PCOC
palliative care
outcomes collaboration

PCOC Version 4: Clinical Manual

Document Version 1.0

December 2025

Palliative Care Outcomes Collaboration Version 4 Clinical Manual

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

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Version control and change history

Version	Date Effective	Approved by	Amendment
1.0	December 2025	PCOC Director, Sabina Clapham	Not applicable - version 1

The Palliative Care Outcomes Collaboration (PCOC) is a national palliative care project funded by the Australian Government Department of Health, Disability and Ageing.

Since 2005, the Palliative Care Outcomes Collaboration (PCOC) has delivered a national platform for standardised clinical data collection, benchmarking, and continuous quality improvement.

PCOC has a protocol for clinical assessment and response. This works in parallel with routine point-of-care data collection, capturing clinically meaningful information (1). This information is used to measure palliative care outcomes through benchmarking against data from other services and supporting continuous quality improvement.

At its core, PCOC offers a framework for routine clinical assessment and response, establishing a common language to identify patient needs, improving access, and ensuring consistent, high-quality palliative care. PCOC measures patient and carer outcomes, supports national benchmarking, and drives service improvement.

Routine assessment and outcome measurement are integral to delivering high-quality, patient-centred care. Consistent use of the PCOC tools enables standardised patient assessment, supports timely identification and management of symptoms, and establishes a clear baseline for monitoring changes in patient needs (2). Routine measurement also promotes engagement of patients, families, and carers based on patient need.

PCOC is funded by the Australian Government, and provides free, voluntary participation to all palliative care services in Australia.

In 2025, PCOC has introduced major updates to ensure that the program remains responsive to the sector's evolving needs.

The PCOC Version 4 Clinical Manual provides detailed information on all clinical items, including their description, collection options, intended use, and opportunities for quality improvement. It guides the national rollout of Version 4 and supports services transitioning from Version 3. The manual serves as a comprehensive reference for clinicians and includes key clinical, quality, and educational resources underpinning best practice in palliative care assessment and response.

The Clinical Manual is designed primarily for clinicians using PCOC in everyday practice, focusing on practical application rather than technical detail.

Secondary audiences include managers, executives, peak organisations, government bodies, and researchers.

This manual should be used alongside the following resources, which together provide a complete framework for implementation, education, and quality improvement:

- **PCOC Implementation Guide**: provides a structured framework to support services in embedding PCOC as a routine part of clinical practice and service delivery (3).
- **Assessment and Response Protocol**: guidance on applying the assessment and response framework in practice. The assessment and response protocol is available as a lanyard card (Appendix 1).
- **Education Guide**: supports services to deliver clinician education. The checklist for developing, implementing, and monitoring programs is available as Appendix 2 (4) .
- **Quality Improvement Guide**: provides a structured approach to using outcome reports for service-level quality improvement (5).
- **Version 4 Data Dictionary**: contains technical specifications, codes, and extraction guidance for IT providers and researchers (6).
- **Data Guideline**: outlines principles and procedures for PCOC data management and appropriate use of PCOC data by services, researchers, and government agencies (7).

The PCOC benchmarks were developed using a combination of consultation with participating services, expert consensus, and evidence from PCOC data. They focus on three key areas: responsiveness to referrals, responsiveness to urgent needs, and symptom and problem outcomes. Detailed information, including national outcome results, is published every six months in the PCOC National Reports, which are available on the PCOC website.

Each clinical data item in this manual is presented in a consistent format to support ease of interpretation and application.

Component	Description
Definition	Defines the item and explains its meaning.
Options	Lists the possible set of values for each item.
Intent	Explains why the item is useful and how it will be used.
Explanatory note	Explains how the item can be applied and highlights any changes from the previous version.
Examples of use	Illustrates examples to support clinical interpretation.
Quality improvement	Describes useful quality improvement tips.

Version 4 of PCOC is organised into two linked levels: Patient level items and Assessment level items.

Patient level items are captured at the first clinical encounter, typically the initial assessment or admission to a palliative care service, (Table 1).

Assessment level items capture the patient's clinical condition, reasons for palliative care, and outcome measures and are collected at the first and subsequent encounters (Tables 2 and 3).

Appendix 3 shows the PCOC clinical form, providing an example of how the PCOC items are collected in practice. It includes a summary of the item definitions and the supportive assessment and response framework, demonstrating how clinicians can apply the tools consistently to guide care planning and clinical intervention.

Table 1: Patient level items

Data item	Description	Purpose/Use	Collection point
Patient identifier	Unique identifier (e.g., MRN)	Track and link patient outcomes across assessments	Admission/first assessment
Date of birth	Patient's date of birth	Describe demographics; adjust and compare outcomes; support equity monitoring	Admission/first assessment
Sex	Patient's recorded sex	Support demographic and equity analyses	Admission/first assessment
State/Territory	Patient's usual state or territory of residence	Support geographic and service access analyses	Admission/first assessment
Postcode	Patient's usual postcode	Explore socioeconomic and regional disparities in access and outcomes	Admission/first assessment
Country of birth	Country where the patient was born	Understand cultural and population health patterns	Admission/first assessment
Preferred language	Patient's preferred language for communication	Supports culturally safe care and analysis of outcomes for CALD* patients	Admission/first assessment
Indigenous status	Whether the patient identifies as Aboriginal and/or Torres Strait Islander	Monitor equity and improve access for First Nations peoples	Admission/first assessment
Diagnosis	Principal life-limiting illness	Explore referral patterns and care needs by diagnosis	Admission/first assessment

*CALD = culturally and linguistically diverse

Table 2: Assessment level items

Data Item	Description	Purpose/Use	Collection Point
Referral date/time	When the patient was referred	Measure time from referral to admission	Admission/comprehensive assessment
Assessment date/time	When assessment occurred	Track sequence and change over time	Each assessment
Assessment type	Comprehensive, ongoing, or separation	Identify assessment timing and data flow	System generated
Referral provider type	Source of referral	Understand referral pathways	Admission/comprehensive assessment
Referring speciality	Referring team/speciality	Identify and improve access patterns	Admission/comprehensive assessment
Setting of care	Care setting (inpatient, community, etc.)	Compare outcomes by setting	Admission/comprehensive assessment
Usual accommodation	Where the patient lives	Understand referral pathways and transitions	Admission/comprehensive assessment
Patient location after assessment	Where patient went after discharge	Describe pathways and service utilisation	Discharge/death
Place of death	Where patient died	To record the location where the patient died	Death
Carer availability	Whether a carer is available	Inform care planning and discharge	Admission/comprehensive assessment
Mode of assessment	In-person, video, or phone	Capture mode of service delivery	Each assessment

Table 3: Clinical tools and outcome measures

Data Item	Description	Purpose/Use	Collection Point
Presence of delirium	Delirium present (Y/N)	Monitor prevalence and trigger assessment	Each assessment
Delirium score	Distress level (0–10)	Evaluate impact and management of delirium	Each assessment
ESAS-PCOC & Delirium rated by	Rater identity (patient/proxy)	Support interpretation of patient-reported outcomes	Each assessment
ESAS-PCOC	Edmonton Symptom Assessment System	Measure symptom burden	Each assessment
RUG-ADL	Resource Utilisation Groups – Activities of Daily Living 4-item function scale	Assess motor and self-care function for benchmarking	Each assessment
AKPS	Australia-modified Karnofsky Performance Status 10-point performance scale	Measure activity, work, and self-care	Each assessment
PCPSS	Palliative Care Problem Severity Score Clinician-rated problem severity 4 domains	Assess symptom severity	Each assessment
Palliative care phase	Clinical phase	Classify palliative care needs	Each assessment

Patient level items are captured at the first clinical encounter, are unique to the patient and do not change across admissions. They are only collected once.

Patient identifier	
Definition	Unique person 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 always used when recording patient and assessment level information for PCOC.
Options	N/A
Intent	To ensure accurate identification and linkage of all clinical and assessment information for each individual within a service. Using a consistent unique person identifier maintains data integrity, prevents duplication, and supports reliable tracking of patient outcomes across episodes of care.
Explanatory note	An IT System specific patient identifier, including a Medical Record Number (MRN)/Unit Record Number (URN), is acceptable to use as the Patient ID.
Examples of use	N/A
Quality improvement	N/A

Date of birth	
Definition	The date of birth of the patient.
Options	Date in DD/MM/YYYY format.
Intent	To derive age for demographic analyses.
Explanatory note	N/A
Examples of use	N/A
Quality improvement	Review the age distribution of patients. Identify trends in outcomes by age and compare access and service utilisation by age. For paediatric patients the Lansky Play-Performance Scale (8) can be used as an age-appropriate alternative to the Australia-modified Karnofsky Performance Status (AKPS) (9). See Appendix 4 for more information.

