PCOC
palliative care
outcomes collaboration

# Patient outcomes in Palliative Care

## National report

## January to June 2019

September 2019

PCOC is a national palliative care project funded by the Australian Government Department of Health

# What is PCOC?

The Australian Palliative Care Outcomes Collaboration (PCOC) is a national palliative care outcomes and benchmarking program. PCOC's primary objective is to systematically improve patient outcomes (including pain and symptom control).

Central to the program is a framework and protocol for routine clinical assessment and response. This works in parallel with a routine point-of-care data collection, capturing clinically meaningful information. PCOC aims to drive improvement in patient outcomes through feedback to individual services and by facilitating service-to-service benchmarking.

The items in the PCOC data collection:

- provide clinicians with an approach to systematically assess individual patient experiences
- include routine Patient Reported Outcome Measures (PROMs) relating to symptom distress
- define a common clinical language to allow palliative care providers to communicate with each other
- facilitate the routine collection of nationally consistent palliative care data for the purpose of reporting and benchmarking to drive quality improvement at service, state, territory and national levels.

The assessment framework incorporates five validated clinical assessment tools:

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

**If you would like more information or have any queries about this report please contact the PCOC national office at pcoc@uow.edu.au or on (02) 4221 4411**

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# Introduction

The Australian palliative care sector is a world leader in using routine clinical assessment information to guide patient centred care and measure patient and family outcomes. Providers of palliative care are commended for their commitment to excellence in delivering evidence-based, patient-centred care by using the routine Palliative Care Outcomes Collaboration (PCOC) assessment framework and contributing patient data toward national outcome measurement and benchmarking. PCOC acknowledges the dedication and willingness of clinicians to improve the care of patients, their families and caregivers. The information collected is not just data - it represents the real-life outcomes of over 40,000 Australians who die an expected death every year.

While the focus of this report is on the most recent information relating to January to June 2019, results over the last three years are also presented to highlight achievements and improvement in outcomes. The most recent information corresponds to 24,562 patients, having 31,826 episodes of care and 73,209 palliative care phases from 138 services who provide palliative care in hospital / hospice or in the person's home.

The purpose of benchmarking is to drive improvement and palliative care service innovation.

A full list of the services included in the national figures can be found at www.pcoc.org.au.

Please use the following key when interpreting the tables throughout this report

| | |
|---|---|
| **-** | **The item is not applicable** |
| **u** | **The item was unavailable** |
| **s** | **The item was suppressed due to insufficient data as there was less than 10 observations** |

# 1 Benchmark summary

**Table 1 Summary of outcome measures by setting**

| Outcomes measure | | Benchmark | Hospital / hospice % | Hospital / hospice BM met? | Community % | Community BM met? | Benchmark Reference No. |
|---|---|---|---|---|---|---|---|
| **Timely commencement of palliative care** | | | | | | | |
| Care commencing within two days of the person being ready | | 90% | 98.0 | Yes | 86.1 | No | 1 |
| **Responsiveness in managing patients with urgent needs** | | | | | | | |
| Patients unstable for three days or less | | 90% | 90.1 | Yes | 85.3 | No | 2 |
| **Symptoms & problems in the absent to mild range at phase end** | | | | | | | |
| **Anticipatory care** *when symptoms or problems are in the absent to mild range at phase start* | Pain (clinician reported) | 90% | 92.4 | Yes | 86.3 | No | 3.1 |
| | Pain (patient reported) | | 91.0 | Yes | 85.3 | No | 3.3 |
| | Fatigue (patient reported) | | 91.3 | Yes | 81.8 | No | 3.5 |
| | Breathing problems (patient reported) | | 95.6 | Yes | 92.8 | Yes | 3.7 |
| | Family / carer problems (clinician reported) | | 93.4 | Yes | 83.8 | No | 3.9 |
| **Responsive care** *when symptoms or problems are in the moderate to severe range at phase start* | Pain (clinician reported) | 60% | 63.7 | Yes | 56.6 | No | 3.2 |
| | Pain (patient reported) | | 59.3 | No | 51.8 | No | 3.4 |
| | Fatigue (patient reported) | | 54.0 | No | 36.8 | No | 3.6 |
| | Breathing problems (patient reported) | | 53.9 | No | 39.6 | No | 3.8 |
| | Family / carer problems (clinician reported) | | 54.9 | No | 46.6 | No | 3.10 |
| **Casemix adjusted outcomes (change scores)** | | | **Score** | **BM met?** | **Score** | **BM met?** | |
| **Clinician reported problems** (PCPSS) | Pain | 0.0 | 0.11 | Yes | -0.03 | No | 4.1 |
| | Other symptoms | | 0.25 | Yes | 0.01 | Yes | 4.2 |
| | Family / carer problems | | 0.20 | Yes | 0.01 | Yes | 4.3 |
| | Psychological / spiritual problems | | 0.21 | Yes | 0.02 | Yes | 4.4 |
| **Patient reported symptom distress** (SAS) | Pain | 0.0 | 0.37 | Yes | -0.10 | No | 4.5 |
| | Nausea | | 0.22 | Yes | -0.05 | No | 4.6 |
| | Breathing problems | | 0.34 | Yes | 0.02 | Yes | 4.7 |
| | Bowel problems | | 0.31 | Yes | 0.04 | Yes | 4.8 |

# 2 Patient outcomes in more detail

## 2.1 Timely commencement of palliative care

Time from date ready for care to episode start reports responsiveness of palliative care services to patient needs. This benchmark was set following feedback and subsequent consultation with PCOC participants. Service providers acknowledge that, whilst there is wide variation in the delivery of palliative care across the country, access to palliative care should be measured based on patient need rather than service availability. As a result, services operating five days a week (Monday to Friday) are not distinguished from services operating seven days a week (All services are being benchmarked together).

**Benchmark 1:** This measure relates to the time taken for an episode to commence following the date the patient is available and ready to receive palliative care. To meet the benchmark for this measure, at least 90% of patients must have their episode commence on the day of, or the day following, date ready for care.

**Table 2 Time from date ready for care to episode start by setting**

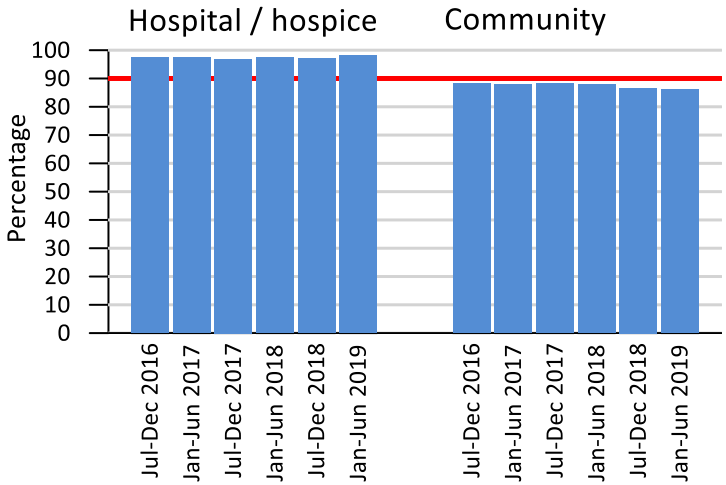
| Time (in days) | Hospital / hospice | | Community | |
|---|---|---|---|---|
| | N | % | N | % |
| **Same day** | 14,097 | 93.7 | 10,948 | 81.8 |
| **Following day** | 645 | 4.3 | 567 | 4.2 |
| **2-7** | 273 | 1.8 | 1,136 | 8.5 |
| **8-14** | 21 | 0.1 | 385 | 2.9 |
| **15 +** | 5 | 0.0 | 342 | 2.6 |
| **Average** | 1.1 | - | 2.4 | - |
| **Median** | 1 | - | 1 | - |

Note: Only episodes that started in this reporting period have been included in the table. Episodes where date ready for care was not recorded are excluded from the table. In addition, all records where time from date ready for care to episode start was greater than 90 days were considered to be atypical and were assumed to equal 90 days for the purpose of calculating the average and median time.

**Interpretation hint:**
Outcome measure 1 only includes episodes that have commenced in the reporting period. As a result, the number of episodes included in the calculation of this benchmark may not match the number of episodes in Appendix A. For more information on data scoping methods, see Appendix C.

**Figure 1** **Time from date ready for care to episode start, all services (BM1)**


a. National benchmark profile for BM1




b. Outcomes over time for BM1

**Key:** National service profile — Benchmark — National results

Note: Only services with 10 or more valid assessments are included in the above graphs.

## 2.2 Responsiveness in managing patients with urgent needs

The unstable phase type, by nature of its definition, alerts clinical staff to the need for urgent changes to the patient's plan of care or that emergency intervention is required. Those patients assessed to be in the unstable phase require intense review for a short period of time.

An unstable phase is triggered if:

- a patient experiences a new, unanticipated problem, and / or
- a patient experiences a rapid increase in the severity of an existing problem, and / or
- a patient's family / carers experience a sudden change in circumstances that adversely impacts the patient's care.

The patient moves out of the unstable phase in one of two ways:

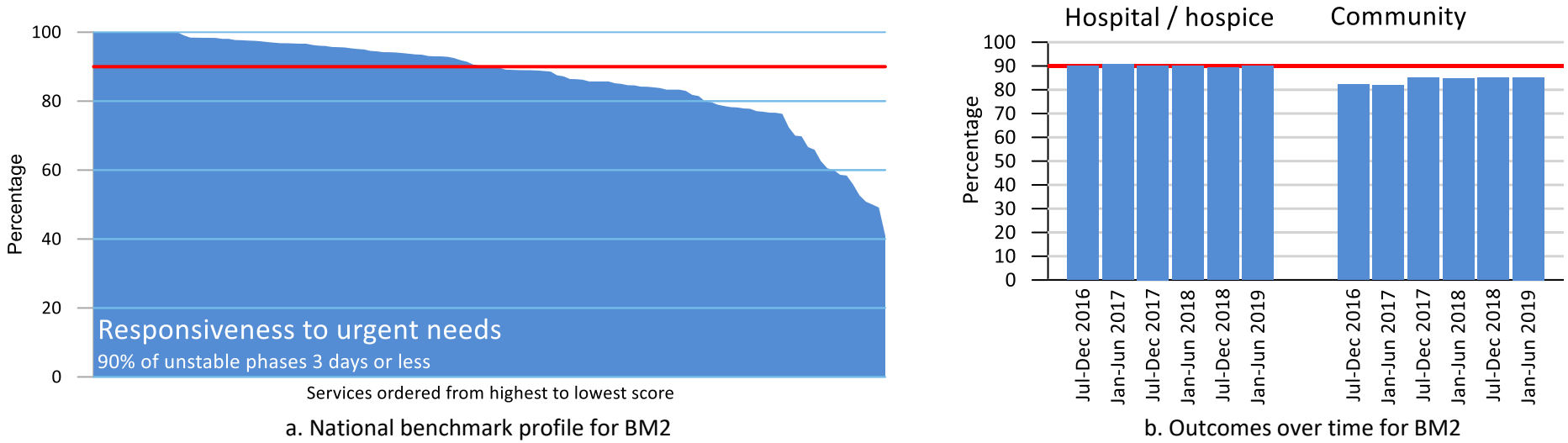
- A new plan of care has been put in place, has been reviewed and does not require any additional changes. This does not necessarily mean that the symptom / crisis has been fully resolved. However, the clinical team will have a clear diagnosis and a plan for the patient's care. In this situation, the patient will move to either the stable or deteriorating phase.
- The patient is likely to die within a matter of days. In this situation, the patient will be moved into the terminal phase.

**Benchmark 2:** This benchmark relates to the time that a patient spends in the unstable phase. To meet this benchmark, at least 90% of unstable phases must last for three days or less.

**Table 3 Time in unstable phase by setting**

| Time in unstable phase | Hospital / hospice | | Community | |
|---|---|---|---|---|
| | N | % | N | % |
| **Same day** | 412 | 6.2 | 1,658 | 34.8 |
| **1 day** | 3,380 | 50.8 | 1,576 | 33.1 |
| **2 days** | 1,537 | 23.1 | 583 | 12.2 |
| **3 days** | 663 | 10.0 | 241 | 5.1 |
| **4 – 5 days** | 407 | 6.1 | 239 | 5.0 |
| **6 – 7 days** | 145 | 2.2 | 138 | 2.9 |
| **8 – 14 days** | 88 | 1.3 | 151 | 3.2 |
| **More than 14 days** | 18 | 0.3 | 174 | 3.7 |
| **Total** | 6,650 | 100.0 | 4,760 | 100.0 |

**Figure 2** **Time in unstable phase, all services (BM2)**




a. National benchmark profile for BM2

b. Outcomes over time for BM2

**Key:** National service profile — Benchmark — National results

Note: Only services with 10 or more valid assessments are included in the above graphs.

## 2.3 Symptoms & problems in the absent to mild range at phase end

The outcome measures presented in this section focus on five symptom and problem areas:

1. Pain - clinician reported severity
2. Pain - patient reported distress
3. Fatigue - patient reported distress
4. Breathing problems - patient reported distress
5. Family / carer problems - clinician reported severity

A positive patient outcome is achieved if the patient, or family/carer, has an absent to mild symptom / problem at the end of a palliative care phase. However, the type of care delivered and the corresponding benchmarks achievement depends on the patient's (or family/carer) level of symptom or problem at start of the phase; scores in the absent to mild range trigger monitoring and review of care plans (anticipatory care), whilst scores in the moderate to severe range trigger interventions and actions to respond to needs (responsive care).

### Anticipatory care

The anticipatory care outcome measures and benchmarks relate to patients who have absent or mild symptom / problem at the start of a phase of palliative care. To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild symptom / problem. Table 4 summarises the number of phases starting with absent to mild symptom / problem, and the percentage of those ending in the absent to mild range.

**Table 4 Achieving absent to mild symptoms/problems at phase end, when absent to mild at beginning**

| Symptom / problem[a] | Hospital / hospice | | Community | |
|---|---|---|---|---|
| | N[b] | % | N[b] | % |
| **Pain** (clinician reported) | 20,313 | 92.4 | 22,497 | 86.3 |
| **Pain** (patient reported) | 17,128 | 91.0 | 22,249 | 85.3 |
| **Fatigue** (patient reported) | 16,374 | 91.3 | 17,403 | 81.8 |
| **Breathing problems** (patient reported) | 19,388 | 95.6 | 22,475 | 92.8 |
| **Family / carer problems** (clinician reported) | 20,915 | 93.4 | 20,987 | 83.8 |

a. Phase records must have valid start and end scores for the PCPSS and / or SAS clinical assessment tools to enable outcomes to be measured.

b. N represents the total number of phases starting with **absent to mild** symptom / problem.

## Responsive care

The responsive care outcome measure and benchmarks relate to patients, or family/carer, who have a moderate or severe symptom / problem at the start of their phase of palliative care. Achieving an absent / mild symptom or problem outcome at phase end has been identified as more clinically challenging, so to meet this benchmark, 60% of these phases must end with the patient experiencing absent or mild symptom / problem.

Table 5 summarises the number of phases starting with moderate to severe symptom / problem and of those, the percentage ending in the absent to mild range.

