

# Evolution and Revolution – 10+ years of cancer advocacy

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## Introduction

*"It is not revolutions and upheavals that clear the road to new and better days, but revelations, lavishness and torments of someone's soul, inspired and ablaze."*

"After the Storm" (1958) Boris Pasternak

The 'storm of cancer' in our lives has driven the passionate efforts of survivor and carer led, 100% volunteer organisation **Cancer Voices South Australia (CVSA)**.

Established in 2007, for 10+ years we have been 'Raising a voice for people affected by cancer', with a focus on 'Good systems, not just good luck!' and on 'Wellness, not just illness'.

The evolving roles, capabilities, achievements and opportunities for cancer survivors are described, illustrating effective consumer advocacy, engagement and influence at the system, organisation and point of care levels<sup>1</sup>

1. Shifting Gears - consumers transforming health. Consumers Health Forum 2018

[https://chf.org.au/sites/default/files/181125\\_shifting\\_gears\\_-\\_consumers\\_transforming\\_health.pdf](https://chf.org.au/sites/default/files/181125_shifting_gears_-_consumers_transforming_health.pdf)

## Method

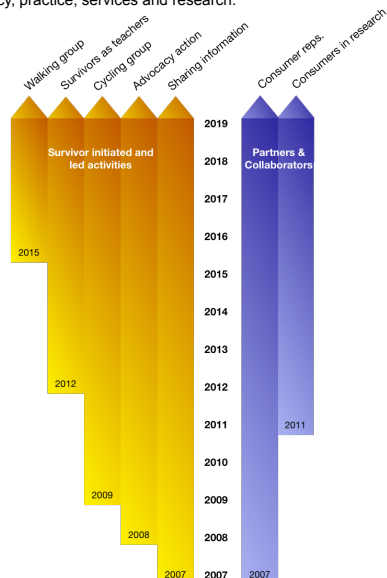
Using qualitative methods, we synthesised the knowledge we have gained about cancer advocacy and the roles of our independent survivor-led organisation in influencing the achievement of better outcomes for people affected by cancer.

## Results

Analysis of the work of CVSA since its inception identifies a number of key elements. We have:

- **built strong relationships** with people affected by cancer, as a solid support network and a reliable information base
- continued to **learn from each other** and provided our members with opportunities to become involved in our advocacy work and core programs
- **raised awareness and knowledge** of cancer related matters through innovative channels eg. social media, cycling group
- focused on wellness not just illness which enables regular personal engagement with people affected by cancer and in the community
- increased our profile as an organisation of integrity, experience, reliability and commitment.
- **focused on quality, safety, access and equity in treatment and care**
- increased education and training using cancer survivors lived experience
- increased involvement of cancer survivors in research
- we have developed the **knowledge, skills and experience** needed to work with the cancer health and research system.
- we have become **resilient, adaptive, aware, involved, innovative and capable**.
- we work **collaboratively and constructively with cancer survivors, carers, health professionals, researchers and policy makers, because together we are stronger** and have more capacity to influence change.

Core activities have grown and evolved, including innovative survivor initiated and led activities (Survivors as Teachers, Cycling and Walking groups) alongside our work as constructive collaborators and partners around safety and quality of care, policy, practice, services and research.



## Timeline of key activities, influence and advocacy



## Impact

By using our collective lived experience as a driver for change, we have achieved the following outcomes:

- **increased active involvement, representation and reflection of the views of people affected by cancer** in relevant cancer forums, committees and conferences, education programs, wellness programs, research projects, reviews and inquiries at the local, state, national and international levels
- diversity in **working relationships and collaboration** with key individuals, organisations, service providers, policy makers, researchers, health professionals and people affected by cancer
- promoted and **improved quality, safety, access and equity in cancer diagnosis, treatment and care**
- increased our capacity in **knowing who and how to influence and to act and respond**, especially when issues arise
- sustained utilisation of **innovative approaches to sharing information** and increasing awareness of cancer related matters eg. via social media, regular personal connections with people affected by cancer and dissemination of information through our networks
- increased involvement and ongoing relationships with cancer researchers, policy makers and health professionals to support improvement and innovation, through representation on governance groups, working groups, committees
- increased education role through the "Survivors as Teachers" program which brings the lived experience of people affected by cancer to students in the medical and health professions and grows the capacity and development of people affected by cancer who present these education programs.

*"It may be the foot soldiers rather than the generals who are the key to change."* "Dementia: Evolution or Revolution?" (2010) Glenn Rees

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

## Conclusions

An expanding and evolving range of core activities have established our influential consumer roles<sup>1</sup> as

- **Change Agents,**
- **Policy influencers,**
- **Community Mobilisers,**
- **Co-designers,**
- **Research Collaborators,**
- **Educators**
- **Experts by experience** – including our
  - experiences of wellness and illness, alongside
  - experiences of health systems & services.

By reflecting the diversity, knowledge and experience of those affected by cancer, CVSA has been able to promote the views of cancer survivors, their partners, family, friends, colleagues and supporters across all cancer types and stages to influence and improve a broad range of issues across the cancer continuum.

We seek to be equal partners in cancer research, policy and services – as well as leaders and motivators to inspire participation of people affected by cancer across the community.

## What next for Cancer Voices SA?

As we look to our next 10 years, we propose 5 aims to positively impact the lives of people affected by cancer:

- **revolutionise the power of consumers** by recognising their lived knowledge, skills and experience and harnessing this at all levels of decision making
- achieve effective and timely **information and communication** eg. patient reported outcomes enabled by technology
- provide **holistic care and a patient centred culture** to assist the physical, psychological, emotional, social, spiritual and practical life matters as well as support for self management for changing needs throughout the cancer continuum
- **education and alliance with people diagnosed with cancer** to enable them to participate in informed decision making about their treatment in ways that they want
- **coordination and integration of care** where a multi-disciplinary approach is embraced, **where new evidence rapidly results in improved practice and standards of care**, and precision medicine, genetic testing and counselling results in improved treatment options.

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 Koelle PSM  
Interim Director, SA Cancer Service,  
Medical Oncologist, Royal Adelaide Hospital,  
Professor of Cancer Medicine, University of Adelaide

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 clinical practice and ongoing education of care providers.

Professor Ian Oliver AM  
Adjunct Professor,  
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## For further information

Cancer Voices SA is a 100% volunteer organisation led by people affected by cancer. Through advocacy, involvement, sharing information and raising awareness we aim to improve the outcomes and experiences of cancer.

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