



**“ACCOMMODATING CHANGE”
A REVIEW OF ACCOMMODATION FOR PEOPLE WITH CANCER
IN NEW SOUTH WALES**

PROJECT REPORT

AUGUST 2009

Project Steering Group



Investigation undertaken by

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Abbreviations Definitions and Acronyms

ABS	Australian Bureau of Statistics
AHS	Area Health Service
AKCC	Auckland Cancer Council
BCNA	Breast Cancer Network Australia
COTA	Council on the Ageing
CNC	Cancer Nurse Coordinator
DOCS	Department of Community Services
Health related	Used to describe activities and costs incurred as part of diagnosis/treatment,/follow up of a patient/carer for example travel for appointments and radio therapy or purchase of wheelchairs or other equipment.
Hospital-Allied	Accommodation used primarily by patients and carers at a nearby hospital
IPTAAS	Isolated Patients Travel and Accommodations Scheme
NGO	Non Governmental Organisation
OSW	Oncology Social Worker
PATS	Patient Assisted Travel Schemes
RPAH	Royal Prince Alfred Hospital
SWOG	Social Work Oncology Group
UICC	International Union against Cancer
VET	(Department of) Veterans Affairs
WWS	WestWood Spice

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The design of the Review was heavily influenced and improved by the comments of an initial Inception Group, and its findings tested, challenged and enhanced by participants in a Pre-Release Workshop. We would like to thank all those who took part for their insight, enthusiasm and participation in the project.

Executive Summary

Cancer Council commissioned this review to investigate issues related to accommodation services in NSW for people with cancer, their families and carers. Can Assist and the Cancer Institute NSW participated in the steering group.

Cancer is the leading cause of death in Australia and the incidence and prevalence of cancer is predicted to increase over coming years with the ageing of the population. There is a higher incidence of some cancers in people living in rural and remote areas of Australia and the Australian Institute of Health and Welfare has found that survival reduces with increasing geographical remoteness. Survival is also lower for those living in low socioeconomic areas compared with the areas having high socioeconomic status.

One of the most commonly identified problems for people with cancer living in rural and remote areas is limited access to services which detect, then treat and support cancer. Access to affordable transport and accommodation services is necessary. Daily radiotherapy treatments, for example, can require many weeks of living away from family, friends and usual support networks for cancer patients living in rural areas. The additional financial, psychological and social problems faced by rural and remote people due to having to travel and seek accommodation to access treatment are considerable. In some cases, people choose surgery rather than radiation therapy or refuse treatments to avoid separation from their homes and communities.

This review outlines the impacts of staying away from home primarily from patients and carers perspectives. It considers the process of arranging accommodation which varies enormously from patient to patient and can be very labour intensive for the staff involved. The project undertook a survey of Oncology Social Workers and others involved in arranging accommodation. This indicated that the most significant factors in determining a patient's need for assistance with accommodation were financial circumstances/stress; patient mobility; the availability of a family member/carer to also travel and the need for specialized support/care.

The review also describes the accommodation currently available and where it is required. There are currently too few beds in hospital - allied accommodation in Sydney, and some of the options available to patients are viewed as substandard and unsafe. Others will become unsuitable in the future as an aging population increases both the number of patients with cancer and the complexity of their needs including mobility and co-morbidity problems. Alternatives to remaining in hospital need to be created for these and other patients to reduce the unnecessary occupancy of acute hospital beds by patients requiring low intensity therapy and support. Affordable accommodation for carers and family members is also important to patient well-being and support.

In other existing cancer treatment centres, new accommodation is required for example in Newcastle and in conjunction with the development of new units in Lismore, and Orange in the shorter term.

Patient and carer interviews and focus groups consistently highlighted a number of features that combine to make “ideal” accommodation. These areas were supported by health professionals’ input. The features are proximity to treatment, transport to treatment, affordability, physical accessibility and facilities (clean, able to be self catering), peer support. There was also a strong indication that on-site management is important.

As more radiotherapy treatment facilities are established by the NSW and Australian Governments in other parts of the state, additional accommodation will also be required and needs to be planned alongside hospital development. Predicting the exact future needs in terms of numbers of beds required in new accommodation facilities is difficult due to a range of factors. Collaborative approaches to developing accommodation for a broader range of patients and carers than only cancer may be a more appropriate and sustainable solution in regional areas.

A constant issue which emerged in this review both for patients in rural and remote areas as well as outer metropolitan areas is the need for better access to affordable transport. Improving access to and utilization of treatment and support for Aboriginal patients with cancer is an important priority.

Achieving equal access to treatment is an important goal of both federal and state health strategy, and this cannot be realized without addressing the challenges of transport and accommodation in NSW.

1.0. Recommendations

A. Collaborative approach to accommodation planning statewide

1. Establish an accommodation task force

- Recognise the need for accommodation and transport support as integral to achieving the goal of equity of access to treatment
- Establish a multi-sectoral taskforce to clarify roles and responsibilities in relation to accommodation provision, identify and agree priority issues to be addressed
- Find ways to implement the recommendations of the September 2007 report to the Senate Committee Affairs Committee “Highway to health: better access for rural, regional and remote patients”
- Ensure broad representation to include a wide range of stakeholders including NSW Health, Cancer Council, Area Health Services, other NGO’s, Divisions of General Practice, private sector, ageing and disability sectors (COTA, Pensioners and Superannuants Association), VET affairs accommodation providers
- Identify the most pressing areas of need and requirements for accommodation facilities, consider the local available options, resources, potential partners, opportunities for collaboration. Aim to ensure that there is adequate affordable accommodation available for every cancer treatment centre.
- Develop a detailed model of the factors impacting on treatment location and take up of accommodation such as patient flows across Area Health Services and Interstate.

2. Develop a range of agreed models for accommodation provision

- Develop a range of models of accommodation facilities for different settings to meet varied needs for care and support, different levels of independence and mobility and differing family requirements. Review models operating elsewhere such as the medihotel and assess suitability for NSW.
- Incorporate issues identified in this project:
 - proximity
 - affordability
 - access
 - psychosocial support
 - standard of facilities

- Develop potential business models to support the viability of facilities including a mix of commercial and public options
- Develop criteria for assessment of quality of accommodation services provided.
- Explore links to clinical services redesign
- Explore integration with treatment centre protocols

3. Ensure accommodation facilities linked with new treatment centres

- Work collaboratively with government and relevant partners in areas where new radiation treatment centres are being established to develop high quality accommodation services based on the findings of the review
- Maintain dialogue with NSW Health Statewide Services Directorate
- Advocate for new services in Orange / Lismore/ Newcastle to incorporate accommodation facilities
- Develop strategies to offer accommodation that is culturally safe and appropriate for Aboriginal patients and families.

4. Advocate for consideration of needs of rural patients in treatment process

- Highlight experiences of travelling patients to relevant staff and impacts of short notice changes/ cancellations
- Minimise delays due to predicable issues such as routine maintenance by (for example) weekend servicing.

B. Co-ordination of accommodation information and arrangements

5. Establish a central information point/service

- Develop a central one-stop shop for easy access to information about accommodation access, types, location and availability. This is to provide a single contact point for health professionals, patients and carers or other community members to access information when it is needed
- Link contact points with the current accommodation service directory and other related cancer support directories
- Establish a telephone help/assistance line which assesses the accommodation needs from callers, provides advise on choices in

specific locations, availability and refers or assists with arranging bookings

- Consider booking options using an internet based tool
- Provide both web-based and free telephone 1800 number contact points
- Provide more information available in multiple languages, video, digital (can be linked to existing web sources)
- Explore the potential for this service to be an expansion of the Cancer Council Help Line
- Develop services and resources information kits for patients and families in accommodation precincts.

6. Develop a dissemination and publicity strategy to promote the central information service

- Ensure wide dissemination of the accommodation contact point details through all related health professionals, cancer networks, community facilities for example libraries, pharmacies
- Explore options to integrate information about the accommodation information service in critical intervention points in the patient journey from testing, diagnosis, treatment, care and support processes. Potential to link with prompts in medical software, treatment/assessment checklists.

7. Foster collaboration between accommodation providers

- Create a network of providers to share information, best practice and collaborate in areas of mutual interest and benefit to patients
- Develop a comprehensive distribution strategy for the updated accommodation directory including publication on Cancer Council website
- Link directory to other available cancer and related service directories
- Ensure that the directory is updated regularly by providers.

8. Improve and streamline local processes for determining needs and arranging accommodation

- Work with the Cancer Institute NSW and other relevant organizations to explore options for improving local processes for assessing accommodation needs earlier

- Review coordination processes at cancer treatment centres to screen patients and assess support needs earlier
- Explore options for Cancer Council and other support NGOs to assist local support arrangements to reduce burden on social and welfare workers
- Monitor opportunities to reduce accommodation needs through changed treatment regimens – for example treating seven days per week and shortening overall length of stay, increasing through-put of machines, new treatment advances, for example, hyper-fractionation.

9. Facilitate IPTAAS processes

- Provide user friendly information and advice from the central information service regarding IPTAAS entitlements and required processes
- Undertake awareness raising/information sessions about IPTAAS to dispel myths.
- Gather data about unmet need for IPTAAS subsidy

C. Address issues of additional financial burden

10. Improve access to IPTAAS financial subsidies for accommodation and transport

- Consider a range of options and solutions for improving access to IPTASS entitlements, including consideration of approaches in other states and territories and the approaches recommended by the Senate Inquiry
- Consult with NSW Health IPTAAS officers to explore options for simplifying processes for access and reimbursements and ensure officers operate consistently
- Liaise with NSW Health to consider options and processes for improving flexibility for disadvantaged patients in the less than 100 kms range and those for whom the cumulative cost of regular travel is significant
- Consider the adequacy of IPTAAS reimbursement and options to ensure that its value is maintained such as index linking; relationship to ATO travel rates; ensure regular reviews.

11. Reduce financial risks to patients such as loss of home or employment

- Undertake advocacy to ensure that banks are aware of the financial burden of cancer and flexibility is encouraged eg in relation to mortgage repayments.
- Encourage best practice in employment so that cancer patients are able to maintain or return to work.

D. Improve transport access

12. Establish collaborative patient transport group

- Establish a collaborative patient transport group, building on the No Transport, No Treatment work to consider broader transport issues for patients and families
- Scope the needs and consider a range of options for improving patient access to transport more broadly than community transport options
- Advocate for solutions to ensure funding supports for patients and their carers which are indexed to keep pace with rising costs of travel
- Work with regional Cancer Council offices and Area Health Services to improve regional transport services/arrangements from outlying communities by tailoring and aligning transport times with treatment centre times. Incorporate issues for all diseases – eg renal patients
- Explore options for establishment of transit lounges in hospital lobbies
- Evaluate “Transport for Health Units” initiatives.

E. Support for rural patients and families

13. Establish hospital based supports for rural patients

- Investigate options for establishment in large metropolitan hospitals of rural liaison officers to support and orientate rural patients and families
- Explore potential for volunteer role in metropolitan hospitals to provide a link and information and support service for rural patients and families. Includes support for carers/families.

F. Address Aboriginal community access to treatment

14. Establish a statewide multi-sector working group

- Review existing groups and initiatives with a similar focus for potential synergy and identify opportunities to expand scope to encompass accommodation and transport issues
- Ensure a holistic and multidimensional approach to take account of issues such as child care which impact on travelling for treatment
- Investigate issues for Aboriginal community members with reference to addressing late diagnosis, lack of access to services, decisions not to treat for cancer; drawing on initiatives in other jurisdictions
- Further investigate cancer treatment and related accommodation and transport issues for Aboriginal people including options for provision of escorts for travel to larger centres
- Investigate possible learning from accommodation work in the Maori community in New Zealand and with Indigenous groups in Canada.

2.0. Introduction

The Cancer Council in collaboration with Can Assist commissioned this review to investigate issues related to accommodation services in NSW for people with cancer, their families and carers. Accommodation has been one of the most significant practical problems raised by people affected by cancer and health professionals and can be critical in relation to quality of life and treatment access issues. Daily radiotherapy treatments, for example, can require many weeks of living away from family, friends and usual support networks for cancer patients living in rural areas.

Two documents have been produced. This report presents a major review of accommodation for people affected by cancer in NSW to address fundamental questions of the nature and adequacy of current accommodation provision, consider future requirements for accommodation in NSW, and options for its delivery.

The review explores how accommodation can be integrated with cancer services in the future, and defines what types of service are required and where they should be located, linked to areas of radiotherapy treatment services. The review also develops an understanding of how issues to do with accommodation may influence the patient's journey with cancer.

The second document presents information on accommodation currently available to people who have to travel for treatment. It identifies 40 facilities closely allied to hospitals exclusively catering for patients and/or their families or carers. These are described as "hospital-allied" facilities. It also identifies 29 accommodation facilities regularly used by patients, some of these have formal agreements with hospitals, however their primary purpose is not health or patient related. These might be commercial facilities, bed and breakfasts or motels for example.

The investigation was undertaken by Team members from the Cancer Information and Support Services Division of Cancer Council working with consultants from WestWood Spice over the period June 2007 to June 2008.

2.1. Project description and scope

The Review of Accommodation for People with Cancer in NSW was a program of work with four main intentions. It investigated the questions:

1. What is the scope and adequacy of current accommodation provision?
2. How does accommodation and associated support impact on the patient cancer journey?

3. How is accommodation currently funded and what are the options for creating models of accommodation that are financially sustainable?
4. What are the requirements for accommodation in NSW and ACT over the next 10 years?

The project reports to the Cancer Information and Support Advisory Committee; a joint committee of the Cancer Council and the Cancer Institute NSW.

This review has been a collaborative effort by WestWood Spice and Cancer Council with its project partner Can Assist. WestWood Spice and Cancer Council took responsibility for agreed aspects of the project which are combined into the final report. Can Assist contributed to the project through participation in the steering committee.

2.2. *Methods*

The broad nature of the investigation lent itself to an approach using multiple methods of inquiry, with an emphasis on seeking a wide range of qualitative and where appropriate quantitative data from the key stakeholders groups. Sampling approaches were tailored to the different groups. A summary of the interviewees is at Appendix 1. The intent and scope of this review precluded undertaking an exhaustive research study of the multiple factors related to accommodation issues. The project methodology was approved by the Ethics Committee of Cancer Council, subject to the requirements that all patients and carers self-nominate to participate and their comments be de-identified in all reporting. The survey and interview instruments are at Appendix 2.

Data for the review was sourced from a) document and literature searches, and b) key stakeholders from the following groups of key informants:

- Accommodation providers and managers across NSW
- A cross section of health and allied professionals in rural and metropolitan patients
- Carers and family members
- Workers with perspectives on issues for Aboriginal community members.

An inception group with a mixture of stakeholders including clinician, accommodation provider, cancer patients representatives, OSW provided guidance at the start of the project and a pre-lease workshop of about 30 people from across NSW commented on the report and its findings and in its final stage.

The main methods used are listed following:

Document, literature and Internet searches

- A literature review of research into the impacts of needing to travel for cancer treatment
- An analysis of data in Cancer Council records to compare patient home postcode to place of treatment, and review of data provided by the Helpline on calls relating to transport and accommodation in the past year
- An Internet investigation of the approaches taken to accommodation for cancer patients in other states and countries.

Stakeholder input

1. Accommodation providers

- A survey of NSW and ACT accommodation providers. Forty hospital-allied facilities were identified and contacted. A further 29 non-hospital-allied facilities were identified and listed.
- Site visits to accommodation providers and interviews with facility managers in NSW, South Australia, Tasmania and New Zealand.

2. Health professionals

- Interviews with 35 health professionals including surgeons, radiation oncologists, Area Health Service cancer care coordinators, social workers, clinical unit managers, palliative care nurses and senior planners.
- An online survey of oncology social workers and cancer care nurses, (metropolitan and rural). The survey was informed by issues identified at initial meetings with members of the Social Workers Oncology Group (SWOG) and tested at a dedicated meeting of the SWOG and their comments on draft surveys.
- Sixty-eight responses were received from across NSW, with input also from hospitals treating patients from NSW in the ACT and Queensland.
- The project was presented at the Cancer Institute Psycho-oncology and Cancer Nurse Coordinator Forum, with over 35 participants in the session.

3. Patients and carers

- Interviews and focus groups with patients and carers; 41 people were interviewed who had been treated for cancer in the past or who were currently undergoing cancer treatment. 26 family members or carers were interviewed.
- Patients volunteered to be part of the review. An invitation to meet with WestWood Spice consultants was circulated in accommodation lodges, and also via cancer support groups and community networks in rural areas.
- Patients and carer volunteers currently staying in accommodation facilities in Sydney, Wagga Wagga and Coffs Harbour participated in focus groups and interviews at those facilities.
- Interviews were also conducted at Lismore and Dubbo which do not currently have hospital-allied accommodation facilities for cancer patients but where this is an identified need.
- A “snowball” technique was used to source patient and family interviewees from rural NSW with an initial invitation to participate via cancer support fora and regional networks. Interviewees also suggested others in their local networks who might be willing to participate.
- Participants included men and women whose experiences related to travelling for treatment for different types of cancer, including breast, prostate, head and neck, bowel. Two carers had travelled because their child was ill; all other interviews related to cancer in adults.
- Focus group participants were all users or former users of hospital-allied accommodation. They were all treated in NSW hospitals; some had travelled from Queensland for treatment.

2.3. *Structure of the report*

Chapter 3 provides background to the project with an overview of cancer in Australia and the factors which create the need for suitable accommodation and transport to treatment.

Chapter 4 discusses who uses hospital-allied accommodation or needs to use it and the processes for arranging health-related accommodation. It suggests improvements based on the input of patients and families as well as Oncology Social Workers and others.

Chapter 5 reports on the experiences of patients and carers who have had to travel to access treatment and the impact this has on the cancer journey.

Chapter 6 reports on existing arrangements for provision of accommodation facilities, how they are funded, where they are located and the extent to which they meet the needs of patients/gaps in provision. The chapter summarises the comprehensive report with detail on each facility. The chapter also discusses the needs of Aboriginal patients.

Chapter 7 outlines the views of patients and carers on the features of an effective facility – their “ideal” accommodation solutions.

Chapter 8 overviews the options available to cancer patients in other states and countries and considers how accommodation services are funded.

Chapter 9 considers the factors related to determining the future requirements for accommodation in NSW including planned changes to radiotherapy provision. The chapter considers the location of possible new facilities and the features of an “ideal” accommodation support service/system.

Quotes from focus group participants, interviewees and survey responses are in shaded boxes and are included where relevant to the topic. Some sections do not include quotes. Where the comment was made in one of the focus groups (Sydney or Wagga Wagga) it will be attributed to a “Focus Group Participant”; when a comment was made in a face to face or telephone interview, it will be attributed to an “Interviewee” with a distinction made between patient and carer views. Comments made by OSW or other professionals show their role. No locations are supplied to ensure anonymity.

