

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.	1	Danish
			2	English
			3	Gaelic (Scotland)
			4	German
			5	Irish
			6	Netherlandic
			7	Norwegian
			8	Swedish
			9	Welsh
			10	Yiddish
			11	Basque
			12	Catalan
			13	French
			14	Greek
			15	Italian
			16	Maltese
			17	Portuguese
			18	Spanish
			19	Albanian
			20	Armenian
			21	Belorussian
			22	Bosnian
			23	Bulgarian
			24	Croatian
			25	Czech
			26	Estonian
			27	Finnish
			28	Hungarian
			29	Latvian
			30	Lithuanian

No.	Item	Item Description	Item Codes	Item Code-Set Description
			31	Macedonian
			32	Polish
			33	Romanian
			34	Russian
			35	Serbian
			36	Slovak
			37	Slovene
			38	Ukrainian
			39	Amharic
			40	Arabic (including Lebanese)
			41	Assyrian (including Aramaic)
			42	Hebrew
			43	Kurdish
			44	Pashto
			45	Persian
			46	Tigrinya
			47	Turkish
			48	Bengali
			49	Gujarati
			50	Hindi
			51	Kannada
			52	Konkani
			53	Malayalam
			54	Marathi
			55	Nepali
			56	Punjabi
			57	Sindhi
			58	Sinhalese
			59	Tamil
			60	Telugu
			61	Urdu
			62	Bisaya
			63	Burmese
			64	Cebuano
			65	Hmong
			66	Ilokano
			67	Indonesian
			68	Khmer
			69	Lao
			70	Malay
			71	Tagalog (Filipino)
			72	Thai
			73	Tetum
			74	Timorese
			75	Vietnamese
			76	Cantonese
			77	Hakka
			78	Hokkien
			79	Japanese
			80	Korean
			81	Mandarin
			82	Teochew
			83	Wu
			84	Afrikaans
			85	Fijian
			86	Aboriginal Languages
			87	Gilbertese
			88	Mauritian Creole
			89	Maori (Cook Island)
			90	Maori (New Zealand)

No.	Item	Item Description	Item Codes	Item Code-Set Description
			91	Nauruan
			92	Papuan Languages
			93	Samoan
			94	Somali
			95	Swahili
			96	Tongan
			97	Other Languages, nfd
			98	Torres Strait Islander Languages
			99	Not stated/Inadequately described
2.1.8	Country of birth	The country in which the person was born	1101	Australia
			1102	Norfolk Island
			1103	Australian External Territories, nec
			1201	New Zealand
			1301	New Caledonia
			1302	Papua New Guinea
			1303	Solomon Islands
			1304	Vanuatu
			1401	Guam
			1402	Kiribati
			1403	Marshall Islands
			1404	Micronesia, Federated States of
			1405	Nauru
			1406	Northern Mariana Islands
			1407	Palau
			1501	Cook Islands
			1502	Fiji
			1503	French Polynesia
			1504	Niue
			1505	Samoa
			1506	Samoa, American
			1507	Tokelau
			1508	Tonga
			1511	Tuvalu
			1512	Wallis and Futuna
			1599	Polynesia (excludes Hawaii), nec
			1601	Adelie Land (France)
			1602	Argentinian Antarctic Territory
			1603	Australian Antarctic Territory
			1604	British Antarctic Territory
			1605	Chilean Antarctic Territory
			1606	Queen Maud Land (Norway)
			1607	Ross Dependency (New Zealand)
			2101	Channel Islands
			2102	England
			2103	Isle of Man
			2104	Northern Ireland
			2105	Scotland
			2106	Wales
			2201	Ireland
			2301	Austria
			2302	Belgium
			2303	France
			2304	Germany
			2305	Liechtenstein
			2306	Luxembourg
			2307	Monaco
			2308	Netherlands
			2311	Switzerland
			2401	Denmark
			2402	Faeroe Islands

No.	Item	Item Description	Item Codes	Item Code-Set Description
			2403	Finland
			2404	Greenland
			2405	Iceland
			2406	Norway
			2407	Sweden
			3101	Andorra
			3102	Gibraltar
			3103	Holy See
			3104	Italy
			3105	Malta
			3106	Portugal
			3107	San Marino
			3108	Spain
			3201	Albania
			3202	Bosnia and Herzegovina
			3203	Bulgaria
			3204	Croatia
			3205	Cyprus
			3206	Former Yugoslav Republic of Macedonia (FYROM)
			3207	Greece
			3208	Moldova
			3211	Romania
			3212	Slovenia
			3213	Yugoslavia, Federal Republic of
			3301	Belarus
			3302	Czech Republic
			3303	Estonia
			3304	Hungary
			3305	Latvia
			3306	Lithuania
			3307	Poland
			3308	Russian Federation
			3311	Slovakia
			3312	Ukraine
			4101	Algeria
			4102	Egypt
			4103	Libya
			4104	Morocco
			4105	Sudan
			4106	Tunisia
			4107	Western Sahara
			4199	North Africa, nec
			4201	Bahrain
			4202	Gaza Strip and West Bank
			4203	Iran
			4204	Iraq
			4205	Israel
			4206	Jordan
			4207	Kuwait
			4208	Lebanon
			4211	Oman
			4212	Qatar
			4213	Saudi Arabia
			4214	Syria
			4215	Turkey
			4216	United Arab Emirates
			4217	Yemen
			5101	Burma (Myanmar)
			5102	Cambodia
			5103	Laos

