Cancer Control New Zealand

Annual Report:
For the year ended 30 June 2014
Highlights at a glance

A major highlight for 2013/14 was the roll-out of five structured reports, via the New Zealand Cancer Registry, based on the Royal College of Pathologists of Australasia cancer protocols. These were successfully developed and implemented, including the extremely complex Breast Cancer Structured Report. These are now in use at nine pathology laboratories with over 60 pathologists enrolled. The roll-out continues.

Other major activities and achievements included:

- the appointment of a new Cancer Control General Manager and Cancer Control New Zealand Board
- the publication of four key documents regarding deaths in New Zealand: palliative care in aged residential care; regional and ethnic projections; and place of death - which enable an assessment of the need for palliative care and provide services across all settings with data to improve service provision and delivery
- the establishment of a Last Days of Life Working Group to develop recommendations on a national approach to care of people in their last days of life
- the launch of an online palliative care research repository
- advice to the Minister of Health on improving the integration of palliative care in line with World Health Organization recommendations.
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Chair’s report

This is Cancer Control New Zealand’s ninth year of operations since being established as the Cancer Control Council in 2005.

A key achievement over this past year has been the enhancements to the New Zealand Cancer Registry, including the development and implementation of structured reporting for individual cancers based on the Royal College of Pathologists of Australasia cancer protocols. For some of these cancers (eg, breast cancer) this has been the first time that a structured report has been successfully developed internationally, and we are gratified at the support we have received from pathology laboratories around New Zealand, where pathologists have given their time to test and provide feedback on the structured reports as they were developed.

Cancer Control New Zealand has ensured that it has fulfilled its role of advising the Minister on issues in cancer control through reporting and advising on issues of importance including such items as:

- the New Zealand Skin Cancer Primary Prevention and Early Detection Strategy
- personalised medicine, genomics and epidermal growth factor receptor testing
- the Radiation Oncology National Linear Accelerator and Workforce Plan.

The Palliative Care Council, which was established by Cancer Control New Zealand in 2008, has had a highly productive year. Initiatives carried out in 2013/14 include:

- the launch of the New Zealand Palliative Care Research Repository website
- identifying the need for palliative care in New Zealand, with the release of four working papers across this field
- the appointment of a Last Days of Life Working Group, which will deliver recommendations on a national approach to the care of people in their last days of life.

Towards the end of this year, several members of the Board retired, and I would like to thank them for their dedicated work over the past few years. I would also like to welcome the newly appointed members, and wish them and the new Board Chair every success.

Dalton Kelly

Interim Chair
Executive summary

Cancer Control New Zealand (CCNZ) is a section 11 committee formed under the Public Health and Disability Act 2000 to provide strategic advice on cancer control and palliative care to the Minister of Health and the Ministry of Health, and to provide leadership and develop strong relationships across the sector to inform national priorities in cancer and palliative care.

To achieve its stated purpose, CCNZ’s secretariat provides the supportive function to three key boards: the CCNZ Board, the Palliative Care Council (PCC) and the New Zealand Cancer Registry Board. In collaboration with the Ministry of Health and via sector engagement, during 2013/14 CCNZ has worked with each of these boards on a range of activities with the purpose of improving the patient journey for all New Zealanders with cancer and life-limiting illnesses.

The CCNZ Board will focus on establishing a cancer research programme to identify the current investment in cancer research and develop a process of matching funding between non-governmental organisations and the Health Research Council to increase the overall cancer research funding pool. In addition, CCNZ will repeat the Voice of Experience Cancer Patient Survey originally conducted in 2009 as requested by the outgoing Minister of Health, to establish how the implementation of changes since 2009 have impacted on the patient experience of cancer outpatient care.

The PCC is focusing on developing guidelines and recommendations on the provision of care to people in their last days of life across all settings. The PCC has also initiated a project to develop recommendations regarding palliative care in aged residential care settings reflective of the changing demographic in New Zealand. Work continues on identifying the need for palliative care in New Zealand since comprehensive data and analysis enable service providers to plan more effectively.

