

The Australian cancer consumer advocacy movement

Celebrating twenty-one years: 1994-2015

What's it all about?

The independent cancer consumer advocacy movement in Australia provides a voice for people affected by cancer. It has a proud record; one we think deserves to be noted and celebrated at our twenty-first year. A hallmark of our achievements has been sharing with the "cancer world" the goal of improving the cancer experience through influence in the areas of diagnosis, information, treatment, research, support and care.

"Nothing about us without us!"

Why do some of us with cancer feel the need to get involved in advocacy when there are perhaps more obvious ways to give back, such as through volunteer support or donations to research? Consumer advocacy – at local, state and national levels, allows us to make a real and visible difference to the cancer experience of many, by making sure the informed view of people affected by cancer is right in the decision-making mix – for any decisions with an impact for us. Some call this the "essential perspective". The evidence shows that meaningful consumer engagement is a win-win for all, with improved outcomes and experiences for those affected by cancer, more patient focussed research and aiding the building of a trusted, responsive health service.

Who are we and what do we do?

Credibility is essential if the consumer voice is to be taken seriously by stakeholders – government, cancer services, health professionals and charities. Maintaining credibility has served the movement well since 1994. Ideally the voice comes from voluntary consumer organisations whose aim is solely to offer that view through:

- nominating informed, trained consumers to committees, research projects, advisory groups, boards etc. who can provide the broad view
- attending and speaking at cancer forums and conferences
- contributing to government inquiries and processes
- responding to media questions and debate
- developing & publishing position statements on consumer identified issues, and
- a strong, well connected consumer network.

This presentation concentrates on the development of the key players and their common aims. We look at how they went about building the capacity of the independent cancer consumer voice, and acquired a respected profile and presence. Other consumer related organisations, whose main function is information, support and/or research funding, may also facilitate a group of consumers to undertake advocacy in their area of interest. Whichever profile, twenty-one unbroken years of cancer consumer advocacy is well worth celebrating; we outline how and why it all began, and how it has diversified and flourished since.

Australian Cancer Consumer Network (ACCN): a much larger (30) group of cancer consumer related organisations and was officially launched at Parliament House, Canberra on 26 November 2014. It published a directory *Who's Who of Cancer Consumer Groups* which enables Members of Parliament and other interested stakeholders to find them. The ACCN's purpose is to share information and ideas, alert each other about opportunities to participate in national cancer related forums and activities – and most of all to be able to muster an even louder voice on national issues if and when necessary.



Cancer consumers meet Parliamentarians, Canberra, 26 Nov 2014

Most ACCN groups are survivor-led, voluntary and represent a lot of cancers, both common and rare. A few come under the umbrellas of Foundations and Institutes with their own roles and funding sources, but which also facilitate a consumer voice. These differences need to be recognised. Strength through independence, financial and in purpose, has proven very compelling, especially when talking to government and politicians.

How do we do it?

- **Partnering** with other organisations and stakeholders which have similar aims on specific issues, or which have the resources to implement policies, projects and change.
- **Training** for consumers to gain the confidence and skills to take their place as representatives of the broad consumer view at decision-making tables or to work with researchers.
- **Matching** informed, trained consumers to requests from stakeholders, for projects, policy development, service & support improvement and research studies.
- **Engagement** in discussion, debate, planning and conferences means the voices are heard by decision-makers, many of whom now require evidence that this has occurred.
- **Communication** through newsletters, speaking, conference presentations, training advice, position statements, media response, websites and social media.
- **Scoping** our members and networks' issues to underpin and direct our advocacy
- **Participation** supports the concept of "nothing about us without us"

What have we achieved?

From the beginning, the movement's objectives have been clear: to improve the cancer journey and outcomes in the areas of diagnosis, information, treatment, research, support and care. To achieve them we have worked in partnership with decision makers and providers of the services, ensuring the patient perspective is heard from planning to delivery.

