

# Illawarra Breast Cancer Support Group

Participatory Program Evaluation  
*Identifying the Meaning & Value of the Support Group  
for Group Members*



*Reflections from our circle of friendship  
in the IBCSG community of care  
July 2007*

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# Illawarra Breast Cancer Support Group

## Participatory Evaluation Report



It was with great pleasure I read this Evaluation Report. There are so many people who have worked tirelessly for the benefit of others and I congratulate them. I especially remember Beth Marlow who was instrumental in the Evaluation activities and the Evaluation Reporting Process. Beth was a patient of mine for over nine years and during this time she became a friend. Her work as a patient advocate was insightful and valued by those she worked with.

This Evaluation Report is a great tribute to her and to others like her. Studies have shown the positive effect of group 'talk' therapy. The cancer journey is one of enlightenment – illuminated by the personalities you meet along the way. Support Groups like the Illawarra Breast Cancer Support Group provide a wonderful service to so many people. Every cancer patient is a daughter/son, sister/brother, mother/father, sibling/friend to so many people. Therefore the impact of their disease will affect their own life and the lives of many others.

I would like to recommend this Evaluation Report to everyone who comes across it, to share the moment of greatness of others and to come to a better understanding of those who are dealing positively with their lives. Beth would have been proud of this publication.

Professor Philip Clingan



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## Illawarra Breast Cancer Support Groups:

Participatory Program Evaluation Identifying the Meaning and Value of the Support Group for Group Members

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## **Illawarra Breast Cancer Support Group Participatory Program Evaluation Executive Summary**

The Illawarra Breast Cancer Support Group (IBCSG) has grown from small beginnings in February 1991, with an initial attendance of twenty-two women, to its current, combined regular monthly attendance at local meetings, of one hundred and twenty-five women in total. The emergence of this Group was an entirely responsive process driven by the activities of identifying, predicting, responding to and meeting the needs of women diagnosed and living with breast cancer. A key element of the growth of the IBCSG has been a responsive/supportive leadership role taken by the inaugural and current Group support leader/facilitator. The success of this role is grounded in the support leader/facilitator's capacity to achieve recognition and credibility in both the clinical and community settings. With the leader/ facilitator's ability to bridge the gap between clinical and community contexts and her capacity to engage and enrol Group participation in all aspects of Group activities, the Group has experienced continued growth in its capacity to care for its members. As a positive step towards self-sustainability, the IBCSG has now become an incorporated body under the Department of Fair Trading and has been successful in an application for Deductible Gift Recipient status from the Taxation Office and donations of gifts and bequests are now tax deductible.

The members of the Support Group see *friendship* as the principal means by which the needs of Group members are recognised, acknowledged and met with appropriate loving, caring and sharing. With 'the hand of friendship' as the central focus for activities, the Group's strengths and resources have been utilised in outreach initiatives which have supported the setting up of a number of Groups in other areas. These areas have included towns on the far South Coast and into Western NSW. The descriptive comments of the Support Group in action are testament to the capacity of the IBCSG to meet the needs of its members and others who come into their circle of friendship. In the recorded comments section of this Evaluation Report, the voices of the women demonstrate the many ways in which their Support Group meets the needs of its members.

The participatory program evaluation was collaboratively designed around key questions raised by Group members, about the meaning and value of their Support Group for those involved. The Evaluation employed critical reflective practice in the context of: whole Group reflection, focus groups, surveys, document and photographic records and policy review. From the outset, the evaluation has been guided by the initial questions mapped out in the focus group and framed in terms of 'community building'. That is, a circle of *friendship building a community of care*, and within that community of care, the unique social space that has provided us with the unit of analysis for judging the meaning and value of the Support Group in action. The sunflower Model developed by members of the Support Group to represent their community of care, is a symbolic representation of the Group in action. The Model provides a thematic link to the Group's traditional symbol of the sunflower with the addition of its nested layers of component parts. Each part of the IBCSG Model is linked symbolically to the centre of the Group's activities in a living, integrated and meaningful relationship that provides for ongoing support, understanding, re-assurance, sharing and caring.

The key outcome of the participatory evaluation was the *generation* of a set of categories of action that define the IBCSG Model in Action. This model incorporates the Group's shared



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values, core processes and indicators of effective practice, together with illustrative visual symbols and a photographic record.

The key categories of action that define the IBCSG are:

Organising	Identifying	Recognising
Including	Nurturing	Celebrating
Building	Empowering	Sharing Strengths

Critical reflection on the collective experience and wisdom of the Group, in relation to the cancer journey, was provided by the Survey findings. These findings indicated both the importance of certain aspects of the cancer journey to members of the IBCSG and an explanation of each of the elements of cancer support along the way. The Evaluation also brings together the IBCSG Model in Action and the acquired wisdom of Group members, as a resource for exploring opportunities for improved practice in breast cancer support. In order to explore these opportunities, the IBCSG's newly-generated categories of action were used as the framework for organising all additional comments from each aspect of 'support' (A,B,C,D) covered in the Survey, i.e. Organising and *Coordinated-integrated Support(A)*, etc.

The final critical review of the IBCSG Model in Action, by participants in focus groups at an AdCare retreat, provided a rating for the perceived 'Importance' of components of the IBCSG Model in Action. With this rating for *importance* in mind, focus group participants then rated their *confidence* in their ability to contribute towards the achievement of each component of the Model in Action. With this dual rating process, Group members identified the possibilities that might exist, for creating more 'practical and locally-relevant supportive environments' based on what they perceived to be 'important' and 'achievable' aspects of effective support.

Engagement in the participatory evaluation activities also afforded Group members the opportunity for capacity-building by raising their critical awareness of reflective evaluation skills, tools and processes. Group members were involved in: framing the evaluation; developing shared understanding and program models; data entry; thematic analysis; scale development; critical reflection; report writing and editing. More importantly, the development of a critical reflective attitude in evaluation activities, has contributed towards the possibility for more informed judgments about the Group's capacity to meet the needs of its members. The Support group's community-building foundation of friendship and caring, together with a more critical attitude, has led to improved capacity for effectively and appropriately translating key elements of international, National and State policy into practice at the local level.

Finally, the wide and varied range of needs that are currently being met by the group and its combined activities, are represented in the diverse opportunities for engagement by Group members. There is the ongoing possibility for many Group members to take on leadership roles as new circumstances arise. Reflection on the foundations of the model in action and on leadership and engagement in this participatory evaluation, has contributed towards a shared understanding of what the 'community of care' does and how and why it works the way it does. In particular, the IBCSG believes that it is their 'Hats model of leadership' that gives their Support Group its unique character. It is also their accepted practice of leadership and member engagement, around a shared values framework for action, which holds the key to both the Support Group's sustainability and its continuing renewal of capacity to meet Group member's current and emerging needs.



## **Introduction to The Illawarra Breast Cancer Support Group**

The Illawarra Breast Cancer Support Group (IBCSG) is an incorporated body that includes within its structure, a number of formal groups. Each of the sub-groups in the evaluation, which include, Warilla, Wollongong, Kiama, the Dragon Boat Group team and the Young Women's Group, make a contribution towards shaping the social space that makes up the IBCSG.

The average attendance at both Wollongong and Warilla is fifty women, while Kiama attracts between twelve and fifteen women each meeting. The Dragon Boat group is attended by up to 22 women for training days on the Lake Illawarra and between 10 and 14 women for competition events which are held throughout New South Wales. The Young Women's Group has a core membership, in its current informal format, of five to ten women.

According to its original formal Constitution, written fourteen years ago (1992), the IBCSG is 'specifically designed to target people who have breast cancer . . . [or have had or are living with]<sup>1</sup> . . . and who may have been subjected to either or all three treatment modes – surgery, radiotherapy and drug therapy [incl. chemotherapy].' The revised version of the Constitution focuses more on the Group activity changing lives and developing self-help strategies. The Group Motto is: *Living well – taking control – Life after Breast Cancer* – an enabling approach that is reflected in the newly-worded Constitution.



*Living well – taking control – Life after Breast Cancer*

The new Constitution, states that the aim of the organisation is:

To improve the quality of life of participants through the provision of a program that enables them to identify specific problems related to breast cancer that adversely influence and change their lives, and to develop self-help strategies to enable them to control that change in lifestyle.



The formally-stated objectives of the IBCSG in the current Constitution are:

- To provide a confidential and supportive group atmosphere where patients and their families can share their feelings and discuss issues relating to breast cancer
- To assist people to resume their usual activities following breast cancer
- To help people deal with changes in their self-esteem and sexuality.

At the level of everyday practice, however, when listening to the voices of the women, the purpose of the Support Group is more holistic and relationship-oriented. The ladies in the current IBCSG make special mention of the type and quality of the space provided in caring for members of the Group.

While there have been male members of the Group who have made a significant contribution, there are no men in the Group at present. Finally, the current Group membership places particular emphasis on the role of the Group in providing 'information for understanding' the experience, the decisions and the circumstances of living with cancer following diagnosis.

The following comments by Support Group members represent the Support Group's shared understanding of their experience. These comments tell something of the story or the ongoing 'biographical work'<sup>2</sup> of the participants, in other words, their acknowledgement and recording of the story of what Group membership means for its members.

### **1.1 IBCSG Narratives – a thumbnail sketch**

There's always somebody in the Group that you can talk to . . . The other person you talk to knows exactly what you are going through . . . There's always a cheery face . . . Going to the Support Group made me feel I was not alone . . . I needed someone to unload on, everything that I felt, exactly what I felt, without having to worry about how it might affect them (family).



I needed something beyond what family and friends could give . . . Support Groups are just like falling into a big cocoon. . . The Support Group is like a 'Cosy Woollen Blanket' full of reassurance and optimism. Friendships are made and bonds are forged. Warmth, happiness and laughter can be found in great quantities. Information and support are there for the asking. Pessimism and doom and gloom are nowhere to be found.



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All the members are different, different families etc. but when we are here we are all the same . . . We are unique . . . Our circumstances are all different but the support group is a level playing field where everyone is equal. . . We're a bit like a bundle of sticks really. By ourselves we can be a bit uncertain and fearful, but put us all together and we become very strong and more confident.



The Illawarra Breast Cancer Support Group is a different type of 'support group' because they've been there and done that. As you say something and you look around the group – people are nodding agreement. In this group, we are catching people before they get upset because there is raised awareness – getting in first, anticipating what people's needs and strengths might be. From the group's perspective, it is a place where friendship is a special gift given freely and with love. Core Evaluation Team focus group comment, 2006.

### 1.2 The IBCSG Member Profiles for Core Groups & Immediate Sub-Groups

**IBCSG Core Groups of Warilla, Wollongong and Kiama** written by Robin Gregory, Helen Bent and Catherine Holland

The three core Groups that make up the IBCSG have distinguishing characteristics. It's these characteristics that define their respective personalities and group dynamics.



The Warilla Group commenced in February 1991 following a request from two women in the general support group for cancer patients, to Gloria Swift, the Area Oncology Nurse Consultant and Breast Care Nurse.

The first meeting was attended by 70 women, a level of attendance that demonstrated the real felt need for such a Group. A committee was elected and the first newsletter, a single handwritten page, was published that same month. In June 1991, at the request of several ladies, who were employed/young mothers and couldn't attend the daytime meetings, the Wollongong branch held its first meeting at the Cancer Care Centre in Wollongong Hospital. The first joint newsletter was published in September 1991. Three years later in June 1994, these two Groups officially became the Illawarra Breast Cancer Support Group with members from both Warilla and Wollongong forming the Committee.

The third of the core Groups, Kiama, was formed in 1999 so that more women from the Kiama/Gerringong areas could attend regular monthly meetings. A representative from each of the Groups represents their membership on the IBCSG Management Committee.





Group profiles are distinguished by age, locality, and individual circumstances because the Groups themselves develop in response to particular needs. For example, some women are unable to attend night meetings, so will travel from Wollongong to Warilla which is a day meeting. Others, who are unable to attend day meetings because they can only get transport at night, attend the Wollongong Group. In general, the Groups have a wide range of ages, stages and phases of living with breast cancer. However, the Warilla Group tends to be characterised by an older age group. Wollongong has a wide variety of ages, physical ability and family/employment circumstances. Kiama is made up of a generally older age group but with a number of dynamic and involved members and with a distinctive energy provided by their caring Group leader.

### **The IBCSG Member Profiles for Immediate Sub-Groups**

#### **The Young Women's Group** *written by Melinda Lincoln*

A newer group to emerge from the three core Groups has been the Young Women's Group. This Group was started in 2002 when some young women let Gloria Swift, Oncology Nurse Consultant, Breast Care Nurse, know that they felt their different needs weren't being met within the larger (and older) main group. The Young Women's Group met formally, once a month at night at the Port Kembla Leagues Club, with Gloria Swift facilitating. Gloria ensured that there were regular guest speakers with information about things more relevant to younger women such as reconstructive surgery, fertility, children, and sexuality. These women ran a successful young Women's Forum in 2002, which brought more women into the group.

Numbers attending the Young Women's Group, however, gradually declined and the following year, the Group disbanded its formal structure in favour of regular, informal dinner gatherings. Numbers for this informal young women's group were boosted in 2005 with some newer younger women who also felt they needed to meet outside the main group. These women began meeting infrequently as well as attending Wollongong BCSG meetings. When more of the women involved in these informal meetings rejoined the workforce they decided to have a regular dinner at the same venue as the already established, continuing informal group.



Currently there are ten regular members in the Young Women's Group ranging in age from mid thirties to mid forties, although sometimes younger women and older women who feel they are 'young at heart' come along. The Group now meets once a month at the Illawarra Master Builders Club in Wollongong with around 5 ladies attending regularly. Many more of the Young Women come to special events such as the Healthy Women's Forum or the Field of Women. Some of the women also attend the Wollongong Group and have

come to retreats, while others who don't come to meetings stay in touch via the newsletter, meet with other women they have befriended during treatment or stay in contact by phone with the young women's representatives or Gloria Swift.





**The IBCSG Dragon Boat Team** written by Catherine Holland

The IBCSG Dragon Boat Team was formed in 2002 and is called Illawarra Dragons Abreast. They provide a much needed opportunity for women to increase their physical activity through paddling, in a fun sport where friendship, encouragement and support are readily available. Their Motto is “friendship, fun & fitness”, and they make sure all new ladies are warmly welcomed. Illawarra Dragons Abreast, train on Lake Illawarra near the Yacht Club on Sunday mornings at 8am, and Wednesday evenings at 6pm.



The dragon boat team is a member of both Dragons Abreast Australia and Dragon Boats N.S.W. Some of the ladies regularly compete in regattas in N.S.W and some members travel to competitions, both interstate and abroad. They have been part of a composite Dragons Abreast Australia team which paddled in New Zealand, Canada and Singapore.

Illawarra Dragons Abreast team members attend fundraising events and seminars, provide information sessions for local

community groups and University students and are seen at many local events. Through paddling they have the opportunity to promote Breast Cancer awareness, put a face to Breast Cancer statistics and to provide hope and inspiration to many by showing there is a ‘Quality of Life’ after a breast cancer diagnosis. Friendships are forged with fellow paddlers and with sister groups all over the country and indeed internationally.

Two special interest Groups, although not formally constituted, have provided highly valued, ongoing informal support for members of the IBCSG. These include the Craft Group and the Aquajog Group.

**IBCSG Craft Group** written by Barbara Dombkims

After a diagnosis of breast cancer, so much of your life is put on hold while you focus on follow-up treatment and getting well again. Taking control of your life is such an important part of recovery. One of the ways of achieving this to getting back to doing the things you love to do, whether they be exercise, spending more time with friends and family or bringing out your creative side.



This need for ‘taking back control of your life’, was recognised as being important to the women of the Support Groups and so in the early nineties our Craft Group was formed. This Group gave our women the opportunity to learn new and interesting crafts from a variety of teachers (some being our own Group members) as well as providing a very important avenue



for women to socialise. Many friendships have been formed over the years and while some participants may not have had a diagnosis of cancer, have come along as carers or support persons for a cancer patient. The Craft Group provides members with an outlet to express their feelings as often as they want and to have someone other than their family as a 'sounding board'.

Most of the craft produced initially, was sold on fund-raising days for the benefit of the Support Group, but the monetary gain has been far outweighed by the companionship and support the women receive by being part of this Craft Group activity. In recent times, our IBCSG bus has been used to bring some of our elderly members to the Group, members who otherwise have no means of transport to come to craft lessons. Again, this initiative has proven invaluable in providing a much needed source of companionship, friendship and support.

### **IBCSG Aquajog Group (Alias: Bruce's Angels)** *written by Win Mitchell*

As Gloria (Swift) is always working on new ideas for the betterment of the Group, so it was at one of the meetings, she suggested aqua-jogging. Gloria suggested that aqua-jogging could be most beneficial for those members of the Group who did not take part in strenuous exercises or for anyone who might be interested, but she did not know how this idea might be received. One requirement to be a member of the aqua-jog 'Team' was that you had to have had cancer or be a friend of someone who had been diagnosed with cancer.

After about six weeks, the idea became a reality. It was then that eight members 'touched down' in the pool at the University of Wollongong for the first time, supervised from the very beginning by Bruce Power as Group instructor and friend. It will be four years in September 2007, since the beginning of our aqua-jogging Group.



The University pool is an outdoor pool, but the pool water itself is usually around 28 degrees so our aqua-jogging continues throughout Summer AND Winter, except during public holidays and three weeks over the Christmas break. The number of aqua-joggers has now increased to a regular 15. There is much laughter and talking whilst jogging up and down the pool and as the depth of the pool varies from 1.2 metres to 2.4 metres, Bruce insists on the wearing of

flotation belts as not everyone in the Group can swim. We don't all keep up with the exercises but Bruce is very understanding and supportive and helps us find our own preferred level of activity. Ages range from mid fifties to eighty plus. The exercises cover various parts of the body and conclude with arm and leg stretches. Some members enjoy doing extra swim laps after the class.

Following the aqua-jog activity session, there is always a hot shower and then a short walk to the pool café for coffee or tea. This is a most happy gathering where ideas are exchanged. Birthdays are remembered with much hilarity – the 'birthday girl' cutting a muffin as birthday cake, into sixteen portions to share and celebrate. Discussion takes place on what is happening next, particularly about Group activities and planning for Christmas parties. Everyone contributes to these discussions and all new members are welcomed in a way that they soon feel at ease with all



the other members of the Group. These meetings usually end with hugs before goodbyes and acknowledgement of the shared commitment to see one another the following Monday at 9.00am.

### 1.3 IBCSG Structure in Practice

One key support/leadership role in the IBCSG is that of Oncology Nurse Consultant, Breast Care Nurse and group facilitator/coordinator. With approximately 125 women in total, regularly attending the three core groups of the IBCSG, this leadership role involves a complex mix of up-to-date clinical knowledge, facilitation, co-ordination, logistics and communication. It also has the person concerned in continuous interaction with a large number of Group member-leaders, across a wide range of activities that make up the IBCSG. This particular support/leadership role has evolved as responsive leadership across related clinical – community spaces. In practice, the role is attuned to, guided by and focussed on recognising, anticipating and meeting both the clinical and the felt needs of women diagnosed and living with breast cancer.

“It’s leadership by listening” . . . (to expressed needs).  
Core Evaluation Team  
focus group comment,  
2006

However, the key support/leadership role is only one of the leadership roles in a cluster of mutually supportive designated leadership positions. The ‘lead’ at any given time within the Group, is taken by those generally accepted as having a real interest in and aptitude for, a particular activity or task. As the core Groups continually evolve around the expressed needs of their members and emerging aspirations (‘Outreach’ program and involvement in ‘Field of Women’), so do the opportunities for taking a leading role in whatever task or circumstances might emerge at any given time.

#### The designated formal leadership roles within the IBCSG are:

- Oncology Nurse Consultant / Group facilitator
  - > Patient contact & support
  - > Leadership by listening to others and enabling others to take on and meet leadership challenges and opportunities
- Group President
- Newsletter Editor
  - > Collector, narrator, collator of Group narrative
  - > Communicator, disseminator, advocate of Group narrative
- Committee roles: Treasurer, Secretary, two vice Presidents,
- Group Representatives: Warilla, Wollongong, Kiama, Illawarra Dragon Boat Team, Young Women’s Group
- Group Leader-Nurturers



Outside these formal roles, however, the Groups and their everyday activities, are characterised by a wide range of both established and emerging formal and informal leadership roles and responsibilities. In the IBCSG, involvement in these roles comes with a strong focus on capacity-building. Whatever their purpose, all designated roles are oriented towards meeting identified support needs of women diagnosed and living with breast cancer. The range of both leadership and



group participation roles is evident in the nested layers of activities that Group members engage in, together with their support network of partners, families, volunteers, health professionals, health services and other organisations.

Overall governance and current direction of the IBCSG is guided by the Management Committee. It is the practice of the Management Committee to accept responsibility for underpinning business decision-making and organisational arrangements. With this arrangement for decision-making, much of the burden of everyday housekeeping is shifted to the Committee, allowing Group meetings to concentrate on their main purpose which is **support**. Any decision-making that impacts on the Group is brought to the whole Group for discussion, reflection and individual or shared input. This reflects the inclusive approach to organisation that underpins group processes.

#### **1.4 Formal & Informal Leadership and Participation Roles in the IBCSG**

- **Oncology Nurse Consultant, Breast Care Nurse/ Group Facilitator** (Recognised health professional with combined clinical, governance, and pastoral responsibilities, both bridging and linking the clinical treatment and community support environments)
- **Management Committee** – elected positions plus appointments
  - President, Vice Presidents (2), Treasurer, Assistant Treasurer, Secretary, Assistant Secretary,
  - Newsletter Editor, Library Coordinator
  - Group Representatives – Wollongong, Warilla, Kiama, Young Women's, Dragon Boats
- **Support Group membership**
- **Special Interest Group Membership:** Representatives in Promotional activities; Dragon Boat Competition at local, State, National & International events; Tap Dancing Group (Entertainment appearances)
- **Newsletter readership** – includes a wide range of interested individuals
- **Outreach Program** design, liaison, organisation, resourcing & follow-up
- **Program Advocacy, Program Promotion, Lobbying for Change** (e.g. Herceptin) – Special Events (Field of Women, Well Women's Seminar, Christmas Luncheons, Celebration of Life Luncheons etc), Community Awareness Programs with Community Partners, Cancer Carers, Conferences, Forums; Workshops & Consumer Representation; Attendance at National Forums eg. BCNA, BCAG etc.
- **Sub-Committees and Function Area Co-ordinators**
  - Newsletter Production and distribution,
  - Resource Production (Outreach Programs, Beginning the Journey Kit, Videos etc),





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- Continuing Education Program for Group membership (i.e. Guest speakers, Oncology Nurse Consultant, Breast Care Nurse/Group Facilitator, Newsletter information sheets/articles/research updates),
  - Record-keeping (photographs/photo-boards, albums, articles, cuttings, resources),
  - Welfare Officer,
  - Ring-a-friend Program,
  - Crop Top/Prostheses Coordinator
  - New name tags & information sheets Co-ordinator
  - Wardrobe Mistress – Pink T-Shirts/Clothing Supply,
  - Meeting Catering,
  - Badges and banners Co-ordinator
  - Stalls & Raffles Co-ordination,
  - Brochure development and publications/ resources
- 
- **Volunteer regulars** e.g. Bus drivers, Resource Library at Cancer Care Centre, Sub-committees (Special events, research projects)
  - **Cancer Care partnerships** liaison and mutual support, information exchange and events planning i.e. Alkira Lodge, Illawarra Cancer Carers, Breast Cancer Network Australia and local Groups e.g. Cancer Patients Support Group, Bowel Cancer Support Group, Gynaecological Support Group etc.
  - **Community Partnerships** with Wollongong High School of the Performing Arts, University of Wollongong, Wollongong Golf Club, Service Clubs etc.



*IBCSG Community Partnership with Wollongong High School of the Performing Arts Dance Group for Field of Women Day in Wollongong 2006*



## **Illawarra Breast Cancer Support Groups:**

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### **1.5 The IBCSG Current Activity Groups**

- Craft Group
- Dragon Boat Group
- Exercise Group (a specifically-designed program at Fernwood)
- Aqua-jog at UOW with Bruce Power
- Tap-dancing Group (Medical Media Awards performance recently)
- Relaxation Groups
- Tai Chi Group

### **1.6 Regional/Rural/International links & Friendship Groups**

- Milton-Ulladulla
- Nowra
- Camden
- Temora
- Griffith
- Dubbo
- Cowra
- Cook Islands
- Canada

### **Cancer Care partnerships**



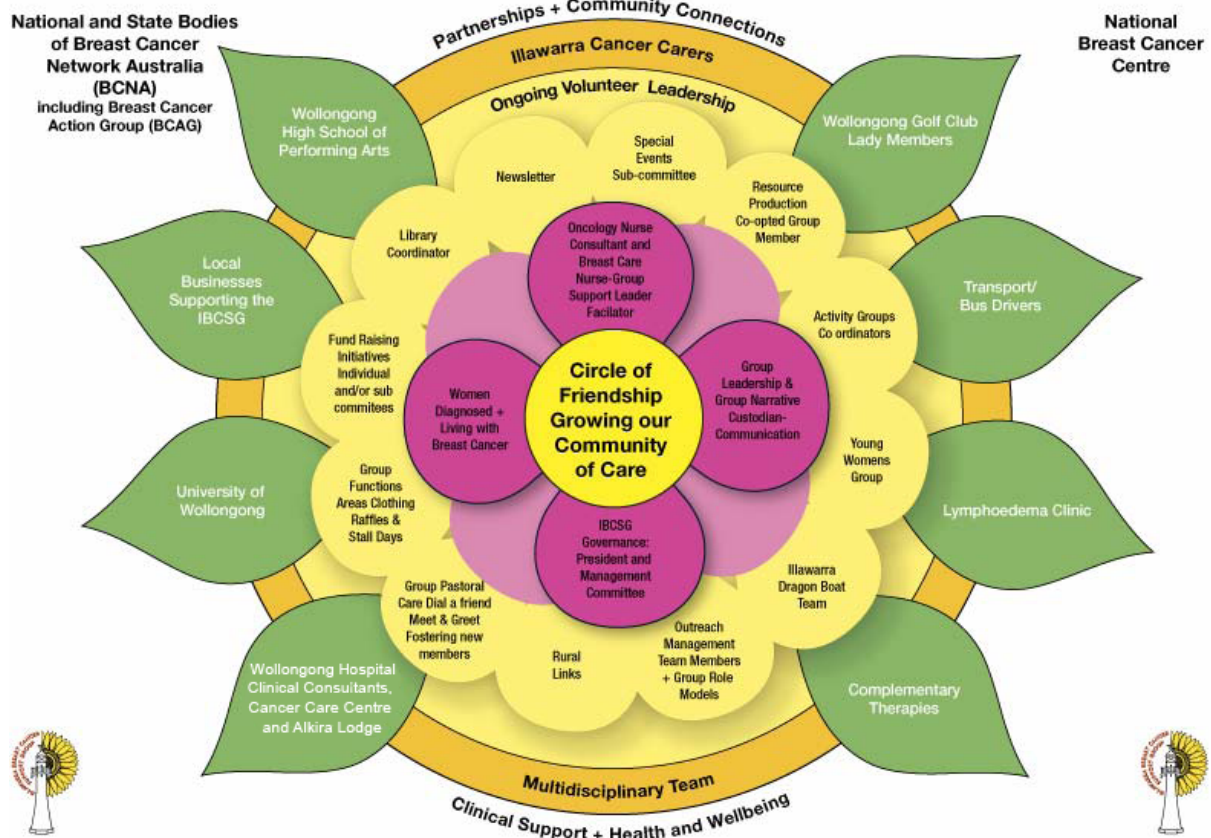
*Illawarra Cancer Carers Caring for Us*



## Illawarra Breast Cancer Support Groups: Participatory Program Evaluation Identifying the Meaning and Value of the Support Group for Group Members

### 1.7

### Illawarra Breast Cancer Support Group Model



### 1.9 Funding and Resourcing of the IBCSG

The IBCSG has recently applied for and achieved the status of a body Incorporated under the Department of Fair Trading. As a result of becoming incorporated, the Group has now acquired its own insurance, public liability and directors' liability arrangements. This move to incorporation was motivated by the need to ensure Group sustainability in a continually changing Health Policy environment. The Health Policy environment has the potential to be somewhat problematic for continuing existence of community-based Support Groups. It is an environment, according to the Cancer Council of NSW, where: 'Support Groups are often undertaken in a voluntary capacity with little direct financial support and variable formal input from health services and cancer organisations.'<sup>3</sup>



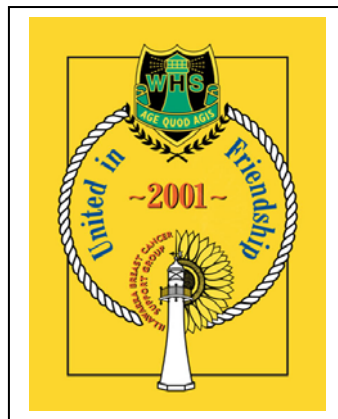
## Illawarra Breast Cancer Support Groups:

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The Group, with incorporation, has made successful application for **Deductible Gift Recipient status** from the Taxation Office and donations of gifts and bequests are now tax deductible. The Authority to Fund-raise from the Department of Gaming and Racing, Office of Charities section, is a legal requirement and ensures accountability. Group accountability has been assured with regard to the way in which the Group receives and handles funds from the community, produces its accounts and audited records, and as a matter of course, publicly demonstrates its accountability. The Authority to Fund-raise also means that if the Group holds a raffle, it is required to operate within set guidelines. This Authority also ensures that if money is raised for a certain project, there is a guarantee that the funds will be used for that purpose. The consequence of registration for the Group has been assurance of transparency and accountability for all stakeholders and relevant authorities.

