

New Zealand Cancer Health Information Strategy



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Foreword

The *New Zealand Cancer Plan* sets out a plan of action to deliver better, faster cancer care to all New Zealanders. One of the key enablers of this Plan is access to timely, accurate and comprehensive information. Better information supports better, more empowered decision-making; not just for clinicians, policy makers and researchers but also for patients, when they decide on a cancer pathway that best meets their individual needs.

The New Zealand health sector is operating in an age where expectations concerning information are high. New technologies foster an expectation of access to real-time and accurate information at the touch of a button. Like its international counterparts, the New Zealand health sector has some way to go before it can realise this vision. Information is currently created and stored by a plethora of local practitioners, clinics, hospitals and non-government providers. Building a view of a patient is therefore very manual and resource intensive, and establishing a reliable and accurate picture across a cancer type, region or demographic group is very challenging.

The *New Zealand Cancer Health Information Strategy* sets the direction for the sector over the next five years. It is a pragmatic approach to achieving the vision of *comprehensive, accessible and accurate information to support the delivery of quality care across the cancer patient pathway*. It is built on the premise that there is no ‘silver bullet’ solution to achieving this goal. It requires commitment from everyone working in the cancer sector to change the way they capture, treat and share information at all stages of the pathway.

Dr Andrew Simpson
National Clinical Director Cancer
Ministry of Health

The *New Zealand Cancer Health Information Strategy* sets out a national approach to organising information for patients and clinicians. It will create an environment where clinicians can track patient care pathways, and patients can better understand what stage of their treatment journey they are on.

Having high-quality and reliable information not only supports better information on treatment outcomes but also helps to strengthen the relationship between clinicians and their patients.

When a person is diagnosed with cancer, their natural reaction is often to research and access information about possible treatment options and likely outcomes. Treating cancer can result in many months (and possibly years) of different therapies and health care follow-up. In this situation, how can consumers and their families be sure that they are accessing the best information about their situation? How can they keep connected to the health system at every step along the care pathway?

The National Health IT Board acknowledges this Strategy as an important building block of the wider health information ecosystem, known as Connected Health. The principle of person-centred health information, which is fundamental to Connected Health, underpins this Strategy.

Graeme Osborne
Director, National Health IT Board and
Information Group
Ministry of Health

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Introduction

Purpose of this Strategy

The purpose of the *New Zealand Cancer Health Information Strategy* is to:

- define a cohesive vision for cancer health information in New Zealand (the Vision)
- align with the *National Health IT Plan*¹ and enable the *New Zealand Cancer Plan 2015–2018*² (the Cancer Plan)
- detail strategies and key activities for achieving the Vision.

‘Cancer health information’ includes all information relevant to the cancer patient pathway. It includes information that all New Zealanders can expect to receive about cancer prevention, cancer health trends and prevalence. It also includes information relevant to groups within New Zealand that have specific cancer information needs; for example, patient support information and research.

The Strategy is a short conceptual document that focuses on principles rather than specific solutions/systems. It provides:

- a framework that supports consistency of access to quality care with a whole pathway view encompassing primary, secondary and tertiary care, and is inclusive of child, adolescent and young adult cancers, palliative care and survivorship
- guidance on priorities for improving the quality of cancer information over a five-year timeframe
- guidance on the alignment of activities over a five-year timeframe, to avoid duplicated efforts/investment.

This Strategy will be used to inform national, regional and local development and investment in cancer health information-based initiatives.

Background

The vision of the Cancer Plan is better, faster cancer care. The Plan aims to improve cancer outcomes for all New Zealanders, irrespective of their ethnicity, gender, locality or socioeconomic status, by allowing them to access services that will reduce their risk of developing cancer, enable their cancer to be detected earlier and provide them with high-quality cancer treatment quickly.

The impact of cancer is much higher for Māori than for the general population. To improve cancer outcomes for Māori, the Cancer Plan is guided by the overarching framework and aspirations set out in the Māori Health Strategy, *He Korowai Oranga*,³ and *Equity of Health Care for Māori: A framework*.⁴

1 Ministry of Health. 2010. *National Health IT Plan*. Wellington: Ministry of Health.

2 Ministry of Health. 2014. *New Zealand Cancer Plan: Better, faster cancer care 2015–2018*. Wellington: Ministry of Health.

3 Ministry of Health. 2014. *He Korowai Oranga*. Wellington: Ministry of Health.

4 Ministry of Health. 2014. *Equity of Health Care for Māori: A framework*. Wellington: Ministry of Health.

The Cancer Plan's overarching goals are to:

- equitably, effectively and sustainably meet the future demand for cancer services
- maintain a high quality of care and improve the quality of life for people with cancer
- ensure fiscal responsibility.

A key enabler of the Cancer Plan is information technology systems that support the consistency and quality of information. The Plan states that by 2018 the Government expects that:

- there will be timely access to comprehensive and accurate patient-level data
- cancer information will be consolidated.

Enabling patients to access their own information online is a core element of the *National Health IT Plan*. This Strategy will support improvements in the quality and range of information available to patients. Patient portals and shared care plans will make it easier for patients to access their cancer information, engage actively in their health care and be effectively supported by a multi-disciplinary team.

Since early 2000, several projects have identified a lack of complete, integrated and consistent cancer information, and the resulting impediment to monitoring and improving patient outcomes and quality of health care. Although there have been a number of attempts to achieve a cohesive vision for cancer information over the years, none have been fully implemented.

Improving the quality of cancer information is an ongoing important priority for the National Health IT Board (NHITB), the Ministry of Health (the Ministry), district health boards (DHBs) and the wider sector. In February 2014, the Central Cancer Network undertook a stocktake of cancer-related information projects and identified at least 30 projects under way (both cancer-specific and in the wider health sector) relevant to this Strategy. At a national level, this includes the National Patient Flow Programme. At a regional level, DHB projects are investigating better support for multidisciplinary meetings, e-referrals, cancer-specific patient administration systems and the data definitions and messaging standards.

These individual projects represent a significant investment; however, there is no national plan linking them with a broad strategic outcome. The lack of a national plan means that there is no certainty that the projects currently under way are those that are the most important ones to do right now, or that will produce deliverables that complement one another. The multitude of projects also perpetuates the problem of inconsistently captured data, which affects accessibility.

Stakeholders and interested parties

Figure 1 shows key stakeholders and parties in New Zealand with an interest in cancer information, and their corresponding needs.

Figure 1: Stakeholder groups and high-level information needs



Context

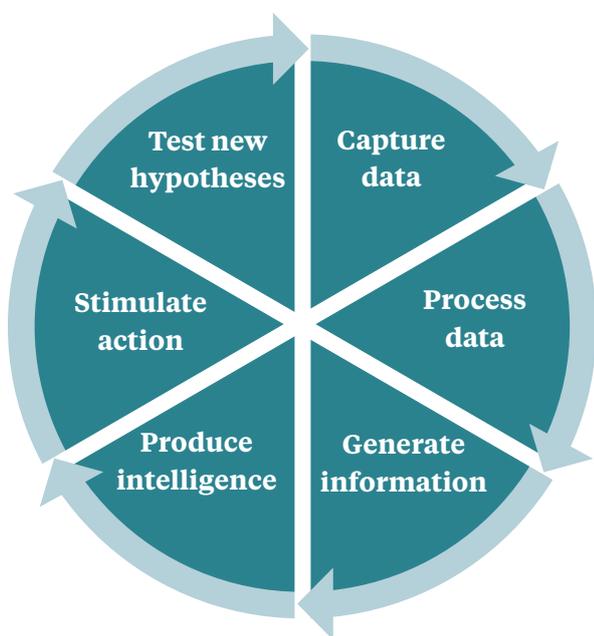
What makes good cancer information?

Globally, various health, and cancer, information strategies have been developed with the aim of establishing comprehensive patient records and accurate and timely cancer intelligence. Most have arrived at the conclusion that there is no single technology solution that will solve cancer information problems. Rather, a robust information model is required to underpin the systems that capture, hold and produce cancer information.

The United Kingdom National Health Service's *An Intelligence Framework for Cancer* outlines a useful example of an information model; it describes the development of 'cancer intelligence' via the following steps:

- capturing activity – the individual actions or interventions about which information is collected
- recording and processing data – ensuring that the interventions are captured and stored in a secure and consistent manner
- generating information – aggregating the data to provide comparable information on cancer services
- producing intelligence – analysing, interpreting and communicating the information
- stimulating action – using the intelligence to improve services
- formulating and testing new hypotheses – using the data and information to generate new knowledge.⁵

Figure 2: Information model used in *An Intelligence Framework for Cancer*



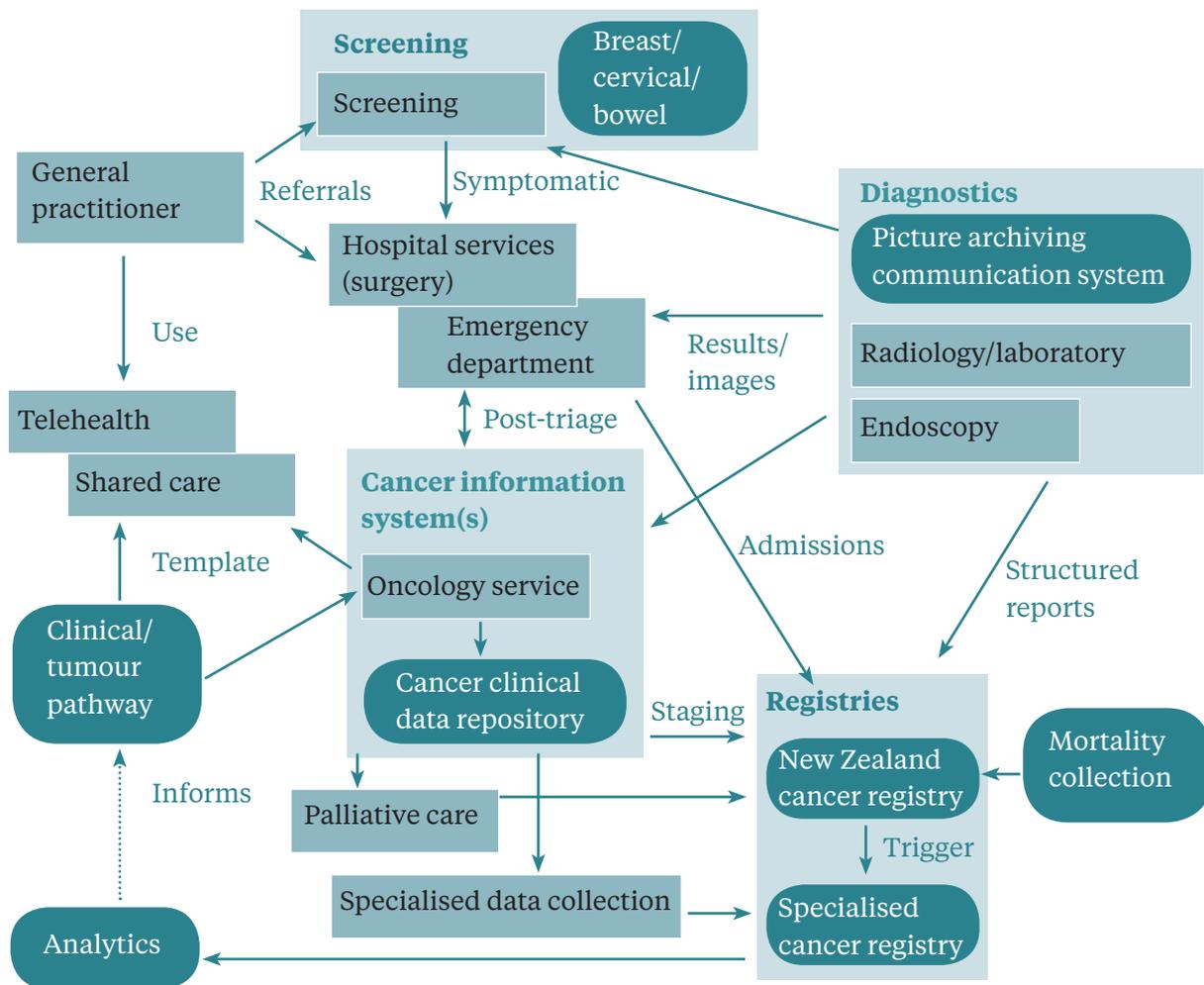
This model may be applied in the New Zealand context. As shown below, the capture of data in New Zealand is fragmented across a plethora of systems, all capturing elements of a patient record in different ways. Until this step of the intelligence cycle is addressed, the sector will not be able to easily generate information or produce intelligence.

⁵ NHS. 2011. *An Intelligence Framework for Cancer*. London: National Health Service, p 14.

The current state of New Zealand cancer health information

Figure 3 provides a conceptual overview of how cancer patient information is currently captured in New Zealand. It shows the plethora of national, regional and clinic-specific systems that all contain elements of a patient record. Although complex in its own right, this conceptualisation is still missing the true extent of (non-linked) databases within each DHB (represented by the dark rounded boxes). It is also missing cancer information that is captured in paper format.

Figure 3: A conceptual model of current national cancer data flows



Source: Ministry of Health's Information Group, Investment and Planning.

Progress has been made in standardising and linking information across DHBs so that health providers may form a single view of each patient. For example, clinical data repositories (CDR) now contain a nationally agreed core set of clinical information in each of the four regions. However, there is still a long way to go before comprehensive, electronic and accessible patient records become the norm. Achievement of this will require significant collaborative effort across all service providers (government and non-government).

Vision and strategic objectives, principles and interventions

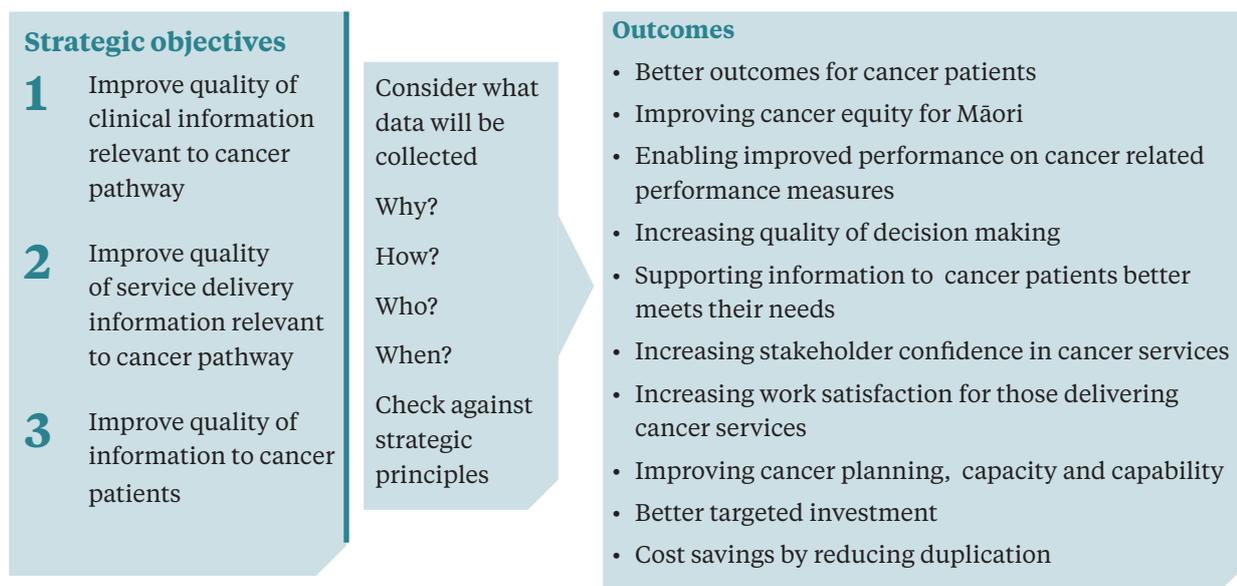
Vision

The vision of the Strategy is to enable the Cancer Plan, and to deliver comprehensive, accessible and accurate information to support the delivery of quality care across the cancer patient pathway.

Strategic objectives

The strategic objectives and outcomes of the New Zealand Cancer Health Information Strategy are illustrated below.

Figure 4: New Zealand Cancer Health Information Strategy strategic objectives



Strategic principles

The following guiding principles underpin this Strategy.

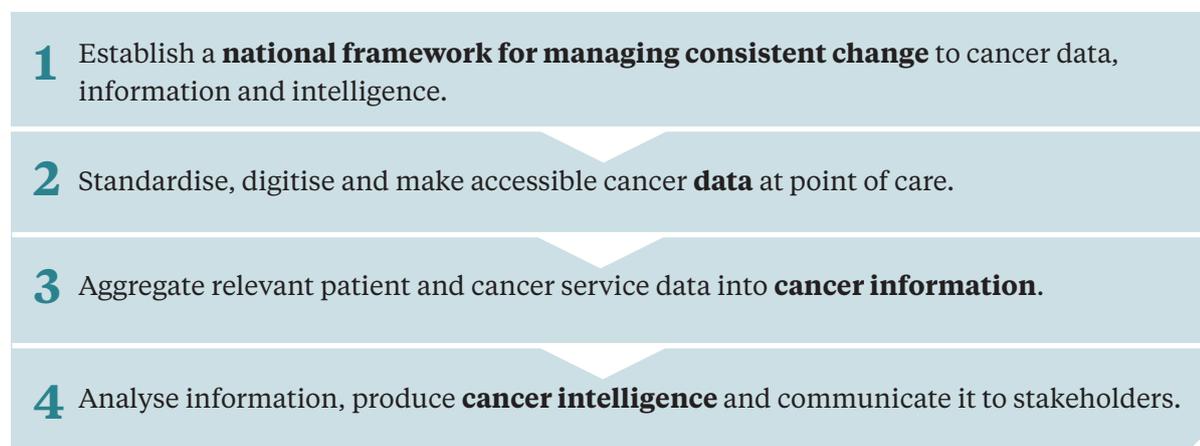
- Stakeholders' needs for cancer health information are understood and supported.
- Collection of patient-specific cancer health data occurs at the point of care wherever possible, and is integrated with patients' health records.
- Duplication of cancer health data is minimised.

- Ethnicity data is collected according to the *Ethnicity Data Protocols for the Health and Disability Sector*.⁶
- Standardised data definitions are adopted including the National Cancer Core Data Standards (HISO 10038.1-3) and the National Specialist Palliative Care Data Standard (HISO 10039)).
- National Health IT Board endorses the Systematised Nomenclature of Medicine – Clinical Terms (SNOMED CT)⁷ as the required system of terminology for point of care applications. SNOMED CT must be used as the system of clinical terminology used to capture cancer health information at point of care.

Strategic interventions

Figure 5 presents four strategic interventions that have been designed to deliver the strategic objectives. In essence, these interventions comprise the Strategy itself. They apply across all stages of the intelligence framework outlined in Figure 2. Implementing these interventions will require a commitment from all stakeholders. The Ministry recommends the implementation take place over a five-year period.

Figure 5: New Zealand Cancer Health Information Strategy strategic interventions



The next section outlines the process for implementing these interventions in more detail.

⁶ Ministry of Health. 2004. *Ethnicity Data Protocols for the Health and Disability Sector*. Wellington: Ministry of Health.

⁷ SNOMED CT is the comprehensive system of clinical terminology distributed in New Zealand by the Ministry of Health and required in all clinical information systems.

Implementation

Approach

The Ministry will implement this Strategy in a phased, prioritised and pragmatic way, taking into consideration the overarching strategic goals. Prioritising the work will ensure the complexities of the New Zealand cancer sector and the current resource constraints do not prohibit change.

National alignment and transparency of cancer information projects is critical.

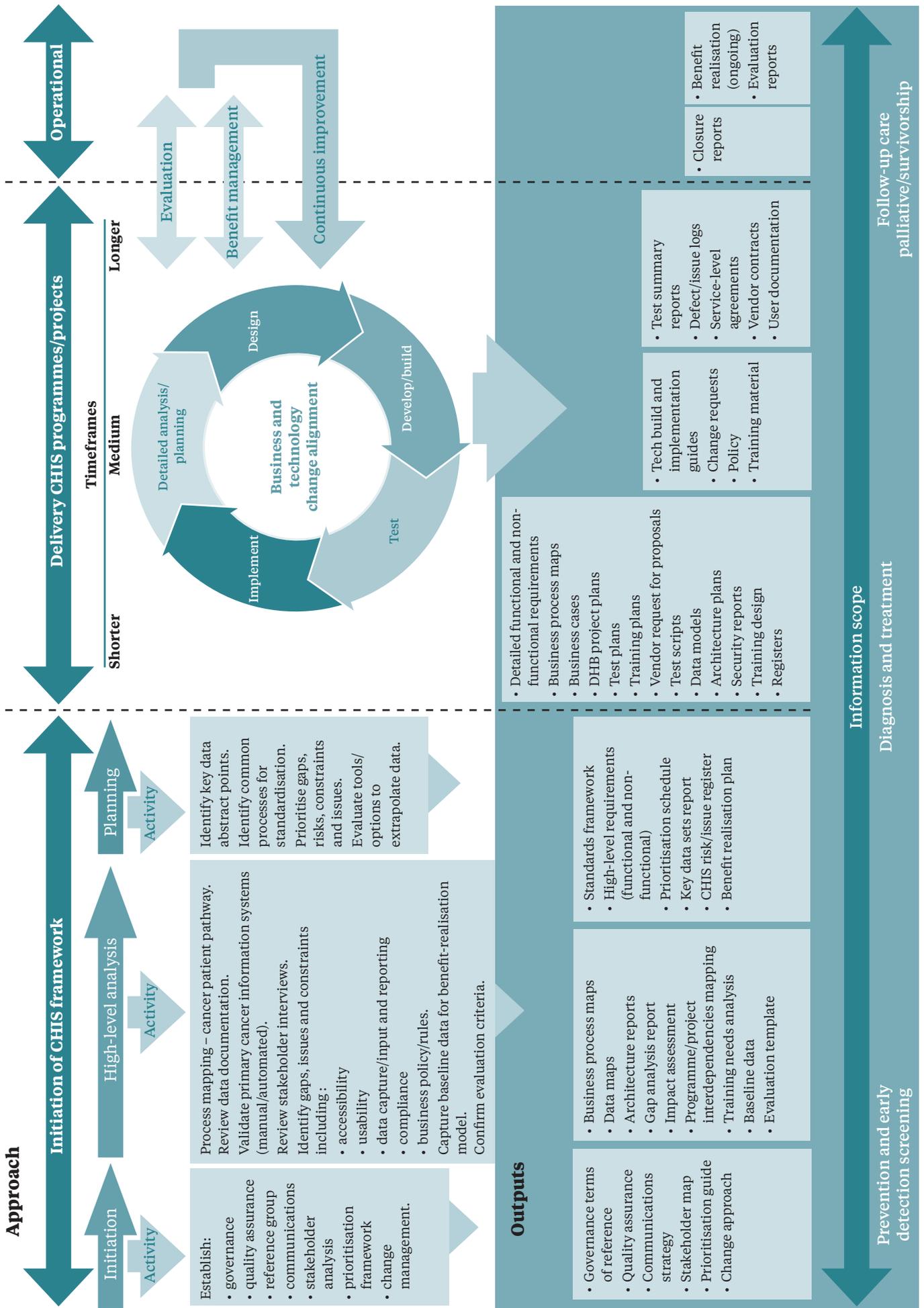
Collaboration will standardise data and processes, and remove duplication of effort. Ultimately, related projects will leverage effectively from each other, resulting in further standardisation and alignment.

Delivery framework

Figure 6 presents the delivery framework for the Strategy. This provides a cohesive approach for implementation and national visibility for the relevant work activities. All projects implementing change to how cancer information is managed are relevant to this Strategy.

The Ministry will revalidate the information captured in the numerous cancer information reviews undertaken over previous years during the analysis phase. This information has assisted many of the programmes already under way and provides a rich source of information in itself.

Figure 6: New Zealand Cancer Health Information Strategy delivery framework



Immediate next steps

The following activities facilitating implementation of the Strategy will commence in 2015–16.

1. **Governance:** a strategy governance board will be established to provide national visibility and decision-making based on agreed priorities.
2. **Prioritisation:** a prioritisation model will be developed to assist the board's decision-making, and ensure we are applying resources to the most needed areas and that changes are aligned to agreed strategic outcomes.
3. **Quality assurance:** business analysis and architecture services will be engaged to design a national approach to data standards and align systems at local, regional and national levels.
4. **Alignment:** identification and mapping of all programmes and projects delivering cancer information improvements will be completed. This will provide national visibility, identify potential duplication of resources and interdependencies between programmes/projects, and improve sequencing. Greater national visibility will create opportunities for the DHBs, regional cancer networks (RCNs) and the Ministry to benefit from each other's work.
5. **Benefit management:** the cross-functional business groups, RCNs and DHBs will capture baseline data to enable the Ministry to measure and track improvements resulting from the Strategy.
6. **Work activities:** work activities will commence under the work streams detailed in the following section.

These activities will support the delivery of the Strategic Interventions outlined above for 2016–17 and beyond.

Work programme for analysis before implementation

Introduction

Analysis work will result in a set of national requirements for standardisation, digitisation, aggregation and reporting of key data points along the cancer pathway.

This output will be used to scope the detailed work programme, provide baseline data on which improvements for the Strategy can be measured and inform governance to enable prioritisation of work.

Rationale

It is accepted that the cancer patient pathway is not necessarily linear; it can vary depending on the patient's entry point into the health system, diagnosis, treatment and outcome.

Analysis work will take these complexities into consideration and ensure work progresses in a timely manner by focusing on standardising the key points of the cancer patient pathway.

Analysis work will include identifying sources of the key points of data, revisiting the Health Information Standards Organisation (HISO) National Cancer Core Data Standards and Tumour Data Standards and ensuring cancer information management aligns with the National Patient Flow Programme.

The existing published data standard is about consistency in the cancer data set collected as part of the clinical process. The new standards resulting from the Strategy will be published in the relevant national data standards and protocol documentation, such as the HISO Standards and the Ministry's Ethnicity Data Protocols.

Responsibility

Regional cancer networks, DHBs and the Ministry will collaborate nationally to undertake the analysis. In doing so, they will link to and expand on work already completed. Development of the cancer data standards will be incorporated into existing and new projects where there are interdependencies.

Timeline

The analysis work will be phased, tackling the key points of the care pathway that provide the most needed information. The Ministry anticipates that improved standardisation in how we capture, access and extrapolate cancer data will be managed under multidisciplinary meeting (MDM), staging, comorbidity and ethnicity work streams.

Table 1 details high-level timeframes for phase 1 of the Strategy.

Table 1: New Zealand Cancer Information Strategy Phase 1 timeframes

Phase 1	Start	Finish
Publish the strategy	1 July 2015	21 August 2015
Establish the governance	1 July 2015	2 September 2015
Complete high-level analysis/process mapping	1 July 2015	30 November 2015
MDM work stream	23 October 2015	1 June 2017
Staging work stream	1 December 2015	30 January 2017
Comorbidity work stream	1 December 2015	30 January 2017
Ethnicity work stream	18 January 2016	24 February 2017
Cancer Data Standards work stream	1 December 2015	31 March 2017
Aggregation and reporting work stream	1 July 2016	28 April 2017
Communication work stream	1 July 2015	3 July 2017

Appendix 1: Stakeholder groups that contributed to this Strategy

Auckland Radiation Oncology	National Cancer Programme, Cancer Programme Steering Group
Breast Cancer Aotearoa Coalition	National Cancer Programme, Cancer Treatment Advisory Group
Cancer Control New Zealand	National Cancer Programme, Hei Ahuru Mowai: National Maori Cancer Leadership Group
Cancer Non-Governmental Organisations (CANGO)	National Cancer Programme, National Cancer Consumer Representative Advisory Group
Cancer Nurses College of New Zealand Nurse's Organisation	National Cancer Programme, Tumour Stream Working Groups
Cancer Society New Zealand	National Health Board, Information Group
District Health Boards	National Health Board, National Radiology Advisory Group
District Health Board Cancer Nurse Co-ordinators	National Health Board, National Screening Unit
Health Quality and Safety Commission New Zealand	National Health IT Board
Health Promotion Agency	National Health IT Board, Consumer Panel
Health Research Council of New Zealand	National Health IT Board, National Information Clinical Leadership Group
IBM, NZ	New Zealand Breast Cancer Foundation
Leukaemia and Blood Cancer New Zealand	New Zealand Cancer Registry Board
Medtech Global	New Zealand Hospital Pharmacists' Association
Melanoma Network of New Zealand Incorporated	Orion Health Limited
Midlands Health Network	Palliative Care Council of New Zealand
Ministry of Health, Bowel and Prostate Cancer Team	Patients First
Ministry of Health, Cancer Services Team	Pegasus Health Limited
Ministry of Health, Elective and National Service Team	Royal Australasian College of Surgeons
Ministry of Health, Maori Health	Royal New Zealand College of General Practitioners
Ministry of Health, Maori Health Service Improvement	Regional Cancer Networks
Ministry of Health, Sector Capability and Implementation Information Management Governance Group	St George's Cancer Care Centre
	University of Otago, Faculty of Medicine

Glossary

Term	Meaning
Cancer pathway (or Cancer patient pathway)	The patient's journey from the initial suspicion through investigations, diagnosis and treatment. For the purposes of the Cancer Plan 2015-18, includes prevention and early detection, investigation and diagnosis and follow up care.
Clinical data repository (CDR)	Four regional data repositories containing a nationally agreed core set of clinical information, and additional clinical data to be determined by each region.
Clinical workstation	Single, secure web-based system that enables clinicians to view integrated patient information. The four DHB regions are working towards having the same regional clinical workstation.
Connected health	An umbrella term for the IT systems and environments that securely share health information via telecommunications.
District health boards (DHBs)	Responsible for providing or funding the provision of health services in their district.
DHB Cancer Nurse Coordinators	Specialist nursing positions employed by DHBs to provide focused support to cancer patients. Ensure that patient experience of their cancer care is as smooth as possible as well as acting as a specialist resource for colleagues and a hub for information sharing.
Faster Cancer Treatment	A Ministry of Health led programme to improve the quality and timeliness of services for patients along the cancer pathway.
IT	Information Technology
Multidisciplinary meetings (MDM)	Bring together clinical expertise from across the cancer care pathway to agree on the most appropriate treatment for care of an individual patient. They are held regularly to discuss newly diagnosed cases of cancer and cases that need further review.
National Cancer Programme	Brings together the work of DHBs, Regional Cancer Networks and the Ministry of Health to implement government priorities for cancer.
National Patient Flow Programme	A Ministry of Health led multiyear programme of work aimed at measuring the patient journey through secondary care services.
New Zealand Cancer Registry (NZCR)	The New Zealand Cancer Registry is a population-based register of all primary malignant diseases diagnosed in New Zealand, excluding squamous and basal cell skin cancers.
New Zealand Breast Cancer Foundation	A not for profit charitable trust that promotes awareness of breast cancer, provides information and education, and raises funds to support breast cancer related initiatives.
Patient administration systems (PAS)	Specialised IT systems that manage patient information in a hospital setting, including patient demographics, appointments, medical records tracking, diagnostic coding and patient tracking.
Patient portals	Secure, online sites, provided by general practitioners, where patients can access their health information and interact with their general practice.

Term	Meaning
Picture archiving communications system (PACs)	Stores or archives the digital images resulting from radiology information systems and makes them available for imaging.
Regional Cancer Networks (RCNs)	Funded by the Ministry of Health to work with DHBs to facilitate and co-ordinate services across health providers at all levels. There are four regional cancer networks in New Zealand that work across organisational boundaries to promote a collaborative approach to service planning and delivery.
Shared care	An initiative supported by the National Health IT Plan involving securely collecting and sharing health information about a person and creating a care plan so the patient and all health professionals, primary, community and hospital, involved in their care can electronically access up-to-date information on which to base clinical decisions.
SNOMED CT	The Systematised Nomenclature of Medicine – Clinical Terms is a systematically organised computer processable collection of medical terminology terms providing codes, terms, synonyms and definitions used in clinical information. It allows a consistent way to index, store, retrieve and aggregate clinical data across specialties and sites of care.
Telehealth	The use of information and communication technologies with appropriately trained health professionals and other health workers to deliver health services and transmit health information over distance.