



Welcome to the fourth issue of the ICBP newsletter

In this issue we will focus on Module 4 which is looking into patients' pathways, from noticing their first symptom to the point of diagnosis and start of cancer treatment. The findings will help us to understand whether longer time intervals can affect cancer outcomes.

In the last issue we featured Module 3 which is focusing on beliefs, behaviours and systems in primary care. Since then, the core "Primary Care Physician" web survey was piloted amongst GPs in the UK. An intensive process of international harmonisation then ensured that comparable instruments were developed for each international partner. Siger Technologies, a web survey design company, have designed and coordinated a web platform of the survey and are hosting the local versions of the survey in most jurisdictions.

The GP survey is now live in most partner jurisdictions and we hope to complete international data collection by the end of the year. Early outputs from the data analysis will then follow in 2013.

Two more programme board members are in the spotlight in this edition – find out why Denmark and Victoria, Australia joined the ICBP. We have created a 'Linked-In' group and updated the webpage: find out more on page 5.

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Focus on Module 4: Root cause of diagnosis and treatment delays exploring patient pathways

The core benchmarking module of the ICBP has reported significant international differences in lung, breast, colorectal and ovarian cancer survival, with England having some of the lowest rates.¹

These differences in cancer survival may be partly linked to differences in the time intervals between a patient's first symptom to the point of diagnosis and treatment.

Module 4 will provide the first robust international comparison of the time intervals from first symptom(s) until diagnosis and start of treatment for cancer patients. This will test the hypothesis that longer time intervals can contribute to poorer cancer outcomes.

Module 4 will also describe and compare the various routes that patients take to enter the cancer pathway and how they are diagnosed. Possible routes to diagnosis that will be explored include:

- Routine or urgent referral
- Referrals from population based screening programmes
- Emergency presentations to hospitals

The results will identify possible targets for actions to reduce delays.

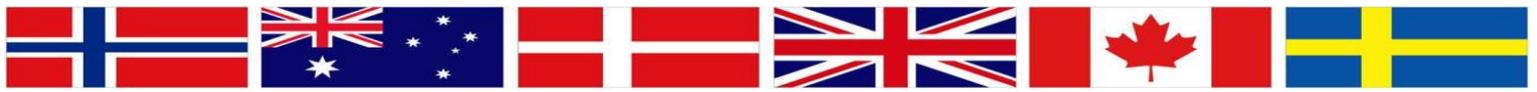
The Surveys

Module 4 data will be collected using paper surveys. Patients with breast, colorectal, lung or ovarian cancer will be invited to complete the survey within six weeks and six months of their diagnosis. The GP and a specialist care consultant of the patients who consent to take part in this study will be invited to complete a further short survey. The health care surveys will provide additional information on the patient's cancer and their journey through the cancer care system including:

- The nature of any referrals
- Investigative tests undertaken
- Patient co-morbidities
- Tumour stage at diagnosis

Participating jurisdictions will collect data for at least 200 patients for each of the four cancer types. The patient sample for the study will be drawn up by cancer registries in participating jurisdictions.

¹ Coleman MP, Foreman D, Bryant H et al. Cancer survival in Australia, Canada, Denmark, Norway, Sweden and the UK, 1995 – 2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data. The Lancet 2011; 9760: 127 – 138



Focus on Module 4:

Root cause of diagnosis and treatment delays by exploring patient pathways

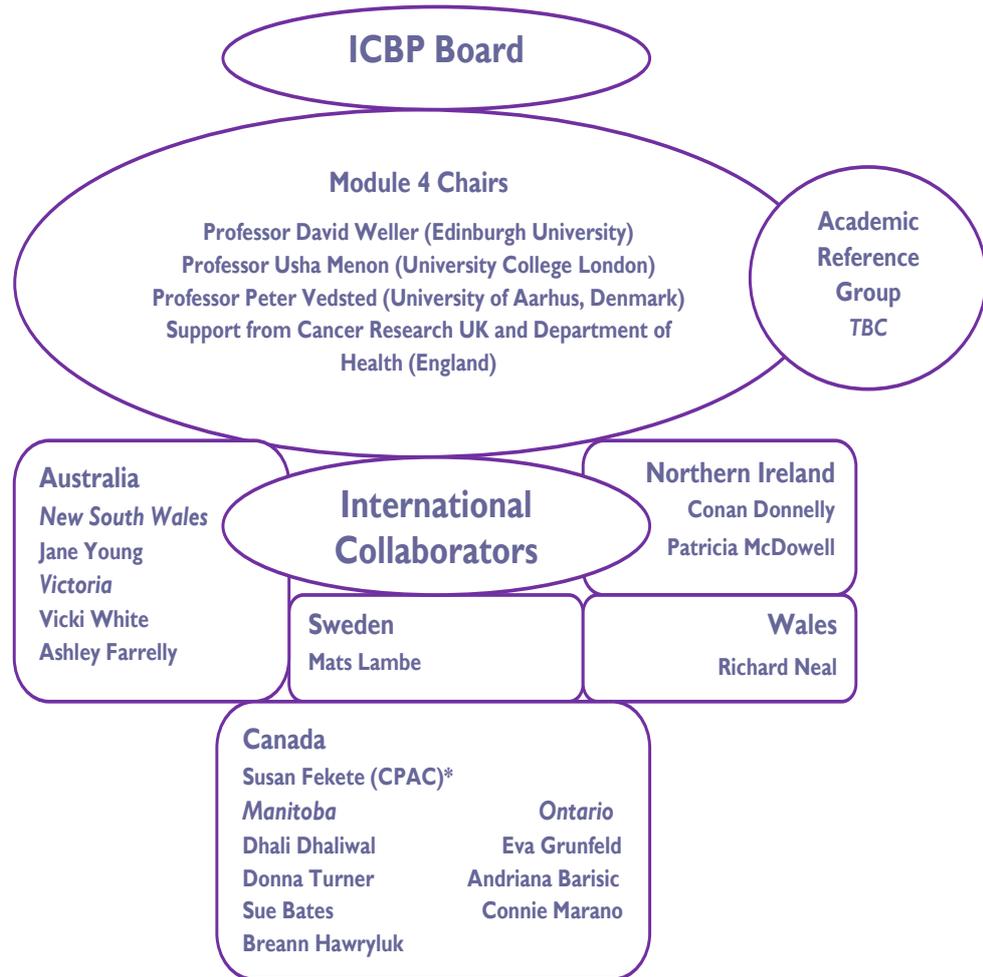
What is next?

The validation process of the questionnaires to be used in the feasibility has recently been completed in England.

Validation of the patient survey included face to face patient interviews, focusing on whether the questions are easily understood and can easily be answered, as well as general acceptability of the questionnaire. GPs and consultants tested the health care surveys with a particular focus on the content validity of each question.

The pilot study in England is due to get underway in autumn 2012. This will assess the feasibility of the protocol and provide a better indication of response rates. Meanwhile, the three questionnaires will be translated and harmonised by all international partners, followed by local pilots in participating jurisdiction.

The main Module 4 study is planned to get underway in early 2013 in all jurisdictions. Data collection for breast, colorectal and lung cancers is expected to take between six and nine months. This period has been increased for up to 12 months for ovarian cancer given the low number of cases in some jurisdictions. First outputs of the main study are expected in late 2013.



Module 4 funding and management

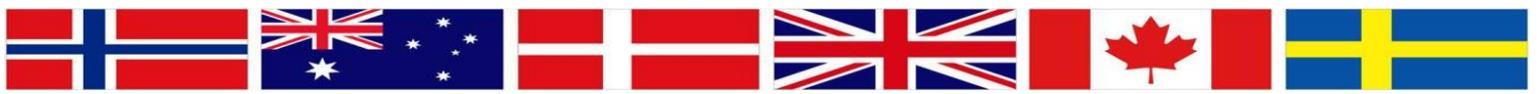
Module 4 is funded through a collaborative model with each participating jurisdiction contributing a proportion of the central costs of the study and financing any associated local costs. Programme Management is provided by Cancer Research UK.

Module 4 governance structure:

Overseen by the ICBP Programme Board, a central team leads Module 4, collaborating closely with a group of international collaborators. An independent Academic Reference Group will be established to provide peer review on methodology, analyses and conclusions.

