



**PSYCHO-ONCOLOGY
CO-OPERATIVE RESEARCH
GROUP**

**RESEARCH
HIGHLIGHTS**

2019/2020



REPORT FROM THE PoCoG CHAIR

There is no doubt that 2020 has been a memorable year for everyone as we continue to face the many personal and professional challenges of COVID-19 across our communities locally, nationally and internationally.

Maintaining our momentum and focus as a national research network has been challenging for us all, especially given the issues faced by people affected by cancer, by our health services in general, our research centres and universities.

I am very proud to say that the PoCoG team and network of members have admirably adapted to these new circumstances. This has involved changes in the way we undertake our work, our engagement with members, and the focus of our research. In regards to the latter we have identified the need to understand the impact of COVID-19 on people with cancer and their treatment, the experience of psycho-oncology clinicians delivering care in very different ways to their patients through telehealth modalities, and moving ahead with our work on some of the ethical dilemmas facing clinicians in cancer care. We have instigated and progressed with research in each of these areas.

Despite the difficulties of maintaining face to face contact and meetings, we have maintained what I believe is a very effective engagement with our Special Interest Groups, and supported initiatives such as webinars, facilitated position statements and reports from these groups.

We have undertaken a highly successful concept development workshop using web-based format, providing another example of the ability to adapt and test new ways of working during the pandemic. Some of these initiatives have provided a good opportunity to innovate in our ways of working, and can potentially increase our reach and connection with colleagues into the future, bringing us “Back to Better” into a post-COVID world, learning from this experience on how we can do our work differently.

A particularly rewarding development has been the progress in Indigenous research programs achieved in our collaboration with the Menzies School of Health Research through Professor Gail Garvey, Dr Abbey Diaz and their team. This has involved collaboration in research addressing multi-morbidity and cancer outcomes among Indigenous people, including our participation in a growing national network in this field, and our growing program of work in cardio-oncology.

We have instigated a web-based resource for psycho-oncology researchers regarding the impact of cancer on Indigenous Australians and important issues to consider in the approaches to Indigenous research. This builds on the joint pre-congress workshop undertaken by this team at the 2019 IPOS Congress on this topic, the first time Indigenous research was featured in this way in the IPOS meeting.

2020 is also marked by the outstanding achievement of Associate Professor Haryana Dillon in leading a successful MRFF grant application (totalling almost \$5m) addressing the needs of people with brain cancer. This outstanding achievement represents the largest research grant achieved by PoCoG and reflects the work of a partnership with the Cooperative Group in Neuro-Oncology (COGNO), Cancer Symptom Trials Group (CST) and Primary Care Collaborative Trials Group (PC4).

The BRAINS program (Brain cancer Rehabilitation, Assessment and Intervention for survivorship Needs) aims to deliver care that encompasses implementing screening for needs assessment and symptoms; exploring optimal models of survivorship care; addressing information needs of patients and carers; caring for caregivers and examining rehabilitative and supportive care interventions in this population.

Our congratulations go to all the investigators and particularly Hary for her outstanding work on this exciting program of such national significance.

Finally, I would like to extend my warm appreciation to the PoCoG team especially Dr Jo Shaw for her exemplary leadership and vision, to Bonnie Laxton-Blinkhorn, our Executive Officer for her outstanding efficient support especially in the work Bonnie has done to facilitate engagement across our members and SIGs.

I wish to also acknowledge and thank the PoCoG staff and the management group including Scientific Advisory Committee Chair (Associate Professor Haryana Dillon) and Deputy Chair, Dr Lisa Beatty and members of that committee for their diligence, adaptability and innovation over this year.

I believe we are well placed to meet (and in many cases exceed) our mission and goals as a unique psycho-oncology network thanks to the work of our members and the support of our clinical community and most importantly our patients and their families, who remain the primary focus of our work



Professor Brian Kelly

Chair of the Psycho-oncology Co-operative Research Group

PoCoG operations are funded by Cancer Australia through their Support for Cancer Clinical Trials Funding Scheme and by the Cancer Institute NSW through their Cooperative Clinical Trials Funding Scheme.

PoCoG's Strategic Aims

Innovative,
high quality
studies

1

To promote and support innovative, high quality psycho-oncology research including studies with potential to impact on cancer outcomes, with an emphasis on those that address the needs of vulnerable populations.

Translation

2

To foster and promote the translation of research findings into: further research, clinical practice and standards of care and policy.

Capacity building
and sustainability

3

To develop capacity in designing and conducting high quality research and working to ensure sustainability.

Consumer and
community
involvement

4

To promote and foster consumer and community involvement in PoCoG activities and research.



REPORT FROM THE SCIENTIFIC ADVISORY COMMITTEE CHAIR –



We hit the ground running in July 2019 with many different projects running and a range of activities planned. While the first part of the year was busy and full of activity, none of us predicted what was to happen in early 2020.

On the back of a scorching summer and devastating fires, since early March the PoCoG team and many of our members have been work from home, physical distancing, and maintaining safe hygiene in response to the rapid emergence of COVID-19. There is no doubt this past six months has tested many of us in ways we did not expect.

2019-2020 has been an eventful year for all of us, in the midst of our funding cycle with Cancer Australia plans we were set to run our second Annual Scientific Meeting in Adelaide in November.

The Annual Scientific Meeting was a highlight of the year with outstanding contributions from members in the form of submitted abstracts and a diverse range of plenary presentations that really made us think about the broader issues of psycho-oncology, trans-diagnostic interventions, access to care, and workforce. This single day was a collegial coming together of old friends and the forming of new connections.

The ADAPT program has been in full swing with data collection commenced across all participating sites. The outputs of this vast amount of work are beginning to emerge with new publications this year and more under review.

Dr Heather Shepherd and the ADAPT team are doing an outstanding job keeping ADAPT running and producing high-quality data.

Our work in the fear of cancer recurrence has continued to grow with new projects underway. Notably, Dr Jenny Liu presented the results of the pilot of her brief oncologist FCR intervention at ASCO.

SAC MEMBERSHIP

A/Professor Haryana Dhillon – SAC Chair

Dr Lisa Beatty – SAC Deputy Chair

Professor Phyllis Butow – Foundation Chair

Professor Brian Kelly – PoCoG Chair

Vacant – PoCoG Deputy Chair

Professor Meera Agar – Ordinary Member

Professor Jane Turner – Ordinary Member

Professor Gail Garvey – Special Advisor

Indigenous Research

Dr Amanda Hutchinson – Ordinary Member

Dr Claudia Rutherford – Ordinary Member

Professor Louise Sharpe – Ordinary Member

Dr Kim Hobbs – OSWA Representative

Dr Laura Kirsten – OZPOS Representative

Dr Donna Milne – CNSA representative

Dr Camille Short – Early Career Researcher

Dr Gemma Skaczkowski – Early Career

Researcher

Dr Ursula Sansom-Daly – Early Career

Researcher

Dr Dan Costa – Special Advisor Biostatistics

Julie Marker – CAG representative

Don Piro – CAG representative

The Scientific Advisory Committee (SAC) is responsible for setting the strategic direction and for ensuring scientific rigour of PoCoG studies.

SAC activities include:

- Setting strategic and scientific direction and priorities and ensuring that these are in line with Cancer Australia principles and key performance indicators
- Reviewing and providing constructive feedback on proposals for PoCoG involvement in research
- Taking part in the ongoing review of PoCoG studies to ensure their scientific rigour and maintenance of minimal research quality standards

The SAC is multidisciplinary with representation from across Australia and includes members with wide-ranging research and clinical expertise related to psycho-oncology.

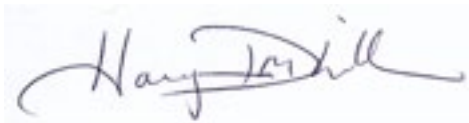
Many other new projects addressing a range of questions in FCR with collaborators around the country and the globe are really building our knowledge and evidenced based care.

COVID-19 had a major impact on the research focus and direction of our group. We rapidly developed projects investigating COVID-19, telehealth, models of care, and cancer, all while maintaining our focus on planned research activity including moral distress amongst health care professionals, fatigue, and multi-morbidity.

I cannot applaud the PoCoG Office and team sufficiently. Our operations have continued uninterrupted and we've seen fantastic new initiatives such as a series of webinars take place, over the last few months.

The efforts of Dr Jo Shaw and Ms Bonnie Laxton-Blinkhorn are extraordinary. Our small team saw some changes with Dr Helen Kamphuis leaving us in January and some difficulties in filling the role has meant a gap in the Research Manager role.

As always, you the members, make all this work possible. Your dedication to the care of people diagnosed with cancer is inspiring and I am grateful to be part of this community.

A handwritten signature in black ink, appearing to read 'Haryana Dhillon', is centered on the page. The signature is fluid and cursive, with a large initial 'H'.

