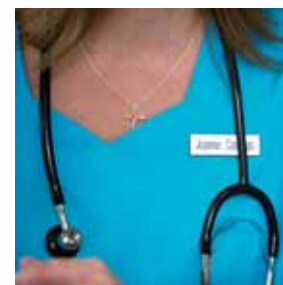




Cancer Collections Framework Project

Final Report

2 March 2006



nzhis
NEW ZEALAND HEALTH INFORMATION SERVICE

 National Screening Unit



Table of contents

Executive summary.....	1
Section 1: Project Background	4
Section 2: Future State Requirements.....	5
Key Information Requirements	7
Gap Analysis.....	9
Section 3: Future State Framework	12
Design and Prioritisation Principles	12
Governance Framework	12
Strategic Options Framework	12
Future Vision/Recommendations.....	13
Roadmap Years 1-5.....	15
Pragmatic Next Steps	17
Appendix A – Current State Analysis.....	18
Appendix B – Project Objectives, Scope, Approach and Steering Group membership.....	25
Appendix C – Stakeholder Contacts List	28
Appendix D – Discussion Points from Stakeholder Interviews.....	29
Appendix E – Collections Review	34
Appendix F – Glossary.....	42

Executive summary

Project Scope and Objectives

Over the last three years the Ministry of Health has developed strategies and action plans to address the challenges it faces in meeting its responsibilities for cancer control, and for ensuring more effective and efficient capture and use of health information nationally. In addition, there is considerable work underway throughout the sector in the area of cancer services and evaluation.

Key strategies and planned actions that are of particular relevance include:

- New Zealand Cancer Control Strategy (2003)
- New Zealand Cancer Control Strategy Action Plan (2005)
- Health Information Strategy for New Zealand (2005)
- Primary Health Care Strategy (2001)
- A Feasibility Study of National Cancer Management Information Systems (2005)

These initiatives provide clear direction for future developments in health care, and implementation of the relevant recommendations has the potential to significantly improve the collection and availability of certain information related to cancer. Given the extensive range of demands for information, it was considered critical to have a framework that could be used to guide future decision making regarding investment and initiatives for cancer related information.

Accordingly the New Zealand Health Information Service (NZHIS) and the National Screening Unit (NSU) commissioned the development of a Cancer Collections Framework to assist them and the Cancer Control Working Party with planning and prioritising information-based initiatives developed in response to the Cancer Control Strategy (published in 2003). This report, The Cancer Collections Framework, defines a strategic 'Roadmap' which describes the future vision and maps out how the Ministry of Health, and the health sector, can move from where it is at present to where it aims to be with regard to cancer information in the future.

The project scope included reviewing the usefulness of current and proposed data collections that record information about cancer, determining key requirements for cancer related information, identifying major gaps and developing a roadmap that should better position the Ministry to answer questions that are being raised about cancer and ensure alignment to cancer strategies.

A cross section of stakeholders related to existing cancer collections, cancer control initiatives, and users of the cancer collections were interviewed regarding their views on the current state and future state requirements for cancer collections. Stakeholder interviews were limited to internal Ministry of Health contacts only.

This report is focused on drawing together those elements that can improve information from across the cancer continuum which can realistically be achieved in a five year timeframe. The future state maps out a vision for high level management information, it is not intended to provide patient level clinical decision making information. However, the future state framework will provide the ability to align cancer information sourced from any context to the cancer strategies.

This report is being tabled for consideration by the project's Steering Group with the intention being that it would then be submitted to the Cancer Control Steering Group to assist future decisions.

Future Requirements and Principles

Using stakeholder interviews, literature, internet reviews and current strategies a set of information requirements were identified that focused around:

- Addressing short comings with current collections which include: inconsistency of data; the inability to measure outcomes; the inability to evaluate treatment/management effectiveness; and the poor timeliness of data from some collections

- Enabling information to be linked more effectively across the cancer continuum from pre cancer through to cancer outcomes, with a need to better understand how diagnosis and treatment impact on outcomes
- Ensuring that information could be accessed and readily analysed to answer key questions at a population, regional, district and local level

In defining future requirements the focus was on ensuring that better information would be available to assist sound national and regional decision making that is cohesive and value adding, not about the management of individual patients. The resulting requirements for improved information were extensive. Consequently a set of design and prioritisation principles was established to guide the future development of Cancer Collections.

Proposed Cancer Collections Framework

The vision for the Cancer Collections Framework is focused on a five year timeframe. The recommendations for developing the framework are essentially pragmatic. They take into account current and planned developments and aim to make the most of systems already in place.

The key elements of the vision are:

- A reporting tool that will provide authorised access to linked data from across cancer collections and national databases e.g. National Health Index (NHI) and Health Practitioner Index (HPI).
- A data laboratory (“virtual information lab”) will be available for validated users to get timely supported access to data that can researched.
- The reporting tool will be able to drill down to sub-population level (e.g. gender, ethnicity, age and region) and to cancer speciality/tumour site.
- Groups providing data will have access to their own data and be able to extract data (up to the previous year) from a comprehensive menu of pre-structured reports. There will also be some ad-hoc report compilation ability for a restricted group of data sets.

This framework provides a vision for an organised approach to expanding the availability and use of cancer related information across a wider range of settings. Access to data that is able to be used in reporting, to test, measure and compare will increase the knowledge base about cancer and increase the potential to provide more answers to cancer related questions.

Increased ability to access information will most likely result in even more questions being asked about detection, staging, treatment and management options and outcomes. The vision includes the data laboratory concept as a means to facilitate ongoing enquiry and discussion about information obtained from the linked data. The reporting tool is another essential part of increasing authorised access, and user friendly reporting ability that will assist with the investigation and answering of cancer questions.

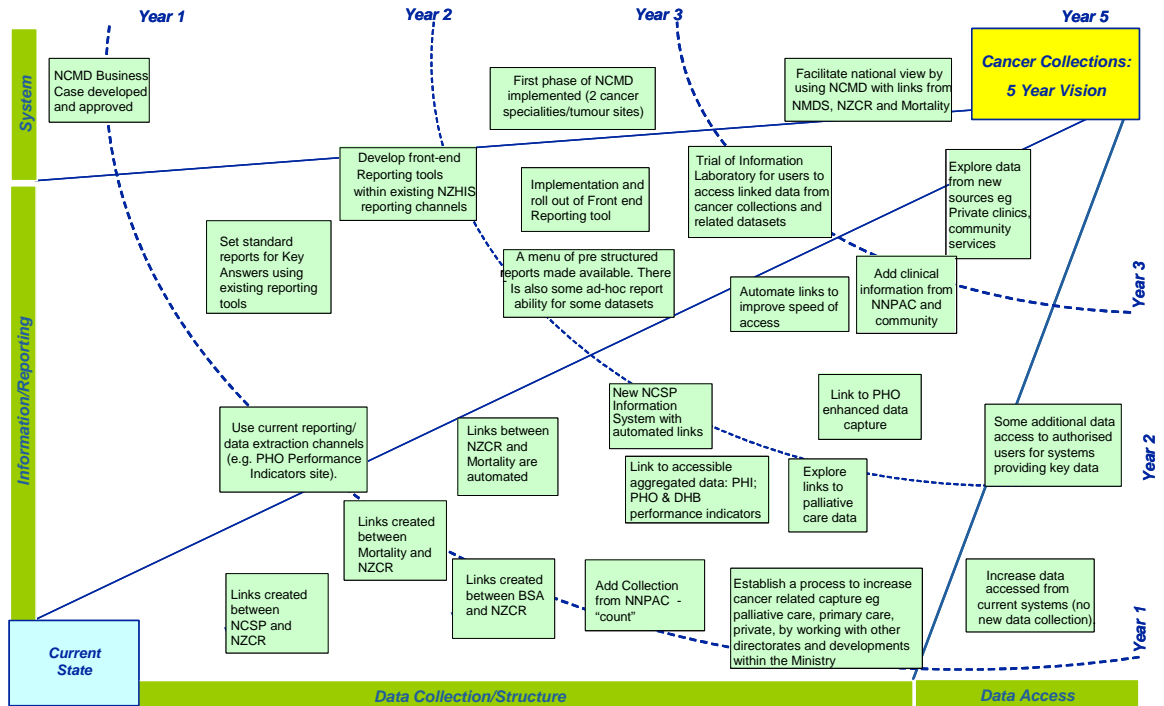
Achievement of this vision will require improvements to be made along four key axes, namely:

- **Data collection/structure** - the input elements such as core data from source systems, collections, population based statistics and available links, depth and breadth of data in scope
- **Systems** - system structure and data transmission, validation and storage
- **Information/reporting** - report structures, information requests, reporting processes and analytical tools
- **Data access** - the appropriate governance of approval for access from across the health sector, and the physical interface and mechanisms of connection, validation and audit trail around access and use of information

These developments will leverage existing collections where possible but will also be dependent on the successful completion of planned implementations and upgrades, such as NHI, HPI, and

National Non Admitted Patient Collection (NNPAC). Other key developments will include establishing the National Cancer Management Database (NCMD) and ensuring that links are made to regional or local “deep” information systems such as Primary Health Organisations (PHO), Familial Bowel Cancer Registers, and to Census information.

The overall roadmap proposed to guide the development of cancer collections is outlined below.



Next Steps

The Cancer Collections Framework will be an important part of the delivery of cancer control strategies and work programmes. It highlights the key projects and could be used by the Cancer Control Council and supporting working groups to assist in monitoring of progress and new developments in cancer control. This Framework encourages collaboration on systems and data set developments between those groups responsible for developments across the cancer continuum such as NNPAC, NCMD and PHO performance indicators. Any decision on implementation of the recommendations would be at the discretion of the governance of the Cancer Control Council and its related work programmes.

Given that the health sector and clinical management practices are continually changing, this Framework is given as a snapshot in time and will ultimately rely on those groups involved in cancer control applying latest knowledge to the use of the strategic options and roadmap. It would therefore be useful to consider whether further work may be required to inform this Framework over time, or whether it would be more appropriate to update it as the major projects covered by the Framework are completed.

Section 1: Project Background

Project Objectives

The development of a Cancer Collections Framework was commissioned by NZHIS and NSU to assist them and the Cancer Control Working Party with planning and prioritising information-based initiatives developed in response to the Cancer Control Strategy (published in 2003).

The purpose of the Cancer Collections Framework is to build a strategic 'Roadmap' which defines the future vision and maps out how the Ministry of Health, and the health sector, can move from where it is at present to where it aims to be with regard to cancer information in the future.

The Terms of Reference identified the following objectives for the Framework:

- Define the current state of the Ministry of Health data collections that record information about cancer in New Zealand.
- Identify any major gaps in current collections.
- Determine what the Ministry of Health's future state should be for collecting cancer related information that will enable the Ministry of Health to answer the questions that are being raised and ensure alignment to cancer strategies.
- Define a strategic roadmap that should enable the Ministry of Health to answer the questions being asked in five years time.
- Provide a formal written report to the Ministry of Health's Cancer Information Work Programme Operational Steering Group on progress of the outputs defined below.

Structure of the Report

The report starts with a brief outline of the future state requirements, followed by the proposed strategic framework. The current state and known developments are contained in Appendix A to provide background to the proposed framework.

For brevity and readability, summarised information is used where pertinent, with the details then being provided in the appendices. Additional core material on the background to this project, such as the project scope, approach, and Steering Group membership can also be found in Appendix B.

Status of this Report

This report brings together the findings from the Cancer Collections Framework project and presents initial conclusions reached by Hewlett-Packard (HP) Business Consulting. Progress updates have been made to the project Steering Group, and findings and potential frameworks for analysis have been discussed with them at key points in the project.

The report presents initial recommendations that, while informed by analysis and discussions with Steering Group members and stakeholders, are HP Business Consulting recommendations.

Section 2: Future State Requirements

Strategic Context

Over the last three years the Ministry of Health has developed strategies and action plans to address the challenges it faces in meeting its responsibilities for cancer control, and for ensuring more effective and efficient capture and use of health information nationally. In addition, there is considerable work underway throughout the sector in the area of cancer services and evaluation.

