

Select Committee



The Australian Senate has been holding an open enquiry into Funding for Research into Cancers with Low Survival Rates. Professor Rosalie Viney and Dr Richard De Abreu Lourenço were invited to appear on 28th August 2017 on behalf of the Australian Health Economics Society (AHES) before the Senate Select Committee presiding over this enquiry. Here is an extract from the opening statement delivered by Professor Viney.

There is no doubt that medical research has made significant breakthroughs that have improved the survival and quality of life for people diagnosed with cancer over the past fifty years, meaning that many cancers can now be treated as chronic diseases. There is equally no doubt that the biggest steps forward have been for more common cancers. The submissions to this inquiry have noted that in the field of cancer research rarity of disease tends to go hand in hand with less research and with lower survival rates. This has meant that, in effect, there is a double challenge for some cancers – for rare cancers, the capacity and opportunity to undertake research has meant that there has been less advance in treatment, and lower survival rates make that research more difficult.

A common concern is that our funding system does not provide incentives for research into rare diseases, that it is fundamentally more difficult

to conduct clinical trials in rarer diseases, and therefore that rare diseases are unable to meet the evidentiary requirements for new treatments to be reimbursed and made available. This raises the question of whether we should have a different level of evidence requirement for rare diseases, or for diseases where there has been limited medical advance.

It is important to note that our system does not intrinsically require the same level of evidence across all treatments and diseases, but rather that it requires the same approach to consideration of evidence – whether the new treatment provides an improvement in health, at an acceptable cost. For a fair and sustainable health system it is essential that all new treatments can demonstrate that they are effective and represent value for money.

This does not mean that they must all provide the same standard of evidence, or that there is a single number that represents what is good value for money. For example, in the deliberations by Australia's Pharmaceutical Benefits Advisory Committee, there are a range of factors beyond the incremental cost-effectiveness ratio that come into play, including the severity of the condition being treated, whether there are any effective alternative treatments and consideration of equity. In this context, it is important to note that our reimbursement decision making committees do not set a minimum standard for the evidence requirements – PBAC has in the past made positive (*continued last page...*)

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An Update from TROG

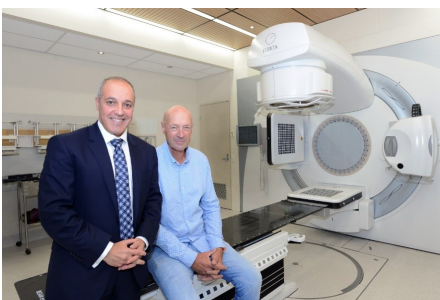
World-first trial pioneers new standard of care for skin cancer

Patients with advanced skin cancer can now be spared from having to undergo chemotherapy, with results from a new TROG Cancer Research study showing that surgery combined with radiotherapy is a more effective treatment.

Professor Sandro Porceddu who headed the 'POST' trial said the results showed that for patients with advanced squamous cell carcinoma (one of the most common forms of skin cancer) of the head and neck, surgery and post-operative radiotherapy resulted in high cure rates, in excess of 85 per cent.

"This confirms that surgery and post-operative radiotherapy should be considered the standard of care for treating this disease. The trial also showed that the addition of chemotherapy did not improve cure rates."

"This will save patients from the added side effects associated with chemotherapy. It will also reduce costs associated with providing cancer treatment," said Professor Porceddu.



Prof. Sandro Porceddu with trial volunteer Robert Schampers.

More than 320 patients from 23 centres from Australia and New Zealand took part in the 10-year trial, which began in 2005.

US Cancer leader to speak at TROG 2018 ASM

TROG is pleased to announce Professor Walter J. Curran, Executive Director of the Winship Cancer Institute of Emory University as the invited international speaker for its 2018 Annual Scientific Meeting (ASM).



Prof. Walter J. Curran.

Prof Curran is an international expert in the management of patients with locally advanced lung cancer and malignant brain tumours and has led several landmark clinical and translational trials in both areas.

The 2018 TROG ASM will be the 30th for the group – a major milestone. The ASM is being held in Hobart from 19-22nd March. Registration is now open. Visit TROG2018.com for more information and to take advantage of early bird rates.

TROG also invites members to submit an abstract from any area of radiotherapy cancer research for oral presentations at the 2018 ASM.

The deadline for abstract submissions is Friday 15 December 2017.

Broadcaster Julie McCrossin announced as TROG's ambassador

TROG Cancer Research is excited to announce Julie McCrossin, well-known and respected broadcaster, as its new ambassador. Julie has experienced cancer firsthand being diagnosed with throat cancer in 2013.

TROG CEO Joan Torony said that Julie was a perfect fit to work with TROG: "We are very much looking forward to working with Julie not only to promote the role of radiotherapy as an effective cancer treatment but also help to let the community know about the important research that TROG Cancer Research undertakes."

According to Julie, research is the key to the innovation that advances cancer treatments: "It will be a real pleasure to help get the message out that funding research and translating the results into clinical care as quickly as is safely possible are absolutely vital for people affected by cancer," said Julie.



Julie McCrossin with a mask

Contributed by Tanya Carlyle, TROG

Ticking all the Right Boxes

One of the advantages of having a public funded health care system, Medicare, is that data on the use of outpatient medical and pharmaceutical services are collected routinely at the point of service. As outlined in our [CREST FactSheet](#) on using Medicare data, this allows clinical trial researchers, health economists and health services researchers to access information on health care use by clinical trial participants more readily than through primary data collection.

The process is relatively straightforward. Prior to the trial commencing, an application is submitted to the Department of Human Services,

providing details of the trial, the dates for which Medicare data are sought, and importantly, the data fields that are to be extracted. There are standard forms to be submitted for this purpose.

The key is that consents are obtained appropriately from trial participants; specifying the relevant dates for data extraction, example fields to be extracted and as approved by the Department of Human Services. It is also important that all the relevant data fields that will be required for subsequent analyses, potentially of cost-effectiveness, should be requested at the time of applying. Patients

will be consenting for their information to be used to help inform an analysis of cost-effectiveness so it is important that the right information is requested from the outset.

Hopefully, you have expertise available on your trial team to be able to navigate the Medicare process, but if in doubt we are happy to provide advice. By consenting patients appropriately, and requesting all the right Medicare data fields, researchers can obtain a wealth of information on health resource use to incorporate into their subsequent analyses.

Public Preferences for Cancer Care

Hardly a news cycle goes by without media coverage of a new cancer therapy and the need to increase funding for cancer care. What such stories usually do not discuss is the implication of that increased funding; in a world of finite resources, increasing funding to one area of health care invariably means reducing it in others as we are forced to trade-off investing in the care of one group of patients in preference for another.

In countries with publicly reimbursed systems like Australia, such decisions are placed in the hands of reimbursement bodies charged with reflecting societal preferences. If such groups are to preference cancer care over other conditions, would they indeed be reflecting the preferences of society at large?

In a recently published systematic review, Morrell et al (2017)¹ report

that across 24 studies (including two from Australia) investigating preferences for health gains in cancer care relative to those in other conditions, there was no consistent evidence to support prioritising spending for health gains in cancer care. The majority of the studies used survey based stated preference methods, such as willingness to pay studies, which varied in their research designs, the specific topics investigated and the populations surveyed (being conducted in different countries). Morrell et al (2017) note that these differences across studies may mask the ability to draw firm conclusions on public preferences for cancer care. The authors found greater consistency across studies when they focused on those that considered preferences based on disease severity. Looking at an additional 12 studies which considered respondents'

preferences based on condition severity, the authors found that there was evidence for prioritising based on condition severity.

The authors note that there is a duality in preferences apparent from the studies reviewed; a view that health gains from cancer care are important, but no consistent evidence to support prioritising such care over other care. They caution that the current evidence base for understanding such preferences is small, and that further research is needed to understand the aspects of cancer care that are valued by the public in order to inform public-sector decision making.

¹ Morrell L, Wordsworth S, Rees S, Barker R. Does the Public Prefer Health Gain for Cancer Patients? A Systematic Review of Public Views on Cancer and its Characteristics. *Pharmacoeconomics*. 2017 August 01;35 (8):793-804.

ANZUP Cancer Trials Group Update

ANZUP exists to improve outcomes for people affected by genitourinary cancers (cancers of the prostate, kidney, bladder or testis) by performing clinical trials to generate evidence to improve treatment and support.