A/Professor Haryana Dhillon
PoCoG SAC Chair

REPORT FROM THE EXECUTIVE OFFICE

The 2019-20 financial year was an extraordinary time for all of us, and the resilience displayed by our community of researchers as they adjusted and adapted to the uncertain environment caused by COVID-19 has been inspiring.

July 2019 seems like a long time ago, but it is helpful to reflect on our achievements in the latter half of last year. Our second Scientific Meeting, held in Adelaide in November, was a tremendous success, with a focus on improving access to psycho-oncology services, this event was an opportunity showcase and celebrate the diverse work happening within our group.

Members had the opportunity to present their work and we were proud to host a variety of plenary speakers from outside psycho-oncology whose reflections and experiences provided valuable insights to the researchers and clinicians within the audience.

With so much uncertainty still ahead of us it is heart-warming to see the generosity and support being shared among our membership, with many people making extra efforts to reach out, connect and collaborate.

Early in 2020 we hosted our first ever virtual concept development workshop, in tandem with PC4. Although we did have some initial reservations about how effective this format would be, they proved unwarranted. Under the expert facilitation of PoCoG SAC Chair Haryana Dhillon and with the support and guidance of our panel, concept author Dr Michelle Peate received valuable feedback on her concept.

The onset of COVID-19 in the first quarter of 2020 caused a rapid pivot in the research priorities for PoCoG, as we considered and responded to the psychological and psycho-social needs of cancer patients and their carers under pandemic conditions.

With the support of our members and SAC we have launched a range of new research projects in light of COVID-19, these include a consideration of the barriers and enablers to implementing telehealth consultations in psycho-oncology during COVID-19, a project exploring the experiences and perspectives of patients and family members, health professionals working in cancer and non-government cancer services regarding the COVID-19 pandemic and a study which considers the impact of COVID-19 on the care of patients with cancer and other multi-morbidities.

More information about these projects, and updates on our other studies are available later in this report, including recruitment figures.

Special Interest Groups provide a vibrant forum for PoCoG members to explore new research ideas and build collaborations. It is testament to the varied interests of our members that we now have groups focused on Cancer Prevention, End of Life Care and Implementation Science launched. These new groups compliment our existing fear of cancer recurrence, Clinicians in Research, South Australian, Adolescent and Young Adult and Early Career Researcher SIGs.

These groups have been a hive of activity over the last few months, with leads developing and hosting a series of webinars to boost engagement and collaboration among our members, despite our inability to meet face-to-face.

Recordings of all these events are available for viewing at any time via the [PoCoG YouTube channel](#).

We'd like to take this opportunity to say a sincere thank you to the members of our Management Team and Scientific Advisory Committee, whose support and encouragement over the last six months has been unerring.

Finally, we would like to say a sincere thank you to all PoCoG committee members, our collaborative partners, our funding bodies and our members for their support and input this year and look forward to strengthening these relationships and working together to continue to *build capacity in psycho-oncology clinical trial research*.



Joanne Shaw
Executive Director



Bonnie Laxton-Blinkhorn
Executive Officer

A blue rectangular banner with a white play button icon in a red rounded square at the top center. Below the icon, the word "FOLLOW" is written in large, bold, white capital letters. Underneath "FOLLOW", the words "US ON YOUTUBE" are written in smaller, white capital letters. A thin white horizontal line is positioned below "US ON YOUTUBE". At the bottom of the banner, the text "@PSYCHO-ONCOLOGY CO-OPERATIVE RESEARCH GROUP" is written in white, underlined capital letters.

2019-20 MEMBERSHIP

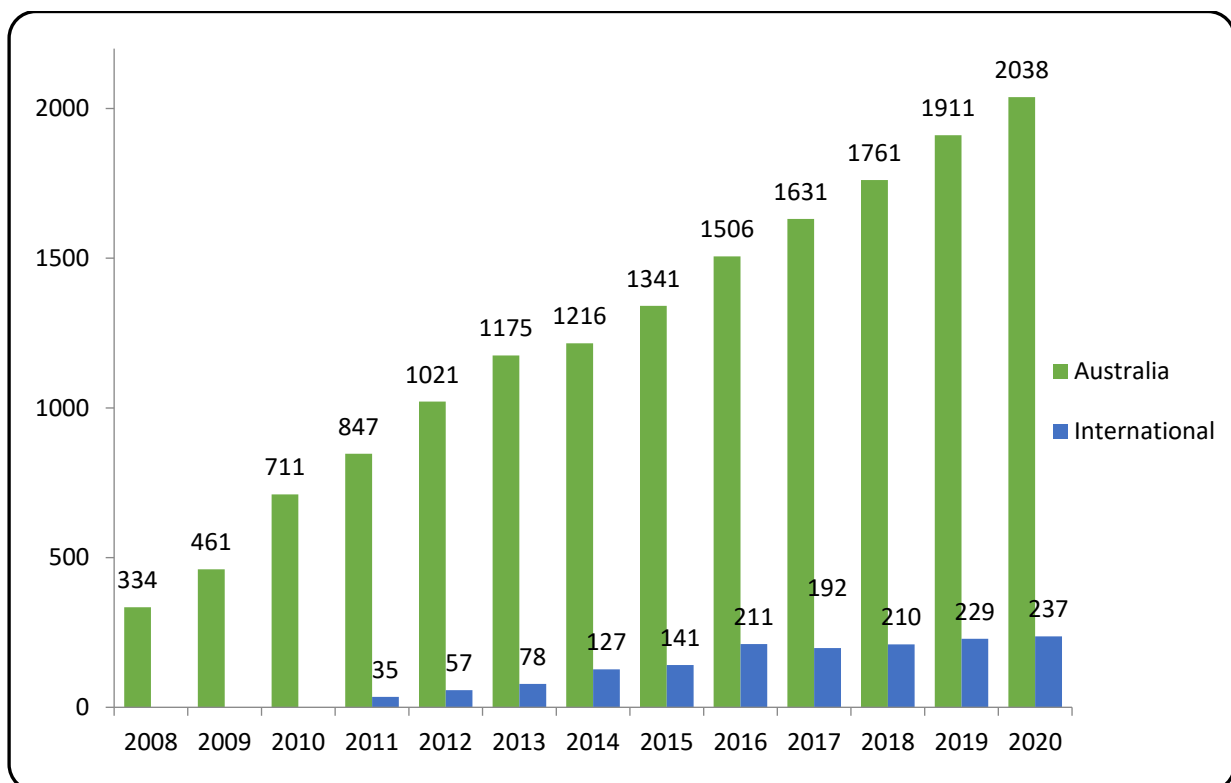
PoCoG membership is open to researchers and health professionals with an interest in psycho-oncology research, as such our members are drawn from a wide range of disciplines.

In 2019-2020 our member numbers increased to **2275**, which included **2038** Australian and **237** international members. Membership has been growing steadily since 2008.

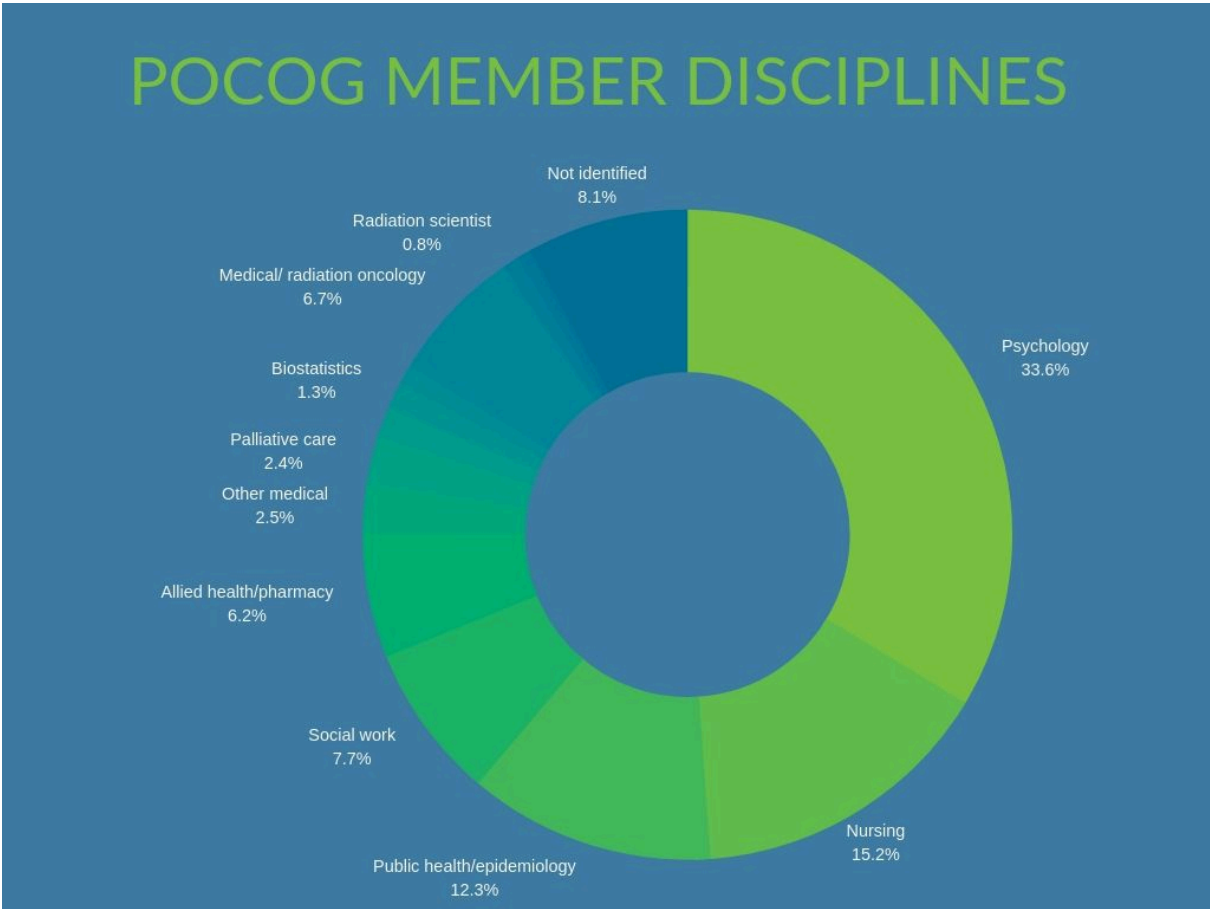
Once again psychology, public health/health promotion and oncology nursing were the top three professional groups at the end of the financial year. We have a significant rural/regional representation of about 12.5 per cent of the total disciplines represented by our membership.

