Outcomes Measures for Palliative Care in New Zealand

Discussion document following the symposium held in Wellington on 17 February 2017

12 May 2017
Foreword from the Hospice NZ CEO

Hospice New Zealand initiated this discussion about outcomes measures and our aim was to facilitate discussion across all palliative care providers in New Zealand. We did not see this as simply a hospice initiative, and we were delighted that the symposium delegates included people from aged residential care, primary care, District Health Boards and the Ministry of Health.

We saw the symposium in February 2017 as the beginning of a discussion, recognising that achieving consistency in outcomes measures would need a national initiative.

One of the key issues for us, following the successful symposium, was whether to move ahead alone, as hospices, or try to move forward together as a sector.

The publication of the Review of Adult Palliative Care and Action Plan by the Ministry of Health on 30 March 2017, gives us some of those answers. We are delighted to see the Ministry taking the lead on the national population-level outcomes framework for palliative care and acknowledging the role played by Hospice NZ in facilitating this discussion with the sector on clinical outcomes measures.

We have now given some further thought to what we can do next – and how to share our thinking with the palliative care sector. This discussion document is intended for those who were at the symposium, and, importantly, for those who were unable to attend. It will help all of us to share the language of outcomes measures and the rationale for introducing them in New Zealand.

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Executive Summary

There is a growing emphasis on outcomes measurement, rather than measuring inputs and processes. Outcomes measurement is fundamentally concerned with what directly affects the patient, and their family and whānau. Outcomes measures are used in clinical care, for clinical audit and for research. They can be specified at patient-level, service level and policy-level. Outcomes measures play an increasing role in improving the quality, effectiveness, efficiency and availability of palliative care.

This increase in focus on outcomes is seen throughout the New Zealand public sector, with Results Based Accountability (RBA) being used widely across social services, health and disability, local government, community development, and environmental development. Streamlined contracting is being implemented for non-governmental organisations, using a results-based accountability approach.

The New Zealand Health Strategy and the Healthy Ageing Strategy, both published in late 2016, make extensive use of outcomes frameworks and outcomes measures. The Long Term Conditions Framework is a good example of how outcomes need to be framed at a population level. The Ministry of Health will take the lead on defining the population level outcomes framework, as clearly articulated in the Review of Adult Palliative Care Services and accompanying Action Plan. A useful starting point for this framework will be “Measuring What Matters”, an outcomes framework developed by the palliative care sector and published in 2012.

Outcomes frameworks describe what to measure, not how to measure. At a service level and patient level, there is a need for outcomes measurement for benchmarking good practice and improving quality. The Action Plan places the responsibility for investigating clinical outcomes measures with Hospice New Zealand and the palliative care sector. The symposium organised by Hospice NZ was the beginning of a conversation to find common ground on tools that measure whether the needs of patients, whānau and carers are being met in New Zealand.

When work began in Europe in 2011 to get consensus on outcomes measures in palliative care, it was found that there were 116 different tools used for clinical care or audit, and 106 tools used for palliative care research. A literature study on outcome assessment in palliative care found at least 528 different outcome assessment instruments had been used. This proliferation of tools does not facilitate comparisons within countries or internationally. There are initiatives in Europe to rationalise core tools to those that have been validated and have sound psychometric properties. Guidance on choosing measures and the implementation of outcomes measurement has been prepared for palliative care in Europe.

The symposium heard from the UK and Australia on work done to implement outcomes measures. The Outcome Assessment and Complexity Collaborative (OACC) project in the UK and the Palliative Care Outcomes Collaboration (PCOC) in Australia use suites of measures, not single measurement tools. Both projects aim to achieve a national set of outcomes measures for palliative care.

While Australia began implementation in 2006 and has established a strong regional support structure, the UK initiative is more recent and still in the process of implementation. There is good evidence that initiatives such as PCOC can improve quality and outcomes, but only if the feedback loop is closed. Measuring performance is not, on its own, enough. To this end, PCOC organises communities of practice and holds PCOC National Benchmarking Workshops, at least four times a
The workshops bring peer services together from across Australia to network and learn from each other. Universities perform a significant role in analysis and research in both countries.

The discussion document describes the measures included in the OACC and PCOC suites, with a comparison between the two, based on key dimensions of care. Importantly, PCOC and OACC share two measures: the phase (called Palliative Care Phase in PCOC and Phase of Illness in OACC) and the Australia-modified Karnofsky Performance Status (AKPS). These two physical-level measures are the foundation for both suites. While PCOC has one item covering both psychological/emotional and spiritual domains, OACC has four items, including one specifically on spiritual needs. This will be an important consideration in matching the philosophy of care in New Zealand, based on Te Whare Tapa Whā, with suitable tools.

Advice from PCOC in Australia is that how and when patient outcome measures are collected are just as important as what is collected. There are notable differences in the frequency with which the two suites of measures are used. Both suites are used at admission, at phase change and on discharge or death. Both suites also use the measure of phase of illness on a daily basis in inpatient settings and at every contact in community settings. OACC uses the changes in phase to trigger the use of all the other questions, but PCOC uses all the measures on a daily basis in inpatient settings and at every contact in community settings. This is a significant difference in workload and data collection.

Both OACC and PCOC have plans to move more collection of outcomes measures from paper to electronic means and to simplify the submission of data for comparisons. In New Zealand, 20 of the 29 hospices use the PalCare system, which already has 26 measures built in, including the full PCOC suite and some OACC measures. There has been some modification of the Houston Medical/VIP software by one of the two hospices using the system, to allow for outcomes measures to be collected. The three hospices use Medtech software and the five hospices with their own systems are not yet thought to have outcomes measures. A more formal survey of current and planned implementation will be conducted to determine the degree of implementation.

A key issue in finding measures across all settings of care will be that aged residential care facilities are required, in terms of their contracts with District Health Boards, to use the interRAI suite of assessments. The interRAI Palliative Care instrument has been approved for implementation, but will be used initially for home care and not aged residential care. The completion of interRAI assessments is a much longer process than required for the completion of the OACC and PCOC measures, while the frequency of use is more intermittent. It is not known whether any outcome measures suitable for palliative care are embedded in the systems of Primary Healthcare Organisations in New Zealand.

For the population level framework, the role of the sector will be to participate fully and actively in the sector leadership workshops envisaged by the Ministry of Health. The key preparation for the meetings will be to familiarise our organisations and members with the language of outcomes measures and the measures that might be feasible to collect.

All parties should advocate strongly for a national outcomes framework and outcomes measures that are applicable across all settings of palliative care. A framework for the discussions is proposed, as developed for discussions across Europe. We recommend using outcomes measures that are internationally applicable, to facilitate comparison and improve the translation of research into practice. The Māori Advisory Group to hospices, Te Rōpū Taki Māori (HNZ), will be approached to provide guidance on measures in a New Zealand context.
In moving forward on clinical outcomes measures, hospices and Hospice NZ will progress clinical palliative care outcomes measures that are appropriate to hospices, while sharing experience widely throughout the sector.

Those hospices that are ready should begin to implement the Phase of Illness and Australia-modified Karnofsky Performance Status (AKPS), regardless of other tools adopted. Hospices that are ready should begin to pilot outcomes measures for all dimensions of care (psychological/emotional, spiritual, impact on carers, family and whānau. A framework providing guidance in implementation across all dimensions of care has been provided by North Haven Hospice.

In the first instance, hospices should consider using a tool from the OACC or PCOC suites, or one of the tools already built in to the software (for those using PalCare). The sharing of experiences in a community of practice, facilitated by Hospice NZ, will help to find tools that are working well in the New Zealand context. This is also an opportunity for hospices to trial, as part of their innovation fund projects, outcomes measures that work across hospices and aged residential care.

A key recommendation is the sharing of experiences of piloting and implementation. Perhaps the time is right to consider the formation of a New Zealand palliative care outcomes measurement collaborative, across all settings of care. This will need further exploration and Hospice NZ will endeavour to progress discussions with the other palliative care organisations, the Palliative Care Advisory Panel (PCAP), and the Ministry of Health. A logical and urgent response is called for before the palliative care sector goes in many different directions and the opportunity for co-ordinated activity is lost.

Hospice NZ is committed to sharing the results and experiences of piloting outcomes measures widely with the palliative care sector, in the interests of developing a common set of measures for use in New Zealand, across all settings of care.
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1. Introduction and Purpose

There is a growing emphasis on outcome measurement, rather than measuring inputs and processes in healthcare. Several countries, including Australia and the United Kingdom, have implemented suites of outcome measures for palliative care, designed to demonstrate they are making a positive and measurable difference to patients and families. Internationally, there are initiatives to encourage the introduction of outcomes measures for palliative care and to use measures that allow for national and international comparisons.

In New Zealand, strategic documents in the health sector increasingly use the terms “outcomes” and “outcomes measurement”. In palliative care, there are some local and regional initiatives already taking place, but no national standardisation or common understanding of how outcomes measurement might be used. This prompted Hospice New Zealand to host a symposium to stimulate discussion and collaboration across the New Zealand palliative care sector.

The Hospice New Zealand Palliative Care Outcomes Symposium was held in Wellington on 17 February 2017, with some 90 attendees from aged residential care, hospital, hospice, District Health Board and research settings. The overall aim of the symposium was to begin a conversation to find common ground on tools that measure whether the needs of patients, whānau and carers are being met in New Zealand.

The questions that the symposium aimed to answer were as follows:
- What are palliative care outcome measures and why are they important?
- Why is a common direction in measurement so important?
- What measures are in the PCOC and OACC toolboxes\(^a\) of measures? What can we learn from those who have implemented patient and whānau palliative care outcome measures?
- Where do we go from here?

This discussion document therefore aims to answer the same questions. It has been produced not only for delegates to the symposium, but also for those who were unable to attend or who need to understand outcomes measures as this area of practice evolves in New Zealand. A summary of the information provided to delegates and the helpful feedback received during the symposium has also been produced\(^1\).

1.1. What are Outcomes Measures?

Outcome measurement is fundamentally concerned with what directly affects the patient, and their family and whānau.

Outcome measurement is a way of measuring changes over time, by using a valid and reliable measure to establish a patient’s baseline health status, and then evaluating changes over time against that baseline\(^2,3\).

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\(^a\) PCOC is the Palliative Care Outcomes Collaboration in Australia.
OACC is the Outcome Assessment and Complexity Collaborative in the United Kingdom.
The formal definition of outcomes measures that is generally adopted is attributed to Donabedian, who described outcomes in healthcare as “the change in a patient’s current and future health status that can be attributed to preceding healthcare”\(^2,3\). The diagram below has been adapted to palliative care and gives useful examples of the difference between inputs, processes, outputs and outcomes measures.

![Figure 1: Measurement in a Palliative Care Context\(^2\)](image)

As outcomes measures are concerned with patient, family and whānau experience, patients are the main source of information for changes in their health status, quality of life or symptoms. Where patients are unable to report, proxy reports are collected from carers or staff. These tools are generally described as Patient-Reported Outcome Measures (PROMs)\(^7\).

The European Association for Palliative Care describes the change in emphasis on measurement in 2015 as follows\(^3\):

“Outcome measurement plays an increasing role in improving the quality, effectiveness, efficiency and availability of palliative care. Until recently, almost all assessments of the quality of palliative care focused on care structures and processes rather than on outcomes.”

Putting this in more direct words, Kamal and colleagues\(^4\) say:

“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.’” [emphasis added]

The importance of outcomes measurement has been recognised for palliative care in New Zealand, with a document “Measuring what Matters” prepared by the Palliative Care Council in 2012\(^5\). The document contains a similar image about the difference between inputs, processes, outputs and outcomes, and is shown in Appendix A. The outcomes framework for palliative care, advocated in “Measuring what Matters”, is considered in section 2.7, with a diagram in Appendix B.
1.2. Uses of Outcomes Measures

The PRISMA\(^\text{b}\) initiative in Europe resulted in guidance on outcome measurement, saying\(^2\): “Outcome measurement has a major role to play in improving the quality, efficiency and availability of palliative care. Measuring changes in a patient’s health over time, and finding out the reasons for those changes, can help service providers focus on learning and improving the quality of services.

Outcome measures, specifically Patient-Reported Outcome Measures (PROMs), are tools that can effectively be used in palliative care to assess and monitor care, either for individual patients, or across populations. PROMs put the patient at the centre of care and focus on what matters to them.”

The European Association for Palliative Care outlines the use of outcomes measures as follows\(^3\): “Outcome measures are widely used in palliative care research to describe patient populations or to assess the effectiveness of interventions, but they are not, as yet, always incorporated into routine clinical practice. Where they have been introduced routinely into practice with timely feedback loops, there is evidence of improved patient outcomes at a systems level.

Patient-reported outcomes position patients at the centre of care and help professionals to focus on what matters to patients and families. Funding from government or commissioners is also becoming conditional on the provision of patient-centred outcomes data in an increasing number of countries.”

PRISMA identified three main purposes for the use of outcomes measures: clinical care, audit and research. The material below is summarised from the PRISMA guidance\(^2\).

In **clinical care**, outcome measures are used to:
- establish patients’ baselines (for example, baseline pain level, existential distress or spirituality);
- assess patients’ symptoms, as well as families’ and patients’ needs/problems;
- monitor changes in patients’ health status or quality of life;
- facilitate communication with patients/families and the healthcare team; and
- aid clinical decision making; evaluate the effect of interventions, care or services.

For the purposes of **clinical audit** (or a broader audit), outcome measures can be used to:
- establish standards of practice for particular disciplines (e.g. medicine, nursing, social work, physiotherapy) or within palliative care teams or organisations;
- assess the care given against established standards, with the view to improving standards;
- determine uptake of service; and
- benchmark or compare standards of practice in one organisation with another organisation.

For the purposes of **research**, outcome measures can be used to:
- screen whether patients meet inclusion criteria for a study;
- assess patients’ functional status;
- measure or describe patients’ symptoms, quality of life and quality of care;

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\(^{b}\) PRISMA is an acronym for “Reflecting the Positive DiverSities of European Priorities for ReSearch and Measurement in End-of-Life Care”. It was a three-year project funded by the European Commission with focus on co-ordinating outcome measurement in palliative care. [http://cordis.europa.eu/result/rcn/55033_en.html](http://cordis.europa.eu/result/rcn/55033_en.html)
Outcomes measures are used at patient-level, service level and policy-level. Patient-reported outcomes (PROMS) can serve goals on different levels at the same time.\(^2\)

- **Patient-level goals**: screening for symptoms and problems, monitoring of symptoms, aid decision making, facilitate communication with patients and within the team.
- **Service/setting level goals**: evaluate and improve the quality of care (e.g. services), demonstrate effect, promote good practice.
- **Policy level goals**: improving and monitoring palliative care practice on policy level (e.g. recommended routine collection and minimum dataset).

