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Minister for Health

- 4 AUG 2012

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Mr Peter Dowling MP
Chairperson
Health and Community Services Committee
Parliament House
George Street
Brisbane QLD 4000

Dear Mr Dowling

I refer to your letter of 27 July 2012 seeking information in relation to funding for palliative care services in Queensland for 2010-2011 and requesting my appearance as a witness to the Inquiry on 22 August 2012.

Queensland Health has prepared the attached submission for consideration by the Committee for its Inquiry into palliative care and home and community services. The submission outlines Queensland Health purchased palliative care services, planning benchmarks, key challenges and opportunities.

The submission also includes a summary table at Appendix 2 which shows total funding to palliative care services in Queensland for the 2010-2011 financial year including a breakdown by individual Hospital and Health Service.

I would like to confirm my attendance as a witness before the Committee on 22 August 2012.

Thank you for bringing this matter to my attention.

Yours sincerely



LAWRENCE SPRINGBORG MP
Minister for Health

Queensland Health

Submission to Health and Community Services Committee

**Inquiry into palliative care and home and community care services in
Queensland**

August 2012

1. Introduction

Queensland Health welcomes the opportunity to provide a submission to the Health and Community Services Committee's Inquiry into palliative care services and home and community care services in Queensland.

There are a number of factors contributing to an increasing demand for palliative care services in Queensland, including a growing and ageing population, and the increasing incidence of cancer and chronic disease (both cancer and non-cancer related).

The patterns of life, disease, dying and death have also changed significantly over the last 100 years. In the past, more people died during childhood or early adulthood. Today, people are living longer with much higher rates of chronic disease and are more likely to die from end stages of advanced chronic illness rather than short-term acute illness or injury as they had done in the past.

In 2009, 77.4% (20,369) of people who died in Queensland were aged 65 years or older; more than three times the number 22.6% (5,947) aged less than 65 years.¹ In line with the ageing of Australia's population, the number of registered deaths in Queensland is projected to more than double over the next 30 years with an estimated 49,000 deaths per annum by 2038 and 66,800 deaths per annum by 2056.²

Cancer remains the most common principal diagnosis related to palliative care provision in hospitals, accounting for approximately 60 per cent of palliative care separations in Australia in 2008-09.³ For diseases other than cancer the two most frequently reported diagnoses were heart failure and chronic obstructive pulmonary disease, which each accounted for two percent of palliative care separations.

The diagnostic groups provided with specialist paediatric palliative care services include:

- Children with life threatening conditions for whom cure may be possible (eg. cancer, irreversible organ failure – not amenable to transplantation or where transplantation fails).
- Conditions that are ultimately life limiting but where long term palliation may be possible (eg. Cystic Fibrosis, Duchenne's Muscular Dystrophy);
- Progressive conditions with no curative options (metabolic conditions e.g. mucopolysaccharidoses, neurodegenerative conditions e.g. Batten disease, neuromuscular conditions e.g. spinal muscular atrophy);
- Stable neurological conditions with life limiting complications (eg. Severe Cerebral Palsy);

In Queensland there are approximately 400 – 500 deaths of children/young people under the age of 20 years⁴ each year. Less than half of these are caused by malignancy

¹ ABS 2009: Deaths Australia

² Reymond, L. Israel, F. Charles, M. Thomson, J. End Stage Care Pathway for Patients in Residential Aged Care Facilities Final Report, Australian Government, Department of Health and Ageing, Local Palliative Care Grants Program: Care Planning sub-program April 2009

³ Australian Institute of Health and Welfare, Canberra. Trends in palliative care in Australian hospitals. Cat. No HWI 112.2011

⁴ Queensland Hospital Admitted Patient Data Collection, Queensland Health (Extracted Feb 24, 2009); Cause of death file, Queensland Health (Extracted Dec 5, 2008)

and approximately 300 of them occur in hospitals. A significant number of deaths (25 %) occur in the peri-natal period. Although these numbers are relatively small compared to the total deaths per year in Queensland, the emotional and physical impact on family, friends and community of a child's death is significant. A consequence of the significant reduction (25 %) reduction in mortality between 1995 and 2005, is the smaller number of health professionals with the experience and training to support dying children and their families.

While trends indicate that people are more likely to die in hospital, the literature indicates that this is not the place of choice.^{5 6} Most people would prefer to die at home. However, the choice of where a person wants to die can also change during illness progression.

One of the greatest challenges for individuals, their families and healthcare providers is initiating difficult conversations about the transition to palliative care and a change in care focus to active symptom control rather than active curative treatment of a life-threatening illness. It is at this point where providers of palliative care need to understand what a 'good death' means to the person who is dying. A 'good death' is described by many as being pain and symptom free, peaceful, in the setting of choice and with the company of close family/friends.

