NSW Health Submission to Senate Community Affairs Committee

Inquiry into Palliative Care in Australia

April 2012

COMMONWEALTH SENATE COMMUNITY AFFAIRS INQUIRY INTO PALLIATIVE CARE IN AUSTRALIA

NSW Health welcomes the opportunity to provide input into the Senate Community Affairs Inquiry into Palliative Care in Australia. The Ministry's submission outlines the current efforts to improve the provision of palliative care across NSW through the NSW Ministry of Health policy directive- *Palliative Care Strategic Framework 2010 – 2013.*

The NSW Ministry of Health is also currently undertaking an analysis of the need for palliative care services across NSW to ensure adequate services are provided across the whole State.

The Ministry will map current palliative care services against population needs and investigate appropriate palliative care population planning tools used in other jurisdictions to assist in future service planning. This will include investigating the current palliative care workforce and identifying any current workforce gaps that can be addressed.

The remainder of the submission responds to the Inquiry's Terms of Reference as outlined below:

Terms of Reference:

The provision of palliative care in Australia, including:

(a) the factors influencing access to and choice of appropriate palliative care that meets the needs of the population, including:
  (i) people living in rural and regional areas,
  (ii) Indigenous people,
  (iii) people from culturally and linguistically diverse backgrounds,
  (iv) people with disabilities, and
  (v) children and adolescents;

(b) the funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent;

(c) the efficient use of palliative, health and aged care resources;

(d) the effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities;

(e) the composition of the palliative care workforce, including:
  (i) its ability to meet the needs of the ageing population, and
  (ii) the adequacy of workforce education and training arrangements;

(f) the adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care to All Australians (NSAP);

(g) advance care planning, including:
  (i) avenues for individuals and carers to communicate with health care professionals about end-of-life care,
  (ii) national consistency in law and policy supporting advance care plans, and
  (iii) scope for including advance care plans in personal electronic health records; and

(h) the availability and funding of research, information and data about palliative care needs in Australia.

Palliative Care in New South Wales (NSW)

Palliative Care in NSW is delivered across a range of healthcare settings from hospital to community care, providing patients and their families and carers with physical, psychological, emotional and spiritual support at a time of great emotional stress.

Palliative Care services, and the professionals who work in this field, form a valuable part of the NSW health system, providing coordinated medical, nursing and allied health care which is delivered, wherever possible, in the location of choice for the person receiving the care.

During 2010/11, NSW Health provided the following palliative care services in public hospital settings:

Table 1: Palliative Care Services in NSW Public Hospitals 2010/11

Palliative care hospital separations (ie number of episodes of care for palliative care)	10,952
Total length of stay for palliative care (ie total number of bed days, including same day stays)	122,653

Source : Health Information Exchange data 2010/11

In NSW palliative care services are provided at primary, specialist, and paediatric care levels, within both metropolitan and rural service models.

Primary palliative care services cover the continuum of care for all people who are experiencing a life limiting illness with little or no prospect of cure. This service incorporates general practitioners, community nurses, allied health staff, and other specialist services such as oncology and aged care professionals, working in the community, residential aged care or acute care facilities. These professionals may have existing relationships with the patient, or be providing interventional care in conjunction with more palliative approaches.

Specialist palliative care services include clinicians with recognised skills, knowledge and experience in palliative care. This level of service is appropriate for patients with a life limiting illness whose conditions have progressed beyond curative treatment, or patients who choose not to pursue curative treatment. Specialist teams include Directors of Palliative Care, medical practitioners with qualifications in palliative medicine, clinical nurse consultants with qualifications in palliative care nursing, palliative care nurse practitioners and social workers with experience in palliative care. Formalised bereavement support and pastoral care is also provided within the specialist team.

Palliative care services in metropolitan NSW Local Health Districts typically include patient beds in acute or sub-acute public hospitals or in a third schedule hospital, inpatient consultations, and community medical and/or nursing services.

In rural Local Health Districts palliative care services comprise nursing services, fly in/out doctors are funded through the Medical Specialist Outreach Assistance Program. Inpatient beds are provided on a clinical needs basis. There are particular challenges for rural and regional palliative care services where there is no locally based specialist medical palliative care service. To attempt to address this shortfall medical specialists from metropolitan Local Health Districts make regular visits to some regional/rural areas.

Specialist paediatric palliative care is provided by metropolitan Children's Hospitals, each offering an integrated palliative care service in the home, hospital and respite/hospice care through the NSW statewide children's hospice.

NSW Palliative Care Strategic Framework

NSW Health's palliative care services are guided by the NSW Ministry of Health policy directive- *Palliative Care Strategic Framework 2010 – 2013*. The Framework outlines the priority areas for improving palliative care services in NSW.

