PCOC
palliative care
outcomes collaboration

# Palliative Care Outcomes Collaboration

# Clinical Manual

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# Version control and change history

| Version | Date Effective | Approved by | Amendment |
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| 1.0 | August 2014 | PCOC Director | Not applicable for first version |
| 1.1 | April 2018 | Sabina Clapham | Revised forms, changing the order of assessment tools – SAS first and phase last. |
| 1.2 | June 2021 | Dr Barbara Daveson | Revised implementation steps and SAS instructions for patients to match implementation guide and 'talking about your symptoms' guide for patients and families. |

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PCOC is an outcome and benchmarking program. PCOC creates a clinical language by embedding five validated clinical assessments to systematically measure and improve patient and family/carer outcomes. For more information visit the PCOC website.

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The complete list of PCOC publications are available from: www.pcoc.org.au

# The Palliative Care Outcomes Collaboration

Central to the PCOC program is a framework and protocol for routine clinical assessment and response. By embedding the framework into routine clinical practice, a common clinical language is created. This helps identify and respond to needs. It also helps with improving access to palliative care, and generating consistent information to plan and deliver care.

The PCOC cycle centres on measuring patient and carer outcomes, benchmarking these outcomes nationally, and using them to identify processes that can be improved. – refer to Figure 1 [1].

PCOC provides support and resources to enable clinicians and organisations to implement the PCOC assessment and response framework out outcome measures and facilitate continuous improvement.

Quality improvement is enabled through our network of Improvement Facilitators, our community of practice, and our quality improvement resources.

