

National Specialist Palliative Care Data Business Process Standard

HISO 10039.1

To be used in conjunction with

HISO 10039.2

National Specialist Palliative Care Data Definitions Standard

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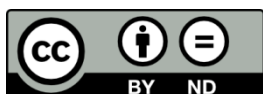
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Updates

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December 2011	1.0			Published as 'Interim' Standard
June 2013	2.0			Changed status from 'Interim' Standard to 'Full' Standard

Related Documents

The development of this Standard referred to the documents listed below. They may be consulted, if required, in order to further clarify this Standard.

HISO

Proposal for Standard: HISO 10039.2 National Palliative Care Data Definitions

Other Publications

New Zealand Palliative Care Strategy (2001)

Draft Specialist Palliative Care Service Specifications (April 2010)

New Zealand Cancer Control Strategy (2003)

New Zealand Cancer Control Action Plan (2005)

Wairarapa Palliative Care Plan (2007)

Ethnicity Data Protocols for the Health and Disability Sector (2004)

Hospice New Zealand Standards for Providing Palliative Care (Working document for discussion, October 2010)

Hospice NZ QPS Benchmarking 2010

New Zealand Legislation¹

Health Information Privacy Code 1994

Privacy Act 1993

¹ These are available on <http://www.legislation.co.nz/> and <http://www.legislation.govt.nz/>

1 INTRODUCTION

1.1 Background

The specialist palliative care community in New Zealand has identified the need for nationally endorsed data standards to provide a basis of a common language for discussions between stakeholders and for understanding palliative care in New Zealand.

While New Zealand does have rich palliative care data sources within individual care organisations, the major deficiency in our current national palliative data sets is a lack of accurate and consistent information about service contacts that can be shared and compared.

This Business Process Standard, and its associated Data Definition document, is intended to ensure that minimum agreed palliative care data is collected and stored in a consistent manner wherever it is collected and stored. The standard provides context for the data definition standard and describes the business processes involved in the collection and storage of palliative care data.

The National Specialist Palliative Care Data standards principally concern themselves with the technical business of collecting and messaging core palliative care data, however it is important that they recognise the principles of He Korowai Oranga – the Māori Health Strategy. The overall aim of He Korowai Oranga is Whānau Ora: Māori families are supported to achieve their maximum health and wellbeing. The standards in this suite are permissive of current, emerging and future models of care and do not lock the palliative care sector into predetermined models of care.

1.2 Information drivers

The primary drivers for the standardisation of information regarding the specialist palliative care pathway are about accessing benefits, such as:

- the ability to consistently report on services for specialist palliative care patients
- measurable quality levels from care regimes
- less variation and improved equity of service provision
- improved decision making
- reduced disparity in care regimes
- allowing assessment of impact of health policy on care
- assisting with understanding of future demand on services, facilitating better planning
- assessment of cost effectiveness of services
- allowing identification of health access inequalities
- improved ability to plan services and utilise resources resulting from the ability to form a national plan for treatment and/or services.

1.2.1 Addressing inequalities

The burden of ill-health falls disproportionately on Māori and on socio-economically disadvantaged individuals, families and communities, so contributing to health inequality.

One of the main purposes of He Korowai Oranga is to improve Māori health outcomes. The standardisation of palliative care data should enhance our ability to:

- collect accurate ethnicity more consistently enabling better understanding of the issues around equity of access and levels of care
- collect data on service provision to assess the affects of different care approaches and protocols.

1.3 About this Document

This document outlines a business model that:

- summarises the overall context of the National Specialist Palliative Care Data Definitions and Business Process
- describes the high-level business processes and information flows related to the observation and collection of data within the specialist palliative care lifecycle
- presents a series of use-cases to describe how the key processes that support the specialist palliative care lifecycle work in various example settings.

This document sits within a wider related group of documents that fully describe the National Specialist Palliative Care Data Definition framework:

Document Number	Document Title	Purpose
10039.1	National Specialist Palliative Care Data Business Process Standard	This refers to the document you are currently reading. It provides a contextual link between the Data Definitions and the real world of palliative care. It includes key business processes and use-cases that provide real world examples of those processes.
10039.2	National Specialist Palliative Care Data Definitions Standard	This describes the National Specialist Palliative Care Data Definitions data set in detail. It includes descriptions, source standards, data types, lengths, domains, verification rules and guides for use for each data element and models the inter-relationship between the elements.

Table 1: Documents in the National Specialist Palliative Care Data Definitions Framework

1.4 Intended Audience

These documents are primarily intended for specialist palliative care services, plus government and private agencies and individuals that are involved in modifying, implementing or building palliative care related information and technology solutions.

The roles of the people likely to use this document may include, but is not limited to, specialist palliative care professionals with an interest in data collection and storage, senior health service managers, IT and project managers, business analysts, programmers, test analysts and information analysts.

The documents will also be useful for information and technology professionals looking to learn more about the palliative care data and information environments.

1.5 Assumptions

The following assumptions apply to this document:

- It provides a high-level overview of core specialist palliative care and related activities as they are practiced in New Zealand. It does not cover detailed nuances, or obscure or infrequent business practices
- business practices not sanctioned by law or regulation are specifically excluded
- it does not provide an implementation pathway. This will need to be addressed as a separate process, sometime in the future, when an implementation pathway becomes clearer.

1.6 Core Definitions

Specialist palliative care is palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals.

Specialist palliative care may be provided by hospice or hospital based palliative care services. Specialist palliative care will be provided through accredited services (or organisations) that work exclusively in palliative care and meet specific palliative care standards as they are developed nationally. Specialist palliative care practice builds on the palliative care provided by generalist providers and reflects a higher level of expertise in complex symptom management, psychosocial support, grief and bereavement. Specialist palliative care provision works in two ways:

1. Directly – to provide direct management and support of patients and families/whānau where more complex palliative care need exceeds the resources of the generalist provider. Specialist palliative care involvement with any patient and the family/whānau can be continuous or episodic depending on the changing need. Complex need in this context is defined as a level of need that exceeds the resources of the generalist team – this may be in any of the domains of care – physical, psychological, spiritual, etc.
2. Indirectly – to provide advice, support, education and training of other health professionals and volunteers to support the generalist provision of palliative care provision.

Generalist palliative care is palliative care provided as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team. In the community, it is provided by general practice teams, Māori health providers, allied health teams, district nurses, and residential care staff etc. In hospitals, it is provided by general ward staff, as well as disease specific teams – for instance oncology, respiratory, renal and cardiac teams.

Some of the generalist providers, e.g. general practice teams, will have on-going contact with a family throughout and following illness. Others, such as district nurses or ward nurses will have episodic contact, depending on the needs of the patient and family. Providers of generalist palliative care will have defined links with (a) specialist palliative care team(s) for the purposes of support and advice or in order to refer patients with complex needs. They will also have access to palliative care education to support their practice².

1.7 Scope

This Standard covers the high-level business processes and information flows relating to the collection and storage of electronic information in the specialist palliative care pathway. It focuses on the attributes common to all specialist palliative care types (i.e. core care). While data elements specific to individual palliative domains are currently out of scope, the design of this standard is such that it is extendable to these areas in the future.

1.7.1 'In scope'

The Standard covers the specialist palliative care business processes and information related to the following areas:

- patient details (i.e. demographic data, including place and date of death)
- episodes of care (i.e. the grouping of service contact data for a specific patient)
- diagnosis detail (i.e. the diagnosis, or diagnoses, for which the patient is receiving specialist palliative care)
- service contact (i.e. data related to the specialist palliative care services provided, including the type of provider, the setting in which they are provided and their purpose).

² New Zealand Palliative Care: A Working Definition, 2007

Specific inclusions to the wider National Specialist Palliative Care Data Definition framework are:

- data, including the minimum data set
- business processes that outline the core pathway of specialist palliative care.

1.7.2 'Out of scope'

The Standard does not specifically cover business processes and information related to the following areas:

- non-specialist palliative care (i.e. generalist palliative care)
- data elements specific to individual palliative care domains (i.e. non-core data)
- definition of a Messaging Standard (messaging structure and content)
- implementation of a Shared Information Repository (SIR)
- generation of any invoices (claims) for services related to episodes of palliative care
- referrals, statuses and discharges of patient, which are covered by a separate HISO standard³
- the prescription, dispensing and administration of medicines, which is covered by a separate HISO standard⁴.

Other specific exclusions are:

- specifying or developing any message exchange or shared patient palliative history capability, including generalised repository reporting
- developing an implementation programme to support the roll out of this standard
- the assessment of technologies and the merits of specific vendor products or emerging terminology standards
- other required processes such as patient consent, privacy, practitioner and health consumer registries and authentication frameworks necessary to realise the business model.

1.8 Interpretation

Within the text of this document, the words 'shall' and 'will' refer to practices that are mandatory for compliance with this standard. The words 'should' and 'may' refer to practices that are advised or recommended.

This standard includes a list of terms related to palliative care used in this document and which may be commonly used in the sector. These terms are outlined in 3.4 Core Terms and Concepts and, more fully, in Appendix A – Glossary.

³ Referrals, Status and Discharges (RSD) - <http://ithealthboard.health.nz/who-we-work/hiso/standards/approved-standards/referrals-status-and-discharges>

⁴ EPharmaceutical Business Process and Messaging Standard - <http://www.ithealthboard.health.nz/who-we-work/hiso/standards/approved-standards>

2 CORE PALLIATIVE CARE PATHWAY

2.1 Introduction

The business processes described in this document provide guidance to the development of the National Specialist Palliative Care Data Definitions. As such, this document defines business processes that assist the development of the Standard. It represents the major processes and business functions that palliative care providers may perform in the provision of palliative care services.

