

## Measuring Health Effects Beyond the Patient

Intuitively, we know that a diagnosis of cancer can impact on the health and quality of life of the families and carers of cancer patients. Measuring those impacts, particularly in a manner that can be used to estimate quality adjusted life years (QALYs) for use in decisions about resource allocation can be challenging. A particular difficulty is how changes in the health and quality of life of families and carers might be reasonably attributed to the occurrence of cancer in the individual for whom they care.

In a recent article, Al-Janabi and colleagues<sup>1</sup> outline three methods they have applied to measure such effects, what they call “spillover” health effects; or how the health status of one individual can influence the health of another. Within their analyses health status was measured using the EUROQoL EQ-5D-5L instrument. Data were available from 1,218 family networks of individuals who had been previously diagnosed with meningitis, including those individuals who had survived meningitis. Respondents completed a number of questions regarding the after effects of meningitis, the EQ-5D-5L and socio-demographics.

Using the EQ-5D-5L results, spillover effects were estimated in three ways: by estimating the likelihood of a decrement in health status due to whether or not after effects of meningitis were present (a comparison of sub-groups); exploring what determines the health status of immediate family members, including the meningitis survivors’ health status, as well as socio-demographic and other context based variables as explanatory factors; and, expanding this second method to explore the health status of the broader family network as a means of estimating the aggregate spillover effect. Using these three methods Al-Janabi et al (2015) derived estimates of the absolute change in QALYs due to meningitis after-effects (arising from the comparison of sub-groups), and relative changes in QALYs (based on the meningitis survivors’ health status) for family members. The results from these three methods are broadly similar; the choice of method depended on the data available and the research context.<sup>1</sup>

Importantly, the authors illustrate how their estimated spillover effects might then reasonably be combined with estimates of patient QALYs to provide a broader assessment of the effects of a health condition or intervention, in this case one associated with meningitis.

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

## ANZ Gynaecological Oncology Group Update

*A/Prof Alison Brand, Chair*

### **ANZGOG Annual Scientific Meeting 2016**

‘New Targets and Better Outcomes for Women with Gynaecological Cancer’ is the theme for the ANZGOG Annual Scientific Meeting next year which will be from the 13<sup>th</sup> to the 16<sup>th</sup> of April at the Intercontinental Double Bay in Sydney. We have an impressive line-up of distinguished international keynote speakers:

- Dr Christian Marth, Gynaecological Oncologist, Austria
- Dr Anuja Jhingran, Radiation Oncologist, Texas, USA
- Dr Michael Birrer, Medical Oncologist, Boston, USA
- Dr Susana Banerjee, Medical Oncologist, UK

The conference program will include two and a half days of scientific sessions focusing on current research practices, innovative new research ideas, target therapies, a quality of life session and a pure science session just to name a few. There will also be an afternoon of workshops germane to research nurses, study coordinators, investigators and consumers. The ASM promises to be an opportunity to network, share knowledge and foster new collaborations.

For further information on the ANZGOG ASM 2016, go to [www.anzgog.org.au](http://www.anzgog.org.au)

### **Engaging Members in Research Development**

ANZGOG held its 3<sup>rd</sup> Annual Development Day in Sydney on the 15<sup>th</sup> of October. This is an initiative to engage members in ongoing research development, to

identify gaps in current research and to recommend options for future studies. ANZGOG’s Ovarian, Cervical and Endometrial Tumour Type Working Groups and the Research Advisory Committee came together for these discussions. The ANZGOG Development Day also provided an opportunity for the Study Coordinator Committee to workshop ways to enhance the research harmonization processes, while the Consumer and Community Committee participated in a concept development workshop.

### **Funding New Research**

As part of the ANZGOG vision for the future, earlier this year, the Group launched ‘The ANZGOG New Research Fund’. This Fund is designed to foster new research ideas that will lead to new trials that will benefit women with gynaecological cancer here in Australia, NZ and elsewhere. This fund, established with monies raised by ANZGOG from corporate, philanthropic and community donations, as well as bequests, is open to all ANZGOG members who wish to apply for support for their research projects. In its first funding cycle, seven applications were received for New Research Fund grants and 3 projects were identified for funding. For further information on the New Research Fund, email [alison.evans@anzgog.org.au](mailto:alison.evans@anzgog.org.au)

*Contributed by Heshani Nessfield, Projects Officer, ANZGOG*



### **Measuring Health Effects Beyond the Patient (cont.)**

While the results they present are specific to meningitis, the methods could be reasonably applied within a cancer setting to measure family and care “spillover” effects associated with a cancer diagnosis. However, they caution that “spillover effects are likely to be context-specific and that direct measurement within the

specific context of the research is likely to be the best solution” (p12). Taking that into account, what this research shows is that with the available data it is possible to assess the broader quality of life effects of a health condition in a manner that can be used to inform decisions of resource allocation.

