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Cost of cancer to the patient

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Reports

Overview: Cost of cancer to the patient

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The escalating financial cost of cancer to patients and their families is emerging as a global phenomenon. Despite diversely funded healthcare systems internationally,[1] cancer causes substantial financial burden to individuals in many different countries, including the USA, Canada and Ireland.[2] Australia is no exception and the articles in this Forum explore the many facets of financial costs in this context.

Although cancer remains a leading cause of death in Australia,[3] survival rates have improved substantially over recent decades and more and more people are living longer following a diagnosis of cancer.[4] Consequently, the prominence of research into the financial aspects of diagnosis, treatment and follow-up for individuals and their families has increased dramatically.[5] Given the growing international body of evidence on the financial issues faced by people diagnosed with cancer,[2,5] there is a need to understand more deeply the magnitude and consequences of financial challenges in the Australian setting to better maximise cancer care.

Christine Paul and colleagues provide an assessment of how patient expenses arise in the Australian healthcare setting despite the predominantly publicly-funded system.[3,6] The review summarises local evidence on the burden, distribution and potential consequences of financial costs on patients and families faced with cancer and provides information on the financial assistance available. The authors also highlight the paucity of accurate, ongoing, system-wide information about the financial cost of cancer care experienced by patients and their families, and the absence of evidence on information needs and financial care.

Camille Schubert describes the key Australian Government regulatory bodies and funding schemes related to cancer care, including a summary of the different types of cost and economic and financial analyses required for evaluations of new cancer technologies.[7] Camille concludes that Australian regulatory agencies and funding bodies consider patient costs. However, some types of cost are often omitted, potentially affecting affordability and access to care for individuals.

While local guidelines recommend including costs in economic analyses informing societal research and reimbursement decisions from a government funding agency, a healthcare and a societal perspective (all costs, including patient and family), in reality the latter seldom occurs.[7-9] Placing greater emphasis on the societal perspective in this context will promote greater research into the cost of cancer to the patient and family. Robust and rigorous analysis will more fully inform decision makers and help to prevent cost shifting.[10,11]

The financial burden of cancer care also falls on to informal (unpaid) caregivers, often family members. Demand for informal caregivers is rising,[12] although broad social changes such as smaller, dispersed families and higher divorce rates are reducing availability.[11] Afaf Girgis and Sylvie Lambert review the financial impact on this vital group of people who are integral to cancer care service provision.[12] The results of the review suggest informal caregiving represents as much as a third of the total financial cost of cancer.

Accurately measuring the costs of cancer to the patient for research purposes is challenging, as discussed by Sophy Shih and Rob Carter.[13] Issues covered include methods of data collection, instruments specifically designed to collect costs incurred by cancer patients, questionnaire development, recall length, specificity, coverage and missing data. The authors suggest advances in information and mobile technologies may overcome existing barriers to robust measurement of resource utilisation and patient costs in cancer research, ultimately improving societal decision making.

Two closely related articles by Louisa Gordon and colleagues and Bogda Koczwara tackle the concept of 'financial toxicity'.[14,15] The former article defines financial toxicity, describes how financial toxicity is measured and reviews the prevalence of financial problems on the individual after a cancer diagnosis. As many as half of cancer survivors have been estimated to have experienced financial stress, a proportion that is even higher (73%) if objective or subjective questions are considered in addition to monetary measures alone.[14]

A major driver of financial toxicity, unemployment and reduced work participation, is discussed in more detail by Bogda Koczwara.[15] The article outlines current knowledge on unemployment and reduced work participation after cancer, associated equity implications and evidence-based strategies to improve work participation, such as physical training and psycho-education. The role of the health care provider in financial wellbeing is raised, highlighting the need (yet again) for multi-disciplinary and multi-sectorial collaboration to improve patient care.

In advanced cancer, addressing financial issues is an important aspect of quality of life from palliative care patients' perspectives.[16] Timothy Ford and colleagues further explore financial issues in this setting, in a review of the evidence of the relationship between financial concerns and advance care planning.[17] The results suggest concerns about being a burden on others and financial worries can influence individual treatment decisions and may motivate and shape advance care plans. Further, the authors propose a useful conceptual model on the role of financial concerns, advance care planning and treatment decisions to guide future research.

Despite this body of research, to date, the actual rather than estimated financial cost of cancer to patients in Australia is largely unknown.[6,14,15] Currently, work is underway by Cancer Council Queensland to investigate the financial impact of diagnosis and treatment through the Everyday Health Survey 'Health System Quality & Costs – How High is the Burden?' This state-wide survey aims to improve understanding of how the cost of cancer impacts patients and influences their access to healthcare services, treatment decisions and compliance with clinical advice. Further, Breast Cancer Network Australia, with the assistance of Deloitte Access Economics, has recently conducted a national survey to determine out of pocket costs of breast cancer patients. Results will be published later this year.

The articles in this Forum provide a valuable overview of the research into the cost of cancer to the patient and their families and highlight the need for more work into this emerging phenomenon to promote equitable, effective and efficient cancer care in Australia.

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Impact of financial costs of cancer on patients – the Australian experience

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Abstract

Although healthcare in Australia is largely publicly funded, there are out-of-pocket costs associated with diagnosis, treatment and survival, even in the public system. In Australia, people with cancer report relatively high out-of-pocket health costs and a heavy burden of out-of-pocket costs relative to income. These costs include travel, hospital stays, specialist fees, parking, treatment prescriptions and over-the-counter medications for supportive care. The financial impacts of the disease extend to reduced or lost employment, early retirement and reduced incomes. The financial costs of cancer in Australia are also unequally distributed in that some cancer types are more costly to the individual. Those living in rural and remote areas also face greater out-of-pocket costs, as do those who use the private health system. Cancer-related costs are not restricted to those experiencing a diagnosis of cancer, but also extend to carers and families and can be enduring. While reducing costs is an important long-term goal, ameliorating financial impacts is also important in the short term. The heavy burden associated with cancer may be reduced if the expected costs of treatment and the availability of assistance become part of treatment conversations and processes.

The large and growing number of cancer survivors in Australia is likely to mean that many Australians experience the costs and financial consequences of cancer for themselves, a family member or friend.[1] Therefore, it is important to understand the perspectives of Australian patients and carers regarding the magnitude and impact of these costs; along with views about current forms of financial support for people affected by cancer.

What the 'patient' pays for cancer care and how much it varies

Although healthcare in Australia is largely publicly funded, there are out-of-pocket costs associated with diagnosis, treatment and survival in the public system. A moderate proportion of cancer care occurs in the private system (either self-funded or under insurance),[2] where out-of-pocket costs can be substantially higher than in the public system. Older Australians with cancer, high blood pressure, diabetes or depression are more likely than those without chronic illness to report high out-of-pocket health costs, and those with cancer or diabetes were more likely than others to spend more than 10% of household income on out-of-pocket costs.[3]

The out-of-pocket costs associated with cancer include general practitioner and specialist gap payments, scans or tests outside the public system, over-the-counter medications for pain relief and other purposes, medical devices, travel, accommodation and personal care, such as managing mouth ulcers during radiotherapy.[4,5] In addition to these costs, many patients also use complementary medicines or therapies such as nutritional supplements, or herbal medicine to support their well-being. For example, a 2010 study of 381 Australian cancer patients found 65% had used complementary or alternative medicine, with users likely to have a higher income than non-users.[6]

In Australia, the estimated lifetime health system cost of cancer treatment was $33,400 per patient in 2008, of which $5000 was borne by individuals.[7] As medical treatment costs escalate, particularly with advances in personalised medicine and supportive care,[8] current costs to the individual may be substantially higher than the 2008 estimate. These overall figures also mask wide personal variation in costs related to cancer type, stage and treatment options. For example, one patient with an early-stage localised solid tumour may have a single surgery, while another patient with haematological cancer may have very long-term treatments involving substantial travel, medications and permanent lifestyle changes.[9] The way in which specific tumour groups are diagnosed can result in particular groups incurring greater personal costs for diagnostic tests. Further, in relation to treatment costs, people diagnosed with breast and prostate cancer are personally responsible for 20% and 32% of treatment costs respectively. On average, cancer patients carry 15% of treatment costs.[7]

It is not known how well out-of-pocket costs are communicated to patients in Australia. The limited available data suggests advance warning about actual out-of-pocket treatment costs is not generally provided. Up to 70% of Australians diagnosed with prostate cancer reported that they spent more for their cancer treatment than expected.[10] In line with this finding and the ongoing emphasis on informed participation in treatment decisions as part of patient-centred care, there have been recent calls for Australian health professionals to disclose the cost of treatment pathways and alternative options to patients while forming treatment plans.[8,11]

What cancer patients report about the actual costs of cancer treatment

While the patient bears a relatively small proportion of the total costs of cancer treatment in Australia,[12] these costs can translate into hundreds of dollars out-of-pocket per month, although this varies considerably between patients. Gordon et al found that while 5% of men who had been diagnosed with prostate cancer reported spending $250 or less for treatment, the median spend for recently diagnosed men was $8000 and some spent up to $17,000.[10] Within this study, 171 men underwent radical prostatectomy and reported a median spend of $6000, which was higher than those who underwent watchful waiting ($3000), active surveillance ($5000), or androgen deprivation therapy ($3375). As the proportion of men who receive radical prostatectomy, particularly robotic-assisted, is likely to increase in the future,[13] the costs of this treatment approach needs to be monitored. In examining other treatment approaches, a survey of 255 cancer patients with multiple tumour types found almost half (46.7%, 95% CI=40.5, 52.8) had medicines prescribed for them solely in relation to their cancer, and a further 11.4% (95% CI= 7.4, 15.3) had been prescribed both cancer-related and non-cancer-related medicines.[14] The preferred strategies by patients for reducing their out-of-pocket costs for cancer treatment were to reduce the costs of parking, medications and treatment-related travel.[15] A study of regional cancer patients also identified travel expenses as the highest share of out-of-pocket costs (71%) followed by medical appointments (10%) and co-payments for medications (9%). Over an average time of 16 months from diagnosis, regionally based cancer patients reported a mean of $4311, and median of $2263 in out-of-pocket costs.[16] Costs were higher for those residing further away from the treating hospital.

How financial costs impact on the experiences of Australian cancer patients

Approximately one-third (34%) of cancer patients in Australia perceived that they had experienced a moderate, heavy or extreme financial burden in the prior three months due to prescribed medicines for cancer treatment or recovery.[14] The consequences of a financial burden included the use of cost-saving strategies, with 12% reporting at least one of the following regarding cancer-related medicines: using over-the-counter rather than prescribed medicine; using medicines from home rather than filling a new prescription; or, using medicines from someone else.[14] Cost-related factors were reported to influence decision-making about cancer treatment by 19% of the cancer patient sample, particularly the costs of travelling to and from treatment (14%), loss of income (14%) and actual costs of treatments (11%). Those who nominated at least one factor influencing their treatment were asked how those factors influenced their decision – 71% indicated the cost-related factor made the decision difficult, but did not change their decision, while a small number chose a different treatment, had treatment for a shorter time or at a lower dose, delayed treatment, or decided not to have treatment due to cost.[17] This finding of forgoing and limiting health service or medication use as a cost-saving strategy has been noted in other Australian studies.[10,18,19] Patients with private health insurance had significantly higher odds of reporting that financial factors had influenced their treatment decision

making,[14] suggesting that patients in the private system face substantial and potentially prohibitive costs which they would not incur if treated in the public system.

The experience of cancer has financial impacts beyond the direct costs of diagnosis, treatment and self-care. The 2003 Survey on Disability, Ageing and Carers reported that for those individuals who were actively undergoing cancer treatment, the probability of employment was reduced by 41% in males and 17% in females.[7] A more recent study found that for those who were employed at the point of cancer diagnosis, almost two-thirds (63.5%, 95%CI=54.1,72.9) experienced a reduction in their household income.[17] The reduction in income for the study sample was approximately half. The Gordon et al study of prostate cancer patients found that on average, respondents in paid employment at diagnosis stated that they had retired four to five years earlier than planned.[10] The experience of substantial out-of-pocket costs, combined with reduced employment or income, has the potential to exacerbate emotional distress associated with cancer. For example, one in five prostate cancer patients, many of whom reported being financially comfortable and university-educated, felt treatment costs caused them a great deal of distress.[10] In a qualitative study of 97 individuals with chronic conditions, including cancer, the financial burden associated with treatment was perceived to be more problematic than even the side-effects and adverse events from medication use.[19] A qualitative study of people with haematological cancer found cancer can "facilitate a spiral to acute and irreversible financial distress."[20]

Which patients bear the greatest burden of cancer care costs

Out-of-pocket costs and the experience of financial burden can vary widely. People with private health insurance have reported double the out-of-pocket costs of cancer than those without insurance, regardless of time since diagnosis.[10] This may be due to higher gap payments, lack of access to subsidised medicines and paying for treatments which would have been free or subsidised if accessed under the public system. Little is known about whether privately-treated or high-income cancer patients perceive they receive (or actually receive) value for money compared to patients treated in the public system. Expenses also appear to be higher among: the recently diagnosed; those living at a greater distance from treatment; those bound to certain treatment types e.g. costs may be higher for radiotherapy; and those residing in certain Australian states.[10,14,16] Those living outside the major cities have 17 times the odds of reporting locational or financial barriers to care compared to those living in metropolitan areas.[15]

While most middle-aged individuals gradually return to work within five years after diagnosis, those who were diagnosed with blood, head and neck, or nervous system cancers, are often unable to resume employment, with middle-aged cancer survivors more likely to choose early retirement or use superannuation funds.[7] The potential income loss associated with cancer survivorship is also experienced by childhood cancer survivors, as this group are less likely to obtain a university education and their average earnings is approximately 10% lower.[7]

How the cost of cancer extends to carers and families

The financial burden of cancer does not rest on patients alone, with the overall cost to the household estimated to be $47,200. In addition, approximately 1.3 million hours of informal care were provided to individuals with cancer in New South Wales alone.[7] Almost three-quarters (72%) of cancer carers reported a negative financial impact of caring and 51% of those previously working full-time had taken leave or reduced working hours. Accessing financial support and government benefits were listed as an unmet need for this group.[21] Often carers do not have access to travel and accommodation schemes. As informal caregivers, individuals are often required to reduce the number of hours of paid employment,[22] often without access to patient-oriented travel and accommodation schemes.

Analysis of population data from the Australian Bureau of Statistics found carers of individuals with neoplasms, blood diseases or immune system disorders were approximately 6.5 times more likely to be out of the workforce as compared to non-carers, even after controlling for age, sex, and education.[22] Qualitative interviews with patients and carers in an Australian community-based cancer palliation program reported carer costs of $370 per month and revealed that the double burden of both individuals' reduced employment caused strain on personal relationships.[18]

Where carers are the parents of children with childhood cancers, the greatest perceived impact of the cancer was perceived financial burden, with extra financial burden associated with vehicle expenses (parking, petrol and additional maintenance) and additional food (ordered meals, meals away from home, maintaining multiple residences).[23] A study by Heath et al found that the highest costs for these parents were associated with airfares (for a minority) and childcare/babysitting (for the majority).[23] Families also reported that community support was mostly in the form of recreational and social activities, with less aid directed to financial assistance. More than three-quarters (77%) of these families reported disruption to work activities. For these families, the estimated family income lost in the 12 months immediately following diagnosis ranged from $500-$50,000. Almost three-quarters (74%) of parents reported experiencing a great or moderate degree of economic hardship following a diagnosis of cancer in a child.

Financial assistance for cancer patients

Government assistance to help relieve the financial stress of cancer includes income support, concessions and subsidies.[24,25] However, government assistance in the form of concessions or subsidies is often insufficient to cover living and medical expenses.[18] Non-government assistance is offered by organisations such as Cancer Council, Leukaemia Foundation and Can Assist, particularly for patients who live in rural areas. Interviews with representatives from Australian Consumer Health Organisations highlighted that professionals within these community-based organisations are keenly aware of the financial burden associated with chronic conditions, particularly the compounding effect of expensive polypharmacy and reduced or lost employment.[26] Some state Cancer Councils can assist with transport and accommodation costs, and in some cases can provide accommodation for regional patients and their carers who travel long distances for treatment. Assistance from Cancer Council and other cancer charities in some states can also include financial counselling, interest-free loans and small one-off payments. Many banks, utility and telecommunications providers have hardship provisions to assist with or restructure debts or regular payments, although anecdotally it appears that awareness of and offer of these services is limited. A survey of 255 oncology outpatients in Australia found 74% did not access financial assistance.[17] Of those not using financial assistance, 43% did not need it, while 37% did need it, but were unaware that financial assistance was available, and 16%, reported there were no relevant forms of assistance. Difficulties with accessing financial assistance included a lack of information, the amount of money being insufficient, the need for up-front payment, applications being too difficult and payments not covering the type of help needed.[17] It is important that financial assistance and counselling is accessed as soon as possible after diagnosis to avoid financial problems spiralling out of control.

What else we need to know about the costs and financial impact of cancer

There is relatively little ongoing, system-wide information about the actual (rather than estimated) out of pocket costs of cancer care experienced by patients and their carers/support persons in Australia, particularly from a life-time perspective and within the private system. There is also very little known about how much and how well the likely out-of-pocket costs are communicated to patients or carers as part of decision-making for their treatment and care. It is likely that such communication is highly challenging, given the emotional and information burden already faced during the diagnostic and decision–making phase.

Longer term financial impacts can be even harder to estimate, including those at the palliative and terminal stages of life. In addition to out-of-pocket costs and loss of income, cancer survivors may face financial discrimination, including difficulty in finding employment, taking out a home or other loan, and obtaining life/health/travel insurance. To date, there is only anecdotal data available regarding these questions, although Legal Aid NSW is currently working with Cancer Council NSW to conduct a survey to gain a better understanding on how health conditions may impact on people's ability to access insurance products in Australia.

Conclusion

The costs and financial impacts of cancer – although partially met by Federal, state and non-government support – remain a substantial and enduring burden for many patients and their families,

with some groups bearing a disproportionate burden. Better monitoring and support in relation to these out-of-pocket costs and exploration of the 'value for money' proposition within the private system are targets for future research. While reducing costs is an important long-term goal, ameliorating financial impacts is also important in the short term. The heavy burden associated with cancer may be reduced if the expected costs of treatment and the availability of assistance become part of treatment conversations and processes.

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Regulatory and government funding agency consideration of monetary costs to the cancer patient

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Abstract

The Australian healthcare system aims to provide accessible healthcare to all citizens, and on a global scale it appears to achieve good health outcomes, with relative efficiency. However, the system is complex and despite various public funding programs, numerous out-of-pocket expenses to patients remain; in cancer patients these are estimated to be significant. The types of costs associated with healthcare are described here, as are the main public healthcare funding schemes in Australia. Decision-makers for these schemes do request information regarding patient costs in economic analyses, however the extent to which cost data are available is limited. Generally and primarily for the practical reasons – but sometimes with a philosophical consideration – only limited information on patient healthcare-related costs will have been considered before a funding recommendation is made. There is a concern that without increased consideration of patient costs, the existing network of public funding schemes in Australia may not adequately ensure the affordability of healthcare.

Few people in Australia understand the true cost of the healthcare services and products they utilise, nor who is responsible for funding the different aspects of their healthcare. The 'healthcare system' comprises individual community service providers – including general practitioners, specialists, community nurses, pharmacists, other allied health professionals and large institutions – mainly public and private hospitals. It is a complex, multi-faceted system, concurrently run by federal and state governments, and regulated private industry. The intention is that the resultant 'web' of health services and structures gives all Australians access to adequate, affordable health care, irrespective of their personal circumstances.[1,2] A number of indicators suggest that despite, or perhaps because of the complexity, the overall system works reasonably well - compared to other OECD countries, Australian life expectancy is relatively high and our health expenditure is relatively low.[3]

Success at improving health across the population over the last century has, ironically, resulted in an increase in cancers because of increased life expectancy, and in turn, investment and research has yielded many new, often expensive, treatment options. Unsurprisingly, providing greater healthcare services to increasing numbers of patients has resulted in rapidly growing cancer healthcare expenditure. The Australian Institute of Health and Welfare estimated annual health system expenditure on cancer increased from approximately $2.9 billion in 2001 to over $4.5 billion in 2009 in real terms based on 2009 prices,[4] however those direct health system expenditures may represent less than half of the overall financial costs of cancer, with patient households incurring a similar magnitude of cancer-related costs as the government; average financial costs were estimated to be in excess of $47,000 per cancer patient in 2005.[5] These figures clearly identify that patient costs need to be an important consideration in government funding decisions and regulation of the healthcare system, if affordable healthcare is to remain the intention of public policy.

At the patient level, the web of different systems can result in confusion and uncertainty; depending on what part of the system is accessed, patient out-of-pocket costs vary greatly.[6,7] Even for a simple service such as a blood test, out-of-pocket costs to a patient depend on: whether the person is admitted to hospital or uses a service as an 'outpatient' and if so, whether that is a public or private hospital outpatient, or not associated with a hospital; whether their doctor bulk-bills or charges a gap; whether the specific type of test required is listed on the government schedule; and whether or not they hold a health care card.

The following review describes decision-making for government funding of healthcare in Australia. It also examines the extent to which individual patient costs are considered by regulatory bodies and funding schemes when making decisions about new policy and healthcare services or products.

What are the different types of costs?

In this review, the costs described relate only to monetary costs. This is consistent with terminology used in the regulatory and funding space. Non-monetary costs, such as life or 'human suffering', whether physical or emotional, are not overlooked, but are considered separately as 'health outcomes', which are not the subject of this paper.

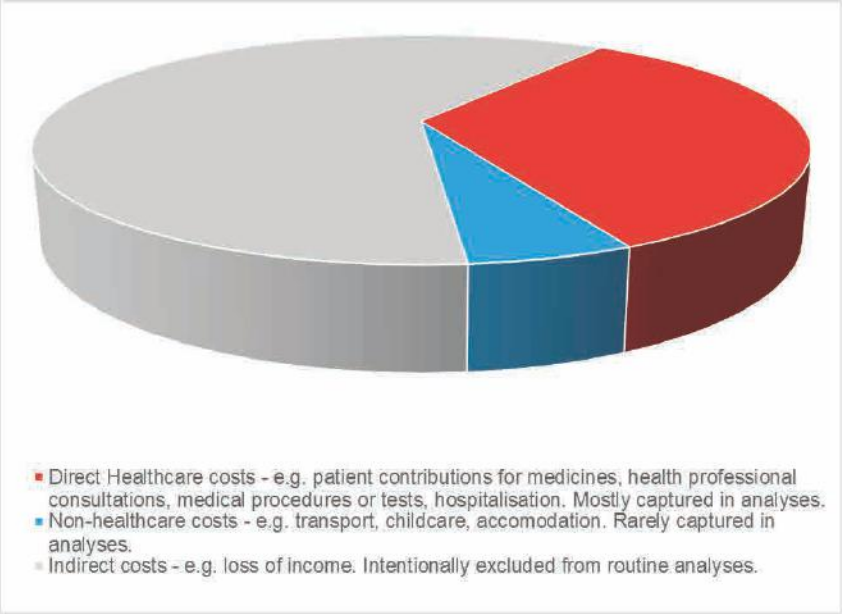
Monetary costs associated with cancer may be categorised as healthcare or non-healthcare related costs. Direct healthcare costs, for example the medicines, investigations and medical consultations, are relatively easy to identify and are routinely considered by regulatory or administrative bodies associated with funding decisions. In addition, the capital and maintenance costs of medical equipment and facilities are also generally considered if relevant. Less obvious, and much more likely to be overlooked - but acutely felt by patients - are direct non-healthcare costs such as transport, parking or child-care associated with hospital visits to receive chemotherapy.

When a healthcare or non-healthcare related direct cost is incurred, there is an immediate financial impact for either, or both the patient and the funding body, and the monetary value can generally be estimated by a receipt. Collectively, all of the direct costs associated with cancer would be expected to make up the total 'financial costs', as described in the introductory paragraphs.

However, there are also indirect costs with monetary impact, for example the inability to work and earn income that would have otherwise be earned had cancer not occurred. Indirect costs, often associated with loss of productivity, may be very relevant at the individual and household level, but are hard to estimate with certainty, and often not apparent to administrators.[5,6]

While all these costs – direct healthcare and non-healthcare costs, and indirect costs – are broadly acknowledged in the study or practice of health economics, the extent to which they are explicitly considered in analyses for regulatory bodies or funding schemes varies. A depiction of the approximate relative sizes of the various types of costs as identified in cancer patients, and a summary of the extent of their inclusion in routine government analyses is shown in figure 1.

Figure 1: *Types of monetary costs associated with cancer and extent to which they are routinely considered by Australian regulatory agencies.*



* Relative sizes are approximate, based on data from Access Economics Pty Limited. Cost of Cancer in NSW.[5]

Key government regulatory bodies and funding schemes

In Australia, various regulatory and/or funding bodies and committees are involved in providing access to publicly funded healthcare services. The two predominant funding schemes for healthcare, and therefore cancer care, at the national level in Australia are the Medicare Benefits Scheme, which facilitates and funds provision of medical services, except those undertaken by public hospitals, and the Pharmaceutical Benefit Scheme, which subsidises medicines. Newly available cancer treatments - services or medicines - that have not previously been listed on the Medical Benefits Scheme or Pharmaceutical Benefits Scheme, or have a listing restricted to specific cancer types or circumstances, but are now considered useful in other types of cancer patients, need to be considered and recommended by the relevant funding scheme's decision-making committee; the Medical Services Advisory Committee (MSAC) or the Pharmaceutical Benefits Advisory Committee (PBAC), before the service or treatment can be publicly funded on these schemes.

Cancer-related healthcare services are generally included under the broader healthcare umbrella and decisions about funding cancer-related healthcare are generally managed by the same funding bodies, and in the same manner, as decisions about funding healthcare in other therapeutic areas. This differs from the UK, for example, where a specific Cancer Drugs Fund exists, with an explicit budget allocation for cancer drugs.[8] The Cancer Drugs Fund is outside of the broader National Health System budget and unregulated by the National Institute of Clinical Excellence, which advises on other drug funding. Multiple arguments exist regarding both the merits and concerns of allocating a public funding body specifically to supply cancer agents outside of the broader healthcare regulatory and funding agency, such as the claim that cancer-specific expertise improves the quality of decisions, but the questionable fairness in providing some patients unequal claim to collective public resources.[9-11]

To initiate consideration of public funding of a service or treatment in Australia, a sponsor – often a pharmaceutical or device company – is required to make a detailed submission of evidence and analyses, including an economic evaluation considering costs to the relevant committee. The submission receives extensive scrutiny and evaluation by independent experts, after which a committee decision is made regarding whether the new item is deemed sufficiently effective and cost-effective to be recommended to the Minister of Health for listing and public funding. In the case of a medical service, an applicant can request that the department organise for an assessment report to be prepared by an independent group.

