



**PALLIATIVE CARE OUTCOMES
COLLABORATION (PCOC)**

Education

Funded by the Australian Government



What is PCOC?

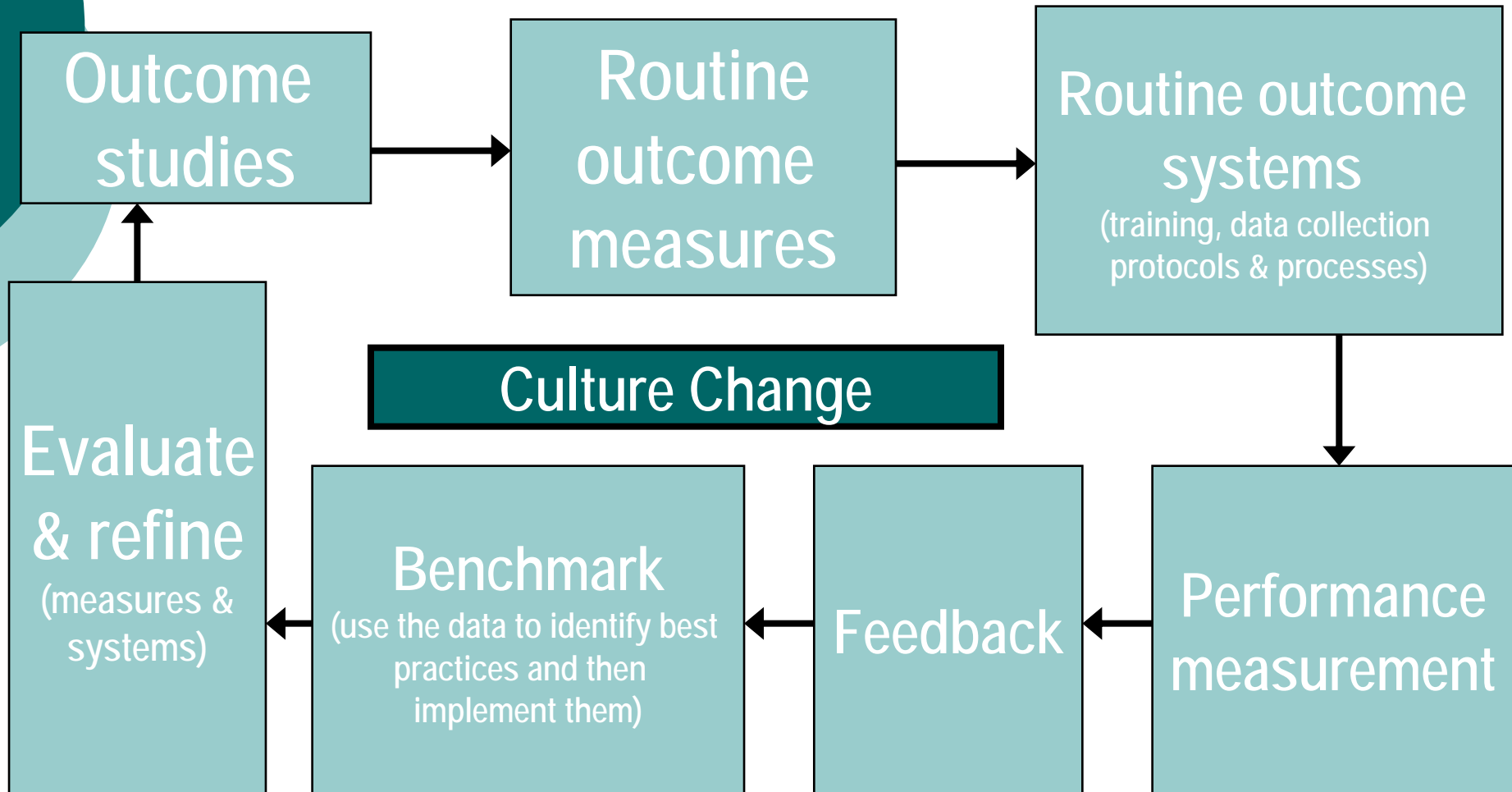
- PCOC is a national approach
 - Towards the routine assessment of palliative care using standardised assessment tools
 - To assist palliative care services deliver quality patient care
 - To demonstrate outcomes



PCOC is

- Continuous quality improvement of palliative care
- Demonstrating outcomes (service and patient/caregiver)
- Using standardised palliative care assessments
- Using a “common language”
- Providing a benchmarking process

The benchmarking cycle





How PCOC aims will be achieved

- Work with services to collect agreed data set
- Assist with incorporating data items and standardised assessment tools into routine practice
- Provide ongoing support through education and assistance with IT
- Analyse the data and provide feedback on the results to individual services which will benchmark with other services



What Happens to the data?

