Australian Government

National Health and Medical Research Council

Submission to the Senate Community Affairs References Committee Inquiry into Services and Treatment Options for Persons with Cancer

March 2005

Introduction

The National Health and Medical Research Council (NHMRC) is a statutory body within the health portfolio. Since 1936 it has been responsible for promoting the development and maintenance of public and individual health standards; encouraging debate on and setting standards for animal and human research ethics and health ethics issues; and managing the Government's commitment to fund health and medical research.

The NHMRC is now established under the *National Health and Medical Research Council Act 1992* which imposes four statutory obligations:

1. To raise the standard of individual and public health throughout Australia;
2. To foster development of consistent health standards between the States and Territories.
3. To foster medical research and training and public health research and training throughout Australia.
4. To foster consideration of ethical issues relating to health.

The NHMRC also has statutory obligations under the *Prohibition of Human Cloning Act 2002* and the *Research Involving Human Embryos Act 2002* and corresponding State and Territory legislation.

The NHMRC pursues initiatives through a series of expert Principal and Working Committees and maintains a strong commitment to evidence-based decision making and community involvement.

This submission responds to matters raised in the Terms of Reference of the Committee's Inquiry into services and treatment options for persons with cancer. The NHMRC would be pleased to discuss these matters with the Committee, if required.

Background

Since 1993, the NHMRC has been active in the field of evidence-based clinical practice. At that time, NHMRC provided leadership to the country by developing a methodology for the development, implementation and evaluation of evidence-based clinical practice guidelines. The methodology[1] is accompanied by a series of toolkits which assist guideline developers in their tasks[2].

In 2000 the *National Health and Medical Research Council Act 1992* was amended to introduce, amongst other changes, the provision for the NHMRC to approve guidelines developed by other organisations provided those organisations had conducted public consultation. The NHMRC requires certain other standards to be met and these are documented in *NHMRC Standards and procedures for externally developed guidelines*[3].

As well as setting the standards for development of clinical practice guidelines, the NHMRC provides additional leadership through its program of assistance to guideline developers. This program involves the provision of expertise in evidence-based medicine, free of charge, to guideline developers once the intended guideline has been accepted onto NHMRC's work program. The implication of this "acceptance" is that the draft guideline will be considered for approval by NHMRC under Section 14 A of the *National Health and Medical Research Council Act 1992.*

NHMRC has been responsible for the development of a number of cancer related evidence-based clinical practice guidelines and, as noted above, has also worked with a range of other organisations developing guidelines. Most notable amongst these other organisations are the Australian Cancer Network and the National Breast Cancer Centre.

Of particular interest to this enquiry are the publications listed in Appendix A, all of which were developed external to NHMRC, but to NHMRC's standards thus attracting NHMRC approval. These guidelines are a source of evidence-based advice relevant to the Terms of Reference of the current Inquiry. Most of the guidelines at Appendix A address specific aspects of cancer, for example advanced breast cancer or non-melanoma skin cancer. Some of the issues addressed in these guidelines are consistent across all cancers, such as communication between health care practitioner and patient, whilst other issues are specific to the type of cancer being treated. In addressing the Terms of Reference, the NHMRC has attempted to summarise and highlight key points from this known evidence base. However, the NHMRC advises that it is not always appropriate to generalise across cancer treatment and thus recommends that the Committee look for further detail in each individual guideline. All the guidelines at Appendix A can be accessed through the publications home page on the NHMRC website.