The New Zealand Cancer Registry Board provides governance, advice and leadership on cancer information to consider what cancer information is required for collection, analysis and interpretation across New Zealand. Key for the New Zealand Cancer Registry Board is a decision on the next steps for the clinical Tumour Node Metastases pilot at Middlemore Hospital. The pilot enables the calculation of the survival of cohorts of patients, which will enable international benchmarking, and measures the impact of screening programmes and new treatments.
Cancer Control New Zealand

Cancer Control New Zealand (CCNZ) was established in 2005. Its role is to provide independent expert advice on emerging issues and successful initiatives in cancer control and to provide leadership in selected major projects, with the objective of assisting the Government in improving the quality, timeliness and accessibility of cancer care in New Zealand.

In order to achieve its objectives CCNZ will report on New Zealand’s performance in providing strategic leadership and direction for cancer and palliative care services. CCNZ’s functions include providing timely advice and recommendations to the Minister on:

- mortality and impacts of cancer
- inequalities in access to cancer care
- the effectiveness of new initiatives in cancer care
- any other matters requested by or agreed with the Minister.

CCNZ will also:

- report on New Zealand’s performance in providing cancer care
- provide strategic leadership and direction, and promote collaboration between cancer related entities.

CCNZ sets out to achieve this by working through its secretariat and the Palliative Care Council (PCC), engaging with the health sector and its partners to inform national priorities and aspirations in cancer care, thus improving the patient journey for New Zealanders.

During the 2013/14 year, CCNZ’s Board comprised 11 members representing every facet of the cancer control sector – academics, medical practitioners and those with extensive experience in cancer nursing and palliative care.

The PCC consists of ten appointed members who represent a range of skills, professional associations and networks.

This range of clinical and research expertise ensures that advice and decisions are based on strong clinical evidence and real world experience. CCNZ and PCC’s clinical, professional and consumer networks have helped identify strategic priorities for cancer control and palliative care related activities, and ensure that CCNZ advice continues to contribute to improved system performance.
CCNZ key initiatives

Reflecting on 2013/14, the following represents some of the key initiatives completed by CCNZ.

During 2013/14 a new General Manager for CCNZ, Andrew Lesperance, was appointed. A decision was made to further develop the secretariat function, with a focus on ensuring a robust service to support three committees – the CCNZ Board, the PCC and the New Zealand Cancer Registry – with an emphasis on system and quality improvement.

The CCNZ Board considered and/or contributed to discussion and the advancement of:

- issues relating to hepatocellular carcinoma and Hepatitis B prevention and detection
- the New Zealand Skin Cancer Primary Prevention and Early Detection Strategy
- the Consensus Statement on Vitamin D and Sun Exposure in New Zealand
- development of a research stocktake and funding strategy
- personalised medicine, genomics and epidermal growth factor receptor testing (EGFR)
- safe handling of cytotoxic agents
- the Radiation Oncology National Linear Accelerator and Workforce Plan
- the development of a multi-year work plan for CCNZ
- contributions to the Colorectal Cancer Screening Advisory Group
- progression of a research ‘Matched Funding’ initiative with the Health Research Council.

There was a focus on better engagement and relationship-building outwardly from CCNZ. This resulted in numerous opportunities for engagement with other committees such as the National Health Committee, Health Workforce New Zealand, Ministry of Health and regional networks. At all times effort was made to ensure issues under consideration were not duplicated, agendas were shared, and a common direction of travel was achieved.

Cancer non-governmental organisation (NGO) sector engagement is crucial to advancing cancer control. Regular engagement with CANGO, the overarching organisation that brings together eight cancer NGOs, was an objective that was well advanced over the past year. Through supporting the NGO sector there are, and will continue to be, opportunities to improve patient care across the continuum. These may take the form of a better understanding of issues in a particular cancer type through to influencing the direction of research funding. This ongoing engagement is key to informing our strategy around horizon scanning.