**Table 5 Achieving absent to mild symptoms/problems at phase end, when moderate to severe at beginning**

| Symptom / problem[a] | Hospital / hospice | | Community | |
|---|---|---|---|---|
| | N[b] | % | N[b] | % |
| **Pain** (clinician reported) | 5,082 | 63.7 | 4,565 | 56.6 |
| **Pain** (patient reported) | 5,660 | 59.3 | 5,434 | 51.8 |
| **Fatigue** (patient reported) | 6,420 | 54.0 | 8,921 | 36.8 |
| **Breathing problems** (patient reported) | 3,386 | 53.9 | 3,470 | 39.6 |
| **Family / carer problems** (clinician reported) | 3,425 | 54.9 | 5,022 | 46.6 |

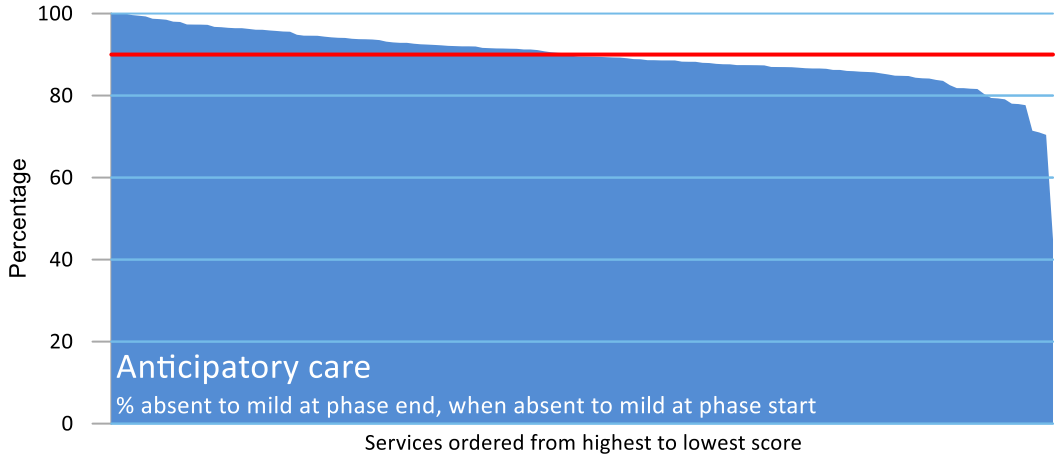
a. Phase records must have valid start and end scores for the PCPSS and / or SAS clinical assessment tools to enable outcomes to be measured.

b. N represents the total number of phases starting with the symptom or problem rated **moderate to severe**.

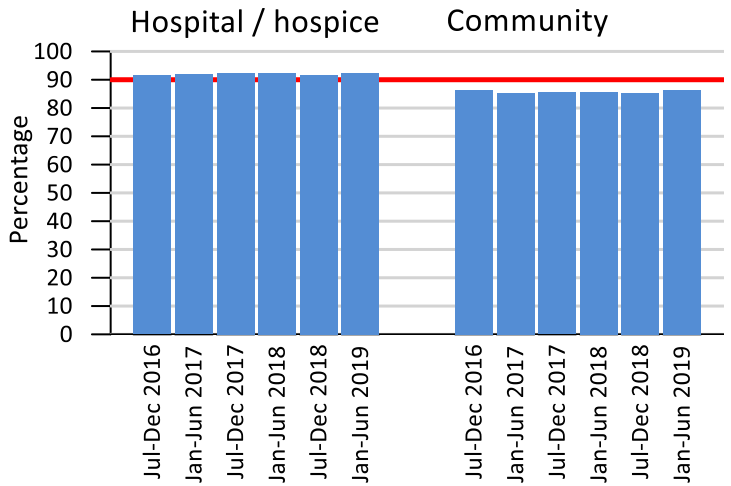
On the following pages, the results for the anticipatory and responsive care benchmarks are presented together for each of the five symptom and problem domains. The graphs included compare the outcomes achieved by all services nationally, as well as showing any changes in outcomes over time.

## Pain (clinician reported problem severity)

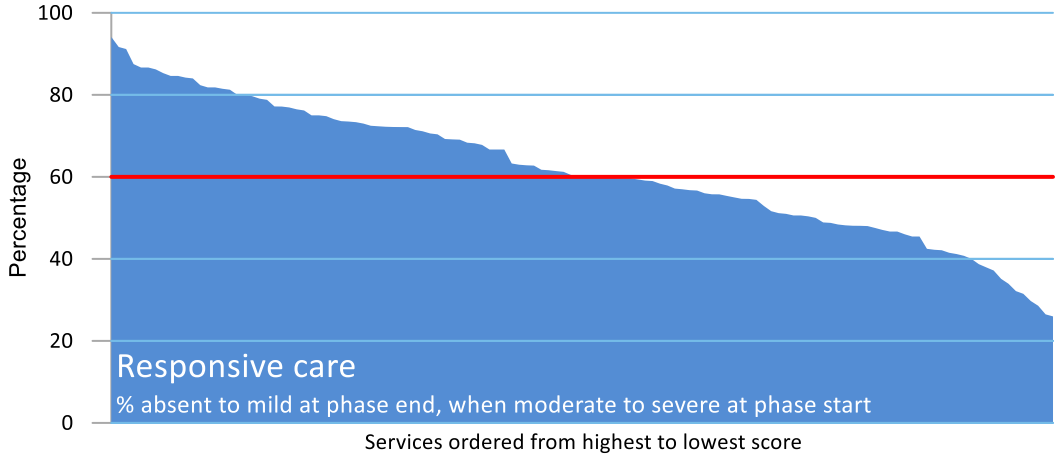
**Figure 3** **Pain, patients with absent to mild problem at phase end**



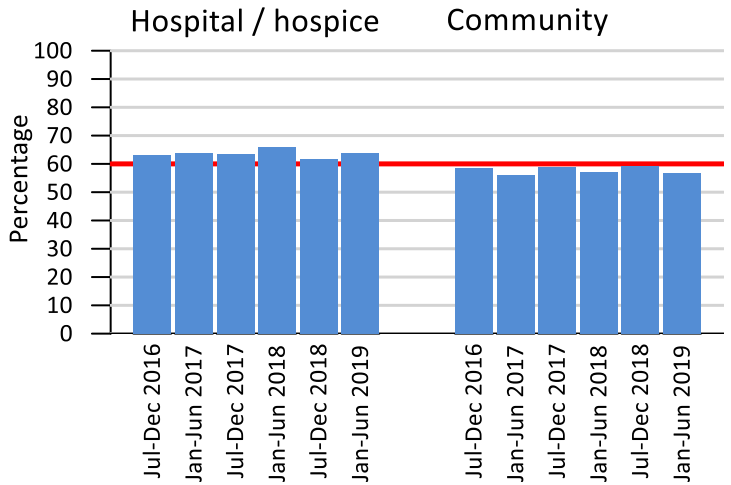

a. National service profile for BM3.1



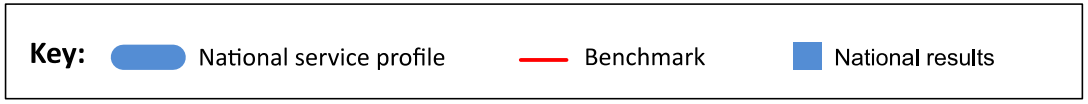

b. Outcomes over time (BM3.1)




c. National service profile for BM3.2



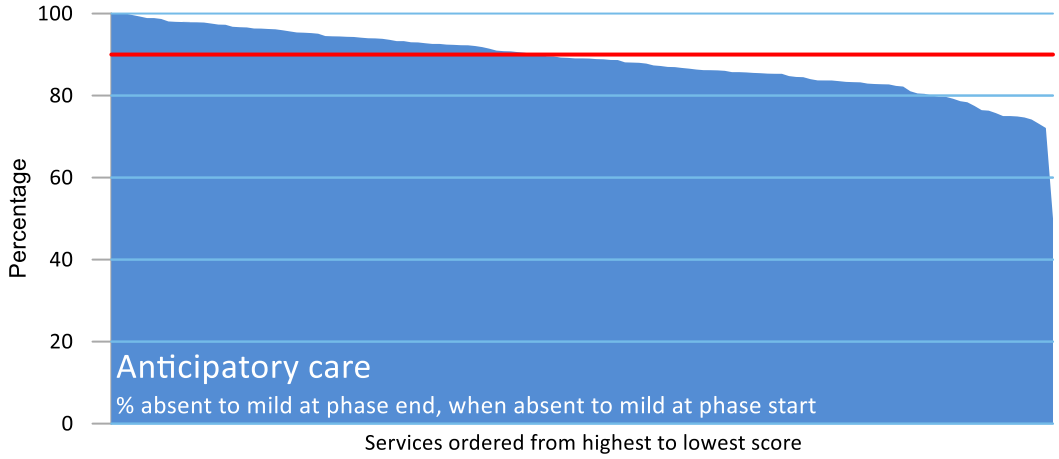

d. Outcomes over time (BM3.2)



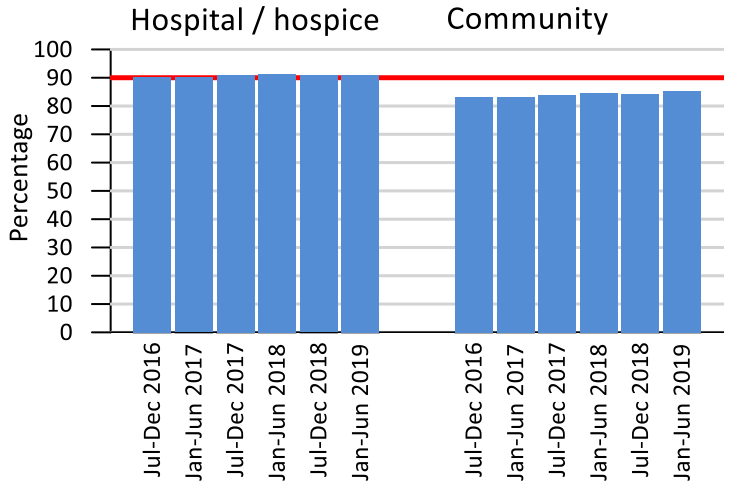

Note: Only services with 10 or more valid assessments are included in the above graphs.

## Pain (patient reported distress)

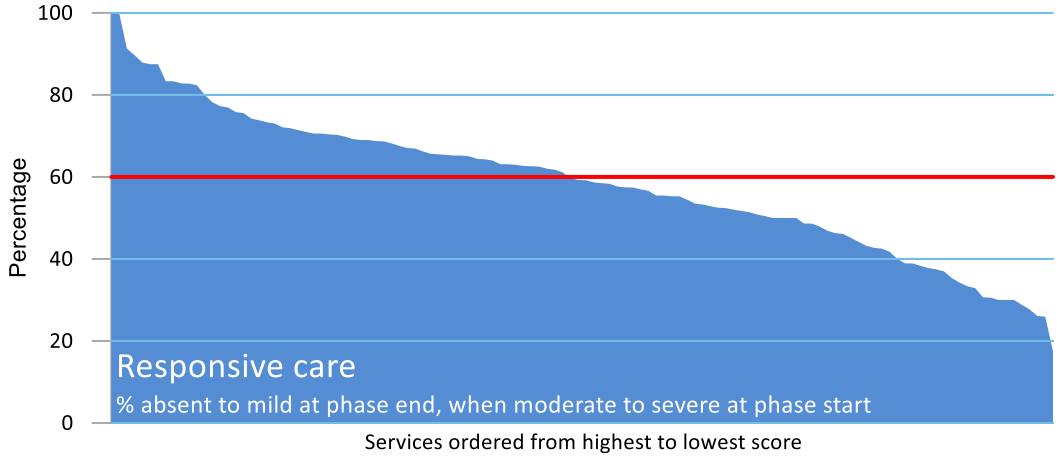
**Figure 4** **Pain, patients experiencing absent to mild distress at phase end**



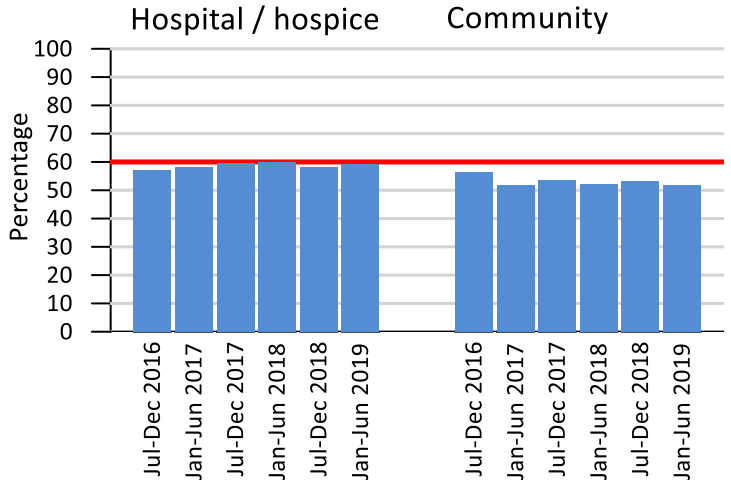

a. National benchmark profile for BM3.3



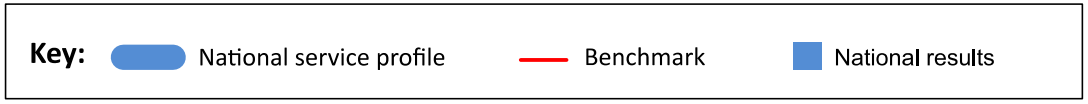

b. Outcomes over time BM3.3




c. National benchmark profile for BM3.4



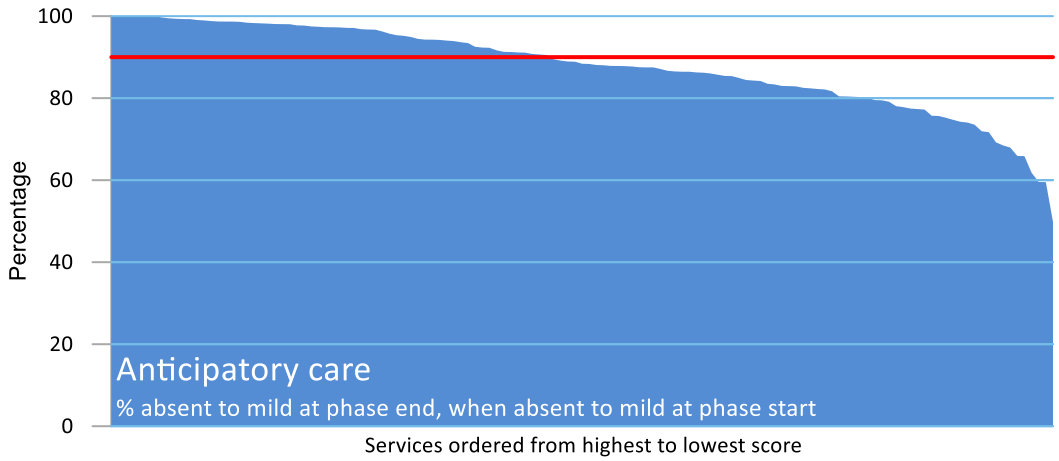

d. Outcomes over time BM3.4



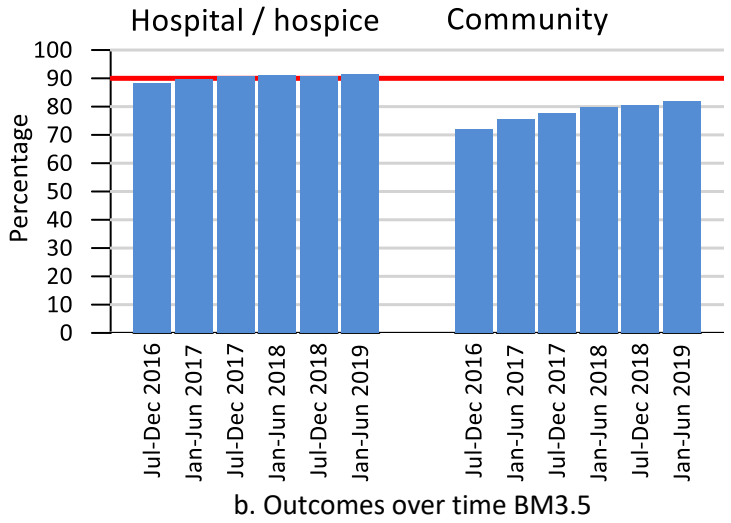

*Note: Only services with 10 or more valid assessments are included in the above graphs.*

## Fatigue (patient reported distress)

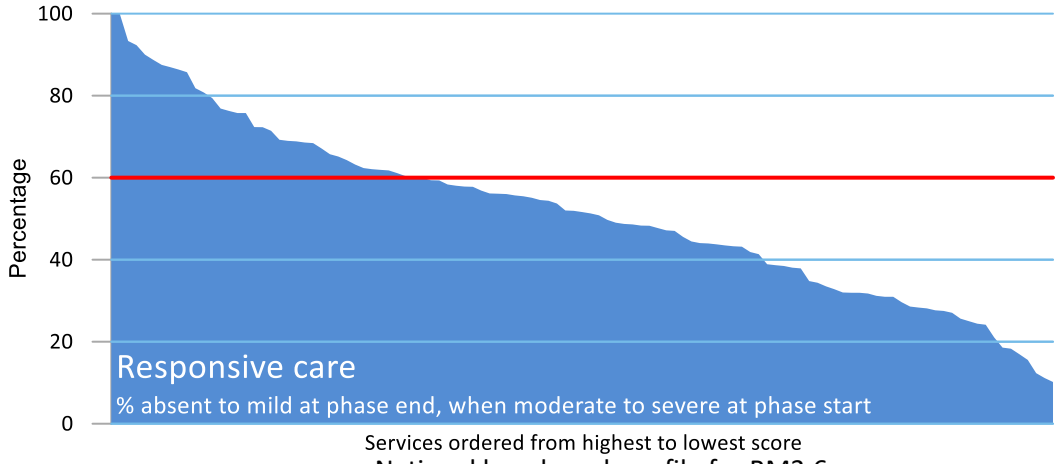
**Figure 5** **Fatigue, patients experiencing absent to mild distress at phase end**



