

BUILDING EFFECTIVE CANCER SUPPORT GROUPS

**Report to the
Department of Health and Ageing**

**The Cancer Council Australia
November 2005**



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Acknowledgements

The project was commissioned and funded by the Australian Government Department of Health and Ageing.

The author and The Cancer Council Australia acknowledge and greatly appreciate the contribution of many individuals and organisations to this project, including members of the consumer subcommittee, The Cancer Council Australia's Supportive Care Committee and the many individuals who willingly participated in the consultation process (listed in appendices). Particular thanks to Jane Cruickshank for her support and leadership as chair of the National Consumer Networks Project.

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Summary

The burden of cancer in Australia is great, with one in three men and one in four women directly affected before the age of 75 years. Cancer prevalence is increasing, and advances in early detection and treatment will lead to a greater number of cancer survivors and people living with cancer in the future.

The diagnosis and treatment of cancer has a significant psychological and emotional impact, often creating considerable distress and reduced quality of life for both the person diagnosed and their carers, family and friends.

Psychosocial care is now recognised as an important part of a multidisciplinary approach to managing cancer, to minimise the physical and psychosocial impact of the cancer and its treatment. The psychosocial needs of people affected by cancer range from minor to clinically significant, and a spectrum of interventions have evolved to address these needs.

Peer support groups and programs are increasingly recognised as an effective means of meeting the needs of people affected by cancer for information and emotional and practical support, based on the premise that shared experience is a valuable coping resource.

Support groups have measurable benefits in improving the coping and adaptation of members, reducing distress and levels of depression and enhancing self-esteem. Participants report benefits such as hope, encouragement and reassurance; the opportunity to exchange information with peers and improve cancer-related knowledge; reinforcement of the normalcy of reactions and a sense of belonging.

It is important to acknowledge that only a small proportion of people affected by cancer participate in support groups and that such groups are not appropriate for all. However, there are arguments that the proportion of people affected by cancer attending groups could and should be improved by increasing awareness about the benefits, improving availability of groups and addressing barriers to participation.

The majority of support groups in Australia are non-therapeutic, peer support groups – either professional-led social support groups or “self-help” groups, typically led by a person with personal experience of cancer. There is a variety of approaches, types, settings, membership “criteria” and other factors, creating a diversity of different support group “models”.

Support groups in Australia: a snapshot

A scoping study was undertaken to determine the number and type of support groups in Australia.

- There are more than 595 support groups for people with cancer across Australia.
- The majority are general groups, for people affected by any type of cancer (226, 38%), groups for women with breast cancer (172, 29%) and groups for men (and their partners) affected by prostate cancer (63, 11%).
- In addition to a variety of other cancer type-specific groups, there are groups that aim to meet the particular support needs of groups such as children or parents of children with cancer, people with advanced cancer, people of culturally and linguistically-diverse backgrounds or Indigenous Australians.
- Support groups are almost evenly divided in terms of setting, with 282 groups meeting in community settings and 235 in hospitals or healthcare facilities.

- More than a third of the groups (220, 37%) are located in capital cities, and 340 in regional areas (remainder unknown or unspecified).
- About half the support groups are peer-led and half professional-led, with a small number co-facilitated by a professional and a person who has had cancer.
- There are a growing number of telephone or “electronic” cancer support groups and services, which may be particularly appropriate to people who are geographically isolated or face physical or psychological barriers to attending face-to-face groups (such as illness, transport difficulties or desire for anonymity).

From recent surveys of support group leaders in Queensland (2005) and NSW (2002) we know that the majority of groups provide general group discussion (information and emotional support), informal or social get-togethers and group education sessions with guest speakers. Most groups meet monthly. The average number of participants at meetings is 12 to 13, but groups report as few as four and as many as 100 regularly attending members.

Most peer support groups are initiated by people affected by cancer themselves, but often are organised under the auspices of or with the support of Cancer Councils, community groups or hospitals and health services. Several formal and informal “networks” of cancer support groups have evolved in Australia in recent years. These networks play an important role in linking and supporting existing groups and facilitating the development of new groups, for example providing resources and training for group leaders.

The evolution and increasing popularity of cancer peer support groups has in part driven the development of a number of cancer consumer and advocacy groups, which aim to represent and promote the interests and concerns of people affected by cancer.

Gaps

Despite high unmet needs and the established benefits of participation in support groups, the majority of people affected by cancer do not attend groups. This may be because of unavailability of groups appropriate to their needs, ie “gaps” in access to support groups. Further research is needed to determine if people affected by cancer, or specific subgroups such as people affected by particular cancer types, want and would benefit from support groups.

There are no or few support groups for people affected by the most common cancers other than breast and prostate. Colorectal cancer is the most common cancer in Australia, but there are only five support groups specifically for people with bowel cancer. There are no support groups for people with melanoma and just two groups for people affected by lung cancer.

The scoping study also highlighted the small number or absence of support groups for other cohorts of people affected by cancer with needs for better informational and emotional support. Many of the contributors to this project also noted these gaps, and referred to a perceived need for and potential benefits of support groups for “underserved” cohorts of people affected by cancer, who have common support needs because of their:

- geographical location
- age
- cancer stage
- culturally or linguistically diverse background
- relationship to a person with cancer eg carers or parents of children with cancer.

This report considers two questions: Is creating more support groups an appropriate means of addressing these apparent gaps? And if so, is a cancer type-specific group more or less effective than a general cancer support group or group for people with advanced cancers of all types? The evidence and opinion seems divided.

It is acknowledged that cancer support groups are not an appropriate or preferred means of accessing psychosocial support for all people affected by cancer eg those with significant psychological distress require specialist interventions; people who are physically debilitated might not be able or willing to participate in face-to-face group meetings. Rather than simply seeking to redress the apparent imbalance in availability of support groups by creating cancer site-specific groups where there are currently none or few, it is important to consider the psychosocial needs and preferences of people with those cancers and the barriers to creating and maintaining support groups for these groups of people.

In line with the focus of the Building Cancer Support Groups policy on facilitating additional support groups for people affected by bowel, lung or ovarian cancer, this report identifies existing peer support groups and programs and explores some of the barriers to creating and sustaining support groups in these areas.

Building cancer support groups

One of the aims of this project was to identify the key principles or “success factors” of effective cancer support groups.

Unequivocal evidence about “what works” for people affected by cancer – both generally, and for specific subgroups with identified needs – is lacking. Conclusions of the relevant meta-analyses, reviews and studies comparing different psychosocial interventions or therapeutic approaches, and studies that have sought to identify the group variable associated with better outcomes are outlined in section 6. But limited evidence means “that it is not possible to conclusively prove that any particular group format is more effective than another in improving outcomes for participants” (Ussher et al, 2003).

There are many hundreds of support groups across Australia, and almost as many different support group “models”. Despite the popularity and apparent effectiveness of the large number of groups for people affected by breast or prostate cancer, it is not possible to identify or create a “template” for a successful group and apply it to create groups for people with other common cancers.

This project identified a number of principles from the few published studies as well as the experience of people leading or coordinating cancer support groups in Australia that appear to be common to groups that are active and considered to be effective.

The evidence and experience of support group leaders indicate that support groups “work best” and are most effective when they:

1. Are established in response to, and adaptive to, community or member needs
Successful groups evolve in response to an identified need and respond to members’ needs, in terms of structure and content.
2. Provide information, emotional support and socialisation
Effective support groups provide a range of activities to meet the diverse needs of individual members for information, socialisation, reduction of isolation and emotional support, and improved coping skills.
3. Have skilled leadership and/or facilitation
Recent research has suggested that the group leader has a crucial role in determining the success or otherwise of cancer support groups. Group participants have highlighted the importance of the leaders’ personality, empathy or understanding, and capacity to ensure everyone has an opportunity to participate.
There is some evidence and a common belief that specific group leadership training for support group leaders is crucial to achieving best outcomes.

4. Maintain adequate number of, and recruit new, members

A peer support group needs an adequate number of people to attend meetings to keep it operational, and recruitment of new members to ensure it remains active and validates the group and the contribution of other members.

5. Involve a health professional or at least establish good links with one

Having a link with a health professional may support group functions and effectiveness by providing resources, practical and informational support, and helping to promote the group to specialists and/or enhance referrals to the group, and also may lend credibility to the group.

6. Are well-organised, structured and supported

Structured peer support groups are more popular with cancer patients and may be more effective.

Some of the difficulties in running groups and potential burnout could be alleviated by sharing responsibilities and tasks with group members and/or having a co-facilitator.

7. Have an appropriate “personality” and level of humour

Group participants identify humour in the group and the group facilitator’s personality as important features that contribute to effectiveness.

Recommendations

The Department of Health and Ageing commissioned this report to provide advice to the Federal Government in facilitating cancer support groups and networks, as outlined in the Building Cancer Support Groups component of the *Strengthening Cancer Care* initiative. Specifically, the Building Cancer Support Groups policy commits funding to seeding grants (contributing to salary and administration expenses) for “support groups in the areas of bowel, lung, ovarian and other cancers”.

There were a number of clear conclusions that informed the recommendations.

1. Build effective cancer support groups

In order to build effective and sustainable support groups for people affected by cancer, the Department of Health and Ageing should offer seeding grants to cancer support group networks or appropriate organisations to:

- 1.1 Review evidence and test and evaluate innovative support group models to address the needs of a particular cohort of people affected by cancer, who may have similar needs because of their cancer type, cancer stage, geographical location, age or particular needs or interests.
- 1.2 Grow or extend existing cancer support groups, to meet the needs of a greater number and/or different group of people affected by cancer.
- 1.3 Establish new cancer support groups to address the support needs of a group of people affected by cancer, with appropriate reference to existing evidence, models and principles to ensure effectiveness.

The capacity of *cancer support group networks* to assist establishment and maintenance of peer support groups has been acknowledged in this report, and hence priority should be given to existing networks or organisations seeking to create networks or otherwise link relevant services.

2. Increase the effectiveness and utilisation of cancer support groups

Given the number of cancer support groups in Australia and the positive experiences of participants (as reported in this study and others), priority should be given to ensuring effectiveness and increasing utilisation of existing and new groups by:

- 2.1 Building capacity and effectiveness of existing support groups
- 2.2 Increasing awareness and understanding of the role and benefits of peer support groups
- 2.3 Supporting initiatives to improve health professionals' awareness of and referral to groups and/or the Cancer Helpline.

3. Support further research

Additional research is essential to support the development of effective and sustainable peer support for people affected by cancer generally and for specific groups of patients and carers with unmet needs. Priority areas include facilitating the development and promotion of support group models and guidelines based on best practice, determining “what works for whom” – assessing the needs and preferences of particular groups of people affected by cancer to determine whether participation in support groups would be appropriate and beneficial or preferred mechanisms of addressing unmet needs; exploring the potential for greater accessibility and utilisation of alternative methods of delivering peer support to people affected by cancer such as telephone or internet groups.

See section 7 for further explanation and examples.

1. Background and context

1.1 Introduction

The Department of Health and Ageing commissioned The Cancer Council Australia to provide advice to the Federal Government in facilitating cancer support groups and networks, as outlined in the Building Cancer Support Groups component of the *Strengthening Cancer Care* initiative.

The Building Cancer Support Groups policy commits funding to seeding grants (contributing to salary and administration expenses) for “support groups in the areas of bowel, lung, ovarian and other cancers”.

The Cancer Services section of the Department has requested a document that will provide an overview of cancer support groups nationally, review and identify best models for consumer support networks for people living with cancer, their families and carers, and identify gaps in consumer support.

The project aims (as prescribed by Department of Health and Ageing) were:

1. Determine the number and range of cancer consumer support groups nationally, covering tumour stream, membership, status, type, etc.
2. Undertake a review of the national and international literature on the best models for consumer support networks
3. Determine gaps in consumer support, particularly in the areas of bowel, lung and ovarian cancer
4. Produce a scoping report covering the above aspects and a detailed final report on the study results.

The project aims were developed at a meeting attended by cancer consumer representatives and nominees of the Department of Health and Ageing, The Cancer Council Australia and the Clinical Oncological Society of Australia (COSA), chaired by cancer survivor Jane Cruickshank, a member of the Cancer Strategies Group and many other national and NSW cancer-related groups and committees. A Consumer Steering Group, composed of cancer consumer representatives invited by the Chair of the Working Party, provided further advice on this project. The members of both groups are listed in appendix 2.

1.2 Burden of cancer in Australia

At current incidence rates around one in three men and one in four women in Australia will have cancer before the age of 75 years. More than 88,000 people were diagnosed with cancer (excluding non-melanocytic skin cancers) and there were more than 36,300 deaths due to cancer in 2001 (AIHW & AACR, 2004).

The cancer burden will continue to rise in coming years. While the age-standardised incidence rates of most cancers are expected to remain relatively stable in the short term, the number of new cases will continue to rise due to the ageing of the Australian population. The largest projected increases are for the most common cancers – prostate cancer in men and breast cancer in women. A large increase is also expected in the number of people affected by lung cancer, with a 38% increase in the number of cases in women and a 17% increase in lung cancer cases in men (AIHW, 2005).

Advances in early detection and treatment will continue to result in improved survival rates for people with cancer, meaning there will be more people living with cancer, and living longer, in the future. At present, well over half of all Australians diagnosed with cancer each year will still be alive five years later. There are an estimated 267,000 Australians living with cancer, many with persistent and incurable forms (ABS, 2004).

1.3 Psychosocial impact of cancer

The diagnosis and treatment of cancer has a significant effect on the lives of many Australians, often resulting in considerable psychological or emotional distress and a reduced quality of life. "Distress" has been defined as an "unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment" (National Comprehensive Cancer Network, 2002). It may include symptoms of depression, anxiety, confusion, fatigue, anger and feelings of diminished control.

According to Australia's *Clinical practice guidelines for the psychosocial care of adults with cancer* (NBCC & NCCI, 2003), many people diagnosed with cancer face practical, emotional and psychological demands in addition to their physical treatment. Up to 66% of people with cancer experience long-term psychological distress: up to 30% experience clinically significant anxiety problems, and prevalence rates for depression range from 20 to 35%.

Emotional distress is common in cancer patients, with most studies detecting significant distress in 35 to 45% of patients (Carlson & Bultz, 2003). For many people cancer distress lessens over time, but it has also been estimated that about one-third of people diagnosed with cancer will experience long-term psychological difficulties and unmet needs for supportive care (Zabora, 1998).

The impact on families of those with cancer is also considerable.

1.4 Benefits of psychosocial support

Psychosocial care is now recognised as an important part of a multidisciplinary approach to managing cancer, to minimise the physical and psychosocial impact of the cancer and its treatment (NBCC & NCCI, 2003).

A range of psychosocial interventions have evolved to address the varying needs of people affected by cancer. It is necessary to have a range of interventions offering different levels of care, such as information, peer support, counselling and psychological or psychiatric interventions, appropriate to the level of distress and expressed need of different patients and carers (Hutchinson, Steginga and Dunn, in press).

There is evidence that various psychosocial interventions benefit people affected by cancer by increasing wellbeing, improving adjustment and coping and reducing distress (Carlson & Bultz, 2003; Cunningham, 2000; Meyer & Mark, 1995; Rehse & Pukrop, 2003). Devine and Westlake's (1995) meta-analysis of 116 intervention studies found that patients with cancer receiving psychoeducational or psychosocial interventions showed much lower rates of anxiety, depression, mood disorders, nausea, vomiting and pain, and significantly greater knowledge about disease and treatment, than the control group.

National guidelines for psychosocial care of adults with cancer report evidence to support the benefits of counselling, relaxation therapy, education programs and cognitive behavioural interventions in improving emotional adjustment and reducing distress in patients with cancer (NBCC and NBCCI, 2003).

In addition to benefiting individuals affected by cancer, psychosocial support may result in savings in health expenditure. It has been estimated that effective psychosocial support services lower health service use by between 7% and 17% (Walker et al, 2003).

Social support is multidimensional and has been defined as the provision of information, practical assistance and emotional empathy and comfort. It may be provided formally by professionals and organisations, or informally by family, friends and peers.

According to a recent literature review, social support, both formal and informal, has been found to reduce distress and enhance quality of life of cancer patients and carers (Ussher et al, 2003). Research has repeatedly identified the pivotal role of social support on adjustment, psychosocial outcome and even survival in people with cancer (Northouse, 1988; Spiegel et al, 1989).

In particular, **peer support programs** have developed to meet needs of people affected by cancer for social, particularly emotional, support. Peer support is a term used to describe the emotional and practical support provided to people affected by cancer by other cancer patients, survivors and carers. It is based on the premise that shared experience is a valuable coping resource. Peer support assists people coping with cancer by providing emotional support and decreasing social isolation (Dunn et al, 1999; Gray et al, 1997).