Sex	
Definition	The sex of the patient.
Options	Male Female Other
Intent	To describe the demographic profile of patients receiving palliative care and to enable analysis of outcomes by sex. Collecting sex supports service planning, equity, and understanding how symptom outcomes vary.
Explanatory note	Options are derived from the Australian Bureau of Statistics (10).
Examples of use	N/A
Quality improvement	Review the sex distribution of patients. Identify trends in outcomes by sex and compare access and service utilisation by sex.

Australian state or territory	
Definition	The Australian State/Territory (or other country) that the patient usually resides in.
Options	New South Wales Victoria Queensland South Australia Western Australia Tasmania Northern Territory Australian Capital Territory Other Australian Territory Not Australia Unknown
Intent	To identify the geographical location of the service providing care. Collecting state or territory information supports regional and national benchmarking, enables comparison of service delivery models across jurisdictions, and informs policy, planning, and resource allocation.
Explanatory note	Australian State or Territory information is collected only once by an organisation, regardless of the patient moving interstate while receiving care by the same organisation.
Examples of use	A patient living near a state border may receive care from services located in different states. In this case, multiple states will be recorded as locations of care. In contrast, if a patient moves to another state while remaining under the care of the same palliative care service, only one state (the service's location) will be recorded.
Quality improvement	Compare access to palliative care by state and territories and geographical distribution of palliative care services.

Australian postcode	
Definition	The postcode of the patient's usual place of residence.
Options	Valid Australian postcode.
Intent	To identify the geographical distribution of patients receiving palliative care and support analysis of service access and equity. Postcode information can be used to examine patterns of care across regions, including rurality and socioeconomic disparities, and to inform service planning and resource allocation to improve equity in access and outcomes.
Explanatory note	N/A
Examples of use	N/A
Quality improvement	Review patient postcode data to identify geographic variations in service access, referral patterns, and outcomes. Use findings to inform service planning, resource allocation, and targeted strategies to improve equity and accessibility for patients across different regions.

Country of birth	
Definition	The country where the patient was born.
Options	Standard Australian Classification of Countries (SACC, 2016).
Intent	To describe the cultural and demographic diversity of patients receiving palliative care. Country of birth information supports understanding of how care needs and outcomes may vary across cultural groups, and helps identify potential disparities in access, communication, and service provision.
Explanatory note	N/A
Examples of use	N/A
Quality improvement	Analyse symptom outcomes (e.g., pain or distress scores) by country of birth to identify differences in reported symptom severity or unmet needs among culturally and linguistically diverse (CALD) populations. Review referral and admission data by country of birth to assess whether patients from CALD backgrounds are accessing palliative care at similar stages of illness compared to Australian-born patients.

Preferred language	
Definition	The language or group of languages reported by a person as the most preferred for communication.
Options	Australian Standard Classification of Languages (ASCL, 2016) Data Length: 2-4 characters.
Intent	To identify the primary language spoken by the patient to support effective communication and culturally appropriate care. Collecting this information enables analysis of outcomes for CALD populations and helps identify potential inequities in access, experience, and outcomes of palliative care.
Explanatory note	This question aims to determine the patient's preferred spoken language and is not used to assess the patient's English proficiency.
Examples of use	N/A
Quality improvement	Review preferred language data to assess the use of translated Edmonton Symptom Assessment System (11). Examine completion rates of assessments and the proportion of proxy-reported data for patients whose preferred language is not English.

Indigenous status	
Definition	Indigenous status is whether a person identifies as being of Aboriginal and/or Torres Strait Islander origin. This data item is based on the Australian Bureau of Statistics standard for Indigenous status.
Options	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
Intent	To identify whether a patient identifies as Aboriginal and/or Torres Strait Islander. This information supports culturally safe and responsive care, enables monitoring of access and outcomes for Aboriginal and Torres Strait Islander peoples, and helps identify and address disparities in palliative care delivery.
Explanatory note	Ask the question exactly as worded in national standards: *"Are you of Aboriginal or Torres Strait Islander origin?"* Do not assume identity based on appearance, name, or location. Record the response provided by the patient or their nominated representative.
Examples of use	If the patient declines to answer, select 'Not stated/inadequately described'. This approach ensures respectful and consistent data collection aligned with national reporting requirements.
Quality improvement	Audit Indigenous status completion rates. Provide education on the importance of accurate identification, standardise data collection practices, and ensure patients are asked respectfully and appropriately about their Indigenous status.

Diagnosis

Definition	The principal life-limiting illness responsible for the patient requiring palliative care.

Options

Diagnostic group	Options
Malignant	Bone and soft tissue
	Breast
	Central nervous system
	Colorectal
	Gynaecological
	Haematological
	Head and neck
	Liver▲
	Lung
	Other gastrointestinal tract
	Other malignancy
	Other urological
	Pancreas
	Prostate
	Skin
	Unknown primary
Diagnostic group	**Options**
Non-Malignant	Cardiovascular disease
	Cerebrovascular disease[ê]
	Dementia[†]
	Diabetes and its complications
	End stage kidney disease
	End stage liver disease
	HIV/AIDS
	Motor neurone disease
	Multiple organ failure
	Other neurological disease
	Other non-malignancy
	Respiratory failure
	Sepsis
	Unknown

▲ Was previously included within 'Other GI'

ê Was previously known as 'Stroke'

† Now combines 'Alzheimer's dementia' & 'Other dementia'

Diagnosis (continued)	
Intent	To identify the primary diagnosis related to the need for palliative care. Recording the principal, life-limiting illness enables consistent classification of patients, supports analysis of disease-specific outcomes, and informs services planning and research.
Explanatory note	If a patient has multiple diagnoses, select the diagnosis that is the primary life-limiting condition that the patient is requiring palliative care for, noting that a malignant diagnosis may not always necessarily be the appropriate choice. When multiple diagnoses are identified, non-clinical/administration staff may need to consult with a clinician to determine the correct Primary Diagnosis.
Examples of use	A patient is diagnosed with prostate cancer and respiratory failure. The reason for referral is respiratory symptoms related to respiratory failure. Record respiratory failure as the primary life-limiting condition.
Quality improvement	Use diagnosis to explore patterns of referral to palliative care. Identify which diagnosis accounts for most referrals and consider whether these align with expected symptom profiles and population needs. Review whether conditions that are under-represented compared to the population catchment and the leading causes of death in Australia. Review ‘other malignancy’, ‘other non-malignancy’ and ‘unknown’ rates. Determine whether these categories represent accurate clinical coding.

Assessment level items capture the periodic assessments completed by clinicians. These assessments include information about the referral, type of care provided, the patient's symptoms and problems at that point in time.

Episodes of care are derived by PCOC based upon the start of the Comprehensive Assessment and ending on the date of the Separation Assessment.

Referral date and time	
Definition	The date and time when the patient is referred.
Options	Date Time in DD/MM/YYYY hh:mm:ss format.
Intent	To understand and evaluate the timing, access, and coordination of palliative care. To calculate the time between referral and first assessment.
Explanatory note	N/A
Examples of use	N/A
Quality improvement	Review the time elapsed between referral date and first assessment for delays that can be improved. Review referral and triage processes. Review responsiveness to out of hours referrals.

Assessment date and time	
Definition	The date and time when the patient is assessed.
Options	Date Time in DD/MM/YYYY hh:mm:ss format.
Intent	To establish the timing, sequence, and frequency of clinical assessments, which are essential for interpreting outcomes and monitoring care delivery. Specifically, it allows measurement between assessments to evaluate clinical change and response to symptom scores.
Explanatory note	An enhancement in Version 4 is the inclusion of all patient assessments, not only those at the start and end of each phase. A new time (24-hour format) field has been added to record the chronological order of multiple assessments conducted on the same day.
Examples of use	N/A
Quality improvement	Use date and time of assessments to review the duration between assessments to monitor frequency of assessment. Review the timing of assessments against workflow to match patient needs and staff availability. Review the timeliness of assessments against changes in phase or symptoms to evaluate how quickly patients are reassessed after a clinical change.