The inclusion of a business process and entity model is necessary to reinforce boundaries for the scope of this Standard.

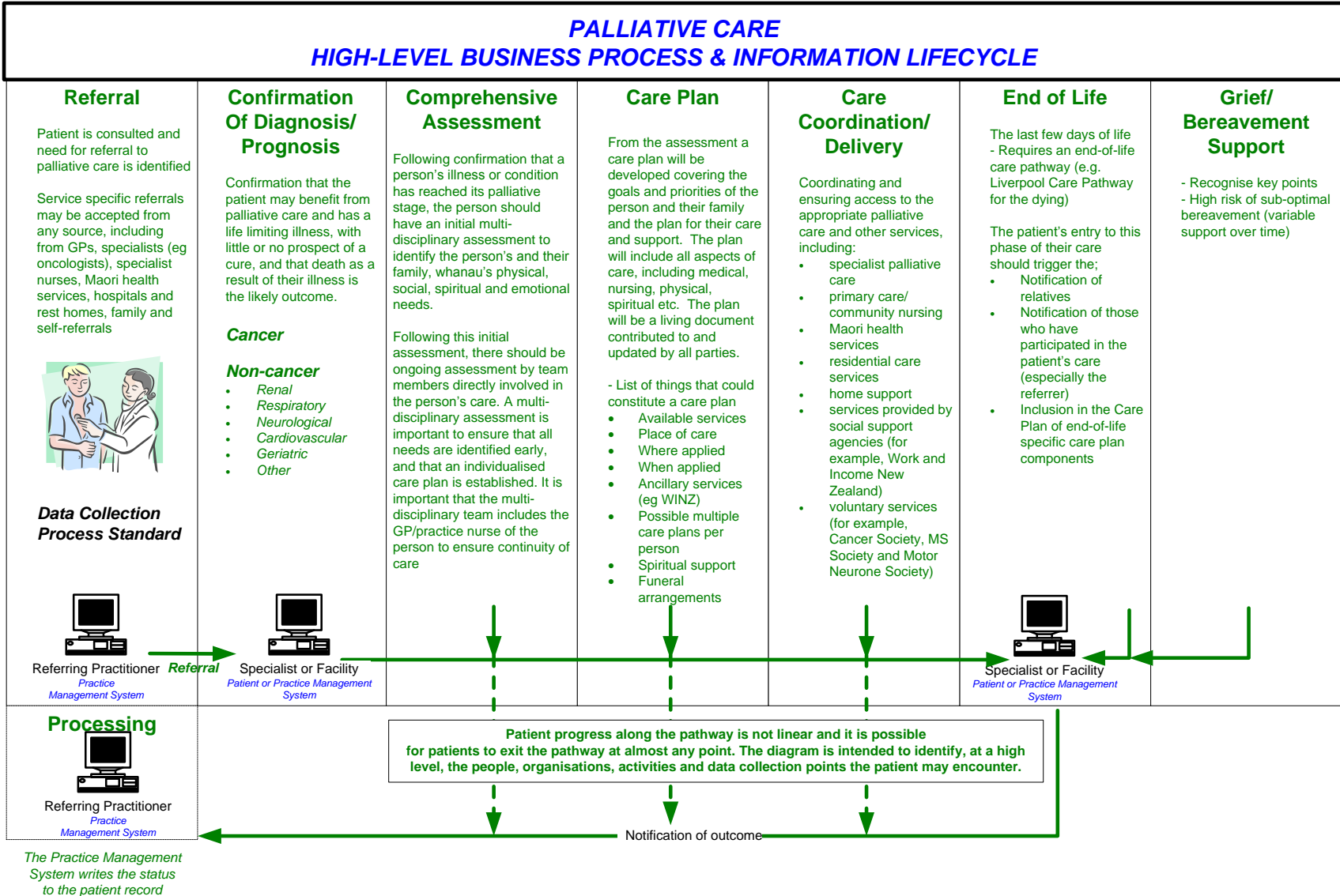
This document reflects the clinical and sector background for the Standard, in terms that should be understandable to all stakeholders, including palliative care providers, business and policy representatives and technical implementers.

2.2 Palliative Care Business Process Interviews

Following on from the creation of the high-level business process and information lifecycle model, and the palliative care business process map, a number of interviews were conducted with palliative care providers to build up the Business Process section of this document.

2.3 High-level Business Process & Information Lifecycle

The development of this business process used a high-level business process and information lifecycle model (see Figure 1) to identify likely people, organisations, activities and data collection points involved in the palliative care pathway.



Ver 1.4

Figure 1: High-level Business Process & Information Lifecycle

3 BUSINESS PROCESSES

3.1 Purpose

This section is a narrative describing the major business processes that were introduced in the business process map and which are referenced in the use-cases described in section 5 Use-cases.

The use-cases describe the palliative care lifecycle for a range of common scenarios, across different palliative care settings. They help determine the supporting information flows and the links between patient, generalist and specialist palliative care.

3.2 General Notes

The Standard supports the capture and storage of core data related to specialist palliative care. It does not require that further (lower level) data is captured, however, this is likely to be undertaken by facilities providing palliative care and doing so would provide completeness of a patient's health record.

Some important considerations that apply to all the use-cases described in this document include:

- it is possible that the patient and/or their family/support will seek alternative opinions from different providers at this point or will decide against palliative care altogether and leave the process
- a patient may leave the process at any time. Although there is provision of data describing how they left specialist palliative care (e.g. death, discharged, transferred), this will not describe why they have left or whether they are still receiving generalist care.

3.2.1 Leaving the pathway or moving between processes

In addition to moving through the above processes, there is the on-going ability for a patient to leave the pathway completely or move between processes in a different manner than the linear approach shown in the business process model. Examples of this may occur where a patient:

- decides to discontinue treatment at any point in the pathway
- changes provider and begins a different pathway of care
- enters or leaves New Zealand at any point in the care pathway (e.g. a patient returning to New Zealand having already received some palliative care overseas).

3.3 Key Actors

The key palliative care providers ('provider') supplying specialist palliative assessments, support services and/or treatments within the business process are:

- palliative care specialists (e.g. any type of medical, nursing or allied health provider who has undergone specialist palliative care training or been accredited through appropriate qualifications).

The providers supplying additional care services to this business process include, but are not limited to:

- palliative care generalists (i.e. any type of medical, nursing, allied health provider who has not undergone specialist palliative care training or been accredited through appropriate qualifications) This includes but is not limited to: health care assistants, district nurses, general practitioners, oncologists, complementary therapists, dieticians, grief counsellors, oncology social workers, psychologists, Māori health workers, occupational therapists, personal care assistants, pharmacists, physiotherapist, podiatrists, social workers, speech therapists, spiritual carers, volunteers.

3.4 Core Terms and Concepts

The following explanation of core terms and concepts are supplementary to Appendix A – Glossary and are intended to make it easier to understand the major business process definitions that follow.

- **Episode of care**

A period of care where a patient receives treatment and/or other services to improve their quality of life. Care of individual patients may occur in discrete episodes, which may be separated in time and location. Each episode of care will involve one or more service contacts and will be based around the organisation providing specialist palliative care services.

- **Multi-disciplinary Team (MDT) Meeting**

A planned, regular meeting of palliative care specialists to review patient cases. The MDT meeting is a key component in the specialist palliative care pathway that may influence the planning and management of treatment of a patient. The MDT meeting can be an important component in:

- diagnosis and prognosis review
- treatment planning and management
- quality assurance.

In general, an MDT meeting will be held regularly with a core group of specialist providers (e.g. physician, specialist nurse etc) but may include other providers on a case-by-case basis for other specialist areas or complex cases (e.g. psychosocial and spiritual assessment, pharmacist, social worker, occupational therapist etc). It may occur with the patient, and/or family/whānau, but in most cases occurs in a separate setting.

- **Prognosis**

An idea of the likely course and outcome of the illness based on individual details about the patient and the type and stage of the illness.

- **Palliative**

An instance of medical care, or treatment, where the intent of care is on lessening the severity of symptoms, and improving quality of life, rather than curing or halting the progression of an illness.

- **Service contact**

Service contacts are services that are provided to, or on behalf of, the patient and/or their carer(s)/family/friends, or whānau that result in a dated entry being made in the client record, except where the service is primarily of an administrative nature (for example, making an appointment on behalf of a client). A palliative care client may receive more than one service contact per day, and may receive different types of assistance within one service contact. The types of care provided at a service contact may for example, include medical care, nursing care and spiritual care.

3.5 Business Process

The following business processes outline a general pathway of specialist palliative care. A generalised approach has been taken for two reasons:

- the overarching National Cancer and Palliative Care Information Systems project focuses on 'core' data and is, therefore, naturally focussed on processes that are common across all specialist palliative care
- the pathway of each patient is governed by many factors (e.g. illness type, patient condition, physical location, individual choice, etc) and is far more complex and dynamic than can be described or modelled here.

A patient enters the specialist palliative care pathway via a referral for assessment and may exit the pathway at any time, via several methods (e.g. transfer or discharge), or continue through the treatment pathway to death.