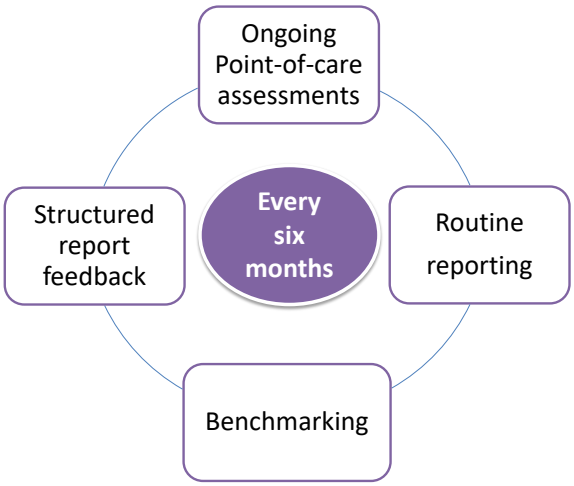



**Figure 1: PCOC Cycle**

# 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.

# 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.

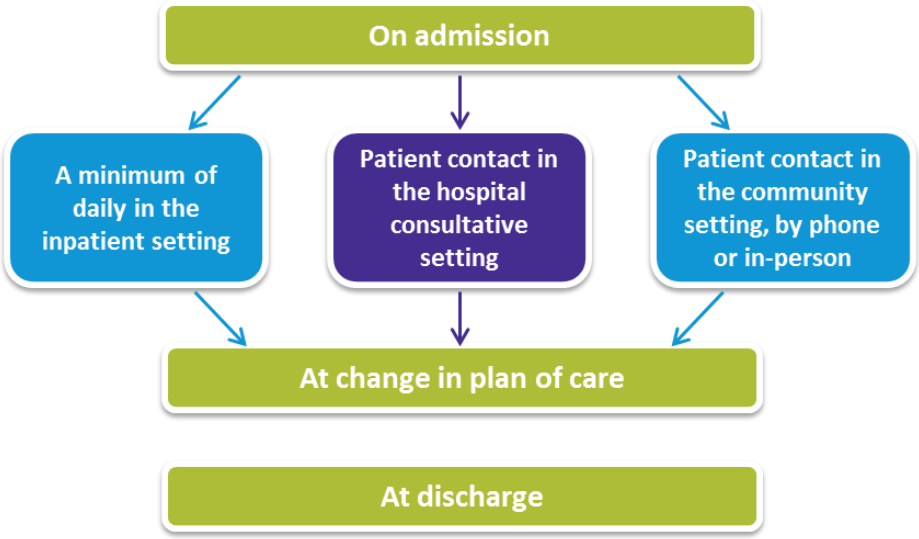



**Figure 2: Frequency of Assessment**

# 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

# Strategies for successful outcome measurement

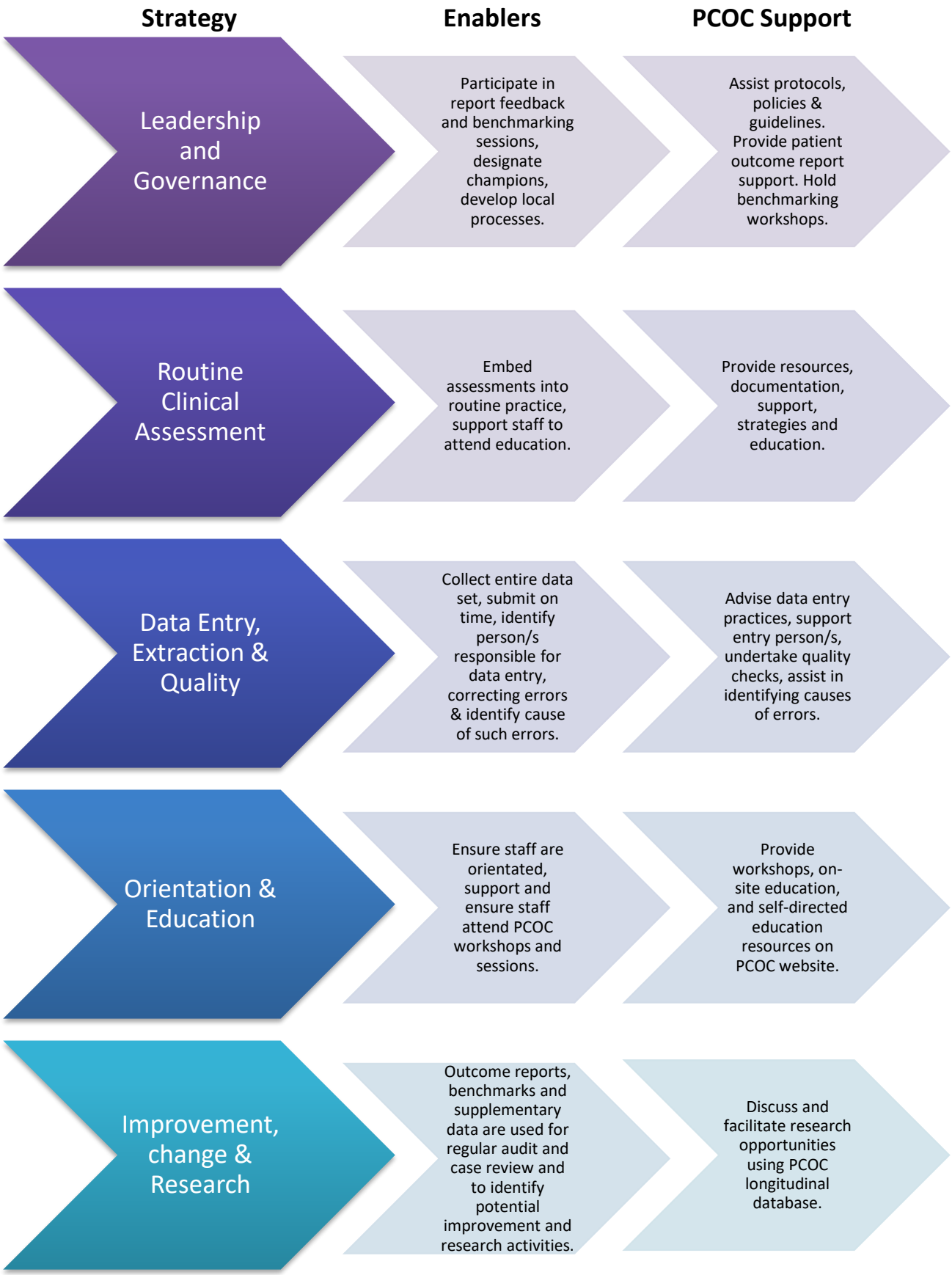



***Figure 3 strategies for successful outcome measurement***

For further information, refer to the PCOC *Implementing PCOC: a guide for services*

# Implementing, Embedding and Sustaining PCOC

For further information, refer to the *Implementing PCOC: a guide for services*

There are five distinct stages in implementing the PCOC program into routine practice at a service and There are three distinct stages in starting PCOC and establishing it as routine practice at a service and organisational level; these are planning, implementing and reviewing. The development of an implementation plan is supported by completion of the readiness assessment.

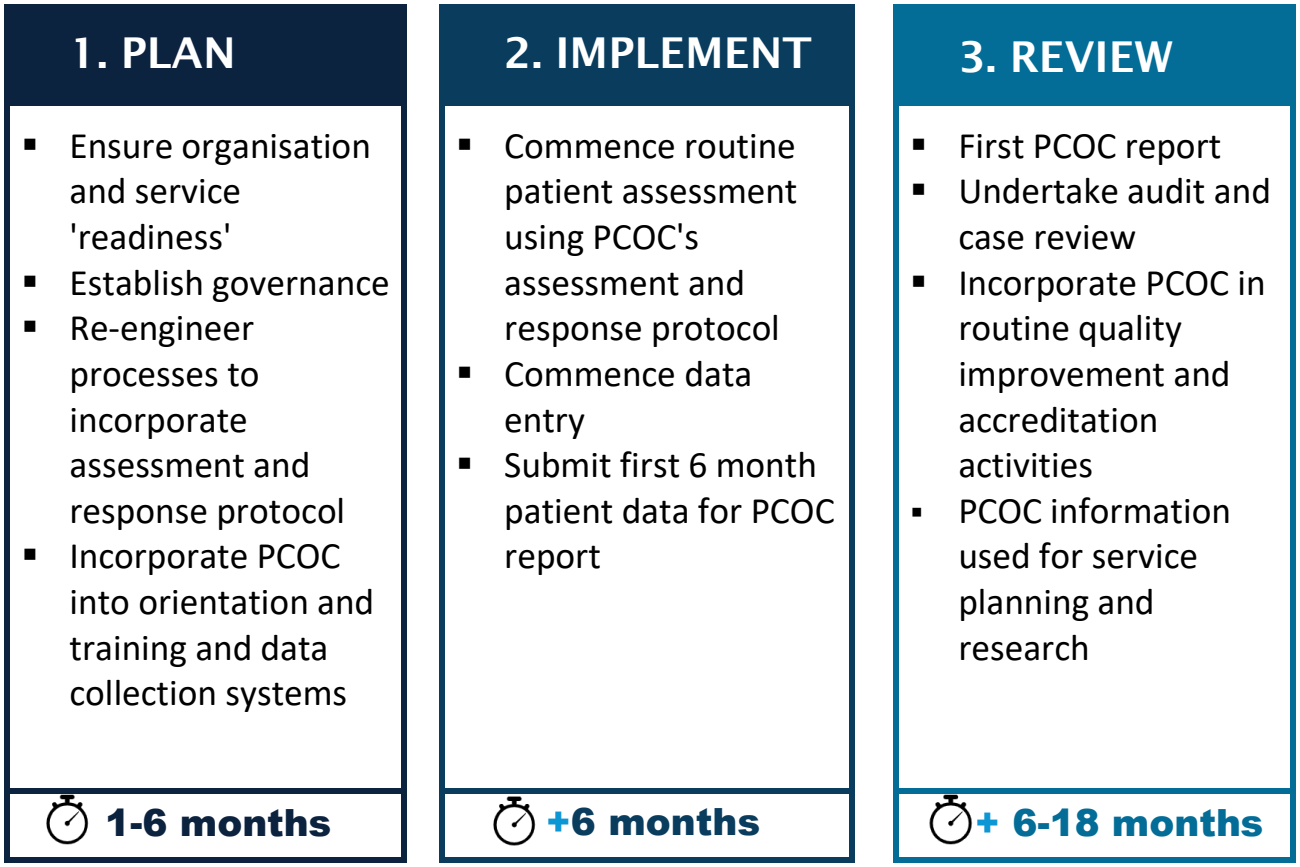



**Figure 4: Implementation Stages**

# Role of the PCOC Clinical Lead

A factor critical to the successful implementation of the PCOC program is the designation of a PCOC clinical lead (champion). This role includes:

- Act as a role model to support and re-inforce the assessment and response processes
- Provide staff with information and orientation to the PCOC resources
- Guide and support staff to complete the Essentials Online course and orientation to PCOC
- Work with the PCOC Improvement Facilitator to support local process for embedding and sustaining PCOC
- Provide feedback to the leadership team on any identified areas for improvement.

# National Outcome Measures and Benchmarks

The objective of PCOC is to drive systematic improvement in patient outcomes through benchmarking. Benchmarking was introduced in 2009 and since then participating palliative care services have achieved statistically significant improvement in all outcome measures.

Outcome measures capture the clinical concepts:

- Timeliness of palliative care
- Responsiveness to urgent needs
- Anticipatory care
- Responsive care
- Change in symptoms adjusted by phase and symptom score

## Timeliness of palliative care

Time from date ready for care to episode start. 90% of patients have their palliative care commence within two days when ready for care.

## Responsiveness to urgent needs

Time in the unstable phase. 90% of patients in the unstable phase have their needs met addressed within 3 days or less.

## Anticipatory Care

90% of patients with absent or mild symptoms/problems at the beginning of the phase have absent or mild symptoms/problems at the end of the phase.

For Pain (SAS), Pain (PCPSS), Fatigue, Breathing problems and Family/Carer Problems

## Responsive Care

60% of patients with moderate or severe symptoms/problems at the beginning of the phase have absent or mild symptoms/problems at the end of the phase.

For Pain (SAS), Pain (PCPSS), Fatigue, breathing problems and Family/Carer Problems

## Change in symptoms relative to the national average (casemix adjusted)

The change in symptoms relative to the national average measures the mean change in symptoms and is adjusted for both phase and for the symptom score at the start of each phase. This measure allows comparison of change in symptom score for 'like' patients. 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.

