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## Executive summary

This report presents the results of a Review commissioned by the Tasmanian Department of Health and Human Services (DHHS). In commissioning the Review, the Department identified a number of increasing challenges for the Tasmanian Palliative Care Service. These include a 22.4% increase in demand for services between 2000 and 2003 and an ageing and highly regionalised Tasmanian population. Staff pressures and turnover had also been identified as a matter of concern for DHHS.

The Review has been overseen by a steering committee appointed by DHHS. The terms of reference for the Review are set out on page 1. In summary, the project had two broad elements. The first was the evaluation element. It included an analysis of existing palliative care services and an analysis of supply and demand. The second is the planning element that includes the development of a model for future palliative care services.

This report provides details of the methodology used during the Review as well as data summaries, findings and recommendations.

### **Summary of review findings**

The Review has analysed the current capacity to respond to current levels of demand and has identified areas of unmet need. We did this by examining normative, comparative, expressed and felt needs.

In relation to normative need, we applied the generic model of care and clinical service planning guidelines developed by Palliative Care Australia (PCA) to Tasmania as a way of measuring normative need. It suggests that the service structure for Specialist Palliative Care Services in Tasmania generally reflects the model of care and balance between community and inpatient services envisaged in the PCA service planning guidelines. In relation to the specific service planning guidelines:

- Tasmania has 50% of the designated palliative care beds that are recommended in the planning guidelines and there are distributional issues with no designated beds available in North West Region;
- Unlike every other jurisdiction in Australia, the Tasmanian palliative care service employs no staff with qualifications in psychology, physiotherapy, occupational therapy, speech pathology or music/art therapy. Instead, these disciplines are sourced (with varying success) from other teams. In turn, the lack of access to allied health therapists has flow-on effects in terms of the existing workforce workload;
- Based on best available data, the Tasmanian palliative care service is currently only servicing about 52% of estimated need (see Table 3 on page 12).

The three dot points above summarise the current gap between supply and demand, with further evidence on this gap provided in Section 4. Given the significant size of the current gap, any movement towards meeting the needs of the target is going to require changes to service delivery and an injection of resources.

In relation to comparative need, we compared Tasmania's need for specialist palliative care services with other parts of Australia. The demographic and epidemiological data suggest that demand for palliative care in Tasmania is likely to grow more rapidly than in other States and Territories due to the highest overall incidence of cancer in Australia and a rapidly ageing population.

In terms of crude staff to population ratios the preliminary figures from the 2003 Palliative Care Australia National Census suggest that Tasmania is at the national average with the staff establishment available in 2004. However, crude staff to population ratios are not an appropriate benchmark for Tasmania and need to be adjusted to take account of Tasmania's demography and epidemiological profile. In order to provide an adequate service, Tasmania needs a staff ratio that is above the national average. The key drivers are low population density, the high proportion of the population living in rural communities, the high incidence of cancer and the high number of older people who live alone. In terms of expressed need, the main body of this report contains a snapshot of historical service utilisation patterns across the State and further information is provided in Appendix 4.

Finally, in terms of felt need, the main body of this report provides a summary of the consultation process that was undertaken in November 2003. In total, 26 consultations were held with 36 organisations and involved over 170 individuals. The key themes that emerged in this process were:

- Issues related to the need for additional resources;
- Issues related to referral patterns and practices;
- Structural issues;
- Organisational issues;
- Private sector issues.

### ***The way forward - a new model of service delivery***

#### **Vision**

Every Tasmanian with a life-limiting illness will receive treatment and care with a palliative approach. Different levels of palliative care will be available, depending on the needs of each person. It will be provided by an integrated network of health care providers that includes, among others, palliative care specialists, rural hospitals and primary care providers of all disciplines.

#### **Target group and role of the specialist palliative care service**

The target group for the specialist palliative care service will be patients with an active, progressive, far advancing disease (whether malignant or non-malignant) with little or no prospect of cure and for whom the primary treatment goal is quality of life. These patients will receive multidisciplinary assessment, consultancy and/or management of their physical, psychological, social, emotional and spiritual needs. The service will provide a grief and bereavement process for the person and their carers/family during the life of the person and continuing after death. The service will be responsible for the education and professional development of other primary and secondary care providers who will be partners in the delivery of the full spectrum of palliative care.

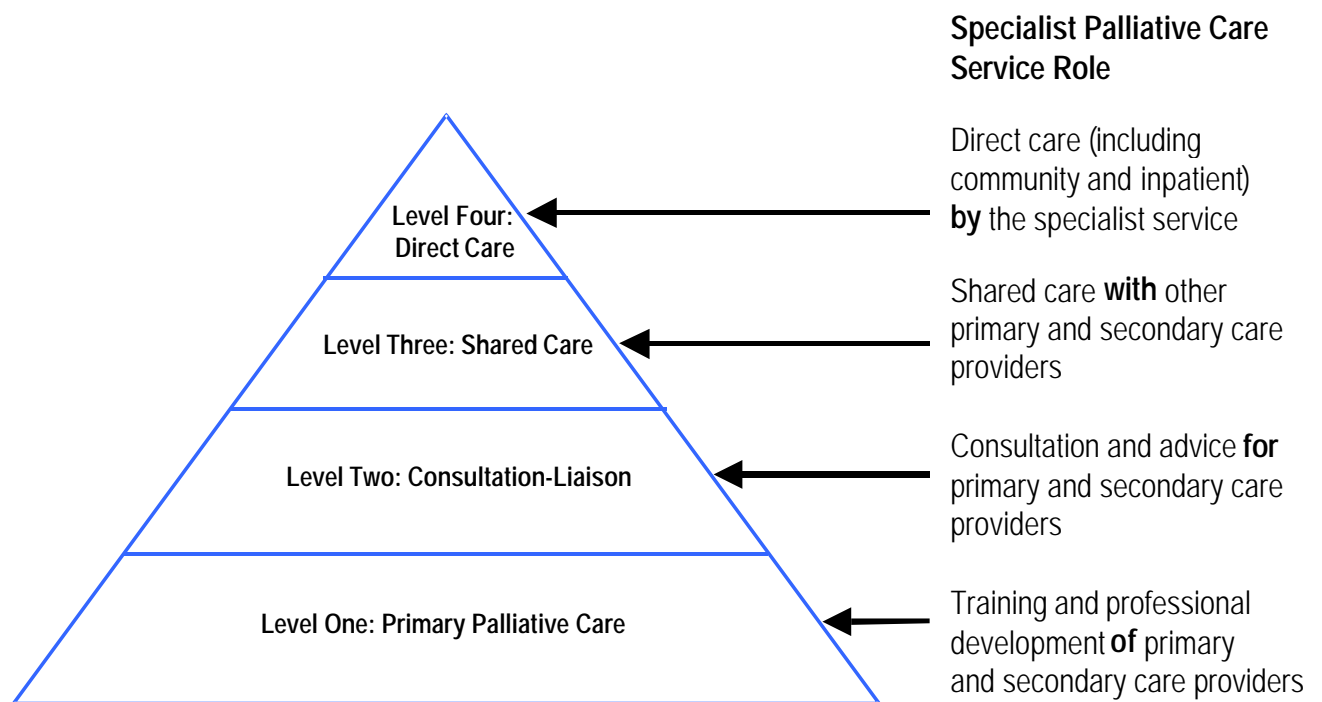
#### **The model in summary**

The new model is based on patients receiving different levels and types of service depending on their needs. The level of care required is specified on the initial referral for palliative care, as are any specific requirements (for example, time-limited or ongoing care). Four levels of care are proposed.

A patient may move between levels of care over time if the needs of the patient change. This would be subject to negotiation between the patient / carers, and their care providers, including their GP and relevant medical specialists. This model is compatible with the model of care being developed in the Rural Palliative Care Project in the North West. It is already in common practice

in some other streams of care (eg, mental health) and is successful partly because it provides clear role delineation for service providers based on the level of need of their patients.

The major change proposed is a clearer delineation of roles based on the intensity of palliative care service provision. This model explicitly recognises that many patients will receive primary palliative care without having any contact with the specialist palliative care service (Level 1). It also makes a clearer distinction between consultation-liaison (Level 2) and shared care (Level 3). This distinction is lacking in the current system. Level 4 direct services may be provided in both designated beds and in the community.



**Recommendation 1.** Adopt a new model of service delivery.

### Tasmanian Integrated Palliative Care Networks

The successful implementation of the tiered model outlined above will require the development of Integrated Palliative Care Networks based on formalised clinical partnerships and role delineation between specialist and generalist services as outlined as Option 4 in Section 7.

Three Integrated Palliative Care Networks are proposed, one for each of the geographic regions. The development of each network should be led by a Statewide working party established for this purpose. Representation should include specialist palliative care services, community health staff and general practitioners, rural/community hospitals and extended care/residential care providers. Regional working groups, established as sub-committees of the Statewide working party, may be required to consider issues specific to each geographic region.

As part of this development, the position of Clinical Coordinator North/North West should be split into two positions, one for each region. The three positions in the South, North and North West should be renamed as Area Manager, Palliative Care, with duty statements updated to reflect their clear responsibility for the management of the entire integrated care network and not solely the management of the specialist palliative care service.

By the end of this planning process, each region should have in place:

- Detailed clinical and social criteria for each of the four levels of palliative care, along with a clear referral pathway to each. This work should be led by the Tasmanian Palliative Care Clinical Management Committee, with each network making relevant adaptations to reflect their unique local circumstances.
- A formal system of partnerships whereby generalist services affiliated with the network will be able to access specialist palliative care consultation liaison and assessment services for their patients (Level 2) as well as shared care (Level 3) as needed. They will have a clear understanding of the criteria and referral pathway for patients requiring Level 4 care.
- Network-wide tools such as clinical protocols, care plans, referral pathways, quality assurance models, multidisciplinary training and professional development in palliative care. Again, the development of these tools should be led by the Tasmanian Palliative Care Clinical Management Committee, with each network making relevant adaptations to reflect their unique local circumstances.
- An education and training strategy to strengthen the palliative care skills and expertise of network members.
- An education and training strategy to allow mainstream providers achieve recognition as a full member of the Integrated Care Network (see Section 10 below).

**Recommendation 2.** Establish three Integrated Palliative Care Networks, including an Area Manager position for each network.

### **Tasmanian Palliative Care Quality and Safety Standards**

Increasing the skill base of hospitals (particularly the rural district hospitals), Multi Purpose Services and residential care facilities and designating palliative care beds in these facilities is a key feature of the recommended model. This will address the genuine issue of rural/remote community access to inpatient/hospice facilities by utilising spare capacity in community hospitals and residential care services rather than relying on stand alone hospice facilities in central locations.

However it requires a clear commitment to provide professional development, education and clinical support services for the hospital or residential care facilities in the network and an agreed shared care framework with the general practitioners who provide primary medical management for the great majority of patients.

It is recommended that:

**Recommendation 3.** The Tasmanian Palliative Care Service be responsible for developing/adopting quality and safety standards for palliative care in Tasmania. These should be based on the national standards. However, the generic standards will need to be modified for the different levels of care (eg, hospital versus residential palliative care and Level 1 versus Level 4 care). Performance indicators, linked to these standards, will be required for each level of care.

Acute hospitals (both public and private), rural community hospitals, Multi Purpose Services (MPSs) and residential care facilities seeking to provide palliative care in Tasmania should be invited to measure their performance against these standards. The Department could also negotiate with relevant accreditation bodies to have these standards built into relevant accreditation processes, as this would strengthen their application.

**Recommendation 4.** Only facilities measuring their performance against these standards be considered in planning for the location of future palliative care beds.

## Hospice Without Walls

We recommend that additional hospice/inpatient beds be commissioned to meet community need. In total, 16 additional designated beds are required to meet the current need. For the reasons set out in Section 5.2 and Section 11, we recommend that Tasmania does not establish any further free-standing hospice units. A better model, and the one we recommend, is that Tasmania commit to a **Hospice without walls**, with new designated beds located in, and spread between, existing acute and rural hospitals.

**Recommendation 5.** Tasmania commit to a **Hospice without walls**, with new designated beds located in, and spread between, existing acute and rural hospitals.

The **Hospice without walls** model will better meet the needs of the significant proportion of the Tasmanian population who live outside the major cities. The implications for each region are discussed in Section 11.

## Specific Developments

Sections 11, 12, and 13 of this report propose a number of developments in relation to specific components of the service. Section 11 recommends specific developments in relation to inpatient and hospice services. Section 12 recommends specific developments in relation to community services, including the medical workforce. Section 13 proposes developments in relation to information, education and training and research. In total, 27 recommendations are made.

## Strategic Investment Priorities

Implementation of some of our recommendations will require a significant investment to put the service on a sustainable footing. However, a range of recommendations can be implemented within existing resources. The following list of developments is proposed to meet the most pressing service needs and workforce development and retention requirements. They are listed in priority order.

### Summary of priority developments

Priority
Priority 1 – Implement the new model of service delivery, based on the introduction of 4 levels of care, 3 integrated palliative care networks and a clear quality and safety framework. In the process, secure the current service base
Priority 2 - Medical workforce
Priority 3 - Professional development
Priority 4 – Allied health workforce
Priority 5 - Nursing workforce
Priority 6 – Palliative care hospice/inpatient beds

Investment decisions are always about trade-offs. Setting priorities in palliative care is no exception.



## Part A Background and context to the Review

### 1 Terms of Reference

#### 1.1 Review Objectives

The Centre for Health Service Development (CHSD) was asked to:

1. Conduct an analysis of Palliative Care Services in Tasmania including:
  - An assessment of current Palliative Care Service activity;
  - Analysis of the capacity to respond to current levels of demand and;
  - Identification of areas of unmet need.
2. Recommend a model for sustainable and effective Palliative Care Services in Tasmania that:
  - Is congruent with the National Palliative Care Strategy, the Tasmanian Palliative Care Plan and Departmental priorities;
  - Advises an appropriate skill mix and professional development needs of staff;
  - Incorporates strategic partnership opportunities;
  - Includes strategies to better integrate palliative care into general health and human services in Tasmania and;
  - Includes strategies for improving community understanding of roles, functions and scope of Palliative Care Services.

In summary, this report has two broad elements. The first is the evaluation element. It includes an analysis of existing palliative care services, including an analysis of supply and demand. The second is the planning element. It includes the development of a model for future services.

### 2 How the Review was undertaken

Organisational change is only warranted if it improves services for consumers. Consistent with this approach, this Review was conducted with a focus on consumer needs, as well as the needs of the staff and the organisation as a whole.

There were four aspects to this Review:

1. A detailed review of relevant background material was undertaken. Available data were analysed with a particular focus on current organisational and staffing structures and projected trends in need for palliative care services.
2. An extensive consultation was held with palliative care management, staff and other key stakeholders across Tasmania. The Review team consulted a total of approximately 170 individuals during 26 consultations with 36 different organisations. A list of groups consulted during the consultation process is provided at Appendix 5.
3. Relevant consultations with palliative care providers and managers in other jurisdictions and with national experts.
4. A literature review on models of palliative care and planning guidelines for palliative care service provision.

No restrictions were placed on the Review team in regard to either the process of the Review or the final recommendations.

## 2.1 **Steering Committee**

A Steering Committee had oversight of the Review. The membership comprised:

- Deputy Director Primary Health
- State Manager, Palliative Care
- Medical Director Palliative Care
- Clinical Coordinator Palliative Care representative
- Policy Officer, Primary Health
- Strategic planning representative, DHHS

## 3 **Context of the Review**

The Review has been undertaken within the policy and organisational context within which palliative care services in Tasmania operate. This includes (but is not limited to) the National Palliative Care Strategy and the Tasmanian Palliative Care Plan 2002-2005. This plan stresses four key priority areas:

1. Respond to community and consumer expectations in meeting the needs of people living with a life limiting illness, and their families;
2. Ensure the delivery of sustainable, consistent and appropriate palliative care services through increased community awareness, practical support, information, education and evaluation;
3. Develop a sustainable, competent, specialised and confident palliative care workforce through collaborative links between education and clinical practice (conjoint appointments), the pursuit of research opportunities, and underpinned by a quality focus; and
4. Develop interdependency and linkages to strengthen partnerships across the health and education system, providing support and education to health professionals, and support to people through the various health care settings.

Central to the philosophy of the Tasmanian Palliative Care Service is the belief that:

***Palliative care is ultimately a reflection of community respect for the gift of life. It respects dying as a shared and unavoidable consequence of living. The role of the Palliative Care Service is to enhance quality of life by ensuring that every person affected by a life limiting illness has the knowledge, capacity and right to access quality palliative care appropriate to their needs.***

The Tasmanian Palliative Care Service aims to provide an overarching service to people and their families, as well as to health and medical practitioners involved in the provision of coordinated, quality care.

At a clinical level, the Service aims to provide comprehensive assessment of people seeking care; drawing on their knowledge and day-to-day experience to anticipate and respond to changes in the progression of the person's illness. At a professional level, the Service aims to promote regular communication and close consultation with health services and practitioners, recognising the importance of collaboration in the provision of palliative care. At a community level, the Service aims to link the person, family and carers to a network of trained volunteers who can

provide practical and emotional support, and who can become valued partners in managing the care of the dying.

The outcomes of referrals to Palliative Care may include:

- Access to referral for palliative care in-patient/community care;
- Specialist assessment, advice, and/or management of symptoms;
- Education of clients and/or primary providers;
- Psychological, emotional and social support for client support for the client, family and/or carers;
- Pharmaceutical and equipment access;
- Linkage to appropriate care options;
- Grief, loss and bereavement support for client and families;
- Spiritual and cultural support and;
- Volunteer support.

### **3.1 Overview of palliative care services in Tasmania<sup>1</sup>**

The Tasmanian Palliative Care Service is a small specialised service that provides a range of direct and indirect services to approximately 2000 individuals and families each year. The Service began operating as a Statewide service in 1997 following a restructure of the Department of Health and Human Services. Organisationally, the Palliative Care Service sits within the Community, Population and Rural Health Division of the Department (see Figure 1).

The Palliative Care Service has a core budget of approximately \$4.5m in the current 2003/04 financial year. It also has time-limited funding for special initiatives, including funding under the National Caring Communities Program and Medical Specialists Outreach Assistance Program (MSOAP). As shown in Figure 2, the Service comprises three community based specialist interdisciplinary teams located in Hobart (South), Launceston (North) and Burnie (North West). These teams comprise registered nurses, doctors, social workers and administrative staff who work closely with volunteer support associations. Clients must be registered to be eligible to receive services from the Tasmanian Palliative Care Service and the palliative care teams operate a 24 hour after hours service for registered clients and their families.

A dedicated 10 bed palliative care inpatient unit operates at (what was) the Repatriation Centre in Hobart. In Launceston, the Department contracts 3 of the 6 palliative care beds at Phillip Oakden House (The Manor Complex), a hospice that is part of a local residential aged care facility. There are no designated inpatient or hospice palliative care beds in the North West of Tasmania. However, acute and rural hospitals and residential aged care facilities in all regions provide inpatient care for patients with life limiting illnesses, including terminal care.

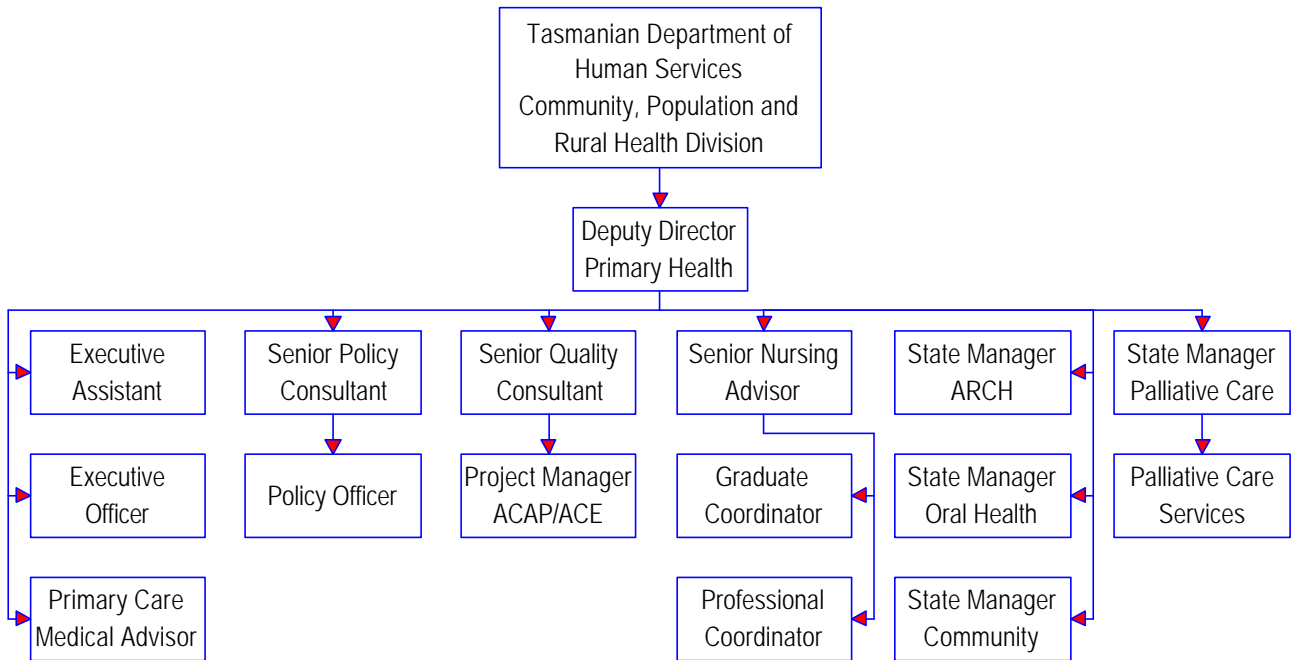
The Statewide service has a staff establishment of 54.6 equivalent full time (EFT) staff made up of 26.45 EFTs attached to the Whittle Ward, 8.20 EFT staff attached to the Community South, 7.53 EFT attached to Community North, 6.86 EFT attached to Community North West and 5.5 EFT Statewide Program Management. There are also 2 Volunteer Coordinators and 0.2 EFT pastoral care workers funded through NGOs or by DVA.