Membership growth

While increased membership is important, we encourage PoCoG members to actively engage with PoCoG activities to increase the scope of psycho-oncology research in Australia.



Professional disciplines of Australian PoCoG members.



| Discipline | Number of members | Percentage of members |
|-----------------------------|-------------------|-----------------------|
| Psychology | 672 | 33.4 |
| Nursing | 302 | 15.1 |
| Public Health/epidemiology | 256 | 12.1 |
| Social Work | 159 | 7.6 |
| Allied health/pharmacy | 127 | 6.1 |
| Medical /radiation oncology | 140 | 6.6 |
| Other medical discipline | 46 | 2.4 |
| Palliative care | 52 | 2.3 |
| Psychiatry | 30 | 1.5 |
| Biostatistics | 25 | 1.2 |
| Health economics | 22 | 1 |
| Radiation scientist | 16 | 0.8 |
| Surgery | 14 | 0.6 |
| Consumer | 4 | 0.6 |
| Discipline not identified | 173 | 8 |
| | 1911 | 100 |

SPECIAL INTEREST GROUP REPORTS

Membership of PoCoG Special Interest Groups is open to all PoCoG members. If you would like to join any of the Special Interest Groups, contact the PoCoG Executive Office.



Fear of Cancer Recurrence (FCR) Interest Group

Professor Phyllis Butow and Dr Ben Smith

The Fear of Cancer Recurrence (FCR) SIG has a mission to promote collaboration and establish Australian research priorities in FCR.

Specific objectives are to:

- Share information about current and planned FCR research and foster collaborations
- Develop a network of clinicians interested in participating in FCR trials
- Support the development of PoCoG supported national FCR grant protocols

The PoCoG FCR SIG has collaborated with the International Psycho-Oncology Society FCR SIG (FORWards) to extend the previously published Delphi study of Australian FCR research priorities to the international setting.

Similar to the Australian study, the results of the international study found that models of care that facilitate greater access to FCR treatment and evaluation of the effectiveness of FCR interventions in real world settings as priority research areas. The study manuscript, led by PoCoG Executive Director Jo Shaw, has been submitted to a special psycho-oncology section of *Frontiers in Psychology on Uncertainty, Anxiety and Fear of Cancer Recurrence* and should be published by the end of 2020.

Considering that improving FCR treatment access was seen as a top priority, the FCR SIG has planned its first webinar on new intervention models to increase the accessibility of FCR treatment for October 2020, which will feature leading Australian FCR researchers Professor Louise Sharpe, Dr Jenny Liu, Dr Maria Ftanou and Dr Fiona Lynch.

To further aid the dissemination of the effective ConquerFear treatment for FCR developed and evaluated by a PoCoG-led collaborative team, PoCoG Executive Officer Bonnie Laxton-Blinkhorn has helped establish an [online FCR hub](#) to share resources and publications related to ConquerFear. [Visit the hub here.](#)



Early Career Researcher (ECR) Interest Group

Dr Gemma Skaczkowski, Dr Camille Short and Dr Ursula Sansom-Daly

The ECR Interest Group provides an opportunity for people in the earlier stages of their research career to participate in a dedicated professional network. The group promotes interactions between ECRs and senior researchers in psycho-oncology and is led by the ECR members of PoCoG's Scientific Advisory Committee.

Our main activities over the past year have included a survey of our ECR members to identify their top areas of need (pre-COVID), which will help us inform our future initiatives.

We have actively promoted the work of our ECR members by highlighting recent publications and achievements in the April PoCoG membership email, and by contributing an 'ECR profile' of Dr Emma Kemp, winner of the Best Oral Presentation by an Early Career Researcher at the 2019 PoCoG Annual Scientific Meeting, to the March PoCoG Newsletter, with plans for a further profile in December 2020.

In response to the impact of COVID-19, we adapted our planned capacity-building workshop and in June 2020 developed and hosted a webinar tailored to the new and emerging challenges of the time, on *Maintaining track record and overcoming challenges during COVID-19*.

The webinar was well attended by 51 ECRs from across Australia, and with the support from the PoCoG Executive office we were able to feature the useful and diverse perspectives of our panellists Prof Afaf Girgis, A/Prof Inger Mewburn, A/Prof Liz New and Prof Claire Wakefield.

As the ECR psycho-oncology community continues to navigate the impact of COVID-19 on their research and work-lives, the remainder of 2020 will focus on a pared back set of priorities, including the finalisation and launch of our Social Media Strategy (currently under review by the PoCoG Executive).



South Australian (SA PoCoG) Interest Group

Dr Amanda Hutchinson and Dr Emma Kemp

The main objective of SA PoCoG is to support and increase networking among early career researchers (ECR) and mid-career researchers (MCR) among PoCoG members based in South Australia.

A secondary goal of this group is to create opportunities for collaboration between members in developing and conducting research.

In 2020, SA PoCoG conducted a survey of members to inform future activities. Results confirmed that the membership is diverse in terms of discipline, career stage, and desired frequency of PoCoG activities.

One outcome was to establish an ongoing seminar series to promote the activities of SA PoCoG members, provide networking opportunities within SA PoCoG and with the broader PoCoG community, and engage with consumer and diverse health professional perspectives.

The first of these will be a webinar held in October to showcase ECR research on cancer survivorship.

The MCR peer-mentoring group continues to meet and provide peer support related to conducting research, writing, and navigating career-related decisions. The cancer-related

fatigue group did not meet due to COVID restrictions and the substantial increases in members' workloads. However, this will resume in 2021.

In 2021, Dr Emma Kemp will take on leadership of the SA PoCoG Interest Group and we will seek a new Deputy SIG Chair.



Adolescent and Young Adult (AYA) Interest Group

Dr Fiona McDonald

The AYA SIG aims to provide an opportunity for people conducting targeted psycho-social research in the AYA area to participate in a dedicated professional network. This SIG aims to facilitate discussion and encourage new learning, increase network opportunities amongst AYA researchers and identify opportunities for collaboration.

In 2019 Dr Eden Robertson stood down as SIG Co-Chair having completed her PhD and accepting an exciting role with Starlight Children's Foundation Australia. Congratulations Eden and thank you for your leadership over the last 4 years. Your enthusiasm within the group will be missed. The AYA SIG is accepting nominations to fill the co-chair role. Contact the PoCoG Executive Office for further information.



Cancer Prevention Interest Group

Professor Monika Janda and Professor Christine Paul

This SIG was launched in June 2019 and is in the formative stages of development. The overarching aim of this group is to ensure that the second dimension of psycho-oncology becomes more prominent within the PoCoG agenda and is better integrated with psycho-oncology practice. The second psychological dimension of cancer being defined as: the psychological, behavioural and social factors that may influence the disease process.

The agreed goals of this group are to:

- Increase focus on prevention
- Foster connections and facilitate partnership in research and practice
- Advocate for cancer prevention

In the last year, the Cancer Prevention SIG wrote a letter to the editor of *Psychooncology* highlighting the importance of cancer prevention activities in the COVID era.

In addition, the group hosted its inaugural webinar Prevention Interest group webinar, as part of the PoCoG lunchtime webinar series. The program included group co-chairs A/Professor Monika Janda and Professor Chris Paul along with Professor Craig Sinclair from Cancer Council Victoria, Dr Kylie Vuong from the School of Public Health at UNSW and Amy Pearn from the Gene Council.

