

The MAUCA Project – Using existing cancer quality of life questionnaires to produce values for economic evaluations

The EORTC QLQ-C30 and FACT-G are two of the most widely used health related quality of life (HRQoL) questionnaires within cancer clinical trials. Both questionnaires measure the HRQoL associated with a condition and its treatment. The questionnaires are scored on an ordinal scale for each of the different dimensions of quality of life, so a higher score represents better quality of life. But this scoring system does not provide the information required for calculating QALYs, because the scores do not represent “utilities” (or QALY weights). There are some methods for mapping the outputs to QALYs, but these have many limitations.

CREST members Professor Rosalie Viney and Dr Richard Norman are part of an international consortium led by Professor Madeleine King working on a project that will allow preference based utilities to be calculated directly from the EORTC QLQ-C30 and FACT-G questionnaires when used in cancer clinical trials. The project follows on from similar approaches that have been used to convert the SF-36 questionnaire to the SF-6D multi-attribute utility instrument.

The MAUCA (Multi-Attribute Utility in Cancer) consortium is currently engaged in a series of studies to convert the EORTC QLQ-C30 and the FACT-G

to multi-attribute utility instruments and then develop scoring algorithms that can be used to calculate utilities directly from patient completed EORTC QLQ-C30 and FACT-G questionnaires. Development of those algorithms has involved essentially two phases: a factor analysis to develop the multi-attribute utility instrument, and then a stated preference task to elicit societal preferences for the different health profiles described by the instruments. The reason that both phases are needed is that it is not practical to ask respondents to value all aspects of the QLQ-C30 or FACT-G instruments. The first phase helps to determine what are the most relevant aspects for preferences. those resulting health states as the basis for the scoring algorithms.

MAUCA is a multi-centre, international consortium. It has completed its pilot phase, and is now entering the full preference elicitation phase of the research. Completion of the project is anticipated to be a major advancement to clinical trialists and health services researchers alike; reducing the need for multiple instruments in the same trial to assess both HRQoL and utility in a consistent and reliable way.

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Patient Input Matters – Reviewing Treatment of mCRC.

Recently, CHERE hosted Lourens Bloem, a Masters of Pharmacy student from Utrecht University, the Netherlands. During his placement with CHERE, Lourens undertook a project to investigate the clinical or patient characteristics that explain why some patients with metastatic colorectal cancer (mCRC) are treated with i.v. 5-FU and others receive oral capecitabine. Data were sourced from the Prince of Wales (POW) hospital, primarily using the MOSAIQ® database.

The available information was used to explore the patient, disease and treatment characteristics that are associated with the choice of drug (5-FU or capecitabine) in the first line setting. The study also investigated the capacity to which proprietary databases, such as MOSAIQ, can be interrogated to inform research.

In all 170 patients with mCRC were identified from MOSAIQ as having received 5-FU and/or capecitabine as their first-line treatment between 1 January 2011 and 31 December 2013. Data were not available from MO-

SAIQ in a form that could be easily extracted, necessitating the use of patients' electronic medical records to access information on demographics, disease characteristics, treatment history and the process involved in deciding between the use of 5-FU or capecitabine. In general, patient identification and data extraction processes were severely complicated by non-standardised record management and limitations in the quality and availability of data.

The results indicated a high degree of specialisation at this centre for the treatment of mCRC; practice variation between physicians could not be analysed due to a lack of statistical power. A logistic regression was carried out on the choice of whether patients received 5-FU or capecitabine as their first line treatment. Controlling for available demographic and disease characteristics, giving the patient a choice between treatments ($p = 0.000$) and the time between diagnosis and treatment commencement ($p = 0.040$) were found to be positively associated with a first-line treatment choice of capecitabine. Living more

than 40 kilometres away from the hospital ($p = 0.041$) was observed to be associated with a choice for 5-FU.

