



From the PoCoG Executive Office

Developing research at PoCoG

PoCoG Concept Development Workshop

PoCoG's first Concept Development Workshop was held on 14 May 2008 at the Rydges Hotel, Camperdown. The 25 participants included members of PoCoG's Executive and Scientific Advisory Committees which include two consumer representatives, PoCoG members who submitted research concepts and invited guests acting as specialist advisors.

This whole day event was very successful. The participants worked very enthusiastically on the six submitted research concepts which addressed a broad range of issues including survivorship, quality of life and genetic counselling.

We would like to thank all the participants for their valuable input. The outcome, it is hoped, will be high quality Psycho-Oncology projects.

The next PoCoG Concept Development Workshop will be held on 17 November 2008, just prior to the COSA Annual Scientific Meeting in Sydney.

Photos (left to right): A/Prof. Elizabeth Lobb presents her research concept; Ms Sally Hodgkinson talks about consumer involvement in research; Workshop participants listen to Dr Michael Jefford's concept presentation.



In this issue

From the PoCoG Executive Office

- Developing research at PoCoG 1, 2
- Priorities in psycho-oncology research focus group results..... 2
- PoCoG member survey 2
- Governance 2
- PoCoG TRS..... 3
- Members' index – new website tool 4
- PoCoG website – latest features 4
- Quality of Life Office 5
- CALD study 5

Psycho-oncology news in Australia

- CeMPED – official launch 6
- Australian-Chinese breast cancer victims suffer double disadvantage 6

In Focus – Psycho-oncology in NZ

- PONZ 3
- Palliative Care Research Interest Group..... 8
- The emotional and interpersonal aspects of fertility damage from cancer treatment in pre-menopausal women 7

Who's Who of PoCoG 7

Useful Resources 4

Scholarships/Fellows & Positions Vacant 9



Results from the focus groups about priority areas in psycho-oncology research

We now have the preliminary results from focus groups about priority areas of research in psycho-oncology, conducted over the past six months by Dr Alison Evans on PoCoG's behalf, with psychologists, nurses, social workers and other health professionals currently working in oncology across Australia. These results were used to promote discussion during the Concept Development Workshop in May. The priority themes are:

- Survivorship
- Distress – Identification, screening and referral
- Distress - Management
- Carers
- Rural/Regional patients
- Health Services issues
- Children and adolescents
- Other specific cancer populations (e.g. older patients, indigenous patients)

The results will be written up for publication before the end of 2008.

Coming soon – A survey of PoCoG members about research priorities in psycho-oncology

We are in the process of designing an on-line questionnaire based on more detailed research questions within each theme identified in the focus groups. The aim is to collect quantitative data and thereby establish the current priority areas for research in psycho-oncology. All members of PoCoG will be invited to participate in this survey. The results will enable future research to target priority areas. This is a great way of getting actively involved as a member of PoCoG without actually leaving your desk, so please look out for further developments and announcements.

Governance

Governance documents now available on-line

PoCoG's three key governance documents are now available on the members-only website:

PoCoG Strategic Plan 2008 – 2010

PoCoG Business Plan 2008

PoCoG Policy and Procedures Manual

You can find these documents on the members-only section of the website under "about us –

organisational structure". These are living documents which will be adapted over time.

The first meeting of the newly formed PoCoG Scientific Advisory Committee (SAC)

The first meeting of the new PoCoG SAC was held on 15 May 2008 at the Rydges Hotel Camperdown, following the Concept Development Workshop. The members talked about their roles and responsibilities on the committee as well as discussing plans and strategic directions for future research at PoCoG.

First progress report submitted to Cancer Australia

We have recently submitted our first 2008 progress report to Cancer Australia. We are pleased to report that most of our projects for this half of the year are on track. It has been a hectic, but very productive, 6 months. Cancer Australia responded with high praise for the group's productivity and direction.

