

CHAPTER 3

IMPROVING CANCER CARE IN AUSTRALIA

Australia's record in treating cancer is among the world's best and age-adjusted mortality rates have steadily declined over the past two decades. However, this statistical success is little consolation to the thousands of Australians diagnosed with cancer every week. The news is usually devastating and bewildering, starting a journey into a complex world of advice, therapies and services, compounded by changes in emotional well being, relationships, work and plans for the future.¹

3.1 This chapter provides an overview of cancer treatment services in Australia, paying particular attention to recognised best practice models of care. It also examines current barriers to the implementation of best practice and makes recommendations to address them.

3.2 In terms of cancer management there are two distinct models of cancer care in Australia. Firstly, the traditional model, where a general practitioner refers a patient to a specialist, usually a surgeon, who conducts the primary intervention and then refers the patient on to other cancer specialists. Secondly, the multidisciplinary model that describes an integrated team approach by all healthcare professionals involved in the patient's care.

Traditional care model

3.3 In the traditional model, a general practitioner refers a patient to a specialist, usually a surgeon, who may remove a tumour and/or refer the patient to a medical oncologist or a radiotherapist. Patients may then see specialists in an ad hoc way (depending on the level of involvement and coordination provided via the GP or surgeon) for opinions and treatment.²

Referral issues

I feel extremely concerned that patients' outcomes often are not optimal because they are not referred to the right person.³

3.4 Witnesses likened the traditional model of care to a 'cancer lottery'. There was confusion right from the time of diagnosis with the referral process mentioned as a major concern due to ad hoc processes and a lack of information for the medical practitioner and the patient. A number of cancer patients told the Committee that the

1 *Submission 65*, p.3 (COSA, CCA, NCCI and NACCHO).

2 *Optimising Cancer Care in Australia*, COSA, CCA and NCCI, February 2003, p.xi; *Submission 65*, p.7.

3 *Committee Hansard* 31.3.05, p.14 (Professor Saunders).

matter of finding a specialist to suit them was pure luck. One witness told the Committee:

How do we find out who is a good person to go to? We were lucky – we had this contact.⁴

Another stated:

It was a serendipitous connection...I had a private medical connection of my own – my mother's partner is friends with a paediatric surgeon who knew the people in Sydney. She sent a list of the five best neurosurgeons in Australia. It was only through those means, which the general public would not have access to that I was given a list of the people who I should be seeing and I was able to find what I would call the best surgeon for me in Australia.⁵

3.5 Information at the time of diagnosis and referral is particularly important. Evidence is available to show that referring patients to doctors who treat high volumes of particular cancers improves survival. A study undertaken in Western Australia looked at women with invasive breast cancer managed by surgeons with a high breast cancer caseload compared with women who are managed by surgeons who treat breast cancer less frequently. The study found the women treated by high caseload surgeons had better outcomes with a reduction in mortality of 30 percent.⁶ The National Health and Medical Research Council (NHMRC) *Clinical Practice Guidelines for the Management of Early Breast Cancer* recommends that women with breast cancer should be treated by specialists who have a demonstrated expertise in breast cancer. Although the *National Service Improvement Framework for Cancer* notes that 'the evidence about caseload, care provision and outcomes in the treatment of cancer in Australia is somewhat inconsistent', it also notes that 'there are opportunities to significantly improve referral pathways by providing information to primary care providers and to people with cancer about cancer services'.⁷ For a lot of diseases and particularly the less common ones, GPs do not necessarily know who to refer patients to or they refer to people they have known for a long time and to whom they have historical referral patterns.⁸

3.6 Cancer patients are increasingly demanding more information at the diagnosis and referral stage to enable them to make an informed decision regarding their choice of specialist. As stated by a representative of Breast Cancer Network Australia:

4 Committee Hansard 20.4.05, p.31 (Mrs Paice).

5 Committee Hansard 20.4.05, p.33 (Mr Pitt).

6 Ingram, D.M, McEvoy, S.P, Byrne, M.J, Fritschi, L, Joseph, D.J and Jamrozik, K, Surgical caseload and outcomes for women with invasive breast cancer treated in Western Australia, *The Breast*, 2005; 14, 11-17.

7 *National Service Improvement Framework for Cancer*, National Health Priority Action Council, March 2004, p.36 and p.32.

8 Committee Hansard 31.3.05, p.14 (Professor Saunders).

Breast cancer consumers want to know whether or not their clinician and their cancer service are practicing best practice. They want to know if they follow the guidelines. They want to know if they are going to be treated in a multidisciplinary team and have access to psychosocial services. This is a real issue for women; they want information.⁹

3.7 The *Directory of Breast Cancer Treatment and Services for NSW Women*, referred to in chapter 1, is an example of how meeting the need for greater information at the time of diagnosis can be successfully met. This Directory is designed to help women, through their GPs, to find the treatment and other breast cancer services which are most appropriate for their needs.

3.8 The Committee received very positive feedback about the Directory and regards it is an important resource which can serve as a model to develop other directories. The Committee considers that the development of a national directory of cancer treatment and services is a vital first step to providing more authoritative and useful information to medical practitioners and cancer patients at the time of diagnosis and referral.

Recommendation 1

3.9 The Committee recommends that Cancer Australia, in association with consumer based organisations such as Cancer Voices NSW and the Breast Cancer Action Group in Victoria, coordinate the development of information about cancer treatment services in each State and Territory. This information would be based on the successful breast cancer treatment directory developed by the Breast Cancer Action Group in NSW, published in 2002, which is also available on the Internet.

3.10 Another way to address the 'cancer lottery' issue and provide more information at the time of diagnosis and referral is to develop preferred referral guidelines for particular tumours. This would provide GPs with the information to know who best to refer patients to and patients would feel reassured that they would be getting the best care.

3.11 *The National Service Improvement Framework for Cancer* supports defined referral pathways between diagnostic and treatment services.¹⁰ Some cancers, such as those affecting the breast, head and neck and advanced gynaecological malignancies, have organised referral pathways in most States. Clinical Oncology Groups, associated with the State cancer councils, have facilitated their introduction in association with specialist colleges. However, there are exceptions and the majority of cancers do not have clear referral pathways, which is not in the best interests of patients. Defined referral pathways are particularly important to assist cancer patients in rural areas.

9 Committee Hansard 18.4.05, p.43 (Ms Timbs).

10 *National Service Improvement Framework for Cancer*, p.32.

3.12 The Committee noted that work is being undertaken in NSW and Victoria to develop referral guidelines and processes so GPs and cancer patients can quickly find the best specialist cancer services to treat their condition. The Committee considers that this work is vital to ensure that people are referred to high quality treatment services in a timely manner.

Recommendation 2

3.13 The Committee recommends that Cancer Australia, in conjunction with State and Territory Governments, develop appropriate referral pathways for the optimal management of all cancers for all Australians regardless of where they live.

Accreditation of cancer services and credentialing of practitioners

3.14 It is important that the referral pathways be linked to services which are accredited and physicians who have appropriate credentials. The move towards accreditation has been assisted by the vigour of the National Breast Cancer Centre (NBCC), the Australian Cancer Network (ACN) and The Cancer Council Australia (TCCA). In 2004, a scoping study of current international and Australian cancer service accreditation systems and processes was commissioned, with a view to developing a discussion paper identifying common themes, principles, criteria and processes that may inform an Australian model of accreditation for cancer services. A *core strategy for cancer care: Accreditation of cancer services – a discussion paper* was released in February 2005. The discussion paper defines accreditation as 'a process of external peer review of an organisation's processes and performance using defined standards with the aim of quality improvement'.¹¹

3.15 The move towards accreditation of cancer treatment services was endorsed in evidence. It was pointed out to the Committee that accreditation already occurs in the USA and Professor Coates expressed the view that it will inevitably come about in Australia as a result of consumer advocacy and demand.¹²

3.16 Professor Elwood, Director of the National Cancer Control Initiative told the Committee that he thought there would be 'wide acceptance within the profession of an accreditation system if it was well constructed, if it was responsive and if it was open and transparent'.¹³

3.17 The Committee noted the difference between accreditation of services or clinics that met certain standards and the credentialing of individual specialists be they a surgeon with a special interest in breast cancer or cancer of the head and neck, or a medical oncologist or radiotherapist.

11 *A core strategy for cancer care: Accreditation of cancer services – a discussion paper*, TCCA, ACN and NBCC, 2005, p.13.

12 *Committee Hansard* 19.4.05, pp.17-18 (Professor Coates).

13 *Committee Hansard* 19.4.05, p.8 (Professor Elwood).

Credentialing is vitally important because the GPs need to know who they are referring to and the patient, above all, should feel some degree of comfort as to where they are being sent.¹⁴

3.18 Credentialing can be defined as 'the formal process used by health care organisations to verify and evaluate the qualifications and experience of a health care professional prior to appointment, reappointment and at other times as required by the organisation, for the purposes of forming an opinion about the health care professional's training, skills, experience and competence'.¹⁵ Credentialing of individual practitioners would involve providing data on outcomes such as the volume of patients they treat, side effects and recurrence rates. Ms Swinburne stated that there is quite a lot of resistance among some members of the College of Surgeons to make such data public.¹⁶ This view was supported by Mr Deverall:

On credentialing: whereas you accredit a centre or clinic, credentialing is for the individual. The colleges do not like this. Their members do not like it. They do not want to have their names in a guidebook, like Cancer Voices NSW did for breast cancer. They prefer the status quo.¹⁷

3.19 However, Ms Marine from the Medical Oncology Group indicated that her organisation has been supportive of a general move towards credentialing. The National Breast Cancer Audit was referred to as an example of progress by the Breast Cancer Network Australia.¹⁸ The audit has been endorsed by the Royal Australasian College of Surgeons and the Section of Breast Surgery as an appropriate means of assessing early breast cancer. Through the audit, surgeons are able to review their results against national aggregated results for certain indicators.¹⁹

3.20 Accreditation and credentialing needs to be driven at the national level, with witnesses suggesting that Cancer Australia would be the appropriate organisation to drive this change and provide standards and guidance.²⁰

3.21 The Committee notes that credentialing is likely to take more time to develop and implement than the accreditation system although both are essential if cancer services in the public and private sectors are to be better organised and improved in the best interests of patients.

14 *Committee Hansard* 31.3.05, p.69 (Mr Deverall).

15 Australian Federation of Medical Women *Reply to Issues Paper on Credentials and Clinical Privileges* accessed at http://www.afmw.org.au/pubs/pub40_ccp.htm on 9.6.05.

16 *Committee Hansard* 18.4.05, p.45 (Ms Swinburne).

17 *Committee Hansard* 31.3.05, p.69 (Mr Deverall).

18 *Committee Hansard* 18.4.05, pp.43-44 (Ms Timbs).

19 Information accessed at <http://www.surgeons.org/asernip-s/auditBreast.htm> on 8 6.05.

20 *Committee Hansard* 31.3.05, p.8 (Professor Saunders).

3.22 Accreditation and credentialing are critically important in the development of sustained, high-quality multidisciplinary treatment and support for patients. The issue now remains as to how quickly and efficiently accreditation of cancer treatment services and credentialing of practitioners can be introduced. The Committee was disappointed that none of the medical colleges provided a submission to the inquiry as they must be the gatekeepers to the successful and speedy introduction of both accreditation and credentialing.

Recommendation 3

3.23 The Committee recommends that, Cancer Australia, together with the Clinical Oncological Society of Australia and the Cancer Council of Australia develop and introduce accreditation and credentialing systems.

Fragmentation of care

3.24 Cancer patients experiencing the traditional model of cancer care felt their care was fragmented as they were passed from specialist to specialist with no clear pathway of care. They reported feeling abandoned:

We were essentially abandoned right at the jump, after the big operation.²¹

After I had the medical treatment, the process called, I think, 'a feeling of abandonment' happened to me.²²

3.25 The Department of Health WA indicated that there is a lack of a coordinated integrated network of cancer services in Western Australia.²³ Professor Bishop, CEO, Cancer Institute NSW added that there should be a more integrated and coordinated approach between primary practitioners and cancer centres.²⁴ Likewise, the Victorian Department of Human Services identified that:

Clear referral pathways and role designation of services to outline appropriate levels of specialisation for the delivery of cancer services will improve awareness and choice for patients, and will ensure that patients have access to the highest quality care.²⁵

3.26 The establishment of integrated and networked cancer services to improve continuity of care is also a key priority action of the *National Service Improvement Framework for Cancer*.

21 *Committee Hansard* 20.4.05, p.28 (Mr Argall).

22 *Committee Hansard* 20.4.05, p.29. (Mr Pitt).

23 *Submission* 44 p.8 (Department of Health WA).

24 *Committee Hansard* 19.4.05, p.48 (Professor Bishop).

25 *Submission* 66, p.2 (Victorian Department of Human Services).

3.27 In response to the perceived fragmentation, New South Wales, Victoria and Western Australia have established initiatives to improve the integration and coordination of cancer services.

3.28 The New South Wales Department of Health's *Clinical Service Framework for Optimising Cancer Care in NSW* and the *New South Wales Cancer Plan* address these issues by ensuring equitable access to best practice care for all patients and the promotion and coordination of cancer control activities. Better integration between general practice and cancer treatment centres is also being fostered by a General Practice liaison program between the New South Wales Divisions of General Practice and the Cancer Institute New South Wales.²⁶

3.29 The Victorian Department of Human Services *Cancer Services Framework* has the integration of cancer service delivery as a major theme. Improved integration of care is being delivered through the establishment of Integrated Cancer Services and the delivery of clinical treatment and care through ten major tumour streams that are designed to reduce variations in care and promote best practice.²⁷

3.30 The Western Australian Government has established a Taskforce to formulate a comprehensive state-wide framework for cancer services that will ensure an integrated approach to cancer care and service delivery.²⁸

3.31 The Cancer Institute New South Wales also suggested that, when established, Cancer Australia could offer an opportunity for improved coordination between Commonwealth and State and Territory based cancer control initiatives.²⁹ The Committee considers that the establishment of Cancer Australia will provide an excellent opportunity for the improved integration and coordination of activities between jurisdictions as well as the wider range of non-government bodies with an interest in cancer.

