

15th March 2005

**The Secretary
Senate Community Affairs References Committee
Suite S1 59
Parliament House
Canberra ACT 2600**

Inquiry into services and treatment options for persons with cancer

Submission from

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One of the most important prognostic features in any cancer is the clinical stage. For example, breast cancer survival has been reported as 85.9% for Stage I cancers and 78.8% for Stage II cancers (1). For melanoma, patients with thin lesions (less than 0.76 mm thick) had a 98% 5-year survival, whereas patients with lesions 4 mm thick or thicker had only a 45% 5-year survival (2). In order to compare treatments, or compare outcomes between different populations, it is therefore vital to know the mix of stages in the comparison groups.

Currently, complete staging data is not collected by any population-based cancer registry in Australia. New South Wales collects a measure of degree of spread (using a definition which is now incorporated in the National Health Data Dictionary), and Stage is collected only by Hospital-Based or Clinical Cancer Registries in major hospitals in several States.

In the treatment of cancer, information about the extent of disease, or Stage, has long been felt to be vital in optimizing both the treatment and the advice given to patients and their families. In 2001, the West Australian Clinical Oncology Group held a symposium to discuss the WACR report, *Cancer survival in Western Australians, 1982-1997*. A concern voiced by many clinicians – as it is the world over - was the limited ability to interpret the survival analysis data because of the lack of adjustment for stage of cancer.

This need was recognized in a recent research project in Western Australia, in which the National Cancer Control Initiative (NCCI) funded a feasibility study to evaluate legal, technical and financial barriers to the routine collection of staging information on a population-wide basis.

Staging data collection cannot be lightly undertaken – however, the Baume report on radiotherapy services (3) recommended that “State and Territory cancer registries should, by 2003, collect information on diagnosed cancer stage and treatment regime for each patient

suffering from cancer” with no discussion of the financial, logistic, or legal issues involved. This project set out to address those issues.

Run as a collaborative operation between the NCCI, the Western Australian Cancer Registry, the WA Clinical Oncology Group and The University of Western Australia, the project was brought to a successful conclusion in which recommendations about the scope of staging data collection efforts, and estimates of the cost, were included. The project has been presented to various local and National forums, including the annual national meeting of the Clinical Oncological Society of Australia in late 2003 – and is currently the subject of a manuscript being considered for publication.

The NCCI funded the project and the production of the final report, *Collection of population-based cancer staging information in Western Australia – a feasibility study* (Threlfall T, Wittorff J, Boutdara P, Fritschi L, Heyworth J, Katris P, Sheiner H. Collection of population-based cancer staging information in Western Australia – a feasibility study. National Cancer Control Initiative (NCCI), Canberra, 2003.)

The report’s conclusions indicate that without additional resources, it is unlikely that any functioning State or Territory Registry would be able to take on the methodology proposed, and start to collect staging information. Nationally, there can be expected to be considerable support for the availability of staging information among clinicians – and among health planners who wish to see the public dollar spent most wisely.

At present, Federal funding of an Australia-wide collection of cancer staging information would seem to offer a unique and valuable opportunity to evaluate the benefit of collection of staging data in Australia. Such an initiative could, via funding support and making use of the acceptance and influence of the National Cancer Statistics Clearing house at AIHW, build on the current co-operative spirit which has produced great advances in the timeliness and consistency of cancer information in Australia.

In conclusion - I urge the committee to place a high priority on Federal funding for the population-wide collection of cancer staging data.

I attach a copy of the final report as sent to NCCI, and a hard copy of the “packaged” version will arrive by mail as soon as possible.

References

- (1) Stevenson JM, Bochenek P, Jamrozik K, Parsons RW, Byrne MJ Breast cancer in Western Australia in 1989. V: Outcome at 5 years after diagnosis Aust NZ J Surg 1997;67:250-5
- (2) Sim FH, Nelson TE, Pritchard DJ Malignant melanoma: Mayo Clinic experience. Clin Proc 1997;72:565-9
- (3) Radiation Oncology Enquiry. A vision for radiotherapy: report of the radiation oncology enquiry. 1-186. 2002. Canberra, Department of Health and Ageing.