Outcomes Measures in Palliative Care
A Guide to Useful Introductory Reading and Resources

The most important papers to start with are shown in surrounded by a box. Some papers and open access journal articles are available directly from websites. For journal articles that are not open access, contact your DHB library, or organisational or local public library for assistance.

1. New Zealand Strategies and “Measuring what Matters”

The New Zealand Health Strategy uses the word “outcome” extensively. In the section on turning the strategy into action (page 37): “In partnership with the health system, and other government agencies, the Ministry of Health will monitor work undertaken on the actions in the roadmap as part of making the Strategy happen. A set of measures, including measures of health outcomes and equity of outcomes, will be used to track progress. These will be shared widely to demonstrate and motivate ongoing learning and change. They will also support the Minister’s annual report on the implementation of the Strategy as required by legislation.” [emphasis added]


The accompanying Roadmap of Actions (on the same website) goes further, saying (page 14): “Possibly one of the most important and achievable gains we can make in the performance of the system will come from making smarter and more transparent use of information. As an integral part of a performance framework based on health outcomes and equity of health outcomes, this improved use of information will bring immediate benefits at the point of care and also in the longer term. It will also help the system as a whole to more purposefully target high-need priority populations.” [emphasis added].

Action 14 in the Roadmap of Actions says: “Develop and implement a monitoring framework focused on health outcomes, with involvement from the health and disability system, service users and the wider social sector.”

The Review of Adult Palliative Care Services¹, which has not yet been published, is likely to have further material on palliative care outcomes. The revised Healthy Ageing Strategy, released in December 2016,² also uses extensive language about outcomes. See particularly the outcomes described under “Respectful end of life”.

The Palliative Care Council completed significant work on an outcomes framework for palliative care at a systems level. The document “Measuring what Matters” remains highly relevant and current for palliative care in New Zealand. It has been used in several DHBs to focus efforts across all palliative care providers.


¹ http://www.health.govt.nz/our‐work/life‐stages/palliative‐care/review‐adult‐palliative‐care‐services
² http://www.health.govt.nz/publication/healthy‐ageing‐strategy
It will be vital to ensure that outcomes measures in New Zealand are developed using the approach and philosophy of He Korowai Oranga. The 2014 refresh of the Māori Health Strategy “expands the aim from whānau ora to pae ora – healthy futures. Pae ora has three elements: mauri ora – healthy individuals; whānau ora – healthy families; and wai ora – healthy environments.” Outcome measures for Māori are an important thread in He Korowai Oranga.


2. The Importance of Quality and Measuring Outcomes in Palliative Care

A useful recent publication by Kamal and colleagues on the importance of measuring quality and outcomes for palliative care has some very direct language for palliative care clinicians. Kamal use a definition of quality which includes outcomes: “Quality health care [is the] degree to which health care services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.”

“Palliative medicine must prioritize the routine assessment of the quality of clinical care we provide. This includes regular assessment, analysis, and reporting of data on quality. Assessment of quality informs opportunities for improvement and demonstrates to our peers and ourselves the value of our efforts. In fact, continuous messaging of the value of palliative care services is needed to sustain our discipline; this requires regularly evaluating the quality of our care. As the reimbursement mechanisms for health care [in the U.S.] shift from fee-for-service to fee-for-value models, palliative care will be expected to report robust data on quality of care.”

“We must move beyond demonstrating to our constituents (including patients and referrers), ‘here is what we do,’ and increase the focus on ‘this is how well we do it’ and ‘let us see how we can do it better.’ It is incumbent on palliative care professionals to lead these efforts. This involves developing standardized methods to collect data without adding additional burden, comparing and sharing our experiences to promote discipline-wide quality assessment and improvement initiatives, and demonstrating our intentions for quality improvement on the clinical frontline.” [emphasis added]


A paper by David Currow and colleagues in Australia describes how patient outcomes measures (PCOC – see later) have been used to improve clinical outcomes at a service level as a result of routine data collection and systematic feedback. The authors emphasise the importance of using measures at the patient level and measures that are internationally comparable.

“Other initiatives have started around the world that are seeking to routinely improve patient outcomes through routine data capture, analysis and feedback using similar processes. There is a need to harmonise measures and ensure that data are also being benchmarked at patient level across these initiatives to understand variations in outcomes between services internationally.”

“Building routine data collection into clinical care is the critical foundation in order to understand patient outcomes. This allows comparison between patients, not simply between services.
Demonstrating the rates of improved symptom control is crucial if, as a community, we are to have confidence in the care that is offered to people at the end of life and to further invest in it.”  
[emphasis added]


3. Very Wide Range of Outcomes Measures

When work began in Europe in 2011 to get consensus on outcomes measures in palliative care, a study was done as to what outcome tools were in use at the time (both clinically and for research). Responses were received from 311 people across Europe, who identified between them 116 different tools used for clinical care/audit and 106 tools used for palliative care research.


A literature study on outcome assessment in palliative care produced an even higher number. The study (up to December 2009) found at least 528 different outcome assessment instruments had been used.