- Uploaded into PCOC national database
- Ad hoc service reports
- 6 mthly report compares your service against all other PCOC services
- **In this service.....**

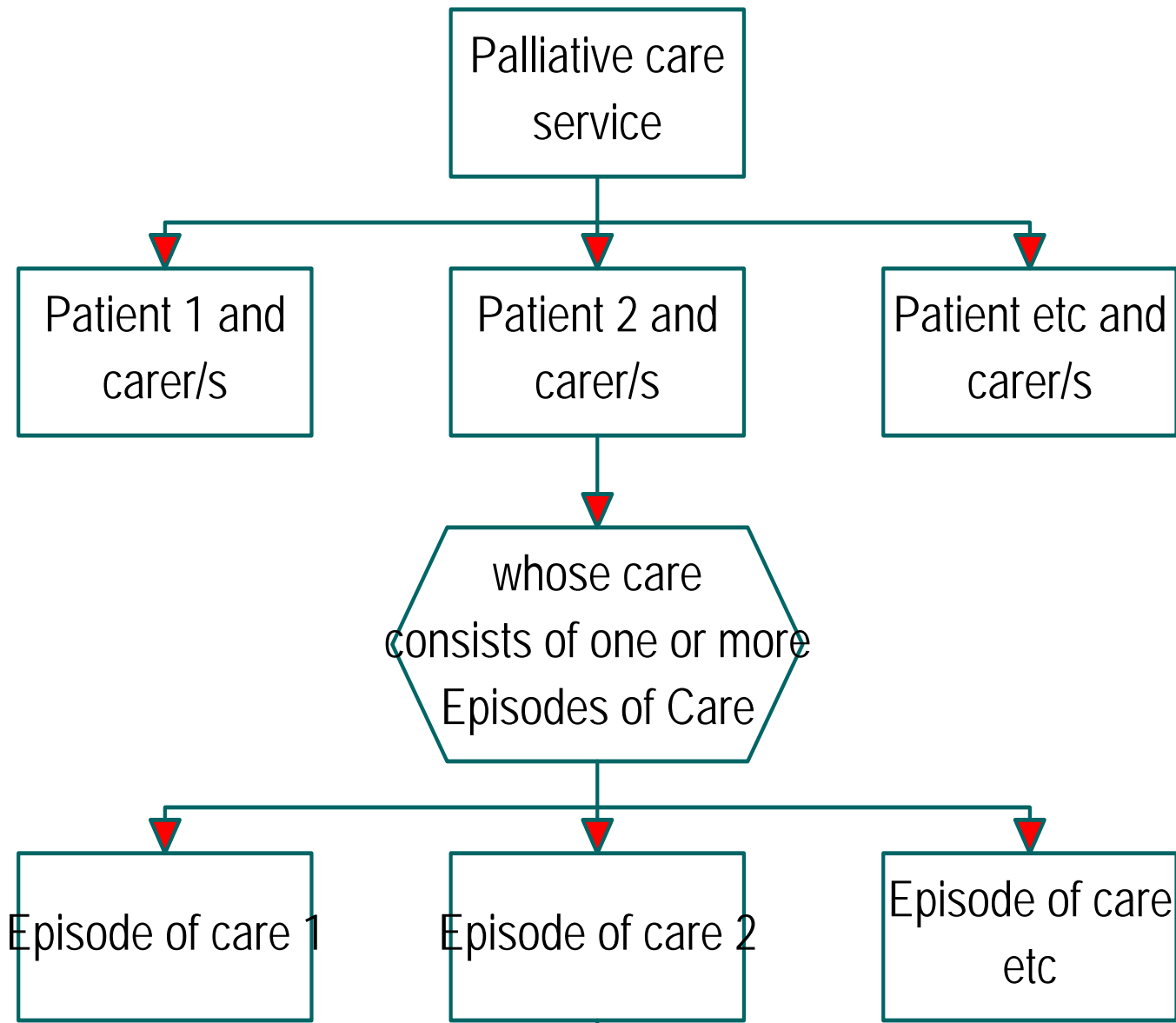


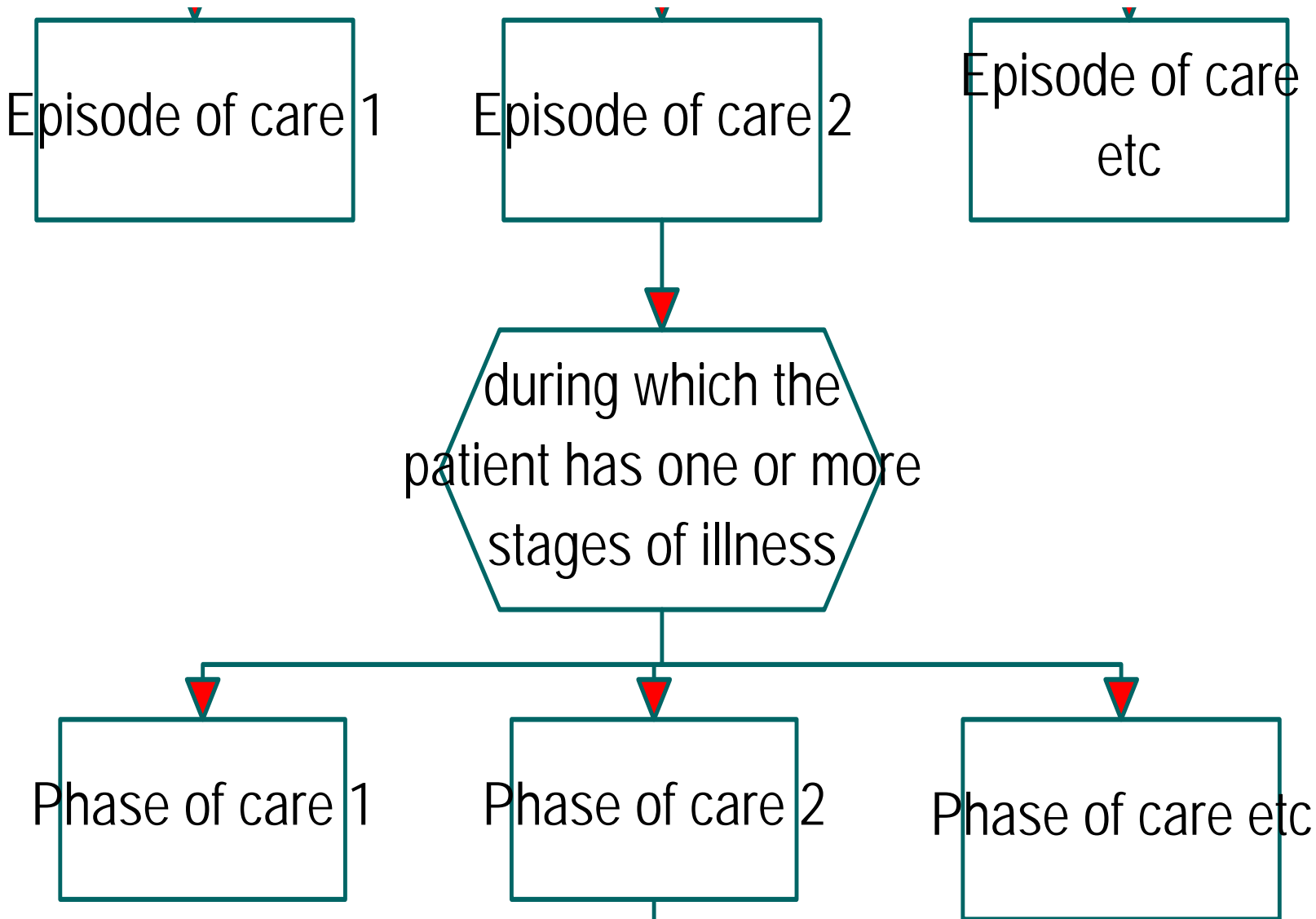
PCOC Information levels

Level 1: Patient- demographic

Level 2: Episode- setting of care

Level 3: Phase- clinical







Level 1 - Patient Data Items

1. Patient identifier
2. Date of birth
3. Sex
4. State identifier
5. Postcode
6. Indigenous status
7. Main language spoken at home
8. Country of birth



Level 1 Patient Information

- Collect at episode start only
- This information is collected by in our service on form

Level 2 - Episode Information

○ **Episode**

- The setting
 - How they enter and exit this setting
 - From where they enter and exit the service
 - Diagnosis
 - Length of episode
-
- A period of contact between a palliative care patient and a palliative care service that is provided by one palliative care service and that occurs in one setting
 - overnight admitted patient or
 - not overnight admitted patient



Level 2 - Episode Data Items

1. Referral date
2. Referral Source
3. Mode of episode start
4. Date of first contact
5. Date of episode start
6. Proposed model of care at episode start
7. Episode type
8. Diagnosis
9. Accommodation at episode start & end
10. Level of support at episode start & end



Level 2 Episode Information

- Document at episode start
- Document at episode end
- Policy & Procedure for documenting information in our service
- This information is collected by in our service



Level 3 - Phase Information

- Patient Condition & trajectory –
 - Acuity, progression of phases
 - Functional Status
 - Performance Status
 - Pain & Symptom Management
 - Psychological/Spiritual Distress
 - Family Carer Distress
 - Length of Phase

Level 3 - Phase Data Items

- 5 Assessments:
 1. Phase start & end date
 2. RUG-ADL phase start & end
