

# PCOC DATA DEFINITIONS VERSION 2

## Level 1 - Patient Level Items

No.	Item	Item Description	Item Codes	Item Code-Set Description
2.1.1	Person/Client Identifier	Unique person identifier within the palliative care service		Any number that is unique for each patient. This number must be used at all times when recording patient, episode or phase details for this patient for PCOC. This number could be the patient record number
2.1.2	Date of Birth	Birth date of patient	dd/mm/yyyy	
2.1.3	Sex	Patient's gender	1	Male
			2	Female
			3	Indeterminate
			99	Not stated/inadequately described
2.1.4	State Identifier	State of usual place of residence	1	NSW
			2	VIC
			3	QLD
			4	SA
			5	WA
			6	TAS
			7	NT
			8	ACT
			9	Other Australian Territory (Australian Antarctic Territory, Cocos (Keeling) Islands, Christmas Island and Jervis Bay Territory)
			10	Other country
2.1.5	Postcode	Postcode of usual place of residence <i>Leave blank if State identifier is 9 or 10</i>		Four digit postcode
2.1.6	Indigenous status	Patient's indigenous status	1	Aboriginal but not Torres Strait Islander origin
			2	Torres Strait Islander but not Aboriginal origin
			3	Both Aboriginal and Torres Strait Islander origin
			4	Neither Aboriginal nor Torres Strait Islander origin
			99	Not stated / inadequately described
2.1.7	Main language spoken at home	The main language reported by a patient as the main language spoken in his/her home.	xx	Standard 2 digit code.
2.1.8	Country of birth	The country in which the person was born	xxxx	Standard Australian Classification of Countries (SACC) 4-digit (individual country) level. ABS catalogue no.1269.0 (1998)

## Level 2 - Episode Level Items

No.	Item	Item Description	Item Codes	Item Code Set Description
2.2.9	Referral date	Date agency received a referral for this patient/client from another party for palliative care services	dd/mm/yyyy	
2.2.10	Referral source	Location of source of referral for this episode	1	Public hospital – other than inpatient palliative care unit
			2	Private hospital – other than inpatient palliative care unit
			3	Public palliative care inpatient unit/hospice
			4	Private palliative care inpatient unit/hospice
			5	General Medical Practitioner rooms
			6	Specialist Medical Practitioner rooms
			7	Community-based palliative care agency
			8	Community-based service
			9	Residential aged care facility
			10	Self, carer(s), family or friends
			11	Other
2.2.11	Mode of episode start	How this episode began	<b>Overnight Admitted Patients</b>	
			1	Admitted from usual accommodation
			2	Admitted from other than usual accommodation
			3	Admitted (transferred) from another hospital
			4	Admitted (transferred) from acute care in another ward
			5	Change from acute care to palliative care while remaining on same ward
			6	Change of sub-acute/non-acute care type
			7	Statistical admission from leave
			9	Other
			<b>All other patients (same day admitted, outpatient and community)</b>	
			A	First visit following new referral
			B	First visit after discharge from being an overnight admitted palliative care patient
			2.2.12	Date of first contact with patient/client
2.2.13	Episode start date	The date a patient/client commences an episode of care	dd/mm/yyyy	For inpatients: date of admission For ambulatory patients: date of first face to face contact
2.2.14	Proposed model of care at episode start	The type of care planned at the start of this episode of care	1	Direct care
			2	Shared care with another service provider/s (cancer care, respiratory, GP, MND, community health care providers)
			3	Consultation/liaison with another service provider
2.2.15	Episode type	The location of the patient for this episode	0	Overnight admitted patient in a non-designated inpatient palliative care bed/unit Go to 2.2.19 <i>(Patient is admitted and discharged on different dates)</i>
			1	Overnight admitted patient in a designated inpatient palliative care bed/unit Go to 2.2.19 <i>(Patient is admitted and discharged on different dates)</i>
			3	Ambulatory Go to 2.2.19 <i>(Patient receives care on a same day admitted or outpatient basis)</i>
			4	Community Go to 2.2.19 <i>(Patient receives care in the home or other non-hospital site)</i>
			5	Consultation service (Patient is seen by a consultative service) If 5 is ticked answer 2.2.16, 2.2.17 and 2.2.18
2.2.16	Reason for consultative service visit	Type of consultative service provided  <i>Complete only if Episode Type is 5 (Consultative). Otherwise leave blank</i>	1	Advice only
			2	One-off consultation
			3	Recurring consultation
			99	Not stated/inadequately described
2.2.17	Location of consultative service	Location where the consultative service was provided  <i>Complete only if Episode Type is 5 (Consultative). Otherwise leave blank</i>	1	Inpatient – designated palliative care bed
			2	Inpatient – non-designated palliative care bed
			3	Hospital-based clinic or centre
			4	Community-based day centre
			5	Residential aged care facility
			6	Home
99	Not stated/inadequately described			

