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WHO DEFINITION OF PALLIATIVE CARE

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.

WHAT ARE THE PALLIATIVE CARE STANDARDS?

The first edition of the Standards was developed by Palliative Care Australia (PCA, then the Australian Association for Hospice and Palliative Care) in 1994 in collaboration with the palliative care community. The Standards represented a set of philosophical standards, reflecting the need at the time to clearly articulate and promote a vision for compassionate and appropriate end of life care. The Standards have since been revised to ensure that they have kept pace with the development of palliative care services across the country and with other health service development work that has occurred over the past decade.


The national palliative care standards were developed to link with standards for national accreditation programs and are intended to be subservient and complimentary to such standards, but have not been updated to link with the National Safety and Quality Health Service Standards. Also since publication of the palliative care standards in 2005, the Australian Commission have published the National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care (ACSQHC 2015). This document is targeted to acute services, but it includes elements relevant to all services. Given that many of the elements between the consensus statement and NSAP overlap, NSAP can provide a means of assessing safety and quality against these recommendations.

Version 2 of the National Safety and Quality Health Service Standards are currently being developed. The current draft includes an expanded focus on actions relating to safe and high quality end-of-life care. Updating of the mapping between the palliative care standards and the most recent version of...
the National Safety and Quality Health Service Standards will support the use of NSAP to assess compliance with those standards.

**WHAT IS THE NATIONAL STANDARDS ASSESSMENT PROGRAM (NSAP)?**

PCA developed and implemented NSAP, which is a quality improvement program available to all specialist palliative care services across Australia. In previous years, the program provided significant support to participating services, including through education, workshops, and peer mentor programs. The current program offers a self-assessment tool to services, and provides services with reports comparing their assessed performance against peers. NSAP also offers three audit tools and provides reports to services utilising those tools.

**THIS REPORT**

This report provides an overview of services self-assessed performance against the quality elements under each of the 13 National Standards. It includes all services participating in NSAP, regardless of their service level (Level 1, 2, 3) service type (direct care, consultative care, ambulatory care), care model (paediatric, adult) or location (metropolitan, regional, rural).

Individual services should note that due to the self-assessment nature of the program, it is not possible to directly compare results to identify whether performance is at a higher or lower quality than other organisations. However, the results may support consideration of where services may like to target improvement efforts, and may also inform the development of national resources and programs, to support services in their areas of greatest need.
PARTICIPATING CENTRES

Since 2010, 178 separate centres have participated in NSAP.

NSAP is intended to be a process of continuous improvement, with this report presenting data on self-assessments submitted by participating centres. More than half of the participating centres have completed more than one cycle of self-assessment (Figure 1).

Figure 1: Cycles completed by participating centres

In addition to self-assessment cycles, NSAP provides three audit tools:

1. Documentation audit
2. Patient interview tool
3. Family evaluation tool

Data on the completion of these audits in 2014 and 2015 by services is detailed in Table 1.

Table 1: Completion of audits

<table>
<thead>
<tr>
<th>Number of services using the tool in 2014 and 2015</th>
<th>Total number of people/documents interviewed/surveyed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Documentation</td>
<td>6</td>
</tr>
<tr>
<td>Patient interview</td>
<td>6</td>
</tr>
<tr>
<td>Family evaluation</td>
<td>29</td>
</tr>
</tbody>
</table>
CYCLES COMPLETED

A total of 297 NSAP cycles have been completed by participating centres (Figure 2). Numbers declined in 2015 due to a reduction in the level of service offered under the NSAP program. Plans for 2016 to simplify the reporting arrangements along with an increased focus on high quality end-of-life care brought about by a greater focus in the draft Version 2 of the National Safety and Quality Health Service Standards may result in an increase in participation.

Figure 2: NSAP cycles completed

Participating centres are dispersed across Australia. Figure 3 shows that the highest number of cycles was completed by services in Victoria. However, the participation per capita did not vary much between jurisdictions, with the lowest participation per capita being in Queensland. In addition, two cycles were completed by services in New Zealand.

