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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

Welcome to the fourth edition of this Newsletter where we inform the sector on progress in the development of the CanShare cancer information sharing platform. Much has been achieved since our March update.

Firstly, I would like to both congratulate Rami Rahal for his recent [appointment as the Chief Executive](#) of Te Aho o Te Kahu and recognise Nicola Hill for her almost year-long tenure as Acting Chief Executive.

The DMR (Data, Monitoring, and Reporting) Team within Te Aho o Te Kahu has been busy and there is much to update regarding CanShare development.

The Structured Pathology reporting programme has made great progress working on up to 40 HISO (Health Information Standards Organisation) standards to describe histopathology reports; this compares favourably to the 50 to 60 current HISO Standards describing all other areas of health. The ACT-NOW programme is rapidly closing in on the completion of its full library of systemic anticancer therapy regimens which will allow an understanding of how patients are being treated throughout the motu. Our Snowflake data analytics database is now operational and in future will drive improved cancer data analytics, monitoring, reporting, and research. Work is also ongoing to allow Te Rēhita Mate Ūtaetae (the Breast Cancer Foundation National Register) to be supported by the CanShare platform.

Behind these outcomes are significant advances in our development of SNOMED CT (the national health terminology) to describe cancer data; and FHIR, the interoperability standard supporting the near real-time sharing of these data. I would also like to acknowledge the time and effort that has been put in by the, now over 250, frontline clinicians who have contributed to the development of CanShare. Highlighted in this Newsletter is Dr Laird Cameron, Medical Oncologist, who has been a major contributor to the ACT-NOW programme, and Steph Kerruish, a Senior Advisor with Te Whatu Ora who has provided unstinting support in our delivery of HISO Standards.

Below: Te Aho o Te Kahu Data, Monitoring and Reporting Team on a rare day together in Wellington.



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



New Zealand's first national chemotherapy regimen library is nearly complete!

A key part of ACT-NOW is the SACT (Systemic Anti-Cancer Therapy) Regimen Library. The Library will help in collecting nationally consistent treatment data, so we can examine variations in access, treatment, and outcomes to identify improvement opportunities.

Currently, this Library contains 629 distinct regimens across 17 cancer streams. A further 176 regimens are in the final stages of development. We expect the Library will be complete in this quarter and will hold approximately 850 regimens across haematology and medical oncology.

Regimen update workshops are underway for most of the cancer streams, which will help the Library evolve to reflect changes in clinical practice and medicine availability.

These regimens are being implemented across most public providers. Currently, data is being collected from across 40% of the motu. This will jump to 70% when the Northern Region Raurau Ngaehe oncology e-prescribing system comes onboard over the coming six to 12 months.

A set of prototype analyses that focus on access, treatment variation and outcomes are being tested and refined with a growing number of dedicated clinicians, pharmacists, and nurses. Their expertise is important in identifying and fixing data quality and methodology issues before any firm conclusions can be drawn from the data. We expect that the ACT-NOW data will be sufficiently mature and well-understood to begin informing quality improvement and other initiatives, like resource modelling, sometime in 2024. The time is fast approaching when you will be able to use ACT-NOW data to help reduce inequities, support resource planning, and drive quality improvement within your region.

Thank you to the almost 200 clinicians, nurses and pharmacists involved so far. This project could not happen without your expertise and time. Please continue championing this work as we implement regimens and resolve any data quality issues within your area.

Data and Snowflake

Snowflake is a purpose-built cloud data warehousing service which gives health organisations access to a range of health datasets within a secure environment for analysis, reporting and research. *Snowflake* is the chosen platform for the National Data Platform. As a cloud native platform, there are advantages around data sharing, inbuilt analytics which we can explore as we develop our data pipelines.

We are an early adopter of *Snowflake* for the ACT-NOW project. Currently we are testing the dataset storage and accessibility, while exploring opportunities for advanced analytics and research.

A tailored data extract process is importing systemic anti-cancer therapy data from oncology e-prescribing systems directly into *Snowflake*. We are testing this data pipeline is working efficiently and the data extracts meet the ACT-NOW data specifications.

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.

It has been another productive quarter for developing national data standards to support the requesting and reporting of pathology for clinical decision making.

Seven new standards were endorsed by the HISO sub-committee for cervical, vaginal, bone marrow and extramedullary haematolymphoid proliferations and neoplasm cancers.

The project team are currently focused on developing 27-40 data standards across gastrointestinal, genitourinary, and soft tissue and bone cancers which we plan to submit to HISO later this year. Read our

spotlight on Stephanie Kerruish who is playing a critical role in the HISO process.

If you want to know more, please contact, john.manderson@tehao.govt or visit our dedicated [data standards page](#).

Breast Cancer registry

Work is continuing with the Breast Cancer Foundation (BCF) to scope how information can be shared between the Breast Cancer Registry and CanShare. The intent is to design an agreed data format for sharing relevant information between platforms, using SNOMED CT and FHIR.

