Mr Elton Humphrey Committee Secretary Australian Senate Community Affairs References Committee Parliament House Canberra. ACT 2600

Dear Sir

### INQUIRY INTO SERVICES AND TREATMENT OPTIONS FOR PEOPLE WITH CANCER

### **Explanatory** Notes

- 1. The Committee has sought urgent expert advice on six issues to assist with its deliberations as it drafts a report for the Australian Senate in relation to the above inquiry. I am pleased to offer this advice, which is supported by a literature review on multidisciplinary care (MDC) for cancer. This was ably prepared by Rachael Moorin, who is a postdoctoral research fellow at the Centre for Health Services Research, School of Population Health, The University of Western Australia. Her literature review is attached in the form of a detailed briefing paper, supported by 47 of the most significant scientific articles, position papers and clinical guidelines on this topic.
- 2. As explained in my letter of 29 April 2005, it is impossible to provide a full answer to a number of the six questions posed by the Committee. This is because the scientific evidence or local information on health service delivery and outcomes necessary to answer all the questions does not exist.
- 3. Throughout this opinion I shall refer to Rachael Moorin's briefing paper using a system of *lineated page* citation. Thus a reference to BP5.7 means a source of information that may be found approximately at line 7 on page 5 of the briefing paper. Also, BPref9 means reference number 9 as cited in the briefing paper. There are a number of additional references used in this opinion that are not cited in the briefing paper. These are numbered and footnoted herein.

### Introductory Remarks

- 4. The term 'cancer' refers to a large group of different diseases that share in common the proliferation and spread of abnormal cells.<sup>BP1.4</sup> A commonly held belief by members of the general public is that cancer is increasing. This is correct, but the precise reasons why an increasing number of Australians have cancer, or have a close relative or friend with cancer, are not widely appreciated. A common tendency is to blame the problem on industrial pollutants, but in Australia pollutants make only a small contribution to the overall cancer burden. Apart from some specific childhood cancers, the risks of most malignant neoplasms increase with age. Thus the gradual demographic shift of the Australian population to an older age profile makes a contribution to the apparent increase in cancer, but this change is occurring slowly and cannot explain what seems like a more dramatic increase in cancer cases in the population. Smoking is the single most important preventable cause of cancer.<sup>1</sup> It causes cancers in at least 14 different body organs, and historically was responsible for an epidemic increase in cancer, especially lung cancer in males.<sup>1</sup> The epidemic of tobacco-caused lung cancer in men peaked in the mid-1980s and has since declined due to the preceding falls in the prevalence of smoking.<sup>2</sup> In women, the epidemic of lung and other tobacco-caused cancers continues to increase due to their later adoption of cigarette smoking. However, even the ongoing increases in new cases of lung cancer in women do not adequately explain why cancer appears to be affecting so many more people with whom we live, work and mingle.
- 5. The most important reason why cancer seems more common is one that is germane to the Senate's inquiry. It is because patients diagnosed with cancer are living longer than in the past.<sup>3</sup> This is not so much because cancer can be cured more often, but rather because comprehensive and multidisciplinary care, including a rapidly expanding range of chemotherapeutic agents, is prolonging the survival of patients with cancer that has already spread, and giving them some additional years of life before they eventually succumb to their disease.<sup>4</sup> These insights into the population dynamics of the modern cancer problem, and the increasing prevalence of 'active cancer' through the modest prolongation of life in patients still destined to succumb, have been made possible by the Western Australian (WA) Data Linkage System.<sup>5</sup> In WA the prevalence of people in the general population ever-diagnosed with cancer increased from 21.9/1,000 in 1990 to 29.7/1,000 in 1998; whereas the prevalence of active cancer (ie, people 'living with cancer' that requires ongoing clinical management) increased from 5.1/1,000 to 7.4/1.000.4 This is the single most important reason why so many of us are now in contact with a relative or friend who is living with cancer.

<sup>&</sup>lt;sup>1</sup> English DR, Holman CDJ, Milne E, Winter MJ, Hulse GK, Codde J, Bower CI, Corti B, Dawes VP, de Klerk N, Lewin GF, Knuiman M, Kurinczuk JJ, Ryan GA. The Quantification of Drug Caused Morbidity and Mortality in Australia 1995 Edition. Commonwealth Department of Human Services and Health, Canberra, 1995 (ISBN 0644-429-798).