Recommendation 4

3.32 The Committee recommends that Cancer Australia in its role of providing national leadership and to foster improvements in the integration of networked cancer services, play a primary role in facilitating the sharing of information about Commonwealth and State and Territory Government cancer initiatives to improve treatment services.

3.33 In contrast to the traditional model of care, cancer patients experiencing some form of multidisciplinary care reported greater satisfaction with services, less personal distress and improved outcomes.

26 Submission 53, p.4 (Cancer Institute NSW) and *NSW Cancer Plan 2004-06*, pp.22, 37.

27 Submission 66, p.2 (Victorian Department of Human Services).

28 Submission 44, pp.1-2 (Department of Health WA).

29 Submission 53, p.22 (Cancer Institute NSW).

I had such a good medical team, they were my support. They were at the other end of the phone, even my specialist. My strategy was relying on them. Because you're having a whole team opinion you know you're taking the right course don't you?³⁰

Multidisciplinary Care

Overseas studies have shown that survival improves and best practice is followed, when treatment is provided by experts working together as a team. This team approach to care is often referred to as multidisciplinary care as it includes a wide range of health professionals. The treatment options are considered by the whole team of specialists with all the relevant expertise present. The result is better organisation and delivery of essential cancer treatment, with fewer delays and improved pathways of care.³¹

3.34 As stated by Dr Page, 'cancer is perhaps unique in that it does usually require a whole range of different services. It requires not just surgical services but also chemotherapy, radiotherapy, psychological services, the network of family and palliative care'.³² In multidisciplinary care (MDC), team members agree on a precise diagnosis and staging of the disease, the best treatment option for the patient and the development of a treatment plan. The patient and the team communicate closely, enabling the patient to make decisions about treatment and care on the basis of the team's comprehensive advice. Communication and the provision of care are managed by a designated care coordinator or the most appropriate specialist member of the team.³³

The benefits of multidisciplinary care in the management of cancer have been demonstrated in a number of studies both in Australia and overseas. There is evidence that decisions made by a multidisciplinary team are more likely to be in accord with evidence-based guidelines than those made by individual clinicians. Patient satisfaction with treatment and the mental well-being of clinicians has been shown to be improved by a multidisciplinary approach to care.³⁴

Definitional Issues

3.35 Multidisciplinary care is now regarded as a basic requirement for the delivery of cancer services. However, it was clear from the evidence provided to the inquiry that there are differences in the use of this term nationally and internationally. Some witnesses who were cancer specialists saw it, exclusively, as a medical model encompassing only surgeons, radiographers, oncologists and pathologists and such.

30 *Submission 71*, p.6 (Breast Cancer Action Group quoting Gail who was diagnosed in July 2001).

31 *Submission 87*, p.3 (DoHA).

32 *Committee Hansard 19.4.05*, p.82 (Dr Page).

33 *Submission 65*, p.7 (COSA, CCA, NCCI and NACCHO).

34 *Submission 39*, p.2 (NBBC).

Consumers, on the other hand felt it was critical that psychosocial support was included in any setting where multidisciplinary treatment was provided. Other witnesses believed a multidisciplinary team should include people such as dieticians and complementary therapists and, most importantly, the patient. However, in submissions and at hearings, it was clear there was universal support for multidisciplinary care as an approach, regardless of who was included in the team.

3.36 The Chief Medical Officer described a multidisciplinary team as 'the surgeon, the medical oncologist, the radiotherapists, nursing staff, dietician and so on. It is a very large group of people with the patient at the centre.'³⁵

3.37 Professor Zalcborg from the Peter MacCallum Cancer Centre, where multidisciplinary care is practiced, defined it as:

A multidisciplinary approach is the bringing together of the relevant disciplines that can address the goals of treatment for that stage of the disease...That is what we try and do at Peter Mac in terms of bringing the expertise together around the table when patients are being discussed.³⁶

3.38 The Committee accepted that sustained multidisciplinary treatment is an integrated team approach including surgeons, oncologists, pathologists, radiologists, physiotherapists, occupational therapists, psychologists and/or others including social workers to provide ongoing psychosocial support if requested by a patient. It may also include practitioners in non-medical disciplines. The Committee acknowledged advice that the composition of a treatment team may alter according to the medical and social needs of a patient at any one time.

The situation overseas

Multidisciplinary care is now an accepted standard for best practice in the delivery of cancer care internationally.³⁷

3.39 In the USA and more recently in the UK, multidisciplinary care is the recommended approach for most or all cancers. Some level of MDC is required by the US Cancer Center's accreditation system and by the UK Cancer Plan.³⁸ It is incorporated in the UK Manual of Cancer Service Standards 2004³⁹ and features in the Canadian⁴⁰ and USA strategies for cancer control.⁴¹

35 *Committee Hansard* 20.4.05, p.91 (Professor Horvath).

36 *Committee Hansard* 18.4.05, p.27 (Professor Zalcborg).

37 *Submission* 36, p.1 (Peter MacCallum Cancer Centre).

38 *Optimising Cancer Care in Australia*, COSA, TCCA and NCCI, February 2003, p.xii.

39 Manual for Cancer Services 2004, accessed on 5 May 2005 at http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4090081&chk=hq28gu.

40 *Canadian Strategy for Cancer Control*, accessed at www.cancercontrol.org, on 5 May 2005.

41 *Ensuring Quality Cancer Care*, accessed at <http://www.iom.edu/report>, on 5 May 2005.

The situation in Australia

3.40 The Committee received conflicting reports regarding how multidisciplinary care is currently delivered in Australia. The Committee heard that some doctors thought they were already providing multidisciplinary care by discussing a case in the corridor with a colleague.⁴² Even treatment at a larger centre does not necessarily mean the care is multidisciplinary.

The fundamental flaw in the current approach is that it is dominated by the particular perspectives of the medical specialities. In this context 'multidisciplinary' refers only to small teams of closely related medical personnel...⁴³

3.41 Professor Holman commented in his report to the Committee that it is difficult to know at a population level how typical a multidisciplinary approach is. The exception is breast cancer where the NBCC undertook a National Survey of Coordinated Care in Breast Cancer in 2004 and found MDC meetings were conducted on new cases of breast cancer in 86 per cent of cases in high-caseload hospitals, 62 per cent in medium-load hospitals and 17 per cent in low-load hospitals. Professor Holman reported that the 'literature suggests that MDC for cancer patients 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'. The Professor concluded that 'at this time, most public tertiary hospitals in Australia's capital cities support a range of multidisciplinary cancer care teams'.⁴⁴

3.42 Multidisciplinary care is recommended in clinical practice guidelines approved by the NHMRC. It has been recognised by the Commonwealth government as part of the National Service Improvement Framework for Cancer and is supported by the Australian Labor Party.

National Breast Cancer Centre leading the way in multidisciplinary care

3.43 The most advanced models of multidisciplinary care in Australia are in breast cancer and children's cancer. The 1994 House of Representatives Report on the Management and Treatment of Breast Cancer recommended MDC as a means of achieving best practice in the management of breast cancer. The National Breast Cancer Centre was established in 1995 and has been leading the way in the treatment of breast cancer and in providing a model for the management of other cancers.

3.44 The question that follows is to what extent can the evidence of improved outcomes for breast cancer when using MDC be generalised to the treatment of other cancers? Professor Holman addressed this issue commenting that:

42 *Committee Hansard* 31.3.05, p.66 (Mr Deverall).

43 *Submission* 92, p.4 (Mr CW and Ms F Parker).

44 Professor D'Arcy Holman, Commissioned Report, p.4.

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.⁴⁵

The development of multidisciplinary care in Australia

3.45 To further the development of MDC in Australia, the NBCC was commissioned by the Department of Health and Ageing to establish a *National Multidisciplinary Care Demonstration Project* for breast cancer in Australia. For the purposes of the project, the NBCC defined MDC as:

An integrated team approach to health care in which medical and allied health care professionals consider all relevant treatment options and develop collaboratively an individual treatment plan for each patient.⁴⁶

3.46 The project was designed to provide information about the impact, cost and acceptability of implementing MDC for women with breast cancer and to obtain information about MDC that would be applicable to other cancers and other chronic diseases and provide recommendations about the implementation of MDC. The project found that MDC improved supportive care, improved communication between clinicians and provided clinicians with greater emotional and intellectual support. The participating clinicians also reported that the multidisciplinary strategies were worthwhile and had improved the care of women with breast cancer.⁴⁷

3.47 The project recommended the following principles to underpin a flexible approach to MDC:

- A team approach, involving core disciplines integral to the provision of good care, with input from other specialities as required;
- Communication among team members regarding treatment planning;
- Access to the full therapeutic range for all women regardless of geographical remoteness or size of institution;
- Provision of care in accord with nationally agreed standards; and
- Involvement of the women in decisions about their care.⁴⁸

3.48 The NBCC undertook a follow up study to the *National Multidisciplinary Care Demonstration Project*, with the *Sustainability of Multidisciplinary Cancer Care*

45 Professor D'Arcy Holman, Commissioned Report, p.4.

46 *National Multidisciplinary Care Demonstration Project*, NBCC, p.2.

47 *National Multidisciplinary Care Demonstration Project*, NBCC, pp.18-28.

48 *National Multidisciplinary Care Demonstration Project*, NBCC, p.5.

Study being published in January 2005. This study explored the sustainability of changes resulting from strategies implemented during the National Multidisciplinary Care Demonstration Project and locally relevant strategies to implement or improve the provision of MDC for women with breast cancer were trialled. They found that the majority of changes resulting from strategies implemented during the demonstration project were sustained in the three multi-site collaborations of health care services located in different States.⁴⁹

3.49 The Committee understands that the NBCC will shortly release a practical guide to assist health service providers in setting up and running multidisciplinary treatment planning meetings. A series of State and Territory based forums to promote the uptake of multidisciplinary cancer care is also being planned.⁵⁰

3.50 The Committee commends this work undertaken by the NBCC as a vital step to increase the practice of multidisciplinary care in Australia.

Palliative Care

3.51 Palliative care is another important part of multidisciplinary treatment. It was raised in submissions as an area in need of further investigation. Although issues relating to palliative care are much broader than this inquiry, a brief summary of the issues raised in evidence is provided in chapter 5.

Conclusion

3.52 The Committee was disturbed to receive evidence which clearly described fragmentation of services, a lack of coordinated care and a lack of application of standard best practice management. The Committee acknowledges that multidisciplinary care is recognised as a key element of best practice in the treatment of cancer and wishes to see it facilitated by the health care system. The Committee notes that there is little data available on the costing of multidisciplinary care as yet, though in terms of improved cancer outcomes the development of models should be actively pursued.

Barriers to implementing multidisciplinary care

3.53 The Committee recognised that MDC for all cancers is an important objective for Australian health services and that structural change will be required to ensure that multidisciplinary care and the practitioners providing it are supported by the health system.

3.54 Barriers to the implementation of MDC raised in submissions and by witnesses included the attitudes and resistance to change of medical practitioners; funding models; the Medical Benefits Scheme and differences in the private and

49 *Sustainability of Multidisciplinary Cancer Care Study*, NBCC, January 2005, p.vi.

50 *Submission 39*, p.2 (NBCC).

public systems; lack of time, resources and clinical staff; and the challenge of covering large geographical areas and the Indigenous population.

A question of patient ownership

3.55 The issue of 'patient ownership' was raised as a barrier to multidisciplinary care as cancer patients become the 'property' of an individual consultant once referred or admitted to hospital. This practice often meant that the patient was not treated by a team as required with standardised multidisciplinary care and did not have the benefit of input from other cancer specialists. It was reported as being more common in the private sector where private hospitals have no full time medical teams backing up the individual consultants, though it could also occur in a public hospital, especially when an individual was admitted as a private patient.⁵¹

Resistance to change

Having sat with cancer patients consulting their oncologists I witnessed questions like 'well what else can be done if I'm terminal like you say?' being told 'nothing' and when probed on complementary/alternative (CAM) treatments received off hand dismissal or being told that 'you can but why waste your money! One oncologist just rolled his eyes upward in dismissal...

So what we have here is a deliberate barrier being put up to deter cancer patients from details of all known evidence-based cancer treatments. This very narrow focus on patient treatment must be removed as a matter of urgency if medical costs are to come down and survival rates improved i.e. GP's, Oncologists and the Public made fully aware of all the treatments already available and their efficacy.⁵²

3.56 The resistance to change of some medical professionals was seen as a generational issue with greater acceptance occurring among younger practitioners. The *National Multidisciplinary Care Demonstration Project* experienced initial resistance to change from some clinicians but this was overcome as participants experienced the benefits of improving care for patients and enhancing communication between those involved in providing that care (reported by 88 per cent). Clinicians also reported a sense of reassurance in being able to discuss complex cases with the team.⁵³

3.57 To facilitate change in these areas, clinical practice guidelines for cancer have been developed primarily by the Australian Cancer Network, supported by the Australian Cancer Society, the National Cancer Control Initiative and the National Breast Cancer Centre and many other speciality and community groups. The NHMRC has assessed and endorsed these guidelines, which are evidence-based, and were

51 *Committee Hansard* 31.3.05, p.67 (Mr Deverall).

52 *Submission* 94 (Mr Cope).

53 *National Multidisciplinary Care Demonstration Project*, NBCC, pp.23-27.

developed in many cases by multidisciplinary teams. They recommend the use of multidisciplinary care to improve patient outcomes and are designed for use by all health professionals who come into contact with people during the course of their cancer journey.

