

# **Palliative Care Outcomes Collaboration**

## **Clinical Manual**

## Table of Contents

Introduction to this Manual .....	5
The Palliative Care Outcomes Collaboration Program .....	4
The PCOC Structure .....	Error! Bookmark not defined.
Frequency of Assessment.....	5
The PCOC Cycle.....	Error! Bookmark not defined.
Key Strategies and Enabling Factors .....	6
Implementing PCOC.....	7
National Outcome Measures and Benchmarks .....	9
Level 1: Patient Information.....	10
Level 2: Episode Information .....	13
Level 3: Phase Information.....	23
Palliative Care Phase.....	27
Resource Utilisation Groups - Activities of Daily Living (RUG-ADL).....	30
Australia-modified Karnofsky Performance Status (AKPS).....	33
Palliative Care Problem Severity Score (PCPSS).....	34
Symptom Assessment Scale (SAS) .....	34
Embedding Palliative Care Assessment.....	40
Assessment Process .....	40
References.....	42

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If you would like more information or have any queries please contact your local quality improvement facilitator or contact the national office at [pcoc@uow.edu.au](mailto:pcoc@uow.edu.au) or phone (02) 4221 4411.

# The Palliative Care Outcomes Collaboration

The Palliative Care Outcomes Collaboration (PCOC) is a nationally funded program designed to embed clinical assessment tools into routine clinical practice. PCOC captures clinically meaningful information across a patient's disease trajectory to facilitate improved patient outcomes. This is achieved by:

- Clinical assessment tools
- Education
- National dataset for palliative care
- Outcome measurement and benchmarking
- Patient outcome reporting
- National benchmark workshops
- Quality improvement
- Research

## Background to PCOC

PCOC is a national program that uses a cycle of routine assessment, measurement of patient outcomes and reporting and benchmarking to drive improvements in palliative care – refer to Figure 1. Evidence shows that services can improve the clinical outcomes for palliative care patients by participating in routine collection and systematic feedback (Currow et al, 2014).

A set of standardised and validated clinical assessment tools capture clinically meaningful information at significant periods in a palliative patient's disease trajectory.

At the service level this information is used to drive improvement through:

- Providing feedback to individual services
- Identifying improvement opportunities
- Providing service-to-service benchmarking as part of routine clinical practice.

Figure 1 PCOC cycle



# Introduction

This manual is designed for palliative care clinicians to understand and utilise the PCOC assessment tools and data items as part of routine clinical practice. The manual includes:

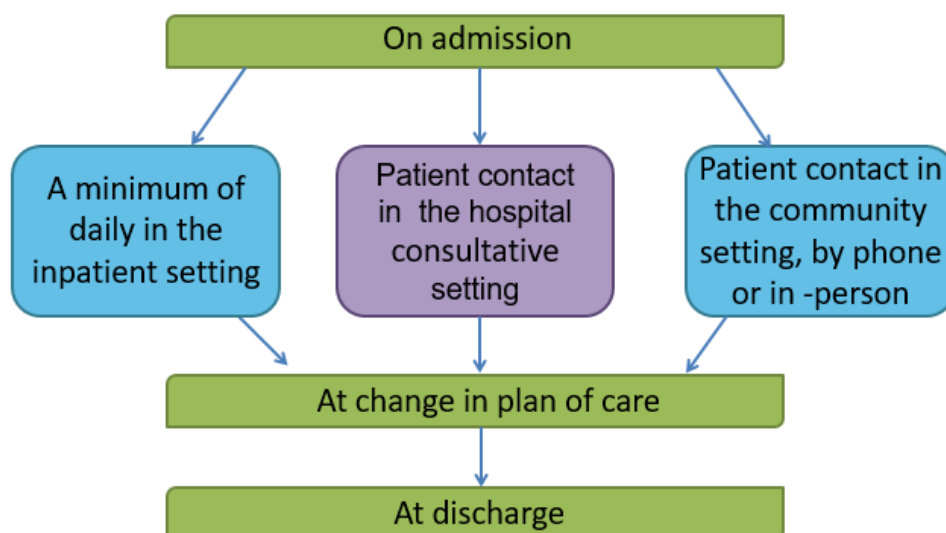
- Assessment tool definitions
- Data item definitions
- Forms
- Information on the benchmarks and outcome measures.

Additional educational resources found at [www.pcoc.org.au](http://www.pcoc.org.au).

## Frequency of Assessment

PCOC provides clinicians with tools to systematically assess individual patient experiences using validated clinical assessment tools. It is helpful to view assessments as palliative care observations or vital signs.

Assessments can be conducted in-person or via the telephone. The frequency of assessment is outlined in the figure. Assessments are conducted daily or at contact to detect changes in patient and family/carer needs.

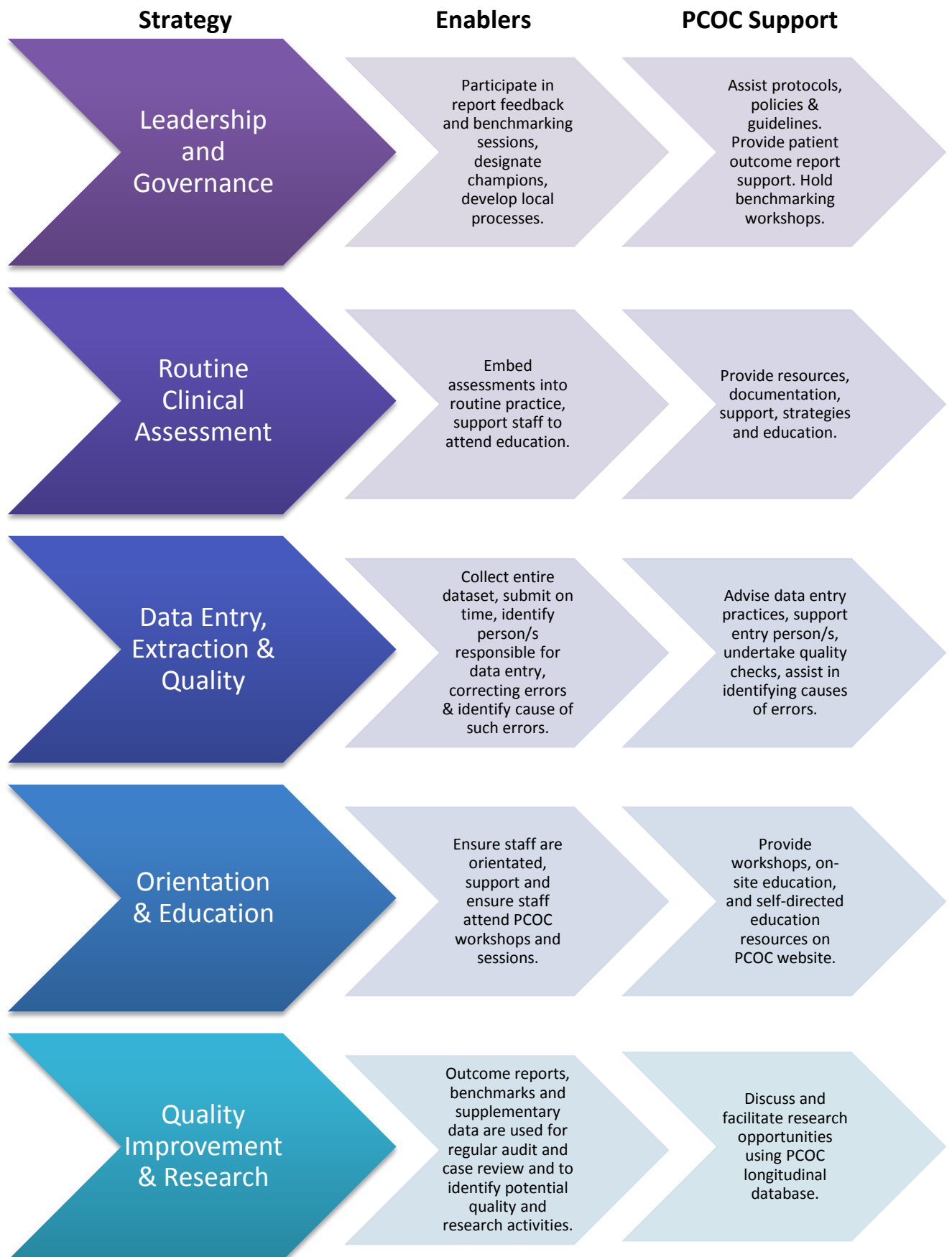


## Benefits of Routine Assessment and Outcome Measurement

- Standard assessment and communication
- Baseline assessment and snapshot of patient needs
- Track and respond to symptom and problems
- Patient, family and carers are part of decision making and care is driven by need
- The palliative care service measures and improves the care it provides

**Better patient  
experience &  
Improved  
outcomes of care**

# PCOC Strategies, Enablers and Support



For further information, refer to the PCOC [Guide for organisations to implement, embed and sustain the Palliative Care Outcomes Collaboration\(PCOC\) program at a service level.](#)

# Implementing, Embedding and Sustaining PCOC

For further information, refer to the [Guide for organisations to implement, embed and sustain the Palliative Care Outcomes Collaboration \(PCOC\) program at a service level.](#)

There are five distinct stages in implementing the PCOC program into routine practice at a service and organisational level; these are planning, implementation, review and monitor, embedding and sustained outcomes and quality improvement – see figure below. The development of an implementation plan is supported by the implementation plan template. These are used together to inform the direction, actions, timeframe, key dates and resources required.

**Figure showing the Stages of Implementing the PCOC Program**



# National Outcome Measures and Benchmarks

The first set of national outcome measures were developed in 2009 and were the subject of extensive consultation at three workshops held in Brisbane, Sydney and Adelaide in May and June 2009 to which all participating services were invited. In December 2009, national benchmarks were formally adopted for each measure.

Following feedback from services attending the 2012 PCOC benchmarking workshops, the benchmark for outcome measure 2 (time in the unstable phase) was revised, with three benchmarks amalgamated into one (for further information see the document time in the unstable phase - revised benchmark). A new item was introduced in version 3 dataset and in 2014 Benchmark 1 was changed from 'Time from referral to first contact' to 'Time from date ready for care to episode start'

In 2015, PCOC introduced three new patient outcome measures and associated benchmarks. These three outcome measures relate to distress due to fatigue and breathing problems (both rated by the SAS) and family / carer problems (as rated by the PCPSS). For further information, refer to the [National Outcome Measures and Benchmarks](#) page on the PCOC website, or refer to the [Development of Benchmarks](#) page.