For Pain (SAS), Pain (PCPSS), Breathing problems, Nausea, Bowel problems, other symptoms, Psychological/Spiritual and Family/Carer Problems

For further information, refer to the National Outcome Measures and Benchmarks page on the PCOC website, or refer to the Development of Benchmarks page.

# Level 1: Patient Information

Patient level information describes demographics. Refer to example of episode form on page 18.

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 Dictionary and Technical Guidelines.

## 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 episodes 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 page18.

For further information refer to the PCOC Data Dictionary and Technical Guidelines.

## 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.

| **Patients admitted for an inpatient episode** |
|---|
| Overnight Admitted – Not Further Specified |
| Overnight Admitted – Designated Palliative Care Bed |
| Overnight Admitted - Non-designated Palliative Care Bed |

| **Patients admitted for ambulatory, clinics or day hospital** |
|---|
| Hospital Ambulatory - Not Further Specified |
| Same Day Admitted |
| Outpatient |

| **Patients admitted for a community episode** |
|---|
| 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:

| Patients admitted for an inpatient episode |
|---|
| 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 |

| Patients admitted for community or ambulatory episode |
|---|
| 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:

| **Patients admitted overnight for an inpatient episode** |
|---|
| 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 |

| **Patients admitted for a community or ambulatory episode** |
|---|
| 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. The documentation of these data items is guided by the PCOC Inpatient, Community Patient or the Hospital Consult/Liaison Patient Episode Forms. These forms provide tick boxes and entry fields for what a clinician should document for each category of information.

| Insert service name and logo here | PCOC palliative care outcomes collaboration | (Complete or affix Addressograph Label here)<br>UPI_____ DOB_____<br>Surname_____<br>Given Names_____<br>Gender Male ☐ Female ☐ Other ☐<br>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**

- ☐ Bone & soft tissue
- ☐ Breast
- ☐ CNS
- ☐ Colorectal
- ☐ Gynaecological
- ☐ Haematological
- ☐ Head and Neck
- ☐ Lung
- ☐ Pancreas
- ☐ Prostate
- ☐ Skin
- ☐ Unknown Primary
- ☐ Other GIT
- ☐ Other Urological
- ☐ Other Malignancy

**Non-malignant**

- ☐ Cardiovascular disease
- ☐ HIV/AIDS
- ☐ End stage kidney disease
- ☐ Stroke
- ☐ Motor Neurone Disease
- ☐ Alzheimer's disease
- ☐ Other dementia
- ☐ Other neurological disease
- ☐ Respiratory failure
- ☐ End stage liver disease
- ☐ Diabetes & its complications
- ☐ Sepsis
- ☐ Multiple organ failure
- ☐ Other non-malignancy

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

- ☐ 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
- ☐ Community palliative care service
- ☐ Community generalist service
- ☐ Specialist practitioner
- ☐ Self, carer(s), family or friends
- ☐ 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
- ☐ Residential aged care facility
- ☐ Other

SERVICE NAME DO NOT WRITE

INPATIENT EPISODE INFORMATION JULY 2014

**Referral Date:** __ __ / __ __ / __ __ __ __ (referral date for this episode)

**Date Ready for Care:** __ __ / __ __ / __ __ __ __ (date the patient is ready/available for admission)

**Episode Start Date / First Contact Date:** __ __ / __ __ / __ __ __ __ (date of admission)

**Episode Start Mode**

☐ Admitted from usual accommodation (complete accommodation at episode start)
☐ Admitted from other than usual accommodation (complete accommodation at episode start)
☐ Admitted from another hospital
☐ Admitted from acute care in another ward
☐ Change from acute care while remaining on same ward
☐ Change from another sub-acute care type e.g. rehab
☐ Other

**Accommodation at Episode Start** (where the patient was prior to hospital admission- complete if admitted from usual or other than usual accommodation)

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

**Episode Type** (where the patient is receiving palliative care)

☐ Overnight admitted designated palliative care bed
☐ Overnight admitted non-designated palliative care bed
☐ Overnight admitted not further specified

## Section 2 (Complete at end of episode)

**Episode End Date:** __ __ / __ __ / __ __ __ __ (date patient's episode of palliative care ends)

**Episode End Mode**

☐ Discharged to usual accommodation
☐ Discharged to other than usual accommodation
☐ Death (in hospital)
☐ Discharged to another hospital
☐ Change to acute care different ward
☐ Change to acute care same ward
☐ Change to another sub-acute care type e.g. rehab
☐ Other

**Accommodation at Episode End** (complete only if discharged to usual accommodation or other than usual accommodation)

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

| Insert service name and logo here | PCOC palliative care outcomes collaboration | (Complete or affix Addressograph Label here)<br>UPI_____ DOB_____<br>Surname_____<br>Given Names_____<br>Gender Male ☐ Female ☐ Other ☐<br>State _____ Postcode _____ |
|---|---|---|

## 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**

- ☐ Bone & soft tissue
- ☐ Breast
- ☐ CNS
- ☐ Colorectal
- ☐ Gynaecological
- ☐ Haematological
- ☐ Head and Neck
- ☐ Lung
- ☐ Pancreas
- ☐ Prostate
- ☐ Skin
- ☐ Unknown Primary
- ☐ Other GIT
- ☐ Other Urological
- ☐ Other Malignancy

**Non-malignant**

- ☐ Cardiovascular disease
- ☐ HIV/AIDS
- ☐ End stage kidney disease
- ☐ Stroke
- ☐ Motor Neurone Disease
- ☐ Alzheimer's disease
- ☐ Other dementia
- ☐ Other neurological disease
- ☐ Respiratory failure
- ☐ End stage liver disease
- ☐ Diabetes & its complications
- ☐ Sepsis
- ☐ Multiple organ failure
- ☐ Other non-malignancy

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

- ☐ 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
- ☐ Community palliative care service
- ☐ Community generalist service
- ☐ Specialist practitioner
- ☐ Self, carer(s), family or friends
- ☐ 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
- ☐ Residential aged care facility
- ☐ Other

SERVICE NAME
DO NOT WRITE

COMMUNITY PATIENT EPISODE INFORMATION JULY 2014

**Referral Date:** __ __ / __ __ / __ __ __ __ (referral date for this episode)

**First Contact Date:** __ __ / __ __ / __ __ __ __ (date of clinical assessment to determine needs)

**Date Ready for Care:** __ __ / __ __ / __ __ __ __ (date the patient is ready and available for care)

**Episode Start Date:** __ __ / __ __ / __ __ __ __ (date the plan of care is documented and initiated)

**Episode Start Mode**

☐ Discharged from being an inpatient palliative care patient

☐ Not discharged from being an inpatient palliative care patient

**Accommodation at Episode Start** (where the patient is currently living)

☐ Private residence (including unit in retirement village)

☐ Residential aged care, low level care (hostel)

☐ Residential aged care, high level care (nursing home)

☐ Other

**Episode Type** (where the patient is receiving palliative care)

☐ Private residence

☐ Residential Aged Care Facility

☐ Community not further defined

## Section 2 (Complete at end of episode)

**Episode End Date:** __ __ / __ __ / __ __ __ __ (date patient's episode of palliative care ends)

**Episode End Mode**

☐ Death (in community)

☐ Discharged for inpatient palliative care

☐ Discharged for inpatient acute care

☐ Discharged to another community palliative care service

☐ Discharged to primary health care e.g. GP

☐ Other

**Accommodation at Episode End** (if discharged)

☐ Private residence (including unit in retirement village)

☐ Residential aged care, low level care (hostel)

☐ Residential aged care, high level care (nursing home)

**Place of Death**

☐ Home

☐ Residential Aged Care Facility

# Level 3:  Phase Information

Phase level information describes a clinically meaningful period in a patient's condition, their functional ability, symptoms (including physical and psychological) and family / carer distress, using five brief 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 education 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

**Key Message**

- Use assessment scores & actions to anticipate & respond to identified needs.

