The CanAct Community

The Cancer Council NSW model for winning through evidence plus people power
Have you spent years trying to convince a government department to bring its policies in line with **best practice evidence**, only to be met by a wall of **bureaucratic indifference**?

Are you impressed by the dedication of your supporters and volunteers who happily contribute their time and energy to **raise awareness** or money, and wonder how you could harness that for **lasting impact**?

Have you been frustrated by the lack of political interest or political will to take action even when opinion polls show **public support** and the **evidence** is clear?

Cancer Council NSW has experienced all these scenarios (and more) and has developed a model to engage, mobilise and organise community members to influence public policy about cancer.

While the context of our model is health specific, some of the principles and processes are relevant for other social issues. You can use our model of grassroots advocacy as a starting point, and develop ideas to suit your own organisation.
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In brief
The Cancer Council NSW CanAct Community is the name and identity of the group of people from across NSW who are interested in persuading decision makers to change policies, programs or funding around cancer issues.

Membership
As at July 2017, around 26,000 people were part of the CanAct Community (defined as people with an active email address and/or mobile phone).

Who joins the CanAct Community?
While many members or their family or friends have been diagnosed with cancer, others join because they care about healthy living and cancer prevention, or believe the health system could do more to help people in need.¹

How do people join the CanAct Community?
- by participating in the two day Community Advocacy Training workshop, which is provided in a generic format or tailored to an Aboriginal audience
- by taking a campaign action (e.g. a photo pledge, petition) and agreeing to have their details added to the CanAct database
- by accepting a specific role such as MP Liaison or a campaign leadership role
- through the supporter survey (conducted biennially), which asks donors to indicate if they are interested in Cancer Council NSW campaigning work
- by responding to invitations to join the CanAct Community via an approach from another part of Cancer Council NSW e.g. Relay for Life, a communication to donors, or the volunteer newsletter, Volunteer Voice.
- through information provided via the cancer consumer group in NSW (Cancer Voices) to its membership

How are members kept up-to-date?
Email and Facebook are used to inform members about campaigns and developments. All members are encouraged to participate in training (e.g. community advocacy training), to become involved in their local networks, and/or to take on specific leadership roles or to take specific actions for campaigns.

All members are invited to participate in campaigns by one or more of the following actions:
- taking an online action (e.g. email your local MP)
- taking an offline action (e.g. having your photo taken for a campaign)
- being part of a team running an action (e.g. attending Relay for Life and collecting photos or signatures, organising a launch or community event for a campaign)

¹ A survey of members in 2014 found that 30% have a direct, personal experience with cancer; 47% had a family member or friend affected by cancer; and 10% identified as being a primary carer.
Why build grassroots advocacy

In the early 2000s, Cancer Council NSW first developed and offered specialised training for community members interested in advocating on cancer issues, in partnership with Cancer Voices NSW. In the beginning, Cancer Council NSW did not follow-up to participants, and they returned to their communities to apply what they had learnt.

In 2005, a review of the community advocacy training program and a survey of past participants, revealed that despite initially being excited and inspired by the training, participants had not applied their training due to lack of support. Many felt isolated and said they needed to be connected, both to the organisation and to other advocates, for momentum and motivation to use their skills.

At the same time, the organisation realised that creating and supporting a widespread community voice on cancer issues would be an important way to build lasting change for cancer.

Based on the feedback from participants and our desire to build an active constituency for advocacy on cancer issues, we established local advocacy networks (known then as Regional Advocacy Networks and now as Cancer Advocacy Networks). These Networks are geographically based, provide a forum for people to convene around common interests, and to support each other in collective grassroots campaigns.

“Time and time again, we have seen that inviting the community to be part of our campaigns, and developing community leadership in advocacy, has helped to not only improve cancer policies in NSW, but also strengthen our relationship with the community. Grassroots advocacy has become a key part of how we engage on cancer policy issues, and in the community.”