The following principles and practices characterise the way in which the IBCSG organises and sustains its current resourcing activities:

- Keeping fund-raising quite separate from support meetings
- Acknowledging all gifts (no matter how large or small)
- Ensuring that donors know where and for what purposes the money is or will be used
- Building strong relationships over the years with golf clubs (particularly ladies groups), a local high school, service clubs and community clubs
- Making applications for support to social and sporting clubs
- Member-volunteers taking ownership of the processes
- Having a health professional as facilitator where the facilitation role is seen as part of paid employment and where the role includes responsibility for working with the support group, in the community and not confined to clinical context boundaries.



### The IBCSG Building Strong Relationships with Wollongong High School of the Performing Arts

<sup>1</sup> Qualification of statement by current participating Support Group members

<sup>2</sup> Yaskowich, K.M. & Stam, H.J. (2003) 'Cancer Narratives and the Cancer Support Group', *Journal of Health Psychology*, Sage publications Vol. 8 (6):720.

<sup>3</sup> The Cancer Council of New South Wales, Research Bulletin, Support Groups, September, 2005.





### SECTION 2: Framing our Participatory Evaluation: What purposes are served by the IBCSG?

The initial framing for this participatory evaluation project, was achieved with a small focus group of key people involved in the IBCSG. In the discussions and reflections that took place, participants identified the purposes that might be served, by an evaluation of the meaning and value of Group activities. These included four key areas of concern:

We should be able to tease out some *general* information about how the variety and extent of group activities would simply not be possible with a self-help group – it's the professional facilitation that makes this possible  
Dr Beth Marlow: Previous Support Group research (2000)

#### How is the Support Group organised?

- To be able to show how the Support Group model is organised – how it all fits together – showing exactly how the model works – what we REALLY do.
- To provide an account of where we have come from and the possibilities – to show the beautiful solid structure and the extraordinary diversity of what happens in the Group – to show there is order in what we do.

#### What values and principles underpin the Support Group processes?

- To show the trust, friendship giving, receiving and group cohesion that is the strength of the Support Group
- To demonstrate, with the evaluation of the model, the trust we have in one another – how women feel safe to share lots of things with each other.
- To be able to show how we work as a team – how we work together for the good of the Support Group
- To show how the Support Group enables us to develop as strong independent women – how we blend and balance strong independence with nurturing – how women develop and do things they never thought they could do.

#### What is the Support Group experience and how does this experience meet individual needs?

- To gain an understanding of both the individual and the Support Group journey
- To understand the contribution of the Support Group to meeting the needs of its members.

#### How do we Understand and communicate what the Support Group does?

- To get people understanding and talking about what we are doing as a Support Group.
- To gain information that we hope we can spread worldwide about what the Support Group does.

### 2.1 Key Questions for the Evaluation

The key questions to be addressed by the evaluation were generated in the context of these initial focus group discussions. According to these members of the IBCSG, the questions that needed to be asked were:

1. What *really* is the Support Group?
2. How do we describe ourselves?
3. What are our values & our principles?
4. How do we relate to one another?
5. What are the core processes that define/identify our Support Group?

The research demonstrates both the complexity of the experience of cancer and the integrated nature of support requirements. From the survivor's perspective, psychosocial support is central, not peripheral.

Dr Beth Marlow: Previous Support Group research (2000)



## Illawarra Breast Cancer Support Groups:

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6. What does our Support Group do that works well for members?
7. What are the essential indicators for success of our Support Group?
8. What might indicate that things are not working so well for Support Group members?
9. What purposes are served by the Support Group?
10. Who benefits from the Support Group – How and Why?
11. What ensures our sustainability as a Support Group?
12. Could others start up a Support Group by doing what we do?

## 2.2 Background to how we went about evaluating the IBCSG

Research into the experience and the function of cancer support groups in general, has highlighted the need for a particular type of evaluation framework. That is, a framework that takes into account both the individuality of the experience and the benefits of the group, when viewed from the perspective of Group members<sup>1</sup>. This approach to evaluation is suggested because membership of a support group is both a unique individual experience and a shared collective experience, of being and growing together.

With evaluation purposes identified by both the initial evaluation planning group and the two evaluation facilitators (Dr Sue Curtis, Evaluation consultant and Dr Beth Marlow, the IBCSG member and researcher), overall evaluation methods and strategies<sup>2</sup> were aimed at gathering information for:

- Documenting the values, principles, processes and roles that contribute to what works
- Identifying of current program relevance, quality improvement, development and sustainability indicators
- Identifying strengths and potential challenges in continuing development and sustainability
- Capacity-building for Support Group members in reflective evaluative processes and tools to identify and meet emerging needs, and
- Providing an information base that could be used by Support Group participants to support development of both self-advocacy and transferability to similar community-oriented support groups for women diagnosed and living with breast cancer.

An important component of this approach to evaluation, is that the activities support group cohesion and collective inquiry, which is organised around the Group's shared values, purposes and identified outcomes. This community-building approach to evaluation also contributes towards community capacity-building. With this type of model, the evaluation outcomes demonstrate the capacity of a community to both meet the needs of and care for, Support Group members. Group members and supportive others involved in this type of evaluation might include a range of stakeholders i.e. Group participants, Group leaders – formal and informal, designated governance bodies and roles, core stakeholders and stakeholder partnerships.

The purpose of the present evaluation was to establish baseline information about the meaning and value of the Support Group for its members. It was also intended that, through participation in the evaluation activities, Group members would be able to develop their own model for ongoing participatory program

There were three main reasons for attending groups: Knowledge (acquiring & sharing information), support (from peers & group leaders) and identification (the companionship of people with shared experiences)  
Dr Beth Marlow: Previous Support Group research (2000)



evaluation. This model could provide a vehicle for evaluating program activities where program participants themselves, in partnership with interested stakeholders, can make use of the framework that was developed to plan and conduct their own program evaluations. In effect, the present evaluation was a 'Pilot' evaluation because was aimed at finding the best possible methodological 'fit'<sup>3</sup> with what the IBCSG *really* does in practice.

## 2.3 How we got started with the evaluation

The evaluation used a range of methods, strategies and tools to establish baseline information and to develop the Group's evaluative skills and capabilities. These methods, strategies and tools were selected because they were appropriate to the skills, knowledge and backgrounds of the participants and tailored to the available resources.<sup>4</sup> The evaluation processes were oriented towards *understanding*, and with this approach, gave voice to and validated the Group member's needs, values and lived experiences<sup>5</sup>.

The present evaluation project builds on the body of work completed with the membership of the IBCSG over a number of years. In this previous research activity, the focus was on the individual perspective of diagnosis and the psychosocial dimension of living with breast cancer and survivorship.

For the present evaluation, the collected wisdom of the Group, recorded across the four areas of interest in previous research activities (APPENDIX 1),<sup>6 7 8</sup> was set out in Survey format (APPENDIX 2) and *re-presented* to participating members as a Survey. It included a summary of all the previous findings about: support; living with cancer; quality of life; and the Support Group. The sections of the Survey related to these areas of interest, provided a set sequence for possible discussion.

## 2.5 Background to Survey Content and format

The collected understandings of previous research with IBCSG included:

- the individual experience of diagnosis and living with cancer;
- individual perspectives on needs; and
- the nature of support requirements.

The process of support involves: A feeling of reassurance (knowing what to expect), sense of control (the ability to make choices and decisions), organisation of care (integrated support network), and validation of experience (being taken seriously).

Dr Beth Marlow: Previous Psycho-social Support Needs research (2003)

Previous research activities were carried out in a traditional psychosocial type of research framework, which maintains a clear distinction between researcher and research participant. These studies were oriented towards understanding:

- Quality of Life issues;
- Cancer Survivorship
- Psychosocial needs, and
- The place of Support Groups in the individual's journey through the cancer experience.

The continuity of inquiry between previous research and the current project was achieved with the formation of an evaluation partnership. This partnership was between the two facilitators, one of whom was a member of the Breast Cancer Support Group (Dr Beth Marlow), highly skilled in



psychosocial research and the other, the current project evaluation facilitator (Dr Sue Curtis). Sue's research expertise and experience was in participatory, community-oriented program evaluation. The Support Group member of this partnership was formerly a University lecturer/researcher into breast cancer-related issues. She had also been a research mentor for students undertaking a Masters degree and supervisor and co-author of published papers related to research carried out with the IBCSG. .

When the Survey was handed out, the Survey items were discussed in small focus groups prior to individual Group members filling in their written responses to statements and questions. By participating in focus group discussions, Group members were able to *re-engage* with what they currently considered to be the meaning and value of the Support Group.

In focus group discussions and Survey responses, Group participants indicated:

- a. Their current level of agreement with previous findings
- b. The degree to which a particular aspect of experience, reported by previous research outcomes, actually represented their own journey; and
- c. The level of importance for them, as an individual, that the Support Group had played in the different aspects of their experience.

The relevance of previous research to our current project is that the support group members have identified for themselves why they joined the breast cancer support group and why some choose to stay with the group.

Dr Beth Marlow: Previous Support Group research (2000)



The reflection on information contained in the Survey categories (APPENDIX 2) provided Support Group members with the opportunity to 'rejoin' the recorded, evolving story, of the Group in action. The Survey represented, for Support Group members, a current update on their collected understandings of individual and shared experiences in the cancer journey.

## 2.4 Background to Focus Groups

Facilitated focus group processes (APPENDIX 3) with a range of activities enabled Support Group members to generate a current, collective, description of the meaning and value for them, of Support Group participation. The planned introductory evaluation activities were organised to invite Support Group members to both engage with and take ownership of, the evaluation processes and outcomes.<sup>9</sup>



A further focus group was an informal reflective discussion, initiated by the Illawarra Dragons Abreast Team for the Team's own purposes. This activity was directed towards identifying the meaning and value of their participation in team activities as the basis for refining the key elements for the new logo (APPENDIX 4):

**'Friendship, Fitness and Fun'**



The introductory focus group activity involved the use of large picture cards (Compatibility Communication System Jumbo Card Set), with a variety of images<sup>10</sup> as a resource for individual reflection. These focus groups were organised so that participants could identify and record their comments about the ways in which the Group had been a support for them in their personal journey. Participants were also asked to use the cards as a prompt to identify action words (key verbs or 'ing' words) that indicated what 'support' had meant for them in their experience of the Group.

The 'action words' generated in these original focus groups were used to test out the relevance, usefulness and appropriateness of four different possible theoretical frameworks for analysing the meaning and value of the Support Group for its members. The purposes served by 'action' words represented the key factors contributing to the effectiveness of the Support Group and at a practical level, the meaning and value of the type of 'support' provided by the Support Group (APPENDIX 5).

Follow-up focus groups conducted at the AdCare Retreat (APPENDIX 6), were designed to facilitate reflection and discussion on the usefulness and appropriateness of the categories of activity (Action Category Codes for Community Building) that had been derived from analysis of the earlier focus group observations, action words and discussions. The AdCare Lifestyle Retreat, held in April 2006 at the Stanwell Tops Conference Centre, was the last retreat for what had until this date, been an annual event. Participants for these focus groups were a mixture of women from across all Support Groups and sub-groups who had attended one or more AdCare retreats during its fourteen year history.

## **2.6 Community-building – the logical framework for Program Evaluation**

Because previous research had been guided by a psychosocial framework it had focused primarily on understandings, concerns, meanings and needs of the *individual*. However, the current partnership made it possible to develop a more participatory approach related to the individual as a social being. In the previous psychosocial research, the traditional distinction between psychological (individual) and sociological (groups) approaches had tended to miss the middle ground. This middle ground was the area in which the individual both understands, and is understood, as a member of a social network or community, and in the case of this Group– as a member of the IBCSG.

Taking into account the information generated in the initial focus groups, the four logical frameworks considered, as possibilities for organising and making sense of the recorded information in this program evaluation were:

1. **Community Building**<sup>11</sup> – *because the initial words and descriptions of meaning and value, provided by the women, aligned very closely with the key elements of what people 'Do' in organising and building community.*
2. **Social Philosophy**<sup>12</sup> – *because the processes that were identified represented the type of activity that is involved in becoming a member of a group and identifying with that group, creating and sustaining the culture of the group and ensuring the cohesiveness and strength of the group.*
3. **Social Capital**<sup>13</sup> – *because the three key elements of social capital: trust, mutual benefit and unconditional giving and receiving, provided the closest possible fit with the*



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*consequences of the type of 'action' that the women generated to describe the meaning and value of the Group.*

4. **Psychosocial** - *because all the previous research undertaken with the Group had been carried out within this framework and this provided the best fit for analysis of the individual experience and journey within the context of the Group.*

The initial set of questions generated by Support Group members to guide the current evaluation and the trialling of possible logical frameworks for making sense of what happened in the Group, led to the adoption of the participatory, process-oriented approach to the evaluation. This approach was chosen because it could accommodate both the psychological and social perspectives into a logical framework of *community building*.

The participatory approach to program evaluation provided a good methodological 'fit' between the principles of community building<sup>14</sup> and Group processes. It was also the *community-building* framework that best supported reflective analysis of the meaning and value of the particular type of 'social space'<sup>15</sup>, that in their initial focus group activities, Group members had indicated they valued.

### 2.7 Social Space – the Unit of Analysis for a community-building framework

A *social space* is a space that enables people to come together and to support their group cohesion. A social space is maintained by the activities of individuals within that space. It is the individuals with their particular interpretation of leadership and participant roles, who structure their lives and activities around a particular life view or values framework that is shared by members of the group.<sup>16</sup> It is this life view and the core values that give the Group its character and identity.



Living with cancer (even in remission) seems to have some peculiarities. There are social attitudes particular to cancer, cancer produces greater fear, more stigma, more pity than other equally life-threatening and debilitating conditions.

Dr Beth Marlow: Previous Survivorship research (2002)

Research into the cancer experience indicates that the provision of a separate social space is of crucial importance to people diagnosed and living with cancer. This is because a diagnosis of cancer calls into question just who you will become, as a person diagnosed with cancer and as a consequence, how you might want to live the rest of your life. It is in this separate social space that women diagnosed and living with cancer can have the opportunity and the support to re-think their priorities and re-invent themselves in a positive and self-sustaining way of being.

*Patients are compelled to re-evaluate their identity and establish how cancer fits into their life story. . . . patients talk about 're-working' their lives in the context of the group . . . The 'separate space' provided by peer support groups, enables patients to explore their lived experience of cancer in ways that are congruent with that experience.<sup>17</sup>*



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- <sup>1</sup> Docherty, A. (2004) 'Experience, functions and benefits of a cancer support group' in *Patient Education and Counseling* 55, 87-93, Elsevier Ireland Ltd. 2003.
- <sup>2</sup> Patton, M.Q. (1997) *Utilization-Focused Evaluation: The New Century Text*, 3<sup>rd</sup> Ed. Sage Publications, Thousand Oaks, California. P.76.
- <sup>3</sup> Whiteford, G. (2005) 'Knowledge, Power, Evidence: A Critical Analysis of Key Issues in Evidence Based Practice' in Whitford, G and Wright-St Clair. *Occupation and Practice in Context*. Elsevier Australia Marrickville, NSW. P.39.
- <sup>4</sup> Lennie, J. (2006) Increasing the rigour and trustworthiness of participatory evaluations: learnings from the field. *Evaluation Journal of Australasia*, Vol.6, No 1. p.30.
- <sup>5</sup> Lather 1991 & Lennie 2002 in Lennie, J. (2006) Increasing the rigour and trustworthiness of participatory evaluations: learnings from the field. *Evaluation Journal of Australasia*, Vol.6, No 1. p.29.
- <sup>6</sup> Yamine, J., Naulty, A., Macha, U., Willis, S., Koster, H., & Marlow, B. (2003). *Quality of life perceptions after surviving a life threatening illness: Cancer and cardiac disease*. Unpublished research report. Psychology Department, University of Wollongong, Wollongong, Australia.
- <sup>7</sup> Marlow, B., Cartmill, T., Cieplucha, H. and Lowrie, S. (2003) 'An Interactive Process Model of Psychosocial Support Needs for Women Living With Breast Cancer' in *Psycho-Oncology*, 12: 319-330.
- <sup>8</sup> Nazenin, M. Smith, N., Robinson, L., Tanconi, L. & Marlow, B. (2004). *Quality of life perceptions after surviving a life threatening illness: Cancer and cardiac disease*. Unpublished research report. Psychology Department, University of Wollongong, Wollongong, Australia.
- <sup>9</sup> Patton, M.Q. (1997) P.111.
- <sup>10</sup> Compatibility Communication System Cards (1999-2001) CCS Corporation Pty Ltd, Martinsville, NSW Australia (Jumbo Cards Set).
- <sup>11</sup> Minkler, M & Wallerstein N. (2002) Improving Health Through Community Organization and Community Building' in Glanz K., Rimer B.K., Lewis F.M. (Eds.) *Health Behaviour and Health Education: Theory, Research and Practice* 3<sup>rd</sup> Ed. John Wiley & Sons Inc. San Francisco CA
- <sup>12</sup> Habermas, J. (1987) *The Theory of Communicative Action, Volume Two: The Critique of Functionalist Reason*, trans. Thomas McCarthy, Polity Press, Cambridge.
- <sup>13</sup> Cox, E. (1995) *A Truly Civil Society*. Boyer Lectures, ABC Books, Sydney, NSW.
- <sup>14</sup> Minkler, M & Wallerstein N. (2002), pp.279-311.
- <sup>15</sup> Bourdieu, P. (1990) *In Other Words: Essays Towards a Reflexive Sociology*, trans. Adamson, M., Stanford University Press, Stanford, California.
- <sup>16</sup> Habermas, J. (1987), P.142
- <sup>17</sup> Yaskowich, K.M. & Stam, H.J. (2003) 'Cancer Narratives and the Cancer Support Group', *Journal of Health Psychology*, Sage publications Vol. 8 (6):730.



## SECTION 3: LITERATURE REVIEW

### 3.1 Current Perspectives on the purposes served by Breast Cancer Support Groups

Coward and Kahn<sup>1</sup>, researchers and writers in the field of breast cancer refer to ‘transcending breast cancer’ and have identified, that for people diagnosed and living with cancer, it’s the group *processes* that can facilitate a range of positive outcomes for them as support group members. These authors have demonstrated that outcomes for support group members can include:

- self-transcendence;
- personal growth;
- positive construction of individual and shared meaning through the experience of diagnosis and living with breast cancer; and
- developing the ‘. . . capacity for reaching out beyond personal concerns and taking on broader perspectives, activities, and purpose’. <sup>2</sup>

Yaskowich and Stam<sup>3</sup>, another leading research partnership in work with cancer support groups, describe their findings in terms of ‘*Cancer Narratives and Cancer Support Groups*’. They explore the unique role of support groups through reflective analysis of the ways in which ‘patients’ are found to be making sense of their lives after diagnosis. These researchers refer to this activity as ‘ongoing biographical work’ on the part of those diagnosed and living with cancer. This biographical work is the *work* of continually developing one’s [life] story, and in the case of breast cancer, making sense of the illness and developing an understanding of what really matters in the context of their life-threatening illness. The developing of one’s story includes the search for a separate *social space*, where those diagnosed and living with cancer feel it is safe to speak without having to protect family members. This separate social space is one in which they have the opportunity to speak freely of their illness, their feelings and their fears.

However, these same researchers<sup>4</sup> do signal the limitations of community groups when it comes to ongoing support. This is because community groups are built around mutual need with a high level of voluntary input required to sustain them. By its very nature, voluntary support is both time and resource-limited and this can impact negatively on group sustainability, with loss of volunteer involvement. Notwithstanding this limitation, these researchers and authors observe that groups do provide for participation in the type of social space that is rarely found in contemporary societies. And more importantly, from the perspective of ladies diagnosed and living with breast cancer, their participation can enable them to experience the possible options for restoring something of the coherence in life that existed for them, pre-diagnosis.

From the community-building perspective, a social space is the type of space that is co-created for and by group participants, and is a space in which group processes continually sustain and build a sense of identity, belonging and community. In their analyses and papers, Yaskowich and Stam<sup>5</sup> have described the processes of community building as ‘. . . joining, belonging and identifying . . . [processes] encompassing a search for a separate social space, where participants can transcend the stigmatizing nature and experience of diagnosis and living with cancer.’ And, with these community building processes participants are, in their accepted practice, engaging in the type of activities that contribute towards:

1. enhanced community capacity;





2. leadership development;
3. critical awareness; and
4. multiple perspectives on gaining both personal and shared power.<sup>6</sup>

Together, these four community-building outcomes characterise the shared strength inherent in community capacity-building, with a dual focus on collaborative social activity and empowerment-oriented advocacy, for and by support group participants.

### **3.2 Current Perspectives on the potential limitations, tensions and difficulties with Breast Cancer Support Groups**

Support Group participants at any one time represent a diverse range of ages, stages and phases in diagnosis, treatment, living with and surviving breast cancer. With this level of variation there is the possibility that the individual experiences within a group, could also vary along an equally wide continuum, from highly positive to very negative. Yaskowich and Stam<sup>7</sup> have indicated that from the perspective of the individual, these different experiences might include the following.

1. With varying stages and severity, group members might not always fully recognise or appreciate one another's experiences and some would rather not be exposed to other's experiences (or conversely, expose others to their previous or current experience as this represents some of the personal challenge and difficulties that others may have to face)
2. When people find themselves at widely differing stages along the treatment continuum or illness trajectory, their needs vary accordingly, and so too the apparent timeliness and appropriateness of a group response to their individual needs
3. A range of different individual experiences and circumstances within the group can influence people's ability to integrate and participate in group activities
4. Newly-diagnosed people searching for hope and reassurance might sometimes find that their initial contacts with support groups actually thwart their sense of hope as a result of unsolicited and insensitive comment from a group member or with accepted practices of self-disclosure in the particular group
5. For some, comparing their own prognosis with other members of the group can result in further isolation
6. For those who are managing well and are long term survivors, some can experience a feeling of 'survivor guilt' when they compare themselves to other group members who are in different and less positive circumstances
7. There is sometimes high level frustration in trying to keep groups going and in sustaining and resourcing group activities
8. Reciprocity (giving and receiving) is sometimes not achieved within the group because the bulk of the load and responsibilities is falling to a dedicated few.

Interestingly, these same researchers report that, in their experience, the patients who are members of support groups are a minority of cancer patients in general.

From the Group or organisational perspective, Kacen and Bakshy<sup>8</sup> have indicated that the experience of communication between different groups can be limited where there are significant differences in the respective organisation's or group's stories (group *narratives* that define who and what we are here for). Such differences in understanding of group activities and purposes



can actually work against mutual understanding and/or productive dialogue between respective cancer support groups, sub-groups and/or representative organisations.

The *identity* of a group or organisation shapes what their accepted priorities might be, their ways of doing things and the type of interactions that are possible with other groups, sub-groups or organisations. These interactions, in turn, reinforce or continually reshape the Group's *chosen identity* and perceived *purposes* as well as the potential for conflict between the perceived purposes of theirs and other groups. Over time, the interactions between groups and/or organisations determine the possible pathways or barriers that evolve with inter-group communication and hence, the potential for either conflict or mutual benefit and support amongst groups, sub-groups and/or organisations.

For example, conflict could occur between an organisation that is a primarily self-selected, self-help organisation focussing on empowerment and reciprocity and another institutional organisational unit that is staffed entirely by professional support personnel.

Alternatively, the professional institutional service-provider organisation might see the type of support that is given in the self-help group as lacking in professional knowledge. The professional service provider group might link this apparent absence of professional knowledge with less than optimal decision-making from a less than complete and appropriate knowledge base.

These authors identify the root of potential for conflict as the *differences* in the way the respective groups/organisations *define the concept of 'support'*. These definitions are represented in both their 'public' and 'private' positioning of their particular stance or in other words, their 'external' (for them out there) and 'internal' (for us here in the Group) narratives.

The public positioning (or external narrative) of a self-help group that could lead to inter-group conflict with a professional service-provider group might be that:

- Self-help groups are filling the gap left by mainstream medical services in response to social-emotional needs
- Patients are the ones who best know their own needs
- People within the self-help group have a sense of vitality and empowerment compared with non-participants diagnosed and living with cancer who are likely to experience weakness and powerlessness in coping with their cancer
- Interest groups see themselves in competition for both clients and resources

The private positioning of a self-help group (private narrative) that could lead to misunderstanding and conflict with professional service providers might include indications that, 'We are:

- Committed to action, activism, taking our fate in our own hands and assuming control of our lives
- Challenging medical establishment monopoly over various aspects of the illness
- Shifting the balance of power between patients and their treatment providers
- Acquiring control over resources that members lack and ceasing to accept passively, the treatment determined by medical staff whilst searching out alternatives that can help
- Counteracting the control of the disease over one's life and what patients may or may not do



- Seeing part of our mission as preservation of memories or a kind of memorial where death and the memory of those departed is open for discussion and part of the culture

From the perspective of institutionalised support services and groups, a positioning (the external narrative) that could lead to misunderstanding and conflict with self-help groups might be represented in claims that:

- The multidisciplinary teams, financed by the institutions concerned, have clearly defined principles for support of patients that determine where and when resources will be allocated
- Decision-making is grounded in evidence-based practice regarding treatment and treatment options
- The content and format of meetings is pre-determined because indicators for what counts as a successful group are based on the beliefs and principles that underpin each group's expectations, priorities and processes.

