Counting the cost:

The true value of investing in cancer treatment

Contents

FOREWORD BY

Rare Cancers Australia and Canteen

We unfortunately hear too many stories of people living with cancer, young and old, who have exhausted the Pharmaceutical Benefits Scheme funded standard of care and are faced with trying to find and fund other ways to stay alive. For some it's accessing clinical trials, but the selection criteria are heartbreakingly tight. For others it's begging pharmaceutical companies for compassionate access to treatments they cannot otherwise afford. And for many, it's dipping into superannuation and other assets, or crowdfunding, to pay $10,000 or more a month to potentially extend their lives.

One of those stories is a man in his 50s, Jerry, who was suffering from bladder cancer. He had paid for two rounds of therapy at $10,000 each and decided to cease the treatment as he was not prepared to leave his wife and children penniless in an attempt to extend his life. He died a few months later.

Another story is Sean's, who was 12 when his mum was diagnosed with cancer. She died four years later. As the eldest child, Sean became responsible for his two younger siblings as they moved from one foster care family to another. Trying to cope with his grief alongside his responsibilities took a significant toll on Sean's mental health. More than 13 years later, Sean's life is still shaped by his mum's death.

Rare Cancers Australia has supported thousands of people with rare and less common cancer and their families over the past 10 years, all of whom have similar stories to tell. **Canteen** has been helping children pick up the pieces after the death of a parent to cancer over the past two decades.

Listening to every one of their experiences – while helping find suitable clinical trials, crowdfunding to help pay for medicines and other unavoidable expenses and supporting them to negotiate for compassionate access – we know we need to do more. Not just for the people who have been diagnosed, but for their families too, because the costs of cancer are not just financial.

Losing a parent before their time devastates families; the disruption and trauma to children is severe and long-lasting, and the societal implications can last for generations. Extending a parent's life brings so many benefits to their family and society in general; it ought to be a no-brainer for any society, but it's not. We simply watch them go. But it doesn't have to be this way. We need to value the benefits of extending a parent's life in a measurable and meaningful way, because it goes far beyond simple economics.

As CEOs of cancer charities we are confronted with these challenges every day. It is heart breaking to watch people confront end of life decisions in the certain knowledge that the treatments they need already exist, but our health system simply has too many barriers to be able to access them. Our inaction on life-extending or lifesaving treatments has consequences on so many levels – the lives of our children and parents are too precious for us not to act. As you read this report, please spare a thought for all those children growing up without a mum or a dad, and then think about how we can – and must – do better.

Thank you.

Richard Vines
Rare Cancers Australia CEO

Peter Orchard
Canteen Australia CEO

About HTANALYSTS

HTANALYSTS has been providing boutique impact measurement and communication services for 20 years. We exist to make a powerful impact on society by driving human-centric outcomes.

> Our purpose is to have a powerful impact on the health of society by connecting people with the best treatments in the fastest amount of time.

Originally founded in 2002, our organisation has grown to become a leader in healthcare and impact assessment consulting, providing services to the healthcare industry. In recent years, our scientific rigour has proven valuable for those outside the traditional pharmaceutical world, and this has seen us grow our capabilities to include expertise in social impact measurement, government services, health ageing and disability.

This report is the culmination of several months of work to understand the impact of a non-curative cancer diagnosis on individuals and their families, and the economic and societal benefits of preventing death. In preparing this report we heard from many people who have experienced non-curative cancer from a variety of perspectives. In the following pages we have synthesised those experiences to tell the story of how cancer radically changes lives and the value of surviving non-curative cancers using the Social Return on Investment (SROI) methodology.

We thank all those who generously contributed their time to help us develop this report, including the people living with cancer, their partners, children, and physicians. We also want to acknowledge all those who have lost a loved one to cancer. We hope we did your experience justice and that this report provides useful insights that will help RCA and Canteen to support all people impacted by cancer.

Acknowledgements

We would like to thank all those who generously contributed their time to help us develop this report, including the people living with cancer, their partners, children, and physicians who spoke about their very personal experiences with **HT**ANALYSTS and assisted in shaping this report.

We are extremely grateful to **HT**ANALYSTS for all their work on developing the social return on investment analysis for this report. We hope the findings will provide a launch pad for changing the way we value the lives of people diagnosed with cancer and the treatments we provide in Australia.

Our thanks also go to Toni Middendorf for the design of the report.

Sponsors

RCA would also like to thank the following for their financial support, which is given without pre-condition or editorial input, for both the 'Counting the cost' report and CanForum 2022, where the report is being launched:

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Glossary

BRCA	Breast cancer gene
CA	Canteen Australia
HTA	Health Technology Assessment
MA	Medicines Australia
MPNST	Malignant Peripheral Nerve Sheath Tumour
NSW	New South Wales
PBAC	Pharmaceutical Benefits Advisory Committee
PBS	Pharmaceutical Benefits Scheme
RCA	Rare Cancers Australia
SROI	Social return on investment
TGA	Therapeutic Goods Administration

Executive Summary

The impact of cancer on Australian families

A cancer diagnosis is a life-changing event for families. In Australia, cancer causes the greatest burden compared with all other major disease groups, with an estimated 151,000 new cancer cases diagnosed in 2021 (1, 2). People dying prematurely is responsible for a large proportion of the overall disease burden and, with 49,000 Australians dying last year (3), cancer continues to have a profound impact on families and across society (2, 4).

The untimely death of a parent, child or sibling devastates families. It leaves an indelible mark on young people, and radically changes their lives (5). Yet, many people with cancer have a high chance of survival if diagnosed efficiently and treated effectively. Emerging cancer treatments can be expensive, particularly when compared to other cancer therapies such as older style, cytotoxic chemotherapy. But the additional cost can be balanced against the immense physical, psychological, social, and economic impacts for people with cancer, their families, and society when a person can successfully treat their cancer (6). This is particularly true when the person with cancer is the parent of young children.

Attributing value to the social benefits of cancer treatment

Rare Cancers Australia (RCA) and Canteen Australia (CA) support Australians whose lives have been forever altered by cancer. As part of that effort, we commissioned **HT**ANALYSTS to determine the broader value of improving survival and quality of life for people living with non-curative cancer, as well as the burden caused by the death of a loved one to cancer.

The analysis aims to understand the social return on investment (SROI) achieved through government funding cancer treatments that prolong survival and improve the quality of life for people with non-curative cancer who have dependent children.

SROI is a process for understanding, measuring, and reporting the broader social, economic, and environmental value created by cancer treatment. Essentially, this analysis captures the dramatic impacts of losing a loved one to cancer and the value of investing in technologies, treatments, or programs that prevent the disruption caused by premature death. While such analysis generates a monetary figure, so that comparison of value can be made within existing health technology assessment (HTA) frameworks, we must recognise that ultimately, we are talking about real people, and the benefit to them and their families of prolonging their survival and improving their quality of life. These social benefits may not be traditional metrics to assess the value of an investment – such as the ability for parents to care for children, to be present at life milestones, to provide stable family and social relationships, and the avoided mental health impacts in the short and longer-term for children – but are priceless in terms of the life-long wellbeing of families.

To put a price on the value created, **HT**ANALYSTS talked to people who have experienced non-curative cancer from a range of different perspectives. **HT**ANALYSTS fused these experiences with scientific evidence and economics to model **an ideal world where all people with a non-curative cancer diagnosis have funded access to an effective treatment that will prolong their survival and quality of life beyond five years. This analysis focuses on people diagnosed with cancer who are also parents of children and young adults under the age of 25, over a five-year period.** To capture this value, the societal impacts on people with cancer, partners, children, family members, close friends, employers, and the Australian Government have been evaluated.

The findings of our social return on investment analysis

The analysis conducted for this report evaluated the societal impact of improving the prognosis of a non-curative cancer diagnosis and found that for every $1 invested in cancer treatments, there is $3.06 of social and economic value created.

SROI ratio

1 : 3.06

The analysis also found that, over the course of five years, investment in new technologies, therapies, and services to extend the prognosis and quality of life of people with non-curative cancer can return $3.17 billion of social value.

$1.04 billion TOTAL INVESTMENT OVER 5 YEARS[1]	
$75,000	annual cost per parent
3,192	parents with cancer treated

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$3.17 billion TOTAL BENEFIT OVER 5 YEARS[1]	
$993,000	total benefit per parent
48,743	people/organisations impacted

[1] The value of benefits incurred in the future are discounted to reflect their present value using an annual rate of 5%, as recommended by PBAC. These values are summed to give net present value of total benefits over 5 years.

Examples such as higher work productivity, higher employee retention, avoided need for income support services and other avoided public costs are crucial to the functioning and sustainability of societies and economies. While benefits such as the ability for parents to care for children, to be present at life milestones, to provide stable family and social relationships, and the prevention of mental health problems in the short and longer-term for children are so important to the life-long wellbeing of families.

The SROI analysis presented in this report demonstrates the scale of the many social benefits from funding life extending medicines for people with non-curative cancer and puts a monetary value on the benefits that flow to families, friends, communities, and governments. Ultimately demonstrating that, although investing in new therapies can have a high upfront cost, there are substantial downstream social and economic benefits in treating people with the best available technologies.

Ensuring social value is incorporated in health technology assessments

Despite the priceless benefits of increasing survival and improving quality of life for people with non-curative cancer diagnoses, we are still failing to recognise this value when considering the cost-effectiveness of new medicines for listing on the Pharmaceutical Benefits Scheme (PBS). When the Pharmaceutical Benefits Advisory Committee (PBAC) determines a drug to not be cost-effective for a particular type of cancer, people die and families are torn apart – unless they can raise the many thousands of dollars required to self-fund their treatment each month. Yet, in many cases, the impact of those treatments on their lives, and the benefits for their families, are considerable and long-lasting, particularly for children.

In other words, the price of not improving the quality of life and prolonging the survival of people diagnosed with cancer costs more than the financial investment in the treatment intervention. Whether we recognise that, and how we assess the cost-effectiveness of that treatment in the future, through our HTA processes, speaks volumes about the value we place on a person's life and the impact of spending more time with their families.

The timely review of our HTA system as a part of the Strategic Agreement 2022 - 2027 between the Australian Government and Medicines Australia, offers a unique opportunity to ensure that the value cancer treatments deliver to people diagnosed with cancer, and beyond, is incorporated in future PBAC decision-making.

We need to shift our collective thinking from the cost of treatments and assess their value and impact.

If we are to overcome the challenges of the HTA system in Australia not being sufficiently person-centred we can, and should, take the opportunity presented by the HTA review and make the changes needed to put people with cancer (and other diseases) in the centre of the process permanently. We must listen to people living with cancer, and their families, in our assessments and understand what they value most with regards to their treatments. It is ultimately through greater engagement that we can change the way our health system values people's lives and more accurately ascertain the real-world value of cancer treatments.

We must now put the needs of people living with cancer at the centre of the discussion of value and adapt how we assess the cost of medicines. We must do this by prioritising people, and what matters most to them; by capturing the social value delivered by their treatments. Otherwise, we must resign ourselves to counting the significant costs of failing to treat people living with cancer and accept responsibility for the devastating consequences.

