# 2021-2022 ANNUAL REPORT

PSYCHO-ONCOLOGY CO-OPERATIVE RESEARCH GROUP



The provision of our PoCoG annual report is an opportunity to reflect on the achievements of this important research network and its future goals and direction.

2021 has presented the ongoing challenges of the COVID-19 pandemic for our communities, health services and universities through this time. PoCoG has been active in driving research that can help understand the impact on people with cancer, their care and treatment and on clinicians and health services in general.

While health care provision has needed to adapt to different modes of delivery over this extended time period, so too have our research methods and focus. PoCoG has also adapted many of its education and research development programs to ensure we remain connected as a research community and can do our best to support all those involved in psycho-oncology through this time.

The pandemic has also served to remind us of the important needs of our patients, families and clinicians in responding to palliative care needs, the impact of COVID related deaths, and the ways in which COVID has highlighted disparities in health care across our communities.

A number of PoCoG initiated forums and meetings over the course of the year have attempted to explore these important issues and support our network through these impacts. Like so many other aspects of the pandemic, it has served to highlight the importance of our connections with each other, and the important dimension of cancer care that is our focus.

We have been working diligently towards to goals and objectives of the newly developing Australian Cancer Plan, and have had the opportunity to directly engage in the discussions held by Cancer Australia to move this forward.

PoCoG operations are funded by Cancer Australia through their support for the Cancer Clinical Trials Funding Scheme.

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It is gratifying to see the recognition of psychosocial aspects of cancer prevention and treatment, the focus on addressing disparities in cancer outcomes, and the needs of priority populations.

I believe we can be confident about PoCoG's ability to support these critically important objectives of the Cancer Plan, building on our existing projects and collaborations, and our work to promote psycho-oncology across the other clinical trial groups.

I particularly would like to highlight the important work being done in collaboration with Professor Gail Garvey of the University of Queensland in working with PoCoG to develop our program focusing on the needs of Aboriginal and Torres Strait Islander people.

This includes the leadership undertaken by PoCoG to promote an Aboriginal and Torres Strait Islander National Advisory Group to support the work of cancer clinical trials groups, which is in the early stages of its development.

Finally I wish to acknowledge the outstanding work and dedication of our team in the PoCoG Executive Office, especially the tireless leadership of Executive Director Associate Professor Joanne Shaw, and the invaluable contribution of Bonnie Laxton-Blinkhorn to keep the wheels of PoCoG moving forward.

PoCoG operations are funded by Cancer Australia through their support for the Cancer Clinical Trials Funding Scheme.

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I also thank the dedicated contribution of our other management committee members: Deputy SAC Chair Associate Professor Lisa Beatty, SAC Chair Associate Professor Haryana Dillon and Research Manager Dr Claire Cooper and the other members of the PoCoG team.

Its important to also recognise the critical role played by our Scientific Advisory Committee and its Special Interest Groups – this is the "engine room" of our research innovation and research networks, and on behalf of PoCoG members wish to express our thanks for their generous contribution to the PoCoG work.

I especially wish to personally thank our team of community advisors who give generously of their experience and expertise.

Thanks to all for your participation in PoCoG and I hope the accompanying report will provide an inspiring update on the progress of this important network.

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Professor Brian Kelly PoCoG Chair

PoCoG operations are funded by Cancer Australia through their support for the Cancer Clinical Trials Funding Scheme.

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# Report from the PoCoG Scientific Advisory Committee Chair

With so much hope for COVID elimination, we have continued to work through and around a disrupted community over this 12 months. I continue to be astounded by the level of engagement PoCoG members have continued to show in our research, delivery of cancer care, and continuing education activities.

Despite the lock-downs, vaccine shortages, fatigue, and increased workloads, so many of you have reminded active and in touch for which I thank you.

It has been another year of meeting via Zoom, for our concept development workshops and committee meetings. There is no doubt we are all missing the in person contact and the added bonuses arising from being able to spend time together. Hopefully 2022-2023 will be the year we can be back together!

This year has seen the ADAPT Program of work coming to a close, with a plethora of papers generated as part of this work. There is so much data reported already and continuing to come out, reflecting the enormity of the program successfully completed.

It has been an extraordinary collaboration between the psycho-oncology research and clinical communities, clinical services across NSW, and of course the people living with cancer who engaged in this component of routine care.

I say my heart-felt thanks to Emeritus Professor Phyllis Butow for her exceptional leadership, to Dr Heather Shepherd who lead the central team, our marvellous central team, and all the investigators who contributed their time and insights so willingly.

Happily, the ADAPT portal continues to be used in clinical practice by a number of services, providing ongoing distress screening in routine cancer care. It has also been used to monitor symptoms in a pilot implementation in South Australia and is forming the backbone of the BRAiNS unmet need screening approach.



# Report from the PoCoG Scientific Advisory Committee Chair

Another exciting development is the partnership between PoCoG and Ramsay Healthcare, to implement the ADAPT portal and clinical pathway in their service in Lake Macquarie Private Hospital, demonstrating the ongoing need for this resource to assist in clinical care.

Our communication has remained strong, with some wonderful webinars and workshops across a broad range of topics. The number of resources freely available on our YouTube channel is growing. This provides a focal point for this collective knowledge..

A/Professor Joanne Shaw continues to lead the PoCoG team with grace and insight. Bonnie Laxton-Blinkhorn has kept us all connected and communicating. We were delighted to welcome Dr Claire Cooper as Research Manager, and grateful for her meticulous work.

With the support of these people and the wider PoCoG staff, we are thriving as an organisation.

There is much to be thankful for despite the challenging circumstances.

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A/Professor Haryana Dhillon Chair of the PoCoG Scientific Advisory Committee

# **Scientific Advisory Committee**

The Scientific Advisory Committee (SAC) is responsible for setting the strategic and scientific direction for studies, and for ensuring they are in line with Cancer Australia's key performance indicators.

