Quality of life considerations in therapeutic research – putting the patient experience first

TCRN Conference Grants Series: Ms Anne Booms

Examining the importance of using a patient’s perception and experience whilst they undergo new and pioneering clinical trials opens opportunities for discussion of scientific progress and policy in quality of life (QOL) research. I was excited to attend the 3rd European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life, Symptom Research and Patient Reported Outcomes in Cancer Clinical Trials Conference in Brussels, Belgium with the support of a 2012 TCRN International Professional Development Grant. This conference brought together an international faculty, providing diverse opinions on QOL from across the globe. Brussels is a beautiful city with a vibrant culture, heritage and of course, its famous chocolates. Personally, going to Belgium was also visiting my home country again and to observe Brussels as a tourist.

With Brussels being the economic centre of Europe, the conference aptly commenced with a health economics debate led by Dr Marisa Matias, University of Coimbra Portugal. Dr Matias talked about increasing health care costs and the use of expensive biological therapies in cancer care contributing to financial strain borne by patients. Cost is now considered a therapeutic “side effect” that poses a significant financial burden to patients. Physicians are facing the task of selecting which patients are worthy of treatment considering their age, stage of disease, financial commitment and the impact on QOL of the cancer treatment being considered. Although issues in relation to the economic impact of cancer treatments need to be addressed, policy makers have raised questions around the effect of such treatment decisions on equity of care.

Improving patient QOL during the cancer treatment process requires a translational research pathway similar to that used in developing curative cancer therapies, according to Prof Charles Cleeland, Department of Symptom Research, University of Texas. Prof Cleeland highlighted that cancer treatment causes high symptom levels that limit treatment tolerability, with patient biology playing a significant role in determining the risk of symptom burden. Prof Sloan from the Mayo Clinic, Minnesota USA, explored the concept of patient reported outcomes and genetic makeup as a novel approach to assessing QOL outcomes. He discussed how developing new methods to predict and prevent symptom burden will become part of personalised cancer care.

Translational pathways can be used as a strategy to speed up the steps between basic science and patient use for curative treatments. Assessing QOL in advanced stage trials can inform patients and physicians about risks and benefits, and can identify ways to improve cancer treatments. We also know that patients with advanced stage cancers are likely to be older. Dr Carol Moinpour from the Fred Hutchinson Cancer Research Centre, Seattle Washington, concluded from health-related (HR) QOL value studies that aging assessment issues are affecting HRQOL outcomes and the provision of HRQOL data. Practical data collection issues may include comorbidities, polypharmacy, social support, and functional and mental status. However improved medical literacy and the successful use of self-reporting methods, together with better statistical methods for analysing datasets with non-random missing data, will lead to more confidence in HRQOL findings.

A key take home message of the conference is that QOL research is an important aspect of clinical trials in cancer care. In general, there are many underlying issues in using self-reported data, patient perspectives and the interpretation of collected subjective data. There is no standard approach to study design, collection, analysis and interpretation of data in clinical trials. QOL objectives need to reflect realistically on expectations versus experiences.

Despite the challenges we face in the provision of cancer care, patient QOL should remain our main concern. Ongoing engagement in international fora such as the EORTC meeting will allow clinicians and researchers to keep up-to-date with the latest advances and achievements in improving the QOL of our cancer patients. In turn, we must consider our own contribution to the design and implementation of QOL assessment in our efforts to improve cancer patient care.

A.B.

Member spotlight: Anne Booms

Anne Booms was recipient of a TCRN International Professional Development Grant for attendance at the 3rd EORTC Quality of Life, Symptom Research and Patient Reported Outcomes in Cancer Clinical Trials Conference, held in Brussels, Belgium in October 2012. As an Oncology Nurse Practitioner with Albury-Wodonga Health, Albury Campus, Anne works across a range of tumour streams in adult oncology. She is a site Clinical Champion for the 2012 TCRN Cancer Challenge of the Year – SpaceEd: a tool to help translate pain assessment and management evidence into routine cancer care practice.

