

Improving the quality of palliative care through patient outcome measurement

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Jockey Club End-of-Life Community Care (JCECC)
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Overview

- An introduction to some important ideas
- Some evidence from Australia that the quality of care can be improved through patient outcome measurement
- Conclusions
 - To be further discussed at the workshop tomorrow

Palliative Care

- Primary goal is quality of life of a patient with an active and advanced life-limiting illness
- Delivered under the management of, or informed by, a clinician with specialised expertise in palliative care
- An individualised interdisciplinary assessment and management plan (and periodic reassessment)
 - Addressing the physical, psychological, emotional, social and spiritual needs of the patient and their carer/s

Health (patient) outcome

A change in an individual or group of individuals that can be attributed (at least in part) to an intervention or series of interventions

3 key ideas:

- change
- attribution
- intervention

Health outcome
 \neq
Health status

Efficacy and effectiveness

- **Efficacy** - the level of benefit expected when health services are applied under ideal conditions
 - Typically evaluated through a RCT
- **Effectiveness** - the level of benefit when a service is rendered under ordinary circumstances by average practitioners for typical patients
 - What we measure and aim to improve in PCOC

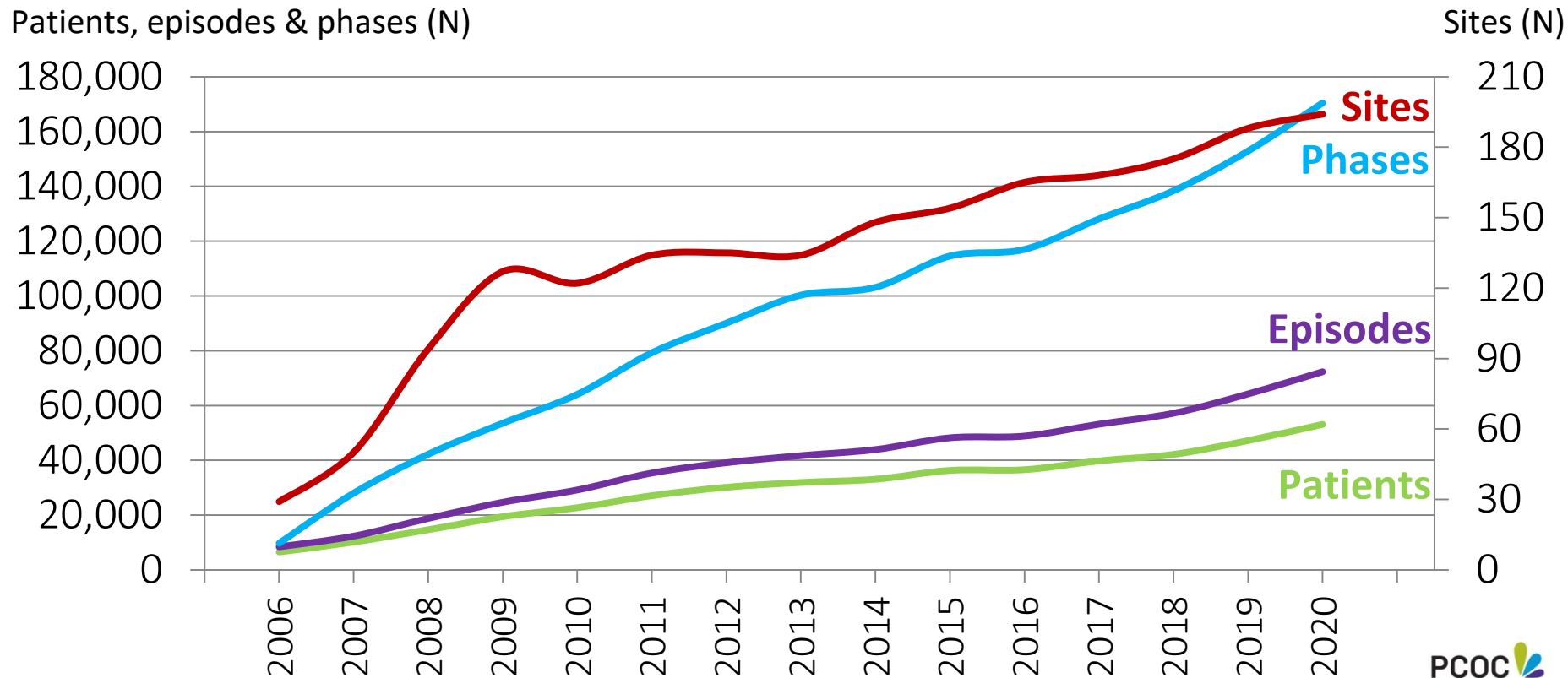
An introduction to the Australian Palliative Care Outcomes Collaboration

A national collaboration established in 2005

Development of PCOC

- Established in 2005 as four university collaboration
 - National palliative care outcome measures adopted in 2005
 - 5 clinical assessment tools
- National palliative care outcome benchmarks progressively from 2009 through sector consultation
- Version 4 of PCOC outcome assessment data set under development for introduction in 2023
- 53,000 patients with PCOC outcome measures in 2020 (~160,000 deaths per year in Australia)

All services in PCOC



The PCOC model

- PCOC aims to embed nationally standardised clinical assessments and point-of-care outcome measures into daily practice
 - Palliative care ‘vital signs’
- In order to drive quality and outcome improvement
 - With a feedback loop to individual services
 - Identifying service improvement opportunities and
 - Facilitating service to service benchmarking

