NATIONAL SURVIVORSHIP THINK TANK

SUMMARY REPORT
April 2009

Prepared on behalf of BCNA by
Alison Evans Consulting

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National Breast Cancer Foundation
EXECUTIVE SUMMARY

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians personally affected by breast cancer. BCNA has identified survivorship issues for women with breast cancer as a priority area. The organisation is ideally placed to inform and contribute to research in this area through its extensive national membership.

In 2009, BCNA led a national Survivorship Think Tank to map current breast cancer survivorship research activity, identify gaps and explore opportunities for BCNA’s involvement in this important area. The Think Tank was funded by the National Breast Cancer Foundation (NBCF). Participants included national leaders in survivorship research, breast cancer clinicians, BCNA staff and Board members, representatives from NBCF and National Breast and Ovarian Cancer Centre (NBOCC) and consumer representatives. Outcomes from the Think Tank will be used to inform the ‘Survivorship’ chapter of the NBCF National Action Plan for Breast Cancer Research and Funding.

Invited speakers provided an overview of international and national cancer survivorship research activity. The roles of NBCF and NBOCC in funding research and translating research outcomes into evidence-based information for patients and health professionals were also described.

Mapping activity prior to and during the Think Tank identified a range of current research activities in cancer survivorship in Australia. Participants then developed a ‘survivorship research matrix’ outlining overarching themes, common aspects of survivorship research activity, key topic areas and factors to be considered in implementation.

Figure: Cancer survivorship research matrix

This matrix was used as a framework for small group discussion about gaps and issues in breast cancer survivorship research in the four key topic areas. Given the broad range of issues and gaps identified and the range of expert views, it was not possible to prioritise one area of research. Priority gaps and issues discussed and identified are outlined below.

- **Physical issues**: priority gaps included research into exercise and breast cancer survival, fatigue, lymphoedema, cognitive function and weight loss/gain.

- **Psychosocial issues (including psychological and socio-cultural issues)**: gaps included appropriate measures of distress for patients and carers, interventions to manage fear of recurrence, approaches to encourage uptake of communication skills guidelines\(^2\) and training, impact on relationships, economic/social-cultural impacts and research relating to vulnerability and resilience.

- **Recurrence (including fear of recurrence and clinical aspects)**: priority gaps included the need for data on recurrence, better tests for metastatic disease, interventions to prevent recurrence, and approaches for managing fear of recurrence.

- **Models of care (including prevention, surveillance and management aspects of follow-up care)**: much of this research is currently in the early stages with a range of issues identified including the importance of assessing the economic costs and benefits associated with models of care, as well as identifying flexible models based on coordinated/integrated approaches to care.

Overarching themes that also emerged during the discussions included the importance of:

- applying current knowledge and exploring barriers to uptake of existing best practice
- building economic analyses into research studies as a strategy to drive future implementation
- utilising a health promotion/wellness model that supports consumer empowerment
- considering the needs of families and caregivers as well as patient needs
- considering the needs of underserved groups.

The Think Tank clearly demonstrated that breast cancer survivorship is a priority area for research in Australia. There was a strong commitment from national leaders in the field to survivorship research and an acknowledgement of the importance of collaborative approaches, including the potential for international collaboration.

BCNA identified a number of priority actions to be undertaken following the Think Tank to utilise the information provided and continue momentum in this area:

- outcomes will be used to inform BCNA’s contribution to the Survivorship chapter of NBCF’s *National Action Plan for Breast Cancer Research and Funding*
- priority areas and headings will be used to guide a BCNA research project exploring women’s survivorship research priorities through a survey of the membership
- BCNA will undertake a project to identify the representativeness of its membership database
- options for communicating with women about survivorship research activity and outcomes will be explored (for example, a regular column in The Beacon)
- consideration will be given to hosting an annual Survivorship Think Tank to support information sharing and priority setting
- outcomes from the Think Tank will be taken to the BCNA Board for further discussion.

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BACKGROUND

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians personally affected by breast cancer. With a membership of over 33,000 individuals across the country and over 200 member groups, BCNA activities focus primarily on advocacy, information provision and support for women with breast cancer.

BCNA has identified survivorship issues following diagnosis and treatment for breast cancer as a priority area. The organisation is ideally placed to inform research priorities in this area based on identified member needs and to contribute to survivorship research initiatives through its broad national membership. BCNA’s interest in such research is to drive improvements in outcomes and quality of life for people affected by breast cancer.

Opportunities for collaboration and information sharing regarding breast cancer survivorship research have been sought previously. In 2007, a Survivorship Workshop was initiated by a consortium of researchers, facilitated by the Psycho-oncology Cooperative Research Group (PoCoG) and funded by the National Breast Cancer Foundation (NBCF) as part of the National Collaborative Breast Cancer Research Grant Program. The aim of the workshop was to ‘...develop collaborative multidisciplinary research endeavours to improve outcomes for women with breast cancer.’ The workshop brought together key researchers, clinicians and consumers to share information on current research projects and to identify new areas of work. Although the major grant application to the NBCF based on the outcomes of the workshop was not successful, a number of the research priorities identified have since been implemented.

