Breast Cancer Treatment Group Chair’s report

The ACT & SE NSW Breast Cancer Treatment Group will remember 2015 as a year of many accomplishments. The publication of the 15-year report is a major milestone and confirms the value of the Quality Assurance Project. The report was successfully launched by Minister for Health Mr Simon Corbell on 1 October 2015. It shows that breast cancer survival has increased over time and that the quality of breast cancer treatment has also improved in our region. This publication provides us with an opportunity to reflect on ways in which we can continue to improve practice and to consider future directions. I would like to thank the John James Foundation and the Radiation Oncology Private Practice Fund for their generous financial support for this publication.

Over the 15-years of the report, we have seen the introduction of multi-disciplinary meetings, an increase in access to breast care nurses, an expansion of physiotherapy services, and numerous medical advances in the diagnosis, staging and treatment of breast cancer. This 15-year report records these changes in treatment and, importantly, records treatment results in a setting outside of clinical trials.

We have known for some time that we have an excellent Project Team. This has been acknowledged publically this year with the Quality Assurance Project Team receiving an Australia Day Achievement Award in January, and in October, Yanping Zhang was named one of the four finalists for the ACT Local Hero in Australian of the Year Awards 2016. Congratulations Yanping!!

Thank you to Associate Professor Kate Pumpa and Kellie Toohey from the University of Canberra for presenting at our meeting in March. The talk “Physical Activity in Breast Cancer Patients” generated a great deal of discussion and highlighted the importance of prescribed physical activity for those diagnosed with breast cancer.

I would like to acknowledge the hard work of the Project team of Yanping Zhang, Thet Khin, and Jenny Green. Thank you also to the numerous specialists, GPs and their administrative teams who have continued to contribute voluntarily to this Project.

I wish you all a Merry Christmas and hope to have your ongoing support and involvement in 2016.

Dr Angela Rezo,
Radiation Oncologist
Chair, ACT & SE NSW Breast Cancer Treatment Group

Features in this issue

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sub-Committee Chair’s Report</td>
<td>2</td>
</tr>
<tr>
<td>Quality Assurance Project Update</td>
<td>3</td>
</tr>
<tr>
<td>Message from Director-General</td>
<td>3</td>
</tr>
<tr>
<td>An epidemiological perspective</td>
<td>4</td>
</tr>
<tr>
<td>A surgeon’s voice</td>
<td>6</td>
</tr>
<tr>
<td>National Breast Cancer Audit</td>
<td>6</td>
</tr>
<tr>
<td>Radiation oncologist</td>
<td>7</td>
</tr>
<tr>
<td>ACT Physiotherapist</td>
<td>7</td>
</tr>
<tr>
<td>Interview with a Canberra GP</td>
<td>8</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>9</td>
</tr>
<tr>
<td>Population-based Breast Cancer Trends</td>
<td>10</td>
</tr>
</tbody>
</table>
Members of the Sub-committee have been extremely busy during 2015. During the 12 months prior to June, the Subcommittee has been focussed on completing the 15-year report. With the diligent assistance of the project staff, subcommittee members spent many hours planning, discussing, writing, checking and editing the report. This was a huge enterprise, done after-hours at night and during weekends. I take this opportunity to express my sincere admiration, thanks and gratitude to all those individuals who supported this work.

Our fantastic project staff have remained committed and totally dedicated. This year they worked extremely hard, and especially so when meeting deadlines for the 15 year report, coping with last minute requests for tables and graphs, and managing multiple divergent manuscript drafts. Ms Yanping Zhang was recognised for her long contribution with a nomination to the ACT Australian of the Year Awards.

Having completed the seminal 15-year report it seems a good time to reflect on the data collection project, on our goals, and to consider options for the future. New innovative treatments for breast cancer are becoming available ever more rapidly. Increased knowledge of the biology of the disease has led to new biomarkers, new diagnostic imaging options, and better staging technologies. Surgical techniques have continued to improve. Supportive care and advice for patients and families is more readily available through our Breast Care and McGrath nurses. To remain relevant, the data collection has gradually evolved to include data items that reflect some of these changes.

