



## Editor's note

Meri Kirihimete whanau! Yes it is just a few short weeks until many of us will be enjoying the treasured time where we share with friends and whanau and most cancer related health services squeeze all they do into a very limited capacity schedule over the Christmas period.

It is a time for reflecting on the year that has past, and those who have passed, along with contemplating new goals for the year to come. What challenges are you going to put to yourself or team in 2020?

Our strength is our membership. The knowledge, skills and energy you all bring. The committee is only ever as effective as the membership that supports us, so thank you for your efforts and communications during the year and thank you for all the hard work and skill you bring to your role, the critical thinking and advocacy you practice despite those tough working conditions. Remember to take care of yourself and to show compassion to each other and the people we work with. Take care out there over summer and remember to Slip, Slop, Slap and Wrap and be safe on our roads.

**Mary-Ann Hamilton & Jane Wright**  
Cancermet Co-editors

## The official opening of the Cancer Control Agency

**The new independent Cancer Control Agency formally opened today at 133 Molesworth Street. Prime Minister Jacinda Ardern and Minister of Health David Clark marked the occasion by announcing the membership of the Advisory Council that will be supporting the Agency.**

"Today's official opening marks the start of a new era for cancer care in New Zealand. The Cancer Control Agency will play a critical role in ensuring all New Zealanders get world-class cancer care, no matter who they are or where they live," Jacinda Ardern said.

"Improving cancer survival rates in New Zealand is a long term challenge that the Agency will play a big part in helping to turn around.

"I'm pleased to announce that Professor Diana Sarfati has been appointed by the State Services



Commission as interim Chief Executive to lead the Agency.

"Professor Sarfati has spent the past three months laying the ground work for the Agency as interim National Director of Cancer Control. I know she will bring the same skill, dedication and depth of knowledge to her new role.

### Membership of the Advisory Council

- **Dr Ashley Bloomfield** – Director General of Health
- **Dr Nina Scott** (Ngāpuhi, Ngāti Whātua) – public health physician and chair of Hei Āhuru Mōwai, the National Māori Cancer Leadership Group.
- **Dr Richard Sullivan** - Deputy Chief Medical Officer at Auckland Hospital, Director Cancer and Blood Directorate, Director Cancer Outcomes Auckland District Health Board and the Director of the Northern Cancer Network.
- **Dr Chris Jackson** – medical director of the Cancer Society, medical oncologist and senior lecturer at the University of Otago.
- **Shelley Campbell** (Ngāti Hine) - CEO of the Waikato Bay of Plenty Cancer Society. Shelley is a life member of the Halberg Foundation, Board member of Enrich, Te Pou, and Le Va.
- **Graeme Norton** – chair of Health Consumer Councils of New Zealand.
- **Professor David Tipene-Leach** (Pōrangahau, Ngāti Kere, Ngāti Manuhiri) - general practitioner and public health physician, David was appointed Professor of Māori and Indigenous Research at EIT in early 2017. He was made a Member of the New Zealand Order of Merit for services to Māori and health in 2018.
- **Ailsa Claire** - Chief Executive of Auckland District Health Board and lead CEO for Cancer, Chair of the Cancer Health Information Strategy Group and Chair of the Northern Region Cancer Governance Group.



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- The Cancer Control Agency (the Agency) is a departmental agency that will provide strong national leadership for, and oversight of, cancer control in NZ.*
- The Agency is a real opportunity to accelerate the work already being done to improve cancer outcomes in NZ.*
- The Agency will drive the implementation of the Cancer Action Plan, which focuses on equity and delivering nationally consistent services for all New Zealanders, no matter who they are or where they live.*
- Professor Diana Sarfati has been appointed Interim Chief Executive of the Cancer Control Agency and will lead the work outlined in the Cancer Action Plan. Professor Sarfati will report directly to the Minister of Health.*
- Professor Sarfati's strong leadership and deep understanding of the cancer landscape will be instrumental in addressing challenges, such as equity.*
- Key priorities for the Agency include providing strong accountability, coordination of various agencies involved in cancer, and working to implement the Cancer Action Plan.*
- As we establish the Agency, we will work alongside the current four*

*regional networks to identify how we refocus our energy and resources to set the new direction for consistency and local innovation.*

- Cancer networks play a vital role in leading consistency of cancer care across the country while maintaining local innovation. A nationwide pool of resources will provide experience and knowledge to better inform outcomes, reduce duplication and remove barriers to information sharing and knowledge development.*
- We will continue our existing relationships with the Adolescent and Youth and Child Cancer networks, who deliver national programmes of work.*
- The Agency is working closely with people impacted by cancer, including their whānau and healthcare professionals. We're also actively working with Māori and Pacific leaders to ensure that they inform the work of the Agency and how we can best engage with them to meet their needs.*
- An Interim Cancer Control Agency Advisory Council has been established to support, provide advice to, and oversee the leadership of the Agency.*
- The Ministry of Health will continue to have a key role in cancer, including prevention, equity and improvement.*

## Q&A

### What is the Cancer Control Agency?

The Cancer Control Agency is a departmental agency hosted by the Ministry of Health, which will provide strong national leadership for, and oversight of, cancer control. The Agency will operate independently, and the Chief Executive will be accountable directly to the Minister of Health.

### What is the new governance structure?

An Interim Cancer Control Agency Council has been established to support the leadership and ongoing direction of cancer control in NZ.

Professor Diana Sarfati has been appointed the interim Chief Executive of the Agency and will be responsible for delivering the outcomes identified in the Cancer Action Plan.

The Agency is establishing five teams to deliver to the commitment areas defined in the Cancer Action Plan:

- 1. Equity**
- 2. Treatment, Quality & Standardisation**
- 3. Data, Information & Reporting**
- 4. Patient-Centred Care**
- 5. Prioritisation, Innovation & Research.**

### What does the Agency structure look like?

The Agency is led by the Chief Executive, and the initial structure will consist of approximately 18 staff. This will grow to about 40 FTEs as the Agency develops its priority work programme and as the budget for the Agency is confirmed.

### How are you engaging with the regional network on the future direction of the Agency?

As we establish the Agency, we will work alongside the current four regional networks to identify how we refocus our energy and resources to set the new direction for consistency and local innovation.

Cancer networks play a vital role in leading consistency of cancer care across the country while maintaining local innovation. A nationwide pool of resources will provide experience and knowledge to better inform outcomes, reduce duplication and remove barriers to information sharing and knowledge development.

We will continue our existing relationships with the Adolescent and Youth and Child Cancer networks, who deliver national programmes of work.

*continued on the next page...*

# Cancer Control Agency - Q & A *continued*

## **How will this cancer agency help people?**

The Agency will drive the implementation of the Cancer Action Plan, which focuses on equity and delivering nationally consistent services for all New Zealanders, no matter who they are or where they live.

The Agency will provide strong leadership and accountability, and will work to address the challenges, including improving equity, in an independent role.

Key priorities for the Agency include providing strong accountability, coordination of various agencies involved in cancer, and working to implement the Cancer Action Plan.

## **Does this mean the Ministry of Health won't have any responsibility for cancer anymore?**

The Ministry will continue to have a key role in cancer across the entire continuum from prevention through to living well with and beyond cancer. The Agency will maintain strong connections with other Ministry teams supporting cancer prevention, treatment and care.

The Agency will be hosted by the Ministry of Health, providing strong accountability, coordinating the various agencies involved with cancer, and working to address challenges including equity.

## **Is this an admission that the Ministry of Health has been ineffective in dealing with cancer?**

No. Addressing cancer is a collaborative responsibility between a number of Government agencies, including the Ministry of Health, non-government organisations, communities and health system partners.

The Agency has the mandate to coordinate across all of these groups to ensure nationally consistent services are available to New Zealanders. This national coordination is consistent with cancer care models of other comparable countries.

## **Who will lead the cancer agency? How was this decision made?**

Professor Diana Sarfati was appointed Interim National Director of Cancer Control by the Director General of Health in September 2019 and has been appointed the Interim Chief Executive role on 1 December 2019. Professor Sarfati has been working to implement the Cancer Action Plan since her appointment started.

## **When will the Cancer Control Agency start working?**

The Interim National Director has already progressed work in preparation for the Cancer Control Agency's opening on 1 December, including determining the workforce, engagement and immediate work plan requirements to deliver the Cancer Action Plan.

## **How have people with cancer and their whānau been considered in setting up this agency?**

The Cancer Action Plan makes it clear we need to work together to find solutions, which means all New Zealanders can help shape and strengthen the plan.