PoCoG Vacancy - Biostatistician (part-time)

PoCoG is still trying to recruit a statistician. If you are interested or know someone who would be please contact Dr Melanie Price, Executive Director on 02 9351 3916 or email pocog@psych.usyd.edu.au

IN FOCUS - Psycho-oncology in New Zealand

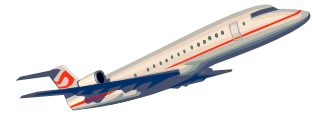
In this issue we put in focus psycho-oncology research in New Zealand. New Zealand members make up about 2% of PoCoG's membership.

Historically there has always been a link between Australian Collaborative Groups and New Zealand. Many other CRGs include New Zealanders in their membership.

In this newsletter we feature a profile and research update from a New Zealand member, Sarah Hunter, and two New Zealand organizational profiles, the Psychosocial Oncology New Zealand (PONZ) and the Palliative Care Research Interest Group.



PoCoG Travel Reimbursement Scheme 2008



The first round of the PoCoG Travel Reimbursement Scheme (TRS) closed on the 4 April 2008. There were 12 applicants, most planning to attend the IPOS congress in Madrid in June this year. All applications were of a very high standard and the budget allowed only partial funding of four successful applications. The TRS Selection Committee made their difficult decisions based on the criteria outlined in the TRS guidelines. Congratulations to the successful applicants. They are:

Ms Danette Langbecker

Master of Applied Science (Research) candidate
School of Public Health
Queensland University of Technology

Conference:

International Psycho-Oncology Society 10th World Congress, Madrid, Spain, June 2008

Title of presentation:

Oral presentation: How can we better meet the information needs of patients newly diagnosed with brain tumours?

Amount awarded: \$4003

Miss Elvira Zilliacus

PhD candidate

Conferences:

European Meeting on Psychosocial Aspects of Genetics, Barcelona, Spain May/June 2008

International Psycho-Oncology Society 10th World Congress, Madrid, Spain, June 2008 (Funded by PoCoG TRS)

Title of presentation:

Oral presentation: A Balancing Act – Patient's and clinician's experiences of tele-health cancer genetic counselling

Amount awarded: \$ 3785

Ms Heather Shepherd

PhD candidate (submitted)

Centre for Medical Psychology and Evidence-based Decision-making

The University of Sydney

Conference:

2008 International Conference on Communication in Healthcare, Oslo, Norway, September 2008.

Title of presentations:

1- Invited symposium presentation - Shared decision-making in general and hospital practice: physicians' and patients' points of views in Canada, France, Australia, Germany and Switzerland.

2 – Oral Presentation: Involving patients in reaching treatment decisions; motivations, consequences and effects on decision responsibility.

Amount awarded: \$2409

Ms Jessica Koehler

Associate Cancer Genetic Counsellor

Conference:

Human Genetics Society Annual Scientific Meeting, Adelaide SA, August 2008

Title of presentation:

Oral presentation: New challenges in cancer genetic counselling: genetic testing for clinical trial eligibility

Amount awarded: \$820

In Focus - Psychosocial Oncology New Zealand (PONZ)

Psychosocial Oncology New Zealand (PONZ) was officially formed in 2005 by a small group of cancer health professionals from around New Zealand. PONZ was established to promote the psychosocial and physical needs of patients with cancer and allied diseases, and aims to support their families at all stages of disease and survivorship through practical supports and resources, counselling, clinical care education, research and advocacy.

The membership includes both health professionals and associate/affiliate members, including non-health professionals, family/whanau, and those who may, or may not, have had cancer.

Whilst in its early stages of developing, PONZ is gaining momentum and is currently undertaking of a national stock take of cancer psychosocial services within New Zealand.

PONZ holds a conference each year. The 2008 conference will be held in Palmerston North on Monday 17th and Tuesday 18th November with additional workshops being held on Sunday afternoon 16th November. Further details are available from the website www.ponz.org.nz or enquiries may be made directly to the Conference Organiser suepeck@xtra.co.nz.



Soon to come on our website – Members' Index

We very excited to announce that we are about to launch the latest feature on our website: the **Members' Index**.