The project team and Subcommittee regularly review the data collected and carefully introduce, after consultation, new items reflecting treatment change, new biomarkers and imaging modalities. Of course, it is the long term follow-up, the longitudinal nature of the project that has made it so useful in assessing changes in patterns of care and treatment effectiveness. The challenge has been to include data items in a parsimonious way to minimise the burden of data collection (the dreaded data form) whilst maintaining the integrity of the long term data in order to allow valid comparisons across time.

The Subcommittee, in the coming year, will be seeking to develop goals going forward, building on our success while accepting the constraint of maintaining the wonderful data collection we already have. A large number of ideas have been canvassed. Examples include collecting more information on breast reconstruction, risk reducing prophylactic surgery and the needs of special groups, for example very young women with breast cancer. Other ideas include looking more accurately at the support patients and families receive from our nurses and psychosocial support teams or the coverage and function of our multi-disciplinary team. Some questions may be addressed by specific research projects based around the project data collection, others may warrant changes or additions to the data set. We would be delighted to receive any ideas or comments from members. The Subcommittee looks forward to presenting some options to the whole group for consideration in due course.

A/Prof Paul Craft
Medical Oncologist
Chair, Data Management Sub-Committee
An Important Message to Participating Clinicians

The bar chart shows the diagnoses of breast cancer cases in ACT and SE NSW have been increasing since the Project started in 1997, but figures for the last 12 months indicate a significant drop in patient consents to participate.

Notifications to the project are still strong, so this suggests that our data providers may have become tired. The Project relies heavily on the support of clinicians to obtain consents and all the necessary data.

We know there are breast cancer sufferers out there keen to participate in this project but lack the information needed to become a participant!

Of the 5700 patients who provided written consent to participate, there are 255 cases pending completion of data entry due to missing information, being mainly treatment or pathology details.

We are optimistic that participation rates will return to previous levels once ALL clinicians are on board and providing data. This project is such a rich source of data, let’s keep the momentum going!!

Quality Assurance Project: 18 years of data collection

A message extract from the Director-General

*News Bulletin Issue 5 – 7 October 2015*

“Breast cancer treatment improving women’s chances of survival

I would like to commend the Breast Cancer Treatment Quality Assurance Project 15 Year Report, released on 1 October 2015, which outlines the findings of breast cancer treatment from diagnosis in the ACT and South East NSW region.

I also wish to acknowledge the Breast Cancer Treatment Group for their invaluable contribution to the health outcomes of women in the ACT and South East NSW, through coordinating, collecting, analysing and interpreting the data.

This 15 year report confirms that breast cancer care delivered by the ACT and SE NSW multidisciplinary teams is of a high quality and that breast cancer survival in our region is excellent. The likelihood that a woman is alive at five and ten years after diagnosis of invasive breast cancer is 91.3 percent and 81.9 percent respectively.

The quality of the data is unique due to the high participation rate, the aggregation of individual case data over a prolonged timeframe and the strong focus on quality assurance.

I also wish to thank all clinicians and patients involved in contributing to the success of this project. The quality of the data is only achievable through significant and collaborative efforts.

The ACT and SE NSW Breast Cancer Quality Assurance Project is conducted by the ACT and SE NSW Breast Cancer Treatment Group, which was created shortly after the release of the National Health and Medical Research Council (NHMRC) Clinical Practice Guidelines for the Management of Early Breast Cancer.”

Nicole Feely
Director-General, ACT Health
Over the past 8 years I have had the pleasure of working on a number of important and topical research studies with several members of the ACT and SE NSW Breast Cancer Treatment Group and have provided epidemiological support in relation to compiling the 10 and 15 year reports. In my experience as a cancer epidemiologist I can say that the BCTG quality assurance dataset is one of the most impressive I have worked with. There are few clinical datasets which are of such high quality, as detailed or complete, or have the level of coverage of the eligible population and length of follow-up of participants. This is a testament to those who originally developed the database, the ongoing enthusiasm of contributors and the meticulous management of the database by Ms Yanping Zhang since its inception over 18 years ago.

