



From the PoCoG Executive Office

Governance

Election of Deputy Chair of the PoCoG Scientific Advisory Committee

Following the decision made at SAC meeting on 15 May 2008 the PoCoG executive office took steps to appoint a Deputy Chair of the SAC. The SAC nominated three of their members as candidates. A/Prof. Elizabeth Eakin was subsequently elected by the Executive Committee to the position of the Deputy Chair of the SAC.

A/Prof Elizabeth Eakin is a Principal Research Fellow in the Cancer Prevention Research Centre of the School of Population Health at the University of Queensland. She holds an NHMRC Career Development Award in Population Health (2003 – 2007), is the immediate past president of the Australasian Society for Behavioural Health & Medicine, and is the former Head of the Behavioural Science Unit in the Viertel Centre for Research in Cancer Control at the Queensland Cancer Fund. Over the past 15 years, she has built a program of research in behavioural approaches to chronic disease prevention and management, with an emphasis on physical activity and dietary behaviour interventions. A/Prof Eakin has collaborations with a number of key Australian and international behavioural science research teams. Research Interests: Cancer Prevention, Health Behaviour Interventions, Nutrition, Physical Activity.

The third meeting of the PoCoG Executive Committee

The third meeting of the PoCoG Executive Committee took place on 14 August 2008. The main item on the agenda was the new format of the Concept Development Workshop (CDW) in November. Details about the workshop are featured in this issue.

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Resignations from PoCoG committees

We regret to announce resignations of two members from PoCoG's Executive and Scientific Advisory Committees due to work and other commitments. Ms Ros Lawson, one of PoCoG's two consumer representatives has stepped down from all her duties on both committees and A/Prof. Michael Jefford has resigned as member of the Executive Committee. A/Prof. Jefford remains a member of the SAC and Ros has agreed to remain with PoCoG as a general member. We would like to thank Ros and Michael for all their help and support.



Developing research at PoCoG

A new format for the PoCoG Concept Development Workshop in November

The latest and most rigorous review of psychosocial interventions for cancer patients (Newell et al, 2002) concluded that evidence is still lacking for the efficacy of many interventions. Poor methodology in relation to design, sampling and measurement has greatly reduced the available pool of studies for review. Relatively poor effect sizes have been reported, in part because whole patient populations (rather than those significantly distressed) have been included. It would appear that limiting the intervention to those who really need it would be more likely to produce clear results and would be more cost-effective for eventual implementation.

The number of cancer patients with clinically significant distress is small. Therefore single site studies are unlikely to be successful.

PoCoG is in a strong position to conduct rigorous, multi-centre intervention studies. Therefore the focus of the Concept Development Workshop (CDW) in November will be to develop a study owned by all PoCoG members, in which our own members recruit patients, deliver the intervention and co-ordinate measurement of outcomes at their own centres.

The November CDW will bring together invited experts and stakeholders, members of the PoCoG Executive and Scientific Advisory committees as well as general PoCoG members and members of the COSA Psycho-oncology Group (OZPOS) to work together on developing the new concept. This is an exciting opportunity to work towards the development of high quality multi-centre trial. We plan to follow this up with another meeting in April 2009 to finalise the concept, explore linkage partnerships and appoint a writing group to write up the grant.

Overall aims of developing this research project are to:

- Develop an evidence-base for Psychologists in Oncology
- Engage the PoCoG members in a collaborative and ongoing trials process
- Capacity build clinician/researchers

References

Newell SA. Sanson-Fisher RW. Savolainen NJ. *Systematic review of psychological therapies for cancer patients: overview and recommendations for future research.* Journal of the National Cancer Institute. 94(8):558-84, 2002



Agenda for the November Workshop

We plan to initially focus on a psychologist / social-worker delivered intervention. It is not clear which intervention is most appropriate for evaluation, nor what is the best research question. For example, it may be time to compare one intervention against another, or a long intervention versus a short one, rather than an intervention against controls.

During the half-day workshop we plan to explore the following aspects of the study design:

- the research question(s) to be addressed
- intervention(s) to be trialled
- the study population
- the mode of delivery of the intervention
- ways to make the study feasible
- consumer involvement in the study

The workshop will include the following components:

- Presentations from invited guests summarising current research on psychological interventions in oncology
- An open forum to discuss design issues
- Small group work to discuss design issues

A Discussion paper will be circulated prior to the workshop to generate thought.

