

# Workshop: improving the quality of palliative care through patient outcome measurement

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Jockey Club End-of-Life Community Care (JCECC)  
International Conference, Hong Kong  
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# Outline of the workshop

- A reminder of key ideas from yesterday
- Three big questions
- How to develop a national system
  
- I welcome questions and comments
  - use the Q&A function and we can talk

# A reminder of some key ideas from yesterday

Please use the Q&A function to ask a question or make a comment

# 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

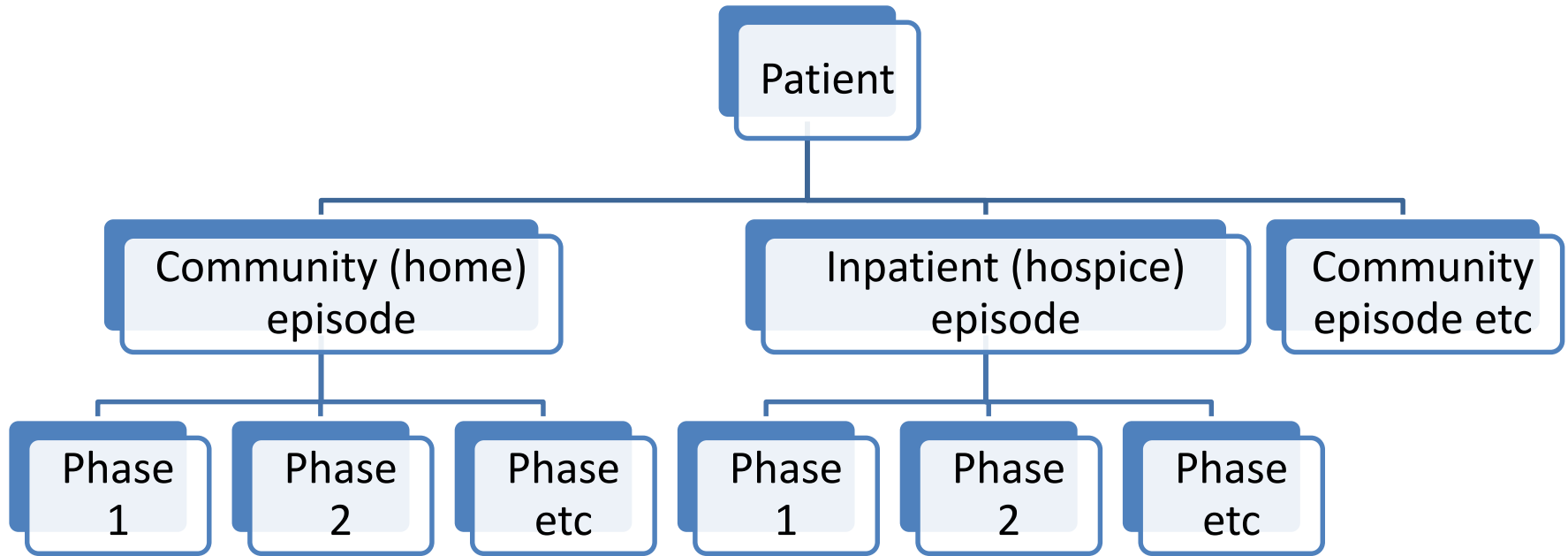
3 key ideas:

- change
- attribution
- intervention

*Health outcome*  
 $\neq$   
*Health status*

*Do you want to measure outcomes or just health status?*

# A hierarchy of outcomes



*At what level do you want to measure outcomes?*

# 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\***

***What outcomes are important in the work you do?***

\* some measures are case-mix adjusted

# Symptom distress or symptom severity?

## Australian approach

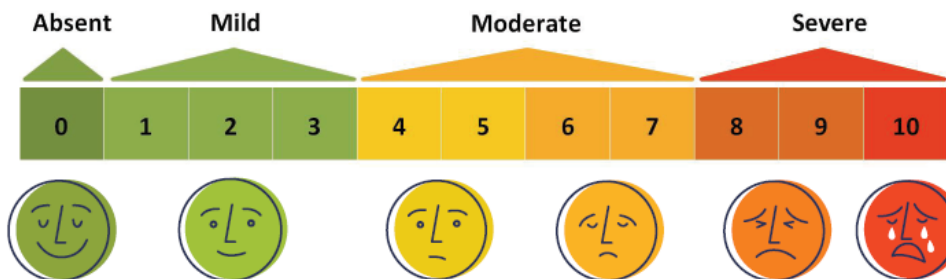
- Symptom Assessment Scale (SAS) measures patient **distress**
  - Patient-rated (or proxy)
- PC Problem Severity Score (PCPSS) rates symptom **severity**
  - Clinician-rated
- Challenges for international benchmarking
  - ESAS captures severity, SAS captures distress

*Do you want to  
measure  
symptom distress  
or severity?  
Patient rated or  
clinician rated?*

# A symptom ruler in every pocket

## Symptom Assessment Scale (SAS)

How much do symptoms bother, worry or distress you on this scale from 0 to 10?



*Do you want to  
adopt standard  
response  
protocols?*

## Symptom Assessment Scale (SAS)



### Symptoms:

- Pain
- Fatigue
- Breathing problems
- Bowel problems
- Nausea
- Appetite problems
- Difficulty sleeping
- Other

**PCOC**  
palliative care  
outcomes collaboration







February 2019



# 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
<b>PAIN</b>	<b>Any discomfort, ache, soreness, stabbing, sharp or dull pain</b>	
<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 <b>within shift</b>
<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 <b>within 30 minutes</b>
<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 <b>immediately</b>

# Three big questions

Please use the Q&A function to ask a question or make a comment

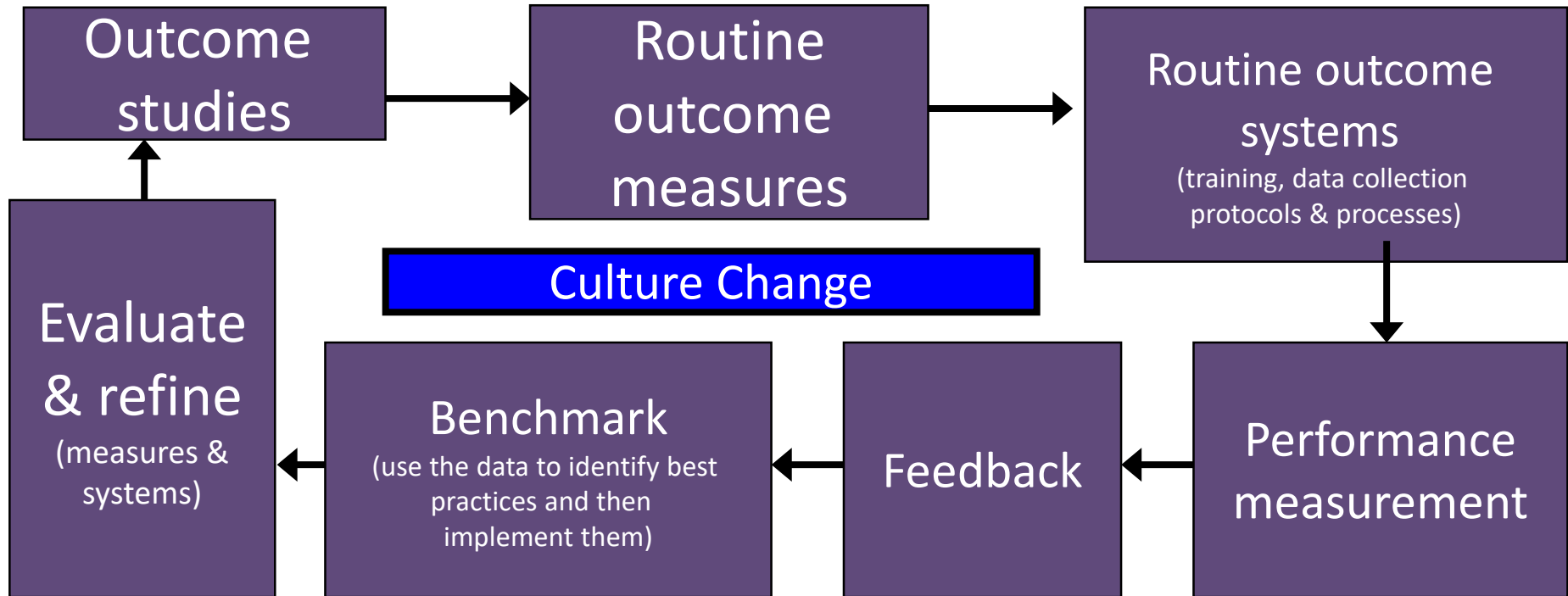
# Three big questions

- (1). What do decision makers, clinicians and patients already know about palliative care patient and carer outcomes in Hong Kong?
- (2) What should decision makers, clinicians and patients ideally know about palliative care patient and carer outcomes in Hong Kong?
- (3) What practical steps can Hong Kong take to improve the evidence on patient and carer outcomes in Hong Kong?

