



Cancer Voices NSW

Annual Report 2020

Presented at the Cancer Voices NSW Annual General Meeting

Friday, 19 February 2021

Via Zoom



Cancer Voices NSW provides the independent voice of people affected by cancer, working to improve the cancer experience of the estimated over 49,000 people who are diagnosed in our state each year.

Established in 2000, we are active in the areas of prevention, diagnosis, information, treatment, research, support and care, survivorship and policy. To achieve this, we work in partnership with providers of these services, ensuring the patient perspective is heard.

Vision

The voice of people affected by cancer

Mission

To lead and advocate for people affected by cancer

To be at the centre of policy, research evaluation and treatment decision-making

Our Values

- Courage - speak up forthrightly
- Inclusion - cancer, statewide
- Transparency - open to all
- Tenacity - always debate our position
- Collaboration - work with others

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Cancer Voices NSW Annual Report 2020

CVN provides the independent voice of people affected by cancer, working to improve the cancer experience of the estimated over 49,000 people who are diagnosed in our state each year.

It is with pleasure that I present the Cancer Voices NSW 2020 Annual Report highlighting the activities of our twentieth year. 2020 was a special and significant milestone in the history of Cancer Voices – our 20th anniversary, two decades of providing the voice of those affected by cancer, a rather significant achievement for a 100% volunteer organisation. 2020 turned out to be a year like no other and as such we will do more to acknowledge and reflect on this milestone when circumstances allow.

This time last year we were dealing with the aftermath of a series of catastrophic natural disasters over many months and the knock on effects including loss of life, livelihoods and homes. We then found ourselves in the midst of the global COVID-19 pandemic. The year was undoubtedly challenging and affected everyone everywhere and everything that we do, forcing us to adapt and innovate. Technology has played a huge part in the changes. Telehealth has become a vital tool and has been rapidly adopted in the care and safety of both patients and health professionals.

Cancer Voices has always operated in the virtual world having never had office space so we added Zoom to our toolkit to provide a mechanism by which the EC could operate efficiently. We continued our focus on the needs and issues of those affected by cancer across a wide and diverse range of issues and areas which included a strong national focus. CVN has also continued to work in conjunction with Cancer Voices Australia (CVA) and the Australian Cancer Consumer Network (ACCN) facilitated by CVA.

We saw collaboration at its best with the federal and state governments working together via the National Cabinet and seeking expert advice on which to base decisions. This played out in health and in the cancer sector. Cancer Voices was involved in collaborative efforts at a state level through the Cancer Institute NSW and our state peak consumer organisation Health Consumers NSW. At a national level, Cancer Council Australia convened a working group of national cancer organisations to identify issues and to coordinate key messaging and information to better support the cancer community.

As well as pursuing our advocacy issues, work on the external review of Cancer Voices' Consumer Involvement in Research (CIR) Program commenced in August. Major components of the Review were a survey and consultations involving interviews across the cancer and broader health community. This Program has been running for 15 years, yet another milestone for our volunteer based organisation. To celebrate 15 years of our Program we produced a new poster [Consumers shaping research – 'Nothing about us without us'](#): an updated summary of its history, process and achievements along with a special report on the Program.

We were delighted to receive an invitation to a virtual meeting with our patron, the Governor of NSW, Her Excellency, The Honourable Margaret Beazley AO QC. Five members of the CVN Executive Committee met with Her Excellency and her husband Mr Dennis Wilson in May.

Opportunities for us to collaborate, contribute and engage on a broad scale to achieve better outcomes for those affected by cancer in NSW and beyond, with both government and cancer and other health organisations, included:

Key appointments to

- Prostate Cancer Foundation (PCFA)
 - The PCFA Survivorship Essentials Expert Panel
 - The PCFA Information and Resource Expert Panel

- NSW Cancer Plan Governance Committee, including the stakeholder engagement process, co-design workshops, progress briefings regarding the development of the fifth cancer plan
- HCNSW NGO Consumer Organisation Taskforce
- Cancer Council Australia, cancer charities organisations collaboration due to COVID)
- Consumers Health Forum
 - Consumer Commission: Beyond COVID-19
 - 2020 Members Policy Forum
- Clinical Oncology Society of Australia, Financial Toxicity Working Group
- Cancer Australia (CA) - National Pancreatic Cancer Roadmap Steering Group
- Health Consumers NSW Board
- Cardio-oncology special interest group

Ongoing engagement with

- Medical Colleges, including the Royal Australian and New Zealand College of Radiologists; Clinical Oncology Society of Australia
- Lymphoedema Action Alliance (LAA)
- Voluntary Assisted Dying legislation in NSW
- health and cancer consequences of unprecedented natural disasters
- Cancer Australia
 - Membership of the Intercollegiate Advisory Group
 - Lung cancer inquiry
- Cancer Council Australia
- Rare and Less Common Cancer Resource Project including involvement of consumers as reviewers & review of draft resources
 - Cancer organisation collaboration
 - 2020 Consumer Forum
- Cancer Council NSW relationship meetings
- Cancer Institute NSW, relationship meetings, COVID related briefings
- Clinical Trials including
 - Access to clinical trials including via the COSA Teletrials Consortium (CVN as a member of the consortium contributed \$5K to this project in 2017)
 - Support for the MRFF grant application for implementation of the Australasian Teletrial Model, Feb
- Culturally and linguistically Diverse communities (CALDs)
 - Multicultural co design workshop
- Relationships between consumers, consumer groups and the pharmaceutical industry
 - Building trust and transparency: including workshop presentation and participation
- Survivorship
 - Peter Mac Survivorship conference and poster abstract

Consultations with

- The Regional Cancer Treatment Centres for Radiation Therapy initiative stakeholder consultations, February
- The George Institute for Global Health and the establishment of an Australian research register, JoinUs
- Healthcare Management Advisors re Radio Oncology Health Programs Grants (ROHPG)
- Telehealth including
 - Health Consumers NSW (HCNSW) - Health Consumers Organisations Taskforce workshop

Endorsements

- The Standard for Informed Financial Consent, (Cancer Council Australia, BCNA, PCFA and Canteen) (March)
- Smoking Cessation in Cancer Patients: Embedding Smoking Cessation Care in Australian Oncology Health Services, Clinical Oncology Society of Australia (July)
- Community Support Organisations' Cancer Survivorship Care Consensus Statement

Submissions included to

- Medicinal Cannabis Inquiry, *Current barriers to patient access to medicinal cannabis in Australia* reported in March with CV referenced in two footnotes
- NSW Independent Bushfire Inquiry, April
- Department of Health
- State Health
- Medical Services Advisory Committee (MSAC)

Special Reports

- Cancer Survivorship and Return to Work (March)
- Telehealth in Cancer Care (June)
- Clinical Trials (September)
- Genetic Testing (December)
- Consumer Involvement in Research (CIR) – 15 Years Special Report (September)

Note: More details can be found in our [2020 newsletters](#) Nos 77-80 on our website

Working with Stakeholders: CVN nominees and the group itself continue to work with the wide range of cancer and relevant health stakeholders, strengthening existing relationships and establishing new ones at both state and national levels. Engagement included key state political parties, MPs and their representatives, government agencies, committees, authorities and organisations, cancer agencies and organisations, consumer organisations, educational facilities, research facilities and organisations, medical colleges and organisations.

Farewells: In late May, Cancer Council Australia CEO, Professor Sanchia Aranda AM, announced her intention to retire from full-time employment around the end of 2020. Sanchia has been CEO of Cancer Council Australia since 2015. Cancer Voices has known Sanchia since 2011 from her time at the Cancer Institute NSW and has acknowledged her contributions and all that she has done for those affected by cancer during her 40 plus year career. We acknowledge the appointment of Tanya Buchanan as Chief Executive Officer, effective 30 November.

Consumer Representation and Training

Our representation is across a wide and diverse range of areas. That representation is strengthened by appropriate training which equips us to be more effective in the roles that we take on.

Consumer Advocacy Training (CAT) courses, held in conjunction with Cancer Council NSW (CCNSW) have been on hold due to a review and the development of a new online training platform. CVN was invited to join that working group.

Consumer Involvement in Research (CIR): 2020 was also the 15th year of our CIR Program. A new poster, [Consumers shaping research – ‘Nothing about us without us’](#) was produced to provide an updated summary of its history, process and achievements. It was accepted as a poster abstract at the Peter Mac Survivorship Conference in March and again at the Sydney Catalyst Early Career and Postgraduate Researcher Symposium in October along with a presentation on CIR. A report was also produced on the Program.

Training was held in September with CCNSW, for the time in an online format. Participants must complete four online modules before attending this session. This provided 12 new “graduates” to support our CIR matching program for researchers seeking to work with informed consumers, now a requirement for most grant approvals. Some funders are now requiring a minimum of two consumers for projects. CIR members take on roles in cancer research projects, as Research Panel Consumer Advisors and on Consumer Review Panels. For the 2020 grant funding cycle, there were 82 requests from researchers and committee organisers involving 133 consumers compared to the 2019 research funding cycle which saw 68 requests involving 102 consumers. Requests also came from further afield including interstate universities and research institutions. Requests have been diverse and covered a wide range of cancer types and issues including diagnosis, treatment and rehabilitation, quality of life, chemotherapy and tailoring new therapies.

Despite the impact of COVID, Cancer Voices members continued to speak at conferences, workshops and symposiums about the benefit of the CIR Program and the value that consumers bring to cancer research. Our CIR consumer community is steady with approximately 130 consumers, 70 of which are very active.

Lee Hunt, who has been administering this important program since 2015, stepped down at the end of 2020. We thank Lee for her valuable contribution and being the constant in this important work during this time. Lee’s long standing involvement and dedication was acknowledged in our 15 year Special Report of the CIR Program in our September newsletter.

Consumers included (Ci): Our Consumers Included logo ‘seal of approval’ program for consumer inclusion continued, though with a lower uptake due to the impact of COVID on cancer related event and conferences during 2020.

The Written Word:

CVN e-brochure has been updated and is on our website.

CVN Newsletters: We finished the year with the 80th edition of our newsletter. Four lengthy newsletters were published during 2020 and emailed to members and stakeholders. Our library of newsletters is also available on our [website](#) for wider access. They provide more details on all our activities throughout the year. 2020 also saw the inclusion of a *Special Report* series by EC member Kathryn Leaney. Many thanks to all who contributed to our newsletter by reporting on issues and their activities in the interest of those affected by cancer. Our thanks also to the Cancer Council NSW and the Cancer Institute NSW for their regular contributions to our newsletter. Cancer Voices is also responsible for the Cancer Voices Australia (CVA) *News Updates* which were incorporated into the CVN newsletters. Major submissions, reports, new and revised position statements, reviews and posters can also be found on the CVN website.

Speaking Out: During 2020 members continued to attend meetings, workshops, seminars, events and conferences virtually. The virtual environment has proved an effective means to contribute the consumer view and it has not only enabled more to participate and keep up to date with cancer matters and also across the wider

health continuum, it has enabled us to access more events both here and overseas. We do, however, miss the networking aspects of these events.

Membership: We continue to welcome new members who are welcome to join our advocacy and CIR activities.

Sadly, due to the nature of cancer, we also lose members.

Membership is steady with group members at 65, and individual membership at around 400. Newsletters are also sent to 150 organisations and health professionals who want to be informed about CVN and issues for people affected by cancer.

We remain a completely independent and voluntary advocacy organisation with our success entirely dependent on the collective efforts of members, consumer representatives and in particular, members of the Executive Committee. Special thanks to the wonderful behind-the-scenes support by Kathryn Leaney, who continues to format our newsletters, facilitate our CVN EC strategic workshops and assist with document updates.

Cancer Voices SA (CVSA): CVN and CVSA continue to collaborate. The two organisations continue to work closely together particularly on policy, reviews, guidelines and submissions.