## 1. Time from date ready for care to episode start

Time from date ready for care to episode start reports responsiveness of palliative care services to patient needs. This measures the time taken for an episode to commence following the date the patient is available and ready to receive palliative care.

**Benchmark 1:** 90% of patients must have their episode commence on the day of, or the day after date ready for care.

## 2. Time in the unstable phase

The unstable phase alerts clinical staff to the need for urgent changes to the patient's plan of care or that emergency intervention is required. Patients assessed to be in the unstable phase require intense review for a short period of time.

**Benchmark 2:** 90% of unstable phases must last for 3 days or less.

## 3. Change in symptoms/problems

Change in symptoms or problems is calculated by the difference in assessment from the beginning of a phase to the end of phase, and is calculated using the measures from both the Palliative Care Problem Severity Score (PCPSS) and Symptom Assessment Scale (SAS).

### Pain (PCPSS & SAS)

Change in pain is calculated by the difference in pain score from the beginning of a phase to the end of phase and is calculated using the pain measures in the Palliative Care Problem Severity Score (PCPSS) and Symptom Assessment Scale (SAS).

**Benchmark 3.1:** At least 90% of patients with absent or mild PCPSS pain at the beginning of their phase of palliative care have absent or mild PCPSS pain at the end of the phase.

**Benchmark 3.2:** At least 60% of patients with moderate or severe PCPSS pain at the beginning of their phase of palliative care have absent or mild PCPSS pain at the end of the phase.

**Benchmark 3.3:** At least 90% of patients with absent or mild SAS pain at the beginning of their phase of palliative care have absent or mild SAS pain at the end of the phase.

**Benchmark 3.4:** At least 60% of patients with moderate or severe SAS pain at the beginning of their phase of palliative care have absent or mild SAS pain at the end of the phase.

### Fatigue (SAS)

**Benchmark 3.5:** At least 90% of patients with absent or mild fatigue at the beginning of their phase of palliative care have absent or mild fatigue at the end of the phase.



**Benchmark 3.6:** At least 60% of patients with moderate or severe fatigue at the beginning of their phase of palliative care have absent or mild fatigue at the end of the phase.

#### **Breathing problems (SAS)**

**Benchmark 3.7:** At least 90% of patients with absent or mild breathing problems at the beginning of their phase of palliative care have absent or mild breathing problems at the end of the phase.

**Benchmark 3.8:** At least 60% of patients with moderate or severe breathing problems at the beginning of their phase of palliative care have absent or mild breathing problems at the end of the phase.

#### **Family/carer problems (PCPSS)**

**Benchmark 3.9:** At least 90% of patients with absent or mild family / carer problems at the beginning of their phase of palliative care have absent or mild family / carer problems at the end of the phase.

**Benchmark 3.10:** At least 60% of patients with moderate or severe family / carer problems at the beginning of their phase of palliative care have absent or mild family / carer problems at the end of the phase.

### **4. Change in symptoms relative to the national average (X-CAS)**

Change in symptoms relative to the national average measures the mean change in symptoms on the PCPSS/SAS that are adjusted for both phase and for the symptom score at the start of each phase. This measure allows services to compare the change in symptom score for 'like' patients i.e. patients in the same phase who started with the same level of symptom. Eight symptoms are included in the measure:

- PCPSS pain, other symptoms, psychological/spiritual, family/carer.
- SAS pain, nausea, bowel problems, breathing problems.

The measure is referred to as the X-CAS, with X representing the fact that multiple symptoms are included and CAS is an abbreviation for Casemix Adjusted Score.

A positive score indicates that a service is performing above the baseline national average and a negative score that it is below the baseline national average.

# Level 1: Patient Information

Patient level information describes demographics. Refer to example of episode form on page 19.

PCOC defines a patient as a person for whom a palliative care services accepts responsibility for assessment and/or treatment as evidenced by the existence of a medical record. Family/carers are included in this definition if interventions relating to them are recorded in the patient medical record.

For further information refer to the [PCOC Data Set Outline](#).

## What is patient information used for?

Demographic information about the patient provides a context to the episode level and phase level information and enhances the meaningfulness of patient outcomes.

## What information is collected?

### Unique patient identifier

Definition: Unique patient identifier established by the palliative care provider. This is usually a medical record/unit record number which is generated for each patient within a service. This number must be used at all times when recording patient episode and phase level information for PCOC.

Document: The medical record number.

### Date of birth

Definition: Date of birth reports the age groups within a service.

Document: The patient's date of birth.

### Sex

Definition: Gender is useful in determining service utilisation and service needs.

Document: One of the following

Male
Female
Indeterminate

## Australian state

**Definition:** The Australian state or territory (or other country) the patient usually resides. This is a geographic indicator and reports the provision of palliative care across the country.

**Document:** One of the following

New South Wales
Victoria
Queensland
South Australia
Western Australia
Tasmania
Northern Territory
Australian Capital Territory
Other Australian territories
Not Australia

## Australian postcode

**Definition:** The postcode of the patient's usual place of residence. This data item reports on utilisation patterns of palliative care.

**Document:** The numerical post code for the area where the patient usually resides or their home address.

## Indigenous status

**Definition:** Identifies persons as being of Aboriginal or Torres Strait Islander origin and reports the utilisation of palliative care by the indigenous population.

**Document:** One of the following

Aboriginal but not Torres Strait Islander origin
Torres Strait Islander but not Aboriginal origin
Both Aboriginal and Torres Strait Islander origin
Neither Aboriginal nor Torres Strait Islander origin

## Preferred language

**Definition:** The language reported by a person as the most preferred for communication. This data item assists in the planning and provision of multilingual services and facilitates program and service delivery for patients and family/carers from culturally and linguistic backgrounds. Preferred language is sourced from the Australian Standard Classification of Languages (ASCL), ABS 2011

**Document:** The language reported by a person as the most preferred for communication.

## Country of birth

Definition: The patient's country of birth. This data item assists in analysis of access to palliative care services by different population subgroups.

Document: The country the patient was born in.

## Primary diagnosis

Definition: The principal life limiting illness responsible for patient requiring palliative care from your service. The principle diagnosis may not be the same as the reason for this episode of care. For example a patient's principle diagnosis is prostate cancer but has been admitted to palliative care due to pain from bone metastasis. The diagnosis is recorded as prostate not bone and soft tissue. This item provides information on diagnosis for outcome analysis and service planning.

Document: One of the following

Malignant – not further defined
Bone and soft tissue
Breast
Central Nervous System
Colorectal
Other GIT
Haematological
Head and neck
Lung
Pancreas
Prostate
Other urological
Gynecological
Skin
Unknown primary malignancy
Other primary malignancy
Nonmalignant – not further defined
Cardiovascular disease
HIV/AIDS
End stage kidney disease
Stroke
Motor Neurone Disease
Alzheimer's dementia
Other dementia
Other neurological disease
Respiratory failure
End stage liver disease
Diabetes and its complications
Sepsis
Multiple organ failure
Other non-malignancy

## Level 2: Episode Information

Episode level includes data items which focus on characterising the setting of palliative care service provision. They also provide information relating to the reasons why and how a palliative care episode starts and ends, the level of support a palliative care patient received both before and after an episode and (where applicable) the setting in which the patient died. Refer to example of episode form on page 19.

For further information refer to the [PCOC Data Set Outline](#).

### What is an Episode of Care?

An episode of care is a period of contact between a patient and a palliative care service that is provided by one palliative care service and occurs in one setting. An episode of care ends when the setting of care changes. Under this definition, a patient receiving palliative care is likely to have more than one episode of care.

### Measuring patient outcomes at the episode level

Episode level information is used to measure responsiveness of palliative care services to patient needs. The date the patient is ready for care and the date the episode of care commences are used to measure responsiveness.

### What information is collected for the Episode Level?

#### Team identifier

**Definition:** Team identity is an option for palliative care services that have multiple teams. It allows a palliative care service to identify which team was responsible for providing care. For example an inpatient unit with two wards or a community service separated by geographic regions.

**Document:** A name and 4-character identifier for the team assigned by PCOC.

#### Referral date

**Definition:** The date a service receives a referral to provide palliative care for a patient for this episode. The referral can be either written or verbal.

**Document:** The date the referral for this episode of care is received.

## Referral source

**Definition:** The facility/organisation from which the patient was referred for this specific episode. Referral source assists in understanding referral patterns for service planning.

**Document:** One of the following

Public hospital – not further defined
Public hospital – palliative care unit/team
Public hospital – oncology unit/team
Public hospital – medical unit/team
Public hospital – surgical unit/team
Public hospital – emergency department
Private hospital – not further defined
Private hospital – palliative care unit/team
Private hospital – oncology unit/team
Private hospital – medical unit/team
Private hospital – surgical unit/team
Private hospital – emergency department
Outpatient clinic
General Practitioner
Specialist Practitioner
Community Palliative Care Service
Community Generalist Service
Residential Aged Care Facility
Self, carer(s), family, friends
Other

## First contact date

**Definition:** The date a clinician has contact with the patient and or carer to determine patient needs following receipt of referral. This contact may be in-person or by telephone.

**Document:** The date clinical contact made with the patient or carer, in-person or by telephone for this episode of care.

## Date ready for care

**Definition:** The date the patient is ready and available to receive palliative care. The date ready for care may be determined by referral or by first contact with the patient / carer.

If a referral is received but the patient is not available for care, the date ready for care will be the date specified by the patient / carer. Reasons for the patient not ready for care may include:

- early referral for planning purposes
- planned holidays.

**Document:** The date identified that the patient is ready to receive palliative care.

## Episode start date

**Definition:** The date when the first in-person comprehensive palliative care assessment is undertaken and documented using the five PCOC clinical assessment tools. The date is required to determine the number of days of each episode of care (elapsed days).

**Document:** The date the episode of palliative care commenced.

## Episode type

**Definition:** The setting of care or location in which the patient is receiving palliative care for this episode. This information allows patients to be grouped into similar settings of care.

**Document:** For the inpatient setting (including consult liaison services) document one of the overnight admitted options. For ambulatory and outpatient clinics document hospital ambulatory, same day admitted or outpatient. For community settings document one of the community options.