3.58 Guidelines endorsed by the NHMRC are currently available for most of the priority cancers and include:

- Early Breast Cancer;
- Advanced breast cancer;
- Skin cancer and melanoma;
- Non-melanoma skin cancer;
- Bowel cancer;
- Prostate cancer;
- Familial aspects of cancer;
- Lung cancer;
- Ovarian cancer; and
- Guidelines for the psychosocial care of people with cancer.⁵⁴

3.59 Witnesses suggested to the Committee that the guidelines should be adopted nationally. Mr Davies, DoHA, noted that there were no incentives to follow the guidelines and no sanctions for failing to do so. Professor Horvath, CMO, added that 'certainly the colleges, most importantly the college of surgeons, have been very forthcoming in encouraging their fellows, as do hospital quality committees. Guidelines tend to come into practice by professional pressure of a multidisciplinary sort rather than by carrot or caveat'.⁵⁵

3.60 The Committee agrees that the NHMRC clinical practice guidelines should be used nationally to provide support for health professionals to deliver best practice care and to better inform cancer patients. To facilitate this, the Committee recommends including the use of clinical guidelines as a criteria for assessment in the accreditation process.

Recommendation 5

3.61 The Committee recommends that the use of and adherence to clinical guidelines is an essential component of multidisciplinary care and must be part of any system of accreditation of cancer treatment services.

54 *National Service Improvement Framework for Cancer*, p.41.

55 *Committee Hansard* 20.4.05, p.89 (Mr Davies and Professor Horvath).

Recommendation 6

3.62 The Committee recommends that multidisciplinary care, consisting of an integrated team approach in which medical and allied health care professionals develop collaboratively an individual patient treatment plan, continue to be widely promoted within the medical and allied health care professions.

3.63 Witnesses also mentioned that the communication skills of some medical practitioners they had dealt with left a lot to be desired. For example:

The registrar said that we can see the surgeon at 5pm that day when he does his rounds. We did see him. He spent less than one minute at our daughter's bedside. Instead, we, her parents, had to run after him down the corridor to speak to him'.⁵⁶

3.64 A number of reports such as *Optimising Cancer Care in Australia* and the *National Service Improvement Framework for Cancer* have identified the need for cancer care providers to improve their communication skills, including specialists, GPs and through the whole care team. The Committee considers that enhanced communication skills training is required at undergraduate and postgraduate levels and that the Colleges should undertake a more active role in the provision of such training for their members. The Committee also notes that the NBCC runs communication skills training workshops for health professionals working with breast cancer patients and that this model could be developed to provide training for all cancers.

Recommendation 7

3.65 The Committee recommends that the curriculum for medical professionals at the undergraduate and postgraduate levels include enhanced communication skills training and that professional Colleges also undertake a more active role in the provision of such training for their members. This training could be based on the National Breast Cancer Centre's communication skills training workshops that have been developed to improve the awareness and capacity of health professionals to communicate effectively with women with cancer.

Medical Benefits Scheme (MBS)

3.66 Despite the evidence regarding best practice and improved outcomes for patients, the Committee found that the practice of multidisciplinary care is very limited beyond some major public hospitals. Although models of cancer care have changed over the last few years, the Committee heard that inflexible funding models are currently acting as a barrier to the implementation of best practice cancer care. Professor Holman identified the general philosophy of the fee-for-service model as a barrier to the development of integrated MDC.⁵⁷

⁵⁶ Confidential Submission 3, pp.2-5.

⁵⁷ Professor D'Arcy Holman, Commissioned Report, p.6.

3.67 This area appeared to be complicated and confusing within the health sector with witnesses providing different accounts of what is and is not funded by the MBS as indicated by the following comments:

- Currently only two clinical areas have access to MBS rebates for MDC, GPs and Physicians. The remainder of clinicians have no access to rebates for MDC. This means there is no incentive for the entire cancer team, which usually includes a broader base of clinicians to provide MDC.
- Private medical, surgical, medical and radiation oncologists can each claim a relevant MBS item only if they review a patient together when the patient is present. This does not reflect best practice in which clinicians may attend multidisciplinary care meetings where several patients are discussed, only one of whom may be their patient, or in cases, where due to the technical aspects of the discussion, it is often not appropriate for the patient to attend.⁵⁸

Current Medicare provisions

3.68 The Department of Health and Ageing provided advice about the current Medicare provisions for multidisciplinary care:

A range of items for Enhanced Primary Care (EPC) were introduced into the Medicare Benefits Schedule (MBS) in 1999. These items focused on prevention and better coordination of care, particularly for older Australians and those with chronic illnesses, including cancer, undertaken in the community by primary care practitioners. The items covered health assessments (700 to 712), care plans (items 720 to 730) and case conferences (items 734 to 779). The care planning and case conferencing items covered provision of these services in the community and at the time of discharge from hospital for private patients.

Case conferencing items were extended to consultant physicians and consultant psychiatrists in the November 2000 and 2002 MBS respectively. The items were limited to out of hospital community case conferences and discharge case conferences (which are seen as making arrangements for a patient's return to the community from hospital).

These items enable medical practitioners (GPs, psychiatrists and consultant physicians) from different disciplines to work collaboratively with each other and other allied health providers in a team-based approach in the management of a patient's complex care needs. The case conference must be held with a minimum number of health professionals attending, there must be at least 4 participants when a case conference is organised by a physician and 3 participants where the case conference is organised by a GP or psychiatrist. The current arrangements do allow for each consultant physician from a different discipline to be paid for attendance at a case conference.

Patients and/or their carers are able to attend case conferences, but do not count towards the minimum number of health practitioners who must participate.

The case conferencing items have been modified over time to better reflect clinical use and this process is on-going. The Department has also been approached to consider the development of sequential case conferencing for private in-patients with complex medical problems managed by geriatricians and rehabilitation physicians and to allow access to the case conferencing items to anaesthetists who provide chronic pain services.⁵⁹

3.69 The NSW Cancer Institute noted the differences in the public and private hospital billing arrangements, saying gap payments for non-admitted services in the private sector can be substantial and may result in some patients making treatment decisions based on financial considerations. The Institute advised that:

in many instances, staff specialists providing non-admitted radiotherapy services to private patients in public hospitals are limited to charging the MBS schedule fee (ie. Patients are bulk billed). However, in the private sector, the gap payments for those non-admitted services can be substantial which places the patients at a significant financial disadvantage.⁶⁰

3.70 The Committee noted that the issue of cancer funding reform is being addressed by the Cancer Funding Reform Project. The Project, reporting through the Health Reform Agenda Working Group to Australian Health Ministers, is examining specific alternative funding arrangements and implementation options to improve access to coordinated, best practice cancer care, including the provision of multidisciplinary care. It is being managed by a multi-jurisdictional group led by ACT Health and will provide options for cancer funding reform by the end of 2005.

3.71 The Committee considers that the establishment and maintenance of multidisciplinary care meetings must be adequately and explicitly resourced by those funding health services.

Recommendation 8

3.72 The Committee recommends that the Cancer Funding Reform Project, established under the auspices of the Health Reform Agenda Working Group and reporting to Australian Health Ministers, include the differences in public and private hospital billing arrangements as an item for investigation and resolution.

Recommendation 9

3.73 The Committee recommends that the Department of Health and Ageing, in consultation with Cancer Australia, enhance current Medicare Benefit

⁵⁹ Submission 87, supplementary information, (DoHA).

⁶⁰ Submission 53, p.8 (Cancer Institute NSW).

Schedule arrangements for relevant specialists and general practitioners to support participation in multidisciplinary care meetings in both hospitals and the community.

Recommendation 10

3.74 The Committee recommends that five multidisciplinary cancer centre demonstration projects be set up in consultation with consumer groups and be funded over three years in different parts of Australia. At least one demonstration project should be in the private sector. Within these multidisciplinary centres different models of psychosocial support, incorporating a range of complementary therapies and taking into account the cultural needs of patients, should be assessed. The assessment of all aspects of the demonstration projects should be scientifically based and involve consumer representatives in the process.

Workforce issues

The issue that I would like to focus on today is the importance of workforce shortages in the provision of multidisciplinary care. I am sure you have heard from other presenters that there are workforce shortages in just about every category of cancer support and every professional area. Lack of personnel in those areas is a bit of a barrier to implementing multidisciplinary care because it is hard, particularly in a rural area, to find the appropriate practitioners to be part of your multidisciplinary group and also because many of these people are very busy anyway and trying to schedule in additional meetings can be problematic. I have members, for example, in certain regional areas of Australia who are working 80 hour weeks and cannot take more than a week off at any one time because they cannot find a locum to fill in. Trying to find time to provide multidisciplinary care and attend meetings is difficult under those sorts of circumstances.⁶¹

3.75 Many witnesses indicated that a major challenge to cancer patients accessing appropriate services was the availability of a sufficient number of skilled health professionals to deliver care. Workforce shortages occur in almost all categories, especially in rural and remote areas, with particular concern being shortages in nursing, general practice, radiotherapy (ie. radiation therapists and medical therapists), and psychosocial support.

3.76 Witnesses mentioned the already heavy workload on some clinicians and expressed concerns about burnout, emphasising the need for health professionals to be adequately supported.⁶² It is important that in order to avoid overload and burnout, especially in the context of the increasing incidence of cancer, the Department of Health and Ageing continue to engage the Colleges in order to develop strategies that

61 *Committee Hansard* 19.4.05, p.73 (Ms Marine).

62 *Committee Hansard* 19.4.05, p.7 (Professor Currow).

will alleviate the identified problems and cope with future demands. The Committee considers that there needs to be more active debate and policy development to enable nurses and other health professionals to undertake procedures that are currently identified as exclusive to doctors.

3.77 In response to a question regarding the resistance to the introduction of nurse practitioners, Professor Saunders stated that it would be important to look at outcomes, 'if the outcomes for the patients, in terms of whatever benchmarks you show for a particular cancer, are as good by another practitioner then that would be reasonable. But there are lots of other complex things such as indemnity cover and insurance. So there is not an easy answer'. Dr Fong responded to the same question by asserting that 'we need new types of health care workers'.⁶³ Professor Bishop also spoke about the need for strategic workforce development and upskilling of staff. He stated 'clearly there is a worldwide and Australian shortage of high-quality nursing staff. We think a lot of effort should be put into skilling the current staff as well as developing new roles in key areas of discipline'.⁶⁴

3.78 The likelihood of further losses from the workforce was highlighted by Ms Dane from the Australian Council of Community Nursing Services who told the Committee that around 50 percent of their workforce could retire within the next couple of years.⁶⁵

3.79 The Cancer Institute New South Wales has called for the better identification of the cancer workforce and suggested its development should be linked to cancer projections and the distribution of cancer patients. The Institute has also identified the need for the development of cancer subspecialisation, especially within multidisciplinary teams and indicated that the maintenance and promotion of specialist skills in rural and outer urban areas could be achieved through education.⁶⁶

3.80 Cancer workforce issues are being addressed through the Australian Medical Workforce Advisory Committee and Australian Health Workforce Advisory Committee. The Australian Medical Workforce Advisory Committee has been established to promote strategic workforce planning and provide advice on national medical workforce matters. The Australian Health Workforce Advisory Committee has been founded to oversee wider workforce planning needs such as the nursing and allied health workforces. The Radiation Oncology Reform Implementation Group has also been established by Australian Health Ministers to address many of the issues raised by the Report of the Radiation Oncology Inquiry, *A Vision for Radiotherapy*, including workforce.⁶⁷

63 *Committee Hansard* 31.3.05, p.18 (Professor Saunders and Dr Fong).

64 *Committee Hansard* 19.4.05, p.49 (Professor Bishop).

65 *Committee Hansard* 20.4.05, pp.8-9 (Ms Dane).

66 *Committee Hansard* 19.04.05, p.49 (Professor Bishop).

67 *Submission* 87, p.22 (DoHA).

3.81 The Commonwealth is undertaking a number of workforce initiatives, with the medical workforce being a focus of the \$4b package for Strengthening Medicare. Substantial funding has been expended on a range of workforce initiatives designed to improve the number of radiation therapists and medical physicists. The Commonwealth's Strengthening Cancer Care Initiative also provides considerable funding over the next four years to support cancer health professionals. The funding will go towards more radiation therapy undergraduate places and professional training packages for nurses, cancer professionals, counsellors and general practitioners. In 2003, the Commonwealth Government announced the creation of 4,000 new publicly funded university places to study nursing over the period 2005-08, with additional funding also being made available over four years towards the costs associated with clinical placements for nurses.⁶⁸

3.82 The Cancer Institute New South Wales is also progressing a range of cancer workforce related initiatives including supporting the professional development year for radiotherapists, establishing new academic posts in the radiation sciences and providing specialist trainee positions.

The cost of Multidisciplinary Care

3.83 There is very little data available on the cost of implementing multidisciplinary care. The Holman Report notes that 'the health economics for MDC for cancer is barely embryonic in its development'. However, the Professor reported that a formal cost analysis of a multidisciplinary melanoma clinic in the US suggested reduced health care costs and a study of multidisciplinary care for breast cancer in NZ documented a reduction on outpatient visits and administrative overheads.⁶⁹

3.84 The *National Multidisciplinary Care Demonstration Project* did not include a formal health economics analysis but provided indicative costs for the set-up and implementation of MDC strategies which focussed on establishing and maintaining MDC case conference meetings. The study seemed to indicate that newly established meetings resulted in a higher average cost but the expectation was that as the meetings become more routine and efficient that there would be an increase in the number of cases discussed and the time required would decrease.⁷⁰

3.85 The Committee recognised that at the State and Territory level and at a service level, adequate resourcing will be required to ensure ongoing sustainability of multidisciplinary care.

68 *Submission 87*, p.31 (DoHA).