Assessment type	
Definition	The type of assessment completed.
Options	Comprehensive Ongoing Separation
Intent	To describe which type of assessment to complete at different time points in a patient's journey.
Explanatory note	Ongoing Assessments are completed to inform the patient's care. If the assessment determines that the patient is for discharge, a Separation Assessment needs to be completed. When a patient dies, a Separation Assessment needs to be completed (excluding clinical assessments). No Separation Assessment is required when a patient is transferred within a service (i.e. consult to inpatient setting) as this change is captured by the completion of a Comprehensive Assessment by the new team. When a Separation Assessment is completed after a patient has already been discharged, the clinical items should be documented as 'Not Assessed'.
Quality improvement	N/A

Referral provider type	
Definition	The location where the patient's referral originated. This is the type of service the patient was referred from.
Options	Public Hospital Private Hospital Outpatient Clinic Specialist Medical Practice General Medical Practice Community Service Residential Aged Care Facility Self, Carer(s), Family, Friends Other
Intent	The intent of collecting the referral provider type is to understand the source, patterns, and pathways of access to palliative care.
Explanatory note	Record the type of service or provider that initiated the referral to palliative care. Select the option that best reflects the setting or organisation making the referral, rather than the individual's professional background (e.g., a hospital referral made by a cardiologist is recorded as 'hospital'). If multiple providers were involved, record the primary source responsible for initiating the referral or coordinating transfer to the palliative care service.

Referral provider type (continued)

Examples of use	A hospital palliative care unit (PCU) has received a referral from a community service which has been accepted. The patient is arriving after hours. All patients arriving after hours at this PCU are required to present via the emergency department. The referral provider type should be the community service. A patient is known to a community service but has presented to the public hospital's emergency department without a referral to the PCU being received or accepted. The emergency department contacts the PCU Consultant, and the patient is accepted to the PCU. The referral provider type is public hospital.
Quality improvement	Monitor referral patterns and engage with underrepresented referral sources. Map the main referral networks and establish regular feedback loops, sharing outcome data to demonstrate the value of palliative care involvement.

Referral speciality

Definition	The field of practice or speciality where the patient's referral originated.

Options

Referral Provider Type	Options
Public hospital Private hospital Outpatient clinic Specialist medical practice Residential aged care facility Community service	Palliative care
	Medical oncology
	Radiation oncology
	Respiratory medicine
	Cardiology
	Haematology
	Geriatric medicine
	Emergency medicine
	Nephrology
	Neurology
	Rehabilitation medicine
	Surgical
	General medicine
	Other
General medical practice Community service Residential aged care facility	General practice Other primary care
Self, carer(s), family, friends	Not applicable

Intent	To identify the clinical speciality or professional group referring to palliative care, supporting analysis of referral patterns, targeted education, and improved integration between palliative care and other specialties.

Referral speciality (continued)	
Explanatory note	Linked to Referral Provider Type.
Examples of use	N/A
Quality improvement	Review referral patterns by clinical speciality to identify which professional groups most commonly refer patients to palliative care. Highlight underrepresented specialties where earlier or more frequent referral may be appropriate (e.g., limited referrals from non-cancer specialties). Target educational initiatives and outreach activities to referrer groups with low referral rates or delayed referrals.

Setting of care	
Definition	The setting in which palliative care is provided.
Options	Overnight Admitted - Designated Palliative Care Bed Overnight Admitted - Non-Designated Palliative Care Bed Same Day Admitted Outpatient Private Residence Residential Aged Care Facility Community - Other
Intent	Identify the care setting (e.g., designated palliative care unit, outpatient clinic, community, residential aged care) to provide context for clinical assessments and outcomes. Supports analysis of service delivery, care transitions, and benchmarking across different environments.
Explanatory note	‘Designated Palliative Care’ is when palliative care is the primary reason for admission and Palliative Care is the patient’s primary team. ‘Non-Designated’ means palliative care is not the primary reason for admission. The Palliative Care team provides consultative support at the request of another primary team. ‘Same day admitted’ refers to day procedure or day hospice. ‘Outpatient’ refers to outpatient clinics. ‘Community – Other’ refers to any community setting that is not outpatient, private residence (including retirement village) or residential aged care e.g. correctional facility, supported residential service, group home, homeless and hotel.
Examples of use	N/A
Quality improvement	Evaluate access and service utilisation by setting of care to determine if this is representative of the service.

Usual accommodation

Definition	The usual accommodation of the patient prior to assessment.
Options	Private Residence Residential Aged Care Facility Group Home Correctional Facility Other
Intent	To record the patient's usual place of residence prior to admission or referral, supporting understanding of social context, care planning, equity of access, and service delivery across different populations.
Explanatory note	Consider where the patient usually lives prior to their initial assessment. For a resident living in a retirement village or other independent living home, select private residence.
Examples of use	Other may include homeless, supported residential services/hostels, crisis accommodation, social housing.
Quality improvement	Examine usual accommodation to assess equity and access to palliative care.

Patient location after the assessment

Definition	The physical location of the patient directly after the separation assessment.

Options

Setting of Care	Options
Overnight admitted - designated palliative care bed Overnight admitted - non-designated palliative care bed	Inpatient - different hospital
	Inpatient – same ward in same hospital
	Inpatient – different ward in the same hospital
Same day admitted Outpatient Private residence Residential aged care facility Community - other	Inpatient
All	Community – usual accommodation
	Community - not usual accommodation, private residence
	Community - not usual accommodation, residential aged care
	Other
	Not Applicable - patient died

Intent	To record the patient's location at the time of separation from palliative care services, supporting analysis of care outcomes, discharge planning, service use, and patterns of end-of-life care or to capture a patient's death.

Patient location after the assessment (continued)

Explanatory note	If 'Not Applicable - Patient Died' is selected, then complete the additional 'Place of Death' item. 'Community - Usual Accommodation' should be used when the patient is returning to their usual community accommodation the same day of separation. This may include residential aged care if that was their usual accommodation prior to their hospital admission. 'Community - Not usual accommodation, residential aged care' should be selected when the patient is being transferred to residential aged care when their previous usual accommodation was elsewhere. This could be on a permanent or temporary basis (e.g. respite). 'Community - not usual accommodation, private residence' is a location different to the usual accommodation identified at the comprehensive assessment. Usually temporary in nature but may develop into usual accommodation. Can include hotel, short/long term rental or a friend's or family member's home but does not include residential aged care. A set of assessments are completed on separation for all options except when the patient dies.
Examples of use	N/A
Quality improvement	Review discharges/transfers missing a complete set of clinical assessments. Regularly audit separation data to identify missing assessments. Investigate reasons for incomplete data (e.g., workflow gaps, timing issues, clinical priorities), and implement targeted improvement actions such as staff reminders, process clarification, or system prompts.

Place of death

Definition	The place where the patient died.

Options

Setting of Care	Options
Same Day Admitted Outpatient Private Residence Residential Aged Care Facility Community	Private residence
	Residential aged care Facility
	Group home
Overnight Admitted – designated PC bed Overnight Admitted – non-designated PC bed	Hospital
All	Correctional facility
	Other
	Unknown

Intent	To record the location where the patient dies, supporting analysis of end-of-life outcomes, care planning, service delivery, and alignment of care with patient preferences.

Place of death (continued)	
Explanatory note	To capture where the patient died.
Examples of use	N/A
Quality improvement	Review trends in place of death data to identify any changes over time. Examine whether recorded places of death align with patient preferences and explore opportunities to improve care planning and coordination to support preferred place of death.