Focussing on whether we have made a difference to individual patients and their families/whânau can help the clinicians and staff in a facility to assess quality improvement efforts for the organisation. At a system level, aggregated results can demonstrate whether a difference is being made for the population and whether services are cost-effective.

The increasing importance of outcomes measures at a national policy level is described by Cassaret and colleagues as follows:\(^6\)

“Nations face numerous challenges in providing high-quality end-of-life care for their citizens, and an ageing population that has a prolonged trajectory of decline and substantial needs for care magnifies these challenges. As nations begin to address these challenges, it will be essential to determine whether their responses are effective.”

Governments need to know whether their citizens are receiving adequate care, whether current programmes are improving care, and how their palliative care outcomes compare with those of other countries.

Currow and colleagues in Australia\(^7\) describe how patient palliative care outcomes measures have been used to improve clinical outcomes at a service level, using routine data collection and systematic feedback. The authors emphasise the importance of using measures at the patient level and measures that are internationally comparable.

### 1.3. Outline of this Discussion Document

The discussion document begins with an explanation of outcomes measures and how they are used. Section 2 outlines the imperative for outcomes measures in the New Zealand public sector and health system, while Section 3 highlights international guidance for implementing and choosing outcomes measures.

Section 4 provides an outline of the tools used in two suites of outcomes measures presented at the symposium and compares the two suites of tools. Section 5 summarises the feedback gathered at the symposium and the themes from the delegates.

Section 6 outlines some of the practical issues to be considered in implementation of outcomes measures in New Zealand. Section 7 begins with a summary of new material on outcomes measures in palliative care from the Ministry of Health, then outlines key points for finding a way forward.
2. Outcomes Frameworks and Measures in the New Zealand Health System

The terms “outcomes”, “outcomes frameworks” and “outcomes measurement” are increasingly found in strategy documents from the Ministry of Health. This section gives a brief introduction to that language, as it affects palliative care. The section shows that the increased focus on outcomes is part of a wider public sector initiative across all of government to use “results based accountability” and contracting for outcomes. Early work by the palliative care sector on an outcomes framework, “Measuring what Matters”, is described and shown how it aligns with the wider developments.

2.1. The New Zealand Health Strategy

The revised “New Zealand Health Strategy: Future directions”8, published in December 2016, is the over-arching document for the direction of the health system. It is accompanied by a “Roadmap of Actions”9, which provides more detail on the action plans.

The revised health strategy8 uses the word “outcome” extensively. In a foreword by the Minister of Health, the importance is established of working towards “all New Zealanders achieving equitable health outcomes, and targeting and tailoring services for those groups who have poorer health and social outcomes than the population on average.”

In practice, this means embedding outcomes measurement throughout the system: “A set of measures, including measures of health outcomes and equity of outcomes, will be used to track progress.” (page 37). Figure 11, on page 39 of the strategy document, shows the expected results within five years, including the statement: “Outcomes are included as an integral part of commissioning and performance management.”

Three actions in the Roadmap of Actions9 deal with these issues in a section entitled “Value and high performance (Te whāinga hua me te tika o ngā mahi)” (pages 15 and 16):

- **Action 14.** “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 framework will reflect the links between people and priority groups, their needs and outcomes of services, and will shift the focus from inputs to outcomes. This work will build on the Integrated Performance and Incentive Framework and results-based accountability, and aims to increase equity of health outcomes, quality and value.”

- **Action 15.** “Work with the system to develop a performance management approach that makes use of streamlined reporting at all levels, to make the whole system publicly transparent. This will draw on service user experience results as well as quality and safety information, and operate within the outcomes framework (Action 14). …”

- **Action 17c.** *Improve commissioning* by using a wider range of service delivery models, expanding the use of contracting for health and equity of health outcomes and building capability to lift the quality of commissioning (as the New Zealand Productivity Commission recommended in its review of More Effective Social Services).”

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8 The relationship between Māori and the Crown under the Treaty of Waitangi, underpins the refreshed NZ Health Strategy and all strategies developed in specific areas of the health system.
The language used in the action plan is important and may not be familiar to the palliative care sector. “Results-based accountability” is described in Section 2.3, with an example of how it is used for long-term conditions in Section 2.4. Streamlined contracting, the new contracting model that builds on results-based accountability, is described in Section 2.6.

### 2.2. Palliative Care Outcomes in Health Strategies

The revised Healthy Ageing Strategy\(^{10}\), released in December 2016, also uses extensive language about outcomes. This document provides the direction and action plan for the next ten years for the health and wellbeing of older people. Palliative care has been included in the section described as “Respectful end of life” (Te mate rangatira i nga-tau whakamutunga o te hunga pakeke).

The document describes the respectful end of life goals as (page 64):

- The health system responds to older people’s goals and care needs at the end stages of life and to the needs of their families, whānau, caregivers and friends involved in their end-of-life care.
- All health care teams are responsive to the cultural needs of different groups.
- Health service providers co-ordinate palliative care to ensure all providers in the health system are used to their fullest. All of those who support people dying in old age are aware of the dying person’s plans and know their own role in achieving those plans.
- People die feeling as comfortable and safe as possible.
- Expert advice and support is available to families and whānau, other carers and the health workforce involved in end-of-life care.

Action 24b (page 65) deals with the development of an outcomes framework, saying: “Develop and agree national service expectations and an outcomes framework for palliative care.” This action is to be led by the Ministry of Health, with DHBs identified as key partners. No time frame is given, but the action plan covers a ten-year period and this action is not flagged as being within the first two years.

The strategy dealing specifically with palliative care, the New Zealand Palliative Care Strategy\(^{11}\), was published in 2001 and is thus now 16 years old. The Review of Adult Palliative Care Services, published on 30 March 2017\(^{12,13}\), contains extensive language about outcomes frameworks and outcomes measures. As this document was not available at the time of the symposium, but is crucial to the way forward on outcomes measurement, it is described and discussed in Section 7.

### 2.3. Results Based Accountability in the Public Sector

It is important to understand that outcomes frameworks are being used more widely than the health system. The New Zealand Government is placing greater emphasis on management systems that demonstrate how the activities of all government agencies contribute to results or outcomes.

Results Based Accountability\(^{TM}\) (RBA) is an outcomes management framework developed by Mark Friedman and described in his book “Trying Hard Is Not Good Enough”. RBA is used internationally and was first introduced in New Zealand by the Ministry of Social Development (MSD) in 2006.
The Ministry of Health, alongside the Ministries of Education, Justice and Social Development, Te Puni Kōkiri, and the Department of Corrections, is now implementing the RBA framework. RBA is used widely across social services, health and disability, local government, community development, and environmental development. New Zealand is now considered one of the world leaders in the application and implementation of RBA.

RBA drives continuous improvement as a strategic planning tool, focused on the outcomes the organisation, service or provider are targeting and what they want to achieve, often referred to as ‘turning the curve’ through improving the performance of their programmes or services.

The RBA framework defines two types of accountability; outcomes at a population level and outcomes for the end users of a service, programme or intervention.

**Population Accountability**

Population accountability is about improving the quality of life for a whole population that is defined by geography and/or characteristics e.g. all patients, their families and whānau who access palliative care. At the population level a result or outcome is a condition of wellbeing for the people in that group. The terms “result” and “outcome” are interchangeable.

No single agency or organisation can achieve a condition of wellbeing for a whole population on its own. It takes the unique contributions of a range of stakeholders who have a part to play in any outcome at a population level. In health, this may include working with other stakeholders, such as social services.

**Performance Accountability**

Performance accountability is about the services, interventions or programmes that are offered to the end user. At the performance accountability level, there are three types of performance measures:

- How much did we do?
- How well did we do it?
- Is anyone better off?

**Implementation and Reporting**

The RBA outcomes framework has seven specific questions both at the population accountability level and at the performance accountability level. The population versus performance distinction is important to understand because it determines who is responsible for what. Population accountability organises work with other stakeholders in a collaborative way to achieve the

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Further information on the seven questions and how to develop an RBA approach to outcomes frameworks is available from several sources. A series of training videos has been produced by the Ministry of Business, Innovation & Employment (MBIE) to help government agencies and NGOs understand more about RBA. See the New Zealand Government Procurement website: [http://www.procurement.govt.nz/procurement/for-agencies/buying-social-services/results-based-accountabilitytm-rba](http://www.procurement.govt.nz/procurement/for-agencies/buying-social-services/results-based-accountabilitytm-rba)


See also the Results-Based Accountability Implementation Guide: [http://raguide.org/](http://raguide.org/)
outcomes for a population group. In contrast, performance accountability organises the service provided, and the design and development of that service to have the greatest impact on the end user.

RBA uses publicly available data and data generated by providers to track the results (often referred to as “Turn the curve” reports). RBA is also the basis for developing performance measures that are used in “streamlined contracting”, discussed in Section 2.6.

This section on RBA shows that the language of “outcomes” and the links between outcomes and contracting are becoming increasingly embedded in the public sector in New Zealand. Any decisions about palliative care outcomes measures need to take this wider context into account.

2.4. Long Term Conditions Outcomes Framework

Using an RBA approach, the Ministry of Health has created a population level outcomes framework focusing on people with Long Term Conditions (LTC). This is a useful example to see how palliative care outcomes at a population level might need to be described. Long Term Conditions Outcomes Framework, Line of Sight, is shown below.

![Long Term Conditions Outcomes Framework, Line of Sight (Part A)](image-url)

Figure 2: Long Term Conditions Outcomes Framework, Line of Sight (Part A)
The LTC Population Outcomes Framework: Line of Sight (Part A) and Indicators (Part B) are part of a suite of documents which include the National Expectations for the Prevention and Management of Long Term Conditions\(^4\). These documents are available on the Nationwide Service Framework Library website. The LTC Indicators (Part B) is still a work in progress and has detailed indicators and measures to “tell the story” of improvement at a population level.

Together, these documents provide guidance to the sector and other agencies on the design, development and delivery of publicly funded services that contribute to reducing the health loss of all New Zealanders impacted by long-term conditions. While palliative care is an element of the Line of Sight, there are no population-level indicators yet listed.

### 2.5. District Health Board Outcomes

The language about outcomes frameworks and outcomes measures is also increasingly seen at District Health Board (DHB) level. The Ministry of Health announced new outcomes measures at a systems level in 2016, saying: “The Health Strategy recommends the development of an outcomes-based approach to performance measurement that will guide the delivery of constantly improving health services.”

System Level Measures (SLMs)\(^f\) are high-level aspirational goals for the health system that align with the five strategic themes of the Health Strategy and other national strategic priorities such as Better Public Service Targets.

The SLMs are part of the DHB annual planning process and provide an opportunity for DHBs to work with their primary, secondary and community care providers to improve health outcomes of their local population. The SLMs connect to contributory measures which:

- contribute to the achievement of SLMs
- are front line service level measurements of health processes or activity – tangible and clinically meaningful
- align with local quality improvement.

The Ministry of Health worked closely with the health sector to co-develop the SLMs currently in use. One of the measures is the patient experience of care.

The Measures Library for System Level and contributory measures is available on the Health Quality Measures New Zealand website. This is a new repository of quality and outcomes measures for New Zealand. The site is run by Patients First, supported by the Health Quality and Safety Commission (HQSC) and the Ministry of Health.

Health Quality Measures New Zealand\(^g\) “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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At the Hospice NZ Palliative Care Outcomes Symposium, the Canterbury Health System Outcomes Framework was described and shown by Dr Greg Hamilton. This provided a good example of the systems-level thinking that DHBs are now required to do as part of their agreements with the Ministry of Health.

Dr Hamilton emphasised how they define the outcomes and then align proxy metrics. While the proxy metrics may be changed more frequently, the outcomes are not. For example, the Canterbury Health System has an outcome “People choose their end of life”. Proxy measures shown at the symposium were:

- Number of advanced care plans published monthly. It has been found that 35% of the general Canterbury population die in hospital, but only 18% with ACP die in hospital.
- In hospital deaths by day of death, using the ICD-10-AM palliative code Z51.5 excluding ARC
- Deaths 90 days post discharge, using the ICD-10-AM palliative code Z51.5 excluding ARC
- Deaths 365 days post discharge, using the ICD-10-AM palliative code Z51.5 excluding ARC.

As there are, as yet, no nationally agreed outcomes measures for palliative care, the palliative care sector is likely to find different requirements from different DHBs. The responsibility to set the key measures, as shown in Section 2.2, is with the Ministry of Health, together with the DHBs. This is expanded on in a newly-released action plan for palliative care, as described in Section 7.1.

### 2.6. Streamlined Contracting for NGOs

There is one further area where the results based accountability developments (Section 2.3) may impact the specialist palliative care sector. A new outcome-focused contracting framework, referred to as “streamlined contracting”\(^h\), has been implemented under the leadership of the Ministry of Business, Innovation & Employment (MBIE). Cabinet directed MBIE to lead the work following a pilot programme in late 2012.

This initiative affects all Ministries, public service departments and the wider state service agencies that contract with non-governmental organisations (NGOs). The Ministries of Social Development, Education, Justice, Te Puni Kōkiri, the Department of Corrections and the Ministry of Health are now implementing the framework.

The streamlined contracting framework is intended to encourage greater consistency, co-ordination, collaboration and information sharing by government agencies and Crown entities. It also aims to reduce the duplication of contract management activity, especially audit and compliance, on NGO providers, which should enable NGOs to focus on service delivery. All streamlined contracts will include performance measures developed using the RBA methodology.

The key elements of streamlined contracting are:

- a common contract template (Outcome Agreement)
- standard government terms and conditions (Framework Agreement)
- a collective approach to measuring outcomes (Results Based Accountability™ or RBA).

These are shown in the diagram below.


RBA is used by the Ministry of Health, through streamlined contracting with health providers across the sector, to identify and work towards improving outcomes, with a focus on the end user (for communities, families and whānau, the individual, client or patient/s).

Note that, while NGOs in palliative care (like hospices) may not yet be affected, it is useful to understand the broader picture and what is happening to other NGOs. To date, the impact on healthcare NGOs has been felt largely by those in the disability sector and those who work with multiple funding agencies.

### 2.7. Palliative Care “Measuring what Matters”

The Palliative Care Council, in consultation with the sector, completed significant work on an outcomes framework for palliative care at a systems level. The resulting document, “Measuring what Matters”\(^5\), remains highly relevant and current for palliative care in New Zealand. It has been used in several DHBs and for regional planning to focus efforts across all palliative care providers.