# How to develop a national system

Based on our PCOC experience

# The benchmarking cycle



# Where we started: small research studies

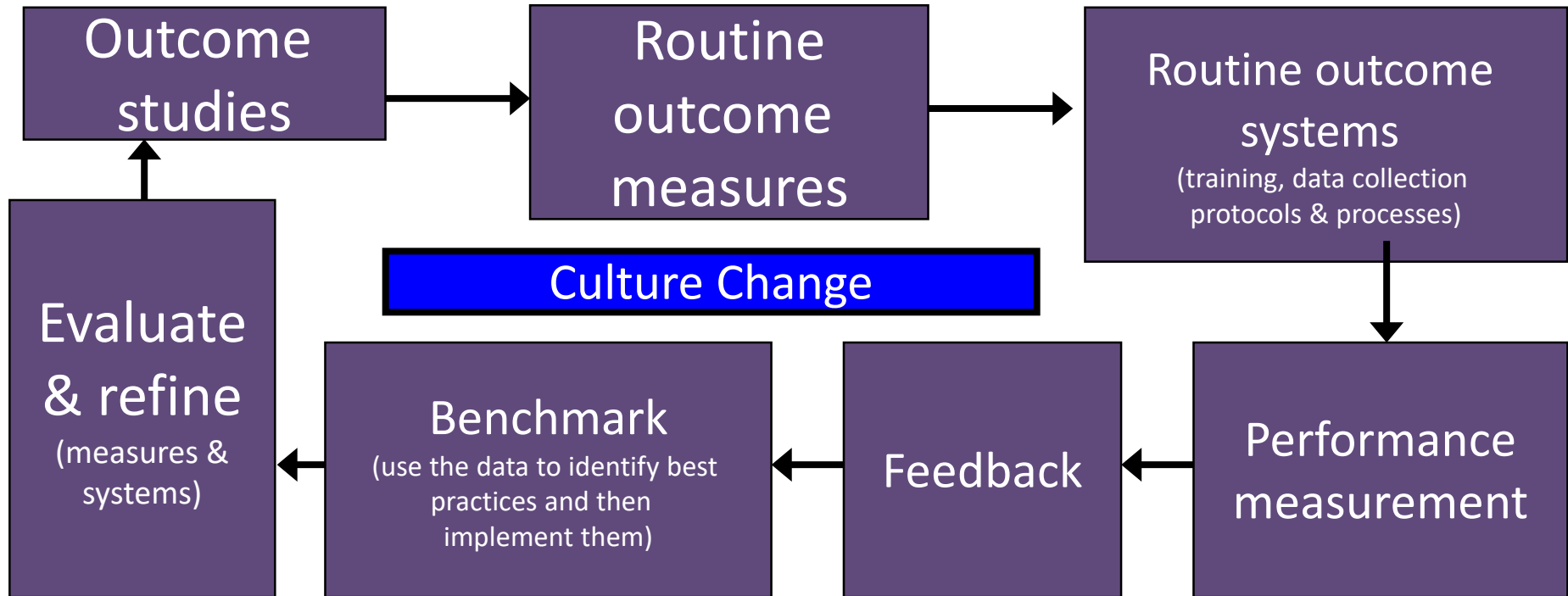
Outcome  
studies



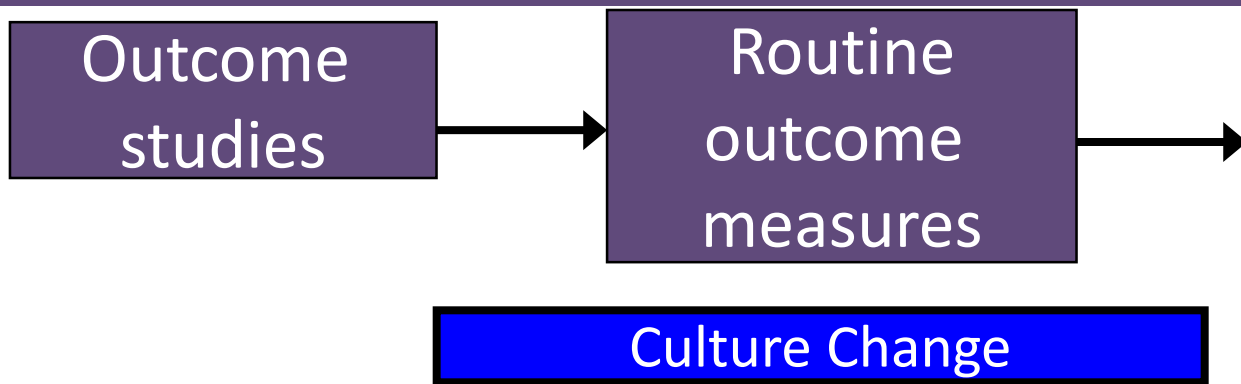
Culture Change

*What outcome studies have already been undertaken that are relevant for the work you do? What were their key findings?*

# The benchmarking cycle



# Select routine outcome measures





# Why collect measures?

## (what is the unit of counting for each?)

- To describe
  - Sociodemographic, diagnoses
- To measure patient and carer outcomes
  - Phase, physical symptoms, psychosocial & family distress, Quality of Life
- To adjust / standardize outcome measures (compare like with like)
  - Phase, function, other?
- To report on process measures and/or service utilisation
  - Including patient experience/satisfaction

# To describe patient and carers

- What is already being collected
  - For what purposes?
- Where are the gaps, what needs to be collected
  - For what purposes?

# To measure patient and carer outcomes

## Phase, physical symptoms, psychosocial & family distress

- What is already being collected
  - For what purposes?
- Where are the gaps, what needs to be collected
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# To report on process measures and/or service utilisation? Including patient experience/satisfaction

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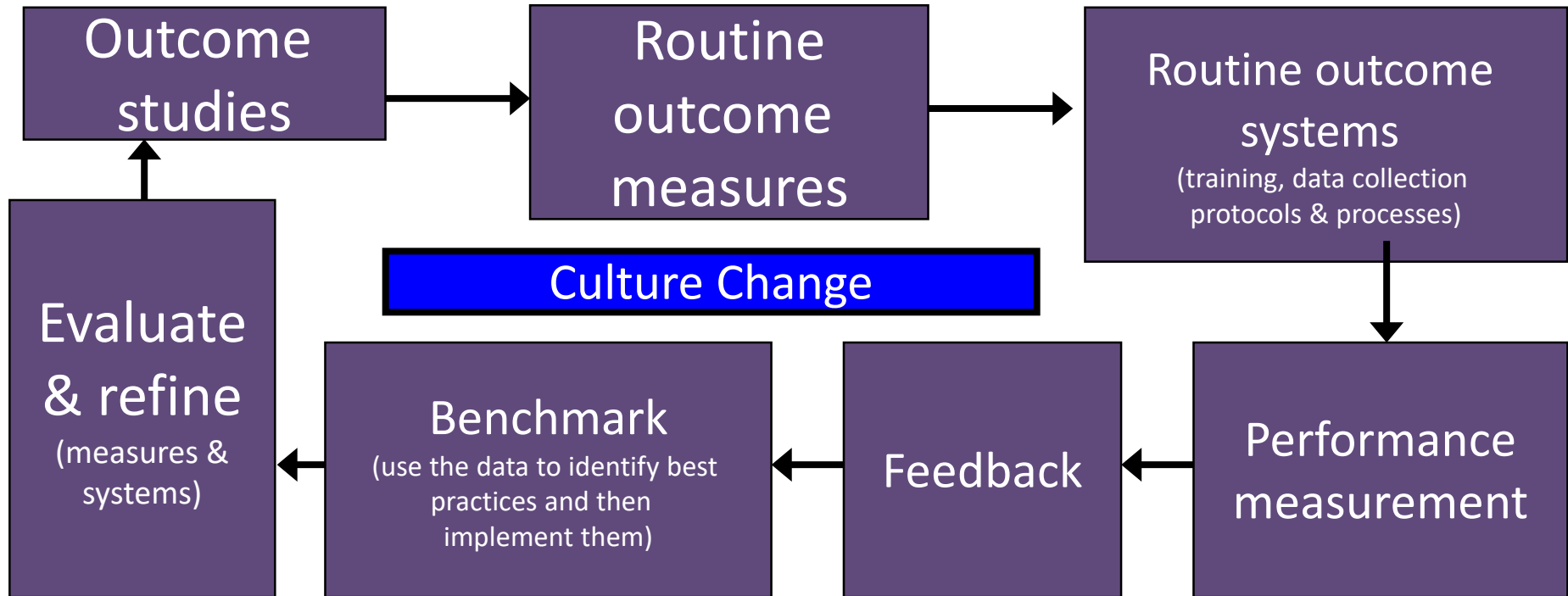
# To adjust / standardize outcome measures (compare like with like): phase, function, other?

- What is already being collected
  - For what purposes?
- Where are the gaps, what needs to be collected
  - For what purposes?

# Quality of life (QoL): an outcome measure?

- What is already being collected
  - For what purposes?
- Where are the gaps, what needs to be collected
  - For what purposes?

