CanShare
Sharing
Cancer
Information

Dr John Fountain
Manager: Data, Monitoring and Reporting
Te Aho o Te Kahu

Mā te kimi ka kite, mā te kite ka mōhio, mā te mōhio ka mārama.

Seek and discover, discover and know, know and become enlightened.

Tēnā koutou katoa,

It is a pleasure to share the fifth CanShare newsletter with news on the many achievements since our last update in September.

Below we share the continuing progress in the national collection of systemic anticancer therapy (SACT) data - a critical piece of knowledge to support patients, clinicians, and build a national understanding of cancer care. Of particular interest is the ongoing implementation of the Northern Region's 'Raurau Ngaehe' oncology e-prescribing software, the first application built to meet CanShare standards. We also share the team's work to develop a Logical Information Model (LIM) which is a critical step to ensure the shareability of information.

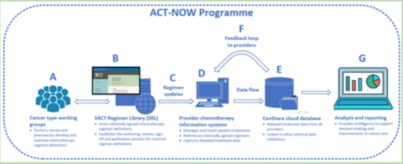
Important work has also commenced with Te Whatu Ora Health New Zealand, and business partners to build a FHIR (Fast Healthcare Interoperability Resources) data repository. This is a major part of the CanShare technology infrastructure which will be covered in detail in a future newsletter.

I am also delighted to highlight more people who have made significant contributions to cancer care and the CanShare programme: Dr Humphrey Pullon, and the data managers who support national data collection. I would also like to recognise the clinicians and care providers who work so hard and diligently, often in challenging situations, to deliver quality care to the people across Aotearoa New Zealand. I hope you all enjoy a break with whānau and friends over the summer months.

Radiation Oncology (ROC)

Recently Alex Dunn and Dr Shaun Costello presented at the Radiation College 2023 Annual Scientific Meeting in Brisbane. Their talk, titled "The New Zealand Radiation Oncology Collection (ROC): Recent successes and future plans" showed how ROC supported quality improvement since 2018 and how future upgrades (under CanShare) will enable new applications such as real-time decision support, auto-population of oncology information systems and clinical trial participant selection. The talk was well received, and they identified several opportunities for trans-Tasman collaboration.

ROC is currently being upgraded to a modern, cloud-based infrastructure. This includes updating ROC data validation rules, data-submission processes, and data quality feedback processes. These are focused on streamlining data submission and data quality activities for data managers. If you would like to know more about this work, please contact Alex Dunn.



Anti-Cancer Therapy – Nationally Organised Workstreams (ACT-NOW)

We are on the verge of providing quality insights to inform decision-making! We have data from 40% of the country. While this data is not yet what we would call CanShare standard, using SNOMED CT for data capture and FHIR for data exchange, there are still valuable insights to be gleaned from this data as part of the ACT-NOW analytics. In 2024 we will onboard the northern Raurau Ngaehe system, a new oncology e-prescribing system that will service the four northern districts. Raurau Ngaehe will use SNOMED CT for data capture and FHIR for near real-time data exchange, which will make it the first CanShare standard system in Aotearoa. It will also be the first vendor system to formally connect to the CanShare infrastructure. This will increase ACT-NOW data coverage to over

70% of Aotearoa, and we will then focus on supporting e-prescribing implementation across Te Manawa Taki region.

A prototype dashboard is providing information across key domains like treatment access, wait-times (from diagnosis to treatment), SACT prescribing patterns and patient outcomes. This dashboard is being tested by approximately 50 clinicians, nurses, and pharmacists across the SACT community. Over time we will expand this group as we systematically identify and act on improvements to the data, analysis, and presentation. 2024 will see a major push into the data quality space as we build confidence in the data and its ability to inform decision-making.

The ACT-NOW SACT Regimen Library (SRL) is almost complete with regimen implementation progressing well across the motu. During 2024 regimen refresher workshops will continue across cancer types to ensure they align with current practice and medicines availability.

We welcome feedback, particularly on ways to drive and maintain data quality, and produce, present and share insights. To learn more, provide feedback, or register your interest in reviewing our prototypes, please email Alex Dunn.

Structured Pathology

Over the last two years we have released, in partnership with the sector, 17 HISO (Health Information Standards Organisation) endorsed pathology data standards. Currently we are developing up to 40 data standards across Gastrointestinal (Pathology lead Dr Michael Lau), Genitourinary (Pathology lead Professor Brett Delahunt) and Soft Tissue and Bone (Pathology lead Dr Pennie Symmans).

The learnings from this mahi are helping us develop industry leading tools to better aid providers and vendors to implement our standards with our clinicians from 2024. Below we share more detail on this exciting development.

To learn more about structured pathology, please contact John Manderson

The CanShare LIM

We are developing a new foundational standards product - the CanShare Logical Information Model or LIM. This will significantly streamline the data standards development process, and better support standards adoption as we begin implementing CanShare from 2024.

To help explain the why, what, and how of the CanShare LIM, we have put together some frequently asked questions below.

What is the LIM?

This is a data model that represents the information requirements for sharing cancer data throughout Aotearoa. It defines the data elements, constraints, and terminology bindings needed for each cancer-related topic, and how they are grouped. This provides a blueprint for representing data consistently across our cancer projects.

Why are we using a LIM?

By representing data consistently across the CanShare platform, the LIM supports the integration of disparate data silos, enabling data to flow more easily between different cancer settings. This enables CanShare's key goals of enabling the timely sharing of relevant and accurate cancer data, supporting clinical and patient decision making at the point of care, and supporting advanced analytics capabilities.