The Members' Index is intended to be an "address book" for professionals working in the field in psycho-oncology. We hope that this new feature will facilitate communication and networking among PoCoG members and become an important instrument in fulfilling PoCoG's first aim: *To bring together researchers, clinicians, health care professionals and consumers with an interest in psycho-oncology to foster collaboration and the exchange of ideas.*

The Members' index will be launched on Monday 30 June 2008

The Members' Index will display some of the information in your user profiles which you entered when you registered as a member. The details which will be displayed include **your name, professional discipline, organisation, state, research interests and email address**. *This information will be restricted to PoCoG members only.* All information you provide is treated as confidential and will not be released to a third party without your prior consent.

Members who have joined recently have been given the choice at registration to join the Members' Index or to opt out. Other members will need to log onto their profiles to make this choice.

Please note that due to logistical considerations this has been set up as an "**opt out**" feature for all existing members.

If you do not wish your information to be displayed on the Members' Index, you need to opt out by:

- logging onto the members' only section of our website with user name and password
- going to "my profile"
- clicking on the box "Do not display information on Members' Index"

or

email pocog@psych.usyd.edu.au or call us on 02 9036 5002.

If you later change your mind you can opt in again by following the steps above and un-clicking the "opt out" box.

If you do not opt out by the 30 June 2008 we will assume that you wish to participate and you will be included in the index automatically.

We hope that you will find this new feature very useful.

Latest features on the PoCoG website

- Quality of Life FAQs – an interactive, database driven goldmine of information about Quality of Life
- Consumer involvement in research FAQs – some practical advice about involving consumers in your research. These were prepared in collaboration with PoCoG's consumer representatives
- Professor Neil Aaronson lecture— an audio recording and PowerPoint slides his lecture; the first of many in PoCoG's seminar series
- Revamped pages about our organisational structure including PoCoG's three key governance documents

Useful resources

The International Cancer Research Portfolio is a website that lists all of the research groups working on cancer research that have been funded by the NCI, ACS, DOD (all US), and CR-UK, MRC etc. The database is completely searchable, and therefore it could be useful for finding international collaborators in your field <http://www.cancerportfolio.org/index.jsp>

This and other useful resources please visit the members-only section of the PoCoG website and go to "Research – Research help"

News from the Quality of Life Office

Resources

Online resources are now available to support researchers in the assessment of HRQoL in people affected by cancer. The resources are freely available to everyone at <http://www.pocog.org.au/content.aspx?page=qolresources> and include:

Frequently Asked Questions (e.g. How do I choose which HRQoL questionnaire to use in my study? Practical issues for clinical trials managers; How should I report the HRQoL component of my clinical trial? The EORTC QLQ and FACIT measurement suites compared; and details of HRQoL issues and disease-specific questionnaires for a variety of cancer types)

Useful links to HRQoL-related websites (including questionnaire websites and databases)

Further reading list (including links to fulltext articles where these are available).

We are keen to receive feedback from PoCoG members and others as to how we might improve or add to these resources. We would also be grateful if those who find the resources useful could help to publicise them by circulating information about their availability and providing links from other websites as appropriate.

Strategic Planning

Our strategic planning meeting was held on May 13th, and was attended not only by our QOL Office advisory group but also by Prof Neil Aaronson from the Netherlands Cancer Institute who gave us an invaluable perspective from the EORTC. The meeting generated a wealth of ideas for potential devel-

opment and highlighted the need to identify priorities in order to make optimal use of the QOL Office's current resources. In a bid to increase these resources and further develop expertise among promising junior researchers, PoCoG has applied for an NHMRC Capacity Building Grant for 5 years of funding to build QOL expertise in Australia, in collaboration with the other Australian clinical trial groups, the NHMRC Clinical Trials Centre and the Peter McCallum Cancer institute, to commence in 2009.

