

A Wealth of Information from Cancer Registries with Linked Data: Cancer 2015

In years gone by, cancer registries were primarily thought as repositories and sources for epidemiological data. Today, the availability of electronic medical and health services records, and expansions in computing power mean that it is now possible to understand much more about the effects of cancer outside of the clinical trial setting using registry information.

In a recently published paper, Lorgely and colleagues (2016), highlight the benefits of being able to link data on cancer incidence, genetic composition, outcomes and health care service use using information. Cancer 2015 is a prospective longitudinal cohort study recruiting participants from five hospitals in Victoria. It includes information on participants' cancer diagnoses, treatment, genomic sequencing and quality of life using the EUROQOL EQ-5D-3L and the EORTC QLQ-C30 instruments. Participants are also asked to consent to have their clinical and outcomes data linked to information on health resource use extracted from Medicare Australia (providing information on medical and pharmaceutical services), and hospital service use through the Victorian Data Linkage Unit.¹

Analysis of the information available from 922 patients in the first phase of Cancer 2015 showed that the larg-

est increases in health service expenditure amongst this cohort were associated with being admitted to hospital as a private patient and receiving treatment with a targeted pharmaceutical therapy. Receiving therapies that might be prescribed for treatment-related side effects (such as anti-emetics and anti-anxiolytics) also contributed to increased costs. Lower costs were observed in participants with higher GP use, those with improved quality of life, and those nearing the end of life (who exited the hospital system for which health service use data were available to enter hospice care).

One of the innovative aspects of Cancer 2015 is the inclusion of genomic information, allowing it to be used to assess changes in clinical practice and health service use according to the presence of genetic mutations. This is anticipated to be a focus of the second phase of the analysis of the Cancer 2015 data. Initial analyses show that there are links between higher health service expenditure and KRAS and TP53 (often associated with CRC and pancreatic cancer respectively), and lower expenditure for ERBB2 mutations (often associated with advanced breast cancer). The authors advise caution in interpreting the result for ERBB2 mutations being associated with lower expenditure given that an anomaly in the linkage consent process meant that data on Commonwealth expenditure on trastuzumab, which previously was not included in Medicare data, were not available for this initial data analysis.

Contact the Cancer Research Economics Support Team:
<http://www.crest.uts.edu.au>

Marion Haas
marion.haas@chere.uts.edu.au;
+61 (2) 9514 4721

Richard De Abreu Lourenço:
Richard.deabreulourenco@chere.uts.edu.au;
+61 (2) 9514 4729

TROG Cancer Research

2016 promises to be another eventful and fruitful year for TROG Cancer Research.

Our 28th Annual Scientific Meeting will be held at the Brisbane Convention & Exhibition Centre, March 14th-17th. The TROG 2016 ASM theme is: 'Value for money in oncology research' and provides a unique opportunity for health professionals with an interest in radiation oncology to engage in learning, networking and collaboration. The meeting features [Subspecialty Group sessions](#), as well as the return of our full-day, interactive [Research Workshops](#), which have been well subscribed.

Planning has been underway for a TROG Consumer Advisory Panel. A Consumer Training Workshop will be held in April 2016 to provide training on the basics of radiation therapy and clinical trials, as well involvement in the TROG Board, Scientific Committee, cancer advocacy, fundraising or by sharing their own cancer journey.

From the discussions on these topics during the workshop, TROG will develop online consumer learning modules. These modules will be used in conjunction with the Cancer Australia eLearning website to provide relevant information to all consumers interested in Radiation Oncology clinical trials.

Earlier this year we farewelled our Chief Financial Officer, Mark Rembish. Mark has been an integral member of the group for the past three years and we wish him all the best. We have now welcomed our new TROG Financial Controller and Company Secretary, Andrew Jenkins, to the team. Andrew will manage TROG's finances and is a part of the executive management team preparing forecasts and budgets, assisting in the allocation of resources and strategic planning.

We have also welcomed back Melissa Crain to the role of TROG QA and Grants Manager, following her maternity leave.

We are excited to announce our newest fundraising event which will be launched in May 2016. *Art4TROG: An exhibition supporting TROG Cancer Research*, will feature a diverse collection of works from established and emerging artists from the Hunter area who have been touched by cancer. Opening night will be held on Friday May 6, 2016 at Newcastle Art Space galleries. Further details and ticket purchases for this event are available from trog.com.au

Contributed by: Katie Vulio, Communications & Media Coordinator, TROG Cancer Research

Cancer 2015 (cont.)

The results from this initial exploration of Cancer 2015 highlight the importance of using linked information to fully understand the experience of cancer, its impact on the patient and on the health care system. The availability of such rich information sets helps to better inform the development of future health care services to meet the needs of patients in a manner

that makes the best use of our available health care resources.

¹ PK Lorgelly, B Doble, RK Knott and The Cancer 2015 Investigators, Realising the value of linked data to health economic analyses of cancer care: a case study of Cancer 2015, *Pharmacoeconomics*, 2016, 34:139-154.

ANZGOG in 2016

ANZGOG is continuing to grow and develop. We were just 400 strong three years ago and now have 701 members. The challenge for us now is to involve every single one of those members in the work of ANZGOG.

One way we do this is through our Annual Scientific Meeting which this year has four outstanding international guest speakers attending on 13th-16th April 2016 at the Intercontinental Hotel, Double Bay, Sydney. These speakers include

- Christian Marth, President of ENGOT, the European Network of Gynaecological Oncology Trial Groups,
- Michael Birrer, Harvard School of Medicine and Director of Medical Oncology at MGH
- Anuja Jhingran, Professor of Radiation Oncology at MD Anderson
- Susana Bannerjee, Consultant Medical Oncologist, Royal Marsden Hospital

THE ASM 2016 will also feature a series of workshops targeted at specialist segments of the ANZGOG membership on the afternoon of Friday 15th April, including:

- a Concept Development Workshop, designed to foster and develop our investigator network. This workshop is developed by Martin Stockler of the NHMRC Clinical Trials Centre and Linda Mileshkin, Chair of ANZGOG Research Advisory Committee.
- radiation oncology workshop developed by Pearly Khaw and Viet Do.
- study coordinators education and workshop.

- gynaecological nurses workshop.
- consumer education and training afternoon.

In addition, there will be a full day focusing on personalised medicine, including linking pure science to the clinic, on Saturday 16th April with an in-depth pure science symposium in the afternoon.

Following the ASM we work to develop the new concepts presented at the meeting into studies ready for funding.

ANZGOG will be taking applications for its New Research Fund grants again mid-year. The New Research Fund was established with monies raised by ANZGOG from corporate, philanthropic and community donations, as well as bequests, and is open to all ANZGOG members who wish to apply for support for their research projects. It was designed to foster new research ideas that will lead to new trials benefiting women with gynaec cancer here in Australia and New Zealand and elsewhere.

These ongoing activities by ANZGOG continue to fuel the enthusiasm of our members and encourage others working in gynaecological cancer to join ANZGOG. Further information is available on our website www.anzgog.org.au.

A/Prof Alison Brand
Chair | ANZGOG

Contributed by: Alison Evans, Executive Officer, ANZGOG

Beaming in on CREST

The theme for this year's Trans-Tasman Radiation Oncology Group (TROG) ASM, March 14th-17th, is 'Value for money in oncology research'. Not surprisingly, this is a theme that is close to the hearts and minds of the team at CREST.

Marion Haas and Richard De Abreu Lourenco will both be attending and participating in the ASM. On Mon-

day, together with Rebecca Montgomery from the TROG Executive Office, they will facilitate a workshop on the collection and use of health economic information in a clinical trial setting. This will use an example, the SAFRON II clinical trial (on the use of stereotactic ablative radiotherapy for oligometastatic lung cancer) to illustrate how questions are formulated from a

ALLG Research Highlight

Chronic lymphocytic leukaemia (CLL) is the most common type of leukaemia. Each year in Australia about 1,000 people are diagnosed with the disease. Almost 80% of cases are diagnosed in people over 60 years. Treatment for CLL has improved in recent years and ALLG trials have shown that when the doses of drugs are carefully adjusted, highly effective chemotherapy can be successfully given to older patients who do not have other serious health problems. However, older and sick patients in particular may find it hard to finish their treatment because of the side-effects.

The new ALLG CLL07 study is an Australian initiative led by Prof Stephen Mulligan. It aims to establish which chemotherapy regimen can be given safely to older patients with health problems, and if treatment results can be further improved by replacing the standard anti-cancer antibody (rituximab), with a newer, more potent antibody (obinutuzumab or GA101). Patients will be randomised to receive GA101 together with one of two types of low dose chemotherapy combinations used in CLL treatment. Patients over 65 years of age who have not previously received treatment for CLL can access the new therapy together with adjusted dose chemotherapy as a clinical trial participant.

The outcome of the study will be mainly measured by the number of side effects that patients experience while having treatment, but the response of the CLL disease will also be taken into account.

The ALLG CLL07 trial also includes a suite of comorbidity indices and frailty scores. Patient reported outcomes will be evaluated using the EuroQol-5D (EQ-5D-5L) and EORTC QLQ-C30 questionnaires. These assessments will be used to compare the outcomes related to the disease and its treatment and also includes QOL considera-

tions from the patient's perspective. Patient reported outcomes will be assessed during baseline and at key time points during the first year and annually thereafter.

This study is the very first ALLG trial to commence its operations fully with the new electronic data capture system, and opened to accrual on 22 September 2015.

The plan is to recruit 120 eligible patients, 60 in each treatment arm, from 15 – 20 ALLG centres. To date six sites have been activated and four patients registered.



ALLG CLL07 lead, Prof Stephen Mulligan.

Contributed by: Janey Stone, Research Officer, ALLG

Beaming in on CREST (cont.)

health economics perspective, the design of relevant data collection instruments and the planning of subsequent analyses. The following day, Marion and Richard will give separate presentations to the open forum on key concepts in economics and health economics and importantly how these have been applied in the literature to answer questions about value in the field of radi-

ation oncology. As well as focusing on the foundations of how to approach economic evaluations, these sessions will use case studies to highlight what might be of particular interest when answering questions about resource allocation and what represents value for money when using radiation therapy.

The True Costs of Cancer – Health Economics to Optimise Healthcare Funding Decisions!

In May this year Dr Alison Pearce, who many of you will know from her earlier work here at CREST, will return to CHERE to commence work on her post-doctoral fellowship; ‘The true costs of cancer – health economics to optimise healthcare funding decisions’.

This work recognises that one of the biggest challenges facing healthcare systems today is prioritising the increasing demands on health resources while maintaining the sustainability of funding. One way of informing that priority setting process, and allocating resources appropriately, is through the use of economic evaluations. But there is debate about whether economic evaluations that take a societal perspective should in-

clude the costs of reduced workforce participation due to illness (known as lost productivity).

In her fellowship, Alison will be exploring if and how cancer-related lost productivity could be considered as part of societal costs in economic evaluations in Australia. Given the potential for cancer to affect workforce participation, this research has the potential to change how cancer, and healthcare, funding priorities are decided in the future. As well as working on her fellowship, there is no doubt that Alison will also be re-engaging with CREST, so we look forward to having her back on the team and in being able to contribute to this important research.

Forthcoming Workshops

In 2016, CREST will be continuing with its program of workshops on the use of health economics in cancer clinical trials. The first of the stand-alone workshops is scheduled in conjunction with the Translation Cancer Research Network (TCRN), to be held on Monday 18th April at the Lowy Institute. This will be a half-day introduction to health economics workshop; look out for information via the TCRN and CREST. This will be followed up on May 9th by a one day workshop on understanding health economics in cancer clinical trials to be hosted at

the Haymarket campus of UTS.

Finally, in conjunction with the Cancer Australia QOL Office and the Asia Pacific Chapter of the International Society for Pharmacoeconomics and Outcomes Research, a workshop will be held in the latter part of August on the assessment of quality of life for use in economic evaluations. Look out for details of registration on all these workshops closer to the scheduled workshop dates.

What has CREST Been up to?

Trial Group Collaborations:

- Participation in the PC4 Peer Review Workshop, Sydney.
- Presentation and preparation at the TROG ASM, 2016.
- Input and advice on a number of NHMRC and Cancer Australia project grants.
- Ongoing advice on the development of trial protocols and data collection forms.

- Brief online survey of Clinical Trial Group Executive Officers regarding health economics services.
- Continuation of the Structured Training Opportunities program.
- Authorship on a publication in BMC Oncology: Siva et al. A randomised phase II trial of stereotactic ablative fractionated radiotherapy versus radiosurgery for oligometastatic neoplasia to the lung (TROG 13.01 SAFRON II). BMC Cancer. 2016; 16 (183): 1-8.

Other Activities: