

# International Collaboration in Cancer Control

*A Report from the Executive Director of the New Zealand Cancer Control Trust on the  
3<sup>rd</sup> International Cancer Control Congress in Cernobbio, Italy  
November 8-11, 2009*

## Executive Summary

International Cancer Control Congresses, of which the congress in Italy was the third of its type, provide an important opportunity for countries like New Zealand to learn about and reflect upon developments in cancer control from an international perspective, to draw upon the expertise of others, to promote New Zealand's unique achievements and to establish and maintain relationships with overseas colleagues. As the sole New Zealand delegate at the congress, I felt a particular responsibility to pursue all of these opportunities.

In this report I have endeavoured to document those presentations and experiences that, in my view, have particular relevance to New Zealand. Through my participation I also have electronic access to all abstracts and presentations, and I would be pleased to source these for use by others.

Topics that the New Zealand Cancer Control Trust believes warrant closer consideration in New Zealand are:

1. *Monitoring and assessing cancer control performance (pp 5-6)*

These include not only measuring and monitoring the cancer burden (incidence, mortality, staging, survival) but also establishing and routinely monitoring a set of key indicators, such as risk factor prevalence, screening coverage, waiting times for therapy, inequalities data, etc. Information provided in this report, including contacts, may be useful to those in New Zealand who are currently undertaking work to establish national cancer control and regional cancer network indicators.

2. *Collaborating internationally in developing cancer-related guidelines (p 6)*

The recent development of trans-Tasman melanoma guidelines by the New Zealand Guidelines Group (NZGG) provides an important model for international collaboration in the development of cancer-related guidelines. Opportunities are likely to exist for future collaboration, which could be explored by NZGG and the Guidelines International Network (GIN), of which NZGG is a member. The support of others involved in the 3<sup>rd</sup> ICC could be helpful in this regard.

3. *Getting the most out of communities of practice (p 9)*

Defined as "networks of people who work on similar processes or in similar disciplines and who come together to develop and share their knowledge", communities of practice are emerging in a variety of forms throughout New Zealand. Examples include national and regional clinical networks and the recently established national Melanoma Network of New Zealand (MelNet). Research being undertaken in Canada could be of assistance in understanding both the structure and means of interaction that contribute to the effectiveness of such networks.

4. *Integrating primary prevention programmes that target common behaviour risk factors (p 13)*

As highlighted previously by the New Zealand Cancer Control Trust, the opportunity exists for a more integrated cost-effective approach to primary prevention of cancer through its alignment with other chronic diseases, in particular cardiovascular disease, chronic respiratory diseases and diabetes.<sup>1</sup> Such an approach has been adopted in number of countries, including Canada, China and Australia. These governments acknowledge that diseases that share key risk factors and related interventions should be addressed together in a systematic and coordinated way. Presentations at the 3<sup>rd</sup> ICCC provide useful models by which such approaches could be developed in NZ.

5. *Integrating primary care into cancer control (p 10-11)*

Primary care is involved in all stages of the cancer pathway, including prevention, diagnosis, treatment and care, and there is growing evidence that primary care-based follow-up for cancers such as breast and colorectal cancer is equally effective as hospital follow-up. Resources such as the Cancer and Primary Care Research International Network could be useful as the role of primary care in cancer continues to be further defined in New Zealand.

6. *UK National Awareness and Early Diagnosis Initiative (p 11)*

Recognising the importance of early cancer detection by individuals and health-care workers coupled with timely referral for assessment/investigation, *The New Zealand Cancer Control Strategy* identifies the need to investigate which interventions to promote early presentation of symptoms, and thus referral for diagnosis and treatment of those with cancer, have the potential to improve survival and quality of life. A comprehensive programme mounted in the UK, including key messages and a review of the evidence base, provide a very useful resource to address the need for action identified in our Cancer Control Strategy.

## **Introduction**

The 3<sup>rd</sup> International Cancer Control Congress (ICCC-3) was held in Cernobbio, Italy from 8-11 November 2009. Over 450 delegates from 47 countries participated in the congress, including only four from the Pacific region (three from Australia and one from New Zealand).