3.0. Background

3.1. *Background to the project*

Cancer is the leading cause of premature death in Australia, killing more Australians than anything else. It is a major contributor to the burden of disease and accounts for significant costs in relation to morbidity and mortality. Australia's population is ageing, and cancer incidence rates are highest in older people. Large increases in the total number of new cases of cancer are predicted, for women an increase of 29% from 40,578 in 2001 to 52,356 in 2011; for men an increase of 32% is predicted (rising from 47,820 in 2001 to 63,087 in 2011)¹.

New South Wales is the most populous state in Australia, with 63% of the population living in Sydney. Cancer registry data indicates that in 2005, 34,227 people were diagnosed with cancer across NSW². The most common cancers were prostate, bowel, breast, melanoma and lung, accounting for 61% of new cases. Men are more likely to be diagnosed with cancer than women. New cases were predicted to increase to 37,550 in 2007³.

Some cancers are more common in remote areas⁴ and while overall survival rates for most cancers are increasing, survival rates are lower for people in rural and remote areas with low socioeconomic profile^{5,6}. Compared with NSW as a whole, age-standardised incidence rates for all cancers were higher in the North Coast Area Health Service (AHS), males in South Eastern Sydney and Illawarra and females in Northern Sydney and Central Coast AHS⁷. Sydney South West has higher age-standardised mortality rates from liver and lung cancers in males; Sydney West from Mesothelioma in males; Hunter New England all cancers and prostate cancer and Greater Western from unknown primary cancer. Survival rates increase with socioeconomic advantage, areas classified by the Australian Bureau of Statistics (ABS) as having high socioeconomic status (defined by factors such as good access to health care and above average education and income) are predominantly located in cities. The difference in survival rates is most marked in males, the

¹ AIHW. *Cancer Incidence Projections Australia 2002-2011* August 2005

² This number excludes non-melanoma skin cancers which are not notified to the registry. Tracey et al op cit

³ Tracey et al op cit

⁴ Tracey E, Baker D, Chen W, Stavrou E, Bishop J. *Cancer in New South Wales: Incidence, Mortality and Prevalence Report 2005* Cancer Institute NSW, November 2007

⁵ AIHW & Australasian Association of Cancer Registries. *Cancer in Australia 2006*. Australian Government June 2007

⁶ AIHW, Cancer Australia, Australasian Association of Cancer Registries. *Cancer survival and prevalence in Australia*. 22 August 2008

⁷ Tracey et al op cit

all-cancer 5 year relative survival was 54% in the lowest socio-economic status quintile compared with 65% in the highest⁸.

The incidence of different types of cancers is changing over time and new treatment modalities are being developed progressively with improved survival rates for some cancers. Australia has a strong record in cancer treatment and age adjusted mortality rates have declined over recent decades.

Cancer treatment services

Cancer is a complex disease requiring a diverse range of specialist and generalist treatment services⁹. Timely access to the best available treatment and support is vital to enhancing survival outcomes for people with cancer. Cancer treatment is provided from a mixture of public and private facilities and national and state governments share various aspects of responsibility for service provision. Treatment centres are located predominantly in metropolitan areas, and some services (predominantly surgery and chemotherapy) can be accessed in larger regional centres. More complex diagnostic procedures are conducted in larger centres and specialised treatment for less common cancers or complex cases is provided in large metropolitan tertiary hospitals. Specialist services are provided in regional areas through attracting specialist staff to local regional areas or by outreach to rural Area Health Services from larger treatment centres. The arrangements for this outreach have developed historically on an ad hoc and largely individualised basis. However there are currently processes in place to more coherently align these within Area Health Services.

Radiation therapy is a vital part of cancer treatment for many cancers. Based on current evidence external beam radiotherapy is indicated as best practice in 52% of cancer patients¹⁰. This is typically delivered on an outpatient basis over an extended period of 6 or more weeks. However Australian studies show that a considerable proportion of patients with cancer are not accessing radiation therapy and are thus receiving sub-optimal care with compromised survival outcomes¹¹.

Radiotherapy has been historically under-resourced in Australia and until recent years there has been very limited availability of radiation treatment outside major metropolitan centres. Radiation oncology units are costly in

⁸ AIHW 2008op cit

⁹ Barton B, Peters L, Kenny L. Radiotherapy in Australia one year after the Baume report: vision or mirage? *Med J Aust*: 2004; 180(20:55-56)

¹⁰ Delaney G, Jacob S Featherstone C, Barton M. The Role of Radiotherapy in Cancer Treatment. *American Cancer Society* August 2005

¹¹ Barton et al op cit

capital outlay and in maintenance and there can be challenges in optimising their operational reach due to the difficulties in attracting qualified staff¹².

The Australian Government and state governments are currently working to increase the number of radiation therapy units in non-metropolitan areas. Private Radiation Oncology Treatment centres have been established in a number of centres with new services approved for NorWest Sydney and Macquarie University Hospital commissioned for 2009¹³. NSW Health has in conjunction with the Cancer Institute NSW been undertaking an intensive planning process to identify where the most appropriate locations are to site new radiotherapy treatment services in order to increase future access of people to treatment. This involves analysis of demographic and epidemiological data and projections and consideration of complex local and state logistical and fiscal factors.

Location of access to treatment

Treatment location is based on a number of factors. For some cancer types there are only a small number of hospitals offering specialist treatments. For others, patients are generally directed to the closest centre offering the treatment they require with the most suitable available timeframe. However, in some cases patients choose to be treated elsewhere because they have access to accommodation or support (either a recommended accommodation facility or close to family or friends). Alternatively they may be directed to a specific treatment centre because of the established professional links or preferences of their general practitioner or medical specialist.

In some cases, patients interviewed during this investigation preferred to travel for treatment rather than be treated locally when non-metropolitan radiation units have waiting lists, or because there is a perception that metropolitan centres will provide a higher quality of treatment in more complex cases.

I have a colleague that comes from ACT to Westmead for radiotherapy and has no accommodation, who do we speak to? Nobody seems to be able to help him.

Query to Cancer Council Helpline

Psychosocial support needs

Many factors impact on the cancer journey of any individual with cancer and the outcomes of the cancer diagnosis can be affected by a range of

¹² Ibid

¹³ Correspondence from NSW Health Statewide Services Branch 25 March 2008

determinants. There is well established evidence that cancer outcomes are improved where there is support for psychosocial needs^{14 15}. It is increasingly recognised that treatment approaches and the nature of service provision and support needs to take account of the whole person, their individual life context and their associated psycho-social needs, as well as support for carers and families¹⁶.

Having a cancer diagnosis is extremely stressful and involves great uncertainty and anxiety for the individual and their family. Impacts may be financial, psychological and social and on key primary relationships. Being able to access appropriate and timely treatment and support is essential for optimising the cancer journey. People living in rural and remote locations usually have to travel to access treatment and be away from home for shorter or longer periods. They face additional psychological and emotional stresses having to be separated from family and their usual social support networks, leaving jobs and businesses and negotiating unfamiliar places^{17 18 19}. Frequently there is uncertainty about how long the person will need to be away from home. Difficulties in accessing appropriate accommodation and transport is well documented as a major stress factor for these patients.

People are very cut off from support, if people have friends and relatives they are lucky. They should have someone there as soon as a person is diagnosed. A specialist needs to give paperwork about what you need to take, what is available in area, how to get there, even GP info. It is traumatic not knowing.

Interviewee (Patient)

People with cancer in rural and remote areas

There is a higher incidence of some cancers in people living in rural and remote areas of Australia and the mortality rates from cancer are higher in rural and remote populations and those with a low socio economic profile^{20 21}.

¹⁴ Botti R, Endacott R et al Barriers in Providing Psychosocial Support for Patients with Cancer. *Cancer Nursing*. 2006;29(4):309-316

¹⁵ Meyer TJ Mark MM. Effects of psychosocial interventions with adult cancer patients: a meta-analysis of randomised experiments. *Health Psychology* 1995;14(2): 101-108

¹⁶ National Breast Cancer Centre and National Cancer Control Initiative. 2003. Clinical practice guidelines for the psychosocial care of adults with cancer. National Breast Cancer Centre, Camperdown, NSW

¹⁷ Payne S, Jarrett N, Jeffs D. The impact of travel on patients' experiences of treatment: a literature review. *European Journal of Cancer Care* 2000

¹⁸ Abell L, Beckmann K et al. Providing accommodation services for rural cancer patients: the experience of South Australia. *Cancer Forum* Vol 31(2) July 2007 98-104

¹⁹ Lightfoot N, Steggles S et al Psychological, physical, social and economic impact of travelling great distances for cancer treatment. *Current Oncology – Vol 1294*

²⁰ AIHW 2006 op cit

²¹ Jong, K., Smith, D.P., Yu, X.Q., Goumas, C., O'Connell, D., Armstrong, B.K. Remoteness and cancer incidence, mortality and survival in New South Wales 1992 to 1996. The Cancer Council NSW, 2002

People in very remote areas have the highest incidence rates of smoking related and alcohol related cancers.

Survival rates for cancer patients continue to be lower for people in rural and remote areas, where patterns of care may vary after diagnosis. The quality/availability of treatment and support services is one factor^{22 23 24}. One of the most commonly identified problems for people with cancer living in rural and remote areas is poor access to transport and accommodation services. The additional financial, psychological and social problems faced by rural and remote people due to having to travel and seek accommodation to access treatment are considerable²⁵.

Duration of treatments can be very variable and unpredictable depending on the type of cancer and the treatment involved as well as the individual recovery of the patient. Patients and family members who need to travel away from home experience severe disruption, dislocation, logistical and financial burdens in accessing treatment. Access to suitable accommodation is critical also for carers and family members to be able to accompany and support loved ones.

Accommodation and transport

Appropriate, accessible and affordable accommodation and associated support can impact significantly on the quality of the cancer journey for both patients and their families and carers. Improved equity of access to health services for residents of rural NSW relies on improved availability, access and coordination of health related transport²⁶. The importance of addressing transport and accommodation support to provide equity of access to health services for rural and remote communities has been acknowledged in a 2007 Senate Inquiry²⁷. The Inquiry notes that under the Australian Health Care Agreements (AHCAs), the States and Territories are required to ensure that people have equal access to public hospital care regardless of their geographic location. Section 10AA of the Public Health Act (NSW) defines a public health service as including community health services and welfare services necessary for medical, hospital and nursing services. Accommodation and transport services associated with hospital services can be viewed as key elements of the public health system²⁸.

²² AIHW, Cancer Australia and Australasian Association of Cancer Registries op cit

²³ Underhill CR, Goldstein D, Grogan P. Inequity in rural cancer survival in Australia is not an insurmountable problem. *Med J Aust* 2006; 185:9:479-480

²⁴ Jong et al op cit

²⁵ Senate committee COSA submission

²⁶ Cancer Council, NCOSS, CTO No transport no treatment. Community transport to health services in NSW. 2007

²⁷ Senate Community Affairs Standing Committee. Highway to health: better access for rural, regional and remote patients. Australian Government. 2007

²⁸ http://www.austlii.edu.au/au/legis/nsw/consol_act/pha1991126/s10aa.html

Having readily available and appropriate transport and accommodation is vital for patients and their carers and families to access treatment, particularly for people living in rural and remote and outer urban areas. This is important when the person is being treated as an inpatient and family and carers want to be close or when the person is receiving treatment such as radiotherapy as an outpatient.

There has been a government funded transport and accommodation subsidy scheme in place since 1987, previously administered by the Commonwealth government but more recently administered by state jurisdictions²⁹.

Community transport schemes are in operation across many areas providing limited local transport options. Recent data indicates that 28% of total community transport trips relate to health facilities (680,000 trips). The primary purpose for community transport is not particularly for health related purposes but more broadly to facilitate access to shopping, education, medical care, social contact, recreation. However, due to a combination of demographic pressures, the demand on community transport for health related purposes has increased, and community transport providers in NSW refuse an estimated 90,000 requests for transport to health services each year³⁰. There are some associated problems including the need for specialised vehicles, concerns about the side effects of treatments for example toxicity of chemotherapy, lack of fit between treatment times and community transport availability times.

NSW health provides 10% of the funding for the 680,000 trips to health services; community transport providers need to fund the service from other sources to meet demand. As with the provision of treatment services there is lack of clarity about who is responsible for transport and accommodation (state or national governments, private or non-government sectors) and no clear definition of roles and responsibilities. The 2007 document “A New Direction for NSW State Health Plan Towards 2010” commits to “Transport for Health Units” as a single, coordinated point of access to non-emergency transport.

There are patients and their families who live in townships or villages far from main centres some of these might have once a week bus services. Community transport services has limited resources, are ‘booked to the brim’ and at times patients are not eligible.

OSW Survey respondent

Every person is a new situation, for example one day recently I organised a VET Affairs car to take a patient back to the Southern Highlands, an airplane to take a patient back to the Riverina and his

²⁹ Cancer Council, NCOSS, CTO op cit

³⁰ Ibid

IPTAAS form, and intervened in a plan to send another patient with cancer back to his hostel by taxi as the hostel manager said they never send him anywhere by taxi as he is aggressive. Hence we booked an ambulance. So I'd say they all got home safely and promptly but I would rate the fact that I spent all my time on them organizing transport as not providing a good service in other areas.

OSW Survey respondent

Barriers to treatment in metropolitan areas

People living in metropolitan areas also face barriers to accessing treatment if they are frail, unable to drive, or do not have carers able to assist with the journeys to and from treatment. Public transport may be unavailable or unsuitable given the impacts of cancer treatments. The transport disadvantage of patients who are too ill to drive and with no supporting driver was highlighted by 95% of respondents to the survey of OSW and CNC.

Community transport is unable to cope with the demand from patients, the report "No Transport No Treatment" (2007) states that metropolitan community transport providers refuse an average of 1 in 6 requests for health transport. Urban community transport groups spend significantly more of their time on health related transport; 44% of their trips compared with 28% of the statewide average.

Most hospital accommodation will only take clients from country areas. People living in Sydney metro area (except under exceptional circumstances) are not usually allowed to stay, they have to travel, this is when transport becomes a major problem as some community transports are better than others at providing transport for chemo and radiation patients.

OSW Survey respondent

Unless a cancer patient lives more than 100 km from treatment centre, they cannot claim IPTAAS; therefore, there are a significant number of cancer patient that are financially disadvantaged because of where they live. It can be very difficult arranging transport to and from the treatment centre for a period on average of six weeks.

OSW Survey respondent

Parking can also be a major problem for patients driving to treatment (both from home and from accommodation lodges). It is expensive and can be difficult to find near treatment sites.

4.0. Arranging Health Related Accommodation

Our inquiries revealed that many people are unaware, or find out by chance that hospital-allied accommodation may be an option for them during treatment. The processes of arranging accommodation vary and many different people can play a role, with different levels of knowledge of facilities, options and supports.

4.1. Who uses/has the need for assistance with accommodation?

The profile of people needing accommodation to access treatment is broad and includes a wide spectrum of cancers, wide range of ages and a range of other co-existing morbidities. There are also varying patient carer and family needs, factors such as accompanying children or other family members, different cultural traditions, short and long term needs and implications, co-morbidities, dietary needs, care needs. In many cases, people use hospital-allied accommodation as a last resort, it is the only place to stay that they can afford.

Families and carers are frequently users of accommodation services particularly people from rural and remote areas, people from other states or countries accessing specialised treatment which is not available locally. Some have family members as inpatients while others are accompanying their partner/family member while they are accessing outpatient treatment.

Carers are often willing to put up with poor standards of accommodation whilst their focus is on an inpatient; for accommodation during outpatient treatment they move to a more expensive option.

The greatest numbers of people require accommodation because of radiotherapy treatment which is generally administered as an outpatient treatment. Each patient is estimated to require 23 nights accommodation. This is calculated with reference to the six week/five days per week treatment pattern usually required (this assumes arrival on Monday and departure on Friday). Radiotherapy treatments alone account for 22.7 average attendances per patient³¹. Additional days are usually required for preparatory assessments, tests and clinician meetings. NSW health is aiming to increase the number of patients who receive radiotherapy to achieve the 52% best practice benchmark; so the total number of patients requiring accommodation will increase.

³¹ Hunter New England Cancer Services Plan 2006-2010. Dec 2006

The project undertook a survey of OSW and others involved in arranging accommodation. 68 responses were received; these indicated that the most significant factors in determining a patient's need for assistance with accommodation were:

1. Financial circumstances/stress
2. Mobility
3. Availability of a family member/carer to also travel
4. Need for specialized support/care.

Each of these factors is discussed in a section below.

My husband was just diagnosed with advanced lung cancer and he is on the pension. Is there any help to pay for petrol as we are doing a lot of driving to ACT and Sydney?

Query to Cancer Council Helpline

My wife doesn't work, we just have a pension. It was hard to find the money for her to visit me in Canberra. It was very expensive.

Interviewee Patient

Financial circumstances/stress

NSW Health operates the program "Transport for Health" with an "Isolated Patients Travel and Assistance Scheme" (IPTAAS). Under this program, people who live in isolated and rural communities are offered financial assistance when they are required to travel more than 100km (one way) from their usual place of residence in order to access in patient or outpatient medical treatment not available locally. IPTAAS will also cover some of the costs of an escort. Patients on clinical trials cannot access IPTAAS.

It is a partial reimbursement scheme. Receipted travel and accommodation costs are reimbursed retrospectively, however the claimant is required to make a personal contribution of \$40 per round trip (\$20 for pensioners). This means significant disadvantage for a patient who lives 100k from treatment but who chooses to commute, as they will pay the first \$40 co-contribution each day for their travel costs, which may total \$7,000-\$8,000 over the course of radiotherapy appointments³². In one area Social Workers apply to Clubs and similar organisations for grants to supply vouchers to patients to assist with petrol costs when they travel for treatment.

³²Senate Community Affairs Standing Committee. Highway to health" op cit

I just wanted to let Cancer Council know that the IPTAAS service is a joke. I have to travel 170 kms for treatment and now I need chemo. I have to pay up front each time \$40 and it only costs \$30 in petrol, so the government is making a profit. The service is very confusing and I feel as I have been travelling to and fro for the treatment over the last three years and have not requested a cent is very hard financially and now it's harder.

Caller to Cancer Council Hotline

Our interviews revealed that information about IPTAAS is not well known and sometimes inconsistent; and some people are informed that they are ineligible to apply when in fact they are. "Myths" exist, and are spread amongst patients, for example that IPTAAS calculates the distance travelled based on the location of the nearest Post Office to your home postcode. (Details of the IPTAAS method can be found in the appendix.)

Each state and territory has its own transport and accommodation subsidy system and this creates further complexity for patients treated interstate. The 2007 Senate Inquiry "Highway to health: better access for rural, regional and remote patients" reviewed the schemes operating across Australia and recommended a more consistent approach. Recommendations made by the Inquiry are in the appendix.

Most hospital-allied accommodation facilities and OSW reported that they assisted patients with IPTAAS claims and they are able to bulk bill for IPTAAS. This support is much appreciated by patients and carers. Many interviewees indicated that they had financial hardship because of cancer treatment, but had found difficulty navigating the IPTAAS system, and in some cases had not claimed. The bureaucratic process in particular securing the signatures of GPs and specialists was criticised. The retrospective nature of reimbursement, where claimants may wait several weeks for payments can be a major problem for the most economically disadvantaged. Several patients and carers interviewed had been given inaccurate information and believed they were ineligible to claim or had incorrect information about their entitlements.