Supporting people to experience a 'good death' requires a system wide, person-centred, integrated and coordinated approach to the delivery of palliative care with a range of service providers including generalist health care staff in acute, community or residential services and specialist palliative care services. Not all people approaching the end of their life, however need specialist palliative care.

The recently introduced health reforms in Queensland bring new opportunities at the local Hospital and Health Service level, for all health care providers (specialist and generalist health providers, community service providers as well as Medicare Locals) to work together to better coordinate the delivery of palliative care services for people who need it, where possible in their setting of choice.

Queensland Health Response to the Inquiry Terms of Reference:

2. The Capacity and Future Needs of Palliative Care Services and the effectiveness, efficiency and adequacy of palliative care services

Palliative care in Queensland is provided in hospital (private and public) and non-hospital environments (including residential facilities, hospices or in a person's home) via a complex service network of providers with multiple funding sources (including the State Government, Australian Government and private contributions) and diverse governance structures. It is an intrinsic component of health and human service care delivery (see *Appendix 1* for definitions).

⁵ Haines IE. managing patients with advanced cancer: the benefits of early referral for palliative care. MJA 2011; 194:107-108.

⁶ http://www.grief.org.au/grief_and_bereavement_support

Queensland Health Palliative Care Services

Queensland Health provides in-patient palliative care as well as services to people in the community. It provides specialist in-patient palliative care services in designated units which are located at the following hospitals: Bundaberg, Caloundra, Gold Coast, Gympie, Ipswich, Logan, Mt Isa, Redcliffe, Rockhampton, The Prince Charles Hospital in Chermide, Toowoomba and Townsville.

A statewide Paediatric Palliative Care Service operates from the Royal Children's Hospital in Brisbane.

Palliative care is also provided in non-designated areas of hospitals. For example, data for 2010/11 shows that a further 18 hospitals (from those listed above) also delivered services under what is termed a *designated palliative care program*. All remaining Queensland public hospitals provided some type of palliative care subacute service where palliative care type was the *principal clinical intent*.

Queensland Health has increased the number of admitted patient episodes for palliative care in Public Acute Hospitals by 66% since 2004/05 and non-admitted occasions of service for palliative care nearly four-fold since 2006/07.

Admitted patient episodes of care for palliative care in Queensland Public Acute Hospitals:

2004/2005	3,971
2005/2006	3,921
2006/2007	4,405
2007/2008	4,266
2008/2009	5,457
2009/2010	5,953
2010/2011	6,599

Source: *Queensland Hospital Admitted Patient Data Collection, Queensland Health (Extracted June 27, 2012)*

Non-admitted patient occasions of service for palliative care in Queensland Public Acute Hospitals:

2006/2007	2,690
2007/2008	4,396
2008/2009	6,677
2009/2010	9,382
2010/2011	10,887

Source: *Monthly Activity Collection, Queensland Health (Extracted June 27, 2012)*

Note: Palliative Clinic Types are only included in data from 2006/2007 onwards, this Clinic Type is not collected for the 'Smaller Hospitals'

Palliative Care in all Queensland Hospitals (public and private)

In the 2010-11 financial year there were 8,278 separations and 83,528 beds days recorded as palliative care in both public and private facilities. A majority of activity occurred in the public sector (79 per cent of separations and 68 per cent of bed days).

Palliative care activity by palliative care type

In public facilities 48 per cent of separations and 52 per cent of bed days were recorded as occurring in a designated palliative care unit. In private facilities 77 per cent of separations and 81 per cent of bed days were recorded this way.

Table: Separations and bed days for palliative care activity in public and private facilities, Queensland 2010-11 by palliative care type.

Palliative care type	Number of Separations	% Separations by care type	Number of Bed days	% Bed days by care type
Public - clinical intent	2756	42	21066	37
Public - designated program	649	10	6166	11
Public - designated unit	3159	48	29451	52
Total public	6564	100	56683	100
Private - clinical intent	353	20	4236	16
Private – designated program	43	<5	791	<5
Private – designated unit	1318	77	21771	81
Total private	1714	100	26845	100
Total public and private	8278		83528	

Source: Queensland Health Admitted Patient Data Collection 2010-11.

Non-admitted and Community Based Palliative Services

There are also a range of non-admitted palliative care services including:

- outpatient services
- facility based consultation services
- outreach, including home based, services; and
- telephone support services.