The purpose of the ICCC-3 was “to promote and foster a global community of practice through enabling extensive participation and dialogue between countries and societies with wide and varying experiences in cancer control”.

The ICCC-3 built upon the achievements of the ICCC-1 (Vancouver, 2005) and ICCC-2 (Rio de Janeiro, 2007) and further elaborated on the theme of international collaboration between high income and low/middle income countries to achieve population-based cancer control.

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<sup>1</sup> Opportunities to reduce the social and economic burden of cancer in New Zealand. Submission to the Minister of Health from the New Zealand Cancer Control Trust on the Report of the Ministerial Review Group of 31 July 2009.

The programme focused on:

- International collaboration
- Establishing sustainable national/large population cancer control strategies
- Promoting broad cross-sectoral participation (e.g., governments, cancer organisations, foundations, NGOs, stakeholders)
- Promoting and fostering of a global community of practice in cancer control.

Specific goals of this congress were:

- Strengthening a strategic alliance between the European Union and African Union
- Defining 'pilot' projects or 'proof of principle' projects and collaborative assistance to enable development and implementation of cancer control action plans through virtual (electronic) and/or face-to face approaches.

As with the previous congresses, emphasis on information sharing and collaboration was reflected in the structure of the programme. This included six plenary sessions to establish a common understanding, with each followed by concurrent two-hour highly participatory round-table workshop sessions designed to address and provide feedback on specific issues. These workshops provided an important opportunity to meet and share perspectives with delegates from other countries.<sup>2</sup>

With regard to Congress related publications (most available from me):

- The plenary and workshop abstracts are on disc; presentations are available through the Congress website (password required).
- A final report, including an analysis of the workshop feedback, will be published within the next few months.
- A number of abstracts are included in the published monograph: *Tumori - a Journal of Experimental and Clinical Oncology*. Vol 95, No 5, September-October 2009.
- A listing of related reference documents and relevant websites is available.
- Resources on chronic disease prevention and control - Public Health Agency of Canada (disc) also is available.
- *Cancer Control*. Edited by Mark Elwood and Simon Sutcliffe. Oxford University Press, January 2010 (978-0-19-9555917-3). This is a multi-disciplinary text intended for "those from any discipline involved in cancer control, but primarily those in public health, health promotion, oncology, and health management. Also economists, patient advocacy/support groups, pharmacists, nurses, psychologists and cancer research staff". It can be ordered from Oxford University Press in Australia via a toll free phone in New Zealand: 0800 44 2502. Cost is \$149.95 plus \$12.50 for shipping.

The following report outlines the context for the congress, followed by sections on each plenary sessions and associated workshop that I attended. Within each, issues of particular relevance and/or which could have practical implications for New Zealand are highlighted, with specific information to enable follow-up.

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<sup>2</sup> At one of the workshops, a delegate from the US National Cancer Institute said that she was delighted to meet me, as New Zealand has a "highly respected" Cancer Control Strategy and is recognised as having a "sophisticated approach" to cancer control. For this reason she had considered applying for a Fulbright Fellowship to visit New Zealand.

## Conference Context

- Globally, nearly 60 million people died from all causes in 2004, with about one-eighth of these deaths resulting from cancer.
- More than 70% of world cancer deaths occur in low-and middle-income countries.
- The world population is projected to increase by approximately 80 million per year in the first half of the 21<sup>st</sup> century, with a disproportionate fraction of this increase being among the elderly, in whom cancer risk is highest.
- ‘Cancer control’ describes the totality of activities and interventions to reduce cancer incidence or mortality, or by alleviating the suffering of people with cancer; it comprises prevention, early detection, diagnosis and treatment, including psychosocial and palliative care.
- At the 58<sup>th</sup> World Health Assembly in 2005, the World Health Organization called upon its 192 members to develop national cancer control plans and programmes. (WHO had been urging countries to develop national plans since the early 1990’s.)
- Cancer control plans provide a blueprint/framework for each country to assess its cancer control needs and to develop interventions based on those needs.

