

Creating guidance for the use of Patient Reported Outcome Measures (PROMs) in clinical palliative care

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Introduction

- ❖ Clinicians' are often not very good at estimating patients' symptoms and needs. Routine use of Patient Reported Outcome Measures (PROMs) in clinical practice enables measuring patients' symptoms and can influence care but is not always achieved. One reason for this, agreed by clinicians and experts, is a lack of guidance.
- ❖ This project aims to provide guidance on how to use Patient Reported Outcome Measures (PROMs) in clinical palliative care.

Methods

- ❖ The 8-steps of implementing PROMs in clinical practice proposed by the International Society for Quality of Life Research (ISOQOL) (1) were used as framework. Recommendations within each step were provided based on previous work, most importantly the booklet 'Outcome Measurement in Palliative Care: The Essentials' (2), the EAPC white paper on Outcome Measures (3) and the ISOQOL guidelines.

Results

Step	Key recommendations
1 Identify the goals for collecting PROMs	Patient level goals: e.g. screening/monitoring for symptoms and problems, Service/setting level goals: e.g. evaluate and improve the quality of care Policy level goals: improving and monitoring palliative care practice on policy level
2 Select patients, setting and timing of assessment	Respondents: The ideal way to collect PROM data is patient report. In palliative care this can be difficult, in which case proxy rating is used Setting: within/outside the clinical setting and within/between visits. Timing: Measurement frequency and questionnaire length should be related.
3 Determine which questionnaire to use	Take several factors into consideration in choosing outcome measure e.g. aim of use, questionnaire available. Choose outcome measure based on (psychometric) evidence, suited for the clinical task. Use multidimensional (specific or generic) measures which allow for comparisons
4 Choose a mode for administering/scoring the questionnaire	PROMS can be collected using self- and interview-administration, while computer-completion is efficient. Explain to patients why PROMS are helpful. Pilot the measure with a few patients
5 Design processes for reporting results	PROM results should be shared with other health care practitioners and patient. Decide how to present results, e.g. numerical info (easy to generate) Store data in accordance with legal requirements
6 Identify aids to facilitate score interpretation	For measures responsive to change use (and determine) the Minimum Clinically Important Difference Cut-off scores can help with interpreting scores. Guidelines or disease management pathways can be linked to PROM scores.
7 Develop strategies for responding to identified issues	PROM scores should go into clinical notes, shared with clinicians/patients, and used to improve care and influence decision-making. PROM scores might be integrated with other clinical data Develop a routine for how PROM scores are used in ward rounds etc.
8 Evaluate the impact of measuring PROMs on practice	Precondition for successful implementation: use change management principles, facilitation and communication Take into account described facilitators/barriers during preparing, implementing, and evaluating PROM measurement in clinical care Evaluate the impact of the PROM implementation: e.g. set up quality improvement initiatives (audits/benchmarking)

Conclusion

- ❖ As PROMs are increasingly being used in palliative care, the proposed guidance is essential and timely. Future work will integrate this work with more questionnaire-specific (i.e. the Palliative care Outcome Scale) guidance and other projects on implementing PROMs in clinical care at the Cicely Saunders Institute, e.g. The OACC project.

References: 1. International Society for Quality of Life Research (prepared by Aaronson N, Choucair A, Elliott T, Greenhalgh et al.). User's Guide to Implementing Patient-Reported Outcomes Assessment in clinical Practice, Version: November 11, 2011. 2. Bausewein C, Daveson B, Benalia H, Simon ST, Higginson IJ. Outcome Measurement in Palliative Care: The Essentials. 2011 3. Bausewein C, Daveson BA, Currow DC et al. EAPC White paper on Outcome Measurement in Palliative Care: Improving Practice, Attaining Outcomes and Delivering Quality Services. Recommendations from the European Association for Palliative care (EAPC) Task Force on Outcome Measurement. 2014

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