 3. SAS phase start & end
 4. Karnofsky phase start & end
 5. Palliative Care Problem Severity phase start & end
- Model of care at phase end
- Reason for phase end



Five Assessment tools

1. Phase
2. RUG - ADL Resource Utilisation Groups – Activities Daily Living
3. Australian Karnofsky Performance Measure
4. Palliative Care Problem Severity Scale (PSS)
5. Symptom Assessment Score (SAS)



Phase Assessment

1. Stable
2. Unstable
3. Deteriorating
4. Terminal
5. Bereaved



Phase Assessment

- The palliative care phase is the stage of a person's illness
- An assessment is holistic and views the patient and family as one unit
- Palliative care phases are not sequential. A patient/family may move back and forth between phases



Stable: Phase 1

- The patient's symptoms are adequately controlled by established management. Further interventions to maintain symptom control and quality of life have been planned
- The situation of the family/carers is relatively stable and no new issues are apparent. Any needs are met by the established plan of care



Unstable: Phase 2

- The patient experiences the development of a **new unexpected problem or a rapid increase** in the severity of existing problems, either of which require an **urgent change** in the management or **emergency treatment**
- The family/carers experience a sudden change in their situation requiring urgent intervention by members of the multidisciplinary team

Deteriorating: Phase 3

- The patient experiences a **gradual worsening** of existing symptoms or the development of **new but expected problems**. These require the application of specific plans of care and regular review but **not urgent or emergency treatment**.
- The family/carers experience gradually worsening distress and other difficulties, including social and practical difficulties, as a result of the illness of the person. This requires a planned support program and counselling as necessary.

