Document information

HISO 10038.0:2017 Preface to the Cancer Data Standards

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Keeping standards up-to-date

HISO standards are regularly updated to reflect advances in health information science and technology. See our website for information about the standards development process. We welcome your ideas for improving this standard. Email standards@health.govt.nz or write to Health Information Standards, Ministry of Health, PO Box 5013, Wellington 6145.

Contents

1 Purpose of this document

This document is a preface to the published cancer data standards and provides guidance for anyone looking to:

- develop a specialised cancer data set specification

- create a new data set containing cancer related data elements

- add new cancer related data elements to an existing data set.

Follow the guidance to ensure that new cancer data set specifications conform to the established standards and can be used with other cancer data sets.

2   Background

The cancer health sector is operating in an age where expectations concerning information are high. New technologies foster an expectation of access to real time and accurate information at the touch of a button. Evidence based medicine must be supported through high quality data collection and analytics.

2.1   Cancer Health Information Strategy

The New Zealand Cancer Health Information Strategy published in 2015 describes a pragmatic approach to achieving the vision of comprehensive, accessible and accurate information to support the delivery of quality care across the cancer patient pathway.

A key goal is to standardise and link cancer data sets in New Zealand. This allows for more reliable comparisons over time, geographical location, disease type and treatment type. This will support answering questions about:

- determinants of cancer
- equity of access to health services
- resource allocation
- service improvement opportunities
- the cancer patient journey and experience
- effectiveness of cancer interventions.

Information on cancer patients is currently collected by a plethora of health providers in many different settings. Building a view of the cancer patient journey – from initial referral to diagnosis, treatment, outcome and survivorship – is therefore a manual and resource intensive process. Establishing a reliable and accurate picture across a cancer type, region or demographic group is challenging.

The New Zealand Cancer Health Information Strategy, developed by over 50 stakeholder groups, sets the strategic direction for the sector to 2020. The strategy is built on the premise that there is no silver bullet solution to achieving its objectives of better quality information for patients, clinicians and service managers. Instead, it frames a number of strategic principles and strategic interventions as a basis for delivery by everyone working in the cancer sector.

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

Improving the quality of cancer information is an ongoing priority for the Ministry of Health, district health boards and the wider sector. In February 2014, the Central Cancer Network undertook a stocktake of cancer-related information projects and identified at least 30 relevant projects underway. At a national level, this includes National Patient Flow. At a regional level, DHBs are investigating better support for multidisciplinary meetings, e-referrals, pathology and radiology information systems and clinical information systems for cancer services.

The Cancer Health Information Strategy will help coordinate the various initiatives to ensure conformance with standards, national consistency in data management and strategic alignment with the New Zealand Health Strategy.

For more on the Cancer Health Information Strategy see the Ministry of Health website: http://www.health.govt.nz/publication/new-zealand-cancer-health-information-strategy.

2.2 Strategic principles

The Cancer Health Information Strategy establishes a set of strategic principles:

- Stakeholders' needs for cancer health information are understood and supported
- Collection of patient-specific cancer health data occurs at the point of care wherever possible, and is integrated with patients' health records
- Duplication of cancer health data is minimised
- Ethnicity data is collected according to *Ethnicity Data Protocols for the Health and Disability Sector*
- Standardised data definitions are used
- SNOMED CT is the clinical terminology standard used to capture cancer information at point of care.

2.3 Strategic interventions

The Cancer Health Information Strategy establishes a set of strategic interventions:

- Establish a national framework for managing consistent change to cancer data, information and intelligence
- Standardise, digitise and make accessible cancer data at point of care
- Aggregate relevant patient and cancer service data into cancer information
- Analyse information, produce cancer intelligence and communicate it to stakeholders..

2.4 Cancer data standards

National cancer data standards include the following:

- HISO 10038.0:2017 Preface to the Cancer Data Standards (this document)
- HISO 10038.1 National Cancer Core Data Business Process Standard
- HISO 10038.2 National Cancer Core Data Messaging Standard
- HISO 10038.3 National Cancer Core Data Definitions.

These are key documents that cancer data set developers should be familiar with when creating or extending a data set.

3 Extending the cancer data standards

Cancer data needs to be collected and reported in a standardised way in order for meaningful comparison across geographic regions, cancer types, health services and time. Standardised data sets also create interoperability between disparate information systems and allow cancer information to be shared more easily.

There are multiple cancer service improvement initiatives happening or planned for the future – for example, radiation oncology service and multi-disciplinary meeting improvements. This ongoing work is likely to produce data set specifications that become part of the wider set of cancer standards.

A programme has been established to implement the Cancer Health Information Strategy. The programme team intends to review and extend the published cancer data standards to cover the major cancer types and to capture more about the diagnostic and treatment process in pathology, radiology, medical oncology, radiation oncology and surgery. The extended data sets will include cancer and tumour type specific data elements. It is anticipated that the majority of the core data definitions in the current standards will remain unchanged.

3.1 Health information standards

A goal of the Cancer Health Information Strategy is to promote the interoperability of data sets, where all cancer data sets adhere to the same data standards and definitions. At present there may exist multiple definitions for the same data element. Consolidating these definitions is a priority.

The Ministry promotes the development and adoption of health information standards through the Health Information Standards Organisation (HISO). Standards produced through the HISO process are published by the Ministry for adoption by DHBs and other health providers. Conformance with HISO standards is a condition of the DHB Operational Policy Framework.

It is important when working on cancer related data sets that HISO standards are followed.

The following standards in particular are important.

3.1.1 SNOMED CT for clinical terminology

SNOMED CT is the standard for clinical terminology in the New Zealand health and disability sector. SNOMED provides a rich and consistent means to exchange, store, retrieve and aggregate clinical data across specialties. SNOMED enables structured information to be collected at point of care, used for clinical documentation and clinical decision support, communicated between health providers and used for data analytics.

DHBs are required by the Ministry to implement SNOMED with all new investment in clinical information systems.

Those developing new data set specifications or adding new data elements to existing data sets or systems must use SNOMED.

More information about SNOMED can be found here: http://www.ihtsdo.org/snomed-ct

3.1.2 Structured reporting guidelines

The Royal College of Pathologists of Australasia (RCPA) promotes the science and practice of pathology and has members in Australia, New Zealand, Hong Kong, Singapore, Malaysia and Saudi Arabia. Their objective is to further the science of pathology by promoting research, discussion and collaboration.

It is anticipated that pathology reporting will move towards a structured or synoptic approach, where, rather than the entire pathology report being written as a free text summary, data elements are recorded as discrete items in their own individual fields. A key advantage of this approach is that individual pathology data elements can be easily extracted, stored and analysed.

The New Zealand Cancer Registry will in future collect pathology data in line with the RCPA structured reporting guidelines.

3.2 Data set specifications

A data set is a collection of related data elements (sometimes called data items or attributes) collected for a given purpose.

A data set specification (or data dictionary) describes the structure of a data set. The specification comprises a comprehensive description of each data element. At a minimum, a data set specification should include the following for each data element:

1. the name of the data element

2. an unambiguous clinical or business definition of the data element

3. the data type and format in which the data element should be collected

4. the data domain from which the data element takes values

5. whether the data element is mandatory, optional or conditional for collection

6. any data standards that pertain to the data element

7. guidance on processes for the collection, verification and use of the data element.

When defining a new data element it is important to explain why the information should be collected. It is also worth thinking about how the information can be collected in a consistent way. Perhaps the new data element is already being collected by someone else.

The Ministry's National Collections, including the New Zealand Cancer Registry, are described on the Ministry of Health website http://www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/collections).