No.	Item	Item Description	Item Codes	Item Code Set Description
2.2.18	Mode of consultative service	How was this service was provided <i>Complete only if Episode Type is 5 (Consultative). Otherwise leave blank</i>	1	Face to face
			2	Telephone/electronic communication
2.2.19	Diagnosis	The broad diagnostic group established after study to be chiefly responsible for occasioning the patient's episode of palliative care.	1	<b>Malignant (neoplasm)</b>
				1.1 Bone and Soft Tissue
				1.2 Breast
				1.3 CNS
				1.4 Colorectal
				1.5 Gynaecological
				1.6 Haematological
				1.7 Head and Neck
				1.8 Lung
				1.9 Pancreas
				1.10 Prostate
				1.11 Skin
				1.12 Other GIT
				1.13 Other Urological
				1.14 Other Malignancy
			1.15 Unknown Primary	
			2	<b>Non-malignant (other diagnosis)</b>
2.1 Cardiovascular				
2.2 HIV/AIDS				
2.3 Kidney Failure				
2.4 Neurological Disease				
2.5 Respiratory Failure				
2.6 Other non-malignancy				
2.2.20	Accommodation at episode start	Type of usual accommodation at the commencement of the episode	1	Private residence (including unit in retirement village)
			2	Residential aged care, low level care (hostel)
			3	Residential aged care, high level care (nursing home)
			4	Community group home
			5	Boarding house
			6	Transitional living unit
			7	Other
2.2.21	Level of Support at episode start	Level of support received at the commencement of the episode.  <i>Complete only if Accommodation at episode start is 1 (Private residence). Otherwise leave blank</i>	1	Lives alone (no support/care provided)
			2	Lives with others (no support/care provided)
			3	Lives alone with external support(s)
			4	Lives with others (who provide support/care)
			5	Lives with others, external support(s)
			6	Other arrangements
			99	Not stated/inadequately described
2.2.22	Episode end date	The date of episode end	dd/mm/yyyy	The date of discharge, death or transfer
2.2.23	Mode of episode end	How this episode ended	<b>Overnight admitted patients</b>	
			1	Discharged to usual accommodation
			2	Discharged to interim accommodation
			3	Death
			4	Discharged to another hospital
			5	Change from palliative care to acute care – different ward
			6	Change from palliative care to acute care – same ward
			8	Discharged at own risk
			99	Other
			<b>Ambulatory patients</b>	
			A	Discharge/case closure
			B	Death (Complete 2.2.26)
			C	Admitted for inpatient palliative care
			D	Admitted for inpatient acute care
			E	Transfer to another palliative care service or to primary care
G	Not known			
2.2.24	Accommodation at episode end	Type of accommodation at episode end	1	Private residence (including unit in retirement village)
			2	Residential aged care, low level care (hostel)
			3	Residential aged care, high level care (nursing home)
			4	Community group home
			5	Boarding house
			6	Transitional living unit
			7	Other
2.2.25	Level of Support	Level of support received at episode	1	Lives alone (no support/care provided)

No.	Item	Item Description	Item Codes	Item Code Set Description
	at episode end	end.  <i>Complete only if Accommodation at episode end is 1 (Private residence). Otherwise leave blank</i>	2	Lives with others (no support/care provided)
			3	Lives alone with external support(s)
			4	Lives with others (who provide support/care)
			5	Lives with others, external support(s)
			6	Other arrangements
			99	Not stated/inadequately described
2.2.26	Place of death	<i>Complete only if Mode of Episode End (item 2.2.23) is B (death). Otherwise leave blank</i>	1	Private residence
			2	Residential aged care setting
			3	Other location

