



University of Wollongong



Measuring outcomes in palliative care

Kathy Eagar

Director, Centre for Health Service Development

Palliative Care Care Planning Workshop,

June 2007, Sydney

Overview

- ◆ Why measure outcomes and quality?
- ◆ What is an outcome?
- ◆ What is benchmarking?
- ◆ Practicalities

Why routine outcome measurement?

- ◆ There is no choice - policy makers and practitioners don't have that luxury
 - political and economic realities
 - equity
- ◆ Without it, there is no choice but to focus on cost and technical efficiency
- ◆ We have to shift the focus from cost to value for money
- ◆ We have to demonstrate that palliative care is an investment, not just a cost

More reasons

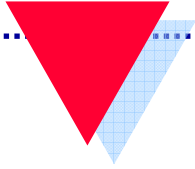
- ◆ After years of a nationally funded palliative care program, we still can't even count the number of patients treated
 - let alone the outcomes for them and their families / carers!
- ◆ Where is the evidence for another national program?
- ◆ While a drawer full of 'thank you' letters may be interpreted by some as an outcome measure, it just isn't enough

There are important consequences if the palliative care sector does not:

- develop an evidence-base,
- routinely collect information, and
- learn how to use it

“In God we trust, all others bring data”

Anonymous treasury official (2010)

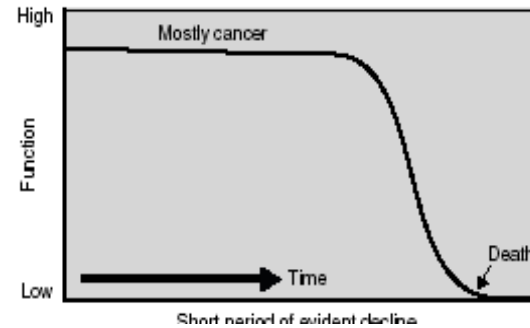
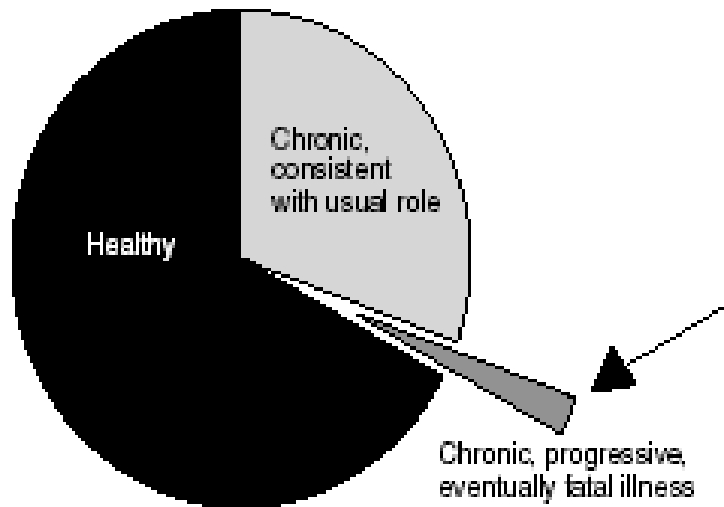


Some rhetoric and some reality

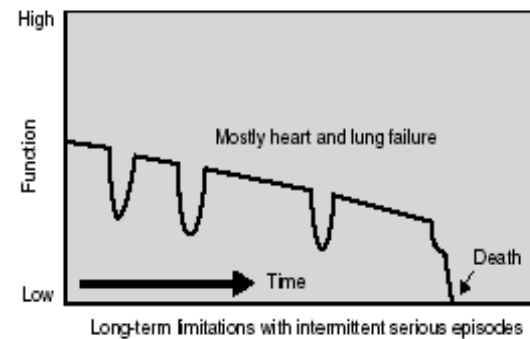
The target group - the rhetoric

- ◆ People with a life-limiting illness who has little or no prospect of cure
- ◆ Whose primary treatment goal is now quality of life rather than cure of the disease
- ◆ The 'consumers' of palliative care also include the patient's family and friends
 - Grief and bereavement support services for the family and carers are an integral part of palliative care.
 - Their outcomes count too.