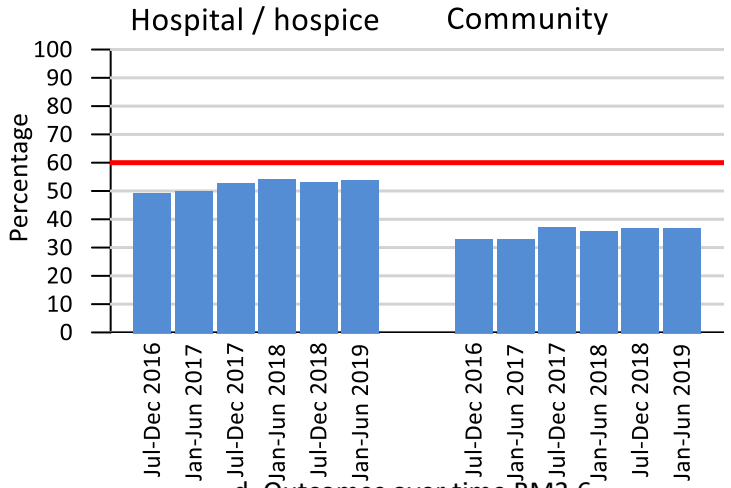

a. National benchmark profile for BM3.5



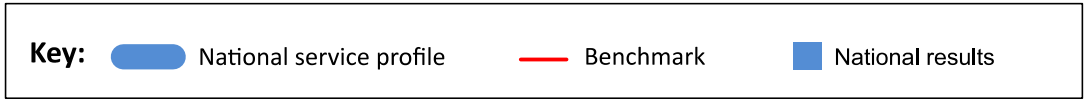

b. Outcomes over time BM3.5




c. National benchmark profile for BM3.6



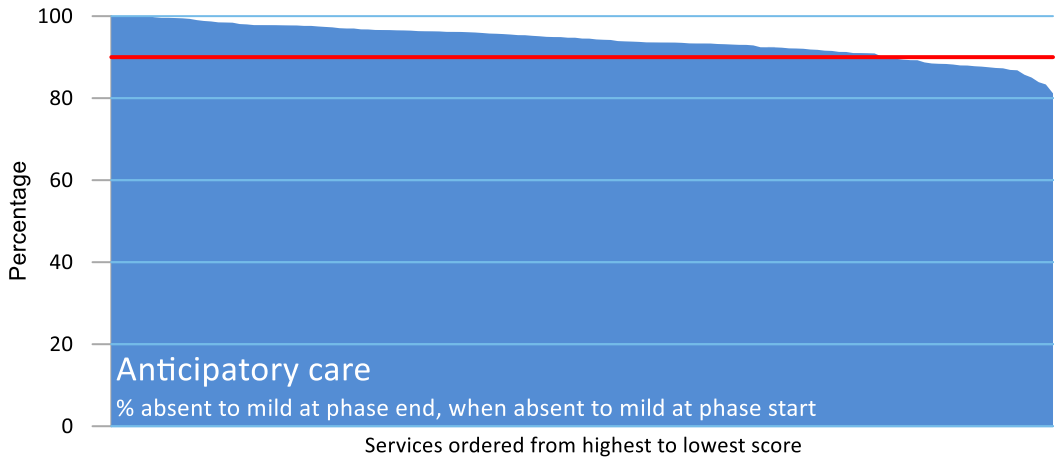

d. Outcomes over time BM3.6



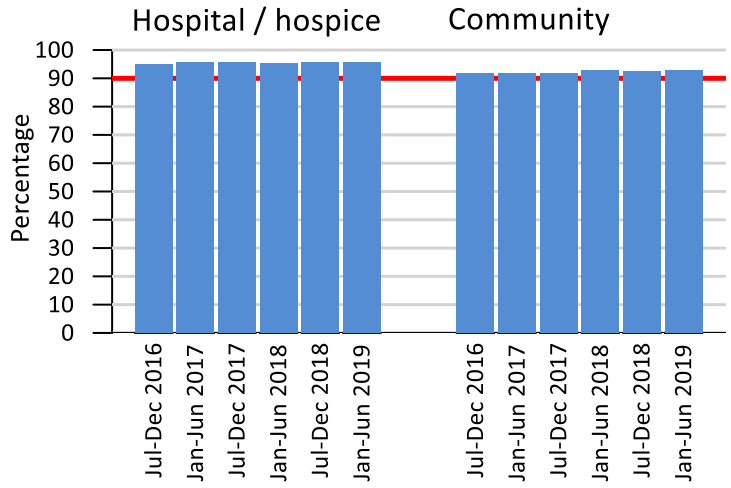

*Note: Only services with 10 or more valid assessments are included in the above graphs.*

## Breathing problems (patient reported distress)

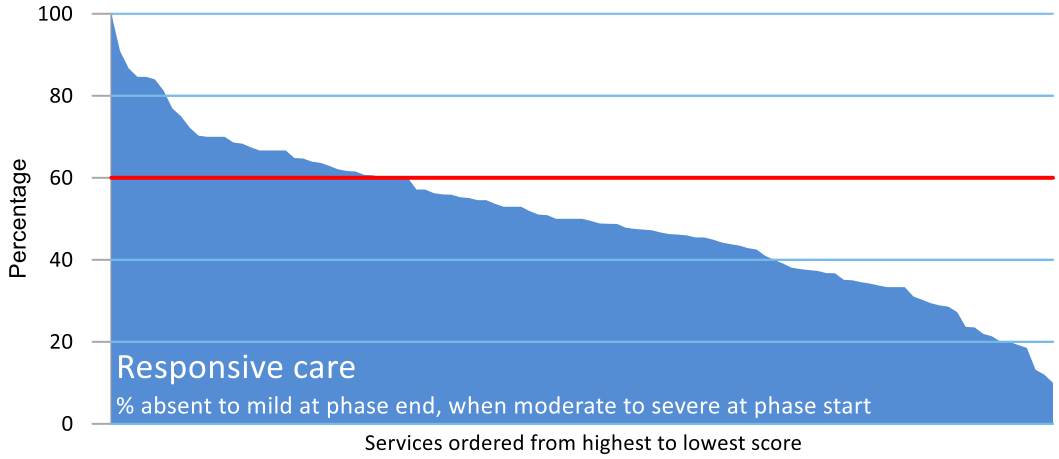
**Figure 6** **Breathing problems, patients experiencing absent to mild distress at phase end**



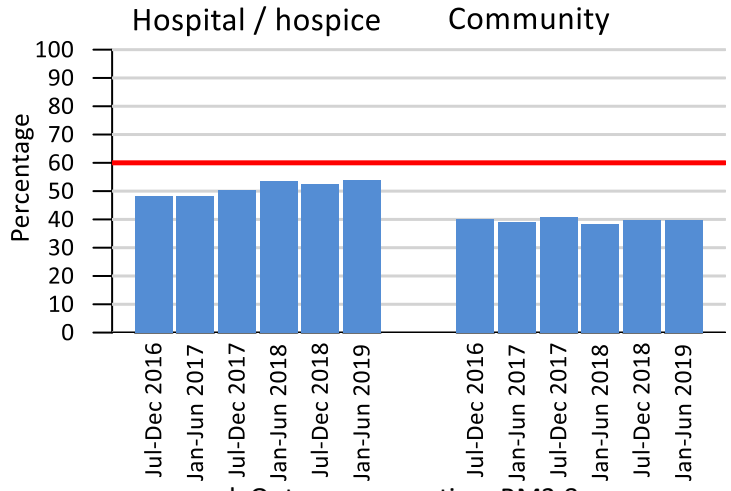

a. National benchmark profile for BM3.7



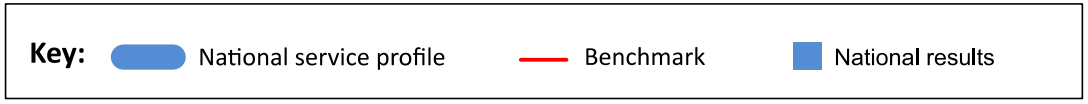

b. Outcomes over time BM3.7




c. National benchmark profile for BM3.8



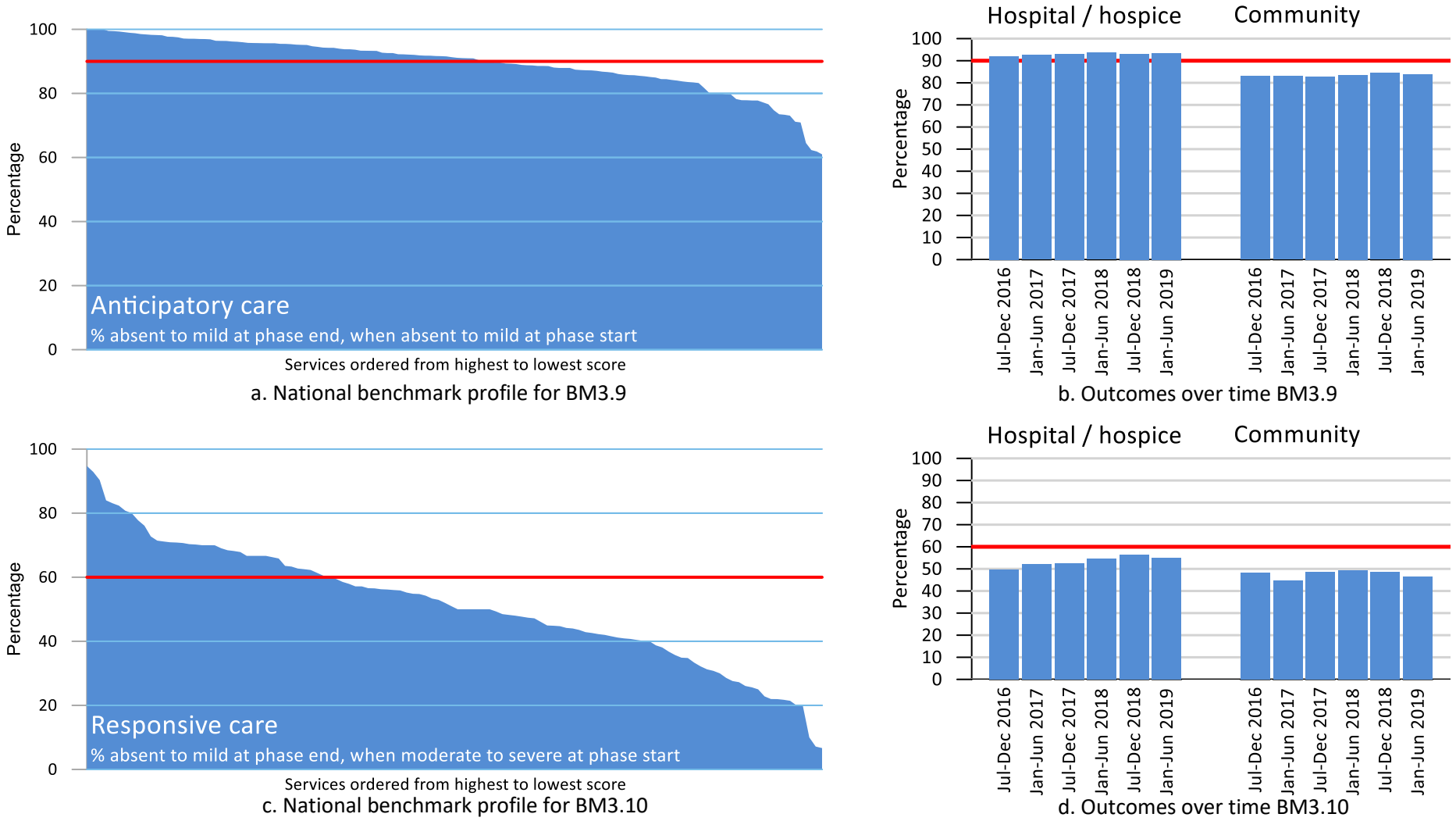

d. Outcomes over time BM3.8




*Note: Only services with 10 or more valid assessments are included in the above graphs.*

## Family / carer problems (clinician reported problem severity)

**Figure 7 Family / carer problems, absent to mild at phase end**




*Note: Only services with 10 or more valid assessments are included in the above graphs.*

## 2.4 Casemix adjusted outcomes

This outcome measure includes a suite of eight casemix adjusted scores used to compare the change in symptoms for similar patients. Patients in the same phase who started with the same level of symptom have their change in symptom compared to the reference period (January to June 2014).

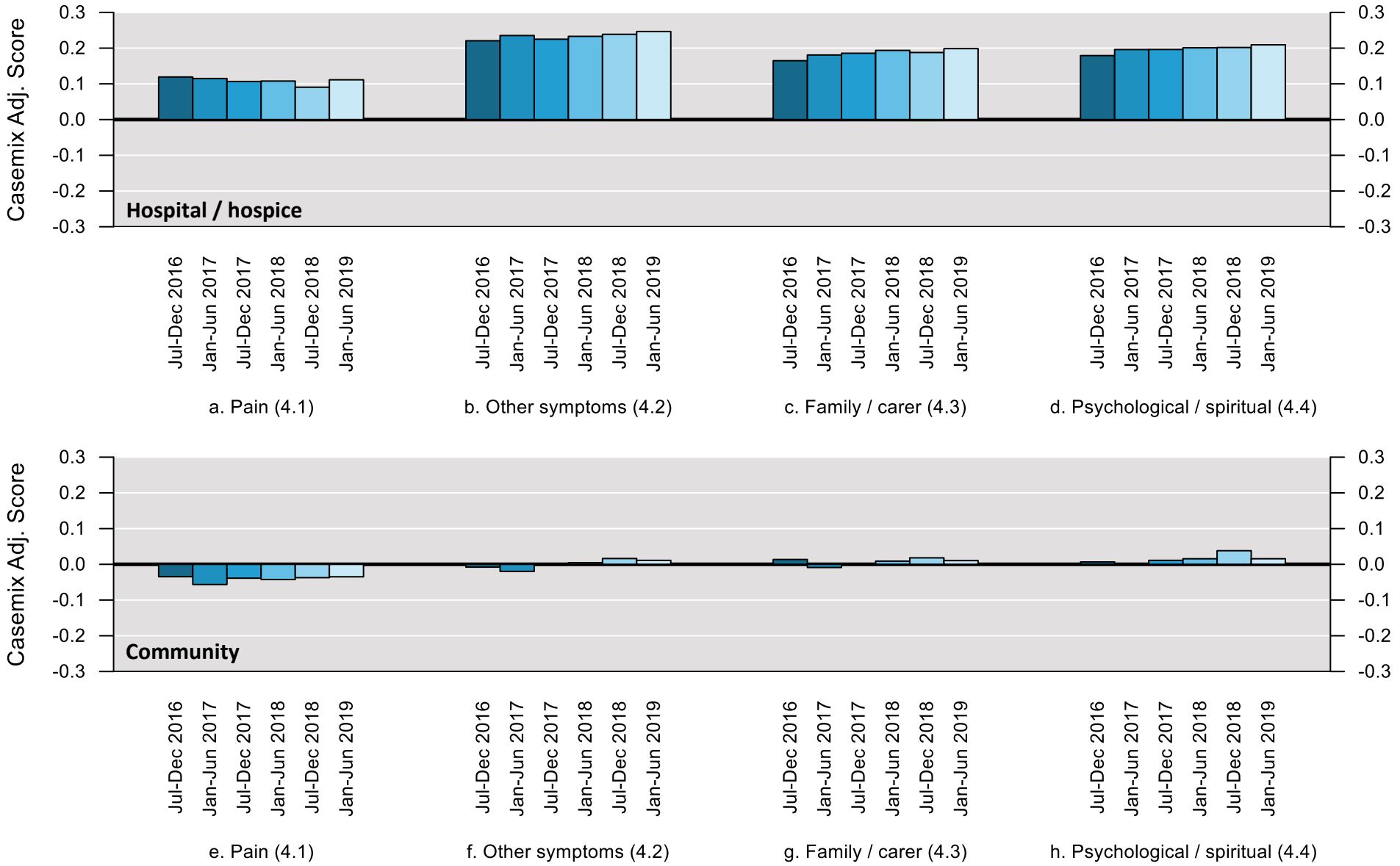
**Table 6 Casemix adjusted outcomes**

| Clinical tool | Symptom / problem | Hospital / hospice | | | | Community | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | Casemix adjusted score | Phases included (N) | Phases at or above baseline (N) | Phases at or above baseline (%) | Casemix adjusted score | Phases included (N) | Phases at or above baseline (N) | Phases at or above baseline (%) |
| **PCPSS** *Clinician reported severity* | **Pain** | 0.11 | 25,395 | 15,965 | 62.9 | -0.03 | 27,062 | 14,988 | 55.4 |
| | **Other symptoms** | 0.25 | 24,896 | 19,158 | 77.0 | 0.01 | 26,249 | 17,107 | 65.2 |
| | **Family / carer** | 0.20 | 24,340 | 17,663 | 72.6 | 0.01 | 26,009 | 16,792 | 64.6 |
| | **Psychological / spiritual** | 0.21 | 25,364 | 16,500 | 65.1 | 0.02 | 26,636 | 14,014 | 52.6 |
| **SAS** *Patient reported distress* | **Pain** | 0.37 | 22,788 | 15,913 | 69.8 | -0.10 | 27,683 | 16,583 | 59.9 |
| | **Nausea** | 0.22 | 22,752 | 20,098 | 88.3 | -0.05 | 26,155 | 21,100 | 80.7 |
| | **Breathing problems** | 0.34 | 22,774 | 18,337 | 80.5 | 0.02 | 25,945 | 18,066 | 69.6 |
| | **Bowel problems** | 0.31 | 22,728 | 18,428 | 81.1 | 0.04 | 25,685 | 19,029 | 74.1 |

