hiso Health Information Standards Organisation
PAEREWA PĀRONGO HAUORA

Interim
National Cancer Core Data
Business Process Standard

HISO 10038.1

To be used in conjunction with

HISO 10038.2 Interim National Cancer Core Data Messaging Standard and Implementation Guide and

HISO 10038.3 Interim National Cancer Core Data Definitions Standard

Copyright Information

This document has been approved as an Interim Standard for the New Zealand health and disability sector by the Health Information Standards Organisation.

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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 http://www.ithealthboard.health.nz/hiso-2010

10004 New Zealand Pathology Observation Code Sets - Information Business Process v4

10008 Pathology and Radiology Messaging Standard v1

10011.1 Referrals, Status and Discharge Referrals (RSD) Business Process v1

10030.1 EPharmaceutical Business Process Standard v1

Other Standards

Health Level Seven Inc, HL7 Standard version 2.4: 2000 – An Application Protocol For Electronic Data Exchange in Healthcare Environments[1]

Health Level Seven Inc, HL7 Standard version 2.5: 2003 – An Application Protocol For Electronic Data Exchange in Healthcare Environments[2]

Other Publications

New Zealand Cancer Control Strategy (2003)

New Zealand Palliative Care Strategy (2001)

New Zealand Cancer Control Action Plan (2005)

A Feasibility Study of National Cancer Management Information Systems (2005)

Cancer Collections Framework Project Final Report (2006)

New Zealand Cancer Registry, Appendix B - HL7 validation & properties

Implementation Guide for Messaging with the National Immunisation Register

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

He Korowai Oranga: Māori Health Strategy (2002)

UICC TNM Classification of Malignant Tumours, 7th Edition (2009)

New Zealand Legislation[3]

Health Information Privacy Code 1994

Privacy Act 1993

[1] This is the document referred to in the text as "HL7 v2.4".

[2] This is the document referred to in the text as "HL7 v2.5".

[3] These are available on http://www.legislation.co.nz/ and http://www.legislation.govt.nz/

1 INTRODUCTION

1.1 Background

In New Zealand there is currently no standardised approach to the collection and storage of cancer management data. The cancer sector has, for a number of years, identified the need for nationally endorsed data standards to improve health outcomes and the cost-effectiveness of care through more consistent and efficient management of health information.

While New Zealand does have rich data sources with regard to cancer incidence and mortality, the major deficiencies in our current national cancer data sets are lack of accurate information about treatment. The Interim National Cancer Core Data Business Process, Data Definitions, and Messaging Standards intend to address that deficiency.

This Business Process Standard, and its associated documents, is primarily targeted at developing a consistent approach to the collection and storage of core cancer data in New Zealand. The standards are not a design specification for information or patient management systems. The development of this suite of cancer data standards aligns with Ministry of Health policy initiatives.

The data work group that developed these standards considered a superset of possible cancer data items. The group was asked to sort those items into categories based on their **relevance** (requirement and utility), **availability** (is it recorded and can it be collected) and **reliability** (accuracy and consistency with definition). The data items that scored highly for relevance, availability and reliability were considered '**core'** and are the basis for these documents.

The suite of Interim National Cancer Core Data standards principally concern themselves with the technical business of collecting and messaging core cancer 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 whanau 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 cancer sector into predetermined models of care.

1.2 Information drivers

The primary drivers for the standardisation of information regarding the cancer care pathway have been around accessing benefits, such as:

- improving the baseline information set for decision making
- advancing the ability to report on national trends around treatment and outcomes for cancer patients
- improving analysis of trends in population health
- assessment of long term analysis of cost effectiveness of new drugs and treatments
- utilising staging data to increase modelling of survival data and the benefits of early diagnosis
- measuring survival rates from specific treatment regimens
- enabling the assessment of best treatment regimens for disease types by best outcomes known
- assisting with understanding the future demand on services and facilitating better planning
- improving ability to assess the impact of health policy on disease states.

1.2.1 Addressing inequalities

The burden of cancer falls disproportionately on Māori and on socioeconomically disadvantaged individuals, families and communities, so contributing to health inequality. Most importantly, the causes of many cancers are understood and significant proportions are preventable or amenable to early detection and cure.

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

- Collect ethnicity data more consistently enabling better understanding of the issues around equity of access and levels of treatment

- collect accurate clinical and pathological cancer staging data to enable the identification of late detection and to contribute to the understanding of and addressing the many factors linked to late detection.
- collect treatment data to assess the affects of different treatment approaches and protocols.

1.3 About this Document

This document outlines a business model that:

- summarises the overall context of the Interim National Cancer Core Definitions, Business Process and Messaging Standards
- describes the high-level business processes and information flows related to the sending and receiving of electronic information passed between parties within the cancer care lifecycle
- presents a series of use-cases to describe the key processes that support the cancer care lifecycle in various settings, including the requirements in terms of supporting information flows.

The standard should be reviewed on a regular basis to ensure it remains relevant and fit for purpose. This standard will initially be implemented as an 'interim standard', after which there will be an initial review. After any agreed changes, the standard will then published as a 'full' standard, after which a review should be scheduled every two years.

It is recommended that people in both technical and non-technical roles read this document first. It should be read in conjunction with the Data Definitions and Messaging Standard documents . The messaging standard is a technical document generally intended for use by those implementing messaging solutions.

This document sits within a wider related suite of documents that fully describe the National Cancer Core Definition framework:

Document Number	Document Title	Purpose
10038.1	Interim National Cancer Core Data Business Process Standard	This refers to the document you are currently reading. It provides a contextual link between the Data Definition and the Messaging Standard, including a business model, key business processes and use-cases that provide real word examples of the business process.
10038.2	Interim National Cancer Core Data Messaging Standard	This is a technical document which describes the structure and content of the message exchanges between sender and receiver, including mandatory, conditional and optional information requirements and the application of the elements described in the Data Definition.
10038.3	Interim National Cancer Core Data Definition Standard	This describes the full National Cancer Core 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: Related Documents in the National Cancer Core Definition Framework

1.3.1 Interim Standard Status

On HISO approval, the document(s) are published and can be implemented as Interim Standard(s). The document(s) remain as 'interim' until evidence that it is fit for purpose and meets the needs of the sector is provided. Any amendments required will also be highlighted during this evidence gathering stage. Once this criteria has been met, HISO will give approval to publish the standard as a Full Standard(s) and notification of this action will be placed on the HISO website. The normal review cycle will then commence.

1.4 Intended Audience

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

The roles of the people likely to use this document may include, but is not limited to 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 as well as consumers and health consumer representatives looking to learn more about the cancer care data and information environments

1.5 Assumptions

The following assumptions apply to this document:

- this document provides a high-level overview of core cancer care and related activities as they are practised in New Zealand. It does not cover detailed nuances, or obscure or infrequent business practices
- the National Cancer Core Data standards are agnostic to models of care and are capable of handling a variety of existing and emerging models of care.
- business practices not sanctioned by law or regulation are specifically excluded
- messaging is one way of addressing inter and intra-organisational exchange of information related to cancer care but is not the only way that information may be exchanged. Alternative approaches should refer to this Standard and align where possible at the process and data level
- not all message interactions/transactions are captured in this Standard (e.g. patient consent, referrals and discharges, ePharmacy). Some of these are covered by other standards, see Related Documents – while others either don't exist or are manual at the time of writing this Standard
- it does not provide an implementation pathway. This will be addressed as a separate process when an implementation pathway becomes clearer.

1.6 Scope

This Standard covers the high-level business processes and information flows relating to the sending and receiving of electronic information passed between parties within the cancer care pathway. It focuses on the attributes common to all cancer types (i.e. core data). While data elements specific to individual cancer domains are currently out of scope, this standard is designed to be extendable to these areas in the future.

1.6.1 'In scope'

The Standard covers the Cancer business processes and information flows related to the following areas:

- patient details (i.e. demographics, date and cause of death)
- diagnosis detail (i.e. the initial suspected diagnosis, the most valid diagnosis and the clinical and pathological data related to these diagnoses)
- episodes of care (i.e. the grouping of treatment data for a specific diagnosis with the same intent)
- treatment modality data (i.e. data related to non-intervention management, surgery, radiotherapy, chemotherapy/haematology, targeted therapy and other therapy).

Specific inclusions to the wider National Cancer Core Definition framework are:

- Data, including the minimum data set
- Business processes that outline the core cancer care pathway
- Definition of a Messaging Standard (messaging structure and content), which will support the transmission of data between cancer care providers and a Regional Clinical Data Repository (RCDR).

1.6.2 'Out of scope'

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

- data elements specific to individual cancer domains
- specific models of care
- the recording of comorbidities. While comorbidities are of obvious importance in the treatment of cancer, they will be recorded as part of the broader set of clinical information collected during diagnosis and treatment and will not be recorded as part of the *core* cancer data set
- The follow-up process. Follow-up is outlined in this standard as it has a direct link to the end of treatment and may result in a loop back to determination of treatment but is not included in the core set of cancer data.
- the generation of any invoices (claims) for services related to episodes of cancer care
- the referrals, status and discharges of patient, which are covered by a separate HISO standard[4]
- the prescription, dispensing and administration of medicines, which is covered by a separate HISO standard[5]
- the orders and/or results of laboratory tests, which are covered by a separate HISO standard[6]
- the registration of cancer diagnoses to the New Zealand Cancer Registry
- the orders and/or results of screening programmes.

Other specific exclusions are:

(a) specifying or developing any message exchange or shared patient cancer history capability, including generalised repository reporting

(b) developing an implementation programme to support the roll out of this Standard

(c) the assessment of technologies and the merits of specific vendor products or emerging terminology standards

(d) other required processes such as patient consent, privacy, practitioner and health consumer registries and authentication frameworks necessary to realise the business model.

1.7 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 cancer 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/or 'Appendix A – Glossary'.

[4] Referrals, Status and Discharges (RSD) - http://www.ithealthboard.health.nz/referrals-status-discharges

[5] EPharmaceutical Business Process and Messaging Standard - http://www.ithealthboard.health.nz/Epharmaceutical

[6] Pathology and Radiology Messaging Standard - http://www.ithealthboard.health.nz/pathology-radiology

2 CORE CANCER CARE PATHWAY

2.1 Introduction

The business processes described in this document provide guidance to the development of the Interim National Cancer Core Messaging Standard. As such, this document defines business processes, information flows and the entity diagram that are considered in the development of the Standard. It represents the major processes and business functions that health care providers may perform in the provision of cancer diagnostic and treatment 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 health care providers, business and policy representatives and technical implementers.

