Breast cancer is common in our region and thanks to early detection and treatment, outcomes for those diagnosed are very good. These factors have resulted in a large workload for health professionals with interest in this sub-specialty. The large volume of work has led to two challenges: finding time to talk to our patients about the project and getting their informed consent to participate, and following up these participants over long periods of time.

Due to the hard work of the project team the participation rate is still high. The high participation rate in this project is one of its greatest strengths. This makes the database truly population-based and therefore tells the real story of outcomes of those with breast cancer in the region. The dual-consent for the Project and the Breast Cancer Tissue Bank remains a high priority. I would like to thank all those who have been involved in giving patients the choice to enter into the project. In particular, I would like to thank the personal assistants to our surgeons.

Continued Page 5...

Dr Angela Rezo
Radiation Oncologist
Chair, ACT & SE NSW Breast Cancer Treatment Group
Data Management Sub-Committee Chair’s report

On behalf of the Data Management Subcommittee I would like to report on the progress of our community-based audit of breast cancer care. We have now been running this project for 15 years. It is especially noteworthy this year, as the recent AIHW report confirmed that the ACT has the highest age adjusted incidence of breast cancer in Australia. As we all know, outcomes from breast cancer treatment can only be assessed with long term observation. The data we have collected over this prolonged period has been invaluable in defining the extent of breast cancer in the region (about 330 new cases per year) and in delineating patterns of care. Although incidence and mortality data are available from cancer registries, only projects like the Breast Cancer Treatment Group can measure prevalence, recurrence and treatment outcomes. Our hard working breast cancer surgeons have been able to benchmark their practice against the whole group and externally, through cooperation with professional college audit programs. We have shown that breast cancer survival rates in the region are at least equivalent to those anywhere in Australia and overseas. Given the high incidence in the ACT, our results are reassuring.

It gives me great pleasure to acknowledge the full time staff members. Yanping Zhang, our Project Coordinator/Data Manager, has been with the project from its design and inception in 1997. Ms Thet Thet Khin, our project officer, joined the team in September this year. We said farewell to Manda Bradley in May. Manda has been a fantastic asset to the project over the last 6 years and we wish her well in the future. The project exists because of funding from the Capital Region Cancer Service of ACT Health. This year we continued to employ Margaret Bentley, a casual medical officer, to undertake data collection and pathology audit in collaboration with the project team.

Finally I wish to acknowledge the continued voluntary participation of over 5,000 patients, both women and men, who allow us to collect information about their treatment and of general practitioners, who generously provide follow-up information.

The challenge for 2013 will be to maintain the data collection in the face of increasing workloads, especially for our surgeons. We look forward to gleaning more insights into breast cancer treatment in coming years.

A/Prof Paul Craft
Medical Oncologist
Chair, Data Management Sub-Committee

A message from the director, BreastScreen ACT

Congratulations – another good, but very challenging year for the Breast Cancer Quality Assurance Project team. We saw the departure of Robyn (Manda) Bradley and welcomed our new Project Officer Thet Khin to the team. Yanping, as always, has been extremely diligent in ensuring that the project has been well coordinated. She has liaised extensively with key stakeholders in the attempt to achieve as high a participation rate as possible. It has been a very challenging year as we now only have three breast surgeons in the ACT (we have had up to 13 in previous years). This has placed a great onus and burden on the three surgeons and the oncologists to obtain consents and provide the data. Some of the outstanding consents and data date back almost 10 years.

The perseverance has paid off though, as we recently registered over 5,000 breast cancer patients. The project can proudly boast that the project has achieved a 93.6% participation rate. Work has now begun in earnest to cleanse the data for the 15 year report. I would like to thank all clinicians who continue to participate in the data collection and those that will be assisting in compiling the 15 year report.

Wishing you all a very safe and happy festive season!

Yvonne Epping
Director, BreastScreen ACT
15 years of data collection: preliminary results

The Quality Assurance Project reached its 15th anniversary in May 2012. To date, 5,050 women and men with breast cancer were enrolled by 49 clinicians throughout the region from June 1997 to December 2012, with 93.6% of patients agreeing to include their information in the Project database.