<sup>&</sup>lt;sup>2</sup> Holman CDJ. Lung cancer - The down side of the epidemic curve. *Cancer Forum* 1991; 15(3): 169-170.

<sup>&</sup>lt;sup>3</sup> Threllfall TJ, Brameld K. Cancer survival in Western Australian residents, 1982-1997. Perth: Health Department of Western Australia, Statistical Series No.60, 2000.

<sup>&</sup>lt;sup>4</sup> Brameld KJ, Holman CDJ, Threllfall TJ, Lawrence DM, de Klerk NH. Increasing 'active prevalence' of cancer in Western Australia and its implications for health services. *Australian and New Zealand Journal of Public Health* 2002; 26(2): 164-169.

<sup>&</sup>lt;sup>5</sup> Holman CDJ, Bass AJ, Rouse IR, Hobbs MST. **Population-based linkage of health records in Western Australia: development of a health services research linked database.** *Australian and New Zealand Journal of Public Health* 1999; 23(5): 453-459.

6. The increasing prevalence of active cancer has profound implications for the planning, provision and financing of health services. An increasing proportion of health care resources will inevitably need to be allocated to cancer care, and more cost-efficient ways of delivering that care will become imperative. This is not to deny the value to the community of promoting better quality, effectiveness and equity of provision of cancer treatments. However, strictly from an economic viewpoint, in absence of an effective cure for most cases of metastatic cancer, unless the cost-efficiency of cancer treatment can be improved, the underlying dynamic has an unfortunate potential to cause the following cost spiral:



### The first question: Will a multi-disciplinary care approach help improve cancer treatment, and if so, what is the evidence that justifies such a conclusion?

7. If the meaning of 'improve cancer treatment' is to promote adherence to clinical guidelines, extend survival and/or to improve quality of life, then the short answer is 'definitely yes' in respect of breast cancer; <sup>BP2.17,36.9;BPref6-9,12-13,16,21,24-26,28-30,36</sup> 'probably yes' in respect of cancers of the ovary and lung; <sup>BP3.7;BPref10,36</sup> and 'possibly yes' in respect of a range of other cancers. <sup>BP3.11,5.1;BPref11,14,15,17,27</sup> The veracity of the evidence in relation to breast cancer has been recognised in Australian national health policy <sup>BP15.8;BPref36</sup> and the clinical guidelines of the professions. <sup>BP2.4</sup> Recommendations in support of MDC for cancer have also been made from credible sources in respect of ovarian cancer and (in the UK) colorectal cancer.

8. Most of the overall body of evidence on MDC comes from non-experimental studies of breast cancer. This is what the NHMRC refers to as Level III evidence, because it arises from comparisons based on observed experiences in the health system, rather than one or more randomised controlled trials.<sup>6</sup> However, some scientific commentators, including myself, see a complementary strength in this form of evidence because of its greater degree of representation of what actually happens in practice.<sup>7</sup> There is a pivotal question as to whether evidence about the utility of MDC in breast cancer can be generalised to the treatment of other cancers. At the present time, the willingness to engage in this form of scientific generalisation is largely a matter of judgment. Such a generalisation would be unwarranted if the suspected mechanisms whereby MDC provides a benefit were thought to be exclusively related to the peculiar biology of breast cancer. In fact, to the limited extent that we understand how MDC exerts its beneficial effect on breast cancer outcomes, the postulated mechanisms are of a generic nature, concerning issues in the organisation and delivery of health care and the patient's holistic well-being rather than any specific aspect of the nature of the disease. This leads me to the conclusion that generalisation of the evidence on breast cancer to other cancers treated by a range of interventions is defensible. The supportive but limited evidence in relation to cancers of the ovary and lung provide some degree of validation that scientific generalisation from breast cancer to other major solid cancers is a reasonable step.

### The second question: How typical is a multi-disciplinary care approach to cancer treatment in Australia? If possible, what percentage of patients have it as an option, and what are the figures for regional Australia, and Indigenous Australian?