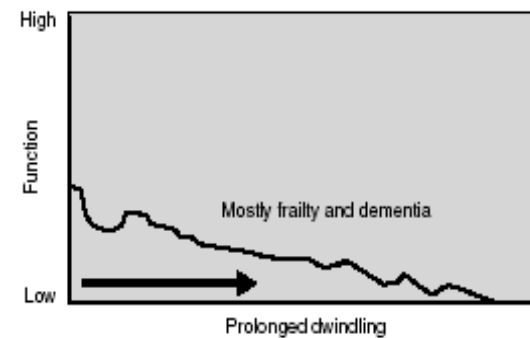
Three trajectories of chronic illness (Rand)



20%



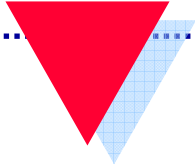
20%



40%

The target group - the reality

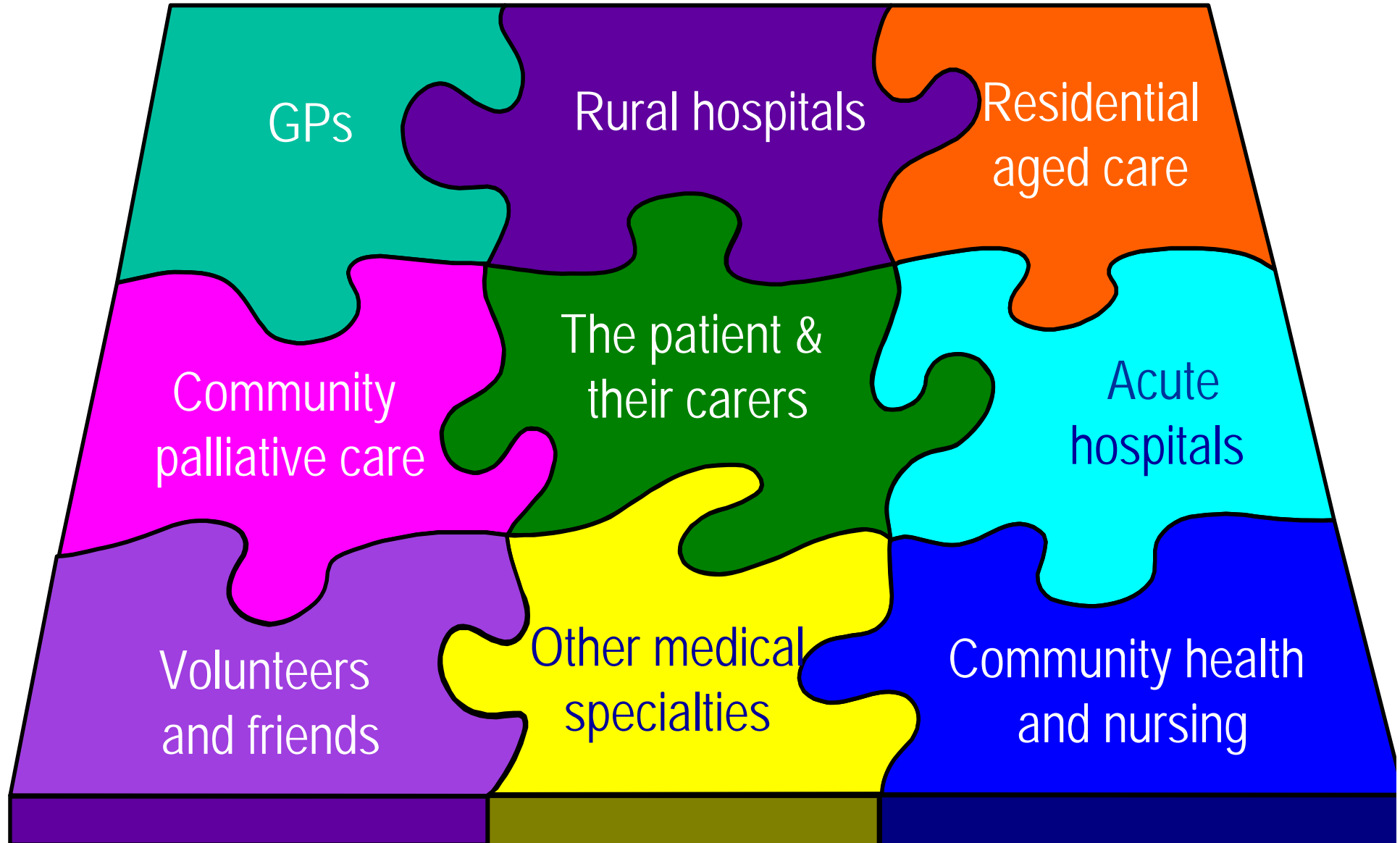
- ◆ On all the evidence, most services focus on patients with cancer
 - but accept patients with other conditions if their trajectory is similar to cancer
- ◆ A significant proportion of people who die from a life limiting illness receive acute care until the day they die
 - and no one measures their outcomes



Models of service provision

The rhetoric

Integrated networks of care




Models of service provision - the reality

- ◆ Uneven distribution of services across and within states and territories
- ◆ Professional silos, not integration, dominate
 - medical specialities and general practice in parallel
- ◆ Culture of 'death as a professional failure' continues to dominate the acute care sector
- ◆ Many patients and families scared of referral to palliative care - it's where you go to die

Service culture - reality?

