



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,

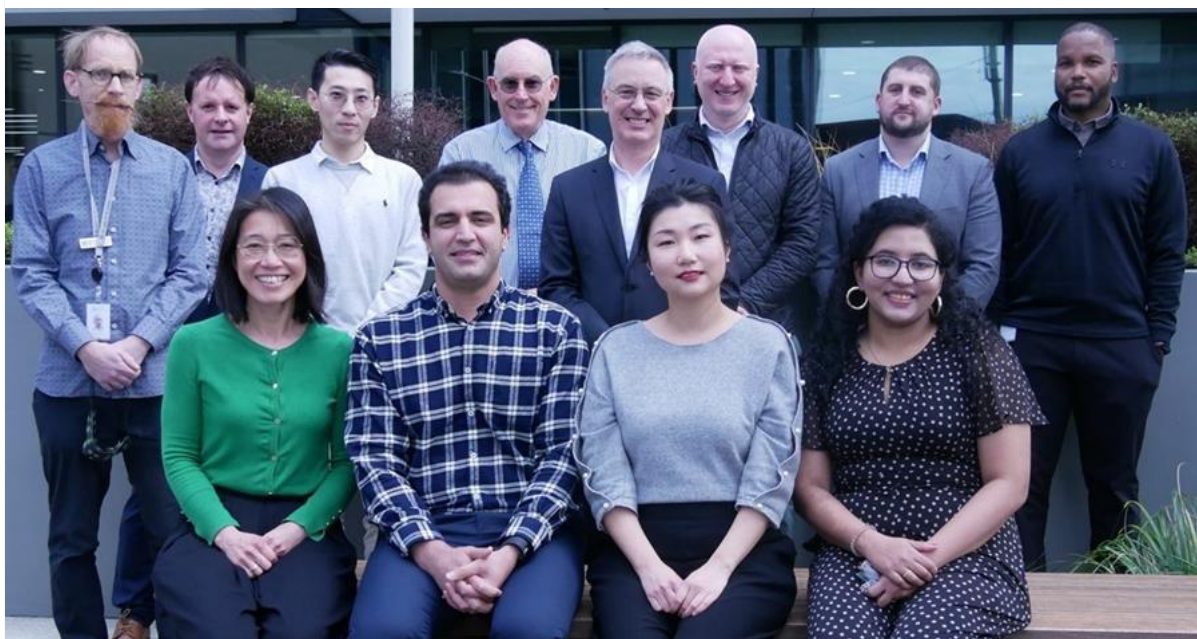
I am delighted to welcome readers to the first newsletter from DMR, the Data, Monitoring and Reporting Team within Te Aho o Te Kahu, the Cancer Control Agency. In this newsletter I'd like to introduce the DMR Team and some of the great health informatics programmes that are now underway to improve our understanding of cancer in Aotearoa and to support the provision of improved care and outcomes for those with cancer. These programmes include the overarching initiative, CanShare, which brings together a range of data sources to allow the timely sharing of complete and accurate cancer data. Within CanShare is the ROC, our Radiation Oncology Collection; ACT-NOW (Anti-Cancer Therapies – Nationally

Organised Workstreams) which focuses on medical oncology and malignant haematology; and our work in structured anatomic pathology reporting.

We are very lucky to have Dr David Hay, Dr Johanna Paddison, Jo-Anne Wilson and Drew Winter as contractors who bring a wealth of knowledge and experience to the CanShare programme and ably support the DMR Team – described below. It is also a privilege to feature Dr Michael Lau, a pathologist from Southern Community Laboratories, Dunedin, who has been an incredible contributor to the structured anatomical pathology reporting work.

We hope that this inaugural DMR newsletter both informs readers of cancer informatics activities within Te Aho o Te Kahu, and answers questions relating to CanShare. Please feel free to share with others.

Data, Monitoring and Reporting (DMR) Team



From left standing: Brent Caldwell, John Manderson, Simon Liu, Shaun Costello, John Fountain, Hazem Abd Elkader, Alexander Dunn, Kieron Mottley.

From left sitting: Yuki Fujita, Vahid Arabnejad, Michelle Liu and Meera Muralidharan.

Absent: Jason Gurney and contractors: David Hay, Johanna Paddison, Jo-Anne Wilson, and Drew Winter.

The Data, Monitoring and Reporting team, commonly called DMR, is tasked to:

- lead the collection, analysis and communication of high-quality cancer data.
- to help drive planning, quality improvement and monitoring activities across the cancer sector to improve equitable cancer outcomes for all New Zealanders.



CanShare is a national health informatics platform that will allow the timely sharing of complete and accurate cancer data. Based on the SNOMED CT medical terminology, FHIR interoperability standard and HISO (Health Information Standards Organisation) Standards, the primary intent of CanShare is to support clinical and patient decision making at the time and point of care. Outcomes from this work will include advanced analytics capability supporting up-to-date monitoring of cancer care throughout the motu. CanShare has a number of programmes addressing areas of cancer data need including: ACT-NOW (Anti-Cancer Therapies-Nationally Organised Workstreams) for medical oncology and malignant haematology, ROC (the Radiation Oncology Collection) for radiation oncology, and structured pathology reporting - with more initiatives to follow.