Note that Graphs 1-3 and Table 1 includes the final number of 4,925 selected for analysis in the upcoming 15-year report.

Graphs 2–3 provide information on women with invasive breast cancer, indicating some changes in the use of adjuvant and hormonal therapies over the last fifteen years.

After 15 years of follow-up, our results show some promising outcomes, with 75.4% of patients being alive and disease free to date (Table 2). Of 415 deaths, 60% were due to breast cancer. This table excludes 399 cases lost to follow-up or their current status is unknown. There are 11 cases where the cause of death is unknown.

Further results will be presented in the 15-year report in the near future. For more details relating to the results please contact Yanping Zhang (yanping.zhang@act.gov.au). You may contact Dr Angela Rezo (angela.rezo@act.gov.au) if you are interested in being involved with the preparation of the 15-year report.

Note

1. Includes only female patients with invasive breast cancer, with surgeries performed between 1997–98 and 2006–07 financial years. The data exclude 399 cases lost to follow-up and 11 cases with cause of death unknown.

2. Data are preliminary and are not for citation.
**Benefits of participating in BCTG as breast care nurse**

As a Breast Care Nurse providing data to the Breast Cancer Treatment Group on behalf of Dr. A-J Collins in the Bega Valley since 2005, competing demands of patient support and data collection can be a challenge. However over the years I have come to view the data collection as a tool to assist in giving a summary of an individual’s breast cancer, their treatment and monitoring for the follow up schedule.

Of course the information provided is not just about individuals but provides a snap shot of what is happening in our area. Many women apart from coping with their own concerns about a breast cancer diagnosis have the additional queries of family and or friends from city areas regarding the care available in regional areas. Being a Breast Care Nurse having the information from the project regarding treatment and long term patient outcomes, I can assist to reassure women and their families. In addition, the information provided in the newsletters at the end of each year provides current answers to general questions relating to breast cancer and treatment.

As a Breast Care Nurse, it is obvious how the information from the project assists me in my role. To my surprise many women when they send back their completed consent forms write little notes, indicating their enthusiasm towards participating in something that will help understand breast cancer. Many women by participating feel they are involved in something bigger than themselves.

Many thanks to team involved with the BCTG for your efforts over the years to keep this flow of up to date information coming.

**Jenny Garner**  
Breast Care Nurse  
Bega

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**From the GPs desk**

The Breast Cancer Treatment Group has entered its 15th year of existence and is to be congratulated for the important role it plays in gathering and refining data about breast cancer in the ACT and surrounding NSW, fostering research and improvement in treatment of the disease.

Breast cancer touches all of our lives, as individuals, partners, relatives and friends of sufferers.

As GPs we are at the front line of suggesting breast screening, teaching self examination, initiating investigations in symptomatic patients, delivering good or bad news about results. When there has been a positive finding, we are counselling patients and worried relatives, on the phone trying to organise speedy specialist appointments, and coordinating referrals to different oncologists. I feel the role of the family GP never diminishes, especially in the long term follow up, and the patients I have followed for many years after a breast cancer diagnosis remain some of the most grateful and loyal in my practice.

It is indeed heartening to be able to follow these patients long term, see them living well, and to tell patients that despite the increased reportage of breast cancer incidence, the death rate from breast cancer itself is declining.

Integral to our knowledge is the availability of accurate data.

I echo Professor Jane Dahlstrom’s words in 2011 honouring the work of Associate Professor John Buckingham, who is greatly missed. He was always passionate about collecting good data, and researching it, encouraging younger colleagues and students to study the data and publish it.

I urge my fellow GPs to always fill in the purple Breast Cancer Treatment Group patient follow up forms, and send them off. Research is important and ultimately benefits all of us, and it only takes a minute!

**Dr Denise Kraus**  
Interchange General Practice  
Canberra City
Breast cancer in Australia: an overview

The Australian Institute of Health and Welfare recently published a document which provided a comprehensive overview of national statistics on breast cancer in Australia.

