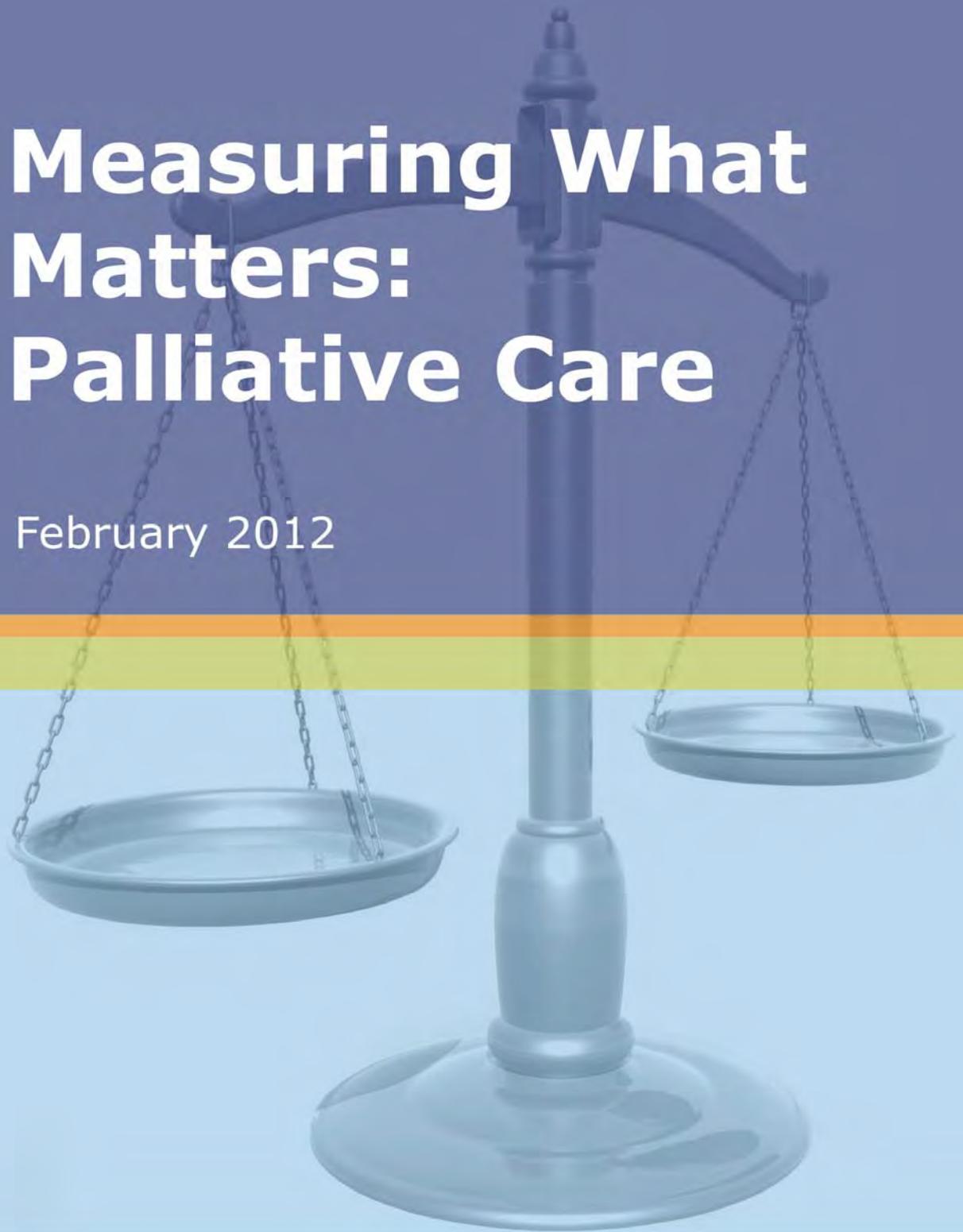


Measuring What Matters: Palliative Care

February 2012



PALLIATIVE CARE COUNCIL
OF NEW ZEALAND



CANCER CONTROL NEW ZEALAND
Mana Whakahaere Matepukupuku Aotearoa

The Palliative Care Council of New Zealand

The Palliative Care Council (PCC) was established in 2008 by Cancer Control New Zealand to provide independent and expert advice to the Minister of Health, and to report on New Zealand's performance in providing palliative and end-of-life care. This is achieved through independent advice on:

- A strategic approach to palliative and end-of-life care that supports and involves the sector.
- Initiatives to reduce inequalities in access to palliative and end-of-life care services.
- How effectively initiatives have been implemented.
- International directions and initiatives in palliative and end-of-life care.

The PCC also reports on progress in implementing the New Zealand Palliative Care Strategy and New Zealand's performance in providing palliative and end-of life care. Although the Council was set up through Cancer Control New Zealand, it is well recognised that the scope of palliative care covers all patients with a "life-limiting or life-threatening condition" not just cancer. This is reflected in the scope of PCC's work, which encompasses all those who would benefit from palliative care.

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Introduction

Progress toward a palliative care strategic vision needs to be monitored and evaluated. Thus, the aim of this document is to establish such a framework for palliative care that will generate data to inform strategic decision making across all health settings in New Zealand.

Identifying the outcomes required to achieve the palliative care strategic vision, as well as the factors that would impact on the realisation of those outcomes is done by articulating how the many different activities and actions being undertaken by individuals and organisations involved in palliative care are contributing to the outcomes fundamental to achieving the vision. Such an articulation will also allow these individuals and organisations to identify where they fit within a strategic context.

By 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 the activities and actions have contributed to changes in the desired outcomes for palliative care.

This document has been developed by the Palliative Care Council of New Zealand (PCC), in consultation with the Ministry of Health and Hospice New Zealand. Other stakeholders have also had the opportunity to provide feedback and comment.

The PCC believes that the framework presented in this document will be a useful starting place for the development of a strategic approach to advance palliative care in New Zealand and replace the increasingly out-of-date *New Zealand Palliative Care Strategy*.

How to use this document

Because managing for outcomes is a relatively new concept for health care in New Zealand, a substantive portion of the document focuses on background information about managing for outcomes and how this can be applied to palliative care. There are four main sections to the document and you may wish to read each in turn or direct your attention to the area you are most interested in.

Section 1: Palliative care in context

Palliative care is a holistic approach to the care of people with progressive, incurable disease that aims to prevent and relieve suffering. It can be of benefit to anyone with a life-limiting or life-threatening condition and is centred upon achieving the best possible quality of life for the individual.

This section includes a brief overview of palliative care in New Zealand with a focus at a strategic level.

Section 2: Managing for outcomes

Outputs are the measurable, observable production of goods or services produced by activities. Outcomes on the other hand, represent a desired change in the state of

society and often take a long time to realise. In the context of this document, outcomes are the results, for the community, of the activities and outputs of individuals and organisations involved in palliative care.

