

Message to Members

With yet another year rapidly coming to an end, our work continues across a range of projects and commitments. It is also a time where we reflect on what has been a very full year with many significant collaborations and contributions at both a state and national level. At the same time we have turned our minds to 2020 which, for us, will be a special and significant milestone in the history of Cancer Voices – 20 years / two decades as the voice of those affected by cancer. More to come as 2020 unfolds.

The Consensus Statement resulting from the **Canberra Health Summit**, held in July this year, was launched on Wednesday, 4 December, with an accompanying program of meetings with government and health department decision makers. The name '**Australian Patient Advocacy Alliance**' (APAA) has been adopted for the ongoing, joint work of the 23 organisations that attended the Canberra summit. Cancer Voices Australia is a member of the APAA.

Cancer Voices will be making a submission to the recently established Australian Senate Inquiry '**into the current barriers to patient access to medicinal cannabis in Australia**'. The Senate's Community Affairs References Committee is conducting the inquiry, which is due to report by 12 February 2020. It has extensive terms of reference. Further details Page 14.

We continue to hear more on **out of pocket costs** associated with a cancer diagnosis. In November research findings were released at a Hunter Cancer Research Alliance event regarding unexpected costs of a cancer diagnoses and their impact along with real stories on how patients have been affected.

Public Consultation for the **Lung Screening Enquiry** is open till February 2020. Links can be found on Pages 12 and 15.

Once again, the achievements and innovation of researchers have been recognised at the **2019 NSW Premier's Research Awards** held at the state Parliament House in late October.

Efforts to introduce **Voluntary Assisted Dying** arrangements have continued during 2019 in Western Australia and New Zealand. Meanwhile, in NSW, Dying With Dignity NSW, has resumed its campaign in support of the introduction of voluntary assisted dying laws.

Plans for our **AGM** in February are in place, please consider joining us. Details regarding **date, time and venue** can be found on the **Noticeboard on Page 2**. **The Nomination Form and our Issues Form** are on **Pages 16-17**. Our annual report will be tabled at the AGM and will then be available on our website. Do remember to fill in the issues form which assists in informing our advocacy focus and direction.

Our thanks to all for your ongoing support and feedback throughout 2019. To our active and committed members thank you for all you do for those affected by cancer.

Wishing you and your loved ones best wishes for the festive season and a very Happy New Year.



**Elisabeth Kochman (Chair) and
the Cancer Voices Executive Team**



Cancer Voices NSW provides the independent voice of people affected by cancer, working to improve the cancer experience of the over 48,000 people who are diagnosed in our state each year. Established in 2000, we are active in the areas of diagnosis, information, treatment, research, support and care. To achieve this, we work in partnership with providers of these services, ensuring the patient perspective is heard.



CVN Notice Board

NOTICE OF ANNUAL GENERAL MEETING 2020

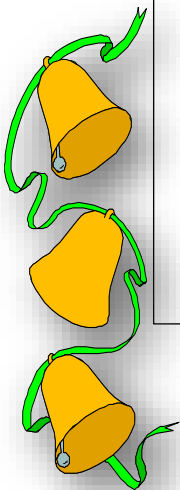
Cancer Voices NSW Inc. invites you to attend its AGM on 21 February 2020 at 10.00am, Level 1, 280 Pitt Street Sydney.

Nominations for the Executive Committee and Office Bearers are invited.

Nominees should be supported by their voting member, cancer support or advocacy group on the **Nomination Form** provided with this Newsletter.

Please complete and mail to PO Box 713, Milsons Point NSW 1565 or scan and email to info@cancervoices.org.au by 14 February 2020.

If you are interested in working with CVN's Executive Committee, we encourage you to contact us. We welcome all CV Members to the meeting. If you plan to attend the AGM, please advise us by 14 February 2020.



SAVE THE DATE

15-16 June 2020

Australian Patient Organisation Network (APON) 2nd Annual Conference will be held in Melbourne.

Registrations will open in early 2020.



3rd Victorian Cancer Survivorship Conference

12-13 March, 2020

A 2020 Vision

Building on learnings Partnering for success

Crown Convention Centre, Melbourne

<https://www.survivorshipconference.com.au/>



SYDNEY CANCER CONFERENCE 2020

10-11 SEPTEMBER 2020

"Bridging research and practice"

Hosted by the University of Sydney, the seventh Sydney Cancer Conference (SCC) will showcase existing and emerging strengths in cancer research across Australia.

- Keep an eye on the Conference website for program details as they are confirmed at <https://sydney.edu.au/cancer-research-network/sydney-cancer-conference-2020.html>
- **Abstracts open on Monday 24th February**
- **Early bird registration opens Monday 23rd March**

CV Executive Committee Member, Shirley Baxter is representing Cancer Voices on the SCC Organising Committee 2020 which will feature international, national and local speakers from all areas of cancer research.

Our thanks to HCNSW for their support via use of their boardroom for our Executive Committee meetings during 2019



CVN Committee News

The CVN Executive Committee (EC) met on 27 November. Given that it was our last meeting for 2019, we addressed a very extensive agenda and ran into 'extra time'. Matters addressed included planning for our AGM – *see details Noticeboard P2*, our annual EC workshop, abstract submissions for several conferences and considering ways to celebrate our special year, our 20 year milestone in 2020. We have been successful with an abstract submission being accepted in poster format for the 3rd Survivorship Conference to be held in Melbourne in March. Our diaries are already being populated with commitments for 2020.

Special thanks

We cannot let the year end pass without thanking those who support us - Kathryn Leaney (newsletter and workshop facilitation), Sandra O'Sullivan (matters financial) and Geoff Vass from Cadzow TECH who continues to support us with all IT matters.

For the third year, special thanks also to Health Consumers NSW who have provided us with a base for our Executive Committee meetings.

Our sincere thanks and best wishes to you all.



Advocacy Updates

Canberra Health Summit update

The Statement indicates that:

Consumer health organisations play a critical role in pursuing advances that improve health outcomes for all Australians. We can, and must, continue to strive for better.