---

[1] NHMRC (1999) *A guide to the development, implementation and evaluation of clinical practice guidelines*, available at: http://www.nhmrc.gov.au/publications/synopses/cp30syn.htm

[2] The tool kits address issues such as systematic literature review, economic analysis, involving consumers, and the use of socio-economic evidence, available at: http://www.nhmrc.gov.au/publications/cphome.htm

[3] Available at: http://www.nhmrc.gov.au/publications/synopses/nh56syn.htm

Response to Terms of Reference

Term of Reference:
(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,
(ii) The role and desirability of a case manager/case co-ordinator to assist patients and/or their primary care givers,

A multidisciplinary team is defined as “a team of health providers from a number of different disciplines.”[4] Multidisciplinary care is recommended “as a means of achieving best practice…through their combined understanding…to diagnose, treat and manage the condition, to the highest possible standard of care.”[5] The evidence shows that it is important that multidisciplinary teams provide care for people with cancer. The benefits to the patient of multidisciplinary care include:

- Early and accurate diagnosis;
- Treatment relevant to the disease;
- Assessment of appropriate support;
- Early identification and treatment of psychological disorders;
- Efficiency of information sharing amongst the treating health care providers; and
- Ability to draw on a range of expertise and experience[6].

Benefits to the treating team include the support provided in the team environment, especially where the behaviour of an individual patient might be confronting or distressing to a team member[7], and where difficult clinical issues, or issues surrounding a failure of a patient to respond to treatment, may arise[8].

In addition to a multi-disciplinary treating team, the NHMRC advises that there is evidence to suggest that it is important to identify a coordinator of care. This coordinator is often a general practitioner, but could be any member of the treating team according to the patient’s individual circumstances. However it is important that the patient concerned selects the coordinator. The importance of a coordinator of care is that he or she can ensure continuity of care[9].

---

[4] National Breast Cancer Centre and National Cancer Control Initiative (2003) *Clinical practice guidelines for the psychosocial care of adults with cancer*, National Breast Cancer Centre, Camperdown, NSW, p210.

[5] Ibid, p210.

[6] Australian Cancer Network and National Breast Cancer Centre (2004) *Clinical practice guidelines for the management of women with epithelial ovarian cancer,* National Breast Cancer Centre, Camperdown, NSW, p57.

[7] Op cit, p41.

[8] Ibid, p83.

[9] National Breast Cancer Centre (1999) *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer*, Commonwealth of Australia, Canberra, pp53-54.

In addition, the NHMRC is aware that many cancer patients can feel confused and disoriented when interacting with the hospital system where much treatment is provided. For this reason the NHMRC asks that consideration be given in-hospital support and coordination to smooth the treatment path.

Recommendation
The NHMRC recommends that the Committee give explicit support to treatment by multi-disciplinary teams, with an identified coordinator of care, as being best practice for cancer patients.

Term of Reference:
(a) the delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:

(iii) Differing models and best practice for addressing psycho-social factors in patient care,

There is strong evidence to suggest that appropriate attention to information provision, psychological interventions and emotional and social support, will result in improved health outcomes including the reduction of psychological morbidity and emotional distress, improved wellbeing and satisfaction with care[10]. This evidence is both general - the psychosocial care of adults with cancer – and specific - the psychosocial support of women with breast cancer[11].

The NHMRC suggests that the Committee review the clinical practice guidelines noted at Appendix A that specifically address psychosocial issues. The two publications are very detailed and cover a range of topics including emotional, physical and end-of-life issues.

Recommendations
The NHMRC recommends that the Committee support the NHMRC-approved *Clinical practice guidelines for the psychosocial care of adults with cancer* as the best practice model for the psychosocial care of adults with cancer.

The NHMRC recommends that the Committee support the NHMRC-approved *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer* as best practice, noting that these guidelines are under review for currency.

---

[10] National Breast Cancer Centre and National Cancer Control Initiative (2003) *Clinical practice guidelines for the psychosocial care of adults with cancer*, National Breast Cancer Centre, Camperdown, NSW, pxi.

[11] National Breast Cancer Centre (2000) *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer*, National Breast Cancer Centre, NSW. [Under review].

Term of Reference:
(a) the delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:

(iv) Differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians, and
(v) Current barriers to the implementation of best practice in the above fields.

According to the National Breast Cancer Centre, younger women in rural and remote Australia with breast cancer spend some considerable time away from home during the course of diagnosis and treatment. For these women, many feel they did not know enough about support mechanisms near the place of treatment (ie away from their home base)[12]. Geographic isolation is also likely to result in increased travel and accommodation costs associated with treatment and greater difficulty accessing support networks[13].