Significant attention was given to ‘horizon scanning’, looking at what is and will be happening in cancer over the next five plus years in order to determine what might be considered in a New Zealand context.

One such area is Information Technology, looking at what information is essential to be collected in order to inform the national cancer quality improvement cycle. Considerable
engagement and discussion was held with the Ministry of Health cancer team throughout the year around this essential strategic direction.

New Zealand Cancer Registry

The CCNZ Board’s main focus for the year was the completion of the New Zealand Cancer Registry upgrade, which was initiated during the 2011/12 year.

Key initiatives achieved during 2013/14.

- The development and roll-out of five structured reports, via the New Zealand Cancer Registry, based on the Royal College of Pathologists of Australasia (RCPA) cancer protocols. These were successfully developed and implemented, including the extremely complex Breast Cancer Structured Report. As of 30 June 2014, these are in use at nine pathology laboratories, with over 60 pathologists enrolled. The roll-out continues.
- The establishment of a new New Zealand Cancer Registry Board within the Ministry of Health and reporting directly to the Director-General for Health.
- The handover of continued take-up of the structured report assistant, by pathologists, to the new New Zealand Cancer Registry Board to monitor and manage.
- The extension of the clinical Tumour Node Metastases (cTNM) pilot at Middlemore Hospital until 30 August 2014 to enable the calculation of the survival of cohorts of patients and to measure the impact of screening programmes and new treatments. Survival figures will also enable international benchmarking.
- The handover of the system to the Ministry of Health with appropriate documentation and guidance for ongoing maintenance and development.
Palliative Care Council

The Palliative Care Council (PCC) was established in 2008 by CCNZ to provide independent and expert advice to the Minister of Health, to report on progress in implementing the New Zealand Palliative Care Strategy and on New Zealand’s performance in providing palliative and end-of-life care. This is achieved through independent advice on:

- a strategic approach to palliative and end-of-life care that supports and involves the sector
- initiatives to reduce inequalities in access to palliative and end-of-life care services
- how effectively initiatives have been implemented
- comparative international directions and initiatives in palliative and end-of-life care.

The PCC is made up of 10 members (see Appendix B for a list of current PCC members).

The PCC meets every two months and reports to the Minister of Health through CCNZ.
PCC key initiatives

During 2013/2014 the PCC continued its focus on collaboration to improve levels of understanding and knowledge of palliative care at all levels and to contribute towards a fully integrated, consistent, quality palliative care system for all New Zealanders based on need. To achieve this aim, during 2013/14 the PCC completed several initiatives.

- Launched the online Palliative Care Research Repository website as a repository for New Zealand based palliative care research.
- Developed and published referral criteria for specialist palliative care services in New Zealand. The purpose of these criteria is to reflect the updated understanding of specialist palliative care in New Zealand and how these services and hospices interface with other providers of palliative care. The criteria will assist with the creation of a more uniform understanding of palliative care provision across the country.
- Continued to progress a project to establish the need for palliative care in New Zealand (refer to the Major Projects section for further information about this project and papers published).
- Provided independent strategic advice to the Minister of Health, including in relation to the effective integration of palliative care based on international recommendations published by the World Health Organization (WHO). The WHO identifies New Zealand as having only preliminary integration of palliative care and therefore opportunities for improvement were noted.
- Initiated a project to establish minimum standards for care of people in their last days of life in response to a UK review of the Liverpool Care Pathway for the Dying Patient (LCP), which recommended that the LCP be replaced by individual care plans (refer to the Major Projects section for further information).
- Provided feedback to the National Ethics Committee on its paper Ethical Challenges in Advance Care Planning published in June 2014.
- Engaged with consumers to ensure their needs remain central to all developments (refer to the Stakeholder Engagement section for further information).
- Continued to foster collaboration and cooperation between bodies involved in palliative care (refer to the Stakeholder Engagement section for further information).
Major projects

New Zealand Cancer Registry upgrade

As noted earlier this involved the development and delivery of five structured reports for pathologist use, based on the RCPA cancer protocols. A pilot for the collection of staging clinical Tumour Node Metastases has been completed and evaluated. The decision is not to roll it out as a stand-alone tool, but to seek opportunities to incorporate it within existing clinical management tools.