2.2 High-level Business Process & Information Lifecycle

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

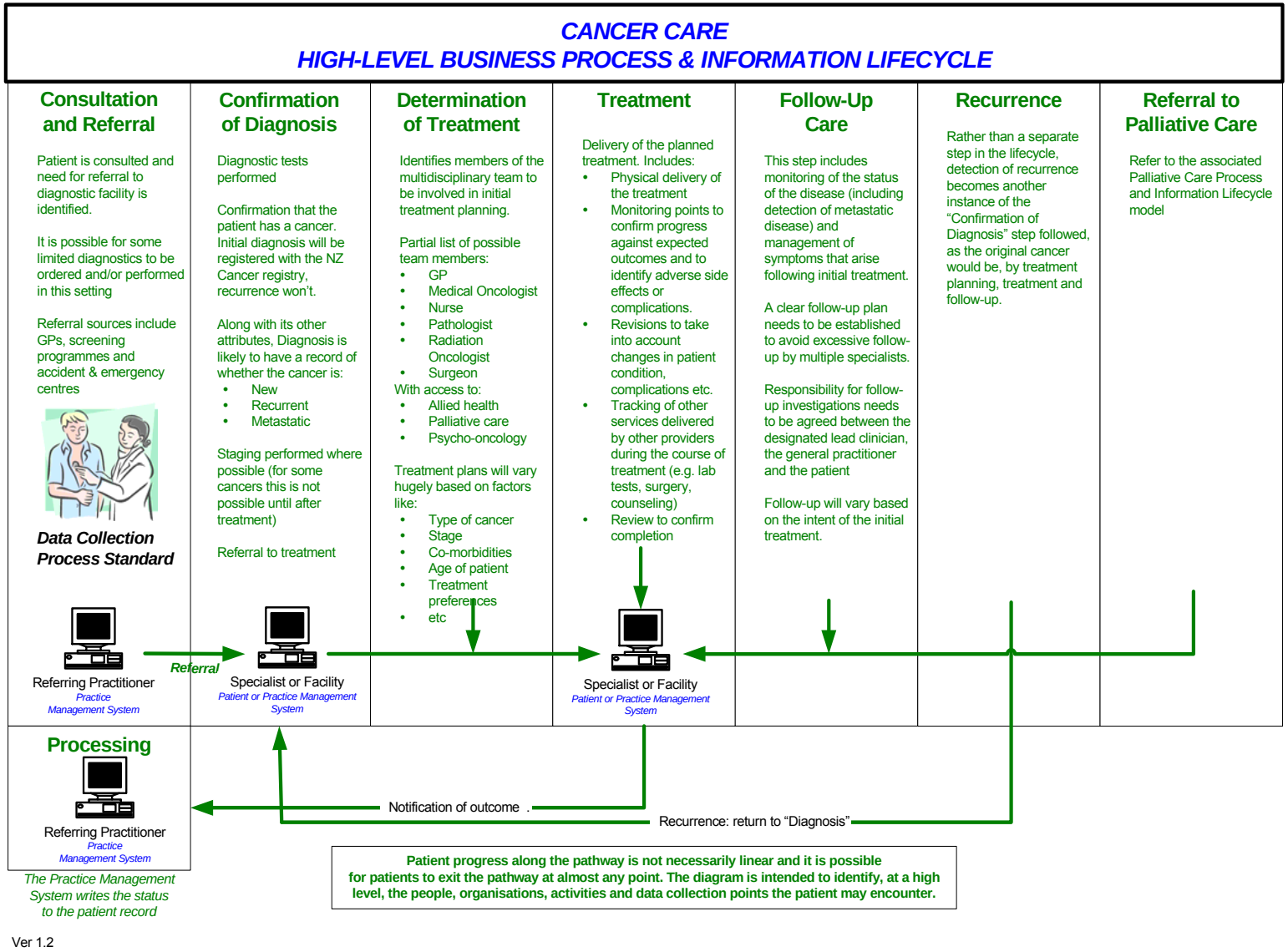

Figure 1: High-level Business Transaction Process & Information Lifecycle

2.3 Cancer Business Process Interviews

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

2.4 Cancer Business Process Map

Following on from the High-level Transaction Process and Information Lifecycle, a business process map was developed to show the cancer care pathway in more detail.

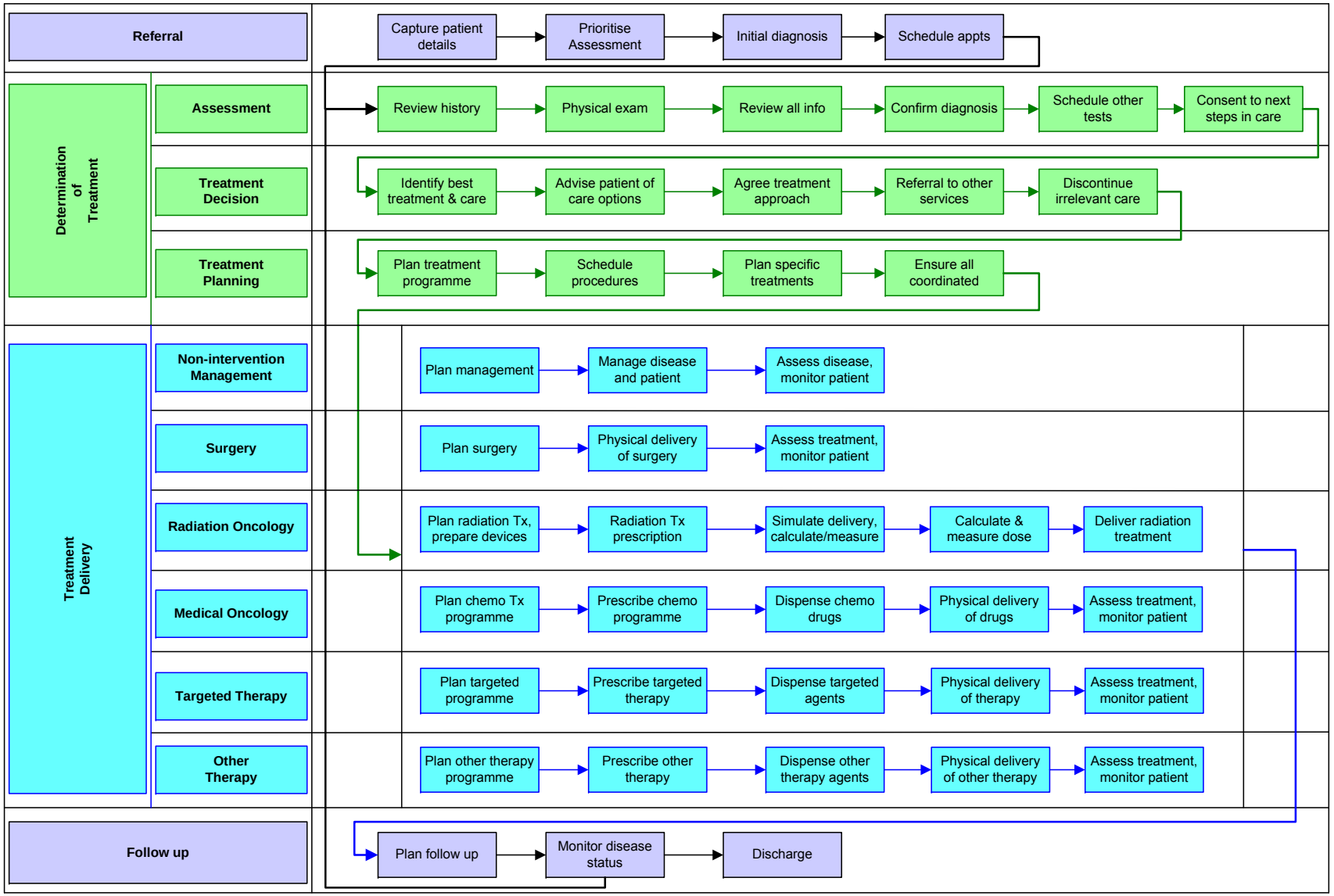

Figure 2: Business Process Mode

3 BUSINESS PROCESSES

3.1 Purpose

This section is a narrative describing the business processes (refer section 3.5) that were introduced in the business process map and which are referenced in the use-cases described in sections 5.1 to 5.5.

The use-cases describe the cancer care lifecycle for a range of common scenarios, across different settings. They help determine the supporting information and information systems requirements. They may provide guidance in the development of the Interim National Core Cancer Data Messaging Standard, and for those intending to implement these standards.

3.2 General Notes

The Standard supports the capture and exchange of core data related to cancer. It does not require that further (lower level) data is captured, however, this is likely to be undertaken by facilities providing cancer 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 will seek alternative opinions from different providers at this point or will decide against treatment altogether and leave the process
- a patient may leave the process at any time. There is currently no method of describing why they have left the process unless a date of death is entered
- it is the responsibility of the health care provider to ensure lawful practice in their respective professions. A list of the current regulations can be found at http://www.legislation.govt.nz.

3.2.1 Leaving the pathway or moving between processes

In addition to moving naturally through the above processes, there is the ongoing ability for a patient to leave the pathway completely or move between processes in a different manner than 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
- begins a new care pathway (for a second primary diagnosis) and undertakes concurrent treatment
- enters or leaves New Zealand at any point in the care pathway. For example, a patient returning to New Zealand having already received partial treatment overseas.

3.3 Key actors

The key health care providers ('provider') supplying cancer diagnostics and treatment within the business process are:

- Medical Oncologists, Haematologists, Radiation Oncologists, Paediatric Oncologists/ Haematologists, Oncology Nurses, Radiation Therapists, Radiographers, Pathologists, Surgeons, General practitioners (GPs),.

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

- General practitioners (GPs), cancer nurse specialists, hospital physicians and other specialists, laboratory pathologists, oncology social workers, psychologists, nurses, palliative care specialists, palliative care generalists.

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:

- **Curative**

  The intent of medical care or treatment that is primarily focussed on eliminating a disease.

- **Diagnosis**

  The various practices used to help identify and describe a disease and broadly falls into two categories:

  - clinical diagnosis, which is based on all of the available information obtained before surgery (e.g. physical examination, radiologic examination, endoscopy etc.);
  - pathological diagnosis, which includes information gained from a pathologist's microscopic examination of a tumour.

- **Diagnostics**

  The various practices used to help identify a disease, especially through the use of specialised imaging equipment (e.g. PET, MRI, CT, X-ray, ultrasound etc) or laboratory analysis (e.g. smear tests, blood markers, bladder-tumour associated urine tests, biopsy etc). Diagnostics may occur at various times, across the care pathway, for the determination of treatment and/or the analysis of the disease response to treatment.

- **Episode of care**

  A period of treatment of an individual, for a given malignancy, where the intent remains the same. It may involve multiple modalities and multiple treatment instances within those modalities. The episode begins with an intention to treat a disease and ends only with relapse / recurrence / progression, intent change or death (i.e. the episode of care is ongoing for a patient in follow-up care, or remission, even though no data is being transmitted to the RCDR).

- **First Specialist Assessment (FSA)**

  In the majority of cases, a FSA is a physical assessment of a patient by a specialist health care provider. In some instances, especially for patients in remote locations, a virtual FSA may take place.

  In some regions, the FSA will be in the form of a consultant-run clinic that includes a number of providers (e.g. registrar, clinical nurse specialist, psychologist, geneticist, pathologist etc), each of whom contributes to the set of skills required for a comprehensive assessment on the day (e.g. coordination, additional diagnostics, psychosocial support etc).

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

  A planned, regular meeting of specialist providers to review the majority of cancer cases. The MDM meeting is a key component in the cancer care pathway that may influence the planning and management of treatment of a cancer case. The MDM can be an important component in:

  - – diagnosis review
  - – treatment planning and management
  - – quality improvement
  - – quality assurance.

  In general, an MDM will be held regularly with a core group of providers (e.g. surgeon, medical oncologist, radiation oncologist, pathologist, radiologist) but may include other providers on a case-by-case basis for specialist areas or complex cases (e.g. haematologist, geneticist, clinical nurse specialists, allied health etc)

  In most instances the MDM occurs either before the first specialist assessment (FSA), or between FSA and treatment. However, not all cancer cases go through the MDM process (e.g. adjuvant

colon, pancreas) and some cases may receive treatment before being discussed at an MDM (e.g. melanoma).

- **Oncology:**
  The branch of medicine that deals with the diagnosis and treatment of cancers. The processes in this document are most concerned with:
  - – surgical oncology: the surgical removal of cancer (hereafter 'surgery')
  - – radiation oncology: treatment of cancer via radiation (e.g. brachytherapy, external beam therapy)
  - – medical oncology: the treatment of cancer via drugs (e.g. chemotherapy)
  - – haematology: the treatment of patients with haematological diseases
  - – paediatric oncology/haematologoy: the treatment of cancer with a particular focus on children.

- **Non-intervention Management**
  The management of a patient through non-interventional methods. A proactive and expectant approach pending a change in the patient's circumstances requiring either intervention or palliative care.

- **Prognosis**
  An idea of the likely course and outcome of the disease based on individual details about the patient and the type, location, stage and grade of the cancer.
- **Palliative**
  An instance of medical care, or treatment, where the intent of care is on lessening the severity of symptoms or on keeping the disease in stasis rather than curing or halting the progression of a disease.

- **Prophylactic**
  Active medical care, or treatment, where the intent is to prevent the onset of a disease or symptom.

- **Referral:**
  The (generally formal) process of handing over the care of a patient, for a particular reason, from one provider to another.
  Referral processes vary across (and within) District Health Boards (DHB). It may take the form of a direct provider-to-provider electronic communication or be passed through a centralised referral office. The actual referral itself may be as structured as a standardised e-referral, a faxed/mailed referral form or a letter; or may also be as informal as a phone call, text message or a conversation in a corridor.
- **Triage:**
  A process of prioritising patients for assessment based on the severity of their condition.

3.5 Business Process

The following business processes outline a general pathway of cancer 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 cancers
- the pathway of each patient is governed by many factors (e.g. disease type, staging, patient condition and physical location etc) and is far more complex and dynamic than can be described or modelled here.

A patient enters the cancer care pathway via a referral for specialist assessment and may exit the pathway at any time, via several methods (e.g. transfer, death or discharge), or continue through the treatment pathway, and out the other side, to follow-up care, remission, and a subsequent discharge from care. As exit may occur at any time, the sub-processes specifically exclude references to the exit methods.

3.5.1 Referral:

The referral process is the initiating step for a patient's journey on the cancer care pathway.

A referral for first specialist assessment (FSA) occurs where a patient has presented to a health care provider (e.g. GP, registrar in an emergency department, hospital ward physician, etc) with symptoms that may indicate a cancer, or where an asymptomatic patient has received abnormal results from a screening process.

Where initial analysis and/or diagnostics indicate the need for specialist assessment the patient is, depending on suspected cancer type, referred to specialist services (e.g. surgeon, oncologist, gynaecologist, urologist etc). This involves a number of key activities including:

- provision of patient details (e.g. personal information, history, existing medications, etc) for clinical and administrative use
- prioritisation of the patient for time to FSA (i.e. triage)
- provision of the initial diagnosis/risk assessment and clinical information used as the basis for the referral (e.g. cytology, histology, x-rays etc)
- arranging any additional diagnostic tests required for FSA (e.g. laboratory tests, imaging).

As well as the initial referral into the cancer care pathway, multiple other referrals may occur along the cancer care pathway (e.g. surgeon to medical oncology, medical oncology to radiation oncology, radiation oncology to surgery etc).

3.5.2 Determination of Treatment:

The determination of treatment is a dynamic section of the pathway that may take place around one specialist assessment or, in a more common scenario, have a number of key points including specialist assessment, further diagnostics and multi-disciplinary team meetings. The determination of treatment includes the following processes:

- assessment
- treatment decision
- treatment planning.

Following the determination of treatment the patient will be treated and then followed up, or referred to other services (e.g. other specialists, palliative care), or discharged from specialist care back to primary care.

3.5.2.1 Assessment:

A patient will generally enter the assessment process via the initial referral but may re-enter this phase, at any time during subsequent stages, due to the diagnosis of progression or relapse/recurrence or the development of a further (new) cancer. The primary goal of the assessment is the confirmation (or refutation) of the suspicion that the patient has a cancer.

The majority of the assessment process is typically undertaken at, or in relation to, an FSA visit. The assessment of some patients may also occur across a second visit (e.g. where a new problem has been identified, or where the results of further diagnostics are returned). The ongoing assessment of the patient continues throughout the entire cancer care pathway.

Activities during an assessment may include:

- discovering what the patient knows about their initial diagnosis, ensuring that the patient is aware of what they are being assessed for and what that assessment process will entail
- reviewing/updating the patient's personal information, clinical history and diagnostic results (e.g. patient demographics, laboratory results, imaging etc)
- reviewing/updating any other medical, family and social history (e.g. medical alerts/warnings, history of cancer in the family, work history that may relate to cancer)

- performing a physical examination
- planning and prescribing any required symptom management (e.g. pain relief)
- discussing and planning, or providing, any social support/counselling
- determining and scheduling any additional required diagnostic and staging tests (e.g. PET, MRI, CT, blood markers etc)
- confirming and recording the most valid diagnosis, including staging (where possible)
- discussing the prognosis, possible next steps in treatment and gaining informed consent to further care/treatment.

The assessment may also incorporate the treatment decision and/or planning.

3.5.2.2 Treatment Decision:

The treatment decision may occur at the time of the FSA or at a later date and, especially in more complex cases, may be informed by MDM advice. The purpose of this process is to identify the best possible course of treatment for the patient, discuss this course with the patient and gain their informed consent on a way forward.

The provider will use all information regarding the disease to identify the best possible treatment based on the specific needs of the patient and the type and stage of the cancer. Key components of the decision include to:

- identify the treatment and care services relevant to the patient and their condition (guided by best practice care for the particular patient clinical circumstances)
- discuss the diagnosis, prognosis, treatment options and intent at the MDM
- discuss the intent of treatment (e.g. prophylactic, curative or palliative) with the patient (and family/support)
- advise the patient (and family/support) of all options for care and treatment, along with any associated benefits and risks
- work with the patient to agree the treatment approach and which care and treatment services will be used
- prioritise other treatments and assessments outside the specialist area (e.g. other branches of oncology, other specialists, dental assessments, speech and language therapist etc)
- provide referrals to any required services in other specialist areas
- discontinue any services and treatments that are no longer relevant.

3.5.2.3 Treatment Planning:

The objective of this process is to plan a coordinated treatment schedule based on the decisions made with the patient in the previous process step.

The provider will plan a treatment programme based on all information gathered to this point regarding the disease and in keeping with the decisions agreed upon with the patient. The provider will schedule procedures in such a way that meets the patient's specific needs, ensures that all treatment is coordinated, and has a phased approach that complies with current best practice.

Details and requirements are specific to each treatment modality and include:

- planning the intent and objectives of the treatment (e.g. prophylactic, curative, palliative etc) and discussing this with the patient
- gaining informed consent for treatment and any specific consent for data collections (e.g. Auckland Breast Cancer Study Group)
- developing a treatment programme that will best meet the objective (e.g. sequencing of surgery, operation plan, radiotherapy course and chemotherapy)
- scheduling any pre-treatment checks and procedures required for specific treatments (e.g. creation of IV access for chemotherapy, dental, audiology and speech language therapy checks prior to radiotherapy, pre-admission clinics for surgery etc)
- prescribing any medication that may be taken prior to, as a part of, or after the treatment delivery (e.g. targeted therapy for appropriate patients, chemotherapy regimens, pain relief)

- making sure that all relevant patient booking and/or admission information is captured (e.g. booking form, health questionnaire, radiation treatment request form)
- ensuring that programmes of care and treatment supervision, which may be provided by several departments, are planned and executed over time and across the range of department specialisations (e.g. audiology appointments, monitoring for toxicity and/or infection).

Scheduling is a key component of treatment planning that continues to occur throughout the lifecycle of the care pathway. It enables effective sequencing of patients through the assessment and treatment pathway. Scheduling of the required care and treatment, including monitoring and revision of bookings is necessary to support a care plan and to gain the best use of limited resource. This is often carried out by clinical nurse specialists, or other key people in the treatment/coordination team, and involves:

- arranging patient bookings for diagnostics, pre-treatment checks or preparation, treatments, follow-up/review/monitoring, etc.
- arranging scheduling (rostering) of the staff and resources required to perform these activities (e.g. chemotherapy day stay beds, time slots on a linear accelerator, booking operating theatres and anaesthetists etc)
- revising bookings in the event of unanticipated changes (e.g. missed appointments, change of patient condition) or revisions to the plan throughout the course of care and treatment.

3.5.3 Treatment Delivery:

The treatment delivery process is concerned with the physical delivery of any treatment appropriate for the patient. The provider tracks the planned services during the physical delivery of treatment and monitors any outcomes.

Where the indicators of treatment success are not as positive as the provider had expected, or if there are any contraindications to further treatment (e.g. infection, toxicity), there may be a need to revise the treatment decision and planning.

Treatment delivery may consist of one or more of the following detailed treatment processes:

- Non-Intervention Management
- Surgery
- Radiation Therapy
- Chemotherapy
- Targeted Therapy
- Other Therapy.

This covers the process and procedures for the delivery of the planned treatment. Considerations include:

- pre-treatment assessment
- physical delivery of treatment
- monitoring points to confirm patient progress against expected outcomes and to identify adverse side effects or complications
- revisions throughout the course of treatment to take into account changes in the patient condition, complications or variations in patient responses
- tracking of other services delivered by other providers during the course of treatment (e.g. laboratory tests, surgery, palliative care, counselling)
- review to confirm completion of care and treatment.

The treatment delivery process is complete when the provider confirms the patient is ready to move into follow-up care.

3.5.3.1 Non-Intervention Management

The non-intervention management process is a proactive period of observation, monitoring and management that may occur between diagnosis (or recurrence/progression) and treatment delivery. Non-intervention management may have curative or palliative intent, and may include:

- planned regular patient observation
- further diagnostics to track the development or progression of cancer
- medical or non-medical management (e.g. symptom management, psychosocial management).

Non-intervention management is a clinical choice to follow an expectant approach pending a change in the patient's circumstances requiring intervention. This differs markedly from a patient being lost in the system (e.g. lost referral) or the personal choice of the patient (e.g. thinking through treatment options).

3.5.3.2 Surgery:

Where surgery is required, the operative procedure is planned, scheduled and performed, and then the patient's post-operative residual disease and condition is monitored.

Surgery processes include:

- planning of surgery (e.g. site, size of tumour, resection margins etc)
- documentation of procedures and processes for the execution of surgery
- liaison with, and scheduling of, other specialists required for the surgery (e.g. anaesthetists, nurse specialists, plastic surgeons etc)
- planning, prescribing and dispensing of any drugs required before or after surgery (e.g. anticoagulants, post-operative pain management etc)
- liaison with, and scheduling of, other specialists required for post-surgery care, diagnostics and/or assessment (e.g. nurse specialists, pathologists, radiologists, oncologists)
- preparation of equipment and other resources required for surgery
- the physical performance of the surgical procedure
- clinical documentation of the outcome of surgery
- the carrying out of post-operative checks and discussions (e.g. explanation of operation, wound check, histology results, referrals to other specialists, plans for follow-up or discharge etc)
- assessment after treatment to provide response evaluation and provision of supportive treatment (e.g. antibiotics), if complications arise.

3.5.3.3 Radiation Therapy:

Where radiation treatment is required, any required devices are prepared, the delivery of radiation is simulated and then the treatment is prescribed. From here, the radiation treatment is calculated and planned, specific appointments are scheduled, and the treatment is delivered.

This involves steps to prepare and safely deliver a course of radiation treatment. These include:

- radiation treatment prescription
- preparation of any required immobilisation devices or moulds
- scheduling of the resources required for treatment appointments (e.g. linear accelerator, superficial X-ray and/or brachytherapy equipment)
- simulation of where the configuration of the radiation fields is planned, to enable accurate delivery of radiation to the target treatment area and to minimise the impact on normal tissues and organs
- calculation and planning of radiation dose distribution (this requires sophisticated physics modeling for measurement and quality assurance of the machine)
- control of linear accelerators for preparing and delivering radiation treatment, including patient positioning and verification, acquiring and viewing images of cancers and surrounding tissue
- preparation and delivery of brachytherapy treatment. This includes positioning of non-radioactive applicators within the treatment site and the loading of radioactive material into the applicators
- preparation and delivery of radioisotope treatment. This includes the preparation of administration devices (e.g. cups, syringes)

- liaison with, and scheduling of, other specialists (e.g. medical oncologists, surgeons, specialist community cancer nurses), which is especially important where treatment is concomitant or closely scheduled
- post-treatment monitoring and assessment to provide response evaluation, toxicity evaluation, the provision of supportive treatment and the discontinuation of specific treatments if complications arise
- documentation of whether the treatment proceeded as planned and, if not, of any changes that were made.