In 2008, a total of 13,567 new invasive breast cancers were diagnosed in Australian females. This is equivalent to 37 females being diagnosed with invasive breast cancer every day. Breast cancer was the most common cancer in females, representing 28% of all reported cancers, with the majority (69%) of cases diagnosed in females of age between 40 and 69.

The number of new breast cancers has more than doubled between 1982 (5,310 cases) and 2008 (13,567). There was a very rapid increase in age-standardised incidence rate between 1990 and 1995 because of introduction of the national breast screening program. Since 1995 the rate has remained fairly stable.

Mortality in breast cancer females is decreasing and survival is improving. A total of 2,680 females died from breast cancer in 2007, making it the second most common cause of cancer related death in Australian females after lung cancer. Between 1982-1987 and 2006-2010, the percentage of 5 year relative survival from breast cancer increased from 72% to 89%. This improvement in survival from breast cancer may be due to the combination of early diagnosis associated with screening, and better treatments.

Australian females diagnosed with breast cancer had better survival prospects compared with females in other countries and regions. However, some subgroups of the population have lower survival including females living in remote areas and Aboriginal and Torres Strait Islander females.

Though far less common, breast cancer does occur in males. In 2008, there were 113 breast cancers diagnosed in Australia. The risk of a male being diagnosed with breast cancer before the age of 85 years was 1 in 688. Between 1982 and 2008 the number of new breast cancers diagnosed in males increased slightly (from 61 to 113 new cases). The age-standardised incidence rate of breast cancer in males remained relatively stable, at about 1 per 100,000.

Given the ageing population, the number of females diagnosed with invasive breast cancer is expected to increase. Projections suggest that in 2020, the number of new breast cancer cases will be about 17,210. This would equate to 47 females being diagnosed with breast cancer every day in 2020.

Dr Alison Davis
Medical Oncologist
Canberra Hospital

Breast Cancer Treatment Group Chair’s report...continued

In this issue of the newsletter there are a couple of articles on breast cancer follow-up. Over the last year, a group of interested health professionals, consumer representatives and administrators met on several occasions to discuss breast cancer follow-up. Various options of follow-up care were discussed. Please refer to these articles for more perspectives on this issue.

This year we had wonderful speakers talking about a range of issues. Kimberley Au, an exercise physiologist, gave a talk titled: “Exercise is medicine for cancer management”. Kimberley spoke enthusiastically (and based on the evidence) about the benefits of appropriate exercise for cancer patients stating that exercise should be considered as an adjuvant therapy. The message was to avoid inactivity and to exercise during and post treatment and to seek professional help for exercise “dose”. We had the pleasure of hearing Kerryn Ernst speak about her role as the MacGrath Foundation Advanced Breast Care Nurse.

Kerryn gave a great account of the aims of the MacGrath Foundation and her personal experience in the job that she is so passionate about. Dr Jeremy Price gave a superb talk about clinical value of Breast MRI at BCTG meeting on 26th November 2012.

Finally, I would like to acknowledge the hard work done by the Project Office team led by Yanping Zhang, the Project Co-ordinator and data manager. I would like to thank Robyn Manda Bradley for her commitment over the years and to wish her well in her new career, and to welcome Thet Thet Khin as the new Project Officer.

Wishing you all a merry Christmas and a safe and happy new year!

Dr Angela Rezo
Radiation Oncologist
Chair, ACT & SE NSW Breast Cancer Treatment Group
Extending breast cancer surgery techniques

For many decades, the choice for women has been between breast conserving surgery (i.e. lumpectomy or wide local excision) and mastectomy. Either may be followed by radiotherapy to the breast or chest wall, respectively. The aim with any breast conserving procedure is to obtain complete removal of the cancer with adequate margins. A secondary but no less important aim is to achieve an adequate cosmetic result which is not always possible. This can result in obvious volume defects, distortion and displacement of the nipple and areola.

In more recent years, a new field of “oncoplastic breast surgery” (OPS) has been developed. This lies somewhere between a traditional lumpectomy and a mastectomy where larger tumors or those in a difficult position can potentially be removed with a breast conserving procedure. The OPS aims to use plastic surgery techniques to reshape the breast after a lumpectomy or to incorporate a lumpectomy in the procedure. This allows the breast cancer to be excised with adequate margins while re-shaping the breast to optimize the cosmetic result. Techniques used include the incorporation of a lumpectomy into a breast reduction-type procedure, re-centralization of the nipple-areola complex and various mammoplasty techniques. OPS techniques can be divided into Level I procedures that can be easily learned and performed by most breast surgeons and Level II procedures, which require more formalized training in plastic surgical techniques.

