

Message to Members

2019 continues to be a very busy year for Cancer Voices, its committee members and representatives. We continue to 'think big and act big', and I believe that that is reflected in our current work.

To achieve better outcomes for those affected by cancer in NSW and beyond, Cancer Voices continues to provide the voice of those affected by cancer through involvement in some big thinking and collaborative initiatives with both government and cancer and other health organisations. This can be seen by our involvement including:

- **Out of Pocket Costs Transparency Working Group**, tasked with the development of the federal health department's website that will provide indicative information to patients and consumers to help minimise the bill shock and financial hardship that can be associated with a cancer diagnosis and treatment;
- **Canberra Health Summit**, a two-day gathering of 23 Australian health consumer organisations representing over 20 million people with the shared ambition to 'improve the health and wellbeing of all Australians through a health system that puts the consumer at its heart; one that draws on the experience of Australians living with health conditions, and embeds consumers at every step of the policy making process';
- **National Preventive Health Strategy**, which aims to provide a long-term vision for improving the health of all Australians and stimulate a shift to achieve a better balance between treatment and prevention.

There have been a significant number of launches, meetings, forums, workshops and conferences taking place where we have had further opportunity to contribute to the 'big picture' of cancer generally.

Further opportunities include the upcoming Cancer Council Australia 2019 Cancer Consumer Forum at the end of October. In November the national consumer organisation Consumer Health Forum Australia is holding a Members Policy Forum in

Canberra with focus on national policies and strategies.

At a state level, the Cancer Institute NSW (CINSW) has an interim review of the current NSW Cancer Plan. NSW Health promoted its Leading Better Value Care statewide programs at its two day August forum.

The media continues to provide a lot of momentum across the health sector identifying and highlighting the many challenges that face us.

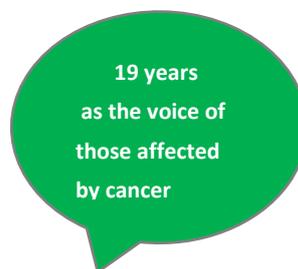
Still at a state level and of concern are the 10% cutbacks that we have been hearing about in recent weeks, not just to health but right across government agencies. 'Leaked' information appeared in the media on 22 October indicating that NSW Health will be collectively required to find cost savings of \$252m including some \$150m from local health districts (LHDs) and \$35m from the Ministry of Health and the Cancer Institute NSW. The government maintains that they are not budgetary cuts but efficiencies to offset budgetary pressure and that front line services will not be affected. We will be voicing our concerns particularly in relation to cutbacks at the LHD level that directly affect the provision of cancer-related programs and services, resulting in further reinforcement of inequalities particularly between metropolitan and rural, regional and remote locations.

Following the annual Consumer Involvement in Research (CIR) training held in September, Cancer Voices has welcomed new members to the CVN CIR program.

October is our anniversary month! 19 years as the voice of those affected by cancer. As you may have guessed that makes 2020 a pretty special and significant year!

As always, best wishes to all

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





CVN Notice Board

2019 Public Seminar Program at the Garvan - Last for the year!

The Garvan Institute runs a public seminar series that is free to attend.
10 December 2019, 10am-11:30am Beyond 2020: Healthcare of the Future.

Registration is essential. [Register now](#)

Seminars are live-streamed on Facebook.

Past seminars can be accessed via
<https://www.garvan.org.au/tours-events/public-seminars/previous-seminars>



Sally Crossing AM Award for an Outstanding Outcome in Cancer Research

Applications now open

Deadline for applicants is **20 December, 2019**.

Full details can be found on the Cancer Council NSW website at

<https://www.cancercouncil.com.au/research/for->



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/>



Patient centred research network (Pacer) webinar

12 November, 2019 presented by Nicole Straiton

Opportunities and strategies for consumer involvement in clinical trials

Go to <http://pacernetwork.org.au/webinars/> and scroll down the list.

WELCOME TO NEW MEMBERS!

A warm and special welcome to our new members including those who have joined following the 2019 Consumer Advocacy Training and the recent Consumer in Research training along with those who have 'found' Cancer Voices and joined directly.



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 Committee News

The CVN Executive Committee met on 25 September. We continue to juggle our advocacy, programs and organisational strategic work.

Recent activities include updating and refreshing our information brochure and our CIR Guides for consumers and researchers - details and links Page 8. We have also developed a list of cancer related conferences and have been preparing and submitting abstracts for conference presentations. In September we had a promotional table at the CINSW

Innovations Conference. Elisabeth Kochman, Jan Mumford and Kathryn Leaney assisted on the day during the breaks. A wonderful way to not only promote Cancer Voices but to also engage with the wide variety of attendees.

We now also have a generic Powerpoint format and content for use when EC members are representing Cancer Voices at conferences and workshops.

Our next meeting is 27 November.



Advocacy Updates

Out of Pocket Costs Transparency Working Group

As reported in our previous newsletter, Cancer Voices Australia is pleased to be involved in the development of the federal health department's website that will provide indicative information to patients and consumers to help minimise the bill shock and financial hardship that can be associated with a cancer diagnosis and treatment. Shirley Baxter, Cancer Voices NSW deputy chair, is the CVA representative.

The website is a high priority for the federal health minister, Greg Hunt. Two working group meetings have been held, the first in Melbourne on 19 July and the second in Canberra on 26 September.

There are three consumer organisations on the working group with Cancer Voices Australia being the only national 'whole of cancer' advocacy organisation. Our involvement therefore is critical and timely in our contributions to the 'big picture' of cancer generally, and in addressing the financial issues that can be so central to the treatment and well-being of people affected by cancer. Consumers want transparency around costs presented in an understandable format in order to make an informed decision.

Shirley Baxter and Murray McLachlan

Out of pocket costs continue to gain media attention

ABC: Following is a link to an informative article on the impact of out-of-pocket costs on people affected by cancer. It is related to the ABC's 'Australia Talks' project that is currently running.

It references the research of Professor Christine Paul from the Hunter Cancer Research Alliance (HCRA).