For diseases such as epithelial ovarian cancer – often difficult to diagnose – general practitioners in rural and remote areas are likely to play a key role in coordinating care, providing psychosocial support and palliative care[14].

The evidence shows that in some culturally and linguistically diverse communities, women may have a strong preference for care from a female health care provider. In some indigenous communities, breast cancer is perceived as women's business. The NHMRC recommends that special care be taken to discuss treatment options and to provide female doctors where possible. The use of Aboriginal Health Workers may also be of value in assisting indigenous women during treatment[15].

Although not specifically included in the terms of reference, the NHMRC would like to highlight the evidence which draws attention to the needs of people from culturally and linguistically diverse communities, wherever they live in Australia. Cultural sensitivities must be taken into account by the treating team. There are specific multi-cultural information services as well as Bi-lingual Information Workers available in Australia[16]. Other NHMRC approved guidelines relating to cancer treatment, listed at

---

[12] National Breast Cancer Centre (2004) *Clinical practice guidelines for the management and support of younger women with breast cancer*, National Breast Cancer Centre, Camperdown, NSW, p48.

[13] National Breast Cancer Centre and National Cancer Control Initiative (2003) *Clinical practice guidelines for the psychosocial care of adults with cancer*, National Breast Cancer Centre, Camperdown, NSW, pp119-120.

[14] Australian Cancer Network and National Breast Cancer Centre (2004) *Clinical practice guidelines for the management of women with epithelial ovarian cancer,* National Breast Cancer Centre, Camperdown, NSW, pp110,132.

[15] Op cit, p48.

[16] Australian Cancer Network and National Breast Cancer Centre (2004) *Clinical practice guidelines for the management of women with epithelial ovarian cancer,* National Breast Cancer Centre, Camperdown, NSW, pp199-201.

Appendix A, also point out the importance of appropriate communication and treatment for people from culturally and linguistically diverse communities.

Recommendations

The NHMRC recommends that the Committee give explicit support to the role of Aboriginal Health Workers and Multicultural Information Services as a means of ensuring that people from diverse backgrounds and cultures receive appropriate treatment on every occasion.

The NHMRC recommends that the Committee give explicit support to the importance of appropriate information giving to people from culturally and linguistically diverse communities and that, wherever possible, the option to consult a female doctor be afforded to women from these communities.

Although the NHMRC has not undertaken a specific study of the barriers to the uptake of best practice in cancer treatment, some of these are referred to in existing guidelines, namely:

- Language barriers and the need for interpreter services[17],[18];
- Cultural issues around family support and leaving home for treatment for extended periods of time, especially for Aboriginal and Torres Strait Islander people[19];
- the cost of services which may affect continued compliance with treatment;
- lack of awareness of cancer and its symptoms, especially amongst people whose language skills or culture mitigate against seeking information or visiting a general practitioner.

Some of these issues are referred to in the NHMRC approved guidelines, especially the psychosocial guidelines.

Term of Reference:

(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 researcher, or are supported by research,

---

[17] National Breast Cancer Centre and National Cancer Control Initiative (2003) *Clinical practice guidelines for the psychosocial care of adults with cancer*, National Breast Cancer Centre, Camperdown, NSW, p113.

[18] Australian Cancer Network and National Breast Cancer Centre (2004) *Clinical practice guidelines for the management of women with epithelial ovarian cancer*, National Breast Cancer Centre, Camperdown, NSW, pp199-201.

[19] National Breast Cancer Centre and National Cancer Control Initiative (2003) *Clinical practice guidelines for the psychosocial care of adults with cancer*, National Breast Cancer Centre, Camperdown, NSW, pp115-117.

(ii) the efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies, and
(iii) the legitimate role of government in the field of less conventional cancer treatment.

Alternative or complementary therapies are used by many Australians and, when used in cancer, are generally seen as an alternative source of hope, and as less toxic options for people who prefer natural therapies[20]. There are doubts about the effectiveness of complementary therapies largely due to the lack of evidence[21].

