Standards for Providing Quality Palliative Care for all Australians

Standard 1
Care, decision-making and care planning are each based on a respect for the uniqueness of the patient, their caregiver/s and family. The patient, their caregiver’s and family’s needs and wishes are acknowledged and guide decision-making and care planning.

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.

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.

Standard 4
Care is coordinated to minimise the burden on patient, their caregiver/s and family.

Standard 5
The primary caregiver/s is provided with information, support and guidance about their role according to their needs and wishes.

Standard 6
The unique needs of dying patients are considered, their comfort maximised and their dignity preserved.

Standard 7
The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care.

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.

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.

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.

Standard 11
The service is committed to quality improvement and research in clinical and management practices.

Standard 12
Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.

Standard 13
Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies.
The Standards and Quality Improvement in End of Life Care

The Palliative Care Standards provide a common 'language' that can be used by services, planners and researchers to describe quality in the provision of end of life care. The thirteen Palliative Care Standards collectively set out the essential components of quality that should be present in the care of patients at the end of their life, regardless of their age, sex, diagnosis, geography, culture or socio-economic status. Each standard describes, by service type (ie primary or specialist) the essential criteria that must be present in order to demonstrate performance against the standard.

The Standards also integrate a basic set of patient rights - for respect, person and family centred care, pain and symptom relief, choice and involvement in decision-making - that must be met to ensure quality of care.

Because they establish and define the essential characteristics of quality, the Standards have an important role in guiding and informing quality improvement programs and activities at the system, service and clinical level. The Standards can also be used to inform performance management, clinical research and service evaluation projects and activities, and can be integrated into service accreditation processes and programs.

The Standards, or even individual criteria of the Standards, can be used to guide quality improvement activities within a unit or service. For example, 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’ might guide a continuous quality improvement project around patient assessment, or inform a study that examines the extent to which patients and their families are included in care planning.

The Standards can also be used together, as a comprehensive set of ‘critical’ elements of quality for the purposes of accreditation or service evaluation.

End of life care, whether it is provided by a primary care provider or a specialist palliative care unit is complex and multi-faceted. Goals of care have to be individualised for all patients, and commonly held assumptions about quality of care and indeed quality of life may not hold true for patients who are dying.

Simple measures of effectiveness or quality will not capture this requirement for individualisation, nor will they be sufficiently sensitive to measure the complex interactions that constitute effective end of life care. It is far more likely that qualitative methods, such as surveys, focus groups, audits, peer review and observation will produce useful information to support quality improvement activities.

A brief overview of some of these methods is provided below.

Survey

Survey methods, such as a patient or staff questionnaire (for example see Tool 1) can provide useful information about patients’ perceptions of the extent to which a service meets established standards of quality. In end of life care, patient and family/caregiver questionnaires or surveys can be used to better understand the extent to which they have felt included in decision-making and care planning (Standards 1 & 2), or to assess the availability and relevance of information provided to patients (Standard 5). There is an increasing range of validated survey tools available in the public domain to support quality activities in end of life care. The use of a validated...
Survey tool increases the reliability of analysis and evaluation and enables comparison of outcomes with similar studies undertaken using the same tool.

Issues to consider when choosing a survey tool:

- What kind of information do you want to gather? Does the survey instrument cover all the areas of interest? Are you interested in the patients’ total experience or a more specific element/experience?
- Who do you want to ask to complete the survey? Do you wish to survey patients, their families, staff or the general community? How many people will you ask to complete the survey?
- What time frame would the information being sought cover? Are you interested in this admission, last week, since diagnosis?

**Using survey tools to gather evidence of performance**

Survey is an effective method of obtaining information to support an evaluation of performance using the Standards as the framework for defining quality. Survey type approaches to gathering information are especially useful to collect patient, family and caregiver perspectives. Some examples of questions linked to the Standards that may be answered using survey methods/tools include:

- caregiver and family access to bereavement support and information (Standard 8)
- perceived responsiveness of the service to caregiver needs (Standard 5)
- the patient and their family’s satisfaction with the achievement of their goals for care at the end of life (Standards 1, 2, 6)
- the patient and their family’s experience with regard to the coordination of care and its contribution to their overall level of burden (Standard 4)
- assessing community capacity with regard to the support of people at the end of life (Standard 9).

Survey may be one useful way of collecting information to support self-evaluation using the Standards as a framework for designing, conducting and analysing quality data. Surveys can also provide useful evidence to demonstrate, for the purposes of performance, evaluation or accreditation, the extent to which a service meets the Standards.

**Focus Groups**

Quality is about meeting and, if possible, exceeding patients’, caregiver’s and family’s needs. Focus groups are one way that services can obtain specific or more in-depth information than can be gathered via survey or individual interview type techniques.

Focus groups may be useful, for example, to explore the needs and experiences of caregivers (Standards 1, 2, 3, 4, 5, 7, 9, 10), or to obtain information about different cultural groups and their specific needs at the end of life (Standards 1, 2, 3, 4, 5, 6, 7, 8, 9, 10).

Some of the key points to remember when conducting a focus group are:

- Establish some simple ‘rules’ with participants before starting the focus group session. This makes it easier to maintain control, to ensure that all members get an opportunity to contribute (it may be the quieter person who has a really important point to make) and to cover all the topics. These ‘rules’ might include:
  - all members should be treated with respect
  - no person should speak at the same time as another
  - all members to be allowed to speak
• people should say what they think or believe, not what they think someone wants to hear
• there are no right or wrong answers
• individuals should speak for themselves only and not on behalf of others.

Commence with an easy, positive, general question, for example:
• What was the most positive experience while your ....... was a patient in this unit?
• How can the service provide better care and support for people in your community?

Continue with approximately 4-5 set questions which will stimulate discussion, for example:
• What did you like about the service?
• What would you like to change?
• What kind of information would you have liked to receive?
• How can our service support members of your community who want to remain at home?

These types of questions generally stimulate a great deal of discussion and result in a large amount of information. It is best to tape focus group sessions so that a record of all that is said can be obtained for later analysis and evaluation. It is difficult to record via notes all the detailed information and comments.

Focus group methods can be used to explore with staff, patients, family members, and specific groups within the community, areas that are not open to either observation or other forms of direct or even indirect measurement. Focus groups can provide useful qualitative data to support practice improvement and to evaluate service quality.

Audit
Audit involves a process of assessment of performance against specific and established criteria. Service and clinical audit can provide a useful indication of the overall performance of a service in defined quality and priority areas. These areas have been established and expressed within the palliative care Standards. Audit can assist a service or team to identify those areas of performance that meet quality standards and also those where there may be gaps in the service/team’s overall performance.

Auditing service processes or clinical care can be a useful tool as part of self-assessment of a service or unit’s performance against the Standards. Chart audit can identify gaps in the coordination of care (Standard 4), the comprehensiveness of the admission assessment (Standard 2) or access to bereavement services (Standard 8).