69 Professor C. D'Arcy, J. Holman, Commissioned Report, p.5.

70 National Multidisciplinary Care Demonstration Project, NBCC, pp.28-31.

Rural and Indigenous Australians and multidisciplinary care

3.86 Regarding multidisciplinary care for rural areas, Mr Gregory, the Executive Director of the National Rural Health Alliance pointed out to the Committee that the multidisciplinary cancer support team is rare in rural and remote areas. He emphasised that it is currently very hard to put together the necessary multidisciplinary team for cancer care⁷¹ and you would have to include the people who are available. In an Indigenous community, you would include the Aboriginal health worker.⁷²

3.87 With tele or videoconferencing, multidisciplinary team meetings can take place over a distance. Witnesses referred to the successful model between Adelaide and Alice Springs which has been in existence for several years and a trial in Victoria from Geelong across the Western District.⁷³

Care coordination

3.88 The terms of reference and evidence have used the terms care coordinators and case managers interchangeably. This report will use the term care coordinator.

3.89 While there would appear to be no precise definition of care coordination in the medical literature, it refers to the 'efforts to reduce fragmentation of services for patients with complex care needs'.⁷⁴ Best practice multidisciplinary care means that the team includes an individual who has responsibility for 'coordinating the patient's transit through the various stages of assessment, treatment and follow-up; for ensuring a patient is well informed; and for advocating that the patient's own decisions and requirements are respected'.⁷⁵ There is evidence that a care coordinator can play a valuable role to ensure continuity of care and deliver the full benefits of a multidisciplinary model which results in better outcomes for the cancer patient.⁷⁶

A person diagnosed with cancer can receive multiple treatments in a variety of settings over extended periods. For example, a recent UK study reported that cancer patients had met an average of 28 doctors within a year of their diagnosis. Add to this the many other health professionals involved and it is clear that patients face a bewildering array of consultations, therapies, options and advice, at a time when they are already distressed by their diagnosis.⁷⁷

71 *Committee Hansard* 20.4.05, p.50 (Mr Gregory).

72 *Committee Hansard* 20.4.05, p.7 (Ms Grealish).

73 *Committee Hansard* 18.4.05, p.50 (Ms Swinburne).

74 *Submission* 65, p.12 (COSA, CCA, NCCI and NACCHO).

75 *A Cancer Service Framework for Victoria*, The Collaboration for Cancer Outcomes Research and Evaluation July 2003, p.xiii.

76 *Submissions* 65, p.12 (COSA, CCA, NCCI and NACCHO) and 27, p.4 (Mr and Mrs Moran).

77 *Submission* 65, p.13 (COSA, CCA, NCCI and NACCHO).

3.90 Witnesses told the Committee that the 'cancer lottery' referred not only to diagnosis and referral but also to the care they received over the sometimes lengthy period of their treatment. They reported a lack of continuity of care across treatment modalities and the private and public sectors. Witnesses said that cancer patients often felt lost in the cancer system and isolated from assistance and information.

I will quickly mention the story of one person who lives in a country town who was a senior nurse in our organisation. She had sarcoma of the face and underwent radical surgery. Her nose was removed and a flap was put in its place. This lady is very intelligent and has worked in nursing for many years. She told me something that I have not forgotten – how abandoned she felt by the medical and health service and the lack of continuity in care. This was from a person who actually knew how to get herself around the health care system. So I keep that in mind and think: what of the people who do not know how to navigate our complicated system?⁷⁸

3.91 The need to improve coordination of the patient journey has been highlighted in a number of national reports including *Optimising Cancer Care in Australia. The National Service Improvement Framework for Cancer* states:

People with cancer will have a designated co-ordinator of care who knows about all aspects of their disease, treatment and support. The care co-ordinator will help people with cancer move between treatment components, ensure that they have access to appropriate information and support and ensure the treatment team is fully aware of a person's preferences and situation. The care coordinator might be a cancer nurse, general practitioner, case manager, cancer specialist or other health professional. The care coordinator may be a different person at different times in the cancer journey but the person with cancer should always be clear about who is their care coordinator.⁷⁹

3.92 The need for a coordinator of care has also been recognised by the States and Territories. For example, the *NSW Cancer Plan 2004-06* has identified care coordination as a critical role to facilitate the optimal sequence and timeliness of care and the Cancer Institute NSW is establishing a Cancer Nurse Co-ordinators Program. Similarly, the Cancer Services Framework for Victoria indicates that specific care coordinators are needed to improve the efficiency of cancer care and recommends the need for multidisciplinary coordinated care.⁸⁰ The Western Australian Government has also recognised the valuable role of care coordinators and is appointing 20. The model of care coordination is to be different depending on where care coordinators are based and what group of patients they are looking after.⁸¹

78 *Committee Hansard* 20.4.05, p.2 (Ms Dane).

79 *National Service Improvement Framework for Cancer*, National Health Priority Action Council, March 2004, p.34.

80 *Submission* 87, p.21 (DoHA).

81 *Committee Hansard* 31.3.05, p.4 (Professor Saunders); *Submission* 44, p.6 (Dept of Health WA).

3.93 However, the question remains, who is best placed to undertake the role of the care coordinator? For example, it could be a cancer nurse, GP or other health professional.

Breast Care Nurse Model

3.94 Specialist breast cancer nurses fill the role of care coordinator effectively in many settings where breast cancer patients receive multidisciplinary care.⁸² GPs are aware of breast cancer treatment centres and the breast cancer screening programs are also linked in, making sure that the majority of women, once diagnosed, have their ongoing management well coordinated. This was identified as of critical importance when women develop progressive breast disease requiring long-term care and support.⁸³ Also, many more elderly patients may have other medical conditions, the management of which needs to be coordinated within the treatment program for breast cancer. This issue was seen by the Committee as of great significance for planning for the future as Australia faces an increasing incidence of all types of cancers due primarily to its ageing population. As the forecast increase in incidence occurs, so the survival of patients is also forecast to improve and Australia will have more people living with their cancer who will require coordinated care.

3.95 The Committee was impressed by the excellent results achieved in the management of breast cancer following the national and regional efforts to improve outcomes in terms of survival and quality of life. It was emphasised that a dedicated breast care nurse played a very important role in helping women through their cancer journey. However, it was also made clear by two breast cancer advocacy groups that this sort of professional resource is not available in every setting where breast cancer is treated.⁸⁴ In their submission, the Peter MacCallum Cancer Centre advised that they have appointed nurse co-ordinators for almost all major cancer types in the past four years. They also reported that they have recently completed an evaluation of a nurse practitioner role in malignant haematology which may act as a model.⁸⁵

3.96 But what happens with the management of other cancers? It appears from evidence that care coordination can be a hit and miss affair. Some specialised units dealing with lung cancer or bowel cancer or head and neck cancers do have senior nurses who 'organise' the clinic and what happens in it, but most settings are not as patient-focussed and could not be directly compared with the breast care nurse.

3.97 The Committee was mindful of the shortages of nurses and of retired nurses wanting work in a capacity such as the care coordinator role for which they would be highly skilled.

82 *Submission 39*, p.3 (NBCC).

83 *Committee Hansard* 18.4.05, p.47 (Ms Manaszewicz).

84 *Committee Hansard* 18.4.05, p.46 (Ms Lockwood).

85 *Submission 36*, p.2 (Peter MacCallum Cancer Centre).

Recommendation 11

3.98 The Committee recommends that all State and Territory Governments that have not yet done so, establish designated care coordinator positions to help cancer patients navigate their way through treatment and provide support and access to appropriate information.

Recommendation 12

3.99 The Committee recommends that use of the breast cancer nurse care coordinator model should be adopted for all cancers and that States and Territories undertake a recruitment drive for skilled health professionals such as retired nurses to help fill these positions.

Role of case manager

When I was diagnosed with cancer I felt fear, anxiety, and confusion. My decisions regarding conventional treatment evolved quite naturally. They were taken on the basis of professional advice given with the best possible intentions. They all seemed to make sense at the time - I am talking about surgery, chemo and radiotherapy. If I had known then what I know now about other factors some of those major decisions about some of those conventional treatments would have been quite different. I was given little general information about cancer. There was no discussion or referral to credible complementary services as either a primary or adjuvant treatment. I can certainly see a role for a case manager as a source of information about cancer generally, and also as a source of information regarding referral to the whole range of services, conventional and complementary.

So it is at that initial stage that information could be provided by that case manager, but they would have to be well-informed and unbiased. In my experience, the oncologist did that for me in the conventional medicine sense, but the oncologist has a bias towards conventional medicine. GPs are too busy to provide that service. I see a possibility for that sort of case manager role being fulfilled by a clinically trained educational nurse, as seems to be the case with patients diagnosed with heart disease or diabetes.

Committee Hansard 18.4.05, p.60 (Mr Peter McGowan).

Who is best placed to coordinate?

3.100 The Committee heard a range of opinions and options regarding from which discipline care coordinators should originate. The options presented included oncology or general nurses, specialist GP nurses, GPs, medical social workers or community pharmacists. The Pharmacy Guild proposed that community pharmacists monitor the symptoms of patients undergoing chemotherapy in their home,⁸⁶ though the Guild representative acknowledged that such a role would involve his organisation in additional ongoing education and training. Several health professionals emphasised

86 *Submission 32, pp.3-4 (Pharmacy Guild).*

the importance of having the care coordinators closely integrated into the multidisciplinary team and working to agreed standards and protocols.

3.101 Witnesses also mentioned that there is a lot more outpatient care being undertaken⁸⁷ and as a result, links with the community need to be stronger so that there is continuity of coordination and support for people when they go home from hospital. Ms Lockwood stated that at the moment there are no links between the hospital sector and the community sector and suggested that there are some easy things that can be achieved 'like faxing a discharge plan to the community health nurse so that she knows a woman with breast cancer is coming'.⁸⁸

3.102 Brian Tumour Australia noted that a care coordinator is particularly needed for brain tumour patients', families and carers as the brain tumour may have started to affect the patient's cognitive abilities. They suggested that if the numbers did not warrant a specific brain tumour case coordinator that there may be some value in a dedicated staff member to assist with the less common or minority cancers.⁸⁹

3.103 In some circumstances an organisation may be the care coordinator. Ms Revell told the Committee that the Cancer Council played a fundamental role in the coordination of her treatment:

I have no problems at all with the treatment in either system (public or private) – it was terrific; it was great – but there was no continuity of treatment or care. It was the Cancer Council that provided that. They stepped in where, in my case, the health service was not adequate...so the main co-ordinator for my well being was actually the Cancer Council.⁹⁰

The need for information

3.104 Witnesses also spoke about their ongoing need for information throughout their cancer journey and that one of their biggest challenges was finding and accessing appropriate, authoritative information. Further along the cancer journey, they needed information about support groups, treatment options, complementary therapies and government assistance. While recognising that the care coordinator is a vital source of information for cancer patients, the Committee considered a common entry point for people with cancer was required to provide consolidated and authoritative information.

Recommendation 13

3.105 The Committee recommends that Cancer Australia provide access to authoritative, nationally consistent, evidence based information on services,

87 *Submission 36*, p.4 (Peter MacCallum Cancer Centre).

88 *Committee Hansard 18.4.05*, p.46 (Ms Lockwood).

89 *Submission 6*, p.3 (Brain Tumour Australia).

90 *Committee Hansard 31.3.04*, p.26 (Ms Revell).

treatment options, government and non-government assistance and links to appropriate support groups which can be used by health professionals including care coordinators, cancer patients and their families. This information should be available in different forms.

Conclusion

3.106 Management of cancer is a complex process that should follow a continuum from the point of screening and/or diagnosis through treatment and supportive care to follow-up and in some cases palliative and end-of-life care in both hospital-based and community settings.

3.107 There was no doubt in the view of the Committee that care coordinators should be an essential part of the treatment of cancer. As to who performs the role should be left to the State and Territory cancer services and will necessarily vary with individual patients. The successful model of the breast care nurses should also be taken into account when determining the most appropriate person to be the care coordinator. In the context of patients in rural and remote areas, care coordinators can play an important part in improving their more complex patient journeys, especially for Indigenous Australians.

Psychosocial support

If people feel supported and feel better, they comment less negatively on every other aspect of their life and their care.⁹¹

3.108 Clinical guidelines state that: 'Optimal care of the patient with cancer incorporates effective physical and psychological care'.⁹² Psychosocial services were consistently identified by witnesses as difficult to access and seen as optional by many clinicians. Major cancer centres throughout Europe and the USA automatically provide access to psychosocial support for cancer patients at the time of diagnosis and thereafter throughout their episodes of treatment. Psychosocial support is as much a part of multidisciplinary care as surgery, radiotherapy or chemotherapy. Not every patient requires support but some require much more assistance than others.

People tend to have been living their life and then they get their cancer diagnosis and it is a different life they move into. They have been working full-time and then all of a sudden they have to negotiate systems like Centrelink, the ministry of housing or palliative care services out in the community - a whole array of services. They have never had any contact with those agencies before, so I find that a large part of what I do is to try to introduce people to the services in a way that I recognise as being at their own time and pace. Often they are still thinking: Hang on, I've got cancer, have I? What does that mean? – let alone trying to put food on the table and

91 *Committee Hansard* 11.5.05, p.10 (Dr Maher).