<b>Patients admitted for an inpatient episode</b>
Overnight Admitted – Not Further Specified
Overnight Admitted – Designated Palliative Care Bed
Overnight Admitted - Non-designated Palliative Care Bed

<b>Patients admitted for ambulatory, clinics or day hospital</b>
Hospital Ambulatory - Not Further Specified
Same Day Admitted
Outpatient

<b>Patients admitted for a community episode</b>
Community – Not Further Specified
Private Residence
Residential Aged Care Facility

## Episode start mode

Definition: Where the patient was admitted from for this episode of care.

Document: One of the following

<b>Patients admitted for an inpatient episode</b>
Admitted from usual accommodation
Admitted from other than usual accommodation
Admitted (transferred) from another hospital
Admitted (transferred) from acute care in another ward
Change from acute care to palliative care while remaining on same ward
Change of sub-acute
Other

<b>Patients admitted for community or ambulatory episode</b>
Patient admitted from being an overnight admitted palliative care patient
Patient was not admitted from being an overnight palliative care patient

## Accommodation at episode start

Definition: The type of accommodation the patient was admitted from for this episode of care.

Document: One of the following for inpatient episodes if the patient was:

- Admitted from usual accommodation
- Admitted from other than usual accommodation.

One of the following for community or ambulatory episodes if the patient was:

- Not admitted from being an overnight palliative care patient.

Private residence (including unit in retirement village)
Residential aged care – low level care (hostel)
Residential aged care – high level care (nursing home)
Other



## Episode end date

- Definition: The date when:
- patient is separated from the current setting of care (e.g. from community to inpatient), or
  - patient dies, or
  - principal clinical intent of the care changes and the patient is no longer receiving palliative care.

The episode end date identifies the period in which the patient's episode of care occurred. The episode start date and episode end date are used to report the number of days for this episode.

- Document: The date the patient was discharged or the date the patient died or date of bereavement phase end.

## Episode end mode

- Definition: The reason this episode of palliative care ended. This information describes how the episode of care ended, determining number of deaths, discharge locations such as other hospitals or number of community discharges to hospital.

- Document: One of the following

<b>Patients admitted overnight for an inpatient episode</b>
Discharged to usual accommodation
Discharged to other than usual accommodation
Death
Discharged to another hospital
Change from palliative care to acute care – different ward
Change from palliative care to acute care – same ward
Change in sub-acute care type
End of consultative episode – inpatient episode ongoing
Other

<b>Patients admitted for a community or ambulatory episode</b>
Death
Discharged for inpatient palliative care
Discharged for inpatient acute care
Discharged to another palliative care service
Discharged to primary health care (e.g. GP)
Other

## Accommodation at episode end

**Definition:** The residential accommodation of the patient if the patient is discharged from the setting of care. Describes the patient's residential accommodation immediately following discharge. It is not completed if the episode ends in death.

**Document:** One of the following

Private residence (including unit in retirement village)
Residential aged care – low level care (hostel)
Residential aged care – high level care (nursing home)
Other

## Place of death


**Definition:** The care setting where the patient dies. Only complete if the episode end mode is death.

**Document:** One of the following

Home
Residential Aged Care Facility
Hospital

## Clinical Forms

The PCOC episode forms for inpatient and community can be found on the following pages. Please see the website for [additional forms](#) including the hospital consult form.

Insert service name and logo here		(Complete or affix Addressograph Label here)
		UPI _____ DOB _____
		Surname _____
		Given Names _____
		Gender Male <input type="checkbox"/> Female <input type="checkbox"/> Other <input type="checkbox"/>
		State _____ Postcode _____

**Inpatient Episode Information**

Ward/Unit name: \_\_\_\_\_

**Section 1** (Complete at start of episode)

**Country of Birth**  Australia  Other, specify \_\_\_\_\_

**Preferred Language**  English  Other, specify \_\_\_\_\_

**Indigenous Status**

Aboriginal but not Torres Strait Islander origin       Torres Strait Islander but not Aboriginal origin  
 Both Aboriginal and Torres Strait Islander origin       Neither Aboriginal nor Torres Strait Islander origin  
 Not stated / inadequately described

**Primary Diagnosis** (principal life-limiting illness)

**Malignant**

<input type="checkbox"/> Bone & soft tissue	<input type="checkbox"/> Gynaecological	<input type="checkbox"/> Pancreas	<input type="checkbox"/> Other GIT
<input type="checkbox"/> Breast	<input type="checkbox"/> Haematological	<input type="checkbox"/> Prostate	<input type="checkbox"/> Other Urological
<input type="checkbox"/> CNS	<input type="checkbox"/> Head and Neck	<input type="checkbox"/> Skin	<input type="checkbox"/> Other Malignancy
<input type="checkbox"/> Colorectal	<input type="checkbox"/> Lung	<input type="checkbox"/> Unknown Primary	

**Non-malignant**

<input type="checkbox"/> Cardiovascular disease	<input type="checkbox"/> Alzheimer's disease	<input type="checkbox"/> Diabetes & its complications
<input type="checkbox"/> HIV/AIDS	<input type="checkbox"/> Other dementia	<input type="checkbox"/> Sepsis
<input type="checkbox"/> End stage kidney disease	<input type="checkbox"/> Other neurological disease	<input type="checkbox"/> Multiple organ failure
<input type="checkbox"/> Stroke	<input type="checkbox"/> Respiratory failure	<input type="checkbox"/> Other non-malignancy
<input type="checkbox"/> Motor Neurone Disease	<input type="checkbox"/> End stage liver disease	


**Referral Source** (referring agency/facility)

<input type="checkbox"/> Public hospital palliative care unit/team	<input type="checkbox"/> Private hospital palliative care unit/team
<input type="checkbox"/> Public hospital oncology unit/team	<input type="checkbox"/> Private hospital oncology unit/team
<input type="checkbox"/> Public hospital medical unit/team	<input type="checkbox"/> Private hospital medical unit/team
<input type="checkbox"/> Public hospital surgical unit/team	<input type="checkbox"/> Private hospital surgical unit/team
<input type="checkbox"/> Public hospital emergency department	<input type="checkbox"/> Private hospital emergency department
<input type="checkbox"/> Community palliative care service	<input type="checkbox"/> Outpatient clinic
<input type="checkbox"/> Community generalist service	<input type="checkbox"/> General practitioner
<input type="checkbox"/> Specialist practitioner	<input type="checkbox"/> Residential aged care facility
<input type="checkbox"/> Self, carer(s), family or friends	<input type="checkbox"/> Other

SERVICE NAME  
DO NOT WRITE

INPATIENT EPISODE INFORMATION JULY 2014

<b>Referral Date:</b> ___ / ___ / _____ (referral date for this episode)
<b>Date Ready for Care:</b> ___ / ___ / _____ (date the patient is ready/available for admission)
<b>Episode Start Date / First Contact Date:</b> ___ / ___ / _____ (date of admission)
<b>Episode Start Mode</b> <input type="checkbox"/> Admitted from usual accommodation                    (complete accommodation at episode start) <input type="checkbox"/> Admitted from other than usual accommodation    (complete accommodation at episode start) <input type="checkbox"/> Admitted from another hospital <input type="checkbox"/> Admitted from acute care in another ward <input type="checkbox"/> Change from acute care while remaining on same ward <input type="checkbox"/> Change from another sub-acute care type e.g. rehab <input type="checkbox"/> Other
<b>Accommodation at Episode Start</b> (where the patient was prior to hospital admission- complete if admitted from usual or other than usual accommodation) <input type="checkbox"/> Private residence (including unit in retirement village) <input type="checkbox"/> Residential aged care, low level care (hostel) <input type="checkbox"/> Residential aged care, high level care (nursing home) <input type="checkbox"/> Other
<b>Episode Type</b> (where the patient is receiving palliative care) <input type="checkbox"/> Overnight admitted designated palliative care bed <input type="checkbox"/> Overnight admitted non-designated palliative care bed <input type="checkbox"/> Overnight admitted not further specified
<b>Section 2</b> (Complete at end of episode)
<b>Episode End Date:</b> ___ / ___ / _____ (date patient's episode of palliative care ends)
<b>Episode End Mode</b> <input type="checkbox"/> Discharged to usual accommodation <input type="checkbox"/> Discharged to other than usual accommodation <input type="checkbox"/> Death (in hospital) <input type="checkbox"/> Discharged to another hospital <input type="checkbox"/> Change to acute care different ward <input type="checkbox"/> Change to acute care same ward <input type="checkbox"/> Change to another sub-acute care type e.g. rehab <input type="checkbox"/> Other
<b>Accommodation at Episode End</b> (complete only if discharged to usual accommodation or other than usual accommodation) <input type="checkbox"/> Private residence (including unit in retirement village) <input type="checkbox"/> Residential aged care, low level care (hostel) <input type="checkbox"/> Residential aged care, high level care (nursing home) <input type="checkbox"/> Other

Insert service name and logo here		(Complete or affix Addressograph Label here) UPI _____ DOB _____ Surname _____ Given Names _____ Gender Male <input type="checkbox"/> Female <input type="checkbox"/> Other <input type="checkbox"/> State _____ Postcode _____
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**Community Patient Episode Information**

Team name: \_\_\_\_\_

**Section 1** (Complete at start of episode)

**Country of Birth**       Australia     Other, specify \_\_\_\_\_

**Preferred Language**       English     Other, specify \_\_\_\_\_

**Indigenous Status**

Aboriginal but not Torres Strait Islander origin       Torres Strait Islander but not Aboriginal origin  
 Both Aboriginal and Torres Strait Islander origin       Neither Aboriginal nor Torres Strait Islander origin  
 Not stated / inadequately described

**Primary Diagnosis** (principal life-limiting illness)

**Malignant**

<input type="checkbox"/> Bone & soft tissue	<input type="checkbox"/> Gynaecological	<input type="checkbox"/> Pancreas	<input type="checkbox"/> Other GIT
<input type="checkbox"/> Breast	<input type="checkbox"/> Haematological	<input type="checkbox"/> Prostate	<input type="checkbox"/> Other Urological
<input type="checkbox"/> CNS	<input type="checkbox"/> Head and Neck	<input type="checkbox"/> Skin	<input type="checkbox"/> Other Malignancy
<input type="checkbox"/> Colorectal	<input type="checkbox"/> Lung	<input type="checkbox"/> Unknown Primary	