PCOC is not a research project nor a data collection

- PCOC aims to improve outcomes for patients and families by changing palliative care clinical practice
- PCOC patient-reported outcome measures (PROMS) are collected every day at point of care &
- As a by-product, PCOC uses PROMS to drive improvements in patient outcomes and service effectiveness

Traditional Quality Improvement program logic

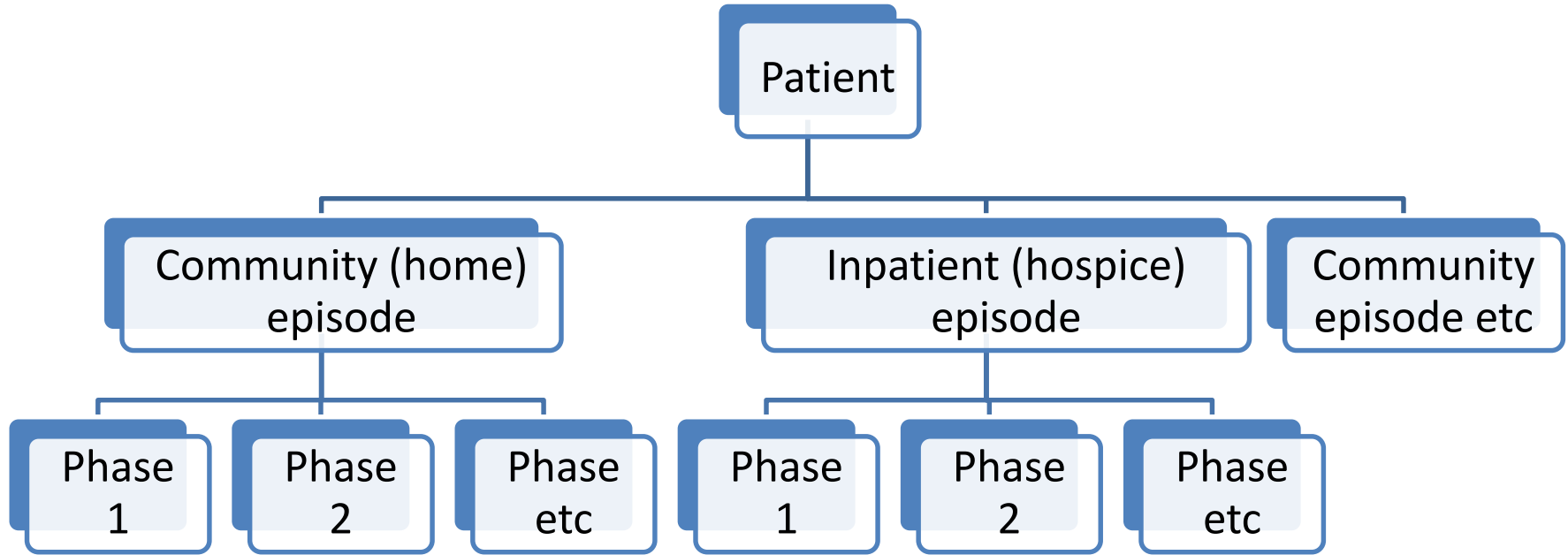
- ***Process improvement drives better patient outcomes***
- Traditional accreditation and quality assurance programs
 - Measure processes against standards
 - Identify processes for improvement and improve them
- Assume that good processes lead to good outcomes and that process improvement results in better outcomes

PCOC program logic

- ***Outcomes drive process improvement***
- Measure patient and carer outcomes against benchmarks
 - By asking patients and families as well as clinicians
- Use patient and carer outcome data to identify processes that could be better
- Repeat