- 9. The answers to these questions are largely unknown at a population level in Australia, <sup>BPref36</sup> except for the clinical management of breast cancer. <sup>BP8.5;BPref 24,36,37</sup> The National Breast Cancer Centre has undertaken a *National Survey of Coordinated Care in Breast Cancer* in an effort to provide an answer to the first question for breast cancer. <sup>BP22.8;BPref39</sup> They found that in 2004, MDC meetings were conducted on new cases of breast cancer in 86% of cases in high-caseload hospitals, 61% in medium-load hospitals and 17% in low-load hospitals. <sup>BP24.14</sup> The figures were a little higher than observed in a survey conducted four years earlier, but differences between the surveys did not allow for a direct comparison.
- 10. In general, the literature suggests that MDC for cancer is practiced most frequently where there is a high degree of centralisation of cancer services in tertiary hospitals. This applies in particular to treatment services for children's cancers, gynaecological cancers and cancers of the head and neck.<sup>BP19.9</sup> At this time, most public tertiary hospitals in Australia's capital cities support a range of multidisciplinary cancer care teams.<sup>BP19.25</sup>

<sup>&</sup>lt;sup>6</sup> NHMRC, National Health and Medical Research Council. **How to review evidence: systematic identification and review of the scientific literature.** Canberra: NHMRC, 2000.

<sup>&</sup>lt;sup>7</sup> Hall SE, Holman CDJ, Finn J, Semmens JB. Improving the evidence base for promoting quality and equity of surgical care using population-based linkage of administrative health records. *International Journal of Quality in Health Care* 2005, in press (accepted 23 March 2005).

11. There is a growing body of evidence, much of it arising from the use of the WA Linked Data System, to indicate that rural populations are disadvantaged with respect to treatment profiles and outcomes of a number of major cancers.<sup>8,9,10,11,12</sup> Place of first treatment in a rural hospital, more so than living in a rural area *per se*, has exerted a negative effect in these studies, although it must be emphasised that lack of information about differences in cancer staging between rural and urban populations has limited our confidence in interpretation. In the case of breast cancer, however, coverage by mammography screening is greater in rural areas of WA than in Perth, leading to the inference that the stage distribution of breast cancer in the bush would be not less favourable than in the metropolitan area. A lower uptake of MDC in rural areas is one possible explanation for poorer cancer outcomes in those populations; however, further research is required to be certain of this assertion. There is some evidence that Australians of indigenous background also experience a less optimal pattern of treatment for some cancers than in other Australians, independently of their place of residence.<sup>13</sup>

### The third question: What are the costs and savings, if any, of a multidisciplinary approach?

- 12. The health economics of MDC for cancer is barely embryonic in its development and thus it is impossible to provide a reliable answer to this question. A formal cost analysis of a multidisciplinary melanoma clinic in the US suggested that it may have reduced health care costs. BP6.15;BPref5,20 Other evidence on costs and saving is of a very limited nature, BP7.4;BPref21 although a study of multidisciplinary care for breast cancer in New reduction in Zealand documented а outpatient visits and administrative overheads.<sup>BP10.13;BPref30</sup> The National Multidisciplinary Care Demonstration Project in Australia did not include a formal health economics analysis.<sup>BP34.16</sup> I am reluctant to express an opinion on whether, as a general principle, MDC comes at a net higher or lower cost than more traditional cancer care delivery.
- 13. I do, however, believe that any such analysis of costs would be highly sensitive to the exact construction of what constitutes MDC for a particular cancer in a particular service delivery context. Marginal costs of MDC will be inevitably much higher for rural populations and relatively lower when MDC is used as the delivery model in a large tertiary hospital.

<sup>&</sup>lt;sup>8</sup> Hall SE, Holman CDJ. Inequalities in breast cancer reconstructive surgery according to social and locational status in Western Australia. *European Journal of Surgical Oncology* 2003; 29: 519-525.

<sup>&</sup>lt;sup>9</sup> Hall SE, Holman CDJ, Hendrie DV, Spilsbury K. Unequal access to breast-conserving surgery in Western Australia 1982-2000. *Australian and New Zealand Journal of Surgery* 2004; 74: 413-419.