The importance of ongoing data collection to monitor and evaluate the quality of treatment provided to women with breast cancer cannot be understated. Not only is this high quality clinical registry crucial to monitoring quality of care and outcomes for women in the area, it also serves as a rich source of data for addressing critical research questions that can guide future clinical practice and improve care for all women diagnosed with breast cancer. Detailed and systematic collection of data on patient characteristics, prognostic indicators, treatments and procedures offers tremendous potential for clinically relevant research to be undertaken, which cannot be addressed using other data sources such as State-based cancer registries that lack this detail. Furthermore, close to population-wide coverage sets the BCTG database apart from many other clinical data collections which collect data within a single hospital in that it avoids the potential biases and limited generalizability of institutionally-based registries.

The value of the BCTG quality assurance database is demonstrated through the various research projects I have been involved in. These include a study comparing outcomes among rural women with their urban counterparts, and an investigation to determine what constitutes safe surgical margins. The findings from both of these studies have important implications for management of breast cancer locally and beyond. For the 15 year report we undertook analyses examining survival, disease progression and compliance with treatment guidelines. Based on the long-term follow-up of outcomes among women participating in the quality assurance database we were able to show significant improvement in survival over time for women diagnosed with breast cancer in the region. Not only has there been a reduction the risk of death from breast cancer over the 15 year period, there has also been a significant reduction in the likelihood of breast cancer recurrence in this time, as shown by the survival curves (below). In parallel the data show significant increases in the proportion of women treated in accordance with evidence based guidelines, from 75% in 1997/98 to 90% in 2011/12. These findings gained considerable media interest at the launch of the 15 year report in October.

I look forward continued involvement with the ACT and SE NSW BCTG on future research projects, and working on analyses for the 20 year report!
Overall survival, breast cancer specific survival and recurrence-free survival among the ACT and SE NSW BCTG cohort

![Graph of Overall survival](image1)

![Graph of Breast cancer recurrence](image2)

![Graph of Breast cancer survival](image3)

**Dr Kerri Beckmann**
Epidemiologist, Centre for Population Health Research
University of South Australia

*Note: Dr Kerrie Beckmann provided assistance with the survival data analysis for the BCTG 15 year report. Dr Beckmann has collaborated with the BCTG previously, providing epidemiological guidance for our team*

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**THANK YOU!**
To John James Foundation

The Breast Cancer Treatment Quality Assurance project 15 year report was successfully launched on 1st October 2015. The authors and Breast Cancer Treatment Group are extremely appreciative of the generous financial support from the John James Foundation for the preparation of this report.
The ACT & SE NSW Breast Cancer Treatment Quality Assurance Project (BCTG QA) recently published its 15 Year Report. This successful collection and examination of data on treatment and outcome of patients diagnosed and treated with breast cancer over the 15-year period (1997-2012) is a significant event in the history of the BCTG QA Project.

This report not only reports to the public the summary of clinical activities and outcome of breast cancer patients treated in ACT and surrounding regions, but also gives feedback to individual clinicians including myself as a breast surgeon on compliance of quality indicators and areas of need for improvement.

I would like to make a few more comments for open discussion.

There is significant percentage of patients in the age group of 50–59 and 60–69, who had non-screen-detected cancers (Table 1, page 16 of the report). As mentioned in the report, there is no data on the information if they had “interval cancers” or if they did not attend the BreastScreen Program. It is more important to know if there was any “missing diagnosis” from the BreastScreen Program. This may require the merging or exchange of data between the BreastScreen Program and the BCTG QA Project.

Table 2 (page 21 of the report) demonstrates the number of operations on a single case. These include the completion axillary surgery if SLNB is positive and re-excision of surgical margins. It has become common to have histological examinations of SLNB and perform completion axillary surgery later if required, as the histological details are now needed for the decision of further axillary surgery. It may be more relevant for the surgeons to know the data on the re-excision groups. The surgeons will select cases carefully for breast-conserving surgery if re-surgery is due to inadequate surgical margins or consider better pre-operative images including breast MRI if it is due to occult or additional pathology.

Not surprisingly, the majority of DCIS were detected from BreastScreen Program and the majority of these DCIS were small lesions (Figure 33, page 52 of the report). It is interesting to note that small number of patients with DCIS had 1-4 lymph nodes involved (Figure 34, page 53 of the report). I wonder if the primary breast pathology could be cancer.

I again congratulate The Breast Cancer Treatment Quality Assurance Project team for their excellent work with the high quality of 15 Year Report.