# The benchmarking cycle





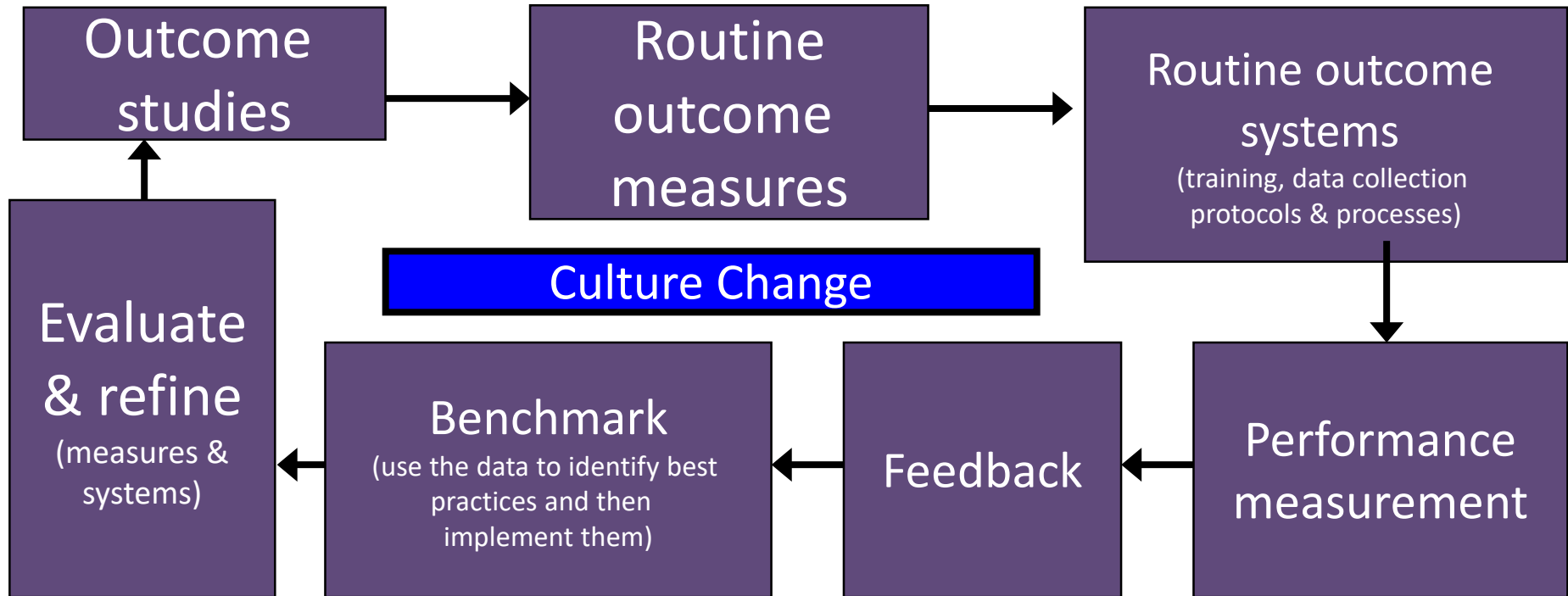


# Routine outcome systems

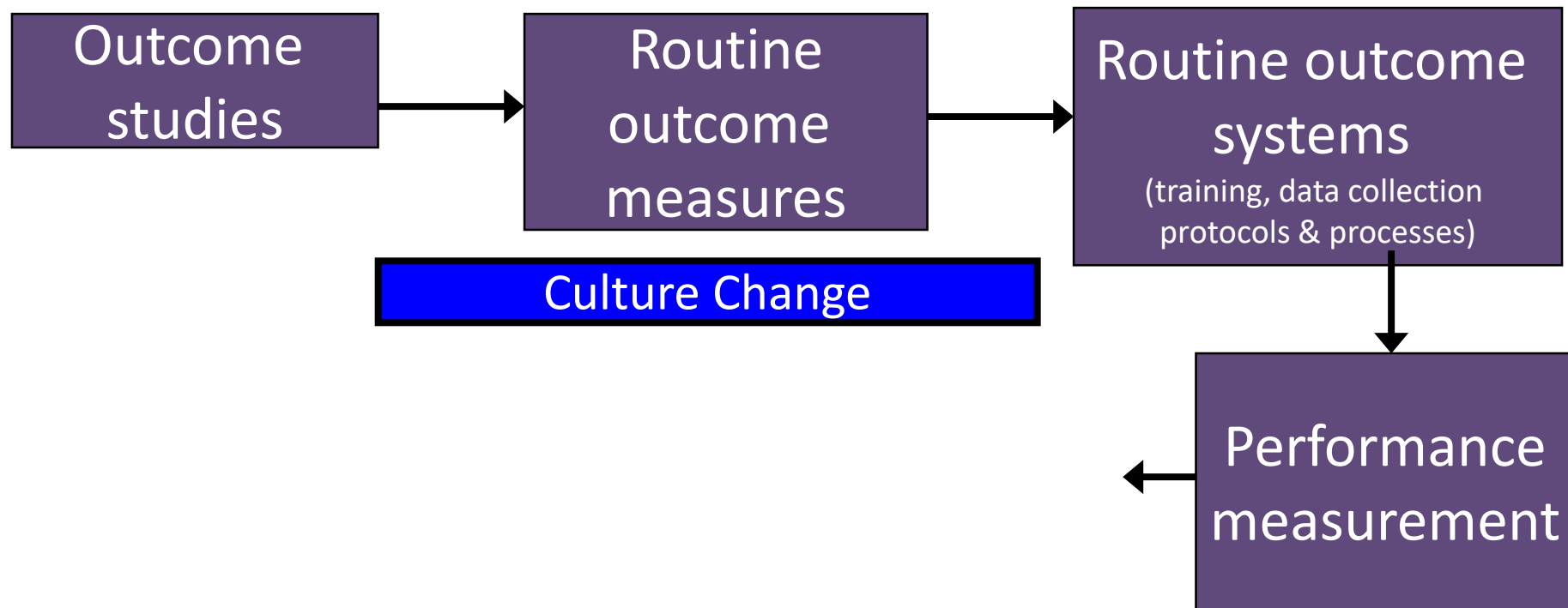
If you decide to introduce patient and family outcome measures:

- What training will be required?
  - Who would develop and deliver it?
- What data collection protocols & processes would need to be developed?
  - How would these best be developed?

# The benchmarking cycle



# Measure outcomes

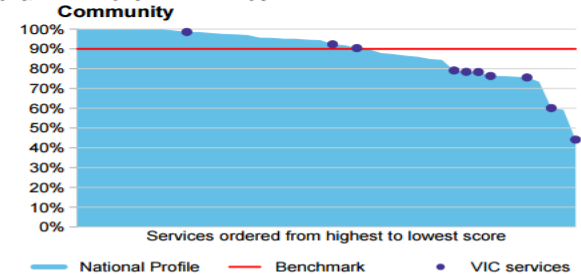
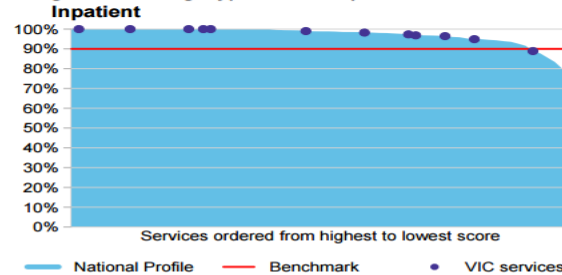


# PCOC Reports and Benchmarking

- PCOC six monthly reports
- A unique report for each service and jurisdiction

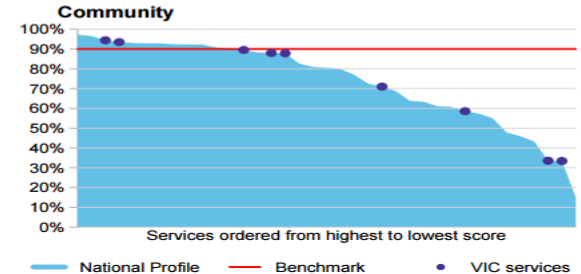
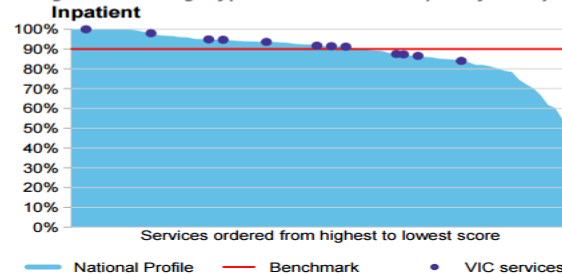
Outcome measure 1 – Time from date ready for care to episode start

Figure 1 Percentage of patients with episodes that commenced on the day of, or the day after date ready for care

