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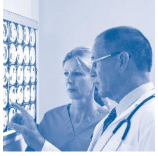

CANCER FORUM

FORUM: Cancer Survivorship

Guest editor: Haryana Dhillon

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CANCER SURVIVORSHIP – AN OVERVIEW

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The number of people living after a diagnosis of cancer has grown with increasing rates of diagnosis, improved treatments and better supportive care.[1] While more people are treated and live longer, many experience poorer general health outcomes, higher rates of comorbidities and complex late or long-lasting effects of their treatments. How the healthcare system, healthcare professionals and the broader community can work together to support those affected by cancer to achieve optimal health outcomes for the duration of their lives is a salient question.

There has been substantial development in the field of 'cancer survivorship', particularly since the Institutes of Medicine landmark report, *Lost in Transition,* was released in 2006.[2] This report documented the poorly coordinated follow-up care of people completing primary treatment for cancer, with the healthcare and community support systems failing to meet their needs. In the intervening decade, cancer survivors and their caregivers have heard about new models of survivorship care proposed, late effects of treatment being given prominence and research into interventions to reduce the burden on survivors being increased.[3] While we are still far from providing evidence-based care for all aspects of survivorship, things have improved for many. This edition of *Cancer Forum* presents a series of articles articulating the state of cancer survivorship in Australia and work to improve psychosocial and cancer outcomes for those living after a diagnosis of cancer.

Consumer and community voice

The first three articles in this Forum, befitting increased holistic care, are from cancer consumer advocates and a community-based organisation. There are differing experiences across the cancer survivor community, but a strong common drive to achieve optimal health.

Chapman shares his personal cancer experience and journey to wellness, articulating the principles of self-management and empowerment that helped him to thrive rather than just survive.[4] We can learn much from these experiences to guide our thinking in developing strategies to engage and empower cancer survivors to seek the support they need at different times during their follow-up care.

Marker challenges all of us to understand the disruption and dislocation a cancer diagnosis brings to many individuals, families and communities.[5] She highlights the gaps in knowledge and care for cancer survivors, with many struggling to access resources to better support them in adjusting to life after cancer. However, it is not all bad news. She also describes some important initiatives and areas for future development in supporting cancer survivors to live better.

Community-based organisations play an important role in supporting individuals and bringing community focus to cancer. Miller and Tang detail how the community and not-for-profit sector can be integrated into the cancer care team and community.[6] Those reading this article will be rewarded with a greater understanding of how this sector works and the plethora of services provided to patients, caregivers, and survivors.

Collectively, these three articles demonstrate the complexity of how cancer survivorship is defined. The US National Coalition for Cancer Survivorship recognises the broadest definition of cancer survivorship: *'An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life.'*[2] Family members, friends and caregivers are also impacted by the survivorship experience. While this broad definition is embraced by some organisations and individuals, from a policy and operational perspective the more common practice continues to define cancer survivorship from the completion of primary anti-cancer treatment. These differing definitions of cancer survivorship are apparent throughout the articles included in this issue. Marker,[5] and Miller and Tang,[6] referring to survivorship from the point of diagnosis, while Agar et al use a nuanced definition that includes people living long-term with incurable cancers,[7] and others,[8,9] again refer to the survivor as the patient in the post-treatment phase. No one definition is right or wrong, rather the differing usage reflects the complexity of defining the experience of being diagnosed and living with a cancer diagnosis. We must always to remember that people impacted by cancer live with the disease, they do not become it.

International and local developments

As discussed above, the field of cancer survivorship has evolved due to the combined efforts of survivors, health professionals and researchers. The strong drive to address the needs of cancer survivors advances these initiatives. Koczwara articulates the successes, challenges and strategies for improving survivorship care from an international perspective.[10] Her insightful comments regarding the impact of these international developments work in the Australian context.

Screening and support in survivorship care

Girgis et al address the issue of screening cancer survivors for psychosocial needs and late effects of treatment.[11] One of the challenges to implementing routine screening has been doing so efficiently, while ensuring the needs of survivors are appropriately managed where concerns are identified. Girgis and colleagues outline the framework used and their experience developing a patient-reported outcomes monitoring system within the NSW electronic medical record system. There is no doubt that their efforts will pave the way for greater integration and efficiency in the future.

While many people live for relatively long periods after their cancer diagnosis, we know a sizable proportion experience poor health and side-effects of cancer and its treatments. Agar et al remind us of the value of palliative care health professionals in achieving excellence in survivorship care.[7] Their role in this context is underexplored; this timely article challenges survivors and healthcare professionals to recalibrate their bias toward palliative care and consider its role in supportive care for cancer survivors.

Interventions to assist survivors

The high rates of unmet needs and poor general health outcomes among cancer survivors have seen a rapid growth in the development of interventions to address these concerns. This issue includes three articles detailing research that aims to address three quite distinct survivorship concerns.

Fear of cancer recurrence is one of the most distressing unmet needs reported by cancer survivors. For many, such fear is a lifelong worry that ebbs and flows around the time of follow-up appointments and anniversaries, however for some it is intrusive and debilitating. Butow et al provide a review of the research into fear of cancer recurrence and detail an ongoing Australian randomised control trial, Conquer Fear, of a psychological intervention designed to address this concern.[8]

People surviving after treatment for head and neck cancer commonly experience a high burden of treatment sequeale that seriously impede their ability to re-engage with their pre-cancer lives. Turner provides details of another ongoing Australian randomised control trial, ENHANCES, evaluating a tailored survivorship intervention in this population.[9] Actively addressing the complex needs of head and neck cancer survivors using an intervention with a strong theoretical base is likely to provide lessons for other complex cancer scenarios.

The third in this set of articles is from a group of exercise physiologists, a profession that is a relative newcomer to the cancer healthcare team. Cormie and colleagues provide a detailed review of the evidence for exercise and cancer survivorship, something about which we will all have to learn.[12] They also go on to describe the gaps in knowledge and translation of research findings into practice. There is no doubt that exercise has an important and increasing role to play in improving the outcomes of cancer survivors.

State of play

The growing international movement to improve follow-up care among cancer survivors is also evident in the Australian oncological community. In 2012, the Clinical Oncology Society of Australia (COSA) established a Cancer Survivorship Group to promote the concerns of survivors, their caregivers, and health professionals regarding the challenges of delivering high-quality care to cancer survivors, given their high level of morbidity and ongoing health concerns.[13] Commitment from Australian healthcare professionals to improving the experience of cancer survivorship is clear from the number and range of individuals participating in this initiative, as well as in the varied projects underway around the country.

In the past 12 months, three major conferences have been hosted in Australia with a deliberate focus on cancer survivorship. COSA and the Union for International Cancer Control ran overlapping survivorship-focused conferences in December 2014 in Melbourne.[13,14] These organisations brought together the diverse professionals working in the cancer survivorship field to celebrate what has been achieved, while inspiring the profession to greater achievements in the future.

The third conference was the Flinders Cancer Survivorship Conference,[15] held in Adelaide under the auspices of the Flinders Centre for Innovation in Cancer, in February 2015. This Australian conference is unique, seamlessly involving cancer survivors, community organisations, healthcare professionals and researchers in robust discussions of how survivorship care can be implemented, the ongoing research and reflections on the future.

COSA led a national discussion among its members regarding a model of survivorship care suitable for the Australian healthcare system. COSA's Model of Survivorship Care was launched at the conference and is now in a process of active stakeholder consultation.[15] The model incorporates the concepts of recovery and wellness as being core to optimal cancer survivorship. At this point, the model focuses on services provided to people after completion of their primary cancer treatment

– it by no means diminishes the impact of a cancer diagnosis on the family and friends of the individual, nor does it diminish the importance of addressing the physical, psychosocial and existential challenges confronting many people from the point of cancer diagnosis. Rather it is an acknowledgement of our limitations, that we cannot be all things to all people.

In order to achieve a national strategy for cancer survivorship that includes research, it is important to articulate a specific problem and how it can be addressed. The Victorian Department of Health Services Cancer Survivorship demonstration projects are an excellent example of policy that supports implementation of novel models of care.[16] Cancer survivors, healthcare professionals and the system need more targeted support to undertake this work using an evidence-based approach.

We hope that this Forum provides readers with an insight into the diverse and active world of cancer survivorship in Australia. We have a wealth of active consumer advocates, dedicated health professional, and some of the leading researchers in this field among us. While much needs to be done to support cancer survivors, we have the drive and skill to achieve this.

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A PERSONAL EXPERIENCE: CANCER AND SURVIVORSHIP SELF-MANAGEMENT

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While surviving cancer is the best possible outcome from a cancer diagnosis, survival often comes with some issues associated with recovering and staying well, in both a physical and a psychological sense. As the science of cancer treatment continues to improve, more of us who are diagnosed will survive the disease and survivorship care will grow as a part of the spectrum of cancer care.

While there are many ‘survivorship programs’ forming, we cancer survivors are not necessarily a ‘one size fits all’ group of people. Taking matters into our own hands may be our best option to get what we truly need from both these programs and the medical community at large. This article briefly discusses my cancer journey and how I participated in my own care.

As I sit writing this article on cancer survivorship, it is Bastille Day 2014 and the 10th anniversary of my cancer diagnosis day. Ten years ago today everything changed forever.

Background

My diagnosis was given to me by a doctor in accident and emergency at a large public hospital, after a routine blood test which my GP escalated to an emergency admission and some late night x-rays. Accident and emergency doctors understandably deal with a lot of trauma, so I might have expected the delivery of the cancer diagnosis to be blunt, and it was. I discharged myself about 30 minutes after this diagnosis. The next day I returned for CT scans and oncologist visits as I started my journey through the confusion of a large hospital with a potentially fatal disease. At about this time I made the first of many decisions – I changed oncologists.

The next two weeks were an intense time of knowledge seeking – PET scans, CT scans, biopsies, heart efficiency testing, bone marrow sampling, blood tests and so many appointments where I always took detailed notes and asked many questions, even if we went over time. Privately, I sought organic food and dietary supplements (always with my oncologist's permission, as I was cautious about contra-indications) as again I tried to do whatever I reasonably could to contribute to my own well-being.

Chemotherapy was a very nervous time (after all, we’ve all heard the horror stories), but I worried unnecessarily upon reflection. Of course I was ill, my hair fell out and my blood count went low, but it was as expected and the anti-nausea drugs were very effective.

After three courses of chemotherapy came the stem cell apheresis. I was fortunate to have healthy bone marrow which made self-donation an option. I had an excellent harvest that saw my stem cell quota collected in one sitting. These stem cells remain cryogenically stored to this day, should the disease ever return and I need a myeloablative ‘re-boot’.

Radiotherapy was next, preceded by the ‘fitment’ process, which gave me my first ever tattoos. I wish I had chosen a red ink (not black) from a cosmetic perspective. That machine did its buzzing thing above my body each day, where the short-term side-effects were so minimal that I queried if the machine was working. However, the late effects still remind me every day that it was. I arranged with the radiotherapists to count me in so that I could exhale continuously during the irradiation and avoid the dreadful ozone taste.

But just as my chemotherapy had ended, so did my radiotherapy and I was back into chemotherapy round two soon enough.

Remission

I recall the meeting where I was told I was in remission and the relief those words brought. Others still tell me I should be happy, but there was no happiness. There was only relief.

So what now? I was officially a cancer survivor, but totally ignorant as to what to do, what was to come and where to seek help. I took my health and well being into my own hands. I met with a physiotherapist to make an appropriate cardiovascular exercise program. I met with my local Cancer Council CEO who was generous with me and gently directed me to a consumer advocacy group. It always struck me as odd that I would be characterised as a ‘cancer consumer’ when I had always thought of consumption being a discretionary activity. No one understands me as well as other cancer ‘consumers’, so I found great comraderie and understanding in the company of other survivors. I watched Lance Armstrong while he spoke of ‘the obligation of the cure’ and cancer advocacy was how many of us sought to fulfil that obligation.

The first few years of my survivorship were about the physical rehabilitation and positive action around the 'obligation of the cure'. But the psychological issues of a near death experience begin to find a place in my thoughts as the physical issues abate. I have compared my state of mind with that of the post-traumatic stress disorder affect. It is similar, but not quite the same. Suffice to say, facing one's own 'use by date' is confronting and there is not always appropriate help available in the community.

To find a psychologist who understands cancer survivorship was a challenge. Many mental health professionals will listen and comment with a "yes, I can imagine how that feels", but only other cancer patients can genuinely say "yes, I know how that feels". Fortunately, I found a psychologist in the paediatric space who was able to advance my self-understanding.

But my core issues remain to this day, principal among them the lack of meaning and value from traditional work. While I was once the ambitious career-focused employee, I now realise that provided you have enough for yourself and your loved ones, the rest is mostly unnecessary. Holding down employment has proven to be difficult from within a body that readily fatigues and is not always trustworthy, and a mind that frames every issue at work against your life and death journey - that ominous presence in your recent past. This issue is still unresolved after 10 years and I'm not sure how, or even if, it will resolve.

I try to frame these issues more as challenges to overcome, and while surviving cancer remains my preferred alternative, the issues faced are still pervasive. As I have heard from many cancer survivors, a cancer diagnosis "is not always a death sentence, but is always a life sentence". Those words are salient and should help all of us understand that we cancer survivors carry the fear (and wisdom) of facing death with us every single day for the rest of our lives. Our templates for life can be significantly changed and these changes can take time to understand and assimilate.

Cancer survivorship programs

It is my hope that one day, every major oncology centre will have a cancer survivor on staff as a cancer 'coach' to support 'cancer consumers' and to help navigate the many and diverse issues that come from this journey as and when they arise.

I found it beneficial to be my own advocate and my own case manager as I navigated both the treatment and the survivorship space. By self-managing where possible, and then seeking good quality professional help when your need exceeds your own capabilities, it is possible to rebuild your new normal in a positive and useful way.

As I wrote earlier, one size doesn't necessarily fit all, but I think it is possible to find your own fit of what you need with what is available. But if you disagree, then please join in to contribute to the 'obligation of the cure'.

RECOVERING FROM AND SURVIVING CANCER: A CONSUMER PERSPECTIVE

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Abstract

This article describes the evolving experience of recovering and surviving cancer from the survivors' perspective. What matters, what helps, what else is needed? Contrasting pictures of emotionally fragile, frightened, isolated and physically-damaged survivors is overlaid by happy, fit and healthy survivors achieving wellbeing irrespective of their cancer prognosis or health challenges. Many 'positives' are reported by survivors, wrought from the cancer experience, with contributing factors including social support, information, complementary therapy use, lifestyle changes and physical activity. Routine monitoring of the physical, emotional and practical issues experienced by survivors may enable better understanding of the essential elements contributing to recovery after cancer. Cancer survivors and their families are an under-utilised source of information, inspiration, knowledge and ideas about survivorship challenges and solutions. What are the opportunities and gaps in our care systems to better support survivors?

Achieving wellness (and being cancer free) is what most people want from the moment they are diagnosed with cancer. A cancer diagnosis rocks a person's physical, psychological, social, economic and spiritual foundations. There are few conditions where the treatment can be so damaging, requiring a period of recovery and ongoing vigilance for both disease and treatment effects. Despite growing numbers of cancer survivors, measures of the impact and duration of cancer or treatment effects on quality of life are poor.[1] Most survivors would agree that "cancer may leave your body, but it never leaves your life,"[2] or in clinical terms "being disease-free does not mean being free of your disease."[3]

What is 'survivorship'?

'Survivorship', 'remission', 'five year survival' – the meanings vary and are unclear to many. 'Survivorship' in practice generally refers to the period after primary treatment ends. This one directional depiction of cancer fails to capture the sometimes circuitous trajectory of many living with cancer, its ongoing treatment, recurrence or progression.[3] Many ask: "Can I call myself a survivor if my prognosis is not good?" "Am I a survivor only after five years?" "Did the 'five year survival' clock reset when I relapsed?" "What do I call myself, if I'm not a survivor?" Considering a 'survivor' as anyone diagnosed with cancer, from the time of diagnosis to the end of life, would overcome these concerns.

Each person's cancer experience is different, but the end of intensive cancer treatment is frequently reported as difficult. However, individuals are often unaware and unprepared for this and left feeling uncertain as to how to recover and reintegrate back into the community. People, their communities and workplaces need to be better prepared for this transition.

Use of individual cancer treatment summaries and survivorship care plans (mapping follow-up schedules and possible side-effects) is sporadic. Survivorship care plans can give guidance on what requires monitoring, when to come back early, things an individual can do for themselves and the follow-up to meet their needs. These should be used routinely.

Survivorship challenges are not routinely recorded or reported. A picture of what these are, how they change over time and what else impacts them is being developed. However, consideration of what supports recovery and what is learnt from people who have made good recoveries is needed. Are survivorship concerns avoided by healthcare professionals because they lack interventions and information to address these concerns?

An international survey of 'survivorship concerns' received 3129 responses, with 98% of reporting at least one post-treatment concern.[2] These included problems with fatigue, concentration, fear of recurrence, grief and identity issues, sexual dysfunction, and pain and/or neuropathy that caused day-to-day functional impairment.[2]

How do cancer survivors recover?

Achieving acceptance is not linear; processing anger, fear and grief can be iterative. 'Survivors' may emerge exhausted with cumulative toxicity and stepping into an environment where people expect them to be ‘fixed’ and back to normal. They can be left feeling isolated and vulnerable. As physical recovery progresses, the emotional impact takes many by surprise. Why some people sail through treatment then don’t cope post-treatment is unknown.

Our expectation of how survivors should feel, think and act underpins the experience. Getting life back to normal with its predictability and control can be comforting. Milestones can be highly anticipated and celebrated. Five year survival is a disease outcome measure significant across all cancers.

‘Learned helplessness’ can develop during treatment and has to be overcome. So many survivors have had this experience, yet outside of the hospital each muddles through, discovering resources by word-of-mouth or the internet, often by chance. Survivors don’t expect oncologists to have all the answers, but increasing knowledge may reasonably be expected after so many years. Survivorship apps are one way to provide tailored information and structured programs. Whether these improve outcomes is not known. While potentially helpful supporting self-care, we need to ensure they are available to disadvantaged groups.

What are survivor priorities?

Cancer may be relegated as professional and home roles as well as relationships and finances are reassembled, while making sense of the experience. Life and lifestyle are often reassessed and priorities changed. It is a time of healing and learning to either ‘sit with’ or seek out solutions to physical and emotional concerns. Many grieve the loss of function, fertility, or a predictable future. Adolescents and young adult survivors can feel out of step with their peers. There is uncertainty about which healthcare professional looks after which concerns. For example, should problems be discussed with the GP or saved until oncology check-ups? Are there other practitioners who can be trusted to know enough about cancer?

‘Scanxiety’, a heightened fear of cancer recurrence at the time of follow-up, is well recognised and particularly difficult for those who have had cancer recurrence or progression. It can be unsettling for survivors who felt unwell yet had a clear result, or felt well when the scans show recurrence. Instincts can’t be trusted. Some survivors find their way into counselling, but not all know, would accept, or can afford this. Anxiety is exacerbated by long waits for follow-up appointments to receive results. Immediate access to test results should always be possible. Cancer survivors learn a lot about interpreting, keeping track and using our own data for self-care, given the opportunity and desire. One hopes that e-health records will enable this soon.

With time ongoing problems can be compounded – “cancer takes its toll, and is cumulative”.[4] Coupled with 'survivor's guilt' can be a lack of trained support or access to multi-disciplinary medical teams for the complex health issues that arise. While survivors can feel lucky to be alive, many would not say they are thriving. They may have survived cancer and have a good ‘living’ prognosis, but their life has changed dramatically.

The road to wellness

Despite this gloomy outlook, there are examples of happy, fit and healthy survivors who have achieved a good level of wellbeing. Many positives are reported by survivors, with modifiable contributing factors being social support, access to information, complementary therapy use, lifestyle changes and physical activity.[5]

By addressing strategies for wellness and coping skills as a shared responsibility, with ‘prescription’ during treatment, some post treatment concerns may be averted. This is highlighted in the blog ‘Survivorship is not a passive sport’.[6] Discussion of lifestyle changes including physical activity, diet, alcohol, smoking and stress need to be initiated early after diagnosis. Despite the known benefits of physical activity for cancer survivors, translating this knowledge into practice is difficult. Survivor-led exercise initiatives can provide insights into this challenge.[7] The health system is not organised to address these components of wellness. Health professionals need training to do this and referral pathways to be established. Many survivors do not expect to be involved in their healthcare in this way, even in the best chronic disease management systems.

We know the prevalence of chronic conditions is significantly higher among people with a history of cancer. This supports the importance of chronic disease management as routine care after a cancer diagnosis.[8] Involving GPs and other practitioners during treatment and beyond is a challenge. Patients are often the communication conduit between clinicians, but are not involved in discussions. More research into survivorship health concerns is needed to identify effective intervention and management strategies.

Survivorship issues needing further research include: fatigue; bowel problems; neuropathy; sleep disturbance; anxiety; physical deconditioning; health impact of work; financial concerns; self-esteem; impact on relationships; impacts on body image and sexuality; and impacts on carers and families.

Returning to work and giving back

Employment is associated with higher levels of health and wellbeing. There is evidence that long-term work absence, work disability and unemployment impact negatively on mental health, physical health, sense of worth and financial position.[9] Recently, returning to work has been recognised as an important issue for recovery and wellbeing, supported by fostering partnerships outside of the traditional health sector pathways. Resources are in development.[10,11]

Survivors, whether in good health or not, often want to 'give back' and help others engage in personally meaningful activities. This can aid personal recovery while supporting others. Examples include: peer support groups; teaching; research; health system planning and improvement; information provision; hope and encouragement; motivation for personal growth and lobbying; as well as collaboration in design and development of research, policy, position statements, information sharing and fundraising.

Creativity and connection

Creative expression of 'what matters to a cancer survivor' is growing. It is led by survivors via social media and digital platforms, which involve 24 hour access to social interaction from the convenience and privacy of personal spaces. "Many cancer survivors are turning online to find a sense of connection and self-construct … (which is) therapeutic for the writer (and) reader... For clinicians, care providers and researchers, these narratives provide rich insights into the lived experience of cancer and offer the possibility of improving the patient experience in more meaningful ways."[13]

In a 'Patients as teachers' initiative, survivor narratives reflect on 'what helped or not' during their cancer journey. Survivors valued good clinician communication, authenticity and honesty; rating humour as part of healing, they want an understanding of the multitude of complex challenges. Participants aimed to promote a culture of mutual respect between health professionals and patients.[14]

Survivors play an important consumer advisory role in the Australian Cancer Cooperative Clinical Trial Groups. Working closely with clinicians and researchers, our experience can inform development of research concepts, protocols, participant information documents and other trial materials. Community engagement and public information initiatives are supported through our collaborative efforts, e.g. Engage, a survivor led initiative of the Australasian Gastro Intestinal Trial Group.[15]

Despite the number of cancer survivors, few are willing to step into consumer advocacy roles. Consumer involvement can be a positive for individuals and to society more broadly. Barriers to survivor engagement include networking with organisations or individuals who create opportunities for involvement and practical support for participation including financial reimbursement, training, mentoring skills and confidence.

What are the barriers to optimal survivorship?

Stigma around a cancer diagnosis can be a powerful barrier in some communities such as indigenous and sexual minorities, and in respect of some tumour types, exemplified by lung cancer. Some high profile cancers are funded and supported better than their less visible counterparts. Geographical location can limit access to support, with those living in rural and remote areas experiencing poorer outcomes. People from low socioeconomic groups commonly experience barriers to accessing care and support. Increasingly, people without internet access or computing skills find it difficult to access information. Advocates from these groups have heavy demands on their time and energy.

Carers, oft neglected, must be mentioned as their need for access to care is often high. The patient-carer relationship is complex, as each seeks to shield the other from this trauma, at times to the emotional detriment of both. Challenges around emotional disclosure, intimacy and psychological distress in the cancer context can be difficult to acknowledge as needs, and expertise in counseling can be difficult to find.

In conclusion, cancer survivors and their families are an under-recognised source of information, inspiration, knowledge and ideas about survivorship, its challenges and solutions. Survivors have a vision of survivorship care:

- Focus on wellness from diagnosis, in partnership, shared responsibility and open communication with our care team.
- Routine active assessment and reporting of the broad physical, practical and psychosocial needs of cancer survivors, to drive practice improvement and research.
- Build self-care capacity, ensuring survivors know what to expect and where to access care, follow-up, and information when required.
- Help to eliminate stigma, inequality and access to care.

Partnerships between clinicians across all healthcare settings, community supports, researchers and people affected by cancer can achieve effective planning of care and research affecting survivors.[16]

Ten things I've learned from cancer:[4]

- Friends matter.
- Optimists have a better quality of life … anger, frustration, sadness, fear and anxiety … those emotions don't subtract from the problem, they add to them.
- I've never been big on prayer … but… it all helps.
- People who practice oncology … are a cut above.
- Cancer takes its toll, and it's cumulative.
- Patients are just the tip of the iceberg. Family, friends, co-workers, caregivers … face not only the impact of the disease and its disruption of daily life, but also the burden of emotional support.
- We can do hard things.
- Everyone's cancer is different.
- People's capacity for kindness and compassion.
- Bucket lists are over-rated. …it's about experiencing what you have, where you are and who you are with…. Life's journey is not a to do list.

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HOW THE NOT-FOR-PROFIT SECTOR CAN ENGAGE AND SUPPORT THE CANCER SURVIVOR COMMUNITY

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Abstract

The increasing amount of research demonstrating the needs of people finishing their cancer treatment brings an increasing amount of discussion within the health sector as how to address these needs in an effective way, regardless of geographic location. The puzzle of how much, when, where and how is a conversation that echoes across Australia, a country which holds a maze of differing health systems across the states and territories. Specialist care is vital for the cancer patient, however what happens afterwards can be a puzzle for many people finishing their treatment. Opening the dialogue between health professionals, consumer groups, cancer charities, government bodies and people affected by cancer has the potential to have a strategic impact for reach and effectiveness with post treatment care. In order to assist the growing number of cancer survivors in this country no matter where they live, we need to have a collaborative approach to post treatment care recognising that 'one size doesn't fit all'.

With the number of people successfully treated for cancer reaching over 65% in most developed countries, there is increasing pressure on the over-burdened health sector to provide quality follow-up service and support.[1] A cancer diagnosis can be a life-changing event and while the number of people successfully being treated is rising, for many, the post-treatment effects can at times be more challenging. These include dealing with the physical effects such as fatigue, changes in cognitive function and pain, as well as the psychosocial sequelae of uncertainty, mood disruptions, anxiety and depression.[2] Returning to the life experienced prior to a cancer diagnosis can be challenging for cancer survivors with financial and/or legal concerns.[2,3] Leaving the acute treatment setting can generate anxious feelings of 'being left' and 'what now'?

> *"I watched one week as a woman attended her last session of chemotherapy and she was surrounded with balloons and loud whistles from her family and she walked out the door to the party. I knew I was finishing my treatment the following week and could not imagine doing anything like that. I felt so alone and I didn't want to celebrate. Who was going to look after me? I didn't even know what had happened."* - female cancer survivor, aged 39

It can take time to adjust to a 'new normal'. The time following treatment is often when processing what has happened begins. Up until then, the whirlwind of treatment takes precedence and cancer survivors are in the 'system', proceeding from day to day, focused on their next appointment, treatment or test.

> *"I am a survivor I feel like I have been through the trenches and some days don't feel like I have made it out the other side very well. No one seems to understand unless you have been through it."* - female cancer survivor, aged 62

The term 'cancer survivor' has varied definitions across the world, however for this review it is used as a term to describe someone who has completed their active phase of treatment and does not have signs of active cancer. Many people do not like the term 'survivor', and there are ongoing discussions in the cancer survivor community to find a more acceptable description. It evokes emotion in some and is an individual's choice as to how they refer to themselves - as a survivor from day one of diagnosis, or post treatment, or never at all.

The period after treatment for survivors (and at times their carers) can be a time for reflection and reassessment of what is important in their life. This often brings a strong sense of 'giving back' to the community or their treatment team.

We can talk about people who have successfully finished their cancer treatment and there is a great deal of literature about the challenges involved. What now? How do we reach as many people as possible to assist them into the future? Survivorship care plans, treatment centres, nurse-led care, follow-up clinics and more, are all positive developments in health care. However, often clinicians and health professionals are perceived as not having enough time to effectively communicate with cancer patients and others on the treating team.[4] With more people successfully treated, where does all this leave a cancer survivor?

Role of not-for-profit organisations in cancer survivorship

It is not just the formal healthcare system that can offer support and services to cancer survivors. The not-for-profit sector, in particular cancer charities, have essential infrastructure, extensive networks, and a focus on being a pivotal point for accessible and sustainable multi-disciplinary support and information. They also have a growing experience with development of a collaborative approach with treatment and survivorship centres and allied health professionals. These processes are core business of cancer charities.

Cancer Councils across Australia have a range of community-based services to support cancer survivors. They can also be an essential partner to health professionals, offering a range of services that complement clinical care, across all cancers and for the whole cancer journey. The evidence-based information that is delivered by qualified health professionals can be accessed by calling 13 11 20. This information and assistance service also provides access to practical assistance like financial, legal, return to work and other support, as well as emotional support such as peer support and counselling. The service is a primary access point for health professionals and consumers.

Cancer Council Australia's website (www.cancer.org.au) is an extensive and trusted portal, detailing services across the nation that are accessible to people across metropolitan, regional and rural locations. Cancer Council publishes a suite of Understanding Cancer booklets, fact sheets, CDs and DVDs. With advances in technology, we are seeing much more support being available online, which improves access for cancer survivors.

Joining forces

Clinicians and other health professionals working in cancer services know very well the resource constraints and problems in the system that can make life more difficult for cancer patients, or stand in the way of optimal care and treatment. Too often, there is a gap between what evidence indicates should happen and what the system is able to provide. Clinicians are at the frontline of the impact system shortcomings have on patients. Clinicians and health professionals can be very powerful advocates for individual patients and even take up the challenge of making improvements within their own setting. However, sometimes systemic change is necessary to ensure long-lasting benefits to all who need it, across all service settings at a state or national level. Working alongside one another is a powerful and collaborative way to ensure change is effective and sustainable.

Not-for-profit organisations can be instrumental in advocating for improvements in the treatment and care of people with cancer, and for public health initiatives to reduce the incidence of cancer in the community and to improve cancer survival. One effective advocacy approach is for not-for-profits to engage those affected by cancer and encourage them to raise issues with decision-makers. The expertise of clinicians should also be drawn upon to understand the problem and to develop appropriate recommendations for improvement. Cancer survivors have powerful stories of personal experiences, which means they are highly motivated and can be very influential advocates.

Over the past decade for example, Cancer Council NSW has worked systematically and deliberately to help cancer survivors find their voice and use their stories to create change. Through the CanAct community and grassroots campaigns, survivors have used their experiences and voice to win policy changes in access to radiotherapy, improvements to patient-assisted transport and subsidy rates, smoke-free legislation, the banning of tobacco displays in shops and increased funding for bowel cancer screening.

A number of survivors have expressed that this has been an important part of their post-treatment experience, helping them to create value from an experience that many would otherwise perceive to have been a burden, or to honour the memory of loved ones lost to cancer.

> *"At last, long after my own cancer experience had been resolved, I'd found in cancer advocacy a real and meaningful way I could 'fight' cancer. Advocacy helped me recognise that having cancer was far from a weakness, a liability or a waste of time as I had thought before. In fact, having cancer was a valuable set of skills and experiences, which when married with strengths and abilities I already had and others the Cancer Council helped me develop, qualified me to do important and effective work".*[5]

We know that politicians are influenced by the personal stories of constituents. Such stories help them understand how a systemic issue affects their local community and turns an abstract policy issue into a very tangible community need or constituent expectation.*

**McNair Ingenuity Survey of NSW Politicians for CCNSW. Unpublished 2006*

Not-for-profit organisations have an opportunity and a responsibility to amplify the voices of their supporters to achieve change to benefit the cancer cause. The prospect of change provides an avenue for supporters to be involved in ways other than fundraising, and uses the unique asset that each supporter brings to the cause – their own story. Involving survivors in this way is also consistent with the principles of consumer involvement.

Engaging survivors in the advocacy work of a not-for-profit also helps ensure that the organisation is well-grounded in the issues that matter to supporters, and provides reach into communities and political decision-makers that is not possible through paid advocacy positions alone.

This experience at Cancer Council NSW shows that with the right support, survivors can develop the skills and confidence needed to become strong voices for change. Feedback from politicians confirms that this is an effective way of influencing the way they think about these issues and the likelihood that they will take action.

Clinicians can help in these endeavors by providing insight into the problems within the system, by encouraging people affected by cancer to join advocacy efforts of non-profits, and by collaborating with not-for-profit organisations on campaigns of relevance.

Utilising lived experiences

As evidence-based organisations, Cancer Councils are the leading independent funders of cancer research in Australia. In 2014, research grants through Cancer Councils nationally totalled more than $65 million. $42.9 million was directly funded research with a further $22.2 million contributed by research funding partners.

Research underpins the prevention, information, support and advocacy programs of the organisation and assists with prioritising the areas where it can have the greatest impact, enhancing outcomes across the entire cancer journey. Cancer survivors and carers have the opportunity to be at the heart of research with their insight into the problems faced by those experiencing cancer. Under the Consumer Involvement in Research Program at Cancer Council NSW and acting as representatives of the community that supports the organisation, specially trained cancer survivors, carers and patients analyse all funding applications and identify those that are of greatest value to them as part of the two-stage review process. This consumer review is undertaken after applications have been through a peer-review process. Listening to the experiences of cancer patients is vital to improving the quality of the cancer patient experience and their subsequent survivorship experience.[4]

Cancer survivors and their carers bring high level skills to many roles within not-for-profit organisations across Australia. The power of their lived experience is unique and they can play a role in assisting people to feel less isolated and increase feelings of well-being while they are ‘giving back’.

> *“Immediately afterwards, of course my wife and I had a lot of re-adjustment to do … we developed our communication skills and as a result grew very much closer together. I’ve been involved with Cancer Connect and also with the Ambassador program, and have made huge new friends all over the place ... I’m communicating and passing on information which would hopefully help other guys to make a decision about getting themselves checked out; (helping) gives me a real positive feeling”.*[6] - male cancer survivor in Connect and Ambassador program.

Opportunities

While follow-up care with the acute treatment team is vitally important, there are opportunities for cancer treatment centres to work closely with organisations such as Cancer Council. This can be done by informing patients finishing treatment of the supportive care, advocacy and research opportunities that are available within their community. Collaboration has an enormous benefit on an overburdened health sector and the community-based organisations are there to assist when the acute phase of treatment has been completed. A simple referral to the information and support service is the gateway to many services that cancer survivors can access over an unlimited time: information, psychosocial and peer-led support; exercise and nutrition programs; counselling and support groups; legal, financial and returning to work support; advocacy and research; and much more. Why wouldn’t these be used more?

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CANCER SURVIVORSHIP – LESSONS FROM AROUND THE GLOBE

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Abstract

The discipline of cancer survivorship has evolved as a result of the concerted effort of survivors, supported by clinicians and researchers aiming to address the unmet needs of survivors resulting from cancer and its treatment. Nearly 30 years later, there is much to celebrate, but still much to be done. Delivering quality cancer care to survivors is not just about delivering good cancer care, but rather improving overall health care for the growing numbers of people affected by cancer. Ensuring that care is evidence-based, cost-effective and adaptable to different health settings remains a constant challenge in the continuingly changing health care environment. International collaborations have potential for strategic advancement of the field through data sharing, priority setting and large scale research initiatives to make a lasting impact at the population level.

It is hard to believe that the field of cancer survivorship is nearly 30 years old. Its birth can be dated to the seminal publication by Fitzhugh Mullan, The Seasons of Survival, published in the *New England Journal of Medicine* in 1985.[1] Mullan, a physician and a cancer survivor, reflected on his and others' experience of cancer survival and the resulting unmet needs of survivors, and called for a "coordinated national research enterprise in the area of cancer survival". It was then that the term 'survivorship' was used for the first time, referring to the experience of survival commencing from the time of the diagnosis and having distinct biomedical and psychosocial dimensions. The article was a call to action articulating next steps needed to be taken by the cancer profession and survivors themselves. Only a year later, it was followed by Mullan convening a small group of 25 individuals in Albuquerque, New Mexico. This meeting led to the creation of the National Coalition for Cancer Survivorship, which has been instrumental in the development and progress of survivorship ever since. These events were indeed revolutionary and visionary – at the time cancer advocacy was still in its infancy, and it had only been 30 years since the first use of chemotherapy and just over 10 years since the declaration of the 'war on cancer' by President Nixon in 1971.

This paper examines key developments in cancer survivorship care and research across the globe from the perspective of how they may impact on and inform care and research in Australia, with particular emphasis on challenges that are best addressed by international efforts and the opportunities for international collaborations. It is outside the scope of this paper to offer a systematic review of all advances in the field, but rather it will focus on those that are most pertinent to the Australian setting and to the question of how survivorship care and research in Australia relates to the global effort on cancer control.

Beginnings – consumer voice in action

Cancer survivorship is the only field of oncology which originated to a significant extent as a result of concerted effort of survivors themselves and their plea to the cancer profession to acknowledge, recognise and address significant challenges experienced as a result of cancer and its treatment. As cancer treatment outcomes continue to improve and survival rates rise, this plea is only gaining in significance. In the US, the establishment of the National Coalition for Cancer Survivorship has led to the creation of the Office of Cancer Survivorship at the National Cancer Institute in 1996, which has since provided a strategic approach to the care and research relating to cancer survivorship. To this day, one of the key drivers in the area of survivorship is through the Livestrong Foundation, which has been instrumental in collecting data on unmet needs of survivors, developing minimum standards and advocating for their adoption. The foundation has supported innovative approaches to care delivery and research through research funding and support of the Livestrong Survivorship Centres of Excellence.[2] While originating in the US, the reach of Livestrong Foundation extends beyond the US, with support of the Global Cancer Summit in Dublin, Ireland in 2009, and establishment of connections with similar organisations around the globe. Likewise in other countries, for example the UK, the major support for survivorship initiatives originates from

MacMillan Cancer Support – one of the largest charities in UK dating back to 1911. Unlike other aspects of cancer care, cancer survivorship has not been primarily driven by oncologists focused on the biomedical model of care and research, but rather cancer clinicians and researchers representing diverse disciplines including psychology, sociology and health services research.

The origins of the field of survivorship may explain some of the challenges that the discipline is facing today. It is possible that its origins from outside of the traditional domain of oncology, have led to its relatively slow integration into mainstream oncology. For some cancer clinicians, survivorship as a field can be an uncomfortable reminder that their well-intended efforts to eradicate cancer may have undesirable consequences. For many, addressing undesirable consequences of cancer and its treatment requires skills in general medicine, psychology and care coordination, which are not necessarily embraced equally by all oncologists. As such, survivorship not only came to oncology from outside, it forces oncology to reach out in order to reconnect with the outside world – the world of community and primary care and general medicine – in order to gain the expertise required to address the problems that survivors grapple with.

Price of success – managing growing demand

While the beginnings of the survivorship movement and its impetus from consumers have largely focused on the recognition of unmet needs of survivors, the practicalities of delivering survivorship care on a large scale have identified additional drivers for change relating to the capacity of the system to manage growing numbers of survivors. At present there are approximately 14 million survivors in the US, two million in the UK and about 32.5 million globally, with the majority representing breast, prostate and bowel cancer survivors. As the numbers increase exponentially, in the setting of a limited cancer workforce, the question that is being asked is will the cancer health care system have the capacity to deliver care to survivors within the acute cancer service?[3]

This concern was not a major issue at the initial stages of development of survivorship care, where the discipline was the domain of selected expert centres and maybe less so in the US, where a national approach to health care delivery is more limited than in other countries. In the UK, the issue of meeting demand within the limited capacity has been recognised from the outset as part of the national strategy for cancer. This recognition led to the development of risk stratification approaches and a focus on enhancing self-management strategies for those survivors considered low risk.[4,5] The recognition of growing demand has led to exploration of how survivorship care can engage with primary care providers for delivery of care for cancer survivors, an approach that is yet to be wholeheartedly embraced by cancer survivors themselves.[6]

Models of care delivery – one size does not fit all

The delivery of survivorship care in the context of cancer and overall health care of an individual is operationalised differently across clinical settings, depending on the predominant models of care and reimbursement, and the drivers that influence them. In the US, where the fee for service predominates and the cancer care models include comprehensive cancer centres, the Survivorship Centres of Excellence and the large academic centres are the mainstay of innovation in the area of survivorship care. The delivery of so-called essential elements of cancer care is very much dependent on creation of a reimbursement structure that supports care delivery.[7] Having said that, the recent introduction of the Affordable Healthcare Act and the movement to capitation payment is likely to lead to a change to this model. In the UK and Canada, with their universal public health care system and high level of reliance on primary care, there is greater scope to deliver care as part of general practice, although the details on how that can be done are yet to be defined. Within these different health systems, a range of models of care are emerging, including nurse-based follow-up clinics, one-off consultation by specialist physicians and shared care with primary care and others.[8,9] To date, little data exist on which of these is more appropriate. What is likely, is that different models may best fit different contexts. A common theme emerging from all models is the inclusion of a treatment summary and a survivorship care plan. Although the content of the survivorship care plan can vary dramatically. Interestingly, the American Society of Clinical Oncology has moved from a very detailed template to a simplified two-page template, while the UK has managed a one page patient-driven care plan. More importantly, there is little data on their utility or cost effectiveness.

The challenge – the diversity of survivorship experience

While there is a wealth of information regarding survivorship care in the US, the UK, Canada and few other developed countries, notably the Netherlands and Scandinavia, in many parts of the world cancer survivorship is not identified as a distinct entity or priority. There are many reasons for this, including less developed advocacy networks of consumers, and greater priorities for immediate cancer care delivery. For example, in parts of Europe where the profession of medical oncology remains unrecognised and where access to cancer drugs is the key priority, cancer survivorship may take second stage. There are only limited data on approaches to care of cancer survivors in low and middle income countries. Again, this may reflect conflicting priorities, limited resources, or other considerations.

It is not only low and middle income countries where the progress in survivorship is lagging behind. There is scarcity of data on the needs of cancer survivors in disadvantaged communities within developed countries with otherwise excellent survivorship credentials. In a recent provocative paper, the survivorship experience has been described as if seen through the lens of 'breast cancerisation' – positive, successful and breast cancer focused, an experience far removed from the reality of the majority of cancer survivors.[10] In fact, survivors themselves have been struggling with the construct of survivorship – many uncomfortable with the term 'survivorship' and challenged by the medicalisation of their experience, where the development of survivorship care as a distinct discipline creates the concept of a new disease, that of being a cancer survivor.[11]

All of which raises a question of whether survivorship should be managed as a distinct entity within the specialised field of cancer medicine. Many problems that survivors identify are not unique to those treated with curative intent, but rather represent a more personal dimension of living with cancer (neither Mullan, nor the National Coalition for Cancer Survivorship definition of cancer survivor draw a distinction between survivorship as applying in the curative setting and after the treatment has finished, but for practical reasons of service delivery, many service providers apply this distinction). Furthermore, nearly half of cancer survivors die of other causes, emphasising the importance of good general medical care outside of oncology as fundamental to good survivorship care. The shift to delivery of survivorship care by primary care providers aligns with these considerations, but many issues regarding how best to deliver care in the primary care setting are yet to be addressed.[12]

The issue of the chronic illness and survivorship interface deserves particular attention. Firstly, because cancer may be considered a chronic illness and strategies for managing it require skills in chronic illness management, including building self-management capacity, health promotion and care coordination, which are not yet incorporated into models of care. Secondly, many cancer survivors suffer from other health problems. Data from Medicare beneficiaries in the US (i.e. for patients 65 years or older) indicate that more than 90% of patients with cancer have at least one other chronic condition and approximately a quarter have five or more.[13] Given that management of co-morbidity is a major health priority for many health care systems, management in the context of cancer survivorship is an important, yet relatively unexplored area.

Survivorship research – need for strategy and collaboration

Similarly to diversity of survivorship care, there is a rich diversity of survivorship research, both in terms of scope and quality. The research output is growing exponentially and there are now opportunities for dedicated research funding in this field. Most importantly, survivorship research is increasingly integrated into existing cancer research programs. For example, in early 2014, the European Organisation for Research and Treatment of Cancer convened a meeting to identify priority areas for survivorship research and considered how data from existing trials could be used to contribute to survivorship research. But gaps in research remain. Its scope remains polarised in the direction of psychosocial research, with less work being done in pre-clinical, laboratory and biomedical research related to survivorship. Similarly, little high level evidence exists on utility of diverse models of health care delivery, implementation research relevant to different clinical contexts, and health economics of survivorship care.

A recent UK study reported the results of a scoping analysis of survivorship research from the last 20 years, concluding that there was paucity of data on later phases of survivorship, most of the evidence was derived from breast cancer studies and there was limited data on rehabilitation and self-management.[14] The authors offered a priority list for future research, which included focus on where research findings have a high likelihood of being 'implementation ready' in a reasonable timeframe and where existing groups with strong track record already exist. They proposed the following as examples of such priority areas: large-scale prospective cohort studies that sufficiently describe needs of long-term survivors and to predict those most at risk; robust randomised trials of well-specified 'delivery ready' interventions and research to determine the most effective and efficient ways to organise care. The second aspect of their recommendation – the existence of the established research group, underscores the fundamental importance of growing national and international collaborations in the area of survivorship to take advantage of collective knowledge and skill, but also to develop a strategic approach to research planning and priority setting. One area where international collaborations would be of great value is that of registries and clinical databases, where international comparisons would be valuable.

Next 30 years – the journey continues

As we enter the next 30 years of survivorship care and research, there is much to celebrate. And there is much to be done. Delivering quality cancer care to survivors is not just about delivering good cancer care, but improving overall health care of the growing numbers of people affected by cancer. Ensuring that care is evidence-based, cost-effective and adaptable to different health settings remains a constant challenge in the continuingly changing health care environment. The journey continues.

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UTILISING EHEALTH TO SUPPORT SURVIVORSHIP CARE

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Abstract

Cancer survivors represent approximately 3.5% of the Australian population. Physical and psychosocial issues experienced as a result of a cancer diagnosis and treatment persist into long-term survivorship. While oncology care pathways that routinely include comprehensive symptom and emotional well-being assessments have been shown to improve patient outcomes, such assessments are not routinely undertaken. Electronic Patient Reported Outcomes (ePRO) systems are increasingly used in cancer clinical care settings and are superior to paper-based PRO assessments, as they can facilitate assessment in a range of languages, as well as automated scoring and generation of real-time feedback reports to the care team. Linkage of ePROs into existing patient records integrates psychosocial information with other clinical information, enabling patient-centred care. In NSW, an ehealth system being developed and pilot tested, supports ePRO assessments which generate real-time feedback to the clinical team and access to self-management resources to assist survivors to better manage their own health and wellbeing.

In 2014, around 128,000 Australians were estimated to have been diagnosed with cancer, this is projected to rise to 150,000 cases in 2020.[1] Approximately 65% of patients live longer than five years post-diagnosis, the vast majority cured from their cancer.[2] With some of the highest cancer survival rates in the world,[3] the prevalence of people living with cancer represents approximately 3.5% of Australians.[4] Increased survival is associated with the persistence of treatment-related side-effects, higher rates of cardiovascular disease, diabetes, osteoporosis and functional decline post-treatment,[5-12] and increased risk of diagnosis of a subsequent or treatment-induced cancer. Psychosocial issues also persist into long-term survivorship, including unmet needs relating to information about late-effects, managing fatigue, genetic risk to family and diet.[13] In 2005, the landmark US Institute of Medicine (IOM) report, *From Cancer Patient to Cancer Survivor: Lost in Transition*,[14] highlighted deficiencies for patients undergoing and completing cancer treatment. Despite this report now being 10 years old, the provision of evidence-based survivorship interventions remains patchy.[15-19]

Person-centred care reflects a movement away from predominantly tumour-focused treatment toward care for the patient as a whole, acknowledging that cancer presents not only physical, but also emotional, social, informational, spiritual and practical challenges for patients and their families.[20,21] Much psychosocial morbidity experienced by cancer patients is not detected by healthcare providers and remains untreated.[22-25] Screening for distress has been advocated as one of the drivers to achieving person-centred care and oncology care pathways that routinely include comprehensive symptom and emotional wellbeing assessments have been shown to improve patient outcomes.[26,27] However, the evidence is not unanimous in support of screening. Bidstrup et al reviewed seven randomised controlled trials,[28] concluding that distress screening has limited effect on psychological well-being, though noting methodological weaknesses in several trials. However, they also concluded that screening could be clinically valuable if it was established "as part of a well-functioning total system," where identification of those at risk was linked with a detailed, theory-based distress management plan and staff training. In a more recent review of 27 studies, Chen et al concluded that routinely collecting patient reported outcome (PRO) measures enabled better patient-centred care in cancer settings where a patient management plan was integrated with routine collection of PROs. There was strong evidence that well-implemented PRO systems with timely feedback improved patient-health care provider communication and patient satisfaction, and might also improve the monitoring of treatment response and detection of unrecognised problems.[29]

Electronic PRO (ePRO) systems, increasingly used in cancer clinical care settings, are superior to paper-based PRO assessments in their potential accessibility in a range of languages, completion in the clinic or remotely, automated scoring of assessments, generation of real-time feedback reports to the care team, and linkage into existing patient records, integrating psychosocial information with other clinical information. Two Australian ePRO systems tested in randomised controlled trials reported some impacts on patient outcomes, or impacts only on sub-groups of patients,[30-32] but both were limited by being 'stand-alone' systems. Their lack of integration into the clinic's electronic health record limited their likelihood of routine adoption and at this point, neither has led to systematic clinic implementation beyond a trial.

PROMPT-Care: a home-grown eHealth system supporting person-centred care

With Cancer Institute NSW and BUPA Health Foundation funding, a collaborative partnership between the South Western Sydney Local Health District and the Illawarra Shoalhaven Local Health District has developed,[33] and is piloting an eHealth system (PROMPT-Care). This project has considered some of the past ePRO attempts and has been well-informed by features identified as important to supporting a successful ePRO system (summarised in table 1) in a review of 33 ePRO systems (70% in the US, none from Australia) in 2013.[34]

The departments participating in the PROMPT-Care development and pilot testing currently use an electronic

Table 1: *Recommended features to support a successful ePRO system*

System design features	Data collection features	Assessment reporting and workflow integration features
• Flexibility – allowing the system to: transition from treatment to survivorship; be able to be used at home as well as at clinics; specify assessment time points or have an open ended schedule (patient completing the assessment whenever they want to). • Integrates treatment-centred and patient-centred perspectives into one system: automatic integration of PRO content tailored to individual patient needs; flexibility in clinician report structure depending on patient need (e.g. treatment report providing detailed toxicity data; survivorship report providing more longitudinal monitoring); integration of patients' self-identified concerns (PRO administration tailored to patient preference).	• User friendly for patients, staff, clinicians and researchers – option to save data when sessions are interrupted with easily understood page layouts and the ability to move quickly through questionnaires. • Minimal burden on staff – ensuring the system includes automated alerts for follow-up assessments. • Ensuring measurement equivalence between electronic assessments and paper-and-pen assessments.	• Integration of PROs with electronic hospital records – allows linkage to automated scheduling and automated linkage/referral to other clinical care providers. • Clinicians accessing and using the PRO reports: i) providing information that is actionable ii) quick and accurate interpretation of results iii) inclusion of general interpretation guidelines iv) identification of meaningful changes v) ability to report PRO scores in a numerical text-based format vi) ability to include graphical representation of PRO scores.

oncology information system (OIS; MOSAIQ, version 2.4, Elekta Inc.) to routinely manage oncology patients in the clinic across all oncology disciplines, with all teams able to view the record. PROMPT-Care supports the electronic collection and importation of PROs directly into the OIS while patients are undergoing treatment and during post-treatment into long-term survivorship. Stored ePRO assessments can be used in routinely generated, real-time reports that inform the treatment team about patients' reported symptoms, unmet needs and distress levels, as well as recommended care pathways uniformly referring patients for specific interventions based on their PROs. This system provides the advantages of supporting personalised care for each individual patient and sending alerts for patients with serious requirements. It will have the following key features:

- Facilitating routine risk-stratified and shared care by supporting more efficient and timely communication with the general practitioner in the survivorship phase as well as during treatment, and stratification of patients according to ongoing need.

- Facilitating self-management by delivering evidence based, tailored self-management information which is responsive to the types and levels of problems and needs identified by survivors, enabling them to take an active role in decision making and managing their ongoing care and recovery.

- Supporting survivors of culturally and linguistically diverse backgrounds by facilitating better communication with patients in their own language, including systematic collection of their PROs and access to self-management resources in different languages.

- Developing the evidence base to identify gaps in care. PROs are increasingly incorporated into almost all clinical trials. Collection of PROs longitudinally through a flexible eHealth system enables assessment of whether subsequent interventions lead to improvement in patient outcomes, with patient-identified needs analysed across patient groups to determine the differential effectiveness of interventions.

While this pilot is the first step in this process, a number of groups have shown the power of developing this across treatment centres. For example, several US groups have reported significant investment in the development of very large database and research collaborations across many health centres, where a data collection model of routine PRO data collection is at the centre of the collaboration.[35-41] The storage of ePRO data with the clinical record opens the possibility of correlating patient outcomes across the entire spectrum of the patient.

Building cancer treatment and survivorship care for the future

The PROMPT-Care project faces the twin challenges of developing a robust, secure, private infrastructure to transfer assessments between patient and institution, and a delivery system to transfer tailored care to specific patients when required. The system is not limited to cancer. However, its delivery of a completed assessment into the patient's electronic record is unique and opens up the possibility of initiating human contact, providing advice about online resources and prompting more specific surveys to delineate problems.

Personal smart device use facilitates patient contact before, during and after treatment, and collection of increased amounts of phenotypic data that may, in time, prove to be important. The use of the OIS as the repository for completed ePROs addresses many issues of security and privacy, and specification of healthcare providers within the OIS makes notification of patient information to other healthcare providers highly feasible.

Pilot testing of this ehealth system in a population of cancer patients initially involving English-speaking patients, will determine feasibility, including overcoming some possible information technology hurdles such as data traversing the hospital information system firewall, data flowing to the correct patient record and an e-report uploading to the clinician in real-time, for example, when the patient e-file is opened. Other challenges include patient acceptance, clinician acceptance and the systematic issues that might be encountered in having patients enter data in the waiting room prior to being seen in a busy clinical area, or at home. Clinical advisory groups will guide appropriate initial questionnaire selection, with a focus on evidence-based, widely accepted and clinically validated tools, and care pathways prompted by PROs indicating high levels of need. Technical advisory groups will work on identifying and overcoming technological challenges of moving data from the assessment device outside secure hospital system firewalls and ensuring data are correctly placed in the OIS. The long-term plans will be to ensure that this system works across various different electronic OISs, with the intention to make this a state-wide rollout.

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ROLE OF PALLIATIVE CARE IN SURVIVORSHIP

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Abstract

There is consensus that survivorship care should be integrated, risk or needs stratified, individualised, coordinated and multidisciplinary. But further research is needed to determine the service models that can best deliver optimal outcomes in the most cost-effective way. Model heterogeneity and diversity is needed to address issues that are disease, treatment or symptom specific, and account for other modifying influences such as comorbid illness and lifestyle. Further work is needed to determine the key elements within models of care configured to support cancer survivors that positively influence outcomes, and how these elements can be best delivered across a diverse range of care settings. In the meantime, adopting a needs based approach to care at the individual patient level will ensure that those in most need have access to relevant support and care from specialist palliative care services. Fortunately, current Australian health reforms provide a climate of plasticity and innovation that is conducive to the paradigm shifts required.

Increasingly, people diagnosed with cancer are living longer as a result of early diagnosis, more advanced technology and the advent of more targeted treatments.[1,2] The survival rate for many common cancers has increased by 30 per cent in the past two decades, with two thirds (66%) of people diagnosed with cancer alive five years after their initial diagnosis.[1]

But, in reality, does cancer survivorship include those where the goal or outcome of treatment is not complete cure? While it could be considered paradoxical to integrate palliative care principles into survivorship care, we would argue that it is not, because palliative care can and does include care to people with potentially curable cancer. Moreover, we suggest that specialist palliative care brings particular expertise that, in some cases, is not readily available from other cancer services. The purpose of this paper is to describe the potential role of specialist palliative care in the provision of supportive care for cancer survivors.

Defining survivorship

While survivorship has been variously defined, it has generally come to be accepted that a 'cancer survivor' is someone who has been diagnosed with cancer and is still alive.[7] For many cancers there is no longer a clear 'post-treatment' period or specific time-point where cure can be declared. Treatment advances mean that many people with overt or covert disease may even remain relatively well for many years.[14] The survivor population is essentially composed of three sub-populations: people who have been effectively 'cured' and are disease free; people living with recurrent disease; and those who have been living with cancer from the time of diagnosis and are either undertaking curative treatment, undergoing active monitoring, or living with incurable disease.[15,16]

Care needs of cancer survivors

Across the cancer survivor sub-groups, there are many similarities in the physical, psychosocial and economic sequelae faced.[14] These include impacts on employment and activities of daily living, physical symptoms, psychological distress, and need for support by family carers.[14] Many cancer survivors also share an ongoing need for health services to provide them with information, monitoring and supportive care.

Importantly, as the patterns of cancer survival change in response to new treatments, and for specific tumour types such as haematological malignancies, there often is uncertainty about prognosis and projected future needs, such that patients, families and providers cannot predict what type or duration of services patients will need.[17,18] While many people who have completed treatment will remain disease free, they will require ongoing support to manage disease recurrence fears, long-term treatment side-effects and a range of co-morbidities.[19] The diversity of these needs necessitates input from a wide range of disciplines with appropriate expertise to address them.[20]

We argue that, while the population and underlying intent of treatment may differ, the same key competencies and skills are required to deliver excellent survivorship, supportive and/or palliative care. Indeed, in some situations, specialist palliative care may bring particular expertise that is not readily available from other services. This view is aligned with the elements outlined in definitions of both survivorship and supportive care. In its broadest definition, supportive care has been defined as: "The provision of the necessary services for those living with or affected by cancer to meet their informational, emotional, spiritual and social, or physical needs during their diagnostic, treatment or follow-up phases, encompassing issues of health promotion, survivorship, palliation and bereavement."[20] In turn, the essential elements of survivorship care have been identified as: 1) prevention and detection of new cancers and recurrent cancer; 2) surveillance for cancer spread and recurrence, or second cancers; 3) intervention for the consequences of cancer and its treatment, including symptoms such as pain and fatigue, medical problems such as lymphedema and sexual dysfunction, psychological distress for either cancer survivor or caregiver, and concerns about employment and return to work; and 4) coordination between primary care and specialist providers specifically involving survivorship care, but also including health promotion, immunisations and care of concurrent conditions.[21]

How palliative care can help

Contrary to popular belief, palliative care has an established philosophy that aims to help people focus on 'living with' rather than 'dying from' progressive advanced illness.[22] As eloquently articulated by the palliative care pioneer, Dame Cicely Saunders: "We are there to help people to live as fully as they can within the confines of their illness, until natural death occurs."[22] This philosophy is reflected in the World Health Organisation (WHO) definition of palliative care as "an approach that improves the quality of life of patients and families who face life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."[23]

Importantly, palliative care has expanded from purely delivering care in the last days of life, to care that is appropriate much earlier in the disease trajectory. This development is reflected in the most recent WHO definition (2002), which emphasises that palliative care is "…applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications."[23] While many palliative care services already provide care for people who have potentially curable cancer, there is a need to ensure that all services are responsive to the needs of other populations, such as cancer survivors who may benefit from specialist palliative care input. Barriers for access to specialist palliative care include service models being limited by prognosis-based referral criteria, funding models and community myths about palliative care being only appropriate for those who are imminently dying.

Designing models of care to meet the needs of 21st Century Australian cancer survivors

For the last decade, specialist palliative care services have been encouraged to adopt a population-based approach to care, but the lack of strong policy drivers means that many services continue to provide a model of care shaped by prognosis as opposed to need. Just as palliative care services were reluctant to extend care to people with non-malignant disease due to restrictive funding models and for fear of being overwhelmed by clinical demands which could not be met with existing resources, the same could be said for extending care and support to cancer survivors, another population with unmet needs.

Despite these barriers, there are numerous opportunities to successfully integrate palliative care principles and access to this skillset across the various essential elements of survivorship care described above. Achieving this integration requires the development of novel models of care or reorientating services to be focused on integration, earlier timing and services tailored to address unmet need.[24]

Like palliative care, survivorship care needs to be patient-centred and responsive to patients' needs, and is underpinned by good communication, information sharing and the encouragement of patient participation.[21] Successful models need to recognise that supportive care needs fluctuate over the course of anti-cancer treatment and beyond.[25] Where cancer is incurable, these needs will tend to increase over time, but fluctuations may still continue.

Internationally, definitions of 'palliative care' versus 'supportive care' lack clarity,[20,26] presenting an opportunity to influence vocabulary and concepts to optimise the client-centredness and continuity of cancer care. One argument has been that use of the term 'supportive care' throughout the disease trajectory may promote symptom management and psychosocial care across cancer stages, and encourage earlier referral to specialist services, including palliative care services if they are best placed to address the patient's needs.[27,28]

It is worth noting that European standards for the provision of supportive and palliative care, published by the European Society of Medical Oncology, in large part do not distinguish stages of disease and emphasise flexible and continuous care via expert multi-disciplinary care from either provider.[29] The society has also established a continuing care section to better integrate supportive and palliative care in patients undergoing chemotherapy.[29]

Emerging evidence from randomised trials is also supportive of specific benefits, which may be achieved with early referral to palliative care, including improved symptom control, satisfaction with care, quality of life and possibly improved survival.[6,30-32] There are several hypotheses as to how these benefits are mediated, which include improved symptom control (including management of anti-cancer treatment related symptoms and toxicities), provision of counselling, greater social support, improving illness understanding and assistance with treatment decision making.[6]

Survivorship programs need to determine minimum standards that allow routine screening for physical and psychological symptoms and adequacy of social support, treatment of physical symptoms with best evidence approaches, access to psychological and spiritual care for the patient and their family, and ongoing care planning considering the benefit/burden of any treatment strategy.[20] Supporting people to remain in the community and to effectively manage their symptoms depends on clinicians partnering and building strong collaborative relationships with patients and their caregivers to promote self-management, which lies at the core of community palliative care services.

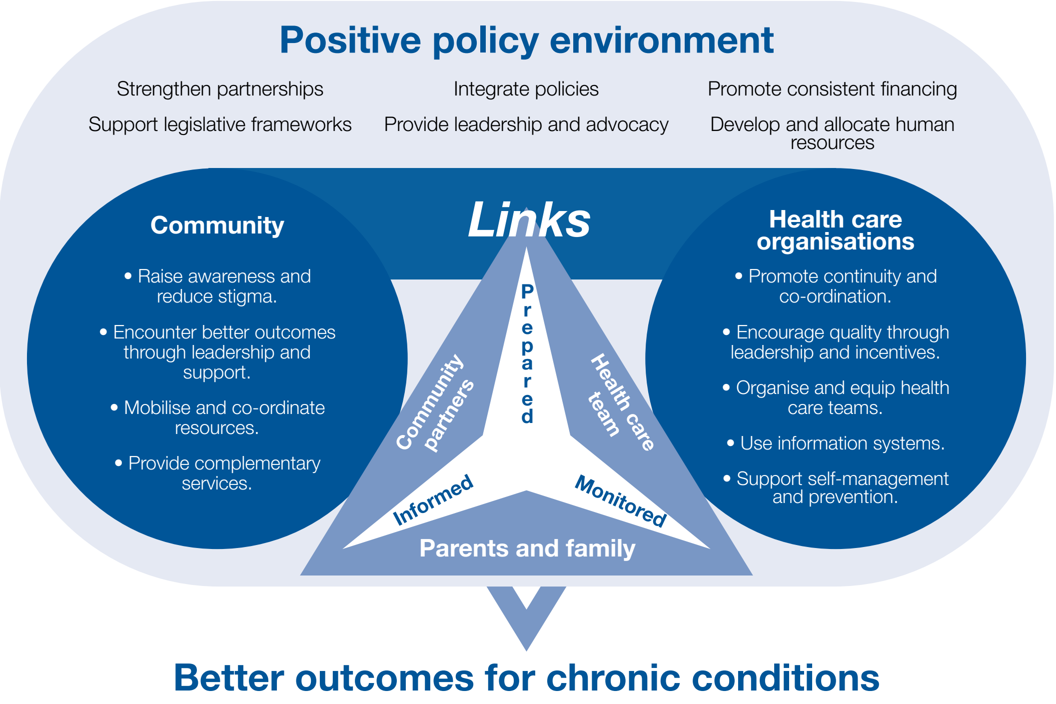
Self-management is a person-centred paradigm referring to a person's ability to manage the consequences of living with a chronic condition, including treatment, physical, social and lifestyle changes.[2] An essential element of effective self-management is building strong collaborative relationships with patients and their family caregivers.[3] Interventions for supporting self-management are well established for other chronic diseases like arthritis and diabetes, but are relatively nascent for cancer. One example where these principles are clearly applicable is in cancer pain management,[5] where patient self-management and education can be particularly effective.

Increasingly, the benefits of a chronic care framework are being recognised for people living with cancer and its consequence (figure 1).[33-35] The key principles of this framework are that patients are empowered to self-manage in the community and that services are configured around the patient and their individual needs rather than around specialty and disciplinary silos.[35]

The American Society of Clinical Oncology has instigated a survivorship task force to develop guidelines focused on supportive and palliative care issues important to survivors, such as fertility preservation and cardiac and pulmonary late-effects.[36] It could be that Australia should consider similar initiatives aimed at better integrating expertise to meet patient needs.

Consideration also needs to be made for when patients are no longer able to attend a tertiary centre for ongoing care, and in this context palliative care is making ongoing progress in developing flexible, rapid response models

***Figure 1:** World Health Organisation's (2002) Innovative care for chronic conditions framework.*



Source: World Health Organisation's Innovative care for chronic conditions: Building blocks for action. 2002. Geneva (p48).[35]

of care in the community, especially at the end of life.[37] But integrating palliative models of care or services which are configured around the patient in the community with secondary and tertiary cancer services represents a particular challenge.[38,39] Moreover, specialist palliative care services as they are currently resourced and configured, would struggle to cope with providing care to people with cancer across the disease trajectory, without some clear planning around better matching resources with patient need and targeted service enhancements.

Re-orientating services

While a variety of evidence-based models exist for integrating generalist and specialist care for people with advanced cancer, fewer are available for earlier in the disease trajectory or for supporting disease-free survivors.[40] Designated oncology and palliative care specialist nurses already play a key role coordinating care and providing education to patients/caregivers and primary healthcare professionals.[41-45] There is considerable scope for these nurses, along with the growing number of cancer and palliative nurse practitioners and practice nurses, to play an even larger role in supporting cancer survivors to manage their persisting symptoms, disabilities and to provide psychosocial support. Models that provide sequential oncology-palliative care, oncology-based supportive/palliative care or concurrent care from different providers, all have potential to deliver high quality care.[38,46] Coordination, communication and clarity of roles are the keys to success.[47,48] In addition to the need for good evidence that these new care models are effective and address the unmet needs of cancer survivors, policy reform supported by funding acceptance of such models by other clinicians providing survivorship care, and a willingness from consumers to engage with palliative care services while they identify as being a cancer survivor, will be required to embed these models into palliative care practice.

Although communication technology can undoubtedly facilitate multi-disciplinary healthcare, especially in rural and remote areas, a ‘virtual’ working environment may present psychological barriers to collaboration.[48] Online and/or patient-held medical records have important potential to support the integration of care between different services and settings, however an evidence-base is lacking.[49]

While there is much hope that palliative care and other cancer services can work together to provide care for cancer survivors in the future, challenges exist. Barriers or stigma to accessing or referring to palliative care services remain, and these may be stronger deterrents when the patient has less advanced disease.[50] Different philosophical perspectives between palliative care professionals and those in oncology can exist – for example regarding the point at which cancer directed treatments becomes medically futile.[51,52] Fundamental to all survivorship programs will be the ability for all specialties and disciplines to consider how patient and family needs are best served by integrating available expertise, which will require in some cases creation of new interdisciplinary relationships and breaking down of silos.[53,46] In taking this work forward, the elements of specialist palliative care which may offer most value add to survivorship programs are summarised in box 1.

Box 1: *Elements of specialist palliative care which may offer most value add to survivorship program.*[3]

- Promoting communication and collaboration between specialist, primary care and community providers.
- Contributing to systematic care planning and negotiating treatment goals based upon a multifaceted assessment of physical, psychological, social and spiritual needs (which degree of contribution varying dependent on disease status).
- Integrating evidence-based, palliative non-pharmacological and pharmacological interventions for specific symptoms (including cancer pain, cancer treatment-related pain, breathlessness fatigue), and maintenance of function/activities of daily living.[4]
- Supporting self-management approaches.[5]
- Supporting patients and their families in making .decisions and care planning.[6]
- Assisting in modifying interventions to better suit the patients' needs (for example exercise program for someone with more advanced illness[8-11], lower limb lymphedema treatment).[13]
- Contributing to the ongoing robust evaluation of models of care.
- Flexibility in location of care delivery (allowing continuity of care if the person is no longer able to attend the hospital clinic or survivorship centre, in-reach into residential care).

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FEAR OF CANCER RECURRENCE: AN OVERVIEW AND AUSTRALIAN PERSPECTIVE

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Abstract

Fear of cancer recurrence is broadly defined as the fear or worry that cancer could return or progress in the same place or another part of the body. It is frequently reported as an unmet need by cancer survivors, and does not appear to diminish with time since diagnosis and treatment completion. Fear of cancer recurrence is almost universal among cancer survivors, and those experiencing high levels of fear of cancer recurrence experience difficulties moving on with life after diagnosis and treatment, and have poorer quality of life. It is a prevalent and persistent issue for cancer survivors, with significant costs for the individual, family and society. Those who are younger have greater symptom burden and greater psychological distress are likely to have higher fear of cancer recurrence. Few intervention studies have been reported in the literature to date to guide health service provision. However, several studies are currently underway in Australia to develop empirically tested theory-driven interventions.

Improved medical treatments for cancer have led to higher survival rates; the five-year relative survival in Australia is currently 66% for all cancers combined.[1] In response, research has increasingly focused on longer-term survivorship issues. One of the most prevalent and severe unmet supportive care needs in cancer survivors, that does not appear to diminish with time since diagnosis, is for help with fear of cancer recurrence.[2,3] This review aims to present current research on this, together with interventions currently under investigation from an Australian perspective.

Conceptualisation and measurement of fear of cancer recurrence

Conceptualisation of fear of cancer recurrence is still evolving, with no widely-accepted understanding of its nature or clinical significance. However, Vickberg's definition of fear of cancer recurrence: "The fear or worry that cancer could return or progress in the same place or another part of the body," has frequently been employed.[3] Fear of cancer recurrence has been characterised as multidimensional, comprising emotional, cognitive and behavioural reactions.[4] Numerous measures have been published that attempt to evaluate the nature and severity of fear of cancer recurrence, but each uses a slightly different approach, employing different definitions and emphasising different aspects of fear of recurrence. Consequently, the setting and purpose of evaluating fear or recurrence should be considered when selecting a measure.[5]

The clinical significance of fear of cancer recurrence is unclear. Despite an apparent association between fear of recurrence and quality of life (QOL), little work has investigated the level or severity of fear of recurrence at which it begins to impact daily life. To date, one study has attempted to establish a clinical cut-off score for fear of cancer recurrence (on the Fear of Cancer Recurrence Inventory Severity Subscale).[6,7] However, the purpose-designed diagnostic interview used in that study has not yet been validated, so the proposed cut-off of 13 can only be considered preliminary. There is some evidence suggesting this cut-off has strong sensitivity but poor discrimination, and may falsely identify many people with clinical levels of fear of cancer recurrence.[8] In the absence of established clinical cut-offs, researchers have employed more descriptive approaches. For example, Lebel et al considered women with breast or ovarian cancer had moderate to high levels of fear of recurrence when they endorsed more than 50% of the 22 items on the Fear of cancer recurrence questionnaire with a 4 or 5 (item range 1-5), and scored in the clinical range which involves total score ≥26, range 0-75 on the validated Impact of Event Scale.[9,10,11]

Prevalence of fear of cancer recurrence

Some degree of fear of cancer recurrence is reported by almost all cancer survivors and their caregivers.[12,13] For example, of 1442 Australian adult cancer survivors diagnosed with one of the eight most common cancers, 46% worried about their cancer returning or getting worse at 12 months post-diagnosis.[14] A recent systematic review found that across different cancer sites and assessment strategies: 39-97% of cancer survivors reported some degree of fear of recurrence (on average 73%); 22-87% reported moderate to high fear of recurrence (on average 49%); and 0-15% reported high fear of recurrence (on average 7%).[15] Some studies have reported even higher levels of fear of recurrence among caregivers than patients.[12] The wide range in prevalence estimates appears due to several factors, including different definitions such as fear of progression versus fear of recurrence, together with measures and sample characteristics.[16]

Fear of cancer recurrence does not always decrease with time, even when the risk of recurrence is low.[15,16] The above-mentioned systematic review identified 21 cross-sectional studies exploring associations between time since diagnosis and fear of cancer recurrence severity, with only one study reporting a significant association,[15,17] reinforcing the stability of fear of recurrence over time.[18] In their longitudinal study, Ghazali et al reported that among head and neck cancer survivors: approximately 50% did not experience significant levels of fear of recurrence; approximately 20% experienced significant levels of fear of recurrence intermittently; and approximately 30% experienced stable and significant levels of fear or recurrence over time.[19] Furthermore, for this last group, fear of recurrence scores did not fluctuate, remaining high over time.

Predictors of fear of cancer recurrence

Younger age is consistently associated with higher fear of cancer recurrence.[3,13,20] There is inconsistent evidence that females, minority groups, and those with lower education, lower income, or in employment, experience higher fear of recurrence.[15] Fulfilling a caregiving role, such as being a young mother, has been associated with higher fear of recurrence,[21,22] although another study found no association between having children, attitudes to future pregnancy, and fear of recurrence in young breast cancer survivors.[23] Thus the contribution of many socio-demographic variables to fear of cancer recurrence remains uncertain.

Counter-intuitively, fear of cancer recurrence is not clearly linked to prognostic indicators such as stage of disease and treatment received.[16,24] For example, in one review, prognostic indicators including TNM stage, prostate-specific antigen level, Gleason score and presence of positive margin, were positively associated with fear of cancer recurrence in 11 studies, but 16 studies reported no association.[15] Similarly, having had a recurrence or metastatic diagnosis was significantly associated with fear of recurrence in five studies, but unrelated in four. However, high subjective risk, illness perceptions and intrusive thoughts have consistently been associated with higher fear of recurrence, while optimism has been associated with lower fear of recurrence.[15,16,25] This suggests that assessment and review of unrealistically high subjective risk, may be a strategy for combating fear of cancer recurrence.[26]

There is strong evidence for a relationship between fear of cancer recurrence and symptom experience, particularly global symptom burden, pain, fatigue and body image concerns.[15,16,24] These symptoms may remind survivors of their cancer diagnosis,[27] and be interpreted as possible signs of recurrence, thereby increasing fear of cancer recurrence. These results suggest that education about the meaning of symptoms and those likely to be related to recurrence may be helpful.

With regards to psychological predictors of fear of cancer recurrence, general distress, depression, anxiety and avoidance have been associated with higher fear of recurrence.[15,16,25] Some studies have also reported an association between fear of cancer recurrence and diagnosed anxiety or psychiatric conditions such as post-traumatic stress disorder, global anxiety disorder, hypochondriasis and obsessive compulsive disorder,[23,28,29] although most cancer survivors do not appear to suffer such co-morbidities.[23] The relationship between psychological factors and fear of cancer recurrence is most likely bi-directional.[15]

Consequences of fear of cancer recurrence

Adjustment to the possibility of cancer recurrence is sometimes reported as more problematic than adjustment to the initial diagnosis.[30] High fear of recurrence levels have been shown to have a negative impact on QOL, psychological adjustment, emotional distress and anxiety, ability to establish future goals and plans, and carer QOL.[15,16,25,31] However, Simard et al argue that the large number of concepts explored means the evidence base for any one psychological impact is weak.[15] Furthermore, Lebel et al showed that change in fear of cancer recurrence did not lead to changes in distress and intrusions/avoidance over time.[32]

Fear of cancer recurrence has been associated with higher use of medical services, including complementary and alternative medicines, and increased medical costs.[13,33] For example, in Australian early-stage breast cancer survivors approximately four years post-diagnosis, those with higher fear of cancer recurrence were more likely to have unscheduled GP visits and use complementary therapies.[13] These women were also more likely to engage in breast self-examination, but avoid formal screening measures such as mammograms and ultrasounds, potentially compromising health outcomes.[13] Thus the impact of high fear of recurrence is wide-ranging, with potential costs to the individual, the family and wider society.

Unmet need for help with managing fear of cancer recurrence

Despite the high prevalence and potential cost of fear of cancer recurrence, survivors report high levels of unmet need for help managing this fear, suggesting many cancer services are not currently providing adequate care in this area. A multi-centre Australian study (n=388) found that fear of cancer recurrence was survivors' greatest area of unmet need, with 26% reporting moderate to high unmet need for help with this fear.[34] The need for effective interventions for fear of recurrence has been recognised by oncology health professionals. In a survey of 141 Australian medical and radiation oncologists, surgeons, nurses, palliative care specialists, psychiatrists, psychologists and social workers, 33% reported spending more than 25% of follow-up consultation time discussing fear of cancer recurrence, 46% found dealing with this challenging and almost all were interested in further training for managing patients with this fear.[35] These results emphasise the need for developing effective, theory and evidence-based treatments for fear of cancer recurrence.

Theoretical perspectives on fear of cancer recurrence

Several theoretical models have been previously used to explain fear of cancer recurrence, though none is universally accepted. These are presented below.

Theory of uncertainty in illness

Although uncertainty is not the same as fear of cancer recurrence, aspects of Mishel's theory of uncertainty in illness may be relevant to understanding this fear.[36,37] According to this theory, uncertainty is the inability to determine the meaning of illness-related events.[36] It is generated when there is inconsistency, randomness, complexity, unpredictability and little information about the illness, its treatment, and related events including symptoms.[36] Integrating uncertainty into one's life and directing it in a desired direction such as reduced uncertainty is an essential task in adaption.[37] Uncertainty about the possibility of cancer recurrence is similarly triggered by intrusive, unpredictable and random events.[38] The difficulty with this causal explanation of fear of cancer recurrence is that some degree of uncertainty about recurrence likely exists for all cancer survivors, yet not all cancer survivors develop clinically significant levels of fear of recurrence.

Self-regulation of illness/common sense model

The self-regulation of illness or common sense model proposes that when individuals are confronted with a health threat, an illness representation is activated consisting of cognitive factors, meaning perceived personal risk of recurrence and emotional considerations including worry about the cancer returning, anxiety about cancer itself, and regret about treatment decisions and these motivational processing systems, act together to guide coping behaviours.[4,39,40] Lee-Jones et al hypothesised that survivors who viewed their cancer as chronic, with negative and uncontrollable consequences, were likely to engage in more emotional processing of health threats and have higher fear of cancer recurrence.[4] There is some evidence for the common sense model in dealing with fear of recurrence; individuals who believe they are vulnerable to cancer are more emotionally aroused by somatic stimuli and display higher levels of fear of recurrence, while adaptive coping strategies are associated with lower fear of recurrence.[4,41-43] However, this model does not address how survivors come to have negative cognitive and emotional responses to cancer.

Self-regulatory executive function model of anxiety disorders

The self-regulatory executive function model addresses maintaining factors associated with anxiety disorders and has been used to effectively treat health anxiety.[44,45-47] The model proposes the cognitive attentional syndrome which consists of: self-focused attention, worry and rumination; attentional bias towards threat-related information; and maladaptive coping behaviours including suppression, avoidance and minimisation. Cognitive attentional syndrome impairs flexible self-control and prevents corrective learning experiences, leading to increased and persistent distressing emotions. The self-regulatory executive function model argues that beliefs about one's thoughts underlie activation of cognitive attentional syndrome.[44] That is, those who believe worry is important and may impact the outcome (e.g. "If I worry I will be prepared") are more likely to engage in cognitive attentional syndrome, in turn intensifying fears and worries about cancer returning. Research has shown that anxious cancer patients display an attentional bias towards threatening stimuli,[48-50] and fear of recurrence level appears to be associated with metacognitions and beliefs about cancer vulnerability.[4,41-43] The self-regulatory executive function model appears particularly applicable to fear of recurrence because the belief that cancer might recur is not entirely irrational, and hence a focus on cognitive processes rather than content could be advantageous, and it explains why elevated emotional responses after cancer diagnosis are maintained.[40]

Relational frame theory and acceptance and commitment therapy

Acceptance and commitment therapy,[51] based on relational frame theory, focuses on increasing cognitive flexibility and emphasises accepting feelings, thoughts and sensations when attempts to control them are counterproductive and prevent the individual acting in line with desired goals and values.[51,52] Acceptance and commitment therapy can address the existential issues that arise when cancer is diagnosed, as it aims to help clients develop more clarity about what is important to them and to establish behavioural goals in accordance with those values.[51] Acceptance and commitment therapy has recently been applied in the cancer context with promising results.[53-55] Also, while it is yet to be empirically evaluated in randomised control trials, Australian psychosocial-oncology health professionals report acceptance and commitment therapy offers clinically useful strategies for treating fear of cancer recurrence.[35]

Intervention studies

The AFTER intervention (Adjustment to Fear, Threat or Expectation of Recurrence) was one of the first psychological interventions specifically designed to address fear of cancer recurrence in head and neck cancer patients.[56,57] This intervention, based on the common sense model, consisted of six face-to-face individual sessions with a specialist nurse and encouraged participants to discuss the likelihood of recurrence, express cancer recurrence-related fears, their triggers and consequences. The manualised sessions also covered excessive checking behaviours and illness beliefs and representations.[56,57] Two assessments were carried out before the intervention, at three and seven months post-treatment completion, and two after, at 11 and 15 months post-treatment completion. The intervention group maintained general anxiety levels before and after the intervention, while the control group had increased anxiety. There was a statistically significant improvement in fear of cancer recurrence for the intervention versus control participants immediately post-intervention, that was not maintained at 15 months. A significant limitation of the trial was its lack of statistical power. Also, participants were not screened for high levels of fear of cancer recurrence prior to study entry, and together with using a three-item fear of cancer recurrence measure, this may have contributed to the mild effects found.

Lebel et al developed a manualised six week cognitive existential group intervention targeting fear of cancer recurrence based on the common sense model,[9] Mishel's uncertainty in illness theory, cognitive models of worry and components of a cognitive-existential group intervention.[58] Stage I-III breast and ovarian cancer patients were eligible for this single-arm pilot if they reported clinically significant fear of cancer recurrence levels (discussed above) and had completed primary treatment. Immediately post-intervention, women experienced significantly lower fear of cancer recurrence, plus significantly lower cancer-specific distress, uncertainty and negative QOL. Changes were maintained at three-month follow-up. These preliminary positive results are tempered by 12 of 56 participants (21%) dropping out over the course of the intervention.

Several studies investigated interventions targeting concepts similar to fear of cancer recurrence. Herschbach et al compared cognitive behaviour group therapy or supportive-experiential group therapy with usual care over 12 months on fear of progression,[59,60] with both intervention groups showing significant reductions in fear of progression over time compared to controls. Heinrichs et al similarly showed that a couple-skills intervention reduced fear of progression compared to a control cancer education program in breast and gynaecological cancer patients and their carers.[61] However, these benefits were not maintained at follow-up, 16 months post-diagnosis. A third study reported that a nurse-led telephone intervention for uncertainty management in long-term breast cancer survivors increased cognitive reframing and cancer knowledge compared to usual care controls.[38]

Though they did not specifically target fear of cancer recurrence, in a single arm pilot study Chambers et al found a non-significant trend for decreased fear of recurrence in Australian men diagnosed with advanced prostate cancer, who participated in an eight-week mindfulness-based program three months post-treatment completion.[62] Lengacher et al reported on a six-eight session Mindfulness-Based Stress Reduction group program designed to improve psychological status generally.[63-65] Significant improvements were seen in fear of recurrence, as well as depression and anxiety, though no long-term data has been published.[63] Thus further research evaluating fear of cancer recurrence specific interventions is required.

There are two interventions currently underway in Australia which specifically target fear of cancer recurrence.* The first is a multi-centre randomised trial comparing a novel psychological intervention called 'Conquer Fear' to relaxation training for cancer patients.[40] Both interventions are manualised and delivered in five sessions over 5-10 weeks by trained psychologists and psychiatrists. Eligible participants are breast, colorectal or melanoma cancer survivors who have completed hospital-based treatment between two months and five years prior, and report a score in the clinical range on the Fear of Cancer Recurrence Inventory Severity Subscale. Conquer Fear incorporates aspects of the self-regulatory executive function model and relational frame theory, together with the common

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**A review of the Australian and New Zealand Clinical Trials Registry on 24th July 2014, found only two studies registered with fear of cancer recurrence as the primary outcome measure. The authors acknowledge other Australian groups may be undertaking research on novel interventions or therapeutic approaches for managing fear of cancer recurrence, but at the time of writing this article they were not registered with Australian and New Zealand Clinical Trials Registry* sense model, to provide a novel metacognitive account of fear of recurrence. The sessions cover attention training, detached mindfulness, meta-cognitive therapy, values clarification and psycho-education to help cancer survivors change how they regulate and respond to thoughts about cancer recurrence. The relaxation training arm focuses on both internal and external stressors associated with fear of recurrence, and teaches progressive and passive muscle relaxation, meditative relaxation, visualisation and 'quick relaxation' techniques. The primary outcome measure is fear of cancer recurrence as measured by the Fear of Cancer Recurrence Inventory, and participants are followed up for six months after intervention completion. This trial is currently recruiting and due for completion in 2016. The second trial in progress is a randomised trial comparing a novel psycho-educational intervention for high-risk melanoma cancer patients to usual care.[66] The psycho-educational intervention comprises a tailored, psycho-educational booklet and three individual, telephone-based counselling sessions delivered by a clinical psychologist focused around their high-risk melanoma clinic appointments. The primary outcome is fear of cancer recurrence as measured by the fear, assessed two-three weeks after their first high risk clinic appointment and again at five and 11 months afterwards.

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ENGAGING PATIENTS IN SURVIVORSHIP CARE PLANNING AFTER COMPLETION OF TREATMENT FOR HEAD AND NECK CANCER

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Abstract

Head and neck cancers include cancers of the tongue, mouth, salivary glands and the pharynx, oro-, hypo- and nasopharynx, nasal cavities, middle ear, sinuses and larynx. Few cancers pose more challenges than cancers of the head and neck. The toxic treatments which have led to improved survival often come at the cost of an adverse impact on body image, confidence and physical problems. For example, difficulty with eating is not just about maintenance of nutrition – it has a profound effect on basic social interactions and relationships. While receiving treatment, patients are closely monitored and assessed, but on completion of a defined treatment protocol, patients report that they feel uncertain about how to manage residual symptoms, and anxious about their future, as they now have more intermittent contact with clinical services. The ENHANCES study is a randomised control trial of a tailored survivorship intervention for patients who have completed treatment for head and neck cancer. Innovative in several respects the study: i) has a strong theoretical base applying principles of chronic disease self-management and behaviour change; ii) is provided by trained oncology nurses who will be able to use these skills across treatment settings; iii) is embedded in clinical care, which is likely to improve acceptability and reduce stigma; iv) incorporates qualitative data exploring issues of feasibility with patients, nurses and administrators; and v) includes an analysis of the health system costs of delivering this intervention.

The increasing attention to survivorship in Australian oncology brings into focus the complexities and breadth of issues involved. Follow-up after completion of cancer treatment typically focuses on treatment of ongoing morbidity, identification of recurrent or new disease, and detection and management of psychosocial distress.[1] However, just as we accept that quality of life in health care refers to more than absence of disease, we need to move toward thinking about survivorship as an opportunity to proactively promote wellness, rather than reactively responding to disability. Unfortunately, to date there is little evidence to inform models of survivorship care which are flexible enough to meet the needs of individuals and able to be delivered in clinical systems which are busy, and often understaffed.

The ENHANCES study team is conducting a randomised control trial of a survivorship intervention for patients who have completed treatment for head and neck cancer. Head and neck cancer treatment poses unique and severe psychosocial and physical challenges, survivors commonly experiencing residual difficulties with disfigurement, pain, eating and fatigue,[2,3] and these symptoms do not necessarily abate over time.[4] In addition, this is one of the few cancers which is more common in rural patients, who usually receive treatment at tertiary referral centres.[5] Hence provision of an intervention at completion of treatment is critical because of limited access to specialised services when patients return home.

The study is being conducted at the head and neck clinics of the Royal Brisbane and Women's Hospital and Princess Alexandra Hospitals. We aim to recruit 120 patients across both sites. Patients will be randomised to one of three arms: i) usual care; ii) information involving provision of a written resource purpose-developed for patients treated for head and neck cancer; and iii) intervention involving a tailored survivorship care plan. Trained oncology nurses will meet with patients randomised to receive the intervention for a face-to-face interview lasting up to 60 minutes, and assist the patient to develop a detailed survivorship care plan. The primary outcome is quality of life, measured using the FACT-Head and neck which captures the unique needs of this population.[6] Secondary outcomes are self-efficacy (Cancer Behaviour Inventory, version 2)[7,] and mood (Hospital Anxiety and Depression Scale).[8] Feasibility and acceptability will be assessed by means of semi-structured interviews with patients, nurses and administrators, and health system cost impact will also be evaluated. Further details of the study are reported elsewhere.[9]

The intervention draws on evidence from the fields of chronic disease management and behaviour change, which have been successfully used in a pilot study of a survivorship self-management care plan with patients with breast and colorectal cancer.[10] The focus of this article is an overview of some of the concepts of chronic disease self-management and behaviour change which are incorporated into the ENHANCES survivorship intervention, and provide examples of some of the approaches which could be applied in routine follow-up.

Principles of chronic disease self-management

The essence of chronic disease self-management is engagement of the patient to be an active participant in his or her health care, rather than a passive recipient of treatment. The person is ideally supported by the health care system and health practitioners to take some control of their healthcare needs, seek support and assistance as needed, and engage in strategies to prevent complications and achieve wellness.[11] Application of a chronic disease model of care is appropriate for patients treated for head and neck cancer in view of the often considerable and persisting morbidities following treatment.

A model of self-management support

Engagement of patients in self-management does not mean that health professionals do not provide information, support or guidance. In fact, the establishment of a supportive context in which the person feels that their unique needs are understood has been demonstrated to lead to increased confidence about being able to manage their health concerns.[12] Oncology nurses participating in the ENHANCES study have completed a comprehensive self-directed training manual and participated in a day-long skills development workshop focusing on communication strategies and development of survivorship care plans.

The approach the nurses will use in delivering the ENHANCES intervention is based on the following model of self-management support:[13]

1. Assess: Nurses meeting with patients randomised to the intervention will assess patients' beliefs, knowledge and behaviour, including their attitudes about the cancer, diet, physical activity and behaviours associated with increased risk of morbidity such as smoking.

2. Advise: After eliciting this information, the nurse will ask permission to explore specific issues in more detail, and provide information. For example, misunderstandings about recommended consumption of fruit and vegetables are common, and this is an opportunity to provide evidence about nutritional guidelines.[5] Similarly, patients may assume that fatigue is best countered by rest, and they will likely benefit from information about the impact of physical activity on well-being and fatigue. Motivational interviewing techniques will be employed as appropriate (discussed below).

3. Agree: Based on the discussion, the patient and nurse will collaborate to define the problems of concern to the patient. There is evidence that self-management interventions cannot be 'one size fits all' and benefit is maximised when the intervention is tailored to the patient's expressed needs.[14] Nurses have identified that this approach is counter to their more traditional roles as experts who assess what they consider to be the patient's problems, which they attempt to 'fix', and this has been a particular focus in training.

4. Assist: The nurse encourages the patient to consider the factors which will make it easy for them to address their problems, as well as the barriers. This might include discussion about community-based supports, friends and family members and the role of the patient's general practitioner, involving problem-solving techniques.

5. Development of a survivorship care plan: the patient defines their goals in behavioural terms. The goals should be as specific as possible (see SMART goals). Attention to self-efficacy (as discussed below) is a core aspect of the interview.

The patient retains a copy of the survivorship care plan, and a copy is forwarded to their GP. The patient is encouraged to record their progress in a diary and set aside time each week to review progress, identify any barriers to achieving their goals, and seek assistance as necessary.

Motivational interviewing

This technique is underpinned by the Trans-theoretical Model of Health Behaviour Change, which contends that an individual passes through a series of stages, and specific techniques can assist the person to move from inactivity/passivity to readiness to initiate change.[15]

At its most basic, an interviewer obtains information about the behaviour, for example, in relation to smoking, asking the patient: "What are some of the good things about smoking?" The next question would be: "What are some of the less good things about smoking?" The interviewer then aims to develop discrepancy by summarising what the patient has said: "So the good things about smoking are…. And some of the less good things are… Having talked about that where does it leave you now?" Core techniques include avoiding arguments and rolling with resistance. The aim is to provide a non-critical environment which can help the individual to take personal responsibility and move towards initiation of behaviour change. This complements the chronic disease self-management approach in which the patient ‘owns’ their healthcare needs, rather than being given an instruction, for example to ‘stop smoking’.

Nurses delivering the intervention will use this technique when providing advice to patients about various aspects of health including smoking, alcohol use and physical activity. It may not be intuitive for health professionals to use this approach, and in the training for the ENHANCES study nurses have focused on seeing ‘sowing the seeds’ as a valuable step, even if the person does not immediately engage in behavioural change.

SMART goals

This approach to goal-setting first emerged in the area of business in 1981.[16] Goals should be specific, measurable, achievable, realistic and in a defined timeframe. The original business approach listed A as assignable, meaning who will do it. There is evidence that goals are more likely to be achieved if they resonate with the person’s identified needs, if they are specific and if a plan is developed for their enactment.[17]

A common example of application is assisting a person who indicates that they “would like to be more active”. In the ENHANCES intervention, nurses will work with the person to develop a clear, defined and measurable goal, such as: “I will go for a 10 minute walk each day.” This will be accompanied by brain-storming about barriers, and ways to increase the likelihood of success, such as arranging to walk with a friend.

Thoughts, self-efficacy and behaviour

It is clear that having knowledge about health matters does not automatically translate into adoption of healthy behaviours and lifestyle. Motivation is affected not only by emotions and experience, but also by thoughts and beliefs. Fear of failure commonly leads to avoidance and becomes self-fulfilling to an extent, as the task is not attempted and the person has no experience of mastery, fuelling negative thoughts about their ability to achieve.

A body of research supports the notion that attitudes and beliefs affect the willingness of people to engage in tasks which can be challenging or demanding. The term self-efficacy refers to a person’s “belief in their ability to succeed at chosen tasks and achieve set goals”.[18] Self-efficacy thus refers to the person’s cognitions about their capacity to respond to challenges and is postulated to predict: i) whether the individual will initiate a response to challenges; ii) how hard they will work at those challenges; and iii) the extent to which they will persist despite adversity or setbacks.

Self-efficacy can be promoted in a variety of ways, the most important of which is performance accomplishment. In essence, repeated success raises expectations of success, so it is likely that the person will ‘give it a go’, in contrast with repeated failures which lower expectations leading to an attitude of: “Why bother, I can’t do it anyway.” If the person has some experience of success followed by later failures which are overcome, that can lead to an increased sense of optimism that even major hurdles can be overcome with sufficient application.

In the ENHANCES study, performance accomplishment will be promoted through setting of small, realistic and achievable goals, incorporating cognitive techniques. The patient diary details the importance of avoiding ‘black and white thinking’. For example, the person might think: “If I can’t exercise for 20 minutes a day, it isn’t worth bothering at all.” In the ENHANCES study, the person is encouraged to view something as better than nothing: “I didn’t manage to go for a walk today, but I guess we all have set-backs from time to time. But I will give it a go tomorrow.” Or: “I managed to walk for five minutes today. It’s not 10 minutes, but I did make an effort, and I think I can build on that.”

Self-efficacy is also promoted through vicarious experience such as seeing others succeed. Patients will not directly observe others succeeding as part of the interview with the nurse, but nurses will describe others’ experiences of success. Thus “I know a man about your age and he thought he wouldn’t be able to manage it. He was really pleased when he had a go and found he could implement < insert goal >.”

This will be supplemented with verbal persuasion, as there is evidence that when a person of status or authority expresses confidence in the person, it increases the chance of the person undertaking the activity. Nurses will offer persuasion along the lines of “In my experience as a nurse for x years, and talking with you now, I really believe you will be able to do this.” We have recruited and trained 15 oncology nurses across both recruitment sites. To date, 17 patients have been recruited and three have completed the survivorship intervention with a trained nurse.

In conclusion, this intervention is likely to be acceptable to patients as it involves generation of a tailored plan developed on completion of treatment, a time of recognised vulnerability. If successful, this study will provide important information about the health system costs, feasibility and effectiveness of this model of survivorship care. There is potential for this model of survivorship care to be adapted to align with the particular physical and emotional concerns of patients with different tumour types, enabling health professionals to provide individualised survivorship care.

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EXERCISE AND CANCER SURVIVORSHIP

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Abstract

Exercise has been identified as an integral component of comprehensive survivorship care and a promising adjuvant therapy to aid in the management of cancer. Leading organisations worldwide now advocate exercise for cancer survivors. Here we briefly review the existing evidence for exercise and survivorship, as well as current research endeavours in Australia. Discussion extends to identify the gaps between research and practice, as well as future research directions needed to drive the field forward. With continued efforts by scientists, clinicians and consumers, there is real potential to strengthen the nexus between scientific evidence and clinical practice and integrate exercise into standard cancer care.

Exercise is considered a safe and effective treatment for people with cancer.[1-3] Research to date has predominately evaluated the impact of exercise among people with localised breast and prostate cancer, however evidence is building for other types and stages of cancer. Clinical research over the last three decades has established the efficacy of exercise in counteracting many of the adverse treatment-related side-effects of cancer. To date, the strongest evidence exists for improving physical function, including aerobic fitness, muscular strength and functional ability,[4] attenuating cancer-related fatigue,[5] improving quality of life across multiple general health and cancer-specific domains,[3] and alleviating psychological distress.[6] Emerging evidence highlights that participation in exercise during or following cancer treatment reduces risk of developing new cancers and comorbid conditions, such as cardiovascular disease, diabetes and osteoporosis,[1] counteracts unfavourable changes in body composition,[7] can minimise sexual dysfunction,[8] decreases pain,[9] and enhances sleep quality.[10]

Further, observations from epidemiological evaluations suggest there is a protective effect of exercise against cancer recurrence and/or cancer specific death in breast, colon and prostate cancer but insufficient evidence for other cancers.[2] Specifically, these observational data show that a higher level of physical activity is associated with a 20-60% risk reduction depending on cancer type in cancer-specific mortality when compared with those who are least active.[2] Importantly, appropriately prescribed and supervised exercise has been consistently observed to be safe for many groups of cancer patients and survivors, including those with advanced disease.[11] Collectively, this compelling literature has contributed to the development of exercise and cancer guidelines, which have subsequently been endorsed by major health organisations.[11-14]

Current exercise guidelines arose from a consensus statement developed by the peak professional body in exercise science worldwide, the American College of Sports Medicine.[11] These guidelines extend the previous position statement by Australia's exercise science organisation, Exercise and Sports Science Australia,[12] and have been incorporated into physical activity recommendations promoted by the American Cancer Society,[13] and the National Comprehensive Cancer Network.[14] These guidelines promote: a) avoidance of inactivity; b) progression towards return to normal activity; and c) participation in at least 150 minutes of moderate-intensity or 75 minutes of vigorous intensity aerobic exercise (e.g. walking, jogging, cycling, swimming) weekly, and two to three resistance exercise sessions each week involving moderate to vigorous intensity exercises targeting the major muscle groups (i.e. lifting weights). While the guidelines are similar to exercise guidelines for adults,[15] cancer type, presence and severity of treatment-related adverse effects, functional state, and cancer-specific precautions need to be considered when identifying optimal exercise prescription for people with cancer. This is a critical caveat which dictates that appropriate screening, prescription and monitoring is required to ensure safety and maximise efficacy in cancer survivors.[11,13,14]

The term 'physical activity' applies to any movement produced by skeletal muscles that requires the body to exert energy. In contrast, 'exercise' is structured physical activity for the purpose of conditioning the body to improve health and fitness. Research has firmly established the relationship between participation in physical activity and improvements in both the general and cancer-specific health and wellbeing of survivors. Recent epidemiological evidence demonstrates that it is not only participation in physical activity that is important for cancer-specific and all-cause mortality, but also the amount that is performed at a moderate to high intensity – that is, at a brisk walking pace or greater.[16-18] This is consistent with decades of exercise science research involving healthy adults and various disease groups, establishing a clear dose-response relationship between exercise and health benefits.[19-22] The specific physiological adaptations to exercise are dictated by the exercise modality performed, and the magnitude of adaptation dictated by the intensity and volume of exercise, relative to the starting point of the individual. Specific exercise is particularly important for counteracting insulin resistance, sarcopenia and declines in cardiorespiratory fitness. While the message for survivors to remain physically active is clearly important, targeted prescription of progressive exercise at an appropriate intensity and volume can optimise benefits to health and wellbeing in cancer survivors.

Current research in Australia

A systematic search of the Australian New Zealand Clinical Trials Registry, Australian Cancer Trials and clinicaltrials.gov databases was conducted to provide a comprehensive overview of the current research trials ongoing in Australia. All trials involving a specified exercise intervention in adult cancer survivors with a site in Australia and an enrolment status of 'recruiting', 'not yet recruiting' or 'closed';

***Table 1**: Summary of registered trials involving clinic-based exercise interventions for cancer patients and survivors currently ongoing in Australia. †*

Trial registration	Cancer type	Target n-Size	Primary outcome	Level of supervision
ACTRN12610000609055 (Deakin University)[40]	Prostate	270	Physical activity level	AEP supervised (2 sessions/week)
ACTRN12613001179729 (Edith Cowan University)[41]	Prostate	240	Sexual wellbeing	AEP supervised (3 sessions/week)
ACTRN12609000450213 (University of Western Australia)	Haematologic	150	Fatigue	AEP supervised (3 sessions/week)
ACTRN12609000971235 (University of Sydney)[42]	Lung	140	Fatigue	AEP/physiotherapist supervised (2 sessions/week)
ACTRN12610001005044 (University of Queensland)[43]	Breast	135	Body composition	AEP supervised (1 session/week-fortnight)
ACTRN12612000097842 (Edith Cowan University)[44]	Prostate	124	Bone mineral density	AEP supervised (3 sessions/week)
ACTRN12611001158954 (Edith Cowan University)[45]	Prostate (advanced only)	90	Physical function	AEP supervised (3 sessions/week)
ACTRN12614000051640 (Edith Cowan University)	Breast	66	Cognitive function	AEP supervised (2 sessions/week)
ACTRN12614000317695 (Deakin University)	Prostate	56	Bone mineral density	AEP supervised (1-2 sessions/ week)

follow-up continuing as of July 16, 2014 were included. Registered trials that hadn't been updated in the last five years were assumed to be completed, or with published outcomes were omitted. A total of 26 clinical trials were identified.

The majority of exercise intervention trials currently ongoing in Australia involve clinic-based programs (table 1). The 17 trials target 1639 participants diagnosed with breast (six trials; n = 379), prostate (five trials; n = 780), lung (three trials; n = 206), bowel/colorectal (two trials; n = 124) and haematologic (one trial; n = 150) cancers. There are a range of outcomes being evaluated, with primary analyses planned for exercise-related variables such as physical activity levels, physical function and cardiopulmonary fitness, as well as general and cancer-specific health issues, including sexual wellbeing, fatigue, body composition, bone mineral density, cognitive function, natural killer cell activity, lymphoedema incidence and severity, and pelvic floor symptoms. The duration of the exercise interventions range from one to 12 months, with an average length of 3.5 ± 2.6 months. Interventions involve an average of 2.3 ± 0.8 exercise sessions per week (range: one to four per week). For the majority of trials, sessions are supervised by an accredited exercise physiologist (AEP) (11 trials; n = 1355), physiotherapists (four trials; n = 204) and fitness trainers (two trials; n = 80). The majority of the interventions incorporate a combined prescription of aerobic and resistance exercise (12 trials). Programs currently underway are also delivering resistance only (three trials) and aerobic only (one trial) exercise, as well as yoga (one trial). Impact exercise such as jumping, skipping, hopping and bounding prescriptions have been incorporated into the two trials examining bone mineral density as a primary outcome. Unfortunately, the intensity of the exercise wasn't specified for the majority of the trials (eight trials), with six trials requiring a moderate to vigorous intensity in line with current guidelines and the remaining three specifying a low, moderate or low-moderate intensity of exercise. Eleven of the trials indicated that the exercise prescription was individualised. Nine of the studies incorporate various other elements to the intervention. One trial was non-randomised with no comparator/control group.

Intervention length	Exercise type	Exercise intensity	Individual prescription	Other aspects of intervention	Enrolment status
3 months	Aerobic and resistance	Low to moderate	Yes	-	Recruiting
6 months	Aerobic and resistance	Moderate to vigorous	Yes	Brief psycho-sexual intervention	Recruiting
3 months	Aerobic and resistance	Not specified	Not specified	-	Recruiting
2 months	Aerobic	Not specified	Yes	Behavioural support	Recruiting
3 months	Resistance	Low	Not specified	Cognitive behaviour therapy and omega-3 supplements	Not yet recruiting*
6 months	Aerobic, resistance and impact	Moderate to vigorous	Yes	Calcium and vitamin D supplements	Recruiting
3 months	Aerobic and resistance	Moderate to vigorous	Yes	-	Recruiting
2 to 4 months (chemotherapy duration)	Aerobic and resistance	Moderate to vigorous	Yes	-	Recruiting
12 months	Resistance and impact	Moderate to vigorous	Yes	Calcium, vitamin D and protein supplements	Not yet recruiting

ACTRN12612000346875 (University of Western Sydney)	Breast	50	Natural killer cell activity	Fitness trainer (3 sessions/week)
ACTRN12614000350628 (Mount Hospital)	Breast (advanced only)	50	Fatigue	Physiotherapist supervised (2 sessions/week)
ACTRN12613000665730 (Queensland University of Technology)	Breast	48	Lymphoedema incidence	AEP supervised (1-2 sessions/week)
ACTRN12613001297718 (University of Melbourne)	Bowel	44	Pelvic floor symptoms	Physiotherapist supervised (2 sessions/week)
ACTRN12612000076875 (Edith Cowan University)	Lung	36	Physical functioning	AEP supervised (2 sessions/week)
ACTRN12611000864921 (Curtin University)	Lung	30	Cardio-pulmonary fitness	Physiotherapist supervised (3 sessions/week)
ACTRN12610000543088 (Flinders Medical Centre)	Breast	30	Lymphoedema severity	Fitness trainer (4 sessions/week)
ACTRN12614000580673 (University of Melbourne)**	Colorectal	80	Physical function	Physiotherapist supervised (1 session/week)

†Registered with the Australian New Zealand Clinical Trials Registry, Australian Cancer Trials or ClinicalTrials.gov as of 16 July 2014; *status of the trial not updated in the last 12 months; ACTRN – Australian clinical trials registration number; AEP – accredited exercise physiologist; ** This is an uncontrolled trial.

Nine of the ongoing trials in Australia incorporate predominately home-based exercise interventions (table 2). These trials are targeting a total of 1672 cancer survivors, with over half of these participants (n = 962) involved in an international trial, with participating sites in Australia.[21,22] This large trial involves survivors diagnosed with colon cancer, with the remaining trials targeting breast (2 trials; n = 300), haematologic (2 trials; n = 160), prostate (2 trials; n = 70), gynecologic (1 trial; n = 30) cancer survivors, as well as survivors with any form of cancer (1 trial; n = 150). Similar to the trials involving clinic-based exercise interventions, a wide variety of outcomes are being evaluated in these studies, with primary outcomes including disease-free survival, fatigue, physical activity level, body composition, quality of life, incontinence, lymphoedema incidence and muscle strength. The majority of these trials (eight trials; 98% of participants) incorporate ongoing support from AEPs,

***Table 2**: Summary of registered randomised control trials involving home based exercise interventions for cancer patients and survivors currently ongoing in Australia. †*

Trial registration	Cancer type	Target n-Size	Primary outcome	Nature of intervention	Level of supervision
NCT00819208 (University of Alberta, University of Sydney)[30]	Colorectal	962	Disease free survival	Home based with face-to-face support	Fitness trainer (1 session/fortnight for 6 months)
ACTRN12611001266954 (Edith Cowan University)	Breast	200	Fatigue	Home based with telephone support	AEP supervised (consult + 1 call per fortnight)
ACTRN12609001086257 (University of Newcastle)[46]	All types	150	Physical activity level	Home based with face-to-face support	AEP education sessions (6 total)
ACTRN12611000338965 (University of New South Wales)	Breast and Colon	100	Fatigue	Home based with telephone support	AEP supervised (consult + 4 calls)

4 months	Resistance	Not specified	Not specified	-	Not yet recruiting*
1.5 months	Aerobic and resistance	Not specified	Yes	-	Not yet recruiting
3 months	Aerobic and resistance	Not specified	Yes	-	Recruiting
2 months	Aerobic and resistance	Not specified	Not specified	Multi-disciplinary education	Not yet recruiting
3 months	Aerobic and resistance	Moderate to vigorous	Yes	Behavioural support	Not yet recruiting*
2 months	Aerobic and resistance	Not specified	Not specified	-	Not yet recruiting*
1 month	Yoga	Not specified	Not specified	Education	Closed: follow-up continuing
2 months	Aerobic and resistance	Moderate	Yes	Multi-disciplinary education	Not yet recruiting

physiotherapists or fitness trainers by either face-to-face and/or telephone. The nature and frequency of ongoing support varies considerably across the interventions. Similarly, the duration of intervention length varies widely, from two months to three years. The exercise prescription wasn't well defined for most trials in terms of the type and intensity of exercise involved. Eight trials specified that the program is to be individualised. Two of the trials incorporated behavioural support and two dietary education, in conjunction with the exercise program. This body of ongoing research will address a number of areas warranting investigation. While for many cancers, efficacy of exercise is established, the optimal prescription variables such as type, intensity and duration require further investigation. Likewise, evaluation of modes of delivery that overcome barriers of distance and access are important for wide-spread reach and will make an important contribution to the field. The current

Intervention length	Exercise type	Exercise intensity	Individual prescription	Other aspects of intervention	Enrolment status
36 months	Aerobic	Moderate to vigorous	Yes	Behavioural support	Recruiting
2 to 3 months (radiation duration)	Aerobic and resistance	Moderate to vigorous	Yes	-	Closed: follow-up continuing
2 months	Aerobic and resistance	Not specified	Not specified	Dietary education	Recruiting
3 months	Not specified	Not specified	Yes	Cognitive behavioural therapy	Recruiting

ACTRN12609000944235 (University of Western Australia)	Haematologic	100	Body composition	Home based with telephone support	AEP supervised (3 sessions/week for first 3 weeks)
ACTRN12611000194965 (University of Queensland)	Haematologic	60	Quality of life	Home based with telephone support	AEP supervised (consult + 1 call per fortnight)
ACTRN12612000527864 (University of Newcastle)	Prostate	40	Incontinence	Home based with telephone support	Physiotherapist supervised (1 session/fortnightly)
ACTRN12613000886785 (Monash Medical Centre)	Gynecologic	30	Lymphoedema incidence	Home based with face-to-face support	Physiotherapist supervised (5 sessions total)
ACTRN12611001169932 (University of Newcastle)	Prostate	30	Muscular strength	Home based	AEP initial consultation (no ongoing supervision)

†Registered with the Australian New Zealand Clinical Trials Registry, Australian Cancer Trials or ClinicalTrials.gov as of 16 July 2014; *status of the trial not updated in the last 12 months; NCT – National clinical trial; AEP – accredited exercise physiologist

research also addresses contemporary survivorship concerns such as sexual wellbeing, sleep disturbance and neuropathy, where exercise may play an important role in the future, and provide further rationale for the role of exercise as part of standard clinical care. While the search is limited only to projects that progressed to the stage of being registered in a primary clinical trials registry, and doesn't include other forms of research, our results give an overview of the important work being undertaken in this space in Australia.

Gaps between research and practice

The majority of Australian cancer survivors do not reach sufficient levels of physical activity (~40%) or are completely inactive (~33%).[23] This is despite endorsement from major cancer organisations nationally and internationally, as well as the reported desire of cancer survivors to participate in appropriately designed and supervised exercise programs.[24,25] Physical activity levels decrease significantly after diagnosis, and often don't return to pre-morbid levels.[26,27] The development of evidence-based programs that incorporate best practice exercise prescription, implemented by qualified allied health professionals (AEPs), and that are systematically available throughout Australia may be required. However, a multifactorial approach is needed to overcome significant challenges, including issues related to access and equity, consumer perceptions, integration with clinical practice and access to clear referral pathways.

The vast majority of the evidence has resulted from interventions delivered by health professionals. In order to optimise the benefits of exercise while maximising safety, the recommendation of exercise to a cancer survivor needs to be coupled with a referral to a qualified exercise professional. AEPs are four-year tertiary trained allied health professionals, most appropriate to provide exercise services for the prevention and management of chronic diseases and/or complex medical conditions. These specialists are highly skilled in identifying the optimal exercise prescription, which takes into account individual need, goals and circumstances. Based on current evidence, it is clear that cancer patients and survivors will benefit from the incorporation of exercise within their treatment and survivorship care plans. As such, moves to incorporate AEPs within multidisciplinary oncology teams are warranted in order to provide integrated care through dedicated exercise consultations. While this level of access to AEPs is not yet readily available throughout Australian hospitals and treatment centres, specialists and other oncology health professionals can refer patients to one of a growing number of AEPs practicing throughout Australia (there are approximately 3000 AEPs currently registered and searchable through an online directory at www.essa.org.au/find-aep/). Currently, cancer patients and survivors are eligible for up to five Medicare subsidised visits to an AEP annually through the Chronic Disease Management Plan.

Future directions

There is a pressing need for prospective randomised control trials of exercise interventions that involve best practice prescription, investigating cancer progression and survival outcomes. These large scale trials, accompanied by extended follow-up, are warranted based on promising epidemiological and animal model evidence.[2,28] Data from such trials are critical to realising the role of exercise as an adjunct therapy for the management of cancer. They are theorised to be the stimulus required to incorporate high quality exercise programs as part of standard cancer care by providing the impetus for: funding of cancer specific exercise programs; oncology specialists to refer patients; and for survivors to participate. Importantly, the optimal exercise prescription for improvement in disease outcomes is yet to be established, especially with regards

Treatment duration	Not specified	Not specified	Not specified	-	Not yet recruiting*
3 months	Not specified	Not specified	Yes	Dietary counselling	Not yet recruiting*
6 months	Pelvic floor muscle rehabilitation	Not specified	Yes	-	Not yet recruiting*
3 months	Lower limb functional exercises	Not specified	Yes	-	Not yet recruiting
3 months	Resistance	Not specified	Not specified	-	Not yet recruiting*

to the dose and timing of exercise, and whether potential effects vary by cancer site, stage or treatment factors. Canada is leading the field in this area, reporting trends towards improved disease-free survival in an exploratory analysis of breast cancer survivors (START trial).[29] As well as launching the first prospective, randomised control trial of an exercise intervention on outcomes of survival in colon cancer, which is currently open for enrolment at 26 centres in Australia (CHALLENGE trial).[30,31]

There are over 100 different types of cancer with various disease trajectories and numerous treatment options, combinations and sequences. This diversity leads to a unique series of adverse physiological side-effects that dictate the need for targeted exercise interventions based on disease and treatment variables.[32] Despite increased research efforts to explore the safety and efficacy of various exercise prescriptions for cancer survivors, there is a dearth of knowledge regarding these effects in a large number of cancer types. Research teams in Australia are starting to investigate relatively understudied cancer groups such as lung and gynaecological cancers, including cancers with poorer prognoses exemplified by pancreatic, brain and mesothelioma cancers. However, more research is required to determine targeted exercise prescription in these survivors. Furthermore, there are little data available to direct practice for advanced and palliative cancer groups. Based on the available early evidence in this area,[33-38] exercise programs show promise in providing significant functional and quality of life benefits to survivors. Importantly, these patients report a desire and perceived ability to participate in exercise programs.[39] Future research in these areas is warranted.

There remain important research questions requiring rigorous scientific investigation to advance understanding in the field of exercise and cancer. Some of the main areas warranting investigation include evaluating the effect of exercise on contemporary survivorship concerns, including understudied but problematic treatment-related effects such as cognitive decline, sexual dysfunction, compromised sleep quality, establishing cost-effectiveness and cost-utility, exploring mechanistic pathways, and developing the use of technology to overcome issues of equity and access. There is also a need to evaluate the effectiveness of systematic community-based exercise programs that can be administered as a standard supportive care service for cancer survivors throughout Australia.

In conclusion, the evidence demonstrating the benefits of exercise during and following treatment for cancer continues to mount. Further international efforts, with Australians significantly contributing to these, are underway to address current gaps in the literature. However, for the benefits of exercise to be realised on a global-scale, the greater challenge will be to translate what we know to be efficacious exercise programs in the research setting into effective programs in the community.

Acknowledgements

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LETTER TO THE EDITOR

THE RARE CANCER EXPERIENCE IN AUSTRALIA

In response to your Forum on ‘Rare Cancers’ (March 2015), rare or less common cancers (RLCs) such as neuroendocrine tumours (NETs) are often overlooked by the health system, resulting in mortality of RLCs double that of the common cancers such as breast or prostate. If you develop an uncommon cancer such as NETs, you have only 40% chance of surviving five years, compared with 90% chance of surviving five years with breast cancer. These odds have not changed for decades.

Even though the number of patients diagnosed with RLC, including NET cancers, is on the rise, and collectively outnumber some common cancers, there is very little available from patient support through to new treatment options. It is therefore the role of consumer lead groups such as The Unicorn Foundation to drive funding for clinical trials (CONTROL NETs), patient support (NET Nurse helpline), raising awareness within the medical community and general public, and advocating for access to new treatments. Unfortunately, without government support, these services are not sustainable. Successful patient outcomes rely on collaboration with the committed specialists working in these areas.

The Unicorn Foundation is grateful to work with interested, innovative and dedicated specialists in the area of NET cancer, however more can be done. A national approach to education needs to be undertaken about RLC and NET cancers and their symptoms, which often mirror more common complaints. Education programs for general practitioners are imperative for early diagnosis. There needs to be urgent action and commitment to effective registries. A cooperative approach from institutions around Australia (not just state based) is important to gather patient information to produce meaningful research and successful clinical trials.

Advancements in awareness of cancers such as ovarian in the last 10 years clearly show what can be achieved with a unified response from government, patients and advocacy groups. Support for a specific RCLs stream from organisations such as the Medical Oncology Group of Australia, the Clinical Oncology Society of Australia and Cancer Australia is imperative if we are to see any improvement to the high mortality rates of the last 20 years.

Highlighting rare cancers in your March issue is definitely a step in the right direction.

Simone Leyden
CEO The Unicorn Foundation

REPORTS

SUPPORT FOR RESEARCH FUNDING 2015

State and territory Cancer Councils, which comprise the member bodies of Cancer Council Australia, are the major non-government sponsors of cancer research and related activities in Australia.

Cancer Councils fund and conduct research that is based on scientific merit and competitive, peer-reviewed assessment to ensure the most judicious use of community fundraising, donations, bequests and merchandise sales.

In 2015, research grants through Cancer Councils totalled more than $70.5 million. Cancer Councils directly funded $48.1 million in research, with a further $22.4 million contributed by our research funding partners.

Please note: for research grants spanning more than one year, only funds to be dispersed in 2015 have been included.

CANCER COUNCIL AUSTRALIA

Cancer Council-funded external research programs

New research grants			**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Name of research program	*Recipients*	*Name of research grant*			
Priority Driven Collaborative Cancer Research Scheme	Dr Linda Mileshkin Peter MacCallum Cancer Centre	RECUPERATE: can REaltime molecular profiling in Carcinoma of Unknown Primary improvE tReAtment ouTcomEs.	$196,000	$0	$196,000
TOTAL RESEARCH FUNDED (new program)			**$196,000**	**$0**	**$196,000**
Continuing research grants					
Priority Driven Collaborative Cancer Research Scheme	Prof Anna Nowak University of Western Sydney	Phase III trial of Concurrent and Adjuvant Temozolomide chemotherapy in non-1p/19q non deleted anaplastic glioma. The CATNON Intergroup Trial.	$6,088	$0	$6,088
Priority Driven Collaborative Cancer Research Scheme	A/Prof Gianluca Severi Cancer Council Victoria	Risk and prognostic factors for glioma in Australia.	$3,044	$35,956	$39,000
Priority Driven Collaborative Cancer Research Scheme	Prof Michael Friedlander Prince of Wales Hospital	An international multi-stage randomised phase III trial of dose-fractionated chemotherapy compared to standard three-weekly chemotherapy for women with newly diagnosed epithelial ovarian cancer.	$84,000	$0	$84,000
Priority Driven Collaborative Cancer Research Scheme	Dr Peter Grimison University of Sydney	Accelerating first-line chemotherapy to improve cure rates for advanced germ cell tumours: an Australian-led, international randomised trial.	$111,000	$0	$111,000
Priority Driven Collaborative Cancer Research Scheme	A/Prof Sandi Hayes Queensland University of Technology	ECHO Trial: exercise during chemotherapy for ovarian cancer.	$98,000	$0	$98,000
TOTAL RESEARCH FUNDED (continuing program)			**$302,131**	**$35,956**	**$338,088**
TOTAL RESEARCH FUNDED **(including new and continuing research programs)**			**$498,131**	**$35,956**	**$534,088**

CANCER COUNCIL ACT

Cancer Council-funded external research programs

New research grants			Cancer Council charitable funding amount 2015	Other funding amount for 2015	TOTAL
Name of research program	*Recipients*	*Name of research grant*			
Cancer Council ACT Cancer Research Project Grant	Dr Danny Rangasamy John Curtin School of Medical Research The Australian National University	Towards repurposing existing ARV drugs as anticancer agents for breast cancer therapy.	$65,000	$0	$65,000
TOTAL RESEARCH FUNDED			**$65,000**	**$0**	**$65,000**

CANCER COUNCIL NSW

Cancer Council-funded external research programs

New research grants					
Name of research program	*Recipients*	*Name of research grant*			
Project grant	Dr Nicole Verrills University of Newcastle	A novel biomarker for luminal B breast cancer.	$119,859	$0	$119,859
The Robyn Trinder Cancer Council NSW Project Grant	Dr Jeff Holst University of Sydney	Starving cancer cells: Developing nutrient uptake inhibitors as prostate cancer therapeutics.	$120,000	$0	$120,000
The Clement Saxton Cancer Council NSW Project Grant	Prof Xu Zhang University of Newcastle	RIP1 as a novel therapeutic target in melanoma.	$107,359	$0	$107,359
Project grant	A/Prof Andrew Spillane University of Sydney	EvAluation of Groin Lymphadenectomy Extent For metastatic Melanoma (Inguinal or Ilio-inguinal Lymphadenectomy for metastatic melanoma to groin lymph nodes and no pelvic disease on PET/CT Scan - a randomised controlled trial); ANZMTG 01.12 EAGLE FM Study.	$120,000	$0	$120,000
Project grant	Prof David (Neil) Watkins Garvan Institute of Medical Research	Rational targeting of the Hedgehog pathway to treat osteosarcoma.	$120,000	$0	$120,000
The Valerie Enid Legge Cancer Council NSW Project Grant	Prof Xu Zhang University of Newcastle	Elevated INPP4B as a biomarker and therapeutic target in colorectal cancer.	$112,359	$0	$112,359
Project grant	Dr Jenny Wang University of NSW	Identifying and targeting a novel self-renewal signalling cascade in leukemic stem cells.	$119,905	$0	$119,905

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Project grant	Dr Anthony Cesare Childrens Medical Research Institute	Kinsase signalling in the Intermediate-state Telomere cell cycle Arrest Pathway (ITAP) during human ageing and in disease.	$120,000	$0	$120,000
Project grant	Dr Ian Johnston University of Sydney	Ibudilast as a therapy for chemotherapy-induced neuropathic pain and cognitive impairments.	$117,463	$0	$117,463
Project grant	Dr Catherine Caldon Garvan Institute of Medical Research	Aneuploidy as a driver of endocrine resistant breast cancer.	$120,000	$0	$120,000
Project grant	Dr Kenneth Micklethwaite University of Sydney	Gene modified T cells expressing a chimeric antigen receptor for a kappa light chain antigen to treat multiple myeloma.	$112,359	$0	$112,359
Project grant	Dr Karen Mackenzie University of NSW	Dyskerin as a novel therapeutic target in neoplastic cells.	$107,359	$0	$107,359
Project grant	Prof Christine Clarke University of Sydney	Role of progesterone in normal breast and its convergence with estrogen action in breast cancer.	$119,859	$0	$119,859
Project grant	A/Prof Marcel Dinger Garvan Institute of Medical Research	Genetic stratification of tumours of the head, neck, pituitary and skull base - identifying prognostic and new therapeutic targets.	$120,000	$0	$120,000
Project grant	Prof David (Neil) Watkins Garvan Institute of Medical Research	Targeting innate chemoresistance in lung adenocarcinoma.	$88,859	$0	$88,859
Project grant	Prof Robert Baxter University of Sydney	Breast cancer therapies that target IGFBP-3 signalling.	$120,000	$0	$120,000
Project grant	A/Prof Bettina Meiser University of NSW	When the stakes are high: psychosocial and behavioural impact of genomic testing for cancer risk.	$118,923	$0	$118,923
Project grant	Prof Anna DeFazio University of Sydney	Novel treatment targets in low-grade serous ovarian cancer.	$119,541	$0	$119,541
Priority-driven Collaborative Cancer Research Scheme	Prof Jacob George University of Sydney	HCC Outcomes mitigation and disease PrEvention through Clinical Partnerships (HOPE).	$170,000	$0	$170,000
TOTAL RESEARCH FUNDED (new program)			**$2,253,845**	**$0**	**$2,253,845**

Continuing research grants

Program grant	Prof Philip Hogg University of New South Wales	Metabolism inhibitors for the treatment of brain and pancreatic cancer.	$450,000	$0	$450,000
Program grant	Prof Murray Norris University of New South Wales	Toward cure of childhood ALL: improved diagnostics, therapeutics and prevention strategies.	$450,000	$0	$450,000
Program grant	Prof Chris Ormandy Garvan Institute of Medical Research	Personalising breast cancer management by discovering the transcriptional basis for tumour phenotype.	$450,000	$0	$450,000

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Program grant	Prof Roger Reddel Children's Medical Research Institute	Alternative Lengthening of Telomeres: from basic biology to drug discovery.	$450,000	$0	$450,000
Project grant	Prof Minote Apte University of New South Wales	Targeting the stroma in pancreatic cancer - a novel therapeutic approach focusing on the hepatocyte growth factor/c-MET pathway.	$120,000	$0	$120,000
Project grant	Dr Linda Bendall University of Sydney	Sphingosine kinases as potential therapeutic targets for acute lymphoblastic leukemia.	$120,000	$0	$120,000
Project grant	Prof Samuel Breit St Vincents Hospital	The role of the TGF-b superfamily cytokine MIC-1/GDF15 in cancer growth and spread.	$119,552	$0	$119,552
Project grant	Prof Xu Zhang University of Newcastle	Targeting PP2A to improve the therapeutic efficacy of mutant BRAF inhibitors in melanoma.	$119,750	$0	$119,750
Project grant	Prof Christine Clarke University of Sydney	Determinants of genomic binding of the progesterone receptor in endocrine target cells.	$120,000	$0	$120,000
Project grant	Dr Nicholas Haass University of Sydney	Effect of three-dimensional tumour organisation on the sensitivity of individual melanoma cells to endoplasmic reticulum stress.	$119,892	$0	$119,892
Project grant	Prof Robyn Ward University of New South Wales	Genetic determination of hereditary MLH1 epimutation as a cause for familial cancer.	$104,892	$0	$104,892
Project grant	A/Prof Lisa Horvath Garvan Institute of Medical Research	Novel strategies to overcome docetaxel resistance in castration-resistant prostate cancer.	$120,000	$0	$120,000
Project grant	Dr Tao Liu University of New South Wales	The critical role of the long intergenic noncoding RNA MALAT1 in neuroblastoma.	$118,552	$0	$118,552
Project grant	A/Prof Deborah Marsh University of Sydney	Monoubiquitinated histone H2B? marking key pathways in ovarian cancer.	$104,892	$0	$104,892
Project grant	Prof Markus Seibel University of Sydney	Novel cytoplasmic functions of the vitamin D receptor in bone metastases.	$119,892	$0	$119,892
Project grant	Dr Elena Shklovskaya University of Sydney	Role of dendritic cell subsets in regulating CD4 T cell memory responses in inflammation and cancer.	$119,062	$0	$119,062
Project grant	Prof Xu Zhang University of Newcastle	Functional consequences of epigenetic repression of PIB5PA in melanoma.	$119,750	$0	$119,750
Project grant	Dr Kerrie McDonald University of New South Wales	The biological basis of success or failure to the anti-VEGF agent, bevacizumab in patients with recurrent glioblastoma.	$117,422	$0	$117,422
Project grant	Prof Edna Hardeman University of New South Wales	The role of epigenetic modifications in longterm memory of irradiation in cancer survivors.	$120,000	$0	$120,000
Project grant	Prof Christopher Liddle University of Sydney	Novel approaches to target cancer stem cells in liver cancer.	$120,187	$0	$120,187

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Project grant	Prof Jacqui Matthews University of Sydney	Developing inhibitors of the LMO4 oncoprotein.	$119,037	$0	$119,037
Project grant	Dr Jeremy Henson Lowy Research Institute University of NSW	Development of the C-Circle biomarker as a cancer diagnostic.	$116,149	$0	$116,149
Project grant	Prof John Rasko Centenary Institute	Consequences of CTCF haploinsufficiency in endometrial carcinoma.	$120,000	$0	$120,000
Project grant	Dr Lionel Hebbard University of Sydney	Metabolic drivers of liver cancer progression.	$120,000	$0	$120,000
Project grant	Prof Peter Croucher Garvan Institute of Medical Research	Defining the critical role of osteoclasts in multiple myeloma cell growth and activation in bone.	$120,000	$0	$120,000
Project grant	Dr Paul Timpson Garvan Institute of Medical Research	Optimising ECM-targeted therapy in cancer using live intravital FRET biosensor imaging.	$119,037	$0	$119,037
Project grant	Prof John Rasko Centenary Institute	Consequences of CTCF mutation in acute lymphoblastic leukaemia.	$119,899	$0	$119,899
Project grant	Prof David Thwaites University of Sydney	Do treatment delivery uncertainties limit the effectiveness of advanced technology radiotherapy treatments?	$119,999	$0	$119,999
Project grant	Prof Michael Rogers Garvan Institute of Medical Research	A new use for old drugs: Anti-tumour effects of bisphosphonates via tumour-promoting myeloid cells.	$120,000	$0	$120,000
Project grant	Dr Megan Chircop Children's Medical Research Institute	Defining the cellular determinants that drive dynamin inhibitor induced cell death and in vivo efficacy against glioblastoma.	$120,000	$0	$120,000
Project grant	Dr Scott Byrne University of Sydney	Skin cancer prevention and treatment by targeting sunlight-activated regulatory B cells.	$120,000	$0	$120,000
Project grant	Dr Hilda Pickett Children's Medical Research Institute	Altered teleomeric chromatin and its role in alternative lengthening of telomeres.	$106,149	$0	$106,149
Project grant	Dr Glen Reid Asbestos Diseases Research Institute	MicroRNA replacement: a novel therapeutic approach for malignant mesothelioma.	$114,380	$0	$114,380
Project grant	Prof John Mattick Garvan Institute of Medical Research	Modular RNA structures guiding epigenetic differentiation.	$117,719	$0	$117,719
Strategic research partnership grant	Prof Andrew Biankin Garvan Institute of Medical Research	Genotype Guided Cancer Therapy (Genomic Theranostics).	$300,000	$0	$300,000
Strategic research partnership grant	Prof Rob Sanson-Fisher University of Newcastle	Behavioural Science Strategic Research Partnership.	$400,000	$0	$400,000
Strategic research partnership grant	A/Prof Gail Garvey Menzies School of Health Research	Strategic Research Partnership to improve cancer control for Indigenous Australians (STREP Ca-CIndA).	$379,258	$0	$379,258

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Strategic research partnership grant	Dr Gillian Mitchell University of Melbourne	The Inherited Cancer Connect (ICon) Partnership.	$391,952	$0	$391,952
Strategic research partnership grant	Prof Andrew Grulich University of New South Wales	Preventing morbidity and mortality from anal cancer.	$400,102	$0	$400,102
45 and Up	Prof Sally Redman Sax Institute	45 and Up Study.	$400,000	$0	$400,000
Priority driven Collaborative Cancer Research Scheme	Dr Kerrie McDonald University of New South Wales	Mechanisms underpinning how brain cancer cells respond to drugs.	$6,175	$0	$6,175
Priority driven Collaborative Cancer Research Scheme	A/Prof Claire Vajdic University of New South Wales	Risk and prognostic factors for glioma in Australia.	$3,044	$0	$3,044
Priority driven Collaborative Cancer Research Scheme	Dr Anna Nowak University of Sydney	Phase III trial of Concurrent and Adjuvant Temozolomide chemotherapy in non-1p/19q non deleted anaplastic glioma. The CATNON Intergroup Trial.	$6,088	$0	$6,088
Priority driven Collaborative Cancer Research Scheme	Dr Lorriane O'Reilly The Walter and Eliza Hall Institute of Medical Research	Understanding the role of NF-kB in the progression of gastric adenocarcinomas and assessment of new therapies	$181,344	$0	$181,344
TOTAL RESEARCH FUNDED (continuing program)			**$7,804,175**	**$0**	**$7,804,175**
TOTAL CANCER COUNCIL-FUNDED EXTERNAL RESEARCH PROGRAMS (including new and continuing research grants)			**$10,058,020**	**$0**	**$10,058,020**

In-house research programs

New research grants

Name of research program			
Australian Research Council Linkage Program. Applying a logic model to link unhealthy food promotion to childhood obesity. Dr Bridget Kelly (University of Wollongong), Kathy Chapman and Clare Hughes (Cancer Council NSW)	$20,000	$67,716	$87,716
Australian Research Council Linkage Program. The independent and combined effects of front-of-pack food labelling systems and health claims on consumers' food-related beliefs and behaviours. Prof Simone Pettigrew (Curtin University of Technology), Clare Hughes (Cancer Council NSW)	$20,000	$146,703	$166,703
Australian Research Council Linkage Program. Enhancing community knowledge and engagement with law at the end of life. Prof Ben White (Queensland University of Technology), Angela Pearce (Cancer Council NSW)	$11,167	$178,036	$189,203
Formative research to guide development of Healthy Sports Club Program. Dr Bridget Kelly (University of Wollongong), Vanessa Rock (Cancer Council NSW)	$41,000	$0	$41,000
Evaluation of the Cancer Council NSW Smoke Free Living Resource and Qualitative Research and Evaluation Capacity Building. James Newland (University of NSW), Michelle Havill and Scott Walsberger (Cancer Council NSW)	$15,000	$0	$15,000
Assessing current strata smoke-free by-laws in NSW. Taverner Research, Michelle Havill and Scott Walsberger (Cancer Council NSW)	$7,700	$0	$7,700
TOTAL RESEARCH FUNDED (new program)	**$114,867**	**$392,455**	**$507,322**

Name of research program	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Continuing research programs			
Cancer Institute Partnership funding. Skin Cancer Prevention Strategy targeting men aged 40 and over; piloting a settings based approach. Vanessa Rock and Irena Brozek (Cancer Council NSW)	$0	$93,763	$93,763
NHMRC Partnership Grant. Who decides and at what cost? Comparing patient, surrogate, and oncologist perspectives on end of life care. Prof Robert Sanson-Fisher (University of Newcastle) & Angela Pearce (Cancer Council NSW)	$37,225	$84,037	$121,262
Cancer Institute Evidence to Practice Grant. Evaluation of a SunSmart primary school policy support intervention. Dr Dean Dudley (Charles Sturt University), Jackie McIver, Vanessa Rock, Kirsten Jackson (Cancer Council NSW)	$30,000	$10,000	$40,000
Cancer Institute Evidence to Practice Grant. Tackling tobacco among Aboriginal families with dependent children: integrating smoking care within family services. Scott Walsberger (Cancer Council NSW)	$1,500	$8,850	$10,350
Australian Research Council Linkage Program. Improving cancer treatment systems: a randomised controlled trial of a consumer action model for cancer patients receiving chemotherapy. Prof Robert Sanson-Fisher (Univesity of Newcastle), Anita Tang, Kathy Chapman, Elizabeth Humphries (Cancer Council NSW)	$53,040	$0	$53,040
NHMRC Project Grant. Cost effectiveness of a systems change intervention for smoking cesation in drug and alcohol treatment centres. A/Prof Billie Bonevski (University of Newcastle), Scott Walsberger (Cancer Council NSW)	$21,577	$207,413	$228,990
NHMRC Partnership Grant. A randomised control trial of online versus telephones based information and support: Can electronic platforms deliver effective care for lung cancer patients? A/Prof Christine Paul (Univesity of Newcastle), Lorna O'Brien (Cancer Council NSW)	$72,000	$77,812	$149,812
Australian Research Council Linkage Program. Rekindle sexuality after cancer: development and testing of a novel web-based psycho-educational resource for both survivors and their partners. Dr Catalina Lawsin (University of Sydney), Annie Miller (Cancer Council NSW	$35,000	$95,500	$130,500
NHMRC Partnership Grant. Healthy Living after Cancer – A partnership project between the NSW, VIC, WA and SA Cancer Councils and the Cancer Prevention Research Centre, University of QLD. Prof Liz Eakin (Cancer Prevention Research Centre, University of Queensland), Kathy Chapman, Lorna O'Brien (Cancer Council NSW)	$35,000	$274,940	$309,940
Three year strategic plan to address sun exposure, skin cancer prevention and vitamin D. University of Newcastle	$15,000	$0	$15,000
Modelling of reducing retail availability of tobacco products. Hunter Medical Research Institute	$25,000	$0	$25,000
Evaluation of the 2014/15 Sun Sound communications campaign. Taverner Research	$10,000	$0	$10,000
Readership survey of Understanding Cancer publications. Angela Pearce, Elizabeth Humphries and Kathy Chapman (Cancer Council NSW)	$5,000	$0	$5,000
Evaluation of the ProBono Program. Angela Pearce, Sarah Penman and Kathy Chapman (Cancer Council NSW)	$2,000	$0	$2,000
Evaluation of Cancer Council Information Centres. Angela Pearce, Annie Miller and Kathy Chapman (Cancer Council NSW)	$2,000	$0	$2,000
NHMRC Early Career Fellowship Grant (A/Prof David Smith). Causes of death in men with prostate cancer.	$0	$60,290	$60,290

Name of research program	Cancer Council charitable funding amount 2015	Other funding amount for 2015	TOTAL
Strategic Research Partnership to improve cancer control for Indigenous Australians (STREP Ca-CIndA). Prof Dianne O'Connell (Cancer Council NSW) and A/Prof Gail Garvey and Prof Joan Cunningham (Menzies School of Health Research)	$0	$98,956	$98,956
NHMRC Centres of Research Excellence Grant: Centre of Research Excellence in Discovering Indigenous Strategies to Improve Cancer Outcomes via Engagement, Research Translation and Training (DISCOVER-TT). Prof Dianne O'Connell (Cancer Council NSW) and A/Prof Gail Garvey and Prof Joan Cunningham (Menzies School of Health Research)	$0	$91,600	$91,600
Prostate Cancer Foundation of Australia Grant (Prof Dianne O'Connell). Clinical practice guidelines for PSA testing and management of test-detected prostate cancer.	$0	$22,420	$22,420
Prostate Cancer Foundation of Australia Grant (Prof Dianne O'Connell). Testing and treatment for prostate cancer in Australia: Epidemiology and modelling.	$0	$244,346	$244,346
NHMRC Partnership Grant. Improving evidence-based care for locally advanced prostate cancer: a randomised phased trial of clinical guideline implementation through a clinical network. Prof Sally Redman (Sax Institute), Prof Dianne O'Connell and A/Prof David Smith (Cancer Council NSW)	$0	$119,074	$119,074
A number of cancer modelling and screening grants being transferred from University of NSW to Cancer Council NSW (A/Prof Karen Canfell): a) Compass pilot Victorian cytology service. b) NZ consultancy HPV testing modelling. c) NHMRC Project Grant, Evaluation of outcomes and cost-effectiveness of implementing next generation vaccination and associated primary HPV-based cervical cancer screening strategies in Australia. d) NHMRC Project Grant, Effectiveness and cost-effectiveness of systematic screening for Lynch Syndrome. e) Prostate Foundation of Australia (Cancer Council NSW lead). f) NHMRC CDF Evaluation of new screening strategies for prevention of cancer; g) Health economic evaluation of new approaches to screening for cancers of the cervix, prostate, colorectum and lung.	$0	$853,190	$853,190
Internal general infrastructure funding for the operation of the Cancer Research Division. A/Prof Karen Canfell	$610,000	$0	$610,000
Cancer Causes Program funding for core research projects and staff. A/Prof Freddy Sitas	$400,000	$0	$400,000
Health Services Research Program, core funding for research support staff to oversee and work on various projects. Prof Dianne O'Connell	$860,000	$0	$860,000
45 and Up Study.	$125,000	$0	$125,000
Biobank operational costs.	$100,000	$0	$100,000
Cancer Lifestyle Evaluation and Risk: a case-control study in NSW (the CLEAR Study). A/Prof Freddy Sitas	$450,000	$0	$450,000
Learning how Australian's deal with menapausal symptoms (Lady Study). Dr Louiza Velentzis	$40,000	$0	$40,000
Tour de Cure Scholarship top-up (Ms Usha Salagane). Hormone replacement therapy: bisphosphonates and cancer	$10,000	$0	$10,000
Linked datasets for Patterns of Care.	$110,000	$0	$110,000
State of Cancer Control Report. Dr Eleonora Feletto	$95,000	$0	$95,000
TOTAL RESEARCH FUNDED (continuing program)	**$3,144,342**	**$2,342,191**	**$5,486,533**

Name of research program	Cancer Council charitable funding amount 2015	Other funding amount for 2015	TOTAL
TOTAL IN-HOUSE RESEARCH PROGRAMS FUNDING **(including new and continuing research grants)**	**$3,259,209**	**$2,734,646**	**$5,993,855**
TOTAL RESEARCH FUNDED **(including Cancer Council-funded external research programs and In-house research programs)**	**$13,317,229**	**$2,734,646**	**$16,051,875**

CANCER COUNCIL QUEENSLAND

Cancer Council-funded external research programs

New research grants

Research project grant	A/Prof Helen Blanchard Griffith University	Development of inhibitors targeting the cancer promoting protein galectin-3.	$100,000	$0	$100,000
Research project grant	Prof Judith Clements Queensland University of Technology	PSA coding variants: functional analysis, multiethnic association and risk models for prostate cancer.	$100,000	$0	$100,000
Research project grant	Dr Lachlan Coin University of Queensland	Using somatic copy number and methylation profiling of circulating tumour DNA to monitor heterogeneous tumour development in breast cancer.	$100,000	$0	$100,000
Research project grant	Prof Thomas Gonda University of Queensland	A small molecule screen for inhibitors of the MYB oncoprotein.	$100,000	$0	$100,000
Research project grant	Dr Elke Hacker Queensland University of Technology	New technologies in skin cancer prevention.	$100,000	$0	$100,000
Research project grant	Prof Geoffrey Hill Queensland University of Technology	Understanding and optimizing graft-versus-myeloma effects after bone marrow transplantation.	$100,000	$0	$100,000
Research project grant	Prof John A/Hooper Queensland University of Technology	Targeting CDCP1 to reduce tumour burden and ascites in clear cell ovarian cancer.	$100,000	$0	$100,000
Research project grant	Dr Murugan Kalimutho Queensland University of Technology	Cep55 is a determinant of aneuploidy cell fate in breast cancer.	$100,000	$0	$100,000
Research project grant	Prof Kum Kum Khanna Queensland University of Technology	The role of PC4 in the tumourigenesis and metastasis of breast cancer.	$100,000	$0	$100,000

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Research project grant	Prof Peter Koopman University of Queensland	Nodal/cripto signalling in germ cell development and tumorigenesis.	$100,000	$0	$100,000
Research project grant	Dr Roberta Mazzieri University of Queensland	Targeting the proangiogenic and immunosuppressive tumour microenvironment in primary and metastatic breast cancer.	$100,000	$0	$100,000
Research project grant	Prof Nigel McMillan Griffith University	Novel therapeutic targets for HPV-driven cancers.	$97,000	$0	$97,000
Research project grant	Prof Colleen Nelson Queensland University of Technology	Development of YB-1 as a therapeutic target in advanced prostate cancer.	$100,000	$0	$100,000
Research project grant	Prof Kenneth O'Byrne Queensland University of Technology	MyRIP and exosomes function to control genomic stability.	$100,000	$0	$100,000
Research project grant	Dr Allison Pettit Queensland University of Technology	Macrophages facilitate prostate cancer bone metastasis.	$100,000	$0	$100,000
Research project grant	Dr Pamela Pollock Queensland University of Technology	Understanding FGFR2 activation in endometrial cancer: Novel mutations, differences in spatio-temporal signaling and alternative activating spliceforms.	$100,000	$0	$100,000
Research project grant	Prof Mark Smyth Queensland University of Technology	A new checkpoint target of cancer immunotherapy.	$100,000	$0	$100,000
Research project grant	A/Prof Amanda Spurdle Queensland University of Technology	Clinical classification of BRCA1/2 gene variants.	$100,000	$0	$100,000
Research project grant	A/Prof Richard Sturm University of Queensland	Human pigmentation pathway in UV-protection and mechanisms of melanoma risk.	$100,000	$0	$100,000
Research project grant	Prof Andreas Suhrbier Queensland University of Technology	Regulation of mTORC2 and Ras signalling by Sin1 isoforms in pancreatic cancer.	$100,000	$0	$100,000
Research project grant	Dr Michele Teng Queensland University of Technology	The role of IL-23 associated cytokines in cancer immunology.	$100,000	$0	$100,000
Research project grant	Prof Brandon Wainwright University of Queensland	A synthetic lethal based approach for the treatment of medulloblastoma.	$100,000	$0	$100,000

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Research project grant	Prof Alpha Yap University of Queensland	Controlling the Rho off-switch: a novel target in breast cancer.	$100,000	$0	$100,000
Travelling fellowships	By invitation		$35,000	$0	$35,000
TOTAL RESEARCH FUNDED (new program)			**$2,332,000**	**$0**	**$2,332,000**

Continuing research programs

Research project grant	Prof Andrew Boyd QIMR Berghofer Medical Research Institute	Characterisation of the function and therapeutic potential of EphA2 and EphA3 in prostate cancer.	$100,000	$0	$100,000
Research project grant	Dr Glenn Boyle QIMR Berghofer Medical Research Institute	Investigating phenotype plasticity in melanoma progression and drug resistance.	$100,000	$0	$100,000
Research project grant	Prof Judith Clements Queensland University of Technology	KLK4 is a key regulator of the reactive stromal microenvironment in prostate cancer.	$100,000	$0	$100,000
Research project grant	Dr Nicole Cloonan QIMR Berghofer Medical Research Institute	MicroRNAs and isomiRs as chemosensitisers in double-stranded break repair defective cancer.	$100,000	$0	$100,000
Research project grant	Dr Bryan Day QIMR Berghofer Medical Research Institute	Understanding the function of salinomycin as a DNA damaging agent and its relevance as a potential therapeutic agent for the treatment of malignant brain tumours.	$100,000	$0	$100,000
Research project grant	A/Prof Greig de Zubicaray University of Queensland	A prospective study of language function following surgical resection of left hemisphere primary brain tumours.	$100,000	$0	$100,000
Research project grant	Dr Thomas Haselhorst Griffith University	Development of a novel glycotherapy for the treatment of B cell derived non-Hodgkin lymphoma.	$100,000	$0	$100,000
Research project grant	Dr Graham Leggatt University of Queensland	Memory CD8 T cell subsets in non-melanoma skin cancer.	$100,000	$0	$100,000
Research project grant	Dr Kelli MacDonald QIMR Berghofer Medical Research Institute	Investigations of the cellular and molecular mediators of chronic graft versus host disease.	$100,000	$0	$100,000
Research project grant	A/Prof Jennifer Martin University of Queensland	Targeting existing therapies with innovative technology platforms to improve survival in brain cancer.	$100,000	$0	$100,000
Research project grant	Prof George Muscat University of Queensland	Protein Arginine Methyltransferase 6 dependent signalling in breast cancer.	$100,000	$0	$100,000

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Research project grant	Prof Colleen Nelson Queensland University of Technology	Characterising insulin signalling in androgen-deprived prostate cancer cells; rationalising current metabolic therapies for adjuvant use in advanced prostate cancer.	$100,000	$0	$100,000
Research project grant	Dr Allison Pettit Mater Research Institute - University of Queensland	The role of macrophages in facilitating hematopoietic stem cell engraftment and reconstitution.	$100,000	$0	$100,000
Research project grant	A/Prof Sally-Ann Poulsen Griffith University	Development of bimodel MRI/PET imaging agents for imaging of hypoxia: the best of both worlds.	$100,000	$0	$100,000
Research project grant	Dr Tarl Prow University of Queensland	Automated image analysis development for early non-melanoma skin cancer detection.	$78,000	$0	$78,000
Research project grant	Dr Derek Richard Queensland University of Technology	BanF1: A critical regulator of the ageing process and genome stability *Koa Iris Greer Research Grant.*	$100,000	$0	$100,000
Research project grant	Dr Aaron Smith University of Queensland	Investigating the role of the NR4A nuclear receptor family in melanocyte function and tumourigenesis.	$100,000	$0	$100,000
Research project grant	Prof Stephen Taylor University of Queensland	Complement C3a receptor, a novel therapeutic target for melanoma.	$100,000	$0	$100,000
Research project grant	A/Prof Jolieke Van der Pols University of Queensland	Risk factors for sessile serrated adenoma.	$100,000	$0	$100,000
Research project grant	Dr Graeme Walker QIMR Berghofer Medical Research Institute	Characterisation of a novel naevus modifier gene on murine chromosome 8.	$100,000	$0	$100,000
Research project grant	Dr James Wells University of Queensland	Chemokine involvement in the differential response of actinic keratosis and squamous cell carcinoma to imiquimod therapy.	$100,000	$0	$100,000
Research project grant	Dr Ingrid Winkler Mater Research Institute - University of Queensland	A new approach to tackling chemotherapy-induced mucositis.	$100,000	$0	$100,000
Research project grant	Dr Bena Cartmill University of Queensland	Does a computerised swallowing, nutrition, and distress screening tool capture those patients and carers who need face-to-face intervention during (chemo)radiotherapy for head and neck cancer?	$25,152	$0	$25,152
Strategic research partnership grant	Prof Frank Gardiner University of Queensland	A randomised trial of robotic and open prostatectomy: integrated multidisciplinary studies to guide patient management.	$150,000	$0	$150,000
Senior research fellowship	A/Prof Sandra Hayes Queensland University of Technology	Exercise is medicine: a non-pharmacological approach to cancer care.	$134,589	$0	$134,589

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Senior research fellowship	Prof Nicholas Saunders University of Queensland	Translating basic science into better cancer treatments.	$155,188	$0	$155,188
Senior research fellowship	Dr Kelli MacDonald QIMR Berghofer Medical Research Institute	Requirements for class II antigen presentation to generate curative anti-leukaemic responses and immunocompetence after transplantation.	$151,070	$0	$151,070
Chair of cancer prevention research	Prof Michael Kimlin University of the Sunshine Coast	Joint Professor of Cancer Prevention Research.	$100,000	$0	$100,000
PhD scholarship	Mr Nicholas Ashton Queensland University of Technology	Characterisation of the role and regulation of human single-stranded DNA binding protein (hSSB1) post-translational modifications. *Marylyn Mayo Scholar*	$30,000	$0	$30,000
PhD scholarship	Ms Mary Mihuta Grifith University	Joint Cancer Council Queensland/ Griffith University PhD Scholarship: A modern-day approach: assessing the effectiveness of web-based cognitive rehabilitation in cancer survivors.	$15,000	$15,000	$30,000
PhD scholarship	Mr Mark Bettington QIMR Berghofer Medical Research Institute	The histological, immunohistochemical and molecular genetic features of serrated colorectal polyps.	$15,000	$0	$15,000
PhD scholarship	Arabella Young QIMR Berghofer Medical Research Institute	Targeted therapy and immunotherapy in breast cancer.	$30,000	$0	$30,000
PhD scholarship	Dr Matthew Roberts University of Queensland	Improving the early detection of prostate cancer: a non-invasive, systems biology approach.	$30,000	$0	$30,000
Cancer Clinical Trial Data Manager Grants	-Cairns Hospital -Gold Coast Hospital -Icon Cancer Care - HOCA Research Centre -Mater Health Services - Medical Oncology & Palliative Care -Nambour Hospital -Oncology Research Australia -Premion -Prince Charles Hospital -Princess Alexandra Hospital – (Surgery, Haematology & Medical Oncology, Radiation Oncology) -Radiation Oncology Services - Mater Centre -Royal Brisbane and Women's Hospital – Gynaecological Cancer, Medical Oncology, Radiation Oncology, Brisbane Colorectal Group -Royal Children's Hospital -Townsville Hospital -Wesley Research Institute		$464,750	$921,250	$1,386,000
TOTAL RESEARCH FUNDED (continuing program)			**$3,478,749**	**$936,250**	**$4,414,999**
TOTAL CANCER COUNCIL-FUNDED EXTERNAL RESEARCH PROGRAMS (including new and continuing research grants)			**$5,810,749**	**$936,250**	**$6,746,999**

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
In-house research programs					
Continuing research programs					
Name of research program					
Viertel Cancer Research Centre			$4,833,693	$1,015,472	$5,849,165
Epidemiology			$434,434	$214,891	$649,325
- Breast Cancer Outcomes Study					
- Geographic inequalities in cancer survival					
Psycho-oncology			$136,435	$281,159	$417,594
- Mindfulness intervention for advanced prostate cancer					
- CancerCope					
- 1,000 Survivor Study					
Community Engagement			$160,894	$0	$160,894
- Engagement with law at end of life					
- Episodic and long-term volunteering					
Australian Paediatric Cancer Registry			$120,798	$0	$120,798
Queensland Cancer Registry			$499,770	$939,000	$1,438,770
TOTAL RESEARCH FUNDED (continuing program)			**$6,186,024**	**$2,450,522**	**$8,636,546**
TOTAL IN-HOUSE RESEARCH PROGRAMS FUNDING (including new research and continuing research grants)			**$6,186,024**	**$2,450,522**	**$8,636,546**
TOTAL RESEARCH FUNDED (including Cancer Council-funded external research programs and In-house research programs)			**$11,996,773**	**$3,386,772**	**$15,383,545**

CANCER COUNCIL SA

Cancer Council-funded external research programs

New research grants			Cancer Council charitable funding amount 2015	Other funding amount for 2015	TOTAL
Name of research program	*Recipients*	*Name of research grant*			
Project grant	Prof Stuart Pitson University of South Australia	Targeting sphigosine kinase 1c degradation to enhance cancer chemotherapeutic sensitivity.	$37,500	$37,500	$75,000
Project grant	A/Prof Natasha Harvey University of South Australia	Regulation of neuro-vascular patterning and morphogenesis by semaphorin/neuropilin signalling.	$37,500	$37,500	$75,000
Project grant	Dr Shaun McColl The University of Adelaide	Regulation of the anti-tumour immune response by a novel chemokine receptor.	$37,500	$37,500	$75,000
Project grant	Dr Michael Samuel University of South Australia	Defining the function of ROCK in establishing a tumour-promoting microenvironment.	$37,500	$37,500	$75,000
Project grant	A/Prof Yeesim Khew-Goodall University of South Australia	Regulating EGFR in breast cancer.	$37,500	$37,500	$75,000
Project grant	Prof Shudong Wang University of South Australia	CDK9 inhibitors for the treatment of castration resistant prostate cancer.	$37,500	$37,500	$75,000
Project grant	Prof Andrew Zannettino University of Adelaide	Cooperating genetic changes that drive MM development: the role of the SAMSN1 and GLIPR1 tumour suppressor genes.	$37,500	$37,500	$75,000
Project grant	Prof Graeme Young Flinders University	A BlOOd teST for colorectal cancer screening (BOOST): Program outcomes relative to faecal occult blood tests.	$37,500	$37,500	$75,000
Travel grants*	To be awarded		$15,000	$15,000	$30,000
PhD Top Up Scholarships	Awarded to two recipients		$17,500	$17,500	$35,000
Infrastructure funding*	To be awarded	One year infrastructure grants.	$560,000	$560,000	$1,120,000
Cancer Council SA research fellow (cancer support)*	Dr Kate Gunn		$65,000	$0	$65,000
TOTAL RESEARCH FUNDED (new program)			**$957,500**	**$892,500**	**$1,850,000**

** Based on financial year to 30 June 2015*

Continuing research programs

Research Chair*	Prof Tim Hughes University of Adelaide		$125,000	$375,000	$500,000

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Research Chair*	Prof David Roder University of South Australia		$125,000	$375,000	$500,000
Research Chair*	Prof Ross McKinnon Flinders University		$125,000	$375,000	$500,000
Principal Research Fellow*	Dr Daniel Worthley University of Adelaide	Identifying and targeting the important supportive cells in cancer.	$105,000	$315,000	$420,000
Principal Research Fellow*	Prof Shudong Wang University of South Australia	New therapeutics for cancer treatment.	$105,000	$315,000	$420,000
Principal Research Fellow*	Dr Caroline Miller South Australian Health and Medical Research Institute (SAHMRI)	Packaging and labeling of tobacco products, food and alcohol.	$105,000	$315,000	$420,000
Hospital Packages*	Prof Guy Maddern The Queen Elizabeth Hospital	Individualised risk assessment and therapeutic intervention for colorectal cancer in South Australia.	$187,500	$562,500	$750,000
Hospital Packages*	Prof David Watson Flinders University	Flinders Centre for Gastrointestinal Cancer Prevention.	$187,500	$562,500	$750,000
Hospital Packages*	Prof Tim Hughes Royal Adelaide Hospital	Advancing T-cell therapy for leukaemia and glioblastoma.	$187,500	$562,500	$750,000
Partnership Grant*	Prof Alex Brown University of South Australia	Cancer Data and Aboriginal Disparities Project.	$125,000	$375,000	$500,000
Infrastructure Funding*	Awarded to nine recipients	Data manager and microarray support.	$97,500	$97,500	$195,000
Infrastructure Funding*	Mr Andrew Stanley University of South Australia	SANT DataLink.	$151,425	$454,275	$605,700
Peter Nelson Leukaemia Research Fellow*	Dr Hayley Ramshaw University of South Australia		$100,000	$0	$100,000
Cancer Genome Facility	Prof Angel Lopez Centre for Cancer Biology		$105,000	$0	$105,000
Cancer Council SA Foundation Chair in behavioural research*	Prof Carlene Wilson Flinders University		$250,000	$0	$250,000
South Australian Clinical Cancer Registry*	SA Health	Central Coordination Unit	$70,000	$250,000	$320,000
TOTAL RESEARCH FUNDED (Continuing Program)			**$2,151,425**	**$4,934,275**	**$7,085,700**
** Based on financial year to 30 June 2015*					
TOTAL EXTERNALLY FUNDED RESEARCH PROGRAMS (including new and continuing research grants)			**$3,108,925**	**$5,826,775**	**$8,935,700**

Name of research program	Cancer Council charitable funding amount 2015	Other funding amount for 2015	TOTAL

In-house research programs

Continuing Research Programs

Behavioural Research and Evaluation Unit*	$855,797	$156,440	$1,012,237
** Based on financial year to 30 June 2015*			
TOTAL INTERNALLY FUNDED RESEARCH PROGRAMS	**$855,797**	**$156,440**	**$1,012,237**
TOTAL RESEARCH FUNDED **(including external and internal research grants)**	**$3,964,722**	**$5,983,215**	**$9,947,937**

CANCER COUNCIL TASMANIA

Cancer Council-funded external research programs

New research grants

Name of research program	*Recipients*	*Name of research grant*			
Cancer Council Tasmania Small Grants 2015	Dr Nikolas Dietis University of Tasmania	Bi functinoal opioids as a novel cancer treatment.	$8,683	$0	$8,683
Cancer Council Tasmania Small Grants 2015	Dr Adele Holloway University of Tasmania	Epigenetic regulation of integrin beta 4 as a predictor of prostate cancer progression.	$14,750	$0	$14,750
Evelyn Pederson Honours Scholarship 2015	Ms Madeline Parker University of Tasmania	Honours in biotechnology medical research.	$10,000	$0	$10,000
Jeanne Foster Scholarship 2015	TBA	TBA	$6,000	$0	$6,000
Cancer Council Tasmania Clinical Trials Data Management 2015 - South	Tasmanian health organisation - south	Employ cancer trials data manager.	$37,500	$0	$37,500
Cancer Council Tasmania Clinical Trials Data Management 2015 - North	Tasmanian health organisation - north	Employ cancer trials data manager.	$32,500	$0	$32,500
TOTAL RESEARCH FUNDED (new program)			**$109,433**	**$0**	**$109,433**

Continuing research programs

Cancer Council Tasmania/University of Tasmania Health Science Research Fellowship 2014	Dr Mai Frandsen University of Tasmania	Reducing the burden of lung disease: using self-affirmation to reduce defensiveness towards health risk information among smokers' (SACO) and 'Supporting expectant mothers to quit' (SEMQ).	$92,446	$0	$92,446

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Evelyn Pedersen Elite Research PhD Scholarship 2013	Ms Jessica Phillips University of Tasmania	Regulation of integrins by RUNX transcription factors in cancer.	$26,250	$0	$26,250
TOTAL RESEARCH FUNDED (continuing program)			**$118,696**	**$0**	**$118,696**
TOTAL RESEARCH FUNDED **(including new and continuing research programs)**			**$228,129**	**$0**	**$228,129**

CANCER COUNCIL VICTORIA

Cancer Council-funded external research programs

New research grants

Name of research program	*Recipients*	*Name of research grant*			
Venture grant	Prof Roger Daly Monash University	Identification of novel therapeutic targets for triple negative breast cancer through integrative kinomics.	$250,000	$0	$250,000
Venture grant	A/Prof Mark Dawson Peter MacCallum Cancer Centre	Genome editing of leukaemia stem cells to identify novel epigenetic therapies.	$250,000	$0	$250,000
Venture grant	Prof Ricky Johnstone Peter MacCallum Cancer Centre	New treatments for multiple myeloma.	$250,000	$0	$250,000
Venture grant	Prof Andreas Strasser The Walter and Eliza Hall Institute of Medical Research	Novel method to find genes that control cancer development.	$250,000	$0	$250,000
Grant-in-aid	Dr Andreas Behren Olivia Newton-John Cancer Research Institute	A novel antibody target in melanoma.	$93,089	$0	$93,089
Grant-in-aid	Dr Colin Clyne Monash University	Understanding how LRH-1 controls breast cancer development.	$100,000	$0	$100,000
Grant-in-aid	A/Prof Phillip Darcy The University of Melbourne	Harnessing the immune system against cancer.	$100,000	$0	$100,000
Grant-in-aid	Dr Andrew Deans St Vincent's Institute of Medical Research	A new target in the chemosensitisation of tumour cells.	$100,000	$0	$100,000
Grant-in-aid	Prof Peter Fuller Monash Institute of Medical Research-Prince Henry’s Institute of Medical Research	The aldosterone receptor in breast cancer.	$100,000	$0	$100,000

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Grant-in-aid	Prof Ross Hannan The University of Melbourne	New ways to treat blood cancers.	$100,000	$0	$100,000
Grant-in-aid	Prof Ygal Haupt The University of Melbourne	Treating prostate cancer by protecting the mechanism for cancer suppression.	$100,000	$0	$100,000
Grant-in-aid	Dr Gemma Kelly The Walter and Eliza Hall Institute of Medical Research	Investigating the role of the Epstein-Barr virus in certain types of lymphoma.	$100,000	$0	$100,000
Grant-in-aid	Prof Christina Mitchell Monash University	Investigating how a novel protein promotes breast cancer.	$99,919	$0	$99,919
Grant-in-aid	Dr James Murphy The Walter and Eliza Hall Institute of Medical Research	How does necrotic cell death contribute to colorectal cancer?	$99,826	$0	$99,826
Grant-in-aid	Dr Mark Shackleton The University of Melbourne	Hippo pathway molecules as new targets for cancer treatment.	$100,000	$0	$100,000
Grant-in-aid	Dr Jake Shortt The University of Melbourne	Non-chemotherapy drug combinations to turn on suicide genes in lymphoma cells.	$99,268	$0	$99,268
Grant-in-aid	Dr Michaela Waibel The University of Melbourne	Tailored therapies for blood cancer.	$99,805	$0	$99,805
Postdoctoral fellowship	Dr Kevin Man The Walter and Eliza Hall Institute of Medical Research	Identifying how the immune system detects and prevents tumor development.	$72,359	$0	$72,359
Postdoctoral fellowship	Dr Justin Chen MIMR-PHI Institute of Medical Research and Baker IDI	Preventing weight loss in cancer patients.	$72,359	$0	$72,359
Postdoctoral fellowship	Two fellowships to be appointed mid-year		$72,360	$0	$72,360
Postgraduate scholarship	Approx 3 science /medical PhD scholarships to be awarded		$325,000	$0	$325,000
Vacation studentships	16 summer Vacation Studentships to be awarded		$30,000	$0	$30,000
TOTAL RESEARCH FUNDED (new program)			**$2,863,985**	**$0**	**$2,863,985**

Continuing research programs

Colebatch Fellowship	A/Prof Sherene Loi Peter MacCallum Cancer Centre	Advancing personalised medicine for breast cancer patients.	$300,000	$0	$300,000

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Dunlop Fellowship	A/Prof Clare Scott The Walter and Eliza Hall Institute of Medical Research	Improvement of ovarian cancer models to support preclinical development of new therapies for ovarian cancer.	$299,268	$0	$299,268
Mesothelioma grant	Dr Thomas John Olivia Newton-John Cancer Research Institute	Melbourne Mesothelioma Research Collaborative. A collaboration to drive clinically meaningful research into mesothelioma.	$110,700	$100,000	$210,700
Grant-in-aid	Dr Jeffrey Babon The Walter and Eliza Hall Institute of Medical Research	Inflammation and cancer.	$99,705	$0	$99,705
Grant-in-aid	Dr Suzanne Cutts La Trobe University	Cancer specific nanoparticles for improved chemotherapy.	$95,902	$0	$95,902
Grant-in-aid	Dr Walter (Doug) Fairlie The Walter and Eliza Hall Institute of Medical Research	The molecular basis of cancer development and drug resistance.	$100,000	$0	$100,000
Grant-in-aid	Dr Stephan Glaser The Walter and Eliza Hall Institute of Medical Research	Cell death and leukaemia.	$100,000	$0	$100,000
Grant-in-aid	A/Prof Kieran Harvey Peter MacCallum Cancer Centre	Upstream signalling in the Hippo tumour suppressor pathway.	$100,000	$0	$100,000
Grant-in-aid	Dr Nicole Haynes The University of Melbourne	Building immunity to cancer with radio-immunotherapy combinations.	$98,467	$0	$98,467
Grant-in-aid	Dr Duangporn Jamsai Monash University	Defining the role of RBM5 gene in lung cancer.	$99,418	$0	$99,418
Grant-in-aid	Prof Brendan Jenkins Monash Institute of Medical Research-Prince Henry's Institute of Medical Research	Role of the TLR2 gene in stomach cancer.	$99,649	$0	$99,649
Grant-in-aid	A/Prof Michael Kershaw Peter MacCallum Cancer Centre	Turning the immune system against cancer.	$100,000	$0	$100,000
Grant-in-aid	Dr Kathryn Kinross The University of Melbourne	PI3K inhibitors for the treatment of ovarian cancer.	$100,000	$0	$100,000
Grant-in-aid	Prof Graham Lieschke Australian Regenerative Medicine Institute	Determining the role of the gene ZBTB11 in causing liver cancer.	$100,000	$0	$100,000

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Grant-in-aid	Dr Daniel Park The University of Melbourne	Discovering human breast cancer risk genes guided by prior publications on the mouse.	$99,691	$0	$99,691
Grant-in-aid	A/Prof Richard Pearson The University of Melbourne	Treating cancer by arresting cancer cell growth.	$100,000	$0	$100,000
Grant-in-aid	Dr Leonie Quinn The University of Melbourne	Identifying new pathways driving cell growth which is fundamental to cancer initiation and progression.	$100,000	$0	$100,000
Grant-in-aid	A/Prof Helena Richardson The University of Melbourne	How deregulation of cell shape regulators leads to cancer.	$100,000	$0	$100,000
Grant-in-aid	Prof Andrew Roberts The Walter and Eliza Hall Institute of Medical Research	Developing a new class of anti-cancer drugs.	$99,736	$0	$99,736
Grant-in-aid	Prof Jamie Rossjohn Monash University	Investigation into tumour recognition by natural killer T cells.	$99,891	$0	$99,891
Grant-in-aid	Dr Oliver Sieber The Walter and Eliza Hall Institute of Medical Research	Discovery of new colon cancer genes predictive for outcome.	$100,000	$0	$100,000
Grant-in-aid	Prof Andreas Strasser The Walter and Eliza Hall Institute of Medical Research	How does anti-cancer therapy cure tumour cells?	$99,730	$0	$99,730
Grant-in-aid	Prof David Vaux The Walter and Eliza Hall Institute of Medical Research	Determining the mechanism of cell suicide pathway.	$100,000	$0	$100,000
Grant-in-aid	Dr Carl Walkley St Vincent's Institute of Medical Research	Gaining a better understanding of bone cancer.	$100,000	$0	$100,000
Postdoctoral fellowship	Dr Alex Delbridge The Walter and Eliza Hall Institute of Medical Research	How to prevent tumour development and kill chemo-resistant cancer cells.	$35,575	$0	$35,575
Postdoctoral fellowship	Dr Marianna Volpert Monash University	CRISP3 is required for prostate cancer progression.	$35,575	$0	$35,575
Postgraduate scholarship	Miss Hendrika Duivenvoorden La Trobe University	The role of myoepithelial proteins in blocking breast cancer invasion.	$29,017	$0	$29,017
Postgraduate scholarship	Mr Dustin Flanagan The University of Melbourne	The role of frizzled 7 in colorectal cancer.	$16,778	$0	$16,778
Postgraduate scholarship	Miss Kai Syin Lee Monash University	Evaluating novel targeted therapies for prevention and treatment of squamous cell carcinoma of the skin and head and neck.	$16,778	$0	$16,778

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Postgraduate scholarship	Ms Soo Hyun Kim The University of Melbourne	Breast cancer metastasis to brain: mechanisms and new therapies.	$24,032	$0	$24,032
Postgraduate scholarship	Miss Emma Nolan The Walter and Eliza Hall Institute of Medical Research	Identification of novel breast cancer genes using a transposon-based mutagenesis screen in mice.	$29,017	$0	$29,017
Postgraduate scholarship	Miss Antonia Policheni The Walter and Eliza Hall Institute of Medical Research	Discovery of cancer genes in lymphomas.	$29,017	$0	$29,017
Support for medical and scientific activities			$120,000	$0	$120,000
TOTAL RESEARCH FUNDED (continuing program)			**$3,137,945**	**$100,000**	**$3,237,945**
TOTAL CANCER COUNCIL-FUNDED EXTERNAL RESEARCH PROGRAMS (including new and continuing research grants)			**$6,001,930**	**$100,000**	**$6,101,930**

In-house research programs

New research grants

Cancer Epidemiology Centre	$0	$1,626,000	$1,626,000
Victorian Cancer Registry	$0	$200,000	$200,000
TOTAL RESEARCH FUNDED (new program)	**$0**	**$1,826,000**	**$1,826,000**

Continuing research programs

Cancer Epidemiology Centre	$4,843,000	$2,265,000	$7,108,000
Behavioural Science Division	$1,291,000	$1,792,000	$3,083,000
Nigel Grey Fellowship Group	$233,000	$151,000	$384,000
Victorian Cancer Biobank	$0	$2,026,000	$2,026,000
Victorian Cancer Registry	$1,849,000	$1,708,000	$3,557,000
TOTAL RESEARCH FUNDED (continuing program)	**$8,216,000**	**$7,942,000**	**$16,158,000**
TOTAL IN-HOUSE RESEARCH PROGRAMS FUNDING (including new and continuing research grants)	**$8,216,000**	**$9,768,000**	**$17,984,000**
TOTAL RESEARCH FUNDED (including Cancer Council-funded external research programs and In-house research programs)	**$14,217,930**	**$9,868,000**	**$24,085,930**

CANCER COUNCIL WA

Cancer Council-funded external research programs

New research grants			Cancer Council charitable funding amount 2015	Other funding amount for 2015	TOTAL
Name of research program	*Recipients*	*Name of research grant*			
Equipment grant	Prof Ursula Kees, Dr Raelene Endersby, Dr Jason Waithman, Prof Martin Ebert, Assistant Prof Willem Lesterhuis and others Telethon Kids Institute	BHP Billiton Cancer Research Equipment Grant.	$500,000	$0	$500,000
Research project grants	Dr Pilar Blancafort Harry Perkins Institute of Medical Research	Novel targeted therapies for triple negative breast cancers.	$100,000	$0	$100,000
Research project grants	Dr Meegan Howlett Telethon Kids Institute	Understanding how leukaemia cells survive in the bone marrow to target them for therapy.	$100,000	$0	$100,000
Research project grants	A/Prof Evan Ingley Harry Perkins Institute of Medical Research	Important ways that leukaemia and other cells communicate in blood diseases.	$100,000	$0	$100,000
Research project grants	Prof Gary Lee The University of Western Australia	A detailed study of how cancer-related fluid collection in the chest makes people breathless.	$99,966	$0	$99,966
Research project grants	Prof Delia Nelson Curtin University	Restoring immune function in the elderly to improve anti-cancer chemotherapy.	$100,000	$0	$100,000
Research project grants	Prof Robert Newton Edith Cowan University	Exercise is a medicine which benefits all cancer survivors: implementation and evaluation of a national exercise program.	$100,000	$0	$100,000
Research project grants	A/Prof Fiona Pixley The University of Western Australia	Identifying 'druggable' targets to prevent the spread of cancer.	$100,000	$0	$100,000
Research project grants	Dr Cleo Robinson The University of Western Australia	Does altering the low oxygen regions within mesothelioma improve effectiveness of chemotherapy?	$99,926	$0	$99,926
Research project grants	Prof Christobel Saunders The University of Western Australia	Towards development of a decision support tool for women with ductal carcinoma in situ of the breast.	$84,524	$0	$84,524
Research project grants	Dr Jennifer Stone The University of Western Australia	Mammographic density as a predictor of breast cancer risk and mortality in Western Australian Aboriginal women.	$98,490	$0	$98,490
Research project grants	Clin/A/Prof Donna Taylor The University of Western Australia	Can surgery for breast cancer be guided more effectively by use of a radioactive seed rather than a hook-wire?	$93,742	$0	$93,742

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Research project grants	Prof Mel Ziman Edith Cowan University	The use of circulating tumour cells to predict treatment response in melanoma patients.	$71,519	$0	$71,519
Suzanne Cavanagh Early Career Investigator Grant	Dr Belinda Guo The University of Western Australia	Development of advanced high-throughput sequencing to diagnose myelodysplastic syndrome.	$35,000	$0	$35,000
Suzanne Cavanagh Early Career Investigator Grant	Dr Muhammad Adnan Khattak Edith Cowan University	A preliminary study to identify biological markers in blood that predict if a patient with advanced melanoma will respond to treatment.	$35,000	$0	$35,000
Suzanne Cavanagh Early Career Investigator Grant	Dr Connull Leslie PathWest	Investigation of mutations causing progression of follicular lymphoma.	$35,000	$0	$35,000
Suzanne Cavanagh Early Career Investigator Grant	Dr Tarek Meniawy The University of Western Australia	The relationship between immune cell response at tumour sites and recurrence of ovarian cancer in patients treated with chemotherapy and surgery.	$34,985	$0	$34,985
Suzanne Cavanagh Early Career Investigator Grant	Dr Pejman Rowshan Farzad The University of Western Australia	Toward better prostate radiation therapy.	$35,000	$0	$35,000
Research felllowship	A/Prof Oliver Rackham Harry Perkins Institute of Medical Research	Correcting gene expression in pancreatic cancer.	$100,000	$0	$100,000
Youngberg Women's Cancer Research Fellowship	Dr Vincent Wallace The University of Western Australia	Improving breast cancer surgery with a tool that helps the surgeon remove all of the tumour in one go.	$100,000	$0	$100,000
Postdoctoral fellowship	Dr Carolyn McIntyre Edith Cowan University	Exercise as medicine in the management of mesothelioma.	$75,000	$0	$75,000
PhD top up scholarship	Ms Britt Clynick The University of Western Australia	Investigation of carcinomas of unknown primary.	$12,000	$0	$12,000
PhD top up scholarship	Ms Olivia Ruhen The Unversity of Western Australia	A holistic approach to improve breast cancer care.	$12,000	$0	$12,000
Lions Cancer Institute PhD Top Up Scholarship	Ms Tracy Seymour The Unversity of Western Australia	The role of stem cell genes in aggressive human brain tumours.	$12,000	$0	$12,000
Honours scholarship	Ms Briony Clark Curtin University	Determining the importance of immune cells and molecules in Luminal B breast cancer.	$7,500	$0	$7,500
Honours scholarship	Mr Alex Discombe Harry Perkins Institute of Medical Research	Understanding cancer cell signalling.	$7,500	$0	$7,500
Honours scholarship	Ms Brooke Strowger Telethon Kids Institute and Murdoch University	Determining the effectiveness of a new cancer drug, JQ1, in combination with conventional drug treatment for childhood brain cancer therapy.	$7,500	$0	$7,500
Honours scholarship	Ms Chelsea Wilson Telethon Kids Institute	Enhancing the immune response to melanoma.	$7,500	$0	$7,500

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Vacation scholarship	Ms Nicola Bailey The University of Western Australia	Use of endobronchial ultrasound guided investigations in Western Australia.	$3,000	$0	$3,000
Vacation scholarship	Mr Aaron Beasley Edith Cowan University	Single cell analysis for the signs of metastatic ocular melanoma.	$3,000	$0	$3,000
Vacation scholarship	Ms Angie Brynjulfsen Curtin University	Lung cancer screening using low dose computed tomography.	$3,000	$0	$3,000
Vacation scholarship	Mr Alex Discombe Harry Perkins Institute of Medical Research	Studying drug resistance in sarcoma.	$3,000	$0	$3,000
Vacation scholarship	Ms Nguyet (Marisa) Duong The University of Western Australia	Investigation of the interactions between the protein Spt5 and the tumour suppressor gene BRCA1 at the molecular level.	$3,000	$0	$3,000
Vacation scholarship	Ms Stephanie Enkel The University of Western Australia	Are pets a risk factor for breast cancer among Western Australian women?	$3,000	$0	$3,000
Vacation scholarship	Mr Liam Johnson Harry Perkins Institute of Medical Research	Does the enzyme ADAM28 affect the aggressiveness of human prostate cancer?	$3,000	$0	$3,000
Vacation scholarship	Mr Tim Rankin Edith Cowan University	Determining the role of ABCB5 protein in melanoma drug resistance.	$3,000	$0	$3,000
James Crofts Hope Foundation Vacation Scholarship	Mr Ryan Begley The University of Western Australia	Reducing the brain damage caused by treating brain tumours with radiation.	$3,000	$0	$3,000
James Crofts Hope Foundation Vacation Scholarship	Ms Lauren Foster The University of Western Australia	The effect of chemotherapy and radiotherapy treatment on stem cell genes in brain tumours.	$3,000	$0	$3,000
Travel grants			$15,000	$0	$15,000
Awards	Dr Prue Cormie Edith Cowan University	Early Career Cancer Researcher of the Year.	$10,000	$0	$10,000
Awards	Prof Wendy Erber The University of Western Australia	Cancer Researcher of the Year.	$20,000	$0	$20,000
Awards	Clin/Prof Bill Musk The University of Western Australia	Cancer Research Career Achievement Award.	$20,000	$0	$20,000
TOTAL RESEARCH FUNDED (new program)			**$2,259,151**	**$0**	**$2,259,151**

Continuing research grants

Capacity Building and Collaboration Grant	Prof Eric Moses, Dr Iris Lansdorp-Vogelar, Dr Hooi Ee, Prof Rob Donovan, Prof David Preen, Ms Delia Hendrie, Prof Jack Goldblatt, A/Prof Mark Jenkins, Prof Peter O'Leary Curtin University, The University of Western Australia, King Edward Memorial Hospital and Sir Charles Gairdner Hospital	Integrating personalised genomics into risk-stratification models of population screening for cancer.	$400,000	$0	$400,000

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2015**	**Other funding amount for 2015**	**TOTAL**
Strategic Research Partnership (STREP) Grants	A/Prof Gail Garvey Menzies School of Health	To improve cancer control for Indigenous Australians.	$100,000	$379,258	$479,258
Infrastructure grant	Curtin University	WA Cancer Prevention Research Unit.	$160,000	$0	$160,000
Research project grants	Dr Roslyn Francis The University of Western Australia	Determining prognosis and treatment response: novel imaging modalities for glioblastoma.	$43,150	$0	$43,150
Professorial chair	Prof Michael Millward The University of Western Australia	Chair of Clinical Cancer Research.	$351,533	$0	$351,533
Research felllowship	Dr Pilar Blancafort The University of Western Australia	Epigenetic tailoring of the cancer genome: novel targeted strategies for the treatment of aggressive breast cancer.	$20,000	$0	$20,000
Research felllowship	Dr Archa Fox Harry Perkins Institute of Medical Research	Novel gene regulation targets for cancer therapy.	$100,000	$0	$100,000
Research felllowship	Prof Lin Fritschi Curtin University	Occupational cancer epidemiology.	$20,000	$0	$20,000
Research felllowship	Prof Daniel Galvao Edith Cowan University	Improving health outcomes after cancer through exercise: a survivorship program.	$80,000	$0	$80,000
Clinical research fellowship	Dr Andy Redfern Royal Perth Hospital	Clinical research fellowship in cancer at Royal Perth Hospital	$100,000	$0	$100,000
Postdoctoral fellowship	Dr Belinda Guo The University of Western Australia	Translational pathology research in cancer.	$75,000	$0	$75,000
Postdoctoral fellowship	Dr Angela Ives The University of Western Australia	Upper gastro-intestinal surgery as treatment for cancer: what influences its use and outcomes?	$60,000	$0	$60,000
Postdoctoral fellowship	Dr Anna Johansson Harry Perkins Institute of Medical Research	Targeting of LIGHT to tumour vessels for anti-cancer combination therapy.	$75,000	$0	$75,000
Lions Cancer Institute PhD top-up scholarship	Mr Philip Hardy The University of Western Australia	Identifying chromosomal and molecular aberrations that correlate to various stress events in human and mouse liver models.	$12,000	$0	$12,000
PhD top-up scholarship	Mr Samuel Taylor The University of Western Australia	Tyrosine kinase inhibitors for treating c-Cbl and Flt3-driven leukaemias.	$6,000	$0	$6,000
TOTAL RESEARCH FUNDED (continuing program)			**$1,602,683**	**$379,258**	**$1,981,941**
TOTAL RESEARCH FUNDED **(including external and internal research grants)**			**$3,861,834**	**$379,258**	**$4,241,092**

BEHAVIOURAL RESEARCH AND EVALUATION UNIT (BREU), CANCER COUNCIL SA

Development of a cancer survivorship monitoring system for South Australia

In South Australia there is currently no mechanism for collecting patient reported outcomes (PROs) experienced by cancer survivors such as quality of life and unmet needs. PROs are not routinely collected in clinical settings and do not form part of clinical cancer registry data due to the difficulty of collecting this information. Data related to PROs are a key gap in population level data to inform cancer control. To address this gap, Cancer Council SA is proposing to implement a survivorship monitoring system for South Australia.

Our plan for this work was presented at the Flinders Centre for Innovation in Cancer Survivorship Conference in February and at the Behavioural Research in Cancer Control Conference in May.

The program of work includes:

- Undertaking a systematic review of academic and grey literature to identify local and international registries that collect PROs. This review, which is near completion, summarises the aims of the registry, patient sample characteristics, data collection procedures, response-rate, administration/governance and PRO measures collected.

- Developing a draft minimum dataset and monitoring survey. The draft minimum dataset will be informed by the systematic review above and a broader review of patient reported outcome instruments.

- Engaging with key stakeholders, including consumers, to garner support for the set-up and implementation of a survivorship registry and the development of an appropriate minimum dataset.

- Conducting a pilot study at a cancer treatment facility to determine the feasibility of collecting PROs post-treatment from cancer survivors who have been treated with curative intent.

- Exploring opportunities for funding to establish registry infrastructure and implement across multiple sites.

A survivorship monitoring system will meet the needs of a range of stakeholders including policy makers, clinicians, researchers and consumers. It will address a critical gap in cancer control data. Data collected will be used to describe and quantify the psychosocial consequences of cancer treatment and will inform health service delivery, policy, research and advocacy.

Men's help-seeking for cancer symptoms

Early detection and treatment of cancer have been associated with improved health outcomes, and may be achieved through asymptomatic screening or timely medical help-seeking for cancer symptoms.

Men appear to be more likely to delay help-seeking for cancer symptoms, which may result in later diagnosis and treatment. Previous observational research has found evidence for a number of psychosocial factors associated with men's help-seeking behaviour (e.g. inaccurate symptom interpretation, fear and embarrassment, gender role norms), however few studies have examined differences between men. Consequently, the purpose of this research is to explore men's help-seeking for cancer symptoms within an Australian context, with a focus on within-group differences (i.e. variation between men). The study specifically aims to:

- Identify psychosocial factors associated with timely and delayed help-seeking for cancer symptoms among Australian men.

- Examine variation in health-related help-seeking behaviour and factors associated with help-seeking behaviour in rural and urban dwelling Australian men.

This study is currently in the data collection phase. Methods include retrospective semi-structured interviews with males diagnosed with cancer in the past 12 months. Interviews explore pathways to cancer treatment, attitudes towards health-related help-seeking, cancer awareness, symptom interpretation and masculine gender role norms. To provide a range of perspectives, participants' spouses are invited to attend a separate interview to explore the participant's pathway to cancer treatment and to discuss attitudes towards health-related help-seeking.

Preliminary findings from this research study were presented at the APS Health Psychology Conference in April 2015.

CENTRE FOR BEHAVIOURAL RESEARCH IN CANCER (CBRC), VICTORIA

Evaluation of tobacco plain packaging

Using surveys of adult smokers and school students, an observational study, audits of tobacco retail outlets and desk research, CBRC has completed an evaluation of Australia's plain packaging policy with larger graphic health warnings.

In aggregate, the studies found plain packaging largely achieved its specific objectives in the first full year of implementation, reducing the appeal of tobacco (especially among adolescents and young adults), increasing the effectiveness of health warnings and reducing the ability of packaging to mislead consumers about smoking harms. Using a cohort study, plain packaging was also associated with an increase in quitting thoughts and attempts.

Early responses to the larger graphic health warnings drove most quitting outcomes, rather than reduced appeal early responses. In addition, there was no evidence to support four claims of adverse outcomes made by the tobacco industry. The policy did not cause chaos in retail outlets – cigarette pack retrieval time in stores did not increase and smokers did not migrate from purchasing in convenience stores to discount outlets. Use of illicit tobacco remained very low and did not increase. Tobacco prices increased among all brands (and did not plunge, as claimed) after plain packaging, especially among premium and mainstream brands. Finally, cigarette consumption among adult smokers remained constant in the first year of plain packaging (and did not increase as claimed), and as would be expected, declined after the late 2013 tax increase.

Read more in the 14 open access papers in the new supplement of the BMJ's Tobacco Control journal http://tobaccocontrol.bmj.com/content/24/Suppl_2.toc.

The work was funded by a mix of government and non-government sources.

National Secondary Students' Diet and Activity (NaSSDA) survey, 2012-13

The NaSSDA survey tracks Australian adolescents' body weight and dietary and physical activity behaviour at both a state and national level. Established by Cancer Council Australia and the National Heart Foundation of Australia in 2009-10, the second wave of data collection was undertaken in 2012-13, with additional funding support from state and territory government health departments. Data were collected from a nationally representative sample of 8888 students in years 8 to 11 from 196 secondary schools via a web-based survey. Measurements of students' height, weight and waist circumference were taken by trained researchers in a confidential setting.

Overall, the survey found 23% of students were overweight or obese, with prevalence higher among males than females. The proportion of students categorised as overweight or obese remained relatively stable between 2009-10 and 2012-13. Just 18% of students reported meeting physical activity recommendations over the past week (a marginal improvement since 2009-10), with males more likely to be sufficiently active than females. A minority of students reported staying within recommended limits (≤2 hours) for use of electronic media for entertainment on both school days (23%) and weekend days (11%), down from 29% and 17% respectively in 2009-10.

Combined, these results indicate there is much scope for improving young people's lifestyle behaviours in line with national recommendations.

NEWCASTLE CANCER CONTROL COLLABORATIVE (NEW-3C), NSW

Click-Connect-Communicate: A randomised control trial of online social support to improve adjustment to haematological cancer

Two thirds of haematological cancer survivors consider talking to someone who has been or is going through a similar experience to be an important part of ideal cancer care. Meeting survivors' increasing interest in peer support is a growing area of service delivery. With use of the internet increasing, it is timely to examine if online peer support leads to health benefits. With funding from the National Health and Medical Research Council (APP1073317) and Cancer Institute

NSW (13/ECF 1-37), this randomised control trial will develop, implement and test the effectiveness of different models of unmoderated online peer support in improving psychosocial wellbeing.

A sample of haematological cancer survivors will be randomised to: 1) minimal ethical care (Leukaemia Foundation website); 2) online peer support (access to a website where participants can meet and engage in one-to-one electronic communication with 'buddies' of their choice from a private online community of haematological cancer survivors); or 3) enhanced online peer support (access to the online one-to-one peer support website plus interactive multimedia web-based self-management information). Psychosocial outcomes will be assessed at baseline, six and 12 months following recruitment. Differences between the group's use and acceptability of the online peer support program will also be assessed.

The study will provide robust evidence of whether unmoderated online one-to-one peer support improves emotional wellbeing, and if the addition of multimedia self-management information is more effective than online peer support alone. It will provide valuable information to service providers and consumers about what forms of social support are beneficial to haematological cancer survivors.

Missed opportunities: general practitioner identification of their patients' smoking status

In order to provide smoking cessation support in line with clinical practice guidelines, general practitioners (GPs) must first ascertain their patients' smoking status. This study examined (i) the accuracy of GP detection of smoking (i.e. sensitivity, specificity, positive predictive value and negative predictive value), and (ii) the GP and patient characteristics associated with detection smoking. Patients were invited to complete a touchscreen computer survey while waiting for their appointment. Patients self-reported demographic characteristics, medical history and current smoking status. Following the patient's consultation, their GP was asked to indicate whether the patient was a current smoker (yes/no/unsure/not applicable).

Overall, 51 GPs and 1573 of their patients in 12 general practices participated. Patient self-report of smoking was 11.3%, compared to GP estimated prevalence of 9.5%. Sensitivity of GP assessment was 66% [95% CI 59-73], specificity was 98% [95% CI 97-98], positive predictive value was 78% [95% CI 71-85] and negative predictive value was 96% [95% CI 95-97]. No GP factors were associated with detection of smoking. Patients with a higher level of education or who responded 'other' were less likely to be detected as smokers than patients who had completed a high school or below level of education.

This data shows that despite the important role GPs play in providing smoking cessation advice and support, a substantial proportion of GPs (34%) do not know their patients' smoking status. This represents a significant missed opportunity in the provision of preventive healthcare. This data has recently been published in *BMC Family Practice.*

CANCER COUNCIL AUSTRALIA

Cancer report shows need to reduce disparities and address growth in patient numbers.

Cancer Council believes a recent report on cancer incidence and mortality in Australia highlights the urgent need to address disparities in treatment outcomes and prepare for an increasing number of cancer patients.

Cancer in Australia 2014, released in December by the Australian Institute of Health and Welfare, showed improved overall survival, with 67% of Australians diagnosed with cancer expecting to be alive in five years. However it also highlighted the stark disadvantages faced by other population and patient groups, including people living in remote areas.

The data also emphasised the relative lack of progress in treating cancers such as pancreatic, brain and lung cancer.

New data shows Australians turning off solariums

New data released in the lead-up to the commercial solarium ban coming into force showed that Australians are ready to ditch the potentially deadly machines.

Cancer Council's National Sun Protection Survey shows that the majority of adults (79 per cent) and adolescents (67 per cent) support the bans on solariums, which have been in place in most states and territories since 1 January 2015.

Bans of commercial sunbeds came into force in NSW, Victoria, South Australia, Tasmania, ACT and Queensland before 1 January 2015. Western Australia has announced that they will also be banning sunbeds, although the date is yet to be announced. There are no commercial solariums currently operating in the Northern Territory.

World Cancer Day 2015

World Cancer Day is organised by the Union for International Cancer Control (UICC) and held annually on the 4 February.

This year's international theme was 'Cancer, Not Beyond Us', putting the focus on the things that all of us can do to help cancer – from early detection and prevention through to quality of life for cancer survivors and access to treatment worldwide.

This World Cancer Day, Cancer Council encouraged Australians to be aware of the simple steps they could take to lower their cancer risk.

One third of cancer deaths in Australia are caused by preventable risk factors such as smoking, limited physical activity, poor diet, sun exposure or not taking part in screening programs.

Report shows cancer leading cause of premature death in Australia

Research released in January shows that cancer is causing unprecedented levels of premature mortality in Australians compared with all other causes of death, highlighting the urgent need for the whole community to do more to prevent cancer and improve patient outcomes.

Director of Public Policy at Cancer Council Australia, Paul Grogan, said the main reason more people were losing their lives to cancers was that Australians were living longer and getting cancer in older age.

"This data should be a wake-up call to all of Australia – governments, communities and individuals," Mr Grogan said. "We need to do more to prevent cancer, support patients and their families and boost research into those cancers where survival is poor."

Vale Mrs Judith Roberts AO

Cancer Council Australia paid tribute to one of its most distinguished former office bearers, Mrs Judith Roberts AO, who died in February in her home city of Adelaide. Mrs Roberts was President of Cancer Council Australia for three years, from 2004 to 2006.

Acting President of Cancer Council Australia, Jane Fenton, said Mrs Roberts would be remembered as one of the great contributors to cancer control in Australia and to public health more generally.

"Mrs Roberts's career highlights include direct involvement in the establishment of cervical and breast cancer screening programs in Australia and her appointment as the first South Australian woman to the National Health and Medical Research Council, and later its executive.

"Mrs Roberts represented Cancer Council Australia's Board with distinction for 11 years, including six years as Vice-President and President during periods of significant progress. She will be remembered for her devotion to public health and her capacity to bring together people from a range of backgrounds to achieve important outcomes."

New research shows almost 2.4 million Aussie adults sunburnt on summer weekends

Research released by Cancer Council in February shows that approximately 430,000 more Australian adults are getting sunburnt on the weekend than they were four years ago, increasing their risk of skin cancer.

Chair of Cancer Council's National Skin Cancer Committee, Vanessa Rock, said the data was a wake-up call that highlighted the need for Government to re-invest in national mass market skin cancer prevention campaigns to ensure adults remained vigilant about skin cancer.

"Our survey indicates that adults are spending more time outdoors in peak UV times than four years ago, increasing their chances of getting sunburnt."

Increase in teenagers' screen use a new threat to long-term-health

Research released by Cancer Council Australia and the National Heart Foundation of Australia in February shows Australian teenagers are spending increasing time in front of electronic devices such as computers, laptops, tablets, video games and TV.

Chair of Cancer Council Australia's Public Health Committee, Craig Sinclair, said the increase in screen use threatened to undermine any modest benefit from a marginal improvement in physical activity levels, which remained critically low.

The updated National Secondary Students' Diet and Activity Survey found 77 per cent of Australian teenagers spent more than two hours using electronic devices for entertainment on school days, compared with 71 per cent in 2010. The proportion of teenagers exceeding the recommended two hours of screen time per day on weekends also increased, from 83 to 89 per cent.

CLINICAL GUIDELINES NETWORK

Cancer Council Australia produces concise, clinically relevant and up-to-date electronic clinical practice guidelines for health professionals. All guidelines are available on Cancer Council Australia's Cancer Guidelines Wiki platform (wiki.cancer.org.au).

Guidelines in development

Clinical practice guidelines for PSA testing and management of test-detected prostate cancer

Cancer Council, together with the Prostate Cancer Foundation of Australia, conducted a public consultation on the draft guidelines from 4 December to 16 January. The feedback has been revised and incorporated and the guidelines have been submitted to National Health and Medical Research Council for consideration. Please email guidelines@cancer.org.au if you would like to be notified when the guidelines have been finalised.

Clinical practice guidelines for the prevention, diagnosis and management of lung cancer

Cancer Council is developing prevention and diagnosis guidelines for lung cancer to complement the treatment guidelines. Systematic reviews for the diagnosis questions are currently being conducted.

Clinical practice guidelines for the management of melanoma

Cancer Council and the Melanoma Institute Australia have commenced revision of the 2008 melanoma guidelines as online wiki-based guidelines. Systematic reviews and systematic review updates are underway.

Clinical practice guidelines for the prevention, early detection and management of colorectal cancer

Cancer Council has commenced revision of the 2005 *Clinical practice guidelines for the prevention, early detection and management of colorectal cancer.* A multi-disciplinary working party, including consumer presentation, has been established and the initial working party meeting was held in June. Systematic reviews are being conducted.

Clinical practice guidelines for the management of sarcoma

In 2013, *Clinical practice guidelines for the management of adult onset sarcoma* were launched. Updated literature has been assessed and the content updated where applicable. The working party met in February to revise and approve all updates. Additional questions relevant to the AYA population are currently being added and will be launched in 2015.

Guidelines on the wiki

Cancer Council's Cancer Guidelines Wiki features the following cancer-based guidelines:

- *Clinical practice guidelines for the diagnosis and management of barrett's oesophagus and Early oesophageal adenocarcinoma*
- *Clinical practice guidelines for the treatment of lung cancer*
- *Management of apparent early stage endometrial cancer*
- *Clinical practice guidelines for surveillance colonoscopy*
- *Clinical practice guidelines for the management of adult onset sarcoma*
- *Clinical practice guidelines for the management of locally advanced and metastatic prostate cancer*
- *Cancer pain management.*

Clinical Oncology Society of Australia guidelines on the wiki

- NETs guidelines
- Head and neck cancer nutrition guidelines
- Early detection of cancer in AYAs
- AYA cancer fertility preservation
- Psychosocial management of AYA cancer patients.

For more information contact the Head, Clinical Guidelines on 02 8063 4100. If you would like to be added to the mailing list for notifications of guidelines open for public consultation, please email guidelines@cancer.org.au.

CLINICAL ONCOLOGY SOCIETY OF AUSTRALIA, COSA

2015 Annual Scientific Meeting (ASM)

The 2015 COSA ASM will be held in Hobart, 17-19 November, at the Grand Chancellor Hotel.

The Hobart Local Organising Committee has done an exceptional job of bringing together a robust program that we hope will attract a large delegation. The theme of ‘Rare Cancers: Common Goals’ is sure to have something of interest for everyone. The committee has taken a creative approach to their interpretation of the rare cancers theme to include sessions on:

- common rare cancers such as melanoma, NETs and sarcoma
- truly rare cancers such as merkel cell carcinoma, PHAEOs and thyroid
- rare cancer sub-types including inflammatory breast cancer, ALK lung cancer and BRAF colorectal cancer
- rare presentations of common cancers such as breast cancer during pregnancy
- genetics and the reclassification of cancer – are all cancers rare?
- supporting rare cancer patients.

The ASM co-convenors, Drs Louise Nott and Allison Black, are medical oncologists at the Royal Hobart Hospital. Other committee members are from the diverse disciplines reflecting COSA’s membership such as radiation oncology, surgical oncology, cancer pharmacy, nursing and cancer care coordination. This has helped to guarantee the program continues to meet the different educational needs of COSA members.

Confirmed invited international speakers to date include:

- Andreas Adam, Professor of Interventional Radiology at the University of London – Professor Adam will be presenting on interventional oncology, a first for the COSA ASM.
- Angelo Paolo Dei Tos, Director of the Department of Oncology and Director of Pathology at the General Hospital in Treviso, Italy – specialises in sarcoma.
- Dr Leeka Kheifets, Professor of Epidemiology at the UCLA School of Public Health – widely known for her work in environmental and occupational epidemiology.
- Brian O’Sullivan, Professor in the Department of Radiation Oncology at the University of Toronto, Canada – internationally recognised for his clinical and research work in sarcoma.
- Poulam Patel, Professor of Clinical Oncology and Honorary Consultant Medical Oncologist at Nottingham University Hospitals NHS Trust – research interests include the immunology of skin-cancer.
- Derek Raghavan, an internationally renowned cancer researcher and medical oncologist and President of Levine Cancer Institute in the US – among other things wrote the text book on rare cancers.

Please visit the ASM website for information about speakers, program updates, registration and abstract submission www.cosa2015.org.

Two new COSA Groups – rare cancers and exercise and cancer

Regular readers of *Cancer Forum* will be aware that the last issue in March featured rare cancers. Concurrent to the preparation of that Forum, COSA was in the throes of establishing a Rare Cancers Group. In accordance with our governing constitution, the support of at least 30 members is required to establish a new group within our society. Thanks to the efforts of Forum Guest Editor, Associate Professor Clare Scott, we easily met that target and the group is now being formalised. Professor Scott is a medical oncologist at the Royal Melbourne Hospital and Laboratory Head at the Walter and Eliza Hall Institute of Medical Research, and has kindly agreed to be the inaugural chair to ensure COSA’s activities in the area of rare cancers are relevant and respected nationally and internationally. Having the 2015 COSA ASM theme on rare cancers is another important factor in reaching that aspiration.

Another growing area of need within the oncology arena is that of exercise and cancer. Recently a group of enthusiastic exercise physiologists who are also active COSA members approached us with a proposal to establish an exercise and cancer group within COSA. We had another overwhelming response in support of this group from COSA members and we are proud to announce Prue Cormie, Exercise Physiologist and Senior Research Fellow at Edith Cowan University Health and Wellness Institute in Perth, has agreed to lead this work for COSA in partnership with her many collaborators.

We hope to report more on the activities of both new COSA groups in future reports.

For more information about COSA activities please visit www.cosa.org.au

Marie Malica
Executive Officer, COSA

FACULTY OF RADIATION ONCOLOGY, RANZCR

Radiation oncology targeting cancer campaign

Raising the profile and presence of radiation oncology remains a major priority for the Faculty. We will continue the work in this area through the Targeting Cancer campaign.

A key achievement of the last few months has been the development of a Community Service Announcement – an advertisement/short film for television and digital media, showcasing radiation therapy as a safe, effective and sophisticated treatment for patients with cancer.

Our film, ‘Targets’, highlights the stories of five different patients who each received radiation therapy as part of their cancer treatment. We have had an amazing response with more than 1000 views on YouTube in the first two days after its launch, and more than 2700 views to date.

The film is available online and has also been accepted to air on SBS and Channel 10. We encourage you to view the film, and share it within your networks.

General Practitioners (GPs) play a crucial role at every stage in the management of a patient diagnosed with cancer. The trusting relationship that exists between a patient and their GP optimises the delivery of health care – from the time of initial diagnosis to treatment planning, surveillance and transition to survivorship or palliative care.

For this reason, the Targeting Cancer campaign has commenced information evenings for GPs, focusing on common cancer management issues, including the role of radiation therapy in everyday general practice. These information sessions, which are held in radiation oncology centres, include a tour of the radiation oncology department so that GPs can see what their patients may experience.

Radiation oncology departments across Australia and New Zealand have been volunteering to host an evening for local doctors. These events will enable GPs to have more input into ensuring patients are informed of all treatment options, and will also serve to build links between GPs and their local cancer centre.

Other Targeting Cancer campaign activities include promoting radiation oncology in medical school curricula, developing more resources for patients and strengthening relationships with consumer organisations and other stakeholders.

Please join us in this important initiative to raise the profile of radiation oncology in any or all of the following ways:

- Visit the website and register your support.
- Follow the campaign on Twitter (@TargetingCancer).
- Visit and ‘like’ the Facebook page.
- Connect to the campaign on LinkedIn.
- Email us your ideas and suggestions for media stories to help drive traffic to the website.

Quality assurance guidelines for radiation therapy services

Delivery of safe and high quality radiation therapy services is of paramount importance to our patients. The Faculty, through its Quality Improvement Committee, has been working on a number of guidelines/position papers on quality matters, and recently completed the Guidelines for Safe Practice of Stereotactic Body (Ablative) Radiation Therapy.

This document is available from our College website. http://www.ranzcr.edu.au/about/faculty-of-radiation-oncology/899-faculty-publication

Advocacy for indigenous health

The Faculty is committed to improving cancer care for Indigenous Australians, and our vision is one where

Aboriginal and Torres Strait Islander people would have equivalent cancer outcomes to the rest of the Australian population.

The Faculty has formed a working party on indigenous health, and developed a two-year action plan, which is framed around:

- creating partnerships with key stakeholders for Aboriginal and Torres Strait Islanders
- improving the knowledge of our members about Aboriginal and Torres Strait culture and values
- establishing opportunities for Aboriginal and Torres Strait Islander Health care workers in radiation oncology
- advocating for Aboriginal and Torres Strait Islanders to ensure that they have access to high quality radiation oncology services that are sensitive to their needs.

Dr Dion Forstner,
Dean, Faculty of Radiation Oncology RANZCR

MEDICAL ONCOLOGY GROUP OF AUSTRALIA, MOGA

The first six months of the year are always busy for MOGA, as new trainees commence speciality training and those trainees who have recently been awarded fellowship move ahead with their careers. Membership of the association continues to grow and there are currently more than 650 members.

Our members

Given increasing membership numbers, changes in membership demographics and changing workforce demands, medical oncology workforce issues remain high on the Association's agenda, as a core strategic priority. Dr Zarnie Lwin, Deputy Chair and Associate Professor Rosemary Harrup, Chair, are progressing a new workforce study.

MOGA recognises the valuable contribution our members make to the development of medical oncology practice, research and education, not only in Australia but globally. Professor Bogda Koczwara was appointed as a Member of the Order of Australia in the 2015 Australia Day Honours Lists: "For significant service to medical oncology through clinical practice, education and cancer research, and through a range of professional organisations." This official acknowledgement recognises Bogda's substantial contribution, including her leadership role in establishing the Australia and Asia Pacific Clinical Oncology Research Development Workshop (ACORD). The 2016 ACORD Workshop will be held from 11-17[2] September, with applications open online from 6 November 2015-22 February 2016 (www.acord.org.au).

Oncology drugs and treatments

In December, Associate Professor Prue Francis presented the results of the practice changing SOFT (Suppression of Ovarian Function) Clinical Trial at the 2014 San Antonio Breast Cancer Symposium as the international Co-Chair of SOFT, published in the *New England Journal of Medicine*. Between December 2003 and April 2011, SOFT enrolled 3066 premenopausal women with hormone receptor-positive, early-stage breast cancer; including 240 women from Australia and New Zealand. The trial was conducted by the Australian and New Zealand Breast Cancer Trials Group and internationally by the international Breast Cancer Study Group, International Group and the North American Breast Cancer Group.

The SOFT results, when combined with the TEXT clinical trial results, will change the way oncologists treat young women with hormone receptor-positive breast cancer who have received chemotherapy and have not reached menopause. These are practice-changing results and a positive step forward in treating women with hormone receptor-positive breast cancer. It provides another step towards personalising treatment for each individual, to give them the best chance of remaining free from breast cancer in the long term.

We are delighted to announce that A/Professor Francis has been awarded the 2015 Novartis Oncology-MOGA Cancer Achievement Award.

Education and professional education

MOGA's educational and professional programs for 2015 are well in hand. A new immuno-oncology forum-Advances and Insights (Melbourne, October 24-25): is being developed by Professor Michael Brown. Practical Skills for Early Career Oncologists, developed by the Young Oncology Group of Australia and held in late March, was attended by 50 young medical oncology consultants. Young oncologists are the largest and fastest growing segment of the Australian medical oncology workforce and this 1.5 day program included presentations on a range of practical skills.

Plans are proceeding well for the association's 2015 Annual Scientific Meeting, Pathways in Medical Oncology: The Path Less Travelled (Hobart, Tasmania, 5-7 August; Best of ASCO® 8 August, www.mogaasm2015.com). The meeting will showcase an innovative scientific and academic program that explores many of the contemporary challenges and advances in medical oncology research, discovery and clinical practice in breast, melanoma, lung and gynaecological cancer.

International guest speakers will include Professor Fatima Cardoso (Portugal), Professor Chih-Hsin James Yang (Taiwan), Professor Adil Daud (US), and Professor Hani Gabra (UK). The program will also focus on lesser covered areas such as head and neck cancer and haematological malignancies.

Presentations from Australian specialists will also take the paths less travelled. Professor Bogda Koczwara will convene a forum on the 'Emerging challenges of cancer survivorship' and Professor Stewart Dunn and Professor Fran Boyle will convene a forum on 'Difficult conversations: sex, death, money and error,' with presenters Associate Professor Linda Mileshkin presenting on 'money' and Professor Dunn on 'error'.

Associate Professor Rosemary Harrup.
Chair, Medical Oncology Group of Australia

CALENDAR OF MEETINGS

AUSTRALIA AND NEW ZEALAND

Date	Name of Meeting	Place	Secretariat
July			
26-27	Sydney Catalyst International Translational Cancer Research Symposium	Sydney, New South Wales	Sydney Catalyst: the Translational Cancer Research Centre Website: http://www.scitcrs.com/ Email: sydneycatalyst@ctc.usyd.edu.au Phone: +61 2 9562 5326
12-14	Australian and New Zealand Urogenital and Prostate Cancer Trials Group (ANZUP) Annual Scientific Meeting	Sydney, New South Wales	ANZUP Website: http://www.anzup.org.au Email: info@anzup.org.au Phone: +61 2 9562 5033
22-25	Australia and New Zealand Breast Cancer Trials Group (ANZBCTG) Annual Scientific Meeting	Perth, Western Australia	ANZBCTG Website: www.bcia.org.au Email: enquiries@bcia.org.au Phone: +61 2 4925 3022
26-30	World Congress on Larynx Cancer 2015	Cairns, Queensland	Australian and New Zealand Head and Neck Cancer Society Website: www.wclc2015.org Email: wclc2015@surgeons.org Phone: +61 3 9249 1273
August			
05-07	Medical Oncology Group of Australia (MOGA) Annual Scientific Meeting	Hobart, Tasmania	MOGA Website: http://www.moga.org.au/ Email: moga@moga.org.au Phone: +61 2 9256 9652
08-11	Human Genetics Society of Australasia (HGSA) 39th Annual Scientific Meeting	Perth, Western Australia	HGSA Website: http://www.hgsa.org.au/ Email: secretariat@hgsa.org.au Phone: +61 2 9669 6602
18-21	Prostate Cancer Conference 2015	Cairns, Queensland	Prostate Cancer World Congress Website: http://prostatecancercongress.org.au Email: pcwc2015@icms.com.au Phone: +61 3 9810 0200
September			
1-4	Palliative Care: Fit for the Future	Melbourne, Victoria	Palliative Care Australia Website: Palliative Care Australia Email: events@palliativecare.org.au Phone: +61 2 6163 8444
2-4	17th Australasian Gastrointestinal Trials Group (AGITG) Annual Scientific Meeting	Sydney, New South Wales	ASN Events Pty Ltd Website: www.asnevents.net.au Email: eg@asnevents.net.au Phone: +61 3 5983 2400
6-9	XVI International Workshop on Chronic Lymphocytic Leukaemia 2015	Sydney, New South Wales	Arinex Pty Ltd Website: www.iwCLL2015.org Email: iwcll2015@arinex.com.au Phone: +16 2 9265 0700
October			
07-10	Australian Clinical Trials Alliance (ACTA) 2015 International Clinical Trials Symposium	Sydney, New South Wales	ACTA Website: http://www.acta2015.com.au/ Email: info@acta2015.com.au Phone: +61 2 9254 5000
17-18	Australian Sarcoma Annual Scientific Meeting	Brisbane, Queensland	TBA

CALENDAR OF MEETINGS

29-31	2nd Global Advances and Controversies in Skin Cancer Conference 2015	Brisbane, Queensland	Cancer Council QLD Website: http://www.gac-sc.org/ Email: admin@ccm.com.au Phone: +61 7 3368 2644
29-1 Nov	Royal Australian & New Zealand College of Radiologists Annual Scientific Meeting (RANZCR)	Adelaide, South Australia	Waldron Smith Management Website: http://www.ranzcr2015.com/ Email: ranzcr@wsm.com.au Phone: +61 3 9645 6311
November			
6-7	Melanoma Summit 2015	Auckland, New Zealand	TBA
9-14	Australasian Leukaemia and Lymphoma Group (ALLG) Scientific Meeting	Melbourne, Victoria	ALLG Website: http://www.allg.org.au Email: info@allg.org.au Phone: +61 3 8373 9702
16-17	Research Administrators' Seminar	Canberra, Australian Capital Territory	TBA
17-19	Clinical Oncology Society of Australia's (COSA) Annual Scientific Meeting 2015	Hobart, Tasmania	ASN Events Pty Ltd Website: www.asnevents.net.au Email: eg@asnevents.net.au Phone: +61 3 5983 2400
December			
3-5	Inaugural International Adolescent and Young Adult (AYA) Oncology Congress	Sydney, New South Wales	Chilli Fox Events Website: www.youthcancerevent.com.au Email: ayacongress@chillifoxevents.com.au Phone: +61 2 8005 1867
9-11	3rd International Conference on UV and Skin Cancer Prevention	Melbourne, Victoria	Arinex Pty Ltd Website: http://uvandskincancer2015.org/ Email: uv2015@arinex.com.au Phone: +61 2 9265 0700
2016			
April			
13-16	8th General Assembly and International Conference of the Asia Pacific Organisation for Cancer Prevention (APOCP8)	Brisbane, Australia	Carillon Conference Management Pty Ltd Website: http://www.apocp8.org Email: admin@ccm.com.au Phone: + 61 7 3368 2644
May			
2-6	Royal Australasian College of Surgeons Annual Scientific Meeting 2016	Brisbane, Queensland	Royal Australasian College of Surgeons Website: http://asc.surgeons.org/ Email: asc.registration@surgeons.org Phone: +61 3 9276 7431

INTERNATIONAL

Date	**Name of Meeting**	**Place**	**Secretariat**
May			
02-05	American Radium Society 97th annual meeting	Kauai, Hawaii	American Radium Society Website: https://www.americanradiumsociety.org/ Email: info@americanradiumsociety.org Phone: +1 310 437 0581
July			
08-11	19th International Conference on Cancer Nursing (ICCN)	Vancouver, Canada	International Society of Nurses in Cancer Care Website: http://www.isncc.org/ Email: info@isncc.org Phone: +1 604 630 5516

CALENDAR OF MEETINGS

28-01 Aug	APOS 12th Annual Conference & IPOS 17th World Congress of Psycho-Oncology	Washington DC, USA	International Psycho-Oncology Society and the American Psychosocial Oncology Society Website: http://www.apos-society.org/2015/index.html Email: info@apos-society.org Phone: +1 434 293 5350
August			
20-22	23rd Asia Pacific Cancer Conference (APCC)	Bali, Indonesia	APCC Website: www.apcc2015.com/ Email: apcc2015@pharma-pro.com Phone: +6221 6386 9502
September			
25-29	European Cancer Congress	Vienna, Austria	European Cancer Organisation (ECCO) Website: http://www.ecco-org.eu/ Phone: +32 2 775 02 01
25-26	4th International Conference on Immunotherapy in Paediatric Oncology (CIPO)	Seattle, Washington	Seattle Children's hospital Website: http://www.seattlechildrens.org Email: cipo2015@seattlechildrens.org Phone: +1 206 987 2000
6-9	18th Reach to Recovery International Breast Cancer Conference	Beijing, China	Reach to Recovery International Website: www.reachtorecoveryinternational.org Email: info@reachtorecoveryinternational.org Phone: +61 7 3634 5100
October			
8-9	VI Inter-American Oncology Conference	Buenos Aires, Argentina	Inter-American Oncology Conferences Website: http://www.oncologyconferences.com.ar/ Email: secretariat@oncologyconferences.com.ar
November			
5-7	Advanced Breast Cancer Third International Consensus Conference (ABC3)	Lisbon, Portugal	European School of Oncology (ESO) Website: http://www.abc-lisbon.org Email: eso@eso.net Phone: +39 02 854 6451
12-14	SIOG Annual Conference 2015	Prague, Czech Republic	International Society of Geriatric Oncology Website: http://www.siog.org Email: laurence.jocaille@siog.org Phone: +41 22 552 3305
18-22	Aortic International Cancer Conference 2015	Marrakech, Morocco	African Agenda Website: http://www.aorticconference.org Email: info@aorticconference.org Phone: +27 (0)21 683 2934
December			
8-12	38th Annual San Antonio Breast Cancer Symposium	San Antonio, Texas	Richard Markow Website: http://www.sabcs.org Email: sabcs@uthscsa.edu Phone: 210-450-1550
18-21	European Society for Medical Oncology (ESMO) Asia Congress 2015	Singapore	ESMO Website: www.esmo.org Email: esmo@esmo.org Phone: +41 (0)91 973 19 00
2016			
April			
16-19	American Radium Society 98th Annual Meeting	Philadelphia, Pennsylvania	American Radium Society Website: https://www.americanradiumsociety.org/ Email: info@americanradiumsociety.org Phone: +1 310 437 0581

CANCER COUNCIL AUSTRALIA

Cancer Council Australia is the nation's peak independent cancer control organisation.

Its members are the leading state and territory Cancer Councils, working together to undertake and fund cancer research, prevent and control cancer and provide information and support for people affected by cancer.

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Cancer Council New South Wales
Cancer Council Northern Territory
Cancer Council Queensland
Cancer Council South Australia
Cancer Council Tasmania
Cancer Council Victoria
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CLINICAL ONCOLOGY SOCIETY OF AUSTRALIA

The Clinical Oncology Society of Australia (COSA) is a multidisciplinary society for health professionals working in cancer research or the treatment, rehabilitation or palliation of cancer patients.

It conducts an annual scientific meeting, seminars and educational activities related to current cancer issues. COSA is affiliated with Cancer Council Australia.

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MEMBERSHIP

Further information about COSA and membership applications are available from:

www.cosa.org.au or cosa@cancer.org.au

Membership fees for 2015-2016
Medical Members: $200
Non Medical Members: $115 (includes GST)

COSA Groups

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Paediatric Oncology
Palliative Care
Psycho-Oncology
Radiation Oncology
Rare Cancers
Regional & Rural Oncology
Surgical Oncology
Survivorship
Urologic Oncology

Information for contributors

Cancer Forum provides an avenue for communication between all those involved in cancer control and seeks to promote contact across disciplinary barriers. To this end, articles need to be comprehensible to as wide a section of the readership as possible. Authors should provide sufficient introductory material to place their articles in context for those outside their field of specialisation. *Cancer Forum* is primarily a review journal, with each issue addressing a particular topic in its 'Forum'. The Forum topic and appointment of Guest Editor(s) are determined by the Editorial Board, which welcomes suggestions. Proffered papers containing primary research findings will be considered for publication in *Cancer Forum* in limited circumstances. Articles will be considered by the Editorial Board and then published subject to two peer-reviews. Generally speaking, authors are encouraged to submit their primary research findings to established cancer research or clinical oncology journals. The following information is provided for contributors invited to prepare manuscripts for *Cancer Forum*.

Format

Prospective authors are encouraged to examine recent editions of *Cancer Forum* for an indication of the style and layout of Forum papers (www.cancerforum.org.au). All manuscripts should be submitted by email to the Forum's Guest Editor(s) and Executive Editor (rosannah.snelson@cancer.org.au) as MS Word documents.
Length: 2000-2500 words.
Font: Arial - 20pt and bold for title, 12pt and bold for headings, 12pt and italics for subheadings and 10pt for text.
Following the title, include your full name, organisation and email address.
Include introductory headings and sub-headings that describe the content.
Number pages in the footer.

Abstract

All manuscripts must include an abstract of approximately 200 words, providing a summary of the key findings or statements. No references or abbreviations should be included in the abstract.

Abbreviations and acronyms

Abbreviations and acronyms should only be used where the term appears more than five times within the paper. They must be explained in full in the first instance, with the abbreviation in brackets.
The Editorial Board reserves the right to remove the heavy use of abbreviations and acronyms that may be confusing to the diversity of our readership.

Photographs, tables and graphs

Photographs and line drawings can be submitted via email, preferably in tiff or jpeg format. If images are not owned by the author, written permission to reproduce the images should be provided with the submission. A maximum of five illustrations and figures and three tables can be submitted with the manuscript. Inclusion of additional items is subject to approval by the Editorial Board. Unless otherwise specified by the authors or requested by the Editorial Board, all images, graphs and tables will be printed in black and white. All figures – including tables and graphs – will be reproduced to *Cancer Forum's* style. Figures containing data (eg. a line graph) must be submitted with corresponding data so our designers can accurately represent the information. Figures and images should be labelled sequentially, numbered and cited in the text in the correct order e.g. (table 3, figure 1). Tables should only be used to present essential data. Each must be on a separate page with a title or caption and be clearly labelled.

Referencing

Reference numbers within the text should be placed after punctuation and superscripted. The maximum number of references is 75. Only papers closely related to the subject under review should be quoted and exhaustive lists should be avoided. Only one publication can be listed for each number. Citation of more than one reference to make a point is not recommended. The Editorial Board prefers a focus on more recent references (in the last 10 years). The list of references at the end of the paper should be numbered consecutively in the order in which they are first mentioned and be consistent with the National Library of Medicine's International Committee of Medical Journal Editors' Uniform Requirements for Manuscripts Submitted to Biomedical Journals. i.e. Halpern SD, Ubel PA, Caplan AL. Solid-organ transplantation in HIV-infected patients. N Engl J Med. 2002 Jul 25;347(4):284-7.

A full guide is available at www.nlm.nih.gov/bsd/uniform_requirements.htmlA guide to abbreviation of journal names can be found at https://www.library.uq.edu.au/faqs/endnote/medical_2010.txt

The Editorial Board will make the final decision on inclusion of manuscripts and may request clarifications or additional information.

For further information or confirmation of the above, please contact:

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