The aim of “Measuring what Matters” was to establish an outcomes framework that would generate data to inform strategic decision making across all settings of palliative care in New Zealand. By

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1 Source: Original slide retrieved MBIE website in 2014. Website subsequently amended.  
http://www.oag.govt.nz/website  
2 The Palliative Care Council (PCC) was part of Cancer Control New Zealand (CCNZ), an independent advisory body to the Minister of Health. CCNZ, together with PCC, was disestablished in August 2015.
measuring how well the desired palliative care outcomes are being achieved, and then comparing
this against future measurement of those same outcomes, it is possible to evaluate the extent to
which changes in activities and actions have contributed to changes in the desired outcomes for
palliative care. The outcomes framework is shown in Appendix B.

The vision for palliative care in New Zealand is: “All people with a life limiting illness, and their
family/whānau, who could benefit from palliative care, have timely access to quality palliative care
that is culturally appropriate and provided in a co-ordinated way.”

Three long-term outcomes that will contribute to palliative care that meets the strategic vision are5:

- Access to palliative care regardless of setting
- All palliative care providers are configured to ensure a seamless care pathway
- Palliative care provision is high quality.

The long-term outcomes are then broken down into key component parts, the systems-level
outcomes5:

- **Sufficient capacity:** Sufficient capacity refers to the resourcing of the palliative care system
to meet the need generated by patients with a life-limiting or life-threatening illness who
would benefit from palliative care.
- **Appropriate referrals:** Referrals are the mechanism by which a patient accesses palliative
care ‘services’; as such, ‘appropriate referrals’ contribute to access to palliative care.
- **Continuity and Co-ordination of care:** Patients receiving palliative care may require a
number of different types of care from different providers. It is important that these
providers and services are aware of and responsive to the various facets of care that the
patient requires that are provided by another part of the health system.
- **Best practice is followed:** Best practice refers to palliative care being provided in a way
that aligns with evidence-based best practice. Implementing best practice ensures that
patients receive the care most likely to meet their needs.
- **Palliative care meets the needs of patients, family and whānau:** Palliative care must meet
the unique needs of the patient, their family and whānau, no matter what their religious,
cultural, ethnic or socioeconomic background, or geographic location/rurality.

Finally, each system-level outcome is broken down into intermediate outcomes. The level of detail enablen
providers to focus on measuring what is important in their region or provider facility, but
also to use the same outcomes language across the country. With the Palliative Care Council no
longer in existence, this agreed palliative care outcomes framework could usefully be used to fill in
the detail needed in the Ministry of Health outcomes frameworks described earlier. It was
recommended at the symposium that this is one of the key issues to take forward, possibly through
the Palliative Care Advisory Panel (PCAP)k. See Section 7.1 for the Ministry of Health action plan on
this point.

It is important to note that “Measuring what Matters” describes what to measure in palliative care
but does not specify how to measure. It is how to measure quality of care and whether the care
meets the needs of patients, family and whānau, that is the subject of this discussion document. We
thus turn our attention to international developments in standardising outcomes measures before
looking at two “toolboxes” of measures that are in use.

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k The Palliative Care Advisory Panel was established in late 2015 to provide advice on palliative care to the
Ministry of Health. This differs from the Palliative Care Council which provided advice directly to the Minister.
3. International Guidance

There has been recognition that outcomes measurement at the end of life is a specialised topic and needs tools specifically designed for and tested in this setting. This section outlines some of the research completed in recent years, the guidance developed as a result, and future work planned.

3.1. Organization for Economic Co-operation and Development (OECD)

The OECD provides a forum in which governments can work together to share experiences and seek solutions to common problems. There are currently 35 members of the OECD, including New Zealand. The OECD has a long history of standardising, collating and analysing data on health system performance. A document published in 2017 discusses the role of the OECD with regard to the development, collection and analysis of patient-reported indicators in future.

A general principle will be for the OECD to work to extend and deepen the benchmarking of health system performance to focus on collecting patient-reported indicators at a disease level, sector level, health-service level, and whole-system level. In each case, the focus will be on enabling international comparison.

The recommendation to Health Ministers is that the OECD should explore collaboration with other international organisations, such as the World Health Organisation, the European Commission, the Commonwealth Fund and the International Consortium for Health Outcomes Measurement (ICHOM), in order to extend and deepen the benchmarking of patient-reported performance indicators.

The OECD should extend its patient-reported outcome measures (PROMs) work to longitudinal studies of chronic disease patients, as this is where the need for more information with regards to care co-ordination is most urgent. While the work is expected to begin with cancer, it is expected to be extended to areas including dementia care, long-term care, palliative care and informal care.

Given the wide influence on data collected by health systems, this is a significant development by the OECD. It may, however, take some years to come to fruition.

3.2. European Association for Palliative Care

Europe has already made substantial progress on reaching consensus on the introduction of palliative care outcomes measures. The European Association for Palliative Care (EAPC) position paper\(^1\) 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 EAPC White Paper\textsuperscript{3} makes 12 recommendations which will be useful as a framework for finding a way forward in New Zealand (see Section 7.2). The recommendations for Europe are as follows:

**Key parameters of measures**

- **Recommendation 1:** Use patient-reported outcome measures (PROMs) that have been validated with relevant populations requiring palliative care and make sure these are sufficiently brief and straightforward and that they allow for proxy reports to be collected for when the patient is unable to self-report.
- **Recommendation 2:** Use multidimensional measures that capture the holistic nature of palliative care.
- **Recommendation 3:** Use outcome measures to assess the needs of unpaid caregivers (family and others) alongside the needs of patients.
- **Recommendation 4:** Use measures that have sound psychometric properties.

**Adequate measure for the task**

- **Recommendation 5:** Use measures that are suited to the clinical task being delivered and also suited to the aims of your clinical work and the population you work with.
- **Recommendation 6:** Use valid and reliable measures in research that are relevant to the research question and consider patient burden when using measures.

**Introduction of outcome measurement into practice**

- **Recommendation 7:** Use change management principles, facilitation and communication to embed outcome measurement into routine clinical practice and evaluate the implementation process to ensure sustained use that penetrates practice within the organisation.

**National and international: outcome comparisons and benchmarking**

- **Recommendation 8:** Relate outcome measurement to quality indicators.
- **Recommendation 9:** Establish and use quality improvement systems to sustain routine practice of outcome measurement and institute interoperable electronic systems to ensure integration of measures and across settings.
- **Recommendation 10:** Use measures that allow for comparisons across care settings and throughout Europe. Therefore, use measures that are culturally sensitive and have validated translations in relevant languages/countries.
- **Recommendation 11:** Advance the field of palliative and end-of-life care through establishing national and international outcome collaborations that work towards benchmarking to establish and improve care standards.
- **Recommendation 12:** To improve and monitor palliative care practice, policy makers should recommend routine collection of outcome data, and then these data should be used to establish a minimum dataset of palliative care outcome measures in order to improve and advance clinical care and research.
3.3. Avoiding Proliferation of Measurement Tools

When work began in Europe in 2011 to get consensus on outcomes measures in palliative care, a study was done under the auspices of PRISMA as to what outcome tools were in use at the time, both clinically and for research purposes15. Responses were received from 311 people across Europe, who collectively identified 116 different tools used for clinical care or audit, and 106 tools used for palliative care research.

A literature study on outcome assessment in palliative care16 produced an even higher number of outcomes measures in use. The study, up to December 2009, found at least 528 different outcome assessment instruments had been used.

PRISMA found that15 “it cannot be expected that individuals can easily access the necessary volume of information to be able to identify, locate, and appraise potential tools”. The authors also found that new tools are not required and advocated that existing tools should be selected and refined.

PRISMA argued that there is an urgent need to rationalise core tools to those that have been developed and validated within our population and have sound psychometric properties. The terms used in assessing measures are listed in the next section.

Stiel and colleagues16 found that there was no single instrument that covered all aspects of care and that holistic outcome assessment of patients, family and multi-professional teams requires a combination of different instruments. It is for this reason that suites of outcomes measures are considered in Section 4.

3.4. Guidance on Choosing Measures of Outcomes

PRISMA provided guidance about choosing outcomes measures, saying2:
“Standardisation and agreement of a core set of tools in palliative care needs to be based on rigorous scientific criteria, rather than by consensus only.”

There are specific issues to consider in choosing measures of patient-reported outcomes (PROMS)17, two of which are given below:

“Choose your outcome measure based on evidence. Ideally, use established outcome measures (rather than developing new ones) that have been validated with relevant patient populations requiring palliative care, that are sufficiently brief and straightforward and allow for proxy reports.”

“Sound psychometric properties such as validity (especially in relevant population), reliability, appropriateness and acceptability, responsiveness to change and interpretability are important to consider.” Table 1 summarises the terms used in testing measures.
PRISMA also provides guidance about using standard measures in a local context, saying:

“When translating outcome measures for use in other countries, it should not simply be a literal translation of the tool. .... Cultural competencies and local differences must be taken into account when translating outcome measures for use in palliative care.”

This will be of particular importance in ensuring that measures used in New Zealand are culturally appropriate. This is discussed further in Section 7.2.

There has been an attempt to develop consensus on the selection of outcomes measures for research. Specifically, outcomes measure for trials and non-randomised studies of palliative and end-of-life care interventions research is needed. The interested reader should see the paper developed in 2013 following the MORECare International Consensus Workshop.

### 3.5. Guidance on Implementation of PROMS

A document describing the steps needed to facilitate a successful implementation of PROMs in clinical palliative care has been prepared by Kings College in London. The guidance is illustrated using the Palliative care Outcome Scale (POS) family of measures, but is also more generally applicable.

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**Table 1: Psychometric Terms**

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Validity</td>
<td>Refers to what a tool is measuring and whether a tool is measuring what it should be measuring</td>
</tr>
<tr>
<td>Face and content</td>
<td>Whether a measure is assessing relevant aspects required, content is appropriate, important, and sufficient and clear. No hard criteria.</td>
</tr>
<tr>
<td>Criterion</td>
<td>How the measure correlates with other instruments that measure similar aspects (the gold standard).</td>
</tr>
<tr>
<td>Construct</td>
<td>The extent to which scores are consistent with theoretical concepts, constructs and hypotheses.</td>
</tr>
<tr>
<td>Reliability</td>
<td>Refers to the extent to which the results in unchanged conditions.</td>
</tr>
<tr>
<td>Inter-rater</td>
<td>Whether similar results are reached when different observers are used to rate the same situation/patient.</td>
</tr>
<tr>
<td>Test-retest</td>
<td>Whether similar results are reached in two time points if conditions are unchanged.</td>
</tr>
<tr>
<td>Internal consistency</td>
<td>Refers to how individual items of the outcome measure correlate with each other.</td>
</tr>
<tr>
<td>Appropriateness and acceptability</td>
<td>Refers to whether a measure is suitable for its intended use, e.g., is the measure not too long? It is important to balance psychometric with clinimetrics (i.e., the feasibility of a measure for clinical use).</td>
</tr>
<tr>
<td>Responsiveness to change</td>
<td>Refers to whether the measure can detect clinical important differences over time (that are related to the course of the disease or to an intervention). When responsive, the Minimum Clinically Important Difference (MCID) needs to be determined (or looked up).</td>
</tr>
<tr>
<td>Interpretability</td>
<td>Refers to whether you can translate the results into something meaningful to the patient, family caregivers or clinician.</td>
</tr>
</tbody>
</table>

1 MORECare: Methods of Researching End of Life Care

m POS and IPOS are part of a family of measures: [http://pos-pal.org/](http://pos-pal.org/)
The sequence of steps recommended in implementing patient-reported outcomes measures is as follows:

- Step 1: Identify the goals for collecting PROMs. These may be patient-level, system level or policy-level goals.
- Step 2: Select patients, setting and timing of assessment.
- Step 3: Determine which questionnaire to use.
- Step 4: Choose a mode for administering/ scoring the questionnaire.
- Step 5: Design processes for reporting results.
- Step 6: Identify aids to facilitate score interpretation.
- Step 7: Develop strategies for responding to identified issues.
- Step 8: Evaluate the impact of measuring PROMs on practice.

Issues in implementation in the New Zealand context are discussed further in section 6 and the implementation of patient-reported outcome measures is described as a key need in section 7.1.
4. Tools for Measuring Outcomes

The Outcomes Symposium heard from speakers from the UK and Australia on work done to implement national outcomes measures for palliative care. Both projects aim to achieve a national set of outcomes measures and both use suites of measures, not single measurement tools.

The Outcome Assessment and Complexity Collaborative (OACC)\(^{19}\) project in the UK aims for agreement on a standardised suite of outcome measures, training materials, support for implementation, feedback and reporting strategies that are nationally applicable. OACC began in 2013 and was piloted with hospitals, hospice and community services in South London, with a view to national implementation, supported by Hospice UK. The project builds upon and feeds into work being done on standardising outcomes measures in Europe. The POS measures\(^{7}\) in the OACC suite are widely used globally, including in Europe, Australia, Asia, Africa and America.

The Palliative Care Outcomes Collaboration (PCOC)\(^{7,20}\) is a programme in Australia that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. PCOC has a much longer history, beginning in 2005, and has been running successfully in Australia for many years. Participation in PCOC assists palliative care service providers to meet the Palliative Care Australia (PCA) Standards for Providing Quality Palliative Care for all Australians. Interest in implementing the PCOC suite has been shown from Singapore, Taiwan and Hong Kong and it has been implemented in some services in England and in a region in Ireland\(^{21}\).

Members of OACC and PCOC are in regular communication and there is some harmonisation of the two suites of measures. A comparison of the suites of measures is dealt with in Section 4.3 below, after consideration of each suite individually.

There are other outcomes measures in wide use, particularly in Canada\(^{22,23}\). New Zealand tends to follow developments in Australia and the UK, and outcomes measures from Canada and the USA were not included in the symposium. Interested readers should consider the work of Palliative Care McGill\(^{8}\) in Canada, and the National Palliative Care Research Center (NPCRC)\(^{9}\) and the Agency for Healthcare Research and Quality (AHRQ)\(^{9}\) in the USA.

4.1. Outcome Assessment and Complexity Collaborative (OACC)

The descriptions in this section summarise material from the booklet that introduces the OACC measures\(^{19}\). The reader is urged to consult the full booklet for more detail.

The OACC suite of recommended measures reflects the key domains of palliative care and holistic assessment. These include the phase of illness, the patient’s functioning, symptoms and other important concerns, and the impact palliative care services are having on the patient’s quality of life and that of the family and whānau. There are six measures in the OACC suite and the recommendation is to implement them together, or in the step-wise order illustrated below.