Carer availability	
Definition	Describes if the patient has a carer available.
Options	No Yes Not Assessed
Intent	To record patient's carer availability, supporting understanding of available social support, planning of care, identification of carer needs, and monitoring outcomes for both patients and carers. The availability of carers can impact the experience of patients in palliative care. Including information on carer availability will support PCOC in recognising and reporting the value of patients experience and outcomes with, and without, carer availability. In the community setting, this item can check for changes in carer readiness/ability to care or fatigue, requiring further resources/referral to external care services.
Explanatory note	'Carer' can be a paid and/or unpaid carer. May include family, friends, a neighbour, or a paid nursing/carer service. A carer may or may not be the next of kin. 'Available' means able to support the patient if, and when, needed (regardless of whether the care is paid or unpaid). In a clinical setting, this item supports care planning, resourcing/ discharge planning.
Examples of use	N/A
Quality improvement	Track patient outcomes in relation to carer availability to identify opportunities to enhance support and improve experiences. Use carer status to recognise and report differences in outcomes for patients with and without carer support. Incorporate carer status into clinical care plans, resource allocation, and discharge planning. In community settings, monitor changes in carer capacity or fatigue to prompt additional resources, referrals, or support services.

Mode of assessment	
Definition	Identifies how the assessment was conducted, in person, by mode of videoconference or by telephone.
Options	In Person Videoconference Telephone
Intent	To record the mode of assessment (in-person or via telehealth), supporting understanding of care delivery methods, monitoring service accessibility, and evaluating the impact of assessment mode on patient outcomes and care quality.
Explanatory note	Mode of assessment may vary for each assessment.
Examples of use	N/A
Quality improvement	Track the proportion of assessments conducted via telehealth versus in-person. Use mode-of-assessment data to identify populations who may face barriers to telehealth (e.g., rural patients, those with limited technology access) and implement strategies to address disparities.

The clinical assessment tools and outcome measures are used at every clinical encounter as part of the multidisciplinary assessment and response framework. This framework is described in detail in the PCOC Assessment and Response Protocol (12). The clinical assessment forms show how the clinical tools and outcome measures are used in practice and provide a summary of the definitions and the response framework (Appendix 3).

PCOC outcome measures provide a standardised way to capture patient symptoms, functional status, and care needs across palliative care services. These measures enable benchmarking at local, state, and national levels, allowing services to monitor performance, identify areas for improvement, and evaluate the impact of interventions over time. By systematically tracking outcomes, PCOC supports a data-driven approach to quality improvement, enhances consistency in care delivery, and promotes better experiences and outcomes for patients and their families.

Presence of delirium	
Definition	Indicates whether delirium is present, based on clinical observation and judgment. Delirium is an acute and fluctuating disturbance in attention, awareness, and cognition that often reflects an underlying medical, psychological, or pharmacological cause. This item captures the clinician's recognition of delirium. If delirium status is uncertain, the clinician should consider using a validated delirium assessment tool (e.g., delirium assessment tools 4AT, CAM, Nu-DESC (13)).
Options	No Yes Not Assessed
Intent	To capture clinician-identified delirium, raising awareness of its prevalence in palliative care patients and supporting assessment, monitoring, and management aligned with the patient's goals of care. Recording this item helps track the occurrence and recognition of delirium in palliative care settings, supporting assessment, management, and communication with the multidisciplinary team.
Explanatory note	The PCOC delirium items , together with the Australian Delirium Clinical Care Standard ('Delirium Standard') (14) forms a delirium monitoring system. Refer to Figure 1, Delirium screening and assessment flowchart. According to the Australian Delirium Clinical Care Standard, '*Delirium is an acute change in mental status that is often triggered by acute illness, surgery, injuries or adverse effects of medicines. Without appropriate screening, early detection is poor, and many cases of delirium are missed'* (The Delirium Care Standard, p9 (14)).
Examples of use	N/A
Quality improvement	Monitor delirium prevalence and patterns. Track the frequency and characteristics of delirium across patient populations to identify high-risk groups and inform targeted interventions. Improve assessment and management of delirium. Use data to review use of validated delirium assessment tools, guide staff education, and ensure treatment aligns with patient goals of care.

Delirium score

Definition	Identifies the patient-rated level of distress associated with delirium symptoms experienced over the past 24 hours. This measure reflects the patient's subjective experience of how distressing the effects of delirium are. It provides insight into the impact of delirium on the patient's wellbeing and helps guide the clinical response to reduce distress and improve comfort.

Options

Score/code	Description
0	Nil distress
1	
2	
3	
4	
5	
6	
7	
8	
9	
10	Worst possible distress
N/A	Not assessed

Intent	To capture the patient's level of distress related to delirium on a 0–10 scale, supporting the monitoring of symptom burden, guiding targeted interventions, and evaluating the effectiveness of management strategies in palliative care.
Explanatory note	This item captures the patient-rated level of distress from delirium over the past 24 hours. Distress may persist following a period of delirium, so its presence may not always coincide with active delirium symptoms. Patients may still be able to take part in self-rating even during or shortly after episodes of delirium, depending on their cognitive and communication abilities. Clinical guidance regarding clinical application is shown in Figure 1, Delirium screening and assessment flowchart.
Examples of use	N/A
Quality improvement	Review the proportion of patient-reported delirium. Encourage self-reporting where possible, even during periods of delirium, to ensure patient experiences are accurately captured and inform individualised care planning.

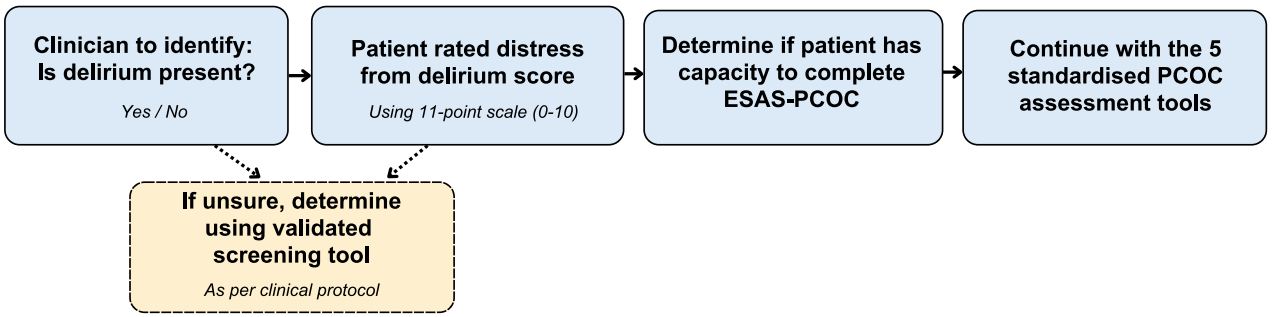

Figure 1: Delirium screening and assessment flowchart

ESAS-PCOC and Delirium rated by	
Definition	Identifies who rated the ESAS-PCOC and Delirium scores.
Options	Patient Family/ Carer Clinician Other
Intent	To identify who completed the ESAS-PCOC and Delirium scores.
Explanatory note	Record who rated the ESAS-PCOC and Delirium Scores. This may be different to the staff member who physically recorded the scores. Patient involvement in symptom reporting supports patient centred care. If a patient is unable to provide a score due to confusion or unconsciousness, then a proxy can be used. When using a proxy a family member/carer should be asked first. If a family member/carer unavailable, then a clinician can be a proxy.
Examples of use	N/A
Quality improvement	Review the proportion of assessments completed by patients versus proxies. Assess patterns where proxy reporting is more frequent and explore strategies to support direct patient reporting where appropriate, ensuring accuracy and patient-centred data collection.

Edmonton Symptom Assessment System for PCOC (ESAS-PCOC)

Definition	ESAS-PCOC uses a 0–10 numerical rating scale to measure patient-reported symptom and problem severity. It includes 11 common symptoms and problems, with the option to record one additional 'other symptom' (11, 16).

Symptom	**Scale**
Pain	(Absent - Worst Possible)
Tiredness *(lack of energy):*	(Absent - Worst Possible)
Drowsiness *(feeling sleepy):*	(Absent - Worst Possible)
Nausea	(Absent - Worst Possible)
Appetite	(Best - Worst Possible)
Shortness of Breath	(Absent - Worst Possible)
Constipation	(Absent - Worst Possible)
Sleep	(Best - Worst Possible)
Depression *(feeling sad):*	(Absent - Worst Possible)
Anxiety *(feeling nervous):*	(Absent - Worst Possible)
Wellbeing *(how you feel overall):*	(Best - Worst Possible)
Other*	(Absent – Worst Possible)

*Other symptom provides the patient with the opportunity to rate one other common symptom or problem that is bothersome, other than those listed. The options to choose from are:

- Dry or Sore Mouth
- Itch
- Swallowing Problems
- Other
- No Other Symptoms Present
- Not Assessed

ESAS-PCOC uses six categories to support consistent scoring. Each category is linked to a descriptor, colour, and facial expression on a Visual Analogue Scale (VAS), making the tool accessible for patients who find numeric ratings difficult.