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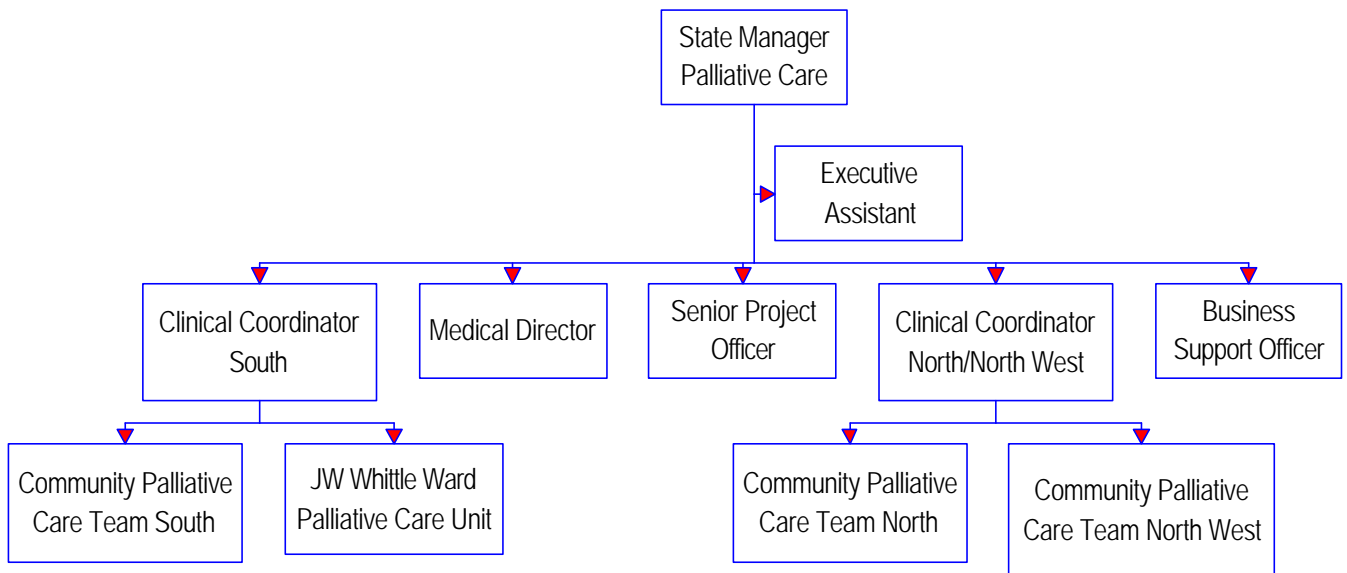
<sup>1</sup> This section is primarily based on information contained in a series of background documents and related reports provided by the Department of Health and Human Services at the commencement of the project. The documents provided an outline the structure of the Tasmanian Palliative Care Service and included available data on historical patterns of service utilisation across the State.

The staff profile by team is shown in Appendix 1 and excludes staffing for the inpatient beds contracted at Phillip Oakden House.

**Figure 1 Where Palliative Care sits in the broader organisation (Feb 2004)**



**Figure 2 Organisational structure of the Tasmanian Palliative Care Service (Feb 2004)**



Non-specialist palliative care services are provided to palliative care clients in the community by general practitioners, generalist community nurses and community based allied health staff. Palliative care clients also receive inpatient and outpatient services in acute hospitals across Tasmania. Tasmanian Palliative Care Service nurses undertake liaison roles with the Royal Hobart Hospital and the Launceston General Hospital.

Approximately 250 palliative care trained volunteers make a significant contribution to palliative care services across the State. These volunteers provide support in a number of settings

including hospices and home based environments. Two Hospice Care Associations coordinate volunteers in the South and the North West regions. In the North region, volunteer services are coordinated directly by a volunteer coordinator employed by the community palliative care team.

Finally, a number of government, non-government and private stakeholders are engaged in the planning and delivery of palliative care through a range of consultative mechanisms.

In 2002 additional funds to recruit two Palliative Care Medical Specialists were accessed through the Commonwealth funded Medical Specialists Outreach Assistance Program (MSOAP). One is based in Launceston and the second is based in Burnie. Prior to this, specialist palliative care medical advice was provided by a Hobart based specialist on a visiting basis. Recruitment of the additional medical specialists has had a marked impact on activity in both the North and North West teams.

### **3.2 Rationale for the Review**

In commissioning the Review, the Department identified a number of increasing challenges for the Tasmanian Palliative Care Service. Service demands have resulted from additional services provided, with these demands expected to rise substantially in the coming years. To ensure that Palliative Care Services can operate an effective and sustainable service into the future, the Department indicated that it will be imperative for the following challenges to be considered:

#### **3.2.1 Service Activity**

In the last three years (2000 to 2003) there has been a 22.4% increase in clients accessing Tasmanian Palliative Care Services. This increased service activity was identified as having a significant impact on the capacity of the service to respond, resulting in people living with a terminal illness being referred to a waiting list.

An additional issue is that the ageing Tasmanian population is expected to result in an increased incidence of chronic conditions and complexity of cases in future years. Australian Bureau of Statistics projections indicate that the number of Tasmanians aged 65 and over will rise to approximately 31% by the year 2051. The level of support required for management of chronic conditions is also expected to increase. This is especially in relation to level of support required for cancer. On a national basis, the goal is that 90% of all cancer deaths receive palliative care services. In Tasmania, only 70% of all cancer deaths receive palliative care services, suggesting that demand for services could continue to increase.

Finally, Tasmania has a highly regionalised population with 70% of the State classified as rural and remote and nearly 50% of the population living in small rural communities, and this demography may require a different approach to the delivery of palliative care.

#### **3.2.2 Staff pressures and turnover**

In commissioning this Review, the Department identified staff pressures and turnover as a matter of concern. The small regional teams were identified as experiencing significant challenges in responding to the growing demand and added case complexity, this often involves difficult family dynamics. Due to low staff numbers and demands for direct client support, there is little opportunity for staff support from colleagues, professional supervision, involvement in professional development opportunities and consultancy activities. Such demands and pressures place staff at a high risk of burnout. Staff turnover rates in Palliative Care are significantly higher than the average for other staff within the Department.

## Part B Review findings

### 4 The need for palliative care

A critical task in the Review has been to analyse the current capacity to respond to current levels of demand and to identify areas of unmet need. Key to this is to define the 'need' for palliative care. We have done this by using a useful description of different types of need that was first developed over thirty years ago<sup>2</sup>. This has been widely used in the health sector over the last 30 years and distinguishes between four different ways of thinking about 'need'. We have used this typology to look at the 'need' for palliative care from all four perspectives. The idea that 'needs' can be defined differently for different purposes is helpful because it does not give primacy to any one type of need. The strongest evidence of 'need' is when these four perspectives coincide.

#### 4.1 Normative need

Normative need is defined by expert opinion regarding appropriate standards, required levels of service and what constitutes an acceptable health status level for a community. Normative needs are based on standards laid down on the basis of experience and consultation. Palliative Care Australia (PCA) has done considerable work defining the normative need for palliative care.

In 2003 PCA published *Palliative Care Service Provision in Australia: A Planning Guide*<sup>3</sup> to assist planners, funders and service providers to plan for palliative care services in their jurisdiction. The Planning Guide provides definitions of palliative care, describes the essential elements of the service system, defines settings of care for service provision and provides staff planning guidelines using a population based approach.

The clinical staff guidelines are based on a population approach and are expressed as clinical staff per 100,000 population and assume that specialist services will work along side referring services. The staffing ratios described represent the "considered view of the Council of PCA and will require validation through implementation...". They provide a target for service development rather than a current benchmark and PCA acknowledges that many viable palliative care services around Australia are currently functioning below these staffing levels.

##### 4.1.1 Target Group

A critical issue in determining the need for palliative care is the definition of the target group. PCA estimates (based on best available empirical evidence) that palliative care services should be involved in:

#### Cancer patients

- The assessment of 90% of patients within the area who die from cancer
- An ongoing consultative capacity for approximately 70% of cancer patients
- Direct care for 20% of cancer patients.

#### Non-cancer patients

- Referral for assessment of 50% of patients expected to die from non-malignant diseases

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<sup>2</sup> Bradshaw, J. (1972) The concept of social need. *New Society*, 3, 640-643

<sup>3</sup> Palliative Care Australia (2003) *Palliative Care Service Provision in Australia: A Planning Guide*. 2<sup>nd</sup> edition. PCA, Canberra <http://www.pallcare.org.au/publications/index.html>

- An ongoing consultative capacity for 30% of these
- Ongoing direct care for 10% of these.

On the basis of current data on cancer and non-cancer deaths, there are approximately 187 deaths from cancer and 187 expected deaths from other causes per 100,000 population per year progressive predictable life limiting illness<sup>4</sup>.

**Table 1** *Current and expected deaths per 100,000 population and referrals to palliative care services annually*

Diagnosis Group	Actual Deaths	Current referrals per 100,000	Recommended referrals for assessment per 100,000	Ongoing consultancy per 100,000	Direct Care per 100,000
Cancer	187	94-168 (50 - 90%)	168 (90%)	131 (70%)	37 (20%)
Non-Cancer	187	17-30 (9 - 16%)	94 (50%)	56 (30%)	19 (10%)
<b>TOTAL</b>	<b>374</b>	<b>111-198</b>	<b>262</b>	<b>187</b>	<b>56</b>

Recent research in the USA by the Rand Corporation<sup>5</sup> paints a different picture. The authors suggest that the concept of dying itself has become less clear. "At one time, a person was healthy, then sick, and either recovered or died quickly...However, this model does not apply well to most chronically ill elderly (a rapidly increasing section of the Tasmanian population). The major problem is that it presumes a sharp transition in which patients come to be "dying" by becoming "terminally ill," and thus needing a different type of care from patients who might recover or remain stable.

Many chronically ill elderly people have ambiguous medical prognoses: they may be sick enough to die but could also live for many years. A more useful way to think about this "near death" condition is to focus on fragility rather than time to death. From this perspective, people living with serious illness at the end of life can be identified not from certainty of timing of death, but from "living on thin ice"—suffering long periods of illness or disability, diminished functioning, and potential exacerbation of symptoms, any of which could prove fatal. They could keep "living on thin ice for some years, or die in a week".

The language typically associated with palliative care often assumes that it means the end of conventional curative care and the beginning of a different type of care. However, chronically ill elderly patients routinely blur this distinction by needing a mix of both kinds of care. Early in the course of their illness, many need both curative treatment as well as "palliative" care aimed at treating symptoms; and late in life, some treatments may still stall the progression of illness, even while most needs are for relieving symptoms and providing support".

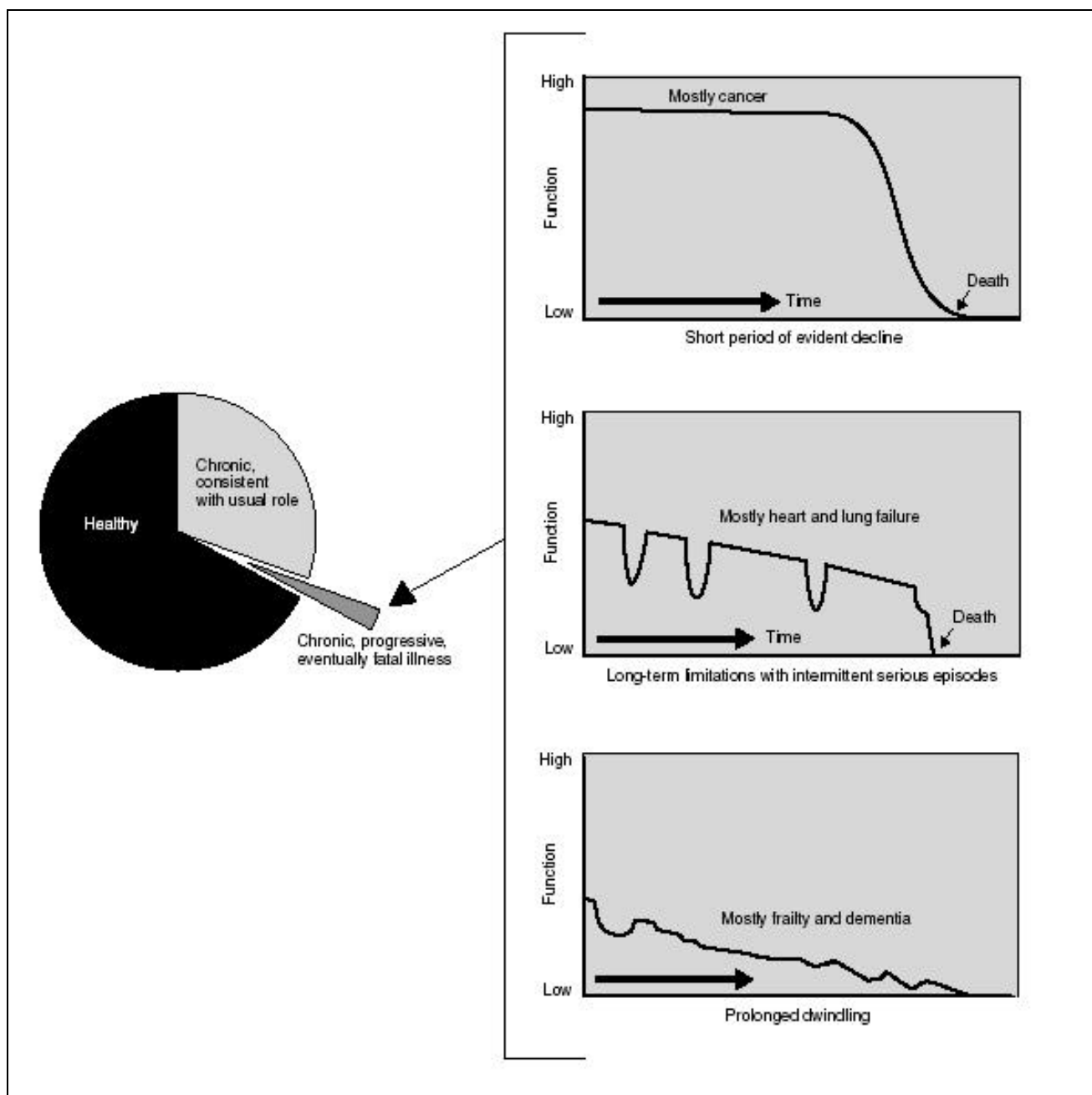
Lynn and Adamson suggest that there are three trajectories of chronic illness (see Figure 3) and that palliative care has a role for all three groups. They analysed US Medicare claims and estimated that about 20% of those who die have a course consistent with the first group (mostly cancer patients); another 20% share the course of the second group (mostly organ system failure patients); and 40% follow the third course (frailty/dementia). The last 20% are split between those who die suddenly and others not able to be classified.

We are not convinced that these population estimates are accurate for Australia. However, the concept of three trajectories of chronic illness is both relevant and helpful in identifying the need for palliative care and in planning future models of provision.

<sup>4</sup> Palliative Care Australia (2003) *Palliative Care Service Provision in Australia: A Planning Guide*. 2<sup>nd</sup> edition. PCA, Canberra <http://www.pallcare.org.au/publications/index.html>

<sup>5</sup> Lynn J and Adamson DM (2003) *Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age*. Rand Health, Rand Corporation, Santa Monica

**Figure 3 Three trajectories of chronic illness<sup>6</sup>**



**Short period of evident decline—typical of cancer**

Most patients with malignancies maintain comfort and functioning for a substantial period. However, once the illness becomes overwhelming, the patient’s status usually declines quite rapidly in the final weeks and days preceding death. Hospice is an important part of the care for this trajectory.

**Long-term limitations with intermittent exacerbations and sudden dying—typical of organ system failure**

<sup>6</sup> Lynn J and Adamson DM (2003) *Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age*. Rand Health, Rand Corporation, Santa Monica. Page 8

Patients in this category often live for a relatively long time and may have only minor limitations in everyday life. From time to time, some physiological stress overwhelms the body's reserves and leads to a worsening of serious symptoms. Patients survive a few such episodes but then die from a complication or exacerbation, often rather suddenly. Ongoing disease management, advance-care planning, and mobilising services to the home are key to optimal care.

### **Prolonged dwindling—typical of dementia, disabling stroke, and frailty**

Those who escape cancer and organ system failure are likely to die at older ages of either neurological failure (such as Alzheimer's or other dementia) or generalised frailty of multiple body systems. Supportive services at home, like Meals on Wheels and home health aides, then institutional long-term care facilities are central to good care for this trajectory.

#### **4.1.1.1 Children and adolescents**

The discussion in the section above did not consider groups with special needs. One key group is children and adolescents. The best estimates of the need for paediatric palliative care come from the UK<sup>7</sup>. They estimate that the annual mortality rate for children aged 1-17 with life-limiting conditions is 1 per 10,000. In relation to morbidity, they note that accurate prevalence data on severely ill children with life-limiting conditions in need of palliative care are not available but estimates tend to converge on 10 per 10,000 children aged 0-19 per annum.

They suggest that, for a district with a child population of approximately 100,000 (the approximate child and adolescent population in Tasmania) in one year:

- 10 are likely to die of a life-limiting condition, 4 of these will die from cancer, 2 of heart disease and 4 of other life-limiting conditions
- 100 are likely to have a life-limiting condition about half of whom will need active palliative care at any one time.

They identify four groups of children requiring palliative care:

#### **Group One**

Life limiting conditions for which curative treatment may be feasible but can fail. Palliative care may be necessary during periods of prognostic uncertainty and when treatment fails. Children in long-term remission or following successful curative treatment are not included. Examples include cancer, irreversible organ failures of heart, liver, and kidney.

#### **Group Two**

Conditions where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but premature death is still possible. Examples include cystic fibrosis and muscular dystrophy.

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<sup>7</sup> Association for children with Life Threatening or Terminal conditions (ACT) and the Royal College of Paediatrics and Child Health (RCPCH) *A Guide to the Development of Children's Palliative Care Services*, Second Edition September 2003 <http://www.act.org.uk>

## Group Three

Progressive Conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. Examples include Batten's disease and mucopolysaccharidosis.

## Group Four

Conditions with severe neurological disability that may cause weakness and susceptibility to health complications, and may deteriorate unpredictably, but are not usually considered progressive.

### 4.1.2 Service Model and System Attributes

The PCA guide describes a service model for palliative care that is based on a network of palliative care providers that includes: -

- Cohesive multidisciplinary specialist palliative care services made up of accredited specialist medical, nursing or allied health professionals who provide primary or consultative care to patients with a life-limiting illness
- Generalist palliative care providers who provide primary care to patients with a life-limiting illness with a palliative care approach. Generalist providers include general practitioners, community health staff primarily community nurses and allied professionals, local hospitals and acute hospitals.

Full definitions are included in Appendix 2.

The key attributes or elements of a quality Palliative Care Service System include:

- A quality management approach that includes compliance with Standards for Palliative Care Provision.
- A service system that ensures all palliative care providers work as part of a network with formalised linkages to ensure that providers offering primary care do not work in isolation and have access to a multidisciplinary specialist palliative care service that includes:
  - Guaranteed 24 hour access to support, advice and consultation from specialist palliative care services
  - Education and up skilling for primary care practitioners and specialist staff
  - Emotional support and psychosocial support
  - Information on effective practice and a research program to support translation of therapeutic advances into practice
- A system of care for patients admitted<sup>8</sup> to the palliative care service and their families that includes:
  - 24 hour access to advice and support to enable the patient to cope with emergency or crisis situations;
  - Integrated and coordinated care arrangements including timely referral and care planning to ensure smooth transition from one service setting to another as required;
  - Bereavement support as a core component of the service; and,

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<sup>8</sup> Admitted patients are those who have been assessed, accepted as a patient and registered with a palliative care service as distinct from new referrals and the general public.

- Access to respite care.

### 4.1.3 Settings of Care and Planning Ratios

Palliative care services can be provided in community settings, designated palliative care beds in hospices and as a consultative service in acute hospitals. Clinical staffing ratios for specialist palliative care services have been developed for each of these settings and are shown by discipline in Table 2<sup>9</sup>.