The Casemix adjusted scores are calculated relative to a baseline reference period. A Casemix adjusted score:

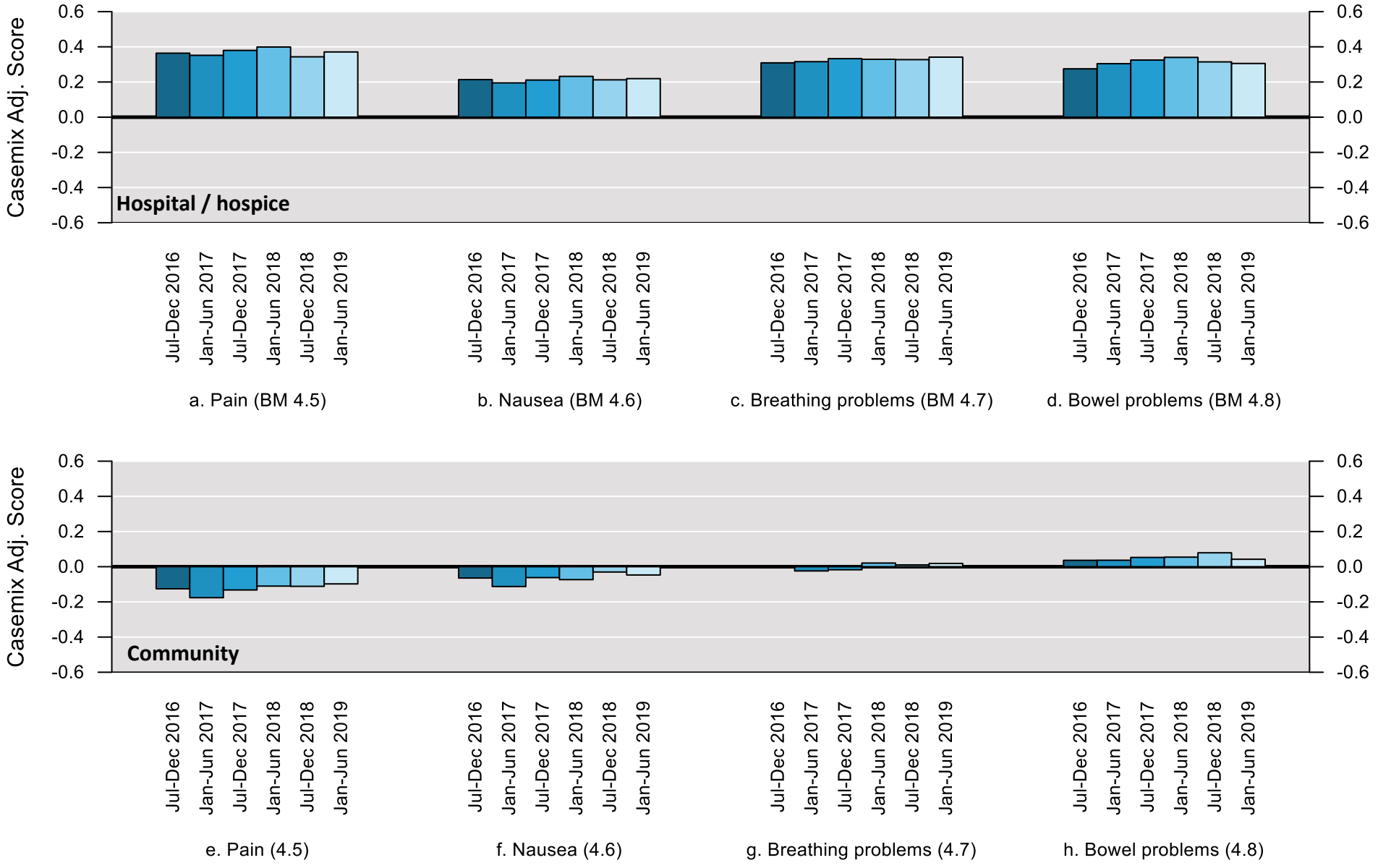
- **greater than 0** means that on average your patient's outcomes were **better than for similar patients** in the reference period
- **less than 0** means that on average, your patients' outcomes were **worse than to similar patients** in the reference period
- **equal to 0** means that on average, your patients' outcomes were **about the same as similar patients** in the reference period

**Figure 8** **Trends in casemix adjusted outcomes - Palliative Care Problem Severity Score (PCPSS)**




Note: Only services with 10 or more valid assessments are included in the above graphs.

**Figure 9** **Trends in casemix adjusted outcomes - Symptom Assessment Scale (SAS)**




Note: Only services with 10 or more valid assessments are included in the above graphs.

# 3 Patient characteristics

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

Table 7 shows the Indigenous status for the patients nationally.

**Table 7 Indigenous status**

| Indigenous status | N | % |
|---|---|---|
| Aboriginal but not Torres Strait Islander origin | 335 | 1.4 |
| Torres Strait Islander but not Aboriginal origin | 16 | 0.1 |
| Both Aboriginal and Torres Strait Islander origin | 28 | 0.1 |
| Neither Aboriginal nor Torres Strait Islander origin | 23,341 | 95.0 |
| Not stated / inadequately described | 842 | 3.4 |
| Total | 24,562 | 100.0 |

Table 8 shows the breakdown of deaths for the patients nationally for the reporting period. All inpatient deaths are reported in the hospital / hospice category while the community deaths are reported in the private residence and residential aged care facility categories.

**Table 8 Place of death**

| Place of death | N | % |
|---|---|---|
| Private residence | 2,316 | 20.1 |
| Residential aged care facility | 1,030 | 9.0 |
| Hospital / hospice | 8,093 | 70.4 |
| Not stated / inadequately described | 63 | 0.5 |
| Total | 11,502 | 100.0 |

**Table 9 Country of birth**

| Country of birth | N | % |
|---|---|---|
| Australia | 15,212 | 61.9 |
| England | 1,683 | 6.9 |
| New Zealand | 422 | 1.7 |
| China | 318 | 1.3 |
| India | 180 | 0.7 |
| Italy | 925 | 3.8 |
| Vietnam | 186 | 0.8 |
| Philippines | 134 | 0.5 |
| South Africa | 109 | 0.4 |
| Scotland | 311 | 1.3 |
| Malaysia | 102 | 0.4 |
| Germany | 266 | 1.1 |
| Greece | 521 | 2.1 |
| Sri Lanka | 83 | 0.3 |
| United States of America | 70 | 0.3 |
| All other countries | 3,379 | 13.8 |
| Not stated | 661 | 2.7 |
| Total | 24,562 | 100.0 |

**Table 10 Preferred language**

| Language | N | % |
|---|---|---|
| English | 21,737 | 88.5 |
| Chinese[(a)] | 339 | 1.4 |
| Hindi[(b)] | 51 | 0.2 |
| Arabic[(c)] | 220 | 0.9 |
| Italian | 452 | 1.8 |
| Vietnamese[(d)] | 127 | 0.5 |
| Greek | 371 | 1.5 |
| Filipino / Indonesian[(e)] | 55 | 0.2 |
| Macedonian / Croatian[(f)] | 235 | 1.0 |
| Spanish[(g)] | 78 | 0.3 |
| Tamil / Malayalam[(h)] | 13 | 0.1 |
| German[(i)] | 18 | 0.1 |
| Korean | 25 | 0.1 |
| Samoan / Tongan[(j)] | 34 | 0.1 |
| African languages | 20 | 0.1 |
| All other languages | 376 | 1.5 |
| Not stated | 411 | 1.7 |
| Total | 24,562 | 100.0 |

**Also includes**
**(a)** Cantonese, Hakka, Mandarin, Wu and Min Nan
**(b)** Bengali, Gujarati, Konkani, Marathi, Nepali, Punjabi, Sindhi, Sinhalese, Urdu, Assamese, Dhivehi, Kashmiri, Oriya, and Fijian Hindustani
**(c)** Hebrew, Assyrian Neo-Aramaic, Chaldean Neo-Aramaic, and Mandaean (Mandaic)
**(d)** Khmer and Mon
**(e)** Bisaya, Cebuano, Ilokano, Malay, Tetum, Timorese, Tagalog, Acehnese, Balinese, Bikol, Iban, Ilonggo, Javanese, and Pampangan
**(f)** Bosnian, Bulgarian, Serbian, and Slovene
**(g)** Catalan and Portuguese
**(h)** Kannada, Telugu, and Tulu
**(i)** Letzeburgish and Yiddish
**(j)** Fijian, Gilbertese, Maori, Nauruan, Niue, Rotuman, Tokelauan, Tuvaluan, and Yapese

The tables on this page show the country of birth and the preferred language respectively. To allow for comparison with the broader Australian community the list of country of birth in Table 9 is in descending order of the most frequent country of birth according to the 2011 Census (e.g. India was the fifth most common country of birth in the 2011 Census). The same approach has been taken with Table 10 (e.g. Italian was the fifth most frequently spoken language in the 2011 census). All other countries and languages have been grouped together to form the categories ‘All other countries’ and ‘All other languages’ respectively.

Table 11 and Table 12 present a breakdown of malignant and non-malignant diagnosis. Diagnosis is the principal life limiting illness responsible for the patient requiring palliative care.

Diagnosis was not stated for 245 (1.0%) patients nationally.

**Table 11 Principal reason for palliative care - malignant diagnoses**

| Diagnosis | N | % of malignant diagnoses | % of all diagnoses |
|---|---|---|---|
| Bone and soft tissue | 274 | 1.5 | 1.1 |
| Breast | 1,373 | 7.7 | 5.6 |
| CNS | 428 | 2.4 | 1.7 |
| Colorectal | 1,866 | 10.4 | 7.6 |
| Other GIT | 1,631 | 9.1 | 6.6 |
| Haematological | 1,184 | 6.6 | 4.8 |
| Head and neck | 930 | 5.2 | 3.8 |
| Lung | 3,686 | 20.6 | 15.0 |
| Pancreas | 1,319 | 7.4 | 5.4 |
| Prostate | 1,336 | 7.5 | 5.4 |
| Other urological | 751 | 4.2 | 3.1 |
| Gynaecological | 951 | 5.3 | 3.9 |
| Skin | 547 | 3.1 | 2.2 |
| Unknown primary | 617 | 3.4 | 2.5 |
| Other primary malignancy | 767 | 4.3 | 3.1 |
| Malignant – nfd | 234 | 1.3 | 1.0 |
| All malignant diagnoses | 17,894 | 100.0 | 72.9 |

**Table 12 Principal reason for palliative care - non-malignant diagnosis**

| Diagnosis | N | % of non-malignant diagnosis | % of all diagnoses |
|---|---|---|---|
| Cardiovascular disease | 1,037 | 16.1 | 4.2 |
| HIV / AIDS | 12 | 0.2 | 0.0 |
| End stage kidney disease | 545 | 8.5 | 2.2 |
| Stroke | 364 | 5.7 | 1.5 |
| Motor neurone disease | 304 | 4.7 | 1.2 |
| Alzheimer's dementia | 286 | 4.5 | 1.2 |
| Other dementia | 525 | 8.2 | 2.1 |
| Other neurological disease | 351 | 5.5 | 1.4 |
| Respiratory failure | 1,112 | 17.3 | 4.5 |
| End stage liver disease | 261 | 4.1 | 1.1 |
| Diabetes & its complications | 42 | 0.7 | 0.2 |
| Sepsis | 267 | 4.2 | 1.1 |
| Multiple organ failure | 139 | 2.2 | 0.6 |
| Other non-malignancy | 1,014 | 15.8 | 4.1 |
| Non-malignant – nfd | 164 | 2.6 | 0.7 |
| All non-malignant | 6,423 | 100.0 | 26.2 |

# 4 Episodes of palliative care

An episode of care is a period of contact between a patient and a palliative care service that is provided by one palliative care service and occurs in one setting – for the purposes of this report, either as a hospital / hospice or community patient.

An episode of palliative care starts on the date when the comprehensive palliative care assessment is undertaken and documented using the five clinical assessment tools.

An episode of palliative care ends when:

- the patient is formally separated from the current setting of care (e.g. from community to hospital / hospice) or
- the patient dies or
- the principal clinical intent of the care changes and the patient is no longer receiving palliative care.

Table 13 presents the number and percentage of episodes by age group and sex. Age has been calculated as at the beginning of each episode.

**Table 13 Patient's age by sex**

| Age group | Male | | Female | |
|---|---|---|---|---|
| | N | % | N | % |
| **< 15** | 22 | 0.1 | 20 | 0.1 |
| **15 - 24** | 46 | 0.3 | 27 | 0.2 |
| **25 - 34** | 141 | 0.8 | 152 | 1.0 |
| **35 - 44** | 298 | 1.8 | 380 | 2.5 |
| **45 - 54** | 913 | 5.5 | 1,106 | 7.3 |
| **55 - 64** | 2,537 | 15.2 | 2,166 | 14.4 |
| **65 - 74** | 4,111 | 24.6 | 3,426 | 22.7 |
| **75 - 84** | 5,065 | 30.3 | 4,013 | 26.6 |
| **85 +** | 3,554 | 21.2 | 3,731 | 24.7 |
| **Unknown** | 50 | 0.0 | 59 | 0.0 |
| **Total** | 16,737 | 100.0 | 15,080 | 100.0 |

Note: Records where sex was not stated or inadequately described are excluded from the table.

Referral source refers to the facility or organisation from which the patient was referred for each episode of care. Table 14 presents referral source by setting.