Other regulatory and funding bodies relevant to Australian healthcare include: the Therapeutic Goods Administration; the arm of the Australian Department of Health responsible for regulation of therapeutic goods, and various additional state or territory government departments and committees that make decisions related to funding of interventions through public hospitals.[12] The Therapeutic Goods Administration licenses products and manufacturers and seeks to ensure acceptable product safety, but does not investigate affordability or consider public funding. Decisions made by the body may indirectly impact patient costs. For example, registering a new medicine that is not funded may increase the likelihood that the treatment is recommended, and determining that a medicine may be purchased over the counter may reduce costs associated with obtaining a doctor's prescription. However, the need for access is a secondary consideration in the decision-making of this body and there is little information to suggest patient costs are considered.[13] Further, at the state government and public hospital decision-making level, there is little information available as to the extent to which patient costs are considered.

Health economic evaluation of costs associated with new technologies

Explicit guidance on the nature of the evidence and the economic and financial analyses that should be included in a submission to the respective Australian decision-making committee is available.[14-16] A proposed treatment or service needs to demonstrate that it is cost-effective to be recommended for funding through these schemes, but 'cost-effective' is not objectively defined. This allows the decision-making body discretion to interpret results of economic analyses in varying contexts which, arguably, is useful and reasonable given the unique needs of different patient groups and the complexities of our healthcare system, however is also frequently criticised as lacking transparency.[17,18]

All assessments of cost-effectiveness require an explicit statement of perspective, as the conclusion of whether publicly funding a new service or medicine is cost-effective will frequently vary, depending on whether it is viewed in the terms of the funding body, broader society or the patient perspective.

The MSAC guidelines request economic analyses be conducted on three levels: a Medical Benefits Scheme or government funding agency level; a healthcare perspective including all healthcare costs, regardless of whether they are incurred by the government or patient or other body; and a societal perspective including all costs.[14,15] However, despite the guidelines suggesting that an analysis from a societal perspective is desirable, in reality to date, few societal assessments have been presented to the MSAC; most assessments represent the healthcare perspective. Likewise, the PBAC guidelines state that the base case economic analyses should consider all healthcare cost impacts and health outcomes associated with an intervention from a healthcare system perspective and suggest additional analyses from a societal perspective should be presented as a supplementary analysis where relevant.[16] Thus it would be fair to say most funding decisions in Australia have considered patient healthcare costs, but few consider broader patient costs that are not specifically healthcare related, even if they are incurred in the course of accessing healthcare services or treatments.

While the inclusion of patient healthcare costs is described as routine, in reality this is less simple. To standardise evaluations, the MSAC and PBAC guidelines assume that patient costs for healthcare services equate to the standard Medicare contribution. However, there is little regulation with respect to medical fees in Australia, and a significant number of medical services are charged to patients at prices far in excess of the Medicare scheduled fee.[6] This type of additional patient cost is likely to be highly concerning for patients – and may directly impact the accessibility and affordability of treatment, yet is rarely brought to the attention of government funding bodies and their decision-makers.

There are both practical and political reasons why the requirement that any societal economic evaluation presented to the MSAC or PBAC be presented distinctly from a healthcare perspective. On practical grounds, the monetary value of indirect costs such as income loss are potentially very significant, but are notoriously difficult to estimate and highly uncertain.[19] Thus routinely including productivity estimates reduces the likely accuracy of economic evaluations and the overall consistency and reliability of the decision-making process. However, perhaps more important, are the ethical implications; only treatments provided to potentially productive members of society will be associated with productivity loss. Including this indirect cost in economic analyses will implicitly favour such treatments and patient populations, relative to treatments that are predominantly used in patients who are not economically productive, including the elderly and severely disabled people. Given both the practical and philosophical concerns faced by public funding decision-makers if they include consideration of patient income loss, it is of little surprise that few public funding decisions are based on economic analyses including productivity.[19,20]

The Australian approach is similar to the approach taken by the National Institute of Clinical Excellence in the UK, and many European agencies, requiring evaluations be conducted from a healthcare perspective at a minimum, and in some cases considering societal perspectives,[21] but contrasts greatly with the United States, where the albeit limited public funding body of Medicare part-funds all drugs approved by regulators, without consideration of cost-effectiveness, nor costs to the government or patients.[22]

Irrespective of the funding body's stated request to be informed of expected societal costs, few economic analyses considered by Australian funding bodies identify patient costs other than immediate healthcare costs.[6] Again, there are practical considerations. It is very difficult to record all non-health costs associated with obtaining healthcare treatment. For some patients, there will be significant transport, childcare and even accommodation costs associated with obtaining cancer treatment, but these will vary greatly depending on the individual circumstances of each patient. To estimate the expected value across the entire Australian patient population would require large datasets that simply don't exist. But without such data, or an alternative approach to funding, some patients risk ongoing hidden cost burdens, or in some cases do not seek adequate care, due to the broader unaffordability of costs associated with obtaining healthcare.[6]

Conclusion

Do Australian regulatory agencies and funding bodies consider patient costs? Invariably they do, and the economic analysis methods that are applied are of international standard. However, some health-related patient costs, and 'non-health' expenses, are often omitted and this may adversely impact on universal access and affordability for people receiving cancer treatment. Ongoing efforts are needed to improve the collection and incorporation of these additional costs and promote the societal perspective in regulatory and reimbursement decisions.

Note: this article expresses the views of the author and does not represent the official position of any government regulatory body.

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Cost of informal caregiving in cancer care

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Abstract

In 2015, approximately 2.7 million Australians were unpaid caregivers, including partners, family members, friends and neighbours. However, the true population of Australian caregivers may be under-estimated due to lack of carer self-identification, and this may be even more so for Australians of culturally and linguistically diverse backgrounds and Aboriginal and Torres Strait Islanders. Increasing cancer incidence and survival has resulted in a corresponding increase in the demand for unpaid caregivers, prompting in-depth exploration of the economic, psychosocial and physical impact of caring. Caregivers' physical health is significantly impacted and is sometimes reported to be lower than the patients they care for, perhaps as a consequence of prioritising the patient's needs and health over their own. Caregivers are also at increased risk of poorer psychological outcomes than the general population, reporting high levels of depression and anxiety. The financial impact is significant, with informal caregiving representing 18-33% of the total financial cost of cancer. The burden of this financial responsibility can adversely impact caregivers' quality of life, limiting their capacity to fulfil other caregiving roles and also having a direct adverse impact on the patients' quality of life. This paper reviews the costs of caregiving, from a financial, physical and psychosocial perspective.

It was estimated in 2015 that 2.7 million Australians were unpaid caregivers, including partners, family members, friends and neighbours, providing short-term or ongoing assistance to someone with a chronic disease or disability.[1] While the majority of caregivers are female, a statistic which is consistent across Australia, the US and Canada, the past few decades have seen an increased proportion of male caregivers.[2-6] Cancer is one of the top 10 health conditions requiring a carer. Across all caregivers, family members constitute the majority, with cancer caregivers more likely to be spouses of the care recipient.[7] The increase in cancer incidence and survival has resulted in a corresponding increase in the demand for unpaid caregivers,[8] prompting in-depth exploration of the economic, psychosocial and physical impact of caring.

Caregivers undertake a very wide range of tasks, including providing practical care, emotional support, household tasks, financial management and advocacy/decision-making. For many caregivers (42-98%), the experience of providing care is associated with positive aspects, including a feeling of accomplishment, improved quality of their relationship with the care recipient and the broader family, and deriving meaning from caregiving.[9] However, many caregivers feel unprepared for their role and the caregiving experience is by no means positive for all who take on that responsibility. The broader financial and health impacts of caregiving are numerous and significant, with accumulating evidence painting a compelling picture of negative impacts of caregiving on the financial standing of caregivers, as well as on their mental, physical and social functioning.[7]

Financial impacts of caregiving

Health system restructuring has led to a greater focus on home-based cancer care as an alternative to in-patient care, which consequently changes the distribution of costs families incur.[10] This shift is an important consideration, as financial status is a significant factor associated with caregiver burden.[11-14] Informal caregiving represents 18-33% of the total financial cost of cancer.[15-19] The burden of this

financial responsibility can adversely impact caregivers' quality of life, limiting their capacity to fulfil other caregiving roles and also having a direct adverse impact on the patients' quality of life.[20,21] In a study by Tsigaroppoulos et al,[22] increased economic burden was the third most common problem reported by 51% of caregivers of patients with advanced cancer, only exceeded by anxiety regarding the patient's future (62%) and troublesome symptoms such as pain (54%). Despite this prevalence, less attention has been given to economic burden than other aspects of caregiver burden, such as emotional burden.

Direct and indirect expenses

The financial cost of caregiving includes direct out-of-pocket as well as indirect expenses, including: taking time off work to care for the patient; paying for treatments and medications; travelling to cancer appointments; paying for accommodation to stay near treatment centres; reorganising daily and home life, such as help with housework; and coping with the disease, including long distance calls to other family members.[23-27] One of the only Australian studies in this area found that half of the caregivers of haematological cancer survivors reported personal expenses related to their role, with the three most common expenses including parking while at hospital (36%), travel to cancer appointments (33%), and drugs or treatments (25%).[27] More than half (52%) of caregivers in this study reported a financial impact because of their role, including taking time off (40%), having less income (29%) and using up savings (19%), and some reported difficulties paying bills (14%) or meeting day-to-day expenses (9%). These caregivers identified free parking (43%), free medication (32%) and being able to access treatment in their region (25%) as strategies to reduce the financial impact.

In two international studies, one from Europe and one from the US, that reported on the total costs of caregiving, one consistent finding was that 85-90% of the total cost was attributed to indirect time cost,[25,28] which included: visiting and waiting during diagnostic tests and/or surgery; travel time; time spent on housework, such as preparing food and drinks; and assisting the patient with activities of daily living. The American study by Van Houtven et al,[28] reported that 89% of time costs was attributed to caregivers' direct care efforts, with the remaining time cost due to cost of sick hours, vacation hours, unpaid hours, work hours lost per week and leisure lost per week. Although representing a lower proportion of the total caregiving cost, direct expenditures were also an important cost, with some of the largest direct expenditures in informal caregiving relating to medication, doctors' visits, household expenses and travel.[25,28] Either as an indirect time cost or a direct expenditure, travelling to the hospital and for appointments was identified across all three aforementioned studies, with Stephens et al highlighting that the time cost involved in travelling is higher than the direct transport cost.[29]

Impact on work

In addition to travel, a proportion of the cost of caregiving is attributed to the impact on the person's work, with reports that 32 to 45% of caregivers needed to work fewer hours to fulfil their caregiving roles and responsibilities.[30-33] However, caregiving also impacted on work more broadly, including having to take some time off work or using holidays or special leave as required, having interrupting phone calls during a work day, changing employment, retiring or quitting altogether.[32,34] A European study found that caregivers were more likely to report absenteeism, impairments while at work, and impairments during daily activities, and a higher mean number of hospitalisations, emergency department visits, and visits to healthcare professionals than non-caregivers.[35] In a month-long American study by Passik & Kirsch,[33] 28% of spousal caregivers reported handling fewer responsibilities at work, 32% had reduced their work hours and 32% felt that they were less effective overall at work. Caregivers missed an average of 2.7 days (SD = 2.95) and took an additional 1.29 (SD = 2.97) sick days and 1.76 (SD = 2.63) vacation days during that time. In one Canadian study, caregivers reported on average seven days lost from work in the previous 30 days.[31] Dubas-Jakobczyk et al found that caregiving for patients with cervical cancer resulted in approximately 873 working days lost in 2012, with significant production lost due to this absenteeism.[36] One review of the financial stress and strain associated with terminal cancer found 10 to 40% of families reported that someone had quit work to provide care.[26]

The impact of caregiving on work has been less studied in the Australian context. Work productivity data, previously unpublished, were collected as part of the Partners and Caregivers Well-Being Study, a five-year longitudinal study of 547 Australian caregivers of patients with the top 10 incident cancers

in Australia.[37-39] Twenty per cent (112/547) of all caregivers surveyed reported having to take sick leave, 6% (31/547) had to stop work and 9% (48/547) had to reduce hours to care for the person with cancer. Furthermore, of the half (n = 262) of the caregivers who were working at the time of the initial survey, that is six months following the patient's diagnosis, 13% reported that their caregiving role adversely impacted their work productivity, and 18% reported that their productivity at work in the last week was lower compared to their productivity in the last six months. These changes in caregivers' work might result in loss of income, as well as lead to concerns about job loss or employability, lack of promotion, and inadequate pension build-up.[23,27,32]

Meeting out-of-pocket expenses

The financial burden of cancer can lead caregivers to use their and other family members' savings, sell assets, take out loans or seek additional work to cover the additional costs and burden of caregiving.[26] A review of the financial strain incurred in the terminal phase of the illness identified that 17 to 38% of patients or their families used most or all their savings.[26] A Korean study found as a consequence of the financial burden endured, caregivers reported losing family savings (68%), altering educational plans for another family member (29%), moving to a less expensive home (20%), and delaying medical care for another family member (14%).[40] In this study, caregivers were more likely to lose their family savings if they had a monthly household income of less than $US833, had fair or poor health status, were married, provided care for more than 12 months after diagnosis, cared for patients with poor performance status or paid high medical expenses. Of note, loss of savings was the variable most strongly associated with caregivers' quality of life, along with requiring caregiving assistance, major life change, inability to function normally, loss of income and altered educational plans.[40] In our Australian longitudinal Partners and Caregivers Well-Being Study, out-of-pocket expenses among caregivers were examined; 75% had out-of-pocket costs and 84% of caregivers said they were meeting out-of-pocket expenses using their income, savings (47%) and loans to cover the additional expenses (3%). The most common expenses for caregivers because of the cancer diagnosis were health care professionals (42%), prescription medicines (40%), travel (32%) and over the counter medicines (32%). Further consequences for some caregivers include house repossession, bankruptcy, loss of independence and relationship breakdown.[23]

Variables associated with financial burden

To date, the literature on the financial cost of caregiving has identified vulnerable sub-groups of caregivers, mostly based on the care recipient's phase along the illness trajectory and cancer stage and/or type.[19,24,25,27,28] Caring for someone in the advanced stage of the disease has been found to be particularly costly for caregivers, especially as it extends for several years, in comparison to other stages along the illness trajectory such as primary treatment and rehabilitation.[15,41] An American study by van Houtven et al estimated that the accumulated economic burden for caregivers in the terminal phase was $US14,234, in comparison to $7028 and $19,701 for those evaluated during the patient's initial phase and continuing phase of disease, respectively.[28] Of note, for caregivers evaluated in the continuing phase, costs had been accrued over 17 months versus seven to eight months for those in the initial and terminal phases. This study further documented that the economic burden was higher for caregivers caring for a woman versus a man, with lung cancer versus colorectal cancer, diagnosed at stage 4 versus stage 1, with lower quality of life, and for caregivers who were working and the patients' spouses, as opposed to other relatives or friends.[28] Yabroff et al also corroborated that the time cost for caregivers varied by cancer type, whereby caregivers of patients with lung cancer incurred costs almost twice as high as those noted for caregivers of patients with breast cancer.[42] Similarly, a difference of almost $US31,000 was noted between the cost of caregiving between the localised stage at diagnosis versus distant stage.[42]

The aforementioned Australian study found that caregivers of patients with a haematological cancer in the active treatment phase reported experiencing more personal expenses than caregivers in the pre-treatment, maintenance, follow-up or remission phases.[27] In this study, male caregivers reported more personal expenses, but less financial impacts than their female counterparts. One study has documented the impact of locality on costs, reporting that rural caregivers face more costs than urban caregivers related to prescription medication, out-of-pocket costs and transportation. However, urban caregivers face more costs related to formal home care.[18] Other factors contributing to caregivers' financial burden include the presence of children at home, being a younger caregiver, caring for a

patient with symptoms or one who needs assistance with activities of daily living, and lower educational attainment by caregivers.[31,43]

Broader costs of caregiving

Unlike the financial costs of cancer, there have been many reviews on the psychosocial impact of cancer on caregivers,[7] and this section only highlights key findings. Since cancer largely remains a disease of the ageing population, caregivers tend to be older themselves and are therefore providing care for someone with a chronic condition while trying to manage their own health and chronic conditions.[44-46] They suffer loss of physical strength, loss of appetite, weight loss, fatigue, pain and sleep disturbance and spouses have been reported to be at greater risk of coronary heart disease and stroke following their partner's cancer diagnosis compared to spouses whose partner does not have cancer.[47,48] Of concern is that caregivers' physical health has been reported to be lower than the patients they care for, perhaps as a consequence of them prioritising the patient's needs and health over their own.[49-51]

In addition to their physical ill-health, caregivers are also at increased risk of poorer psychological outcomes than the general population, with approximately a quarter reporting depression and 40% reporting anxiety.[52-56] In some contexts, the levels of distress, anxiety and depression have been reported to exceed those of the patients for whom they care.[53,57,58] While anxiety and depression tend to decrease over time for the majority of caregivers, of concern is a subgroup of caregivers who experience clinical levels of anxiety or depression at six months following their care recipient's cancer diagnosis and continue to experience such clinical levels throughout the first two years post-diagnosis.[52,59] These findings underscore the importance of screening for caregiver distress early to identify those most in need of support, to help ameliorate potential negative impacts of their caregiving experience.

While understanding and addressing the negative impacts of caring on caregivers' health and wellbeing is important in and of itself, it is also important because of the mutuality in response between caregivers and the patients for whom they provide care. A meta-analysis reported a significant moderate, positive association ($r=0.29$, $p<0.001$) between patient and caregiver distress, suggesting an interdependent reaction to the cancer diagnosis and, therefore, that addressing the caregiver's distress may also have a positive impact on the patient's distress.[60]

Unknown cost for some caregiver sub-groups

The true population of Australian caregivers may be under-estimated due to lack of carer self-identification, and this may be even more so for Australians of culturally and linguistically diverse (CALD) backgrounds and Aboriginal and Torres Strait Islanders. The physical, psychosocial and financial costs experienced by these sub-groups may be even more pronounced, if the caregivers are themselves of CALD or Indigenous backgrounds, as well as the patients they are caring for. Although there is increased recognition of these groups' vulnerability, there has been little research documenting the extent of the costs experienced by these sub-groups.

Australia is one of the most CALD countries in the world, with approximately 28% of Australians born overseas.[61] The influence of cultural and linguistic diversity on the caregiving experience and outcomes is potentially quite complex. It is estimated that 25 to 30% of caregivers in Australia are from CALD backgrounds,[1,62] however the size of the population of non-CALD caregivers who are providing care for CALD patients is unknown. Australian research has reported CALD patients as having significantly lower quality of life, higher incidence of clinical depression, greater side-effects and being less satisfied with their cancer care than their English-speaking counterparts, with unmet needs relating to emotional support, information and coordination of care.[60,64] These variables are likely to impact on their caregivers' coping and well-being. For example, in the Australian Partners and Caregivers Well-Being Study, 63% of CALD caregivers reported high anxiety at six months post-diagnosis, compared to 36% of Australian-born caregivers ($p<.05$). The difference was maintained over two years of follow-up. CALD caregivers also reported poorer physical health than the Australian-born caregivers, a finding partially explained by the high reliance on family for caregiving across many cultures.[65]

Australian statistics suggest that 12% of the Aboriginal and Torres Strait Islander population are caregivers, compared to 10% of non-Indigenous Australians, Indigenous Australian carers are on average 12 years younger (average age 37) than non-Indigenous Australian carers,[66] with a large proportion living in rural and remote areas. While across the caregiver population, many caregivers are trying to manage their own health and chronic conditions at the same time as providing care for someone with a chronic condition, this is even more acute for Indigenous Australian caregivers, who are between 1.5 and three times as likely as non-Indigenous caregivers to need assistance with self-care, mobility and/or communication.[46,66] The financial burdens of caregiving are also more pronounced in this population, with Indigenous caregivers earning lower income and less likely to be in employment compared to non-Indigenous Australian caregivers.

Conclusion

The cost of providing informal care to cancer patients is significant, not only from a financial standpoint, but also in terms of the physical, psychological and social impacts of caregiving. For some Australians, particularly those of CALD background and Indigenous Australians, the costs are amplified. Future research is needed to document the direct and indirect costs of caregiving and determine the costs, particularly among vulnerable groups.

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Measurement of resource utilisation in cancer clinical studies – tools, issues and challenges

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Abstract

Inclusion of economic evaluations alongside cancer clinical trials necessitates the collection and analysis of resource utilisation and cost data alongside outcomes. The purpose of this paper is to describe and discuss the measurement of cost in clinical studies, particularly resource utilisation. Cost data collection can be conducted retrospectively through linkage of treatment data with claims data, such as Medicare, or by patient recall (questionnaires). Prospective approaches include the patient diary. Measures and data collection tools are usually modified by researchers to fit the purpose and target population of their specific study. There is strong agreement on the inclusion of direct medical and non-medical costs in economic evaluations. The balance of opinion is that inclusion of indirect costs is appropriate; but agreement on exactly 'which indirect costs' and in 'what context' differs. However, narrow study perspectives mean that inter-sectoral resources are often overlooked. In addition to the two cancer-specific instruments included in the Database of Instruments for Resource-Use Measurement, there are numerous resource utilisation measurement tools used in a broad range of clinical research with heterogeneous intervention characteristics and outcome measures. Despite this, very few studies report validated cost/resource use instruments. Further, many cost analyses ignore long-term care costs, non-medical costs borne by patients and important costs incurred in other sectors, such as social services. There is no 'gold standard' for resource utilisation instruments and the agenda for future research is lengthy. For example, many issues such as recall length, accuracy in recall of medical terms and medicines, specificity versus comprehensiveness of the instrument and missing data, remain to be addressed. Innovation in mobile technology will likely revolutionise data collection and may overcome many of the existing barriers to robust measurement of resource utilisation for cancer clinical trials and improve societal decision making.

Health economic assessment and economic evaluation is growing, owing to the need to demonstrate cost-effectiveness of a new health technology, pharmaceutical product, intervention, program or service.[1,2] Hence, economic evaluation alongside a randomised controlled trial (RCT) is increasingly used in research to inform decision making for clinical practice and service planning.[3] The purpose of this paper is to describe and discuss the measurement of cost in clinical studies, particularly resource utilisation in the healthcare sector for cancer.

Cost assessment in economic evaluation involves the identification, measurement and valuation of costs relevant to both the intervention/s under consideration and the comparator.[4] Identification of relevant costs depends on the context of decision making and the study questions to determine the scope of cost inclusion. Measurement of costs assesses the quantity of the services and goods related to the delivery of the intervention/s and comparator. Valuation of costs assigns a unit cost or price to resource items related to the interventions of interest in a consistent year of analysis. Symmetry in methods across intervention and comparator is important to facilitate comparability and confidence in cost results.

Cost assessment for economic evaluation alongside clinical studies

Guidelines for economic evaluation and health technology assessment have been developed and increasingly utilised by health economists and evaluators. For example, the National Institute for Health and Care Excellence in the UK has a health economics guidelines manual underpinning clinical and public health guidance.[2] The International Society for Pharmacoeconomics and Outcomes

Research has published and updated the *Good Research Practices for Cost-Effectiveness Analysis* guidelines for conducting and reporting the economic evaluation alongside clinical studies.[5] In Australia, the Pharmaceutical Benefits Advisory Committee has developed and regularly revises guidelines for the preparation of submissions for consideration of pharmaceutical product reimbursement.[1] In the US, updated guidelines of the Second Panel on Cost-Effectiveness in Health and Medicine were published in 2016.[6] The updates build on the original work of the 1996 recommendations for the conduct and reporting cost-effectiveness analyses.[7] These guidelines, although acknowledging different contexts, settings and study aims, recommend the inclusion of health resource use data in conducting economic evaluations.

Examples of medical resource items include medicines, medical services and procedures, hospital services, diagnostic and investigational services, community-based services and any other direct medical costs. The guidelines also recommend the inclusion of indirect costs, although guidance on where and how these costs should be included varies. Indirect costs include time and travel costs, productivity impacts in the general economy and domestic production, together with informal care to patients provided by carers/families. An example of impact and cost considerations across various sectors from different perspectives is illustrated in figure 1.

Figure 1: *Impact Inventory Template, Source: Sanders G et al 2016.*[6]

Sector	Type of Impact (list category within each sector with unit of measure if relevant)[a]	Included in This Reference Case Analysis From...Perspective?		Notes on Sources of Evidence
		Health Care Sector	Societal	
Formal Health Care Sector				
Health	Health outcomes (effects)			
	Longevity effects	☐	☐	
	Health-related quality-of-life effects	☐	☐	
	Other health effects (eg, adverse events and secondary transmissions of infections)	☐	☐	
	Medical costs			
	Paid for by third-party payers	☐	☐	
	Paid for by patients out-of-pocket	☐	☐	
	Future related medical costs (payers and patients)	☐	☐	
	Future unrelated medical costs (payers and patients)	☐	☐	
Informal Health Care Sector				
Health	Patient-time costs	NA	☐	
	Unpaid caregiver-time costs	NA	☐	
	Transportation costs	NA	☐	
Non–Health Care Sectors (with examples of possible items)				
Productivity	Labor market earnings lost	NA	☐	
	Cost of unpaid lost productivity due to illness	NA	☐	
	Cost of uncompensated household production[b]	NA	☐	
Consumption	Future consumption unrelated to health	NA	☐	
Social Services	Cost of social services as part of intervention	NA	☐	
Legal or Criminal Justice	Number of crimes related to intervention	NA	☐	
	Cost of crimes related to intervention	NA	☐	
Education	Impact of intervention on educational achievement of population	NA	☐	
Housing	Cost of intervention on home improvements (eg, removing lead paint)	NA	☐	
Environment	Production of toxic waste pollution by intervention	NA	☐	
Other (specify)	Other impacts	NA	☐	

[a] Categories listed are intended as examples for analysts.

[b] Examples include activities such as food preparation, cooking, and clean up in the household; household management; shopping; obtaining services; and travel related to household activity.[18]

NA indicates not applicable.

Measurement of resource use varies in complexity from a macro top-down approach that focuses on frequency of use of pre-costed activity components, exemplified by the Australian Refined Diagnostic Related Groups,[8] to a micro approach that identifies expenditure categories, including salaries and wages, capital, consumables and overheads, and individual patient utilisation data.[9] Measurement can be conducted retrospectively, prospectively, or by using mixed methodologies, depending on the study context. Methods include reviewing relevant patient treatment records, using administrative data

collections, linkage with claims data, questionnaire or survey administration, and the use of patient diaries.[1,10,11] Within the Australian healthcare system, services and care pathways are segregated and financed by state and/or commonwealth governments. For example, palliative and supportive care for cancer patients requires a broad range of services provided by diverse disciplines across all healthcare sectors with primary, secondary and tertiary care providers.[12] Therefore, many data sources are required to estimate healthcare costs along the care pathways. Data sources include Medicare claims, health records held by general practitioners, health professionals and hospitals, or patient recall.[13-15]

Questionnaires, logs and diaries are commonly used by health economists to record patient-level health services utilisation (including patient out-of-pocket costs) or indirect costs, e.g. travel costs, time costs and impact on their productivity.[16-19] These patient-level costs are usually based on patient recall or prospective recording by clinical study participants. Retrospective questionnaires may be subject to recall bias, whereas prospective diaries can be burdensome and subject to partial completion.[20,21] A study comparing these two collection approaches for rectal cancer patients concluded that the cost questionnaire with structured, closed questions could replace a cost diary for recall periods of up to six months.[20] Our experience supports the view that diaries can be problematic and resource intensive. For example, in a clinical trial where young women were recruited into a life-style modification intervention, a paper-based diary was not efficient in data collection as the participants easily misplaced and overlooked the diary.[22]

There is no gold standard for the development of resource utilisation instruments. Numerous instruments, mostly not validated, have been designed to collect self-report cost and resource usage for economic studies in a broad range of clinical research.[23] Information is reported by patients, their parents/carers, healthcare professionals and even researchers. Various administration methods are employed to complete the data collection, either in person by the researchers, by mail-out to patients, through telephone interviews, or via computer and internet interface.[14,24,25] Costs can be borne by different sectors and are generally reported as ‘costs to government as the third-party payer of healthcare services’, ‘costs to individuals as out-of-pocket expense’, the ‘cost of informal care’ to families and ‘productivity gain/loss’ to the general economy.[26-28]

Tools used in collecting resource utilisation data in cancer patients

A web-enabled Database of Instruments for Resource-Use Measurement (DIRUM) was developed by the Medical Research Council Network of Hubs for Trial Methodology Research in the UK.[29] DIRUM offers a repository of methodological papers related to resource use and cost measurement. At its inception, there were 54 resource utilisation instruments used in the UK for inclusion in the database.[23] The database has expanded to 81 instruments up to March 2017, incorporating those from other countries including Australia,[30] and the scope has extended to include inter-sectoral cost measurement outside the healthcare sector. This web-based database is a very useful resource for researchers conducting cost assessments, but these instruments may not be generalisable to other countries due to the diversity in healthcare systems from country to country.