Professor Aaronson's lecture on Quality of Life

On 13 May 2008 Professor Neil Aaronson presented a public seminar at the University of Sydney. Neil Aaronson's lecture summarised the current state of the art in assessment of HRQoL not only in research but also as a means of monitoring the well-being of individual patients in daily clinical practice. The evidence that Neil provided for the value added to clinical trials by HRQoL assessment will be especially useful for anyone needing to argue for its inclusion in future research. The audience included a broad mix of researchers, health professionals and consumers, resulting in a lively discussion that spanned the key issues in current HRQoL research.



The lecture is now available as a digital Power-Point-audio recording on the PoCoG website.

News from the CALD study

Our current two CALD studies – Unmet Needs and Prognosis Communication - are carried out with strong community partnerships. We believe that this is essential for informing the development of an effective and culturally appropriate methodology. We have established three advisory groups comprising social workers, community health workers, psychologists, general practitioners, palliative care specialists, oncologists, consumers, and religious leaders from the Arabic, Greek and Chinese-speaking communities in NSW. They contribute to the study by attending consultative meetings 2 times a year. We have sought their feedback in relation to the study design and its feasibility in each cultural context, as well as seek-

ing their input in terms of interpreting any cultural issues identified in our interim results.

We recently held our fourth Community Partners Meeting on 23 May. Our community partners made constructive and valuable suggestions about our national Unmet Needs survey. The feedback included the relevance of items about CALD specific needs, clarity of expression in their community language, and the design and layout. They also critiqued the interim results of our Prognosis Study from an insider perspective. Their invaluable input has been used to guide the study development and analysis.



PSYCHO-ONCOLOGY NEWS IN AUSTRALIA

CeMPED – official launch

The **Centre of Medical Psychology and Evidence-Based Decision Making (CeMPED)** will be launched at the Sydney Cancer Conference, University of Sydney, on Friday 25th July.

CeMPED combines two very active existing research groups within the University of Sydney, the Medical Psychology Research Unit and the Sydney Health Decision Group. CeMPED is a truly cross-faculty, multidisciplinary organization sitting within the School of Psychology, the School of Public Health and the Dept of Medicine.

CeMPED's mission is to support excellent research across the interface of Psychology, Medicine and Public Health to answer questions about: the behavioural factors which promote good health and prevent disease; ways to enhance the psychosocial adjustment of patients and carers; ways to increase use of evidence in health care decision making; and ways to support patients to be more involved in their own health care.

CeMPED's research strengths lie in three themes: **doctor-patient communication; evidence-based, shared decision making; and Psycho-Oncology.**

CeMPED is co-directed by Prof Phyllis Butow (Psychology), Prof Martin Tattersall (Medicine) and A/Prof Alexander Barratt (Public Health). It currently has over 40 staff and students. Since 1995, the staff of CeMPED have won over 70 peer reviewed grants, worth over \$20,000,000, published over 250 articles in high impact factor journals, been active in the media and community organizations to promote the implementation of their research.

The CeMPED website will be launched in July. Information about CeMPED can currently be found at the websites of the Medical Psychology Research Unit (<http://www.psych.usyd.edu.au/mpru/>) and the Sydney Health Decision Group. (<http://www.health.usyd.edu.au/shdg/>).

Australian-Chinese breast cancer victims suffer double disadvantage

Chinese women living in Australia who suffer from breast cancer, are at a double disadvantage. Not only do they go through the devastating treatment process, but they also experience isolation due to language barriers and cultural beliefs which tend to limit their social support.

These are the major findings which have emerged from a study undertaken by a team led by Dr Cannas Kwok and Professor Kate White in the Faculty of Nursing and Midwifery at the University of Sydney. The study sought to gain insight into and probe the experiences of immigrant Chinese women diagnosed with breast cancer.

Central to the study were three focus groups which involved 23 women. Participants were recruited through a Chinese Cancer Support Group (CanRevive). The interviews were conducted in either Mandarin or Cantonese.