A score greater than 0 reflects increasing severity across the domains. Higher individual or total scores indicate greater symptom burden.

Edmonton Symptom Assessment System for PCOC (ESAS-PCOC) (continued)

Options

Score/code	Description
0	Absent / Best Possible
1	Mild
2	
3	
4	Moderate
5	
6	
7	
8	Severe
9	
10	Severe – worst possible
N/A	Not assessed

Intent	To routinely capture patient-reported symptoms and problems to support timely identification, management, and evaluation of physical and psychosocial symptoms and problems. ESAS-PCOC enables clinicians and services to monitor symptom and problem trajectories, evaluate care effectiveness, and inform quality improvement activities.
Explanatory note	ESAS-PCOC is a patient-reported outcome measure (PROM). Patient reporting is feasible in most clinical scenarios; however, proxy reporting may be used when the patient is unable to self-report (15). ESAS-PCOC captures symptom and problem severity over the last 24 hours, not just at the time of assessment. PCOC has developed a modified version of the ESAS tool (ESAS-PCOC) which integrates key elements from the original ESAS, ESAS-revised (ESAS-r), and ESAS-Constipation and Sleep versions (11).
Examples of use	N/A
Quality improvement	Regularly review ESAS-PCOC data to identify patterns of persistently high symptom and problem scores (e.g., pain, breathlessness, fatigue) and implement targeted symptom management strategies. Encourage patients to self-report whenever possible and provide education on how to use the scale accurately. Ensure translated versions of ESAS-PCOC are available. Discuss high or worsening symptom and problem scores in multidisciplinary team meetings to identify service-level gaps, refine care pathways, and guide continuous quality improvement initiatives.

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

Definition	The Resource Utilisation Groups-Activities of Daily Living (RUG-ADL) scale measures a patient's level of functional dependence in performing basic motor activities of daily living (16). It consists of four items: Bed mobility, Toileting, Transfers, and Eating. Each item is rated according to the degree of assistance needed, ranging from complete independence to full dependence (Appendix 4). The individual item scores are summed to generate a total RUG-ADL score, which reflects the patient's overall level of physical dependency.

Options

For Bed Mobility, Toileting and Transfers
(1) Independent or supervision only
(3) Limited physical assistance
(4) Other than two-person physical assist
(5) Two-person (or more) physical assist
Not Assessed

For Eating
(1) Independent or supervision only
(2) Limited assistance
(3) Extensive assistance, total dependence or tube fed
Not Assessed

Intent	The RUG-ADL provides a structured way to assess and monitor a patient's functional status, supporting clinical decision-making, care planning, and resource allocation (e.g., staffing and equipment needs).
Explanatory note	The RUG-ADL is based on what the person does, not what they can do. This is best achieved by asking "*Do you…?*" rather than "*Can you…?*". There is no score of '2' for bed mobility, toileting and transfers, as 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. An unconscious, terminal patient should score 3 for the eating item, as the patient will require extensive assistance with mouth care. Further information and videos on the RUG-ADL are available on the PCOC website.
Examples of use	'Other than two persons physical assist' is a one-person assist with equipment.
Quality improvement	Review patients with a RUG-ADL score of 10 or higher on admission to ensure care plans appropriately reflect their higher dependency needs. Consider the implications for equipment provision, staffing levels, and allied health referrals to optimise safety and care quality.

Australia-modified Karnofsky Performance Status (AKPS)

Definition	The Australia-modified Karnofsky Performance Status (AKPS) is a measure of the patient's performance across the dimensions of activity, work and self-care at phase start (9). A single score between 10 and 100 is assigned by a clinician based on their 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. Further information and videos on AKPS assessment is available on the PCOC website.

Options

Score/Code	Description
100	Normal; no complaints; no evidence of disease
90	Able to carry on normal activity; minor signs or symptoms
80	Normal activity with effort; some signs or symptoms of disease
70	Cares for self; unable to carry on normal activity or to do active work
60	Requires occasional assistance but is able to care for most of their needs
50	Requires considerable assistance and frequent medical care
40	In bed more than 50% of the time
30	Almost completely bedfast
20	Totally bedfast and requiring extensive nursing care by professionals and/or family
10	Comatose or barely rousable
0	Dead
N/A	Not Assessed

Intent	To measure the patient's overall performance status, reflecting their ability to carry out daily activities, level of independence, and need for assistance. This supports clinical assessment, care planning, and prognostication in palliative care.
Explanatory note	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. The Lansky Play-Performance Scale can be mapped and used as a replacement of AKPS for children (Appendix 5).
Examples of use	N/A

Australia-modified Karnofsky Performance Status (AKPS) (continued)

Quality improvement	Use AKPS to identify patients experiencing rapid functional decline and ensure timely review of care goals and family communication. A sudden drop in AKPS score often signals the need for escalation, anticipatory prescribing, or advance care planning. Services can enhance prognostic awareness by incorporating AKPS trends into clinical review and multidisciplinary discussions. Use AKPS scores at the start of palliative care to evaluate referral timeliness and referral pathways.

Palliative Care Problem Severity Score (PCPSS)

Definition	The Palliative Care Problem Severity Score (PCPSS) is a clinician-rated tool designed to provide a screening assessment of the severity of problems experienced by patients in palliative care (17). It evaluates four key domains: 1. Pain: physical discomfort experienced by the patient. 2. Family/carer distress or concerns impacting the patient or their family/carers. 3. Psychological/spiritual issues affecting wellbeing. 4. Other symptoms any additional symptoms not captured in the first three domains. Each domain is scored on a four-point scale (0–3), reflecting the severity of problems over the past 24 hours. The PCPSS provides a concise, clinician-rated overview of the patient's overall symptom burden and problem severity, supporting screening, care planning, and monitoring across the multidisciplinary team. Further information and videos on PCPSS are available on the PCOC website.

Options

Score/Code	Description
0	Absent
1	Mild
2	Moderate
3	Severe
N/A	Not assessed

Intent	To provide a clinician-rated assessment of problem severity across key palliative care domains, supporting timely identification of high-burden problems, care planning, monitoring of changes over time, and prioritisation of interventions.
Explanatory note	The tool is intended for screening and monitoring, providing a quick overview to guide multidisciplinary care planning and prioritisation. Clinicians should consider the patient's clinical context and any relevant proxy information when scoring domains such as family/carer or psychological/spiritual distress.

Palliative Care Problem Severity Score (PCPSS) (continued)

Examples of use	Other symptoms may include nausea, vomiting, anorexia, itch/irritation, constipation, diarrhoea, wounds, incontinence, fatigue, dyspnoea, oedema, confusion and agitation etc. Psychological/spiritual may include anxiety, fear, request to die, anger, depression, sadness, unrealistic goals, denial and agitation etc. Family/carer may include denial, anger, caregiver fatigue, sensory impairment, unrealistic goals, financial, family/carer conflict, legal, accommodation issues etc. Delirium may cause patients to experience certain signs/symptoms found in the 'Other symptoms' and/or 'Psychological/spiritual' domains.
Quality improvement	Evaluate severity of scores alongside palliative care phase. Misalignment may indicate a need for education on accurate patient assessment.

Palliative care phase

Definition	Phase is a classification of an individual's palliative care trajectory, used to describe the distinct stages in the patient's journey (18). Phase assignment should be guided by the phase definitions (Appendix 6) and phase algorithm (Appendix 7) to ensure consistency and alignment with assessment data. The four phases are: 1. Stable: Adequate symptom and problem control. No change in care plan required. 2. Unstable: Urgent change in care plan or emergency treatment required to address severe needs. 3. Deteriorating: Non-urgent change in care plan required to address increasing needs. 4. Terminal: Death likely within a matter of days.

Options

Phase number	Description
1	Stable
2	Unstable
3	Deteriorating
4	Terminal

Intent	To identify the patient's and family's needs, develop the care plan, guide referral and triage decisions, and inform the frequency of clinical assessments.

