

## Impacting cancer through community engagement

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Jenny Beach has worked for Cancer Council NSW since 1997, starting as a Regional Programs Coordinator in Orange. Since that time she has worked as the Regional Manager in the Western Region NSW, managed cancer related health policy, and helped establish regional networks. She currently works as Director, Statewide Services Division where she leads a network of ten regional offices spanning metropolitan, regional, rural and remote communities in NSW. Here they focus on enabling each community to adapt Cancer Council NSW strategic directions to the local context so it works for them and the people in their community or region.

Prior to working with Cancer Council, Jenny worked throughout rural and regional NSW as a registered nurse, in regional media, and in a variety of small businesses.

Jenny was born and has lived most of her life in Western NSW. She is a passionate advocate for services in rural and regional NSW, and believes that community connections and local leadership hold the key to creating social networks and change. Her divisional strategy is guided by the belief that the greatest difference can be made by treating cancer as a social issue, where every one of us can make a contribution to this change.

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### Background

Much of what leads to cancer is socially determined and is therefore no longer the singular domain of health professionals but rather the responsibility of each and every one of us.

Despite the numerous advances made in diagnosing and treating cancer in recent times, and increases in information regarding how to prevent cancer, people in communities are still inclined to think ...“It won’t happen to me”.

This belief changes dramatically for all concerned when faced with the reality of a diagnosis of cancer; for the individual, friends and family there are many questions and much confusion. Then follows disbelief, fear, anger and acceptance as they face decision making, upheaval, change, uncertainty and challenges that they had never believed would happen to them. Throughout all of this, the greatest benefit and support can be offered by an informed network of connected individuals and communities.

As rural, regional and remote Australia changes in terms of social and economic maturity, communities are beginning to rethink their networks and assets, and work on moving their beliefs and passions into fact-based actions. So when we deal with health issues, we must rethink the way in which we provide the support to enable these communities to change, to build capacity and ownership, and to act. Communities are the new superheros in saving thousands of lives every year.

Hallmarks of healthy communities start with connection. A connected community has **energy and vitality**. Amongst other things, “Vitality relies on communities “rethinking” assets, developing networks, building local cooperation and acting on local passion and motivation”. Therefore current approaches to treating cancer in rural and regional areas may be partial, and focus largely on cancer as a disease. By tackling it in a more comprehensive way, we can assist people to act on their passion and motivation, and build community confidence in their ability to change the lifestyle, the decisions, and the outcomes. It is important in taking this approach to begin to understand community values, to find new ways for people to get involved and contribute, and to re-evaluate perceptions. This is the point where we begin to talk about community organising, unity and participation, and volunteerism.<sup>1</sup>

An engaged community can change the state of cancer throughout the entire spectrum of life. Together they can provide the social change necessary to understand what causes cancer, to increase the behaviours and environments that prevent cancer and to support people through cancer.

## About cancer and Cancer Council NSW

Cancer remains, and will remain the biggest killer worldwide, with 1 in 2 people expected to get cancer in their lifetime by 2020. In high income countries it is expected to increase by 26% and in underdeveloped countries by 200%.<sup>2</sup>

The real changes in outcomes lie in prevention—it is unanimously agreed that 50% of cancers are preventable, but some people say it is much more. This is where communities can exercise the social change that will alter the future.

Our Statewide Services Division is a network of ten regional offices spanning metropolitan, regional, rural and remote communities in NSW. The Division works to organise and mobilise communities in support of making a difference in the fight against all cancers. We believe that together we can beat cancer.

Five years ago our Statewide Services Division was considered the delivery arm of Cancer Council, with staff and volunteers working side by side in delivery with outcomes defined by head office. However we were continually challenged to achieve the **best** outcomes and community engagement and action was not explicit nor understood. We realised that this had to change to build local relevance and ownership.

The Division now works with four guiding principles, and these support the philosophies of building community engagement.

- **Appreciative Inquiry**—the practice of focusing and building on positive attributes and outcomes, to build future strategies.
- **Personal responsibility**—being accountable for the perceptions, standards and outcomes delivered by you, your team and your community.
- **Continuous Improvement**—a commitment to constant review and improvement of practices, programs, services and processes.
- **Social Responsibility**—where our programs and services are guided by a commitment to provide benefit for society as a whole. The local context is our way of ensuring we are appropriate in the differing social, cultural, and economic environments.<sup>3</sup>

**Aim:** To take a leadership role to engage people and communities to take action and therefore achieve a significant impact upon cancer in our society.