Taking into account the limitations of using data from one Centre, the results of this study suggest that the main factor influencing a first-line treatment choice for mCRC patients treated at the POWH is providing the patient with a choice between treatment options. When they were given a choice, the data suggest that patients were more likely to choose capecitabine. This project was also instrumental in highlighting the strengths and limitations of a database like MOSAIQ for use in research. It has generated much discussion regarding the potential for the information in databases like MOSAIQ to inform not only health services research, but also clinical based research questions.

PC4 Concept Development Workshop - Wednesday 24th September

Registrations close Monday 21st July for the PC4 Concept Development Workshop (CDW) to be held on Wednesday 24th September.

This is an excellent opportunity to have nationally-recognised experts (and potential grant reviewers!) provide feedback on your research. The workshop is the ideal forum to:

- Decide the potential of an early research idea

- Build upon a research outline
- Strengthen a grant application
- Network with experts in clinical trial development
- Gain insights into the grant review process

PC4 encourages early and mid-career researchers to attend, although the workshop is appropriate for ALL researchers. Submitted concepts will be reviewed and all applicants notified of the outcome by Tuesday 29th

July.

If your concept is selected we will assist you to prepare your concept for presentation at the CDW.

For more information: please visit the PC4 website (<http://www.pc4tg.com.au/-News-Events-.html>) or contact Katie Shaw on 08 9346 7365 or katie.shaw@uwa.edu.au.

Returns to Cancer Research: Comments on a recent publication.

There are many ways in which researchers quantify the impact of their work; the numbers of publications, how the results change practice, or the effects of a particular intervention on patient survival and quality of life. Glover et al (2014) expand on these types of metrics by estimating the internal rate of return on cancer research in the UK.¹

In their analysis, the authors assess the return generated from the resources invested in cancer research when benefits are measured in monetary terms. That is, they estimate the value in monetary terms of the changes in outcomes that are produced from research compared with the cost of producing cancer research and the subsequent changes in treatment practices. Outcomes in their analysis were measured using quality adjusted life years gained (QALYs), and each QALY was assumed to be worth £25,000 (using the average threshold from the National Institute for Health and Care Excellence).¹ The analysis considered publicly funded cancer investment in the UK between 1970 and 2009, in the areas of smoking cessation, cervical screening, breast screening, bowel cancer screening, and the treatment of prostate, breast and colorectal cancers.

The results of the analysis indicated a net monetary benefit (the difference between the costs and benefits across all the areas investigated) of £124 billion, with an internal rate of return of 10%. However, these results were highly dependent on the benefits produced by smoking cessation programs; excluding smoking cessation from the estimation of the costs and outcomes reduces the internal rate of return to 2.4%.

The authors are clear about the limitations of carrying out such an analysis. This includes, but is not limited to: difficulties in attributing research funding and outputs to one indication; the results are sensitive to how outcomes are valued; the cross-fertilisation of effects between indications is not captured; and it is sensitive to the quality of the data on costs and effectiveness.¹ Other potential limitations to how this analysis might apply in other research settings or countries lie in the breadth of its analysis. As noted, the largest contributor to the IRR was smoking cessation programs. It is reasonable that these results showing a relatively high rate of return (10%) are therefore most applicable to research related to smoking cessation programs. The other issue is how the effects of failed research might be captured within such a framework.

In particular, the sensitivity of the results to the estimated costs and outcomes illustrates the importance of having robust estimates of the costs and outcomes of new interventions; the estimated returns on research calculated within the paper rely on the published estimates of costs and QALYs. Having good data from clinical trials for both of those metrics provides greater confidence in being able to estimate the expected returns to society from investing in such research.

A link to this paper is available on the CREST website:
<http://www.chere.uts.edu.au/CREST>

Reference:

1 Glover M, Buxton M, Guthrie S, Hanney S, Pollitt A, Grant J. Estimating the returns to UK publicly funded cancer-related research in terms of the net value of improved health outcomes. *BMC Medicine* 2014; 12:1-20.

TROG Cancer Research report

The Trans Tasman Radiation Oncology Group (TROG Cancer Research) has seen many positive developments recently including a change in membership rules, a new mobile app for patients, four new trials approved for development and the formation of a Consumer Advisory Panel.

The TROG Constitution was recently amended and now all members qualified in their profession or specialist involved in TROG clinical trials may apply for full membership, and have full voting rights on TROG matters. We are looking forward to the positive changes that this multi-disciplinary approach will bring to TROG.

This year's Annual Scientific Meeting saw an unprecedented number of proposals for new trials. A total of fifteen were submitted with nine being approved for further development these trials can be viewed in the *Our Research* section of www.trog.com.au.

TROG's next Annual Scientific Meeting will be held March 24-26, 2015 at City Hall, Newcastle. TROG's ASM provides a forum for radiation oncologists, cancer care clinicians, physicists, radiation therapists, data managers, research nurses, clinical trial coordinators and personnel from allied health fields to meet and discuss TROG's current portfolio of clinical trials, potential new trials and new technologies. Our invited international speaker is Professor Kevin Franks, consultant clinical oncologist at the St. James's Institute of Oncology (SJIO) in Leeds, UK. Registrations open August at www.trog.com.au.

TROG has maintained its focus on patient support, most recently through the development of a free mobile app, *TROG ClinTrial Refer*, which puts information about TROG trials at the fingertips of patients and clinicians. By simply choosing a disease type and nearest hospital, users can access a list of potentially suitable trials, opening up further

opportunities for treatment and care. To download the app on your smartphone or tablet search for *TROG ClinTrial Refer* in the Apple App Store or on Google Play for Android. The app was funded with the 'Innovation in Cancer Clinical Trials' award TROG received at the 2013 NSW Premier's Awards for Outstanding Cancer Research.

We are also pleased to announce the formation of a new TROG committee aimed at supporting consumers who provide input into TROG's research programs. The TROG Consumer Advisory Panel (CAP) will provide support, mentoring and training to TROG consumers.

Finally, TROG is proud to congratulate TROG member Professor Thomas Kron, who was recognised in June for his services to medicine, research and education with an Order of Australia medal.

Workshop update

In April 2014, CREST ran its first health economics workshop specifically designed for consumer representatives: *Health Economics in Cancer Research – A Consumers' Guide*.

Fourteen representatives from various trial groups attended an all-day session on the role health economics plays in making new health care treatments available in Australia, in particular pharmaceuticals and medical services. Participants in

the workshop were not only able to learn about the processes involved in new treatments being funded in Australia, and how health economics information contributes to this, but also about the very important role that consumers have to play. A second outing of this workshop is about to be held in Melbourne (July 16th).

Representatives from the trial groups also attended the *Under-*

standing Health Economics in Cancer Research held at the Cancer Australia offices in Melbourne on June 17th.

Plans for a second run of this workshop for this year (initially to be held alongside the COSA meeting) have been put on hold. Stay tuned for more information about future upcoming health economics workshops.

ANZBCTG Report: Recognition for Breast Cancer Clinical Trials Researcher

Professor John Forbes AM has been recognised as one of the world's leading scientific researchers, with the release of Thomson Reuters list of "The World's Most Influential Scientific Minds: 2014".

The list is composed of researchers who have published the highest number of articles that rank among those most frequently cited by fellow researchers. Professor Forbes is one of 65 Australians from the international list of 3,215 individuals across all fields of science and one of just seven Australians recognised in the area of Clinical Medicine.

Professor Forbes is the Director of Research at the Australia and New Zealand Breast Cancer Trials Group (ANZBCTG), and is Professor of Surgical Oncology at the University of Newcastle and Director of Surgical Oncology at the Calvary Mater Newcastle Hospital.

Professor Forbes has Chaired and Co-chaired many international clinical trials over the past 35 years, the results of which have led to new and improved treatment options for women diagnosed with breast cancer in Australia and New Zealand and throughout the world. He was the International Study Co-Chair of the IBIS-I and IBIS-II pre-

vention clinical trials which have led to women at increased risk of breast cancer having more options to manage their risk.

"This is recognition of our global collaborations in breast cancer clinical trials. I thank all researchers in Australia and New Zealand and worldwide who have contributed to this important area of research. The participation of thousands of women in breast cancer clinical trials has been instrumental and we are very grateful for their shared commitment to improving the outcomes of all women now and for future generations," Professor Forbes said.

"It is an endorsement of the quality of the research undertaken by the ANZBCTG, in what is an internationally peer reviewed process. As a result of clinical trials research, we have made significant improvements to the treatment options available to women diagnosed with or at risk of breast cancer and to survival rates, helping more women to survive their breast cancer long term."



The ANZBCTG is Australia's national organisation dedicated entirely to breast cancer research. It conducts a national clinical trials research program for the treatment, prevention and cure of breast cancer. The research program involves multi-centre clinical trials and collaboration with 84 institutions and over 700 researchers throughout Australia and New Zealand and many more globally. More than 14,000 women have participated in ANZBCTG breast cancer clinical trials

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 word from the ANZMTG

Australia has the highest incidence of melanoma in the world and it is often referred to as Australia's national cancer. The Australia and New Zealand Melanoma Trials Group (ANZMTG) coordinates and conducts quality research within the field of melanoma, conducting both national and international trials. Our free membership is currently composed of over 700 members from a diverse range of backgrounds including research, health care and melanoma support networks.

ANZMTG's growing clinical trial portfolio is notable, in light of the rapid advances of new melanoma treatments and technology. Our current and new trials in development vary in scope, however all have the same aim of ensuring that our research will translate to better prevention, treatment and care of current and future melanoma patients. We are working closely with CREST to ensure that the health economics aspect of each trial is appropriate and well documented, and we also continue to openly collaborate with other expert groups and individuals to ensure our trials are robust and meaningful.

The research output of ANZMTG reflects the hard work and dedication of the various collaborators, investigators and project team members throughout the year.

ANZMTG's 2013 highlights included the presentation and publication of a number of trials at major melanoma meetings including 8 original research articles, 25 oral presentations, 13 poster presentations and involvement in 2 workshops.

Our Annual Scientific Meeting is taking place in Perth on 9th October 2014 and we welcome any member from the Cancer Cooperative Trials Group to attend if they are interested to know more about what we do. The focus will be on new research proposals and the meeting will provide a good insight as to what you can expect from ANZMTG in 2015. Please contact anzmtg@melanoma.org.au for more information, or visit our website www.anzmtg.org. The meeting will be held in conjunction with the National Melanoma Conference hosted by the Scott Kirkbride Melanoma Research Centre team and held in the newly opened Harry Perkins Institute of Medical Research, which takes place on 10th and 11th October, making it a very worthwhile trip.

ANZMTG Australia and New Zealand
Melanoma Trials Group

What has CREST been up to?

Over the last three months, the CREST team has continued to work with the CTGs and Cancer Australia:

Trial Group Collaborations:

- Prepared audits on planned clinical trials, and reviewed concepts for forthcoming concept development workshops (eight in total).
- Provided advice on the conduct of health economic analyses in ongoing studies (eg. PC4 and ANZCHOG studies).
- Worked on various NHMRC Project Grant application re-

buttals.

- Commenced a structured training opportunity with researchers from Sydney Children's Hospital.

Health Economics Workshops:

- One day consumer workshop held in Sydney, March 2014.
- One day introductory workshop held in Melbourne, June 2014.
- Presented at the QoL Office Protocol Workshop, May 2014.

Ongoing updates of the CREST website: <http://www.chere.uts.edu.au/CREST>.

Other Activities:

- Participated in the Genomic Cancer Medicine Workshop, Kinghorn Cancer Centre NSW
- Presentation at the POWH on determinants of mCRC treatment choice.
- Presentation to Cancer Australia Staff Seminar series on CREST.