The private stated purposes (internal narrative) of institutionalised support services that could lead to conflict with the perceived purposes of self-help groups might be:

- What counts as professional behaviour, functioning and identity within a context of heavy workloads and limited scope of roles and positions is determined by the complexity of system pressures and the demanding nature of the illness
- One's own helplessness against the disease and dealing with the uncertainty and needs in patients' lives is amplified by the pressure experienced in being a member of a multidisciplinary team
- Accountability to the system and professional obligations has to be considered when determining priorities in response to patient's needs and the requirements of a casework approach

The IBCSG has elements of both professional facilitation and self-help membership so the distinctions noted in the foregoing research are less directly relevant. However, the indicators of potential for disruptive conflict between professional support services and the IBCSG as a self-help Group, could inform the Group's current reflections on inter-group communication, interaction and collaborative endeavour. This is particularly the case when relationships between the core Groups, sub-groups and related interest groups or professional support organisations, are engaged in substantively different types of activity that they count as 'cancer care support'.

From the perspective of the present participatory evaluation, the foregoing observations provided by Kacen and Bakshy<sup>9</sup> provide a useful background to inform critical reflection, interpretation and evaluation, of both internal and external threats to viability and sustainability of the IBCSG. Alternatively, it might also identify the potential for productive, boundary-spanning communication, advocacy, trust and mutual benefit, between the IBCSG and the broader cancer care community.

### **3.3 Indicators of meaning and value for a community-building evaluation framework**

In a community-building framework, the foundations on which people *organise* themselves, are an important factor for understanding how and why the group works for its members. The way



## Illawarra Breast Cancer Support Groups:

Participatory Program Evaluation Identifying the Meaning and Value of the Support Group for Group Members

they identify common challenges and goals, mobilise their resources around shared purposes and then develop and implement strategies for achieving their collective purposes and goals, are all sources of information for identifying and understanding what the community does and how it works.

So too, is the basis on which people *identify* as a member of the group and together, *nurture* the skills and capabilities for effective community membership within the social space which they have created.

Finally, it is the processes by which the community recognises, celebrates and shares its strengths with one another that are of primary importance, when we are seeking to understand the value of the Groups. To understand just how the community which constitutes the Support Group maintains and sustains its coherence, vitality, solidarity and membership. While researchers indicate<sup>10</sup> that there is limited evidence as to how participation in a support group might affect the experience of living with cancer, they do raise the possibility of involvement for empowerment-oriented social action, which can be seen in advocacy for both self and others.



The core idea of Frankl's work in Coward and Kahn (2005) is that people develop the capacity for 'self-transcendence' or re-inventing 'self' in the process of adopting a new way of *being* and *seeing* oneself. This is accomplished with an attitude of giving, receptiveness and acceptance. With this attitude, Support Group participants have the potential to create the type of community-building structures and processes that enable Support Group members to '... recognize and contribute their 'gifts', the totality of which represent the building blocks or assets of a community that enable it to care for its members.'<sup>11</sup>



In recognising and sharing their 'gifts', Support Group members can find themselves contributing to a culture of shared leadership. In this context, 'leadership' occurs naturally from within the group and is based on interests, capabilities, availability for tasks and confidence in both modelling and undertaking leadership roles at whatever level is required.

Presentation of book 'Beginning The Journey' narratives, from "Don't tell Gloria" Project for her 60<sup>th</sup> birthday. Part of 'My Journey Pack' now given to newly-diagnosed women and Group participants



### 3.4 Current Policy Imperatives for Judging Meaning, Value & Purpose of a Support Group

Program evaluation activities at the local level are both constrained and guided by the relevant policy documents of the broader health system. It is these policy statements which determine what can count as legitimate *evidence* of success. It is also the broader policy statements that identify the type of activities and outcomes that will be supported and resourced within the current funding structures and, therefore, the criteria by which programs might be deemed to be effective and appropriate.

The international 'gold standard' for judging appropriateness and effectiveness in community-related population health initiatives has been for many years, the Ottawa Charter for Health Promotion (WHO 1986)<sup>12</sup>. The five key strategies from Ottawa Charter were to:

1. *Build healthy public policy* beyond health care
2. *Create supportive environments* for socio-ecological approach to health
3. *Strengthen community actions* through concrete and effective community planning strategies
4. *Develop personal skills and social development* through information, education and enhancement of life skills
5. *Reorient health services* beyond the responsibility for curative and clinical services towards health

These key strategies provide the broader umbrella of public policy into which the potential criteria for *success* of the IBCSG might be judged. However, successive international statements based on the Ottawa Charter could be of even greater relevance in judging the meaning and value of the IBCSG, because they provide a picture of community action at the local level.

An important policy document not mentioned in the NSW Cancer Plan 2004-2006<sup>13</sup>, is the follow-up to the Ottawa Charter – the Jakarta Declaration of 1997 on Leading Health Promotion into the 21<sup>st</sup> Century with health promotion that makes a difference<sup>14</sup>. The very practical strategies of the Jakarta Declaration included:

- Raising awareness about the changing determinants of health
- Supporting the development of collaboration and networks for health development
- Mobilising resources for health promotion
- Accumulating knowledge and best practice
- Enabling shared learning
- Promoting solidarity in action
- Fostering transparency and public accountability in health promotion

The implications of this policy for current practices that might count as effective action within a Support Group, are the particular references to:

- **Consolidating and expanding partnerships** for health and social development between different sectors at all levels of governance and society. These are partnerships that provide mutual benefit through the



sharing of expertise, skills and resources. Partnerships that are based on agreed ethical principles, mutual understanding and respect.

- **Improving community capacity and empowering the individual** – where health promotion is carried out BY and WITH people, improving both the ability of individuals to take action and the capacity of groups, organisations or communities to influence the determinants of health. This would involve practical education, leadership training and access to resources. This means enabling more consistent, reliable access to the decision-making process and the skills and knowledge to effect change.
- **Securing an infrastructure for health promotion and new mechanisms for funding locally.** Creating new and diverse networks for inter-sectoral collaboration which provide mutual assistance and facilitate exchange of information on which strategies have proved effective in which settings.

Group activities such as these, identified following the Jakarta Convention, demonstrate both community capacity-building and empowerment-oriented social action, which in their own right, reflect a community ‘strengths-based’ approach to what might count as effective action for building and sustaining the relevance and usefulness of a Support Group to its participating members.

One recent publication with particular bearing on the question of support groups, identifies what the Ottawa Charter would look like if it were drafted in the current era of globalisation and health needs. This publication provides the insights and recommendations developed by Don Nutbeam, PVC University of Sydney in his 2005 paper, ‘What would the Ottawa Charter look if it were written today?’<sup>15</sup>.

Nutbeam suggests that ‘healthy public policy’ could be reinterpreted to mirror the healthy cities movements, where locally determined policy with a far greater range of political and governance structures, governs the day-to-day lives of many. Secondly, we are experiencing the evolution of wide variation in health settings and a more subtle interpretation of supportive environments associated with development of practical and locally relevant health promotion interventions. In this context, it IS possible to address the full range of determinants of health by *creating* defined ‘supportive environments’.

Nutbeam suggests that the challenge is to learn from the different settings-based approaches, to find out just how these practical interventions might best be adapted to a greater variety of social, political and economic circumstances. Thirdly, Nutbeam indicates that there has been little progress in reorienting health services to achieve investment in health promotion. He proposes that our task is now to assemble compelling evidence of *the return on investment* offered by *health promotion*.

With the fourth consideration of health-related personal skills and social development, Nutbeam suggests that the idea of building *health literacy* is a way forward. This would mean a focus on health literacy which demonstrates how different approaches to health education can produce significantly different outcomes. He sees the challenge as investment in communication and educational methods that have a sound theoretical base to achieve the highest levels of *health literacy*.



Finally, Nutbeam suggests that a reorienting of health promotion, to the strengthening of community action for health, could be achieved by strengthening of social capital to create enhanced community capacity. Social capital is the three-way resource of trust, mutual benefit and unconditional giving and receiving that underpins effective social action for enhanced community capacity<sup>16</sup>. By this the author refers to both the extraordinary range and the quality of experience that is demonstrated in *community action for health*. In the development of community capacity for health, this is the type of action and the evidence to support the process of strengthening social capital, has not until now, been adequately considered.

The ‘**Healthy People 2005 – New Directions for Public Health NSW Health 2000**’,<sup>17</sup> is particularly relevant to the current Support Group evaluation because its strengths-based approach focuses on the possibilities for individuals making decisions and choosing actions that support their health. A key contribution of this policy, to support for a community strengths-based approach, is:

... identification of the need for creation of social and physical environments that promote health and support individuals in their choices for better health and well-being.

The **NSW Cancer Plan 2004-2006**<sup>18</sup> provides a guide to current thinking on support for people diagnosed and living with cancer. Within this policy document, the seven policy themes, having direct bearing on the type of support foreshadowed as best practice in cancer care, are identified as:

1. Patients’ rights/ empowerment
2. Self-determination & responsibility for patients
3. Shared decision-making
4. Patient rights in a patient-centred philosophy & service
5. Patient-centred care – patient/consumer-centred practices
6. Consumer and community advice on committees & working parties
7. Adopting a population health approach to the major burden of cancer in NSW

These themes reflect worldwide policy positioning in relation to cancer care, with a strong leaning towards *empowerment-oriented action*. This aspect of cancer care was also introduced in the NSW Cancer Plan with reference to **World Summit Against Cancer for the New Millennium, Paris, 2000 – Charter of Paris (WSAC 2000)**. This Summit generated a 10 point international declaration aimed at mobilising efforts to improve treatment, *empower* cancer sufferers and guarantee their rights worldwide. The currently evolving movement to define and adopt cancer patients’ *rights* as critical to recognising and *protecting the value and dignity* of individuals with cancer, was also noted in these discussions.

A theme of *self-determination and responsibility* related to cancer support, was represented in the **Association of European Cancer Leagues (ECL) Oslo, Norway 2002 – Joint Declaration on the Promotion and the Enforcement of Patients’ Rights** (ECL 2002). This declaration put *patients’ rights* at the centre of the cancer care continuum and emphasised the rights of confidentiality, and *self-determination*. In addition, the declaration endorsed the significance of *patient responsibility* during the course of their care. The NSW Cancer Plan 2004-2006, was built on this underlying concept with reference to service provision in the patients’ journey. The



Cancer Plan advises that assistance be given to patients in *empowering decision-making*, especially at critical intervention points. (p.19, 7.3).

*Shared decision-making* is highlighted in the NSW Department of Health – Government Action Plan for Health – NSW Dept. Health Chronic Care Program/ Consumer and Community Participation Implementation Group: **‘Partners in Health – Sharing information and making decisions together’**, NSW Health 2001. The recommendations arising from this forum put the case for *consumer participation* in services development and delivery, with consumers and health care workers *sharing information and making decisions together*.

A strong orientation towards *patient rights in a patient-centred philosophy & service* is reflected in the **NSW Department of Health Patient Charter, ‘You and Your Health Service Patient Charter’**. This policy highlights the core indicators of affective action as *respect, involvement, self-determination, individual needs, choice, access and assistance*.

**The Clinical Service Framework for Optimising Cancer Care in NSW 2003**, provides clear directives for *Patient-centred care and patient/consumer-centred practices*. Standard 3 of the Framework, referred specifically to how patient-centred care will be demonstrated when the health system is addressing both ‘technical excellence and quality of care to achieve legitimacy in the eyes of those it serves.’(p.11). This policy identifies the need for *a key contact* in care coordination, as a *source of information and support in patient’s decision-making* and issues related to *psychosocial well-being*.

**The NSW Cancer Plan (2004)**, in its summary of Strategic Areas and Goals, and in its goal areas 10 and 11, makes particular reference to service provision and the patient’s journey and gives a clear indication of what cancer care might look like, if practices based on *patient-centred care* were to be effective and appropriate. Goal 10 states specifically, that *cancer care is to be centred on the patient’s needs*. Goal 11 further advises that cancer patients, carers and their families, need to be provided with access to *appropriate psychosocial and practical support*.

Finally, the NSW Cancer Plan 2004 – 2006, takes up the theme of empowerment and advocacy for cancer patients with its attention to *Consumer and community advice on committees & working parties*. This policy proposes that there be regular meetings of *consumers to participate* in the planning cycle of the NSW Cancer Plan and to have *direct input* into the Cancer Institute NSW for *consumer issues* and for cancer control.

This same NSW Cancer Plan (p.23) states that it aligns its strategies with **‘all available resources, adds value to previous and existing efforts, identifies and responds to ranked priorities and builds strategically upon existing expertise’**. However, the policy framework does appear to have limitations with regard to provision for local input and the potential for improving community-capacity building and empowering the individual. The limitations that emerge relate in particular to the principles and practice advocated in the Jakarta Declaration. These relate to the development of partnerships that provide for mutual benefit through the sharing of expertise, skills and resources.

The limitations of current policy being translated into practice are represented in the current capacity of the Health system, to recognise ‘expertise’ and ‘innovation’ at the local level where





this might differ from accepted practice. With this ‘gap’ between policy intent and practical action at the level of community, there is the potential for a less than optimal capturing of ‘all available resources’ and options for mutual shaping and resourcing of effective everyday practice in achieving the best possible outcomes in patient-centred care.

The current IBCSG evaluation addresses this apparent ‘gap’. If Cancer Care is to reflect the ‘gold standard’ and its subsequent policy embodiments of a population health and health promotion approach, then it might be that development of a Cancer Support equivalent section to the ‘Implications for clinical cancer services’ (p.24) is called for, one that focuses on;

*... strengths-based, psycho-social protocols that reflect best practice and increase knowledge and participation of patients with ‘individuals making decisions and choosing actions that support their health, and creating social and physical environments that promote health and support their individual choices.’*  
(8.1, p.23)

The Cancer Plan (8.4, p.24) identifies support groups as those affected by and/or living with cancer, groups who ‘meet regularly about common issues and provide emotional and practical support to one another.’ The current participatory evaluation has been designed to enhance both the depth and breadth of shared understanding about the meaning and value that support groups might provide, for those diagnosed and living with breast cancer.

### **3.5 Implications of Policy Positioning for IBCSG Program Evaluation**

In summary, current policy document themes provide a set of principles for identifying essential elements of what counts as necessary and appropriate ‘**support**’ in the role and purpose of a Breast Cancer Support Group. Based on the aforementioned policy documents, these key principles might include, at the policy level:

- *Locally-determined policy* with a greater range of political & governance structures
- Development of *practical and locally-relevant ‘supportive environments’* with a settings-based approach
- *Capturing of compelling evidence* of Return On Investment with setting-based health promotion
- Focussing on health literacy with *investment in communication and education*
- *Developing enhanced community capacity* for health through the strengthening of social capital

... and at the level of the individual participating in a Support Group:

- Care centred on the patient’s needs with respect to *individual needs, choice, access and assistance*
- A *key contact* in care coordination as *source of information and support for psychosocial well-being*
- Provision of *appropriate psychosocial and practical* support
- Patient empowerment with respect to decision-making
- Assurance of patient rights, including *respect, involvement, self-determination,*
- Provision for *sharing of information and making decisions* together
- Protection of *patient’s value & dignity,*
- Consumer participation with *direct input into consumer issues*



From the perspective of the current IBCSG participatory evaluation, these key principles also provide an imperative for evaluation activities, to both identify and contribute to, capacity building amongst Support Group membership. The evaluation therefore, incorporates tools and capacity-building processes, for both individual and shared self-understanding. These tools, which represent a mixed methods approach<sup>19</sup>, have been included to assist Support Group participants in identifying and categorising what they value in their Support Group (support, empowerment, rights, value and dignity), as a foundation for ongoing relevance and self-advocacy.

<sup>1</sup> Coward, D.D. and Kahn, D.L. (2005) Transcending Breast Cancer: Making Meaning From Diagnosis and Treatment, *Journal of Holistic Nursing*, Vol.23 No. 3, September: 264-283.

<sup>2</sup> Coward, D.D. (1998, 2003) in Coward, D.D. and Kahn, D.L. (2005) Transcending Breast Cancer: Making Meaning From Diagnosis and Treatment, *Journal of Holistic Nursing*, Vol.23 No. 3, September: p.267.

<sup>3</sup> Yaskowich, K.M. & Stam, H.J. (2003) 'Cancer Narratives and the Cancer Support Group', *Journal of Health Psychology*, Sage publications Vol. 8 (6): 720-737.

<sup>4</sup> Yaskowich, K.M. & Stam, H.J. (2003), p.735.

<sup>5</sup> Yaskowich, K.M. & Stam, H.J. (2003), p.720.

<sup>6</sup> Minkler, M & Wallerstein N. (2002) Improving Health Through Community Organization and Community Building' in Glanz K., Rimer B.K., Lewis F.M. (Eds.) *Health Behaviour and Health Education: Theory, Research and Practice 3<sup>rd</sup> Ed.* John Wiley & Sons Inc. San Francisco CA: p.287.

<sup>7</sup> Yaskowich, K.M. & Stam, H.J. (2003), pp.730-731.

<sup>8</sup> Kacen, L. & Bakshy, I. (2005) Institutional Narratives in the Discourse Between Oncology Social Workers and Cancer Patients' Self-Help Groups in *Qualitative Health Research*, Vol. 15, No.7, September, pp. 861-880.

<sup>9</sup> Kacen, L. & Bakshy, I. (2005), pp. 861-880.

<sup>10</sup> Coward, D.D. and Kahn, D.L. (2005), p.266.

<sup>11</sup> Minkler, M & Wallerstein N. (2002), p.285.

<sup>12</sup> Ottawa Charter for Health Promotion (1986), *First International Conference on Health Promotion* Ottawa, 21 November. World Health Organization, Health and Welfare, Canada and Canadian Public Health Association. URL: <http://www.health-care.au.com/Ottawa%20Charter.htm>

<sup>13</sup> Cancer Institute NSW (2004) *NSW Cancer Plan 2004 – 2006*, The Cancer Institute NSW, Eveleigh, NSW.

<sup>14</sup> World Health Organization, Division of Health Promotion, Education & Communication, The Jakarta Declaration, 4<sup>th</sup> *International Conference on Health Promotion into the 21<sup>st</sup> Century*, CH-1211 Geneva 27, Switzerland. URL: <http://www.who.int/healthpromotion/conferences/previous/jakarta/declaration>

<sup>15</sup> Nutbeam, D. (2005) What would the Ottawa Charter look if it were written today? *Reviews of Health Promotion and Education Online*. URL <http://www.rhpeo.org/reviews/2005/19/index.htm>

<sup>16</sup> Cox, E. (1995) *A Truly Civil Society*. Boyer Lectures, ABC Books, Sydney, NSW.

<sup>17</sup> 'Healthy People 2005 – New Directions for Public Health NSW Health 2000'

<sup>18</sup> Cancer Institute NSW (2004) *NSW Cancer Plan 2004 – 2006*

<sup>19</sup> Lennie, J. (2006) Increasing the rigour and trustworthiness of participatory evaluations: learnings from the field in *Evaluation Journal of Australasia*, Vol.6, No.1. 27-35.



## **SECTION 4: Methodology for Participatory Program Evaluation**

The participatory evaluation approach to program evaluation adopted for this Project, takes as its guide, the criteria outlined by Michael Quinn Patton in *Utilisation-Focused Evaluation*<sup>1</sup>. These principles and their program evaluation equivalents include:

- Involve evaluation participants in: establishing priorities; learning the evaluation logic and skills; focusing questions, interpreting data; data-based decision-making and connecting processes to outcomes.
- Participants make the major focus and design decisions. They draw and apply conclusions.
- Participants focus the evaluation on processes and outcomes they consider to be important and to which they are committed.
- Participants work together as a group and the evaluation facilitator supports group cohesion and collective inquiry.
- All aspects of the evaluation, including the data, are understandable and meaningful to participants.
- Internal accountability is highly valued.
- The evaluator role is that of facilitator, collaborator and learning resource. Participants are decision-makers and evaluators.
- The evaluation facilitator recognizes and values participants' perspectives and expertise and works to help participants recognise and value their own and each other's expertise.
- Status differences between the evaluation facilitator and participants are minimised.

In summary, the present program evaluation is based on this participatory approach and has as its focus, the usefulness of information for Group participants and program stakeholders.<sup>2</sup> This is an approach that is very practical. The activities directly involve stakeholders in reflecting on and identifying the value and the effectiveness of their own program in action. In the course of evaluation activities, Group members will have used a range of theories, methods and data sources<sup>3</sup> as tools and information for judging the meaning and value of what they do in their Group.

With increased understanding of the Support Group and what it does, the Group members will also be building their capacity to maintain and sustain ongoing program evaluation for:

- Continuous improvement
- Assessment of effectiveness, efficiency and appropriateness
- Accountability and
- Transferability.

### **4.1 Mixed Methods approach to information gathering, analysis and interpretation**

The present evaluation aligns with the recommendations made explicit by a leading Australian consultant in the field of participatory evaluation, June Lennie<sup>4</sup>, in taking steps to assure trustworthiness of the evaluation processes and outcomes. The evaluation program began with a focus group to identify potential stakeholders and to identify how and when these stakeholders could be personally invited to take part in the evaluation processes.



The evaluation activities engaged a wide range of opportunities for communication and participation. These included: focus groups within existing meeting structures and activities; informal discussion sessions in activity groups; stepwise refining of the theoretical framework; Survey participation; identification of information resources; email communication and building of group identity and involvement with this information exchange; data entry and data analysis; critical reflection workshops; interpretive summaries, report writing, editing and communication of, and advocacy for evaluation involvement and evaluation findings. The consequence of this approach was a continual building of mutual trust, engagement and openness of communication.

In particular, the evaluation activities had to be shaped by the needs of the women in the Groups. To be inclusive, the evaluation activities had to fit around the ‘urgency and importance’ criteria of a particular, time, place, setting, group make-up and Group member availability. The circumstances meant that the needs of the evaluation often had to take second place to those of the current moment in time and to be postponed to a later date and context, with perhaps different people assuming the intended roles for particular activities. The fluidity and responsiveness with which Group members were used to interacting, meant that there was always a ‘right time and a right place’, for evaluation activities to be carried out.

The outcome of this approach to engagement and involvement has been optimum participation by a wide range of women across the spectrum of Support Group activities and a seamless transition of responsibilities across different participants in the evaluation processes. It has also meant that the evaluation timeline was necessarily extended to accommodate the required level of flexibility. Over time, this has been most beneficial for the level of engagement by Group members, as it has resulted in a growing critical mass of Support Group members becoming centrally involved in the evaluation processes. This engagement and involvement has been empowering for an increasingly wide range of participants, both as critical reflective thinkers for the Group and as contributor to the evaluation process.

While the evaluation has documented relevant quantitative and demographic data, the core focus has been on the qualitative component of information for description and decision-making. The purpose of the evaluation is essentially that of theory-building – of developing an accurate representation of the nature, the meaning and value of the IBCSG in action. For this purpose, it is qualitative data that has been the focus for critical reflection and interpretive analysis of the meaning and value of the Support Group for its members.

Whitford,<sup>5</sup> in her writing about ‘knowledge, power and evidence’ explains why qualitative data might have so much to offer in circumstances such as the present evaluation.

Qualitative inquiry processes:

1. Are context specific and capture context-bound narratives. This is important in assisting us to address the ‘life-world’ of the people .... And the myriad of influences upon [that ‘life-world’ as well as] understanding the context relatedness between what people do and the state of their health. . . .
2. Offer an “emic or insider’s” perspective and experience. This is crucial to understanding the meaning construction of the individual, group or community in relation to specific health-related concerns.



3. Are “iterative.” That is they allow for new and sometimes highly unexpected findings to emerge, compared to hypothetico-deductive approaches; and finally,
4. The power relationship in qualitative research approaches allows for greater opportunity of participant/informants to have ownership or control over data and findings, hence becoming stakeholders in potential changes emerging from the research.

## 4.2 Evaluation sequence and participant involvement

The evaluation sequence and processes were iterative, involving discussion, recording, reflection, analysis, interpretation and review process, with each cycle of reflective inquiry. It was through these cycles that, over time, an increasing number of Support Group participants became involved in building a shared understanding of the meaning and value of the IBCSG in action.

Reflective practice in a community environment is an inherently ‘messy’ and complex process with multiple, parallel pathways, iterative cycles and planned activities going on at any one time. In addition to this complexity, there is the inherent ebb and flow of community engagement with a wide spectrum of involvement across many activities. For example, all reflective evaluation activity was put on hold for the October 2006 ‘Field of Women’ event in Wollongong where 15,000 silhouettes (each silhouette representing someone affected by breast cancer during the course of one year), were ‘planted’ in WIN Stadium. This is one of many regular events in which the women of the IBCSG are involved.



**Field of Women 2006 – 15,000 Silhouettes**



The program evaluation steps listed below, therefore, are a fairly accurate (but not prescriptive) representation of the sequence of activities and events over time. These included:

1. Focus Group with core stakeholders to identify evaluation purposes, stakeholders, potential outcomes for IBCSG
2. Formation of Evaluation facilitation partnership
3. Introductions and intentions to IBCSG members
4. Collaborative development of evaluation approach and initial planning activities
5. Review of previous research outcomes, design and development of Survey
6. Review of literature and critical reflection on potential theoretical frameworks
7. Collaborative design of Focus Group activities, resources, processes, intended outcomes
8. Initial Focus Group – recording of collective story and individual perspectives
9. Development of recording formats and spreadsheets
10. Refinement of Focus Group processes and subsequent Focus Groups
11. Review of literature on Support Groups (ongoing)
12. Initial reflective analysis of collective ‘story’ and finding best theoretical ‘fit’ for logical framework for evaluation
13. Sharing and reflection on potential logical framework
14. Development of draft action Categories (IBCSG in action) and confirmation of veracity with Group members
15. Development of process steps for thematic coding of qualitative data according to Support Group in Action Categories
16. Confirmation of theoretical ‘fit’ between Action Categories and qualitative data
17. Data entry of quantitative data from Survey and recorded comments
18. Calculation of mean and standard deviation for all quantitative results from Survey and generation of progress report
19. Involvement of University of Wollongong academic mentors in spreadsheet set-up for data recording
20. Capacity- and skills-building for thematic analysis
21. Thematic analysis of Focus Group and Survey comments
22. Development of Goal Attainment Scales across a number of focus groups
23. Critical reflection on Importance and Confidence scales for each of the Support Group in Action Categories at AdCare Retreat
24. Collation of current evaluation format and outcomes in draft Report for initial stages
25. Sharing of draft Report with full Committee, feedback and recommendations for next steps
26. Refinement of Support Group in Action Categories, with selection in focus groups, of representative comments for indicators of effective action.
27. Development and collection of Co-contributor sections of report from amongst Support Group members
28. Collation of all findings and writing of final draft report
29. Review and editing of draft report by key stakeholders
30. Invitation for review and reflection on draft report by IBCSG members
31. Confirmation of permission to release Report from IBCSG membership and Committee



- 32. Printing of Report and planning for launch
- 33. Public launch of Report and beginning of subsequent participant-led evaluation cycle

In all, the evaluation activities have spanned 21 months starting in June 2005 and continuing to March 2007.

### **4.3 Thematic analysis of qualitative data**

The Categories of Action that were developed from the keywords and comments recorded in focus group reflections and discussions, provided the logical framework for Support Group members to reflect on the meaning and value of what happens in the space that they have created.

We developed, over time, a team of people working on the data and carrying out coding activities. These activities involved coding of qualitative data according to the Action Categories, with team members taking responsibility for selecting key statements that best represented each of the Action Categories and sub-sets of activity. The selection of representative comments was grounded in their individual and shared experience of being diagnosed and living with breast cancer. As such, coding and selection were subject to continuous validation of appropriateness and sufficiency with regard to representation of their 'life-world' and the social space that for them, counts as the Support Group in action.