The name '*Australian Patient Advocacy Alliance*' (APAA) has been adopted for the ongoing, joint work of the 23 organisations that attended the Canberra summit. Cancer Voices Australia is a member of the APAA. The Alliance aims to achieve:

- a consumer-centric healthcare system that delivers timely and equitable access to the best treatment, care and support;
- health policies that are co-designed with consumers involved at every step of the health policy development process;
- systemic reforms of health policies affecting all Australians with chronic conditions.

The Alliance's five recommendations, contained in the Statement, are that the Australian Government:

1. codify the principle of consumer co-design in health policy making in relevant regulations, ministerial determinations or official guidance documents of Commonwealth agencies. After this is complete, conduct a review across the health portfolio to identify, measure and ensure a

diverse range of consumers are engaged in all relevant policy-making;

2. fund a feasibility study to consider the establishment of a national system to capture patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs) to drive better clinical practice and patient outcomes;
3. through the Council of Australian Governments (COAG) Health Council commission the Productivity Commission to review and update the current performance measures used in Australia's National Health Agreement to modernise and improve patient-centred outcomes;
4. commission an independent review of Australia's Health Technology Assessment system – with consumers at the centre of the inquiry – to determine how the evaluation of new health technologies and services keep pace with global standards;
5. fund the development of a whitepaper to identify opportunities where artificial intelligence (AI) and machine-learning (ML) can be deployed to support better health outcomes in Australia.

Murray McLachlan

National Preventive Health Strategy update

One of the outcomes of the Canberra Health Summit involved the taking up of the offer by the federal

health minister, Greg Hunt, for representatives to contribute to the development of the National Health Preventive Strategy (NPHS) through membership of the strategy development Executive Steering Committee. These representatives are Jane Hill, CEO, Ovarian Cancer Australia, and Deidre Mackechnie, CEO, MS Australia. Their work is guided by the Summit's [Preventive Health position statement](https://www1.health.gov.au/internet/main/publishing.nsf/Content/national-preventive-health-strategy), details at <https://www1.health.gov.au/internet/main/publishing.nsf/Content/national-preventive-health-strategy>

A roundtable, held in September, and a number of workshops held in November, have progressed the development of the NPHS. The workshops were on:

- prevention
- physical activity and nutrition
- research, and
- tobacco.

A draft NPHS remains due for public consultation in the first half of 2020.

Murray McLachlan

Hunter Cancer Research Alliance event: Counting the cost of cancer: the financial burden of a cancer diagnosis

The Hunter Cancer Research Alliance provided the opportunity to learn more about the impact of cancer through its forum 'Counting the cost of cancer: the financial burden of a cancer diagnosis', held on Thursday, 7 November at the Hunter Medical Research Institute in Newcastle.

The event included a presentation by Professor Chris Paul, from the Faculty of Health and Medicine, University of Newcastle, on the findings from her research work in studying patient and family experiences of unexpected costs in cancer treatment and the extent to which the impact is felt.

Further information on Chris's work can be found at <https://www.abc.net.au/news/2019-08-15/financial-cost-of-cancer-leaves-patients-in-poverty/11374356> and at <https://www.abc.net.au/news/2019-10-24/private-health-insurance-and-cancer-treatment-under-microscope/11621884>

As a representative of Cancer Voices NSW, I presented on the intent of, and work to date on, the development of the federal government's Out of Pocket Costs Transparency website, which is on track to be launched by the end of 2019.

A panel session followed, which provided real stories of what effects a cancer diagnosis can have, with both Danielle Foster and Lisa and Brent Sengstock speaking from the heart which I'm sure had a real impact on the audience.

Danielle Foster was twenty-six years old when she was diagnosed with breast cancer. With no known family history, Danielle discovered her cancer was a result of a rare gene mutation. Even with private insurance, her family faced a bill of over \$20,000 to cover chemotherapy, surgeries and IVF treatment. Danielle now works with Cancer Council NSW as Community Relations Coordinator for the Newcastle region.

Brett Sengstock was diagnosed with a blood cancer in mid-2017. Following a long and difficult period of treatment since then, Brett has recently entered remission. Before his cancer diagnosis, his wife Lisa ran a small business that she had to close during this challenging time, devoting her attention to caring for her husband.

In addition, Stephen Dooker, Financial Counsellor for Cancer Council NSW in Newcastle, talked about the support that CCNSW provides to those who are struggling with their finances with the aim of empowering them to make effective choices that will reduce the stress involved from building financial pressures.

The panel session also allowed me, in response to a question from the floor, to talk about the approach CVN took

with this year's state election in focusing on the need for changes to the Isolated Patient Travel and Accommodation Scheme (IPTAAS) to remove the inequities that still exist for cancer patients in relation to their geographical location and access to participation in clinical trials.



Murray McLachlan presenting at the forum



Panel discussion at the forum.

Murray McLachlan

Voluntary Assisted Dying update

Efforts to introduce voluntary assisted dying arrangements have continued during 2019 in Western Australia and New Zealand.

In Western Australia, new laws offer a choice to competent adults with a terminal illness and six months or less to live, while those dying of neuro-degenerative diseases (such as Motor Neurone Disease or Multiple Sclerosis) with twelve months or less to live would also be able to access the provisions.

The Western Australian *Voluntary Assisted Dying Bill* (following earlier approval without amendment in the Legislative Assembly), Was approved by the Legislative Council after over 100 hours of debate on 4 December, by a vote of 24-11. The amended bill was subsequently given final approval by the Legislative Assembly on 10 December.

Unlike the Victorian law, whose provisions commenced earlier this year, the Western Australian arrangements allow a patient to choose a medical practitioner to administer the drug used to end the patient's life. In Victoria, a doctor can only administer the drug if a patient is physically incapable of doing so.

In New Zealand, the parliament has voted by 69 to 51 to legalise euthanasia, which would allow terminally ill people with less than six months to live the opportunity to choose assisted dying if approved by two doctors. The decision follows eight parliamentary debates since 2017 on the *End of Life Choice Bill*. The reform was supported by the New Zealand Prime Minister, Jacinda Ardern.