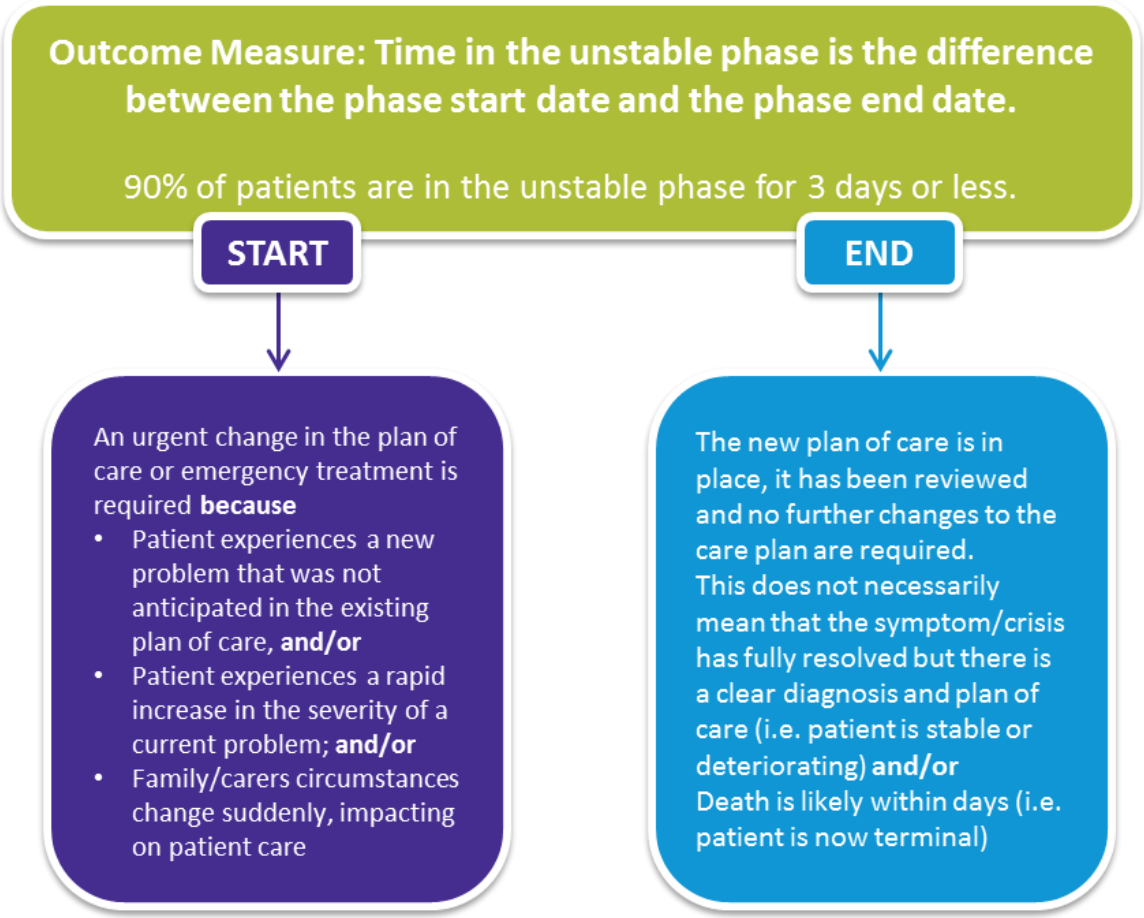



**Figure 5: Patient outcomes at phase level**

## Assessment scores and recommended response

Refer to the Assessment and Response Protocol for further information. For each assessment tool there are recommended response and follow up actions which provide a framework to anticipate and respond to identified needs. Refer to the Palliative Assessment and Clinical Response form.

## Anticipatory care and responsive care

The assessment and response framework aligns with the PCOC outcome measures and benchmarks relating to anticipatory and responsive care. A positive patient outcome is achieved if the patient has absent to mild symptom / problem at the end of a phase. However, whether care is anticipatory or responsive depends on the level of symptom / problem at the start of the phase.

- The absent to mild range of symptom and problems scores trigger monitoring and review of care plans. This is referred to as anticipatory care.
- The moderate to severe range of symptom and problems scores trigger interventions and actions to respond to needs. This is referred to as responsive care.

## Assessment and response: form and lanyard cards

The assessment and response protocol is used in combination with the PCOC lanyard cards and the Assessment and Response form. This package enables the clinician to determine an appropriate response and action to the patient's (and family/carers) needs. There are two lanyard cards, one providing abbreviated definitions and the other one providing a guide to clinical response to assessments. These two documents and lanyard cards together make up the assessment protocol package.

## What information is collected for phase?

| Data | Definition | Document |
|---|---|---|
| **Phase start date** | The date each new phase starts. | The start date for the first phase and the date of each phase change. |
| **Phase end date** | The date each phase ends. | The date the phase ended. |
| **Reason for phase end** | 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. | One of the following:<br>▪ Phase changed to Stable<br>▪ Phase changed to Unstable<br>▪ Phase changed to Deteriorating<br>▪ Phase changed to Terminal<br>▪ Death<br>▪ End Bereavement Phase/Post Death Support<br>▪ Discharge |
| **Assessment score at phase start** | The SAS, RUG-ADL, AKPS, PCPSS score at each new phase start. | The documentation of these scores is guided by the assessment and response protocol. |
| **Assessment score at phase end** | The SAS, RUG-ADL, AKPS, PCPSS score at each phase end. | |

## Clinical forms

The PCOC assessment and clinical response form can be found on the following pages and an example of a completed form can be found in appendix B. The PCOC Assessment and Response Form is used in all palliative care settings. These forms provide tick boxes and entry fields for what a clinician should document for each category of information Please see the website for additional forms including the hospital consult form.

| **Palliative Assessment and Clinical Response** | | (Please complete or affix Label here)<br>UPI:<br>Surname<br>First name:<br>DOB: |
|---|---|---|
| **[Insert Service Name Here]** | PCOC palliative care outcomes collaboration | |