No.	Item	Item Description	Item Codes	Item Code-Set Description
			5104	Thailand
			5105	Viet Nam
			5201	Brunei Darussalam
			5202	Indonesia
			5203	Malaysia
			5204	Philippines
			5205	Singapore
			5206	East Timor
			6101	China (excludes SARs and Taiwan Province)
			6102	Hong Kong (SAR of China)
			6103	Macau (SAR of China)
			6104	Mongolia
			6105	Taiwan
			6201	Japan
			6202	Korea, Democratic People's Republic of (North)
			6203	Korea, Republic of (South)
			7101	Bangladesh
			7102	Bhutan
			7103	India
			7104	Maldives
			7105	Nepal
			7106	Pakistan
			7107	Sri Lanka
			7201	Afghanistan
			7202	Armenia
			7203	Azerbaijan
			7204	Georgia
			7205	Kazakhstan
			7206	Kyrgyz Republic
			7207	Tajikistan
			7208	Turkmenistan
			7211	Uzbekistan
			8101	Bermuda
			8102	Canada
			8103	St Pierre and Miquelon
			8104	United States of America
			8201	Argentina
			8202	Bolivia
			8203	Brazil
			8204	Chile
			8205	Colombia
			8206	Ecuador
			8207	Falkland Islands
			8208	French Guiana
			8211	Guyana
			8212	Paraguay
			8213	Peru
			8214	Suriname
			8215	Uruguay
			8216	Venezuela
			8299	South America, nec
			8301	Belize
			8302	Costa Rica
			8303	El Salvador
			8304	Guatemala
			8305	Honduras
			8306	Mexico
			8307	Nicaragua
			8308	Panama
			8401	Anguilla

No.	Item	Item Description	Item Codes	Item Code-Set Description
			8402	Antigua and Barbuda
			8403	Aruba
			8404	Bahamas
			8405	Barbados
			8406	Cayman Islands
			8407	Cuba
			8408	Dominica
			8411	Dominican Republic
			8412	Grenada
			8413	Guadeloupe
			8414	Haiti
			8415	Jamaica
			8416	Martinique
			8417	Montserrat
			8418	Netherlands Antilles
			8421	Puerto Rico
			8422	St Kitts and Nevis
			8423	St Lucia
			8424	St Vincent and the Grenadines
			8425	Trinidad and Tobago
			8426	Turks and Caicos Islands
			8427	Virgin Islands, British
			8428	Virgin Islands, United States
			9101	Benin
			9102	Burkina Faso
			9103	Cameroon
			9104	Cape Verde
			9105	Central African Republic
			9106	Chad
			9107	Congo
			9108	Congo, Democratic Republic of
			9111	Cote d'Ivoire
			9112	Equatorial Guinea
			9113	Gabon
			9114	Gambia
			9115	Ghana
			9116	Guinea
			9117	Guinea-Bissau
			9118	Liberia
			9121	Mali
			9122	Mauritania
			9123	Niger
			9124	Nigeria
			9125	Sao Tome and Principe
			9126	Senegal
			9127	Sierra Leone
			9128	Togo
			9201	Angola
			9202	Botswana
			9203	Burundi
			9204	Comoros
			9205	Djibouti
			9206	Eritrea
			9207	Ethiopia
			9208	Kenya
			9211	Lesotho
			9212	Madagascar
			9213	Malawi
			9214	Mauritius
			9215	Mayotte

No.	Item	Item Description	Item Codes	Item Code-Set Description
			9216	Mozambique
			9217	Namibia
			9218	Reunion
			9221	Rwanda
			9222	St Helena
			9223	Seychelles
			9224	Somalia
			9225	South Africa
			9226	Swaziland
			9227	Tanzania
			9228	Uganda
			9231	Zambia
			9232	Zimbabwe
			9299	Southern and East Africa, nec
			9998	Other, Not Elsewhere Classified
			9999	Not Stated, Inadequately Described

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	Overnight Admitted Patients	
			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
			All other patients (same day admitted, outpatient and community)	
			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	First contact (telephone or face to face) by palliative care service following receipt of referral	dd/mm/yyyy	
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 (Patient is admitted and discharged on different dates)
			1	Overnight admitted patient in a designated inpatient palliative care bed/unit Go to 2.2.19 (Patient is admitted and discharged on different dates)
			3	Ambulatory Go to 2.2.19 (Patient receives care on a same day admitted or outpatient basis)
			4	Community Go to 2.2.19 (Patient receives care in the home or other non-hospital site)
			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

No.	Item	Item Description	Item Codes	Item Code Set Description
			6	Home
			99	Not stated/inadequately described
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	Malignant (neoplasm) 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	Non-malignant (other diagnosis) 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	Overnight admitted patients	
			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
			Ambulatory patients	
			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)

No.	Item	Item Description	Item Codes	Item Code Set Description
			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 at episode end	Level of support received at episode end. <i>Complete only if Accommodation at episode end 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
2.2.26	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	Limited assistance			
3	Extensive assistance/total dependence/ tube fed			
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	
2.3.38	Reason for phase end	The reason this phase ended	1	Phase change
			2	Discharge/Case closure
			3	Died or Bereavement phase

No.	Item	Item Description	Item Code Set	Item Code Set description
			4	Bereavement phase end
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. <i>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	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	Limited assistance
3	Extensive assistance/total dependence/ tube fed			
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			