Terminal: Phase 4

- Death is likely in a matter of days and no acute intervention is planned or required
- The family/carers recognise that death is imminent and care is focussed on emotional and spiritual issues as a prelude to bereavement
- Some signs of this phase may include:
 - Profoundly weak
 - Essentially bed bound
 - Drowsy for extended periods
 - Disoriented for time and has a severely limited attention span
 - Increasingly disinterested in food and drink
 - Finding it difficult to swallow medication



Bereaved: Phase 5

- Patient has died and bereavement support is offered
- A planned bereavement support program is available including referral for counselling as necessary
- Record only one bereavement phase per patient – not one for each family/carer member



Phase Documentation

- At episode start
- At phase change or discharge / case closure
- **In this service -**



Resource Utilisation Group- Activities Daily Living (RUG-ADL)

- The RUG-ADL is a 4 item scale measuring motor function with activities of daily living:
 - Bed mobility
 - Toileting
 - Transfer
 - Eating
- RUG-ADL tells us about the patient's functional status and the assistance they require for their activities of daily living

RUG Item	Score	Definition
BED MOBILITY		Ability to move in bed after the transfer into bed has been completed.
Independent or supervision only	1	Able to readjust position in bed, and perform own pressure area relief, through spontaneous movement around bed or with prompting from carer. No hands-on assistance required. May be independent with the use of a device.
Limited physical assistance	3	Able to readjust position in bed, and perform own pressure area relief, with the assistance of one person.
Other than two persons physical assist	4	Requires the use of a hoist or other assistive device to readjust position in bed and provide pressure relief. Still requires the assistance of one person for task.
Two or more persons physical assist	5	Requires 2 or more assistants to readjust position in bed, and perform pressure area relief.

RUG Item	Score	Definition
TOILETING		Includes mobilising to the toilet, adjustment of clothing before and after toileting and maintaining perineal hygiene without the incidence of incontinence or soiling of clothes. If level of assistance differs between voiding and bowel movement, record the lower performance.
Independent or supervision only	1	Able to mobilise to toilet, adjusts clothing, cleans self, adjusts clothing, has no incontinence or soiling of clothing. All tasks are performed independently or with prompting from carer. No hands-on assistance required. May be independent with the use of a device. May be independent with the use of a device.
Limited physical assistance	3	Requires hands-on assistance of one person for one or more of the tasks.
Other than two persons physical assist	4	Requires the use of a catheter/uridome/urinal and/or colostomy/bedpan/commode chair and/or insertion of enema/ suppository. Requires assistance of one person for management of the device.
Two or more persons physical assist	5	Requires two or more assistants to perform any step of the task.

RUG Item	Score	Definition
TRANSFER		Includes the transfer in and out of bed, bed to chair, in and out of shower/tub. Record the lowest performance of the day/night.
Independent or supervision only	1	Able to perform all transfers independently or with prompting of carer. No hands-on assistance required. May be independent with the use of a device.
Limited physical assistance	3	Requires hands-on assistance of one person to perform any transfer of the day/night.
Other than two persons physical assist	4	Requires use of a device for any of the transfers performed in the day/night. Requires only one person plus a device to perform the task.
Two or more persons physical assist	5	Requires 2 or more assistants to perform any transfer of the day/night.

RUG Item	Score	Definition
EATING		Includes the tasks of cutting food, bringing food to mouth and chewing and swallowing food. Does not include preparation of the meal.
Independent or supervision only	1	Able to cut, chew and swallow food, independently or with supervision, once meal has been presented in the customary fashion. No hands-on assistance required. If individual relies on parenteral or gastrostomy feeding that he/she administers him/herself then Score 1.
Limited assistance	2	Requires hands on assistance of one person to set up or assist in bringing food to the mouth and/or requires food to be modified (soft or staged diet).
Extensive assistance/ dependence/ total tube fed	3	Person needs to be fed meal by assistant, or the individual does not eat or drink full meals by mouth but relies on parenteral/ gastrostomy feeding and does not administer feeds by him/herself.