A number of strategies and planned actions are particularly relevant to development of the Cancer Collections Framework:

- New Zealand Cancer Control Strategy (2003)
- New Zealand Cancer Control Strategy Action Plan (2005)
- Health Information Strategy for New Zealand (2005)
- Primary Health Care Strategy (2001)
- A Feasibility Study of National Cancer Management Information Systems (2005)

These initiatives provide clear direction for future developments in health care, and implementation of the relevant recommendations could be expected to achieve significant improvements in the collection and availability of certain information related to cancer. They were therefore carefully considered in developing the recommendations of this report. More detailed information on each initiative is outlined in Appendix A.

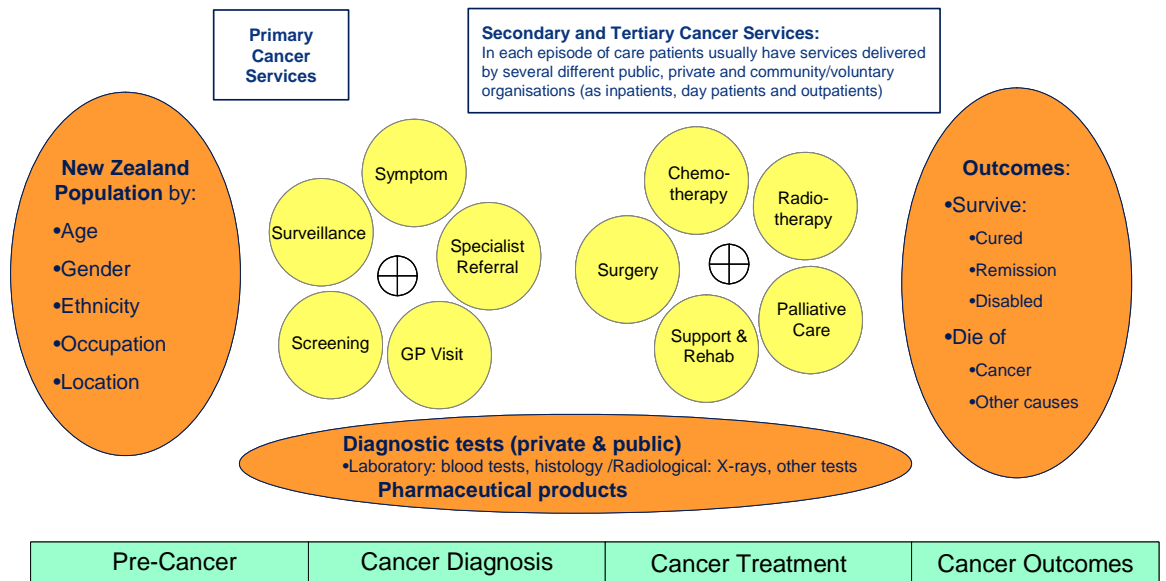
Stakeholder Perspectives

Stakeholders related to existing cancer collections, cancer control initiatives, and those who are users of the cancer collections were interviewed regarding their views on the current state and future state requirements for cancer collections. Stakeholder interviews were limited to internal Ministry of Health contacts only. (A list of stakeholders interviewed is in Appendix C.)

Discussions with stakeholders were focused on where their system, collection or initiative interacted with patients along the Cancer Continuum using the original diagram that was developed as part of the Feasibility Study of National Cancer Management Information Systems. They were firstly asked what key questions do they need to answer in fulfilling their responsibilities, and secondly to identify issues they experienced with accessing the data required to develop these answers. Stakeholders were also asked to give their perspective on the future requirements, if they anticipated any significant change in requirements, and what that might involve.

The feedback from stakeholders has led to a revised cancer continuum diagram.

Figure 1: The Revised Cancer Continuum Diagram



Note: Arrows are not inserted in this diagram as progression through the continuum is non-linear, potentially multi-staged and frequently cyclical in nature. There is also potential for remission to pre-cancer status.

The wide-ranging need for information across the cancer continuum falls into two categories which themselves form a continuum of detail and aggregation. These are:

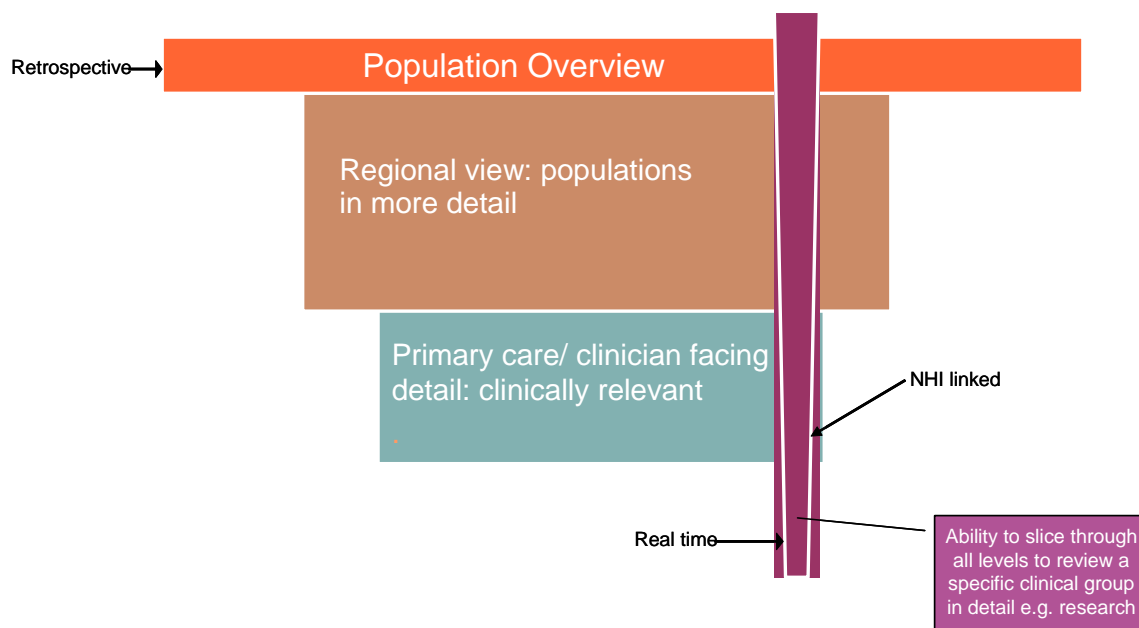
- Clinical – person specific detail
- Population – aggregated data for either the population as a whole or specific population subsets

The concept of the cancer continuum was used as an analytical tool in developing the Cancer Collections Framework. In particular, it was used in interviews with stakeholders and in analysis of the current cancer data collections to identify gaps and highlight other issues regarding information along the continuum.

Although the stakeholders interviewed were internal to the Ministry of Health, they were collectively responsible for a wide range of outcomes throughout the health sector, and worked with a cross section of agencies (e.g. disease prevention, screening, primary health, clinical areas and workforce planning). The views of information they required fell across a broad spectrum, ranging from high level population outcome analysis to analysis of pathways through cancer diagnosis, treatment and survival at a more local/individual level. Resourcing of cancer services was also identified as a key information requirement.

Through stakeholder interviews it was evident that the need to answer certain key questions at population, regional, district, local and/or individual levels is increasingly important for achieving comprehensive, co-ordinated cancer control in New Zealand. (Refer Figure 2).

Figure 2: Summary of Data Views



At the population level, population views can be used to answer questions at a national level based on aggregate data that does not need to be linked back to the individual.

At the next (regional) level more detail may be accessed to answer questions for populations through local collection of data, or through extraction of data from broader databases using identifiers (such as the NHI or demographic information held within databases).

At the primary care/clinician level more detailed, clinically relevant information is collected (and required) for the management and care of individual patients.

The vertical slice shown through the horizontal layers represents the need to be able to slice through all levels of information to answer questions relating to a specific clinical group. This may involve an aspect of management such as diagnosis, or a diagnosis group such as bowel cancer.

Key Information Requirements

Using stakeholder interviews, current strategies and the literature/web review, a number of key information requirements were identified. These have been used to form a view of the data elements that would be necessary to meet these requirements.

Some of these information requirements can already be met, in whole or part, through existing systems. Some are being achieved with proxy measures, while others are outside existing reporting possibility – for example, where gathered through privately funded research.

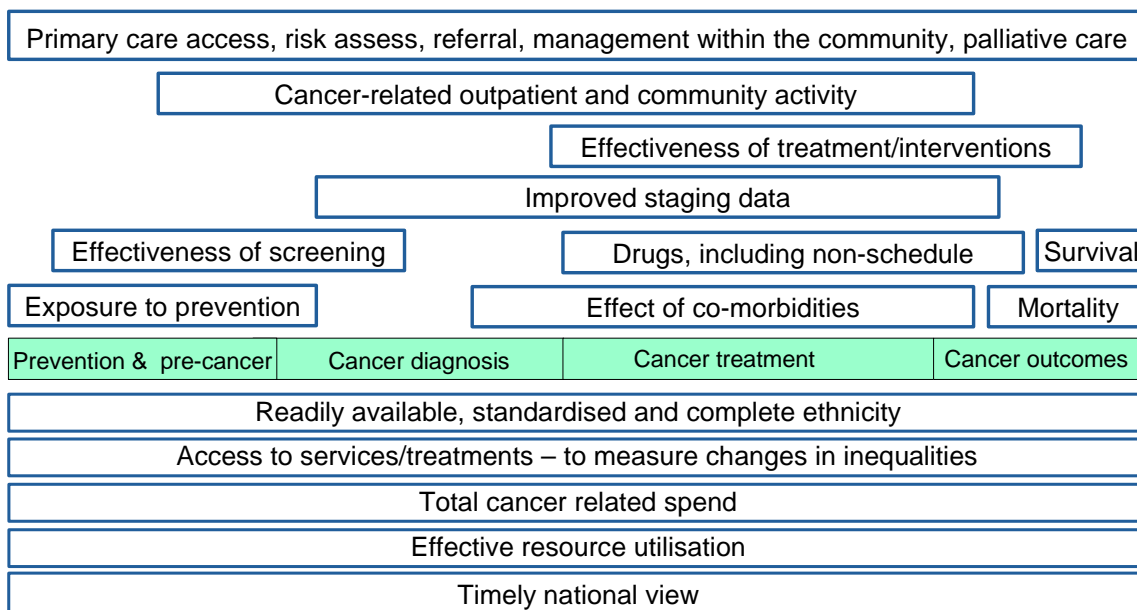
The key information requirements identified are shown in Figure 3 on the next page:

Figure 3: Key Information Requirements

Pre-cancer/ prevention	<ul style="list-style-type: none"> • Success of prevention initiatives • Level of exposure to screening initiatives • Level of exposure to risk factors <ul style="list-style-type: none"> - Smoking - Obesity - Alcohol - Occupational exposure - Sun exposure - Nutrition • Familial surveillance • Success of relevant screening initiatives 	Linkages between the stages of the cancer continuum (pre-cancer/risk through to access to services, treatment and outcomes) also need to be understood.	Differential outcomes from stage at diagnosis	Effectiveness of specific treatment(s) and treatment combinations
Diagnosis	<ul style="list-style-type: none"> • Success of relevant screening initiatives • Disease specific incidence • Disease specific prevalence • Disease specific stage at diagnosis 			
Treatment	<ul style="list-style-type: none"> • Access to interventions • Speed of access to interventions • Intervention volumes • Intervention/treatment type • Intervention/treatment mix 			
Outcomes	<ul style="list-style-type: none"> • Differential outcomes from stage at diagnosis • Effectiveness of specific treatment(s) and treatment combinations • Total cancer mortality rate • Disease specific mortality rate • Complications and co-morbidities • Surveillance of survivors for new cancer • Equivalency with international outcomes 			
Workforce/ resources	<ul style="list-style-type: none"> • Resource utilisation • Resource forecasting 			

The key information requirements identified by stakeholders listed above related to data requirements drawn from patient and service provider interactions across the cancer continuum. In order to understand where on the continuum these data elements may arise, they are mapped against the cancer continuum in Figure 4 on the next page:

Figure 4: Data Requirements Mapped Across the Cancer Continuum



Gap Analysis

Currently each of the information areas listed in Figure 4 above has either limited, incomplete or inconsistent data capture, delays in the supply of, or some issues with the accessibility to, or use of, captured information.