In addition, Queensland Health has existing contracts with a range of non-government providers of palliative care services in the community and Hospital and Health Services also purchase or 'script' services for individual palliative care patients from community based non-government providers of palliative care.

The availability of these services varies across the state. Data collection regarding this activity is in its infancy and not consistently reported at a statewide level. Notwithstanding this, Queensland Health has used a population based funding distribution model to improve the distribution of funds to purchase these services across the state.

Funding for Palliative Care Services

Queensland Health spent an estimated \$51.3 million on the provision of admitted public hospital subacute palliative care in Queensland in 2010-2011 (see Appendix 2 for a summary of palliative care funding for 2010-2011 by Hospital and Health Service). In addition, Commonwealth and state funding provided to Queensland Health for non-hospital based palliative care services in 2011-2012 was approximately \$17 million.

Through the National Partnership Agreement on Improving Public Hospital Services (NPA IPHS) Queensland Health is increasing palliative care services in both hospitals and community settings by 44 beds/bed equivalents at a cost of \$47 million by 30 June 2014.

The plan includes:

- 10 new palliative care beds at QE11 Hospital. These beds were opened in early 2012.
- 10 new palliative care beds at Redlands.
- Funding for general sub-acute beds using existing infrastructure in many regional and rural hospitals, some of which will support palliative care.
- An initial \$1.5 million per annum to various non-government organisations for the provision of palliative care in the community.
- Additional funding to six Hospital and Health Services to purchase additional palliative care services from non-government providers.

Activity Based Funding

Activity Based Funding (ABF) is a new funding framework used to manage the delivery of public health care services across Queensland. The ABF framework allocates health funding to Queensland Health hospitals based on the cost of health care services (referred to as ‘activities’) delivered, including palliative care.

Clinical Services Capability Framework: palliative care

The Queensland *Clinical Services Capability Framework for Public and Licensed Private Health Facilities (CSCF) V3.0* outlines the minimum service requirements, staffing, support services and risk considerations for both public and private health services to ensure safe and supported service delivery. The CSCF provides a useful resource to guide specialist palliative care service planning and delivery by individual Hospital and Health Services. Figure 2 shows the CSCF V3.0 palliative care service levels.

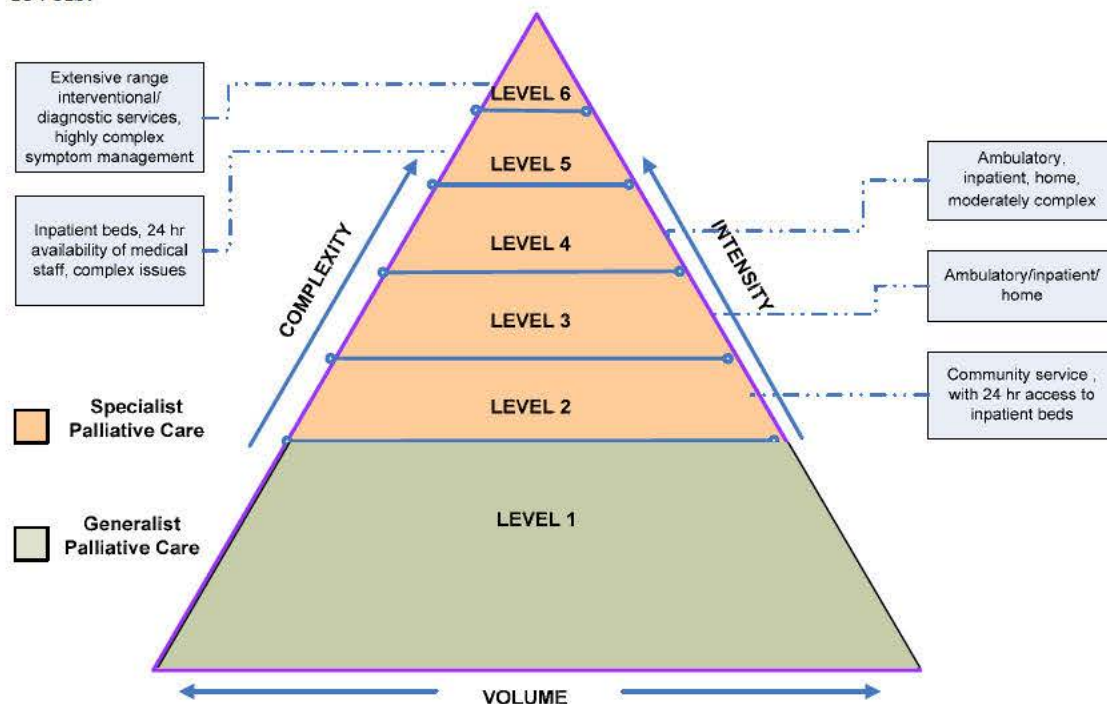


Figure 2: CSCF V3.0 Palliative care service levels

A person's care needs determine the level of access they require to specialist palliative care. Most palliative care is delivered outside of the specialist palliative care services, with people being supported by generalist palliative care services (Level 1) in the community, across a range of health settings (Level 2 to Level 4 palliative care services). A small number of people with complex needs can benefit from access to specialist palliative care services.