Jim L’Estrange, CEO
Key structures and options for participation
People can participate in the CanAct Community in a range of ways, including:

- the local Cancer Advocacy Networks
- a closed Facebook group for leaders
- an open CanAct Facebook page.

Key roles have been developed for members of the CanAct Community to encourage and support higher levels of engagement. These roles include Network Facilitators and MP Liaisons, as well as campaign specific leadership roles as required.

Local Cancer Advocacy Networks
The purpose of local advocacy networks is to connect passionate local people with each other to:

- act as local voices and eyes and ears for cancer-related issues
- identify and campaign on local issues that need to be resolved
- run local actions in support of statewide or national campaigns.

How they work
Generally, networks meet monthly or every second month. They are facilitated by a local community member or a leadership team of community members.

Local Cancer Council NSW staff support Network activity and often provide strategic advice to the local groups considering issues and campaign strategy. This provides a strong link between the interests of the organisation and the work of local Networks. Networks are more vibrant when they are working on engaging local issues as well as supporting statewide or national campaigns.

Members of local Cancer Advocacy Networks discuss local campaigns at the launch of Cancer Council NSW’s 2015 State Election campaign
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The activities of the Cancer Advocacy Networks must include the following factors:
• all local campaigns must be evidence-based and solution-oriented
• campaigns must be aligned and not in conflict with Cancer Council NSW position on an issue
• Cancer Advocacy Networks apply a process of exploring and agreeing on local issues and strategy, so that campaigns and actions reflect the collective perspectives and interests of members.

MP Liaison Program
The MP Liaison program connects a trusted Cancer Council NSW volunteer to their local MP, to become an ambassador for Cancer Council messages, including advocacy ‘asks’.

The MP Liaison volunteer is responsible for establishing a strong, positive, ongoing and mutually beneficial working relationship with their local MP, on behalf of Cancer Council NSW. The aim is that the MP will develop a stronger affinity for Cancer Council NSW and therefore be open to, and positive about, our recommendations for policy action.

Insights from MPs helped develop the MP Liaison program. These included:
• the importance of localising issues and relationships
• accountability that comes from knowing the person making the ask is a local.

The program also uses the principles of reciprocity, with the MP Liaison offering support and opportunities beneficial to the MP (media exposure, brand association, and timely access to information), as well as requesting support from the MP on policy issues.

While MP Liaisons have often volunteered with Cancer Council NSW in other roles, the high-risk and important nature of the role means they go through a...
rigorous selection and training process.

**Recruitment:** There is a formal process of application, interview and approval. Selection is based on being able to represent the broad range of interests of Cancer Council NSW while managing their own personal political views as Cancer Council NSW is non-partisan.

**Training:** Complete a one-day course.

Since the beginning of the program, Cancer Council has acknowledged that the MP Liaison role is not suitable for every volunteer. If a volunteer cannot be recruited in a particular electorate, then the MP is not assigned one.

MPs are advised that they have been assigned an MP Liaison, and a letter of introduction is sent from the CEO to the MP.

MP Liaisons receive regular communication from the Policy and Advocacy team at Cancer Council NSW, and support from local staff.
Segmenting the CanAct Community membership
As with any group, individuals have varying levels of interest and commitment to activities. Cancer Council offers a range of ways to keep people engaged at different levels of commitment, while also encouraging people to ‘step-up’ to the next level of involvement.

The segments of participation are reflected in the circles of commitment diagram below.²

**KEY:**
- **CORE** – community leaders. Take highest action AND organise others in action
- **COMMITTED** – those that take higher level action (eg RAN/ CAN members, advocacy trained, active individuals)
- **CONGREGATION** – those that take action
- **CROWD** – members of the CanAct community
- **COMMUNITY** – those connected to Cancer Council NSW (eg donors, RFL, ABMT volunteers)

**CLOSER TO THE CORE:**
- Meeting with decision makers
- Handling media
- Organising other advocates
- Local campaigning by Cancer Advocacy Networks
- Running events

The tasks described above are:
- Harder to do – require more skill or commitment, so less take part
- Shows the issue is deeply felt (people care ALOT)
- Greater political impact
- Transformative – actions at these layers grow an individual’s skill and capacity and the effectiveness of the CanAct Community
- What we would call “community organising”

**MOVING AWAY FROM THE CORE/COMMITTED:**
- Standard email, letter, photo pledges and petitions

The tasks described above are:
- Easy to do, so many people will take part
- Shows issue is widely felt (lots of people care)
- Limited political impact
- Largely transactional – participants skill and commitment does not grow as a result, but these actions grow the community in size and provide an easy first step for people to take
- What we would call “mobilising”

- Email updates are sent to all CanAct Community as needed. They are used to inform, invite, feedback, and celebrate achievements. We deliberately decided against a regular interval newsletter, in favour of an ‘as needed and relevant’ approach.
- At local Cancer Advocacy Network level – there is a much higher level of contact and participation and communication. Face to face meetings, email lists, Facebook groups or pages.
- At leadership level – there are statewide gatherings, closed Facebook group, specific training, teleconferences, strategy advice and feedback.

² The Circles of Commitment concept has been adapted from Warren, R. The Purpose Driven Church: Growth without compromising your message and mission. 1995. A summary of key points of relevance for campaigning is available here: http://www.jrmyprtr.com/wordpress/wp-content/uploads/2014/01/purpose-driven-campaigning.pdf
Impact of the CanAct Community

Since 2002, Cancer Council NSW has adopted approaches that mobilise and organise community members for advocacy action on cancer-related issues.

In that time, grassroots advocacy and the CanAct Community have played key roles in securing government responses including:

- removing the exemptions for pubs and clubs under the Smoke-free Environment Act (announced 2004, effective 2007)
- securing legislation to remove cigarettes from sight in shops (announced 2008, effective 2009)
- securing legislation for a wide number of smoke-free outdoor areas (announced 2012, effective from 2013)
- updated and improved policy for sun protection in public schools (2013)
- improvements to Isolated Patients Travel and Accommodation Assistance Scheme, a financial assistance program for country patients who need to travel for specialist health care (2006, 2011, 2012 and 2015)
- increased funding for bowel cancer screening (2012)
- ban on commercial solariums (announced in 2012, effective 2014)
- abolishing co-payment for chemotherapy and other highly specialised drugs charged to patients. Both major parties announced a policy in the lead up to the March 2015 state election, in line with our policy recommendation. From 1 October 2015, tens of thousands of patients benefitted from this change, with patients being better off by around $1400 per annum. The cost to government is $76 million.
- a record $100 million investment into palliative care in NSW, as part of the 2017-2018 NSW Budget (announced June 2017, effective July 2017)

At a local level, campaigns by local Cancer Advocacy Networks have led to:

- Free and dedicated car parking spots for cancer patients at certain hospitals
- Enforcement of smoke-free zones at hospitals
- Local councils adopting smoke-free outdoor area policies
- Additional services for lymphoedema patients at a local hospital
- Reinstated visiting medical specialist services in a rural region

“I’m just lucky to be given the chance to voice the issues and experiences that like so many, we have faced.”

(Nicole, a community advocate, after being part of a delegation to meet with Premier Baird in early 2015)
While it can be challenging to quantify the impact from these wins, a few measures include:

- An additional 11,500 patients in NSW benefitted from extending the eligibility criteria for IPTAAS in 2006³
- Tens of thousands of people who use Highly Specialised Drugs in NSW will benefit from the abolition of the gap fee⁴
- All pub and club workers in NSW were protected from second-hand smoke at work. We had calculated that at least 75 pub and bar workers in NSW were dying each year as a result of exposure to second-hand smoke while at work⁵
- All children in NSW aged between 5 and 12 years, who spend 7 hours a day for up to 40 weeks a year, and are now better protected from the sun during this time. There are 600,000 children in primary school alone in any one year
- at least 35,000 bowel cancer deaths prevented with the additional $95.9M investment into free bowel cancer screening⁶.

Frequently Asked Questions

What are the demographics of the CanAct Community?
In 2014, a survey of CanAct Community members’ found that:
- average age of members was 56 years, with just 7% of members under 30 years
- majority of members were female (70%)
- almost half (43%) the members live in Sydney
- CanAct members tend to be highly educated, with 44% holding university qualifications, and 22% with post-graduate qualifications
- Over half (56%) are in paid employment, with 30% working full-time
- One-third (33%) are retired
- Proportion of members who identify as being of Aboriginal or Torres Strait Islander descent is 2%, roughly matching population levels
- Over half (58%) of the respondents have no regular care responsibilities, and only 22% have dependent children.

Other characteristics and trends of interest:
- The majority (91%) of members support an active government. This means that CanAct members are more in favour of government action than the general population (65%)
- Almost three-quarters (73%) of members are involved in one or more community groups or activities in addition to the CanAct Community
- Voting intention was divided equally between the two major political parties
- Just over one in three (34%) believe that they can make a big impact on their community being a better place to live, with 40% believing they can make a moderate impact
- Almost all (97%) agree with the statement “Individuals have a responsibility to act and try to improve their local community, just as the government does”
- 79% of members would recommend that others join the CanAct Community, with active members far more likely to do so (87%)
- Members rated Cancer Council NSW as good in terms of communicating with CanAct members about how to get involved in specific campaigns (74% good); and in providing simple ways to get involved in campaigns (72% good).

Why does the CanAct Community have a name and separate identity?
Grassroots advocacy and campaigning is a specific function in Cancer Council NSW, aligned with the key strategic priority of ‘advocacy’. The people who accept responsibility for being part of our advocacy efforts deserve specific recognition. Those who are actively involved relate to, and value, the CanAct identity, including wearing their CanAct t-shirts with pride.

Cancer Council NSW trains and supports the CanAct Community, and it is visually linked to the organisation by use of the daffodil and the brand colours.
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The key benefits of giving this work and the people involved a specific name and identity include:

- a sense of community. Research shows that it is important for people to feel that they are part of something larger, and to have a recognised identity and a platform for building relationships with people of similar interests.
- it distinguishes this form of action from those more commonly associated with volunteering or supporting Cancer Council NSW e.g. donating, fundraising.
- makes visible the accumulated impact of grassroots advocacy as the various campaign wins can be attributed to the CanAct Community.
- defines the role of those involved, while allowing for the diversity of involvement. There is no single ‘role’ that captures all the options under the CanAct Community umbrella, so a collective term is more efficient.
- provides a community-based face to the advocacy work.

How do we train and support the CanAct Community?
Cancer Council invests in regular face-to-face training opportunities for the CanAct Community, both to attract new members and to offer ongoing development for existing members of the CanAct Community.

The standard training options include:

- Community Advocacy Training – two day workshop offered 3-4 times per year, in collaboration with Cancer Voices. The workshop covers key topics relating to advocacy and campaigning, as well as sessions about cancer policy and decision makers. Participants learn about the impact of consumer advocacy, the processes of policy making, MP engagement, public narrative, and campaign planning. The workshop includes interactive sessions and practical activities.
- Aboriginal Community Action (Advocacy) – a tailored version of the Community Advocacy Training workshop designed and co-facilitated by an Aboriginal person, for Aboriginal people. This program was developed in partnership with the Aboriginal Health and Medical Research Council (AHMRC) in NSW.
- MP Liaison training – a one day program for volunteers suitable for the role of MP Liaison. Training covers building influence with your MP, understanding the role and perspective of MPs, public narrative, opportunities for political engagement of relevance for cancer issues, and MP engagement protocols.

Other development opportunities for CanAct members have included:

- Leadership gatherings – held every 18-24 months for CanAct members with leadership roles such as Cancer Advocacy Network facilitators and MP Liaisons. These have tended to focus on developing leadership and community organising skills including team building and team structure, relational conversations, and public narrative (e.g. Camp CanAct).
- MP Liaison Summits – occasional convention for all MP Liaisons to provide further skill development and gain input on political engagement strategy (e.g. Power in Partnership).
- Specific development workshops for leadership roles associated with particular campaigns such as pre-election campaigns (e.g. Planning 4 Change, Unite 4 Change).
- Scholarships to relevant conferences, offered on a competitive basis to leaders in the CanAct Community.

8 Han, H How Organizations Develop Activists, 2015 p147-151
9 Some of the items on this list were one-off, or discontinued.
• CanAct Conversations – an occasional series of evening seminars with guest speakers
• Circulating information about externally hosted professional development opportunities of relevance where there is little or no cost.

How do the local Cancer Advocacy Networks operate in practice?
Local Networks vary in their size, vitality, and structure. While we encourage a basic approach, we also recognise that groups need to develop in ways that will reflect their membership and local circumstances.

Key elements we strongly encourage in all local advocacy networks include:
  • Local community leadership – whether the group has a single facilitator/chair, or a leadership team, these roles are fulfilled by members of the community, not by Cancer Council NSW staff
  • Support from local Cancer Council NSW staff to the Network and its leadership
  • Establishing a regular meeting schedule that suits the members and the level of activity of the group
  • Making time for relationships and socialising, at the meetings themselves, and outside of formal meetings
  • Providing ways for everyone to participate and contribute i.e. sharing work and responsibility.

Factors of an effective Cancer Advocacy Network include:
  • Strong and active facilitator
  • Regular attendance by sufficient numbers of people good local staff support – for the facilitator, for logistics and for recruitment of members
  • A local issue to focus on a relational culture (relationships between members, commitment to each other and as well as common issues of interest)

Where some of these factors are missing, Cancer Advocacy Networks may be less able to function effectively, and additional support may be needed. It is normal for networks to go through periods of growth and decline.

How does the CanAct Community add strength to our work?
• Impact: we have been able to build stronger relationships with a wider range of MPs because of the CanAct Community. Our successful campaign outcomes have markedly increased in line with the depth and sophistication of the CanAct Community and our grassroots campaigning.
• Reach: provides physical and ongoing presence across NSW, far in excess of anything that could be achieved through paid staff alone.
• Community voice and perspective: having many community members supporting our cause and our message. For many issues, having community members actively participating in public policy debates and processes is an essential counterweight to vested commercial industries (e.g. Big Tobacco).
• Connections: network and ripple effect because each member of the CanAct Community brings their own social and professional connections that enables them to spread the word and engage in action.
• Credibility: that comes with lived experience and personal stories of community members.
• Constituency: MPs care about the things that matter in their own electorates. CanAct members are able to talk to MPs as constituents, explaining how policy issues decided in Macquarie St (or Canberra) affect people in their own backyard.

All this adds up to a significant impact on strategic goals that benefit the organisation and our cause.
How are CanAct Community decisions made e.g. how to decide on campaign issues (State or local)?
For statewide, centrally managed campaigns, the Policy and Advocacy team is responsible for deciding on campaigns, taking into account input and suggestions from others in Cancer Council NSW. Selection criteria for grassroots campaigns include:
- evidence of a problem
- clear policy solution within the power of the relevant authority (generally the state government)
- community interest in the issue.

Other considerations include – is the impact and benefit for the community significant; addressing disparities in health outcomes, and should Cancer Council NSW have a supporting or lead role on the issue.

Since 2012, we have included a process that engages the CanAct Community and other internal stakeholders in helping to prioritise issues for campaigns.

What guidance is provided to the CanAct Community to ensure that local campaigns, and individual actions taken by advocates, are appropriate?
Cancer Council NSW guides and supports the CanAct Community through the following:
- opportunities for training and development (2 day community advocacy training, specific campaign training, scholarships for conferences, role training)
- resources, tips and guidance for campaign actions and input into campaign planning processes
- a clear policy advocacy agenda
- shared campaign strategy and specific calls to action
- a website and Facebook page.