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<sup>1</sup> Patton, M.Q. (1997) *Utilization-Focused Evaluation: The New Century Text*, 3<sup>rd</sup> Ed. Sage Publications, Thousand Oaks, California. P.100.

<sup>2</sup> Patton, M.Q. (1997)

<sup>3</sup> Lennie, J. (2006) Increasing the rigour and trustworthiness of participatory evaluations: learnings from the field in *Evaluation Journal of Australasia*, Vol.6, No.1, 27-35.

<sup>4</sup> Lennie, J. (2006), pp. 27-35.

<sup>5</sup> Whiteford, G. (2005) 'Knowledge, Power, Evidence: A Critical Analysis of Key Issues in Evidence Based Practice' in Whitford, G and Wright-St Clair. *Occupation and Practice in Context*. Elsevier Australia Marrickville, NSW. Pp.41-42.



## SECTION 5: Participatory Program Evaluation Findings

The IBCSG's key drivers identified by participants echo research findings<sup>1, 2</sup> that highlight the inherent capacity of people faced with adversity to relate to things outside themselves. This literature describes how, by reaching out, they find new purpose and meaning in their lives.

In particular, the IBCSG's key drivers, generated in focus group activities, reflect the capacity of people to expand the boundaries of their self-concept and in so doing, decrease the negative impact of cancer diagnosis on personal well-being.<sup>3</sup> Researchers have found<sup>4</sup> that people find '*strength*', '*hope*' and '*meaning*' in their search for information and support, and through their positive approach to becoming advocates for both themselves and for others living with cancer, are able to resolve the negative effects of diagnosis.

The Support Group's three key drivers, spanning all categories and sub-sets of action in their model of practice, define the character of the IBCSG. The drivers have been identified as: *Hoping, Loving & Accepting*.

The first of the Group community building categories of activity, identified by the membership in focus groups, defines what it means to be one of **Us**; the second, the way individuals (**Me**) develop their skills and capabilities as a member of this Group, and thirdly, how **We**, the Group members, maintain and sustain our Group membership. It was the elements of the current 'group narrative' that were recorded during these sessions and from this information, the building of The IBCSG Model in Action.

### 5.1 The IBCSG Model in Action: Summary Table of Categories & Sub-sets of Action

#### **This is Us**

*The processes the group engages in to identify shared problems and goals, mobilise its collective resources and develop and implement strategies for achieving shared purposes.*

#### **This is 'US'**

<b>a.1</b>	<b>'US' Organising what we do</b>	We organise ourselves around communicating for understanding with each of us knowing, inspiring, listening and teaching
<b>a.2</b>	<b>'Us' Including one another</b>	Our Group activities are based on simply being there for each other and interacting and working together
<b>a.3</b>	<b>'Us' Building our Group</b>	The Group space is built around trust where everyone can see and choose different ways of being in the Group, whatever the individual need or circumstances





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### This is ME

*Processes that support me in gaining control over my life and my environment. Processes that increase competence and problem-solving ability so that individuals and the Group are empowered to take control over their lives and their environment.*

#### This is 'Me' in the Group

<b>b.1</b>	<b>Me <i>Identifying</i> what I want to know and need to ask when I'm making decisions</b>	The Group provides a safe space for self-reflective, self-directed questioning, learning and decision-making
<b>b.2</b>	<b>Me <i>Nurturing</i> and being nurtured by others</b>	A safe space for giving and receiving where comforting and reassuring go hand in hand with developing and healing
<b>b.3</b>	<b><i>Empowering</i> Me to be everything that I can be</b>	Members can experience personal growth ranging from self-improvement to self-transformation (self-transcendence – the new ME!)

### How 'We' maintain and sustain our Group

*By acknowledging and drawing on our shared strengths for positive action, WE generate group assets that we can draw on for supporting one another and caring for the members of our Group.*

#### How 'We' maintain and sustain our Group

<b>c.1</b>	<b>We <i>Recognise</i> and appreciate feeling positive</b>	In our Group we focus on feeling positive by approaching and appreciating one another
<b>c.2</b>	<b>We <i>Celebrate</i> the lighter side of life</b>	We celebrate the lighter side of life by laughing, celebrating and enjoying things
<b>c.3</b>	<b>We <i>Share</i> our strengths</b>	We value interactions based on the strength of togetherness

## 5.2 Meaning and Value of IBCSG: Previous Research Findings

### Survey Responses & Interpretative Comments

The aims for the Survey, constructed from previous research findings and re-presented to the Support Group members in the current evaluation, were four-fold. Firstly to provide Group members with the opportunity to *re-engage* with ongoing conversations about the meaning and value of the Support Group for those diagnosed and living with breast cancer. Secondly, the intention was to provide Group members with a condensed overview of findings from previous Group involvement in research activities. Presented in Survey format, these findings provided participants/respondents with a resource for continuing reflection and discussion with regard to the currency of previous findings for the *present* membership. For this reason, the involvement of the women was referred to as that of participants/respondents for the combined introductory focus group discussions around Survey content areas and the subsequent written Survey response. Finally, the comments provided a rich resource for enhancing understanding of the new



Categories of Action that the women have generated to explain, define and differentiate their Group and the purposes served by the Group (This is US, This is ME and this is how WE maintain and sustain our Group).

As a data set, the Survey responses represented a 'snap-shot' in time and while the Survey was constructed to gain numeric data, of greater importance were the written comments provided by respondents that explained the 'why' for the weightings they recorded in their responses. For this reason, it is important to look at the quantitative results in light of the comments that have been recorded for each of the sections of the Survey (A,B,C,D).

The quantitative data derived from the Survey reflected the respondents' different ages, stages and phases of living with breast cancer and variations in timing for their Support Group involvement. Some Survey respondents were local and had always been so. Others had come into the Illawarra region at some point in their journey after having been diagnosed with Breast Cancer. A number of respondents, although living all of their lives in the region, did not know of the IBCSG until some time following their diagnosis and/or treatment. This reflects the findings of Yaskowich and Stam,<sup>5</sup> and identified in an earlier section of this Report: 'When people find themselves at diverse stages along the treatment continuum or illness trajectory, their needs vary according to where they find themselves and so too does the apparent timeliness and appropriateness of the group response to their individual needs'.

Given the wide variation in ages, stages and phases of diagnosis and treatment, combined with time of contact with and/or participation in the Support Group, the present Evaluation acknowledges the limitations of a 5-point Likert Scale Survey<sup>6</sup> and total responses, for interpreting the quantitative data provided by the respondents. It was not possible, on a simple five point Likert Scale to differentiate three important aspects of personal journey.

- Individuals, who for whatever reason, were not aware, following their diagnosis and/or treatment, of the IBCSG or the support it offers, and
- Individuals who were unable or unprepared to come to the group in earlier phases and stages
- Individuals for whom the statement was 'Not Applicable' (Scored a '1' as the option of NA was not available)

A greater range of scores within a particular category in the Survey have been interpreted with reference to the standard deviation (SD) in responses. These scores do not necessarily represent discontent with the role or activities of the IBCSG, but rather, that the individual, for a range of reasons and circumstances, was not a member of the group at the time of personal need.

The pattern of responses for the Survey demonstrated that those who recorded a low score of 1, often felt the need to provide an explanatory comment. For those who recorded a high score of 5, there was less of a tendency to comment and for those who scored between 2 and 3, there was, in general, no comment. The primary purpose served by the quantitative responses, for this program evaluation then, was to identify areas where focus group discussions might lead to a deeper understanding of the statement-related concerns and issues and enhanced capacity to meet the needs of all women within the Support Group.

For future evaluative activities, of greater interest could be a focus group with women who at one stage attended the Support Group, but who have since, for whatever reason, chosen to discontinue their involvement.



### **The pattern of statements and Survey responses were as follows:**

A1 *Strongly Disagree(1) / Strongly Agree (5) with statement*

A1.1 *Not very like my experience at all(1) / Very like my experience(5)*

A1.2 *Not important for me(1)/ Extremely important for me(5)*

### **5.3 Survey Results**

The following summary of Survey response data, both quantitative and qualitative, provides an overview of the Support Group demographics and the pattern of responses including weightings and standard deviation for each component of the four sections (A, B, C & D). The women's voices, as illustrative comments recorded by respondents, were selected by Group members involved in the wide range of activities that make up the IBCSG Model in Action. The selection of illustrative comments was made on the basis of information relevant to the meaning and value of the Support Group for those concerned.

#### **Demographics of Survey Respondents**

Number of respondents and the number of participants in the Core Groups:

- Kiama = 12/12
- Warilla = 30/50
- Wollongong = 32/50

**Combined groups = 74 individuals completed the Survey**

Age of Survey Participant/Respondents:

- The average age for all Groups combined was 65 years
- On average, respondents from the Warilla group were aged 71 years, and for the Wollongong group, 61 years.
- The Warilla group also has a slightly wider age range (11.1 years) than either Kiama (7.1 years) or Wollongong (9.5 years).

Time since diagnosis for Survey participant respondents:

- The average time since diagnosis was 6 years, although the Warilla group had a wider range of years since diagnosis with 1-30 years. Kiama and Wollongong had a much narrower range of years since diagnosis with 1-10 years and 1-13 years respectively.
- For all groups, members had, on average, been involved in the IBCSG for between 4.5 and 5.7 years.

Support Group meeting attendance for Survey participant/respondents:

- The percentage of individuals attending every month differed significantly amongst the groups. More than half of the combined groups' members attended every month (63%).
- 91.7% of Kiama members attended every month
- 36.6% of Warilla members attended every month, and 56.6% attended most months
- 65.6% of Wollongong members attended every month and 28% attend most months
- These figures do not differ significantly from the most recent survey.



### Findings about Support on a 5 Point Likert Scale.

A. Findings about Support: 'In general women wanted their cancer treatment, professional care and support to be well organized (A1), they wanted a sense of personal control (A2)												
	A1 Mean	A1 SD	A1.1 Mean	A1.1 SD	A1.2 Mean	A1.2 SD	A2 Mean	A2 SD	A2.1 Mean	A2.1 SD	A2.2 Mean	A2.2 SD
Kiama	5	0	4.5	1.2	4.8	0.9	4.9	0.3	4.2	1.1	4.7	1.2
Warilla	4.9	0.4	4.4	1	4.9	0.3	4.8	0.4	4.1	1.2	4.8	0.9
Wollongong	4.9	0.9	4.4	0.9	4.6	0.8	4.7	0.6	3.8	1.3	4.4	0.8

A. Findings about Support: . . . they wanted to be taken seriously (A3), and they wanted reassurance about what was happening to them (A4)'. . .												
	A3 Mean	A3 SD	A3.1 Mean	A3.1 SD	A3.2 Mean	A3.2 SD	A4 Mean	A4 SD	A4.1 Mean	A4.1 SD	A4.2 Mean	A4.2 SD
Kiama	5	0	4.5	0.8	4.7	1.2	5	0	4.6	1.2	4.6	1.2
Warilla	4.9	0.4	4.6	1.1	4.8	0.6	4.9	0.4	4.1	1.2	4.7	0.9
Wollongong	5	0	4.3	0.9	4.8	0.5	4.9	0.3	4.2	1.2	4.5	0.9

### Comments for 'Support' Statements: A1, A2, A3, A4

#### A1 Cancer treatment, professional care and support to be well organised . . .

- My specialist referred me to the Group and Gloria phoned me before I went to hospital. A Group member visited me in hospital and gave me valuable information which was a great help in my recovery.' (WA2)
- 'I didn't join the Support Group during treatment (I wanted the world to see me as normal – not sick) but during my recovery phase I was ready.' (KA3)
- In some ways I was a step ahead of my medical team due to my contact with the Group. (WA12)
- Because you have contact with people in the Group and hear their experiences, good and bad, it makes you aware of what is available and you can seek it out." (WO1)

#### A2 Being in Control . . .

- I was aware of the Group at onset of diagnosis . . . I was directed and encouraged to take control of care and treatment right from the start and knew what to expect. The Group kept me in control throughout my journey. (WA12)
- Being Support Group members, we have learnt to gain as much information about our disease as possible which then assists in making the **right** choices and decisions. (WO1)
- I would have liked Dr [Oncology] to have been able to help more with my choice on having . . . treatment. I got quite distressed as it had to be my choice and I didn't understand it. (K9)
- I had massive support from family and friends and did not consider this (the Group) important for me. However, these days I like to hear other women's stories and we are now supportive of one another. (WA7)



### **A3 Being taken seriously . . .**

- To be taken seriously is important to one's mental attitude' (WA24)
- As a member we don't always agree with others' treatment choices, but we know these decisions are difficult to make and we respect that. (WO1)
- . . . in the Group you feel supported and even the most minor aspect is addressed, making you feel good. (WA12)
- Doctors didn't seem to understand how I was feeling or why I would be crying – Gloria and the women in the Group just know. This is so important to me. (WO12)

### **A4 A sense of reassurance by being told what to expect . . .**

- I always felt reassured and if something was worrying me it only took a phone call. And you knew even if you had to leave a message, your call would be returned ASAP. (WA12)
- By sharing information and practical advice with each other we gain reassurance even though we sometimes have different reactions to treatment. (WO1)
- Unfortunately I was diagnosed in November and finished treatment in February, so the Support Group was in recess during this time. It was only later I learned so much more about my treatment and its outcome. (WO11)

### **Findings about 'Living with cancer'**

<b>B. Findings about Living with cancer:</b> 'Many people reported that being diagnosed and living with cancer, made them feel different from other people – more aware of self (B1), continue to experience changes (B2)												
	B1 Mean	B1 SD	B1.1 Mean	B1 SD	B1.2 Mean	B1.2 SD	B2 Mean	B2 SD	B2.1 Mean	B2.1 SD	B2.2 Mean	B2.2 SD
Kiama	5	0	5	0	5	0	4.8	0.4	4.8	0.4	4.9	0.3
Warilla	4.7	.67	4.6	0.9	4.5	1.1	4.4	0.9	4.3	1.1	4.4	1
Wollongong	4.9	0.4	4.7	0.7	4.6	0.6	4.7	0.6	4.4	0.9	4.7	0.5

<b>B. Findings about Living with cancer:</b> feeling different from others in situations (B3) Feeling different from how others react (B4)												
	B3 Mean	B3 SD	B3.1 Mean	B3.1 SD	B3.2 Mean	B3.2 SD	B4 Mean	B4 SD	B4.1 Mean	B4.1 SD	B4.2 Mean	B4.2 SD
Kiama	4.9	0.3	4.8	0.4	4.6	1.2	4.9	0.3	4.8	0.4	4.5	1.3
Warilla	4.7	0.6	4.6	0.7	4.7	0.6	4.7	0.6	4.4	0.9	4.5	1.1
Wollongong	4.4	0.8	4.3	0.8	4.4	0.9	4.8	0.5	4.3	0.9	4.6	0.7

### **Comments for 'Living with cancer' Statements:**

#### **B1 People feel more aware of themselves, others and life in general**

- People who knew I had had breast cancer, spoke and looked at my breasts when they spoke. The Support Group spoke to my face. (K10)
- I want to spend more time doing what really matters and I realise I play an important part in a lot of people's lives. (WA12)
- I didn't so much feel different from others as more aware of myself (and things). (WO26/WA5)



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- When I joined the group I learned how to have hope for the future through association with long-term survivors - who became my role models for survival (K3)

### **B2 People find they continue to experience changes long after diagnosis**

- As the journey continues and I learn more through the Group and meet more people with cancer diagnosis, I find I am still experiencing changes. (WO12)
- I experience many changes and look to the Support Group for guidance re changing doctors, hospitals. (K10)
- Will it return, is always at the back of my mind, but seeing lots of ladies still enjoying life years after cancer is encouraging. (WA12)
- Every day's a new day, challenges to meet. One is always aware of any changes in one's body. (WO31)

### **B3 People find they continue to experience changes long after diagnosis**

- Members recognise that people require different levels of support at different stages in their cancer journey, and are usually able to offer that (WO1)
- It's not the support group one feels different in, but how I had to deal with my career and social events, especially being a sufferer of lymphoedema made me feel and look different (K3)
- I think sometimes this will just depend on the person without outside factors affecting their feelings (WO26)
- Sharing concerns and the camaraderie among friends at the meetings is absolutely amazing for one's successful recovery (WO18)

### **B4 How a person feels about diagnosis can be very different from how other people react**

- People don't like to discuss it much and I felt family and friends took their cue from me. I was positive due to the knowledge I had gained from the group (WA12)
- We could talk to each other on people's reactions [some friends couldn't understand the physical or mental changes in us] (K9)
- Family and friends don't always re-act the way you would like at times. Don't always give you the support you thought you would get from them (K10)
- Unless a person has been along the same path it is sometimes hard for them to fully understand or empathise (WA10)

### **Comments for 'Quality of life Statements: C1, C2, C3, C4**

<b>C. Findings about Quality of Life:</b> Participants reported that, after diagnosis, they had concerns about both physical and mental health (C1); they noticed changes in their relationship with others (C2)												
	C1 Mean	C1 SD	C1.1 Mean	C1.1 SD	C1.2 Mean	C1.2 SD	C2 Mean	C2 SD	C2.1 Mean	C2.1 SD	C2.2 Mean	C2.2 SD
Kiama	4.7	0.7	4.7	0.7	5	0	5	0	4.5	1	4.8	0.4
Warilla	4.7	0.8	4.7	0.6	4.7	0.6	4.96	0.2	4.7	0.9	4.8	0.5
Wollongong	4.6	0.9	3.9	1.2	4.5	0.9	4.97	0.2	4.7	0.8	4.8	0.6



C. Findings about Quality of Life: they were worried about losing their independence (C3); and they re-evaluated what was important in life (C4).												
	C3 Mean	SD	C3.1 Mean	SD	C3.2 Mean	SD	C4 Mean	SD	C4.1 Mean	SD	C4.2 Mean	C4.2 SD
Kiama	3.7	1.3	2.5	1.1	4	1.5	4.8	0.7	4.5	0.8	4.3	1.3
Warilla	4.3	1.2	3.9	1.3	4.1	1.4	4.9	0.3	4.9	0.4	4.7	0.6
Wollongong	4.5	0.9	3.0	1.5	3.9	1.1	4.9	0.3	4.4	1.1	4.5	0.7

**C1 After diagnosis, women had concerns about both physical and mental health**

- o Both physical and mental adjustment required a lot of effort, but I found that encouragement from the Support Group was very helpful (WA24)
- o Talking with others helped me deal with the mental changes particularly. Seeing women a couple of years down the track, looking well and with hair really helped me see the end of the tunnel. (WO12)
- o I found that workshops, focus groups and guest speakers provided through the Support Group helped immensely. Social worker and Psychologist invaluable in 'one-on-one' situation (K3)
- o Because it's a shared journey others know that some days you cannot achieve something that would have needed little effort before, and that you feel like you are on an emotional roller-coaster - down one day, very positive the next. (WO1)
- o With everything I have been through . . . my cancer was simply another hiccup in my life (WO15)

**C2 Having good relationships (with family, friends, medical professionals) becomes even more important after a cancer diagnosis**

- o This Support Group is very important to me. Being able to openly discuss fears etc. is so very important and a very big part of the healing process (WO3 / WO31)
- o My family have been marvellous to me, also my doctor has been caring. BCSG is supportive and kind (WA10)
- o When I told the Group about my diagnosis some ladies came and hugged me, others wished me well which was greatly appreciated. If it wasn't for these people you would be so alone and frightened (WO15/WO19)
- o Some of the best discussions were in the support bus on the way home (WA26)

**C3 After diagnosis women were worried about losing their independence**

- o Support members were able to assist with practical and emotional support which can 'lighten the load' and therefore enable the women to regain their independence (WO1)
- o No-one in our group has lost their independence. Help in any area is available in the asking (K10)
- o I think it depends on the severity of the diagnosis and probably the age of the person involved (WO22)
- o Through my association with older members of the Group I can see a big dependency issue, particularly for those without close family support. I don't feel this is relevant at this stage for me (K3)





- o Fortunately I'm doing OK so far so this section is not applicable to my situation (WA28)

The weightings recorded for C3 statements were emphatically on the side of 'did not lose independence'. These were the lowest scores for the entire questionnaire and this may have been because it was the only question framed in terms of the 'loss' associated with diagnosis. If the respondent weighted the statements with a high score, it would have meant that the person saw themselves as 'losing their independence' and this for them, according to the comments, was not in the longer term, an acceptable description of their situation.

#### **C4 People diagnosed with cancer rethink their main priorities in life**

- o By participating in some group programs - e.g. stress management - we are taught to try and eliminate unnecessary stresses from our daily lives and to identify main priorities and put all your positive energy into them (WO1)
- o Life is totally rearranged, important things are done when you can and unimportant things are never looked at (WO19)
- o I like to live every moment and be with my friends- which I do – not to mention my family [too] (WA5)
- o I very much wanted to continue as before and my professional and family life are still very important, so no, I didn't rethink [my priorities] (K3)

#### **Comments for 'Support Group' Statements: D1, D2, D3, D4**

<b>B. Findings about the Support Group: Women attended the Support Group to gain knowledge (D1), to get and give support (D2)</b>												
	D1 Mean	D1 SD	D1.1 Mean	D1.1 SD	D1.2 Mean	D1.2 SD	D2 Mean	D2 SD	D2.1 Mean	D2.1 SD	D2.2 Mean	D2.2 SD
Kiama	4.9	0.3	5	0	5	0	4.8	0.9	4.6	0.9	5	0
Warilla	5	0	4.9	0.3	4.8	0.4	4.9	0.3	4.8	0.5	4.8	0.5
Wollongong	4.9	0.3	4.7	0.8	4.9	0.3	4.9	0.3	4.7	0.8	4.9	0.4

<b>A. Findings about the Support Group: to be in a group of people who have gone through similar experiences (D3) and to influence their sense of self in a positive way (D4)</b>												
	D3 Mean	D3 SD	D3.1 Mean	D3.1 SD	D3.2 Mean	D3.2 SD	D4 Mean	D4 SD	D4.1 Mean	D4.1 SD	D4.2 Mean	D4.2 SD
Kiama	5	0	5	0	5	0	4.9	0.3	4.8	0.6	4.8	0.6
Warilla	4.8	0.2	4.9	0.3	4.9	0.4	4.8	0.4	4.6	0.6	4.7	0.6
Wollongong	4.8	0.2	4.7	0.8	4.8	0.5	4.9	0.4	4.7	0.8	4.8	0.6

#### **D1 Women attended the Support Group to learn more about cancer and how to cope with it**

- o Information is important to this diagnosis. Before I joined the group, it was a shadow. Now I seek professional advice and knowledge from those who have facts. Yes I feel I have got the strength and courage and positive experience for me (WO14)
- o I gained lots of knowledge due to the group. Medical people do not always explain or consider the individual (WA12)



- Over the years we have had a wide variety of guest speakers, who give information which helps us understand more about cancer, new treatments, etc. This enables us to make the right choices - knowledge is power (WO1)
- D2 Attending the Support Group enables women to get and to give support**
  - We have sad times but mostly we laugh at ourselves, people who have been through it don't belittle your anguish (WO19)
  - I don't think I give much back to the group at all, but I get lots of support and comfort from it (WA12)
  - Giving support to new members at meetings, through Breastscreen volunteering etc, one repays one's benefits (WO18)
  - In a way - for me – just listening is enough (WA5)
- D3 Attending the Support Group enables women to be with other women who have gone through similar experiences**
  - For me, it is a very positive experience to be in close contact with so many women who have experienced cancer, done what they have to be well again, then get on with life (WO1)
  - It is very important to identify with people having the same experiences. I go about my daily life often not thinking about cancer. But when I meet at the group I realise how lucky I am to be part of such a caring group of ladies (WA12)
  - Encourages 'togetherness' because we have all "been there, done that"! (WA24)
  - There is no substitute for the understanding and sharing by women of all ages and nationalities at our group meetings (WO18)
- D4 Attending the Support Group can have positive outcomes in terms of personal growth**
  - It has opened up so many new things for me; public speaking, Dragon Boat racing, performing on stage to name a few. I feel I have grown in confidence and am more likely to try new experiences (WO1)
  - I am an entirely different person now - I have not only had personal growth but have transformed (WO12)
  - My confidence took a nose-dive when I was diagnosed and it took many years to fully regain this. I'm not sure what, if any, role the support group played (K3)
  - . . . I have a great positive outlook thanks to the Cancer Support Group, family and friends (WO21)
  - Gloria is responsible for a lot of this [personal growth] as she is good at recognising strengths in us that we may not have realised (WO26)

The above comments, recorded by Survey respondents, constitute a critical review of the meaning and value of previous research findings for the current IBCSG Model in Action. They also provide an in-depth background for defining and refining the current meaning and value of the Support Group for its member participants.



## 5.4 The IBCSG Model in Action: Meaning and Value for Group Members



One of the concluding evaluation activities, in which the members of the Support Group took part, was a series of focus groups, in which the participants reflected on the meaning and value of the sub-sets of action for the IBCSG Model in Action. Looking back over the recorded statements related to each of the categories and sub-sets of action, participants were able to select:

- A symbol for the sub-set of action (acceptance or replacement of original CCS Card with Group action photo),
- A key statement that exemplified the particular sub-set of action, and
- A range of descriptive statements that describe what they valued about, for example – ‘ORGANISING’.

These descriptive statements of what is valued by the Group, provided a set of key indicators of effective practice for the categories and respective sub-sets of action. It is these categories that define their Model in Action for a Community of Care.

### (a.1) Summary statement to represent ORGANISING in our Group



‘You focus on things said, and each person’s thoughts are shared. Therefore a uniform decision is made. [For this to happen] . . . any group setting up needs a ‘Gloria’. Love, support, knowledge, enthusiasm etc. etc. is the key’



What we mean by ‘US ORGANISING’: ‘We organise ourselves around communicating for understanding with each of us knowing, inspiring, listening and teaching’

What we value about ‘US ORGANISING’:

- People listen and learn about the best way to organise things
- Sitting and sharing ideas, respecting that we have a common bond and that we will be able to get more information
- People in the Support Group know what to say so we gain from everyone
- The Group is an opportunity to have people [there] who know what we are going through, you just have to ask



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### (a.2) Summary Statement for US INCLUDING one another



There were people from all walks of life and races and there was a common reason for being there, so in a way we were there for each other and had a common goal.

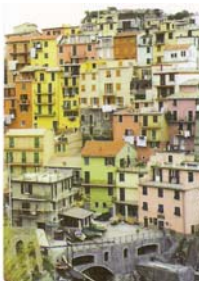


What we mean by 'US INCLUDING' one another: Our Group activities are based on simply being there for each other and interacting and working together.

What we value about 'US INCLUDING' one another:

- Being able to be comfortable with each other with no judgment
- Working towards the same goal and giving support
- Communicating, making new friends, with all the loving and helping hands that are here in a group of like-minded people
- No longer alone – feeling part of a big family

### (a.3) Summary Statement to represent US – BUILDING our Group



Individuals of different strengths and weaknesses, standing, supporting, shoulder to shoulder protecting each other.



What we mean by 'US BUILDING' our Group: The Group space is built around trust where everyone can see and choose different ways of being in the Group, whatever the individual need or circumstances.

What we value about 'US BUILDING':

- Members are accepted for who they are, trusting each other, yet existing independently
- Every person is different bonding together by sharing ideas, having fun, doing things we wouldn't normally do
- People are able to trust that there are many avenues in which to gain support
- Good support and inspiration from others can help to overcome obstacles



## Illawarra Breast Cancer Support Groups: Participatory Program Evaluation Identifying the Meaning and Value of the Support Group for Group Members

### (b.1) Summary Statement to represent ME IDENTIFYING within the Group



I had so many questions when I started my journey and the BCSG certainly answered many of them.