**Table 14 Source of referral**

| Referral source | Hospital / hospice | | Community | |
|---|---|---|---|---|
| | N | % | N | % |
| Public hospital | 9,829 | 62.3 | 8,577 | 53.4 |
| Private hospital | 1,363 | 8.6 | 1,765 | 11.0 |
| Outpatient clinic | 95 | 0.6 | 147 | 0.9 |
| General medical practitioner | 308 | 2.0 | 2,351 | 14.6 |
| Specialist medical practitioner | 459 | 2.9 | 870 | 5.4 |
| Community-based palliative care agency | 2,894 | 18.4 | 230 | 1.4 |
| Community-based service | 22 | 0.1 | 176 | 1.1 |
| Residential aged care facility | 65 | 0.4 | 1,010 | 6.3 |
| Self, carer(s), family or friends | 121 | 0.8 | 446 | 2.8 |
| Other | 186 | 1.2 | 408 | 2.5 |
| Not stated / inadequately described | 428 | 2.7 | 76 | 0.5 |
| Total | 15,770 | 100.0 | 16,056 | 100.0 |

Table 15 gives a summary of the length of palliative care episode. Table 16 details the length of episode by setting. The length of episode is calculated as the number of days between the episode start date and the episode end date. Bereavement phases are excluded from the calculation and episodes that remain open at the end of the reporting period (and hence do not have an episode end date) are also excluded.

**Table 15 Length of episode (in days) summary by setting**

| Length of episode | Hospital / hospice | Community |
|---|---|---|
| Average length of episode | 9.5 | 37.3 |
| Median length of episode | 5.0 | 25.0 |

Note: Records where length of episode was greater than 180 days were considered to be atypical and are excluded from the average calculations. Only episodes ending during the reporting period are included.

**Table 16 Length of episode by setting**

| Length of Episode (days) | Hospital / hospice | | Community | |
|---|---|---|---|---|
| | N | % | N | % |
| Same day | 1,386 | 8.9 | 468 | 3.4 |
| 1-2 | 3,290 | 21.2 | 895 | 6.4 |
| 3-4 | 2,265 | 14.6 | 779 | 5.6 |
| 5-7 | 2,551 | 16.5 | 1,136 | 8.1 |
| 8-14 | 2,861 | 18.5 | 1,823 | 13.1 |
| 15-21 | 1,399 | 9.0 | 1,358 | 9.7 |
| 22-30 | 886 | 5.7 | 1,266 | 9.1 |
| 31-60 | 702 | 4.5 | 2,276 | 16.3 |
| 61-90 | 106 | 0.7 | 1,174 | 8.4 |
| 90 + | 47 | 0.3 | 2,769 | 19.9 |
| Total | 15,493 | 100.0 | 13,944 | 100.0 |

Note: Only episodes that end during the reporting period are included.

**Table 17 How hospital / hospice episodes start**

| Episode start mode | N | % |
|---|---|---|
| Admitted from community[1] | 9,483 | 60.1 |
| Admitted from another hospital | 3,137 | 19.9 |
| Admitted from acute care in another ward | 2,285 | 14.5 |
| Change from acute care to palliative care – same ward | 313 | 2.0 |
| Other[2] | 129 | 0.8 |
| Not stated / inadequately described | 423 | 2.7 |
| Total | 15,770 | 100.0 |

[1] includes: admitted from usual accommodation, admitted from other than usual accommodation.

[2] includes: change of sub-acute/non-acute care type and other categories.

**Table 18 How hospital / hospice episodes end**

| Episode end mode | N | % |
|---|---|---|
| Discharged to community[1] | 5,035 | 32.5 |
| Discharged to another hospital | 813 | 5.2 |
| Death | 8,093 | 52.2 |
| Change from palliative care to acute care[2] | 136 | 0.9 |
| Change in sub-acute care type | 148 | 1.0 |
| End of consultative episode – inpatient episode ongoing | 712 | 4.6 |
| Other | 154 | 1.0 |
| Not stated / inadequately described | 414 | 2.7 |
| Total | 15,505 | 100.0 |

Note: Only episodes ending during the reporting period are included.

[1] includes: discharged to usual accommodation, discharged to other than usual accommodation.

[2] includes: change from palliative care to acute care – different ward, change from palliative care to acute care – same ward.

**Table 19 How community episodes start**

| Episode start mode | N | % |
|---|---|---|
| Admitted from inpatient palliative care | 5,697 | 35.5 |
| Other[1] | 10,222 | 63.7 |
| Not stated / inadequately described | 137 | 0.9 |
| Total | 16,056 | 100.0 |

[1]includes: patient was not transferred from being an overnight patient.

**Table 20 How community episodes end**

| Episode end mode | N | % |
|---|---|---|
| Admitted for inpatient palliative care | 4,239 | 30.4 |
| Admitted for inpatient acute care | 4,148 | 29.7 |
| Admitted to another palliative care service | 113 | 0.8 |
| Admitted to primary health care | 710 | 5.1 |
| Discharged / case closure | 1,041 | 7.5 |
| Death | 3,409 | 24.4 |
| Other | 252 | 1.8 |
| Not stated / inadequately described | 39 | 0.3 |
| Total | 13,951 | 100.0 |

Note: Only episodes ending during the reporting period are included.

# 5 Profile of palliative care phases

The palliative care phase type describes the stage of the patient's illness and provides a clinical indication of the level of care a patient requires. The palliative care phase is determined by a holistic clinical assessment which considers the needs of the patients and their family and carers. A patient may move back and forth between the stable, unstable, deteriorating and terminal phase types and these may occur in any sequence. See Appendix E for more information on the definition of palliative care phase.

The clinical assessments are assessed daily (or at each visit) and are reported on admission, when the phase changes and at discharge.

**Table 21 Number of phases by phase type and setting**

| Phase type | Hospital / hospice | | Community | |
|---|---|---|---|---|
| | N | % | N | % |
| Stable | 8,740 | 24.8 | 14,070 | 37.1 |
| Unstable | 6,650 | 18.8 | 4,760 | 12.6 |
| Deteriorating | 12,432 | 35.2 | 16,199 | 42.7 |
| Terminal | 7,489 | 21.2 | 2,869 | 7.6 |
| Total | 35,311 | 100.0 | 37,898 | 100.0 |

Note: Bereavement phases have been excluded due to inconsistent data collection and bereavement practices. Bereavement phases are not included in the total phases count.

**Table 22 Average phase length (in days) by phase type and setting**

| Phase type | Hospital / hospice | Community |
|---|---|---|
| Stable | 6.6 | 20.6 |
| Unstable | 1.9 | 2.9 |
| Deteriorating | 5.1 | 12.3 |
| Terminal | 2.0 | 3.0 |

Note: Phase records where phase length was greater than 90 days were considered to be atypical and are excluded from the average calculations.

Table 23 presents the first phase of the episode.

**Table 23 First phase of episode by setting**

| First phase | Hospital / hospice | | Community | |
|---|---|---|---|---|
| | N | % | N | % |
| Stable | 2,253 | 14.7 | 5,740 | 41.2 |
| Unstable | 4,824 | 31.4 | 840 | 6.0 |
| Deteriorating | 6,593 | 42.9 | 6,809 | 48.9 |
| Terminal | 1,703 | 11.1 | 536 | 3.8 |
| Total | 15,373 | 100.0 | 13,925 | 100.0 |

Note: This table only includes the first phase if the episode has started in the reporting period.

Table 24 presents information relating to the manner in which stable phases ended. A stable phase will end if a patient moves into a different phase (phase change), is discharged or dies. Figure 10 summarises the movement of patients out of the stable phase by setting. This movement from one phase to another is referred to as phase progression and is derived by PCOC.

Similar information is presented for the unstable (Table 25, Figure 11), deteriorating (Table 26, Figure 12) and terminal (Table 27, Figure 13) phases on the following pages.

**Table 24 How stable phases end by setting**

| How stable phases end | Hospital / hospice | | Community | |
|---|---|---|---|---|
| | N | % | N | % |
| Patient moved into another phase | 4,278 | 48.9 | 9,555 | 67.9 |
| Discharge / case closure | 4,356 | 49.8 | 4,222 | 30.0 |
| Died | 101 | 1.2 | 236 | 1.7 |
| Not stated / inadequately described | 5 | 0.1 | 57 | 0.4 |
| Total | 8,740 | 100.0 | 14,070 | 100.0 |

**Figure 10 Stable phase progression**

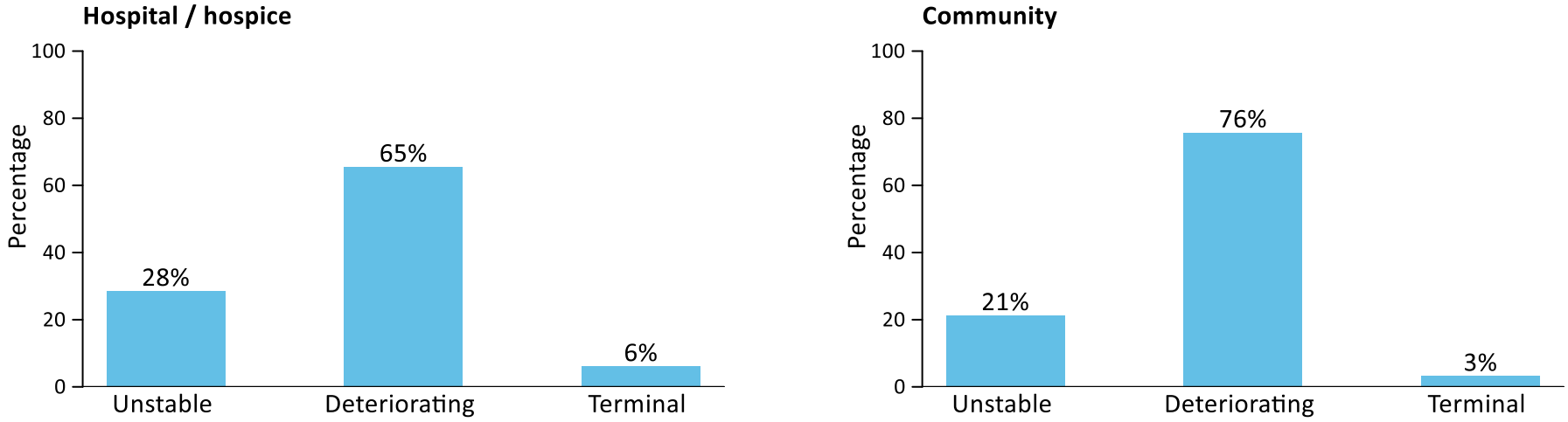


Table 25 How unstable phases end by setting

| How unstable phases end | Hospital / hospice | | Community | |
|---|---|---|---|---|
| | N | % | N | % |
| Patient moved into another phase | 6,104 | 91.8 | 2,946 | 61.9 |
| Discharge / case closure | 442 | 6.6 | 1,746 | 36.7 |
| Died | 103 | 1.5 | 56 | 1.2 |
| Not stated / inadequately described | 1 | 0.0 | 12 | 0.3 |
| Total | 6,650 | 100.0 | 4,760 | 100.0 |

Figure 11 Unstable phase progression

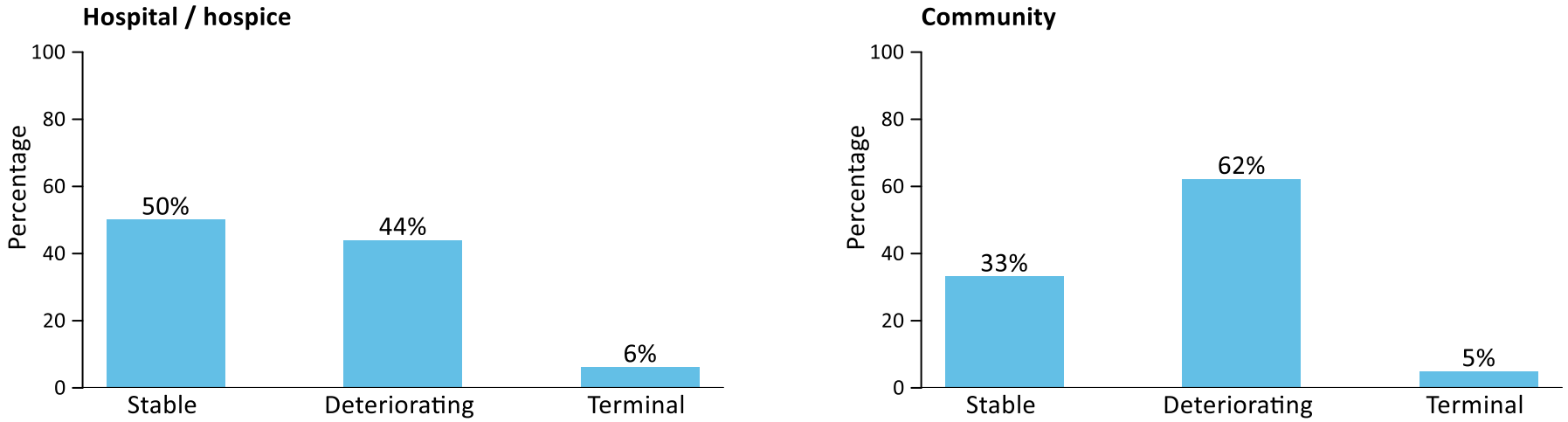


Table 26 How deteriorating phases end by setting

| How deteriorating phases end | Hospital / hospice | | Community | |
|---|---|---|---|---|
| | N | % | N | % |
| Patient moved into another phase | 9,065 | 72.9 | 11,001 | 67.9 |
| Discharge / case closure | 2,275 | 18.3 | 4,238 | 26.2 |
| Died | 1,083 | 8.7 | 922 | 5.7 |
| Not stated / inadequately described | 9 | 0.1 | 38 | 0.2 |
| Total | 12,432 | 100.0 | 16,199 | 100.0 |

Figure 12 Deteriorating phase progression

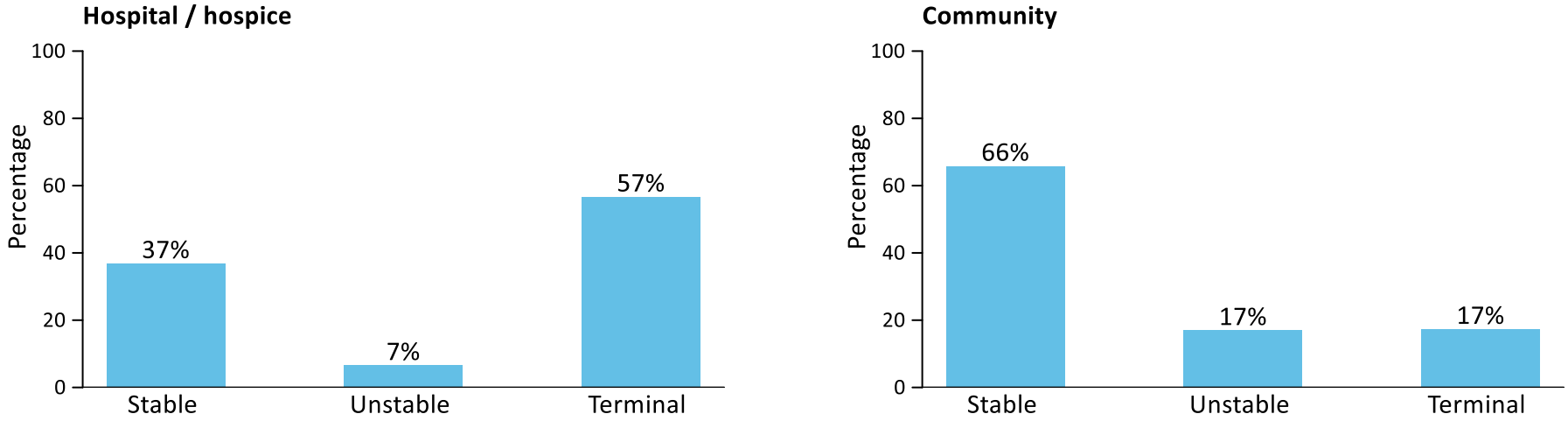
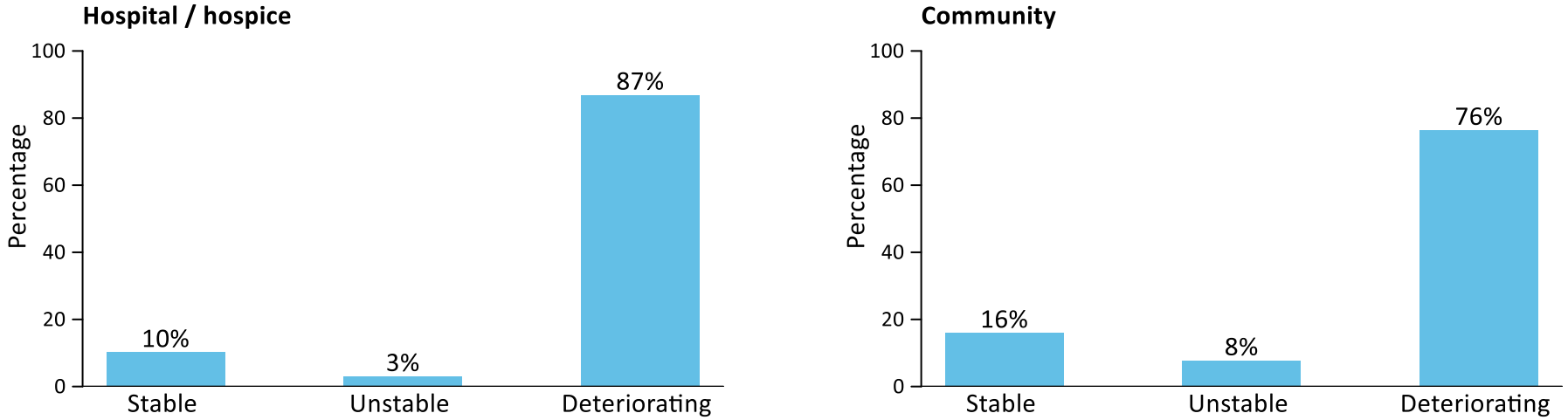


Table 27 How terminal phases end by setting

| How terminal phases end | Hospital / hospice | | Community | |
|---|---|---|---|---|
| | N | % | N | % |
| Patient moved into another phase | 335 | 4.5 | 402 | 14.0 |
| Discharge / case closure | 284 | 3.8 | 272 | 9.5 |
| Died | 6,868 | 91.7 | 2,184 | 76.1 |
| Not stated / inadequately described | 2 | 0.0 | 11 | 0.4 |
| Total | 7,489 | 100.0 | 2,869 | 100.0 |

Figure 13 Terminal phase progression



# 6 Symptoms and problems

The Palliative Care Problem Severity Score (PCPSS) is a clinician rated screening tool to assess the overall severity of problems within four key palliative care domains (pain, other symptoms, psychological / spiritual and family / carer). The ratings are: 0 - absent, 1 - mild, 2 - moderate and 3 - severe. Table 28 shows the percentage scores for the hospital / hospice and community settings.