**Method:** An 'open-source' approach was taken to build and connect respectful, local arrangements in strategy, operations and activity. This would occur by enabling each community to adapt Cancer Council NSW strategic directions to the local context so it works for them and the people in their community or region. It involves an organic approach where the initial contacts take place with committed individuals and it is through their local connections that the community begins to build strength, interest and commitment.

At a regional level, an **Advisory Committee** was established in each region focusing on strategic leadership and development for that region in areas including cancer prevention, support, advocacy and fundraising. Each Regional Advisory Committee has written and committed to a series of milestones for their development and focus for the next two years. These committees guide and facilitate the strategic planning for their region, ensuring an appropriate and localised context for the work of defeating cancer.

In practice this means that the health issues, the capacity of communities and the programs that the communities adopt will vary depending on the readiness, ability and needs of each region, and in fact each community. Instead of a top down/organisational approach, planning starts within the community and action takes place based on local willingness, capacity and priorities. Since these committees formed, they have grown in their understanding and knowledge, and therefore in their contribution both at a regional level, and at a state level.

Members are often seen as the public face in their region, opening events, attending meetings, and advocating personally to their elected representatives. The Chair of the committee will generally have a close relationship with the Regional Manager, providing guidance, advice and wise counsel.

**Community Cancer Networks** provide the local context, the action and the insight in metropolitan, regional, rural and remote areas. Action and passion are key attributes. There are over 20 networks across NSW. In the Sydney regions, some of these Community Cancer Networks are supported by the physical infrastructure of **hubs** which are vibrant centres for volunteering and action. **Cancer Information Centres** are another initiative that engages with people at the right time in their cancer diagnosis. A community connector is a key success factor in working with any group. In an organic approach, networks can develop due to a geographic community connection, with people who want to contribute; however, at other times they develop from collaborations/networks of people with a common focus (eg: a tobacco network).

Cancer Council began by supporting the development of networks in a geographic sense, however have progressed to see them form at times from other interested groups who started working on a particular health issue. They become the 'go-to' people when locals wish to either find information, or to contribute through specific action.

Network members can be seen attending events, talking to their local media, coming together to advocate for issues that need to be changed in their community, supporting people, and providing general and specific information that they know is relevant at the time. These groups generally have a simple annual plan that describes what their focus for the year will be, how they are helping people and what functions they will attend. Typically their focus is drawn from local experiences and the greatest need for change. For example: one network is working to gain parking facilities for cancer patients at their treatment centre, another to ensure that Council supports smoke free environments. Other networks have decided that they will become a group of community speakers and are called on by service groups, schools and community groups to talk about cancer, how to prevent it and how it is treated. These groups provide a 'call to action' where they demonstrate that every individual can do something to change the state of cancer and help those around them. They show us how this can be done and they encourage others to join them.

Leadership to engage people and communities to take action is about **Social Mobilisation**. And it is recognised by some that at this point in time, this is the way we will make the greatest difference to cancer outcomes. There has been much work done with institutions, workplaces, media, government, health services, schools etc, but we lack the broad civil society that we now need to work with if we are to create the social movement that will truly change the face of cancer in our communities.

Essentially we know many cancer causes, we have the information, we have the ingredients and we know what needs to change. Now we need to challenge the communities to use the power that only they hold. It is about involving all people, all groups, all institutions, and all health workers across the spectrum of a life. Instead of thinking of cancer as purely a disease to be treated clinically, we are opening another powerful front in the fight against cancer, and involving all people and all communities.

Steve Hildebrand (deputy campaign manager for the Obama campaign) describes the priorities of government being influenced by the wrong people and having misplaced priorities, but he remains adamant that if you want to fight for change, it must come from the bottom up in a "movement".<sup>4</sup>

Most of us would resonate with the description of the fact that people do care, but most times they remain passive, and choose passive over active. They will send an email rather than pick up the phone, lie on the couch and watch TV rather than become an activist to effect change in their community. However, there is a message for all of us and that is that when people are asked and given the opportunity get involved, they get excited, and they truly enjoy it. To do this we simply need "community organisers".