Approaches using newer technology such as intensity modulated and image guided radiation treatments (IMRT and IGRT respectively) require high specialisation of planning and treatment delivery systems.

3.5.3.4 Chemotherapy:

Where a chemotherapy treatment programme is planned, the drugs are prescribed, dispensed, administered and the patient's condition (during and after treatment) is monitored.

Chemotherapy processes include:

- planning of chemotherapy treatment programmes (e.g. adjuvant, neo-adjuvant and therapeutic) based on the disease type
- planning and scheduling of chemotherapy cycles based on the disease type, the specific chemotherapy treatment and the individual patient's needs (e.g. required gaps between cycles, treatments between chemotherapy cycles)
- prescribing of chemotherapy regimens (which may include special authorities)
- dispensing of chemotherapy drugs
- planning, scheduling and carrying out of physical procedures, processes and equipment for the administration of chemotherapy drugs (e.g. patient booking and admission, outpatient clinics, IV equipment etc)
- liaison with, and scheduling of, other specialists required for concomitant care, diagnostics and/or follow-up (e.g. nurse specialists, pathologists, radiation oncologists, surgeons)
- ongoing assessment to provide response evaluation and provision of supportive treatment, or the discontinuation of treatment, if complications arise or the disease does not respond in the expected manner (e.g. infection, toxicity).

3.5.3.5 Targeted Therapy:

Targeted therapy, while not synonymous with hormone therapy, is still largely comprised of hormone therapy.

Where a hormone therapy programme is planned, hormone agents are prescribed, dispensed and administered, and the patient's condition is assessed.

Hormone therapy processes include:

- planning of hormone therapy treatment programmes (e.g. adjuvant, neo-adjuvant and therapeutic)
- prescribing of hormone therapy programmes (which may include the need for special authorities)
- dispensing of hormone therapy drugs
- education of patient around procedures and processes for the self-administration drugs
- discussion with, and documentation for, the patient's general practitioner (GP) regarding the ongoing prescription of any hormone therapy and monitoring of adverse effects
- liaison with, and scheduling of, other specialists where other treatment is required (e.g. surgeons, radiation oncologists)
- ongoing assessment to provide response evaluation and provision of supportive treatment, or the discontinuation of treatment, if complications arise or the disease does not respond in the expected manner (may include education to primary care providers who will provide ongoing assessment).

3.5.3.6 Other Therapy:

Treatments other than surgery, radiotherapy, chemotherapy or targeted/hormone therapy may be used for various intents in the treatment of cancer (e.g. prophylactic, curative, palliative etc). Examples of other therapies include:

- stem cell transplantation (e.g. autologous or allogenic)
- differentiation inducers
- gene therapy
- immunotherapy
- vaccine therapy
- anti-angiogenesis molecule therapy
- apoptosis inducer therapy
- targeted therapy (e.g. small molecule and monoclonal antibody therapies).

The process around other therapies may include (but is not limited to):

- identification and planning of suitable therapy programmes outside of surgery, radiotherapy, chemotherapy or targeted therapy
- planning, prescribing and dispensing of other therapy drugs, where applicable
- procedures and process for the physical administration of the therapy
- liaison with, and scheduling of, other providers involved in physical administration of treatment (e.g. nurses for stem cell transplantation) and/or those providing concomitant treatment (e.g. surgeons, radiation oncologists, medical oncologists etc)
- education of other providers or patients where the therapy is self administered
- assessment during treatment to provide response evaluation, toxicity evaluation, the provision of supportive treatment, or the discontinuation of specific treatments if complications arise or the disease does not respond to treatment in the expected manner
- the provision of special assessment and monitoring following treatment (e.g. haematology treatments may require long periods of inpatient care and high dependency nursing).

3.5.4 Follow-up

The follow-up process is out of scope, as mentioned previously, but is outlined here as it has a direct link to the end of treatment and may result in a loop back to the Determination of Treatment section of the process.

Follow-up occurs after the completion of active intervention and concerns the planning of a structured follow-up schedule as well as the carrying out of such monitoring. The point at which active intervention (including non-intervention management) ends, and follow-up begins, is arbitrary and can vary with local practice. Rather than an extension in the care pathway, any detection of progression or relapse/recurrence (which can, in fact, occur at any time), will result in the care pathway returning back to the “Assessment” stage.

The process around follow-up includes:

- planning, scheduling and the ongoing coordination of a suitable follow-up schedule, which may involve several providers sharing the follow-up care
- monitoring the response of the evaluable disease to treatment (e.g. checking for any progression or the relapse/recurrence of the treated disease)
- evaluating the resolution or development/redevelopment of any adverse effects as a consequence of treatment (e.g. toxicity, secondary cancers, thyroid function, psychosocial issues etc)
- scheduling of required procedures that enable evaluation (e.g. physical examinations, imaging, blood tests, biopsies)
- carrying out of scheduled follow-up assessment.

The health care provider will take into account relevant information from the treatment delivery process to plan an appropriate follow-up schedule for the patient.

The follow-up process has no standard and varies greatly depending on

- disease type and staging
- provider and/or care environment (e.g. variations in public versus private and within DHBs, facilities, departments and from provider to provider)
- patient needs (e.g. patients in a palliative care setting are being monitored there, paediatric patients require special long-term follow-up processes)
- social and personal reasons.

4 INFORMATION FLOW

4.1 Interim National Cancer Core Data Definitions

HISO 10038.3 Interim National Cancer Core Data Definitions is a national set of minimum agreed cancer data to be collected and stored in a consistent manner. This data set has been developed with a sector working group and will, along with this document, form the basis for the National Cancer Core Data Messaging Standard. The Interim National Cancer Core Data Definitions define nine principal entities:

- For each *Patient* there will be one or more *Diagnosis*.
- For each *Diagnosis* there may be one or more *Episode of Care*.
- For each *Episode of Care* there may be one or more instances of treatment. These are:
    - *Non-intervention Management* and/or
    - *Surgery* and/or
    - *Radiation Therapy* and/or
    - *Chemotherapy* and/or
    - *Targeted Therapy* and/or
    - *Other Therapy*.

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

4.2 Interim National Cancer Core Data Messaging Standard

HISO 10038.2 Interim National Cancer Core Data Messaging Standard is a national standard defining the syntax of observation messages, detailing cancer care, that support the processes outlined in this document and their associated data standards. It should be used in conjunction with this document and the *Interim National Cancer Core Data Definitions* document.

For full information on the syntax see the *Interim National Cancer Core Data Messaging Standard* document.

4.3 Future Implementation

The implementation of a a Regional Clinical Data Repository (RCDR) is not in the current scope of these standards, however the sector and Ministry of Health representatives involved in these standards envisage this occurring in the near future.

An implementation document would be required to detail subjects such as:

- Privacy and Security
- Health Message Exchange (HMX)
- Regional Clinical Data Repository (RCDR).

The implementation of privacy and security protection measures is an important factor for all information sharing solutions. Implementation of an RCDR would include further consultation with health professionals, health care consumers, information specialists and legal advisors. Consideration would be given to:

- what data, in addition to the Cancer Core Definitions set, is stored in the RCDR
- consent models, including opt-in or opt-out
- the roles, rights and responsibilities related to accessing or updating information in an RCDR
- the logging of information regarding access and actions.

5 USE-CASES

The use-cases in this section deal with what may be considered 'normal' aspects of the cancer care pathway and how messaging will occur. They are not intended to cover all possible journeys through the cancer care pathway. They are provided as examples only.

Note: The dotted lines at the start and end of episodes of care in these use-cases are indicative of scope start/end only. Whether an episode of care actually ends (i.e with relapse/recurrence/progression, intent change or death), or continues indefinitely, is noted in the process description following the use-case diagram.

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

The following use-case is an example of a single diagnosis with a single episode of care. The patient is a 23-year-old male who has visited a GP with a lump and tenderness in a testicle. A physical examination and ultrasound arranged by the GP results in a suspicion of tumour and a referral to a specialist who confirms the diagnosis and begins the treatment process

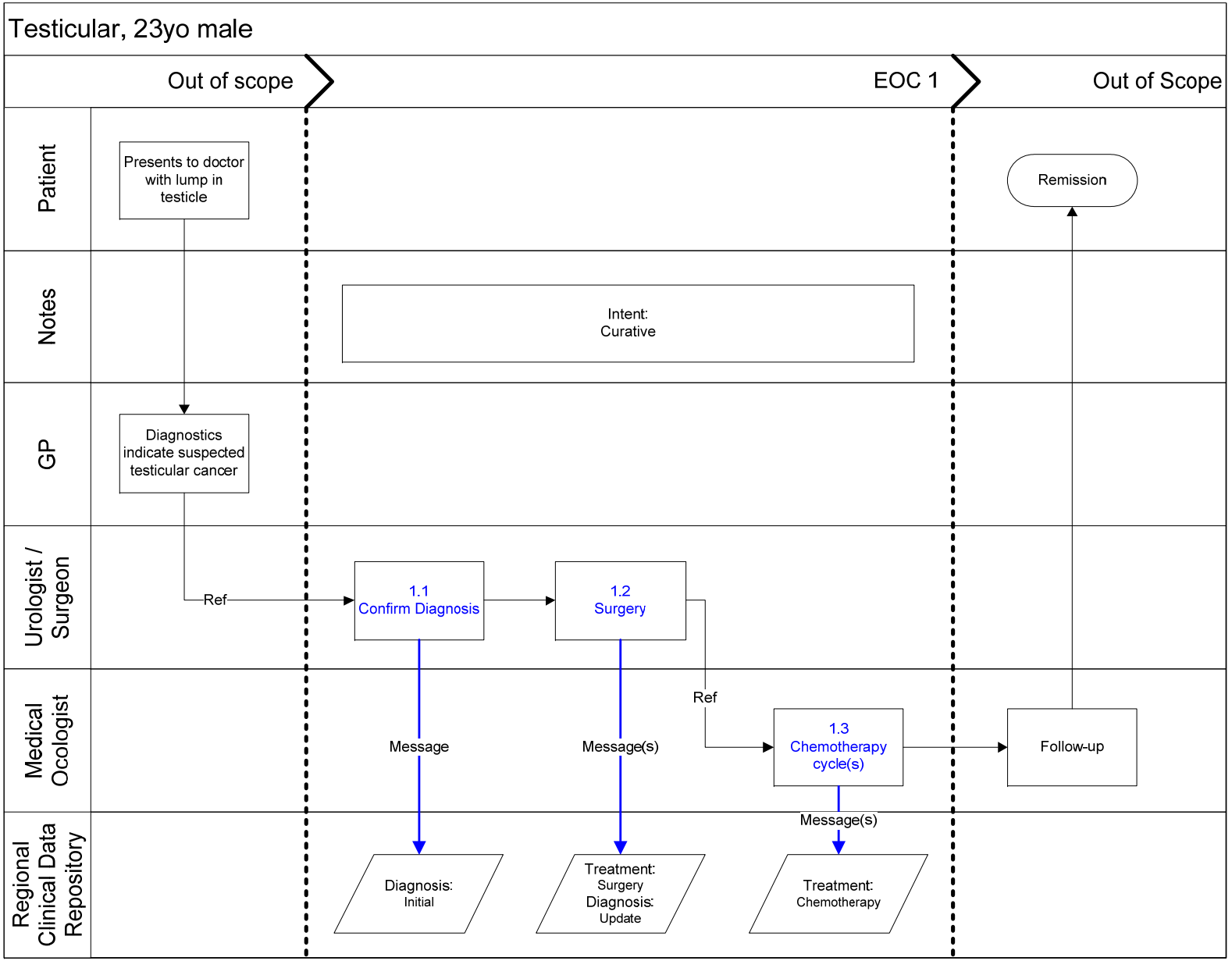

Figure 3: Use-Case 1 – Single Diagnosis, Single Episode of Care

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:

1.1 Confirmation of diagnosis: • referral received by surgeon detailing information, from the GP, about the patient's medical history, diagnostics etc • physical examination and blood markers confirm the suspected clinical diagnosis of testicular cancer • discussion at MDM results in a decision to treat via surgery with subsequent chemotherapy • discussion follows with the patient who gives informed consent. Message from provider system to RCDR regarding patient and (initial) diagnosis details.
1.2 Surgery: • Pre-surgery clinic detailing the treatment and follow-up care • Surgical removal of tumorous testicle • Post-surgery histological pathology confirms a diagnosis of stage II mixed nongerminomatous tumour • Post surgical follow-up to check patient condition and detail next steps in care. Message from provider system to RCDR regarding patient, treatment and (updated) diagnosis details.
1.3 Chemotherapy: • Medical oncologist meets with patient to plan and schedule chemotherapy cycles • Several cycles of chemotherapy are prescribed, dispensed and administered • The response of cancer to treatment is observed and measured and the patient's condition is monitored • A follow-up schedule is planned in consultation with the patient • The episode of care continues. Message from provider system to RCDR regarding patient, treatment and (updated) diagnosis details.