A major element of the decision was the inclusion, to secure the passage of the legislation, of the requirement for a referendum on the issue, which will be held in conjunction with the New Zealand election in 2020. A recent poll suggested that 72% of New Zealanders support some form of assisted dying.

Meanwhile, in NSW, Dying With Dignity NSW, <https://dwdnsw.org.au> has resumed its campaign in support of the introduction of voluntary assisted dying laws. It is encouraging members of the community to write to, and meet with, their local MP, write letters to local newspapers, talk to friends and family and keep spreading the word about the need for voluntary assisted dying laws in New South Wales.

Murray McLachlan



Consumers Health Forum (CHF) Australia

The CHF Members Policy Forum was held at the Shine Dome in Canberra on 12 November with around 60 CHF members in attendance. The day was expertly facilitated by Leanne Wells, CEO, CHF with the support of the CHF team.

'CHF has indicated that feedback following the event found that members particularly enjoyed the chance to talk policy and network with their peers.'

The day was split into three sessions:

- a scene-setting session with invited speakers from the Productivity Commission and a message from Minister, Greg Hunt;
- a discussion session to capture feedback from members for CHF's pre- budget submission;
- a session on long term strategic priorities which covered three key policy areas namely the proposed National Medicines Policy Review, the 10-year Primary Health Care Strategy and the 10 year Preventive Health Strategy.

Scene-setting

Minister Hunt, through a video message, spelt out the Government's priorities to reform primary health care, to develop a **10-year preventive health strategy** and **to improve mental health services**. He drew attention to the formation of the Youth Health Forum and the constructive relationship he has with CHF.

Michael Brennan, Chair of the Productivity

Commission gave a frank and fascinating overview of how economists view health care. You [can view his slides and read his speech here](#).

Professor Stephen King, who chairs the productivity commission [Inquiry into Mental Health](#), discussed some of the draft key recommendations from that Inquiry. CHF will be responding to the recommendations and invites feedback from members. Feedback is due by 23 January 2020.

Member's input into pre-budget submissions

The second session was an opportunity for members to make suggestions for what initiatives CHF should include in our submission for the 2020 Federal Budget. These suggestions are currently being incorporated into the CHF submission which will be circulated to members for feedback prior to being finalised and submitted

Long term strategic policy developments

During the third session updates were provided on the progress of the primary care and preventive health strategies with presentations from departmental officials, followed by a robust question and answer session. The session outlined the consultation process to be used for both strategies and explored the issues raised to date.

‘There was a clear feeling in the room that consumers and consumer organisations needed to be engaged at all stages of the development of the strategies. CHF is on the steering committee for both strategies and will continue to consult with members as the strategies are developed to ensure the full spectrum of consumer concerns and solutions are canvassed.

There was also a presentation and discussion around the proposed review of the National Medicines Policy. Members had questions about the scope and purpose of the review with much of the discussion focussing on how it can be brought up to date to accommodate the new generation of medicines, therapies and treatments, especially personalised medicines. The review is due to commence in March next year and CHF will be seeking members input throughout the process.’

The CHF AGM followed the Members Policy Forum.

Note: Some content from CHF.



Consumer Involvement in Research (CIR)

Cancer Voices NSW continues to provide nominees for requests by researchers and stakeholders, via the *Request a Consumer Representative* form on the Cancer Voices website. Our nominees have undertaken the Consumer in Research training organised by Cancer Council NSW in conjunction with CVNSW. The next consumer training day will be held at the CCNSW head office in September 2020.

The 2019 funding cycle was another busy time for our CIR program. There were 68 requests from researchers and project officers for consumers to provide input into research projects and become members of committees and working groups. The requests involved 102 of our CIR members. Thank you to everyone who readily agreed to assist when asked. There was a wide range of cancer projects, including best practice care and enhancing family carer involvement, risk factors for different cancers, genetic testing and repurposing of immunotherapy drugs.

The 2020 funding cycle requests have already commenced with 27 consumers matched to 12 projects. Two of the requests were for working groups where our consumers will support both cancer research direction and management of cancer services.

The requests come from within NSW and other states around Australia. The use of teleconferences has

enabled us to match consumers to interstate projects. Where funding allows, our consumers have been able to travel interstate for different research and committee activities. Thank you to Cancer Voices South Australia who help us with interstate requests for consumers.

Update your Contact Details

We anticipate an increase in the number of requests between December 2019 and April 2020 as researchers prepare their grant applications. It is important that we have a current email address that you access regularly so we can provide the consumer matches. I ask that you check your emails regularly over the coming months. Thank you to those members who have recently updated their contact details. This ensures that you remain actively involved in the program.

Please notify us if you are unable to be involved for a period of time either due to holidays, work commitments or health issues. If you have additional details that you feel will help with our matching to projects, please feel free to contact us.

Lee Hunt

Consumer in Research Training modules can be accessed at the Cancer Council Australia website at <https://cancercouncil.litmos.com.au/selfsignup/register/3064?type=2>

Consumers Involved in Research – expanding networks and educating researchers

Through Cancer Voices I have recently been connected with Dr Catherine Carmichael, a mid-career researcher investigating a rare type of acute myeloid leukaemia (AML) at the Australian Centre for Blood Diseases (ACBD) at the Alfred Hospital in Melbourne.

In November I travelled to Melbourne to meet Catherine in person and make a presentation on consumer involvement in research at one of their regular department seminars. The Coordinator of the Consumer Buddy Program at the Walter and Eliza Hall Institute (WEHI) and one of their consumers also made presentations. It was a great opportunity to hear how one of the leading research organisations in Australia manages their consumer program.

I utilised the recently-developed CVN presentation template and included slides on my experience as a patient. The presentation was well received by the predominately early and mid-career researchers present who do not have regular contact with leukaemia patients despite being located in a hospital.