BCNA’s national Survivorship Think Tank held in March 2009 involved national leaders in survivorship research and information. The outcomes from the Think Tank will be used by BCNA to, among other things, inform the ‘Survivorship’ chapter of the NBCF National Action Plan for Breast Cancer Research and Funding, to be released in late 2009. This report provides a summary of the Think Tank outcomes.

BCNA AND RESEARCH

Involvement in research is relatively new territory for BCNA; however its broad national membership represents a valuable resource to be used in a research setting. Strategies for BCNA’s involvement in research are outlined below. Examples of each of these strategies have already been implemented with a considerable degree of success.

- **Review and Survey Group**: a group of over 760 women accessible via email with an identified interest in responding to research questions and surveys.
- **Seat at the Table advocates**: trained consumer representatives who can provide input as advisory group members for research projects from the project outset.
- **Collaborative research projects**: externally led projects undertaken with researchers, typically governed by a memorandum of understanding with joint intellectual property.
- **BCNA research projects**: internally led projects driven by BCNA and outsourced as required.

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NATIONAL SURVIVORSHIP THINK TANK

The national Survivorship Think Tank was held on 20 March 2009 in Melbourne with a view to mapping current cancer survivorship research activity, identifying gaps and exploring opportunities for BCNA’s involvement in this important area of research. The Think Tank was funded by the NBCF.

The specific objectives of the Survivorship Think Tank were to:

- exchange information on national and international survivorship research efforts
- identify and endeavour to map current research and information activity on cancer survivorship within Australia
- seek opportunities for collaboration
- offer advice on the optimal use of BCNA’s database for research on survivorship
- inform BCNA’s contribution to the survivorship section of the NBCF’s National Action Plan for Breast Cancer Research and Funding to be released in late 2009.

The Think Tank aimed to build on outcomes from the 2007 NBCF workshop, providing a forum for discussion of ongoing and future collaborative research strategies.

The Think Tank agenda included a mix of presentations, small group work and plenary discussion (see Appendix I).

DEFINITION OF SURVIVORSHIP

In planning and conducting the Think Tank, BCNA recognised that a broad range of definitions of ‘survivorship’ are currently in use. The working definition of survivorship research used during the Think Tank was: ‘Research that focuses on all aspects of a woman’s (or man’s) life that may be affected by a diagnosis and treatment for breast cancer. This includes the health care system and services that provide support and care to women (and men) with breast cancer’.

THINK TANK PARTICIPANTS

The Think Tank was attended by 25 participants, including national leaders in survivorship research, breast cancer clinicians, BCNA staff, Board members, representatives from NBCF and National Breast and Ovarian Cancer Centre (NBOCC) and consumer representatives. Areas of expertise included:

- clinical psychology
- psychiatry
- medical oncology
- general practice
- nursing
- behavioural science
- translational research
- health sociology.

A list of participants and their survivorship research interests is provided in Appendix II. Further information about the research activities of participants is provided in the Think Tank Background paper.4

CURRENT STATUS OF SURVIVORSHIP RESEARCH

INTERNATIONAL SURVIVORSHIP RESEARCH ACTIVITY

Professor Afaf Girgis, Director, CHeRP (Cancer Council NSW, University of Newcastle & Hunter Medical Research Institute); Chair, HMRI Health Behaviour Research Program; Executive, Psycho-Oncology Cooperative Research Group (PoCoG)

Professor Girgis presented a brief overview of international survivorship research activity and identified a number of international sources of information including:

- Cancer Survivorship Research initiatives coordinated by the National Cancer Institute in the US [http://dccps.nci.nih.gov/ocs/](http://dccps.nci.nih.gov/ocs/)
- National Cancer Survivorship Invitational Workshop organised by the Canadian Partnership Against Cancer [http://www.partnershipagainstcancer.ca/invitational](http://www.partnershipagainstcancer.ca/invitational).

Professor Girgis described the approach taken by the Canadian Partnership Against Cancer to determine priorities in survivorship research. An invitational workshop held in March 2008 involved 84 participants, around one-third of whom were cancer survivors. The workshop identified 7 priorities for a Canadian survivorship research agenda.\(^5\)

- standards & guidelines
- care plans
- models of care
- communication
- advocacy
- knowledge translation
- research.

A second workshop held in November 2008 focused on the research agenda and included attendees from community treatment agencies, community-based organisations, academic institutions, policy-oriented organisations and cancer survivors. Importantly, funders were invited to be involved in the planning process.

An iterative process was used to prioritise unanswered questions in survivorship research identified by the participants. In total, 30 priorities were agreed from an initial pool of 250 questions identified by participants as unanswered at this stage; strategies to address each of the priority areas were then developed.

The top 5 priorities identified for cancer survivorship research were:

- measurement and development of relevant and appropriate tools for use in survivorship research (seen as underpinning all the other research priorities)
- effective care models across a range of issues
- effective interventions across a range of issues
- mechanisms underlying long-term effects of cancer diagnosis and treatment (including behavioural, psychological and physical effects)

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• needs and characteristics of unique populations.

