

OUTCOME MEASURES IN PALLIATIVE CARE

RESOLVE
Resolving Symptoms in Cancer



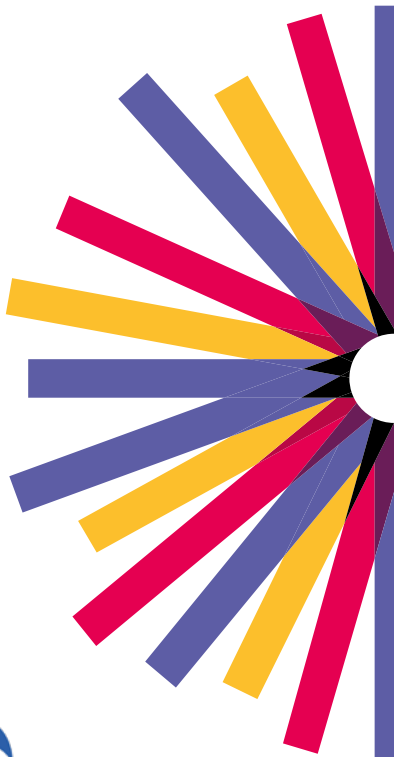
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research



Welcome to the RESOLVE Programme: which aims to improve the well-being, health status, and symptom experiences for people living with advanced cancer across Yorkshire. The Programme is funded by Yorkshire Cancer Research.

	<i>I have not had this symptom in the last 3 days</i>	<i>Little or no effect on activities or concentration</i>	<i>Some effect on activities or concentration</i>	<i>at least 3 times a week</i>
Pain	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Shortness of breath	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Weakness or lack of energy	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Nausea (feeling like you are going to be sick)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Vomiting (being sick)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Poor appetite	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Constipation	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Mouth problems	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Drowsiness	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Poor mobility	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

Please list any other symptoms not mentioned above, and tick one box to show how they have

The purpose of this programme is to implement routine and systematic assessment and monitoring of symptoms and other concerns into palliative care practice.

The project is supporting and enabling clinical teams to use and evaluate routine symptom assessment and outcome measures within palliative care settings. Outcome measures provide healthcare professionals with information that allows them to assess and monitor changes in wellbeing of patients. However, they are not consistently used in clinical practice. The RESOLVE project aims to address this through developing, implementing, and evaluating a new Yorkshire-wide Outcomes and Assessment Collaborative in routine palliative care practice.

The RESOLVE programme is a four-year collaborative programme of research and implementation led by the Universities of Leeds and Hull.

It consists of 3 workstreams:

Workstream 1:

To identify patients in Primary Care who need palliative care and improve access to palliative care services. This is led by the University of Leeds.

Workstream 2:

To implement validated patient-centered outcome measures into clinical practice, evaluating and improving standards of care. This is led by the University of Hull, with the team based at Hull York Medical School.

Workstream 3:

To improve management of three challenging symptoms encountered within palliative care: pain, breathlessness, and fatigue-exhaustion. This is led by the University of Leeds.

This booklet gives an overview of the Outcome Measures linked to **Workstream 2** of the Project. The following pages describe these Outcome Measures:

- ⊙ Palliative Phase of Illness
- ⊙ Australia-modified Karnofsky Performance Scale
- ⊙ The Integrated Palliative care Outcome Scale
- ⊙ Barthel Index – short form

PALLIATIVE PHASE OF ILLNESS

‘Phase of illness relates to the plan of care, not the illness’

Palliative Phase of Illness describes the urgency of care needs for a person receiving palliative care. It considers the care needs of both the patient and the family.

How to use Phase of Illness in practice

The Phase can be one of five possible Phases:

- ⊙ **Stable** (if the symptoms and concerns are controlled and no review is required)
- ⊙ **Unstable** (if urgent, unexpected symptoms or issues which need a change in care plan are present)
- ⊙ **Deteriorating** (if there are gradual and more expected symptoms or issues which need regular but not urgent review)
- ⊙ **Dying** (if the patient is expected to die in the next few days)
- ⊙ **Deceased** (if the person has died and usual after death care is being provided to family)

The first four Phases of Illness can occur in any order and may vary in duration. Patients may move between Phases in any sequence and the Phases do not last any set length of time. A patient may have two or more Phases in any episode of care.

The ‘stable’, ‘unstable’ and deteriorating’ **Phases are NOT reliant**

on stage of disease or prognosis, and may occur at any point in the illness trajectory, and in any order.

'Dying' Phase takes precedence over any other Phase.

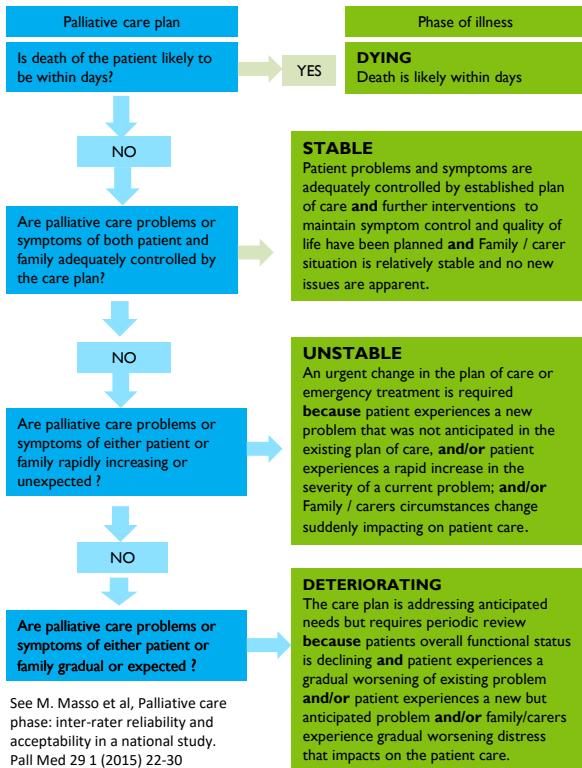
Please note that the Deteriorating Phase is NOT the same as 'a deteriorating patient' as used in acute care. Its meaning here is related to the plan of care as above.

A Phase change is assigned when there is a clinical change reflecting a move between these Phase descriptions (above) OR patient moves care setting.

How often should Phase of illness be assessed and recorded?

Phase of illness should be assessed and recorded daily (for in-patients) and with each contact (in the community). It should not be assessed more often than once a day in any setting.

Phase of illness allocation in accordance with phase definition



Palliative Phase of Illness

PHASE	START of PHASE	END of PHASE
1. STABLE	Symptoms and concerns are controlled and managed. A review to the care plan is not needed (unless something changes)	Symptoms and concerns of the patient and/or family increase, requiring changes to the existing plan of care OR the patient moves into/out of hospice/hospital/care setting
2. UNSTABLE	Urgent and unexpected symptoms and concerns have arisen which need intervention quickly and the palliative care plan to be changed	The care plan is not needing further changes. This does not necessarily mean that the symptoms have resolved, but there is a clear plan of care addressing them OR the patient moves into/out of hospice/hospital/care setting
3. DETERIORATING	Symptoms and concerns are more gradual and anticipated - a care plan is in place to address them, but this needs regular review	The symptoms or concerns are controlled or resolved (i.e. now stable) or an urgent change in the care plan is needed (i.e. now unstable) and/or death is likely within days (i.e. now dying) OR the patient moves into/out of hospice/hospital/care setting

Palliative Phase of Illness



PHASE	START of PHASE	END of PHASE
4. DYING	Death is expected in the next few days	Patient dies or condition changes and death is no longer likely within days OR the patient moves into/out of hospice/hospital/care setting
5. DECEASED	The patient has died	All care after death is completed

Palliative Phase of Illness was developed by Kathy Eagar and colleagues in Australia, and is used with permission. Further details can be found at:

Masso M, Allingham SF, Banfield M et al. Palliative Care Phase: inter-rater reliability and acceptability in a national study. *Palliative Medicine*. 2015;29(1):22-30.

Mather H, Guo P, Firth A et al. Phase of Illness in palliative care: Cross-sectional analysis of clinical data from community, hospital and hospice patients. *Palliative Medicine*. 2018;32(2):404-12.

AUSTRALIA-MODIFIED KARNOFSKY PERFORMANCE SCALE

The Australia-modified Karnofsky Performance Scale (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 and based on observations of a patient's ability to perform common tasks relating to activity, work, and self-care. A score of 100% signifies normal physical abilities with no evidence of impairment. Decreasing numbers indicate a reduced performance status.

How to assess AKPS

1. Use the AKPS definitions to determine the initial rating on admission or commencement of an episode of care.
2. Assess daily (in an inpatient setting), or with each visit (in a community setting or outpatient setting).
3. Re-assess whenever there is a Phase change and at the end of an episode of care.