I was also able to meet a new member of the Cancer Voices family whilst in Melbourne. I would encourage any consumers who have the opportunity to present to a wider group of researchers to do so. Cancer Voices can assist with a PowerPoint presentation that has a general overview about the benefits and ways of including consumers in research, the matching process and latest statistics. These can be tailored to your specific needs and your own story and presentation style.

Sarah Lukeman

HCRA Research Symposium

I attended the 2019 Hunter Cancer Research Symposium held on 8 November 2019 in Newcastle.

Associate Professor Pradeep Tanwar was the first keynote speaker on the 'Role of lifestyle choices in gynaecological cancer development'. I have been involved as a consumer with Pradeep's team since 2017 and am aware of his work, which was profiled on ABC 7:30 report on 4 December (<https://iview.abc.net.au/show/7-30/series/0/video/NC1901H191S00> until 3 January).

Women can reduce their risk of ovarian cancer by 50% by taking an oral contraceptive pill for 3-5 years. This is a

significant option for young women with a family history of breast or gynaecological cancers, who may want to have a family and thought a hysterectomy was their only risk reduction option.

Professor Liz Sullivan spoke on 'Patient experiences, clinical practice and birth outcomes of women with gestational breast cancer in Australia'. For all the women in the study, convincing their doctor that something was wrong was the first hurdle. The need for a cross-disciplinary management plan across the 2 departments was highlighted to improve both communication and the patient experience. The role of breast care nurses was critical for all.

A/Prof David Pryor from the Princess Alexandra Hospital in Brisbane spoke on 'A collaborative approach to the challenge of liver cancer'. I was surprised to learn that 25% of the Australian adult population has non-alcoholic fatty liver disease (NAFLD) but may be unaware of their status. NAFLD is a causative factor for liver cancer and is contributing to the increasing prevalence of this disease. There is no screening program for liver cancer in Australia, which may be an area of advocacy for the future.

Dr Nick Zdenkowski is a medical oncologist at the Calvary Mater Newcastle and presented on 'Implementation of shared decision-making for women with operable breast cancer who are considering neoadjuvant systemic therapy'. In Germany, chemotherapy is routinely administered before surgery, but this is not the case in Australia. Dr Zdenkowski has found that those patients who have chemotherapy before surgery have a better psychosocial outcome than those who have it after.

Dr Craig Gedye is a medical oncologist and cancer researcher who spoke on 'What's wrong with clinical trials and how we can fix them'. He claimed that only 10-15% of what doctors do is evidence based; that 1 in 7 trials show that we are doing the wrong thing; and that clinical trials are both expensive and exclusive as they don't include 'real' people. Certainly room for improvement!

Dr Lisa Mackenzie highlighted the disparity in telehealth provision in "Surgeons' perceptions of the acceptability and feasibility of telehealth outpatient consultations: A national cross-sectional survey". From a high of 65%, some surgeons are not using telehealth at all. Discussion of these results will hopefully bring about a change in those slow to take up this initiative that

makes travel and accommodation burdens lighter for regional and remote patients.

Sarah Lukeman

Conference Reports

RANZCR Annual Scientific Meeting 2019

The RANZCR Annual Scientific Meetings (ASM) provide an opportunity to learn about recent advances in the fields of clinical radiology, radiation oncology and interventional radiology. They comprise a high-quality scientific program, events and an award ceremony. Each year it takes place at a different location in Australia or New Zealand. In 2019 it was held in Auckland, New Zealand.

One session included an update on particle therapy in Australia. The particle therapy centres will be nationally coordinated so there is equal access for all Australian and New Zealand patients. Site preparations are underway for the first proton centre in Adelaide, expected to be operational in 2023. As well as treating patients, research will be undertaken at the centre with TROG Cancer Research coordinating Clinical Trials. There will be a National Registry which will research long-term toxicity of particle therapy and a Tumour Board for candidates with different tumour types. A Proton Therapy Referral Panel will be set up within the next twelve months.

Prof Hans Langendik from the University Medical Centre Gronigen, The Netherlands, spoke on the concept of Model-based Indications for proton therapy where the aim is dose escalation to the tumour, whilst sparing healthy tissue and avoiding critical structures. The use of Randomised Clinical Trials (RCT) is not a suitable method for testing new technology. The alternative is an evidence-based method. Using a Model-based approach there are three requirements for selecting particle therapy over photon therapy (X-rays): dose to target should be biologically equivalent; there needs to be a lower dose to the surrounding tissue; there needs to be risk reduction to the patient. Data collection of toxicities and control of proton therapy treatment is then compared to that of photon therapy.

In the Netherlands they use a pre-selection tool for choosing which patients have proton therapy. In this process the toxicity rates of the proton patients are compared to the expected toxicities if they had photon treatment. This allows the collection of data for

determining proton therapy toxicity for the different tumour types and locations. The major finding from the Netherlands' research was that in head/neck patients their recovery was much quicker after proton therapy. They were able to eat after 5 weeks, as compared to photon therapy which took a much longer recovery time. The tumour types presently being treated in the Netherlands with protons are paediatric, base of skull, eye melanoma, lung, central nervous system tumours, head/neck, breast and mediastinal lymphoma.

Dr Eun Ji Hwang from Sydney-West Radiation Oncology Network spoke about her research, International Indications for Particle Therapy: a Systematic Review. The study was based on clinical outcomes. Her results indicated that there is a reduction in hospital stays using proton therapy due to lowering of toxicities, particle therapy is equal to photon therapy and there is a suggestion of reduced mortality using particle therapy.

Another session included the results of research into recruitment for clinical trials. Dr Drew Mogahanski from Atlanta Veterans Affairs Medical Centre, United States, presented interesting insights into the challenges of clinical trial recruitment in head/neck cancer patients. In his research he found 30% of patients withdraw or suspend their involvement with clinical trials. The vast majority fail due to poor accrual. He highlighted the challenges of recruiting for Randomised Clinical Trials.

