

Appendix 1: Administrative health regions

<p>New South Wales (8 health regions)</p> <p>Metropolitan Northern Sydney/Central Coast South Eastern Sydney/Illawarra Sydney South West Sydney West</p> <p>Rural Greater Southern Greater Western Hunter/New England North Coast</p>	<p>Victoria (8 health regions)</p> <p>Metropolitan North Western Metropolitan Eastern Metropolitan Southern Metropolitan</p> <p>Rural Barwon South Western Region Gippsland Region Grampians Region Hume Region Loddon Mallee Region</p>
<p>Queensland (3 health regions)</p> <p>Northern Area Health Service Central Area Health Service Southern Area Health Service</p>	<p>Western Australia (5 health regions)</p> <p>Metropolitan North Metropolitan Health Service South Metropolitan Health Service Women's and Children's Health Service</p> <p>Rural South West Area Health Service WA Country Health Service</p>
<p>South Australia (11 health regions)</p> <p>Metropolitan Southern Adelaide Health Service Central Northern Adelaide Health Service Children, Youth and Women's Health Service Other</p> <p>Country Eyre Hills, Mallee, Southern South East Mid North Northern & Far Western Riverland Wakefield</p>	<p>Tasmania</p> <p>Tasmania constitutes one region</p>
<p>Australian Capital Territory</p> <p>The ACT constitutes one region</p>	<p>Northern Territory</p> <p>The NT constitutes one region</p>

Appendix 2: Regional strategic plan survey form

The following text and table were sent to each state and territory health department for completion.

National palliative care performance indicator 1

August/September 2005

This document provides information and a tool for state/territory health authorities for the purpose of reporting National Palliative Care Performance Indicator one. Together with three other performance indicators, this indicator was endorsed by the PCIF in 2003, and re-endorsed in August 2005 following small amendments to the wording. The indicator reads:

'The proportion of administrative health regions that have a written plan for palliative care which incorporates palliative care elements.'

Collection process and timeline:

5 September – 7 October	State/territory health departments collect and assess the strategic plan(s) from the agreed administrative health regions in their state/territory. Note that in Tasmania, the ACT and the NT only one plan is required. It is suggested that assessment is carried out by two to three departmental staff, including the PCIF-member.
7 October	Due date for sending the results to the AIHW (by email).

Definitions:

Administrative health region: The administrative unit with responsibility for administering health services in a region, area, district or zone, and for developing and implementing strategic and other plans for health service delivery, as specified by each state and territory.

Written strategic plan² which incorporates palliative care elements: a regional plan, or an aggregation of the region's sub-units' plans. The plan may be specifically for palliative care or a general health service plan that includes palliative care elements.

² A strategic plan typically has a mission statement, outlines a vision, values and strategies, and includes goals and objectives. A strategic plan may: serve as a framework for decisions; provide a basis for more detailed planning; explain the business to others in order to inform, motivate & involve; assist benchmarking & performance monitoring; stimulate change and become a building block for the next plan.

Important further guidelines

The palliative care elements in the plan **must** include all of the following aspects:

- timeframe (the beginning and end-date in years), with a minimum time period of two years to demonstrate a strategic focus
- measurable objectives relating to: service access, quality, utilisation, responsiveness and evaluation.
- demonstrated stakeholder involvement in plan development, such as the inclusion of a description of the consultation process in the strategic plan document
- demonstrated links with the National Palliative Care Strategy
- implementation strategies (can include resources identified for service delivery)
- evidence of ongoing development in subsequent plans.

Name of state: STATE

Name of person completing this form: ...

Contact phone number: ...

Date completed: ../../2005

Please indicate below whether the region has a written plan for palliative care which incorporates palliative care elements and which is according to the definitions provided.

Meaning of the possible answers:

Yes: the administrative health region has a written strategic plan which incorporates palliative care elements, and which includes all compulsory strategic plan aspects.

No: the administrative health region does not have a written strategic plan which incorporates palliative care elements, or the region has a plan with only partial coverage of the compulsory strategic plan aspects.