**Non-malignant**

<input type="checkbox"/> Cardiovascular disease	<input type="checkbox"/> Alzheimer's disease	<input type="checkbox"/> Diabetes & its complications
<input type="checkbox"/> HIV/AIDS	<input type="checkbox"/> Other dementia	<input type="checkbox"/> Sepsis
<input type="checkbox"/> End stage kidney disease	<input type="checkbox"/> Other neurological disease	<input type="checkbox"/> Multiple organ failure
<input type="checkbox"/> Stroke	<input type="checkbox"/> Respiratory failure	<input type="checkbox"/> Other non-malignancy
<input type="checkbox"/> Motor Neurone Disease	<input type="checkbox"/> End stage liver disease	

**Referral Source (referring agency/facility)**

<input type="checkbox"/> Public hospital palliative care unit/team	<input type="checkbox"/> Private hospital palliative care unit/team
<input type="checkbox"/> Public hospital oncology unit/team	<input type="checkbox"/> Private hospital oncology unit/team
<input type="checkbox"/> Public hospital medical unit/team	<input type="checkbox"/> Private hospital medical unit/team
<input type="checkbox"/> Public hospital surgical unit/team	<input type="checkbox"/> Private hospital surgical unit/team
<input type="checkbox"/> Public hospital emergency department	<input type="checkbox"/> Private hospital emergency department
<input type="checkbox"/> Community palliative care service	<input type="checkbox"/> Outpatient clinic
<input type="checkbox"/> Community generalist service	<input type="checkbox"/> General practitioner
<input type="checkbox"/> Specialist practitioner	<input type="checkbox"/> Residential aged care facility
<input type="checkbox"/> Self, carer(s), family or friends	<input type="checkbox"/> Other

SERVICE NAME  
DO NOT WRITE

COMMUNITY PATIENT EPISODE INFORMATION JULY 2014

<b>Referral Date:</b> ___ / ___ / _____ (referral date for this episode)
<b>First Contact Date:</b> ___ / ___ / _____ (date of clinical assessment to determine needs)
<b>Date Ready for Care:</b> ___ / ___ / _____ (date the patient is ready and available for care)
<b>Episode Start Date:</b> ___ / ___ / _____ (date the plan of care is documented and initiated)
<b>Episode Start Mode</b> <input type="checkbox"/> Discharged from being an inpatient palliative care patient <input type="checkbox"/> Not discharged from being an inpatient palliative care patient
<b>Accommodation at Episode Start</b> (where the patient is currently living) <input type="checkbox"/> Private residence (including unit in retirement village) <input type="checkbox"/> Residential aged care, low level care (hostel) <input type="checkbox"/> Residential aged care, high level care (nursing home) <input type="checkbox"/> Other
<b>Episode Type</b> (where the patient is receiving palliative care) <input type="checkbox"/> Private residence <input type="checkbox"/> Residential Aged Care Facility <input type="checkbox"/> Community not further defined
<b>Section 2</b> (Complete at end of episode)
<b>Episode End Date:</b> ___ / ___ / _____ (date patient's episode of palliative care ends)
<b>Episode End Mode</b> <input type="checkbox"/> Death (in community) <input type="checkbox"/> Discharged for inpatient palliative care <input type="checkbox"/> Discharged for inpatient acute care <input type="checkbox"/> Discharged to another community palliative care service <input type="checkbox"/> Discharged to primary health care e.g. GP <input type="checkbox"/> Other
<b>Accommodation at Episode End</b> (if discharged) <input type="checkbox"/> Private residence (including unit in retirement village) <input type="checkbox"/> Residential aged care, low level care (hostel) <input type="checkbox"/> Residential aged care, high level care (nursing home)
<b>Place of Death</b> <input type="checkbox"/> Home <input type="checkbox"/> Residential Aged Care Facility

## Level 3: Phase Information

Phase level information describes a palliative care patient's stage of illness, functional ability and levels of pain and symptom distress, using five clinical assessment tools.

The five clinical assessment tools used in PCOC assess the key domains of palliative care. These are palliative care phases, the patient's functional status and performance, pain and other common symptoms, the patient's psycho/spiritual and family/carer domain. This information describes the clinical condition of the patient during the episode.

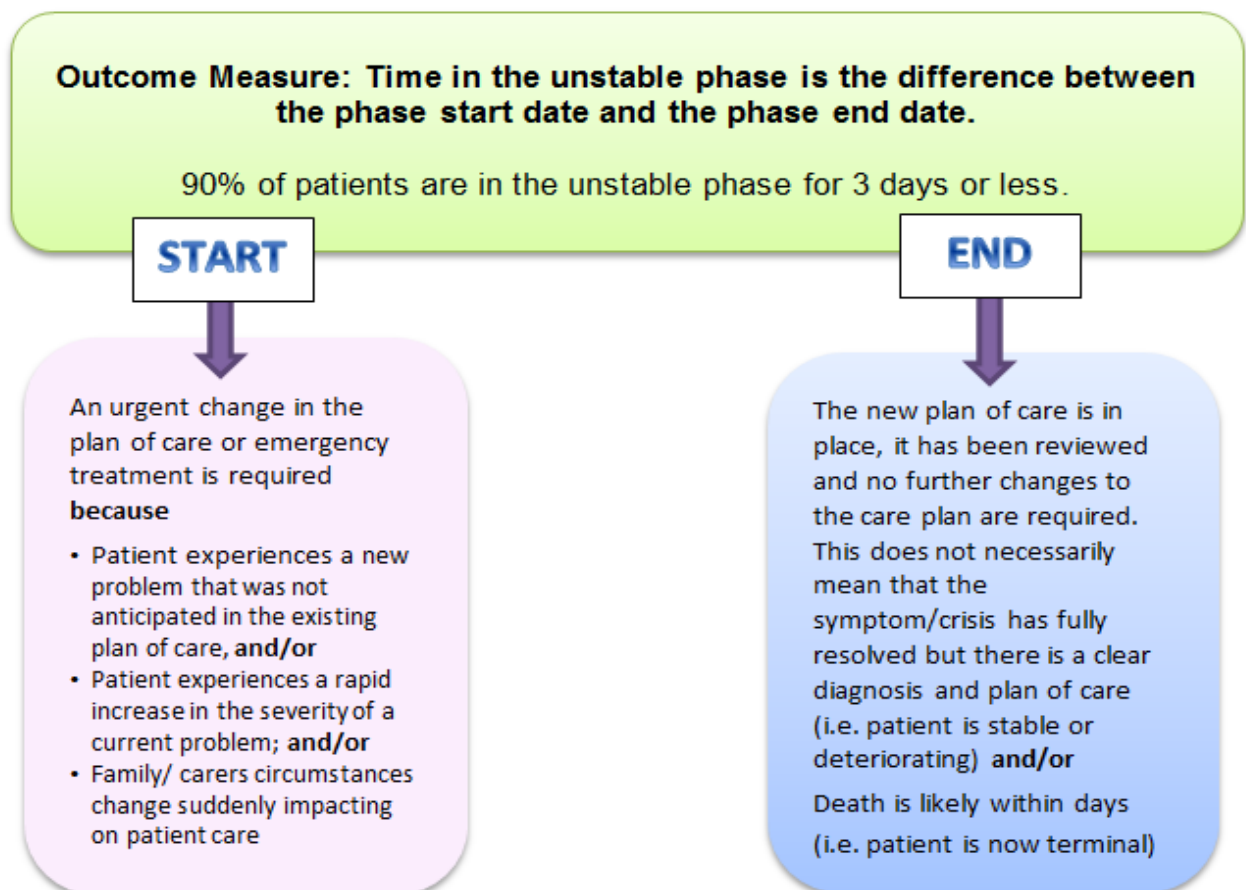
The five assessment tools are:

- Palliative Care Phase
- Resource Utilisation Groups-Activities of Daily Living
- Australia-modified Karnofsky Performance Status
- Palliative Care Problem Severity Score
- Symptom Assessment Scale

Further information on the assessment tools including videos are on the [Introduction to Assessment Tools](#) page on the PCOC website.

### Measuring patient outcomes at the phase level

The clinical assessments are assessed daily for inpatient or at each community patient contact. They are reported at admission, when the phase changes and at discharge. There are three outcome measures using phase level information



# What information is collected for phase?

## Phase start date

Definition: The date each new phase starts.  
Document: The start date for the first phase and the date of each phase change.

## Phase end date

Definition: The date each phase ends.  
Document: The date the phase ended.


## Reason for phase end

Definition: The reason the phase ended. This data item reports the progression of phases over time. When reason for phase end is a phase change the subsequent phase must be different to the previous phase.

Document: One of the following:

Phase changed to Stable
Phase changed to Unstable
Phase changed to Deteriorating
Phase changed to Terminal
Death
End Bereavement Phase/Post Death Support
Discharge



Palliative Assessment and Clinical Response					(Please complete or affix Label here)														
<b>[Insert Service Name Here]</b>										UPI:									
										Surname									
First name:																			
DOB:																			
Assess on admission, daily, at phase change and on discharge																			
Year 20																			
Date																			
Time																			
<b>Palliative Care Phase (1-4 Died or D/C) Refer to complete definition</b> <b>Stable = Monitor    Unstable = Urgent action required    Deteriorating = Review plan of care    Terminal = Provide EOL care</b> <b>Died = record date, no further assessment required    Discharge (D/C) = assess at discharge</b>																			
<b>Palliative Care Phase</b>																			
<b>RUG-ADL Refer to complete definition</b> <b>4 - 5 = Monitor</b> <b>6 - 10 = assist x 1</b> <b>10+ = assist x 1, consider equipment, staff requirements, falls risk, referral</b> <b>15+ = as above, pressure area risk, consider carer burden and MDT review</b> <b>18 = as above, full care assistance x 2</b>																			
Bed mobility																			
Toileting																			
Transfers																			
Eating																			
Total RUG ADL (4-18):																			
<b>Problem Severity Score Actions (0-3) Refer to complete definition and rate each domain</b> <b>0 = Continue care    1 = Monitor and record    2 = Review/change plan of care; referral, intervention as required    3 = Urgent action</b>																			
Pain																			
Other Symptoms																			
Psychological / Spiritual																			
Family / Carer																			
<b>Australia-modified Karnofsky Performance Status Scale (10-100) Refer to complete definition</b> <b>Consider MDT review at score of 50 or below</b>																			
AKPS																			
<b>Symptom Assessment Scale (0-10) Rate experience of symptom distress over a 24hr period</b> <b>0 = absent 10 = worst possible</b> <b>0 = Continue care    1 -3 = Monitor and record    4-7 = Review/change plan of care; referral, intervention as required    8-10 = Urgent action</b>																			
Distress from difficulty sleeping																			
Distress from Appetite																			
Distress from Nausea																			
Distress from Bowels																			
Distress from Breathing																			
Distress from Fatigue																			
Distress from Pain																			
Completed by Patient, Fam/Carer or Clinician																			
Staff Initials																			