Anne is a member of the Border Medical Oncology Research Unit (BMORU) TCRN member group, and currently provides patient support and follow up to patients admitted under the BMORU clinical research programs, in collaboration with the trial nurses. In 2013, Anne plans to expand her research activity by investigating outcomes and quality of life issues of cancer patients in regional NSW & Victoria.
Putting a price on quality of life
Dr Richard Norman, Centre for Health Economics Research & Evaluation

The current uncertainty regarding the appropriate methods for the collection, analysis and interpretation of HRQOL data in clinical trials presents many complexities for the translation of promising research discoveries into improved health outcomes for patients with cancer. From the perspective of Health Technology Assessment, and more specifically health economics, this is a crucial issue in how we as a nation make decisions regarding public reimbursement for new (and often expensive) technologies and pharmaceuticals, both in oncology and more broadly.

Public decision-making through, for instance, the Pharmaceutical Benefits Advisory Committee or the Medical Services Advisory Committee, generally considers health economic evidence as one of the major determinants in their discussions. When identifying the improved outcomes associated with any new technology, the standard approach is to combine issues surrounding QOL with mortality. The reason for doing so is it aims to facilitate sensible comparison between interventions which improve one, the other, or both. While mortality is a clearly defined endpoint, quality of life measures are subject to uncertainty. How do we ask patients to describe their health? How often over the course of their treatment? How do we place a value of the subsequent health profile? These remain live and highly policy-relevant questions, and are the subject of much research both in Australia and internationally.

A major source of uncertainty arises when clinical trials choose not to include a QOL measure amenable to economic evaluation. In these circumstances, submissions for public subsidy require quality of life scores derived from other sources. This can often lead to uncertainty in generalisability, and delays listing of worthwhile drugs (and hence access for patients in need). While groups undertaking trials must be mindful of the burden that extra data collection can have on often very ill patients, it should be noted that much work at the intersection of health economics and QOL has focused on reducing this burden by producing small instruments (through, for instance, factor analysis), which are able to capture QOL changes in a variety of different settings in cancer and beyond.

R.N.

Congratulations to the recipients of the Round 1 2013 TCRN Conference & Professional Development Grants

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Stay tuned for the announcement of more Round 1 2013 TCRN Conference & Professional Development grant recipients as our pending awardees receive confirmation of abstract acceptance.
It’s grant time again... Check out the research support services that TCRN members can take advantage of in 2013

As many of our members enter into the depths of the annual grant writing period, we’d like to remind all TCRN members of our existing research support services in addition to introducing a brand new opportunity for 2013.

**HEALTH DATA SETS**

The TCRN is pleased to collaborate with the Adult Cancer Program, Prince of Wales Clinical School, UNSW, to make health data sets collected by their researchers accessible to TCRN members for wider translational cancer research purposes. Datasets are made available through Research Data Australia.

These clean and structured data resources provide a wealth of information for researchers wishing to either build upon a current line of research or instigate new interrogations. Members are encouraged to browse the shared collections with the view to initiating efficient reuse of data to accelerate research advances for the improvement of clinical practice and treatment outcomes:


For further information about the health data set collection, contact the Information Officer at info.acp@unsw.edu.au

**LOWY BIOREPOSITORY GRANT APPLICATION ASSISTANCE**

The Lowy Biorepository offers a grant application assistance service for researchers wanting to include the costs of biospecimens and associated data that are a direct requirement of your research project for 2013 grant rounds, such as NHMRC.

The Biorepository can provide a quote for specimen access and storage, and a description of Lowy Biorepository services and benefits, to include in your application.

The TCRN is pleased to have supported the development of a brand new Lowy Biorepository website, where you will find further information about this service and instructions for submitting a grant assistance request:

[www.biorepository.unsw.edu.au](http://www.biorepository.unsw.edu.au)

TCRN members are also reminded that a member discount will apply for your use of the Lowy Biorepository services, including specimen storage, processing, retrieval and management systems.

**TCRN CONSUMER ADVISORY COMMITTEE**

We are very pleased to introduce the TCRN Consumer Advisory Committee (CAC) as a new research support service for our members in 2013.

The CAC comprises members with diverse skills, experiences and interests in a range of cancer types, and an experienced chairperson, and will provide the TCRN and its members with advice, guidance and recommendations from a consumer perspective.

The CAC is commencing its activities by undertaking a consumer review of NHMRC and Cancer Australia Priority-driven Collaborative Cancer Research Scheme (PdCCRS) grant applications of the TCRN membership. Members who responded to our call for CAC review requests in January will receive committee review of their grant application materials, and recommendations for improving the research experimental design and/or proposal content from a consumer perspective. In addition, an appropriate primary ‘consumer partner’ from within the TCRN CAC will be identified for each submitted research project for ongoing researcher liaison.

The provision of a grant review service is just the beginning of the CAC’s input into the TCRN. It is anticipated that the CAC will become involved in many aspects of the Network, including being a resource to the TCRN’s Leadership Council as well as creating ongoing, sustainable consumer engagement with all the members of the TCRN, not just researchers. It is our hope that the CAC will become a source of advice and guidance to the entire TCRN membership.

More about the TCRN consumer engagement service can be found on our website.

**TCRN PhD Skills & Development Program**

The TCRN PhD Scholarship Top-up Awards are designed to enhance the translational cancer research capabilities of PhD students who possess research interests aligned with the TCRN’s core strengths. Through the top-up awards scheme, the TCRN currently supports 12 PhD students undertaking studies in UNSW Medicine, with our 2013 Round 1 Awardees soon to be announced.

As part of the professional development package provided for Top-up Awardees, the TCRN has designed a PhD Skills & Development Program for commencement in 2013. PhD students will participate in two one-day workshops structured to provide specific skills and knowledge related to translational research, cross-discipline collaboration, biostatistical analyses, consumer engagement and research communication. The first of our one-day workshops will be held on Friday 15th March at the Prince of Wales Hospital.

Further information about the research interests of all TCRN PhD Scholarship Top-up Awardees can be found on our website:

CANCER CHALLENGE OF THE YEAR 2012 PROJECT UPDATE
The Spaced Education (‘Q stream’) Pain Assessment Challenge

The Spaced Education (‘Q stream’) Pain Assessment TCRN Cancer Challenge of the Year 2012 project is now in full swing! It is fabulous to begin 2013 with the detailed project planning and approval process having been finalised and the focus now moving to implementation.

Clinical Champions
A HUGE thank you to the all of the local Clinical Champions for their ongoing support and assistance to get the project started and the enthusiasm they have generated within their departments:

- Anne Booms - NP, Border Medical Oncology/Albury Hospital
- Carina Falomir - CNE, St George Hospital
- Rachelle Frith - CNE, Prince of Wales Hospital
- Fiona Gillanders - CNC, St George Hospital
- Sarah Hayes - CNE, Prince of Wales Hospital
- Zane Healy - DON, Albury Hospital
- Kim King - CNE, Royal Hospital for Women
- Gemma Leake - CNE, Sutherland Hospital
- Louisa Robinson - CNC, Prince of Wales Hospital

Case based learning scenarios
The Expert Advisory Group has refined the 12 case based learning scenarios for the cancer care setting. Each case focuses on a different aspect of cancer pain assessment practices. All of the cases contain a take home message and links to relevant evidence and resources.

Enrolling participants
Spaced Education (‘Q stream’) Pain Assessment Challenge participant information sessions have been being conducted across the five sites throughout late January and early February 2013. The support and enthusiasm from each of the participating sites has been outstanding.

Shortly after enrolling, participating doctors and nurses will be emailed two new case studies every two days for completion. At ‘spaced’ intervals, approximately every 5–8 days, repeat case studies are emailed to participants – a process continuing until the participant has correctly completed each case study twice in a row. Participants receive immediate feedback about whether their responses are correct or not, and are also provided with feedback about how aligned their response is to their peers. They also receive links to relevant educational resources.

More information about the Spaced Education methodology can be found at: http://wedg.qstream.com/info/howitworks

WHAT IS ‘SPACED EDUCATION’?
Spaced Education is a novel method of online education that combines two core psychology research findings: the spacing effect and the testing effect.

The spacing effect refers to the research finding that information that is presented and repeated over spaced intervals is learned and retained more effectively.