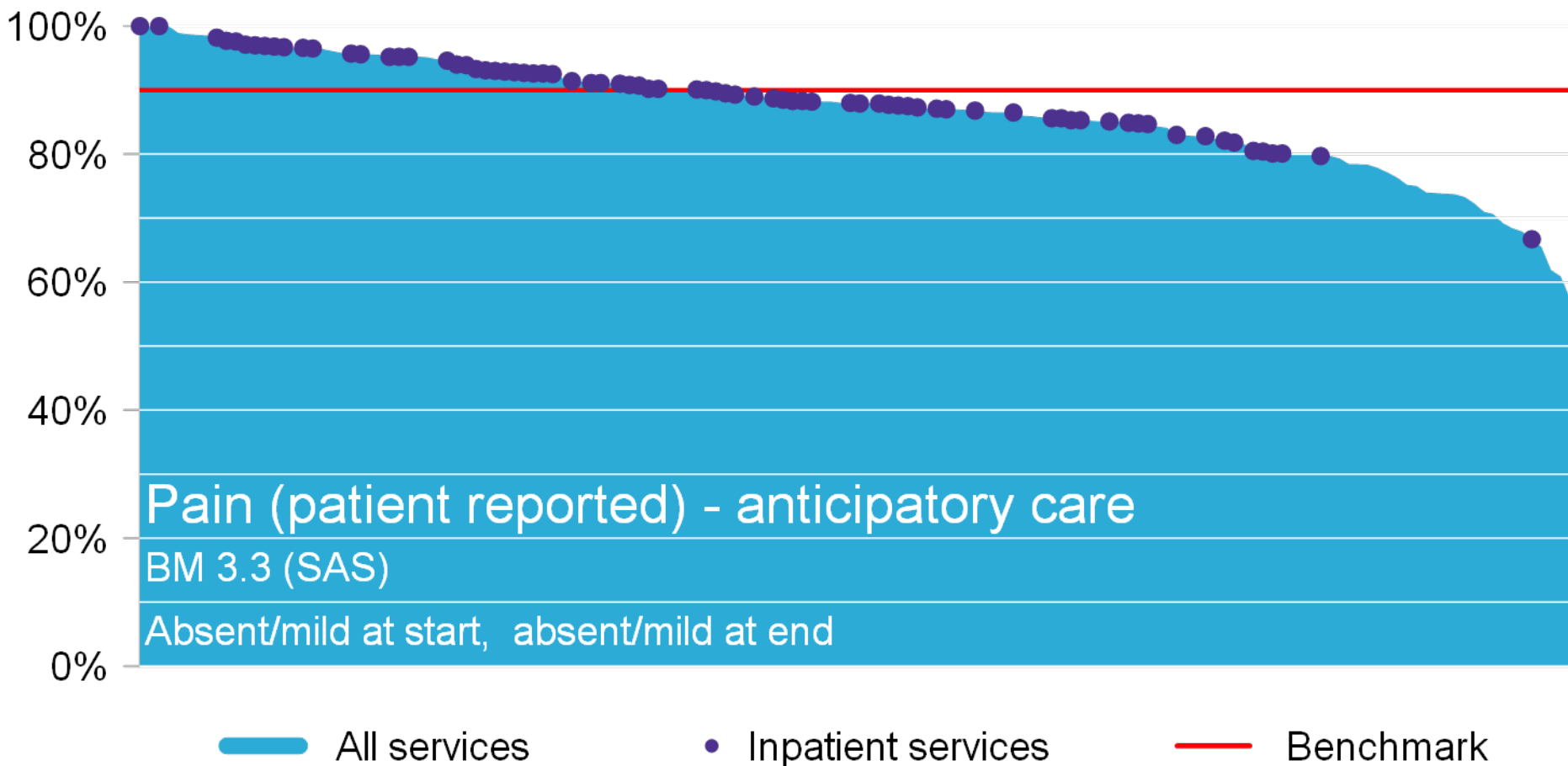


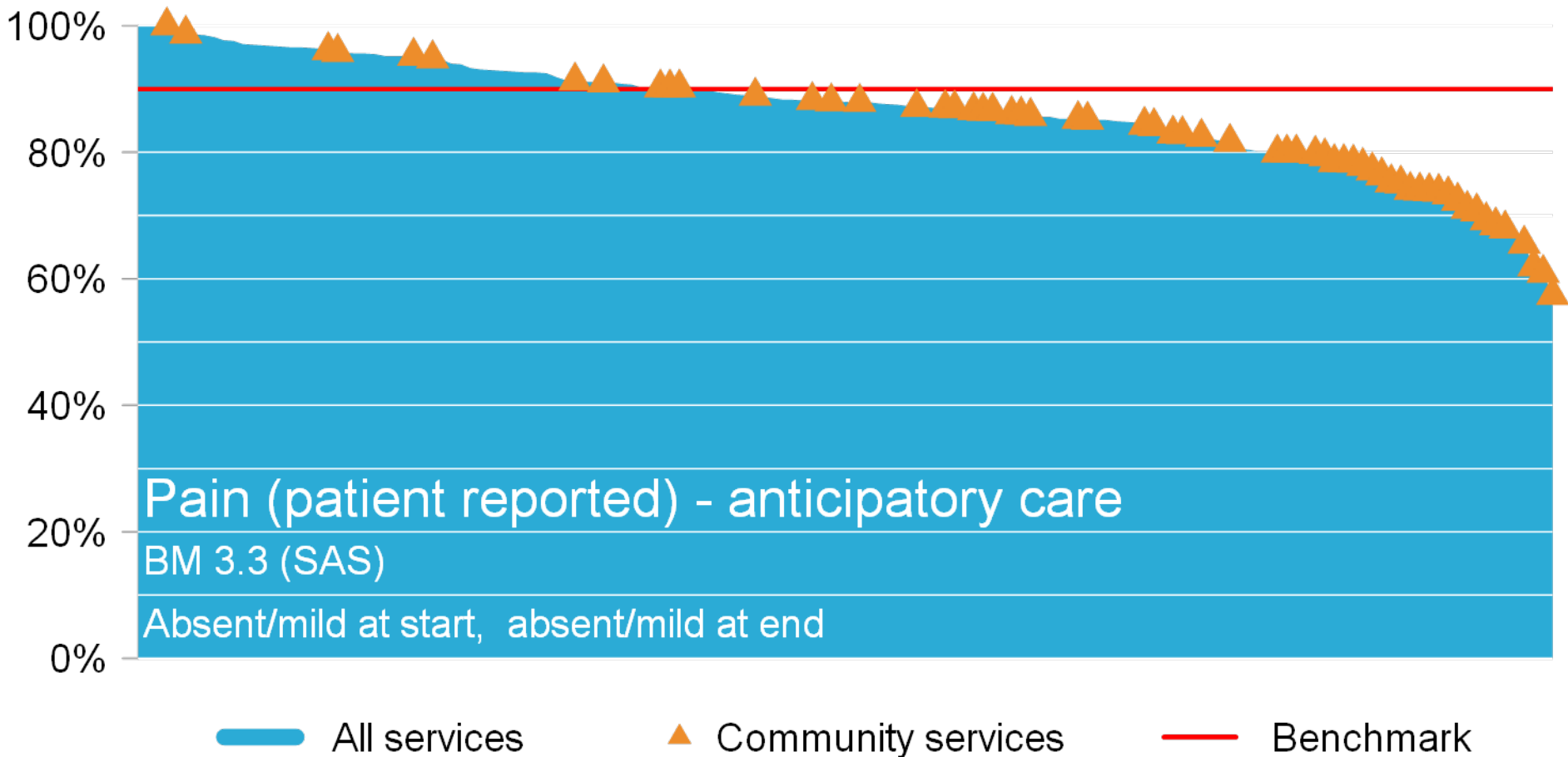
Outcome measure 2 – Time in unstable phase

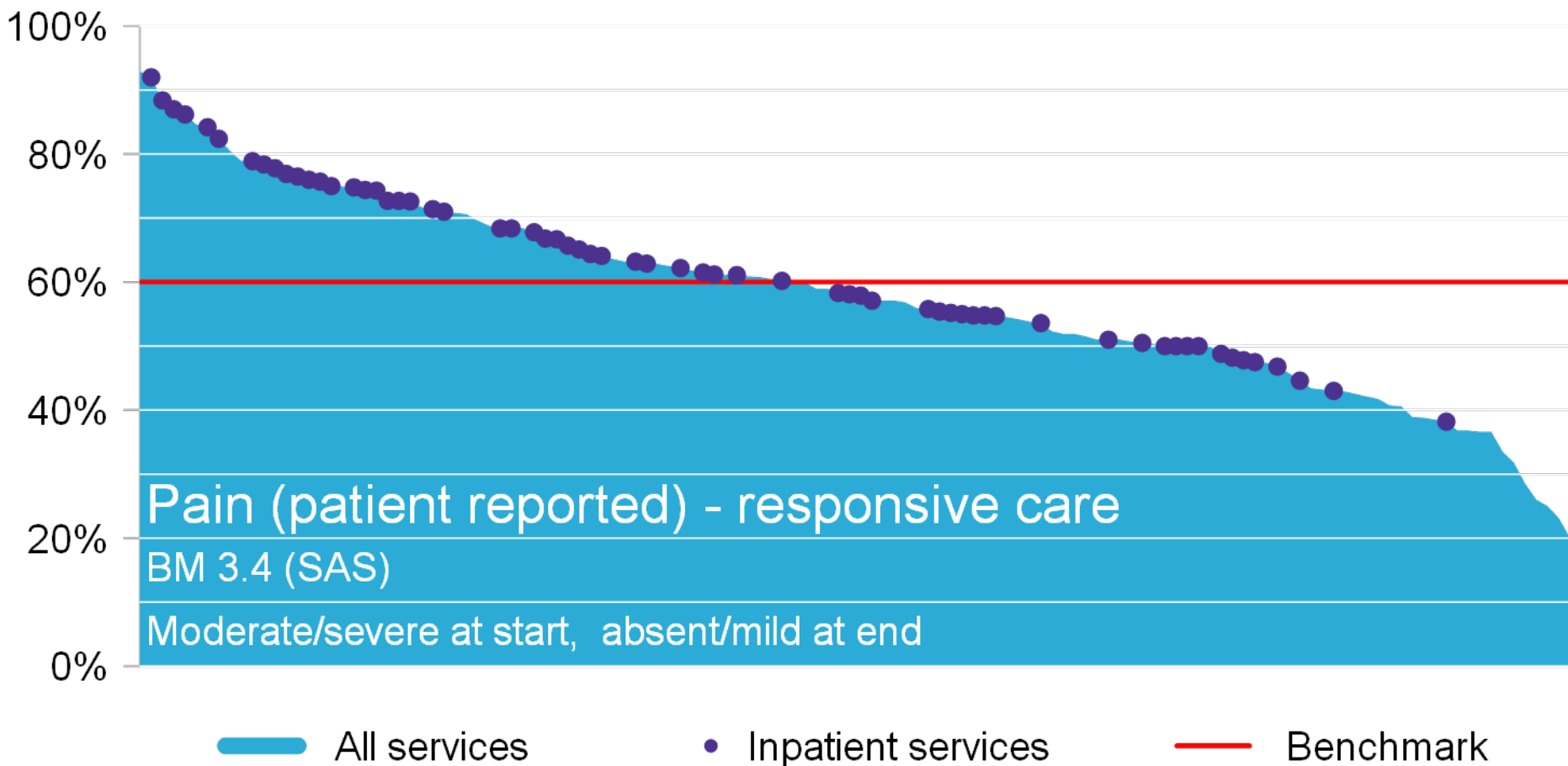
Figure 2 Percentage of patients in the unstable phase for 3 days or less