Key concepts

A hierarchy of outcomes

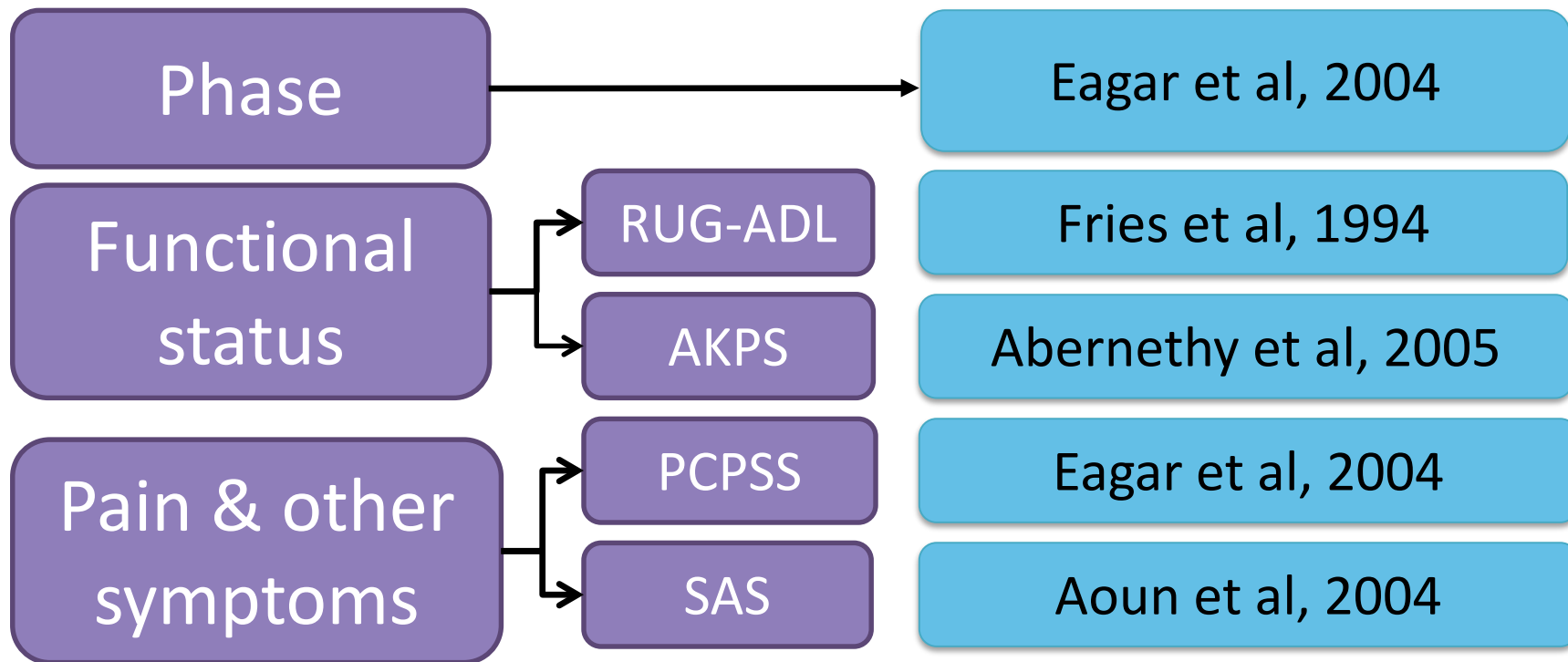


Unit of measurement

- Patients have one or more episodes of palliative care (defined by setting) – hospital/hospice or home
- Episodes of care consist of one or more Palliative Care Phases (stage of illness):
 - Stable
 - Unstable
 - Deteriorating
 - Terminal
- The 'outcome' is the change from beginning to end of each phase measured against the outcomes of comparable patients

Bereavement phase is out of scope

Five clinical assessment tools



Symptom distress or symptom severity?

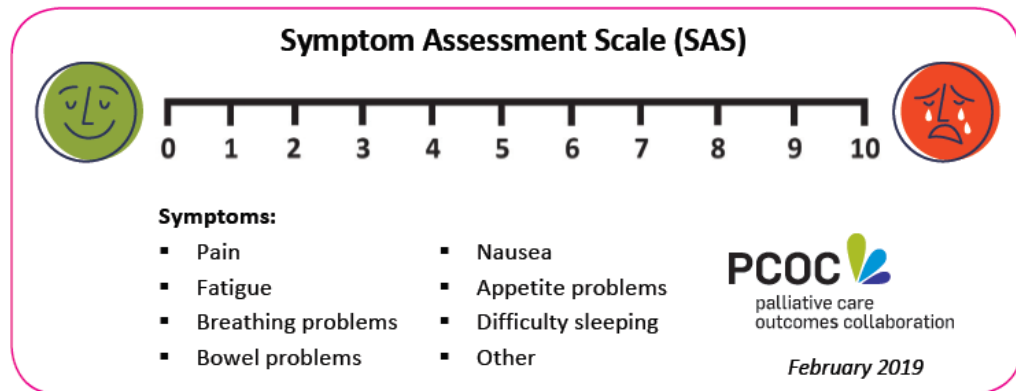
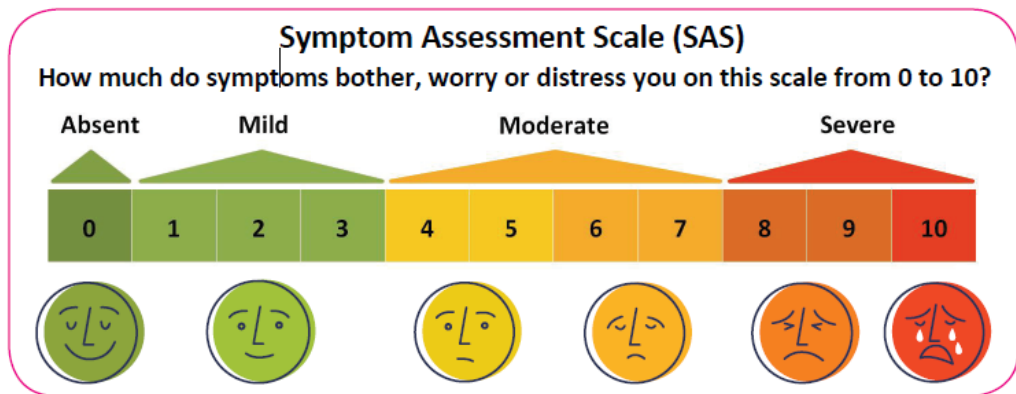
- Symptom Assessment Scale (SAS) measures patient **distress**
 - Patient-rated (or proxy)
- PC Problem Severity Score (PCPSS) rates symptom **severity**
 - Clinician-rated
- Challenges for international benchmarking
 - ESAS captures severity, SAS captures distress

