



Cancer Voices SA

Raising a Voice for People Affected by Cancer

Annual Report 2019



Focussing on good systems, not just good luck, wellness – not just illness, and enabling our ‘lived experiences’ to shape the care and supports that people with cancer and those that care for us need now and into the future.



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Cancer Voices SA, 10+ years of cancer advocacy, action and achievements



Cancer Voices SA - 2019 in Summary

The purpose of Cancer Voices is to influence the achievement of **better outcomes for South Australians affected by cancer**. I am so proud of the work Cancer Voices SA (CVSA) has been involved in during 2019 and for what we have achieved. We have provided a vital role in bringing the voice of the consumer to a broad range of **cancer services, policy and research**.

Our Executive Team members and supporters are involved in research activity that includes **ideas generation, concept development, input into grant applications, review of grant applications, building research/consumer relationships and engaging in the development of training resources for researchers working with consumers**. We also work with Cancer Voices NSW in providing a free service to researchers and research organisations to connect them with people who have successfully completed the 'Consumer in Research' Training. Requests for our involvement in research initiatives continues to increase with our roles expanding to research co-supervisor, Associate Investigators and researcher partners. This reflects many years of building relationships and successful consumer advocacy and demonstrates the esteem in which our knowledge, experience and input is held in South Australia and nationally.

In 2019 we have also continued to build relationships with people affected by cancer; key cancer organisations; community organisations and policy makers; pursuing matters related to **safety; quality; access; equity; prevention; diagnosis; treatment and associated issues, follow-up care, palliative care training; digital technology in cancer health; and wellness**.

We have written to the Minister for Health and Ageing, SA Health Chief Executive, Interim Director of SA Cancer Services, Commissioner of Excellence and Innovation in Health, and subsequently met with the Chief Executive and Interim Director to discuss directions for Cancer Services and the role of CVSA. It was good to see that in the main, our directions were in alignment and that CVSA could both contribute to policy

development and identify opportunities to advocate for outcomes we were seeking to achieve.

Our core programs, Survivors as Teachers, Sunday Cycling Team and Tuesday Walking Group continue to promote our focus on education and wellness, both physical and psychological, and are well supported by our members. Their commitment to a healthy lifestyle and the discussions had during these programs about their lived experience, current research and cancer services, continues to be the foundation upon which our cancer advocacy work is built. It was exciting that we, led by Julie Marker, established a new walking group on Fridays - Consumers and Researchers Walk and Talk which had the added benefit of cross fertilisation of ideas and understanding.

This year we were nominated for a Westpac Foundation grant and were fortunate enough win one of the one hundred \$10,000 grants available. Our application sought the funding to rebuild our website and we have begun the process of selecting a web designer. This should be completed by the end of June 2020 and enable much improvement in our online capacity. From the beginning of CVSA the organisation were innovators in using an online presence to communicate and we are grateful to Westpac for their support.



We were also fortunate to receive \$2500 from Flinders Centre for Innovation in Cancer (FCIC) towards travel costs associated with the Survivorship Conference in Sydney. This funding provided three people with support towards the conference and we are grateful to FCIC for their generous support.

As a 100% volunteer, not for profit organisation CVSA manages our governance arrangements mainly by email and teleconferences. All Executive Team members are volunteers and we require community donations and the sale of cycling gear to remain financial. We are indebted

to those people who have given so generously. Without you we could not continue our work. That said, we are resolute in our continued commitment to raising a voice for South Australians affected by cancer and I look forward

to working with the Executive Team, CVSA members and others supportive of our work, to continue our critical cancer advocacy work throughout 2020 when we will be considering strategic directions for 2020 – 2025.

CVSA Strategic Directions 2015-2020

Values	Vision	Purpose
Advocacy Involvement Awareness Information	That all people affected by cancer are central to their treatment and ongoing care, with good systems and information underpinning their experiences and outcomes.	To raise an independent voice to influence the achievement of better outcomes for South Australians affected by cancer.
<i>We deliver our values, vision and purpose through:</i>		
Engagement and Influence		
<ul style="list-style-type: none"> Promoting quality, safety, access and equity in treatment and care by representing and reflecting the views and diversity of people affected by cancer in appropriate forums, reviews and inquiries at the local, state, national and international levels. Identifying and building relationships with key individuals, organisations, policy makers, researchers and people affected by cancer. 		
Programs and Projects		
<ul style="list-style-type: none"> Sustaining and enhancing our core programs through continuous and active involvement with our stakeholders. Proactively engaging and collaborating in projects that support the achievement of our values, vision and purpose, using our cancer experience and knowledge. 		
Effective Strategy and Operations		
<ul style="list-style-type: none"> Effectively managing our operations through a collaborative and transparent approach. Improving the public profile and capability of Cancer Voices SA and its membership. Developing Cancer Voices SA policy and position statements, in collaboration with Cancer Voices Australia, to underpin our values, vision and purpose. 		
<i>We achieve our purpose and vision by working with cancer survivors, carers and stakeholders.</i>		