The most common formats are peer support groups and one-to-one support. Peer support groups may be peer or professionally-led but in contrast to clinically driven psychological interventions, they are typically initiated by people affected by cancer or local communities themselves. More recently, methods of providing dyadic (one-to-one) or group peer support via telephone and the Internet have evolved (see section 3.5).

Evidence of the benefits of peer support groups is further explored in section 2.1.

1.5 Definitions

For the purpose of this study and report the following definitions were used:

Cancer consumer

Someone who has been affected by cancer including patients, survivors and carers or family members. The term "**person affected by cancer**" is preferred and is generally used instead. (While acknowledging the many other people who have an interest in cancer including oncology specialists and other health professionals, Cancer Council staff, etc. this definition is limited to those who have had a personal experience as a cancer patient or carer.)

Cancer support group

A group providing practical and/or emotional support to people affected by cancer. Support groups include therapeutic and peer support or self-help groups, peer-led and professional-led groups, and telephone and web-based group support programs. Groups may be formed to meet specific needs, such as tumour-specific, age-appropriate or culturally-diverse, or to serve a particular geographical region. They may be open-ended (continuing) or closed (usually time-limited and restricted membership).

Cancer support network

The Building Cancer Support Groups policy refers to the development of "cancer support networks". The intention was that support groups funded "will develop partnerships and working relationships with similar support groups/organisations and enhance the planning and delivery of direct modes of support to cancer consumers" (Cancer Services section, Department of Health and Ageing).

Existing networks of support groups are discussed in this report in the section entitled "Cancer support group networks".

Facilitator or group leader

An individual who leads support group meetings – may be trained or untrained; cancer consumer or health professional (or both).

Peer support

Support provided by people with similar problems or illnesses; based on the premise that mutual sharing of experiences and information is beneficial for participants.

Psychosocial

Aspects of people's lives related to psychological, emotional, relationship and social issues.

1.6 Methods

A part-time project coordinator was employed for a period of six months, from May to October 2005.

Scoping study

Lists of cancer support groups were provided by the state and territory Cancer Councils (listed in appendix 3), to enable development of an overview of the number and types of support groups currently available to people affected by cancer in Australia.

Because of limitations of time and resources, the scoping study was restricted to collating existing data about cancer support groups in Australia from the state and territory Cancer Councils. Cancer Councils collect and regularly update information about support groups and programs of all types to assist Cancer Helpline staff providing information about supportive care options for people affected by cancer.

The limitations of relying on these data are acknowledged in section 3.3. It was not possible within the scope of this project to otherwise seek to identify existing groups (eg by "snowballing" techniques) or to survey all groups to confirm or add to the information provided by Cancer Councils.

Literature search

A literature search was undertaken to identify published articles about the nature, effectiveness and factors that contribute to successful outcomes of cancer support groups, both in the Australian setting and overseas.

The objective was not a comprehensive literature review but to identify meta-analyses and reviews of the benefits and effectiveness of cancer support groups, as well as articles that compared or evaluated different types of support groups and/or otherwise considered the organisational, structural and other factors that might influence whether a group is "successful" in meeting the needs of people affected by cancer (generally or a specific subgroup).

As the great majority of cancer support groups are non-therapeutic, the emphasis was on research that investigated the factors related to effectiveness of peer or professional-led peer support groups. But key conclusions (relating to possible "success factors") of meta-analyses and reviews of psychological interventions are noted, as these may be informative.

Computer-based searches of the PubMed and PsychInfo databases were done using the key words "cancer", "support" and "group", "cancer", "self-help" and "group", and "cancer" and "psychosocial" and "support". Abstracts were reviewed to assess the potential relevance of the articles. Further relevant articles were identified from reference lists and journals with several relevant articles were further searched.

Consultations

The project coordinator conducted face-to-face and telephone interviews with cancer support group leaders and facilitators, Cancer Council staff and coordinators of cancer support networks, and other stakeholders, to collect information about support groups and to identify the various models that exist, principles that may be associated with effectiveness, challenges in creating and sustaining groups and perceived gaps and needs. All contributors are listed in appendix 1.

The project coordinator spoke with a number of facilitators and leaders of cancer support groups that had been nominated, for a variety of reasons, as “successful” or “effective” groups. Quotes or comments referenced to individual contributors are indicated by italicised names in brackets eg (*Keogh*).

In addition, because of the project focus on perceived gaps in support for people affected by lung, bowel or ovarian cancer, leaders or facilitators of all or most of the existing cancer type-specific groups for people with these cancers were consulted.

2. Cancer support groups

“The only authentic people in my cancer journey were the people who had had cancer. Having people who had walked the walk was really crucial. These were the only people I could be really honest with.” (Keogh)

Cancer support groups first became popular in the 1970s and 1980s, and have rapidly burgeoned as people affected by cancer have increasingly sought mutual help and support to address their psychosocial needs. Professionally led therapeutic groups also emerged over the past two decades as varying models of therapy were explored “under the broad rubric of improving quality of life” (Kissane et al, 2004).

Cancer support groups offer mutual support and information to people affected by cancer – predominantly those who are undergoing treatment for or living with cancer, but there are also groups that are open to or specifically for carers and family of people with cancer.

However, only a minority of people diagnosed with cancer participate in support groups – anecdotal claims being that about 5% of newly diagnosed patients will attend a group, some for only a short period. It is acknowledged that peer support groups are “not for everyone” (many people feel they have adequate social support and/or that they would not benefit from a group), but also that potentially many more people affected by cancer could benefit from effective support groups, but are unaware of or unable to access groups appropriate to their needs.

2.1 Benefits of support groups

Reviews of the research literature have found improvement in quality of life, coping and affect in participants in cancer self-help groups (Borne et al, 1986), non-directive, professionally led groups (Hogan et al, 2002) and directive group interventions (Fawzy et al, 1995; Meyer and Marks, 1995). There also have been indications of improvements in survival duration, although recent research has not confirmed this (Edelman et al, 2000).

Research demonstrates that support groups do have measurable benefits for their members including:

- improvements in coping and adaptation (Edelman et al 2000, Gray et al, 1996, Samarel et al 1998)
- reductions in general psychological distress (Bultz et al, 2000; Helgeson, 1999)
- improvements in levels of depression (Bultz et al, 2000; Fawzy et al, 1990; Hosaka et al 2001; Montazeri et al, 2001; Spiegel, Bloom & Yalom, 1981; Targ & Levine, 2002)
- reductions in anxiety (Hosaka et al, 2001; Motazeri et al, 2001; Samarel et al, 1998; Targ & Levine, 2002)
- enhanced self-esteem (Edelman et al 1999)
- positive effect on immunological response (Fawzy et al 1990).

Although not all people affected by cancer may benefit from support groups (Helgeson et al, 1999, 2000), groups overall appear to improve patient quality of life across a number of different formats. *Even support to carers or the partners of cancer patients has led to important effects on the patient (Bultz et al, 2000).*

According to Campbell et al's (2004) review of peer support evaluation studies (provided by volunteer cancer survivors to cancer patients), non-randomised studies found participants had a better understanding of the cancer experience and were better informed as a result of receiving peer support. Hope, encouragement and reassurance were common emotional benefits described in virtually all of the peer support programs. However, in contrast to earlier reviews, this review found the few randomised studies showed peer support groups did not improve quality of life.

Support groups allow participants to “gather the information most valuable to them – stories of similar experience and endurance” (Davison et al, 2000).

Group participants report many benefits, such as:

- the opportunity to share experiences and exchange information about cancer and cancer treatments, leading to greater cancer-related knowledge and improved ability to relate to health professionals,
- mutual encouragement and support; empowerment, hope and confidence
- reinforcement of the normalcy of reactions
- increased confidence
- the ability to develop new relationships and socialisation and
- a sense of belonging.

A recent NSW study found that the majority of people affected by cancer attending support groups have an improved sense of empowerment and psychological wellbeing. Members of 173 cancer support groups in NSW were interviewed. They believed support groups gave them freedom to discuss issues considered taboo or a burden on the family, a decreased sense of isolation and increased confidence in communicating with health professionals (Ussher et al, 2003).

Ussher et al's (in press) further qualitative study with members of nine peer support groups in NSW found that participants positioned “increased empowerment and agency” as the most significant benefit of groups support. This included increased confidence and a sense of control in relation to self, living with cancer, and interactions with others, in particular the medical profession.

A difficulty in assessing benefits of support groups *en masse* is that individual member perceptions of the functions of the group vary. For example, a study by Jeffries (2002) of the needs of women with ovarian cancer found that within a patient support group, when a member experienced a recurrence or died, some members found this difficult to accept and believed it reduced their ability to encourage one another and maintain strength, while others believed it allowed them to look realistically at their illness which they found beneficial.

In addition to benefits for participants, support groups offer cost-effective help to people affected by cancer (Bottomley, 1997a) and their cost-efficiency advantage over individual interventions could be an argument for greater availability of and referral to groups in the health system.

2.2 Types of support groups

Cancer support groups for people affected by cancer have evolved in a variety of forms. But they generally are characterised by small numbers of participants, regular meetings, emphasis on personal participation, voluntary attendance and provision of emotional support. An exception to some of those general principles has been prostate cancer support groups, which generally involve larger numbers of participants and greater emphasis on education and information to assist decision-making.

For the purposes of this project, cancer support groups are generally considered as either:

1. Formal, professionally-led therapeutic or structured psychoeducational groups, most of which focus on cognitive-behavioural or supportive-expressive techniques and teaching coping strategies.
2. Supportive interventions – peer support groups that are intended to allow members to express emotions and to adjust to the cancer situation through mutual help and support (sharing experiences, giving and receiving information, reducing social isolation and improving relationships through better communication).

These groups may be professionally-led social support groups (eg education and/or peer discussion groups), usually set up and/or facilitated by health professionals as an extension of their work, or “self-help” groups, typically led by a volunteer, who has had personal experience of cancer and is not a health professional.

Discussion about types of support groups is complicated by the absence of agreed definitions and the overlap between styles of intervention. Peer support groups may be termed social, self-help, community or voluntary groups. Many professionally facilitated groups (as many as 60%, according to Davison et al, 2000) “misleadingly” identify themselves as self-help groups. Peer support groups generally provide education and information as well as emotional support, while therapeutic interventions that are delivered in a group format also assist through the provision of peer support.

One common differentiation is that peer-led groups avoid hierarchy and members determine what they need and how their needs can best be met, while professionally led groups are characterised by active intervention and leadership (Gray, Fitch, Davis and Phillips, 1997). Self-help group members can be both givers and receivers of support. As peer support groups have increased in prevalence and significance there has been a tendency towards increased involvement of health professionals, often as advisers or supporters rather than active facilitators or leaders.

Support groups have traditionally required face-to-face interaction, but facilitation of groups via telephone or Internet is becoming increasingly common for some groups of people affected by cancer. Further information about these models of delivery is included in section 3.5.

Peer support groups

The great majority of support groups in Australia are non-therapeutic, peer support groups.

Even within this subset of support groups, there is a variety of approaches, types and settings. These groups provide different services, experiences and benefits to members depending on such factors as:

- Membership of the group: Some groups are formed by people to meet specific needs ie for people with a specific disease (eg prostate cancer) or similar experience (eg parents of young children with cancer). Others are formed to serve a particular geographical region. Many are “general” groups, open to people affected by any type of cancer and usually to both patients and carers.
- Preferences of members eg predominantly seeking information, to learn coping skills or primarily wanting a social group.
- Professional training, skills and interests of the facilitator or leader.
- Setting: Groups may meet at a hospital or health centre, in a community venue or at a Cancer Council regional office. Some meet in private homes or cafes.
- Timing: “Open” groups are not limited to a certain number of sessions and members can join the group at any time. “Closed” groups are restricted to members who join at the beginning and usually conducted over a limited time period.
- Longevity: Some groups form and then wane as a need is met; others have continued for 20 years or more.
- Delivery method: Traditionally support group members meet face-to-face, generally on a weekly or monthly basis. But there is increasing availability and use by people affected by cancer of telephone group support and online support groups and mailing lists.

3. Cancer support groups in Australia

3.1 Overview

A scoping study was undertaken, collating information about support groups collected by each of the state and territory Cancer Councils, to present an overview of the state of cancer support groups in Australia.

There are more than 595 support groups for people with cancer across Australia. The majority are general groups, for people affected by any type of cancer (226, 38%), groups for women with breast cancer (172, 29%) and groups for men (and their partners) affected by prostate cancer (63, 11%). In addition to a variety of other cancer type-specific groups, there are groups that aim to meet the particular support needs of groups such as children or parents of children with cancer, people with advanced cancer, people of culturally and linguistically-diverse backgrounds or Aboriginal Australians.

Support groups are almost evenly divided in terms of setting, with 282 groups meeting in community settings and 235 in hospitals or healthcare facilities. More than a third of the groups (220, 37%) are located in capital cities.

About half the support groups are peer-led and half professional-led, with a small number co-facilitated by a professional and a person who has had cancer.

3.2 Results

Number of support groups

There are more than 595 cancer support groups in Australia. (See *Limitations* below).

Number of support groups by state/territory

ACT	9
NSW	234
NT	10
QLD	95
SA	65
TAS	18
VIC	113
WA	51

Number of support groups by cancer type or participant demographics/interest (specificity)

Aboriginal	2	1 for women only
Acoustic neuroma	1	
Advanced cancer (general)	7	1 for women only (excludes groups for women with advanced breast cancer – listed under Breast) 1 telegroup
Bowel	5	
Brain	8	1 telegroup
Breast	172	12 specifically for young women 6 for women with advanced cancer 2 for partners of women with breast cancer 1 for Spanish-speaking women
Carers and family members	16	2 for parents of children with cancer (1 telegroup) 1 for children of parents with cancer (telegroup) 1 for adults with cancer re talking to their children about cancer (telegroup) 1 for families with young child or parent with cancer
Cervical	2	
Children with cancer	3	1 playgroup for under 5s + support for parents 1 for children with leukaemia
General	226	1 for adults with cancer re talking to their children (telegroup) 1 art therapy 1 Cantonese 1 Chinese 1 Italian 1 Vietnamese 2 online
Gynaecological	8	1 gynae + breast 1 online
Haematological	2	
Head and neck	4	
Hydatiform mole (chorionepithelioma)	1	
Larynx (laryngectomees)	15	
Leukaemia	6	1 Myelodysplastic syndrome
Lung	2	1 telegroup
Lymphoedema	11	
Lymphoma	2	
Men	3	
Mesothelioma	4	2 groups for “asbestos-related disease”, could include people with lung cancer
Myeloma	3	

Non English-speaking (also included by cancer type)	7	1 Cantonese 1 Chinese 2 Greek (women) 1 Italian 1 Spanish (breast) 1 Vietnamese
Ostomates*	11	
Ovarian	4	1 includes gynae cancers
Pancreatic	2	
Prostate	63	
Retinoblastoma	1	
Women	8	2 for Greek women 1 for Aboriginal women

* Most people who have a stoma have had surgery for bowel cancer, although a small number may have had bladder cancer or ulcerative colitis.

Setting

Number of support groups by setting (excluding WA groups, for which this information was not provided):

Hospital/healthcare facility	235
Community	282
Online/telephone	10
Unknown/unspecified	17

Number of support groups by geographical location:

Metro (capital cities)	220
Regional (includes rural)	340
Online/telephone	10
Unknown/unspecified	25

The proportion of “general” groups is higher in regional (35%) than in metro (28.5%) areas.

Facilitation

Number of support groups by facilitation type:

Peer-led	245
Professional-led (Includes health professionals such as psychologists, social workers, nurses; professional group facilitators/therapists; and Cancer Council counsellors)	253
Co-facilitated (peer/professional)	16
Unknown/unspecified	81

3.3 Limitations of data collection and reporting

State and territory Cancer Councils maintain databases of information about all known support groups in their regions to assist Cancer Helpline staff providing information about supportive care options for people affected by cancer. It was not possible within the scope of this project to otherwise seek to identify existing groups or to survey all groups to confirm or add to the information provided by Cancer Councils. Hence, it is acknowledged that there are additional support groups currently operating in Australia.

Also, the lists provided by some Cancer Councils were restricted according to organisational policies regarding provision of information about support groups. The Cancer Council NSW list excluded services that do not support the use of conventional therapy and/or encourage the use of “alternative therapies” in place of conventional medicine. The Cancer Council Victoria provided details only of groups that have signed an “accreditation” agreement with the Cancer Council, agreeing to abide by guidelines. The Cancer Council Victoria is aware of an additional 25 support groups in Victoria which are not accredited, or have been operating for less than 12 months.

Organisations and services that offer social or peer support programs but not in the form of traditional “support groups”, or may provide support as an adjunct to another primary aim, were excluded. So, for example, CanTeen programs (peer support programs for young adults affected by cancer), Dragons Abreast (dragon boating teams of women living with or survivors of breast cancer) and Living with Cancer education programs were not included.