## Opening Ceremony

By far the most stimulating and engaging speaker was the Honourable Mary Harney, Minister for Health and Children, Republic of Ireland, who spoke for 45 minutes without notes. Ireland’s population (4.2 million) and experience in cancer control (their strategy was published in 2006) may warrant closer examination by New Zealand, particularly in light of her comments that:

- Ireland is a world leader in cancer prevention (particularly in tobacco control)
- Ireland’s success in cancer control is due, in part, to its close relationship with cancer control leaders in the US and Canada
- Ireland will soon be establishing four cancer networks
- Cancer control policies cannot be implemented without clinical buy-in; Ireland achieved this by bringing Professor Tom Keane from the British Columbia Cancer Control Agency to head of the national cancer control programme for 2 years
- Ireland reduced the number of hospitals offering specialist types of surgery, which means that patients do have to travel further
- However, “patients confuse convenience with quality”, and they now accept that they may have to travel for specialist surgery
- If a country organises services well, it will attract back doctors who have left
- Engaging consumers and seeking their support is essential
- Ireland has a single health entity and no longer has 11 health boards
- Health will always be a political issue; for this reason, it needs collaboration between political and clinical communities and clinical leaders to champion cancer control.

**Plenary Session A: Planning and Monitoring Population–Based Systems**  
**Workshop Session 4: Cancer Plans: Their Rationale and Design and Evaluation of their Performance**

The focus of this session was on how to measure and monitor the cancer burden, how current and future needs for cancer control services are determined and how to monitor and assess the performance of cancer plans and services. Particular emphasis was given to

how high income countries might be able to help/support those low/middle income countries that lack good planning information. Some key points from presentations:

- Cancer registries are essential tools for cancer control, i.e. both for developing policy as well as evaluating whether policies have been effective. They should:
  - Provide for key measures of incidence, prevalence, mortality and survival
  - Be adequately resourced (essential), with a sustained commitment and trained personnel.
- WHO's efforts to assist countries plan and implement effective national cancer control programmes (NCCP) include:
  - An online NCCP core-self-assessment tool, based on the WHO evaluation framework described in the WHO manual on how to develop effective programmes (*Cancer control knowledge into action: WHO guide for effective programmes, WHO 2006-2008*)
  - Inviting countries to use the tool as part of their NCCP monitoring and evaluation once it has been finalised
  - Further information on congress website (Workshop 4, Presentation A4-1, C.Sepulveda).
- The online web portal Cancer Control P.L.A.N.E.T. [Plan, Link, Act, Network with Evidence-based Tools] was designed by the National Cancer Institute for cancer control planning, programme implementation and evaluation systems in the US. See: <http://cancercontrolplanet.cancer.gov/>. The on-line tool is structured around a five-step process of comprehensive cancer control planning, including the latest evidence reviews on the effectiveness of different approaches to cancer prevention, control and early detection. Although North American, the site provides information of relevance to other countries, e.g. systematic reviews of evidence-based interventions and a research to practice cyber seminar series. Having enrolled, I now receive notification of such seminars and invitations to participate.
- The Netherlands has a NCCP Monitor that reports national data on a selected set of indicators. See [www.npknet.nl/monitor](http://www.npknet.nl/monitor) (an English version is available but not on the site). They have published a small card in English that shows results from 2007 and 2008, as compared to their 2010 goal.
  - Measures include:
    - Primary prevention: smoking, fruit consumption, vegetable consumption, obesity, physical activity, physical inactivity
    - Secondary prevention: breast cancer screening (attendance rate, referral rate, positive predictive value); cervical screening (attendance rate; incidence per 100,000)
    - Cancer care: cancer incidence per 100,000, stage at diagnosis, time from diagnosis to treatment, compliance to guidelines, five-year relative survival and cancer mortality per 100,000).
  - Patients were involved in Monitor development, and the Netherlands stresses the importance of this.
  - For further details contact: Renee Otter ([r.otter@ikno.nl](mailto:r.otter@ikno.nl)).
- The Canadian Partnership Against Cancer has a National System Performance Reporting System (how cancer control is working in Canada, rather than an evaluation of the cancer control plan itself) developed by:
  - A national workshop at which cancer control professionals narrowed several hundred indicators identified through an in-depth literature review to several dozen
  - A committee of senior cancer control professionals and administrators that reduced the list further, based on specific prioritization criteria; following a

national survey, these were reduced to 17 indicators (e.g. incidence & mortality data, survival analyses, risk factor prevalence, wait times for therapy, system infrastructure and progress in such areas as availability of cancer staging information)

- Some work also has been done to examine indicators according to social determinants data
- One measure of supportive care is identifying how many clinics measure psychological distress
- Further details are available on the congress website (Workshop 4, Presentation A4-3, H.Bryant) or from Heather Bryant: [heather.bryant@partnershipagainstcancer.ca](mailto:heather.bryant@partnershipagainstcancer.ca).