3.5.1 Referrals:

3.5.1.1 Referrals in to a specialist palliative care programme:

The referral process is the initiating step for a patient and family/whānau journey on the specialist palliative care pathway. The referring provider should have explained the patient's diagnosis and prognosis, to the patient and/or their support people, before making the referral to specialist palliative care.

Referrals for specialist palliative care generally come from medical practitioners (e.g. general practitioners, specialists, hospital physicians etc) and, in some instances, from clinical nurse specialists (e.g. oncology, respiratory etc). However, with the right information, referrals may also come from a variety of other areas depending on the processes of the receiving organisation and/or the type of specialist palliative care required. Other people making referrals may include:

- district nurses
- community organisations (e.g. Disability Support Link)
- family, whānau
- patients (i.e. self-referrals).

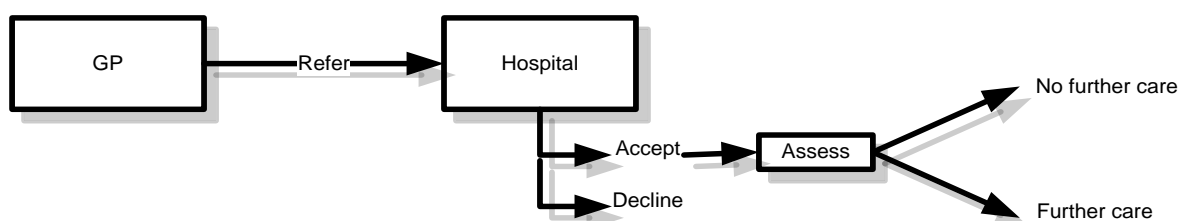


Figure 2: Referral Pathway

Incoming referrals are triaged and patients will enter the assessment phase based on priority. Some organisations accept all referrals and then discharge patients who are assessed as not currently requiring specialist palliative care. Others will not accept a referral until the patient's prognosis and palliative needs have been fully assessed and a requirement for specialist palliative care has been established. In most instances the inpatient admission criteria are more specific than community care.

Referrals may be received in many formats, including phone calls, paper-based referral forms and letters and electronic referrals.

3.5.1.2 Referrals out of a specialist palliative care programme:

In a similar manner to incoming referrals for specialist palliative care, outgoing referrals for related health services do not follow a specific model or standard. They may occur at any point in the palliative care pathway and are, in most instances, for palliative treatment (though may be for diagnostic/assessment purpose, or curative treatment of either related or unrelated illnesses). Outgoing referrals are usually paper-based. They often take the form of a letter but are sometimes subject to the referral requirements of the organisation to which the patient is being referred and, as such, may take the form of a particular organisation's referral form.

Referrals may be sent to a variety of specialists (e.g. urologists, respiratory physicians, oncologists etc), to other medical/nursing groups (e.g. district nurses etc), other community carers (e.g. psychosocial, cultural or religious etc) or to other organisations providing specialist palliative care.

No specific patient data is provided at this time.

3.5.2 Assessment:

The assessment process is a dynamic, recurring section of the pathway that will take place as soon as is practically possible after the referral is received. The assessment includes the following processes:

- Confirmation of Diagnosis/Prognosis
- Multi-disciplinary Assessment.

Following initial assessment, the patient will be cared for and treated as required, and based on need, monitored and reassessed until discharge, transfer to another service or death.

3.5.2.1 Confirmation of Specialist Palliative Care Need:

The confirmation of the patient's diagnosis and prognosis, as per the incoming referral, are important factors in the acceptance of a patient onto the palliative care pathway. At this point specialist palliative care service staff assess the patient to confirm that they:

- have a life limiting illness, and
- may benefit from specialist palliative care.

The confirmation of a need for specialist palliative care may take place via a comprehensive assessment. This is where one or more providers make an initial assessment of the patient's palliative needs. Although this may include multiple providers, it is unlikely to be flagged as a true multi-disciplinary assessment - generally this would be recorded as two separate service contacts for the same day. Some complex cases, in some organisations, do actually combine this stage with the multi-disciplinary assessment (see 3.5.2.2).

Where a patient is assessed as not requiring specialist palliative care services, they are likely to be declined back to the referring provider awaiting further development with regard to their palliative needs.

This process and its outcome, like so many others in the palliative care pathway, is not completely linear or straight forward. It may require a significant assessment and reassessment of the patient, including their mental and physical condition, and their support/care environment.

3.5.2.2 Multi-disciplinary Assessment:

The multi-disciplinary assessment is constructed by a MDT and is a best practice approach to care assessment and planning. It forms an integral part of the palliative care pathway and is important in identifying the full needs of the palliative care patient.

The MDT is likely to include medical and nursing staff at a minimum but may also include, depending on the providing organisation and/or a particular patient's needs, other related providers (e.g. pharmacist, physiotherapist, social worker, counsellor, chaplain) and/or family members, whānau or support people. In a community setting the multidisciplinary team may include the patient's generalist palliative providers (e.g. general practitioner (GP), practice nurse, district nurse etc).

With the exception of patients who die before being assessed at a multi-disciplinary assessment, every patient should be discussed at such a meeting at some point on their care pathway - though not necessarily all at the same set points in the pathway (e.g. the multi-disciplinary assessment may be weekly for community patients, daily for inpatients and more often for patients with specific needs in their end of life phase). The decision as to when the first multi-disciplinary assessment occurs will depend on:

- whether all relevant referral information has been received
- the providing organisation's triage process
- personal and/or family issues or requests
- the patient's diagnosis and prognosis.

The multi-disciplinary assessment may take place with all health care providers coming to a central location away from the patients (e.g. at a morning staff meeting) or with the patient (e.g. hospital ward rounds, or at private residences for community care). In some instances an MDT meeting will not take place but, in these scenarios, it is likely that one of the team's specialist palliative providers will have at least made a comprehensive assessment.

3.5.3 Care Delivery:

The care delivery domain covers several key areas around the actual provision of palliative care:

- Care plan
- Care coordination and delivery
- End of life care
- Grief / Bereavement support.

3.5.3.1 Care Plan:

The care plan is an integral part of the consultative nature of specialist palliative care. It is a living document regarding symptom management and guides on-going care. It may be held with the patient's medical notes or by patients themselves.

The care plan constantly evolves as new issues, or potential issues, are identified and dealt with.

It may include some or all of the following:

- needs assessment
- holistic assessment (physical, spiritual, psychosocial, cultural)
- communication with the patient's GP and other medical/nursing support people
- consultation with the patient, family, whānau and/or support person
- the creation of genograms (pictorial display of a person's family relationships and medical history)
- education regarding the boundaries of specialist/generalist palliative care
- recording action plans, desired outcomes and actual outcomes for each issue, progress toward goals, variations to plan
- patient notes and consultation letters
- notes from the multi-disciplinary team members other than the medical/nursing ones (e.g. social workers, occupational therapists, pharmacists, physiotherapists etc)
- acceptance from the patient and/or family/whānau support person.
- advance care planning

The shape of a care plan is highly dependant on the patient's location (i.e. inpatient or community care) and, if the patient is located at a private residence, on their level of support and the ability of their carers.

Patients may occasionally be in a specialist palliative service for several years, seeing a number of different health care workers over that period, so the care plan is an important record of care.

3.5.3.2 Care Coordination and Delivery

Care coordination is the formal management of palliative care workers, and related individuals or organisations, providing palliative care or any related services and/or provision of equipment to patients in a community setting.

Care delivery includes both medical/nursing health care (specialist and generalist) as well as related non-medical/nursing care (e.g. social, cultural, spiritual, religious, and personal care etc) or equipment provision (e.g. hospital beds, wheelchairs, commodes, etc).

The multi-disciplinary meeting and care plan are important precursors to this phase as they set the scene around the individual patient care and are often revisited as a part of dynamic care coordination. In many instances each patient is assigned a single "lead" carer (usually a registered nurse) to manage care coordination and delivery. In community settings district nurses often deliver the day-to-day services with palliative specialist nurses coordinating care.

Care coordination and delivery may include outpatient clinics or day groups for community patients (e.g. day stays, guest speakers, meals, fellowship and social groups).

Close relationships with external providers are important to ensure there is good coordination and communication between providers and the people (e.g. oncologists, Māori health providers social workers, physiotherapists, district nurses, religious and/or cultural support etc) and organisations (e.g. Cancer Society, Life Links, Multiple Sclerosis Society (MS Society), Motor Neurone Society, rest homes and private hospitals involved in the provision of related services.

3.5.3.3 End of Life Care

End of life care is a dynamic and evolutionary process where the patient is assessed regularly and is more intensive than other areas of the palliative care pathway. It differs slightly between the inpatient and community care environments and includes:

- Diagnosis of “dying”
- More regular patient assessment than normal
- Management of the symptoms of dying (e.g. medication and/or change of position to help with breathing, products to manage incontinence)
- Education for carers and family, whānau and support people (e.g. Liverpool Care Pathway’s ‘What To Expect When Someone Is Dying’, North Shore’s “Sunset Book”).

End of life care pathway is a systematic care pathway for the last days and hours of a patient’s life. It may consist of an externally developed formal process such as the Liverpool Care Pathway for the Dying Patient (LCP)⁵, an in-house process, or an informal approach.

An end of life care plan is generally initiated when a diagnosis of “dying” is made. Occasionally, a patient may be removed from an end of life care plan due to recovery from a dying state but this is rare.