Resource Utilisation Group- Activities Daily Living (RUG-ADL)

- Determine the score for each of the 4 domains, and total the score
- Minimum score is 4 - maximum is 18
- Total score 4 = person is independent
- Total score 18 = person requires total assistance of 2 persons
- Record what the person actually does, not what he/she is capable of

RUG-ADL Documentation

- At episode start/1st phase start date
- At phase change (end of one phase –start of next phase)
- Phase end for Discharge / case closure
- **In this service -**



Australian Karnofsky Performance Scale (AKPS)

- Assesses performance status
- Assesses 3 dimensions of health status
 - Activity
 - Work
 - Self care

Australian Karnofsky Performance Scale

100	Normal with no complaints or evidence of disease.
90	Able to carry on normal activity but with minor signs of illness present.
80	Normal activity but requiring effort. Signs and symptoms of disease more prominent.
70	Able to care for self, but unable to work or carry on other normal activities.
60	Able to care for most needs, but requires occasional assistance.
50	Considerable assistance and frequent medical care required.
40	In bed more than 50% of the time.
30	Almost completely bedfast.
20	Totally bedfast and requiring extensive nursing care by professionals and/or family.
10	Comatose or barely arousable.
0	Death.

Karnofsky Performance Scale (AKPS) Documentation

- At episode start/1st phase start date
- At phase change (end of one phase –start of next phase)
- Phase end for Discharge / case closure
- **In this service -**



Palliative Care Problem Severity Score (PSS)

- A score for the overall degree of distress
- Includes a specific rating for the family
- Is assessed by the clinician

Problem Severity Score

- Measure includes four domains
 - pain
 - other symptoms
 - psychological/spiritual
 - family/carer
- The score for PSS are:

0	Absent
1	Mild
2	Moderate
3	Severe



Problem Severity Score

Pain

- The degree of overall pain

Problem Severity Score

Other Symptoms

- Record the degree of distress
- The following list may be used as a guide:
 - Nausea/vomiting
 - Anorexia
 - Itch/irritation
 - Constipation/diahorrea
 - Wound/ulcer
 - Confusion/delirium
 - Dyspnoea
 - Oedema
 - Incontinence
 - Weakness/fatigue

Problem Severity Score

Psychological / Spiritual

- Record the score for overall degree of psychological/spiritual problems of the patient

- The following list may be used as a guide:

Anxiety/fear

Anger

Depression/sadness

Unrealistic goals

Request to die

Agitation

Confusion

Problem Severity Score

Family / Carer

- Record score for the overall degree of family / carer problems 0-3
- The following list may be used as a guide:

Cultural

Anger

Financial

Denial

Non-English speaking

Difficult communication

Family/carer conflict

Family/carer accommodation

Sensory impairment

Unrealistic goals

Caregiver fatigue

Legal

Palliative Care Problem Severity (PSS) Documentation

- At episode start/1st phase start date
- At phase change (end of one phase –start of next phase)
- Phase end for Discharge / case closure
- **In this service -**



Symptom Assessment Scale (SAS)

- Is a seven-item patient rated tool to measure symptom distress in cancer or palliative care patient
- Ratings are recorded to demonstrate the patient's progress and changes in condition
- Other symptoms can be added.



Symptom Assessment Scale

Seven symptoms:

1. insomnia
2. appetite problems
3. nausea
4. bowels
5. breathing
6. fatigue
7. pain

Symptom Assessment Scale

- Assesses symptoms from the patient's perspective
- Identifies the patient's priorities in terms of distress
- Tracks individual symptoms over time
- Identifies the effectiveness of clinical interventions
- Measures changes in symptoms, improvements or deterioration

Symptom Assessment Scale: Using the Scale

A score of zero (0) would indicate that you are not having any problems with that symptom

None	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	Worst
at all	0	1	2	3	4	5	6	7	8	9	10	Possible

A score of ten (10) would indicate you are having the worst possible experience with that symptom

Ask about each symptom...

5. Breathing problems

6. Fatigue

7. Pain

None Worst Possible
at all 0 1 2 3 4 5 6 7 8 9 10

Pick a number that most closely matches how you feel....

Symptom Assessment Scale

Record the results....

Date	3/8	4/8	5/8	6/8	7/8	8/8
Insomnia	5	4				
Appetite problems	4	3				
Nausea	5	3				
Bowel problems	6	3				
Breathing problems	0	0				
Fatigue	8	8				
Pain	6	2				



Additional Symptoms

- If the patient identifies additional symptoms to those listed on the scale, add these symptoms to the scale in the same manner
- If the patient identifies more than one pain it is important to assess each one separately.

Symptom Assessment Scale

Recording additional symptoms

Date	3/8	4/8	5/8	6/8	7/8	8/8
Breathing	0	0				
Fatigue	8	8				
Pain 1. Knee	5	3				
Pain 2. Shoulder	6	3				
Restlessness	7	6				



Symptom Assessment Scale Using a Proxy

- If the patient experiencing symptoms is unable to rate symptom distress, a proxy can be used.
- A proxy is some one who can answer the SAS items from the patient's perspective.