**Table 2 PCA Australia: Specialist Palliative Staffing Guidelines per 100,000 population**

	Community based service EFT/ 100,000 pop	EFT per 125 acute inpatient beds	Designated palliative care beds EFT per 6.7 beds
Specialist+		1.50	
Registrar+		1.00	
Resident	-	-	0.25
Liaison psychiatry		0.25	
<b>All Medical</b>		<b>2.75</b>	<b>0.25</b>
CNC	1.00	0.75	
Clinical Nurses	2.00		
Registered/enrolled nurses			6.5 hours / patient day
Discharge planning		0.25	
<b>All Nursing</b>	<b>3.0</b>	<b>1.0</b>	
Social Work	0.50	0.25	0.25
Bereavement support	0.25	0.10	0.10
Pastoral care	0.25	0.25	0.25
<b>Subtotal, allied health psychosocial</b>	<b>1.0</b>	<b>0.6</b>	<b>0.6</b>
Psychology	0.25	0.10	0.10
Speech pathology	0.20	0.20	0.20
Dietician		0.20	
Physiotherapy	0.40	0.20	0.20
Occupational therapy	0.40	0.20	0.20
Pharmacist		0.25	0.10
Music/art therapy	0.50		0.25
<b>Subtotal, allied health therapy</b>	<b>1.75</b>	<b>1.15</b>	<b>1.05</b>
<b>Volunteer Coordinator</b>	1/40 direct	1/50 direct	1/50 direct
	1/65 process	1/65 process	1/65 process

+ Palliative care specialist and registrar have community and inpatient responsibilities

**Community settings** include the patient's private home or a community living environment such as an aged or supported care facility. Staffing ratios in nursing and allied health are based on a

<sup>9</sup> No estimate is provided for the number of general practitioners with palliative care expertise required to serve a population of 100,000 or the number of community nurses who have a palliative care as part of their generic workload that are required.

specific number of EFT positions per 100,000 population for community services and it should be noted that specialist medical staff resources cover both inpatient and community settings.

**Inpatient settings** can include designated palliative care beds in rural community hospitals, designated beds in teaching hospitals or a purpose built hospice. The guidelines estimate that in a population of 100,000, 295 patients will require an average of 7 inpatient palliative care bed days each year. Based on occupancy levels of 85%, a minimum of 6.7 designated palliative care beds per 100,000 population is the recommended ratio. In the Tasmanian context, it is important to note that this figure potentially includes designated palliative care beds in rural hospitals. We return to this later in this report.

Palliative care services provide consultation and liaison services in **acute hospitals** and their specific roles include assessment, symptom management and consultation; discharge planning for all palliative care patients; and education of health care providers throughout the hospital. The planning ratio used for an acute hospital consultative service is 1.5 palliative care specialists and 1 registrar per 125 acute beds.

The Planning Guidelines also recognise **rural and remote areas** have specific needs and local health care workers need access to specialist palliative care providers who can assist with the development of an appropriate care plan. This care plan often includes clinical management and may require a formal agreement with a specialist palliative care service to facilitate timely access to care.

#### 4.1.4 How Tasmania compares with normative standards

We have applied the generic model of care and clinical service planning guidelines developed by Palliative Care Australia to Tasmania as a way of measuring normative need.

##### 4.1.4.1 Target group

Table 1 showed PCA estimates of the palliative care target group. We used those estimates and applied them to the Tasmanian population. No weighting was applied to take account of demographic factors that may affect demand for palliative care (see Section 4.2.1.1). The results are shown in Table 3. It shows that Tasmanian palliative care services are receiving referrals for more than 90% of cancer patients but only about 10% of patients with non-malignant conditions.

**Table 3** *Current and expected deaths for the Tasmanian population and expected referrals to palliative care services annually*

Diagnosis Group	Deaths based on PCA estimates	Current referrals <sup>10</sup>	Current as % of PCA estimate	Recommended referrals for assessment	Current as % of PCA estimate	Recommended ongoing consultancy	Recommended Direct Care
Cancer	885	832	94.0%	797	104.4%	620	177
Non-Cancer	885	92	10.4%	797	11.6%	266	89
<b>TOTAL</b>	<b>1770</b>	<b>924</b>	<b>52.2%</b>	<b>1593</b>	<b>58.0%</b>	<b>885</b>	<b>266</b>

These figures differ significantly from the estimates of the target group produced by Lynn and Adamson in the Rand study. They estimated that only about 20% of those who die of a chronic condition have cancer, with the remaining being patients with conditions such as organ system failure, frailty and dementia. While 20% appears to be too low in the Australian context, the Rand estimates, in combination with the PCA estimates, suggest that the target group of the Tasmanian

<sup>10</sup> Number of referrals to community teams in 2002/03

palliative care service should include a larger number of patients with non-malignant conditions than is presently the case.

In relation to children, only 4 children aged under 10 years were registered with the service and died during 2002/03. However, consultations with the various hospitals suggest that there is a well-established medical consultation-liaison relationship between palliative care and paediatrics.

#### **4.1.4.2 Service Model**

The Tasmanian Palliative Care Service has the majority of the key service elements in place suggested by PCA including:

- A specialist service provided by geographically based multidisciplinary teams;
- Education, professional development and consultancy services provided to primary and secondary care providers who provide non-specialist palliative care services;
- Assessment and care planning for registered clients in the community, a consultation and liaison service for primary care providers including general practitioners and community nurses and for acute hospitals and residential care services;
- Designated palliative care beds are available in two Regions;
- Medical and nursing staff available to provide 24 hour access for registered clients and their carers;
- Bereavement support provided by designated social work positions attached to the Community Teams; and
- Each Team has access to a volunteer coordinator.

The viability of some of these service components given workload and workforce issues, the effectiveness of current networking arrangements and the challenges inherent in Tasmania's demography are discussed as issues in the following sections.

#### **4.1.4.3 Designated Palliative Care Beds**

The PCA guidelines recommend 6.7 designated beds per 100,000 population based on 85% occupancy rates. Using this measure Table 4 shows that, on this basis, Tasmania requires 31.5 designated palliative care beds with 15.4 required in South Region, 8.7 in North and 6.7 in North West.

Table 4 indicates that, with 16 beds<sup>11</sup>, Tasmania has half the beds 'needed' under the PCA guidelines. In terms of regional access, there are no beds in the North West, the South with 10 beds has 65% of the recommended target beds and the North with 6 beds had 70% of the PCA recommended target.

Bed requirements change if higher occupancy rates are used as standard. For example, if occupancy of 90% is used then bed requirements reduce to 6.3 per 100,000 with 29.6 beds required and if occupancy is 95% (6.0 bed per 100,000) then 28 beds would be required in Tasmania.

It is important to note that this table includes only beds that are formally designated as palliative care beds. Palliative care is also provided in both acute and district hospitals but these beds are not formally designated for palliative care.

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<sup>11</sup> St John's campus of Calvary Health Care in Hobart has 10 private beds supported by the Palliative Care medical staff but these are general medical beds not designated palliative care beds.

**Table 4 PCA Designated Palliative Care Bed Requirements**

Region	Population 2001	Designated Palliative Care Beds in Tasmania	Beds based on PCA 6.7/100,000 population	% PCA Target
South	230,745	10	15.4	65%
North	135,357	6	8.7	70%
North West	107,206	0	6.7	0%
<b>Tasmania</b>	<b>473,308</b>	<b>16</b>	<b>31.5</b>	<b>50%</b>

#### 4.1.4.4 Palliative Care Staffing

As at February 2004, the Tasmanian Palliative Care Statewide Service had a staff establishment of 54.6 EFT. An additional 2.2 EFTs were provided through NGO or DVA funding (see Appendix 1). This establishment includes approximately 12 EFT with Statewide management and/or team/service administrative or hotel service roles that are not covered by PCA clinical guidelines. We have applied the clinical guidelines to the adjusted staffing complement by discipline.

##### Palliative Care Medical Staff

The PCA medical staffing ratio is 1.5 specialists and 1.0 registrar per 100,000 population for doctors working across settings and 0.25 EFT resident medical staff and 0.25 EFT liaison psychiatry per 6.7 designated beds.

There are four specialists and a 0.8 EFT registrar currently available in the Tasmanian Palliative Care Service. The medical specialist positions include 2 MSOAP appointments supporting the North and North West Regions and the positions in the South include 0.2 EFT time allocation for the Medical Director of the Statewide Service.

Table 5 compares the PCA target staffing with the actual staffing by discipline and region. The PCA planning ratio suggests that Tasmania requires 7 specialists and 4.6 FTE registrars. The available medical staffing is 57% of the PCA specialist medical target and 22% of the palliative care registrar requirements.

**Table 5 Palliative Care Specialist Medical Workforce<sup>12</sup>**

Region	Pop 2001	PCA Specialist Target EFTs	Specialist Actual	Specialist +/-	PCA Registrar Target EFTs	Registrar Actual	Registrar +/-
South	230,745	3.5	2.0*	-1.5	2.3	0.8	-1.5
North	135,357	2.0	1.0#	-1.0	1.3	0	-1.3
North West	107,206	1.5	1.0#	-0.5	1.0	0	-1.0
<b>Tasmania</b>	<b>473,308</b>	<b>7.0</b>	<b>4.0</b>	<b>-3.0</b>	<b>4.6</b>	<b>0.8</b>	<b>-3.8</b>

\*South Specialist establishment includes the Medical Director of the Statewide Service (0.2 EFT) and medical staff coverage of the community team and the Whittle Ward.

# Denotes MSOAP positions

<sup>12</sup> The number of medical staff has fallen since we completed our review due to recent resignations.

## Palliative Care Community Nurses

The PCA planning ratio for Palliative Care Community Nurses is 3.0 per 100,000 population or 17.3 EFTs for Tasmania as a whole.

As shown in Table 6, there are 12.4 ETF Nurses overall in Tasmania or 72% of the PCA target staffing. These figures exclude the two Clinical Coordinators for the North/North West and for South who are part of service management. If these positions are included, Tasmania has 14.4 EFTs and 83% of the PCA community nursing target.

In terms of distribution by region, North West has 83% of the PCA target staffing (reflecting the heavier workload in the community due to the absence of local designated beds) compared to 65% in North and 70% in South.

**Table 6 Community Palliative Care Nursing<sup>13</sup>**

Region	Pop 2001	PCA Target EFT	Actual	Nursing +/-
South	230,745	8.7	6.1	-2.6
North	135,357	4.6	3.0	-1.6
North West	107,206	4.0	3.3	-0.7
<b>Tasmania</b>	<b>473,308</b>	<b>17.3</b>	<b>12.4</b>	<b>-4.9</b>

## Psychosocial Support, Bereavement and Volunteer Coordination

The PCA planning ratio for psychosocial support services in Community Teams is 0.5 EFT social workers and 0.25 bereavement support positions per 100,000. This translates into the equivalent of 3.5 EFTs for Tasmania and 3.38 EFTs are available (see Table 7).

The social work positions attached to the community teams provide the full range of psychosocial services including elements of case management, client and carer counselling and bereavement support. In other services the support functions and bereavement counselling may be separated.

Designated inpatient units require 0.6 EFTs for 6.7 beds for psychosocial support and pastoral care or the equivalent of 1.43EFTs for the 16 designated beds available and 2.8 EFT for the 31.5 recommended under the PCA guidelines. Only a 0.2 EFT designated palliative pastoral care position is currently available with other psychosocial support sourced from the Community Team or the Hospital allied health pool.

There are approximately 250 palliative care volunteers across Tasmania and three EFT Volunteer Coordinators including 2 working for NGOs. This gives a ratio of 1 Coordinator to 83 volunteers whereas PCA recommends 1 to 40 for direct support volunteers and 1 to 65 for indirect support. Specialist palliative care services in other States have similar ratios to Tasmania and local review is required to determine whether the current ratios are adequate for the type of support services being provided by volunteers in each region.

<sup>13</sup> This table includes the two liaison positions attached to the RHH and the LGH.

**Table 7 Community Social Worker and Volunteer Coordinator**

Region	Pop 2001	PCA Target EFT	Actual	Variance	Volunteer Coordinator Target	Actual
South	230,745	1.7	1.14	-0.541	1:40	1:83
North	135,357	1.05	1.14	0.09	1:40	1:83
North West	107,206	0.75	1.0	0.25	1:40	1:83
<b>Tasmania</b>	<b>473,308</b>	<b>3.5</b>	<b>3.28</b>	<b>-0.201</b>	<b>1:40</b>	<b>1:83</b>

### Community and Inpatient Allied Health Therapy Staff

The PCA guidelines suggest that Community Teams need the support of the equivalent of 1.25 allied health therapy staff per 100,000 drawn from psychology, physiotherapy, occupational therapy, speech pathology and 0.5 EFT to provide music and art therapy.

There are no designated allied health therapy staff attached to the Community Teams or Inpatient Units in Tasmania and these personnel are sourced from the Community Health Services or the general hospital allied departments. Consultations indicate that most Community Teams do not have adequate access to therapy staff on request and that the palliative care nurses are also providing some therapy input for some patients. However, as palliative care, community assessment and care management are all part of the Primary Health subdivision, there are clearly opportunities for allied health services to be provided to palliative care by other teams.

The indicative requirement for allied health positions using the PCA guidelines is 5.8 EFT drawn from psychology, physiotherapy, occupational therapy and speech pathology and 2.3 music/art therapy EFTs for Community Teams (see Table 8).

The indicative requirement for the 16 available designated hospice beds is 2.5 EFTs in allied health. If Tasmania met the hospice target of 31.5 beds, 4.9 EFT would be required.

**Table 8 Indicative Allied Health Therapy Requirements**

Region	Pop 2001	PCA Allied Health Therapy – community teams EFT	PCA Music/Art Therapy – community teams EFT	Tasmania (community only)	Variance (community only)
South	230,745	2.9	1.2	0.0	-4.1
North	135,357	1.6	0.7	0.0	-2.3
North West	107,206	1.3	0.5	0.0	-1.8
<b>Tasmania</b>	<b>473,308</b>	<b>5.8</b>	<b>2.3</b>	<b>0.0</b>	<b>-8.2</b>

#### 4.1.5 Summary of findings in relation to normative need

The service structure for Specialist Palliative Care Services in Tasmania generally reflects the model of care and balance between community and inpatient services envisaged in the PCA service planning guidelines.

In relation to the specific service planning guidelines:

- Tasmania has 50% of the designated palliative care beds that are recommended in the planning guidelines and there are distributional issues with no designated beds available in North West Region. But this figure is based solely on beds that are formally designated as palliative care beds. Palliative care is also provided in both acute and district hospitals but these beds are not formally designated for palliative care.
- The projected bed requirements also indicate that no region has the population base to support a 20 bed hospice unit which is the minimum sized unit for efficient staffing<sup>14</sup>. The costs associated with freestanding units of 10 beds or less are disproportionately high and providing equitable geographic access to small inpatient units may require an unacceptable trade-off in terms of adequately resourced community teams and inpatient services unless innovative solutions to access and provision can be found.
- The Community Team staffing is below the relevant planning ratio in several disciplines. One of the most significant shortfalls is medical staffing where 5.6 EFT are available compared to the 11.6 EFTs required or a shortfall of 57%.
- Unlike every other jurisdiction in Australia, the Tasmanian palliative care service does not employ staff with qualifications in psychology, physiotherapy, occupational therapy, speech pathology or music/art therapy. Instead, these disciplines are sourced from other teams. Access to this expertise was identified as an issue during the Review. A total of 10.7 EFT allied health therapists across both community and inpatient services would be required to bring Tasmania up to the PCA standard. Provision needs to be made in planning future allied health requirements for the growing palliative care workload.
- For community based palliative care nurses the shortfall is 2.4 EFT or 14% if the Clinical Coordinators are included and 4.4 or 25% if they are excluded.
- The available psychosocial staff providing social work and bereavement counselling is within the planning parameters. However, they are taking on roles that would be undertaken by allied health therapists in other jurisdictions. Investment in allied health therapy services could be expected to have a flow-on effect onto the workload of psychosocial staff.

## 4.2 Comparative need

We have examined comparative need objectively, by comparing Tasmania's need for specialist palliative care services with other parts of Australia. Likewise, we compared the availability of specialist palliative care services in Tasmania with the availability of equivalent services elsewhere.

When need is defined in a comparative way, a region, population group or person is considered to be in 'need' if they have more health problems, or less access to health services, than other regions, population groups or individuals.

In the current context, measures of comparative need have included assessing differences between regions within Tasmania and differences between Tasmania and other parts of Australia. The results are summarised below.

If the data were available, it would also have been desirable to examine differences between different groups of consumers (defined by disease [eg, malignant versus non-malignant conditions and by population groups [eg, children versus adults, different cultural groups and so on]). However, we were unable to identify useful comparative need data at this level of detail.

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<sup>14</sup> This figure is based on consultation with palliative care experts during the course of the Review

## 4.2.1 How Tasmania compares with other mainland areas and how the 3 regions compare

Benchmarking for most health services is an evolving field and this is especially true for relatively new or emerging areas of specialisation such as palliative care that encompass a range of service providers and settings of care and a mix of generalist and specialist providers.

### 4.2.1.1 Demographic Characteristics Affecting Demand for Palliative Care

The following demographic and social characteristics will drive demand for palliative care in Tasmania relative to other States and shape the needs of the service system:

- Excluding non-melanocytic skin cancers, Tasmania has the highest overall incidence of cancer nationally with a 1 in 3 risk of developing cancer before the age of 75 years.
- Tasmania has an older population than the national average and the percentage of older people is predicted to increase from 13.5% in 2001 to 14.8% in 2006 and 31.8% by 2051 with most rapid growth in the 85 years plus age group.
- Health outcomes and access to health services are generally poorer for people living in rural and remote areas. Forty-seven percent of Tasmanians live outside the cities of Hobart, Clarence, Glenorchy, Launceston, Devonport and Burnie and the proportion of people aged 70+ living in rural areas is almost double the national average. Different service models are required to provide timely and appropriate access to palliative care in rural and remote communities.
- Tasmania is the State with the greatest level of disadvantage and is second only to the Northern Territory nationally on the ABS Index of Relative Socioeconomic Disadvantage.
- Tasmania has the highest rate of people living alone. People living alone are more likely to require hospice-based care rather than home-based care.

### 4.2.1.2 Indicative National Staffing Comparison

The National Census of Palliative Care Services conducted every five years by Palliative Care Australia provides the best snapshot of the state of play nationally. However, analysis of the 2003 Survey was not complete before the conclusion of this Review and the data on service types and staffing levels in the 1998 Census<sup>15</sup> was seen as too dated for a reasonable comparison.

However, PCA kindly provided preliminary staffing data from the 2003 Census to assist with the interstate comparisons in this Review. These data are still subject to final verification and as a result the State/Territory data shown in Table 9 for the nominated sample of providers is indicative only.

We have taken the total staffing as reported by the number of respondents listed in each jurisdiction and using the 2001 population, developed a crude staff to 100,000 population ratio for each State and Territory and compared this to the Tasmanian Palliative Care Service Staff establishment.

Using this method the national average is 9.4 FTE per 100,000 population ranging from 5.8 FTE in Queensland to 13.6 in Western Australia. Tasmania with approximately 9.7 FTE clinical staff

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<sup>15</sup> Palliative Care Australia *State of the Nation 1998: Report of the National Census of Palliative Care Services*. Palliative Care Australia, Canberra. October 1999

(including the service coordinators and the 2 MSOAP funded medical officers) is at the national average.

All other jurisdictions report some dedicated allied health therapy staff, with occupational therapy and physiotherapy the most common disciplines.

**Table 9 Indicative Palliative Care Specialist Staffing by Jurisdiction. Preliminary PCA 2003 Census Data**

State/Territory	ACT	NSW	NT	QLD	SA	VIC	WA	TAS
Pop 2001	311,900	6,371,700	210,700	3,655,100	1,467,300	4,645,000	1,851,300	456,700
No Respondents	1	39	2	30	17	42	27	Establishment
Doctors	3.5	47.7	2.3	12.7	13.3	12.6	8.1	4.8
Nurses	21.4	470	5	136.8	100.9	329.4	199	32.3
Social Workers	0.6	21.2	1	5.1	4.7	23.27	2.3	3.2
Bereavement	0.7	7.7		4.9	6.6	17.9	3.6	
Pastoral Care	1	7.1	0.8	2.4	1	13.5	3.7	0.2
Volunteer Coordinator	1	9.3	0.3	8.4	7.1	11.8	5.8	3
Physiotherapist	0.7	9.38		2.9	5.6	3.4	0.9	
Occ. Therapist	1	9.7	0.7	1.7	0.9	2.4	1.6	
Speech Pathology		2.7		0.4	0.2	0.2		
Total FTE	30.9	623.78	12.1	205.3	157.3	456.47	252	43.5
<b>FTE/100,000 pop</b>	<b>10.0</b>	<b>9.8</b>	<b>5.8</b>	<b>5.6</b>	<b>10.7</b>	<b>9.8</b>	<b>13.6*</b>	<b>9.7</b>

\* WA returns may have overstated the palliative care nursing staff establishment in several small hospitals

#### 4.2.1.3 Service Structures and Models of Care

Crude staffing ratios do not address the differences in rural and urban service mix, economies of scale or access issues that face States such as Tasmania. There are also variations in the models of care nationally and in highly urbanised and rural/regional areas within each jurisdiction.

We have collated information from the Palliative Care Service Director from Hunter Area Health Service in NSW and snapshots of service models in South Australia and Western Australia to provide a broad comparison of service models in place in populations with some similarities to Tasmania. These comparisons are reported in full in Appendix 3.

The Hunter Region in NSW was selected as it is relatively similar to Tasmania in terms of its geography and its catchment area. Consequently it is worth briefly examining the way that palliative care services are structured in the Hunter.

#### Palliative Care in the Hunter Region<sup>16</sup>

The Hunter Region is located 90 minutes north of Sydney, covers an area of 25,000 square kilometres and has a population of approximately 520,000. This includes the Lower Hunter (Newcastle, Port Stephens, Lake Macquarie, Maitland, Hunter Valley Wine Country), Barrington Tops (Gloucester and Dungog) and the Upper Hunter (Singleton, Muswellbrook, Scone, Merriwa, Murrurundi) and the Great Lakes.