Some patients are also reluctant to claim or to access support from organisations such as Can Assist and the Cancer Council. They find it hard to ask for help and don't want "charity".

We tried to get IPTAAS but not told until the end that we had to keep receipts, it was too hard, and it was a problem to get into Dubbo and do

the paperwork. You are already upset and you don't want on top of that to feel like you are asking for charity.

Interviewee (Carer)

IPTAAS? We couldn't be bothered – in those situations you don't want to jump through hoops. Health fund helped with travel costs – they were easy, could give them an estimate and they gave you a rate.

Interviewee (Carer)

It's hard to keep paying the bills at home and you worry about missing something that arrives while you are away.

Focus Group Participant (Patient)

Travelling for treatment places dual burdens on patients and their families. They have to maintain the expenses associated with their homes as well as funding accommodation and travel within a city. Associated costs of purchasing food, laundry and telephone calls are additional to medical and other health related expenses (such as wheelchair hire etc). Keeping in touch with family and friends at home is very important during the separations caused by treatment. Access to telephone is vital and the cost of relying on mobile phones was highlighted as a concern by many patients.

I've spent 140 dollars in four weeks just on phone calls.

Focus Group Participant (Patient)

People who need to access accommodation facilities are of diverse socio-economic circumstances. Almost all the people interviewed commented on the additional financial burden of accessing treatment and being away from home.

A group identified by OSW as particularly disadvantaged were those with middle-incomes and mortgages; ineligible for hardship supports but unable to work during cancer treatments and possibly unable to maintain mortgage or other loan repayments. Banks were found to be unreceptive to requests for flexibility and patients found they had limited options, resorting to using superannuation and even selling their homes.

Several of those interviewed who were able to absorb the additional costs related to accessing cancer treatments expressed great relief about this and noted how stressful it must be for those who have limited financial means.

Private health insurance won't pay for what you actually need, for example, a wheelchair; the Health fund paid \$2,000 – that's the maximum they will pay. IPTAAS – we were reimbursed \$900 but I can't work out what has paid for, one plane trip maybe. I am just glad we could scrape the money together.

Interviewee (Carer)

A number of people interviewed had had to give up work by their employers during treatment due to being absent for an extended or uncertain period. Others with small holdings or rural businesses were not able to continue to operate these whilst they were absent for long periods and ultimately had to close their business. People with properties experience the stress of arranging for stock to be cared for and additional expenses associated with others maintaining their property.

When the Newtons took their first cancer trip, they had to close the farm for three months. It almost sent them broke and they had to put themselves in to more debt so Chrissey could finish her treatment.

ABC Four Corners 5 June 2006

When I was first diagnosed I lost my job. I said I was going to Sydney for treatment and my boss said don't bother coming back.

Interviewee (Patient)

Mobility support needs

Feedback from OSW indicates that a significant constraint on their ability to source affordable accommodation for patients is the level of mobility of the patient. This has two aspects. Accessibility of accommodation to patients who have difficulty walking or climbing stairs and transportation to treatment (covered in other sections in more detail).

Many accommodation lodges are not purpose built and are without lifts or wheelchair access. Residents are expected to be personally mobile, that is able to get themselves to and from treatment with minimum support or with the assistance of a companion. Where lodges are unstaffed, significant problems can arise for residents. In one example, a couple in their 80's from the country had to wait outside their accommodation lodge until another resident entered or exited because the main door was broken and they were unable to walk down a steep slope to the alternative door.

This issue is likely to become more significant with the ageing population and predicted increase in numbers of older people with cancer and other co-morbidities including impaired mobility.

Availability of an accompanying family member/carers

Many cancer/accommodation lodges require patients to be accompanied. Patients are expected to have companion(s) who are not only available for the duration of treatment, but are also willing to share a room. Critical issues can arise for people who do not have a companion, especially if they have care needs such as dressings, inaccessible wounds, tracheotomy changes, medication administration which may often result in them being admitted as an inpatient.

Need for specialized support/care

Interviews with Oncology social workers suggested groups of people for whom accommodation is particularly challenging to arrange. Other stresses impacted by the cancer diagnosis can exacerbate incapacity to arrange accommodation. Needs change and people who were relatively independent pre-treatment may require significant support further in the cancer journey. For instance older people who are no longer going to be able to live independently may require interim arrangements or step-down facilities until alternative accommodation can be arranged. Short term transitional care in a supported facility may enable others to subsequently resume independent living. If interim accommodation facilities are not available for these patients they may continue as inpatients which contribute to the problems of bed shortages in acute settings.

Travel home for patients from rural NSW immediately after discharge may also involve difficult journeys with the risk of road traffic accidents, kangaroos on the road being one example highlighted in submissions to this review.

People with significant mental health issues frequently have multiple problems and are more likely to be linked into mental health services which support their arrangements. However it was noted by OSW that people with mental illness who are stable on medications can become destabilised due to the effect of the cancer medications and their previous accommodation, for example their previous boarding house accommodation is no longer suitable.

An OSW gave a case study that illustrates the challenges faced in arranging accommodation for a young single parent. They were forced to travel to Sydney interstate for specialised treatment with two young children, and had no close family or friend support. The OSW spent almost a whole day “jumping through bureaucratic hoops” in their

words to secure support, eventually approaching DoCS for assistance. Unfortunately this meant the family's situation was "officially" described as potential neglect, although the outcome was that much needed child care was obtained.

The OSWs noted that there are significant challenges for people who do not have a strong command of English and where there are literacy issues. Recent policies of locating refuges to rural communities may exacerbate this issue.

There can also be different accommodation and support needs for people post cancer treatment compared with pre-diagnosis due to the impact of the cancer and of the treatment which can mean people are less mobile and less independent generally at least for a period of time.

SWOG also highlighted the fact that there can be home circumstances where people receiving cancer treatment from home need to seek alternative accommodation due to for instance eviction, family violence and domestic conflict, low incomes (where cost of treatment reduces capacity to continue to pay existing rents etc). People who are homeless or in emergency housing – or after treatment require alternative housing as they have lost their previous housing can also need alternative accommodation.

Aboriginal people were generally noted to not access the available accommodation facilities (see Section 6.2). Accommodation Providers reported limited experience of catering for occupants from non English speaking backgrounds or with specific cultural needs.

4.2. Admission as inpatient

Accommodation options are very limited for some categories of patients. Social workers reported in interviews that patients will need to be admitted to undergo radiation therapy for complex treatments, such as head and neck cancers (where food intake is problematic), spinal cord compression, bone marrow transplant, post operative, or when lack of mobility, dementia or other co-morbid conditions. Frail elderly people are more likely to be given radiation therapy as an inpatient.

For some people who are initially able to manage independently in accommodation, the side effects of treatment and deteriorating health can mean that they subsequently need to be admitted as an inpatient.

For some, if there is a serious issue with accommodation unavailability – a bed on a ward will be looked for.

At times patients who have finished treatment as an inpatient but still are not well enough to go home to manage independently will need to stay in hospital where there are no adequate step-down facilities available locally.

Where there are issues of guardianship, there can be disagreements and delays in decision making around treatment, location of treatment site, accommodation issues.

4.3. *The processes of arranging accommodation*

Patient and family arranged

Patients may make their own arrangements to stay in hotels, motels or with friends or relatives, and are sometimes unaware that there is assistance available from hospital-allied accommodation and social workers and accommodation liaison officers. Patients may be recommended directly to an accommodation solution by their doctor, or they may approach a facility because a friend or acquaintance had stayed there previously.

I had nowhere else to stay – I've no family here, the lodge was recommended by Dr X near <location>.

My daughter and son found <accommodation facility>, I stayed with my brother before, that didn't work. I am lonely here, my husband is in xxxx.

I don't know anyone in Sydney. I transferred 5 months ago from <state 1> I was diagnosed in <state 2>. Breast cancer, I stayed with my brother. I said to the surgeon I don't want treatment because nowhere to stay. Then I transferred here so I could have radiation in Sydney.

Quotes from 3 Focus Group Participants (patients undergoing treatment)

Health workers involved

The survey responses of OSW and CNC indicated that the process of arranging accommodation for patients is very variable, with over 20 different roles within the health care system identified as being involved depending on the circumstances. The roles most commonly involved are listed in the table below.

Table 1: Main roles involved in arranging accommodation

Role	Response count
Social Worker	53
Cancer Care Coordinator	23
Accommodation Liaison Officer	20
Ward staff	17
Radio therapy staff	17
Clinical Nurse Consultant	14
Secretary to Doctor	14
Medical Officer	11
Cancer Nurse Specialist	10
Palliative Care Nurse	9

Other roles also listed, but less frequently by survey respondents were clinician's assistant, director of nursing, nursing unit manager, accommodation lodge staff, other members of social work dept, general secretariat staff, welfare workers, Leukaemia Foundation, community nurses, district nurses, cancer support service personnel.

Social workers and cancer nurses in rural areas link in with social workers in the large treatment centres to assist with local accommodation arrangements. Problems reported by OSW included the length of time involved in administrative aspects of the role such as actually making travel bookings and securing IPTAAS funding, as well as the difficulties in ensuring up to date information on accommodation options and alternatives when lodges were full. The importance of the role of accommodation officers was highlighted, however these posts are not in place in all major hospitals.

A lot of people need help to make their own arrangements - booking tickets etc. The Northern Territory has a scheme and when the patient was ready to go home the hospital advised them and they got back to the patient the same day with all the details and paid for the tickets as well. It can take an inordinate amount of my day to arrange transport which takes away from other services I think I should offer.

OSW survey response

Other factors in arranging accommodation

A range of factors were identified which impact on the processes and approach to arranging accommodation and the type of accommodation chosen. These include:

- **The urgency of travel** - in some cases people are advised to leave immediately for Sydney. In these cases their arrangements need to be made hastily, often with a short term stay in mind and there is not the opportunity to investigate the full range of options and support available.
- **Whether or not support is available** for the patient as some accommodation is unsuitable for patients without carers. Support is needed to be able to independently prepare meals, do laundry, access the treatment service etc.
- **The nature of the care required** - for instance if there are care needs such as wound care, specialized medication, mobility support. Only one accommodation facility in Sydney, Jean Colvin, has qualified nursing staff available to assist patients.
- **Who needs to accompany the patient?** It may be difficult to secure accommodation suitable for families with children for example.
- **The point of entry** of the patient into the care system can affect the quality of information and support they receive in accessing accommodation. For instance patients may be referred directly from a GP to a city specialist without having contact with the local cancer centre or hospital staff such as social workers. The patients can miss out on the support and knowledge and experience of the range of facilities available from the health system staff.
- **Admission and discharge dates** - uncertainty of admission and discharge dates impact the ease of making arrangements for accommodation. Patients and carers don't always know how long they will require accommodation for or may need to cancel at the last minute if a procedure is rescheduled.
- **The knowledge of and familiarity with the treatment centre** can impact on how easy it is for people to get from the transport service (plane/train) to the accommodation facility and their knowledge of services around the accommodation facility for example supermarkets, public transport, laundry etc.
- **The quality of local information available about accommodation options and facilities.** Regional cancer and other health staff were more likely to have information about options in their most commonly accessed centres, rather than a knowledge of broader options.

People are very cut off from support, if people have friends and relatives they are lucky. They should have someone there who as soon as a person is diagnosed specialist needs to give paperwork (booklet etc) about what you need to take, what is available in area, how to get there, even GP info. It is traumatic not knowing.

Interviewee (Carer)

Some of the lodges and individual social work departments have developed packs of information to help with orientation to both the hospital and accommodation arrangements before travelling. These include maps, details of local facilities such as supermarket, laundry, parking, transport and other features of the hospital.

Working in a large rural area, difficulties arise more for people in more isolated areas. Connections for transport to Sydney are difficult. The cost and time needed to travel, the fear that a lot of rural people have about cities and their cancer. There are always answers, however, it is about having someone with the time to talk and help arrange transport and accommodation that will alleviate anxiety. Most bookings for Sydney are made on clinic days that are always busy and on Fridays.

OSW Survey response

However OSWs noted that leaflets can be of limited value, and sometimes patients were swamped with written information, particularly early in diagnosis. The Cancer Institute is undertaking initiatives to support the patient information pathway to assist with this issue. In relation to accommodation and transport, the OSW view was that the best solution was a single point of contact in each metropolitan hospital or a single phone number providing a people-based service.

For some Aboriginal patients from rural and remote areas nuns arrange to meet them at Sydney Central and look after getting them to their accommodation.

4.4. Admission/discharge of patients

In both focus groups and interviews, many rural patients and carers highlighted difficulties associated with the timing of notification of appointments and scheduling of appointment times at metropolitan treatment centres. From their perspective, people who contacted them to arrange hospital admissions (for example for surgery) demonstrated no awareness of

the travel time involved to get to an appointment, or the logistics of having to leave home 24 hours in advance of an admission. There were instances of key information not reaching people who were already in transit to the treatment centre. Also unrealistic requests such as “we can see you but only if you can get here in the next half an hour” which added to the stress and distress experienced by people.

It is difficult with operations – they tell you to phone that morning, but if you go 1000k to get to Sydney then have to wait overnight, then find out yes or no for a bed it is very difficult. We had already driven as far as Katoomba and were told there was no bed. We were told to phone again at 12:00. When we did they said a bed would be ready in half an hour, it was totally impractical but when we said that we were told “if you are too late the bed will be gone”.

Interviewee (Patient)

Making arrangements for accommodation can be complicated by the uncertainty of admission and discharge dates. Patients and carers don't always know how long they will require accommodation for or may need to cancel at the last minute if a procedure is rescheduled.

Accommodation lodges near hospitals can also act as a step down or intermediate facilities for patients from remote areas who are discharged following inpatient procedures. They are able to access medical support close by and attend check-ups with their clinician before returning home.

4.5. Process improvements

Coordination of accommodation information

Suggestions for process improvements focus on better coordination of accommodation information and arrangements linked to appropriate stages of the patient journey. This may be facilitated through work underway to develop “patient information pathways” which match the information needs of patients with the clinical pathway.

To address the practical issues of travelling for treatment, a central “one-stop shop” for easy access to information about accommodation access, types, location and availability is recommended. This is to provide a single contact point for health professionals, patients and carers or other community members to access information when it is needed, possibly using a telephone help/assistance line which assesses the accommodation needs from callers, provides advice on choices in specific locations, availability and refers or assists with arranging bookings. Alongside initial information it is important to

develop services and resources, information kits for patients and families in accommodation precincts. Any system would need to be able to cope with the realities of the cancer treatment process such as changes in appointments, equipment unavailability, short notice cancellations and the need to stay for a longer period than anticipated when booking.

An important adjunct to an information service is ongoing work to raise awareness that it is available both to patients and professionals. A publicity strategy could include wide dissemination of the accommodation contact point details through all related health professionals, cancer networks, community facilities, for example libraries, pharmacies, and the exploration options to integrate information about the accommodation information service in critical intervention points in the patient journey from testing, diagnosis, treatment, care and support processes. There is potential to link with prompts in medical software, treatment/assessment checklists.

Radiotherapy treatment

Some hospitals are identifying ways to treat differently more intensive regimes which may maintain the impact of the treatment with the added benefit of reducing the time away from home. Patients are now being offered pre-treatment consultations closer to patient home bases rather than on site in the treatment centre.

Equipment maintenance can be a reason radio therapy is cancelled. Machines require a day a month for servicing so if a patient requires five weeks of radiotherapy this may extend the duration of the treatment to six weeks because they have missed a day. One hospital professional suggested that servicing at weekends, although inconvenient to engineers, would permit a whole extra day of patients to be treated for each machine. They noted that in a private hospital setting, maintenance was always carried out at weekends to maximise the number of patients treated.

5.0. The experiences of patients and carers

The review sought the views and experiences of patients, carers and family members currently undergoing treatment or having previously having had to travel for treatment. We sought understanding of the impact of travelling and accommodation on respondents and also impacts on treatment decisions. The views reported here were mostly people who had utilized public accommodation facilities, however some had made their own arrangements and/or stayed with family, at least on some occasions. Health professionals and others in the study also commented on their observations of patient experiences.

5.1. How does accommodation and associated support impact on the patient cancer journey?

Needing to travel for treatment and to seek suitable accommodation was widely acknowledged to add significant stress to patient's carers and families. This is during a period of already extreme distress and psychological pressure and uncertainty. OSW reported that they frequently work with patients who are so anxious about travel and accommodation that they ask no questions relating to their cancer.

The key issues arising in relation to accommodation needs for patients and carers were the suitability of the facilities to match their needs (for example accompanying family members including children, mobility levels), availability, affordability, access to information about available accommodation and support to make accommodation arrangements. Linked issues related to transport access and affordability were constantly cited as a major issue and stress.

Uncertainty is a frequent stressor with for instance, patients travelling to Sydney, frequently at very short notice for diagnostic tests, assuming they would be away for several days and subsequently being admitted for emergency treatment. Short-term temporary accommodation which can be very costly becomes unsuitable for people requiring a longer term stay.

In one case the patient and partner from a large rural centre flew at very short notice to Sydney for tests, expecting to be away only overnight. However, the person with cancer was admitted immediately for treatment and ended up being in Sydney for over four months. The partner had to manage in many different accommodation arrangements, including for several weeks staying on the ward and using the patient bathrooms. The couple over a period of 18 months

spent more than 9 months in Sydney and experienced a range of different forms of accommodation, much of which was highly unsatisfactory. It took some time for them to be fully aware of the options available to them. “It really helped once we got to know how to work the system.”

Interview (Patient and Carer)

Health professionals interviewed across all disciplines emphasised that accommodation availability and suitability is a critical issue for cancer patients.

Impact on Treatment decisions

I would sleep in a train for the best treatment.

Focus Group participant

In what ways does accommodation availability and suitability impact on treatment decisions, i.e. uptake and completion and type of treatment? There are indications and anecdotal evidence from health professionals that some people may decide against a particular treatment because of having to be away for an extended period and the time it would take to get to the treatment. However, it is hard to accurately ascertain the extent to which people decline treatment because of accommodation issues alone. Treatment decisions are likely to be influenced by a complex mix of issues for instance fear, not wanting to be away from home and family as well as the logistics and costs of accommodation. One clinician commented: “We don’t see people who decline treatment – hard to know exact reasons.”

The most commonly cited example of cancer treatment decisions being influenced by travel and distance were in relation to rural women with breast cancer choosing surgery rather than radiation therapy. Surgery can be done in a hospital closer to home and require less time away from home compared with radiotherapy requiring treatment over at least six weeks in a facility far away and requiring travel and accommodation. One surgeon reported that where appropriate he advocated breast conservation and radiotherapy but that he found some young women preferred radical mastectomy to avoid travel and separation. The stage of cancer may also influence the treatment decision. This is supported by one study of metastatic breast cancer³³ which found:

³³ Management of metastatic breast cancer :an examination of socio-economic and regional impacts.
Access Economics Pty Ltd 24 May 2007 page 15- 16

Women almost always prefer to have the best treatment available but often at considerable inconvenience and cost. If therapy is in a curative setting, women are more likely to find ways to overcome access constraints, but in a palliative setting this is less likely. Women are more likely to opt for more radical therapies (eg, mastectomy) in regional than urban areas, to avoid the need to travel.