There is an emerging outcomes based and health economic literature that suggests that early referral to specialist palliative care leads to higher patient satisfaction, more appropriate care in the setting of choice, better quality of life for patients and families and cost efficiencies for the health system.^{7 8}

Specialist palliative care services support generalist palliative care providers by providing consultation/liaison, shared or direct care, particularly when these services experience challenges in providing pain and symptom control, spiritual and psychological support. It is important however, to ensure that the public system does not duplicate and/or compete with the private system, thereby creating viability and sustainability issues.

Admitted services in the private sector

In the private sector 26 facilities are licensed to provide palliative care services in 228 beds. It should be noted that beds licensed to provide palliative care may be provided in a range of ward settings, including general medicine and oncology, and not all licensed beds are used solely for the purpose of palliative care.

A majority (74 per cent) of public designated palliative care beds are in facilities offering palliative services at a more specialised level (CSCF levels 5 and 6) while a majority (63 per cent) of private licensed palliative care beds provide palliative care services at a more generalist level (Levels 2 to 4) (Figure 2).

Level 5 and 6 specialist palliative care services generally include a designated palliative care unit and multi-disciplinary team which provides consultancy services across acute/sub-acute ward areas in hospitals; day therapy; outpatients; as well as in the community where a person lives.

There are over 40 specialist palliative care services (government and non-government) across Queensland providing CSCF V3.0 service levels ranging from Level 2 to Level 6. The level and model of specialist palliative care services provided by Queensland Health varies across Hospital and Health Services.

Hospice service models also vary, with some offering specialist palliative care service to people in their own home, or inpatient beds with 24-hour onsite service, while others may have a combination of these services.

⁷ Temel J et al Early Palliative Care for patients with metastatic non-small cell lung cancer N England Journal of Medicine 363:733-742, 2010 (<http://www.nejm.org/doi/full/10.1056/NEJMoa1000678>)

⁸ Palliative Care Australia submission to Senate Inquiry into palliative care (pp132-134)(2012)

Statewide Paediatric Palliative Care Service (PPCS)

A life limiting condition is defined as one where the child is not expected to live beyond the age of 18 years. All of these children, who range in age from 0-18, including peri-natal patients, will require a general practitioner and paediatrician to oversee their care within the community. They also require a local hospital where they can be admitted for symptom management and during times of intercurrent illness. The service needs to be able to respond appropriately to referrals of all age groups, including peri-natal, up to the age of 18 years.

Generally, families living in regional and rural areas are cared for by a paediatrician, general practitioner and the local specialist palliative care (sometimes in partnership with the PPCS).

Within Brisbane, the PPCS is available to consult on children living in the metropolitan area and also complex cases outside of Brisbane when requested (this may be due to complexity of the case or related to patients being referred back to a regional or rural centre from one of the tertiary hospitals).

Although the service is based at the RCH in Brisbane, consultation and support is available throughout Queensland and northern New South Wales through the use of technology (telehealth). PPCS clinicians are able to provide the appropriate care and support in a timely manner and in the location that is most convenient to the family.

Other Statewide Services

There are a number of state-wide palliative care support services which provide information and advice for people, families and communities, capacity building in the workforce, research, education, and advocacy. State-wide information and advice about palliative care is available through the Palliative Care Helpline and the Queensland Health Paediatric Palliative Care Service.

CareSearch is a national online resource that provides palliative care information and evidence. The Centre for Palliative Care Research and Education (CPCRE) is a state-wide service that works in partnership with service providers across all sectors and offers a coordinated approach to education and delivery of state-wide education programs. Palliative care research involving teams across sectors and in partnership with universities significantly helps to guide the delivery of contemporary palliative care and capacity building for the future.

A range of resources and programs to support education and training in palliative care are also available. The workforce is further supported in palliative care service delivery through the state-wide service Program of Education in the Palliative Approach (PEPA) funded by the Australian Government Department of Health and Ageing. The PEPA aims to improve the quality, availability and access to palliative care for people who are dying, and their families, by improving the skills and expertise of health practitioners.