For more information about the workshop log into the members-only section of the PoCoG website and click on the Concept Development Workshop link on your "welcome" page.



A statistician recruited!



We are pleased to announce the arrival of our part-time biostatistician, Ben Colagiuri. Ben is in the final stages of his PhD in the School of Psychology, the University of Sydney and currently teaches undergraduate psychological statistics at the university.

As PoCoG's biostatistician Ben is primarily responsible for advising and assisting with analysing data produced by PoCoG protocols.

However, Ben will also be available to provide statistical advice to all Australian and New Zealand PoCoG members on a limited basis and time permitting. This statistical advice will normally take the form of answering members' questions regarding the best ways to analyse a data set or conducting power and sample size calculations for members.

At this stage we have allocated each member with

a maximum of **6 hours free advice per year** with any additional advice being charged at \$120 per hour, although these arrangements may change depending on demand.

To request statistical advice send Ben an email (details below) with some brief background information about the study and the advice you seek. Ben will then email you with an estimate of the likely timeframe in which he will be able to provide the advice which will depend on internal PoCoG commitments and the complexity of the advice sought.

Ben will be working on Wednesdays and Thursdays and can be contacted on:

Ph: (02) 9351 6304

Fax: (02) 9036 5292

Email: pocogbiostats@psych.usyd.edu.au.

Useful resources - Cancer Learning

This website is being developed on behalf of Cancer Australia, a Commonwealth statutory body, as part of the effort to develop educational resources for health professionals working in cancer care. You can view the website on www.cancerlearning.gov.au

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

Survey of PoCoG members about research priorities in psycho-oncology

Our on-line survey entitled: **Identifying research priorities and research needs among health and research professionals in psycho-oncology** is about to end. This research priorities study is PoCoG's first study to involve all of its membership.

PROGRESS REPORT

We are currently in week 5 of the survey

- Number of invitations sent: 296
- Number of surveys completed in week 1: 58
- Number of surveys completed in week 2: 72
- Number of surveys completed in week 3: 112
- Number of surveys completed in week 4: 139
- Total number of surveys completed to date: 149

The survey will close on Friday 12 September

2008. Please consider participating if you have not done so already. We are hoping to achieve our target response rate of 200.

Please make sure you click the "submit" button when you finish your survey.

If you decided not to participate and do not want to receive any more reminder emails please click on the survey link, go to the survey consent page and click "I do not agree" and **submit**.

Thank you to those who have already participated.

If you have any questions about the survey please contact

Monika Dzidowska, Executive officer, PoCoG

Email: monikad@psych.usyd.edu.au



Soon to come to our website – Members' Email Forum

We delighted announce that we are about to launch the latest feature on our website:

The Members' Email Forum.

The need to design a PoCoG email forum arose from the organisation's goal to promote psycho-oncology research and support emerging new researchers in this area. The development of the PoCoG email forum is funded by Cancer Australia.

The aims of the email forum are:

- to provide members of PoCoG with a tool to establish networking and/or mentoring relationships among researchers in psycho-oncology
- to provide a useful means of communication for research and health professionals in psycho-oncology both within Australia and across the world
- to provide a forum for discussion and exchange of ideas
- to foster collaborations between researchers conducting work in the same area.

The forum is essentially an email-based bulletin board. A member of PoCoG can send a question to all other members who subscribe to this feature by logging onto the forum and typing the question in the question box. Upon submission, a notification is sent to the forum moderator (currently the PoCoG Executive Officer) who activates the question. The question is then emailed to all participating members.

This email contains:

- The question title
- The text of the question
- Three links which let the participant: 1) view the original question, 2) respond to the question, 3) opt out of that discussion.

When someone posts a reply to a question, an email is sent to all participating members.

This email contains:

- The question title
- The text of the reply
- Three links which let the participant: 1) view the original question, 2) respond to the question, 3) opt out of that discussion.

Discussions will be made inactive by the website administrator if there are no replies for a substantial period of time (~2 months).