Vale – Chris Christensen, Chair Cancer Voices SA. We were saddened to hear the news of the passing of our Cancer Voices SA (CVSA) friend and colleague, Chris Christensen on 31 October 2020. Several CVN members joined her moving farewell online on 12 November. Chris was Chair of CVSA. She showed amazing tenacity and determination and used her own scenario for the betterment of those affected by cancer. A shining light and inspiration to all. To quote her colleague, friend and former chair, Julie Marker, 'she has worked to improve health policies, health service delivery and research activities spanning the cancer pathway.' Chris was diagnosed with primary peritoneal cancer in 2010. She joined CVSA in 2013 and became chair in 2017. Chris was highly regarded and will be missed by all who knew her.

The Executive Committee

The Executive Committee (EC): The 2020 AGM and workshop in February were the last face to face events for our EC due to the pandemic with all ensuing CVN meetings and workshops being held online via Zoom. Whilst we have missed meeting face to face at the offices of Health Consumers NSW (HCNSW), use of the online environment has made it easier for our regional members to join in and be 'seen' and to invite guests to join us.

Members for 2020 were Elisabeth Kochman (Chair), Murray McLachlan (Deputy Chair, Hon Sec), Shirley Baxter (Deputy Chair), Sandra O'Sullivan (Treasurer), Lee Hunt, Bev Noble, Roberta Higginson, Jan Munford, Sarah Lukeman, Lillian Leigh, Kathryn Leaney and Dan Kent. Members of the EC sit across a wide range of special interest areas. Teamwork has continued to underpin our ability to cover key issues and achieve desired outcomes. Former EC member David Campbell has continued in the role as an Advisor on political matters. We thank him for his ongoing support. Special thanks also to CVN EC member Dan Kent, who facilitates the ACCN on behalf of CVA.

CVN EC Workshops: Following our AGM in February, Executive Committee members participated in a strategic planning workshop with focus on two of our Programs, Consumers Included (Ci) and Consumer Involvement in Research (CIR) Program. Marketing and communication consultant Geoff Michels was present to guide and assist us with our discussions and directions relating to the use of our Consumers Included logo. We are grateful for his support.

Teamwork is a crucial element and we continued to see that at work this year through our CIR Review. I would particularly like to acknowledge the ongoing support of our two deputy-chairs, Murray McLachlan and Shirley Baxter during 2020.

Financial: The Treasurer's Report for 2020 is presented separately. As a 100% voluntary organisation we are grateful for all donations received, no matter the amount, as it all helps.

Special thanks to Sandra O'Sullivan who has continued to support Cancer Voices as our Treasurer since 2001.

Reflection and Thanks

For a 100% voluntary organisation to reach 20 years, we must be doing something right. We acknowledge the dedication and contribution of the more than 50 members who have been involved with the Cancer Voices EC over the past 20 years and the leadership of the past four chairs.

We cannot do what we do in the interests of people affected by cancer without a lot of encouragement and support. We recognise the valuable volunteer work of members and appreciate and acknowledge pro bono services including Health Consumers NSW who, for the third year, provided us with a convenient location for our meetings during 2020. Unfortunately, due to COVID, we were only able to use their boardroom in January. We are grateful for the support provide by Geoff Vass from Cadzow TECH Pty Ltd regarding our IT and website needs and issues since 2016, and Geoff Michels, marketing and communication consultant. A BIG thankyou to all.

To members of the Executive Committee and to our nominees who contribute significant time, expertise and effort to work in positions as consumer representatives, in advocacy and advisory capacities with decision-makers, thank you for your wonderful support, enthusiasm, commitment and contribution throughout the year. And of course, thank you to our stakeholders and supporters who respect and seek our views and work with our representatives. Together we can and will continue to make a real difference.

We finished the year with COVID upsetting the holiday arrangements of many around the country, and the prospect that a number of candidate vaccines will bring some much need relief to the fight against COVID-19 and the return to a more normal life.

The CVN team and its partner organisations have demonstrated outstanding ability to be flexible and innovative in a rapidly changing COVID world and we look forward to the challenges and opportunities as we move into our 21st year.

Elisabeth Kochman, Chair 2020

www.cancervoices.org.au



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