National Palliative Care Standards

Palliative Care Australia *Standards for providing quality palliative care for all Australians* has set the national standards for best practice in palliative care and includes information on the expected level of care and relationships between primary care and specialist palliative care services.

A continuous improvement framework for specialist palliative care services is supported by two national programs *The National Standards Assessment Program (NSAP)* and the Palliative Care Outcomes Collaborative (PCOC).

Queensland Health Service Planning Benchmark for Palliative Care

The currently endorsed Queensland Health services planning benchmark for palliative care is:

- 4.9 adult palliative care beds per 100,000 weighted population or 3.9 adult public beds per 100,000 weighted population when consideration is given to private hospital and hospice provision.

The benchmark is based on a projection methodology combining total population projections weighting by age and sex using palliative care weights. It is focussed on designated palliative care beds where a designated bed refers to a bed which supports palliative care which is provided by, or with the support of, a specialist in palliative care.

The benchmarks are used for the projection of health service activity and the translation of this activity into treatment space requirements to assist capital infrastructure planning. More recently, service planning benchmarks have provided a point of reference in discussions regarding the purchasing of health services in Queensland. The benchmarks not intended to address issues of clinical competence, workforce requirements, or patient safety.

The benchmarks do not determine if a service is to be delivered or established (except where minimum volumes are stated); instead they are platforms on which to base planning for the delivery of the service into the future.

Benchmarks are developed by Queensland Health following extensive literature reviews and in consultation with clinicians, and other stakeholders, in Hospital and Health Services (HHS). The development process is designed to ensure that the benchmarks align with the service being delivered and any emerging trends in service delivery.

The endorsed Queensland Health service planning benchmark for Adult Palliative Care is currently under review, and a discussion paper has been disseminated to internal stakeholders for comment.

End of Life and advance care planning

Queensland Health recognises that end of life consideration and advance care planning enables health services to deliver the right care, in the right place and at the right time.

Quality in end of life care is ‘everyone’s business’ not just that of palliative care services. There are many factors which determine where a person is cared for at the end of their life including patient/family choice, the physical environment and appropriate clinical supervision. These decisions are best made through discussions between the patient, their family and the treating physician. Advance care planning documents can also ensure wishes can be known and acted on.

Queensland Health recognises there are significant and complex clinical, ethical and legal considerations in making decisions to withhold or withdraw life-sustaining measures and has existing policies and developed educational resources in relation to this.

Key Issues and Challenges for Queensland Health Palliative Care Services

Access to specialist palliative care

Many of the specialist palliative care services in Queensland are located in the major metropolitan centres, and this poses a particular challenge in terms of ensuring access for people living in rural and remote parts of the state. There are also variations in the availability of palliative care services across Hospital and Health Services. The complexity of current care arrangements, where multiple providers can be involved, has also resulted in differences in the approach of palliative care services delivered across Queensland.

The establishment of Hospital and Health Services (HHS) as independent statutory bodies provides the opportunity to better coordinate and integrate health services between all providers across the care continuum at the local level, including palliative care services. Whilst Queensland Health will be responsible for Statewide planning, HHS will be responsible for the planning and delivery of public health services in their local area based on locally identified priorities.

The vital role which specialist palliative services have in providing consultation and liaison to other specialist providers as well as a range of generalist health providers including General Practitioners will need to be supported at the HHS level into the future. In this way, the capacity of all providers to deliver person-centred palliative care will be enhanced and access to palliative care will be improved for people who need it.

Residential aged care facilities are increasingly being seen as important in the delivery of palliative care.^{9 10} The Productivity Commission¹¹ has suggested palliative care should be core business for aged care services. There are several studies which demonstrate how palliative care can be facilitated in residential aged care settings,

⁹ Palliative Care Australia. Submission to the Australian Senate Standing Committee Community Affairs Inquiry into Palliative Care in Australia April 2012

¹⁰ Productivity Commission, Canberra. Caring for Older Australians: Inquiry Report. 2011

¹¹ Productivity Commission, Canberra. Caring for Older Australians: Inquiry Report. 2011

including work undertaken by the Brisbane South Palliative Care Collaborative which demonstrated how a Residential Aged Care End of Life Pathway improved the quality of palliative care provided in residential aged care and reduced inappropriate admissions to hospital.¹²

The Australian Government in response to the Productivity Commissions report in its Living Longer Living Better aged care reform package recognised that aged care providers are increasingly being involved in the delivery of palliative care and is funding some initiatives to improve advanced care planning advisory services for aged care providers and general practitioners as well as expanding the existing palliative care training program for staff in residential aged care facilities and home care package services.