One remote area palliative care nurse commented that people who have closer access are more likely to opt for chemotherapy.

You very rarely see people go away from their family for five weeks.

Radiotherapy is very effective – but over a distance, hard for people from lower socio-economic groups to access.

In a 2003 Queensland study, 46 rural cancer patients with the option of travelling for radiotherapy were interviewed. Thirty two participants had breast cancer; of these seven (15%) chose not to have a lumpectomy and associated therapies such as radiotherapy, preferring a mastectomy. The reasons cited as factors in this decision included the choice not to travel (five participants); family concerns (three participants); financial reasons (three participants); surgeon's advice (two participants)³⁴.

Women in living in rural areas when diagnosed have been found to have slightly lower five year relative survival than women in urban NSW³⁵.

Impact of delays in accommodation availability on patients

Some health professionals indicated that treatments can be delayed due to lack of accommodation; however this was not widely reported and is difficult to quantify. Several commented on needing to schedule treatments around accommodation availability and accommodation providers reported that clinicians would call to check availability of a bed before booking a patient for a procedure. It is difficult to assess the impacts of delays on patients other than the consequent compounding of uncertainty and anxiety.

³⁴ Martin-McDonald K, Rogers-Clark C, Hegney D, McCarthy A, Pearce S. Experiences of regional and rural people with cancer being treated with radiotherapy in a metropolitan centre *International Journal of Nursing Practice* 2003 : 9:176-182

³⁵ Jon K, Smith, DP, Yu, XQ, Goumas, C O'Connell D, Armstrong, B.K. Remoteness and cancer incidence, mortality and survival in New South Wales 1992 to 1996. Cancer Council, 2002

There were however accounts from patients of staying in more or less satisfactory motel accommodation until a place in a hospital-allied facility was available.

Interviews with OSW and discussions with the SWOG highlighted the way that extended stays in hospital due to lack of suitable accommodation post treatment can contribute to bed blocks and affect patient flows considerably.

Remote home base/lack of familiarity with the city

Rural patients and carers reported significant stress and anxiety about being in a large city such as Sydney for treatment. They are frequently reluctant to leave family, property or pets, or are concerned about travelling to a large city perhaps for the first time. The challenges and stresses for rural patients are illustrated by the quotes below:

The idea of travelling to Sydney was terrifying. I prefer to be in Wagga Wagga, it's better for country folk, but even this feels like a big town.

Focus Group Participant

"It was like a big nightmare. It really was. We didn't know how to catch a bus. We didn't know about public transport. We didn't know who to get if we needed help. We didn't know how to get from point A to point B. Everything was done and in a taxi and you just hoped he knew what he was doing. Very bewildering."

"Far from Health" ABC broadcast 5 June 2006

An accommodation lodge in Launceston Tasmania has identified that concerns about their dog, in some cases the only companion of single older men in rural Tasmania, were so significant that the men were refusing or absenting themselves from treatment. As a result the lodge is establishing kennels on site.

Other issues to do with being away from home

Patients and carers identified problems with living away from home for long periods. Carers commented "what do you do when you aren't allowed to be on ward?" If they are unable to return to their accommodation, they find themselves spending long hours in the hospital coffee shop or equivalent. Similarly one patient noted that he had one hour of treatment each day which left 23 hours to fill. Normally a very active person he found little to occupy him

in a lodge environment, and he acknowledged that a bed and breakfast, hotel or motel would have been even worse.

Some hospital-allied facilities are addressing this through programs of activities, volunteer involvement and informal social functions, morning teas and barbecues.

6.0. Existing Accommodation Facilities

6.1. *Accommodation facilities*

Accommodation types

Three types of accommodation are identified in NSW:

- Commercial – where cancer patients and their carers/families access facilities used by other travellers, occasionally at a subsidized rate negotiated by a hospital. Examples include Rydges, Formule 1, Comfort Inn and other hotels located near to hospitals. Some hospitals have achieved close working relationships with commercial facilities, an example is below:

The “resident manager” offers self-contained apartments at the Newtown Square property near Royal Prince Alfred Hospital (RPA). An on-site manager looks after 20-30 of the 230 units there which are available overnight. He leaves a set of keys with the accommodation liaison service/security at RPA so that patients and their carers brought in overnight/in emergencies have somewhere to stay. RPA leased four units for two years, but for the past year has relinquished the tenancies. The units are available to all RPA patients/carers and have been used regularly by radiotherapy patients. The resident manager was asked if there was anything distinctive about offering this service to patients. He commented that flexibility was important; needing to understand that appointment times could change at short notice meaning that patients required or would want to cancel accommodation arrangements. “It is not unusual from someone to come down for a test and just book to be here one night and then discover they have to stay for three weeks.”

- Specialist/cancer – accommodation dedicated to cancer patients and their families. Examples include Jean Colvin, Lilier Lodge, Shearwater Lodge, Bezzina House, Leukaemia Foundation services.
- Specialist/open – accommodation for patients and carers travelling for treatment (cancer, heart, kidney conditions, families of paediatric patients for example). Examples include the facility at Ashfield associated with Royal Prince Alfred Hospital, the proposed facility at Lismore (joint cancer and paediatric). In many specialist/cancer accommodation units rooms not required for cancer patients are made available to others. This may be on a case by case basis, or in some services it is planned, for example Shearwater Lodge in Coffs Harbour

retains rooms to respond to the needs of traffic accident victims and their families; Bezzina House has an arrangement with the St George Hospital Sleep Clinic to make use of rooms over the weekend when cancer patients have gone home. Hospital staff, for example medical residents at times occupy spare rooms at Shearwater Lodge.

Summary of facilities for NSW patients

Accompanying this report is a comprehensive directory of facilities. The directory identifies 40 hospital-allied accommodation facilities with 828 rooms and 1736 beds providing accommodation to patients from NSW attending treatment for cancer at 29 treatment centres. Each facility was surveyed either via a site visit or written response to a questionnaire. The survey included three accommodation facilities and five treatment centres used by NSW residents located in Brisbane as well as one accommodation facility and one treatment centre used by NSW residents located in Canberra.

An additional 29 commercial facilities were identified as providers of non-hospital-allied accommodation. These are listed and considered separately in the directory.

The majority of facilities only accept patients who live more than 100kms away. The average room occupancy rate for hospital-allied facilities Monday to Friday is 79%. On-site facilities (co-located with hospitals) have an average room occupancy rate of 81%. Off-site facilities have an average room occupancy rate of 73%.

There are fewer facilities than needed, with the largest shortfall reported in Newcastle and Central Sydney. Royal Prince Alfred Hospital (including Sydney Cancer Care Centre) has the most accommodation available. However, most facilities are off-site. A new facility is currently in planning.

The “stock” of facilities is typically older in style; patients may be expected to share bathrooms and design issues such as the lack of lifts or stairs and entrances make them unsuitable for those with mobility problems. Ageing facilities require significant investment to ensure suitable accommodation will be available in the future. Twelve accommodation facilities reported intentions to redevelop:

- Accommodation – Royal Prince Alfred Hospital (in planning)
- Blue Gum Lodge (closing in 2011)
- The Canberra Hospital Residences
- Leukaemia Foundation Accommodation – Waverton
- Leukaemia Foundation Accommodation – Westmead
- McAuley House, New Lambton (in progress)

- Ron Dunbier House – Liverpool
- Ronald McDonald House – Wagga Wagga
- Ronald McDonald House – Westmead
- Royal North Shore Hospital Cancer Care Centre (in planning)
- St Vincent's Hospital Accommodation Services
- Vera Adderley Residence

Service users generally live in rural and regional areas (especially the Central West) and travel to accommodation facilities in Sydney and Western Sydney. In the Hunter region most patients come from the Hunter New England Area.

6.2. Accommodation provision

The role of NSW Health, Area Health and individual hospitals

There is no statewide co-ordinated approach to the provision and maintenance of accommodation for cancer patients, their carers and family members who need to travel for treatment for cancer or other health conditions.

The arrangements and facilities which exist have been established on an ad hoc basis at a local level and through a variety of processes. Some purpose built facilities have been established and developed through local community initiatives, some initiated and supported through charities, service clubs or non-government organisations. Many of the accommodation facilities are not purpose built. Others such as Bezzina House were developed as a result of initiatives of the local Cancer Treatment Centre (at St George Hospital).

Whilst the importance of support to access treatment is recognised by NSW Health there are no formal systems in place to exercise explicit responsibility for the provision of accommodation. There is no directive or provision for accommodation in the NSW Cancer Plan which articulates the standards for clinical treatment and nature of service provision across the state. Partial subsidy of accommodation and transport costs for accessing treatment is provided for in the IPTAAS scheme which is administered at Area Health Service level. Area health plans do recognize that inequality of access to treatment does influence health outcome. (HNEH plan is an example, identifying transport as a strategic priority) however there is no directive to resource solutions.

Within health services, planning for physical (capital) facilities is undertaken at a more global level by Area Health Services and not in response to the needs of individual disease or population groups. Accommodation in close proximity to treatment facilities is required for a range of conditions, for example renal, cardiac or cancer.

There is no stated obligation on the part of treating hospitals to provide accommodation, although some hospitals have committed to supporting patients and carers. As an example, see the extract from the Royal North Shore website

“We recognise that the sort of accommodation Rotary Lodge traditionally provided is a vital part of the acute services at RNS. This type of accommodation will be provided on site in the final redevelopment³⁶.”

NSW hospitals do in fact provide accommodation for patients and carers, however feedback from OSW and patients indicates that the quality is in some cases very poor. These poorer services are not prioritized or resourced adequately.

It’s an old nursing home. It was more like camping. There were a whole load of safety issues, for example electric plug hanging out of wall, heaters broken, freezing, windows broken, no manager. It wasn’t even clean. Doesn’t matter how basic facilities are, safety features are essential. There has to be a minder for sick people. You have to have someone responsible – for example the fire alarm went off, no one knew where fireboard was, no one looking after sick people. There needs to be support for elderly frail coming to help – for example tell people where to get spare toilet paper. It needs someone to be camp mother, for example to call ambulance.

Interview (Carer)

The Inquiry “Highway to Health” provides a clear direction for State and Federal action.

NGO/service club roles

The role of NGO’s and charities and service clubs and local community fund raising in accommodation provision and support is considerable. It fills a significant gap and provides a valuable community service. Subsidies for accommodation and transport costs can provide critical assistance when there is additional stress from costs for cancer treatment. Patients, carers and families are very appreciative of the support and facilities provided.

³⁶ <http://www.nscchealth.nsw.gov.au/rnsredevelopment/faqs/003753249.shtml>

Accommodation provision and management

In some cases the NGOs/ Service Clubs manage the accommodation services, either on a purely voluntary basis (such as Coffs Harbour Regional Cancer Services cottages) or with a paid manager/caretaker and management committee (for example Bezzina House, Shearwater Lodge, Lilier Lodge, Blue Gum).

Accommodation managers commented that having such facilities supported by local communities is seen to be of great benefit. There was a very strong expression of the local community ownership and pride – even though local residents may not necessarily directly benefit from the facilities. Ongoing fund raising for specific additions, upgrades and refurbishment forms part of community engagement process. The Lismore community for example aims to raise over three million dollars for a facility to benefit people travelling into Lismore for cancer and paediatric treatments.

Two NGOs focussing on accommodation are the Leukaemia Foundation and Can Assist.

The Leukaemia Foundation has made accommodation one of its priority services and they provide specific facilities for people and carers with haematological cancers. They offer self-contained units with car service. These are considered to be excellent and frequently praised as the gold standard.

The Foundation provides accommodation in Canberra, close to Canberra Hospital; in Newcastle, across the road from the Mater hospital; near Westmead hospital and in Waverton where six, two bedroom self contained apartments provide accommodation for other treatment centres in Sydney. The experience of using the facility in Waverton is described by a carer in the quote below.

The units were very good, we had our own laundry, the children could come and stay. It is free – no charge even for phone, electric. The way they did it was really good – all you had to do was food, the place was ready for you, great spot, there was transport. You could try and relax and be normal, and forget about what would happen.

Interview Carer

Can Assist provides assistance to cancer patients and their families through a network of branches and three accommodation services. They provide financial assistance with travel, equipment, wigs and other items; and subsidised accommodation and specialised care at Jean Colvin Hospital and

Ecclesbourne (in Sydney) and Lilier Lodge in Wagga Wagga (in collaboration with Cancer Council). Jean Colvin is the only service in Sydney which accommodates up to 37 patients and offers 24 hours per day nursing. This service is highly valued by patients and highlighted by OSW as the only option for some people who would otherwise be forced to remain inpatients. Carers are able to stay at Ecclesbourne, a 26 bed hostel. Lilier Lodge offers 20 rooms to patients of the Riverina Cancer Care Centre and their companions/carers.

Local branches of Can Assist where possible will cover accommodation costs not covered by IPTAAS and top up the travel allowance paid by IPTAAS for people in need. This is done to prevent people having to pay out money up front and then wait an extended time for reimbursement. This is a cash flow service to people having cancer treatment and endeavours to bridge the gaps left by IPTAAS in NSW.

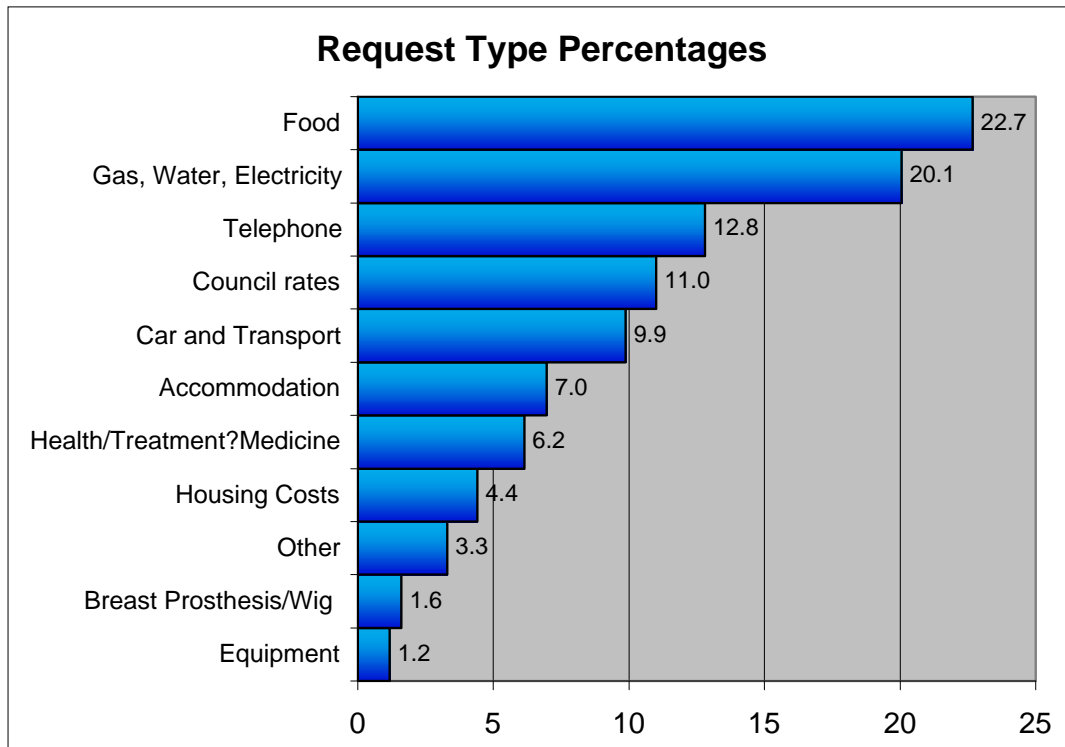
6.3. Accommodation and transport financial support Cancer Council grants

Cancer Council makes grants of up to \$300 available to cancer patients, with \$525,000 disbursed in 2007/8 to 1910 people. Recipients are spread across NSW.

Recipients of financial assistance travel an average of 75.6km to see a social worker, with the furthest 1516km.

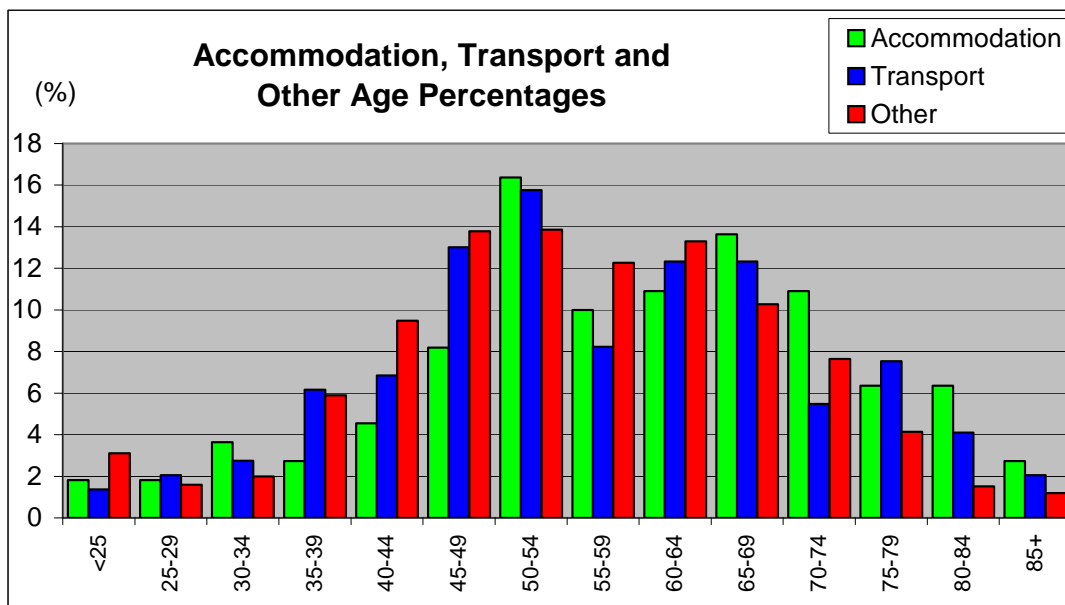
The chart following (Figure 1) summarises the types of support requested. Almost 23% of requests for assistance are for food. Travel (car and transport) is requested by 9.9% and accommodation by 7%, however assistance with “essentials” such as food, utilities bills, rates are also associated with living away from home during treatment.

Figure 1: Types of assistance requested from Cancer Council



The type of request varies according to age of the recipient. The demand for accommodation and transport assistance is greater than other forms of assistance in the 25-34, 50-54 and 65 and over age groups illustrated by Figure 2.

Figure 2: Accommodation/transport assistance from Cancer Council by age



Gaps in provision

There is a gap in provision for those who are not well enough to stay home but not sick enough to be admitted to hospital. Only one accommodation service, Jean Colvin, provides nursing support to residents. Other accommodation lodges would call an ambulance if someone needed health related care, or were unable to cope alone (for example to prepare their own meals or manage a journey to and from treatment).