Introduction

A cancer diagnosis is always a life-changing event; it has a profound impact on the person receiving the diagnosis, their family, friends and colleagues, and has far reaching consequences across communities from a physical, emotional, and economic perspective. Cancer remains one of Australia's toughest health challenges and, with an estimated 151,000 new cancer cases diagnosed annually (1, 2), almost every Australian will be impacted by cancer at some stage in their life, whether it be through their own experience, or that of a close family member or friend (2). Currently, there are one million Australians living with, or who have previously had, a cancer diagnosis, and this number continues to increase (7, 9).

Cancer remains among the leading causes of death in Australia with 49,000 deaths in 2021 – one every 11 minutes – and is responsible for one in three deaths in Australia (3). The untimely death of a parent, child or sibling devastates families. It leaves an indelible mark on young people, and radically changes their lives (5). Children are commonly the most heavily impacted by a diagnosis of cancer in the family (10, 11), with evidence demonstrating that young people dealing with a parent's cancer diagnosis are three to six times more likely to experience high, or very high, levels of psychological distress than their peers (5). The death of a child from cancer also has catastrophic impacts on loved ones, placing bereaved parents and siblings at risk for both physical and psychosocial morbidities (12, 13).

However, many people have a high chance of improving quality of life and prognosis if their cancer is diagnosed and treated efficiently and with targeted treatment options. The mortality rate for all cancers combined is decreasing, and the overall five-year cancer survival rate has increased from 51% in 1998-1992 to 70% in 2013-2017 (7). A significant proportion of cancer burden can be reduced through earlier detection, improving access to effective cancer treatments, and addressing health disparities that stem from socio-economic, geographic, and other sources of disadvantage (2, 5).

Over the last 20 years many significant advances in cancer treatment and care have occurred, including through early detection, genomic technology, and immunotherapies. Investments in cancer research and the subsequent improvements in diagnosis and treatment have contributed to improving the quality of life and prognosis for many people with cancer (14). Nonetheless, not all therapeutic advances make it into their hands and therefore people are still dying prematurely, causing massive disruption to their immediate families.

Barriers to receiving effective cancer therapy in Australia

Despite the rapid emergence of transformative cancer treatments, the timeframe to get these treatments to people with cancer is lengthening. This is of particular concern for people with advanced disease, who may only have a short time to live. In Australia, as with many other countries around the world, we use HTA to inform our decisions about which health technologies can be sold in Australia, and which ones qualify for subsidies from the Australian Government (15). HTA is a multidisciplinary decision-making framework with several advisory and regulatory bodies conducting HTAs in Australia. The Therapeutic Goods Administration (TGA) assesses the safety, quality and efficacy of new health technologies; while three principal health technology advisory committees assess whether health technologies qualify for subsidies – the Medical Services Advisory Committee, the Prostheses List Advisory Committee and the PBAC. For clarity, when discussing HTA, this report is only referring to the processes of the PBAC as this is the committee that assesses medicines for listing on the Pharmaceutical Benefits Scheme (PBS) based on their cost-effectiveness.

HTA provides a pathway to achieving subsidised access to a new medical technology but are a time-consuming and complex process. For pharmaceuticals, the time between submission to the TGA for regulatory approval, which makes a drug available to people in Australia, and PBS listing, which makes it subsidised by the public healthcare system, is at least 14 months; and some medicines may take several attempts to achieve a successful listing (16). At times, medicines that received a positive recommendation from the PBAC are still not freely available for people with cancer because of unsuccessful negotiations between pharmaceutical companies and government in reaching a mutually agreeable price.

Recent research advances in areas such as genomics has led to new innovative treatments which are increasingly complicated to evaluate and fund. This includes radiopharmaceuticals that deliver radiation therapy directly and specifically to cancer cells, new service models like healthcare in the home and the introduction of immunotherapy, which harnesses the body’s immune system to fight cancer. In particular, cell and gene therapies, such as CAR-T (which uses genetically engineered T-cells to recognise and kill cancer cells), have been recently introduced into the Australian market, but the time to achieving subsidised access has been drawn out (17).

There are a growing number of people in Australia unable to access innovative cancer technologies, therapies and services compared with abroad. Australia is one of the five worst countries in terms of ‘indication coverage’ for cancer medicines – intended as the number of indications covered by the public healthcare system – that do achieve subsidised access (18). There are also proven health promotion and prevention programs that sit unfunded, particularly for rare cancers, where there are large funding disparities (19).

In addition, rare cancers are often complicated by a late diagnosis – or misdiagnosis – making the cancer more difficult to treat (20). People diagnosed with rare and less common cancers[1] frequently experience more challenges throughout a cancer journey, and so do their families (21, 22). Depending on the type of cancer, access to clinical trials and research programs – which at times can represent the only treatment option – can be limited, as rare cancers attract less funding due to the relatively fewer people diagnosed (20, 23). Despite these challenges, investments in cancer research are contributing to the development of treatments, which harness the power of genome sequencing and genetic testing to facilitate earlier detection and create individualised treatments (20). Developments in cancer screening programs and treatments are important contributors to cancer survival rates and require continual investment by government and associated organisations (24).

While emerging cancer treatments can be expensive, particularly when compared to other cancer therapies such as older style, cytotoxic chemotherapy, the additional cost can be balanced against the immense physical, psychological, social, and economic impacts for people diagnosed with cancer, their families, and the broader society when a person can effectively treat their cancer (6). This is particularly true when the person with cancer has young children.

Despite the significant advances in cancer care in the past few decades, the benefits of these advances remain unavailable to most people and their families. Until our funding mechanisms evolve to assess the broader benefits of these emerging treatments and we value the positive impact they can have more broadly, the access barriers faced by people with cancer will continue and worsen (18).

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[1] In Australia, a rare cancer is defined as one which has fewer than 6 diagnoses per 100,000 of the population and a less common cancer is one which has fewer than 12 diagnoses per 100,000 of the population.

Rationale for the study

> Even though cancer survival rates in Australia are among the highest in the world, there are still a range of barriers limiting people from accessing potentially lifesaving and life-extending cancer technologies, treatments, and services.

These can be summarised as:

1. Increased timeframe required to achieve subsidised access to new medications.
2. Increased complexity in the process of evaluating novel technologies.
3. Unsuccessful price negotiations between pharmaceutical companies and government leading to further delays in access despite positive recommendations from the PBAC.
4. Proven health promotion and prevention programs that sit unfunded.
5. Limited access to clinical trials and research programs for some rare cancers.

In many cases these barriers are caused by delays in making solutions available and funded by the public health system, and this is often due to difficulties in justifying the additional cost, particularly when there are cheaper, widely used alternatives such as cytotoxic chemotherapy and palliative measures (21).

To justify the additional cost of technologies, treatments, and services, there has recently been a call for a fundamental shift in the assessment process to capture the entirety of benefits including the social, clinical, and economic impacts along with the wellbeing of people with cancer, their family and close friends. This report will address the barriers summarised above by **providing an evidence-based assessment of the value created by additional investment in cancer care, and the impetus for providing timely access to treatment options that improve quality of life and prolong survival for people with non-curative cancer**.

SROI is a robust method to capture these broader impacts, relying heavily on the input of key stakeholders to identify and understand each impact's importance and duration, and if any were attributed to external factors.

This project evaluates the societal impact of extending and improving the prognosis of a non-curative cancer diagnosis, including the impact on people with cancer, their partners, children, family members, close friends, employers, oncology health care professionals, hospitals, and government. The analysis offers a greater insight into the real value of cancer treatments and the difference they can really make not only for people living with cancer, but also for their partners and children. While SROI analyses generate a monetary figure so that comparison of value can be made within existing HTA frameworks, we must recognise that ultimately, we are talking about real people and the value to them and their families of surviving cancer. Those benefits are priceless.

A framework for social return on investment analysis

This report is a forecast SROI analysis, aimed at predicting the societal impacts that could result if we improved the quality of life and prolonged survival of people with non-curative cancer who are parents of a child or children <25, over a five-year period. This period was chosen for the following reasons:

- Five-year survival rate is commonly used to estimate the prognosis of a person diagnosed with cancer; and
- A five-year period limits the uncertainty associated with long-term outcomes.

It should be noted that this study is based on an ideal scenario where all people with non-curative cancer can be treated effectively to improve quality of life and prolong survival beyond five years. While limiting the analysis to five years is likely to capture many of short-term impacts such as being present for children's milestones, financial struggles and need for support services, it may exclude long-term benefits such as being present for weddings or the birth of grandchildren.

The SROI methodology is based on identifying key outcomes of an activity relying on the direct reporting of the experience from the key stakeholders. Stakeholder engagement is key to avoid self-referential thinking, and incorrect assessment of impact due to not having lived the experience in the first-person. The SROI framework delivers both a qualitative and quantitative evaluation of the outcomes of, in the case of this analysis, investing in life-extending cancer treatments. The relationship between inputs, outputs and outcomes is called the "theory of change". The theory of change is a way to explain how impact is created from the perspective of the people affected.

While the investment required to improve access to life-extending treatments has a clearly identifiable market price, the financial valuation of some of the outcomes can represent a challenge. The framework estimates the social value of investing in effective cancer treatments by assigning a financial proxy to each outcome for each stakeholder. The framework also considers adjustments to the social value that are made based on estimations of deadweight (what would have occurred anyway), displacement (what activities were displaced by the intervention), attribution (what other organisations contributed to the outcomes) and drop off (whether the outcomes experienced decline over time).

This process generates a story that fuses evidence, economics and real-world experience, to assess how cancer affects people, families, and the broader society. These steps allow for an annual assessment of the impact of investing in life-extending cancer treatments over a five-year time horizon[1]. Comparing the value of the investment with the value of the economic and social value created, allows an SROI ratio to be estimated. This ratio shows the social value generated by each dollar invested.