Section 2 introduces the concept of managing for outcomes, including definitions of key terms, understanding intervention logic, and how this approach is applied in practice.

Section 3: Articulating outcomes for the palliative care system in New Zealand

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

This section outlines a series of outcomes for the “palliative care system” in New Zealand and presents a framework that uses a logic model approach. The framework outlines the important intermediate and long-term outcomes for palliative care that will contribute to the strategic vision.

Section 4: The Framework in detail

The final section breaks down the palliative care outcomes framework into its component parts and provides detailed discussion on the different outcomes and the factors that will contribute to success. The key components are:

- *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 whom 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 Coordination 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 whanau*

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.

Section One: Palliative Care in Context

What is palliative care?

Palliative care is a holistic approach to the care of people with progressive, incurable disease that aims to prevent and relieve suffering through “early identification and impeccable assessment and treatment of pain and other symptoms”¹ (p. 84).

Palliative care can be of benefit to anyone with a life-limiting or life-threatening condition, including, but not limited to, cancer, end stage organ failure (heart, liver, kidney, lung) and neurological disorders, as well as a wide variety of childhood diseases and disorders. It embraces all spheres of health including physical, psychological, social and spiritual aspects of wellbeing, all centred upon achieving the best possible quality of life for the individual.² Palliative care is an integral component of the health care continuum and may be provided when curative or disease modifying treatment has come to an end, or while treatment directed at the disease is still being given. Palliative care also encompasses the family/whānau and carer(s) of the dying person, and may continue to support these people after the person’s death.

Specialist palliative care is usually accessed through a hospice inpatient unit, a community palliative care service or a hospital palliative care service. Specialist care is provided by health professionals who have undergone specific training and/or accreditation in palliative care/medicine, and who work in the context of an expert interdisciplinary team. These teams work exclusively in palliative care and may provide direct consultation and care, or advice to other health care teams about the care of palliative or imminently dying patients.

Generalist palliative care is provided by any health care professional who is not part of a specialist palliative care team. It incorporates a palliative approach to the care of those affected by life-limiting illness regardless of setting; this may be from general practice teams, Māori health providers, allied health teams, district nurses, and residential care staff. It is also provided in hospitals by general wards, as well as disease specific specialty teams such as oncologists, surgeons and respiratory physicians.

The Palliative Care Strategy

In February 2001 *The New Zealand Palliative Care Strategy* was launched with the aim of setting in place “a systematic and informed approach to the provision and funding of palliative care services” for all people in New Zealand who are dying from an incurable, progressive disease³. To achieve this, the Palliative Care Strategy outlined nine key strategies for achieving its vision:

1. Ensure access to essential palliative care services.
2. Each District Health Board (DHB) to have at least one local palliative care service.

¹ World Health Organization. (2002). *National Cancer Control Programmes: Policies and Managerial Guidelines*. 2nd Edn. Geneva: World Health Organization.

² Palliative Care Subcommittee and New Zealand Cancer Treatment Working Party (2007). *New Zealand Palliative Care: A Working Definition*. Wellington: Ministry of Health. URL [http://www.moh.govt.nz/moh.nsf/pagesmh/2951/\\$File/nz-palliative-care-definition-oct07.pdf](http://www.moh.govt.nz/moh.nsf/pagesmh/2951/$File/nz-palliative-care-definition-oct07.pdf).

³ Ministry of Health. (2001). *The New Zealand Palliative Care Strategy*. Wellington: Ministry of Health.

3. Develop specialist palliative care services.
4. Implement hospital palliative care teams.
5. Develop quality requirements for palliative services.
6. Inform the public about palliative care services.
7. Develop the palliative care workforce and training.
8. Ensure that recommendations from the Paediatric Review⁴ are implemented.
9. Address issues of income support.

*The New Zealand Cancer Control Strategy*⁵ also emphasises the need for palliative care as an integral part of the cancer control continuum. In particular, Goal four, Objectives six and seven of the Strategy relate specifically to the provision of palliative care for people with cancer and their family/whānau.

Objective 6: Continue to improve access to essential palliative care services that provide appropriate symptom relief and emotional, spiritual, cultural and social support for those with cancer and their family and whānau.

Objective 7: Ensure an integrated and comprehensive service is provided to all those with cancer who require palliative care and their family and whānau.

The Council believes that the framework contained in this document will be a useful starting place for the development of a strategic approach to replace the increasingly out-of-date *Palliative Care Strategy 2001*. It is apparent that services have evolved organically with no central leadership, resulting in a lack of cohesion and strategic direction.⁶ As a result, organisations are providing different services in different ways, and there is no way of measuring how these activities are contributing to overall palliative care outcomes. Organisations may not have been recognised previously as providing palliative and end-of-life care, such as primary care and aged residential care and it is important that a whole system approach is taken, rather than looking only at providers of specialist palliative care.

⁴ Health Funding Agency and the Paediatric Society of New Zealand. (1998). *Through the eyes of a child: a national review of paediatric specialty services*. Wellington: Health Funding Agency.

⁵ Ministry of Health. (2003). *The New Zealand Cancer Control Strategy*. Wellington: Ministry of Health.

⁶ The Palliative Care Council. 2010. Palliative Care Council Position Statement on the New Zealand Palliative Care Strategy. <http://www.cancercontrolnz.govt.nz/files/Position%20Statement%20on%20NZ%20PCS.pdf>

Section Two: Managing for Outcomes

Managing for outcomes

Outcome measurement is an approach to planning and managing projects that helps organisations to be clear about what their projects are doing, as well as what they are changing.⁷ This approach allows organisations to demonstrate and measure their results, which in turn can demonstrate value for investment. This is a particularly important component of accountability when public funds are being spent.

A key component of managing for outcomes is having a strategic view that identifies the intermediate and long term outcomes and high level impact that an organisation wishes to achieve. The strategic view is a holistic picture of a system, in this case the palliative care system, that links outcomes to the actions and activities of health providers. Furthermore, it identifies how changes at the level of activity impact on outcomes. This is the basis of the 'logic chain' shown in Figure 1, which links together the resources (inputs) and activities to the desired results – outputs, outcomes and impact.

Having a strategic view is important because it:

- Helps individual service providers to identify where they fit within a large and complex palliative care system
- Provides a basis for monitoring and evaluating progress in palliative care
- Helps to identify where changes can be made to the way that the palliative care system operates so that it will be more likely to realise the desired palliative care outcomes
- Helps to develop a robust, methodical cycle of continuous improvement, known as “managing for outcomes”.

Outcomes versus outputs

There are distinct and important differences between outputs and outcomes.

