CanShare Sharing Cancer Information

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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 has been a busy time for the CanShare programme since our last update. Progress of our ACT-NOW (Anti-Cancer Therapy – Nationally Organised Workstreams), Structured Pathology, and ROC (Radiation Oncology Collection) programmes has been very encouraging, and is outlined below. The Analytics Team has also delivered with the launch of the excellent 'Cancer in Numbers in Aotearoa New Zealand' section on our website. This is certainly worth a visit.

We are thrilled that Dr Linda Bird, of SNOMED International fame, has joined the Data, Monitoring and Reporting (DMR) Team to work on CanShare. A short 'taster' describing the benefits of SNOMED CT is included below, as is an introduction to Linda herself.

CanShare has just published to the New Zealand Health Terminology Server its first tranche of 72 reference sets (becoming available in April) - doubling the number now available to the sector. Many more will be published over time to fully describe CanShare data, with another major release planned for October.

Great work is also underway in the development of HISO (Health Information Standards Organisation) Standards to describe CanShare. HISO published its first standard in 2004, and has now published 54; the CanShare Structured Pathology Team have in excess of 80 standards under development, highlighting how detailed and robust the CanShare implementation will be.

Finally, I am pleased to announce that Ah-Leen Rayner, Chief Executive of New Zealand Breast Cancer Foundation and Nicola Hill, Acting Chief Executive of Te Aho o Te Kahu, have signed a partnership proposal for the integration of Te Rēhita Mate Ūtaetae (the Breast Cancer Foundation National Register) into the CanShare Platform. This is an exciting opportunity to understand how best to bring a currently separate cancer dataset into the CanShare environment. As other registers are linked with CanShare an increasing wealth of knowledge will become accessible, improving our understanding of cancer in Aotearoa and leading to improved outcomes for whānau with cancer.

Below: Te Aho o Te Kahu Data, Monitoring and Reporting Team on a rare day together in Wellington (absent: Assoc Prof Jason Gurney and Dr Brent Caldwell).

Boosting the Benefits of CanShare with SNOMED CT – Dr Linda Bird

CanShare is a leading initiative to enable the collection, sharing, and analysis of cancer data in New Zealand. As a semantically-rich clinical terminology, SNOMED CT will play a pivotal role in CanShare.

SNOMED CT is maintained and distributed by SNOMED International and customised for cancer care in Aotearoa by the Data, Monitoring and Reporting (DMR) Team at Te Aho o Te Kahu (with the kind support of the New Zealand SNOMED CT National Release Centre at Manatū Hauora, Ministry of Health).

SNOMED CT will help to '*boost the benefits*' of CanShare in the following ways:

Data entry: Standardising the sets of codes used to capture different types of clinical data

Clinical terms: Offering terms for each clinical meaning that are selected by New Zealand clinicians and designed specifically for the cancer domain

Data sharing: Supporting the consistent sharing of cancer data using codes that uniquely identify each distinct clinical meaning

Decision-making: Supporting decision-making by enabling patient data to be aggregated in multiple ways based on its clinical meaning, queried using advanced logic techniques, and linked to clinical rules and guidelines based on the meaning of codes in a patient's record

Clinical research and analytics: Enabling powerful clinical research and data analytics across a wide variety of clinical data, using the rich web of definitional relationships in SNOMED CT and its powerful query language (Expression Constraint Language – ECL).

Over the last few months, the DMR team has made great progress by developing our first 72 SNOMED CT reference sets. Each reference set has been carefully designed for a specific purpose, technically validated to ensure that the concepts selected are consistent in meaning, and reviewed by a team of clinical experts. In some cases, new SNOMED CT concepts were authored to ensure the complete

coverage of clinical requirements. And for every concept in these reference sets, a clinician-friendly term was selected as the preferred term to use for cancer data in Aotearoa. This careful curation of each reference set is critical to ensure that cancer data can be collected, shared, and queried in a consistent and reliable way.

This first delivery of SNOMED CT reference sets for CanShare includes:

- 10 reference sets used only by the Anti-Cancer Therapy – Nationally Organised Workstreams (ACT-NOW) Data Standard

- 6 histology reference sets for haematolymphoid tumours (based on the WHO (World Health Organization) Classification of Tumours, 5th edition)

- 43 TNM (Tumour, Node, Metastasis) cancer staging reference sets for breast and haematologic malignancies (based on the AJCC Cancer Staging Manual, 8th edition)

- 13 reference sets used across a range of cancer data standards (including ACT-NOW)

These CanShare reference sets will be published as part of the next SNOMED CT New Zealand edition, and will be available (from April 2023) for file download from the New Zealand SNOMED CT Distribution Service, for API access via the New Zealand Health Terminology Service (NZHTS) and for browsing through both the SNOMED International SNOMED CT browser and CSIRO's Shrimp browser (with NZHTS login).