Participants have the ability to selectively opt out of receiving notification emails about discussions in which they do not want to participate. This is done through a link provided in the notification emails. This feature is useful in controlling the amount of email traffic received from the forum. PoCoG members can choose not to take part in the email forum at any time by checking a box in their user profiles on PoCoG's website.

The Members' Email Forum will be launched on Monday 15 September 2008

The inaugural discussion will be initiated by member of the PoCoG Scientific Advisory Committee, Dr Monika Janda. Dr Janda is a senior research fellow at the Institute for Health and Biomedical Innovation, School of Public Health, Queensland University of Technology.

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 to participate in the Members' Email Forum, 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 "Block emails sent from the Members' Email Forum"**

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 "Block emails sent from the Members' Email Forum" box.

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



PSYCHO-ONCOLOGY NEWS IN AUSTRALIA

Combining face to face and telephone delivery in a professionally led group for women with secondary breast cancer

Despite strong evidence for the efficacy and efficiency of group interventions for people with cancer, in Australia, professionally led groups are less prevalent than peer support groups for cancer patients, and individual psychosocial interventions are often favoured over group interventions as they are considered to be more targeted to individual needs. Fears persist amongst some health professionals that putting people with cancer together in a group, especially people with secondary cancer, may harm participants by making them depressed or exposing them to the loss of other group members through death.

A Brisbane based professionally led group for women with secondary breast cancer, delivered face to face and by telephone has found on the contrary, significant improvement in psychological well being and reduced distress after 12 months in the group on two standardised measures (ABS, IES). These outcomes are comparable to controlled studies of similar group interventions with similar patient populations, and baseline scores indicated a clinically distressed sample. These findings were published in *Counselling and Psychotherapy Research*, Volume 8 Issue 1, March 2008.

doi:10.1080/14733140801889071 (<http://dx.doi.org/10.1080/14733140801889071>)

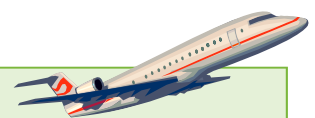
This weekly supportive-expressive group has been running since 1999 in Brisbane and since 2001, with the introduction of telephone conferencing, has been delivered throughout Queensland. This unique form of delivering the group has had unexpected advantage for women, in that the use of the telephone has enabled both rural and sick women to participate in the group, thus overcoming many of the problems of recruitment associated with groups such as these. The group is modelled on the work of David Spiegel at Stanford University and similar to groups offered in Melbourne as part of a randomised controlled trial that found that while SEGT did not prolong survival, it improved quality of life, ameliorated and prevented new DSM-IV depressive disorders, reduced hopelessness, trauma symptoms and improved social functioning (Kissane et al., 2007).

The Advanced Breast Cancer Group in Brisbane launched a website in 2006 to support and extend

its services www.advancedbreastcancergroup.org and in April this year launched a DVD resource 'You're not alone: a film about living with secondary breast cancer' based on interviews with three women from the group which is being nationally distributed by The Cancer Council Queensland via the Cancer Helpline 13 11 20. The Advanced Breast Cancer Group is also associated with a national online forum for women with breast cancer, which was established in 2006 and now has over 500 subscribers. This forum is run by volunteers, all of whom have breast cancer themselves.

The Group is led by two experienced group therapists Mary O'Brien and Pia Hirsch who are interested in partnering with researchers either as part of a larger comparative study of other psychosocial interventions or in a qualitative study. Having demonstrated the effectiveness of the group, they would now like to be able to identify what works, as learning what it is about the group that is beneficial is important in order to replicate these benefits in other groups, with other cancer populations.

For further information contact Mary and Pia on 07 32172998 or email wps2@bigpond.net.au



PoCoG Travel Reimbursement Scheme 2008

Round 2 of the PoCoG TRS will open on 19 September 2008 and close on 10 October 2008.

In this round special consideration will be given to members attending the PoCoG Concept Development Workshop.

Please keep checking the TRS page on the PoCoG website for new developments and announcements.



