

# Outcome measures in palliative care; a new Clinical Decision Support Tool and Guidance for the Palliative care Outcome Scale

**New research carried out by the Cicely Saunders Institute at King's College London and published by BMC Medicine shows that:**

- A Clinical Decision Support Tool (CDST) for responding to Palliative care Outcome Scale (POS) scores for i) information needs, ii) family anxiety, iii) depression, and iv) breathlessness, and accompanied Guidance on implementing Patient Reported Outcome Measures (PROMs) in clinical palliative care have been developed.
- Good patient care, psychosocial support, and open communication are important for all POS scores. Assessment and (non)pharmacological interventions are appropriate for increasing scores.
- 8 Steps (from identifying measurement goals to evaluation of impact) can guide the implementation of PROMs.

**Policy recommendations:**

- Robust outcomes measures (the POS family of measures) are now available for use across palliative and end of life care.
- This CDST and the Guidance provide clinicians with the resources to support implementation and use of POS. Items of POS are recommended for use in the UK and internationally.

## Introduction

Patient-reported measures are recommended to support choice and empower patients to actively participate in their care. However, doctors, nurses and other clinicians are uncertain how to use such measures (1-3). When using the Palliative care Outcome Scale, patient scores on the items i) information needs, ii) family anxiety, iii) depression, and iv) breathlessness were found by clinicians to lead to most uncertainty.

The Cicely Saunders Institute has therefore developed two sets of guidance:

1. A Clinical Decision Support Tool (CDST) for how to respond to POS scores for: i) information needs, ii) family anxiety, iii) depression, and iv) breathlessness.

2. Accompanied guidance on how to implement PROMs in clinical palliative care, with a focus on the POS family of measures.

## Summary of research

The CDST was created based on evidence and expert opinion. Based on systematic literature searches recommendations were created on how to respond to the specified symptoms. In an online study, patient representatives, clinicians, and researchers rated the appropriateness of the recommendations for different severity of problems in the CDST.

The implementation guidance was based on data from previous literature and created with help from experts in the field.

## Results

The CDST helps support clinical care and improve evidence-based outcomes for patients with progressive illness and their families, addressing four specific areas of clinical uncertainty. Good patient care, psychosocial support and empathy, and open

communication are central to supporting patients and families affected by all POS concerns. Detailed assessment is recommended for increasing problems (i.e. scores), followed by non-pharmacological interventions and for breathlessness and depression, pharmacological interventions.

The accompanying Guidance builds on the 8-step International Society for Quality of Life Research framework (4). These steps cover the entire spectrum of implementing PROMS, from identifying the goals for measuring PROMS; via selecting of a questionnaire, to evaluation of the impact of measuring PROMS on practice.

### Policy recommendations

Robust outcomes measures (the POS family of measures) are now available for use across palliative and end of life care.

This CDST and the Guidance provide clinicians with the resources to support implementation and use of POS.

Items from POS are recommended for national use in the UK (see: [http://www.endoflifecare-intelligence.org.uk/national information standard/palliative care dataset/proposeddataitems](http://www.endoflifecare-intelligence.org.uk/national_information_standard/palliative_care_dataset/proposeddataitems)) and internationally (see: <http://pos-pal.org/doc15/s19114en.pdf>.)

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