We have noted that there is a significant overlap in the data collected by the BCF and CanShare projects, including systemic anti-cancer therapy (ACT-NOW), radiation oncology collection (ROC), structure pathology and multidisciplinary meeting data (MDM). We will continue to work with the BCF to review these areas and aim to streamline the data flow, to enable consistent, real-time sharing.

The BCF team recently attended the national Radiation Oncology Working Group (ROWG) meeting to outline a proposed bi-directional data-sharing agreement between Te Aho o Te Kahu and the BCF. This would be a mutually beneficial arrangement that would streamline data capture for the BCF and provide access to richer BCF data for Te Aho o Te Kahu. Early work has begun on updating governance and data access frameworks to bring this agreement to life.

SNOMED CT update

Linda Bird

SNOMED CT (clinical terms) provides a fundamental building block for sharable, understandable and analysable cancer data. The CanShare team has been working closely with clinicians to customise SNOMED CT to meet the needs of Aotearoa's cancer data users, through the addition of localised terms, value sets, and new clinical meanings. These customizations are incorporated into the New Zealand SNOMED CT edition and published twice yearly by Te Whatu Ora on the national health

terminology server (known as the 'NZHTS'
- <https://nzhts.digital.health.nz/fhir>).

In April 2023, 72 CanShare reference sets (containing cancer-related SNOMED CT codes) were published on the NZHTS. The upcoming October release of SNOMED CT NZ will increase this to 298 CanShare reference sets. These reference sets are designed to support a range of cancer data, including histology (for haematolymphoid, breast, genitourinary, female genital, thorax, and digestive tumours), topography, grading, staging, scoring, treatment intents, disease responses, and cancer streams. The work so far has focused on:

- Selecting clinician-friendly terms for cancer-related content
- Adding additional NZ SNOMED CT content where there are gaps in the international edition.
- Developing SNOMED CT reference sets for use in CanShare data standards,

We are also exploring an approach to cancer data that supports the diagnostic and treatment pathways by helping to identify more targeted sets of values based on the cancer type, histology and body location.

Our DMR team are committed to enhancing expertise in healthcare terminology - ten team members have either successfully completed or are currently completing the SNOMED foundation course. Ten have also completed or are currently completing either the SNOMED CT authoring or implementation course. This is the largest collection of SNOMED CT qualified and experienced practitioners in the country.

The DMR team has also been working closely with vendors to ensure that the SNOMED CT cancer content meets the needs of system implementers, and to provide them with implementation guidance and support. Through its work with both clinicians and vendors, the DMR team has established itself as national leaders in SNOMED CT implementation and analytics.

FHIR update

Alex Dunn

Fast Healthcare Interoperability Resources (FHIR) is the national standard for the exchange of health data between systems like Lab Information Systems, Oncology Information Systems and MDM systems. Current work focuses on developing FHIR standards across priority projects like ACT-NOW and Structured Pathology. These standards define, in great detail, how the SNOMED CT based data captured under each CanShare project are packaged up and exchanged between IT systems. This creates possibilities for the rapid and seamless movement of structured data to wherever it is needed, to support point of care decision-making, real-time capacity management or secondary uses for analytics and research. Opportunities include things like the auto population of patient MDM records from upstream pathology, other diagnostic and treatment data. CanShare FHIR draws heavily on similar overseas initiatives such as the [mCODE](#) initiative.

Spotlight on...

Stephanie Kerruish



Stephanie (Steph) Kerruish, Senior Advisor – Standards, Architecture and Standards, Data and Digital, Te Whatu Ora.

Since 2011, Steph Kerruish has been working with stakeholders in the development and maintenance of health sector data and information standards.

Steph is keen to see clinical information standardised that will support interoperability and reduce challenges faced by poor quality health data. She feels that having high quality and consistent information that can be

shared within the health system will support improvements to health services and individual health outcomes.

Steph works closely with the team at Te Aho o Te Kahu in the development of their standards to ensure they follow a robust process so the standards they develop will satisfy the [Health Information Standards Organisation](#) (HISO) Committee.

Steph enjoys working with the team in Te Aho o Te Kahu and admires what they are doing. She feels it is innovative and the buy-in that is received from the health sector is to be applauded.

One of the latest standards related developments that Steph is most excited about is the NZ Health Terminology Service. The service offers terminology and code set lookups, downloads, and syndicated feeds via APIs (application programming interfaces). The service includes terminologies such as SNOMED CT, NZ Medicines Terminology (NZMT), and MedDRA. The resources in the Terminology Service will support interoperability, enabling patients and clinicians to enjoy better communication and a more joined-up experience using high quality health data. The Terminology Service is freely available. For more information see: [New Zealand Health Terminology Service](#). Te Aho o Te Kahu have contributed to the evolution of the Terminology Service by creating a number of value sets (list of SNOMED CT terms) to support their FHIR resources.