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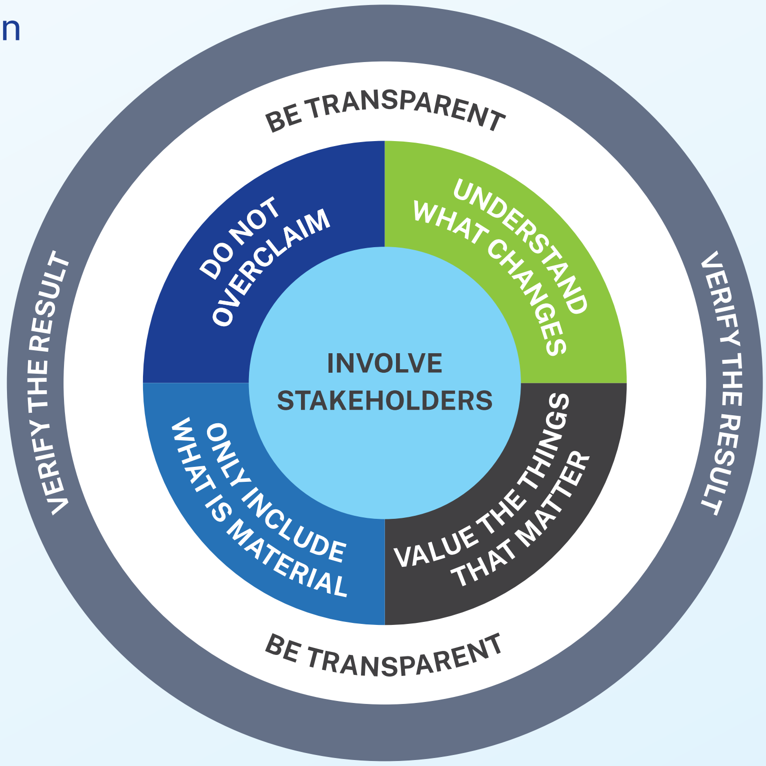
1 The value investments incurred in the future are discounted to reflect their present value using an annual rate of 5%, as recommended by the PBAC https://pbac.pbs.gov.au/

Seven principles of social return on investment analysis

- ● **PRINCIPLE 1:**
  Involve stakeholders
- ● **PRINCIPLE 2:**
  Understand what changes
- ● **PRINCIPLE 3:**
  Value the things that matter
- ● **PRINCIPLE 4:**
  Only include what is material
- ● **PRINCIPLE 5:**
  Do not overclaim
- ○ **PRINCIPLE 6:**
  Be transparent
- ● **PRINCIPLE 7:**
  Verify the result



PRINCIPLES		DEFINITION
1	**Involve stakeholders**	Stakeholders are individuals or organisations who impact or are impacted by an intervention. Stakeholders should inform what gets measured and how outcomes are measured and valued.
2	**Understand what changes**	The SROI process needs to clearly articulate how the change of social, economic, and environmental impacts have occurred, whether it is intentional or non-intentional, as well as if that change is positive or negative. Organisations are encouraged to communicate the sequence of events resulting in impact for their stakeholders in an impact map known as the "theory of change".
3	**Value the things that matter**	Financial proxies should be used to recognise the value of outcomes that may not typically be measured in other types of economic evaluations. This provides an estimate of the social value of an intervention in a more objective and comparable manner. For example, the cost of psychological counselling services for mental health outcomes.
4	**Only include what is material**	It is important to include information about the outcomes of an activity and who has been involved in affecting (or has been affected by) that change. Organisations should determine which information to include based on if it would affect the stakeholders involved (those who affect or are affected by the change experienced).
5	**Do not overclaim**	The SROI should only claim that value which the intervention is responsible for creating. This requires consideration of what would have happened without intervention, how much the intervention contributed to the outcomes generated, and what contributions other organisations/entities had on those outcomes.
6	**Be transparent**	Transparency gives the analysis more credibility. Therefore, each decision relating to the outcomes, stakeholders, indicators, sources, and methods of information collection should be clearly explained and documented.
7	**Verify the result**	External validation of the SROI analyses will help lend credibility and enable stakeholders at all levels to better evaluate the outcomes reported. A process called independent assurance can serve organisations seeking such third-party verification of the reliability of an SROI analysis.

The SROI methodology is broadly broken down into six main stages:

Guided by the principles on page 14, there are six main steps involved in calculating the SROI. These stages involve identifying and measuring outcomes and, where appropriate, applying financial proxies to represent those outcomes. The overall value of the outcomes is calculated and then compared to the investment required to generate them, indicating cost-effectiveness or SROI.

STEP 1:
Establishing scope and identifying key stakeholders

STEP 2:
Mapping outcomes

STEP 3:
Evidencing and valuing outcomes

STEP 4:
Establishing impact

STEP 5:
Calculating the SROI

STEP 6:
Reporting, using and embedding

Limitations and considerations

Within the SROI framework, changes and outcomes have been identified and verified by the stakeholders. These abstract, narrative, or non-quantitative changes must be priced and adjusted according to stakeholder's perspectives and adjusting factors such as deadweight, displacement, and attribution.

In summary, SROI is a form of stakeholder-driven evaluation blended with cost-benefit analysis tailored to social purposes. It tells the story of how change is being created, places a monetary value on that change, and compares it with the costs of inputs required to achieve it.

This methodology accounts for a broader concept of value, measuring change in ways that are relevant to the people or organisations that experience displacement, and drop off (see Methodology section for further details). **Thus, it is essential to understand that the values are derived from the perceptions of the stakeholders and not from traditional financial models of predictive analysis.**

The SROI values of one project should not be compared with that of a different project because the perceptions and resulting benefits to the beneficiaries of different projects will vary.

How do we assess SROI?

Stakeholder engagement

Stakeholder engagement is vital to identify and understand the importance of changes, how to estimate changes and how to value the outcomes. A total of 30 participants were recruited for stakeholder consultations by direct email outreach by RCA or CA. Consultations were conducted between 4th April 2021 and 8th June 2021. For the purposes of this analysis, stakeholders included people living with cancer, their partners, children and physicians.

The stakeholder engagement process was divided into two major stages:

Stakeholder Interviews

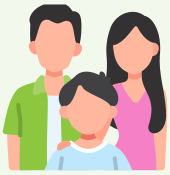
To identify key outcomes and revise the theory of change.

Follow-up questionnaire

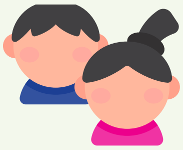
To validate and value outcomes.

Stakeholder groups

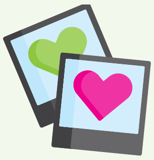
Parents with cancer



Children <12



Close family & friends



Employers of patients

Partners

Children 12-24

Government

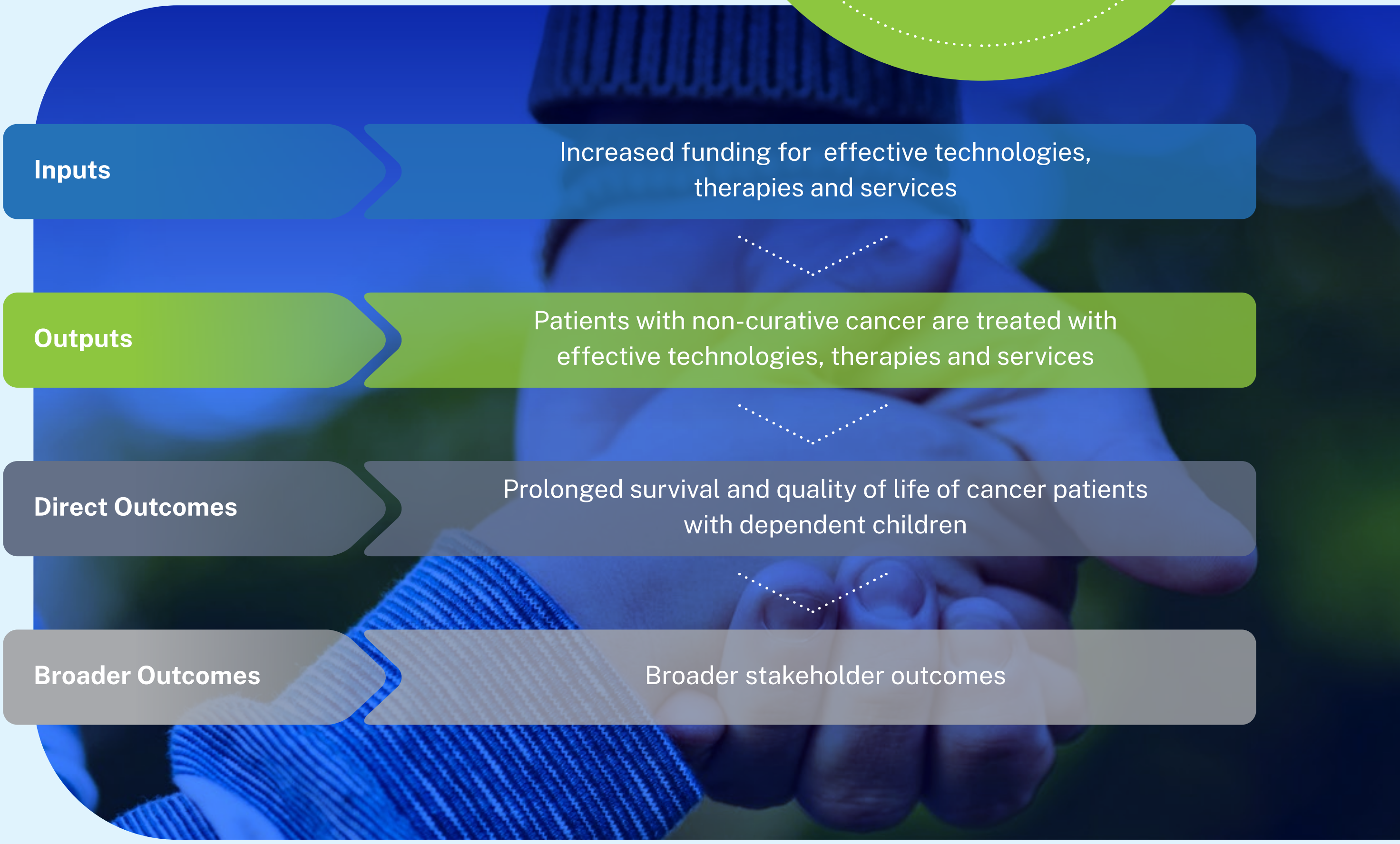
Employers of partners

Theory of change

In the context of an SROI, the theory of change aims to map the sequence of events resulting in impact for a stakeholder group. The theory of change is informed and guided by the stakeholder groups that experience the change, to capture the real-world experience of those affected. To avoid over claiming and overvaluation, only material changes are valued to assess the social return of improving quality of life and prolonging survival for people with non-curative cancer.

The draft theory of change was developed by **HT**ANALYSTS in consultation with RCA and CA based on secondary research, and was subsequently refined to incorporate findings from the stakeholder consultations. The theory of change framework employed in this analysis is depicted below.

The theory of change maps how direct patient outcomes lead to broader outcomes for stakeholders.



Inputs	Increased funding for effective technologies, therapies and services
Outputs	Patients with non-curative cancer are treated with effective technologies, therapies and services
Direct Outcomes	Prolonged survival and quality of life of cancer patients with dependent children
Broader Outcomes	Broader stakeholder outcomes

Calculating the value

This report aims to predict the societal impacts of improving the quality of life and prolonging survival for people with cancer by modelling an ideal world where all parents with non-curative cancer (<5-year prognosis) have funded access to an effective technology, therapy or service that prolongs their survival beyond five years. Outcomes of survivorship were derived from stakeholder interviews and encompassed both outcomes associated with improved prognosis and quality of life (such as being able to continue to care for children), and outcomes associated with bereavement (such as mental and emotional burden for partners).

Illustrative outcome

Financial proxy

Valuing outcomes involves the monetisation of non-financial outcomes by assigning them appropriate financial proxies

Proportion

What proportion of stakeholders experience each outcome?