The testing effect refers to the research finding that the long-term retention of information is significantly improved by testing learners on this information; testing becomes not just a means to measure knowledge, but a stimulus for knowledge to be stored more effectively in the long-term memory.

For more information
If you would like any more information about the project or would like to participate in the project as a TCRN member (individually or as a department), please contact the 2012 CCY Project Coordinator, Nicole Heneka, on 02 8383 2110 or via email: rheneka@stvincents.com.au

Next steps
- Collection of baseline survey and chart audit data.
- Development of a new learning module related to minimising opiate errors in cancer and palliative care settings.
- Feeding back the pain assessment chart audit data to each participating site.

Read all about project progress in the next edition of Nexus.
Member activity reporting
A big thank you to all TCRN members who have completed their online activity reporting for the 2012 calendar year. The scope and extent of publication and grant activity amongst the membership is significant, and a strong indicator of the quality research and impact of activities being implemented throughout the TCRN member institutions.
Members are encouraged to share news of fresh collaborations, funding successes, research publications and professional development activities as these occur, by updating your activity on the TCRN website member portal.

2013 LOWY CANCER SYMPOSIUM

‘Discovering Cancer Therapeutics’
Designed for basic research scientists, oncologists and other health care professionals, the second Lowy Cancer Symposium will highlight Australasia’s research strengths, including recent developments in personalised pancreatic cancer therapy and hypoxia-activated cancer drugs.
When: 15–17 May, 2013
Where: Lowy Cancer Research Centre, University of New South Wales, Sydney
Registration: Opens Monday 11th February, 2013; Early Bird Registration closes Friday 15th March, 2013
Abstract submission deadlines: Oral abstract - 15th March; poster abstract - 5th April, 2013
For further information, online registration and abstract submission visit the symposium website at www.lowycancersymposium.org

NELUNE CANCER GRAND ROUNDS 2013

The Nelune Cancer Grand Rounds are back for 2013!
The first Cancer Grand Round of the year will be held on Thursday 28th February, 8–9am, with light breakfast provided from 7:30am.
Where: John Dwyer Lecture Theatre, Edmund Blackett Building, POWH, Randwick. Click here for directions.
The Nelune Cancer Grand Rounds will be held on the last Thursday of each month, from 8–9am.
Look out for details of the monthly Cancer Grand Rounds series in each edition of Nexus.

TCRN CANCER CHALLENGE OF THE YEAR
2013 application process now open!
What do you think is the greatest unmet need in translational cancer research in 2013?
The TCRN Cancer Challenge of the Year (CCY) is back again in 2013 with a facelift!
As a unique funding opportunity, the 2013 CCY aims to fund translational research projects designed to address a new cancer or generic problem related to cancer. The CCY targets research initiatives capable of producing a demonstrable outcome within a 12 month period – creating solutions to today’s priority problems in order to make rapid and appropriate gains in the improvement of cancer patient care and treatment outcomes.
The 2013 CCY award process will follow an innovative 3-step formula: Step 1 is to identify the unmet need – the ‘Challenge’!

We are calling on all TCRN members, the wider research community and the public to get involved and help the TCRN to identify a Cancer Challenge for 2013.
All details of the 2013 CCY award process can be found on the CCY website: www.tcrn.unsw.edu.au/cancer-challenge-2013

We encourage everyone to visit the website and to become engaged in the interactive 2013 CCY processes, either to post a Challenge, to comment on a posted Challenge or to vote for your favourite Challenge.
Together we can shape a Cancer Challenge that, if addressed, will have significant impact on patient care and treatment practices in a tangible timeframe.
This open call for Challenges will run from Thursday 24th January to Sunday 17th February, 2013.

GETTING THE MOST FROM THE TCRN WEBSITE

Bookmark these pages and let the TCRN website work for you.
Are you...
Interested in projects of the TCRN?
www.tcrn.unsw.edu.au/our-projects
Looking for research support services?
www.tcrn.unsw.edu.au/research-support-services
Wondering about the latest news in the network?
www.tcrn.unsw.edu.au/news-events
Wanting details of current funding opportunities?
www.tcrn.unsw.edu.au/funding-opportunities
Thinking about defining ‘translational research’?
www.tcrn.unsw.edu.au/translational-research-definitions

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