3.5.3.4 Grief/Bereavement Support

Grief/Bereavement support is the support of people, and the management of care services, around the death of a patient. Grief/Bereavement support is especially important during end of life care, and in the period following death, but essentially begins at the point where a patient is accepted into specialist palliative care. It is a fluid process intended not just for the family, whānau and support people but also for the patient receiving palliative care.

Grief/Bereavement support can range from an important formal step in a documented care pathway, through needs based case-by-case support, to no bereavement support at all.

Providers are aware of the need to look for requests and/or flags signalling the requirement for extra bereavement support services. Grief/Bereavement support may be discussed at the daily multi-disciplinary meeting.

Grief/Bereavement support may include:

- group or individual support sessions
- biography, memorial and/or remembrance services
- follow-up contacts with family, whānau and/or support people (e.g. phone call at one month, card at one year etc)
- support and/or counselling for staff.

This support is often dependent on the patient, especially when it occurs as an informal part of the process. It may be provided by a range of practitioners which can include (but is not limited to) counsellors, chaplains social workers and cultural support staff.

⁵ Liverpool Care Pathway for the Dying Patient (LCP) is an integrated care pathway developed to transfer the hospice model of best practice care to patients in all settings, during their last days and hours of life.

4 INFORMATION FLOW

4.1 Background

The documents in this standard are about the creation of a national approach to specialist palliative care information collection and storage. They reference, and utilise, pre-existing standards wherever possible (e.g. NHI for patient data and PCOC and AIHW for service/episode data).

While this approach may be useful with regard to the future collation of data for benchmarking and/or planning purposes, there is no intention for the information to flow transactionally between providers or from providers to a shared information repository (however, this standard does allow for such an information flow to be developed at a later date).

4.2 National Specialist Palliative Care Data Definitions

HISO 10039.2 National Specialist Palliative Care Data Definitions is a national set of minimum agreed specialist palliative data to be collected and stored in a consistent manner. The data set has been developed with a sector working group and will, along with this document, form the basis for the specialist palliative care standards. The National Specialist Palliative Care Data Definitions define six principal entities.

- For each *Patient* there will be one or more *Episode of Care*.
- For each *Episode of Care* there may be one or more *Diagnosis* and *Service Contact*.
- For each *Service Contact* there will be one or more *Contact Purpose* and *Provider Occupation*.

The logical relationship between these entities is displayed in the entity diagram in Appendix B – Core Palliative Care Entities. For full information on these entities, and their corresponding data items, see the *National Specialist Palliative Care Data Definitions* document.

5 USE-CASES

Palliative care is a dynamic and complex process that would be difficult, if not impossible, to model in full. The following use-cases deal with scenarios that may be considered simplified examples of the specialist palliative care pathway. The intent of these use-cases is to show the flow of the palliative care pathway and to illustrate the episode of care concept, rather than detail all types of specialist palliative care scenarios fully.

5.1 Use-Case 1 – Community Care, Single Episode of Care

The following use-case is an example of a patient who has reached the terminal stage of colorectal cancer. A discussion with their medical oncologist leads to a referral to palliative care specialists with a community arm. Assessment, discussion with the patient and their family/whānau present, and the initial MDT meeting results in a decision to coordinate shared care between the family/whānau with General Practitioner and district nurse support and specialist palliative care coordination and planning.

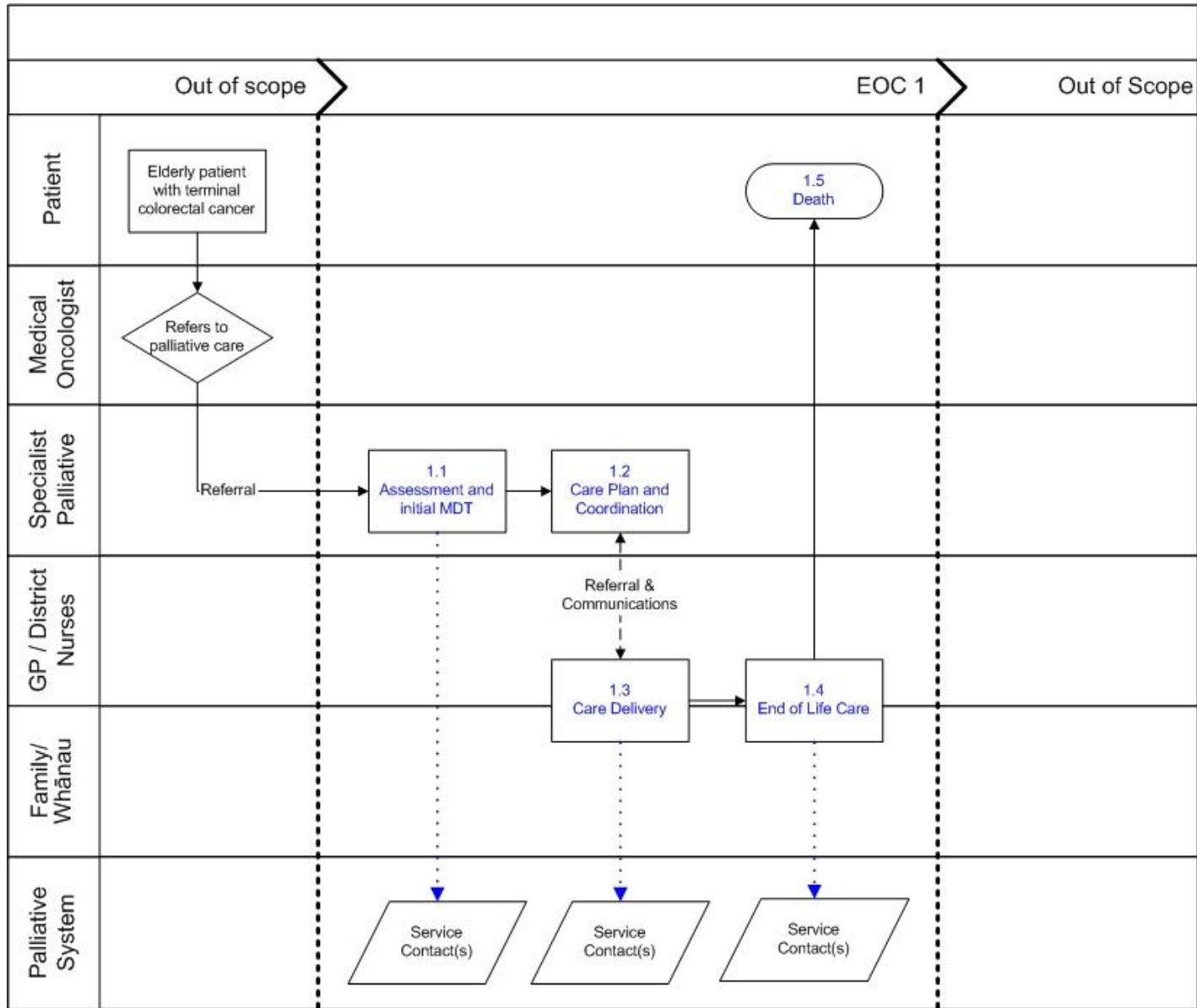


Figure 3: Use-Case 1 – Community Care, Single Episode of Care

5.1.1 Process Description

A high-level description of each numbered process step in the use-case above is outlined in the table below:

<p>1.1 Assessment and MDT:</p> <ul style="list-style-type: none"> • Patient referred in from District Health Board (DHB) medical oncologist. • Initial comprehensive assessment and MDT finds that the patient meets criteria for admission to the specialist palliative care program. • Lead specialist palliative carer is established. • Communication with GP and district nursing team is established, as required. • Patient is admitted to the specialist palliative care program with family/whānau and community generalist care and specialist support.
<p>1.2 Care Plan and Coordination:</p> <ul style="list-style-type: none"> • Lead specialist palliative carer coordinates a care plan and discusses with the patient and their family/whānau. • It is agreed that care will be carried out by the patient’s family/whānau, GP and district nursing team with full support of the specialist palliative team and coordination from the lead specialist palliative carer, as required.
<p>1.3 Care Delivery:</p> <ul style="list-style-type: none"> • Patient care is delivered and recorded by the family/whānau with help from the GP and district nursing team. • Ongoing communication, regarding patient condition, takes place between family/whānau, district nursing team and the hospice-based specialist lead carer.
<p>1.4 End of Life Care:</p> <ul style="list-style-type: none"> • A diagnosis of dying is made by MDT. • Care team place patient onto an in-house end of life care plan, discussing any appropriate issues and the signs of dying with family/whānau • Family/whānau deliver end of life care with GP and district nurse support as well as specialist palliative care advice. • Care team gain a good understanding of family/whānau support and decide, in consultation with the family/whānau, that no formal bereavement support will be required.
<p>1.5 Death:</p> <ul style="list-style-type: none"> • Patient dies. • Offer bereavement/grief counselling and any follow-up assistance established. • Episode of care ends

Table 2: Use-Case 1 – Process Steps

5.2 Use-Case 2 – Inpatient Hospice Care, Single Episode of Care

This use-case represents the example of a patient with advanced emphysema, whose DHB-based respiratory physician has referred for specialist palliative care. Comprehensive assessment results in the acceptance of the referral and admission for inpatient care. The hospice plans and provides the majority of care, with external spiritual support provided by the patient's personal spiritual advisor. Following death, the patient's family/whānau are referred to an associated volunteer group for the provision of bereavement counselling (after which, the episode of care ends).