There are 48 Encore groups (including one newly-formed for Aboriginal women in Kempsey) in addition to the breast cancer support groups total. The YWCA Encore program is primarily an exercise program for women who have experienced mastectomy, lumpectomy or breast reconstruction surgery, but includes support and education. There is reference in this report to other forms of peer and psychosocial support – and the value and benefits of these services must be acknowledged – but this scoping study was limited to support *groups*.

Similarly, the only electronic support groups that were included in these results were those that function as groups, meeting at a particular time and with a facilitator. Other online “groups” and programs are acknowledged in section 3.5.

The type and amount of information gathered by each Cancer Council differs widely, so it was possible to report only the results above. For example, details of membership numbers are not maintained, because of the constant fluctuation of participant numbers in most groups. Because of limited information the group setting was categorised as either hospital/healthcare or community (everything else eg community centres, Cancer Council offices, private or business venues).

Specificity of cancer support groups (whether open to people affected to cancers of any type, termed “general”, or membership limited to people with a particular cancer type eg prostate, bowel or stage eg advanced breast cancer) was determined from the group description in most cases. Where specificity was not stated or clearly evident from a group’s name, it was assumed that the group was “general”. Where multiple groups are offered by an organisation, ie different groups for people with particular cancer types, stage of illness or other characteristics, each was separately listed if known.

3.4 What else do we know about support groups in Australia?

A number of Australian studies have been conducted in recent years, providing additional information about support groups in some states.

A 2002 audit of support groups in NSW, funded by The Cancer Council NSW, identified 178 active support groups (Ussher et al, 2003). There are now 234 groups in NSW according to data provided by TCCN for this study (recently reviewed), indicating that interest in developing and participating in groups has increased at a reasonable rate.

Results:

- There was a mix of general cancer support groups and groups specific to a particular type of cancer.
- Around two-thirds of groups were based in rural settings, one-third urban.
- Over half of the support groups (61%) were facilitated by either one or two health professionals, typically social workers, nurses, psychologists or counsellors. About 20% of groups had a person with cancer in a leadership role in the group.
- Group meetings were most frequently held in either a health care setting (60%) or community (26%) setting.
- The most frequently cited aims of the groups were psychological and emotional support, information/education and social support.
- Most groups were open (allowing new members to join at any time), and had an average attendance of 13 participants.
- The most common frequency of meetings was monthly (63%). Over three-quarters of groups regularly invited speakers to present at their meetings.

Earlier this year the Queensland Cancer Fund conducted a cross-sectional descriptive mail survey of cancer support groups in Queensland to assess the current activity and services provided by cancer support groups across Queensland, including type of leadership, mode of delivery and group support structures. Surveys were completed by 58 group leaders.

Results:

- Groups were mostly managed and had meetings facilitated by a person previously diagnosed with cancer. About one-quarter of groups were managed/facilitated by a health professional, and 15% were jointly managed/facilitated by a cancer consumer and a health professional.
- The type of services and activities provided by the groups consisted predominantly of general group discussion (73%), informal/social get-togethers (70%) and group education sessions with guest speakers (70%).
- The majority of groups (52%) had been formed within the past 5 years, with the longest-running group running for 35 years.
- The median number of attendees at meetings was 12, but groups reported as few as 4 or as many as 100 members.

An “inventory” of peer support for prostate cancer (Steginga et al 2005) identified a wide range of groups providing psychological support to men with prostate cancer in Australia. Most groups were managed and led by men who had had prostate cancer (71%), with the remainder facilitated by health professionals. Half of the group leaders reported that they rarely or never worked with clinicians. Most groups had general discussion meetings (93%) and education sessions with guest lecturers (81%). One-to-one telephone peer support and newsletters were also commonly provided.

The Cancer Council Victoria is presently collating responses to a mail survey of all known cancer support groups in Victoria, seeking information about support group leaders/facilitators (including whether they've undertaken training, and their training and support needs), members of support groups, and the organisation, activities and funding of groups.

3.5 Telephone and internet support groups

“[For people with] rare cancers, electronic support groups are a ‘lifesaver’. They are the way of the future in many disease areas.” (Strangman)

A growing number of telephone or “virtual” (web-based or email) cancer support groups are emerging to meet the needs of people affected by cancer in Australia.

These formats can be helpful to people with less prevalent cancers, for whom there are few or no traditional support groups (even people with rare cancers can find peers online), those preferring anonymity in order to find information or discuss sensitive issues, people in regional/rural areas without access to face-to-face support groups, and people who are too ill to travel to a meeting venue or have transport difficulties.

Telephone support groups, as distinguished from dyadic telephone peer support, operate in a similar way to face-to-face groups, enabling peers to gain and share advice and emotional support. All the known telegroups in Australia are professionally-facilitated.

The number of virtual or electronic support groups is rapidly growing. Most of what are termed electronic support groups are actually mailing lists, newsgroups, web-based discussion forums and chat rooms. Cancer chat rooms – which enable 24-hour, spontaneous, anonymous, peer support – are proliferating around the world. It is generally accepted that moderators, who scan messages for appropriateness before they’re published, are essential to prevent the spread of misinformation.

However, there is an increasing number of online support groups which, like traditional face-to-face groups, meet at specified times (in chat rooms), and may be restricted to a certain number of participants. Although most are unmoderated, some are facilitated by trained professionals such as oncology nurses, counsellors or by a person with cancer or cancer survivor.

Anecdotal evidence shows that electronic peer support groups might be beneficial interventions, although there are recognised dangers also, including inaccurate or inappropriate information, hoaxes, spam and lack of physical contact. A randomised controlled trial involving recipients of a breast cancer mailing list suggests that a web-based support group can be useful in reducing depression and cancer-related trauma as well as perceived stress (Winzelberg et al, 2003). Like face-to-face self-help support groups, content analyses of electronic cancer support groups have found an emphasis on information giving or seeking, encouragement and support, and sharing personal experiences (Eysenbach, 2003).

There are several existing telegroups and internet support groups provided by Australian organisations or predominantly for/used by people affected by cancer in Australia (in addition to several hundred international sites and services) including:

Telephone support groups

- The Cancer Council NSW telephone group counselling program includes groups for:
 - Young people aged 10 - 18 who have a parent with cancer
 - Parents needing advice around talking to their kids about cancer
 - People affected by lung cancer
 - People affected by brain tumours
 - Adults with advanced cancer (of any type)
 - Carers

Telegroups comprise six to eight participants and are supported by two professional facilitators (one of whom is an oncology nurse, able to provide information in response to treatment-related questions). Most meet fortnightly or monthly and provide coping skills, communication strategies and emotional support.

- There are two known telephone groups for women with breast cancer: the Pine Rivers Breast Cancer Telephone Support Service (Brisbane, Queensland), and the Gippsland Women's Health Service (Vic), which provides monthly support, education and information sessions by telephone conference for young women with breast cancer.
- At least two support groups for women with advanced breast cancer conduct group support meetings with some women attending in person and some, due to illness or remoteness, participating by teleconference (Women's Psychotherapeutic Service in Queensland and BreaCan in Victoria).

Online support groups

- The Cancer Support Association of Western Australia hosts a twice-weekly online support group in the chatroom on its website, moderated by a professional counsellor: www.cancersupportwa.org.au. The chatroom operates on a first-come-first-served basis, and allows users to save a record of the online conversation. The CSA also offers one-to-one counselling online (limited to the member and a counsellor) and a bulletin board, on which users can post questions and await responses.
- The Cancer Council WA is developing online support groups (one general, one for women with gynaecological cancers). The groups are restricted to referred participants and facilitated by a Cancer Council staff member. (<http://www.cancerwa.asn.au/helpline/chat.php>).

Other electronic support "groups" and mailing lists

- There are three Australian-based email discussion groups for people dealing with the diagnosis of a brain tumour: the OzBrainTumour list (<http://health.groups.yahoo.com/group/OzBrainTumour/>), established in 2000 and providing a forum for exchange of information about all aspects of dealing with brain cancer, and a list specifically for carers and former carers, called OZBT carerplace (<http://health.groups.yahoo.com/group/OzBTcarerplace/>). A new discussion forum was launched in 2005, <http://www.btsurvivor.com/>, which is "dedicated to discussing survivorship, treatment options available now and those options on the horizon that show promise", and includes exchange of information about use and side effects of various therapies including non-conventional treatments.
- B-Mail is a mail list server for women with breast cancer wanting to "talk" to peers. It is provided by the NSW Breast Cancer Institute and described as an "electronic community of people interested in breast cancer" including patients, survivors, families and friends, clinicians and health professionals.
- The Gynaecological Cancer Society hosts a moderated online electronic mail discussion group, talk@gcsau.org. This group, or mailing list, is intended to provide general group support to people affected by gynaecological cancers or those providing physical, psychological or spiritual care.
- Australian Kidney Cancer Online Support (Akcoss) was formed when seven Australians with kidney cancer met on an international list serve and realised that there was very little support or information available in Australia for people with kidney cancer. The site includes an online forum.
- The National Ovarian Cancer Network (OvCa) hosts an online, moderated forum for women with ovarian cancer and carers.
- The YANA (You are not alone now) Prostate Cancer Support Site (www.yananow.net) has been specifically designed to provide support to men newly diagnosed with prostate cancer, their partners and children. It has a "mentors" page, providing email links to men with prostate cancer who are volunteer peer supports.

In addition, a number of organisations are known to be currently developing or trialling alternate modes of delivering peer support to groups of people, including:

- The Leukaemia Foundation is developing online forums and considering the potential uses of webcasting.
- CanTeen is trialling methods of linking young people affected by cancer who are geographically separated in the top half of Queensland, including teleconferencing and videoconferencing, and is also establishing online forums for different membership groups.
- A trial of a Closed Circuit Television (CCTV) link of isolated cancer patients in the New England area has been recently completed and results are soon to be published.

4. Cancer support group networks

Most peer support groups are initiated by people affected by cancer themselves, but often are organised under the auspices of or with the support of Cancer Councils, community groups or hospitals and health services.

Several formal and informal “networks” of cancer support groups have evolved in Australia in recent years. Support group networks have been established by organisations such as the state and territory Cancer Councils, Prostate Cancer Foundation Australia and Brain Tumour Australia to link and support existing groups and help facilitate the development of new groups.

Some networks invite groups to become affiliated members, agreeing to adhere to guidelines or rules, while others are more informal coalitions of groups within a region or providing similar support. Like support groups, these networks may be professionally supervised eg the Australian Lung Foundation’s patient support activities are overseen by several clinicians, or peer supervised, eg the Support and Advocacy Committee of the Prostate Cancer Foundation of Australia.

Cancer support networks aid the development and maintenance of support groups by facilitating contact between groups, enhancing communication between support groups and the auspicing organisation (eg Cancer Council) as well as local health agencies; provide information about cancer and cancer support; and often providing resources and/or training for group facilitators.

The formation of networks helps prevent duplication of services and may encourage development of complementary support services in regions, in terms of group type or timing of meetings.

Many support groups also rely on these support group networks for financial, practical or organisational support. Consultations with support group leaders and support group network convenors revealed that most groups relied on one or more sources of support or funding to sustain groups, including:

- reliance on volunteers
- Cancer Councils (see below)
- hospitals or community health services (see below)
- corporate supporters and communities (for donations or in kind provision of meeting rooms, equipment and other services such as printing or photocopying)
- Federal, state/territory and/or local government grants.

As an indication, a Queensland Cancer Fund survey of cancer support groups in Queensland found that more than 40% of groups described the Queensland Cancer Fund as the main source of support for the group; 25% listed hospitals, 20% private organisations and 16% Community Health Centres as the main source of support, with some having more than one source. The type of support included meeting rooms (68%), photocopying and postage (59%), a health professional to facilitate meetings (32%), training for members (16%) and funds (13%). But, one-fifth of the groups (20%) received no support from any source.

4.1 Cancer Councils

Each of Australia's state and territory Cancer Councils has developed initiatives to ensure people affected by cancer have access to high-quality, community-based support groups.

In response to evidence showing the benefits of support groups in meeting psychosocial needs and requests for assistance from current groups and those wanting to start their own groups, the Cancer Councils offer a range of services and resources to support the creation and maintenance of support groups, such as:

- resources such as information kits, including advice and template documents for people establishing new groups or running groups
- group leader training and support (eg a contact person for advice or opportunities to "debrief" with trained counsellors)
- a link to other cancer support groups and newsletters providing information and a forum to exchange ideas
- cancer information, guest speakers or other resources for meetings
- expert assistance and advice.

Most Cancer Councils have a dedicated staff member whose role is to assist groups. Some provide staff as group facilitators, co-facilitators or facilitator "supporters" for groups, eg helping to evaluate the needs and effectiveness of a group, or to provide advice or assistance when needed.

Group leader training programs aim to develop the group management skills of current leaders, as well as developing new leaders to help sustain groups by preventing burn out and encouraging succession planning. Training programs also provide an opportunity for group leaders to network and exchange information and ideas. In NSW, The Cancer Council also runs communication workshops for regular participants of cancer support groups, many of whom find themselves in the position of providing informal peer support.

4.2 Hospitals and health services

Many Australian hospitals and health services coordinate or host at least one cancer support group. Most have a nominated staff member who coordinates the provision of and/or information about support services including groups.

Where support groups are organised and/or led by volunteer peers, the hospital or health service often assists groups by providing a meeting venue and equipment and supporting a staff member to co-facilitate meetings, provide advice and information, create formal linkages between group leaders to encourage information exchange and development of skills and between the groups and hospital or health service (to assist in promotion and encouraging referrals). Hospitals and health services also might support groups by developing resources, newsletters, etc.

Several large hospitals have a dedicated cancer support centre. Two long-running and well-regarded centres are Cansupport at Sydney's Royal North Shore Hospital and the Cancer Support Centre at the Sydney Adventist Hospital. Cansupport was established 25 years ago and now has almost 90 volunteers providing peer support individually and via groups led by a professional facilitator. The Sydney Adventist Hospital Cancer Support Centre provides information, education, support and counselling. The Centre provides assistance and resources for support group facilitators.

In NSW in October 2005, for the first time, support group coordinators from several metropolitan hospitals met to talk about identified gaps, successes and challenges, improving cross-referral and developing complementary services (rather than duplicating groups) and opportunities for professional development. This meeting provided an insight into the wide range of professionals running groups (not just psychologists or social workers) and an opportunity to identify similarities and "some quite wide differences" in organisation and delivery of support services by hospitals (*O'Reilly*).

4.3 Community cancer support centres

There are now a few independent, community-based cancer care or cancer support centres in Australia, which offer a variety of supportive services, including groups, to people affected by cancer.

The Cancer Care Centre in Adelaide, formed in 1985, provides an integrated program of self-help for people affected by cancer including courses, support groups, seminars, counselling and resource sharing. Most services are provided by volunteer, trained support workers.

The Cancer Support Association of WA formed as a support group in 1984, later growing to provide a range of holistic, evidence-based self-care and healing services and information resources.

Similarly, although “centre-less”, the Cancer Patient Support Group, Illawarra, acts as a network of cancer type-specific groups and other services, providing opportunities for group leaders and members to interact, and resources and support to the groups and their members.

4.4 Cancer type-specific support group networks

The **Prostate Cancer Foundation’s** network of support groups has evolved in response to the proliferation of patient-initiated groups across Australia. More than 60 prostate cancer support groups are affiliated members of the Prostate Cancer Foundation of Australia. The Foundation provides resources for group leaders and speakers and hosts an annual conference, providing an opportunity for group convenors to network and exchange information.

The Foundation’s state/territory chapters network existing support groups and also seek to facilitate new groups where there is an evident need and people interested in developing a group (both usually identified as a result of an awareness evening). State chapters work with their local Cancer Councils in most regions to access training for group leaders.

The Prostate Cancer Foundation recently has employed a dedicated National Support and Advocacy Manager to work with the National Support Group Network and the Support and Advocacy Committee to, among other tasks, assist and develop current and future support groups and enhance and manage the relationship between PCFA and state Cancer Councils to maximise opportunities for support and assistance.

The **Australian Lung Foundation** has recently established a National Lung Cancer Patient Support Network – a group of organisations, including The Australian Lung Foundation, the state and territory Cancer Councils, Asbestos Diseases Society, Peter MacCallum Cancer Institute and Sydney Adventist Hospital – to identify and implement projects that will address support needs of people affected by lung cancer. The ALF currently coordinates a network of 104 support groups for people with lung disease, predominantly chronic obstructive pulmonary disease.