<sup>&</sup>lt;sup>10</sup> Hall SE, Holman CDJ, Sheiner H. The influence of socio-economic and locational disadvantage on patterns of surgical care for lung cancer in Western Australia 1982-2001. *Australian Health Review* 2004; 27(2): 69-80.

<sup>&</sup>lt;sup>11</sup> Hall S, Holman CD, Sheiner H, Hendrie D. **The influence of socio-economic and locational disadvantage on survival after a diagnosis of lung or breast cancer in Western Australia**. *Journal of Health Services Research & Policy* 2004; 9(Suppl.2): 10-16.

<sup>&</sup>lt;sup>12</sup> Hall SE, Holman CDJ, Wisniewski ZS, Semmens J. **Prostate cancer: socio-economic, geographical and private-health insurance effects on care and survival.** *BJU International* 2005; 95:51-58.

<sup>&</sup>lt;sup>13</sup> Hall SE, Bulsara CE, Bulsara MK, Leahy TG, Culbong MR, Hendrie D, Holman CDJ. Treatment patterns for cancer in Western Australia: does being indigenous make a difference? *Medical Journal of Australia* 2004; 181(4): 191-194.

# The fourth question: What conclusions can be drawn, and an outline of the reasons for them, on the quality of life effects and extended survival times due to a multi-disciplinary approach?

14. My conclusions on the effects of MDC on survival and quality of life were reported in paragraphs 7-8. As to reasons, because there is a lack of exactness in the definition of what constitutes MDC, there is also a lack of clarity about which component(s) of MDC as a general notion are the most effective components and at what marginal cost. For example, is MDC for breast cancer more effective because: (i) more patients receive adjuvant therapy (the *multi-modal therapy* component); (ii) continuing professional education and quality assurance is enhanced by peer-review of clinical decisions (the *best practice* component); (iii) more patients are enrolled in clinical trials (the *leading edge* component); (iv) higher case loads produce a beneficial practice effect (the *specialisation* component); or (v) patients are supported by cancer care nurses or other psychosocial resources (the *holistic care* component)? Many of the studies covered by the briefing paper allude to observed improvements in one or more of these aspects of care, <sup>BPref6-22,44</sup> but no study has attempted to tease apart the separate effects of components of a MDC intervention. Even in the most studied area of breast cancer care, the relative importance of different intervention components and different causal pathways remains uncertain.

### The fifth question: What identifiable barriers prevent a wider take-up of a multidisciplinary care approach to cancer treatment?

15. The main barriers identified in the literature are cost, payment systems and the organisation of the health system. Fee-for-service arrangements in the private sector are still based primarily on a one-on-one service delivery model, with one doctor and one patient as the parties in a service contract. This situation is changing with respect to the management of elderly patients and those with chronic diseases by general practitioners, with the launch of the enhanced primary care Medicare items for health assessments, multidisciplinary care plans and case conferences, commencing from November 1999<sup>14,15,16</sup> No such system of items exists to support services such a case conferences between cancer specialists, and this plus the general philosophy of the fee-for service model has been identified as a major barrier to the development of integrated MDC for cancer in Australia, and especially inhibits those aspects that require team meetings. BP18.11,19.4,33.9;BPref9,44 There are significant overheads involved in the organisation of team meetings and within the private sector it remains unclear as to how such overheads are to be funded. The same applies to the source of funding for specialised ancillary supports (eg, specialist nursing and allied health professionals) required to implement a full MDC model.<sup>BP20.1</sup>

<sup>&</sup>lt;sup>14</sup> Aust Govt Dept Health and Ageing. Enhanced Primary Care – Medicare Benefits Items. Available at: <u>www.health.gov.au/epc/index.htm</u>.

<sup>&</sup>lt;sup>15</sup> Royal Australian College of General Practitioners. **Enhanced Primary Care.** Available at www.enhancedprimarycare.org.au/welcome.

<sup>&</sup>lt;sup>16</sup> Wilkinson D *et al.* Evaluation of the EPC MBS Items and the General Practice Education, Support and Community Linkages Program. Final Report. July 2003. Canberra: Commonwealth Department of Health and Ageing, 2003.