This is an important initiative for enabling the collection of complete and accurate cancer data, joining currently disparate data siloes, and providing a means to share timely clinical cancer information throughout the health care system to support clinical care and patient needs.

Over the past year some 200 contributors including health care practitioners, subject matter experts and consumers have been consulted or participated in working groups to advise on the construction of CanShare. Alongside the technical aspects of CanShare, we are building

the partnerships critical to give effect to Te Tiriti o Waitangi, in particular Māori Data Sovereignty, in the development and use of cancer data. Liaisons have also been established with Te Whatu Ora (Health New Zealand), a cloud database is being built, and much work undertaken in the individual programmes comprising CanShare, as outlined below.

In our next newsletter we will outline the actions we are taking to give effect to Te Tiriti o Waitangi, being equity-led and person and whānau-centred in all our mahi.

Structured Pathology Reporting of Cancer in Aotearoa New Zealand Data Standards Update



Background

Pathology needs to prepare for a more digital standards-based health data environment. The ever-increasing complexity of cancer treatment requires a greater level of pathology reporting. However, the sector is facing major challenges with legacy/paper-based data systems and processes notwithstanding funding issues and increasing workload pressures.

Te Aho o Te Kahu is working with pathology services to support their transition to a more interoperative digital health environment. This will be assisted through the development and national adoption of data standards to facilitate the sharing of standardised pathology information.

Over the coming year, draft data standards will be developed for requesting and reporting all cancers.

We want to acknowledge the invaluable contributions from health care practitioners, especially our pathologist community, and equity and technical subject matter experts from across the country who are supporting this mahi.

Updates

- Our new [project website](#) went live alongside the new [data standards manager](#) site where anyone can provide feedback and source data standards at any time.
- HISO (Health Information Standards Organisation) has just endorsed our second cancer group with Breast cancer draft data standards.
- HISO also endorsed our overarching draft [Preface](#) which outlines the background and our approach to develop, publish and maintain data standards.
- The Gynaecological workstream is well underway with Cervical/Vaginal being co-developed in partnership with the National Cervical Screening Unit (NCSP), and the Gastrointestinal workstream has just started.

If you have any general questions, please contact info@teaho.govt.nz.

If want to be actively involved in data standard development, please contact John.Manderson@Teaho.govt.nz or visit the Te Aho o Te Kahu website for more details - [Te Aho o Te Kahu - Pathology Data Standards](#).

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



The [Anti-Cancer Therapy – Nationally Organised Workstreams \(ACT-NOW\)](#) programme was launched in 2018 with the aim to develop a detailed database of information on patients receiving systemic anti-cancer therapy across New Zealand. ACT-NOW engages with the medical oncology, haematology, pharmacist and nursing communities to identify and reduce variation, enhance equity of access and support resource planning.

Although affected by COVID-19, ACT-NOW regimen development and publication has continued. Nineteen of 20 regimen development workshops have now been held and ACT-NOW is scheduled to have all regimens across adult medical oncology and haematology published to the SACT Regimen Library (SRL) by December 2022. A huge thankyou to all who have found time to participate in these workshops.

The ACT-NOW data specification, outlining key data items for the national collection to support analyses into equity, clinical quality, and resource planning, went out for public consultation in March, and was finalised in July 2022.

Te Aho o Te Kahu is working closely with Te Whatu Ora Data and Digital to design and build the IT infrastructure to receive, validate, store, link and analyse ACT-NOW data. This infrastructure and the associated processes

relating to data submission and data quality are being loosely modelled on the national Radiation Oncology Collection (ROC).

Test data have been collected from all public and some private providers using electronic information systems and is supporting the development of prototype analyses, with the purpose of deriving early insights from ACT-NOW data and informing data quality/completeness activities. Early prototype analytics focus on treatment access, survival trends, and hospitalisations due to regimen toxicities.

This year represents a strong pivot from the development of regimen and other data standards to the implementation of these standards nationwide. Key activities for 2022 include continued implementation of SRL regimens, implementation of the ACT-NOW data standard, collection of test data from providers and the ongoing development of prototype analyses and generation of insights from provider data. We will continue to work closely with providers on these planning and implementation activities.

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](#).

HISO Data Standards

Te Aho o Te Kahu is working with a range of clinical specialities to transition to an interoperable digital health environment through the development and subsequent national adoption of HISO data standards over the coming years. We have already released data standards for Pathology and Systemic anti-cancer therapies with many more in development to advance the timely sharing of cancer data.