More recently, the group has written and submitted a PoCoG response to the National Preventive Health Strategy consultation paper.



End of Life Care (EoLC) Interest Group
Professor Liz Lobb, Dr Ursula Sansom-Daly

In July 2019 PoCoG established a new special interest group (SIG) for clinicians and researchers working in end of life care (EoLC).

The goals of this interest group are:

- To share information about current and planned EoL research and foster collaborations
- To develop at least two PoCoG supported national EoL grant protocols for submission over the next three years.
- To grow a network of clinicians/researchers interested in participating in and contributing to EoL studies

The EoLC SIG held an initial ZOOM meeting to discuss the formation of the group and this was followed by two surveys with the membership. The first in November 2019 was to gain a sense of the composition of the group; their disciplines; their current research and their research interests. The second survey in April/May 2020 drilled down further to identify the key research areas of interest.

The EoLC SIG currently has 42 members. Participants are primarily female with a mean age of 62 years (range 29 – 66 years). 50 per cent of respondents were NSW based, although all states were represented in the survey responses. One New Zealand member also contributed. 65 per cent (n=13) of respondents indicated that they worked clinically in end of life care, primarily with adult populations, with 45 per cent of respondents reporting having worked in EoLC for more than 10 years.

50 per cent of respondents were primarily university based, with a further 20 per cent based in a hospital setting. 35 per cent of respondents reported a psychology background with a further 20 per cent classifying themselves as working in research more broadly.

In clarifying their expectations of group membership, the primary reasons for joining the interest group were networking and building collaborations (45 per cent) and the opportunity to engage with activities that promote capacity building through educational activities (30 per cent). In line with these expectations, 50 per cent of respondents perceived the role of the interest group was to promote collaboration and networking and providing mutual support and encouragement (20 per cent).

The main research priorities of the EoLC SIG are end of life communication; family and carers; support and training for health professionals.



Clinicians' Research (CRIG) Interest Group

Dr Laura Kirsten, A/Professor Ilona Juraskova, A/Professor Lesley Stafford

The Clinician's Research (CR) Interest Group aims to encourage and foster clinician-initiated research while appreciating the limitations encountered when conducting research in a clinical setting. Activities of the CRIG include concept development workshops, dedicated seminars and discussion on topics relevant to the group, an email forum, and updates on training initiatives or funding opportunities relevant to clinician research in psycho-oncology.



INSPIRE -Implementation Science Special Interest Group

Dr Nicole Rankin and Dr Carolyn Mazariego

This newly established group was formed in response to a growing interest in implementation trials in psycho-oncology, as identified at the 2019 PoCoG strategic planning day. INSPIRE recognises PoCoG membership interest in the field of implementation science, and how it might be relevant for incorporation into psycho-oncology research.

INSPIRE currently has two co-chairs, a communications coordinator (Ms Elizabeth Beasley) and an early career research coordinator (Dr Mona Faris), with capacity to increase the governance group in the future.

The group is in its formative stages of development. The purpose of INSPIRE is to promote knowledge exchange and research collaboration amongst PoCoG members specifically related to implementation science, its methodology and use within psycho-oncology clinical trials research. As of September 2020, there are 47 registered members in the INSPIRE SIG. Two events have been held in 2020:

- A webinar entitled 'Implementation science and multi-centre psycho-oncology trials' held in June and featured three presentations from Dr Nicole Rankin (Multi-centre pragmatic trials in psycho-oncology), Dr Donna Milne (Practice-led research: from the clinic to a potential trial) and Dr Heather Shepherd (Research-led trials: the ADAPT trial). From 71 registrants, we had 36 attendees engaged in this activity. We received 12 participant evaluations post-event and utilised this feedback to refine the groups' Terms of Reference.
- An initial meeting was held in September to discuss the Terms of Reference and potential work program. The meeting attracted 18 participants who indicated strong interest in planning the group's future activities. A regular newsletter and activities (e.g. webinars, concept development workshops and/or master classes) were endorsed.

A work program for 2021 will be finalised and may include collaborative events with other communities of practice in implementation science.

CONSUMER ADVISORY GROUP UPDATE

The Consumer Advisory Group is as an advisory body to PoCoG and functions as a sub-committee of the Scientific Advisory Committee. The main purpose of the JcAG is to advise PoCoG members on research, including study proposals, methods, measures, and priorities from a consumer perspective.

I think we will all remember 2020 for all the challenges that we have faced. There have been so many changes and impacts on society with COVID and we have all reacted differently, working from home, and via Zoom/online and phone meetings.

This year the Consumer Advisory Group (CAG) changed from the combined JcAG (Joint Consumer Advisory Group), as we separated from our partnership with PC4. Consumers within the group made a choice to stay with both or align particularly with PoCoG or PC4.

This has led to change and capacity issues that are being worked through, as is the impact of COVID 19 on research programs, along with new projects assessing the psycho-oncology impacts of COVID 19 in the community.

I am new to the scientific committee and wish to thank the past consumer members Julie Marker and Max Shub for their contributions.

Some of the highlights from the last year I have valued and some excellent developments are: PoCoG's new YouTube Channel, webinars for training and development, the PoCoG Symposium held in the SAMHRI building in Adelaide prior to the COSA conference (November 2019) and also the pre-conference Psycho-oncology Professional Day, which focused on sexual dysfunction among cancer patients.

The PoCoG symposium '*Revolutionising Access to Psycho-oncology*' offered several thought-provoking presentations around the social determinants of health and one thing that struck me was mention of the vulnerability indicators.

As a consumer I value the research that PoCoG members undertake. The webinars and training provided by PoCoG along with our ability to participate in concept development workshops, mean we can contribute to the excellent research being undertaken.

Many of us participate in your projects as consumer representatives and provide an ongoing commitment during the life of that project. As CAG members we value our ability to make meaningful contributions to your research and represent the many cancer survivors.

Don Piro and Julie Marker

Consumer Advisory Group Representatives

CAG Membership 2019-2020







Elle Ackland
Louise Bailey
George Fishman
Julie Marker
Celia Pavelieff
Don Piro
Max Shub
Jason White



PoCoG Studies

PoCoG aims to foster collaboration to develop large-scale, multi-centre, psycho-oncology studies of clinical relevance and importance, which would be difficult for any one team to undertake.

In light of this, a PoCoG study will, in principle:

-  Target a psychosocial, behavioural or supportive care issue
-  Be amenable to intervention in the short or long term
-  Have a strong rationale and methodology
-  Be collaborative
-  Endeavour to engage populations which are typically underrepresented in clinical trials
-  Be industry independent
-  Have a PI who is committed to obtaining funding for the study

PoCoG STUDY PROFILES FROM THE 2019-20 FINANCIAL YEAR

PoCoG supports innovative high-quality psycho-oncology research including studies with the greatest potential to improve outcomes for cancer patients and those that address the need of vulnerable populations. PoCoG studies can be either:

PoCoG Administered: studies conceptualised and/or administered by PoCoG SAC/PoCoG Office

OR

PoCoG Supported: member studies where PoCoG has contributed to concept development, scientific review and/or support with study design, protocol development and/or statistical analysis plan.

PoCoG ADMINISTERED STUDIES OPEN TO RECRUITMENT IN 2019-20

PoCoG-2015-105: Implementing a sustainable and supported clinical pathway for managing anxiety and depression in cancer patients. A cluster randomised controlled trial to evaluate different implementation strategies. (ADAPT Cluster RCT)

Aim: A cluster randomized controlled trial (RCT) to evaluate the efficacy of a supported, tailored implementation strategy versus a standard implementation strategy for the A & D clinical pathway.

Investigator Team: ADAPT Program Group

Funder: Cancer Institute NSW

Recruitment: 1754

PoCoG-2015-109 - Understanding the barriers and facilitators of referral of patients to online therapy programs amongst health professionals at hospital-based cancer clinics

Aim: To explore the perceptions of health care staff working in cancer care toward online psychological therapy programs. The research questions include:

- What potential barriers do health care staff see to the uptake of online psychological therapy programs in routine cancer care
- What potential facilitators do they see to the uptake of online psychological therapy programs in routine cancer care
- What models of care do they view as the most acceptable for incorporating online psychological therapy programs in routine cancer care?

Investigator Team: ADAPT Program Group

Recruitment: 25

PoCoG-2016-01: Genetic Cancer Risk in the Young

Aim: The study will examine the psychosocial impact of living with uncertainty over a prolonged period of waiting for genomic testing results

Investigator Team: Phyllis Butow, Megan Best, Ilona Juraskova, Ainslie Newson, David Thomas

Funder: NHMRC, Cancer Institute NSW, The Garvan Institute

Recruitment: 1095

PoCoG-2016-02: Molecular Screening and Therapeutics Program

Aim: The study examines the psychological predictors of outcomes of patients receiving actionable results after psychosocial impact of living with uncertainty of genomic testing

Investigator Team: Phyllis Butow, Megan Best, Ilona Juraskova, Ainslie Newson, David Thomas

Funder: NHMRC, Cancer Institute NSW, The Garvan Institute

Recruitment: 1541

PoCoG-2016-04 Clinician views on discussing genomic testing with cancer patients

Aim: The research project is aiming to explore the challenges encountered by medical oncologists in returning genomic results to their patients, and what support would make this task easier. This information will be used to guide the education initiatives for younger oncologists.