A key outcome of the workshop was identification of the need for a coordinated program of research that incorporates translational aspects to ensure that best practice is implemented in the long term.

In the plenary discussion that followed Professor Girgis’ presentation, participants discussed the challenge of implementing best practice, using as an example the issue of implementing models of community-based and nurse- or GP-led follow-up care. Participants recognised the importance of minimum guidelines or standards to ensure that the same standard of follow-up care is achieved regardless of where care is managed. It was highlighted that the priority should be to define expected outcomes rather than focusing exclusively on process issues.

**NATIONAL SURVIVORSHIP RESEARCH ACTIVITY**

Professor Phyllis Butow, Co-Director and NHMRC Principle Research Fellow, Centre for Medical Psychology and Evidence-based Decision-making (CeMPED), University of Sydney; Chair, Psycho-Oncology Co-operative Research Group (PoCoG)

Professor Butow presented a summary of current areas of cancer survivorship research activity in Australia. Plenary discussion following the presentation and feedback from participants after the workshop identified additional research areas, which have also been included in the table below.

**Table 1. Current activity in survivorship research in Australia: an overview**

<table>
<thead>
<tr>
<th>Research area</th>
<th>Research topics</th>
<th>Researchers</th>
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</table>
| Meaning of survivorship        | • Qualitative research identifying concepts of liminality*, hope and awareness of death  
                                | • Workshops for survivors to increase meaning and adjustment (not yet evaluated)   | • Emma Sayers and Miles Little (NSW)  
                                |                                                                | • Cancer Council NSW                                              |
| Unmet needs for survivors and carers | Measures:                                                                 |                                                            |
|                                | • Survivor and carer measures developed and evaluated in NSW  
                                | • Other measures developed internationally                           | • Katherine Hodgkinson, Phyllis Butow, Afaf Girgis, Rob Sanson-Fisher (NSW) |
| Research into unmet needs:     | • large heterogeneous study in NSW (clinic-based recruitment)  
                                | • several large registry-based studies in NSW (longitudinal study into 8 most incident cancers as well as partners and caregivers study), Queensland (colorectal cancer and gynaecological cancer) and WA (breast cancer) | • Katherine Hodgkinson (NSW)  
                                |                                                                | • Afaf Girgis and Allison Boyes (NSW)                           |
|                                |                                                                                   | • Anna Hawkes and Vanessa Beesley (QLD)                       |
|                                |                                                                                   | • Helen Milne (WA)                                            |

*Liminality is a term used to describe the changed state in which many cancer survivors live after their period of illness.*

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<table>
<thead>
<tr>
<th>Research area</th>
<th>Research topics</th>
<th>Researchers</th>
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<tbody>
<tr>
<td>Fear of recurrence</td>
<td>• NSW research focusing on:</td>
<td>• Belinda Thewes (NSW) collaborating with Scottish and Danish researchers</td>
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<td></td>
<td>o measurement</td>
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<td>o cause and predictors</td>
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<td>o optimal management</td>
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<td>Long-term side effects of breast cancer</td>
<td>• Cognitive dysfunction as a result of adjuvant therapy (including international IBCSG trial involvemen: Co-BIG and Co-SOFT)</td>
<td>• Kelly-Anne Phillips (VIC) and Janette Vardy (NSW)</td>
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<td>treatment</td>
<td>• Lymphoedema: prevalence, diagnosis, risk factors, impact and management</td>
<td>• Sandi Hayes (QLD), Terry Haines (QLD), Sharon Kilbreath (NSW); Neil Pillar (SA)</td>
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<td></td>
<td>• Infertility: decision making and options for reducing infertility</td>
<td>• Michelle Peate (NSW) and Kelly-Anne Phillips (VIC) (POEMS study)</td>
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<td></td>
<td>• Menopause: managing menopause caused by treatment; role of goserelin in preventing early menopause (POEMS study)</td>
<td>• Martha Hickey (WA)</td>
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<td>• Impact of TRAM flap breast reconstruction on self-esteem and body image</td>
<td>• ANZBCTG</td>
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<td>• Olivia Hill (NSW)</td>
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<td>Workplace and insurance issues</td>
<td>• Research into why people leave the workforce after a cancer diagnosis</td>
<td>• Queensland Institute for Medical Research</td>
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<td>Interventions to improve survival and</td>
<td>• Exercise for Health study - physical activity intervention trial with functional and QoL outcomes</td>
<td>• Liz Eakin &amp; Sandi Hayes (QLD)</td>
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<tr>
<td>reduce risk of recurrence</td>
<td>• Intervention study of impact of physical activity on survival after breast cancer</td>
<td>• Liz Eakin &amp; Sandi Hayes (QLD) and ANZBCTG</td>
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<td></td>
<td>• Impact of hormonal therapies on breast cancer survival (SOLE and LATER trials</td>
<td>• ANZBCTG</td>
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<td></td>
<td>• Wellness clinics and health promotion models</td>
<td>• Kate White (NSW)</td>
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<td>• Breast Cancer Survivors Healthy Lifestyle Study: randomised controlled trial to test the effects of information and advice on adopting healthy lifestyle behaviours in breast cancer survivors</td>
<td>• Annabel Pollard (VIC)</td>
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<tr>
<td>Models of follow-up</td>
<td>• Survivorship care plans:</td>
<td>• Meagan Brennan (NSW)</td>
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<td></td>
<td>o views of health professionals and women with breast cancer on care plans</td>
<td>• Michael Jefford (VIC)</td>
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<td>o pilot study on use of care plans</td>
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<td></td>
<td>• Different models of follow-up care (phone and nurse-led interventions)</td>
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<td>Family history and genetic risk</td>
<td>• Contralateral prophylactic mastectomy in high risk women and the role of chemoprevention to prevent second primary cancers</td>
<td>• KConFab</td>
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<td></td>
<td>• Range of studies using the Australian</td>
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</table>
Breast Cancer Family Study cohort looking at host (rather than tumour) factors that might influence survivorship in early-stage breast cancer