Symptom Assessment Scale Documentation

- At episode start/1st phase start date
- At phase change (end of one phase –start of next phase)
- Phase end for Discharge / case closure
- **In this service -**



Case Study

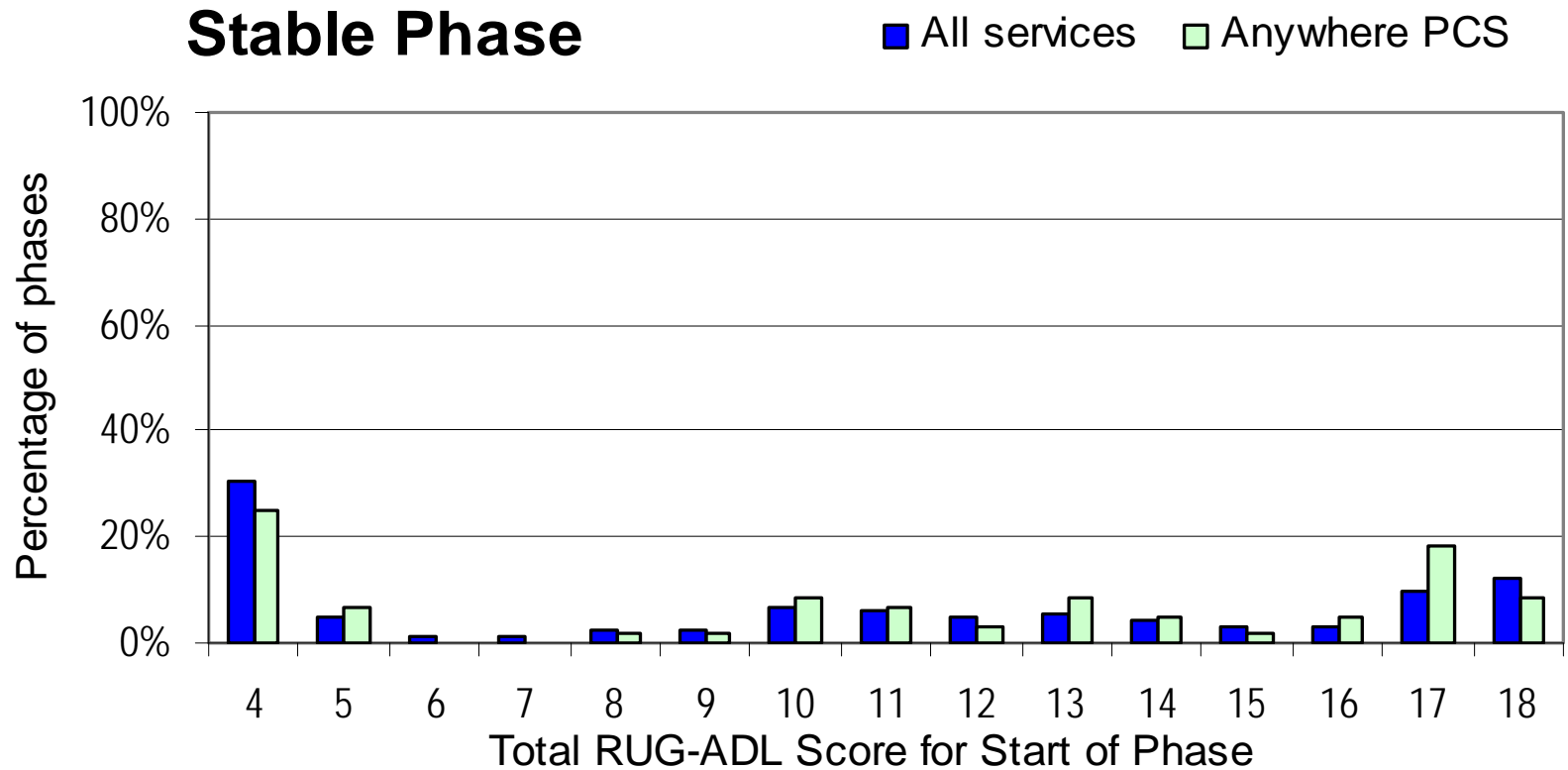
- Refer to your handouts for case study details
- In groups undertake assessments
- Discuss results