Assess on admission, daily, at phase change and on discharge

| | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Year 20** | **Date** | | | | | | | | | | | | | | |
| | **Time** | | | | | | | | | | | | | | |
| **Patient Rated Score** | **Symptom Assessment Scale (0-10)** *Rate experience of symptom distress over a 24hr period* *0 = absent 10 = worst possible*<br>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 | | | | | | | | | | | | | | |
| | Distress from Appetite | | | | | | | | | | | | | | |
| | Distress from Nausea | | | | | | | | | | | | | | |
| | Distress from Bowels | | | | | | | | | | | | | | |
| | Distress from Breathing | | | | | | | | | | | | | | |
| | Distress from Fatigue | | | | | | | | | | | | | | |
| | Distress from Pain | | | | | | | | | | | | | | |
| | Rated by Patient, Fam/Carer or Clinician Use codes = Pt, FC, Cl | | | | | | | | | | | | | | |
| **Clinician Rated Score** | **Problem Severity Score Actions (0-3)** *Refer to complete definition and rate each domain*<br>0 = Continue care 1 = Monitor and record 2 = Review/change plan of care; referral, intervention as required 3 = Urgent action | | | | | | | | | | | | | | |
| | Pain | | | | | | | | | | | | | | |
| | Other Symptoms | | | | | | | | | | | | | | |
| | Psychological / Spiritual | | | | | | | | | | | | | | |
| | Family / Carer | | | | | | | | | | | | | | |
| | **Australia-modified Karnofsky Performance Status Scale (10-100)** *Refer to complete definition*<br>Consider MDT review at score of 50 or below | | | | | | | | | | | | | | |
| | **AKPS** | | | | | | | | | | | | | | |
| | **RUG-ADL** *Refer to complete definition*<br>**4 - 5** = Monitor<br>**6 - 10** = assist x 1<br>**10+** = assist x 1, consider equipment, staff requirements, falls risk, referral<br>**15+** = as above, pressure area risk, consider carer burden and MDT review<br>**18** = as above, full care assistance x 2 | | | | | | | | | | | | | | |
| | Bed mobility | | | | | | | | | | | | | | |
| | Toileting | | | | | | | | | | | | | | |
| | Transfers | | | | | | | | | | | | | | |
| | Eating | | | | | | | | | | | | | | |
| | **Total RUG-ADL (4-18):** | | | | | | | | | | | | | | |
| | **Palliative Care Phase (1-4 Died or D/C)** *Refer to complete definition*<br>**Stable =** Monitor **Unstable =** Urgent action required **Deteriorating =** Review plan of care **Terminal =** Provide EOL care<br>**Died =** record date, no further assessment required **Discharge (D/C) =** assess at discharge | | | | | | | | | | | | | | |
| | **Palliative Care Phase** | | | | | | | | | | | | | | |
| **Staff Initials** | | | | | | | | | | | | | | | |

## Symptom Assessment Scale

## Complete Definition

**Patient Rated distress relating to symptoms over a 24hr period**

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.

**Usage:**

1. 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 *Symptom Assessment Scale Form for Patients*.
2. 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.

**Proxy:** a family / carer or clinician who rates symptom distress on behalf of the patient though observational assessment. Use the following codes to describe Patient = Pt, Fam/Carer= FC or Clinician =Cl

**Instructions**: patient to consider their experience of the individual symptom or problem over the last 24 hours and rate distress according to

A score of 0: means no distress from the symptom

A score of 1: means the symptom is causing minimal distress.

A score of 10: means the symptom is causing the worst possible distress.

**SAS translations available on the PCOC website www.pcoc.org.au**

## Problem Severity Score

## Complete Definition

**Clinician rated assessment of problems over a 24hr period**

Global assessment of four palliative care domains to summarise palliative care needs and plan care.

The severity of problems are rated and responded to following using the scale:

**0 = Absent; 1 = Mild; 2 = Moderate; 3 = Severe**

**Pain:** overall severity of pain problems for the patient

**Other Symptoms:** overall severity of problems relating to one or more symptoms other than pain

**Psychological / Spiritual:** severity of problems relating to the patient's psychological or spiritual wellbeing. May be one or more issues.

**Family / Carer:** problems associated with a patient's condition or palliative care needs. Family / Carer do not need to be present to asses needs as written, verbal or observational information may be used.

## Australia-modified Karnofsky Performance Status

## Complete Definition

**Clinician rated assessment of performance relating to work, activity and self-care over a 24hr period**

100. Normal, no complaints or evidence of disease
90. Able to carry on normal activity, minor signs or symptoms of disease
80. Normal activity with effort, some signs or symptoms of disease
70. Care for self, unable to carry on normal activity or to do active work
60. Occasional assistance but is able to care for most needs
50. Requires considerable assistance and frequent medical care
40. In bed more that 50% of the time
30. Almost completely bedfast
20. Totally bedfast & requiring nursing care by professionals and/or family
10. Comatose or barely rousable

## Resource Utilisation Group – Activities of Daily Living

## Abbreviated Definition

**Clinician rated assessment of dependency over 24hr period**

**For Bed Mobility, Toileting & Transfers**

1. Independent or supervision only
3. Limited physical assistance
4. Other than two person physical assist
5. Two or more person physical assist

**For Eating**

1. Independent or supervision only
2. Limited assistance
3. Extensive assistance / total dependence / tube fed

**Complete RUG-ADL definitions available on the PCOC website www.pcoc.org.au**

## Palliative Care Phase

## Abbreviated Definition

**Clinician rated assessment**

1. **Stable** Symptoms and problems are adequately controlled by established management. Monitor, review, anticipate & respond.
2. **Unstable** An urgent change in the plan of care or emergency treatment is required due to development of a new problem &/or a rapid increase in the severity of existing problems &/or family/carer problems. Urgent response required.
3. **Deteriorating** The plan of care is addressing anticipated needs but requires periodic review due to gradual functional decline &/or worsening of existing symptoms &/or the development of new but expected problems &/or family/carer problems. Review & change care plan
4. **Terminal** Death likely in a matter of days. Monitor, review & respond

**Complete Phase Definitions available on the PCOC website www.pcoc.org.au**

## 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 [2]. 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.

**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** |
| **Stable** | Continue as per plan of care. | Continue as per plan of care.<br>Commence discharge planning if appropriate. |
| **Unstable** | Urgent intervention and escalation required.<br>Change plan of care.<br>Urgent medical review and or allied health services.<br>Review within 24 hours. | Continue urgent action, adjust plan of care, refer, and intervene.<br>When no further changes to the care plan are required, change Phase. |
| **Deteriorating** | Change in plan of care required to address increasing needs.<br>Referral to medical or allied health may be required. Family / carer support may increase. | Review and change plan of care.<br>When deterioration plateaus, change Phase to Stable. |
| **Terminal** | Commence end of life care (adjust plan of care if required).<br>Discuss change in condition with family and those important to the patient. | Continue end of life care as per plan of care.<br>Communicate changes to family and others important to the patient.<br>If patient not likely to die within days, re-assess Phase.<br>End the Episode of Care when patient dies. |
| **Bereavement** | Provide bereavement support to family and those important to the patient. | If family require ongoing support, refer to appropriate service (family member becomes a client in their own right). |