Australian Karnofsky Performance Status (AKPS) – Definitions

AKPS Score	Description of Performance Status
100%	Normal, no complaints, no evidence of disease
90%	Able to carry on normal activity, minor signs or symptoms of disease
80%	Normal activity with effort, some signs or symptoms of disease
70%	Cares for self, but unable to carry on normal activity or to do active work
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, unable to care for self, requires equivalent of institutional or hospital care, disease may be progressing rapidly
0%	Dead

AKPS conversion to ECOG

AKPS Score	ECOG Score	Meaning
100	0	<p>Fully functional</p> <p>Dead</p>
90	1	
80	1	
70	2	
60	2	
50	3	
40	3	
30	4	
20	4	
10	4	
0	5	

THE INTEGRATED PALLIATIVE CARE OUTCOME SCALE (IPOS)

The IPOS is a questionnaire developed to assess the palliative care symptoms and concerns which patients and their families most often report. It is a validated measure that can be used in clinical care, audit, research and training.

IPOS helps identify the issues that are most relevant to patients at the time of the assessment. As palliative care patients live with their condition, expectations can change, as may the priority the person attaches to particular issues. IPOS can capture the patients' shifting priorities through these changes. It is important not to assume that particular symptoms or issues will remain constant. Completing the measure allows the aspects which are important to be reflected. IPOS should be completed at:

- ⊙ First assessment
- ⊙ Change of Phase, discharge or death

It is important to gain agreement and understanding of why IPOS is used, for each team, to ensure engagement and overall purpose.

More information about IPOS is available at ***www.pos-pal.org***

The Integrated Palliative care Outcome Scale (IPOS)



Q1: What have been your main problems or concerns over the past 3 days?

Then: How has the following symptom or concern affected you over the past 3 days?

	Score	
• Pain	• 0	Not at all
• Shortness of breath	• 1	Occasionally
• Weakness	• 2	Sometimes
• Nausea	• 3	Most of the time
• Vomiting	• 4	Always
• Poor appetite		
• Constipation		
• Sore or dry mouth		
• Drowsiness		
• Poor mobility		
• Anxious or worried about illness		
• Family anxious or worried?		
• Feeling depressed?		
• Practical issues?		

Please notice **the scale alters** for questions including peace, expression of feelings, information and practical problems

- | | | |
|--|-----|------------------|
| • Over the past 3 days have you felt peaceful / at peace? | • 0 | Always |
| • Have you been able to share feelings with family or friends? | • 1 | Most of the time |
| • Over the past 3 days have you had as much information as you wanted? | • 2 | Sometimes |
| | • 3 | Occasionally |
| | • 4 | Not at all |

BARTHEL – SHORT FORM

The Barthel scale is an ordinal scale used to measure performance in activities of daily living (ADL). Each performance item is rated on this scale with a given number of points assigned to each level or ranking. It uses ten variables describing ADL and mobility. A higher number is associated with a greater likelihood of being able to live at home with a degree of independence following discharge from hospital. The amount of time and physical assistance required to perform each item are used in determining the assigned value of each item.

Record the actual score, rather than the potential for the patient.

Barthel Index

A measure of activities of daily living.

Record actual, not potential, functioning.

Information can be obtained from the patient's self-report, from a separate party who is familiar with the patient's abilities (such as a relative), or from observation.

Bowels

- 0 Incontinent (or needs to be given enemata)
- 1 Occasional accident (once per week)
- 2 Continent

Bladder

- 0 Incontinent or catheterised and unable to manage
- 1 Occasional accident (max once per 24 hours)
- 2 Continent for over 7 days

Toilet Use

- 0 Dependent
- 1 Needs some help but can do something alone
- 2 Independent (on and off, dressing and wiping)

Dressing

- 0 Dependent
- 1 Needs help but can do about half unaided
- 2 Independent (including buttons, zips, laces etc.)

Grooming

- 0 Needs help with personal care
- 1 Independent face/hair/teeth/shaving

Barthel Index

Bathing

- 0 Dependent
- 1 Independent (or in shower)

Feeding

- 0 Unable
- 1 Needs help cutting, spreading butter, etc.
- 2 Independent (food provided within reach)

Stairs

- 0 Unable
- 1 Needs help (verbal/physical/carrying aid)
- 2 Independent up and down

Mobility

- 0 Immobile
- 1 Wheelchair independent, including corners, etc.
- 2 Walks with help of one person (verbal or physical)
- 3 Independent (but may use any aid, e.g. stick)

Transfer

- 0 Unable – no sitting balance
- 1 Major help (one or two people, physical), can sit
- 2 Minor help (verbal or physical)
- 3 Independent

Mahoney FI, Barthel DW. Functional evaluation: the Barthel Index. *Md State Med J.* 1965;14:61-65.

Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. *Int Disabil Stud.* 1988;10(2):61-63



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Further resources:
IPOS: www.pos-pal.org

Monthly ECHO Outcomes Webinar

(supported by Hospice UK)
Please see the link below to
register to the network:
<https://tinyurl.com/y336ky7p>

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