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\(^{a}\) IPOS is used in the OACC suite. POS and IPOS are part of a family of measures: [http://pos-pal.org/](http://pos-pal.org/)

\(^{b}\) Palliative Care McGill: [http://www.mcgill.ca/palliativecare/](http://www.mcgill.ca/palliativecare/)

\(^{c}\) National Palliative Care Research Center (NPCRC): [http://www.npcrc.org/content/37/Mission.aspx](http://www.npcrc.org/content/37/Mission.aspx)

\(^{d}\) Agency for Healthcare Research and Quality (AHRQ) [https://www.ahrq.gov/](https://www.ahrq.gov/)
Phase of Illness

Phase of Illness describes the distinct stage in the patient’s illness, according to the care needs of the patient and their family and whānau. There are five phases: stable, unstable, deteriorating, dying and deceased. The definitions are given in Table 2, overleaf.

The measure was originally developed and refined in Australia, and is now in common use in many other countries, including the UK. Phase of Illness supports case-mix classification and is used for different levels of palliative care reimbursement in the UK.

Phase of Illness is recorded at first assessment/on admission, at subsequent assessments/contacts during a spell of care, and at discharge or death. In inpatient settings, it is recorded on a daily basis, while in the community it is recorded at every contact. It has the potential to assist with quick and efficient communication both within and across teams, ensuring that the care plan is modified as needs change, and allowing clinicians to spend more time with patients and families/whānau. It takes one to two minutes to complete.

Australia-modified Karnofsky Performance Status (AKPS)

The patient’s overall performance status is assessed in three dimensions: activity, work and self-care. The measure results in a single score between 0% and 100%, as shown in Table 3.

The AKPS is recorded at first assessment or on admission to the palliative care team. Subsequently, AKPS should be recorded when Phase of Illness changes and at discharge or death. Completion time for this measure is less than two minutes.

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1 Measures used to group patients based on different utilization of healthcare resources.
Table 2: Definitions for Phase of Illness

<table>
<thead>
<tr>
<th>Phase</th>
<th>This is the current phase if...</th>
<th>This phase ends when...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stable</td>
<td>Patient’s problems and symptoms are adequately controlled by established plan of care and further interventions to maintain symptom control and quality of life have been planned and family/carer situation is relatively stable and no new issues are apparent.</td>
<td>The needs of the patient and/or family/carer increase, requiring changes to the existing plan of care.</td>
</tr>
<tr>
<td>Unstable</td>
<td>An urgent change in the plan of care or emergency treatment is required because the patient experiences a new problem that was not anticipated in the existing plan of care and/or the patient experiences a rapid increase in the severity of a current problem and/or family/carer circumstances change suddenly impacting on patient care.</td>
<td>The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/ies has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) and/or death is likely within days (i.e. patient is now dying).</td>
</tr>
<tr>
<td>Deteriorating</td>
<td>The care plan is addressing anticipated needs, but requires periodic review because the patient’s overall functional status is declining and the patient experiences a gradual worsening of existing problem(s) and/or the patient experiences a new, but anticipated, problem and/or the family/carer experience gradual worsening distress that impacts on the patient care.</td>
<td>Patient condition plateaus (i.e. patient is now stable) and/or urgent change in the care plan or emergency treatment and/or family/carer experience a sudden change in their situation that impacts on patient care and urgent intervention is required (i.e. patient is now unstable) or death is likely within days (i.e. patient is now dying).</td>
</tr>
<tr>
<td>Dying</td>
<td>Dying death is likely within days.</td>
<td>Patient dies or patient condition changes and death is no longer likely within days (i.e. patient is now stable and/or deteriorating).</td>
</tr>
<tr>
<td>Deceased</td>
<td>The patient has died; bereavement support provided to family/carers is documented in the deceased patient’s clinical record.</td>
<td>Case is closed.</td>
</tr>
</tbody>
</table>

Table 3: Australia-modified Karnofsky Performance Status (AKPS) Scores

<table>
<thead>
<tr>
<th>AKPS Score</th>
<th>Description of performance status</th>
</tr>
</thead>
<tbody>
<tr>
<td>100%</td>
<td>Normal, no complaints, no evidence of disease</td>
</tr>
<tr>
<td>90%</td>
<td>Able to carry on normal activity, minor signs or symptoms of disease</td>
</tr>
<tr>
<td>80%</td>
<td>Normal activity with effort, some signs or symptoms of disease</td>
</tr>
<tr>
<td>70%</td>
<td>Cares for self, but unable to carry on normal activity or to do active work</td>
</tr>
<tr>
<td>60%</td>
<td>Able to care for most needs, but requires occasional assistance</td>
</tr>
<tr>
<td>50%</td>
<td>Considerable assistance and frequent medical care required</td>
</tr>
<tr>
<td>40%</td>
<td>In bed more than 50% of the time</td>
</tr>
<tr>
<td>30%</td>
<td>Almost completely bedfast</td>
</tr>
<tr>
<td>20%</td>
<td>Totally bedfast and requiring extensive nursing care by professionals and/or family</td>
</tr>
<tr>
<td>10%</td>
<td>Comatose or barely arousable, unable to care for self, requires equivalent of institutional or hospital care, disease may be progressing rapidly</td>
</tr>
<tr>
<td>0%</td>
<td>Dead</td>
</tr>
</tbody>
</table>
The AKPS is an efficient and pragmatic way of summarising the performance of a patient and can be predictive of survival. In conjunction with the Barthel Index, it provides a useful clinical picture of functional status and gives an indication of the resources required to care for a patient. The AKPS score and the Barthel Index score (used for inpatients and in care homes) can aid in prognostication and discharge planning.

**Integrated Palliative care Outcome Scale (IPOS)**

The original Palliative care Outcome Scale (POS) was developed in the 1990s and has been extensively validated. POS is available in 11 languages, including English, and additional versions have been published. There are extensions for specific conditions, including multiple sclerosis, Parkinson’s disease and end-stage renal disease. IPOS integrates the most useful measures from previous versions and is intended to replace POS.

IPOS includes 10 questions to measure symptom burden, with items that measure physical, psychosocial, social and spiritual domains. It allows patients to list their main concerns, to add other symptoms they are experiencing, and to state whether they have unmet information or practical needs. The “gold-standard” is the patient version of IPOS, as self-reported outcomes are preferred. If this is no longer feasible, a staff version of IPOS can be used.

The POS measures are used in different settings, including home, hospital, hospice and, nursing home. POS-Dem is being developed for use in people with dementia living in care homes.

Completion time for the original POS was shown to be 10 minutes for both patients and health professionals, with the time being reduced as users became familiar with the measure. Although results are expected to be similar, a study examining the use of IPOS is currently under way.

**Views on Care**

Views on Care includes four questions that should be completed by the patient. The questions assess the patient’s own rating of their quality of life and their view of the impact of the service on their main problem(s) and their overall wellbeing. It can provide staff with an indication of whether or not they are having a positive impact on patients’ lives.

The development of the measure was led by St Christopher’s Hospice in the UK, and was adapted in collaboration with the Cicely Saunders Institute to ensure it can be used together with the patient version of IPOS. It is a relatively new measure and is being tested alongside IPOS. Preliminary work indicates that it takes less than two minutes to complete. It should be used together with IPOS at phase change and at discharge. Note that it should not be used at first assessment or on admission.

**Barthel Index** (for inpatients and care homes)

The Barthel Index is used for inpatients only and may also be useful for those in care homes. In the UK, it is not needed for people receiving palliative care in their own homes.

The Barthel Index is a measure of the patient’s ability to perform ten common activities of daily living relating to use of toilet, mobility and eating. Lower scores indicate a reduced ability to perform daily activities. Performance over the preceding 24–48 hours should usually be considered in scoring.
Scores on individual items provide an indication of areas in which a patient is not independent and requires assistance. A total score is produced by adding up the scores on individual tasks. The highest possible summary score is 20, indicating complete independence; the lowest score is 0, indicating complete dependence. Changes of more than two points in the total score reflect a probable genuine change in ability to perform activities of daily living. Changes in scores may also be useful predictors of survival.

It should be completed at first assessment or on admission to the palliative care team (or as close to the time of admission as feasible). Subsequently, the Barthel Index should be completed when the Phase of Illness changes and at discharge. The time taken for completion can vary widely. When completed by patients or health professionals familiar with the patient and their abilities, completion takes five minutes or less. However, when new observations are needed before scoring, completion time can be much longer.

**Living Situation**

The living situation, which asks whether the patient lives alone, was included in the OACC suite of measures as a single item. It is collected only once (on admission) and it is not technically an outcome measure. It allows the team to assess the patient’s support network, living situation and environment more adequately and may be used in future commissioning in the UK.

Note that this item would probably not be needed in New Zealand. There are several HIS0 measures for specialist palliative care\(^2\) which capture living situation and support at the beginning and end of an episode of care.

**Carer measures, including Zarit Carer Interview**

The Zarit Carer Interview is a caregiver-reported measure of family (unpaid caregiver) strain. It was designed to capture the stresses unpaid caregivers can experience when providing care. The original 22-question instrument was reduced to a six-item version that is recommended for use in palliative care.

The Zarit Carer Interview includes questions about different ways in which the caregiver role can negatively affect the carer. It comprises six questions that should be completed by the unpaid caregiver or by the caregiver with help from a health professional. This measure allows services to capture the nature and extent of the burden caregivers experience and, if appropriate, prompts them to take actions that support caregivers in their role.

Individual scores for single questions (items) can be used as indicators of severe burden or need for support. Information from individual question scores repeated over time also allows staff to monitor change over time. Summary scores can be generated by adding the individual question scores. Increasing summary scores indicate higher informal caregiver burden; the highest possible score is 24 and the lowest is 0.

The Zarit Carer Interview should be completed as close as possible to the date of first assessment or admission of the patient, and subsequently at changes in Phase of Illness and at discharge or death. Completion time can vary, depending on whether the measure is completed by a caregiver or with help from a health professional. It takes an experienced clinician some two to three minutes to complete.
In addition, the OACC team recommend adding two further questions, as shown in Table 4. The first question asks whether the carer and his/her family are receiving as much help and support as they need. This question is derived from the National Surveys of Bereaved People (VOICES) in the UK. The second question assesses the impact the palliative care service is having on the carer. It is not used at the first meeting with the palliative care team.

These additional questions allow services to retrospectively assess whether they are providing sufficient support and whether their actions have a positive impact on carers. This supports services’ ability to highlight their holistic practices and impact beyond the patient alone.

Table 4: Additional Carer Questions

<table>
<thead>
<tr>
<th>Overall, do you feel you and your family are receiving as much help and support from services as you need when caring for him/her?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Taking everything into account, do you think the palliative care team is making a difference to how things are going for you at present?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5</td>
</tr>
<tr>
<td>I don’t know</td>
</tr>
</tbody>
</table>

4.2. Palliative Care Outcomes Collaboration (PCOC)

Material in this section is summarised from the PCOC Clinical Manual PCOC and papers written about the implementation in Australia. The reader is urged to consult these documents for more information.

PCOC is a voluntary national quality programme in Australia that aims to embed nationally standardised clinical assessments and point-of-care data collection into daily practice. The initial PCOC dataset was collected by a small number of services for 18 months, beginning in January 2006. A second version was developed under the guidance of the PCOC Scientific and Clinical Advisory Committee and a third version was implemented from 2012. Participation in PCOC is voluntary and open to specialist palliative care services across Australia. PCOC represents about 90% of patients seen by the specialist palliative care sector in Australia.

PCOC is described as measuring the “vital signs” of palliative care. In order to drive quality and outcome improvement, there is a feedback loop to individual services as well as meetings to facilitate benchmarking between services. Community services are measured separately from inpatient services as a group.
PCOC is closely aligned with national priorities and the need for national outcomes measures. The Australian Government released a national palliative care strategy in 2000 and agreement was reached to improve the provision of palliative care service, to report national minimum data to the Department of Health and Ageing, and to develop and report on performance indicators. To support the implementation of the strategy, a service development centre was established. PCOC is a virtual centre, bringing together four research centres (three palliative care and one health services research) and is funded by the Australian Government Department of Health and Ageing.

PCOC data is collected at three levels, as shown in Figure 5. The patient receives palliative care in one or more settings of care and one or more phases of illness during the episode of care. Patient outcomes are structured and reported at the patient, episode and phase level.

Figure 5: Three Levels in the PCOC Structure

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Outcomes Measures for Palliative Care in New Zealand
There are five measures in the PCOC suite of outcomes measures. The first two, Palliative Care Phase and the Australia-modified Karnofsky Performance Status (AKPS), provide information on the status of the patient, as with OACC. The three further measures are the Palliative Care Problem Severity Score (PCPSS), the Symptom Assessment Scale (SAS), and Resource Utilisation Groups – Activities of Daily Living (RUG-ADL). Each measure is described briefly below.

**Palliative Care Phase**

Palliative Care Phase has the same meaning as the Phase of Illness described for OACC and given previously in Table 2. There are five phases and the wording in Australia is slightly different for the last two phases:
- Stable
- Unstable
- Deteriorating
- Terminal (described as Dying in OACC)
- Bereaved (post death support) (described as Deceased in OACC).

It is noted that palliative care phases are not sequential and that a patient can move back and forth between phases. PCOC recommends a minimum of daily assessment for inpatients and at each contact (phone or in-person) for community patients or in hospital consultative patients. Assessment may be conducted in person or over the phone (except for initial assessment at episode start).

**Australia-modified Karnofsky Performance Status (AKPS)**

This is the same measure as collected for OACC and as shown previously in Table 3.

PCOC uses the AKPS much more often than does OACC. Under OACC, AKPS is collected at the beginning, when Phase of Illness changes, and at the end. PCOC also collects AKPS at the beginning (episode start), at phase change, and at discharge, but also recommends collecting a minimum of daily for inpatients and at each contact for community patients or hospital patients. The assessment may be conducted in-person or over the phone (except for initial assessment at episode start).

**Palliative Care Problem Severity Score (PCPSS)**

PCPSS is clinician rated and facilitates the assessment of four palliative care domains: pain, psychological/spiritual, other symptoms and family/carer. The family/carer domain measures problems associated with a patient’s condition or palliative care needs. Each domain is rated on a four-point scale measuring the severity of the symptoms (0=absent, 1=mild, 2=moderate, 3=severe). The domain scores are used as triggers for referral, intervention or further assessment.

PCOC also uses PCPSS at episode start, at phase change, at discharge, daily for inpatients, and at each contact for community patients or hospital patients.

**Symptom Assessment Scale (SAS)**

SAS describes the patient’s level of distress relating to the seven most common physical symptoms experienced by palliative patients: difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain.
The instrument is designed to be a patient rated tool but also allows for rating by a family member or clinician. Highly rated or problematic symptoms may trigger other assessments and the use of additional assessment tools.

PCOC also uses SAS at episode start, at phase change, at discharge, daily for inpatients, and at each contact for community patients or hospital patients.