The Ministry ran a comprehensive consultation process in September and October 2019 to get feedback from people on the draft Cancer Action Plan. Feedback has been used to develop the final version, which will be launched by the end of 2019.

We want to thank everyone who has shared their feedback and stories about cancer control in New Zealand.

## **How has the workforce been considered in setting up this agency and Cancer Action Plan?**

The health workforce is critical to the success of the Cancer Action Plan.

We know the workforce face a number of challenges. We also know that we need to enhance the workforce and identify ways to work better together.

A strong, sustainable health workforce is one of our critical priorities.

We want to continue engaging with the workforce - and people impacted by cancer - about what we could do differently, or better, and how we should prioritise this.

## **What should we know about the Cancer Action Plan?**

The Cancer Action Plan is a system-wide approach that covers the full spectrum of cancer control, from prevention and screening to treatment and palliative care. This is the first Cancer Action Plan that focuses more broadly than just treatment.

The Plan demonstrates a commitment to ensuring all New Zealanders living with cancer have access to high quality care, no matter who they are or where they live.

The plan will steer New Zealand's cancer control for the next decade and has a strong focus on achieving equity for all New Zealanders. The plan also has a strong emphasis on working in partnership with Māori.

The Agency is actively working with Māori leaders, Pacific leaders

and Consumer groups to start a conversation on how we can best engage with them longer term to improve outcomes.



[<< Click here to read the action plan here](#)

# REPORTS FROM THE 2019 NZSO Conference

## From Fiona Fagg...

**I was fortunate, with the help of an NZNO Cancer Nurse College grant, to be able to attend the Nurses Programme of the New Zealand Society for Oncology conference, Friday 25th October.**

Wellington put on two beautiful days of sunshine to showcase the iconic waterfront setting and cement a valuable learning experience. I want to mention some of the presentations which resonated most strongly with me as a registered nurse working in an outpatient oncology setting.

**Dr Jason Gurney** is an Epidemiologist from Otago with many strings to his bow in the field of research into Māori health and inequalities. His session entitled "Hard Facts and Home Truths: Inequities in cancer incidence, mortality and survival for Māori" demonstrated exactly that. Sessions with many graphs and statistics often make nurses' eyes glaze over, but not so with Dr Gurney. His graphs left us in no doubt that Māori achieve considerably worse outcomes in treatment and survival statistics in all tumour streams except prostate cancer and maybe melanoma. Mate pukupuku,

with its many connotations for cancer, death and disease, certainly has more devastating consequences when comparing Māori with non-Māori. He finished his talk with hope for the future which carried over into the following panel discussion.

Panel discussions often have the audience feeling mostly sympathy for those made to sit up front like rabbits in headlights and awkwardly try to speak to the topics put to them.

The panel however gave passionate insight into the awareness there is regarding research inequities and also demonstrated to us that there is hope for future outcomes for Māori. This needs to be remembered by all of us – from those involved in trials and research, primary health providers, oncologists planning treatments, to nurses working with their patients. All of us can help make a difference.

My real focus for the conference had always been **Dr Rose Liu's** presentations on skin toxicities and treatment in EGFRi therapies, and she didn't disappoint. Dr Liu runs oncologic dermatology clinics based at Westmead Hospital in Sydney. EGFRi therapies are increasingly

used and funded, which increases the corresponding skin toxicity issues for many people. This would indicate as increasing need for dermatology expertise in oncology teams – both medical and nursing. Dr Liu provided the blueprint for care, discussing anatomy and physiology, to symptom recognition, and management plans. Much of what she said was not new, but she was clear and straight-forward in her approach. Her take-home message for everyone was principally not to think of, or call these toxicities, rashes. These are specific papulopustular eruptions with specific assessment features and treatment requirements.

I have a particular interest in, and focus on, oral cancer treatments, and because I have seen some very severe skin reactions I came away feeling much more secure in the knowledge that I have and the advice that I give these patients and more confident to share this knowledge with my colleagues. I plan to provide extra resources for patients and colleagues to support best care for people experiencing these toxicities. Who knew the ideal bleach solution for paronychia is 5ml of 5-6% household bleach to 2.5L of water, or equal parts water and white vinegar. Another little gem of information!

This was an excellently managed and run day for oncology nurses with very worthwhile topics of interest for reflection and to support practice. I would again like to thank the Cancer Nurses College and NZNO for making my attendance possible.



*It was pleasing to see the contribution of posters produced by nurses at the NZSO conference. The winner of the Nursing poster award went to Liz Sommer (left) and runner-up was Bronwyn Perry (right). Congratulations.*

*See their full poster detail on page 3. We also feature the great posters of Sara Farrant and Sue Callahan and Mary Cotter on page 4.*

# REPORTS FROM THE 2019 NZSO Conference

CONTINUED FROM PREVIOUS PAGE...

*From Anne Liggins...*

**I was fortunate to receive a CNC grant to attend NZSO this year, and would like to share a few of the highlights. As a nurse coordinator in the Cancer and Blood Research Trials Unit at Waikato Hospital, I found the research and practice-based presentations very useful and relevant to my role.**

It was a great privilege to hear **Professor Ron Jones** speak about the forgotten women in the 'unfortunate experiment'; the unethical observation of women with cervical cancer at National Women's Hospital. Professor Jones was a whistle-blower who put his career on the line to fight for the rights and lives of cervical cancer patients, at great personal cost. I am very keen to read his book "Doctors in Denial", and would encourage others to read his account of an incredible piece of New Zealand's medical history. Professor Jones' moving presentation concluded with a lengthy standing ovation and many teary eyes.

**Professor Mei Krishnasamy** spoke about the \$1M grant she has received to develop a Cancer Nursing Research Innovation Hub within the Victorian Comprehensive Cancer Centre in Melbourne. The research hub offers an amazing opportunity to support and promote nurse-led cancer research. This is especially important for qualitative research that addresses patient needs in

a holistic and comprehensive way that often lacks the attention and funding given to medical research.

Breaking off into the nurses' stream we heard **Tess Ostapowicz**, a research nurse from the Malaghan Institute, present the initiation of the CAR T-cell study. This study is a fantastic opportunity for patients with relapsed and refractory B-cell lymphoma who have no other treatment options, to receive chimeric antigen receptor T-cells manufactured locally at the Malaghan Institute. Another presentation on the CAR T-cell study was given the following day by **Dr Rob Weinkove**, clinical director at the Malaghan Institute, adding further scientific depth to the previous day's learning.

Two other presentations I gained a lot from were given by **Dr Rose Liu** from Westmead Hospital, on skin toxicities associated with anti-EGFR therapies and optimal skin management. Dr Liu reviews and treats patients in a dermo-oncology clinic; an important role given the frequency of treatment-related skin toxicities amongst cancer patients. I found her presentation perfectly pitched for cancer nurses, giving a refresher on the anatomy and physiology of skin toxicities along with a very simple guide to determining whether or not a rash is caused by an anti-EGFR agent, and the appropriate management of these skin toxicities.

NZSO and the Cancer Nurses College conference are always a great opportunity to network with colleagues from other DHBs. I was surprised at the small turnout of nurses this year, and would encourage nurses to attend in the future.



**Both Dr Rose Liu and Prof Mel Krishnasamy have kindly allowed us access to their slides from their presentations at conference.**

- *Skin toxicities associated with anti-EGFR therapies*
- *Optimal skin management of patients on anti-EGFR therapies*
- *Building a novel model of nurse-led, follow-up care for people affected by multiple myeloma one project at a time.*

 [Click here to view their slide presentations via the NZSO programme](#)

## Prof. Ron Jones at NZSO

**For many who attended the New Zealand Society of Oncology (NZSO) conference in Wellington the highlight was Prof. Ron Jones's presentation - Doctors in Denial: The forgotten women in the 'unfortunate experiment'.**

He took us all on a most authentic journey through a sentinel event, the realities of why informed consent is so essential and the long reaching human perspectives and health penalties for the women who endured the real consequences of this health and research history event.

As Prof Jones presented his keynote speech you could hear a pin drop. In between the multiple subconscious gasps, palpable bewilderment and the rustle for tissues, there was profound sadness at how this could have happened such a short time ago in our own history and with the realization how important it is to forever be uncomfortable with the truth, so it is never forgotten or rewritten.

It forced us to confront the nature of power and bullying, the personal and professional risks where whistle blowing may be the last resort to advocate for patient safety and our own inherent duty to tell and expose the truth, particularly within each of our professional mandates.