Problems were also reported for young families with nowhere to stay. Some facilities provide for them and encourage and support them for example linking into local schools, however many accommodation lodges do not accept children and OSW reported referring people to campsites and caravan parks as alternatives. In one example a woman with cancer received treatment as an inpatient, her 12 month old baby and husband stayed in a car park in the car.

Generally the accommodation facilities available do not address the cultural needs of some community groups. For instance, requirements for men and women not to be in shared common areas or lack of adequate accommodation for numerous family members to accompany the patient.

There are currently fewer accommodation facilities than needed in NSW, with the largest shortfall reported in Newcastle and Central Sydney.

Royal Prince Alfred Hospital (including Sydney Cancer Care Centre) has the most accommodation available. However, most facilities are off-site. A new facility is currently in planning. Twelve accommodation facilities reported intentions to redevelop, and this will cause interim problems for patients.

6.4. Accommodation and transport issues for Aboriginal patients

There are well documented disparities in health between Aboriginal and non-Aboriginal Australians and it is well known that Aboriginal people are less likely to access mainstream services and more likely to be diagnosed late with poorer outcomes for a range of health conditions^{37 38}. Accurate cancer data is poor for Aboriginal people in most parts of Australia however where it is available it indicates that cancer diagnosis is more likely to be at end stage and people are more likely to be seen in palliative care³⁹. Mortality data from 1999-2003 show that there were 1.5 times as many deaths from cancer among Indigenous males and females as would be expected based on the rates of non-Indigenous Australians⁴⁰. In rural and remote areas where

³⁷ Thomson N ed. The health of Indigenous Australians. 2003. Oxford University Press. Melbourne

³⁸ Cunningham J Diagnostic and therapeutic procedures among Australian hospital patients identified as Indigenous. *Med J Aust* 2002; 176:58-62

³⁹ Condon JR, Barnes T, Cunningham J, Armstrong BK. Long-term trends in cancer mortality for Indigenous Australians in the Northern Territory. *Med J Aust* 2004; 180: 504-507.

⁴⁰ http://www.aihw.gov.au/indigenous/health/health_conditions.cfm#cancer. Accessed 22 Aug 2008

Aboriginal people make up a higher proportion of the population there is a higher incidence of some cancers and also worse survival rates from cancer. Late diagnosis and poor prognosis for Aboriginal people with cancer is due to a complex range of reasons (socio-economic, cultural, psychological, historical) which include lack of awareness and understanding of health issues, higher levels of risk factors for multiple chronic diseases, lack of access to appropriate, culturally safe services).

Questions regarding issues and needs of Aboriginal people in relation to cancer related accommodation were asked of a range of health professionals including Aboriginal health staff. Their comments in relation to issues for Aboriginal people in NSW emphasized Aboriginal people are impacted by multiple financial and social barriers which can limit their access to transport, communication, accommodation services and facilities. For instance, there can be a lack of private cars in rural and remote Aboriginal communities, lack of money for petrol or to pay for public or community transport, limited or no phone access. Accessing available IPTAAS subsidies is limited due to the difficult administrative processes and the reality that Aboriginal people are unlikely to be able to pay up front for transport. One remote area Aboriginal Medical Service stated that their transport service transports takes people to the nearest large regional centre for treatment.

There is a range of systemic barrier to Aboriginal people accessing health care and under-utilization of health services, particularly mainstream health services. Among other reasons this can be due to fear and previous negative personal and family experiences, leading to mistrust and reduced willingness to seek professional support. Oncology clinicians and services reported seeing very few Aboriginal patients.

Aboriginal people may be unlikely to take up treatment options if it means being away from home. It was reported that for Aboriginal people living in remote communities there is apprehension about visiting even larger regional centres, let alone facing the prospect of travel to Sydney. Community and family responsibilities and concerns can prevent them from being away from their community for extended periods. Ngadu, the Aboriginal hostel in Sydney reported having had no recollection of Aboriginal people with cancer staying at the hostel in recent years.

If they do agree to travel, welfare staff in regional centres can spend inordinate amounts of time in making arrangements for Aboriginal community members to travel to Sydney to optimise the likelihood that a patient will access treatment. Contacting family in the city to arrange support can be difficult and time consuming, where people relocate frequently and are less likely to have phone. Even where extensive effort has been applied to making transport and accommodation arrangements for Aboriginal patients the patient may not turn up.

Sudden changes in treatment times can create problems – the example was given of Aboriginal patients and families being on the train on their way from their remote community to Newcastle for treatment when notified that their appointment time had been changed.

Aboriginal liaison officers in hospitals play a big role in supporting and advocating for Aboriginal inpatients in general. The Hunter New England Area Health Region is piloting an Aboriginal Care Coordinator Role in a new model of support.

One Aboriginal woman in our area with gynaecological cancer has needed to travel to Sydney for treatment a number of times. The first couple of times she went alone but then refused to keep going for further treatment unless her family could go with her. We have put so much time and effort into arranging travel and accommodation for her and several family members and had to seek financial support to do this. And we know that if we didn't she just would not go.

Cancer Services Manager

There is a pressing need in NSW for a wider investigation of systemic issues which are barriers to Aboriginal people accessing cancer treatment and for the development of transport and accommodation services which are culturally safe and appropriate. As noted later in this report this might include consideration of the experience of other countries indigenous populations.⁴¹

In designing accommodation facilities which more closely meet the needs of Aboriginal people the following factors need to be considered:

- The design and nature of the physical space, for example openness, access to outdoor space
- Making the environment culturally safe and welcoming for Aboriginal people, using art for example
- Providing flexibility of accommodation to allow for multiple family members, where there may be several carers, who want to be in a room together with the person
- For Aboriginal people in accommodation on their own, arranging for there to be a friendly person to chat to, have a cuppa with while staying in unfamiliar surroundings

⁴¹ Ring Ian, Brown Nglare The Health Status of Indigenous peoples and others BMJ editorial 23 August 2003. <http://www.bmj.com/cgi/content/full/327/7412/404?ck=nck>

- Broader consideration of addressing the support needs of family members for Aboriginal patients needing to travel out of their community for treatment for example alternative child care. Many Aboriginal people have responsibility for grandchildren and multiple nieces and nephews.

For those needing treatment it is extremely difficult to travel, have treatment and get home again, especially difficult if there is no family support. An important strategy in enhancing the likelihood of Aboriginal people taking up treatment is the availability of support for an escort service – to travel with the person and be a guide and companion.

I have had three Aboriginal ladies in the last two years who have not gone through with their radiotherapy treatment in Sydney (two head and neck, one breast). They were all transferred to hospital for treatment – at quite advanced stages – started chemo/radio in hospital – then home, pretty poor compliance for a whole lot of reasons – too hard with families.

Palliative Care Nurse, remote area hospital

7.0. Patient and carer perspectives on ideal accommodation

Patients and carers were very appreciative of the facilities made available to them, whatever the quality. They described themselves as lucky and expressed concern for people who were not able to use the lodges.

Patient and carer interviews and focus groups consistently highlighted a number of features that combine to make “ideal” accommodation. These areas were also emphasized by the OSW and CNC survey and peer support was raised in many individual interviews with health professionals.

The features are:

1. Proximity to treatment
2. Transport to treatment
3. Affordability
4. Physical accessibility and facilities (clean, able to be self catering)
5. Peer support

There was also a strong indication that on-site management is important; facilities without any clear point of reference for questions or issues were more likely to be criticised by patients and carers and bad experiences were recounted in interview.

7.1. Proximity to treatment

The most important feature for both patients and carers is proximity to treatment. Ideally accommodation is on the hospital campus so that no transport is required and carers are able to come and go from visiting inpatients easily and safely at different times of the day.

When people are very ill, they need an advocate. On the ward they said “come at 7am to see the Doctor”, and I can do that.

Focus Group Participant (carer)

The biggest thing is access, you are on hand. They called me onto the ward because things took a turn for the worse and I could get there quickly.

Focus Group Participant (carer)

If you are close to hospital you can stay as late as you like – I could walk, with no travel costs.

Interview (carer)

Other patients and carers reported anxiety when it was difficult to get to and from accommodation. In one facility security guards were provided to walk people from the hospital to accommodation at night.

7.2. Transport

Patients and carers appreciated accommodation facilities that made transportation to treatment easy, either via volunteer drivers or shared minibus. In some cases arrangements are also made to take people shopping and for group social outings.

Radiation makes me tired – I can't drive; to have transport from accommodation to hospital is wonderful.

Focus group participant

Carers reported however that whilst transportation linked to some facilities was good for accessing treatment, it was not designed for them to access wards early or late in the day.

The absence of coordinated transport can be a stress; rural patients reported difficulties negotiating city traffic and highlighted the problems with locating and paying for parking near hospitals in Sydney.

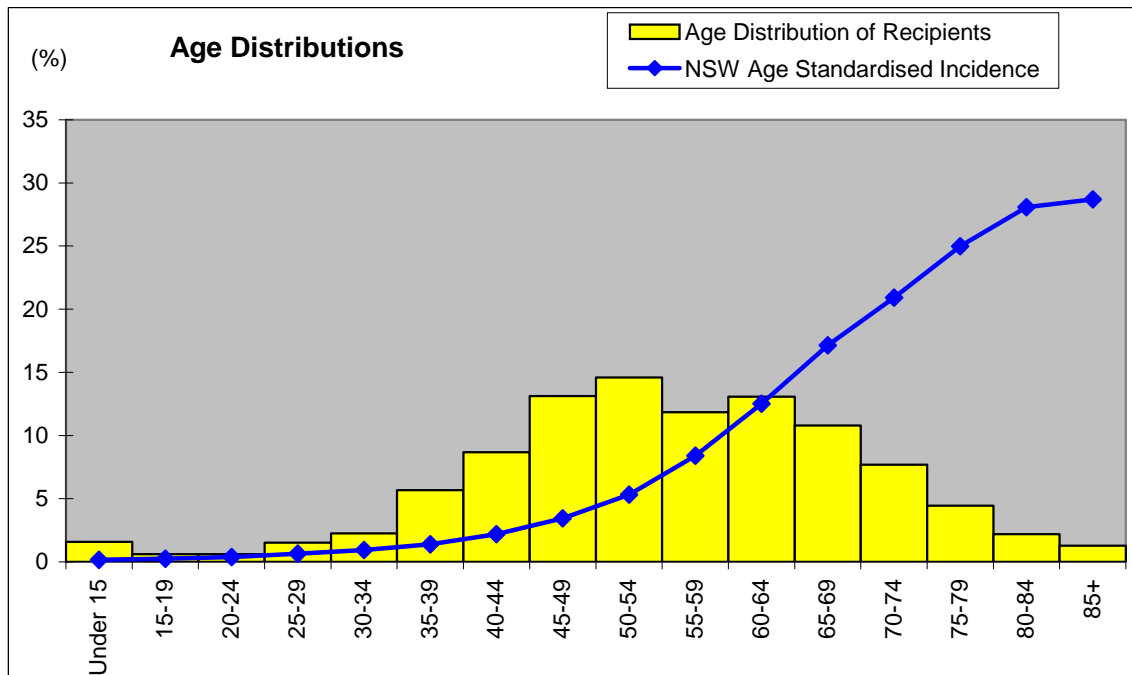
7.3. Affordability

Having quality accommodation which was affordable is critical. However even where accommodation costs are subsidized in hospital-allied facilities, there is still a significant cost factor involved for most people. One interviewee pointed out that the hospital-allied accommodation meant that they had probably spent \$10,000 over the course of her partner's treatment rather than \$30,000.

The graph below in Figure 3 relates to financial assistance provided by Cancer Council. It shows that the age distribution of recipients peaks in the 45-54 and 60-64 age groups. While the increased assistance in the 60-64 age groups is expected since the NSW cancer incidence rate increases greatly at these age groups, the proportion of recipients in the 45-54 age groups is significantly higher than the proportion of new cancer cases at this age.

Increased financial assistance for this group may then be due to family expenses and pressures as well as the impact of loss of income from reduced employment.

Figure 3: Cancer Council financial assistance and age distribution



Amongst the most disadvantaged are the people who are self employed who are unable to work and face the dual costs of supporting a home as well as costs of travel and accommodation. There is also significant disadvantage experienced by those who live within 100k of a treatment centre but are unable to drive/travel each day.

I have to travel 187kms round trip for radiotherapy and I am wondering what help is available as it is going to cost me a lot of money for the full six weeks.

Can you tell me where I may be able to get a subsidy for transport as I have to travel to xxx for radiation every day for five weeks and its 75km each way.

Queries to Cancer Council Helpline

Small support grants can make a considerable difference, one focus group participant required support to ensure he did not lose his home, a caravan, whilst paying for an accommodation lodge.

An option recommended by several health professionals was increased assistance to subsidize the cost of local commercial accommodation to ensure its affordability for patients.

“I would be in a barn if I weren’t here.”

Focus group participant

7.4. Physical access and facilities

The basic requirements are a place to sleep, bathroom and cooking facilities. People travelling for treatment did not expect luxurious accommodation; in fact in our study it was very rare for patients and carers to be critical even when they were describing accommodation with poor facilities. People valued cleanliness, security of personal food supplies in communal kitchens and not having to share a bathroom. Provision of laundry and telephone facilities at reasonable cost can be important. There was also a great appreciation of levels of comfort which provided a homely, less than spartan environment including comfortable beds, a supply of books and videos for example.

The facilities in Canberra were old, there was no en-suite. We had bed bugs. Here couldn’t be better. It is modern, fresh, clean, there is privacy but a communal kitchen means you go out and mix. If you went to a motel you would just sit in your room.

Focus Group Participant

Having access to shared communal facilities for cooking and informal socializing was valued highly.

A number of patients and carers and also several health professionals commented on the value of creating an accommodation environment which was like “a home away from home”.

7.5. Peer support

The accommodation lodge environment offers the opportunity of peer support to both patients and carers. Facilities vary in the degree to which this is cultivated, some scheduling regular morning teas or barbecues for people to

meet, others design in shared space (kitchen and lounges) to create a community setting. Comments from carers reflect the high value placed on this aspect of lodges:

We've been here three and a half months, my partner has been in hospital all that time. I don't know anyone in Sydney, the people in the lodge are like family. I've no idea where I would have been otherwise.

Focus Group Participant

Carers described lodges as an oasis, a place that understood the experience of critical illness and anticipated their needs on the cancer journey. In some ways being away from home allows them to focus on their role as carer, and also to access support themselves.

Being in the lodge is a relief, I don't have to gate keep ... the phone calls at home drive you mad when there is no news, nothing to say.

Focus Group Participant

This is my job – to support and advocate. The <lodge manager> has been marvellous.

Focus Group Participant

7.6. On site management

Patients and carers commented positively in both interview and focus group about onsite management of lodges. They valued the smooth operation of facilities and for the personal and psycho-social support role that many managers play. At those sites without on-site management, patients and carers voiced concerns about how to resolve practical problems and what to do in an emergency such as a fire alarm. Hospital security staff were called to one facility when a lock broke and the person was unable to access their room. On-site management can play a key role facilitating peer support by hosting informal events where new arrivals can meet other residents.

7.7. Additional suggestions

To support patients and carers in accessing local services and support having information about the surrounding areas is helpful. For instance, when patients are otherwise relatively well and wish to be engaged and busy, or for

carers who have time on their hands but in unfamiliar surroundings. Suggested solutions included information so that people can make contact, if they feel well enough, with libraries and community organisations. There may also be a role for volunteers who offer additional support for individuals who choose to access it. In some lodges volunteers take groups shopping for example and organize weekend excursions.

7.8. Comments on staying with family and friends

Many cancer patients are able to stay with friends and family during treatment and a number of people interviewed (patients and carers) expressed gratitude that they had that option available to them. This in many cases can afford additional personal emotional and practical support (for instance being driven to hospital for treatment). Whilst this can work very well, it is not without difficulties and there were others interviewed in the project who preferred to stay in accommodation lodges when possible.

I stayed with my daughter in law, but I didn't like being a burden. When I am here (in the accommodation facility) I don't feel guilty if I want to speak about cancer.

Comments from two Focus Group Participants

I was very lucky – I had an aunt in Sydney and it was close to the hospital and so I could stay with her each time I went for treatment.

Interviewee (Patient)

8.0. Accommodation options elsewhere

Chapter 8 describes some examples of options available to cancer patients in other states and countries.

8.1. *Hope Lodges*

The International Union Against Cancer (UICC), the only international NGO dedicated to the global control of cancer, promotes the concept of “Hope Lodges”. UICC notes that in many countries, resources for specialized cancer treatment are located in main centres, and people have to travel for cancer treatment which can take several months. “Hope Lodges” offer a way of enabling people to access treatment who would otherwise be prevented. UICC has consulted with members to develop standards for cancer accommodation and guidelines for setting up lodges⁴²; the lodges based on the standards have spread from the first (established in Toronto by the Canadian Cancer Society in 1957) to other countries including the United States, Tunisia, France and Turkey. The American Cancer Society runs 20 Hope Lodges nationwide, with a further three planned to open in 2008. In March 2008 it opened a new facility in New York, offering 60 rooms over 11 floors with communal space and kitchens. Staying there is free for patients who travel an hour or more for cancer treatment in New York City.

UICC states “Cancer Care is not just about medical technique, but should also include psycho social and economic care⁴³.” Guidelines for a site include:

- Located near the hospital
- Easily accessible
- Lodge to feel like a home – common areas, kitchen, dining room, arts and crafts room
- Individual rooms (en-suite)
- Admin offices
- An infirmary
- An office for a social worker
- Wheelchair/ramps

⁴² Web address: http://www.uicc.org/index.php?option=com_content&task=view&id=14276&Itemid=200

⁴³ UICC Handbook on website page 6

8.2. *South Australia*

The Cancer Council in South Australia owns and operates three facilities in Adelaide:

- Greenhill Lodge, a 55 room model with the equivalent of a three and a half star rating
- Flinders Lodge, a 66 room motel
- Seaview Lodge, a group of eight single bedroom and one two bedroom self-contained units.

Priority is given to cancer patients and carers, with any vacant accommodation made available to people with other medical conditions, friends of people with cancer and commercial guests. Rates vary as summarized in the table below:

Table 2: Accommodation rates in South Australia

Cancer patients and carers living more than 100k from Adelaide	\$30 single/ \$60 double
Cancer patients and carers who are pensioners/ health care card holders living less than 100k from Adelaide	By arrangement
People with other medical conditions	\$40 single/ \$60 double
Commercial guests	\$60 single/ \$80 double

The facilities are tailored for cancer patients, with an on-site part-time OSW, volunteer program, support group, meals suitable for specialized dietary requirements and information. Transport to treatment is arranged with a volunteer mini bus.

One of the sites also has a transit room for rural patients driven in by bus for treatment. It enables them to wait in comfort away from the hospital environment whilst other patients complete their appointments. This service is a pilot of the State Health Service. The bus driver is paid and is assisted by a volunteer.