Other national cancer-specific consumer organisations, such as the **Breast Cancer Network Australia**, the **National Ovarian Cancer Network**, the **Myeloma Foundation of Australia** and the **Australian Council of Stoma Associations**, most of which have support groups as members, do not facilitate groups or financially support them. But they do provide information to support group leaders and members, assist networking and information exchange via their newsletters and other mediums, and encourage participation by providing referrals to and/or information about existing groups. Similarly, the **Leukaemia Foundation of Australia** acts as an umbrella organisation for several independently-organised support groups across Australia, though it has taken on a more active role in sustaining some peer-led groups when the group leaders have died or retired from the role.

These organisations also enhance the provision of support for people affected by cancer by identifying gaps and encouraging the development of groups to meet specific needs. The NSW consumer advocacy organisation **Cancer Voices NSW** has assisted in the formation of statewide tumour-specific cancer support networks for people affected by cancers for which there are few traditional support groups – the NSW Lung Cancer Group in 2004 and more recently, in association with The Cancer Council NSW, NSW Gynae Cancer Voices to link (primarily via email) women affected by gynaecological cancers.

4.5 Cancer consumer and advocacy groups in Australia

The evolution and increasing popularity of cancer peer support groups has in part driven the development of several cancer advocacy or consumer groups, to promote the interests and concerns of people affected by cancer. Many peer support groups have engaged in individual advocacy (representing someone or a group of people) as adjuncts to their core function of providing emotional and informational support. Several advocacy groups have evolved as networks of support groups, to undertake the systemic advocacy (seeking broad change) that individual groups find difficult.

Cancer advocacy groups seek to represent the interests of and advocate for measures to address issues of concern to a group of cancer consumers. These groups may have support groups as members and/or have an interest in promoting and encouraging supportive care, but providing emotional support or support groups is not a core activity. As acknowledged above, these groups provide information that assists their support group members, generally via newsletters, conferences or forums, etc.

The personal benefits for cancer consumers involved in cancer advocacy groups generally comes from the outward focus on changing health service delivery, but members acknowledge that the peer interaction, while incidental, is immensely supportive.

Cancer advocacy groups in Australia have differing structures and objectives, but generally are established and directed by cancer consumers to voice the views, concerns and needs of particular groups of people affected by cancer. There are several tumour-specific cancer advocacy/consumer organisations as well as three state/territory Cancer Voices organisations and emerging cancer consumer groups/networks in most other states and territories, namely:

- Australian Council of Stoma Associations
- Brain Tumour Australia
- Breast Cancer Network Australia
- Breast Cancer Action Groups in NSW and Victoria, Action on Breast Cancer WA and Breast Cancer Voice (NT)
- Cancer Voices ACT
- Cancer Voices NSW
- Cancer Voices Victoria
- Cancer Voices WA
- CanTeen
- Laryngectomee Associations in each state/territory
- Leukaemia Foundation
- Myeloma Foundation of Australia
- National Ovarian Cancer Network
- Prostate Cancer Foundation of Australia's Support and Advocacy Committee

Cancer consumer networks are also in development in Queensland and Tasmania.

Many people affected by cancer have acknowledged the need for a new national group or network to represent and voice the common interests and concerns of people affected by cancer in Australia.

In recognition of this need a meeting of representatives of the existing national (cancer type specific) and state/territory advocacy and consumer groups was convened on 19 October, hosted and supported by The Cancer Council Australia.

Participants agreed to establish a new organisation to identify and voice the common concerns and interests of people affected by cancer at a national level. This organisation will complement existing activities of national organisations representing people affected by a particular type of cancer and the state/territory Cancer Voices organisations and other emerging consumer advocacy groups and networks.

5. Gaps

5.1 The support needs of people affected by cancer

“Almost everybody benefits from getting support and information from somewhere. There is an assumption among health professionals that you only refer people who are having difficulties. That damages the reputation of support groups. Support is essential for every patient because it helps improve capacity for coping.” (O’Reilly)

The extent to which a person with cancer has support and feels supported has been identified as a major factor in their adjustment to the disease. The need for support will vary depending on the person’s individual strategies and to what extent emotional concerns impair their daily living (NBCC and NCCI, 2003).

There is a growing belief that all people affected by cancer need to receive appropriate information at least, and some assessment of support needs. Hutchison et al (in press) suggest cancer-related information and brief support from a health care professional in the treatment team or cancer-related telephone helpline, and other information focussed interventions such as decision support and patient education, should be *universal* care for anyone affected by cancer. In Hutchinson et al’s tiered psychosocial intervention model, peer support programs and psycho-educational programs are listed as level 2 interventions, suitable for people with mild to moderate distress.

People affected by cancer with clinically-significant distress, depression or other psychological needs require specialist or acute therapeutic interventions, but peer support groups may be beneficial for the majority of people affected by cancer whose levels of distress are relatively mild and are predominantly seeking information and shared experiences.

A survey of the supportive care needs of almost 900 Australian cancer patients found high levels of unmet needs across a range of domains, including patient care and support. Sanson-Fisher et al (2000) found that patients currently receiving treatment for cancer of the lung, bowel, colon, rectum or brain were significantly more likely to report a need for care and support than patients receiving treatment for breast cancer.

The *Guidelines for the psychosocial care of adults with cancer* (NBCC and NCCI, 2003) cite evidence that patients with laryngeal, lung, gynaecological or colorectal cancer report significant restrictions to social activities, and notes that a lack of social support correlates with levels of depression. If the restriction to social interaction is related to stigma or embarrassment, support groups could provide a “safe” forum for people affected by these cancers to gain support, confidence and social interaction.

Despite high unmet needs and the established benefits of participation in support groups, the majority of people affected by cancer do not attend groups. Is this because of unavailability of groups appropriate to their needs, ie “gaps” in access to support groups? Further research is needed to determine if most people affected by cancer or people with particular cancer types want and would benefit from support groups.

5.2 Lack of support groups for people affected by common cancers

In Australia there are no or few support groups for people affected by the most common cancers other than breast and prostate (the most prevalent cancers in Australian women and men respectively).

The table below shows the number of support groups in Australia for people affected by each of the 10 most frequently occurring cancers and for women with ovarian cancer, because it was identified as a priority cancer for development of support groups, along with bowel and lung cancers, in the Federal Government's *Building Cancer Support Groups* initiative.

Cancer site	New cancer cases (2001) ¹	Five year survival rate ² M / F	Number of cancer type-specific support groups
Colorectal	12,844	C: 58.3 / 58.7 R: 56.6 / 60.6	5 + 11 groups for ostomates*
Breast	11,886	84	172
Prostate	11,191	82.7	63
Melanoma	8,885	90 / 94.6	0
Lung	8,275	11 / 14	2 (1 telegroup)
Non Hodgkin's Lymphoma	3,499	54.6 / 55.8	2 (lymphoma)
Unknown site	3,304	13.4 / 11.4	
Bladder	2,954	70.8 / 64.7	0 (11 groups for ostomates*)
Kidney	2,458	59.9 / 57.5	0 (1 online service)
Stomach	1,902	22.6 / 24.8	0
Ovarian	1,295	42	4 + 8 gynaecological cancer groups

* Most people who have a stoma have had surgery for bowel cancer, although a small number may have had bladder cancer or ulcerative colitis.

Colorectal (bowel) cancer is the most common cancer in Australia, with more than 12,800 new diagnoses each year, but there are only five support groups for people with bowel cancer. There are no support groups for people with melanoma and just two groups for people affected by lung cancer.

Many people affected by these common cancers may attend one of the more than 220 "general" cancer support groups currently operating, which are open to people with cancers of any type. There are also a small number of groups for people with advanced cancer (7) and groups for women (8) or men (3) with any type of cancer. It was not possible to seek to assess membership of these various groups within the scope of this project.

People with less common cancers also might benefit from the provision of a greater number and range of psychosocial support services, but the greater difficulties of establishing and maintaining support groups for people with less prevalent cancers has been noted. Again, further research is necessary to determine if people affected by cancers where there appear to be "gaps" want, and would benefit from, increased availability of support groups.

Importantly, availability of a relatively large number of support groups does not necessarily indicate that there are not "gaps" in supportive care. Despite wide availability of breast cancer support services and groups, a survey of women with breast cancer found that 15% would have liked more emotional support and counselling for themselves, and 9% wanted more for

¹ Number of new cancer cases for the 10 most frequently occurring cancers in Australia plus ovarian cancer (AIHW & AACR, 2004).

² AIHW & AACR (2001).

their families. About half of the younger women and 29% of older women needed additional services at some point (Williams et al, 2002). There is also an identified need for specific groups for women with advanced breast cancer and to meet the particular information and support needs of young women with breast cancer (eg Thewes et al, 2004).

5.3 Other gaps in availability of support groups

The scoping study also highlighted the low number or absence of support groups for other cohorts of people affected by cancer with identified needs for better informational and emotional support.

Many of the contributors to this project also noted these gaps, and referred to perceived need for and potential benefits of support groups for currently “underserved” cohorts of people affected by cancer, who have common support needs because of their:

- Geographical location
- Age
- Cancer stage
- Culturally or linguistically diverse background
- Relationship to a person with cancer, eg carer or parent of a child with cancer.

Geographical location

There are no or few groups in most rural and many regional areas of Australia. This is generally attributed to population numbers – support groups need a minimum membership base to be sustainable and effective. For example, the experience of prostate cancer support group convenors in Queensland is that a population of about 30,000 is needed to ensure a viable support group – one with members “who have had experience in most situations and can provide peer support to all comers” (*Broughton*). Support group convenors suggest a minimum number of participants required for an effective group is six to eight, and that a membership base of about twice that number is necessary to allow for attrition (*O’Reilly, Anderson*).

Age

The informational and emotional support needs of people affected by cancer and cancer survivors differ according to age.

There is evidence that younger people affected by cancer may suffer higher levels of distress, which might be due to a larger disruption of social and familiar roles, such as raising small children and establishing careers, perception that it is “less fair” for a young person to have cancer and/or more limited life experience and problem-solving skills (Carlson et al, 2004).

Several studies have highlighted the importance to support group participants of identifying with other members of the group, hence a preference to be in a group with others of a similar age. Recent studies have highlighted the need for age-specific groups or at least acknowledgement within groups of distinct age-specific needs to reduce feelings of isolation experienced by younger people affected by cancer (eg Thewes et al, 2004; Vivar and McQueen, 2005). Dunn et al (in press) recommend investigation into different psychosocial sequelae among younger and older patients with colorectal cancer based on evidence of very different difficulties and concerns of each group.

It is increasingly recognised that adolescents and young adults with cancer have unique needs to both child and adult cancer patients. The specific challenges in managing the treatment of young people affected by cancer have been acknowledged, and their supportive care needs also are distinct from those of other groups of cancer patients.

Cancer stage

People with advanced cancers have higher levels of distress and different support needs to newly diagnosed patients with good prognoses. Some argue that people with advanced cancers of different types have more in common in terms of psychosocial needs than, for example, with newly diagnosed people with early stages of the same cancer type.

There also has been growing acknowledgement in recent years of the ongoing and distinct psychosocial needs of cancer survivors.

While most long-term survivors cope effectively with the psychosocial issues they face, advice and help from informal social support and particularly from self-help groups seem beneficial (review by Vivar and McQueen, 2005). Women with breast cancer, for example, report a wide variety of ongoing psychosocial and information needs including need for support.

While the need for a large supportive network decreases over time, "sharing ideas with others in a similar position can help women understand the course of survivorship and see that the sequelae of breast cancer are not unique to them" (Vivar and McQueen, 2005).

Again, the need for education and support programs to be age-specific has been highlighted, given differences highlighted in survivors' needs and barriers to participation in groups eg young survivors' need for expedient return to work; older survivors' difficult with travel and reluctance to attend evening programs (Narsavage and Romeo, 2003).

People of culturally or linguistically diverse backgrounds

Despite Australia's multicultural population, there are few groups that offer culturally or linguistically appropriate support to different groups of people affected by cancer: 1 Cantonese, 1 Chinese, 1 Italian, 1 Vietnamese, 2 Greek (women) and 1 Spanish (breast cancer).

There are only two groups for Indigenous Australians, one in western Sydney and one for women currently being established in Newcastle. An Encore group for Aboriginal women with breast cancer has recently been established in Kempsey, NSW. The need for groups specifically for Aboriginal people affected by cancer was highlighted by Joy Reid, who is facilitator of a group in development for Aboriginal women with cancer in the Hunter region of NSW:

"I identified the need from my own experience and how I felt and how I was treated when I went through the process. I went to one support group ... and they just started asking me all sorts of questions [about how to increase Aboriginal people's participation in the group]. It took away my need; I wanted a group where it is about my individual needs."

Carers and family members

There is an increasing burden on carers resulting from earlier discharge of cancer patients from hospital, growing use of outpatient services and longer survival. Supportive care providers acknowledge that carers, particularly carers of palliative care patients, have distinct and generally unmet needs for emotional, as well as practical, support.

The clinical practice guidelines for the psychosocial care of adults with cancer acknowledge that families and carers may benefit from information about support services and groups that can provide assistance, support and counselling. But there are few services and groups available.

There is evidence that the partners and children of people with cancer are also vulnerable to psychological distress and have unmet needs for information and emotional support. In an Australian study of people with advanced cancer in the palliative care setting, one third of their spouses and one quarter of their offspring showed evidence of substantial psychological distress warranting specific support (Kissane and Burns, 1994).

5.4 Is creating more support groups the solution?

Cancer support groups are not an appropriate or preferred means of accessing psychosocial support for all people affected by cancer. People with cancer who have significant psychological distress affecting quality of life require specialist interventions. For those who are physically debilitated and/or more seriously distressed, participation in face-to-face support groups may not be possible or beneficial.

Support group leaders and support group network convenors (and many published studies) have highlighted a number of factors associated with the absence or low number of support groups for people with certain types of cancer, including:

- Low prevalence of the disease within the general population and poor prognosis – support groups need a certain number of members to be functional and sustainable.
- Low survival rate.
- High levels of morbidity due to the disease and treatment – poor health, treatment-induced inability to drive or frequent readmissions to hospital may make regular attendance at face-to-face meetings difficult.
- Geographic challenges – many people are unable or unwilling to travel long distances to attend a support group.

People in some demographic groups that have a low incidence of cancer have identified peer support as a preferred source of support (Dunn and Steginga, 2000, referring to young women with breast cancer). Peer support groups also may be a preferred style of psychosocial intervention for specific groups for whom social stigma or isolation is a problem. While there are indications that people with diseases considered stigmatising (eg breast and prostate cancer) are more likely to seek support in the form of self-help groups than others with equally serious, but less “embarrassing”, diseases such as heart disease (Davison, Pennebaker and Dickerson, 2000), it is unclear whether these people specifically seek out unstructured, peer support groups (or would be willing to participate in other psychosocial support) or what form of intervention would be most efficacious.

Forming traditional face-to-face support groups for people affected by particular cancers may not necessarily be possible, or may not be the best means of meeting their psychosocial support needs.

General or type-specific groups?

Assuming a support group *is* appropriate, the question of whether a cancer type-specific group more or less effective than a general cancer support group or group for people with advanced cancers of all types remains unresolved.

The experience of many convenors and facilitators of cancer support groups (eg Weis, 2003, and many leaders consulted for this project) is that site-specific groups are helpful for people affected by cancer as they allow them to discuss problems with peers and facilitate self-disclosure. For example, while some people with bowel or ovarian cancer participate in general support groups, there is an assumption that most are reluctant to do so because of the nature of their disease and impact of treatment. (See page 38 for evidence of the needs/preference of women with ovarian cancer for cancer type-specific groups.)

Mandy O'Reilly, Manager of Cansupport, believes newly-diagnosed patients tend to look for cancer type-specific groups, but “as they work their way through treatment and begin addressing psychosocial issues, many begin to realise there is a great commonality of response”.

An Australian study of the benefits of support groups concluded that people attending heterogenous (general) groups, especially if led by non-health professionals, had greater improvements in general and mental health than those in cancer type-specific groups, particularly in relation to rapidly falling anxiety levels (Ussher et al, 2003).

This conclusion is supported by many support group facilitators who argue that heterogeneous groups are not harmful and may be preferable:

"It's not about the specifics of the disease; it's the impact of what is happening to a person psychologically, relationships in their life and treatment ramifications. There are a lot of parallels despite the idiosyncrasies of the disease." (Anderson)

"I'm not offering medical advice so it doesn't matter what cancer they have. The shock of diagnosis and difficulty for family and overall experience is common to all cancers. I don't want to be turning people away because they don't have a particular cancer." (Falconer)

On the other hand, there is evidence of increased demand for cancer type-specific peer support (including groups) with the increasing popularity and usage of one-on-one peer support programs (such as Cancer Connect) that match people seeking support with former patients with similar disease, treatment and demographic characteristics. There are also anecdotes of increasing demands for information and support that is disease or issue specific eg the Leukaemia Foundation reported increasing interest from patients in disease-specific education programs, from which support groups often develop (*Williams*).