It is possible to count those screened, those diagnosed, those who had surgical treatments and those who died of cancer (or with cancer as the primary cause of death). However, in all other areas even a count is incomplete in so far as knowing which of the presenting patients are cancer related.

A number of priority information gaps were also consistently identified by stakeholders as most critical to address:

- Resource utilisation – technical capacity, technical lifespan, workforce factors such as skill, recruitment, demographics and availability¹
- Stage of cancer (not consistently recorded at data collection points for individuals along the cancer pathway/continuum)
- Effectiveness of interventions from prevention through to complex treatment regimes
- Ability to track changes in addressing inequalities
- Survival information post treatment
- Palliative care information
- Outpatient information
- Ability to compare access of different groups/sub-populations to cancer/cancer prevention services

¹ If resource issues are not resolved, they will impact on the ability to meet all other areas.

- Ability to compare outcomes between individuals enrolled/not enrolled in screening programmes

Figure 5 below shows the high level gaps in each area of the cancer continuum once current and planned developments are taken into account.

Figure 5: Gap Analysis

Focus Area	Current Systems	Planned Developments	Data gaps and limitations to the ability to Answer Cancer Questions
Pre-cancer/ Prevention	<ul style="list-style-type: none"> • Screening programme information systems provides data on individuals within registers • Census data at population level can be used to map risk factors • Public Health Intelligence (PHI Online) reporting site shows risk factors (e.g. smoking, diet) by geographical region 	<ul style="list-style-type: none"> • National Cervical Screening Programme (NCSP) to be redeveloped 2006/2007 – will implement automated electronic interfaces to New Zealand Cancer Registry (NZCR), Mortality Collection. • Familial Bowel Cancer Register may expand to national scope within the next few years 	<ul style="list-style-type: none"> • Unable to compare outcomes for women in screening programmes with those outside • Unable to map risk factors at sub-population level (aside from by region) • Unable to map risk factors to individuals • Risk factors limited to those captured through Public Health surveys
Diagnosis	<ul style="list-style-type: none"> • Captured by New Zealand Cancer Registry (NZCR) 	<ul style="list-style-type: none"> • Enhancements to NZCR will strengthen data set 	<ul style="list-style-type: none"> • Data on tumour, staging or extent of the disease is not always available
Treatment / management (including Palliative care)	<ul style="list-style-type: none"> • Inpatient data • National Booking Reporting System • Pharmhouse Warehouse • Breast Screen Aotearoa (BSA) 	<ul style="list-style-type: none"> • Proposed NCMD to capture treatment information – this will be for 2 cancer specialities/tumour sites per year from sign-off of business case. • NNPAC will capture outpatient contact data (and eventually clinical data) once it is extended • BSA and Cervical Screening system upgrades will provide greater access to linkable data 	<ul style="list-style-type: none"> • Treatment effectiveness cannot be determined • Interactions between treatments and their consequences are not known • Information on treatment by private hospitals is limited, paper based and is subject to major time delays • Very little palliative care data available
Outcomes	<ul style="list-style-type: none"> • Death captured by Mortality Collection 	<ul style="list-style-type: none"> • A proxy for survival using post intervention contacts with services should be available through NNPAC (and eventually clinically relevant data) once it is developed 	<ul style="list-style-type: none"> • Not all individuals' survival/ quality of life post-treatment is tracked • Deaths that are related to underlying cancer are not understood due to historical lack of secondary cause coding

Focus Area	Current Systems	Planned Developments	Data gaps and limitations to the ability to Answer Cancer Questions
Workforce	<ul style="list-style-type: none"> Ministry of Health is currently putting in place a web portal providing links to available (but disparate) workforce information District Health Board (DHB) staffing planning systems 	<ul style="list-style-type: none"> Health Practitioners Index (HPI) under development 	<ul style="list-style-type: none"> Unable to establish a national view of cancer workforce Unable to model future workforce requirements to plan and fund training
Resources	<ul style="list-style-type: none"> Pharmhouse Warehouse Healthpac databases 	<ul style="list-style-type: none"> If issues are resolved for these collections (refer Figure 2) additional data may be available linked to individuals 	<ul style="list-style-type: none"> Unable to establish a sub-population view of the cost of treatment/drugs Unable to determine the actual cost of cancer services

Additional details on key issues raised during stakeholder interviews are outlined in Appendix D.

Section 3: Future State Framework

Design and Prioritisation Principles

Based on the review of strategies and other information gathered through research and interviews with stakeholders, twelve principles are identified for developing a national view of cancer (the Cancer Collection Framework). The recommended design principles for the Cancer Collection Framework are:

- Be value adding, i.e. improve ability to answer the key questions
- Prioritise answering key questions well at a national/regional level (ahead of the ability to drill down to individual local/level)
- Use and improve existing collections where feasible rather than build something new
- Data quality is a critical requirement
- Minimise impact on staff providing data or systems access: technical, operational and clinical
- Comply with applicable legislation
- Be designed for longevity of data view (to facilitate a consistent basis for analysis over time)
- Be flexible to adapt to changes in the health/cancer sectors
- Achieve maximum benefit that can be gained for smallest appropriate cost
- Include short term solutions where they do not negatively impact current or planned developments
- Apply a “correction at collection” standard, where data issues are encouraged to be addressed at their source
- Ensure adherence to information policies such as privacy, security and governance for the data management and handling that is within NZHIS’s responsibility

Governance Framework

Any future work on the Framework for Cancer Collection, links, developments and reporting enhancements will be under the governance of the Cancer Control Steering Group and must be consistent with the Framework that has been developed for national collections.

Strategic Options Framework

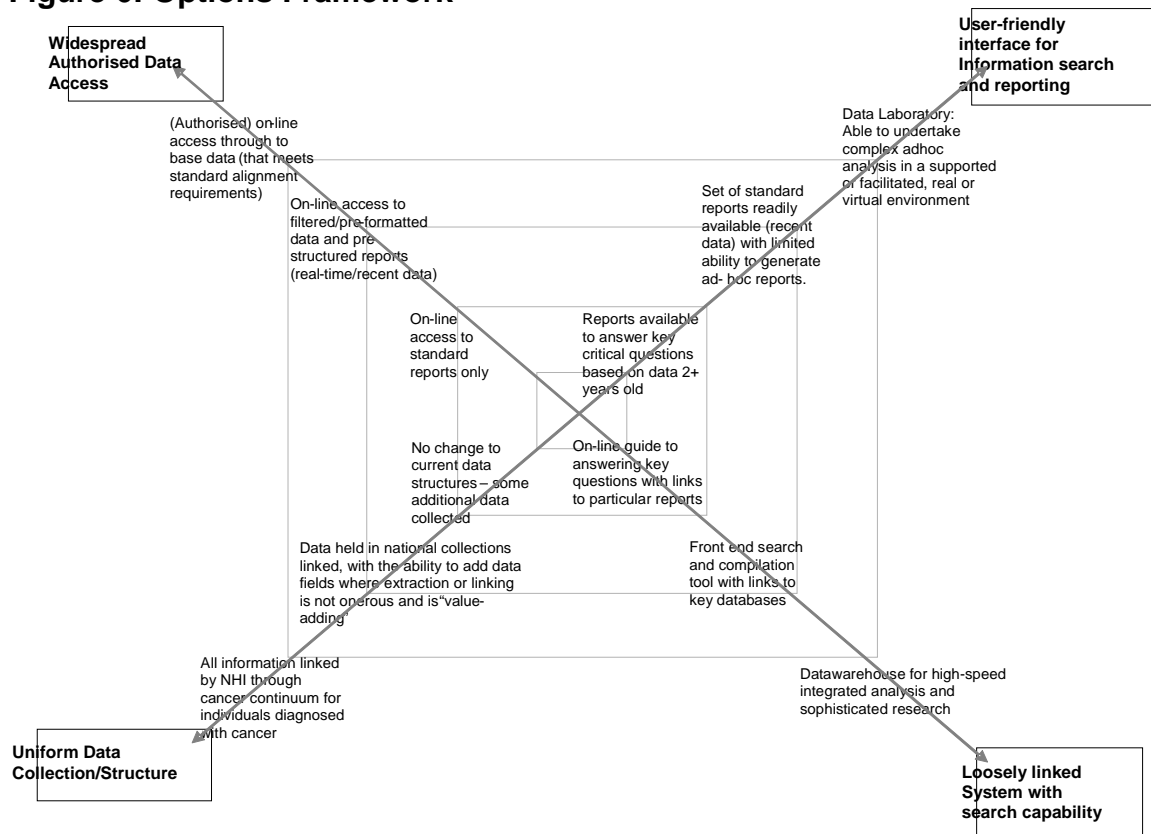
In designing the Cancer Collections Framework, four areas of strategic options were identified for the future state:

- **Data collection/structure.** This includes the input elements such as core data from source systems, collections, population based statistics and available links, depth and breadth of data in scope.
- **Systems.** This covers system structure and data transmission, validation and storage.
- **Information/reporting.** This includes report structures, information requests, reporting processes and analytical tools.

- **Data access.** This includes both the appropriate governance of approval for access across the health sector, and the physical interface and mechanisms of connection, validation and audit trail around access and use of information.

For the strategic options area, choices need to be made about how far it is ideal to go in defining the boundaries of the Cancer Collections Framework (refer Figure 6 below).

Figure 6: Options Framework



The options framework in Figure 6 above shows a spectrum of choice against the strategic options. The most readily achievable outcomes are found at the centre. The more ambitious outcomes are located towards the outer edge of the spectrum. Choices relating to the extent of intended progress into each of these dimensions need to be weighed against the design principles outlined previously in this section.

Future Vision/Recommendations

The vision for the Cancer Collections Framework is focused on a five year timeframe. The recommendations for developing the Framework are essentially pragmatic, i.e. they take into account current and planned developments and aim to make the most of systems already in place.

The proposed five-year vision is therefore as follows:

- A reporting tool that will provide authorised access to linked data from across cancer collections and national databases (e.g. NHI, HPI).
- A data laboratory ("virtual information lab") will be available for validated users to get timely supported access to researchable data.
- The reporting tool will be able to drill down to sub-population level (e.g. gender, ethnicity, age and region), and to cancer speciality/tumour site.