<table>
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<tr>
<th>Prevention/screening</th>
<th>Course and predictors of post-treatment distress in cancer survivors</th>
<th>Kerryann Lotfi-Jam (PhD student at Peter MacCallum Cancer Centre, VIC)</th>
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<tr>
<td>Needs of specific populations</td>
<td>Specific needs of migrant populations (Arabic, Vietnamese, Greek)</td>
<td>Phyllis Butow (NSW)</td>
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<td></td>
<td>Qualitative study of survivorship care experiences of rural women with BC (recruited via BCNA)</td>
<td>Liz Eakin (QLD)</td>
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<td></td>
<td>Health inequalities in breast cancer survivorship (socio-economic, demographic and geographic differences)</td>
<td>Samantha Thomas (VIC)</td>
</tr>
<tr>
<td>Use of information</td>
<td>Qualitative studies using sociological, media and public health approaches to explore how women access, interact with and interpret information across the cancer journey</td>
<td>Samantha Thomas (VIC)</td>
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In addition, a range of information resources have been developed including:

- a free DVD for people completing potentially curative treatments for cancer ‘Just take it day to day: a guide to surviving life after cancer’ (Peter MacCallum Cancer Centre)
- ‘Life after cancer’ booklet (free) (Peter MacCallum Cancer Centre and Cancer Council Victoria)
- website in development at [http://www.petermac.org/lifeaftercancer/](http://www.petermac.org/lifeaftercancer/) (Peter MacCallum Cancer Centre)
- NBOCC web- and print-based resources on survivorship, lymphoedema, menopause and follow-up (see section below)
- breast reconstruction information resource in development for women considering breast reconstruction following mastectomy (Olivia Hill).

**TRANSLATING RESEARCH INTO PRACTICE**

*Ornella Care, Program Manager, National Breast and Ovarian Cancer Centre*

Ms Care described the role played by NBOCC in translating research findings into meaningful, evidence-based information for consumers and health professionals. She described the NBOCC’s ‘evidence loop’ approach for developing evidence-based recommendations and information and highlighted recent NBOCC initiatives in the area of survivorship, including:

NBOCC projects in progress in the area of survivorship include:

- development of principles for a shared care approach to follow-up care for women with breast cancer
- development, conduct and evaluation of a demonstration project involving shared care between tertiary and primary care
- clinical practice guidelines on follow-up care after treatment for breast cancer, including resources for tertiary and primary care
- review of risk factors for recurrence, including the impact of diet and exercise, with a view to producing evidence-based consumer information.

SURVIVORSHIP AS A RESEARCH PRIORITY

*Sue Carrick, Head National Research Strategy, National Breast Cancer Foundation*

Ms Carrick presented an overview of the role of consumers in informing research priorities for NBCF. She reported that NBCF has provided over $55 million for breast cancer research to date. Research activities are predominantly priority driven. Ms Carrick described the importance of consumers in identifying priorities for research and highlighted previous examples of how NBCF has weighted research proposals based on consumer priorities identified through BCNA. Examples include:

- provision of $2.1 million for lymphoedema research
- provision of dedicated funds to explore issues for younger women with breast cancer.

Ms Carrick indicated that survivorship provides another example of how consumers can inform research priorities, with NBCF and BCNA collaborating on the survivorship section of the *National Action Plan for Breast Cancer Research and Funding*. She described a range of other ways in which NBCF has supported research into survivorship, including:

- support for the 2007 workshop on survivorship
- support for the UICC ‘Reach to Recovery’ conference to be held in Australia in May 2009
- funding for the BCNA Survivorship Think Tank.
SURVIVORSHIP RESEARCH ACTIVITY

Think Tank participants developed a ‘survivorship research matrix’ outlining overarching themes, common aspects of survivorship research activity, key topic areas and factors to be considered in implementation. This matrix was then used as a framework for small group discussion about gaps and priorities in survivorship research.