**Resource Utilisation Groups – Activities of Daily Living (RUG-ADL)**

RUG-ADL describes the level of functional dependence, based on what a person actually does, rather than what they are capable of doing. It consists of four items: bed mobility, toileting, transfers and eating. The questions and scoring are available in the PCOC Clinical Manual20.

PCOC also uses RUG-ADL at episode start, at phase change, at discharge, daily for inpatients, and at each contact for community patients or hospital patients.

**Additional Surveys**

Although these are not part of the daily assessment tools, PCOC also does periodic collections of patient and carer experience28.

### 4.3. Comparison of OACC and PCOC Measures

A poster by PCOC and OACC researchers29 shows a useful table to compare the two suites of measures. Table 5 below is derived from the complete table, which is given in Appendix C. The authors found as follows:

“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.”

PCOC and OACC share two measures: the phase (called Palliative Care Phase in PCOC and Phase of Illness in OACC) and the Australia-modified Karnofsky Performance Status (AKPS). These two measures are the foundation for both suites.

PCOC researchers found that the addition of palliative care phase was key to understanding some of the variation in patient-reported outcomes and they strongly advocate using this measure30. Work in the UK on new reimbursement models for palliative care also found that palliative care phase was an important measure to understand variation in utilisation24.

Table 5 shows the number of items in each domain and measure used. While PCOC has one item covering both psychological/emotional and spiritual domains, OACC has four items, including one specifically on spiritual needs.
Table 5: Comparison of PCOC and OACC Measures  
Sources: Key domain analysis adapted\textsuperscript{29}. Frequency\textsuperscript{19,20}

<table>
<thead>
<tr>
<th>Key Domain</th>
<th>PCOC Measures</th>
<th>OACC Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage of Illness</td>
<td>Palliative Care Phase (1 item)</td>
<td>Phase of Illness (1 item)</td>
</tr>
<tr>
<td></td>
<td>Australia-modified Karnofsky Performance Status (AKPS) (1 item)</td>
<td>Australia-modified Karnofsky Performance Status (AKPS) (1 item)</td>
</tr>
<tr>
<td>Physical</td>
<td>Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) (4 items)</td>
<td>Barthel Index (Inpatients only) (10 items)</td>
</tr>
<tr>
<td></td>
<td>Palliative Care Problem Severity Score (PCPSS) (2 items)</td>
<td>Integrated Palliative care Outcome Scale (IPOS) (10 symptoms + other)</td>
</tr>
<tr>
<td></td>
<td>Symptom Assessment Scale (SAS) (7 symptoms + other)</td>
<td></td>
</tr>
<tr>
<td>Psychological/</td>
<td>PCPSS (1 item)</td>
<td>IPOS (3 items)</td>
</tr>
<tr>
<td>Emotional</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spiritual</td>
<td>PCPSS (1 item)</td>
<td>IPOS (1 item)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family/Carer</td>
<td>PCPSS (1 item)</td>
<td>IPOS (1 item)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Zarit Carer Interview (6 items)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Additional questions (2 items)</td>
</tr>
<tr>
<td>Patient Views</td>
<td>Views on Care (4 items)</td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td>PCOC Measures</td>
<td>OACC Measures</td>
</tr>
<tr>
<td>Every day in IPU</td>
<td>All measures</td>
<td>Phase of Illness only</td>
</tr>
<tr>
<td>Every contact in</td>
<td>All measures</td>
<td>Phase of Illness only</td>
</tr>
<tr>
<td>community</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phase Change</td>
<td>All measures</td>
<td>All Measures</td>
</tr>
</tbody>
</table>

PCOC uses one question for carers, while OACC uses a total of nine questions. The OACC suite also includes the Views on Care measures. The four questions assess the patient and family rating of their quality of life and their view of the impact of the service on their main problems and overall wellbeing. PCOC does do periodic collections of patient and carer experience\textsuperscript{28} that are not part of the tools compared above.

At the symposium, Kathy Eager from PCOC cautioned delegates, saying:

“How and when you collect patient outcome measures are just as important as what you collect. Don’t focus too much on the selection of measures.”
There are notable differences in the frequency with which the two suites of measures are used. Both suites are used at admission, at phase change and on discharge or death. The OACC Views on Care measures are the only exception, as these assess impact of care retrospectively and are thus not used on admission.

Both suites also use the measure of phase on a daily basis in inpatient settings and at every contact in community settings. OACC uses changes in phase to trigger the use of all the other questions. However, PCOC uses all the measures on a daily basis in inpatient settings and at every contact in community settings. This is a significant difference in workload and data collection.

PCOC and OACC have been implemented successfully in hospices that have inpatient and community settings of care, as well as consultative services in hospitals. At this stage of development, both suites are used for specialist palliative care services but are expanding to general settings of palliative care.

PCOC is planning for how primary palliative care providers and care homes may participate in future. IPOS-Dem (part of the IPOS family used by OACC) is a proxy-completed measure for people with dementia living in care homes. It is derived from IPOS, and developed for use by unqualified care staff working in care home settings. Validation of this instrument is still in progress.

Further consideration of issues relating to outcomes measures in residential care is given in Sections 6.4 and 6.5.
5. Themes from Feedback during the Symposium

The key points from feedback received during the Outcomes Symposium are reflected below. More information is provided in a separate document entitled “Outcomes measures for palliative care in New Zealand: Key themes from delegates”.

The feedback from the facilitated table conversations has been summarised using the three themes identified.

<table>
<thead>
<tr>
<th>Key themes</th>
<th>Feedback</th>
</tr>
</thead>
</table>
| Elements of design and development| **Patient at the centre**: The key message from participants emphasised responsiveness to the patient, their whānau and family. *Measuring what Matters* (pg. 25) states that “Effective palliative care must meet the needs of patients, their families and whānau, regardless of their religious, cultural, ethnic or social economic background or geographic location/rurality. Going forward any design and development of assessment tools to assist in improving the experience must place the patient at the centre.**  

**Including whānau and family**: Working with the whānau and family of the patient receiving care was considered an essential part of the palliative care service. Reflection on “how well did we treat you” is often left to the whānau and family of the patient to provide anecdotally, after the death of the person. The design of outcome measures would be strengthened by an integrated approach to reflect the needs, aspirations and goals of the whānau and family. This will support efforts to understand people’s beliefs and preferences, and support service improvement in quality of interaction between the provider and the service user.  

**The New Zealand context**: A key component of successful service design is meeting the needs of specific populations groups, providing culturally appropriate palliative care through treatment and support. Assessment tool design and development requires that reflection at its foundation, inclusive of indigenous knowledge and frameworks of health, e.g. the concept of “Te Whare Tapa Whā” the four cornerstones (or sides) of Māori health, tailoring to the specific cultural circumstances of a patient, their whānau and family.  

**Build on work already done**: “Don’t reinvent the wheel”; consider work has undertaken to produce a considerable “body of knowledge” within the New Zealand context including *Measuring What Matters: Palliative Care* (2012); understand what “tools” are available for measuring and what they measure e.g. interRAI.  

**Agreement on terminology used**: What is meant by outcomes? It was highlighted in several conversations that a glossary of terminology was important and agreement of definitions was required. |
**Dynamics of implementation**

**Agreement on collaboration:** There was an agreement on a collaborative approach this would be key to successfully developing and implementing an outcomes tool.

**National agreement and integration:** There was a high-level consensus for a national approach or regional approach (refer Southern DHB). Trialling a pilot to begin with was endorsed in some of the conversations. Educating and training of staff were seen as essential. Feedback included comments to support a quality improvement cycle which provided opportunity for services to evaluate progress against the measures; feedback to funders about gaps and the need; support a way to have a central depository that allows sharing of information. Discussion on incentives to adopting such tools needed consideration.

**Continuous improvement:** Equity: participants endorsed using data from outcomes as a tool to address equity. It is expected that provision of a tool would influence improving equity of service provision, and service design with the service reaching a wider demographic across the general population and the quality of the service provided.

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**Sector expectations**

**Uniting the sector:** Working together as a sector with a centralised outcomes measurement tool was considered beneficial. There was some discussion on an across systems approach, including specialist and primary providers, in all settings.

**Having one voice:** Looking at the role of leadership; Hospice New Zealand mandating for their membership, and advocacy for the palliative care sector. Sustainability issues: the question of funding was raised in some of the conversations.

Delegates to the symposium were asked what tools they are currently using and what tools they plan to implement. There were sometimes multiple people attending from the same facility and the questions were asked in an open-ended way, which makes interpretation difficult. Some answered that they used a named software system or benchmarking service, without identifying specific measures.

Nevertheless, by combining responses from the same facility, it was possible to identify at least the following existing usage of the PCOC and OACC measures, as follows:

- PCOC suite of measures – five hospices
- OACC suite of measures – one hospice
- Australia-modified Karnofsky Performance Status (AKPS), in both OACC and PCOC suites – four hospices
- Palliative Care Problem Severity Score (PCPSS), in PCOC suite – ten hospices
- Palliative care Outcome Scale (POS) or Integrated Palliative care Outcome Scale (IPOS), in OACC suite – five hospices and one DHB.

In addition, four hospices use the Edmonton Symptom Assessment Scale (ESAS), which is not in PCOC or OACC. Of interest for the later discussion about interRAI, usage of the interRAI assessment tools was listed by five hospices, together with aged care facilities and a DHB.
6. Issues in Implementing Outcome Measures

These issues were not specifically dealt with in the Outcomes Symposium but arise from comments made by speakers or from issues raised by delegates.

6.1. Links to National Benchmarks

A notable feature of the collection of outcomes measures in Australia is that the PCOC dataset supports reporting on the agreed national outcomes measures. As described in Section 4.2, PCOC is the result of the need to improve quality in palliative care, initiated by and funded by government.

Some examples of the 20 national benchmarks adopted in Australia\(^4\) are:

- **Benchmark 1**: 90% of patients must have their episode commence on the day of, or the day following date ready for care.
- **Benchmark 2**: 90% of patients are in the unstable phase for three days or less.
- **Benchmark 3.1**: At least 90% of patients with absent or mild PCPSS pain at the beginning of their phase of palliative care have absent or mild PCPSS pain at the end of the phase.
- **Benchmark 3.2**: At least 60% of patients with moderate or severe PCPSS pain at the beginning of their phase of palliative care have absent or mild PCPSS pain at the end of the phase.
- **Benchmark 3.3**: At least 90% of patients with absent or mild SAS pain at the beginning of their phase of palliative care have absent or mild SAS pain at the end of the phase.
- **Benchmark 3.4**: At least 60% of patients with moderate or severe SAS pain at the beginning of their phase of palliative care have absent or mild SAS pain at the end of the phase.
- There are similar measures for fatigue, breathing problems and family/carer issues.
- In addition, there are ten case-mix adjusted benchmarks for change in symptoms relative to the national average. These cover pain, nausea, breathing problems, bowel problems, other symptoms, psychological/spiritual problems and family/carer problems.

There has also been significant development of outcomes measures for palliative care at a national level in Belgium and the Netherlands.\(^31\)

An issue for the palliative care sector in New Zealand has been whether to wait for national direction on what outcomes measures are needed, and whether to wait for initiatives at regional or District Health Board level, or to proceed by service (hospice, hospital, aged residential care, primary care). New developments since the symposium make this clear, as outlined in Section 7.1.

6.2. Support for Implementation

Both OACC and PCOC are significant initiatives that have been funded to provide support for implementation and have a strong research component. It is instructive to consider the academic linkages and the extent of the infrastructure that has been developed in each case.

OACC Implementation

The OACC project\(^1\) is led by the Cicely Saunders Institute\(^1\), at King’s College, London. OACC is funded by the Guy’s and St Thomas’ Charity and supported by project BuildCARE. OACC works in collaboration with the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Palliative and End of Life Care Theme. CLAHRC South London, where OACC was first implemented, is a partnership between King’s Health Partners, St. George’s, University of London, and St George’s Healthcare NHS Trust. Hospice UK works in partnership with the Cicely Saunders Institute to support the implementation of OACC.

In 2015, the OACC team consisted of seven people\(^1\), including three project co-leads with extensive academic experience:

- Professor Irene Higginson, Director of Cicely Saunders Institute
- Dr Fliss Murtagh, Reader and Consultant in Palliative Medicine
- Dr Barbara Daveson, Cicely Saunders International Lecturer in Health Services Research in Palliative Care.

The team\(^u\) includes a project manager, data analysis capability and two Quality Improvement Facilitators (QIFs). The Cicely Saunders Institute is also the home for the development of the POS family of measures, of which IPOS is included in the OACC suite of measures.

OACC produces a resource pack\(^v\) and a “How to” guide on implementation\(^3\). The OACC Palliative Care Outcome Measures Resource Pack includes sets of outcome measures, guidance booklets on how and when to implement measures, and training resources, including training videos, animated PowerPoint presentations and prompt cards. There is a charge of GBP150 per pack. Purchasing a pack provides access to monthly webinars and a telephone support line.

Feedback and formal evaluation of the implementation are critical parts of the OACC project.

PCOC Implementation

There are now many outcome centres (15-20) in Australia\(^2\). PCOC is managed alongside three other outcome centres by the Australian Health Services Research Institute (AHSRI), situated at the University of Wollongong:

- Palliative Care Outcomes Collaboration (PCOC)
- Australasian Rehabilitation Outcome Centre (AROC)
- Electronic Persistent Pain Outcome Centre (ePPOC)

New Zealand organisations, including the Accident Compensation Corporation (ACC), participate in AROC and ePPOC, but not PCOC as yet. AROC and ePPOC are funded by users, while PCOC is funded by the Australian Government Department of Health.

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\(^1\) Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation: [http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/index.aspx](http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/index.aspx)
\(^u\) OACC Project: [http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/research/studies/oacc/index.aspx](http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/research/studies/oacc/index.aspx)
PCOC is a virtual organisation, governed by the Management Advisory Board (MAB) with an external chairman. The Board is responsible for the strategic and executive management of PCOC, including its clinical and scientific governance, and for compliance. The Board meets twice a year.

PCOC divides Australia into four zones to engage with palliative care service providers. Each zone is represented by a chief investigator from one of the four collaborative centres:

- **Central Zone**: Professor Kathy Eagar, Australian Health Services Research Institute, University of Wollongong
- **North Zone**: Professor Patsy Yates, Institute of Health and Biomedical Innovation, Queensland University of Technology
- **South Zone**: Professor David Currow, Department of Palliative and Supportive Services, Flinders University
- **West Zone**: Assistant Professor Claire Johnson, Cancer and Palliative Care Research and Evaluation Unit, University of Western Australia.

Each zone is also represented by one or more quality improvement facilitators, whose role includes supporting services to participate in PCOC and facilitating ongoing service development and quality improvement. The national team, located at ASHRI, at the University of Wollongong, co-ordinates the patient outcomes reporting, education programme and quality activities across the four zones.