CVSA Areas of Engagement and Influence

Cancer Voices SA Executive Team members and supporters are engaged and influence a range of South Australian and Australian organisations. Team members are on a range of committees, working groups and advisory groups as well as presenting at conferences (see 'Presentations' section below) and taking part in reviews. In 2019 activities for engagement and influence included:

- Meeting with SA Health Chief Executive and Director of SA Cancer Services re Directions for Cancer in SA Chris Christensen, Julie Marker
- Ongoing involvement** and membership as **consumer reps**
 - of the SA Pathology Safety and Quality Group and SA Pathology consultation, Chris
 - SAHMRI Consumer Advisory Committee; development and feedback on the SAHMRI Research Toolkit by Chris Christensen
 - FCIC Wellness Centre Committee, Chris Christensen
 - PhD student Imogen Ramsey is 'Developing a patient-reported core outcome set for cancer survivorship population monitoring' with Julie Marker as consumer co-Supervisor throughout this 3yr research study due to be submitted in 2020 (photo)
 - PhD project in the Australian Centre for Precision Health – with consumer co-supervisor Steph Newell commenced mid 2019
 - SA Cancer Research Biobank - Governance Committee, Dr Eric Browne and Steph Newell
 - Consumer Engagement in health services, policy and research – multiple ongoing activities



involving a number of the Executive Team

- FCIC workshop ‘Preparing for Cancer Australia grant applications’ consumer insights by Dr Agnes Vitry, a speaker, and Julie Marker.
- The Advertiser, [Chris Christensen was interviewed for an article about Ovarian Cancer](#) (photo)
- Participation in
 - National Clinical Governance Framework Focus Group
 - SANT Data Linkage Research and Consumer Conversations Workshop
 - SAHMRI Registry Randomised Trials Colloquium
 - Care Search Seminar
- Multiple Grant application reviews by Karen Van Gorp, Julie Marker and Chris Christensen
- Medical teaching curriculum reviews - Feedback by Julie Marker and Chris Christensen to the University of Adelaide and Flinders University
- Newsletter article co-authored by Julie Marker for University of Sydney for Bowel Cancer Awareness Month
- **Julie Marker** was awarded the [Health Consumers Alliance of SA inaugural ‘Consumer Advocates Award’](#) for 2019, in recognition of **tireless work in partnership with health and or community services to improve consumer experience and health outcomes.**



Cancer Voices SA Projects and Programs

CVSA core programs

- [Cycling](#) – Weekly Sunday rides and Annual Challenge Ride – **Thank you to Con Nakos**, and all who ride with us! (photo)
- Walking – weekly, [Tuesdays in Belair National Park](#) and new Friday Group ([Consumers and Researchers - Walk & Talk](#)) (photo)
- [Survivors as Teachers program](#) – leading and supporting 17 tutorials/yr involving Adelaide, Flinders & University of SA medical, nursing and health science students
- Consumers in Research program – creating and supporting consumer engagement and opportunities



CVSA becomes involved in a range of projects as well as continuing to undertake our core programs. The range of projects and programs we are asked to participate in grows annually.

- Membership of the
 - SA Chemotherapy Standards Working Group – Chris Christensen
 - SA Cancer Clinical Trials Network – Chris, Julie, Karen van Gorp
 - Cancer Australia Stage, Treatment and Recurrence Steering Committee (STAR) – Dr Agnes Vitry
 - Partnering with Consumers Advisory Group (SALHN) – Chris Christensen
- Presentations at the Survivorship Conference, COSA Conference



Research Related

- [The Australian Roadmap for Digital Health in Cancer Care](#) Consumer rep –Chris Christensen (photo)
- Consumer representative Ovarian Cancer UniNSW Chris Christensen
- Consumer representative for the Ovarian Cancer Research Foundation - Chris
- Review of Grant Applications including input, feedback and review – all Exec Team
- Membership of the SA Comprehensive cancer research consortium
- Membership of the Bowel Cancer Research Interest Group
- Board member – Melanoma Patients Australia – Karen van Gorp
- Board member – Unicorn Foundation (Neuroendocrine Tumours) Jackie Barreau
- Membership of the Reference Group for the Advance Care Directive Research
- Contribution to the Partnering with Researchers project an ongoing project with SAHMRI and Flinders University including planning and preparation of workshops, feedback, analysis and review
- Participation by Agnes Vitry in the Health Translation SA Workshop
- Contribution to the Consumers in Research program
- Ongoing active membership of Julie Marker in the Consumer Advisory Groups of the Australasian GastroIntestinal Trials Group AGITG, Primary Care Collaborative Cancer Clinical Trials Group PC4, and Psycho-Oncology Trials Group PoCoG
- Associate Investigators on numerous grant funded projects and grant applications



Presentations for student and staff teaching, at conferences, events and community groups.