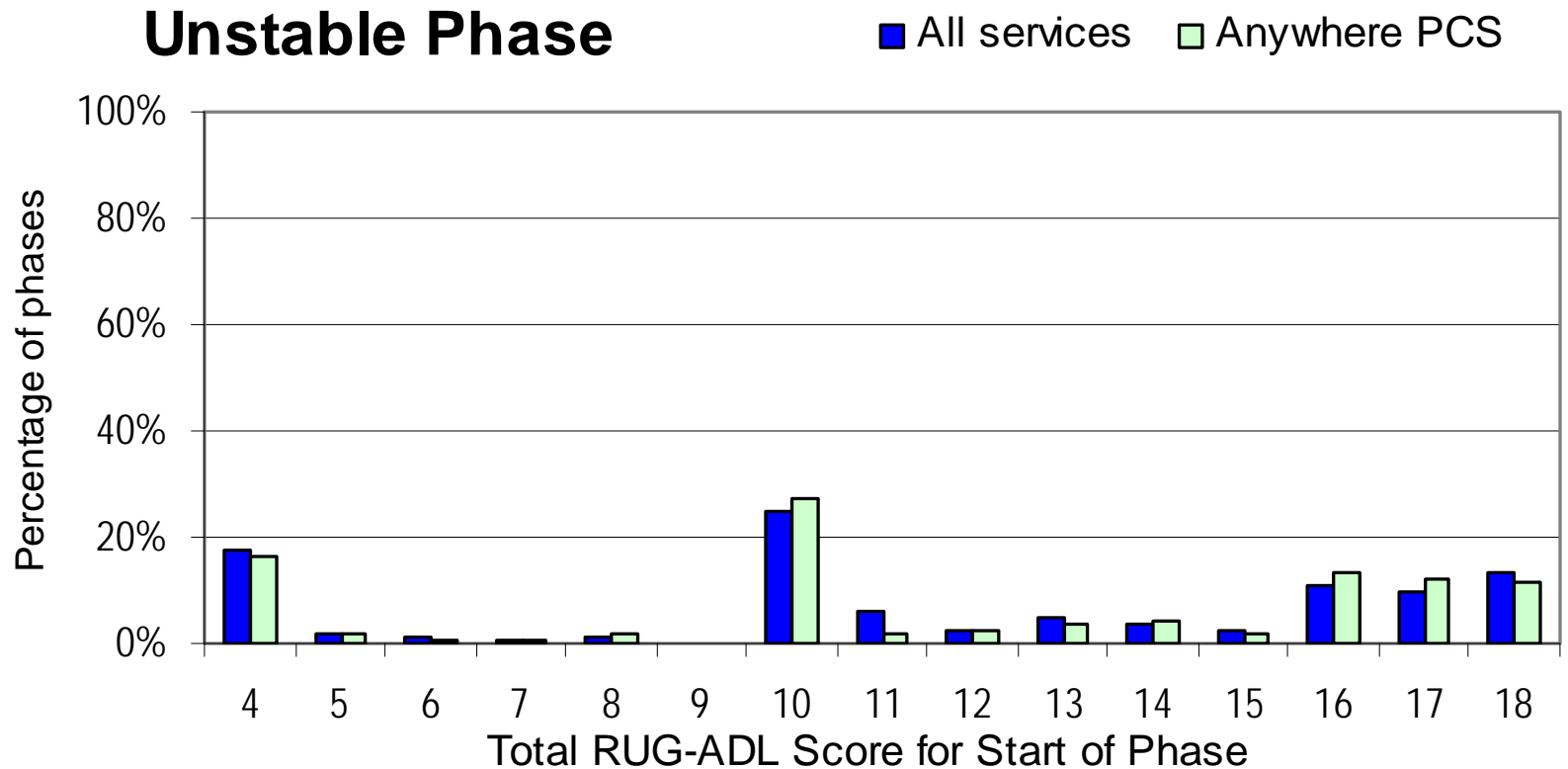
Outcomes

- Data to evaluate palliative care
- Use of common assessment tools
- Better understanding about what palliative care does