The PCOC Quality Improvement Facilitators (QIFs) are the first point of contact for palliative care services and provide:

- Education in clinical assessment tools and protocols
- Assistance with process re-engineering
- Embedding PCOC assessments into routine practice
- Structured feedback after each report
- Facilitating access to the evidence on how to improve
- Supporting and promoting PCOC champions
- Networking ‘like’ services and encouraging services to benchmark with each other

PCOC provides an extensive Toolkit for Services to support palliative care services and clinicians to implement and embed the programme within the routine practice of their service.

Kathy Eager warned delegates that there is good evidence that clinical registries such as PCOC can improve quality and outcomes, but only if the feedback loop is closed. Measuring performance is not, on its own, enough. To this end, PCOC organises communities of practice and holds PCOC National Benchmarking Workshops, at least four times a year. The workshops bring peer services together from across Australia to network and learn from each other.

**Issues for New Zealand**

Both OACC and PCOC provide extensive support for implementation, which is beyond the scope of any one part of the palliative care sector to implement alone. This is considered further in Section 7.2, as one of the suggestions on the way forward.

An advantage of adopting the PCOC suite would be the ability to compare New Zealand directly with our Australian colleagues, as occurs with other trans-Tasman initiatives. However, PCOC is built around the national outcomes framework and measures chosen for Australia and it is not yet known what measures may be adopted at a national level in New Zealand by the Ministry of Health.

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6.3. Palliative Care IT Systems and Reporting

Both OACC and PCOC have plans to move more collection of outcomes measures from paper to electronic means and to simplify the submission of data for comparisons. In this section, the collection and sharing of palliative care data in New Zealand is discussed, and the current availability of outcomes measures in software systems is described.

In New Zealand, data standards for specialist palliative care were published in December 2011 and revised in June 2013. These HISO Standards for Specialist Palliative Care26,33 do not contain any outcomes measures from the OACC and PCOC suites, or any other patient-reported outcomes. These standards are for specialist palliative care, which is typically provided by hospices and hospital palliative care teams34.

Hospice Software Systems

The extent of implementation of the HISO standards has been investigated in hospices. For the year-ended June 2016, 70% of hospice patients were with hospices that used software that fully implemented the HISO standards. There are four major software providers, as well as some hospices with their own systems:

- **PalCare software**: 19 hospices (20 in FY2017) with 60.4% of patients. Fully HISO-compliant.
- **Houston Medical/VIP software**: two hospices with 9.2% of patients. Fully HISO-compliant.
- **Medtech software**: three hospices with 8.7% of patients.
- **Own systems**: five hospices (four in FY2017) with 21.7% of patients.

PalCare, an Australian-based software company, already has all the PCOC measures and reporting for their Australian clients. PalCare has a total of 26 outcomes measures and assessment tools currently available in the system35. Of these, six of the tools are used in PCOC or OACC. The system has all five PCOC measures and three of the six OACC measures. More detail on the assessment tools available in PalCare is provided in Appendix D.

All the PalCare assessment tools are already available to hospices in New Zealand. Not all hospices are using the outcomes measures available but some, like North Haven Hospice, have used selected outcomes measures extensively for several years. It would thus be relatively easy for PalCare users to extend their use of outcomes measures, and support already exists through the PalCare Users Group.

None of the PCOC or OACC measures are currently built into the Houston Medical/VIP system as part of the standard package. However, Arohanui Hospice36 has added several tools as part of the customisable system and is considering others3. These could potentially be shared with other users of the system. POS-S, one of the family of POS measures has been implemented, whereas IPOS is the version used in the OACC suite of measures.

The Medtech system was built around primary care, rather than specialised palliative care. Accordingly, Medtech has not yet implemented the HISO standards for specialist palliative care nor any outcomes measures for palliative care that could be used by hospices.

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*POS-S, BEDS, Braden and Falls Risk assessment added. The Clinical Governance group is looking at others.*
Hospital, Residential Aged Care and Primary Health Organisation Systems

The extent of implementation of the HISO standards for hospital palliative care teams is not known. Hospitals in New Zealand participate, together with Australian hospitals, in sharing data through the Health Roundtable\(^\text{y}\). This non-profit membership organisation collects, analyses and publishes information comparing organisations and identifying ways to improve operational practices. Palliative care data is one of the areas in which data are being shared between hospitals.

At this stage, little is known about the IT systems used in aged residential care and whether there are any that have outcomes measures. Some aged residential care facilities participate voluntarily in sharing data through an Australian organisation, QPS Benchmarking\(^\text{z}\). The measures shared include financial, clinical, staffing, and health and safety measures, as well as satisfaction surveys.

Aged residential care facilities are required, in terms of their contracts, to use the interRAI assessment instruments, which are discussed in more detail in the next section. interRAI assessments are also a requirement for providing support in the home.

It is not known whether any outcome measures suitable for palliative care are embedded in the systems of Primary Healthcare Organisations (PHOs) in New Zealand.

There are thus challenges in how any common measures of outcomes can be implemented in New Zealand without significant leadership and direction from the Ministry of Health, the Health Information Standards Organisation (HISO) and the Health Quality and Safety Commission (HQSC).

6.4. interRAI in New Zealand

The Ministry of Health has worked with DHBs, the aged residential care sector and providers of home-based care to implement interRAI\(^\text{aa}\) assessments throughout New Zealand. The tools were developed by interRAI\(^\text{bb}\) and provide a comprehensive clinical assessment of medical, rehabilitation and support needs and abilities, such as mobility and self-care.

The tools are used to assess the health of older people in the home and community, hospital and residential care settings, and enable assessment and care plans to be developed on a consistent basis throughout New Zealand. The use of interRAI in aged residential care facilities has been mandatory since July 2015.

Figure 6 shows the interRAI suite of assessments and how all rely on a common core of questions. The common core is said to be about 80% of the questions, with each version adding the balance of 20%. Explanations of the petals are contained in Table 6, below the diagram.

\(^\text{y}\) The Health RoundTable: https://www.healthroundtable.org/JoinUs/Home/Welcome.aspx
\(^\text{z}\) QPS Benchmarking: https://www.qpsbenchmarking.com/. The organisation has a page on palliative care, saying that has developed benchmarks with Hospice New Zealand. This is historic and use of the service was always voluntary. Not all hospices in New Zealand use the benchmarking service.
\(^\text{aa}\) interRAI New Zealand: interRAI New Zealand: http://www.interrai.co.nz/
\(^\text{bb}\) interRAI is the acronym for International Resident Assessment Instrument. The name refers both to a suite of assessment instruments and to the organization that developed them. The organization is a not-for-profit collaborative network of 60 researchers and clinicians from over 30 countries engaged in improving health care for persons who are elderly frail or disabled. Membership of interRAI includes obligations to share anonymous data internationally and to provide support to other members.
Table 6: InterRAI Versions and Implementation in New Zealand \(^{37,38}\)

<table>
<thead>
<tr>
<th>Name of assessment</th>
<th>Purpose of assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contact Assessment (CA)</td>
<td>A shorter, screening assessment suitable for people with short term or non-complex needs to support living at home</td>
</tr>
<tr>
<td>Community Health Assessment (CHA)</td>
<td>Designed to explore the level of complexity of clients and identify general health and living issues for community clients.</td>
</tr>
<tr>
<td>Home Care Assessment (HC)</td>
<td>Designed for people with more complex needs who are able to live at home. Once a certain level of need is identified the person is referred to residential care.</td>
</tr>
<tr>
<td>Long Term Care Facilities Assessment (LTCF)</td>
<td>Assessment designed for people in residential care to develop and update their care plans.</td>
</tr>
</tbody>
</table>

**interRAI assessments in New Zealand currently**

**interRAI assessments which have not yet been implemented in New Zealand**

<table>
<thead>
<tr>
<th>Name of assessment</th>
<th>Purpose of assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute Care (AC)</td>
<td>for frail older persons in acute hospital settings</td>
</tr>
<tr>
<td>Post-Acute Care (PAC)</td>
<td>for persons in inpatient sub-acute settings</td>
</tr>
<tr>
<td>Assisted Living (AL)</td>
<td>for persons with low levels of need in residential settings</td>
</tr>
<tr>
<td>Community Mental Health (CMH)</td>
<td>for persons in community mental health service settings</td>
</tr>
<tr>
<td>Mental Health (MH)</td>
<td>for persons in inpatient mental health services</td>
</tr>
<tr>
<td>Intellectual Disability (ID)</td>
<td>For persons with intellectual disability</td>
</tr>
<tr>
<td>Persons With Disability (PWD)</td>
<td>(currently in development)</td>
</tr>
<tr>
<td>Palliative Care (PC)</td>
<td>for persons in palliative care programmes</td>
</tr>
</tbody>
</table>
According to interRAI\textsuperscript{37}:

"The interRAI methodology differs from other assessments in that the purpose of assessment is to consider the older person’s functioning (as opposed to status). They are specifically designed to find opportunities for improvement and/or any risks to the older person’s health, which then form the basis of a care plan."

"The assessments are designed so that each version includes items common across the person’s continuum of care, e.g. home, hospital or residential care, as well as focusing on items particular to that context, e.g. home care considers the person’s ability to cook meals which is not included in the long-term care version."

The Palliative Care Council\textsuperscript{cc} had taken an interest in the introduction of the interRAI Palliative Care instrument\textsuperscript{dd} in order to facilitate changing to more appropriate care plans at the end of life. There are 17 sections to the five-page instrument:

- Section A: Identification information
- Section B: Intake and initial history
- Section C: Health conditions
- Section D: Nutritional status
- Section E: Skin condition
- Section F: Cognition
- Section G: Communication
- Section H: Mood
- Section I: Psychosocial well-being
- Section J: Functional status
- Section K: Continence
- Section L: Medications
- Section M: Treatments and procedures
- Section N: Responsibility/Directives
- Section O: Social supports
- Section P: Discharge
- Section Q: Assessment information

The interRAI Palliative Care assessment tool has been trialled in New Zealand and a decision has been taken to begin implementation. An implementation plan is being developed and the instruction may begin as early as mid-2017\textsuperscript{39}. However, the training and implementation are planned only for existing interRAI Home Care assessors with community clients\textsuperscript{39}, and not for aged residential care facilities.

The question of whether interRAI assessments could be used for outcomes measurement was the reason a presentation on interRAI was included at the Outcomes Symposium. These instruments are used primarily for assessment about changing care plans and the frequency of use is very different to that of the PCOC or OACC measures. For example, in residential aged care facilities, the Long Term Care Facilities Assessment (LTCF) is used only every six months.

At this stage, no information is available on how frequently the Palliative Care (PC) assessment should be used and it will be a decision for each DHB, based on their model of care\textsuperscript{39}. In any event, it will not initially be implemented in aged residential care. The completion of interRAI assessments is also a much longer process than required for the completion of the OACC and PCOC measures.

\textsuperscript{cc} An advisory body, under Cancer Control New Zealand, to the Minister of Health. Disbanded in 2015.

\textsuperscript{dd} interRAI Palliative Care instrument: \url{http://www.interrai.org/palliative-care.html}
Work is being done in Belgium\textsuperscript{40} to determine the validity of the interRAI Palliative Care instrument in nursing homes. A qualitative study\textsuperscript{41} found that the instrument takes less time than other interRAI instruments as it is less extensive. However, the first assessments took 45 minutes to complete, while, after one year, the time taken reduced to 20 minutes. Users found that “filling out the instrument was an extensive, laborious and time consuming process.”

Further work in Belgium\textsuperscript{42} uses the interRAI Palliative Care (PC) instrument alongside the Palliative care Outcome Scale (POS), part of the OACC suite of measures. The main objective is to evaluate whether the palliative care needs of nursing home residents are better met and whether symptoms associated with palliative care situation are reduced after using the interRAI PC over the course of a year. One year after introducing the interRAI PC, no reduction in residents’ needs and symptoms were found in the intervention nursing homes, although reductions were found in the nursing homes that had not yet used any interRAI instrument. The authors think this may suggest that the use of an interRAI instrument other than the interRAI PC specifically, can improve care.

In the feedback from the symposium delegates\textsuperscript{1}, there was mention of the usage of interRAI assessment tools by some hospices. interRAI has been an important standardisation of the assessments for home support and entry to residential care in New Zealand. Any attempt to bring together outcomes measures across hospices and aged residential care will need to grapple with the mandatory nature of interRAI in aged residential care and the requirements of the Ministry of Health and DHBs in this regard.

6.5. Outcomes Measures across all Settings of Care?

There is a tension between the need to have common outcomes measures across all settings of palliative care and the needs particular to some settings of care.

The five papers below were included in the Outcomes Symposium pre-reading list. They are not an exhaustive survey of the literature, but they are recent papers that give some idea of the issues that arise in different parts of the system:

- **Hospices and hospitals:** Improving national hospice/palliative care service symptom outcomes systematically through point-of-care data collection, structured feedback and benchmarking\textsuperscript{7}.
- **Residential aged care:** Measuring end-of-life care and outcomes in residential care/assisted living and nursing homes. \textsuperscript{43}
- **Day care:** Implementing Outcome Measures within an Enhanced Palliative Care Day Care Model\textsuperscript{44}.
- **Intensive care units:** Priorities for Evaluating Palliative Care Outcomes in Intensive Care Units\textsuperscript{45}.
- **Paediatric palliative care:** Health-related quality-of-life outcome measures in paediatric palliative care: A systematic review of psychometric properties and feasibility of use\textsuperscript{46}.
- **Research:** The selection and use of outcome measures in palliative and end-of-life care research: the MORECare International Consensus Workshop\textsuperscript{18}.

At the heart of the desire to use common outcomes measures across all settings of care is a patient-centred view of health systems. It makes logical sense that the quality of palliative care should be held to the same standard for all New Zealanders, regardless of the part of the country they live in or the setting of care.
Yet each of the settings of care has very particular needs about what to measure, and the choice of tools may be influenced by research in that area of practice (for example, paediatrics) and by comparisons made between organisations (for example, the hospital benchmarking that occurs in conjunction with Australian hospitals).

It is thus vital that the Ministry of Health take the lead in bringing together all parties in palliative care to resolve what measures can be used across all settings of care. At the same time, particular settings of care may develop additional measures according to their own needs.

### 6.6. The Need for Communities of Practice

Communities of Practice (CoPs) across health care are a means of generating and sharing knowledge and improving organisational performance at all levels.

There are already initiatives in many parts of the country of hospices implementing palliative care outcomes measures, as highlighted in Section 5 and the separate document on feedback from the symposium\(^1\). North Haven Hospice has provided an excellent example of how outcomes measures can be embedded at a facility\(^2\). It is also a good example of why communities of practice are important and why setting up a mechanism for sharing developments like this will be recommended in Section 7.