What we mean by IDENTIFYING within the Group: Identifying what I want to know and need to know and ask when I'm making decisions for me – the Group is a safe space for self-reflective, self-directed questioning, learning and decision-making.

What is valued about IDENTIFYING within the Group:

- I feel comfortable asking questions within the Group where questions are answered satisfactorily and honestly
- The Group is a place for self-directed decision-making and reframing
- The Group is a space to find your inner self
- There is trust in our medical teams
- People all over the world have the same problems – these problems don't just happen to us

### (b.2) Summary Statement to represent NURTURING within the Group



Because we hug and kiss and comfort – it makes us feel welcome and is so simple that everyone can give and receive – This can be healing.



What we mean by NURTURING within the Group: Me nurturing and being nurtured by others. The Group is a safe space for giving and receiving where comforting and reassuring go hand in hand with developing and healing.

What we value about NURTURING within the Group:

- Friendship, caring, comfort, personal growth and mateship – you're not alone
- Nurturing and friendships of all ages bring meaning back into life
- In the world, people don't always know their next door neighbour. In the breast cancer Group, we come a-knocking and we can come in. It's the door that doesn't get slammed in your face
- There is a softness to the Group too





**(b.3) Summary Statement to represent EMPOWERING within the Group**



I aim to climb and reach  
the top and master what  
is stacked against me



What we mean by EMPOWERING within the Group: Being everything that I can be for me. Members can experience personal growth ranging from self-improvement to self-transformation.

What we value about EMPOWERING within the Group:

- The Support Group has given me more tolerance. I feel I have more patience. My priorities are right now. I know what is more important to me now
- There is strength, energy and power coming from this group – you can take as much or as little as you want from it and for some this will be empowering
- The beginning of each new day empowers me to get on with self-improvement and confidently move forward
- I have taken steps to rise above adversity and reach the top. Now I am no longer alone

**(c.1) Summary Statement to represent how WE RECOGNISE one another within the Group (to Maintain and Sustain our Group)**



Joining a group is a new  
journey – a mutual  
connection – heartening,  
optimism, with people  
here for many years. It's  
an optimistic way of  
overcoming adversity.



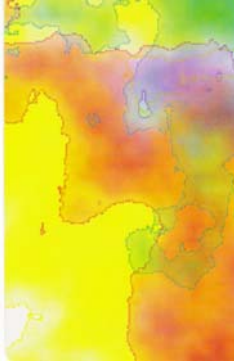
What we mean by RECOGNISING one another within the Group: In our Group we focus on feeling positive by approaching and appreciating one another.

What we value about RECOGNISING one another within the Group:

- After going home – the Support Group has given you back self-esteem, we stop feeling sorry for ourselves and we can be positive
- A kind word or kind gesture means a lot, it's the small things, taking time to appreciate, being nice and light and cheerful – a pick-me-up when I'm down
- Bringing us together and appreciating what each person does
- Everyone is together, with combined purpose and goals bringing a positive result– by touching, meeting, getting to know, reaching out – being there.



**(c.2) Summary Statement to represent how WE CELEBRATE in the Group**



We see the lighter side of life and laughter. The individual pieces come together to make a pattern

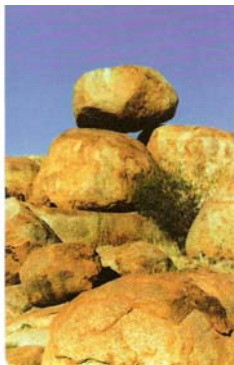


What we mean by CELEBRATING In the Group: We celebrate the lighter side of life by laughing, celebrating and enjoying things.

What we value about CELEBRATING in the Group:

- Laughing and enjoying together, celebrating spontaneity and youthfulness, being yourself with no judgement
- A place to go by yourself or with others, there's always someone there for you. It's an ongoing place of peace and quiet with no judgment, that celebrates life
- You're allowed to behave in many ways people do not necessarily expect
- We get together and celebrate our journey in breast cancer

**(c.3) Summary Statement to represent how WE SHARE STRENGTHS in the Group**



These rocks remind me of the strength and solidarity of friends within the Group and the people I've met.



What we mean by SHARING STRENGTHS in the Group: We value interactions based on the strength of togetherness.

What we value about SHARING STRENGTHS in the Group:

- We need each others' differences to break barriers; we are all alike in some ways and value differences to learn through each others' warmth, strengths and togetherness





- Journeying together – two are better than one, there is strength in numbers, holding each other together and complementing each other
- Supporting each other, sharing the good times, good food, good coffee, we balance each other out with support, strength and camaraderie that you won't find elsewhere – we all have a bond.

As a framework for action based on community-building, the IBCSG Model in Action, set out in the above categories, provides a unique blueprint for achieving the outcomes that are currently valued and enjoyed by Group members.

### **5.5 Bringing Together The IBCSG Model in Action and Acquired Wisdom from Previous Research Findings**

While not directly relevant to the meaning and value of the Support Group for its members, apart from the final section of the Survey, the comments provided by Support Group members in their overall Survey responses demonstrate where they believe the focus should be when Community Building is the logical framework for action. With their comments, the women of the IBCSG have provided information for better understanding what policy imperatives such as '*practical and locally-relevant 'supportive environments' with a settings-based approach*' might look like when translated into the type of practice that is involved in 'community-building'.

When the comments recorded by members of the IBCSG in their Survey responses are organised according to the new framework for action developed by the Group, these comments provide an in-depth descriptive account their 'blueprint' in action. In the following analysis, comments related to the Group's definition of 'Organising', across all Survey sections have been collated to provide an in-depth description of what 'Organising' might mean in the way of practical action for: Co-ordinated and integrated Support (A); Living with cancer (B); Quality of Life (C); and Support Group Involvement (D).

The 'importance' of each of the IBCSG Model categories of action (Organising, Building etc.), is indicated by the mean rating attributed to the respective Action Categories during a focus group at the AdCare Lifestyle Retreat in April, 2006. The level of confidence these participants felt, in their ability to achieve these varied activities within the Support Group, is represented by a mean score for the respective areas. The AdCare tables, included below, provide for a comparative analysis of 'importance' and 'confidence' ratings across the range of action categories from the IBCSG Model in Action. As with the Survey responses the same limitations apply, so comments have been included to provide a context for interpreting the numeric data.

#### **Action Category ORGANISING (a.1)**

The Group organises itself around communicating for understanding with its membership taking responsibility for knowing, inspiring, listening and teaching. There were a large number of comments recorded by participants that fell into this category of action. This demonstrates the potential for this type of Organising, as defined by the Support Group, to complement existing clinical and psychosocial support strategies.



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### Survey comments related to ORGANISING (a1 & A,B,C,D)

The IBCSG defines Organising in terms of the activities of organising ourselves around communicating for understanding with each of us knowing, inspiring, listening and teaching.

#### Organising & Co-ordinated and Integrated Support (A)

When Survey respondents commented on the need for well-co-ordinated and integrated support, the women referred to their lack of knowledge in the initial stages, their lives being a 'bit of a blur' and the importance of the link person (Gloria Swift) and the Support Group, particularly with regard to 'normalising' initial reactions and understanding of side-effects, complications, medications and treatments.

It was difficult 'tying things together' and with little time to research or even comprehend what is going on at this time, the role of the 'link' person and then the Support Group, was seen, by those who knew of and accessed this support, to have made a big difference. Being in control was seen by many to be adversely impacted by absence of knowledge of the Support Group, or inability to take in the possibilities for support, in the early stages of diagnosis and treatment. Finally, the experience and understanding of those in the Group related to information needs and being 'kept informed', was seen as a positive.

#### Organising & Living With Cancer (B)

Women commented on the positive impact of long term survivor role models and information exchange in developing hope for the future, as well as the Group being a resource for knowledge and guidance in dealing with choices and changes.

#### Organising & Quality of Life (C)

Both the quality and the diversity of information obtained through involvement in Support Group activities, received favourable comment, as did the possibility for open and frank discussion for understanding the journey. Positive feelings gained from Group involvement were identified as: feeling safe and confident and knowing support was within easy reach and always readily available. The wide range of targeted activities was seen as a supportive environment for rethinking and re-establishing priorities. However, one comment focused on the absence of involvement and support for partners and children of patients.

#### Organising & Support Group Involvement (D)

Women highlighted the gaining of much information from the support Group and with the added advantage of supportive learning processes that involved relevant expert input and other women willing to listen, talk and share. The Group is seen as an environment in which the individuals and their circumstances are given consideration and where knowledge is seen as 'power' to make the right choices. There was also a comment in this section of the Survey responses about the need to involve partners.

### AdCare Retreat Reflections on Importance and Confidence for Organising

Organising	Importance Rating /10	Standard Deviation	Confidence Rating/10	Standard Deviation
	8.75	0.8	8.3	1.06



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With regard to importance, the comment was that this way of Organising the Group, ‘... helps us to grow individually and we gain so much’. The level of confidence was indicated by the following comments: ‘It’s been happening every meeting’ and ‘I take part in all that is offered’. The only reservation mentioned was that ‘You can’t please everyone’.

### **Survey Comments Related to INCLUDING (a.2 & A,B,C,D)**

The IBCSG defines ‘Including’ as their activities based on simply being there for each other and interacting and working together. There were no comments that were considered to meet the criteria for Including, in relation to ‘well organised and integrated support’ (A).

### **Including and Living with cancer (B)**

In this category of activity, there were comments regarding the need for the Group because... you ‘just don’t know it’s [the cancer] gone’, because of the encouragement of seeing lots of Group members enjoying life years after cancer, of being with people going through the same problems and feeling reassured because people had experienced the same thing. At times, just seeing other women in worse situations than yourself could put things into perspective. Additional support was gained from the understanding provided by other women who had all experienced a diagnosis – who understood ‘the shock, fear and worry about the future.’

### **Including and Quality of Life (C)**

There was only one comment recorded for ‘Including’ and this could point to a ‘gap’ in the Group’s connection between ‘simply being there for each other’ and ideas around ‘losing independence and confidence’. The experience of one first time Group member was in fact, a less than positive ‘including’ into the Group, when her expressed need was apparently discounted. This new Group member noted that: ‘For the rest of the meeting I felt as if I shouldn’t be there. It was an incredibly off-putting experience.’

### **Including and Support Group (D)**

There was a strong sense, post treatment, that something important had been missed by not attending the Group in the early days of diagnosis and treatment, with one respondent labelling her behaviour as ‘silly not to go’. This feeling was amplified when viewed from even further down the track e.g. three years. But once again, there is the recognition of individual differences with a comment that, ‘It’s not for some girls. I respect that.’ However, the feeling of not being alone and in good hands is the positive side of Group participation. Most positive comments with regard to the Support Group and Including, related to the positivity, experience, certainty and availability at any time, of love, comfort, friendship and support.

### **AdCare Retreat Reflections on Importance and Confidence for Including (a.2)**

Including	Importance Rating/10	Standard Deviation	Confidence Rating/10	Standard Deviation
	8.7	0.8	8.1	1.3

Comments included the fact that their lives had improved and that ‘importance’ was related to ‘knowing we are there for each other’. Others commented on the importance of including the provision of different activities to suit all ages where different activities and talks could help



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different people in different ways. In terms of ‘confidence’ – this has been happening for the past two years that one participant had been attending and she predicted that this will only grow. However, if it was a group just starting out, the level of confidence would be unlikely to be rated so highly, as it is likely that this kind of confidence requires a ‘track record’.

### **Survey Comments Related to BUILDING (a.3 & A,B,C,D)**

The IBCSG defines ‘Building’ in terms of the Group space which is built around trust where everyone can see and choose different ways of being in the Group, whatever the individual need or circumstances.

#### **Building and Co-ordinated and Integrated Support (A)**

There is an acknowledgement within the Group and tacit understanding, that everyone has their own way of dealing with things in their personal journey and that this needs to be respected. The important principle is to provide reassurance, whatever the personal choices and decisions.

#### **Building and Living with Cancer (B)**

There is an understanding within the Group that different people require different levels of support at different stages in their cancer journey and that the group can usually provide support of the type that is needed at the point of need.

#### **Building and Physical and Mental Changes (C)**

Within the Group, there is acknowledgement of the fact that there are some days where it is impossible to achieve even the smallest of tasks because of the ‘emotional roller coaster’ – that one day it can be a downer and the next – very positive. The way in which Group members respond to the circumstances of others, particularly new members, has been highlighted as a critical component of Group awareness for the respecting and honouring of individual needs ‘whatever they may be’.

#### **Building and the Support Group (D)**

There is a feeling amongst Group members, that people who don’t go to Group meetings don’t seem to have the insight or direction that being in the Group can provide – that some seem unable to join because they come from the position of, ‘I don’t need the Group’. From the perspective of those who do attend the group, there is the experience that that you are not left on your own because you can always approach someone – of any age. The opportunity to confide without judgment or criticism, with openness and frankness and confidence that nothing will be repeated elsewhere, is highly valued amongst Group members. There is also a strong feeling of acceptance that some want to talk and some want to just stand back and that this is very much appreciated.

### **AdCare Retreat Reflections on Importance and Confidence for Building (a.3)**

Building	Importance Rating/10	Standard Deviation	Confidence Rating/10	Standard Deviation
	8.7	0.4	8.2	0.8

The indication was that individuals could all bring their different ideas to the Group and share, care and stand together as one, knowing that one’s lifestyle improves. This ‘Building’ was



indicated as being present now and with a high level of confidence in its provision for Group members

### **Survey Comments Related to IDENTIFYING (b.1 & A,B,C,D)**

The IBCSG defines 'Identifying' in terms of what they want to know and need to ask when they are making decisions. This occurs within the safe space provided by the Group for self-reflective, self-directed questioning, learning and decision-making. This category of action in the IBCSG Model is apparently, the most significant when bridging the clinical/community divide.

#### **Identifying and Co-ordinated and Integrated Support (A)**

Group members mention the feeling of 'readiness' for Group participation and the fact that this comes at different times for different people, in different circumstances. Some want to just focus on 'life goes on' and be seen as 'normal' – not sick, in the recovery phase. There is an oft-mentioned regret from many, however, that they had not joined earlier.

For those who did attend the Group from the earliest days of diagnosis and treatment, the benefits mentioned are the gaining of knowledge about the 'dis-ease' and of what to expect and confidence and control throughout their journey. As an ongoing supportive environment, Group members have highlighted encouragement, advice and the opportunity to ask questions. There is also the opportunity to gain information for making the right choices and decision, while being respected for whatever decisions you come to, because decisions are acknowledged as being difficult to make.

#### **Identifying and Living With Cancer (B)**

There is acknowledgement that although you are continually learning and meeting more people with cancer in the Group, you still continue to experience changes.

#### **Identifying and Physical and mental changes (C)**

There is also acknowledgement that being a member of the Group empowers individuals and supports them in their decisions and thoughts about a change of priorities.

#### **Identifying and Physical and The Support Group (D)**

Knowledge is seen as enabling individuals to make the right choices – 'knowledge is power'. It was also a help to some when Group members realised that they were perhaps better off than some others and this helped to put things into perspective. But more than this, being able to be part of and to identify with a Group, where others have had the same experience, can still be so caring of one another, has proved personally valuable.

### **AdCare Retreat Reflections on Importance and Confidence for Identifying (b.1)**

Identifying	Importance Rating/10	Standard Deviation	Confidence Rating/10	Standard Deviation
	9.5	0.7	9.3	0.9

Learning about the cancer operation was seen as very important and increased confidence over the years, came with this knowledge. In relation to confidence in achieving this type of environment, listening, sharing and caring helping everyone to enjoy each other with review and



updates always being available, this area of activity was given the highest rating. A lower score was recorded for one person who recorded the comment – ‘Not there enough’.

### **Survey Comments Related to NURTURING (b.2 & A,B,C,D)**

The IBCSG defines ‘Nurturing’ as a two-way process where the Group provides a safe space for giving and receiving and where comforting and reassuring go hand in hand with developing and healing.

#### **Nurturing and Co-ordinated and Integrated Support (A)**

The Group environment provides a space where people can speak with others who understand how you feel and can give you hope to carry on. Seeing women alive, looking happy, and living with cancer after the diagnosis and treatment, is a help to others in their journey. This type of relationship builds strong *friendships* where support of whatever type is needed (laughing or crying) is only a phone call away. It is one thing to be ‘told’ about the medical events that are recommended by professionals (It seems like you are the only one going through this shocking news) and another to be with people who ‘feel what you feel’.

#### **Nurturing and Living With Cancer (B)**

Being welcomed as a ‘single’ person with concerns and anxieties and living with cancer were valued, as was the type of welcome – one with open minds for a stranger to the Group.

#### **Nurturing and Physical and Mental Change (C)**

The ‘uplifting’ compassion, understanding and wonderful spirit of the ‘ladies’ within the Group, is appreciated by new members. Group members feel ‘comfortable’ in this space. The practical and emotional support provided can ‘lighten the load’ and enable women to regain their independence.

#### **Nurturing and The Support Group (D)**

Seeing others looking happy and nicely groomed is seen as inspiration to take care of your appearance and to be ready to help someone [else] down the track. There is a sense in the Group that the women REALLY care about others and caring itself is seen as part of survival and a healthy outlook that enables one to physically fight, with the love, support and knowledge of the close network.

### **AdCare Retreat Reflections on Importance and Confidence for Nurturing (b.2)**

<b>Nurturing</b>	<b>Importance Rating/10</b>	<b>Standard Deviation</b>	<b>Confidence Rating/10</b>	<b>Standard Deviation</b>
	9.6	0.5	9.5	0.7

Nurturing was seen as a very important part of support. ‘It was the most important development for my healing process.’ ‘Reassurance gives a great deal of support in healing’ and finally, ‘A hug goes a long way’. In terms of ‘confidence’, one comment indicated that nurturing, love, comforting and reassurance had been a huge part of their healing, probably more than any medicine. Acceptance and not being alone was also noted in terms of confidence that nurturing was available. However, one comment which rated confidence in nurturing lower than the others, suggested that there was ‘not enough’.



### Survey Comments Related to **EMPOWERING** (b.3 & A,B,C,D)

The IBCSG defines this category of action – as ‘Empowering’ the individual to be everything that they can be. The Group provides an environment in which individuals can experience personal growth ranging from self-improvement to self-transformation.

#### **Empowering and Co-ordinated and Integrated Support (A)**

The Group motto is ‘Living Well – Taking Control’. Comments indicate that Group members feel they would not be as well or as strong as they are today without the Group and that with the Group they had learned to care for themselves and live life to the fullest. There is a feeling that individuals can express themselves outwardly, strongly and confidently without being socially ‘judged’. Mutual learning each meeting engenders confidence to ask questions of doctors and specialists. Previously, this same person would have sat and not questioned anything.

#### **Empowering and Living with Cancer (B)**

Because of the Group’s encouragement, individuals feel proud to be a survivor. With the loss of the individual’s confidence, stamina, strength, memory and concentration, the Support Group helps by encouraging and providing access to craft activities and social groups. The Empowerment is important to those who know, when asked, that they can help new members by being there for a phone call or a visit.

#### **Empowering and Physical and Mental Changes (C)**

Encouragement from the Support Group is seen as very helpful when a lot of effort in physical and mental adjustment is required. This is where talking with others helps and seeing women a couple of years down the track looking well and with hair, really helps to see the end of the tunnel. One comment highlighted the shift from ‘not wanting to live’ to ‘living life to the fullest’ as the reason why they keep attending the Support Group. After one’s world has been ‘turned upside down’, it was possible with the Support Group to be learning and developing concepts previously outside of personal experience. This was particularly the case with ‘rethinking’ with time out to be doing the things that keep you happy.

#### **Empowering and The Support Group (D)**

Before one respondent joined the support group, the diagnosis was simply a ‘shadow’. Information was important to the diagnosis and now, professional advice and knowledge is sought from those who have the facts. With information comes strength, courage and a positive experience. Information also puts one in a better position to help friends, as does the positive experience of being in close company with women who have had cancer, done well, and got on with their lives.

Without the Support Group, I wouldn’t know what I know now. I would hate to think of my life without it, as it had a major influence on my sense of self in a positive way. (Survey:KA9)



Group support is recorded as bringing you out of the ‘cancer shell’ and opening up new opportunities like public speaking, Dragon Boat racing and performing on the stage, which grows your confidence to try new experiences. Some report the experience of being transformed, the feeling of being an entirely different person. They describe the experience of coming into the group as ‘a mouse’, or ‘a flower bud’ and then opening up and





showing the beauty inside. It is the experience of a mouse becoming a gentle lion and this is seen time and time again in the group.

### **AdCare Retreat Reflections on Importance and Confidence for Empowering (b.3)**

<b>Empowering</b>	Importance Rating	Standard Deviation	Confidence Rating	Standard Deviation
	9.3	0.5	9.4	0.5

This was seen to be very important with the comment that 'self-esteem comes with self-confidence'. With regard to confidence in empowering within the Group, one participant commented that they were amazed at the continual personal growth that was taking place. Increasing confidence was equated to time spent with like-minded friends and continuous attendance.

### **Survey Comments Related to RECOGNISING (c.1 & A,B,C,D)**

The IBCSG defines this category of action in terms of recognising and appreciating feeling positive. In the Group, we focus on feeling positive and approaching and appreciating one another.

#### **Recognising and Co-ordinated and Integrated Support (A)**

Members realise the positive stance after a couple of meetings. After a time in the Group, hearing other women's stories is appreciated, as is being supportive of one another.

#### **Recognising and Quality of Life (C)**

The experience of being around such positive people was described as 'wonderful' and the hugs and well-wishes when someone tells the Group about a diagnosis are greatly appreciated.

#### **Recognising and The Support Group (D)**

The positivity of the Group has been mentioned as 'making the road back less rocky' and even with limited involvement, the positive attitude is found to be encouraging. One respondent commented that, although in the upper end of the age group, for her, a wide-ranging involvement across activities still engendered a positive outlook.

### **AdCare Retreat Reflections on Importance and Confidence for Recognising (c.1)**

<b>Recognising</b>	Importance Rating/10	Standard Deviation	Confidence Rating/10	Standard Deviation
	9.8	0.3	9.5	0.5

Group members indicated that they had never had so many friends, that they were like regimental soldiers being focused and appreciating one another, frequently reaching out and holding one another. A high level confidence was also recorded for this sub-set of activity.



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### Survey Comments Related to **CELEBRATING** (c.2 & A,B,C,D)

The lighter side of life is celebrated in the Group by laughing, celebrating and enjoying things.

#### Celebrating and The Support Group (D)

The only comments volunteered across all Survey responses that could count as ‘celebrating’ were recorded in the Support Group category of statements/questions. In this section of the Survey, one respondent mentioned ‘Having fun, fitness and friendship in boats’ and highlighted how the Group is not all ‘doom and gloom’, that there was ‘Much fun, laughter and friends.’ (WO14)

Celebrating, however, was one of two sub-sets of action that was rated with a perfect ‘10’ for importance, by the AdCare Retreat participants.

#### AdCare Retreat Reflections on Importance and Confidence for Celebrating

<b>Celebrating</b>	Importance Rating/10	Standard Deviation	Confidence Rating/10	Standard Deviation
	10	0	9.8	0.3

Group members indicated that Celebrating made them feel alive and worthwhile again, and that people threw themselves into the enjoyment of life. This was seen to be absolutely essential. As too, was giving yourself permission to behave in ways that you would not normally. All except one participant rated their confidence at ‘10’ for Celebrating, with one person rating a ‘9’ for ‘cautiously confident’. The disparity between importance of this sub-set of action and the absence of comments from the Survey could indicate the need for a focus Group to discuss the possibilities. This is one area in particular, where the community context can provide that which is absent in a clinical setting.

### Survey Comments Related to **SHARING STRENGTHS** (c.3 & A,B,C,D)

The IBCSG values interactions based on the strength of togetherness.

#### Sharing Strengths and Living With Cancer (B)

One Survey response highlighted the reciprocity that can flow from knowing that others are going through the same difficulty that you have and the situations you experienced. In sharing strengths, members of the Group can support others in their ‘highs and lows, their tough days and their sunny times.’ (WO14)

#### Sharing Strengths and the Support Group (D)

There were a large number of comments in the Survey about Sharing Strengths. The primary focus was on reciprocity with





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a strong sense of appreciation for the knowledge that others could provide from their own experience. 'I have also gained so much from giving support. The experience of others helped me so much through the chemo. (WO12) 'It is a two-way thing, we gain support when we are diagnosed and can give it when it is needed by new members, or when someone is not well.' (WO1) The repaying of one's benefits to others in need was seen as a very positive opportunity to 'give back', an opportunity that was available through membership of the Group. One respondent even went so far as to say 'Sharing is caring and caring is part of survival' (WO31) From a very personal perspective, one respondent commented that: 'I have constantly been given support . . . and I believe I make a difference in the world by supporting others.' (WO12)

And finally, the quality of sharing in the bus on the way home, was once again highlighted with the comment that the discussions that took place in this space, during 'the journey home, were sometimes more important than the meeting.' (WA26)

### AdCare Retreat Reflections on Importance and Confidence in Sharing Strengths (c.3)

Sharing Strengths	Importance Rating/10	Standard Deviation	Confidence Rating/10	Standard Deviation
	10	0	9.7	4.8

This was the second of the two sub-sets of action rated with a perfect '10'.

## 5.6 Implications for Complementarity of Clinical/Community Support Environments

The activities within the Support Group and its community context, mean that recognition, celebration and sharing of strengths can enhance substantially, the depth, breadth and nature of support available to women diagnosed, living with and surviving breast cancer. The comments from Support Group members indicate *what they mean* by 'support' in a community context and therefore, a possible explanation as to why a 'community environment' might offer the type of 'support' that could complement their cancer care within the 'clinical context'.

The Support Group's explanations of what they *mean by support*, also provide a resource for health professionals in clinical settings, to identify the links and/or gaps between traditional clinical and psychosocial elements of support and the type of support that becomes possible within a community context. In so doing, the comments highlight the aspects of 'support' where there is the potential for a complementary and positive connection between current clinical and community practices and where there is also the potential for the building and resourcing of complementary clinical/community partnerships, for achieving that which has been noted earlier in the Report:

. . . optimum capturing of 'all available resources' and options for mutual shaping and resourcing of effective everyday practice in getting the best possible outcomes with patient-centred care.

## 5.7 The IBCSG Model in Action: Goal Attainment Scales

A Goal Attainment Scale (GAS)<sup>7</sup> is a situation-specific, slice-in-time picture of the key elements of action that describe the possibilities for the social space that is the Support Group in action.



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These situation-specific, participant-generated scales, provide qualitative, action-oriented, process-based<sup>8</sup> indicators for the effectiveness of their Group in action. By defining what it might look like if they achieve what they are hoping to achieve, the group develops a shared understanding of where they are heading and what it could be like when they get there. With this shared picture in place, the group can then identify what it might look like if they achieve 'worse than expected (-1)', 'much worse than expected (-2)', 'better than expected (+1)' and 'much better than expected (+2)'.

With weightings attached to each of the respective sets of *possible 'outcome' descriptors*, the Group can 'measure' the return on energy, resources and social capital invested, in achieving these outcomes. Secondly, it is also possible, with critical reflection at any given point in time, to use the indicators and their weightings to represent the current effectiveness and appropriateness of the program in action.

For a Model of Action with community building as its core activity, it is the *return on social capital invested* – that is, the return on 'trust', mutual benefit' and 'unconditional giving and receiving', that is of greatest significance. This is because it is *social capital* that is both the currency and the accumulated wealth in a 'community of care'. This type of capital is not the accepted Return on Investment (ROI), of the corporate and bureaucratic systems, but rather ROSCI<sup>9</sup>, the *capital* that counts in a community context. It is 'social capital' that is the type of capital required for achieving the outcomes that are valued by the Support Group.