The Strategic Framework is aligned with the goals of the National Palliative Care Strategy, setting out five priority areas for strengthening palliative care services in NSW, namely:

- Improving NSW palliative care service planning and delivery
- Implementing the National Standards for Providing Quality Palliative Care
- Improving the palliative care workforce capacity
- Improving palliative care data
- Strengthening evidence based practice

Implementation of the Strategic Framework will occur through the Palliative Care, and Paediatric Palliative Care, Development Planning Frameworks 2011 – 2014. Strategies from these planning frameworks will become target actions in Local Health District Palliative Care Service Plans.

The Development Planning Frameworks draw their principles from the Palliative Care Strategic Framework. These principles are:-

- Equity - ensuring equal access to palliative care services for people with equal need, irrespective of personal characteristics such as gender, cultural background or place of residence
- Access - providing responsive, culturally and linguistically appropriate end of life and palliative care services, made available locally whenever possible
- Community engagement - the participation of patients, carers and communities in decision-making
- Responsiveness - to local population needs through palliative care service funding, planning and provision
- Partnerships - developing and maintaining links with other providers who play an important role in the delivery of end of life and palliative care services
- Multidisciplinary and evidence-based approaches - multidisciplinary teams delivering evidence-based end of life and palliative care services to achieve optimal outcomes for patients and carers.

The Planning Frameworks identify a range of activities, partnerships and education approaches to meet the five priorities of the Strategic Framework.

Mapping of NSW Palliative Care Services

The NSW Ministry of Health is currently undertaking an analysis of the need for palliative care services across NSW to ensure adequate services are provided across the State.

The Ministry will map current palliative care services against population needs and investigate appropriate palliative care population planning tools used in other jurisdictions to assist in future service planning. This will include investigating the current palliative care workforce and identifying any current workforce gaps that can be addressed. An examination of current training and resources available to support volunteers is also being undertaken.

Comments in relation to the Terms of Reference of the Inquiry into the provision of palliative care in Australia:

(a) the factors influencing access to and choice of appropriate palliative care that meets the needs of the population, including:
- **(i) people living in rural and regional areas,**
- **(ii) Indigenous people,**
- **(iii) people from culturally and linguistically diverse backgrounds,**
- **(iv) people with disabilities, and**
- **(v) children and adolescents;**

NSW Health comment:

The provision of equitable access to specialist services such as palliative care is particularly challenging for rural and regional areas. Influencing factors include shortages of both general practitioners and specialists. In an attempt to improve access, palliative care specialists from metropolitan areas make regular visits to regional and rural health facilities. These arrangements are not considered sustainable unless they are part of an established network.

Within NSW a 'pop up' model is to be trialled for paediatric palliative care as one method of ensuring that appropriate service is provided on an as-needed basis. The model establishes multidisciplinary systems to provide primary carers with access to palliative consultations and support services as necessary. This is a shared care model between primary health services, community based services and specialist paediatric palliative care services. The role of specialist paediatric palliative care service is to provide education, advice and support to other service providers to manage the palliative care needs of the child and family. This is also being considered as an appropriate model for other groups including those living in rural and regional areas.

(b) the funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent;
(c) the efficient use of palliative, health and aged care resources;
(d) the effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities;

NSW Health comment:

There is room for improvement in the provision of consistent coordinated care across the palliative care, primary health care and aged care sectors, particularly with regard to care in residential aged care facilities. Funding for the provision of specialist palliative care in aged care facilities is generally on the basis of time limited project funds.

The resumption by the Federal Government of aged care services including Home and Community Care (HACC) provides an opportunity to create more streamlined service provision to older people and ensure that clear referral guidelines and pathways are developed between services. In particular, there is an opportunity to improve referral pathways of appropriate aged care services for people who are in receipt of specialist palliative care services.

Models to support improvement in coordination of care are currently being developed. An example of such a model is a three year Council of Australian Governments (COAG) funded project that supports the transition of patients from in-patient palliative care at Calvary

Hospital in Kogarah, NSW to local high-level residential aged care facilities in partnership with local Divisions of General Practice. Once trials such as this are evaluated and established to be effective, appropriate funding needs to be provided to ensure that these models can be rolled out.

(e) the composition of the palliative care workforce, including:
(i) its ability to meet the needs of the ageing population, and
(ii) the adequacy of workforce education and training arrangements;

NSW Health comment:

Resource issues exist in regional/rural settings in medical/nursing and allied health. The Australian and New Zealand Society of Palliative Medicine (ANZSPM) estimates that Australia currently has only half the required number of palliative care specialists, and that this shortage is becoming more acute.

Federal funding underpinning the whole palliative care structure does not include funding for community services. This results in a skewed model emphasising inpatient services over community based services. The provision of effective palliative care services depends upon adequate primary/generalist care supported by specialist palliative care and consultative services in the community and residential aged care facilities.

There is a need for development of evidence based planning tools that can guide decisions on appropriate medical/nursing staff, and waiting times for services and beds/services required against population.

