

# **National palliative care performance indicators**

## **Report on the National Palliative Care Performance Indicator Data Collection 2005**

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### **Australian Institute of Health and Welfare**

Board Chair  
Hon. Peter Collins, AM, QC

Director  
Penny Allbon

Any enquiries about or comments on this publication should be directed to:

Clara Jellie  
National Data Development and Standards Unit  
Australian Institute of Health and Welfare  
GPO Box 570  
Canberra ACT 2601  
Phone: (02) 6244 1250

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# Abbreviations

AHCA	Australian Health Care Agreement
AIHW	Australian Institute of Health and Welfare
DoHA	Department of Health and Ageing
DSS	data set specification
HACC	Home and Community Care (Program)
METeOR	Metadata Online Registry
NCSDD	National Community Services Data Dictionary
NDDSU	National Data Development and Standards Unit
NHDD	National Health Data Dictionary
NHPC	National Health Performance Committee
NHPF	National Health Performance Framework
NMDS	national minimum data set
NPCP	National Palliative Care Program
NPCS	National Palliative Care Strategy
PCA	Palliative Care Australia
PCDWG	Palliative Care Data Working Group
PCIF	Palliative Care Intergovernmental Forum
PI	performance indicator
PIDWG	Performance Indicator Development Working Group

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# Executive summary

This report presents the findings of the first national collection of performance indicator data for Australia's palliative care sector. The information collected was designed to support the calculation of four national performance indicators that were developed and agreed in 2003 by the Palliative Care Intergovernmental Forum (PCIF) which consists of representatives of the states and territories and the Australian Government. The four performance indicators are based on the goals and objectives that make up the National Palliative Care Strategy (DoHA 2000), which provides the basis for informing palliative care policy and service development. The performance indicators provide some information on the extent to which the Strategy has been implemented.

The Australian Government Department of Health and Ageing commissioned the Australian Institute of Health and Welfare to undertake data development work to enable the capture of information that supports the calculation of the four performance indicators, and to run a trial data collection. The project thus aimed both to provide data for the derivation of the agreed performance indicators and to trial data collection processes and definitions.

This work was carried out in 2005, in collaboration with the Palliative Care Data Working Group (PCDWG), a working group of the PCIF, and involved two collections:

- the Regional Strategic Plan Collection – referred to as the Strategic Plan Collection
- the National Palliative Care Agency Data Collection – referred to as the Agency Collection.

The two collections are collectively known as the National Palliative Care Performance Indicator Data Collection (referred to as the PI Collection). Data definitions, survey instruments and feedback mechanisms were developed for each collection.

## Scope

### Strategic Plan Collection

The criteria for what constituted the scope of the Strategic Plan collection were developed by the PCDWG. Each of the states and territories then applied the criteria to identify their administrative health regions. Thirty-eight regions were nominated across the jurisdictions (see Appendix 1).

### Agency Collection

The PCDWG also developed criteria for what constituted a palliative care agency. Based on these criteria, agency listings were compiled by each of the jurisdictions; all agencies on these listings were surveyed (395 Australia-wide), although 103 agencies were subsequently excluded following further consultation with the states and territories. Of the remaining 292 agencies that were thought to be in scope for the Agency collection, 180 agencies participated in the collection.

Chapters 2 and 5 discuss the problems encountered in defining palliative care agencies in scope for this collection. Work on refining the definitions is continuing, and recommendations will be made for use in future collections.

## Performance indicator results

The performance indicator results are summarised below. Details about these results and how they relate to the Strategy are presented in Chapter 2.

<b>Regional Strategic Plan Collection 2005</b>	
<i>PI 1: The proportion of administrative health regions that have a written plan for palliative care that incorporates palliative care elements</i>	<b>66%</b>
<b>National Palliative Care Agency Data Collection 2005<sup>(a)</sup></b>	
<i>PI 2: The proportion of palliative care agencies, within their setting of care, that routinely undertake or undergo formal assessment against the Palliative Care Australia Standards</i>	
Mostly community setting	<b>36%</b>
Mostly inpatient setting	<b>25%</b>
Similar amount of service in both settings	<b>41%</b>
<b>Total across all settings</b>	<b>34%</b>
<i>PI 3: The proportion of palliative care agencies, within their setting of care, that actively collect feedback from patients/consumers and staff (within the workforce) relating to services and service delivery</i>	
Mostly community setting	<b>75%</b>
Mostly inpatient setting	<b>65%</b>
Similar amount of service in both settings	<b>68%</b>
<b>Total across all settings</b>	<b>71%</b>
<i>PI 4: The proportion of palliative care agencies, within their setting of care, that have formal working partnerships with other service provider(s) or organisation(s)</i>	
Mostly community setting	<b>95%</b>
Mostly inpatient setting	<b>96%</b>
Similar amount of service in both settings	<b>100%</b>
<b>Total across all settings</b>	<b>96%</b>

(a) Results are presented by 'most common setting of care'. For more detail on care settings, see Section 2.3.2.

The figures suggest that, on the whole, palliative care services are meeting the important aspects of the National Palliative Care Strategy that are identified through the performance indicators. Although the performance indicators do not specify benchmarks (i.e. the optimal or desirable proportion of services that should meet the performance indicator criteria), the one performance indicator that suggested there is room for improvement related to the proportion of services that routinely undertake or undergo formal assessment against the Palliative Care Australia (PCA) Standards. The majority of agencies reported that they do not formally monitor and evaluate their service against these standards, although this may be because the agencies evaluate their services against other standards not recognised within the scope of the Agency Collection or they may assess their services against the PCA Standards on an informal basis only or as an ad hoc activity only.

No major differences in the achievement of the performance indicators were obvious across the different palliative care settings (i.e. between services that mainly deliver care in community settings, those that mainly deliver care in inpatient settings, and those that provide a similar amount of services in both settings), although agencies that mostly provided inpatient services were somewhat less likely to undertake or undergo formal assessment against the PCA Standards than the other agency categories.

## **Issues related to the collections and definitions**

Overall, feedback and analysis of data indicated that both trial collections ran successfully. A number of lessons were, however, learnt and will inform future collections.

### **Strategic Plan Collection**

- There is a need for further definition of common situations where it may be unclear whether a strategic plan exists – for example, where a regional restructure takes place and certain health areas under which the existing palliative care plan had been written are now amalgamated into a larger region or where a region has a current draft strategic plan.

### **Agency Collection**

- Some agencies experienced computer disk failure when they tried to save the survey and feedback forms to the disk provided. This was able to be overcome (for agencies that sought help) but the technology would need to be more carefully tested prior to any future collection.
- Some data entry errors were identified. Wherever possible, these were followed up with agencies and corrected.
- Some users reported problems related to difficulty in understanding and/or answering some questions, suggesting the need to further develop some definitions. In particular, participants requested further definition of the terms ‘at least one staff member’ and ‘palliative care practitioner’ (Question 6) and ‘formal working relationships’ (Question 10).

Chapter 4 provides details of feedback provided by respondents in relation to specific questions.

## **Lessons learnt and future directions**

The project obtained important information relating to implementation of four aspects of the National Palliative Care Strategy across the palliative care sector. The project team recommend that continued reporting against the agreed performance indicators occur and that the data obtained through this trial be used as baseline data to monitor changes in implementation over time.

In addition to the performance indicator reporting, a major aim of the project was to assess the data collection process – including the integrity of the data definitions used and other aspects of implementation of the data collection. A detailed discussion of specific issues and recommendations for future data collections is provided in Chapter 5.