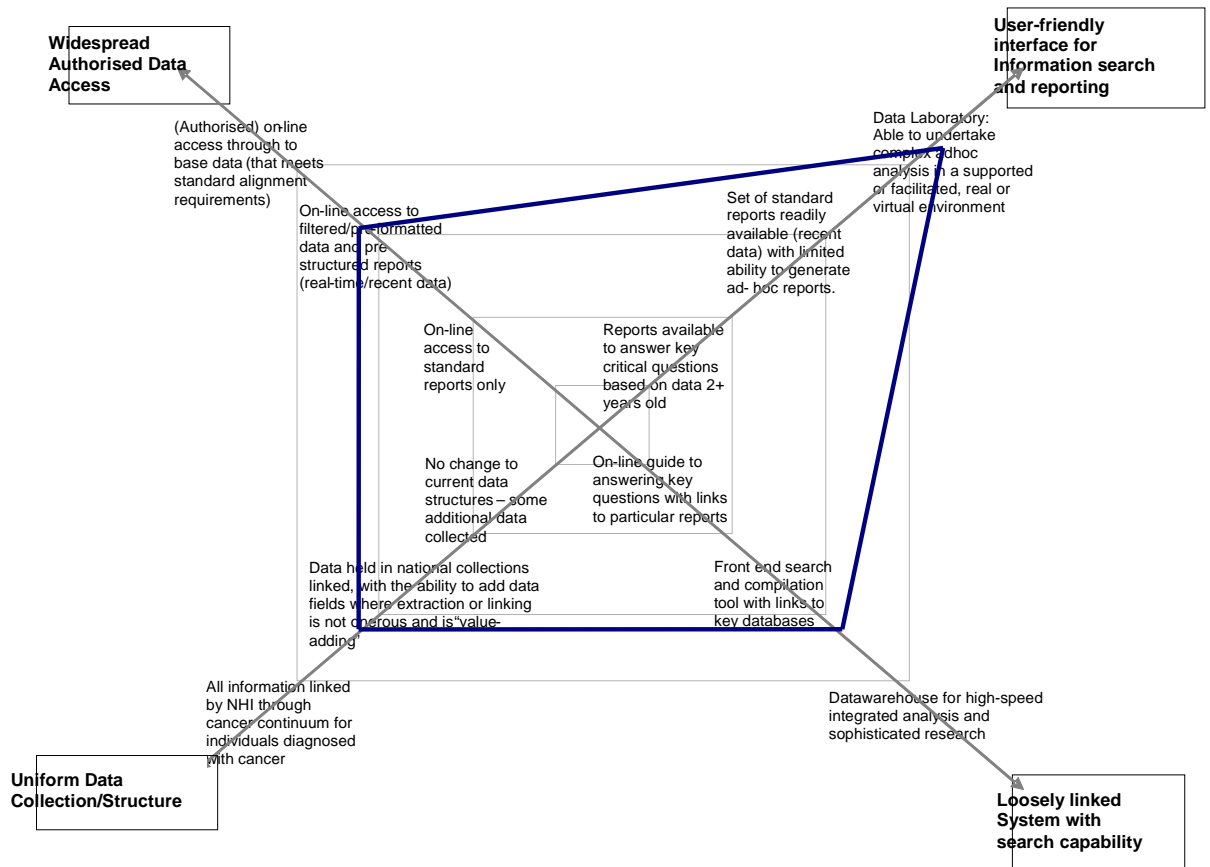
- Groups providing data will have access to their own data and be able to extract data (up to the previous year) from a comprehensive menu of pre-structured reports. There will also be some ad-hoc report compilation ability for a restricted group of data sets.
- Improvements in data quality will continue to be encouraged, e.g. ethnicity data, where standards and processes of improvement are already well underway to collect the best possible ethnicity at source.
- Data coding for cancer will be aligned between the national collections and for any collections added to the Cancer Control Framework. Coding will continue to be comparable with international standards.

The premises underlying the five-year vision are as follows:

- National Health Index (NHI) upgrade is complete and an individual's NHI number will be able to be used as an anchor to link data collected on individuals at points throughout the screening pathway.
- Development of the Health Practitioners Index (HPI) is complete.
- The National Cancer Management Database is in place and linked to front-end reporting tool. If the NCMD is developed as per the business case it will fill a number of significant data gaps (from diagnosis to completion of treatment) for cancer specialties/tumour sites covered.
- Links are in place between the NCMD and the NSU screening programme datasets, the New Zealand Cancer Registry and the Mortality Collection (as per NCMD feasibility study). This will allow users to pull together segments of the cancer continuum such as: pre-cancer access to services (screening programmes only), stage of cancer at diagnosis, and death.
- Links to PHO systems provide some additional data on risk exposure/prevention/pre-cancer outside of national screening programmes.
- Link to NZ Statistics census information through geo-coding/location information provides population-level data on risk-exposure.
- Links are in place to regional/local "deep" information systems that capture research information that is important at both a regional and national level for assisting policy development (for providing appropriate screening/intervention for high risk groups, e.g. Familial Bowel Cancer Registers (Auckland and Christchurch)).
- Good (although possibly still incomplete) palliative care data is available from organisations contracted to DHBs and links through NCMD and/or DHB systems.
- Comprehensive Cancer Workforce data may still not be easily viewed at a national level, depending on sophistication of the Ministry held database and the level of interaction achieved (if any) with the HPI.
- NNPAC outpatient data regarding access to cancer-related services, treatment for cancer and cancer-related complications input/linked to NCMD.
- Private hospital National Minimum DataSet (NMDS) data regarding access to cancer-related services, treatment for cancer and cancer-related complications is submitted within 12 months of discharge.

The dimensions of the five year vision are positioned against the options framework shown in Figure 6 above, predominantly on the middle ground. This is shown in Figure 7 on the next page:

Figure 7: Five-Year Vision Relative to Options Framework



The options identified on this framework have been developed into the actions listed in the five year Roadmap to the desired future state.

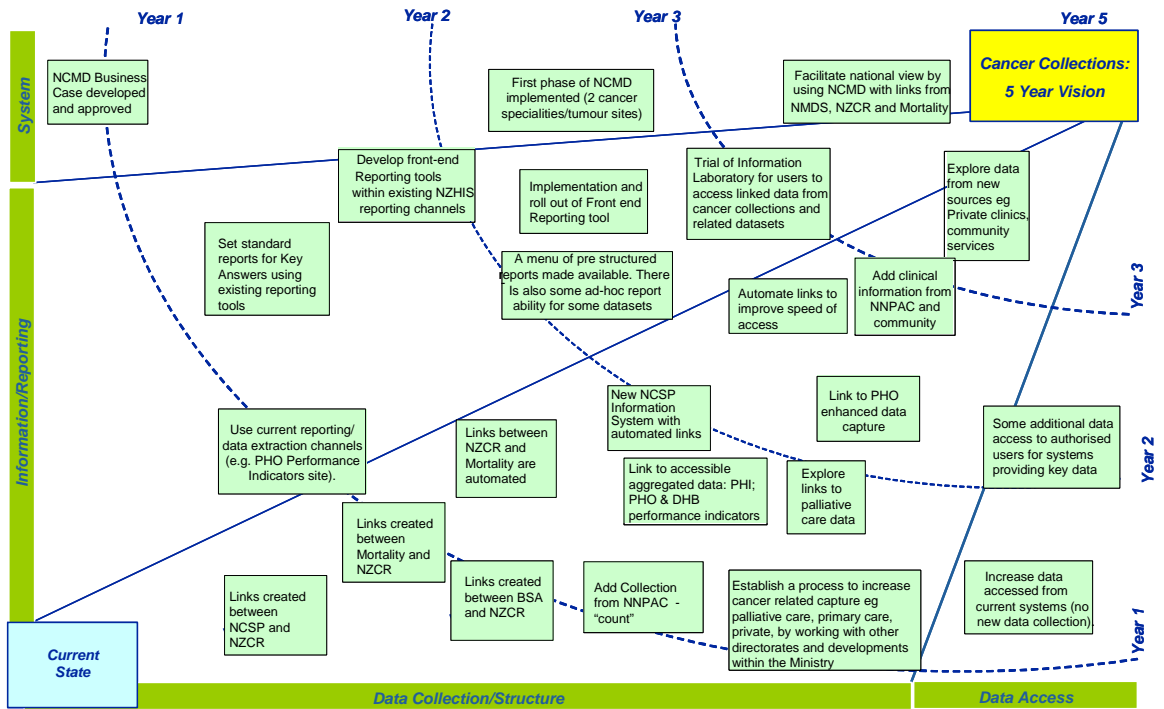
Roadmap Years 1-5

Within the next 18 months improvements will have been completed for the New Zealand Cancer Registry and the Mortality Collection. These changes will not only support the implementation of the proposed NCMD, but will make it easier to link to other cancer systems and databases (such as the NSU screening systems). These improvements will therefore enable some effective interim/short-term solutions to be put in place to better answer many of the key questions (refer Figure 3: Key Information Requirements) for cancer control at a national level.

There are achievable and pragmatic steps that can be taken to maximise the potential of the existing systems, planned implementations and enhancements. These form the basis for the roadmap to the future state, but are not exclusive of future changes and developments within the cancer service sector.

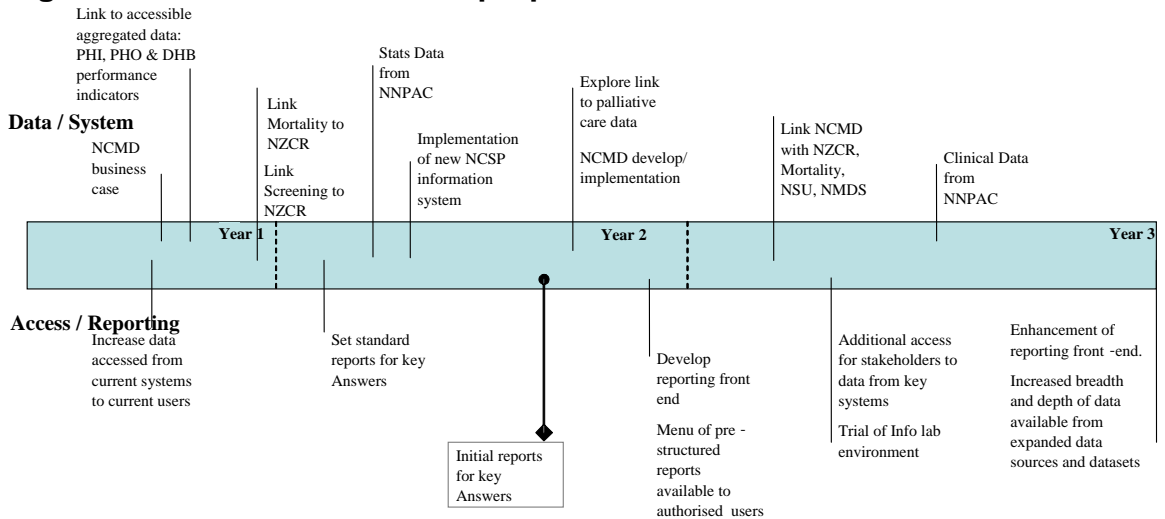
These are shown in the “Roadmap” Figure 8 on the next page:

Figure 8: Roadmap Years 1-5



A timeline showing the potential order of events in the first three years is shown in Figure 9 below:

Figure 9: The First 3 Years – A proposed Outline for Cancer Collection



Pragmatic Next Steps

As a starting point towards implementing the future state vision for Cancer Collections, the following steps are proposed to the Framework for Cancer Collections Steering Group.

- Encourage the inclusion of this framework within the existing cancer control strategies and work programmes, understanding that any application of the suggested actions and timeframes would be at the discretion and guidance of the governance arrangements for those groups.
- Work with key projects and strengthen those common links identified to enable new developments and monitoring of progress in cancer control.
- Encourage the development of a set of regular research reports using information sourced from across the cancer continuum that will answer key questions for treatment and other gap areas.
- Encourage collaboration on systems and data set developments across the cancer continuum such as NNPAC, NCMD and PHO performance indicators.
- Support the ongoing improvements in data quality.
- Support data coding for cancer that is aligned between national collections and encourage the same for any new collections added to the Cancer Control Framework.

Given that the health sector and clinical management practices are continually changing, this Framework is given as a snapshot in time and will ultimately rely on those groups involved in cancer control applying latest knowledge to the use of the strategic options and roadmap. It would therefore be useful to consider whether further work may be required to inform this Framework over time, or whether it would be more appropriate to update it as the major projects covered by the Framework are completed.

Appendix A – Current State Analysis

Current Strategic Context

Over the last three years the Ministry of Health has developed strategies and action plans to address the challenges it faces in meeting its responsibilities for cancer control, and for ensuring more effective and efficient capture and use of health information nationally. In addition, there is considerable work underway throughout the sector in the area of cancer services and evaluation.

The implementation of standards, methods, processes and definition of interdependencies between health sector services and their datasets (even where cancer is not their key service, but a proportion of the cases are cancer related) are essential in order to maximise the benefit to the New Zealand public.

Key strategies and planned actions relevant to the Cancer Collections Framework are outlined below.

New Zealand Cancer Control Strategy (2003)

Specific actions to improve control of cancer in New Zealand have been identified in the New Zealand Cancer Control Strategy, and more recently measures for progress have been outlined in the Cancer Control Strategy: Action Plan.