92 *Clinical practice guidelines for the psychosocial care of adults with cancer*, NBCC, NCCI and NHMRC, p.3.

making sure they have an income. There is so much for the person to try to integrate at one time.⁹³

3.109 It is well documented that emotional distress is very common in cancer patients. Many studies have looked at distress levels and quality of life in cancer patients. Quality of life covers a broad spectrum of issues in cancer care, including physical, social, cognitive, spiritual, emotional and role functioning as well as psychological symptomatology, pain and other common physical symptoms. Emotional distress refers to problems such as anxiety, depression and fears around the cancer experience. The *Clinical practice guidelines for the psychosocial care of adults with cancer* reports that 'up to 66 per cent of people with cancer experience long term psychological distress; 30 per cent experience clinically significant anxiety problems; and that rates for depression range from 20 to 35 per cent'.⁹⁴

3.110 Reviews and meta-analytical studies show that psychological interventions help patients to cope better with cancer and treatment, and that this may lead to an increased survival rate as well as lower rates of service utilisation and pharmacological intervention. As noted by Dr Hassed:

We can say that effective psychosocial support programs that significantly improve the mental, emotional and social health of the participants who go through them are associated with significantly longer survival and better survival.⁹⁵

3.111 Research also shows that psychological intervention can be useful in the areas of adherence to treatment regime, pain management, treatment of negative mood, self-management interventions, managing communication and complementary therapies.⁹⁶

...Cancer is a multifaceted disorder, and psychosocial factors, which are so easily forgotten, have a major influence on the incidence, progress and outcome of cancer.⁹⁷

3.112 Although the prevalence of distress, anxiety and depression is common, medical practitioners have been found to have difficulties identifying, or are unaware of, the psychological concerns of their patients or of disorders such as depression. Hence the true prevalence of psychosocial distress amongst cancer patients is under-reported and ultimately under-treated. Consumers believe that clinicians are not sufficiently aware of the psychosocial aspects of care and that the clinical guidelines

93 *Committee Hansard* 18.4.05, p.93 (Ms Todd).

94 *Clinical practice guidelines for the psychological care of adults with cancer*, NBCC, NCCI and NHMRC, p.vi.

95 *Committee Hansard* 18.4.05, p.57 (Dr Hassed).

96 *Submission* 38, pp.4-6 (APS).

97 *Committee Hansard* 18.4.05, p.78 (Mr Stokes).

should be implemented for all cancer services and their use encouraged through medical and nursing training.⁹⁸

If we continue to have our services offered in cancer care based around medical treatment, we will continue to have patients feeling abandoned. When the treatment finishes...people are abandoned by the system. Once they do not access medical services, the other supportive services are not available.⁹⁹

3.113 Witnesses reported that appropriate and timely referral of cancer patients in need of psychosocial services is not routinely undertaken¹⁰⁰ and that this is much more difficult in a work culture that emphasises physical, rather than emotional patient needs. As noted by Professor Zalcborg:

Psychology and social work in the community are particularly the areas not adequately supported by current systems.¹⁰¹

3.114 Mr Ulman, Director of Survivorship at the Lance Armstrong Foundation told the Committee about a survey the Foundation undertook in November 2004 where 1,000 cancer survivors across the USA were asked what they were dealing with as a result of their cancer diagnosis:

49 per cent of these people interviewed said that their non-medical needs - that is, their emotional, practical and physical non-medical needs - were currently going unmet by the health care system...more than half - 53 per cent of the people surveyed said that they agreed that the practical and emotional consequences of dealing with cancer were harder than the medical issues.¹⁰²

3.115 Evidence presented at the hearings and in written submissions indicated that few public hospitals in Australia provide adequate funding to sustain the provision of psychosocial support for cancer patients and their carers. Whilst most hospitals can report the existence of general consultant liaison psychiatry and clinical psychology programs, very few of these services are funded to the extent whereby dedicated services for cancer patients could be provided. The Peter MacCallum Cancer Centre reported that:

At Peter Mac we are very lucky. We have managed to employ psychologists and we have a strong bank of social workers and limited psychiatry, but that would be unusual in most hospitals across Australia...¹⁰³

98 *Committee Hansard* 19.4.05, p.44 (Ms Crossing).

99 *Committee Hansard* 20.4.05, p.3 (Ms Grealish).

100 *Committee Hansard* 19.4.05, p.35 (Ms Crossing).

101 *Committee Hansard* 18.4.05, p.37 (Professor Zalcborg).

102 *Committee Hansard* 12.5.05, p.2 (Mr Ulman).

103 *Committee Hansard* 18.4.05, p.29 (Professor Aranda).

3.116 Professor Bloch, who will spend time at Memorial Sloan-Kettering Cancer Centre in New York, which is a recognised world leader in the field of cancer treatment, stated by way of comparison that they have 'no fewer than 10 psychiatrists, 10 psychologists, six training posts and 11 doctoral and postdoctoral fellowships. He acknowledged that Sloan-Kettering is the largest cancer centre in the USA but said 'it seems to me to be a reflection of how much we still have to catch up'.¹⁰⁴

3.117 The Australian Psychological Society told the Committee of the limited services they are able to provide to cancer patients:

We may have either a clinical or a health psychologist whose speciality is not oncology, who might see at best – as a passing acquaintance – half the patients in the ward. I worked in an oncology ward. At best you met perhaps half of those patients at the bedside. You did serious work with no more than 10 per cent. That is just the public hospital sector. We have not even talked about the private hospital sector, where in many instances you would not find a psychologist anywhere in the centre.¹⁰⁵

3.118 Witnesses working in the sector said that due to the lack of staff, the emergency medicine model prevails where social workers may be called in for emergency cases, when someone is in serious distress¹⁰⁶ and referral to psychiatrists occurs if there is a major problem such as suicidal depression. Oncology social workers agreed, saying that due to the critical shortage of specialist oncology workers, they operate largely on a crisis driven model of service'.¹⁰⁷ Mr Hochberg emphasised that most services are inpatient focussed and to access social work services as an outpatient you need to be in crisis.¹⁰⁸

3.119 Witnesses reported that the provision of psychosocial care is hampered by the absence of positions funded either through State health systems or through Medicare. They reported that under Medicare, the rebate for psychosocial health professionals is limited and does not meet the needs of most cancer patients.¹⁰⁹ Published HIC information indicates that last year new Medicare benefit items were introduced for allied health services for people with chronic conditions and complex care needs. The items allow for a 'maximum of five services per patient per 12 month period. Patients need to have a chronic condition and complex care needs which are being managed by their GP under an Enhanced Primary Care multidisciplinary care plan. The need for allied health services must also be identified in the patient's care plan'.

104 *Committee Hansard* 18.4.05, p.82 (Professor Bloch).

105 *Committee Hansard* 18.4.05, p.85 (Mr Stokes).

106 *Committee Hansard* 18.4.05, pp.85-86 (Mr Stokes).

107 *Committee Hansard* 18.4.05, p.89 (Mr Hochberg).

108 *Committee Hansard* 18.4.05, p.96 (Mr Hochberg).

109 *Committee Hansard* 18.4.05, p.29 (Professor Aranda).

3.120 Eligible services include those provided by Aboriginal health workers, audiologists, chiropractors, chiropodists, dieticians, mental health workers, occupational therapists, osteopaths, physiotherapists, podiatrists, psychologists and speech pathologists.¹¹⁰ However, the existence of the MBS items did not seem to be well known. The Committee was concerned that a five services maximum per 12 month period may be insufficient for chronic cases involving complex care needs.

Recommendation 14

3.121 The Committee recommends that the Department of Health and Ageing improve health professional and consumer awareness of allied health services for people with chronic conditions and complex care needs that can be claimed under the Medical Benefits Schedule. Current claim usage of allied health services should be determined and an evaluation should be conducted 12 months after promotion of the Medical Benefit Schedule items available.

Recommendation 15

3.122 The Committee recommends that Cancer Australia examine appropriate funding mechanisms for programs and activities like those operated by the Gawler Foundation, which specialise in providing learning and self-help techniques based on an integrated approach for cancer patients and their carers. This examination should include consideration from a health and equity point of view of providing Medicare deductibility for cancer patients accessing these services.

3.123 In the past few years, the Australian peak cancer organisations have released several clinical practice guidelines for the management of specific cancers that have also been endorsed by the NHMRC and the Australian Government. Increasingly these guidelines are including sections on the psychosocial aspects of cancer care and some have been dedicated totally to this area. In 2003, the NBCC and NCCI developed *Clinical practice guidelines for the psychosocial care of adults with cancer*. These guidelines were produced for use by all relevant health professionals who come into contact with cancer patients during their journey and were endorsed by the NHMRC.

3.124 These evidence based guidelines have been internationally recognised as a significant contribution to the field of psychosocial aspects of cancer care. Some psychosocial interventions with cancer patients are summarised below:

- Appropriate counselling improves the well being of people with cancer;
- Providing patients psychosocial support before undergoing treatment reduces psychological distress;

110 Accessed at http://health.gov.au/internet/wcms/publishing.nsf/Content/health-medicare-health_pro-gp-pdf-allied-cnt.htm on 19.5.05.

- A variety of psychological interventions, including cognitive behavioural supportive group, family and couples therapy as well as relaxation techniques are useful for decreasing distress in patients;
- Cognitive, behavioural, supportive and crisis interventions, as well as combinations of education and behavioural or non behavioural interventions and anti-anxiety medications, are effective in the treatment of anxiety and depression;
- Supportive psychotherapy, in combination with anti-depressants is effective for the management of post-traumatic stress disorder; and
- Relaxation therapy, guided imagery systematic desensitisation, supportive interventions and education together with cognitive behavioural interventions, are beneficial for patients with physical symptoms.¹¹¹

3.125 The Cancer Institute NSW and the Department of Health WA called for the broad application of the NHMRC-approved guidelines for the psychosocial care of adults with cancer. The Committee is aware that in 2003 the NCCI, in conjunction with the NBCC, developed a dissemination and implementation strategy for these guidelines involving four modules including interactive educational workshops for health professionals, health professional summary cards, consumer summary cards and a rural and remote strategy. The strategy commenced in 2004.

Recommendation 16

3.126 The Committee recommends the continued implementation and dissemination of the *Clinical practice guidelines for the psychosocial care of adults with cancer* to health professionals and people and families affected by cancer.

3.127 Non-Government Organisations, especially the State and Territory Cancer Councils, strongly advocate the provision of psychosocial support and are currently the major service providers in this field.

3.128 The Cancer Help Lines, run by the Cancer Councils throughout Australia, are often the first port of call for many newly diagnosed cancer patients and their carers who are seeking more information and support. Professor Hill provided statistics on Cancer Help lines calls, reporting that '80 per cent of them talk about management and treatment; 45 per cent, diagnosis; 30 per cent, side effects; 45 per cent are interested in psychological and emotional support issues and 35 per cent are interested in recurrence and advancement of the disease'.¹¹²

3.129 It would seem that Australia does reflect some international practices with non-government organisations overseas providing information resources and

111 *Clinical practice guidelines for the psychosocial care of adults with cancer*, NBCC, NCCI and NHMRC, pp.7-10.

112 *Committee Hansard* 18.4.05, p.15 (Professor Hill).

guidance. Mr Ulman advised that at the Lance Armstrong Foundation 'we are always encouraging and empowering people to seek out resources that may or may not be beneficial to them but are not always easily accessible or that physicians are not always referring people to'.

3.130 The provision of psychosocial support for cancer patients was identified as one of the 13 priorities in the report *Priorities for Action in Cancer Control 2001-2003*. The report recommended 'Improving the psychosocial care of people with cancer through provision of psychologists in cancer centres and clinics'.¹¹³ The recommendations were all subjected to intensive scrutiny in order to assess the levels of scientific evidence and were developed for the benefit of Commonwealth and State and Territory governments in their development of cancer treatment services. The report confirmed that a high proportion of people diagnosed with cancer suffered from severe psychological problems such as anxiety and depression. Psychosocial interventions such as cognitive behavioural therapy were identified as effective in reducing morbidity in the acute phase of the illness and longer-term psychotherapies as effective in helping patients with advanced cancer. Of significance to the provision of health services, the report stated that:

An intervention that aims to reduce psychosocial morbidity in people with cancer, both when newly diagnosed and in the latter stages of recurrent or persistent cancer, would address an important health problem and could have a substantial impact on cancer-related morbidity.¹¹⁴

3.131 Evidence suggests that where psychologists and psychiatrists are available in public hospitals, the service they are able to provide for cancer patients and carers is limited. The importance of providing psychosocial care for the patient and carer was repeatedly stressed in the *Optimising Cancer Care in Australia* report.

Recommendation 17

3.132 The Committee recommends that psychosocial care be given equal priority with other aspects of care and be fully integrated with both diagnosis and treatment, including the referral of the patient to appropriate support services.

Recommendation 18

3.133 The Committee recommends that patients and carers should be made aware of additional support services provided by organisations such as The Gawler Foundation in VIC, Balya Cancer Self Help and Wellness Inc in WA and Bloomhill Cancer Help in QLD.

3.134 The Committee recognised the underprovision of psychosocial support services in the public sector and considers that State and Territory health budgets need

113 *Priorities for Action in Cancer Control 2001-2003*, Cancer Strategies Group, p.viii.

114 *Priorities for Action in Cancer Control 2001-2003*, Cancer Strategies Group, p.50.

to address service delivery funding arrangements to deal with this significant unmet need confronting cancer patients.

Recommendation 19

3.135 The Committee recommends that State and Territory Governments consider ways to increase the availability of psychosocial support services.

3.136 It became evident to the Committee as the Inquiry progressed that, without the input from voluntary support groups in the non-government sector, most cancer patients would be unable to access professional help when needed. Health professionals presenting evidence also expressed their frustration at consistent inadequate funding for psychosocial support. The exception to this rule appeared to be the support provided for breast cancer patients, especially at major centres and where breast care nurses were employed.

Conclusion

3.137 Ideally, every cancer patient in Australia should have a right to appropriate psychosocial assessment and intervention from the time of diagnosis, as close as possible to where their primary treatment is being delivered. The Committee agreed that there is ample evidence to indicate that appropriate psychosocial service provision can improve a cancer patient's journey by alleviating clinical levels of distress, in particular anxiety and depression.