8.3. *Victoria - Medihotels*

In 2001 Victoria started to introduce Medihotels as part of a strategy to manage demand for acute beds⁴⁴. It is an alternate model of care which

⁴⁴ Victorian Department of Human Services Review of Medihotels: Future Directions Summary Report

provides accommodation for patients who do not need acute care but need to be on-site or close to care, perhaps after an operation or during treatment. The model is designed to manage demand by freeing up multi-day beds. Some medical supervision is provided but not clinical care; patients are admitted to hospital if required, for example because of complications.

Eight hospitals now run Medihotels, with a range of models including locating the hotel in ward areas, in separate buildings and within a commercial hotel. A summary of the facilities is in the appendix.

A 2006 detailed evaluation of the Medihotels indicates that the goals of freeing up acute beds has been achieved and that patient satisfaction is high.

8.4. *Tasmania – Spurr Wing Lodge, Launceston*

Spurr Wing is an accommodation lodge in Launceston for cancer patients set up in collaboration with the Peter McCallum Cancer Clinic and situated directly opposite the hospital. It was established and is maintained by a consortium of nine local service clubs and charities who have equal representation on the governing Board. Each member “owns” a room and fundraises for its ongoing maintenance. Patients from remote and interstate locations and their families are able to use the facilities. The full time on-site manager has a clinical background in cancer care. When it was noticed that many patients from isolated rural Tasmania were most concerned about separation from their dogs and had no means of ensuring the animals were okay; they are setting up on-site kennels in response.

Hobart currently has no hospital-allied accommodation and the Cancer Council Tasmania assists people with vouchers subsidizing the cost of commercial accommodation.

8.5. *New Zealand – Domain Lodge Auckland*

New Zealand has six cancer treatment centres for radiation oncology. Auckland Hamilton, Palmerston North, Wellington, Christchurch and Dunedin. Patients are not able to choose where they are treated and all offer the same radiotherapy protocols. The Cancer Societies in New Zealand have been involved in accommodation for 30-40 years. The other five regions offer hostel type accommodation, largely run by volunteers, some with a part-time manager. Only patients are catered for, no supporters.

Auckland Cancer Council (AKCC) has been on the site of the lodge for 30 years, originally purchasing an old motel near the hospital for patient accommodation. Redeveloping the site 10 years ago, Auckland Cancer Society chose to develop patient accommodation which would also appeal to a commercial and tourist market.

Domain Lodge is located five minutes walk from the hospital, 10 minutes from the university, and convenient for a park and city centre. It houses the Cancer Councils head office, fundraising and support functions as well as providing patient and commercial accommodation. Researchers are collocated with the university.

Domain lodge offers hotel standard accommodation to patients and supporters. Paid reception and housekeeping staff are employed. Patients have access to AKCC support (nursing, support groups, library) if they wish. Residents share a communal kitchen which is a deliberate strategy to encourage people to mix with others and avoid isolation during treatment. Most people get themselves to and from treatment, although transport services are available.

The only people turned away are those who are too frail, those who need medical or hospice care.

People are encouraged to return home at weekends and maintain links with their communities – this offers the opportunity to cater for weekend visitors to Auckland.

Patients in New Zealand who have to travel for treatment are subsidized by the Ministry of Health⁴⁵. The New Zealand scheme has variable rates so reimbursement for accommodation is higher in Auckland (up to \$100 per night) than in a regional area in line with the actual cost of accommodation.

In practice AKCC subsidises those who cannot pay and those not eligible for the subsidy (for example they live too close but are unable to travel to treatment). AKCC covers the gap through its commercial and fundraising activities. Accommodation is described as a “cornerstone” activity.

AKCC employs a specialist hotel manager supported by the Board and senior staff.

Maori and Cancer Services

The Ministry of Health in New Zealand commissioned a report into access to cancer services for Maori. Published in 2005⁴⁶ the report identifies a number of challenges for the Maori community, they are 18% more likely to be diagnosed with cancer than non-Maori, but nearly twice as likely as to die from cancer. The report makes a number of recommendations designed to facilitate access to services and recognize the distinctive nature of Maori Whanau family/community involvement in the health setting. Strategies include the need for specialist publications, resources and health promotion

⁴⁵<http://www.moh.govt.nz/moh.nsf/c7ad5e032528c34c4c2566690076db9b/dfdc0c6efbdb241fcc2570d700031842?OpenDocument>

⁴⁶[http://www.moh.govt.nz/moh.nsf/0/B454B56F387CEE0FCC256FF70015139F/\\$File/maoricancerserviceaccess.pdf](http://www.moh.govt.nz/moh.nsf/0/B454B56F387CEE0FCC256FF70015139F/$File/maoricancerserviceaccess.pdf)

activities as well as practical resourcing of culturally appropriate accommodation and travel support as well as child care.

8.6. Canada

Canadian patients who need to travel more than 40km for their cancer treatment are able to stay free (Monday – Friday) at lodges established by Cancer Treatment Centres and the Canadian Cancer Society. There are eight lodges across Ontario for example and three in British Columbia. Other Canadian States' Cancer Councils offer different support including financial assistance to attend lodges, discounted accommodation at hotels near hospitals through a partnership with Westin Hotels where there are no lodges (Alberta). The extract⁴⁷ below describes facilities in British Columbia.

Accommodation

If you are travelling away from your loved ones for outpatient cancer care, we invite you in the Interior, on the Island or in Vancouver.

If space permits, patients undergoing other health related treatments are also welcome. The daily rate at any Lodge includes three meals a day. We provide 24-hour nursing supervision, caring volunteer support and a host of amenities. There are comfortable fireside lounges, activity rooms, libraries and great food - all in close proximity to treatment centres. Accommodation is provided on a shared basis, with en-suite bathrooms. The facilities are smoke-free, scent-free and wheelchair accessible.

If you will be staying at a Lodge, you'll need to be mobile and able to manage your personal care. Otherwise, we suggest that a support person accompany you.

Canada has also undertaken work to improve the health outcomes of the indigenous population facing similar challenges to Australia.

8.7. Ireland – St Lukes Dublin

Ireland has four radiotherapy treatment centres. Three of these are in Dublin and one in Cork. A key objective of the National strategy is equal access to

⁴⁷ http://www.cancer.ca/ccs/internet/standard/0,2939,3278_376544__langId-en,00.html

treatment regardless of location. Small compared with NSW at 70,000km² (NSW is over 800,000 km²), nevertheless Ireland has significant problems in ensuring access to treatment, local roads and transport infrastructure is lacking⁴⁸.

St Luke's hospital is Ireland's only specialist oncology hospital with six linear accelerators. It offers free accommodation for radiotherapy patients in a Monday- Friday service at Oakland Lodge, in the gardens of the hospital. The facility has 49 rooms of which 28 have a second bed for a carer. 24 hour nursing cover is provided with two full-time nurses on duty in the day with a third in the afternoon and one at night. Breast cancer nurses, Social workers and support group facilitators visit the lodge on a regular basis. There is also a program of hospital managed/funded complementary therapies (aromatherapy, massage) employing a full-time therapist. Leisure activities such as media/computer room arts and crafts and gardening are offered.

The facility is funded by the Department of Health and the "Friends of St Lukes" a charitable foundation.

8.8. *Billeting*

As part of the exploration of the options for accommodation for people with cancer in NSW who have to travel for treatment, we also investigated billeting. This option was suggested by the Advisory Committee to the Cancer Council in Western Sydney, and has also been raised by two cancer patients/families in interview.

As far as we have been able to establish, there are no billeting or home-stay programs currently in Australia for cancer patients or their families. BCNA uses billeting for conference participants. Issues arising in billeting cancer patients are listed in Appendix 2.

⁴⁸ Boyd, Alan Patient Empowerment and Autonomy in Cancer Care: Oakland Lodge and a Dedicated Transport Service St Luke's Hospital Dublin. 13 May 2005. Paper published by European Health Management Association

9.0. Future requirements for accommodation in NSW

The review findings reported here provide important evidence and information about the nature and quality of accommodation features and the supporting system arrangements which are required to meet the needs of cancer patients and carers. There are also clearly identifiable areas of existing unmet needs both in terms of quality and quantity which need to be addressed.

There are also future capacity needs which need to be considered as the incidence and prevalence of cancer are forecast to increase.

The key questions framing deliberation in estimating future requirements are:

- Where are accommodation facilities required – determined for cancer patients largely on the future location of radiation therapy treatment centres?
- What type of accommodation facilities will best meet the need - specialized cancer facilities only, multiple health related accommodation support needs, commercial/public facilities mix, varied levels of care and support?
- What size/capacity of facilities are required – for which patients and carers, for how many, for different family configurations?
- What business models/partnership arrangements will make the accommodation facility sustainable - for example, what are the appropriate mixes of roles for State or Federal Government, individual NGO, multiple NGOs, corporate partners, multiple partnerships?
- What levels and sources of income will be necessary for sustainability – what are the levels of dependence on voluntary income?

The issue of ensuring an appropriate standard of accommodation is critical, both in terms of supporting patients on the cancer journey and providing culturally safe and welcoming environments for diverse community needs.

9.1. *Proposed new radiotherapy units across NSW*

Research suggests that radiotherapy in cancer treatment is indicated in 52% of cases⁴⁹. Actual radiotherapy utilization is significantly below this figure, using two areas of NSW as examples, proportions of patients with new

⁴⁹ Delaney G, Jacob S, Featherstone C, Barton M The Role of Radiotherapy in Cancer Treatment Estimating Optimal Utilization from a Review of Evidence-Based Clinical Guidelines. *American Cancer Society* 2005

cancers actually receiving radiotherapy treatment was approximately 30% for Hunter residents and 42% for New England⁵⁰ (2003 figures).

Detailed planning has been undertaken by NSW Health through the Joint Radiotherapy Planning Committee for the future establishment of radiation therapy units. Extensive modelling to determine statewide need and service feasibility has involved analysis of complex data including demographic trends, epidemiological projections of cancer incidence, likely patient flows (see below), and consideration of local infrastructure capacity, service arrangements etc. in identified areas of need. A key consideration for the establishment of new treatment units is the local capacity for stable staffing for units to ensure optimal utilization and access for people in the region (see the map at Figure 3 below).

Planning for any new radiation therapy units should be undertaken in tandem with establishment of, wherever possible, co-located accommodation which meets the UICC standards.

Private providers have also received Australian Government approval to establish new private Radiation Oncology Treatment Centres in several Sydney locations.

9.2. Location of new accommodation facilities

1. Existing demand indicates that new accommodation facilities are required to support existing treatment services at:

- Sydney Central in the vicinity of RPAH
- Newcastle
- North Sydney

2. Short term future need to support new radiation therapy units:

- Lismore – new unit due to be commissioned in 2010. Extensive planning and funds raised already undertaken for accommodation facility with combined cancer and paediatric facility. Cancer Council has allocated support monies
- Orange – new unit due to be commissioned in June 2010. Need for accommodation identified by community and services, need to address issues for Dubbo. Early planning and discussion underway, Council is very supportive.

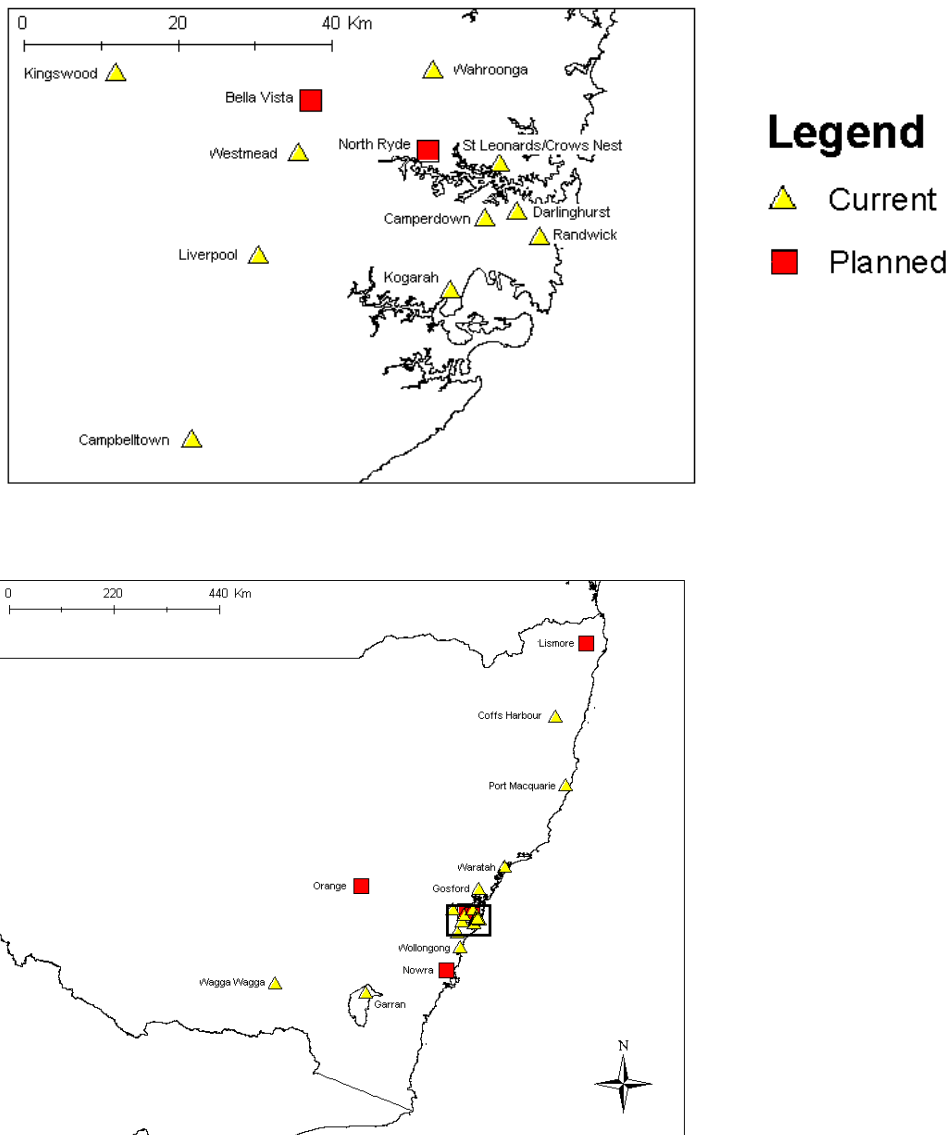
⁵⁰ Hunter New England Cancer Services Plan 2006-2010 (December 2006)

3. Longer term future need for accommodation to support proposed new units/ additional bunkers at:

- Wollongong/Shoalhaven
- Central Coast
- Liverpool

Figure 3: NSW Radiotherapy Centres Map

Radiotherapy Centre Locations



9.3. Type of future accommodation facilities

Patient type – cancer or broader health issue

Given the complexity of factors that impact on numbers of people requiring accommodation and the varied levels of success in maintaining high occupancy rates in recently established cancer facilities, a range of broader approaches may better suit future requirements.

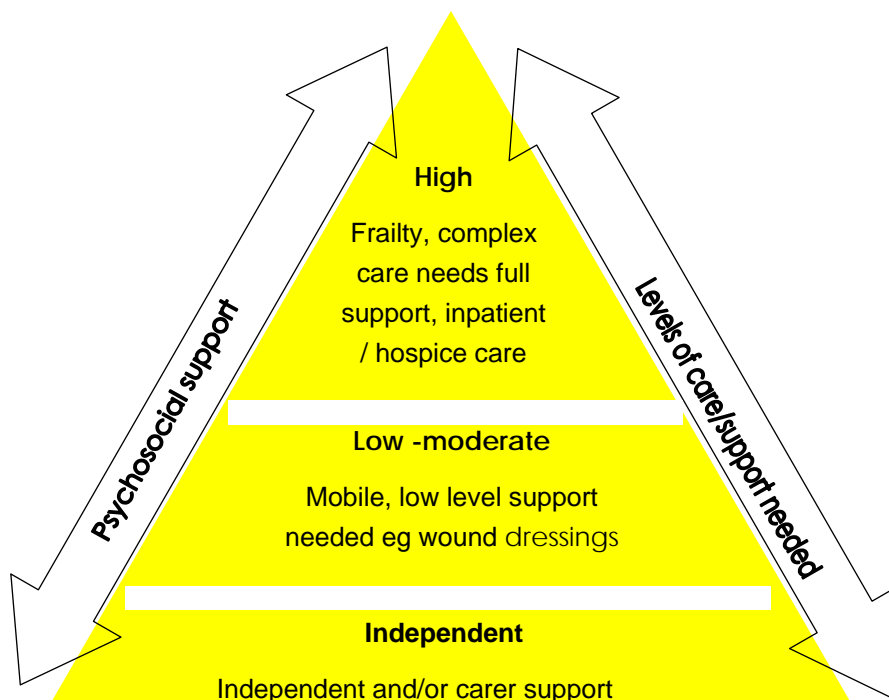
There are wider needs for various types of accommodation and levels of support for patients and carers in the health system other than cancer patients. This is particularly so with the ageing of the population and the increasing prevalence of chronic conditions and complex co-morbidities. While specific purpose built cancer accommodation may be appropriate and viable in some locations, other sites, particularly in regional areas may serve community needs better by being inclusive of broader needs such as for renal and cardiac patients, step down and transitional care patients (see below) and carers and families of inpatients.

This can allow for greater alignment with Area Health Service facility planning and facilitate the establishment of potential collaborative ventures with a range of partners including Area Health Service, local government, other NGOs, service clubs, corporate/commercial entities.

Care and support levels

People with cancer requiring accommodation have varying care support needs as indicated in Figure 4 below.

Figure 4: Levels of care support needed



With the ageing of the population and the increasing prevalence of older patients with chronic conditions and multiple co-morbidities there is increasing pressure on health systems to appropriately meet patient needs and contain costs. Acute shortages of hospital beds is an increasing problem and frequently due to occupancy by older patients with a range of complex conditions. Patients may be admitted due to inadequate community support or insufficient time on emergency presentation for detailed assessment. Other patients with cancer and other conditions following treatment may have levels of need for care and support which prevent them from managing independently at home or in the existing style of most cancer accommodation facilities.

Usually these patients do not require the level of care provided in an acute facility, however will often need to be admitted as an inpatient either during or following cancer or other treatment. This situation is currently very costly for health systems and limited hospital beds are utilized inappropriately. Existing cancer accommodation facilities, other than Jean Colvin Hospital, do not provide any level of nursing or personal care and require patients to be able to manage independently or with a carer.

A range of initiatives are being undertaken at state and national level to address this issue through hospital admission reduction or diversion programs at the one end and step-down and rehabilitation facilities at the other. Also transitional care programs provide lower intensity care in a live-in setting⁵¹ following which patients may subsequently return to independent living or move to alternative long term accommodation such as a nursing home.

Consideration of meeting such broader community needs for accommodation could include facilities with varied levels of care according to need. With a relatively basic level of additional personal and/or nursing care, this type of facility could be an adjunct to hospital services in providing a transitional or step-down facility to prevent admissions or to speed discharge time. There are valuable opportunities to develop mixed accommodation models which link with Area Health Service strategies – including transitional aged care programs and clinical service redesign initiatives.