"We found that while initial reactions of shock and disbelief to being diagnosed differed little from those of mainstream Australian women," says Professor White, who has many years of research experience in the breast cancer field. "However, after that Chinese cultural beliefs had a strong impact on the way they experienced and coped with the disease."

Among other key factors which emerged from the focus groups was a strong belief that the migration experience itself was responsible for the development of their breast cancer. They experienced isolation due to a lack social supports they were used to in China, and also as a result of their lack of English proficiency and 'culture shock'.

It was clear from all the focus groups that even women who had undergone mammograms suffered from misconceptions, such as that screening was actually a preventative measure. They thus neglected symptoms they themselves had discovered and reacted with frustration and anger when they were later diagnosed with cancer.

Unlike the pattern in the Caucasian population, the women did not find members of the health care team a source of support at all. This was due largely to the fact that language problems made it difficult for them to communicate particularly with surgeons.

Instead they found that their families were their best source of strength and support during their cancer experience. However, even this was very limited as most of their extended family members live in their home countries.

Almost all women expressed a strong need for cancer and treatment information in Chinese. They were frustrated because while they had little English proficiency, all the information they received was in English. The majority of women saw themselves as being victimised not only by having breast cancer but also by the lack of culturally sensitive cancer support services and resources.

"Based on the findings, we are now planning to survey a larger sample of Chinese women with breast cancer, through the NSW Cancer Registry, to further explore this area," says Dr Kwok, the chief investigator whose expertise is in breast cancer among Chinese women.

Who is Who of PoCoG



Name:

Sarah Hunter RN MNurs(Hons)

Position:

Doctoral Candidate, School of Nursing, Faculty of Medical and Health Sciences, University of Auckland, Auckland, New Zealand.

Research interests:

Young adults with cancer.

Q. Tell us something about yourself

A. I am married with 2 children, 2 cats, 2 fish and one rabbit

Q. One thing you enjoy most about your work

A. Interaction with wonderful people.

Q. Your professional/psycho-oncology/ research pet hate

A. Research snobbery

Q. Your inspiration?

A. People who are unlucky enough to have to endure cancer and its effects

Q. Your favourite quote or motto?

A. 'If at first you do succeed, try not to look too astonished' (Furry Logic, Jane Seabrook)

Q. The funniest thing that has ever happened to you at work?

A. Finding out at the end of a long day in a busy male ward that my very old white uniform did nothing to cover the completely mismatched underwear I was wearing – green and pink, to be precise.

Q. Which book have you read most recently?

A. Marian Keyes – 'Anybody out there?'

Q. Your first-ever job

A. In the kitchen at a huge rest-home.

👁 In Focus - The emotional and interpersonal aspects of fertility damage from cancer treatment in pre-menopausal women)

The aim of this qualitative study is to ascertain and articulate the emotional and interpersonal aspects of fertility damage from cancer treatment in pre-menopausal women, as a factor in their ongoing quality of life. Chronic Sorrow Theory will provide the analytical lens through which the data will be interpreted. Research into psycho-social issues related to infertility in general has described a grief reaction related to the impact of infertility on self-esteem, relationships and intimacy, and hopes/plans for the future. This study will expand on this research by examining fertility damage as a result of cancer treatment in New Zealand women and will contribute to both national and international knowledge of the impact on women of fertility damage from cancer treatment.

As diagnoses of cancer are made earlier in the course of the disease and treatments become increasingly effective, survival rates from cancer are rising. This leads to an elevation of the importance of issues related to ongoing quality of life, including fertility. There are differing estimates of potential fertility damage for pre-menopausal women undergoing cancer treatments, ranging from 30-95%. Fertility damage can result from all of the main treatment modalities currently used in cancer care. Anecdotal evidence from my own clinical practice and that of other senior oncology nurses in the region sug-

gests that fertility is seen as an important consideration for pre-menopausal women diagnosed with cancer, and that the impact of potential damage to fertility is both considerable, and often unreported. Accordingly, further research into both the physiological management of treatment-induced fertility damage, and the psycho-social impact on patients and their significant others, is highly recommended. It is noted in particular that research into the emotional impact of cancer-treatment induced infertility is both lacking, and needed.