<sup>16</sup> Source: Personal communication with Dr John Cavenagh, Senior Staff Specialist, Division of Palliative Care, Newcastle Mater Hospital

The Hunter Area Health Service (HAHS) is responsible for providing health services to the population of the Hunter Region. It provides public health, health promotion, community health, acute hospital, aged, mental health, rehabilitation and palliative care services. For planning purposes, the Region is divided into three sectors – Greater Newcastle, the Lower Hunter and the Upper Hunter.

Palliative care services in the Hunter Region operate under a ‘hub and spoke’ model where the ‘hub’ is the tertiary referral Palliative Care Service based at the Mater Newcastle Hospital and the ‘spokes’ are the specialist palliative care and other teams that provide community based services. For a client to receive services, they must be referred by a GP or a medical specialist (typically 50% of referrals come from each group) and be registered with the Palliative Care Service.

Inpatient services are provided in a 20 bed inpatient hospice unit located in a stand alone building at the Newcastle Mater Hospital. For clients to be admitted to the hospice, they must meet the definition of palliative care and be willing to sign a ‘not to be resuscitated order’. The main reasons for admission to the hospice are symptom control, management of the terminal phase of care and respite care. The proportion of hospice patients with a diagnosis of cancer is approximately 95%.

Specialist community based services are provided by an interdisciplinary team comprising 8 nurses, 3 occupational therapists (2 of whom operate a day hospice), 1 physiotherapist, 1 social worker and 1 pastoral care worker. This service operates under a ‘shared care’ model with services shared by specialist palliative care staff, GPs and general community health staff. The majority of the palliative care team’s time is spent providing consultation/liaison services to community based staff and directly to clients and carers. These services are provided both in the clients homes and in local hospitals.

A twenty four hour/seven day a week after hours service is provided by the specialist palliative care nursing team. However, services are only available to clients who reside within a 20 kilometre radius of the Newcastle Mater Hospital (which happens to be located near the centre of Newcastle). Approximately 120 clients at any one time are registered with the palliative care service within this 20 kilometre area. About 25% of this group typically require intensive care with a further 25% requiring visits from the Palliative Care team on more than a weekly basis. The remaining 50% comprise a mix of clients who are stable but require fortnightly visits together with clients who are stable and require only occasional visits.

On the other hand, after hours services outside the 20 kilometre area are provided by community nurses based in local community health centres with the Palliative Care team providing a consultation/ liaison service as required.

Several distinguishing features about the Palliative Care Service model are worth noting for consideration in Tasmania:

- On-call nursing staff have access to a back-up medical consultation/liaison service provided on a rotation basis by the palliative care specialists and the 5 GP visiting medical officers. It is not uncommon for this service to be used several times per night. In addition, on-call nursing staff have access to a back-up consultation/liaison nursing service from the hospice based nursing staff.
- Emphasis is placed on the rotation of specialist palliative care nurses between the hospice and the community based teams. This policy recognises the importance of seeking to prevent ‘burn-out’ by offering options for staff otherwise working on an on-call basis.
- Five local GP visiting medical officers with expertise in palliative care are employed on a fee for service basis to support the Palliative Care Service. They operate within the overall 20 kilometre area with each GP having responsibility for a designated sector. The GPs undertake a primary assessment of all new clients including consulting with the client’s GP and attending

the hospice on a weekly basis to present new clients to a team meeting. Following their initial assessment, the GP's also provide a consultation/liaison service for clients within their sector.

Specialist medical palliative care services in the Hunter Region consist of the Director (Professor), 3 full time palliative care specialists, a 0.5 FTE Hospital Medical Officer and, in normal circumstances, a Senior Resident Medical Officer and Registrar position. Medical staff have significant teaching duties within the Medical School of the University of Newcastle.

### **South Australia and Western Australia**

Both South Australia and Western Australia have a mixed urban, regional and remote population structure and have designated palliative care services attached to major hospitals in the metropolitan areas. The key features of how care is provided in regional communities is as follows

- In regional SA there are no dedicated palliative care beds for acute care. Rather palliative care is managed by the local community health service via district nurses, GP's, domiciliary and allied health support.
- Community or local district hospitals in regional areas in SA have developed palliative care suites as part of their general bed complement and this allows clients and families to access services close to where they live.
- The bulk of palliative care in SA is provided through coordinated care in the community.
- In WA designated beds are planned on the basis of 5 beds per 100,000 population.
- There is a relatively small specialist medical staffing based in Perth and WA provides Statewide support to community health professionals through its palliative care telehealth service and education services, both based at the Cottage Hospice. Medical practitioners are supported through the WA Combined Palliative Care Outreach Service, which is a 24x7 telephone advisory line serviced by rostered palliative care physicians.

#### **4.2.1.4 The comparative need for palliative care in the three Tasmanian regions**

Appendix 4 contains a detailed analysis of performance and activity data collected by palliative care nurses which highlights several of the key differences between the Regions and the Regional Community Teams. The key findings include:

#### **Population Characteristics**

Two thirds or more of the client population of the Southern and Northern Teams live in metropolitan areas compared to 54% in North West. The size of the rural/remote population in North West combined with low population density contributes to access issues for clients and additional travel requirements for Palliative Care staff and consultants.

#### **Workload and Service Characteristics**

In 2002/03, the Southern Team had 51.6% of the client base (2082) followed by North West (1037) with 25.7% and North (913) with 22.6%. The North West client load and referral base is larger than it's regional population share and this may reflect the age profile of the community and/or an increase in referrals following the appointment of a palliative care specialist to the Region. In terms of service characteristics:

- The South Community Team with 48.8% of the population had 48% percent of referrals, 47% of admissions and 45% of deaths. Southern provided the lowest number of out of hours services in 2002/03 with provision skewed toward direct client or carer support (67%) with limited out of hours support for other service providers. This suggests that the Southern Team

may be providing a higher primary care workload for palliative care patients compared to Teams in the other Regions.

- The North Community Team with 28.6% of the population had 23.5% of total referrals, 24.9% of admissions and 25.4% of deaths. This Team provided 35% of the out of hours contacts (801) with 55% provided for clients and carers and 45% for service providers.
- The North West Team with 22.7% of the population had 29% of referrals, 28.4% of admissions and 29.6% of deaths. This team provided the highest number of out of hours services (38% or 871) of all the Teams and supplied 58% for service providers compared to the Statewide average of 47%. This suggests that the North West Team relies more heavily on general practitioners and other primary health services than other Teams.

### **Trends in Demand**

All teams experienced growth in referrals, admissions and client numbers between 2001/02 and 2002/03.

- Referrals grew by 101 in the South (30%), 57 in North (36%) and 47 in North West (21%) between 2001/02 and 2002/03.
- Admissions increased by 34 in the South (10%), 21 in North (11.7%) and 2 in North West (1%) between 2001/02 and 2002/03
- Client numbers grew by 230 (33.7%) in North, and 108 (5.5% and 11.6% increase respectively) in the South and North West between 2001/02 and 2002/03.

### **Place of Death**

There are significant differences between the Regions in terms of place of death:

- In the North West, a significantly higher proportion of patients died at home (45% in 2001/02 and 39% in 2002/03 compared to a Statewide average of 31%) and in hospital settings (49% in 2002/03 compared to the average 38%) than Tasmania as a whole or the other Regions. This reflects the absence of designated hospice beds in the Region.
- In Southern access to the hospice meant that only 24% of patients died at home, 33% in a hospice setting (State average 22.1%) and only 5.5% died in a nursing home (average 8.8%).
- In the North 35% of patients died at home, 29.5% died in the hospice and 23% died in a hospital setting. Between 2001/02 and 2002/03 there was a 30% increase in the proportion of deaths at home, fairly constant hospice usage and a 40% decline in deaths in hospital settings.

### **4.2.2 Summary of findings in relation to comparative need**

Demographic and epidemiological data suggest that demand for palliative care in Tasmania is likely to grow more rapidly than in other States and Territories due to the highest overall incidence of cancer in Australia and a rapidly ageing population.

Access will continue to be a key consideration in service planning because of the high proportion of people over the age of 70 years who live in rural and remote communities and the high levels of socioeconomic disadvantage in the Tasmanian community.

In terms of crude staff to population ratios the preliminary figures from the 2003 Palliative Care Australia National Census suggest that Tasmania is at the national average with the staff establishment available in 2004.

While there has been growth in demand overall, there are important differences between the regions in terms of demand for palliative care relative to population share, place of death and models of care used.

The absence of hospice beds in the North West is contributing to a higher ratio of deaths at home and in hospital settings than the Tasmanian average and the converse is true in the South. There also appears to be greater reliance on other primary health care services in the North West reflecting distances and the needs of a dispersed population.

There may be opportunities to improve access and address key workforce issues and service effectiveness by adopting some elements of the model operating in the Hunter region of NSW and in rural areas in South Australia and Western Australia. These are discussed in the following sections.

### **4.3 Expressed need**

Expressed need defines need in terms of what services people use. It is based on what you can infer about a community through observing its use of services. A community or person who uses a lot of services is assumed to have high need. A community or person who does not is assumed to have low needs. However, expressed need is influenced by the availability of services. If one community has many, well distributed resources, its population is likely to use more services than a community with few services.

#### **4.3.1 Snapshot of current service utilisation data**

The Department of Health and Human Services provided a series of background reports and other documents outlining the structure of the Tasmanian Palliative Care Service and historical service utilisation patterns across the State.

The following brief summary is based on information extracted from the Performance Indicator Activity Data Report supplied by the Tasmanian Palliative Care Service and analysed in Appendix 4. Trends are shown over three years wherever possible but some fields are not available in all years due to changes to the palliative care data collection between 2000/01 and 2002/03.

##### **4.3.1.1 Snapshot of Activity in 2002/03**

- As shown in Table 9, the community service in 2002/03 had a total of 4,063 clients, 924 new referrals, 807 admissions and 672 deaths and provided 2,298 out of hours services.
- Fifty three percent of out of hours services were spent providing direct services to clients (1,219) and 47% (1,079) were spent providing indirect services (providing advice and support to other service providers).
- An average of 340 clients were accessing the service each month.

##### **4.3.1.2 Trends in Demand – Community Teams**

- The number of referrals across the State increased by 205 or 28.5% between 2000/01 and 2002/03. Suggested reasons for this include the changing client age profile; increased pressure on other community-based services, clients with little or no in-home support and the higher acuity of community clients.
- The number of admissions has grown by 83 or 11.5% and the admission uptake was 88% in 2002/03.

- The gap between the number of admissions and deaths increased from 29 in 2000/01 to 106 in 2002/03 indicating earlier referral to the service, especially in the South.
- Direct client contact after hours grew by 4.9% and indirect contacts after hours declined by 1.3%.

**Table 10 Community Based Services – Summary Statistics 2000/01 – 2002/03**

	2000/01	2001/02	2002/03	Net Change	% Change
Clients	3320	3633	4063	743	22.4
Referrals	719	836	924	205	28.5
Admissions	724	750	807	83	11.5
Deaths	695	653	672	-23	-3.3
Direct after hours	1162	1278	1219	57	4.9
Indirect after hours	1093	1012	1079	-14	-1.3

#### 4.3.1.3 Trends in Demand - Inpatient Services

Data for the hospice services provided by the Whittle Ward in the South and Phillip Oakden House in the North between 200/01 and 2002/03 are shown in Table 11.

This indicates that there were 201 hospice deaths in 2002/03 and 335 separations.

- The number of hospice deaths increased by 17% in the Whittle Ward (3 year trend) and by 28% (2 year trend) at Phillip Oakden House.
- Length of stay has declined marginally at both sites and occupancy rates have increased.
- Length of stay in the Whittle Ward at 11.7 days in 2002/03 exceeds the PCA planning guideline average of 7 days per patient but is lower than the actual 15 day national average reported by the AIHW.

**Table 11 Inpatient Activity Summary**

UNIT	2000/01	2001/02	2002/03	Change	% Change
<b>WHITTLE WARD</b>					
Length of stay	12	11.7	11.7	-0.3	-2.5
Separations	248	245	234	-14	-5.6
Deaths	138	146	161	23	16.7
% occupancy	77.2	79.5	84.3	7.1	9.2
<b>PHILLIP OAKDEN HOUSE</b>					
Length of stay	NR	9.98	9.00	-0.98	-9.8
Separations	75	68	101	26	34.7
Deaths	NR	39	50	11	28.2
% occupancy	76	84.2	92.2	16.2	21.3

#### 4.3.1.4 Palliative Care Client Characteristics – 2002/03

In 2002/03, 90% of Palliative Care clients had a primary diagnosis of cancer and 10% had a non-cancer diagnosis. Approximately 32% of Palliative Care clients accessed the service from rural

locations. This compares with rural communities representing about 50% of the Tasmanian population.

In terms of age:

- 9% of clients were aged less than 50 years including 4 children aged 10 years and under
- 40% of clients were aged 50 to 70 years
- 31% were in the 70 to 80 age group
- 20% were aged 80 years and above.

Fifty three percent of clients were male and 47% were female.

#### **4.4 Felt need**

Felt need recognises that there are qualitative and subjective elements to the notion of 'need' and defines it in terms of what individuals state their needs to be or say they want. Gaining input to programs through using the direct experience of people who can articulate felt needs is an accepted way to balance other inputs from experts and comparative data on advantage/disadvantage, and utilisation data on who currently gets what.

##### **4.4.1 Key themes from the consultations conducted as part of the Review**

During November 2003, the Review team conducted a series of 26 consultations with representatives from 36 different stakeholder organisations across the State. The consultation process included meetings with specialist palliative care inpatient and non-inpatient services, generalist services such as community nursing and the three Tasmanian Divisions of General Practice and relevant non-government organisations and university Departments. A full list of the agencies consulted is provided at Appendix 5. In total, more than 170 individuals participated in the consultation process over a one week period.

The consultations were conducted as informal sessions typically of two hours duration. Participants were encouraged to raise any issues that they considered to be of importance to their particular service or of importance to the Tasmanian Palliative Care Service more generally. Participants were specifically asked to comment on administrative and structural issues that they feel needed to be addressed to ensure the short term or long term viability of the service. Participants were assured that any comments they made would remain confidential and that they could raise any matters that they considered important.

As would be expected, a wide range of issues were identified during the consultation process. In our view, with a small number of exceptions, the views expressed can reasonably be described as variations on a number of themes. There was a high degree of consistency across the three regions in terms of the types of issues raised, although there were some differences due to local circumstances and differences in context.

We have summarised below the major issues that were raised during the consultation process. This summary is not an attempt to record each individual comment made during the consultation sessions. Rather, it is intended to synthesise those issues that were raised on several occasions under a set of headings that reflect the key themes that emerged during the process.

##### **4.4.1.1 Resource Issues - Specialist Palliative Care Services**

- The most significant issue that emerged across the consultations with both specialist inpatient services and the community palliative care teams was the need for additional funds to be made available to employ medical, nursing, and allied health staff. There was a strong view

expressed by staff across both settings and in each region that the current level of resources is causing a high level of stress amongst staff and having a significant impact on staff morale.

- In relation to medical services in the South region, it was felt that an appropriate mix of medical staff would comprise:
  - One dedicated position for the palliative care community team, South;
  - One dedicated position for Royal Hobart Hospital;
  - One dedicated position for the Whittle Ward; and
  - One dedicated registrar position.
- A consequence of the lack of medical resources was noted in terms of the fact that a '1 in 2' roster arrangement has been in place for some years. There was a strong view that this arrangement is neither acceptable nor sustainable.
- In relation to inpatient nursing services in the South region, it was felt that the current arrangement with 2 nurses rostered during the afternoon shift is insufficient particularly when several patients are likely to die during a shift.
- It was felt that a more appropriate mix of nursing staff would comprise 4 nurses during the day shift, 2.5 nurses during the afternoon shift and 2 nurses on the night shift.
- Concerns were also expressed about the frequency with which nursing staff working in the specialist palliative care teams in each region are required to be 'on call'.
- The principal areas in which it is felt that adequate services are not able to be provided as a result of the lack of human resources include:
  - Education and continuing education services both within the palliative care service and more widely to community and primary care staff;
  - Education resources such as videos and information bulletins;
  - The capacity for the provision of inpatient services to non-malignant patients;
  - Counselling services;
  - Bereavement support services;
  - A range of nurse educator functions;
- It was felt that the number of beds operating on the Whittle Ward is insufficient to meet the current demand for inpatient services in the South region. This problem is exacerbated by the fact that beds are sometimes occupied by patients who have been stabilised and are waiting for residential aged care placement.

#### **4.4.1.2 Resource Issues –Community Nursing and Primary Care**

- A key staffing issue that arose for community nurses concerns the unpredictable resource requirements associated with providing care to palliative clients. It was noted in several consultations that palliative clients are significantly more resource intensive than other community clients, particularly in the terminal phase of care. If a community nurse is providing services to several palliative clients, it is often not possible to complete the expected number of home visits during a rostered shift.
- A further key issue raised by community nurses relates to issues associated with the increasing complexity of medication regimes being prescribed to palliative patients. It was felt that an increasing proportion of community nurses time is being spent assisting clients in medication management. It was felt that in some cases, clients and their carers are being expected to administer medications without an appropriate level of education and support.

- This group of providers also recognised the need for additional human resources to be allocated to the specialist palliative care teams. Most notably, staff from these services felt that continuing education and training in specific palliative care issues are not being adequately provided as a result of the current staffing levels.
- The Divisions of General Practice in each region specifically expressed the view that additional resources should be made available to allow specialist medical staff to train and educate GPs on issues such as pain management. This is particularly relevant where GPs only occasionally provide services to palliative clients.

#### **4.4.1.3 Referral Issues**

- There was a consistently expressed view across almost all generalist providers that the system for referring to the three palliative care teams is excellent and almost always occurs without delay. There was widespread praise for the willingness of the palliative care teams to accept referrals whenever required.
- It was noted that there is some confusion and differences in clinical practice amongst generalist providers regarding appropriate referral practices and timing. Particular issues raised included:
  - The timing of referral of aged care clients to specialist palliative care services;
  - The reluctance amongst some clinicians in rural and remote areas to refer to specialist palliative care services where those services are provided from outside the local area;
  - Considerable variation across disciplines within primary care providers regarding the appropriate timing of referrals to specialist palliative care services.

#### **4.4.1.4 Structural Issues**

- Views were sought during each consultation in relation to the current structure of the Palliative Care Service in terms of it operating as a stand alone service. In almost all consultations, strong support was expressed for maintaining this structure. It was felt that the stand alone structure provides the service with a clearly recognisable identity that would be at risk of being lost if the service was dissolved and became part of a broader service.
- The major structural issue raised in the consultations in the North West region related to the need for a dedicated hospice service. This view was expressed in strong terms in each consultation in that region. Whilst there was a unanimous view that there should be a hospice service in the North West located in Burnie, there was not a strong view regarding the type of facility in which the hospice should be located.
- There was widespread recognition for the significant amount of work undertaken by volunteers across the three regions. In some consultations, it was suggested that this work was not sufficiently recognised by the Department and that additional funding should be made available to increase the number of 'night sit' services able to be provided by volunteers.

#### **4.4.1.5 Organisational/Administrative Issues**

- There was overall support for the current organisational structure of the service in which the palliative care teams provide a consultation/liaison service. The following points were noted in relation to the structure of some elements of the Service:
  - Although the palliative care teams do not include physical therapy allied health staff such as physiotherapists and speech pathologists, the palliative care teams can sometimes

broker provision of these services on behalf of community nurses and other primary care teams.

- There were mixed views amongst community nursing teams in relation to developing a 'key worker' model whereby interested individuals are encouraged to develop their knowledge of palliative care nursing practices. However, some community nursing teams feel that this is a sensible approach that has worked in other specialty areas. Other teams are strongly of the view that this should not be required of community based teams as the service should be provided by the palliative care teams.
- There was a level of concern expressed regarding the lack of communication between hospital outpatient clinics providing services to palliative clients and both community palliative care teams and primary care providers.

#### **4.4.1.6 Private Sector Issues**

- Consultations were held with several private sector organisations including private hospitals and residential aged care providers. The key theme that emerged was that there is unmet need for inpatient palliative care services in each of the three regions. In several instances, providers expressed a strong interest in exploring options for introducing or expanding their role in palliative care service provision.

### **4.5 Short-term services and projects**

Tasmania currently has special project funding for initiatives under the Commonwealth Caring Communities and the Rural Palliative Care Programs. A summary of these projects is provided below. As discussed in the final section of this report, these projects have the capacity to act as significant levers for longer-term change. However, all are funded for a finite period and there is no secured source of funding to maintain them after their current funding ceases.

#### **4.5.1 Caring Communities Project – Empowering the Midlands Community**

This project, sponsored by the Midlands Multi Purpose Health Centre, is designed to increase the knowledge and skills of local health professionals, key community organisations and residents regarding palliative care issues and to develop a collaborative model of local practice, support the recruitment of volunteers and establish an equipment pool for local palliative care patients. This 18 month project is due for completion in November 2004.

#### **4.5.2 Caring Communities Project – Collaborative Palliative Care in Rural Communities**

This project, sponsored by the Department of Health and Human Services and based in Launceston, aims to develop and articulate an agreed system of collaborative practice and service provision between primary practitioners in rural areas, palliative care consultants and palliative care volunteer coordinators. The 30 month project is aiming to improve referral and communication systems, provide needs based professional development and education, develop a cooperative system of activity and outcomes monitoring and evaluation, and, undertake collaborative development of system tools such as clinical pathways, practice guidelines, assessment tools and clinical indicators.

Evaluation will determine the effectiveness of each of the elements of this program but it is hoped that the programs and processes that are developed will become the foundation for collaborative practice across the State. This project is linking into the North West Rural Palliative Care Project, discussed below.

### **4.5.3 North West Tasmania Rural Palliative Care Project – North West Tasmania Division of General Practice**

The aim of this project sponsored by the North West Tasmania Division of General Practice is to develop and evaluate a sustainable model of general practice palliative care provision in rural and remote communities. It is one of eight demonstration projects around Australia that are testing the model initially piloted by the Murrumbidgee Division in NSW. The project is well supported by major stakeholders including the NW Rural Clinical School and the Tasmania Palliative Care Service and it is expected that the findings of the three year project will inform the primary health model of palliative care for Tasmania as a whole described in Section 9.

Funding is available until 2006 and again the independent evaluation will determine those elements of the program that need to be retained to support a sustainable practice model.

## 5 Summary of perceived problems and critical issues

The Tasmanian Palliative Care Service has been evolving in line with staffing availability, requirements under the Australian Health Care Agreements, funding and partnership opportunities and changing community perceptions about the type of care that people with life limiting illnesses require.

This section explores some of the key issues about the current model of care and the focus of the service that were raised in the consultations with staff and other stakeholders and in review of the available data. Perceived service needs and gaps are also discussed.

### 5.1 Structural Issues

#### 5.1.1 The organisational structure of palliative care

The current organisational structure is that the Department directly administers an inpatient unit (the Whittle Ward) and directly manages palliative care as a small, but specialised, Statewide service. This direct management role is in addition to its policy and planning responsibilities.

We canvassed in our consultation process (see Section 4.4.1.4) whether there might be a better organisational structure. We also explored several alternatives, some of which have distinct strengths.

On balance, we recommend no change. In later sections of this Review we recommend a substantial agenda of change and development. Changing the organisational structure of palliative care may bring some advantages. But it would necessarily distract from the critical task of achieving the improvements in service delivery that we have proposed. The successful implementation of a new model of service delivery (see Section 8), the establishment of regional Tasmanian Integrated Palliative Care Networks (Section 9) and a Tasmanian Palliative Care Accreditation System (Section 10) have priority over an internal reorganisation.

The achievement of these changes will require leadership and investment in managing the change process. The current leadership group is well placed to lead the change process. The only recommended organisational change is that the position of Clinical Coordinator North/North West be split into two positions, one for each region. The three positions in the South, North and North West should be renamed as Area Manager, Palliative Care, with duty statements updated to reflect their clear responsibility for the management of the entire integrated care network and not solely the management of the specialist palliative care service. This is consistent with our proposal to establish a Tasmanian Integrated Palliative Care Network in each region (Section 9).

#### 5.1.2 Target group and role of palliative care services

While all National and Tasmanian palliative care policies and plans are clear that the target group of palliative care is broader than those with malignant conditions, the data demonstrate that only about 10% of clients have a non-malignant condition. While the low usage of the service by patients with non-malignant conditions undoubtedly reflects the unwillingness of some clinicians to make referrals for these patients, it also reflects the structural reluctance of the service to accept them.

The service is not structured or resourced to provide care for patients such as those with organ failure whose condition oscillates and who typically will die quite suddenly after experiencing a long period of suffering limitations and having intermittent exacerbations of their symptoms (see Figure 3 on page 8). Indeed, consultation with staff suggested that, because of resource pressures, there is a reluctance to accept referrals for these patients because of the potential

duration of their illnesses and potentially difficulties in discharging them during periods in which their condition has stabilised. The outcome is that the service is essentially a palliative care service for patients with malignant conditions and for patients whose trajectory of illness is expected to be similar to those with malignant conditions. Many patients who would benefit from palliative care are disenfranchised in the process (see Table 3).

### **5.1.3 Balancing clinical work, training and professional development**

Palliative care is a specialty that needs to operate primarily as a consultative service where specialist teams provide consultation, liaison and support services to enable primary health care professionals, staff in general hospital settings and family and community members to deliver the majority of direct patient care.

A key challenge for most specialist palliative care services is to develop a service model and framework that is responsive to local circumstances (workforce, geography and demography) and that strikes the right balance between providing direct patient care and consistent provision of consultation services, education and training and related support to the wider network of service providers.

Feedback to the Review indicates that the growth in workload has meant that clinical staff are increasingly focusing on direct service delivery and consultation/liaison. The focus on professional education and collegial support has diminished to the point where primary care providers often reported that they feel unsupported and ill prepared for their role. This has a flow-on effect of increasing referrals to the Specialist Community Teams which exacerbates workload pressures and can lead to tougher client access criteria or waiting lists for service.

Investing in a structured and needs based approach to professional education and training is therefore a priority for the Service.

There are no reliable historical data available on the volume of education, consultation and direct care provided by the Specialist Teams although the data in Table 20 on page 64 provides a snapshot of recent activity for the hospital liaison nurses.

## **5.2 Size and economies of scale**

Given the size and demography of Tasmania, palliative care is not alone in experiencing structural problems that result in diseconomies of scale. That said, the problem is further compounded for palliative care because it is one of the smaller clinical specialties.

The two existing hospice/inpatient services – Whittle Ward in Hobart and Phillip Oakden House in Launceston – are too small to achieve any economies of scale and commissioning a stand alone unit in the North West would simply compound the problem. As a simple example, a minimum of 2 nurses is required on a night shift in any unit. This is the case whether there are 3 or 10 beds. A four (4) bed unit thus needs to be staffed at a level equivalent to a high dependency unit.

Tasmania has three options. One is to accept that there is a price premium to be paid in those services where it cannot achieve any economies of scale. The second is to integrate palliative care services with other inpatient services to achieve some economies without sacrificing the palliative care focus. This includes making better use of district hospitals by equipping them with the skills and expertise to provide palliative care for their local residents and by giving them improved access to consultancy and shared care services. The third is to expand such specialist inpatient services to the point that they can achieve economies of scale. The options for the future are set out in Section 7.

## **5.3 Staffing and Critical Mass Issues**

### **5.3.1 Medical staffing**

The establishment of a sustainable medical workforce is urgent.

Unlike other States and Territories, Tasmania has not recognised fellowship of the Australasian Chapter of Palliative Care of the Royal Australasian College of Physicians (RACP) as a specialist qualification. Other States and Territories have recognised this qualification in order to attract and retain palliative care medical staff. By not taking similar action, Tasmania is currently uncompetitive in attracting or retaining palliative care physicians. The two doctors attracted under the MSOAP are both recognised in Tasmania as medical practitioners. Both would be recognised as a staff specialist if working in States such as Victoria or New South Wales. A further apparent implication is that this is the reason that the Launceston General Hospital has not given admission rights to the palliative care physician located in the north.

The current medical workforce is expected to carry a workload that is not sustainable. The current Medical Director has worked a one in two roster for many years as well as carrying a full workload by day. His position is currently carrying a one in three roster. The sole positions in the North and North West are effectively on duty/on call 24 hours a day, 7 days a week. There are some specialties where this is not a problem as the call rate is not high. Palliative care is not in this category. Palliative care patients require 24 hour access to doctors who can respond to their needs. It is not realistic to expect doctors to be able to do this on a 24/7 basis.

The net effect is that Tasmania is not in a position to attract new palliative care specialists and has little to offer to those currently employed. If the current staff were to leave, it can be expected that Tasmania would have significant difficulty attracting doctors to replace them.

### **5.3.2 Nursing services**

The major factor that threatens current palliative nursing is the after hours service. Nurses we consulted regard the \$1 per hour they are paid to be on-call to be insulting and indicative of a system that does not value their contribution. The current arrangements create perverse incentives, as telephone work is not paid. Call out payments are only paid for home visits. Experienced and skilled palliative care nurses are able to resolve the great majority of problems over the phone. They should be remunerated for doing so.

A further issue in relation to the after hours service is that a number of occupational health and safety issues remain outstanding. For example, individual staff do home visits alone at night and there is no system for anyone else to know where they are. Mobile phone reception is patchy or non-existent in parts, there are no duress alarm systems in place and only a rudimentary system of risk assessment. Staff working the after hours roster are then expected on duty the following day.

The major gap between supply and demand is in the south. The current staff to patient (annual) workload ratios<sup>17</sup> are approximately:

- 1:346 South (and this is with a 'waiting list')
- 1:308 North
- 1:243 North West

As resources have become tighter, both professional education and bereavement support have been reduced. These two roles have now largely been abandoned by some teams. The reduction/cessation of professional education to staff working as community nurses and in facilities such as residential aged care facilities has important longer-term implications. Reducing the ability of primary care, residential care and rural hospital providers to provide primary palliative care will lead to an increase in demand for specialist palliative care services. This will further compound the current resource problems.

Increasing the number of palliative care nurses will not, by itself, solve the problem. There is a need to dedicate resources and to recognise that effective professional development requires effective educators. Doctors and nurses can become effective educators but these qualifications (in themselves) do not make them so.

### **5.3.3 Multidisciplinary/interdisciplinary care**

For the purposes of this Review, we use the two terms interchangeably. We note that a distinction has been made in previous Tasmanian palliative care policy documents. However, the two terms are used interchangeably (rightly so) across the mainstream health system.

A core policy attribute of palliative care is its multidisciplinary approach. In reality, there is a large gap between the policy and the practice.

One reason is that the service does not have a multidisciplinary workforce. Palliative care teams are predominantly nursing teams, with back up from sole medical and social work positions. No team employs a psychologist, an occupational therapist, a physiotherapist or a speech pathologist or has a formal consultation-liaison psychiatry service in place. Access to allied health professionals varies between the teams and depends on informal arrangements that have been negotiated locally, mostly with individual therapists.

Some of these arrangements work very well. In particular, the north has strong support from experienced and interested therapists working at the Launceston General Hospital. However, the availability of each discipline across the State is dependent on informal arrangements rather than being a systematic feature of the Tasmanian approach to palliative care.

The model in the South was initially designed to allay fears when the service was established that it would 'steal' patients from other specialties. Patients are referred separately for medical palliative care and for nursing/social work. They are not referred for multidisciplinary palliative care. This is not the case in either the North West or the North.

Consultation in the South suggests that referral patterns are now mature and historic concerns largely resolved. It is time to introduce referral for multidisciplinary care across the whole of Tasmania.

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<sup>17</sup> Based on clients at month end, annualised.

### 5.3.4 Bereavement support

In practice, there is very little bereavement support available for families and carers and even less for people with special needs (eg, bereavement support for parents after the death of a child). There is also little bereavement support for health professionals such as community nurses who, in some cases, have cared for patients over extensive periods.

## 5.4 Process Issues - overcoming variations in the model of care

Even though the Tasmanian Palliative Care Service is run as a Statewide program there are distinct differences evident between the regions in the way services are provided and the mix of direct care, consultation and education services available.

### 5.4.1 Settings of care based on agreed patient need

The available service utilisation data suggest that you are more likely to die in a hospice (33%) or hospital setting (38%) in the South, at home (35%) or in a nursing home (22%) in the North and in hospital (49%) or at home (40%) in the North West. The lack of designated palliative care beds in the North West compared to the South partially explains the difference between these two regions. However, the differences with the North, where more patients die in hospital than in the Phillip Oakden House hospice, suggests that there is either a need for additional hospice beds or better referral pathways into the existing hospice beds.

Some of the variation between the regions could be explained by differences in patient acuity or predictive factors for hospice care such as the patient living alone rather than differences in referral patterns. However, there are no data on patient clinical characteristics or phase of care collected to inform this issue. Irrespective, these variations in practice have implications for the cost of services and for the workload and focus of the Community Teams.

### 5.4.2 Partnership framework with general practitioners

The South Community Team provides limited out of hours support to other service providers whereas the North West Team provides 58% of out of hours consultation for other service providers (see Appendix 4). This suggests that the clinical framework for working with local GPs providing primary care for patients requiring palliative care requires considerable refinement and an agreement on the role of general practitioners in the continuum of care and their educational and support requirements.

The Hunter model makes extensive use of general practitioners with palliative care expertise as part of the sector/regional medical workforce and this model provides one option for Tasmania to overcome the specialist recruitment issues highlighted elsewhere.

A collaborative model for GP provision of after hours consultative and assessment services for a defined catchment population has been piloted with considerable success by the Murrumbidgee Division of General Practice in NSW<sup>18</sup>. This model is now being rolled out as a series of national demonstration projects with a focus on testing the generalisability of the model to other settings. The Rural Palliative Care Project being sponsored by the North West Tasmania Division of General Practice is one of those sites. This model should be regarded as the prototype for what should be progressively adopted, with relevant local modifications, as the Tasmanian model of palliative care in all three regions.

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<sup>18</sup> Cromwell D, Senior K, Owen A, Gordon R, and Eagar K (2003) *Can the National Palliative Care Strategy be translated into a model of care that works for rural Australia? An answer from the Griffith Area Palliative Care Service (GAPS) experience*. Centre for Health Service Development, University of Wollongong  
[http://www.uow.edu.au/commerce/chsd/caring\\_communities.html](http://www.uow.edu.au/commerce/chsd/caring_communities.html)

### 5.4.3 Common standards and clinical protocols

There is a need to develop common standards and clinical protocols for referral, intake, admission, allocation and intervention across the teams, and between disciplines (medicine, nursing, social work, pastoral care and volunteer support and coordination), both internally and externally. This will enable fairer assessment of workloads across teams and disciplines in the future and provide a better basis for workforce planning.

Pain management and effective prescribing for symptom control are key aspects of palliative medicine and the emergence of new therapies and better targeting of existing regimes is an important cost and quality issue. Several stakeholders we consulted indicated that the Specialist Service needs to develop evidence based protocols for prescribing by primary care professionals and specialists that take account of the phase of care, the efficacy of emerging therapies and the appropriate prescribing of high cost drugs such as the new medications being used palliatively for control of the neurological pain in a minority of palliative care patients.

## 5.5 Information, education and training

### 5.5.1 Information

Palliative data collection protocols and the use of information systems currently vary both between regions and between services within regions. The core method of capturing and storing information is paper based with information stored in the client's medical record. A small number of locally developed information systems are maintained by some services. In some cases, a range of clinical tools are also collected by the palliative care teams and used to inform clinical management decisions.

Tasmania needs an information system that supports the provision of a palliative care **system of care**, and not just a palliative care service. That system includes the public, private and non-government sectors. One implication is that GPs, community nurses and others need to be able to share electronic information with specialist palliative care providers.

Such information needs to be collected and shared as a key strategy for promoting the coordination and integration of patient care. This requires more than standard referral and assessment forms. It also requires the introduction and use of standard assessment instruments, the collection of meaningful clinical data and the transmission of that information to relevant care providers.

DHHS has initiated the Community Client Health Profile (CCHP) Project, which will implement the MedTrak application as a core information system for the Division of Community Population and Rural Health (CPRH). This is a major project, not only for CPRH but also for DHHS. MedTrak will be developed to support the service delivery requirements of the diverse range of community based health services within CPRH. When implemented, it will include an electronic health record and will provide various levels of client management functionality.

In this context, Palliative Care has already developed a 'Business Requirements' document which details the proposed requirements, functions and support needs for a Palliative Care Client Information System (PCCIS). This document correctly notes that this initiative represents an opportunity to establish a consistent, statewide approach to a range of data collection issues such as the use of common clinical tools. A business case approach for a PCCIS has also been completed and recommended CCHP as the preferred option. This recommendation has subsequently been approved by the CCHP Steering Committee. Scoping, development and implementation is expected to occur over the 2004/05 and 2005/06 financial years.

## 5.5.2 Education, Training and Research

Specific education and training issues in relation to the medical and nursing workforces were discussed above. The bigger issue is the need to further develop strategic partnerships with the University of Tasmania and relevant universities on the mainland. The university links are strong in the North and North West, but appear less so in the South. Research expertise in palliative care is developing and training programs are in place. Active education and research programs are a critical component of a quality service and need to be encouraged and nurtured. Adequate numbers of palliative care staff are a prerequisite to this.

The broader challenge is to provide education and training to staff working in the broader health system. As part of the National Palliative Care Strategy, Tasmania has recently received \$167,000 over 2 years to establish a Program of Experience in the Palliative Approach (PEPA). PEPA will provide flexible learning packages tailored to the needs of the clinicians working in mainstream services who wish to enhance their palliative care skills. The emphasis will be on provide flexible learning packages tailored to individual needs. PEPA funding will fund 50 places over the two year period. These may be a block period or a day over a flexible period. Placements will be for a minimum of 10 days. The education work placement and post support program within PEPA will fund agencies to backfill positions for professionals participating in the program. Funding for host facilities is capped at \$6,000 over 2 years. Project support at the State level is equivalent to 0.4 EFT in year one and 0.3 EFT over year two. Implementation is behind schedule but is due to commence in August 2004.

While PEPA provides an excellent opportunity to broaden the skill base in Tasmania, it will (at least in the short-term) place extra demands on existing palliative care staff and \$6,000 over 2 years will do little to compensate for this. The nurse educator positions proposed later in Section 13.2 will be important in both reducing the demands on existing staff and maximising the educational experience for participating clinicians.

## 6 Overall assessment of the current palliative care service

The Tasmanian Palliative Care Service is a high quality service that is doing well within existing resources and has achieved a great deal since the service reorganisation in 1997. It now provides access to community and consultative services in each region in Tasmania that are generally consistent with nationally recognised models of care and feedback from stakeholders indicates that the service is highly valued, accessible and responsive.

The service has been innovative in marshalling resources from external funding sources such as MSOAP and Commonwealth grants to expand programs on the ground and it has entered into effective clinical and strategic partnerships with Divisions of General Practice, with universities and the Rural Clinical School, with hospitals and with residential care providers. The service has also engaged successfully with local communities to increase awareness and understanding about palliative care and has encouraged community organisations to develop grass roots volunteer programs.

Not surprisingly, as the profile, level of trust and community understanding and expectations of the service have grown the referral base and workload has expanded to the point where the service is now a victim of its own success.

Some significant problems have developed as the service has evolved and the current arrangements are unsustainable without a significant increase of resources. Many staff are stressed and, in some cases, feel seriously demoralised and devalued. Resources are stretched and the service in the South has a waiting list. Given the nature of a palliative care service, it is simply unacceptable to have a waiting list. Either a patient needs palliative care and should be able to receive it in a timely manner. Alternately, a patient does not need palliative care and should be referred elsewhere.

Demand is increasing due to population ageing, increasing clinical complexity because of the availability of new clinical interventions and pain management drugs and increasing community expectations about the care that people with life limiting illnesses should receive. A particular issue for Tasmania is that patients who live alone are significantly more likely to require hospice/inpatient care than those who live in a supportive family environment. Tasmania has the oldest population profile and the highest proportion of people who live alone in Australia.

Sustainability of the current model depends on a small number of staff (particularly, but not solely, medical staff) who work in positions that will be difficult, if not impossible, to replace under the current model and funding arrangements. The viability of the current service is dependent on a small number of key staff. If they were to leave, the service is at serious risk.

## **7 Options for the future of Tasmanian Palliative Care services: 2004-2009**

We considered four options for the future. In brief, these were:

### ***Option 1 Status Quo***

This is not a viable option but was included for the sake of completeness. The service as it is now is extremely fragile and is not sustainable in the longer-term. Without additional resources, the service is at risk of imploding.

### ***Option 2 Status Quo, but with additional resources***

This option maintained the current model of care but involved an increase of resources to eliminate waiting lists and to achieve a sustainable level of medical, nursing, allied health and bereavement services. Our assessment was that this option would result in short-term improvements. However, it would not result in a sustainable improvement in the system of care.

### ***Option 3 Reorientation and development into a specialist Life Limiting Illness Service***

The option involved the reorganisation, development and expansion of the service into a specialist 'Life Limiting Illness' service, with the new service to be put into place over the next two to five years. The major goal of this option would be to expand the service so that it achieves critical mass. This is critical to achieving a sustainable service. A second goal was to better equip Tasmania to more effectively meet the palliative care needs of patients with diverse trajectories of illness (see Figure 3).

The target group for this service would be patients who have a life limiting illness with no prospect of a long-term cure. It would include patients who may be expected to live for years and (unlike current palliative care) not just weeks to months. The care of patients with non-cancer conditions would become a core role of the service.

The service would have 6 roles:

- Stabilisation and management of symptoms;
- Transitional care for patients after an acute exacerbation of their illness, providing a 'pathway to home';
- Planned respite;
- End of life care;
- Education and training; and
- Research.

Such a service would require joint funding by Palliative Care and by other programs currently providing care for patients with life-limiting illnesses. This would have implications for both the Hospitals and Ambulance Service Division and the Community, Population and Rural Health Division of the Department of Human Services.

Our assessment is that this is the logical and, indeed, inevitable development path for palliative care. However, we discounted it as an option at this point in the development of Tasmanian palliative care services.

#### ***Option 4 Integrated Palliative Care Networks based on formalised clinical partnerships and role delineation between specialist and generalist services***

This is our preferred option and forms the basis of the plan in the next section. It establishes a formal tiered network of affiliated palliative care providers across Tasmania. They include specialist palliative care services, community health staff and general practitioners, rural/community hospitals and extended care/residential care providers.

Generalist services affiliated with the network would be able to access specialist palliative care consultation liaison and assessment services for their patients, network wide tools such as clinical protocols, care plans, referral pathways and quality assurance models and multidisciplinary training and professional development in palliative care.