The patient survey will include questions on:

- The length of three specific time intervals between onset of first symptoms, first healthcare professional contact, definitive diagnosis and start of treatment
- The events/symptoms that prompted the patient to seek medical attention
- The number of visits to healthcare providers made prior to diagnosis



Spotlight on Programme Board member: Robert Thomas, Victoria, Australia:

Chief Clinical Advisor for Cancer, Department of Health, Victoria

Biography

Bob Thomas was the Foundation Professor of Surgery, University of Melbourne, at the Western Hospital, Victoria followed by appointment as Professor and Director of Surgical Oncology at the Peter MacCallum Cancer Centre. He demitted from this position in December 2009 and was appointed the Victorian government's Chief Clinical Advisor for Cancer and Chair of the Advisory Council of the Victorian Cancer Agency.

Professor Thomas has been heavily involved in the development of cancer reforms within Australia. He has been a past President of the Clinical Oncological Society of Australia, Chair of the National Committee creating the Colorectal Cancer Guidelines and a member of the Ministerial Taskforce on Cancer.

He was instrumental in the development of the discipline of Surgical Oncology in Australasia and was responsible for the creation of the Surgical Oncology Group within the Royal Australasian College of Surgeons. He is the immediate past Editor-in-Chief of the ANZ Journal of Surgery and has served as Chair of National Health and Medical Research Council panels. Professor Thomas has ongoing research interests in the molecular pathology of gastrointestinal tumours.

He has published over 100 peer reviewed scientific papers and chapters in books. He was honoured by the Royal Australasian College of Surgeons with the "Excellence in Surgery Award".

Professor Thomas is passionate about cancer reform, working to provide all Victorians with the benefits of multidisciplinary care, appropriate psychosocial support for cancer patients and carers and access to the best translational research.

Victoria's Cancer Action Plan 2008-2011

The Victorian government supported and funded the development of a plan to deal with the increasing burden of cancer in our community, estimated to increase by 30% in the next decade. This plan builds on various initiatives progressed in the previous years to lay the basis of an integrated plan to impact on the burden of cancer. A cancer services framework had previously resulted in the creation of funded Integrated cancer services, covering the country and city designed to provide an on the ground cancer network to improve care.



The plan includes four action areas:

- reduce major cancer risk factors and maximise effective screening
- ensure rapid translation of research working through the Victorian Cancer Agency
- invest in system development including new technologies
- support patients and carers throughout their cancer journey

The plan had aspirational goals to increase survival of patients beyond what would normally be expected by 2015 and contained 65 targets for achievement in multiple areas. The plan was funded for Aus\$150M with \$80M dedicated to the research strategy.

Overall the plan has engendered great cooperative spirit amongst cancer professionals and has been successful in promulgating major improvements in cancer care.

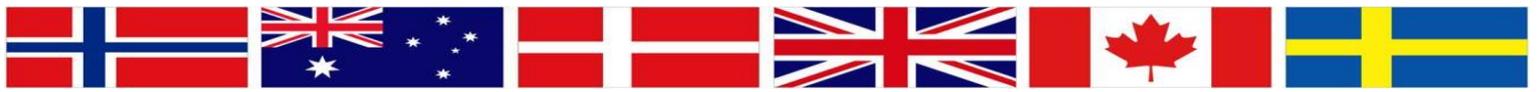
Q & A with Robert Thomas

Q: What is your role as chief cancer advisor?

This is a new role for our jurisdiction. Essentially it is a lead role for cancer matters within the government advising the Head of the Department of Health and the Health Minister. It is an advisory role but it is well supported within the Department of Health. It is the most significant role of clinician engagement so inevitably has expanded to cover more general clinical issues. I lead all the relevant committees overseeing the progress of the plan, managing quality matters in the department and directing the integrated cancer services. I also represent this state in the federal arena on cancer matters.

Q: Victoria's motivation for joining ICBP

This program commenced in Victoria by the Victorian Cancer Registry (VCR) and Professor David Hill, the early interest was in benchmarking outcomes in Module 1. The Department of Health joined the Cancer Council of Victoria, the organisation which houses the VCR, in partnership because of interests in cancer outcomes, in particular to gain insights into the likely clarification of possible causes of variation in outcomes. Our interest is in the rural, regional and metropolitan areas, where we have demonstrable differences in survival.



Spotlight on Programme Board member: Søren Brostrøm, Denmark:

Head of Department of Hospitals and Emergency Services, Danish Health and Medicine Authority



Biography

Søren Brostrøm received his medical degree in 1995 from the University of Copenhagen. He defended his PhD in 2003, and received a Master of Public Administration in 2011 from the Copenhagen Business School. He had his postgraduate medical training in the university hospitals in Copenhagen, becoming a specialist in obstetrics and gynaecology, and subsequently a subspecialist in urogynaecology and pelvic floor surgery.