**The North Haven Hospice Model**

The North Haven Hospice guidelines apply to all members of the multi-disciplinary team and to the assessment of all patients, family and whānau. A holistic assessment is conducted of the patient, according to the principles of Te Whare Tapa Whā, which includes assessment of physical, mental, emotional, spiritual and cultural needs. The assessment acknowledges any advance care plan that may be in place and documents the informed choices and preferences of the patient and their family and whānau.

Where support and guidance are provided to those who care for patients in residential aged care facilities, a comprehensive documented assessment is not usually required. However, if an assessment is completed it must be documented and shared with staff at the facility.

The following tools are mandatory, with the frequency of use given:

- ESAS (Edmonton Symptom Assessment System) - Admission to the service
- Fall risk assessment - Admission to the service, admission to IPU, and following any fall or change in functional status.
- General Health Assessment - Admission to the service and update on admission to IPU
- Genogram\(^\text{ff}\) - Admission to service
- Medical assessment - Admission to IPU
- PPS (Palliative Performance Scale) - Admission to the service
- Risk management assessment - Admission to service (community patients)
- SES (Spiritual, Emotional and Social Assessment) - Admission to the service
- CSNAT (Carer support needs assessment) - Within one month of patient admission to service

\(^1\) Information on the initiatives at North Haven Hospice has been provided by Dr Warrick Jones, the Medical Director; Elizabeth Lee, the Quality and Safety Manager; and Walter Nasarek, the IT co-ordinator. The Chief Executive Officer is Leonie Gallaher. Permission to share this with others has been given.

\(^\text{ff}\) A genogram is essentially a family map and a visual representation of whakapapa.
There are also other tools agreed for specific purposes, such as pain, oral assessment and mental state. For each mandatory and optional tool, the guidelines give information under the following headings:

- What and why
- When
- Documentation
- By whom.

The information collected on these outcomes measures is captured in the PalCare system used by North Haven Hospice. Timelines are identified for completion of certain assessments to enable risks, priorities and change in health or functional status to be identified and acted on appropriately. If a mandatory assessment cannot be completed as expected, an explanation is documented on PalCare.

Assessments are reviewed and updated as changes in functional and health status, and/or support needs are identified. Assessments for all patients in the IPU are reviewed at least daily or more often as indicated by the patient’s condition.

North Haven Hospice has also developed audit tools for regular audits of patient documentation. There are two tools, one for patients in the community and one for patients who had been admitted to the IPU. These tools audit a subset of patient documents to determine whether the outcomes measures have been applied as set out in the guidelines. For example:

- **SES (Spiritual, Emotional & Social Assessment):** initial assessment commenced at first visit and completed (considering the immediate needs of the patient) within a month of referral, unless there is a specific reason documented in PalCare.

It is not known how many other hospices have developed similar guidelines. A key recommendation for hospices will therefore be to share developments like this with others who have implemented outcomes measures and those considering implementation.

While the symposium had some people from aged residential care, hospital palliative care and general practice, these areas cannot be said to have been fully represented. It is essential that a forum is made available for continuing the conversation with all parties in palliative care, and that patient, family and whānau voices are also part of the conversation.

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68 The genogram is done on paper and scanned into the PalCare system.
7. Key Points for Finding a Way Forward

The feedback from delegates at the symposium was overwhelmingly in favour of moving forward on outcomes measurement in a co-ordinated way. There were strong calls for a common understanding of outcomes measures, as it was apparent at the symposium that different levels of outcomes are being considered when people use the phrase “outcomes measures”. Above all, there were persistent and strong calls for leadership from the Ministry of Health.

This discussion document has thus far expanded on the material covered in the pre-reading for the symposium, presented at the symposium and collected after the symposium. At the time of the symposium in February 2017, the Review of Adult Palliative Care Services had not yet been released.

In the Review of Adult Palliative Care Services and particularly the accompanying Action Plan, the Ministry of Health has taken the leadership position asked for by the sector. They have proposed a way forward for the introduction of an outcomes framework and national outcomes measures for palliative care. This section therefore begins with key points from the Review and Action Plan, followed by recommendations as to how the sector might move forward with the Ministry on clinical outcomes measures.

7.1. Review and Action Plan for Palliative Care 2017

The Ministry of Health released the Review of Adult Palliative Care Services with an accompanying Palliative Care Action Plan on 30 March 2017. The Review sets out five priority areas:

- Increase emphasis on primary palliative care
- Improve quality in all settings
- Grow the capability of informal carers in communities
- Respond to the voices of people with palliative care needs and their families and whānau
- Ensure strong strategic connections

The priority to “Improve quality in all settings” focuses extensively on outcomes frameworks and outcomes measurement. The Review states (page 14):

“While all of the actions coming from the Review will help to improve various aspects of quality, understanding and measuring outcomes is a key element in achieving this improvement.”

“To progress this priority area the Review proposes establishing a national agreement on service expectations, including quality standards, and increasing the visibility of palliative care quality indicators in accountability arrangements. These goals could be advanced by developing the following three building blocks:

- National service expectations for palliative care will centralise current expectations for publicly funded services, and support a range of commissioning and contracting models. They will also provide clear accountability and links to current guidelines and service standards where national consistency or guidance is needed; for example, Te Ara Whakapiri: Principles and guidance for the last days of life.
- An outcomes framework to support, and be supported by, the National Service Expectations. The outcomes framework would take a results-based accountability approach and build on the existing outcomes framework, ‘Measuring What Matters’, developed by the Palliative Care Council of New Zealand. It will inform what is important to measure and the purpose of the measurement.
In summary, there are four actions to improve quality in all settings:

- “Agree national service expectations for palliative and end-of-life care for use in all settings (for example, aged residential care, primary care, hospitals and hospices).
- Establish an outcomes framework to support a range of commissioning models using a results-based accountability approach.
- Agree a core, national set of outcome, quality and activity data for palliative care (across all providers).
- Include palliative care quality indicators in the system outcomes monitoring framework.”

These are expanded on in the Palliative Care Action Plan\textsuperscript{13}, with timelines. The full text from the action plan, as it pertains to quality, is included as Appendix E of this discussion document. The first three action plan items, due for completion in 2017, are given in Table 7.

### Table 7: Priority 3: Improve quality in all settings. First three short-term actions due in 2017\textsuperscript{13}

<table>
<thead>
<tr>
<th>Action</th>
<th>Who</th>
<th>When</th>
</tr>
</thead>
<tbody>
<tr>
<td>The sector agrees on a population outcomes framework. Agree on population-level quality indicators for palliative care. Include access and equity in the indicators.</td>
<td>Sector leaders Ministry of Health</td>
<td>2017</td>
</tr>
<tr>
<td>The sector investigates clinical outcome measures to assure quality of care for individuals receiving palliative care. (This work is under way with a discussion paper developed in February 2017.)</td>
<td>Hospice NZ and sector</td>
<td>2017</td>
</tr>
<tr>
<td>Agree on an independent evaluation framework for the outcomes of the innovation funding proposals to improve the quality of palliative care in aged residential care, primary care and community settings.</td>
<td>Ministry of Health</td>
<td>2017</td>
</tr>
</tbody>
</table>

### 7.2. Recommendations on Moving Forward

The Palliative Care Action Plan\textsuperscript{13} succinctly separates the responsibilities for population-based outcomes and outcomes measures needed by the palliative care sector, saying (page 20):

“Words that describe outcomes can be confusing. The Ministry of Health develops population-based targets and outcomes. The palliative care sector is considering the best approach for New Zealand to reflect and report on clinical palliative care outcomes.”

This is a crucial distinction and is central to the points on moving forward discussed below.
Moving Forward at a National Level

The Ministry has taken the lead in facilitating the work needed at a population level (page 13):

“To achieve this, the action plan sets out sector leadership workshops that the Ministry of Health will resource and facilitate with the aim of building cross-sector palliative care leadership for cross-sector work and initiatives.”

The role of the sector is therefore to participate fully and actively in the sector leadership workshops that are organised by the Ministry of Health. The key preparation for the meetings is to familiarise our organisations and members with the language of outcomes measures and the measures that might be feasible to collect.

It seems likely, from measures adopted at a national level in other countries, that there may be only a few key measures chosen. In some countries, more measures are adopted over time; detail is given in Section 6.1 of the 20 measures currently in use at a national level in Australia. The frequency of submission might be something like six-monthly or annually and the measures chosen may, in time, be related to those driven by the OECD (Section 3.1).

A useful way to understand the sorts of high-level measures that may be chosen is to consider those in the Long Term Conditions: Population Level Outcomes Framework - Line of Sight (Part A) and the Indictors (Part B)\(^{14}\), as outlined in Section 2.4. These national-level documents were developed through agreement with DHBs and the sector, and are available on the Nationwide Service Framework Library. While palliative care is an element of the Line of Sight, there are no population-level indicators yet listed.

The European Association for Palliative Care (EAPC) White paper\(^3\) recommends using outcomes measures that allow for international comparisons. The recommendations in the White paper (see Section 3.2) can usefully be used as a framework for New Zealand decisions about national measures. The work being planned by the OECD on outcomes measures (see Section 3.1) should also be kept in sight as the national outcomes measures are considered.

It will be necessary to ensure that the language used in any measurement tools is culturally appropriate for the New Zealand context.

Hospice NZ recommends that all parties advocate strongly in sector forums for a national outcomes framework and outcomes measures that are applicable across all settings of palliative care.

We recommend using the recommendations in the European Association for Palliative Care (EAPC) White paper as a framework for the national discussions.

We recommend using outcomes measures that are internationally applicable, to facilitate comparison and improve the translation of research into practice.

We recommend that Te Rōpū Taki Māori (HNZ), the Māori Advisory Group to hospices, are approached to provide guidance on designing outcomes measures for equity in access to palliative care.
Moving Forward: Hospices and Hospice NZ

Hospices themselves have needs for outcomes measurement at a clinical level, for benchmarking good practice and improving quality.

Outcomes measures can inform service development by providing a way to monitor and measure:

- How well are we doing?
- Are we giving the patient the best care possible?
- What do we know?
- What are we trying to improve or change?
- How well are we providing the services in a timely, culturally appropriate manner to our patients, their family and whānau?

The collection of outcomes measures by hospices will contribute towards a baseline of information that can be used towards quality improvement at the service level and contribute towards the population level indicators across the palliative care sector.

The feedback from the symposium on the tools already in use by hospices\(^1\), summarised in Section 5, shows that there has already been some implementation of measures from the OACC and PCOC suites. Some hospices seem to have progressed substantially in implementation, while others have not yet started implementation. There are also requests in some regions from the DHB to begin to discuss appropriate outcomes measures.

All hospices using the PalCare software already have the capability to capture all of the PCOC measures and several of the OACC measures. The PalCare software has a total of 26 outcomes measures and assessment tools currently available in the system, as described in Section 6.3 and listed in Appendix D. In the year ended June 2017, 20 hospices, covering an expected 60.4% of hospice patients, are using the PalCare system.

A further two hospices, with an expected 9.2% of patients, are using Houston Medical/VIP software. While this software does not have outcomes measures built in, Arohanui Hospice has extended the software to cover several measures and will make this available to the other hospice using the same software. The remaining seven hospices use either Medtech software or their own systems. These hospices have not yet fully implemented the HISO standards for specialist palliative care and are not thought to have implemented any outcomes measures as yet. It will be helpful to do a more formal survey of the degree of implementation of outcomes measures across all hospices, to facilitate setting up communities of practice to learn from one another.

North Haven Hospice, as described in Section 6.6, has already moved to a comprehensive use of outcomes measures, using the PalCare software. They have a guidance document for all staff and routinely audit the collection of outcomes measures. It is this extent of experience that makes it essential that hospices have a way to share in the learnings of others as they move forward. This is a role that Hospice NZ can facilitate for all member hospices.

A key understanding in the implementation of outcomes measures is Figure 4, which shows the step-wise Introduction of the OACC suite of measures. Importantly, PCOC and OACC share two measures: the phase (called Palliative Care Phase in PCOC and Phase of Illness in OACC) and the Australia-modified Karnofsky Performance Status (AKPS). These two physical-level measures are the foundation for both suites. Hospices that are able to do so should therefore begin to implement Phase of Illness and Australia-modified Karnofsky Performance Status (AKPS), regardless of other tools adopted.
A key concern in practice about the use of PCOC is the added burden of collection, as all measures are collected not only on admission and change of phase, but every day in IPU and at every contact in the community. The OACC measures, in contrast, are collected on admission and on change of phase. Opinions differ on the need to collect measures more frequently. In encouraging hospices to collect the phase of illness and the AKPS, it is recommended that they adopt the OACC frequency of collection as a minimum. This is the sort of issue that a vibrant community of practice needs to resolve.

Those hospices that are ready should begin to pilot outcomes measures for other dimensions of care (psychological/emotional, spiritual, impact on carers, family and whānau), as described in Section 4.3 and Table 5. In the first instance, they should consider using a tool from the OACC or PCOC suites, or one of the tools already built in to the PalCare software (for those using that software). This is where sharing experiences in a community of practice will help to find tools that are working well in the New Zealand context, as demonstrated by the North Haven Hospice experience.

It is envisaged that this “soft-piloting” of outcomes measures by those who are willing and able to do so, will be coupled with extensive sharing of experience between hospices and sharing of high-level results with the wider palliative care sector. This is also an opportunity for hospices, as part of their innovation fund projects, to trial outcomes measures that work across hospices and aged residential care. Any learnings need to be shared in communities of practice to enable a convergence on measures that are useful in the New Zealand context.

Hospices and Hospice NZ will progress clinical palliative care outcomes measures that are appropriate to hospices.

Hospices that are able to do so will begin to implement Phase of Illness and Australia-modified Karnofsky Performance Status (AKPS), regardless of other tools adopted. The frequency of collection should follow the OACC approach, as a minimum.

Those hospices that are ready will begin to pilot the other outcomes measures from the OACC or PCOC suites.

Share, share, share. Hospices will share experience and developments with outcomes measures, regionally and nationally.

Hospices will trial outcomes measures that work across hospices and aged residential care as part of their innovation fund projects. Recommend that hospices trial outcomes measures that work across hospices and aged residential care as part of their projects.

Hospice NZ will establish an outcomes measurement reference group, a community of practice, where hospices can share experiences of piloting and implementation.

Hospice NZ will approach Te Rōpū Taki Māori (HNZ) to consider the appropriateness for Māori of the outcomes measures in the OACC and PCOC suites, as well as other measures that hospices may find to be more useful in the New Zealand context.
Moving Forward: A New Zealand Palliative Care Outcomes Measurement Collaborative?