The Palliative Care Service Self Assessment Tool (Tool 7) is a service audit tool that assesses service/team performance across a range of key functions and areas. It is an example of an audit tool and responses in single areas could be used to provide evidence of performance against the Standards.

Observation
Much can be understood about the quality of care provided through the use of simple observational techniques. The collection of this information assists in developing a knowledge base to support quality assessment and improvement activities. Caring for people at the end of life, whether this occurs in hospital, at home, in a residential aged care facility or in a specialist palliative care unit is complex and not easily measured or assessed. In fact for many areas critical to quality (ie respect for the individuality of the patient), observation of direct care over many
interactions may be the only way to collect meaningful information about quality of care. There may be no written records to review, for example in the patient’s medical record, of the complex interpersonal relationships between patients and their professional caregivers that have much to do with what is described as ‘good’ in relation to end of life care. Direct observation, combined with information, for example patient satisfaction survey data, is often the most reliable way of evaluating the actual performance of caregivers (for example, observing for compliance with procedures or assessing the involvement of caregiver’s in care planning and assessment). Observational studies can also be used to assess competency of staff, especially in those areas that require behavioural as well as technical skill.

Observation based techniques usually utilise tally sheets or checklists of some sort to ensure that a consistent record of observation is maintained. Observation may also be used in conjunction with other tools, particularly those used to gather information on patient satisfaction or perceptions (eg focus groups, patient interviews and satisfaction surveys). In this way there is a capacity to gain an understanding of not only what is happening (ie through observation) but also why it happens and how it is perceived or evaluated by those involved, including patients and their families.

There are a number of important things to take into consideration when undertaking an assessment based on observation:

• Prepare for observations carefully. Clearly identify what is being observed and what you are looking for. The Standards and the specific elements can be used to construct an observational ‘checklist’ based on key quality areas.

• Ensure information is collected in a systematic and consistent manner an observation schedule should be used. This provides clear instructions to the observer as to what is to be observed and the categories in which observations are to be placed. It also allows for a plan to observe the process at different times/situations.

• The observer should take care to maintain confidentiality by not discussing observations with others or by leaving notes around.

• The observer should try to be inconspicuous when observing and not take notes in front of those being observed.

• The observer should always remain neutral in any dispute witnessed.

• The observer should include their own reactions to what is observed in the data recorded, to later reflect on how other people may have been feeling at the time of observation.

Observation based methods can be used to assess performance relative to Standards 1-4, and Standard 6

Measuring patient/family/caregiver satisfaction

Patient satisfaction is one measure of their overall evaluation of the quality of the care and treatment they received at the end of life.

Patient satisfaction is a concept used widely to measure quality within the health care system. In spite of its widespread use, there still exists considerable debate around the concept of satisfaction and its validity as a measure of quality. It is increasingly obvious that satisfaction is a complex concept that is influenced to a great degree by a person’s personal history, values, expectations and personal circumstances. Whether patient satisfaction is a valid unitary concept or not, a fundamental goal for the use of patient satisfaction as one of a number of measures of quality of care, is to obtain a patient/family/caregiver perspective and feedback.
Some key considerations for the use of patient satisfaction as a quality indicator are set out below:

- Patient satisfaction assessment should be conducted at regular intervals as expectations and community values may shift.
- The principle purpose should be to identify the patient’s (or family’s/caregiver’s) perspective on the quality of care.
- Satisfaction surveys should be used in conjunction with other quality information and data to evaluate performance against the Standards.
- Satisfaction is a complex concept aligned with one or more facets of quality. Satisfaction on its own does not indicate the overall level of quality of a service, process or function.

Satisfaction can be assessed as either a global indicator of quality (Were you satisfied with the care you received while a patient of our service?) or in focused areas, depending on the purpose and scope of the evaluation.

Some areas where patient satisfaction indicators are useful include:

- assessing communication – how, when information was provided (written and verbal)
- responsiveness to patient/family/caregiver needs – responsiveness to calls for assistance, recognition and assessment of needs etc
- impact of the physical environment – an important area in the care of patients who are dying as family often wishes to remain in close proximity, access to family areas etc
- planning for discharge – adequacy of discharge plans, involvement of family in discharge planning, coordination of care, availability of services
- continuity of care – coordination of care, transfer between care settings, communication between various professional caregivers
- empathy – caring attitudes of staff, individual attention and expressed compassion
- outcome of care – meeting patient/family/caregiver expectations.

Patients, their families and caregivers can also be surveyed as to their satisfaction with the accessibility of services and the range of services provided, enabling a patient perspective to be introduced into the service planning level.
This section contains a small number of tools that have been developed to support quality improvement and evaluation in end of life and palliative care. We have also included in this Section and later in Section 8 further resources, links and information on a range of other assessment and evaluation tools and methods.

It is important to choose the right method and the most appropriate tools for a given study or project. Evidence of performance against the Standards can be collected and assessed in any number of ways. Standard 1 for example, can be demonstrated by providing evidence of patient involvement in care planning or by examining the components of the admission and assessment process to ensure they facilitate assessment of the unique needs of individual patients. All of the Standards can be demonstrated in a number of ways, depending on which element is of interest, or according to the context in which it is being studied.

The Standards can be used to help define a quality problem, to inform the analysis of service or clinical data, to establish a goal or objective for service improvement initiatives or to shape a service review or audit.

The following eight tools have been provided as a ‘start-up’ kit for services wishing to undertake a quality improvement project. The full details of the source of each of the tools are provided, along with instructions on how to administer/use the tool and advice if necessary on the interpretation or evaluation of results. The tools can be found at the end of this section.

<table>
<thead>
<tr>
<th>Tool</th>
<th>Palliative care outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Patient experiences – patient questionnaire</td>
</tr>
<tr>
<td>2</td>
<td>Patient experiences – staff – questionnaire</td>
</tr>
<tr>
<td>3</td>
<td>Carer experiences with palliative care</td>
</tr>
<tr>
<td>4</td>
<td>Community awareness of palliative care</td>
</tr>
<tr>
<td>5</td>
<td>Community Awareness, Remote Aboriginal and Torres Strait Islander Communities</td>
</tr>
<tr>
<td>6</td>
<td>Palliative Care providers</td>
</tr>
<tr>
<td>7</td>
<td>Palliative Care Service Self Assessment</td>
</tr>
<tr>
<td>8</td>
<td>General health care organisational survey about palliative care</td>
</tr>
</tbody>
</table>

In addition to these tools the table following (Table 1) sets out a number of further tools that have been developed by researchers for evaluating different elements of end of life care. The full reference details have been given for each of the tools listed in Table 1. Access to information and other tools can be found later in Section 8 of the guide.
TABLE 1: Tools for evaluating elements of end of life care