**Table 28 PCPSS at beginning of phase by phase type**

| Phase type | Problem | Hospital / hospice (%) | | | | Community (%) | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | Absent | Mild | Moderate | Severe | Absent | Mild | Moderate | Severe |
| **Stable** | Pain | 49.5 | 41.6 | 7.8 | 1.1 | 48.8 | 46.9 | 4.0 | 0.3 |
| | Other symptoms | 38.3 | 51.3 | 9.4 | 1.0 | 26.1 | 65.7 | 7.8 | 0.4 |
| | Psychological / spiritual | 52.5 | 41.5 | 5.3 | 0.8 | 41.6 | 53.4 | 4.7 | 0.3 |
| | Family / carer | 53.5 | 40.1 | 5.6 | 0.8 | 39.7 | 53.2 | 6.6 | 0.5 |
| **Unstable** | Pain | 29.8 | 35.8 | 26.0 | 8.3 | 20.1 | 28.8 | 35.1 | 16.0 |
| | Other symptoms | 20.4 | 42.7 | 29.8 | 7.1 | 7.8 | 29.9 | 47.8 | 14.5 |
| | Psychological / spiritual | 36.2 | 45.3 | 15.7 | 2.8 | 18.7 | 46.1 | 30.3 | 5.0 |
| | Family / carer | 35.6 | 44.7 | 16.0 | 3.7 | 14.6 | 40.0 | 37.4 | 8.0 |
| **Deteriorating** | Pain | 37.9 | 42.5 | 16.6 | 3.0 | 32.8 | 49.3 | 16.5 | 1.4 |
| | Other symptoms | 26.0 | 47.3 | 22.5 | 4.2 | 11.6 | 57.0 | 29.7 | 1.7 |
| | Psychological / spiritual | 41.6 | 45.3 | 11.4 | 1.6 | 24.3 | 58.5 | 16.3 | 1.0 |
| | Family / carer | 38.5 | 44.7 | 14.1 | 2.6 | 21.3 | 56.5 | 20.6 | 1.6 |
| **Terminal** | Pain | 47.2 | 39.0 | 11.3 | 2.4 | 42.2 | 43.6 | 11.8 | 2.5 |
| | Other symptoms | 42.1 | 39.3 | 15.1 | 3.5 | 31.6 | 44.9 | 20.0 | 3.5 |
| | Psychological / spiritual | 61.8 | 31.4 | 5.7 | 1.1 | 50.4 | 36.5 | 11.5 | 1.6 |
| | Family / carer | 33.5 | 44.3 | 18.4 | 3.7 | 16.1 | 50.2 | 29.4 | 4.3 |

The Symptom Assessment Scale (SAS) is a patient rated (or proxy) assessment tool and reports a level of distress using a numerical rating scale from 0 - no distress to 10 - worst possible distress. The SAS reports on distress from seven symptoms, these being difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. It provides a clinical picture of these seven symptoms from the patient's perspective.

The SAS scores are grouped in Table 29 using the same categories as the PCPSS i.e. absent (0), mild (1-3), moderate (4-7) and severe (8-10). Alternative graphical representations of the SAS profile by phase type can be found in Figure 14 and Figure 15.

**Table 29 Symptom distress at the beginning of a phase by phase type**

| Phase type | Symptom | Hospital / hospice (%) | | | | Community (%) | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | Absent | Mild | Moderate | Severe | Absent | Mild | Moderate | Severe |
| **Stable** | Difficulty sleeping | 80.8 | 13.5 | 4.9 | 0.8 | 73.8 | 20.6 | 5.0 | 0.5 |
| | Appetite problems | 74.6 | 18.8 | 5.5 | 1.1 | 63.6 | 30.1 | 5.7 | 0.6 |
| | Nausea | 84.5 | 11.4 | 3.5 | 0.6 | 84.8 | 13.1 | 1.8 | 0.2 |
| | Bowel problems | 72.7 | 19.4 | 6.5 | 1.4 | 74.7 | 20.6 | 4.1 | 0.6 |
| | Breathing problems | 71.4 | 20.0 | 7.5 | 1.1 | 63.1 | 29.0 | 7.3 | 0.6 |
| | Fatigue | 47.4 | 33.7 | 16.9 | 2.1 | 28.0 | 48.3 | 21.9 | 1.9 |
| | Pain | 50.4 | 35.6 | 12.6 | 1.5 | 50.0 | 42.3 | 6.9 | 0.9 |
| **Unstable** | Difficulty sleeping | 65.8 | 18.7 | 11.8 | 3.7 | 50.5 | 23.7 | 20.5 | 5.4 |
| | Appetite problems | 57.6 | 24.7 | 13.9 | 3.8 | 44.9 | 31.7 | 18.6 | 4.8 |
| | Nausea | 69.9 | 16.2 | 10.6 | 3.3 | 61.8 | 17.9 | 15.4 | 5.0 |
| | Bowel problems | 60.9 | 22.2 | 12.6 | 4.3 | 55.8 | 23.2 | 16.0 | 5.0 |
| | Breathing problems | 57.2 | 21.7 | 15.5 | 5.6 | 49.3 | 26.2 | 18.3 | 6.1 |
| | Fatigue | 33.0 | 30.4 | 29.3 | 7.4 | 20.7 | 30.8 | 37.8 | 10.7 |
| | Pain | 31.0 | 30.4 | 27.8 | 10.8 | 19.9 | 29.7 | 33.6 | 16.8 |
| **Deteriorating** | Difficulty sleeping | 76.0 | 14.7 | 7.9 | 1.4 | 65.7 | 24.5 | 8.8 | 1.0 |
| | Appetite problems | 68.1 | 21.1 | 8.9 | 1.8 | 51.5 | 36.5 | 10.7 | 1.3 |
| | Nausea | 78.2 | 14.0 | 6.3 | 1.4 | 75.7 | 18.4 | 5.4 | 0.5 |
| | Bowel problems | 67.6 | 20.5 | 9.8 | 2.1 | 65.2 | 25.6 | 8.2 | 1.0 |
| | Breathing problems | 61.6 | 21.9 | 13.3 | 3.2 | 54.0 | 31.0 | 13.4 | 1.5 |
| | Fatigue | 40.1 | 29.8 | 25.4 | 4.7 | 19.9 | 41.9 | 34.6 | 3.6 |
| | Pain | 39.6 | 35.4 | 21.3 | 3.6 | 35.3 | 44.8 | 17.6 | 2.3 |
| **Terminal** | Difficulty sleeping | 93.6 | 4.4 | 1.7 | 0.3 | 82.6 | 9.9 | 6.3 | 1.1 |
| | Appetite problems | 94.2 | 4.2 | 1.1 | 0.4 | 88.6 | 7.4 | 2.6 | 1.4 |
| | Nausea | 94.4 | 3.9 | 1.4 | 0.3 | 88.5 | 7.9 | 3.0 | 0.6 |
| | Bowel problems | 91.0 | 6.4 | 2.2 | 0.4 | 81.4 | 13.9 | 4.3 | 0.5 |
| | Breathing problems | 72.4 | 16.0 | 9.1 | 2.5 | 67.7 | 20.5 | 10.0 | 1.8 |
| | Fatigue | 80.9 | 9.8 | 7.5 | 1.8 | 73.7 | 13.2 | 9.8 | 3.3 |
| | Pain | 56.0 | 29.3 | 13.0 | 1.8 | 47.6 | 35.6 | 14.7 | 2.1 |

**Figure 14** **Profile of symptoms and problems by phase type – hospital / hospice setting**

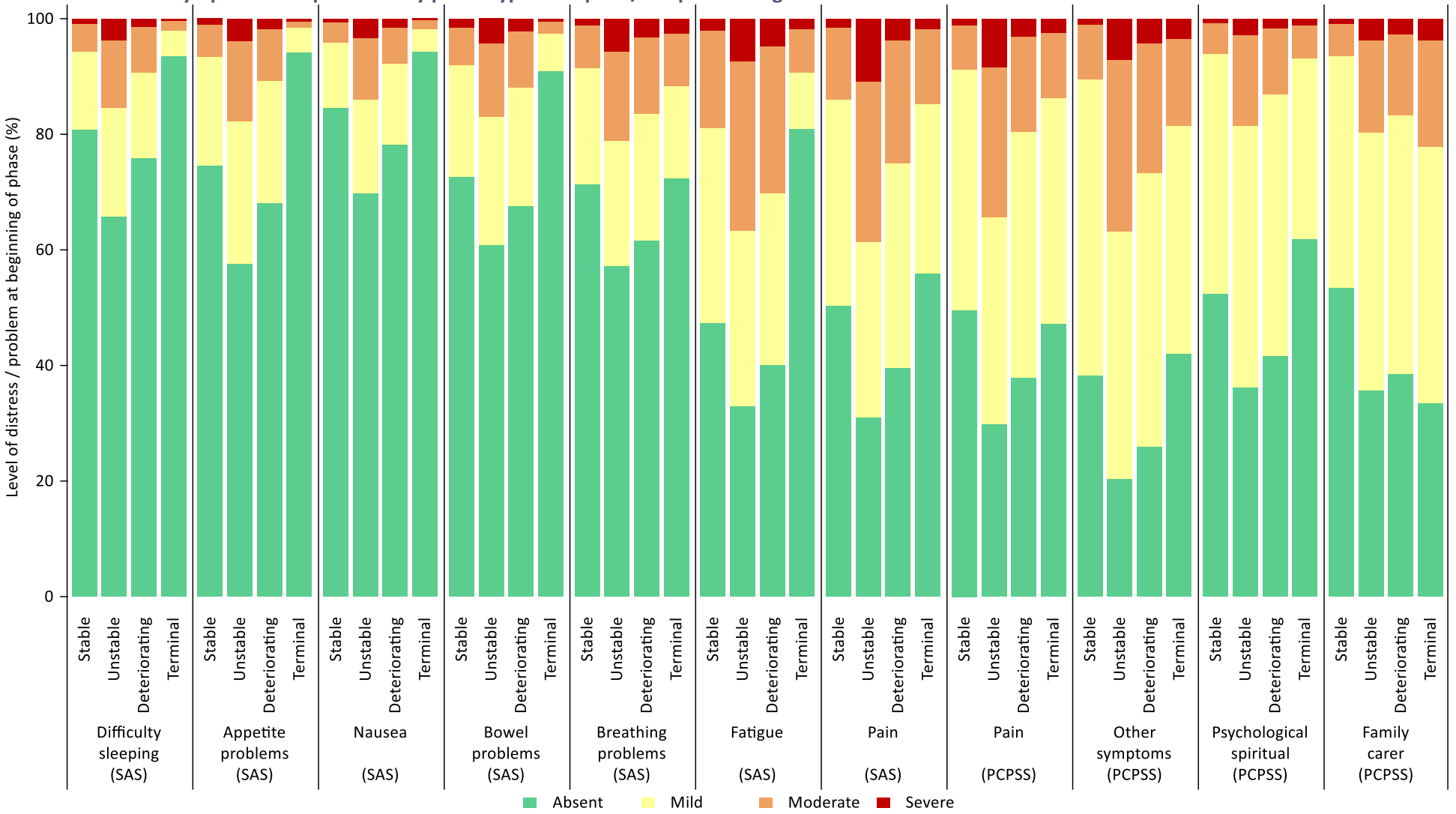
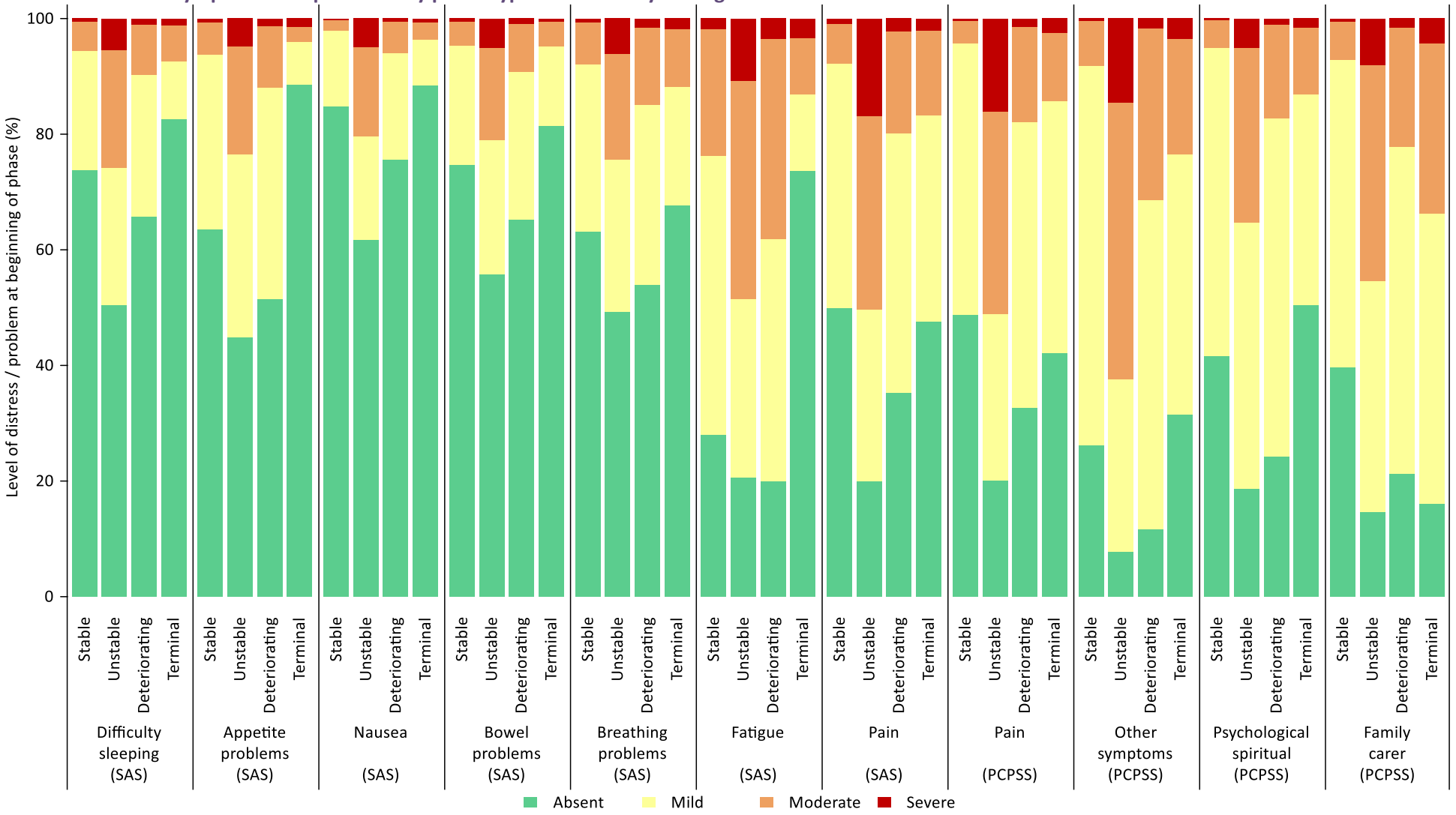


**Figure 15** **Profile of symptoms and problems by phase type – community setting**



# 7 Functional status and level of dependence

The Australia-modified Karnofsky Performance Status (AKPS) is a measure of the patient's overall performance status or ability to perform their activities of daily living. It is a single score between 0 and 100 assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care. Table 30 shows the data for the AKPS at phase start.