Palliative care phase (continued)	
Explanatory note	Phases may not follow a sequential order; a patient episode can begin in any phase and transition to any other phase. Phase is used to describe the distinct stages in the patient's journey and to summarise the needs of patient, family and carer. 'Bereavement/ Post Death Phase' is an important part of palliative care however it is not used in Version 4. Phase type is determined using multiple assessment tools (ESAS-PCOC, RUG-ADL, AKPS, PCPSS) and should not be used in isolation.
Examples of use	Phase can be integrated into referral, triage, communication processes in and between teams and multidisciplinary team meetings.
Quality improvement	Regularly review whether the assigned phase corresponds with other assessment measures (e.g., PCPSS, ESAS-PCOC). Misalignment may indicate the need for reassessment or staff education. When recording a patient's phase, include indicators supporting the classification to improve clarity, communication, and clinical decision-making.

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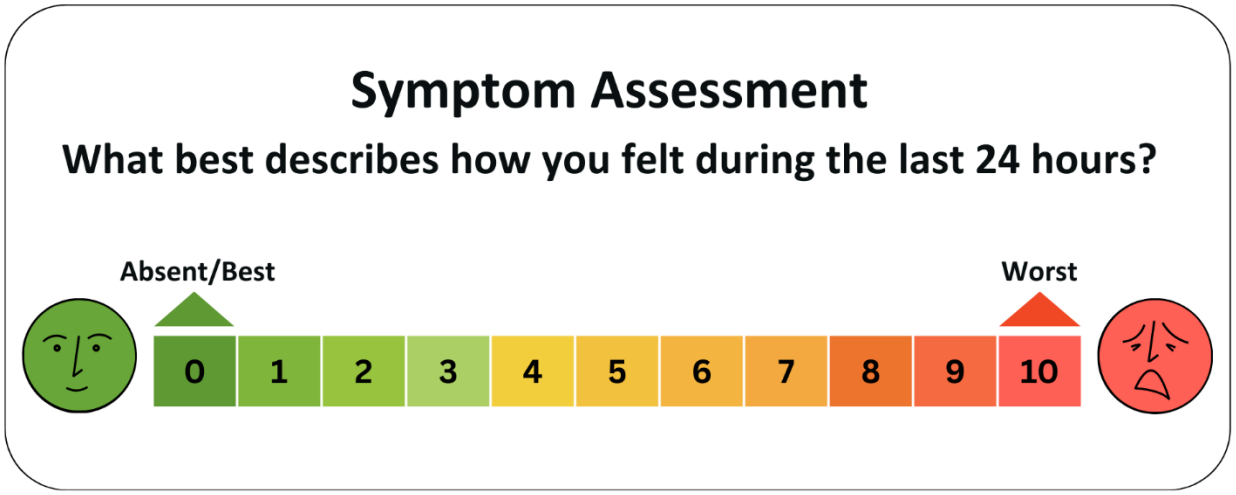
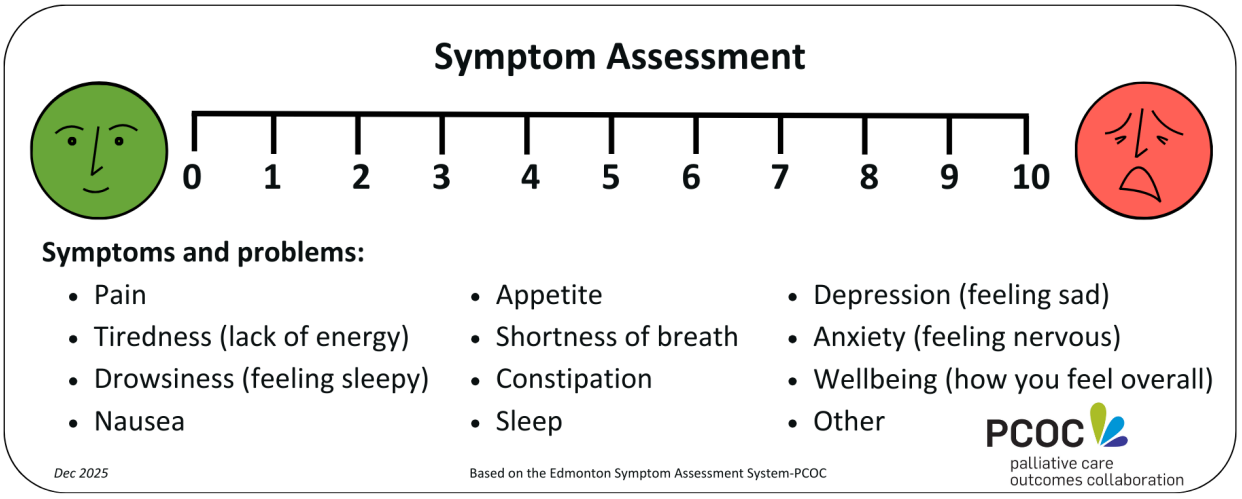
Appendices

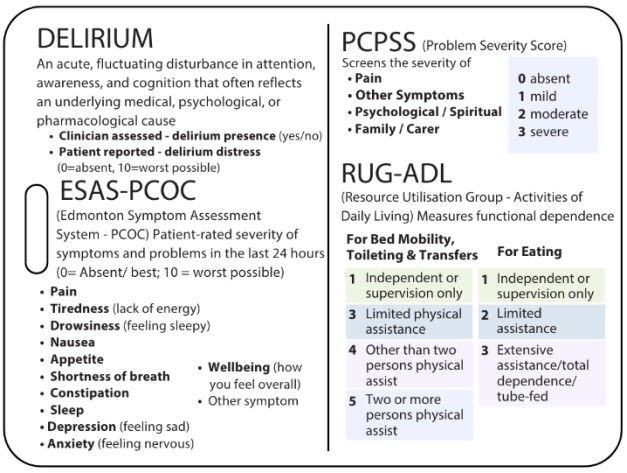
Appendix 1: Assessment and response lanyard card

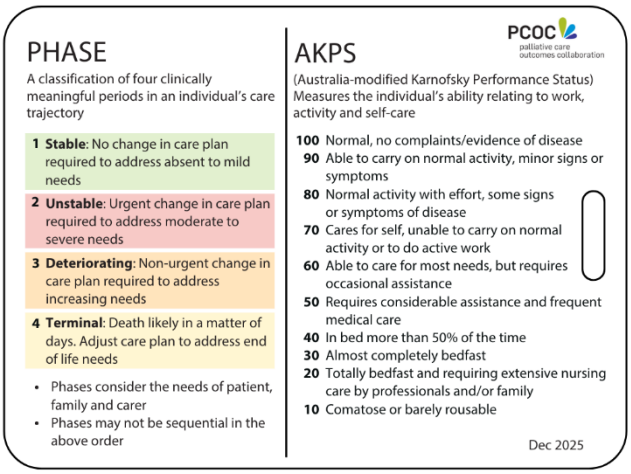
Ruler:



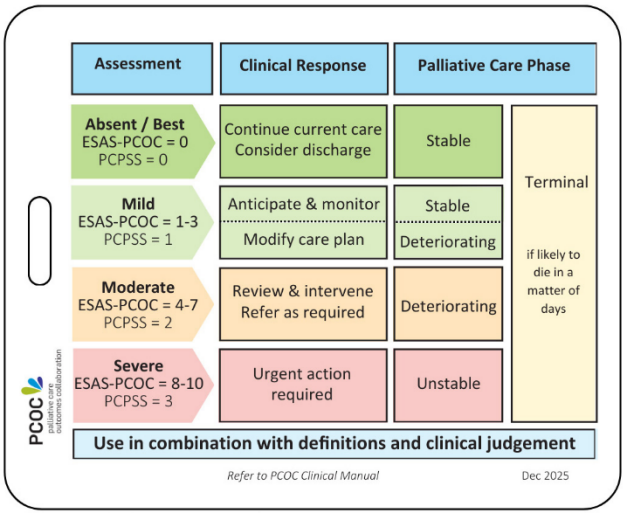


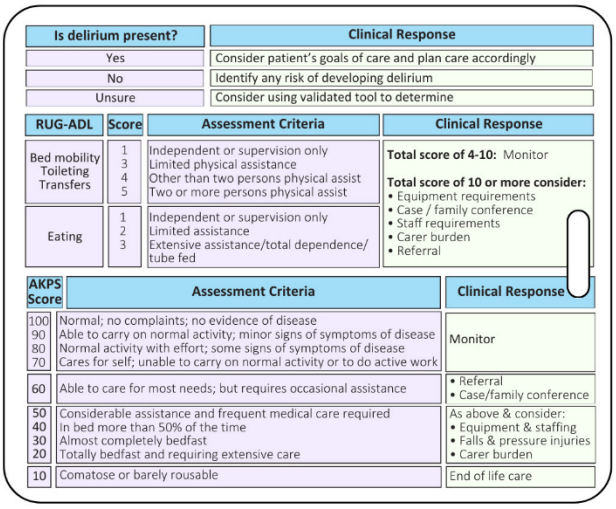
Lanyard Definition:





Lanyard Guide:





Checklist for developing, implementing and monitoring PCOC education requirements

This checklist is designed for managers, educators and clinicians with responsibility for clinical implementation and ongoing education of the PCOC assessment and response protocol and outcome measures.