Palliative Care Workforce

The Queensland Palliative Care Training Oversight Committee is working to achieve an integrated training pathway across Queensland. 2012 marked the first year that the Rural Medical Officer recruitment campaign incorporated the Palliative Medicine pathway, which resulted in an increase in the number of applicants who will be placed across the state in accredited, funded positions.

Palliative Care Nurses Australia has been working with the Centre for Palliative Care Research and Education to develop competency framework for all levels of specialist nurses based on international palliative care nursing competency frameworks in the United Kingdom and New Zealand. The development of operational specialist palliative care competency frameworks and supported training needs to occur in all other disciplines to support access to specialist palliative care (CSCF levels 4-6) to for people who need it.

Up-skilling and capacity building of the generalist, non-palliative medicine/care workforce, junior staff and medical, nursing and allied health students in the provision of high quality end of life care needs to be an integral part of the role of specialist palliative care services. Accordingly, consideration needs to be given to the time involved in doing this work in the resourcing of specialist palliative care services.

Respite Care

Respite care is an important part of providing palliative care in the community and through supporting families and carers in this way, can potentially avoid unnecessary hospital admissions and carer fatigue.

There are limited options available for the provision of respite care to families and carers of people receiving palliative care, and acute and subacute hospital beds are in some cases the only available option for this purpose.

Respite care is also a large area of need for families with a child with a life limiting illness – particularly those children with non-cancer diagnoses. A holistic approach is required as some children will require legitimate extended inpatient stays in hospital which can be related to the burden of care in their life limiting condition, in addition

¹² Reymond L, Israel F, Charles, M. A residential aged care end of life pathway (RAC EoLCP) for Australian aged care facilities. Australian Health Review 2011;35:350-356

to the acute medical problem they are presenting with. The high demand of prolonged and complex care on families caring for their child at home can result in varying degrees of social isolation, relationship strain and financial hardship. These pressures can impact significantly on a family's continuing ability to care for their child.

There are limited out of home respite facilities in Queensland, and these facilities can find it difficult to care for children with life limiting conditions and complex symptoms and needs (e.g. seizures, requirement for suction, administration of opioid analgesia or rectal medications).

There is further complexity with difficulties experienced in finding suitable carers to provide respite. Some families prefer in home respite while others will prefer out of home respite. It can be difficult to provide emergency respite to children and their families although increased subacute beds at the Royal Children's Hospital has increased capacity to provide 'short break' care since July 2011.

Paediatric Palliative Care

There are challenges in relation to the access of services spread across a number of campuses, in particular, the Royal Children's Hospital, Mater Children's Hospital and neonatal units at the Royal Brisbane and Women's Hospital and Mater Mother's Hospital. The model of providing one service across multiple campuses presents difficulties in terms of time, travel and clinical handover. Many of these challenges have been met by improving communication supports, the uptake of telehealth, developing networks of care and creating forums for clinicians to both provide input and receive education around palliative care issues.

It can be difficult for families to negotiate the health care system as each child and family often has unique needs and multiple agencies are often required. Accessing information about all of these agencies and service providers can be difficult for families. It is also challenging to ensure different service providers are providing co-ordinated care.

The Mater Children's Hospital has established a Complex Care Service and the Royal Children's Hospital has a Paediatric Palliative Care Service to try and meet this need for children with life limiting conditions. There is good collaboration between these two services. However, the needs are great and cannot always be met. Further, there can be a discrepancy in care provided to children who are referred to these services and those who are not. The Paediatric Palliative Care Service currently receives 70 – 80 referrals each year. Case conferences with families and other service providers has been one method of improving co-ordination of care.

Bereavement support has been identified as area requiring further development and support and the PPCS is committed to providing this support for families as the grieving period can begin at diagnosis and continue well past the death of a child. There are also minimal supports and services available to support bereaved siblings. While bereavement services have been established at the Royal Children's Hospital (and Mater Mother's Hospital), there is a need to grow these services to keep up with demand. There is also a need to collaborate and support non-government providers of these unique services for children.

Intake criteria for children need to be flexible and inclusive (rather than exclusive) and health professionals need education on providing flexible and individualised care to each child. The Paediatric Palliative Care Service provides care to more non-cancer patients than cancer patients (65 % versus 35 %).

Meeting the Challenges

The challenge for Queensland Health is for Hospital and Health Services to establish local service networks with integrated and coordinated links between government and non-government services, social and community supports, carers and family to provide timely and appropriate person-centred palliative care.

