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Friday 18 March 2005

Elton Humphery
Secretary
Community Affairs References Committee
The Australian Senate
Parliament House
CANBERRA ACT 2600

Dear Mr Humphery

#### **Inquiry into Services and Treatment Options for Persons with Cancer**

Please find attached a submission from the Peter MacCallum Cancer Centre to this Inquiry.

As far as possible, our submission addresses the Terms of Reference of this Inquiry.

Key staff from the Peter MacCallum Cancer Centre would be available to give evidence at any public hearings organized by this Inquiry. In particular, we would want to stress the importance of those support services required as a result of the increased provision of ambulatory care in this area.

If you have any queries about this submission, please contact Professor Sanchia Aranda: Director of Cancer Nursing Research at Peter Mac. Professor Aranda can be contacted on telephone number (03) 9656 3760 or via email at Sanchia.Aranda@petermac.org

With kind regards

Craig Bennett Chief Executive Officer

Attached x 1

#### **Senate Inquiry into Services and Treatment Options for Persons with Cancer**

A submission on behalf of Peter MacCallum Cancer Centre.

- (a) The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:
- (i) the efficacy of a multi-disciplinary approach to cancer treatment

Multidisciplinary care is now an accepted standard for best practice in the delivery of cancer care internationally. While there is limited scientific evidence to support this approach it is reported by consumers to improve their experience of care and has been included in most cancer site specific guidelines suggesting a consensus amongst cancer professionals that this is the recognised standard of practice. Multidisciplinary care emphasises the need to carefully assess the stage of the illness and to set treatment goals appropriate to that stage. This assessment and treatment planning process can help to avoid patients receiving less than optimal treatment and assists in coordinating the multiple facets of modern cancer treatment where the patient is likely to receive more than one form of treatment, often delivered concurrently.

Once a treatment plan is established, a multidisciplinary team can be mobilised to implement this treatment plan where all relevant professionals have clearly defined roles in patient management. With this approach the specific make-up of the team implementing the treatment will depend on the treatment plan and may differ from that which assesses the appropriate treatment in the first place.

# (ii) the role and desirability of a case manager/case co-ordinator to assist patients and/or their primary care givers

We are supportive of the Senate Committee's emphasis on such role development, specifically the potential role of nurses in improving the patient and family experience of cancer care. Evidence from both Australia (NBCC Specialist Breast Nurse Project) and overseas has provided strong support for the role of the specialist breast nurse in improving the treatment experience and psychosocial outcomes of women with breast cancer. There is emerging but less robust evidence to support the application of this nursing role in other cancers. There is also strong support from consumers for such roles. The

Peter MacCallum Cancer Centre is leading the way in this regard, having appointed nurse coordinators in almost all major cancer sites in the past four years. There is however a continuing need to continue to evaluate the roles. The case management model has not been strongly researched outside of the USA and in that context the models have been principally concerned with cost containment rather than patient outcome maximisation.

When the roles have been implemented in Australia there has been an absence of key performance indicators or any data collection that might help to judge the success or otherwise of the roles. There is significant conflation of the concepts of specialist nurse, case manager and care coordinator in the literature and confusion between roles that manage system wide issues (points of access, service data etc) and those that maximise the quality of the patient experience (patient education, treatment coordination). Thus there is a lack of role definition and little clarity about the skills required for roles and an absence of appropriate role preparation programs. Linked to this are the unanswered questions relating to the potential for advanced practice nursing roles in cancer care (such as the Nurse Practitioner), to both enhance patient outcomes and reduce the burden of work from specialist doctors.

At Peter Mac we have recently completed a thorough evaluation of a nurse practitioner role in malignant haematology that may serve as a model for other developments. We have also recently submitted a draft process for developing a national framework on cancer nursing to the Australian Government Department of Health and Aging that offers a way forward in developing the cancer nursing workforce.

## (iii) differing models and best practice for addressing psycho/social factors in patient care

The NHMRC guidelines for the psychosocial care of adults with cancer are a world-leading guide to what Australia should be providing in terms of psychosocial care. This ranges from how health professionals should be prepared in terms of skills such as eliciting and responding to patient concerns through to outlines of the disciplines required in service delivery. To date little energy or funds have gone in to evaluating models of service delivery that support the implementation of these guidelines into practice. One project, conducted under the Victorian Breast Services Enhancement program evaluated a model titled "C-Care" where specialist breast nurses used a structured clinical interview to assess psychosocial concerns and where appropriate refer patients to other psychosocial health professionals.