Analytics Team

The analytics team provides high-quality analytical support to stakeholders and Te Aho o Te Kahu. The team supports the delivery of the DMR data analysis work priorities, which drive planning, quality improvement and monitoring activities across the cancer sector to

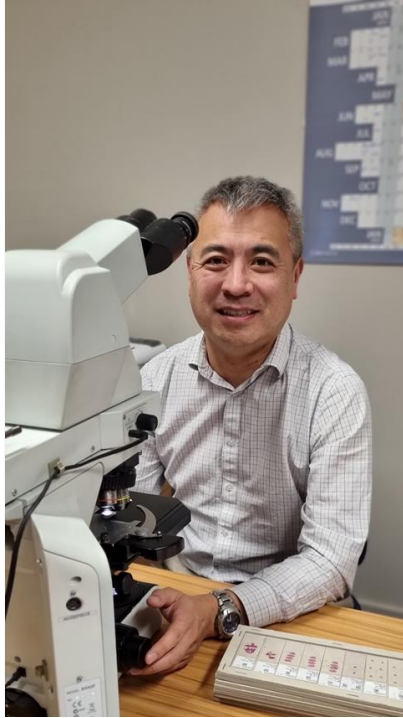
improve equitable cancer outcomes for all New Zealanders. The team's work program include:

- Quality Performance Indicators (QPI) – analysis and visualisation dashboard
- Fast Cancer Treatment (FCT) – reporting and data quality enhancements
- Radiation Oncology Collection (ROC) – reporting and data quality enhancements
- Cancer Psychological and Social Support Initiative (CPSSI) – data collection and reporting
- Support the development of Anti-Cancer Treatment – Nationally Organised Workstreams (ACT-NOW), Structured Pathology and CanShare
- Input to Ministerial and Official Information Act (OIA) enquiries.

Reports

Since May 2020, Te Aho o Te Kahu released a series of reports outlining the impact of COVID-19 on cancer services in New Zealand. The report focuses on the aspects of the cancer care pathway for which we have readily available data, including diagnosis, surgery, medical oncology, radiation oncology and haematology. This report compares 2022 with an average of 2018/19 data and provides additional graphs comparing 2022 data with that from 2021, 2020 and 2018/2019. The next report is planned for release in early September, including data to the end of June 2022.

The aim of this work is to collate evidence on delays to cancer diagnosis and treatment to support policy development and response planning. You can find more information on the reports on the [Te Aho o Te Kahu - Cancer care and COVID-19](#) webpage.



PARTNER SPOTLIGHT

Dr. Michael Lau

Michael graduated MB ChB from the University of Otago in 1992 and has been a Fellow of the Royal College of Pathologists of Australasia since 2005. He works as a Consultant Anatomic Pathologist at Southern Community Laboratories, Dunedin (a branch of Asia Pacific Healthcare Group) and his current practice includes thoracic, gastrointestinal/liver, genitourinary and renal pathology (and occasionally lymphoma pathology). He also has interests in structured cancer reporting and oncology biomarkers.

Michael, as lead pathologist for Te Aho o Te Kahu Structured Pathology data standards project, has been instrumental in advancing this mahi in partnership with the sector since early 2021. With his passion, expertise and engaging style, he led our first cancer group workstream for Thoracic (Lung, Pleura, Thymus) resulting in HISO approval in May 2022. Alongside advising all other workstreams in development, Michael is taking a lead role in the Gastrointestinal cancer workstream over the coming year.

He is the lead pathologist for the Asia Pacific Healthcare Group in the field of PD-L1 scoring, and in 2021 presented at Current Trends in Immuno-Oncology on this topic. He also presented that year at the NZMS Immunohistochemistry Workshop on PD-L1 as well as other oncology immunohistochemical biomarkers. Currently, he is working with Te Aho o Te Kahu ACT-NOW programme on the potential development of a standardised

combined molecular-immunohistochemical oncology biomarker list across all tumour streams for Aotearoa.

Previously, Michael has contributed to the NZ Bowel Screening Histology Data Standard and is the lead anatomical pathologist for Bowel Screening at Southern Community Laboratories. In addition, he has co-written the Pathology curriculum for the Royal Australian and New Zealand College of Radiologists, for which he is a regular examiner in their Part II Vivas.

Publications from the team:

- [Risk factors and prognostic implications of diagnosis of cancer within 30 days after an emergency hospital admission \(emergency presentation\): an International Cancer Benchmarking Partnership \(ICBP\) population-based study](#), The Lancet Oncology Volume 23, Issue 4 April 2022. Hazem Abd Elkader co-authored this article and did some of the analyses.

- [The impact of COVID-19 on lung cancer detection, diagnosis and treatment for Māori in Aotearoa New Zealand](#) by Senior Epidemiologist Jason Gurney et al in the *New Zealand Medical Journal*.

- [Using national data to model the New Zealand radiation oncology workforce in Journal of Medical Imaging and Radiation](#), Journal of Medical Imaging and Radiation Oncology (2022). Contributors - Alex Dunn, Shaun Costello, Fiona Imlach, Emmanuel Jo, Jason Gurney, Rose Simpson and Diana Sarfati.

Conference presentations:

- Health Informatics New Zealand (HiNZ) Digital Health Conference -John Fountain and Zeeman van der Merwe presented on the Information Standards Challenges of Cancer Care (March 2022).

- New Zealand Lung Cancer Conference 2022 (June 30 - July 1) - John Fountain, Jason Gurney and Alex Dunn presented their work.

- John Fountain presented at the SNOMED NZ Open Forum Hui Tuwhera (June 2022).

- John Fountain presented at the NZ Familial Breast & Ovarian Cancer Meeting (NZFBOC) (August 2022).



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