Achievements have been notched up under all these objectives. We take particular pride in our success in improving:

- access to multidisciplinary cancer treatment and coordinated care
- the range and quality of information for cancer patients, including guidelines, directories of specialists and clinical trials, eg Australian Cancer Trials and CanRefer websites
- more support, coordination and survivorship services
- the direction and value of research
- policies for cancer services (eg Optimising Cancer Care NSW)
- funding for new comprehensive cancer centres
- public debate re human gene patents and access to medical cannabis
- programs for nominating capable consumer representatives
- capacity building through training in advocacy, representation and research
- access to superannuation tax free for all people dying, at any age, of a terminal illness
- matching service to researchers to help meet the requirements for consumer involvement of funders, via Cancer Voices' websites.

Conclusion

Cancer is a major health priority for Australia and Australians. It is now the single greatest cause of death (ABS) and sees over 120,000 new diagnoses (AIHW), with some hundreds of thousands of people living with their cancer.

It was, and is, overwhelmingly necessary that the voice of those affected by cancer be heard by decision-makers towards improving the cancer experience for Australians, their families and friends; most importantly in the areas of diagnosis, information, treatment, research, support and now survivorship. This has been the goal and the achievement of the Australian cancer consumer movement which is celebrating its first twenty one years of successful advocacy.

References

1. Cancer Australia's & Cancer Voices Australia's *National Framework for Consumer Involvement in Cancer Control* notes "the evidence is that where consumers are viewed as equal and integral members of health services, cancer research groups and policy development, there will be improved outcomes and experiences for those affected by cancer. In addition, meaningful consumer engagement can build a trusted and confident health service."
2. S Crossing: *Celebrating 20 years of the Australian cancer consumer movement, 1994-2014*, Cancer Forum Vol 38, no 3, Nov 2014.
3. Examples are detailed in consumer groups' newsletters and in publications eg. *A Decade of Success: Cancer Voices NSW 2000-2010*, ISBN 978-0-646-55881-3, and *Women for Women with Breast Cancer: Breast Cancer Action Group NSW 1997-2007*, ISBN 978-0-646-48431-0.

Milestones 1994-2015

Breast Cancer women lead the way

1994

The Breast Cancer Action Group (BCAG) began it all and shaped the Australian model of volunteer, survivor-led cancer consumer advocacy.

1995

BCAG's first and successful campaign was to get Taxol for breast cancer onto the PBS.

1995

The National Breast Cancer Centre (NBCC) was established; along with a Consumer Advisory Group of representative women from all states and territories.

1997

Breast Cancer Action Group NSW (BCAG NSW) established, based on the Victorian model

1998

A visit to Washington DC in 1998 to learn about advocacy, with encouragement from Hillary Clinton.

1998

NBCC seed-funded development of a nation-wide consumer organisation: the Breast Cancer Network Australia (BCNA) began, growing to 90,000 supporters today.

The cancer consumer voice goes generic

2000

Recognising that most people with cancer faced very similar issues, the Cancer Voices movement took off, initially in NSW and soon after in the other states – NSW, VIC, QLD, SA, WA and ACT (subsequently two name changes; Cancer Action Group in VIC and CanSpeak in QLD).

2001

BCNA led the successful campaign to have Herceptin made available without cost to women (HER2 positive) with advanced disease.

2002

BCAG NSW published the first Directory of Breast Cancer Treatment & Services

2005

Cancer Voices begins its Consumer Involvement in Research Program: training, matching and priorities.

2005

Cancer Voices Australia established to provide a voice on national level issues for the states' Cancer Voices organisations and their members.

2007

A seven week campaign led by three BCAG NSW members influenced a change in federal legislation to allow access to superannuation tax-free for all people dying of a terminal illness.

2014

Australian Cancer Consumer Network (ACCN) launched, facilitated by Cancer Voices Australia.

Finding cancer consumers

Find informed cancer consumer representatives by contacting Cancer Voices at
E: info@cancervoices.org.au

For more information, or contact details for cancer consumer organisations, generic or specific. See website www.cancervoicesaustralia.org.au for a link to the ACCN Who's Who Directory 2014.



cancer voices australia

cancer voices nsw