A symptom ruler in every pocket

The 'Vital Signs' of
palliative care

Assessed at each home
visit and during every
shift in hospital







PCOC assessment and
response protocol



Guide for Daily Symptom Assessment Scale (SAS) by care workers

Instructions for use

1. Ask the Resident to tell you their symptom score
2. If Resident unable to tell you, use the descriptions below as a guide for the score
3. Respond as per actions

SYMPTOM	SAS SCORE GUIDE	ACTION
PAIN	Any discomfort, ache, soreness, stabbing, sharp or dull pain	
<div>0</div>  <div>1 - 3</div> 	Resident states there is no distress from pain OR does not show signs of distress from pain	No action
	Scores 1-3 or may appear slightly uncomfortable	Report to RN/Supervisor within shift
<div>4 - 7</div>  	Scores 4 to 7 OR shows signs of distress from pain such as groaning, moaning, or grimacing	Report to RN/Supervisor within 30 minutes
<div>8 - 10</div>  	Scores 8-10 OR shows a lot of distress from pain, such as crying, groaning, grimacing, holding or guarding parts of the body, either when lying or sitting, or on movement	Report to RN/Supervisor immediately

Outcome Measures

Focus is on individual patient outcomes regardless of the setting of care

There are **20** benchmarks:

1 benchmark on **timeliness of care**

1 benchmark on **responsiveness to urgent needs**

6 benchmarks on **pain management***

9 benchmarks on **symptom management***

3 benchmarks on **family/carers problems***

* some measures are case-mix adjusted

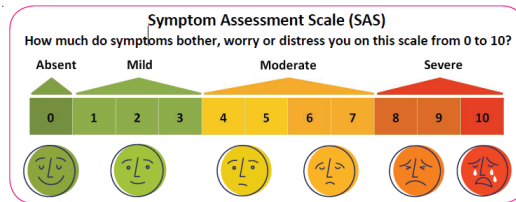
Some evidence from Australia

PCOC Australia 2020

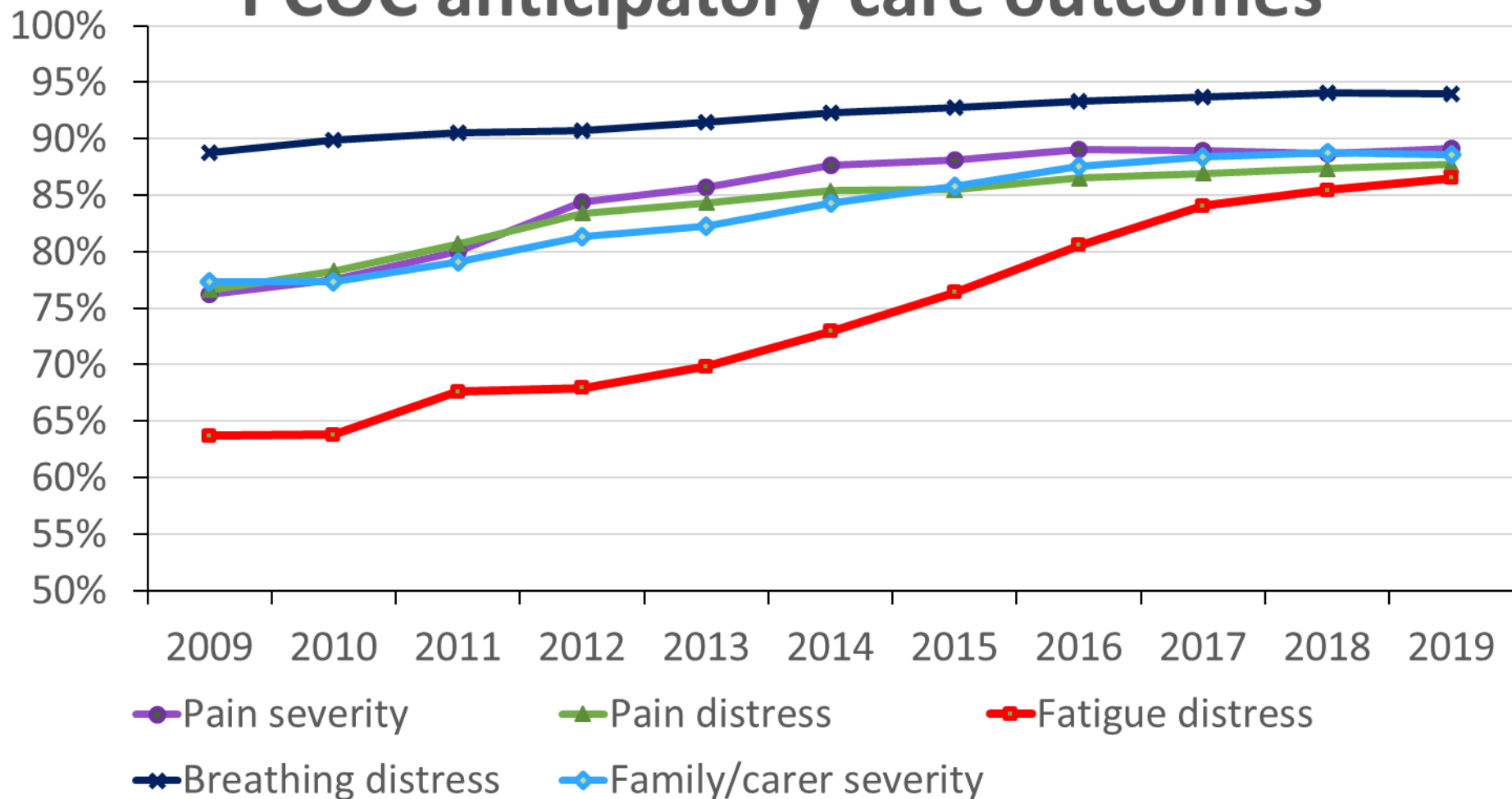
Measure		Total
Inpatient	Patients	28,083
	Phases	78,340
Community	Patients	28,125
	Phases	92,387
All settings	Patients	53,116
	Phases	170,727