Dr Laird Cameron



Dr Laird Cameron is a Medical Oncologist specialising in lung, mesothelioma, and head and neck malignancies.

Having initially completed a BSc majoring in biochemistry, Laird graduated from Otago Medical School in 2003. He undertook his core general medical and oncology training in Wellington, gained fellowship with the Royal Australasian College of Physicians in 2015 and completed a clinical fellowship at the Peter MacCallum Cancer Centre in 2016.

Laird has been treating lung cancer at Auckland Hospital since his return to New Zealand in 2016. He leads the lung medical oncology team at Te Puriri o Te Ora, is the New Zealand representative on the Thoracic Oncology Group Australasia, and the vice president of New Zealand Society for Oncology. He is a Senior Lecturer in the department of oncology and Auckland University and is committed to improving the health of New Zealanders with cancer through active involvement in translational research.

Laird has played a critical role in the development of CanShare workstreams. Laird contributes heavily to the ACT-NOW lung regimen development group and has strong knowledge of both funded and unfunded SACT treatments being used across Aotearoa. Laird also co-chairs the ACT-NOW Data Specification Working Group (DWG), which has identified the key data fields for capture by ACT-NOW to best support improvements to equity, quality, and efficiencies within the SACT domain. Laird has also helped to define tumour stream models relevant to New Zealand oncology services, and his involvement across a range of local and national projects, and across various cancer domains like medical oncology and pathology, has been critical in supporting cohesion, not just within individual CanShare projects, but across the entire CansShare programme of work.

Publications and presentations

Fountain J. CanShare: an overview – National Brain Tumour Registry. New Zealand Aotearoa Neuro-Oncology Society Winter Conference. 2023, 26 August.

Fountain J. An update: CanShare and Te Rēhita Mate Ūtaeta. Te Rēhita Mate Ūtaeta (Breast Cancer Register) Clinical Advisory Group National Meeting. 2023, 31 August.

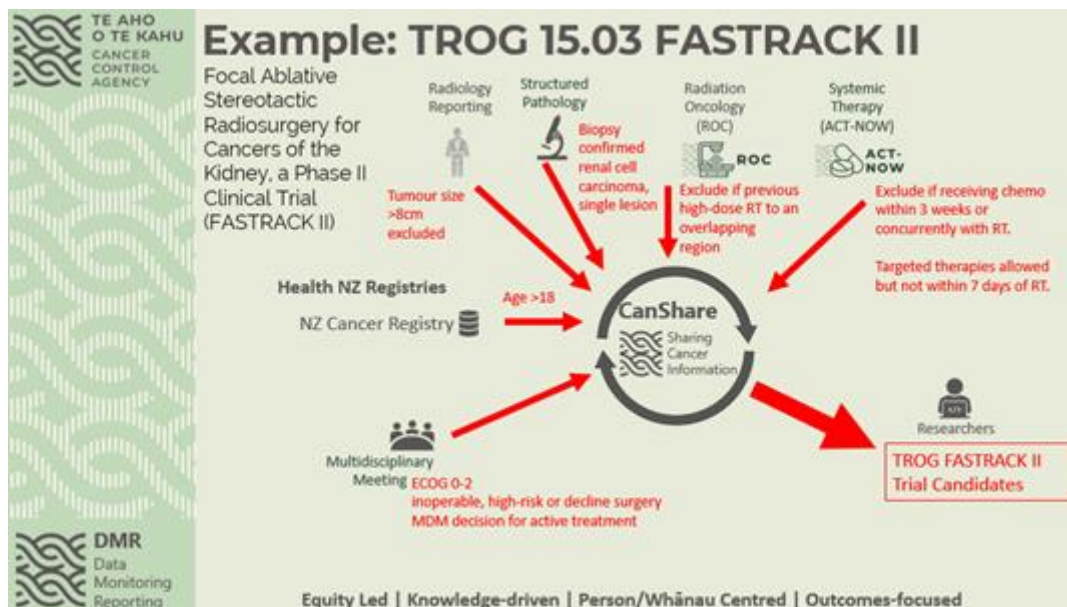
Manderson J. An update: Māori data sovereignty. Te Rēhita Mate Ūtaeta (Breast Cancer Register) Clinical Advisory Group National Meeting. 2023, 31 August.

Northern Bowel Cancer Working Group

Alex Dunn outlined CanShare to the Northern Bowel Cancer Working Group (NBCWG). The group were enthusiastic at the prospect of improvements in real-time data sharing, reductions in double entry, and improvements in analytics and research. Members recognised that the CanShare infrastructure would also create new opportunities for real-time operational analytics and dashboards, and opportunities to better apply decision-support algorithms and early warning systems.

TROG (Tasman Radiation Oncology Group)

Alex Dunn presented a radiation focused overview of CanShare to the Trans-Tasman Radiation Oncology Group (TROG). TROG is a clinical trial focused on an Australasian research group. Alex demonstrated how the various CanShare workstreams could contribute to clinical trial participant selection.



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