Figure 1: Cancer survivorship research matrix

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IDENTIFIED SURVIVORSHIP RESEARCH GAPS

Research gaps in each of the four key topic areas (physical issues, psychosocial issues, recurrence and models of care) were identified through small group discussion followed by plenary feedback. Groups were self-appointed based on participant research interests. Participants were asked to prioritise gaps where possible. However, time constraints and the broad range of participant interest areas did not allow consensus on priority areas to be reached during the Think Tank.

The small group exercise was followed by a facilitated plenary discussion, providing an opportunity for all participants to contribute to the mapping and gap identification process in each of the four topic areas.
Physical issues
The priority gaps in research into the physical aspects of breast cancer survivorship identified by Think Tank participants are outlined below.

- **Exercise and breast cancer survival:**
  - measurement of the impact of exercise on disease-free survival
  - large-scale research studies into how to encourage behavioural change
  - measurement of the impact of exercise on outcomes throughout the cancer journey
  - mechanisms by which physical activity can improve disease outcomes

- **Fatigue:**
  - research into the causes of sustained fatigue
  - identification of approaches for treating fatigue

- **Lymphoedema:**
  - research into causative factors for lymphoedema and early changes
  - identification of effective management approaches
  - approaches for measurement of chest wall lymphoedema

- **Cognitive function:**
  - research into the causes of ‘cancer brain’/’chemo brain’ including the contribution of different treatments (chemotherapy, hormonal therapy)
  - measurement of the duration of symptoms and the impact of changes in cognitive function on functional and psychosocial ability, including qualitative data (objective vs self-report)
  - identification of effective management approaches

- **Weight loss/weight gain**

Other areas identified in which research would be valuable included:

- impact of breast cancer treatment on bone health (some research activity underway)
- identification of interventions to minimise and manage the impact of treatment with taxanes, eg arthralgias
- identification of management options for younger women experiencing early menopause, including complementary therapies
- exploration of approaches to protect fertility, including the timing of treatment
- approaches for management of long-term pain, including breast and chest pain and prevention and treatment of peripheral neuropathy
- approaches for management of the long-term impacts of diagnosis and treatment on sexuality (research to date has focused on physical aspects rather than exploring vulnerability and management)
- exploration of the long-term impacts of treatment on cardiovascular disease, including prevention strategies and approaches to management.
During the plenary discussion, a number of research studies in this area were identified, including:

- investigation into the impact of exercise on weight gain (Liz Eakin, QLD)
- pilot study on pain (Fran Boyle, NSW)
- impacts on cognitive function (international study involving Kelly-Anne Phillips (VIC), Janette Vardy (NSW))
- pilot study on body image (Jane Turner, QLD)
- impact of Qi-Gong on sexual function (Byeongsang Oh, University of Sydney).

**Psychosocial issues**

Participants considered both psychological and socio-cultural issues for breast cancer survivors. A range of gaps in research were identified. Time constraints did not allow prioritisation of these gaps by workshop participants.

- **Measures of distress**
  - development of measures to distinguish between groups with high and low needs
  - development of measures that are relevant for partners, caregivers and children

- **Fear of recurrence**
  - identification of interventions to manage fear of recurrence
  - measurement of the impact of medical communication on fear of recurrence

- **Uptake of guidelines for communication**
  - exploration of the barriers to uptake of communication skills guidelines
  - development of measures to assess communication skills
  - assessment of the costs to the system and community of poor communication

- **Impact on relationships**
  - comprehensive study of the impact of a diagnosis of breast cancer on relationships (family, partner)
  - exploration of the factors that dictate whether families do or do not seek support
  - identification of interventions to minimise or manage the impact of breast cancer diagnosis and treatment on relationships

- **Economic/social/cultural impacts**
  - collation of available data in this area
  - research into the economic, social and cultural impacts of diagnosis and treatment for breast cancer for different population groups (ATSI, CALD, low SES, rural etc), identifying the challenges for different groups and how social networks and cultural beliefs influence a woman’s response

- **Vulnerability and resilience**
  - identification of the factors that influence increased vulnerability or resilience to distress caused by diagnosis and treatment for breast cancer.

During the plenary discussion, participants emphasised the importance of ‘wellness models’ for women with breast cancer (ie models that don’t just focus on disease management but promote healthy lifestyle strategies and encourage optimal functioning of the individual). The importance of accurate communication of messages was also discussed, with recognition of
the wide array of information available to women and the importance of understanding how women use and apply the information they receive.

**Recurrence**

While recurrence was covered by a number of the groups, the fact that it is commonly identified as a key issue by women who have completed treatment for breast cancer meant that it was discussed as a separate category.

Issues identified in relation to recurrence included:

- ‘recurrence’ has several different definitions (local recurrence, new primary, metastatic disease) and that the risk and therefore the key messages vary for different subsets of women based on family history and genetic aspects
- data about recurrence is limited because there is no single notifiable event in a diagnosis of metastatic disease so the extent of the problem is not fully understood
- issues around recurrence relate not only to fear of recurrence but also how the risk of recurrence can be reduced.

Priority gaps identified in research into recurrence are outlined below.