The overall purposes of the New Zealand Cancer Control Strategy are to reduce the incidence and impact of cancer and to reduce inequalities in respect to cancer. The goals of the New Zealand Cancer Control Strategy are to:

- Reduce the incidence of cancer through primary prevention
- Ensure effective screening and early detection to reduce cancer incidence and mortality
- Ensure effective diagnosis and treatment to reduce cancer morbidity and mortality
- Improve the quality of life for those with cancer, their family and whanau through support, rehabilitation and palliative care
- Improve the delivery of services across the continuum of cancer through effective planning, co-ordination and integration of resources and activity, monitoring and evaluation
- Improve the effectiveness of cancer control in New Zealand through research and surveillance

The Cancer Control Strategy: Action Plan incorporates and builds upon existing activities which contribute to cancer control. In many cases the recommended actions are designed to:

- Close existing gaps in services, or reduce duplication
- Ensure greater co-ordination of services being developed
- Ensure that scarce and finite resources are used efficiently and effectively.

Health Information Strategy for New Zealand (2005)

The Minister of Health in presenting the Health Information Strategy for New Zealand (HIS-NZ) identified the key components for enabling more effective information sharing. Many of the action zones identified in HIS-NZ (for example, electronic referrals, discharge summaries and chronic care and disease management) specifically impact people with cancer.

HIS-NZ proposes the standard for connection and communication development. It sets out a plan for a national network strategy and national system access, underpinned by the development of an anchoring framework which aims to “retrofit” the NHI and HPI on to national collections and data sets (so that the ability to link information is improved).

Primary Health Care Strategy (2001)

The Primary Health Care Strategy provides a clear direction for the future development of primary health care so that it can play a more central role within the health system. The Primary Health Care Strategy outlines how a different approach to primary health care will improve the health of all New Zealanders through:

- A greater emphasis on population health, health promotion and preventative care
- Community involvement
- Involving a range of professionals and encouraging multidisciplinary approaches to decision making
- Improving accessibility, affordability and appropriateness of services
- Improving co-ordination and continuity of care
- Provision and funding of services according to the population’s needs as opposed to fee for services when people are unwell.

The evolving role of Primary Health Organisations (PHOs) has led to an increase in the elements of data being provided by primary care organisations through their PHO to their local DHB. Once governance and use of data issues are resolved, there is the potential for this to expand to a regional view of data with greater span and depth than currently available. This would start to provide a regional view of the patient care for cancer related illness and other areas of health.

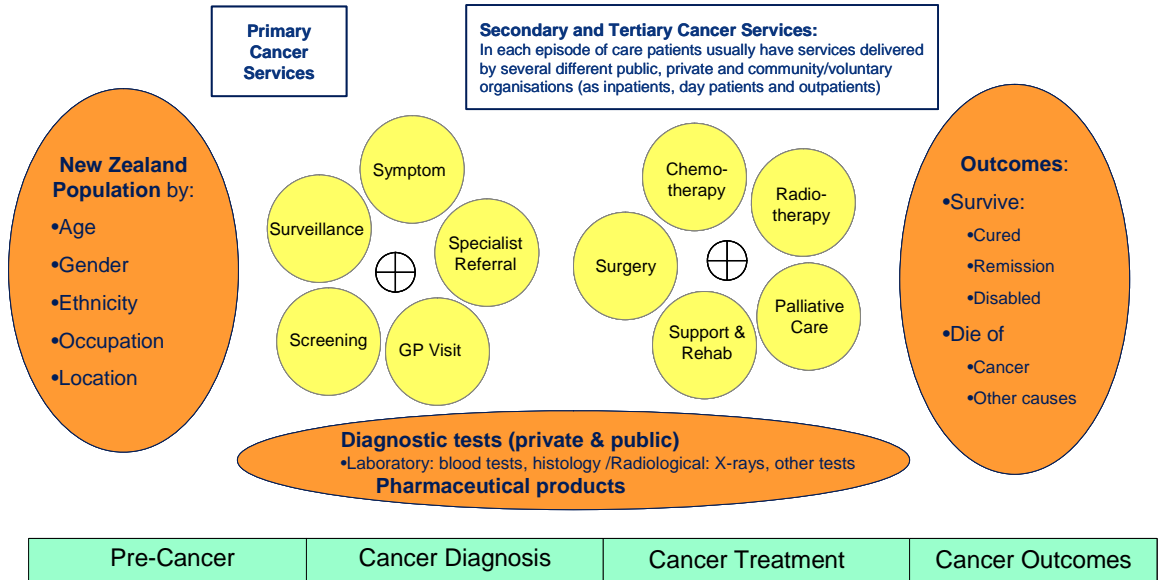
A Feasibility Study of National Cancer Management Information Systems (2005)

In response to the Cancer Control Strategy, and in line with the goals of HIS-NZ, the Feasibility Study of National Cancer Management Information Systems recommends the development of a National Cancer Management Database (NCMD). The recommended structure (and related processes) for the NCMD aims to improve the collection of data related to treatment of individuals diagnosed with cancer, so that their pathway through the “cancer continuum” from diagnosis to the completion of treatment can be better seen and understood.

Within the feasibility study, a diagram of the cancer continuum was outlined as a view of the contact points between individuals diagnosed with cancer and health providers/procedures throughout treatment, recovery, care or death. The diagram shows the many-staged nature of diagnosis and treatment processes. The lack of arrows can be understood in the context of the non-linear and potentially cyclical nature of disease progression. A revised version of this diagram is shown below².

² Diagram revised for this study based on feedback from stakeholder interviews.

Figure A.1 The Cancer Continuum



Review of Cancer Collections

The following tables provide an outline of the collections reviewed for this project:

- The first table (Figure 9) relates to whether collections are either currently used in the NZCR, or are a currently available system, holding data about patients interactions with services across any part of the cancer continuum.
- The second table (Figure 10) provides an overview of planned developments where potentially useful data elements may be sourced – even though these systems may not be cancer specific.

The review process involved a desk based study of documents on the collections, and their data dictionaries, and included a discussion with a manager or other involved person for the collection. Actual data held, and outputs from these collections were not reviewed, however a recommendation was made to test a small set across the collections for potential for usefulness of linking.

Further detail about these collections can be found in Appendix E.

Figure 9: Current collection systems capturing relevant information about patients with cancer

Health Information Holding System	Status of Collection	Current state: Data is currently being used in the New Zealand Cancer Registry (NZCR)	Current Potential Data already available to reduce gaps across the Cancer continuum	Future State: Potential for the collection to hold or provide additional data relevant for Cancer
National Health Index (NHI)	Longstanding with regular update process	In use Provides the ability for demographic breakdown of data into age, gender, location and ethnicity		Processes to improve accuracy of data entry for ethnicity will increase reliability of this category
National Minimum Dataset (NMDS)	Established 1993, but holds some information back to 1988. Has an annual incremental upgrade process	In use Provides detailed capture of admissions to hospitals, including diagnoses of diseases and injuries and surgical or other intervention procedures undertaken while admitted	Occupation is an optional element. Some hospitals hold and pass occupation. This could be tested for its ability to part fill the occupation gap in the NZCR	The planned development of Electronic Discharge summaries may provide additional data.
Mortality Collection	Longstanding (provides data from 1988). Currently being upgraded	In use Captures all deaths where cancer is primary underlying cause. There are historical limits related to coding of primary reason for death where some that were cancer related may not have been identified		Enhanced capture and coding of factors causing death will add a new level for analysis
New Zealand Cancer Registry (NZCR)	Operating in its current form since 1994, was originally established in 1948. Mandatory reporting required by legislation Currently being upgraded	In use All primary malignant cancer diagnoses and laboratory test results collected. Auditing has shown a very high confidence in coverage	Occupation is a current gap which is identified, with a possible partial fix identified under NMDS	The register will provide the pivotal point for other cancer related collections such as the NCMD
Breast-Screen Aotearoa (BSA) National Monitoring Database	Established 1998. Planned for upgrade	Used through formal requests to report on the programme. Process being established to compare cancer information between NZCR and BSA	Data is exchanged with NZCR, and could be linked in a more direct way than at present	Future state could have an integrated electronic data exchange with the New Zealand Cancer Register, Mortality collection and NCMD

Health Information Holding System	Status of Collection	Current state: Data is currently being used in the New Zealand Cancer Registry (NZCR)	Current Potential Data already available to reduce gaps across the Cancer continuum	Future State: Potential for the collection to hold or provide additional data relevant for Cancer
National Cervical Screening Programme (NCSP) Register	Established 1992. Currently at RFI for upgrading	Used through formal requests to report on the programme Process established to compare NCSP with NZCR	Data could be linked on NHI and be nationally accessible to authorized users	Future state could have an integrated electronic data exchange with the New Zealand Cancer Register, Mortality collection and NCMD
Medical Warnings System	Associated with the NHI. Variable use by the sector No plans for change	Not used	No consistent elements for cancer	No planned changes that would introduce ability for consistent cancer information Potential to standardise cancer related alerts that could be visible on admission
National Booking Reporting System (NBRS)	Established 2000. Annual review process for updating	Not used	Some outpatient data captured which may be useful for timing of interventions if linked. No current plans to expand the capture for bookings such as outpatient performed chemotherapy	Potential for specific cancer related flags in eventual system development
PHO Performance Indicators	Phase 1 is operational, and phase 2 changes are being implemented	Not used		Potential for additional indicators once process smoothed out. Data elements would need to be negotiated, and probable vendor involvement needed if requiring change
PHI Online	Online in 2005, with an initial data set drawn from NZHIS collections and the New Zealand Health Survey. Further development pending	Not used	Useful for providing baseline and comparators for population health survey data –at a regionally aggregated level	If supplied with geo-coding could display more population level information
Labs Claims Warehouse	Datawarehouse fed by extracts from Laboratory service providers	Not used All cancer related tests received are already reported up to the NZ Cancer Register – although not from this database	Potential to link to existing non-cancer related tests that can inform patient status – see Appendix E for examples	This would enable linking to additional information that informs on patient health status around cancer diagnosis and interventions

Health Information Holding System	Status of Collection	Current state: Data is currently being used in the New Zealand Cancer Registry (NZCR)	Current Potential Data already available to reduce gaps across the Cancer continuum	Future State: Potential for the collection to hold or provide additional data relevant for Cancer
Pharm-house	Data warehouse fed by extracts from Pharmacy service providers	Not used	Currently data captured for funded drugs (only). Changes are being considered	If issues with sourcing all data regardless of funding are resolved, this would have even more value
HealthPAC	Multiple databases set up for purpose of payment for services	Passes Labs data on cancer tests	There is potential for provision of a "count" of attendances at services where the data is held with NHI by HealthPAC	If issues regarding the purpose of the collection are resolved, it will be useful for interim community based services counting.
"Get Checked"	Currently payment for services for diabetes and diabetic risk assessments	Not used	Limited cover, and largely aggregated so not currently useful to cancer	Additional capture, planned that would broaden the coverage and usefulness as many risks are universal to diabetes, CVD, and cancer. This is one of the few risk assessment data collections at present.

Figure 10: Systems Under Development with data that could be linked to the Cancer collection

Health Information Holding System	Status of Development	Future State: Potential for the collection to hold or provide additional data relevant for Cancer
National Non-admitted Patient Collection (NNPAC)	In progress. A count will be captured from 1 July 06 and progressing to clinical detail trial	Contacts with outpatient and community service, rehab and support services can be counted, and eventually clinically relevant coding obtained
Primary Care Collection	Identified on HIS-NZ roadmap, but no business case yet	Would enable significant gaps from primary care diagnosis, interventions and referrals to be filled
National Cancer Management Information System (NCMD)	At business case	Will link and/or collect staging, treatment, and outcomes data from point of diagnosis to the end of treatment for individuals with cancer. Will provide linkages to other systems (such as the National Cancer Registry, Mortality Collection and Screening programmes information systems) regarding pre-cancer and outcomes
Health Practitioner Index (HPI)	In progress. implementation commencing in 2006	Improved linkages will assist the ability to assess access and inequalities, and the effects of targeted improvements by measuring clinician coverage, location and in future potentially clinician ethnicity and languages spoken
Electronic Discharge Summaries	Identified on the HIS-NZ roadmap as 2006/2007	This will standardise the capture of existing discharge summaries that could provide additional clinical detail
Electronic referrals	Identified on the HIS-NZ roadmap as 2008/2009	This will add a layer of relevance for referral patterns, as well as standardising the clinical information exchange
National system access for NHI	Identified on the HIS-NZ roadmap as 2007/2008	Clinical service providers can ensure accurate NHI capture – enables wider linking of information.