His last clinical post was as a consultant urogynaecologist at the national tertiary referral centre, with a focus on urodynamic and neurophysiological investigations as well as specialized surgery including robotic laparoscopy. His research interests include pelvic floor neurophysiology and conservative therapy of lower urinary tract disease in women.

He has served on the boards of a number of national and international scientific associations, as well as being an associate editor and active reviewer of the peer reviewed literature in the field. He joined the National Board of Health in September 2011 in the position as Head of Department, Hospital Services and Emergency Management.

‘...the knowledge and results from the ICBP will be integrated in some of the initiatives of Denmark’s Cancer Plan III in 2012’

Organisation details and history of the National Board of Health in Denmark

The National Board of Health (NBH) in Denmark was established in 1909. NBH is the supreme national healthcare authority which plays an important role in the Danish healthcare sector. In cooperation with decision makers, the task of NBH is to establish the best settings for prevention and optimal treatment of illness, suffering and functional limitations for the individual within the Danish healthcare sector.

NBH advises and assists the Ministry of the Interior and Health as well as other authorities with the administration of health care services, and informs Danish citizens on specific health issues and on how to lead a healthy life. Furthermore, NBH monitors and evaluates health conditions, and endeavours to be on front edge of professional knowledge within the health care area.

The Danish Cancer Plan

In the field of cancer prevention and treatment NBH has, in cooperation with decision makers and clinical experts developed three cancer plans over the last decade. The main focus of Cancer Plan I (2000) was to ensure disease-specific improvements at the clinical level, whereas the main focus of Cancer Plan II (2005) was to ensure coherent patient courses. These two cancer plans are by now implemented within the Danish health care system.

In 2010 Cancer Plan III was developed and politically agreed on. This focuses primarily on early diagnosis, rehabilitation, palliation as well as involvement of patients and their relatives in the patient courses. NBH plays a major role in the Cancer Plan III. This year the majority of the initiatives will be implemented in the Danish health care system over the next few years.

Q & A with Søren Brostrøm

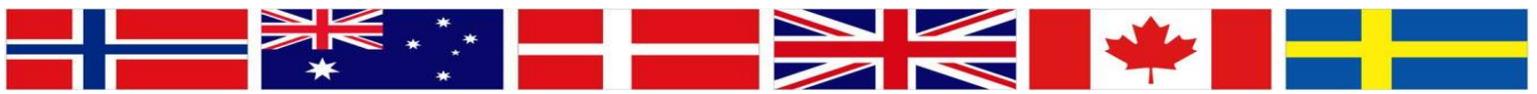
What are you hoping the ICBP can do for Denmark?

We believe that Denmark’s participation in the ICBP is a unique opportunity to gain important knowledge. Furthermore, we expect to learn from countries which are comparable to Denmark. We are especially concerned because the rates of cancer survival are lower in Denmark than in most of the participating countries.

We expect that the project will contribute positively to the national efforts within the cancer area in Denmark in several ways:

- We hope to increase our knowledge on organisation and implementation within the cancer area
- We hope to gain inspiration on how to improve the Danish cancer survival rates
- We hope to gain knowledge on, whether the Danish initiatives already implemented within the cancer area have had any effects on survival rates

Parts of the knowledge and results from the ICBP will be integrated in some of the initiatives of Denmark’s Cancer Plan III in 2012.



New ICBP *Linked – In Group*

We have created an ICBP *Linked-In Group* to further strengthen the communications between jurisdictions and collaborators.

This 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 website](#). This is a closed group, so people can only join the group or view discussions and posts if we add them as members.

What is new on the ICBP webpage?

We have updated our webpage to give more detail about some of the ICBP research Modules:

Module 1: Epidemiology

Module 2: Population awareness, attitudes and beliefs about cancer

Module 3: Role of primary care in diagnosing cancer

Please find the additional pages at: www.icbp.org.uk

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:



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



CARE + RESEARCH

An agency of the Provincial Health Services Authority



GUIDELINES AND AUDIT
IMPLEMENTATION NETWORK



WE ARE
MACMILLAN.
CANCER SUPPORT