- **Data**
  - collection of comprehensive data about recurrence to underpin other research in this area

- **Tests for metastatic disease**
  - research to develop better tests to detect the presence of metastases

- **Interventions**
  - research into the role of exercise and diet in preventing recurrence (health promotion model)

- **Managing fear of recurrence**
  - development and communication of key messages about recurrence for women to help them manage fear of recurrence.

Other gaps identified included:

- the role of complementary therapies in preventing recurrence
- exploration of strategies to ensure compliance with treatment (with recognition of the language issues around the word ‘compliance’, which has implications of ‘failure’).

During the plenary discussion, participants discussed the challenge of undertaking large-scale studies around recurrence given that recurrence rates in breast cancer are relatively low. Caution was raised over conducting studies in high-risk breast cancer populations due to the potentially limited applicability of results to the broader breast cancer population.

**Models of care**

Research into models of care was seen to be at an early stage with a number of questions and issues yet to be addressed. Participants recognised the work in progress to develop and test survivorship care plans and emphasised that the impact of such care plans has not been assessed. Some work on alternatives to specialist-led follow-up has also been undertaken: several randomised controlled trials have shown that GP follow-up of women with early stage breast cancer / early bowel cancer is safe, effective and well received; a systematic review of nurse-led versus specialist follow-up showed similar results.
Key issues identified included:

- models of care should not be limited to detection of recurrence but should reflect the four components of good survivorship care recommended by the US Institute of Medicine: (i) prevention of recurrent and new cancers; (ii) surveillance for cancer recurrence as well as for medical and psychosocial late effects; (iii) strategies to deal with the broad consequences of cancer and its treatment; (iv) coordination between specialists and primary care providers.

- models of care should involve a coordinated/integrated approach that encourages patient (and carer) involvement / empowerment

- studies exploring models of care should incorporate evaluation of economic benefits and costs as well as possible barriers to implementation

- it is unlikely that one model of management/follow-up will be appropriate in all circumstances, therefore research into a range of models, including flexible models, will be important

- models of care should include screening for distress/unmet need

- models should incorporate longitudinal (repeat) assessment

- demonstration projects and feasibility studies in a range of settings relevant for the Australian context will be important

- models of care should take account of the potential for future changes in the way healthcare is delivered, with a movement towards community-based care and increasing use of complementary and non-traditional therapies.

KEY MESSAGES

The Think Tank clearly emphasised that cancer survivorship is a priority area for research in Australia, with attendance by national leaders in the field. There was a strong commitment from participants to the importance of survivorship research and an acknowledgement of the importance of collaborative approaches. The potential to draw on international research activity and to seek collaboration about shared issues was also discussed.

While a broad range of issues were identified, it was not possible during the Think Tank to prioritise any one particular area of research.

However in addition to the topic areas identified above, some overarching themes emerged from the discussion throughout the day, including:

- the importance of applying current knowledge and exploring barriers to uptake of existing best practice

- the importance of building economic analyses into research studies as a strategy to drive future implementation

- support for a health promotion/wellness model that supports consumer empowerment

- the importance of considering the needs of families and caregivers as well as the needs of the patient

- the importance of considering the need of underserved groups.

While there was good awareness among participants of current research activity, the potential for improved information sharing with the broader community about research activity was identified, with opportunities highlighted for BCNA in terms of informing women about the areas in which research is happening.

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OPPORTUNITIES FOR COLLABORATION

INVolVEMENT OF BCNA

A range of potential roles for BCNA in contributing to improvements in research and information about survivorship issues for women with breast cancer were identified in addition to their existing activities (see page ). These included:

- promotion of current research activity and outcomes through a regular question and answer section with key researchers in *The Beacon*, as well as themed issues to address particular aspects of survivorship
- ongoing support and participation in research through BCNA’s membership database
- contribution to the NBCF’s *National Action Plan for Breast Cancer Research and Funding*.

Participants acknowledged the benefits of access to the BCNA membership and advocates for individual research projects but identified some issues to be considered or resolved in relation to BCNA’s involvement in research, including:

- the representativeness of the membership to the broader population of women with breast cancer
- how intellectual property issues are managed, in particular around the timing of promotion of research findings that may be published in peer-reviewed literature
- standard guidelines about incentives for participation of consumers in research projects that take account of state-based procedures
- ensuring that women aren’t inundated with requests to participate in research projects.

COllaborATIONS

Throughout the Think Tank a number of opportunities were identified for ongoing collaboration and information sharing.