Please complete this table:

Administrative health region	Yes/No please cross	Title of plan (where one exists)
	Yes [] No []	

THANK YOU FOR COMPLETING THIS FORM

Appendix 3: Agency survey form



Trial National Palliative Care Agency Data Collection

IMPORTANT:

- * This form is to be completed, **in conjunction with the Guidelines document**, by a member of staff with a good knowledge of agency policy and procedure.
- * **Return by** the 23rd September 2005.
- * **Return to** your state/territory department Returning Officer. See pages 8 and 9 of the guidelines document.
- * To **Save** this file follow the instructions provided in the guidelines document on page 7.

Agency Details

1. Agency identifier

Supplied by the AIHW

For instructions go to page 10 of the guidelines

2. Agency name

For instructions go to page 10 of the guidelines

3. State or territory

Select one code only

For instructions go to page 10 of the guidelines

Other territories includes Cocos (Keeling) Islands, Christmas Island and Jervis Bay Territory

4. During the past 12 months, in which setting(s) did your agency deliver palliative care services?

Tick as many checkboxes as applicable

For instructions go to page 11 of the guidelines

- 1 Private residence
- 2 Residential - aged care setting
- 3 Residential - other setting
- 4 Non-residential setting
- 5 Inpatient - designated palliative care unit
- 6 Inpatient - other than a designated palliative care unit
- 7 Outpatient - in a hospital/hospice

5. During the past 12 months, in which setting(s) nominated in Q4, did your agency most commonly deliver palliative care services?

Select one code only

For instructions go to page 11 of the guidelines

* Community-based settings include private residences, residential aged care, other residential settings, non-residential settings and outpatient settings.

6. Does your agency employ at least one staff member who is a palliative care practitioner?

Select one code only

For instructions go to page 12 of the guidelines

Feedback Collection

7. Does your agency actively and routinely collect feedback relating to services and service delivery from clients and/or staff?

Select one code only

For instructions go to page 13 of the guidelines

If yes, go to Q8. If no, go to Q10

8. Which feedback mechanism(s) does your agency employ to actively and routinely collect feedback from clients?

Tick as many checkboxes as applicable

For instructions go to page 13 of the guidelines

- 1 Questionnaire - periodic face-to-face interview
- 2 Questionnaire - face-to-face interview upon exit
- 3 Questionnaire - telephone
- 4 Questionnaire - other
- 5 Feedback focus group
- 6 Other
- 7 Not applicable

If other, please specify (100 char limit)

9. Which feedback mechanism(s) does your agency employ to actively and routinely collect feedback from staff?

Tick as many checkboxes as applicable

For instructions go to page 14 of the guidelines

- 1 Questionnaire - periodic face-to-face interview
- 2 Questionnaire - face-to-face interview upon exit
- 3 Questionnaire - telephone
- 4 Questionnaire - other
- 5 Feedback focus group
- 6 Other
- 7 Not applicable

If other, please specify (100 char limit)

Partnerships

10. Do you have formal working partnership(s) with other service provider(s) or organisation(s)?

Select one code only

For instructions go to page 15 of the guidelines

If yes, go to Q11. If no, go to Q12

11. With which type(s) of organisation(s) does your agency have formal working partnership(s) in place?

Tick as many checkboxes as applicable

For instructions go to page 16 of the guidelines

- 1 Palliative care services
- 2 Hospitals
- 3 Community nursing agencies
- 4 Residential aged care facilities
- 5 Allied health services
- 6 Aboriginal health services
- 7 Medical practices
- 8 Integrated health centres
- 9 Universities/research centres
- 10 Other

If other, please specify (100 char limit)

Palliative Care Australia Standards

12. Does your agency routinely undertake or undergo formal assessment against the Palliative Care Australia standards?

Select one code only

For instructions go to page 17 of the guidelines

If yes, go to Q13. If no, go to Q14

13. What method(s) is used to assess your agency against the Palliative Care Australia standards?

Tick as many checkboxes as applicable

For instructions go to page 18 of the guidelines

- 1 Formal self-assessment
- 2 In-depth external review

Subcontracting Arrangements

This information is being collected to gain insight into the subcontracting arrangements that are in place between organisations that provide palliative care.