<table>
<thead>
<tr>
<th>Domain</th>
<th>Tool</th>
<th>Reliability &amp; Validity reported</th>
<th>Mode of Administration</th>
<th>No of items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance care planning</td>
<td>Toolkit of Instruments to Measure End of Life Care – Bereaved Family Member Interview¹</td>
<td>Y</td>
<td>Interview administered</td>
<td>7 items</td>
</tr>
<tr>
<td>Caregiver well-being</td>
<td>Caregiver Strain Index²</td>
<td>Y</td>
<td>Interview administered</td>
<td>13 items</td>
</tr>
<tr>
<td>Continuity of care</td>
<td>Picker Commonwealth Single Item³</td>
<td>Y</td>
<td>Self administered</td>
<td>Single item</td>
</tr>
<tr>
<td></td>
<td>McCusker Scale⁴</td>
<td>Y</td>
<td>Interview administered</td>
<td>4 items</td>
</tr>
<tr>
<td></td>
<td>Chao Patient Perception⁵</td>
<td>Y</td>
<td>Mailed survey/chart audit</td>
<td>23 items</td>
</tr>
<tr>
<td>Emotional symptoms</td>
<td>Profile of Mood States⁶</td>
<td>Y</td>
<td>Interview administered</td>
<td>11 items</td>
</tr>
<tr>
<td></td>
<td>Memorial Symptom Assessment Scale⁷</td>
<td>Y</td>
<td>Self administered</td>
<td>23 items</td>
</tr>
<tr>
<td></td>
<td>Rand Mental Health Inventory (MHI-5)²</td>
<td>Y</td>
<td>Self administered</td>
<td>5 items</td>
</tr>
<tr>
<td>Functional status</td>
<td>Barthel Index⁹</td>
<td>Y</td>
<td>Self administered</td>
<td>10 items</td>
</tr>
<tr>
<td></td>
<td>FIM Instrument¹⁰</td>
<td>Y</td>
<td>Interview administered</td>
<td>18 items</td>
</tr>
<tr>
<td>Grief &amp; bereavement</td>
<td>Grief Resolution Index¹²</td>
<td>Y</td>
<td>Interviewer or self administered</td>
<td>7 items</td>
</tr>
<tr>
<td></td>
<td>Anticipatory Grief Scale¹²</td>
<td>Y</td>
<td>Self or interviewer administered</td>
<td>27 items</td>
</tr>
<tr>
<td>Physical symptoms</td>
<td>McGill Pain Questionnaire¹³</td>
<td>Y</td>
<td>Self or interviewer administered</td>
<td>11 items</td>
</tr>
<tr>
<td></td>
<td>Edmonton Symptom Assessment Scale¹⁴</td>
<td>Y</td>
<td>Self administered or proxy administered</td>
<td>9x 100mm visual analogue scales</td>
</tr>
<tr>
<td>Quality of life</td>
<td>McGill Quality of Life Questionnaire¹⁵</td>
<td>Y</td>
<td>Self administered</td>
<td>17 items</td>
</tr>
<tr>
<td></td>
<td>Missoula-VITAS QOL Index¹⁶</td>
<td>Y</td>
<td>Self administered</td>
<td>27 items</td>
</tr>
<tr>
<td></td>
<td>EORTC (QLQ C-30)¹⁷</td>
<td>Y</td>
<td>Self administered</td>
<td>30 items</td>
</tr>
<tr>
<td></td>
<td>FACT/FACIT (Fact-G)¹⁸</td>
<td>Y</td>
<td>Self administered</td>
<td>27 items</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>Medical Outcomes Study-Satisfaction survey¹⁹</td>
<td>Y</td>
<td>Self administered</td>
<td>21 items</td>
</tr>
<tr>
<td></td>
<td>FAMCARE¹⁰</td>
<td>Y</td>
<td>Interview administered</td>
<td>20 items</td>
</tr>
<tr>
<td>Spirituality</td>
<td>Meaning in Life scale¹¹</td>
<td>Y</td>
<td>Interview administered</td>
<td>15 items</td>
</tr>
<tr>
<td></td>
<td>Spiritual Well-being Scale²²</td>
<td>Y</td>
<td>Self administered</td>
<td>20 items</td>
</tr>
<tr>
<td></td>
<td>Death Attitude Profile¹³</td>
<td>Y</td>
<td>Self administered</td>
<td>21 items</td>
</tr>
</tbody>
</table>

The following eight tools have been provided as a ‘start-up’ kit for services wishing to undertake a quality improvement project. The full details of the source of each of the tools are provided, along with instructions on how to administer/use the tool, and advice if necessary on the interpretation or evaluation of results.
Evaluation Tools 1 & 2

Purpose
These tools are based on the Patient Outcome Scale (POS). The original POS was devised following a systematic review of outcome measures used in palliative care. This review concluded that there was a paucity of clinical questionnaires that could adequately reflect the holistic nature of palliative care. The POS was designed to overcome some of the limitations associated with existing outcome measurement scales in palliative care. It evolved using a literature review of measures, work by a multi-professional project group with individuals who worked in different palliative care settings and a patient representative. The POS was then piloted in hospice, home, hospital and other community settings. The questionnaire covers: physical symptoms, psychological symptoms, spiritual considerations, practical concerns, emotional concerns and psychosocial needs.

How should these tools be used?
These tools could be used by projects with a focus on improving the outcomes for palliative care in an active phase of their engagement with a service provider. However, it should only be used by those projects with a suitable level of ethical approval for administering the questions to patients under the care of a palliative care service.

How to administer these tools?
There are two versions of the questionnaire, one for patients to complete (Evaluation Tool 1) and the other for staff (Evaluation Tool 2). It is a flexible tool, the usage of which can be determined by the needs of local services. It has also been shown to be a credible clinical, research and audit tool, which is acceptable to both patients and staff. The POS can be used routinely to guide clinical practice and monitor service interventions. Moreover, the POS is a valuable audit tool that can help meet the current statutory requirements on clinical governance.
Evaluation Tool 1
Palliative Care Outcomes Patient Questionnaire

About you

Your sex
☐ Male
☐ Female

Your age

Do you identify as Aboriginal or Torres Strait Islander?
☐ Yes
☐ No

Do you identify with a particular ethnic origin or cultural background?
☐ Yes
☐ No

If yes, please specify your ethnic origin or cultural background:

About how you have been feeling

Please answer the following questions by ticking the box next to the answer that is most true for you. Should you require assistance in filling in this form, feel free to ask someone to help you. Your answers will help us to keep improving your care and the care of others. Thank You.