According to the State Services Commission:

- Outputs are “*goods or services delivered*”. (www.ssc.govt.nz)
- Outcomes are “*the impacts on, or the consequences for, the community of the outputs or activities of government. In common usage, however, the term 'outcomes' is often used more generally to mean results, regardless of whether they are produced by government action or other means. An intermediate outcome is expected to lead to an end outcome, but, in itself, is not the desired result. An end outcome is the final result desired from delivering outputs. An output may have more than one end outcome; or several outputs may contribute to a single end outcome.*” (www.ssc.govt.nz)

An output is a measurable, observable, production of a good or service that creates the potential for the desired result (outcome). Individuals or organisations usually have a high degree of control over the production of an output.

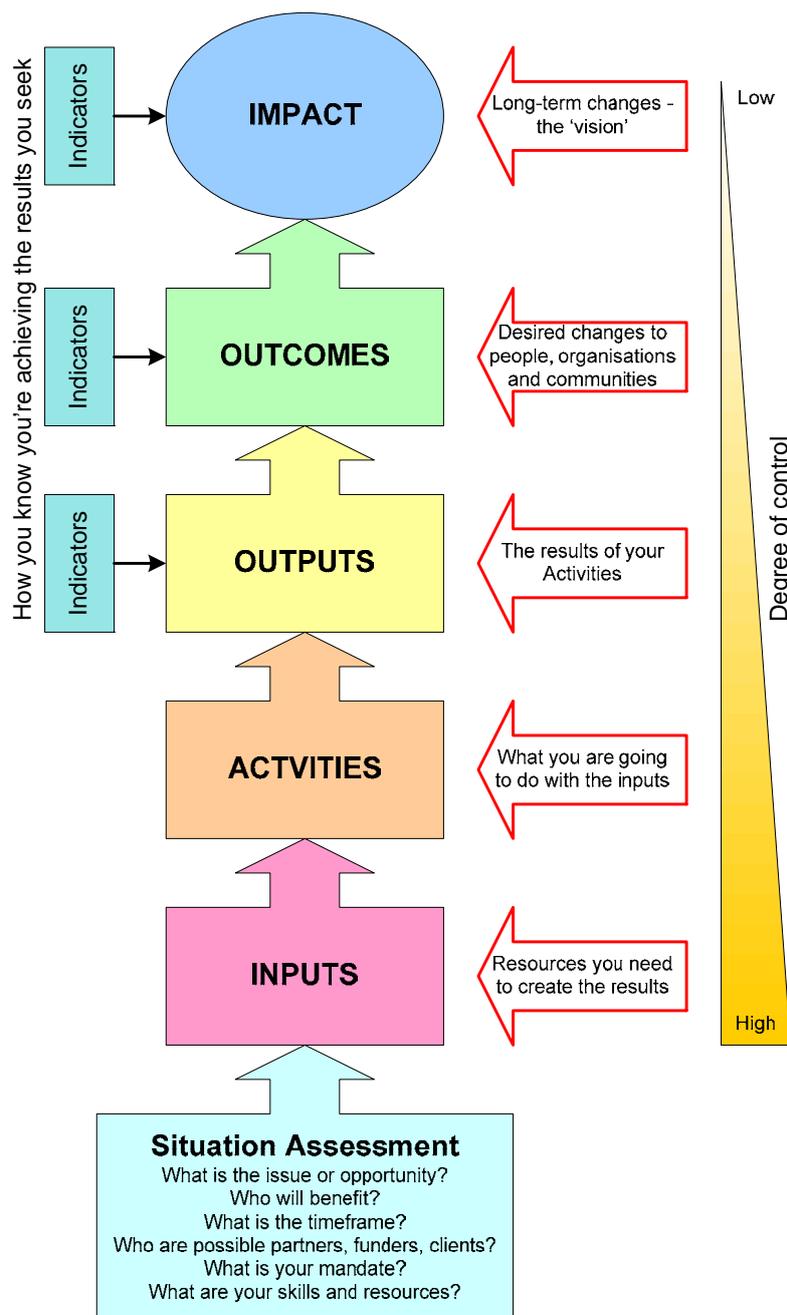
⁷ Plan:Net Ltd. (2002). *Splash & Ripple. Using outcomes to design and guide community work*. Calgary: Plan:Net Limited.

An example of an output might be the development of a palliative care module for undergraduate medical and nursing training. This would be the result of activities that have been undertaken to produce the module, such as a review of current undergraduate curriculum, evaluation of courses available internationally and consultation. These activities are very much under the control of the project manager; however they have less control over the resulting module content (the output). A measurable indicator could be the actual production of the education module.

Outcomes, on the other hand, represent a change in the state of society and often take a much longer time to realise. Outcomes are often more difficult to measure than outputs, and their occurrence cannot be controlled, rather it is influenced through the activities and outputs of individuals and organisations.

Following the example above, if the palliative care undergraduate module is implemented, it would be hoped that an outcome would be greater awareness of palliative care among health care professionals. This may lead to a better understanding of when and how to refer a patient to specialist services, ultimately influencing the number of appropriate referrals to specialist palliative care services, which in turn should increase access to palliative care services regardless of setting. These outcomes are not under the control of the project manager, as there are many factors that can influence them, such as the level of uptake of the module and the attitude of health professionals.

Figure 1: The Logic Chain



What does it mean in practice?

Outcomes are influenced by many factors; some are in our control and others are not. Because of this, organisations (especially government departments) are not accountable for achieving outcomes, but they are held accountable for 'managing for outcomes'. In other words, they continue to be accountable for the delivery of outputs and for altering the mix of outputs as circumstances dictate. Good information on results, on what is working and what is not, helps in decisions about what activities to start, what to stop and what to continue or expand. This is where a strategic view of palliative care will be particularly useful.

In practice, managing for outcomes means focusing on outcomes (results) in every aspect of management. Organisations that are managing for outcomes:

- Have a clear vision of why they exist, what they want to achieve and how well they are achieving against this
- Plan their work keeping in mind a clear set of objectives, activities, outputs, outcomes and measures of success
- Deliver what they have planned, and in a manner that is consistent with public service ethics, values and standards while meeting standards of timeliness, quality, accuracy, etc
- Take stock of their progress by monitoring, measuring, reviewing and evaluating as they go
- Learn from success and failure, and modify what they do and how they do it in response
- Report publicly on their results, promoting transparency to Parliament and the public and providing a basis for dialogue about future decisions; and
- Have an adaptive and innovative culture and seek continuous improvement.⁸

Essentially, 'managing for outcomes' is about planning, implementing and evaluating programmes in a cycle of continuous improvement (Figure 2), where results and lessons from implementing a programme are incorporated back into the way that programmes operate. There are four important steps that will be carried out when a programme or organisation is managing for outcomes:

- *Direction setting*

Setting a strategic vision that a programme aims to achieve in the medium to long term.