The following key priority areas will provide the focus for palliative care service delivery by Hospital and Health Services:

1. Person centred palliative care is based on informed choice and individual needs.
2. Palliative care is ‘everyone’s business’ and integrated into all health services.
3. Equitable access to coordinated palliative care is available to people who need it, in their place of choice.
4. Education and training is essential to improve awareness of palliative care and the capacity of services to provide palliative care.
5. Quality palliative care services are informed by evidence.

Improving access to palliative care at the Hospital and Health Service level will involve promoting a better understanding of the role generalist services can play in the delivery of palliative care services in consultation with specialists. By working together better, access to palliative care services will be improved for people with a life-threatening illness.

3. Opportunities for reforms to improve collaboration and cooperation between chronic, disability and other services.

The establishment of Hospital and Health Services (HHS) has created an opportunity to ensure that services are organised and delivered in a manner that meets the needs of the local communities under the governance of a skilled local board. Under the Hospital and Health Boards Act 2011 the functions of a HHS include, amongst other things:

- to ensure the operations of the Service are carried out efficiently, effectively and economically;
- to contribute to, and implement, Statewide service plans that apply to the Service and undertake further service planning that aligns with the Statewide plans;
- to develop local clinical governance arrangements;
- to cooperate with other providers of health services;
- to cooperate with local primary healthcare services; and,
- to consult with health professionals, health consumers and members of the community about the provision of health services

In addition, each HHS is required to develop and publish a clinician engagement strategy to promote consultation with health professionals. They also are required to develop a consumer and community engagement strategy to promote consultation with health consumers and members of the community about the provision of health services.

Further each HHS is to use its best endeavours to agree on a protocol with local primary healthcare organisations to promote cooperation between the HHS and these primary health care organisations in the planning and delivery of health services.

These reforms will provide a platform to enable better co-ordination and integration of care between public and private services, including palliative care services. The reforms are also designed to ensure that there is an opportunity to build a stronger interface between the health, aged care and disability services sectors.

These reforms also provide the opportunity build collaborative and formal partnerships between palliative care providers and other community care providers to provide efficient and seamless community care round-the-clock.

Meeting the equipment and support service needs of children with life limiting conditions (for example in-home respite hours) can be very expensive. It is important that disability services and the Medical Aids Subsidy Scheme (MASS) are responsive to these children's needs and provides equipment and services in a timely manner. Where is this problematic, a flexible funding option for children with life limiting conditions which can complement and enhance existing funding arrangements (without causing other funders to withdraw) is critical.

There is a further layer of complexity which affects children with disabilities and life limiting conditions as there are grey areas around who takes the primary responsibility for support and care under these circumstances. There is a need for a specific model of care for disabled patients. This requires a co-ordinated and cross-departmental response for these children (from Queensland Health, Disability Services Queensland and Education Queensland). Such a response is on occasion achieved for some cases. However, a more systemic approach (including policy formation) is required to achieve this for all children with both a disability and life limiting condition.

Recognising and supporting the delivery of palliative care outside the public hospital system is important to ensure continuity of care for the patient. This support will require a significant amount of training plus on-call availability of the Specialist Palliative Care Service providers.

Queensland Health will continue to work with the Commonwealth Department of Health and Ageing to ensure that the Commonwealth's aged care reforms are responsive to the hospital and health system. It will also continue to work closely with the relevant State and Commonwealth Departments regarding disability service reform. This will include improving access to disability and aged care services where these services are appropriate.

4. Consideration of segmenting the current Home and Community Care service system based on carers, health workers and relevant experts.

Queensland Health is a provider of services funded by the Home and Community Care (HACC) Program. In 2010-2011, Queensland Health Service Districts were collectively contracted by the Department of Communities to provide 1.5 million hours of HACC services worth more than \$70.2 million. The majority (60%) of these HACC services were for Domestic Assistance namely, bill paying, dishwashing, shopping, cleaning and clothes washing and ironing.

The Council of Australian Governments (COAG) agreed that the Commonwealth would assume full policy, funding and operational responsibility for aged care services (excluding WA and Victoria). This decision meant that the existing HACC program, which supports older people as well as younger people with a disability, would be split, with the Commonwealth assuming funding and policy responsibility for clients aged 65 years and older (50 years and older for people from an Aboriginal and Torres Strait Island background), and the state assuming the responsibility for younger people.

The National Health Reform Agreement (NHRA) Schedule F gives effect to the COAG decision. Under this agreement, 2011-12 was treated as a transition year with the State continuing to administer the entire HACC program with cross billing arrangements occurring between the State and the Commonwealth, in keeping with the age split of the program.

From 1 July 2012, the Commonwealth (via the Department of Health and Ageing (DoHA)) is funding and administering the aged component of the HACC program through direct funding agreements with service providers and the State (via the Department of Communities, Child Safety and Disability Services (DCCSDS)) having separate contractual arrangements for clients in the younger age group.