14. Does your agency subcontract (an)other agency(ies) to provide services to palliative care clients?

Select one code only

For instructions go to page 18 of the guidelines

If yes, go to Q15. If no, go to Q16

15. Did you answer the questions in this palliative care agency collection on behalf of the subcontracted agency(ies)?

Select one code only

For instructions go to page 19 of the guidelines

16. Is your agency ever responsible for providing palliative care to clients on behalf of another agency/organisation, for example through a subcontracting arrangement?

Select one code only

For instructions go to page 19 of the guidelines

Thank you for completing this form. Please go to the Feedback form.

Appendix 4: Agency feedback form

This feedback form provides your agency with an opportunity to comment on the Palliative Care Agency Trial Data Collection.

Please take some time to complete this form, and return it, together with the completed MS Excel worksheet to your state/territory health department.

AGENCY NAME	
AGENCY IDENTIFIER	

Name and contact number of Agency staff completing this form	
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1. Did your agency have any difficulty opening the MS Excel Collection form?

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2. Did your agency find the electronic collection form easy to complete? e.g. tick boxes easy to fill, drop down menu options easily selected

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3. Did your agency access the collection help line or the collection help website? If so, did you receive the help you required?

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4. Palliative Care Agency Collection questions

4.1 The following table lists the questions that formed the Palliative Care Agency Trial Data Collection. For each question, outline whether you had difficulties understanding the question, the guidelines to the question, and answering the question. If your agency's response is *Yes* to any of these questions, please provide further explanation in the space provided.

Agency details		
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	Did you have difficulty <u>understanding</u> this question or the corresponding guidelines for this question?	Did you have any difficulty <u>answering</u> this question?
1. Agency identifier	YES/NO	YES/NO
2. Agency name	YES/NO	YES/NO
3. Agency state/territory	YES/NO	YES/NO
4. During the past 12 months, in which setting(s) did your agency deliver palliative care services?	YES/NO	YES/NO
5. During the past 12 months, in which setting(s) nominated in Q4, did your agency most <i>commonly</i> deliver palliative care services?	YES/NO	YES/NO
6. Does your agency employ at least one staff member who is a palliative care practitioner?	YES/NO	YES/NO

Feedback collection		
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	Did you have difficulty <u>understanding</u> this question or the corresponding guidelines for this question?	Did you have any difficulty <u>answering</u> this question?
7. Does your agency actively and routinely collect feedback relating to services and service delivery from clients and/or staff?	YES/NO	YES/NO
8. Which feedback mechanism(s) does your agency employ to actively and routinely collect feedback from clients?	YES/NO	YES/NO
9. Which feedback mechanism(s) does your agency employ to actively and routinely collect feedback from staff?	YES/NO	YES/NO

Partnerships

	Did you have difficulty <u>understanding</u> this question or the corresponding guidelines for this question?	Did you have any difficulty <u>answering</u> this question?
10. Do you have <u>formal</u> working partnerships with other service provider(s) or organisation(s)?	YES/NO	YES/NO
11. With which type(s) of organisations does your agency have formal working partnerships in place?	YES/NO	YES/NO

Palliative Care Australia Standards

	Did you have difficulty <u>understanding</u> this question or the corresponding guidelines for this question?	Did you have any difficulty <u>answering</u> this question?
12. Does your agency routinely undertake or undergo formal assessment against the Palliative Care Australia Standards?	YES/NO	YES/NO
13. What method(s) is used to assess your agency against the Palliative Care Australia Standards?	YES/NO	YES/NO