Anticipatory care

- Care that anticipates the needs of the patient and their family (carers) and that prevents severe problems developing
- Percentage of patients with absent or mild symptoms who stay that way
- Starts with a green score, ends with a green score

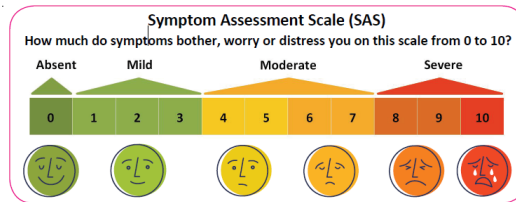


PCOC anticipatory care outcomes

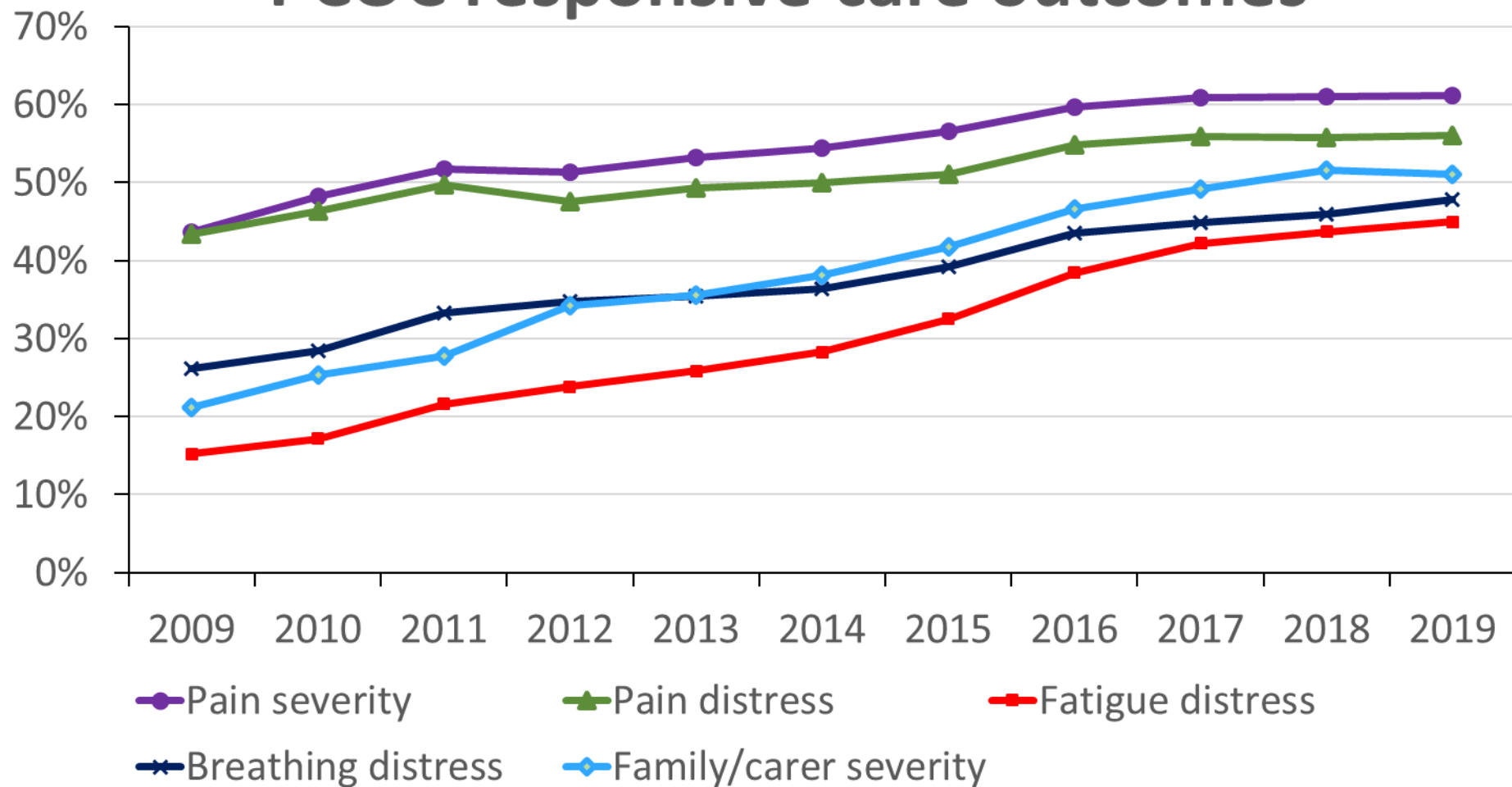


Responsive care

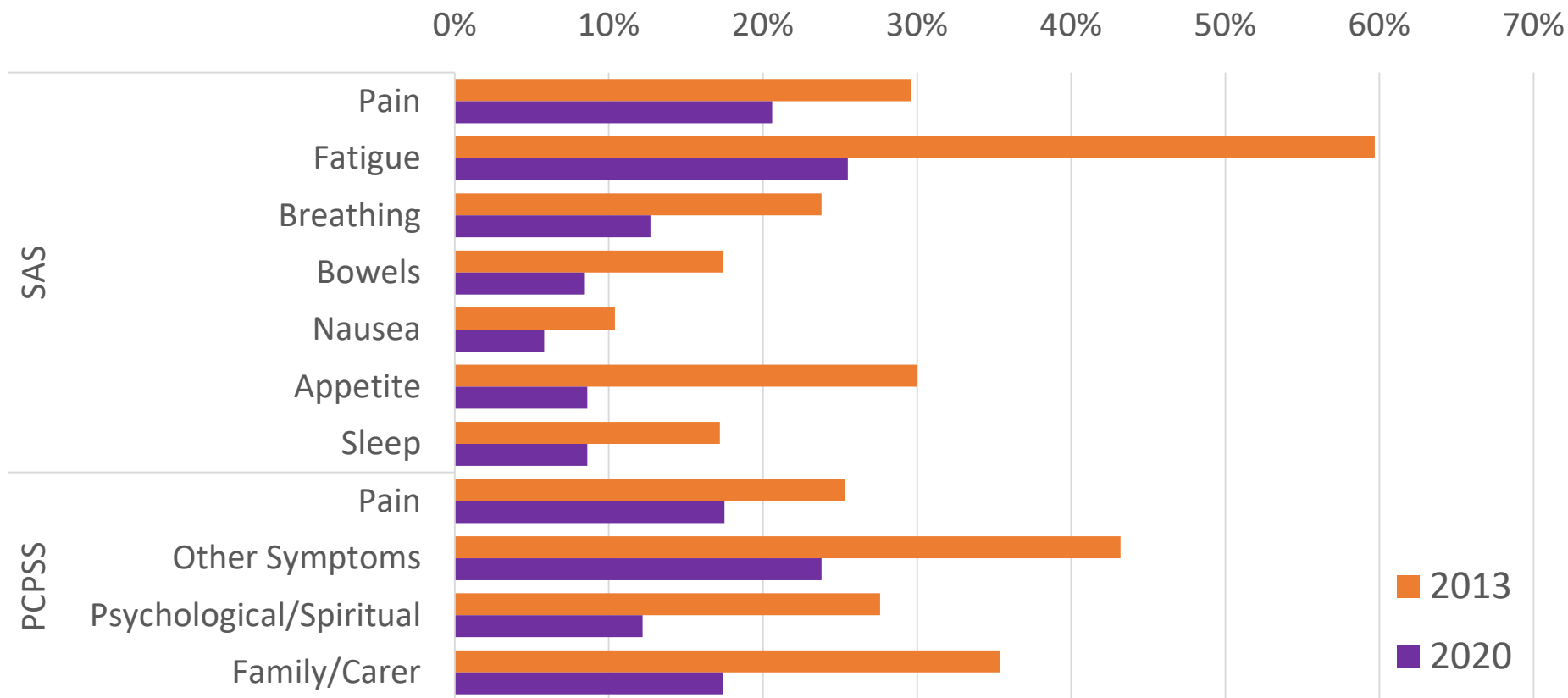
- Care provided to patients with moderate or severe symptoms
- Percentage of patients with moderate to severe symptoms who have absent or mild symptoms at phase end
- Starts with an orange or red score, ends with a green score