**Plenary Session B: Cancer Control: Europe and the World: International  
“Collaborative Interest Group Workshop”  
Workshop 6: Cancer Control: International Collaboration on Clinical Practice  
Guidelines**

This session had two themes, with the first to promote ongoing geographic collaboration already established at the first and second congresses. The second was to generate interest on topics of broad interest or requiring focus that might benefit from collaboration. Some key points:

- UICC (International Union Against Cancer) is “the most important global NGO” in cancer control, with 300 member organisations in 103 countries.
- The CONCORD study (originally planned to provide a trans-Atlantic comparison of cancer survival) now brings together data from 101 population-based registries in 31 countries. NZ has expressed an interest in being included. Data analysis has been published in Coleman MP, Quaresma M, Berrino F et al; CONCORD Working Group. Cancer survival in five continents: a world wide population-based study (CONCORD). *Lancet Oncol*. 2008 Aug; 9(8):730-56. Further details on congress website (see Plenary Session B, PB-3 – Professor Michel Coleman).
- The Lance Armstrong Foundation has conducted a survey on global perceptions of cancer (following on from the LIVESTRONG Global Cancer Summit in Ireland in 2009). See: [www.livestrong.org/commitmentmap](http://www.livestrong.org/commitmentmap) (with reference to NZ).
- Those of us involved in the guidelines workshop at the congress recommended that a community of practice for international collaboration in development of cancer-related guidelines may be useful, with the following suggestions:
  - The Guidelines International Network (GIN)<sup>3</sup> could be asked to facilitate
  - Also, the ADAPTE Collaboration (a systematic approach for the adaptation of guidelines produced for use in one cultural and organisational context to be used in a different cultural and organisational context) may be another option (<http://www.adapte.org/>).
  - Further contact regarding these possibilities is invited by Jill Petrella, Quality Coordinator, Canadian Care Nova Scotia ([jill.petrella@ccns.nshealth.ca](mailto:jill.petrella@ccns.nshealth.ca)).

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<sup>3</sup>The New Zealand Guidelines Group (NZGG) was a founding organisation of GIN and continues to participate in international conferences and contribute to GIN working groups.

**Plenary Session C: Cancer Control: Establishing Effective Primary Prevention and Population-Based Screening Programs**  
**Workshop 1: Food, Nutrition, Physical Activity and Cancer Prevention: Policy Implications of the 2007 and 2009 World Cancer Research Fund/American Institute for Cancer Research Reports**

The focus of this plenary session and linked workshops was on evidence-based pragmatic and contextual approaches to the development of effective prevention and early detection programmes in the context of high, middle and low resource settings. Emphasis was given to the need to capitalise on what already exists in the international community rather than reinventing the wheel. Highlights include:

- Dr Geoffrey Cannon, Chief Editor, World Cancer Research Fund International, who spoke passionately about:
  - *Food, Nutrition, Physical Activity and the Prevention of Cancer: a Global Perspective* (2007) as well as the companion report, *Policy and Action for Cancer Prevention*: both available at <http://www.dietandcancerreport.org/>.
  - He described the 2007 report as “the most authoritative and comprehensive report ever published on diet and cancer”. It includes the panel’s judgements of the strength of the evidence causally relating food, nutrition and physical activity with the risk of cancer of the sites reviewed, and with weight gain, overweight and obesity. (Professor Jim Mann of the University of Otago was a member of the Expert Panel.)
  - The 2007 report provides recommendations on public health goals (for populations, and therefore for health professionals) as well as personal recommendations (for communities, families, and individuals).
  - The companion Policy Report (2009) provides advice and guidance on what can be done to influence and change the lifestyle choices that people make, as they relate to their risk of cancer. It is aimed at “policy-makers and decision-takers at all levels, from global and national to local”.
  - He emphasised the importance of cancer prevention being addressed within the context of chronic diseases; he also argued for the need for legislation: “all significant advances in population health required and involved the use of law and regulation”.
  - “At a population level, no lower-income country, and increasingly few of the higher-income countries, has the human or material resources to treat cancer. The most rational and feasible policy is prevention.”
  - “To control and prevent cancer and other epidemic diseases in populations, focus not on the biology and pathology of the diseases, but on their behavioural, and social, political, economic and environmental causes.”
  - It was clear from the discussion that followed that not everyone at the congress shared Dr Cannon’s enthusiasm nor agreed totally with the magnitude of risk outlined in the 2007 report. This was especially apparent in the subsequent afternoon plenary, where some argued that some of the recommendations, if implemented, could be contradictory.
- With regard to cancer screening, Professor E.L. Franco (Epidemiology and Oncology, McGill University) spoke of the need for proper evaluation of the collective evidence for or against a screening intervention, including the many issues and sources of biases that affect the interpretation of all types of study designs, in evaluating the efficacy of a screening test. In his view, “cervical screening is one of the best forms of screening”, and there is insufficient evidence to support screening for prostate cancer to reduce mortality.

- Other key points raised in session:
  - Population interventions should have the same weight as clinical interventions.
  - Civil society has a crucial role in achieving change, e.g. changes in public policy: the general population does not realise its power/influence for change.
- The workshop on the World Cancer Fund nutrition reports highlighted the need for a focus on behaviour change in relation to nutrition and physical activity; it also urged those responsible for national policy/priorities to draw upon the 2009 policy report in identifying the types of interventions for which there is evidence of effectiveness. Workshop leaders also stressed the potential impact upon other chronic diseases of implementing the 2007 report.

<p><b>Plenary Session D: Comprehensive Cancer Control: Research and Development: Knowing What We Do and Doing What We Know Workshop 5: Translating Research into Practice</b></p>
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This was a thought-provoking and sometimes controversial plenary session, with a focus on getting evidence-based cancer control interventions into practice. One of the themes was the need to explore potential public/commercial partnerships. While the potential for scepticism was acknowledged, particularly in relation to partnerships with the food industry (for example, the industry-supported “Americans Against Food Taxes” – [www.nofoodtaxes.com](http://www.nofoodtaxes.com) - to oppose ‘academics’ arguing in favour of tax on sugared beverages, etc). John Kerner of the Canadian Partnership Against Cancer (formerly with the US NCI) argued that a partnership of trust between public/private players needs to be established. Some of his key points:

- It’s all too easy to slip into blame mode, assuming that the food industry is equivalent to the tobacco industry.
- “You don’t have to sell out but you do need to understand who the right partners are and what their motives are.”
- We need to have conversations with the industry and ascertain what they want; from this opportunities for collaboration may emerge.
- He gave the example of Kellogg’s in Canada inserting 1 mil pedometers in cereal boxes to support implementation of the “Canada on the Move” project (findings reported in the Canadian Journal of Public Health, 97 (Suppl1), March/April 2006).
- He also highlighted the importance of using an informed decision-making model to select cancer control interventions (see: Kerner, JF. Integrating research, practice, and policy: what we see depends on where we stand. *J Pub Health Management & Practice*. 2008, 14(2): 193-98). View at: [http://www.cancercontrol2009.com/speaker\\_presentations/presentations/Tuesday/Plenary/KERNER%20INTRO%201330.pdf](http://www.cancercontrol2009.com/speaker_presentations/presentations/Tuesday/Plenary/KERNER%20INTRO%201330.pdf)

Daniel Campos of Argentina and the US NCI [Role of the Public Sector in Clinical Research Practice and Policy] argued for more publicly funded clinical research/trials to take place in developing countries. Limitations of having the majority of clinical trials taking place in the developed world through sponsored pharmaceutical company research include:

- Recommended treatments that do not reflect ethnic(genetic), cultural and resource differences between developed and developing countries
- Little research on those cancers that are primarily found in developing countries.