Surgical trainees in Breast Surgery are encouraged to obtain training in this area and there are formal Oncoplastic units operating in Australia and overseas that offer Fellowship training in OPS. As part of this, a pilot Audit of Breast Reconstruction and OPS has been commenced and is currently in its first six-month trial. OPS and breast reconstruction have been shown to be safe techniques in cancer surgery, however, as with all newer surgical techniques; rigorous audit of results is required. It is hoped that this will eventually be incorporated into the National Breast Cancer Audit.

OPS is a new and exciting area in breast surgery that greatly expands surgical techniques. It requires close collaboration in a multidisciplinary framework, for example with radiologists to define and localize tumours better before surgery. It will benefit all patients both with aesthetic results and cancer treatment and it will hopefully make decisions about surgery easier.

Dr Carolyn Cho
Surgeon, Oncoplastic Subcommittee
Breast Surgeons of Australia and New Zealand Inc.

Breast Cancer Tissue Bank

The Breast Cancer Tissue Bank Project in Canberra has now entered its third year of operation in a fruitful collaboration with the Westmead Millennium Institute. Despite a cut in funding in the project which has led to two collection centres in Sydney ceasing recruitment of new donors and other centres reducing recruitment targets, the Canberra collection centre has maintained its level of operations with the additional grant support of the Radiation Oncology Private Practice Fund. Collection of additional treatment data from the Radiation Oncology and Medical Oncology departments has begun and is ongoing. As of the end of October 2012, 443 participants have been recruited from our region. The Breast Cancer Tissue Bank at the time had a total of 4580 enrolled subjects with 87620 available biological samples.

The publication of a series of landmark articles in the June 21, 2012 issue of Nature [http://www.nature.com/nature/journal/v486/n7403] covering a number of new discoveries made from genome sequencing of breast cancer has highlighted how important this Tissue Bank resource is for translational research and development of treatments. It is apparent now that there is a wide diversity in breast tumours on the genomic level with different driver mutations that may be targeted in different and novel ways.

www.abctb.org.au

A/Prof Desmond Yip
Principal Investigator, Breast Cancer Tissue Bank,
ACT Collection Centre
Post mastectomy radiotherapy and breast reconstruction

Most women diagnosed with breast cancer will undergo breast conservation therapy. For some women, however, a mastectomy may be surgically necessary or personally preferred. Postmastectomy radiotherapy (PMRT) has been shown to reduce the risk of breast cancer recurrence and increase the chance of survival in selected groups of women.

Generally breast reconstruction is delayed until after radiotherapy due to the increased risk of complications. The need for PMRT, however, is not always known prior to surgery and, therefore, some women will receive radiotherapy to their reconstructed breast.

Breast reconstruction may be performed using an artificial implant, the woman’s own tissue (called an autologous reconstruction often from the tummy or back) or a combination of both.

So what are the potential complications after radiotherapy? The commonest reported complication to implant reconstruction is capsular contraction. This occurs when the normal scar tissue around the breast implant hardens and “contracts”. This can distort the position, shape, and appearance of the implant, causing it to feel hard and sometimes painful. In severe cases surgical revision is necessary. Capsular contraction can occur without radiation (reported rates of between 0-20%) but is increased in women who receive radiation to the implant (15-50%). Generally the risk of contraction is 3 times greater in women who receive radiotherapy. Other potential complications are infection, implant rupture and loss of the implant. The risks of complications to autologous reconstructions are less, but include fibrosis or hardening and distortion of the breast.

Despite these potential complications most women are still happy with the cosmetic result of their reconstruction.

Good or excellent cosmetic results have been reported in 51-75% of women with implant/tissue expander reconstructions and around 80-85% in women with autologous reconstructions after radiotherapy.