<p style="text-align: center;"><b>Palliative Care Phase</b></p> <p style="text-align: center;"><b>Abbreviated Definition</b></p> <p><b>Clinician rated assessment</b></p> <ol style="list-style-type: none"> <li><b>Stable</b> Symptoms are adequately controlled by established management</li> <li><b>Unstable</b> Development of a new problem or a rapid increase in the severity of existing problems</li> <li><b>Deteriorating</b> Gradual functional decline and worsening of existing symptoms or the development of new but expected problems</li> <li><b>Terminal</b> Death likely in a matter of days</li> </ol> <p>Complete Phase Definitions available on the PCOC website <a href="http://www.pcoc.org.au">www.pcoc.org.au</a></p>	<p style="text-align: center;"><b>Resource Utilisation Group – Activities of Daily Living</b></p> <p style="text-align: center;"><b>Abbreviated Definition</b></p> <p><b>Clinician rated assessment of dependency over 24hr period</b></p> <table border="0"> <tr> <td style="vertical-align: top;"> <p><b>For Bed Mobility, Toileting &amp; Transfers</b></p> <ol style="list-style-type: none"> <li>Independent or supervision only</li> <li>Limited physical assistance</li> <li>Other than two person physical assist</li> <li>Two or more person physical assist</li> </ol> </td> <td style="vertical-align: top;"> <p><b>For Eating</b></p> <ol style="list-style-type: none"> <li>Independent or supervision only</li> <li>Limited assistance</li> <li>Extensive assistance / total dependence / tube fed</li> </ol> </td> </tr> </table> <p>Complete RUG-ADL definitions available on the PCOC website <a href="http://www.pcoc.org.au">www.pcoc.org.au</a></p>	<p><b>For Bed Mobility, Toileting &amp; Transfers</b></p> <ol style="list-style-type: none"> <li>Independent or supervision only</li> <li>Limited physical assistance</li> <li>Other than two person physical assist</li> <li>Two or more person physical assist</li> </ol>	<p><b>For Eating</b></p> <ol style="list-style-type: none"> <li>Independent or supervision only</li> <li>Limited assistance</li> <li>Extensive assistance / total dependence / tube fed</li> </ol>
<p><b>For Bed Mobility, Toileting &amp; Transfers</b></p> <ol style="list-style-type: none"> <li>Independent or supervision only</li> <li>Limited physical assistance</li> <li>Other than two person physical assist</li> <li>Two or more person physical assist</li> </ol>	<p><b>For Eating</b></p> <ol style="list-style-type: none"> <li>Independent or supervision only</li> <li>Limited assistance</li> <li>Extensive assistance / total dependence / tube fed</li> </ol>		
<p style="text-align: center;"><b>Problem Severity Score</b></p> <p style="text-align: center;"><b>Complete Definition</b></p> <p><b>Clinician rated assessment of problems over a 24hr period</b></p> <p>Global assessment of four palliative care domains to summarise palliative care needs and plan care.</p> <p>The severity of problems are rated and responded to following using the scale:</p> <p><b>0 = Absent; 1 = Mild; 2 = Moderate; 3 = Severe</b></p> <p><b>Pain:</b> overall severity of pain problems for the patient</p> <p><b>Other Symptoms:</b> overall severity of problems relating to one or more symptoms other than pain</p> <p><b>Psychological / Spiritual:</b> severity of problems relating to the patient's psychological or spiritual wellbeing. May be one or more issues.</p> <p><b>Family / Carer:</b> problems associated with a patient's condition or palliative care needs. Family / Carer do not need to be present to assess needs as written, verbal or observational information may be used.</p>	<p style="text-align: center;"><b>Australia-modified Karnofsky Performance Status</b></p> <p style="text-align: center;"><b>Complete Definition</b></p> <p><b>Clinician rated assessment of performance relating to work, activity and self-care over a 24hr period</b></p> <ol style="list-style-type: none"> <li>100. Normal, no complaints or evidence of disease</li> <li>90. Able to carry on normal activity, minor signs or symptoms of disease</li> <li>80. Normal activity with effort, some signs or symptoms of disease</li> <li>70. Care for self, unable to carry on normal activity or to do active work</li> <li>60. Occasional assistance but is able to care for most needs</li> <li>50. Requires considerable assistance and frequent medical care</li> <li>40. In bed more than 50% of the time</li> <li>30. Almost completely bedfast</li> <li>20. Totally bedfast &amp; requiring nursing care by professionals and/or family</li> <li>10. Comatose or barely rousable</li> </ol>		
<p style="text-align: center;"><b>Symptom Assessment Scale</b></p> <p style="text-align: center;"><b>Complete Definition</b></p>			
<p style="text-align: center;"><b>Patient Rated distress relating to symptoms over a 24hr period</b></p> <p>The Symptom Assessment Scale describes the patient's level of distress relating to individual physical symptoms. The symptoms and problems in the scale are the seven most common.</p> <p><b>Usage:</b></p> <ol style="list-style-type: none"> <li>Best practice is for the patient to rate distress either independent or with the assistance of a clinician or family/carer using a visual of the scale such as the <i>Symptom Assessment Scale Form for Patients</i>.</li> <li>Symptom distress may be rated by proxy. This only occurs when the patient is unable to participate in conversation relating to symptom distress i.e. Terminal phase.</li> </ol> <p><b>Proxy:</b> a family / carer or clinician who rates symptom distress on behalf of the patient through observational assessment.</p> <p><b>Instructions:</b> patient to consider their experience of the individual symptom or problem over the last 24 hours and rate distress according to</p> <p style="padding-left: 40px;">A score of 0: means the symptom or problem is absent</p> <p style="padding-left: 40px;">A score of 1: means the symptom or problem is causing minimal distress.</p> <p style="padding-left: 40px;">A score of 10: means the symptom or problem is causing the worst possible distress.</p> <p>SAS translations available on the PCOC website <a href="http://www.pcoc.org.au">www.pcoc.org.au</a></p>			

## Palliative Care Phase

The palliative care phase identifies a clinically meaningful period in a patient's condition. The palliative care phase is determined by a holistic clinical assessment which considers the needs of the patients and their family and carers. Further information on the [palliative care phase](#) is on the PCOC website.

The phases provide a framework for referrals, triage and care planning as well as communication between teams. Phases were based on the following principles:

- In palliative care, the focus is on patient needs, goals and priorities rather than the disease.
- In palliative care, the patient and their carers are the unit of care.
- Palliative care patients have episodes of care that include acute exacerbations.
- Such episodes are applicable at home or hospital (Smith 1993) describes the needs of the patient and their family and carers.

### How to document Phase, RUG-ADL, AKPS, PCPSS, SAS

1. Use the phase definitions and the algorithm to determine the first phase.
2. Assess routinely. PCOC recommends a minimum of daily for inpatients and at each contact (phone or in-person) for community patients or in hospital consultative patients.
3. Assess whenever there is a change in the patient's needs or a change in the family or carer needs impacting on the patient's care.
4. Assessment may be conducted in-person or over the phone (except for initial assessment).

**NOTE**

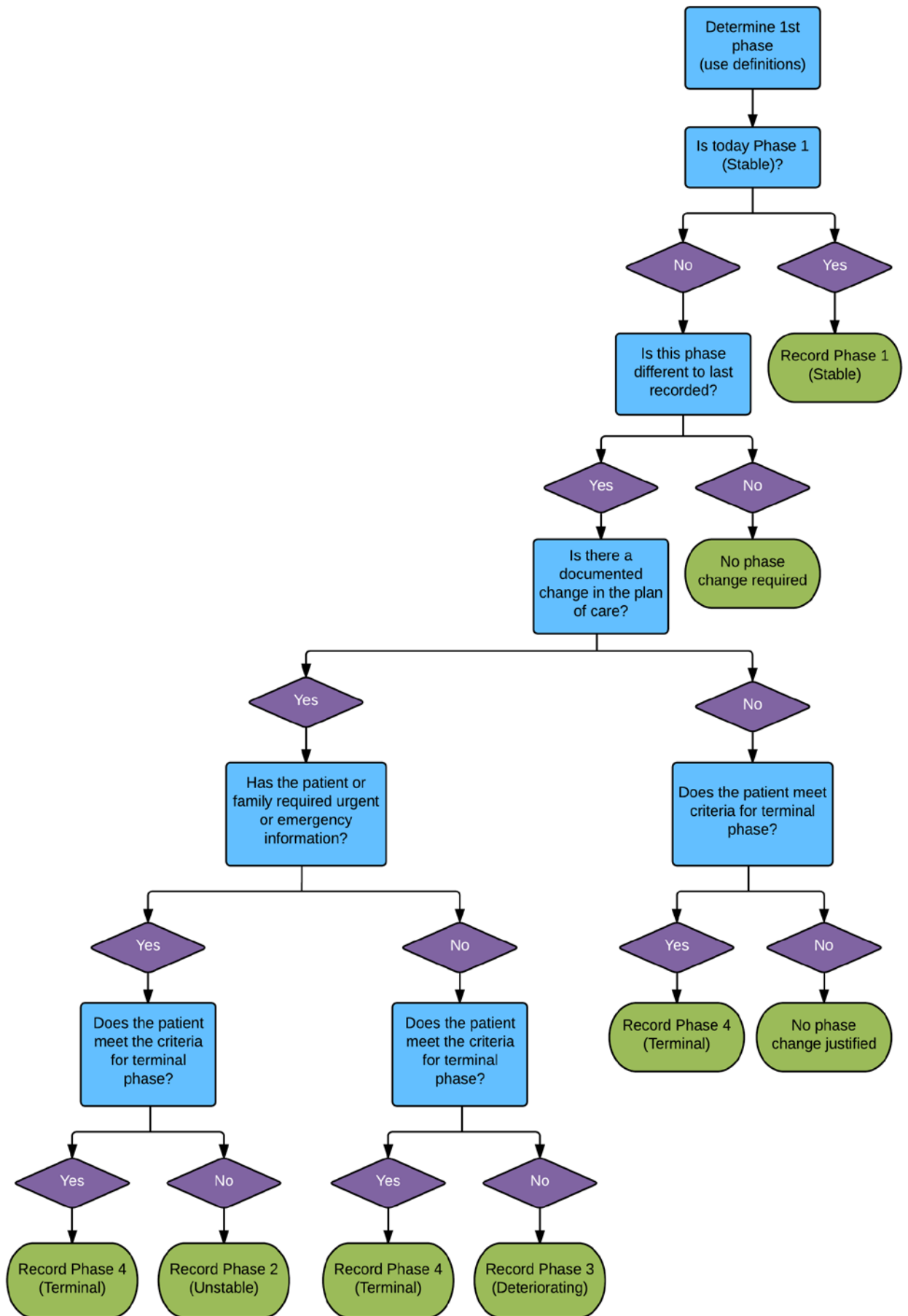
- Palliative care phases are not sequential. A patient can move back and forth between phases.