4. Choosing and Introducing Outcomes Measures

Europe has made substantial progress on reaching consensus on outcome measures. The European Association for Palliative Care (EAPC) position paper concludes: “The White Paper recommends the introduction of outcome measurement into practice and outcomes that allow for national and international comparisons. Outcome measurement is key to understanding different models of care across countries and, ultimately, patient outcome having controlled for differing patients’ characteristics.” The White Paper has 12 recommendations and the paper is worth reading in detail.


3 For those who do not have library access, a full-text version is held at: https://www.researchgate.net/publication/278040088_EAPC_White_Paper_on_outcome_measurement_in_p
A very useful publication for organisations considering outcome measures for the first time is “Outcome Measurement in Palliative Care: The Essentials”. In simple language it covers what outcomes measures are and how to determine a “good” measure: “A measure is ‘good’ if it can be shown to have validity, reliability, responsiveness to change, appropriateness and acceptability.” The publication links outcomes measures to processes for improving quality and a useful section lists websites, journal articles and book chapters on outcomes measures.


5. Suites of Outcomes Measures

There are two major suites of outcomes measures, PCOC in Australia and OACC in the UK. Each has a number of outcomes measures that have been widely implemented. A very helpful summary and overview of the tools in each suite of measures is presented in the poster below.


The authors found that “While PCOC and OACC share a common aim and many similarities, some measures used by these initiatives differ. Additionally, the required measurement frequencies are not yet completely aligned. However, the ultimate goal of both initiatives is to achieve a national clinical outcomes set, collected and submitted by the majority of specialist palliative care services. Availability of such data brings us one step closer to cross-national comparisons of routinely collected outcome data in palliative care.”

5.1 Palliative Care Outcomes Collaboration (PCOC)

PCOC is a national program in Australia “that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. Participation in PCOC is voluntary and can assist palliative care service providers to improve practice and meet the Palliative Care Australia (PCA) Standards for Providing Quality Palliative Care for all Australians.” The PCOC dataset includes the following tools:

a. Palliative Care Phase
b. Australia-modified Karnofsky Performance Status (AKPS) scale
c. Palliative Care Problem Severity Score (PCPSS)
d. Symptom Assessment Scale (SAS),
e. Resource Utilisation Groups – Activities of Daily Living (RUG-ADL)

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5.2 Outcome Assessment and Complexity Collaborative (OACC)

The OACC project in the UK “seeks to implement outcome measures into palliative care services to measure, demonstrate and improve care for patients and their families.” The project “aims to agree on a standardised suite of outcome measures, design training materials and support implementation, as well as establish feedback and reporting strategies that are nationally applicable.” The OACC tools are:

a. Phase of Illness
b. Australia-modified Karnofsky Performance Status (AKPS)
c. Integrated Palliative care Outcome Scale (IPOS) (see more below)
d. Views on Care
e. Barthel Index (for inpatients and care homes)
f. Carer measures, including Zarit Carer Interview

The International Palliative Care Outcome Scale (IPOS)

IPOS and POS are part of a family of tools that “measure patients' physical symptoms, psychological, emotional and spiritual, and information and support needs. They are validated instrument that can be used in clinical care, audit, research and training.” Website: http://pos-pal.org/

“The POS measures are widely used globally including in Europe, Australia, Asia, Africa and America. POS ... is available in 11 languages including English.” There are extensions for specific conditions, including multiple sclerosis, Parkinson’s disease and end-stage renal disease. POS-Dem is in the process of being developed for use in people with dementia living in care homes. “The POS measures are used in different settings, including home, hospital, hospicnd, nursing home.”


See also the paper described earlier, as this describes how PCOC is used in practice.


6. Outcomes Measures for Particular Settings and Groups of Patients

The list below contains additional resources for particular situations or groups. The ones listed below are recent and provide some insight into the use of outcomes measures in particular settings of care.


7. Examples of Outcomes Measurement Development in New Zealand

While outcomes measures are described as important in various strategy documents, it is harder to find examples of the tools actually used for measurement at a patient and family / whānau level. Many of the examples below describe systems-level measures rather than patient-level measures.

An example of the outcomes measures and the tools used in measurement is found in the work by Te Puni Kōkiri on the Whānau Ora Outcomes Framework. The framework has long-term outcomes (11-25 years), medium-term outcomes (5-10 years) and short-term outcomes (1-4 years). There is a document describing the indicators and measures used for the short-term outcomes. “These key indicators are to monitor progress at a population or system level.”


An example of a project dealing with outcome measures at a facility level are projects on hospital outcomes.


The Ministry of Health announced new outcomes measures at a systems level in 2016. “The Health Strategy recommends the development of an outcomes-based approach to performance measurement that will guide the delivery of constantly improving health services.”


There is a new repository of quality and outcomes measures for New Zealand, called Health Quality Measures New Zealand. The site is run by Patients First, supported by the Health Quality Safety Commission (HQSC) and Ministry of Health. Health Quality Measures New Zealand “is a sector-wide library of measures used within the New Zealand Health System. It is a single collection point for all measures and their definitions. It provides a platform to allow the collaboration on those measures.”


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