- University of SA Nursing Students – Difficult Conversations – Chris Christensen & Maxine Williams
- Relay for Life – Living with Cancer – Chris Christensen
- Blackwood/Coromandel Rotary Clubs – The work of Cancer Voices – Julie Marker
- Flinders-University of the Third Age – The work of Cancer voices – Julie Marker
- Survivors as Teachers – 15 tutorials/yr at University of Adelaide (Thank you to all who present their insights to the medical students. Without you we would not be able to run our program. Thank you to Julie Marker and Cath Caon for coordination and facilitation throughout the 8 years of this program.)
- RMIT 3rd year radiation science student presentation by Courtney Oake
- Flinders University Masters Students –Health Safety and Quality – Chris Christensen
- Cancer Council Biggest Morning Tea – Chris Christensen
- Flinders University Allied Health students – Living with Cancer – speakers Scott Nussey & Jack Graham, and psychologist Dr Lisa Beatty (photo)
- Conference presentations:
 - Survivorship 2019 Conference –
 - Poster: [Evolution and Revolution, 10+ years of cancer advocacy](#). (a poster celebrating the 10+ yrs history of CVSA) Chris & Julie



- Exploring the experiences of cancer Carers, a panel session led and facilitated by Chris Christensen, with Lesley Shears & other speakers.
- Vikki Bedford was a speaker at the RANZCR Particle Therapy Conference (Royal Australian and New Zealand College of Radiology)
- Clinical Oncology Society of Australia 2019 Conference
 - Why a roadmap is needed for digital health in cancer care – a consumer perspective – Chris Christensen (photo)
 - Breakfast session panels- consumer speakers
 - What is needed to ensure optimal care and outcomes for older people with cancer in Australia – Julie Marker
 - CALLED OUT: Exploring inequalities and improvements for CALD patient access to cancer clinical trials – Girija Nadagouder (photo)



- Poster: [Consumer driven priority setting – A practical example: Are iron deficiency, oxaliplatin and neuropathy linked?](#) Brian Wall & Julie Marker

Operations and Management

Our operations continue to be run as efficiently as possible and we are always grateful for any donations we receive. Thank you to all who have donated in 2019. We cannot survive without your support.

- Executive Team meetings and work mostly via teleconference and emails
- Collaboration with Cancer Voices NSW
- Donation of a Yellow and Black Rug by [Tricia La Bella's Knit a Care Square](#) group, for fundraiser raffle (photo)
- Westpac Foundation Application
 - Westpac Foundation Grant Recipient 2019/20
- Community Achievement Award Application
 - Finalist in the Ricoh-Australia **Customer Service** category, **Community Achievement Award 2019**
- Ongoing management of financial matters thanks to Julie Marker, Con Nakos, Angela Gregory and Maurice Woolard for undertaking this role.



Chris Christensen
Chair, Cancer Voices South Australia



Testimonies to our impact & influence

If I consider how far we have come in 10 years, I think that SA is ahead of some other jurisdictions in our working with consumers, for the very reason that we have had CVSA there to challenge, guide and encourage us along the path of true consumer engagement.

The bringing alive of "nothing about us, without us" has made sure that cancer consumers in SA have a seat at every table, and a voice in every conversation.

We have moved from "should we consider having a consumer voice?" through "where is the consumer voice?" to "ah, good, you are here, with us". So that includes research partnerships as well - real involvement in developing research protocols and being members of the team - almost unthinkable a decade ago.

Professor Dorothy M K Keefe PSM
Interim Director, SA Cancer Service,
Medical Oncologist, Royal Adelaide Hospital,
Professor of Cancer Medicine, University of Adelaide

Cancer Voices had a seat at the table from the beginning of the development of the Flinders Centre for Innovation in Cancer. Their input kept us accountable and focused on making the centre responsive to needs of patients and their loved ones.

Professor Bogda Koczwara AM
Senior Staff Specialist, Department of Medical Oncology,
Flinders Medical Centre
National Breast Cancer Foundation Practitioner Fellow

Cancer Voices SA has been particularly valuable in joining us in planning and participating in cancer research projects. Research is essential to underpin advocacy and the participation of Cancer Voices provides the unique perspective from lived experience that ensures that the questions asked are those most relevant to consumers. This in turn facilitates research translation into policy or and clinical practice and ongoing education of care providers.

Professor Ian Oliver AM
Adjunct Professor,
Faculty of health and Medical Sciences, University of Adelaide