### How Goal Attainment Scales Work

With a GAS, the Group can brainstorm what the 'expected outcomes (0)' might look like if all goes to plan and everything is in accord with the Support Group values and principles, outlined in the Model in Action. If the Group were to give itself a rating that put them in the 'worse than expected (-1)' category, this could indicate the need for some 'risk management'. If this rating for how things are going were to be given by the participants, then the Support Group might benefit from shared reflection using the following three key questions:

1. What is working well for us,
2. What might not be working so well, and
3. What might we do to make things work better.

If, after shared reflection, the Support Group were to place themselves in the 'much worse than expected (-2)' category, then this would indicate a serious need to rethink how they were doing things. It could also signal that there had been a shift away from established values and principles identified in the Model in Action.

On the other hand, should a shared reflection identify that the Group is doing 'better than expected (+1)', then it might be time to recognise, celebrate and/or reward effective and appropriate contributions. It could still prove useful and beneficial for the Group, if they rate their current activities with a (+1) to consider the three questions listed previously, with a view to enhancing their capacity for empowerment, advocacy and transferability of their Model in Action. It is the 'much better than expected (+2)' rating that could signify for the Support Group, that they have both individually and collectively achieved a measure of self-transcendence.



### **IBCSG Draft Goal Attainment Scales for possible indicators**

The draft Goal Attainment Scales generated by the respective focus groups, represent five different perspectives on the potential for effectiveness and appropriateness of action in the Support Group. As such, they are initial drafts for future critical reflection and provide a resource for thinking about ‘what might be’. They also provide baseline information for the Group as a whole and for sub-Groups to identify and to measure their performance. These identified indicators of performance and the measures, could provide a foundation for continuing to improve the Groups’ capacity to meet the needs of women diagnosed and living with breast cancer. It was the highest rating category (Much Better Than Expected +2) that in particular, for these groups, focused on empowerment, advocacy and transferability of the benefits that they have enjoyed.

With the inspiration and Group aspiration expressed in their possible indicators for ‘Much Better Than Expected’ in the Goal Attainment Scales, that could provide a blueprint for people in other areas who might want to set up a support group modelled on the IBCSG. The IBCSG, in the following draft Goal Attainment Scales, has provided indicators that they see as necessary, based on their experience and collective wisdom, for creating a safe, supportive space. More importantly, they also provide a clear picture of areas that *might* need careful risk-management, in order to achieve the type of outcomes currently enjoyed by the IBCSG.

The following Goal Attainment Scale with indicators of the full range of possible outcomes, taking into account both ‘likely’ and ‘unlikely’ possibilities, was constructed during a brainstorming session, by IBCSG members currently in a leadership role.



***Indicators for the IBCSG Community of Care building ‘personal empowerment  
as a resource for caring’***



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The GAS examples below are NOT an indication of what is happening for the IBCSG, but rather a **visioning exercise** that covers the whole range of potentialities that might arise for any support group. The remaining draft scales are included in APPENDIX 7.

RATING	INDICATORS
(+2) MUCH BETTER THAN EXPECTED	<ul style="list-style-type: none"> <li>o Rural trips/ presentations through personal empowerment as a resource for caring for women in other areas</li> <li>o Taking responsibility for presentations in areas of personal knowledge</li> <li>o On-time, committed, dedicated participation</li> </ul>
(+1) BETTER THAN EXPECTED	<ul style="list-style-type: none"> <li>o Sense of purpose, ownership, leadership – initiating – spin-offs</li> <li>o Claiming ownership of the group by taking ownership &amp; responsibility</li> <li>o Pre-empting meeting and exceeding support/contribution opportunities</li> <li>o People offering their strengths, gifts, service for group – within their capabilities</li> <li>o Taking responsibility outside the group – encouraging to step beyond the group (i.e. Young group organizing themselves)</li> <li>o Taking on responsibility for special tasks to take weight off Committee</li> </ul>
(0) EXPECTED OUTCOMES	<ul style="list-style-type: none"> <li>o Good attendance at meetings/ maintenance of numbers</li> <li>o People want to come and are enthusiastic</li> <li>o People return after their first meeting</li> <li>o All communicating, laughing – cohesiveness, feeling comfortable</li> <li>o Nurturing of and including new people</li> <li>o People are included through building trust in initial supportive relationships</li> </ul>
(-1) WORSE THAN EXPECTED	<ul style="list-style-type: none"> <li>o When people go off on a tangent of their own, threatening group cohesion</li> <li>o Inappropriate use of group to meet own needs</li> <li>o Having to give attention to certain people to the detriment of others in the group</li> <li>o Having to ensure a safe space for people where the behaviour of some is outside normal bounds</li> <li>o People coming out of meetings disgruntled</li> <li>o In-fighting, undercurrents, mistrust</li> <li>o Destruction of trust within the group</li> </ul>
(-2) MUCH WORSE THAN EXPECTED	<ul style="list-style-type: none"> <li>o An increase in undercurrents to the point where there are power plays</li> <li>o Group losing energy and capacity to care for others</li> <li>o Committee working against rather than with group leaders for the good of the women</li> <li>o People take on roles for personal power rather than for the good of the group</li> </ul>

<sup>1</sup> Frankl, V. (1963, 1969) in Coward, D.D. and Kahn, D.L. (2005) Transcending Breast Cancer: Making Meaning From Diagnosis and Treatment, *Journal of Holistic Nursing*, Vol.23 No. 3, September.

<sup>2</sup> Frankl, V. (1963, 1969) in Coward, D.D. and Kahn, D.L. (2005)

<sup>3</sup> Coward, D.D. (1997) Constructing Meaning from the Experience of Cancer. *Seminars on Oncology Nursing*, 13(4), pp.248-251.

<sup>4</sup> Frankl, V. (1963, 1969) in Coward, D.D. and Kahn, D.L. (2005), p.265.

<sup>5</sup> Yaskowich, K.M. & Stam, H.J. (2003) 'Cancer Narratives and the Cancer Support Group', *Journal of Health Psychology*, Sage publications Vol. 8 (6):730-731.

<sup>6</sup> DeVellis, R.F. (2003) Scale Development: Theory and Applications, Applied Social Research Methods Series, Vol.26. Sage Publications, Thousand Oaks, California. Pp.51-90.



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<sup>7</sup> The Australian Youth Foundation and Dr Colin Sharp (1996) *START: Do-it-yourself Evaluation Manual: An integrated approach to project management and evaluation*. The Australian Youth Foundation, Sydney, Australia. Pp. 38-39.

<sup>8</sup> Curtis, S. (1996) *Quality appraisal of Higher Education Research: An action-oriented, process-based alternative to performance indicators*. Unpublished Doctoral Thesis, University of Wollongong.

<sup>9</sup> Curtis, S. (2005) ROSCI – A Work in progress.



## SECTION 6: CONCLUSION

### The IBCSG - Succeeding with Policy-into-Practice

The IBCSG, in its various organisational groupings, has demonstrated the practical equivalent of new directions in health policy promoted by Healthy People 2005 -New Directions in Public Health plan (NSW Health 2000):

To provide enabling circumstances for ‘. . . individuals making decisions and choosing actions that support health, and creating social and physical environments that promote health and support their individual choices’ (NSW Cancer Plan, 8.1, p.23).

By creating an environment representative of the basic population health principles (Ottawa Charter, WHO 1986), the IBCSG has developed its own self-directed, self-organising, *community of care*. The present program evaluation, therefore, has focused on the IBCSG Model in Action, as a structure for improving health through community building.<sup>1</sup> By reflecting on and identifying what the Support Group does, the Group members have been able to make explicit, in their Model in Action, just what they are – and that is, ***a circle of friendship growing their community of care***. The most frequently mentioned elements of this community of care are: friendship, understanding, reassurance, sharing and caring, with the most prominent being that of *friendship*.

The foregrounding of ‘friendship’ as the central core of Group relationships, may explain the notable difference between Support Groups in general, as indicated by the findings of the Ussher et al. study in a Report to the Cancer Council of NSW published in 2005<sup>2</sup> and the current participatory evaluation findings for the IBCSG. In the 2005 Report, on the relationship between type of organisation and effectiveness of support groups, the relational basis for group participation was identified in terms of ‘group as surrogate family’.

With Stage 2 of the study carried out by Ussher and colleagues, the general descriptive terms that emerged as the focus group’s sub-themes<sup>3</sup>, align very closely with those represented by the IBCSG evaluation. For example, the language used to define the sub-themes ‘Life in the Support Group Family’ included: a sense of community; Not alone – metaphorically/literally; Non-judgmental acceptance; Empathy/understanding; Being cared for; Safe environment for expressing feelings and fears; Positive atmosphere; and Humour. However, the language that identifies the core of support group relations as ‘surrogate family’ is a point of difference between that study and the current participatory evaluation.

The distinction between the two studies underlines the caution proposed by Kacen and Bakshy<sup>4</sup> where they indicated that ‘limitations might be experienced where differences in the stories or group narratives of various stakeholding groups, could actually work against mutual understanding and/or productive dialogue between respective cancer support groups, sub-groups and/or representative organisations.’

For members of the IBCSG, however, there were no comments that painted their core relationship structure as that of ‘surrogate family’. By contrast, there was a notable emphasis in the IBCSG,





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on the importance of family, enhanced appreciation of family and ‘... a sense of gratitude on a daily basis for the gift of life, family and friends’. (WO31) It may be that seeing themselves as part of a ‘circle of friendship and a ‘community’ of care, IBCSG members gave themselves permission to think about their circumstances in terms of the strength of their shared circle of friends and community of care.

The strength drawn from the Group is reflected in the comment from one member who said, ‘People don’t like to discuss it much and I felt family and friends took their cue from me. I was positive due to the knowledge I had gained from the Group’. (WA12) While one Group member indicated that ‘family and friends don’t always react the way you would like at times – don’t always give you the support you would like at times’ (KA10), there was no indication that the Support Group, was in any way seen as ‘surrogate’, ‘substitute’ or ‘replacement’ for their family. The essence of feeling conveyed by members of the IBCSG can be represented in the comment, ‘It gives you a tap on the shoulder and shows you where your priorities lie – and that is quality time with family and friends.’ (WA12)



Quality of time with family and friends

The IBCSG, with their community of care approach to improving the well-being and health promoting choices of members, has demonstrated that it embodies the key elements of community organisation and community building.<sup>5</sup> The accepted processes the Groups use for organising themselves around communication for understanding, are centred on identifying, nurturing and celebrating community strengths and creating an environment of friendship through the sharing of these strengths. The outcome of this focus for Group relationships is a strong sense of reassurance from being understood. ‘This is what the Support Group was good at – reassurance.’ (WO14)

As Group members engage in the Group processes, their activities demonstrate a noticeable shift from the pathology-related framing of diagnosis and treatment to a community-building focus representative of the Ottawa Charter’s five key strategies and priority areas for action, listed in the NSW Cancer Plan 2004 – 2006.



Table 1: The Ottawa Charter in Breast Cancer Support Group Custom and Practice

Ottawa Charter <sup>6</sup>	IBCSG - Policy into Practice
1. <i>Build healthy public policy</i> beyond health care	Providing a vehicle for extending, amplifying and implementing the intent of healthy public policy, through access to a support group that is a self-organising and self-sustaining <i>community of care</i> (a.1, a.2, a.3)
2. <i>Create supportive environments</i> for socio-ecological approach to health	Providing a network of relationships that constitute a continually renewable resource of community strengths and the capacity of the community to care for its own.(c.1, c.2, c.3)
3. <i>Strengthen community actions</i> through concrete and effective community planning strategies	Providing a self-organising community focussing on planning and action directly relevant to participants' expressed interests and needs and identified options for effective action (b.1, b.2, b.3)
4. <i>Develop personal skills and social development</i> through information, education and enhancement of life skills	Providing an environment that has as its core organising principle – processes of communicating for understanding, knowing, inspiring, listening and teaching across the range of shared community concerns and interests (a.1, b.1, b.3)
5. <i>Reorient health services</i> beyond the responsibility for curative and clinical services towards health	Providing shared support for self-management and ownership of health promoting behaviours which complement clinical-curative service provision in the health care continuum (b.1, b.2, b.3)

## 6.1 IBCSG Evaluation Findings: The Model in Action for Community-Building

The members of the IBCSG have created a distinct and separate social space in which women diagnosed, living with and surviving breast cancer, can be supported by group processes that continually sustain and build their sense of identity, belonging and community. With their Model in Action, they have been able to identify the ways in which they contribute towards the capacity of Group members to ‘. . . transcend the stigmatizing nature and experience of diagnosis and living with cancer.’<sup>7</sup>

With the principles and values that they have identified as their ‘Model in action’, the members of the IBCSG have demonstrated what it they do to enhance their community capacity and facilitate leadership development across the range of activities that are available to Support Group membership. In demonstrating what they ‘do’, the members of the Support Group have defined what they ‘are’ – *a circle of friendship growing our community of care*.

## 6.2 Community Capacity Building

The development of community capacity across the IBCSG and its sub-groups and activities, is demonstrated in the Support Group’s ability to provide practical and achievable options for translating policy-into-practice. The following table demonstrates some of the ways this has been achieved in terms of practical action by the IBCSG.



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Current Policy Imperative	IBCSG in Action
1. <i>Locally-determined policy</i> with a greater range of political & governance structures	<ul style="list-style-type: none"> <li>○ The IBCSG is an incorporated body that includes within its structure, a number of formal Groups.</li> <li>○ The IBCSG has the status of an Incorporated body under the Department of Fair Trading, with its own insurance, public liability, directors liability arrangements, tax deductibility etc.</li> <li>○ Overall governance and current direction of the IBCSG is guided by the Management Committee with responsibility for underpinning business decision-making and organisational arrangements, so that much of the burden of everyday housekeeping is shifted to the Committee, allowing meetings to concentrate on their main purpose which is <b>support</b>.</li> <li>○ Any decision-making that impacts on the Group is brought to the whole Group for discussion, reflection and individual or shared input because an inclusive approach to organisation underpins group processes.</li> </ul>
2. Development of <i>practical and locally-relevant 'supportive environments'</i> with a settings-based approach	<ul style="list-style-type: none"> <li>○ The core Groups that make up the IBCSG have distinguishing characteristics that define their respective personalities and group dynamics and therefore the way in which they come together and operate.</li> <li>○ A responsive Group leadership role, identifying, predicting, responding to and meeting the needs of women as the need becomes evident, at whatever point the women find themselves on their journey</li> <li>○ As a framework for, action based on community-building, the IBCSG Model in Action, set out in the action categories, provides a unique blueprint for achieving the outcomes that are currently valued and enjoyed by Group members.</li> </ul>
3. <i>Capturing of compelling evidence of Return On Investment</i> with setting-based health promotion	<ul style="list-style-type: none"> <li>○ Participation by a wide range of women across the spectrum of Support Group activities and a seamless transition of responsibilities across different participants in the evaluation processes in the development of their Model in Action and Goal Attainment Scales</li> <li>○ It is the return on social capital invested (ROSCI) – that is the return on 'trust', mutual benefit' and 'unconditional giving and receiving', which is of greatest significance for a Model of Action with community building as its core activity because social capital is the currency with which valued outcomes are achieved</li> </ul>
4. Focusing on health literacy with investment in communication and education	<ul style="list-style-type: none"> <li>○ We organise ourselves around communicating for understanding with each of us knowing, inspiring, listening and teaching</li> <li>○ People listen and learn about the best way to organise things</li> <li>○ Sitting and sharing ideas, respecting that we have a common bond and that we will be able to get more information</li> <li>○ People in the Support Group know what to say so we <u>gain from everyone</u></li> </ul>



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<p>5. <i>Developing enhanced community capacity for health through the strengthening of social capital</i></p>	<ul style="list-style-type: none"> <li>○ Gloria Swift is a resource for building social capital (trust, mutual benefit and unconditional giving and receiving) in the meeting of women's needs as they arise.</li> <li>○ The Support Group has demonstrated their ability to strengthen community action for health by building social capital that is used as a continually renewable resource for ongoing development of community capacity</li> </ul>
<p><b>. . . and at the level of the individual participating in the Support Group:</b></p>	
<p>6. Care centred on the patients' needs with respect to <i>individual needs, choice, access and assistance</i></p>	<ul style="list-style-type: none"> <li>○ We organise together by sitting and sharing ideas, respecting that we have a common bond and that we will be able to get more information</li> <li>○ The Group is an opportunity to have people [there] who know what we are going through, you just have to ask</li> <li>○ IDENTIFYING within the Group: Identifying what I want to know and need to know and ask when I'm making decisions for me – the Group is a safe space for self-reflective, self-directed questioning, learning and decision-making.</li> </ul>
<p>7. <i>A key contact in care coordination as source of information and support for psychosocial well-being</i></p>	<ul style="list-style-type: none"> <li>○ The current Support Group leader/facilitator is someone who has demonstrated that she is able to work between groups and systems as well as across the gaps that exist at the local level between systems of care</li> <li>○ Doctors didn't seem to understand how I was feeling or why I would be crying – Gloria and the women in the Group just know. This is so important to me</li> <li>○ The importance of the link person (Gloria Swift) and the Support Group, particularly with regard to 'normalising' initial reactions and understanding of side-effects, complications, medications and treatments.</li> </ul>
<p>8. Provision of appropriate psychosocial and practical support</p>	<ul style="list-style-type: none"> <li>○ Provision of a separate social space, where participants can transcend the stigmatizing nature and experience of diagnosis and living with cancer</li> <li>○ Positive assets gained from Group involvement were identified as: feeling safe and confident and knowing support was within easy reach and always readily available.</li> <li>○ The Group environment provides a space where people can speak with others who understand how you feel and can give you hope to carry on. Seeing women alive, looking happy, and living with cancer after the diagnosis and</li> </ul>



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	<p>treatment, is a help to others in their journey.</p> <ul style="list-style-type: none"> <li>○ 'A hug goes a long way'. In terms of 'confidence', one comment indicated that nurturing, love, comforting and reassurance had been a huge part of their healing, probably more than any medicine.</li> </ul>
9. Patient empowerment with respect to decision-making	<ul style="list-style-type: none"> <li>○ Action category Identifying: Identifying what I want to know and need to know and ask when I'm making decisions for me – the Group is a safe space for self-reflective, self-directed questioning, learning and decision-making.</li> <li>○ Information was important to the diagnosis and now, professional advice and knowledge is sought from those who have the facts. With information comes strength, courage and a positive experience.</li> <li>○ There is a feeling that individuals can express themselves outwardly, strongly and confidently without being socially 'judged'. Mutual learning each meeting engenders confidence to ask questions of doctors and specialists.</li> </ul>
10. Assurance of patient rights, including <i>respect, involvement, self-determination</i>	<ul style="list-style-type: none"> <li>○ By participating in some group programs - e.g. stress management - we are taught to try and eliminate unnecessary stresses from our daily lives and to identify main priorities and put all your positive energy into them</li> <li>○ Life is totally rearranged, important things are done when you can and unimportant things are never looked at</li> <li>○ The Support Group provides an environment where you will be taken seriously and this is important to one's mental attitude</li> <li>○ As a member of the Support Group, we don't always agree with others' treatment choices, but we know these decisions are difficult to make and we respect that.</li> </ul>
11. Provision for sharing of information and making decisions together	<ul style="list-style-type: none"> <li>○ Organising: We organise ourselves around communicating for understanding with each of us knowing, inspiring, listening and teaching</li> <li>○ In some ways I was a step ahead of my medical team due to my contact with the Group.</li> <li>○ Because you have contact with people in the Group and hear their experiences, good and bad, it makes you aware of what is available and you can seek it out.</li> </ul>
12. Protection of patient's value & dignity	<ul style="list-style-type: none"> <li>○ Implications of Previous Research for Rethinking Practitioner-Patient relationships in Cancer Care: Dr Beth Marlow. Re-orienting the "centre" in "patient centred care"</li> <li>○ Doctors didn't seem to understand how I was</li> </ul>



	<p>feeling or why I would be crying – Gloria and the women in the Group just know. This is so important to me.</p> <ul style="list-style-type: none"> <li>○ In the Support Group you feel supported and even the most minor aspect is addressed, making you feel good.</li> </ul>
13. Consumer participation with direct input into consumer issues	<ul style="list-style-type: none"> <li>○ IBCSG support for attendance of members at Patient Advocacy training programs and participation in relevant discussion forums</li> <li>○ Representation at local, State and National forums to represent Support Group interests.<sup>8</sup></li> <li>○ Authoring of position papers, articles, research findings as a resource for diffusion<sup>9</sup> of evolving frameworks and models (previous research) and advocacy for ‘patient-centred care’ (APPENDIX 8) in policy-making and decision-making forums</li> </ul>

### 6.3 Leadership Development through capacity-building

The IBCSG has at its core, four key roles that build and sustain its membership based on its responsive and continually-evolving circle of friendship and community of care environment. These key roles include the:

- ✦ Clinically-qualified and community-engaged Group Support leader/ Group facilitator,
- ✦ Governance team of President and Management Committee,
- ✦ Group narrative recorder/facilitator (Newsletter Compiler/Writer/Editor),
- ✦ Group Leader roles for respective core Groups and sub-groups.

The Core Group is organised around communication for understanding with the key linking role of the Oncology Nurse Consultant, Breast Care Nurse/ Group Support Leader/Facilitator. This support leadership role bridges the divide between clinic and community, between the acute, clinical, curative model environments of diagnosis and treatment and the strengths-based community support model of the Support Group environments. This role has involved identifying, predicting, responding to and meeting the needs of women as these needs were identified, at whatever point in their journey. Underpinning the success of this responsive support/leadership role, has been the inaugural and current support leader’s capacity to achieve recognition and credibility in both the clinical and community environments. She is someone who has demonstrated that she is able to work between groups and systems as well as across the gaps that exist at the local level between systems of care, especially those between the clinical and the community contexts of care.

With these attributes, the current Group support leader/facilitator is able to provide a bridge for communication and two-way understanding, learning and support across the clinical-community divide. As such, Gloria Swift is a resource for building social capital (trust, mutual benefit and unconditional giving and receiving) in the meeting of women’s needs as they arise. It is this capability, embodied in the current Group leader/facilitator that demonstrates what policy-into-practice might look like if it were to become a designated role such as that described in the Clinical Service Framework for Optimising Cancer Care in NSW 2003.



The stated intention, of this Clinical Service Framework, is to provide clear directives for *Patient-centred care and patient/consumer-centred practices*. In particular, Standard 3 of the Framework, refers specifically to how patient-centred care will be demonstrated when the health system is addressing both 'technical excellence and quality of care to achieve legitimacy in the eyes of those it serves.' (p.11). This policy identifies the need for a *key contact* in care coordination, as a *source of information and support in patient's decision-making* and issues related to *psychosocial well-being*.



It is evident from the IBCSG, that someone accepting this bridging role needs to have a thorough working knowledge of, access to and relationship with, the respective systems and groups with whom they are involved. In other words - they have to have earned their stripes - the trust and respect of all groups with whom they are working.

From the clinical perspective, Gloria Swift employs a support leadership style that is seen by Group members to be grounded in knowledge, personal talent, sensitivity and service. In a way, Gloria Swift, with her capacity to span the

clinical/community divide, is the symbolic 'head' of the 'way we do things now' in the Breast Cancer Support Group. 'We are so lucky to have a wonderful leader, Gloria. She can motivate but still be so caring and helpful. A good head is nothing without a strong body and a good strong body goes nowhere without the head.' (WO19)

Gloria Swift also takes on a 'stewardship' function with her Group facilitation and it is this function that is directed towards protecting the Group and the Group's social space. There is consistent monitoring so that people don't do anything that will damage the Group, its standing and/or its relationship with others. 'Good manners' and consideration are part and parcel of the Group in action, particularly as these relate to partnerships and supporters of Group activities.

The current model of facilitatory leadership appears to be based on positive elements of Human Resource Leadership<sup>10</sup>, and in particular on listening, coaching, participation and empowerment. The pattern of facilitation revolves around matching people and their strengths to tasks and opportunities, as they arise. People are encouraged to take a step towards a leadership role and then to develop their own version of the 'hat' they have taken on. People 'become' their hat and their 'hat' becomes them.

This approach to facilitation of the Group, provides a fertile ground for experimentation, growth and transformation of identity through *shared leadership*, an evaluation finding strongly represented in the Group's 'Building' and 'Empowering' categories of community-building action. The idea of shared leadership is that type of leadership which is built around a network of fluid relationships with the underlying assumption that everyone has leadership



qualities that can be ‘pooled and drawn upon as needed, when working with others on vital common issues.’<sup>11</sup>

There is a culture within the IBCSG of making sure that people do what is necessary to sustain and to nurture what is important to the Group, particularly with leadership of activities and tasks. People who take on a ‘leadership hat’ or leadership role are very protective of the task for which they have assumed responsibility. There is a strong sense of ownership and responsibility towards the Group’s shared values and purpose, and particularly where this involves commitment to maintaining the integrity of a role or task.

It is this point of ‘leadership’, however, which represents the widest gap between the findings of the 2005 Report to the Cancer Council of NSW and the present participatory program evaluation. Once again, it could be that ‘language’ and the limitations of chosen interpretive frameworks, may be the reason for apparent discrepancies. The survey responses in the Stage 1 Audit of Support groups (n=417) in the Ussher et al. study, indicated that 61% of Support Groups were ‘professionally led’. The Summary and Conclusions of Stage 2: Part 11 of the study reiterates the positioning of support group as ‘surrogate family’ and the group leader as a ‘strong attachment figure, or surrogate parent’.<sup>12</sup> From a clinical perspective, someone diagnosed with cancer, is initially dependent on the medical team for survival. However, if this ‘clinical dependency model’ were to be translated into an ongoing group leadership style, it may prove to be somewhat limiting for the type of support that could be provided, the group potential and continuing growth and sustainability of group membership.

‘Leadership’ is a highly problematic descriptor for a role within a group because styles of leadership and the consequences of choice of style, can have a profound impact on a range of capacities within a group. These include the capacity for: flexibility, responsibility, standards, recognition and rewards, clarity of purpose, and commitment within the group.<sup>13</sup> If, as the Ussher et al. study identifies in their original audit, that 61% of the audited support groups for all cancers were led by professionals, then it may be that the combined and complementary findings of the Ussher et al. study and the present participatory evaluation, point towards the need for an in-depth study of leadership styles for effective Support groups. This type of information could then provide a well-grounded platform for leadership development programs across all cancer support groups.

When viewed from the perspective of the current participatory evaluation, the concept of dependency on a ‘leader’ as ‘surrogate parent’ does not fit comfortably with the IBCSG narrative of ‘community-building’ and ‘empowerment’. Nor does it fit with their model of ‘shared leadership’ which has been identified by Group members, as the ‘Hats’ model of leadership.

### **The IBCSG HATS model of leadership for Group Functions**

Group members indicate that they experience the Group environment as a safe space for trying out and accepting a variety of often initially daunting, but as they grow, enormously satisfying leadership roles. This type of environment provides for the possibility of seamless transition by individual Group members across the many roles and tasks required for Group action. This way of operating reflects the shared leadership style described previously.





It is not leadership from any one person that is required, it is an aspect of leadership each of us summons from within. In this respect, the same qualities we have sought in one person can be found distributed among many people who learn, in community, to exercise their “leadership” at appropriate moments. This occurs when people are vitally concerned about issues when executing their responsibilities. Leadership thus becomes a rather fluid concept focusing on those behaviours which propel the group forward. (John Nirenberg, 1993, p.198)<sup>14</sup>

By involving group members in an activity where they can develop and reclaim *control* in their lives – by taking on a task or role in a territory where they have had previous experience - Group members are able to find a way of becoming involved again, which in turn, aids the healing process.