A similar level of investment to Option 2 will be required over the next two years to address the most pressing specialist medical and nursing staff needs and to create the capacity to provide the required training and professional development for community and hospital staff.

Better equipping rural district hospitals, Multi Purpose Services and residential care facilities to provide quality palliative care is also a feature of this approach. This will address the genuine issue of rural/remote community access to inpatient/hospice facilities by better utilising community hospitals and residential care services rather than establishing stand alone hospice facilities in central locations. The rural hospital palliative care model is well developed in South Australia, Western Australian and most of rural NSW and is cost effective.

However it requires a clear commitment to provide professional development, education and clinical support services for the hospital or residential care facilities in the network and an agreed shared care framework with the general practitioners who provide primary medical management for the great majority of patients.

## Part C The way forward

### 8 A new model of service delivery

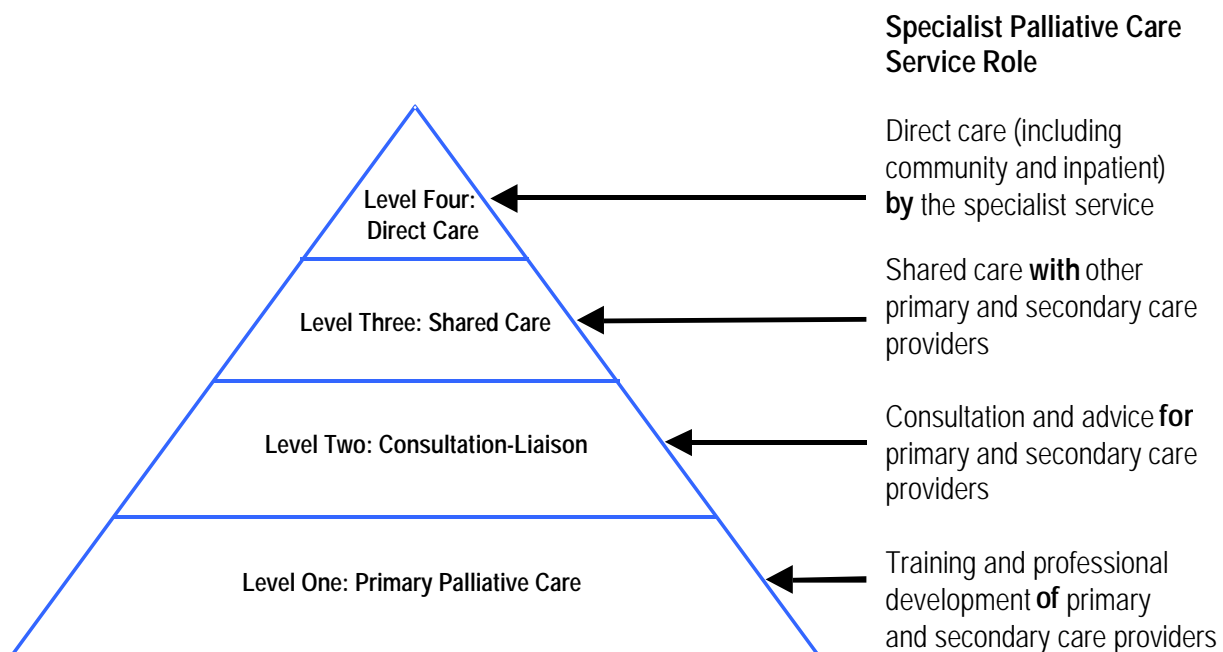
#### Vision

Every Tasmanian with a life-limiting illness will receive treatment and care with a palliative approach. Different levels of palliative care will be available, depending on the needs of each person. It will be provided by an integrated network of health care providers that includes, among others, palliative care specialists, rural hospitals and primary care providers of all disciplines.

#### Target group and role of the specialist palliative care service

The target group for the specialist palliative care service will be patients with an active, progressive, far advancing disease (whether malignant or non-malignant) with little or no prospect of cure and for whom the primary treatment goal is quality of life. These patients will receive multidisciplinary assessment, consultancy and/or management of their physical, psychological, social, emotional and spiritual needs. The service will provide a grief and bereavement process for the person and their carers/family during the life of the person and continuing after death. The service will be responsible for the education and professional development of other primary and secondary care providers who will be partners in the delivery of the full spectrum of palliative care.

#### The model in summary



The new model of service proposed is based on patients receiving different levels and types of service depending on their needs. The level of care required is specified on the initial referral for palliative care, as are any specific requirements (for example, time-limited or ongoing care).

A patient may move between levels of care over time if the needs of the patient change. This would be subject to negotiation between the patient / carers, and their care providers, including their GP and relevant medical specialists.

This model is compatible with the model of care being developed in the Rural Palliative Care Project in the North West. It is already in common practice in some other streams of care (eg,

mental health) and is successful partly because it provides clear role delineation for service providers based on the level of need of their patients.

### **Level One Solely primary palliative care**

- Level 1 patients with non-complex life-limiting illnesses are managed by their GP/community nurse and other (non-palliative care) specialist providers as relevant.
- Level 1 palliative care patients will not have any contact with the palliative care service.
- No information about patient's receiving Level 1 care will be collected by the palliative care service.
- Based on best available estimates, between 20-30% of all patients will receive Level 1 care. The majority of these will be in the stable or deteriorating stages of their illnesses.
- The quality of Level 1 care will be dependent on the ability of the specialist palliative care service to provide high-quality training and education to Level 1 providers and on the participation of Level 1 providers in an Integrated Palliative Care Network (see next section).

### **Level Two Primary palliative care with specialist consultation-liaison services provided by the palliative care service**

- The role of the specialist palliative service with a Level 2 patient is to provide one-off assessments and/or care planning and/or advice to the patient's primary palliative care providers.
- Primary palliative care providers may include a primary care service, another specialist service (eg, oncology, paediatrics), hospitals (including rural district hospitals) and residential care facilities.
- Medico-legal responsibility for the patient rests with the patient's primary palliative care providers.
- The 'client' of the palliative care service is the primary care provider, rather than the patient and their carers.
- Level 2 care will include the provision of a consultation-liaison service to the rural hospitals.
- Palliative care services will collect only basic data about the patient and the services they receive from the specialist palliative care service.
- Based on best available estimates, between 30-50% of all patients would receive Level 2 care. The majority of these will be in the stable or deteriorating stages of their illnesses.

### **Level Three Shared palliative care**

- The specialist palliative care service will share the assessment and care planning function for Level 3 patient's with the primary care or other specialist services involved in the patient's care.
- This may also include shared direct care, such as the palliative care service providing the after-hours service.
- Medico-legal responsibility for Level 3 patients is shared.
- The 'client' of the palliative care service is the patient and their carers.
- Level 3 care will include inpatient shared care with the rural hospitals.
- Palliative care services will collect comprehensive data about the patient and the services they receive from the specialist palliative care service.

- Based on best available estimates, between 20-30% of all patients will receive Level 3 care. The majority will be in the unstable and terminal stages of their illnesses.

#### **Level Four Direct palliative care from the palliative care service**

- Level 4 patients will be referred to the palliative care service and the palliative care service will become the primary provider of the patient's palliative care. In doing so, the palliative care service will involve relevant other clinicians (such as general practitioners, community nurses) in their care.
- Medico-legal responsibility for this palliative care will rest with the palliative care service.
- The patient's other health needs will continue to be met by their GP / community nurse.
- Unlike the present model, direct care may be provided in any setting (inpatient, hospice or in the patient's home).
- Palliative care services will collect comprehensive data about the patient and the services they receive from the specialist palliative care service.
- Based on best available estimates, less than 10% of all patients would receive Level 4 care. The majority of these will be in the unstable and terminal stages of their illnesses and will be treated in a hospice setting.

The major change proposed here is a clearer delineation of roles based on the intensity of palliative care service provision. This model explicitly recognises that many patients will receive primary palliative care without having any contact with the specialist palliative care service (Level 1). It also makes a clearer distinction between consultation-liaison (Level 2) and shared care (Level 3). This distinction is lacking in the current system. Direct care (Level 4) may be provided in both the inpatient and the community setting.

A fundamental prerequisite for this model is that the skills and expertise of mainstream primary and secondary care providers are strengthened to allow them to deliver quality palliative care services. This will require a significant strengthening of the role of the specialist palliative care service in education, professional development and consultancy services.

**Recommendation 1.** Adopt a new model of service delivery, based on four delineated levels of care.

## **9 Tasmanian Integrated Palliative Care Networks**

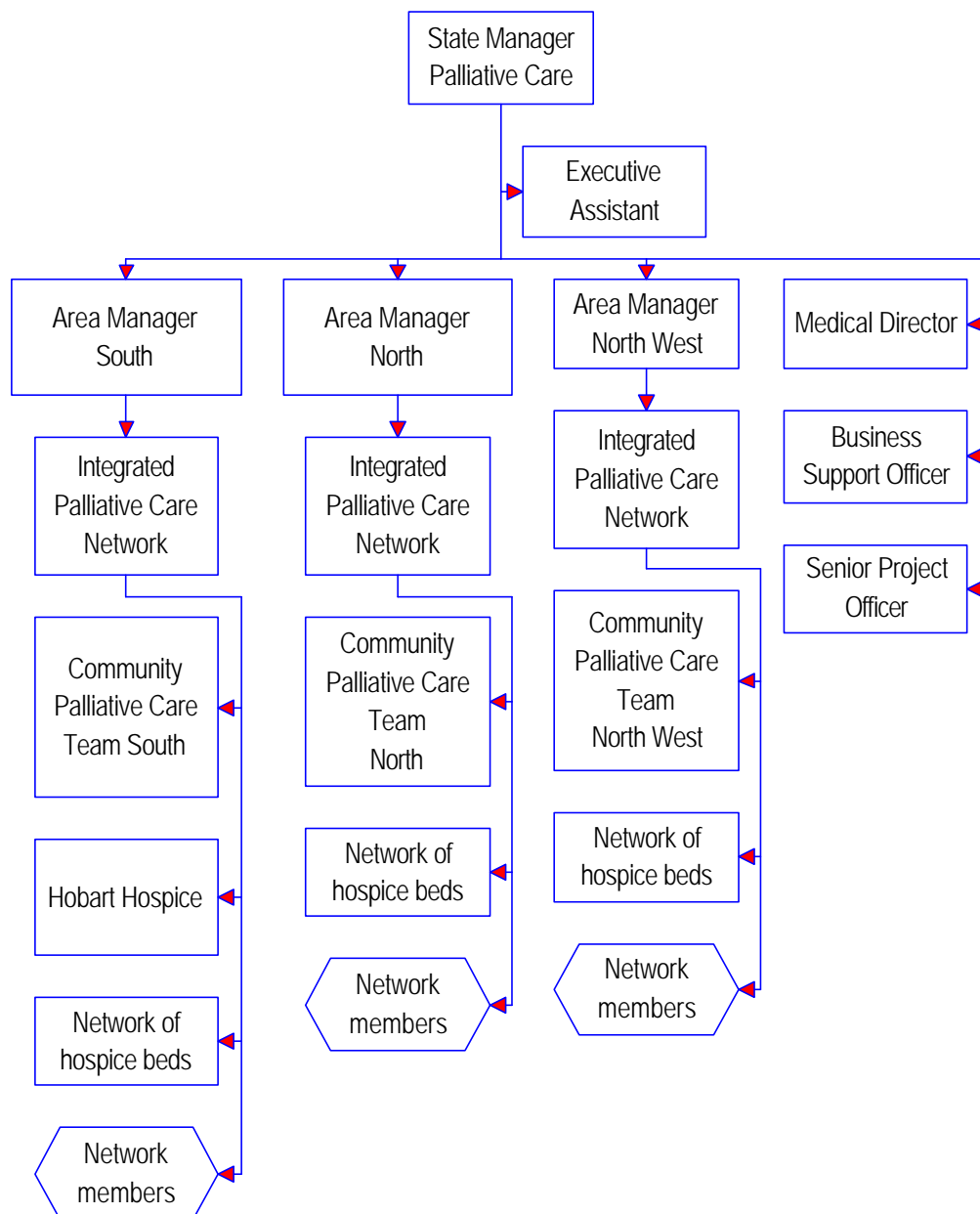
The successful implementation of the tiered model outlined above will require the development of Integrated Palliative Care Networks based on formalised clinical partnerships and role delineation between specialist and generalist services as outlined as Option 4 in Section 7.

Three Integrated Palliative Care Networks are proposed, one for each of the geographic regions. The development of each network should be undertaken by a Statewide working party established for this purpose. Representation should include specialist palliative care services, community health staff and general practitioners, rural/community hospitals and extended care/residential care providers. Regional working groups, established as sub-committees of the Statewide working party, may be required to consider issues specific to each geographic region.

As part of this development, the position of Clinical Coordinator North/North West should be split into two positions, one for each region. The three positions in the South, North and North West should be renamed as Area Manager, Palliative Care, with duty statements updated to reflect their clear responsibility for the management of the entire integrated care network and not solely the

management of the specialist palliative care service. The recommended networks in the context of the broader organisation are shown in Figure 4.

**Figure 4 Recommended organisational structure**



By the end of this planning process, each region should have in place:

- Detailed clinical and social criteria for each of the four levels of palliative care, along with a clear referral pathway to each. This work should be led by the Tasmanian Palliative Care Clinical Management Committee, with each network making relevant adaptations to reflect their unique local circumstances.
- A formal system of partnerships whereby generalist services affiliated with the network will be able to access specialist palliative care consultation liaison and assessment services for their patients (Level 2) as well as shared care (Level 3) as needed. They will have a clear understanding of the criteria and referral pathway for patients requiring Level 4 care.

- Network-wide tools such as clinical protocols, care plans, referral pathways, quality assurance models, multidisciplinary training and professional development in palliative care. Again, the development of these tools should be led by the Tasmanian Palliative Care Clinical Management Committee, with each network making relevant adaptations to reflect their unique local circumstances.
- An education and training strategy to strengthen the palliative care skills and expertise of network members.
- An education and training strategy to allow mainstream providers achieve recognition as a full member of the Integrated Care Network (see Section 10 below).

**Recommendation 2.** Establish three Integrated Palliative Care Networks, including an Area Manager position for each network.

## 10 Tasmanian Palliative Care Quality and Safety Standards

Increasing the skill base of hospitals (particularly the rural district hospitals), Multi Purpose Services and residential care facilities and designating palliative care beds in these facilities is a key feature of the recommended model. This will address the genuine issue of rural/remote community access to inpatient/hospice facilities by utilising local community hospitals and residential care services rather than relying on stand alone hospice facilities in central locations.

However it requires a clear commitment to provide professional development, education and clinical support services for the hospital or residential care facilities in the network and an agreed shared care framework with the general practitioners who provide primary medical management for the great majority of patients.

It is recommended that:

**Recommendation 3.** The Tasmanian Palliative Care Service be responsible for developing/adopting quality and safety standards for palliative care in Tasmania. These should be based on the national standards. However, the generic standards will need to be modified for the different levels of care (eg, hospital versus residential palliative care and Level 1 versus Level 4 care). Performance indicators, linked to these standards, will be required for each level of care.

Acute hospitals (both public and private), rural community hospitals, Multi Purpose Services (MPSs) and residential care facilities seeking to provide palliative care in Tasmania should be invited to measure their performance against these standards. The Department could also negotiate with relevant accreditation bodies to have these standards built into relevant accreditation processes as this would strengthen their application.

**Recommendation 4.** Only facilities measuring their performance against these standards be considered in planning for the location of future palliative care beds.

## 11 Specific developments - inpatient / hospice services

We recommend that additional hospice/inpatient beds be commissioned to meet community need. In total, 16 additional designated beds are required to meet the current need. For the reasons set out in Section 5.2 and below, we recommend that Tasmania does not establish any further free-standing hospice units. A better model, and the one we recommend, is that Tasmania commit to a **Hospice without walls**, with new designated beds located in, and spread between, existing acute

and rural hospitals. The **Hospice without walls** model will better meet the needs of the significant proportion of the Tasmanian population who live outside the major cities.

### 11.1 North West

We carefully considered the views of representatives of the North West community in relation to the need for a co-located hospice in the North West. We agree strongly that palliative care beds are required. But a stand-alone hospice, even if co-located, is not the right solution. Our reasons are:

- It would be too small to achieve economies of scale;
- It would not be possible to provide adequate medical (and possibly also nursing and allied health) coverage unless at the expense of community-based care; and
- Given the dispersed population in this region, any free-standing unit in one location will necessarily result in poor physical access for people living in other parts of the region.

A better approach, and the one we recommend, is that a **Hospice without walls** be established in the North West. In a **Hospice without walls**, designated palliative care beds are established across the region in hospitals (acute and rural district) with suitable facilities. As demand increases over time, other existing facilities (MPSs and/or residential care) could also be contracted to provide **Hospice without walls** beds in the North West within the fabric of their broader facility. In all cases, there should be service agreements between the specialist Palliative Care service and the provider that specifies governance and management arrangements, and also arrangements for the conjoint appointment of clinical staff.

The normative planning data indicate (see Table 4 on page 14) that the North West requires 7 beds to meet PCA standards. However, a larger number of **Hospice without walls** beds is justified as the total bed number will include some in rural district hospitals and some of these will necessarily have a low occupancy rate. There would be advantages in establishing 2-4 of these beds in one facility in terms of training and the recruitment and retention of specialist palliative care staff.

**Recommendation 5.** The development of the proposed new hospice not proceed. Instead, a **Hospice without walls** be established in the North West, with designated palliative care beds being established across the region in existing hospitals (acute and rural district) with suitable facilities.

### 11.2 North

As the normative planning data indicate (see Table 4 on page 14), the North requires an additional 3 beds to meet PCA standards. However, as with the North West, a larger number of beds could be justified if the total bed number includes some in community rural hospitals.

We considered the possibility of recommending the expansion of the Phillip Oakden unit to provide the additional required beds. On balance, that is not our preferred approach. As with the North West, the dispersed population in this region means that having all beds in one location results in poor physical access for people living in other parts of the region. Accordingly, our recommended approach is that a **Hospice without walls** is also established in the North, with additional designated palliative care beds being provided across the region in existing hospitals (acute and rural district) with suitable facilities. In all cases, there should be service agreements between the specialist Palliative Care service and the provider that specifies governance and management arrangements, and also arrangements for the conjoint appointment of clinical staff.

- Recommendation 6.** Increase the bed base in the North by establishing a **Hospice without walls**, with designated palliative care beds being established across the region in existing hospitals (acute and rural district) with suitable facilities.

### 11.3 South

Ideally, the Whittle Ward, Hobart unit should be expanded from 10 to 16 beds, with the possibility of physical relocation into the Royal Hobart Hospital (RHH) being considered in the process. Expansion from 10 to 16 beds could be achieved at marginal recurrent cost and allow the unit to achieve better economies of scale. Relocation into the RHH would have significant advantages in terms of medical coverage and continuity of care. However, relative to other needs, neither expansion nor relocation of the unit at this time is a priority.

We recommend that this unit be renamed as the Hobart Hospice. There exists a strong community perception that the unit is only for Veterans. Whilst the Department of Veterans Affairs designated the Unit originally to commemorate Sergeant JW Whittle VC, the Unit now has a broader community role and a change of name is timely.

As with the other regions, a **Hospice without walls** should also be established in the South to cater for the significant proportion of the regional population who live outside Hobart. The Hobart Hospice could then focus on those who live in, or close to, Hobart and those with particularly complex care needs.

- Recommendation 7.** The Whittle Ward not be expanded or relocated at this time due to competing priorities.
- Recommendation 8.** The Whittle Ward be renamed as the Hobart Hospice.
- Recommendation 9.** Increase the bed base in the South by establishing a **Hospice without walls**, with designated palliative care beds being established across the region in existing hospitals (acute and rural district) with suitable facilities.

## 12 Specific developments - community services

The reasons for the following recommendations were presented in Section 5.

### 12.1 Medical

- Recommendation 10.** Tasmania to make an internal decision to recognise fellowship of the Australasian Chapter of Palliative Care of the RACP as a specialist qualification for employment purposes.
- Recommendation 11.** Fellowship of the Australasian Chapter of Palliative Care of the RACP should also be regarded across Tasmania as the appropriate qualification for the granting of hospital clinical privileges in palliative care. In turn, this would result in all palliative care physicians employed in Tasmania who hold a Fellowship of the Australasian Chapter of Palliative Care of the RACP being granted hospital admitting rights at all relevant hospitals. The current situation, in which this is determined individually by the three acute hospitals, is not in the best interests of patients.
- Recommendation 12.** Establish a sustainable medical service across Tasmania. The minimum number of palliative care specialists for a sustainable

service is 3FTE South, 2FTE North and 2FTE North West, all of whom are backed up by a network of general practitioners. Attracting and retaining this workforce will require a substantial increase in resources.

**Recommendation 13.** Establish an accredited palliative medicine registrar training program, initially in conjunction with an interstate provider, that will allow Tasmania to train and retain its own palliative medicine workforce.

## 12.2 Nursing

**Recommendation 14.** Introduce a specified kilometre limit for after hours home visits. All patients requiring after hours assistance will continue to telephone the specialist palliative care service and, wherever possible, their issues will be resolved over the phone. If resolution over the phone is not possible:

- Patients living within the specified kilometre limit will receive a home visit.
- Patients living outside the specified kilometre limit will have an emergency plan in place<sup>19</sup>.