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

#### Current members:

- A/Professor Haryana Dhillon Chair
- A/Professor Lisa Beatty Deputy Chair
- Professor Brian Kelly PoCoG Chair
- Professor Phyllis Butow Founding Chair
- Professor Meera Agar Member
- Dr Dan Costa Member
- Dr Abbey Diaz Early Career Researcher Member
- Dr Joanna Fardell Member
- Dr George Fishman Community Advisory Group Member
- Professor Gail Garvey Special Adviser First Nations Research
- A/Professor Georgia Halkett Member
- Ms Kim Hobbs OSWA Representative
- A/Professor Amanda Hutchinson Membe
- Dr Emma Kemp Early Career Researcher Member
- Dr Laura Kirsten OZPOS Representative
- Dr Donna Milne CNSA Representative
- Dr Ursula Sansom-Daly Member
- Professor Louise Sharpe- Member
- A/Professor Joanne Shaw Member
- Professor Jane Turner Member
- Dr Nienke Zomerdijk Early Career Researcher Member

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The 2021-2022 financial year was another challenging year and the ongoing resilience and flexibility displayed by our community of clinicians and researchers has been extraordinary.

Despite successfully adapting to work under the conditions caused by the pandemic, return to a more normal way of operating has been a great source of relief.

#### **ADAPT** and **PiGEON**

ADAPT and PiGeON, two of our flagship studies, were completed in the last year.

The Cancer Institute NSW funded ADAPT program developed patient and health professional resources to support implementation of the Australian Clinical Pathway for Identification and Management of Anxiety and Depression in Cancer (ADAPT CP) including development of an online portal that operationalised the ADAPT CP.

A Cluster RCT evaluated two implementation strategies to promote uptake of the ADAPT CP in oncology services. Twelve oncology services participated in the cluster RCT (9 metropolitan 3 regional). 696 patients participated across the services resulting in 1323 screening events.

Results confirmed at higher levels of anxiety and depression the enhanced support (intervention arm) provided to sites did improve adherence to the ADAPT CP recommendations for referral and follow up compared to core support (control arm), although overall there was no difference in adherence.

The implementation of the ADAPT CP was also found to be a cost-effective strategy which can reduce health service cost regardless of implementation arm. However even with high acceptability, implementation of health service change is challenging and although services were motivated to implement the ADAPT CP they experienced barriers to implementation. Adequate resourcing and high-level commitment are key.

# **Report from the Executive Office**

To date, ADAPT has resulted in 17 publications (with more to come) and the results of the program have been presented as poster and presentations on 74 occasions at oncology and health services conferences across the life of the program.

The PiGEON Project comprised two inter-related longitudinal studies exploring the psychosocial, behavioural and ethical issues and outcomes of cancer genomic testing. PiGEON recruited participants from two cancer genomic studies: 1939 advanced cancer patients undergoing comprehensive genomic profiling to determine targeted treatment options within the Cancer Molecular Screening and Therapeutics (MoST) Program; and 1379 cancer patients with features suggestive of a genetic aetiology as well as blood relatives, who will undergo germline genomic profiling through the Genetic Cancer Risk in the Young (RisC) Study.

Results show that obtaining health information about self and for family appear to be the main drivers for undertaking cancer genomic testing. There is a need to consider innovative and flexible methods of communication and consent for genomics in clinical practice as patients have limited knowledge of the accuracy and utility of genomics which can lead to unrealistic expectations.

Patients waiting for genomic results do not experience major psychological morbidity, however some do experience distress and uncertainty during this period. Receiving a nonactionable genomic result or an actionable without ensured access to treatment, may cause increased distressed in advanced cancer patients. This suggests that pre-testing assessment and counselling addressing uncertainty and self-efficacy, and post-results support may be beneficial for patients.

Finally, the results showed that family communication in the genomic context is complex and suggests a need for family-centred interventions and resources to facilitate communication of relevant information within families.

To date the PiGeON team has had close to 30 journal articles published, with more in the pipeline and the team have presented findings at a range of international and national conferences.

# **Report from the Executive Office**

#### The BRAiNS Program

With completion of ADAPT and PiGEON, progress on the BRAiNS program (Brain cancer Rehabilitation, Assessment and Intervention for survivorship NeedS) has scaled up.

This national collaboration with the Cooperative Group in Neuro-Oncology (COGNO), Cancer Symptom Trials Group (CST) and the Primary Care Collaborative Cancer Clinical Trials Group (PC4) will 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.

The program will also create a repository of information resources, a national care coordination service and develop and roll out interventions to address gaps in care, including a collaboration with CanTeen to support young adult brain cancer survivors to re-engage with life.

The full list of studies associated with the BRAiNS project is provided later in this report.

#### **PoCoG Scientific Meeting**

Although it feels like a very long time ago now, PoCoG hosted a virtual Scientific Meeting at the end of 2021. This important event in the PoCoG calendar happens every other year and gives members, and invited experts, an opportunity to present their psycho-oncology research to a wider audience. Our 2021 meeting also included virtual posters and short presentations.

To avoid Zoom fatigue, we structured the meeting as a series of lunchtime webinars over two weeks. This format worked well as it enabled registrants to pick and choose their interest areas. Highlights included a full session on <u>learnings from the ADAPT program</u> and another on <u>clinician self-care during COVID-19</u>. We look forward to returning to a face-to-face format in 2023.

Recordings from all the sessions at the Scientific Meeting are available on our <u>YouTube</u> <u>channel.</u>

# **Report from the Executive Office**

#### **Special Interest Groups**

PoCoG Special Interest Groups (SIGs) offer members an opportunity to progress their research goals and collaborate with researchers and clinicians with shared interests. Over the last financial year PoCoG SIGs have been a great source of activity and innovation through the development and delivery of an ongoing series of lunchtime webinars, which provided members with a forum to meet and share their work, despite the restrictions caused by COVID-19.