- *Planning*

Identifying the dynamic relationships between different parts of a programme and articulating how the various activities carried out and outputs produced by a programme contribute to the overall outcomes that are desired. Intervention logic is a useful way of developing such a conceptualisation – this will be explained further below.

- *Implementation*

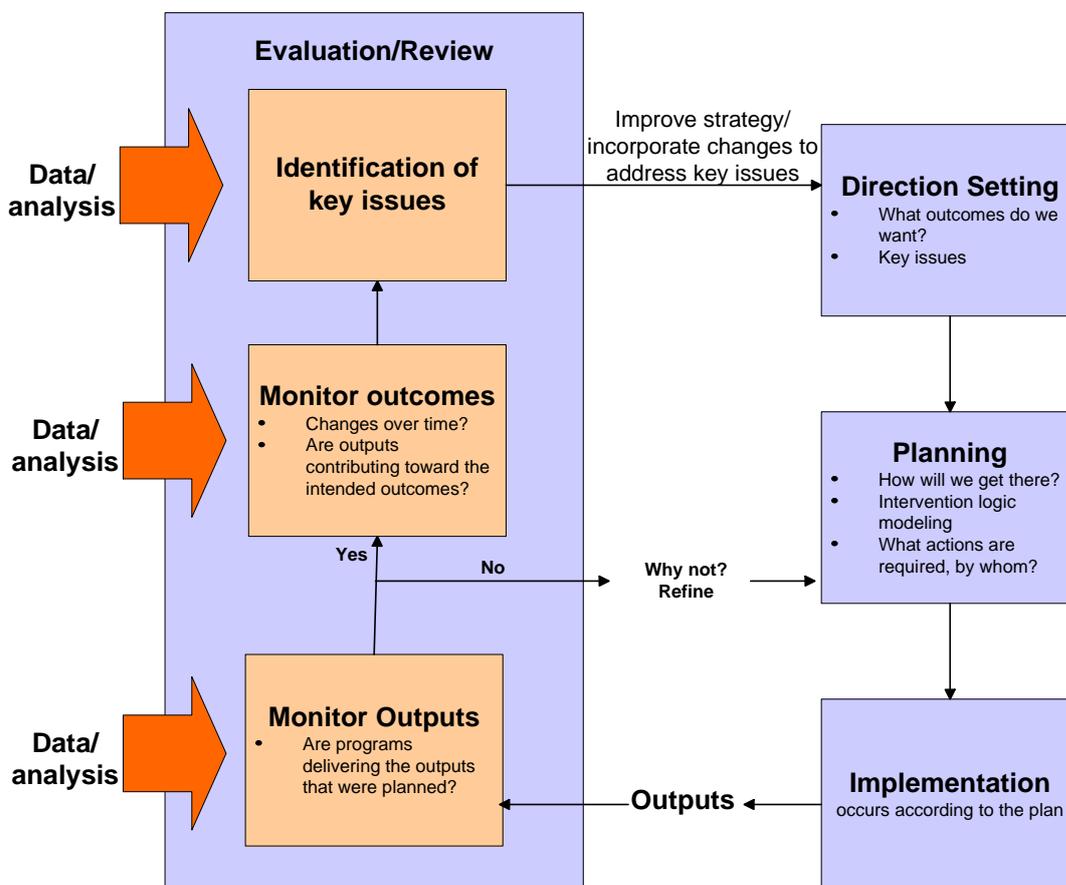
The operational aspects of a programme include things like budgeting, service delivery, communication, collaboration and cooperation - especially where there are multiple agencies working toward shared outcomes. The key function of 'implementation', in a managing for outcomes context, is to deliver the operational aspects of a programme (i.e. the inputs and activities) in a way that reflects the plan that has been developed.

- *Evaluation*

Evaluation assesses not only how a programme performed in relation to how it was planned to perform, but also how robust that plan was to begin with. Information about performance – that is, evaluation findings - must then be used to inform subsequent iterations of direction setting, planning and implementation. The criteria that are used to assess performance should be developed at the planning stage.

⁸ State Services Commission (2005) Getting Better at Managing for Outcomes - self assessment tool. Managing for outcomes - what does it mean in practice?. Wellington: State Services Commission. Available from: <http://www.ssc.govt.nz/node/1906>.

Figure 2: Cycle of continuous improvement



Intervention logic - a brief explanation

As Figure 2 shows, once a strategic direction has been identified it is necessary to plan how a programme will operate to achieve that vision. One way of doing this is through the use of ‘intervention logic’, which follows the logic chain approach.

Intervention logic is essentially a simplified picture of a programme that conveys a series of cause and effect scenarios. It traces a path of causality from activities and outputs through to a range of intermediate and longer term outcomes. This allows for the identification of activities and outputs that will have the greatest impact on outcomes, as well as areas where gaps exist. It therefore helps to identify the types of initiatives (i.e. activities and outputs) that will contribute most to the achievement of the desired outcomes.

PCC, in consultation with a range of stakeholders has developed an intervention logic diagram for palliative care in New Zealand (Figure 3). This identifies the range of outcomes that are necessary to achieve the strategic vision for palliative care in New Zealand.

Each of the outcomes could be achieved by an almost infinite number of possible outputs and activities, however there are a number of factors that constrain the ability

of the palliative care sector (and the health system more generally) to produce this vast range of outputs.

Fiscal and workforce shortages are but two of the many barriers that constrain the ability of the palliative care and wider health systems to implement the 'perfect mix' of outputs to achieve the desired outcomes. The challenge when developing intervention logic is to identify - given the constraints that exist - which types of activities and outputs can be produced, and which types of outputs are most likely to contribute to the desired outcomes.

Section Three: Articulating Outcomes for the Palliative Care System in New Zealand

What is the “Palliative Care System”?

The “palliative care system” encompasses all those organisations and individuals that provide palliative care as either their core business or a component of their broader service. The term “palliative care system” can mean different things to different people. Likewise, to refer to organisations involved in palliative care as being ‘generalist’ or ‘specialist’ is to oversimplify the complex way in which palliative care is delivered.

However, for this document to articulate the roles and responsibilities of the different parts of the “palliative care system” it is necessary to adopt some terms that can be used to describe the different components of this complex system. Therefore, the following terms are used consistently and intentionally. These terms are important because they are used in the next section of this document to refer to specific types of organisations.

Palliative care services – this term refers to any individual or organisation whose core work focuses on delivering palliative care, for example a hospice or hospital palliative care team.