Christine will be presenting her findings, along with other speakers who will talk about their experiences of the impact of OOPCs at a symposium on 7 November in Newcastle. Murray McLachlan will represent Cancer Voices to speak about the federal government's OOPC Transparency Website project. [Read the full story](#)

SBS: Insight program, 24 September - [Is private health care worth the premium price tag?](#) - featured several personal stories of OOP expenses.

Australian Health Review, journal of the Australian Healthcare and Hospitals Association, published an online academic article in September which finds that OOP health expenditure as a proportion of household spending on all goods and services increased by more than 25 per cent between 2009-10 and 2015-16.

[Access the study here.](#)

Key consumer health organisations unite at the Canberra Health Summit, 23-24 July 2019

The Canberra Health Summit, a two-day gathering of 23 Australian consumer health organisations representing over 20 million people, was held in the nation's capital on 23 and 24 July 2019.

Organisations participating included: Arthritis Australia, Bowel Cancer Australia, Cancer Voices Australia, Dementia Australia, Diabetes Australia, Endometriosis Australia, Lung Foundation Australia, MS Australia and Rare Cancers Australia.

The purpose of the Summit, which was a follow-on to the 'Advocacy in Action' event held in early 2017 (attended by CVN's Shirley Baxter and Bev Noble), was to pursue policy change by speaking with one voice on systemic solutions to improve access, break down

barriers, and drive innovation that improves health outcomes for Australians. The shared ambition of the Summit was to ‘improve the health and wellbeing of all Australians through a health system that puts the consumer at its heart; one that draws on the experience of Australians living with health conditions, and embeds consumers at every step of the policy making process’.

One of the pleasing aspects of the Summit was the commonality of issues of concern across most if not all of the organisations, and the shared commitment to ensuring that the patient and consumer is at the centre of all health-related decision making. It also confirmed that both Cancer Voices NSW and Cancer Voices Australia are on the right track as regards the focus areas we have identified, and the individual issues that we are pursuing through our advocacy and our presence at, and input to, decision-making contexts.

The second day of the Summit, held at Parliament House, included informative presentations from the Minister for Health, Greg Hunt, the Shadow Minister for Health, Chris Bowen, and The Greens Spokesperson on Health, Richard Di Natale.

As a result of the Summit, five recommendations will be taken to the federal government in relation to:

1. consumer co-design
2. Patient-reported Experience Measures (PREMs) and Patient-reported Outcome Measures (PROMs)
3. patient performance measures
4. new technology
5. Artificial Intelligence

As Cancer Voices Australia’s representative at the Summit, I found the two days stimulating and energising and a great opportunity to meet the leaders of a broad range of health consumer organisations, with the primary outcome a Consensus Statement to be presented to and discussed with federal members of parliament by both individual organisations and on a collective basis.

Through our involvement in, and commitment to, the Canberra Health Summit, Cancer Voices Australia is well-placed to build on its past successes in cancer-related health advocacy at the national level.

Murray McLachlan

New 10 year National Preventive Health Strategy announced in August

The federal Minister for Health, Greg Hunt, has announced the development of a National Preventive Health Strategy. The ten-year Strategy will form the main focus of the Government’s programs and funding that aim to help ‘people live well for longer’. It is intended that the Strategy will provide a long-term vision for improving the health of all Australians and stimulate a shift to achieve a better balance between treatment and prevention.

This is thought to be the first time that a Coalition government has committed so strongly to prevention as a major element of its overall health policy. The Minister has clearly articulated that emphasis has to be placed on systematically shifting the health system to achieve a better balance between treatment and prevention, as expressed during his address to the National Press Club on 14 August 2019: <https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/national-press-club-address-long-term-national-health-plan>

The main components of the Strategy are:

- immunisation
- cancer screening
- obesity
- smoking
- public education (health literacy), and
- research.

It is understood that the cancer screening component will look at further implementation of current programs for bowel and breast cancers, and the possible addition of programs for lung, melanoma, and prostate cancers. (See Page 14 re lung cancer initiative by Cancer Australia).

Cancer Voices Australia (CVA) has contributed to the development of the Strategy in its early stages through its attendance at, and participation in, the Canberra Health Summit (CHS) held in July this year, at which the Minister indicated his intention that the consumer and patient voice would be a central part of the Strategy’s development, and of the Strategy itself.

Further, three workshops were held in mid-September, through which CVA presented cancer-wide perspectives to the development of a set of principles and positions that the CHS representatives will present through the strategy development process. The CHS is

represented on the Strategy's Expert Steering Committee by Jane Hill (CEO, Ovarian Cancer Australia) and Deidre Mackechnie (CEO, MS Australia). The steering committee held its first meeting at the end of September.

The next steps in the development of the Strategy will be:

- topic-specific consultations during October and early November, to provide an opportunity to share ideas and to update participants on the work currently underway
- the Expert Steering Committee will meet again in mid-November to consider the outcome of the consultations
- there will be a public consultation on the draft Strategy in the first half of 2020.

Further information about the Strategy, including the Communique from the first steering committee meeting, can be read [here](https://www1.health.gov.au/internet/main/publishing.nsf/Content/national-preventive-health-strategy):
<https://www1.health.gov.au/internet/main/publishing.nsf/Content/national-preventive-health-strategy>

Murray McLachlan

Health Conditions and Insurance Report

Cancer Voices reported on the online July release of this report in our last newsletter. Several Cancer Voices NSW EC members joined other guests, including stakeholders, at the official launch of the health conditions and insurance report entitled '*What's the risk? Access to insurance for people living with health conditions*' on 22 August at the NSW Teacher's Federation Conference Centre.

Speakers included Brendon Thomas, CEO, Legal Aid NSW and Lillian Leigh who spoke about the report and used her own personal experiences with travel insurance since her lung cancer diagnosis to highlight some of the many challenges and frustrations faced trying to obtain insurance when dealing with a major health issue.

We heard phrases such as 'do far better'; 'lazy and outdated'; 'unnecessary and unfair'; 'unfair discrimination'; 'beginning of a fair and better future'.