## Phase Definitions

| 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. | |
|---|---|
| **START** | **END** |
| **Stable** | |
| Patient problems and symptoms are adequately controlled by established plan of care **and**<br>▪ Further interventions to maintain symptom control and quality of life have been planned **and**<br>▪ Family/carer situation is relatively stable and no new issues are apparent. | The needs of the patient and / or family/carer increase, requiring changes to the existing plan of care. |
| **Unstable** | |
| An urgent change in the plan of care or emergency treatment is required **because**<br>▪ Patient experiences a new problem that was not anticipated in the existing plan of care, **and/or**<br>▪ Patient experiences a rapid increase in the severity of a current problem; **and/or**<br>▪ Family/ carers circumstances change suddenly impacting on patient care. | ▪ 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) **and/or**<br>▪ Death is likely within days (i.e. patient is now terminal). |
| **Deteriorating** | |
| The care plan is addressing anticipated needs but requires periodic review **because**<br>▪ Patients overall functional status is declining **and/or**<br>▪ Patient experiences a gradual worsening of existing problem **and/or**<br>▪ Patient experiences a new but anticipated problem **and/or**<br>▪ Family/carers experience gradual worsening distress that impacts on the patient care. | ▪ Patient condition plateaus (i.e. patient is now stable) **or**<br>▪ An urgent change in the care plan or emergency treatment **and/or**<br>▪ 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) **or**<br>▪ Death is likely within days (i.e. patient is now terminal). |
| **Terminal** | |
| Death is likely within days. | ▪ Patient dies **or**<br>▪ Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating). |
| **Bereavement – post death support** | |
| ▪ The patient has died<br>▪ Bereavement support provided to family/carers is documented in the deceased patient's clinical record. | ▪ Case closure<br>Note: If counselling is provided to a family member or carer, they become a client in their own right. |

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.

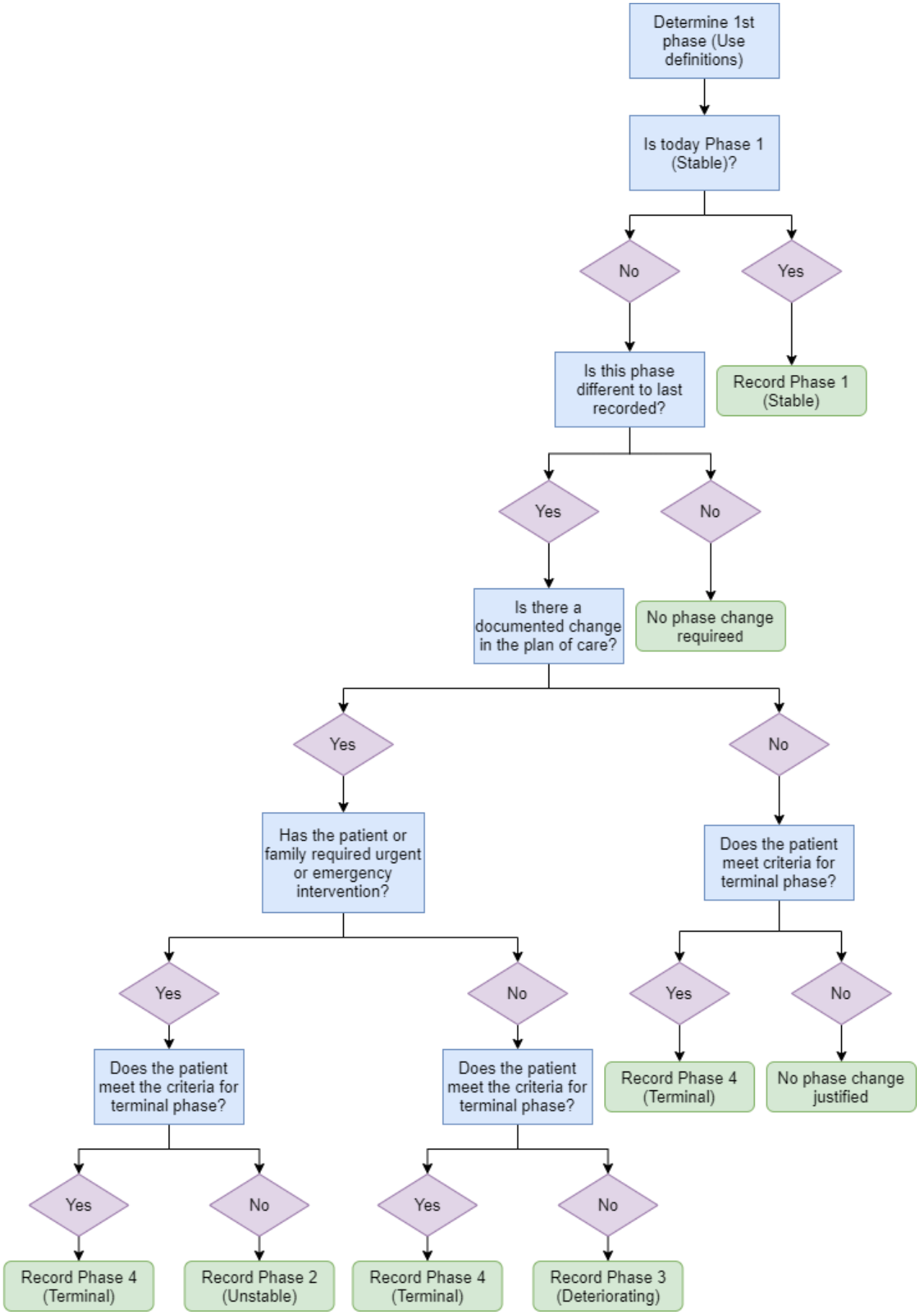



**Figure 6: Phase level assessments flow chart**

## 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 [3]. 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 |
|---|---|---|
| BED MOBILITY | | 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.<br>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. |
| TOILETING | | 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.<br>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 |
|---|---|---|
| TRANSFER | | 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.<br>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. |
| EATING | | Includes the tasks of cutting food, bringing food to mouth and chewing and swallowing food.<br>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. |

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** |
| **Bed mobility, Toileting, Transfer** | Independent / supervision only | 1 | ▪ Provide equipment if required (monkey bar, walking stick etc.).<br>▪ Monitor for changes. |
| | Limited physical assistance | 3 | ▪ Ensure care plan clearly describes the assistance required by staff.<br>▪ Consider a Falls Prevention Plan.<br>▪ Provide equipment if required. |
| | Other than two person physical assist (one person plus functional aid/s) | 4 | ▪ Provide equipment / device as required.<br>▪ Ensure care plan clearly describes the assistance required by staff and instructions regarding use of device.<br>▪ Provide clear instructions to the patient regarding use of the device. |
| | Two or more person physical assist | 5 | ▪ Ensure care plan clearly describes the assistance required by staff.<br>▪ Provide equipment. |
| **Eating** | Independent / supervision only | 1 | ▪ Monitor for changes. |
| | Limited assistance | 2 | ▪ Provide assistance required according to service guidelines / protocols.<br>▪ Ensure care plan clearly describes the assistance required by staff. |
| | Extensive assistance / total dependence / tube fed | 3 | ▪ Ensure care plan clearly describes the assistance required by staff.<br>▪ Provide mouth care according to service guidelines / protocols. |
| **Total Score Range** | | | **Recommended Actions for Total Score** |
| Total Score of 4-5 | | | Independent. Monitor |
| Total Score of 6-13 | | | Requires assistance<br>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 [4]. 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.