Subcontracting Arrangements

	Did you have difficulty <u>understanding</u> this question or the corresponding guidelines for this question?	Did you have any difficulty <u>answering</u> this question?
14. Does your agency subcontract (an)other agency(ies) to provide services to palliative care clients?	YES/NO	YES/NO
15. Did you answer the questions in this palliative care agency collection on behalf of the subcontracted agency(ies)?	YES/NO	YES/NO
16. Is your agency ever responsible for providing palliative care to clients on behalf of another agency/organisation, for example through a subcontracting arrangement?	YES/NO	YES/NO

5. General comments on the Palliative Care Agency Collection

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6. If you answered yes to question 14 of the collection, please provide the name(s) of the agencies with which you have this arrangement.

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7. If you answered yes to question 16, please provide the name(s) of the agencies with which you have this arrangement.

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The suggestions and comments made by your agency are invaluable and much appreciated.

THANK YOU!

Appendix 5: Summary of general respondent feedback

Following is a selection of comments received from agencies that completed the survey feedback form:

Prefer hard copy surveys, too much reading, not enough time, is this useful, I'm sure you can't get a proper picture with these questions.

Clear concise guidelines.

Easy to use. Doesn't take too much time to complete.

Very easy forms to understand and complete.

Easy to follow, easy to do. Need to reduce some of the space made available for the answers.

Found guidelines to be useful in completing the survey.

Easy to follow, easy to do. Perhaps need to reduce some of the space made available for the answers.

This has been challenging due to area health services amalgamating which may suggest that data may be incomplete or inconsistent.

It took more time to complete this evaluation than the actual questionnaire.

Disk was fine until it wouldn't be saved. Therefore sent in paper form. Honestly don't have time to look up websites to clarify why disk isn't working.

I found the form relatively easy to complete with good explanations in the guidelines.

Easy to follow instructions and complete. Unfortunately disk did not accept changes (i.e. saving). The questionnaire does not leave room to expand on the situation existing at the Royal North Shore Hospital.

It is exceptionally painful to have to do this on the computer and written form!!! Disk would not allow me to save the data I had entered!!

Please don't make this so difficult—we are all busy with our clinical loads and don't have time or the enthusiasm to mess around with dodgy disks! An information collation is so important for palliative care but no one will do it if it is not well thought out.

After completing the data required on the disk it would not save as the diskette was full! On Excel and had not even started the feedback form. Certainly took MORE than 5 minutes. At least 2 hrs on the computer.

The document was very easy to complete. User friendly and with the provision of a variety of ways to return the form it caters to everyone needs. Guidelines were thorough to ensure you understood question. Clearly demonstrated what was acceptable to meet the questions standard. E.g. formal agreement was well defined to ensure the reader could be certain if their agreements met the Data standards.

Easy to do other than opening Excel file then saving to email off—hence mailed off.

Was fairly simple to complete, particularly if I can do it electronically. It would have taken me 10 minutes if I had done it freehand, it's taken me two hours to get to this stage!

Seems pretty straight forward. Size and length of the instruction booklet is a bit daunting.

The survey was clear and user friendly. Definitions and terminology of phrases would eliminate ambiguity regarding 'palliative care practitioner'.

I found the Data Collection format to be user friendly on the whole.

Improved awareness of the need to be assessed against the Palliative Care Standards.

Easy and quick. Guidelines reference book very handy. Just a comment re floppy disks – not all computers have A: drives anymore (mine did but not all do).

Very easy to follow and did not take a lot of time.

Too short a time frame between receipt of form and required return.

Timeframe very short for completion. Floppy disk 'full' unable to accept data. Excel programme seemed to deliver the 'drop down' facility to some questions.

It arrived quite close to the deadline. When relying on internal mail etc. things can get quite held up. Nevertheless I was still late sending it back due to my own actions.

Information booklet was helpful. Timeframes to complete short and no significant pre notification.

Superb form. [What is] point of exercise, given there is no differentiation between specialist palliative care services and primary care palliative care services it will be hard to make any meaningful conclusions on this data. Would be happy to discuss creation of survey relevant to actual service provision models and resourcing.

