Services graduate training scheme at Cancer Research UK before taking up the ICBP role. As part of this she worked with the National Cancer Intelligence Network on an England wide cancer dataset project, as well as managing a CR-UK finance project and communicating CR-UK's health information messages. She has a PhD in structural biochemistry.

Donia Sadik, Programme Administrator

Donia has worked at Cancer Research UK for several years, previously in the Science Funding and Operations Directorate being responsible for co-ordinating CR-UK's fellowship schemes and providing secretariat support to funding committees. She was also first point of contact to CR-UK PhD students and their supervisors.

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 partners and funders

The ICBP is a partnership which involves many collaborators and funders. These include:



National Cancer Action Team
Part of the National Cancer Programme



CANADIAN PARTNERSHIP
AGAINST CANCER



PARTENARIAT CANADIEN
CONTRE LE CANCER



Cancer Services
Co-ordinating Group

Grŵp Cydgysylltu
Gwasanaethau Cancer



Llywodraeth Cymru
Welsh Government



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority