In 2018, the ACT & SE NSW Breast Cancer Treatment Group (BCTG) Quality Assurance Project continued the important work of recording clinical outcomes for people diagnosed with breast cancer in our region and providing feedback that enables the ongoing delivery of high-quality breast cancer care. I would like to acknowledge and congratulate the project team, led by Yanping Zhang, for continuing their diligence in maintaining a high quality and secure database while developing strategies to ensure ongoing recruitment. In this newsletter, there are thoughtful reflections of breast cancer treatment in the last 20 years as well as articles on some exciting developments in breast cancer treatment. We look forward to the modernisation of data collection methods as detailed in A/Prof Paul Craft's report, and we look forward to working on the 20-year report due for publication in 2019.

Continued on page 5

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

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Data Management Sub-Committee Chair’s Report

At this time of the year we momentarily pause and consider progress made and challenges ahead for the Quality Assurance Project. We have completed another 12 months of subject enrolment and data collection. A manuscript has been prepared looking at risk factors for recurrence in early breast cancer. And, most importantly, work has started on preparing the 20-year report. It is an exciting prospect to be able to summarise changes (and improvements) in the care of persons with breast cancer over such a long period.

For the 20-year report we have planned a one-off match of the breast cancer data base with the National Death Index which will provide a further check of the vital status of participants in the project. This information will supplement the manual reporting we receive about the progress of persons who have been treated. Fortunately, the outcomes continue to surprise us on the “up-side” with results better than expected based on historical experience and trial results.

Looking forward, the Data Management Sub-committee remains committed to modernising the data collection, particularly through collaboration with the Epidemiology Branch of the Health Directorate. A minor protocol amendment to allow the data match through the Australian Institute of Health Welfare will be followed up with a more comprehensive review of our methods to maintain data quality and compatibility with the current data set, but with enhanced capture of new information. Some of the other contributions to the Newsletter attest to the rapid pace of change in breast cancer care, with new knowledge informing best practice at an increasing rate. Progress has been occurring in surgical techniques, radiation therapy, drug therapy, supportive care and in survivorship.

The data collection has had to adjust to take the new knowledge into account. The Quality Assurance Project, from its inception, has always been about speeding the introduction of new, evidence based care, into our routine practice in a timely and efficient way. In this way we seek to improve the outcomes for people affected by breast cancer.

I thank the Data Management Sub-committee for their work through the year and especially for their forbearance. I thank the team of Thet Khin, Jenny Green, and Helen Porritt, and of course Yanping Zhang. They continue to work above and beyond. Especially I would congratulate all of the clinicians who continue to support the work, always on a voluntary basis. And finally, I thank again those affected by breast cancer, who trust us to safely collect and store their information.

We look forward to a productive 2019 and the excitement of producing the 20-year report.

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

THANK YOU!

Radiation Oncology Private Practice Fund

We would like to thank the Radiation Oncology Private Practice Fund for their generous financial support to the BCTG Quality Assurance Project for 2018/2019. This support allows us to assist clinicians to complete the treatment section of the Data Collection Forms and results in high quality data that serves as a basis for current and future research studies and publications.

Breast Cancer Treatment Quality Assurance Project Team
The Quality Assurance (QA) Project has been running for over 21 years. In 2000 we had 700 diagnosed breast cancer cases which has now risen to 7,700. In 2000 we had two staff members and presently still have two staff members with some extra staff hours supported by some additional funding provided by the Radiation Oncology Private Practice Fund (ROPPF). Thank you to ROPPF for keeping the QA Project going.

Figure 1: The 21 year data set has demonstrated how the treatment of cancer has progressed, and better clinical outcomes have been achieved. It has identified how surgery has developed and how overall the patient’s quality of life has improved through a better understanding of the disease, its causes and subsequent treatments. The information gathered and stored in the BCTG database provides a rich source of information for clinicians and researchers. This information is the subject of the BCTG 20-year report currently in production.

Figures 2 and 3: The number of patients are identified by place of surgery and year and illustrates the significant progress over the 20 year period. Thank you to the 7,050 breast cancer patients who provided written consent to participate in the project. Thank you to the participating clinicians for their voluntary contribution. We also thank all GPs in the ACT and surrounding regions for their ongoing support by providing valuable follow up information. Up to now, about 31,000 follow up forms have been collected from GPs and clinicians and entered on the BCTG QA Project database.

Figure 4: Our current data collection uses paper forms and often suffers from human error e.g. when filling in the forms or by data entry staff misreading or misinterpreting handwriting on the forms.

I recently attended the Health Data Analytic (HDA) conference and Annual Scientific Meeting of the Australasian Health Research Data Managers’ Associations (AHRDMA). This was a timely opportunity to catch up with digital health network colleagues, and I took home some good ideas about how to improve our work and why our priority is to move from paper to electronic data collection. I was also impressed by so many speakers, who described the benefits of translating electronic health data to make a measurable impact on clinical care. The meetings have also emphasized the legal and ethical challenges and solutions in the era of Big Data, showing that “better information means better care”.

The BCTG Data Management Subcommittee is working on a revised protocol for electronic data collection. The new system will be more streamlined and provide a faster, more efficient and more cost effective process for data collection and management.

Yanping Zhang
Quality Assurance Project Coordinator/Data Manager
ACT & SE NSW Breast Cancer Treatment Group
Breast Cancer Treatment Group Quality Assurance Project Collaboration with the BreastSurgANZ Quality Audit

The Australian Capital Territory and South East New South Wales Breast Cancer Treatment Group Quality Assurance Project (BCTG QA Project) is one of the longest running longitudinal studies in Australia.

BreastSurgANZ Quality Audit (BQA) is the longest running electronic data collection in Australia.

The Breast Cancer Treatment Group established the ACT & SE NSW Breast Cancer Quality Assurance Project in 1997, as a one year study. This followed the 1995 publication of the Australian government national guidelines for the management of early breast cancer.

The BQA began life in 1998 as a pilot study, and is now directed by the Breast Surgeons of Australia and New Zealand (BreastSurgANZ).

It is mutually advantageous that these two singular projects form a collaboration where the BCTG QA Project can provide valuable and accurate data for inclusion in the BQA on behalf of ACT & SE NSW breast surgeons.

The BCTG QA Project database includes information on each patient from basic demographic information, through procedures and treatment (pre & post-surgery) and tumour pathology, to updating patient status via continuing follow up. This data is submitted annually to the BreastSurgANZ Quality Audit on behalf of ACT & SE NSW breast surgeons. This has occurred since 2001.

It is important that the data submitted to BQA is of high quality, accurate and statistically sound. This is not always an easy task and it is sometimes necessary to go to great lengths to obtain patient data, verify and validate that data. Of the 21 years of the study, these latter years are finding breast surgeons less able to find time to collect and provide the information for the Data Collection Forms.

Notably, the BQA itself has undergone a number of changes over the last two years, both in personnel and in BQA software, now including updated High Quality Performance Indicators.

These factors have all added to the level of workload in the BCTG office, but it is satisfying to see that the end result delivered, is a quality product!

Jenny Green
Project Officer (one day/week)
Breast Cancer Treatment Group Quality Assurance Project

Reflections of a Rural General Surgeon

I have been working in Goulburn as a General Surgeon with an interest in breast cancer surgery now for 25 years. There have of course been many changes to treatment over this period and great improvements in survival. I believe the result of all these changes is that treatment is now individualised for the patient and her own particular pathology.

Many factors have helped me to continue treating breast cancer in this environment including continuing education at the Royal Australasian College of Surgeons (RACS) meetings, Australasian Society for Breast Disease meetings and Mayo Clinic Interactive Surgery Symposia. In addition, the continuing support from multidisciplinary specialists in radiation oncology, medical oncology, radiology and pathology and the support from Breast Care nurses as well as the support of local General Practitioners and 20 years of attendance at BreastScreen ACT assessment clinics.

The Breast Cancer Treatment Group Quality Assurance Project has also been vital to me, not only allowing me an avenue for compulsory RACS audit requirements but giving me feedback about my patient’s treatments and outcomes.

I believe many patients prefer to have treatment close to home so I have kept on going, trying to keep up with the changes in treatments and technology.

It has been an honour and a privilege to treat these patients who tend to be my most grateful patients and the ones who keep seeing me for follow up for the longest time.