It was clear Prof Jones was deeply affected by his part both personally and professionally and we marvel at the strength, motivation and resilience in such a humble man. If you were unable to attend you may like to read some more of his reflections so please do access his book or see this taster via this North & South article...

 [North & South article](#)

# STUFF - a creative approach to providing key information and guidance to newly diagnosed adolescent and young adult (AYA) cancer patients

Liz Sommer RN

Wellington Regional Hospital Blood and Cancer Centre, New Zealand  
AYA Cancer Network Aotearoa, New Zealand

## Background:

While a cancer diagnosis is challenging for anyone, the AYA patient population generally have little, if any previous experience with managing such a major life-changing event and as such may be more likely to experience confusion, anxiety, depression and loss of confidence than older patient cohorts. Their heightened developmental need for privacy and autonomy may also make them less likely to seek support and information or to express their worries to others.

## Vision:

To create an age-appropriate interactive resource designed specifically for adolescents and young adults (AYAs) newly diagnosed with cancer. Part patient handbook, part journal **STUFF** is intended to provide inspiration, acknowledgement, reassurance and practical guidance and to act as something of a roadmap with which to traverse the messy, challenging terrain of cancer treatment as an adolescent or young adult.

## Development:

Initial development began with conversations between long-time AYA patient Petra Kotrotsos, the AYA cancer Specialist Nurse at CCOHB and a highly talented volunteer, Ana Matsis whose experience in communication and publishing was invaluable.

Ten AYA patients, past and present were then invited to complete a short survey or to engage in a one-on-one interview to inform the content and format of the book. Five key content areas were identified and these became the "chapters" of **STUFF**. Direct quotes from these interviews appear throughout the booklet to highlight the concerns commonly experienced by AYAs and to provide inspiration and reassurance.

The title "**STUFF**" (I need to know) - Ngā mea me mohio au - was chosen to reflect the messy mix of issues facing this special patient group and to veer away from more medically focused resources. Special thanks to AYA Lani Hirini for her Te Reo Maori translations of the chapter headings.



## Content & Production:

The five topic areas chosen were –

1. The Heart, Head and Social **STUFF**/Te ngakau, te hinengaro, me nga mea pāpori – feeling scared, sad, out of control and all those other big emotions; stuff that seems weird; impact on future plans, education, relationships, sexuality and more
2. **STUFF** that might help/Ngā mea hei awihina pea – ideas for maximising support and self-care
3. Treatment **STUFF**/ Ngā mea maimoatanga – what to expect, explanation of medical terms, tests, scans, treatment modalities, blood results
4. Useful **STUFF**/Ngā mea whaipānga – contact details for hospital departments, recommended websites and useful support organisations
5. Personal **STUFF**/Ngā mea matawhāloro – blank space allocated for patients' personal reflections (writing, drawing, scribbling etc) and suggestions for creative self-expression

A focus group of AYAs generously gave their feedback on an initial draft to fine-tune both content and design. They offered a clear message about style, emphasising that it needed to be friendly and relaxed rather than clinical or "preachy". A repeated reminder was that everyone's experience of cancer is unique and that while your own feelings and perceptions may be different to other AYAs they are equally valid and worthy of acknowledgement.

## Outcome and Future Possibilities:

**STUFF** has been well-received by AYAs and would naturally lend itself to being produced in a digital format in the future. It is currently being edited for use at Canterbury DHB and may also prove useful for those working with adolescents and young adults diagnosed with other significant or chronic health issues.

## Acknowledgements:

The fully fledged version of **STUFF** was produced with a raft of generous contributions from the funders (Wellington Hospital Foundation), designers (Movie), printers and paper merchants but most importantly of course the young AYA cancer patients and survivors who gave their time, energy and wisdom to help make the journal the best it could possibly be.



## Improving the patient experience one resource at a time

Bronwyn Perry, CNS

Canterbury Regional Cancer and Haematology Service,  
Christchurch Hospital, Canterbury District Health Board

Canterbury  
District Health Board  
Te Pōwhiri Hauora o Waitaha



...focused on creating a health system and community where people take greater responsibility for their own health...

Canterbury DHB vision, mission statement and values

...health care related education has evolved from a relationship based on paternalism to one of partnership to ensure consumers are key stakeholders in own health care...

Ellery, S. (2013).

...5. The right to be told things in a way that you understand 6. The right to be told everything you need to know about your care and treatment...

HDC Code of Rights

## Why develop a video?

Senior nursing team, continually reviewing and updating information for people commencing drug treatment for cancer.

- Nurses play an important role in total patient care, including education.
- Written resources developed and updated.
- Integrative review 2013 for Masters in Nursing – identified gaps.
- Current practice allows all patients to be allocated a one hour appointment with an oncology nurse to go over their specific cancer treatment. We have between 9-12 appointments available per week.

Researchers found that adding a teaching video to standard education process enhanced information retention.

- Patients and families have easier access to technology.
- A locally produced resource will provide patients/families the correct information. It can be used by other treatment units within our catchment area.
- Research has identified that video resources are viewed more than once.
- Patient can choose which resource best suits their learning style.
- Forewarned is forearmed. Use of video was found not to increase anxiety therefore safe to use before formal education.
- Allow it to be seen in own home with family and friends. Generates questions and allows discussion when in face to face session.

- Increasing number of people being diagnosed and living with cancer
- Cancer is becoming a chronic health condition
- Aging population
- More treatment options available
- Diverse population

- Constrained resources – health professionals, appointment times, physical space
- Fiscal constraints
- Our current practice is not sustainable



## The process – how to improve the balance

- Radiation colleagues had developed a similar video. They shared this with patients starting treatment. Access is obtained from Canterbury DHB website and can be viewed on a mobile device.
- Script developed so that we could get important points across.
- Designed as a virtual journey through the process of receiving treatment and beyond.
- Multi-disciplinary team review and participation. Existing resources and our own experts were involved in developing content.
- Funding obtained from trust fund.
- Local production company engaged to tell our story.

## Project design

Factors that were considered while developing the content we wanted to share.

- Health literacy of the patient/family- using simple language but still using correct terminology.
- Consistent information was important so we used our current checklist to ensure that all aspects of chemotherapy education were covered.
- Recently updated patient information was used to guide content. This had been reviewed by the Patient Information Group which consists of the multidisciplinary team along with consumer and service group representatives to check that it was fit for purpose.
- Multidisciplinary approval allowed input from our colleagues and experts when considering what information was important to reinforce with the patient when writing the script.
- To be authentic we used our staff who are currently practicing in the oncology field to be filmed in the video.
- Did not use real patients in video due to sensitivity and confidentiality.

## Results



## Implementation

- Video available on CDHB site – [www.cdhb.health.nz/medicaloncology](http://www.cdhb.health.nz/medicaloncology)
- Update written patient information to include instructions on how to access video.
- Review how our patient education is delivered by nursing staff to utilise the use of the video.
- Provide staff training across service using updated resources.

## Future goals

- Consider adding appropriate subtitles to meet needs of specific patient groups:
  - Te Reo
  - The hearing impaired
  - For those whom English is a second language
- Review updated process to see if we can increase capacity of chemotherapy education sessions within resources available.

## Acknowledgements

Oncology Trust Fund – Jean Procter Estate  
Thank you to the Oncology Service staff members who volunteered to be the 'patients', Oncology Day Ward nursing staff who 'treated' our patients, Ruth Gerring CNS, Charlotte Tongney CNS, Sarah Ellery NP, Jenny McLachlan Medical Oncologist, John Griffin and his team from Orly Productions, Jessica Takke Graphic Designer Medical Illustration.

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# Patient Held Record

## A novel Communication Tool for an Outpatient Oncology Day Unit

Sue Callahan RN and Mary Cotter RN

### Southern Blood and Cancer Service

#### Patient Held Record

Hei aukahaaua matawai eke, he hōhiki nga paitai me mahi. Kōwhiri ki te whakamātaua, kōwhiri ki te mātauranga.



*Cancer is a journey, we are here to help and support you along the way.*

#### Important – please read

This booklet is a self-driven record of how you are during your treatment and can be useful in enabling your Oncology team to optimise your care.

We encourage you to share the information you have written with your Health Care Team when you attend appointments.

This is your record. Please take care as it contains some of your personal health information.

### Whakatauki (Proverb)

He aha te mea nui o te ao?

*What is the most important thing in the world*

He tangata! He tangata! He tangata!

*It is the people! It is the people! It is the people!*

### The Background

Accurate communication between the patient and their oncology team is vital in optimising outcomes.

Sue and Mary are oncology nurses working in an Outpatient Oncology Day Unit in Invercargill. They observed common issues that they felt impacted on the flow of communication between the patient and their oncology team including ...

- At medical review prior to their next chemotherapy sometimes patients portrayed themselves in an overly optimistic presentation. This could be in contrast to how their significant other perceived that they had been.
- Sometimes patients would write their questions, symptoms or concerns on scraps of paper to bring to clinic. These were sometimes left at home or misplaced.
- Patients were given a lot of verbal information and instructions at clinic - this was not always written down and had the potential to be forgotten.

Patients can misreport adverse effects from treatment if it is done retrospectively. Medical Oncology review is generally 2 – 3 weeks post the previous treatment and therefore time (and chemo-brain) can diminish the accuracy of reporting symptoms.

Sue and Mary developed a booklet they hoped would improve communication by enabling patients to record their symptoms in real time. This patient driven tool aimed to be a "one stop shop" to enhance information sharing.

**"Patient-reported outcomes are an increasingly popular tool to optimise care and bridge the gap between patient experience and clinician understanding"** (Yang, Manhas, Howard and Olsen 2018).

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<https://www.invercargill.co.nz>  
<http://www.advancedcancerplanning.org.nz>

### The Process

Sue and Mary researched patient diaries and self-reporting tools across New Zealand and the United Kingdom.

They developed a draft Patient Held Record (PHR) specifically with their Southern patients in mind.

Any advice written in the booklet was aligned with the e-vi-Q website and local protocols.

The PHR was critiqued by nurses, consultants and other members of the multi-disciplinary team.

Over a period of three months the draft PHR was presented and given to 35 patients at their nurse led education session.

The patients then had the opportunity to use the booklet across the next six months.

Questionnaires were developed and were given to both patients and nurses to evaluate the effectiveness of, their response to, and the value of the PHR.

### Results

61% of the patient questionnaires were returned.

90 % of these had a very positive response to the booklet.

Some of the comments were...

*"Loved my plunket booklet, means I can be proactive in a constructive way which is to my benefit after all"*

*"Very helpful and informative. Good for keeping appointments, keeping records of your blood tests for quick reference and also records of side effects. I would refer to it regularly!"*

*This enabled us to keep track of treatment – record questions – helpful to refer to after consultations"*

*"Very useful. It was a reminder at what to ask at the next appointment with Oncology"*

- 100% of the nursing questionnaires were returned and the feedback was largely positive.

Some of the comments were...

*"Good tool to try and promote independence and understanding"*

*"Gives the patient good prompts as to what side-effects to look out for and what is important to report when they are with the Doctor or Nurse"*

*"Can be used to assist with chemo pre-assessment to get a fuller picture on how the patient has been in the days / weeks prior to next chemo cycle"*

- A cultural prospective was sought to ensure inclusiveness

The feedback from both questionnaires and the cultural team was used to modify and enhance the PHR.

The final copy was launched in September 2018.

#### Acknowledgements

We would like to acknowledge that some of the inspiration for our PHR came from previously published Patient Diaries and booklets.

Patient Held Record – Wellington Hospitals and Health Foundation  
Communications booklet – West Coast DHB  
Haematology patient diary – Leukemia and Blood Foundation  
Your Chemotherapy Record – Northern Cancer Network, UK

### What is the PHR

The PHR is a booklet that the patient uses to record their post treatment adverse effects in real time using the symptom prompt guide located on the treatment record pages.

The diary format allows patients to expand on their symptoms if necessary, record questions they want to ask and note medications they may be running out of.

We encourage our patients to make the booklet their own by filling in their own details, keeping track of appointments and following the important advice and information nestled into the booklet.

The PHR can be an interactive tool between the care team and their patient both on treatment days and when they attend their outpatient clinic appointment.

It is useful to refer back to when a patient is describing specific symptoms as well as a place to record advice, appointments or blood results.

61% of the patient questionnaires were returned.  
90 % of these had a very positive response to the booklet.  
Some of the comments were...

**Treatment record Cycle 01**

Date of treatment: \_\_\_\_\_  
Chemotherapy Regime: \_\_\_\_\_

**Have you had any adverse effects with this cycle?**

Type of side effect: \_\_\_\_\_ When did it start: \_\_\_\_\_ (Day, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49, 50, 51, 52, 53, 54, 55, 56, 57, 58, 59, 60, 61, 62, 63, 64, 65, 66, 67, 68, 69, 70, 71, 72, 73, 74, 75, 76, 77, 78, 79, 80, 81, 82, 83, 84, 85, 86, 87, 88, 89, 90, 91, 92, 93, 94, 95, 96, 97, 98, 99, 100)

What is the effect? \_\_\_\_\_  
How often? \_\_\_\_\_  
How long? \_\_\_\_\_  
What is the impact? \_\_\_\_\_  
What is the impact on your life? \_\_\_\_\_  
What is the impact on your work? \_\_\_\_\_  
What is the impact on your family? \_\_\_\_\_  
What is the impact on your social life? \_\_\_\_\_  
What is the impact on your mental health? \_\_\_\_\_  
What is the impact on your physical health? \_\_\_\_\_  
What is the impact on your emotional health? \_\_\_\_\_  
What is the impact on your spiritual health? \_\_\_\_\_  
What is the impact on your overall health? \_\_\_\_\_

What medications relating to my treatment am I running out of? \_\_\_\_\_

Should test that: Hb, WBC, Plate, Creat, Urea

**Questions to ask at Oncology appointment**

1. \_\_\_\_\_  
2. \_\_\_\_\_  
3. \_\_\_\_\_  
4. \_\_\_\_\_  
5. \_\_\_\_\_  
6. \_\_\_\_\_  
7. \_\_\_\_\_  
8. \_\_\_\_\_  
9. \_\_\_\_\_  
10. \_\_\_\_\_

**Comments / Changes in treatment / Advice**

1. \_\_\_\_\_  
2. \_\_\_\_\_  
3. \_\_\_\_\_  
4. \_\_\_\_\_  
5. \_\_\_\_\_  
6. \_\_\_\_\_  
7. \_\_\_\_\_  
8. \_\_\_\_\_  
9. \_\_\_\_\_  
10. \_\_\_\_\_

**What medications relating to my treatment am I running out of?**

1. \_\_\_\_\_  
2. \_\_\_\_\_  
3. \_\_\_\_\_  
4. \_\_\_\_\_  
5. \_\_\_\_\_  
6. \_\_\_\_\_  
7. \_\_\_\_\_  
8. \_\_\_\_\_  
9. \_\_\_\_\_  
10. \_\_\_\_\_

### Outcome

The PHR is offered to our patients at the nurse led education session prior to their first chemotherapy. An explanation is given about the format of the booklet and how it can enhance information recording and sharing.

Most patients respond enthusiastically to receiving the PHR.

We find the booklet facilitates the process of the patients being able to communicate their adverse effects with greater detail and accuracy.

This enables the care team to respond with appropriate advice and make changes to treatment and supportive measures as required.

We think the questionnaire response from one of our nurses sums it up...

*"The patients feel a loss of control when confronted with a diagnosis of cancer, putting any control back into their lives is empowering. I think this booklet helps with this"*

# Patient Reported Outcomes in Colorectal Cancer

Sara.E.Farrant<sup>2,3</sup>, Thomas Aitken<sup>3</sup>, Elizabeth.R.Dennett<sup>1,2,3</sup>, Ali Shekouh<sup>2,3</sup>, Kirsty.M.Danielson<sup>1,3</sup>

1. Department of Surgery & Anaesthesia, University of Otago, Wellington, New Zealand

2. Department of General Surgery, Capital and Coast DHB, Wellington, New Zealand

3. Surgical Cancer Research Group, University of Otago, Wellington, New Zealand



### Introduction

New Zealand has one of the highest incidences of Colorectal Cancer (CRC) in the developed world. Due to advances in treatment, coupled with an ageing population, there are increasing numbers of patients progressing to survivorship. Although this is a positive outcome it has led to a rise in patients living with myriad symptoms that diminish their Quality of Life (QoL). Patient reported outcome (PRO) tools measure the impact that treatment has on patients function, symptom burden, financial impact, and the resultant effect on the patients QoL. It is known that deprivation and psychosocial factors can influence PRO's, however, PRO tools are relevant to support clinical discussions, patient participation and education, inform service requirements, and guide resource allocation.