Investigator Team: Phyllis Butow, Mandy Ballinger, Megan best, Subo Thavaneswaran, David Thomas, David Goldstein, Bettina Meiser

Recruitment: 108

PoCoG-2016-105: management of clinical anxiety in cancer care: A national survey to explore clinician need for anxiety management training

Aim: To explore the preparedness and current practice of Australian cancer health care professionals (CHCP) to assess and manage anxiety in patients with cancer

Investigator Team: Brian Kelly, Haryana Dhillon, Lisa Beatty, Monika Janda, Lisa Lampe, Donna Milne, Joanne Shaw

Recruitment: 100

PoCoG-2016-201: How depressed and anxious people make help-seeking decisions

Aim: To explore decision-making related to help-seeking for mental health concerns among patients with cancer and anxiety/ depression.

Investigator Team: Joanne Shaw, Haryana Dhillon, Phyllis Butow, Richard De Abreu Lourenço, Dr Lisa Beatty, Dr Laura Kirsten

Recruitment: 7

PoCoG-2016-401: PiGeon.1 Cancer risk in the young

Aim: Investigating family communication of genomic test results and interactions with healthcare professionals.

Investigator Team: Phyllis Butow, Ainsley Newson, Megan Best, Bettina Meiser, Ilona Juraskova, David Goldstein, Katherine Tucker, Mandy Ballinger, Timothy Schlub

Recruitment: 75

PoCoG-2016-402: PiGeon.2: Molecular screening and therapeutic program

Aim: To explore psychological, behavioural and ethical impact of molecular tumour profiling (MTP) for advanced cancer patients.

Investigator Team: Phyllis Butow, Ainsley Newson, Megan Best, Bettina Meiser, Ilona Juraskova, David Goldstein, Katherine Tucker, Mandy Ballinger, Timothy Schlub

Recruitment:65

PoCoG-2018-09: A research agenda for fear of cancer recurrence

Aim: FCR is the fear, worry or concern relating to the possibility that cancer will come back or progress - it is pervasive amongst cancer survivors. Whilst research in the field of FCR has increased dramatically recently, many issues remain unaddressed. Setting a clear research agenda would move the field forward. This study aimed to use a Delphi approach, to identify FCR research priorities for Australia.

Investigator Team: Phyllis Butow, Louise Sharpe, Haryana Dhillon, Joanne Shaw, Lisa Vaccaro

Recruitment: 31

PoCoG-2019-101: PRO Pictogram ESAS study 1

Aim: To develop a pictorial version of the Edmonton Symptom Assessment Scale (revised) for use with CALD and lower literacy cancer populations.

Investigator Team: Heather Shepherd, Joanne Shaw, Haryana Dhillon, Phyllis Butow

Recruitment: 20

PoCoG-2020-501: Experiences and perspectives of patients and family members, health professionals working in cancer care and non-government cancer services regarding the COVID-19 pandemic

Aim: To explore experiences of COVID-19 on treatment decision making, psychological well-being, workforce changes, moral distress and unmet needs specifically related to the pandemic, from the perspectives of cancer patients/survivors and their family members, health professionals working in cancer care and non-government cancer services

Investigator Team: Phyllis Butow, Joanne Shaw, Lisa Beatty, Laura Kirsten, Ilona Juraskova, Brian Kelly, Louise Sharpe, Haryana Dhillon, Phillip Beale, Ray Chan, Maria Cigolini, Polly Harvard, Zoe Butt

Recruitment: 25

PoCoG-2020-502: Barriers and Enablers to Implementing Telehealth Consultations in Psycho-oncology during the COVID-19 Pandemic: lessons for future implementation

Aim: To explore the barriers and enablers to delivery of psycho-oncology services via telehealth and identify predictors of attitudes to use of telehealth in psycho-oncology

Investigator Team: Joanne Shaw, Brian Kelly, Lisa Beatty, Phyllis Butow, Haryana Dhillon, Laura Kirsten, Zoe Butt

Recruitment: 19

PoCoG-2018-20: An international research agenda for fear of cancer recurrence/progression - online survey

Aim: To elicit initial views regarding research priorities pertaining to fear of cancer recurrence/progression, to guide investigators and funding bodies.

Investigator Team: Phyllis Butow, Louise Sharpe, Joanne Shaw, Haryana Dhillon, Sophie Lebel, Nick Hulbert Williams, Ben Smith

Recruitment:21

PoCoG-2018-21: Focus group consultation on international research agenda for fear of cancer recurrence/progression

Aim: To provide in-depth qualitative data on research priorities regarding fear of cancer recurrence/progression, to guide investigators and funding bodies.

Investigator Team: Phyllis Butow, Louise Sharpe, Joanne Shaw, Haryana Dhillon, Sophie Lebel, Nick Hulbert Williams, Ben Smith

Recruitment:16

PoCoG-2018-22: Delphi survey for international consensus on research agenda for fear of cancer recurrence/progression

Aim: To develop international consensus on research priorities regarding fear of cancer recurrence/progression to guide investigators and funding bodies.

Investigator Team: Phyllis Butow, Louise Sharpe, Joanne Shaw, Haryana Dhillon, Sophie Lebel, Nick Hulbert Williams, Ben Smith

Recruitment:25

PoCoG SUPPORTED STUDIES OPEN TO RECRUITMENT IN 2019-20

PoCoG-2009-11: The CHALLENGE Trial. A Phase III Study of the Impact of a Physical Activity Program on Disease-Free Survival in Patient with High Risk Stage II or Stage III Colon Cancer: A Randomised Controlled Trial

Aim: To determine the efficacy of Physical Activity in reducing disease recurrence in patients with localised colon cancer. The primary hypothesis is that a PA program will improve disease-free survival (DFS) in patients with resected stage II and III colon cancer who have completed adjuvant therapy. In addition, it is hypothesised that exercise can improve fatigue, quality of life (QOL), physical functioning and body composition

Investigator Team: Janette Vardy, Stephen Clarke, Haryana Dhillon

Recruitment: 258

PoCoG-2013-04: Cognitive rehabilitation for breast cancer survivors with perceived cognitive impairment

Aim: To evaluate two cognitive rehabilitation programmes in localised breast cancer survivors with perceived cognitive dysfunction after chemotherapy: 1) a structured neurocognitive learning programme (Attention Process Training [APT], aimed at improving underlying cognitive deficit) and 2) a systematic teaching of strategies to compensate for the functional impact of cognitive deficits (Compensatory Strategy Training [CST]).

Investigator Team: Janette Vardy, Melanie Bell, Melanie Price, Haryana Dhillon

Funder: Cancer Council NSW

Recruitment: 63

PoCoG-2018-01: Large-scale data to understand person-centred outcomes in cancer survivors

Aim: The 45-and-up "Large-Scale data to understand person-centred outcomes in cancer survivors - qualitative sub-study" is one component of a mixed-methods study seeking to generate population-based quantitative and qualitative evidence on person-centred outcomes in cancer survivors, across different cancer types, and compared to those without cancer. The qualitative study is:

- conducting a systematic review of reviews of qualitative studies on cancer survivors to summarise the evidence and identify gaps in the literature
- conducting in-depth semi-structured interviews with sub-groups of cancer survivors to explore aspects of survivorship not well represented in the literature, and which appear to be areas of diversity in quantitative analyses of 45-and-up data.

Investigator Team: Emily Banks, Phyllis Butow, Bogda Koczwara, Grace Joshy, Rebecca Lidsaar-Powell, Nicole Rankin, Wei Du

Recruitment: 18

PoCoG-2018-02: ‘Scanxiety’: Scan-associated anxiety in patients with advanced solid cancers

Aim: To refine the definition of "Scanxiety" or scan-associated anxiety, by conducting focus groups with patients and health care professionals, and then by developing a questionnaire to determine how common and severe a problem this is, and to determine what factors improve or worsen it.