The report identifies the opportunity for further ongoing collaborative work through twelve recommendations. Again, our thanks and gratitude to Legal Aid NSW for funding this project and compiling this report.

To access the report

<https://www.legalaid.nsw.gov.au/publications/reviews-and-submissions>

Elisabeth Kochman

Lymphoedema Action for NSW - - including the Lymphoedema Action Alliance (LAA)

The LAA met 16 July. Whilst disappointed that there was no commitment at the March state election to our ask, there is now a much greater awareness and understanding of lymphoedema and the need for more public services to manage and treat it. During the Federal election, the Liberal party released a statement promising further funding of \$8m over 4 years to ensure access to compression garments across all states. The Australasian Lymphology Association (ALA) (representing therapists) and the LAA (representing consumers and interested parties) were scheduled to attend a meeting to explore the garment scheme.

Lymphoedema Support Group of SA (LSGSA) has had some positive progress with support from an MLC who raised a motion in the South Australian Legislative Council calling for a compression garment scheme and dedicated public lymphoedema services.

The LAA continues to pursue improved services and access to compression garments across the states.

Elisabeth Kochman

NSW Cancer Plan – progress review

The NSW Cancer Plan 'sets out the state's blueprint for reducing the incidence of cancer, increasing survival and improving quality of life, treatment and care for people affected by cancer'.

The NSW Cancer Plan, developed by the Cancer Institute NSW (CINSW) in collaboration with the community, clinicians, health organisations and people affected by cancer, is a roadmap for cancer control in our state. This is the fourth plan since the establishment of the CINSW in 2003.

CINSW has completed an interim evaluation of the current NSW Cancer Plan 2016-2020.

Cancer Voices welcomed the opportunity to attend one of a series of workshop reviews to hear about the evaluation of the current plan and planning for the next NSW Cancer Plan.

I represented Cancer Voices at the first workshop on 2 September. Whilst being invited to this review, we were certainly disappointed when we learned prior to

the event that there had been some 1,000 consultations, and none included consumers. The evaluation document noted that *'most stakeholders considered that the voice of those affected by cancer is missing from the document'*. I voiced this at the workshop that I attended with the need to remedy the lack of consumer consultation being noted as regards the review of the Cancer Plan.

Shirley Baxter

Victorian Cancer Plan 2020-2024 - Melbourne consultation

The Department of Health and Human Services (Vic) has been conducting a series of consultations to help inform the development of the Victorian Cancer Plan 2020-2024.

Workshops were scheduled throughout October with two scheduled in Melbourne and eight others around regional Victoria.

Cancer Voices members have been participating and contributing to the consultation process. Jacqueline Lesage attended the first Melbourne consultation where there were 50 attendees and 2 consumer advocates present on the day.

Attendees worked in groups but with only two consumers on the day, there was not representation for each discussion group.

The plan covers Prevention; Screening and early detection; Treatment; Wellbeing and Support; Research.

Elisabeth Kochman

LGBTI partnership between Cancer Institute of NSW and ACON

The Cancer Institute of NSW (CINSW) has announced funding to ACON (formerly the AIDS Council of NSW) to provide more support to prevent and detect cancer in NSW lesbian, gay, bisexual, transgender and intersex (LGBTI) communities. The funding of \$1.2million over three years will 'help raise awareness of lifestyle and other factors that can help prevent cancer, and encourage greater participation in cancer screening programs.

Founded during the 1980s, and previously focused on work to address HIV/AIDS issues in gay and bisexual men, ACON in more recent times has expanded its programs and activities to include people who identify as lesbian, gay, bisexual, transgender or intersex, and who are sexually and gender diverse.

Many LGBTQ people experience cancer-associated risks that are higher than the general population, including in relation to alcohol consumption and smoking, and lower participation in screening programs. For some, there may be a reluctance to make use of health services, resulting from a perceived or real lack of inclusivity in those services. This can be more of an issue in rural, regional and remote locations, or among Indigenous and culturally and linguistically diverse communities where acceptance of LGBTI identities can be less widespread than in the wider community.

ACON and the Institute have worked together over the last four years to develop a range of community-led engagement initiatives around cancer screening and prevention. These have included:

- Our United Front in 2018 (in conjunction with BreastScreen NSW), aimed at increasing knowledge and participation in breast screening among LGBTI people
- #AtYourCervix in 2017, the first Australian campaign focusing on increasing cervical screening in LGBTI communities, and
- Smoke Free, Still Fierce in 2016, which tackled smoking rates among lesbian, bisexual and queer women in NSW.

The new funding, and previous campaigns, are a welcome addition to efforts to help ensure that all people in the NSW community have access to information and support that is targeted at, and appropriate for, their individual needs.

Further information about the programs can be found at <https://www.cancer.nsw.gov.au/about-us/news/new-partnership-to-improve-lgbtq-cancer-outcomes>

Murray McLachlan

NSW Health Leading Better Value Care (LBVC)

The statewide program designed to improve the health outcomes and experiences of people with specific conditions.

Details at

<https://www.health.nsw.gov.au/value/pages/default.aspx>

and

<https://www.health.nsw.gov.au/Value/Pages/leading-better-value-care.aspx>

International Lung Conference, Barcelona 7-12 September 2019

A major feature of the conference was the new program **STARS (Supportive Training for Advocates in Research and Science)**. Lillian Leigh is one of five mentors in this program. Sue McCullough also attended the conference and participated with Lillian in the program as one of the five mentees.

Further details on the STARS program at <https://www.iaslc.org/Research-Education/Supportive-Training-for-Advocates-in-Research-and-Science-STARS>

Highlights of the 20th world conference on Lung Cancer at https://cancerworld.net/news/highlights-of-the-barcelona-20thworld-conference-on-lung-cancer/?utm_source=Newsletter&utm_medium=CW87&utm_campaign=26%20Sept19

Also see details of the Cancer Australia National Targeted Lung Cancer Screening enquiry on Page 13.