Among the limitations of relying on research undertaken by pharmaceutical and biotechnology companies are:

- Their primary objective is to get their product evaluated quickly and, if found to be effective, approved for marketing (rather than how best to integrate active new agents into cancer treatment regimens for a variety of cancer sites, age groups, etc).
- Their research is generally limited to experimental agents and will not, for example, compare treatment modalities nor identify the most effective treatments which national health care systems should make available.

The published abstract for the above presentation stresses the importance of having national and international clinical trial networks; it also identifies clear outcomes for conducting clinical trials globally. (See Plenary Session D – abstract 2)

In leading the workshop on translating research into practice, John Kerner asked if “tens of billions are spent on research discovery and thousands of billions on health service delivery worldwide, by both the public and private sectors, what is spent to connect the two”? In his view, the answer may be viewed as “decimal dust”. At present “it takes 17 years for 14% of new scientific advances that actually improve outcomes to be implemented population-wide”.

Among the workshop presentations were two initiatives that warrant a closer look by New Zealand:

- The Canadian Partnership Against Cancer’s Knowledge Management Strategy
  - Developed to address the need for coordinated mechanisms to make use of Canadian population and public health knowledge (see background paper: [http://www.nccmt.ca/pubs/KMpaper\\_EN.pdf](http://www.nccmt.ca/pubs/KMpaper_EN.pdf)).
  - Its aim is to reduce duplication of effort & resources across provincial and territorial cancer systems through effective knowledge management (KM)
  - One of the tools developed for KM is a web-based portal: [www.cancerview.ca](http://www.cancerview.ca). One of its aims is to link health professionals, provide access to up-to-date integrated information such as cancer guidelines, prevention policies, incidence rates and clinical trials, as well as an online workspace for groups and organisations. Another and more recent aim is to provide online information for people affected by cancer. Criteria have been developed for what can be included on both.
  - They use ‘webinars’ to promote the site, as well as e bulletins and newsletters.
- Canadian Communities of Practice (COPS)
  - Communities of practice are defined in the above strategy as “networks of people who work on similar processes or in similar disciplines, and who come together to develop and share their knowledge in that field for the benefit of both themselves and their organization(s). They may be created formally or informally, and they can interact.”
  - The project examines two informal pan-Canadian COPs with different structures to ascertain how effective they are in guideline implementation. (The types of communication used by both include face-to-face meetings, teleconferences, video links, emails, etc).
  - Conclusion: Understanding both the structure and means of interaction can assist in identifying facilitators and barriers to successful knowledge translation and professional learning within collaborative communities.

- More work is needed around virtual communities of practice. (Further information about these will be helpful to those establishing such communities in New Zealand, such as the Melanoma Network: [www.melanoma.org.nz/melnet](http://www.melanoma.org.nz/melnet)).
- The British Columbia Cancer Agency also has a programme of “General Practitioners in Oncology” where GPs who express an interest in cancer care can be trained at BCCA, then take a lead role in the community, e.g. to administer chemotherapy; also, all GPs are kept in the loop at all times regarding their patients who are receiving treatment.
- Contact Barbara Poole: [bpoole@bccancer.bc.ca](mailto:bpoole@bccancer.bc.ca).

**Plenary Session E: Cancer Control: “Organization of” Population-Based Programs: Europe & the World**  
**Workshop 3: The Organization of Primary Care Systems [Priorities]**

This session examined models for planning and delivery of population-based cancer control, including the principles and content, implementation in different resource settings and the role of government, NGOs and other parties in support of models of interdisciplinary collaboration. The first presentation was on the International Atomic Energy Agency’s Programme of Action for Cancer Therapy (IAEA/PACT) to enable low-resource countries to provide equitable treatment and care. Two other papers of particular relevance to NZ were:

- F.P. Cuevas: Integration of primary prevention programmes which target the common behavioural risk factors of the major non-communicable diseases (NCD)
  - An integrated approach to chronic disease prevention is now recommended by the WHO.
  - While effective primary prevention can impact on diabetes incidence and coronary heart disease mortality in a five year time frame, the impact on cancer incidence and mortality usually takes decades.
  - At a minimum, these approaches ensure consistent messages and sharing of resources.
  - Formalised alliances are important in implementing NCD approaches,
  - Australia has recently adopted a chronic diseases approach that includes asthma, cancer, diabetes and CVD.  
<http://www.health.gov.au/internet/main/publishing.nsf/Content/pq-ncds>)
  - It also is important to look at the process by which such approaches have been developed, e.g. establishing a “Coalition Council” of allied organisations and a technical working group. (Australia has an Australian Chronic Disease Prevention Alliance.)
  - In response to my question as to the major challenges faced in achieving a NCD prevention approach in the Philippines, Ms Cuevas replied that they followed Australia’s advice (Robert Burton’s) to have five major organisations as a coalition and to have them identify a common agenda without interfering with disease-specific issues.
- David Weller: Primary care integration into cancer control (Professor Weller has worked in New Zealand and Australia and currently is at the University of Edinburgh)
  - Primary care is involved in all stages of the cancer journey, with growing evidence, for example, that primary care-based follow-up for cancers such as breast and CRC is equally effective as hospital follow-up.
  - There is a need to ensure that the role of primary care in cancer control is clearly defined.

- WHO has just released the document *Primary Health Care: Now more important than ever*.
- Also see: The Cancer and Primary Care Research International Network (Ca-PRI) - an open, multidisciplinary network for researchers in primary cancer care and related areas. Ca-PRI was founded in 2008 and welcomes researchers from all disciplines related to research and development in the fields of cancer care in primary care: <http://www.ca-pri.com/>.

Workshop presentations of interest to NZ (particularly to the NZGG and implementation of the *Suspected Cancer in Primary Care Guideline*):

- Sara Hiom (Cancer Research UK): The National Awareness and Early Diagnosis Initiative – NAEDI
  - A public sector/third sector partnership between the Department of Health, National Cancer Action Team and Cancer Research UK. Its role is to co-ordinate and provide support to activities that promote the earlier diagnosis of cancer.
  - Work streams on website include awareness measurement, reducing primary care delay, key messages and review of the evidence base: ([www.naedi.org.uk](http://www.naedi.org.uk) & [www.spotcancerearly.com](http://www.spotcancerearly.com)).
  - Also, the 3 December 2009 edition of the *British Journal of Cancer* is devoted to articles on earlier diagnosis of cancer, including evidence for the National Awareness and Early Diagnosis Initiative (edited by Mike Richards and Sara Hiom): <http://www.nature.com/bjc/journal/v101/n2s/index.html>.
  - The NAEDI research programme also is looking at messages around obesity and diet in order to establish messages that transcend disease silos (i.e., chronic disease messages).
- Contact also made with Dr Christine Campbell, Scottish School of Primary Care, University of Edinburgh ([christine.campbell@ed.ac.uk](mailto:christine.campbell@ed.ac.uk)). (Several years ago I met with her in Edinburgh to learn about their CRC screening trial.) Christine may be able to provide references to research on the role of primary care in providing sun protection advice (an issue likely of interest to the Implementation Advisory Group of the Melanoma Guidelines for Australia and New Zealand and to the Health Sponsorship Council).

**Plenary Session F: Cancer Control: Critical Factors Influencing the Establishment, Maintenance and Sustainability of Population-Based Programs**  
**Workshop 5: Role of Patient and Public Engagement in Comprehensive Cancer Control**

The final plenary session focused on how the relevant stakeholders in cancer control need to collaborate to create a coherent case for the maintenance and sustainability of cancer control activities. Presentations and discussions addressed the interaction of cancer and NCD approaches to manage chronic diseases and how to bring people together across all sectors, including government, NGO, provider and the public. A particular emphasis was given to how countries support public and societal engagement and the role of civil society.