Postmastectomy radiotherapy may also affect the type of reconstruction recommended to women after treatment. Most surgeons will not recommend an implant after radiotherapy due to the changes in blood supply and the tissues ability to heal after radiotherapy. An autologous reconstruction allows unirradiated tissue to be brought to the chest wall and usually results in a much better cosmetic outcome than a permanent implant after radiotherapy.

Every patient is different in terms of their need for radiotherapy and their postmastectomy reconstruction options. It’s important to discuss these issues with your own surgeon or radiation oncologist.


Dr Lisa Sullivan
Radiation Oncologist
Shared follow up care with GPs

The journey through treatment for breast cancer can be complex and difficult. As General Practitioners, we are passionate about providing continuing whole woman care as our patients navigate this journey and beyond. We believe women need a “medical home” where they can find support, information and coordination of care, and that home should be a general practice where a woman has a known and trusted GP. With this principle in mind we have started the process of developing a formal Shared Care guideline between ACT Health Directorate and General Practice for women who have completed initial treatment for early breast cancer. There are pivotal points in the treatment process where input from our specialist colleagues is essential, and these may vary with each individual. However the follow up care follows a standard, predictable course for the majority of women. GPs are concerned about the increasing development of treatment “silos” and feel strongly that a woman’s ongoing treatment for breast cancer can be safely and effectively managed in the context of other care she and her family might require in general practice.

A move away from hospital centred care must be designed to ensure that essential follow up is carefully managed and monitored. All the treating team including the patient must have access to information of already performed investigations and the ongoing management plan. Developing this Shared Care Guideline will require consideration of existing protocols from elsewhere; development of a locally specific shared record; clear documentation of referral pathways; processes, particularly when unscheduled specialist input is required, and education of GPs, nurses and specialists once the protocol is agreed. Consumer input will be an important part of this process. Although in its early stage, I believe there is a general commitment to the development of a Shared Care guideline, and this will ultimately help women with more streamlined, integrated and holistic care.

Dr. Helen Toyne
GP Advisor, ACT Health Directorate

Thank you to all GPs

Your response does make a difference!

To date, 15,700 follow-up forms were sent out to clinicians and GPs. For some patients it may be their first follow-up (1 year after initial treatment) or in this fifteenth year of the project, their 15th year of follow-up. The information collected from these forms is vital to the success of the Project, and in producing valuable statistics, which will lead to improved treatment for patients with breast cancer.

Of the 15,700 forms sent out, the Quality Assurance project office has received 15,300 responses from General Practitioners so far. It is never too late to send in a form since information can be backdated.

If you have any purple forms lying around, please let us know by returning the form to the “Breast Cancer Treatment Quality Assurance Project”, ACT Health, 1 Moore Street, Reply Paid 825, and CANBERRA ACT 2601.

Generally, a specialist clinician may see a patient for between 1 to 5 years. Any time after one year, the GP may be the only source of contact with the patient. The project does not contact the patient directly but it depends on the goodwill in time and effort from the GPs for feedback. So a huge thank you to all the GPs who contributed toward the pursuit of improved treatment for their patients.

Breast Cancer Treatment Quality Assurance Project Team
Shared follow up care for early breast cancer patients: a specialist perspective

Last year we reviewed the data to support the shared follow up care of women treated for early breast cancer. This is an important issue for Canberra and the surrounding community as we have so many women surviving breast cancer and now it is creating overcrowding of oncology clinics (a great problem to have!). This year we have started the concept of shared routine follow up care in consultation with breast cancer specialists, general practitioners and breast cancer nursing staff.

Medical evidence, and indeed our Australian breast cancer guidelines, support routine breast cancer follow up visits being performed by a variety of health practitioners as being safe. Shared care would include follow up visits performed by general practitioners and in some cases may include nurse practitioners or breast care nurses, rather than surgeons, radiation or medical oncologists only.