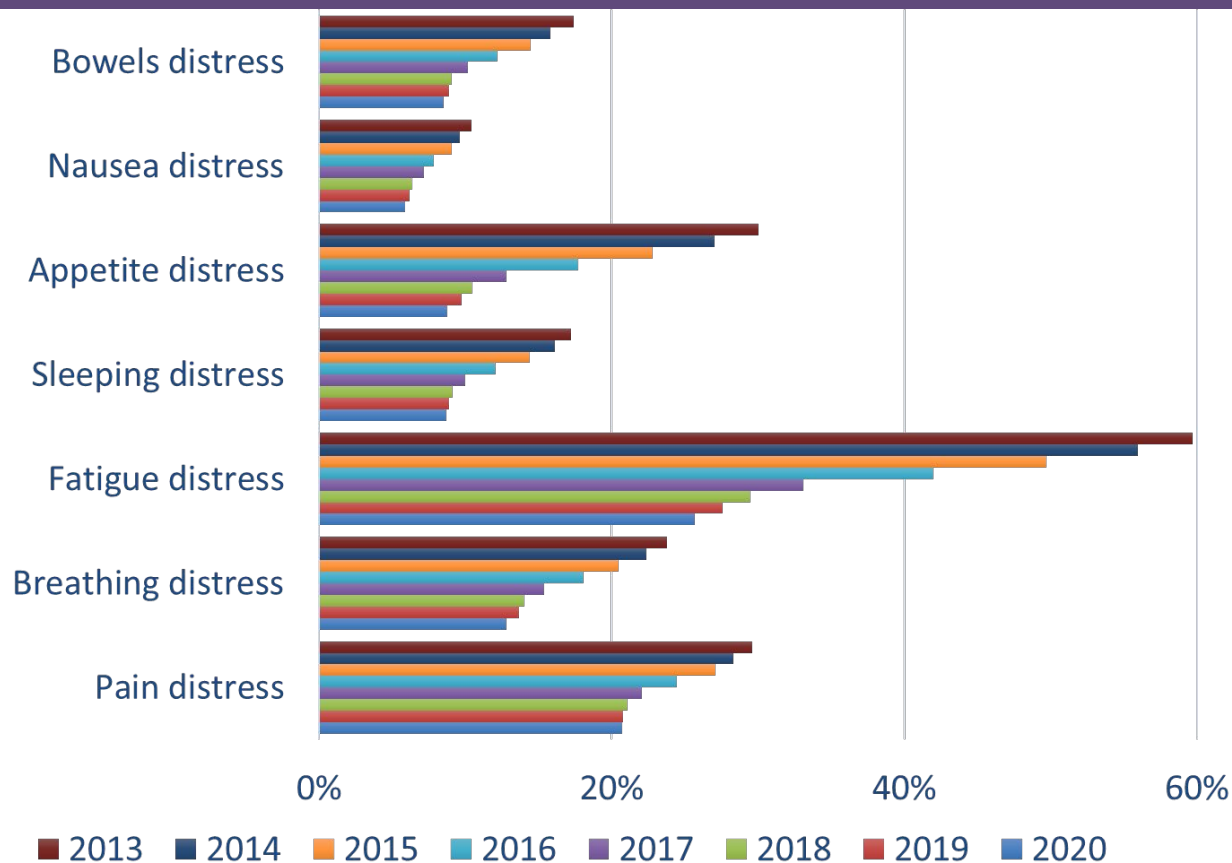
PCOC responsive care outcomes



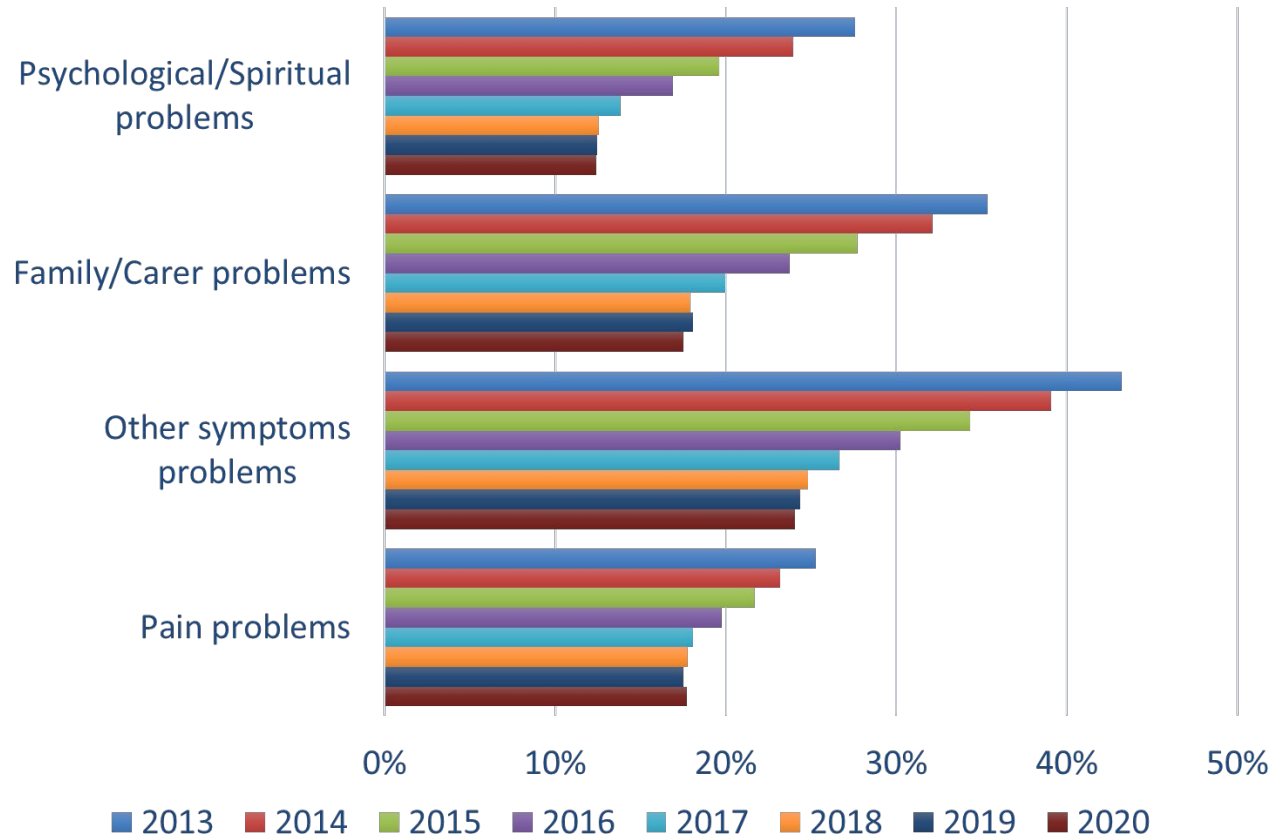
Patients with moderate to severe symptoms or distress at phase start



