

RESOLVE - Understanding the processes underpinning the successful implementation of Patient-Centred Outcome Measures

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## What are patient-centred outcome measures?

Outcome = "the change in a patient's current and future health status that can be attributed to preceding healthcare"



## What are patient-centred outcome measures?

#### Patient-centred outcome measures (PCOMs) – standardised and validated

questionnaires that provide us with information about a person's health and well-being

START	END
Stable	•
Patient problems and symptoms are adequately controlled by established plan of care and • Further interventions to maintain symptom control and quality of life have been planned and • Family/carer situation is relatively stable and no new issues are apparent.	The needs of the patient and / or family/carer increase, requiring changes to the existing plan of care.
Unstable	
<ul> <li>An urgent change in the plan of care or emergency treatment is required because</li> <li>Patient experiences a new problem that was not anticipated in the existing plan of care, and/or</li> <li>Patient experiences a rapid increase in the severity of a current problem; and/or</li> <li>Family/ carers circumstances change suddenly impacting on patient care.</li> </ul>	<ul> <li>The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) and/or</li> <li>Death is likely within days (i.e. patient is now terminal).</li> </ul>
Deteriorating	
The care plan is addressing anticipated needs but requires periodic review because • Patients overall functional status is declining and/or • Patient experiences a gradual worsening of existing problem and/or • Patient experiences a new but anticipated problem and/or • Family/carers experience gradual worsening distress that impacts on the patient care.	<ul> <li>Patient condition plateaus (i.e. patient is now stable) or</li> <li>An urgent change in the care plan or emergency treatment and/or</li> <li>Family/ carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (ie patient is now unstable) or</li> <li>Death is likely within days (i.e. patient is now terminal).</li> </ul>
Terminal	
Death is likely within days.	<ul> <li>Patient dies or</li> <li>Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating).</li> </ul>
Bereavement – post death support	·
<ul> <li>The patient has died</li> <li>Bereavement support provided to family/carers is documented in the deceased patient's clinical</li> </ul>	Case closure Note: If counselling is provided to a family member or carer, they become a client in their own right.

**Palliative Phase Of Illness** 

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick <u>one box</u> that best describes how it has <u>affected</u> you <u>over the past</u> week.

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Pain	0	1	2	3	4
Shortness of breath	0	1	2	3	4
Weakness or lack of energy	0	1	2	3	4
Nausea (feeling like you are going to be sick)	0	1	2	3	4
Vomiting (being sick)		1	2	3	4
Poor appetite	0	1	2	3	4
Constipation		1	2	3	4
Sore or dry mouth	0	1	2	3	4
Drowsiness	0	1	2	3	4
Poor mobility	0	1	2	3	4

#### Integrated Palliative care Outcomes Scale (IPOS)

AKPS ASSESSMENT CRITERIA	SCORE
Normal; no complaints; no evidence of disease	100
Able to carry on normal activity; minor sign of symptoms of disease	90
Normal activity with effort; some signs or symptoms of disease	80
Cares for self; unable to carry on normal activity or to do active work	70
Able to care for most needs; but requires occasional assistance	60
Considerable assistance and frequent medical care required	50
In bed more than 50% of the time	40
Almost completely bedfast	30
Totally bedfast and requiring extensive nursing care by professionals and/or family	20
Comatose or barely rousable	10
Dead	0

#### The Australia-modified Karnofsky Performance Scale (AKPS)



# Uses of patient-centred outcome measures

<ul> <li>For better individual patient care:</li> <li>Person-centred</li> <li>Supports assessment</li> <li>If responded to well, improves care</li> <li>Person-level outcomes</li> </ul>	<ul> <li>For better team working:</li> <li>Focuses patient reviews</li> <li>Improves team workload planning</li> <li>Enhances intra and inter- team communication</li> </ul>	
<ul> <li>Organisation quality improvement:</li> <li>Aggregated cohort data</li> <li>Service evaluation and development</li> <li>Quality improvement</li> <li>'Business intelligence' to support/sustain resourcing</li> </ul>	<ul> <li>To improve care at population level:</li> <li>Who is accessing palliative care with what benefit?</li> <li>Population-level benchmarking</li> <li>Integration with other health and social care services</li> </ul>	

#### Adapted from Greenhalgh. Qual Life Res (2009) 18



## The **RESOLVE** project

#### Aims

 To use implementation theory to understand and explain the causal mechanisms that underpin successful implementation of Person-Centred Outcome Measures within palliative care.

2. Collaboratively develop theoretically informed strategies to address challenges





## Theoretical Framework: Normalisation Process Theory (NPT)



- Consists of 4 constructs that explore the inter-connected processes through which outcome measures are implemented into routine practice:
  - Coherence: how individuals and groups <u>understand</u> outcome measures
  - 2. Cognitive Participation: what people do to <u>engage in,</u> <u>legitimize, and build a community around</u> the use of outcomes measures
  - 3. Collective action: <u>skills and resources</u> within the organisation
  - 4. Reflexive Monitoring: how people <u>assess the value</u> of oucome measures



## **Key findings: Coherence**

#### **General challenges**

• *Difficulty scoring:* Due to perceived subjectivity of measures

#### Measure-specific challenges

- Ambiguity/confusion over Phase of Illness meaning
- Frequency of use and version of IPOS





## **Key findings: Cognitive participation**

- Top down approach to implementation: An autocratic approach led to people feeling detached from the implementation and use of measures
- Inconsistent (or lack of) communication: 'Out of sight, out of mind'





### **Key findings: Collective action**

• *Battling with electronic systems:* To input data onto, use it within, and extract it off the electronic systems used within a service





## **Key findings: Reflexive monitoring**

Reinforcing use through demonstrating value: Through feedback of data to those who use outcome measures.
 When this was not done, outcome measures were often seen as a 'tickbox exercise'



## To summarise putting outcome measures into practice

Bradshaw, A., Santarelli, M., Mulderrig, M., Khamis, A., Sartain, K., Boland, J. W., Bennett, M. I., Johnson, M., Pearson, M., & Murtagh, F. E. M. (2020). Implementing person-centred outcome measures in palliative care: An exploratory qualitative study using Normalisation Process Theory to understand processes and context. Palliative Medicine.

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## **Recommendations and ways forward**

#### Those leading implementation and using outcome measures:

- Is there sufficient training/educational support?
- Do people know how to use outcome measures appropriately?
- Are efficient I.T. systems in place that can be easily used?
- Is everybody included in implementation?
- Are there people championing change?
- How are outcome measures being integrated into team working?
- Are outcome measures being fed back?



For more training/educational resources, visit: <u>https://www.hyms.ac.uk/research/research-</u> <u>centres-and-groups/wolfson/resolve/resolve-</u> <u>training-resources</u>



Thank you

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