- Recruitment Pathways: not all patients are being screened for eligibility. Examples of issues that occur when recruiting are poor recruitment methods, the recruiter does not explain the trial clearly and the ethics process is slow.
- Hidden Challenges: both intellectual and emotional. There is poor communication regarding the explanation of randomisation, eligibility, choices not explained without bias from the clinician or recruiter discussing the trial and the language used isn't balanced.
- Patient Preferences: the patient comes with preconceptions and has already made their decision prior to the discussion and the recruiter doesn't challenge their preconceptions. The patient is not well educated by the recruiter about the trial.

When recruiting for clinical trials, it is vital that doctors explain that the optimal treatment isn't known but both options are choices for cancer control. For a clinical trial to be evidenced-based, randomisation must ensure there is a balanced number in both treatment options.



The RANZCR ASM has been awarded the Consumers Included (Ci) logo since its inception. The award of the logo demonstrates that RANZCR is committed to engagement with consumers in a meaningful way. It ensures that networked consumers learn more about the latest research and information. This improves the quality of consumers in research programs and committees. Four Cancer Voices NSW members are consumers on RANZCR committees.

Lee Hunt

5th International Symposium on the System of Radiological Protection

The Australasian Radiation Protection Society (ARPS) and Australian Radiation Protection and Nuclear Safety Agency (ARPANSA) hosted the 5th International Symposium on the System of Radiological Protection in Adelaide this year. The symposium offered the opportunity for more than 400 hundred professionals, experts and researchers world-wide to discuss their respective concerns and current challenges faced in all areas of radiological protection, as well as the way forward through new research. The program covered three themes: mines, medicine and Mars.

The Keynote Lecture in the medicine theme was delivered by Professor Brendan Murphy, the Chief Medical Officer of Australia. Healthcare practitioners covered topics such as innovation in patient dose monitoring, the global spread of particle therapy and considerations in radiation safety and the use of artificial intelligence in CT dose optimisation.

This year's symposium was the first time a consumer has been asked to present at the conference. My presentation titled, *Patients' perspectives on radiation in healthcare*, focused on the importance of patients being informed of the risks and known side-effects of radiation therapy and other cancer treatments in order to be active participants in decision making regarding their healthcare. The following summarises my presentation.

Like all other cancer treatments radiation therapy often causes side-effects. These are different for each person and depend on the type of cancer, its location, the radiation therapy dose and the patient's general health. Most people will have some mild side-effects during and just after treatment.

Radiation therapy is an integral part of cancer treatment with more than 50% of all cancer patients receiving radiation therapy at some point in time. As

more people are surviving cancer and living longer, knowledge about long-term effects of treatment is expanding.

One of the important, late side-effects of radiation therapy are radiation-induced second malignancies - RISM. Radiation therapy contributes to about 5% of the total treatment-related second malignancies. However the incidence of only radiation on second malignancies is difficult to estimate because there are multiple factors that predispose the patient. As children and young adults are likely to survive for longer duration after anti-cancer therapy, they are at the greater risk. For a given dose, children are around 10-fold more sensitive to develop RISM when compared to adults, and women are more prone to develop a second malignancy, compared with men.

Cardiotoxicity, that is problems in the heart and vascular system, is a risk when a large volume of heart muscle is exposed to a high dose of radiation. It can develop within days or months after radiation but often develops years later. It can reduce the patient's quality of life and increase the risk of death from cardiac-related causes.

Radiation-induced fibrosis is a long-term side-effect of external beam radiation. Radiation therapy can cause an increased production of fibrin and makes tissues less stretchy. Fibrin is a protein found in the body that accumulates and causes damage in radiated tissue over time. How this affects the patient depends on which part of the body was treated. Fibrosis may cause the bladder to hold less urine, the breast to feel firmer, the arm or leg to swell, breathlessness due to the lungs being less stretchy and narrowing of the oesophagus, making it difficult to swallow.

The main goal of cancer treatment is to extend life, but the quality of that extended life is also important for the patient. The researcher, doctor and patient team need to embrace physical, mental and emotional health and incorporate quality of life issues in their consideration of the treatment options. The World Health Organisation has noted that the main goals of cancer treatment are not only to cure or prolong patient lives, but also 'to ensure the best possible quality of life for cancer survivors.'

Some patients don't care much how a treatment affects quality of life. They want to fight to get to a particular milestone, even if their quality of extra life is poor. For others, quality of life is as important as length of life, or maybe even more so.

The risks and side-effects from radiation therapy need to be effectively communicated to the patient. Frequently in the culture of "doctor knows best", the cancer patient trusts their doctor to do what is appropriate and doesn't discuss the attendant risks.

However, cancer patients need to be informed of the risks and known side-effects prior to treatment and should be given the opportunity to discuss the matter in more detail with the treating specialist. They must be allowed to analyse the benefits against the risks. If the patients are able to review the side-effects, they can decide if they can endure the effect or not. They should also be made aware of how common side-effects are and options for managing them.

Providing cancer patients with information helps with decision making, prepares them for treatment and helps with managing adverse effects associated with it, reduces anxiety and depression, increases satisfaction with treatment and helps to improve their quality of life.

To support understanding by patients, the creation of patient-centred resources regarding radiation treatment and possible side-effects are needed. Written information allows the patient to reflect on what will be involved during the therapy, enables an accurate understanding for discussion with family and friends and becomes an excellent reference for managing both short-term and late-onset therapy-induced side-effects.

Radiation therapy techniques have changed significantly over the past few decades, thanks to improvements in engineering and computing. Major advances in radiation therapy have made it more precise, reducing side-effects and improving cancer control. Current techniques such as conformal radiation therapy and intensity modulated radiation therapy (IMRT) accurately shape the beams to fit the cancer. There is integration of imaging information in every phase of the treatment, from simulation to planning to delivery. These advances mean less healthy tissue receives radiation, reducing the risk of side-effects.