**Recommendation 15.** Resolve the human resource and industrial issues surrounding the after hours service. The introduction of a specified kilometre limit for after hours home visiting proposed above will resolve some of the current problems. But the other safety and industrial issues discussed in Section 5.3.2 also need to be resolved.

**Recommendation 16.** Introduce a two-tiered model of professional development. Tier One involves education and development of the specialist palliative care workforce. Tier Two is education and development of the mainstream workforce working in community nursing, residential care, rural hospitals, and other clinical specialities.

**Recommendation 17.** Tier One (Education and development of the palliative care nursing workforce) is best achieved through a partnership with a university on a mainland with a demonstrated track record in palliative care education and research. The University of Tasmania should also be invited to participate in this arrangement as part of the Department's 'Partners in Health' agreement with the university. The partnership should agree on the best approach for the professional development of palliative care nursing. But it should also have a broader role in relation to palliative care providers of other disciplines.

**Recommendation 18.** Tier Two (Education and development of the mainstream nursing workforce working in community nursing, residential care, rural hospitals, and other clinical specialities) is best achieved by establishing dedicated Clinical Nurse Educator positions who can work with palliative care nurses rather than by increasing the number of palliative care nurses for this purpose. The requirement is for 1 EFT in the South and 0.5 EFT in both the North and the North West.

<sup>19</sup> The default emergency plan would specify that the patient will be directed to their closest rural hospital with a designated palliative care role. The after hours nurse will phone the hospital, arrange for the patient to be admitted over night and provide advice to the hospital about the patient's management. The specialist palliative care service will contact the hospital the following morning to follow-up on the patient and, if necessary, undertake a hospital or home visit that day.

### **12.3 Multidisciplinary/interdisciplinary care**

- Recommendation 19.** Create one multidisciplinary referral system for palliative care in the South.
- Recommendation 20.** As resources become available, expand palliative care teams to include access to other allied health disciplines. Palliative care patients need access to clinical psychology (particularly for patients with complex psychosocial issues and complex bereavement), occupational therapy and physiotherapy (particularly for patients with mobility and other complex functional problems and patients requiring access to equipment and aids) and speech pathology (particularly for patients with swallowing problems). This should initially occur by formalising arrangements with community health and with hospitals to ensure that all teams have formally negotiated access to allied health therapists as required. Given that palliative care, community assessment and care management are all part of the Primary Health subdivision, negotiations for better access to allied health therapists should be driven by the subdivision. As resources allow, this should be developed to include part or full time positions within the palliative care community teams. The additional provision of this expertise will have a flow-on effect in reducing the workload pressures on the palliative care nurses and social workers.

### **12.4 Bereavement support**

- Recommendation 21.** Review the current approach to bereavement support in each team, the workload and focus of the current social work positions and, as resources allow, establish a bereavement services coordinator position in all three community teams.

### **12.5 Partnership framework with general practitioners**

- Recommendation 22.** Regard the Rural Palliative Care Project in the North West as the prototype for what should be progressively adopted, with relevant local modifications, as the Tasmanian model of palliative care in all three regions.

### **12.6 Common standards and clinical protocols**

- Recommendation 23.** The Tasmanian Palliative Care Clinical Management Committee be given the responsibility of developing standards and clinical protocols for referral, intake, admission, allocation and clinical interventions.

## **13 Specific developments – information, education and training**

### **13.1 Information**

Information needs to be collected and shared as a key strategy for promoting the coordination and integration of patient care and the Tasmanian Integrated Palliative Care Networks proposed in Section 9. This will clearly require an investment in information technology by DHHS. The

implementation of the Palliative Care Client Information System would represent a major achievement in this context.

In order to achieve this, the Tasmanian Palliative Care Service should participate in Health Connect (a national initiative) and link into the IT initiatives of the Intelligent Island Board.

A set of data collection protocols needs to be developed and implemented across all members of the Integrated Palliative Care Networks. It is critical to ensure that these protocols include more than just standard referral and assessment forms. They must ensure that meaningful clinical data are collected and made available to the wide range of relevant care providers. Specifically, the system must allow public, private and non-government sectors, GPs, community nurses and others to be able to share electronic information with specialist palliative care providers. Formal affiliation of providers through the Integrated Palliative Care Networks will be critical for this purpose.

A standard palliative care data set needs to be agreed and implemented on a Statewide basis. In our view, it is logical for the clinical assessment tools to comprise those items that will be captured by the Rural Palliative Care Project in the North West. One of the key objectives of that project is to enhance the capacity of palliative care agencies to integrate service delivery practices and related information sharing processes.

### Recommended data set

- A 'Palliative Care Stage of Illness Dataset' is to be collected routinely on palliative care clients in the North West Region as part of the Rural Palliative Care Program project. The elements in this dataset, as shown below, are collected each time there is a change in a client's 'phase of care'. It requires only a modest investment of effort in terms of staff training and education. The benefits of this type of data collection have been shown to be significant in terms of improved understanding of clinical practice and outcomes<sup>20</sup>.
- The 'Palliative Care Stage of Illness Dataset' comprises:
  - Palliative care 'Phase of Care' instrument;
  - Reason for Palliative care 'Phase of Care' change;
  - The 'Palliative Care Problem Severity Score' instrument;
  - The 'Resource Utilisation Group/Activities of Daily Living' instrument;
  - The 'Karnovsky Scale' instrument.
- The Statewide collection should also capture "Level of Care" as set out in Section 8.

**Recommendation 24.** Information needs to be collected and shared as a key strategy for promoting the coordination and integration of patient care and the Tasmanian Integrated Palliative Care Networks proposed in Section 9. An investment in information technology is required.

**Recommendation 25.** A set of data collection protocols needs to be developed and implemented across all members of the Integrated Palliative Care Networks. Section 13.1 sets out a recommended set of such items.

## 13.2 Education, Training and Research

<sup>20</sup> See, for example, Cromwell D, Senior K, Owen A, Gordon R, and Eagar K (2003) *Can the National Palliative Care Strategy be translated into a model of care that works for rural Australia? An answer from the Griffith Area Palliative Care Service (GAPS) experience*. Centre for Health Service Development, University of Wollongong. [http://www.uow.edu.au/commerce/chsd/caring\\_communities.html](http://www.uow.edu.au/commerce/chsd/caring_communities.html)

- Recommendation 26.** Actively encourage and nurture education and research programs and strategic partnerships with the University of Tasmania and relevant universities on the mainland.
- Recommendation 27.** Significantly increase investment in education and professional development of the mainstream health professional workforce, including the implementation of the Program of Experience in the Palliative Approach (PEPA).

## 14 Strategic Investment Priorities

Implementation of some of our recommendations will require a significant investment to put the service onto a sustainable footing. However, a range of recommendations can be implemented within existing resources. The following list of developments is proposed to meet the most pressing service needs and workforce development and retention requirements. They are listed in priority order.

### **14.1 *Implement the new model of service delivery and, in the process, secure the current service base***

As part of implementing the new model of service delivery, it will be essential to re-finance the medical specialist positions in the North and North West when MSOAP funding eventually terminates and to make adequate provision for the recurrent costs of existing services.

### **14.2 *Medical Workforce***

Ensure credentials of palliative care specialists are recognised in Tasmania and currently employed specialists are appropriately remunerated.

Establish between 2 and 3 additional medical specialist positions attached to the Community Teams to provide reasonable staffing for after hours and consultative services. In all Regions the option of appointing a panel of affiliated general practitioners as visiting medical officers remunerated on a fee for service basis (in line with the Hunter Region model) to fulfil aspects of this role should be explored.

The GPs would undertake a primary assessment of all new clients including consulting with the client's GP and attend Community Team/Hospice meetings for case review. Following their initial assessment, the GP's would also provide a consultation/liaison service for clients within their defined catchment.

### **14.3 *Professional Development***

Implement a two tiered model of professional development. At the first tier, establish a partnership for the professional development of the palliative care workforce. At the second tier, establish dedicated Clinical Nurse Educator positions for each of the three networks to work with palliative care nurses to provide education and development of the mainstream nursing workforce working in community nursing, residential care, rural hospitals and other clinical specialties. The requirement is for 1.0 EFT in the South and 0.5 EFT in both the North and North West.

### **14.4 *Allied Health Workforce***

In total, 8.2 EFT positions are required to bring Tasmania up to PCA standards. The first priority is for each community team and inpatient/hospice unit to have access to a psychologist, a physiotherapist, an occupational therapist and a speech pathologist. The immediate requirement is for 2.0 EFT positions (with a mix of part-time therapists) in each of the three regions.

### **14.5 *Nursing Workforce***

Establish 3 additional clinical nursing positions for the Community Teams to meet the growth in demand for palliative care services, eliminate waiting lists and achieve a more equitable staff to patient ratio across regions.

These additional positions should be distributed as follows – 1.5 FTE in the South, 1.0 FTE in the North and 0.5 FTE in the North West.

In combination with the professional development positions above, these additional nursing positions will address the 4.4 EFT shortfall identified in the comparison with the PCA guidelines and provide a rurality factor for the North and North West.

### 14.6 Palliative care hospice/inpatient beds

Establish a **Hospice without walls** in each region with designated beds located in, and spread between, existing acute and rural hospitals.

#### South Region

Maintain the 10 existing palliative care beds and, in addition, establish a network of designated palliative care beds in acute and rural district hospitals across the Southern Region.

#### North West Region

Establish a network of designated palliative care beds in acute and rural district hospitals across the North West Region.

#### North Region

Maintain the 3 palliative care beds at Phillip Oakden House. Establish a network of designated palliative care beds in acute and rural district hospitals across the Northern Region.

### 14.7 Summary of priority developments

Table 12 lists the top 6 priorities we have identified that will require additional resources. Other needs, but with a lower priority, were identified in previous sections.

**Table 12 Summary of priority developments**

<b>Priority</b>
Priority 1 – Implement the new model of service delivery, based on the introduction of 4 levels of care, 3 integrated palliative care networks and a clear quality and safety framework. In the process, secure the current service base
Priority 2 - Medical workforce
Priority 3 - Professional development
Priority 4 – Allied health workforce
Priority 5 - Nursing workforce
Priority 6 – Palliative care hospice/inpatient beds

Investment decisions are always about trade-offs. Setting priorities in palliative care is no exception.

## 15 Levers for change

The successful implementation of a new Tasmanian model of service delivery will require careful change management and investment. Several projects currently in progress have an important role to play in this change process. These projects are important initiatives in their own right. But

they are equally important as strategic elements of the broader change management process that will be required. They are:

- The Program of Experience in the Palliative Approach (PEPA) – see Section 5.5.2.
- The North West Tasmania Rural Palliative Care project– see Sections 4.5.3 and 5.4.2.
- The ‘Empowering the Midlands Community’ project - see Section 4.5.1.
- The ‘Collaborative Palliative Care in Rural Communities’ project – see Section 4.5.2.

Building these projects into the change management process will be an essential task over the next year.

## Appendix 1

### Palliative care staffing

**Table 13 Palliative Care Service Staff Profile as at February 2004**

Area	Position	No of EFTS	NGO's / DVA funded	Total
<b>Whittle Ward</b>	Medical Specialist -Including Statewide Medical Director -shared	1.8		
	Registrar	0.8		
	Reg Nurses	11.75		
	Enrolled Nurses	5.64		
	Admin Support	1.0		
	Pastoral care		0.2	
	Hospital Assistants	5.46		
	<b>Total</b>	<b>26.45</b>	<b>0.2</b>	<b>26.65</b>
<b>Community South</b>	Reg Nurses	6.08		
	Social Work- shared	1.12		
	Admin Support	1.0		
	Volunteer Coordinator NGO		1.0	
	<b>Total</b>	<b>8.20</b>	<b>1.00</b>	<b>9.20</b>
<b>Community North</b>	Medical MSOAP funded	1.0		
	Reg Nurses\	3.03		
	Social Work	1.14		
	Admin Support	1.0		
	Volunteer Coordinator - State	1.0		
	<b>Total</b>	<b>7.53</b>	<b>0.00</b>	<b>7.53</b>
<b>Community North West</b>	Medical MSOAP funded	1.0		
	Reg Nurses	3.3		
	Social Work	1.0		
	Admin Support	1.0		
	Volunteer Coordinators (NGO)		1.0	
	<b>Total</b>	<b>6.3</b>	<b>1.0</b>	<b>7.30</b>
<b>Management</b>	State Manager	1.0		
	Exec Assistant ( temp 2 yr contract )	1.0		
	Senior Policy	1.0		
	Business Support	0.5		
	Statewide Medical Director	0.2		
	Clinical Coordinator North and Northwest	1.0		
	Clinical Coordinator South	1.0		
	<b>Total</b>	<b>5.5</b>	<b>0.0</b>	<b>5.5</b>
<b>Grant Total</b>		<b>54.54</b>	<b>2.20</b>	<b>56.24</b>

## Appendix 2

### ***Palliative Care Australia Definitions***

A *Palliative Care Provider* is a medical, nursing or allied health professional who provides primary care with a palliative care approach to patients with a life-limiting illness.

A *Specialist Palliative Care Provider* is a medical, nursing or allied health professional, recognised as a specialist by an accrediting body (or who primarily works in palliative care if an accrediting body is not available), who provides primary or consultative care to patients with a life-limiting illness.

A *Specialist Palliative Care Service* is a service provided by a cohesive interdisciplinary network of specialist palliative care providers.” (p 10)

## Appendix 3

### ***Palliative Care Models in the ACT, South Australia and Western Australia***

#### **ACT**

**Population** – 311,900

**Metro** – 298,800

**Other** – 13,100

The ACT Hospice (Clare Holland House administered by the Little Co. of Mary) has 19 dedicated palliative care beds managed by 3 pall care specialists (1 director and 2 community medical officers). These specialists are assisted by 20.27 FTE nursing staff.

The three medical officers are responsible for:

- Clinical management of acute care patients
- Clinical management of patients overseen by community nurses
- Outreach consultation to hospitals on invitation to the program

These medical officers are supported by 7.8 FTE community nurses (home based palliative care team). The MO's used to be managed by ACT Community Care but are now a part of Calvary Hospital.

**Model of Care** – Predominantly Consultation Liaison.

#### **South Australia**

**Population** – 1,467,300

**Metro** – 1,045,200

**Other** – 422,100

In Metropolitan Adelaide there are four main providers of palliative care each attached to a major hospital. Each of these four areas has a specialist palliative care team responsible for acute care and community care.

In regional SA there are no dedicated palliative care beds for acute care. Rather palliative care is managed by the local community health service via district nurses, GP's, domiciliary and allied health support.

The bulk of palliative care in SA is provided through coordinated care in the community.

#### ***Metropolitan Adelaide***

All metropolitan hospitals provide palliative care as a component of their core business. Not all patients with palliative care needs are managed by palliative care specialists with some specialists from disciplines such as oncology, respiratory and cardiac care choosing to maintain ongoing management of their patients.

Of the beds described as dedicated palliative care, there are:

- 43 hospice beds in 4 hospices

- 16 beds in 3 hospitals are dedicated, but not quarantined palliative care beds with the remaining hospitals providing palliative care on an 'as required' basis.

### **Rural centres**

While there are no dedicated palliative care beds in country regions, there are good facilities that are utilised by palliative care clients and their families as needed. Many local hospitals have developed small suites or comfortably furnished rooms to allow palliative care patients to die in more comfortable surroundings. These family rooms greatly increase the capacity for family members to more actively participate in the care of the dying person.

### **The number of specialist palliative care staff**

This is also difficult to determine and varies on what is included. For example, are palliative care volunteer coordinators considered a 'palliative care specialist'?

- In metropolitan Adelaide's specialist palliative care services there are approximately 40 FTE of clinicians. Of these approximately, 26% are Medical, 47% are nursing and 27% are Allied Health disciplines (excluding volunteer coordinators). This also doesn't include a further 12 FTE of palliative care nurses who are employed in the community Royal District Nursing Service. The nursing numbers don't include nurses employed to work in hospices – although these could be considered as specialists as well.
- Medical staff on rotation through the palliative care services aren't included in the medical numbers.
- There are palliative care coordinators employed in country regions that could be considered a specialists.

Of the above specialists, the bulk of time is spent on managing community based clients, an estimate would be 80% but this varies across services.

### **Western Australia**

**Population** – 1,851,300

**Metro** – 1,244,300

**Other** – 607,000

There are a mixture of beds in public and private hospitals in WA planned on a ratio of 5/100,000 population.

**Table 14 Palliative Care resources in Western Australia**

Area	Dedicated Private Beds	Public Beds	Total Beds	Benchmark Beds <sup>1</sup>
<b>Metropolitan WA</b>				
East Metro dedicated beds	0	0.0	0.0	23.2
North Metro dedicated beds	31.0 <sup>2</sup>	18.1 <sup>2</sup>	46.1	24.4
South Metro dedicated beds	9.0 <sup>3</sup>	12.5 <sup>3</sup>	21.5	25.4
Additional equiv Gov hospital beds		15.1	15.1	
<b>Total Metropolitan</b>	<b>40.0</b>	<b>45.6</b>	<b>85.6</b>	<b>73.0</b>
<b>Country WA</b>				
Country dedicated beds	12.1 <sup>4</sup>	5.9 <sup>4,5</sup>	18.0	
Additional equiv Gov hospital beds		14.3	14.3	
Total Country & SW	12.1	20.2	32.3	22.3
<b>Total State</b>	<b>52.1</b>	<b>65.8</b>	<b>117.9</b>	<b>95.3</b>

1. Based on 50 beds per million population

2. Hollywood Private Hospital 22-bed unit less 3.3 public beds; Cottage Hospice 26-bed facility less 13.7 public beds; Joondalup Health Campus 1.1 public bed

3. Murdoch Community Hospice 20-bed facility less 11.0 public beds; Peel Health Campus 1.5 public beds

4. SJOG Bunbury 4-bed unit less 1.1 public beds; SJOG Geraldton 4-bed unit less 0.8; Albany Private Hospice 4-bed co-located facility; Busselton Private Hospice 2-bed co-located facility

5. Avon Hospice 4-bed co-located public unit

### How palliative care is supported in the community

WA provides Statewide support to community health professionals through its palliative care telehealth service and education services, both based at the Cottage Hospice, and to medical practitioners through the WA Combined Palliative Care Outreach Service, which is a 24x7 telephone advisory line serviced by rostered palliative care physicians.

The hospice service of the Silver Chain Nursing Service provides community-based palliative care in the metropolitan area, and a mix of health services and some non-government agencies (including Silver Chain) provide community based services in country areas.

## Appendix 4

### Activity/Performance Indicators and Demographic Data

The data below has been extracted from the information extracted for this Review from Department of Health and Human Service Performance Reports.

#### Activity Indicators

As shown in Table 15, in 2002/2003 the Community Service had a total of 4,063 clients, 924 referrals, 807 admissions and 672 deaths and provided 2,298 out of hours services. Overall fifty three percent of the out of hours services were for clients (1,219) and 47% (1,079) were for service providers.

**Table 15 Palliative Care Community Team Key Indicators – 2002/03**

Indicator	South	North	North West	Total
Clients Accessing Service	2082	913	1037	4032*
Referrals	440	217	267	924
Admissions	377	201	229	807
Not Admitted	63	16	38	117
Client Load	2459	1116	1266	4841
Deaths	303	171	199	673
Discharges	52	9	40	101
Clients End Month	2104	934	938	3976
Direct after hours	416	437	366	1219
Indirect after hours	209	364	505	1078
% Clients	51.6%	22.7%	25.7%	100%

\*Some client data are missing in Regional tally

#### Activity by Region

Table 16 shows the distribution of Community Team activity by region in 2002/03. In terms of overall demand the South Community Team had 51.6% of the client base (2082) followed by North West (1037) with 25.7% and North (913) with 22.7%.

**Table 16 2002/03 Indicators by Regional Community Team**

Region	South	North	North West	Total
Pop	230,745	135,357	107,206	473,308
% Clients	48.8	28.6	22.7	100
% Referrals	51.6	22.6	25.7	100
% Admissions	47.6	23.5	28.9	100
% Deaths	46.7	24.9	28.4	100
% Av Clients	45.0	25.4	29.6	100
% Direct AH	52.9	23.5	23.6	100
% Indirect AH	34.1	35.8	30.0	100
% Total OOH	19.4	33.8	46.8	100

The South Community Team with 48.8% of the population had 48% percent of referrals, 47% of admissions and 45% of deaths. The average Community Team client numbers (clients + admissions-deaths) in the South are marginally higher than the regional population share (non age/sex adjusted). The South Team provided the lowest number of out of hours services in 2002/03 and provision is skewed toward direct client or carer support (67%) with limited out of hours support for other service providers. This suggests that the South Team and the hospice are providing a significant proportion of the primary care workload for palliative care patients compared to Teams in the other regions.

The North Community Team with 28.6% of the population had 23.5% of total referrals, 24.9% of admissions and 25.4% of deaths. This Team provided 35% of the out of hours contacts (801) with 55% provided for clients and carers and 45% for service providers.

The North West Team with 22.7% of the population had 29% of referrals, 28.4% of admissions and 29.6% of deaths. This Team provided the highest number of out of hours services (38% or 871) of all the Teams and supplied 58% of OOH services for other service providers compared to the State average of 47%.