Identifying the need for palliative care

This involved the publication of a series of working papers that seek to understand the need for palliative care in New Zealand and assist service providers across all settings with service planning and provision:

- *Palliative Care in Aged Residential Care: Background and Research in New Zealand* (PCC Working Paper 2, July 2013)

These papers take an evidence-based approach and will lead to recommendations which will seek to improve the effectiveness of palliative care and enable an opportunity for the Ministry of Health, district health boards, aged residential care facilities, and hospices to more accurately plan future resources and cultural requirements, thus improving palliative care service planning, provision and delivery.

Development of national standards for last days of life

The PCC appointed a Last Days of Life Working Group, which has a comprehensive work programme in place to deliver recommendations on a national approach for care of people in their last days of life.
CCNZ Board matters

Changing Terms of Reference

During the year the Terms of Reference for CCNZ remained unchanged, with agreement that the new Board Chair (once appointed) would review these with the Minister of Health.

Resignations and appointments

Associate Professor Chris Atkinson resigned from his role as Board Chair during 2013/14 (and remained on the Board). Mr Dalton Kelly, the Deputy Chair, acted as Interim Chair. Board appointments expired during the term and the Minister of Health was in the process of appointing and re-appointing Board members at the end of June 2014.

Redesign of the CCNZ website

CCNZ is currently redesigning its website to reflect better sector engagement, the new Board membership, and ensure it is compliant with government web standards.
Stakeholder engagement

CCNZ engaged with stakeholders, the public and media through meetings, the cancer control website (www.cancercontrolnz.govt.nz), the establishment of a new palliative care research repository website, media releases and e-newsletters.

CCNZ has liaised closely with a range of groups, including:

- Australian and New Zealand Society of Palliative Medicine, to collaborate on matters of mutual interest, most recently regarding terminology related to palliative and end-of-life care, and on the applicability for New Zealand of work occurring in Australia
- the Ministry of Health cancer team, and the bowel screening and prostate cancer taskforce groups, where CCNZ and PCC have held cross-committee appointments
- CANGO, to facilitate sector development and understanding where possible
- regional cancer networks, to understand their various work streams, avoid duplication and support areas of common interest such as information services initiatives
- hosting Dr Simon Sutcliffe (President of the International Cancer Control Congress), during our June 2014 Board meeting in Wellington. Dr Sutcliffe provided his perspective on issues such as workforce planning and future cancer trends
- specialist palliative care providers, to develop referral criteria for specialist palliative care
- the International Collaborative on Best Care for the Patient, to inform work being completed on the Last Days of Life project
- the Ministry of Health’s Palliative Care Advisory Group, via joint meetings with the PCC, to reduce duplication of effort and remain informed of respective group’s work programmes
- the New Zealand Royal College of General Practitioners (NZRCGP), to understand a number of issues, including palliative care education for GPs. An NZRCGP member is represented on the Last Days of Life Working Group
- the paediatric palliative care sector, to understand and support paediatric palliative care. A paediatric palliative care nurse practitioner has been appointed to the PCC
- the aged residential care sector, to strengthen links and take steps to ensuring increased recognition of the provision of palliative care in aged residential care
- the Central Region Cancer Network’s consumer committee, to ensure the engagement of the consumer voice
- the Māori palliative care community, to support the planning of palliative care appropriate to Māori via the appointment of two Māori members to the PCC
- ongoing representation by CCNZ staff and PCC members at relevant national and international conferences, to provide expert comment and/or suggestions for change
- RCPA, over the development of structured reporting in line with the RCPA tumour protocols.
Priorities for 2014/15

The following activities are planned for 2014/15:

CCNZ secretariat

- Provide support to the CCNZ Board, the PCC and the New Zealand Cancer Registry by completing the following key tasks:
  - revising the Board orientation handbook
  - reviewing all terms of reference with Board Chairs
  - refreshing the PCC membership
  - working with the chairs to update systems and processes regarding good governance.
- Continue sector engagement including with the Minister of Health, Ministry of Health, NGOs, professional organisations, and the research sector to ensure effective communication, risk mitigation and prioritisation of issues.