Estimated through stakeholder questionnaires, secondary research, and discussions with patient advocacy organisations

Attribution

Accounts for contribution of external factors to the outcome in addition to the intervention

Estimated through stakeholder questionnaires, by asking respondents to estimate the proportion of change attributable to external variables

Drop off

Accounts for change in impact of the intervention over time

Estimated using the author's judgement supported by discussions with patient advocacy organisations

$11,771 100% 100% (1-0%) (1-20%) (1-10%) (1-10%)

Importance

A weight representing importance was applied to each valuation to account for the degree to which the outcome matters to the stakeholder

Estimated through stakeholder questionnaires, secondary research, and discussions with patient advocacy organisations

Displacement

Accounts for a degree of change in the outcomes that would have been produced by an intervention or activity which was displaced by the present intervention

Estimated using the author's judgement supported by discussions with patient advocacy organisations

Deadweight

Accounts for a degree of change in the outcomes that would have occurred without the intervention

Estimated using the author's judgement supported by discussions with patient advocacy organisations

The above example demonstrates the process of valuing these outcomes and is based on the outcome of "avoided mental and emotional burden" for partners, during the five-year modelled period. Throughout the results we refer to examples of avoided consequences, due to the nature of the ideal scenario being modelled whereby everyone experiences greater than five-year survival, with near normal quality of life. But we recognise the reality that for people living with non-curative cancer diagnoses, even the most promising treatments may not provide permanent delay.

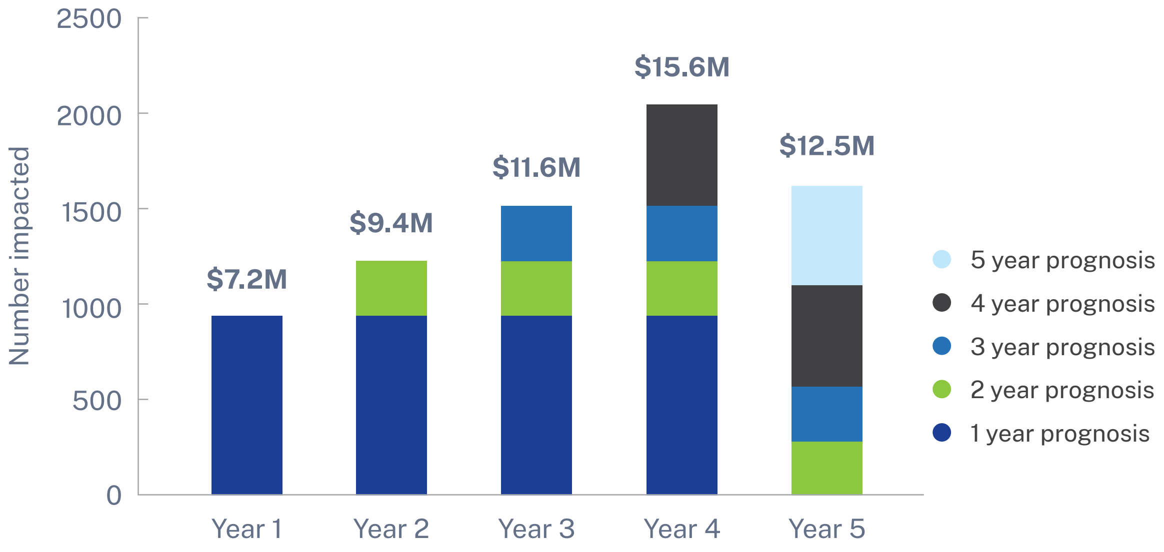
Illustrative outcome

4 years duration

Each year a proportion of the patient stakeholder cohort avoid a cancer related death and begin experiencing outcomes of survivorship – creating value for the people with cancer and for those around them. This proportion was determined based on Australian Institute of Health and Welfare data on the cumulative mortality of people with a cancer prognosis of less than five years (25). Based on the duration of time that each impact lasted for, the number of stakeholders impacted over five years has been calculated for each outcome.

As captured through stakeholder questionnaires, bereaved partners experienced mental and emotional burden for an average of four years after their partner died. The estimated number (and associated value) of partners avoiding this outcome over five years is depicted in the figure below.

Number impacted and financial value of avoiding mental and emotional burden over five years



$56 million
Total value over 5 years

$48 billion
Present day value over 5 years[1]

This process is repeated for each outcome. The present-day value of all outcomes is summed to estimate the total societal impacts of prolonging and improving the quality of life of people with cancer.

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[1] The value of benefits incurred in the future are discounted to reflect their present value using an annual rate of 5%, as recommended by the PBAC. These values are summed to give net present value of total benefits over five years.

The human experience

Only by living an experience are we truly able to describe its impact, and ultimately tell a story of how change is created. This is one of the core tenants of SROI analyses. Part of conducting this analysis involved interviewing people living with non-curative cancer, their partners, children, and physicians, to understand how having a cancer diagnosis impacts the person receiving it and everyone around them (see Methodology section for additional details). Their stories demonstrate that cancer has profound physical, psychological, social, and economic impacts on people's lives, which persist following the death of a loved one.

All information collected through the interviews has been anonymised, but three participant case-studies are presented to share in more detail some of the stories that were used for this analysis.

Jane

In 2019, Jane was diagnosed with a rare genetic mutation of ovarian cancer, when her daughter was 16 years old. Jane is a single mother, carer for her father with bladder cancer and was working full-time at a pharmaceutical company at the time of her diagnosis. Jane was “gobsmacked” at the news, as nobody thought her symptoms were cancer related – not even her GP. With normal blood tests and a breast cancer gene (BRCA) negative result, Jane was initially misdiagnosed.

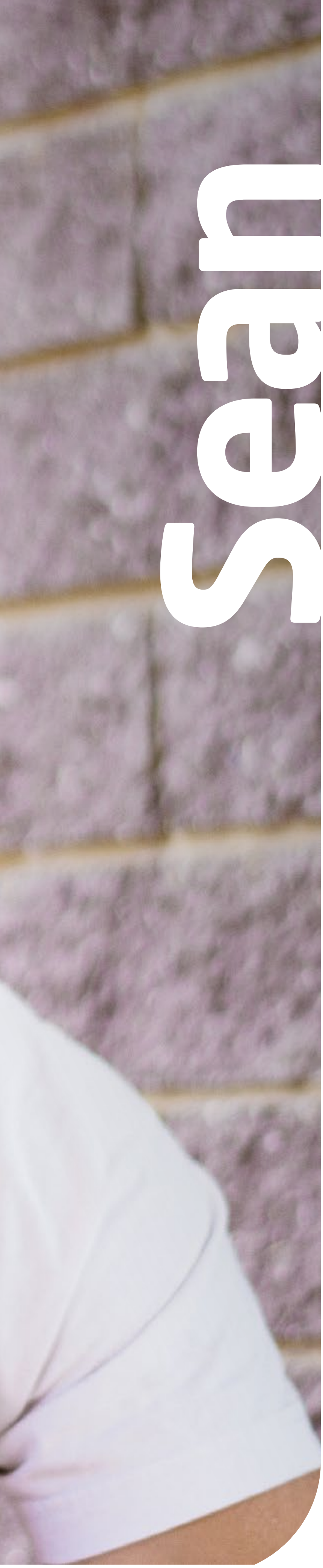
Following thorough investigations – including sending tumour tissue to the United States – Jane was eligible for a specific blood test (CA 125) that is used to help diagnose ovarian cancer, which she suggested should be more routinely done for women in Australia.

Jane was treated with seven cycles of chemotherapy, peritonectomy surgery and olaparib/LYNPARZA™ (a maintenance treatment) for 15 months, which was not available on the PBS at the time. Jane believes that working in the medical industry for 20 years improved her ability to navigate the healthcare system and understand her treatment options, and she is not sure how she would have managed otherwise. Although olaparib/LYNPARZA™ is now available on the PBS, Jane explained that tracking Medicare reimbursements was a challenging process and at times she had to self-advocate for treatments.

> Stress is contraindicated when you’re suffering from cancer, but financial toxicity is real and increases stress in a person.

During this time, Jane’s doctors referred her to RCA, who supported her in raising money to cover the cost of olaparib/LYNPARZA™ treatment. Jane is currently in remission and believes that her treatment was only possible because of the support and peace of mind that RCA provided her and her family. Jane stated that her daughter was extremely brave throughout her cancer journey and is now studying at university and has been able to return to work.

> Cancer is out of my control, but what I can control is my effort at school and being a good role model for my brothers to follow.



Sean

Cancer first entered Sean's life when his mum was diagnosed with cervical cancer in 2005. At the time of her diagnosis, Sean was 12 years old, and his younger brothers were 10 and 8. All the boys were in primary school when their mum first started chemotherapy treatment, and Sean remembers her always being extremely passionate about him and his siblings maintaining their education throughout her cancer journey. Sean's parents divorced when they were young and his mum was from Malaysia, so the boys did not have any close family members in Australia to turn to for support.

As the eldest child, Sean quickly became responsible for his two younger siblings and gained a lot more at-home responsibility. He remembers always being an advocate for his younger brothers, especially at school, stating:

> There was a lot of attention focused on me and I became the leader of the family.

Following chemotherapy and surgery, Sean's mum relapsed in 2007 and fell exceptionally unwell. Sean shared that adjusting to their house becoming a place of care, managing the house and taking a further increase in caring and household responsibilities, was an extremely challenging time in his life, which other young people his age simply never had to deal with.

Sean first noticed a shift in his mum's condition when the Silver Chain nurses frequently started visiting the house. Despite his mum's best efforts to try to prepare and protect the boys, Sean remembers that palliative care was still a large shock for him as he was too young to understand. He also recalls that there was a lot of uncertainty about where the boys would go to live after their mum passed away.

After their mum sadly passed away from cervical cancer in 2009, Sean and his brothers moved from one foster care family to another, after things did not quite work out with their first foster care family due to the difficulties of dealing with grief and other challenges.

Despite receiving assistance from the local school community, the added responsibilities took a toll on Sean's mental health. Sean's life is still shaped by his mum's aspirations, especially when it comes to their education, sharing that his goal in life is to make his mum proud and that he wishes his mum was here to share his achievements with him.

Sean sought grief counselling at CA shortly after his mum's death, which he said really helped him process his thoughts. Although his brothers did not have the same success, he continues to seek psychological help when major events happen in his life. Sean is extremely grateful for the support CA provided him throughout his mum's cancer journey, sharing that:

> No matter what was happening in my personal or school life, Canteen was the one constant, which gave me the safety, security and stability I needed.

Nick's wife Nicole was diagnosed with adenoid cystic carcinoma (ACC) – a rare salivary gland cancer – when she was just 33 years old. At the time of her diagnosis in September 2018, their son was 11 months old, and Nicole was due to return to her job as an occupational therapist, after being on maternity leave. The couple were together for 16 years and Nick described them as a "young and happy family", but Nicole's ACC diagnosis instantly turned their world upside down.

Nicole was diagnosed with ACC after experiencing atypical back pain, neck pain and jaw numbness, that doctors said was most likely caused by Nicole picking up her son the wrong way and something dental related. They were told Nicole was "young, fit and healthy" following investigations in the emergency department, and if concerned they could present to another hospital. Shortly after they received a second opinion, and after countless scans Nicole was diagnosed with stage 4 ACC. When Nicole was diagnosed, the cancer had already metastasised to her bones, and Nick explained that Nicole's jaw numbness was the result of a tumour wrapping itself around the main facial nerve.

During this time, Nick was extremely grateful that he could take one year off work to become the primary carer for his wife and son. He expressed that his only focus was making sure that his wife was not in pain and ensuring they were spending quality time together as a family.

Despite immediately starting chemotherapy (on her son's 1st birthday), Nicole's pain escalated dramatically over a short period of time, and she became wheelchair bound within a couple of months.

> Throughout Nicole's treatment journey the couple encountered several challenges, as ACC has limited treatment options being a rare cancer. Initially, Nicole was treated with chemotherapy and palliative radiation therapy, both of which were unsuccessful due to significant side effects.

Nick endeavoured to find an appropriate clinical trial for his wife, but finding the correct trial posed more challenges. "The way in which clinical trials are run should and can change. It's a convoluted process and difficult to try and find who is running what trials in NSW, and how to get in contact with them", stated Nick.

Fortunately, after many delays, RCA was able to help the couple access a subsidised immunotherapy, but in the end Nicole developed a rare side effect to the treatment and and active treatment was ceased.

Nicole passed away in January 2020, after an admirable 15-month battle with cancer. Today, a lot of things have changed for their family, but Nick shared that the hardest part is being a widower and not having Nicole around for their son. He also expressed his frustration that it takes a tragedy for people to realise that the only thing that matters in life is family, explaining that his perspective on life and what he values has completely changed.

Nick is now working closely with organisations to help educate employers about the best way to support staff members who have been diagnosed with cancer, and their carers. This business, *MyMuse*, was founded by Nick's new partner, Nikki, who has unfortunately experienced the same tragedy as Nick, having lost her soulmate to a rare cancer three years ago. Nick and Nikki are forging a path forward and helping to create a more empathetic and supportive environment for those who are faced with the reality of losing a loved one. Nick explained there is still a lot of cancer stigma in workplaces and in society, which they both endured. Nick continues to endure the consequences of this stigma to this day. Despite things becoming more manageable over time, Nick's feelings of loss and sadness can still overwhelm him as if it was yesterday that Nicole passed away.

Nick

> The way in which clinical trials are run should and can change. It's a convoluted process and difficult to try and find who is running what trials in NSW, and how to get in contact with them.

Summary of the experience of people living with cancer and their families

This section describes the collective experience of the people living with non-curative cancer and their families who were interviewed for this study. This feedback was used to set the scene of our analysis and understand the beginning of the person's cancer journey leading to the outcomes and value created by having an effective treatment option for people with non-curative cancer.

Initial diagnosis

A cancer diagnosis is a shocking experience for the entire family, but each person involved experienced it in a different way.

Every person remembered being in extreme disbelief when they were diagnosed with cancer for the first time.

I didn't expect to have a major illness like this at my age.

Immediately after receiving a cancer diagnosis, most people disclosed they were instinctively thinking about their family and the best way to communicate the news, while others were instantly worried about missing their children's milestones and leaving their family with reduced support.

Parents found communicating their cancer diagnosis extremely challenging, with most explaining that they were reluctant to talk about their diagnosis to protect their family.

Overall, the way parents communicated their diagnosis varied, but children generally valued their parents being open and honest about their illness. The ability to openly talk about the diagnosis and the disease helped children dealing with their parent's cancer.

"Canteen was a critical support because my parents were not sharing any information."

Some parents took several weeks to process the news and waited until they knew more about their prognosis, while others were extremely transparent from the start.

Partners often felt overly optimistic, but also confused at the same time, when they were initially informed about their loved one's cancer diagnosis. During this time, partners played a large role in supporting the entire family, commonly trying keep everyone's life normal, somewhat sheltering their children. However, partners who did this also mentioned that they would not keep their children sheltered if they had their time again.

Despite the circumstance, how a child responded to the news of their parent's cancer diagnosis depended on their age. While all children were in shock when they understood what was happening, children older than 12 were commonly more affected than children younger than 12.

"When I heard about the diagnosis I thought, that happens to other families, or in movies, not to my family."

Most older children remember knowing something was wrong prior to being told about the diagnosis, and being in denial until their parent's illness progressed, where they were given a lot more responsibility. Their emotional distress generally reflected their feelings of hopelessness and lack of control.

"I couldn't financially support the family because I wasn't old enough and I couldn't fix the cancer because I'm not a doctor."

In comparison, younger children could not fully comprehend how sick their parent was – with most believing they had a cold and would eventually recover.

Challenges of diagnosis

Some people disclosed that they initially received an incorrect diagnosis, or that it took more than one visit to a GP to receive the correct investigations or referral. One partner lost her loved one to cancer due to a misdiagnosis from eight different private specialists, prior to being diagnosed with a Malignant Peripheral Nerve Sheath Tumour (MPNST) – an insidious and exceptionally rare cancer.

"If he wasn't grossly misdiagnosed, we probably could have saved his life."

Another common theme that evolved was that people living with cancer often felt stigmatised at work, which frequently led to people feeling depressed, isolated, or overly sheltered.

Several people explained that they did not feel unwell at the time of their diagnosis and wanted to continue with their day-to-day activities. However, most people stated that this was challenging, because they were being treated differently by their colleagues and friends.

To overcome this, some people explained they had to find new meaning in life, and others resigned from work. However, one person disclosed that they regretted making this decision, stating that finding employment following a cancer diagnosis is a complicated process.

"I thought resigning was my only option."

One of the partners supported this view, sharing that it was extremely difficult to witness their loved one lose their drive and purpose in life, when all they wanted to do was return back to work and try to live normally.

"Most people diagnosed with cancer do not want to stop working. Employers need to create a workplace that facilitates people who are ill, enabling them to work in some capacity."

> Everyone treated me as if I was unwell all the time, and never let me do anything.

The treatment experience

Everyone's treatment experience is unique, but overall, it was evident that those who were diagnosed with a rarer cancer – in addition to having to go through the intrinsically difficult process of a cancer diagnosis – were also often presented with limited, or no treatment options at all.

"Every week was a dice roll; we knew tumours were growing and there was nothing we could do about it."

The majority of people reported they either had difficulty understanding treatment options, accessing treatment, finding clinical trials, keeping track of doctor's appointments and/or managing finances – all while trying to look after their own wellbeing and that of their families.

With the additional burden of debilitating side effects, some people commented that this put a strain on family dynamics, especially partner relationships, who often also had to take leave from work to support the family. This additional burden particularly affected children in solo-parenting families, because in the absence of a partner, the eldest child commonly had to fulfill this role.

Consequently, the eldest child was regularly the most affected by their parent's treatment journey, often being the person responsible for taking their parent to appointments, paying rent, grocery shopping, managing the house and looking after siblings.

> It was common for these children to feel a lot of guilt during this time, putting a lot of pressure on themselves to be the best child and caregiver possible, with children younger than 12 missing the guidance their parent provided.

Close friends and local school communities were also discussed as important support networks, that were extremely valued by people living with cancer and their families. In addition to the value of emotional and psychological support, nearly all shared the importance of ongoing financial support.

Almost every person with cancer, partner and child talked about the economic impacts of cancer treatment. Most families were fortunate enough to obtain financial assistance from patient organisations such as RCA, via crowdfunding support on the 'Patient Treatment Fund' platform, which was both an economic and psychological relief.

"RCA funding covered a significant proportion of the treatment costs, including previous treatments."

For instance, some people were required to travel internationally to access treatment, a few experienced rural geographical barriers, while others had to pay out of pocket for immunotherapy and allied health treatments.

"Knowing that there are treatments on the horizon has a profound impact on your sense of hope, it fills you with a genuine sense of optimism that you can hold onto, which carries you through the tough days."

> I was always thinking about the consequences of my actions – everything I would do – and how it would affect him.

Calculating the SROI of improving survival of non-curative cancer beyond five years

For every $1 invested...

$3.06 of social and economic value is created by improving the prognosis and quality of life of people living with non-curative cancer

Investment value

$1.04 billion

Total value created

$3.74 billion

Total present value

$3.17 billion

After discount rate – 5%

Net present value

$2.13 billion

Present value minus investment

VALUE CREATED

Five years of investing in new technologies, therapies, and services to extend the prognosis and quality of life of people with non-curative cancer generated generates

$2.13 billion of social value

Forecast value created exceeds the investment

Payback for investment in under 2 years

SROI ratio

1 : 3.06

=

Present value of benefits: **$3.17 billion**

Present value of investment: **$1.04 billion**

Investing in improving quality of life and prolonging survival of people with non-curative cancer

A range of innovative cancer technologies, therapies, and services are emerging with improvements in overall survival and quality of life for people with cancer – including radiopharmaceuticals, new service models like healthcare in the home, and the introduction of immunotherapy, which harnesses the body's immune system to fight cancer. Although investing in innovative therapies can have a high upfront cost, the results of this analysis show how there are substantial downstream social and economic benefits in treating people with cancer with the best available technologies.

To represent the upfront cost of extending the survival and quality of life for all people with non-curative cancer, an investment of 50% more than the current highest cost government funded cancer therapies was applied.

$51,500

Annual cost per patient of highest priced Government funded cancer therapies[1]

$75,000

Estimated annual cost to extend survival and quality of life of a person with advanced cancer[2]

3,192

Number of parents diagnosed with non-curative cancer in Australia per year [3]

$1.04 billion

Net present value of total investments over five years[4]

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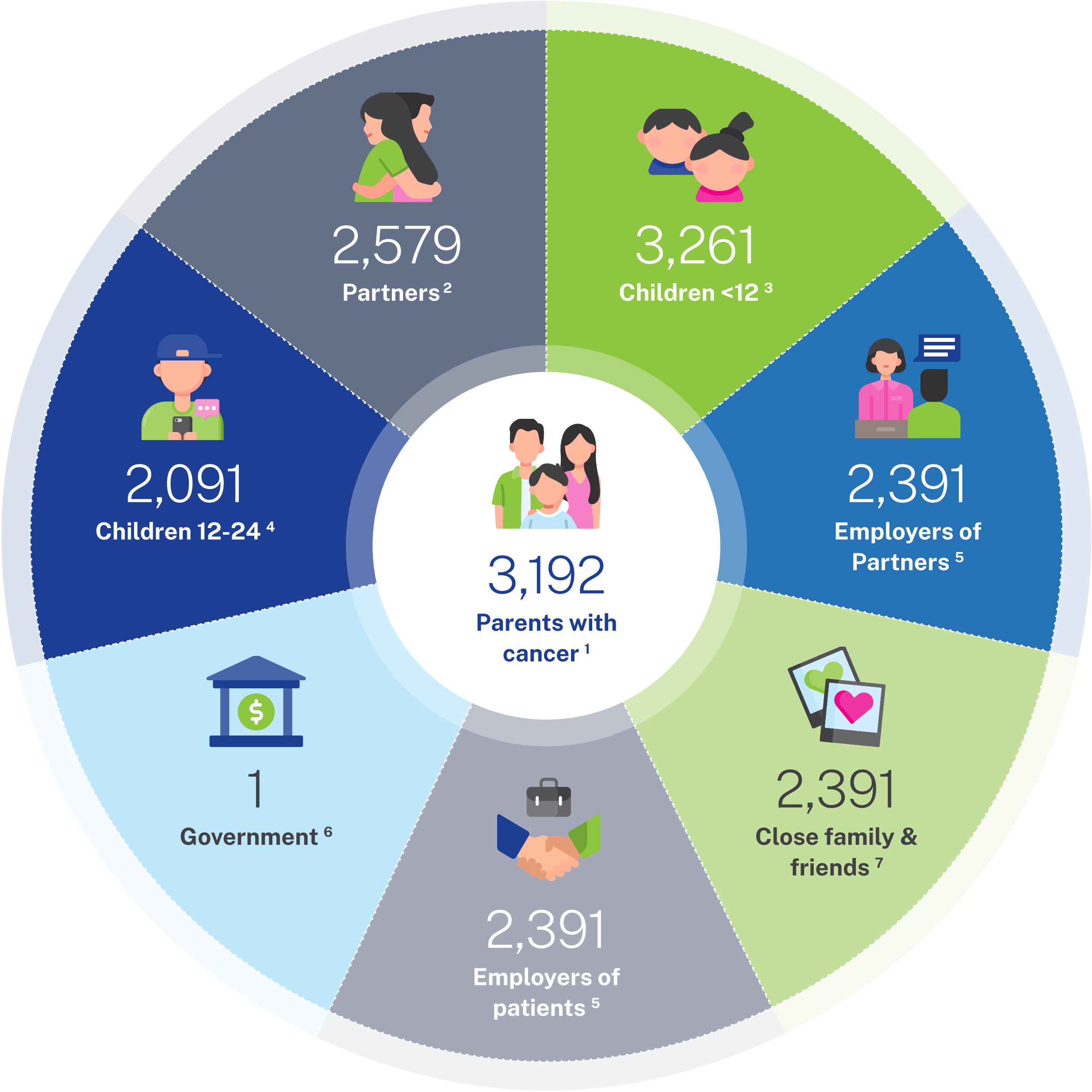
[1] Total annual cost of the current highest cost cancer therapies was calculated based on the average price of the top 25 highest Government cost cancer therapies (2019-20) and yearly patient co-payments, assuming all parents are < 65 (concessional rates not included) and monthly prescriptions are required per patient.

