



**TE AHO
O TE KAHU**
CANCER
CONTROL
AGENCY



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 second CanShare newsletter, keeping you up to date on our programme to implement national sharing of cancer information to support the clinician and person/whānau at the time and place of care.

I want to acknowledge the generous contribution that nearly 200 clinicians have made to the CanShare programme over the past year - especially remarkable given the challenges the health system has faced.

We have two new DMR team members: Kate Wakefield, oncology pharmacist; and Tash Hope, radiation therapist. Both have already made an impact with their knowledge and eagerness to contribute to improving cancer care in Aotearoa.

We are also collaborating with Dr Scott Campbell, an Associate Professor at the University of Nebraska, on the authoring of [SNOMED CT](#) concepts, the ever-important coding system underpinning CanShare.

Recently I had the privilege of briefing the Minister of Health, the Honourable Andrew Little, on the CanShare programme and he has expressed an interest in how this important initiative progresses.

In this issue we highlight our commitment to Te Tiriti of Waitangi and equity, provide updates on some of our key work and shine the spotlight on Dr Chris Jackson, medical oncologist, and Dr David Hay, health informatician and [FHIR](#) expert. Their expertise and commitment directly support improvements in the national delivery of cancer care.

There are some exciting developments currently underway - I am looking forward to sharing these next year. I hope you all can take a well-deserved break over Christmas and New Year and I look forward to connecting again in 2023.

Upholding Te Tiriti o Waitangi, being an equity-led and whānau-centred Agency



Our work often involves researching and analysing cancer data to inform best practice. We are committed to ensuring appropriate safeguards are in place to protect individuals' data including:

- ensuring all cancer information is used appropriately for the purpose for which it was intended
- giving effect to Te Tiriti o Waitangi by treating data as a taonga (treasure) to secure and protect Māori data from misuse. We recognise the rights and interests of Māori in the collection, ownership, and application of data.

This commitment is fundamental to driving equity-focused decisions and to ensure Māori have the information they need to exercise their tino rangatiratanga.

Our approach

We are actively working to better understand and put into practice our obligations including safeguards for all our data projects and activities. We are in a unique position to harness the equity-led capability and focus of Te Aho o Te Kahu to guide our mahi.

We are currently:

- undertaking an environment scan of the data governance and Māori data sovereignty work underway by Te Aka Whai Ora with Manatū Hauora and Te Whatu Ora to understand current direction of travel, timelines and implications
- working with [Hei Āhuru Mōwai](#) to connect with Māori data governance and sovereignty expertise
- engaging with groups such as [He Ara Tangata](#), our Consumer Reference Group to seek their input eg, patient factors for anti-cancer systemic therapies
- updating equity impact assessments for key development projects

- supporting equity-focused data analytics activities eg, [Quality Performance Indicators](#) (QPIs).

As we continue delivering critical projects our 'nothing about me without me' approach will enable us to deliver together more effectively.

Structured Pathology Reporting of Cancer Data Standards Update



Background

[Pathology](#) is integral to the diagnosis and treatment of cancer. There is an increasing number of parameters needed from pathologists - meaning pathology data systems need to be able to cope with more comprehensive cancer information. However, there are many challenges with legacy and manual data systems and processes, funding, and resourcing constraints.

We are working with pathology services to support their transition to a more interoperative digital health environment. This will be assisted through the development of data standards to facilitate the sharing of standardised pathology information.

Updates

Significant data standard development is underway led by our pathologists with support from requesting clinicians.

- Draft data standards for breast and thoracic cancers were endorsed in early 2022.
- The gastrointestinal (GI) workstream is well underway with draft working standards being developed for all cancers. They will then be released for peer review and wider consultation in the new year.
- The gynaecological workstream is currently developing cervical and vaginal standards, followed by the remaining cancers over the coming months.
- The urinary/male workstream has completed prostate cancers with kidney standards underway. All remaining cancers will be developed over the coming year.
- The haematological workgroup has just been formed to develop standards for bone marrow, haematopoietic and lymphoid tissue cancers. Draft versions are being developed for peer review before wider consultation in early 2023.
- We are actively working to better understand and put into practice our obligations and responsibilities to embed Te Tiriti o Waitangi, and being equity led and whānau centred in the development of data standards.

Please visit our [dedicated data standards page](#) for more information.

If you want to be actively involved in data standard development, please contact john.manderson@Teaho.govt.nz.

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



ACT-NOW seeks to better understand how chemotherapy is being delivered across the country by collecting treatment-related data from public and private chemotherapy providers and working with stakeholders to identify opportunities that can drive improvements for people with cancer and their whānau.

All 20 ACT-NOW regimen development workshops have now been held and we are scheduled to have all regimens across adult medical oncology and haematology published to the [SACT \(Systemic Anti-Cancer Therapy\) Regimen Library](#) in early 2023. Follow-up workshops in 2023 are being planned for most cancer streams, to ensure regimens remain up-to-date and reflective of current practice and medicine availability.

We are working closely with Te Whatu Ora Data and Digital to design and build a cloud-based IT infrastructure to receive, validate and store ACT-NOW data. This infrastructure is based on the [SNOWFLAKE cloud platform](#) and will become the data repository for all future CanShare analytics across DMR projects.

Recent work on ACT-NOW prototype analytics has focused on reconciling data collected from oncology e-prescribing systems with the Te Whatu Ora Pharmaceutical claims database to help validate the ACT-NOW data and identify and fill gaps in data coverage.

If you would like more information on ACT-NOW, contact Alex Dunn Alexander.Dunn@Teaho.govt.nz or visit the website for more details [Te Aho o Te Kahu - ACT-NOW Programme](#).