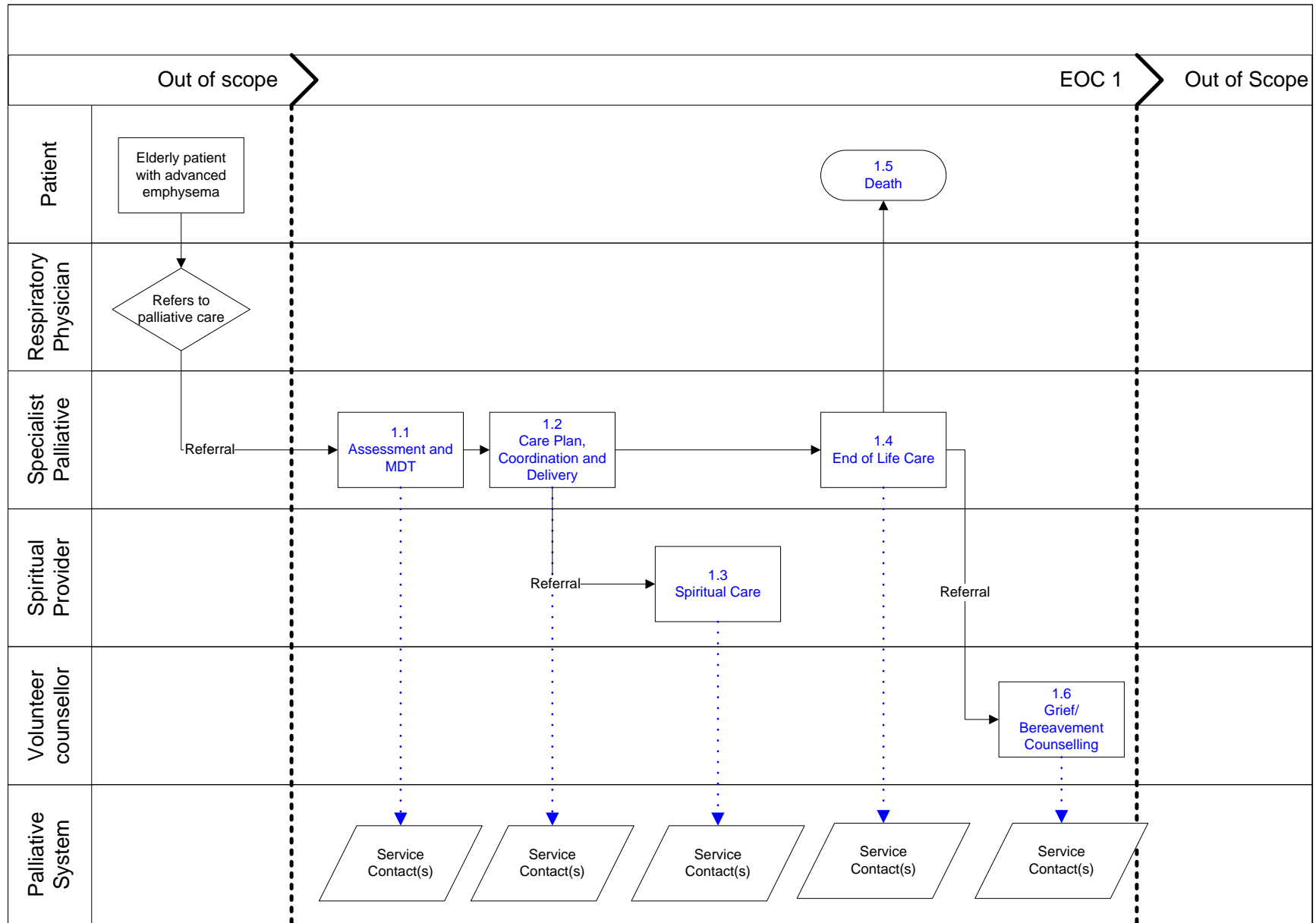


Figure 4: Use-Case 2 – Inpatient Hospice Care, Single Episode of Care

5.2.1 Process Description

A high-level description of each numbered process step in the use-case above is outlined in the table below:

<p>1.1 Assessment and MDT:</p> <ul style="list-style-type: none"> • Patient referred in from DHB respiratory physician. • Initial comprehensive assessment and MDT finds that the patient meets criteria for admission to the specialist palliative program and that inpatient admission would allow the best provision of care. • Lead specialist palliative carer is established. • Patient is admitted as inpatient.
<p>1.2 Care Plan, Coordination and Delivery:</p> <ul style="list-style-type: none"> • Lead specialist palliative carer coordinates a care plan and discusses with the patient and their family/whānau. • Care is carried out and recorded by the full palliative team and is coordinated by lead specialist palliative carer. • Ongoing communication is carried out with family/whānau regarding patient condition.
<p>1.3 Spiritual Care:</p> <ul style="list-style-type: none"> • Patient requests visits from their own spiritual advisor (e.g. priest, rabbi, tohunga etc). • Several visits are made and each is recorded by the specialist palliative care team.
<p>1.4 End of Life Care:</p> <ul style="list-style-type: none"> • A diagnosis that the patient is dying is made by the MDT. • Care team place patient onto Liverpool Care Pathway and discuss appropriate issues and the signs of dying with family/whānau.
<p>1.5 Death:</p> <ul style="list-style-type: none"> • Patient dies. • Family/whānau is supported by care team on the day.
<p>1.6 Grief / Bereavement Counselling:</p> <ul style="list-style-type: none"> • Post bereavement contact with the family is made by palliative care team and a need for counselling is established. • Palliative care team refer patient's family to their counsellors. • Family/whānau receive bereavement counselling. • The episode of care ends with the end of bereavement counselling.

Table 3: Use-Case 2 – Process Steps

5.3 Use-Case 3 – Community and Inpatient Care, Multiple Episodes

The third use-case is an example of a patient, referred from a GP, who has advanced immune deficiency from HIV/AIDS and severe pneumonia.

The initial episode of care, coordinated and supported by the GP, other specialist carers and with hospice specialist palliative support, takes place in a community setting with care from the family/whānau and district nursing support. After a period of care, the patient is discharged from the hospice specialist palliative care program after making significant health gains (ending the episode of care).

A few months later the patient's health deteriorates significantly and their GP refers them back to the specialist palliative team for a second episode of care. The same community care setting is agreed, and carried out, until such point where the patient's family can no longer provide adequate care and the patient is admitted to the hospice for end of life care and subsequent death. During this second episode of care, the patient is admitted to the local hospital for a concurrent episode of specialist palliative treatment (see Use-Case 4 – Concurrent Episode of Care for further information).

A significant period elapses (in which the second episode of care is closed) before the family/whānau approaches the specialist palliative team for bereavement support and a third episode of care ensues.

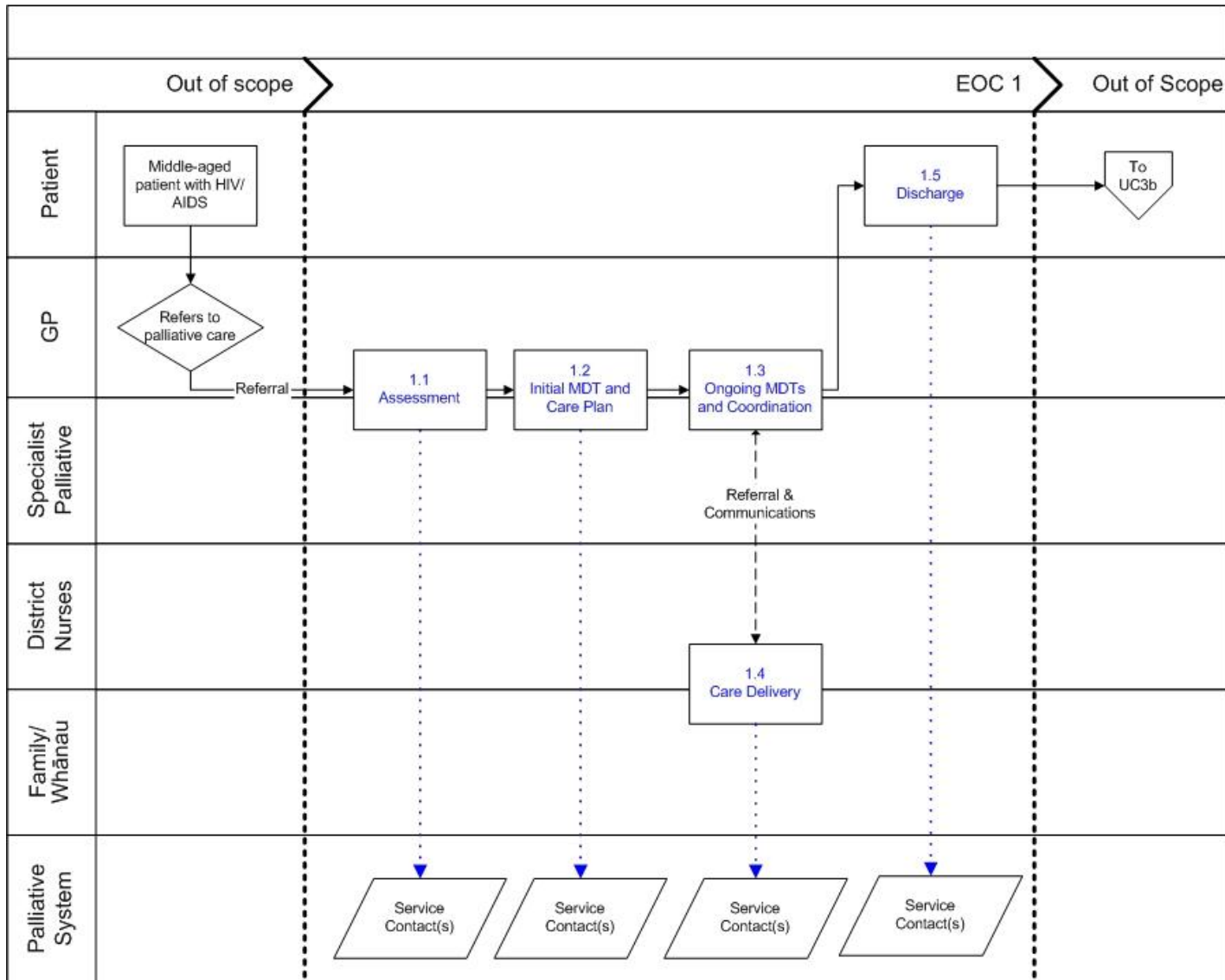


Figure 5: Use-Case 3 – Community and Inpatient, Multiple Episodes of Care (part a)