I would like to thank the team, Yanping Zhang, Jenny Green, in particular Thet Khin for assisting me getting consent and collecting data from my patients. Last but not least I would also like to thank my patients and families who gave the consent for participating in the Project in order for us to continue to improve our service.

Dr Mike He
General Surgeon and Surgical Oncologist
(Breast, Melanoma and Sarcoma)
**Fellowship using the ACT and SE NSW Breast Cancer Treatment Group Database**

I was fortunate to get an Australian National University fellowship in breast cancer under supervision of Dr Rezo. The research project involved evaluating the role of IHC4 score in determining risk of loco-regional recurrence utilizing the ACT and SE NSW breast cancer treatment group database. The project involved close collaboration with the pathologist at The Canberra Hospital, Bruce Shadbolt, and lastly Ivana Sestak from Queen’s University London who is one of the original researchers of the IHC4 score. I had protected research time, regular fortnightly meetings with Dr Rezo who was extremely supportive and provided input at all stages of the project in spite of her overwhelming clinical workload. The project team manager at the BCTG is Yanping Zhang who is so experienced and well versed with all aspects of the database. She and Thet (Project Officer) provided the appropriate data required for the project and provided guidance as needed with data retrieval. The research paper was selected for presentation at several national and international conferences and also won the award for the ‘Best of the Best Oral Presentation (Clinical Research)’ at COSA 2014.

Dr Roopa Lakhanpal  
MBBS, FRANZCR  
Radiation Oncologist

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**Breast Cancer survivorship issues addressed by ACT physiotherapists**

Survival from breast cancer continues to improve as surgery and adjuvant therapies are refined. It is however, recognised that there can be significant and ongoing survivorship issues. These include lymphoedema, upper limb musculo-skeletal morbidity and reduced levels of physical fitness, all potentially influencing psychosocial morbidity. Estimates of the incidence of breast cancer related lymphoedema vary but recent systematic reviews and meta-analysis state a range of 16.6–21% with increased incidence occurring with time following treatment. (Stuiver MM et al 2015). Up to 41% of survivors experienced a decline in upper body function in one study of 287 Australian women. (Hayes et al 2010)

The physiotherapists from the ACT Lymphoedema Service seek to address these issues by taking a proactive model of service delivery with the aim of providing timely, effective and evidence based services to this patient group.

Early detection and management of lymphoedema is facilitated by the availability of pre operative bioimpedance assessment.

All patients that undergo breast cancer surgery involving the axilla at Calvary Bruce, Calvary John James and Queanbeyan Hospitals are seen by physiotherapists on the ward. Prior to discharge they are given advice about appropriate exercises and follow-up. Those that have undergone axillary surgery that is greater than a sentinel node biopsy are referred for physiotherapy follow up.

Physiotherapy follow up will involve ongoing screening for the development of lymphoedema. The bioimpedance device can detect an increase in extracellular fluid before any visible or even subjective feelings of swelling are present. If signs of early lymphoedema are detected, management is immediately offered to the patient. It has been shown that if such early intervention occurs, chronic lymphoedema may be prevented.

Rehabilitation of upper body function is facilitated by guiding patients through a programme of exercises and stretches, scar massage and active encouragement to return to physical activities.

A Lymphoedema Awareness education session is run every month for people at risk of developing lymphoedema.

For women who develop lymphoedema, comprehensive assessment and management strategies are implemented. Current best practice management offered may include compression bandaging, prescription of compression garments and education in skin care, exercise and self massage. Low level laser, graduated compression pump and kinesiotaping are other modalities utilised.

For more information please contact the Physiotherapy Department, Calvary Health Care Bruce on 6201 6190.

Gemma Arnold  
Lymphoedema Service Coordinator and Senior Clinician
The General Practitioner has a key role not only in the diagnosis but also in the referral, continuing care and follow up of breast cancer patients. They are in the ideal position to manage aftercare and follow up issues for breast cancer survivors as well as for their general health care.

Recently BCTG staff* interviewed Dr Ying Liu, a General Practitioner in Canberra.

Tell us a little bit about yourself and your work.