Date completed	
Completed by	

Education activities	**Comment**
A designated PCOC clinical lead (champion) provides a brief introduction about PCOC to all clinical staff as part of orientation. Short videos About PCOC and PCOC explained (~10min)	
Clinical staff complete the PCOC essentials program clinicians module (~30min)*	
Managers and clinical leads with responsibilities to receive and disseminate PCOC reports complete the PCOC essentials program, managers module (~15min)*	
All clinical and management staff have a copy of the PCOC assessment and response protocol and/ or [insert local guideline/policy protocol here]	
All clinical staff receive the PCOC lanyard cards (definitions and assessment and response) and the ESAS-PCOC ruler	
All clinical staff receive training on how to correctly use the PCOC assessment tool*: 1. Observe a complete assessment including a patient-reported ESAS-PCOC 2. Undertake a complete assessment, including a patient-reported ESAS while being observed by an educator or clinical lead (champion)	
All clinical staff attend the PCOC Fundamentals webinar – a webinar aimed at educating participants on how to understand and use the PCOC assessment tools. For webinar details, go to the 'Education' page on the PCOC site	
Clinical leads (champions) attend PCOC workshops annually (*Implementing Assessment and Response* and *Using Reports for Quality Improvement*). For workshop details, go to the 'Education' page on the PCOC site.	
Clinical leads (champions) provide ongoing education using the set of videos (~5min each)*	
Clinical leads (champions) undertake audits and case review using PCOC templates. For details, go to the 'PCOC documents' page on the PCOC site under the '*Quality Improvement*' heading.	

***Note:** as part of an ongoing education and skills maintenance strategy, it is recommended to complete these activities annually.

PCOC palliative care outcomes collaboration

Community Palliative Care Form

Team name, if required _____

UPI/ URN/ MRN/ Patient ID:_____ (affix label here)
Surname: _____
First name: _____
DOB: __ / __ / ____ Sex: ☐ Male ☐ Female ☐ Other
State: _____ Postcode:_____

PATIENT INFORMATION

Country of birth ☐ Australia ☐ Other: _____
Preferred language ☐ English ☐ Other: _____

Indigenous status *(Select one)*
☐ 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

Principal Life-Limiting Diagnosis *(Select one)*

Malignant
☐ Bone & Soft Tissue
☐ Breast
☐ Central Nervous System
☐ Colorectal
☐ Pancreas
☐ Liver
☐ Other Gastro-Intestinal Tract
☐ Haematological
☐ Head & Neck
☐ Lung
☐ Prostate
☐ Other Urological
☐ Gynaecological
☐ Skin
☐ Unknown primary
☐ Other malignancy

Non-Malignant
☐ Cardiovascular Disease
☐ HIV/AIDS
☐ End-Stage Kidney Disease
☐ Cerebrovascular Disease
☐ Motor Neuron Disease
☐ Dementia
☐ Other Neurological Disease
☐ Respiratory Failure
☐ End-Stage Liver Disease
☐ Diabetes & its complications
☐ Sepsis
☐ Multiple Organ Failure
☐ Other Non-Malignancy

COMPREHENSIVE ASSESSMENT: Complete at the start of community palliative care

ADMISSION INFORMATION

Date & time patient referred ___ / ___ / ___ ___:___
Date & time of assessment ___ / ___ / ___ ___:___

Referral provider type where did the referral come from? *(Select one)*
☐ Public hospital
☐ Private hospital
☐ Outpatient clinic
☐ Specialist medical practice
☐ Self, carer(s), family, friends
☐ General medical practice
☐ Community service
☐ Residential aged care facility
☐ Other

Referral speciality, which speciality referred the patient? *(Select one)*
☐ Palliative care
☐ Medical oncology
☐ Radiation oncology
☐ Respiratory medicine
☐ Cardiology
☐ Haematology
☐ Geriatric medicine
☐ Emergency medicine
☐ Nephrology
☐ Neurology
☐ Rehabilitation medicine
☐ Surgical
☐ General medicine
☐ General practice
☐ Other primary care
☐ Not applicable – self, carer, family, friend referral
☐ Other

Setting of Care *(Select one)*
☐ Private residence
☐ Residential aged care facility
☐ Community – not further specified
☐ Same day admitted
☐ Outpatient

Patient's usual accommodation *(Select one)*
☐ Private residence
☐ Residential aged care facility
☐ Group home
☐ Correctional facility
☐ Other

Does the patient have a carer (see definitions) **who is available to provide care?** *(Select one)*
☐ Yes
☐ No
☐ Not assessed

Proceed to clinical assessment →

SEPARATION ASSESSMENT: Complete at death, discharge, or prior to changing setting of care

SEPARATION INFORMATION

Date & time of separation ___ / ___ / ___ ___:___

Patient location after separation Where is the patient being discharged to?
☐ Community - usual accommodation
☐ Community - not usual accommodation, private residence
☐ Community - not usual accommodation, residential aged care
☐ Inpatient
☐ Other
☐ Not applicable – patient died

Proceed to clinical assessment

Place of death *(If applicable)*
☐ Private residence
☐ Residential aged care facility
☐ Group home
☐ Correctional facility
☐ Other
☐ Unknown

If patient died, no clinical assessment required

PCOC palliative care outcomes collaboration

Community Palliative Care Clinical Assessment Form

UPI/ URN/ MRN/ Patient ID:_____(affix label here)
Surname: _____
First name: _____
DOB: ____ / ____ / ____ Sex: ☐ Male ☐ Female ☐ Other
State: _____ Postcode: _____

Team name (ward/unit), if required _____

ONGOING ASSESSMENT:
Complete at initial contact; at each contact; at phase change; and prior to separation If not assessed, enter N/A

Year:	**Date**													
	Time													
Mode of assessment (F=face-to-face, T =Telephone, V=Videoconference)														

Delirium

Clinician-assessed **Is delirium present?** (Yes / No)													
Patient-reported **distress** from **Delirium** (0 = Absent, 10 = Worst possible)													
Guide to clinical response	If delirium is suspected, confirm with a validated tool. Consider patient's goal of care and plan care accordingly												

Edmonton Symptom Assessment System (ESAS-PCOC)
Patient (or proxy) reported symptom and problem **severity** in the last 24 hours

PATIENT- REPORTED

Pain (0 = No pain, 10 = Worst possible)													
Tiredness (lack of energy) (0 = No tiredness, 10 = Worst possible)													
Drowsiness (feeling sleepy) (0 = No drowsiness, 10 = Worst possible)													
Nausea (0 = No nausea, 10 = Worst possible)													
Appetite* (0 = **Best** appetite, 10 = Worst possible)													
Shortness of breath (0 = No shortness of breath, 10 = Worst possible)													
Constipation (0 = No constipation, 10 = Worst possible)													
Sleep* (0 = **Best** sleep, 10 = Worst possible)													
Depression (feeling sad) (0 = No depression, 10 = Worst possible)													
Anxiety (feeling nervous) (0 = No anxiety, 10 = Worst possible)													
Wellbeing (how you feel overall)* (0 = **Best** wellbeing, 10 = Worst possible)													
Other symptom (D = Dry or sore mouth; I = Itch; S = Swallowing; Ot = Other; N = No other symptom)													
Other symptom score (0 = Absent symptom; 10 = Worst possible)													
Guide to clinical response	0 to 3: Anticipate and monitor, modify plan as required			4 to 7: Review, intervene and refer as required					8-10: Urgent action				
ESAS-PCOC & distress from delirium **Rated by** (P=Patient, F=Family/carer, C=Clinician, O=Other)													