Table 2: Use-Case 1 – Process Steps

5.2 Use-Case 2 – Single Diagnosis, Multiple Episodes of Care

This use-case deals with a 70-year-old male who has visited a GP for an annual health check. One observation of this check-up is a laboratory test showing an elevated prostate-specific antigen (PSA) score. The GP schedules a future check-up for further monitoring. The future check returns a result indicating a rising PSA level and that, alongside the results of a digital rectal exam presents a basis for a referral to a urologist.

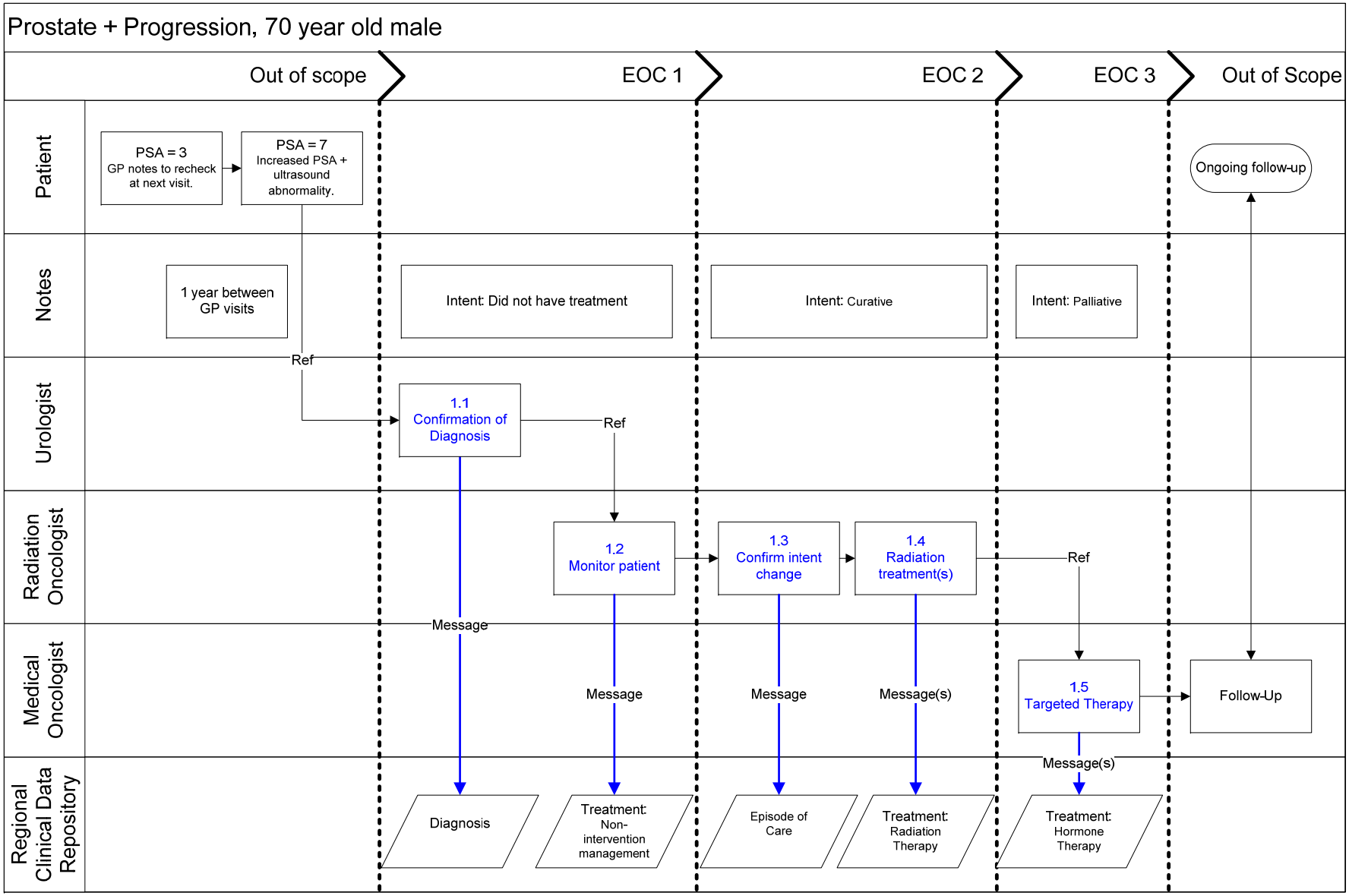

Figure 4: Use-Case 2 – Single Diagnosis, Multiple Episodes of Care

5.2.1 Process Description

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

1.1 Confirm diagnosis: • referral received by a urologist, detailing information about the patient's medical history, diagnostics etc • consultation with patient, with further diagnostics • confirmation of diagnosis via biopsy • discussion with patient about treatment options results in a decision to refer to a radiation oncologist. Message from provider system to RCDR regarding patient and diagnosis details.
1.2 Monitor patient: • radiation oncologist's consultation with the patient, and a multidisciplinary team, results in a decision to monitor the disease status and patient's condition rather than treat. Message from provider system to RCDR regarding patient and treatment details.
1.3 Confirm intent change: • radiation oncologist monitors the disease and finds changes that indicate the need to treat • consultation with the patient results in informed consent to proceed with treatment • change of treatment intent (from 'did not have treatment' to 'curative') results in a new episode of care. Message from provider system to RCDR regarding patient and episode of care.
1.4 Radiation Therapy: • radiation therapy is planned and scheduled • radiation therapy treatment is carried out (e.g. 2 x high-dose radiation brachytherapy treatments, 1 x external beam linear accelerator treatment) • the radiation oncologist monitors the disease status and checks the patient for adverse effects. Message from provider system to RCDR regarding patient and treatment instance details.
1.5 Targeted Therapy: • some time after the last radiation therapy treatment, a referral is received (from the radiation oncologist) detailing progression of the disease • all case details are reviewed by the medical oncologist • a decision is made about whether to treat and palliative intent of treatment is decided • a new episode of care begins (triggered by both the progression and the change of treatment) • targeted therapy is planned, prescribed and dispensed to the patient for self-administration • This episode of care continues indefinitely. Message from provider system to RCDR regarding patient, progression and treatment instance details.

Table 3: Use-Case 2 – Process Steps

5.3 Use-Case 3 – Multiple Diagnoses, Single episodes of Care

This use-case deals with a single patient with two primary diagnoses. These are represented by a use-case split into two respective sections (3a and 3b).

The first case represents the patient presenting to a GP, as a 2-year-old, with a list of symptoms indicating a failure to thrive. Initial blood tests indicate a leukaemia so a referral to a paediatric haematologist is made and an episode of care ensues. Confirmation of diagnosis occurs and treatment via stem cell transplant follows.

After a period of remission, the same patient (now 13 years old) presents to the GP with headaches that may indicate a new malignancy. A new episode of care follows, where the patient is diagnosed with a new malignancy and further treatment takes place.

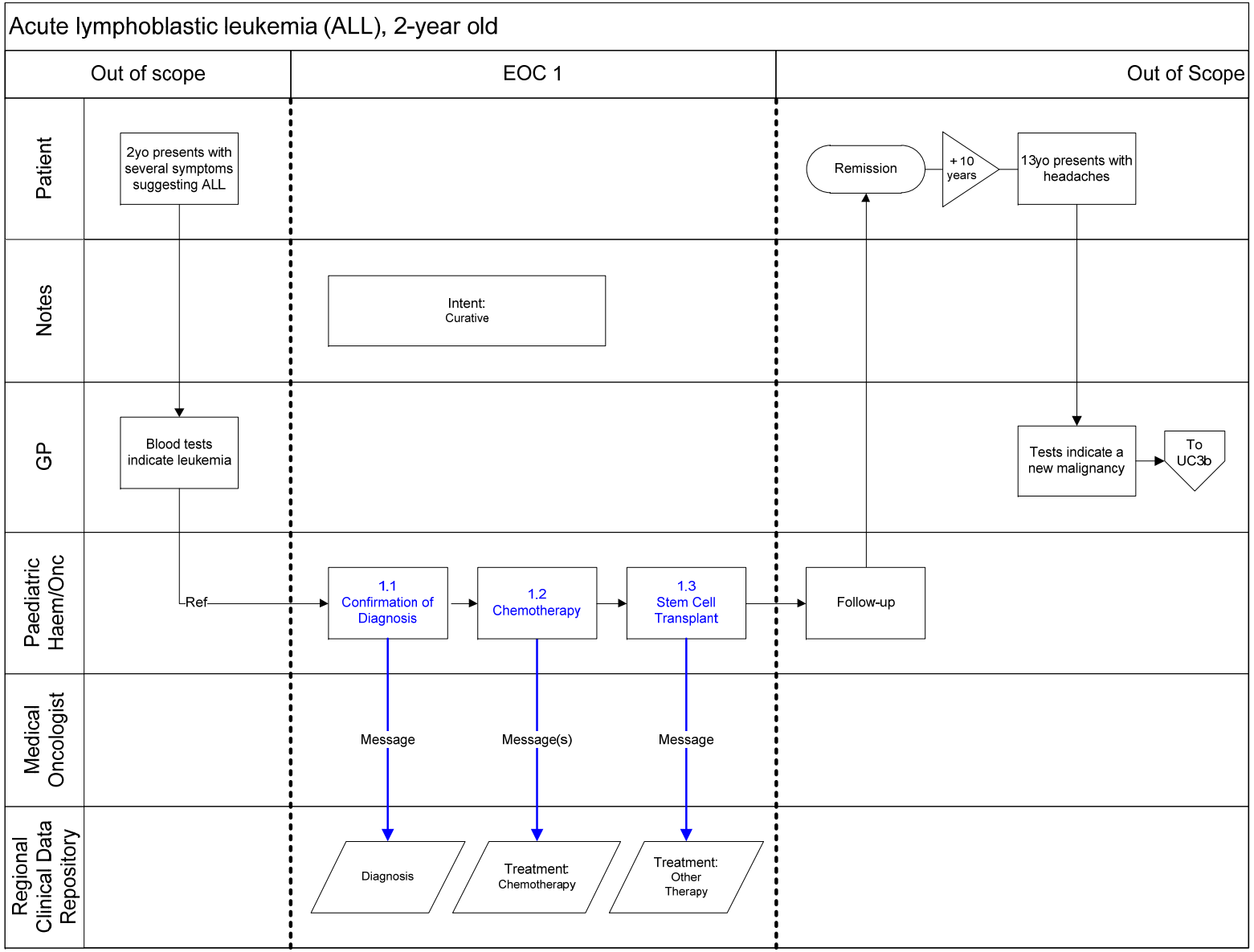

Figure 5: Use-Case 3 (part a) – Multiple Diagnosis, Single Episodes of Care

5.3.1 Process Description (part a)

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

1.1 Confirmation of diagnosis: • referral received detailing information about the patient's medical history and diagnostics etc • consultation with patient's parents takes place, along with further diagnostics • confirmation of diagnosis and staging • discussion with patient's parents results in a decision to treat and informed consent. Message from provider system to RCDR regarding patient and diagnosis details.
1.2 Chemotherapy: • paediatric haematologist plans and schedules a multiagent chemotherapy regimen • the treatment is successfully carried out over a period of 2.4 years • the disease status is assessed and patient is monitored for any adverse affects. Message from provider system to RCDR regarding patient and treatment details.
1.3 Other Therapy: • paediatric haematologist plans and schedules stem cell transplant • the treatment is successfully carried out • the disease status is assessed and patient is monitored for any adverse affects • follow-up care is planned and scheduled • this episode of care continues indefinitely. Message from provider system to RCDR regarding patient and treatment details.