Ovarian Cancer Forum September 2019

This forum was held in Sydney on 20 September. It was organised by the Centre for Community-Driven Research (CCDR). A similar event was also held in Melbourne. The day was facilitated by Dr Catherine Holliday, chief executive of CCDR and long term “friend” of CVN.

The forum brought together local patients, carers, study partners, clinicians, researchers and decision-makers. CVN presented on the day. Other very informative presentations included

- **ANZGOG Survivors Teaching Students project** which is a Cancer Australia Supporting people with cancer Grant initiative, funded by the Australian Government. The program is affiliated with Ovarian Cancer Australia to extend reach. <https://www.anzgog.org.au/inform/news/survivors-teaching-students-caitlin/>
- **Rare Ovarian Cancer Inc**, newly established to raise funds for vital research for Juvenile Granulosa Cell Tumour (JGCT) a rare and incurable ovarian cancer that has been found in babies as young as 4 months old. <https://rocinc.org.au/>
- **Dr Kristina Warton, TCRN UNSW**, who is currently trying to develop a new blood test to help detect ovarian cancer early. (Kristina has a CVN / TCRN consumer in her project team).

Key stakeholder organisations including CVN, were able to participate in facilitated discussions regarding the presentations and to listen to the experiences of patients and carers including issues around diagnosis (particularly lack of early detection testing) and treatment, BRCA gene, their needs and expectations for the future. Out of pocket costs and insurance issues were also raised. A valuable discussion that assists Cancer Voices to keep informed and continue to identify and stay across the generic cancer issues.

CCDR is conducting a study, which was also discussed, to understand the experience of patients with ovarian cancer within the Australian health system and their expectations of future treatment, care, information and support. This study is still open for recruitment.

Further details ibless@cc-dr.org

Elisabeth Kochman

Cancer Council Australia 2019 Consumer Forum

Cancer Voices was one of some 30 organisations invited to participate in the Cancer Council Australia 2019 Cancer Consumer Forum on 29 October to ‘*explore policy issues of relevance to all cancer organisations with dynamic discussion of shared priorities, agenda setting and the development of opportunities to work collaboratively.*’ More details in our next newsletter.

Sally Crossing AM Award for an Outstanding Outcome in Cancer Research

Applications are now open for the second year of the Sally Crossing AM Award for an Outstanding Outcome in Cancer Research. This award is a collaboration between Cancer Council NSW, Cancer Voices NSW, the Belalberi Foundation and the Crossing Family. It recognises ‘outstanding achievements in cancer research, inclusion of consumers and delivery of significant benefit to the cancer community’

This is a generous \$50,000 individual award dedicated to the memory of the late Sally Crossing AM and provided by the Belalberi Foundation and the Crossing Family.

Deadline for applicants is 20 December, 2019.

Full details can be found on the Cancer Council NSW website at

<https://www.cancercouncil.com.au/research/for-researchers/sally-crossing-award/>

Updated guides associated with Cancer Voices consumer in research program

Cancer Voices has recently updated the two guides associated with our Consumer involvement in Research program. These guides were originally produced in 2014 to assist both consumers and researchers working together on research projects to understand the respective roles and how to maximise the experience. Additional tips and hints have been included in both guides along with a link to the recently launched Australian Cancer Trials *Consumer Involvement and Engagement Toolkit* (Refer article Page 10 for further details).

Both guides are available on our website at <https://www.cancervoices.org.au/consumer-involvement-in-research-program/> or individually at [Guide for Consumers](#) [Guide for Researchers](#)

Petition for a national inquiry to streamline/ improve research ethics and governance in Australia

As cancer survivors, many of us know that slow and inconsistent research ethics and governance processes could be costing lives when access to new treatment trials are delayed. Even some 'low risk' studies have inordinately protracted passage through some ethics committees which seem to have lost sight of the aim to improve access to different models of care.

Petition for a national inquiry to look into this at

<https://www.thepetitionsite.com/en-au/981/617/971/we-need-a-national-inquiry-to-streamlineimprove-research-ethics-and-governance-in-australia/>



Consumer Involvement in Research (CIR)

The 2019 Consumer involvement in Research training was held at the Cancer Council NSW (CCNSW) on 20 September. Our CIR Coordinator, Lee Hunt, was a presenter on the day and Deputy Chair, Murray McLachlan was also in attendance. Both welcomed the opportunity to meet and speak with the participants during the breaks.

The training comprises completion of four short modules followed by a half day face to face workshop at CCNSW where the consumers meet researchers, workshop scenarios and are involved in discussions which prepare them for their contribution to cancer research.

A warm welcome to the fifteen participants who undertook the training this year. These new graduates have been sent welcome letters and have been added to our CIR data base.

They bring a wealth of experience and added diversity including cancer types, professional and cultural backgrounds, and rural demographics, all of which will greatly enhance their contribution to research projects and cancer committees.

Our thanks to CCNSW, in particular Jane Hobson and Stephanie Ohlback, for their hard work and dedication to ensuring the ongoing success of the CIR program.

Some of our members take on a wide variety and / or number of projects whilst others have their 'own policy' about what they will put their hand up for. We do ask that you check your emails regularly and respond to any emails from Cancer Voices as soon as possible to enable us to complete the linking of researcher requests with suitable consumers in a timely manner.

Cancer Voices has a pretty special and unique community of interest in our *Consumer Involvement in Research Program*. We are grateful for your generosity of time and more importantly the value and experience that you contribute to the projects that you choose to get involved with to ensure quality cancer research.

Elisabeth Kochman

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

Prince of Wales (PoW) Round Table: Consumer Involvement in Research Presentation

The roundtable program at PoW provides a forum to advance collaborations between laboratory and clinical researchers, and facilitate strategic partnerships between the Nelune Comprehensive Cancer Centre (Prince of Wales Hospital), UNSW Sydney, the Lowy Cancer Research Centre, the Translational Cancer Research Network (TCRN), and South Eastern Sydney Local Health District.

Several times a year, researchers and clinicians are invited to attend such a forum to hear about a wide range of current topics that are relevant to them.