[2] Price is ~50% more than the current highest costs cancer therapies.

[3] Over 3.3 million Australian families were estimated to be living with dependent children in 2021 (26, 27); 16,454 of these families are expected to have one parent diagnosed with cancer in 2021. Age standardised cancer incidence was applied (28) and adjusted for the proportion of parenting aged cancer patients diagnosed with a prognosis <5 years.

[4] The value of investments incurred in the future are discounted to reflect their present value using an annual rate of 5%, as recommended by the PBAC. These values are summed to give net present value of total investments over five years.

How many people are impacted by a non-curative cancer diagnosis?



1 Over 3.3 million Australian families were estimated to be living with dependent children in 2021 (26, 27); 16,454 of these families are expected to have one parent diagnosed with cancer in 2021. Age standardised cancer incidence was applied (28) and adjusted for the proportion of parenting aged cancer patients diagnosed with a prognosis <5 years (7).

2 Over 2.7 million coupled Australian families were estimated to be living with dependent children in 2021 (26, 27); 13,295 of these families are expected to have one parent diagnosed with cancer in 2021 (28). Age standardised cancer incidence was applied (3) and adjusted for the proportion of parenting aged cancer patients diagnosed with a prognosis <5 years (7).

3 There were over 3.1 million estimated dependent children under the age of 12 in 2021 (26, 27); 16,809 of these children will have one parent diagnosed with cancer in 2021 (3). Age standardised cancer incidence was applied (28) and adjusted for the proportion of parenting aged cancer patients diagnosed with a prognosis <5 years (7).

4 There were over 2.2 million dependent children aged 12-24 in 2021 (26, 27); 10,777 of these children will have one parent diagnosed with cancer in 2021 (3). Age standardised cancer incidence was applied (28) and adjusted for the proportion of parenting aged cancer patients diagnosed with a prognosis <5 years (7).

5 The employment rate of parents/partners with dependent children was 92.7% (29).

6 Government is counted as one stakeholder.

7 Based on a study commissioned by Snap Group Limited surveying over 10,000 people aged 13-75, the average number of close friends per person was estimated to be 7.2 (30). To avoid double counting, it was assumed that 50% of friends are shared by both partners.

Outcomes for parents with cancer

The key outcomes of effective therapy for parents with cancer include continued ability to care for children, continued financial support for a family, being present for life milestones and feeling hopeful about the future. Under the ideal scenario modelled in this analysis, survivorship beyond five years also prevents the emotional distress of saying goodbye to loved ones. While the fear of recurrence is an important outcome for people with cancer, this can be experienced irrespective of the effectiveness of treatment.

PROLONGED SURVIVAL AND IMPROVED QUALITY OF LIFE FOR PEOPLE DIAGNOSED WITH NON-CURATIVE CANCER

INTERMEDIATE OUTCOMES

- More time spent with family
- Ability to work and progress in career
- Reduced need for future interventions
- Regained a sense of normality
- Continued enjoying life
- Avoided transition to palliative care

FINAL OUTCOMES

1. Ability to care for children
2. Being present for life milestones
3. Continue to support family financially
4. Feeling hopeful about the future
5. Avoided emotional distress about saying goodbye to loved one
6. Fear of recurrence

$1.09 billion

TOTAL VALUE GAINED OVER FIVE YEARS FOR

Parents living with a non-curative cancer

Ability to care for children

$164M

For parents with a non-curative cancer diagnosis, additional life years gained from an effective cancer therapy allowed them to continue to raise their children. As all people with non-curative cancer in this analysis receive an effective technology, therapy or program that extends prognosis and improves quality of life, they will all be able to continue caring for their children as normal.

"When my treatment side effects are managed and the disease is under control, I can pretty much do everything that most other mums are doing – picking my child up from school, watching them play sport and doing things together as a family."

Being present for life milestones

$225M

Missing out on key life milestones such as anniversaries, graduations, or a child's first day of school was one of the greatest fears felt by parents who received a non-curative cancer diagnosis. A key value of effective treatment is extending life to experience these milestones. As all people in this analysis receive an effective technology, therapy or program which extends prognosis and improves quality of life, all will continue to live and experience life milestones with their families.

"It's mine and my kid's life journey and I struggled with the thought of missing their milestones."

Continue to support family financially

$531M

The death of a parent is an emotionally devastating experience which is worsened by the financial implications of losing the income of a parent. For some families, losing the income of a parent was the difference between keeping or selling their house or needing to rely on government income support. Effective therapies may be more easily tolerated and therefore allow more parents to continuing working to financially support their family.

"Finances are the biggest challenge in terms of planning for the future."

Feeling hopeful about the future

$51M

Being diagnosed with cancer can create uncertainty, with people describing the burden of not being able to plan for the future. Effective therapy allows people to regain a sense of normality and to continue planning for a life free from progression – with about 60% of people feeling hopeful about the future after receiving an effective treatment.

"When the first treatment became available, I got more hopeful that there would be others."

Avoided emotional stress of saying goodbye to loved ones

$122M

Saying goodbye to loved ones is a heartbreaking experience that can be delayed through effective treatment. Bereaved partners described the experience of watching a parent saying goodbye to their children as one of the hardest things they will ever do. As all people in this analysis receive an effective technology, therapy or program which extends prognosis and improves quality of life, the assumption is that they will avoid the immediate emotional distress of saying goodbye to their families.

Fear of recurrence

-$5.7M

An SROI captures the change experienced by people and organisations, whether that change is positive or negative. Although surviving a non-curative cancer diagnosis leads to numerous social and economic benefits, fear of recurrence is a negative impact experienced by people diagnosed with cancer in the years following treatment, even if the treatment received was highly effective. After receiving effective treatment, around 80% of people diagnosed with cancer experienced a fear of cancer recurrence. Although previous studies have reported a lower proportion of people diagnosed with cancer experiencing a fear of recurrence (31–52%), parents with dependent children may be more likely to experience this outcome due to the added concern about the potential impacts on their family (33).

"I am always worrying about every little ache and pain."

Outcomes for partners

If a person survives a non-curative cancer diagnosis, as in this ideal scenario, there are several positive impacts experienced by their partner. These key outcomes include the ability to experience life in partnership, avoidance of mental health impacts, and stability of their career, social relationships, and family relationships. Surviving cancer allows people to return to work, relieving the financial stress experienced by their partner and family. They can also help raise their children, lowering the overall parental workload for their partner.

PROLONGED SURVIVAL AND IMPROVED QUALITY OF LIFE FOR PEOPLE DIAGNOSED WITH NON-CURATIVE CANCER

INTERMEDIATE OUTCOMES

- Avoided funeral costs
- Avoided burden of seeing your children grieve
- Avoided loneliness
- Avoided grief
- Avoided guilt associated with moving on and enjoying life
- Partner being around for life milestones
- Being able to make decisions with partner

FINAL OUTCOMES

1. Career stability
2. Stable social relationships
3. Stable family relationships
4. Lower parental workload
5. Avoided mental and emotional burden
6. Avoided financial stress
7. Experience life with a partner

$218M

TOTAL VALUE GAINED OVER FIVE YEARS FOR

Partners of people living with a non-curative cancer

Career stability

$53M

In most cases, partners of people with a non-curative cancer diagnosis experienced significant career disruptions during the illness and following the death of a loved one. During these times, most partners took time off work to grieve and spend more time with their children. Additionally, many chose to change careers, with some unable to heal from the passing of their partner with their current work. Others required a new role to earn more money to support their family. All bereaved partners experienced some career instability for up to two years after their partner passed away.

"My kids don't want me to return back to work because they just want to be with me."

Stable social relationships

$5.9M

Several people reported they feared losing their friends – especially those of their late partner's – following the loss of a loved one. Most bereaved partners commented they lost touch or grew apart with friends, either because their own interests changed or because of conflict. All bereaved partners reported unstable social relationships after their partner passed away, but many also told us they received overwhelming support from close friends.

"I now miss out on things because I'm single, which is really hurtful."

Stable family relationships

$4.0M

Many bereaved partners spoke about how family dynamics change after a loved one passes away. Partners explained that disagreements are often inevitable at this time when emotions run high and difficult decisions need to be made. Adding to this volatile situation is the fact that everyone grieves differently and may be at varying stages of this process, thus have feelings that conflict with others. Half of all bereaved partners stated their family relationships were permanently impacted by the loss of a loved one.

"People think death brings families closer together, but it can cause family friction and break ups."

Lower parental workload

$27M

After losing a significant other, solo parents are faced with the overwhelming challenge of managing a household alone. This may include picking up unfamiliar tasks previously performed by a partner while balancing work and caring for children. All bereaved partners reported an increased workload at home after they became a solo parent. This emotional and physical stress is avoided if a person receives effective therapy and can continue to share the domestic workload.

Avoided mental and emotional burden

$48M

Bereavement can have a big impact on a person's mental health, with many partners facing severe bouts of depression and/or anxiety following the death of a loved one. All bereaved partners suffered from mental health impacts at some point in time after their partner passed. This is supported by several studies, which demonstrate a significant relationship between the onset of a mood, anxiety and alcohol use disorder and the unexpected death of a loved one (31, 32). Partners are also faced with the challenge of telling their children about the death of a parent, which is difficult to explain, particularly when children are too young to understand the permanency. Avoiding the mental health impacts of losing a loved one was extremely important to stakeholders, as supported by data from over 27,000 participants in the National Epidemiologic Survey on Alcohol and Related Conditions which reported that 30% of participants identified the unexpected death of a loved one as the most traumatic event in their lives (31).

"A lot of things have changed, and it does get easier over time, but when the feelings of loss and sadness hit – they hit hard."