Primary palliative care providers – (also known as providers of generalist palliative care) this term encompasses all individuals and organisations that provide palliative care as a component of their service, but their substantive work is not in the care of people who are dying. In the context of end of life care, a primary palliative care provider is usually the first contact medical, nursing or allied health professional who undertakes an ongoing role in the care of patients with an eventually fatal condition.⁹ A primary palliative care provider may have a broad health focus, such as a General Practitioner or district nurse, or be a specialist in another area, such as oncology, cardiology or respiratory medicine.

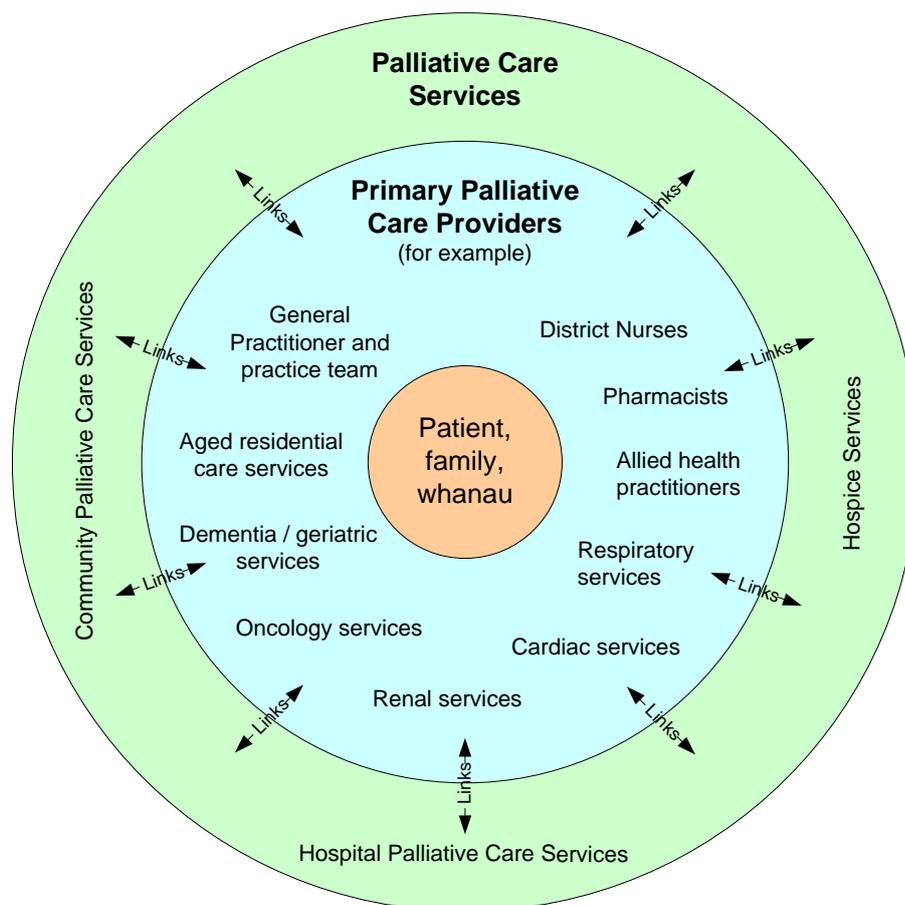
Palliative care system – this refers to palliative care services, primary palliative care providers and the other factors that enable them to deliver palliative care, such as communication and coordination between providers. Without these ‘other factors’ palliative care providers cannot function as part of a “system”.

Figure 3 depicts the palliative care system, with the patient, their family and whanau being central to the working of the system, and immediately adjacent to their primary providers who are supported by specialist palliative care services.

It is not simply the existence of primary palliative care providers and palliative care services that comprises the palliative care system; it is the links that exist between them that tie together ‘a system’. An Interdisciplinary Team approach to palliative care is one example of how such links can be developed and maintained.

⁹ Palliative Care Australia (2008) *Palliative and end of life care glossary of terms*. Deakin, ACT, Palliative care Australia.

Figure 3: The palliative care “system”



A palliative care outcomes framework

Using the principles of outcomes management and the definitions discussed above, a framework has been developed to articulate the desired outcomes and impact of activities across the palliative care sector. At this stage the framework does not look at activities and associated outputs, rather it provides the ‘strategic view’ that must be in place before we can begin the process of evaluation. The logic model component of the framework is depicted in Figure 4 showing the important palliative care outcomes. These are explained in detail on subsequent pages.

By expanding on this framework and adding relevant activities and outputs, organisations will be able to summarise their projects to show:

- What they intend to do,
- What they intend to change,
- Why their project is important, and
- Their resource requirements.

This will then provide a basis for monitoring and evaluation once a project is underway. A monitoring component should be standard part of any project and will collect data on a regular basis to assess progress, inform the need for modifications to the project and provide a baseline to measure change. Key to this process is

establishing indicators that will give an appropriate measure of whether the project is achieving the desired results.

Evaluation is a more in-depth analysis and is done only periodically. It looks more comprehensively at the project and, using monitoring data, charts progress toward longer term results.

The PCC will use this same framework in a broader context to monitor and evaluate projects and initiatives across the palliative care sector to see how they are contributing towards the desired outcomes and vision.