| 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 | ▪ Consider completing an advance care planning discussion with the patient and their substitute decision-makers. |
| Patient has AKPS of 60 | ▪ Consider referral to allied health if patient has been in active work and is no longer able to work. |
| Patient has AKPS of 50 | ▪ Consider discussion at multidisciplinary team meeting and review care plan<br>▪ Provide appropriate equipment as required<br>▪ Consider referrals for community packages<br>▪ Complete a caregiver assessment. |
| Patient has AKPS of 40 or 30 | ▪ Consider discussion at multidisciplinary team meeting and review care plan – patient may be commencing deterioration and further supports may be required.<br>▪ Consider pressure area care.<br>▪ Provide appropriate equipment as required (for example, alternating pressure mattress).<br>▪ For community patients – consider impact of care on family caregiver. Complete a caregiver assessment. |
| Patient has AKPS of 20 or 10 | ▪ Commence end of life care planning<br>▪ If death is likely in days, change to Terminal Phase. |

## Palliative Care Problem Severity Score (PCPSS)

The PCPSS and PCOC SAS assessments are used to measure symptoms and problems experienced by the patient and family/carer [5]. The PCPSS is clinician rated and supports the global screening for the overall degree of problems within four key palliative care domains (pain problems, symptoms other than pain, psychological / spiritual problems and family / carer problems). PCPSS is a four point numerical rating scale (0-3). 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 |

## PCOC Symptom Assessment Scale (SAS)

PCOC Symptom Assessment Scale (SAS), which is a valid and reliable patient-reported measure able to be used by patients in a variety of palliative care settings as part of routine clinical care [6]. The scale assesses eight symptom dimensions: pain, insomnia, nausea, bowel problems, appetite problems, breathing problems and fatigue. An 'other' item may be added to the measure. Perceived distress is evaluated on a 0–10 numerical scale with zero representing absent distress, 1 being mild distress and 10 being the worst possible.

For each of the eight dimensions, there are 11 levels in the response options. The response options range from 'absent' to 'severe' distress. A score of 0 indicates that the patient is distress free, meaning that the score >0 effectively identifies distress for each domain in the scale. In order to assist patients to discriminate between these 11 response options reliably, the PCOC SAS response options have been grouped into six intensity categories. Each category has a corresponding descriptor, colour and facial expression. Higher total scores and higher individual item scores represent higher levels of distress [6]. PCOC SAS is patient-reported outcome measure. Patient reports are feasible in most clinical scenarios, although proxy reporting is required sometimes [7]. A 'patient-report' is defined as an occasion where the patient reported on their own symptom distress. Further information and videos on the PCOC 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.

Translated versions of the PCOC SAS forms are available on the PCOC website.

| Potential actions following PCPSS and PCOC SAS assessments | |
|---|---|
| **PCPSS & SAS Score** | **Recommended Actions** |
| **Absent**<br><br>**PCPSS = 0**<br>**SAS = 0** | ▪ Problem / symptom distress absent.<br>▪ Continue with current care.<br>▪ Routine assessment.<br>▪ Phase may be Stable or Terminal. |
| **Mild**<br><br>**PCPSS = 1**<br>**SAS = 1-3** | ▪ Problem / symptom distress managed by existing plan of care and routine care.<br>▪ Treat problem / symptom according to service protocols.<br>▪ Monitor and record any relevant information.<br>▪ Phase may be Stable, Deteriorating or Terminal. |
| **Moderate**<br><br>**PCPSS = 2**<br>**SAS = 4-7** | ▪ Problem / symptom distress requires change in plan of care, referral and escalation.<br>▪ Document review and implement any new interventions as per care plan.<br>▪ Phase may be Deteriorating or Terminal. |
| **Severe**<br><br>**PCPSS = 3**<br>**SAS = 8-10** | ▪ Problem / symptom distress requires immediate action.<br>▪ Plan of care is ineffective.<br>▪ Urgent intervention, referral and escalation required.<br>▪ Change of care plan indicated.<br>▪ Review within 24 hours.<br>▪ Phase Unstable or Terminal. |

# PCOC Symptom Assessment Scale - Information for patients Available in 15 languages

Talking about your symptoms is important
Symptoms are feelings or sensations in your body or mind that are causing you discomfort, pain or suffering. We want to know about the distress (concern or worry) caused by your symptoms. We need to understand this, so we can manage it well.

What will you be asked to do?
We will ask you to score each symptom between 0 and 10. You will be asked to look at the scale below and pick the number that matches how you feel. Use the face, colour or word to help with this.

Before you answer, please think about your experience of each symptom on that day. Please score your symptoms yourself. If needed, a member of your family or one of the clinical staff can help.

What do the scores mean?

0 means that you have no distress or worry from that symptom.

1 means that you are experiencing slight distress or worry from that symptom.

10 means that you are experiencing the worst possible distress or worry from that symptom.

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

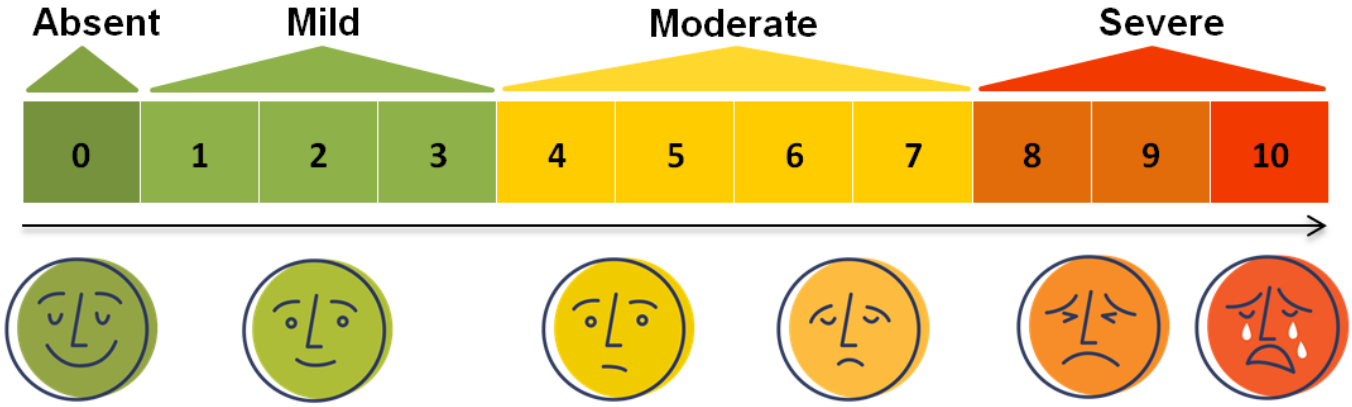
PCOC
palliative care
outcomes collaboration

(Please complete or affix Label here)

UPI:
Surname
First name:
DOB:

# Symptom Assessment Scale

Please use this form to tell us about the symptoms that bother, worry or distress you. This information will help us to meet your needs.