Radiation therapy research is looking at ways to make radiation therapy more precise, effective and affordable. MRI-Linacs will help visualise and target the tumour during treatment, allowing greater precision in cancer treatment. This new technology enables the treating specialist to see where the radiation dose is being delivered and keeps the radiation directly on target. As the human body is a dynamic system and

tumours move during radiation treatment, there are several solutions for real-time tumour targeting being developed. Kilovoltage Intrafraction Monitoring -KIM- is one of the technologies being clinically pioneered in Australia to turn today's standard linear accelerator into tomorrow's real-time cancer targeting systems. It is purely a software solution.

Rethinking cancer treatment system designs with the patient experience, safety and costs in mind, may improve global access to radiation therapy. Radiation therapy will be increasingly used in the oligometastatic setting, given the positive results of several clinical trials.

As radiation therapy is needed by approximately 50% of cancer patients in their treatment journey, there needs to be on-going research to ensure that radiation therapy effectively targets the tumour and minimises potential side-effects.

As a Consumer Advocate, I emphasised the importance of patients being informed of the risks of radiation therapy, both short and long-term, along with those of other cancer therapies, to enable them to be active participants in their treatment path.

In a later session, I joined five world experts in a panel discussion on raising awareness of radiation protection in medicine. I was given the opportunity to reinforce the importance of clear, accurate information being given to the patient about the risks of RT treatment. Written information should be provided at the initial consultation so that the patient and their carers can review the details throughout and beyond their treatment. Following the session, I was approached by a member of the World Health Organisation (WHO) who asked if I can provide input into the development of their patient resources on radiology and radiation oncology.

Written information enables clear understanding of what the patient may experience during their treatment and becomes a reference throughout treatment and following treatment. As some side-effects can appear many years after treatment has been completed, written information will assist the cancer patient to know when and where they should seek assistance to manage emerging side-effects.

Lee Hunt

The Voices being heard

Meetings

- Consumers Health Forum Australia (CHFA) Members Policy Forum, Canberra 12 November
- CHFA AGM, Canberra, 12 November
- Cancer Council NSW Consumer Review Panel, 13 November
- Out of Pocket Costs Working Group, Teleconference, 15 November
- Cancer Council NSW Advocacy working group, 18 November
- Sydney Cancer Conference organising committee, teleconference, 18 November
- Cancer Australia ICAG, 21 November
- Cancer Council Australia, RLCC Teleconference, 27 November
- Health Consumers NSW, 27 November
- CVN Executive Committee, 27 November
- COSA Teletrials Consortium, Teleconference, 4 December
- Cancer Council NSW Advocacy Working Group, 9 December
- UTS, IMPACT, 13 December
- Cancer Institute NSW Quarterly meeting, 16 December
- Cancer Council NSW AGM, 16 December

- Sydney Cancer Conference organising committee, teleconference, December
- Cancer Australia, 19 December

Conferences/Forums/Events:

- Hunter Cancer Research Alliance Forum, Counting the cost of cancer: the financial burden of a cancer diagnosis, 7 November
- Hunter Cancer Research Alliance Symposium, Newcastle, 8 Nov
- CHF / BCNA webcast, 11 November
- Australian Centre for Blood Diseases (ACBD), Alfred Hospital/Monash Uni, Melbourne, 12 November
- International Symposium on the System of Radiological Protection, Adelaide. 17-21 November
- Children's Medical Research Institute (CMRI), Presentation and Lab Tour (ProCan), Westmead, 21 November
- National Breast Cancer Foundation (NBCF) Presentation and Lab Tour, Kinghorn Cancer Centre, 28 November

Submissions / Feedback

- CA EBC EWG review of draft guidelines
- CCA rare and less common cancers resource project resource review



Cancer Institute NSW Update

2019 NSW Premier's Awards for Outstanding Cancer Research

Once again, the achievements and innovation of researchers have been showcased at the annual NSW Premiers Research Awards. The commitment, dedication, passion and enthusiasm were all on display as recipients accepted their awards.

The annual NSW Premiers Research Awards event was held on 30 October at NSW Parliament House, and was hosted by Professor David Currow, Chief Cancer Officer and CEO of the Cancer Institute NSW. This event "celebrates excellence and innovation in cancer research". There was a prerecorded message from the Premier of NSW, Gladys Berejiklian. The Hon Bronnie Taylor MLC, Minister for Mental Health, Regional Youth and Women, represented the Premier. Minister Taylor is also very passionate about matters cancer having been an oncology nurse in regional NSW for some 20 years.

Award winners

- Outstanding Cancer Researcher of the Year – Professor Glenn Marshall
- Wildfire Highly Cited Publication – The Australian Pancreatic Cancer Genome Initiative
- Outstanding Cancer Research Fellow – Dr Matt Dun

- Outstanding Cancer Clinical Trials Unit – Northern Sydney Cancer Centre

See full details of the awards and the recipients at <https://www.cancer.nsw.gov.au/about-us/events/premiers-research-awards>

Cancer care in NSW receives positive review from patients

'A new survey reveals 99 per cent of people in NSW are reporting a positive experience of the cancer care they receive'.

https://www.cancer.nsw.gov.au/about-us/news/cancer-care-in-nsw-receives-positive-review?utm_source=CNI-1911&utm_medium=email&utm_campaign=OtherStkHldrs

The Bureau of Health Information [Outpatient Cancer Clinics Survey 2018](#), produced in partnership with the Cancer Institute NSW, gives first-hand insight into the experiences of people being treated for cancer across the state.

<https://www.bcna.org.au/news/2019/11/bcna-welcomes-telehealth-rebate/?fbclid=IwAR10eyEOZcVHL0jl0arweR-9VHisqYxpf9SIf04PshXocyy7NMia06nwUv8>

<https://www.greghunt.com.au/media/media-releases/>

<https://www.greghunt.com.au/55-million-investment-to-give-new-hope-to-australians-living-with-rare-cancers/>

<https://www.greghunt.com.au/20-million-for-ovarian-cancer-research/>

<https://www.greghunt.com.au/game-changing-cancer-medicines-now-within-reach-for-2200-australians/>

For all the latest from Cancer Institute NSW go to <https://www.cancer.nsw.gov.au/>

Public Consultation for the Lung Cancer Screening Enquiry

Public consultation will be open through the Department of Health Consultation Hub from December 2019 to 17 February 2020 at

<https://consultations.health.gov.au/cancer-care/cancer-australia-lung-cancer-screening-enquiry/>



The Rise of the Consumer Voice

Breast Cancer Network Australia (BCNA) and Consumers Health Forum of Australia (CHF) held a free joint webcast “The Rise of the Consumer Voice” on 11 November.