1 Over the past 3 days, have you been affected by pain?
☐ Not at all no effect
☐ Slightly – but not bothered to be rid of it
☐ Moderately – pain limits some activity
☐ Severely – activities or concentration markedly affected
☐ Overwhelmingly – unable to think of anything else

2 Over the past 3 days, have other symptoms (eg feeling sick, having a cough or constipation) been affecting how you feel?
☐ Not at all
☐ Slightly
☐ Moderately
☐ Severely
☐ Overwhelmingly

3 Over the past 3 days, have you been feeling anxious or worried about your illness or treatment?
☐ Not at all
☐ Occasionally
☐ Sometimes – affects my concentration now and then
☐ Most of the time – often it affects my concentration
☐ Can’t think of anything else completely preoccupied

4 Over the past 3 days, have any of your family or friends been anxious or worried about you?
☐ Not at all
☐ Occasionally
☐ Sometimes – it seems to affect their concentration
☐ Most of the time
☐ Yes, always preoccupied with worry about me

5 Over the past 3 days, how much information have you and your family or friends been given?
☐ Full information – always feel free to ask what I want
☐ Information given but hard to understand
☐ Information given on request but would have liked more
☐ Very little given and some questions were avoided
☐ None at all

6 Over the past 3 days, have you been able to share how you are feeling with your family or friends?
☐ Yes – as much as I wanted to
☐ Most of the time
☐ Sometimes
☐ Occasionally
☐ Not at all with anyone
7 Over the past 3 days, have you been feeling depressed?

- No, not at all
- Occasionally
- Sometimes
- Most of the time
- Yes, definitely

If you have ticked “Most of the Time” or “Yes, definitely” for this question, please speak with your nurse or doctor at your next visit.

8 Over the past 3 days, how much time do you feel has been wasted on appointments relating to your health care (e.g., waiting around for transport or repeating tests)?

- None at all
- Up to half a day waste
- More than half a day wasted

9 Over the past 3 days, have any practical matters resulting from your illness, either financial or personal been addressed?

- Practical problems have been addressed and my affairs are as up to date as I would wish
- Practical problems are in the process of being addressed
- Practical problems exist which were not addressed
- I have had no practical problems

10 Have you been involved in decisions about your treatment or practical matters as much as you would like?

- Yes, all of the time
- Most of the time
- Sometimes
- Occasionally
- No, not at all

11 Please list or describe the things that had the greatest effect on your quality of life in the past three (3) days.

Please say whether each thing you list made your quality of life better or worse during this time. If you need more space, please use a separate page.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

12 How did you complete these questions?

- On my own
- With the help of a friend or relative
- With help from a member of staff

If, after completing these questions, you feel you would like more help with any symptoms or problems, please speak with your doctor or nurse.

This is the end of the survey. Thank you for your time.
Evaluation Tool 2
Palliative Care Outcomes Staff Questionnaire

About the patient

Sex  
☐ Male  ☐ Female

Age

Does the patient identify as Aboriginal or Torres Strait Islander?  
☐ Yes  ☐ No

Does the patient identify with a particular ethnic origin or cultural background?  
☐ Yes  ☐ No

If yes, please specify ethnic origin or cultural background:

About how the patient feels

Please answer the following questions by ticking the box next to the answer that you think most accurately describes how the patient has been feeling. Thank you

1  Over the past 3 days, has the patient been affected by pain?

☐ Not at all no effect  ☐ Slightly – but not bothered to be rid of it  ☐ Moderately – pain limits some activity

☐ Severely – activities or concentration markedly affected  ☐ Overwhelmingly – unable to think of anything else

2  Over the past 3 days, have other symptoms (e.g. feeling sick, having a cough or constipation) been affecting how they feel?

☐ Not at all  ☐ Slightly  ☐ Moderately  ☐ Severely  ☐ Overwhelmingly

3  Over the past 3 days, has the patient been feeling anxious or worried about their illness or treatment?

☐ Not at all  ☐ Occasionally  ☐ Sometimes – it seems to affect their concentration

☐ Most of the time – often affects their concentration  ☐ Patient does not think of anything else, completely preoccupied with worry and anxiety

4  Over the past 3 days, have any of their family or friends been anxious or worried about the patient?

☐ Not at all  ☐ Occasionally  ☐ Sometimes – it seems to affect their concentration  ☐ Most of the time

☐ Yes, always preoccupied with worry

5  Over the past 3 days, how much information has been given to the patient and their family or friends been given?

☐ Full information – patient feels free to ask  ☐ Information given but not always understood by the patient

☐ Information given on request – patient would have liked more  ☐ Very little given and some questions have been avoided  ☐ None at all

6  Over the past 3 days, has the patient been able to share how they are feeling with family or friends?

☐ Yes, as much as they wanted to  ☐ Most of the time  ☐ Sometimes  ☐ Occasionally

☐ No, not at all with anyone
7 Over the past 3 days, do you think that the patient has been feeling depressed?
   ☐ No, not at all ☐ Occasionally ☐ Sometimes ☐ Most of the time ☐ Yes, definitely

8 Over the past 3 days, how much time do you feel has been wasted on appointments relating to the health care of the patient (e.g., waiting around for transport or repeating tests)?
   ☐ None at all ☐ Up to half a day wasted ☐ More than half a day wasted

9 Over the past 3 days, have any practical matters resulting from their illness, either financial or personal been addressed?
   ☐ Practical problems have been addressed and their affairs are as up to date as they would wish
   ☐ Practical problems are in the process of being addressed ☐ Practical problems exist which were not addressed
   ☐ The patient has no practical problems

10 Has the patient been involved in decisions about their treatment or practical matters as much as they would like?
   ☐ Yes, all of the time ☐ Most of the time ☐ Sometimes ☐ Occasionally ☐ No, not at all

11 Please list or describe the things that you think had the greatest effect on the quality of life of the patient in the past three (3) days.
   Please say whether each thing listed made their quality of life better or worse during this time.
   If you need more space, please use a separate page.
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

12 How did you complete these questions?
   ☐ Without discussing it with the patient or their family or carers ☐ After discussion with the patient
   ☐ After discussion with the patient’s family or carers

This is the end of the survey. Thank you for your time.
Purpose

The items in this tool were developed as a result of work with the patients and carers involved in the Griffith Palliative Care Service (GAPS). These items are supplemented with items from the QLD/NSW ongoing needs assessment tool.

How to administer this tool

This tool is designed to be used with a carer while they are looking after the patient rather than retrospectively. It is designed to be brief and simple in order to minimise respondent burden.

When using this tool it is essential that you advise the carer that their participation is voluntary, their responses are confidential and that their responses will not affect the quality of the service they receive. Ethical permission will be needed to elicit information on the experiences of carers.
About you

Your sex

- Male
- Female

Your age

- 

Do you identify as Aboriginal or Torres Strait Islander?

- Yes
- No

Do you identify with a particular ethnic origin or cultural background?

- Yes
- No

If yes, please specify your ethnic origin or cultural background:

About your experiences with the palliative care service

Please answer the following questions. If the question does not apply to your situation, please tick the Don’t know box.