Below: SNOMED CT Team members Tash Hope, Dr Linda Bird, and Kate Wakefield (absent Dr Brent Caldwell).

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

The ACT-NOW programme looks at how chemotherapy is being delivered across the motu and will use national data collected to identify ways chemotherapy can be improved for people with cancer and their whānau.

After 3 years the Systemic Anti-Cancer Therapies (SACT) Regimen Library (SRL) is nearing completion, with the haematology regimens undergoing publication over the first half of 2023.

So far there have been over 400 regimens published to the SRL across 12 cancer types. We anticipate that implementation of SRL regimens across providers will result in over 400 'low quality' regimens being abandoned, representing a key step towards providing more standardised and evidence-based chemotherapy treatment across Aotearoa.

ACT-NOW has been spearheading the development of a cloud-based infrastructure to securely receive, validate, store, and analyse data collected under the CanShare programme. Early data extracts have been received from several chemotherapy providers, and these are being used to develop early insights and further refine this system. This platform will serve as the CanShare analytics layer, with analysts across the sector able to leverage this infrastructure and data.

Throughout the remainder of 2023 ACT-NOW will seek to onboard additional providers into this system, including additional private providers, and the large

Raurau Ngaehe project to support chemotherapy delivery and data capture in the Northern region, when it goes live later this year.

Structured Pathology Reporting of Cancer Data Standards Update

Developing and supporting the national adoption of data standards to facilitate the timely sharing of pathology information for decision making.

Another busy quarter working with health care practitioners from across the motu to develop data standards while engaging with vendors and providers to support implementation planning over the coming years.

Nine standards have been endorsed by HISO with 40 data standards currently being developed across gastrointestinal, genitourinary, gynaecological and haematological cancer groups. The next set of standards to be submitted to HISO are bone marrow, extramedullary hematolymphoid and cervical/vaginal with more to be submitted once signed-off by their working groups. In addition, another 30 (approx.) data standards will be developed over the coming year for remaining cancer groups.

Alongside standard development, we are building productive relationships with pathology vendors and providers to plan for the implementation of standards over the coming years. More information will be shared on our progress in this area in future updates.

If you want to know more, please contact john.manderson@tehao.govt. or visit out dedicated data standards page.

Analytics Team achievements

Cancer in Numbers webpage
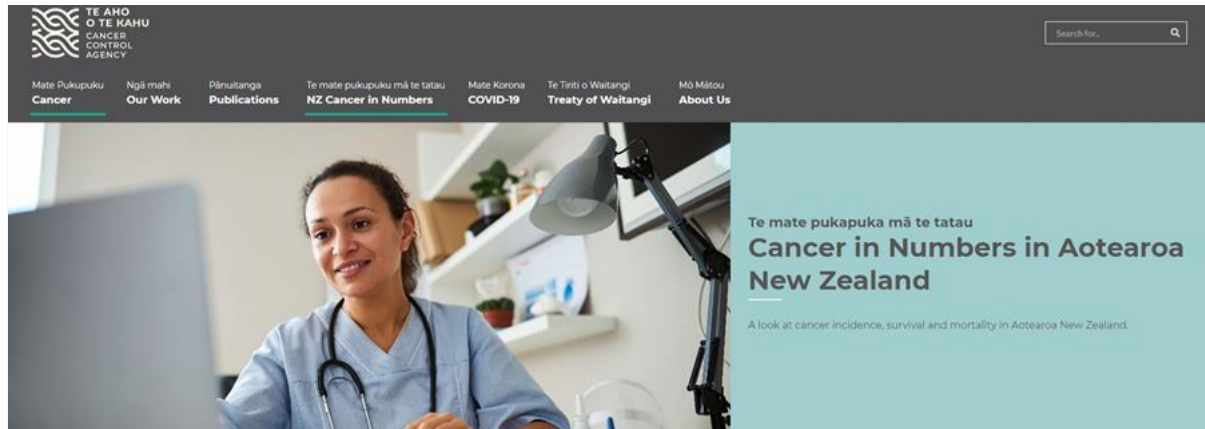
The [Cancer in Numbers in Aotearoa New Zealand](#) webpage is now live on the Te Aho o Te Kahu website and provides up-to-date data on cancer incidence, mortality, and trends in cancer statistics for the most common cancers. Data by ethnicity can highlight cancer inequities for diverse groups in our country. Feel free to share the link with your stakeholders or use the graphs/info in your presentations.

Pancreatic cancer quality performance indicator (QPI) monitoring report

The draft pancreatic cancer QPI monitoring report and technical specifications are going through the data checks and sign-off process. We intend to publish those documents and update the Cancer Care Data Explorer in April 2023.