Panel members shared their views including the challenges associated with the meaningful involvement of health consumer representatives in decision making and what current opportunities and issues consumer representatives should be aware of.

The discussion included the personal experience from each of the panel members, all having a significant background in advocacy in representing consumers in health. Some of the points discussed covered a variety of aspects:

- Consumer engagement is a form of disruption. Sending the right person, someone who’s put in the work and will drive an outcome is key. Knowing they are going back out to report is quite compelling.
- Dangerous to be a lone advocate – need to have a voice representative of others, not only personal

experience. Have a consensus position within an organisation and others following consultation.

- Preparation: read up on everything you get on projects and organisations. Be fearless and have courage in having a voice.
- Be prepared to work to prove yourself pretty quickly within a team who are then less likely to be resistant to having a consumer on their committee; and don’t go on about stuff - pick your mark.
- Takes time to build skills and for relationships to become meaningful; be patient and put in the work.
- If an appointment seems tokenistic, explain why you are being made to feel this way to the Chair outside of the meeting to seek resolution.

In summary, having a clear understanding of your motivation and sense of pathways is important. Consumer representative advocacy is genuinely one of the most satisfying roles you can do.

Shirley Baxter



Electronic Newsletter

This is the third electronic version of the Newsletter. We would love to hear what you think of it. A printed version will continue to be sent to those who would like to continue to receive it in print form.

Drop us a line at info@cancervoices.org.au and let us know what you think.

A consumer-centred future of health

Deloitte's 2019 global healthcare consumer survey finds evidence that the future is now

This survey finds people are exhibiting traditional 'consumer behaviours' when it comes to health care: They are willing to shop for deals, disagree with their doctor, and use technology to track and maintain their health

Full details at https://www2.deloitte.com/us/en/insights/industry/health-care/global-health-care-trends-survey.html?id=us%3A2em%3A3pa%3A1ife-sciences-and-health-care%3Aeng%3Aadi%3A112219&fbclid=IwAR3jU4h08Au5mSgZs1LxDVg8RwPUp0gnEhjWT7Nv2mSptTKPyTYUJEYswzI&mc_cid=0b6ab37f72&mc_eid=e66bc5605f

Dates just released!

Garvan Institute of Medical Research - Seminars 2020

- Lifestyle and Disease – Wednesday, 25 March 2020, 10am – 11:30am
- Cancer – Wednesday, 24 June 2020, 10am – 11:30am
- Seminars are free to attend, but fill up quickly so [registration is essential](#).

If you can't attend, seminars are livestreamed on [Facebook](#) and videos are available on the Garvan website after the event.

- [Register now](#)

REMEMBER the full archive of previous newsletters is here:

<https://www.cancervoices.org.au/news-updates/>

THANKS to the Team who bring you this Newsletter:

Kathryn Leaney for formatting, Murray McLachlan for proof reading and Elisabeth Kochman as compiler and editor and all our contributors.

Special thanks to Geoff Vass for his ongoing pro bono technical support.

We hope you find it interesting, even inspiring! Let us know about any other advocacy issues you think we should feature and/or work on, and if you would like to help.

We welcome enquiries to Info@cancervoices.org.au

Medicinal Cannabis update

The Australian Senate recently established an ‘Inquiry into the current barriers to patient access to medicinal cannabis in Australia’. The Senate’s Community Affairs References Committee is conducting the inquiry, which is due to report by 12 February 2020. It has extensive [terms of reference](#)

https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Medicinalcannabis

The inquiry has resulted from advocacy work during 2019, particularly by Lucy Haslam through her organisation United in Compassion.

Cancer Voices Australia will make a submission to the inquiry, which will focus on a national framework for medicinal cannabis which is needed to address the inequities that are likely to result from medicinal cannabis programs being different in individual states and territories.

If you would like to contribute to the CVA submission, please send your ideas and experiences about medicinal cannabis access to info@cancervoices.org.au marked for the attention of Murray McLachlan. Alternatively, you may prefer to make your own submission directly to the inquiry.

In a sign the federal government considers medicinal cannabis an important element in the treatment of cancer, the Minister for Health, Greg Hunt, has announced that it is investing \$3 million from the Medical Research Future Fund to examine the benefits of medicinal cannabis for pain, symptom and side effect management for cancer patients.

The Minister’s [media release](#) <https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/3-million-for-research-into-medicinal-cannabis-benefits> indicated that ‘there have only been a limited number of well-designed clinical studies on medicinal cannabis, and we need to increase the evidence base to support medical professionals to make their decisions.’

The government’s decision to fund the research has resulted in particular from the advocacy of Olivia Newton-John, who ‘for many years has been an advocate for breast cancer awareness and research, and through her personal experience and ongoing

efforts has helped shine a light on the benefits associated with medicinal cannabis’.

Murray McLachlan

Sony Foundation Launches National Fertility Preservation Service for youth cancer patients

Cancer Voices was pleased to see the announcement that the Sony Foundation will be funding a service to collect, transport, freeze and store reproductive tissue for young cancer patients. This free fertility-preserving treatment will be available to cancer patients aged 13-30 years, wherever they live in Australia.

This is a significant quality of life issue for young people that can be overlooked during initial diagnosis and is often out of reach due to cost, time or location. According to the Sony Foundation, only 4% of young women and 25% of young men currently undergo fertility preservation before starting chemotherapy and they hope this service will improve this.