Cancer type-specific support groups have evolved not only in response to incidence levels, but the needs and preferences of people affected by particular cancers. The majority of cancer specific support groups are for women with breast cancer and men with prostate cancer. This reflects the fact that these are the most common cancers for each gender, but there also is evidence to support the benefits of support group participation, and a preference for support groups, from the women and men affected by these cancers.

The solution is not to simply redress the apparent imbalance in availability of support groups by creating cancer site-specific groups where there are currently none or few. It is necessary to consider the psychosocial needs and preferences of people with those cancers and the barriers to creating and maintaining support groups for these specific groups of people affected by cancer.

Alternative group support mechanisms

The unmet social support needs of certain cohorts of people affected by cancer might be better addressed by alternatives to the traditional face-to-face support group.

"Barriers" to establishing or sustaining groups such as low prevalence within a geographical region, high morbidity, transport difficulties or embarrassment may be addressed by alternate methods of delivering group support, such as via telephone or internet support groups.

Telephone support groups may be a preferred medium for people with cancer types that have a high morbidity and mortality rate. The Cancer Council NSW has observed growing interest and significant benefits reported by people with lung, brain or advanced cancers participating in its telephone group counseling program.

Campbell et al's (2004) review of peer support evaluation studies found that telephone and internet support programs were particularly beneficial to people with less common forms of cancer, to those who were housebound or geographically distant and to those desiring privacy. Davison et al (2000) also found that patients with diseases that present physical barriers to attending support groups (eg MS and chronic fatigue syndrome) showed the highest rate of online support group participation. Whether internet support groups appeal to or benefit all persons living with cancer or only a subset has not been explored.

Also, Helgeson et al (2001) have suggested that a one-to-one peer support service, such as Cancer Connect, where peer supports are trained and supervised, may be more effective than peer support groups.

5.5 Support for people affected by bowel, lung and ovarian cancers

The Building Cancer Support Groups policy within the Federal *Government's Strengthening Cancer Care* initiative commits funding to the development of additional support groups for people affected by cancer, particularly those with bowel, lung or ovarian cancer.

This section identifies existing peer support groups and programs for people affected by bowel, lung or ovarian cancer and explores some of the actual and perceived barriers to creating and sustaining support groups.

Bowel cancer

Bowel cancer is the most common cancer in Australia. Prevalence is rising due to population ageing and it is anticipated that the introduction of population screening programs will increase awareness of bowel cancer as well as the number of people living longer with bowel cancer.

According to the recently published *Clinical practice guidelines for the prevention, early detection and management of colorectal cancer* (NHMRC, 1999) there is evidence that up to 50% of patients with colorectal cancer suffer depression and many suffer problematic levels of anxiety and psychological distress. There is also evidence that families of colon cancer patients experience adjustment problems.

Dunn et al (in press) found that several bowel cancer patients surveyed found support from others with similar experience to be beneficial, emphasising the importance of support groups. Participants also reported difficulty in obtaining information about what they could expect in the long term, a need support groups might help address.

Existing support services

This project identified five support groups specifically for people affected by bowel cancer, and 11 groups for people with stomas (the majority of whom have had bowel cancer, though some may have stomas as a consequence of treatment for bladder cancer or ulcerative colitis). There are two professional-led, hospital-based groups reportedly in development in regional NSW (Gosford and Coffs Harbour).

The bowel cancer support group at the Sydney Adventist Hospital is the largest group, with 18-20 members attending each fortnightly meeting. Groups in the Illawarra region (NSW) and Hobart (Tas) have very low numbers of regular participants, and another bowel cancer support group, in regional Victoria, "temporarily closed" during the course of this project due to lack of members.

One-on-one telephone peer support services for people with colorectal cancer are provided by the Cancer Councils in NSW, Queensland, South Australia and Victoria. These services link people with bowel cancer to trained men and women who have had bowel cancer, who are similar in terms of age, gender, treatment type and other relevant factors. In contrast to the small number of people participating in support groups, many more people affected by bowel cancer are utilising one-on-one peer support: more than 300 in NSW over the past six years, and 38 in Victoria in 2004.

Barriers to establishing and sustaining groups

The existing bowel cancer-specific support groups have low numbers of participants and identified common challenges in recruiting additional members, such as allaying patient and carer concerns about embarrassment and failure of doctors and health professionals to refer patients to groups (*Barrett, Taylor*). Despite the challenges, the facilitator of the SAN group believes bowel cancer-specific support groups are necessary to recruit patients (*Taylor*).

The Cancer Council Victoria has commenced a project, with funding support from the Federal Government's Building Cancer Support Groups initiative, to investigate factors contributing to low uptake of peer support by people affected by bowel cancer and to trial and evaluate different models of peer support to address or overcome barriers identified.

A Canadian study to examine bowel cancer patients' interest in support group programs and barriers to attendance found that while a significant proportion of patients were interested, only a minority ultimately participate in support groups (Bui et al, 2002). The most frequently cited reason for non-attendance was a perception of adequate support at home, followed by living too far away, no perceived need of support, and not feeling well.

Bui et al note that previous studies have found that men are less likely than women to participate in support groups, and presenting gender-sensitive support groups might increase men's participation in bowel cancer support programs.

Lung cancer

People with lung cancer are consistently ranked as having the highest levels of distress and need for support (Carlson et al, 2004; Zabora et al, 2001; Sanson-Fisher et al, 2000). Studies indicate patients with lung cancer have rates of psychological distress between 15% and 25%, climbing to 69% as the disease becomes more advanced. Depression has been identified in about one-third of patients before treatment and persisted in more than 50% of patients following treatment (ACN, 2004).

The clinical practice guidelines for the prevention, diagnosis and management of lung cancer (2004) identify a range of psychological therapies available to assist in enhancing coping and relieving distress in patients with lung cancer. The acute needs of many people affected by lung cancer may not be effectively addressed by participation in non-therapeutic peer support groups.

A project to assess the support needs of patients with lung cancer and develop an appropriate model or models of peer support for patients and their families is underway in Victoria. The Peter MacCallum Cancer Centre (with funding support from the Federal Government's Building Cancer Support Groups initiative) plans to determine the general and unique support needs of people affected by lung cancer, determine the reasons existing support services are under-utilised and develop, pilot test and evaluate a model or models for providing support to lung cancer patients. Depending on analysis of patient needs, the project will consider the applicability of peer-led versus professionally-led programs and individual versus group based support.

An NHMRC-funded randomised controlled trial also is underway, evaluating "an innovative program to address the needs of people with incurable cancer", which is expected to provide information about the unmet needs and quality of life of people with lung cancer.

Existing support mechanisms

There is only one support group specifically for people affected by lung cancer in Australia, provided by the Sydney Adventist Hospital. The group meets fortnightly with members attending the group in person and others linked by telephone, and is professionally facilitated.

The Australian Lung Foundation has recently established a National Lung Cancer Patient Support Network – a group of organisations, including The Australian Lung Foundation, the state and territory Cancer Councils, Asbestos Diseases Society, Peter MacCallum Cancer Institute and Sydney Adventist Hospital – to identify and implement projects that will address support needs of people affected by lung cancer. The Network has identified the existing support groups for people affected by lung cancer and is exploring models and barriers to facilitating more groups. The ALF received a Building Cancer Support Group grant to develop lung cancer support groups in Queensland.

There are two support groups and a telephone support service (provided by the Asbestos Diseases Society) for people affected by asbestos-related diseases, which may include people with lung cancer.

Barriers to establishing and sustaining groups

The high mortality and morbidity rate for lung cancer patients impacts on group participation in several ways: there is a small number of potential participants; patients, particularly those with advanced disease, are often too unwell to travel to attend support groups; and, conversely, patients who are relatively well or having longer prognoses are reluctant to attend as “they are not keen to see patients with further advanced disease” (*Taylor*).

Respiratory physician Kwun Fong, who chairs the Australian Lung Foundation’s National Lung Cancer Patient Support Network, has admitted that specialists have previously been unsupportive of the idea of support groups for people with lung cancer, fearing the impact of seeing others with more advanced disease and dealing with deaths will have a negative impact.

However those running or seeking to create groups for people with lung cancer claim they are an effective and positive way of providing emotional support to patients and their families.

Ovarian cancer

There is evidence to support the need or preferences of women with ovarian cancer for cancer-specific support groups. Ferrel et al (2003) report that peer support for women who share the same diagnosis provides a safe haven in which women can express their fears and concerns to others who have ‘walked in their shoes’. Women with ovarian cancer have cited the benefits of peer support to include encouragement and reinforcement, sharing of coping mechanisms for symptom management and the opportunity to help others (Fitch, Gray and Franssen, 2000).

Fitch et al’s study of the views of more than 260 Canadian women with ovarian cancer found that while most were satisfied with the medical information they received, they were dissatisfied with information regarding psychosocial issues, such as contacting other ovarian cancer survivors. The study also found that 26% of ovarian cancer patients in remission and 28% experiencing recurrent disease expressed a desire to participate in support groups, but they were not provided the opportunity.

Ferrell et al’s qualitative analysis of comments by women with ovarian cancer found that many women thought their inability to find ovarian cancer-specific support groups meant that no one survived the disease.

Existing support mechanisms

There are four support groups for women with ovarian cancer in Australia, one of which is open to women with other gynaecological cancers, and nine groups for women with gynaecological cancers.

One-on-one peer support is provided via the Cancer Connect program in NSW, Queensland, South Australia and Victoria. In NSW a relatively high number of referrals to Cancer Connect gynaecological cancer volunteers has been seen as an indication of the need and preference for one-on-one support (*Batt*). This year The Cancer Council NSW and Cancer Voices NSW helped establish a network of women with gynaecological cancers to provide a forum (primarily via email) for women to exchange information and support.

The National Ovarian Cancer Network (OvCa) hosts an online, moderated forum, which it has found to be popular, particularly for women who are geographically isolated or too unwell to attend a face-to-face group.

Barriers to establishing and sustaining groups

Perhaps the greatest barrier to creating sustainable support groups for women with ovarian cancer is the relatively low incidence. There simply are fewer women with ovarian cancer available to organise, facilitate and attend groups. Even at major hospitals providing ovarian cancer care attempts to establish ovarian or even general gynaecological cancer support groups have failed because of a lack of interest (O'Reilly, Robertson).

The existing groups have responded to this challenge by having health professionals or well women volunteers assume responsibility of organising and/or facilitating groups. The WA ovarian cancer support group is supported by a Cancer Council counsellor and group members are rostered to set up the meeting venue and lead the group. Groups that have been established and run by patients without professional support have generally lasted only a short time and been unsuccessful (Gower).

Sustaining groups is also difficult for the facilitator:

“Dealing with frequent deaths of members was very confronting and wearing. I have been in this job for 15 years, and I found it really hard.” (Robertson).

Roslyn Robertson, psychologist at the Royal Hospital for Women, also noted that many women did not want to attend a group run at the hospital, some reacting quite angrily to the suggestion as they did not want to return to the hospital environment post-treatment.

Again, the opinion of oncologists and other health professionals and their reluctance to refer patients to support groups was identified as a barrier. An illustrative comment from one ovarian cancer survivor was that her gynaecologist said it would be “too depressing and too confusing” to have a support group for women with gynaecological cancers.

A recent survey of Australian women with ovarian cancer and their carers and family members found that nearly 60% of respondents indicated that they received too little information about support services. When asked what is important to them, many of the women indicated they wanted the opportunity to talk to someone with similar experience (Francis, 2005).

Research underway

The Australian Ovarian Cancer Study (AOCS) Quality of Life Study aims to examine the role of psychosocial variables in predicting the quality of life, recurrence and survival and to identify the support needs of women with ovarian cancer and their partners/carers. The study by Diana Grivas and Phyllis Butow et al commenced recruitment in May 2005.

6. Building cancer support groups

Despite the reported benefits and relative popularity of support groups as psychosocial support mechanisms, only a minority of people affected by cancer join support groups, the dropout rate is high and little is known about factors that influence utilisation and effectiveness of support groups of different types.

One of the aims of this project was to identify the key principles or “success factors” of effective cancer support groups. The first issue to be considered is how to evaluate groups and the outcomes by which support group “effectiveness” can be defined and measured.

There are several instruments and measures used by researchers investigating the impact of psychosocial interventions on outcomes such as quality of life, anxiety, depression, social support or self-esteem. However most studies of cancer support groups have not used validated instruments but questions developed by the authors themselves to assess outcomes such as participant satisfaction and perceived benefits of support groups or group leaders’ perceptions of the usefulness of groups for members.

In their examination of the effectiveness of support groups for people with cancer in NSW, Ussher et al (2003) conducted a workshop to encourage stakeholder and consumer participation in the design of the project. It was agreed that the five key outcomes by which support group effectiveness should be assessed were health-related quality of life, cancer-related empowerment, anxiety, depression and satisfaction with the group.

There is general consensus that effective cancer support groups should significantly improve the mental, emotional and/or social health of participants. The question of whether participation in support groups – generally or specific types of groups – can positively impact on physical health and survival is yet to be resolved.

6.1 The evidence: what works?

Unequivocal evidence about “what works” for people affected by cancer – both generally, and for specific subgroups with identified needs – would better inform the development of support groups (and other psychosocial support interventions). Many researchers have highlighted the need for further research that will, to quote one, “address the issues of how and for whom specific interventions do or do not carry positive effects” (Stanton, 2005).

Attempts to compare the benefits or outcomes of different types of groups have been hindered by the lack of agreed definitions of different types of interventions. Support groups or programs rarely have a single focus and may include a combination of modalities such as psychoeducation, supportive care, stress management, relaxation, etc. Peer support groups generally include educational activities, often supported by a health professional, and psycho-educational programs delivered in a group format will, as a consequence, include an aspect of peer support. Much of the research does not distinguish clearly between studies of conventional group psychotherapy and those of support groups. Many studies that claim to study self-help groups are actually studies of psychotherapy or support groups led by a professional. However, most of these groups have in common some apparently therapeutic qualities, such as opportunities for disclosure, decrease in isolation, psychological adjustment and simply “meeting people like me”.

Comparisons of different psychosocial interventions or therapeutic approaches

There is now well-established evidence that different types of psychosocial interventions and groups are effective for patients at different points of their cancer journey. Short-term interventions may be sufficient for people with good prognoses or in early stages of the disease (when information needs are high), but long term group support seems best for those with advanced disease.

Fawzy (1995) summarised the types of interventions that had been proved helpful for patients with cancer according to phase of disease or prognosis:

- *Diagnosis, initial treatment (good prognosis)*
Short-term, structured, psycho-educational. Usually last 6 to 10 weeks and are institution based.
- *Recurrence/retreatment (ongoing disease but longer-term prognosis)*
Ongoing, less structured, supportive in nature, patient issues-driven, perhaps less frequent, perhaps monthly rather than weekly.
- *Terminal/palliative (short prognosis)*
Long-term or ongoing, structured and goal-oriented (eg symptom management, dealing with end of life issues), supportive. Usually weekly or more often and are institution based.

Research has shown that education (tailored to the type and phase of cancer), coping skills and emotional support (from trained health professionals as well as family and friends) are helpful both individually and in combination. A structured intervention consisting of health education, stress management/behavioural training, coping including problem-solving techniques, and psychosocial group support seems to offer significant benefit for patients newly diagnosed or in the early stages of their treatment (Fawzy and Fawzy, 1998).

Meta-analyses and reviews of the literature suggest that:

- *Educational programs are superior.*
Educational programs are more effective in improving quality of life in adult cancer patients than social support, coping skills training or psychotherapy (Rehse and Pukrop's metaanalysis, 2003; Fawzy et al, 1995; Helgeson et al, 1999); but interventions that include components designed to enhance self-regulation and increase self-efficacy with regard to cancer-related issues (such as improving coping skills and teaching how to recognise and restructure negative expectations) produce larger effect sizes than do interventions with few or no such components (Graves, 2003).
- *Structured groups are better.*
Structured group interventions led to positive changes (Edelman et al, 1999a; Helgeson et al, 1999) while less structured groups did not (Helgeson et al, 1999; Spiegel et al, 1981). Structured coping skills programs more beneficial than social support groups (Telch and Telch, 1986; Cunningham and Tocco, 1989). Both structured problem-focused interventions (eg with problem solving, education and behavioural methods) and supportive therapy have benefits over no treatment; some evidence that structured interventions may offer more benefit than those of a purely supportive nature (Bottomley, 1997b).

There is some evidence to support the hypothesis that "differences in dose, duration, timing and clinician competence may shape the efficacy of psychosocial interventions" just as they do for medical treatments (Sherman et al 2004).

- *Longer interventions may be more beneficial than short programs.*
Durations of more than 12 weeks were significantly more effective than shorter interventions (Rehse and Pukrop's meta-analysis, 2003). Quality-of-life improvement appeared to be greater for a standard 6-week support group program than a "weekend intensive" intervention (Cunningham et al, 1995).