**Please note 0 represents 'best' for Appetite, Sleep and Wellbeing*

Continue to next page

PCOC palliative care outcomes collaboration

Community Palliative Care

Clinical Assessment Form

Team name, if required _____

UPI/ URN/ MRN/ Patient ID:_____ (affix label here)
Surname: _____
First name: _____
DOB: __ / __ / __ Sex: ☐ Male ☐ Female ☐ Other
State: _____ Postcode: _____

ONGOING ASSESSMENT (Continued) If not assessed, enter N/A

Year:	Date													
Time														

CLINICIAN - ASSESSED

Resource Utilisation Groups – Activities of Daily Living (see scoring guide)

Bed mobility (1, 3, 4, 5)													
Toileting (1, 3, 4, 5)													
Transfers (1, 3, 4, 5)													
Eating (1, 2, 3)													
Total RUG-ADL (4 to 18)													
Guide to clinical response	If total score is 10 or more, consider equipment needs, case/family conference, staff requirements, carer burden, referral												

Australia-modified Karnofsky Performance Status (see scoring guide)

AKPS (10 to 100)													
Guide to clinical response	If score 60 or lower, consider referral as appropriate. If score 40 or lower, consider also equipment needs, staffing, falls risk, pressure injuries, and carer burden												

Palliative Care Problem Severity Score (0 = absent 1 = mild 2 = moderate 3 = severe)

Pain													
Other symptoms													
Psychological / spiritual													
Family / carer													
Guide to clinical response	0 to 1: Anticipate and monitor, modify plan as required				2: Review, intervene and refer as required					3: Urgent action			

Palliative Care Phase

Phase Type													

	Stable (S)	Unstable (U)	Deteriorating (D)	Terminal (T)
Definition	Adequate symptom and problem control. No change in care plan required	Urgent change in care plan or emergency treatment required to address severe needs	Non-urgent change in care plan required to address increasing needs	Death likely in a matter of days
Guide to clinical response	Continue current care Anticipate and monitor for changing needs	Urgent action	Review & intervene; Refer as required	Adjust care plan to address end of life needs

Clinician initials													

DEFINITIONS & SCORING GUIDE

Refer to PCOC Clinical Manual for the complete definitions www.pcoc.org.au

Carer Availability

- *Definition of Carer:* paid and/or unpaid person who provides care, support and assistance. May include family, friends, a neighbour, or a paid nursing/carer service. A carer can be different from next of kin/person responsible.
- *Available* means able to support the patient if required.

Delirium: Clinician-assessed presence of delirium, and patient-reported (or proxy) distress from delirium in the last 24 hours

- *Definition:* an acute change in mental status that is often triggered by acute illness, surgery, injuries or adverse effects of medicines (Australian Commission of Safety and Quality in Health Care, 2021).
- *Characteristics:* disturbances in consciousness, attention, cognition and perception that develop over a short period of time (usually hours to a few days). Patients with delirium may be agitated and restless (hyperactive delirium), or quiet and withdrawn (hypoactive delirium). Patients may also move between these two subtypes (mixed delirium). The onset of delirium is quick (over hours to a few days) in comparison to dementia.

Edmonton Symptom Assessment System (ESAS-PCOC): Patient-reported severity of symptoms and problems in the last 24 hours

- *Best-practice:* patient rates their own symptoms, which is key to delivering person-centred and value-based care.
- *How to use this tool:* Elicit ratings from patient through conversations to understand the symptoms from the patient's perspective, then conduct a more in-depth clinical assessment as needed. Provide intervention/escalation if necessary.
- If a patient is unable to provide a score, e.g. due to confusion, unconsciousness, communication difficulties, then a proxy can be used. When using a proxy, consider a family/carer first. If family/carer unavailable, then a clinician may score.
- Translated patient flyer and forms are available to download from the PCOC website.

Resource Utilisation Groups – Activities of Daily Living: Clinician assessment of functional dependence over a 24-hour period

Scoring guide:

For Bed Mobility, Toileting & Transfers

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

For Eating

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

Australia-modified Karnofsky Performance Status:

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

Scoring guide:

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

Palliative Care Problem Severity Score: Clinician assessment of problems in the last 24 hours

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

- *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 one or more problems relating to the patient's psychological or spiritual wellbeing
- *Family/Carer:* severity of one or more family/carer problems associated with a patient's condition or palliative care needs. Written, verbal or observational information can be used to assess needs if family/carer are not present

Stable (S)	**Unstable (U)**	**Deteriorating (D)**	**Terminal (T)**
Adequate symptom and problem control. No change in care plan required	Urgent change in care plan or emergency treatment required to address severe needs	Non-urgent change in care plan required to address increasing needs	Death likely in a matter of days. Adjust care plan to address end of life needs.

Appendix 4: Resource Utilisation Groups-Activities of Daily Living (RUG-ADL)

BED MOBILITY		The ability to move in bed after the transfer into bed has been completed
Item	**Score**	**Definition**
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.
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.
Item	**Score**	**Definition**
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.
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.
Item	**Score**	**Definition**
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.

Appendix 5: Lansky Play-Performance Scale

The Lansky Play-Performance Scale (8) is a validated measure of functional performance for paediatric patients, capturing a child's level of activity, play, and independence. It provides an age-appropriate alternative to the Australia-modified Karnofsky Performance Status (AKPS).

While the AKPS assesses function through work and self-care, the Lansky Scale reflects play-based activity as a marker of wellbeing. Scores range from 100 (fully active) to 10 (no play, confined to bed), enabling clinicians to track functional change.

In PCOC Version 4, the Lansky Play-Performance Scale may be used in place of the AKPS for children and young people. This ensures developmentally appropriate assessment.

Score	Lansky play-performance scale	AKPS
100	Fully active, normal	Normal; no complaints; no evidence of disease
90	Minor restrictions in physically strenuous activity	Able to carry on normal activity; minor sign of symptoms of disease
80	Active, but tires more quickly	Normal activity with effort; some signs or symptoms of disease
70	Both greater restriction of, and less time spent in active play	Cares for self; unable to carry on normal activity or to do active work
60	Up and around, but minimal active play; keeps busy with quieter activities	Able to care for most needs; but requires occasional assistance
50	Gets dressed, but lies around much of the day; no active play; able to participate in all quiet play and activities	Considerable assistance and frequent medical care required
40	Mostly in bed; participates in quiet activities	In bed more than 50% of the time
30	In bed; needs assistance even for quiet play	Almost completely bedfast
20	Often sleeping; play entirely limited to very passive activities	Totally bedfast and requiring extensive nursing care by professionals and/or family
10	No play, Does not get out of bed	Comatose or barely rousable
0	Unresponsive; dead	Dead

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** ▪ Further interventions to maintain symptom control and quality of life have been planned **and** ▪ 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** ▪ Patient experiences a new problem that was not anticipated in the existing plan of care, **and/or** ▪ Patient experiences a rapid increase in the severity of a current problem; **and/or** ▪ 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** ▪ Death is likely within days (i.e. patient is now terminal).
Deteriorating	
The care plan is addressing anticipated needs but requires periodic review **because** ▪ Patients overall functional status is declining **and/or** ▪ Patient experiences a gradual worsening of existing problem **and/or** ▪ Patient experiences a new but anticipated problem **and/or** ▪ Family/carers experience gradual worsening distress that impacts on the patient care.	▪ Patient condition plateaus (i.e. patient is now stable) **or** ▪ An urgent change in the care plan or emergency treatment **and/or** ▪ Family/ carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (ie patient is now unstable) **or** ▪ Death is likely within days (i.e. patient is now terminal).
Terminal	
Death is likely within days.	▪ Patient dies **or** ▪ 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 ▪ Bereavement support provided to family/carers is documented in the deceased patient's clinical record.	▪ Case closure 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 (2015) 22-30.

Appendix 7: Phase algorithm