Analytics Team

The analytical team is currently working on or providing support to:

- Radiation Oncology Collection (ROC) dashboard enhancement
- Cancer in Numbers website enhancement
- COVID and Cancer service report for the period ending September 2022
- Cancer Psychosocial Support Services Initiative (CPSSI) dashboard development
- Pancreatic Quality Performance Indicator (QPIs) analysis and report.

ROC remains a heavily utilised dataset across the sector and by Te Aho o Te Kahu. The [current ROC dashboard](#) was developed over two years ago to provide information to those involved with service provision about patients accessing radiation therapy and how treatment protocols differ by treatment centre.

ROC data is currently being used to support workforce and LINAC capacity planning as part of our Cancer Services Planning (CSP) programme, as well as tracking the uptake of new treatment techniques and regimens like SABR and extreme hypofractionation.

ROC relies heavily on the efforts of the ROC 'data managers' – people in each of the radiation centres who submit the ROC data and help address any gaps or data quality issues. Most data managers are radiation therapists or system administrators taking on this role on top of their regular workload each quarter. We recognise and appreciate the critical, behind-the-scenes role that the ROC data managers play in the ongoing success of ROC.

There will be a more detailed introduction to the new and improved ROC dashboard in the next update.

PARTNER SPOTLIGHT

Dr. Chris Jackson



Dr Chris Jackson Chris Jackson is a medical oncologist at Te Whatu Ora – Southern and a senior lecturer at the University of Otago. Until recently he was also the medical director of the Cancer Society, where he was a strong advocate for a national approach to cancer control and had a significant role in the establishment of Te Aho o Te Kahu. Chris is now on our Advisory Council and chairs the Clinical Assembly.

Chris worked with the DMR team during COVID on the Cancer Agency COVID Agile Response Team (CACART) that worked to direct, collect, and analyse data relating to cancer registrations and cancer activity during the pandemic. CACART also worked with medical oncologists on planning for the possible scenario of an overwhelmed cancer system – a scenario which, fortunately, never eventuated. He says that our COVID reports had near real time availability of key metrics of cancer registrations, surgeries, radiation treatments, First Specialist Appointments, and chemotherapy deliveries, outstripping the speed of most other countries' data availability. He believes that this rapid data availability helped keep cancer services on track during COVID.

His other key role with the DMR team is through the ACT-NOW project which he pitched to the Ministry of Health before Te Aho o Te Kahu was able to make it a reality. This is a national library of chemotherapy regimens (and other systemic anti-cancer therapies) which aims to build consensus and data availability about chemotherapy use and outcomes for patients treated for cancer.

Alongside the radiation collection, we have the world's most comprehensive cancer treatments resource, covering both public and private sectors. Chris says this collection has the potential to drive quality improvement, improve access to treatments, inform workforce planning and resource usage, monitor patient outcomes, and ensure equity of access to treatment, making it a jewel in the cancer-planning crown.

PARTNER SPOTLIGHT

Dr. David Hay



David is working with the DMR Team to develop the FHIR design and architecture for the Structured Pathology and ACT-NOW workstreams of CanShare, with the vision that all cancer related information can be stored in a FHIR-based repository and made available to clinicians, the patients, and for analytics.

He is active in the national and international standards community as chair emeritus of [HL7 New Zealand](#) and is a co-chair of the FHIR Management Group. He has served on HISO (Health Information Standards Organisation) and currently edits the New Zealand Base FHIR implementation guide, being a consensus guide developed by HL7 New Zealand.

David graduated from medical school, then moved into the health IT sector. He developed practice management software for primary care, which was the first programme in New Zealand to receive electronic laboratory results. He then moved to work as a solutions architect for a services management organisation, producing several solutions: internal eReferrals application, community-based case management solution, plus an application to track and report on clinical tasks within the hospital.

He also participated in several national programmes, including the medical records transfer project GP2GP and ePrescribing.

He writes about FHIR on his blog fhirblog.com and has developed a range of freely available tools widely used to educate developers and designers about FHIR - [clinFhir](#) and [connectathon manager](#) which are supported by [InterSystems](#). David has spent many years professionally and personally designing, educating, and advising on health informatics. In recognition of this David was awarded the Excellence in Health Informatics award 2016 by ITx New Zealand.

Conferences:

John Fountain and John Manderson presented to the New Zealand Society of Oncology (Together Stronger) meeting, 22-25 September on 'Structured Pathology Reporting and Data Capture.

John Fountain attended the SNOMED CT Expo 2022, Lisbon, Portugal, 29 – 30 September.

He also presented to the Te Manawa Taki End to End Colorectal Cancer Pathway Symposium on 2 November on CanShare.

And finally was John was part of the panel discussion about CanShare and the opportunities for cancer data at the Te Aka Mātauranga Matepukupuku - Centre for Cancer Research, University of Auckland, Inaugural Symposium on the 25 November.

Publications:

Jason Gurney and Dr Elizabeth Dennett published [Understanding disparities in post-operative mortality for Indigenous patients](#) in the New Zealand Medical Association Journal.

Michelle Mako and Jason Gurney published the Lancet Oncology article [Te Aho o Te Kahu: weaving equity into national-level cancer control.](#)

Health Informatics New Zealand (HiNZ) featured CanShare work in their recent eHealth news. You can read the article here: [New data platform to share cancer information - Health Informatics New Zealand \(hinz.org.nz\).](#)

Alex Dunn, Jason Gurney and Shaun Costello were part of the team which published '[Driving quality improvement through better data: the story of New Zealand's Radiation Oncology Collection](#)' and was published in [Journal of Medical Imaging and Radiation Oncology \(2022\)](#).



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