Tissue, egg and sperm freezing, and patient support including counselling, will be provided by the National Ovarian and Testicular tissue Transport and Cryopreservation Service (NOTTCS) at the Royal Women’s Hospital in Melbourne. It is available to any patient facing surgery, chemotherapy or radiotherapy that may reduce their fertility.

Please spread this good news to your networks and encourage health practitioners to raise fertility preservation with young people and refer them to this free service.

For further information, contact NOTTCS at NOTCCS@thewomens.org.au or (03) 8345 3227 or see the press release at <https://www.sonyfoundation.org/blog/the-fertility-fight---sony-foundation-launches-national-fertility-preservation-service-for-youth-cancer-patients>

Sarah Lukeman

AUSTRALIAN CANCER CONSUMERS NETWORK (ACCN)

The ACCN currently has 29 member organisations including Cancer Voices NSW. The Australasian

Lymphology Association recently advised that they wished to join the ACCN and we look forward to welcoming them on board.

During the month, ACCN members were forwarded information on the following:

- Charter of Health Care Rights
- Two FREE webinars presented by Australian Centre for Value-Based Health Care in November
- CT IQ survey: Barriers and enablers for sites recruiting participants for clinical trials
- Ethics approval issues
- Clinical Trail Refer November 19 Newsletter
- Flinders University – Womens’ Health and Alcohol Survey
- Consumer-pharmaceutical industry relationships workshop in March 2020

Dan Kent for ACCN

Australian Clinical Trials Alliance (ACTA)

The ACTA info@clinicaltrialsalliance.org.au comprises 5 Reference Groups. As reported in the last Newsletter the Consumer Involvement Guidance Working Group launched a Toolkit for Researchers/Research Organisations to involve Consumers in designing clinical trials. A Consumer Information Pack was also included. The Working Group will be teleconferencing in early December to finalise a plan to achieve wide distribution of the Toolkit to research organisations.

The ACTA Reference Group which looks at Embedding Clinical Trials in Healthcare has as one of its projects a project to “develop simplified, consumer-endorsed, standard content for patient information sheets and consent forms (PISCF), with accompanying guidance, for participants in low/negligible risk comparative effectiveness trials”.

I have joined a small group working on this project and we have a timeline to have the final doc/template completed by the end of June 2020.

Dan Kent

From Cancer Australia

Australians invited to have their say on a national lung cancer screening program

Cancer Australia is inviting the public to have your say on the Lung Cancer Screening enquiry through a dedicated Consultation Hub.

Early diagnosis of lung cancer is critical to improving outcomes, with more than 50% of lung cancer cases being diagnosed at an advanced stage. Advanced stage at diagnosis is associated with poorer survival. Lung cancer is the leading cause of cancer death in Australia, accounting for nearly 1 in 5 of all cancer deaths.

The Lung Cancer Screening enquiry is being held to investigate the feasibility for a national lung cancer screening program for people at high risk of lung cancer. This will include a review of national and international evidence on the benefits and harms of lung cancer screening, target population groups, and the design and effective implementation of a national lung cancer screening program in the Australian setting.

Cancer Australia is undertaking a broad consultation process through the dedicated Consultation Hub, to seek views and input on the Lung Cancer Screening enquiry from members of the public, Aboriginal and Torres Strait Islander communities, people affected by cancer, health professionals, clinical colleges, researchers and research institutes, cancer organisations, peak bodies and governments.

Submissions are also invited from population groups who could benefit most from lung cancer screening due to reasons such as remoteness, language, culture, age or mobility.

All interested stakeholders are invited to have your say. **The Consultation Hub will be open from 9 December 2019 to 17 February 2020 at consultations.health.gov.au.**

For more information about the Lung Cancer Screening enquiry, visit <https://canceraustralia.gov.au/about-us/lung-cancer-screening-enquiry>

Follow Cancer Australia on Twitter @CancerAustralia to make sure you get all the news and updates on the Lung Cancer Screening enquiry.



NOTICE OF ANNUAL GENERAL Meeting 2020

Cancer Voices NSW Inc. invites you to attend it AGM on Friday 21 February 2020 at 11.30am at Level 1, 280 Pitt Street, Sydney NSW

Nominations for the Committee and for Office Bearers are invited.

Nominees should be supported by their voting member cancer support of advocacy group, on the form provided below. Please complete and mail to PO Box 713, Milsons Point NSW 1565, or scan and email to info@cancervoices.org.au by 14 February 2020.

If you are interested in working with CVN’s Executive Committee, we encourage you to contact us ASAP. If you plan to attend the AGM, please advised by 14 February 2020 to ensure access.

The CVN Annual Report 2019 will be tabled at the AGM and then accessible on our website.

CVN Executive Committee NOMINATION FORM 2020

I

Hereby consent to be nominated for the position of:

(Please circle)

Name

Address

Signature Date

Nominating Organisation:

Address

Proposed by:

Address.....

Signature.....Date

Seconded by:

Address.....

Signature.....Date.....

CVN Priority ISSUES FOR ADVOCACY IN 2020

Cancer Voices NSW provides the independent voice of people affected by cancer, working to improve the cancer experience of the more than 48,000 people who are diagnosed in our state each year. Established in 2000, we are active in the areas of diagnosis, information, treatment, research, support and care. To achieve this we work in partnership with providers of these services, ensuring the patient perspective is heard.

This is a year-end opportunity for you to let us know what you think we should be working on to improve the journey of people affected by cancer in NSW during 2020 - the areas listed below are a guide to start thinking.

This is an annual process to ensure we are working in the interests of those we represent at state, and sometimes national, level.

Add pages if you wish, to provide us with more detail. Please complete and mail to Cancer Voices NSW at PO Box 713, Milsons Point NSW 1565, or email info@cancervoices.org.au **THANK YOU!**

1.	BETTER ACCESS TO QUALITY CARE
2.	BETTER ACCESS TO INFORMATION
3.	FIXING THE SYSTEM
4.	SURVIVORSHIP & SUPPORT
5.	PRIORITIES FOR CANCER RESEARCH
6.	OTHER