### Level 3 - Phase level items

No.	Item	Item Description	Item Code Set	Item Code Set description
2.3.27	Date of phase start	The date this phase began	dd/mm/yyyy	
2.3.28	Phase	Palliative Care Phase.  <i>Note: The first phase begin date = episode begin date</i>	1	Stable
			2	Unstable
			3	Deteriorating
			4	Terminal
			5	Bereaved
2.3.29	RUG-ADL functional scores at phase start	RUG-ADL scores as recorded within 24 hours of the start of the phase.  Note: a score of 2 is not valid on the bed mobility, toileting or transfer items	For bed mobility, toileting & transfers:	
			1	Independent or supervision only
			3	Limited physical assistance
			4	Other than two persons physical assist
			5	Two-person physical assist
			For eating:	
			1	Independent or supervision only
2.3.30	Symptom Assessment Score (SAS) at phase start	SAS as recorded within 24 hours of the start of the phase.		Insomnia, appetite problems, nausea, bowels, breathing, fatigue and pain (7 items)
			0-10	Not at all - Worst Possible
2.3.31	Palliative Care Problem Severity scores at phase start	Pain score as recorded within 24 hours of the start of the phase	0	Absent
			1	Mild
			2	Moderate
			3	Severe
2.3.32	Palliative Care Problem Severity scores at phase start	Other symptom score as recorded within 24 hours of the start of the phase	0	Absent
			1	Mild
			2	Moderate
			3	Severe
2.3.33	Palliative Care Problem Severity scores at phase start	Psychological/Spiritual score as recorded within 24 hours of the start of the phase	0	Absent
			1	Mild
			2	Moderate
			3	Severe
2.3.34	Palliative Care Problem Severity scores at phase start	Family/Carer score as recorded within 24 hours of the start of the phase	0	Absent
			1	Mild
			2	Moderate
			3	Severe
2.3.35	Karnofsky functional score at phase start	Score on the Australian Modified Karnofsky Scale as recorded within 24 hours of the start of the phase	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 his 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 arousable
0	Dead			
2.3.36	Model of care at phase end	The type of care provided at the end of this phase of care	1	Direct care
			2	Shared care with another service provider/s (cancer care, respiratory, GP, MND, community health care providers)
			3	Consultation/liaison with another service provider
2.3.37	Date of phase end	The date on which a patient completes a phase of care	dd/mm/yyyy	<i>Default to new episode</i>
2.3.38	Reason for phase end	The reason this phase ended	1	Phase change
			2	Discharge/Case closure
			3	Died or Bereavement phase
			4	Bereavement phase end

No.	Item	Item Description	Item Code Set	Item Code Set description
2.3.39	Number of days seen	The total number of direct contact days during this phase <i>Note: Not collected on overnight admitted episodes</i>		
2.3.40	RUG-ADL functional scores at phase end	RUG-ADL scores as recorded within 24 hours of the end of the phase.  Note: a score of 2 is not valid on the bed mobility, toileting or transfer items  <i>Complete only if reason for phase end is (2) Discharge/Case closure</i>	For bed mobility, toileting & transfers:	
			1	Independent or supervision only
			3	Limited physical assistance
			4	Other than two persons physical assist
			5	Two-person physical assist
			For eating:	
			1	Independent or supervision only
2.3.41	Symptom Assessment Score (SAS) at phase end	SAS as recorded within 24 hours of the end of the phase <i>Complete only if reason for phase end is (2) Discharge/Case closure</i>		Insomnia, appetite problems, nausea, bowels, breathing, fatigue and pain (7 items)
			0-10	Not at all - Worst Possible
2.3.42	Palliative Care Problem Severity scores at phase end	Pain score as recorded within 24 hours of the end of the phase <i>Complete only if reason for phase end is (2) Discharge/Case closure</i>	0	Absent
			1	Mild
			2	Moderate
			3	Severe
2.3.43	Palliative Care Problem Severity scores at phase end	Other symptom score as recorded within 24 hours of the end of the phase <i>Complete only if reason for phase end is (2) Discharge/Case closure</i>	0	Absent
			1	Mild
			2	Moderate
			3	Severe
2.3.44	Palliative Care Problem Severity scores at phase end	Psychological/Spiritual score as recorded within 24 hours of the end of the phase <i>Complete only if reason for phase end is (2) Discharge/Case closure</i>	0	Absent
			1	Mild
			2	Moderate
			3	Severe
2.3.45	Palliative Care Problem Severity scores at phase end	Family/Carer score as recorded within 24 hours of the start of the phase <i>Complete only if reason for phase end is (2) Discharge/Case closure</i>	0	Absent
			1	Mild
			2	Moderate
			3	Severe
2.3.46	Karnofsky functional score at phase end	Score on the Australian Modified Karnofsky Scale as recorded within 24 hours of the end of the phase  <i>Complete only if reason for phase end is (2) Discharge/Case closure</i>	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 his 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 arousable
0	Dead			