I was trained as a doctor in China, and have been practising as a General Practitioner in Canberra since 1996. Approximately 20% of my patients are from a non-English speaking background, the majority of whom are from Asian countries. Over the years I have seen many women diagnosed with breast cancer and have continued to see those patients during their treatment and follow up care.

So have you been involved with the BCTG project since its beginning?

Yes, I have. The NHMRC Guidelines for Breast Cancer were first released in 1995 and subsequently the Breast Cancer Treatment Group set up in the ACT & SE NSW region in 1996. I was very pleased to be involved as one of the original general practitioners to assist with that data collection.

How do you see the GP’s role in a patient’s breast cancer diagnosis and treatment?

The GP is one of the first connections a patient will make when diagnosed with breast cancer. Because that diagnosis is a great shock, our role is central to them on their long treatment road to recovery. Therefore as a GP we need to provide clear information about available options for our breast cancer patients. Patients trust their GP to provide competent care, advice, and coordinate the continuing whole person approach to that guidance.

What do you feel that an integrative doctor like yourself brings to breast cancer care that patients find unique?

Breast cancer is a very personal diagnosis. The first step is to be able to provide the correct advice to my patients, to help them receive the best care and increase their survivorship. To do this I need to have the most up to date information at my fingertips. As a female General Practitioner, I feel I have a responsibility to my patients to use every means available to research breast cancer treatment and options post diagnosis.

What else do you feel is particularly important to your evaluation and continuing care of breast cancer patients?

The patient’s continuing care and follow up beyond diagnosis is fundamental to that patient’s wellbeing and continued health. Eighteen continuous years of breast cancer research in the region that is the BCTG project, is highly significant and has become a valuable research tool for all.

Where does purple fit into breast cancer research?

The colour purple represents among other things physical and mental healing, strength and abundance. The purple BCTG Follow-up form is an important part of the BCTG project and its outcomes. To me it represents continuing care for another breast cancer survivor, and by filling in that purple form, a small part of an extremely valuable tool for future care and treatment for my patients. The few minutes of my time needed to fill in the purple Follow-up form can make a difference. No matter how busy I am, I try to make time to complete the purple BCTG Follow-up forms as soon as they are put on my desk.

*BCTG staff: Yanping Zhang & Jenny Green from Breast Cancer Treatment Quality Assurance Project
The Breast Cancer Tissue Bank

The Breast Cancer Tissue Bank Project in Canberra has been running since 2009. The central management hub is at the Westmead Millennium Institute in NSW and there are 10 affiliate sites across Australia. The ACT is still active in collecting new cases along with Royal North Shore Hospital, Liverpool Hospital, John Hunter Hospital, St John of God (Perth) and the Brisbane Breast Bank in enrolling new patients. As of the end of October 2015, 7105 have been recruited onto the Australian Breast Cancer Tissue Bank project with 790 from our region. The local operations of the ACT collection centre is funded by research grants from the Radiation Oncology Private Practice Trust Fund since 2012. Elaine Bean of ACT Pathology continues as the local Tissue Bank Officer responsible for processing of biological samples and maintaining the database. Rowena Penafiel has been working with the Breast Cancer Treatment Group to keep the treatment data associated with the Bank up to date.

www.abctb.org.au

A/Prof Desmond Yip
Principal Investigator, Breast Cancer Tissue Bank,
ACT Collection Centre

Acknowledgements

The Breast Cancer Treatment Group has reached 18 years and we would like to thank all the participants for the generous contribution of their precious time, hard work in assisting with the completion of BCTG data collection and follow up procedures. Special thanks to all the surgeons, the medical receptionists, general practitioners, practice managers, practice nurses, breast care nurses including McGrath Breast Care Nurses, administrative staff, radiologists, BreastScreen ACT, ACT Registry of Births, Deaths & Marriages, NSW Registry of Births, Deaths & Marriages, Bosom Buddies, Breast Cancer Network Australia, a large number of pathologists such as from ACT Pathology and Capital Pathology and Breast Cancer Tissue Bank Project Team. Finally, we acknowledge Eisai (Halaven), AstraZeneca, and Novartis for sponsoring the Breast Cancer Treatment Group meetings and also thanks to Lyn North and staff at University House, ANU for providing the venue and resources for our meetings.