PSYCHO-ONCOLOGY NEWS IN NEW ZEALAND

The Informational and Emotional Needs of Women Having Treatment For Gynaecological Cancers In The South Island of New Zealand

Dianne Harker, Research Nurse, Department of O & G, University of Otago Christchurch, NZ

Glynis Cumming, Clinical Nurse Specialist, Christchurch Women's Hospital, Christchurch, NZ

Peter Sykes, Gynaecological Oncologist, Department of O & G, University of Otago – Christchurch, NZ

Meg Biggs, Information Nurse, Cancer Society of New Zealand, Canterbury West Coast Division, Christchurch, NZ

Sarah Kidd, Social Work Practitioner, Christchurch Women's Hospital, Christchurch, NZ

Betty Robson, Registered Nurse, Outpatient Department, Christchurch Women's Hospital, Christchurch, NZ

Introduction

Informational and emotional needs are recognised as integral to psychosocial support for people with cancer. The specific aim of this project was to explore the perspectives and experiences of women diagnosed with a gynaecological cancer (ovarian, cervical, uterine or vulval cancers).

In particular, we aimed to identify:

How well the informational and emotional needs of women having treatment for gynaecological cancers in the South Island of New Zealand are being met.

To identify gaps in our service delivery.

As a service we will then identify strategies to

further meet the needs of our patients. The project was approved by the regional Ethics Committees.

We are grateful for funding support from Women's Health Division (Canterbury District Health Board), Canterbury/West Coast Division of the Cancer Society NZ, Thomas Tippett Trust Fund (New Zealand Nurses Organisation) and the Department of O & G, University of Otago - Christchurch for their support.

Methods

A descriptive survey was utilized. The questionnaire was adapted and modified from a large European project to reflect the local context. Data was collected over a 12 month period from women referred to the South Island Gynaecology Oncology Service. At the time of the survey, the women involved had a gynaecological cancer diagnosis. Therapy (surgery, radiotherapy or chemotherapy) was either in process or scheduled.

One hundred and eighty women were approached to participate in this study within three months of receiving their diagnosis. After consenting, women were given the questionnaire to complete and return within 6 weeks. A self addressed envelope was provided for this purpose.

Data analysis for this study is now complete and a paper is being prepared for publication.



In Focus - PoCoG MEMBERS AT CONFERENCES AROUND THE WORLD travel reports from recipients of the PoCoG Travel Reimbursement Scheme

Australian Society of Genetic Counsellors Conference—Jessica Koehler

In August 2008, PoCoG kindly supported me to attend the Australasian Society of Genetic Counsellors (ASGC) Conference held in Adelaide. I work as a cancer genetic counsellor and found the 2 day conference to be very beneficial. It included a workshop from some prominent genetic counsellors on maximising the clinical supervision process for students on placement. This was also not only interesting from the perspective of a supervisor but also as somebody continuing her own professional supervision.

A number of PhD students presented their research in the field of genetic counselling and it was encouraging to see how many genetic counsellors are incorporating

research into their practice. One oral presentation in particular addressed the professional complexities of being both a researcher and a clinician.

In my role as a cancer genetic counsellor, I am peripherally involved in a number of research projects. Though most of my work is clinically based, our clinic works closely with the Psychosocial Research Group at Prince of Wales Hospital. A colleague and I recently compiled a case series of patients who underwent genetic testing to determine their eligibility for an oncology clinical trial. These cases raised unique practical and psychosocial issues in the genetic counselling setting and it was great to have the opportunity to give an oral presentation on this work at the ASGC conference.

Jessica Koehler

Who is Who of PoCoG



Name:

Danette Langbecker B Hlth Sci (Pub Hlth)

Position:

PhD Scholar, School of Public Health, Queensland University of Technology

Research interests:

Brain tumours, supportive care, caregivers

Q. Tell us something about yourself

A. During my undergraduate degree, I read about a local group in Chennai, India, who were trying to improve the nutrition of slum children by increasing their vegetable intake. School was free and included a lunchtime meal of dhal, but for many of the kids it was their only meal of the day. The program asked parents to give 1 rupee (about 3 cents at the time) per day for their child, and older girls used the money to buy vegetables, which they then added to the dhal. The group wanted international volunteers to come over and help collect data to see if the program was having an

impact on the children's growth, and also to help raise the profile of the program in the area. I went over and volunteered for a short time, and just fell in love with travel and India, and also became fascinated with research.

Q. One thing you enjoy most about your work

A. I love that I'm not sitting in front of a computer all day, that I meet new people and get to understand differing perspectives and experiences.