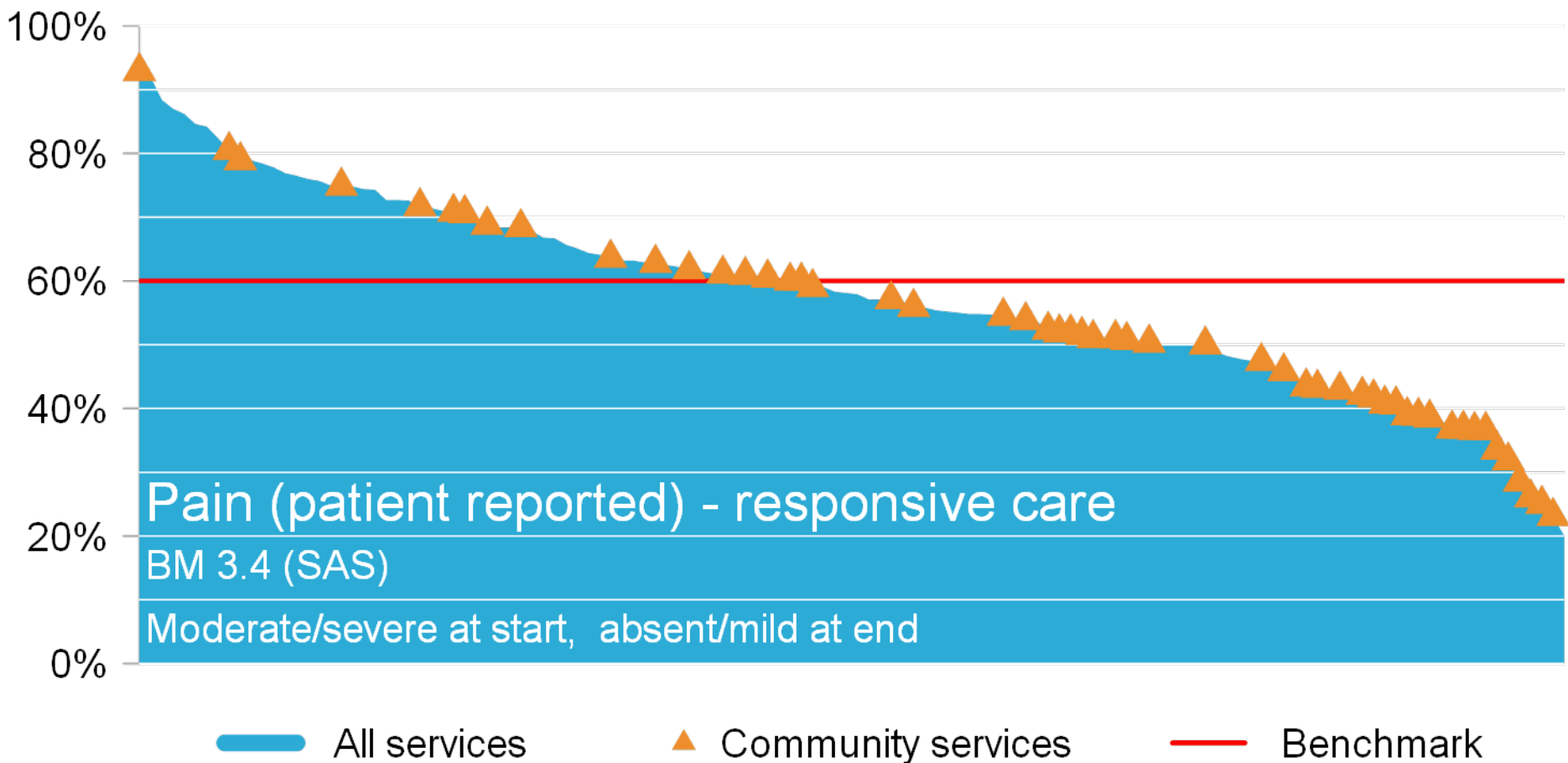


outcomes colla











# Casemix adjusted outcomes

- Casemix adjusted scores for benchmarking pain and symptoms
- Change in pain & symptom depends on where you start
- Measure controls for phase type & start score
- Investigating ways to improve measure i.e. setting of care and diagnosis.

# Change in pain & symptoms depends on where you start

Phase	SAS Pain at Start	Average change
Stable	0	-1.26
	1	-0.74
	2	-0.81
	4	-0.50
	5	0.34
	6	0.56
	7	1.24
	8	1.84
	9	2.20
	10	2.60

So, need a composite measure to control for both phase type & start score

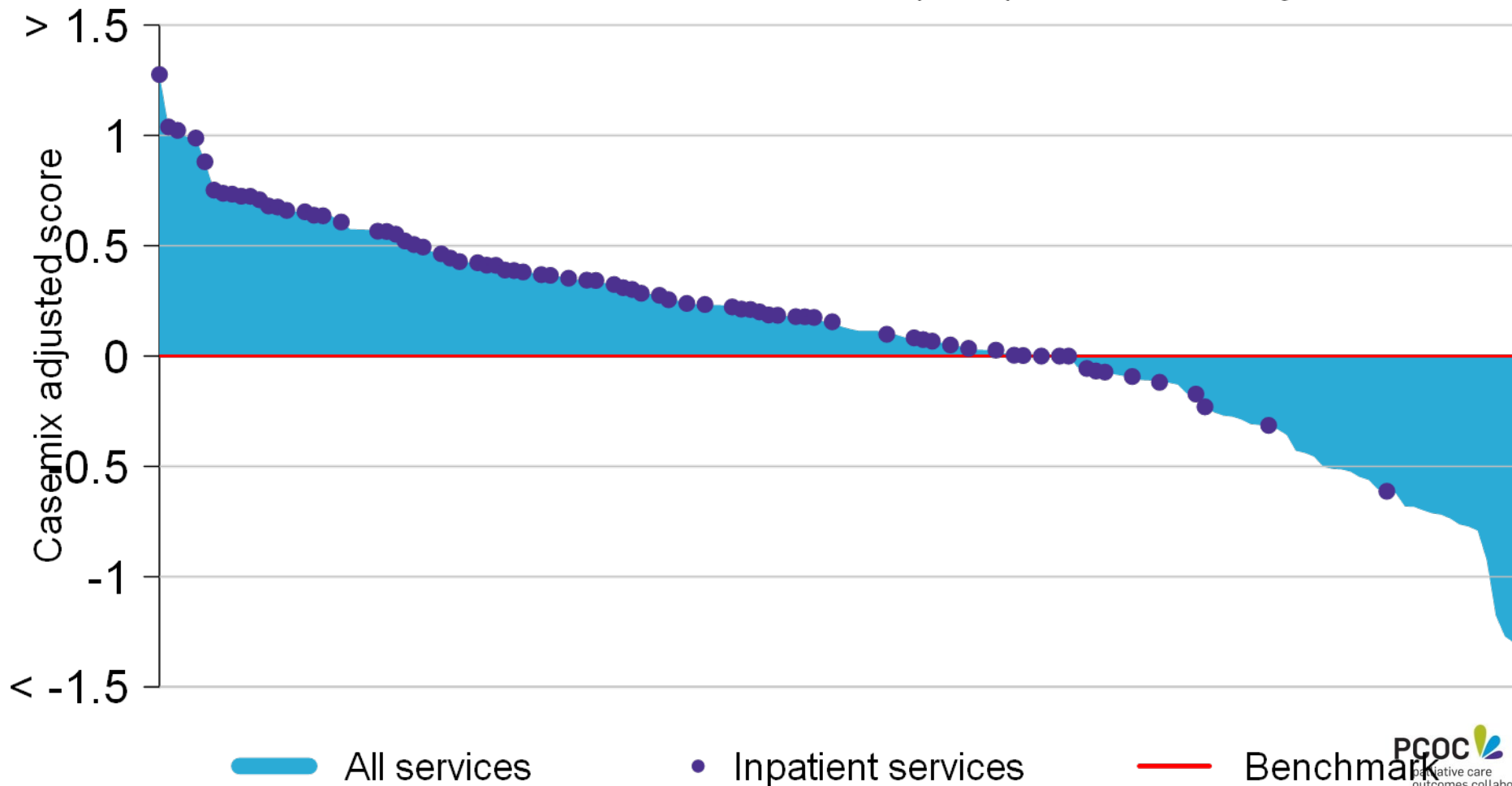
Negative= pain gets worse

Positive = pain gets better

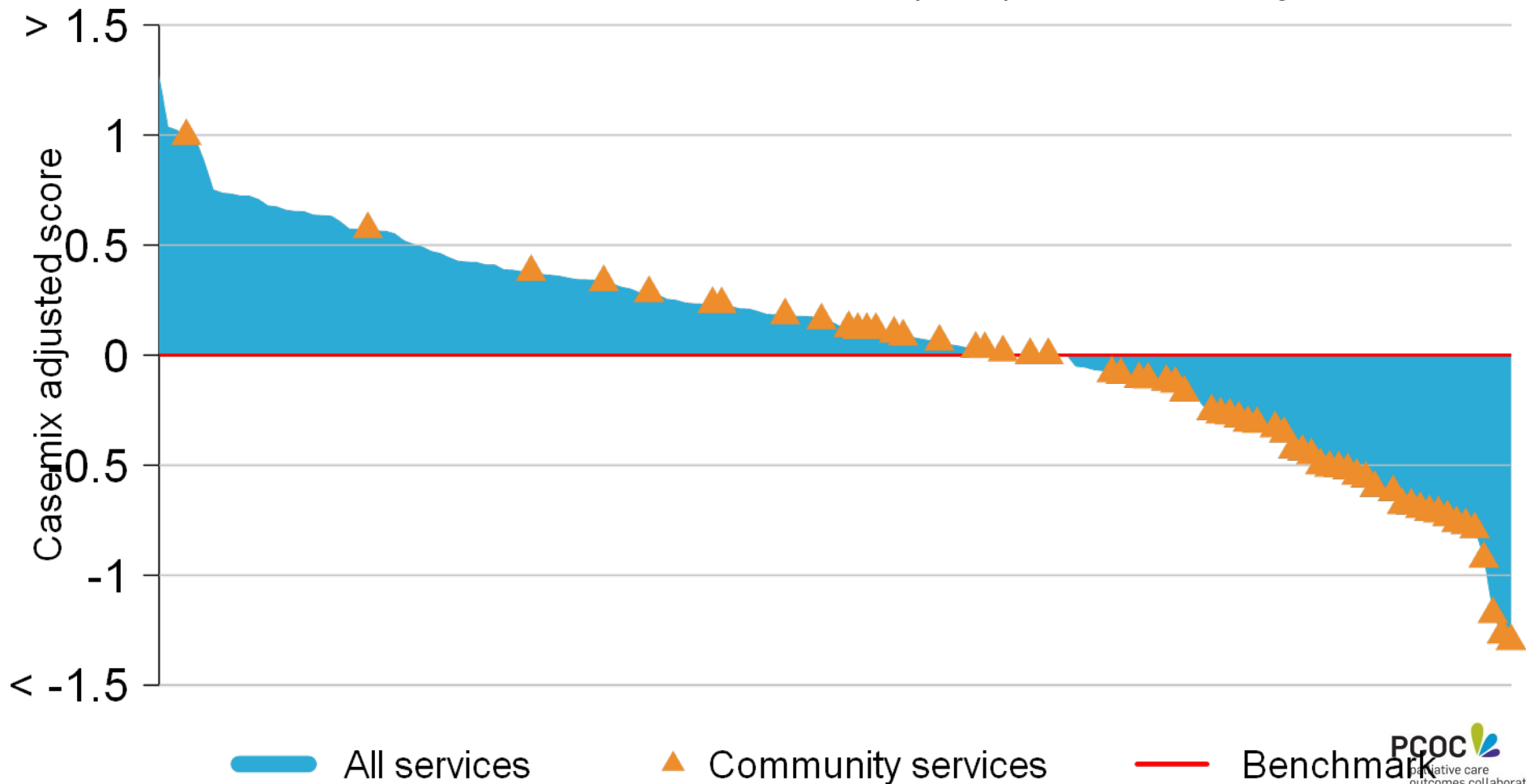
# Understanding casemix adjusted scores

- Greater than 0
  - > on average, patients' change in pain/symptom score was **better** than similar patients in the reference period.
- Equal to 0
  - > patients pain/symptom score changed **about the same** as similar patients in the reference period.
- Less than 0
  - > patients' change in pain/symptom score was **worse** than similar patients in the in the reference period