### Study Aims

- The primary aim of this pilot was to evaluate the acceptability of two international PRO measurement tools in the New Zealand population and provide preliminary analysis.
- Secondary aims were to a) compare the New Zealand Index of Socioeconomic Deprivation (NZiDep) with an addressed based score (NZDep2013) to measure levels of deprivation and b) determine which tool to apply to gauge an accurate measurement.

### Methods

Two PRO measurement tools were applied to 42 patients undergoing treatment for Colorectal Cancer at Wellington Hospital between November 2018 and January 2019;

EORTC Quality of Life Questionnaires C29 and C30  
Questionnaires pertained to general QoL and CRC specific questions

During the past week have you:

	Not at all	A little bit	Quite a bit	Very much
49. Have you had unintentional release of gas/flatus from your stoma bag?	1	2	3	4
50. Have you had leakage of stool from your stoma bag?	1	2	3	4
51. Have you had sore skin around your stoma?	1	2	3	4
52. Did frequent bag changes occur during the day?	1	2	3	4
53. Did frequent bag changes occur during the night?	1	2	3	4
54. Did you feel embarrassed because of your stoma?	1	2	3	4
55. Did you have problems caring for your stoma?	1	2	3	4

Table 1: Exert from the EORTC QoL C30

Patient feedback was sought by asking standardized questions to assess acceptability of length and content of the PRO tools

NZiDep Survey and NZDep 2013 (address based data) were applied and compared to gauge actual against assumed level of deprivation.

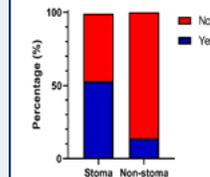
Total Number	42
Median Age (IQR denotation)	67 (12)
Gender (%)	
Male	22 (52.4%)
Female	20 (47.6%)
Ethnicity (%)	
NZ European	27 (64.3%)
Other European	9 (21.4%)
Māori	4 (9.5%)
Asian	2 (4.8%)
Site of Primary Tumour (%)	
Colon	26 (61.9%)
Rectum	16 (38.1%)
Time since surgery (median)	2-42 months (9 months)
Surgical procedures	
High anterior resection	32 (76.2%)
Right Hemicolectomy	3 (7.1%)
Low anterior resection	7 (16.7%)
Stoma	3 (7.1%)

Table 2: Demographics

Preliminary analysis of the PRO data was performed using GraphPad Prism. Fishers Exact Test was used for categorical data.

### Results

- 95.2% agreed the survey was a suitable length
- 97.6% agreed the survey content was appropriate
- 97.6% agreed the survey content helpful
- 50% suggested PRO should cover a wider timeframe and include questions about the patient experience.
- 33% match between the NZiDep Survey and the NZDep 2013
- 24.4% of patients experienced some level of financial difficulty



Statistical significance (p<0.02) was reached for patients experiencing negative body image with the presence of a stoma compared to those without.

Figure 1: Negative Impact on Body Image - Stoma presence

5 of 11 patients with a Low Anterior Resection (AR) reported an impact on normal activities.

Conversely, 1 of 12 patients with a High AR noted an impact on normal activities. This did not reach statistical significance (p=0.07).

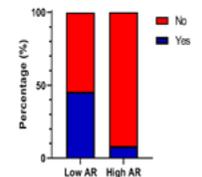


Figure 2: Impact on activity by Surgery type

### Conclusions and Future Directions

- Patients were satisfied with the length and content in the PRO tools.
- The PRO will be implemented over a 5 year surveillance period, addressing the need to survey a longer timeframe.
- Experience is a matter of importance to patients but is better captured using alternative tools.
- Analysis of this small sample reveals the impact of a stoma, corroborating findings in larger international studies and the PRO tool should be modified to include an AR Syndrome Score.
- There is underestimation of the financial burden carried with a cancer diagnosis and the required treatment. The NZiDep Survey better measures patients underlying deprivation levels.



## Report from the chair

### Tēnā koutou katoa

*It's hard to believe it's nearly Christmas already. It has been a busy year in the world of cancer nursing.*

*As many of you will be aware the college has just had our Biannual General Meeting (BGM) in conjunction with the New Zealand Society for Oncology (NZSO) conference. A huge amount of work went into this from the organising committee and I would like to say a most sincere thank you to our nurse representatives Cathy Teague and Kate Whytock (current CNC vice secretary) who arranged the nursing programme. It would be fair to say this was a resounding success.*

*The speakers were fantastic, personal highlights for me included:*

- **Prof Mei Krishnasamy**, Chair in Cancer Nursing in the Department of Nursing at the University of Melbourne, Research and Education Lead for Nursing for the Victorian Comprehensive Cancer Centre and Director of the Academic Nursing Unit at the Peter MacCallum Cancer Centre in Melbourne, who spoke on building capability for nurse-led research across Australia and New Zealand;
- **Dr Rose Liu**, Department of Dermatology, Westmead Hospital, Sydney, New South Wales, who spoke on Skin toxicities associated with anti-EGFR therapies and led a workshop on assessment and optimal skin management of patients on anti-EGFR therapies.
- Last but not least **Professor Ron Jones**, author of 'Doctors in Denial: The forgotten women in the 'unfortunate experiment', who was the whistle blower that led to the 1988 Cartwright Inquiry.

*The BGM itself was fairly brief with no remits or unexpected items for discussion this year. Elections were held electronically prior to the meeting, as this was the first time the college received more nominations than committee vacancies. It was good to see electronic*

*voting in action. Although voting participation was not high it was reflective of the national trends within NZNO. It is also heartening to see increased interest in cancer nursing leadership at a national level. I am pleased to say all of the standing members of the college committee were voted back on.*

*I would like to welcome our newest committee member **Maarie Hutana** from Canterbury District Health Board, who will be joining us from our February 2020 meeting.*



*We also said goodbye to **Felicity Drumm** who is standing down, she has held various portfolios in her time on the committee and she will be sorely missed.*

*Special thanks to our hard-working committee member **Kate Whytock** who was part of the organising committee for the NZSO conference and ensured a robust excellent nursing stream programme.*

*Submissions on the New Zealand Cancer Action Plan 2019-2029 have closed and the Interim Cancer Control Agency Board has been announced. The Board will oversee the finalisation and implementation of the Cancer Action Plan and the establishment of the recently established Cancer Control Agency, one of the key priority actions in the Plan.*

*The Cancer Nurse College committee were disappointed nursing representative was not included on the board, however we will continue to advocate for nursing representation at all levels of the cancer programme.*

*Finally I would wish you all a safe and restful Christmas season.*

*Nga mihi*

**Kirstin Wagteveld (Unahi)**  
**Chairperson - CNC**

# Cancer Nurses Conference 2021

## Expression of Interest

**The Cancer Nurses College Committee are calling for expressions from interest from regional cancer nursing groups to host the CNC Conference 2021 and form a hosting committee**

**This will be a significant milestone event - 25 years from the inaugural Cancer Nurses College (previously Section) AGM.**

### PLEASE NOTE

- The CNC BGM is a requirement to be held during this conference.
- A seeding grant is provided by CNC which is returned to the CNC operating account on completion of the conference.
  - Conference profit is shared equally with CNC and the hosting conference committee to support regional nursing cancer education.
- Your submission should include proposed dates, venue, organizing committee members, conference theme with equity related lens/agenda items, potential speakers/topics (and additional local attractions/benefits).

**Please submit a brief proposal to the CNC committee by 30th January 2020 to [cancernursesnz@gmail.com](mailto:cancernursesnz@gmail.com)**

# Self-management for people living with long-term conditions



## Thank you to the Cancer Nurses College for the education grant.

I work as a Cancer Support Nurse Specialist for Cancer Society Auckland Northland where I work with a team of nurses who are both community-based and who work at Domain Lodge in Information Services. Our role is to visit clients at home recently diagnosed with cancer or undergoing chemotherapy or radiation therapy. We offer support and information about cancer and cancer treatments, help to manage symptoms or treatment side-effects and offer emotional support and understanding.

I used the grant towards post-graduate study at The University of Auckland. I chose to complete Self-management for Living with Long-term Conditions such as, for example, cancer. I chose this paper as it was focussed on learning new skills to strengthen my ability to assess and support client's self-management along with improving patient-centred goal setting and planning skills. The paper was structured around six study days, two Flinders care plans and two assignments. I have discussed the highlights of the course below.