### **Description of the ‘Hats Model’ in Action as told by Support Group Collator of ‘Group Narrative’**

The ‘Hats’ model<sup>15</sup> is about working with strengths – *together the job gets done*. The different strengths of Group members complement one another and it is these different strengths that are recognised and drawn on as the need or task arises. It is a very fluid way of organising together to get things done.

Gloria’s responsible for a lot of this as she is good at recognising strengths in us that we may not have realised. (WO26)

The ‘Hats’ model of leadership is a bit like a garden with ‘companion planting’ where those plants that do well together are grouped together. The whole thing is complementary, without even thinking about what is happening. One Group member says something and the next person comes in and links to that comment to build what is being said and done. The shared task of leadership is so unconscious that at times we finish each other’s sentences. We seem to know what each other is going to say in the moment and then add what comes next.

For us (the IBCSG as it is today), it’s *the people* that make it possible to be uniquely US. Other groups might be able to ‘get the hats’ to wear – but their group will be different according to WHO is wearing them. This has been the same for us over time. What we have now works very well but this has evolved with the people who have taken on the roles and tasks. So every Group – although they may have the same ‘hats’, will have a unique character depending on the character of those who choose to, or are chosen to, wear these hats.

The ‘hats’ are the ‘functions’ that make up the Group space. They are the ‘plan’ for the Group in action. That is why the person wearing the hat can really change the nature of the ‘hat’ or ‘function’. The Group can be taken in a very different direction with very different consequences for how the Group operates (What the Group ‘means’ by each of the ‘hats’ and what the Group ‘values’ in terms of what is done in the name of the respective ‘hats’). For example, we might have the same roles in two different Groups, but with different people in those respective roles – the Groups might be completely different.



Our Group is the group it is, and the force it has become, because of the people in it. There needs to be a range of levels and strengths – of involvement and leadership, a range that enables people to complement one another and to grow as individuals. ‘Everyone contributes in a way they can. Some can be good leaders and others are just hard workers.’ (WO19) It’s like a tribe. People have a function according to what they bring to the group. A space exists for a function in the tribe and someone comes and fills it in their unique way. That space may not have been known or even

obvious to the Group – until the person grows into the particular function that is to become part of the Group space. It is a matter of someone planting the seed and nurturing it.

In the ‘hats’ model of leadership, people go where they are needed and the ‘needs’ are like the children of a traditional tribe – where everyone looks after them. It’s the ‘needs’ in the Group that are for us, ‘the children’. The ‘needs govern priorities and the flow of energy and attention at any point in time. The ‘hats’ model of leadership is a natural, responsive flow that continually evolves as we collectively meet the ‘needs’ of the Group and create the unique social space that is the IBCSG.

*A social space* is a space that enables people to come together and to support group cohesion and it is maintained by the activities of individuals. It is the individuals in their leadership and participant roles, who structure their lives and activities around a particular life view or values framework that is shared by members of the group.<sup>16</sup>

It is this ‘life-view or values framework’ that the Group has made explicit in the community-building framework of their Model in Action with the defining categories:

- Organising, Including and Building;
- Identifying, Nurturing and Empowering; and
- Recognising, Celebrating and Sharing Strengths.

## **6.4 Critical Awareness of the Group**

With their demonstrated development, evolution and sustainability of *practical and locally-relevant ‘supportive environments’*, the IBCSG has provided a model of what a ‘settings-based approach’ might look like if it were to make available, supportive relationships based on ethical principles and mutual understanding at the local level. The women of the IBCSG have attested to their capacity for engaging both in and with, health promoting activities that are carried out by and with the people concerned. These people are the women diagnosed, living with and surviving breast cancer. With this Model of Action happening at the local level, there is readily available evidence of improved ability of individuals to take positive action. The action taken demonstrates that the group processes are clearly oriented towards enhancing both their health and the capacity of their community of care, to influence the determinants of health and well-being for their membership.



## Illawarra Breast Cancer Support Groups:

Participatory Program Evaluation Identifying the Meaning and Value of the Support Group for Group Members

With Group member involvement in the evaluation process, there is now a core of Support group members who have grown both their critical awareness about the Support Group and their understanding of reflective evaluation tools and processes. With their involvement, has been the growth of understandings about different ways in which they have currently taken action or indeed, might take action in the future, to achieve individual and shared power.<sup>17</sup> Their involvement has meant that they could also use this evaluation experience to identify they type of continuing and emerging support that is both *effective* and *appropriate*. And finally, with their involvement, has come the 'power' to understand the real value of what they do, an understanding that is available to the IBCSG for continually building its resources and better meeting the needs of Support Group members, at whatever age, stage or phase of the journey they find themselves.

The Illawarra Breast Cancer Support Group is a different type of 'support group' because they've been there and done that . . . From the group's perspective, it is a place where friendship is a special gift given freely and with love.

Core Evaluation Team focus group comment, 2006.



<sup>1</sup> Minkler, M & Wallerstein N. (2002) Improving Health Through Community Organization and Community Building' in Glanz K., Rimer B.K., Lewis F.M. (Eds.) *Health Behaviour and Health Education: Theory, Research and Practice 3<sup>rd</sup> Ed.* John Wiley & Sons Inc. San Francisco CA. pp.279-311.

<sup>2</sup>Ussher, J., Butow, P., Wain, G., Smith, K, Stenlake, A., Kirsten, L. and Sandoval, M. (2005) *Research into the Relationship Between Type of Organisation and Effectiveness of Support Groups for People with Cancer and Their Carers. Report to the Cancer Council of NSW.* School of Psychology, University of Western Sydney, Medical Psychology research Unit, School of Psychology, University of Sydney and Department of Gynaecological Oncology, Westmead Hospital.

<sup>3</sup> Ussher, J., et al. (2005), p.9.



<sup>4</sup> Kacen, L. & Bakshy, I. (2005) Institutional Narratives in the Discourse Between Oncology Social Workers and Cancer Patients' Self-Help Groups in Qualitative Health Research, Vol. 15, No.7, September, pp. 861-880.

<sup>5</sup> McNight (1987) in Minkler, M & Wallerstein N. (2002) Improving Health Through Community Organization and Community Building' in Glanz K., Rimer B.K., Lewis F.M. (Eds.) *Health Behaviour and Health Education: Theory, Research and Practice 3<sup>rd</sup> Ed.* John Wiley & Sons Inc. San Francisco CA.

<sup>6</sup> Ottawa Charter for Health Promotion (1986), *First International Conference on Health Promotion* Ottawa, 21 November. World Health Organization, Health and Welfare, Canada and Canadian Public Health Association. URL: <http://www.health-care.au.com/Ottowa%20Charter.htm>

<sup>7</sup> Yaskowich, K.M. & Stam, H.J. (2003) 'Cancer Narratives and the Cancer Support Group', *Journal of Health Psychology*, Sage publications Vol. 8 (6): p.720.

<sup>8</sup> Ussher, J., et al. (2005).

<sup>9</sup> Oldenberg, B. and Parcel, G.S. (2002) Diffusion of Innovations, in Glanz K., Rimer B.K., Lewis F.M. (Eds.) *Health Behaviour and Health Education: Theory, Research and Practice 3<sup>rd</sup> Ed.* John Wiley & Sons Inc. San Francisco CA. Ch.14.

<sup>10</sup> Bolman, L.G., & Deal, T.E. (1997) *Reframing Organizations: Artistry, Choice, and Leadership 2<sup>nd</sup> Ed.* Jossey-Bass Publishers, San Francisco. Pp.308-9.

<sup>11</sup> Sandmann, L.R. and Vandenberg, L. (1995) A Framework for 21<sup>st</sup> Century Leadership. *Journal of Extension*, December, Volume 33, Number 6. <http://www.joe.org/joe/1995december/al.html>

<sup>12</sup> Ussher, J., et al. (2005), p.10.

<sup>13</sup> Goleman, D. (2000) 'Leadership That Gets Results' in *HBR*, Harvard Business School Press, Boston, USA.

<sup>14</sup> Nirenberg, J. (1993) *The living organization: Transforming teams into workplace communities.* Homewood: Doubleday/Currency. P.198.

<sup>15</sup> Gregory, R. (2007) 'The IBCSG "Hats Model" of Leadership'. Record of observations by Member of IBCSG, Collector, narrator, collator of Group narrative.

<sup>16</sup> Habermas, J. (1987) *The Theory of Communicative Action, Volume Two: The Critique of Functionalist Reason*, trans. Thomas McCarthy, Polity Press, Cambridge, P.142

<sup>17</sup> Minkler, M & Wallerstein N. (2002), p.287.



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## APPENDIX 1: Dr Beth Marlow's Review of Previous IBCSG Research Activities

### RESEARCH WE HAVE ALREADY

Information summarised by working from the patient perspective outward

Note: 'Survivor' is the term used to replace references to 'patient'

#### ***Summarising our Quality of Life research:***

The Quality of Life (QOL) project was designed to go back to the basics of what constitutes QOL, that is, to ask participants what they thought were the important areas in which their QOL was affected by a diagnosis of life threatening illness. The research participants (cancer survivors, cardiac disease survivors, carers of cardiac disease survivors, older and younger university students) gave varying accounts of the degree to which their QOL had been affected by the illness. Nonetheless, the aspects of their lives affected could be summarised into four distinct categories; mental and physical health, relationships, independence and life re-evaluation. The first three categories were true for all participating groups. The fourth category, "life re-evaluation", was common to all groups except the younger students. Life re-evaluation, a reviewing of priorities, was an almost universal decision for the participants diagnosed with a life threatening illness.

The relevance to our current project is, firstly, the QOL of participants was affected in all domains of their lives – psychological and social as well as physical. For most participants the greatest disruption occurred, predictably, at diagnosis and during treatment. QOL usually improved as time went by. Secondly, and more importantly, people were in general very successful at accommodating to their changed circumstances and demonstrated their resilience in the ways they articulated their re-evaluation of life priorities. Adjustment to these major life changes can be assisted by provision of relevant information and support, especially if it is made available at key times during the process (which, of course, requires a longer commitment than the immediate treatment period, and, of course, is something the support group is well placed to do).

Yammine, J., Naulty, A., Macha, U., Willis, S., Koster, H., & Marlow, B. (2003). *Quality of life perceptions after surviving a life threatening illness: Cancer and cardiac disease*. Unpublished research report. Psychology Department, University of Wollongong, Wollongong, Australia.

Nazenin, M. Smith, N., Robinson, L., Tanconi, L. & Marlow, B. (2004). *Quality of life perceptions after surviving a life threatening illness: Cancer and cardiac disease*. Unpublished research report. Psychology Department, University of Wollongong, Wollongong, Australia.

#### **Cancer Survivorship Research**

Living with cancer (even in remission) seems to have some peculiarities. There are social attitudes particular to cancer; cancer produces greater fear, more stigma, more pity than other equally life threatening and debilitating conditions.

#### ***Summarising our Survivorship research:***

In our research, "survivorship" refers to the many aspects of *living* with cancer, from the time of diagnosis onwards. The project was designed to focus on the effects of marginalisation that many people experience after diagnosis. The findings from interviews conducted with 16 female cancer survivors can be summarised in terms of the *areas of perceived differences* with others (self-identity, relationships, beliefs and values, lifestyle and well-being) and the nature of *change* associated with those areas (awareness, time, context, conflict). Experiences of marginalisation were more intense at particular times and in certain circumstances and the experiences were sometimes positive, sometimes negative, and sometimes a mixture of both.

The relevance to our current project is in the recognition that firstly, a cancer diagnosis is typically of great concern for the patient and for those around the patient, and secondly the diagnosis tends to have long-term, often life-long effects; that is to say that, for whatever reasons, it is understood differently from other diagnoses of serious illness. Because of the widespread and lingering effects of the diagnosis, it is important to offer supportive care long after the acute care (the medical treatment) has finished.

Mitzak, P. (2002). *Liminality: The paradox of cancer survivorship*. Unpublished Honours Thesis. Psychology Department, University of Wollongong.

### ***Summarising our research on Psychosocial Support Needs:***

Psychosocial support has been long recognised as an important aspect of cancer care and now it is a specific goal in the policy developed by the Cancer Institute. The study we undertook used focus group discussions to establish what breast cancer survivors (80 women) identified as their main areas of need at diagnosis and afterwards. From the data we were able to develop a model of the *process* of support, something rather different from the lists and categories of needs usually identified in such research. The model consists of four categories of need: *Feeling of Reassurance* (knowing what to expect), *Sense of Control* (the ability to make choices and decisions), *Organisation of Care* (integrated support network), and *Validation of Experience* (being taken seriously). The categories are interrelated and describe how participants would like the support process to happen as they interact with various health professionals. If the process works well, the particular and individual needs of a client can be properly and clearly articulated.

The relevance to our current project is that the model provides a snapshot of what multidisciplinary care would look like from the perspective of the client. The research demonstrates both the complexity of the experience of cancer and integrated nature of support requirements. From the survivor's perspective psychosocial support is central, not peripheral.

Marlow, B., Carmill, T., Cieplucha, H. & Lowrie, S. (2003). An interactive process model of psychosocial support needs for women living with breast cancer. *Psycho-Oncology*, 12. 319-330.

### ***Summarising our research on Support Groups:***

The researchers gathered information from 76 women attending breast cancer support groups in Wollongong, Wagga Wagga and Kiama. For all groups there were three main reasons attending groups: *knowledge* (acquiring and sharing information); *support* (from peers and group leaders); and *group identification* (the companionship of people with shared experiences). A model was developed to show the place of the support group in the individual's journey through the cancer experience.

The differences between the urban and rural groups were not great. However, the rural women identified a greater need for assistance to their families; they tended to form smaller informal associations as well as attending the formal meetings; and, they had to be more self-directed in seeking out information. Finally, membership tended to change over time. Typically still coming to terms with their diagnosis, newer members wanted use the resources of the group to help them cope. As time went by, some members dropped out, hopefully having gained what they wanted, but others chose to stay both for the support they still found valuable and to *offer* support to others.

The relevance to our current project is that the support group members have identified for themselves why they joined the breast cancer support group and why some choose to stay with the group. We should be able to tease out some *general* information about how the variety and extent of group activities would simply not be possible with a self-help group – it's the professional facilitation that makes this possible (we don't however, have specific information on the question of professional versus self-help facilitation). Maybe it is worth mentioning the experience of the Wagga group though, when they lost their facilitator.

Borham, V., Knight, L., Shalhoub, S., Wilcock, R., Wilcoxon, H. & Marlow, B. (2000). *The contributory role of support groups in meeting the psychosocial needs of women with breast cancer*. Unpublished research project for Graduate Diploma in Applied Psychology. Psychology Department, University of Wollongong.

### ***Other UOW research with the support groups to consider:***

Heather Davey (1999), with Nadia Crittenden supervising, investigated the roles of doctors and complementary practitioners in meeting the needs of younger women (under 50 yrs) with breast cancer. Participants reported a number of unmet needs, but said that, in general, their complementary practitioners were better at meeting their needs. Many cancer patients are not clear about the precise roles and responsibilities of their medical practitioners, highlighting an area that requires clarification.



*Lis Lane* (200?) PhD Thesis on 'the role of others in validating helpful constructions of the breast cancer experience'. The study involved the development and testing of a model of 'living with cancer' and a subsequent intervention to assist women in the reconstruction of the meaning of their experiences.

*Lauren Schubert* (2000), with Beth supervising, investigated "differentiation of self" (a secure sense of self combined with a balance of intimacy and independence in relationships). The questionnaire based study showed that participants living with breast cancer reported as secure a sense of self as people not living with cancer.

Lane, L.G. (2002) 'Living in the Shadow: a personal construct model of adjustment to breast cancer survival and tests of its clinical usefulness'. Unpublished Doctoral Thesis, University of Wollongong.

**Notes for future Inquiry: Other information /references**

There was, in this research, considerable overlap between the three interpretive categories generated – Knowledge, Mutual Support & Identification' and accepted generic Psychosocial Support categories of "Informational, Emotional and Instrumental or Tangible Support' (Bloom 1986).

NBCC actively promoting multidisciplinary care - see [www.nbcc.org.au/mdc](http://www.nbcc.org.au/mdc)

BCNA priorities for 2005-6

- improve psychosocial care of women diagnosed with breast cancer
- standardise the delivery of breast cancer services across Australia
- implement the NBCC clinical practice guidelines nationally and evaluate implementation
- eliminate discrimination on the basis of a diagnosis of breast cancer or genetic information." p. 7 Breast Cancer Network Aust. *The Beacon* Issue 31, Winter 2005

We want to know how relevant and accurate the previous findings from group reflection are in the context of current circumstances, as perceived by Group current Group participants. Our strategy will be to develop a Questionnaire or Survey that captures the essence of previous findings and use this to generate a snap-shot of current understandings, perspectives, experiences amongst the Group membership.

## APPENDIX 2: SURVEY Participatory Evaluation of the Illawarra Breast Cancer

The Illawarra Breast Cancer Support Group Committee and Gloria Swift have requested a pilot program evaluation to identify the key factors that contribute to the effectiveness of this group, as a model for structured, community-oriented care.

Dr Sue Curtis has accepted the Group's invitation to work with stakeholders in identifying the key factors of the current program model and in establishing indicators of effective practice for the Support Group as a working model for structured, community-oriented care.

The participatory pilot program evaluation will use a combination of shared reflections, focus groups, workshops, surveys and collaborative reviews of program history, to incorporate the experience, understandings and voices of core stakeholders into the evaluation process.

The outcome of the program evaluation will be a documented record of:

- a profile of indicators of effective practice for structured, community-oriented care;
- a framework and processes for ongoing, integrated program evaluation by core stakeholders using these indicators of effective practice;
- a core stakeholder evaluation of the contribution and value of the Illawarra Breast Cancer Support Group model for structured, community-oriented care; and
- the effectiveness and appropriateness of essential elements in this model for contributing towards specific goals in strategic areas identified by the NSW Cancer Plan 2004-2006.

The attached survey has been developed by Sue Curtis of Ortran Consulting, in collaboration with Beth Marlow of the Illawarra Breast Cancer Support Group.

The survey has been designed for you, as a member of the Illawarra Breast Cancer Support Group, to confirm (or question) previous findings and to help us in making the links between the Group's previously acquired wisdom and the role that the Support Group has played in the personal journeys of group members.

We are asking these questions to better understand what group members value about being involved with the Support Group as a contribution to the quality of structured, community-oriented care.

Your confidentiality is guaranteed. All responses will be aggregated. Comments will be used only as a basis for interpreting numerical responses.

*Previous research resulted in findings about:*

- A. Support**
- B. Living with Cancer**
- C. Quality of Life**

Getting Started: Making the links between previous Support Group research findings and the experience of current Group members

### Demographic Details:

My age is \_\_\_\_\_ yrs

My age when diagnosed with cancer was \_\_\_\_\_ and I received this diagnosis \_\_\_\_\_ yrs ago, OR, \_\_\_\_\_ months ago

I have been attending the support group for \_\_\_\_\_ yrs, OR \_\_\_\_\_ months, OR

I am a new member and this is my first meeting ☐

I attend the support group meetings	---->	every month	<input type="checkbox"/>
	---->	most months	<input type="checkbox"/>
	---->	occasionally	<input type="checkbox"/>
	---->	rarely	<input type="checkbox"/>

**In the following statements, please circle the number that best represents your personal perspective and experiences and add any comments that might help us to better understand your selection of weightings**

### A. Findings about 'Support' indicated that:

In general, women wanted their cancer treatment, professional care and support to be well organised; they wanted a sense of personal control; they wanted to be taken seriously; and they wanted a feeling of reassurance about what was happening to them. The following statements represent the different aspects of 'support'.

**A1** It is important that the various aspects of cancer treatments, professional care and support are **well co-ordinated and integrated**.

Strongly disagree		1	2	3	4	5	Strongly agree	
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**A1.1** It is important that the various aspects of cancer treatments, professional care and support are **well co-ordinated and integrated**.

Not like my journey at all	1	2	3	4	5	Very like my journey
----------------------------	---	---	---	---	---	----------------------

**A1.2** The Breast Cancer Support Group in this aspect of my journey was:

Not important for me	1	2	3	4	5	Extremely important for me
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**Comments:**

**A2** It is important that patients have some sense of **being in control** – that they are able to make choices and decisions.

Strongly disagree ☹️ 1 2 3 4 5 Strongly agree 😊

**A2.1** It is important that patients have some sense of **being in control** – that they are able to make choices and decisions.

Not like my journey at all 1 2 3 4 5 Very like my journey

**A2.2** The Breast Cancer Support Group in this aspect of my journey was:

Not important for me 1 2 3 4 5 Extremely important for me

**Comments:**

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**A3** It is important that a person's **individual experience** of cancer is taken seriously (feelings, fears, sense of who one is).

Strongly disagree ☹️ 1 2 3 4 5 Strongly agree 😊

**A3.1** It is important that a person's **individual experience** of cancer is taken seriously (feelings, fears, sense of who one is).

Not like my journey at all 1 2 3 4 5 Very like my journey

**A3.2** The Breast Cancer Support Group in this aspect of my journey was:

Not important for me 1 2 3 4 5 Extremely important for me

**Comments:**

---

**A4** It is important that people experience a sense of reassurance by **being told about what they can expect** from treatments.

Strongly disagree ☹️ 1 2 3 4 5 Strongly agree 😊

**A4.1** It is important that people experience a sense of reassurance by **being told about what they can expect** from treatments.

Not like my journey at all 1 2 3 4 5 Very like my journey

**A4.2** The Breast Cancer Support Group in this aspect of my journey was:

Not important for me	1	2	3	4	5	Extremely important for me
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**Comments:**

## **B. Findings about 'Living with Cancer' indicated that:**

Many people reported that being diagnosed, and living with cancer, made them feel different from other people. The following statements represent the different aspects of 'living with cancer'.

**B1** After cancer diagnosis, people **feel more aware** of themselves, others and life in general.

Strongly disagree	☹	1	2	3	4	5	Strongly agree	☺
----------------------	---	---	---	---	---	---	-------------------	---

**B1.1** After cancer diagnosis, people **feel more aware** of themselves, others and life in general.

Not like my experience at all	1	2	3	4	5	Very like my experience
----------------------------------	---	---	---	---	---	----------------------------

**B1.2** The Breast Cancer Support Group in this aspect of my journey was:

Not important for me	1	2	3	4	5	Extremely important for me
-------------------------	---	---	---	---	---	-------------------------------

**Comments:**

---

**B2** People find that they **continue to experience changes** related to living with cancer, long after their diagnosis.

Strongly disagree	☹	1	2	3	4	5	Strongly agree	☺
----------------------	---	---	---	---	---	---	-------------------	---

**B2.1** People find that they **continue to experience changes** related to living with cancer, long after their diagnosis.

Not like my journey at all	1	2	3	4	5	Very like my journey
-------------------------------	---	---	---	---	---	-------------------------

**B2.2** The Breast Cancer Support Group in this aspect of my journey was:

Not important for me	1	2	3	4	5	Extremely important for me
-------------------------	---	---	---	---	---	-------------------------------

**Comments:**

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**B3** Just **how different from other people a cancer survivor feels** depends on the situation or group in which they find themselves.

Strongly disagree ☹️ 1 2 3 4 5 Strongly agree 😊

**B3.1** Just **how different from other people a cancer survivor feels** depends on the situation or group in which they find themselves.

Not like my experience at all 1 2 3 4 5 Very like my experience

**B3.2** The Breast Cancer Support Group in this aspect of my journey was:

Not important for me 1 2 3 4 5 Extremely important for me

**Comments:**

---

**B4** How the person with cancer feels about the diagnosis can be very different from **how other people react** to that person's diagnosis.

Strongly disagree ☹️ 1 2 3 4 5 Strongly agree 😊

**B4.1** How the person with cancer feels about the diagnosis can be very different from **how other people react** to that person's diagnosis.

Not like my experience at all 1 2 3 4 5 Very like my experience

**B4.2** The Breast Cancer Support Group in this aspect of my journey was:

Not important for me 1 2 3 4 5 Extremely important for me

**Comments:**

---

## **C. Findings about 'Quality of Life' indicated that:**

Participants reported that, after diagnosis, they had concerns about both physical and mental health; they noticed changes in their relationships with others; they were worried about losing their independence; and they re-evaluated what was important in life. Most people were determined to make the best of their lot. The following statements represent different aspects of 'quality of life'.

**C1** It takes a lot of effort to come to terms with the **physical and mental changes** after a cancer diagnosis.

Strongly disagree ☹️ 1 2 3 4 5 Strongly agree 😊

**C1.1** It takes a lot of effort to come to terms with the **physical and mental changes** after a cancer diagnosis.

Not like my experience at all	1	2	3	4	5	Very like my experience
----------------------------------	---	---	---	---	---	----------------------------

**C1.2** The Breast Cancer Support Group in this aspect of my journey was:

Not important for me	1	2	3	4	5	Extremely important for me
-------------------------	---	---	---	---	---	-------------------------------

**Comments:**

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**C2** Having **good relationships** (with family, friends, medical professionals) becomes even *more important* after a cancer diagnosis.

Strongly disagree ☹️	1	2	3	4	5	Strongly agree 😊
-------------------------	---	---	---	---	---	---------------------

**C2.1** Having **good relationships** (with family, friends, medical professionals) becomes even *more important* after a cancer diagnosis.

Not like my experience at all	1	2	3	4	5	Very like my experience
----------------------------------	---	---	---	---	---	----------------------------

**C2.2** The Breast Cancer Support Group in this aspect of my journey was:

Not important for me	1	2	3	4	5	Extremely important for me
-------------------------	---	---	---	---	---	-------------------------------

**Comments:**

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**C3** **Losing their independence** is a major concern for people diagnosed with cancer.

Strongly disagree ☹️	1	2	3	4	5	Strongly agree 😊
-------------------------	---	---	---	---	---	---------------------

**C3.1** **Losing their independence** is a major concern for people diagnosed with cancer.

Not like my experience at all	1	2	3	4	5	Very like my experience
----------------------------------	---	---	---	---	---	----------------------------

**C3.2** The Breast Cancer Support Group in this aspect of my journey was:

Not important for me	1	2	3	4	5	Extremely important for me
-------------------------	---	---	---	---	---	-------------------------------

**Comments:**

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**C4** People diagnosed with cancer **re-think their main priorities** in life.

Strongly disagree	☹️	1	2	3	4	5	Strongly agree	😊
-------------------	----	---	---	---	---	---	----------------	---

**C4.1** People diagnosed with cancer **re-think their main priorities** in life.

Not like my experience at all	1	2	3	4	5	Very like my experience
-------------------------------	---	---	---	---	---	-------------------------

**C4.2** The Breast Cancer Support Group in this aspect of my journey was:

Not important for me	1	2	3	4	5	Extremely important for me
----------------------	---	---	---	---	---	----------------------------

**Comments:**

## D. Findings about the ‘Support Group’ indicated that:

In general, women reported that they attended the support group to gain knowledge; to get and give support; and to be in a group of people who had similar experiences. They also reported that being in the group influenced their sense of self, mostly in a positive way.