- Agree
- Disagree
- Don’t know

1. I feel that adequate attention is paid by the service to my needs as a carer
2. I have been provided with all the equipment I need to help me in my caring role
3. I feel confident about using the equipment that has been supplied
4. I have been supplied with clear instructions about what to do in an emergency
5. I feel confident that every effort is being made to keep the person I am looking after free of pain
6. I know who to contact for help if I need it
7. I feel secure that help and advice is available 24 hours a day for me
8. The palliative care staff are helpful and friendly
9. I feel comfortable with the palliative care staff visiting my home
10. Respite is available so that I can have a break if I need it
11. I know there are people I can contact for support after the person I am caring for has died

1 Overall the support and assistance I have received has been:

- Excellent (no improvement necessary)
- Good (my needs are met, but the service could be improved)
- Satisfactory (most of my needs are met)
- Poor (few of my needs are met)
2 Have you had someone to help you with practical tasks?

☐ Yes, I've had all the help I need  ☐ Yes, but not enough  ☐ I haven't needed help  ☐ No

3 Did anyone give you information on whether you would qualify for a Carer Payment or Allowance?

☐ Yes, I was given all the information I need  ☐ Yes, it was mentioned but not in any detail

☐ I haven’t needed any financial help  ☐ No

4 Did someone give you information about available support services?

☐ Yes, I was given all the information I need  ☐ Yes, it was mentioned but not in any detail

☐ I haven’t needed any help  ☐ No

5 Did someone give you practical training in lifting, managing medicine or other tasks?

☐ Yes, I was given all the training I need  ☐ Yes, I was given a bit, but not enough

☐ I haven’t needed any help  ☐ No

This is the end of the survey. If you would like to add any comments about your experience, please do so below.

Thank you for your time.
Purpose
The purpose of this tool is to obtain an understanding of general community awareness of palliative care in the communities where projects have a focus on influencing organisations and individuals not directly concerned with palliative care activities and services. This focus might include awareness raising in local community service agencies, schools, sporting or recreational clubs or in organisations or business groups that might find information on palliative care to be relevant to their activities, such as funeral director or solicitors with an interest in advance care directives.

When should this tool be used?
This tool is best used “before” and “after” some form of promotional activity, media campaign or after specific presentations by speakers. Ideally the tool might be administered a second time in the form of a “follow up” approach after a suitable period of time has elapsed from a campaign being undertaken, to see what impact might have been made.

How to administer this tool?
The tool is best used in a survey style approach in a local community, targeting people who are intended to have some exposure to educational or promotional material.
**Evaluation Tool 4**

**Palliative Care Outcomes Community awareness of palliative care**

---

### About you

Your sex  
- [ ] Male  
- [ ] Female  

Your age  

-  
-  
-  

Do you identify as Aboriginal or Torres Strait Islander?  
- [ ] Yes  
- [ ] No  

Do you identify with a particular ethnic origin or cultural background?  
- [ ] Yes  
- [ ] No  

If yes, please specify your ethnic origin or cultural background:  

---

### About palliative care

1. Have you heard of palliative care?  
   - [ ] Yes  
   - [ ] No  
   - [ ] Not sure  

2. How would you rate your knowledge of palliative care?  
   - [ ] No knowledge  
   - [ ] General knowledge only  
   - [ ] Professional/extensive knowledge  

   If you ticked "no knowledge", please skip the next questions and move straight to Question 8. Otherwise, please proceed with the questions on this page.

3. What does a palliative care service do?  

---

---

4. What services or organisations provide palliative care in your community?  

(tick all that you know provide palliative care in your local community)  

- [ ] Hospital  
- [ ] Community health centre  
- [ ] Residential aged care facility  
- [ ] Community nursing services  
- [ ] Hospice  
- [ ] General Practitioners  
- [ ] Other (please describe):  

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---

---

5. Do you think these services meet the palliative care needs of your community?  
   - [ ] Yes  
   - [ ] No  
   - [ ] Don’t know
6 If no, how could palliative care be improved in your community?

☐ We need a hospice  ☐ We would like the hospital to be more aware of the needs of palliative patients
☐ We need home based care  ☐ We need a 24 hour a day helpline  ☐ More volunteers in palliative care
☐ Other (please describe below):

7 Where did you learn about palliative care? (tick all that apply)

☐ General Practitioner  ☐ Community health centre  ☐ Community nursing service
☐ Residential aged care facility  ☐ Hospital  ☐ Hospice  ☐ Television/radio  ☐ Relatives/friends
☐ Internet  ☐ Other (please describe):

8 Have you ever looked after someone who was dying?

☐ Yes  ☐ No  If no, move straight to Question 12

9 In what capacity have you looked after someone who was dying? (tick all that apply)

☐ Relative  ☐ Friend  ☐ Volunteer
☐ Health care professional  ☐ Manager of services  ☐ Pastoral care worker
☐ Other (please describe):

10 How confident did you feel when looking after the person who was dying? Confident:

☐ All of the time  ☐ Most of the times  ☐ Undecided  ☐ Somewhat  ☐ Not at all

11 Did you feel that you had enough support to undertake this role?

☐ Yes  ☐ No  ☐ Don’t know

12 How important is each of the following in palliative care?

Please use a scale from 1 to 6 to rank the importance of each service.
Please write “1” next to the most important service,”2” against the next most important and so on.

☐ Choice for the patient  ☐ Home based care  ☐ 24 hour a day call out service
☐ The provision of information/education  ☐ The provision of equipment/home modifications
☐ Hospice care  ☐ Other (please describe):

This is the end of the survey. Thank you for your time.
Evaluation Tool 5

Purpose
The purpose of this tool is to obtain an understanding of general community awareness of palliative care in Aboriginal and Torres Strait Islander communities. It was developed through a review of the literature and through consultation with agencies that have experience in providing palliative care to Aboriginal and Torres Strait Islander communities.

When should this tool be used?
This tool is designed to be exploratory and can be used from the time that work begins with Aboriginal and Torres Strait Islander communities. Given the nature of the consultation process, and the developing network of contacts that evolve, it may be necessary to re-visit this tool throughout the duration of the project.

How to administer this tool?
These questions are designed to be used as a guide for community discussions, small group and individual interviews. It may be necessary to work with a local community member or translator to ensure that there is understanding of the concepts in the tool. Palliative care may be a concept that is not widely understood in some communities. Each question has a series of prompts that help the person leading the discussion or interview to obtain the information that is desired.
1. Have you ever heard of palliative care before? What do these words mean to you?
   
   Prompt: Sometimes people get sick and they can’t get better. Care for people who are like this is called palliative care.

2. Is there any support in the community to help people who are not going to get better? (people who are finishing up?)
   
   Prompt: People who have this kind of sickness may want to stay on their country and be looked after by their families. Do you know anyone like this? Do you know if their families are getting any help? What sort of help are they getting?

3. Do you know that there are services that can help people and their families?
   
   Prompt: The palliative care service can provide help for people and their families. They can provide things like wheelchairs and comfortable beds. They can make sure that the sick person doesn’t have any pain.