Potential actions following Phase assessment		
Palliative Care Phase	Actions if this is a new Phase	Actions if Phase is the same as previous assessment
<b>Stable</b>	<ul style="list-style-type: none"> <li>▪ Continue as per plan of care.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Continue as per plan of care.</li> <li>▪ Commence discharge planning if appropriate.</li> </ul>
<b>Unstable</b>	<ul style="list-style-type: none"> <li>▪ Urgent intervention and escalation required.</li> <li>▪ Change plan of care.</li> <li>▪ Urgent medical review and or allied health services.</li> <li>▪ Review within 24 hours.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Continue urgent action, adjust plan of care, refer, and intervene.</li> <li>▪ When no further changes to the care plan are required, change Phase.</li> </ul>
<b>Deteriorating</b>	<ul style="list-style-type: none"> <li>▪ Change in plan of care required to address increasing needs.</li> <li>▪ Referral to medical or allied health may be required. Family / carer support may increase.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Review and change plan of care.</li> <li>▪ When deterioration plateaus, change Phase to Stable.</li> </ul>
<b>Terminal</b>	<ul style="list-style-type: none"> <li>▪ Commence end of life care (adjust plan of care if required).</li> <li>▪ Discuss change in condition with family and those important to the patient.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Continue end of life care as per plan of care.</li> <li>▪ Communicate changes to family and others important to the patient.</li> <li>▪ If patient not likely to die within days, re-assess Phase.</li> <li>▪ End the Episode of Care when patient dies.</li> </ul>
<b>Bereavement</b>	<ul style="list-style-type: none"> <li>▪ Provide bereavement support to family and those important to the patient.</li> </ul>	<ul style="list-style-type: none"> <li>▪ If family require ongoing support, refer to appropriate service (family member becomes a client in their own right).</li> </ul>

## Phase Definitions

<p>The palliative care phase identifies a clinically meaningful period in a patient's condition. The palliative care phase is determined by a holistic clinical assessment which considers the needs of the patients and their family and carers.</p>	
<b>START</b>	<b>END</b>
<b>Stable</b>	
<p>Patient problems and symptoms are adequately controlled by established plan of care <b>and</b></p> <ul style="list-style-type: none"> <li>▪ Further interventions to maintain symptom control and quality of life have been planned <b>and</b></li> <li>▪ Family/carer situation is relatively stable and no new issues are apparent.</li> </ul>	<p>The needs of the patient and / or family/carer increase, requiring changes to the existing plan of care.</p>
<b>Unstable</b>	
<p>An urgent change in the plan of care or emergency treatment is required <b>because</b></p> <ul style="list-style-type: none"> <li>▪ Patient experiences a new problem that was not anticipated in the existing plan of care, <b>and/or</b></li> <li>▪ Patient experiences a rapid increase in the severity of a current problem; <b>and/or</b></li> <li>▪ Family/ carers circumstances change suddenly impacting on patient care.</li> </ul>	<ul style="list-style-type: none"> <li>▪ The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) <b>and/or</b></li> <li>▪ Death is likely within days (i.e. patient is now terminal).</li> </ul>
<b>Deteriorating</b>	
<p>The care plan is addressing anticipated needs but requires periodic review <b>because</b></p> <ul style="list-style-type: none"> <li>▪ Patients overall functional status is declining <b>and</b></li> <li>▪ Patient experiences a gradual worsening of existing problem <b>and/or</b></li> <li>▪ Patient experiences a new but anticipated problem <b>and/or</b></li> <li>▪ Family/carers experience gradual worsening distress that impacts on the patient care.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Patient condition plateaus (i.e. patient is now stable) <b>or</b></li> <li>▪ An urgent change in the care plan or emergency treatment <b>and/or</b></li> <li>▪ Family/ carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) <b>or</b></li> <li>▪ Death is likely within days (i.e. patient is now terminal).</li> </ul>
<b>Terminal</b>	
<p>Death is likely within days.</p>	<ul style="list-style-type: none"> <li>▪ Patient dies <b>or</b></li> <li>▪ Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating).</li> </ul>
<b>Bereavement – post death support</b>	
<ul style="list-style-type: none"> <li>▪ The patient has died</li> <li>▪ Bereavement support provided to family/carers is documented in the deceased patient's clinical record.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Case closure</li> </ul> <p>Note: If counselling is provided to a family member or carer, they become a client in their own right.</p>

M. Masso, S. Frederic. Allingham, M. Banfield, C. Elizabeth. Johnson, T. Pidgeon, P. Yates & K. Eagar, "Palliative care phase: inter-rater reliability and acceptability in a national study", Palliative Medicine 29 1 (2014) 22-30.



## Resource Utilisation Groups - Activities of Daily Living (RUG-ADL)

The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) consists of four items (bed mobility, toileting, transfers and eating) and assesses the level of functional dependence, based on what a person actually does, rather than what they are capable of doing. The RUG-ADL is reported on admission, at phase change and at discharge. The RUG-ADL describes the level of functional dependence. It is a four-item scale measuring motor function with activities of bed mobility, toileting, transfer and eating. Further information and videos on the [RUG-ADL](#) is available on the PCOC website.

Item	Score	Definition
<b>BED MOBILITY</b>		
Ability to move in bed after the transfer into bed has been completed.		
Independent or supervision only	1	Able to readjust position in bed, and perform own pressure area relief, through spontaneous movement around bed or with prompting from carer. No hands-on assistance required.  May be independent with the use of a device.
Limited physical assistance	3	Able to readjust position in bed, and perform own pressure area relief, with the assistance of one person.
Other than two persons physical assist	4	Requires the use of a hoist or other assistive device to readjust position in bed and provide pressure relief. Still requires the assistance of one person for task.
Two or more persons physical assist	5	Requires two or more assistants to readjust position in bed, and perform pressure area relief.
<b>TOILETING</b>		
Includes mobilising to the toilet, adjustment of clothing before and after toileting and maintaining perineal hygiene without the incidence of incontinence or soiling of clothes. If level of assistance differs between voiding and bowel movement, record the lower performance.		
Independent or supervision only	1	Able to mobilise to toilet, adjusts clothing, cleans self, has no incontinence or soiling of clothing. All tasks are performed independently or with prompting from carer. No hands-on assistance required. May be independent with the use of a device.
Limited physical assistance	3	Requires hands-on assistance of one person for one or more of the tasks.
Other than two persons physical assist	4	Requires the use of a catheter/uridome/urinal and/or colostomy/bedpan/commode chair and/or insertion of enema/suppository.  Requires assistance of one person for management of the device.
Two or more persons physical assist	5	Requires two or more assistants to perform any step of the task.

Item	Score	Definition
<b>TRANSFER</b>		
Includes the transfer in and out of bed, bed to chair, in and out of shower/tub. Record the lowest performance of the day/night		
Independent or supervision only	1	Able to perform all transfers independently or with prompting of carer. No hands-on assistance required.  May be independent with the use of a device.
Limited physical assistance	3	Requires hands-on assistance of one person to perform any transfer of the day/night
Other than two persons physical assist	4	Requires use of a device for any of the transfers performed in the day/night. Requires only one person plus a device to perform the task
Two or more persons physical assist	5	Requires 2 or more assistants to perform any transfer of the day/night.
<b>EATING</b>		
Includes the tasks of cutting food, bringing food to mouth and chewing and swallowing food.  Does not include preparation of the meal.		
Independent or supervision only	1	Able to cut, chew and swallow food, independently or with supervision, once meal has been presented in the customary fashion. No hands-on assistance required. If individual relies on parenteral or gastrostomy feeding that he/she administers him/herself then Score 1.
Limited assistance	2	Requires hands on assistance of one person to set up or assist in bringing food to the mouth and/or requires food to be modified (soft or staged diet).
Extensive assistance/total dependence/tube fed	3	Person needs to be fed meal by assistant, or the individual does not eat or drink full meals by mouth but relies on parenteral/gastrostomy feeding and does not administer feeds by him/herself.

## How to document RUG-ADL

1. Use the RUG-ADL definitions to determine the initial RUG-ADL score at the start of the episode of care.
2. Assess routinely. PCOC recommends a minimum of daily for inpatients and at each contact (phone or in-person) for community patients or in hospital consultative patients.
3. Assess whenever there is a phase change.
4. Assess at episode end when a patient is discharged.
5. Assessment may be conducted in-person or over the phone (except for initial assessment at episode start).
6. Record the score as assessed. The RUG-ADL may be entered directly into an electronic patient record or on a clinical form to be entered into a data system (e.g. SNAPshot). Examples of clinical forms are on our website <http://ahsri.uow.edu.au/pcoc/forms/index.html>.

## NOTE

- There is no score of “2” for bed mobility, toileting and transfers. For bed mobility, toileting and transfers the change from independent/supervision to limited assistance was found to equate to a three-fold increase in resources. For eating, the same change equated to a two-fold increase in use of resources.
- The RUG-ADL is based on what the person actually does, not what they are capable of doing. This is best achieved by asking “Do you...?” rather than “Can you...?”
- How do you score the unconscious or terminal patient for the item eating? Score 3 to indicate extensive assistance and total dependence as the patient does not feed him/herself.