Avoided financial stress

$30M

In many cases, cancer treatment causes significant financial burden for families. RCA supported many families during their treatment journey by facilitating fundraising opportunities. Following the passing of a loved one, a partner's financial related stress depended on their place of employment, insurance status and financial position. Half of all the bereaved partners experienced economic impacts after their partner passed away.

"Trying to access insurance money was so incredibly stressful, especially on top of grieving and looking after the kids."

Experience life with a partner

$50M

The loss of a partner is devastating and requires a big life adjustment for their partner. Partners described the difficultly of coming home without having someone with whom they could share their day or make joint decisions. As all people in this analysis receive a therapy which extends prognosis and quality of life beyond five years, they are all assumed to continue experiencing life with their partner.

"Without my partner there is no one to share responsibility and discuss life decisions with."

Outcomes for teenagers and young adults

The key outcomes for teenagers and young adults with parents who, in this ideal scenario, survived a non-curative cancer diagnosis include stability of family and social relationships, maintained performance at school, more time to enjoy youth, parents being around for life milestones and mentorship from a parent (33). A parent surviving a non-curative cancer diagnosis, beyond five years, also prevents their children from the immediate, related negative mental health impacts.

PROLONGED SURVIVAL AND IMPROVED QUALITY OF LIFE FOR PEOPLE DIAGNOSED WITH NON-CURATIVE CANCER

INTERMEDIATE OUTCOMES

- Avoided change in living arrangements
- Regained a sense of normality
- Less responsibility
- Avoided trauma of seeing a parent suffer
- Avoided financial stress
- Avoided legal stress
- More time/flexibility to define a career path

FINAL OUTCOMES

1. Stable family relationships
2. Maintained performance at school/work
3. Stable social relationships
4. Avoided mental and emotional burden
5. Avoided behavioural impacts
6. Parent being around for milestones
7. More time to enjoy youth with fewer responsibilities
8. Mentorship from parent

$222M

TOTAL VALUE GAINED OVER FIVE YEARS FOR

Teenagers and young adults[1] of parents living with a non-curative cancer

[1] Aged 12-24

Stable family relationships **$5.5M**

The death of a parent was described as a highly stressful life event for bereaved teenagers and young adults and their families. While teenagers and young adults at this time are in significant need of support, they may not receive it because of changes in the family situation and family roles post-bereavement (34). Although some families grew closer after the loss of a loved one, in other cases the remaining parent struggled with their grief and found it challenging to provide sufficient support for their teenagers and young adults. These teenagers and young adults experienced reduced time, attention, and support, causing a strain on their family relationships.

"I became responsible for ensuring my siblings attended school, making sure they learned to take responsibility for themselves and eventually learning how to be financially independent." – 22 year old

Maintained performance at school/work **$6.8M**

The impact of losing a loved one may also affect school and/or work performance, as concentration becomes more difficult. A few teenagers and young adults stated they felt a lot of pressure to perform well at school after their parent passed away, with expectations from their remaining parents, teachers, and friends. A study by a Purdue University researcher found that all bereaved undergraduates had significantly lower grade-point averages than a comparative group of students (35). This negative impact is avoided when the parent of a teenager or young adult survives.

"My brain wasn't the same when I was grieving, I couldn't sit down and focus." – 20 year old

Stable social relationships **$2.8M**

Social isolation was commonly experienced by teenagers and young adults, with many stating they often felt guilty spending time with their friends when their parent was alive, that they thought they could not invite friends over, and that they were no longer able to relate to people their own age. Literature supports this finding, outlining that adolescents with a terminally ill parent often have lower social competence, despite parents trying to maintain normalcy of their children's social lives (36). As a family regains a sense of normality and control, teenagers and young adults said they were able to return to their social lives more easily.

"I struggled to connect with people my own age, especially in year 11 and 12." – 17 year old

Avoided mental and emotional burden $34M

Teenagers and young adults aged between 12 and 24 years were able to understand that death is a part of life, and as a result, this age group generally experienced significant mental health impacts. Studies have reported that teenagers and young adults experience more mental and emotional burden when compared to younger children, with adolescents considered to be the most at risk of negative psychological outcomes (37). Most teenagers and young adults sought psychological help from CA or similar services following the death of a parent, with most reporting they either experienced symptoms of, or were diagnosed with, anxiety and/or depression. These negative impacts can be avoided when the parent survives.

"I don't know how I would have managed without Canteen." – 18 year old

Avoided behavioural impacts $5.3M

Some teenagers and young adults turned to substance abuse as a coping mechanism after the death of a parent. Illegal behaviours commonly stemmed from associating with the wrong crowd at school. In one situation, a teenager was asked to leave their new foster care because of their behaviour. This is reflected in numerous studies which link childhood bereavement with substance abuse and higher risk of criminal behaviour (38, 39). These negative impacts can be avoided when the parent survives.

"One of my brothers started hanging out in the wrong crowd and getting into trouble." – 14 year old

Parent being around for life milestones $147M

Experiencing life milestones without someone you always imagined would be there can be extremely challenging. According to literature, teenagers and young adults are likely to re-experience the loss of a parent during certain key milestones throughout their life (40). This analysis demonstrated that adolescent children are significantly impacted, with one young adult reporting they've avoided going to graduations, getting their drivers licence, and that they will never get married.

"I do have more freedom to do things now Mum has passed, but I would trade that all to be able to have her back." – 16 year old

More time to enjoy youth with fewer responsibilities $8.0M

When a parent is terminally ill, they become less physically and emotionally available for their family. Parental roles often change during this time, with teenagers and young adults becoming the person to take on additional responsibilities in the absence of a partner. Most bereaved teenagers and young adults stated they were happy to take this on, but they often became socially isolated as a result. When a parent survives, teenagers and young adults can continue to enjoy their youth without sacrificing opportunities to enjoy their youth.

“My social life just wasn’t important anymore.” – 18 year old

Mentorship from parent $12M

Parent mentoring is particularly crucial for teenagers and young adults (41). Most teenagers and young adults interviewed valued their parents guiding them throughout their lives. When a teenager or young adult loses this support, it leads to devastating psychological and physical effects on their wellbeing, with research indicating that bereaved teenagers and young adults are more vulnerable to symptoms of depression, anxiety, and withdrawal in comparison to non-bereaved teenagers and young adults (42). These negative impacts are avoided when a parent survives.

“I ended up living with my guardian, but cultural differences made this difficult at times.” – 15 year old

Outcomes for younger children

The key outcomes for younger children with parents who, in this ideal scenario, survived a non-curative cancer diagnosis include stability of family relationships, maintained performance at school, parents being around for life milestones and mentorship from a parent. A parent surviving a non-curative cancer diagnosis also prevents their children from experiencing emotional distress or fearing sickness and death.

PROLONGED SURVIVAL AND IMPROVED QUALITY OF LIFE FOR PEOPLE DIAGNOSED WITH NON-CURATIVE CANCER

INTERMEDIATE OUTCOMES

- Avoided change in living arrangements
- Regaining a sense of normality
- Avoided fear of sickness/death

FINAL OUTCOMES

1. Stable family relationships
2. Maintained performance at school
3. Parent being around for milestones
4. Mentorship from parent
5. Avoided emotional distress

$324M

TOTAL VALUE GAINED OVER FIVE YEARS FOR

Younger children[1] of parents living with a non-curative cancer

Stable family relationships **$4.8M**

The death of a parent was described as a highly stressful life event for bereaved children and their families. While children at this time are in significant need of support, the inverse can happen because of changes in the family situation and family roles post bereavement (34). Although some families grew closer after the loss of a loved one, in some cases a child's remaining parent was struggling with their own grief and found it challenging to provide sufficient support for their children. For children, this led to reduced time, attention, and support, causing a strain on their family relationships. Additionally, a prospective longitudinal study of 80 bereaved children (age 2-17) found a significant increase in conflict with siblings (43). After the passing of a parent, some children changed guardianship or were transferred to foster care. These disruptions to family relationships are avoided when the parent survives.

"Grief was a hard experience to share with my siblings, everyone processed it individually." – 12 year old

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[1] Under the age of 12

Maintained performance at school $7.3M

Following the death of a parent, younger children found it difficult to maintain concentration and felt unmotivated at school, as supported by substantial evidence in literature on the impacts of childhood bereavement (43-45). Some children were socially disrupted, and many were at risk of dropping out of school all together. For many this impacted school performance, with existing studies showing that children who have lost a parent are more than twice as likely to perform poorly at school (44, 45). These impacts are avoided when a child's parent survives.

"My youngest sibling started skipping school and he was eventually kicked out." – 11 year old

Parent being around for milestones $287M

Experiencing life events without a parent can be extremely challenging for a younger child. Children who have lost a parent to cancer often find key life events that call for celebration, such as the first day of school or a primary school graduation, to be distressing.

"Not having Mum physically here to see all our big moments in life is an ongoing thing, which others take for granted." – 12 year old

Mentorship from parent $19M

This outcome was developed based on conversations with bereaved children, who reported that they witnessed their younger siblings miss out on vital mentorship years from their parent. This shift in parental guidance during important developmental years often had social and psychological impacts on younger children. This negative impact is avoided when a parent survives.

"My youngest brother was most heavily impacted, as he had the least amount of time with our parents." – 11 year old

Avoided emotional distress $5.6M

Children are able to experience grief and loss from a very young age; however, this grief is expressed differently to adults. Although younger children did not always understand the implications of cancer, with many believing their parents had a cold and would recover, younger children were still highly emotionally affected by the passing of their parent. The symptoms of emotional distress varied depending on the age of the child, however common themes included anxiety, behavioural issues or fears of sickness and death. High levels of anxiety and distress have been described in several existing studies of bereaved children (46, 47).

"I didn't realise how sick he was, I thought it was a cold." – 9 year old

Outcomes for close family and friends

The key outcomes for close friends and family of people who, in this ideal scenario, survived a non-curative cancer diagnosis, included avoided mental and emotional burden and avoided financial stress.

PROLONGED SURVIVAL AND IMPROVED QUALITY OF LIFE FOR PEOPLE DIAGNOSED WITH NON-CURATIVE CANCER

INTERMEDIATE OUTCOMES

- Avoided transfer of guardianship
- Avoided financial support for bereaved family

FINAL OUTCOMES

1. Avoided financial impacts
2. Avoided mental and emotional burden

$608M

TOTAL VALUE GAINED OVER FIVE YEARS FOR

Close family/friends of people living with a non-curative cancer

Avoided financial impacts

$8.1M

The loss of a friend can have broader financial impacts on those around them. The amount and type of financial support from friends or family was varied, with some helping with mortgage repayments, while others took over guardianship of the bereaved children. According to research by the National Cancer Institute in America, up to 34% of Americans diagnosed with cancer borrow money from friends or family to pay for care (48). That figure may vary in Australia.

"I don't know how they did it. The allowance she gave me was a very substantial amount – $100 a week as a 14-year-old until I was 17 and working."

Avoided mental and emotional burden

$600M

The loss of a friend can have a prolonged effect on a person's mental and emotional health, with families describing the intense grief felt by some close friends and family. One bereaved child described the suicidal thoughts her mother's best friend experienced after her death. A study of over 9,500 Australians who had experienced the death of a friend reported poor mental health for these individuals for up to four years (49).