In August 2019, I was invited to present at one such Round Table event on the topic of Consumer Involvement in Research. I was joined on the podium by Gino Lori, a member of Cancer Voices, A/Professor Phoebe Phillips, Head, Pancreatic Cancer Translational Research Group, Deputy Director, Adult Cancer Program, and Stephanie McMillan, TCRN Program Manager.

We all spoke about involving consumers in research – Gino and I from the consumer’s perspective with Phoebe giving the researcher view of consumer involvement and Stephanie covering how the TCRN supports researchers with consumer involvement.

The session was well attended with well over 30 people in attendance. It was a wonderful opportunity to spread the word about consumer involvement in research and as a result, I have picked up two new researchers at UNSW who are working on nanotechnology.

Kathryn Leaney

Health Literacy Initiative - 2019 High School Cancer Symposium and Competition

I participated in the inaugural NSW High School Cancer Symposium and Competition at UNSW on 13 September 2019. And what a fabulous event it turned out to be.

The Australian Cancer and Health Sciences Competition (ACHSC) is a not-for-profit organisation created by medical students in Victoria to improve health literacy among high school students, with a particular focus on cancer.

This year, the concept came to NSW with the High School Cancer Symposium and Competition for Year 10 students. For this inaugural event, around 150 participated, some coming from as far as Ulladulla to be involved.

I was invited to participate as a ‘survivor’ and member of the Consumer Advisory Panel (CAP) of the Translational Cancer Research Network (TCRN) at UNSW. The opportunity to improve health literacy and to interest students in thinking about a career in research was too good an opportunity to miss.

The day began for the students with two keynote speakers. First was A/Professor Phoebe Phillips. Phoebe is the Leader of the Pancreatic Cancer Translational Research Group, Deputy Director of the Adult Cancer Program at the Lowy Cancer Research Centre, and Deputy of the Cancer Theme at University of NSW. This was followed by an address by A/Prof Joshua McCarroll who is a Group Leader based at the Children’s Cancer Institute at UNSW. He leads a team of researchers working on identifying new therapeutic drugs to treat childhood and adult cancers including, brain, pancreatic and lung cancer.

Other activities on the day included a tour of a research lab and a visit to the Museum of Human Disease. The students also sat for an ‘exam’ based on material they had been sent beforehand. The top two students from the exam will have the opportunity to do work experience at one of the university labs during a school break.

For the ‘Meet a Survivor’ section, I was joined by three fellow CAP members. Between 11.30 am and 2.30 pm, the four of us ‘survivors’ met with groups of between 6 and 15 students for around 15 minutes per group and told them about our own experience with cancer and answered their questions. It felt a bit like speed dating (or what I imagine speed dating would feel like) but it was fascinating. By the end I had told my story to around 80 students and teachers and also many of the medical students in attendance.

The opportunity to talk to the students about a real person’s experience of a cancer journey was invaluable. Even the medical students learned something – the personal side of a cancer diagnosis and treatment. While not all students enjoyed the experience, most did and I could see many of them were genuinely interested. I’m sure this experience will influence many of them to choose subjects in Year 11 that will lead to further studies in science and biology.

All four CAP members who participated found the experience rewarding and humbling and, given the opportunity to participate in 2020, we will certainly say ‘Yes!’.

Kathryn Leaney

Australian Clinical Trials Alliance (ACTA) Launch of a consumer involvement and engagement toolkit

The ACTA formed in 2013 with financial seeding support from the Victorian Government. In June 2017 with a \$5 million **Medical Research Future Fund (MRFF)** grant to the Australian Clinical Trials Alliance (ACTA), the Australian Government demonstrated its clear commitment to supporting health and medical research focused on improving patient outcomes and advancing evidence-based healthcare.

ACTA comprises a membership of organisations involved in/with medical research in Australia. Much of ACTA's work is undertaken via (volunteer) Reference Groups – one of which is the Strengthening Consumer Engagement in Developing, Conducting and Reporting Clinical Trials Reference Group. I became a member of this Reference Group in late 2017.

Following many teleconferences of that Reference Group, in early 2019 I was invited to join the Consumer Involvement and Engagement Guidance Working Group which was tasked with developing a "Consumer Involvement and Engagement Toolkit".

There was a pressing need for this Toolkit which could be used by medical researchers/research organisations and consumers interested in medical research. Both international and local research has shown that the involvement and engagement of consumers enhances medical research questions and provides improved outcomes for patients. In Australia public funding of research (eg through the NHMRC or Cancer Australia) requires the involvement of consumers in designing the grant application – this "consumer involvement" is not a requirement of many other funding organisations albeit that the evidence still holds true that research questions are enhanced through consumer involvement.

In early October 2019 the ACTA held an International Conference titled "Better Health through Best Evidence" at the Sydney International Convention Centre. There were over 400 attendees and outstanding international and local speakers. One of the highlights of the Conference was the launch of the Toolkit. It can be found at <https://involvementtoolkit.clinicaltrialsalliance.org.au/> and you may care to read the section on Consumers at <https://involvementtoolkit.clinicaltrialsalliance.org.au/consumers>

Dan Kent

University of Sydney Pacer Network

The **PACER Network** is a joint initiative of [The University of Sydney](#), and the [Kids Research at The Children's Hospital at Westmead](#), [Westmead Hospital](#), and the [Westmead Institute for Medical Research](#). The network was established in 2018. Its aim is to facilitate knowledge exchange, cross-disciplinary collaboration, and innovation in conducting and implementing patient-centred outcomes research and patient involvement in research' (see the Pacer website at <http://pacernetwork.org.au/about/>)

They run webinars and workshops around patient-centred research <http://pacernetwork.org.au/events/> Jan Mumford, who wears multiple hats including member of Cancer Voices NSW EC, Executive Director Genetic Alliance Australia & Chair Consumer Advisory Panel, Australasian Gastro Intestinal Trials Group participated in the panel on 10 September entitled **Ensuring meaningful and sustained consumer involvement in health research**. All webinars are recorded and can be accessed at <http://pacernetwork.org.au/webinars/>

In order to view the webinars you need to be a member of PACER. This can be easily done via the above link and includes name, email, organisation, interests (optional). Once you have done this you will be able to access the link to the 10 September webinar (scroll down the list) and download.