- ◆ An unspoken belief that:
 - A drawer full of 'thank you' letters is enough?
 - Care for people with life limiting illnesses is straightforward and that there are no adverse outcomes?
 - Outcomes cannot be improved?
 - ◆ After all, the patient is going to die no matter what we do
 - By definition, palliative care achieves good outcomes and doesn't need to waste precious resources to prove it? OR
- ◆ A clinical system ready for the challenge of routine outcome measurement?



What is an outcome? The Palliative Care Evaluation and Outcomes Framework

Reference: Evaluation and palliative care: a guide to the evaluation of
palliative care services and programs
<http://www.palliativecare.gov.au/publicat.htm>

A hierarchy of outcomes

- ◆ Level 1: Impact on, and outcomes for, consumers
 - patients, families, carers, friends, communities
 - focus of this paper
- ◆ Level 2: Impact on, and outcomes for, providers
 - professionals, volunteers, organisations
- ◆ Level 3: Impact on, and outcomes for, the system
 - structures and processes, networks, relationships

How do you assess an 'outcome'?

Whose assessment counts?

The Person

- ◆ Live as long as possible
- ◆ Have friends
- ◆ Have things to do
- ◆ Come to terms with loss
- ◆ Be happy
- ◆ Function as independently as possible
- ◆ Have maximum confidence and control
- ◆ Get better

The Provider

- ◆ Minimum pain and other symptoms
- ◆ Minimum carer burden
- ◆ Minimum burden on the health system

The Payer

- ◆ Maximum improvement at minimum cost?
- ◆ Minimum burden on society?

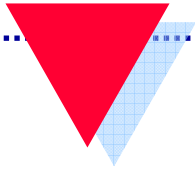
Health Outcome

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



Outcomes have to be linked to the
goal of the intervention

No change, or an arrest in the rate of
decline, is a good outcome if that is the
goal of care

A Matrix of Outcomes

	Quality of Life			
		Improve	Same	Worse
Length of Life	Longer	+++++	+	--
	Same	+++		---
	Shorter	++	-	-----

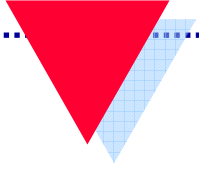
**A
diagnosis
is not an
outcome!**

Outcomes assessment can't be a one-off event

- ◆ Need reassessment, based on a protocol:
 - clinical criteria (eg, diagnosis, pall care phase)
 - pre-agreed time periods (eg, each 90 days) or
 - natural bookends (eg, hospital discharge)
- ◆ Types of outcomes at these points:
 - alive or dead (level 1)
 - better or worse (level 2)
 - better or worse than expected (level 3)
 - value for money (level 4)

Quality and outcomes measurement

- ◆ Diversity of palliative care service models, with little evidence of what models work best in what situations
- ◆ Little consistency in data collection methods
 - some services collect extensive data while others collect little or no data
 - numerous databases
 - lack of clarity in data item definitions