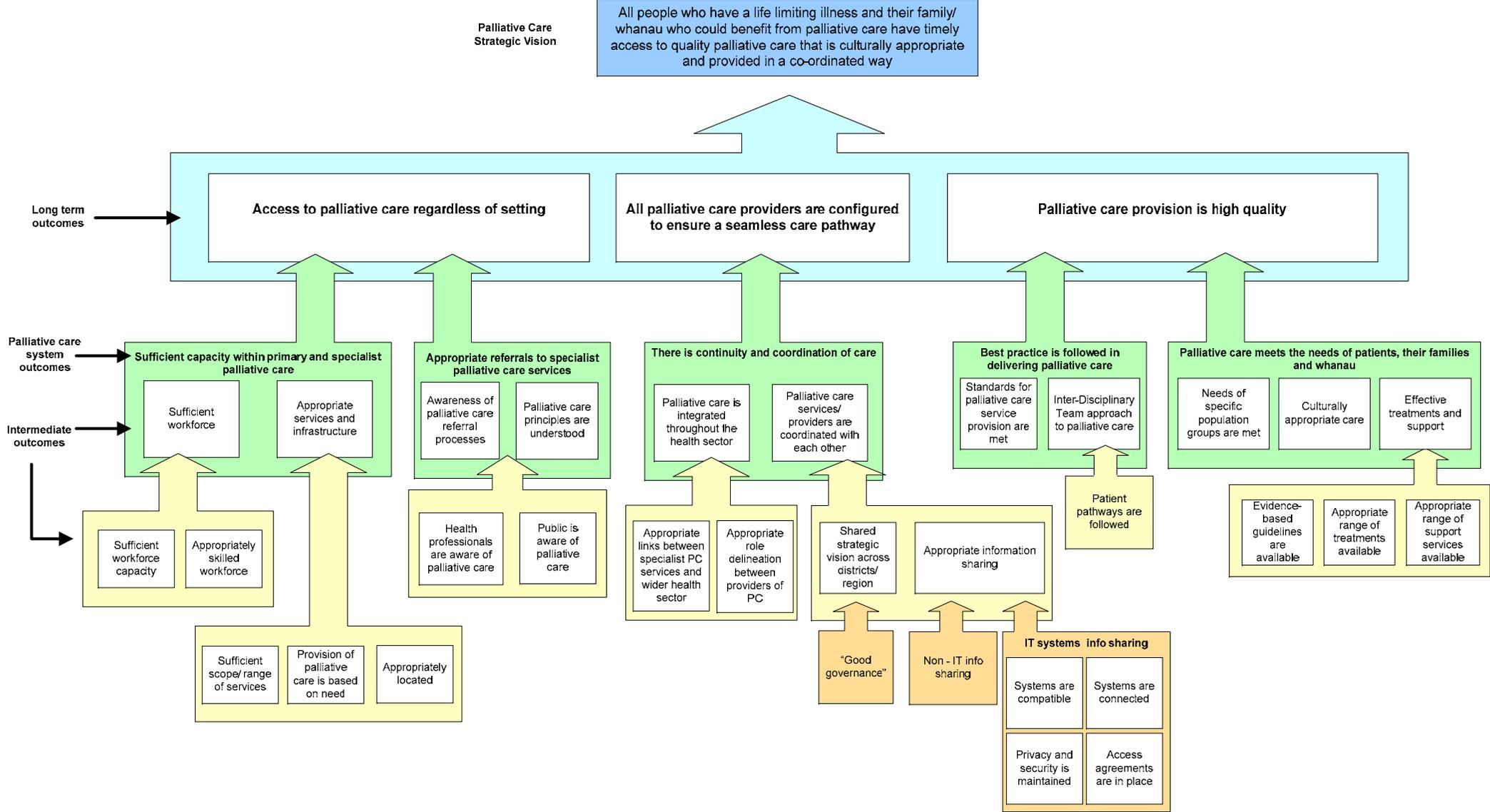
How will the framework be used?

Given that constraints are a reality, PCC believes that a pragmatic approach must be taken. Instead of identifying a 'perfect mix' of outputs and activities to achieve the overall palliative care outcomes, and then trying to impose the production of these outputs on organisations, PCC believes that as a first step it is necessary to identify how the range of activities and outputs currently being produced, contribute to the outcomes contained in the intervention logic.

The purpose of evaluation is not simply to capture information about what has happened in the past, but rather to provide information that can serve as a basis for future decisions to be made. That is, performance information will be produced not solely to identify problems, but rather to identify solutions to problems.

Once this evaluative information has been produced the Palliative Care sector will be invited to discuss the information that has been generated and make decisions about how the mix of outputs might be altered to better achieve the desired outcomes.

Figure 4: Palliative care outcomes framework



Palliative care strategic vision

The palliative care strategic vision has been taken from the New Zealand Palliative Care Strategy. This 'vision' sets a strong strategic direction that will be reached through the achievement of a range of lower level outcomes. However, to ensure that the vision is consistent with current international concepts of palliative care, it has been amended to focus on people with a *life-limiting illness*, rather than those who are "dying", and in order to be more encompassing the reference to "services" has been removed.

Consequently, the strategic vision used in this framework reads:

All people who have 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 coordinated way.

Long term outcomes

The long term outcomes that will contribute to high quality palliative care that meets the strategic vision are:

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

These outcomes are important because together they constitute the things that are necessary to achieve the palliative care strategic vision.

1. Access to palliative care regardless of setting

This outcome refers to the ability of palliative care providers to deliver care to those who would benefit from receiving it. The overall level of 'access' to palliative care will be determined by the following 2 factors:

- The **capacity** of palliative care providers to deliver care.
 - Without sufficient capacity, providers will be unable to deliver palliative care to all patients who would benefit from receiving it. Important components of capacity are workforce, services and infrastructure. Not all providers of palliative care are configured in such a way that palliative care is recognised as a core component of their service. Where this is the case, these providers must establish appropriate links with specialist palliative care services to ensure that patients are able to access an appropriate range of services.

And,

- The **referral** mechanisms by which patients gain access to **specialist** palliative care services.
 - Without appropriate referral mechanisms primary palliative care providers will not be able to effectively refer patients to specialist

palliative care services to meet their needs. Important components of the referral mechanisms are awareness (especially among health professionals, but also the general public) of the process for referral to palliative care services, and understanding palliative care principles, especially recognition of when patients would benefit from referral to a particular palliative care service.

A change in one or both of these system level factors will result in a change to the overall level of access to palliative care. There are numerous factors that influence both capacity and referrals. These are explained further below.

2. All palliative care providers are configured to ensure a seamless care pathway

Patients with life-limiting or life-threatening conditions often have co-morbidities or complex needs that require treatment or management from a range of different health services, as well as needing support from community and/or social services. These services are usually provided by numerous different individuals and organisations in a variety of settings.

While the organisations that deliver care are often distinct and separate entities, it is important that patient's experience a seamless transition between those providers.

A seamless pathway is achieved through **continuity** and **coordination** of care. Without a seamless care pathway particular aspects of care may be disjointed, duplicated by multiple providers, or neglected altogether.

3. Palliative care provision is high quality

Once the patient, their family and whānau are receiving ('seamless' and 'accessible') palliative care, that care must be 'high quality'.

For palliative care to be high quality it must follow **best practice** and **meet the needs of patients, family and whānau**.

Intermediate outcomes

The palliative care system level outcomes are those that represent a change within the palliative care system.

These 'system level' outcomes are important because they give rise to the long term outcomes, which represent a change in the state of society.

The palliative care system level outcomes are:

- 1. Sufficient capacity within primary and specialist palliative care,**
- 2. Appropriate referrals to specialist palliative care,**
- 3. Continuity and coordination of care,**
- 4. Best practice is followed in delivering palliative care, and**
- 5. Palliative care meets the needs of the patient, their family and whānau.**

A note on inequalities

Many of the organisations that have been consulted during the development of this document have asked how 'inequalities' are incorporated.

PCC believes it is absolutely essential for inequalities in palliative care to be addressed in a meaningful way. Too often, frameworks such as these indicate a focus on inequalities by depicting an 'overarching' or 'underpinning' box that says 'inequalities'.

PCC believes that inequalities can only be meaningfully addressed if viewed in terms of outcomes. That is, there is little value in simply stating that an inequalities focus will be incorporated at all stages. To identify and address unequal outcomes it is absolutely essential that all outcomes are measured through an inequalities 'lens'. To this end, 'inequalities' will be addressed in this framework when PCC comes to measure outcomes.