3.138 The Committee noted that all descriptions of multidisciplinary care in whatever setting, included the provision of psychosocial support. It was evident to the Committee that the availability of adequate psychosocial support in 2005 is as haphazard as properly funded multidisciplinary cancer care in Australia. The Committee supports greater use of the *Clinical practice guidelines for psychosocial care of adults with cancer* as a resource for all relevant health professionals involved in any aspect of the patients cancer journey and recommends their usage be encouraged by professional colleges. The Committee also supports the continuation of the implementation and dissemination strategy for the psychosocial guidelines.

3.139 The Committee considers the various cancer support groups play an important role in assisting people to deal with the psychosocial impact of cancer.

Robert's story

During an internal bladder inspection by the surgeon, I was informed that I had a large and dangerous tumour in my left kidney and that it and the surrounds had to be removed urgently. Whilst in discomfort and some pain from this medical procedure I attempted to ask questions of the surgeon as to potential alternatives and what this meant for me but received only brief answers that added up to zero choice. This was traumatic for me both as a result of the diagnosis and from the lack of knowledge of my condition and personal options.

I did have a further chance to consult with the surgeon prior to the operation and discovered more information regarding the medical procedures but was not advised as to survival potential either from the operation or from potential metastasis of the cancer. I was not offered or advised of any other services that may have assisted me through this traumatic time, e.g., psychological counselling. I was under the distinct impression that a surgeon will comment only on the area directly under his expertise...

At the six monthly post-operative checkup a large tumour was detected in my left lung and I was referred to a cardio-thoracic surgeon who rapidly admitted me to Fremantle Hospital for a lower left lobectomy (removal of a lung lobe) for a diagnosed renal cell carcinoma metastasis. Subsequent histology reported that it was not that cancer type but a lung cancer. (bronchio-alveolar non-small cell carcinoma).

Post-operative tests showed metastasis of this cancer and that it was inoperable. The cardio-thoracic surgeon, while sympathetic, would not advise me on future medical possibilities or probabilities and simply referred me to an oncologist and said goodbye.

The oncologist briefly described the cancer in laymans terms and advised me that this particular cancer did not respond to any currently available medications. He could not or would not offer me any projections on my survivability and simply advised me to come back when the pain became difficult. This was rather depressing.

While arranging my affairs and attempting to investigate palliative care options I was advised by my house cleaner about an experimental cancer drug trial underway at Sir Charles Gairdner Hospital in Perth... I contacted the State Department of Health and was referred to the research team under Professor Millward at that hospital. After much testing and a requested referral from my oncologist, I was accepted on to a drug trial in October, 2004. My oncologist had not advised me about the existence of these trials.

Whilst there have been some difficult times on this experimental trial the results after one cycle of treatment were that there has been some reduction in the cancer mass, there are no new metastatic sites and there has been a major improvement in my wellbeing. I have now chosen a different oncologist.

Throughout this period, any assistance I have received to ease my way through the medical maze, to attempt to deal with the knowledge of imminent death and to finally arrange my financial and legal affairs has generally been accidental and usually the result of a few good people volunteering their help. The only group of people in the medical system who showed what I interpreted as a level of continuing 'genuine care' were the nursing staff. I cannot rate them highly enough both for their technical expertise and for their humanity.

Submission 83, pp.2-4 (Mr Robert Bergman)

Cancer care in regional, rural and remote areas

Significant health system changes are required if rural and remote patients are to be treated in line with Medicare principles and have equity of cancer care and outcomes¹¹⁵

3.140 It is estimated that around 30 per cent of people with cancer live outside a major population centre¹¹⁶ and studies indicate that this places them at a disadvantage to survive their cancer. The Rural Doctors Association of Australia (RDAA) reported research which shows that people in country areas who are diagnosed with cancer are 35 per cent more likely to die within five years than cancer patients in the city. The figures are even worse for gender specific cancers like cervical or prostate cancer with death rates three times higher in the country compared with metropolitan areas.¹¹⁷

3.141 The reasons given for the different rates of survival include: access to treatment; presenting with more advanced conditions at diagnosis; lower levels of education; lower social and economic status and increased risky lifestyle behaviours.

3.142 Ms Hall, a lecturer at the School of Population health in the University of WA, reported 'access issues and barriers exist at diagnosis, referral and treatment stages' for the rural cancer patient.¹¹⁸ The RDAA believes difficulties in accessing screening and diagnostic services are part of the reason for the imbalance between cancer outcomes for rural and urban Australia.¹¹⁹ As an example, Dr Page from the Rural Doctors Association reported that breast screening services are not provided in rural and remote areas in a consistent way.¹²⁰ Dr Rogers-Clark also noted that a common theme for rural women with breast cancer is 'the current fragmentation of care, with limited referral and significant gaps in the provision of ongoing supportive care'.¹²¹ At the referral stage, rural medical practitioners may not always have adequate information for appropriate referrals due to the low numbers of cancer patients they see. The RDAA suggested this could be addressed by the development of well defined referral pathways tailored to the needs of rural patients.¹²² Witnesses suggested that the combination of referral pathways with greater use of clinical practice guidelines would assist to alleviate disparities.

3.143 The Committee considered that because of the low numbers of cancer patients, rural GPs and their patients would benefit from the development of defined

115 *Submission 5*, p.2 (Ms Sonja Hall).

116 *Submission 87*, p.23 (DoHA).

117 *Submission 41*, pp.2-3 (RDAA).

118 *Submission 5*, p.1 (Ms Sonja Hall).

119 *Submission 41*, p.4 (RDAA).

120 *Committee Hansard 19.4.05*, p.81 (Dr Page).

121 *Submission 46*, p.1 (Dr Rogers-Clark and Ms Ellem).

122 *Submission 41*, p.3 (RDAA).

referral pathways for cancer sites to ensure they are referred to the appropriate care as quickly as possible. The use of existing clinical practice guidelines should be further encouraged for rural medical practitioners.

3.144 The RDAA highlighted that 'even when cancer is detected early, more country people are dying because of a service fragmentation and a lack of adequate treatment facilities in regional areas'.¹²³ Witnesses reported that many regional and rural centres in Australia have only limited access to specialist cancer services. 'In the case of medical oncology, 86.5 per cent of medical oncologists are located in a metropolitan capital city, with a further 8 per cent in large regional centres and 5.5 per cent in smaller rural or remote areas'.¹²⁴

3.145 As with other parts of the health sector, there are serious workforce shortages in rural and regional Australia¹²⁵ which means that, as noted earlier, multidisciplinary teams are rare, there is even less access to psychosocial support and cancer patients are disadvantaged in accessing complementary therapies.¹²⁶

Accessing complementary services in regional Australia

In my experience with conventional services in regional Australia - and Albury-Wodonga is a large provincial city - they were excellent. Hospitals, oncologist, radiotherapists and chemotherapy were all available. Referrals to Melbourne hospitals and visits to Melbourne hospitals for surgery were all there and efficient. From my regional point of view that worked extremely well. Complementary services are a little bit more difficult. They are mostly sited in main cities, in my case Melbourne, and it was quite difficult to transpose what you learned in a complementary medicine sense to the rural setting. It is very difficult to get sympathetic doctors to assist you in your complementary program in the regional centres.

Committee Hansard 18.4.05, p.60 (Mr Peter McGowan).

3.146 Witnesses believed that coordination of care was particularly important for rural cancer patients to ensure they are making informed choices regarding the most suitable treatment for their situation.

3.147 Research shows that rural people are more likely to smoke, drink to excess, eat a diet high in animal fat and are less likely to be exercising regularly. 'They are also exposed to occupational risks including chemical pollution and sun exposure'.¹²⁷ Despite this, witnesses informed the Committee that rural people have less access to public health education programs due to limited television transmission and the

¹²³ *Submission 41, p.4 (RDAA).*

¹²⁴ *Submission 37, p.3 (MOGA).*

¹²⁵ *Submission 61, p.5 (NRHA).*

¹²⁶ *Submission 61, p.8 (NRHA).*

¹²⁷ *Submission 41, p.5 (RDAA).*

tendency to leave school earlier. They emphasised that national public health programs are failing in rural areas as they have not been adjusted for relevance to the rural environment and suggested the development of new public health programs targeting rural Australians.¹²⁸ The need to tailor information and programs to reduce risk in communities and individuals with special needs has been recognised in the National Service Improvement Framework.

3.148 Public health programs focusing on disease prevention for rural Australians also need to be better targeted. Although this issue is broader than the terms of reference, it was mentioned as a concern by a number of witnesses. The Committee accepted that more targeted health education programs are required for rural Australians to address the higher levels of risky lifestyle behaviours as these can lead to later diagnosis and complex cancer.

3.149 Economic and physical barriers such as distance, lack of transport and the need to travel, impact on treatment choices for the rural cancer patient.¹²⁹ Some people with cancer do not wish to travel away from their family and support networks to obtain treatment and may accept levels of treatment which are not going to give them the best chance of survival or the best results.¹³⁰ Dr Page reported that researchers have found that not only are rural women with breast cancer less likely to have radiotherapy, they are less likely to have breast conserving surgery. Dr Page explained that if a patient with breast cancer has breast conserving surgery and has radiotherapy, their five-year survival prognosis is as good as if they had radical surgery such as a mastectomy. She added that if they do not have radiotherapy, there is an unacceptably high rate of recurrence.¹³¹ Dr Page indicated that studies have found rates of radiotherapy are low because it is primarily available only in metropolitan areas and would involve too much travel.¹³²

The way forward

In principle, tackling rural inequality in cancer care and outcomes requires a combination of improved primary healthcare, access to expert multidisciplinary services, and co-ordination of the two.¹³³

3.150 Witnesses reported that successful rural cancer services are usually linked to a major hospital in a capital city which provides a visiting outreach service in a shared care arrangement with local practitioners.¹³⁴ 'Outreach services involve transporting

128 *Committee Hansard* 19.4.05, p.87 (Ms Stratigos).

129 *Submission* 33, p.5 (Breast Cancer Network Australia).

130 *Submission* 41, p.4 (RDAA).

131 *Committee Hansard* 19.4.05, p.82 (Dr Page).

132 *Committee Hansard* 19.4.05, p.87 (Dr Page).

133 Jong, K.E, Vale, P.J and Armstrong, B. K, *Medical Journal of Australia* 2005; 182 (1) 13-14.

134 *Submissions* 4, p.6 (Mr Deverall) and 68, p.1 (Ms Heathcote).

city-based specialists to remote locations to treat people living in those communities and to provide advice to regional physicians'.¹³⁵ Witnesses supported the development of outreach specialist services from comprehensive cancer centres.

3.151 More comprehensive cancer centres are evolving in some larger regional centres. Several of these centres are conducting multidisciplinary meetings and are providing outreach services to smaller towns in their area. The centre at Albury-Wodonga was mentioned, which now has 'five resident oncologists, a clinical trials unit, oncology pharmacist and a two-machine radiotherapy service'. Regional cancer centres have also been established in Ballarat, Bendigo Wagga Wagga, Port Macquarie, Lismore and Townsville.¹³⁶

3.152 Enhancing links between metropolitan and rural centres can be achieved in a number of ways including visiting specialists and participation in multidisciplinary case conferencing through videoconferencing or by telephone.¹³⁷ To improve professional networks, the Federal Government has committed to a mentoring program linking metropolitan teaching hospitals to regional centres to help promote multidisciplinary approaches.¹³⁸ 'Over the four years from 2005-06, the Government is allocating \$14.1m in new funding to assist hospitals, providers and support networks to develop and implement cancer care mentoring. The national agency, Cancer Australia, will oversee this measure. Funding will be used to help link major urban teaching hospitals to regional and bush nursing hospitals in regional centres and help foster multidisciplinary approaches in regional areas where on the ground support is less comprehensive. The measure will encourage specialists and other leading health professionals from centres of excellence in cancer treatment to spend more time in rural and regional areas and be available to consult with regional colleagues'.¹³⁹

3.153 Some cancer patients do receive components of their care outside major treatment centres and close to their place of residence¹⁴⁰ and witnesses suggested there are opportunities to develop this aspect of care. As an example, Dr Page suggested that with improved education and training, chemotherapy could be provided in more rural areas and there have been successful pilots in NSW. She stated:

There is no reason that I can see why you can't have GPs and nurses trained up with advanced skills, specialist oncologists linking in by videoconferencing or teleconferencing and the individual patient perhaps

135 *Submission 65*, p.21 citing the Cancer in the Bush, Optimising Clinical Services conference report, 2001, The Cancer Council Australia, COSA, Department of Health and Ageing.

136 *Submission 65*, p.21 (COSA, CCA, NCCI and NACCHO).

137 *National Service Improvement Framework for Cancer*, p.37.

138 The Howard Government Election 2004 Policy, *Strengthening Cancer Care*, p.4.

139 Accessed at <http://www.health.gov.au/internet/budget/publishing.nsf/Content/health-budget2005-hbudget-hfact1.htm> on 1.6.2005.

140 *Submission 87*, p.24 (DoHA).

doing a once or twice a year visit back to the metropolitan centre, if that is required.¹⁴¹

Video and Teleconferencing

3.154 With videoconferencing, multidisciplinary team meetings can take place over a distance. Witnesses referred to the successful model between Adelaide and Alice Springs which has been in existence for several years and a trial in Victoria from Geelong across the Western District¹⁴² but noted that the cost of technology is the biggest problem in rural areas.

3.155 Telemedicine (or telehealth as was preferred by some witnesses) uses telecommunication to give regional and rural clinicians access to practitioners in metropolitan cancer centres, other disciplines and to enable case conferencing by phone or video link. Telemedicine has a role in managing remote or very complex cases. It may also have a role in linking regional providers into metropolitan multidisciplinary teams in areas where there are not sufficient practitioners to set up a local multidisciplinary team. However, criticisms of telemedicine include that it can be 'time consuming, constrained by technical limitations, unable to support the high numbers of cancer patients in regional areas. It is also unsupported by Medicare'.¹⁴³ The National Rural Health Alliance also mentioned legislative difficulties where the person may be operating over a State border and need to be registered in more than one jurisdiction.¹⁴⁴

3.156 The Committee accepts that the challenge is to provide services in regional, rural and remote areas using a multidisciplinary approach with specialist input as required. They agreed work needs to be done to establish clear referral pathways to assist GPs refer cancer patients to the best care quickly. The Committee agreed services outside major treatment centres should be encouraged to develop links with centres of expertise and commended the Federal Government initiative to establish a mentoring system to link health professionals in regional hospitals with cancer professionals in metropolitan teaching hospitals.