**Table 30 Australia-modified Karnofsky Performance Status (AKPS) at phase start by setting**

| AKPS assessment at phase start | Hospital / hospice | | Community | |
|---|---|---|---|---|
| | N | % | N | % |
| Comatose or barely rousable (10) | 3,971 | 11.2 | 1,109 | 2.9 |
| Totally bedfast and requiring extensive nursing care (20) | 8,675 | 24.6 | 3,771 | 10.0 |
| Almost completely bedfast (30) | 5,237 | 14.8 | 3,021 | 8.0 |
| In bed more than 50% of the time (40) | 7,040 | 19.9 | 5,781 | 15.3 |
| Requires considerable assistance (50) | 5,182 | 14.7 | 9,345 | 24.7 |
| Requires occasional assistance (60) | 3,344 | 9.5 | 8,211 | 21.7 |
| Cares for self (70) | 704 | 2.0 | 3,851 | 10.2 |
| Normal activity with effort (80) | 222 | 0.6 | 778 | 2.1 |
| Able to carry on normal activity; minor signs or symptoms (90) | 50 | 0.1 | 156 | 0.4 |
| Normal; no complaints; no evidence of disease (100) | 10 | 0.0 | 8 | 0.0 |
| Not stated/inadequately described | 876 | 2.5 | 1,867 | 4.9 |
| Total | 35,311 | 100.0 | 37,898 | 100.0 |

**Figure 16** Distribution of AKPS at episode start

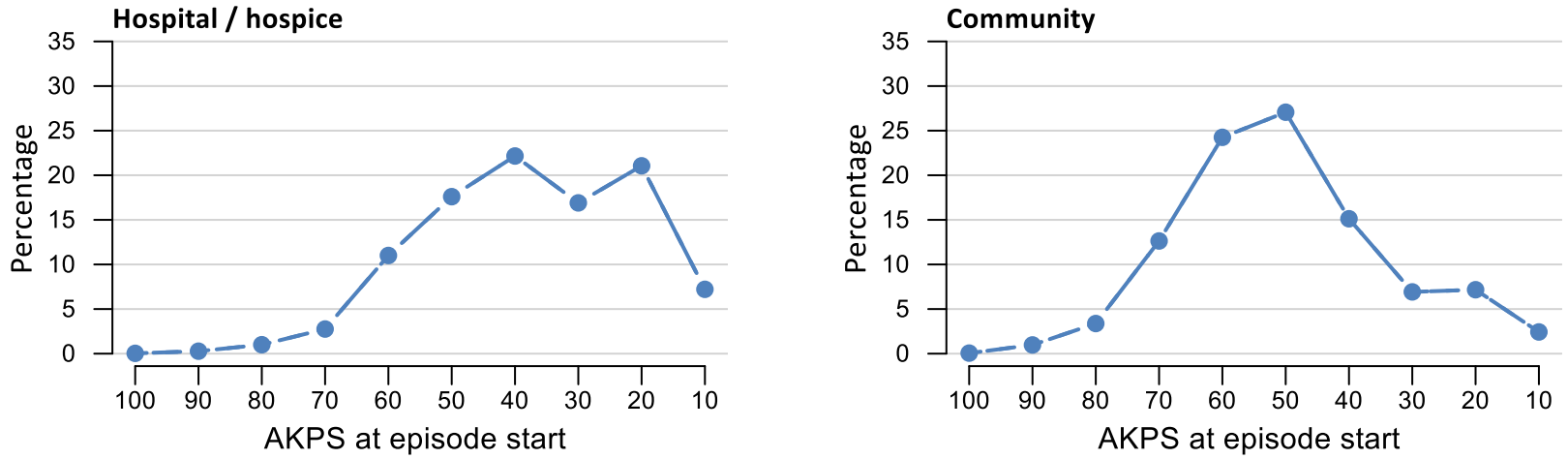



**Figure 17** Distribution of AKPS at phase start by phase type

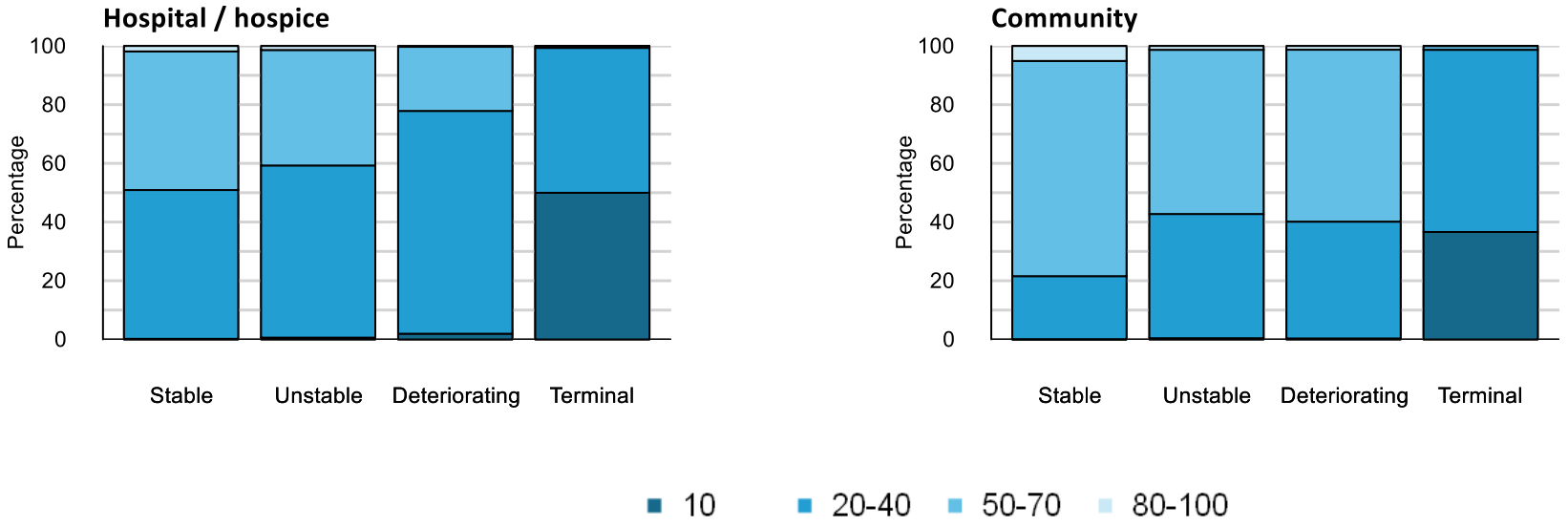
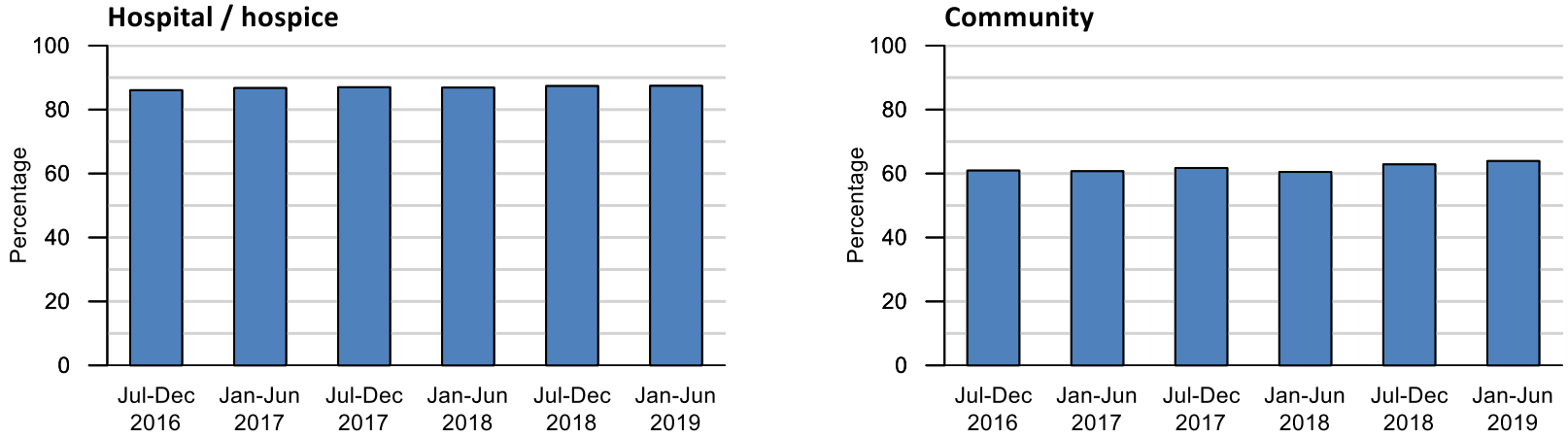


**Figure 18** **Percentage of phases beginning with an AKPS of 50 or less overtime**



The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) tool consists of four items (bed mobility, toileting, transfers and eating) and assesses the level of functional dependence. The RUG-ADL items are assessed daily (or at each visit) and are reported on admission, when the phase changes and at discharge. Table 32 summaries the RUG-ADL items at the beginning of each phase for hospital / hospice and community patients.

**Table 31 The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) at phase start by setting**

| Item | RUG-ADL assessment at phase start | Hospital / hospice | | Community | |
|---|---|---|---|---|---|
| | | N | % | N | % |
| **Bed mobility** | Independent or supervision only (1) | 9,589 | 27.8 | 21,926 | 62.0 |
| | Limited physical assistance (3) | 6,158 | 17.8 | 4,666 | 13.2 |
| | Other than two person physical assist (4) | 3,855 | 11.2 | 2,795 | 7.9 |
| | Two or more person physical assist (5) | 14,919 | 43.2 | 5,966 | 16.9 |
| **Toileting** | Independent or supervision only (1) | 6,279 | 18.2 | 18,426 | 52.2 |
| | Limited physical assistance (3) | 7,382 | 21.4 | 6,892 | 19.5 |
| | Other than two person physical assist (4) | 4,917 | 14.2 | 3,654 | 10.3 |
| | Two or more person physical assist (5) | 15,937 | 46.2 | 6,357 | 18.0 |
| **Transfers** | Independent or supervision only (1) | 6,199 | 18.0 | 18,221 | 51.6 |
| | Limited physical assistance (3) | 7,205 | 20.9 | 7,059 | 20.0 |
| | Other than two person physical assist (4) | 4,631 | 13.4 | 3,510 | 9.9 |
| | Two or more person physical assist (5) | 16,473 | 47.7 | 6,518 | 18.5 |
| **Eating** | Independent or supervision only (1) | 14,271 | 41.5 | 23,626 | 67.4 |
| | Limited physical assistance (2) | 7,286 | 21.2 | 5,746 | 16.4 |
| | Extensive assistance/total dependence/tube fed (3) | 12,865 | 37.4 | 5,687 | 16.2 |