The following systems/collections are considered additional potential data sources that fall outside of the direct jurisdiction of the Ministry of Health and therefore were not reviewed in detail. They may however, have the potential to provide additional details on some cases that would enhance overall analysis and understanding. They are:

- Palliative care systems
- Child & Youth mortality database
- Boutique databases (e.g. Gynae Oncology)
- Familial surveillance databases (e.g. Familial Bowel Cancer Registry)
- Risk factor evaluation sets (e.g. Predict)

Through ongoing and planned future developments, the current state is evolving from a legacy of isolated development with unique code sets, towards unified coding and reporting across systems.

However, the current information available regarding an individual's journey throughout the cancer continuum has points of disconnection throughout. There are silos containing wealth of clinical and statistical information about certain aspects of a patient's condition or treatment. At the same time there can be a lack of easily accessible information about other interventions received or management decisions made, such as the inputs that precede or follow any given event point.

Appendix B – Project Objectives, Scope, Approach and Steering Group membership.

The development of a Cancer Collections Framework was commissioned by NZHIS and NSU to assist them and the Cancer Control Working Party with planning and prioritising information-based initiatives developed in response to the Cancer Control Strategy (published in 2003).

The purpose of the Cancer Collections Framework is to build a strategic 'Roadmap' which defines the future vision and maps out how the Ministry of Health, and the health sector, can move from where it is at present to where it aims to be with regard to cancer information in the future.

The Terms of Reference identified the following objectives for the Framework:

- Define the current state of the Ministry of Health data collections that record information about cancer in New Zealand.
- Identify any major gaps in current collections.
- Determine what the Ministry of Health's future state should be for collecting cancer related information that will enable the Ministry of Health to answer the questions that are being raised and ensure alignment to cancer strategies.
- Define a strategic roadmap that should enable the Ministry of Health to answer the questions being asked in five years time.
- Provide a formal written report to the Ministry of Health's Cancer Information Work Programme Operational Steering Group on progress of the outputs defined below.

Project Scope

This project was triggered by the environmental scan required for the Replacement Information Systems Project for the National Cervical Screening Programme (NCSP) being conducted by the National Screening Unit (NSU), and NZHIS workstreams for the New Zealand Cancer Registry (NZCR) systems upgrade, the Mortality Collection systems upgrade, and the proposed National Cancer Management database (NCMD).

There was awareness of the need for wider integration of cancer related information across key points of patient contact with the health sector. Improved access to integrated information would be expected to increase knowledge transfer between services, and improve system effectiveness for patients.

The NZHIS and NSU jointly commissioned HP Business Consulting to conduct the review and prepare a vision for a future framework for cancer information, and to lay out a proposed roadmap to that future state in this report

The Cancer Collections Framework project has identified key information requirements across the continuum of cancer care, and where there are gaps in meeting these. It has analysed which of these gaps are critical to fill but require more work to achieve this in the near future and which gaps can be filled with current information systems by facilitating easier means of connection or data transmission.

Key activities included:

- Review current and potential sources of cancer information in the New Zealand health sector.
- Consult with internal Ministry of Health Stakeholders.

- Provide a “Roadmap: document for achieving the preferred state, including a high level description.
- Review and consolidate/prioritise strategic options with the Steering Group.

Project outputs are planned to be presented to the Cancer Control Council Steering Group for use in validating ongoing requirements and work plans. External validation of prioritisation is outside of the project scope.

Approach

To provide context to the analysis of the cancer data collections, current government initiatives and policies in the fields of cancer and health information were reviewed (such as the Cancer Control Strategy, the Primary Health Strategy and the Health Information Strategy New Zealand), and a desk based web/literature survey was undertaken on cancer control in New Zealand and overseas.

Interviews were undertaken with key stakeholders within the Ministry of Health in order to understand what the current issues are regarding cancer data requirements and availability from the existing data collections.

In parallel, a review was performed of the New Zealand health information systems that are either current, or planned and funded for implementation. The purpose was to identify those already being used as sources for cancer information, to review potential sources under development, and to provide an overview of high level issues with these sources, in relation to cancer information.³

Once current state and environmental issues were gathered, key issues and perceptions were highlighted and discussed with the Steering Group for the project where validation was sought. The key information requirements were identified in the discussion and review process. A gap analysis was conducted between the current state ability of the systems to meet these key information requirements, and the future state requirements.

The framework for evaluating the options for the future state was established, and a set of design and prioritisation principals were compiled to guide its development. Current and known developments were then placed onto the roadmap to the future state. Proposed additional developments were then added in accordance with the design and prioritisation principles.

A 5 year roadmap was then drawn, and to add clarity, adapted into a timeline identifying the next steps. This timeline was only constructed for the first 3 years, as the detailed plan for years 4 and 5 may require review, depending on the achievement of the first 3 years, and the possibility of additional valuable information sources coming on line that have not been considered here.

The Steering Group members were consulted formally at Steering Group meetings, with some informal one-on-one discussions, for feedback and review during this framework development.

³ In addition, with approval from the Steering Group, a small test was undertaken of the HealthPac collections, to determine if there would be any benefit in pursuing additional data from this source. This was considered as an option for potentially sourcing – even on a simple numbers basis, current gaps in information.

Steering Group Membership

The steering group was convened from members of the NSU and NZHIS

Member	Title
Mike Rillstone (to end November 2005)	Group Manager NZHIS
Karen Mitchell	Group Manager NSU
Tracey Vandenberg	Clinical Coding Services Manager NZHIS
Susan Hanna	Team Leader, Cancer Registry NZHIS
Graham Templeton (to January 2005)	Project Manager, NZHIS
Catherine Scollay	Manager IS, NSU

Appendix C – Stakeholder Contacts List

Names of those contacted during the current state review, and future state requirement evaluation. Names in brackets were contacted but unavailable within the timeframes needed for inclusion, those listed alongside were agreed to represent the same interests. Some were representing more than one perspective.

- Amanda Newton – Senior Advisor Health Information Strategy and Policy, Corporate and Information Directorate; National Booking Reporting System
- Andrew Holmes – Manager Outcomes Performances Systems, Clinical Services Directorate
- Barry Borman – Manager (Epidemiologist) Public Health Intelligence
- Brendan Kelly – Chief Advisor Health Information and Strategy NZHIS; HPI
- (Colin Feek – DDG Clinical Services Directorate) – Andrew Holmes
- Catherine Scollay – Manager IS, National Screening Unit
- Cynthia Maling – Public Health: Group Manager Non-Communicable Diseases, Cancer Control Strategy
- David Press – Team Leader, Analytical Services, NZHIS
- (Debra Keylard – Business Intelligence Manager NZHIS) - David Press; Acting Manager Business Intelligence Unit, NZHIS
- Deborah Woodley – Health Services Manager; Cancer Control Council
- Hazel Lewis – Clinical Leader Cervical Screening, NSU
- Graham Templeton – Project Manager, NZHIS
- Jon Foley – Senior Analyst, MoH; PHO Performance Monitoring
- Jane Lyon – Clinical Advisor, Long term Conditions
- Karen Mitchell – Group Manager National Screening Unit (NSU)
- Madeleine Wall – Clinical Leader Breast Screening Aotearoa, NSU
- Mhairi McHugh; Principal Technical Specialist, DHBNZ Funding and Performance; National Non-Admitted Patient Collection
- (Linda Gillam – National Services Development Manager, HealthPAC) Margery Farrant; Lee Harrison - Service Development, HealthPAC
- Peter Thomas – NZHIS Acting Data Management Services Manager; NMPI, NMDS, MHINC
- Susan Hanna – Team Leader, Cancer Registry NZHIS
- (Teresa Wall) Paula Searle, Charissa Makowharemahi – Maori Health Directorate
- Tracey Vandenberg – NZHIS Clinical Coding Services Manager
- Vicki McLaughlin – Outcomes Performance Systems, Clinical Services Directorate
- Vladimir Stevanovic – NZHIS – Clinical Advisor Team Leader, Clinical Analysis NZHIS

Appendix D – Discussion Points from Stakeholder Interviews

This appendix summarises the key themes and comments made by the stakeholders interviewed regarding the national Cancer Collections Framework. These discussions were used to shape the recommendations of this document. The potential usefulness for a national cancer view is identified for each of the following themes.

Full and accurate staging data

Availability of full and accurate staging from point of diagnosis was identified as one of the key cancer specific data requirements. This could be used to help identify or eliminate late detection as a factor in the variable mortality rate across regions and nationally.

Useful for understanding cancer management because: There is a known evidence base for the fact that early detection in most cases can increase the chance of survival.

Availability, variability and completeness of Ethnicity data

Ethnicity data was identified as inconsistent across parts of the cancer continuum. There is awareness that coding of Ethnicity is improving, but this remains a high priority for services and researchers. Interest was in both the Maori vs European groupings, as well as Pacific peoples as a sub-grouping.

Useful for understanding cancer management because: Ethnicity information is useful for better understanding issues around equity of access and levels of treatment by ethnic groupings for evaluation of targeted programmes.

Ability to evaluate effectiveness of treatment, interventions, or management

There is a lack of ability to know, outside of specific research projects, what effect treatments, interventions and management practices are having on outcomes.

Useful for understanding cancer management because: The desire to maximise effective treatment, with least harm, requires consistent data for evaluation. The capture of management information will also facilitate understanding of the interrelated effects of interventions performed concurrently or sequentially.

Ability to track changes in addressing inequalities

There is a lack of ability to measure and understand the factors that drive inequalities in outcomes. Specific research has highlighted that some regions as well as some ethnic groups have had a poorer outcome compared to others in New Zealand.

Useful for understanding cancer management because: There is a need to increase evaluation of measures related to inequalities and to be able to track any changes, and so enable evaluation of the programmes that are addressing these inequalities.

Outcomes

There is a desire to have the ability to measure not only survival, but level of impairment free survival. Measuring outcomes includes, but is not exclusive to, the ability to see mortality, and the time between diagnosis of cancer and of subsequent mortality. The ability to measure morbidity is also seen as important as this includes the level of impairment caused during the disease process.

Useful for understanding cancer management because: The ability to measure not only survival, but level of impairment, or impairment free survival can be useful to validate or disprove treatment outcomes.

Timeliness of National data

Current processes involved in the collection, collation, cleansing, and publication of health data mean that in some instances the data is well over 2 years out of date once released. An opinion was expressed that a smaller set of data that is more timely would be more useful to that stakeholder, than a large, late set.

Useful for understanding cancer management because: Diagnostics and interventions can undergo a significant change in a short period, and the delay in seeing these effects can limit the ability to rapidly implement potential improvements.

Consistency of data collection

There needs to be a consistent approach in the use of questions asked, and the classification, coding and description of responses and results in order to be able to undertake comparison. Coding needs to be consistent to an international standard across all sources, primary care, outpatients, private services, like those already done within Inpatients.

Useful for understanding cancer management because: Comparability across differing services and settings would be made easier, and more valid, where a consistent standard is applied.

Primary Care contacts

There was interest in being able to understand the whole patient journey, including the care provided by Primary care clinicians. There are some specific projects starting to look at mapping cancer journeys to close this knowledge gap.

Useful for understanding cancer management because: Primary care forms a vital part of the cancer continuum. The ability to understand management flow, to and from primary care could provide improved ability to plan efficient processes for both patient care, as well as for information sharing across sectors.

Risk factor incidence and assessment

Another gap that was identified was the ability to see the incidence of risk factor assessments and their results. Often the primary care clinician is the only source of this information.

Useful for understanding cancer management because: There are a known set of risk factors, and speculation on the effect of more targeted prevention or screening programmes. The first step in being able to establish these is the ability to identify the at risk population in a way that the eventual outcomes can be measured against the same population.