3.157 The Committee accepts that rural patients should be provided with access to and choices of treatment so that they are not disadvantaged by virtue of their place of residence. The Committee also notes that cancer patients in rural areas will not be able to access all cancer services locally as it is impractical to fund the infrastructure for cancer treatment such as radiation in rural areas due to the expense, the small numbers of patients and absence of cancer specialists. Therefore, there will be an ongoing need for people to travel for some components of their treatment and the Committee spoke to witnesses at length about the State travel and accommodation schemes.

141 *Committee Hansard* 19.4.05, p.83 (Dr Page).

142 *Committee Hansard* 18.4.05, p.50 (Ms Swinburne).

143 *Submission* 65, p.21 (COSA, CCA, NCCI and NACCHO).

144 *Committee Hansard* 20.4.05, p.51 (Mr Gregory).

Travel and accommodation assistance schemes

3.158 Cancer is a difficult disease to treat remotely and cancer patients living in rural and remote areas of Australia often have to travel significant distances to larger centres for assessment and treatment. They may also need to relocate for lengthy periods of time for treatment, resulting in loss of income, separation from family and support structures, and occasionally patients refusing adjuvant therapy (usually radiotherapy and chemotherapy) because of the huge disruption to their lives. Dr Page expressed the following view:

Having services like radiotherapy only available in metropolitan areas and expecting people to have to travel to them and to pay for their accommodation in order to be able to attend them – quite apart from depriving them of their family and social supports at the time – I really think it is not okay. It is shifting the costs of medicine onto the people who are least able to afford it, those who are sick and those who come from low socio-economic groups.¹⁴⁵

Organisations and cancer patients were vocal in their criticism of the travel and accommodation schemes due to variation between States and Territories of the rules and the ways they are applied (See Table 3.1). Witnesses reported that funding is sometimes by reimbursement which is problematic for those without means and some reported that patients were simply unaware of the schemes. For others, the paperwork was so onerous at a time when they were very unwell, that they did not utilise it.

3.159 Dr Page provided an example of the costs involved:

I have a colleague in the state who, at the moment, has a patient with prostatic cancer, that man is in Sydney now having radiotherapy, and he will be having it for six to eight weeks. The radiotherapy is being given in a 15 minute dose on a daily basis for the six to eight week period. After taking into account his travel and accommodation assistance package, which is provided, it is costing him \$85 a night in accommodation. This is not an amount of money that an impoverished low socioeconomic and particularly low-educated rural person can afford.¹⁴⁶

3.160 The Commonwealth originally funded the travel and accommodation assistance schemes but handed both the funding and the responsibility to the States in 1987. Now the Commonwealth provides block funding to the States and Territories but its application is determined by the States.

145 *Committee Hansard* 19.4.05, p.81 (Dr Page).

146 *Committee Hansard* 19.4.05, p.81 (Dr Page).

Table 3.1: Summary of IPTAAS in Australia

State/ Territory	Eligibility requirements	Travel assistance	Accommodation assistance	Patient contributions
NSW	Patient must usually live more than 200 km from the nearest treating specialist	Assistance provided at economy surace rail or bus rates Fuel subsidy of 12.7c/km for private car	Commercial:\$33/night (single) or \$46/night (double) Private: \$30/week after 1 st week for pensioner patients with a Health Care Card	\$40 (\$20 for pensioner or Health Care Card holders) personal contribution deducted from the total benefits paid per claim
VIC	Patient must live more than 100 km from the nearest treating specialist	Assistance provided for the most direct means of public transport (economy rate) Fuel subsidy of 13c/km for private car	Commercial: Up to \$30/night for a maximum of 120 nights in a treatment year Private: Not eligible	Patients who are not concession card holders will have the first \$100 deducted from their payment each treatment year
QLD	Service must be more than 50 km from the patient's nearest public hospital	Assistance provided at the cost of the least expensive form of public transport from the town of local hospital to the transport terminal of the town the patient is travelling to Fuel subsidy of 10c/km for private car	Commercial: \$30/night for concession card holders; non-concession card holders must pay for the first four nights accommodation in a fiscal year Private: \$10/night for concession card holders; non-concession card holders to meet first four nights accommodation	Nil
SA	Patient must live more than 100 km from the nearest treating specialist	Assistance provided at economy rate for bus/ferry/train less a patient contribution of \$30 Fuel subsidy of 16c/km for private car	Commercial: Up to \$33/night, no reimbursement on first night for non-concession card holders Private: Not applicable	Patient contribution of \$30 deducted from total travel benefits: means tested exemption for genuine hardship

State/ Territory	Eligibility requirements	Travel assistance	Accommodation assistance	Patient contributions
WA	Patient must live more than 100 km from the nearest treating specialist	Assistance provided at economy rate for the least expensive form of transport (bus/train/plane) Fuel subsidy of 13c/km for private car	Commercial: Up to \$35/night. Non-concession card holders are required to pay for the first three nights accommodation Private: \$10/night	Non-concession card holders pay the first \$50 for a maximum of 4 trips in a financial year
TAS	Patients must live more than 75 km from the nearest treating specialist	Assistance provided at economy bus travel from patient's residence Fuel subsidy of 10c/km for private car	Commercial: up to \$30/night Patients not on a pension are required to pay for the first two nights Private: not applicable Limit of \$2000 travel and accommodation costs/patient paid each year by Government	Card holders: \$15/trip; maximum contribution \$120/fiscal year Non card holders: \$75/trip; maximum contribution \$300/fiscal year
NT	Patient must live more than 200 km from the nearest treating specialist	Assistance provided at the cost of an economy return bus trip from the bus depot closest to the patient's residence Fuel subsidy of 15c/km	Commercial: Up to \$30/night Private: \$10/night	Nil
ACT	Available to permanent residents of the ACT who are required to travel interstate for specialist medical treatment which is not available in the ACT	A maximum entitlement for travel by coach/train (Can/Syd/Can) is \$40/adult and \$20/child Greater reimbursement for travel to cities other than Sydney Travel by private car receives \$40/trips (Can/Syd/Can)	Commercial: Up to \$30/night Private: \$10/night	Nil

Source: *Optimising Cancer Care in Australia*, 2003, pp.116-7.

3.161 In most State capitals the Cancer Councils have hostel accommodation of a high standard and arrange transport to the various clinics. They also provide a level of support for patients and their carers. Whatever the patient receives by way of the accommodation scheme is accepted by the Cancer Councils. For those patients who don't qualify for assistance the rate is negotiated on the basis of the ability to pay.

3.162 Ronald McDonald House provides a service for children (mostly the parents) being treated at children's hospitals. There are 12 Ronald McDonald Houses. Their policy is relative to the government assistance scheme in each centre and they accept whatever the government scheme pays for accommodation. If the family doesn't qualify for assistance the rate is by negotiation.¹⁴⁷

3.163 It appears there is not enough accommodation of a reasonable standard to meet current demand. The cash amounts provided by each State and Territory for accommodation differ, but, universally, cannot meet the costs of reasonable accommodation, should accommodation not be available in a Cancer Council hostel or similar. This places a heavier and unfair burden on patients from rural and remote areas of Australia. If accommodation is a continuing problem at present, it is going to get worse as the incidence of cancer increases. It appears the non-government sector is the best qualified to deal with this aspect of support, however, they will not be able to sustain all accommodation services on their charitable donations.

3.164 Representatives from the Breast Cancer Network Australia and Breast Cancer Action Group recommended that accessible and reasonable cost accommodation for patient and spouse/carer close to treatment centres should be provided. They also asked for greater flexibility to be able to judge each case on its merits rather than hard and fast rules. Ms Swinburne gave the following example:

Patient Assistance Transport Scheme (PATs) reflects more than just the problem with the travel scheme, it reflects a bigger problem concerning the states and the Commonwealth and the relationship between them. An example is women who live near borders. A woman who lives in Byron Bay has to travel to a treatment centre in NSW to be able to get PATs, even though Brisbane or the Gold Coast are much closer and her family and support could be there. There are a lot of things that are not sensible as part of the scheme. There are a lot of bureaucratic difficulties and challenges for women.¹⁴⁸

3.165 Mr Gregory told the Committee that the eighth National Rural Health conference in Alice Springs in March 2005 recommended there should be an immediate national review of the State schemes that assist patient and carer transport and accommodation. The purpose would be to introduce a uniform approach which provides people from remote and rural areas with reasonable reimbursement for

147 Mr Deverall, personal communication, 5.5.05.

148 *Committee Hansard* 18.4.05, p.48 (Ms Swinburne).

accessing services that are not available in their own communities.¹⁴⁹ This echoes proposals from the National Rural Health Alliance, the Baume Inquiry, and submissions for a collaborative Commonwealth, State and Territory task force to address the problems associated with the existing travel and accommodation subsidy schemes for people from rural and remote areas.

3.166 Mr Gregory suggested the characteristics of an improved scheme would include: 'more information about it, less variation within and between jurisdictions, carers and escorts being eligible; assessment being based on psychosocial needs and not merely medical grounds; consideration being given to those on low incomes and who incur a major loss of income; and attention to boundary and eligibility issues relating to a second opinion and treatment of choice'.¹⁵⁰

3.167 The Radiation Oncology Jurisdictional Implementation Group (ROJIG) Committee of Inquiry reviewed the issue of travel and accommodation. Both the Baume report and ROJIG have recommended that, States and Territories, at the very least, observe a uniform standard of benefits to be paid under the travel assistance schemes. The report provided a set of principles to help jurisdictions improve patient access, which include the following issues:

- Eligibility, accommodation, transport and mileage benefits – including assistance continuing to be based on distance rather than time taken to travel to a specialist treatment centre;
- Patient contributions – with a focus on targeting maximum financial assistance towards those most in need;
- Escort/carers eligibility and benefits – aiming to reduce financial barriers to the participation of an escort/carers in supporting eligible patients;
- Research – building on the evidence base for parameters of patient travel assistance schemes;
- Awareness raising – both at facility level and through collaborative Commonwealth, State and Territory strategies;
- Availability of subsidised accommodation facilities for radiotherapy patients – to be considered in the service development framework for radiation oncology; and
- Community involvement – including enhancing patient navigation of the local care system through greater involvement of the community and non-government sector.¹⁵¹

149 *Committee Hansard* 20.4.05, p.48 (Mr Gregory).

150 *Committee Hansard* 20.4.05, p.48 (Mr Gregory).

151 Radiation Oncology Jurisdictional Implementation Group Final Report, September 2003, p.10.

3.168 The Committee endorses these standards and recommends fixed term reviews for the amount allocated by the Commonwealth to cope with the increasing incidence of cancer in the Australian population.

Recommendation 20

3.169 The Committee recommends States and Territories adopt and implement the consistent approach to the benefits for travel and accommodation recommended by the Radiation Oncology Jurisdictional Implementation Group to ensure that benefits are standardised across Australia. These benefits should be indexed or reviewed annually for increases in travel and accommodation costs.

Cancer care for Indigenous Australians

One of the greatest challenges facing the Australian health care system is to prevent the occurrence and progression of disease and reduce suffering for Indigenous Australians as effectively as it does for Australian's generally.¹⁵²

3.170 Cancer is a leading cause of death for Indigenous and non-Indigenous Australians but the improved cancer outcomes for non-Indigenous Australians are offset by the situation for Indigenous Australians. Research from the Northern Territory and South Australia show that Aboriginal people and Torres Strait Islanders with cancer are twice as likely to die from the disease as non-Indigenous people with the disease.¹⁵³ Also research has shown that in the NT, cancers affecting Indigenous Australians are largely preventable.¹⁵⁴

3.171 The reasons for poorer cancer outcomes for Indigenous Australians are complex but include less access to prevention programs, later-stage diagnosis, higher rates of deadlier cancers, linguistic and cultural differences and beliefs about cancer contributing to a reduced likelihood of completing a treatment program. Despite the identification of these factors, the reasons why successes in cancer control have not been shared by Indigenous Australians are not fully understood and the lack of a national data set is impeding an increased understanding.¹⁵⁵

152 John Condon, Aboriginal and Torres Strait Islander Primary Health Care Review: Consultant Report No 5, *Cancer, Health Services and Indigenous Australians*, p.1.

153 Lowenthal, R.M, Grogan, P and Kerrins, E.T, Reducing the impact of cancer in Indigenous communities: ways forward, *Medical Journal of Australia* 2005; 182(3): 105-106.

154 Condon, J.R, Barnes, T, Cunningham, and Armstrong, B, Long-term trends in cancer mortality for Indigenous Australians in the Northern Territory, *Medical Journal of Australia* 2004; 180 (10):504-507.

155 Lowenthal, R.M, Grogan, P.B, Kerrins, E.T, Reducing the impact of cancer in Indigenous communities: ways forward, *Medical Journal of Australia* 2005; 182 (3): 105-106.