Size and capacity of accommodation facilities to meet future requirements

There are challenges in predicting accommodation capacity need in a particular location. In designing and building new accommodation facilities initial determination of projected capacity need (in terms of numbers of beds/rooms) is a prime planning consideration. This is both to meet the

⁵¹ 'Live-in' setting refers to facility based accommodation with a more home-like, less institutional feel and with space available for therapy. This setting can be part of an existing aged care home or health facility, for example a separate wing of a hospital.

community demand/need and also to devise appropriate business models that will ensure financial viability for the organizations involved in the venture. There are also challenges due to the complex interaction of likely factors which will influence patient flow and accommodation needs and uptake at each location and there needs to be a detailed site specific analysis to inform each new accommodation venture.

Appendix 2 contains a worksheet applied to a recent exercise to determine accommodation required in an area of New South Wales as an illustration of the process involved.

Predicting patient flows to a specific treatment unit

Patient flows to a particular radiation therapy unit based on projected local cancer incidence projections will vary according to:

- Type of cancer and treatment (surgery/chemo/radiotherapy)
- Stage of progression and severity of disease
- Factors which may require the person to be admitted as an inpatient even if treatment is deliverable by outpatient facilities for example frailty, dementia, co-morbidities restricting mobility, need for care support (for example head/neck) availability of a carer
- Patient choice of treatment type
- Patient preference for treatment centre location
- Doctor referral pathway to treatment centre for example Sydney/Brisbane rather than Coffs Harbour
- Delays and waiting lists at the treatment centre – may result in patients choosing alternative centres where they can get treatment more quickly.

Predicting patient accommodation needs

Apart from varying patient flows locally, the level of need for use of purpose built accommodation by patients using a radiation therapy treatment service will be influenced by a further set of (largely unpredictable variables) such as:

- Distance of home from treatment centre i.e. numbers of projected cancer patients living more than 100kms from the treatment centre
- Availability of a carer
- Access to family and friends to stay with
- Personal choices regarding alternative accommodation
- Levels of mobility, independence, frailty

- Carer, family requirements for accommodation
- Outcomes, responses to treatment
- Decisions regarding continuation/completion of treatment
- Knowledge of accommodation availability.

Other local variables (particularly in regional centres) which may influence demand for accommodation and relate specifically to the operation of the treatment service include the total capacity of treatment unit/s and ability to operate to full capacity which can be affected by workforce issues and staff unavailability, equipment breakdown, selective scheduling of patients, waiting lists for prioritisation of patients.

9.4. *Broader health and accommodation needs and opportunities*

Health services face particular challenges with the provision of services for an ageing population. Health services have an urgent need to reduce the occupancy of costly acute beds for patients who are not well enough to manage independently at home, but do not require the level of inpatient care of an acute setting. Some of these may be local residents, other patients may live at a distance and need to travel for tests or procedures to the larger regional centre and not be well or robust enough to return on the same day. This so-called “bed-blocking” results in limited availability and extended waiting lists for hospital beds and has been a core focus of activity in NSW over recent years through the Clinical Services Redesign Program and a range of new initiatives for older people mostly focused on diverting people into more appropriate assessment, services and support in community settings. Commonwealth Transitional Care Programs provide packages of care in live-in settings to improve physical and mental confidence to restore optimum levels of independence following a hospital stay⁵².

Other patients and carers requiring accommodation include for instance:

- Older people undergoing rehabilitation or step-down care/support post acute admission
- People undergoing cardiac catheterization
- Patients undergoing renal dialysis
- Families of young people and children who are inpatients.

Area Health Services Aged Care and Rehabilitation Plans detail a range of strategies to provide improved care for older people incorporating short term accommodation facilities such as for the Transitional Residential and Short

⁵² Details can be accessed at <http://www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf/Content/transition+care-1>

Term Accommodation plans which could potentially be linked with a broader accommodation service for cancer patients.

9.5. *Developing sustainable business models*

In order to develop robust models of accommodation and support which are sustainable, tailoring of alternative approaches to different sites will be important.

Key considerations/questions for each potential new location are:

- Whether the facility will be for cancer patient's families and carers only or whether other patients and families will be included?
- Whether a combination with a commercial enterprise is desired and/or feasible?
- Potential partners in the initiative for example service clubs, area health services, private providers, other charities, community groups or foundations, other disease/health groups?

Current hospital-allied accommodation facilities vary in the extent to which they are self sustaining. Some facilities receive significant in-kind support from hospitals including administration of bookings and invoicing, assistance with cleaning, laundry and general maintenance. Without these types of support, facilities need to ensure ongoing fundraising and community support, as income from IPTAAS will not cover items such as the costs of depreciation or where loans have been taken out to build the facility.

Many services are reliant on IPTAAS for all of their revenue, however there is no process in place to review the level of subsidy to check if any adjustments are needed to keep pace with changes in the economy. We understand that the level of contribution \$33 per night has not changed since 1987⁵³. This means the real value of the IPTAAS contribution goes down as the cost of living increases.

A range of options and configurations need to be considered in the design and development of facilities which are tailored to meet needs at each site. Any new facility will need to address community and population health needs, resource availability, potential partners and opportunities, individual organizational needs and priorities. Specific consideration needs to be given to a range of related factors (see Tables 3 and 4 below) including intended occupants, the accommodation style and types of facilities to be provided, the levels of care and support required to meet the needs of the intended occupants and the location of the facility. Decisions need to be made about management and partnership arrangements, funding options and income

⁵³ Information from Ronald McDonald House provided to Senate inquiry paragraph 3.89

sources, in line with the desired investment and commitment levels of each interested party in order to develop a financially sustainable facility.

A detailed business case and feasibility study taking account of all of these factors needs to be undertaken for each proposed new facility.

Table 3: Cancer accommodation models and management/business options

Variable	Options	Examples
Occupants	Patient and carer only	Cancer only Other conditions – cardiac, renal, sleep clinic, Hospital bed diversion e.g. frail aged/post inpatient – early discharge/step-down
	Families	Single or multiple capacity A & E provision
	Hospital staff	Registrars, students etc
	Commercial/ paying guests	Adelaide, Auckland, when vacancy
Style and facilities	Self-contained units	Leukaemia Foundation - reliant on patient/carer independence
	Self catering units plus communal/ social facilities	Bezzina Lodge
	Bedroom plus communal/ social facilities	Lilier Lodge
	Hostel – room only	
	On site manager	Full time 24 hours including weekend Working week only Limited availability/phone access

	Emergency contact	Phone/buzzer
	Hotel/ motel/ B&B	Subsidized/not subsidized
Levels of care/ support	No patient/carer support	Full independence/carer support expected
	Variable levels of nursing support	Wound dressing, observations etc
	Full 24 hour nursing support	Access to emergency medical care
Location	On hospital campus	Easy walking distance
	Off campus	Regular free transport to treatment centre (volunteer/other)
		No transport – private/public transport only
Establishment/ management	Single entity NGO/ charity/ service club	Sole management -
	Partnership – NFP	2 NGOs/ multiple NGO/ service clubs e.g. Spurr Wing
	Partnership – NFP and FP	1 or more NGO/service club corporate/philanthropic
	Private FP	
	Multiple entity partnership	1+ NGO, government/corporate/philanthropic
Investment level	Capital grant - start up only	
	Ongoing management/ maintenance	
	Periodic contribution/ grants	
Income sources	IPTAAS only	With or without patient co-contribution

	Patient Private health fund	
	Subsidies – in kind from hospital	Maintenance/depreciation Administration of bookings, payments, IPTAAS Cleaning
	Grants/funds	Local fund raising contributions

Table 4: Financial considerations in establishing a facility

Costs	Items to be considered
Establishment/start up	<p>Land, capital – building or refurbishment</p> <p>Legal – possibly setting up new legal entity to run service, considering who owns property, runs risk of any financial losses etc.</p> <p>Costs of raising funding</p> <p>Costs of project management</p> <p>Furnishing rooms and other essential equipment</p> <p>Registration/inspections</p> <p>Possible transport provision / purchase of vehicle</p>
On-going	<p>Depreciation</p> <p>Insurance/ rates/ utilities/ phone</p> <p>Facility governance</p> <p>Taking and administering bookings</p> <p>Staffing/ on-site management/ reception nursing</p> <p>Training</p> <p>Patient support</p> <p>Cleaning</p> <p>Laundry (on or off-site)</p> <p>Maintenance/ gardening/ waste</p> <p>Perishables</p> <p>Administration and running costs of transport if required</p> <p>Ongoing fundraising if required (for new/replacement equipment, additional patient supports etc) and donor support</p> <p>Marketing/ publicity/ advertising</p> <p>Possibly franchise arrangements (if commercial model tied to chain)</p>

10.0. APPENDICES

Appendix 1: Tables summarising numbers interviewed

Summary of work with patients (numbers of people)

Location	Focus Group (number of sessions)	Face to face interview	Telephone interview
Jean Colvin	18 (2)	0	0
Bezzina House	0	1	0
Wagga Wagga	11 (1)	2	0
Dubbo	0	3	2
Coffs	0	2	0
Lismore	0	0	2
Total	29	8	4

Summary of work with families/carers

Location	Focus Group (number of sessions)	Face to face interview	Telephone interview
Jean Colvin	0	0	0
Bezzina House	4 (1)	1	0
Wagga Wagga	7 (1)	2	0
Dubbo	0	3	4
Coffs	0	1	0
Lismore	0	2	2
	11	0	6

Summary of work with professionals

	Interview face to face	Telephone interview	Discussion groups*
OSW - rural	1 (Dubbo) 1 (Lismore)	1 (Coffs) 2 (Grafton)	35
Other SW/WW	3 Dubbo (1 ALO)	0	
OSW – Sydney	2	3	
CNC – rural Or CCC	2 (Dubbo) 2 (Wagga) 1 (Lismore)	1 (Moree) 1 (Coffs)	
CNC - Sydney	0	1	0
Palliative Care – rural	1 Dubbo	1 Lismore	0
NUM Oncology unit - rural	1 Dubbo	1 Coffs	0
Clinician – surgeon	0	0	1
Clinician – radiation oncologist	1	7	
Can Assist - rural	0	1	0

Includes inception group, Cancer Institute conference and SWOG meeting, excludes online survey.



Appendix 2: Questions for individual interviews

What type of cancer have you experienced – yourself or your family member?

What has this involved in relation to having to travel for treatment?

Have any decisions about treatment options been influenced by where the treatment would take place?

What has been your experience in accessing accommodation to enable you to get treatment or for you to support, care for or visit a person having treatment?

Who arranged it?

Where did you stay?

How well did it suit your needs?

What sort of costs were associated with the accommodation? How much of this was out of your pocket?

What do you consider are the most important features in accommodation for people who have to travel away from home for cancer treatment?

What has been the impact for you and family and friends of having to travel for treatment?

What do you think would make things better for people with cancer who have to travel away from home for treatment?

Focus Group format/questions

- 1 Thanks for attending
- 2 Introduce selves
- 3 Explain project aims
- 4 Issue consent card, emphasise confidentiality, can leave at any time, how material will be used. Ask for signature
- 5 Start questions
 - a. Ask people to introduce themselves – first name, where from, why they are in Sydney, keep record to note type of cancer, type of accommodation(s) used, patient or family member
 - b. Ask why they decided to stay at this lodge? Were there any alternatives?
 - c. How has travelling to get treatment impacted on them/their families?
 - d. What features is it important that accommodation for people with cancer has?
 - e. What is their experience of transport from home to treatment/ from the lodge to treatment?
 - f. Any ideas for the future?
- 6 Thanks for attending. Highlight helpline number (on cards?) and invite to use callback service if they have more to add (or friends so).

Accommodation Review Survey

1. Review of Accommodation for People with Cancer in NSW

The aim of this survey is to gather the views and experience of people involved in arranging accommodation and transport for people with cancer during their treatment.

It should take you about 10 minutes to complete online.

If you prefer, a paper copy is available.

The survey is anonymous, however if you are willing to become more involved, there are two ways you can help:

1. by giving us more information in a telephone interview
2. by collecting information so that we can find out more about the experiences of people with cancer.

There is a section at the end of the survey where you can add your details if you are able to help.

Many thanks
Angela Cotroneo Chair SWOG
Graham Newling TCCN

2. Referring patients to accommodation

1. Please tell us the name of the hospital(s) you are linked with or based in

2. Do you help patients, carers or family members to find a place to stay while they need to be away from home for treatment?

- yes
 no

3. Who else is involved in this process? Please tick all that apply

- Clinical Nurse Consultant
 Accommodation Liaison Officer
 Clinician's assistant
 Palliative care nurse
 Ward staff
 Radio therapy staff
 Cancer Nurse Specialist
 Cancer Care Coordinator
 Medical officer
 Secretary to Doctor
Other (please specify)

4. If others are also involved in making frequent referrals to accommodation services, please add their contact details here so that we can send them a survey

Name
Position
Email address

Accommodation Review Survey

Name
Position
Email address

5. What types of accommodation are you referring patients to at present? Please tick all that apply

- Specialised hospital accommodation service
- Hotel (many rooms, reception staffed etc)
- Bed and Breakfast or similar (few rooms, no reception)
- Boarding house
- Rooms in staff residence
- Hospice
- Private hospital
- Caravan Park
- In Patient beds
- Nursing home
- Hostel

Other (please specify)

6. Please enter the names of the places you refer patients or families to for SUPPORTED accommodation (Support = staff on site to assist patients with cancer)

7. Please enter the names of places you refer people to for UNSUPPORTED accommodation

8. What proportion of your patients do you assist by arranging or providing accommodation

- not many - less than 10% 10-25% 25-50% 50-75% over 75%

9. What proportion of cancer patients from your local area need to stay away from home to receive treatment?

- less than 10% 10-25% 25-50% 50-75% over 75%

Accommodation Review Survey

10. What proportion of those patients would you assist to arrange accommodation?

- less than 10%
 10-25%
 25-50%
 50-75%
 over 75%

11. If you are in a metropolitan hospital, what proportion of rural patients would you assist to find accommodation:

- less than 10%
 10-25%
 25-50%
 50-75%
 over 75%

12. Please rate these factors for their significance in determining a patient's need for assistance with accommodation?

1=not significant 5=very significant

	1 - not significant	2	3	4	5 - very significant
Type of cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stage of cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Age of patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Availability of family member/carer to also travel	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Financial circumstances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mobility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psycho social factors (home situation/stress)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health/dementia/learning difficulty	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Need for specialised support / supervision / care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Remote home base / unfamiliar with city	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>				

13. What attributes of hospital and allied accommodation are most important to meet the needs of cancer patients? Please rate the following attributes on a scale of 1 not important to 5 essential

	1 - not important	2	3	4	5 - essential
Proximity to treatment centre	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Staffed 24h/day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transport	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Affordable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Range of food options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Self contained units	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical accessibility (lift/ramps etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Quality or star rating of the premises	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caters for Families	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Peer support available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to range of health professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bulk billing for IPTAAS/equivalent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comments:	<input type="text"/>				

Accommodation Review Survey

14. Which of the following options do you think would improve the coordination of accommodation options for cancer patients? Tick all that apply

- One stop shop - a single point for referral for accommodation in all Sydney metro hospitals
- Dedicated Accommodation Officers located in major hospitals
- Rural Liaison Nurses in metro hospitals
- Resources to support booking at point of diagnosis
- Kiosk in hospitals
- More resources at your workplace to help make enquiries and arrangements for patients
- Status Quo
- Website / enhanced information

Other (please specify)

3. Transport

15. Do you help cancer patients and their families by arranging transport to their treatment?

- Yes
- No

16. What proportion of cancer patients in your hospital require assistance with transport to treatment

- None
- Less than 25%
- 25-50%
- 50% - 75%
- Over 75%

17. What are the forms of transport disadvantage experienced by the patients you assist ? (Tick all that apply)

- Don't own car
- Own car but are too ill to drive and have no supporting driver
- Too old to drive and have no supporting driver
- No appropriate public or community transport available
- Can't afford public or community transport
- Too old or frail for public transport which is available
- Distance to drive too great
- Condition too serious to consider transport
- Health risks posed by shared transport
- Unable to park close to treatment

Other (please specify)

18. How would you rate transport to treatment services for cancer patients in your area?

- Awful
- Bad
- Average
- Good
- Excellent

Appendix 3: IPTAAS method of calculating distance travelled

TRAVEL 100km distance limit: The 100km one-way limit reflects the principal reason for and primary focus of the Scheme, which is to assist isolated rural people who are most disadvantaged in accessing specialist medical treatment not available locally. The most direct route from the claimant's usual place of residence to the treatment centre measures the distance travelled. To enable Transport for Health-Health Transport Unit to apply standard measurements between localities to ensure a consistent and objective application of the distance criteria under the Scheme, Transport for Health-Health Transport Units are supplied with global positioning system (GPS) software which is updated regularly to take into account improved road networks and improved technology.

When calculating the distance travelled: Officers are to ensure that the distance travelled is calculated as the most direct route from the claimant's usual residential address to the actual address of the treatment/consultation. In all cases, the full address is to be used, for example, 12 Smith Street Smithville NSW. Where a street number cannot be located by the distance calculator, the street name is to be used e.g. Smith Street Smithville NSW. Where a claimant lives on a property and does not have a conventional street address, the IPTAAS application form asks the claimant to advise the distance from their property to the first town they reach on their journey. Officers should then calculate the distance travelled from the outermost boundary of that town to the treatment address.

If officers do not have access to GPS to calculate distances, there are a number of web-based tools that allow distance calculation from specific address to specific address. These sites include <http://www.whereis.com.au> and <http://www.nrma.com.au>

Source: IPTAAS Administration Manual

Appendix 4: Recommendations Senate Community Affairs Committee

Inquiry “Highway to Health”

20 September 2007

List of Recommendations

Recommendation 1

7.105

That the next Australian Health Care Agreement recognise the fundamental importance of patient assisted travel schemes and include:

- A clear commitment to improvement of services;
- A clear allocation of funding for the schemes;
- A clear articulation of the services and supports that people using transport schemes can access; and
- A commitment to regular monitoring of access and service provision.

Recommendation 2

7.110 That as a matter of urgency, the Australian Health Ministers' Advisory Council establish a taskforce comprised of government, consumer and practitioner representatives to develop a set of national standards for patient assisted travel schemes that ensure equity of access to medical services for people living in rural, regional and remote Australia.

7.111 That, in establishing national standards, the taskforce:

- Identify relevant legislative, geographic, demographic and health service variables of the States and Territories impacting on access;
- Identify barriers to access including costs of travel and accommodation, restrictions on escort eligibility and access to transport;
- Assess the impact of co-payments;
- Identify mechanisms to improve access for patients travelling between jurisdictions;

- Identify, as a matter of priority, core, minimum standards that are relevant to all jurisdictions particularly in relation to eligibility criteria and subsidy levels; and
- Give consideration to the development of optimal, outcomes-based standards that support consistent, quality outcomes for consumers, whilst enabling different State/Territory approaches that are responsive to local need.