(f) the adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care to All Australians (NSAP);

NSW Health comment:

The standards are a useful framework for assessing quality in palliative care. Assessment against the Standards is compulsory for all NSW Ministry of Health specialist palliative care services.

However, the standards are only applicable to specialist palliative care services and do not apply to primary care services that provide palliative care. For many regional and rural areas, the majority of palliative care is provided through such primary care services.

(g) advance care planning, including:
(i) avenues for individuals and carers to communicate with health care professionals about end-of-life care,

NSW Health comment:

Some significant general misperceptions exist with regard to Advanced Care Planning (ACP), that require correction:

- ACP is not a one off conversation resulting in a document.
- ACP should not only happen late in the course of illness.
- ACP is not only about end of life planning and death.
- ACP is not about choosing when to move to palliative care (there is an implicit misperception that palliative care is incompatible with so-called active measures).
- ACP is not akin to euthanasia.

There is a significant cultural taboo around 'death talk' in the community and within the health system. Much needed community dialogue about death and dying can be facilitated in an environment where planning in advance becomes the normal event.

The use of nationally consistent terminology around ACP and end of life care should be promoted. Uptake of the AHMAC *National Framework for Advance Care Directives* 2011 will assist in this regard.
http://www.ahmac.gov.au/cms_documents/AdvanceCareDirectives2011.pdf

Non-Government Organisations could be contracted to distribute individual and carer resources, particularly lay language resources on ACP (what it is and how to do it), as well as realistic information about cardiopulmonary resuscitation and its outcomes in patients with serious, chronic life-limiting illness and the typical trajectories of those chronic life-limiting illnesses.

Online portals, such as the newly developed NSW interagency "*Planning Ahead Tools*" website (www.planningaheadtools.com.au) could be utilised as single points of access for financial and health planning information and resources.

Resources to meet the needs of Aboriginal and culturally and linguistically diverse communities are also required. These groups have different needs for information relating to end of life that are generally not met.

ACP could be included as a mandatory standard for accreditation in Australian aged care facilities.

Development of a Medicare Benefits Schedule item for ACP discussions would facilitate communication of end of life care in the primary care setting.

(g)(ii) national consistency in law and policy supporting advance care plans, and

NSW Health comment:

Legal clarity in advance health care planning is essential to support both individuals and treating clinicians in end-of-life decision-making and decision-making when an individual's capacity is impaired. For an individual, legal certainty about Advanced Care Directives (ACDs) gives assurance that documented wishes regarding their future health care will be respected; for the clinician this provides reassurance that they are acting within the law when they act to respect and uphold decisions recorded in ACDs or by appointed substitute decision maker/s. In respect of NSW, the law was clarified by the Supreme Court judgment of Hunter and New England Area Health Service v A [2009] NSWSC 761.

More generally, there have been a number of developments in the common law, including HNEAHS v A and Brightwater Care Group (Inc) v Rossiter [2009] WASC 229, which have given practical clarification of a substantial number of the issues of concern, setting principles while retaining a degree of flexibility for clinicians at the frontline level.

AHMAC developed the *National Framework for Advance Care Directives* to assist harmonisation of policy and legislation surrounding use of Advance Care Directives (as one tool for advance care planning). The *Framework* has now been referred to the Standing Committee of Attorneys-General to consider legislative mechanisms that would further facilitate harmonisation (rather than standardisation) of relevant laws across jurisdictions.

(g) (iii) scope for including advance care plans in personal electronic health records;

NSW Health comment:

In NSW, "*My Health Record*" is a paper-based personal health record that includes advance care planning information. Maintaining this resource, with update of contents as required, is the preferred approach in NSW until the national personally controlled electronic health record (PCEHR) system is implemented.

PCEHR provides a potential solution to the 'transportability' problem that confounds current paper-based approaches where a document developed in one care setting e.g. in a residential aged care facility, is not transferred to another, or if it is, is not recognised as authoritative by health professionals.

Including advance care planning in the PCEHR should not be limited to including an Advance Care Directive, as they may vary across Australia, although this would not be an issue in NSW, and there is no exclusive prescribed form for an Advance Care Directive.. Taking a principle based approach of recording the completion of key advance care planning activities would be preferred.

Key activities to be recorded would include:

- Identification of the lawful substitute decision maker – either appointed enduring guardian (or similar) or other 'person responsible' under Guardianship provisions
- Completion of an Advance Care Directive by the individual
- Discussion(s) with carer, family, friends
- Discussion(s) with health or legal professionals
- Completion of an Advance Care Plan

Encouraging a record over time of discussions and appointments would facilitate best practice in advance care planning.

(h) the availability and funding of research, information and data about palliative care needs in Australia.

NSW Health comment:

Currently palliative care data is only consistently collected in acute settings. There is no consistent data collection for community based palliative care services. Consideration could be given to developing a national palliative care minimum data set that will apply across acute, sub acute and community settings.