**Figure 19** Distribution of Total RUG-ADL at episode start

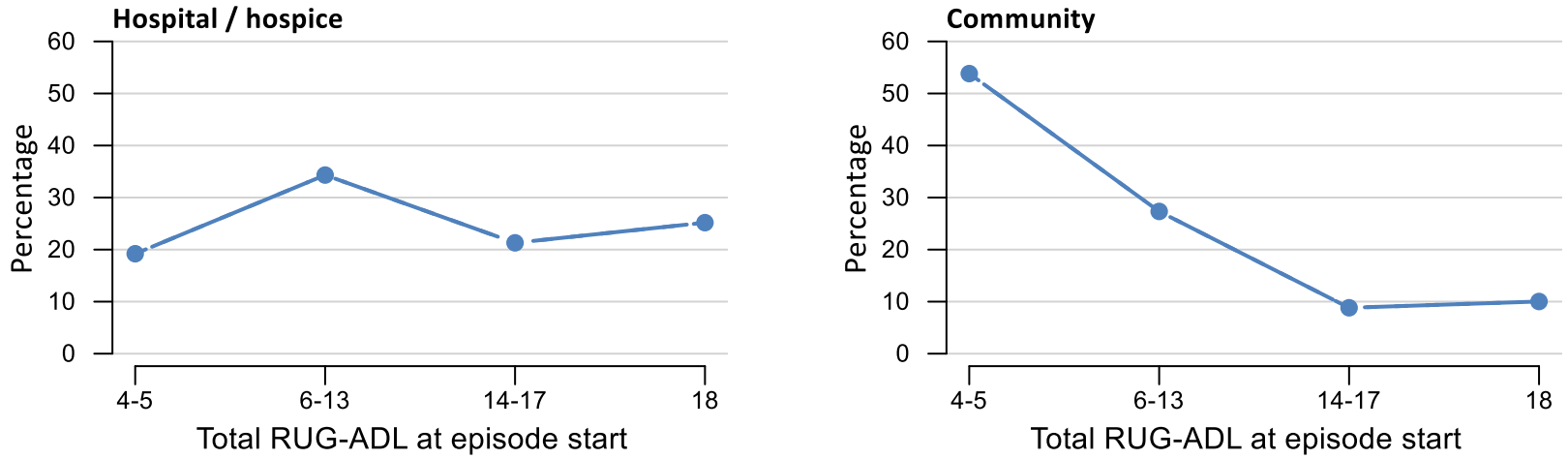



**Figure 20** Distribution of Total RUG-ADL at phase start by phase type

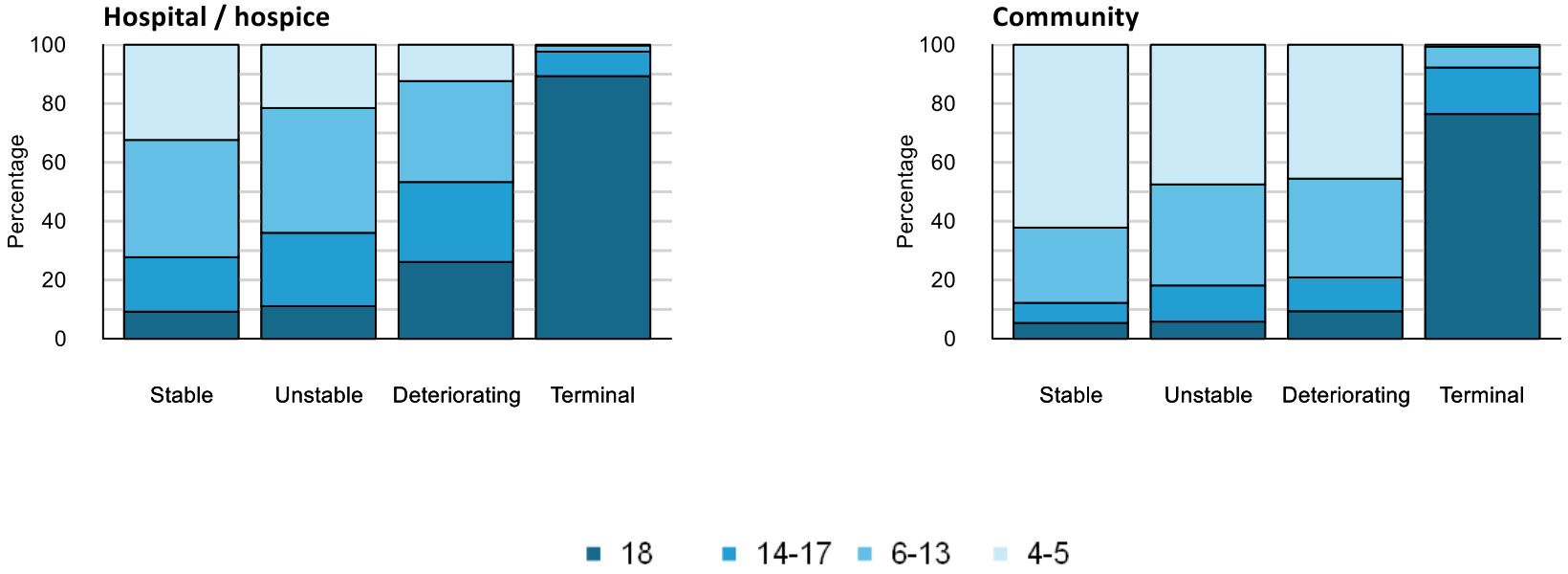
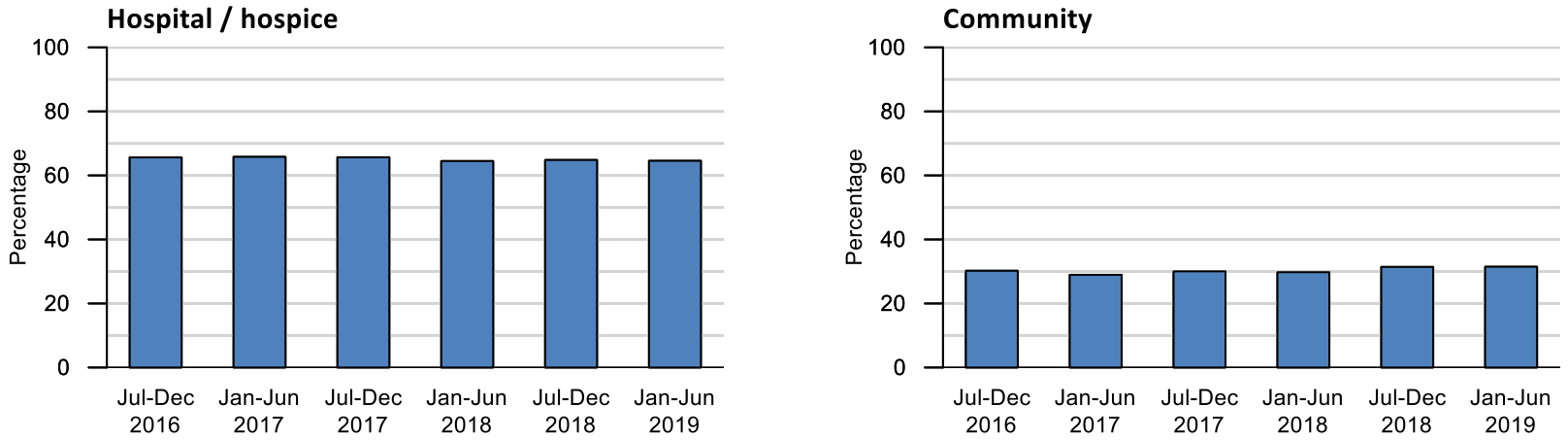


**Figure 21** **Percentage of phases beginning with a Total RUG-ADL of 10 or more overtime**



# Appendices

## A Summary of data included in this report

During the reporting period, data were provided for a total of 24,562 patients who between them had 31,826 episodes of care and 73,209 palliative care phases. These total numbers are determined by a data scoping method. This method looks at the phase level data first and includes all phases that ended within the current reporting period. The associated episodes and patients are then determined (Appendix C contains a more detailed explanation of this process). Table 32 shows the number of patients, episodes and phases included in this report.

**Table 32 Summary of patients, episodes and phases by setting**

| | Hospital / hospice | Community | Total |
|---|---|---|---|
| **Patients (N)** | 13,148 | 12,695 | 24,562 |
| **Episodes (N)** | 15,770 | 16,056 | 31,826 |
| **Phases (N)** | 35,311 | 37,898 | 73,209 |
| **Patients (%)** | 53.5 | 51.7 | 100 |
| **Episodes (%)** | 49.6 | 50.4 | 100 |
| **Phases (%)** | 48.2 | 51.8 | 100 |
| **Average number of phases per episode*** ** | 2.2 | 2.2 | 2.2 |

* Patients seen in both settings are only counted once in the total column and hence numbers/percentages may not add to the total.
** Bereavement phases are excluded from this count.
*** Average number of phases per episode is only calculated for closed episodes that started and ended within the reporting period and excludes bereavement phases.

Table 33 shows the number of completed episodes and phases by setting for each month in the current reporting period.

**Table 33 Number of completed episodes and phases by month and setting**

| Setting | | Jan | Feb | Mar | Apr | May | Jun |
|---|---|---|---|---|---|---|---|
| Hospital / hospice | Completed episodes (N) | 2,613 | 2,518 | 2,672 | 2,534 | 2,721 | 2,447 |
| | Completed phases (N) | 6,120 | 5,657 | 6,211 | 5,952 | 6,114 | 5,257 |
| Community | Completed episodes (N) | 2,418 | 2,186 | 2,402 | 2,323 | 2,402 | 2,220 |
| | Completed phases (N) | 6,471 | 5,924 | 6,540 | 6,285 | 6,547 | 6,131 |

Table 34 shows the number of patients, episodes and phases for over time and is reported by setting of care.

**Table 34 Number of patients, episodes and phases by setting and reporting period**

| | Hospital / hospice | | | | | | Community | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Jul-Dec 2016 | Jan-Jun 2017 | Jul-Dec 2017 | Jan-Jun 2018 | Jul-Dec 2018 | Jan-Jun 2019 | Jul-Dec 2016 | Jan-Jun 2017 | Jul-Dec 2017 | Jan-Jun 2018 | Jul-Dec 2018 | Jan-Jun 2019 |
| **Patients**[1] | 12,173 | 11,885 | 12,360 | 12,091 | 12,437 | 13,148 | 8,733 | 10,038 | 10,504 | 11,562 | 12,097 | 12,695 |
| **Episodes** | 14,221 | 14,008 | 14,549 | 14,403 | 14,679 | 15,770 | 11,099 | 12,790 | 13,317 | 14,687 | 15,252 | 16,056 |
| **Phases**[2] | 33,798 | 33,044 | 33,577 | 33,023 | 33,641 | 35,311 | 26,238 | 30,285 | 31,209 | 35,241 | 36,494 | 37,898 |
| **Phases per episode**[3] | 2.4 | 2.4 | 2.3 | 2.3 | 2.3 | 2.2 | 2.2 | 2.2 | 2.2 | 2.3 | 2.3 | 2.2 |

[1] Patients seen in both settings are only counted once in the total column and hence numbers/percentages may not add to the total.

[2] Bereavement phases are excluded from this count.

[3] Average number of phases per episode is only calculated for closed episodes that started and ended within the reporting period and excludes bereavement phases.

## B Data item completion

As shown in Table 35, Table 36 and Table 37 below, the rate of data completion is very high. In reviewing these tables, it is important to note that in some cases some data items are not required to be completed. For example, place of death is only required for patients who have died. Hence the complete column in the following tables only refers to the percentage of complete records where the data item was relevant.

PCOC strongly encourages services to complete and submit the whole data set on every patient as non-completion may result in services being excluded from relevant benchmarking activities or erroneous conclusions being drawn. Low completion of data items may also distort percentages and graphs in some sections.

**Table 35 Item completion (%) - patient level**

| Data item | % completion |
|---|---|
| Date of birth | 100.0 |
| Sex | 100.0 |
| Indigenous status | 96.6 |
| Country of birth | 97.3 |
| Preferred language | 98.6 |
| Diagnosis | 99.0 |

**Table 36 Item completion (%) - episode level, by setting**

| Data item | Hospital / hospice | Community | Total |
|---|---|---|---|
| Date of first contact | 99.3 | 99.6 | 99.4 |
| Referral date | 99.8 | 99.9 | 99.8 |
| Referral source | 97.3 | 99.5 | 98.4 |
| Date ready for care | 97.9 | 96.3 | 97.1 |
| Mode of episode start | 97.3 | 99.1 | 98.2 |
| Accommodation at episode start | 99.7 | 98.2 | 98.7 |
| Episode end date[1] | 99.5 | 90.0 | 94.7 |
| Mode of episode end | 97.3 | 99.7 | 98.5 |
| Accommodation at episode end | 99.1 | 98.8 | 99.0 |
| Place of death | - | 98.1 | 98.1 |

[1] Episode end date item completion may be affected by open episodes.

**Table 37 Item completion (%) - phase level, by setting**

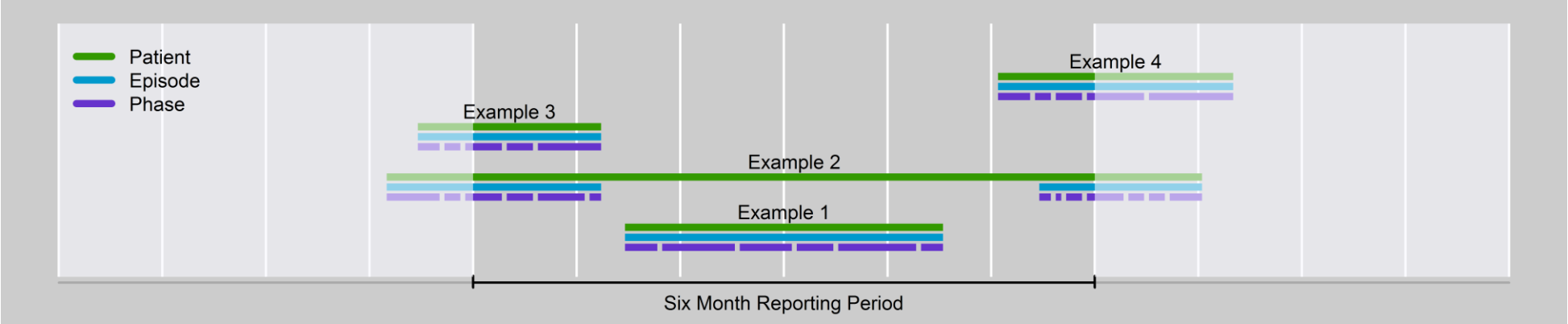
| Data item | Sub-Category (where applicable) | At phase start | | | At discharge | | |
|---|---|---|---|---|---|---|---|
| | | Hospital / hospice | Community | Total | Hospital / hospice | Community | Total |
| RUG-ADL | Bed mobility | 97.8 | 93.3 | 95.4 | 75.7 | 52.2 | 61.9 |
| | Toileting | 97.7 | 93.2 | 95.4 | 75.7 | 52.2 | 61.9 |
| | Transfers | 97.7 | 93.2 | 95.4 | 75.7 | 52.2 | 61.9 |
| | Eating | 97.5 | 92.5 | 94.9 | 75.7 | 51.8 | 61.6 |
| PCPSS | Pain | 99.2 | 94.9 | 97.0 | 79.9 | 52.6 | 63.9 |
| | Other symptom | 97.4 | 92.5 | 94.9 | 78.9 | 51.5 | 62.8 |
| | Psychological / spiritual | 99.1 | 93.9 | 96.4 | 79.8 | 51.9 | 63.4 |
| | Family / carer | 96.2 | 91.9 | 94.0 | 75.4 | 50.9 | 61.0 |
| SAS | Difficulty sleeping | 89.1 | 89.9 | 89.5 | 67.1 | 49.2 | 56.6 |
| | Appetite problems | 89.1 | 91.6 | 90.4 | 67.2 | 50.3 | 57.3 |
| | Nausea | 89.1 | 92.8 | 91.0 | 67.1 | 51.2 | 57.7 |
| | Bowel problems | 89.0 | 91.8 | 90.4 | 67.3 | 50.1 | 57.2 |
| | Breathing problems | 89.1 | 92.3 | 90.8 | 67.4 | 51.3 | 57.9 |
| | Fatigue | 89.0 | 93.0 | 91.1 | 67.9 | 51.6 | 58.3 |
| | Pain | 89.1 | 95.6 | 92.5 | 67.7 | 53.4 | 59.3 |
| AKPS | - | 97.5 | 95.1 | 96.3 | 75.6 | 54.0 | 63.0 |

| Data item | Hospital / hospice | Community | Total |
|---|---|---|---|
| Phase End Reason | 99.9 | 99.6 | 99.8 |

## C Data scoping method

The method used to determine which data is included in a PCOC report looks at the phase level records first. All phase records that end within the 6 month reporting period are deemed to be "in scope" and would be included in the report. The episode and patient records associated with these phases are also deemed to be "in scope" and hence would also be included in the report. Figure 22 below displays four examples to help visualize this process.

**Figure 22 Diagram of the PCOC data scoping method**




In Example 1, the patient (represented by the green line) has one episode (represented by the blue line). This episode has six phases (represented by the purple line segments). All six phases would be included in the report as they all end within the reporting period. Hence, the episode and patient would also be in the report.

In Example 2, the patient has two episodes - the first having six phases and the second having seven phases. Looking at the phases associated with the first episode, the last four will be included in the report (as they end within the reporting period). The first two phases would have been included in the previous report. For the phases relating to the second episode, only the first three end within the reporting period, so only these would be included in the report. The following four phases would be included in the next report. Both of the episode records and the patient record would also be included in the report.

In Example 3, the patient has one episode and five phases. Only the last three phases will be included in the report as they are the only ones ending within the reporting period (the first two phases would have been included in the previous report). The episode and patient records would be included in the report.

In Example 4, the patient again has one episode and five phases. This time, only the first three phases will be included in the report (the last two phases will be included in the next report). Again, the episode and patient records would be included in the report.

## D Interpreting benchmark profile graphs

The national profile graphs present the comparison of all palliative care services participating in PCOC. In each graph, the shaded region describes the national profile for that outcome measure.

## E Palliative Care Phase definitions

| Phase type | Start | End |
|---|---|---|
| **Stable** | ▪ Patient problems and symptoms are adequately controlled by established plan of care **and**<br>▪ Further interventions to maintain symptom control and quality of life have been planned **and**<br>▪ Family / carer situation is relatively stable and no new issues are apparent. | ▪ The needs of the patient and / or family / carer increase, requiring changes to the existing plan of care. |
| **Unstable** | An urgent change in the plan of care or emergency treatment is required **because**<br>▪ Patient experiences a new problem that was not anticipated in the existing plan of care, **and / or**<br>▪ Patient experiences a rapid increase in the severity of a current problem; **and / or**<br>▪ Family / carers circumstances change suddenly impacting on patient care. | ▪ The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom / crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) **and / or**<br>▪ Death is likely within days (i.e. patient is now terminal). |
| **Deteriorating** | The care plan is addressing anticipated needs but requires periodic review **because**<br>▪ Patients overall functional status is declining **and / or**<br>▪ Patient experiences a gradual worsening of existing problem **and / or**<br>▪ Patient experiences a new but anticipated problem **and / or**<br>▪ Family / carers experience gradual worsening distress that impacts on the patient care. | ▪ Patient condition plateaus (i.e. patient is now stable) **or**<br>▪ An urgent change in the care plan or emergency treatment **and / or**<br>▪ Family / carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) **or**<br>▪ Death is likely within days (i.e. patient is now terminal). |
| **Terminal** | Death is likely within days. | ▪ Patient dies **or**<br>▪ Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating). |

# Acknowledgements

**Contributions** PCOC wishes to acknowledge the valuable contribution made by the many staff from palliative care services who have spent considerable time collecting, collating and correcting the data and without whose effort this report would not be possible.

**Disclaimer** PCOC has made every effort to ensure that the data used in this report are accurate. Data submitted to PCOC are checked for anomalies and services are asked to re-submit data prior to the production of the PCOC report. We would advise readers to use their professional judgement in considering all information contained in this report.



**Suggested citation** Connolly A, Burns S, Allingham S, Foskett L, Clapham S and Daveson B (2019) *Patient Outcomes in Palliative Care in Australia: National report for January – June 2019*. Palliative Care Outcomes Collaboration, Australian Health Services Research Institute, University of Wollongong