5.3.1 Process Description

A high-level description of each numbered process step in the use-case above is outlined in the table below:

<p>1.1 Assessment:</p> <ul style="list-style-type: none"> • Patient is referred in from GP after immune deficiency issues lead to severe case of pneumonia. • Initial comprehensive assessment finds that the patient meets criteria for admission to specialist palliative care program. • Lead specialist palliative carer is established. • Links are established between community care team, family/whānau and specialist palliative support. • Patient is admitted to specialist palliative care program.
<p>1.2 Initial MDT and Care Plan:</p> <ul style="list-style-type: none"> • Lead specialist palliative carer works with the patient, family/whānau, GP and district nurses to establish a care plan that meets the patient needs and their personal wishes. • Hospice MDT, with GP and district nursing input, agrees to care plan and makes suggestions regarding potential changes. • Patient and family/whānau agree to care plan changes.
<p>1.3 On-going MDTs and Coordination:</p> <ul style="list-style-type: none"> • Services and equipment provision is coordinated by the hospice-based lead specialist palliative carer.
<p>1.4 Care Delivery:</p> <ul style="list-style-type: none"> • Patient care is delivered and recorded by the family/whānau along with help from their GP and the district nursing team. • Ongoing communication, regarding patient condition, takes place between family/whānau, GP, district nursing team and the hospice-based lead specialist palliative carer.
<p>1.5 Discharge:</p> <ul style="list-style-type: none"> • An unexpected and significant improvement to the patient's health occurs and the patient is discharged back to GP and family/whānau care. Episode of care ends.

Table 4: Use-Case 3 – Process Steps (part a)

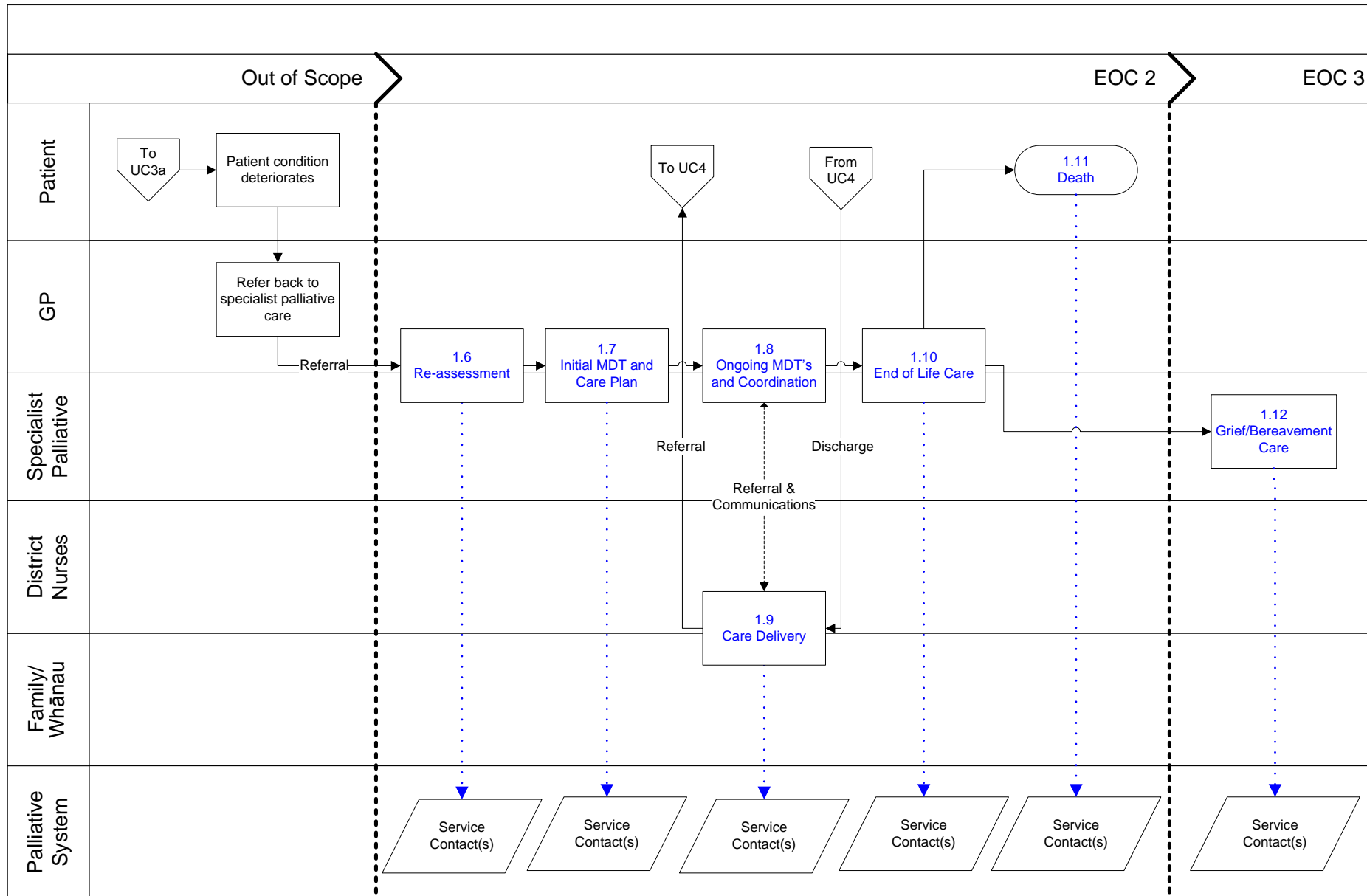


Figure 6: Use-Case 3 – Community and Inpatient, Multiple Episodes of Care (part b)

5.3.2 Process Description

A high-level description of each numbered process step in the use-case above is outlined in the table below:

<p>1.6 Re-assessment:</p> <ul style="list-style-type: none">• Patient's condition deteriorates to a point where specialist palliative support is required.• Patient is referred in from GP and a comprehensive assessment finds that the patient meets criteria for admission to community care.• Lead specialist palliative carer is established.
<p>1.7 Initial MDT and Care Plan:</p> <ul style="list-style-type: none">• Lead specialist palliative carer works with the patient, GP, family/whānau and district nursing to establish a care plan that meets the patients needs and personal wishes.• Hospice MDT, with GP and district nursing input, agrees to care plan and makes suggestions regarding potential changes.• Patient and family/whānau agree to care plan changes.
<p>1.8 Ongoing MDTs and Coordination:</p> <ul style="list-style-type: none">• Services and equipment is coordinated by lead specialist palliative carer at the hospice.
<p>1.9 Care Delivery:</p> <ul style="list-style-type: none">• Patient care is delivered and recorded by the family/whānau along with help from their GP and the district nursing team.• Ongoing communication, regarding patient condition, takes place between family/whānau, GP, district nursing team and the hospice-based lead carer.• During this section of care the patient is admitted to hospital palliative care for care services that cannot be carried out by the current care providers (see Use-Case 4 – Concurrent Episode of Care).• Nursing team note that family/whānau are showing signs of the strain of looking after the patient.• Nursing team discusses the patient's condition with the family/whānau and recommends that the patient is admitted to inpatient hospice care.
<p>1.10 End of Life Care:</p> <ul style="list-style-type: none">• An MDT diagnosis of dying results in the end of life pathway being triggered (LCP for the community).• Patient and family/whānau agree that inpatient hospice care will be best, and the patient is transferred to the hospice.• Palliative care team switch patient to inpatient LCP process.• The family/whānau approach specialist palliative care team, near the patient's time of death, to discuss what to expect in the last days of life and the grieving process.
<p>1.11 Death:</p> <ul style="list-style-type: none">• Patient dies.• Family/whānau are supported on the day.• Family/whānau are contacted a few weeks after the patient's death. The second episode of care ends.

1.12 Grief/Bereavement Counselling:

- Family/whānau contact the specialist palliative care provider, a few months later, looking for support.
- The specialist palliative care team invite family/whānau back for grief/bereavement group sessions and a new episode of care is opened.
- The third episode of care ends after the last family/whānau grief/bereavement group session.

Table 5: Use-Case 3 – Process Steps (part b)

5.4 Use-Case 4 – Concurrent Episode of Care

This use-case represents a concurrent episode of care, where a patient (from Use-Case 3 – Community and Inpatient Care, Multiple Episodes) is referred into the hospital based specialist palliative care service for specialist services that cannot be provided by their community care team or specialist palliative support. The episode of care is carried out and the patient is discharged back to their community care team.