Figure 3: Participation by jurisdiction
For each Standard, participating centres rate implementation of actions to improve quality of palliative care delivery for that Standard as either a high, medium or low priority. Aggregated results from all services suggest that actions to improve Standards 1, 8 and 11 rank the highest (Figure 4). These Standards relate to patient-centred decision-making and care planning, bereavement support and commitment to quality improvement and research in clinical and management practices respectively. A more detailed review of these Standards can be found in the relevant sections.

Figure 4: Priority of improvement actions across Standards
STANDARD 1

STANDARD: CARE, DECISION MAKING AND CARE PLANNING ARE EACH BASED ON A RESPECT FOR THE UNIQUENESS OF THE PATIENT, THEIR CAREGIVER/S AND FAMILY. THE PATIENTS, THEIR CAREGIVER/S AND FAMILIES' NEEDS AND WISHES ARE ACKNOWLEDGED AND GUIDE DECISION MAKING AND CARE PLANNING.

Quality Elements

1. The patient's care plan takes into consideration the patient and family's description of their experience and needs.
2. The patient (or an appropriate surrogate) and families priorities and plans are discussed and an advance care plan is documented.
3. Variation from the documented patient preferences about care is documented and reviewed by the team.
4. Care plans accommodate the evolving needs and preferences of the patient and family.
5. The adult patient with decisional capacity determines the involvement of the family in decision-making and communication about the care plan.
6. Patients and their families are provided with up to date and appropriate information to meet their needs and support their participation in care planning and decision-making.
7. The interdisciplinary team communicates the palliative care plan with patient approval to all involved health professionals when patients transfer to different care settings.

Self-assessed performance against the quality elements of Standard 1 was strong, with most quality elements being performed by most services always or often. Quality element 2, relating to the documentation of an advance care plan was less consistently applied across services than other elements. 14% of participating services rarely or never achieved this element.

37% of services rated this Standard as a priority for their improvement actions – the highest of any of the Standards. Therefore, when considering development of resources and training programs, focus on the elements in this Standard may be most beneficial.

Figure 5: Performance against Standard 1
STANDARD 2

THE HOLISTIC NEEDS OF THE PATIENT, THEIR CAREGIVER/S AND FAMILY ARE ACKNOWLEDGED IN THE ASSESSMENT AND CARE PLANNING PROCESSES, AND STRATEGIES ARE DEVELOPED TO ADDRESS THOSE NEEDS, IN LINE WITH THEIR WISHES.

Quality Elements

1. The first assessment is interdisciplinary, coordinated and documented.
2. Treatment and care are individualised with consideration of the patient’s needs and preferences (physical, social, emotional, cultural and spiritual).
3. The assessment of the patient and family expectations includes preferences for the type and place of care and these are documented.
4. The patient assessment is reviewed and updated on a regular basis based on patient condition and need.
5. Validated clinical assessment tools are used where they are available.
6. There are arrangements in place that support Level 1 and 2 services to achieve improved outcomes for patients (Level 3 services only).

Services performed highly against quality elements 2, 3 and 4, with aggregated ratings suggesting these elements are achieved by over 80% of services always or often. This supports the premise that specialist palliative care services have expertise in the provision of patient-centred care. It also suggests that in spite of more variable performance in completing advance care plans (Standard 1), services do document patient and family preferences for the type and place of care.

Only around 65% of participating services are using validated clinical assessment tools when available all or most of the time. Identification of barriers to the use of such tools may be warranted to enable services to utilise such tools more readily.

Figure 6: Performance against Standard 2
STANDARD 3

ONGOING AND COMPREHENSIVE ASSESSMENT AND CARE PLANNING ARE UNDERTAKEN TO MEET THE NEEDS AND WISHES OF THE PATIENT, THEIR CAREGIVER/S AND FAMILY.

Quality Elements

1. The regular assessment of pain and other symptoms (including but not limited to shortness of breath, nausea, fatigue and weakness, anorexia, insomnia, anxiety, depression, confusion and constipation) is documented in the patient record. Validated instruments, where available, should be used to undertake clinical assessment.