Investigator Team: Kim Tam Bui, Prunella Blinman, Belinda Kiely, Haryana Dhillon, Christopher Brown

Recruitment: 222

PoCoG-2018-03: Clinician Intervention to Reduce Fear of Recurrence in Cancer Survivors

Aim: Fear of cancer recurrence (FCR) affects 50-70 per cent of cancer survivors. Evidence-based psychological interventions for FCR are effective but resource-/time-consuming. This study aimed to evaluate an oncology delivered intervention to reduce fear of cancer recurrence

Investigator Team: Jia (Jenny) Liu, Jane Beith, Phyllis Butow, Belinda Kiely, Annabelle Goodwin, Mun Hui, Catriona McNeil

Recruitment: 60

PoCoG-2018-05: Fear of recurrence in patients with stage II colon cancer participating in the DYNAMIC study - Circulating tumour DNA analysis informing adjuvant chemotherapy

Aim: The study will prospectively measure FCR in the context of a RCT, in which circulating tumour DNA (ctDNA) analysis is informing adjuvant chemotherapy in individuals with stage II colon cancer to determine the prevalence rate and severity of FCR, and the association between FCR anxiety, depression and HRQL. The study will compare FCR in patients with known positive ctDNA status, negative ctDNA status, and unknown ctDNA status in the context of deciding about adjuvant chemotherapy, and determine the course of FCR over time and its potential predictors

Investigator Team: Sue-Anne McLachlan, Jeanne Tie

Recruitment: 78

PoCoG-2018-06: Collaboration and Communication in Cancer Care for Aboriginal and Torres Strait Islander people: The 4Cs Project improving patient-centred care and treatment outcomes

Aim: To explore the current models of cancer care, service provision and support provided to Indigenous cancer patients in participating services; (2) Adapt an existing Radiation Therapy Talking Book (RTB) to create an Indigenous Radiation Therapy Talking Book (IRTB) for Indigenous cancer patients; (3) Evaluate the use of the IRTB to: Indigenous Cancer Patients and Cancer Services Staff; (4) Estimate the costs, and likely consequences, of nation-wide implementation of the Indigenous Radiation Therapy Talking Book. (5) Adapt an existing surgical and medical oncology Question Prompt List (QPL) for use with Indigenous patients

receiving non-radiation treatments. (6) Examine whether the use of a QPL for Indigenous cancer patients receiving non-radiation treatments is acceptable for use by Indigenous patients and consultants.

Investigator Team: Gail Garvey, Haryana Dhillon, Joan Cunningham, Michael Penniment, Sabe Sabesan, Georgia Halkett, Siddhartha Baxi, Adam Stoneley, Luke McGhee

Recruitment:21

PoCoG-2018-07: Early Detection of Chemotherapy-Induced Cardiomyopathy

Aim: Cancer therapy-induced cardiotoxicity is an unfortunate and potentially fatal complication of cancer treatment. This project aims to improve the outcomes for cancer patients and cancer survivors by improving patient access to appropriate and timely cardiovascular care. Specifically, we will utilize novel biomarkers and imaging modalities to develop and test a risk stratification tool for early diagnosis and detection of cardiovascular complications of cancer therapy.

Investigator Team: Aaron Sverdlov and Doan Ngo

Recruitment: 172

PoCoG-2018-08: Caring for the carer: improving self-efficacy to provide care and reducing anxiety and burden among family carers of primary brain tumour patients

Aim: To develop and examine the usability, feasibility and safety of an online psychoeducational intervention for family carers of patients with primary brain

Investigator Team: Danette Langbecker, Helen Haydon, Georgia Halkett, Anna Nowak, Althea Blackler

Recruitment: 0

PoCoG-2018-10 Development of a BRCA1/2 founder mutation population screening program for the Jewish community

Aim: Assessment of two new BRCA Jewish Founder Mutation screening programs for the Jewish community. An online program in Sydney providing pre-test information and obtaining consent for testing online, is being compared to a program in Melbourne which provides pre-test information through group information sessions and written consent obtained during the sessions. Results are being provided by email, face-to-face consultations or phone, depending on the test results, the participant's family history, as well as participants randomly selected to obtain results through a face-to-face consultation. Questionnaires are being distributed after pre-test information, 2 weeks following the receiving of results, 12 months after carriers receive results, and 24 months after carriers receive results.

Investigator Team: Nicole Cousens, Leslie Burnett, Lesley Andrews, Bettina Meiser

Funder: Jewish Communal Appeal Philanthropic Funding

Recruitment: 2100

PoCoG-2018-11: Reconnect: Social skills in survivors of childhood cancer; A mixed methods study

Aim: To determine the prevalence and predictors of social difficulties amongst childhood cancer survivors, as well as to identify the key areas of social development that may be compromised by a diagnosis of childhood cancer based on the social cognitive-integration of abilities model (SOCIAL). Reconnect also aims to identify the preferences of survivors, parents and teachers regarding future social skills interventions for survivors of childhood cancer (e.g. content, delivery mechanism and timing).

Investigator Team: Joanna Fardell, Claire Wakefield, Richard Cohn, Suncica Lah

Recruitment: 89

PoCoG-2018-12: Fear of recurrence in patients with locally advanced rectal cancer participating in DYNAMIC-RECTAL

Aim: To assess Fear of Cancer Recurrence levels using a validated self-reporting questionnaire in the context of a randomized clinical trial (the DYNAMIC-RECTAL study).

Investigator Team: Sue Anne McLachlan

Recruitment: 49

PoCoG-2018-17: The psychological benefits of cognitive rehabilitation and neuropsychological feedback in addressing self-reported cognitive impairment in cancer survivors

Aim: Single arm pilot study, where women who have completed chemotherapy in the past 12 months undertake online cognitive assessment and questionnaires, receive feedback on these cognitive and self-report measures from a psychologist via telephone and written summary, and then participate in an interview to discuss their experiences of receiving this feedback

Investigator Team: Heather Green, Tamara Ownsworth, Haryana Dhillon, David Shum, Shu-Kay Ng, Jasotha Sanmugarajah, Haitham Tuffaha

Recruitment: 14

PoCoG-2018-16: Cancer survivors experiencing Cancer Related Fatigue: A Phase 2 study evaluating a combined Physical Activity (PA) and Mindfulness Based Stress Reduction (MBSR) program

Aim: To determine if a combined PA and MBSR intervention is feasible and active in improving CRF in cancer survivors.

Investigator team: Ashanya Malalasekera, Sue Butler, Jane Turner

Recruitment: 7

PoCoG-2019-04: Scan-associated anxiety in people with cancer: perspectives of nurses

Aim: Scan-associated anxiety (scanxiety) and tumour marker-related anxiety is commonly described on social media and in patient forums. We aimed to explore the experiences of genitourinary cancer nurses on scanxiety and tumour marker-related anxiety through an anonymous survey distributed at a national genitourinary trials meeting.

Investigator Team: Kim Tam Bui, Prunella Blinman, Belinda Kiely, Haryana Dhillon, Christopher Brown

Recruitment: 34

PoCoG-2019-03: Association between receipt or omission of radiotherapy and health-related quality of life and fear of breast cancer recurrence: A PROSPECT sub-study

Aim: To determine if levels of FCR and HRQoL differ in the medium to long-term between cohorts of women with low risk BC: Group A) women who had PROSPECT MRI and did not receive RT, Group B) women who had PROSPECT MRI and still received RT, Group C) women not approached for PROSPECT who received RT as routine care and did not have MRI, matched to Group A, and Group D) women not approached for PROSPECT who received RT as routine care and did not have MRI, matched to Group B and to provide qualitative data on a large cohort of women (Groups A, B, C and D) with low risk breast cancer in terms of psychosocial experience of de-escalation therapy and MRI staging.

Investigator Team: Lesley Stafford, Bruce Mann, Allison Rose, Leslie Gilham, Susan Thomas, Anita Skandarajah, John Collins.

Recruitment: 230

PoCoG-2019-07: Mutational Assessment of newly diagnosed breast cancer using Germline and Tumor genomics (The MAGIC study)

Aim: To assess the feasibility of integrating several steps of providing important germline and mutation information to treating clinician within a clinically relevant timeframe

Investigator Team: Lesley Stafford, Bruce Mann, Sarah-Jane Dawson, Paul James, Geoffrey Lindeman, Sherene Loi, Dilanka de Silva, Anita Skandarajah, Ian Campbell

Recruitment: 6

PoCoG-2020-04: Prostate Cancer Patient's Preferences for Image Guidance Procedures: A Discrete Choice Experiment

Aim: To assess and understand prostate cancer patient's preference in image guidance procedures/techniques during radiation therapy treatment, through a Discrete Choice Experiment (DCE), and to examine the trade-offs patients make when choosing between the different levels of the attributes

Investigator team: Amy Brown, Tilley Pain, Alex Tan, Emily Callander, Kerriane Watt

Recruitment: 478

PoCoG-2020-05: Randomized controlled phase 2 trial evaluating laser photobiomodulation for the treatment of chemotherapy-induced peripheral neuropathy (CIPN)

Aim: determine the activity, feasibility, and safety of laser PBM for treatment of established CIPN (defined as numbness, tingling and pain affecting the hands and feet). Hypothesis: 6 weeks of PBM will improve patient symptoms of CIPN

Investigator team: Christina Sian Hwa Teng, Dr Janette Vardy, Dr Mark Teng, Chris Brown

Recruitment: 0

PoCoG ADMINISTERED STUDIES: CONCEPTS DEVELOPED IN 2019-20

PoCoG-2016-101: Collaborative care in the management of clinical depression in cancer care. A national study to evaluate a collaborative care model for management of depression in cancer that incorporates community based clinical psychologists, GPs and hospital-based psycho-oncology

Aim: To evaluate in a pragmatic randomised controlled trial (pRCT) the effectiveness, acceptability and cost-efficacy of a collaborative care intervention for depressed cancer patients

Investigator team: Jane Turner, Joanne Shaw, Lisa Beatty, Brian Kelly, David Kissane, Laura Kirsten, Meera Agar, Kerry Sherman, Louise Sharpe, Ursula Sansom-Daly

Status: In development

PoCoG-2019-301: A research agenda for cancer related fatigue

Aim: To establish Australian research priorities for cancer-related fatigue across disease groups and stages.

Investigator team: Haryana Dhillon, Joanne Shaw, Corrinne Renton, Meera Agar, Linda Brown

Status: In development

PoCoG-2019-102: PRO Project Pictogram ESAS-R study 2

Aim: To evaluate whether a pictorial scale, used to measure health symptoms, is acceptable to patients. This will help health professionals to better identify patient problems and provide better care and support.

Investigator team: Heather Shepherd, Joanne Shaw, Haryana Dhillon, Phyllis Butow

Status: In development

PoCoG-2020-101: Exploring "Moral Distress" among Healthcare Professionals in Oncology and/or Palliative Care in Australia: A Qualitative Study

PoCoG-2020-601: CoGent study: evaluate an innovative CONsent in GENomics Testing intervention, (the CoGent intervention, combining a genomic QPL+DCP), specifically tailored to rare cancer patients, to improve the quality of consent to genomic research and patient outcomes

Investigator team: Phyllis Butow, Matilda Haas, Mandy Ballinger, David Thomas, Bettina Meiser, Lisa Dive, Timothy Schlub, Kathy Tucker, Ilona Juraskova, Joanne Shaw

Status: In development

PoCoG SUPPORTED STUDIES: CONCEPTS DEVELOPED IN 2019-20

PoCoG-2011-07: ConquerFear Advanced: A randomized control trial to reduce fear of cancer recurrence in patients with advanced disease

Aim: To evaluate in a randomised controlled trial, the efficacy of an intervention (Conquer Fear Advanced) based on a novel model of cancer-related anxiety and a proven intervention, in reducing the impact of fear of cancer recurrence (FCR) in cancer survivors with advanced disease.

Investigator Team: Louise Sharpe, Phyllis Butow, Jane Turner, Belinda Thewes, Jane Beith, Ben Smith

Status: Awaiting funding

PoCoG-2011-09: iConquerFear: A randomised controlled trial of an online self-management intervention to reduce fear of cancer recurrence

Aim: To evaluate the efficacy of iConquerFear, an online self-management intervention, in reducing fear of cancer recurrence (FCR) severity (primary outcome) and ameliorating FCR-related outcomes including cancer-related distress, anxiety, depression, and healthcare utilisation/costs (secondary outcomes), in curatively-treated cancer survivors, compared with an attention control (online relaxation training) in a randomised controlled trial (RCT).

Investigator Team: Ben Smith, Louise Sharpe, Phyllis Butow, Jane Turner, Belinda Thewes, Jane Beith

Status: Awaiting funding

PoCoG-2018-15: Light Enhanced Cognitive Behavioural Therapy (CBT+) for Sleep and Fatigue: A Randomized Controlled Trial during Chemotherapy for Cancer

Aim: Aim 1 Test the efficacy of cognitive behavioural and bright light therapy (CBT+) compared to relaxation audio and basic psychoeducation (CONTROL) for improving symptoms of sleep disturbance and fatigue. Aim 2 Test the efficacy of CBT+ versus CONTROL for psychological outcomes. Aim 3 Exploratory aim to test potential mechanisms and moderators of the intervention efficacy.

Investigator Team: Joshua Wiley, Bei Bei, Sheila Garland, Sonia Ancoli-Israel, Haitham Tuffaha

Status: In development

PoCoG-2019-201: Ensuring equity and access to optimal health care: Applying patient reported outcome measures to guide resource allocation, health system performance and individual care.

Aim: To develop systematic approaches to routine application of PROMs accessible to all, with provision of meaningful individual and aggregated PROMs data to patients, clinicians and health system decision makers, to influence all levels of healthcare.

Investigator team: Phyllis Butow, Rosalie Viney, Gail Garvey, Haryana Dhillon, Joanne Shaw
Status: On hold

PoCoG-CDW-2019-02: Randomised control trial of a multi-disciplinary intervention for the management of fatigue in community palliative care: A feasibility study

Aim: To determine the feasibility of a multi-modal intervention for fatigue in patients with advanced life-limiting illness referred to a community palliative care setting

Investigator team: Dr Gemma Ingham, Dr Katalin Urban
Status: In development by CST

PoCoG-2019-401: iScreen - every cancer patient every need

Aim: To implement a systemic approach to online screening of cancer patients for their unmet needs and distress and address these needs using an evidence-based clinical pathway.

Investigator team: Bogda Koczwara, Phyllis Butow, Lisa Beatty, Joanne Shaw, Heather Shepherd, Haryana Dhillon
Status: In development

PoCoG-CDW-2019-01: Cancer-Related Fatigue Clinic Study

Aim: Phase 1: To develop a CRF Clinic Model of Care and test the feasibility and acceptability of a CRF Clinic and Phase 2: To test the effectiveness of the CRF Clinic compared to usual care and to test the cost-effectiveness of a CRF Clinical model of care compared to usual care.

Investigator team: Ray Chan, Patsy Yates, Carmelita Escalante
Status: In development

PoCoG-CDW-2019-05: Reducing CVD risk after a cancer diagnosis among indigenous and non-indigenous Australians

Aim: To provide a systems-wide perspective of CVD in cancer, by investigating, for NSW residents diagnosed with cancer over a 10-year period:

- The prevalence of pre-existing and treatment-induced CVD in people diagnosed with cancer and its effect on their clinical course, outcomes and health care use/cost
- Variations in the above between Aboriginal and Torres Strait Islander people and non-Indigenous people, and by country of birth, sex, age group, cancer type, remoteness and area-level socioeconomic status.

Investigator Team: Abbey Diaz, Aaron Sverdlov Kalinda Griffiths Joanne Shaw Doan Ngo Joan Cunningham Brian Kelly Gail Garvey Emily Callander Lisa Whop Nick Zdenkowski
Status: Awaiting funding

PoCoG-2019-05: Phase II trial evaluating web-based cognitive behaviour for sleep disturbance in early stage breast cancer patients on (neo) adjuvant chemotherapy

Aim: To assess the feasibility and acceptability of web-based cognitive behaviour for sleep disturbance in early stage breast cancer patients during treatment.

Investigator Team: Emma-Kate Carson, Belinda Kiely, Janette Vardy, Haryana Dhillon

Status: In development

PoCoG-2020-03: LATER (life after cancer) Study: Online platform for managing symptoms

Aim: To develop and evaluate an online platform delivering evidence-based interventions to reduce common symptoms matched to individual need for women cancer patients to improve quality of life.

Investigator Team: Michelle Peate, Martha Hickey, Jennifer Marino, Michael Jefford, Christobel Saunders, Debra Anderson, Michael Friedlander, Bruce Mann, Ines Rio, Nicole Kinnane

Status: Awaiting funding

PoCoG-2020-02: Impact of the COVID-19 pandemic on care of patients with cancer and multimorbid conditions

Aim: To ensure the delivery of patient-centred care in the face of COVID-19 and beyond, understanding patient perceptions and experiences is crucial. Our aim is to capture perceptions, experiences and concerns about cancer and multimorbidity management now and over the next 3-12 months.

Investigator Team: Jasmine Yee, Haryana Dhillon, Bogda Koczwara, Jon Emery, Claudia Rutherford, Raymond Chan, Kristi Milley, Sharon Lawn

Status: In development

PoCoG PUBLICATIONS AND ACADEMIC OUTPUT

The research output from PoCoG administered and supported studies is indicative of the hard work of our members. Below is a list of publications and conference abstracts for the year 2019-2020:

The feasibility of implementing an innovative collaborative care model to treat cancer-related depression in the community: evaluation report. Kissane D, Murphy G, Loupis A, Maciejewska A, Melia A, Bobevski I, O'Callaghan C, Wong ZW, Richardson G, Antill Y, McLeod V, Chan R, Fletcher J, Duggan N, Milvain C, Sherwell S and Anna Kilgour. Report to Victorian Department of Health, 2019

Bartley N, Best M, Jacobs C, Juraskova I, Newson AJ, Savard J, Meiser B, Ballinger M, Biesecker B, Butow PN. *Cancer patients' views and understanding of genome sequencing: a qualitative study.* Sydney Catalyst International Translational Cancer Research Symposium, Sydney, Australia, September 2019.

Bartley N, Best M, Jacobs C, Juraskova I, Newson A, Savard J, Meiser B, Ballinger M, Thomas D, Biesecker B, Butow P. *Cancer patients' views and understanding of genome sequencing: a qualitative study.* Journal of Medical Genetics. 2020; doi. 10.1136/jmedgenet-2019-106410

Best M, Bartley N, Butow PN, Napier C, Jacobs C, Juraskova I, Newson AJ, Savard J, Meiser B, Goldstein D, Biesecker BB, Ballinger M, Thomas D, Smit AK. *Family communication about genomic testing: A qualitative study.* Familial aspects of Cancer: Research and Practice (KConFab), Kingscliff, Australia, August 2019.

Best M, Napier C, Ballinger M, Davies G, Bartley N, Schlub T, Juraskova I, Meiser B, Thomas D, Butow PN. *Cancer patient knowledge and attitudes towards germline genome sequencing.* Familial aspects of Cancer: Research and Practice (KConFab), Kingscliff, Australia, August 2019.

Best M, Butow PN, Jacobs C, et al. *Who should access germline genome sequencing? A mixed methods study of patient views.* Clin Genet. 2020; 97: 329- 337.

Best M, Jacobs C, Savard J, Smit A, Davies G, Napier C, Tucker K, Thomas D, Butow PN, Newson AJ. *Advanced cancer patients' preferences for return of molecular profiling results.* Sydney Catalyst International Translational Cancer Research Symposium, Sydney, Australia, September 2019.

Best M, Napier C, Juraskova I, Goldstein D, Jacobs C, Savard J, Meiser B, Thomas D, Ballinger M, Butow PN, Newson AJ, Biesecker B. *Patient perspectives on molecular tumor profiling: "Why wouldn't you?"* Sydney Catalyst International Translational Cancer Research Symposium, Sydney, Australia, September 2019.

Best M, Butow P, Jacobs C, Juraskova I, Savard J, Meiser B, Goldstein D, Ballinger ML, Bartley N, Napier C, Davies G, Thomas DM, Biesecker B, Tucker K, Schlub T, Newson AJ. *Advanced cancer patient preferences for receiving molecular profiling results* [published online ahead of print, 2020 Jun 16]. Psychooncology. 2020; 10.1002/pon.5446. doi:10.1002/pon.5446

Butow PN, Bartley N, Jacobs C, Juraskova I, Goldstein D, Newson AJ, Savard J, Meiser B, Ballinger M, Napier C, Thomas D, Biesecker B, Best M. *The Psychosocial Issues in Genomic Oncology (PiGeOn) Project*. Sydney Catalyst International Translational Cancer Research Symposium, Sydney, Australia, September 2019.

Butow P, Davies G, Napier CE, Schlub T, Best, M, Bartley N, Juraskova I, Meiser B, Ballinger ML, Biesecker B, Goldstein, D, Thomas DM. *Assessment of the value of tumor variation profiling perceived by patients with cancer*. JAMA Network Open. 2020; 3(5), e204721-e204721. doi:10.1001/jamanetworkopen.2020.4721.

Butow P, Davies G, Napier C, Thomas DM, Bartley N, Goldstein D, Ballinger ML, Juraskova I, Schlub T, Tucker K, Meiser B, Young MA. *Return of results after somatic tumor mutation profiling in advanced cancer: psychological impacts*. Journal of Clinical Oncology. 2020; 38: (15) 1541-1541.

Davies G, Butow P, Napier CE, Bartley N, Juraskova I, Meiser B, Ballinger ML, Thomas DM, Schlub TE, Best M. *Advanced cancer patient knowledge of and attitudes towards tumor molecular profiling*. Translational Oncology. 2020; 13:(9)100799. doi.org/10.1016/j.tranon.2020.100799.

Liu J, Bui K, Serafimovska A, Kiely B, Hui M, Goodwin A et al. *CIFeR: A novel clinician-led intervention to address fear of cancer recurrence (FCR) in breast cancer survivors*. Journal of Clinical Oncology. 2020; 38 (15): 12115-12115.

Murphy, MJ, Newby, JM, Butow, P, et al. *Randomised controlled trial of internet-delivered cognitive behaviour therapy for clinical depression and/or anxiety in cancer survivors (iCanADAPT Early)*. Psycho-Oncology. 2019; 1- 9. <https://doi.org/10.1002/pon.5267>.

Napier C, Best M, Davies G, Bartley N, Juraskova I, Meiser B, Ballinger M, Thomas D, Schlub T, Butow PN. *Patient knowledge of and attitudes towards tumour molecular profiling*. Australian Precision Oncology Symposium, Adelaide, Australia, November 2019.

Napier C, Best M, Bartley N, Jacobs C, Juraskova I, Goldstein D, Newson AJ, Savard J, Meiser B, Ballinger M, Thomas D, Biesecker B, Butow PN. *Patient perspectives on molecular tumor profiling: "Why wouldn't you?"* Australian Precision Oncology Symposium, Adelaide, Australia, November 2019.

Napier C, Butow PN, Davies G, Bartley N, Ballinger M, Biesecker B, Juraskova I, Meiser B, Schlub T, Thomas D, Goldstein D, Best M. *How much do cancer patients value whole genome sequencing? A cross-sectional survey using the willingness-to-pay technique*. European Society of Human Genetics (ESHG) 2020.2. Livestream. June 2020, Virtual poster presentation.

Sansom-Daly UM, Patterson P, Beattie A, McGill BC, Cohn RJ, Wakefield CE. *Partnering with community organisations to deliver an online cognitive-behavioural therapy group program for adolescent and young adult cancer survivors: Ways forward and lessons learned*. Victorian Cancer Survivorship Conference, Melbourne, Australia, March 2020. Oral presentation.

Sansom-Daly UM, McGill BC, Patterson P, Beattie A, Cohn RJ, Wakefield CE. *Partnering with community organisations to deliver an online cognitive-behavioural therapy group program for adolescent and young adult cancer survivors: Ways forward and lessons learned*. Australasian Society for Behavioural Health and Medicine (ASBHM) Annual Scientific Meeting, Sydney, Australia, February 2020. Oral presentation.

Shepherd HL, Geerligs L, Butow P, et al. *The Elusive Search for Success: Defining and Measuring Implementation Outcomes in a Real-World Hospital Trial*. *Front Public Health*. 2019; 7:293.

Smith AB. *What are the psychosocial challenges facing testicular cancer survivors and how can technology help to address them?* Clinical Oncological Society of Australia 46th Annual Scientific Meeting, Adelaide, Australia, November 2019.

Smith AB. *Research and clinical perspectives on the challenges faced by AYAs living with testicular cancer*. CanTeen and Clinical Oncological Society of Australia Youth Cancer Service Community of Practice Meeting. Adelaide, Australia, November 2019.

Smith AB. *The psychosocial challenges facing testicular cancer survivors*. Clinical Oncological Society of Australia Trainees Weekend. Adelaide, Australia, November 2019.

Smith AB, Heiniger L, Rincones O, Grimison P, Stockler M, Tran B, Toner G, Olver I, Klein B, Butow PN. *Web-based self-management intervention (e-TC 2.0) shows limited feasibility as a means of reducing psychological morbidity in distressed testicular cancer survivors on a broad scale*. Psycho-Oncology Co-operative Research Group Scientific Meeting, Adelaide, Australia, November 2019.

Smith AB, Rincones O, Heiniger L, Grimison P, Tran B, Stockler MR, Toner G, Cohen B, Olver I, Klein B, McLannett M, Butow PN. *Online psychological self-management intervention for testicular cancer survivors (e-TC 2.0): promising acceptability & preliminary efficacy, but limited feasibility*. *Journal of Psychosocial Oncology Research & Practice*; Accepted 26/6/20.

Smith-Uffen, M.E.S., Johnson, S.B., Martin, A.J. et al. *Estimating survival in advanced cancer: a comparison of estimates made by oncologists and patients*. *Support Care Cancer* (2019) doi:10.1007/s00520-019-05158-5.

Untaru R, Chen D, Kelly C, May A, Collins NJ, Leitch J, Attia JR, Proietto AM, Boyle AJ, Sverdlov AL, Ngo DTM. *Suboptimal Use of Cardioprotective Medications in Patients with a History of Cancer*. *JACC: CardioOncology*. 2020; 2(2): 312-315.

Vaccaro L, Butow PN, Lee D, et al *Fidelity is fundamental: intervention predictors in advance care plans in terminal cancer*. *BMJ Supportive & Palliative Care* 2019;9:397-403.

Yuen J, Cousens N, Barlow-Stewart K. et al. *Online BRCA1/2 screening in the Australian Jewish community: a qualitative study*. *J Community Genet* 2019; 11: 291-302



NEED HELP WITH A CONCEPT?

PoCoG members can access expert advice from our Scientific Advisory Committee at any time or submit a proposal to a concept development workshop.

Visit the Research Section of our website for information and to apply for supported study status.



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