- *Group interventions appear to be at least as effective as individual counselling* in the few comparison studies that have been conducted (Cain et al, 1986; Fawzy & Fawzy, 1996).
- *Clinician experience is positively associated with stronger effects* of group psychological interventions aimed at reducing anxiety and depression (Sheard & Maguire's meta-analysis, 1999).

Peer support or self-help groups are the most widely available, yet the least researched, type of support group for people affected by cancer. There is a lack of evidence-based information about the nature and effectiveness of non-therapy cancer support group, and few studies that directly compare peer support programs of different types (eg professional-led v peer-led; predominantly information v peer discussion).

Helgeson (2003) reviewed the support group intervention literature (in a number of areas, including cancer) and concluded that there is little evidence for the effectiveness of peer discussion group interventions. In the cancer literature, there was more evidence for the benefits of informational support than emotional support. Helgeson concluded that peer support group interventions are more likely to have positive effects if:

1. informational support from experts is included
2. emotional support groups are of longer duration, and
3. emotional support groups are really group therapy guided by clinicians.

Group variables associated with better outcomes

Ussher et al (2003) investigated the associations between group variables (location, specificity, setting, leader qualification and leader cancer experience) and the outcomes of anxiety, depression, physical and mental quality of life, self-efficacy and satisfaction (controlling for demographic variables, disease information and level of social support) for participants in support groups in NSW.

The researchers concluded that:

- People who attended support groups in a community setting had better mental quality of life, were less depressed, found the group more helpful and were more satisfied with the group's activities than those who attended support groups in a hospital.
- People who attended a group led by health professionals were more anxious than those attending a group led by non health professionals.
- People in general cancer support groups were more satisfied with the activities of their group than those attending groups targeting a specific cancer.

However, the authors note that it was not possible to determine whether the group factors *caused* the outcomes.

Follow up questionnaires were completed by individuals six and 12 months later. Overall, general, mental health, anxiety, depression and self-efficacy ratings of people attending cancer support groups improved over time.

The group characteristic associated with the most difference in outcome was specificity of the group – whether it was heterogenous (general) or cancer site specific. People attending heterogeneous groups, particularly if led by non-health professionals, appeared to do better, particularly in relation to rapidly falling anxiety levels.

Other key findings:

- Urban groups had better outcomes on several measures, particularly for carers in the groups.
- Group setting had some minor impact on mental health status (improved slightly in people attending groups in hospitals; slightly decreased in community group members) and levels of depressions (decreased in carers attending hospital groups).

- There was an improvement in mental health status of participants in groups led by health professionals, however it was higher overall for those in non-health professional led groups. For carers, the results were the opposite, with a decline in mental health status for carers in groups led by non-health professionals. Mental health status improved in those led by a facilitator with no personal cancer experience, but remained fairly stable in those led by someone with a personal cancer experience.

But, the authors concluded that “the limited evidence available means that it is not possible to conclusively prove that any particular group format is more effective than another in improving outcomes for participants” (Ussher et al, 2003).

6.2 Lessons from existing groups

Breast and prostate cancers are not only common cancers, but also have a high proportion of survivors – hence why the support groups for people affected by these cancers are the largest, longest-running and considered to be effective.

Despite the success and proliferation of these groups, there is not one single model, and it is not possible to identify or create a “template” for a successful group and apply it to create groups for people with other common cancers.

To highlight this point, consider the diversity of some of the groups that were nominated as successful or effective groups:

The **Southern Fleurieu Cancer Support Group** (SA) has been very effective in securing local community and business support and funding, and in addition to offering several groups has established a drop-in centre and resource library, a telephone helpline, workshops and courses and a “carers” support team. Managed by a team of volunteers, it is well regarded as being professionally run and providing quality information and a variety of peer-led support groups.

Several of the **prostate cancer support groups** across Australia (eg the Adelaide, Brisbane, Gold Coast and Sydney Adventist Hospital groups) are extraordinary by virtue of the numbers of people attending meetings. Each of these groups has several hundred members, who receive regular newsletters, and average 70 to 80 participants at their monthly meetings. These groups also are distinguished by their emphasis on the participation of wives and partners of men affected. They are described as being semi-formally run, “like Rotary club meetings”, but with great levels of humour. The focus of most is on providing information to assist decision-making. The larger groups support and mentor new and smaller groups. For example, the Sydney Adventist Hospital Prostate Cancer Support Group – a very successful and well-resourced group with 450 members and regular meeting attendance of 70-80 people – develops resources to assist other support groups by video-recording and distributing presentations by expert speakers to whom smaller and rural groups would not have access.

The **Kalamunda Support Group** (WA) has been running for more than 20 years, and has an average of 20 to 30 participants at each monthly meeting. Four trained facilitators share the responsibility, with two jointly facilitating each meeting. The focus is “less about survival; more about getting on with life”, with guest speakers generally discussing health and lifestyle rather than cancer-specific topics. There’s “not a lot of talk about cancer – members are not looking for information about cancer; they’re interacting within their current lives” (*Pearce*).

The **LifeForce Foundation** provides eight week group programs for people affected by cancer and for carers. Participants are encouraged to continue attending for at least a year. The groups are lead by two trained facilitators and focus on counselling and meditation. The focus, says counsellor and group leader Caro Jonas is on “how people can be kind on themselves. Cancer strips away their humanity, energy, caring for themselves.”

CanRevive provides a range of social support services for Chinese-speaking people affected by cancer. Weekly general support groups attract an average of 40 participants, who come to discuss topics such as “how to be more happy, how to face cancer fear, healthy lifestyle, how to deal with family”. The discussion is followed by gentle exercises, then lunch (participants each bring a dish of food), at which participants are paired with people affected by the same cancer so they can talk “just like a big family” (Lee). Several members travel long distances because this is the only group that meets their needs.

The **Gawler Foundation** (Vic) started Australia’s first active cancer self help group in 1981. Its weekly group meetings and residential programs remain extremely popular. The 12 week group program incorporates principles of nutrition, positive thinking, psychosocial support, meditation and spirituality. The program developed from and responded to the experience of participants. As a consequence “there are lots of elements” to meet various needs. Groups are led by specially trained facilitators and are open to people with any type or stage of cancer.

The **Southside Cancer Support Group** was established five years ago and has about 12 active members, down from previous highs of about 30 members. In addition to monthly meetings, facilitator Brian Walton has encouraged “a fair bit” of telephone and email communication between meetings to assist members to develop support networks and relationships with others in the group, “and I think it works”. Walton also attributes the group’s success to the level of humour: “it’s not a despondent group”. The group seldom has guest speakers, largely because of the difficulty of getting experts to speak to such a small group, but focuses on peer discussion and mutual support.

The experience of people who have established and run these and other existing peer support groups provides valuable information about the factors that contribute to the sustainability and effectiveness of particular groups, as well as the difficulties and challenges of creating and sustaining groups.

As Dunn et al (2003) note, attempting to judge the helpfulness of peer support programs using the randomised controlled trial as the principal criteria of worthiness may be inappropriate. Instead, “data derived from descriptive studies based on the experience of practitioners and consumers may provide worthy evidence of the contribution of peer support”.

Similarly in this project, while the literature was searched for appropriate evidence of the “success principles” of effective support groups, the experience of the many support group facilitators and convenors consulted should be given appropriate credence.

6.3 Characteristics of effective support groups

There have been few studies that have explored how differentiating factors, such as group leadership and/or facilitation, nature of the group (does it provide information, support, meditation?), membership (demographic, attendance at meetings), length of group existence and setting of meetings (eg community, hospital, Cancer Council), contribute to group survival or effectiveness.

There is no single model of support group that will “fit all” people affected by cancer. But a number of characteristics have been identified, from the few published studies as well as the experience of people leading or coordinating cancer support groups in Australia, which appear to be common to groups that are active and considered to be effective. Several of these principles have evolved from increasing understanding of common reasons (further discussed below) why some support groups disband or are ineffective in meeting psychosocial support needs.

Research by Wituk et al (2002) has established that the primary factors that discriminated between active and disbanded self-help groups were:

- the number of new people to attend a meeting, average group meeting attendance,
- length of existence,
- leadership diversification,
- outreach to potential group members, and
- support from national and local organisations.

Professional involvement was not related to group survival.

Ussher et al (2003) conducted focus group interviews and ethnographic observation of 9 support groups for people with cancer to examine the support group experience for participants.

They found that the main characteristics of effective support groups, regardless of type of group or professional background of the leader were:

- providing a caring and safe atmosphere for the open discussion of feelings;
- humour;
- non-judgemental acceptance;
- education and information giving.

Principles of effective support groups

The evidence and experience of support group leaders indicates that support groups “work best” when they embrace at least some of the following principles (in no particular order).

1. Established in response to, and adaptive to, community or member needs

Successful groups evolve in response to an identified need within a region or a cohort of people affected by cancer. Support groups inevitably change over time as the composition of the group and needs of both members and the broader community change. A successful group responds to its members needs, both in terms of structure and content.

Both community-based and hospital/healthcare-based groups tend to form in response to requests from people affected by cancer. Generally individuals who are either seeking to participate in a group or want to establish a group because they perceive a need contact an organisation, such as The Cancer Council or Prostate Cancer Foundation, for advice and support. Groups tend to evolve when there are a number of requests for the same type of service or there is a clear community need and preference for the type of group, often identified as a consequence of Living with Cancer course or public meeting. For example, many prostate cancer groups have evolved from prostate cancer information/awareness meetings in regional areas, at which interest in a group and a potential leader or leaders are identified.

As Ussher et al (in press) concluded, it is not the type of group, nor the professional background of the leader, which is important, but “whether the group provides a supportive environment, mutuality, and a sense of belonging, and whether it meets the perceived needs for community, unconditional acceptance, and information provision for the individuals attending” (Ussher et al, in press).

2. Provide information, emotional support and socialisation

As noted above, there is a body of evidence that education (tailored to the type and phase of cancer), coping skills and emotional support (from trained health professionals as well as family and friends) are helpful both individually and in combination.

Effective support groups provide a range of activities to meet the diverse needs of individual members, rather than just unstructured discussion, for example, or being a purely social group. They also act as conduits or referrers to further information and support if required by members.

A recent survey of support group coordinators in NSW (Ussher et al, 2003) found the five most commonly nominated reasons for joining a group were:

1. "Knowing I am not alone"
2. Hearing about current medical research
3. Becoming more informed about the drugs used in cancer treatment and their side effects
4. Learning about how other people deal with having cancer and comparing my methods for dealing with cancer to theirs
5. Relaxing with others who understand my experience because they are going through the same thing.

This reinforces group participants' desire for information, socialisation, reduction of isolation and emotional support, and improved coping skills. "Information" is not restricted to evidence-based information about new treatments for the disease, for example, but includes information and advice provided as a result of the shared experiences of group members, such as what is 'normal' in terms of side effects, for example. Group participants consistently rate support groups as an invaluable source of information about the course of cancer, new medical and complementary treatments and ways of coping with side effects (eg Ussher et al, in press).

Effective support groups provide emotional support and a sense of belonging by way of "mutuality", the unique mutual understanding of the experience of cancer.

Some organisations also claim that in addition to education and supportive relationships, effective groups provide self-help strategies like meditation or relaxation therapies (eg *Gawler Foundation, LifeForce Foundation*).

"More groups are starting now and tend to focus on one aspect – information providing, existential, emotional expression ... One of the strengths [of our groups] is that we have elements of all these things mixed into a blend that seems to work." (Gawler)

Support groups in disguise?

Anecdotally people with cancer often feel they don't need "support" or that peer support groups would not be beneficial, but may attend groups that are offering information, meditation or exercise therapy, for example.

"[Cancer patients] are now much better informed. They are not looking to sit around in the group and tell their story; they're looking for information. We're conscious of weaving support into the information. The "connectedness" with others is still where the healing comes. If offered a support group, they will say they haven't got time for that. But if it is under the guise of an information group they will come for that and often stay for discussion/support." (Watchman)

Cancer Councils and the Leukaemia Foundation reported increasing demands from patients for very disease-specific or issue-specific (eg "taking control" or survivorship) information or education sessions, from which support groups often evolve.

Several studies have noted that men are less likely to participate in support groups than women and that educational formats may be more appealing than emotional support. Krizek et al (1999) suggested the description of "information session" be used as an alternative to "support group" as a potential strategy to increase men's participation.

Interestingly, prostate cancer support groups in Australia have proliferated in recent years. While named “support groups” the success of these groups in attracting large numbers of participants has been attributed to the focus on providing information, particularly to assist decision-making re treatments. There are indications that once they join support groups, men value the same features and remain involved as long as women do (Krizek et al, 1999).

“When [men] come they offer great support to each other. They may come for information, but take away support, or come feeling need for support, but gain from the information presented. It is important that they should be linked and that people should be introduced to the groups in the least threatening way possible.” (O’Reilly)

Similarly, the popularity and success of Encore groups has been attributed to the fact that the format engages people who generally don’t want to go to support groups. While women who have had breast cancer surgery go for the exercise therapy because they “want to do something proactive and good for them, rather than sitting around talking” (Treadgold), they benefit from the information and support provided.

3. Skilled leadership and/or facilitation

Recent research has suggested that the group leader has a crucial role in determining the success or otherwise of cancer social support groups (Lieberman & Golant, 2002). An Australian study (Ussher et al, 2003) identified the group leader as an important influence in providing a sense of cohesion, continuity and security in the group, acting as a strong attachment figure or surrogate parent. Study participants highlighted the importance of the leaders’ personality, empathy or understanding, and capacity to ensure everyone has an opportunity to participate.

But there is little in the literature about the desirable personal and professional characteristics of group leaders. There is a diversity of opinion among support group convenors and supportive care professionals across Australia about whether the most effective leadership and/or facilitation of cancer support groups is provided by a peer, health professional or combination of both. Some people with cancer have strong feelings about group leadership; some feel that only someone who has “been there” can provide the necessary empathy and leadership, while others prefer a professional who can provide information or education and a sense of stability for the group.

It is acknowledged that some groups do need professional leadership by, or at least close links with, a health professional experienced in the support of cancer patients eg groups for young women with breast cancer (Steginga and Dunn, 2001) or groups for people with advanced cancers and/or cancers with high mortality rates (such as lung or pancreatic cancer).

In any case, given the clear role of leadership in the effectiveness of support groups, it is essential that leaders are trained and supported to maximise their capacity.

The importance of group leadership training

“Conducting a support group probably seems easy to many who have not tried it. It is, after all, just ‘sitting around and talking’ ... Yet high quality treatment of this kind, knowing what to say and to whom, requires extensive training and experience, no less so than administration of medical remedies. Basic psychosocial intervention is often left to health care workers who are motivated to help patients in this way, but have little relevant training.” (Cunningham, 2000)

There is some evidence and a common belief that specific group leadership training for support group leaders is crucial to achieving best outcomes. Peer support groups (which are often regarded as the least technically demanding psychosocial intervention for professionals) can have adverse effects if they are not appropriately facilitated (Helgeson et al, 2001).

A recently published study of the challenges and training needs of support group leaders in NSW found that common difficulties identified included:

- dealing with people's different communication styles and needs;
- dealing with recurrence, metastases and death;
- practical issues, including resources, setting the programme and funding security;
- maintaining personal balance and preventing burn out;
- establishing group credibility;
- dealing with group cycles; and
- leading groups in rural areas.

(Kirsten et al, 2005)

Leaders who had not had professional training experienced more difficulties, particularly in dealing with group process and practical issues, and reported greater supportive needs.

A review by Price et al (in press) found that available research data illustrates that both professional and peer support group leaders acknowledge a need for better support, training and information.

Training in group facilitation and responding appropriately to issues such as disease progression, death and dying may be as necessary for health professionals as peer leaders, since many health professionals leading groups have not had prior training or experience in oncology or running groups.

A study of the impact of a specific group leadership training for cancer support group leaders found that group members achieved better psychological outcomes if their group leaders actively intervened in group interactions using skills such as summarising, refocusing and reframing (Lieberman, Yalom and Miles, 1973).

Burn out of group leaders is a significant contributor to the termination of a group. Appropriate training and support for group leaders and facilitators is an important strategy to help prevent it. As noted in the review by Price et al (in press), while many cancer organisations provide introductory training and information kits, no advanced training or support interventions for group leaders are available.

4. Maintain adequate number of, and recruit new, members

A peer support group needs an adequate number of people to attend meetings to keep it operational. Recruiting new members, maintaining adequate group numbers and maintaining member participation and group interest have been identified as challenges of sustaining support groups (Kirsten et al, 2005; Galinsky & Schopler, 1994; Wituk et al, 2002). Wituk et al (2002) hypothesise that having new members provides those already attending the group a chance to provide the same type of support they previously received, validating the group and their contribution.