2. Validated instruments are used to undertake clinical assessment (cross reference with 2.5).

3. Response to patient reports of symptom related distress is timely and actions are documented.

4. Regular re-evaluation of the effectiveness of treatment is undertaken and includes patient and family feedback. Results are documented.

5. Patient phase changes are assessed and documented.

6. The family's understanding of the patient's condition is routinely assessed and documented.

7. The capacity of the family to secure supports required to meet their needs is routinely assessed.

Services performed quite highly in the assessment and documentation of symptoms (elements 1 and 3). However, a lower proportion of services consistently used validated instruments to undertake clinical assessment (element 2), assessed and documented phase changes (element 5) and assessed and documented the families understanding of the patient’s condition (element 6). There seems to be a marked improvement on all quality elements against this standard over the reporting period.

Figure 7: Performance against Standard 3
STANDARD 4

CARE IS COORDINATED TO MINIMISE THE BURDEN ON THE PATIENT, THE CAREGIVER/S AND FAMILY.

Quality Elements

1. The assessment process and care plan reflect a coordinated approach to care delivery that will ensure continuity of care across all required care settings.
2. There are formal agreements in place with other service providers which clearly set out the protocols, policies, procedures and guidelines that will support quality care at the end of life.
3. Referrals are made to appropriate services to meet the identified social needs of the patient and family. These may include access to services that provide for example:
   - help in the home,
   - help at school or work
   - assistance with transportation
   - rehabilitation,
   - counselling, and/or
   - equipment
4. There is an identified care coordinator (e.g. lead agency or clinician) who takes responsibility for the overall plan of care.
5. Discharge plans and/or plans for referral to another organisation are discussed with the patient and family to ensure they accommodate their needs and wishes.

In the most part, services performed very highly across the elements of Standard 4. This suggests that specialist palliative care services may be well equipped to provide coordinated care, and a true inter-disciplinary approach to care for people at the end of their lives. Performance was least consistent for element 2, which refers to the establishment of formal agreements with other services providers to support care coordination. However, the lower priority rating for this Standard (15% rate it as a high priority) suggests that services may not consider formal arrangements necessary.

Figure 8: Performance against Standard 4
STANDARD 5

THE PRIMARY CAREGIVER/S IS PROVIDED WITH INFORMATION, SUPPORT AND GUIDANCE ABOUT THEIR ROLE ACCORDING TO THEIR NEEDS AND WISHES.

Quality Elements

1. The assessment of carers identifies their needs, their desired level of involvement and their ongoing willingness and ability to participate in the provision of care.
2. Carers are provided with up to date information and resources that are adapted to meet their needs and that inform their participation in care planning and delivery.
3. The provision of patient related information to caregivers is consistent with:
   - the consent and wishes expressed by the patient, or previously specified wishes should the patient no longer be capable of providing such consent,
   - the current amendment of the Commonwealth Privacy Act 1988,
   - relevant state and territory privacy legislation.
4. Effective networks are established with support services to meet the carer’s needs. (Cross reference to 4.2)
5. Carers have adequate support and information to manage emergency and out-of-hours situations.

Around 75% of services always or often achieve elements 1 and 2 of this Standard, which requires assessment of carer’s needs and willingness to be involved in the provision of care, and the provision of information and resources to carers to support their role in care planning and delivery. Only 6% of services rarely or never achieve these elements. However, there is room to improve consistency of the achievement of these elements within those services that achieve these only sometimes.

Of interest, there was not strong correlation between those 20% of services that rated this as a high priority for improvement, and those services that only achieved these elements sometimes or rarely. Carers provide a large component of care at the end of life, and are important in increasing the rate of deaths at home, where this aligns with the patient and families wishes. Communication of the importance of supporting carers is necessary to ensure that carers are able to participate in the care of their family member wherever they are willing and able to do so.

Figure 9: Performance against Standard 5
STANDARD 6

THE UNIQUE NEEDS OF DYING PATIENTS ARE CONSIDERED, THEIR COMFORT MAXIMISED AND THEIR DIGNITY PRESERVED.