- The Australian New Zealand Breast Cancer Trials Group (ANZBCTG) website ([http://www.anzbctg.org/](http://www.anzbctg.org/)) lists current breast cancer trials and may be a source of information about trials to which sub-studies could be linked.
- The Psycho-Oncology Cooperative Research Group (PoCoG [http://www.pocog.org.au/](http://www.pocog.org.au/)) maintains a database of members and their research interests and has processes in place for development and review of research protocols through its protocol development workshops and Scientific Advisory Committee; special interest groups in priority areas are being planned.
- National Breast and Ovarian Cancer Centre (NBOCC) provides opportunities for feedback about survivorship priorities through the advisory groups to inform current and future business plans, with the potential for demonstration projects to test different models.
- National Breast Cancer Foundation (NBCF) provides funding opportunities, with work underway to highlight survivorship as a priority issue through the national plan.
NEXT STEPS

With survivorship as a priority area, BCNA identified a number of actions that would be undertaken following the Think Tank to utilise the information provided and continue momentum in this area:

- outcomes will be used to inform BCNA’s contribution to the Survivorship chapter of the NBCF’s *National Action Plan for Breast Cancer Research and Funding*

- priority areas and headings will be used to guide a BCNA research project exploring women’s survivorship research priorities through a survey of the membership

- BCNA will undertake a project to identify the representativeness of its membership database

- options raised by participants for communicating with women about research activity and outcomes will be explored (for example, options for a regular column in *The Beacon*, or particular themes for editions of *The Beacon*)

- consideration will be given to hosting an annual Survivorship Think Tank to support information sharing and priority setting.
# APPENDIX I: THINK TANK AGENDA

## SURVIVORSHIP THINK TANK

**Friday 20 March 2009**  
10.15am–4.00pm  
Holiday Inn, Melbourne Airport, Melbourne  
**Facilitator:** Lyn Swinburne, CEO, BCNA

<table>
<thead>
<tr>
<th>Time</th>
<th>Agenda item</th>
<th>Facilitator/presenter</th>
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<tbody>
<tr>
<td>10.00–10.15am</td>
<td><strong>Registration</strong> (Tea/Coffee on arrival)</td>
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<tr>
<td>10.15–10.50am</td>
<td><strong>Welcome, overview and introductions</strong></td>
<td>Lyn Swinburne</td>
</tr>
<tr>
<td>10.50–11.30am</td>
<td><strong>Overview of survivorship research activity</strong></td>
<td>Afaf Girgis, Phyllis Butow, Sue Carrick, Christine Giles</td>
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<tr>
<td></td>
<td>• International activity</td>
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<tr>
<td></td>
<td>• Survivorship research in Australia</td>
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<tr>
<td></td>
<td>• Translating research into outcomes</td>
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<td></td>
<td>• Survivorship as a research priority</td>
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<tr>
<td>11.30am–12.30pm</td>
<td><strong>Mapping Australian survivorship research &amp; information activity</strong></td>
<td>Lyn Swinburne, Small groups</td>
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<tr>
<td></td>
<td>• Plenary discussion: current and future activities</td>
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<tr>
<td></td>
<td>• Small group work: identification and prioritisation of gaps</td>
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<tr>
<td>12.30-1.15pm</td>
<td><strong>Lunch</strong></td>
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<tr>
<td>1.15-1.55pm</td>
<td><strong>Mapping Australian survivorship research &amp; information activity (cont’d)</strong></td>
<td>Lyn Swinburne</td>
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<tr>
<td></td>
<td>• Small group feedback and priority setting</td>
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<tr>
<td>1.55–2.55pm</td>
<td><strong>Research ideas</strong></td>
<td>Lyn Swinburne, Small groups</td>
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<tr>
<td></td>
<td>• Small group work: collaborative research ideas</td>
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<tr>
<td>2.55–3.10pm</td>
<td><strong>Afternoon tea</strong></td>
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<tr>
<td>3.10–3.50pm</td>
<td><strong>Action plan</strong></td>
<td>All</td>
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<td></td>
<td>• Small group feedback, prioritisation of issues and actions</td>
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<tr>
<td>3.50–4.00pm</td>
<td><strong>Summary and next steps</strong></td>
<td>Lyn Swinburne</td>
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<tr>
<td></td>
<td>• Summary of key outcomes and next steps</td>
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<tr>
<td>4.00pm</td>
<td><strong>Close</strong></td>
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</tbody>
</table>
## APPENDIX II: THINK TANK PARTICIPANTS