Resource utilisation factors

There are known incidence rates and trends, and known population expansion rates, however accurate and detailed knowledge on the specific amount of resources required, both human and asset related, currently used for cancer management is not available across all points in the cancer continuum.

Useful for understanding cancer management because: Planning for the future requires an understanding of total cancer patient dependence on treatment modalities and their availability and constraints. For example in Radiotherapy some of the constraints are: staffing, machines available, machine downtime, machine lifespan, and bunker space available.

Total spend on cancer

Currently there is no readily achieved, sound basis for arriving at a total cost for cancer patient care. This is where it would include those areas that overlap into other services, such as radiology, theatre time, and imprest pharmaceuticals. This also includes the desire to understand costs for specific forms of cancers, or those associated with stage of detection.

Useful for understanding cancer management because: In order to validate funding decisions, and to be able to plan for anticipated growth or change in cancer management, a sound understanding of fully absorbed cost needs to be achieved.

Emergency Department data for cancer related activity

Emergency services provided to cancer patients are not well understood. While many emergency department systems capture information on the reason for attendance, and there is some coding of this information, the coding it is not presently required in the NMDS. This contributes to one of the gaps in cancer continuum, unless the patient goes on to be admitted, where the reason for their attendance, and any complications are coded and passed into the NMDS.

Useful for understanding cancer management because: Emergency service attendance can provide pointers to the patient status outside of admission or treatment contacts. Over time, delayed consequences of management interventions, or validation of early intervention criteria could be determined, with the ability to correlate reasons for attendance with other known factors for patients with cancer.

Drug usage

A comprehensive view of the medications involved in supporting and treating those with cancer was seen as important. This includes the ability to see the use of non schedule drugs, which can include newly released or otherwise unfunded drugs, or the use of standard products for itch, burn, pain, constipation etc.

Useful for understanding cancer management because: There is considerable research about targeted drugs over a controlled set of cases. A wider view of dispensing and total population could provide the ability for development of high level hypotheses about dispensing options in cancer management.

Laboratory results

There was an interest expressed in seeing a widening of results reported from the current state of just those that provide cancer diagnoses results. E.g. Incidence of smear tests taken prior to diagnosis of abnormal results, where these historical smears are not currently held on the cervical register. There is also interest in the ability to see infection results that may themselves be a risk factor for cancer. Another interest is to be able to measure changes that occur with management decisions and interventions.

Useful for understanding cancer management because: Laboratory results often precipitate, or validate cancer management decisions, therefore being able to identify and understand these inter-relations across the care provided in cancer continuum would provide a useful data source for future management.

Private sector cancer related activity

There is a slow process of obtaining data from the private sector, even when it is for publicly funded activity. Understanding of, and comparability of the privately sourced cancer management is somewhat limited.

Useful for understanding Cancer management because: Differences in equity of access may also be understood where there is the ability to control for personal choice or preference.

Comparability of management decision and outcomes is important for the ongoing ability to plan for the most effective and efficient service to patients with cancer.

Exposure to prevention programmes

There is little ability to measure the long term effects of passive (self sought) or active (targeted programmes to at risk individuals) prevention programmes and whether there is any impact on incidence. There is known to be many forms of cancer prevention education, even down to magazine articles, which may have some effect or impact on certain individuals who actively choose to alter lifestyle choices and so try and reduce the possibility of developing cancer.

Useful for understanding cancer management because: Measurement of this factor would facilitate larger studies of the long term effects of passive or active prevention programmes.

Co-morbidities and their effects

There are many questions about the impact of co-morbidities and their effect on outcomes. An example is: Does pre-existing diabetes impact the severity or progress of certain types of cancer? What is the progression rate of Human Papilloma Virus to cervical cancer in a given population within New Zealand?

Useful for understanding cancer management because: While New Zealand has a much smaller population than most comparable countries, it is still possible that differences in the presence of co-morbidities and their management may affect the interventions selected, or outcomes achieved, for patients with cancer. The ability to know our own population in detail will give the best basis for achieving the established cancer control goals.

Desired reporting

Clinicians have expressed a desire to see a move towards real-time reporting that is able to be searched. The accessibility and ability to search needs to be enabled from disparate locations in order to be effective for mobile clinicians.

Useful for understanding cancer management because: While not isolated to cancer care, many Clinicians desire to see a faster flow of data as this would enable the best possible management decision to be made, on the maximum amount of available information at the time of the decision.

Improving access to existing data

The comment was made, that accessing data is predominantly done by those people who know already how the system works, and what they need to do to obtain access. There are another group of people who would like to access data, but don't know what they would be able to get, or how to go about it.

Overall the desire is to see

- Less barriers to access(reduced process steps to authorisation)
- More timely access (for example not having to wait 6 months for approval), and
- The ability to access electronically.

Useful for understanding cancer management because: Improving the ability to access data increases the potential for clinicians and managers to make more active use of available information in informing cancer management decisions.

Palliative care data

There are few electronic palliative care information systems that collect detailed information on patients in their care, and there are few reporting requirements that are consistently required across the country. Some have reporting requirements to the DHB's in their region, but others,

while having some funding relationship, are yet to develop any patient level reporting. This limits the ability to evaluate the numbers of cancer related cases seen through palliative care services, and the common practice is via management surveys and estimations.

Palliative care clinicians also initiate cancer management and treatment decisions that may use public, private, or palliative care resources. These are not currently able to be measured. Their impact on morbidity, mortality, and resource utilisation is not well understood.

Useful for understanding cancer management because: Improving the ability to understand the palliative care range of services, and their impact on mortality and morbidity, is an important part of closing the gaps across the cancer continuum.

Appendix E – Collections Review

Review of Collection Systems undertaken as a background to the strategic framework

The current knowledge about a patient's journey throughout the Cancer Continuum is largely limited to either clinical studies, or to those areas of clinical and statistical information that deal in detail with a given aspect of a patient's condition or treatment. At the same time there is a lack of information about many other treatments, and the inputs that both precede and follow any known event point.

The current state is still evolving through the history of some isolated developments, and unique code sets, towards unified coding and reporting ability across systems

The following system overviews are not intended to imply strengths or weaknesses of the various cancer (or cancer-related) collections listed, or that cancer is the only measure for assessing their usefulness. The overviews contain a brief description of each collection as it exists currently (or as it is planned to operate once development is complete) and its benefits and limitations relative to cancer control, as input to development of the Cancer Collections Framework.

Part 1: A brief overview of currently operational Collection Systems

National Health Index (NHI)

The National Health Index is a national database containing demographic information about all users of publicly funded health services in New Zealand and is the cornerstone of all NZHIS's data collections. Each health care user is assigned a unique seven character identification number.

There was an issue around accuracy of ethnicity information, due to systems, processes and data handling errors. A programme of work is addressing these issues, to ensure standards in application and use of ethnicity codes going forwards.

There are some known occurrences of duplicate records for individuals, and there are processes in place to identify and merge these records. Over time the rate of duplicates is declining.

Benefits to Cancer Collection:

The National Health Index forms a fundamental part of a true national view, as it provides the mechanism by which multiple services to patients can be connected together.

Limitations for Cancer Collection:

The above issues of speed of access to this Index from some service areas and duplicate numbers, are well underway to being addressed.

National Minimum Dataset (NMDS)

The NMDS was set up in 1993 to be a national collection of public and private hospital discharge information. It includes coded clinical information for Inpatients and day patients, and was back loaded with data to 1988.

It is used for policy formation, performance monitoring, research and review, and also supports the WIES weighted patient funding process.

There have been issues with the geographic information as the Domicile codes are often manually entered into the source Inpatient system without electronic validation against the patient address. One estimate based on re-coding puts the error rate in 2003 domicile code data

at 20%. More recent measures of accuracy of geo-coding were not found during the timeframe of this project.

Benefits to Cancer Collection:

This is a long standing and increasingly robust data collection of admitted patients, holding useful clinical management information in the diagnoses and procedure code fields. There is an annual process for incremental changes.

Limitations for Cancer Collection:

There is a known gap, that is, not all Radiological Procedures are recorded. The NMDS also contains records from private hospitals that do not provide the same level of clinical information as public hospitals. Information about the stage of disease is not reliably reported through the NMDS.

Mortality Collection

This provides data on deaths registered in New Zealand from 1988 onwards (with data from 1970 to 1987 also available on request). It is used for public health research, policy formulation, development and monitoring of health initiatives and programmes, and cancer survival studies. It also feeds into the World Health Organization for use in international comparisons of mortality statistics.

The NZHIS Mortality Collection classifies the underlying cause of death for all deaths registered in New Zealand, including all registered foetal deaths (stillbirths), using the ICD-10-AM 2nd Edition and the WHO Rules and Guidelines for Mortality Coding. Selected contributing causes are also coded, including any cancer recorded on the death record that is not reported as the underlying cause of death. Foetal and infant data is a subset of the mortality collection. Extra variables such as gestation and birth weight are collected for these records.

Benefits to Cancer Collection:

The NHI database is updated with dates of death from the Mortality Collection data, thus allowing calculation of cancer survival. It also provides a source of notification to the Cancer Registry of previously unreported cancers which have been clinically diagnosed and for which no histological samples have been examined.

Limitations for Cancer Collection:

The data is currently about 2 years behind, with issues around the processes affected as a result of prolonged coroners' enquiries, and delayed notification of the causes of death for these cases.

Not all contributing causes of death are recorded e.g., immunosuppression due to chemotherapy would not be coded.

New Zealand Cancer Registry (NZCR)

This was set up in its current form in 1994 after the Cancer Registry Act 1993 and Cancer Registry Regulations 1994 were introduced to increase reporting of primary cancers in New Zealand. Prior to this a partial collection goes back to 1948.

It is a population-based register of all primary malignant diseases diagnosed in New Zealand, (excluding squamous cell and basal cell skin cancers). Data is used in research, monitoring, and evaluating of cancer screening programmes.

Since the Cancer Registry Regulations 1994 came into effect, laboratory test results of cancer have been collected, and consequently the data quality and completeness have significantly improved.

Occupation is a known gap within the register, which was a previously held data element that was discontinued and yet is now again considered desirable for tracking potential risk exposure.

Benefits to Cancer Collection:

The NZCR provides the crux for the collection, as it is the definitive point for registration of all new diagnoses of cancer. Auditing demonstrates a high level of confidence in the coverage of this collection.

Limitations for Cancer Collection:

There are some limitations on the detail coded, as factors such as staging or extent of disease are not always provided from the diagnosing source. The NZCR does not collect and hold any treatment information.

Breast Screening Aotearoa (BSA)

BreastScreen Aotearoa (BSA) was established in 1998 and is a free national breast x-ray (mammography) service that aims to detect breast cancer in its early stage. This programme is offered to all women in New Zealand aged between 45-69 years who have no symptoms.

BSA services are delivered by eight Lead Providers (LP's) across the country. Each LP maintains their own operational information system containing the information on women within their care who are participating in the programme. Each LP's system and database are audited by BSA.

Each LP provides monthly extracts as defined by BSA. These are sent to the national monitoring database which is currently hosted by NZHIS. Each month NZHIS then sends a complete copy to BSA who then perform data quality check and provide reports. Any corrections required in the data are reported to the LP, with the LP sending the corrected data from their system through to the national monitoring database.

Benefits to Cancer Collection:

The BSA information systems hold women's test results, diagnosis (including tumour size) and cancer treatment data for those women who receive treatment through BSA (delivered by the 21 DHBs). Data collected by BSA systems is regularly audited and assessed as being of good quality.

Limitations for Cancer Collection:

Data is not currently collected for women screened or receiving treatment outside BSA.

National Cervical Screening Programme Register (NCSP)

The National Cervical Screening Programme (NCSP) is a cancer screening programme to reduce deaths from invasive cervical cancer. The programme is designed to provide a pathway aimed at the detection and treatment of pre-cancerous squamous cell changes of the cervix.

The NCSP Register (NCSP-R) initially comprised 14 stand-alone registers in 14 area health board regions which became fully operational in early 1992. In 1997 these registers were reconfigured into a central register which is now managed by the National Screening Unit (NSU).