At Peter Mac we are currently planning a further evaluation of this model in other tumour streams that will include a model of collaborative practice between nursing, medicine, social work, psychology and psychiatry services. Clearly no implementation of such psychosocial guidelines should be done outside of a robust evaluation framework given the paucity of evidence to support practice in this area and the many role boundary issues that are likely to arise.

# (iv) differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians

The delivery of best practice services to people (both Indigenous and non-Indigenous) in rural and remote Australian provides specific challenges. Some models of care are under evaluation such as the single radiotherapy machine trials in Victoria. Our view is that any models for regional Australia need to ensure that regional services are linked to academic programs and shared clinical pathways with larger metropolitan cancer services. This will ensure that there are no differences in standards of treatment between regional and urban Australia and build the necessary relationships with tertiary services that support the care of patients, particularly those with complex needs. Thus models of care and funding arrangements should support partnerships between large urban centres and smaller regional services using both physical and virtual systems of service sharing.

### (v) current barriers to the implementation of best practice in the above fields.

- (i) the provision of multidisciplinary care:
  - absence of Medicare rebates for specialist case conferencing
  - poor recognition in state government funding for outpatient services of the complexity of multidisciplinary clinics where more than one specialist will be involved
  - limited capacity to delivery multidisciplinary care in the private sector
- (ii) the role and desirability of case manager/case co-ordinators
  - lack of role clarity and definition
  - absence of role preparation programs

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 poor evaluation of existing attempts to extend the specialist breast nurse model into other cancers

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- limited funding to explore role development, particularly advanced practice roles.
- (iii) differing models and best practice for addressing psycho/social factors
  - limited availability of psychosocial health professionals in healthcare, particularly clinical psychology
  - absence of rebates for psychology and social work through the Medicare system limiting availability of services outside public inpatient settings in a context where cancer care is increasingly ambulatory in nature.
  - Absence of robustly evaluated models of psychosocial service delivery, particularly models that emphasise cross disciplinary collaboration.
- (iv) differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians.
  - Lack of infrastructure to support virtual communication between regional and urban centres
  - Lack of formal linkages between regional and urban service sectors
  - Competitive nature of health services in terms of funding allocations.
- (b) How less conventional and complementary cancer treatments can be assessed and judged, with particular reference to:
- (i) the extent to which less conventional and complementary treatments are researched, or are supported by research

Clearly a critical issue in the assessment of the value of less conventional or complementary treatments depends on the claims being made. Thus it is important that definitions of such treatments clearly distinguish between those claiming to improve wellbeing and those claiming to modify the cancer disease process. There is a growing and increasingly robust body of evidence to support the use of complementary treatments, alongside conventional cancer treatments, to modify the symptoms associated with cancer and its treatment and to assist the person to manage the daily challenges associated with having cancer. However, the research to support less conventional treatments aimed at being an alternative approach to treating cancer as a disease is

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almost completely absence and is not of the same scientific rigour as expected for conventional cancer treatments.

# (ii) the efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies

The Peter MacCallum Cancer Centre is supportive of the use of complementary therapies aimed at the relief of the symptoms associated with cancer or to enhance the wellbeing of patients, where these are supported by evidence from appropriately conducted clinical trials. However, we condemn the use of unproven treatments aimed at modifying the disease and suggest that such treatments must be subject to the same level of evaluation as for conventional treatments.

#### (iii) the legitimate role of Government in the field of less conventional cancer treatment.

The first role of Government in this area is protection of the public. This protection should include similar regulations to those governing the credentialing of conventional health professionals and the public access to conventional medicines. Protection also includes ensuring the public has access to high quality information about less conventional cancer treatments. Secondly, the Government can support the rigorous evaluation of less conventional treatments through specific funding to allow well conducted studies of their effectiveness to be conducted. This will ensure that support is provided for innovative approaches to cancer treatment while ensuring the public is protected from individuals seeking to benefit from the vulnerability of people with cancer and their families.

Professor Sanchia Aranda Director of Cancer Nursing Research Peter MacCallum Cancer Centre

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