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

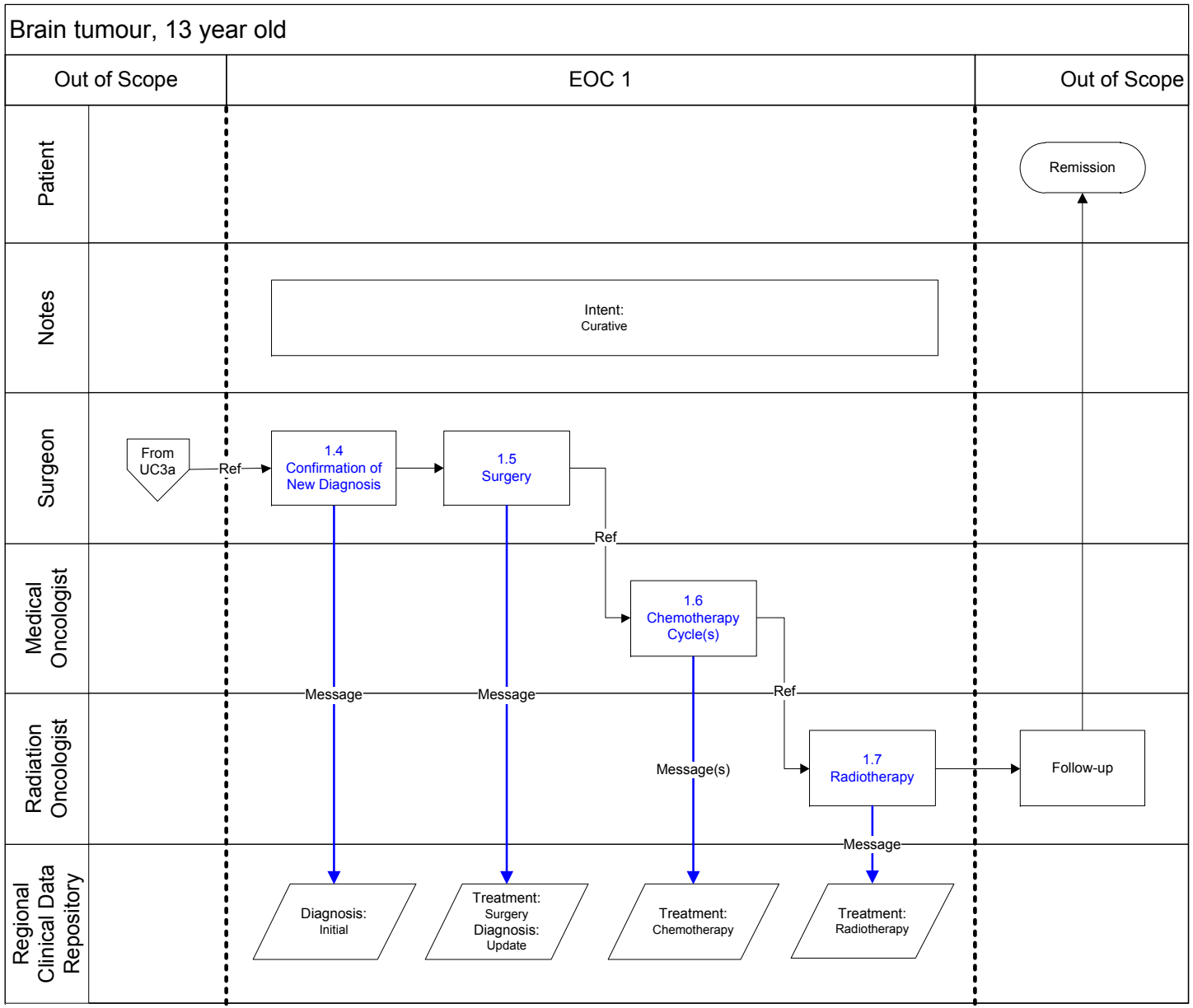

Figure 6: Use-Case 3 (part b) – Multiple Diagnosis, Single Episodes of Care

5.3.2 Process Description (part b)

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

1.4 Confirmation of new diagnosis: • referral received detailing information about the patient's medical history, diagnostics etc • consultation with patient, and the provider of care from the last diagnosis, with the possibility of further diagnostics • confirmation of diagnosis • discussion with patient results in a decision to the treat the patient, with a curative intent, via surgery and chemotherapy. Message from provider system to RCDR regarding patient and diagnosis details.
1.5 Surgery: • pre-surgery clinic detailing the treatment, intent of treatment and follow-up care • surgical removal of the tumour • post surgical assessment to check patient condition, discuss surgery outcomes and detail next steps in care. Message from provider system to RCDR details patient and treatment details.
1.6 Chemotherapy: • chemotherapy is planned and scheduled • chemotherapy treatment is carried out (e.g. 6 x 4-weekly cycles) • monitor disease status and check the patient for adverse effects • discuss next steps of treatment with patient and surgeon. Message from provider system to RCDR regarding patient and treatment instance details.
1.7 Radiotherapy • external beam radiotherapy to the remainder of the primary tumour and the surrounding area • post treatment follow-up to check patient condition and detail next steps in care • follow-up care is planned and scheduled • this episode of care continues indefinitely (concurrent to the ALL episode)**.** Message from provider system to RCDR regarding patient and treatment instance details.

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

5.4 Use-Case 4 – Single Diagnosis, Multiple Episodes of Care

This use-case deals with a single patient who has one primary diagnosis but goes through two episodes of care.

The first episode of care represents the curative episode of care for a 45-year-old patient who has presented to a GP with a bowel obstruction that leads to the discovery of other colorectal cancer symptoms. A referral to specialist care initiates an episode of care consisting of surgery and chemotherapy. The subsequent discovery of disease progression results in a change of intent and a new episode of care. This second episode ends with the patient's death.

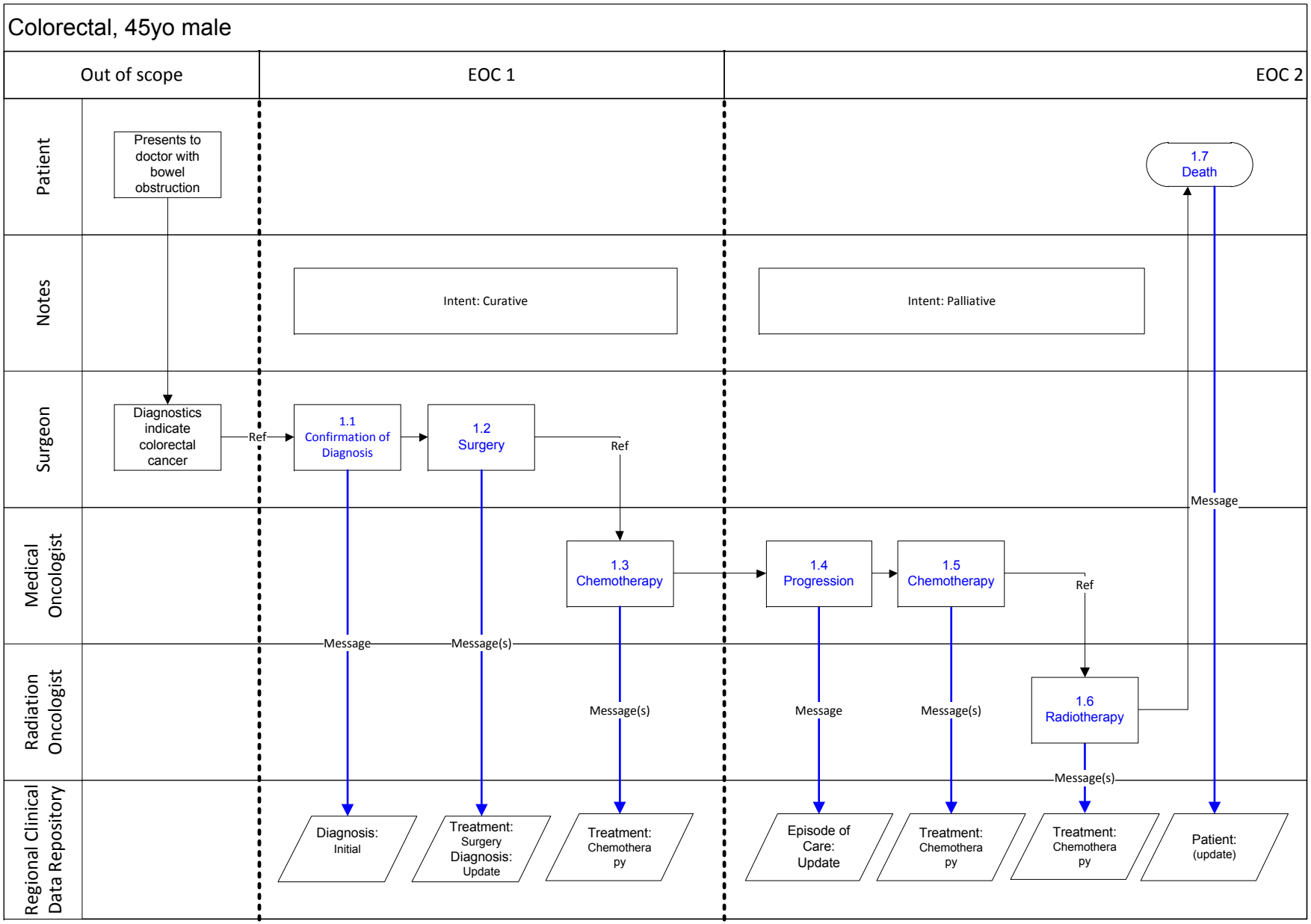

Figure 7: Use-Case 4 – Single Diagnosis, Multiple Episodes of Care

5.4.1 Process Description

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

1.1 Confirmation of diagnosis: • referral received detailing information about the patient's medical history, diagnostics etc • consultation with patient with the possibility of further diagnostics • confirmation of diagnosis • discussion with patient results in a decision to the treat the patient, with a curative intent, via surgery and adjuvant chemotherapy. Message from provider system to RCDR details patient and diagnosis.
1.2 Surgery: • Pre-surgery clinic detailing the treatment, intent of treatment, follow-up care and scheduling of chemotherapy • Surgical removal of the tumour • Post surgical follow-up to check patient condition and discuss next steps in care. Message from provider system to RCDR regarding patient and treatment details.
1.3 Chemotherapy: • chemotherapy is planned and scheduled • chemotherapy treatment is carried out (e.g. 6 x 4-weekly cycles) • monitor disease status and check the patient for adverse effects. Message from provider system to RCDR regarding patient and treatment details.
1.4 Confirmation of progression: • diagnostics confirm disease progression • consultation with patient to discuss change of intent, resulting in a decision to change intent from curative to palliative • disease progression and intent change trigger the end of one episode of care and the start of a new one. Message from provider system to RCDR details patient and episode of care changes.
1.5 Chemotherapy: • further chemotherapy, of a different type, is planned and scheduled • chemotherapy treatment is carried out (e.g. 3 x 4-weekly cycles) • monitor disease status and check the patient for adverse effects. Message from provider system to RCDR details patient and treatment details.
1.6 Radiotherapy: • external beam radiotherapy to the remainder of the tumour and the surrounding area • post treatment follow-up to check patient condition and detail next steps in care**.**

Message from provider system to RCDR regarding patient and treatment instance details.
1.7 Patient dies: • patient dies between expected radiation therapy treatments • the second episode of care ends with the patient death. Message from provider system to RCDR regarding patient details (i.e. date and cause of death).