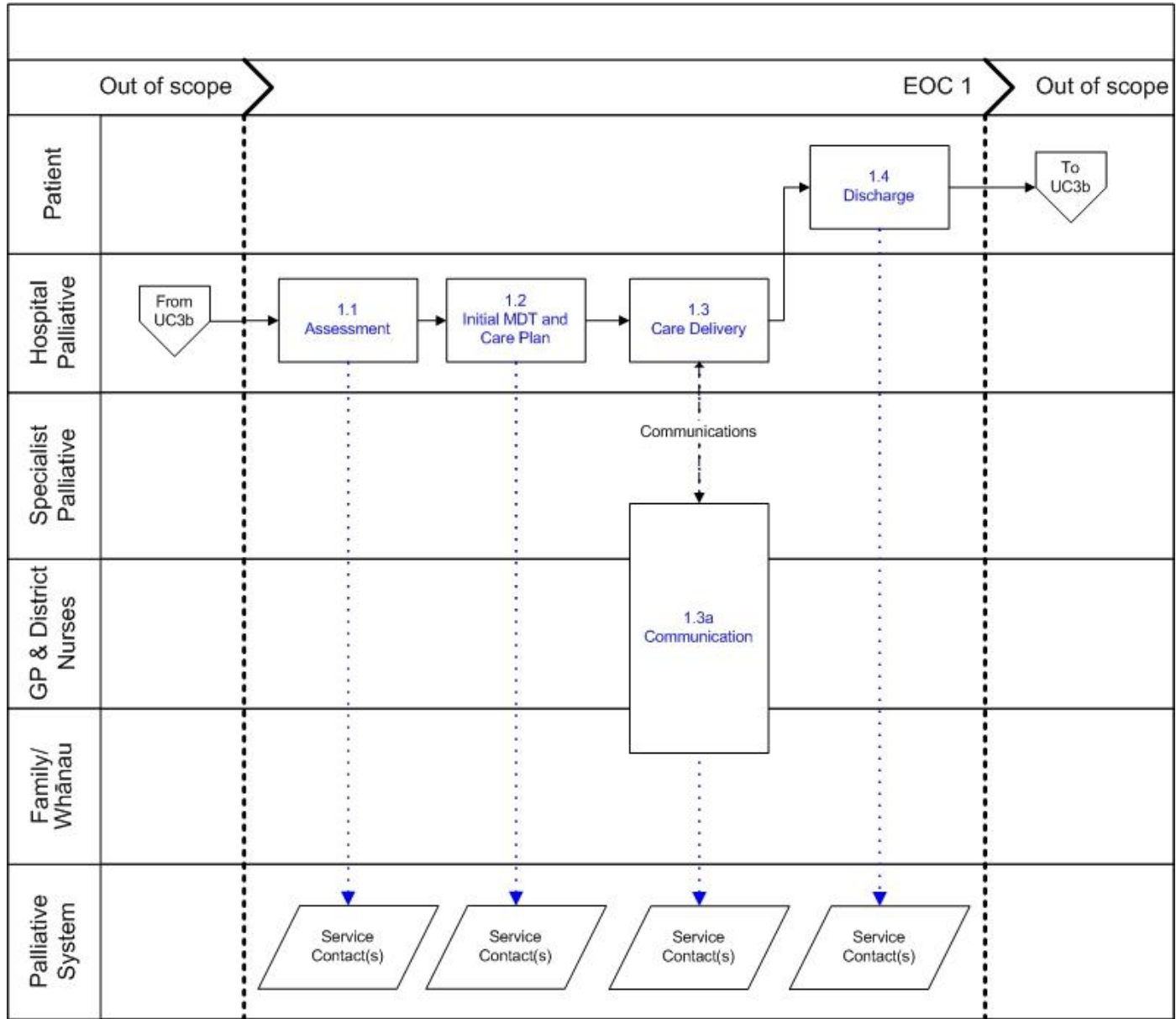


Figure 7: Use-Case 4 – Concurrent Episode of Care

5.4.1 Process Description

A high-level description of each numbered process step in the use-case above is outlined in the table below:

<p>1.1 Assessment:</p> <ul style="list-style-type: none">• Patient referred into hospital palliative care from hospice.• Referral accepted and the lead specialist palliative carer is established.• Patient is admitted as inpatient.
<p>1.2 Initial MDT and Care Plan:</p> <ul style="list-style-type: none">• MDT discusses patient and decides on treatment.• Care plan is completed.
<p>1.3 Care delivery (and communication):</p> <ul style="list-style-type: none">• Hospital palliative care team carry out intensive IV therapy on patient.• Communication occurs between hospital palliative care team and all community care providers (e.g. family/whānau, district nurses, specialist palliative support and GP).
<p>1.4 Discharge:</p> <ul style="list-style-type: none">• Care delivery is completed.• Patient is discharged back to community carers.

Table 6: Use-Case 4 – Process Steps

5.5 Use-Case 5 – Hospital Based, Single Episode of Care

This use-case represents a single episode of care, where a patient is admitted into hospital-based specialist palliative care following presentation at an emergency department with severe chest pain. The patient is referred to terminal care in a hospice but the episode of care is carried out within the hospital ward setting (where the patient dies before a hospice bed becomes available).

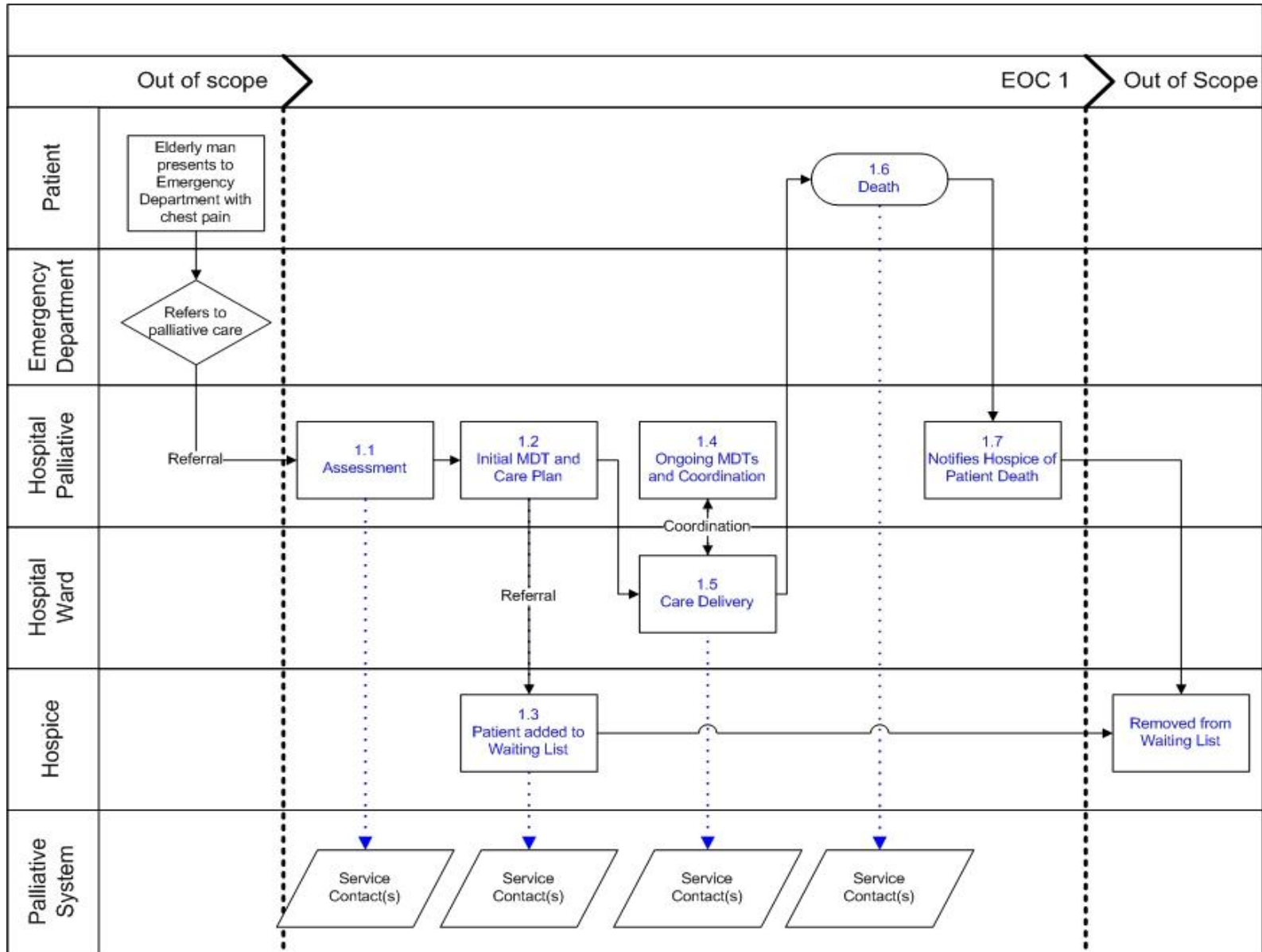


Figure 8: Use-Case 5 – Hospital Based Episode of Care

5.5.1 Process Description

A high-level description of each numbered process step in the use-case above is outlined in the table below:

<p>1.1 Assessment:</p> <ul style="list-style-type: none"> • Patient declines surgery and is referred into hospital palliative care. • Assessment made by palliative team and referral accepted. • Patient is admitted into hospital ward.
<p>1.2 Initial MDT and Care Plan:</p> <ul style="list-style-type: none"> • MDT discusses patient and decides on palliative care options. • Lead specialist palliative carer is established and a care plan is completed.
<p>1.3 Patient added to Waiting List</p> <ul style="list-style-type: none"> • Patient is reluctant to go into residential care facility but agrees to be referred to hospice for terminal care. • Hospice has large number of people waiting for a bed so patient is placed on waiting list.
<p>1.4 On-going MDT's and Coordination</p> <ul style="list-style-type: none"> • On-going MDT's discuss patient situation and care plan. • Palliative team liaises with ward staff, hospital social worker and hospice.
<p>1.5 Care delivery (and communication):</p> <ul style="list-style-type: none"> • Ward staff carry out day-to-day care of the patient with palliative support. • Care plan carried out with the patient receiving strong pain relief and social support. • Communication occurs on an on-going basis between hospital palliative care team and ward staff.
<p>1.6 Death:</p> <ul style="list-style-type: none"> • Patient dies.
<p>1.7 Notify Hospice of Patient Death</p> <ul style="list-style-type: none"> • Hospital notifies hospice of death and patient is removed from hospice waiting list.

