




Appendix G – Patient (or Palliative) Outcome Scale

<p>“ Wow Me with Data “</p>  <p>Paul McIntyre and Glenna Thornhill</p>	<p>“ Know which abnormality you are going to follow during treatment. Pick something you can measure. ”</p> <p>Meador, A Little Book of Doctors’ Rules.</p>
<p>“Standards are not neutral ... They are as much about power and control as they are about ‘best practice’. For every standard adopted, something else shifts in the system – and it’s usually something we have neither predicted nor sought to measure. These issues are complex and subtle. It is small wonder that trials with deterministic designs and predefined outcome measures fail to capture them.</p> <p>Trish Greenlagh, British Medical Journal 2009</p>	<p>“ Box-ticking has often improved the care I provide my patients despite my assumption that my practice is already evidence-based. ”</p> <p>Trish Greenlagh, British Medical Journal 2009</p>
<p>Outcome</p> <p>“ ... any end result attributable to health services intervention ... “</p> <p>Measure should be clinically relevant, practical, valid, reliable, able to show change over time.</p>	<p>Implementing patient reported outcome measures (PROMs) in palliative care - users' cry for help.</p> <p>Bausewein Health Qual Life Outcomes 2011</p>
 <p>Outcome Measurement in Palliative Care <i>The Essentials</i> Bausewein C, Davison B, Benalia H, Simon ST, Higginson IJ</p>	<p>lit review outcomes in PC J Publ Health Med 1999</p> <p>reliability/validity POS Qual Health Care 1999 Health Qual Life Outcomes 2004</p> <p>Higginson, et al.</p>

	<p>Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale</p> <p>Harding Health Qual Life Outcomes 2010</p>
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<p>Psychological Well-Being and Quality of Care: A Factor-Analytic Examination of the Palliative Care Outcome Scale</p> <p>Siebert, et al JPSM 2010</p>	<p>Use of the Palliative Outcome Scale in Argentina: A Cross-Cultural Adaptation and Validation Study JPSM 2008</p> <p>Validation and Clinical Application of the German Version of the Palliative Care Outcome Scale JPSM 2005</p>
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 <p>POS use around the world</p>	<p>Doing secondary data-analysis on POS-datasets. & POS/ESAS/MSAS/interRAI LTC www.euro-impact.eu</p>
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<p>Palliative (Patient) Outcome Scale</p> <ul style="list-style-type: none"> <input type="checkbox"/> 10 items + open question <input type="checkbox"/> pt/family/staff versions <input type="checkbox"/> 12 language translations <input type="checkbox"/> modular optional versions <input type="checkbox"/> add-on symptom card 	 <p>Assessment Staff Training Team Comm Goal Attainment Audit Outcomes Research</p>
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“engagement by both patient and clinician in endlessly adaptive work of dealing with illness ... attention to here and now contextual detail is crucial. An excessive focus on standards reinforces the erroneous notion that the quality benchmark can be wholly established and expressed in the language of decision science.”

“Box-ticking has often improved the care I provide my patients despite my assumption that my practice is already evidence-based.” Trish Greenlagh, British Medical Journal 2009

<p>Is It Feasible and Desirable to Collect Voluntarily Quality & Outcome Data Nationally in Palliative Oncology Care?</p> <p>Currow, 2008.</p> 	<p>Establishing a Regional, Multisite Database for Quality Improvement and Service Planning in Community-Based Palliative Care and Hospice</p> <p>Bull, et al.</p> <p>Journal of Palliative Medicine 2009</p>
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	 <p>“ Statistics & Stories “</p> <p>Cicely Saunders, in “Pioneers of Hospice” DVD</p>
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	<p>“ Being able to sit together and listen to meaningful music together allowed Mom and (our) family to express and feel pain and happiness and sadness without having to struggle to put it into words. ”</p> <p>CHIPCS Music Therapy Evaluation 2009</p>
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<p>Use of serial qualitative interviews to understand pts’ evolving experiences & needs.</p> <p>Murray, et al.</p> <p>British Medical Journal 2009 </p>	<p>Using POS as part of a multi-methods study of supportive care needs of non-cancer patients.</p> <p>Primary Palliative Care Research Group The University of Edinburgh</p>
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“create an environment of watchful concern that motivates everyone to reflect on how best to serve the community“