CCNZ Board

- Complete inquiries regarding Hepatitis B vaccination and hepatocellular carcinoma.
- Establish a research programme that will:
  - undertake a national stocktake of current investment in cancer research
  - further progress the development of matching funding between NGOs and the Health Research Council to increase the overall cancer research funding pool.
- Repeat the Voice of Experience Cancer Patient survey originally conducted in 2009 at the request of the Minister of Health. (Note: This is a multiyear programme which will progress beyond the 2014/15 year.)
- Continue horizon scanning, international comparisons and benchmarking for the purpose of identifying areas of potential improvement.

Palliative Care Council

- Complete the Last Days of Life project delivering:
  - Working Paper 5 – Care of People in Their Last Days of Life: New Zealand Based Approaches
  - Working Paper 6 – International Evidence and Best Practice of Models of Care for People in Their Last Days of Life: A Literature Review
  - Working Paper 9 – Family/Whānau Perspective on Caring for People in Their Last Days of Life in New Zealand
  - A final report – consensus document on standards of care during the last days of life.
- Update to the PCC 2012 document New Zealand Palliative Care Glossary.
- Undertake the Palliative Care in Aged Residential Care project:
- Working Paper 8 – Palliative Care in Aged Residential Care: Frailty in Aged Residential Care in New Zealand
- Working Paper 13 – Palliative Care in Aged Residential Care: Comparison of Standards in Hospice and Residential Care.

- Maintain the New Zealand Palliative Care Research Repository website established in early 2014.
- Encourage uptake and implementation of the Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand.

**New Zealand Cancer Registry**

- Progress delivery of up to five new structured reports if funding is agreed.
- Evaluate and decide on the next steps for the clinical Tumour Node Metastases pilot at Middlemore Hospital.
- Contribute to thought leadership in the cancer information sector including input to the trial of the Orion patient management proof of concept.
- Consolidate the Ministry of Health and the New Zealand Cancer Registry boards into one effective governance group to consider what cancer information is required for collection, analysis and interpretation across the New Zealand sector.
- Contribute editorial support to the annual New Zealand Cancer Registry publications.
National and international meetings attended

In September 2013, members of CCNZ attended the New Zealand Society of Pathologists Annual Scientific Meeting held in Nelson, to present the Colorectal Cancer Structured Report, the first of the reports developed through the New Zealand Cancer Registry upgrade project.
Financials

CCNZ’s total budget for 2013/14 was $848,099, which comprised personnel, operational, professional services, and specialist project funding including funding for the CCNZ Board, the PCC and the New Zealand Cancer Registry (refer to Figure 1 for the budget breakdown). Professional services incorporates expenses relating to the support of the three boards supported by CCNZ, while special projects refers to funding to support specific projects, which for 2013/14 refers to the New Zealand Cancer Registry Upgrade project and the Last Days of Life project.

Figure 1: CCNZ Budget 2013/14
Appendix A: Cancer Control New Zealand Board members (2013/14)

Associate Professor Christopher Atkinson (Chair)
- Oncologist at the Canterbury District Health Board
- Medical Director and a past resident of the Cancer Society of New Zealand

Mr Dalton Kelly (Acting Chairperson)
- Chief Executive of the Cancer Society of New Zealand

Ms Shelley Campbell
- CEO of the Sir Peter Blake Trust

Professor Brett Delahunt
- Professor of Pathology and Molecular Medicine at the Wellington School of Medicine and Health Sciences, University of Otago
- Adjunct Professor of Biological Sciences at Victoria University of Wellington
- International Vice President of the International Academy of Pathology
- Chair of the New Zealand Cancer Registry Board of Management