Quality Elements

1. The concerns, hopes, fears and expectations of the patient are addressed openly and honestly in a way that is appropriate for their age, culture and social situation.
2. The care plan is revised when the patient is assessed as in the terminal phase to reflect the needs of the patient and family.
3. There are timely and appropriate clinical responses to patients who experience distressing symptoms.
4. Patient and family wishes regarding the care setting for the death are documented.
5. Any inability to meet these preferences is reviewed by the team.
6. The family is educated regarding the signs and symptoms of approaching death, in a way that is appropriate for their age, culture and social situation.
7. Plans are in place for the certification of death, including plans for certification after hours.
8. There are processes in place to respond to the need for urgent assessment and guidance for Primary Care, Level 1 and 2 services caring for patients at the end of life (Supplementary element for Level 2 and 3 services).

Performance against Standard 6 is very strong. While the achievement of 96% of services always or often implement a timely and appropriate clinical response to patients who experience distressing systems, supporting those services who are not achieving this level of service is important given the importance of this element in the high quality delivery of end-of-life care.

Figure 10: Performance against Standard 6
STANDARD 7

THE SERVICE HAS AN APPROPRIATE PHILOSOPHY, VALUES, CULTURE, STRUCTURE AND ENVIRONMENT FOR THE PROVISION OF COMPETENT AND COMPASSIONATE PALLITIVE CARE.

Quality Elements

1. The organisation has a written philosophy and objectives which are incorporated into clinical practice.
2. When appropriate care is provided in the setting preferred by the patient and their family.
3. The care setting provides an appropriate environment to support patient and family interaction and comfort. This should include as a minimum privacy, flexible or open visiting hours, and space for families to visit.
4. The care setting provides a safe environment for patients, families and staff.
5. The national palliative care standards form part of the organisation’s education and training program.

Performance against Standard 7 was strong, with 2015 being the year in which most elements were applied most consistently by services. 92% of services assess their service as always or often providing appropriate care in the setting preferred by the patient and their family. Studies suggest that in Australia, most patients wish to die at home, while only 14% of people do so. It may be valuable to compare the rate of achievement of home deaths supported by specialist palliative care services compared with other services, and also to compare the patient’s wishes with regard to place of death for those patients that have access to specialist palliative care compared to those that do not. This may provide information about whether specialist palliative care services are providing an environment that is more acceptable to patients at the end of their lives than non-specialist services.

Element 5 is not consistently achieved by services. This element is the incorporation of the national palliative care standards into the organisation’s education and training programs. However, given only 13% of services rank this standard as a high priority for improvement actions (the lowest proportion of all standards), it may be that services do not consider this a barrier to delivering a high quality service.

Figure 11: Performance against Standard 7
STANDARD 8

FORMAL MECHANISMS ARE IN PLACE TO ENSURE THAT THE PATIENT, THEIR CAREGIVER/S AND FAMILY HAVE ACCESS TO BEREAVEMENT CARE, INFORMATION AND SUPPORT SERVICES.

Quality Elements

1. The organisation has policies and procedures that guide its bereavement support program.
2. The interdisciplinary team includes professionals with culturally appropriate education and skills to meet the needs of the service's patients and their families when they experience loss, grief and bereavement.
3. Families are clinically assessed to identify those at risk of complicated grief and bereavement.
4. Clinical assessment is undertaken to identify those family members suffering depression, anxiety and sadness associated with loss, grief or bereavement.
5. The family's need for support is reassessed on an ongoing basis, including after the death of the patient.
6. Culturally appropriate information and resources about loss, grief and the availability of bereavement support services is routinely available to families before and after the death of the patient.
7. The staff and volunteers involved in bereavement support undergo a formal education program and are provided with support in their role.
8. Referrals to specialist mental health and counselling professionals are made when clinically indicated.
9. The service provides education to primary care and Level 1 specialist palliative care services and the community about loss, grief and bereavement (supplementary element for Level 2 services).
10. The service provides support to primary care, Level 1 and 2 specialist palliative care services and their patients who are at risk of complicated bereavement (supplementary element for Level 3 services).
Standard 8 is inconsistently applied by many participating services, with performance dipping below 50% of services achieving some of the elements all or most of the time. 18% of services rarely or never assess family members to identify those at risk of complicated grief and bereavement and 25% of services rarely or never provide staff with access to formal education and support for their role in bereavement support.