External access and/or data entry to the NCSP-R is generally through manual requests, provision of floppy disks, or electronic transfers to NCSP Regional Services or NSU system administration staff.⁴ There is some online access to screening histories.

This NCSP-R is currently being redeveloped. There are plans to ensure that the new NCSP information system has improved collection of data, enables easier access to a national view of data, and to incorporate automated electronic links to related datasets such as the New Zealand Cancer Registry, Mortality Collection and the proposed NCMD.

⁴ Note: Online access for laboratories to the NCSP Register for smear history information has recently been implemented for two laboratories

Benefits to Cancer Collection:

The NCSP-R captures test results (negative or positive for pre-cancerous/cancerous cells) and information on screening services accessed by women. Since 2005 the NCSP-R has captured pre-cancer diagnosis (colposcopy) and treatment information.

Limitations for Cancer Collection:

Data is not currently collected for women screened or receiving treatment outside the NCSP. Data is also not currently collected on a woman's treatment once she has been diagnosed with cancer.

Women may choose to withdraw from the programme, and their screening information is then no longer held.

Medical Warnings System (MWS)

This was set up originally as part of the National Master Patient Index (NMPI, a precursor of NPI) in 1977. It holds information on adverse reactions and critical notifications, and is mainly used for registering severe drug, product, and substance allergies.

While identified as a source for the proposed NCMD, there is currently little information regarding cancer status or treatment. There is one field available, however this is free text and subject to very varied application.

At present there is no programme of work identified to enhance this collection for increased benefit to cancer.

Benefits to Cancer Collection:

None in its current state.

Limitations for Cancer Collection:

Updates are done via the Center for Adverse Reactions Monitoring (CARM) based on submitted information from GP's, so is second-hand, time delayed, and tends towards only critical medication reactions.

National Booking Reporting System (NBRS)

This was set up in 2000 and holds information by Health Speciality Code (HSC) and booking status. It shows how many patients are waiting for treatment, and also how long they have had to wait before receiving treatment.

The NBRS contains details of all booking status events involving a healthcare user who: *both receives a priority for an elective medical or surgical service, and is likely to receive publicly funded treatment.*

Information is collected about the first specialist assessment, their assessed priority, and their booking status. Cancer related surgery would not be identifiable from the general surgery, as they both are under the same Specialty code.

There are some Outpatient statistics reported, however this is not currently at the level of detail of procedures for cancer such as chemotherapy.

Benefits to Cancer Collection:

Currently would provide the ability to know waiting times for planned procedures for known cancer cases where a link by NHI is made.

There is potential for cancer related extension to collection to be considered if and when a re-write of the current booking system is performed.

Limitations for Cancer Collection:

Limited clinical information is available. Matching on NHI from a known cancer population would be indicative of level of overall health care being received, albeit not necessarily that related to cancer.

Primary Care Indicators

Primary care indicators arose out of the requirement within Clinical Services Directorate for PHO Performance Monitoring. There have been 2 phases to date.

- The first phase established the process for data submission, and was limited to readily available electronically captured elements. These tended to be high level.
- The second phase is in rollout at present, with vendors for primary care Patient Management Systems making changes to their underlying product to enable capture and reporting of prioritised indicators. These are split into clinical and management indicators with the majority being clinical.

Benefits to Cancer Collection:

This development is helping improve the connection between the Primary Care sector and Ministry of Health.

Limitations for Cancer Collection:

Submission of data is at an aggregated level.

Issues of purpose and use of data needs to be negotiated with the Primary Care sector.

PHI Online (Public Health Intelligence)

PHI online is a readily accessible, high level demographic, web enabled display of a small set of population health data. Currently this collection holds data from two sources. The New Zealand Health Survey – which includes Chronic Diseases and Risk & Protective Factors, and data sourced from the New Zealand Health Information Service, such as hospitalisation rate, cancer registrations, and mortality.

These collections can be broken down further to specific risks, e.g. Smoking, and Specific cancers (currently only Breast, Cervical, Colorectal, Lung and Prostate).

The data is provided in a regionalised form, displaying the DHB regions, and giving a National average. There are some datasets that do not have complete data for all regions, these are identified and excluded, but do not hinder the other regions from displaying for that measure.

Benefits to Cancer Collection:

This is a visually interesting, discussion stimulating representation of health measures, including those for key cancers and mortality. It provides ready access to aggregated data from any web browser. It provides a visual and numeric way of viewing risk and protective factors.

There is potential and interest in expanding the data elements represented within this display to promote further discussion, debate and interest in national and regional health issues.

Limitations for Cancer Collection:

Only a selection of data elements currently available, and these are regionalised and are not drillable at present. There are plans to take them down a level to geo-coding where this is available.

There is no representation of PHO, but if available as a value this could be included, however rules around overlapping geography would need to be developed.

Laboratory Claims Warehouse

The Laboratory Claims warehouse contains the data processed for laboratories through HealthPac, plus some additional labs data from Pegasus Health and Medlab South. All cancer related pathologies are required to be reported to the New Zealand Cancer Registry.

Benefits to Cancer Collection:

Linking to this warehouse on NHI would allow the ability to see associated tests being performed that were not directly associated with cancer diagnosis, but were indicators of patient status. For example seeing a wound swab post radiotherapy treatment or surgery could suggest

the risk of infection; an arterial blood gas test could indicate the possibility of respiratory complications; a white cell count, which is critical to measuring the response to chemotherapy.

As with any dataset, detailed analysis would be needed to determine if there were any significant relationships, but without the base data, no analysis could be done without specific targeted research of a select population.

Limitations for Cancer Collection:

One of the most significant factors is the degree of analysis that would be required to filter the relevant results from such a large data-source. The gradual expansion of the area of data mining could assist in this process in years to come. Not all records have an associated NHI, although this is being addressed.

Pharmacy Warehouse

The Pharmacy warehouse contains claim and payment information from pharmacists for subsidised dispensings that have been processed by the HealthPAC General Transaction Processing System (GTPS). Additional information is sourced from: Statistics NZ (Geographical and Census data; claimant data is geo-coded by the NZHIS geo-coding engine); HealthPAC (provider reference data); Pharmac (the Pharmac Schedule and mappings).

The Pharmaceutical Collection is accessed by authorised NZHIS and Pharmac staff for maintenance, data quality, audit and analytical purposes. Authorised members of the Ministry of Health and DHBs have access, via Business Objects and the secure Health Information Network. Business Objects contains a subset of the data described in the Data Dictionary.

Benefits to Cancer Collection:

The ability to see cancer related dispensing information would be of great interest and importance for cancer management.

Limitations for Cancer Collection:

Currently only dispensing funded on the schedule is captured. This excludes some of the newer treatments that have yet to complete funding approval, and some over the counter, or patient preferred alternatives to funded options. Not all dispensing has a NHI recorded, although this is progressively being resolved.

HealthPac

HealthPac receives the funding claims from the Health Sector, and process the payments for services. While auditing and processing claims is its primary directive, it holds some patient level data where this is provided in the course of lodging a claim.

HealthPac currently has multiple databases set up for discrete purposes; however a project is underway to provide a consolidated database to provide a unified view for Auditing and Compliance.

Benefits to Cancer Collection:

A count and grouping of activities, obtained using a link by NHI, could help to fill in the blanks between hospital admissions. Even if only aggregated numbers, it could be possible to compare the rate of services, for example home help or domiciliary nursing, to cancer patients in the year post diagnosis.

These collections may be the only available data source for some services until new systems are developed and implemented, for example, Primary Care Collection.

Limitations for Cancer Collection:

The use and purpose of the data would need to be addressed if there was a desire to use this as an interim source for primary care, community and other funded services. Suppliers of data may not submit data for all services provided, and some Providers will not be represented in Health Pac collections at all. Not all records passed to HealthPac have an NHI recorded.

Part 2: A brief overview of planned or proposed Systems Development

National Cancer Management Database

This has been through a feasibility study, and is progressing to business case development. If approved, there is projected to be an anticipated phased implementation process over a 4 year time period.

The drive for this arose out of the New Zealand Cancer Treatment Working Party - Information Technology Subgroup sitting under the Cancer Control Council. The work identified deficiencies in the current situation whereby cancer databases are “not comprehensive nor well coordinated”, as well as a lack of information on what is considered key areas within cancer, such as stage and details of treatment.

Benefits to Cancer Collection:

This proposed development would form a core component that enhances the ability to view, report and understand questions related to cancer treatment and management within New Zealand. Cancer management and interventions have changed significantly over time, and there is a much greater emphasis on non-admitted services that have been difficult to count and measure. This database will enable a more detailed view of cancer management.

Limitations for Cancer Collection:

The limitations will be due to the availability and quality of cancer management information from source systems, and the existing gaps in treatment information collection from non-inpatient services. Over time, these gaps are anticipated to close.

National Non Admitted Patient Collection

This collection is in the development phase with the basic collection of patient attendances due 1 July 06. This will encompass person identifier, an attendance type, and a count. The HPI is not currently included in the collection as it is not universally available across the sources, and further work needs to be done around the business rules e.g. who is coded as the HPI for an attendance group clinic that could be performed by any one of several attending doctors from House Surgeons to Consultants.

The second phase will consist of adding in more clinical information such as procedures performed. This will be piloted in 2007. There are also known issues with Ownership and Overview – Governance issues between the Data Dictionary (purchasing) and the Data Definitions (events)

Benefits to Cancer Collection:

This will provide the minimum dataset view for non-admitted cases of which there is an increasing number. This in itself will contribute to closing the gap of ability to see non-admitted services to cancer patients.

Limitations for Cancer Collection:

The initial dataset will be a count only. Clinical information will require significant investment in capability for capture and coding.

Health Practitioner Index

This planned dataset will hold the national practitioner identifier and related details. It will also be an enabler to authorised secure transmission of clinically related data between providers at all levels of health care. The current timeframe for implementation commencing is 2006, although uptake will be progressive as systems become capable of both looking up the HPI, and holding the required values.

The HPI dataset itself has the capacity to store the practitioners' ethnicity, location, and languages spoken, however mechanisms for the population and updating of these fields are not yet clarified.

Benefits to Cancer Collection:

The ability to know the ethnicity of providers could assist with the evaluation of programmes that use the “by Maori for Maori” principle. The ability to see ethnicity and languages could help test theories around issues of access to services. The location of the practitioner compared to the location of the patient will help the ability to measure location demands, and potentially assist in the workforce planning for cancer services.

Limitations for Cancer Collection:

It is likely that the use-ability of this collection will be initially quite limited, but will expand over time with uptake by other source systems, and support from practitioners.

Primary Care Collection

This collection is identified in the HIS-NZ Action Zones and if progressed along the outlined timeframe it should have data collection established in 3-5 years. It is in the early days, with the business case yet to be written, however there is a general understanding that the intention would be to encompass a National Minimum Data Set for Primary Care.

The Primary Care collection could provide significant knowledge about the early diagnostic and prognostic factors, and would enable a future state with a significantly more knowledge rich environment for those carers. This development is sitting with the Clinical Services Directorate

Benefits to Cancer Collection:

This will enable a view or minimum dataset to measure what level of services are being provided by primary care providers.

Limitations for Cancer Collection:

Timeframe for implementation and extent of stakeholder buy-in are risks. Capacity and refinement will take some time to bed in.

Appendix F – Glossary

BSA	Breast Screen Aotearoa
CARM	Centre for Adverse Reactions Monitoring
DHB	District Health Board
HIS-NZ	Health Information Strategy for New Zealand
HPI	Health Practitioners Index
HSC	Health Specialty Code
MHINC	Mental Health Information National Collection
MoH	Ministry of Health
NBRS	National Booking Reporting System
NCMD	National Cancer Management Database
NCSP	National Cervical Screening Programme
NHI	National Health Index
NMPI	National Master Patient Index (precursor to the NHI)
NNPAC	National Non Admitted Patient Collection
NSU	National Screening Unit
NZCR	New Zealand Cancer Registry
NZHIS	New Zealand Health Information Service
PHI Online	Public Health Intelligence Online
PHO	Primary Health Organisation
WIES	Weighted Inlier Equivalent Separations