Dr Kate Grundy
- Consultant Physician in Palliative Medicine at Christchurch Hospital, Canterbury District Health Board (1999 to present)
- Clinical Senior Lecturer at Christchurch School of Medicine, University of Otago
- Chair of the Palliative Care Council of New Zealand

Associate Professor Jonathan Koea
- Hepatobiliary surgeon and surgical oncologist who works in Auckland, New Zealand
- Member of the Te Ātiawa iwi

Professor David Lamb
- Consultant radiation oncologist at the Wellington Cancer Centre

Dr Scott MacFarlane
- Paediatric Oncologist at Starship Children’s Hospital
Mrs Catherine Smith
- Clinical Nurse Specialist at Canterbury District Health Board

Dr John Waldon
- Research advisor with a special interest in the rights, health and well-being of children

Dr Richard North
- Medical oncologist in the Bay of Plenty working at both Tauranga and Whakatāne hospitals
- Honorary lecturer for the University of Auckland School of Medicine
Appendix B: Palliative Care Council members

Dr Kate Grundy (Outgoing Chair)
- Consultant Physician in Palliative Medicine at Christchurch Hospital, Canterbury District Health Board
- Clinical Senior Lecturer at Christchurch School of Medicine (University of Otago)

Karyn Bycroft
- Nurse Specialist, and Nurse Practitioner Candidate, in Paediatric Palliative Care based at Starship Children’s Hospital at Auckland District Health Board

Bob Fox
- Consumer representative on the PCC
- Recently retired after seven years with the Royal New Zealand College of General Practitioners, where he was Communications Manager

Kate Gibb
- Registered Nurse, and is the Nursing Director for Older Persons Health for Canterbury and West Coast district health boards

Dr Carol McAllum
- Palliative medicine specialist working at Hawke’s Bay Hospital and Cranford Hospice (2007 – present)
- Honorary senior lecturer in palliative care with the University of Auckland (2005 – present)

Helen Sawyer
- Clinical Nurse Specialist, and Nurse Practitioner Candidate, in Palliative Care based at Dunedin Hospital, Southern District Health Board
- Palliative Care Nurses New Zealand representative on the PCC

Mary Schumacher (Interim Chair)
- Chief Executive of Hospice New Zealand

Dr Jason Kohumutunga Tuhoe
- Medical officer working alongside the South Auckland community at Totara Hospice
Stephanie Turner
- Director of Māori Health and Disability for MidCentral District Health Board

Dr David Wilson
- Rural/remote GP in Whitianga since 1991. Prior to that spent two years teaching medicine in the islands of Micronesia, funded by the University of Hawai‘i.
Appendix C: New Zealand Cancer Registry Board members

**Professor Brett Delahunt (Chair)**
- Professor of Pathology and Molecular Medicine, Wellington School of Medicine and Health Sciences

**Professor Ross Lawrence**
- Assistant Dean of Waikato Clinical School
- Professor of primary care

**Professor Mark McKeage**
- Medical Oncologist, University of Auckland
- Professor and Co-Director, University of Auckland

**Graeme Osborne**
- Director, National Health IT Board, Ministry of Health
- Director Information Technology, Ministry of Health

**Andrew Simpson**
- National Clinical Director, Ministry of Health

**John Keating**
- Southern Cross Specialist Centre

**Don Mackie**
- Chief Medical Officer, Ministry of Health
Appendix D: Cancer Control New Zealand secretariat staff

Andrew Lesperance – General Manager

David Alsford – Analyst

Naomi Brewer – Senior Analyst

Stephanie Calder – Project Manager, Last Days of Life

Lance Goodall – Project Manager, New Zealand Cancer Registry

Dr Mary Clare Tracey – Senior Analyst

Heather McLeod – Senior Analyst (Palliative Care)