Next webinar 12 November 2019

'Opportunities and strategies for consumer involvement in clinical trials' with presenter **Nicola Straiton** at Kids Research, The Children's Hospital at Westmead

Also refer Noticeboard on Page 2 for details

New Psychosocial Model of Care for Men with Prostate Cancer from PCFA

https://www.prostate.org.au/model-of-care/?utm_medium=email&utm_campaign=Psychosocial%20Model%20of%20Care&utm_content=Psychosocial%20Model%20of%20Care+CID_07ec876bdbbfeff7694c7e89cca8b96d&utm_source=Email%20marketing%20software&utm_term=CLICK%20HERE%20TO%20DOWNLOAD%20THE%20DOCUMENTS

The Voices being heard

Meetings

- RANZCR Interventional Radiology Committee Teleconference, 31 July
- Cancer Australia Guide to Early Breast Cancer Expert Working Group Meeting, 13 August
- CINSW quarterly meeting, 2 September
- Cancer Voices SA Teleconference, 11 September
- Canberra Health Summit National Preventive Health Strategy teleconference, 18 September
- CVN EC, 25 Sept
- Out of Pockets Costs Transparency Working Group, Canberra, 26 September
- Pink Hope, 3 October
- Cancer Council NSW quarterly meeting 21 October
- Cancer Council NSW Advocacy Working Group 21 October
- Sydney Cancer Conference Organising Committee, 23 October
- UTS, student project, 22 October
- Cancer Council Australia Rare and less common cancers resources project Teleconference 23 October
- RANZCR, Faculty of Radiation Oncology, 25 October
- Pink Hope, Teleconference, 31 October

Conferences/Forums/Events:

- Prince of Wales Round Table: Consumer Involvement in Research Presentation; 20 August
- Australian Gastrointestinal Trials Group ASM, 21-23 August Adelaide
- Legal Aid NSW, 'What's the Risk' Insurance Report launch, 22 August
- NSW Health Value Based Health Care Forum, 28-29 August

- CINSW Cancer Plan review workshop, 2 September
- International Lung Cancer Conference, 7-12 September, Barcelona
- University of Sydney Pacer webinar, 10 September
- 2019 High School Cancer Symposium and Competition, 13 September
- Consumer Involvement in Research Training, Cancer Council NSW, 20 September
- Centre for Community Driven Research, Ovarian Cancer Forum, 20 September
- 26th Genetic Alliance Awareness Week launch, 24 September, NSW Parliament House
- CINSW Innovation Conference, including promotional table, 26 September
- Office of Fair Trading, Role of the Committee, webinar; 3 October
- Australian Cancer Trials Alliance, 3-5 October
- Prince of Wales Roundtable: Implementation of Mainstreaming of Genetic/Genomic Testing in the Setting of Ovarian Cancer and Other Cancers; 15 October
- Health Consumers NSW AGM, 18 October
- RANZCR ASM, 16-20 October, Auckland
- Cancer Council Australia 2019 Cancer Consumer Forum 29 October
- Cancer Institute NSW Premiers Research Awards, 30 Oct, NSW Parliament House

Submissions / Feedback

- CINSW; Review of smoking cessation and cancer patient information resource, August
- Australian Medical Council, assessment of training, education, professional development for RANZCR, September
- CCA Rare and Less Common Cancers project draft resource, October
- Conference abstracts, October

Life Insurance Products and Genetic Testing in Australia

The Moratorium on Genetic Tests in Life Insurance came into effect from 1 July 2019 and will end on 30 June 2024. This means that from 1 July 2019, there will be a temporary suspension of the use of genetic test results as part of an insurance application up to

the value of \$500,000 (for death and total permanent disability), \$200,000 for trauma and \$4,000 a month for income protection.

<https://www.genetics.edu.au/publications-and-resources/facts-sheets/fact-sheet-20-life-insurance-products-and-genetic-testing-in-australia>

This will be a continuing advocacy issue.

Cancer Council NSW Update

Understanding Immunotherapy, a guide for those affected by cancer

This fact sheet will help you to understand more about checkpoint immunotherapy, a treatment offered to some people with cancer and understand how immunotherapy may help treat cancer. Details at <https://www.cancercouncil.com.au/cancer-information/cancer-treatment/immunotherapy/>

Unique podcast series offers a new way for advanced cancer patients to access trustworthy information

Cancer Council NSW has recently launched its new podcast series, 'The Thing About Advanced Cancer', focusing on the challenges surrounding a diagnosis of advanced cancer. Hosted by cancer survivor and broadcaster, Julie McCrossin, ten episodes feature interviews with both cancer experts and people with a lived experience of advanced cancer, and explore the practical as well as the existential issues that people may face.

Advanced cancer patients have many complex decisions to make, but when they go looking for answers they don't always find trustworthy information.

This podcast provides evidence-based information and practical tips and encourages listeners to discuss their concerns with health professionals. It also opens up the conversation about the deep fears and tough questions that come with advanced cancer.

The Thing About Advanced Cancer podcast series is available on the Cancer Council NSW website at cancercouncil.com.au/podcasts, as well as via Apple Podcasts and other podcasting apps. Cancer Council's earlier series, known as 'The Thing About Cancer', is also available.

The 10 episodes cover key issues

- What does advanced cancer mean?
- Treatment options for advanced cancer
- Living well with advanced cancer
- Caring for someone with advanced cancer
- Living with dying
- Caring for someone in their last months
- The role of hope and purpose in advanced cancer
- Managing pain when cancer is advanced
- Preventing delirium when cancer is advanced
- Managing breathlessness when cancer is advanced

Cancer Council Helpline

Talk to a qualified health professional

Call 13 11 20

Monday to Friday 9am – 5pm

Cancer Institute NSW Update

New partnership to improve LGBTI cancer outcomes
See article and link on Page 6.