I found completing the Flinders care plans beneficial and interesting. The Flinders programme was developed by Flinders University in Australia. It is a health care provider-led evidence-based self-management programme. The Flinders care plan offers a set of tools and structured processes to allow

a healthcare provider and client to work together to undertake a holistic, structured assessment of self-management behaviours. Further, it allows a collaborative approach to identify key problems, issues and goals the client wants to focus. These form the basis of a summary care plan that captures actions and anticipated issues for the following twelve months. To complete the care plans I interviewed two of my current clients. They both felt that it was beneficial for their self-management and the care plan enabled me to ask them questions other than purely clinically based. For example, about their emotional and spiritual well-being and managing the impact of their diagnosis on social aspects of their life. These are not the types of questions I normally ask, and the patient may have felt uncomfortable with me asking these types of questions directly if not for the understanding of this being holistic and collaborative. After completion we received a Flinders Certificate of Competence.

As part of the second assignment I completed a clinical audit by interviewing ten clients who access oncology services in Auckland using the Patient Assessment of Chronic Illness Care (PACIC) and ten Cancer Society Auckland Northland Cancer Support Nurse Specialists (CSNS) by using the Modified Patient Assessment of Chronic Illness Care (MPACIC). PACIC was developed to assess clients who live with a long-term condition from their perspective with

regards to the quality of care that they receive and how that can influence their self-management behaviours and client-centred outcomes. MPACIC aims to measure care delivery from the viewpoint of the health care provider. This audit was interesting and reinforced that the CSNS plays an important role supporting clients living with cancer. I intend to share the audit results and learnings with my colleagues and the PACIC and MPACIC tools can be used for further audits.

During one of the study days we discussed motivational interviewing. Motivational interviewing is a collaborative conversational approach to behaviour change that is designed to strengthen a client's commitment to, and motivation for, change. It is designed to help someone move from feeling ambivalent about needing to change a behaviour, to believing they need to change the behaviour, to believing they can change the behaviour. This was a good reminder of how to support the client's self-efficacy. We spent time discussing mindfulness, again a reminder that, as nurses, if we do not know how to look after ourselves, we are unable to look after others.

I enjoyed completing this paper and look forward to implementing new skills and resource tools with the aim of benefiting the clients I visit. Finally, I look forward to sharing knowledge with my colleagues.

**Tanja Rogers**



Linking professionals in melanoma in New Zealand

## Canterbury Regional Skin Cancer Study Day

An all-day course for nurses

Friday 21 February 2020

Room 314, Level 3 Manawa

276 Antigua Street, Christchurch

*Hosted by Canterbury Clinical Nurse Specialists/Cancer Nurse Coordinators and MelNet, this one-day course will provide an overview of skin cancer prevention, early detection, treatment and care with a focus on melanoma. It will increase understanding of the journey of a skin cancer patient and the critical role of a nurse throughout this journey.*

*The cost of attending this course is \$50.*

**>> [Click here to register](#)**

**>> [View the programme](#)**

For more information contact:  
Katrina Patterson, Chief Executive, MelNet

**E:** [melnet@melnet.org.nz](mailto:melnet@melnet.org.nz)

**M:** 0274926650

# Report on the 21st Annual Scientific Meeting, Australasian Gastro-Intestinal Trials Group **AGITG Trials in Action**

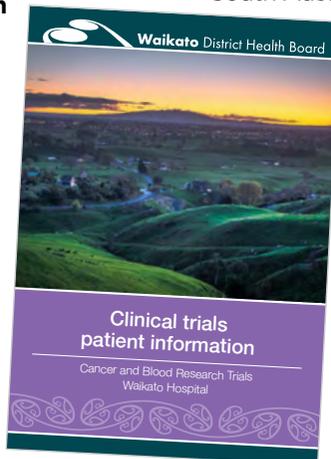
**The theme of this meeting was “Challenging the enigmatic nature of gastro-intestinal cancers”, with a focus on rare and underfunded cancers and cancer subtypes and convened by Dr Lorraine Chantrill, Medical Oncologist.**

The meeting program included interactive multidisciplinary workshops, new concepts Symposium and plenary sessions. Current clinical trials were presented including the SPAR study that is running Waikato Hospital, updating delegates on the status of the trial and provided investigators an opportunity to comment and ask questions.

## The topics presented included

- **Rare cancers: how can we do better?**
- **Biology and pathology of GI cancer**
- **Cutting edge translational science in GI cancer**
- **The Neoadjuvant approach in operable tumours and other controversies in pancreatic cancer**
- **Bugs, drugs and biologicals in GI cancer**

I had the privilege to give a poster presentation, about our project of a clinical trial booklet for patients. There has been very positive feedback on the booklet, especially from the consumer advisory panel.



Some research units in NZ will be adopting this format when developing their own.

A dedicated study coordinator workshop was held a day before the start of the main meeting. This workshop focused on a wide range of topics by experts in the field such as safety reporting, serious breaches, GCP/ Protocol and risk-based monitoring. Pancreatic cancer was also a focus at this meeting and I learnt a lot from Dr Matt Burge who spoke about gastro-intestinal-related issues. I also had the opportunity to tour the South Australian Health and Medical

Research Institute, which is not far from Adelaide Hospital. This makes it easy for collaborative research to take place. The tour included a lecture on translational research, presented by Dr Susan Woods and A/Prof Dan Worthley.

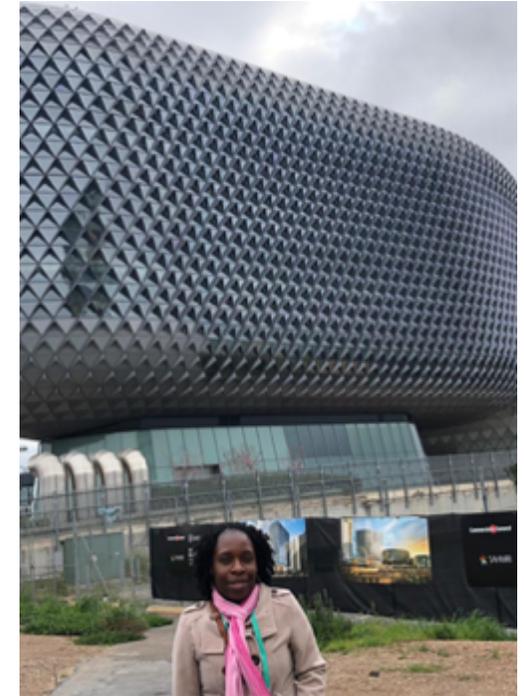
I found of particular importance, the study coordinator workshop and also the joint consumer/study



coordinator forum was very valuable. Dr Claudia Rutherford presented on quality of life and survivorship of patients with colorectal cancer. Dr Rutherford also presented a colorectal survivorship model; that includes symptoms, physical functioning, lifestyle behaviour, financial toxicity, physical functioning and supportive healthcare. There was also an interactive

consumer and clinician presentation by Mr Grant Baker and Mr Andy Phay. They spoke about initiatives that are patient-focused such as telehealth, apps that explain clinical trials, remind patients on when to take medications and scheduling systems. More of these apps are in development and will become part of trials. It was an opportunity to discuss the challenges and success stories of various trial centres in the Australasian region.

Prof Jobin spoke at the opening plenary session that was entitled “Rare cancers: How can we do better”. His presentation was very interesting and focused on the predictive power of microbiota, microbiota diversity, impact on the treatment of some cancer such as pancreatic and predicting patient outcomes.



*Tour of South Australian Health & Medical Research Institute*

The meeting had many other interesting topics and discussions. There was a wide variety of sponsor displays and an extensive collection of poster presentations.

Overall I enjoyed the conference and networking with other members of the research team and consumer advocates.

I am grateful to the Cancer Research Trust who awarded me a Professional Development Grant to attend this Meeting, Wendy Thomas (CNM) and my colleagues for the support to attend this meeting.

**Lindah Chikazhe, MN**  
**Nurse Coordinator - Cancer and Blood Research Trials Unit, Waikato Hospital**

# REPORT FROM THE NET Nurse Workshop

**Having never previously attended a NET study I took the opportunity to extend my limited NET knowledge with the overall aim of becoming more confident in dealing with NET patients. The NOVARTIS Nurses Workshop provided valuable learning covering pathological and radiological diagnoses and a range of treatment options.**

Of particular interest was Prof. Chris Hemmings presentation on staging and grading of NETs which demonstrates the histopathological challenges of making a NET diagnosis. The presence of chromogranin A, synaptophysin expression in tissue, and 5-hydroxyindoleacetic acid (5-HIAA) in urine are diagnostic. Mitotic count and Ki67 index are proliferative markers which determine grade.