Ref: <sup>1</sup> Al-Janabi H, Van Exel J, Brouwer W, et al. Measuring Health Spillovers for Economic Evaluation: A Case Study in Meningitis. Health Econ 2015.

## adapt With PoCoG

A large team of investigators from PoCoG, including NSW, national and international research and clinical experts (including Prof Phyllis Butow, Prof Brian Kelly, Prof Afaf Girgis, A/Prof Philip Beale, Dr Laura Kirsten) and a collaboration with CREST were awarded a Cancer Institute NSW Translational Program Grant in April 2015. The overall goals of the **ADAPT** (Anxiety and Depression Pathway) Program, are to facilitate the integration of a newly developed clinical pathway for anxiety and depression in cancer patients into routine care as well as to develop and evaluate implementation strategies to promote uptake of the pathway in the Australian health context.

As a Program Grant, ADAPT has a number of study protocols under its banner. These include: development and piloting of health professional and patient resources; development and evaluation of a new online CBT program with a cancer focus (iCAN ADAPT); and, a cluster randomised trial of implementation strategies to support ADAPT. The focus of the first two years is the development and piloting of the components of the ADAPT Portal and work is already underway in developing and collating resources as well as building the IT infrastructure to support the systems needed for the planned cluster randomised controlled trial (RCT) in years 3-5.

The cluster RCT planned to start in year three of the program includes detailed costing of implementation

strategies, and the costs of care associated with the pathway. This health economics analysis, led by Prof Rosalie Viney, a CI on the Program Grant will compare costs of the intensive and the moderate implementation strategies to estimate the resource use required if the intervention was rolled out into practice across the Australian health care system. These costs are expected to include awareness campaigns and in-service education sessions at each site, training and support of local champions, audit and feedback, face-to-face education and IT support, staff time in following the pathway, numbers of patients seen by psycho-social staff, and costs associated with hosting the online intervention. The ADAPT Program includes the opportunity for a doctoral candidate to investigate the health economics aspects of the research program, with supervision led by Prof Rosalie Viney. Further details about this opportunity will be available in 2016.

For further information about ADAPT please contact Dr Heather Shepherd, ADAPT Research Fellow and Program Manager at [heather.shepherd@sydney.edu.au](mailto:heather.shepherd@sydney.edu.au) or on +61 2 8627 0828.

*Contributed by Dr Heather Shepherd, ADAPT Research Fellow and Program Manager*



### *Do you have a trials group newsletter?*

*CREST can provide articles which introduce CREST services, or which provide commentary on a health economics topic of interest to your members.*

*Please contact us if you would like to discuss the possibilities.*

## A Cornucopia of Concepts...

It's been a busy quarter for many of the Cancer Australia Clinical Trial Cooperative Groups in running concept development and ideas generation workshops to identify new study and trial concepts to support in the years ahead. CREST representatives have attended and participated in a number of workshops to provide input not only on the potential for those concepts to address questions of resource allocation or practice change, but also to contribute to the general discussion on research design.

In late September and October Marion Haas and Richard De Abreu Lourenco participated in three separate concept development workshops (CDWs) convened by ANZUP in Sydney, and focusing on a number of new trial concepts in various tumour streams, namely prostate cancer (September 23<sup>rd</sup>), renal cell carcinoma (28<sup>th</sup> September) and bladder cancer (14<sup>th</sup> October). Later on

October 15<sup>th</sup>, Patsy Kenny attended the PoCoG CDW held in Melbourne, which focused on five concepts for new studies reviewed throughout the day. Richard attended the ALTG Ideas Generation Workshop in Melbourne on 13<sup>th</sup> November, which was an interactive subgroup-based format focused on generating new clinical trial and study concepts. Finally, Marion attended the PC4 CDW in Melbourne on 25<sup>th</sup> November, at which she presented as part of a special forum on clinical trials for survivorship research.

Participating in workshops like these is a core component of what we do at CREST; it is never too early in the trial design process to be asking questions about whether a study or trial can be used to change practice or convince decision makers to invest in a new treatment.

## Quality of Life in Paediatric Cancer Survivors...

Paediatric cancers are known to have a major impact on the quality of life of patients and their families at the time of their treatment. Less is perhaps known about the longer-term quality of life of survivors of paediatric cancers and how this might differ between individuals. CHERE is currently hosting Ramon Tillemans, a Masters of Pharmacy student from Utrecht University in the Netherlands, who is investigating this very question. Working with data about the quality of life of 415 paediatric cancer survivors, from the Long-term follow-up study, collected by the Behavioural Sciences Unit, Kids Cancer Centre, Ramon is seeking to understand the differences between individuals that influence quality of life, including:

- The types of cancers and their treatments;
- The era (time) in which patients were treated;
- The use of other health care services, including specialised follow-up survivor care; and
- Patient specific demographic and socio-economic factors.

Within the study, quality of life assessments (using the EUROQoL EQ-5D-5L) are self-reported for a cohort of survivors of paediatric cancer patients, with quality of life reported for the parents of other survivors of paediatric cancer within the same cohort. This will allow Ramon to not only consider the factors affecting patients' own longer-term quality of life, but whether influences on parents' longer-term quality of life can also be discerned.

This is a joint project with the Behavioural Sciences Unit, who is proudly supported by the Kids with Cancer Foundation, and The Kids Cancer Alliance (<http://www.behaviouralsciencesunit.org>). Ongoing advice and support to Ramon comes from Claire Wakefield, Joanna Fardell and Christina Signorelli, as well as the team at CHERE. Look out for future details on the results from this research!

## An Update from COGNO..

The 8<sup>th</sup> COGNO Annual Scientific Meeting (ASM) was held on 23<sup>rd</sup>-24<sup>th</sup> October. Congratulations to Dr Cecilia Gzell (Convenor) and the 2015 organising committee on a successful meeting. To see a report of the ASM, please keep an eye out for Issue 20 of the COGNO newsletter at <http://www.cogno.org.au/content.aspx?page=newsletters>.

Save the date for our 2016 ASM! Next year we will be holding a combined meeting of the 13<sup>th</sup> Asian Society for Neuro-Oncology (ASNO) Meeting and 9<sup>th</sup> COGNO Annual Scientific Meeting, "*Neuro-Oncology: is the landscape changing?*" to be held from Sunday 11<sup>th</sup> - Thursday 15<sup>th</sup> September 2016 in Sydney, Australia. Confirmed international speakers include:

**Professor Roger Stupp MD**, Professor and Chairman, Department of Oncology & Director, University Hospital Cancer Center, University of Zurich, Switzerland

**Professor Mitchel Berger MD FACS FAANS**, Professor and Chairman, Department of Neurological Surgery, UCSF, USA

**Professor Paul Mischel MD**, Head, Laboratory of Molecular Pathology, Ludwig Institute for Cancer Research, USA and Professor, University of California San Diego, USA

**Associate Professor Arjun Sahgal BSc MD FRCPC**, Associate Professor of Radiation Oncology and Surgery, University of Toronto, Canada and Deputy Chief, Department of Radiation Oncology, Odette Cancer Centre, Canada

**Professor W. K. Alfred Yung MD**, Professor and Chair of Neuro-oncology, The University of Texas MD Anderson Cancer Center, USA

**Professor Gregory Riggins MD PhD**, Professor of Neurosurgery and Oncology, Johns Hopkins University School of Medicine, USA

**Assistant Adjunct Professor Mary Lovely PhD RN CNRN**, Assistant Adjunct Professor, UCSF School of Nursing, USA

For further information please visit our website <http://www.cogno.org.au/content.aspx?page=cognoasm-home2016>, or contact [cogno@cogno.org.au](mailto:cogno@cogno.org.au) if you wish to be added to our mailing list.

*Contributed by Yi Feng, COGNO*



## Grant Season is Upon Us!!

Even though the final funding outcomes for this year's grant round are pending, thinking for next year's competitive NHMRC and PDCCRS funding has already kicked off. The team at CREST can assist with developing your forthcoming applications in a number of ways. From conducting a written CREST audit of your study design in terms of its suitability for an economic evaluation, to providing ad-hoc advice (phone or e-mail) on protocol development, or participating in protocol and grant development and grant workshops. There are numerous ways that CREST can assist in the development of your grant. We are happy

to provide this advice without any expectation that our team members would be involved in the grant or trial if it proceeds (that is a matter for you and your trial team, and further ongoing involvement by CREST may or may not be appropriate).

If you would like to use CREST for health economics input to your protocol prior to submitting a grant, either contact your trial group Executive Officers, or Richard De Abreu Lourenço at CREST directly at: [Richard.deabreulourenco@chere.uts.edu.au](mailto:Richard.deabreulourenco@chere.uts.edu.au).

## The National Blood Cancer Registry

In 2012, the ALLG opened a registry with a focus on patients with acute myeloblastic leukaemia (AML). The original concept was that the registry would collect standardised baseline data in AML and function as a common pathway into ALLG trials. To date a total of 650 patients have been registered and the Registry has been operating using paper case record forms.



In a major new development, the Registry has now been officially reconstituted as the National Blood Cancer Registry (NBCR) and will collect information from patients with a suspected, known or diagnosed blood cancer who voluntarily consent to the collection of data with or without samples taken according to the standard of care at the treating hospital.

*Amanda Jager, CRA responsible for the NBCR*

There are no NBCR required assessments and all data collected are according to the standard of care assessments at the respective treating hospitals for the diagnosis, treatment and follow up of the patients. The timing of these data collections varies according to the specific blood cancer diagnosis.

The ALLG NBCR may facilitate a number of functions associated with ALLG clinical trials and thereby promote improved outcomes for patients. Some of the advantages to the establishment of the NBCR are:

1. The NBCR will enhance patient participation in clinical trials by facilitating cross referral of patients to sites that are running ALLG clinical trials.
2. The clear detail of tests to be conducted at baseline will align with ALLG clinical trial screening procedures

to minimise burden on the patient and to ensure that the correct samples are collected at the correct time points, thus maximising participation in ALLG clinical trials.

3. The NBCR will also facilitate the implementation of central review and central testing of factors critical to the successful treatment of blood cancers, and enhance consistency in clinical trial populations to ensure trial results are meaningful.

4. The collection of samples, together with access to data provides a valuable resource for researchers, allowing for future unspecified research. This ensures clinical trial results remain relevant in the current landscape of blood cancer treatment.

The details of the data and samples requested from sites are based on the expected standard of care assessments for each disease type. The collection of samples is encouraged as a means to maximise future research, with timepoints determined based on when the patient would be having normal standard samples collected and tested.



*Sri Joshi, Data Manager for NBCR*

The NBCR is under the control of the ALLG Registry Management Committee (RMC) which oversees all aspects of its functioning. Particular attention is paid to management of the different disease groups and management of confidentiality of patient data is also an important issue. The RMC will assess proposals from researchers, which will also need ethics approval. The ALLG looks forward to the utilisation of the wealth of data to bene-

## The National Blood Cancer Registry (cont)

fit blood cancer research.

In an exciting new development, from December the method of data collection is changing to an electronic data capture (eDC) system. This will streamline processes for data management both at sites and in the ALLG Trial Centre. Individual hospital sites will retain full access to their participants' data.

The NBCR will continue to collect AML data including demographic data, disease specific information including diagnosis/baseline information, molecular and cytogenetic status, treatment received and patient outcomes.

The NBCR will expand and add additional diagnoses over the coming period. The first to be added will be data for the category of uncommon lymphoma. This includes mucosa-associated lymphoid tissue, splenic marginal zone lymphoma, nodal marginal zone lymphoma and

Waldenstrom's macroglobulinaemia. These rare conditions are difficult to investigate due to low numbers of cases. It is hoped that the NBCR data will support studies to improve outcomes for patients with these conditions. Data collection for acute lymphoblastic lymphoma (ALL) is planned to commence in February 2016.

Further information on the National Blood Cancer Registry can be obtained at the ALLG website at [www.allg.org.au](http://www.allg.org.au). Any questions regarding the eDC implementation should be directed to Megan Sanders, Program Manager, at [Megan.Sanders@allg.org.au](mailto:Megan.Sanders@allg.org.au).

*Contributed by Janey Stone, Research Officer, ALLG*

## What has CREST been up to?

### Trial Group Collaborations:

- Participation in a range of CDWs – see the item in this newsletter for details.
- Presentation to the ALLG Scientific Meeting and facilitation of round table discussions on health economics, Melbourne November 11<sup>th</sup>.
- Preparations for the TROG ASM, 2016.
- Attendance at the GCCTI Annual Workshop.



*Richard De Abreu Lourenco leading a round-table discussion on health economics at the ALLG Scientific Meeting*

- Ongoing advice on the development of trial protocols and data collection forms.

### Other Activities:

- Ongoing meetings with the Clinical Trial Group Executive Officers.
- Continuation of the Structured Training Opportunities program.
- Update of the Medicare Data FactSheet to include new contact information for the Department of Health (see the CREST website for details).
- Publication of a commentary in *Lancet Oncology*: De Abreu Lourenco R, Hall J. Paying for the expanding role of primary care in cancer control. Volume 16, No. 12, p1228–1229, September 2015.