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# Meaningful and relevant outcome measures in palliative medicine

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# Focus

- Practical issues around obtaining patient/family caregiver outcomes
- How this can be used to support appraisal and reflect our effectiveness as palliative care clinicians
- What outcome measures are the most meaningful/relevant and how to implement them

# What is an 'outcome measure'?

- 'outcome' is often used in a lay sense to mean 'the result or consequence of something'
- 'outcome measure' has specific meaning in health – a measure of 'change in health status for patient and/or family' rather than measure of structure/processes needed to deliver care (which are easier to measure, but which don't always make impact on health status)
- distinct from experience measures
  - 'a measure of patient / family's perceptions about ... the health care they have received' (Coulter et al, 2009)

# Practical issues – who records?

- ideally patients themselves (Patient Reported Outcome Measures - PROMS) **BUT**
  - in palliative care many too ill or lack capacity to complete; ~ 60% hospice pts and ~15-25% community patients need help completing outcome measures (Etkind 2014).
- proxy reporting (family or staff) is both necessary and useful (Kutner 2006)
- therefore appropriate to use proxy measures for appraisal and revalidation purposes
- person-centred outcome measures (PCOMs) proposed instead of PROMs (Etkind 2014)

# Practical issues – how to use for appraisal and revalidation?

- Evidence of the introduction of an outcome or experience measure into clinical practice
- Evidence of use of outcome or experience measures in audit, service evaluation or research
- Patient-level data reports which relates to interventions of a specific professional (more difficult to obtain, since most palliative care is underpinned by team working)

# Practical issues – how to use for appraisal and revalidation?

- Use of feedback from outcome or experience measures for yourself and/or other team members to directly influence patient care
- Documentation of the use of feedback from outcome or experience measures to directly modify team practices and processes
- Contribution to regional or national initiatives requiring outcomes and experience measures, such as regional outcomes initiatives, the national Palliative Care Clinical Dataset, the Palliative Care Funding currency, etc

# Practical issues – how to implement?

- Involve key people
- Prepare your systems (especially IT)
- Preparing the team
- Training
- Starting to use the outcome measures
  - Go step by step, revisit training
- Feeding back data to inform care
- Understanding what is working and what is not
- Using the data to improve care
  - Also audit, service improvement, business case, appraisal, annual report, national data, currency, etc

# What outcome measures to use?

## 1. Phase of illness

- Australian modified definitions (good reliability)

## 2. Functional status

- Australian modified Karnofsky Performance Scale
- valid, reliable, in cancer & non-cancer, more discriminatory than ECOG or WHO
- (could also use ECOG or WHO but less discriminatory)
- Barthel 10 item (for inpatients only)

## 3. Problem severity

- Integrated Palliative care Outcome Scale IPOS (+ Views on Care)
- valid, reliable, sensitive to change, brief
- (could also use ESAS or MSAS-SF but symptoms only)

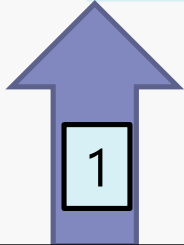
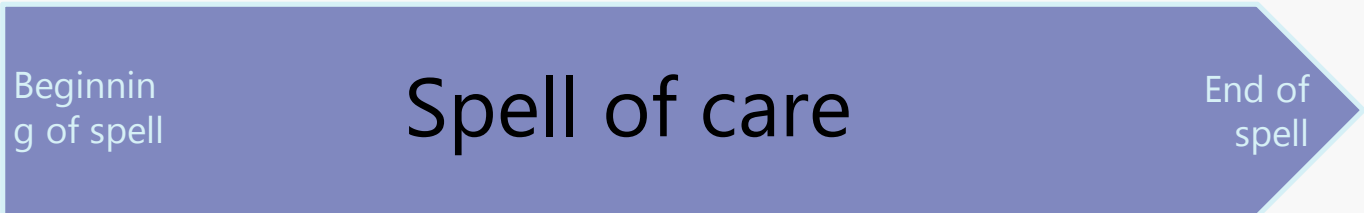
## 4. Family caregiving strain

- 2 carer questions (+ Zarit Carer Interview)

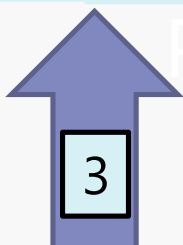




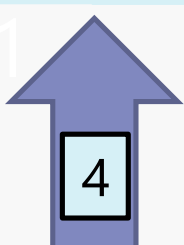
**2** Monitor phase of illness daily or with each contact



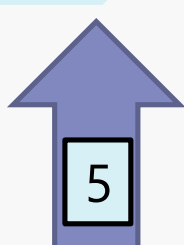
Phase of illness  
AKPS  
IPOS  
Barthel (IP\* only)  
Carer measures\*



AKPS  
IPOS  
Views on Care  
Barthel (IP\* only)  
Carer measures\*



AKPS  
IPOS  
Views on Care  
Barthel (IP\* only)  
Carer measures\*



AKPS  
IPOS  
Views on Care  
Barthel (IP\* only)  
Carer measures\*

\* IP = Inpatient

\* Carer measures as close to first assessment / admission or phase change or discharge as possible

# Resources to support you

- Document: *Appraisal Metrics for Consultants and SSAS doctors in Specialist Palliative Care*
- In partnership with Hospice UK, the Cicely Saunders Institute is providing Resource Packs (training and other support materials) to help palliative care services implement outcome measures, through the **OACC project** (see <http://goo.gl/Des4P1>).
- Any palliative care service can register interest in accessing these Resource Packs
  - simply email [oacc@kcl.ac.uk](mailto:oacc@kcl.ac.uk)





**Further information:**

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