Outcomes



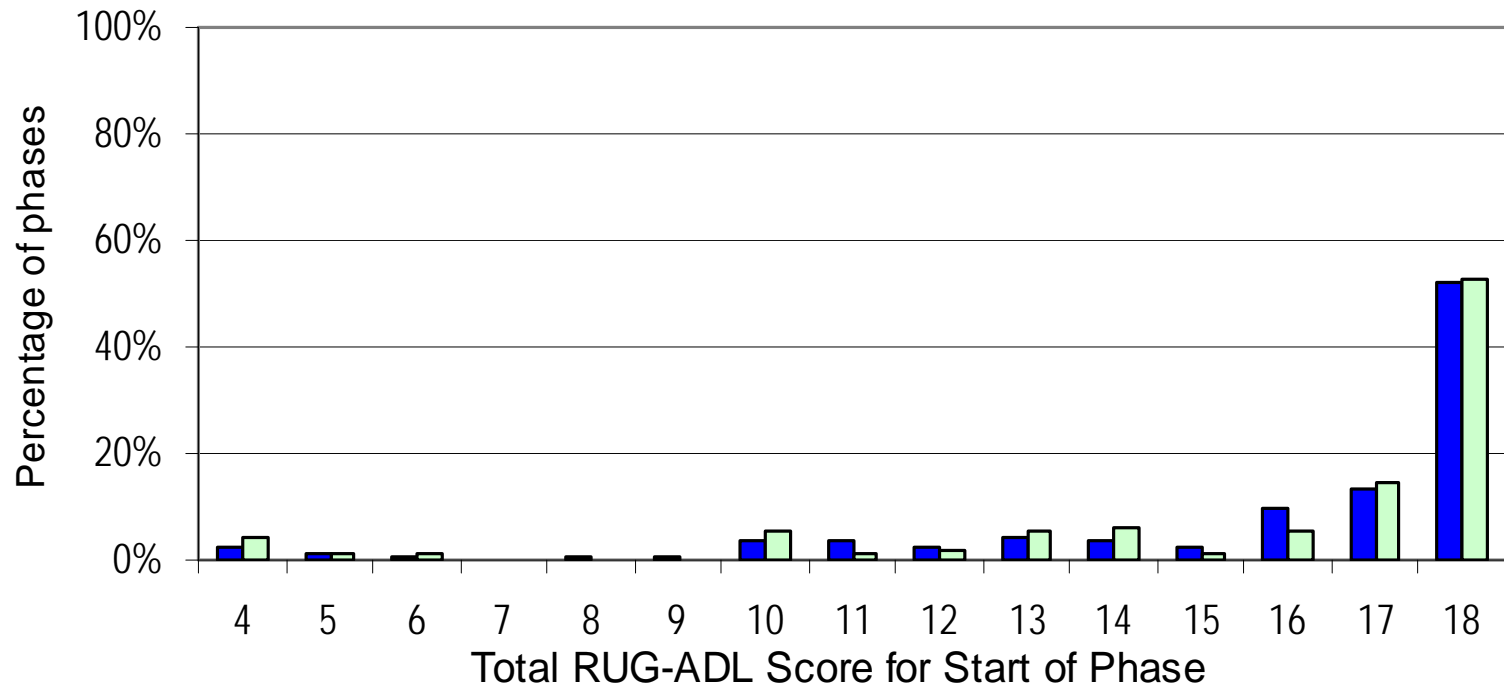
Outcomes



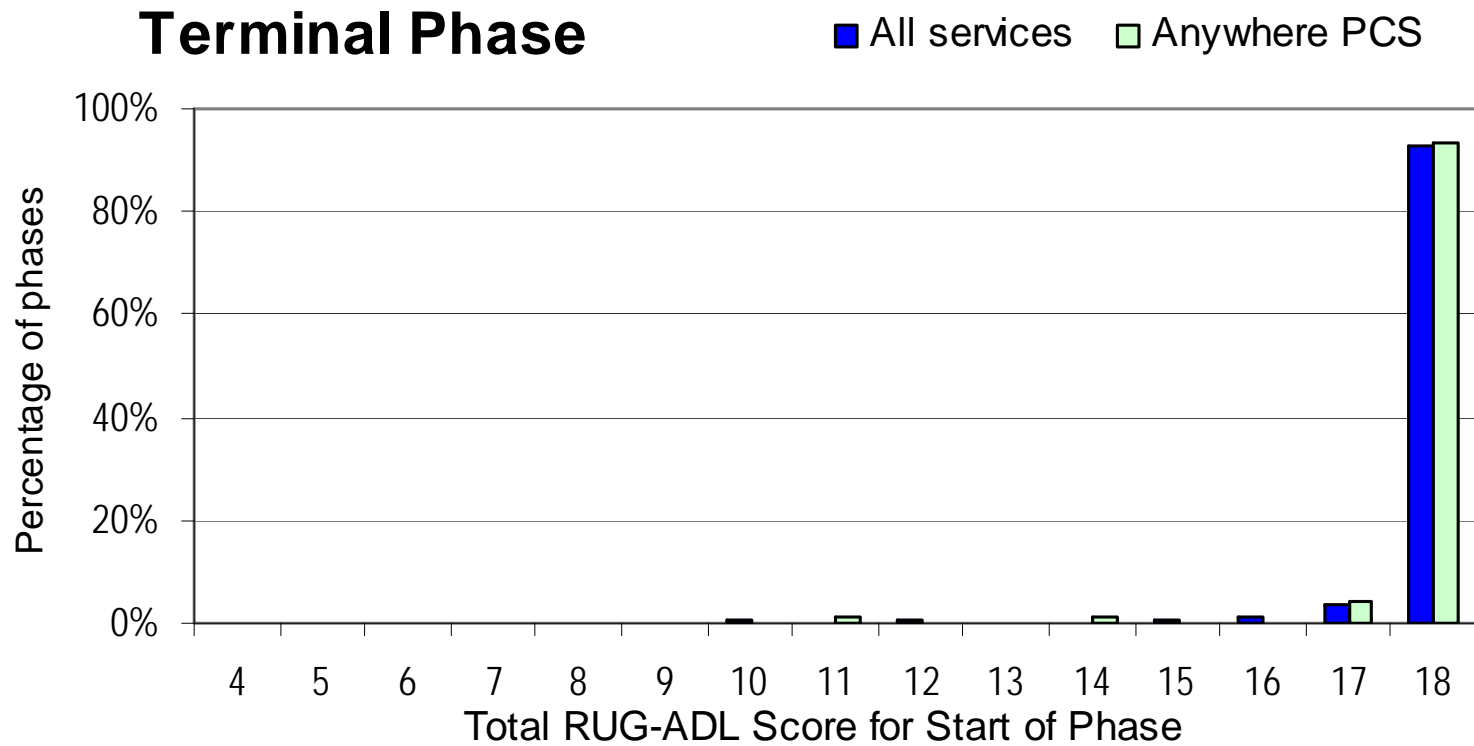
Outcomes

Deteriorating Phase

■ All services ■ Anywhere PCS



Outcomes





Discussion