4. What sort of help do you think people who are finishing up might want in this community?
   
   Prompt: Help to stay at home, perhaps making the house more safe to move around, perhaps even getting a wheelchair.

5. What sort of help do you think that the people looking after them might need?
   
   Prompt: How to keep the sick person comfortable, what sorts of food to give them, who do I ask for help?
6 If a sick person needs lots of help, like care all through the night, where is the best place for them to go?

Prompt: Do you think they could be cared for at home, or do you think they would need to go to a hospital?

7 When a person is dying (finishing up) in hospital, do you think they should be able to come home to their community?

Prompt: How important is it for people to die on their own country with their families?

8 Do you think that there are people in the community who would be interested in getting training to look after dying people (people who are finishing up) in this community?

Prompt: Find out people's names, if they have volunteered themselves or another person, and if they have had any prior caring experience.

9 Do you think that the Council here would support a program to train local people to care for people who are dying (finishing up)?

10 Is there anyone who can share a story about caring for someone who was finishing up?

Prompt: Did you look after them at home. Who helped? Did you think you needed more help?

What could be done to make things easier for you and the person you were looking after?
Evaluation Tool 6

Purpose
This tool is designed to assess the level of knowledge and awareness of Palliative Care Providers who are working in specialist palliative care services. It also assesses their attitudes and confidence of providing palliative care in their profession.

When should this tool be used?
This tool is ideal for “before” and “after” comparisons in an attempt to gauge how awareness, attitudes, confidence and knowledge may have changed during the life of a specific palliative care intervention.

How to administer this tool?
This questionnaire is designed to be brief to minimise disruption to busy professionals. It can be administered either face to face or it can be sent to individuals to complete themselves.
Evaluation Tool 6
Palliative Care Providers

About you

Your sex  □ Male   □ Female

Your age

Do you identify as Aboriginal or Torres Strait Islander?  □ Yes   □ No

Do you identify with a particular ethnic origin or cultural background?  □ Yes   □ No

If yes, please specify your ethnic origin or cultural background:

Your discipline:

Your palliative care training (tick all that apply)

□ Specialist qualification

□ On the job training

□ Short courses or other formal training not leading to a specialist qualification

□ No training

About your views on palliative care

Please rate your degree of confidence with the following patient / family interactions and patient management topics, by ticking the relevant box below

1 =  Need further basic instruction

2 =  Confident to perform with close supervision / coaching

3 =  Confident to perform with minimal consultation

4 =  Confident to perform independently

<table>
<thead>
<tr>
<th>Patient/family interactions and clinical management</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  Answering patients questions about the dying process</td>
<td></td>
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<tr>
<td>2  Supporting the patient or family member when they become upset</td>
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<tr>
<td>3  Informing people of the support services available</td>
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<tr>
<td>4  Discussing different environmental options (eg hospital, home, family)</td>
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<tr>
<td>5  Discussing patients wishes for after their death</td>
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<tr>
<td>6  Answering queries about the effects of certain medications</td>
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<tr>
<td>7  Reacting to reports of pain from the patient</td>
<td></td>
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</tbody>
</table>
### Patient/family interactions and clinical management

<table>
<thead>
<tr>
<th>No</th>
<th>Statement</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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</thead>
<tbody>
<tr>
<td>8</td>
<td>Reacting to and coping with terminal delirium</td>
<td></td>
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<tr>
<td>9</td>
<td>Reacting to and coping with terminal dyspnoea (breathlessness)</td>
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<tr>
<td>10</td>
<td>Reacting to and coping with nausea / vomiting</td>
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<tr>
<td>11</td>
<td>Reacting to and coping with constipation</td>
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<tr>
<td>12</td>
<td>Reacting to and coping with limited patient decision-making capacity</td>
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</tbody>
</table>

### Views about death and dying

Please indicate how much you agree or disagree with each of the following statements, by ticking the box that best describes how you feel. (There are no right or wrong answers).

<table>
<thead>
<tr>
<th>No</th>
<th>Statement</th>
<th>Agree Strongly</th>
<th>Agree</th>
<th>Unsure / Mixed</th>
<th>Disagree</th>
<th>Disagree Strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>The end of life is time of great suffering</td>
<td></td>
<td></td>
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<tr>
<td>2</td>
<td>Little can be done to help someone achieve a sense of peace at the end of life</td>
<td></td>
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<tr>
<td>3</td>
<td>The use of strong pain medication can cause the person to stop breathing</td>
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<tr>
<td>4</td>
<td>I am not comfortable caring for a dying patient</td>
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<tr>
<td>5</td>
<td>I am not comfortable talking to families about death</td>
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<tr>
<td>6</td>
<td>When a patient dies I feel that something went wrong</td>
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<td>7</td>
<td>Feeding tubes should be used to prevent starvation at the end of life</td>
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<tr>
<td>8</td>
<td>Residential aged care facility/hospitals are not good places to die</td>
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<tr>
<td>9</td>
<td>Families have the right to refuse a medical treatment, even if that treatment prolongs life.</td>
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<tr>
<td>10</td>
<td>Dying patients should be referred to a hospice or acute care.</td>
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<tr>
<td>No</td>
<td>Statement</td>
<td>Agree Strongly</td>
<td>Agree</td>
<td>Unsure / Mixed</td>
<td>Disagree</td>
<td>Disagree Strongly</td>
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</tr>
<tr>
<td>1</td>
<td>Pain at the end of life is an inevitable part of the dying process</td>
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<tr>
<td>2</td>
<td>Pain medication should be given as needed to terminally ill patients</td>
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<tr>
<td>3</td>
<td>Spiritual care should be given as needed to terminally ill patients</td>
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<tr>
<td>4</td>
<td>I do not like talking about death and dying with patients</td>
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<tr>
<td>5</td>
<td>Palliative care should be the standard medical treatment for patients who are suffering from a terminal illness</td>
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<tr>
<td>6</td>
<td>Patients should have the right to determine their own degree of medical intervention</td>
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<tr>
<td>7</td>
<td>Addiction to oral morphine is not a serious issue given that terminally ill patients have a short time to live</td>
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<td>8</td>
<td>Opening discussions of end of life care should be deferred until there is no further effective curative treatment available</td>
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<tr>
<td>9</td>
<td>Estimation of pain by an MD or RN is more valid measure of pain than patient self report</td>
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<tr>
<td>10</td>
<td>Complete pain relief is a reasonable goal for even when the pain is not caused by a terminal condition such as cancer</td>
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<tr>
<td>11</td>
<td>Patients have the right to determine their own level of psychosocial intervention</td>
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<tr>
<td>12</td>
<td>The most appropriate person to make end of life decisions is the patient’s primary care provider</td>
<td></td>
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<tr>
<td>13</td>
<td>A patient should experience discomfort prior to receiving the next dose of pain medications</td>
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<tr>
<td>14</td>
<td>Patients should be maintained in a pain free state</td>
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<tr>
<td>15</td>
<td>As a rule, terminally ill patients prefer not to talk about death or dying</td>
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</tbody>
</table>
Please indicate the importance of the issues below in terms of the problems they create for you in caring for a dying patient by ticking the box that best describes your feelings. (There are no right or wrong answers).