**Trends in Demand**

**Figure 5 Trends in demand and utilisation**

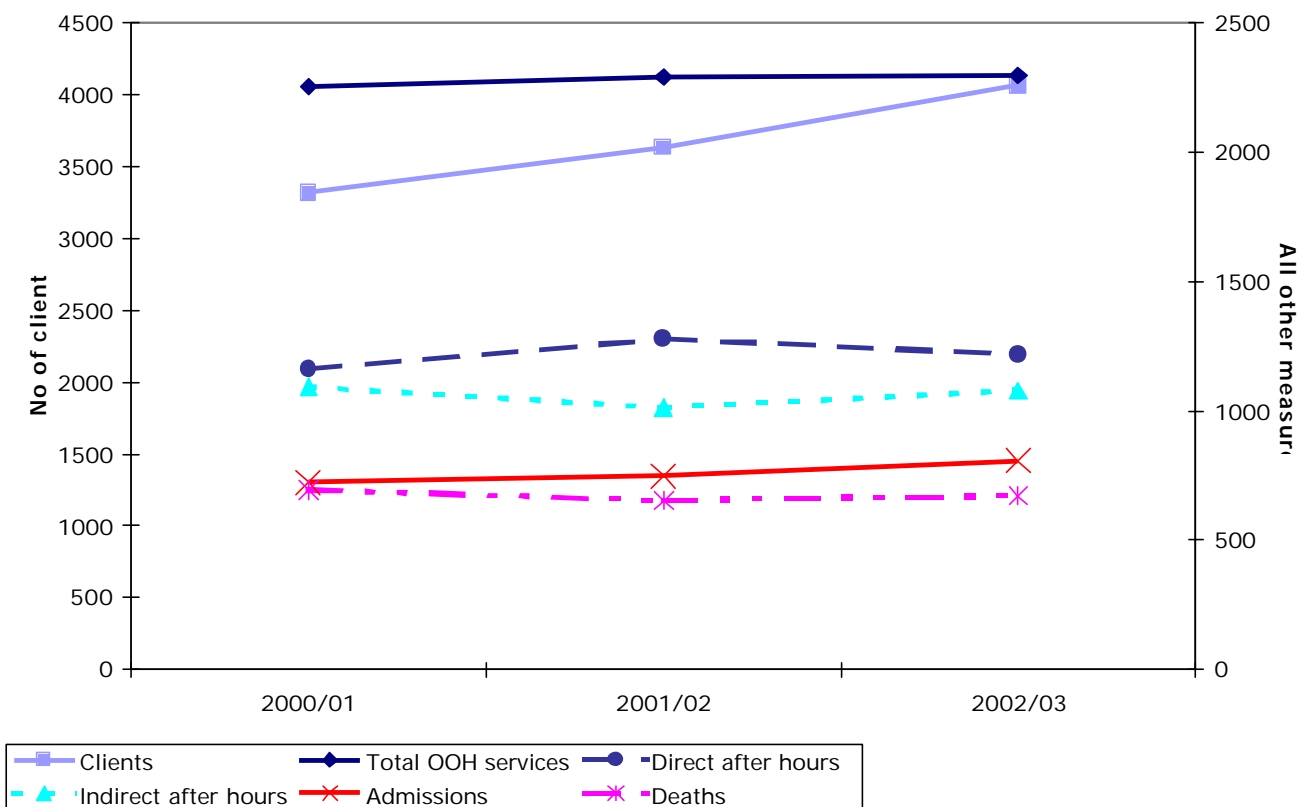


Figure 5 shows trends over the last three years. The same information is presented in tabular form in Table 17. The client base grew by 22%, average admissions increased by 11.5%, deaths declined by 3.3 % and total out of hours services increased by 1.9% between 2000/01-2002/03.

The increased client load reflects growth in demand due to combination of growth in referrals and longer life expectancy of palliative patients due to earlier referral.

Deaths as a proportion of admissions fell from 96% in 2000/01 to 83% in 2002/03. This is mainly attributable to trends in the South Community Team. This reflects a combination of early referral and a decline in the percentage of deaths at home compared to hospice or hospital settings.

Out of hours services to patients and carers increased by 5% overall and out of hours services to other service providers declined marginally (1.3%).

**Table 17 Trends in Demand – 2000/01-2002/03**

	2000/01	2001/02	2002/03	Net Change	% change
Clients	3320	3633	4063	743	22.4
Admissions	724	750	807	83	11.5
Deaths	695	653	672	-23	-3.3
Direct after hours	1162	1278	1219	57	4.9
Indirect after hours	1093	1012	1079	-14	-1.3
Total OOH services	2255	2290	2298	43	1.9

### Trends by Region

**Figure 6 Trends in demand by region**

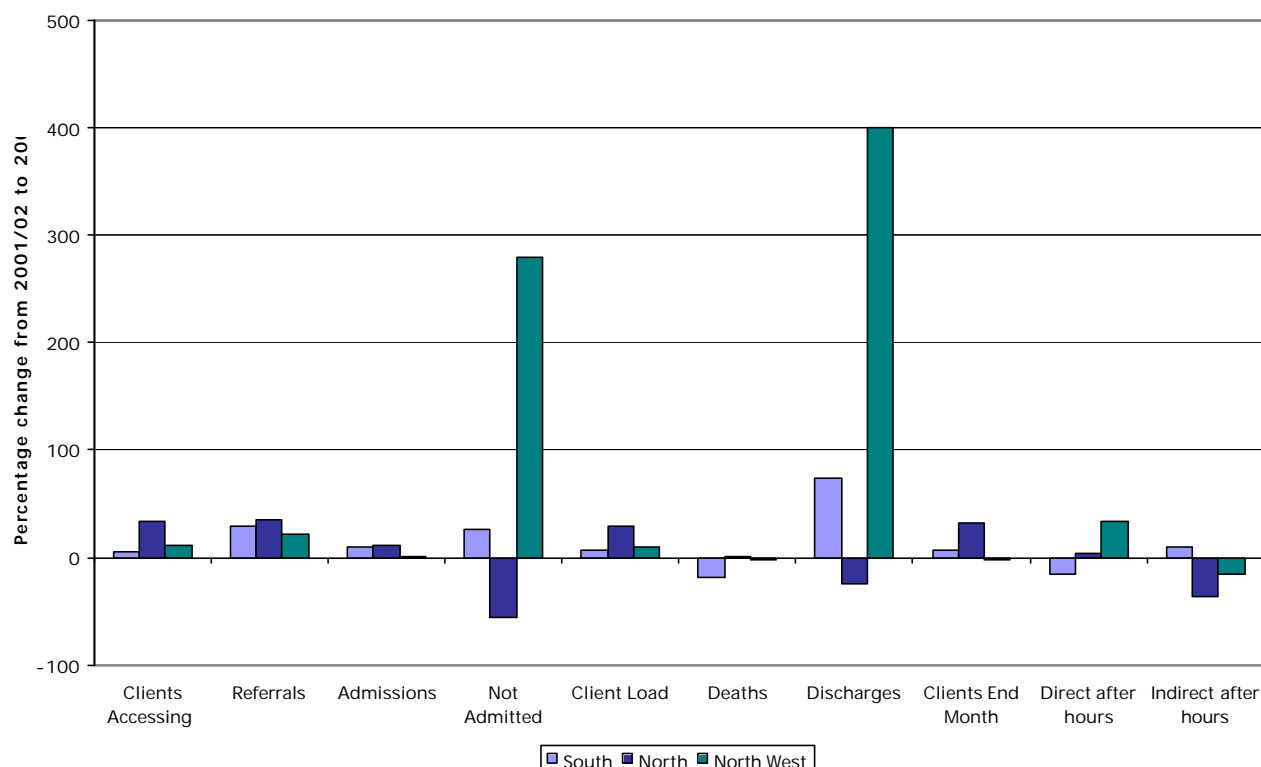


Figure 6 and Table 18 shows the trends by Region. Some indicators (referrals, deaths and out of hours services) are available for the three year period whereas other data including number of clients, admissions and client load are only available for 2001/02 and 2002/03. The trends in Figure 6 based only on changes between 2001/02 and 2002/03 whereas three year data are included in the table where they are available.

**Table 18 Community Team Summary by Region**

	2000/01	2001/02	2002/03	Change	% Change
<b>South</b>					
Clients Accessing		1974	2082	108	5.5
Referrals	339	383	440	101	29.8
Admissions		343	377	34	9.9
Not Admitted		50	63	13	26.0
Client Load		2317	2459	142	6.1
Deaths	371	322	303	-68	-18.3
Discharges		30	52	22	73.3
Clients End Month		1965	2104	139	7.1
Direct after hours	496	458	416	-80	-16.1
Indirect after hours	191	271	209	18	9.4
<b>North</b>					
Clients Accessing		683	913	230	33.7
Referrals	160	216	217	57	35.6
Admissions		180	201	21	11.7
Not Admitted		36	16	-20	-55.6
Client Load		863	1116	253	29.3
Deaths	170	143	171	1	0.6
Discharges		12	9	-3	-25.0
Clients End Month		708	934	226	31.9
Direct after hours	418	456	437	19	4.5
Indirect after hours	566	311	364	-202	-35.7
<b>North West</b>					
Clients Accessing		929	1037	108	11.6
Referrals	220	237	267	47	21.4
Admissions		227	229	2	0.9
Not Admitted		10	38	28	280.0
Client Load		1156	1266	110	9.5
Deaths	203	188	199	-4	-2.0
Discharges		8	40	32	400.0
Clients End Month		960	938	-22	-2.3
Direct after hours	274	364	366	92	33.6
Indirect after hours	436	430	505	-70	-16.1

The data indicate that all teams experienced growth in referrals, admissions and client numbers between 2001/02 and 2002/03.

- Referrals grew by 101 in the South (30%), 57 in North (36%) and 47 in North West (21%) between 2001/02 and 2002/03.
- Admissions increased by 34 in the South (10%), 21 in North (11.7%) and 2 in North West (1%) between 2001/02 and 2002/03

- Client numbers grew by 230 (33.7%) in North, and 108 (5.5% and 11.6% increase respectively) in the South and North West between 2001/02 and 2002/03.

### Inpatient Services

Data for the hospice services provided by the Whittle Ward in the South and Phillip Oakden House in the North region between 200/01 and 2002/03 are shown in Table 19.

**Table 19 Inpatient Activity Summary**

UNIT	2000/01	2001/02	2002/03	Change	% Change
<b>WHITTLE WARD</b>					
Length of stay	12	11.7	11.7	-0.3	-2.5
Separations	248	245	234	-14	-5.6
Deaths	138	146	161	23	16.7
% occupancy	77.2	79.5	84.3	7.1	9.2
<b>PHILLIP OAKDEN HOUSE</b>					
Length of stay	NR	9.98	9	-0.98	-9.8
Separations	75	68	101	26	34.7
Deaths	NR	39	50	11	28.2
% occupancy	76	84.2	92.2	16.2	21.3

This indicates that there were 201 hospice deaths in 2002/03 and 335 separations. The number of hospice deaths increased by 17% in the Whittle Ward (3 year trend) and by 28% (2 year trend) at Phillip Oakden House. Length of stay has declined marginally at both sites and occupancy rates have increased.

Length of stay in the Whittle Ward at 11.7 days in 2002/03 exceeds the PCA planning guideline average of 7 days per patient but is lower than the actual 15 day national average reported by the AIHW.

### Hospital Consultation/Liaison

The data in Table 20 provides a snap shot of the Acute Hospital consultation service provided to Royal Hobart Hospital, Launceston General Hospital and the North West Regional Hospital and the Midlands Community Hospital by the regional Palliative Care Teams. The data are for a 3 month period from July to September 2003 and not all measures were collected by each Team. The available data indicate that:

- There were 170 referrals, with 52% being seen solely by the liaison nurses and 48% being seen by both a medical officer and a liaison nurse.
- There were substantial variations between the hospitals with medical staff in the South seeing two thirds of the patients referred while medical officers were only involved in 13% of patient referrals in the North and 15% in the North West.
- In terms of education and information sessions, 14 were recorded or the equivalent of 1 session per week. Half the sessions were provided in the South, 36% in the North and 14% in the North West. The highest number of participants per session was in North West with 38 participants in 2 sessions.
- There were 119 clinical meetings recorded and 90% occurred in the South and North Regions.

- A total of 18 consultations were reported with 61% in the South, 17% in the North and 22% in the North West.

**Table 20 Hospital Consultation/Liaison Data by Region – July-September 2003**

Measure	South RHH		North LGH		North West NWRH / MCH		Total	
	Number	%	Number	%	Number	%	Number	%
<b>Patients</b>								
New patients referred	108		16		46		170	
No. seen by liaison nurse alone	36	33.3	14	87.5	39	84.8	89	52.4
No. seen by medical and liaison nurse	72	66.7	2	12.5	7	15.2	81	47.6
No. clients already known to service	43	39.8	3	18.8	6	13.0	52	30.6
Deaths (not referred to service)	21	19.4	8	50.0	NR	0.0	29	17.1
<b>Education, meetings and consultations</b>								
Education/information	7	50	5	36	2	14	14	100
No participants	73	45.3	50	31.1	38	23.6	161	100
Meetings	53	44.5	54	45.4	12	10.0	119	100
Consults	11	61	3	17	4	22	18	100

### Client Demographic Data

The following demographic snapshot relates to patients who died in 2002/03.

### Place of Death

Data on the place of death of registered patients with the Palliative Care Service in 2002/03 indicates that 31% of clients died at home, 22% died in a hospice, 39% died in a hospital setting and 9% died in a nursing home. Table 21 shows the place of death in 2001/02 and 2002/03 and highlights the overall trend of a slight shift from home to hospice.

**Table 21 Place of Death 2001/02 -2002/03**

	South		North		North West		Total Deaths	
	No	%	No	%	No	%	No	%
<b>2001/02</b>								
Home	84	26	38	27	84	45	206	31.5
Hospice	90	28	39	28	0	0	130	19.9
Hospital	111	35	55	38	83	43.5	255	39.1
Nursing Home	37	12	11	8	21	11.5	62	9.5
<b>Total</b>	<b>322</b>	<b>101</b>	<b>143</b>	<b>101</b>	<b>188</b>	<b>100</b>	<b>653</b>	<b>100.0</b>
<b>2002/03</b>								
Home	73	24	56	35	78	39.5	207	30.8
Hospice	99	33	50	29.5	0	0	149	22.1

	South		North		North West		Total Deaths	
	No	%	No	%	No	%	No	%
Hospital	109	36	36	22	89	45	234	34.8
Nursing Home	17	5.5	20	12	22	11	59	8.8
District Hospital	5	1.5	9	1	10	4	24	3.6
<b>Total</b>	<b>303</b>	<b>100</b>	<b>171</b>	<b>100</b>	<b>199</b>	<b>100</b>	<b>673</b>	<b>100.0</b>

There is significant variation between the regions with:

- North West recording 45% of deaths at home and 43.5% in a hospital setting in 2001/02 and 39.5% at home and 49% in a hospital setting in 2002/03. This suggests the need for designated palliative care beds in the region.
- The North recording a 30% increase in the proportion of deaths at home, fairly constant hospice usage and a 40% decline in deaths in hospital settings over the period.
- The South recording a marginal decline in the proportion of deaths at home. Deaths in the hospice increased from 28% to 33%, hospital deaths rose marginally and deaths in nursing homes dropped by 50%.

### Place of Residence

Overall, 68% of clients lived in metropolitan areas and 32% lived in rural areas but the mix varied between Teams. The differences are shown in Table 22.

Seventy-two percent of the South and 68.4% of the North Team clients lived in metropolitan areas while for the North West 46% of clients lived in rural Areas. This contributes to access problems for clients and travel requirements for Palliative Care Service staff and consultants.

**Table 22 Location of Client – 2002/03**

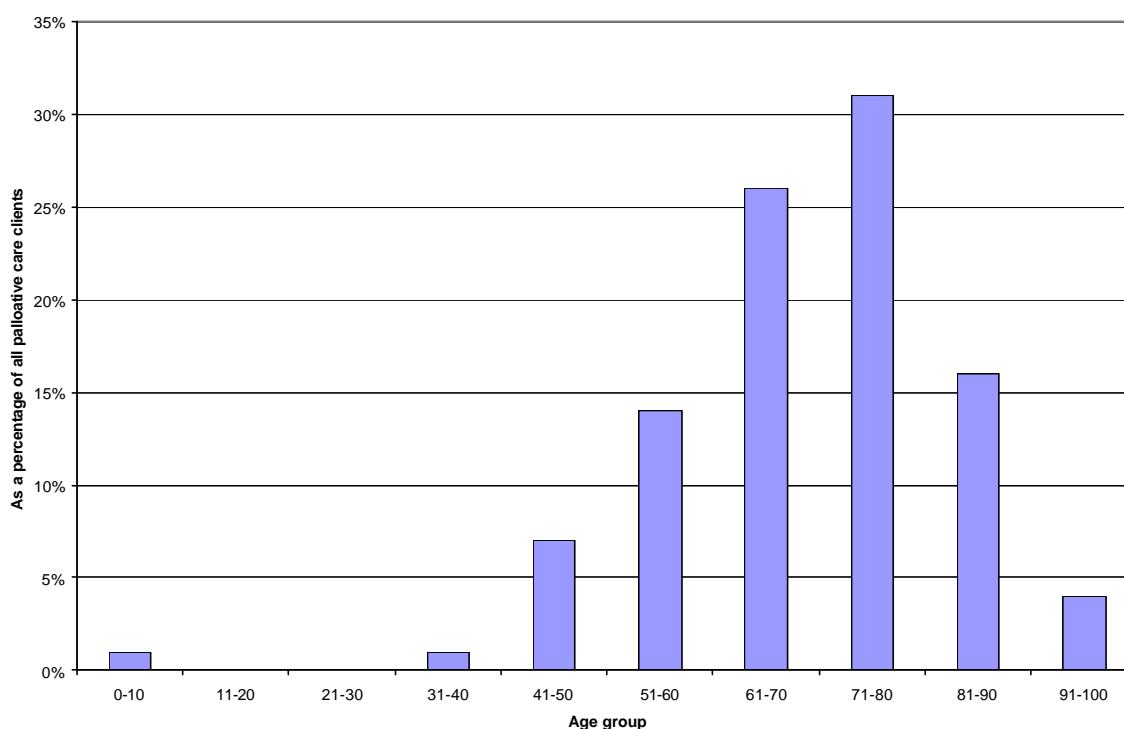
	South		North		North West		Total	
	No	%	No	%	No	%	No	%
<b>Metro</b>	234	77.2	117	68.4	107	53.8	458	68.1
<b>Rural</b>	69	22.8	54	31.6	92	46.2	215	31.9
<b>Total</b>	<b>303</b>	<b>100.0</b>	<b>171</b>	<b>100.0</b>	<b>199</b>	<b>100.0</b>	<b>673</b>	<b>100.0</b>

### Age Profile

Figure 7 profiles the age breakdown of palliative care clients in 2002/03. In that year:

- 9% of clients were aged less than 50 years including 4 children aged 10 years and under
- 40% of clients were aged 50 to 70 years
- 31% were in the 70 to 80 age group
- 20% were aged 80 years and above.

**Figure 7 Age profile of Palliative Care Clients 2002/03**



The age spread indicates the need for palliative care services to have good referral and consultation linkages with acute hospitals including adult and paediatric services and with residential care facilities.

### Diagnosis

In 2002/03 90% of palliative care clients who died had a diagnosis of cancer and 10% a non cancer illness.

**Table 23 Palliative Care Patients by Diagnosis 2002/03**

Diagnosis	No	%
Cancer	606	90
Non Cancer	66	10
<b>Total</b>	<b>672</b>	<b>100</b>

## Gender

Fifty three percent of the palliative care patients in 2002/03 were male and 47% were female.

**Table 24 Gender of Palliative Care Clients 2002/03**

<b>Sex</b>	<b>No</b>	<b>%</b>
Male	362	53
Female	310	47
<b>Total</b>	<b>672</b>	<b>100</b>

## Appendix 5

### *List of consultations undertaken as part of the Review*

- 1 Palliative Care State Management Team
- 2 Aged, Rural and Community Health Services - South Region
- 3 Aged, Rural and Community Health Services - North Region
- 4 Aged, Rural and Community Health Services - North West Region
- 5 Australian Nursing Federation
- 6 Australian Nursing Home and Extended Care
- 7 Carer's Association of Tasmania
- 8 Calvary Private Hospital, Hobart
- 9 Cancer Council of Tasmania
- 10 DHHS, Senior Managers
- 11 DHHS, Strategic Planning and Development, Disability Services
- 12 DHHS, Mental Health Services
- 13 DHHS, State Manager, ARCH
- 14 DHHS, ACAT North
- 15 Division of General Practice - South Region
- 16 Division of General Practice - North Region
- 17 Division of General Practice - North West Region
- 18 Faculty of Health Science, University of Tasmania
- 19 Hobart District Nursing Service
- 20 Hobart Private Hospital
- 21 Hospice Care Association of Tasmania
- 22 Karingal Home for the Aged
- 23 Launceston General Hospital - Medical, nursing and allied health staff
- 24 North West Regional Hospital
- 25 Palliative Care Community Team - South
- 26 Palliative Care Community Team - North
- 27 Palliative Care Community Team - North West
- 28 Palliative Care Inpatient Service - Whittle Ward
- 29 Philip Oakden House/OneCare
- 30 Royal Hobart Hospital - Medical, nursing and allied health staff
- 31 South Eastern Nursing Service
- 32 St Lukes Private Hospital
- 33 St Vincents Hospital
- 34 Tasmanian Association of Hospice and Palliative Care
- 35 The Gardens Aged Care Facility
- 36 School of Nursing
- 37 University of Tasmania, Faculty of Health Science