Some people consider a measure of a successful group to be its longevity of the group and/or the number of members. But "active" does not necessarily mean effective. There is anecdotal evidence that many long-running groups tend to become purely social rather than support groups. They may provide an important social network for a group of members but discourage new members because of the perception of a clique, or fail to meet the informational and supportive care needs of more recently diagnosed patients.

Does a low number of members mean a group is unsuccessful? Or simply that there is low prevalence in the area or that the group is not well known or promoted? A large membership is often considered a marker of a successful group, but unless well facilitated and structured, a group meeting with a large number of participants may not be effectively meeting the support needs of individual members.

Participation is encouraged when group meetings are held at a convenient time for the group members. With an increasing number of cancer survivors returning to employment, there are now more groups meeting in evenings rather than during the day, as was most common for the traditionally less structured “cup of tea and chat” support groups.

Having a number of regular, long-standing participants was identified as a factor that aided integration of new members. These “seeding members” are “reassuring, and help new members seed into a group; help them feel that they are not alone on the journey” (Jonas).

5. Involve a health professional or at least establish good links with one

“The capacity and enthusiasm of our Oncology Nurse Consultant – both as facilitator and as a link between specialists and support groups – is key.” (Barrett)

The majority of cancer support groups have a link with a health service, either informal eg health service provision of a meeting room, or formal eg the group leader was employed by the health service (Kirsten et al, 2005).

Having a link with a health professional may support group functions and effectiveness by:

- providing access to speakers and resources, such as a meeting venue or photocopying;
- encouraging referral of patients and families to the group and/or promoting the group to specialists and other health professionals;
- answering questions that arise during group meetings and/or directing members to other resources.

The Cancer Council NSW advises groups that the presence of a health professional in an advisory capacity lends credibility to a group. This may help in securing financial support and improving referrals of patients to groups (Kirsten et al, 2005). However, the difficulty of finding a suitable health professional with an interest and time to support groups has been noted.

“The reality is through rationalisation of resources in health services, it is hard to find the right person to be involved with a cancer support group. Cancer support groups do need that level of involvement or backup support that comes from health services.” (Abell)

6. Well-organised, structured and supported

Research has established that structured therapeutic groups are superior to unstructured, purely supportive, groups.

Similarly, it seems that structured peer support groups are more popular with cancer patients and may be more effective. A hypothesised reason for the success of prostate cancer support groups in recruiting and retaining members is that the structure of the meetings is appropriate to the needs of the patient cohort. Unlike most other cancer support groups, prostate cancer groups are typically more structured – some described as being run like business or Rotary group meetings – which is comforting to many men in the age group most commonly affected by prostate cancer.

Simple practices, such as keeping notes and records of what happens at meetings and what needs to be followed up may encourage member involvement and group cohesion, ensuring members feel their concerns, questions and suggestions are taken seriously.

Support groups that are auspiced by or members of cancer support group networks (see section 4) have access to resources such as template forms, a recommended structure or guidelines for running groups and a skilled workforce to support group leaders.

Organised or lead by a team of members or co-facilitators

There are many tasks involved in establishing, facilitating and/or running a support group, and it is common for an individual volunteer to “burn out”. Because of the voluntary nature of most peer support groups, the work and responsibility for action can fall upon a few individuals, and this may not be sustainable in the long run.

Group leaders believe some of the difficulties in running groups and potential burn out could be alleviated by sharing responsibilities and tasks with group members and/or having a co-facilitator (Kirsten et al, 2005).

A small committee of interested people with a shared enthusiasm but different skills and talents can share the workload and also ensure the group’s activities and style are informed by a range of people rather than one individual. So, “no one person feels they have to carry the whole load, and there is no-one that operates out of the model ‘I’m right’. Everyone has a say.” (Bowes).

Having a co-facilitator or team of members involved in group administration also helped identify and commence training of a “successor” to the group leader, reducing the pressure that many leaders have identified – that if they become ill or choose to give up the role, the group would fold. However, many group leaders have reported difficulty in recruiting other group members to take on leadership roles or responsibilities (Kirsten et al, 2005; Steginga et al, 2002).

Co-facilitation has been found effective in increasing the effectiveness of groups and preventing burnout of leaders, by sharing the responsibility and enabling facilitators to discuss issues that arise in the group. Two or more facilitators may take turns in leading the group, jointly facilitating large groups or running concurrent, separate sessions for cancer patients and carers, for example.

Have appropriate levels of financial and organisational support

The business of running a group, such as fundraising, advocacy, public relations and outreach activities may erode the emotional and informational support benefits.

Practical considerations like having a venue and resources and support needed to run meetings is important for sustainability and to give participants a feeling of “security. For people already “dealing with the uncertainty of death”, having to worry about the uncertainty of the group continuing is an added burden. In addition, the “energy you have to put in to securing funds” distracts group facilitators from their efforts to support people affected by cancer (O’Brien).

7. Appropriate group “personality” and level of humour

“My family and friends would have nominated me as the last person to go to a support group. But there was something different about this support group as distinct from most of the others I have ever had anything to do with. As well as very good professional information, there was an informality, warmth and genuine support there. (Toohey)

There are also factors that clearly are associated with the popularity and effectiveness of groups that can’t be rigorously assessed or quantified. Support group leaders and participants, and those who refer people affected by cancer to groups, recognise that each group has its own personality or spirit.

A survey of support group coordinators in NSW (Ussher et al, 2003) found the five features of groups rated by respondents as important or very important were:

1. The group facilitator giving each person who wants to enough opportunity to talk
2. Welcoming new members and helping them settle in the group
3. Having enough humour in the group
4. The group facilitator's personality
5. The group facilitator understanding how things have been for you.

Several of the group leaders and members consulted in the course of this project identified the energy and enthusiasm of the group leader or facilitator or a core group of members as a key success factor.

One of "the most striking issues" to emerge from a survey of group participants was the emphasis on the level of warmth and humour between participants, which many believed was a key factor in maintaining group cohesion (Ussher et al, in press). Participants also believed humour worked to reduce self-doubt, or stopping individuals taking themselves too seriously, and was often used as a coping mechanism for dealing with difficult experiences.

6.4 Barriers to support group participation

“One of the primary gaps is in discharge plans. I hear [from patients] all the time, ‘I just didn’t know you existed’. And then they get very angry.” (Watchman)

Despite evidence of the benefits of support groups for people affected by patients, very few cancer patients participate. There is some research and many hypotheses about why and which groups of people affected by cancer do or do not attend groups.

Two of the most commonly reported barriers to participation by patients in cancer support groups are lack of referral from doctors and health professionals, and lack of awareness or understanding about groups (meaning patients may hesitate to self-refer).

The decision not to participate may be due to adequate support elsewhere or preferring to cope through disengagement. However, as Grande et al (in press) have noted, if lack of participation is due to misperception about groups or lack of encouragement, beneficial support group participation could and should be increased.

Research has established that the oncologist’s opinion regarding support groups is an important factor in a patient’s decision to participate (Edgar et al, 2000). There is considerable evidence that most oncologists, general practitioners and other health professionals do not refer cancer patients to or provide information regarding social support groups or services (Guidry et al, 1997; Infante et al, 2004; Matthew et al, 2002). Doctors and nurses have expressed concerns about the potential for support groups to provide incorrect or inappropriate information, have negative effects of associating with the very ill, cultivate false hope or encourage unconventional therapies.

According to the report of the recent Senate Community Affairs References Committee Inquiry (2005), many cancer patients told the Committee that “access to support in many cases was not automatic, most stumbled across support groups and government assistance and most did not obtain the support they needed”, with a notable exception in the case of breast cancer.

Reduced periods in hospital, as a consequence largely of improved treatments and lessened recovery time, further reduce the likelihood of people affected by cancer receiving appropriate information about or referrals to support. As Rankin et al (2004) note, women with breast cancer who were discharged from hospital within 48 hours were significantly less likely to meet a breast cancer support service volunteer. They conclude that “if the growing trend of early discharge from hospital continues, it will be necessary to ensure that information provision about supportive care programs, including peer support, is well timed and tailored to suit ... needs”.

The “shortness of hospital stay and fragmented care” also makes it difficult for cancer support groups in regional areas to recruit people with cancer who have left the area to have treatment elsewhere (*Telefson*).

7. Conclusions and recommendations

Cancer support groups have rapidly proliferated in Australia over the past two decades, driven by increasing patient awareness and demand for information, desire to meet others with the same disease and concerns, and a lack of acceptable, alternative psychosocial support mechanisms.

The continuing interest and participation in cancer support groups suggest that this mode of support meets needs that are not met by other social support networks, such as family and friends, or services. While some contributors suggested that the popularity of cancer support groups has peaked, with increased awareness and “openness” about cancer and greater acceptability and use of individual counselling and psychological therapies, there is evidence that the number of groups is continuing to rise (up from 178 in NSW in 2002 to 230 in mid-2005) and anecdotal evidence that enquiries about joining or establishing groups are increasing rather than waning.

This project has identified existing cancer support groups in Australia, highlighted gaps in availability of groups and barriers to establishing and sustaining groups and, from the existing evidence and experience of group leaders, identified a number of factors associated with group effectiveness. This information informs several recommendations to facilitate the establishment of effective support groups for people affected by cancer in Australia.

Acknowledging that effective cancer support groups respond to community needs and evolve “from the ground up”, the goal was to identify the best mechanisms for supporting and maximising the effectiveness and utilisation of support groups without “stifling”, “medicalising” or over-regulating groups (to use terms used by contributors to this project).

In light of the level of interest in support groups, it is timely to review and improve knowledge about which group factors are associated with effectiveness, where the gaps are, the capacity of traditional support groups to address unmet needs, and the potential for greater accessibility and benefits of alternate models of peer support.

7.1 Conclusions

1. Many people affected by cancer in Australia have unmet psychosocial needs, some of which can be effectively addressed by participation in a support group.

Many people affected by cancer have unmet psychosocial needs, which could be addressed by participation in an effective cancer support group. The benefits and acceptability of support groups as a mechanism for providing psychosocial support to people affected by cancer has been established.

There is a spectrum of psychosocial need. Patients and carers who experience clinically significant levels of distress require specialist psychological interventions. However, for people with lesser levels of distress, or seeking information, emotional support and/or opportunities to socialise with others who understand the experience of having cancer, peer support services can be extremely beneficial. Ensuring the optimal appropriate utilisation of community-based cancer support groups also relieves pressure on services intended for people with acute levels of psychological distress.

As stated in the *Optimising Cancer Care in Australia* report (COSA, TCCA and NCCI, 2002):

“There is a need for greater investment in broadly based support services that are readily available and low cost, to complement and supplement professional resources that may be best applied to those with ongoing psychological difficulty. Greater use of community-based interventions, such as one-on-one peer support, self-help groups, or guided group therapy (more efficient than individual psychological interventions) may be required, provided there is evidence for their effectiveness. There are many cancer support groups ... that provide or are keen to provide supportive interventions.”

There are potentially large benefits to participants and the broader community in facilitating the development of effective, low cost, well-managed, community-based cancer support groups.

2. There are no or few support groups for people affected by common cancers or groups of cancer patients with particular social support needs.

The absence of support groups for people affected by common cancers, such as bowel, melanoma, lung, bladder, kidney and stomach cancers is acknowledged in section 5. This report has also highlighted the absence or low number of groups that might address unmet support needs of other “cohorts” of people affected by cancer, such as young people, Aboriginal Australians, people of culturally and linguistically diverse backgrounds, carers and family members and long-term cancer survivors.

This project has acknowledged the lack of evidence about whether, or what type of, support groups might be appropriate for these patients and their carers. Little is known about their needs and preferences or the potential benefits of support group participation (general or cancer type-specific groups), highlighting the need for further research and development of evidence-based frameworks and advice to encourage development of appropriate peer support interventions.

3. Cancer support group networks assist the development, maintenance and recognition of support groups.

As highlighted in this report, support group networks assist the establishment and maintenance of peer support groups. Such networks do or could support the development of effective cancer support groups by:

- identifying and promoting “best practice”,
- linking groups and promoting exchange of information and ideas
- providing resources, infrastructure or organisational support to support existing groups and assist the establishment of new groups
- providing or directing group leaders to appropriate training programs
- providing cancer information and/or encouraging the provision of quality, evidence-based information
- promoting support groups (generally, and individual groups) – to increase awareness and make it easier for people to access groups.

The existence of cancer support group networks does not prohibit development of “independent” groups, but would help facilitate the development of new groups that were most likely to be effective and sustainable.

4. There is a little evidence about “what works for whom” to inform the development of support groups for people with cancer generally and for specific subgroups with different needs.

Cancer support groups are largely a community-based and community-created intervention, hence most have been established by well-intentioned people affected by cancer or health professionals, but generally without an “evidence base”. This is in part because evidence about what makes an effective or sustainable support group, and the benefits of different kinds of interventions to group participants, is lacking. A recent literature view and study by Australian researchers concluded that “the limited evidence available means that it is not possible to conclusively prove that any particular group format is more effective than another in improving outcomes for participants” (Ussher et al, 2003).

While it is not possible to define a single model for an effective peer support group, a number of principles or “success factors” have been identified and should be considered in building new groups or increasing the effectiveness and sustainability of existing groups.

In light of the findings of this project, supporting the establishment of groups without reference to a clear need and to existing evidence or principles that are associated with effectiveness, is likely to be unsustainable and not beneficial to people affected by cancer.

5. Many existing cancer support groups are underutilised. There is a need to build the capacity and effectiveness of existing groups, increase awareness and address barriers to participation.

There is evidence that existing cancer support groups may be underutilised, with many ceasing to operate each year because of a failure to attract new members or maintain sufficient number of members. If the low participation rate is due to lack of awareness, misperceptions about groups, or lack of referral, it could be increased to extend the benefits to more people affected by cancer.

As noted in section 6.4, two of the most commonly cited barriers to recruiting members of cancer support groups are lack of awareness or understanding about groups and lack of referral by doctors and other health professionals.

7.2 Recommendations

The Building Cancer Support Groups policy, part of the Federal Government's *Strengthening Cancer Care* initiative, commits funding to seeding grants contributing to salary and administration expenses for "support groups in the areas of bowel, lung, ovarian and other cancers".

1. Build effective cancer support groups

In order to build effective and sustainable support groups for people affected by cancer, the Department of Health and Ageing should offer seeding grants to cancer support group networks or appropriate organisations to:

- 1.1 Review evidence and test and evaluate innovative support group models** to address the needs of a particular cohort of people affected by cancer, who may be similar in terms of:
- (a) cancer type: people affected by a specific type of cancer, particularly bowel or lung cancer
 - (b) cancer stage: people with the same phase of disease or prognosis eg all or a subgroup of people with advanced cancer, or people with metastatic disease but good long-term prognoses
 - (c) geographical location: people living within a specific region, or efforts to link people living in rural and remote regions across a broader area
 - (d) age: a group catering to the particular needs of young people with bowel cancer, for example
 - (e) particular needs/interests eg carers, culturally and linguistically diverse groups, Indigenous Australians.

Applicants should be required to detail the nature and objectives of the "developmental" work to be undertaken. Examples of the type of project that might be supported include:

- Review of literature and/or further research to identify, develop and promote "best practice" peer support for a cohort of people affected by cancer, by cancer type, cancer stage, age or particular needs
- Development, trial and evaluation of different modes of delivering support eg telephone or internet to improve access to and participation in support groups by people affected by cancer, particularly those living in rural and regional areas or otherwise unable or unwilling to participate in traditional face-to-face groups.

- 1.2 Grow or extend existing cancer support groups**, to meet the needs of a greater number and/or different group of people affected by cancer.
For example, initiatives aimed at extending the reach of a lung cancer support group by the use of telephone or video conferencing; modifying an effective breast cancer support group to include and meet the support needs of women with ovarian cancer; or providing resources, training and support to build capacity and effectiveness of existing groups.

- 1.3 Establish new cancer support groups** to address the support needs of a group of people affected by cancer, with appropriate reference to existing evidence, models and principles to ensure effectiveness.

Applicants should be required to explain the appropriateness and advantages of a support group in addressing the gap or need, and advise of existing evidence or models, or other mechanisms to ensure sustainability and effectiveness of the group.

The Building Cancer Support Groups policy refers to the development of “cancer support networks”. The intention was that support groups funded “will develop partnerships and working relationships with similar support groups/organisations and enhance the planning and delivery of direct modes of support to cancer consumers” (Cancer Services section, Department of Health and Ageing).

The capacity of *cancer support group networks* to assist establishment and maintenance of peer support groups has been acknowledged in this report, and hence priority should be given to existing networks or organisations seeking to create networks or otherwise link relevant services. This would most efficiently facilitate creation of new groups and capacity-building of existing groups by clearly identifying gaps and preventing unnecessary competition, duplication of services or proliferation of group models found to be ineffective or unsustainable.