<table>
<thead>
<tr>
<th>No</th>
<th>Statement</th>
<th>Very Important</th>
<th>Important</th>
<th>Unsure</th>
<th>Less Important</th>
<th>Not Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Control of pain</td>
<td></td>
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<tr>
<td>2</td>
<td>Managing depression</td>
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<td>3</td>
<td>Legal concerns</td>
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<td>4</td>
<td>Ability to meet spiritual needs</td>
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<tr>
<td>5</td>
<td>The patient’s emotional needs</td>
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<tr>
<td>6</td>
<td>Communication with the family</td>
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<tr>
<td>7</td>
<td>Communication with other palliative care staff</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>8</td>
<td>Communication with (other) doctor/s</td>
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<tr>
<td>9</td>
<td>Uncertainty about what is best care</td>
<td></td>
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<td></td>
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<tr>
<td>10</td>
<td>Other (please describe):</td>
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</tbody>
</table>
Please tick the boxes to indicate whether you would like future education on any of the following topics:

- [ ] Pain assessment and management
- [ ] Dealing with terminal delirium
- [ ] Dealing with nausea and vomiting
- [ ] Dealing with terminal dyspnea
- [ ] Dealing with constipation
- [ ] Use of intravenous hydration and/or non-oral feeding in end of life care
- [ ] End of life communication skills – giving bad news, talking with family, discussing prognosis, discussing various treatment options
- [ ] End of life ethics: DNR orders, advanced directives, decision making capacity
- [ ] Spirituality and cultural aspects of end of life care
- [ ] Other (please specify below)

Please list any other topics here

This is the end of the survey. Thank you for your time.
Purpose

This tool is a modified form of an instrument called “Supportive care of the dying: A Coalition for Compassionate Care Organisational Assessment: System Grid and Assumptions” developed by the Centre to Advance Palliative Care. The modifications made CHSD (Centre Health Service Development) involve slight changes to the language used in the tool to make it appropriate for use in an Australian setting.

The objective of this tool is stated by the developers as:

• to provide a tool for organisations and systems to use as they assess themselves looking at supportive structures which make it possible to deliver outstanding services and are not unintentionally maintaining structures that inhibit such services.

The system assessment tool will allow organisations to self-rate their structures as supportive, inhibitive, or not present. Given this rating, they will also be able to self-rate their own perception of actual effectiveness in assisting to meet the stated objective or outcome. This self-analysis, along with data from patients, families, bereaved families, and professionals, will assist organisations to target interventions for rapid cycle improvement. Systems may not personally offer specific services or programs, but have a method in place to refer persons in a manner that maintains continuity of care.

How to administer this tool?

The tool is designed to be completed during a meeting or group discussion. The designers estimate that the process requires 2-4 hours and suggest that it should be done in at least 2 different sessions. This could be done with existing communities, eg, palliative care committees, ethics committees, quality committees, etc., or could be done as a structured focus group within your organisation.
**Vision and Management Standards**

<table>
<thead>
<tr>
<th>Please indicate one</th>
<th>Rate the degree to which the statement is true of your service</th>
<th>Rate priority for future action</th>
</tr>
</thead>
<tbody>
<tr>
<td>P= Present</td>
<td>0= Not at all</td>
<td>0= Not at all-no action required</td>
</tr>
<tr>
<td>NP= Not Present</td>
<td>10= Fully implemented and effective</td>
<td>10= Undertaken as a matter of urgency</td>
</tr>
</tbody>
</table>

We have a vision for excellence in end of life care

Our service objectives includes a focus on end of life care

Administration executive staff support implementation of initiatives to improve care at end of life

Medical staff support implementation of initiatives to improve care at end of life

Management objectives include a focus on end of life care

Education resources are designated to support development of competencies and practices in end of life care

Excellent caregivers (both formal and informal) and caregiving examples are honoured and their stories made visible

**Practice Standards (procedures, policies, care protocol)**

<table>
<thead>
<tr>
<th>Please indicate one</th>
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</tr>
<tr>
<td>NP= Not Present</td>
<td>10= Fully implemented and effective</td>
<td>10= Undertaken as a matter of urgency</td>
</tr>
</tbody>
</table>

The population we serve is defined and communicated

Confidentiality standards are clearly communicated

Cultural/religious guidelines are integrated

Organ/tissue donation guidelines are implemented

Comfort, care and palliative care Standards are implemented. Includes guidelines for pain and symptom management, and hydrate/ nutrition
<table>
<thead>
<tr>
<th>Please indicate one</th>
<th>Rate the degree to which the statement is true of your service</th>
<th>Rate priority for future action</th>
</tr>
</thead>
<tbody>
<tr>
<td>P= Present</td>
<td>0= Not at all</td>
<td>0= Not at all-no action required</td>
</tr>
<tr>
<td>NP= Not Present</td>
<td>10= Fully implemented and effective</td>
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</tr>
<tr>
<td>Hospice care is available</td>
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<tr>
<td>Complementary or integrative therapies are supported</td>
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</tr>
<tr>
<td><strong>Space Standards (inpatient/hospice services only)</strong></td>
<td></td>
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</tr>
<tr>
<td>Patient’s rooms are comfortable, homelike, support family visits and confidentially</td>
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</tr>
<tr>
<td>Family homelike or living room type space is available</td>
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<tr>
<td><strong>Visiting Standards (inpatient/hospice services only)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Welcoming for families</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support for family ADL’s available</td>
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</tr>
<tr>
<td>24 hour visiting with numbers, hours and age, for close friends/family as defined by ill person/family with respect of other patient care needs</td>
<td></td>
<td></td>
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<tr>
<td>Families participate in care as desired</td>
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<tr>
<td>Children are welcomed with supervision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pets visiting with supervision and respect of other patient care needs is welcomed</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Spiritual, Religious and Cultural Standards</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support is available 24 hours a day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Links/communication with community established</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prayer and other spiritual/religious practices overtly available</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Please indicate one of: P = Present, NP = Not Present</td>
<td>Rate the degree to which the statement is true of your service</td>
<td>Rate priority for future action</td>
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<td></td>
<td>0 = Not at all</td>
<td>0 = Not at all—no action required</td>
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<tr>
<td></td>
<td>10 = Fully implemented and effective</td>
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</tr>
</tbody>
</table>

- **All staff are expected to integrate spiritual/cultural care within practice**
- **Support for professional caregivers readily available**