Highlights of our lunchtime webinar series included a session on <u>conducting research with</u> <u>vulnerable groups</u>, which was hosted by the SA PoCoG and a very popular session which explored <u>implementation considerations for researchers conducting systematic reviews</u>.

These webinars are available to watch on the <u>PoCoG YouTube channel</u> and given their popularity and ease of access will continue, even as our transition back to face-to-face continues.

#### **Community Advisory Group**

The Community Advisory Group (CAG) advises PoCoG and its members on ways to ensure a patient-centred focus in our research activities, through contributing to the development of research projects, attendance at workshops and meetings and advocacy work.

Three of our longest standing members, Max Shub, George Piro and Julie Marker retired from the CAG this year and we owe them a great debit of gratitude for their hard work and generous contributions over the years.

We recently conducted a very successful recruitment round to appoint new members to our CAG to replace those who have left and are happy to report that we have increased our team to nine.

These new members have a diverse range of experiences as both patients and carers and we look forward to introducing them you soon.

# **Report from the Executive Office**

#### **Concept Development Workshops**

Concept development workshops (CDWs) continued online in the last financial year and enabled us to continue supporting members to bring their research ideas to fruition.

During our CDWs, Scientific Advisory Committee members and invited experts, support PoCoG members to develop and refine their research ideas. In line with Cancer Australia priorities, our CDW in May was a call for research proposals with priority groups as their focus. This hugely successful workshop resulted in two new supported studies which you can read about later in this report.

I'd like to take a moment to acknowledge the PoCoG Management Team and SAC, who work hard to ensure our research program is practical, relevant and achievable and to say thank you to all PoCoG members for your participation and engagement over the last 12 months.

To learn more about PoCoG activities and to join visit <u>www.pocog.org.au</u>.

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Associate Professor Joanne Shaw PoCoG Executive Director

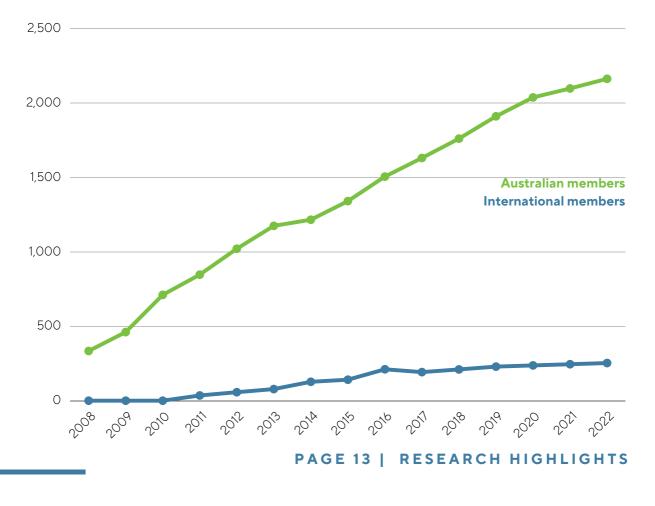
# 2021-2022 Membership

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.

While increasing member numbers is important, we are more focused on encouraging members to engage with PoCoG activities to increase the scope of psycho-oncology research in Australia.

In 2021-2022 our member numbers increased to 2416 which included 2163 Australian and 253 international members,

It is pleasing to note we have a significant rural/regional representation of 11 per cent of the total disciplines represented by our membership.



# **Membership Growth**

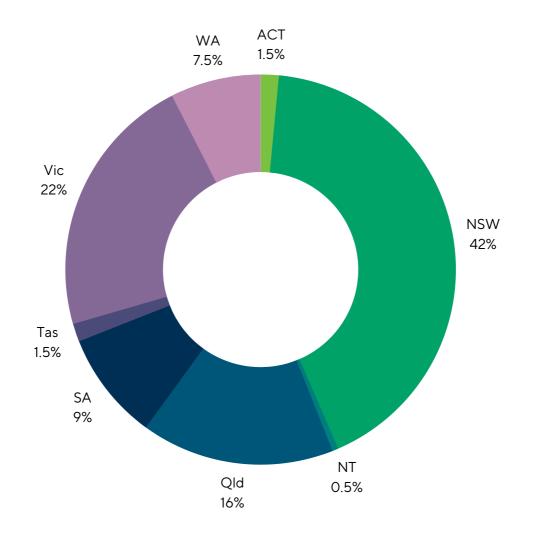
# 2021-2022 Membership

# Membership by State and Territory

PoCoG aims to:

- bring together researchers, clinicians, health care professionals and consumers to share ideas and form new collaborations and networks and
- develop national research capacity and collaborations to conduct large-scale, multicentre research of clinical relevance and importance, which would be difficult for a single team to undertake.

As such we encourage researchers and clinicians across Australia to join and this is visible in the state-by-state breakdown of our membership.



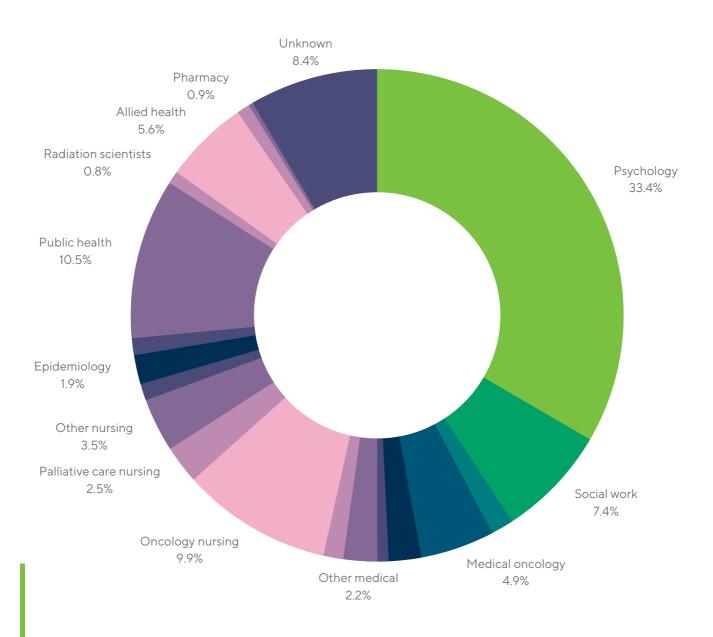
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# 2021-2022 Membership

# **Member Disciplines**

The PoCoG membership is multi-disciplinary and comprised of researchers, clinicians and health professionals from a wide range of disciplines.

Once again, psychology, public health/health promotion and oncology nursing were the top three professional groups represented among our membership at the end of this financial year.



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# 33%

Percentage of PoCoG members who identified psychology as their discipline

12%

Percentage of PoCoG members who are from regional/remote areas.

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# **Special Interest Group Reports**

#### **Cancer Prevention Special Interest Group**

Professor Monika Janda and Professor Christine Paul

The overarching aim of this group is to ensure that the second dimension of psychooncology 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

To this end, the Prevention SIG held two online meetings in the last financial year and used these for planning the year's activities and to compile comments for the National Preventive Policy consultation.

Otherwise the group is now working on one of its KPIs to do a systematic review of anticipatory anxiety and its role in cancer prevention and early detection, which is going along full steam.

# **Special Interest Group Reports**

#### Early Career Researcher (ECR) Special Interest Group

Dr Nienke Zomerdijk, Dr Emma Kemp, Dr Abbey Diaz

The ECR Special Interest Group (SIG) provides an opportunity for members 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.

This year, the ECR SIG hosted a capacity building event for ECR members on 'Building Brilliant Collaborations'. Twelve ECRs attended the event and heard from three senior leaders in the PoCoG executive group. Discussions focused on how to find, establish, and foster strong collaborations with other researchers and clinicians to advance our research programs and build our track records. In small break-out rooms, ECRs had the opportunity to ask the senior research leaders questions about navigating this period of our careers, as we begin to establish our research independence and leadership.

The group has been actively promoting presentations by ECR and non-ECR members via Twitter. At IPOS 2022, Nienke and the PoCoG account were identified as 'key influencers' at the event. In addition, we promoted the work of ECR members in PoCoG newsletters by contributing profiles of Dr Joshua Trigg and Dr Tracey DiSipio.

In 2021, the group successfully matched mentees and mentors for the PoCoG ECR Mentoring Program. The objective of the program is to support the career development of ECRs and provide an opportunity for mid-career researchers to build leadership skills. The 1st year evaluations indicated that program was well received. Suggestions for improvement included additional guidance for setting mentee goals and opportunity for additional engagement in group settings with other mentors/mentees.

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# **Special Interest Group Reports**

### End of Life Care (EoLC) Special Interest Group

Professor Liz Lobb, Dr Ursula Sansom-Daly

This Special Interest Group (SIG) for clinicians and researchers working in end of life care (EoLC) was established to:

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

This year the EoLC SIG has had a somewhat quieter year as Professor Lobb received a large MRFF Grant on bereavement and mental health outcomes during COVID-19 and Dr Sansom-Daly having taken some leave during 2021.

A ZOOM meeting was held on 5 May, 2022 to re-energise the group, re-visit our KPIs; update on individual activities and explore possibilities for 2022. In particular, expressions of interests were sought for an authorship group for a systematic review and a discussion was held on interest in potential research studies.

Following the meeting we conducted a mini poll of the EoLC SIG members to determine the feasibility of future research studies and we posed three questions to the group:

- are you still keen on being active in the group/contribute to new research studies
- do you have access to clinical populations to recruit (patients)
- do you currently supervise research students who could assist

We received an enthusiastic response and as a result, the SIG has recently convened a writing sub-group who are planning a systematic review of interventions relevant to the delivery of optimal psychosocial care in the context of palliative care and end-of-life. The writing group has met several times already to advance this goal. The SIG is also in discussions to plan a symposium at a national conference likely in 2023.

# **Special Interest Group Reports**

#### Fear of Cancer Recurrence (FCR) Special Interest Group

Professor Louise Sharpe and Dr Maria Ftanou

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 FCR SIG hosted a webinar as part of the ASM, which included a keynote presentation by Dr Rachel Menzies, who presented theoretical and empirical evidence suggesting that death anxiety is likely to be important for fear of cancer recurrence, as well as other mental health conditions.

The webinar also included a range of shorter abstract presentations, where researchers had an opportunity to present their FCR research findings to the wider PoCoG membership.

Finally, Dr Maria Ftanou replaced Dr Ben Smith as co-lead of this group at the beginning of 2022, joining Professor Louise Sharpe. Ben continues to be involved in the group and we'd like to thank him for his generous contribution during his tenure.

# **Special Interest Group Reports**

#### Implementation Science Special Interest Group (INSPIRE)

A/Professor Nicole Rankin, Dr Carolyn Mazariego, Dr Mona Faris and Elizabeth Beasley

The Implementation Science Special Interest Group (INSPIRE) was established to provide an opportunity for clinicians and researchers to collaborate and exchange knowledge in the field of implementation science within psycho-oncology.

In August 2022, the INSPIRE team were delighted to facilitate a webinar, titled 'Creating the DREAM TEAM: how to build capacity for implementation science research projects', which featured Dr Heather Shepherd (Senior Lecturer and Senior Research Fellow, University of Sydney), A/Prof Natalie Taylor (Director of Research, School of Population Health, University of New South Wales, Sydney), A/Prof Stephanie Best (Senior Research Lead, Peter MacCallum Cancer Centre), and Dr Bea Brown (Program Manager, University of Sydney).

The webinar provided information on how to find and build the 'dream team' for implementation research. The speakers discussed the importance of recruiting a team with diverse skills and expertise, how they decided which skills were most important, and where they have found researchers to collaborate with.

They also discussed what funding bodies consider when assessing a research team. There were 55 registrants for the event, and great engagement in the question-and answer session.

# **Special Interest Group Reports**

#### Implementation Science Special Interest Group (INSPIRE)

A/Professor Nicole Rankin, Dr Carolyn Mazariego, Dr Mona Faris and Elizabeth Beasley

The INSPIRE team circulated an email in June 2022, that featured findings from the program of work translating the Australian Clinical Pathway for the Screening, Assessment and Management of Anxiety and Depression in Cancer Patients (ADAPT CP), and highlighted the research of a PoCoG member who works in implementation science, Dr Alison Young.

Recent publications in implementation science within the field of psycho-oncology were also featured.

In December 2021, INSPIRE and the Prevention SIG collaborated on a webinar as part of the PoCoG ASM, which focused on prevention and implementation science methods in research and practice.

We will develop an agenda for 2023 and strive to increase the membership of INSPIRE.

# **Special Interest Group Reports**

#### South Australian Special Interest Group (SA PoCoG)

Dr Emma Kemp

SA PoCoG aims to build capacity for high quality psycho-oncology research in South Australia through the development of early and mid-career researchers and building strong networks and research collaborations.

Specific objectives are to:

- Support and increase networking among early career researchers (ECRs) and mid-career researcher (MCR) SA PoCoG members
- Facilitate consumer and multi-disciplinary involvement in research
- Create opportunities for collaboration between members in developing and conducting research
- Review the current organisation and activities of SA PoCoG

SA PoCoG aimed to meet these objectives in 2021-2022 by continuing our twice yearly seminar series, holding two further webinars on 'Conducting research with vulnerable groups' in October and 'Digital Health in SA Psycho-oncology' in June 2022.

Each of these events promoted a mix of academic university-based and clinician/service organisation speakers and prompted encouraging levels of attendee engagement during panel discussion/question time. 52 and 74 PoCoG members registered to attend these webinars respectively.

Plans for face-to-face networking were again put on hold due to COVID resurgence in South Australia. However, an informal networking event for ECRs and MCRs is intended for the last quarter of 2022.

Dr Emma Kemp remains the lead of this special interest group; despite seeking expressions of interest, a deputy lead is still to be appointed.

# **Special Interest Group Reports**

#### Adolescent and Young Adult (AYA) Special Interest Group

The AYA SIG aims to provide an opportunity for people conducting targeted psychosocial 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.

The AYA SIG is currently accepting nominations to fill the role of chair. Contact the PoCoG Executive Office (pocog.office@sydney.edu.au) for further information



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# **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**

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 needs of vulnerable populations. PoCoG studies can be either:

**PoCoG Administered:** studies conceptualised and/or administered by the PoCoG SAC or Executive Office.

OR

**PoCoG Supported:** 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 2021-22

PoCoG-2019-30: Conquer Fear in ovarian cancer.

**Aim:** To determine the suitability of the Conquer Fear intervention to address fear of cancer recurrence or progression in women with ovarian cancer and their partners.

**Team:** Haryana Dhillon, Joanne Shaw, Louise Sharpe, Phyllis Butow.

PoCoG-2021-802: Development and evaluation of a cancer-specific cognitive behavioural therapy training program for community-based psychologists -pre-post design through Ramsay Psychology.

**Aim:** To determine the effectiveness of training community-based psychologists to deliver treatment for anxiety and depression in cancer patients.

**Team:** Joanne Shaw, Sue Sinclair, Nicola Ware, David McGrath, Heather Shepherd, Lisa Beatty, Laura Kirsten, Jane Turner, Brian Kelly, Melea Charles-Walker.

# PoCoG Administered Studies open to recruitment in 2021-22

PoCoG-2021-901: Development of telehealth psycho-oncology consensus recommendations.

**Aim:** The COVID-19 pandemic triggered rapid implementation of telephone and videoconference telehealth across Australia. PoCoG investigated the barriers and enablers to wider implementation post pandemic. Psychologists working in oncology face unique challenges such as working with patients experiencing existential issues, and report inadequate training in conducting telehealth psychology. This research aims to address the paucity of evidence available to guide adaption of therapy to telehealth through the development of evidence-based consensus recommendations for psychooncology.

**Team:** Claire Cooper Lisa Beatty, Laura Kirsten, Brian Kelly, Jane Turner, Louise Sharpe, Maree Grier, Kim Hobbs, Nienke Zomerdijk, Jemma Gilchrist, Haryana Dhillon, Helen Haydon, Nicci Bartley, Joanne Shaw.

**PoCoG-2022-05:** Making decisions about psycho-oncology treatment options, piloting a patient decision aid.

**Aim:** To assess the perceived usability of a psycho-oncology specific Patient Decision Aid and obtain preliminary data on the PDA's effect on key decisional outcomes of knowledge, preparation for decision-making and anxiety.

Team: Joanne Shaw, Claire Cooper, Emily Ying Wu.

# PoCoG Supported Studies open to recruitment in 2021-22

PoCoG-CDW-2019-06: HP-Prepare and ACT- A communication skills education program for health professionals to help people with head and neck cancer manage psychological distress.

**Aim:** This study proposes to examine the feasibility and acceptability of an advanced communication skills training for health professionals (HP), using the principles of Acceptance and Commitment Therapy (ACT).

**Team:** Chandrika Gibson, A/Prof Georgia Halkett, A/Prof Moira O'Connor.

# PoCoG-2021-07: Implementation of a Clinician Intervention to Reduce Fear of Recurrence in Cancer Survivors (CIFeR\_2 Implementation Study).

**Aim:** To determine the barriers and facilitators to routine implementation of an oncologist-delivered education and communication intervention during routine oncology clinic follow-up appointments, to address FCR in breast cancer patients.

Team: Jenny Liu, Jane Beith, Phyllis Butow, Joanne Shaw, Anastasia Serafimovska.

# PoCoG Supported Studies open to recruitment in 2021-22

PoCoG-2021-03: Assessing the acceptability, feasibility and utility of a nurseled survivorship program for patients with metastatic melanoma who are long-term responders to immunotherapy or targeted therapy: a pilot study.

**Aim:** To co-design a survivorship program for people with metastatic melanoma who are long-term responders to immunotherapy or targeted therapy and to assess the acceptability, feasibility and utility of the survivorship program.

**Team:** Julia Lai-Kwon, Sarah Heynemann, Haryana Dhillon, Iris Bartula, Sarah Lane.

# PoCoG-2021-04: Ticking off the Bucket List – using Virtual Reality to improve quality of life in palliative care.

**Aim:** To assess the feasibility and acceptability of using VR in palliative care to increase patients' quality of life and wellbeing. More specifically, we aim to:

- Establish the effects of multiple personalised VR sessions on quality of life, depression, distress, anxiety and pain measures in patients receiving palliative care
- Determine the acceptability and usefulness of VR from patients, carers/families and hospital staff perspectives.
- Identify potential barriers for a broader implementation (e.g., recruitment rate, ease of sourcing tailored content, technical problems).

**Team:** Amanda Hutchinson, Tobias Loetscher, Dimitrios Saredakis, Hannah Keage.

# PoCoG Administered Studies: Concepts in development in 2021-22

#### PoCoG-2022-04: Exploring the experience of fear of cancer recurrence in caregivers.

**Aim:** To explore experiences of fear of cancer recurrence (FCR) among caregivers of people with a cancer diagnosis.

Team: Joanne Shaw, Kyra Webb, Louise Sharpe, Hannah Banks.

# PoCoG-2021-801: Ramsay ADAPT Implementation and pilot evaluation of sustainable and supported clinical pathway for managing anxiety and depression in cancer patients.

**Aim:** To evaluate the feasibility and acceptability of implementing the ADAPT Clinical Pathway into routine care in a private cancer service in Australia; and to identify health professional, patient, community, and systems factors which enable or hinder adoption of this model into routine care in the private hospital sector.

**Team:** Joanne Shaw, Melea Walker- Charles, David McGrath, Heather Shepherd, Lisa Beatty, Laura Kirsten, Jane Turner, Brian Kelly, Nicci Bartley, Claire Cooper, Luna Rodriguez-Grieve.

#### PoCoG 2021-101: Bereavement Stepped Care.

**Aim:** To develop an evidence-based bereavement model of care for Nepean Blue Mountains Local Health District (NBMLHD) that includes all aspects of bereavement processes: screening, education, training, follow-up and care provision, and that is suitable for a diverse population.

**Team:** Laura Kirsten, Cindy Wilson, Betsy Sajish, Joanne Shaw, Nicci Bartley, Claire Cooper, Luna Rodriguez-Grieve.

PoCoG-2022-06: SUN-SHINE- Co-creation of sarcoma specific online information resources for people diagnosed with sarcoma and their families.

**Aim:** To co-design sarcoma specific digital information resources (SUN-SHINE – Sarcoma Unmet Needs – Shared design of Information and Education resources) for people diagnosed with sarcoma and their carers.

**Team:** Mandy Basson, Tania Rice-Brading, Georgia Halkett, Mariana Sousa, Moira O'Connor, Richard Carey-Smith, Annie Ryan, Joanna Fardell, Haryana Dhillon, Joanne Shaw, Simon Carroll, Lee Westbrook, Matilda Gorce.

PoCoG-2022-03: Ensuring ethical and flexible consent in cancer genomic research and clinical practice.

**Aim:** To develop an innovative intervention for COnsent in GENomic Testing (CoGenT) aiming to transform cancer patients' experiences of genomics by improving the quality of decision-making and consent.

**Team:** Jolyn Hersch, Ilona Juraskova, Phyllis Butow, Mandy Ballinger, Matilda Haas, Christine Cockburn, Lauren O'Hara, Nicole Bartley, Rebekah Laidsaar-Powell, Kirsten McCaffery.

**PoCoG-2021-02: Meditation for the reduction of anxiety and existential distress in** palliative care.

**Aim:** To evaluate the impact of a concentrative meditation practice on existential distress and anxiety in people receiving palliative care.

Team: Angela Rao, Wei Less, Diana Ferreira.

PoCoG-2022-01: First Nations Australians and head and neck cancer: Mapping service use, patient journeys and co-designing culturally safe cancer services and survivorship care.

**Aim:** To map the experiences of First Nations people, and their families, following a diagnosis of head and neck cancer. Map the acute and post-acute health care service utilisation and needs of First Nations people with HNC and their families, and examine if difference exist by remoteness and understand the health professional perspectives of delivering culturally responsive, person-centred cancer care to First Nations people and their families.

**Team:** Bena Brown, Gail Garvey, EC Ward, R Nund, Daniel Lindsay, A Jansen.

# PoCoG-2021-06: BRIDGES-4AYA: An online information resource to bridge the gaps between treatment and education/ employment for Adolescent and Young Adults (AYAs) with cancer.

**Aim:** To develop an online information resource to bridge the gaps between treatment and education/ employment for Adolescent and Young Adults (AYAs) with cancer.

**Team:** Joanna Fardell, Sarah Ellis, Ursula Sansom-Daly, Pandora Patterson, Jennifer Chard.

PoCoG 2021-03: Assessing the acceptability, feasibility and utility of a nurse-led survivorship program for patients with metastatic melanoma who are long-term responders to immunotherapy or targeted therapy: a pilot study.

**Aim:** To assess the acceptability, feasibility and utility of a nurse-led survivorship program for patients with metastatic melanoma who are long-term responders to immunotherapy or targeted therapy.

Team: Julia Lai Kwon.

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PoCoG 2022-07: Identification of factors impacting on widespread and sustainable implementation of professionally-led, theoretically-informed, stage-specific groups for women living with metastatic breast cancer (mBC) in Australia.

Aim: 1. Systematically review the literature on advanced cancer groups to establish what is known about the perceived benefits, and barriers and facilitators to establishing and maintaining stage-specific, peer or professionally-run advanced cancer groups.
2. Map the number, type, model of practice, location, membership, funding, history and future direction of existing (and defunct) mBC groups in Australia.

3. Understand what value and role women with mBC and the healthcare professionals involved in their care place on mBC support groups.

4. Co-design (with women with mBC and facilitators of advanced cancer groups), test and implement a resource to help hospitals, cancer centres, breast care nurses, counsellors etc. understand how to establish and maintain an advanced cancer support group.

**Team:** Andrea Smith, Sophie Lewis, Marika Franklin, Kerryn Ernst, Mary O'Brien, Pia Hirsch, Kirsty McRuvie, Frances Boyle.

PoCoG-2022-02: RT-ePrepare: development and feasibility of a novel web-based psycho education intervention for people requiring immobilisation masks during radiotherapy.

**Aim:** To trial (using a large-scale multistate step-wedge design) online education combined with virtual communication skills workshop for RTs and implementing distress screening prior to commencing radiotherapy.

**Team:** Georgia Halkett, Haryana Dhillon, Penelope Schofield, Moira O'Connor, Dion Forstner, Elizabeth Coyne.

PoCoG-2022-11: Improving consistency and equity of care for fear of cancer recurrence through an evidence-based, culturally sensitive and implementation-ready clinical pathway.

**Aim:** To develop and pilot the implementation of a culturally sensitive clinical pathway for fear of cancer recurrence (FCR).

**Team:** Ben Smith, Prof Afaf Girgis, A/Prof Jo Shaw, Prof Gail Garvey, A/Prof Natalie Taylor, Dr Jenny Liu, Dr Alison Pearce, Dr Laura Kirsten, Dr Heather Shepherd, Ms Annie Miller, Ms Iman Zakhary, Uncle John & Aunty Liz Dickson, Orlando Rinconces.

# PoCoG-2022-12: FearLess Phase III - A stepped care intervention for fear of cancer recurrence in people with Stage III or IV melanoma.

**Aim:** To evaluate the efficacy and cost-effectiveness of Fear- Less in reducing FCR in advanced melanoma patients who are experiencing elevated FCR, using a multi-centre RCT design with in-built economic evaluation.

**Team:** Iris Bartula, Robyn Saw, Maria Ftanou, Jemma Gilchrist, Skye Dong, John Chalmers, Lisa Gomes, Ben Smith, Mbathio Dieng, Serigne Lo, Mandy McGrath, Tran Mei, Grace Kouvelis.

# PoCoG-2022-13 Transforming colorectal cancer survivorship with digital delivery of multi-disciplinary care.

**Aim:** to demonstrate effectiveness of a telehealth-delivered MDT survivorship clinic (e-MDT); testing implementation, and measuring uptake, outcomes, access, acceptability, scalability, and costs.

**Team:** Janette Vardy, Haryana Dhillon, Adrian Bauman, Meera Agar, Natalie Taylor, Eng-Siew Koh, Richard De Abreu Lourenco, Kylie Vuong, Cindy Tan, Joanne Shaw.

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PoCoG-2021-05: Optimising equitable access to cancer research participation for Aboriginal and Torres Strait Islander people: Development of culturally-responsive resources to guide informed decision-making.

**Aim:** To codesign resources - an information package, question prompt list, and decision aid to be responsive to the needs of Australia's First Nations people considering participation in cancer research; and confirm resource acceptability/appropriateness.

**Team:** Bena Brown, Joanne Shaw, Gail Garvey, Bronwyn Morris, Joan Cunningham, Euan Walpole, Rowena Ivers, Michael Jefford, John Gilroy.

# The BRAiNS Program

The studies below are part of the BRAiNS program (Brain cancer Rehabilitation, Assessment and Intervention for survivorship NeedS) a PoCoG administered program of work.

**Aims:** BRAiNS aims to 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.

#### Studies:

PoCoG-2020-07 LaTCH: Group Cognitive Rehabilitation via Telehealth for Brain Cancer PoCoG-2020-08: RE-CLAIM Life intervention PoCoG-2020-09: Care for the Carer website evaluation PoCoG-2020-10: Caregiver experience of an educational intervention PoCoG-2020-11: Tele-mast RCT PoCoG-2020-701: Implementation of Screening and Referral Pathways in Brain Cancer PoCoG-2020-702: Development and piloting of the patient-focussed model of care PoCoG-2020-703: RESTORE self-guided CRF web resource - RCT PoCoG-2020-704: Identification of neuroscience-cognitive care coordinator training needs

PoCoG-2020-705: BRAiNs supportive care survey

**Team:** Chief investigators on the BRAiNS program are: Meera Agar, Thea Blackler, Raymond Chan, Richard Cohn, Haryana Dhillon, Claire Foster, Georgia Halkett, Helen Haydon, Brian Kelly, Eng-Siew Koh, Dianne Legge, Anna Nowak, Tamara Ownsworth, Kerryn Pike, Mark Pinkham, Nicole Rankin, Joel Rhee, Ursula Sansom-Daly, Fiona Schulte, Joanne Shaw, Jane Turner.

# **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 conference abstracts and posters for the 2021-2022 financial year.

#### Papers

Bartley N et al. Experiences and perspectives of cancer stakeholders regarding COVID-19 vaccination Asia Pacific Journal of Clinical Oncology early online https://doi.org/10.1111/ajco.13808.

Best M et al. Preferences for return of germline genome sequencing results for cancer patients and their genetic relatives in a research setting. European Journal of Human Genetics. 2022; 30: 930-937. 11 March. https://doi.org/10.1038/s41431-022-01069-y.

Best M et al. Return of comprehensive tumour genomic profiling results to advanced cancer patients: a qualitative study. Supportive Care in Cancer. 2022; 9 July 2022. https://doi.org/10.1007/s00520-022-07272-3.

Best M et al. Validation of the multidimensional impact of Cancer Risk Assessment Questionnaire to assess impact of waiting for genome sequencing results. Psycho-Oncology. 2022; 31(3). https://doi.org/10.1002/pon.5908.

Butow P et al. Staff perspectives on the adoption and feasibility of a clinical pathway for anxiety and depression in cancer care, and mid-implementation adaptations. Asia-Pacific Journal of Clinical oncology (vol. 17, pp. 146-146).

Butow P et al. Validation of the Knowledge of Genome Sequencing (KOGS) scale in cancer patients. Patient Education and Counseling. 2022. https://doi.org/10.1016/j.pec.2022.06.009.

Butow P et al. The impact of COVID-19 on cancer patients, their carers and Oncology health professionals: A qualitative study Patient Education and Counselling 2022 Jul; 105(7): 2397-2403.

# **Publications and academic output**

Butt Z et al. Barriers and Enablers to Implementing Telehealth Consultations in Psychooncology. Psychooncology 2022 Aug;31(8):1365-1373. doi: 10.1002/pon.5939. Epub 2022 Apr 27.

Cousens N et al. Evaluation of two population screening programmes for BRCA1/2 founder mutations in the Australian Jewish community: a protocol paper, June 2021BMJ Open.

Davies F et al. Uptake of an online psychological therapy program (iCanADAPT-Early) when implemented within a clinical pathway in cancer care centres. Psycho-Oncology, 31(2), 338-341.

Davies F et al. Promise unfulfilled: Implementing web-based psychological therapy in routine cancer care, a qualitative study of oncology health professionals' attitudes. Psycho-Oncology (2022).

Goria S et al. A Delphi-based approach to developing the contents of an online resource, Care Assist, for male caregivers of women with breast cancer. Psychooncology. 2022; 1-9. https://doi.org/10.1002/pon.5962.

Ladwa R et al. Telehealth cancer-related fatigue clinic model for cancer survivors: a pilot randomised controlled trial protocol (the T-CRF trial). BMJ open, 12(5), p.e059952.

Lim C et al. The long haul: Lived experiences of survivors following different treatments for advanced colorectal cancer: A qualitative study. European J of Oncology Nursing 2022; 58 (102123).

Maccora J et al. The sleep, cancer and rest (SleepCaRe) trial: Rationale and design of a randomized, controlled trial of cognitive behavioral and bright light therapy for insomnia and fatigue in women with breast cancer receiving chemotherapy, Contemporary Clinical Trials, 2022, 106877, ISSN 1551-7144, https://doi.org/10.1016/j.cct.2022.106877.

# **Publications and academic output**

Meiser B et al. Psychological predictors of cancer patients' and their relatives' attitudes towards the return of genomic sequencing results. European Journal of Medical Genetics. 2022; 65(4):104516. https://doi.org/10.1016/j.ejmg.2022.104516.

Meiser B et al. Psychological predictors of advanced cancer patients' preferences for return of results from comprehensive tumor genomic profiling. American Journal of Medical Genetics A. 2022; 188A: 725-734. https://doi.org/10.1002/ajmg.a.62563.

Ownsworth T et al. Scoping the psychological support practices of Australian health professionals working with people with primary brain tumor and their families. Psychooncology. 2022; 31( 8): 1313-1321. https://doi.org/10.1002/pon.5929.

Shaw J et al. Development, acceptability and uptake of an on-line communication skills education program targeting challenging conversations for oncology health professionals related to identifying and responding to anxiety and depression. BMC Health Services Research, 22(1), 1-11.

Tiller J et al. Population-based BRCA1/2 testing programmes are highly acceptable in the Jewish community: results of the JeneScreen Study, June 2022 Journal of Medical Genetics.

Umstead K et al. Further validation of the Perceptions of Uncertainties in Genome Sequencing (PUGS) scale among patient with cancer undergoing tumor sequencing. Clinical Genetics. 2022;102(2): 110-116. https://doi.org/10.1111/cge.14169.

Vatter S et al. Psychological outcomes in advanced cancer patients after receiving genomic tumor profiling results. Health Psychology. 2022 Jun; 41(6): 396-408. https://doi.org/10.1037/hea0001181.

Yuen J et al. Online BRCA1/2 screening in the Australian Jewish community: a qualitative study, July 2020 Journal of Community Genetics.

# Publications and academic output

#### Presentations

Brown B et al. Development of a Radiation Therapy Talking Book for Aboriginal and Torres Strait Islander people with cancer undergoing radiotherapy. Australian Society for Medical Imaging and Radiation Therapy Annual Scientific Meeting, Cairns, 19-22 May.

Butow P et al. How did the implementation of the ADAPT CP play out for staff, services and patients? 2022 COSA Symposium.

Dilanka L De Silva et al. Abstract P3-09-02: Mutational assessment of newly diagnosed breast cancer using Germline and tumor genomICs. Cancer Res 15 February 2022; 82 (4\_Supplement): P3-09-02. https://doi.org/10.1158/1538-7445.SABCS21-P3-09-02, abstract presented at San Antonio Breast Cancer Symposium.

Fairless H et al. Service mapping of radiation therapy to improve care for First Nations people with cancer. Australian Society for Medical Imaging and Radiation Therapy Annual Scientific Meeting, Cairns, 19-22 May.

#### Posters

Lai-Kwon J et al. Feasibility, acceptability and utility of a pilot nurse-led survivorship program for people with metastatic melanoma. European Oncology Nursing Society (EONS 15) Conference, Paris, France, September 2022.

Lai-Kwon J et al. Assessing the feasibility, acceptability and utility of a nurse-led survivorship program for people with metastatic melanoma (MELCARE)- protocol for 5a pilot study. Australasian Melanoma Conference, Virtual, November 2021.



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