Among the issues highlighted in this session were the growing disparities in cancer burden between the developed and developing world. According to Peter Boyle, of the International Cancer Research Institute (France):

- *The World Cancer Report* (IARC 2008; Boyle P, Levin B (Eds)) provides sobering data on the significant increase in the cancer burden in low to medium income countries.
- In the 1960's approximately one third of the global cancer burden was diagnosed in low income and lower-middle income countries; this year, just over one half of the global cancer burden is to be found in these countries.
- In 2020, it will have risen to around three quarters of the global cancer burden.
- Worldwide cancer burden (2008):
  - 12.5 million new cases
  - 7.6 million deaths
  - 28 million living with cancer
- Worldwide cancer burden by 2030:
  - 26.4 million new cases
  - 17.1 million deaths
  - 80 million living with Cancer
- World tobacco deaths if current smoking patterns continue:
  - Estimated total for the 21<sup>st</sup> century: ~1000M (1 billion)
  - Compare with the 20<sup>th</sup> century total: ~100M (0.1 billion)
- Economist Intelligence Unit Report (2009):
  - The link between improved health outcomes, including extended life expectancy and economic development is a hot topic in academic research.
  - High income countries have 38.7% of the global cases of cancer and yet they spend 93.8% of the total global expenditure on cancer.
- Peter Boyle made an impassioned plea that “steps must be taken urgently to erase/reduce the huge disparities which currently exist”.
- “Failure to do anything about the increase in cancer in low to medium income countries will be a calamity.”

The following session provided further information about how countries, like the Philippines, have developed a chronic disease prevention approach:

- Sustaining a National Coalition for NCD Prevention (Philippine Experience)  
Frances Cuevas, Chief Health Program Officer, National Center for Disease Prevention and Control, Department of Health, the Philippines:
  - The coalition was formed through formalised alliances by way of a Memorandum of Agreement that involved:
    - 40 organisations
    - Agreeing as an organisation to contribute to the programmes and activities approved by the Council, while maintaining its own independent programmes and avoid open conflict with similar actions of the Coalition
    - Activities to be undertaken linked with KPIs.
  - Objectives of the Coalition are to:
    - Promote policy and legislative environment supportive to the practice of healthy lifestyle
    - Enhance people’s awareness and practice of healthy lifestyle
    - Enhance surveillance mechanisms for NCD.
  - Strategies of the Coalition:
    - Policy and legislation
    - Information dissemination and advocacy campaigns
    - Surveillance and monitoring
    - Resource development and generation.
  - Factors that facilitated coalition building include:

- Availability of quality data
- New knowledge on the concept of integrating
- NCD prevention and control
- Positive experiences in working together
- Meagre resources which necessitated pooling of resources
- Credible and valued leadership of the DOH and other stakeholders.

A final workshop led by Ms Pat Kelly (Canada) on the Role of Patient and Public Engagement in Comprehensive Cancer Control (CCC) provided an inspiring Congress ending for me. Since Pat began her career in “citizen advocacy” in 1987, when as a young mother she was diagnosed with breast cancer, she has worked to ensure community participation in cancer control. Apparently her efforts were crucial in working alongside Simon Sutcliffe to mobilise community support for Canada’s Campaign to Control Cancer (now the Canadian Partnership against Cancer).

According to Pat, there are at least two ways to begin and maintain Comprehensive Cancer Control Programs. One way is a “top down” approach, in which governments or international organizations design, build, fund, and maintain CCC. Another is the “bottom up” approach, beginning with community participation and building grass-roots movements of individuals (e.g., patients). This session therefore focused on community involvement by patients, the general public and non-governmental organizations (NGOs) in maintaining CCC.

In addressing the workshop, Pat Kelly described *Go Public* - a global mobilisation project that involved “community conversations on cancer control” in 36 countries, including New Zealand. Key points from the publication provided to me by Pat:

- *Go Public* was the “largest inaugural global focus group on cancer”.
- Conversations within 36 countries (developed and developing) ranged in size from 3 to 150 participants, held in-person and over the Internet (2,341 participants in total).
- *Go Public* allowed individuals not only to share their stories about cancer, but also to feel as if they could influence the future direction of cancer control.
- Themes that emerged:
  - Reconsider “cancer control” as an external marketing slogan
  - Inspire action: the cancer community should work together to create a coordinated public health message that empowers the public to take charge of their health
  - Consider community conversations as an awareness tool
  - Engage in systems thinking: the cancer community should be more coordinated and should take a systemic and coordinated approach to solving cancer
  - Build a coordinated and culturally-appropriate strategy for assisting developing countries.
- *Go Public* went beyond a simple conversation/exchange of ideas. It served as an important catalyst for building individual and collection action.
- See: <http://www.controlcancer.ca/gopublic/>.

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