ACT Australian of the Year 2016 – Local Hero Finalist

On Thursday 15th October 2015, the Head of Service ACT, David Nicol, announced three of ACT Public Service Employees had been selected as finalists for the 2016 ACT Australian of the Year Awards.

The Breast Cancer Treatment Group is very proud that Yanping Zhang, BCTG Project Data Manager, was selected as one of the finalists for the ACT Australian of the Year 2016, Local Hero Award.

Yanping was selected for her dedication in data management and as a medical researcher. Yanping and her team built one of the world’s most comprehensive and enduring breast cancer research studies, which has become an important data source for the study of breast cancer treatment and management.

In his announcement on the 15th October, David Nicol, A/Head of Service acknowledged the contribution made by each of the finalists.

“Each year the Awards celebrate the achievement and contribution of Australians who are role models for us all. They inspire us through their achievements and challenge us to make our own contribution to creating a better Australia…… Please join me in congratulating these finalists. Recognition of this calibre is just a reflection of their tireless efforts and significant achievements which enhance the Canberra community for all of us.” Congratulations Yanping!
Population-based Breast Cancer Trends for the ACT

The ACT Cancer Registry data is coded by Cancer Institute NSW alongside the NSW Cancer Registry. We have recently received data up to 2013 following a long hiatus caused by delays in the implementation of the new NSW cancer registries system. We are excited to begin analysing and reporting on this data and expect to publish some preliminary results in the 2016 ACT Chief Health Officer’s Report and also potentially on the ACT Health website.

From data previously reported in the 2014 ACT Chief Health Officer’s Report, female breast cancer is the most common cancer affecting women with more than twice the number of cases for colorectal cancer, the second most common cancer in women (see Figure 1).

The incidence of female breast cancer is increasing over time, however it is important to note that mortality is decreasing despite the increase in incidence. National statistics show that for 2007-2011, 89.6% of women with breast cancer were still alive five years after diagnosis. This is significantly higher than for the period 1982-1986 (72.2%).

The age-standardised rate of female breast cancer in the ACT is higher than for other states and territories and Australia combined. Some risk factors associated with female breast cancer include age, affluence, family history, high degree of breast density, endogenous oestrogens, other hormonal factors and personal lifestyle factors. It is likely that a higher prevalence of some of these risk factors contributes to the higher rate of breast cancer in the ACT, but more research is needed.

Data collected by the Breast Cancer Treatment Group (BCTG) and data from the ACT Cancer Registry (ACTCR) complement each other—the ACTCR provides population level trends and the BCTG provides clinical data. Together these data provide an important part of the breast cancer picture for the ACT.

Figure 1: Common cancers in females (breast, colorectal, melanoma & lung), incidence, 1986–2009

Source: ACT Cancer Registry

Notes:
- Rates are age-standardised to the 2001 Australian Standard Population and presented per 100,000 population.
- Rates are calculated as 3-year leading averages ie the average of the year reported and the two previous years.

References
2 Breast cancer risk factors: a review of the evidence, National Breast and Ovarian Cancer Centre, July 2009

Elizabeth Chalker,
Manager, ACT Cancer Registry, Epidemiology Section, Health Improvement Branch, ACT Health

Condolences

Anna Wellings-Booth passed away in October 2014. Anna was a breast cancer survivor and a breast cancer advocate. She was an active member of the Breast Cancer Treatment Group since its foundation in 1997.

Margaret Anne Hodgson (aka Dr. Margaret Bentley) also passed away in December 2014. Margaret was involved with the Breast Cancer Quality Assurance Project work for about 2 years and made great contribution to the data collection.

Anna and Margaret are deeply missed.
A look back at BCTG 2015

Launch of BCTG 15 year report by Simon Corbell

BCTG at Bosom Buddies 20th Anniversary Dinner

ACT Health Australia Day Award

Receiving ACT Health Australia Day Team Award from Peggy Brown

ACT Health Australia Day Award

At 15 year report launch

BCTG Meeting dates for 2016

BCTG Meetings will be held in Drawing Room, University House, ANU at 6:00 pm on Monday of

- 7th March 2016
- 25th July 2016
- 14th November 2016
Contact Details

Any clinical questions should be directed to Dr Paul Craft at the Canberra Hospital on (02) 6244 2220.

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