Radiation Oncology Collection (ROC) online tool enhancement

The ROC online tool, launched in 2017, makes aggregated-level radiation therapy treatment information available to cancer centres and districts to improve access to treatment, guide resource allocation and help ensure treatment is delivered in the most efficient and clinically appropriate manner.

In July last year we ran a survey and held a workshop to get feedback from users and find out what additional improvements they would like. In the recent update, we introduced some enhancements based on this feedback:

- The user guide and reports on methodology on the Home page and Methodology page have been updated to reflect the current methodology and coding standards.

- Improved the general look and feel - chart area is maximised, and legend labels are simplified.

- For the demand modelling, population projection to 2040 is updated using the revised population estimate recently published by Te Whatu Ora.

We are working on other enhancements such as additional reporting focusing on the uptake of hypofractionation and projected cancer incidence by cancer type to give more precision on the demand modelling. We will keep you informed of progress.

Please check out the ROC online tool here or if you want to know more or have any feedback, please contact Yuki.Fujita@teaho.govt.nz

SPOTLIGHT ON DMR TEAM MEMBERS

Dr Linda Bird

The DMR Team is delighted to welcome Dr Linda Bird as the SNOMED CT implementation lead for the CanShare programme. As has already been outlined SNOMED CT is the fundamental terminology building block that CanShare is

built upon - getting it right underpins the success of this national multiplatform programme.

Linda has global expertise in SNOMED CT implementation, information modelling, data analytics, semantic interoperability and HL7 FHIR. Before joining the CanShare team, Linda worked at SNOMED International (2014-2022) where she led their global implementation support team. She also served as head of education and developed several international standards and guides, including the SNOMED CT query language (ECL), machine readable concept model and COVID-19 guide. Prior to this Linda has worked for MOHH Singapore, NEHTA Australia, DSTC Australia and Asymetrix USA.

The SNOMED CT aspects of CanShare are in the safest of hands with Linda training, guiding, and managing DMR's SNOMED CT Team.

Dr Shaun Costello

After completing training at the Royal Free Hospital, London Shaun first went to Aberdeen to study for the MRCP. After passing the exam in 1986 he moved to Glasgow to train in Clinical Oncology. He qualified in 1990 with the FRCR, picking up an MSc in Medical and Clinical Oncology on the way.

On moving to New Zealand in the 1990s Shaun spent a year in Christchurch Hospital and was then appointed Consultant in Oncology at Dunedin Hospital in 1992. He was involved in developing and directing the National Stereotactic Radiosurgery Service in 1994.

In 2001 he was recruited to Ontario, Canada as Medical Director for the new cancer centre in Grand River, which opened July 2003. In 2002, he became fellow of the Canadian College (FRCPC) and an Assoc Prof of the University of Ontario.

He was re-recruited to Dunedin in September 2003 to work in the Oncology Service, in December 2003 he was appointed Director of Medical Services for Healthcare Otago and was also appointed as the Clinical Director of the Southern Cancer Network. He re-signed as Medical Director for the District Health Board but remains the CD of the Cancer Network / Southern Hub and the Medical Director of Radiation Oncology.

Shaun is Clinical Advisor to the DMR team and provides input into all areas of the DMR work programme. Shaun was the driving force behind the national Radiation Oncology Collection (ROC). Since its go-live in 2017 Shaun has been actively involved in using ROC data to help drive improvements such as increased national uptake of hypofractionation and advanced radiotherapy techniques like Stereotactic Ablative Body Radiotherapy (SABR), as well as initiatives to improve access for patient groups that could benefit from radiotherapy but where access rates are currently low.

Building on ROC, and leveraging this experience, Shaun also provides significant input to the ACT-NOW project, seeking to replicate the success of ROC in the chemotherapy space, and contributes to a range of other CanShare projects to help ensure cohesion and clinical relevance.

Publications and Presentations:

- Dr. Linda Bird is featured in HiNZ (Health Informatics New Zealand) eHealth news! Read the column 'Movers and Shakers - Summer 2023' here Movers and Shakers - Summer 2023 - Health Informatics New Zealand (hinz.org.nz)

- John Fountain presented at the HiNZ Conference in Rotorua in December on - CanShare: Learnings from a National SNOMED CT / FHIR Implementation.

- David Hay also presented on 'Using FHIR and SNOMED CT to collect cancer data in the CanShare project for analysis and care delivery' at HiNZ Conference.

- Linda Bird conducted SNOMED CT training seminar last week attracting over 30 participants. Given the high level of interest, we will look at organising seminars to support the understanding of SNOMED CT and FHIR in future.

If you were forwarded this update and you would like to receive it directly - sign up here.