Family-centred care is a key principle of the delivery of palliative care, encompassing supporting the family to cope during the patient’s illness and in their bereavement. 36% of services rated implementation of improvement actions for this standard as a high priority. The performance against this standard indicates a need to continue to ensure that services are provided with sufficient resources to support their delivery of bereavement support, as a core component of the delivery of high quality palliative care.

Figure 12: Performance against Standard 8


STANDARD 9

COMMUNITY CAPACITY TO RESPOND TO THE NEEDS OF PEOPLE WHO HAVE A LIFE LIMITING ILLNESS, THEIR CAREGIVER/S AND FAMILY IS BUILT THROUGH EFFECTIVE COLLABORATION AND PARTNERSHIPS.

Quality Elements

1. The organisation participates in the development and delivery of community capacity building initiatives.
2. The organisation participates in the promotion and support of local and national palliative care awareness initiatives.
3. The organisation has established links with other services providers and relevant community and government organisations.
4. The organisation has in place mechanisms to assess the needs of the community they serve.
5. Patients, families and the community are provided with opportunities to provide input into the evaluation of the service.
6. Community involvement in education programs, service development and evaluation is planned and formalised (supplementary element for Level 2 and 3 services).

Performance against element 3 of Standard 9 is consistently achieved across most services, with most organisations having established links with other service providers and relevant government and community organisations. However, performance against those elements requiring actions within the community, including development of community capacity (element 1), palliative care awareness initiatives (element 2), assessment of community needs (element 4) and involvement in community programs (element 6) are not implemented consistently by a large proportion of participating services.

Many services also struggle with providing patients, families and the community opportunity to provide input to the evaluation of the service (element 5), with only 54% of services doing this all or most of the time, and 24% of services doing this rarely or never. Supporting services to improve against this element will become increasingly important as revised versions of the National Safety and Quality Health Service Standards are likely to increase requirements on consumer participation in the development and evaluation of services.

Figure 13: Performance against Standard 9

![Standard 9 Performance Chart]
STANDARD 10

ACCESS TO PALLIATIVE CARE IS AVAILABLE FOR ALL PEOPLE BASED ON CLINICAL NEED AND IS INDEPENDENT OF DIAGNOSIS, AGE, CULTURAL BACKGROUND OR GEOGRAPHY.

Quality Elements

1. The service supports and promotes continuity of care across settings and throughout the course of the patient's illness.
2. Referral policies are clear, applied consistently and result in non-discriminatory access to services based on clinical need.
3. Policies for prioritising and responding to referrals in a timely manner are documented.
4. The profile of population accessing the service is compared with those in the community and inequities of access addressed.
5. Where demand for palliative care services exceeds available capacity, there are strategies in place with other organisations to meet consumer needs.
6. The organisation has mechanisms in place to regularly assess unmet need in the community and provide estimates future need.
7. Patients and families have access to palliative care expertise and staff 24 hours per day, seven days per week.
8. Respite care services are available for the families and caregivers of patients.
9. Policies and procedures are in place to ensure respect and responsiveness to community diversity.
10. The service can accommodate the language, dietary and ritual practices of patients and their families.
11. The team has access to and utilises appropriate interpreter services as required.
Services consistently applied activities to support continuing of care across settings throughout the course of the patient’s illness (element 1). However, as with Standard 9, elements where the service is expected to engage with the broader community to assess needs are performed less consistently (elements 4 and 6).

Another area for future focus is access to respite services for patients and families. While only 64% of services stated that such services are made available all or most of the time, only 10% of services are rarely or never able to provide access to such services, with a large proportion being able to provide access to respite some of the time.