<table>
<thead>
<tr>
<th>Participant</th>
<th>Institution/ affiliation</th>
<th>Current areas of research/activity in survivorship</th>
</tr>
</thead>
<tbody>
<tr>
<td>A/Professor Fran Boyle</td>
<td>Mater Sydney, University of Sydney, Pam McLean Cancer Communications Centre</td>
<td>Survivorship care planning  \  Exercise  \  Cognitive function  \  Prevention of early menopause  \  Prevention of late relapses  \  Fertility decision aids</td>
</tr>
<tr>
<td>Ms Allison Boyes</td>
<td>Centre for Health Research &amp; Psycho-oncology (CHeRP), University of Newcastle</td>
<td>Psychosocial wellbeing post-treatment</td>
</tr>
<tr>
<td>Dr Meagan Brennan</td>
<td>The Patricia Ritchie Centre for Cancer Care and Research, Mater Hospital, Sydney</td>
<td>Survivorship care planning</td>
</tr>
<tr>
<td>Professor Phyllis Butow</td>
<td>Centre for Medical Psychology and Evidence-based Decision-making (CeMPED), University of Sydney</td>
<td>Measures of unmet need  \  Fear of recurrence  \  Optimal follow-up</td>
</tr>
<tr>
<td>Ms Sue Carrick</td>
<td>National Breast Cancer Foundation (NBCF)</td>
<td>Head, National Research Strategy for NBCF</td>
</tr>
<tr>
<td>A/Professor Liz Eakin</td>
<td>Cancer Prevention Research Centre, The University of Queensland</td>
<td>Lifestyle interventions  \  Broad-reach intervention delivery modalities  \  Translation of research into practice  \  Exercise</td>
</tr>
<tr>
<td>Ms Ornella Care</td>
<td>National Breast and Ovarian Cancer Centre (NBOCC)</td>
<td>Consumer information resources (web- and print-based)  \  Clinical practice guidelines (follow-up)  \  Shared care</td>
</tr>
<tr>
<td>Professor Afaf Girgis</td>
<td>Centre for Health Research &amp; Psycho-oncology (CHeRP) Cancer Council NSW &amp; University of Newcastle</td>
<td>Psychosocial outcomes post-treatment for patients, carers and partners  \  Effectiveness of Palliative Care Needs Assessment Guidelines and Palliative Care Needs Assessment Tool  \  Development and evaluation of impact of a complementary Consumer Toolkit and GP Caregiver Needs Toolkit</td>
</tr>
<tr>
<td>Dr Craig Hassed</td>
<td>Monash University, Department of General Practice</td>
<td>Health promotion  \  Lifestyle management  \  Mind-body medicine and psycho-oncology  \  Mindfulness-based stress management  \  Support groups</td>
</tr>
<tr>
<td>Ms Olivia Hill</td>
<td>University of Sydney</td>
<td>Decision making around breast reconstruction following mastectomy  \  Self-esteem and body image</td>
</tr>
<tr>
<td>Participant</td>
<td>Institution/ affiliation</td>
<td>Current areas of research or activity in survivorship</td>
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</tr>
<tr>
<td>A/Professor Michael Jefford</td>
<td>Peter MacCallum Cancer Centre / Cancer Council Victoria</td>
<td>Development of consumer information resources (DVD print and web) ‘Comprehensive survivorship package’ including question prompt list, survivorship care plan template, nurse-led end of treatment session, and nurse-led telephone follow-up Course and predictors of post-treatment distress in cancer survivors</td>
</tr>
<tr>
<td>Dr Sharon Kilbreath</td>
<td>University of Sydney</td>
<td>Lymphoedema (diagnosis and treatment)</td>
</tr>
<tr>
<td>Dr Belinda Thewes</td>
<td>Centre for Medical Psychology and Evidence-Based Decision-Making, School of Psychology, University of Sydney</td>
<td>Fear of recurrence in younger women with a history of breast cancer Information processing biases in cancer patients with high levels of fear of recurrence Fertility issues and early menopause in cancer survivors</td>
</tr>
<tr>
<td>Dr Samantha Thomas</td>
<td>Department of General Practice and Primary Care Research, Monash University</td>
<td>Exploration of how women access, interact with and interpret information across the cancer journey</td>
</tr>
<tr>
<td>Dr Jane Turner</td>
<td>School of Medicine, University of Queensland</td>
<td>Lymphoedema Promotion of active coping Strategies to reduce/address cognitive problems Impact on relationships</td>
</tr>
<tr>
<td>Dr Janette Vardy</td>
<td>Sydney Cancer Centre, University of Sydney</td>
<td>MRI and cognitive studies Ginkgo biloba in breast cancer patients Cognitive rehabilitation studies in cancer survivors Use of complementary medicines Physical activity</td>
</tr>
<tr>
<td>Professor Kate White</td>
<td>Faculty of Nursing and Midwifery, University of Sydney</td>
<td>Sexuality and sexual function after cancer Partner support Lymphoedema</td>
</tr>
</tbody>
</table>

The following BCNA staff, Board members and members also attended the Think Tank:

Ms Lyn Swinburne CEO (workshop facilitator)  
Ms Marg O’Donnell Incoming Chair, BCNA Board  
Ms Michelle Marven Policy Manager  
Ms Spiri Tsintziras Special Projects Manager  
Ms Ami Seabrook Research and Policy Officer  
Ms Helen Shields Locum Project Officer  
Ms Susan Timbs BCNA member and Seat at the Table advocate

The Think Tank was also attended by the report author, Dr Alison Evans of Alison Evans Consulting.
APPENDIX III: PHOTO OF THINK TANK PARTICIPANTS

Front row (left to right):
Ornella Care, Janette Vardy, Lyn Swinburne, Sharon Kilbreath, Afaf Girgis, Sue Carrick, Fran Boyle

Second row:
Sue Timbs, Belinda Thewes, Allison Boyes, Olivia Hill, Michael Jefford, Jane Turner, Kate White, Meagan Brennan, Helen Shield

Back row:
Alison Evans, Samantha Thomas, Craig Hassed, Michelle Marven, Liz Eakin, Marg O’Donnell, Phyllis Butow, Ami Seabrook