Table 6: Use-Case 4 – Process Steps

5.5 Use-Case 5 – Multiple Diagnosis, Single Episodes of Care (extended)

This use-case deals with a single patient who has two primary diagnoses and goes through an extended episode of care.

The first episode of care represents an extended period (10 years) of palliative non-intervention management, and subsequent chemotherapy, for a 50-year-old female patient who has presented to a GP with symptoms indicating chronic lymphocytic leukaemia (CLL).

During the post-treatment follow-up period, the patient presents to the medical oncologist with a breast lump. A physical examination is undertaken, subsequent biopsy results confirm a new diagnosis (of breast cancer), and a new episode of curative care begins for that specific disease.

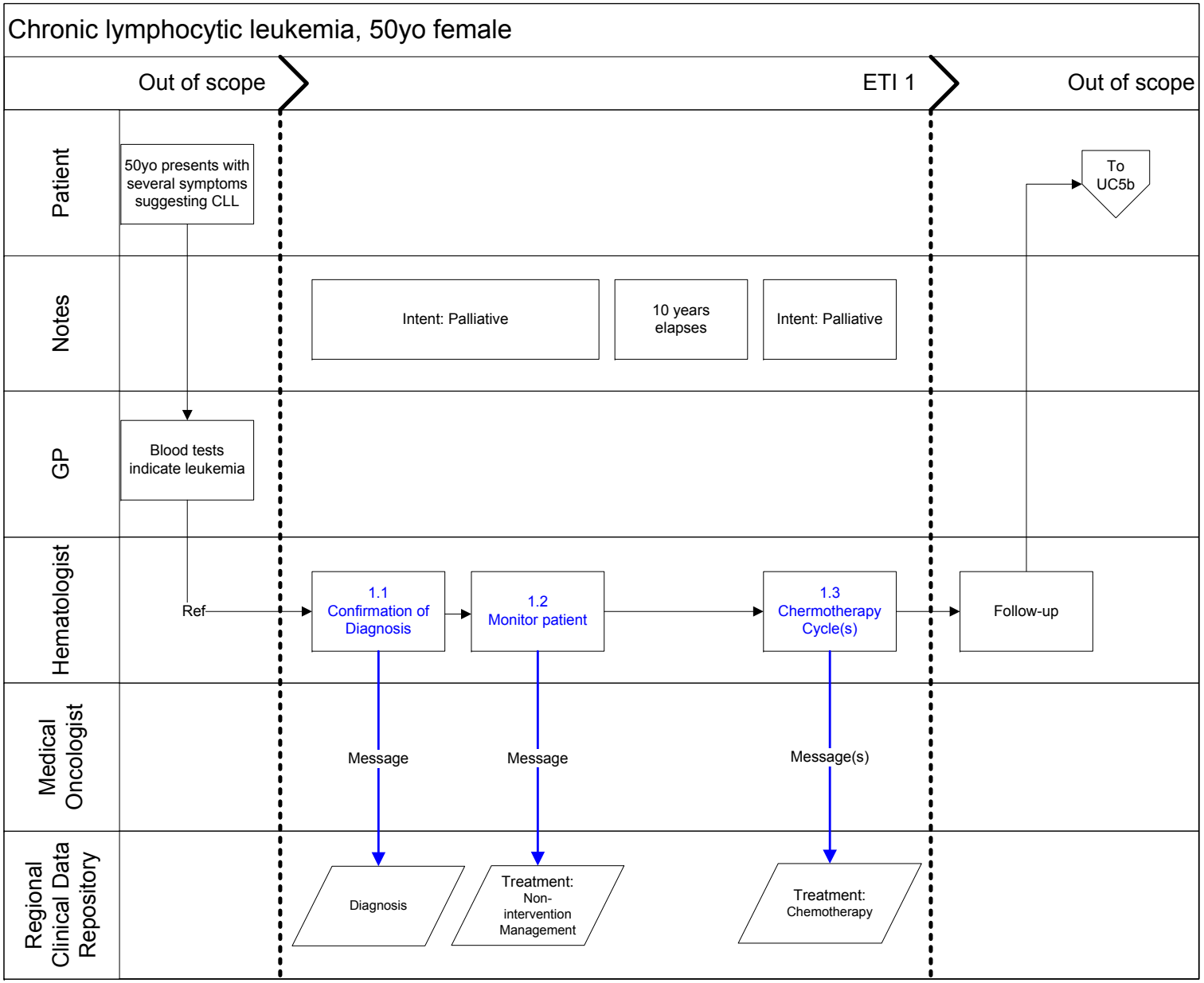

Figure 8: Use-Case 5 (part a) – Multiple Diagnosis, Single Episodes of Care (extended)

5.5.1 Process Description

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

1.1 Confirmation of Diagnosis: • referral received detailing information about the patient's medical history, diagnostics etc • consultation with patient, with the possibility of further diagnostics • confirmation of diagnosis • discussion with patient about the disease results in a decision to monitor the patient, over an extended period, with an intent to treat palliatively when required. Message from provider system to RCDR details patient, diagnosis and intent of treatment.
1.2 Monitor patient: • haematologist monitors the patient regularly for changes in disease status • consultation with the patient during this period revolves around disease status and patient comfort • changes in the disease status, after ten years, results in a decision to commence chemotherapy. Message from provider system to RCDR details patient and treatment details regarding non-intervention management.
1.3 Chemotherapy: • chemotherapy is planned scheduled • chemotherapy treatment is carried out (e.g. 3 x 8-weekly cycles) • monitor disease status and check the patient for adverse effects • plan and schedule follow-up visits • this episode of care continues indefinitely. Message from provider system to RCDR details patient and treatment details.

Table 7: Use-Case 5 (part a) – Process Steps

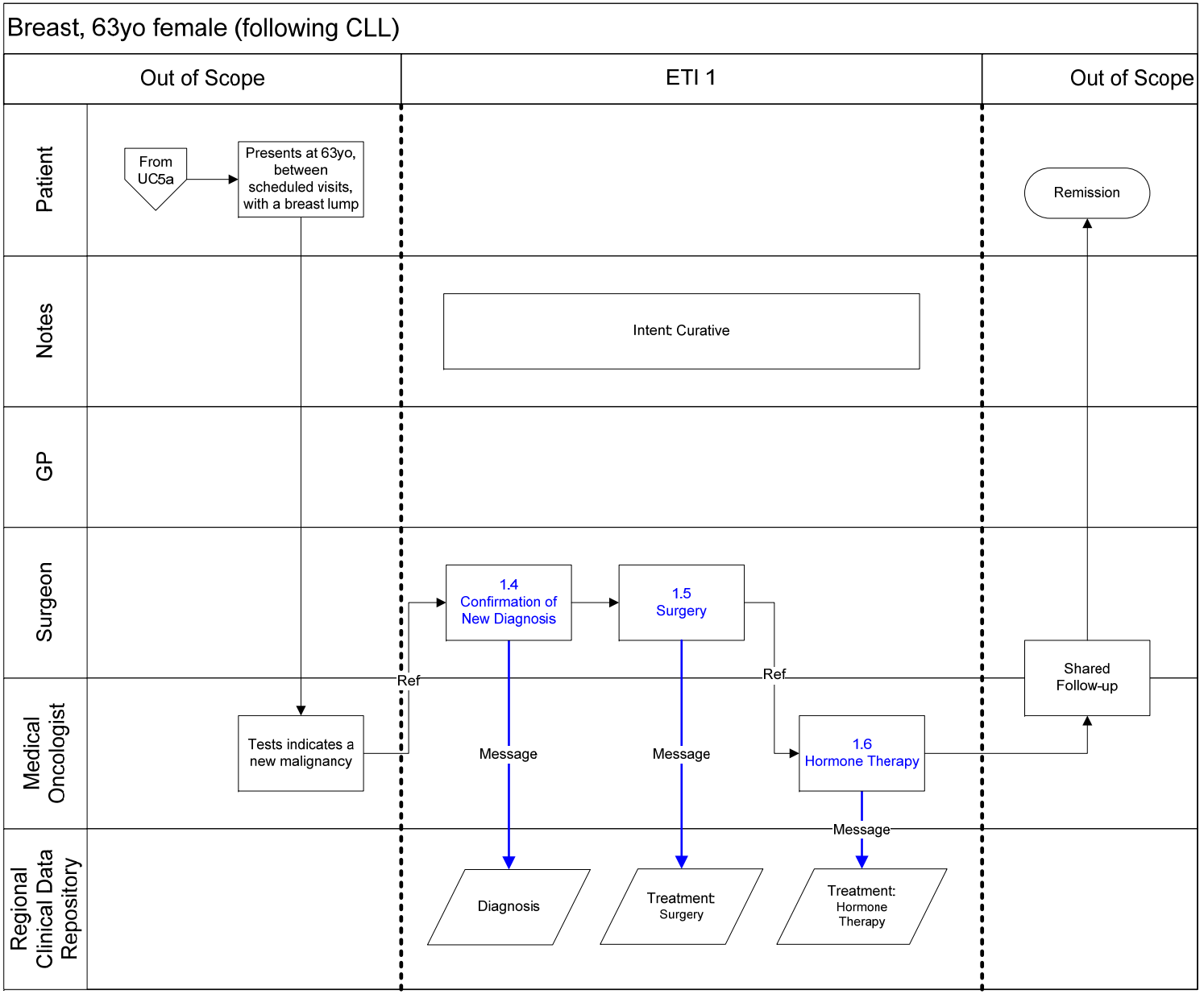

Figure 9: Use-Case 5 (part b) – Multiple Diagnosis, Single Episodes of Care (extended)

5.5.2 Process Description

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

1.4 Confirmation of diagnosis: • referral received detailing information about the patient's medical history, diagnostics etc • consultation with patient, and the provider of care from the last diagnosis, with further diagnostics (including a biopsy) • confirmation of breast cancer diagnosis via biopsy pathology • discussion with patient results in a decision to the treat the patient, with a curative intent, via surgery and chemotherapy. Message from provider system to RCDR details patient, diagnosis and intent of treatment.
1.5 Surgery: • pre-surgery clinic detailing the treatment, intent of treatment and follow-up care • successful surgical removal of the tumour • post surgical follow-up to check patient condition and detail next steps in care. Message from provider system to RCDR details patient and treatment details.
1.6 Targeted therapy: • targeted therapy is planned and prescribed • GP is advised and educated around prescribing and monitoring processes • patient is educated in regards to hormone therapy self-administration • this episode of care continues indefinitely (concurrently with the CLL episode). Message from provider system to RCDR details patient and treatment details.