The advantage of shared follow up care would include more flexibility for breast cancer survivors and their doctors. For many women, it may be a great relief for their GP to resume their routine care and be freed from the acute hospital setting. Some women find specialist follow up visits stressful and an unpleasant reminder of their previous breast cancer treatment. Other women may be worried about losing more regular contact with their oncologist and may find the specialist follow up in the hospital setting very reassuring. Clearly any devised system needs to have flexibility to accommodate the preferences of different individuals and their treating doctors. It would also need to ensure open communication between the different health practitioners and prompt re-entry to the specialist clinic for women with problems.

As a group we are keen to progress shared follow up care of breast cancer survivors in the A.C.T. and are pleased that there is an interest among Canberra’s general practitioners also. We are fortunate that Dr Helen Toyne, GP advisor for the ACT Health Directorate, has taken on the role of advocating for the development of Shared Care Guidelines in the ACT.

The issues involved in shared follow up care are quite complex and there will never be a “one size fits all” approach. From the specialist perspective there may be some anxiety about completely handing over follow up care to general practitioners. For women on endocrine therapy and particularly those with significant side effects from treatment, there may be benefit to occasional specialist review to maximise compliance with medication and optimise management of toxicity. Intermittent specialist review also ensures that we can update women regarding new breast cancer developments from clinical trials, which may be relevant to them. Amongst other things, we hope to be able to establish a database of women on routine breast cancer review so that no one is “lost to follow up”, and again to ensure best possible care in the long term.

Dr Nicole Gorddard
Medical Oncologist
Canberra Hospital

Thank you

The Quality Assurance Project has reached 15 years and we would like to thank all the participants for their generous contribution of their precious time, and hard work in helping us for completion of BCTG Data collection and follow up procedures. In particular, we would like to thank the surgeons, medical oncologists, radiation oncologists, radiologists GPs and breast care nurses for their patience, collaboration, care, and hard work. We would also like to thank ACT Pathology, Capital Pathology and Tissue Bank Project Team for their support.
Presentations

February
Dr. Nicole Gordddard, the medical oncologist from Canberra Hospital gave a presentation of “Breast Cancer Follow up and Shared Care Models”.

May
Kimberley Au, exercise physiologist from Clinic-88 gave a talk titled: ‘Exercise is medicine for cancer management’.

August
Kerryn Ernst talked about her role as the McGrath Foundation Clinical Nurse Co-ordinator for advanced breast cancer. Kerryn gave an excellent presentation on the McGrath Foundation resources and on the work she is doing in the ACT supporting women with advanced breast cancer.

November
Dr Jeremy Price, Radiologist, TCH, BreastScreen ACT and Universal Medical Imaging, Kingston gave a (superb!) presentation on the clinical value of Breast MRI, using recent clinical cases to illustrate its various roles. As part of the pre-operative work-up Jeremy said that MRI was particularly useful in younger women with denser breasts where the extent of disease was often not clear from conventional imaging. Invasive lobular cancer was another group where there was often much more extensive disease than first anticipated. Jeremy also demonstrated that many cases of DCIS did not show any calcification on mammograms and yet could be very extensive and clearly shown by MRI.

Jeremy then presented results from using MRI screening for local ACT and SE NSW women at increased breast cancer risk. From a total of 567 screening MRI studies performed over a period of 6 years, 15 additional cancers had been detected using MRI. Jeremy is now commencing a Breast MRI service on the new 3.0 Tesla magnet which has recently been installed in the Calvary Public Hospital as a Public-Private Partnership with Universal Medical Imaging, a private practice based in Kingston, ACT.

Publications

Prognostic value of LINE-1 retrotransposon expression and its subcellular localization in breast cancer.

Posters


Honour Walk

Chief Minister Katy Gallagher launched the unveiling of the 2012 additions to the ACT Honour Walk on 11 May 2012. The photo was taken in the pedestrian area, Ainslie Avenue between London Circuit and City Walk in Canberra City.
2013 dates for BCTG meetings

BCTG meetings will be held in the Drawing Room, University House, ANU at 6:00pm on:

• Monday, 18th March 2013
• Monday, 29th July 2013
• Monday, 4th November 2013.

Breast Cancer Treatment Group

BCTG Group photo taken on 26 November 2012 at the BCTG meeting.

Acknowledgements

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The BCTG newsletters, reports, publications and information of interest can be found at:
Contact Details

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

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