### Bereavement Support Standards

- **Bereavement support groups offered**
- **Follow-up is available for 100% who have died**
- **Follow-up contact to address clinical questions initiated by clinician/primary care providers within 2-4 weeks of death**
- **Memorial services conducted for staff and families**
- **Bereavement support 1:1 for families is available**
- **Bereavement support 1:1 for professionals is available**

### Psychological and Emotional Standards, including Pastoral Care

- **Referral and support is available 24 hours**
- **Support available for professional caregivers**
- **Support groups for patient/families easily available**
- **Virtual support groups available (e.g., chat groups, telephone conference groups)**
<table>
<thead>
<tr>
<th></th>
<th>Please indicate one</th>
<th>Rate the degree to which the statement is true of your service</th>
<th>Rate priority for future action</th>
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<tr>
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<td></td>
<td>NP = Not Present</td>
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</tr>
<tr>
<td>Communication Standards</td>
<td></td>
<td></td>
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<tr>
<td>Care preference, values, spiritual, emotional, and relationship needs as well as decisions routinely and accurately communicated and honoured</td>
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<tr>
<td>Doctor communication during the dying process occurs frequently</td>
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<tr>
<td>Transfer of care occurs with communication preferences, values, spiritual/emotional, and relationship needs and patient/family care decisions</td>
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<td></td>
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</tr>
<tr>
<td>Standards and expectations about excellent end of life care routinely communicated to community</td>
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<td></td>
</tr>
<tr>
<td>Communication with community spiritual care providers routine as well as specific</td>
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<tr>
<td>Professional Experiential Education during Orientation and as Continuing Education</td>
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<tr>
<td>Organisation values and strategic objectives</td>
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<tr>
<td>Ethics – End of life care</td>
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<td></td>
<td></td>
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<tr>
<td>Practice standards</td>
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<td></td>
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<tr>
<td>Quality improvement standards</td>
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<td></td>
<td></td>
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<tr>
<td>Communication</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Grief and Bereavement</td>
<td></td>
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<tr>
<td>Patient/Family supports</td>
<td></td>
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<tr>
<td>Professional caregiver/staff support</td>
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<tr>
<td>Spiritual/religious/cultural standards</td>
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<tr>
<td>Individual performance expectations</td>
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<tr>
<td>Quality Improvement Standards</td>
<td>Rate the degree to which the statement is true of your service</td>
<td>Rate priority for future action</td>
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<tr>
<td></td>
<td>P= Present NP= Not Present</td>
<td>0= Not at all 10= Fully implemented and effective</td>
<td></td>
</tr>
<tr>
<td>Routine feedback from patients, family caregivers and bereaved family, and community partners is obtained</td>
<td>Rate priority for future action</td>
<td>Rate priority for future action</td>
<td></td>
</tr>
<tr>
<td>Quality priorities include response to above</td>
<td>Rate priority for future action</td>
<td>Rate priority for future action</td>
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<tr>
<td>Significant events are assessed for learning and quality improvement</td>
<td>Rate priority for future action</td>
<td>Rate priority for future action</td>
<td></td>
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<tr>
<td>“Stories” are shared and used to teach about care and to set standards</td>
<td>Rate priority for future action</td>
<td>Rate priority for future action</td>
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</tr>
<tr>
<td>Research to continue developing new ways to improve care is developed or findings are applied to practice change initiatives</td>
<td>Rate priority for future action</td>
<td>Rate priority for future action</td>
<td></td>
</tr>
<tr>
<td>Annual objectives and priorities include focus on end of life care</td>
<td>Rate priority for future action</td>
<td>Rate priority for future action</td>
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<tr>
<td>Staff Support Standards</td>
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<tr>
<td>There are systems and policies that support bereavement leave for those the person defines as close or family</td>
<td>Rate priority for future action</td>
<td>Rate priority for future action</td>
<td></td>
</tr>
<tr>
<td>There are systems and policies that allow flexibility in work time during illness, caregiving and bereavement</td>
<td>Rate priority for future action</td>
<td>Rate priority for future action</td>
<td></td>
</tr>
<tr>
<td>Palliative care providers are supported in reaching out to fellow providers with practical help</td>
<td>Rate priority for future action</td>
<td>Rate priority for future action</td>
<td></td>
</tr>
<tr>
<td>Acuity and patient assignments provide time to “be with” the patient and family during the process of dying</td>
<td>Rate priority for future action</td>
<td>Rate priority for future action</td>
<td></td>
</tr>
<tr>
<td>Professional caregivers are supported to attend memorial/funeral service of patients</td>
<td>Rate priority for future action</td>
<td>Rate priority for future action</td>
<td></td>
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</tbody>
</table>
Purpose
This tool is designed to capture information about the level of awareness and involvement that a particular organisation has about palliative care.

When should this tool be used?
This tool is ideal for “before” and “after” comparisons in an attempt to gauge how awareness and involvement may have changed during the life of the project.

How to administer this tool?
Ideally this tool is completed during a team meeting, and as a result reflects a consensus of opinion among the team. In the case of individuals with opinions that are very different to the rest of the group it is possible for them to complete the tool alone. It is important in the box provided which method was used.
Evaluation Tool 8
General health care organisational survey about palliative care

About your agency / service

Agency name (optional)

Location (optional)

Date completed

This Survey was completed (tick one)

☐ Through an agency/group meeting to consolidate one response

☐ By an individual expressing their own views, and not necessarily those of the agency

Description of your agency / service

☐ Hospital

☐ Community health service

☐ Community nursing service

☐ General practice / Medical centre

☐ Community organisation

☐ Training organisation

☐ Multi-purpose health centre

☐ Other (please describe):

1 How does your organisation define palliative care?

2 What services or organisations provide palliative care in the community?

(tick all that you know provide palliative care in the community in which you work)

☐ Hospital

☐ Community health centre

☐ Community nursing service

☐ General practitioners

☐ Hospice

☐ Residential aged care facility

☐ Other (please describe):

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________
3 What information sources about Palliative Care are recommended by you organisation?

- Hospital
- Community nursing service
- Hospice
- Television/radio
- Internet
- Community health centre
- General practitioners
- Residential aged care facility
- Relatives/friends
- Other (please describe):

4 To what extent does your organisation provide information about Palliative Care?

- Not an information provider
- Provides information in some areas of palliative care
- Provider of general knowledge only
- Provides professional/extensive information about palliative care

5 How is your organisation involved in Palliative care?

- Carer support
- Direct care provider
- Providing specialist palliative care services
- Volunteer training and support
- Providing general palliative care services
- This organisation is not involved
- Other (please describe):

6 To what extent does your organisation coordinate with (other) palliative Care Services in your community?

- Do not coordinate with palliative care services (no others exist)
- Coordinate with a limited number of (other) palliative care services
- Do not coordinate with palliative care services (others do exist)
- Coordinate extensively with (other) palliative care services

This is the end of the survey. Thank you for your time.