**D1** Attending the support group enables women to **learn more about cancer** and how to cope with it.

Strongly disagree	☹️	1	2	3	4	5	Strongly agree	😊
-------------------	----	---	---	---	---	---	----------------	---

**D1.1** Attending the support group enables women to **learn more about cancer** and how to cope with it.

Not like my experience at all	1	2	3	4	5	Very like my experience
-------------------------------	---	---	---	---	---	-------------------------

**D1.2** The Breast Cancer Support Group in this aspect of my journey was:

Not important for me	1	2	3	4	5	Extremely important for me
----------------------	---	---	---	---	---	----------------------------

**Comments:**

---

**D2** Attending the support group enables women to **get and give support**.

Strongly disagree	☹️	1	2	3	4	5	Strongly agree	😊
-------------------	----	---	---	---	---	---	----------------	---

**D2.1** Attending the support group enables women to **get and give support**.

Not like my experience at all	1	2	3	4	5	Very like my experience
-------------------------------	---	---	---	---	---	-------------------------





**D2.2** The Breast Cancer Support Group in this aspect of my journey was:

Not important for me	1	2	3	4	5	Extremely important for me
-------------------------	---	---	---	---	---	-------------------------------

**Comments:**

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**D3** Attending the support group enables women to be with other women who have gone through **similar experiences**.

Strongly disagree		1	2	3	4	5	Strongly agree	
----------------------	---	---	---	---	---	---	-------------------	---

**D3.1** Attending the support group enables women to be with other women who have gone through **similar experiences**.

Not like my experience at all	1	2	3	4	5	Very like my experience
----------------------------------	---	---	---	---	---	----------------------------

**D3.2** The Breast Cancer Support Group in this aspect of my journey was:

Not important for me	1	2	3	4	5	Extremely important for me
-------------------------	---	---	---	---	---	-------------------------------

**Comments:**

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**D4** Group participation can have positive outcomes in terms of **personal growth**.

Strongly disagree		1	2	3	4	5	Strongly agree	
----------------------	---	---	---	---	---	---	-------------------	---

**D4.1** Group participation can have positive outcomes in terms of **personal growth**.

Not like my experience at all	1	2	3	4	5	Very like my experience
----------------------------------	---	---	---	---	---	----------------------------

**D4.2** The Breast Cancer Support Group in this aspect of my journey was:

Not important for me	1	2	3	4	5	Extremely important for me
-------------------------	---	---	---	---	---	-------------------------------

**Comments:**

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**E** Have we **missed anything** important about your own experience, or about the Illawarra Breast Cancer Support Group, that will help us to better understand the role of the Support Group in the journeys of survivors?

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Thank you for completing the Questionnaire

## APPENDIX 3: Focus Group Process Steps

### Illawarra Breast Cancer Support Group

### Survey Workshop - Wollongong Group

Date: Tuesday 28 March, 2006

Time: 7.30 pm to 8.45 pm

Venue: Congregational Church Hall, Market Street, Wollongong

Workshop Facilitators: Sue Curtis, Beth Marlow & Nadia Crittenden

#### Workshop Activities

Schedule	Item	Outcomes	Resources/Arrangements
7.30	Distribute copies of Survey, pen and Jumbo CCS Card to each participant's chair Have 2x A4 pages on clipboards plus pens for 7 scribes (assuming 50 people) Have Flipcharts set up out the front with whiteboard markers Identify women who would be prepared to act as scribes for a group of five – invite them to take on this role (purple ribbon role)	<ul style="list-style-type: none"> <li>Resources ready for first two activities</li> </ul>	Flip chart holder/chart set up Surveys CCS Jumbo Card Pack – card on each seat Post-it pad sheets (3 per person) A4 Pages + Pens
7.45	<ul style="list-style-type: none"> <li>Introductions – Sue, Beth &amp; Nadia</li> <li>Sue - Overview of the activities</li> </ul> Intro as per Cover sheet on Survey – <b>walk through cover sheet</b> <ul style="list-style-type: none"> <li>A creative look back at type of support provided by IBCSG (Jumbo Pack cards) – Hand out purple ribbons for scribes</li> <li>Looking back over our needs and the role of the IBCSG using the Survey with four groups doing one section each during the session</li> <li>What people are doing when the Group is working well for members– action words that really mean something</li> <li>Group will be given feedback as we collate information into a coherent framework</li> </ul>	<ul style="list-style-type: none"> <li>Establishing expectations and overview of range of activities to be covered by Group</li> </ul>	
8.00	<ul style="list-style-type: none"> <li>A creative look back at type of support provided by IBCSG (Jumbo Pack cards) – Ask scribes to go first so everyone will know what to do - DEMO</li> <li>Ask the seven (7) scribes to use the card on their seat to briefly identify some small way in which the Support Group has supported them in their personal journey</li> <li>Facilitator record on flipchart – then groups of seven with facilitators</li> <li>Scribes record – read back and check with group members</li> <li>Stay in groups of seven and now look to the front for next activity</li> </ul>	<ul style="list-style-type: none"> <li>A varied range of descriptors of support that go beyond the immediately obvious</li> <li>List of descriptors on Flip chart</li> </ul>	<ul style="list-style-type: none"> <li>Flip Chart – record of what is said by participants</li> <li>Purple ribbons</li> <li>Clipboards loaded for scribes</li> <li>Form into groups of five – including scribe</li> </ul>
8.10	Intro - Beth [3mins] <ul style="list-style-type: none"> <li>Survey looking at relevance of past group research to understanding what the group does</li> <li><b>Model of task – DEMOGRAPHIC details first</b></li> </ul>	<ul style="list-style-type: none"> <li>Completed Survey section for each Group</li> <li>List of</li> </ul>	<ul style="list-style-type: none"> <li>Group Labels – A,B,C,D</li> <li>A4 sheet for each Group + pens</li> <li>Survey for each person</li> </ul>

	<ul style="list-style-type: none"> <li>• <b>Questions come in 3 parts – example A – read out instructions then intro – DISCUSS – fill in – support one another if needed (especially with demographic details)</b></li> <li>• <b>Note importance of ‘Comments’</b></li> </ul>	comments made by Group members in discussion re particular category of questions	
8.20	<ul style="list-style-type: none"> <li>• 10 mins to read your section, discuss with each other, then complete your section individually</li> <li>• Scribe hands out individual copies of the Survey and gets ready to support the group</li> <li>• All to do Part A of the Survey then IF you have time – go on to Part B</li> </ul>	<ul style="list-style-type: none"> <li>• Completed Section of Survey per Group</li> <li>• A4 page of Comments scribed during discussion for each Group</li> </ul>	<ul style="list-style-type: none"> <li>• Spare A4 sheets, pens</li> </ul>
8.30	<ul style="list-style-type: none"> <li>• Feedback by respective Group spokespersons re any concerns and comments made for respective categories of questions</li> <li>• Participants are provided with stamped/addressed envelopes by scribe - to take to return Surveys when they have completed all four sections.</li> </ul>	<ul style="list-style-type: none"> <li>• Flip chart recording of presentations</li> </ul>	<ul style="list-style-type: none"> <li>• Flip chart &amp; Pens</li> </ul>
8.40	<ul style="list-style-type: none"> <li>• Ask participants to think of a special time when the Group REALLY was a great support to them.</li> <li>• Beth &amp; Sue to model – identifying 3 key verbs (these words will help to guide and focus the evaluation)</li> <li>• Participants asked to work in Groups of seven again to identify 3 key verbs – one person to act as scribe</li> </ul>	<ul style="list-style-type: none"> <li>• Key drivers for effective action in the IBCSG model</li> </ul>	<ul style="list-style-type: none"> <li>• A4 sheets + pens per Group of three</li> <li>• Flip chart for recording words</li> </ul>
8.45	Thanks & closure – with identification of partners who will support each other in completing the Survey and posting it by early next week.	Commitment to complete Survey and post	

## APPENDIX 4: Dragon Boat Focus Group for New Logo

### THE SPIRIT of our DRAGONS ABREAST

**Cyclists:**

Fitness for my own wellbeing – getting fit and healthy if breast cancer comes back

**Kid's painting:**

Friendship and fun, Laughter – happiness, not worrying about other things – friendship

**Globe:**

Lot of travelling – different parts of the world – different people, friendship

**Cyclists:**

Ongoing fitness, health, wellbeing!

**Handshake:**

Partnership – experience similar things, travelling the same path

**Trust:**

Trust – can be about anything

**Handshake:**

Trust – Dragons Abreast is like a support group within a group – a closeness among paddlers – one step more – partnership, friendship

**Kid's painting:**

Fun card – fitness, great fun

**Tulips:**

Means flowers on the water to me – connection, inspiration, all together standing really strong, strength from numbers – memory of ones you lose, the Dragon boaters – always part of the whole deal!

**Pond:**

The water, peace, tranquility – flowers on the water – exercise – all that we do on the water

**Trust:**

I can talk to the Dragon Boaters much more deeply(?) than ?????? friends – trust – what is said in the group stays in the group

**Help:**

Helping others – helps me too – works both ways – because a small group works very well – also my way of helping – bringing new ones in and helping myself by exercising, helps self esteem/confidence

**Bush track:**

Peaceful – gives me ??? – can walk many steps going forward – very comfortable out with nature – with others – not alone

**Pond:**

Reflections of water – ideal place to be

**Sunrise/sunset:**

Sunrise/sunset – I'm there to see it. I'm alive, there to see it – Water most relaxing, peaceful – To be there with water – Even when rough you admire it. Water always there, strength from water – feel it

**Pond:**

Learnt to paint – every venue reminds me – peace and beauty – Never did painting – but now do it my own way. Water – an element

**Fruit:**

Sustaining – veggies – more competitive/competition(?) – health

**Bush track:**

Bush land landscape – peace, support. Often have to drive down these to get to venue – company, safe to confide

## **DRAGON BOATING**

We would like to give you an insight into what Dragon Boating is all about.

Our Motto is **“Friendship, Fun and Fitness”**

We had 31 members last year and this year so far we have 35, we are always willing to welcome new members.

Dragon Boat group has come together because of our interest in a water based sport and the fun we get from paddling.

We find FRIENDSHIP, SUPPORT, CARE & KINDNESS all of which we give to others and receive in abundance in return.  
HELPFULLNESS, by helping others and passing on the message there is life after a breast cancer diagnosis it raises our self esteem/confidence and we ourselves are being helped.  
INSPIRATION, we inspire ourselves to achieve and in doing so inspire others.

We have forged bonds with other DA groups and have made long standing friendships with ladies from all over Australia. We have formed a partnership together, we are all travelling the same path just as we are all in the same boat as a crew paddling as one.

We find FUN  
LOTS OF HAPPINESS & LAUGHTER  
ENCOURAGEMENT

When in the boat all our worries connected to breast cancer disappear. We don't worry about what treatment we have received or may have to receive in the future. We may board the boat thinking we have aches and pains, feeling tired or generally unwell all these feelings soon evaporate.

We find FITNESS – Level of fitness and health has improved.  
Our own WELLBEING has improved.  
We find a SENSE OF PEACE and TRANQUILITY on the lake at 8am Sunday morning, sun rising into the sky and the mountain range in the background.

- Over half of our members are involved on a non competitive social and fitness side. The ladies are happy to come along on a Sunday morning and or Wednesday evening to paddle, talk or to go for a walk.
- On average for most regattas we have approximately 12 ladies who like to enter and compete. We normally combine with other DA groups to get a boat on the water.
- We like to forge bonds with our sister DA groups. We visit Canberra a couple of times a year to either train, compete and we always socialize. Last July we travelled to Merimbula/Eden to both train and socialize.
- We have maybe 6 or 7 ladies who have at times ventured further afield, 5 to NZ in 2002, 5 to Vancouver in 2005 and 4 to Singapore in 2006. We sometimes appear at Australian and other Masters Games in Canberra, Adelaide, Gold Coast and Newcastle etc. On these occasions we always paddle in a combined team with ladies from all over Australia.

### **My Story with Dragon Boating**

I joined the Dragon Boat group when it began in 2002. I have found an opportunity to rekindle my love of travel and to compete in regattas normally in and around Sydney, north to the Central Coast and south to Ulladulla. I have visited Adelaide, Canberra, Newcastle, Gold Coast, and Nagambie in Victoria to compete in Masters Games, State and National titles. I ventured further afield to New Zealand in 2002, Vancouver in 2005 and to Singapore in 2006. More often than not for the Sydney regattas we combine with another DA team but when we travel away we combine with DA ladies from all over Australia.

## APPENDIX 5: Keywords to Describe What ‘Support’ Means to Members of IBCSG

<i>Core Group Values which span all Action Categories</i>			
<b>hoping</b> <b>loving</b> <b>accepting</b>			
<b>a.</b>	<b>Organising</b> (principles)	<b>Including</b> (core activities)	<b>Building</b>
‘Us’. What the group does.	listening knowing talking understanding communicating teaching inspiring	working together interacting travelling bussing being there for each other supporting meeting greeting joining helping	aiming absorbing contacting mimicking trusting counselling just being building
<b>b.</b>	<b>Identifying</b>	<b>Nurturing</b>	<b>Empowering</b>
‘Me’. What the individual gains.	thinking needing changing questioning journeying advising learning choosing decision-making reflecting rethinking identifying relaxing	alleviating exciting sympathising comforting healing receiving crying developing caring reassuring being there hugging	exercising fulfilling living awakening conquering gaining confidence self-improving transforming doing growing flowering meditating
<b>c.</b>	<b>Recognising</b>	<b>Celebrating</b>	<b>Sharing Strengths</b>
‘We’ Maintain & Sustain our Group	comparing appreciating approaching feeling positive cruising coping thanking	laughing entertaining tickling dancing singing enjoying teasing	sharing encouraging joking paddling

## APPENDIX 6: AdCare Retreat Workshop

**Facilitators:** Sue Curtis & Beth Marlow

**Dates:** Tuesday 4<sup>th</sup> April to Thursday 6<sup>th</sup> April

**Time:** 1.30pm – 3.00pm (if not a little earlier)

**Number of participants:** 10 per workshop (3 groups per session)

### Resources:

3 flip chart pads

Categories of Activity on 3 large flip chart sheets

Pins to pin up sheets in tent

Whiteboard markers

Clipboards for each participant

Pens for each participant

Packet of A4 paper

CCS Card pack for each person

CCS Jumbo Card pack

GAS (x2) for each of the three groups

Plain paper A4 sheets for 3 scribes

### Workshop Process Steps

1. Intro Workshop – thankyou for attending - overview of process steps – confidentiality guarantee (Sue)
2. Intro to activities as per sheet & demographics (Beth)
3. Intro to ‘What we do in the IBCSG’ on flip charts and the activity to follow (Sue)
4. Demo of CCS card to that represents the first Action Category in each group - + explanation (Sue & Beth) – then demo of weighting for Importance and Confidence.
5. Select scribes
6. Allocation of sections to groups – have a go with first statement in section allocated. Ask scribe to record as much as possible what people are saying re the cards they chose. Check in with each person by reading back what has been recorded – Anything else????
7. Review process – any questions, difficulties, support required.
8. Groups go on to next statement – complete weighting – stop to review process again and check in with participants.
9. Participants complete final statement
10. Keywords activity with whole group – Sue to tell story of Lawyer & suit of armour.
  - a. Could you think of the words someone might use to describe their experience of living with breast cancer if they were not able to be a member of a group and wanted to be?
  - b. If someone chose to and was able to be a member of a breast cancer support group in their personal journey, what words might they use to describe the experience of that journey?
11. Goal Attainment Scales for Support Groups and Retreat. Introduce concept of how we might expect things to be going if they were working well for us (Sue) – walk through the Goal Attainment Scale format – the purposes that could be served
12. Round circle closure and thanks for participating

### Sample of AdCare Worksheets

*Building on our knowledge of the Support Group: Checking our Findings so far*

1. Demographic Details
2. With the following statements, please circle the number that best represents your personal perspective and experiences and add any comments that might help us to better understand your selection of weightings
3. The AdCare Retreat Worksheet Sample

## APPENDIX 6 Cont.: AdCare Retreat Workshop

### Organising, Including and Building as a Group: This is ‘Us’ - What the Group Does

<b>Organising:</b> The Illawarra Breast Cancer Support group has a distinctive way of organising based <b>on communicating for understanding through knowing, inspiring, listening and teaching.</b>	<p>How <b>important</b> is this statement to you?</p> <p>1 2 3 4 5 6 7 8 9 10 (not very) (very)</p> <p>Comment:</p>	<p>How <b>confident</b> are you that you could achieve this in your Group?</p> <p>1 2 3 4 5 6 7 8 9 10 (not very) (very)</p> <p>Comment:</p>
<b>Including:</b> Participatory membership of the Illawarra Breast Cancer Support Group is based around the <b>core activities of simply being there for each other and interacting and working together.</b>	<p>How <b>important</b> is this statement to you?</p> <p>1 2 3 4 5 6 7 8 9 10 (not very) (very)</p> <p>Comment:</p>	<p>How <b>confident</b> are you that you could achieve this in your Group?</p> <p>1 2 3 4 5 6 7 8 9 10 (not very) (very)</p> <p>Comment:</p>
<b>Building:</b> The Illawarra Breast Cancer Support Group continually builds and sustains itself by <b>providing an environment of trust where members experience a flexible approach that models different ways of ‘being’ within the Group</b>	<p>How <b>important</b> is this statement to you?</p> <p>1 2 3 4 5 6 7 8 9 10 (not very) (very)</p> <p>Comment:</p>	<p>How <b>confident</b> are you that you could achieve this in your Group?</p> <p>1 2 3 4 5 6 7 8 9 10 (not very) (very)</p> <p>Comment:</p>



## APPENDIX 7: Goal Attainment Scales – GAS #1-5

**IBCSG Participants DRAFT GOAL ATTAINMENT SCALE #2: What we (small focus group of IBCSG membership) think will be happening if we are going . . . . .**

RATING	INDICATORS
<b>+2</b> <b>MUCH</b> <b>BETTER</b> <b>THAN</b> <b>EXPECTED</b>	<ul style="list-style-type: none"> <li>○ Self-sustaining Group not entirely reliant on a single leadership role</li> <li>○ On-going and solid connections with related groups – sharing, networking, outreach</li> <li>○ Liveliness and adaptability</li> <li>○ Group members have access to really good communication pathways with medical professionals i.e. with acceptance of advocacy (i.e. for self &amp; others) as a normal way of interacting with health professionals for mutually beneficial outcomes</li> </ul>
<b>+1</b> <b>BETTER</b> <b>THAN</b> <b>EXPECTED</b>	<ul style="list-style-type: none"> <li>○ Good variety and relevance of presentations</li> <li>○ Greater sharing of roles and responsibilities</li> <li>○ Less criticism from Health Professionals</li> <li>○ Better connections between medical professionals and the Group</li> <li>○ Healthy questioning and critical reflection</li> </ul>
<b>0</b> <b>EXPECTED</b> <b>OUTCOMES</b>	<ul style="list-style-type: none"> <li>○ Getting good information</li> <li>○ Lots of friendships</li> <li>○ Acceptance</li> <li>○ Well-organised</li> <li>○ Concern about outreach</li> <li>○ Lots of warmth and encouragement for new members</li> <li>○ Lots of laughter</li> <li>○ Whole lot of other options for involvement – flexibility</li> <li>○</li> </ul>
<b>-1</b> <b>WORSE</b> <b>THAN</b> <b>EXPECTED</b>	<ul style="list-style-type: none"> <li>○ Boring meetings</li> <li>○ Rumblings of resentment</li> <li>○ Burned out Committee members/key roles</li> <li>○ Criticisms from outsiders</li> <li>○ New members looking stressed and not returning</li> <li>○ Loss of services/funding considered by Group to be primary infrastructure</li> </ul>
<b>-2</b> <b>MUCH</b> <b>WORSE</b> <b>THAN</b> <b>EXPECTED</b>	<ul style="list-style-type: none"> <li>○ Fractures in the Group that can't be repaired</li> <li>○ Hi-jacking to other personal agendas</li> <li>○ Using people up</li> <li>○ Rigidity/inability to adapt</li> <li>○ Negativity</li> </ul>

**IBCSG Participants DRAFT GOAL ATTAINMENT SCALE #3 - AdCare Retreat  
focus Group with Advocacy orientation: What I think will be happening if we are  
going .....**

RATING	INDICATORS
<b>+2</b> <b>MUCH BETTER THAN EXPECTED</b>	<ul style="list-style-type: none"> <li>○ Celebrating success</li> <li>○ Government funding</li> <li>○ Doctors eagerly refer people</li> <li>○ Medicines on the free list due to advocacy</li> <li>○ Powerful force where medical profession sits up and listens</li> <li>○ Specialists turning to us for support</li> </ul>
<b>+1</b> <b>BETTER THAN EXPECTED</b>	<ul style="list-style-type: none"> <li>○ Have to get a bigger space – with people encouraging others to come</li> <li>○ Need a microphone</li> <li>○ Abundance of ideas for new activities</li> <li>○ People not wanting to go home</li> <li>○ People looking forward to next [. . .]</li> <li>○ Having our own hall</li> </ul>
<b>0</b> <b>EXPECTED OUTCOMES</b>	<ul style="list-style-type: none"> <li>○ Keen listening to speakers</li> <li>○ Everyone getting on – laughter</li> <li>○ Lots of interaction and sharing</li> <li>○ Having fun discussing things in common</li> <li>○ Different types of meetings – ever-changing according to needs of group</li> <li>○ Meeting in a safe space with acceptance and reassurance</li> </ul>
<b>-1</b> <b>WORSE THAN EXPECTED</b>	<ul style="list-style-type: none"> <li>○ Drop off in numbers – attendance</li> <li>○ Long periods of silence</li> <li>○ Tension – less joy and laughter</li> <li>○ People walking out of meetings</li> <li>○ People not wanting to participate</li> <li>○ Grumblings</li> </ul>
<b>-2</b> <b>MUCH WORSE THAN EXPECTED</b>	<ul style="list-style-type: none"> <li>○ Power struggles</li> <li>○ Only the executive turns up to meetings</li> <li>○ Meetings are run very rapidly</li> <li>○ Group not listening to members needs</li> <li>○ Boring meetings</li> </ul>

**IBCSG Participants DRAFT GOAL ATTAINMENT SCALE #4 - for AdCare  
Retreat focus group with a ‘smaller groups’ orientation: What I think will be  
happening if we are going .....**

RATING	INDICATOR
<b>+2</b> <b>MUCH BETTER THAN EXPECTED</b>	<ul style="list-style-type: none"> <li>○ Too many people (need for smaller groups)</li> <li>○ Relationships continue outside the Group</li> <li>○ Gloria can have a good night’s sleep</li> <li>○ Good Press – the Group is well known – the norm in our society</li> <li>○ People referred to the Group by professionals</li> </ul>
<b>+1</b> <b>BETTER THAN EXPECTED</b>	<ul style="list-style-type: none"> <li>○ Increasing number for and demand for smaller groups</li> <li>○ More personal and intimate groups</li> <li>○ Too many people for one group – everyone wants to come</li> <li>○ Good communication between group</li> <li>○ Very enjoyable – people want to repeat the experience</li> </ul>
<b>0</b> <b>EXPECTED OUTCOMES</b>	<ul style="list-style-type: none"> <li>○ Right leadership - someone to follow in organised way but without dictating – a background organiser</li> <li>○ Compatibility of people for smaller groups</li> <li>○ Group allows for individual circumstances</li> <li>○ Have to be open to change – different ways of doing things</li> <li>○ A mix between well and sick people</li> </ul>
<b>-1</b> <b>WORSE THAN EXPECTED</b>	<ul style="list-style-type: none"> <li>○ People become isolated</li> <li>○ Sites of conflict</li> <li>○ People fragment into smaller groups</li> <li>○ Unhappy people – backbiting – jealousy</li> <li>○ Power struggles</li> </ul>
<b>-2</b> <b>MUCH WORSE THAN EXPECTED</b>	<ul style="list-style-type: none"> <li>○ People not interested</li> <li>○ Boring meetings</li> <li>○ Bad press</li> </ul>

**IBCSG Participants DRAFT GOAL ATTAINMENT SCALE #5 - for AdCare  
Retreat focus group with a ‘new group starting up’ orientation: What I think will be  
happening if we are going .....**

RATING	INDICATORS
<b>+2</b> <b>MUCH BETTER THAN EXPECTED</b>	<ul style="list-style-type: none"> <li>○ Community facilities/ groups, recognising/catering for breast cancer Groups</li> <li>○ Increased community awareness</li> <li>○ Children seeking support – information to help [ . . . ]</li> <li>○ Willingness to get out and give information to others (i.e. Temora)</li> <li>○ Ongoing retreats such as Stanwell Tops</li> </ul>
<b>+1</b> <b>BETTER THAN EXPECTED</b>	<ul style="list-style-type: none"> <li>○ Strong leader delegating – shared leadership load</li> <li>○ Friendships coming out of meetings</li> <li>○ Respect for every body – respect for people’s space</li> <li>○ Individual needs being met</li> <li>○ Laughter, happy environment – with kindness</li> <li>○ Small new groups – stay small and develop as needed</li> <li>○ Sub-committees help with workload</li> </ul>
<b>0</b> <b>EXPECTED OUTCOMES</b>	<ul style="list-style-type: none"> <li>○ Very strong leader who knows what they are doing</li> <li>○ Plans for when group gets too large – how to move to smaller groups – ages, stages, interests</li> <li>○ Nucleus of support people for leader</li> <li>○ Understanding of shyness and the extra time needed to fit in</li> <li>○ People have to be able to have a say – not afraid to talk – the Group is open and welcoming to suggestions</li> </ul>
<b>-1</b> <b>WORSE THAN EXPECTED</b>	<ul style="list-style-type: none"> <li>○ Too overpowering an environment</li> <li>○ People react with ‘Don’t want to know!’</li> <li>○ No strong leader – start too big</li> <li>○ Set goals too high at start-up</li> <li>○ People don’t know who to contact or where to go</li> </ul>
<b>-2</b> <b>MUCH WORSE THAN EXPECTED</b>	<ul style="list-style-type: none"> <li>○ Small mindedness</li> <li>○ Lack of cooperation</li> <li>○ Lack of support from outside (health professionals)</li> <li>○ People not able to get information/resources</li> <li>○ Negativity from the medical profession – just ‘Go home and get on with it!’</li> </ul>

## APPENDIX 8: Reorienting the ‘Centre’ in Patient-centred Care

### Implications of Previous Research for Rethinking Practitioner-Patient relationships in Cancer Care: Dr Beth Marlow

#### Re-orienting the “centre” in “patient centred care”

(This is something I would like to promote as policy change in “patient centred care”)

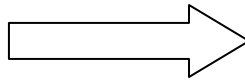
“Patient centred care” is a fundamental tenet of current cancer policy. From the patient’s perspective, however, there is still a difficulty in interpreting what this means in practice.

1. The health professional’s view, based in the medical model, tends to pathologise the patient along with the condition, as follows:

#### Medical professional

**“I” (the agent)**

‘I am the one taking responsibility’



#### Patient

**“You” (the other)**

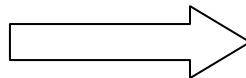
‘You are the one receiving the treatment’

2. The perspective from the patient’s point of view is reversed. This too needs to be reflected in policy and practice. The patient perspective is:

#### Patient

**“I” (the agent)**

‘I am the one living with cancer’



#### Medical professional

**“You” (the other)**

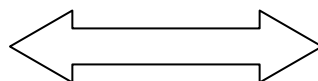
‘You are the one helping me manage the disease’

3. We are not expecting the medical profession to *replace* their perspective with the patient’s perspective, but it would help enormously if it were incorporated into the consultation and treatment process. It would provide the basis for a genuine conversation and do much to enhance “patient centred care”, as in the following:

#### Patient

**“I” (the agent)**

‘I can call on my life experience, my skills, my family and friends, my community’



#### Medical professional

**“I” (the agent)**

‘I can call on my own expertise and the support of a multidisciplinary team’

N.B. I am not proposing this as an “equal” relationship; I think that would be an over-simplification. Obviously medical practitioners have greater knowledge and skill (thank goodness) when it comes to treatments. But when the patient’s own capabilities and other non-medical resources are taken into consideration as well, there is more everyone can call on to assist the treatment, recovery and survival process.