Problems with data quality

3.172 There are considerable limitations to our understanding of cancer in Indigenous Australians as information on cancer is not as comprehensive for Indigenous as for non-Indigenous Australians. A number of reports and publications call attention to the fact that no national information is available for Indigenous people on cancer mortality, incidence, survival and services such as screening programs.¹⁵⁶

3.173 As noted in *The National Cancer Prevention Policy 2004-06* produced by the Cancer Council of Australia 'only two States and one Territory collect reasonable data which indicates that Aboriginal and Torres Strait Islander cancer deaths are much higher than the general population'.¹⁵⁷

3.174 Information gathering is improving but this lack of data and data limitations are barriers to the development and implementation of more targeted health policies and service delivery. *Australia's Health 2004* suggests data collection and better identification of Indigenous Australians in surveys and administrative records is necessary to provide better quality information about their health and to assess improvement.¹⁵⁸

3.175 It is important to note that much of what is reported may represent under-estimates of numbers of Aboriginal and Torres Strait Islander peoples as identification of persons of Aboriginal and Torres Strait Islander origin is incomplete.¹⁵⁹

3.176 A recent paper in the *Medical Journal of Australia* reported that between 1991 and 2000 in the NT, Indigenous people with cancer of the colon and rectum, breast, cervix and non-Hodgkins lymphoma were more likely to be diagnosed with advanced disease than non-Indigenous people, and this is likely to reduce chances of survival.¹⁶⁰ It appears likely that the more advanced disease at diagnosis in Indigenous people is due to low awareness of potentially dangerous early symptoms, lateness in seeking medical advice and poor access to or low quality of primary care, diagnostic or specialist services.¹⁶¹ Further research is required to investigate the reasons for later

156 Condon, J.R, Armstrong, B.K, Barnes, A and Cunningham, J, Cancer In Indigenous Australians: a review, *Cancer Causes and Control* 14; 109-121, 2003.

157 *The National Cancer Prevention Policy 2004-06*, The Cancer Council Australia May 2004, p.7.

158 *Australia's Health 2004*, p.336.

159 Condon, J.R, Armstrong, B.K, Barnes, A and Cunningham, J, Cancer in Indigenous Australian's: a review, *Cancer Causes and Control* 2003, 14; 109-121, p.111.

160 Condon, J.R, Barnes, T, Armstrong, B.K, Selva-Nayagam, S and Elwood, J.M, Stage at diagnosis and cancer survival for Indigenous Australians in the Northern Territory, *Medical Journal of Australia* 2005; 182 (6): 277-280.

161 *Submission 61*, supplementary information, p.1 (NRHA).

diagnosis and Dr Condon suggests this research should focus on the primary care services and Indigenous people themselves.¹⁶²

3.177 A review of the Commonwealth's Aboriginal and Torres Strait Islander primary health care program was completed in 2003-04. One of the consultancy reports was *Cancer, Health Services and Indigenous Australians*. This paper looked at the performance of the Australian health system in relation to cancer control for Indigenous Australians in the Northern Territory as one way of providing insight into the relationship between health care and a range of issues including survival rates for Aboriginal and Torres Strait Islander Australians. Key findings of the report included:

- An examination of cancer data which shows that the health system is not operating as effectively for Indigenous as for other Australians;
- While different patterns of incidence of cancer for Indigenous compared to non-Indigenous Australians can be partially explained by different cancer risk factors, Indigenous survival is lower for almost all sites which is partially due to delayed diagnosis and lower chance of cure;
- Primary health care has a key role in significantly improving survival for non-Indigenous Australians; and
- Similar improvements are possible for Indigenous Australians if primary health care programs are strengthened and access improved to primary and specialist services.¹⁶³

3.178 Like rural cancer patients, distance is often a factor in accessing services for Indigenous Australians in remote or rural areas. The Australian Bureau of Statistics reports that 25 per cent of Indigenous Australians were living in remote or very remote areas compared to only two percent of non-Indigenous Australians.¹⁶⁴

3.179 As with rural Australians, specialist outreach services were suggested to improve cancer services for Indigenous Australians. Research suggests that specialist outreach services which interact with primary health care providers, such as Aboriginal health care workers, can improve access to specialist care for Indigenous people in remote areas and can reduce communication and cultural barriers.¹⁶⁵ Further research on the model has shown that specialist outreach can provide a more equitable means of service delivery than hospital based services alone. The outreach model

162 Condon, J.R Cancer and Indigenous Australians in the Northern Territory, Doctoral thesis, Charles Darwin University, 2004.

163 *Submission 87*, pp.24-25 (DoHA).

164 Australian Bureau of Statistics 4704.0 *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples*, 2003.

165 Gruen, R.L, Bailie, R.S, d'Abbs, P.H, O'Rourke, I.C, O'Brien, M. M and Verma N, Improving access to specialist care for remote Aboriginal communities: evaluation of a specialist outreach service, *Medical Journal of Australia* 2001; 174 (10): 507-511.

should be responsive to local community needs, have an adequate specialist base and be able to integrate with and have capacity to build a multidisciplinary framework.¹⁶⁶

3.180 In August 2004, a forum on 'Reducing the impact of cancer on Aboriginal and Torres Strait Islander Communities: Ways Forward' was held in Darwin. A report of the forum was recently published in the *Medical Journal of Australia*. It highlighted that the challenges in healthcare delivery for rural and remote Australia are compounded by the cultural, linguistic and socioeconomic barriers unique to Indigenous communities.¹⁶⁷

3.181 The Cancer Council Australia is developing a national advocacy strategy aimed at reducing the disparities in cancer outcome between Indigenous and Non-Indigenous Australians. The strategy will be based on the recommendations made at the discussion forum in Darwin.

3.182 As with rural Australians, witnesses suggested that national health education programs are not suitable for most of the Aboriginal population and the development of targeted programs is required.¹⁶⁸ The need to tailor information and programs to reduce risk in communities and individuals with special needs such as Indigenous Australians has been recognised in the National Service Improvement Framework.

3.183 Dr Condon provided an example of two successful models which have been largely responsible for improved outcomes in the area of cervical cancer. Between 1991 and 2001 the incidence of cervical cancer decreased by 25 per cent and mortality decreased by over 50 per cent over a similar period. The two programs which have played a major role in this result are firstly the NT Well Women's Screening Program which is suggested as a service delivery model that overcame many barriers which have been identified such as lack of knowledge about cervical cancer and awareness of pap test screening and communication difficulties between mainstream health services and Indigenous women. The second program is the Gynaecology Outreach Service which has improved access to specialist services for women with pap test abnormalities. Dr Condon suggests these results can be achieved for other cancers with such innovative and targeted programs.¹⁶⁹

Recommendation 21

3.184 The Committee recommends Cancer Australia, in consultation with Aboriginal and Torres Strait Islander people and the States and Territories,

166 Gruen, R.L, Weeramanthri, T.S, and Bailie, R.S, *Journal of Epidemiology and Community Health* 2002; 56: 517-521.

167 Lowenthal, R.M, Grogan, P.B, Kerrins, E.t, Reducing the impact of cancer in Indigenous communities: ways forward, *Medical Journal of Australia*, 2005;182 (3):105-106.

168 *Submission* 65, p.29 (COSA,CCA, NCCI and NACCHO).

169 *Submission* 43, p.2 (Dr Condon).

auspice work to improve access to cancer screening, diagnosis and treatment for Aboriginal and Torres Strait Islander people that is culturally appropriate.

Conclusion

3.185 The fragmentation of cancer services and the need for a more integrated and networked approach to cancer services was identified as a major problem by a number of witnesses and jurisdictions. The Committee noted the many national and State cancer initiatives from the submissions provided and that the *National Service Improvement Framework for Cancer*, a joint Commonwealth and State and Territory government initiative, has been developed. The Framework provides clarity about what the evidence suggests about timely and effective care across the continuum, including where health services require multidisciplinary care and coordination. The Committee was informed that three jurisdictions, New South Wales, Victoria and Western Australia, are developing initiatives designed to improve both the integration and coordination of their cancer services.

3.186 The Committee accepts multidisciplinary care as best practice and sees benefit in defining standards. However, the Committee notes that given the mix of private and public services and significant regional variations in delivery and access to services, a flexible principle-based approach to MDC is required to tailor care according to local services, stage of the disease and wishes of the patient.

3.187 The Committee accepts that promotion of the benefits of MDC is needed at a national level through the *National Service Improvement Framework for Cancer* and notes that adequate resourcing at the State/Territory level will be required to ensure the ongoing sustainability of MDC. The Committee recognises that current funding models do not adequately support the use of multidisciplinary care, particularly in the private system, and a review of this area of the MBS is necessary to ensure the further development of multidisciplinary care in Australia.

3.188 The Committee recognises the work undertaken by the National Breast Cancer Centre, acknowledges the successes achieved in the area of breast cancer treatment and care and recommends breast cancer care as a model for the development of services and support for patients with other cancers.

3.189 To provide more information to patients at the time of diagnosis and referral the Committee acknowledged the success of the NSW Breast Cancer Services Directory and the Committee recommends that Cancer Australia coordinate the development of such a directory in each State and Territory.

3.190 The Committee commends and encourages the work underway in many areas to develop tumour streams which will include referral pathways. This will particularly assist rural cancer patients to obtain appropriate and timely care. To drive this work, the Committee recommends Cancer Australia commission the States and Territories to develop appropriate referral pathways for the management of all cancers.

3.191 The Committee commends the development of the discussion paper regarding the accreditation of cancer services and acknowledges the need to move quickly towards the accreditation of cancer services and credentialing of practitioners to increase the amount of information available for the GP and patient at all stages, but particularly at the diagnosis and referral stage. The Committee recommends Cancer Australia facilitate the development and introduction of accreditation and credentialing systems. The Committee would encourage individual health practitioners and hospitals to utilise available clinical practice guidelines approved by NHMRC and suggests that use of the guidelines be included as a criterion for accreditation.

3.192 Care coordinators are of vial importance to assist cancer patients navigate their way through the system and help them find high quality, evidence based information to make informed decisions regarding their treatment. Although there are differing opinions on who is best placed to take on this role, the Breast Cancer Nurse is a successful model which could be adapted to suit individual circumstances and different clinical settings.

3.193 The Committee recognises that a diagnosis of cancer can bring with it not only physical but emotional and practical challenges as well. The need for psychosocial care is well documented and the Committee commends the implementation and dissemination strategy for the *Clinical practice guidelines for the psychosocial care of adults with cancer*. The education of medical students at the undergraduate and postgraduate levels about psychosocial support and better communication with patients is also supported by the Committee.

3.194 A further challenge identified during the course of the Inquiry was cancer workforce shortages in almost all categories, especially in rural and remote areas. Of particular concern were shortages in nursing, general practice, radiotherapy (ie. radiation therapists and medical therapists), and psychosocial support. Jurisdictions acknowledged that workforce shortages are being experienced internationally as well as nationally. The Committee acknowledged that cancer workforce issues are being addressed by the Commonwealth and State and Territory Governments in a collaborative manner through the Australian Medical Workforce Advisory Committee, the Australian Health Workforce Advisory Committee and the Radiation Oncology Reform Implementation Group. The Committee recognises the shortages in the health care workforce and encourages investment in the cancer workforce, strategic workforce development and upskilling of staff to ensure the further development and usage of the multidisciplinary care model.

3.195 The Committee is encouraged by the development of regional cancer centres and supports the development of outreach services and tele/videoconferencing to address access issues for the regional cancer patient and to support the development of a multidisciplinary approach. The Committee also supports training and education of rural health professionals so that more cancer services can be provided closer to home, thereby reducing the burden of patient travel. The Committee was very concerned to hear from many witnesses about the inequalities of the State travel and

accommodation assistance schemes and recommends the standardisation of the schemes to ensure consistency of entitlements.

3.196 The Committee recognises cancer in Indigenous people as a health priority and wishes to involve Indigenous groups in developing a national response. The Committee saw the development of culturally appropriate care as a priority, and recommended that Cancer Australia, in consultation with Indigenous people and the States and Territories, work to improve access to cancer screening, diagnosis and treatment.

Justus – An indigenous story

Justus had been sick for some weeks and his grandmother who was often his primary carer, had taken him to the Princess Margaret Hospital a number of times. In each instance though, they had been sent home with no diagnosis save inferences raised by medical staff that Justus may have had some emotional problems due to his home situation. My mother finally tracked down an old family doctor who demanded the hospital undertake a CT scan upon Justus who was by now very sick, and that did then reveal his tumour. Unfortunately, as Justus was not a private patient and as the PMH did not have an MRI scan it was a number of days before the hospital could tell us more about the tumour and whether an operation might be possible. The emergency doctor indicated to Justus's mother, and myself who was also present, that it was unlikely he could be treated and therefore he would die. The PMH surgeon met Justus mother at the hospital on Saturday and told us there would be no operation... A number of days had passed between the emergency room diagnosis and the surgeon's opinion. Not once in that time had we been offered any counselling despite the overwhelming tragic news we had been given...

Even after Justus was admitted to the cancer ward, it was really only his mother who was offered counselling and information about cancer services. This was despite the fact that his grandmother had also been a primary carer, and I had been, in the Aboriginal sense, his second mother. My family felt that the hospital did not understand the extended Aboriginal family, in which family members other than parents often had close relationships...

The Charles Gairdner Hospital offered alternative treatment, and once Justus (and myself) had a reiki treatment. Although Justus's steroid treatment had made him ravenous most times, I noticed after the reiki a calmness had descended on him and he walked straight past the candy bars on the way out. I really think it is children who should have first preference for alternative treatment, and PMH should talk to the Browne's treatment centre at SCGH so that children can take advantage of the treatments at the hospital. In the days that Justus was passing, it would have been good to have had alternative treatments to help him, but as it was we couldn't even seem to get toys or paints from the cancer OT.

I know that his own doctors at the hospital and the nurses, were very kind and did the best they could. I also understand a psychologist may have been appointed after Justus passed. Not long before Justus passed a baby owl flew into the hospital and was kept a few days until better. Justus had passed the morning he was to be released and all his family were there to see the baby owl fly off. We would have liked to have said something in his name, however, there was no opportunity given.

I have wondered since if Aboriginal families are just not reached out to the same way as white families, perhaps people think we deal with cancer in our own way. It's not true, we need support and help like everyone else.

Submission 95 (Ms Hannah McGlade).