1. Write the day or date in the first row.
2. Use the scale above to choose a number between 0 and 10 that shows how bothered, worried or distressed you are.
3. You can add other symptoms in the blank space at the bottom of the list.

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

| Palliative Assessment and Clinical Response | | (Please complete or affix Label here) |
|---|---|---|
| **[Insert Service Name Here]** | PCOC palliative care outcomes collaboration | UPI: 20000145<br>Surname: Doe<br>First name: John<br>DOB: 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 | | | | | | | |
| **Patient Rated Score** | **Symptom Assessment Scale (0-10)** *Rate experience of symptom distress over a 24hr period* *0 = absent 10 = worst possible*<br>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 | 3 | 3 | 3 | 3 | 3 | 3 | 0 | | | | | | | |
| | Distress from Appetite | 2 | 2 | 2 | 2 | 2 | 2 | 2 | | | | | | | |
| | Distress from Nausea | 0 | 0 | 0 | 0 | 0 | 0 | 0 | | | | | | | |
| | Distress from Bowels | 2 | 2 | 2 | 2 | 2 | 2 | 0 | | | | | | | |
| | Distress from Breathing | 0 | 0 | 0 | 0 | 0 | 0 | 2 | | | | | | | |
| | Distress from Fatigue | 3 | 3 | 3 | 3 | 3 | 3 | 0 | | | | | | | |
| | Distress from Pain | 2 | 2 | 5 | 3 | 2 | 2 | 2 | | | | | | | |
| | Rated by Patient, Fam/Carer or Clinician Use codes = Pt, FC, Cl | Pt | Pt | Pt | Pt | Pt | Pt | Pr | | | | | | | |
| **Clinician Rated Score** | **Problem Severity Score Actions (0-3)** *Refer to complete definition and rate each domain*<br>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 | 1 | 2 | | | | | | | |
| | **Australia-modified Karnofsky Performance Status Scale (10-100)** *Refer to complete definition*<br>Consider MDT review at score of 50 or below | | | | | | | | | | | | | | |
| | **AKPS** | 60 | 60 | 40 | 40 | 30 | 20 | 10 | | | | | | | |
| | **RUG-ADL** *Refer to complete definition*<br>**4 - 5** = Monitor<br>**6 - 10** = assist x 1<br>**10+** = assist x 1, consider equipment, staff requirements, falls risk, referral<br>**15+** = as above, pressure area risk, consider carer burden and MDT review<br>**18** = as above, full care assistance x 2 | | | | | | | | | | | | | | |
| | 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 | | | | | | | |
| | **Total RUG-ADL (4-18):** | 10 | 10 | 14 | 14 | 14 | 18 | 18 | | | | | | | |
| | **Palliative Care Phase (1-4 Died or D/C)** *Refer to complete definition*<br>**Stable =** Monitor **Unstable =** Urgent action required **Deteriorating =** Review plan of care **Terminal =** Provide EOL care<br>**Died =** record date, no further assessment required **Discharge (D/C) =** assess at discharge | | | | | | | | | | | | | | |
| | **Palliative Care Phase** | 1 | 1 | 3 | 3 | 3 | 4 | 4 | Died | | | | | | |
| **Staff Initials** | | | | | | | | | | | | | | | |

| Palliative Assessment and Clinical Response | | (Please complete or affix Label here) |
|---|---|---|
| **[Insert Service Name Here]** | PCOC palliative care outcomes collaboration | UPI: 20000146<br>Surname: Doe<br>First name: Jane<br>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 | | | | | | | | | | |
| **Patient Rated Score** | **Symptom Assessment Scale (0-10)** *Rate experience of symptom distress over a 24hr period* *0 = absent 10 = worst possible*<br>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 | 5 | 2 | 2 | | | | | | | | | | |
| | Rated by Patient, Fam/Carer or Clinician Use codes = Pt, FC, Cl | Pt | Pt | Pt | Pt | | | | | | | | | | |
| **Clinician Rated Score** | **Problem Severity Score Actions (0-3)** *Refer to complete definition and rate each domain*<br>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 | | | | | | | | | | |
| | Other Symptoms | 1 | 1 | 1 | 1 | | | | | | | | | | |
| | Psychological / Spiritual | 0 | 0 | 1 | 0 | | | | | | | | | | |
| | Family / Carer | 1 | 1 | 1 | 1 | | | | | | | | | | |
| | **Australia-modified Karnofsky Performance Status Scale (10-100)** *Refer to complete definition*<br>Consider MDT review at score of 50 or below | | | | | | | | | | | | | | |
| | **AKPS** | 60 | 60 | 40 | 50 | | | | | | | | | | |
| | **RUG-ADL** *Refer to complete definition*<br>**4 - 5** = Monitor<br>**6 - 10** = assist x 1<br>**10+** = assist x 1, consider equipment, staff requirements, falls risk, referral<br>**15+** = as above, pressure area risk, consider carer burden and MDT review<br>**18** = as above, full care assistance x 2 | | | | | | | | | | | | | | |
| | Bed mobility | 3 | 3 | 4 | 3 | | | | | | | | | | |
| | Toileting | 3 | 3 | 4 | 3 | | | | | | | | | | |
| | Transfers | 3 | 3 | 4 | 3 | | | | | | | | | | |
| | Eating | 1 | 1 | 2 | 1 | | | | | | | | | | |
| | **Total RUG-ADL (4-18):** | 10 | 10 | 14 | 10 | | | | | | | | | | |
| | **Palliative Care Phase (1-4 Died or D/C)** *Refer to complete definition*<br>**Stable =** Monitor **Unstable =** Urgent action required **Deteriorating =** Review plan of care **Terminal =** Provide EOL care<br>**Died =** record date, no further assessment required **Discharge (D/C) =** assess at discharge | | | | | | | | | | | | | | |
| | **Palliative Care Phase** | 1 | 1 | 3 | 1 | | | | | | | | | | |
| **Staff Initials** | | | | | | | | | | | | | | | |

# A brief overview of the processes and resources for successful routine outcome measurement

## Resources for embedding routine outcome measurement

There are a number of essential resources available on the PCOC website to enable the embedding routine outcome measuring. These include but are not limited to:

- Implementing PCOC: a guide for services
- PCOC's assessment and response protocol
- Web-based education package and Education guide for services
- PCOC assessment and response form
- PCOC SAS form for patients and 'talking about your symptoms' PCOC SAS flyer
- Audit and case review tools

## PCOC clinical assessment and response 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.

### Assessment Frequency

Establishing processes and roles and responsibilities for assessment and response is essential and enables the clinical team to collect patient outcome information in a standardised way. The following steps provides a guide for when to use the PCOC assessments:

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

### Assessment Processes

- Assessments are routinely completed as a suite at each assessment occasion
- There is a clear escalation and response processes, including roles and responsibilities for responding to identified needs
- Assessment scores are documented or recorded at point of care
- 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 form and visual aid
- Translated versions of the SAS patient form are used
- 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 and response framework

A multi-pronged approach is the best strategy for embedding the assessment tools into routine practice. Three key components are the PCOC Improvement Facilitator, the Clinical Lead (i.e. service facilitator) and embedding of resources for accurate assessment.

# References


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