The implementation of clinical palliative care outcomes measures in the UK and Australia has required considerable support, as outlined in Section 6.2. For example, PCOC is funded by the Australian Government Department of Health and has links to four universities to provide analytical support and clinical leadership. Each of the four regional zones has one or more quality improvement facilitators, whose role includes supporting services to participate in PCOC and facilitating ongoing service development and quality improvement. A national team co-ordinates the patient outcomes reporting, education programme and quality activities across the four zones.

In Australia, there is also a very clear link between the national outcomes measures adopted and the measures gathered at a clinical level for aggregation and reporting.

In New Zealand, work still needs to be done by the Ministry of Health on the national palliative care outcomes measures. Any implementation by hospices, and other organisations that are able to progress piloting clinical outcomes measures, will inform the national discussions. But the full implementation of outcomes measures across all of palliative care would seem to need greater support and co-ordination than could be provided by any one part of the sector.

Perhaps the time is right to consider the formation of a New Zealand palliative care outcomes measurement collaborative, across all settings of care. This will need further exploration and Hospice NZ will endeavour to progress discussions with the other palliative care organisations, the Palliative Care Advisory Panel (PCAP), and the Ministry of Health. A logical and urgent response is called for before the palliative care sector goes in many different directions and the opportunity for co-ordinated activity is lost.

Hospice NZ is committed to sharing the results and experiences of piloting outcomes measures, in the interests of developing a common set of measures for use in New Zealand, across all settings of care.
References

1. Hospice New Zealand. Outcomes measures for palliative care in New Zealand: Key themes from delegates. Summary of feedback received from delegates to the symposium held in Wellington on 17 February 2017 Wellington: Hospice New Zealand; 2017. URL: http://www.hospice.org.nz


31. Virdun C. Senior lecturer, Faculty of Health, University of Technology Sydney. Personal communication by email, 15 February 2017.
38. interRAI Australia. interRAI Coordinating Centre Australia & New Zealand: The Range of Instruments, ; 2014. URL: http://www.interrai-au.org/index.htm
Appendix A: Managing for Outcomes Logic Chain


Situation Assessment
What is the issue or opportunity?
Who will benefit?
What is the timeframe?
Who are possible partners, funders, clients?
What is your mandate?
What are your skills and resources?

Long-term changes – the ‘vision’
Desired changes to people, organisations and communities
The results of your activities
What you are going to do with the inputs
Resources you need to create the results

Degree of control
High
Low
Appendix B: Outcomes Framework for Palliative Care in New Zealand

Source: “Measuring what Matters”\(^5\), page 17
### Appendix C: Comparison of PCOC and OACC Outcomes Measures

Source: International advances in outcome measurement in palliative care: One step closer to cross-national comparisons of routinely collected outcome data in palliative care ²⁹

<table>
<thead>
<tr>
<th>Key Domain</th>
<th>PCOC Measures</th>
<th>OACC Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stage of illness</strong></td>
<td><strong>Palliative Care Phase</strong>&lt;br&gt;Palliative Care Phase is a single item measure that assesses patients' stage in their illness trajectory</td>
<td><strong>Palliative Care Phase</strong>&lt;br&gt;Palliative Care Phase is a single item measure that assesses patients' stage in their illness trajectory</td>
</tr>
<tr>
<td></td>
<td><strong>Australia-modified Karnofsky Performance Status (AKPS)</strong>&lt;br&gt;The AKPS is a single item measure and gives an indication of overall performance</td>
<td><strong>Australia-modified Karnofsky Performance Status (AKPS)</strong>&lt;br&gt;The AKPS is a single item measure and gives an indication of overall performance</td>
</tr>
<tr>
<td></td>
<td><strong>Resource Utilisation Groups - Activities of Daily Living (RUG-ADL)</strong>&lt;br&gt;The RUG-ADL measures four levels of motor function with activities of daily living</td>
<td><strong>Resource Utilisation Groups - Activities of Daily Living (RUG-ADL)</strong>&lt;br&gt;The RUG-ADL measures four levels of motor function with activities of daily living</td>
</tr>
<tr>
<td></td>
<td><strong>Palliative Care Problem Severity Score (PCPSS)</strong>&lt;br&gt;The PCPSS includes two items on physical symptoms, assessing &quot;pain&quot; and &quot;other symptoms&quot;</td>
<td><strong>Palliative Care Problem Severity Score (PCPSS)</strong>&lt;br&gt;The PCPSS includes two items on physical symptoms, assessing &quot;pain&quot; and &quot;other symptoms&quot;</td>
</tr>
<tr>
<td></td>
<td><strong>Symptom Assessment Scale (SAS)</strong>&lt;br&gt;The SAS is patient-completed and assesses patients' level of distress relating to seven individual physical symptoms, plus &quot;other&quot; symptoms</td>
<td><strong>Symptom Assessment Scale (SAS)</strong>&lt;br&gt;The SAS is patient-completed and assesses patients' level of distress relating to seven individual physical symptoms, plus &quot;other&quot; symptoms</td>
</tr>
<tr>
<td><strong>Physical</strong></td>
<td><strong>PCPSS</strong>&lt;br&gt;The PCPSS includes one item on psychological problems, this is combined with spiritual problems</td>
<td><strong>PCPSS</strong>&lt;br&gt;The PCPSS includes one item on psychological problems, this is combined with spiritual problems</td>
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<td><strong>PCPSS</strong>&lt;br&gt;The PCPSS includes one item on spiritual problems, this is combined with psychological problems</td>
<td><strong>PCPSS</strong>&lt;br&gt;The PCPSS includes one item on spiritual problems, this is combined with psychological problems</td>
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<td><strong>PCPSS</strong>&lt;br&gt;The PCPSS includes one item on family/carer problems</td>
<td><strong>PCPSS</strong>&lt;br&gt;The PCPSS includes one item on family/carer problems</td>
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<tr>
<td><strong>Psychological / Emotional</strong></td>
<td>-</td>
<td><strong>Integrated Palliative care Outcome Scale (IPOS)</strong>&lt;br&gt;The IPOS is patient- or staff-completed and includes 10 items on common physical symptoms, plus questions about any &quot;other&quot; symptoms</td>
</tr>
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<td></td>
<td><strong>PCPSS</strong>&lt;br&gt;The PCPSS includes one item on psychological problems, this is combined with spiritual problems</td>
<td><strong>IPOS</strong>&lt;br&gt;The IPOS includes three items on psychological issues, incl. anxiety, depression and ability to share feelings</td>
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<td></td>
<td><strong>PCPSS</strong>&lt;br&gt;The PCPSS includes one item on spiritual problems, this is combined with psychological problems</td>
<td><strong>IPOS</strong>&lt;br&gt;The IPOS includes one item on spirituality, asking whether someone is at peace</td>
</tr>
<tr>
<td><strong>Spiritual</strong></td>
<td><strong>PCPSS</strong>&lt;br&gt;The PCPSS includes one item on family/carer problems</td>
<td><strong>IPOS</strong>&lt;br&gt;The IPOS includes one item on family/carer worry/anxiousness</td>
</tr>
<tr>
<td></td>
<td><strong>PCPSS</strong>&lt;br&gt;The PCPSS includes one item on family/carer problems</td>
<td><strong>6-item Zarl carer Interview</strong>&lt;br&gt;The Zarl Carer measure is carer-completed and includes six items focused on carer strain/burden</td>
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<tr>
<td><strong>Family/Carer</strong></td>
<td>-</td>
<td><strong>Additional carer questions</strong>&lt;br&gt;These two questions are carer-completed and include one item on help and support received and one on the difference made</td>
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<td></td>
<td>-</td>
<td><strong>Views on Care</strong>&lt;br&gt;This measure is patient-completed and assesses the impact of a service on quality of life</td>
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<tr>
<td><strong>Other</strong></td>
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Appendix D: PalCare Software Assessment Tools

Source: PalCare Assessment Tools Guide

Tools in the PCOC and OACC suites

- Palliative Care Phase (Acuity) - part of both PCOC and OACC suites
- Australian Karnofsky Performance Scale (AKPS) - part of both PCOC and OACC suites
- Palliative Care Problem Severity Score (PCPSS) - part of PCOC suite
- Resource Utilisation Group Activities of Daily Living (RUG-ADL) - part of PCOC suite
- Symptom Assessment Scale (SAS) / Edmonton Symptom Assessment Scale (ESAS) - part of PCOC suite.
- Patient Outcome Scale – Patient / Staff (POS) – part of OACC suite

Other assessment tools validated by research and publication

- Carer Support Needs Assessment Tool (CSNAT) - support needs of carers
- Confusion Assessment Method (CAM) Tool - assists in the differential diagnosis of delirium
- Falls Risk Assessment Tool (FRAT) - falls risk status, risk factor checklist, and action plan
- Hospital Anxiety Depression Scale (HADS) - screens for anxiety and depression
- Mini Mental State Examination (MMSE) - assessment of cognitive function
- Missoula-Vitas Quality of Life Assessment (MVQOL) – importance of 5 quality of life domains
- Waterlow Pressure Ulcer Risk Assessment Tool - estimated risk of developing a pressure area

Other assessment tools used in practice

- Bariatric Assessment - Body Mass Index (BMI), equipment used for moving and mobilising
- Complicated Bereavement Risk Assessment Tool (CBRAT) - risk of prolonged grief
- Risk Screening Tool – equivalent to CBRAT for family network.
- General Health Assessment (GHA) - also called the Nursing Assessment. Sections can also be used in isolation – the System Specific Assessments.
- Grief Impact Monitor (GIM) - impact of grief experienced by carer
- Holistic Grief Assessment – assessment of impact of bereavement on family network client
- Medical Assessment – assessment of patient by medical staff
- Occupational Therapy (OT) Home Assessment – assessment of home environment
- Oral Assessment Tool – structure and function of oral system, including voice and swallowing
- Pain Assessment - in-depth assessment of a nominated pain site
- Physiotherapy Assessment - mobility, transfers, balance, strength, range of motion. Includes the Modified Elderly Mobility Scale (MEMS)
- Social/Emotional/Spiritual Assessment Instrument (SES) - social, emotional, spiritual needs
- Wound Assessment – documentation of each wound

hh OACC uses the newer IPOS rather than POS. PalCare expects to implement IPOS during 2017.

ii Selected in conjunction with the PalCare User Groups in Australia and New Zealand.
Appendix E: Palliative Care Action Plan - Quality

Priority 3: Improve quality in all settings

Why is this important?
People want to be confident that high-quality palliative care is available when they come to the end of their life. Agreed standards for quality palliative care build workforce capability and high-performing teams.

What does success look like?
People are confident they can readily access high-quality palliative care for themselves or loved ones. There is national agreement on what high-quality palliative care is. All areas of the health system use quality standards of adult palliative care. Nationally we target care better throughout life, including at end of life and for bereavement.

What are the opportunities for change?
Having a core set of performance outcomes helps to improve the quality of service across all groups involved in adult palliative care.

As Groeneveld et al (2017) observe, ‘Clinical teams and palliative care providers share the responsibility in leading improvements and reducing variation in care by defining good practice and measuring their activity, costs and outcomes.’ This action plan provides a way for this to happen by setting up the structure and impetus for cross-sector clinical leadership and consumer engagement.

Words that describe outcomes can be confusing. The Ministry of Health develops population-based targets and outcomes. The palliative care sector is considering the best approach for New Zealand to reflect and report on clinical palliative care outcomes.

How will this be achieved?
The Ministry of Health will facilitate a health and community leaders’ forum and consultation with interest groups. Small working groups will lead the next steps.

Priority 3 actions

Short-term actions, 2017–2018: Initiate and design

<table>
<thead>
<tr>
<th>Action</th>
<th>Who</th>
<th>When</th>
</tr>
</thead>
<tbody>
<tr>
<td>The sector agrees on a population outcomes framework.</td>
<td>Sector leaders</td>
<td>2017</td>
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<tr>
<td>Agree on population-level quality indicators for palliative care.</td>
<td>Ministry of Health</td>
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<tr>
<td>Include access and equity in the indicators.</td>
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<tr>
<td>The sector investigates clinical outcome measures to assure quality of</td>
<td>Hospice NZ and</td>
<td>2017</td>
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<tr>
<td>care for individuals receiving palliative care. (This work is under</td>
<td>sector</td>
<td></td>
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<td>way with a discussion paper developed in February 2017.)</td>
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<tr>
<td>Agree on an independent evaluation framework for the outcomes of the</td>
<td>Ministry of Health</td>
<td>2017</td>
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<tr>
<td>innovation funding proposals to improve the quality of palliative</td>
<td></td>
<td></td>
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<tr>
<td>care in aged residential care, primary care and community settings.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Action</td>
<td>Who</td>
<td>When</td>
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<tr>
<td>Implement Healthy Ageing Strategy action: ‘Support the implementation of Te Ara Whakapiri: Principles and guidance for the last days of life’.</td>
<td>End-of-life care providers</td>
<td>2017</td>
</tr>
<tr>
<td>Use research and evaluation results to review quality dimensions for palliative care in aged residential care facilities. Development of older people’s palliative care clinical care guides for residential aged care, in collaboration with Te Ara Palliative Care and End of Life Research Group, UoA, aged care sector, and Ministry of Health.</td>
<td>Te Ara Palliative Care and End of Life Research Group, University of Auckland, aged care sector, and Ministry of Health.</td>
<td>2017–2018</td>
</tr>
<tr>
<td>Collaborate in developing an outcomes framework.</td>
<td>Cross-sector</td>
<td>2018</td>
</tr>
<tr>
<td>Agree on minimum service expectations for palliative and end-of-life care for use in all settings (for example, aged residential care, primary care, hospital and hospice). Use a range of channels to communicate minimum expectations for palliative care across all care providers.</td>
<td>Sector leaders</td>
<td>2018</td>
</tr>
</tbody>
</table>

Innovation funding proposals: Ministry funded and hospice managed national process supporting the development and evaluation of high quality business plans to improve the quality of, and access to, community palliative care services, specifically through aged residential care, primary care and/or other community services.

Medium-term actions, 2019–2024: Implement

- Test and trial minimum service expectations as they are implemented and monitor them across all settings.
- Assess nationwide results of the evaluation of innovation funding outcomes. Make recommendations for next steps.
- Test and trial guidelines for palliative care in aged residential care facilities as they are implemented.
- Agree on indicators for population-level outcomes for palliative care. Co-design methods for measurement.
- Trial and test new training approaches that have resulted from best practice. Define ways to scale-up successful approaches.
- Prioritise and select key issues to focus on for next steps and use a continuous improvement cycle.

Long-term actions, 2025–2030: Embed

- Assess the impact of minimum service expectations across all settings and target special strategies.

Source: Ministry of Health (2017) Palliative Care Action Plan, pages 20 and 21