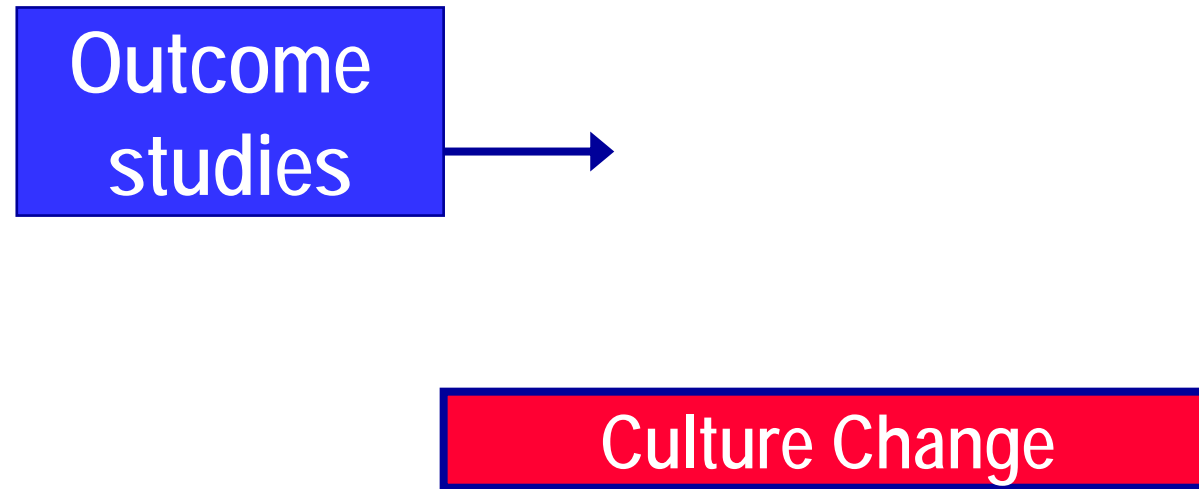


Benchmarking

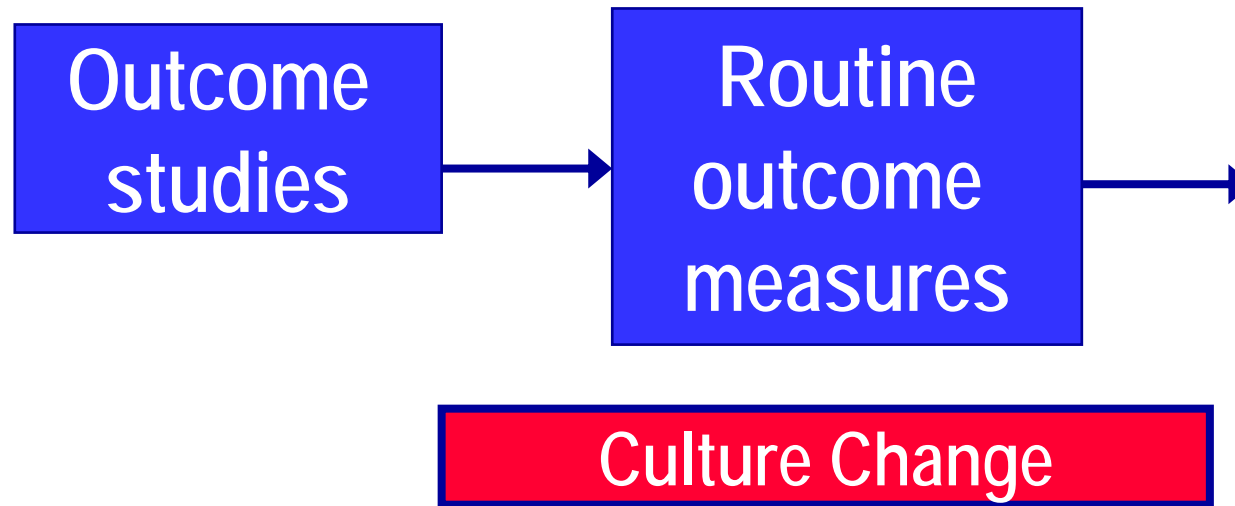
What is benchmarking?

- ◆ 'Finding and implementing best practice' (Bullivant (1994)).
- ◆ 'The ongoing, systematic process to search for and introduce international best practice into an organisation'
 - ◆ Australian Manufacturing Council (1994).
- ◆ So:
 - benchmarking is the process of establishing 'best practice' and
 - a benchmark is a standard of performance derived from that process.