There are two key ways in which this study will contribute to existing knowledge on the topic. Firstly, there are as yet no published studies in this area involving the New Zealand population, although there is a study in progress looking at the impact of pelvic radiotherapy on wider sexuality in the same population and a study looking at the psycho-sexual morbidity associated with gynaecological cancers in general. Secondly, although the concept of chronic sorrow has been studied in the United States in couples dealing with infertility and in people with cancer, it has not been used for the purposes proposed here.

Sarah Hunter RN MNurs(Hons)
 Doctoral Candidate
 School of Nursing
 Faculty of Medical and Health Sciences
 University of Auckland, New Zealand

👁 **In Focus - Palliative Care Research Interest Group, Dunedin School of Medicine, University of Otago, Dunedin New Zealand**

The Palliative Care Research Interest Group in the Dunedin School of Medicine was established in July 2005 by a group of postgraduate students undertaking Masters, PhD, and Postdoctoral research in palliative care together with other academic staff when the Professor of Palliative Care (Professor Rod McLeod) then based at the Dunedin School of Medicine moved to Auckland.

The group initially met to provide a focal point of peer support for students and researchers carrying out palliative care research, and early meetings included presentations by students of their research, either planned or underway. The group has now grown to include people from other parts of NZ with a diverse range of interests, including 7 PhD students; 2 Master's students; and supervisors from the Departments of Preventive and Social Medicine, General Practice, Oncology, Palliative Care and Psychological Medicine. Other interested people include the palliative care nurse at Dunedin Public Hospital, and the Education Officer and nurses from the Otago Community Hospice. People in other areas of the country include Professor Rod MacLeod and various students around NZ.

Topics of research presentations have include Spirituality in Cancer Care, the Ethics of Hope, Palliative Care in the Community, an Ethnography of Culture in Palliative care, Survivorship, End of Life Care in Rural Communities, and Chinese Cultural Understandings of End-of-Life Care.

The aims of the group are to:

Provide support and encouragement for post-graduate students wherever they may be e.g. nurses doing distance courses;

Meet monthly for research presentations, discussion of issues, and reporting back on conferences attended;

Act as an advocacy group. For example, we supported the local Otago District Health Board palliative care proposal and made a submission to Palliative Care New Zealand (although little progress has been made by the latter due to lack of Government funding);

Explore funding opportunities for research in palliative care. For example, we now have access to a charitable trust – this is set up as a separate entity outside of the university and money raised will go towards developing a resource library and other projects.

Some members are also members of PoCoG and are on the emailing list of the International Observatory on End of Life Care, University of Lancaster, UK. They also have links with the Department of Population Studies, Goodfellow Unit, University of Auckland and the Palliative Care Research Group in Auckland. Their objectives remain to work towards developing palliative care research in New Zealand, continue postgraduate student support and build closer links with institutions involved in providing palliative care education and research.

Roz McKechnie,
Coordinator
Palliative Care Research Group
Email: don.roz@xtra.co.nz



Call for papers

Patient Education and Counseling (PEC) invites papers for a special issue on Patient-Centered Communication in Cancer Care. For more information please go to <http://www.pocog.org.au/news.aspx?id=39>

Scholarships and Fellowships

HOTT FELLOWSHIP AWARDS

Application round is now open. Closing date: 7 July 2008

For more information go to: www.cosa.org.au

Or contact Margaret McJannett (COSA) margaret.mcjannett@cancer.org.au

Positions vacant in psycho-oncology

Chair in Health Disparities in Cancer

Simon Fraser University (SFU) and the BC Cancer Agency (BCCA) have identified disparities in cancer as an important area for research development and have formed a partnership to co-fund a Chair in Health Disparities in Cancer. For more information about this position please go to www.pocog.org.au

Humour corner

From the packet of a well known confectionary brand:

“Chocolate is cheaper than therapy and no appointment is required”



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