**Figure 14: Performance against Standard 10**
STANDARD 11

THE SERVICE IS COMMITTED TO QUALITY IMPROVEMENT AND RESEARCH IN CLINICAL AND MANAGEMENT PRACTICES.

Quality Elements

1. There is regular and systematic measurement, analysis, review, evaluation, goal setting and revision of the processes and outcomes of care provided by the program.
2. Quality improvement activities are routine, regular, reported and are shown to influence patient and family outcomes.
3. The clinical practices of the service reflect the integration and dissemination of research and evidence of quality improvement.
4. The views of patients and carers are incorporated into quality improvement activities.
5. There is robust and rigorous clinical audit review.
6. The service participates in benchmarking processes that support sustainable quality improvement within the organisation.
7. The service participates in external benchmarking processes (supplementary element for Level 2 and 3 services).

Performance against Standard 11 was less consistent between organisations, with a high proportion of participating services rarely or never achieving some of the quality elements (>20% of services for elements 4, 5 and 6). This is of particular concern given this is a rating of services that have chosen to participate in the NSAP program, suggesting they have a fairly high level of commitment to assessing and improving quality. The organisational elements outlined in the National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care (ACSQHC 2015) reiterate the importance of structural and organisational support in the delivery of safe and high quality end-of-life care, and further promulgation of this consensus statement as well as revisions to the National Safety and Quality Health Service Standards may go some way to improving activity against this Standard. 29% of services identified this standard was a high priority for improvement activities.

Figure 15: Performance against Standard 11
STANDARD 12

STAFF AND VOLUNTEERS ARE APPROPRIATELY QUALIFIED FOR THE LEVEL OF SERVICE OFFERED AND DEMONSTRATE ONGOING PARTICIPATION IN CONTINUING PROFESSIONAL DEVELOPMENT.

Quality Elements

1. The service employs health professionals with the appropriate qualifications, credentialing and experience to meet the physical, psychological, asocial, cultural and spiritual needs of both patients and family.
2. Staff in clinical leadership and management positions have recognised qualifications and experience in relevant fields.
3. Formal training needs assessment is undertaken for all members of the multidisciplinary team to identify education and training needs.
4. Training and professional development are accessible to staff.
5. Continuing professional education incorporating the national palliative care standards is regularly provided to staff and participation is recorded.
6. Policies and procedures are in place to guide recruitment, screening, training, work practices, support, supervision and performance evaluation of volunteers if they participated in the service.
7. Volunteer services are coordinated and supervised by an appropriately educated and experienced professional team member.

Services assessed the qualifications and experience of staff as appropriate in the majority of services (elements 1 and 2), and also performed quite highly on providing access to training and professional development (element 4), with less than 2% of services stating they rarely or never are provided access to training and development. However, performance was less consistent with regard to including the national palliative care standards into continuing professional education with significant deterioration from previous years to 2015. Some services have work to be done on management of volunteers, but some services have commented this is because they do not have volunteers. Over 50% of services rated this standard as a low priority for improvement activities.

Figure 16: Performance against Standard 12
STANDARD 13

STAFF AND VOLUNTEERS REFLECT ON PRACTICE AND INITIATE AND MAINTAIN EFFECTIVE SELF-CARE STRATEGIES.

Quality Elements

1. There are procedures in place to identify and respond to critical incidents. Critical incident procedures focus on system enhancements, not on blame for individuals.
2. Employee assistance programs and/or counselling services are available to staff and volunteers to meet their identified needs.
3. There are education programs in place to enable staff and volunteers to develop effective coping strategies.
4. The service encourages staff and volunteers to make use of available supports, whether formal or informal.

100% of services in 2015 always or often had procedures in place to identify and respond to critical incidents and to provide assistance such as counselling to staff. However, only 50% of services always or often had education programs in place to support staff and volunteers to develop effective coping strategies. Performance was even less consistent across paediatric services, which is surprising given that the impact on staff may be greater due to the longer timeframe for engagement with the families. 22% of all services and 29% of paediatric services rarely or never provided education to assist staff develop coping strategies.

Figure 17: Performance against Standard 13