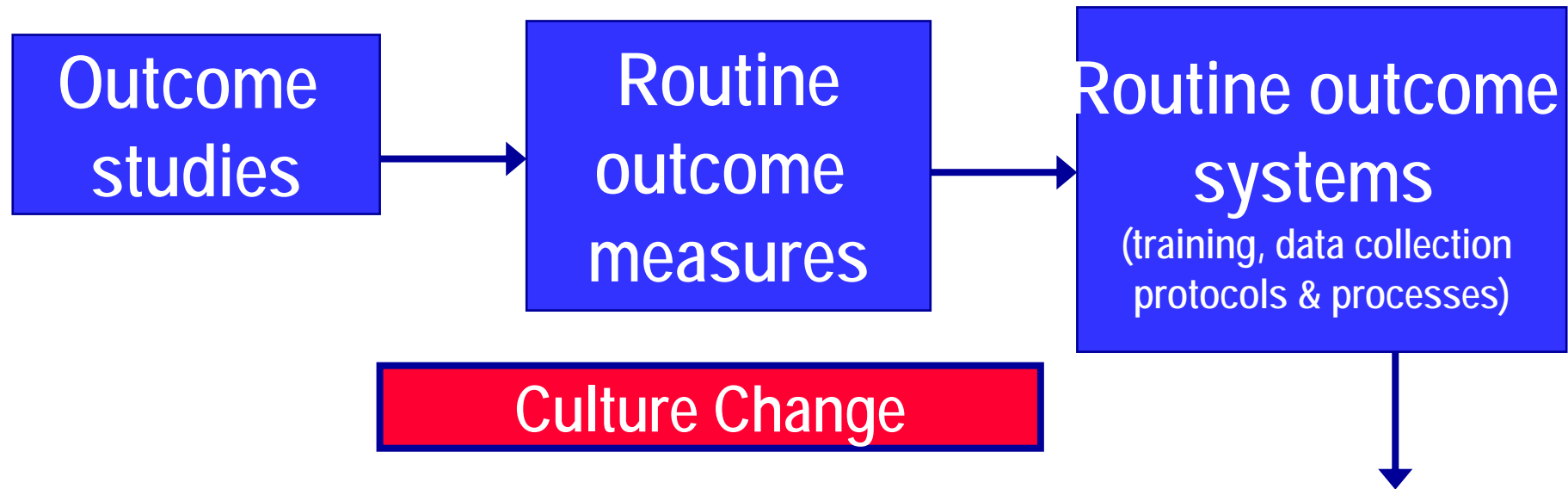
Where PC sits on the development path



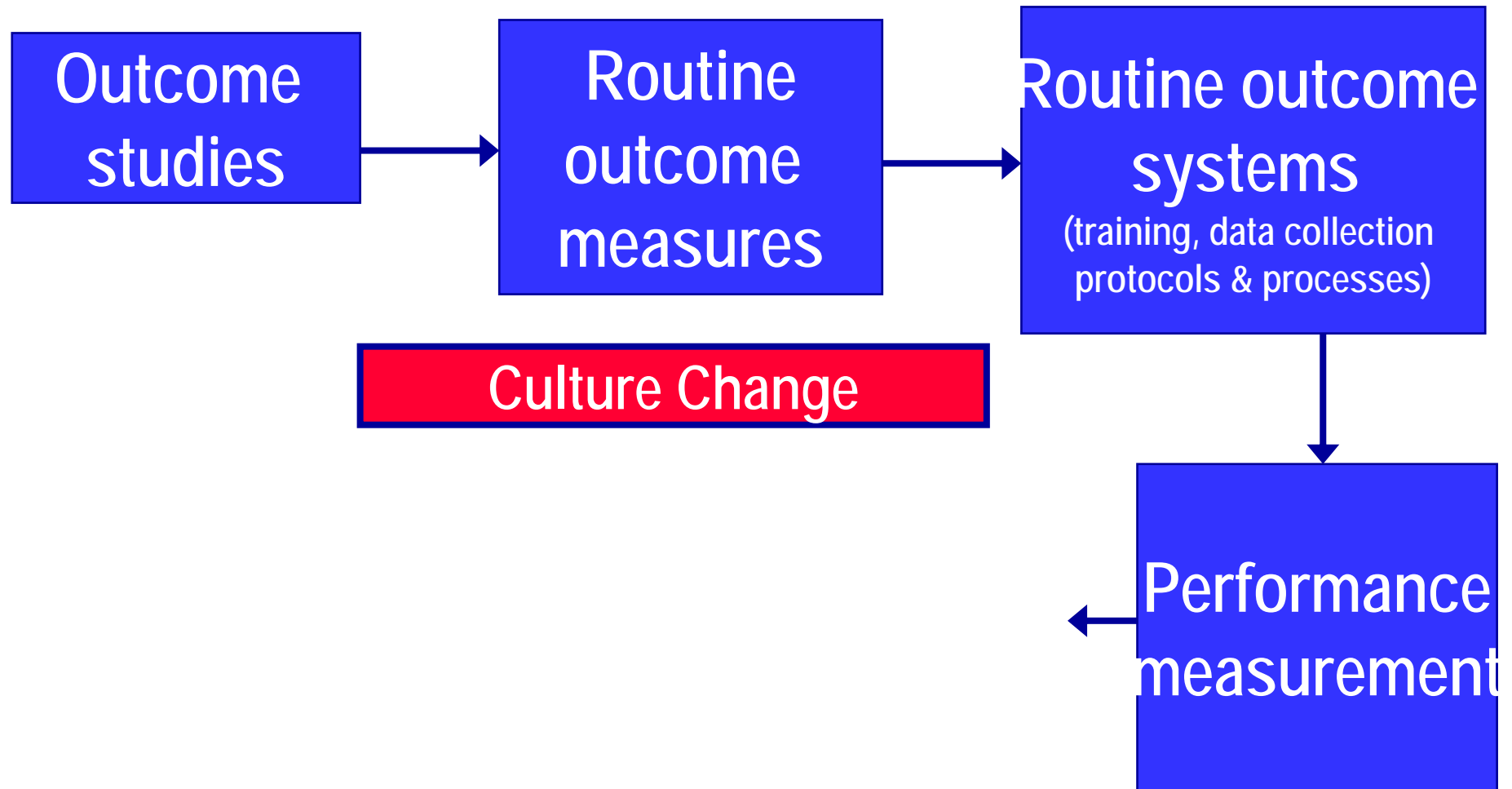
Current developments



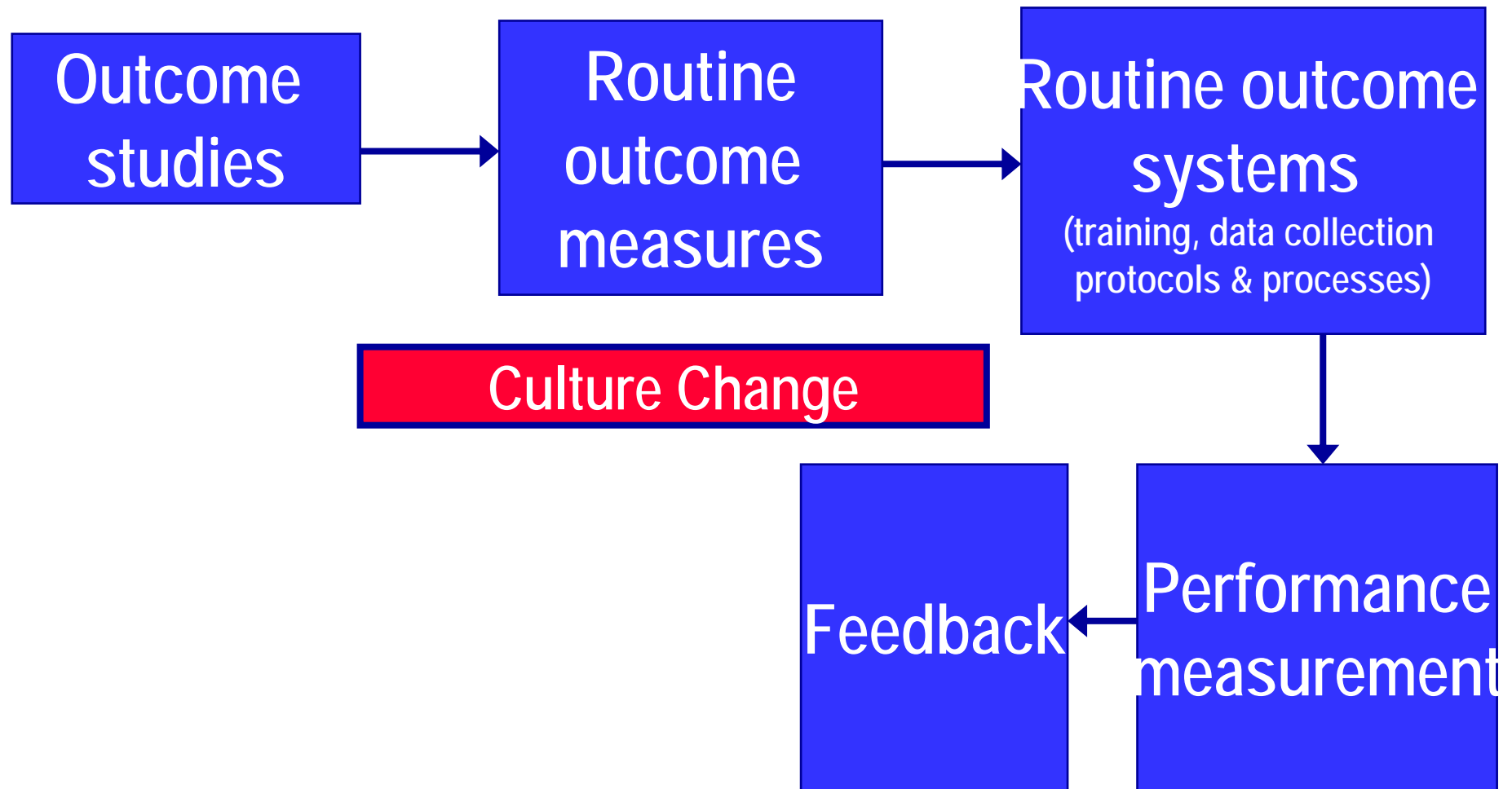
The path ahead



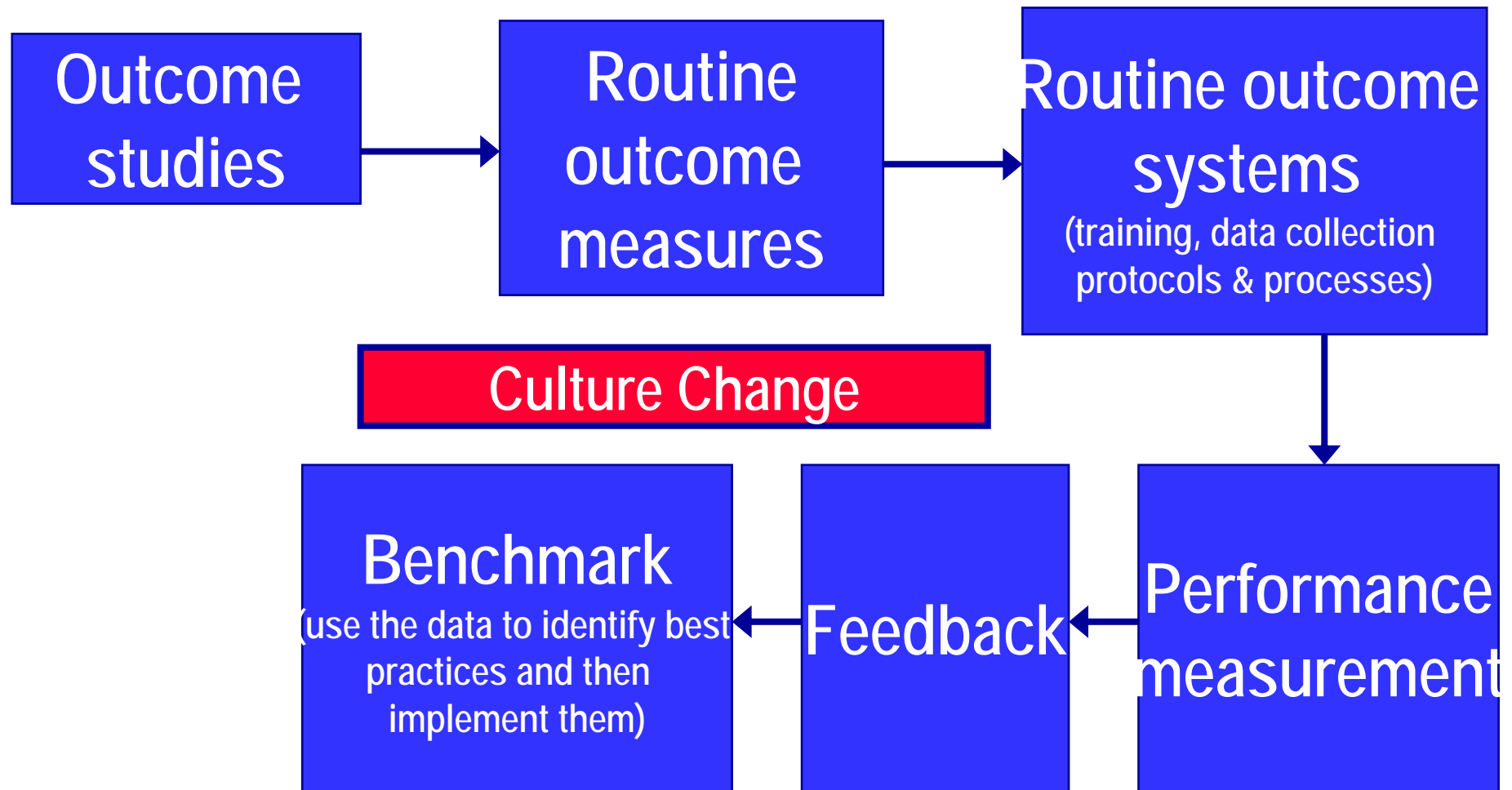
The path ahead



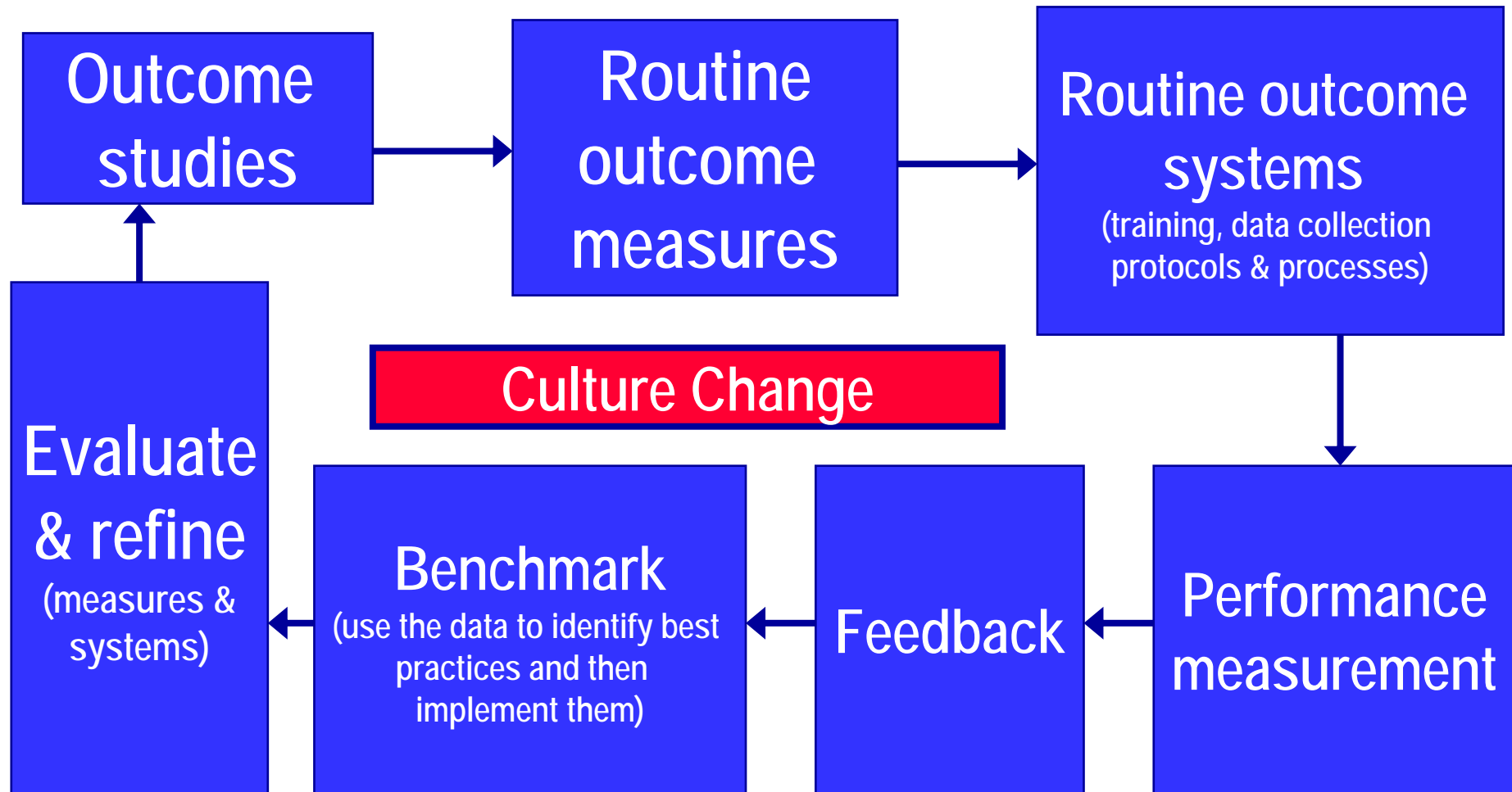
The path ahead

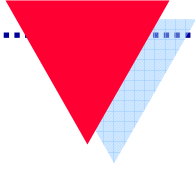


The path ahead



The benchmarking cycle





Some practicalities

Evidence is needed on effectiveness, not efficacy