2019 CINSW Innovations Conference was held in Sydney on 26 September. This year's theme was '**Equity of outcome in cancer control**' - the impact / connection between poverty and obesity, that comorbidities are common across cancer and higher in indigenous populations, mental health issues, lack of screening for most cancers, being able to get into a GP and that outcomes are based on timely diagnosis. Services such as radiation therapy need a critical mass of health professions as higher volumes are safer and have better outcomes. The right support is required to achieve this. Many innovations that have been

developed to address needs were presented and on display via e-posters on the day.

The following link contains **the program** for the day along with the **video links to all the sessions**. You can also **view the e-posters** which are listed at the end of the program.

https://www.cancer.nsw.gov.au/2019-innovations-conference?utm_source=CNI-1910&utm_medium=email&utm_campaign=OtherStkhdrs#gallery

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

Genetic Alliance Australia

Genetic Disorders Awareness Week is held annually to highlight exceptional work done in the area of rare genetic conditions. It was started 25 years ago by Dianne Petrie OAM, who founded Genetic Alliance and has been a calendar highlight for people who support those affected by rare genetic conditions. The event is attended by families, genetic counsellors, student genetic counsellors, teachers, researchers, support group leaders, genetic educators, politicians and health professionals.

The theme for this year was **Genetics and Changing Dynamics**. These changes have been brought about by people who are driving the changes for their respective health communities. Speakers on the night:

- Cath Holliday spoke about the Centre for Community Driven Research (CCDR) and how it will be contributing to Australian health care and international perspectives. She acknowledged Sally Crossing's 'bottom up energy and collaboration. CCDR established the Australian Patient Organisation Network earlier this year via its inaugural conference in April.

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- Laila Hallam spoke of her experience with her father and told how they engaged with the health system and felt at the time they did 'ok'. Now in hindsight, she has realised much could have been done differently and she has taken on a role to advocate for others.
 - Megan Donnell and Natalia Elkheir both have children with different fatal rare genetic conditions. Megan spoke about raising money for research and the challenge of the perception that as a charity they needed to be at arm's length yet being fiscally responsible for donations to research work. Natalia said she could be 'defeated or defined' by her family's experience and spoke about how she had stepped into a leadership role when the previous president needed more time with her family. Natalia said that she knew that another mother or father would be there when it was time for her to step down and care for her daughter.

There are different facets of dynamic change being brought about by these dedicated passionate people for their families and loved ones.

Victor Dominello, the Minister for Customer Service, was host for this event which was held at NSW Parliament House

Further details at <http://www.geneticalliance.org.au>

Jan Mumford

Cancer Council Australia project report

Cancer Council Australia's Rare and Less Common Cancers resource project continues to progress well with the first of the factsheets currently being reviewed. We will keep you informed of progress and release of the resources.

As previously reported, consumers have been involved, including in focus groups and interviews and will also be involved in the review of the new resources. Cancer Voices is a member of the steering committee. This project is being funded by Cancer Australia.

Rare Cancers Australia Knowledgebase

The KnowledgeBase is an online resource which includes a 200+ rare cancer directory, specialist hospitals with cancer centres, multi-disciplinary teams, treatment options, clinician contacts with special interests in rare cancers and related health care professionals, support services (including financial support) as well as relevant clinical trial listings. It will be continually updated and expanded.

Details at <http://knowledge.rarecancers.org.au/>

Releases from Cancer Australia

National Targeted Lung Cancer Screening Program enquiry launches

In an Australian first, Cancer Australia convened a workshop in Sydney in September to explore the feasibility of a national targeted lung cancer screening program.

Lung cancer is the leading cause of cancer death in Australia and kills more people annually than breast and bowel cancer combined. It is estimated there will be more than 12,000 new cases of lung cancer diagnosed in Australia this year, and more than 9,000 deaths. It is estimated that there were more than 2.5 million current daily or former-smokers between the ages of 55 and 74 years in Australia in 2017-2018.

The Workshop was the first stage of an enquiry to investigate the potential for a targeted national lung cancer screening program that was announced by the Minister for Health Greg Hunt in August 2019.

"On behalf of Cancer Australia, I am delighted to have been asked to look at prospects, process and delivery of a national targeted lung cancer screening program for Australia," said Professor Dorothy Keefe, Cancer Australia CEO.

"This announcement recognises the growing evidence to support lung cancer screening and acknowledges the importance of continuing efforts to reduce deaths from lung cancer."

"I look forward to making regular progress announcements through our Cancer Australia website

until the enquiry concludes in October 2020 with a report delivered to Minister Hunt.”

“This announcement recognises the ongoing research into lung cancer screening and acknowledges the importance of continuing efforts to reduce deaths from lung cancer.”

The enquiry will be underpinned by a consultative and inclusive process and participants include consumers, key opinion leaders, health providers, policy makers, expert advisors and representatives from peak cancer bodies and professional colleges.

This enquiry will focus on targeted screening of high-risk groups, including consideration of Aboriginal and

Torres Strait Islander communities, and people living in rural and remote communities.

The National Targeted Lung Cancer Screening Program enquiry will establish the evidence-informed foundation for targeted lung cancer screening including the benefits and harms of screening, cost effectiveness, initial scoping of the target population and understanding the screening and assessment pathway. <https://canceraustralia.gov.au/about-us/news/national-targeted-lung-cancer-screening-program-enquiry-launches>

(Note: This is part of the new National Preventive Health Strategy launched in August, refer Page 4)

Supporting best practice in the care of people with metastatic breast cancer

A new resource designed to support best practice, patient-centred care for people with metastatic breast cancer in Australia was released in October. The *Cancer Australia Statement – Influencing best practice in metastatic breast cancer* (the Statement) aims to support improved, evidence-informed decisions for cancer care, to engage consumers in their care, and to drive improvements which reduce unwarranted variations in cancer care and outcomes.

The Statement highlights 10 key appropriate and inappropriate metastatic breast cancer practices, to influence and enhance best practice breast cancer care across the continuum and in the Australian context.

The Statement supports and encourages people with metastatic breast cancer and health professionals to participate actively in conversations around the key practices, which will help patients to make evidence-informed decisions about their care.

