

Breast Cancer Network Australia
Submission to Cancer Research Leadership Forum
White Paper – Toward a national cancer plan



May 2012

About Breast Cancer Network Australia

Breast Cancer Network Australia is the peak national organisation for Australians personally affected by breast cancer. We empower, inform, represent and link together people whose lives have been affected by breast cancer.

BCNA represents more than 67,000 individual members and 291 Member Groups from across Australia.

BCNA works to ensure that women diagnosed with breast cancer and their families receive the very best information, treatment, care and support possible. BCNA is represented by the pink lady silhouette, which depicts the organisation's focus – women diagnosed with breast cancer

Breast Cancer Network Australia (BCNA) welcomes the opportunity to provide comment on the Cancer Research Leadership Forum's White Paper – Toward a National Cancer Plan (White Paper).

BCNA supports all efforts to improve the quality and scope of cancer research in Australia, where this will reduce the impact of cancer in the community and for individuals. As a breast cancer organisation, we have drawn on our knowledge of breast cancer and the experiences of women who live with breast cancer to develop this submission.

We have chosen to address only those questions asked in the White Paper for which we have relevant expertise and experience: questions 1, 3, 4, 5, 7, 8, 9.

BCNA Key Messages

1. We support a well-conceived and well-managed national cancer research plan that contains specific goals to reduce the impact of cancer on the community and individuals. The plan should also ensure cancer research funding addresses all facets of cancer: prevention, diagnostics, treatment, psycho-social considerations, survivorship and cure.
2. BCNA believes that a National Cancer Research Plan should draw on and adapt current successful models of cancer research fundraising to increase funds raised to other cancers, as well as supporting continued growth to existing cancer areas. Strategies to ensure translation of research into practice, to reduce the impact of cancer should also be addressed, and can be adapted from current successful models.
3. Research priorities should align with prevalence and impact of cancer in the Australian community.
4. A national cancer research plan should ensure that meaningful consumer representation is an integral part of all funded research. Although consumer

representation may be of limited direct assistance in basic biomedical research projects (for example, laboratory research at the cellular or genetic level), having consumer representatives involved even at this stage can be beneficial. Consumer representatives, particularly those trained in both science and communication skills, can prove invaluable in terms of communicating promising research outcomes to the broader community.

Introduction

A well-conceived and well managed national cancer research plan should ultimately aim to reduce the impact of cancer in Australia.

A good plan will ensure that all types of cancers are considered, addressed and funded appropriately. This should not be entirely weighted by types of cancers in terms of incidence, prevalence or mortality. Best practice examples of cancer research funding and translation of research findings into practice should be examined, adopted and modified for other cancer types. This should be done with the goal of funding research that may benefit broad cancer treatments.

Lessons from Breast Cancer Research and Funding

Scientists and clinicians have made enormous progress in the understanding and treatment of breast cancer over the last couple of decades. In some instances, the benefits have extended beyond breast cancer-specific treatment to other cancer areas. However there is still significant work to be done to address the ongoing impact of breast cancer on the Australian community.

- Breast cancer is still the most common invasive cancer amongst Australian women.¹
- Breast cancer accounts for a significantly larger number of Disability-adjusted life years (DALYs), than any other cancer in women and men.²
- The incidence of breast cancer is higher in younger age groups, compared with all other common cancers.³
- Breast cancer remains one of the leading causes of cancer death in Australian women, despite the decrease in mortality rates over the last two decades. In 2006, 2618 women died from breast cancer.⁴

Much of the improvements in breast cancer survival and the quality of life of women can be attributed to research. BCNA believes that a National Cancer Research Plan should investigate successful models of cancer funding, and use and adapt these models to improve funding and awareness of other cancer types. A key example is the significant success of the National Breast Cancer Foundation (NBCF).

Since inception, the NBCF has raised not only significant amounts of money for breast cancer research, but has successfully engaged the broader Australian community in their mission. This is an outstanding success story, and provides a model that could be adapted and used for other cancer types.

¹ Australian Institute of Health and Welfare & National Breast and Ovarian Cancer Centre 2009. Breast cancer in Australia: an overview, 2009. Cancer series no. 50. Cat. no. CAN 46. Canberra: AIHW.

² Ibid.

³ Ibid.

⁴ Ibid.

We can also look to breast cancer for models to successfully translate research into practice, and to directly address the impact of cancer on the community. This includes investment in health services research that has led to the development of multidisciplinary teams for the treatment of women with breast cancer, and the development of national clinical guidelines to increase compliance with the evidence based treatment of women. These examples will be discussed in more detail in the submission.

Is a national plan the way forward?

BCNA is of the view that a national cancer research plan should aim to reduce the impact of cancer disease in Australia. The White Paper states that “cancer plans are effective”. Although the White paper examines the beneficial outcomes of USA and UK national cancer plans, these outcomes focus primarily on an increase in funding overall, increases in clinical trial involvement, and increases in the funding and attention given to under-funded cancers.

Whilst we believe these to be very good outcomes, we query whether these national plans have achieved the objective of reducing the cancer impact. There must be an evidence-based rationale for a national cancer research plan. Successful national plans that have resulted in the reduction of cancer impact on the community should be identified, and examined further in the development of a national plan.

Key Questions

Q1. What should be the objectives of a national cancer research plan?

The primary objective of a national cancer research plan should be to reduce the impact of cancer in Australia.

To this end, a national cancer research plan should:

- Have a specific and tangible goal of reducing the impact of cancer in Australia
- Ensure cancer is adequately and appropriately researched across the broad spectrum of research type: prevention, screening, diagnosis, treatment, psycho-social issues, survivorship issues, and cure.
- Ensure that all scientific research modes are considered for funding, with a focus on assessing each individual proposal on its merits.
- Ensure that research is funded that addresses the unique needs of people living with metastatic cancer. Women living with secondary breast cancer often tell us that they desperately want to see advancements in better treatments for secondaries, and a stronger and more coordinated research focus on the cure and prevention of metastatic disease.
- Seek to improve the quality of life for people with cancer.

Q3 What is the right balance between investigator initiated and priority driven research?

Though BCNA supports the prioritisation of cancer research insofar as it is part of a larger plan to address the impact of cancer, we are also mindful of the fact that many beneficial cancer research outcomes are thanks to investigator initiated projects. We also believe that there should be some mechanism available to ensure that research is channelled into promising research which is otherwise unable to attract funding from pharmaceutical companies or other sources.

BCNA believes that decisions pertaining to the balance between investigator-initiated and priority driven research should be made by independent experts in the area. These sorts of

decisions must be informed by science; all research must be assessed independently on its individual merits.

Q4 How should the proportional allocation of funding to different types of research be determined? (e.g. basic, clinical, psychosocial, prevention, etc)

Australian women (and a small number of men) with breast cancer have benefited from the funding of a wide range of research types. The complexity and incidence of breast cancer however, means that progress is still needed across the spectrum of research areas.

We recognise that both psychosocial and survivorship research has traditionally received less funding and focus than other research such as basic science research. These areas of research are important in contributing to the understanding and management of the impact of cancer and its treatment on those affected, and their families and carers. As the incidence of cancer increases, so does the prevalence of survivors and people living with secondary cancers. Research that addresses the needs of these groups of people should be considered a priority in a national cancer research plan.

Prevention Research

A national cancer plan should include a concentrated focus on research into preventative measures. Whilst factors, such as tobacco use, have been identified as a clear primary cause of lung cancer, there are many other lifestyle/environmental factors connected to other types of cancers that require more thorough research. For example, research into alcohol use, nutrition and physical activity should be identified as an important area for further research in a national cancer plan. Not only do the findings from preventative research benefit the wider community, they inform and empower those people who might be concerned about a recurrence of their own cancer. Women with breast cancer often tell BCNA that they are confused about the extent to which physical activity, and what type of physical activity, will lessen their risk of a recurrence. The research has not yet resolved these questions, and much more is needed so that people are able to take active and well-informed measures to lessen their risk of developing all types of cancers.

Survivorship Research

Research into survivorship issues has developed in a largely haphazard manner in Australia to date, directed by the specialist interests of particular researchers and the areas of priority defined, often in isolation, by funding bodies and government departments.

A comprehensive survivorship research program that is driven by the key concerns and priorities of people actually living with the disease is needed to ensure that research is meaningful and of direct benefit to those people and their families. BCNA hope that a national cancer research plan will address this gap.

“As survivability rates increase, people are living longer but many are living longer with chronic pain. Research into chronic pain relief is an area of great need.” -
BCNA Consumer Representative

Supportive Care Research

Improved quality of life is of paramount importance to people with cancer. Research into pain relief and supportive care must be regarded as integral and essential elements of a national cancer research program, whatever the possibilities of cure.

“I was recently involved as a consumer representative on a research project looking at alternative radiotherapy options for women with breast cancer. Because of the many weeks of treatment, quality of life outcomes were obvious areas to investigate. But little research appears to have been undertaken. Quality of life is so important to people diagnosed with cancer. It is very difficult to measure due to the different and subjective experiences of

individuals. Nevertheless more studies are needed to identify ways of defining and measuring it and so develop better and tailored ways to improve the QOL of those with cancer".

BCNA Consumer Representative

Psycho-social Research

With the incidence of cancer expected to rise significantly over the next 20 years⁵, support for people living with cancer must be an integral and evidence based part of their care. Research into this aspect of cancer care is vital.

As a member-based breast cancer organisation, we are aware that all types of research have resulted in beneficial outcomes for women with breast cancer, and that much more research is needed to prevent, diagnose and treat early and advanced breast cancer, as well as support women and their families who have been diagnosed. There is little doubt that this, too, applies to other cancer types.

Q5. Should funding for certain cancers be prioritised, and how should such priorities be determined?

A national plan should focus on practical strategies to increase funding for cancer research.

A national plan should look to the success achieved in specific cancer areas, and to identify how these models can be adapted for other cancer types and areas. The role that the NBCF has played in increasing funding to breast cancer research, and community support and awareness of the value of breast cancer research, is a great example of that success.

In addition, a national plan should identify strategies for translating research outcomes that have led to direct improvements in the treatment, care and survival of those diagnosed with cancer into practice.

The case study below exemplifies the benefits of investing in health services research. This research led to the development of multidisciplinary care, which in Australia was first used in the treatment of women with breast cancer. The second case study highlights the highly successful model of translating research findings into practice through national guideline development.

Case Study: Multidisciplinary Care

Investment in health services research in the breast cancer field led to the development of multidisciplinary care (MDC). In implementing the model the then National Breast and Ovarian Cancer Centre found that *"the principles of multidisciplinary care developed for breast cancer can be used as the basis for developing similar frameworks for other cancers and other chronic diseases requiring multidisciplinary input."*

An audit undertaken by the National Breast and Ovarian Cancer Centre in 2006 found that at some level, MDC was happening in gynaecological, breast, colorectal, lung and prostate cancer. While progress on implementation appears to be slow in some of these other cancer areas (although this may have changed in the intervening years), what this does demonstrate is that investment in breast cancer has direct and translatable positive flow on effects for a wide range of other cancer areas.

⁵ AIHW 2012. Cancer incidence projections, Australia 2011 to 2020. Cancer series no. 66. Cat. no. CAN 62. Canberra: AIHW.

Case Study: National Clinical Guidelines

The National Breast and Ovarian Cancer Centre (now incorporated with Cancer Australia) invested in the development of national clinical guidelines for the management of women with both early and secondary breast cancer. These guidelines have been extremely successful in ensuring more consistent, evidence based treatment of women with breast cancer across the country. The updating of the guidelines on a regular basis ensures that the latest research findings can be efficiently translated for health professionals, and incorporated into clinical practice. This model is now being adapted for lung cancer (by Cancer Council Australia), and has great potential to benefit other cancer types, and ultimately those living with cancer.

It is also important to recognise that research into site-specific cancers has benefited other types of cancer. Breast cancer research in particular has led to better outcomes in terms of understanding and treating cancers of other sites, and examples of these are given in the case studies below. When making decisions regarding the prioritisation of cancer funding, the potential for research to benefit more than the targeted cancer site should be considered.

Case Study: Genetic research

Both basic and epidemiological research has resulted in beneficial outcomes in terms of understanding how breast cancer may be prevented. For example, the discovery of the BRCA1 and BRCA2 gene mutations has resulted in women with a familial history of breast cancer now having the option to address their increased risk at an early stage.

This discovery also has the potential to benefit people with other types of cancer. It has been discovered that men with mutations in the BRCA1 and particularly the BRCA2 gene, have an increased risk of *prostate cancer* – a major development in our understanding of this disease.

Case Study: Basic Research and Targeted Therapies

Clinical treatment research led to the discovery of tamoxifen as a highly effective treatment for a large proportion of breast cancers, and it has been used for more than 30 years to treat breast cancer in both women and men⁶. In the UK tamoxifen is now also used to treat or prevent side effects of breast tenderness and swelling in some men with prostate cancer.⁷

Herceptin is a highly effective treatment for women with a particular type of breast cancer known as HER2 positive breast cancer, which has led to a significant increase in survival rates for these women. Building on this history, Herceptin is now showing good promise in the treatment of esophageal cancers, with Phase III clinical trials currently underway. In addition, the US Food and Drug Administration (FDA) in 2010 approved Herceptin for use in HER2 positive metastatic stomach cancer.

These case studies demonstrate the value that breast cancer-specific research has had in the treatment and management of other cancer types. A national cancer research plan

⁶ <http://www.cancer.gov/cancertopics/factsheet/Therapy/tamoxifen>

⁷ <http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Hormonaltherapies/Individualhormonaltherapies/Tamoxifen.aspx>
<http://www.lifeclinic.com/fullpage.aspx?prid=525130&type=1>

should recognise that when assessing cancer research proposals, the potential for the outcomes of that research to benefit other types of cancer should not be overlooked.

As a leader in effective models of funding and translation of research, it is critical to maintain and continue to grow current levels of support for breast cancer research and translation. This will ensure continued innovation and new models and strategies into the future, which can continue to lead the way for other cancer areas.

Q7. What strategies will ensure that basic research findings are effectively implemented to provide the greatest impact on cancer clinical care?

Early and meaningful involvement on the part of policy professionals, health economists, and other professionals (for example, science communicators) will go some way to ensure that basic research findings are effectively implemented. Scientists are, rightly, guided by purely scientific methods and outcomes and are not always expected to consider the policy implications or implementation of their findings. Having other professionals, such as health economists, engaged at an early stage of the research design process may assist to have these sorts of issues considered from the outset.

Early and meaningful participation on the part of trained consumer advocates has been shown to lead to an increase in study participation and awareness on the part of people to whom the research might benefit. Again, consumer representation, even at the basic research level, can often result in improved communication of important findings.

Having health economists involved early in the research process ensures that the costs and benefits of research outcomes for Australians can be a part of the research design. With this sort of insight assisting the research team, policymakers can be more effectively engaged to make informed decisions about the cost benefits of translating the research findings into practice.

In addition, drawing on and building on existing successful models of translation, such as Cancer Australia's development of national clinical guidelines can work very effectively to support the translation of research into practice.

Finally, supporting the translation of research findings into practice should not be confined only to basic science research findings as this question suggests, but should extend across all forms of research, including survivorship, psychosocial and supportive care research.

Q8. How can consumers be more effectively engaged in research planning and funding decisions?

BCNA strongly supports the inclusion of consumer representatives at every stage of the clinical research process, where appropriate.

It is important to note that some cancer organisations, including BCNA, currently provide highly regarded training programs for consumers to support their involvement in cancer advocacy, policy development and research. BCNA coordinates its Seat at the Table Program, which provides high quality training and critical ongoing support for women with breast cancer to represent the needs of the broad population of women with this disease. The Consumers' Health Forum also uses a similar model very successfully.

Open communication between researchers and consumer representatives is a valuable asset, and can lead to excellent, tangible outcomes, particularly for clinical research.

"Consumer advocates play a key role as a communication channel between the researchers and potential participants".

BCNA Consumer Representative

Effective involvement of consumers requires strategic and considered selection processes, to match consumers and their skills to the right opportunities, as well as ongoing support throughout their involvement. Consumer participation is not simply a matter of circulating documents or putting their name to planning decisions. Consumers must be supported in a meaningful and genuine way in order to contribute in a meaningful way. This requires consumer participation that is planned well, adequately resourced and modified to ensure that the 'right' consumer representatives are involved.

Q9. How can collaborative links between the basic, clinical and policy aspects of cancer research be improved?

Again, engaging policymakers and other professionals early on in the research process may improve these collaborative links. Engagement with consumer representatives will also lead to improved collaboration, as will adapting current successful models for translating research into practice.

Conclusion

BCNA is interested in the progress of the White Paper development, and we are keen to communicate the outcomes to women with breast cancer. We would welcome the opportunity to attend the CRLF national cancer research summit in September 2012. Please do not hesitate to contact Maxine Morand, Chief Executive Officer at mmorand@bcna.org.au or phone (03) 9805 2500 to discuss further.

Yours faithfully



Maxine Morand
Chief Executive Officer