I recognise that the future for surgeons like me is limited with increasing specialization of breast surgeons, oncoplastic surgery etc., but for me, it has been a great journey with my patients and I am very thankful for it. I will continue on for as long as I can.

Dr Margaret Beevors
General Surgeon
Ellesmere Specialist Centre, Goulburn
Farewell and Welcome

I would like to once again acknowledge the hard work and commitment from the Breast Cancer Treatment Group (BCTG) Quality Assurance (QA) Project team. It has been a very productive year and is culminating in the cleansing and finalising the 20 year data set. A huge thank you to Yanping, Thet, Jenny and Helen for their continued commitment to the project.

I would like to thank and farewell the following people who, over the years, have actively participated in, and contributed to, the BCTG QA Project; Angela Rezo, Gemma Arnold, Joan Bartlett, Anne Bicknell, Susan Bell, Kay Johnson, Di Summerhayes, and Jane Twin.

We are very fortunate to have had Dr Angela Rezo as Chair of the BCTG over the last 8 years. Angela has been instrumental in progressing the project and achieving great outcomes. The most notable of these include, the completion of the 15-year Report, launched by the ACT Health Minister, Simon Corbell in Oct 2015, supporting the collaboration with the Breast Cancer Tissue Bank, and obtaining a variety of eminent guest speakers. Furthermore, without Angela’s support to secure the financial assistance from the Radiation Oncology Private Practice Fund (ROPPF) we would not have been able to continue to collect and validate the individual client data.

On another note, I would like to welcome Dr Lisa Sullivan as the new Chair of the BCTG for 2019, a new group member and Clinical Coordinator from BreastScreen ACT, Dr Karen Pahlow and a Director of Cytology from Capital Pathology, Dr Tracey Lu.

Looking forward to 2019 with great anticipation and the hope that we may complete the data analysis for the 20-year report.

Yvonne Epping
Director
BreastScreen ACT

Breast Cancer Treatment Group Chair’s Report (continued)

I continue to be impressed by the wide range of health professionals and consumer representatives that make meaningful contributions to the meetings, and by the enormous voluntary contributions to the database made by treating clinicians, GPs, together with their administrative teams, and of course the invaluable contribution of the breast care nurses. Without these voluntary contributions, the Project would simply not exist, and certainly would not have been sustainable for so many years.

I would like to thank our excellent 2018 speakers, Dr Elly Law, Dr Farhan Syed, and Prof Karine Chevreul whose talks are summarised in this newsletter and would also like to thank our industry sponsors.

I would like to thank the Radiation Oncology Private Practice Fund for their ongoing financial support. I warmly welcome Dr Lisa Sullivan who will be taking over as Chair of the Breast Cancer Treatment Group in 2019. Dr Sullivan is a radiation oncologist and breast cancer expert who will, no doubt, make an excellent contribution to the BCTG in her new role.

Dr Angela Rezo
Radiation Oncologist
Chair, ACT & SE NSW Breast Cancer Treatment Group
Pathology, Central to the Diagnosis, Treatment and Management of Patients with Breast Cancer

A pathological diagnosis is the result of a complex series of activities, mastered by the pathologist. It involves processes of observation, perception, attention, memory, hypothesis creation/problem solving, communication, among others. Over the past 20 years the complexity of the information provided in the pathology report for breast cancer has increased enabling more refined, and personalised, treatment of patients with breast cancer.

Pathologists from ACT Pathology and Capital Pathology have been members of the ACT & SE NSW Breast Cancer Quality Assurance Project (BCTG QA Project) since its inception in 1997. The founding pathologists included Ian Clark, Jane Dahlstrom, Sanjiv Jain, Dugald McCallum and Jane Twin. I have been fortunate to be a member of the Data Management Subcommittee since it formed. This has meant, among other tasks, troubleshooting queries in relation to definitions and “cleaning” of pathology data entries. The extracted information from the pathology reports has continuously needed updating with advances in our understanding of how pathology parameters can guide management and predict prognosis. Currently pathology forms more than 11 of the 33 current BCTG data items available to clinicians and researchers.

The pathologists have thus had a central role in the success of our project. I wish to acknowledge all pathologists, from practices in our region, for their contributions to BCTG.

Prof Jane Dahlstrom
Anatomical Pathologist
ACT Pathology,
The Canberra Hospital

Pathologist Roles in Breast Cancer Care

Capital Pathology, under the leadership of Dr Ian Clark (CEO of Australia Pathology and Capital Pathology), is a National Association of Testing Authorities (NATA) accredited medical testing laboratory that provides quality pathology services in the ACT, South Coast, Snowy Mountains and Goulburn regions. We have contributed to the Breast Cancer Treatment Group (BCTG) Quality Assurance (QA) project from the very beginning and for a period of over two decades, and we are very proud that we are still continuing to do so.

We are in an exciting era and are witnessing rapid advances in breast cancer care. As Pathologists at Capital Pathology, we provide quality pathology assessment for each individual patient’s specimen, including determining whether a tumour is benign or malignant, as well as how far and how rapid the tumour has grown within the breast and whether it has spread to lymph nodes or to other organs. We also determine the kinds of proteins the tumour expresses, such as Estrogen receptor (ER), Progesterone receptor (PR) and Human epidermal growth factor receptor-2 (Her2), and our analysis determines whether or not the tumour should be treated with endocrine therapy (like tamoxifen, among others) or anti-Her2 therapy (like trastuzumab, among others).

We are now also able to provide genetic testing through Sonic Genetic for the BRCA gene test and Prosigna for breast cancer patients. These novel testings can help predict the likelihood of recurrence of a tumour after treatment, especially in early stage breast cancer and can be beneficial for certain family members.

With ever-increasing numbers of patients being enrolled with BCTG QA project and increasing data complexity, our Pathologists are committed to refining our structured reports for breast cancer and other tumour reporting to facilitate future data collection for the BCTG project group in order to benefit evidence-based medicine with the highest quality of care for local breast cancer sufferers.

Dr Tracey Lu
Director of Cytology
Anatomical Pathologist,
Capital Pathology
20 Years of Breast Cancer in Radiation Oncology

In the last 20 years, there have been some amazing changes in Radiation Oncology and the treatment of breast cancers; in part due to developments in computer technology and in part due to a better understanding of the disease. When I started as a registrar we had single slice planning with manual contours and a simple planning system that made no accounting for differences in lung and bone dose absorption. Treatments were given in the same doses as today, but bolus was used every second or third day for chest wall patients. As time has gone we have moved through the era of conformal radiation with trials in partial breast irradiation. There have been advances in breast brachytherapy and implantable radiation devices and we have also seen the Targeted intra-operative radiotherapy (Targit) trial of localised breast radiation. We have been able to define precisely who benefits from localised partial radiation and who does not. We have seen trials of boost vs no boost, and defined the populations who do not require breast boost and also defined a population of women in whom the benefit of radiation is marginal. Hypofractionated trials have shown that most patients can now be treated with a shortened fractionation schedule which is more convenient and safe.

Technically we are now planning our patients in much more conformal precise ways and treatment with Intensity Modulated Radiation Therapy (IMRT) has meant that patients experience less toxicity and more homogeneous breast dose.

We have been able to compensate more for variations in individual anatomy with contouring of the nodes and breast and internal mammary chain nodes. Computerised planning has meant that doses to these structures are reported on and defined much more accurately than with previous treatment techniques that relied on a “one size fits all” approach. Toxicity has reduced as radiation oncologists are more cognisant of heart and lung doses and how to plan to avoid these with 4D planning techniques such as Deep Inspiration Breath Hold (DIBH).

In the pathology lab, we now define different subtypes of breast cancer that behave and differ in their outcome. As we move into the era of personalised medicine, challenges will be to define if and how we can tailor our treatments even more. The answer is likely to be defined by the laboratory and answered in the clinic or clinical trial. The challenge will be to apply all we have learnt in the last 20 years to each different group and to look for new ways to improve our patients’ outcomes.

Dr Lyn Austen
Radiation Oncologist
Senior Staff Specialist
The Canberra Hospital

Liquid Biopsy in Breast Cancer: A Potential Game Changer

Considerable progress has been made in the treatment of a selected group of patients with breast cancer over the last two decades. Medical Oncologists still rely on imaging procedures with ionizing radiation and serum tumour markers to assess for treatment response or disease progression. New minimally invasive technologies are desperately needed in breast cancer to overcome limitations of current monitoring methods and provide more real-time information. Liquid biopsies are more convenient for patients with minimal procedural risk and can be performed on a serial basis to provide very comprehensive information regarding the patient’s malignancy.

We have collaborated with the University of Canberra on a project to identify circulating tumour cells (CTCs) and cancer stem cells (CSCs) using peripheral blood. During the last two years, over one hundred serial blood samples from 20 patients with advanced breast cancer were collected and analysed using state of art DEPArray technology. We have been successfully able to identify, isolate and characterize CTCs and CSCs. We have studied the expression of various immune cell surface markers and carried out extensive immunological workup.

Serial sample collection has allowed us to observe several real-time CTCs and T-cell changes while patients are having standard systemic treatment. We have been able to study epigenetic reprogramming with lysine-specific demethylase inhibition and also been able to reinvigorate exhausted T-cells. Efforts are currently ongoing to identify molecular signature to predict response to immunotherapy.

Over time, liquid biopsies could play a future role in routine clinical practice once clinical utility and validity have been demonstrated. There is an opportunity for us in Canberra to collaborate with our local research institutions and share knowledge to advance the science further.

Dr Laeeq Malik
Medical Oncologist
The Canberra Hospital
Breast Cancer Treatment Group 2018 Newsletter

Breast Cancer – The Whole Person Journey – a GP Perspective

Across 25 years of general practice, I have often ‘walked the breast cancer journey’ with my patients. Each one leaves an indelible mark.

Often not sick when first diagnosed, they come for screening without a breast lump. They feel healthy and normal only to have the wind taken out of their sails with an unexpected diagnosis of breast cancer.

A diagnosis of breast cancer changes a person’s life profoundly. First, there are the decisions about specialist services and surgery, and then comes adjuvant therapy such as chemo, radiation or hormone, to navigate. Each issue has an impact on a person’s physical and emotional health.

GPs must be there to walk the journey and address the needs of the ‘whole person’ as well as those of the patient’s family. Our patients trust us to seek advice about services, treatments, nutrition, lifestyle, exercise, sexual health and mental health. It’s not always easy but fortunately breast cancer has a high survival rate and, in the most part, a positive outcome.

Over the years, I have welcomed each purple form received from the Breast Cancer Treatment Group as an opportunity to reflect on every personal journey. When the journey does not end well, the GP role remains a constant guide, with the goal of bringing compassion and quality of life as a focus of care.

Dr Anne-Marie Svoboda
Medical Director GP Liaison Unit, Canberra Health Services

Reflection on the Purple Follow-up Form

Having been asked to write these few words by Thet Khin, I thought “what will I write?”

It started me thinking about the youngish sufferers of breast cancer. As I work in a small regional city, I have close contact with patients. Associated with me either as patients or socially are a group of six women who were diagnosed between the ages of 39 and 51 within the last 10 years. Their cancers are not the same but all had complex histology and some had positive lymph nodes. This was previously a forerunner of a poor prognosis. So far all are doing very well; four with no further recurrence and two with secondaries diagnosed but are well. Those with children are watching them grow up and mature. I think often of them and am grateful for the incredible advances in the treatment of breast cancer since I started practising medicine 43 years ago.

I think of the two young mothers who died about 15 years ago, one diagnosed two months postpartum and died within 3 years leaving behind young children, and the other, who had young children passed away within 5 years of diagnosis, just wishing that they had had the advantage of these latest advances.

My thoughts are focussed whenever I receive the purple form. Just a day after I was asked to do this reflection I received one and had to notify that my patient had died but as a result of her other complex medical issues, maybe exacerbated by the aggressive treatment given for her unusual breast cancer.

Although filling in forms is the last thing one wants to do at the end of a busy session, if it contributes to further research into breast cancer and the continuation of the amazing pace of improvement in the treatment of this disease then it is a small sacrifice to make.

Dr Sue Storrier
GP at Marima Medical Clinic, Goulburn, NSW
The Purple Breast Cancer Patient Follow-up Forms: Its Importance to Patient Survival Data

The purple Follow-up forms are sent to participating General Practitioners (GPs) with the aim of seeking the current status of breast cancer patients. Each GP’s response regarding patient status, such as Alive & Disease Free, or suffering a Recurrence or Deceased, is entered into the Breast Cancer Treatment Quality Assurance project (BCTG QA Project) database. Survival outcomes are reported to the BCTG and individual treating clinicians at 5 year, 10 year, and 20 year intervals. The purple Follow-up forms have been used to track patient survival since 1998 thereby creating over 20 years of valuable longitudinal patient survival data. This is unique in this country. The priceless dataset serves as a basis for the treatment and management of breast cancer, and research and publications, hence, the significance and importance of returning the completed purple Follow-up forms to the BCTG office in a timely manner.

The BCTG QA Project would like to thank all GPs for contributing their time and attention to accurately completing the purple Follow-up forms.

If you become aware that there is any change in a patient’s disease status please contact the Project Officer on 02 5124 1641.

BCTG QA Project Team

ACKNOWLEDGEMENTS

The Breast Cancer Treatment Group Quality Assurance project (BCTGQA Project) has exceeded 20 years and we would like to thank all participants for generously contributing their precious time and expertise in helping us to achieve BCTG data collection.

Special thanks to all surgeons, medical oncologists, radiation oncologists, medical receptionists, general practitioners, practice managers, practice nurses, breast care nurses including the McGrath Breast Care Nurses; administrative staff; radiologists; BreastScreen ACT; the ACT and NSW Registries of Births, Deaths & Marriages; Bosom Buddies; Breast Cancer Network Australia; and all pathologists, especially those from ACT Pathology and Capital Pathology.

Finally, we acknowledge AstraZeneca, EISAI, and Novartis for sponsoring the Breast Cancer Treatment Group meetings. We appreciate the contribution of the guest speakers, Ms Elly Law, Dr Farhan Syed and Prof Karine Chevreul, who shared their knowledge during 2018. Last but not least thank you to John Curtin School of Medical Research, ANU, and Vanillabean for providing the venue, resources and catering for our meetings.
Presentations at the Breast Cancer Treatment Group’s Meetings 2018

March

Dr Elly Law, psychologist from Cancer Counselling Service, shared and spoke of the “Directions in Survivorship” research. The impact of cancer on the survivor and the caregiver such as physical, mental/emotional, financial, educational, informational, system of care, social, societal, communication, relationship provider and employment issues. The research has shown that anxiety levels vary with the type of the cancer. It is important to keep monitoring the anxiety of the survivor as well as the caregiver. The anxiety of the caregiver may be higher than the anxiety of the survivor. Future plans to reduce the barriers were presented and discussed.

June

Dr Farhan Syed, Radiation oncologist, The Canberra Hospital, spoke about “Radiotherapeutic Advances in Management of Brain Metastases in Breast Cancer”. After lung cancer, breast cancer is the second most common cancer to spread to the brain. The risk factors for brain metastases (BM) in breast cancer were elaborated. The difference between whole brain radio therapy (WBRT) and stereotactic radiosurgery (SRS) was explained with pros and cons. SRS is being used more in The Canberra Hospital and the results are favourable. Information about clinical trials such as Local HERO and Beyond BM – SC 24 was also shared.

November

Prof Karine Chevreul, Head of Health Services Research Projects in Health Economics and Health Services Research Unit at the Paris Hospital, shared her experience of “Big Data and health research in France”. Prof Chevreul described the National Strategy for Health which was designed to address the perceived social inequalities in health and improve efficiency in health care delivery and safety of care in France. Data linkage from hospitals, medical records, national health records and many different care systems was explained, as was data linkage, access (public/private), technology and security of health data records. The presentation included the solution and steps taken by the French government to address these issues, updated as recently as October 2018.
BCTG Meeting Dates for 2019

- Monday, 1st April 2019
- Monday, 22nd July 2019
- Monday, 25th November 2019

Photos from BCTG Meetings in 2018

BCTG meeting June 2018 in Board Room, at John Curtin School of Medical Research, Australian National University

Project Coordinator, Yanping Zhang provided an update report to the BCTG at November’s meeting

Photo from a Data Management Sub-Committee Meeting

*From left to right: Jenny Green, Yanping Zhang, Carolyn Cho, Angela Reza, Jane Dahlstrom, Paul Craft, Robin Stuart-Harris, and Yvonne Epping*
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Further information about the Breast Cancer Treatment Group Quality Assurance Project is available on our website

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