- 16. A closely related barrier, and one that has caused controversy in health system arrangements, <sup>BP7.13;BPref 22</sup> is whether it is preferable for patients to be treated in centralised specialist MDC centres for cancer care; or whether practicability and medical politics dictate that a networked 'hub and spoke' model of district centres relating to a specialist centre is to be preferred. The UK has backed the concept of cancer networks in its approach to planning cancer services. <sup>BP11.5;BPref 32</sup> The tyranny of distance in Australia adds to the challenge of centralised cancer centres and even cancer network models, despite the gradual increase in availability of telemedicine facilities. <sup>BP19.17;33.13</sup> For example, attempts at creating networks for breast cancer treatment in Australia have not all been successful, due to the sustained levels of resources and effort that are required. <sup>BP44.18;BPref45</sup>
- 17. There is suboptimal access to radiotherapy services in many parts of Australia, fuelled by workforce shortages, inadequate capital investment in equipment in the public sector and sometimes a relative communication void between radiotherapy and other cancer services.<sup>BP24.22BPref39</sup> Communication failure between specialists, general practitioners and other health professional in general is a conspicuous area of risk, even after MDC cancer teams have been formed.<sup>BP13.1,38.1</sup>
- 18. The National Multidisciplinary Care Demonstration Project in Australia has attempted to develop a range of flexible solutions to address barriers such as those outlined above with respect to breast cancer.<sup>BP32,4;BPref9,44</sup> Part of the solution has been a pragmatic approach that recognises in the Australian context that the desire for team meetings must be tempered by funding and logistical realities.<sup>BP34,3</sup> This demonstration project has been extensively evaluated from an organisational perspective through the Sustainability of Multidisciplinary Cancer Care Study.<sup>BP44,7;BPref45</sup> The study was essentially qualitative and has identified factors important to reducing barriers to MDC for breast cancer in Australia. These include the needs for dedicated funds and personnel; a routine schedule of team conferences (not ad hoc); team member awareness of patient benefits; leadership from medical opinion leaders; and a system that can adapt to a public sector environment in which chaotic reorganisation has become the norm.<sup>BP45,2</sup>

## The sixth question: What is the level of use, efficacy and benefits in terms of health outcomes and cost effectiveness of psychosocial support in Australia?

- 19. There are a range of health benefits, including improved survival and quality of life, associated with the provision of psychosocial support services to women with breast cancer, <sup>BP46.12;BPref8,12,46</sup> and people diagnosed with cancer generally. <sup>BP17.346.12;BPref36,46</sup> For example, there is evidence that counseling reduces anxiety and depression, behavioural therapies reduce anxiety and anticipatory nausea in relation to chemotherapy and radiotherapy, and that specialist home care nursing improves quality of life during palliative care. <sup>BP46.24;BPref46</sup>
- 20. In Australia, our knowledge of the level of use of psychosocial supports has been limited to accounts of specific projects concerning MDC strategies for breast cancer, including specialist breast care nurses.<sup>BP4.1,16.11,37.10;BPref36,44</sup> I am unaware of any population-based data on cancer patient access to psychosocial supports.

21. The cost-utility of some selected psychosocial supports has been examined and reported.<sup>BP47.8;BPref47</sup> In one cost-utility analysis, breast care nurses and counseling by a psychologist were ranked fourth and fifth relative to the performance of other cancer interventions. They did not perform as well as primary prevention, performed at a level comparable to cancer screening programs, and were ahead of therapeutic interventions.<sup>BPref47</sup>

#### Summary

22. In summary, there is ample evidence that MDC is beneficial for breast cancer patients and reasonable grounds to conclude that the principles of MDC should be encouraged as a preferred general model of cancer care in Australia. However, there remain many unanswered questions concerning the extent to which an 'ideal' model of MDC for cancer, incorporating all of its desired components, is affordable and warranted in the Australian context. Economic analysis of MDC is much needed but sadly lacking. Ethical considerations lead one to the conclusion that a priority in this area should be policy initiatives that encourage the provision of a 'pragmatic' model of MDC to populations, such as rural and indigenous populations, who currently receive relatively little of this form of best practice. Policy initiatives of this type should be preceded and followed by a reliable system of measurement and evaluation.

Yours faithfully

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