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

A. In research, things always take longer than you anticipate!

Q. Your favourite quote or motto?

A. . 'The knowledge that you have emerged wiser and stronger from setbacks means that you are, ever after, secure in your ability to survive.' JK Rowling.

Q. Which book have you read most recently?

A. 'The Memory of Running' by Ron McLarty.

Q. Your first-ever job

A. My first-ever job was babysitting neighbourhood kids – everyone survived.

In Focus - PoCoG MEMBERS AT CONFERENCES AROUND THE WORLD travel reports from recipients of the PoCoG Travel Reimbursement Scheme

International Psycho-Oncology Society 10th World Congress in Madrid, Spain—Danette Langbecker

With the assistance of a PoCoG travel grant, I recently presented my research at the International Psycho-Oncology Society 10th World Congress in Madrid, Spain. My study builds on earlier research which highlighted that many patients diagnosed with a brain tumour have unmet information and support needs. My research aims to improve information exchange between patients, caregivers and health professionals.

Health professionals who treat patients with a brain tumour may be the most relevant source for understanding how information exchange can be improved. Therefore during the first phase of my research, I interviewed professionals using structured group concept mapping techniques. This method allowed the identification of elements of ideal brain tumour care and perceived relationships between elements. It further explored, for each of the identified ideal elements in brain tumour care, the perceived importance, feasibility and extend to which they are currently already provided.

Thirty health professionals participated in at least one of three data collection activities: brainstorming ideas to improve care via telephone interviews; sorting ideas into categories based on meaning or theme and rating each idea as to its importance, feasibility, and current

provision; and interpreting the quantitative results in focus groups and interviews. Over 600 ideas were generated during the brainstorming phase, which were reduced to 42 ideas using content analysis.

Of these 42 ideas, three were ultimately seen as most important to improve care and the most feasible to put into practice: 1) provision of a care coordinator as the central point of contact, coordination and follow up; 2) for doctors to encourage patients to ask questions and help them feel comfortable asking questions; and 3) for patients to have a plan of action for what to do if something goes wrong. Participants also identified seven distinct clusters interrelated by communication which contribute to ideal brain tumour care: psychological support, specialist services, multidisciplinary care, family support, information, practical services, and tools for health professionals.

Qualitative analysis of interviews and focus groups to interpret these findings is ongoing. However, this study identified important and feasible ideas for improving information delivery, and provided me with the most promising targets for intervention development.

Danette Langbecker B Hlth Sci (Pub Hlth)

PhD Candidate, School of Public Health/ Institute of Health and Biomedical Innovation, Queensland University of Technology, Brisbane



Latest feature on the PoCoG website

A Map of psycho-oncology research centres around the world located under “Research Help”.

As part of our efforts to foster collaborations and networks among researchers in psycho-oncology we are developing a directory of psycho-oncology research centres around the world. We anticipate that this feature will assist researchers in psycho-oncology to:

- identify collaborating centres for studies
- identify centres for PhD / post-doctoral studies / work experience
- identify centres/individuals with expertise in a particular area
- Foster collaborations between researcher conducting work in the same area

Click on a continent to access a list of research centres in this part of the world.

Positions vacant in psycho-oncology

Arabic-speaking Research Assistant

Temporary 12 months (part-time, 16-20 hours per week) or 6 months (full-time), hours negotiable

A Research Assistant who is fluent in both Arabic and English is required to work as part of the Psychosocial Research Group (<http://prg.med.unsw.edu.au>), Department of Medical Oncology, Prince of Wales Hospital, to undertake an interview-based study of Arabic-Australians' community perceptions of cancer, hereditary cancer and genetics.

Duties include identifying participants, conducting interviews, analysis and writing up a journal article. Essential criteria: Fluency in both Arabic and English; degree in psychology or other health related discipline; and previous research and/or interviewing experience. Training will be provided, as required. Salary depending on experience: Level 4 or 5 UNSW (\$51,991 to \$64,186 pro rata) plus superannuation.

Please send your CV, outlining any relevant experience.

For further information please contact A/Professor Bettina Meiser

Email: b.meiser@unsw.edu.au Phone: (02) 9382 2638.



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