

Slide 3 in the initial presentation and in this one: Patient Reported (not Centered) Outcome Measures (PROMs)

ADD : Person Centred ... (PCOMs)

• Slide 4 in the initial and in this presentation :

Integrated Palliative (not patient) Outcome Scale

ADD as a second bullet : Patient and proxy version

Outcome Measurement in Palliative Care

The Essentials

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Patient Reported Outcome Measures (PROMs) or Person Centred... (PCOMs)

- Definition : "the change in a patient's current and future health status that can be attributed to preceding healthcare"
- Why use PROMs : 1. Mapping patients' symptoms and problems (baseline future measure change)
 - 2. Support communication & professional decision making
 - 3. Illustrating effectiveness and quality of care
- *Nevertheless* : Implementing them routinely in everyday practice is still a challenge

Outcome measure	Number of items	Completion time	Additional comments
Palliative care Outcome Scale (POS) ⁵	10 items on physical symptoms, emotional, psychological and spiritual needs, provision of information and support I open question on main problems	mean time 6.9 min (patients) and 5.7 min (staff); repeated assessments of patients and staff mean time < 4 min ⁵	scores from 0 ('no effect') to 4 ('overwhelming'): patient, staff and carer version; widely used palliative care measure freely available after registration
POS-S Symptom list	10 symptoms 2 questions about the symptom that affected the patient the most and that has improved the most	few minutes	scores from 0 ('no effect') to 4 ('overwhelming'); additional symptom versions available for other conditions (POS-S MS, POS-S renal); freely available after registration
Distress Thermometer ⁹	overall distress score 20 symptoms, 5 items on practical problems, 4 on family problems, 5 on emotional problems, 2 on spiritual concerns	median length of time 5 min, with 75% taking no more than 10 min ¹⁰	distress score 0-10; other items yes/no
Edmonton Symptom Assessment Scale (ESAS) ⁶	9 symptoms and 1 "other problem"	approximately 5 min ¹¹	each symptom with NRS 0-10 developed to measure the most commonly experienced symptoms in cancer patients; freely available
Memorial Symptom Assessment Scale (MSAS) ¹²	28 physical and 4 psychological symptoms	20-60 min, ¹³ short form < 5 min	measuring presence, frequency, severity and distress of symptoms; short form version available (MSAS-SF) only presence and distress of symptoms developed for cancer patients but also used in other conditions
Hospital Anxiety and Depression Scale (HADS) ⁷	14 items (7 depression, 7 anxiety)	2-6 min ¹⁴	developed to assess depression and anxiety for people with physical illness; not freely available
EORTC QLQ-C30 ¹⁵	5 functional scales (physical, role, emotional, social, and cognitive), 3 symptom scales (fatigue, nausea/vomiting and pain), a global health status/ QoL scale and six single items (dyspnoea, insomnia, appetite loss, constipation, diarrhoea, and financial difficulties)	first assessment 12 min (SD 7.5 min), second assesment 11 min (SD 6.5 min) ¹⁵	not freely available, widely used in cancer research; modular supplement available for a range of malignancies(lung, breast, gastric, brain etc.)
EORTC QLQ-C15-PAL ¹⁶	pain, physical function (3 items), emotional function (2 items), fatigue (2 items), QoL (1 item), symptoms (6 items)	< 20 min ¹⁷	not freely available, shortened version of the EORTC QLQ-C30 for palliative care patients

Integrated Palliative Outcome Scale (IPOS)

IPOS:

- 17 items' questionnaire
- Patient and Proxy versions
- Translated +/- validated in 17 languages
- captures the impact of symptoms and problems (including patient and family anxiety, information needs, practical problems and spiritual dimensions of well being)



The Palliative care Outcome Scale outline for new & current users

The POS measures are a group of tools developed to measure Palliative care needs of patients and their families. They are validated instruments that can be used in clinical care, audit, research and training. They are widely used globally including in Europe, Australia, Asia, Africa and America. The POS measures are specifically developed for use among people with advanced diseases such as cancer, respiratory, heart, renal or liver failure, and neurological diseases. They are free to download and use, just register on our website. Here you will also find other free resources.

Below is a short summary of the generic versions available, who the measures are for, what languages they are known to be translated in to and a brief description of the measure itself. Disease specific measures are also available for download from our website.

POS measure version	Versions to be	Known languages	Brief description of POS
available	completed by:	translated into at present	measure
IPOS (Integrated POS) (Being validated in many different settings where palliative care patients may receive care)	Patient and Staff (3 day recall period and 1 week recall period)	English <i>Currently being validated in:</i> German Swedish Greek Romanian Israeli Japanese Chinese simplified Chinese traditional Turkish Polish French Italian Portuguese	IPOS is a new development, integrating the most important questions from POS, POS-S and the APCA African POS. It has been welcomed by patients and professionals as a more streamlined measure which is brief, yet which still captures their most important concerns - both in relation to symptoms, but also extending to information needs, practical concerns, anxiety or low mood, family anxieties and overall feeling of being at peace.