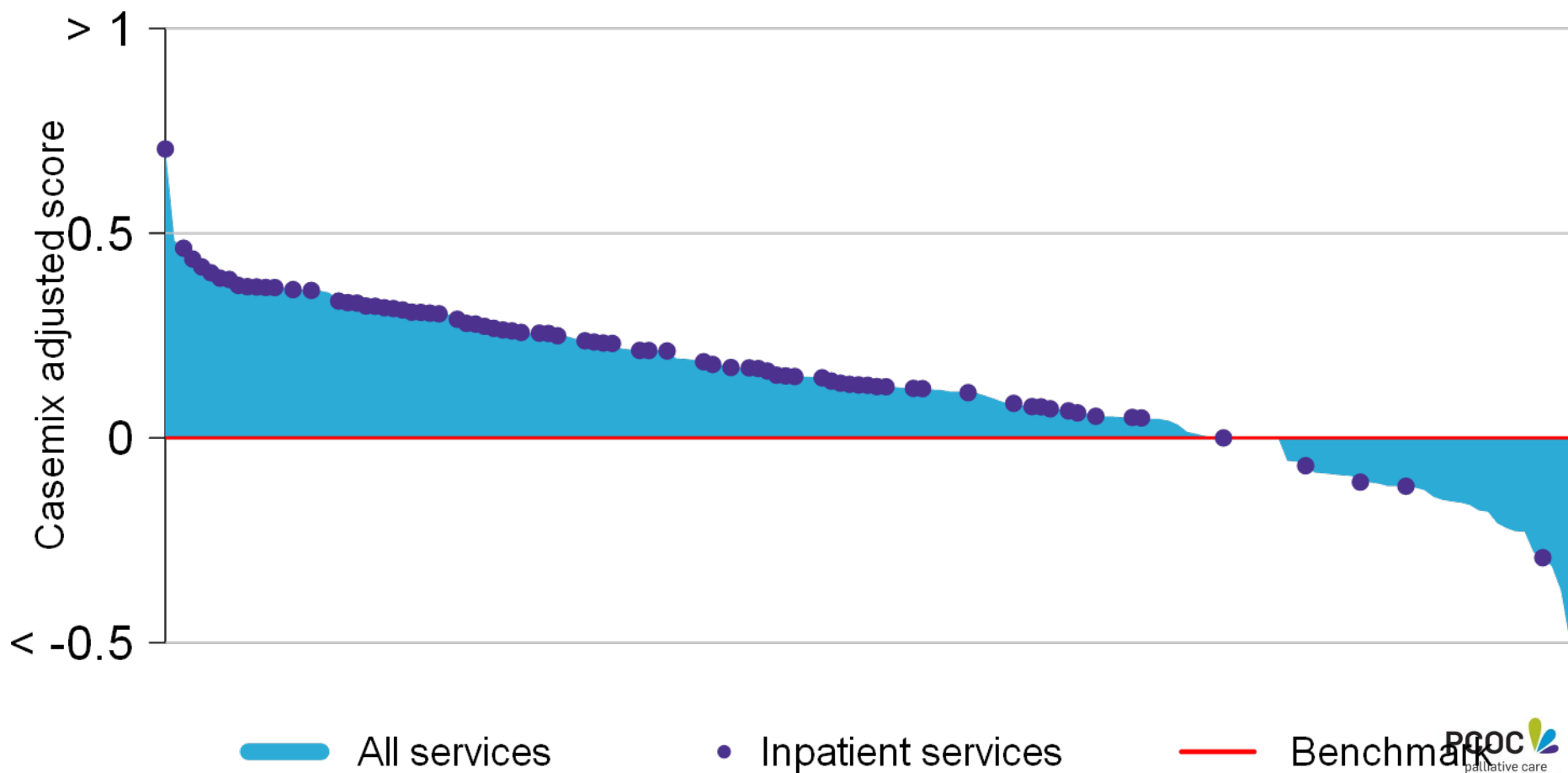
## Pain (SAS) - casemix adjusted score



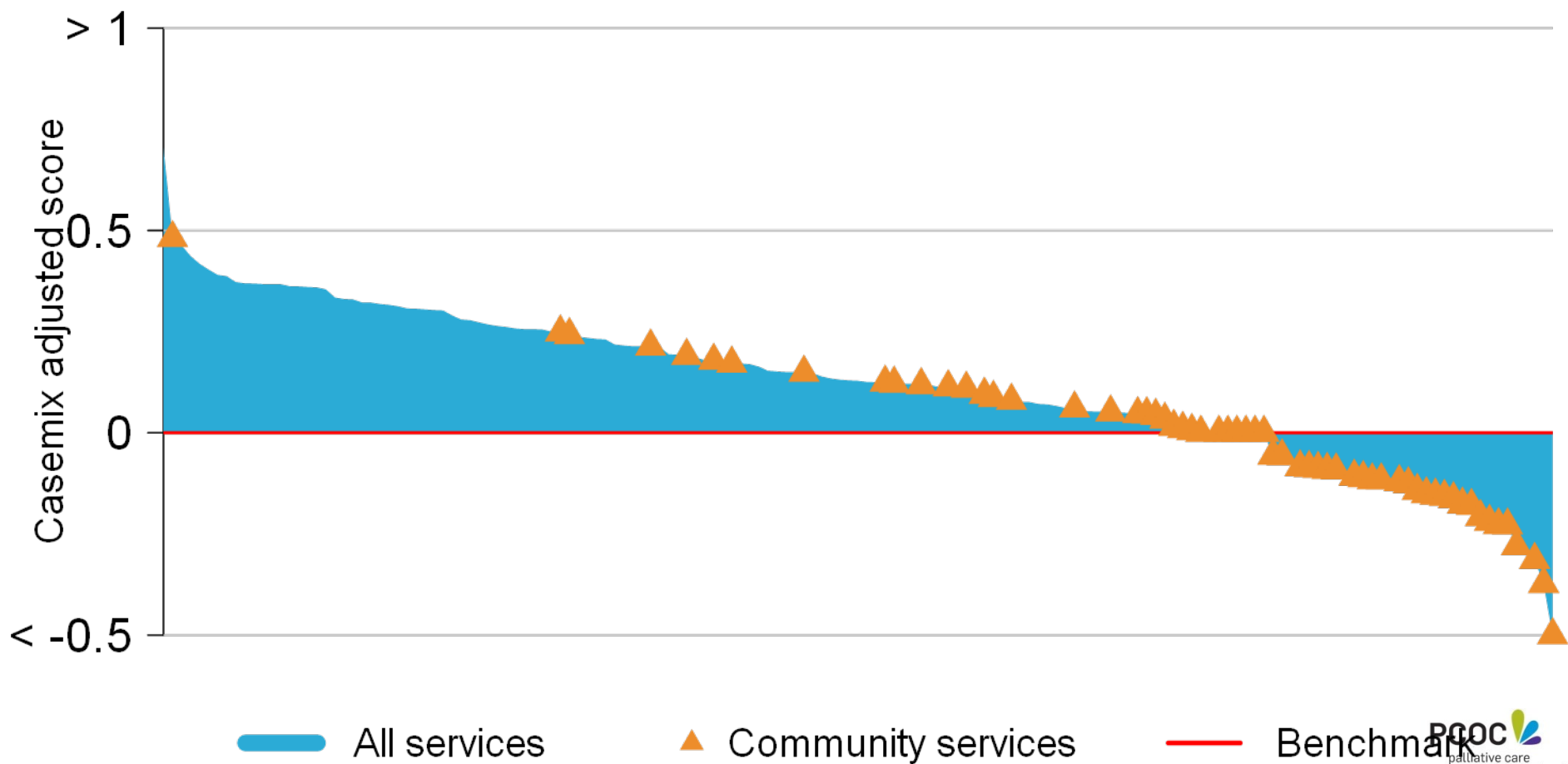
## Pain (SAS) - casemix adjusted score



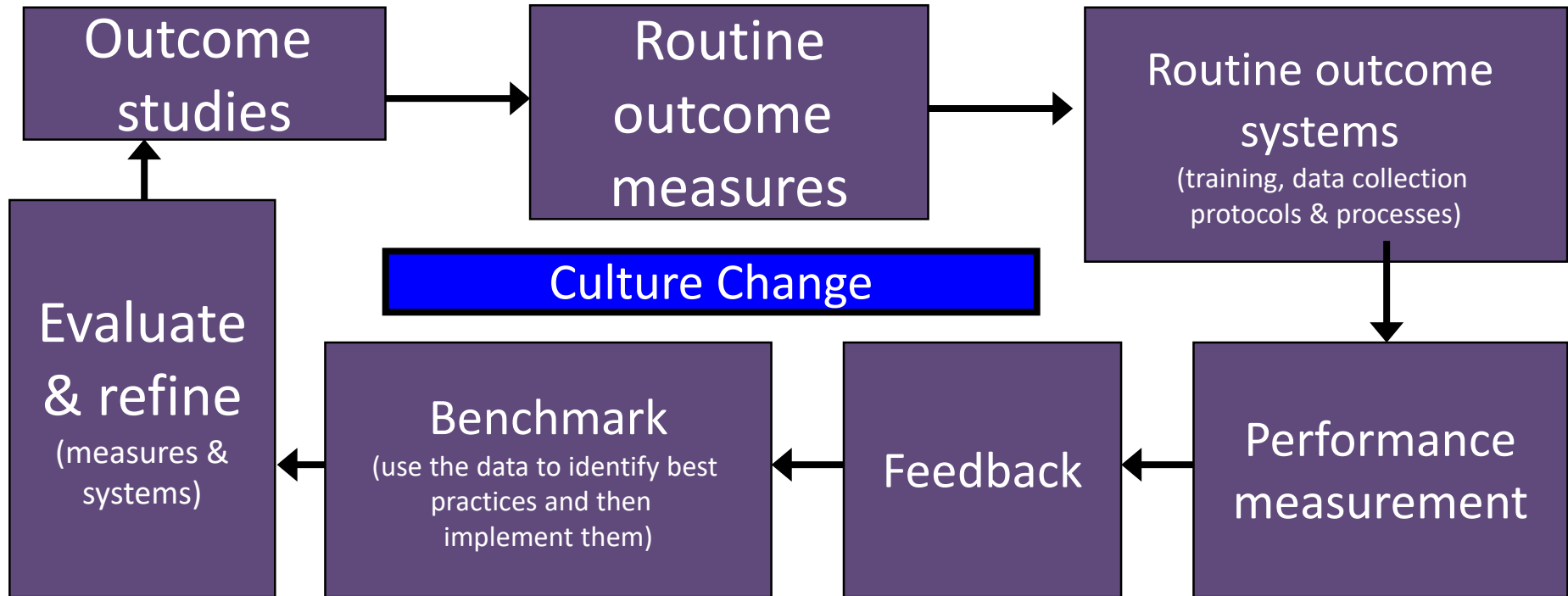
## Family/carer (PCPSS) - casemix adjusted score