Applications for NHMRC project grants to support complementary medicines research have, to date, been minimal with the number of applications ranging from 8 to 15 in any one year. The success rate of these applications has varied from 0% in 2004 to 21.4% in 2003. The latter figure is close to the normal success rate for all project grant applications.

The generally low success rate for these applications reflects the lower competitive standard of the applications as assessed by the NHMRC's peer review process. The NHMRC believes that the most appropriate way to increase the overall research effort in complementary medicine research generally is to encourage institutions to identify researchers in that area and provide mentoring and advice from experienced NHMRC recipients on strategies to improve the number and quality of applications.

There is frequently controversy surrounding alternative or complementary cancer therapies. A recent case in point is that of Dr John Holt, a Western Australian physician offering radiowave (also referred to as microwave) cancer therapy. Since August 2004 there has been considerable media attention paid to Dr Holt's therapy and the claims of a number of his patients that they have been cured. This media attention resulted in greater numbers of people approaching Dr Holt's surgery for treatment. The Minister for Health, the Hon Tony Abbott MP, asked the NHMRC to review the safety and efficacy of Dr Holt's treatment regimen in particular and microwave cancer therapy in general. The reference to NHMRC was made under Section 9 of the *National Health and Medical Research Council Act 1992*. The NHMRC is unable to comment about the content of the report at this stage but expects to provide an interim report to the Minister for Health by the end of March 2005, with a final report later in 2005.

Conclusion

There are a number of relevant, up to date, high quality, evidence-based clinical practice guidelines on the treatment of cancer. Those approved by the NHMRC can be found on the NHMRC website. Organisations such as the National Breast Cancer Centre and the Australian Cancer Network are very experienced in developing such guidelines and should be encouraged to continue.

---

[20] Australian Cancer Network (2004) *Clinical practice guidelines for the prevention, diagnosis and management of lung cancer*, pp179-180
[21] Ibid, p180.

The lack of research into complementary therapies funded by NHMRC is a result of lower quality applications, thus leading to a lack of success. However, it is also not clear what the gaps in research knowledge are. It is hoped that at least one of these issues – microwave treatments – will be resolved through the current NHMRC review.

Appendix A

Publications developed by other organisations and approved by NHMRC under Section 14A of the *National Health and Medical Research Council Act 1992*

Title	*Developed by*	*Publication Date*
Clinical practice guidelines for the management of women with epithelial ovarian cancer	Australian Cancer Network and National Breast Cancer Centre	2004
Clinical practice guidelines for the prevention, diagnosis and management of lung cancer	Australian Cancer Network	2004
Clinical practice guidelines for the management and support of younger women with breast cancer	National Breast Cancer Centre	2003
Clinical practice guidelines for the psychosocial care of adults with cancer	National Breast Cancer Centre and National Cancer Control Initiative	2003
Clinical practice guidelines: evidence-based information and recommendations fort the management of localised prostate cancer	Australian Cancer Network	2002
Clinical practice guidelines: non-melanoma skin cancer. Guidelines for treatment and management in Australia	Australian Cancer Network	2002
Clinical practice guidelines for the management of advanced breast cancer	National Breast Cancer Centre	2001
Clinical practice guidelines for the management of early breast cancer – 2nd edition	National Breast Cancer Centre	2001
Guidelines for the prevention, early detection and management of colorectal cancer: A guide for general practitioners	Australian Cancer Network	2000
Guidelines for the prevention early detection and management of colorectal cancer: A guide for patients , their families and friends	Australian Cancer Network and Clinical Oncology Society of Australia	2000
Guidelines for the prevention, early detection and management of colorectal cancer	Australian Cancer Network and Clinical Oncology Society of Australia	1999

Clinical practice guidelines for the management of cutaneous melanoma	Australian Cancer Network	1999
Familial aspects of cancer: a guide to clinical practice	Australian Cancer Network and Clinical Oncology Society of Australia	1999
Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer	National Breast Cancer Centre	1999