### Potential actions following RUG-ADL assessment:

Item	Description	Score	Recommended Actions
<b>Bed mobility, Toileting, Transfer</b>	Independent / supervision only	1	<ul style="list-style-type: none"> <li>▪ Provide equipment if required (monkey bar, walking stick etc.).</li> <li>▪ Monitor for changes.</li> </ul>
	Limited physical assistance	3	<ul style="list-style-type: none"> <li>▪ Ensure care plan clearly describes the assistance required by staff.</li> <li>▪ Consider a Falls Prevention Plan.</li> <li>▪ Provide equipment if required.</li> </ul>
	Other than two person physical assist	4	<ul style="list-style-type: none"> <li>▪ Provide equipment / device as required.</li> <li>▪ Ensure care plan clearly describes the assistance required by staff and instructions regarding use of device.</li> <li>▪ Provide clear instructions to the patient regarding use of the device.</li> </ul>
	Two or more person physical assist	5	<ul style="list-style-type: none"> <li>▪ Ensure care plan clearly describes the assistance required by staff.</li> <li>▪ Provide equipment.</li> </ul>
<b>Eating</b>	Independent / supervision only	1	<ul style="list-style-type: none"> <li>▪ Monitor for changes.</li> </ul>
	Limited assistance	2	<ul style="list-style-type: none"> <li>▪ Provide assistance required according to service guidelines / protocols.</li> <li>▪ Ensure care plan clearly describes the assistance required by staff.</li> </ul>
	Extensive assistance / total dependence / tube fed	3	<ul style="list-style-type: none"> <li>▪ Ensure care plan clearly describes the assistance required by staff.</li> <li>▪ Provide mouth care according to service guidelines / protocols.</li> </ul>
<b>Total Score Range</b>		<b>Recommended Actions for Total Score</b>	
Total Score of 4-5		Independent. Monitor	
Total Score of 6-13		Requires assistance May be at risk of falls and pressure areas.	
Total Score of 14-17		Requires assistance of 1 plus equipment. Greater risk of falls and pressure areas.	
Total Score of 18		Requires 2 assist for all care. Greater risk of pressure areas.	



## Australia-modified Karnofsky Performance Status (AKPS)

The Australia-modified Karnofsky Performance Status (AKPS) Scale is a measure of the patient's performance across the dimensions of activity, work and self-care at phase start. It is a single score between 10 and 100 assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care. A score of 100 signifies normal physical abilities with no evidence of disease. Decreasing numbers indicate a reduced performance status. A score of 0 indicates the patient has died, however this score is not used as no further patient assessments are documented following the death of a patient. Further information and videos on [AKPS assessment](#) is available on the PCOC website.

### How to assess AKPS

1. Use the AKPS definitions to determine the initial score at the start of an episode of care.
2. Assess routinely. PCOC recommends a minimum of daily for inpatients and at each contact (phone or in-person) for community patients or in hospital consultative patients.
3. Assess whenever there is a phase change.
4. Assess at episode end when a patient is discharged.
5. Assessment may be conducted in-person or over the phone (except for initial assessment).

AKPS ASSESSMENT CRITERIA	SCORE
Normal; no complaints; no evidence of disease	100
Able to carry on normal activity; minor sign of symptoms of disease	90
Normal activity with effort; some signs or symptoms of disease	80
Cares for self; unable to carry on normal activity or to do active work	70
Able to care for most needs; but requires occasional assistance	60
Considerable assistance and frequent medical care required	50
In bed more than 50% of the time	40
Almost completely bedfast	30
Totally bedfast and requiring extensive nursing care by professionals and/or family	20
Comatose or barely rousable	10
Dead	0

Potential actions following AKPS assessment	
Point on AKPS Scale	Recommended Action
Patient has AKPS of 90, 80 or 70 at episode start	<ul style="list-style-type: none"> <li>Consider completing an advance care planning discussion with the patient and their substitute decision-makers.</li> </ul>
Patient has AKPS of 60	<ul style="list-style-type: none"> <li>Consider referral to allied health if patient has been in active work and is no longer able to work.</li> </ul>
Patient has AKPS of 50	<ul style="list-style-type: none"> <li>Consider discussion at multidisciplinary team meeting and review care plan</li> <li>Provide appropriate equipment as required</li> <li>Consider referrals for community packages</li> <li>Complete a caregiver assessment.</li> </ul>
Patient has AKPS of 40 or 30	<ul style="list-style-type: none"> <li>Consider discussion at multidisciplinary team meeting and review care plan – patient may be commencing deterioration and further supports may be required.</li> <li>Consider pressure area care.</li> <li>Provide appropriate equipment as required (for example, alternating pressure mattress).</li> <li>For community patients – consider impact of care on family caregiver. Complete a caregiver assessment.</li> </ul>
Patient has AKPS of 20 or 10	<ul style="list-style-type: none"> <li>Commence end of life care planning</li> <li>If death is likely in days, change to Terminal Phase.</li> </ul>

## Palliative Care Problem Severity Score (PCPSS)

The Palliative Care Problem Severity Score (PCPSS) is recommended as a clinical tool which can be used for initial screening and ongoing coordination of specialist palliative care (Bostanci, Hudson et al. 2012). Clinician rated, it facilitates the global assessment of four palliative care domains: pain, psychological/spiritual, other symptoms and family/carer. The family/carer domain measures problems associated with a patient's condition or palliative care needs. Each domain is rated on a 4 point scale measuring the severity of the symptoms: 0 =absent, 1 =mild, 2 =moderate and 3 =severe. The domain scores are used as triggers for referral, intervention or further assessment (Smith and Firms 1994, Eagar, Gordon et al. 2004). Further information and videos on the [PCPSS](#) is available on the PCOC website.

The PCPSS domains	The PCPSS score
Pain	0 Absent
Other symptoms	1 Mild
Psychological/spiritual	2 Moderate
Family/carer	3 Severe

### How to assess PCPSS

1. Score the overall severity of the problems experienced on admission or at episode start.
2. Assess at episode start.
3. Assess routinely. PCOC recommends a minimum of daily for inpatients and at each contact (telephone or in-person) for community patients or in hospital consultative patients.
4. Assess whenever there is a phase change.
5. Assess at episode end when a patient is discharged.
6. Assessment may be conducted in-person or over the phone (except for initial assessment at episode start).
7. Record the score as assessed. The PCPSS scores may be entered directly into an electronic patient record or on a clinical form to be entered into a data system (e.g. SNAPshot). Examples of clinical forms are on our website <http://ahsri.uow.edu.au/pcoc/forms/index.html>.

## Symptom Assessment Scale (SAS)

The Symptom Assessment Scale (SAS) describes the patient's level of distress relating to individual physical symptoms. The symptoms and problems in the scale are the seven most common experienced by palliative patients; difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. The instrument is designed to be a patient rated tool but also allows for rating by proxy. Further information and videos on the [SAS](#) is available on the PCOC website.

### NOTE

- The Symptom Assessment Scale measures distress relating to common symptoms and problems.
- Highly rated or problematic symptoms may trigger other assessments.
- The Symptom Assessment Scale may trigger the use of additional assessment tools.

## How to assess SAS

1. Determine if the patient can rate the degree of their distress for each symptom. When unable a family member or clinician rates the degree of distress based on observations and other assessments.
2. Utilise the SAS brochure and SAS patient form to rate symptom distress on a scale of 0-10 (see page 37). Symptoms that are not present are given a rating of '0'. Symptoms that are present are rated on a scale of 1 to 10. Additional symptoms (e.g. multiple pain sites, vomiting, cough) may be added in the blank spaces on the form and assessed in the same way. However these are not submitted to PCOC for reporting.
3. Assess at episode start.
4. Assess routinely. PCOC recommends a minimum of daily for inpatients and at each contact (phone or in-person) for community patients or in hospital consultative patients.
5. Assess whenever there is a phase change.
6. Assess at episode end when a patient is discharged.
7. Assessment may be conducted in-person or over the phone (except for initial assessment at episode start).
8. Record the score as assessed. The SAS scores may be entered directly into an electronic patient record or on a clinical form to be entered into a data system (e.g. SNAPshot). Examples of clinical forms are on our website <http://ahsri.uow.edu.au/pcoc/forms/index.html>.

[Translated versions](#) of the SAS forms and SAS brochure are available on the PCOC website.

Potential actions following PCPSS and SAS assessments	
PCPSS & SAS Score	Potential actions
<b>Absent</b>  <b>PCPSS = 0</b> <b>SAS = 0</b>	<ul style="list-style-type: none"> <li>▪ Problem / symptom distress absent.</li> <li>▪ Continue with current care.</li> <li>▪ Routine assessment.</li> <li>▪ Phase may be Stable or Terminal.</li> </ul>
<b>Mild</b>  <b>PCPSS = 1</b> <b>SAS = 1-3</b>	<ul style="list-style-type: none"> <li>▪ Problem / symptom distress managed by existing plan of care and routine care.</li> <li>▪ Treat problem / symptom according to service protocols.</li> <li>▪ Monitor and record any relevant information.</li> <li>▪ Phase may be Stable, Deteriorating or Terminal.</li> </ul>
<b>Moderate</b>  <b>PCPSS = 2</b> <b>SAS = 4-7</b>	<ul style="list-style-type: none"> <li>▪ Problem / symptom distress requires change in plan of care, referral and escalation.</li> <li>▪ Document review and implement any new interventions as per care plan.</li> <li>▪ Phase may be Deteriorating or Terminal.</li> </ul>
<b>Severe</b>  <b>PCPSS = 3</b> <b>SAS = 8-10</b>	<ul style="list-style-type: none"> <li>▪ Problem / symptom distress requires immediate action.</li> <li>▪ Plan of care is ineffective.</li> <li>▪ Urgent intervention, referral and escalation required.</li> <li>▪ Change of care plan indicated.</li> <li>▪ Review within 24 hours.</li> <li>▪ Phase Unstable or Terminal.</li> </ul>

# Symptom Assessment Scale - Information for patients

## Available in 15 languages

### What does the Symptom Assessment Scale measure?

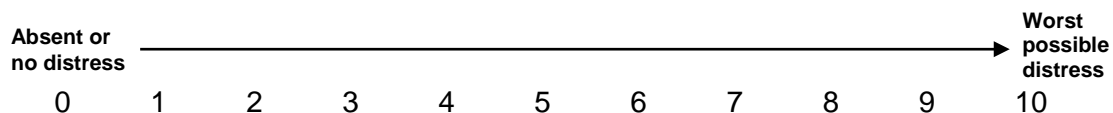
The Symptom Assessment Scale measures how severe your distress is, relating to each of the following symptoms:

Difficulty sleeping	Breathing problems
Appetite problems	Fatigue
Nausea	Pain
Bowel problems	

If you are experiencing distress from any other symptoms or problems not listed above, please let your health professional know.