Patients with moderate to severe distress over time



Patients with moderate to severe symptoms over time



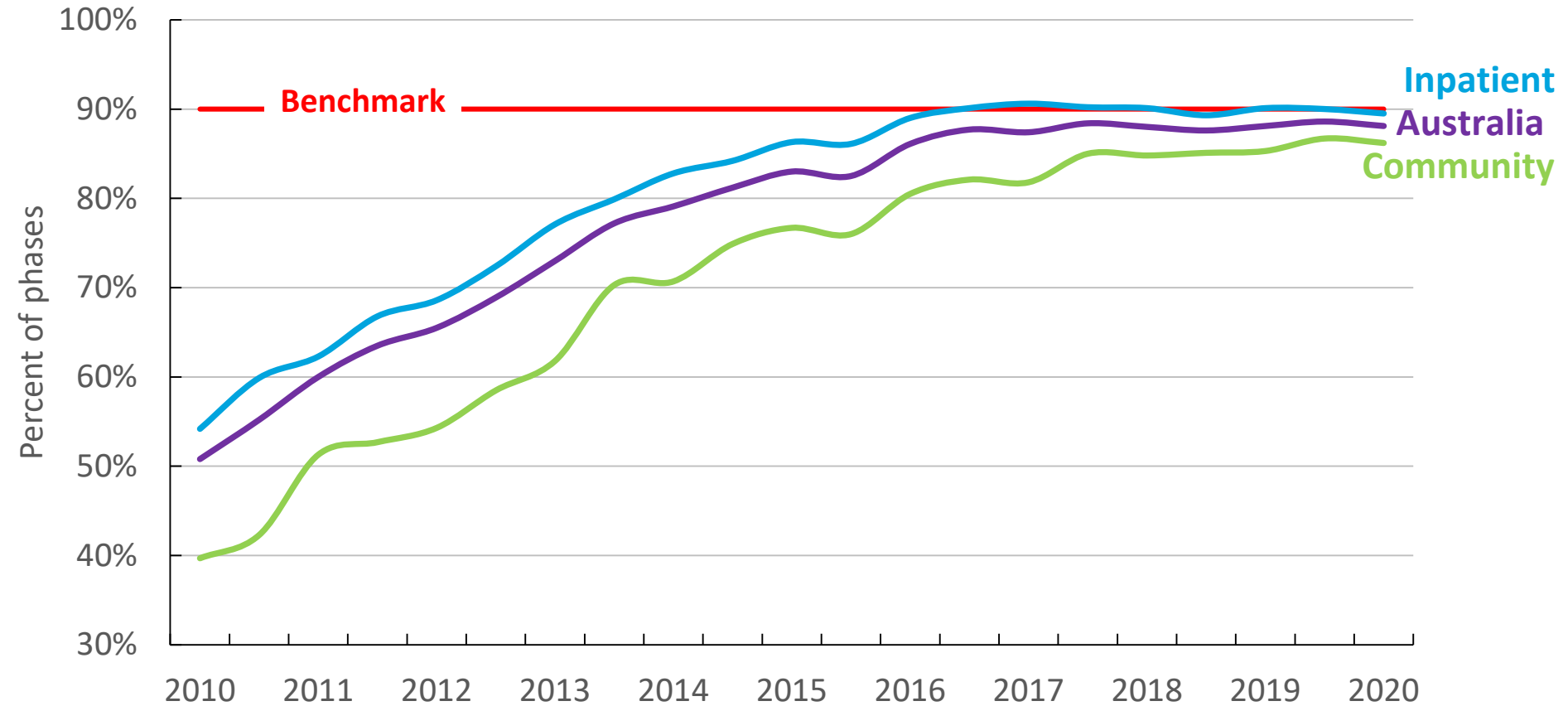
Outcome Measure 2

90% of patients in the unstable phase for 3 days or less

An unstable phase is triggered if an urgent change in the plan of care or emergency treatment is required because

- **Patient** experiences a new problem that was not anticipated in the existing plan of care, and/or
- **Patient** experiences a rapid increase in the severity of a current problem; and/or
- **Family/ carers** circumstances change suddenly impacting on patient care.

% patients unstable 3 days or less



What we have learned

To be discussed in more detail at the
workshop tomorrow

The easy part is selecting the measures

- We spent a lot of time in the early years selecting measures and establishing collection systems
- We did not spend enough time thinking about how to change clinical practice
 - We made an assumption that, if clinicians were given data on their outcomes, they would know how to improve their practice
 - Very few did, most did not

Choice is important

- Patients and families have the right to choose their place of care and place of death
- Evidence on outcomes across settings is integral for patients to make informed choices
 - So we have the same assessment tools and benchmarks across all settings of care and across both public and private sectors



The Outcomes Gap

- Patients who die in hospital are 51% more likely to have no moderate or severe symptoms just prior to death compared to similar patients who die at home
 - Odds ratio 1.51 (confidence interval 1.27-1.78)
- Outcomes have improved significantly over the last 15 years in both inpatient and community settings
 - But the gap between them has not closed

There is more to do

- Patient and carer outcomes continue to improve
 - No evidence that improvements are plateauing
- A population approach
 - PCOC currently reports on ~50% of all predictable deaths in Australia
 - Goal is to progressively expand to develop a population-level picture of palliative and end of life care in Australia

International partnerships and benchmarking

- Australian services are interested in benchmarking against international best practice
- Growing international interest in Australian PCOC model
 - PCOC is providing our material free of charge to other countries - see our PCOC website
 - Ireland and Taiwan are already benchmarking with us
 - Other countries (Canada, Singapore, Japan) at various stages
- We would welcome a collaboration with Hong Kong