2. Increase the effectiveness and utilisation of cancer support groups

Given the number of cancer support groups in Australia and the positive experiences of participants (as reported in this study and others), priority should be given to ensuring effectiveness and increasing utilisation of existing and new groups by:

2.1 Building capacity and effectiveness of existing support groups

It is recommended that the Department of Health and Ageing consider whether the Building Cancer Support Groups funding could be extended to cancer support group networks, to provide small grants to individual support groups to assist with administration expenses and/or provide other forms of organisational support or infrastructure to improve the effectiveness and sustainability of groups.

In particular, the important role of the support group leaders has been highlighted in this report and other research. Training and development of leaders is essential to effectiveness, and hence supporting the development of group leadership training programs would enhance the effectiveness of existing and new groups.

There is some concern that the effectiveness and viability of existing services are compromised through lack of adequate funding

Support group leaders in NSW have identified formal provision of funding as a means of increasing group recognition and credibility among key stakeholders, thus increasing the referral of new patients and helping to maintain adequate membership numbers (Kirsten et al, 2005).

Several surveys of support group leaders and participants (QCF survey, Steginga et al 2002) have identified what support groups want to enhance their effectiveness, reach and membership and sustainability, including:

- financial support (for administrative expenses such as printing, postage, venue hire)
- an appropriate and permanent meeting venue
- access to speakers
- advice/assistance in managing organisations and group dynamics
- facilitator/group leader training and support
- health professional support in promoting and increasing referrals to groups.

2.2 Increasing awareness and understanding of the role and benefits of peer support groups

It is recommended that Cancer Australia or another lead agency explore benefits of and issues in developing a national database of information about support groups and acceptable methods of disseminating information to people affected by cancer and to health professionals. Issues to be considered include whether the information should be available online and publicly accessible, or only via referral to Cancer Helpline. It could be a valuable consumer resource, explaining benefits of and different models of peers support.

Such resources would help build a common understanding of the role and types of peer support groups and improve dissemination of information about groups to allow people affected by cancer, as well as health professionals and other “referrers”, to determine what is available and might best meet their needs. Such initiatives would not attempt to evaluate, rank or regulate the provision of peer support groups.

The Senate Community Affairs References Committee’s report of the inquiry into services and treatment options for persons with cancer recommended that:

*“Cancer Australia provide access to authoritative, nationally consistent, evidence based information on services, treatment options, government and non-government assistance and **links to appropriate support groups** [my emphasis] which can be used by health professionals including care coordinators, cancer patients and their families. This information should be available in different forms.”*

Formal accreditation of cancer support groups is not recommended, as several challenges or barriers have been identified, including the cost and practical difficulties of accrediting community-based groups, the difficulties in assessing “what works”, the transient nature of community-based groups and the traditional resistance of groups to regulation or attempts to “professionalise” them.

Instead, there is substantial interest in a means of gathering consistent information about support groups to increase awareness and accountability of groups and provide sufficient and appropriate information about the nature of the group, its membership, facilitator and setting, etc. to enable potential users (patients/carers) or referrers (Cancer Councils, health professionals, et al) to evaluate which groups might best meet their needs.

Information to be gathered might include:

- Purpose and goals or therapeutic modality of the group eg education, social outings, cognitive therapy, behavioural training
- Who is it for? Who are the current members – cancer type/s; gender; only people with cancer or carers/family also; stage of disease – newly diagnosed, advanced, etc.
- How it provides support eg by regular meetings where members can openly discuss concerns, educational sessions, referral to other psychosocial support options, regular newsletters, etc.
- Facilitation/leadership – Is the leader a peer or professional? What training/qualifications do they have? What is the role of volunteers?
- Setting eg hospital, community centre, etc?
- Whether fees are charged. Who are the supporters and funding sources?

The availability of such information also would assist group providers and facilitators to improve cross-referrals and to minimise duplication and instead develop complementary services in terms of membership or timing.

2.3 Supporting initiatives to improve health professionals' awareness of and referral to groups and/or the Cancer Helpline.

Guidelines for the psychosocial care of adults with cancer (NBCC and NCCI, 2003) recommend that clinicians have up-to-date knowledge of the peer support programs and groups available in their area, and ensure that people affected by cancer are aware of their availability. One of the "recommended steps" in ensuring that all people with cancer have adequate emotional and social support is that clinicians and the treating team "provide the patient and their family and carers with information about support services and peer support programs and how these can be accessed" (p 70).

Some of the potential mechanisms of increasing recognition and understanding of the role and benefits of support groups, and thus increasing referral and enhancing self-selection, include:

- Recognition of and referral of people affected by cancer to appropriate psychosocial care including support groups as a requirement for cancer service accreditation;
- Credentialling of organisations running or hosting support groups;
- Improved discharge planning for patients, to ensure appropriate information is provided about psychosocial support options, including support groups and/or referral to The Cancer Councils' Cancer Helpline as a central point for information, support and referral to appropriate services.

If health professionals are encouraged or expected to provide information about and referrals to support services, they would need access to an up-to-date and authoritative source of information about support groups that may be appropriate to their patients. To be useful, this "register" of groups would have to include sufficient level of information to enable health professionals and people affected by cancer to determine which groups or programs would be appropriate to their needs. (See 2.2).

Matthew et al (2002) suggested that health care professionals' referrals and attitudes towards cancer psychosocial support services may be improved by "assembling a concise directory of locally available resources, directing this information to [those] who refer directly to cancer organisations, improving collaboration between agencies, increasing staff support, and targeting particular services ... for program monitoring and development". Carroll et al (2000) found that having family doctors complete a questionnaire assessing their attitudes towards cancer self-help groups, followed by educational material specific to their concerns, changed their attitudes toward groups, but noted that further study was needed to determine whether behaviour changed.

There is evidence that interventions aimed at targeting information about groups to patients and encouraging professional endorsement of groups increases participation by those who are ready to take up the option of peer support, rather than exert undue pressure to join a group (Grande et al, in press).

Of course it would be important to ascertain the capacity of existing support groups to cope effectively with more members before planning an intervention to encourage participation.

3. Support further research

Additional research is essential to support the development of effective and sustainable peer support for people affected by cancer generally and for specific groups of patients and carers with unmet needs.

There is a need for further research to:

- 3.1 Facilitate the development and promotion of support group models and guidelines based on best practice. This could be achieved by establishing a “virtual” national clearing house to gather, summarise and disseminate existing evidence and coordinate further study of effective cancer support groups and other models of peer support.
- 3.2 Determine “what works for whom” – assessing the needs and preferences of particular groups of people affected by cancer to determine whether participation in support groups would be appropriate and beneficial or preferred mechanisms of addressing unmet needs. It is also important to examine the mechanisms used and experience of social support by people who don’t attend support groups or drop out of groups.
There is also an acknowledged need to extend the focus of such research. Most studies to date have focused on breast cancer, with a growing interest of late in prostate cancer; and most on people with early stage disease, rather than those with advanced disease, or survivors.
- 3.3 Explore the potential for greater accessibility and utilisation of alternative methods of delivering peer support to people affected by cancer, particularly people living in rural and regional areas or otherwise unable or unwilling to participate in traditional face-to-face groups, such as telephone or internet groups, and one-to-one peer support.

Appendix 1

Key informants: List of individuals and organisations consulted

All members of the Consumer Steering Committee, listed in appendix 1

Liz Abell, Manager, Cancer Information and Support Services, The Cancer Council SA

Doreen Akkermann, Director of the Cancer Information and Support Service, The Cancer Council Victoria

Heather Allan, Executive Director - Clinical Relations, The Australian Lung Foundation

Karen Anderson, Senior Counsellor, The Cancer Council WA

Ella Ashley, The Cancer Council Tasmania

Jean Barrett, Secretary, Cancer Patient Support Group (Illawarra) Inc.

Gerald Barry, Chair, Australian Council of Stoma Associations

Joan Bartlett, CEO, The Cancer Council ACT

Gill Batt, Director, Cancer Information and Support Services, The Cancer Council NSW

Don Baumber, Co-Chair, Prostate Cancer Foundation Australia Support and Advocacy Committee

Gary Bowes, Prostate Support Association North East Group

Spence Broughton, Chairman, Queensland Chapter Council of Prostate Cancer Foundation Australia

Jean Dagleish, Director of Cancer Services, The Cancer Council Tasmania

Irene Durant, Cancer Information Consultant, The Cancer Council ACT

Gill Falconer, facilitator, Cancer Support Group, Kingsley Homestead

John Friedsam, Family Support Project Coordinator, The Cancer Council NSW

Juliet Gale, LungNet Development Manager, The Australian Lung Foundation

Dr Ian Gawler, founder and Therapeutic Director, The Gawler Foundation

Helen Geltch, Supportive Care Coordinator, The Cancer Council ACT

Andrew Giles, CEO, Prostate Cancer Foundation Australia

John Gower, CEO, Gynaecological Cancer Society

Julie Hassard, Deputy Director, Cancer Information and Support, The Cancer Council Victoria

Jean Hawkett, Secretary, Southern Fleurieu Cancer Support Group

Tony Hawkett, Southern Fleurieu Cancer Support Group

Marg Hegarty, Deputy Director, Community Services, Queensland Cancer Fund

Marg Hodgetts, Support Services Coordinator, The Cancer Council NT

Caro Jonas, co-founder and counsellor, LifeForce Foundation

Tracy King, Myeloma Foundation Support Nurse (NSW)

Nicole Kinnear, National Encore Manager, YWCA of Australia

Ella Lee, support group facilitator, CanRevive

Amanda Leigh, Director Cancer Services Division, The Cancer Council WA

Noel Lockyer-Stevens, Manager Community Support & Information Services The Cancer Council Western Australia

Bill McHugh, Queensland Chapter Council of Prostate Cancer Foundation Australia

Barry Oakley, Adelaide Prostate Support Awareness Group

Mary O'Brien, Women's Psychotherapy Service (Qld)

David Oliver, Director, Brownes Cancer Support Centre

Mandy O'Reilly, Manager, Cansupport, Royal North Shore Hospital

Kim Pearce, Project Coordinator, Supportive Care Development Unit, The Cancer Council NSW

Tony Pearce, co-facilitator, Kalamunda Support Group (WA)

Joy Reid, group leader, PI-TUL Aboriginal Women's Cancer Support Group (Hunter, NSW)

Roslyn Robertson, Psychologist, Royal Hospital for Women, Sydney

Brian Rosengarten, Vice President, Myeloma Foundation of Australia

David Sandoe, Co-Chair, Prostate Cancer Foundation Australia Support and Advocacy Committee and co-convenor, Sydney Adventist Hospital Prostate Cancer Support Group

Pam Sandoe, co-convenor, Sydney Adventist Hospital Prostate Cancer Support Group

Ann Simpson, President, Southern Fleurieu Cancer Support Group

Terri Smith, National Programs Manager, Breast Cancer Network Australia

Suzanne Steginga, Director, Community Services, Queensland Cancer Fund

Denis Strangman, former Chair of Brain Tumour Australia and Chair of the International Brain Tumour Alliance

Kathriye Strassnick, Cancer Support Programs Coordinator, The Cancer Council SA

Lyn Swinburne, CEO, Breast Cancer Network Australia

Rosemary Taylor, facilitator, bowel and lung cancer groups, Sydney Adventist Hospital Cancer Support Centre

Leonie Tellefson, Arrarat Centre for Community Health

Joy Tight, convenor, Lymphoedema support group, Sarina (Qld)

Graham Torney, Secretary, Queensland Chapter Council of Prostate Cancer Foundation Australia

Claire Treadgold, National Programs Manager, CanTeen, and former Encore Program Manager, YWCA

Brian Walton, Southside Cancer Support Group

Susie Warwick, CEO, National Ovarian Cancer Network

Sue Watchman, Manager, Cancer Care Centre (SA)

Sue Westcott, NSW Bowel Cancer Support Service

Peter Williams, Cancer Support Groups Coordinator, The Cancer Council Victoria

Dr Anna Williamson, acting CEO, Leukaemia Foundation

Ann Young, Chief Social Worker, Noarlunga Health Services (Onkaparinga Cancer Support Project)

Contributions and helpful information also were gathered at several meetings the author was invited or permitted to attend:

- Cancer Voices ACT meeting, Canberra, 19 July
- Cancer Voices NSW Steering Group, Sydney, 27 July
- Queensland Cancer Fund's consumer network, Brisbane, 8 August
- Meeting to establish a gynaecological cancer support network in NSW, hosted by the Cancer Council NSW and Cancer Voices NSW, Sydney, 13 July
- Public meeting to discuss need for a state cancer advocacy group, hosted by The Cancer Council Victoria, Melbourne, 25 June.

The Cancer Council SA convened meetings of representatives of local cancer consumer groups, and of cancer support group convenors and Cancer Connect volunteers, on 1 August, to help inform this project.

Participants:

Jenny Ball]
Pru Crouch]
Jan Davies] Cancer Connect volunteers
Keith Johnson]
Margit Keogh]
Fiona Redfern]

Barbara Cook, Breast Cancer Network Australia
Lee Cooper, CanTeen
Cecily Dollman, Royal Adelaide Hospital Support Groups Coordinator
Kate Fisher, CanTeen
Conrad Gawlik, Childhood Cancer Association
Will Hallahan, Executive Officer, Palliative Care Council of SA
Allan Hayward, Leukaemia Foundation
Jean Hawkett, Secretary, Southern Fleurieu Cancer Support Group
Tony Hawkett, Southern Fleurieu Cancer Support Group
Chris Hygonnet, TCCSA Cancer Support Programs
Ellen Kerrins, Cancer Control Programs Group Executive, The Cancer Council SA
Angela Lawry-Jones, Leukaemia Foundation
Lena Leone, TCCSA Cancer Support Programs
Margret Ryan, TCCSA Cancer Support Programs
Pam Sandys, Asbestos & Related Diseases Support Society of SA
Ann Simpson, President, Southern Fleurieu Cancer Support Group
Kathriye Strassnick, TCCSA Cancer Support Programs
Sue Watchman, Manager, Cancer Care Centre

Appendix 2

Project planning meeting participants

The following representatives attended a preliminary meeting to discuss Federal Government support of cancer consumer networks at The Cancer Council Australia in February 2005, at which the aims of this project were developed:

Ian Kemp]	Cancer Services,
Dr Rosemary Knight]	Department of Health and Ageing
Chris Dunstone]	
Jane Cruickshank]	
Sally Crossing]	
Don Baumber]	Cancer consumers
John Stubbs]	
Professor Alan Coates AM		The Cancer Council Australia
Margaret McJannett		The Cancer Council Australia / COSA
Gill Batt		The Cancer Council NSW

Consumer Steering Group

Jane Cruickshank, Chair of Cancer Consumer Networks Project Working Party; Member of the Federal Government's Cancer Strategies Group; founding member, Cancer Voices NSW

Don Baumber
Co-Chair, Prostate Cancer Foundation-Support and Advocacy Committee; Cancer Alliance Network

Sally Crossing AM
Chair, Cancer Voices NSW; and Chair, Breast Cancer Action Group NSW

Clive Deverall
Chair, Cancer Voices WA; member of The Cancer Council Australia Board; member of the Cancer Strategies Group

Margit Keogh
Group leader, Barossa Valley Cancer Support Group; The Cancer Council SA nominee

Ian Roos
The Cancer Council Victoria consumer network nominee

David Sandoe
Co-Chair, Prostate Cancer Foundation-Support and Advocacy Committee; member of Cancer Voices NSW

Denis Strangman
Former Chair, Brain Tumour Australia; member of Cancer Voices ACT

John Stubbs
Leukaemia Foundation; member of Cancer Voices NSW

Leonie Young
Queensland Cancer Fund consumer network nominee

Appendix 3

State and Territory Cancer Councils

The Cancer Council ACT

The Cancer Council NSW

The Cancer Council NT

The Cancer Council SA

The Cancer Council Tasmania

The Cancer Council Victoria

The Cancer Council WA

Queensland Cancer Fund

The Cancer Council Australia Supportive Care Committee

Liz Abell, Manager, Cancer Information and Support Services, The Cancer Council SA

Joan Bartlett, CEO, The Cancer Council ACT

Gill Batt, Director, Cancer Information and Support Services, The Cancer Council NSW

Allison Boyes, Centre for Health Research and Psycho-Oncology

Con Casey, consumer

Jean Dagleish, Director of Cancer Services, The Cancer Council Tasmania

Julie Hassard (previously Suzi Grogan), Deputy Director, Cancer Information and Support, The Cancer Council Victoria

Deborah Harrison, consumer

Marg Hodgetts, Support Services Coordinator, The Cancer Council NT

Amanda Leigh, Director Cancer Services Division, The Cancer Council WA

Suzanne Steginga, Director of Community Services, Queensland Cancer Fund

Associate Professor Brenda Wilson (Chair), CEO, The Cancer Council SA

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