### How do I use the Symptom Assessment Scale?

Your health professional will ask you to rate each of the symptoms or problems listed above between 0 and 10, using the scale below:



Think about your experience of the individual symptom or problem over the last 24 hours and rate according to how severe your distress has been. Record your rating on the form for completion by patients.

A score of **0**: means the symptom or problem is absent or that you have no distress associated with that symptom.

A score of **1**: means that you are experiencing minimal distress from the symptom or problem.

A score of **10**: means you are experiencing the worst possible distress associated with the symptom or problem.

For accuracy and consistency, it is best if you score your symptoms on your own using the Symptom Assessment Scale provided for you (see the back of this leaflet). If you would prefer, you may like to do this with a family member or carer. Your health professional will also be able to help you.

If you are the carer of a person who is unable to rate their own symptoms, your health professional may ask you to do this on their behalf. It is important that you look for signs of distress and rate according to how much distress you think each symptom is causing for the person you are caring for.

### When do I use the Symptom Assessment Scale?

Your scores may change daily and it is important that your health professionals know this information.

Your health professional will tell you how often and when you need to score your symptoms.

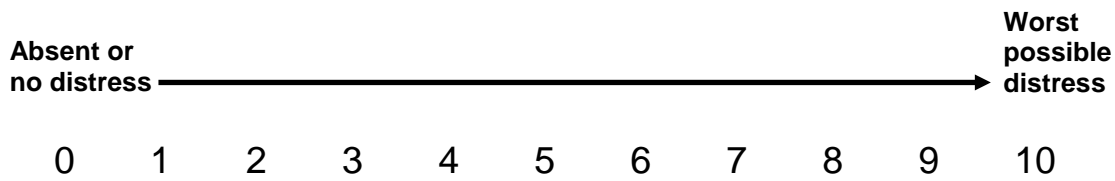
**If you have any questions about the Symptom Assessment Scale please speak to your health professional.**

# Symptom Assessment Scale

Form for completion by patients


Name: \_\_\_\_\_


1. Write the day or date in the space provided
2. Select a number between 0 and 10 using the diagram below
3. Record your score
4. Add in any other symptoms or problems that are causing you distress in the blank spaces, below the listed symptoms



0 = means the symptom is absent or you have no distress caused by the symptom.  
 10 = means you are experiencing the worst possible distress caused by the symptom.

Date/Day									
Difficulty sleeping									
Appetite problems									
Nausea									
Bowel problems									
Breathing problems									
Fatigue									
Pain									

Palliative Assessment and Clinical Response										(Please complete or affix Label here)												
<b>[Insert Service Name Here]</b>										<b>UPI:</b> 20000145 <b>Surname:</b> Doe <b>First name:</b> John <b>DOB:</b> 06/01/1934												
										Assess on admission, daily, at phase change and on discharge												
										Year 2013 Date		05/01	06/01	07/01	08/01	09/01	10/01	11/01	11/01			
										Time		11:34	12:01	10:59	11:02	11:00	11:15	11:03	16:55			
<b>Palliative Care Phase (1-4 Died or D/C) Refer to complete definition</b> Stable = Monitor    Unstable = Urgent action required    Deteriorating = Review plan of care    Terminal = Provide EOL care Died = record date, no further assessment required    Discharge (D/C) = assess at discharge																						
<b>Palliative Care Phase</b> 1    1    3    3    3    4    4    Died																						
<b>RUG-ADL Refer to complete definition</b> 4 - 5 = Monitor 6 - 10 = assist x 1 10+ = assist x 1, consider equipment, staff requirements, falls risk, referral 15+ = as above, pressure area risk, consider carer burden and MDT review 18 = as above, full care assistance x 2																						
<b>Clinician Rated Score</b> Bed mobility    3    3    4    4    4    5    5 Toileting    3    3    4    4    4    5    5 Transfers    3    3    4    4    4    5    5 Eating    1    1    2    2    2    3    3 <b>Total RUG ADL (4-18):</b> 10    10    14    14    14    18    18																						
<b>Problem Severity Score Actions (0-3) Refer to complete definition and rate each domain</b> 0 = Continue care    1 = Monitor and record    2 = Review/change plan of care; referral, intervention as required    3 = Urgent action																						
Pain    1    1    2    1    1    1    1 Other Symptoms    1    1    1    1    1    1    1 Psychological / Spiritual    0    0    1    1    1    1    1 Family / Carer    1    1    1    1    1    2    2																						
<b>Australia-modified Karnofsky Performance Status Scale (10-100) Refer to complete definition</b> Consider MDT review at score of 50 or below																						
<b>AKPS</b> 60    60    40    40    30    20    10																						
<b>Symptom Assessment Scale (0-10) Rate experience of symptom distress over a 24hr period</b> 0 = absent 10 = worst possible 0 = Continue care    1 -3 = Monitor and record    4-7 = Review/change plan of care; referral, intervention as required    8-10 = Urgent action																						
<b>Patient Rated Score</b> Distress from difficulty sleeping    3    3    3    3    3    0    0 Distress from Appetite    2    2    2    2    2    2    0 Distress from Nausea    0    0    0    0    0    0    0 Distress from Bowels    2    2    2    2    2    0    0 Distress from Breathing    0    0    0    0    0    2    2 Distress from Fatigue    3    3    3    3    3    0    0 Distress from Pain    2    2    5    3    2    2    2 Completed by Patient, Fam/Carer or Clinician    pt    pt    pt    pt    pt    pr    pr																						
<b>Staff Initials</b>																						

Palliative Assessment and Clinical Response					(Please complete or affix Label here)										
<b>[Insert Service Name Here]</b>					UPI:		20000146								
					Surname:		Doe								
					First name:		Jane								
					DOB:		08/04/1931								
Assess on admission, daily, at phase change and on discharge															
Year 2013 Date		11/02	12/02	13/02	14/02										
Time		11:34	12:01	10:59	11:00 D/C										
<b>Palliative Care Phase (1-4 Died or D/C) Refer to complete definition</b> Stable = Monitor    Unstable = Urgent action required    Deteriorating = Review plan of care    Terminal = Provide EOL care Died = record date, no further assessment required    Discharge (D/C) = assess at discharge															
Palliative Care Phase		2	2	1	1										
<b>RUG-ADL Refer to complete definition</b> 4 - 5 = Monitor 6 - 10 = assist x 1 10+ = assist x 1, consider equipment, staff requirements, falls risk, referral 15+ = as above, pressure area risk, consider carer burden and MDT review 18 = as above, full care assistance x 2															
Bed mobility		3	3	3	3										
Toileting		3	3	3	3										
Transfers		3	3	3	3										
Eating		1	1	1	1										
Total RUG ADL (4-18):		10	10	10	10										
<b>Problem Severity Score Actions (0-3) Refer to complete definition and rate each domain</b> 0 = Continue care    1 = Monitor and record    2 = Review/change plan of care; referral, intervention as required    3 = Urgent action															
Pain		3	2	1	1										
Other Symptoms		3	2	1	1										
Psychological / Spiritual		0	0	0	0										
Family / Carer		2	1	1	1										
<b>Australia-modified Karnofsky Performance Status Scale (10-100) Refer to complete definition</b> Consider MDT review at score of 50 or below															
AKPS		50	50	50	50										
<b>Symptom Assessment Scale (0-10) Rate experience of symptom distress over a 24hr period</b> 0 = absent 10 = worst possible 0 = Continue care    1 -3 = Monitor and record    4-7 = Review/change plan of care; referral, intervention as required    8-10 = Urgent action															
Distress from difficulty sleeping		5	4	4	4										
Distress from Appetite		6	5	5	4										
Distress from Nausea		8	5	3	3										
Distress from Bowels		2	2	1	1										
Distress from Breathing		0	0	0	0										
Distress from Fatigue		8	8	5	4										
Distress from Pain		8	8	2	2										
Completed by Patient, Fam/Carer or Clinician		pt	pt	pt	pt										
Staff Initials															

# Embedding Palliative Care Assessment

Refer to the PCOC website for a [Guide to implement, embed and sustain](#) and the [Assessment Package](#).

## PCOC Clinical Assessment Framework

Five validated clinical assessments provide clinicians with tools to systematically assess individual patient experiences and to develop plans of care that address patient need. The clinical assessment framework consists of:

- Palliative Care Phase (Phase)
- Resource utilisation Group – Activities of Daily Living (RUG-ADL)
- Australia-modified Karnofsky Performance Status (AKPS)
- Palliative Care Problem Severity Score (PCPSS)
- Symptom Assessment Scale (SAS)

## Assessment Frequency

- On admission (commencement of episode of palliative care).
- A minimum of daily in palliative care inpatient settings.
- At each contact in community and in-hospital consultation / liaison service settings.
- At change in care plan or patient / family needs.
- At discharge

## Assessment Process

- Assessments are routinely completed as a suite at each assessment occasion
- Assessment scores are documented or recorded at point of care
- Assessment relates to a 24hr period
- Assessments are completed directly by the community palliative care clinician (not a third party).
- The full Phase definition is made available for clinicians to refer to for patient assessment
- Family / carers included in phase assessment
- There is awareness, use and availability of the SAS patient brochure and form
- Translated versions of the SAS patient brochure and form are used
- A Visual Analogue Scale is available for use when assessing distress
- Assessments are part of the triage, assessment and care planning processes
- Assessments are routinely discussed in multidisciplinary meetings
- Allied health teams use the assessment tools

## Support to embed the assessment framework

A multi-pronged approach is the best strategy for embedding the assessment tools into routine practice. Three key components are the PCOC Quality Facilitator, the service facilitator (i.e. champion or lead) and embedding of resources for accurate assessment. Refer to protocol implementing, embedding and sustaining PCOC for further information on embedding the PCOC program.

## Resources for embedding the assessment tools

There are a number of essential resources available on the PCOC website to enable the embedding of the assessment tools into routine practice. These include but are not limited to:

1. Embedding & Sustaining PCOC Bi-annual self-assessment
2. Orientation schedule
3. A 10-minute video presentation: Orientation to PCOC assessment tools
4. A 12-minute DVD: Understanding PCOC
5. PCOC assessment tools lanyard card
6. PCOC assessment form
7. SAS form and brochure for patients



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