CanAct members with leadership roles are registered as volunteers, and subject to a Code of Conduct, and work to an agreed Position Description.

Appointment to a number of high impact leadership roles involve an Expression of Interest and a rigorous selection process to match individuals to specific roles. Examples include – MP Liaisons, local campaign leaders, participation in leadership summits, and sponsored conference attendance.

What staffing resources are required to support CanAct Community?
Cancer Council NSW, like many state and national non-government organisations, has centralised functions (including the Policy and Advocacy team), and regional offices providing a physical presence, delivering programs and outcomes for the local community.

The Policy and Advocacy team is responsible for Cancer Council NSW’s advocacy strategy – identifying key policy issues for advocacy (in consultation with Cancer Council NSW staff and the CanAct community), training of CanAct members, campaign strategy, community organising and mobilising strategy, political engagement strategy, mass communications with CanAct members.
Local Cancer Council NSW staff are key partners in delivering on policy and advocacy outcomes. Together with the staff from the Policy and Advocacy team, local field staff:

- recruit community members to attend training, fill specific leadership roles and the CanAct Community in general
- assess local political opportunities and relationships, and local political engagement
- support local Cancer Advocacy Networks and leaders, including meetings and local campaigns
- integrate state campaign actions into other Cancer Council activities such as fundraising or local events
- engage local media
- relationship management with and between local CanAct members.

All new regional staff are orientated to the advocacy function and encouraged to participate in the Community Advocacy Training workshop as soon as practicably possible. Each regional staff member responsible for advocacy is supported by a specific member of the Policy and Advocacy team, as well as from the team as a whole.

Members of the CanAct Community with specific leadership roles (Cancer Advocacy Network facilitator, Cancer Advocacy Network member, MP Liaison) and are registered volunteers, are also closely supported by staff from the local Cancer Council NSW office.

How do politicians react to the CanAct Community? Does it jeopardise the organisations relationship with political decision makers?

Sometimes, non-government organisations are fearful about community members becoming actively involved in advocacy and interacting with MPs. Our experience has been that with the appropriate support and guidance, community members add enormous value and impact to the advocacy efforts of non-government organisations.

MPs and staff of MPs confirmed the usefulness of community members working together with Cancer Council in a qualitative evaluation undertaken on behalf of Cancer Council NSW. Comments include:

- “There is not a health advocacy group organised in the electorate. The Cancer Council is doing that”
- “Instead of being lobbied by the guy in a suit... we are actually spoken to by an individual from our communities.”

The former Minister for Cancer (Verity Firth) led the 2008 reforms on banning the display of tobacco in stores, despite concerted opposition from the tobacco industry and retailers. In a public address in 2015, she reflected that community activism was key to securing these reforms: “if you want to defeat big money interests, you need to show public support. We knew that we had to build community momentum, and this is where Cancer Council NSW was absolutely brilliant and organised on the ground. Cancer Council had events at schools, rallied their membership, created media opportunities.”

The Hon Jillian Skinner, Minister for Health in the O’Farrell and Baird Government has publicly acknowledged the strong advocacy efforts of Cancer Council, including the focus on engaging the community in campaigns.

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10 Keynote address to Sydney University School of Public Health Research Presentation day 28 September 2015
11 Including in her address to the Cancer Council’s 60th anniversary celebration in 2015
How does the work of the CanAct Community overlap with other functions of Cancer Council NSW?

Interaction with other functions and teams of Cancer Council NSW:

- regional network and staff who are responsible for engaging communities in different parts of NSW – support local advocacy networks and campaigns, recruit individuals to training, support leaders
- close link to donor management – include achievements and campaigns in retention e-news to regular donors;
- events – always look for opportunities to cross-promote, and to include actions for campaigns in events (particularly Relay For Life)
- media and communications (including digital) – generally a core part of any campaign team
- patient programs – source of intelligence and insight on the dimensions, scope and nature of problems affecting cancer patients; source of promoting actions and campaigns; and recruitment for CanAct Community.