◆ Efficacy

- the level of benefit expected when health services are delivered under ideal conditions.

◆ Effectiveness

- the level of benefit when a service is rendered under ordinary circumstances by average practitioners for typical patients.

◆ And that means we need routine measures

Standard measures

- ◆ That work in routine practice already exist
 - no need to reinvent the wheel. Some examples:
 - PCOC:
 - ◆ phase, functional status, problem severity
 - CHSD palliative care evaluation toolkit
 - ◆ tools for all 3 levels (consumer, provider, system)
 - Lots of others - eg
 - ◆ Care Search <http://www.caresearch.com.au>
 - ◆ Palliative Care Australia - Standards and self audit
 - ◆ Toolkit of Instruments to Measure End-of-Life Care <http://www.chcr.brown.edu/pcoc/toolkit.htm>

Engaging consumers and carers

- ◆ Their views are fundamental to measuring outcomes in palliative care
- ◆ Lots of evidence in the literature that patients and carers are happy to participate
- ◆ Informed consent
 - information,
 - comprehension and
 - voluntary choice

Conclusion

- ◆ A key challenge for the palliative care sector is to consistently collect meaningful data
- ◆ Standardised tools and data item are key
 - requires lots of education
 - need to be built into everyday practice, not treated as an add-on
 - information needs to be fed back to those who collected it
- ◆ Improvement comes by doing
 - perfection comes later!