The following pages describe each of the outcomes in more detail along with the factors that will influence its occurrence, and, where appropriate, include examples of how an 'inequalities' focus will be incorporated for relevant outcomes.

Section Four: The Framework in Detail

Sufficient capacity

Why is this outcome important?

Sufficient capacity refers to the resourcing of the palliative care system. Without sufficient capacity people who would benefit from palliative care are not able to receive it.

What factors will contribute to success?

The key components of capacity in the palliative care system are workforce and services and infrastructure.

Sufficient workforce capacity will be achieved when there are a sufficient number of skilled workers employed to match the demonstrated need of people who would benefit from palliative care.

Appropriate service and infrastructural capacity will be achieved when:

- there is a sufficient range of palliative care services to meet the needs of all palliative care patients and their family and whanau
- the provision of palliative care in all settings is based on an assessment of patient needs rather than an assessment of whether the resources are available to provide palliative care
- palliative care services are provided in the right geographical location, in the right settings

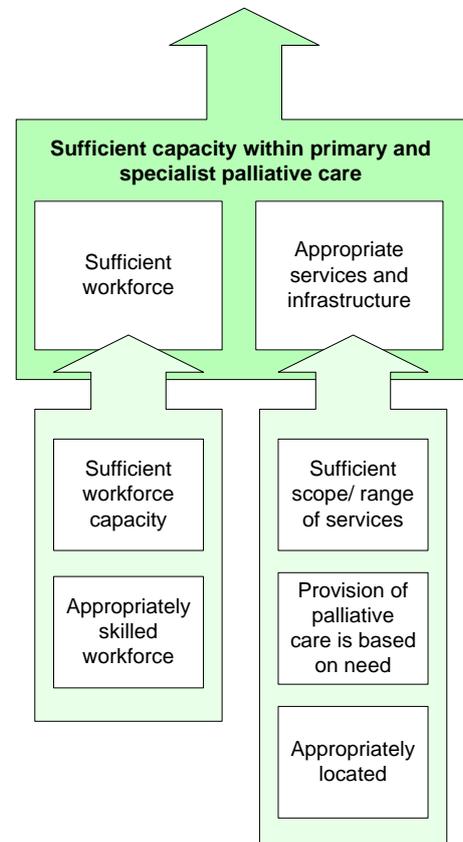
How will inequalities be included?

By examining *workforce capacity* it will be possible to identify inequalities. Including whether:

- the workforce has skills in cultural competency
- the make-up of the workforce reflects that of the patient population, including in terms of ethnicity and age

By examining the *services and infrastructure* that comprise the palliative care system it will be possible to identify inequalities, including:

- whether there are geographical inequalities in the location of services, including rural versus urban, and provision of services/providers in low socioeconomic areas



Appropriate referrals

Why is this outcome important?

Referrals are the mechanism by which a patient accesses palliative care 'services', and as such 'appropriate referrals' contribute to access to palliative care. Appropriate referrals relates not only to the number of referrals, but the balance of referral sources.

Appropriate referrals also means that all people who require the input of Specialist Palliative Care services are referred in a timely way.

What factors will contribute to success?

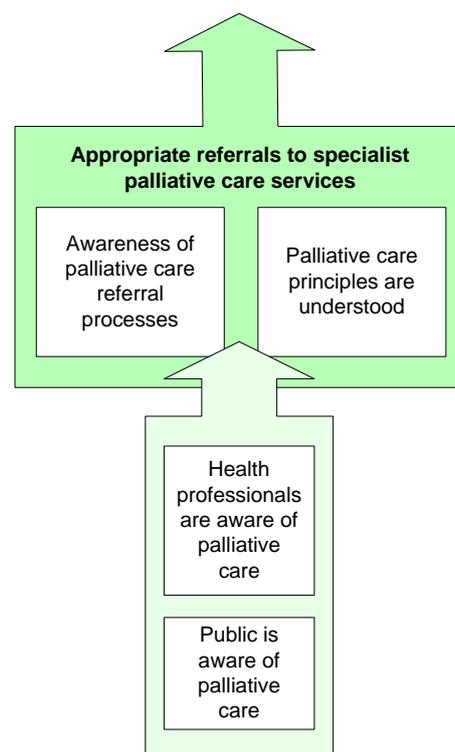
The key components of appropriate referrals are awareness of palliative care referral processes and understanding of palliative care principles. That is;

- If health practitioners and the public understand the principles of palliative care (including the benefits of palliative care, and when it would be appropriate to provide palliative care); and
- If there is awareness among health practitioners and among the public of the processes for referring a person who would benefit from palliative care to a palliative care service, then the result should be appropriate referrals to palliative care services. It would also mean that those people for whom it is more appropriate to receive palliative care from another provider would continue to receive palliative care in that setting

How will inequalities be included?

By examining the number of referrals to palliative care services it will be possible to identify inequalities, including, for example:

- the number of referrals, by age, rurality, ethnicity, sex and location



Continuity and coordination of care

Why is this outcome important?

Continuity and coordination contribute to seamless care pathways and refer to the connections that exist between different facets of a patient's care. Patients receiving palliative care may require a number of different types of care from different providers/services (including symptom management, social support, psychological support, etc), and may also be undergoing disease modifying treatment. It is important that the different providers and services are aware of, and responsive to the various facets of care that the patient requires.

What factors will contribute to success?

The key components of continuity and coordination of care are integration with the wider health sector and coordination between providers of palliative care.

Palliative care will be integrated with the wider health sector when:

- appropriate links exist between specialist palliative care 'services' and palliative care providers in the wider health system. This will allow specialist palliative care services to communicate with and support those parts of the health system providing other aspects of palliative care, thus facilitating a connected approach to patient care
- there is appropriate role delineation between providers and services of palliative care. This will ensure clarity among providers of palliative care in the wider health sector about which components of palliative care they should provide, and what aspects of a patient's care are best provided by a specialist palliative care service. Role delineation is especially important for palliative care providers whose primary focus is not the delivery of palliative care, e.g. oncology services, surgical services, general practices

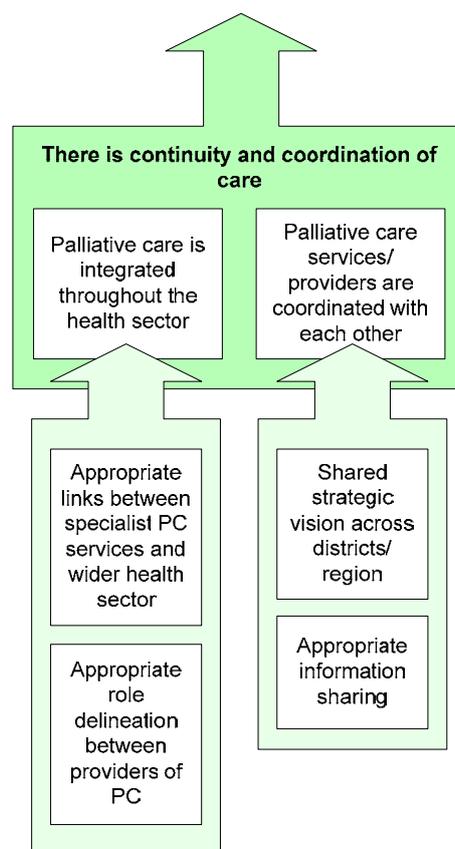
Palliative care will be coordinated when:

- there is a shared strategic vision for palliative care across districts and/or regions. This will allow providers of palliative care to work towards the same overarching goals for service delivery and improvement
- there is appropriate information sharing across and between providers, including compatible and connected information and communication technology systems

How will inequalities be included?