In Queensland, the current ratio of the number of clients in the older versus younger aged cohorts is 78:22. The younger aged cohort receives a greater proportion of the funding with approximately 26% of the funding being spent on services.

In terms of the proportion of clients receiving Queensland Health provided HACC services a reported 83.2% of clients are in the older cohort, who receive 86.5% of service units.

In keeping with the devolution of responsibility and accountability under the health care reforms in Queensland, the contractual arrangements for the HACC program is a matter negotiated directly between Hospital and Health Services and the relevant funding bodies. Queensland Health has previously adopted a policy of no-growth in the provision of HACC services where the non-government sector has the capacity to deliver services. This policy position has been adopted to ensure that the non-government sector is able to further develop.

Key issues for Queensland

Following the operational split of the HACC program, each HACC provider will be required to sign two separate agreements: one with the Commonwealth Department of Health and Ageing (DoHA) for the aged component of the HACC program, and one with the State (via DCCSDS) for the residual component of the existing HACC program.

As a provider of HACC services, this split will result in an increase in the transaction costs associated with administering two separate funding agreements. To minimise the impact of this Queensland Health has assisted the Department of Communities in its negotiations with the Commonwealth Department of Health and Ageing to ensure that there is due recognition of such things such as quality, common data reporting arrangements to minimise the impost that this split will have on providers and indeed the level of services provided for clients.

Under the NHRA, the Commonwealth has agreed that it will not substantially change the service system before 2015. There is however a risk that the service system may incrementally change resulting in a substantially different service system.

A further risk is that, the age split may result in existing providers deciding not to deliver services to a particular age group. For instance, an older person aged 64 who is approaching their 65th birthday and is already in receipt of HACC services from a particular provider with whom they have an established relationship, faces having to change to a new provider after their 65th birthday if the existing one is not contracted by the Commonwealth to provide services to older HACC clients.

The contractual arrangements by both the Commonwealth and the State are designed to mitigate this risk enabling non-significant variations in the volume of services between different age groups for providers that support both age groups. These contractual arrangements, however can not address circumstances where a provider is not contracted to deliver services to the older age group.

For Queensland Health the availability and delivery of effective community care services, regardless of a person's age is essential in avoiding unnecessary hospitalisations.

Appendix 1

WHO Definition of Palliative Care

<http://www.who.int/cancer/palliative/definition/en/>

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

Appendix 2: Summary of Palliative Care Funding for 2010-2011

Hospital and Health Service	Case-mix funding for in patient palliative care in 2010-2011	Commonwealth funds to purchase NGO palliative care 2010-2011	NPA IPHS Schedule E 2010-2011	Contracted NGO Palliative care funding 2010-2011	State \$ 2010-2011	Total Funds
Cairns and Hinterland	5,628,399.00	723,216.00				6,351,615.00
Cape York	68,628.00	46,336.00				114,964.00
Central QLD	2,958,228.00	473,284.00				3,431,512.00
Central West	123,711.00	24,892.00				148,603.00
Children's Health QLD	257,355.00	107,890.00				365,245.00
Darling Downs*	1,799,679.00	955,966.00		444,750.00		3,200,395.00
Gold Coast	6,285,783.00	716,751.00		306,970.00		7,309,504.00
Mackay	1,104,369.00	231,794.00				1,336,163.00
Mater Public Hospitals	1,451,121.00	164,023.00				1,615,144.00
Metro North	10,087,413.00	1,310,182.00		1,486,734.00		12,884,329.00
Metro South	8,056,566.00	1,367,675.00	361,000.00			9,785,241.00
North West	180,600.00	173,474.00				354,074.00
South West	226,653.00	128,732.00				355,385.00
Sunshine Coast	4,014,738.00	882,600.00		423,609.00		5,320,947.00
Townsville	3,736,614.00	728,414.00				4,465,028.00
West Moreton*	2,454,354.00			613,927.00		3,068,281.00
Wide Bay	2,912,175.00			154,117.00		3,066,292.00
Torres Strait Northern Peninsula		47,328.00				47,328.00
St Vincent's Hospital* *				1,208,250.00	4,685,362.18	\$5,893,612.18
Community Services Purchasing		27,720.00				\$27,720.00
Total	\$51,346,386.00	\$8,110,277.00	\$361,000.00	\$4,638,357.00	\$4,685,362.18	\$69,141,382.18

*In 2010-2011 Darling Downs and West Moreton were a single District.

**QLD Health has an existing contract with St Vincent's which includes this funding for the provision of palliative care