## Family/carer (PCPSS) - casemix adjusted score

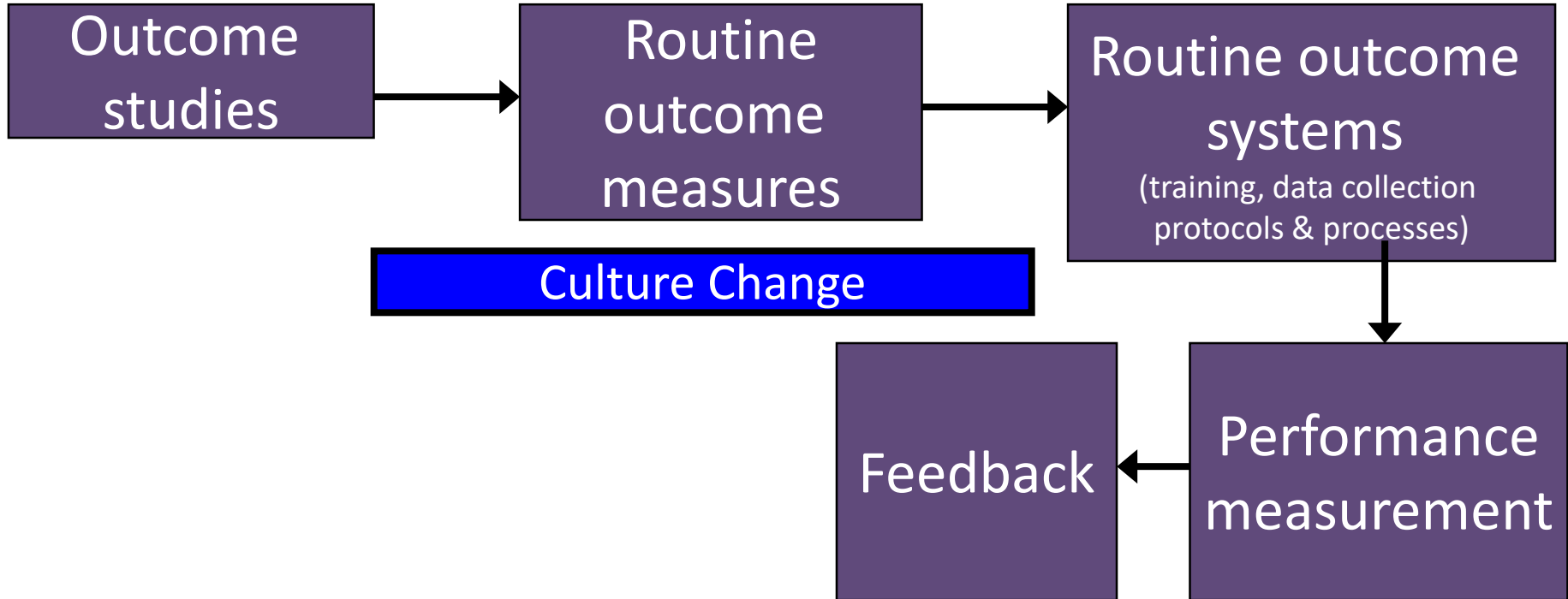


# The benchmarking cycle





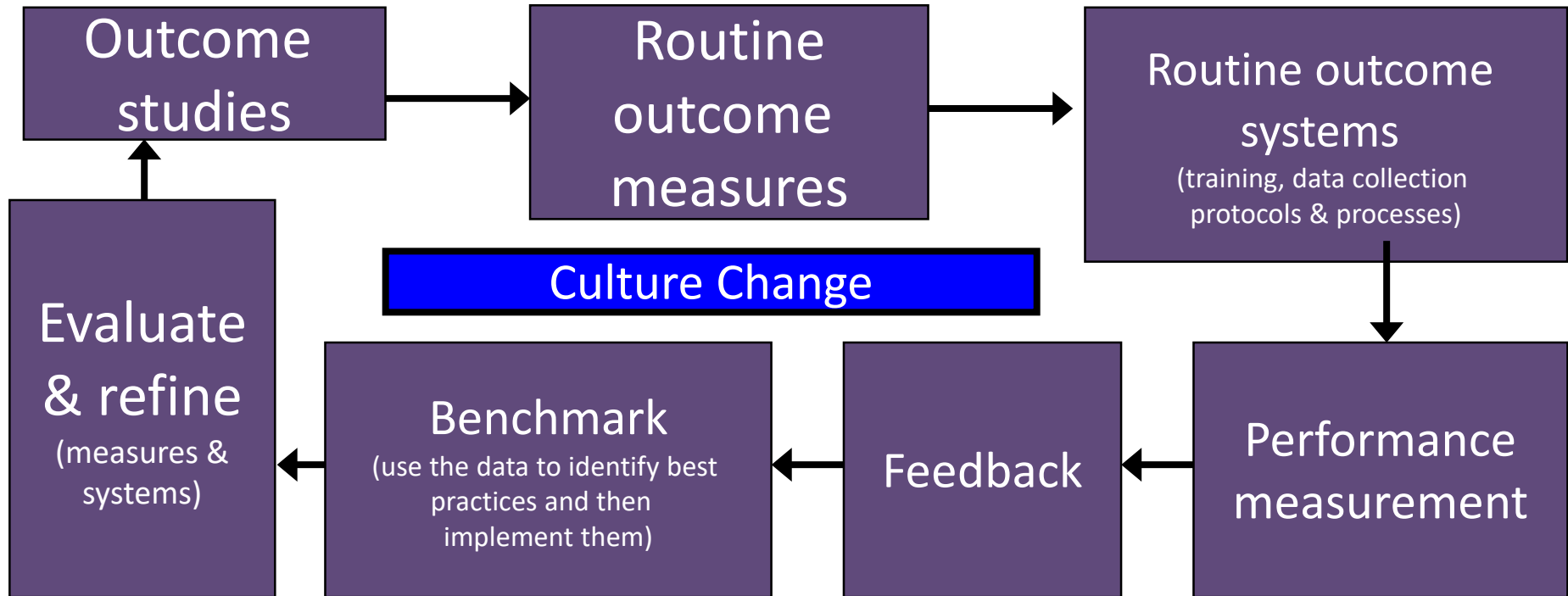
# Learn from experience



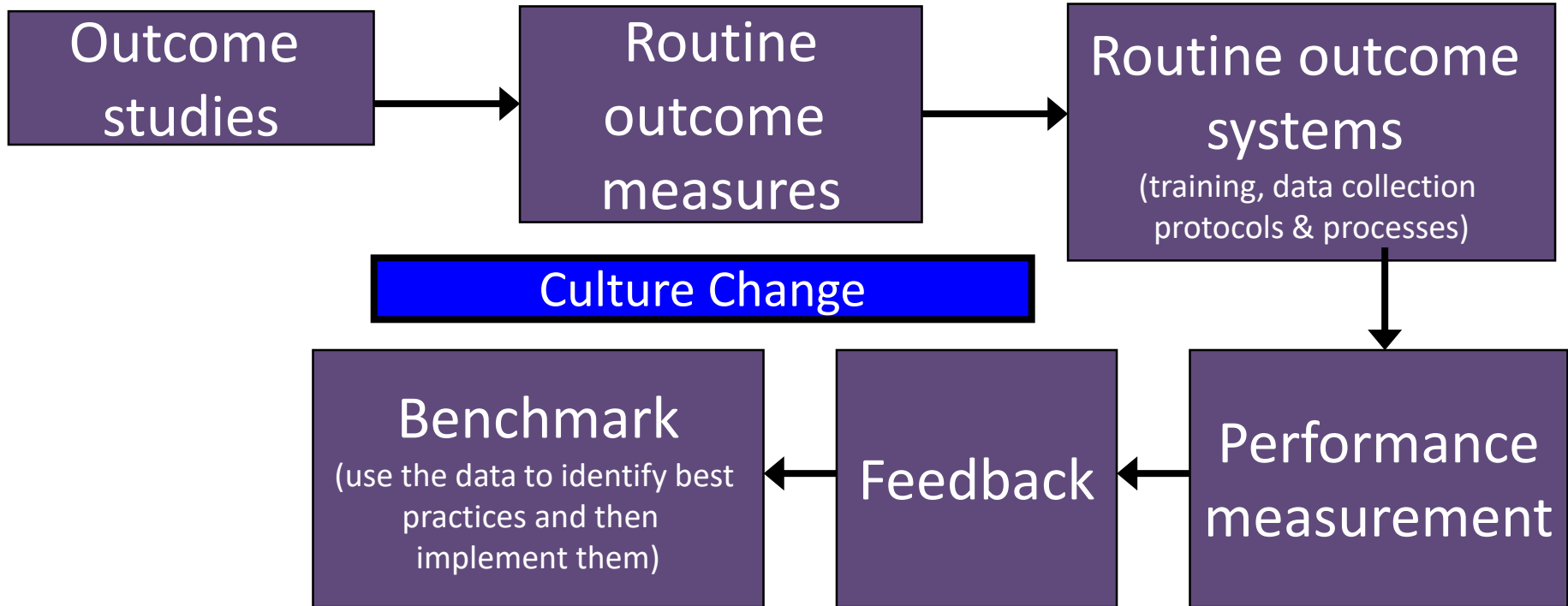
# PCOC Improvement Facilitators

- A national network of PCOC Facilitators who are the first point of contact for each service. Role:
  - Education in the clinical assessment tools and protocols
  - Assistance with process re-engineering
    - Embedding PCOC assessments into routine practice
  - Structured feedback after each report
  - Facilitating access to the evidence on how to improve
  - Supporting and promoting PCOC champions
  - Networking 'like' services and encouraging them to benchmark with each other

# The benchmarking cycle

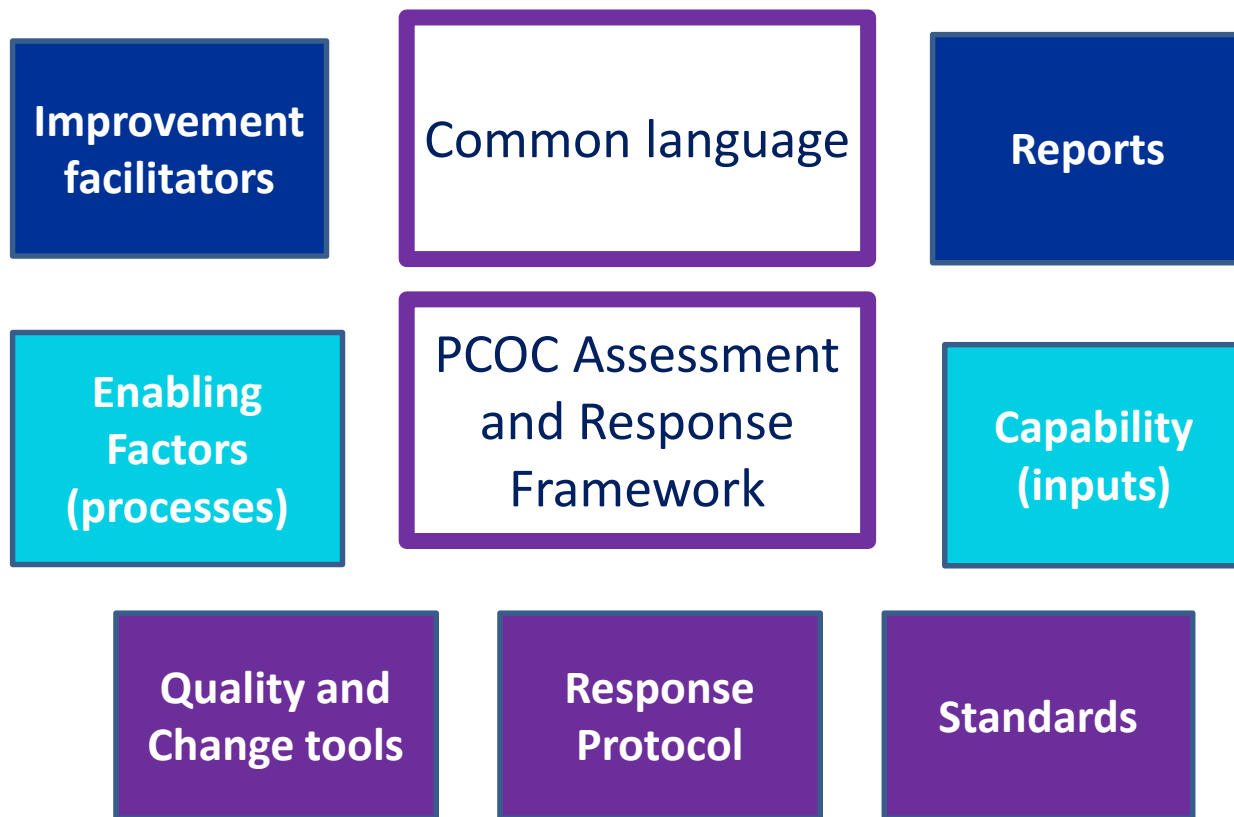


# Use the data to identify best practice

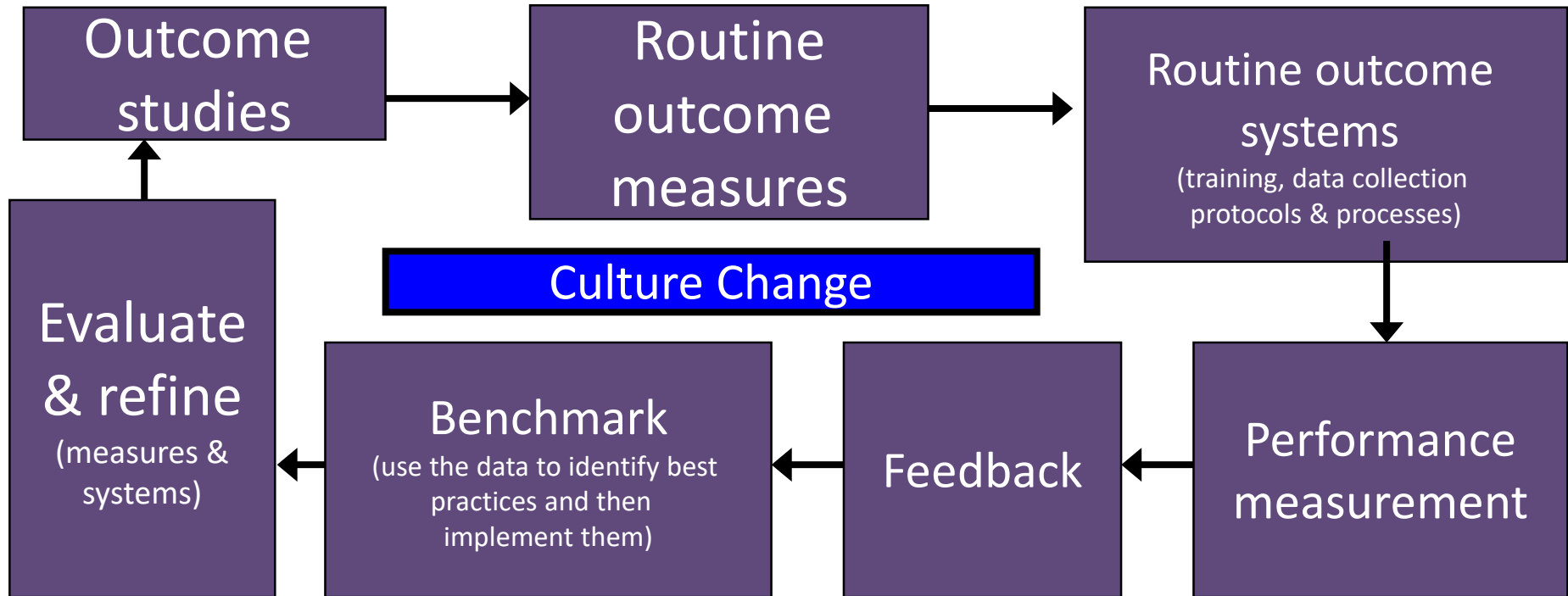


# Teams need tools to help them improve:

## PCOC toolbox for improvement



# The benchmarking cycle



# Discussion and recommendations

- (1). What do decision makers, clinicians and patients already know about palliative care patient and carer outcomes in Hong Kong?
- (2) What should decision makers, clinicians and patients ideally know about palliative care patient and carer outcomes in Hong Kong?
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