By examining links between specialist PC and the wider health sector it will be possible to identify inequalities. Including whether:

- services are coordinated in such a way that all those requiring palliative care have equal access to appropriate levels of care where and when they need it



Best practice is followed

Why is this outcome important?

Delivering palliative care in a way that aligns with best practice techniques will ensure that patients receive care that is effective. Standards of, and guidelines for, palliative care provision are examples of best practice.

What factors will contribute to success?

The key components of best practice are standards of palliative care provision are met and the adoption of an inter-disciplinary team approach to palliative care.

Standards for palliative care provision will be met when:

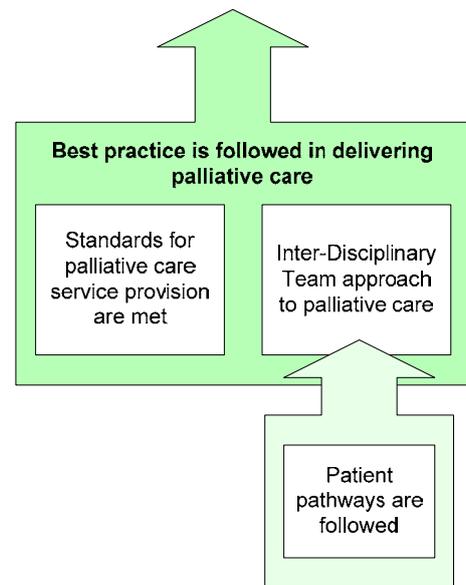
- providers of palliative care adopt nationally agreed standards and receive accreditation/credentialing appropriate to the setting in which the palliative care is provided. The appropriate level of accreditation will differ depending on whether the setting is a hospital, hospice, aged care or in primary care, for example

An inter-disciplinary team approach will be achieved when:

- palliative care is provided by a team of health professionals with an appropriate breadth of skills and knowledge who work together in a coordinated way. This will allow for the right care to be delivered by the most appropriate health professional at the right time, leading to a seamless patient journey. This approach will also encourage better coordination and a smoother transition between palliative care providers and services

How will inequalities be included?

There are currently no relevant inequality markers for this outcome because it is primarily service focussed.



Palliative care meets the needs of the patient, their family and whānau

Why is this outcome important?

Effective palliative care must meet the needs of patients, their families and whānau, regardless of their religious, cultural, ethnic or socioeconomic background or geographic location/rurality. This outcome is largely patient-reported; the only accurate source of information about whether the needs have been met is the patient themselves, and their family and whānau.

What factors will contribute to success?

The key components of meeting patient need are meeting the needs of specific population groups, palliative care being culturally appropriate, and provision of effective treatments and support.

The needs of specific population groups will be met when:

- palliative care is provided in a way that is tailored to the specific circumstances of a patient; this includes children, the elderly, disabled people, etc

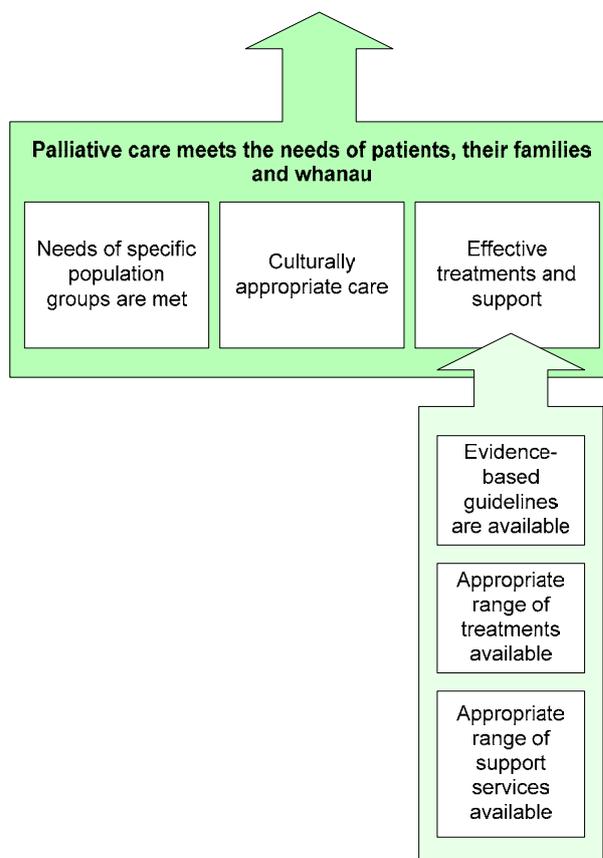
Culturally appropriate care will be achieved when:

- palliative care is provided in a way that is tailored to the specific cultural circumstances of a patient; this includes Maori, Pacific, Pakeha/NZ European, and all other cultures, as well as the cultural needs of the patient's family and whānau

Effective treatments and support will be achieved when:

- evidence-based guidelines for palliative care are available, and guide the practice of all those who provide palliative care
- an appropriate range of treatments are available for physical and psychological symptoms
- an appropriate range of support is available. Combined with an appropriate range of treatments, this will ensure a holistic approach to palliative care that addresses all dimensions of a patient's needs, including psycho-social, spiritual, cultural, and physical symptom management

This is similar to the outcome "palliative care services/providers are coordinated with each other" except that the focus here is not on the seamlessness of the pathway, but rather the effectiveness of care that results from a seamless system. Such seamlessness ensures that all aspects of a patient's needs are addressed.



How will inequalities be included?

By examining whether palliative care meets the needs of patients, their families and whānau, it will be possible to identify inequalities, including whether:

- the needs of specific population groups, such as children, the elderly and disabled patients are met
- palliative care is delivered in a way that is appropriate to the cultural circumstances of patients, including Maori, Pacific, European and other cultures
- the treatments and support available to patients meet their needs, including by ethnicity, geography, age and sex