Table 8: Use-Case 5 (part b) – Process Steps

APPENDIX A – GLOSSARY

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

Term	Definition	Reference
Adjuvant	Treatment, given after surgery, where all detectable disease has been removed but where there remains a statistical risk of relapse due to occult disease.	National Cancer Institute www.cancer.gov
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.	National Cancer Institute www.cancer.gov
Brachytherapy	A type of radiation therapy in which radioactive material sealed in needles, seeds, wires, or catheters is placed directly into or near a tumour.	National Cancer Institute www.cancer.gov
Business Process	A collection of related, structured activities or tasks that produce a specific service or product (serve a particular goal) for a particular customer or customers.	
Cancer	A term for diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems.	National Cancer Institute www.cancer.gov
Care Pathway	The entire process of diagnosis, treatment and care that a patient goes through.	
Chemotherapy	Treatment that uses drugs designed to destroy or prevent further growth of cancer cells	National Cancer Institute www.cancer.gov
Clinical	Having to do with the examination and treatment of patients.	National Cancer Institute www.cancer.gov
Concomitant	Occurring or existing at the same time as something else. In medicine, it may refer to a condition a person has or a medication a person is taking that is not being studied in the clinical trial he or she is taking part in.	National Cancer Institute www.cancer.gov
CT	A series of detailed pictures of areas inside the body taken from different angles. The pictures are created by a computer linked to an x-ray machine. Also called CAT scan.	National Cancer Institute www.cancer.gov
Curative	Treatment with the intent of tending to overcome disease and promote recovery.	www.medical-dictionary.com
Cytology	The study of cells using a microscope.	National Cancer Institute www.cancer.gov
Data element	A single piece of data, e.g. first name, last name, etc.	HISAC Glossary

Term	Definition	Reference
Data set	Collection of data groups used for specific purposes.	HISAC Glossary
Diagnosis (clinical)	The result of the process of identifying a disease (such as cancer) from its signs and symptoms.	National Cancer Institute www.cancer.gov
Diagnosis (pathological)	The result of the process of identifying a disease (such as cancer) from 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 by means of their symptoms or signs (clinical diagnosis) and/or its structural and functional manifestations (pathological diagnosis).	www.medical-dictionary.com
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
Digital signature	A digital signature is data appended to (or a cryptographic transformation of) a data unit, to prove the source and integrity of the data unit and to protect against forgery.	Health Network Code of Practice
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/hiso-2010
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
Dose	The amount of medicine taken, or radiation given, at one time.	National Cancer Institute www.cancer.gov
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	A period of treatment, for a given malignancy, where the intent remains the same. It may involve multiple treatments and multiple instances of treatments within those modalities. The episode ends only with relapse, intent change or death (i.e. the episode continues for a patient in follow-up care, even though no data is being transmitted to the RCDR).	10038.3 Interim National Cancer Core Data Definitions
External beam	A method for delivering a beam of high-energy x-rays to a patient's tumour.	www.radiologyinfo.org
Facility	A single physical location from which health goods and/or services are provided.	Refer facility code table at www.nzhis.govt.nz
First Specialist Assessment	The first assessment by a specialist medical practitioner for a particular referral.	NZHIS Glossary

Term	Definition	Reference
Follow-up	Monitoring a person's health over time after treatment.	National Cancer Institute www.cancer.gov
FSA	See 'First Specialist Assessment'.	
General Practitioner	An appropriately qualified and registered medical professional, with knowledge and skills to provide personal, family, whanau, and community orientated comprehensive general practice care.	Royal NZ college of General Practitioners
GP	See General Practitioner.	
Haematologist	A doctor who has specialised in haematology. A haematologist's work includes the care and treatment of patients with haematological diseases.	
Haematology	The branch of internal medicine, physiology, pathology, clinical laboratory work, and pediatrics that is concerned with the study of blood, the blood-forming organs, and blood diseases	
Health Message Exchange (HMX)	A system that manages the flow of messages to and from parties participating in a business process where information is exchanged.	ePharmaceutical Standard www.ithealthboard.health.nz/hiso-2010
Health Network Code of Practice	Released in 2002, amended October 2006, the Health Network Code of Practice details the security practices needed to comply with the Health Information Privacy Code for health providers and health and disability information users.	SNZ HB 8169:2002
HISO (2010)	Health Information Standards Organisation (2010). A group is to support 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/hiso-2010
Histology	The study of tissues and cells under a microscope.	National Cancer Institute www.cancer.gov
HL7	Health Level 7 – an application protocol for electronic data exchange in healthcare environments.	www.HL7.org
HMX	Health Message Exchange.	Epharmaceutical Standard www.ithealthboard.health.nz/hiso-2010
Hormone Therapy	Treatment that adds, blocks, or removes hormones. Also called endocrine therapy, hormone therapy, and hormone treatment.	National Cancer Institute www.cancer.gov
Health Practitioner Index (HPI)	A national standard that provides identifiers to uniquely describe the registered practitioner, health care worker, delivery location and facility or organisation who authorises a health transaction.	http://www.ithealthboard.health.nz/hpi
ICD-10	The international standard diagnostic classification for all general epidemiological, many health management purposes and clinical use.	www.who.int/classifications/icd/en/

Term	Definition	Reference
Imaging	In medicine, a process that makes pictures of areas inside the body. Imaging uses methods such as x-rays (high-energy radiation), ultrasound (high-energy sound waves), and radio waves.	National Cancer Institute www.cancer.gov
Informed consent	A process in which a person is given important facts about a medical procedure or treatment before deciding whether or not to participate. It also includes informing the patient when there is new information that may affect his or her decision to continue.	National Cancer Institute www.cancer.gov
Interim Standard	Standards are initially published as 'Interim' standards. After they have been implemented, and evidence of them being fit-for-purpose is provided, they are republished as Full standards	
Medical Oncologist	A doctor who specializes in diagnosing and treating cancer using chemotherapy, hormonal therapy, biological therapy, and targeted therapy.	National Cancer Institute www.cancer.gov
Medical Oncology	The practice of diagnosing and treating cancer using chemotherapy, hormonal therapy, biological therapy, and targeted therapy.	
Message	Data elements combined in a single entity and formatted in such a way as to be able to be sent between two parties and to then be able to retrieve each data element.	HISAC Glossary
MRI	A procedure in which radio waves and a powerful magnet linked to a computer are used to create detailed pictures of areas inside the body.	National Cancer Institute www.cancer.gov
Modality	A method of treatment. For example, surgery and chemotherapy are treatment modalities.	National Cancer Institute www.cancer.gov
MoH	Ministry of Health – the NZ Government's principal agent and advisor on health and disability.	www.moh.govt.nz
Multi-disciplinary Team (MDM)	A treatment planning approach in which a number of doctors (and sometimes other providers) who are experts in different specialties review and discuss the medical condition and treatment options of a patient. Also called tumour board review.	National Cancer Institute www.cancer.gov
National Health Index (NHI)	The NHI holds the following information: name (including alternative names such as maiden names), NHI number, address, date of birth, sex, New Zealand resident status, ethnicity; date of death, and flags indicating any medical warnings or donor information. Clinical information is not recorded on the NHI.	www.nzhis.govt.nz
National Health Index (NHI) number	A unique identifier that is assigned to every person who uses health and disability support services in New Zealand.	www.nzhis.govt.nz
Neo-adjuvant	Treatment given as a first step to shrink a tumour before the main treatment is given.	National Cancer Institute www.cancer.gov
Non-intervention	A proactive period of observation, monitoring	10038.3 Interim National Cancer

Term	Definition	Reference
Management (NIM)	and management that may occur between diagnosis (or recurrence/progression) and treatment delivery.	Core Data Definitions
Oncology	The study of cancer.	National Cancer Institute www.cancer.gov
Other therapy	Treatments other than surgery, radiotherapy, chemotherapy or hormone therapy may be used for various intents in the treatment of cancer. See *Interim National Core Cancer Data Definitions* for further information.	
Palliative	Treatment with the intent of relieving the symptoms and reduce the suffering caused by cancer and other life-threatening diseases.	National Cancer Institute www.cancer.gov
Pathologist	A doctor who identifies diseases by studying cells and tissues under a microscope.	National Cancer Institute www.cancer.gov
PET	A procedure in which a small amount of radioactive chemical is injected into a vein, and a scanner is used to make computerised pictures of areas inside the body where the glucose is used. Also called positron emission tomography scan.	National Cancer Institute www.cancer.gov
Prognosis	The likely outcome or course of a disease; the chance of recovery or recurrence.	National Cancer Institute www.cancer.gov
Prophylactic	A form of treatment with intent to prevent or protect.	National Cancer Institute www.cancer.gov
Provider	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. In this document provider always refers to, unless otherwise specified, a person registered as a health care provider.	ePharmaceutical Standard www.ithealthboard.health.nz/hiso-2010
Radiography	The use of x-ray (radiograph) to help physicians diagnose and treat medical conditions.	www.radiologyinfo.org
Radiation Oncologist	A doctor who specializes in diagnosing and treating cancer using radiation (In NZ these specialists may also prescribe and treat with chemotherapy or hormone therapy).	National Cancer Institute www.cancer.gov
Radiation Oncology	The practice of diagnosing and treating cancer using radiation.	National Cancer Institute www.cancer.gov
Radiation Therapist	A member of a skilled team of health professionals, working under supervision of a radiation oncologist, who treat patients using radiation.	www.wnmeds.ac.nz
Referral	The intent to transfer care of a patient, in part or in whole, by one health care provider to another health care provider.	ePharmaceutical Standard www.ithealthboard.health.nz/hiso-2010
Referring specialist	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	ePharmaceutical Standard www.ithealthboard.health.nz/hiso-

Term	Definition	Reference
	care provider.	2010
Resection margins	The distance between the tumour and the edge of the tissue.	www.breastcancer.org
RCDR (Regional Clinical Data Repository)	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	National Health IT Plan www.ithealthboard.health.nz
Sector	The Health and disability sector.	ePharmaceutical Standard www.ithealthboard.health.nz/hiso-2010
Specialist	An individual health provider who administers specialist treatment or advice.	ePharmaceutical Standard www.ithealthboard.health.nz/hiso-2010
Staging	The extent of a cancer in the body. Staging is usually based on the size of the tumor, whether lymph nodes contain cancer, and whether the cancer has spread from the original site to other parts of the body.	National Cancer Institute www.cancer.gov
Standard	A consensus based document that is developed by a balanced expert committee taking into consideration input received through public comment consultation. Standards are generally widely applied and have high status.	HISAC Glossary
Surgeon	A doctor who removes or repairs a part of the body by operating on the patient.	National Cancer Institute www.cancer.gov
Surgery	A procedure to remove or repair a part of the body or to find out whether disease is present. An operation.	National Cancer Institute www.cancer.gov
System message	A message for computer system consumption that is automatically initiated by a trigger event, e.g. electronic notification receipt of a prescription order by a HMX, which transmitted it to the originator of the prescription order, i.e. without intervention by any user.	ePharmaceutical Standard www.ithealthboard.health.nz/hiso-2010
Targetted therapy	Targeted therapy is a general term that refers to a medication or drug that targets a specific pathway in the growth and development of a tumour.	
Therapeutic	Having to do with treating disease and helping healing take place.	National Cancer Institute www.cancer.gov
Transfer	The movement of a patient from one health care provider or facility to another. This may or may not involve a geographical movement.	
Treatment	Medical or surgical management of a patient.	www.medical-dictionary.com
Triage	The sorting out and classification of patients to determine priority of need and proper place of treatment.	www.medical-dictionary.com

APPENDIX B – CORE CANCER CARE ENTITIES