Dr Dean Harris's whirlwind of evidence-based options for medical oncology highlighted how limited the options are for NET patients in the publicly funded arena and demonstrated how NETs can be viewed as an emerging disease process. The endocrinology session led by Dr Veronica Boyle highlighted some of the challenges of endocrine testing for both patient and nurse. Developing an understanding of the scope of disease presentation and symptoms has significantly broadened my knowledge for clinical practice.

The most valuable learning I found to be the PRRT patient presentations. The lack of support for these patients due to self-funded travel to Peter Mac in Melbourne really highlighted the importance of a key person to navigate their care and someone to provide crucial, on-going support. The broad spectrum of symptoms resulting from secretory substances significantly affects quality of life, even in the presence of indolent tumour growth.

The take away message is that NETs are a heterogeneous group of diseases that present with a wide range of symptoms, requiring a variety of diagnostic tests and similarly broad range of treatment options. Secretory substances can have significant impact on quality of life and require on-going management.

**Libby Rea Brownlee**  
**Oncology Nurse Specialist | GI team**  
**Regional Cancer & Blood Service, Auckland Hospital**

**Since the study day there has been exciting news...**

For those patients requiring PRRT (Peptide Receptor Radionuclide Therapy) it seems there is strong support from the MOH to provide this service in New Zealand and the wheels are in motion exploring how this may be achieved. In the interim funding is potentially available through the MOH treatment fund. Patients require discussion at the national NET MDT meeting and have a supporting letter from the chairperson to enable access to the treatment funds.

To keep up to date with what's happening in the NET world Avril Hull and others do a superb job as administrators of a closed Facebook page for health professionals interested in education, training and updates related to neuroendocrine cancer in NZ. The page is called NZ NET Cancer Nurses and HCP

Also advocating for those with NET cancer is the Unicorn Foundation, a registered charity aiming to provide support and information to patients, families and medical professionals involved in the treatment for Neuroendocrine Tumours/Cancer (NET Cancer).

 [Visit the Unicorn Foundation website for more info](#)



## The National Cervical Screening Programme (NCSP) will be **changing the recommended starting age for cervical screening from 20 to 25 years in 2019.**

A new media campaign is being created for 25 to 29 year old women to raise awareness of the importance of cervical screening and inform them of the change to the screening start age. The campaign concepts have tested well with consumers and sector audiences and a final concept is being developed. The campaign is planned to go live nationwide during February next year, and will be supported by a provider toolkit from early 2020.

 [Please see the key findings of the cervical screening research key findings here...](#)  
or the cheat sheets pages 4-7.

### **Human papillomavirus (HPV) Immunisation messaging**

It is important to remember that HPV causes 99 percent of cervical cancers and persistent HPV infection is the most important risk factor in developing cervical cancer. For this reason the NCSP, along with the Ministry's Immunisations team, actively encourages the promotion of Human papillomavirus (HPV) immunisations to young women and men. Even if individuals have previously been exposed to the HPV virus, the vaccine can offer a level of protection against cervical cancer. Regular cervical screening continues to be a vital part of cervical cancer prevention.

**Practice point: Remember to incorporate cancer prevention messages in your relevant patient and whanau cohorts.**

This is one very important way to change our cervical cancer outcomes: **prevention, prevention, prevention!**

This article is part of a new initiative for Cancernet... There are so many wonderful support organisations working hard to provide much-needed and appreciated services for people affected by cancer and other illnesses. We'll profile them also start compiling a permanent *Directory for Supportive Care organisations* as a resource you can refer back to.



## Creativity, support and inspiration

**CanBead was founded in 2010 by courageous woman Sarah Clifford. Sarah was diagnosed with melanoma in 2008 and while undergoing treatment in Christchurch in February 2010 she was given jewellery making supplies from a friend.**

During her 28 days of radiation treatment, she created and wore a different necklace each day. This process provided not only an excellent distraction and fun but also a great sense of purpose and accomplishment.

Sarah knew by starting beading workshops that she could help so many others in similar situations. Since then

CanBead has become The CanInspire Charitable Trust and has added CanTackle to the list of services.

CanInspire prides itself on being able to share its free of charge services to those experiencing illness, trauma and loss and to those who support them.

- **CanBead** is our jewellery making workshop which is a great way for our participants to spend a few hours creating something unique and sharing time with others in similar situations.
- **CanTackle** is our fly-fishing workshop which teaches our participants the art of creating fishing flies, learning casting, and getting out on the water to give it a go.

Because we work with host agencies in our different regions, we suggest that if you wish to attend a workshop to get in touch with us and we can direct you to the closest agency.

Create - Support - Inspire: these three words are the motto of CanInspire and we hope that every one of our previous and new participants feels the joy our workshops can bring.

CanInspire has reached thousands of people and will continue spreading joy in the future.

 [Learn more about Canspire](#)

**Kylie Curwood**  
**CanBead National Coordinator**

## Supportive Care organisations DIRECTORY



CanInspire

 [www.caninspire.org.nz](http://www.caninspire.org.nz)

Shocking Pink

 [www.shockingpink.org.nz](http://www.shockingpink.org.nz)

Need to talk? Text 1737

 [www.1737.org.nz](http://www.1737.org.nz)

Email us on:  
[cancernursesnz@gmail.com](mailto:cancernursesnz@gmail.com)  
if you have a worthy organisation that should feature here...

Dear ISNCC Full Member,

The International Society of Nurses in Cancer Care are calling for nominations to the Board of Directors. Please see below for more information and should you have any questions feel free to reach out.



## CALL FOR NOMINATIONS Election to the ISNCC Board of Directors 2020 Executive & Portfolio Positions

ISNCC is seeking nominations from individuals interested in opportunities to be involved in ISNCC at the Board level. Individuals with experience working with ISNCC or within national cancer nursing societies with experience relevant to the advertised portfolios are encouraged to nominate.

Nominees will need a good command of written and spoken English, access to electronic and telephone communication and be prepared to travel at least annually for Board of Directors meetings. Nominators must be a member of a national cancer nursing society in his/her country or, if no cancer nursing society in that country, a member of a national nursing society, or regional/international oncology nursing society (e.g. EONS, AONS, ISNCC), and working in the field of cancer nursing. Self-nominations are eligible.

Official voting on the nominated directors will take place after the nominations deadline by full members of ISNCC. These positions will commence on July 1st, 2020.

### Open Executive Positions

- President-elect
- Treasurer-Secretary

### Open Portfolio Positions

- Conference Management Committee Chair
- Policy and Advocacy Committee Chair

For more detailed information and nominations form please click on the links below.

[> Nominations Information](#)

[> Nominations Form](#)

Should you have any questions about this I invite you to contact me at [info@isncc.org](mailto:info@isncc.org).

**Leya Duigu, Association Manager**  
**International Society for Nurses in Cancer Care**

## Call For Expressions of Interest (Nurse Authors)

### Apply to receive editorial support to publish your manuscript!

The ISNCC Editorial Assistance Program (EAP) is a new program that aims to mobilize volunteers to provide editorial support to authors from a non-English speaking background in preparation of their manuscript towards submission to a peer-reviewed journal. This initiative forms part of ISNCC's efforts to enhance knowledge dissemination at a global level.

ISNCC is accepting applications from prospective nurse authors for the initial pilot trial of the program in 2020. Prospective authors need to have a manuscript related to cancer control currently in progress.

Eligibility criteria for the author:

- Be a nurse and member or global citizen of ISNCC;
- Be from a low- to middle-income country as defined by the World Bank;
- Reside in a country or region where English is not the primary language;
- Be able to submit a partially or fully complete draft of the manuscript as part of the application;
- The content of the manuscript must be directly related to cancer control.
- For research or quality improvement project reports, the project must be completed prior to applying for the program.
- Be committed to complete the manuscript over a period of 3-6 months.

**> To express interest fill in this Online Form**

and email your draft manuscript to Professor Ray Chan email: [Raymond.Chan@qut.edu.au](mailto:Raymond.Chan@qut.edu.au).

Expression of interest applications without a draft manuscript will not be considered.

Deadline for Expressions of Interest is 31st January 2020.