The LIM will streamline the data standards development process by creating a library of reusable data building blocks. These will:

- reduce the time health care professionals spend validating data standards
- ensure consistent data collection across all modalities and specialities of cancer care
- streamline clinical and technical review processes to align with changes in clinical reporting protocols

- provide a more efficient process for building implementable forms and questionnaires.

What is in the LIM?

It contains:

- a collection of data groups, representing common sets of cancer-related data. For example, patient details, a specimen, a body site, the dimensions of a tumour, the staging of a cancer, or the results of an immunohistochemistry test;
- a collection of compositions, which combine these data groups into a document for a specific cancer-related purpose. For example, a pathology request for a breast tumour, a pathology report for colorectal cancer, a systemic anti-cancer therapy care plan, or a surgical procedure summary; and
- a set of implementable questionnaires generated from the compositions to collect data using the defined data elements and standardised value sets.

How the LIM links to FHIR and SNOMED CT

HL7 FHIR (Fast Healthcare Interoperability Resources) and SNOMED CT (clinical terms) are the two fundamental standards the CanShare platform is designed to integrate. For example:

- Data elements are defined using FHIR data types, for example, Codeable Concept
- Codeable data elements are bound to SNOMED CT value sets and fixed values from the NZ SNOMED CT edition on the NZ HTS (Health Terminology Server)
- Data groups are designed with an associated FHIR clinical resource in mind, to make it easier to map to FHIR resources for implementation
- FHIR questionnaires are generated from compositions to create implementation artefacts.

What are the next steps?

These will include:

- building a library of common data groups to support a range of use cases for colorectal, breast and soft tissue cancers
- developing LIM compositions and questionnaires to support planned standards and implementations, including histopathology requests and reports for colorectal cancers
- expanding the library of common data groups, compositions, and questionnaires to support additional use cases, including for gastrointestinal, genitourinary, bone, thorax and haematology cancers.

This foundational mahi will speed up both the release of HISO endorsed data standards and pilots and implementation planning with the sector.

For more information, please contact Linda Bird.

Spotlight on Dr Humphrey Pullon

Clinical Haematologist, Dr Humphrey Pullon specialises in haematological malignancies, including lymphoma and autologous bone marrow transplantation. Humphrey has served the Te Manawa Taki region, working from Waikato Hospital and the Rotorua Haematology Outreach Clinic since 1992. He was appointed as Clinical Director of the then Midland Cancer Network in 2012, and when Te Aho o Te Kahu was established in 2019, he transitioned across as a Clinical Advisor, with a special focus on blood cancer. More recently he has served as the Chair of the Haematology Working Group, and along with Cushla Lucas has led the Stem Cell Transplant and Cellular Therapy work stream of the Cancer Services Planning programme.

Beyond his wider contribution across Te Aho o Te Kahu work programmes, Humphrey has played a key role in developing CanShare. He was part of the Radiation Oncology Collection (ROC) team in 2018 and played a critical role in its implementation. More recently, Humphrey championed the ACT-NOW project and contributed heavily to its haematology regimen and data specification groups. He has been involved in the Structured Pathology project and sits on the CanShare Data Standards Clinical Review Group to help ensure relevance and consistency of data standards across CanShare workstreams. Humphrey brings an equity focus to his work and has made a strong contribution to equity focused reporting requirements across CanShare projects.

In 2022 Humphrey was awarded the New Zealand Public Service Medal for his work in the public service, as a doctor, an equity champion, and for his broad contribution to improving outcomes for people with cancer in Aotearoa.

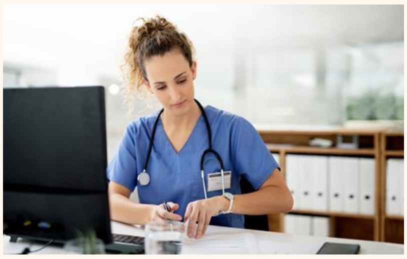
Humphrey, thank you for your huge contribution to almost every area of the CanShare programme!

Breast cancer quality performance indicator (QPI) monitoring report

Breast cancer is the most common cancer in Aotearoa, with approximately 3,500 people diagnosed with it each year. Te Aho o Te Kahu and the Breast Cancer Foundation NZ are currently working together on the calculation of a set of breast cancer diagnosis and treatment QPIs (Quality Performance Indicators).

We also have a services agreement in place with the Breast Cancer NZ Registry Trust (BCNZRT) to calculate and report on the breast cancer QPIs using their data. This is the first time we are calculating QPIs using data from a third party, as the BCNZRT data is more detailed than that of the New Zealand Cancer Registry.

We plan to release the breast cancer quality monitoring report in the first quarter of 2025.



Cancer data managers

Data manager is a loose term we've used to describe the small number of people in the sector who are directly responsible for the provision of data to our key data collections, particularly ROC, ACT-NOW, CPSSS (psychosocial) and FCT. They often have primary jobs as radiation therapists, pharmacists, nurses, psychologists, social workers, IT-system superusers, database administrators or managers to name a few, and serve as data managers over and above their primary role and in addition to their regular workload. These individuals operate behind the scenes and in relative silence to ensure that data of the highest possible quality is submitted on time, in the correct format and to the correct place. They possess an eye for detail, a deep understanding of the data and IT-systems they work with and have the unenviable job of telling doctors when their data is not up to scratch!

Without data managers we would not have any national cancer data collections like ROC, ACT-NOW or FCT, and any of the insights these projects continue to produce. Thank you to these data managers for being key enablers of the CanShare programme and the valuable insights and quality improvement activities.

TE AHO
O TE KAHU
CANCER
CONTROL
AGENCY

✉ Forward

Te Aho o Te Kahu
Info@teaho.govt.nz