In the DIRUM database, there are two instruments specifically designed to collect costs incurred by cancer patients, the UK Cancer Costs Questionnaire and the Assessment of Nausea in Chemotherapy Research (ANCHoR) Questionnaire. The UK Cancer Cost Questionnaire was used to describe the economic burden of UK cancer survivorship one year post-diagnosis for breast, colorectal and prostate cancer patients treated with curative intent.[31] Included resource usage items were community-based health and social care, medications, travel costs and informal care. The questionnaire is part of an electronic data collection system for obtaining relevant patient-level clinical and financial information to estimate social costs by using a standard cost-of-illness framework. Similarly, direct medical and non-medical costs and indirect costs to patient and families, including social care and workdays lost, were collected by the ANCHoR Health Economic Questionnaire.[32] The ANCHoR questionnaire was designed to collect patient-level costs in a RCT for the management of chemotherapy-related nausea.

Ridyard and Hughes examined the DIRUM database’s instruments for reliability, validity, pilot testing and questionnaire completion rates.[23] Little evidence of reliability testing existed in the instruments included in the DIRUM database. Some degrees of validity, including content validation, face validation, criterion validation or convergent validation, were observed in approximately half of these

instruments. Less than half of instruments were piloted, using a variety of methods, and less than 10% tested the cognitive or patient comprehension of the instructions and questions. The review of these 54 instruments raised many unanswered questions which need to be addressed, including: i) the effect of question sequencing; ii) the optimal recall length; iii) accuracy in recall of medical terms and medicines; iv) specificity versus comprehensiveness of the instrument; v) treatment of missing data; vi) the appropriateness and transferability of generic instruments; and vii) the challenge of instrument development in multi-national trials.

There are also numerous resource measurement tools which have been used in many types of clinical studies with heterogeneous interventions characteristics and outcome measures for cancer patients. In Australia, the Cancer Research Economics Support Team at the University of Technology Sydney have published a series of factsheets to aid clinicians and researchers in understanding and developing economic evaluations alongside their clinical studies.[15] These factsheets provide guidance on how to conduct health economic studies in cancer effectiveness trials, with the intention of creating opportunities to conduct cross-trial investigations in broader research areas. Practical guides and specific topics in trial design, data collection and analysis in health economics are provided by the online resources. However, details of cost measurement and instrument development are absent and the factsheets do not address issues of instrument acceptability and appropriateness.

Issues and challenges in resource utilisation measurement

Generally, data collection tools are modified by research teams to fit the purpose and target population for their specific studies. While understandable, this process may lack the rigour required to ensure modified questionnaires are reliable and valid. Pilot consultation with trial participants provides a way to validate the acceptance and appropriateness of the questions in the collection tool. Past and current economic studies show that response rates are often not ideal and there is little evidence of analysis in questionnaire completion rates that exists in the literature.[23] Our experience confirms that study participants may not feel comfortable providing financial information, but a more detailed exploration of the factors influencing the completion of health resource utilisation data collection is needed.

The current literature on health resource use measures predominantly focuses on: i) comparison of data sources; ii) methods for data collection; and iii) the validation of self-report questionnaires with administrative data.[33-35] A systematic review of validated self-reported questionnaires for measuring resource utilisation found very few studies reporting validated instruments, particularly compared to the sheer numbers of economic evaluations conducted.[33] Among the 15 studies included in the systematic review, great variation existed in target populations, conditions studied, the age of patients, the length of questionnaires and the relevant resource sections included. On the other hand, validation of self-report questionnaires with clinical records or administrative databases does have limitations. For example, clinical records are often fragmented across the health system and therefore sufficient information for accurate costing may not be readily available from these sources.[36]

A recent study examined the full scope of out-of-pocket costs, lost income and the management of finances during cancer treatment.[37] Many non-medical costs were identified in the qualitative exploration study, including modification to housing arrangements, special clothing, fitness costs and the impact of an altered diet. Although only 14 cancer patients completed the interview, these patients with a diagnosis of breast, colorectal, lung or prostate cancer, revealed a foundation issue of unexpected financial shock after the diagnosis. These costs impose a significant financial burden to cancer patients and are usually omitted by economic assessment in many studies.

Another review paper identified that many cost analyses ignore long-term care costs and costs occurring in other sectors, such as social service.[36] Unsurprisingly, most clinical studies and trials focus on the measurement of cost and consequences within the healthcare sector due to its narrow perspectives of study analysis. The impact of the intervention on other sectors such as housing, education and social welfare is usually overlooked. Some guidelines, including those prepared by the Pharmaceutical Benefits Advisory Committee, recommend that only healthcare resources be included in assessments due to their decision making context, such as a Department of Health perspective. A key issue is that cost identification/measurement should be carefully considered based on the study questions and decision context from a broader societal perspective if possible. Other issues include

the need for symmetry across costs and outcomes, particularly in regard to tracking costs through time and data tractability.

Future trends in resource utilisation data collection for clinical studies

Mobile technology has advanced enormously in recent decades and mobile phone apps and tablets are gradually being adopted in healthcare service and research. The applications of mobile technology range from appointment reminders to enhancing treatment compliance, delivering interventions and data collection.[38-41] This innovation, denoted as mobile health (mHealth), has become a powerful platform in the healthcare sector.[42] An example of the technology assisted data collection in research is the mobile device application development, TherApp (Therapy App), currently in randomised control trials of upper limb orthoses for children with cerebral palsy.[43] The application can be installed in mobile phones and tablets for recording frequency, duration and complications of wearing the orthoses each day during enrolment in randomised control trials. Alerts and prompts are sent to the parent of the child participant if no responses are received. Therapies received and attendance of medical appointments are also recorded by a weekly prompt question. Safety and privacy is ensured by password protected access to TherApp for each study participant and secure data storage and transfer.

Such mobile applications for collecting data in cancer patients are practical and are expected to improve the accuracy of data in cost measurement, as the app acts like a real-time cloud diary. Using a mobile device may assist in overcoming the problems of paper-based diary described earlier. The data collected can be compared with or complement other forms of data collection, such as questionnaires administered at time points during the trial or study. These innovative technologies can be further adopted through knowledge translation from research to routine clinical practice.[44]

Conclusion

Measurement of costs and resource utilisation in cancer clinical studies is a pivotal component of economic evaluation. Measurement instruments for resource utilisation are generally designed to fit the decision context, target population, disease and intervention for each study. Variation in data inclusion and administration methods exist due to the inherent nature of fit-for-purpose instruments. This then takes us back to clarity on costing principles and this is where the health economist can help to set research on the right footing.

In cancer clinical studies, there is a strong agreement on the inclusion of healthcare related resources that are direct medical and non-medical costs. The balance of opinion is that inclusion of indirect costs is appropriate, but agreement on exactly ‘which indirect costs’ and in ‘what context’ differs – there is more agreement on inclusion of costs in time, travel and informal care than for productivity impacts. Further, inter-sectoral resources outside the healthcare setting are often overlooked. The vast majority of tools used in clinical trials/studies are not validated and many issues, such as recall length, accuracy in recall of medical terms and medicines, specificity versus comprehensiveness of the instrument, missing data, etc. are yet to be addressed. Innovation in mobile technology will revolutionise future clinical studies in data collection, intervention delivery and adoption for routine practice.

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Financial toxicity – what it is and how to measure it

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Abstract

The term 'financial toxicity' is broadly used to describe the distress or hardship arising from the financial burden of cancer treatment. In much the same way as physical side-effects of treatment like fatigue, nausea or blood toxicities, financial problems after cancer diagnosis are a major contributor to poorer quality of life, treatment non-adherence and delayed medical care. This article describes what financial toxicity is, how it is measured, how common it is and what the implications are for further research and clinical practice. A recent review shows a wide range of measures used to describe the financial burden of cancer. Using monetary measures, the magnitude of financial stress was between 28-48% in cancer populations. Possible solutions to reduce the family financial burden include mandating full disclosure of doctors' fees and charges related to treatment and strategies to empower patients to improve their treatment decision making. Furthermore, screening tools such as the COST-FACIT 11-item survey may assist health professionals to identify those patients at high risk of financial stress and refer them to support services. Minimising financial stress is important for patients and measuring financial toxicity helps to expose flaws in health systems and subsequently ensure that citizens receive quality cancer care.

For patients and their families with cancer, the financial impact of this disease can be devastating. Although this may also be a problem for patients with other serious diseases, patients with cancer are particularly vulnerable, in part due to the high costs associated with multiple components of care, advancements in technologies, new oncology pharmacotherapies and surgical techniques, increased use of imaging, and genetic testing.[1] Ancillary costs such as travel, parking, accommodation, medical aids, home help and child care can also mount up. Further, improvements in survival mean that most people with cancer are living longer, but with increased risk of functional decline and comorbidities causing substantial personal and societal burden.[2] As most health systems face ever-constrained budgets, there is increasing reliance on patients to make larger co-payments and financial contributions to their healthcare.[3,4]

Since all healthcare systems differ, their organisation and funding mechanisms largely determine the degree of financial hardship experienced by citizens when a major health shock occurs, such as a diagnosis of cancer. In low income countries, where affordability and access to healthcare is low, patients with cancer may not even present to health services when symptoms arise, or only present to a doctor when the cancer has spread and death is imminent.[5] Poor provision of a public health sector, strong cultural beliefs about illness and geographical barriers to receiving cancer treatment compound the problem.[6] In high income countries, patients with cancer often believe they are sufficiently

protected from high medical costs through their public health system or health insurance policies, only to discover inadequate coverage and subsequent 'bill shock' as invoices arrive.[7] Health systems claiming to have 'universal health coverage' in practice may not be truly universal. For example, Australians do not have access to free basic dental health services.[8] Additional patient out-of-pocket expenses are common even in countries where there is universal health care or when individuals purchase private health insurance.[1,4,8] High out-of-pocket healthcare costs have led to the recent conceptualisation of 'financial toxicity'. This paper outlines the notion of financial toxicity - a new term originating in oncology by Zafar and colleagues in 2013,[9] - and describes what it is and how it is measured. The popularity of this term has grown because of the clear link to patient loss of wellbeing, placing it in the same context as physical toxicities.

What is financial toxicity?

There is no standard definition of financial toxicity. Together with the terms financial hardship and financial burden, which are used interchangeably, the term is broad and non-specific. However, the occurrence of financial toxicity has two key contributors: 1) high medical payments by individuals/households; and 2) reduced income while being treated or recovering from cancer. Some physical and mental impairments of cancer treatment also lead to permanent work cessation.[10,11] The extent of financial burden is worse for individuals facing the dual problem of high out-of-pocket medical expenses or outgoings and concurrent loss of earnings or incomings. In some research studies, financial hardship has been captured as 'catastrophic spending', which is defined as spending greater than 30% of household income on healthcare.[5]

The ways that individuals cope with financial burden fall into two broad categories: raising income through seeking financial assistance, early return to work and increasing debt/borrowings and the like; or reducing spending by forgoing or delaying healthcare, choosing a less expensive option and similar steps. However, these strategies are not available to all individuals. A diagnosis of cancer can be very fearful for patients and questioning their health professional on fees is often a low priority.[3] Also, patients with cancer may not be informed of less expensive options unless they are confident and proactively search for this information. For example, in our research involving men with prostate cancer,[3] the choice of receiving brachytherapy treatment in private practice was offered to one man at an upfront cost of $15,000 for the brachytherapy seeds and a further $10,000 for the surgical procedure requiring three days in hospital. With further research, he was advised he could receive the same procedure at a public hospital at no cost. However, in the same study, another participant reported paying $16,000 for a prostatectomy by a private surgeon, later regretting his decision when he learned other less-invasive and less expensive options were relevant, but never discussed by his specialist. In economic terms, these scenarios are examples of 'asymmetric information' between the consumer and provider, partly influenced by the lack of market competition and demonstrating market failure in the healthcare sector. Market failure in healthcare has many sources, but generally describes the scenario where resources are not being allocated efficiently and it is possible that patients could be better off. Market corrections via regulations or government intervention are usually required. Strategies to empower patients to engage in optimal decision marking in healthcare are also important.[12]

Measuring financial toxicity

There have been numerous studies over the last 10 years specifically among individuals and families on the topic of the financial burden of cancer. Several reviews have been published covering selected aspects, for example, perceptions of cancer-related financial hardship or reported impact on quality of life.[13] In a recent systematic review,[12] the current extent of financial toxicity was assessed from studies published within the previous three years. Further, it described the latest measures or tools researchers employ to understand this occurrence.

The measures of financial toxicity varied widely among the studies and therefore were categorised into three types of measures:

1) Monetary - currency values of out-of-pocket expenses and percentage of out-of-pocket spending to income ratios.

2) Objective - question sets on tangible solutions to ease financial burden such as to increase debt levels, borrow money from family or friends, sell assets, withdraw money from retirement or savings funds, file for bankruptcy.

3) Subjective - question sets on perceptions of cancer-related financial burden and which cover the psychological impacts.

However, even within these three categories, there was heterogeneity relating to the scope of data collected. For example, monetary measures included either direct medical expenses or direct and indirect expenses such as travel, accommodation or parking. It is important to note that most measures used in the studies in our review were not validated or tested for reliability. Therefore, how rigorous they are at measuring what they are supposed to measure is uncertain. Monetary measures are problematic when relying on participant recall, while comparability across studies is difficult when cost components differ and cover different time periods. With 72% of studies using cross-sectional designs, drawing causal inferences between financial toxicity outcomes and determinants was not possible.[12] Financial hardship may have existed prior to the cancer or due to other concurrent health conditions. The cancer experience might have not caused, but exacerbated existing financial problems.[14-16] Directionality and temporality issues are also present in these cross-sectional designs. However, other methodological strengths in the study design exemplified by good response rates >50%, large samples and analysis indicated by adjustment for potential confounders, provide confidence when the interpreting the results.

There are few Australian studies examining the economic burden on patients with cancer.[3,10,17-19] Although they provide snapshots of the burdens Australians face for breast cancer,[17] prostate cancer,[3] colorectal cancer,[10] mixed cancers,[19] and patients with cancer in rural locations,[18] these studies include small and selective samples which preclude generalisations. Two of the studies are over a decade old.[17,18] More recently, one study observed changes in employment after colorectal cancer (n=239) and compared findings with a non-cancer control group in middle-aged working adults.[10] The findings showed 27% had not returned to work 12 months after their diagnosis compared with 8% leaving work in the matched general population group.[9] The median time off after cancer was 91 days and 75% of the sample took up to six months off work. In a sample of men recently diagnosed with prostate cancer (within 16 months of the survey) (n = 65), men reported spending a median $8000 (interquartile range $14,000) for their cancer treatment, while 75% of men spent up to $17,000.[3] Twenty per cent of all men found the cost of treating their prostate cancer caused them 'a great deal' of distress.

How common is financial toxicity?

Considering the measurement variation and issues reported above in 25 of the most recent studies in this field,[12] evidence for the extent of financial toxicity following cancer is imprecise. When monetary measures alone were used, the findings from the recent review indicated the frequency of financial toxicity among cancer survivors ranged from 28 to 48%.[12] When financial toxicity was measured with participants responding to objective or subjective questions, the frequency ranged from 16 to 73%. Some of the factors which were consistently associated with financial toxicity were being female, low income at baseline, younger age, adjuvant and anti-neoplastic therapies, advanced cancer, more recent diagnosis and living further away from treatment centres. In three studies, the financial burdens were examined within cancer populations alongside non-cancer control groups.[6,20,21] All indicated statistically significantly higher burden for individuals with cancer relative to non-cancer control groups. The above-mentioned review had consistent findings with two other reviews.[4,13] One assessed perceived financial burden and found 15 to 78% experienced financial hardship, with low income households identified as the most significant risk factor.[13] A second US-based review, found high prevalence of tangible measures and non-adherence to treatments as coping mechanisms to high financial costs.[4]

There is also evidence from several studies to indicate financial toxicity lives up to its name in impacting the quality of life of patients with cancer. Mental well-being was markedly worse for patients experiencing financial toxicity in three recent studies.[15,22,23] Increased financial burden among 2108 patients with cancer was the strongest independent predictor of poor quality of life in the US study by Fenn et al.[24]

Implications for research

The categories used in reporting outcomes in the recent review may help researchers design studies in future and determine exactly which aspect of hardship they are targeting. The measurement of financial toxicity in cancer should be standardised as this would increase the comparability of research findings across samples, aiding pooling of results and interpretation across different settings.

One such tool,[25] the COST-FACIT, has recently been developed by Souza et al. This 11-item survey covers objective and subjective questions about financial stress and work-related issues during the past seven days and uses a Likert scale rated from 'Not at all' to 'Very much'. A recent study demonstrated the reliability and validity of this tool in patients with metastatic cancer.[26] In addition, as reductions in work income are an important aspect of financial toxicity, the Institute for Medical Technology Assessment Productivity Cost Questionnaire (iPCQ) may also be useful in future research.[27] The iPCQ measures productivity losses of paid work due to absenteeism and presenteeism (present at work but underperforming), and unpaid work. It comprises 18 items and questions are phrased 'over the past four weeks'. Although there are calls for further validation studies of the COST-FACIT and iPCQ,[25,27] these are probably the best tools currently available compared with unvalidated and less comprehensive options. Further research is needed to more accurately estimate the extent of financial toxicity and to understand the extent of the impacts on patient health and access to healthcare. For example, are patients forgoing medications or doctors' appointments? Are patients delaying optimal recovery from cancer? Are patients forced to compromise treatment options? Does the experience of financial toxicity aggravate other toxicities?

Implications for cancer care services

Financial toxicity among families facing cancer exists in the context of the health system, how health services are organised and who pays for them. Financial considerations can be seen as a secondary priority when patients face the stressful experience of cancer and deciding on treatment. Although financial toxicity itself is a complex problem and unique to the patient's circumstances, greater awareness and acknowledgement of financial toxicity is likely to lead to solutions that optimise patient outcomes by cancer care professionals, governments, patients and families, and welfare providers. Healthcare professionals should understand that poorer health outcomes in their patients may arise, not only from the cancer, but also from the financial fallout from cancer.

Financial toxicity can be viewed as a 'household' issue and it can affect any patient regardless of their apparent socioeconomic status. The occurrence of financial toxicity is a function of financial outgoings and expenses alongside the financial incomings, usually from employment, which may be reduced while undergoing cancer care. It is likely that in public health systems where out-of-pocket costs for direct medical services are minimal, wage losses from the time required to receive the cancer treatment and recovery may be more important.[28]

Suggestions to ameliorate the financial burden for patients in tangible ways have included: 1) mandating the full disclosure by doctors of estimated fees and charges related to treatment from all sources; 2) improved communication between health professionals and patients to raise any financial concerns and the ability of patients to return to work should they need/wish to and; 3) creating opportunities for patients to make treatment decisions fully informed of the likely burden.[7,29]

Appropriate discussions about financial concerns should begin from the start of treatment and critical time points, for example upon completion of treatment, preparing patients and their families for the potential financial effects that could have an ongoing impact. Furthermore, screening tools such as the COST-FACIT could be administered for this purpose and may assist health professionals to identify those patients at high risk and refer them to support services.

Conclusion

There is consistent and growing evidence that financial toxicity exists for a significant proportion of patients with cancer. Although the evidence is of moderate quality, it is an important issue to patients and their families. It can have a very negative impact on quality of life and cause distress. Prospective, longitudinal study designs with non-cancer comparison groups would provide more

definitive evidence on the extent of financial toxicity and ultimately inform interventional work. Measuring financial toxicity is possible through the use of new validated tools, but it is important to acknowledge the overall complexity of this topic and the absence of firm definitions or a conceptual model informing this body of evidence.

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Unemployment after cancer – a hidden driver of financial toxicity

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Abstract

While financial toxicity due to the high costs of cancer treatment is increasingly recognised as a significant challenge for cancer patients and survivors, the impact of reduced work participation as a major driver of financial toxicity is only just coming to light. Unemployment and reduced employment after a cancer diagnosis is associated with reduced financial reserves, impaired quality of life, and possibly reduced survival. Loss of work after cancer disproportionally impacts on those already more vulnerable, such as low income employees and the very young, with impact persisting for some for many years. Research needs to focus on quantifying and predicting the impact of reduced work participation on quality and quantity of survival, and development of interventions to assist with meaningful work participation for cancer survivors.

Financial toxicity, defined as financial distress or hardship experienced as a result of cancer treatment,[1] has attracted increasing attention in recent years as research shows that high costs associated with cancer treatment can lead to increased distress, reduced quality of life and even shortened survival.[2,3] It is paradoxical that the great progress in development of better cancer treatments including rapid emergence of personalised medicines, new diagnostic approaches and novel surgical interventions, has led to reduced affordability of treatment by those who need them.[4]

While the focus of financial toxicity has traditionally been on escalating costs of treatments, tests and procedures, the financial burden is always the function of the cost of an item, such as a drug, surgical procedure, diagnostic test or even transport to attend the clinic, and the ability to pay, which reflects the financial reserves of an individual – their existing savings and their ability to generate new income through employment. Indeed, evidence shows that cancer patients often face a 'double whammy' of financial toxicity. At the time when cancer patients face the challenge of increased costs, they are often at their most vulnerable in regards to their ability to generate income to meet the additional expenses.[5]

This paper outlines the current knowledge regarding unemployment and reduced work participation after cancer, with a particular focus on their relationship to financial toxicity. It examines current strategies to improve work participation after cancer and discusses implications of this knowledge on cancer research and practice.

Work after cancer

Approximately half of cancer patients are younger than 65, when employment is an important part of their lives.[6] Cancer diagnosis and cancer treatment can have profound impact on one's ability to continue employment because of physical, psychological and existential issues associated with the diagnosis and treatment. Symptoms like depression, fatigue, cognitive dysfunction or peripheral neuropathy may adversely affect one's ability to undertake work. This is particularly so in the setting of high demand professions and in situations where there is little flexibility in the workplace to accommodate temporary reduced capacity.[7]

Not surprisingly, evidence demonstrates that cancer survivors have reduced ability to maintain employment and experience reduced quality of employment when compared to cancer-free controls. Cancer survivors are 1.4 times more likely to be unemployed than controls, with approximately 30% of previously employed cancer survivors not returning to work at five years after diagnosis.[8,9] Failure to

return to work in cancer survivors is associated with reductions in quality of life and poorer financial status.[7] Cancer survivors are more likely to experience presenteeism (working while sick) within five years of cancer diagnosis, suggesting that the impact of cancer on work ability is not just on the quantity but also quality of work.[10] While for cancer survivors, the impact of cancer on work is expected to lessen over time, patients with metastatic cancer are likely to face a fluctuating and ultimately deteriorating course of work ability, with increased symptom burden impacting on their ability to work.[11]

Little is known about how much of the change in employment is driven by a change of life priorities and existential concerns about the value of work in the setting of potentially limited life expectancy versus inability to work, although studies suggest that cancer patients and survivors often feel that work is a financial necessity rather than existential choice.[12] This is not withstanding recognition of the non-financial benefits of employment including sense of normality, purpose, social connection and meaning, all very valuable in the otherwise disrupted universe of cancer.[13]

Financial impact of unemployment

Most of the research examining employment after cancer has focused on the social and existential impact of employment, with studies examining and quantifying the financial impact of unemployment emerging only recently. A systematic review by Altice and colleagues of financial hardship in cancer survivors reported 18 studies from the US that referred to productivity losses among cancer survivors with mean annual indirect costs to survivors ranging from $US380 in prostate cancer to $8236 in breast cancer.[2] An analysis of a national Medical Expenditure Panel Survey conducted in the US showed that compared to individuals without a cancer history, non-elderly colorectal and breast cancer survivors experienced statistically significant annual excess employment disability and productivity loss at work.[14]

In Australia, Paul and colleagues conducted a cross-sectional survey of oncology outpatients in two hospitals – metro and rural – with 255 responses returned. Of the respondents, 67% reported a change of employment, the most common being reduced hours, retirement or resignation/unemployment, and 63% reported reduced household income. The authors concluded that the data suggest that the financial impact of unemployment seemed to be the major driver of financial toxicity.[15] Gordon and colleagues compared the self-reported financial hardship of colorectal cancer survivors in Queensland at six and 12 months following diagnosis with that of a matched general population group.[16] After matching on seven socio-demographic variables, self-reported financial hardship among middle-aged workers with colorectal cancer was poorer at six months but had improved and was comparable to a general population comparison group at 12 months after diagnosis. Fifteen per cent of cancer survivors experienced a shortage of money to pay for living essentials. Middle-aged working cancer survivors who ceased or reduced work were more likely to perceive themselves as not being financially comfortable, compared with those who had continued work.

Who is affected by unemployment after cancer?

Similarly to financial toxicity in general, the impact of unemployment has a flow-on effect on the entire household. Zajacawa and colleagues reported on a large longitudinal study in the US and showed that the time after diagnosis was associated with reduction in probability of employment for cancer survivors, reduced working hours, reduced income and, most importantly, reduction in the overall household income.[17] The impact appeared greater for men than women, reflecting men's greater paid workforce participation. In contrast, in a Swedish study of 3626 parents of survivors of childhood cancer, the financial impact was greater and longer lasting for mothers, with employment reduced for six years, than fathers, although both genders were affected.[18] Thus, financial toxicity of unemployment was not just an acute toxicity – it had a late and long-lasting effect.

The impact of unemployment is greatest in those already most vulnerable, blue collar workers more than white collar workers,[19] those on lower incomes,[20] or very young.[21] There is very little data on patients from ethnically diverse, indigenous or rural and remote backgrounds, where job skills may be more limited and the job market smaller with fewer re-training opportunities.

Unemployment after cancer is, of course, not just a function of an individual's abilities and cancer status, but is influenced by societal trends including the job market, and cultural expectation of who should work and what is expected of work after the cancer diagnosis. There is little known about how work after cancer is valued in different cultural and societal settings, and how work participation is further impacted by available alternatives to work, for example social security, disability support, retraining, insurance and support of friends and family.

Unemployment and survival

One of the most thought-provoking observations about unemployment after cancer is a suggestion of association with inferior survival. A large study by Maruthappu and colleagues examined World Bank and World Health Organisation data to correlated survival for different cancers categorised as treatable, as exemplified by breast, prostate, colon and untreatable, such as lung and pancreas, during the time of the global financial crisis with employment and changes in public expenditure on health.[22] The study examined data from 75 countries representing over 2.106 billion people for unemployment analysis and 79 countries representing 2.156 billion for the public expenditure on health analysis. The study showed that the rise in unemployment was associated with increased mortality, especially for cancers in the treatable category, which may reflect limited access to care during the times of economic downturn.

Similarly, an Italian study of financial distress in participants of cancer clinical trials showed that worse financial difficulties were associated with a higher risk of death in this cohort of participants who, on the basis of trial participation and universal health coverage in Italy, were considered relatively protected from the threat of financial toxicity.[23] The authors postulated that the increased risk of death associated with financial distress was a reflection of employment loss and that in turn was a proxy for severity of underlying cancer and thus higher mortality.

Both studies present intriguing findings which, while unexpected, are consistent with the findings of increased mortality associated with inability to pay and bankruptcy after cancer reported elsewhere.[3] To date no equivalent Australian data exists.

Addressing the challenge of work after cancer

As the financial and non-financial impact of reduced employment becomes apparent, there is a great need for effective strategies to address this issue. To do so, it is important to gain a greater understanding of the magnitude of the problem, predictors and comparisons in different settings. At present, most studies of work after cancer have a cross-sectional design and use a variety of measures, making comparison across countries and settings very difficult. The measures include return to work rates at six, 12 or 24 months, disability rates, time of work and sick leave and work status. While many studies examine quality of life as secondary endpoint, few focus specifically on work ability and quality of employment.[24] A greater harmonisation of measures would facilitate sharing knowledge from different countries and settings.

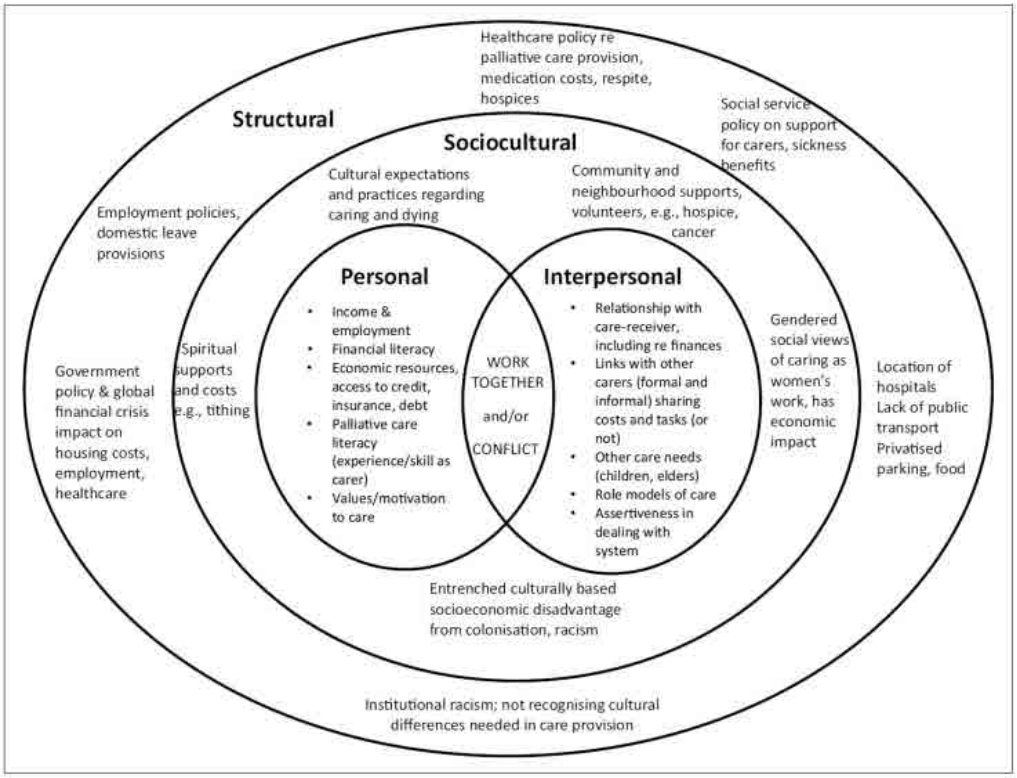
As already indicated, financial toxicity derived from unemployment relates to the costs, so one cannot be considered without the other. The rising costs of care are likely to unmask the hidden vulnerability of precarious employment. As such one should consider the two concepts as part of the same spectrum of financial vulnerability facing cancer patients and survivors (figure 1).

The factors that impact on financial costs of care are complex and multilevel (figure 2). Addressing them requires a broad consideration of not only physical and psychological dimensions of health, but also their social and cultural determinants. Healthcare providers need to consider financial wellbeing as an important aspect of wellness of a patient or survivor and consider the impact of cancer on work and financial security when discussing the impact of cancer treatment on the patient and their family. There is no doubt that this approach poses significant challenges to healthcare providers – while estimating a price for a new treatment is relatively straightforward, predicting impact of cancer treatment on employment depends on many variables – type of employment, type of cancer treatment, attitude to work, work flexibility, job market, cultural expectations regarding employment and societal support to those who cannot work and many others. Advising a patient regarding the impact of cancer treatment on their work requires close collaboration between healthcare providers

and employers, often with input from specialists like occupational physicians and rehabilitation specialists. Clinicians need access to reliable information on work after cancer, skills in assessing work ability and ability to refer complex cases to specialised services like occupational physicians and rehabilitation physicians.

Figure 1: *Relationship between financial toxicity, vulnerability and security as a function of cost and ability to pay.*

Figure 2: *Dimensions that impact on cost of care. Adapted (with permission) from Gott et al.*[25]



Interventions to improve work participation after cancer

A 2015 Cochrane review by de Boer and colleagues updated the evidence on return to work interventions.[24] The review identified 15 randomised controlled studies of 1835 patients. All studies were conducted in high income countries and most focused on breast cancer (seven) and prostate cancer (two). The review found moderate evidence that multidisciplinary interventions incorporating physical training, psycho-education and vocational components improve return to work after cancer. Although most multidisciplinary interventions had a vocational component, the review identified no studies assessing vocational interventions focused on employment. All studies were aimed at the patients and there were no studies directed at the workplace. The authors recommended that more targeted, vocational interventions warranted further evaluation and that studies should examine the impact of interventions in other cancer groups and other ethnicities, and examine outcomes with longer follow-up focusing not just on numbers returning to work, but also the rates of work retention and productivity measures. The authors also identified missed opportunities in research where clinical trials evaluating complex interventions for cancer patients, for example exercise and healthy lifestyle interventions, currently do not include work participation as an endpoint.

To add to the authors' conclusions, it is notable that most of the studies of return to work interventions do not include data on cost-effectiveness of the interventions which would be critical to facilitate implementation. In contrast to Germany, Scandinavia and the Netherlands, Australia does not have established cancer rehabilitation programs with a focus on vocational rehabilitation. Introduction of such programs would require evidence, not only of effectiveness, but also cost-effectiveness to provide justification for funding from the public purse.

Both clinical practice and future research in this area requires a close collaboration between patients, healthcare providers, employers and insurers to ensure that the complex challenge of work after cancer is addressed at all levels where impact is required. But this approach requires a radical overhaul of how we support cancer patients, how we design research and who we see as key stakeholders in the process.

Conclusion

The issue of financial toxicity is emerging as a significant burden for patients and their families. It extends beyond the price of new treatments and reflects the subtle interplay between cost and ability to pay. It has disproportional impact on those most vulnerable to poor outcomes already. Addressing this emerging challenge requires a paradigm shift in how we see wellness of cancer patients and survivors, and the role of the health profession in ensuring wellness. Research and practice in this area requires collaboration with partners not traditionally engaged with healthcare professionals, like employers and insurers. Finally, the design of future cancer clinical trials needs to take into account the impact of unemployment and financial vulnerability on quality and quantity of survival.

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Concerns about cost of future medical care as a factor in advance care planning: Review and agenda for future research

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Abstract

This review explores the evidence for a relationship between healthcare related financial concerns and advance care planning. Large-scale surveys of public opinion in the US have found that people perceive the financial domain to be an important aspect of quality of life and a major concern regarding end-of-life care, and qualitative research has found that financial worries have been found to be a distinct domain of patients' self-perceived burden on their family. Concerns about being a burden on others have some influence on treatment decisions and advance care planning. Healthcare related financial concerns have some basis in fact, as consumers' out-of-pocket costs continue to escalate in some countries. Further research is warranted about healthcare related financial concern and its impact on motivation for engaging in advance care planning, and the content of those plans. A conceptual model of the relationship is proposed to guide further research. This includes three sets of variables: person characteristics such as health literacy, marital/family status and health state; the trait or state of healthcare related financial concern; and behavioral outcomes such as advance care planning and treatment decisions.

Despite the expansion of palliative care and hospice care, the dying experience in the United States and many other countries is still associated with high levels of suffering, some of which could have been avoided.[1-3] Death is a difficult outcome to accept, and patients and families as well as providers often pursue curative options, even when the efficacy of such pursuits is medically unlikely.[4,5] The prevalent use of aggressive end of life interventions such as mechanical ventilation and resuscitation is associated with increased suffering for the patient as well as the bereaved family members.[6,7] Advance care planning (ACP) may help to ensure that patients and families receive the care they really want and need toward the end of life.[7-9] However, too few people have meaningful, comprehensive conversations with their families and healthcare providers about their values and preferences.

Given that many people are hesitant to talk about death and dying,[4,10] it is possible that concerns about costs of care could provide an additional element of motivation to overcome the natural reluctance to discuss these topics. In some countries, families may be fully or partially responsible for the costs of healthcare. Out-of-pocket expenses are a serious consideration for patients considering certain treatments in some countries, and in diverse countries, people rate financial burdens as a one their top considerations regarding death and dying.[11,12] In Australia, which has one of the highest out of pocket expenses per capita, 16% of adults reported cost as a barrier to health care access.[13,14] This review explores the extent to which there is evidence that healthcare related financial concern motivates people to engage in ACP. A conceptual framework is then proposed to guide further research on this topic.

Advance Care Planning

ACP is the process of making decisions about the care you would want in the event a medical crisis renders you unable to speak for yourself.[15] It is a process that should be undertaken by every individual over the age of 18, but many do not consider future medical decision-making until it is, unfortunately, too late.[16,17] In an effort to shift these conversations away from the point of crisis, evidence-based programs such as Respecting Choices,[18] The Conversation Project,[19] and Vital Talk,[20] encourage healthy adults to reflect on these decisions earlier by normalising these conversations within the medical, community and familial contexts. Efforts to encourage lifelong ACP typically focus on the consideration of values and past care experiences, the careful selection of a healthcare agent or surrogate decision-maker, and affirmation of the agent's ability to honour the care decisions of the individual. This process may vary from a traditional legal process in that it can be lengthy, very personal, tailored to individual health and prognosis, and inclusive of the individual's spirituality and social support network.

The stages of ACP match an individual's life or disease progression. For healthy adults or those with manageable chronic illnesses, the Respecting Choices program encourages imagining various scenarios that result in the individual having 'little chance' of recovering the ability to know who you are or who you are with to consider goals of treatment.[21,22] The individual is then asked to communicate care preferences to a surrogate decision-maker and complete an advance medical directive.

Individuals with a terminal diagnosis may extend ACP to include medical orders that support care preferences. Many states are evolving beyond the traditional Durable Do Not Resuscitate order to the POLST Paradigm.[23,24] POLST (Physician Orders for Life Sustaining Treatment) is also a facilitated shared decision-making model wherein medical orders clearly specify treatments the patient would want and direct that treatment the patient does not want shall not be provided.

To identify prior research on healthcare related financial concerns in relation to advance care planning and treatment decisions, a semi-structured literature review was conducted using both peer-reviewed academic databases (PubMed & Web of Science), as well as grey-literature results from both Google and Google Scholar. Boolean constructs of multiple terms were created to cover the interaction of terms for finances (finan*, economy*, & cost*), healthcare (health*, treatment, & medical), and anxiety (worry, worries, anxi*, fear, concern*, & burden). Specific searches for 'medical bankruptcy' and 'surprise medical costs' were also conducted.

Inclusion criteria for retaining results included direct relevance to the context of financial concern for individual costs of healthcare. Exclusion criteria included economic analysis of systemic or public finance, financial advice/analysis that focused exclusively on retirement, psychological or psychiatric definitions of 'anxiety' that did not include healthcare finances as a source, and in the case of grey literature, sources that demonstrated bias in their analysis towards an outcome that provided financial gain for the author or publisher. Studies were ranked by their impact and the limits of their generalisability by reviewing their sample size and citation counts. As some terms still yielded large amounts of results with widely heterogenous applicability to the contexts of this review, a secondary review applied filters for end of life and/or death-related decision-making to narrow the results. Finally, studies cited in relevant meta-analysis or further reviews were manually reviewed.

Findings

Costs of care for cancer and other diseases

As health economists have shown in numerous studies of cancer, there is often a spike in hospitalisations and costs of care in the final months of life,[25-27] and end-of-life care that is of poor quality is often also quite expensive.[28] While most health economics studies in the US have focused on costs to payers and health systems, some financial burden hits the patients and families directly,[29-32] as well as indirectly via insurance plans and governments. The US has high rates of healthcare-related bankruptcy, medical debt and healthcare related financial anxiety.[11,31-32] More than 15 million US Medicare recipients spend greater than 20% of their income on healthcare-related expenses, with lower income and chronically burdened patients being at the greatest risk.[33] There have been recent reports of patients foregoing targeted therapies for cancer because of out-of-pocket costs they cannot

afford, and clinician-researchers have begun to describe and study 'financial toxicity' as a side-effect of advanced cancer treatment.[34-36]

Numerous studies have shown the poor quality of life experienced by many patients and families toward the end of life.[1,4,5] Most patients have a strong aversion to the scenario of 'dying on a machine', preferring instead to die at home with controlled symptoms being high priority.[37] Despite this, the rates of hospitalisation and intensive care unit (ICU) admission in the last months of life have been increasing.[38-40]

Impact of ACP

ACP can help to ensure that one's future care is concordant with one's values and wishes, and help to ensure that family members and providers are all aware of those wishes to avoid disagreements and conflicts.[7-9,42] While ACP is not limited to avoiding procedures and life support, several well-designed studies have found that patients who have engaged and documented their conversations about their goals for medical care have been shown to be less likely to be admitted to an ICU or pursue aggressive treatments at the end of their life. For example, a prospective observational study of patients with advanced cancer and their caregivers found those who had ACP conversations were less likely to have resuscitation, ventilation or ICU admission, and were enrolled in hospice earlier.[6] A study of patients with advanced dementia found that those who had previously completed an ACP were less likely to be admitted to an ICU and to die in a hospital, and their healthcare cost less.[43] A large-scale study of US Medicare expenditures found that in high-spending regions, ACPs that specified limits in care were associated with higher probabilities of using hospice and lower probabilities of dying in hospital, as well as lower costs.[44] A randomised controlled trial in Canadian nursing homes found the ACP intervention arm led to fewer hospitalisations and lower costs.[45] A prospective study of patients with cancer found that those who had ACP conversations had one-third lower costs of care in the final week of life, and that lower costs were associated with higher quality of life.[28] Other studies have also shown a relationship between ACP and costs of care, but used questionable methods or measures, and a systematic review on this topic found that only half of 18 studies meeting review criteria found a positive relationship between ACP and costs.[46]

Patient perceptions of burden

As patients face and prepare for their deaths, they often focus on how their lives and their final care will shape how they will be remembered by their loved ones. Interventions that focus on this sense of generativity or shaping a patient's legacy with their family, have been shown to be effective in increasing a patient's quality of life.[47] Conversely, there is often a strong desire among patients to avoid feeling like they are burdensome to others. Much research has been done on the topic of self-perceived burden (SPB), which has been found to be a salient concern across countries and cultures.[48] SPB appears to be rather prevalent, and to have considerable influence on the choices that patients make. Cohen-Mansfield,[49] studying hospitalised elderly persons, found that their concerns about burdening others were the most important factor in treatment decisions, findings that were echoed by later studies,[50-52] including decisions about CPR and dialysis.

Financial worry is a domain identified in several qualitative studies of perceived burden.[53-55] One study conducted in Kenya found that worry about being a financial burden on others was a significant aspect in quality of life near death.[55] Another study found that both healthy adults and those with chronic illness had concerns about being 'an intolerable burden' on others when asked to reflect on 'states worse than death', and that one of the five domains of this burden was financial.[53] A third study identified financial issues as one form of SBP among minority and non-minority persons.[54] Financial issues do not appear to have been specified in the quantitative studies of self-perceived burden.[48]

As McPherson's review points out,[48] there may be a significant difference between patient and caregiver (and provider) perceptions of burden; the only study in their review that compared both perspectives found a modest correlation. This is an important issue in advance care planning – if a patient is sensitive to SPB, they may want to avoid treatments or scenarios when they are most at risk for being burdensome. Conversely, their next of kin may be sensitive to avoiding feelings of guilt, and may want to engage in treatments and efforts at life support to avoid guilt at the time of death. This is the kind of discordance that is useful to unearth prior to a crisis, so that the patient selects an agent they can trust to be true to their own wishes, and the agent and family members can understand what decisions and wishes the patient has made, and why.

Large-scale surveys

Three recent public opinion surveys link financial concerns to quality of life at end of life and advance care planning. A statewide survey in California asked 1669 participants to rate the importance of 12 different factors at the end of life.[56] 'Being at home' was endorsed as 'extremely important' by 33%; 'Living as long as possible' by 36%; 'Having loved ones around me' by 60%; 'Being comfortable and without pain' by 66%; and 'Making sure family not burdened financially by my care' by 67%, the most of any factor. Similarly, in a cross-country survey of adults in the US, Italy, Japan and Brazil, both US and Japanese adults ranked 'making sure your family is not burdened financially by your care' as their top concern for end of life care.[12] Our survey of 600 adults in the Richmond Virginia area in 2014 focused on ACP issues,[57] asking what concerned participants the most about future healthcare treatment. Of those expressing any concern (474), 9% said 'That wishes are followed', 11% said 'Quality of healthcare' and 46% said 'Cost of treatments', the most of any factor.

These three surveys give some indication that healthcare related financial concern is a key factor in perceptions of quality of life and dying, and may potentially play a role in motivating people to engage in ACP. Further research could explore this issue more fully, particularly since the financial domain in self-perceived burden research has not been studied using quantitative approaches.

The path ahead

In some countries, a significant share of healthcare costs falls on patients and families;[11-13,25-29] concerns about such costs and the potential for medical debt have prompted research on the 'financial toxicity' of cancer treatments.[34-36] Qualitative research has revealed that healthcare related financial concern is a distinct domain of self-perceived burden,[53-55] and SPB has been shown to be related to treatment decisions and advance care plans.[49-52] Large surveys suggest concerns about the costs of future treatments are salient for advance care planning, and are a key element of quality of life near the end of life.[12,56,57]

The implication for healthcare practice is that clinicians or lay persons who are facilitating ACP conversations should be cognisant of these concerns and the role they may play in people's motives and choices. Further, ACP facilitators should be forewarned of potential discordance between the individual making an ACP, and their surrogates or agents, regarding the importance of financial costs that may be incurred from treatment decisions. Despite this, financial decision-making is not a central theme in ACP models such as Respecting Choices. While an individual may express concerns or identify financial-related stressors in a facilitated conversation, the current model does not actively seek this information from the individual.

There is sufficient cause to study healthcare related financial concern (HRFC) as a phenomenon that may be playing a role in advance care planning and treatment decisions. To help guide such efforts the following foundational questions and conceptual model are proposed:

- Can the financial domain of SPB, as identified in qualitative research, be operationalised and measured in quantitative research?

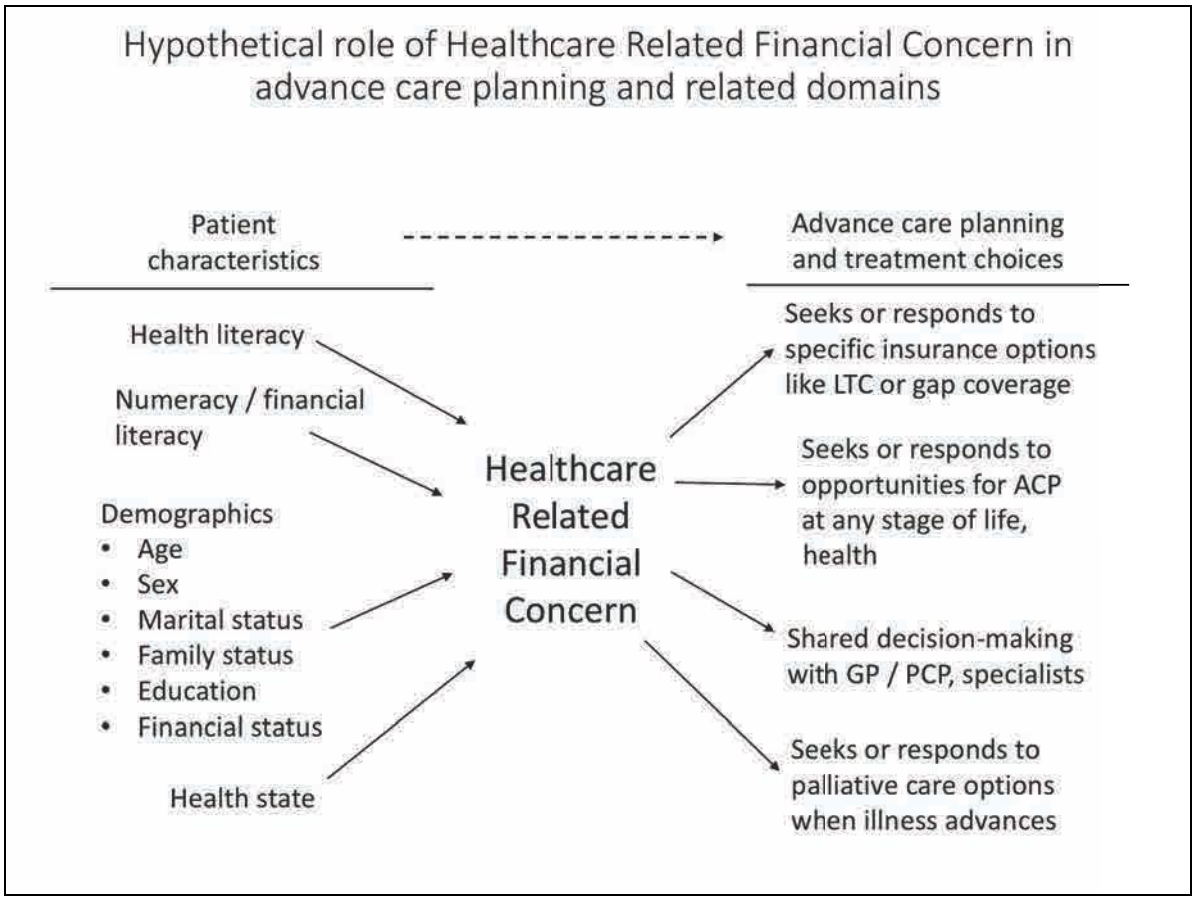
- How much concordance is there between patient perceptions, care-giver perceptions and actual out-of-pocket costs for various treatment scenarios common in ACPs such as resuscitation? How does this differ by country, or within a country?

- Do financial concerns constitute a distinct motivation or reason for people to have ACP conversations and prepare advance directive documents? Do those concerns shape the kinds of decisions people make in their advance directives, such as avoiding hospitalisation or intensive care?

In the proposed model (figure 1), the patient and family characteristics are presumed to have both direct and indirect effects – via HRFC – on advance care planning and treatment choices. If HRFC itself can be primed or otherwise manipulated, then the effects could be readily measured. Research methods such as large-sample surveys could determine whether various demographic characteristics or capabilities (health literacy for example) are correlated with HRFC or the behavioral outcomes on the right side of the figure, while experiments could be conducted to manipulate levels of HRFC as a

state to investigate its effects on behaviour. Research using this model could be initiated in any country and then expanded to others.

Figure 1: *Conceptual model for guiding future research on this topic. LTC = long-term care (skilled nursing). GP / PCP = general practitioner / primary care provider.*



Conclusion

Financial concerns seem to be a salient domain of quality of life and self-perceived burden among patients, and may motivate and shape advance care planning and treatment decisions.

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Clinical application of optimal care pathways at a regional cancer centre

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Abstract

Objective: To assess the feasibility of clinical application of recently produced Optimal Care Pathways and explore patterns of care for oncology patients receiving care based in the City of Greater Bendigo.

Design, setting and participants: A retrospective audit of hospital administrative and medical records data undertaken at Peter MacCallum Cancer Centre (PeterMac) and Bendigo Health between January and June 2016. Eligible cases were PeterMac patients with a residential address in the City of Greater Bendigo and who received care based at the PeterMac Bendigo campus as a new patient between 01 January and 31 December 2015.

Outcome measures: Congruence of routine care with timeframes for steps described in the Optimal Care Pathways for cancer patients commissioned by the Victorian Department or Health and Human Services.

Results: Assessment of congruence of routine care to the Optimal Care Pathways was complicated by missing data. Where data were available, many pathways of care did not fit the Optimal Care Pathway process map template, due to screening-related or asymptomatic presentations or appropriate deviations in clinical management responsive to individual patient need.

Conclusion: This study is the first to report feasibility of mapping routine care against the parameters recommended by the Optimal Care Pathways, and to provide guidance for the future assessment of usual care of cancer services to best practice guidelines.

The delivery of health care across Australian states and territories is complicated by a plethora of different policies and system-oriented approaches to the delivery and remuneration of health services.[1] Further complicating the delivery of health care is the diverse landscape and geographical magnitude across which care must be provided.[2,3] Health outcomes for people affected by cancer and living in regional and rural areas, are worse compared to matched metropolitan counterparts,[4,5] with the incidence of all cancers, and burden of death from cancer, higher for people in regional and rural areas.[6,7]

In 2015/16, the Victorian Department of Health and Human Services published a series of optimal care pathways (OCPs) that describe consensus guidance regarding best practice in cancer care for 15 tumour types. Each pathway maps the patient's journey from early detection and diagnosis to survivorship or end-of-life care, and provides recommendations for treatment timeframes and models of care at specific points throughout the care pathway. The OCPs were designed with the intention of contributing to the improvement of both clinical outcomes and patient experience, irrespective of the geographical location of service delivery. The pathways are now nationally endorsed by the National

Cancer Expert Reference Group, Australia's only government endorsed, high-level, expert national cancer forum.[8,9]

Although encouraged, integration of OCPs as frameworks for cancer service delivery is not mandated, but rather they are presented as an opportunity to map usual care against the optimal pathway, identifying potential for process and system enhancement.[8-10] To date, there has been little exploration or consideration of how usual care can be mapped against OCPs for patients in regional cancer centres.

This study set out to explore patterns of care for oncology patients receiving care, based in the City of Greater Bendigo, against the recommendations set out in OCPs, using routinely collected hospital administrative and medical records data. Bendigo was selected as the data collection site as it represents a large regional centre with an established integrated cancer service and presentation and management of common tumour types. The study explored pathways of patients with breast, lung and prostate cancers and reports on the congruence of routine care provided to this cohort of regional Australian cancer patients as assessed against optimal care pathways.[10] For the purpose of the study, the terms 'regional' and 'rural' are used interchangeably, recognising that there are issues unique to each.

Methods

Data sources and patients

The study was a retrospective audit of hospital administrative and medical record data conducted at the Peter MacCallum Cancer Centre (PeterMac), East Melbourne campus, from January to June 2016, with supplementary data collection undertaken at Bendigo Health over a three week period in May, 2016. The study took part prior to the relocation of PeterMac to the Victorian Comprehensive Cancer Centre in Parkville, Melbourne.

Eligible cases were PeterMac patients with a residential address in the City of Greater Bendigo and who received care based at the PeterMac Bendigo campus as a new patient between 1 January and 31 December, 2015. Patients were considered new if they had not attended PeterMac previously, or were attending a different PeterMac clinic for the first time. Postcodes (3515, 3523, 3550, 3551, 3555, 3556, 3557, 3558 and 3570) were used to identify eligible cases from an Excel spreadsheet of PeterMac administrative data supplied by the Health Information Service (HIS), of all patients presenting in the study period. Clinic attendances for these patients were then reviewed through electronic medical records to assess the treatment-based location of care. With the exception of possible one-off imaging and procedural appointments, or one-off consultations with alternate treating teams that did not result in a transfer of care to that treating team, patients were considered to have had their care based in Bendigo if the entirety of the patient's oncology needs could be met at the PeterMac Bendigo campus and Bendigo Health in the study period.

Data extraction

Referral information, disease characteristics and treatment details (including episode of care dates) for eligible patients were extracted from the PeterMac electronic record using a standardised form. Data extracted from the medical record included all information needed to populate detailed process maps to allow comparisons between patient patterns of care and OCPs. Additional event data was extracted from Bendigo Health paper medical records to supplement and contextualise information extracted from PeterMac records. The data extraction form was piloted and revised using the first 10 cases; once finalised data were extracted for all patients including the first 10 cases.

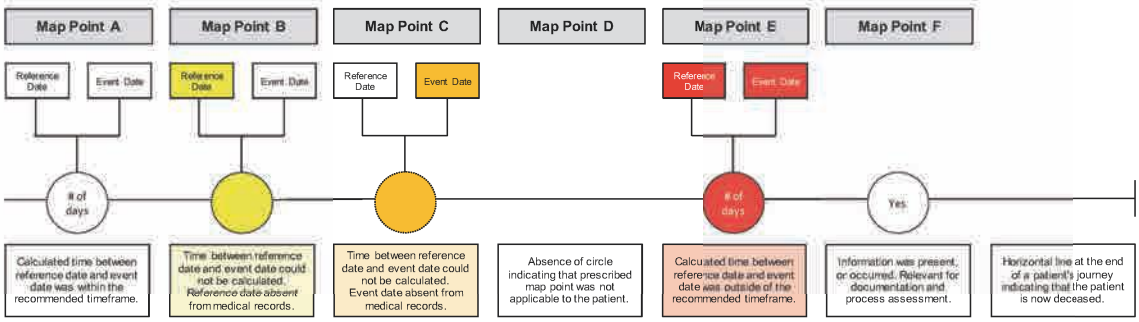
Patients with one of the three most prevalent cancer types excluding non-melanoma skin cancer (breast, prostate and lung cancer) were process mapped, to ensure adequate numbers to support meaningful comparisons of data gathered within and across cancer types. Non-melanoma skin cancers were excluded as these pathways are commonly brief compared with other tumour types.

Process mapping

Process maps allow for visual representation of multiple, independent or interdependent events that occur at definable time points.[11] In this study each eligible patient journey from first symptomatic presentation to last health service contact was mapped (figure 1). Episode of care dates were used to

create a chronologically-ordered list of events to populate a purposively designed process map template for each patient's journey during their treatment. Data were used to develop a process map and to compare patient pathways with recommendations set out in the OCPs.

Figure 1: *Diagrammatic representation of process mapping*
Process mapping can be used to visualise the patient journey from first symptomatic presentation to last health service contact. Patient progression through their care is represented linearly over time. Relevant map points are represented by circles, each corresponding to a step in the OCP framework. Calculated map point timeframes are compared with timeframes recommend by the OCP framework.



Results

A total of 141 patients were considered for process mapping, consisting of 53 breast cancer patients, 45 lung cancer patients and 43 prostate cancer patients.

Breast cancer

Process maps were constructed for 51 of 53 breast cancer patients. Two breast cancer patients were excluded from process mapping as neither had histories with Bendigo Health's HIS.

Data for women with breast cancer were grouped according to mode of entry into their treatment pathway. These groupings included GP-initiated pathways (n=20, 39%), screening-initiated pathways (n=21, 41%), and other pathways (n=10, 20%). The other pathways grouping included patients with insufficient medical record information to accurately determine the initiation of their pathway.

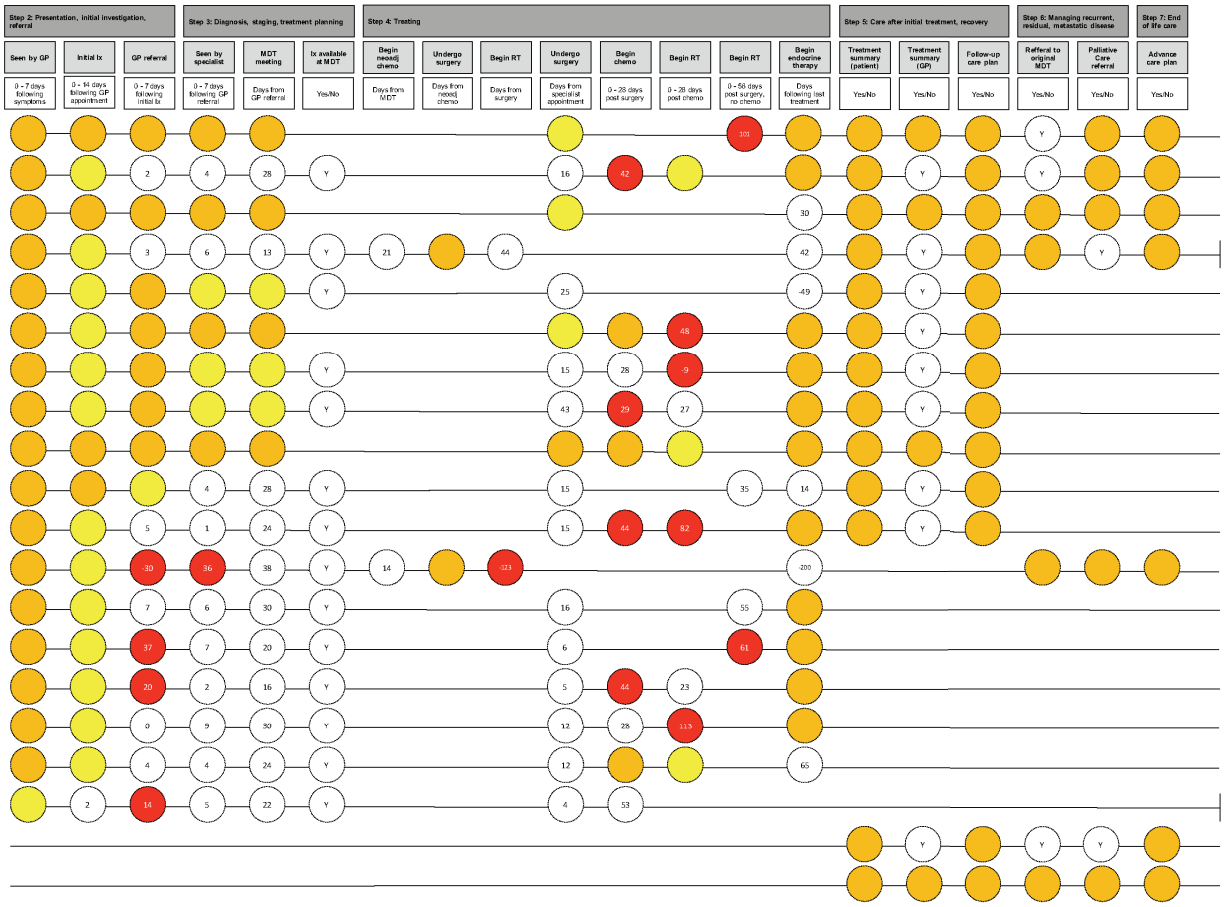
Patients with GP-initiated pathways were mapped according to the prescribed OCP pathway (figure 2); however, patients with screening-initiated and other pathways fitted less easily within the prescribed OCP pathway, and their mapping was truncated to exclude map points relating to GP presentation and referral. Due to this, it was not always possible to compare timeframes for patients with screening-initiated and other pathways against OCP timeframes, as many of the published OCP timeframes require GP-related reference dates for calculation.

Data necessary to map patients' treatment pathways against the OCP recommendations were frequently missing from the medical records and many process map points were unable to be populated. Only 12 (60%) patients with GP-initiated pathways, 7 (33%) patients with screening-initiated pathways, and no patients with other pathways, had 50% or more of their required process map points.

The most frequently missing process map point for all breast cancer patients was the treatment summary provided to the patient, with this information unavailable for any of the 41 patients for whom it was relevant. Only one of 41 patients had information relating to a follow-up care plan.

The most populated map point was the treatment summary for GPs, available for 35 (85%) patients for whom this was relevant. For the purposes of this study, any correspondence to the GP that outlined the diagnosis and previous treatments of the patient was considered a treatment summary.

Figure 2: *Process maps for patients with breast cancer*
Process maps were completed for 20 patients with breast cancer and who had GP-initiated pathways. GP, General Practitioner; Ix, Investigation; MDT, Multi-disciplinary team; Neoadj, Neoadjuvant; Chemo, Chemotherapy; RT, Radiotherapy.



Within the GP-initiated pathway, 16 process map points were outside the timeframes recommended in the OCPs, with three of these occurring before the timeframe was designated to start. Nine map points were calculated to be outside of the recommended timeframe for patients with screening-initiated pathways and no map points were calculated outside the defined timeframe for patients with other pathways.

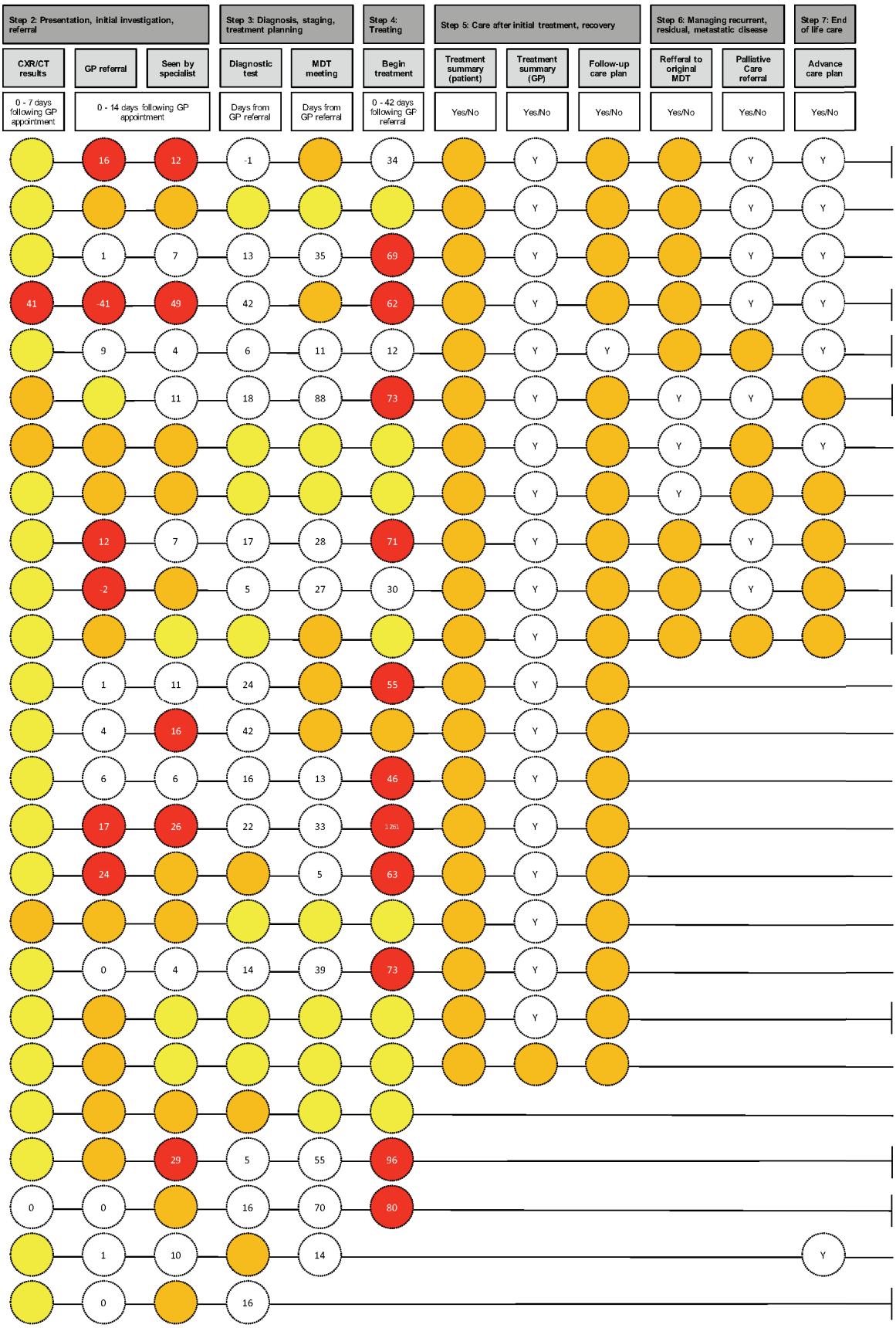
Lung cancer

Process mapping was completed for 43 of 45 lung cancer patients. Two patients with lung cancer were excluded as they could not be located by Bendigo Health's HIS.

Patients were grouped by mode of entry into the pathway, which for lung cancer included patients with GP-initiated pathways (n=25, 58%), patients whose initial presentation was to the Emergency Department (ED) (n=6, 14%), patients with incidental findings (n=9, 21%), and patients with other pathways such as those already under the care of respiratory physicians and those with pathways that could not be determined (n=3, 7%).

Patients with GP-initiated pathways were mapped according to the OCP recommendations for lung cancer, which begins at symptomatic presentation to the GP (figure 3). Patients with all other pathways into the system fitted less easily within the prescribed OCP pathway due to their mode of entry, and their mapping was truncated to exclude map points relating to GP presentation and referral. Due to this, it was not possible to compare timeframes for these patients to OCP timeframes as all OCP timeframes for lung cancer require GP-related reference dates for calculation.

Figure 3: *Process maps for patients with lung cancer*
Process maps were completed for 25 patients with lung cancer and who had GP-initiated pathways. CXR, Chest X-Ray; GP, General Practitioner; MDT, Multi-disciplinary team.



Only 14 (56%) patients with GP-initiated pathways, four (67%) patients with ED-initiated pathways, six (67%) patients with incidental findings and one (33%) of the patients with another pathway, had 50% or more of their required process map points. The most frequently missing process map point for all lung cancer patients was the treatment summary provided to the patient, with this information unavailable for any of 34 patients for whom it was relevant. Only one of 34 patients had information relating to a follow-up care plan. The most populated map point was the treatment summary for GPs, which was available for 30 (88%) patients.

For patients with GP-initiated pathways, 23 map points were outside of the recommended timeframe and two of these occurred before the timeframe was designated to start. Reasons for delays included the need for repeated biopsies, patient requests for active surveillance and the management of comorbid conditions.

Prostate Cancer

Data were extracted for 43 of 45 prostate cancer patients. Three prostate cancer patients were excluded, two of whom were unable to be identified through Bendigo Health's HIS, and one of whom had notes that were inaccessible during the data collection period.

Prostate cancer patients were unable to be considered in this study as only six (14%) of 43 patients had 50% or more of their required process map points. The most frequently available information was the radiotherapy start date following diagnosis, available for 17 (40%) patients.

Discussion

This is the first study, to our knowledge, to test the feasibility of applying OCPs to a clinical setting. Difficulties were encountered in the utilisation of OCPs to map pathways of care for all three cancer types explored in this study.

Pathway initiation is an important consideration for the OCP framework, which currently and predominantly focuses on symptomatic GP presentation as a pathway starting point. Given that many breast cancer patients present through screening-initiated pathways, it will be important for the OCP framework to give additional consideration to asymptomatic screening as an entry point in future, and provide adjusted timeframes for breast cancer treatment as appropriate.

For lung cancer patients, GP-presentation is not necessarily appropriate or what happens for patients, and many in this study began their treatment journeys with ED presentations, incidental findings and referrals from respiratory physicians whom they were seeing for other concurrent respiratory illnesses. Process mapping for patients without GP-initiated pathways were necessarily truncated to exclude GP-related map points, and the entirety or complexity of the patient's treatment journey was subsequently not reflected in the completed process map.

Similarly, some lung cancer patients presented to their GP, from where they were sent to the nearest ED with a letter due to the urgency of their symptoms. For the purposes of this study, these patients were considered to have a GP-initiated pathway. However, they are in fact distinctly different to other patients with GP-initiated pathways who do not provoke such urgency, and it was not possible for this to be reflected by the pathway.

In compiling the process maps for the breast, lung and prostate cancer patients, it became apparent that large amounts of information needed to map patients' treatment pathways to OCP recommendations were missing from medical records. This was particularly true for prostate cancer, primarily due to patients receiving private treatment through a urologist, and there being no medical records relevant to their cancer care available in the public service.

Data requiring communication between the health service and the GP were most frequently missing, which had several downstream consequences. Pathway mapping requires information about the symptoms that lead to GP presentation and information around GP referral. If the date of presentation with symptoms and the date of GP referral are unavailable, the time between landmark events cannot be calculated and the mapping of several points is affected.

Where information was readily available, it was frequently related to correspondence from the treating oncology team to the GP, or related to the cancer treatment itself (surgery, chemotherapy, radiotherapy). This information is the most routinely collected by the health service and therefore these data were well represented in this study. However, commencement dates for chemotherapy were more likely to be missing in the medical records than the date of chemotherapy completion. Chemotherapy completion dates impact downstream treatment decision-making and are therefore important in correspondence between clinicians. This highlights a discrepancy in the medical records between the information required for optimal care mapping and the information regularly documented by the health service.

Comparing deviations in the timeframes calculated from medical record data with the timeframes recommended in the OCPs was difficult as deviations due to patients' unique clinical needs are recognised as often necessary and appropriate. To use OCPs as a standard for best practice therefore not only requires reference and event date information to calculate an individual's pathway timeframes, but also requires additional contextual information about treatment decision-making processes and a knowledge of appropriate clinical decisions relevant to an individual. Additionally, many patients had map points that occurred earlier in their treatment pathways than recommended by the OCPs, and this type of deviation cannot be accommodated in the current iteration of the OCPs. The OCP timeframes also do not currently allow for consideration of delayed diagnoses, self-discharge, patient-requested active surveillance against medical advice and complicated ethical scenarios, all of which were encountered in the sample for our study.

Based on the study results, the following recommendations are proposed to strengthen the potential of OCPs to deliver against their intent:

1. Where data are to be used to benchmark practice against OCPs, they should be collected prospectively with a standardised template. Prospective data collection will seek to improve accuracy, efficiency and utility of mapping processes.

2. Routine collection of the nature of the patient's symptoms and the date they are reported to have begun, the date patients present to the GP and date of GP referral, as well as commencement dates for chemotherapy and radiotherapy, need to be included in hospital medical records. These data represent landmark events in the OCP framework, and unavailability of dates complicates comparison of routine care to optimal timeframes.

3. Hospitals should continue their efforts to increase communication with GPs and allied health practitioners, and these communications should be documented in the medical records. These data represent specified processes in the OCP framework, and documentation will ensure completeness of mapping results.

4. Timeframes should be developed for alternate modes of entry into the pathways for each tumour type, including for asymptomatic screening-initiated pathways in breast cancer, and ED and incidental pathways for lung cancer. Adjusted timeframes are needed to support the appraisal of care for alternate modes of entry.

5. Standardised treatment summary templates could be developed and utilised by hospitals to enhance communication of treatment information to GPs and patients, and minimise burden on hospital staff.

6. Patient-friendly treatment summaries and follow-up care plans should be provided to patients and documented in the medical record. This data, was most frequently missing from medical records, offers opportunity for process enhancement.

7. Further consideration should be given to the role of clinical judgement in treatment decision-making and how subsequent deviations from the OCP timeframes could and should be interpreted.

Conclusion

This study is the first to assess the feasibility of application of OCPs in a clinical setting for the purpose of mapping regional cancer care to best-practice pathways. While OCPs offer an opportunity for service and process enhancement, in order to best utilise OCPs in future research or health service assessment, a variety of considerations and amendments will be required. Given the variability of patient needs, some pathways may never map directly to OCPs and many more may appropriately deviate from the OCPs at differing stages.

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Support for research 2017

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 2017, research grants through Cancer Councils totalled almost $60 million. Cancer Councils directly funded just under $41 million, with a further $19 million contributed by our research funding partners.

Please note: for research grants spanning more than one year, only funds to be disbursed in 2017 have been included.

- Cancer Council ACT - $413,333
- Cancer Council NSW - $17,439,069
- Cancer Council Queensland - $10,514,017
- Cancer Council South Australia - $9,393,071
- Cancer Council Tasmania - $120,067
- Cancer Council Victoria - $18,570,376
- Cancer Council Western Australia - $3,507,775

CANCER COUNCIL ACT

Externally Funded Research Programs

New research grants

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Project Grants	Professor Thomas Preiss, The Australian National University	Mechanisms and targets of protein synthesis dysregulation in cancer	$200,000		$200,000	All
Project Grants	Professor Geoffrey Farrell, The Australian National University	How exercise prevents obesity-related hepatocellular carcinoma: insights for chemoprevention of liver cancer	$100,000		$100,000	liver
TOTAL RESEARCH FUNDED (New Program)			**$300,000**	**$0**	**$300,000**	

Externally Funded Research Programs

Continuing research grants

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Ellestan Dusting Cancer Research Bequest Grant	Professor Ross Hannan, The Australian National University	Development of broad spectrum, non-genotoxic cancer treatments for acute myeloid leukaemias and multiple myeloma	$113,333		$113,333	AML Multiple myeloma
TOTAL RESEARCH FUNDED (New Program)			**$113,333**	**$0**	**$113,333**	
TOTAL EXTERNALLY FUNDED RESEARCH PROGRAMS (including new and continuing research grants)			**$413,333**	**$0**	**$413,333**	
TOTAL RESEARCH FUNDED (including external and internal research grants)			**$413,333**	**$0**	**$413,333**	

CANCER COUNCIL NSW

Externally Funded Research Programs

New research grants

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Project Grant	A/Prof Graham Neely University of Sydney	RG 17-01 Functional genomics to overcome cancer drug resistance	$150,000	$0	$150,000	All cancers
Project Grant	Prof Christopher Ormandy Garvan Institute of Medical Research	RG 17-02 A new way of suppressing metastasis	$148,917	$0	$148,917	Breast cancer
Project Grant	A/Prof Alexander Swarbrick Garvan Institute of Medical Research	RG 17-03 Systematic analysis of the role for miRNA in breast cancer aetiology and treatment	$150,000	$0	$150,000	Breast cancer
Project Grant	A/Prof Jeff Holst University of Sydney	RG 17-04 Nutrient stress-mediated adaptive responses as novel targets in BRAF mutant melanoma	$150,000	$0	$150,000	Melanoma
Project Grant	Prof Maija Kohonen-Corish Garvan Institute of Medical Research	RG 17-05 Determine the role of MCC silencing in the promotion of colon cancer and how it can be targeted with anti-invasive therapy	$150,000	$0	$150,000	Colon
Project Grant	Prof Gregory Dore University of New South Wales	RG 17-06 The impact of improving hepatitis C treatment on hepatocellular carcinoma	$145,906	$0	$145,906	Liver
Project Grant	Prof Stephen Ackland University of Sydney	RG 17-07 The SPAR Trial: a randomised placebo-controlled phase 2 trial of simvastatin with preoperative chemoradiation for rectal cancer	$150,000	$0	$150,000	Rectal
Project Grant	A/Prof Elgene Lim Garvan Institute of Medical Research	RG 17-08 Progesterone as an anticancer agent in early breast cancer	$154,111	$0	$154,111	Breast cancer
Project Grant	Dr Kenneth Micklethwaite University of Sydney	RG 17-09 Optimisation of Transposon Tools for the Clinical Production of Chimeric Antigen Receptor T-cells	$150,000	$0	$150,000	Leukaemia
Project Grant	Prof Peter Metcalfe University of Wollongong	RG 17-10 High resolution dosimetry for MR image-guided radiation therapy	$136,136	$0	$136,136	All cancers

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Project Grant	Prof Katharina Gaus University of New South Wales	RG 17-11 T cell receptor (TCR) signalling in adoptive T cell therapy against B cell lymphoma	$150,000	$0	$150,000	Lymphoma
Project Grant	Dr Maya Kansara Garvan Institute of Medical Research	RG 17-12 Targeting IL-23 in osteosarcoma	$146,797	$0	$146,797	Osteosarcoma
Priority driven Collaborative Cancer Research Scheme	Dr Elizabeth Hovey University of Sydney	RGPd 17-13 Phase III Intergroup Study of Radiotherapy with Concomitant and Adjuvant Temozolomide versus Radiotherapy with Adjuvant PCV Chemotherapy in Patients with 1p/19q Co-deleted Anaplastic Glioma or Low Grade Glioma: the CODEL trial	$60,000	$221,534	$281,534	Brain
Priority driven Collaborative Cancer Research Scheme	A/Prof Eva Segelov University of Sydney	RGPd 17-14 ASCOLT: Aspirin for Dukes C and High Risk Dukes B Colorectal Cancers. An International, Multi-centre, Double Blind, Randomised Trial	$70,000	$213,460	$283,460	Coorectal
Priority driven Collaborative Cancer Research Scheme	Dr David Ziegler University of New South Wales	RGPd 17-15 Synthetic retinoid therapy for Diffuse Intrinsic Pontine Gliomas	$65,500	$272,050	$337,550	Brain
TOTAL EXTERNAL RESEARCH FUNDED (New Program)			**$1,977,367**	**$707,044**	**$2,684,411**	

Externally Funded Research Programs

Continuing research grants

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Project Grant	Prof Murray Norris Children's Cancer Institute	PG 16-01 Improving outcomes for children with leukaemia through molecular targeted therapies	$449,996	$0	$449,996	Leukaemia
The Harry McPaul Program Grant	A/Prof Claire Wakefield University of New South Wales	PG 16-02 The Harry McPaul Program Grant - Development and implementation of real-world, sustainable, interventions to prevent chronic physical and mental health conditions in paediatric cancer survivors and their families.	$449,101	$0	$449,101	Childhood cancer
Project Grant	Prof John Wiggers University of Newcastle	PG 16-05 Community prevention of cancer: building the evidence base for translation into policy and practice	$449,538	$0	$449,538	All cancers

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Program Grant	Prof Rob Sanson-Fisher University of Newcastle	PG 16-09 Improving and maintaining holistic cancer survivor outcomes. A system-based program	$0	$0	$0	All cancers
The Kay Stubbs Project Grant	Prof Susan Clark Garvan Institute of Medical Research	RG 16-02 The Kay Stubbs Project Grant - Exploring and Exploiting the DNA Methylation Profile of endocrine resistant breast cancer	$113,633	$0	$113,633	Breast cancer
The Kay Stubbs Project Grant	Prof Peter Croucher Garvan Institute of Medical Research	RG 16-03 The Kay Stubbs Project Grant - Anti-sclerostin- a novel, dual action agent to treat multiple myeloma	$120,000	$0	$120,000	Myeloma
Project Grant	Prof David Gottlieb University of Sydney	RG 16-04 Co-administration of malignancy and infection specific T cells after allogeneic stem cell transplant for acute leukaemia with CD34+ stem cells	$120,000	$0	$120,000	Leukaemia
Project Grant	Prof Philip Hansbro University of Newcastle	RG 16-05 Identification of genomic mutations associated with the development and progression of lung cancer for use in early diagnosis	$120,000	$0	$120,000	Lung cancer
Project Grant	Dr Phoebe Phillips University of New South Wales	RG 16-08 Reprogramming the tumour microenvironment by therapeutically targeting heat shock proteins in pancreatic cancer	$120,000	$0	$120,000	Pancreatic cancer
Project Grant	A/Prof Hilda Pickett Children's Medical Research Institute	RG 16-09 Developing treatment strategies to target telomere maintenance in cancer	$119,004	$0	$119,004	All cancers
Project Grant	Prof Roger Reddel Children's Medical Research Institute	RG 16-10 G-quadruplex DNA: a molecular target for treatment of cancers using the Alternative Lengthening of Telomeres (ALT) mechanism	$120,000	$0	$120,000	All cancers
The Susan and James Freeman Project Grant	A/Prof Stuart Tangye Garvan Institute of Medical Research	RG 16-11 The Susan and John Freeman Project Grant - Mechanisms underlying impaired anti-EBV and anti-tumour immunity causing B-cell lymphoma in primary immunodeficiencies	$120,000	$0	$120,000	Lymphoma
Project Grant	Prof Xu Dong Zhang University of Newcastle	RG 16-12 Co-targeting CD47 and the MAPK pathway in melanoma	$58,282	$0	$58,282	Melanoma
Project Grant	Dr Mustafa Khasraw University of Sydney	RG 16-13 VERTU - Veliparib, Radiotherapy and Temozolomide trial in Unmethylated MGMT Glioblastoma	$119,516	$0	$119,516	Brain cancer

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Priority-driven Collaborative Cancer Research Scheme	Prof Finlay Macrae Melbourne Health	RGPd 16-16 CaPP3: a randomized double blind dose inferiority trial of aspirin in Lynch Syndrome	$96,780	$0	$96,780	Lynch syndrome
Priority-driven Collaborative Cancer Research Scheme	A/Prof Manish Patel University of Sydney	RGPd 16-17 Developing a Patient-Reported Symptom Index for Non-muscle Invasive Bladder Cancer	$77,720	$0	$77,720	Bladder cancer
Project Grant	Prof Christopher Liddle University of Sydney	RG 14-02 Novel approaches to target cancer stem cells in liver cancer	$59,663	$0	$59,663	Liver cancer
Strategic Research Partnership Grant	Prof Rob Sanson-Fisher University of Newcastle	CSR 11-02 Behavioural Science Strategic Research Partnership	$400,000	$0	$400,000	All cancers
Strategic Research Partnership Grant	A/Prof Gail Garvey Menzies School of Health Research	SRP 13-01 Strategic Research Partnership to improve cancer control for Indigenous Australians (STREP Ca-CIndA)	$380,961	$0	$380,961	All cancers
Strategic Research Partnership Grant	Dr Gillian Mitchell University of Melbourne	SRP 13-02 The Inherited Cancer Connect (ICon) Partnership	$391,952	$0	$391,952	All cancers
Strategic Research Partnership Grant	Prof Andrew Grulich University of New South Wales	SRP 13-11 Preventing morbidity and mortality from anal cancer	$387,068	$0	$387,068	All cancers
45 and Up	Prof Sally Redman Sax Institute	45 and Up Study	$400,000	$0	$400,000	All cancers
Project Grant	Dr Nicole Verrills University of Newcastle	RG 15-03 A novel biomarker for luminal B breast cancer	$119,859	$0	$119,859	Breast cancer
The Robyn Trinder Cancer Council NSW Project Grant	Dr Jeff Holst University of Sydney	RG15-04 Starving cancer cells: Developing nutrient uptake inhibitors as prostate cancer therapeutics	$120,000	$0	$120,000	Prostate cancer
The Clement Saxton Cancer Council NSW Project Grant	Prof Xu Zhang University of Newcastle	RG15-05 RIP1 as a novel therapeutic target in melanoma	$103,735	$0	$103,735	Melanoma
Project Grant	A/Prof Andrew Spillane University of Sydney	RG 15-06 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	Melanoma

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Project Grant	Prof David (Neil) Watkins Garvan Institute of Medical Research	RG 15-07 Rational targeting of the Hedgehog pathway to treat osteosarcoma	$120,000	$0	$120,000	Bone cancer
The Valerie Enid Legge Cancer Council NSW Project Grant	Prof Xu Zhang University of Newcastle	RG 15-11 Identifying and targeting a novel self-renewal signalling cascade in leukemic stem cells	$119,995	$0	$119,995	Leukaemia
Project Grant	Dr Anthony Cesare Childrens Medical Research Institute	RG 15-12 Kinsase signalling in the Intermediate-state Telomere cell cycle Arrest Pathway (ITAP) during human ageing and in disease	$120,000	$0	$120,000	All cancers
Project Grant	Dr Catherine Caldon Garvan Institute of Medical Research	RG 15-14 Aneuploidy as a driver of endocrine resistant breast cancer	$120,000	$0	$120,000	Breast (80%), Endocrine (20%)
Project Grant	Dr Kenneth Micklethwaite University of Sydney	RG 15-15 Gene modified T cells expressing a chimeric antigen receptor for a kappa light chain antigen to treat multiple myeloma	$107,359	$0	$107,359	
Project Grant	Dr Karen Mackenzie University of NSW	RG 15-16 Dyskerin as a novel therapeutic target in neoplastic cells	$117,359	$0	$117,359	All cancers
Project Grant	Prof Christine Clarke University of Sydney	RG 15-17 Role of progesterone in normal breast and its convergence with estrogen action in breast cancer	$119,859	$0	$119,859	Breast cancer
Project Grant	A/Prof Marcel Dinger Garvan Institute of Medical Research	RG 15-19 Genetic stratification of tumours of the head, neck, pituitary and skull base - identifying prognostic and new therapeutic targets	$120,000	$0	$120,000	Head & neck (70%), Endocrine (20%), Bone (10%)
Project Grant	Prof David (Neil) Watkins Garvan Institute of Medical Research	RG 15-20 Targeting innate chemoresistance in lung adenocarcinoma	$104,359	$0	$104,359	Lung cancer
Project Grant	Prof Robert Baxter University of Sydney	RG 15-21 Breast cancer therapies that target IGFBP-3 signalling	$120,000	$0	$120,000	Breast cancer
Project Grant	A/Prof Bettina Meiser University of NSW	RG 15-22 When the stakes are high: Psychosocial and behavioural impact of genomic testing for cancer risk	$115,762	$0	$115,762	Breast cancer
Project Grant	Prof Anna DeFazio University of Sydney	G 15-23 Novel treatment targets in low-grade serous ovarian cancer	$119,816	$0	$119,816	Endocrine (ovarian)

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Priority driven Collaborative Cancer Research Scheme	Prof Jacob George University of Sydney	RGPd 15-18 HCC Outcomes mitigation and disease PrEvention through Clinical Partnerships (HOPE)	$170,000	$0	$170,000	Liver cancer
TOTAL EXTERNAL RESEARCH FUNDED (Continuing Program)			**$6,823,675**	**$0**	**$6,823,675**	
TOTAL EXTERNALLY FUNDED RESEARCH PROGRAMS (Including new and continuing research grants)			**$8,801,042**	**$707,044**	**$9,508,086**	

Internally Funded Research Programs

New research programs

Name of research program	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Cancer Research Division				
Lynch Syndrome Cancers. Dr Natalie Taylor.	$148,931	$0	$148,931	Lynch Syndrome
Hide and seek with hereditary cancer: Translating evidenceinto practice to identify colorectal cancer patients with a high risk of Lynch syndrome. Dr Natalie Taylor. Funded by a Cancer Institute NSW (CINSW) Career Development Fellowship (CDF) Grant.	$0	$43,014	$43,014	Lynch Syndrome
Hide and seek with hereditary cancer: Improving detection of colorectal cancer patients with a high risk of Lynch syndrome. Dr Natalie Taylor. Funded by a PdCCRS Project Grant from Cancer Australia.	$0	$24,053	$24,053	Lynch Syndrome
Cancer Programs Division				
A randomised trial to implement systematic distress screening and structured care for callers using Cancer Councils' telephone service. Hannah Baird, Annette Beattie; in partnership with A/Prof Christine Paul, Dr Allison Boyes, Dr Tara Clinton-McHarg, Prof Patrick McElduff (University of Newcastle) and Prof Paul Jacobson (H Lee Moffitt Cancer Center and Research Institute, University of South Florida). NHMRC Project Grant with the University of Newcastle.	$24,977	$129,921	$154,898	All cancers
Yarning about cancer: supporting Indigenous breast cancer peer support group leaders project. Kim Pearce, Sally Carveth (Cancer Support Unit). Funded by a Cancer Australia grant and a Ralph Lauren Pink Pony Seeding Grant.	$0	$10,000	$10,000	Breast cancer
Tackling Tobacco Mental Health Project. Scott Walsberger, Rebecca Ireland, Laura Twyman (Tobacco Control Unit). Funded by NSW Ministry of Health.	$0	$188,429	$188,429	All cancers
Understanding views of oncology health professionals about Cancer Council Support Services. Angela Pearce, Kathy Chapman, Hannah Baird, Elizabeth Humphries, Annie Miller.	$80,259	$0	$80,259	All cancers
TOTAL INTERNAL RESEARCH FUNDED (New Programs)	**$254,167**	**$395,417**	**$6649,584**	

Internally Funded Research Programs

Continuing research programs

Name of research program	Cancer Council charitable funding amount 2017	Other funding amount for 2017	TOTAL	Research focus
Cancer Research Division				
Internal general infrastructure funding for the operation of the Cancer Research Division - includes Biobank. Prof Karen Canfell.	$780,098	$0	$780,098	All cancers
Cancer Council NSW Prostate Cancer Group funding for core research projects and staff. A/Prof David Smith.	$244,249	$0	$244,249	Prostate and other urological cancers
Cancer Council NSW Lung Cancer Group core funding for research support staff to oversee and work on various projects. Dr Marianne Weber.	$412,503	$0	$412,503	Lung cancer
Cancer Council NSW Cervix, Breast and HPV Group, core funding for research support staff to oversee and work on various projects. Prof Karen Canfell.	$561,047	$0	$561,047	Cervical cancer
Cancer Council NSW Colorectal Cancer Group core funding for research support staff to oversee and work on various projects. Dr Eleonora Felletto.	$92,072	$0	$92,072	Colorectal cancer
Cancer Council NSW Methods Group core funding for research support staff to oversee and work on various projects - Includes 45 and Up Cohort Study Infrastructure funding. Prof Dianne O'Connell.	$1,240,124	$0	$1,240,124	All cancers
Cancer Council NSW Health Economics Group core funding for research support staff to oversee and work on various projects. Dr Lennert Veerman.	$382,708	$0	$382,708	All cancers
HPV testing modelling. Prof Karen Canfell. Funded via a New Zealand Ministry of Health Grant.	$0	$201,863	$201,863	Cervical cancer
Testing and treatment for prostate cancer in Australia: Epidemiology and modelling. Prof Dianne O'Connell. Funded via a Prostate Cancer Foundation of Australia Grant.	$0	$84,689	$84,689	Prostate cancer
Fifteen year quality of life, survivorship and survival outcomes for prostate cancer: The NSW Prostate Cancer Care and Outcomes Study. A/Prof David Smith. Funded via a Cancer Institute Career Development Fellowship.	$0	$229,155	$229,155	Prostate cancer
A phase II randomised controlled trial of high dose Vitamin D in localised prostate cancer cases with intermediate risk of progression (Pros-D). Dr Visalini Nair-Shalliker. Funded via a Prostate Cancer Foundation of Australia Grant.	$0	$252,673	$252,673	Prostate cancer
Effectiveness and cost-effectiveness of systematic screening for Lynch Syndrome in Australia. Prof Karen Canfell. Funded via an NHMRC Project Grant.	$0	$234,129	$234,129	Lynch Syndrome
Evaluation of outcomes and cost-effectiveness of implementing next generation human papillomavirus (HPV) vaccination and associated primary HPV-based cervical cancer screening strategies in Australia. Prof Karen Canfell. Funded via an NHMRC Project Grant.	$0	$153,925	$153,925	Cervical cancer

Name of research program	Cancer Council charitable funding amount 2017	Other funding amount for 2017	TOTAL	Research focus
Evaluation of new screening strategies for prevention of cancer. Prof Karen Canfell. Funded via an NHMRC Career Development Fellowship Grant.	$0	$89,318	$89,318	Cervical cancer
Comparative Modeling to Inform Cervical Cancer Control Policies. Prof Karen Canfell. Funded via a US National Cancer Institute Grant.	$0	$226,949	$226,949	Cervical cancer
Effectiveness and Cost-Effectiveness of HPV Vaccination and HPV-Based Cervical Cancer Screening Strategies in China. Prof Karen Canfell. Funded via an NHMRC Project Grant.	$0	$142,561	$142,561	Cervical cancer
NHMRC IRIISS Funding - Independent Research Institutes Infrastructure Support Scheme 2016.	$0	$110,000	$110,000	All cancers
Cancer Council NSW Pathways. Prof Karen Canfell.	$1,009,397	$0	$1,009,397	All cancers
Cancer Programs Division				
Improve your long game campaign. Liz King, Clare Knight (Skin Cancer Prevention Unit). Cancer Institute NSW Partnership funding.	$0	$150,000	$150,000	Melanoma and other skin cancers
Enhancing community knowledge and engagement with law at the end of life. Angela Pearce (Evaluation Unit) in partnership with Prof. Benjamin White, Prof Lindy Willmott (Queensland University of Technology), A/Prof Cheryl Tilse, Prof Jill Wilson (University of Queensland), Dr Deborah Lawson (Cancer Council Victoria), Prof Jeffrey Dunn (Cancer Council Queensland). This research is funded by the Australian Government through an Australian Research Council Linkage Grant.	$0	$54,887	$54,887	All cancers
Supporting people with cancer – Locally led Aboriginal Cancer Support Networks. Kelly Williams, Marion Carroll, Rhian Paton-Kelly, Brenna Smith, in partnership with Kerri Lucas, Catherine Wood, Dr Jenny Hunt, Angela Nicholas (AHMRC Research team). Funded by a Cancer Australia grant	$10,000	$40,000	$50,000	All cancers
An e-learning program in smoking cessation for health and community sector professionals who work with high-prevalence groups. Scott Walsberger and Amani Sobhan. Funded by a Cancer Institute NSW grant.	$0	$11,000	$11,000	All cancers
Quantifying intake of food prepared outside home during emerging adulthood. Lyndal Wellard, Kathy Chapman, Clare Hughes, Wendy Watson (Nutrition Unit) in partnership with Prof Margret Allman-Farinelli (University of Sydney). This research is funded by the Australian Government through an Australian Research Council Linkage Grant.	$25,000	$67,348	$92,348	All cancers
Applying a logic model to link unhealthy food promotion to childhood obesity. Kathy Chapman, Clare Hughes (Nutrition Unit) in partnership with Dr Bridget Kelly (University of Wollongong). This research is funded by the Australian Government through an Australian Research Council Linkage Grant.	$20,000	$43,931	$63,931	All cancers
Healthy Living after Cancer - A Partnership Project between the NSW, WA and SA Cancer Councils and the Cancer Prevention Research Centre, University of Queensland. Kathy Chapman, Hannah Baird, Liz Hing, Jerome Krish (Cancer Support Unit). Funded by an NHMRC Partnership Grant with the University of Queensland.	$30,000	$288,432	$318,432	Localised cancer types (excluding Myeloma)

Name of research program	Cancer Council charitable funding amount 2017	Other funding amount for 2017	TOTAL	Research focus
Cancer Information and Support Webinar Series for the Chinese community. Annie Miller, Jill Mills, Bee Lim (Practical Support Unit). Funded by a Cancer Australia grant.	$6,666	$37,000	$43,666	All cancers
Evaluation of CCNSW's Improve Your Long Game program. Liz King, Clare Knight, Stuart Wright, Phoebe Nicholls.	$25,425	$0	$25,425	Melanoma and other skin cancers
Evaluation of CCNSW's Sun Sound program. Liz King, Stuart Wright, Ally Hamer.	$24,250	$0	$24,250	Melanoma and other skin cancers
TOTAL INTERNAL RESEARCH FUNDED (Continuing Programs)	**$4,863,53**	**$2,417,861**	**$7,281,399**	
TOTAL INTERNALLY FUNDED RESEARCH PROGRAMS (Including new and continuing research grants)	**$5,117,705**	**$2,813,278**	**$7,930,983**	
TOTAL RESEARCH FUNDED (Including external and internal research grants)	**$13,918,747**	**$3,520,322**	**$17,439,069**	

CANCER COUNCIL QUEENSLAND

Externally Funded Research Programs

New research grants

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Project Grant	Dr Jyotsna Batra Queensland University of Technology	Genetic association study of miRSNPs with risk and prognosis of prostate cancer	$100,000	$0	$100,000	Prostate cancer
Project Grant	Dr Lionel Hebbard James Cook University	Clarifying the controversial role of fructose in liver cancer	$100,000	$0	$100,000	Liver cancer
Project Grant	Prof Elisabeth Isenring Bond University	Supplemental Prophylactic Intervention for Chemotherapy-induced Nausea and Emesis (SPICE) trial	$100,000	$0	$100,000	Cancer treatment
Project Grant	A/Prof Kiarash Khosrotehrani The University of Queensland Diamantina Institute	Predictors of mortality in thin melanomas	$100,000	$0	$100,000	Melanoma
Project Grant	Dr Graham Leggatt The University of Queensland Diamantina Institute	Local targeting of immunomodulatory molecules on CD8 T cells in non-melanoma skin cancer	$100,000	$0	$100,000	Skin cancer
Project Grant	Dr Siok Tey QIMR Berghofer Medical Research Institute	Treatment of chronic graft-versus-host disease with regulatory T cell-directed therapy – insights from gene-marking	$100,000	$0	$100,000	Cancer treatment
Project Grant	Dr Antiopi Varelias QIMR Berghofer Medical Research Institute	Understanding the interplay between cytokines and intestinal dysbiosis following stem cell transplantation	$100,000	$0	$100,000	Cancer treatment
Project Grant	Dr James Wells The University of Queensland Diamantina Institute	Memory CD8+ T-cell function in squamous cell carcinoma	$100,000	$0	$100,000	Skin cancer
Project Grant	Prof Alpha Yap The University of Queensland	Down-regulation of RhoA signalling mediates HGF/MET-induced tumour progression	$100,000	$0	$100,000	All cancers
Project Grant	Dr Li Zhang Griffith University	Prevention of central venous catheter infection and occlusion by needleless connector design and disinfection in haematology-oncology patients	$100,000	$0	$100,000	Cancer treatment

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Travelling Fellowships	By invitation		$35,000	$0	$35,000	All cancers
Provision for special projects	By invitation		$40,000	$0	$40,000	All cancers
TOTAL EXTERNAL RESEARCH FUNDED (New Program)			**$1,075,000**	**$0**	**$1,705,000**	

Externally Funded Research Programs

Continuing research grants

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Project Grant	Dr Fares Al-Ejeh QIMR Berghofer Medical Research Institute	The MEK5-ERK5 pathway in triple negative breast cancer: progression and therapy	$100,000.00	$0.00	$100,000.00	Breast cancer
Project Grant	Prof Lisa Chopin Queensland University of Technology	The ghrelin receptor antisense long non-coding RNA, GHSROS, as a potential target for prostate cancer therapy	$100,000.00	$0.00	$100,000.00	Prostate cancer
Project Grant	Prof Judith Clements Queensland University of Technology	Targeting kallikrein proteases to improve treatment options for ovarian cancer	$100,000.00	$0.00	$100,000.00	Ovarian cancer
Project Grant	Dr Bryan Day QIMR Berghofer Medical Research Institute	Advancing a novel therapy to target brain cancer stem cells	$100,000.00	$0.00	$100,000.00	Brain cancer
Project Grant	Dr Eloise Dray Queensland University of Technology	Deciphering the role of the protein phosphatase EYA4 in genomic maintenance and breast cancer avoidance	$100,000.00	$0.00	$100,000.00	Breast cancer
Project Grant	Dr Stacey Edwards QIMR Berghofer Medical Research Institute	Identifying new breast cancer genes from GWAS	$100,000.00	$0.00	$100,000.00	Breast cancer
Project Grant	Dr Mathias Francois The University of Queensland	SOX18-VEGF cross-regulation during angiogenesis and blood vascular development	$100,000.00	$0.00	$100,000.00	Basic Science

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Project Grant	Dr Kate Gartlan QIMR Berghofer Research Institute	RORyt inhibition as a novel therapeutic for the prevention of graft-versus-host disease after allogeneic stem cell transplantation	$100,000.00	$0.00	$100,000.00	Leukaemia
Project Grant	Prof Rajiv Khanna QIMR Berghofer Medical Research Institute	Impact of immune contexture on clinical outcome of adoptive immunotherapy	$100,000.00	$0.00	$100,000.00	Prevention
Project Grant	Prof George Muscat The University of Queensland	Elucidating the role of the nuclear hormone receptor RORy1 in breast cancer	$100,000.00	$0.00	$100,000.00	Breast cancer
Project Grant	Dr Dominic Ng The University of Queensland	Mitotic spindle regulation by a novel Aurora A control mechanism	$100,000.00	$0.00	$100,000.00	Prevention
Project Grant	Dr Michael Piper The University of Queensland	Regulation of stem cell differentiation during cerebella development and medulloblastoma	$100,000.00	$0.00	$100,000.00	Childhood Brain cancer
Project Grant	Prof Mark Smyth QIMR Berghofer Medical Research Institute	Checkpoint blockade and denosumab in the treatment of established primary and metastatic cancers	$100,000.00	$0.00	$100,000.00	Skin cancer and Prostate Cancer
Project Grant	A/Prof Raymond Steptoe The University of Queensland Diamantina Institute	Does lymphoma avoid immune destruction by inducing T-cell tolerance?	$100,000.00	$0.00	$100,000.00	Lymphoma
Project Grant	A/Prof Vicki Whitehall QIMR Berghofer Medical Research Institute	Sessile serrated adenoma prevention in a preclinical study	$100,000.00	$0.00	$100,000.00	Bowel cancer prevention
PhD Scholarship	Arabella Young QIMR Berghofer Medical Research Institute	Targeted therapy and immunotherapy in breast cancer	$4,416.65	$0.00	$4,416.65	Breast cancer
Senior Research Fellowship	Prof Sandi Hayes Queensland University of Technology	Exercise is medicine: a non-pharmacological approach to cancer care	$71,392.00	$0.00	$71,392.00	All cancers
Cancer Council Queensland/ University of the Sunshine Coast Joint Chair of Cancer Prevention Research	Prof Michael Kimlin University of the Sunshine Coast	CCQ/USC Joint Chair of Cancer Prevention Research	$100,000.00	$0.00	$100,000.00	Prevention

Name of research program	*Recipients*	Cancer Council charitable funding amount 2017	Other funding amount for 2017	TOTAL	Research focus
CCQ/QCOG Clinical Trials Support Scheme	Genesis Cancer Care	$489,343.00	$783,164.00	$1,272,507.00	All cancers
	Gold Coast University Hospital				
	Holy Spirit Northside - Brisbane Colorectal Group				
	ICON Cancer Foundation				
	Lady Cilento Children's Hospital				
	Mater Health Services - Medical Oncology & Pallaitive Care				
	Mater Medical Research Institute				
	Nambour Hospital				
	Oncology Research Australia				
	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, Haematology & BMT				
	Toowoomba Hospital				
	Townsville Hospital				
	Wesley Medical Research				
TOTAL RESEARCH FUNDED (Continuing Program)		**$2,165,152**	**$783,164**	**$2,948,316**	
TOTAL EXTERNALLY FUNDED RESEARCH PROGRAMS (including new and continuing research grants)		**$3,240,152**	**$783,164**	**$4,023,316**	

Internally Funded Research Programs

Continuing research programs

Name of research program	Cancer Council charitable funding amount 2017	Other funding amount for 2017	TOTAL	Research focus
Viertel Cancer Research Centre	$2,990,168	$1,050,225	$4,040,393	
Epidemiology - cancer in Indigenous Australians - prostate cancer - cancer in children - analysis and reporting of cancer statistics and patterns - breast cancer outcomes - UV exposure, vitamin D and melanoma	$13,385	$201,333	$214,718	

Name of research program	Cancer Council charitable funding amount 2017	Other funding amount for 2017	TOTAL	Research focus
Psycho-oncology - developing accessible and effective supportive care interventions - identifying needs for patients and carers	$282,754	$67,685	$350,439	
Community engagement - building capacity for cancer control agencies - meeting the needs of regional and rural communities	$386,673	$0	$386,673	
Australian Paediatric Cancer Registry	$258,754	$0	$258,754	
Queensland Cancer Registry	$251,137	$988,587	$1,239,724	
TOTAL RESEARCH FUNDED (Continuing Program)	**$4,182,871**	**$2,307,830**	**$6,490,701**	
TOTAL INTERNALLY FUNDED RESEARCH PROGRAMS (including new and continuing research grants)	**$4,182,871**	**$2,307,830**	**$6,490,701**	
TOTAL RESEARCH FUNDED (including external and internal research grants)	**$7,423,023**	**$3,090,994**	**$10,514,017**	

CANCER COUNCIL SOUTH AUSTRALIA

Externally Funded Research Programs

New research grants

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
BEAT CANCER PROJECT - A joint initiative of Cancer Council SA, South Australian Health and Medical Research Institute, SA Health and University of Adelaide, University of South Australia and Flinders University						
Project grant	Prof Hamish Scott, University of SA and SA Pathology	Using familial haematological malignancies and germline variants to identify new haematopoietic and pan-cancer genes	$75,000		$75,000	Blood cancers
Project grant	Prof Murray Whitelaw	Exploring cross interference between the Hypoxia Inducible Factor and Single Minded 2 in prostate cancer, breast cancer and sarcoma	$75,000		$75,000	
Project grant	A/Prof Janni Petersen, Flinders University	Ammonia, an alternative nitrogen source supporting cell proliferation	$75,000		$75,000	All cancers
Project grant	Prof Ian Olver, University of SA	Improving the management of chemotherapy-induced nausea by assessing and treating nausea as a symptom cluster	$75,000		$75,000	All cancers
Project grant	A/Prof Michael Sorich, Flinders University	Dynamic Prediction of Immune Checkpoint Inhibitor Response and Toxicity	$75,000		$75,000	Advanced melnoma
Project grant	Prof Pamela Sykes, Flinders University	Increasing tumour kill during radiotherapy while reducing damaging side effects to normal tissue	$75,000		$75,000	Prostate cancer
TOTAL RESEARCH FUNDED (New Program)			**$450,000**	**$0**	**$450,000**	

Externally Funded Research Programs

Continuing research grants

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
BEAT CANCER PROJECT - A joint initiative of Cancer Council SA, South Australian Health and Medical Research Institute, SA Health and University of Adelaide, University of South Australia and Flinders University						
Cancer Council SA Chair in Cancer (Behavioural Science)	Professor Carlene Wilson		$250,000	$0	$250,000	All cancer
Research Chair*	Professor Tim Hughes, University of Adelaide		$250,000	$375,000	$625,000	All cancer
Research Chair*	Professor David Roder, University of South Australia		$250,000	$375,000	$625,000	All cancer
Research Chair*	Professor Ross McKinnon, Flinders University		$250,000	$375,000	$625,000	All cancer
Principal Research Fellow*	Dr Daniel Worthley, University of Adelaide	Identifying and targeting the important supportive cells in cancer	-	$315,000	$315,000	All cancer
Principal Research Fellow*	Professor Shudong Wang, University of South Australia	New therapeutics for cancer treatment	$210,000	$315,000	$525,000	All cancer
Principal Research Fellow*	Dr Caroline Miller, South Australian Health and Medical Research Institute (SAHMRI)	Packaging and labeling of tobacco products, food and alcohol	$210,000	$315,000	$525,000	All cancer
Cancer Council SA Research Fellow (cancer support)	Dr Kate Fennell / Dr Lisa Beatty		$65,000		$65,000	
Hospital Packages*	Professor Guy Maddern, The Queen Elizabeth Hospital	Individualised Risk Assessment and Therapeutic Intervention for Colorectal Cancer in South Australia	$187,500	$562,500	$750,000	Colorectal Cancer
Hospital Packages*	Professor David Watson, Flinders University	Flinders Centre for Gastrointestinal Cancer Prevention	$187,500	$562,500	$750,000	Gastro-intestinal Cancer
Hospital Packages*	Professor Tim Hughes, Royal Adelaide Hospital	Advancing T-cell therapy for leukaemia and glioblastoma	$187,500	$562,500	$750,000	Leukaemia

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Partnership Grant*	Professor Alex Brown, University of South Australia	Cancer Data and Aboriginal Disparities Project	$250,000	$375,000	$625,000	All cancer
Infrastructure Funding*	Clinical Cancer Registry		$160,000	$97,500	$257,500	All cancer
Infrastructure Funding*	Mr Andrew Stanley, University of South Australia	SANT DataLink	$151,425	$454,275	$605,700	All cancer
Infrastructure Funding*	A/Prof Caroline Miller, SAHMRI	Clinical Cancer Regitstry	$70,000	$250,000	$320,000	All cancer
Project grant	Prof Richard D'Andrea, University of South Australia	The role fo the GADD45A gene in AML pathogenesis and response to therapy	$37,500		$37,500	Leukaemia
Project grant	A/Prof Lisa Jamieson, University of Adelaide	The effectiveness and cost-effectiveness of oral cavity cancer screening among Aboriginal and Torres Strait Islander Australians	$37,500		$37,500	Oral
Project grant	Dr Caroline Miller, SAHMRI	Sugar sweetened beverages and obesity - evidence to advance a public health response	$37,500		$37,500	Prevention
Project grant	A/Prof Benedetta Sallustio, University of Adelaide	Prevention of heart damage during anthracycline cancer chemotherapy	$37,500	$37,500	$75,000	All cancers
Project grant	Dr Amanda Townsend, University of Adelaide	Genome-wide association study of single nucleotide polymorphisms as predictive biomarkers for sensitivity to anti-EGFR antibody therapy for metastatic colorectal cancer with wild-type RAS	$37,500	$37,500	$75,000	Colorectal
Project grant	Prof Eric Yeoh, University of Adelaide	Colonic and anal sphincteric dysmotility after radiotherapy for prostate cancer	$37,500	$37,500	$75,000	Prostate
Fellowship*	Dr Carmela Ricciardelli, Robinson Institute, University of Adelaide	Lin Huddleston Ovarian Cancer Research Fellowship	$100,000	$50,000	$150,000	Ovarian
Fellowship*	Dr Hayley Ramshaw, Centre for Cancer Biology	Peter Nelson Leukaemia Research Fellowship Fund	$100,000		$100,000	Acute myeloid leukaemia
TOTAL RESEARCH FUNDED (Continuing Program)			**$3,103,925**	**$5,096,775**	**$8,200,700**	
TOTAL EXTERNALLY FUNDED RESEARCH PROGRAMS (including new and continuing research grants)			**$3,553,925**	**$5,096,775**	**$8,650,700**	

* Based on Financial Year to 30 June 2017

Internally Funded Research Programs

Continuing research programs

Name of research program	Cancer Council charitable funding amount 2017	Other funding amount for 2017	TOTAL	Research focus
Behavioural Research and Evaluation Unit*	$742,371		$742,371	
			$0	
			$0	
TOTAL RESEARCH FUNDED (Continuing Program)	**$742,371**	**$0**	**$742,371**	
TOTAL INTERNALLY FUNDED RESEARCH PROGRAMS (including new and continuing research grants)	**$742,371**	**$0**	**$742,371**	
TOTAL RESEARCH FUNDED (including external and internal research grants)	**$4,296,296**	**$5,096,775**	**$9,393,071**	

CANCER COUNCIL TASMANIA

Internally Funded Research Programs

New research grants

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Cancer Council Tasmania Small Grants 2017	Dr Rachel Nimmo	The Bonser Family Research Grant	$8,077	$6,000	$14,077	cancer control
Cancer Council Tasmania Small Grants 2017	Dr Phillipa Taberlay	Mi-tec Publishing Medical Research Grant	$14,990	$6,000	$20,990	cancer control
Cancer Council Tasmania Clinical Trials Data Management 2017 - South	To be allocated - THS (South)	Employ cancer trials data manager	$37,500		$37,500	cancer control
Cancer Council Tasmania Clinical Trials Data Management 2017 - North	To be allocated - THS (North)	Employ cancer trials data manager	$32,500		$32,500	cancer control
Jeanne Foster Scholarship 2017	Jo Burke	Jeanne Foster Scholarship 2017	$2,100		$2,100	cancer control
Jeanne Foster Scholarship 2017	Dr Anand Kumar	Jeanne Foster Scholarship 2017	$2,900		$2,900	cancer control
Evelyn Pedersen Honours Scholarship 2017	Thomas Halbe	Cancer Council Tasmania Evelyn Pedersen Honours Scholarship 2017	$10,000		$10,000	cancer control
TOTAL RESEARCH FUNDED (New Program)			**$108,000**	**$12,000**	**$120,067**	

Externally Funded Research Programs

Continuing research grants

Name of research program	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Cancer Council Tasmania / University of Tasmania Health Science Research Fellowship 2014 - Dr Mai Frandsen - 'Reducing the burden of lung disease: using self-affirmation to reduce defensiveness towards health risk information among smokers (SACO)' and 'supporting expectant mother to quit (SEMQ)'	$46,233		$46,233	cancer control

Name of research program	Cancer Council charitable funding amount 2017	Other funding amount for 2017	TOTAL	Research focus
Cancer Council Tasmania / University of Tasmania Health Science Research Fellowship 2017 - TBA. Closing date 26 June 2017			$0	cancer control
Evelyn Pedersen Elite Research PhD Scholarship 2017 - TBA. Closing date 30th June 2017			$0	cancer control
TOTAL RESEARCH FUNDED (Continuing Program)	**$0**	**$0**	**$0**	
TOTAL INTERNALLY FUNDED RESEARCH PROGRAMS (including new and continuing research grants)	**$108,067**	**$12,000**	**$120,067**	
TOTAL RESEARCH FUNDED (including external and internal research grants)	**$108,067**	**$12,000**	**$120,067**	

CANCER COUNCIL VICTORIA

Externally Funded Research Programs

New research grants

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Grant-in-Aid - Girls Night In	Dr Lan Nguyen Monash University	Elucidating the dual functions of YAP in breast cancer	$97,284	$0	$97,284	Breast
Grant-in-Aid	Dr Urmi Dhagat St Vincent's Institute of Medical Research	How does the protein hormone interleukin-3 regulate cell signalling in leukaemic cells?	$99,599	$0	$99,599	Leukaemia
Grant-in-Aid	A/Prof Hui Gan La Trobe University	Anti-EGFR ADCS for colorectal and breast cancer	$97,000	$0	$97,000	Bowel, Breast
Grant-in-Aid	Prof Suzanne Garland The Royal Women's Hospital	Assessment of potential tests for anal cancer screening	$92,660	$0	$92,660	Anal
Grant-in-Aid	Prof John Hopper The University of Melbourne	Automated measures that predict risk and masking of breast cancer	$99,842	$0	$99,842	Breast
Grant-in-Aid	Dr Ian Majewski The Walter and Eliza Hall Institute of Medical Research	Targeting cell survival pathways to treat cancer	$99,815	$0	$99,815	Leukaemia, Lymphoma
Grant-in-Aid	Dr Kate Murphy The University of Melbourne	A novel treatment for heart failure in cancer and with chemotherapy	$72,644	$0	$72,644	Bowel, Pancreatic
Grant-in-Aid	Dr Belinda Parker La Trobe University	Predicting the benefit of therapies for patients with triple negative breast cancer	$96,378	$0	$96,378	Breast
Grant-in-Aid	A/Prof Helena Richardson La Trobe University	Determining how a novel protein controls cell shape and cancer progression	$100,000	$0	$100,000	All epithelial cancers, particularly lung and pancreatic cancers
Grant-in-Aid	Dr Adam Uldrich The University of Melbourne	Examining the anti-cancer properties of gamma delta T cells.	$99,335	$0	$99,335	Melanoma, Multiple Myeloma
Grant-in-Aid	A/Prof Carl Walkley St Vincent's Institute of Medical Research	Understanding how blood cancers form	$100,000	$0	$100,000	Leukaemia, Myelodys-plastic syndrome

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Postdoctoral Fellowship	Ms Sophea Heng Hudson Institute of Medical Research	The function of a membrane protein in early endometrial cancer development	$74,692	$0	$74,692	Endometrial, may be applicable for all cancers
Postdoctoral Fellowship	Dr Kirsteen Tullett Monash University	Targeting the immune cell receptor CLec9A for cancer immunotherapy	$74,692	$0	$74,692	All cancers
Postdoctoral Fellowship	Two fellowships to be appointed mid-year		$74,692	$0	$74,692	
Vacation Studentships	16 summer Vacation Studentships to be awarded		$30,000	$0	$30,000	
TOTAL EXTERNAL RESEARCH FUNDED (New Program)			**$1,308,633**	**$0**	**$1,308,633**	

Externally Funded Research Programs

Continuing research grants

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Colebatch Fellowship	A/Prof Sherene Loi Peter MacCallum Cancer Centre	Advancing personalised medicine for breast cancer patients	$300,000	$0	$300,000	Breast
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	Breast
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	Leukaemia
Venture Grant	Prof Ricky Johnstone Peter MacCallum Cancer Centre	New treatments for multiple myeloma	$187,500	$0	$187,500	Multiple Myeloma
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	Breast, Leukaemia and Lymphoma

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Lyall Watts Mesothelioma Research Grant	A/Prof Kieran Harvey Peter MacCallum Cancer Centre	What causes mesothelioma and how can we treat it?	$116,666	$0	$116,666	Mesothelioma
Lyall Watts Mesothelioma Research Grant	Dr Peter Janes La Trobe University	Targeted antibody therapy for malignant mesothelioma	$128,335	$0	$128,335	Mesothelioma
Grant-in-Aid - Girls Night In	Prof Peter Fuller AM Monash University	The aldosterone receptor in breast cancer	$100,000	$0	$100,000	Breast
Grant-in-Aid	Prof Colin Clyne Monash University	Understanding how LRH-1 controls breast cancer development	$100,000	$0	$100,000	Breast
Grant-in-Aid - Bruce Ward	A/Prof Phillip Darcy The University of Melbourne	Harnessing the immune system against cancer	$100,000	$0	$100,000	All cancers
Grant-in-Aid	A/Prof Simon Harrison The University of Melbourne	New ways to treat blood cancers	$125,000	$0	$125,000	All cancers
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	Prostate
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	Lymphoma
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	Bowel
Grant-in-Aid	Dr Mark Shackleton The University of Melbourne	Hippo pathway molecules as new targets for cancer treatment	$100,000	$0	$100,000	Melanoma
Grant-in-Aid	Dr Jake Shortt The University of Melbourne	Non-chemotherapy drug combinations to turn on suicide genes in lymphoma cells	$100,000	$0	$100,000	Leukaemia, Lymphoma
Grant-in-Aid	Dr Michaela Waibel The University of Melbourne	Tailored therapies for blood cancer	$99,805	$0	$99,805	Leukaemia, Myelo-proliferative neoplasms (MPN), paediatric leukaemia

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Grant-in-Aid	Dr Nicole Haynes The University of Melbourne	Targeting HER2+ breast cancer with novel combination therapies	$99,840	$0	$99,840	Breast
Grant-in-Aid	Dr Peter Janes Monash University	Developing new therapies to fight drug resistant breast cancers	$99,661	$0	$99,661	Breast
Grant-in-Aid	Prof Stephen Nutt The Walter and Eliza Hall Institute of Medical Research	Exploring new molecular targets on plasma cells as therapies for multiple myeloma	$100,000	$0	$100,000	Multiple Myeloma
Grant-in-Aid	Dr Gretchen Poortinga The University of Melbourne	Understanding how cancer cells become resistant to a novel treatment of blood cancers	$99,483	$0	$99,483	Leukaemia, Lymphoma
Grant-in-Aid	A/Prof Louise Purton St Vincent's Institute of Medical Research	Identifying better treatments for blood cell cancers	$100,000	$0	$100,000	Leukaemia
Grant-in-Aid	Prof Jamie Rossjohn Monash University	Exploring how tumour cells are recognised by Natural Killer cells	$100,000	$0	$100,000	Leukaemia, Lymphoma and Haemato-logical malignancies
Grant-in-Aid	Dr Karen Sheppard The University of Melbourne	Understanding why melanomas stop responding to therapy that inhibits cells from growing	$98,921	$0	$98,921	Melanoma
Grant-in-Aid	Prof Andreas Strasser The Walter and Eliza Hall Institute of Medical Research	How does competition between cells impact tumour development	$100,000	$0	$100,000	Leukaemia and Lymphoma
Grant-in-Aid	Prof Jose Villadangos The University of Melbourne	Improving cancer killing with live cell therapy	$100,000	$0	$100,000	All cancers, Leukaemia, Lymphoma
Grant-in-Aid	Dr Florian Wiede Monash University	Defining a novel immunotherapy for more effective cancer treatment	$100,000	$0	$100,000	Bowel, Breast, Lung, Lymphoma and Melanoma
Research Grant - Girls Night In	Dr Yuan Cao The University of Melbourne	Blocking the spread of breast cancer spread using a protein-based therapy	$98,837	$0	$98,837	Breast
Postdoctoral Fellowships	Dr Dustin Flanagan The University of Melbourne	Novel avenues to target and treat stomach cancer	$36,831	$0	$36,831	Gastric cancer

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Postdoctoral Fellowships	Dr Farhana Sultana The University of Melbourne	Self-sampling for HPV testing	$18,415	$0	$18,415	Cervical cancer
Support for medical and scientific activities			$198,000	$0	$198,000	
TOTAL RESEARCH FUNDED (Continuing Program)			**$3,857,120**	**$0**	**$3,857,120**	
TOTAL EXTERNALLY FUNDED RESEARCH PROGRAMS (Including new and continuing research grants)			**$5,165,753**	**$0**	**$5,165,753**	

Internally Funded Research Programs

New research programs

Name of research program	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Cancer Epidemiology Centre		$200,000	$200,000	epidemiology
Behavioural Science Division		$370,950	$370,950	behavioural science; prevention
TOTAL RESEARCH FUNDED (New Program)	**$0**	**$570,950**	**$570,950**	

Internally Funded Research Programs

Continuing research programs

Name of research program	Cancer Council charitable funding amount 2017	Other funding amount for 2017	TOTAL	Research focus
Cancer Epidemiology Centre	$5,085,751	$2,014,666	$7,100,417	epidemiology
Behavioural Science Division	$950,470	$690,682	$1,641,152	behavioural science; prevention
Nigel Grey Fellowship Group	$236,948	$664,206	$901,154	tobacco control
Victorian Cancer Biobank	$0	$102,500	$102,500	tissue bank
Victorian Cancer Registry	$0	$3,088,450	$3,088,450	registry
TOTAL RESEARCH FUNDED (Continuing Program)	**$6,273,169**	**$6,560,504**	**$12,833,673**	
TOTAL INTERNALLY FUNDED RESEARCH PROGRAMS (including new and continuing research grants)	**$6,273,169**	**$7,131,454**	**$13,404,623**	
TOTAL RESEARCH FUNDED (including external and internal research grants)	**$11,438,922**	**$7,131,454**	**$18,570,375**	

CANCER COUNCIL WESTERN AUSTRALIA

Externally Funded Research Programs

New research grants

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Research Project Grants	A/Prof Pilar Blancafort Harry Perkins Institute of Medical Research	A novel strategy to kill triple negative breast cancers	$100,000		$100,000	Breast
Research Project Grants	Dr Renee Carey Curtin University	How can we best prevent future cancers in Australia?	$95,000		$95,000	Prevention
Research Project Grants	Dr Archa Fox Harry Perkins Institute of Medical Research	Investigation of the role of a new gene regulator, Neat[1] (Nuclear Paraspeckle Assembly Trasncript[1]), in breast cancer metastasis	$99,917		$99,917	Breast
Research Project Grants	Clin A/Prof Nicholas Gottardo Telethon Kids Institute	Improving the cure rates of childhood brain cancer	$97,176		$97,176	Neuro-blastoma; Brain
Research Project Grants	A/Prof Evan Ingley Harry Perkins Institute of Medical Research	Hitting the off-switch to stop cancer cells spreading	$100,000		$100,000	Bone
Research Project Grants	Dr Brendan Kennedy The University of Western Australia	Micro-elastography: A new surgical tool to reduce the number of re-excision breast cancer surgeries	$100,000		$100,000	Breast
Research Project Grants	Dr Sally Lansley Institute for Respiratory Health	The effect of fibroblast growth factor 9 on the body's natural immune response to mesothelioma	$81,581		$81,581	Lung; Mesothelioma
Research Project Grants	Prof Fiona Pixley The University of Western Australia	Preventing breast cancer from spreading by stopping immune cell movement.	$100,000		$100,000	Breast
Research Project Grants	Prof Bruce Robinson The University of Western Australia	The effect of therapy on the immune systems to recognize mutated proteins	$100,000		$100,000	Lung; Mesothelioma
Research Fellowship	A/Prof Georgia Halkett Curtin University	A research plan for testing education and support programs for people diagnosed with either brain cancer or head and neck cancer and their carers.	$115,000		$115,000	Head and Neck; Brain

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Research Fellowship	Dr Willem Lesterhuis The University of Western Australia	Identifyng new effective treatments for mesothelioma	$20,000		$20,000	Mesothelioma
Postdoctoral Fellowship	Dr Vinicius Cavalheri Curtin University	Prognostic significance of physical activity and sedentary behaviour in people with advanced non-small cell lung cancer	$75,000		$75,000	Lung; Mesothelioma
Collaborative Cancer Grant Scheme for Early to Mid Career Researchers	Dr Lixin Chin The University of Western Ausralia	A handheld micro-elastography probe: a new surgical tool to reduce the number of re-excision surgeries in breast cancer treatment	$16,667	$31,933	$48,600	Breast
Collaborative Cancer Grant Scheme for Early to Mid Career Researchers	Dr Elin Gray Edith Cowan University	Understanding how cancer cells communicate with other cancer cells and with the immune system to improve cancer treatments	$16,667	$26,563	$43,230	Melanoma
Collaborative Cancer Grant Scheme for Early to Mid Career Researchers	Dr Richard Norman Curtin University	What aspects of cancer care are most important to patients and the general public?	$16,667	$21,085	$37,752	All Cancers
Collaborative Cancer Grant Scheme for Early to Mid Career Researchers	Dr Nicole Smith The University of Western Australia	Targeting four-stranded DNA conformations to modulate gene expression in breast cancer	$16,667	$29,002	$45,669	Breast
Collaborative Cancer Grant Scheme for Early to Mid Career Researchers	Dr Nita Sodhi-Berry The University of Western Australia	Asbestos Removalists' Health Study	$16,667	$33,205	$49,872	Lung; Mesothelioma
Collaborative Cancer Grant Scheme for Early to Mid Career Researchers	Dr Sarah Ward The University of Western Australia	Identifying genetic causes of poor survival outcomes in patients with thin melanoma	$16,667	$33,210	$49,877	Melanoma
Suzanne Cavanagh Early Career Investigator Grant	Dr Lixin Chin Harry Perkins Institute of Medical Research	The smart surgical glove: a new tool to reduce the number of re-excision surgeries in breast cancer treatment	$35,000		$35,000	Breast
Suzanne Cavanagh Early Career Investigator Grant	Dr Evelyne Deplazes Curtin University	Peptides from spider venom as new anti-cancer drugs	$32,220		$32,220	Melanoma; Breast; Prostate
Suzanne Cavanagh Early Career Investigator Grant	Dr Benjamin Dessauvagie Pathwest	Digital technology to improve diagnosis of Breast Cancer	$34,957		$34,957	Breast
Suzanne Cavanagh Early Career Investigator Grant	Dr Bo He Harry Perkins Institute of Medical Research	Exploring new ways to stop lung or breast cancer from spreading	$35,000		$35,000	Lung; Breast

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Suzanne Cavanagh Early Career Investigator Grant	Dr Melanie McCoy The University of Western Australia	Treating bowel cancer - does the immune system have a role to play?	$34,729		$34,729	Bowel
PhD Top Up Scholarship	Ms Jessica Kretzmann The University of Western Australia	Designing new materials that deliver gene therapies to breast cancer	$6,000		$6,000	Breast
PhD Top Up Scholarship	Ms Ciara Duffy Harry Perkins Institute of Medical Research	Treating the most aggressive breast cancers using molecules from natural substances	$6,000		$6,000	Breast
Honours Scholarship	Mr Jack Cooper The University of Western Australia	Establishing a definitive role for a key cancer regulator in neuroblastoma	$7,500		$7,500	Neuro-blastoma; Brain
Honours Scholarship	Mr Joshua Murphy The University of Western Australia	Targeting metabolism in mesothelioma: choosing an arrow	$7,500		$7,500	Mesothelioma
Honours Scholarship	Ms Katharine Potaka The University of Western Australia	Identifying the role of novel mutations in the development of infant acute lymphoblastic leukaemia	$7,500		$7,500	Blood
Honours Scholarship	Ms Fiona Nugent Harry Perkins Institute of Medical Research	Investigating the cross-talk between genetic mutations and epigenetic silencing in genes that prevent cancer	$7,500		$7,500	All Cancers
Student Vacation Scholarship	Mr Derrick Chan The University of Western Australia	Understanding megakaryocyte genetic abnormalities in patients with myeloproliferative neoplasms (MPN) and association with bone marrow scarring	$3,000		$3,000	Blood
Student Vacation Scholarship	Ms Melissa Hawksley The University of Western Australia	Investigating the impact of the lack of skeletal muscle mass on poeple with malignant pleural mesothelioma	$3,000		$3,000	Lung; Mesothelioma
Student Vacation Scholarship	Ms Reanne Ho The University of Western Australia	The role of platelets in metastasis of solid tumours	$3,000		$3,000	All Cancers
Student Vacation Scholarship	Ms Audrey Kim Harry Perkins Institute of Medical Research	Discovery of novel genes driving breast cancer cells resistance to anti-hormonal therapy	$3,000		$3,000	All Cancers
Student Vacation Scholarship	Mr Joshua Murphy The University of Western Australia	Targeting metabolism in mesothelioma: aiming for the Achilles' heel	$3,000		$3,000	Lung; Mesothelioma
Student Vacation Scholarship	Ms Fiona Nugent Harry Perkins Institute of Medical Research	Can genome editing restore the expression of the PTEN tumour suppressor and reduce cell proliferation in triple-negative breast cancer?	$3,000		$3,000	Breast

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Student Vacation Scholarship	Ms Elizabeth Perica Curtin University	Realistic three-dimensional (3D) printed models for pre-operative planning and assessment in hepatocellular carcinoma.	$3,000		$3,000	Liver
Student Vacation Scholarship	Mr Ryan Teh The University of Western Australia	Finding new blood markers for monitoring oral cancers	$3,000		$3,000	Oral
James Crofts Hope Foundation Student Vacation Scholarship	Mr Jack Cooper The University of Western Australia	Establishing a definitive role for a key cancer regulator in neuroblastoma	$3,000		$3,000	Neuro-blastoma
James Crofts Hope Foundation Student Vacation Scholarship	Mr Ivan Lau Curtin University	Diagnostic applications of 3D printing in the assistance of pre-surgical planning of brain tumours in children	$3,000		$3,000	Brain
Travel Grants			$15,000		$15,000	
Awards	Dr Rishi Kotecha Telethon Kids Institute	Early Career Cancer Researcher of the Year	$10,000		$10,000	Leukaemia
Awards	Prof Mariapia Degli-Esposti The University of Western Australia	Cancer Researcher of the Year	$20,000		$20,000	Leukaemia
Awards	Prof Michael Milward The University of Western Australia	Cancer Research Career Achievement Award.	$20,000		$20,000	All cancers
TOTAL RESEARCH FUNDED (New Program)			**$1,492,582**	**$174,998**	**$1,572,580**	

Externally Funded Research Programs

Continuing research grants

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Professorial Chair*	Prof Michael Millward The University of Western Australia	Chair of Clinical Cancer Research	$351,918		$351,918	All Cancers
Research Project Grants	Dr Elin Gray Edith Cowan University	Blood based tests to guide treatment of metastatic melanoma	$99,591		$99,591	Melanoma

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
Research Fellowship	Dr Pilar Blancafort Harry Perkins Institute of Medical Research	Epigenetic tailoring of the cancer genome: novel targeted strategies for the treatment of aggressive breast cancer	$100,000		$100,000	Breast
Research Fellowship	Prof Daniel Galvao Edith Cowan University	Improving health outcomes after cancer through exercise: a survivorship program	$80,000		$80,000	All Cancers
Research Fellowship	Clin/A/Prof Nicholas Gottardo Telethon Kids Insitute	Improving the cure rates for the childhood brain cancer, medulloblastoma	$100,000		$100,000	Brain
Research Fellowship	A/Prof Steven Mutsaers Institute of Respiratory Health	Small non-coding RNAs in malignant mesothelioma	$80,000		$80,000	Lung; Mesothelioma
Research Fellowship	A/Prof Oliver Rackham Harry Perkins Institute of Medical Research	Correcting gene expression in pancreatic cancer	$100,000		$100,000	Pancreatic
Youngberg Women's Cancer Research Fellowship	Dr Vincent Wallace University of Western Australia	Improving breast cancer surgery with a tool that helps the surgeon remove all of the tumour in one go	$107,000		$107,000	Breast
Clinical Research Fellowship	Dr Andy Redfern Fiona Stanley Hospital	Clinical Research Fellowship in Cancer at Royal Perth Hospital	$50,000		$50,000	All Cancers
Postdoctoral Fellowship	Dr Yi Huang The University of Western Australia	To develop blood tests that can predict the risk of primary liver cancer	$52,500		$52,500	Liver
Postdoctoral Fellowship	Dr Rajesh Thomas The University of Western Australia	Improving fluid removal methods to optimise benefits in patients with cancer-related fluid collection in the chest	$16,875		$16,875	Lung; Mesothelioma
Postdoctoral Fellowship	Dr Carolyn McIntyre Edith Cowan University	Exercise as medicine in the management of mesothelioma	$75,000		$75,000	Lung; Mesothelioma
Cancer Epidemiology Initiative	Prof Lin Fritschi Curtin University	CancerCouncil Western Australia Cancer Epidemiology Network (CCEN)	$115,000		$115,000	All Cancers
Strategic Research Partnership (STREP) Grants	A/Prof Gail Garvey Menzies School of Health	To improve cancer control for Indigenous Australians	$100,000		$100,000	All Cancers
Infrastructure Grant	Curtin University	WA Cancer Prevention Research Unit (WACPRU)	$160,000		$160,000	All Cancers

Name of research program	*Recipients*	*Name of research grant*	**Cancer Council charitable funding amount 2017**	**Other funding amount for 2017**	**TOTAL**	**Research focus**
PhD Top Up Scholarship	Ms Meenu Chopra Harry Perkins Institute of Medical Research	Improving tumour detection using multimodality imaging	$12,000		$12,000	Breast; Liver
PhD Top Up Scholarship	Ms Britt Clynick The University of Western Australia	Investigation of carcinomas of unknown primary	$12,000		$12,000	Cancer of Unknown Primary
PhD Top Up Scholarship	Ms Olivia Ruhen The University of Western Australia	A holistic approach to improve breast cancer care	$12,000		$12,000	Breast
Lions Cancer Institute PhD Top Up Scholarship	Ms Tracy Seymour The University of Western Australia	The role of stem cell genes in aggressive human brain tumours	$6,000		$6,000	Brain
*Support for Medical and Scientific Activities			$210,311		$210,311	
TOTAL EXTERNAL RESEARCH FUNDED (Ongoing)			**$1,840,195**	**$0**	**$1,840,195**	
TOTAL EXTERNALLY FUNDED RESEARCH PROGRAMS (Including new and continuing research grants)			**$3,332,777**	**$174,998**	**$3,507,775**	

*Based on financial year to 30 June 2018

Western Australian Cancer Prevention Research Unit (WACPRU), Curtin University

Evolution of Crunch&Sip – focusing on increasing children's vegetable intake

The recent burden of disease analyses released by the Australian Institute of Health and Welfare highlight the importance of diet in the prevention of a range of diseases, especially cancer. Fruit and vegetables are particularly important cancer-preventing foods. Dietary behaviours are established early in life, making childhood nutrition interventions that target fruit and vegetable consumption an important component of health policy and practice.

The Crunch&Sip program has been implemented by Cancer Council WA in Western Australian schools since 2005, and has since been adopted in some other Australian states. The aim of the Crunch&Sip program is to encourage schools to allocate time for the consumption of fruit and vegetables during class time to increase children's intake of these important foods. Over 40% of WA primary schools currently participate in the Crunch&Sip program.

Most primary school-aged children in Western Australia are now consuming appropriate quantities of fruit, but their vegetable intake is still woefully inadequate. To address this problem, the Crunch&Sip program has recently evolved to feature a specific focus on vegetables. Cancer Council WA has conducted a study to assess the receptiveness of school staff and parents to adopting a vegetable focus for Crunch&Sip. The study yielded positive results. For example, 66% of surveyed primary school teachers reported that they would be supportive of converting the Crunch&Sip program to have a primary focus on vegetables. Along with increasing vegetable intake, such a strategy was considered by teachers to be useful in teaching children good eating habits, encouraging them to sample a broader range of vegetables, and minimising the mess associated with eating during class time. The vegetables that were nominated as being most appropriate for consumption during class time were carrots, celery, cucumber and capsicum.

The primary perceived barriers to focusing on vegetables in Crunch&Sip were reported by teachers to be a preference among children for fruit over vegetables and a lack of parental support. Various strategies were reported as having the potential to overcome these barriers, including the availability of engaging classroom resources (e.g. colourful posters depicting vegetables) and information materials to send home to parents.

Cancer Council WA has used these results to pilot a vegetable-focused version of Crunch&Sip in 32 WA schools. The project included curriculum resources focused around vegetables, newsletter inserts, parent letters and vegetable merchandise. The results have been promising, with the number of children bringing at least some vegetables for Crunch&Sip each day doubling over the pilot period. In addition, positive changes were observed in teachers' knowledge and confidence to teach children about vegetables, and in perceived student and parent attitudes towards vegetables. Based on these results, the revised program has been rolled out to all schools in WA.

References

Sharp G, Pettigrew S, Wright S, et al. Potential in-class strategies to increase children's vegetable consumption. Public Health Nutrition 2017;DOI: https://doi.org/10.1017/S136898001700012X

Behavioural Research and Evaluation Unit (BREU), Cancer Council SA

Cancer Screening Checklist trial

The Cancer Screening Checklist is designed to prompt a discussion between general practitioners and their patients about relevant screening programs, which in turn should improve participation in cancer screening preventative programs. Cancer Council SA, in collaboration with the Country SA Primary Health Network, received funding from the Australian Government to develop this resource, which ask patients to identify if they have taken part in screening for breast, ovarian or colon cancer.

As part of the evaluation plan for the trial of the checklist at 10 rural general practices in South Australia, a patient satisfaction survey was developed. The aim was to assess patient satisfaction with the process of receiving the checklist, completing it and discussing the checklist with their GP during their appointment. Checklists and patient satisfaction surveys are distributed within the practices by the reception staff to all patients meeting the eligibility criteria, which includes being over 50 years of age.

Previous research has indicated patients are open to, and expect the opportunistic offering and performance of preventive activities by their GP (Frank, Stock & Aylward, 2011; Grol, 2016). Results from the trial of the checklist and patient satisfaction survey will assist in refining processes for checklist dissemination, and the frequency and duration for checklist usage as part of normal routine for GP clinics in rural areas.

Continuing the evaluation of the ‘Give up smokes for good’ social media campaign

The ‘Give up smokes for good’ campaign is an anti-smoking social marketing campaign developed as part of the Tackling Smoking initiative in South Australia, which is part of SA Health’s commitment under Closing the Gap. The campaign aims to support Aboriginal people to quit smoking and to encourage smoke-free cars and homes. It is based on the powerful images and messages of Aboriginal community ambassadors. Ongoing evaluation with the community for each phase of the campaign has informed its development, including the images and messages to maintain relevance for the Aboriginal community in South Australia. Cancer Council SA is funded to undertake this evaluation by Drug and Alcohol Services South Australia.

The evaluation objectives for 2017 see a return to the use of focus groups to gather qualitative data and will include the following: (i) Identify the preferred campaign materials by comparing current and new creatives; (ii) for each poster, identify to what degree the campaign material is easy to understand and believable, makes the individual think about their own or others smoking behaviours and motivates and empowers the person to take action to quit smoking or talk to someone about quitting; (iii) identify the links to culture; (iv) identify the preferred call to action; and (v) explore community reaction to the images and messages.

The evaluation of this campaign will demonstrate the relevance of newly created social marketing material by comparing it to previous campaigns, aiming to create the most influential and relevant material to achieve the campaign aims. These results will be fed back to the community and the wider health professional community through publication and conference presentation.

Newcastle Cancer Control Collaborative (New-3C), NSW

Haematological cancer patients' perceptions of advance care planning

Background

Advance care planning (ACP) describes the process of discussing or documenting preferences for future medical care. ACP supports doctors and family members to make decisions that are respectful of patients' preferences in situations where patients no longer have capacity to make or communicate their wishes. ACP may improve patient satisfaction with care and reduce stress, anxiety and depression. Assessment of perceptions of ACP among people diagnosed with haematological cancer will inform approaches for improving communication about end of life care for haematological cancer patients, families and clinicians.

Aims

To investigate haematological cancer patients' perceptions of communication about end of life care, including:

- willingness to answer survey questions about ACP
- preferences for timing of ACP discussions
- self-reported completion of ACP elements.

Method

Longitudinal survey study of adult haematological cancer patients. Eligible patients (attending second follow-up appointment after receiving diagnosis; life expectancy of ≥12 months) are provided with a study pack by their haematologist. Study surveys 1 and 2 are mailed or e-mailed to consenting patients at 1- and 12-months post-recruitment, respectively.

Preliminary results (survey 1)

To date, survey 1 has been completed by 48 participants (intended n = 90; consent rate = 26%; response rate = 89%). Mean participant age is 67.8 years (SD=11.0). The majority are males (58%), have completed high school or higher education (96%) and were born in Australia (73%). Ninety-four per cent (n=45) were willing to answer questions about ACP. Forty-four per cent (95% CI: 0.29, 0.60) indicated that they would prefer to begin ACP discussions with their haematologist when diagnosed. The proportion reporting ACP completion was: advance directive (7%); appointment of enduring guardian (27%); discussed preferences for life-prolonging treatments with haematologist (14%) or partner/family (27%); discussed preferences for location of end of life care with doctor (2%) or partner/family (14%).

Conclusion

Despite the potentially confronting nature of ACP discussions for haematological cancer patients, their families and doctors, a substantial minority of haematological cancer patients appear to value having early conversations about preferences and expectations for medical care. Changes in patients' preferences between the 1 and 12 month surveys will be assessed once data becomes available. Low study consent rates present a potential limitation for the generalisability of the findings.

Dissemination

This was one of several studies presented by New-3C at the 13th Behavioural Research in Cancer Control Conference, 3-5 May, Melbourne. Other New-3C presentations included:

- Do people with cancer and their support persons agree on end of life issues?
- Who decides and at what cost? End of life preferences of medical oncology outpatients
- Barriers to the provision of optimal care to patients dying in hospitals: perceptions of nurses
- A discrete choice experiment to assess cancer patients' preferences for when and how to make treatment decisions
- What models of peer support are most appealing to cancer patients? A cross-sectional survey
- A consumer action model to improve delivery of patient centred care: Challenges and successes.

Centre for Behavioural Research in Cancer (CBRC), Victoria

Which emotions evoked by anti-smoking advertising help increase recall and quit attempts?

While there is strong evidence that anti-smoking advertising that generates high levels of negative emotion is better recalled and motivates quitting, the effectiveness of campaigns that evoke positive emotions is less clear. Funded by an NHMRC/VicHealth Partnership Grant, A/Prof Sarah Durkin and colleagues investigated the types and combinations of emotions evoked by anti-smoking advertising that were most likely to increase spontaneous recall and quit attempts. Data were from repeated cross-sectional surveys of Victorian smokers and recent quitters exposed to a wide range of tobacco control campaigns at varying intensities from 2012 to 2015. Emotion responses from these surveys and from independent ad rating studies enabled categorisation of ads into different emotion types, which were then linked with advertising exposure data (gross ratings points). Those exposed to greater levels of high fear or high sadness advertisements in the past three months were more likely to spontaneously recall these adverts, whereas those exposed to high positive emotion adverts were less likely to do so. In contrast, those exposed to greater levels of high fear and/or high positive emotion adverts, but not high sadness adverts, were more likely to report having made a quit attempt and sustaining that attempt within the past three months. Findings suggest that adverts that evoke high negative emotions are likely to cut through other advertising and be recalled easily, unlike positive emotion adverts. Airing high fear and high positive emotion adverts together may be particularly efficient and effective at prompting serious quit attempts.

Evaluation of the Victorian LiveLighter 'Sugary Drink' campaign

The LiveLighter 'Sugary Drink' campaign was originally produced in Western Australia and launched in Victoria in October, 2015. Targeting adults aged 25-49 years, the campaign graphically depicts visceral fat around vital organs and focuses on the contribution of sugary drink consumption to the development of toxic fat and ultimately disease (https://www.youtube.com/watch?v=QGSTfRUEnDY). The evaluation of the campaign, led by Dr Belinda Morley, aimed to assess its impact on Victorian adults' awareness, knowledge and sugary drink consumption. Using a pre-post cohort design, population surveys (N=900) were undertaken in the campaign (Victoria) and comparison state (South Australia), with 78% successfully followed-up after the campaign (Victoria: N=673; South Australia: N=730). Almost half (48%) of Victorian adults indicated they were aware of the campaign. A significant reduction in frequent sugary drink consumption (four+ cups/week) was observed in Victoria (31% cf. 22%) compared to South Australia (30% cf. 29%). This was accompanied by a non-significant trend towards increased water consumption (four+ cups/day) among overweight/obese sugary drink consumers in Victoria (66% cf. 73%) compared to South Australia (68% cf. 67%). These findings provide compelling evidence that the LiveLighter campaign reduced sugary drink consumption among Victorian adults. This outcome is notable in a context where public health campaigns are competing with high levels of sugary drink product advertising. With continued investment, LiveLighter should help sustain and enhance improvements in behavior, which could ultimately contribute to reducing obesity-related chronic disease over the longer term.

Cancer Council Australia

Cancer Council Australia's key public policy priorities over the past three months include increasing participation rates in Australia's National Bowel Screening Program, along with a range of other public health, clinical and supportive care issues.

A highlight of Cancer Council's guidelines work (see below) over the period was its submission to the National Health and Medical Research Council (NHMRC) of new draft guidelines for the prevention, early detection and management of colorectal cancer. The project involved a systematic review, which included 77,596 published papers across all clinical questions. Notably, draft recommendations in the population screening chapter included promoting increased participation in the current age cohort (50-74) as the most cost-effective way to increase program benefits compared with extending the age range at either end.

In clinical and supportive care policy, and of particular relevance to this edition of *Cancer Forum*, Cancer Council is increasingly focused on the relationship between out-of-pocket patient costs, psychosocial distress, variations in clinical outcomes and overall inequity. Cancer Council is undertaking a survey of health professionals as part of a scoping exercise to better understand how financial distress impacts on clinical and consumer decisions and observed levels of distress in patients.

Cancer Council is also promoting greater prioritisation of health systems research, including in relation to current policy activity, such as the Senate inquiry into research for poor-survival cancers and the NHMRC reform agenda. In February, Cancer Council established a new principal Health Services Advisory Committee to provide independent advice on these and other clinical policy matters.

Since the last issue of *Cancer Forum*, Cancer Council has responded to the following consultations, including jointly with the Clinical Oncology Society of Australia on clinical matters:

- Australian Government Department of the Environment and Energy Ministerial Forum on Vehicle Emissions - Discussion Paper 'Better fuel for cleaner air', March 2017
- Commonwealth Department of Health consultation on the draft National Health Genomics Framework, March 2017
- Senate Select Committee inquiry into funding for research into cancers with low survival rates, March 2017
- Therapeutic Goods Administration consultation on proposed process and post-market requirements for provisional approval pathway for prescription medicines, May 2017
- Australian Government Department of the Health - Social and Cultural Determinants of Indigenous Health Consultation, May 2017.

For further information, contact Head of Public Policy, Paul Grogan, on paul.grogan@cancer.org.au

Clinical Guidelines Network

Cancer Council aims to produce concise, clinically relevant and up-to-date electronic clinical practice guidelines for health professionals, accessible on its wiki platform at wiki.cancer.org.au.
For more information, or to be added to the mailing list for notification of guidelines open for public consultation or guidelines launches, please email guidelines@cancer.org.au.

Cancer Council Australia guidelines

Guidelines in development

Guideline	Status
Clinical practice guidelines for the prevention, diagnosis and management of lung cancer	Public consultation for second set of prevention and diagnosis draft content is open from 3 July to 30 July 2017. The third set of systematic reviews and draft content development is in progress.
Clinical practice guidelines for the diagnosis and management of melanoma	Public consultation for second set of draft content was held Jan/Feb and content is being finalised. Email guidelines@cancer.org.au to be notified when the final content is published. Further systematic reviews are in progress and the third set of draft content will be made available later this year.
Clinical practice guidelines for the prevention, early detection and management of colorectal cancer	The guidelines were open for public consultation from 10 March to 8 April 2017. Feedback from the public and NHMRC has been considered and the guidelines will be tabled for principal NHMRC committee comment/approval in mid-July.
Clinical practice guidelines for surveillance colonoscopy	Guidelines revision commissioned by Department of Health and systematic review updates are underway.
Basal cell carcinoma, squamous cell carcinoma (and related lesions) – a guide to clinical management in Australia	Guidelines revision commissioned by Department of Health.

Published guidelines

Guideline	Last updated
National Cervical Screening Program: Guidelines for the management of screen detected abnormalities, screening in specific populations and investigation of abnormal vaginal bleeding	Launched in March to prepare for the transition to the renewed National Cervical Screening Program in December 2017.
Clinical practice guidelines for PSA testing and management of test-detected prostate cancer	August 2015
Clinical practice guidelines for the diagnosis and management of Barrett's oesophagus and early oesophageal adenocarcinoma	September 2014
Clinical practice guidelines for the treatment of lung cancer	December 2012 (update in progress)

Management of apparent early stage endometrial cancer	March 2012
Clinical practice guidelines for surveillance colonoscopy	December 2011 (update in progress)
Clinical practice guidelines for the management of adult onset sarcoma	February 2015
Clinical practice guidelines for the management of locally advanced and metastatic prostate cancer	April 2010

Clinical Oncology Society of Australia guidelines

Guidelines in development

Guideline	Status
Guidelines for the safe prescribing, dispensing and administration of systemic cancer therapy	Public consultation was held 29 May to 23 June and content is being finalised.

Published guidelines

Guideline	Last updated
Clinical practice guidelines for tele-oncology	December 2015
Diagnosis and management of gastroenteropancreatic neuroendocrine tumours guidance	August 2012
Evidence-based practice guidelines for the nutritional management of adult patients with head and neck cancer	August 2013
Early detection of cancer in AYAs	May 2012
AYA cancer fertility preservation	September 2012
Psychosocial management of AYA cancer patients	June 2012

Other guidelines

Guideline	Last updated
Cancer pain management	August 2013

Clinical Oncology Society of Australia

COSA Annual Scientific Meeting (ASM)

The 2017 COSA ASM will be held at the new International Convention Centre Sydney. We have changed our schedule slightly and will run from Monday 13 to Wednesday 15 November, with pre-conference workshops on Sunday 12 November. The program for COSA's 44th ASM will focus on immunotherapy, with a subtheme of implementing quality and safety in cancer care.

Invited international speakers confirmed to date:

- Dr Matthew Hellmann – medical oncologist from Memorial Sloan Kettering (MSK) in the US. Dr Hellmann specialises in the care of patients with lung cancers. He is a member of MSK's Immunotherapeutics Group, where they design and lead early-phase clinical trials of immunotherapies for patients with a variety of cancers.

- Dr Monika Krzyzanowska – medical oncologist and health services researcher at the Princess Margaret Cancer Centre in Toronto, Canada. Dr Krzyzanowska's research focuses on the science and practice of healthcare quality as it relates to the delivery of cancer care. She is the Chair Elect of the ASCO Quality Care Symposium.

- Dr Anja Mehnert – psychologist at the University Medical Centre Leipzig in Germany. Dr Mehnert's main research focus includes the prevalence of mental disorders in cancer patients and the impact of cancer and treatment-related factors. She also has extensive expertise in investigating issues of employment and work in cancer survivorship, as well as distress and demoralisation in patients with advanced disease and palliative care.

- Dr Dana Rollison – Vice President and Chief Data Officer at Moffitt Cancer Centre in Florida, US. Her work bridges analytics strategies across research, clinical and operations. Dr Rollison's primary research focuses on the potential role of viral infections in cancer etiology and the epidemiology of myelodysplastic syndromes.

- Prof Mary Wells – Professor of Cancer Nursing Research and Practice at the Nursing, Midwifery and Allied Health Professions Research Unit, University of Stirling, Scotland UK. Professor Wells is a cancer nurse with a clinical academic background in health services research within oncology.

These international experts will be joined by an esteemed Australian faculty, including Jonathan Cebon, Jon Emery, Georgina Long, Alex Menzies, Richard Scolyer, Mark Shackleton, Shankar Siva, and Christopher Steer to name a few. Full details of speakers, the program, abstract submission and registration information is available on the conference website www.cosa2017.org.

Working with Cancer Council Australia

In COSA's role as medical and scientific advisors to Cancer Council Australia, we often collaborate on submissions to government and have submitted the following joint submissions:

- National Digital Health Strategy Consultation (January 2017)
- NSW Health Consultation on Statewide Biobanking Consent (February 2017)
- Response to the National Health Genomics Policy Framework 2017-2020 (March 2017)
- Senate inquiry into funding for research into cancers with low survival rates (March 2017)
- Provisional approval pathway for prescription medicines: Proposed process and post-market requirements (May 2017)

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

Marie Malica
Executive Officer, COSA

Medical Oncology Group of Australia

The Medical Oncology Group of Australia (MOGA), the professional organisation for medical oncologists and the profession, plays a leading role in the national oncology sector. Recently, MOGA gave evidence to the Public Hearing of the Senate Select Committee into Funding for Research into Cancers with Low Survival Rates and contributed a major submission to facilitate national discussion around this issue.

Education in medical oncology

MOGA works closely with the Royal Australasian College of Physicians on education for medical oncology trainees and professional development for consultants. Dr Rachel Wong, Deputy Director of Oncology, Eastern Health, is Project Lead for a new educational initiative, ASCO Education Essentials, that is being piloted in 2017. This self-directed learning program for trainees provides access to a range of valuable resources including over 100 e-learning courses.

A new 1.5 day professional development program for young medical oncologists presented in late April provided a unique opportunity to build professional skills in assertiveness and interview communications, as well as all how to be a clinical trials principal investigator. The program was designed in collaboration with human resource management experts and some of the major Australian clinical trials groups.

Plans for MOGA's Annual Scientific Meeting, Real World Oncology: Translating Discovery in to Practice, to be held in Melbourne from 2-4 August, are proceeding well under the leadership of Convenor, A/Prof Linda Mileshkin. The program explores many contemporary challenges and advances in research and clinical practice, with a strong focus on breast, colorectal, geriatric oncology, supportive care and genomics. Five international speakers have been secured for the meeting, including Prof Fatima Cardoso, Prof Hyman Muss, Prof Sebastian Stintzing and Prof Matthew Ellis. We will also be joined by Dr Christopher Jackson, Medical Director, Cancer Society of New Zealand and PIPER project (colorectal cancer) clinical lead.

Our members, our workforce

In 2017, MOGA membership has grown to 660. As a medical speciality with a growing and evolving membership, the importance of workforce planning and development is paramount. Our leadership role in this area has attracted strong international interest and Dr Zarnie Lwin will be presenting on the 2016 Workforce Study to the Japanese Society for Medical Oncology in July.

Research and advocacy

MOGA takes a leading role in research and advocacy, focused on oncology drugs, treatments and patient care. We recently developed new position statements on biosimilars and genomics. We are also developing some practical guidelines on chemotherapy dosing and contributed to a submission on the National Digital Health Strategy.

The Association has also supported a submission on Somatic Tumour Gene Panel for Determination of Therapy, including the creation of a new MBS item number. There is a proven clinical utility to predictive gene mutation evaluation and a panel assessment is clearly the most efficient application. This implementation would facilitate BRAF V600 and RAS mutation testing in colorectal cancer, and EGFR and ALK gene rearrangement status testing in lung adenocarcinoma.

Associate Professor Chris Karapetis
Chair, Medical Oncology Group of Australia

Faculty of Radiation Oncology

Funding of radiation therapy

The Faculty welcomes the Government's announcement of the first proton therapy centre expected to be operational in South Australia by 2020. Proton therapy is a form of highly targeted external beam radiation that uses heavier particles instead of X-rays or electrons. It is particularly beneficial to paediatric patients, and adult patients with tumours in certain areas like the skull base or spine.

The Faculty's Particle Therapy Special Interest Group will support this facility to have a national focus. We also trust there will be government support, not only make treatment accessible to all Australians for whom it is indicated, as well enable the necessary research in this area.

Unfortunately, this announcement is in stark contrast to nationwide cuts in the Radiation Oncology Health Program Grants scheme to standard radiation therapy services that will impact on tens of thousands of cancer patients. The scheme is a Commonwealth initiative that provides capital funding for radiation oncology services outside of Medicare.

The effects of these cuts on the sector and on patient care are likely to be catastrophic in the long term. The Faculty has done a significant amount of advocacy work against the proposed changes in recent months, including several conversations with the Minister for Health and with the Department. We have also indicated our willingness to develop alternative proposals for saving that the sector would be more able to absorb without adverse effects on patient access to quality radiation therapy.

We encourage all our stakeholders to support us in our advocacy efforts against these changes. If you need any further information, or have any suggestions, please write to faculty@ranzcr.edu.au.

Radiation therapy for prostate cancer

The Radiation Oncology: Targeting Cancer campaign aims to increase awareness of radiation therapy as an effective, safe and sophisticated treatment for cancer, among cancer patients and their families, as well as health professionals, in particular GPs.

Targeting Cancer is currently focusing on advocacy in the prostate cancer setting, and our message is that before any man undergoes definitive therapy for localised (including locally advanced) prostate cancer, he should consult with a radiation oncologist about his radiation therapy treatment options.

The Faculty recently hosted a 'Design and Discovery' workshop, with radiation oncologists, GPs, consumers and other stakeholders, to formulate a strategy and develop a practical work plan for how to influence policy relating to prostate cancer referrals.

Engaging radiation oncology professional groups, government, consumer organisations and other key stakeholders is crucial to our success in advocacy. We have strong support from consumer organisations and key allies. Ms Lee Hunt, consumer member on the Faculty Council and a Cancer Voices executive member, has distributed information on prostate cancer treatment options to over 160 Prostate Cancer Support groups around Australia, receiving very positive responses and support.

Cancer Council Australia, the Prostate Cancer Foundation Australia and NSW Cancer Institute have developed a Prostate Cancer Treatment Options flyer which emphasises the importance of men seeing a radiation oncologist and being fully informed before they make treatment decisions.

Prof Ian Gardner, Principal Medical Adviser from Department of Veterans' Affairs has written an article to encourage their members to get full advice before having prostate cancer surgery.

Please like Targeting Cancer on Facebook, or follow @targetingcancer on Twitter, and help us promote radiation therapy as a safe and cost-effective cancer treatment option.

Dr Dion Forstner
Dean, Faculty of Radiation Oncology