## Partnerships and collaborations

We face a dramatic increase in the number of Australians aged over 65 years in the next 15 years. There are 85 000 people over 65 in 2010, and this will rise to around 140 000 in 2026.<sup>5</sup>

This ageing population means we will see more people diagnosed with cancer in the next 20 years.

There are many people in numerous groups, organisations and institutions who are working on cancer. However with the scope of cancer that we face in the future, there is no organisation that can cure cancer alone. Therefore it is important for everyone to join together and collaborate to truly make a difference. We must put aside the differences, find the common goal, build strength and capacity, work without bias or ownership and build on what we know and what has worked together.

## Measurement

The Statewide Services Division at Cancer Council NSW is responsible for engaging with and developing capacity in communities. Capacity is often difficult to measure, and has previously only been described in qualitative terms.

### Challenges in measuring capacity

- How do we know if we are succeeding in building capacity?
- Can we recognise the elements that will increase capacity?
- Can we recognise early signs of a decrease or lack of capacity to initiate change?

Cancer Council has developed a formal, objective and numeric way of measuring, and recording capacity in parts of their communities, capturing the ability of communities to take action and achieve desired strategic outcomes. It tracks capacity increases and decreases and has the ability to highlight problems both within regions, and at a state level.

We developed a balanced scorecard to use on a local, regional and state level. This evaluates both quantitative and qualitative measures, reporting back on the capacity in groups, committees, partnerships and in infrastructure such as hubs. It is completed by staff and has the capacity to be extended to the community groups so that information can be sourced and validated.

It uses a series of questions and graded responses which ultimately provides a “score” to assess and monitor changes in capacity of Advisory committees, Relay for Life committees, Community Cancer Networks and partnerships.

From here, projects happen, people care, and they begin to gather, to talk and to act.

### Outcomes/benefits of using the scorecard

- Provides a consistent assessment of the capacity of groups, partnerships/stakeholders and committees over time
- Provides indications of the capacity of a community to deliver particular programs, and therefore assists in planning where delivery should take place
- Provides a numeric assessment at committee/stakeholder level, regional level and state level. Data is amalgamated at all of these different levels
- The elements that will lead to successful events or projects are identified and monitored in the initial stages. If they are not in place, scores will be low, and the project/event can be treated as “at risk” and therefore needing a different set of interventions
- Can provide a picture of each individual community’s strength, and therefore is an indicator of where projects are on track to succeed
- Highlights areas at risk—by demonstrating low capacity. This provides leading indicators, enabling preventative action to be taken before a group, program or event is actually at risk
- Identifies risks, enabling treatments to be initiated
- Provides time specific action points for use by staff and managers<sup>6</sup>

We have created over 30 tangible measures of success, containing objectives, criteria and scoring (eg. percentage of increased connections or agreed upon milestones with partners). These measures are being revised and improved following almost two years of comprehensive data.

In practice, the balanced scorecard has provided monitoring and evaluation involving a cycle of continuous improvement where insight is used to improve:

- The connections with individuals and communities
- Contributions of the wider community (capacity)
- The impact we make so that together we can beat cancer.

Greater details and an introductory paper will be provided for those interested in trying to measure the capacity and ownership in communities, or successful community engagement.

## Results and analysis

We have seen a 33% growth in the number of **partnerships**, including local Government partnerships, across the state in the past 12 months, with many more collaborations and networks in development. In addition all partnerships have achieved the desired baseline of capacity measures.

The number of **networks** has increased from 27 in September 2009 to 34 in September 2010.

Notably, from September 2009 to September 2010, the averages of all measures of capacity have achieved scores above the desired baseline. These include:

- Hubs baseline = 2.5
  - Sep Quarter average results = 2.74
- Regional Advisory Committee baseline = 2.5
  - Sep quarter average results = 2.59
- Community Cancer Networks baseline = 2
  - Sep quarter average results = 2.07

## Conclusions

Instead of cancer only being an issue for those with cancer, community engagement prides open the cancer conversation and awakens people to the realisation that they too, have an active role to play in cancer prevention. The greatest contribution and impact upon cancer at this point in time will be through social mobilisation of all people in all communities.

## References

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