Appendix 6: Palliative Care Australia Standards

Following is a summary of the current standards for palliative care as defined by Palliative Care Australia (PCA 2005a):

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 maximized 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.

Glossary

Administrative health region	The administrative unit with responsibility for administering health services in a region, area, district or zone and for developing and implementing strategic and other plans for health service delivery, as specified by each state and territory.
Agency data	Information that is collected about each agency – for example, the agency’s setting of care or feedback mechanism. It does not refer to aggregated information about patients.
Community-based palliative care	Palliative care delivered in residential and non-residential community-based settings, which include the person’s private residence; a community-living environment such as an aged or supported care facility; a day centre such as a day respite centre, a day therapy centre or a palliative care day centre; or an outpatients department.
Formal working partnership	A formal working arrangement with other organisations that enable clients to move smoothly between services and service settings to meet their clinical and social needs. It can involve any of the following arrangements: service agreement, formal liaison, referral and discharge planning process, formal and routine consultation, protocol, partnership working group, and memorandum of understanding with other providers.
Hospice	An establishment dedicated to providing inpatient palliative care to patients with life-limiting illness.
Life-limiting illness	An illness that can be reasonably expected to cause the death of a patient in the foreseeable future.
Palliative care	Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting 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 (WHO 2003).
Palliative care agency	An organisation or organisational sub-unit that is either a government service or an incorporated business with an ABN, which manages one or more palliative care practitioners, and is responsible for the provision of palliative care to patients and/or their carer(s)/family/friends and/or related services to health professionals, counsellors and volunteers.
Performance indicator	A measure that quantifies the level of performance for a particular aspect of (health) service provision and allows comparison between service providers, modes of service provision, or both (NHPC 2000).
Primary care provider (in the palliative care context)	A medical, nursing or allied health professional who adopts a palliative approach, has a primary or first-contact relationship with the person with a life-limiting illness, and whose substantive work is not with patients with a life-limiting illness.
Setting of care	The type of physical setting in which a service is actually provided or could be provided to a client, irrespective of whether or not this is the same as the usual location of the service-providing agency.

Strategic plan

A written document that describes a plan for the delivery and direction of services. The plan may be specifically for palliative care or a general health service plan that includes palliative care elements.

References

AIHW (Australian Institute of Health and Welfare) 2004. National palliative care information collection: a way forward for community-based palliative care. Canberra: AIHW.

AIHW (unpublished). Guidelines to the Trial National Palliative Care Agency Data Collection 2005. Canberra: AIHW.

DoHA (Department of Health and Ageing) 2000. National Palliative Care Strategy: a national framework for palliative care service development. Canberra: DoHA.

HDSC (Health Data Standards Committee) 2006. National health data dictionary. Version 13. Canberra: AIHW.

LCMHC (Little Company of Mary Health Care) 2003. A snapshot of palliative care in Australia. Canberra: Australian Government Department of Health and Ageing.

NCSDC (National Community Services Data Committee) (forthcoming). National community services data dictionary. Version 4. Canberra: AIHW.

NHPC (National Health Performance Committee) 2000. Fourth national report on health sector performance indicators: a report to the Australian Health Ministers' Conference. Sydney: NSW Health.

NHPC 2001. National health performance framework report. Brisbane: Queensland Health.

PCA (Palliative Care Australia) 1999. Standards for palliative care provision. 3rd ed. Canberra: PCA.

PCA 2005a. Standards for providing quality palliative care for all Australians. 4th ed. Canberra: PCA.

PCA 2005b. A guide to palliative care service development: A population-based approach. Canberra: PCA.

SESAHS (South Eastern Sydney Area Health Service) 2001. Development of national higher level performance indicators for palliative care: final report. Prepared for Commonwealth Department of Health and Ageing. Sydney: SESAHS.

WHO (World Health Organization) 2003. WHO definition of palliative care. Viewed November 2005, <<http://www.who.int/cancer/palliative/definition/en/>>.