7.112 Development of the national standards should include (but not be limited by) consideration of the following areas:

- Patient escorts including approval for:
- Psycho-social support;
- Approval for more than one caregiver to accompany a child; and
- Approval for a caregiver to accompany a pregnant woman.
- Eligibility:
- Identify a means other than the distance threshold to determine eligibility that takes into account a broader range of factors such as public transport access and road conditions; and
- Referral on the basis of the nearest appropriate specialists where an appointment can be secured within a clinically acceptable timeframe.
- Appeals processes.

Recommendation 3

7.114 That the taskforce report to the Australian Health Ministers' Advisory Council expeditiously so that national standards can be formulated and instituted within twelve months of tabling of the Committee's report.

Recommendation 4

7.116 That the taskforce develop a performance monitoring framework, which enables ongoing assessment of State/Territory travel schemes against the national standards and relevant goals set out in the (revised) Healthy Horizons Framework, and facilitates continuous quality improvement.

Recommendation 5

7.117 That the Australian Health Ministers' Advisory Council establish a mechanism to monitor performance, identify areas for improvement and review the standards as required.

Recommendation 6

7.119 That the taskforce review existing administrative arrangements to make them less complex, including development of a simplified generic application form; consideration of an on-line application process; and revision of the authorisation processes.

Recommendation 7

7.123 That the Australian Health Ministers' Advisory Council determine transport and accommodation subsidy rates that better reflect a reasonable proportion of actual travel costs and encourage people to access treatment early.

Recommendation 8

7.124 That the taskforce identify appropriate mechanisms against which to review subsidy levels on a regular basis to keep pace with changes in living costs.

Recommendation 9

7.125 That all States and Territories adopt a pre-payment system, whether by vouchers, tickets or advance bookings, for patients experiencing financial difficulty with the initial outlay.

Recommendation 10

7.126 That the Commonwealth Government initiate negotiations with the private health insurance sector to encourage insurers to offer products that include transport and accommodation assistance.

Recommendation 11

7.127 That State and Territory Governments develop memoranda of understanding that underpin clear, workable reciprocal arrangements for cross-border travel.

Recommendation 12

7.129 That State and Territory Governments expand travel schemes to cover items on the Medical Benefits Schedule – Enhanced Primary Care and live organ donor transplants (with assistance to the donor and recipient) and access to clinical trials.

Recommendation 13

7.131 That the taskforce develop a marketing and communication strategy that targets consumers and health practitioners. Consideration should be given to the role of the Divisions of General Practice in educating GPs about the scheme.

Recommendation 14

7.133 That appropriate, on-site (or nearby) accommodation facilities be incorporated into the planning and design of new hospitals/treatment centres.

Recommendation 15

7.134 That State and Territory Governments work proactively with charities and not-for-profit organisations to provide affordable patient accommodation and services. This should include:

- Developing administrative arrangements that facilitate organisations' access to PATS funding;
- Establishing memoranda of understanding with charitable organisations, which set out commitments to quality service delivery; and
- Developing partnerships with the non-government sector to provide suitable patient accommodation.

Recommendation 16

7.138 That State and Territory Governments, in consultation with Indigenous representatives and Indigenous Health Services, identify and adopt best practice standards and develop programs to improve Indigenous patients' access to medical services by:

- Ensuring continuity of care for Indigenous patients by establishing liaison services and improving coordination in, and between, remote communities and treatment centres;

- Accommodating the cultural and language needs of Indigenous patients from remote communities, particularly in respect to the provision of escorts and translators; and
- Expanding access to appropriate accommodation services.

7.139 In establishing these best practice standards and programs government and Indigenous representatives should:

- Identify and build on existing examples of good practice by health services in Indigenous communities and State and Territory programs; and
- Establish clear governance and administrative arrangements for the delivery of programs, including consideration of the most appropriate bodies to provide day-to-day administration of services (for example, a government body or community-managed Aboriginal and Torres Strait Islander health services)

http://www.aph.gov.au/SENATE/committee/clac_ctte/completed_inquiries/2004-07/pats/report/index.htm

Appendix 5: Example worksheet for exploring accommodation requirements

Background to the Area

- Number of people the Area Health Service provides care for
- Features of the geographical area
- Number of local government areas
- Nature of the area rural/metropolitan or mixed
- Travel distance and time required between service centres
- % of NSW population service is provided to
- Distribution of the population
- Predictions of population growth/decline over next 5/10 years, any variances within region (e.g. growth on coast, inland decline)
- Features of the population/demographics
- Predictions in demographics
- Particular features of the population e.g. % Indigenous or other features of diversity, socio-economic profile.

Cancer in the area

Where cancer diagnosis and treatment is undertaken.

Inpatient Cancer Services:

- Self-sufficiency rate for cancer inpatient services, (the extent to which it can meet the demand for cancer services from the resident population within the health service area)
- Services provided by private hospitals
- Totals of Inpatient services (can be calculated in two ways; by “separations”, that is the instance of patient separation from the community; and “bed days”, the total days occupied by patients in hospital beds)
- Referral patterns from regions to hospitals (e.g. if they refer to Brisbane not Sydney)
- Any patterns of cancer patients travelling into the region from other AHS or interstate. These referral patterns may also reflect transport links (e.g. it may be easier for patients to fly to Sydney from Tamworth than to travel by road to Newcastle).

Non inpatient:

- A summary of non inpatient services

- Radiation therapy capacity number of linear accelerators/assumed annual throughput
- The proportion of new cancers receiving radio therapy in the region (the benchmark of best practice treatment is approximately 52 % of new cases).

Projected Demand for Health Services

Factors such as ageing population, proportion of the population aged 50 and over predicted⁵⁴.

New cases of cancer (i.e. cancer incidence) typically expected to increase by 25%, 2003 to 2011.

Prevalence (the number of cases of an illness or condition that exists at a particular time in a defined population, and is important as an indicator of people who need ongoing support services or re-treatment). The prevalence of cancer is about three times the incidence.

Projections – Inpatient amount

Inpatient service provision is estimated to increase. This is relevant to the issue of accommodation because of requirement of patients from rural areas for overnight stays immediately before admission (which is often early in the morning) and for post-operative supervision and care. It will also influence the accommodation required for family members/carers who travel to support inpatients.

Projections – Non In patient residents who will require radiotherapy

Possibly compare with the benchmark 52%/capacity of linear accelerators would be required, (each typically with throughput of 331 new courses but this depends on treatment modes) and excluding re-treatments.

Requirement for accommodation

The extent of the requirement for cancer related accommodation may be roughly estimated with reference to:

- A. The incidence of cancers in rural areas

⁵⁴ HNEH Area Cancer plan p13

- B. The distances travelled by rural patients for treatment, resulting in the presumed need for overnight accommodation for patients and/or the companions of inpatients.
- C. The pattern of radiotherapy treatment, generally five days per week for six weeks, which is a primary cause of patients needing to be away from home.
 - Consider the average annual incidence of new cases of cancer in the region.
 - Breakdown by local government area if possible.
 - Deduct groups of patients closer than 100k to treatment centre.

This figure is therefore an estimate of the patients who may have required accommodation because of their home location.

To adjust for the predicted cancer incidence, this estimate is increased by 25% in line with the Cancer plan assumptions.

Table 5: Calculating numbers of patients travelling

		Total
Average incidence – new cases of cancer		
Deduct cases who are most likely to be able to stay at home		N = patients travelling
Increase by 25% to reflect assumptions in cancer plan		N x 25% = predicted patients travelling

Table 6: Calculating numbers of patients travelling for radiotherapy

		notes
Predicted new cancer patients in who will need to travel for treatment		
If 52% of new cancer patients treated with radiotherapy		(- x 52%)

If xx% of new cancer patients treated with radiotherapy e.g. 30%		(- x 30%)
If yy% of new cancer patients treated with radiotherapy e.g. 42%		(- x 42%)

xx – is lower figure based on past performance

yy – is based on predicted AHS figure (realistic based on number of machines available etc).

Notes to the calculations

- The minimum number of patients requiring accommodation during cancer radiotherapy treatment is estimated at ___ and the maximum ___ per annum.
- This calculation produces conservative estimates of the number of people travelling for treatment as it is based on new incidence and does not take account of re-treatment. The NSW Cancer Council experience is that 25% of patients will require re-treatment.
- This estimate does not include provision for companions of inpatients, nor does it include patients who require accommodation during chemotherapy or for other reasons such as clinician appointments or participation in clinical trials.
- It also does not factor in the proportion of patients who are likely to receive radiation therapy as an inpatient due to a range of factors including frailty, co-morbidities and complex cancers.
- As noted earlier, there are patterns of referral which mean that patients may be treated in other centres, however there are compensating “inflows” from residents outside the region.
- Other variables include patients electing not to have radiotherapy, patients with co-morbidities/conditions which require inpatient treatment.
- Technical issues such as equipment problems with linear accelerators and the availability of staff qualified to use the machines also influence the numbers of patients requiring accommodation during treatment.
- If the AHS decided to acquire additional linear accelerators and locate them in another region, to achieve the 52% target, the pattern of accommodation usage may change.

- Similarly, treatment modalities may change, so that patients are offered radio therapy twice a day or seven days a week. This could alter demand for accommodation significantly.
- Transport projects to enable more patients to stay at home will also influence accommodation requirements.

Accommodation Facilities - Projected future requirements

Each radiotherapy patient is estimated to require 23 nights accommodation. This is calculated with reference to the six week/five days per week treatment pattern usually required (this assumes arrival on Monday and departure on Friday). As noted earlier, radiotherapy treatments alone account for 22.7 average attendances per patient. Additional days are usually required for preparatory assessments, tests and clinician meetings. A figure of 23 days is used in the table below to calculate the total days accommodation required for rural patients (based on new cases receiving radiotherapy).

Table 7: Calculation total days accommodation required

New Cases	Total days accommodation
Upper	
Mid	
Low estimate	

These figures are conservative and do not take account of the needs of carers of inpatients for accommodation, nor do they reflect re-treatment or chemotherapy.

Other factors to consider include ageing population, numbers of retirees relocating to areas of NSW, in the future people may be distant from family member support during treatment or possibly be alone (following the death of their partner) and thus in greater need of supported transport and accommodation than the current population.

Additional capacity will be required for re-treatment of cancer and accommodation for carers of inpatients. It will also be important to consider provision for those who may live closer to the hospital but are unable to manage independently at home. These include for instance, people with limited mobility, co-morbidities, frailty, specific medication or wound management requirements. Without an accommodation facility, such patients will require inpatient services.

Types of accommodation facility

The Review of Accommodation for Cancer Patients in NSW identified three types of accommodation:

- Commercial
- Specialist/cancer
- Specialist/open.

Interviews with patients and their companions/carers indicated that the most important factors in accommodation during treatment from their perspective were:

- Proximity to the hospital
- Affordability
- Physical accessibility and level of comfort
- Peer support.

Size of accommodation facility

The size of the accommodation facility required in an area is not necessarily derived solely from the numbers of radiotherapy patients treated, although they are a significant group who need to stay away from home for long periods. Other factors such as the needs of an ageing population receiving other treatments or within the 100km subsidised area could increase demand, whilst future decisions to site linear accelerators elsewhere may reduce demand. Marketing of the accommodation facility to raise awareness of what is available and encourage full occupancy will be important.

Other patients and carers requiring accommodation include for instance:

- Older people undergoing rehabilitation or step-down care/support post acute admission
- People undergoing cardiac catheterization
- Patients undergoing renal dialysis
- Families of young people and children who are inpatients.

Issues to consider in developing accommodation:

- Further examination of the needs of all patients who need accommodation during cancer treatment, and the opportunities NGOs to partner to meet the needs of all people who travel for health related reasons

- Investigation of the planning of Area health to meet the 52% target for radio therapy in the region and the impact of any additional linear accelerators on treatment locations/accommodation requirements
- Impact of any transport projects
- Consideration of the capital required for such a project
- Consideration of opportunities to work in partnership with other stakeholders to develop a mixed facility for differing patients and carer needs (cancer, renal, older people, people with other multiple chronic conditions, families of children etc) aligned also with Area Health priorities/initiatives
- Sustainable funding options, who will operate a new facility for 20 years? Who would meet the cost of any operating shortfall?
- Consideration of the most appropriate model of service? Motel style? Hope Lodge model with shared kitchen/meeting facilities? Supported by nursing staff? A mixed range of these facilities?
- What legal and financial structures need to exist for charitable collaboration to proceed?

See also Tables 3 & 4 in Review.

Appendix 6: Billeting issues

A billet is a private home, providing temporary accommodation. People travelling are hosted by people they (typically) don't know. Originating in the military context; billeting is used for groups requiring accommodation for a fixed period when travelling, who would not be able to afford or do not want to pay for accommodation. Examples are sports teams, church/community groups. Unlike the original military situation, people volunteer to billet others.

Billeting - Issues arising

There are a number of features of travelling for cancer treatment or to support cancer patients which are different from travelling to study or for a holiday/event.

- Cancer treatment may be stressful, and have side effects which are unpleasant or which people prefer to deal with privately
- Patients and carers reported that staying with family members does not always work, people feel they are a burden and are unable to speak freely in someone else's home
- After treatment or appointments with cancer specialists, patients and carers may wish to have their own space, or conversely might need emotional support and hosts will not necessarily be in a position to respond
- Unpredictable in length – complications may mean a short stay turns into a long visit
- Cancer patients or their families may find a billet unsuitable for any reason, but feel unable to complain or leave
- Hosts may be drawn into the individual challenges faced by the patient in ways they are unprepared for, and there would need to be clear delineation of roles (for example to ensure that hosts were not expected to provide transport or counselling).

The main advantages of a billeting scheme centre around:

- Low costs to the patient/carer
- Placement with a host who has experience of the cancer journey to call on may have benefits in helping people navigate the system
- Patients and families who normally live in rural NSW spoke as part of this investigation about their reluctance to travel to Sydney and fear of aspects of the city, and hosting could help provide "a friendly face", individual support and assistance with orientation. (This may be a role

which should be considered outside of the establishment of a billeting program.)

Cancer patient case study

One interviewee accompanied their partner to Sydney for inpatient treatment in central Sydney. They breed dogs, and arranged accommodation via a dog breeder's network. The main difficulty was that the host lived a long way from the hospital, and travelling into the city each day meant a drive and then train journey of over an hour and a half.

The interviewee recommended using networks (for example bowling or animal breeding) as a way to link in with others with similar interests for help with accommodation.

Considerations in establishing a billeting program

We could not find any examples of formal billeting programs for cancer patients in Australia.

If a program was established, central coordination would need to ensure:

- Hosts/volunteers recruited and trained
- Premises inspected, appropriate insurances obtained
- All risks identified and appropriate systems were in place to eliminate/mitigate
- Support and oversight of placements maintained during the stay, to ensure that patients/supporters/hosts were supported to end the placement/find alternatives if it wasn't working for any reason.

Criteria for matching:

- Proximity or convenience for public transport (for families including out of hours)
- Similar interests/experience
- Clear guidelines on what is included/not included (Breakfast? Other meals?)
- Advice on tax implications if any charge is made.

Appendix 7: Remoteness and cancer incidence, mortality and survival in New South Wales 1992 to 1996

Summary of comparisons across accessible and remote areas for incidence, mortality and survival

Cancer type	Incidence	Mortality	Survival
All cancers			Lowest survival in males and females in remote areas
Smoking related cancers	Highest in males and females in very remote areas		Lowest survival in females in remote areas
Alcohol related cancers	Highest in males in very remote areas		
Head and neck	Highest in males in remote areas	Highest in males in remote areas	
Oesophagus	Highest in males in moderately accessible areas		Lowest survival in males in highly accessible areas
Stomach	Lowest in males in moderately accessible areas	Lowest in males in moderately accessible and remote areas	
Colon			Lowest survival in females in moderately accessible areas
Rectum			Lowest survival in males in remote areas
Liver	Highest in males in highly accessible areas	Highest in males in highly accessible areas	

Pancreas		
Lung		Lowest survival in males in moderately accessible areas
Melanoma	Lowest in remote areas for males and females	Highest survival in males in moderately accessible areas
Breast		
Cervix		Lowest survival in remote areas
Ovary		
Other uterine		
Prostate	Highest in remote areas	Lowest survival in remote areas
Kidney		
Bladder		
Brain		Lowest survival in females in moderately accessible areas
Non-Hodgkin lymphoma		
Multiple myeloma		
Leukaemia		

Legend - Chi-square test for association between rate and ARIA $p < 0.01$

Rates more adverse in moderately accessible and/or remote areas

Rates more adverse in highly accessible and/or accessible

No significant difference in rates

<http://www.nswcc.org.au/editorial.asp?pageid=768>

SOURCE:

Jong, K., Smith, D.P., Yu, X.Q., Goumas, C., O'Connell, D., Armstrong, B.K.
Remoteness and cancer incidence, mortality and survival in New South Wales
1992 to 1996. Cancer Council, 2002

Published by Cancer Council, January 2002

Appendix 8: Summary of Medihotel model features

Table 2.1: Summary of Medihotel Model Features

Model Features	TAH	RMH	SVHM	RVEEH	BH	MMC	ARMC	RCH
Implementation date	2001	2001	2002	2004	2006	2006	2004	2004
Location	Hospital – in ward area	Hotel	Hospital – in ward area	Hospital – in ward area	Hospital – in ward area	Hospital – in ward area	Hospital – separate building	
Number of Beds	15 + 5 'flexi' beds	8	10	10	8	8	14 + 7 carer beds	3 Temporary increase to 11 beds – winter strategy.
Hours of operation	24 hours / 7 days per week	24 hours / 7 days per week	1pm Sunday to 7pm Friday	Monday to Saturday from 6pm to 10am each day	2pm Sunday to Thursday	24 hours / 7 days per week	Sunday pm to Friday pm	7 days per week
Management arrangements	Manager – combined unit NUM. Report through Nursing – to change to Manager Patient Flow. Own staff.	Manager – shares with HITH. Part of Ambulatory Care & Continuing Care Management Division.	Manager – combined Unit Manager Part of Hospital Demand and Mental Health Directorate. Own staff	Manager – Acute Ward NUM, Clinical Care Coord and A/II Nursing Supervisor manage resources. Staff rotate from acute ward.	Co-located with Admission & Day Surgery Units. Medihotel Manager reports to Director Ambulatory services	Stand alone unit with NUM. Reports directly to Director of Nursing.	Shares a NUM with the Ambulatory Care Centre. Reports through the Manager Home & Ambulatory Care Services.	Managed jointly with the Parent Accom. & Post-natal Mother's Unit by a midwife.
Staffing	1 Div 1 nurse	Nil	1 Div 1 nurse	1 Div 1 nurse	1 Div 1 nurse	1 Div 1 nurse	1 Div 1 nurse	1 midwife
Organisational linkages	MADU: Clinical units; Investigative Departments; Hospital Demand Management	Clinical units; Investigative Departments; pre-admission clinic, allied health, HITH, Neurology Day Treatment Ctr	Treatment Ctr Accom Service Clinical units; investigative Departments; Hospital Demand Management	Integral part of hospital service. Agreement with Dental Hospital for access.	Selected clinical units.	Clinical units; Hospital Demand Management.	Clinical units; Hospital Demand Management.	Rehabilitation Unit