Here's information on a great service... If you would like more resources to have available at your workplace please email: [communications@homecaremedical.co.nz](mailto:communications@homecaremedical.co.nz)

 [Click here to order the "Need to talk? 1737" wallet card](#)

## "Need to talk? 1737" is the national mental health and addictions helpline

1737 is a free and confidential service that connects people with a trained mental health and addictions counsellor. It is available any time 24 hours a day, 7 days a week, 365 days a year by text or phone call.

More information is available at [www.1737.org.nz](http://www.1737.org.nz).

### What can someone call about?

Anyone feeling stressed, anxious, worried, depressed, needing advice on mental health or addictions issues can call or text.

### Who answers the calls?

Calls are answered by trained counsellors who use proven behavioural support techniques.

1737 is run as part of the National Telehealth Service. The same trained mental health professionals who currently respond to calls, texts, webchat and emails across the existing National Telehealth Service mental health and addiction helplines (depression, gambling and alcohol drug helplines), support people who call or text 1737.

### What does the service provide?

- When someone texts or calls 1737 a counsellor will work with the person to develop a care plan. This could include referral to another service, additional counselling or providing information and support.
- Brief intervention counselling services (primary counselling services where alternative counselling services are not available).
- Transfer and signposting to other services (e.g. face-to-face service providers).

### Is the service confidential?

Yes, 1737 is completely confidential. People can remain anonymous if they wish. However, if it becomes clear that someone is at risk of harm, it may be necessary for Police or ambulance services to be contacted.

### Is 1737 the helpline name?

Yes, the full name is "Need to talk? 1737" (with the question mark included). The extended version is: "Need to talk? Free call or text 1737 for support from a trained counsellor, any time."

### Why the number 1737?

This new service has been designed with in-depth input from Kiwis. Research showed us that some people found 0800 numbers difficult to remember. 1737 is a short and easy to remember number.

### What is the National Telehealth Service?

The National Telehealth Service was established in 2015. Integrated services include Healthline, Quitline, Alcohol Drug, Gambling, Poisons, Immunisation, Depression helpline, and The Early Mental Health Response service and the national mental health and addictions helpline Need to talk? 1737.

1600 contacts are made to the service every day. Over 270 frontline staff work on the National Telehealth Services, from five contact centres and from home offices across New Zealand.

All services are available 24/7, with interpreters available in over 40 languages.

A national telehealth service delivered by Homecare Medical

## NEED TO TALK?

# 1737

FREE CALL OR TEXT ANY TIME

WE'RE HERE

Free call or text 1737 any time, 24 hours a day

You'll get to talk to (or text with) a trained counsellor.  
Our service is completely free.



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## Research Review New Zealand

Research Review publications bring the best of 10,000 global medical journals to your inbox every issue with commentary from New Zealand experts. All you have to do is register. Oncology specific research information is available in the following...

### Medical Oncology

- [Breast Cancer](#)
- [Colorectal Oncology](#)
- [Immuno-Oncology](#)
- [Lung Cancer](#)
- [Renal Oncology](#)

### Haematology

- [Haematology](#)
- [Lymphoma and Leukaemia](#)
- [Multiple Myeloma](#)

### Māori Health

- [Māori Health Review](#)



## Free resources available from ONS on safe handling of cytotoxic drugs

### Clinical questions and answers *FREE!*

- [Should nurses administer and care for patients receiving chemotherapy while pregnant, breastfeeding, or trying to conceive?](#)
- [What safe-handling precautions need to be used with chemotherapy, biotherapy, and immunotherapy?](#)
- [What are medical surveillance recommendations for those who administer chemotherapy and biotherapy?](#)
- [Should sterile or nonsterile barrier precautions \(e.g. gown, gloves, mask, sterile drape\) be used when handling VADs?](#)



### Standards and position statement *FREE!*

- [ASCO/ONS Chemotherapy Administration Safety Standards](#)
- [Ensuring Healthcare Worker Safety When Handling Hazardous Drugs](#)

### Video *FREE!*

- [The Risk of Handling Hazardous Drugs While Pregnant](#)

### Book

- [Safe Handling of Hazardous Drugs \(Third Edition\). Download a free sample chapter](#)

### Toolkits *FREE!*

- [Safe Handling of Checkpoint Inhibitors](#)
- [Safe Handling of Oncolytic Viruses](#)
- [Toolkit for Safe Handling of Hazardous Drugs for Nurses in Oncology](#)
- [Oral Chemo Guide](#)



## GUIDELINES FOR CONTRIBUTING TO CANCERNET...

### Why contribute? Why publish?

- To share knowledge
- To advance your field of practice
- To disseminate key findings or opinions
- To contribute to policy debates

### Introduction

Cancernet is a newsletter that is published three times a year by the New Zealand Nurses Organisation Cancer Nurses College. Cancernet aims to inform and encourage nurses managing people with cancer to share opinion, resources, clinical practice and continuing professional development.

### Types of articles

All types of articles are welcomed and can include;

- *Opinion*
- *Clinical practice*
- *Case studies*
- *Continuing practice development*
- *Literature review*
- *Advanced study (e.g. BSc or MSc) write-ups*

### Submitting your work

- Articles should be submitted in Microsoft Word via email to [cancernursesnz@gmail.com](mailto:cancernursesnz@gmail.com)
- Acknowledgement of receipt of your submission will then
- Acknowledgement of receipt of your submission will be sent by email.

### Word count

Opinion articles should be between 700-1000 words long. However, clinical-based articles and literature reviews and advanced study articles, these can range from between 1,500 and 3,500 words, including references.

### Illustrative and images

Authors must obtain permission for the use of illustrative material or images and ensure that this material is labelled and captioned.

### Referencing

A recognised referencing system to be used. If the reference list is long, the reference list is available on request from the author.



**A Google search for cancer brings up over 570 million results.**

For patients with specific cancers - where's a good place to start?

[cancerinfo.co.nz](http://cancerinfo.co.nz)

- Blood Cancer
- Breast Cancer
- Ovarian Cancer
- Bowel Cancer
- Cervical Cancer
- Skin Cancer
- Brain Cancer
- Lung Cancer
- Stomach Cancer



**29 MARCH - 1 APRIL, 2020**  
**LONDON, UK**

**International Conference on Cancer Nursing 2020**

*The theme for ICCN 2020 is Innovation and Inspiration: Celebrating the Global Impact of Oncology Nurses.*

 [Click here for more information](#)

**13 - 14 APRIL, 2020**  
**LONDON, UK**

**27th Cancer Nursing & Nurse Practitioners Conference**

*Theme: Expedite Innovation and Encouraging Advances in Nursing and Cancer Care*

**29 APRIL - 3 MAY, 2020**  
**SAN ANTONIO, TEXAS, USA**

**Oncology Nurses Society (ONS) Annual Congress**

*Power. Passion. Purpose - Join 4,000 of your peers to shape and revolutionise the future of cancer care.*

 [Click here for more information](#)

**16 - 20 JUNE, 2020**  
**BRISBANE, AUSTRALIA**

**Cancer Nurses Society of Australia Annual Congress**

*Theme: Precision Care Everywhere.*

 [Click here for more information](#)

A GENTLE REMINDER TO PLEASE REMEMBER TO **invite your traditional and non-traditional cancer colleagues to become Cancer Nurse College members**

i.e. Nurses who are NZNO members who work with cancer patients in any context i.e. emergency department nurses, medical and surgical nurses, mental health nurses and community and primary care nurses, who all share our work as cancer nurses. It's easy and it's free and you can belong to up to three colleges and sections. Stronger together - Kotahitanga.

 [Join Cancer Nurses College](#)

The Cancer Nurses College  
**2020-21 COMMITTEE**

*Jane Wright, Sarah Ellery, Rosie Howard, Kirstin Unahi, Katie Whytock, Mary-Ann Hamilton, Anne Brinkman, Fiona Sayer, Maarie Hutana*



The Cancer Nurses College committee **INVITES ALL MEMBERS** to join us on the new 'Cancer Nurses College NZNO' Facebook Group.

*Ask questions, share thoughts, ideas, research, innovative practice, or concerns. Click the 'Join Group' button and one of our lovely Admins will add you. Easy as that! Hope to see you there!*

 [Click here to visit the page...](#)

**Cancer Nurses College badges**



are now available for purchase for \$8 each.

They can be purchased from the CNC committee or by emailing us on [cancernursesnz@gmail.com](mailto:cancernursesnz@gmail.com) and using internet banking.

Cancer nurses **committee**

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*We welcome contributions to Cancernet. Interesting stories, notices and photos relevant to our nursing community are always appreciated. Email us at*

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