In July this year, 330 delegates attended ANZUP's 8th Annual Scientific Meeting (ASM) in Melbourne. With more than 50 speakers, panellists, session chairs and e-poster presenters taking part in a host of multi-disciplinary sessions, there was something for everyone working in genitourinary cancers.



A plenary at the 2017 ANZUP ASM

The program included a highly successful new Translational Research Symposium, the popular MDT Masterclasses (which were broadcast via live webcast and featured interactive polling) and an expanded PCFA ANZUP Nurses Symposium. The 2017 ASM's international faculty of five experts provided a global perspective on many of the key issues facing GU cancer specialists.

ANZUP's annual Community Engagement Forum, held as part of the ASM, brought together patients, their families and clinical experts. Speakers and panel discussions covered quality of life, treatment choices, survivorship, impacts on intimacy and how to find reliable

information online.

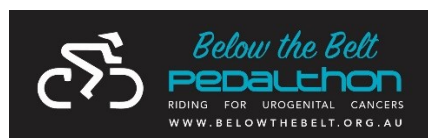


ANZUP Chair Professor Ian Davis, Chief Executive Officer Margaret McLannett and Professor Silke Gillissen.

The ASM closed with an awards presentation, including the announcement of five Below the Belt Research Fund recipients. Backed by the Below the Belt Pedalthon fundraiser in September, the fund enables ideas nurtured by ANZUP's Concept Development Workshops to progress with the allocation of vital funds.

Successful research studies include the development of an evidence-based online exercise support for men with metastatic prostate cancer, a qualitative exploration of patient perception of adherence to treatment advice, development of a cooperative multi-centre cystectomy database and bipolar androgen therapy (BAT) in men with metastatic castrate-refractory prostate cancer.

ANZUP continues to work with CREST on a number of projects, including the health economic analysis of ICECaP. CREST continues to be active participant at many of ANZUP's Concept Development



Workshops and the ASM.

This year's Pedalthon, which will be held at Eastern Creek on 19th September, will celebrate its fourth year of fundraising for four cancers by pushing the combined total over \$1 million. With around 40 teams registered at the time of writing, there's still time for anyone interested to sign up or support those putting their legs on the line at www.belowthebelt.org.au.

ANZUP is also gearing up for the 2017 Seminal Advances in Prostate Cancer Preceptorship in collaboration with Monash Institute for Health and Clinical Education (MIHCE) in Melbourne on 3 and 4 November. With 2017 Preceptors including Professor Henry Woo and A/Professor Arun Azad, the 2017 course will be an exceptional learning opportunity for trainees and junior specialists.

Registrations are also open for the 2017 Best of GU Oncology Evening Symposium in Sydney on Wednesday 8 November. Led by Symposium Chair, Professor Henry Woo, the Best of GU will round out ANZUP's highly regarded event calendar for 2017. For more information see www.anzup.org.au.

Contributed by Michelle Bowers, ANZUP



Breast Cancer Trials - New Name for the ANZBCTG

For almost 40 years, the Australia and New Zealand Breast Cancer Trials Group (ANZBCTG) has been committed to finding new and improved breast cancer treatments and prevention strategies for every woman. This has been supported by our fundraising department, the Breast Cancer Institute of Australia (BCIA), which has raised more than \$80 million for our research program in the last 20 years thanks to the generosity of individuals and corporate supporters.

Our work has improved the treatment of breast cancer, led to changes in the way breast cancer is managed and together with our international collaborators, has saved millions of lives.

The clinical trials landscape has changed markedly since the ANZBCTG formed some four decades ago and we are operating in an in-

creasingly competitive and disruptive research and not-for-profit environment in Australia and New Zealand. For this reason, the ANZBCTG embarked on a lengthy and extensive rebranding project over the last year with the aim of bringing our two brands, the ANZBCTG and the BCIA, together under one name.

Our new name is **Breast Cancer Trials** and it will be launched in September 2017. It clearly defines the research we conduct which is our unique point of difference to other breast cancer and cancer charities. Our new logo recognises our place in the world, with a map of Australia and New Zealand, and resembles a



fingerprint which speaks to the tailoring of breast cancer treatments to every person and their unique set of circumstances.

So while our name has changed, our commitment to collaborative, high quality breast cancer clinical trials research has not. We are still the same group of world-class professionals based in Australia and New Zealand on a mission for people affected by breast cancer to live better, to live longer, and to never die from breast cancer.

Breast Cancer Trials is grounded and defined by one simple belief: We can and we will find new and better treatments and prevention strategies for every person affected by breast cancer that saves lives today, tomorrow and forever.

Contributed by Anna Fitzgerald, Breast Cancer Trials

A Commitment to Building Capacity...

At CREST we have a strong commitment to sharing knowledge and building capacity within the clinical trial community to embed health economics in research design, implementation and analysis. One of the ways we aim to build that capacity is through our workshop series. Most recently, we held a workshop for consumer representatives working with the CTGs; **Health Economics in Cancer Research – A Consumers' Guide** was held at UTS on 21st August. Despite being hit by this year's nasty flu season, the workshop proceeded with lively discussion and participation by representatives from a number of groups and even one of

the other Technical Support Groups. At a time when there are weekly reports in the media about new initiatives in cancer funding, notably through the Medical Research Futures Fund, participants were exposed to a range of presentations – including from the Deputy Chair of the PBAC, Jo Watson – on the role of consumers in the funding of health technologies in Australia, and how they can be involved in and influence the collection of evidence in clinical trials to inform reimbursement decisions.

The next workshop in the series, and the final one for this calendar year, will be on 20th November; **Prefer-**

ences in Cancer Trials. This workshop will provide an overview of the steps involved for the design, implementation and analysis of stated preference survey using discrete choice experiments (DCE), with applications to the field of cancer research. Importantly, it will also address the “why” in terms of the types of questions DCEs can be used to address and how the results can be used.

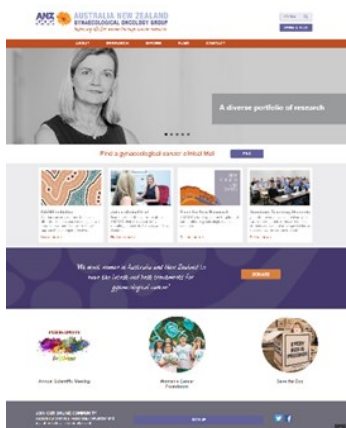
The Preferences workshops will be presented with a mix of lectures and team based activities; with active discussion an important part of the day. Look out for the call for registration in the coming weeks.

A Few Words from ANZGOG

ANZGOG aims to improve outcomes and quality of life for women with gynaecological cancer through conducting and promoting cooperative clinical trials and undertaking multi-disciplinary research into the causes, prevention and treatments of gynaecological cancer.

New Website

We have recently launched our new website, with enhanced clinical trial search features, an events calendar, news articles, and a full list of publications resulting from ANZGOG studies.



Visit the new ANZGOG website.

Tool for clinicians and consumers: A direct link to the ANZ Clinical Trials Registry (ANZCTR) provides for easy look-up of trials recruiting patients for gynaecological cancer research. We are discussing broader categories with ANZCTR to enable a search for all seven types of gynaecological cancer as well as quality of life studies for which gynaecological cancer patients who may be eligible.

Take a look at www.anzgog.org.au

Clinical Trials Report

Our ANZGOG-led, international, mul-

ticentre trial 'OUTBACK', assessing the role of adding chemotherapy to standard radiation in the treatment of locally advanced cervical cancer has reached its recruitment target and is now closed to accrual.

A surgical trial 'STATEC', looking at the role of lymphadenectomy in the treatment of high risk endometrial cancer has been granted central ethics approval and is now working on site activation.

Several other studies, including ICON9 (ovarian cancer), STICS and STONEs (chemoprevention based on aspirin for patients at high risk of ovarian cancer) and two OASIS studies (VIP and MOCCA) will open later on this year, having obtained funding from various sources. Four studies were granted funding from our Fund for New Research.

Results of ANZGOG trial Paragon were published recently in the International Journal of Gynecological Cancer: <https://doi.org/10.1097/IGC.0000000000000978>

Funding Research

Fund for New Research and OASIS: Applications for ANZGOG's Fund for New Research grants and OASIS Initiative funding have recently opened.

The Fund for New Research grants is designed to foster new pre-clinical, pilot or other studies which may lead to a full study. In 2017 grants up to \$50,000 will be offered. Find out more at

<https://www.anzgog.org.au/research/fund-for-new-research/>

The aim of OASIS is to provide operational support and funding for inno-

vative signal-seeking Phase II trials in well-defined subsets of patients with recurrent ovarian cancer. Each project is assessed on its individual merits and budget requirements and must meet all OASIS criteria. Find out more at

<https://www.anzgog.org.au/research/oasis-initiative/>

For advice and assistance please contact Tracey Meares, Project Manager – Research research@anzgog.org.au or phone +61 2 8071 4884.

Community fundraising: 'Save The Box' is an awareness campaign to get people talking about gynaecological cancer and fundraise for ANZGOG's research. This year, we are asking people to register and carry a 'Save the Box' Money Box with them for 7 days asking people for donations. Registrants are supported to create their own fundraising pages on Everyday Hero, and ask their friends and colleagues to support their challenge to 'Save the Box'.



Take the 'Save the Box' Moneybox challenge to raise funds and awareness for ANZGOG research.

To date over \$28,000 has been raised by more than 200 participants!

If you would like to take the challenge and raise funds and awareness for gynaecological cancer research please go to www.savethebox.org.au

Contributed by Ruth Gordon, ANZGOG

Health Economics at the Senate Select Committee

recommendations on the basis of evidence from Phase I trials, from single arm studies, from comparisons of case series with historical cohorts. But in this context, it needs to be recognised that there may be less confidence in the evidence and it is appropriate that this is reflected in the decisions, either through risk sharing arrangements, through managed entry or through prices that reflect the level of certainty.

A key issue here is that trials need to be designed with the reimbursement decision – the end point of “if this treatment works, what next” in mind. So, for example, it is important to ensure that clinical trials are designed with the capacity to capture health system resource use associated with the treatment and adverse events and side effects, that quality of life is measured, and that longer term outcomes are considered. Early involvement of health economists in trials can assist with this, and [Cancer Australia](#) has provided funding for national technical services to build capacity in economic evaluation, quality of life and genomics.

The second issue is whether there is capacity to address the challenges for rare cancers and cancers with low survival rates by changing the models of funding research. Here it is notable that the current funding through NHMRC, is not intrinsically biased towards any particular health problems. However, when there are low patient numbers and poor survival, there are additional challenges in undertaking research – for example, the need to coordinate across multiple centres and multiple researchers, the value of bringing together clinical researchers and laboratory scientists across multiple lines of research that would benefit from models that encourage collaboration - for example,

targeted calls for research or specific research streams to address gaps, and research infrastructure to support patient registries, biobanks and increased awareness of the value of participating in clinical trials. What must not be compromised in this is the importance of funding excellence in research, and maintaining standards of scientific quality and feasibility.

Finally, it is important that medical research does not focus only on “discovery”, but also on translation of research into practice, and research that provides for advances across the whole spectrum of health care – providing potential for new treatments but also ensuring high quality care at all stages of disease.

Patients with rare cancers and cancers with low survival rates will have to negotiate the health system, make choices, face decisions about where and how to be treated. Fundamentally we must ensure that the health system provides them with treatment options and the capacity to make informed choices. Equally, we need to understand what are the drivers of investment choices made by agents in the health system, and how to continue to ensure value for money across the whole continuum of health care. We need to understand quality of life, quality of health services and what is of value to patients and their families. And we need to be able to provide patients with accurate information to inform their choices. For these reasons, health services research is equally important, if not more important to patients with rare cancers and cancers with low survival rates as it is to any other patients in the health system.

Contributed by Prof. R Viney

What has CREST been up to?

Trial Group Collaborations:

- Provision of collaboration reports to CTGs (for inclusion in Cancer Australia reports).
- Ongoing advice on the development of trial protocols and data collection forms.
- Attended TROG Scientific Advisory Committee.

Workshops:

- Conduct of the CREST Workshop on Health Economics in Cancer Research – A Consumers’

Guide.

Other Activities:

- Continuation of the Structured Training Opportunities program.
- Attendance and presentation at the ANZUP ASM.
- Appearance at the Senate Select Committee on Research into Low Survival Cancers.
- Activity report to Cancer Australia.