View the practices, supporting consumer information and videos at canceraustralia.gov.au/statement

Childhood Brain Cancer Awareness Day

Minister for Health Greg Hunt has announced that the Morrison Government has launched an annual Childhood Brain Cancer Awareness Day along with an additional \$7 million in research funding through the Medical Research Future Fund, to help support children and their families living with the devastating disease.

The inaugural Childhood Brain Cancer Awareness Day aims to raise public awareness of the impact of childhood brain cancer on patients, family and carers and to focus on the importance of childhood brain cancer-related research’. Further information at <https://canceraustralia.gov.au/about-us/news/inaugural-childhood-brain-cancer-awareness-day>

Endometrial Cancer

[Endometrial Cancer Risk Factors](#) web-based information will help the community to better understand risks associated with personal and lifestyle factors, family history and genetics, reproductive factors, and medical history and medications.

The information helps women of all ages to know what to do to reduce their risk of endometrial cancer, including through healthy lifestyle choices. Maintaining a healthy body weight is particularly important in reducing the risk of endometrial cancer, and engaging in sufficient physical activity and breastfeeding are other protective factors that lower the risk of endometrial cancer. For more information, visit <https://endometrial-cancer.canceraustralia.gov.au/risk-factors>.



Reducing rural health inequalities

Financial barriers to Regional, Rural and Remote cancer patients, including access to clinical trials

Patient assistance travel and accommodation schemes have been a focus of Cancer Voices advocacy work at various times in our 19 year history.

We are now developing a comparison of the regional, rural and remote patient travel assistance schemes in each State, including exclusion criteria such as participation in clinical trials. We are also interested in the financial impediment to treatment across State boundaries.

If you have any experience of using the travel and accommodation assistance scheme, or travelling interstate to receive treatment, we would like to hear from you, positive or negative.

We are collecting stories now to help develop a survey on the issue that will be released early next year.

Our current position statement on the NSW Isolated Patients Travel and Accommodation Scheme (IPTAAS) is available on our website at <https://www.cancervoices.org.au/wp-content/uploads/2018/07/CVN-Position-Statement-IPTAAS-equity-June-2018.pdf>

Please contact our regional representative on the CVN Executive, Sarah Lukeman on 0427 191 724 or sarahlukeman@hotmail.com to discuss further, and feel free to extend this request through your networks.

Cancer Voices is the independent, volunteer voice of people affected by cancer - since 2000

Australian Commission in Safety and Quality in Health Care

Australian Charter of Healthcare Rights

Consultation Open

The second edition of the [Australian Charter of Healthcare Rights](#) (the Charter) was released in August 2019. It describes the rights that consumers, or someone they care for, can expect when receiving health care in Australia.

To support implementation of the Charter, the Commission has developed a guide for consumers. The guide provides consumers with information on their healthcare rights and how to discuss concerns with their healthcare provider or service.

The Commission invites you to view the draft consumer guide and provide feedback [via an online survey](#).

Your feedback is important. The survey takes approximately 25-30 minutes to complete. You can choose to skip questions if you prefer to only provide feedback on some sections of the consumer guide.

This survey will be **open until 6 December 2019**. Please circulate this survey within your networks.

If you have any questions in relation to this consultation, please contact the Partnering with Consumers team on (02) 9126 3600 or partneringwithconsumers@safetyandquality.gov.au.



Consumers Included – a logo “seal of approval”

- Acknowledging consumer participation
- Trademarked December 2017

Consumers Included – a logo “seal of approval” A Cancer Voices initiative, launched in late April 2016, and Trademarked in December 2017. The purpose of the Consumers Included (Ci) logo is to encourage and acknowledge organisations which enable consumers to participate in conferences, meetings and other events which are of interest to them – and which will benefit from their involvement.

Further information can be found on the Consumers Included website at <http://consumersincluded.wordpress.com/> which advises applicants on how to apply for its use, as well as listing those who have been awarded approval to use the logo.

If you have any questions, please contact us at info@consumersincluded.org.au

For more information go to the Ci tab on Cancer Voices Australia’s website www.cancervoicesaustralia.org.au

STOP PRESS

Cancer Council Australia 2019 Cancer Consumer Forum was held in Sydney on 29 October.

Representatives from 19 national cancer organisations along with Cancer Council consumer representatives were present at this inaugural event. There was also rural and regional representation. With the agenda to *'explore policy issues of relevance to all cancer organisations with dynamic discussion of shared priorities, agenda setting and the development of opportunities to work collaboratively'*, there was a positive vibe and energy along with recognition of the strength of collaboration and the power of a unified voice to address matters that impact and affect those affected by cancer.

The day was well balanced with presentation / discussions and brainstorming sessions, details of which are to be collated and summarised. There was focus on financial burden and informed financial consent along with Optimal Care Pathways (OCPs), 'the national standard for high quality cancer care for all Australians'. These key issues provided a segway for the raising and highlighting of many other issues common to the cancer organisations present.

Our thanks to Cancer Council Australia.

We hope to bring you more in our next newsletter.

Elisabeth Kochman

Australian Cancer Consumer Network (ACCN) was established in 2014. The ACCN brings cancer-consumer groups together to share information, experiences and issues. It currently numbers close to 30 groups covering many specific cancers and some generic cancer groups. It is convened by CVA via CV member Dan Kent.

Member organisations have been invited to update their organisation's details for the website directory. We thank those who have responded. The updates are currently being formatted for upload to the directory.

Thirteen member organisations had representation at the Cancer Council Australia 2019 Cancer Consumer Forum, refer previous article.

Note: Coverage of our activities and involvement at a national level has been included in the main body of this newsletter.

Cancer Voices Australia is the independent, the volunteer voice of people affected by cancer – since 2000

THANKS to the Team who bring you this Newsletter:

Kathryn Leaney for formatting, Murray McLachlan for proof reading and Elisabeth Kochman as compiler & Editor & 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: Info@cancervoices.org.au

REMEMBER our full archive of previous newsletters is here:

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