Table 7: Use-Case 5 – Process Steps

APPENDIX A – GLOSSARY

Terms defined in this glossary apply to both this document and the Messaging Standard document. Not all terms are used in both documents.

Term	Definition	Reference
AIHW	Australian Institute of Health and Welfare. Australia's national agency for health and welfare statistics and information.	www.aihw.gov.au
Assessment	A process used to learn about a patient's condition. This may include a complete medical history, medical tests, a physical exam, a test of learning skills, tests to find out if the patient is able to carry out the tasks of daily living, a mental health evaluation, and a review of social support and community resources available to the patient. Assessment also includes how patient, family/whānau and/or caregivers are coping	National Cancer Institute (USA) www.cancer.gov New Zealand Cancer Society http://www.cancernz.org.nz/
Business Process	The business process(es) that constitute all, or part of, an eHealth system or application	
Care coordination	Care coordination is the formal management of palliative care workers, and related individuals or organisations, providing palliative care or any related services and/or provision of equipment to patients in a community setting.	
Curative	Treatment with the intent of tending to overcome disease (or illness) and promote recovery.	www.medical-dictionary.com
Data element	A single piece of data, e.g. first name, last name, etc.	-
Data set	Collection of data groups used for specific purposes.	-
Diagnosis (clinical)	The process of identifying a disease/illness (such as palliative) from its signs and symptoms.	National Cancer Institute (USA) www.cancer.gov
Diagnosis (pathological)	The process of identifying a disease/illness (such as cancer) from examining its structural and functional manifestations (especially in body tissues and organs).	www.medical-dictionary.com
Diagnostics	That part of medicine which has to do with ascertaining the nature of diseases/illnesses by means of their symptoms or signs (clinical diagnosis) and/or its structural and functional manifestations (pathological diagnosis).	www.medical-dictionary.com

Term	Definition	Reference
DHB	District Health Board. The organisation responsible for ensuring the provision of publicly funded health and disability support services for the population of a specific geographic area.	www.moh.govt.nz
Discharge	The relinquishing of patient care in whole or in part by a health care provider or organisation.	Referrals Status and Discharges standard www.ithealthboard.health.nz/who-we-work/hiso/standards/approved-standards
Disease type	An alteration in the state of the body or of some of its organs, interrupting or disturbing the performance of the vital functions.	www.medical-dictionary.com
EHR	See 'Electronic Health Record'.	
Electronic Health Record	An electronic longitudinal collection of health information, based on an individual patient, entered by health providers, which can be distributed over a number of sites, and in a number of settings. The record is controlled by an agreed access policy.	From Strategy to Reality – The WAVE Project, MOH 2001
Episode of care	An episode of care is a period of care when patients and their families receive services to improve their quality of life. Care of individual patients may occur in discrete episodes, which may be separated in time and location. Each episode of care will involve one or more service contacts.	National Specialist Palliative Care Data Definitions
First Specialist Assessment	The first assessment by a registered palliative care specialist for a particular referral.	NZHS Glossary
FSA	See 'First Specialist Assessment'.	
General Practitioner (GP)	An appropriately qualified and registered medical professional, with knowledge and skills to provide personal, family, whānau, and community orientated comprehensive general practice care.	Royal NZ college of General Practitioners
Generalist Palliative Care	Generalist palliative care is palliative care provided for those affected by lifelimiting illness as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team. It is provided in the community by general practice teams, Māori health providers, allied health teams, district nurses, and residential care staff etc. It is provided in hospitals by general ward staff, as well as disease specific teams – for instance oncology, respiratory, renal and cardiac teams.	New Zealand Palliative Care: A Working Definition, 2007

Term	Definition	Reference
HISO (2010)	Health Information Standards Organisation (2010). A group who supports and promote the development, understanding and use of fit-for-purpose health information standards to improve the New Zealand health system.	www.ithealthboard.health.nz/who-we-work/hiso
MOH	Ministry of Health – the NZ Government's principal agent and advisor on health and disability.	www.moh.govt.nz
Multi-disciplinary Assessment (MDA)	A comprehensive treatment planning approach in which a number of medical and nursing providers (and sometimes other health providers), who are experts in different specialties/disciplines, review and discuss the medical condition and treatment options of a patient. An MDA may include psychosocial input and an holistic (Te Whare Tapa Whā) health assessment.	Te Whare Tapa Whā http://www.maorihealth.govt.nz/moh.nsf/pagesma/445
Multi-disciplinary Team (MDT)	A multidisciplinary team consists of a team of professionals, including representatives of different disciplines, who coordinate the contributions of each profession, which are not considered to overlap, in order to improve patient care. Members of a multidisciplinary team might include GPs, surgeons, medical or radiation oncologists, palliative care specialists, pastoral care workers, nurses, social workers, occupational therapists, physiotherapists, dieticians, volunteers, pharmacists or care assistants.	Palliative Care Australia. (2008). <i>Palliative and end of life care glossary of terms</i> (1st Edn). Deakin West, ACT: Palliative Care Australia.
National Health Index (NHI)	A unique identifier that is assigned to every person who uses health and disability support services in New Zealand.	http://www.health.govt.nz/our-work/health-identity/national-health-index
Palliative	Treatment with the intent of relieving the symptoms and reduce the suffering caused by palliative and other life-threatening diseases and illnesses.	National Cancer Institute (USA) www.cancer.gov
PCOC	Palliative Care Outcomes Collaboration, Australia. A voluntary quality initiative to assist palliative care services improve practice and meet the Standards for Providing Quality Palliative Care for all Australians - developed by Palliative Care Australia.	http://www.caresearch.com.au
Prognosis	The likely outcome or course of a disease or illness - the chance of recovery or recurrence.	National Cancer Institute (USA) www.cancer.gov

Term	Definition	Reference
Provider	<p>A person, facility or organisation that provides patient health care services, including services to promote health, to protect health, to prevent disease or ill-health, treatment services, nursing services, rehabilitative services or diagnostic services.</p> <p>In this document provider always refers to, unless otherwise specified, a person registered as a health care provider.</p>	<p>Epharmaceutical Standard www.ithealthboard.health.nz/who-we-work/hiso/standards/approved-standards</p>
Referral	<p>The intent to transfer care of a patient, in part or in whole, by one health care provider to another health care provider.</p>	<p>Epharmaceutical Standard www.ithealthboard.health.nz/who-we-work/hiso/standards/approved-standards</p>
Referring specialist	<p>A 'referred-to' health care provider who is referring a patient for advice or treatment, but not back into the care of the referring health care provider.</p>	<p>Epharmaceutical Standard www.ithealthboard.health.nz/who-we-work/hiso/standards/approved-standards</p>
Sector	<p>The Health and disability sector.</p>	<p>Epharmaceutical Standard www.ithealthboard.health.nz/who-we-work/hiso/standards/approved-standards</p>
Shared Information Repository (SIR)	<p>A database holding information related to a patient's medical history that is accessible by authorised parties with a 'need-to-know' inquiry related to a patient or cohort of patients</p>	<p>Epharmaceutical Standard www.ithealthboard.health.nz/who-we-work/hiso/standards/approved-standards</p>
Specialist	<p>An individual health provider who administers specialist treatment or advice.</p>	<p>Epharmaceutical Standard www.ithealthboard.health.nz/who-we-work/hiso/standards/approved-standards</p>
Specialist Palliative Care	<p>Specialist palliative care is palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals.</p>	<p>New Zealand Palliative Care: A Working Definition, 2007</p>
Standard	<p>A consensus based document that has been developed by a balanced expert committee taking into consideration input received through public comment consultation. Standards are generally widely applied and have high status.</p>	-
Transfer	<p>The movement of a patient from one health care provider or facility to another. This may or may not involve a geographical movement.</p>	-
Treatment	<p>Medical or surgical management of a patient.</p>	<p>www.medical-dictionary.com</p>
Triage	<p>The sorting and classification of patients to determine priority of need and proper place of treatment.</p>	<p>www.medical-dictionary.com</p>

APPENDIX B – CORE PALLIATIVE CARE ENTITIES