"She was feeling suicidal because she felt the friend she lost was the only person who could truly understand her."

Outcomes for employers

Employers are affected by the death of employees or employee family members. Improving the prognosis and quality of life of people with non-curative cancer, as in this ideal scenario, leads to downstream financial benefits due to higher employee retention, higher work productivity and less time off work.

PROLONGED SURVIVAL AND IMPROVED QUALITY OF LIFE FOR PEOPLE DIAGNOSED WITH NON-CURATIVE CANCER

INTERMEDIATE OUTCOMES

- Less absenteeism from work
- Improved team morale
- Reduced stress in the workplace

FINAL OUTCOMES

1. Higher employee retention
2. Higher work productivity
3. More time at work

$106M

TOTAL VALUE GAINED OVER FIVE YEARS FOR

Employers of people, or partners of people, living with a non-curative cancer

Higher employee retention

$97M

The death of an employee not only has a profound impact on the morale and mental health of the workplace, but also an economic burden on the business. Some studies have calculated the direct cost of hiring new employees by adding up costs across separation, replacement and training activities, while others consider percentages or multiples of the employee's salary in calculating the direct cost of turnover (69). Human Resources Director Australia reported in November 2019 that it costs organisations a staggering $18,982 on average to hire one employee (70). This is considered a conservative estimate, with some sources reporting a cost of up to 1.5 times the employee's salary (69). This financial impact is avoided when people receive an effective technology, therapy or program that improves their prognosis and quality of life, allowing them to continue working.

Higher work productivity

$7.5M

Many employees who have lost a loved one to cancer had an impacted performance at work. This was either due to poor mental health or a result of prioritising time with their family over their time at work. Results from a 2011 study by Medibank Private estimated an average productivity loss of 2.7% due to presenteeism, defined as the lost productivity that occurs when employees come to work but, as a consequence of illness or other medical conditions, are not working at their full capacity (50). This corresponds to a loss of more than six working days per person per year for an average Australian worker – representing the financial impact of reduced employee productivity following bereavement.

More time at work

$1.6M

Employees who suffered a death in their family often needed time off work to arrange the funeral and adapt to life after the loss of their loved one. The National Employment Standards require all organisations in Australia to provide full and part-time employees with at least two days of paid compassionate leave – which represents the minimum financial impact of bereavement to employers (51).

Outcomes for the Australian Government

When cancer causes the death of a parent, reliance on social funding mechanisms may increase. Prolonging and improving the quality of life of people living with non-curative cancer ensures that parents are able to continue to provide for their children without additional funding from government. The Australian Government realises downstream budgetary savings, in this ideal scenario, in the form of avoided increases in childcare support, income support, housing support, mental health services, end-of-life care, drug and alcohol rehabilitation centres and family tax benefits.

PROLONGED SURVIVAL AND IMPROVED QUALITY OF LIFE FOR PEOPLE DIAGNOSED WITH NON-CURATIVE CANCER

FINAL OUTCOMES

1. Avoided income support services
2. Avoided increased demand for mental health services
3. Avoided increased demand for childcare support
4. Avoided cost of drug and alcohol rehabilitation
5. Avoided increased Family Tax Benefits
6. Avoided cost of end-of-life care
7. Avoided increased demand for housing support

$605M

TOTAL VALUE GAINED OVER FIVE YEARS FOR

the Australian Government

Avoided income support services

$68M

Parents who survive a non-curative cancer diagnosis and return to work are less likely to require income support services. The Parenting Payment is a fortnightly payment for the main carer of a child, which can be used by parents experiencing financial stress following a loss of their partner. Along with the increased demand for these services after the death of a partner, a solo parent household can claim higher payments, increasing the overall government spending ($850.20 vs $565.40 per fortnight) (52). This financial impact is avoided when a parent with a non-curative cancer diagnosis can continue to support their family financially.

Avoided increased demand for mental health services

$11.3M

Due to the mental and emotional impact of losing a loved one, family members commonly sought professional help during the grieving process. This is supported by a magnitude of studies, which demonstrate a significant relationship between the onset of a mood, anxiety and alcohol use disorder and the unexpected death of a loved one (31, 32). The Better Access initiative helps people access mental health professionals by subsiding the cost of up to 20 sessions (53). This increase in demand for mental health services is reduced by improving the prognosis and quality of life of people with non-curative cancer using effective technology, therapies, or services.

Avoided increased demand for childcare support

$11.3M

Improving the prognosis and quality of life of people with non-curative cancer ultimately results in fewer families who may require new childcare support. The Child Care Subsidy is the main way the Australian Government helps families with childcare fees. As reported by the Australian Institute of Family Studies, children in families of employed single parents were most likely to be in some form of childcare followed by children with two employed parents (54). This correlates to an increase in the total government-funded childcare subsidies, which is avoided when a parent with a non-curative cancer diagnosis can continue caring for their children.

Avoided cost of drug and alcohol rehabilitation $37M

Studies have revealed a range of behavioural impacts after the loss of a parent, including substance abuse (38, 39). The Australian Government funds a variety of programs designed to prevent negative life-course trajectories, including contributing to 71% of rehabilitation fees (55). Avoiding the mental health and behavioural impacts of losing a parent to cancer results in reduced government spending on rehabilitation.

Avoided increased Family Tax Benefits $10M

Improving the prognosis and quality of life of people with non-curative cancer reduces the financial impacts of losing a parent to cancer and consequently reduces the number of newly solo parents relying on tax benefits. The Family Tax Benefit Part B (FTB B) provides extra support to solo parent families (59, 60), and this financial impact is avoided when a parent with a non-curative cancer diagnosis can continue to support their family financially.

Avoided cost of end-of-life care $443M

There is an extensive array of health care services delivered during the final year of life for a person dying from cancer, with high associated costs (56, 57). In the last year of life people commonly have an increase in the number of hospital episodes, emergency department presentations, and subsidised prescription medicines. As reported by Access Economics, cost of palliative care alone is estimated to be $1,570 per person (58). Data from The Sax Institute's study of over 266,000 people in NSW aged over 45, estimated the total health system costs for a person's last year of life was $49,733 per person (59). These financial impacts are avoided when a parent's prognosis and quality of life is extended using effective technology, therapies, or services.

Avoided increased demand for housing support $14M

The Rent Assistance program aims to improve housing affordability for families experiencing financial stress. As reported by the Commonwealth Department of Family and Community Services, children in single parent households were significantly more likely to claim rent assistance than those in couple families (60). This financial impact may be avoided when a parent with a non-curative cancer diagnosis can continue to support their family financially.

Overall findings

This analysis sought to understand the societal impacts of prolonging and improving the quality of the lives of people with cancer by modelling an ideal world where all parents with non-curative cancer (<5-year prognosis) have funded access to an effective technology, therapy or service that prolongs their survival beyond five years.

The analysis found that for every $1 invested in cancer treatments for parents with non-curative cancer, there is $3.06 of social and economic value created by improving their prognosis and quality of life.

The analysis also found that over the course of five years, investment in new technologies, therapies, and services to improve the prognosis and quality of life of people with non-curative cancer can generate $2.13 billion of social value.

This ultimately demonstrates that, although investing in new therapies can have a high upfront cost, there are substantial downstream social and economic benefits in treating people with the best available technologies.

This analysis focused on a very small proportion of all cancer diagnoses – just those who were the parents of young children and adolescents – because of the clear long-term and far-reaching consequences of the loss, at a young age, of a parent to cancer. But it should be noted that whatever the age of the person diagnosed with cancer, and their family structure, the consequences are no less important. The value demonstrated above may therefore be far greater when considering all other people diagnosed with non-curative cancer.

Including social value in health technology assessments

By placing a monetary value on the many social benefits of treatments, this report demonstrates the sheer scale of the impact on people diagnosed with cancer, and society more broadly, and quantifies those benefits in a way that enables a comparison within our current HTA system. Examples such as higher work productivity, higher employee retention, avoided need for income support services and other avoided public costs are crucial to the functioning and sustainability of societies and economies. Other benefits may not be traditional metrics to assess the value of an investment – such as the ability for parents to care for children, to be present at life milestones, to provide stable family and social relationships, and the avoided mental health impacts in the short and longer-term for children – but are so important to the life-long wellbeing of families.

HTA systems in Australia and around the world have increasingly been criticised for not being sufficiently ‘person-centred’. Despite the benefits of people surviving non-curative cancer diagnoses, we are still failing to recognise this value when assessing new medicines for listing on the PBS. It has also been argued that the approach for assessing the value of health care interventions does not sufficiently incorporate a personal perspective, representing a substantial missed opportunity (61, 62).

The substantial return on investment demonstrated through this analysis indicates that our current system of measuring the value of medicines is only capturing a small proportion of the total benefit generated by treating people with non-curative cancer. When considering the cost-effectiveness of medicines for listing on the PBS, we have lost sight of the fact that beyond the medical benefits, the social benefits of funding life-extending medicines, at an individual level, are priceless.

Recommendations for changing HTAs to be more person-centred have included considering other impacts of treatment, such as the effects on the person’s family, the convenience in receiving care and the development of a model structure for economic evaluation that actually reflects the person’s journey through the various treatment options (61, 63, 64). The Australian Government, through its Strategic Agreement 2022-2027 with Medicines Australia (MA), has committed to conduct an independent HTA review, which is already underway. This timely review offers a unique opportunity to ensure that the true value that cancer treatments deliver to people living with cancer, and beyond, is incorporated in future PBAC decision-making.

How can we put social value at the centre of our HTA system?

Through the Strategic Agreement, the Australian Government and MA have committed to working with patient representatives to co-design and implement a new process to elevate the lived experience and support PBAC assessments (65). The Strategic Agreement states that the '*Enhanced Consumer Engagement Process*' is intended to facilitate the capture of informed consumer perspectives earlier, to effectively inform the assessment of submissions for reimbursement (65).

If we are to overcome the challenges of the HTA system in Australia not being sufficiently person-centred we can, and should, take the opportunity presented by the HTA review and make the changes needed to put people with a lived experience in the centre of the process permanently. This means elevating the position of people with a lived experience and patient organisations as partners within the review process and formalising their engagement with the Strategic Agreement now, and for future agreements.

Capturing personal experience and outcome measures also presents a valuable opportunity to enhance the decision-making processes of the PBAC. In 2021, RCA published a report on the rights and roles of Australians with cancer and called for the Australian Government to establish a formal mechanism that would integrate them as experts in our health system (66). The report further called for the meticulous capture of high-quality data on the lived experience of people with cancer, including their preferences, experience, and outcomes. Delivering on this ask, through the HTA review, would significantly improve the way in which the existing consumer feedback is incorporated into the PBAC's assessments.

Conclusions

The impact on families and young people following a cancer diagnosis is substantial, and reducing the burden caused by that diagnosis has far-reaching benefits – not just for those directly affected, but across society. When the PBAC determines a drug to not be cost-effective for a particular indication, people die and families are torn apart – unless they can raise the many thousands of dollars required to fund their treatment each month. We know firsthand that too many people would not be here today if they had not been able to pay for life-extending treatments that were unavailable on the PBS.

In many cases, the impact of those treatments on people's lives, and the benefits for their families, are considerable and long-lasting – particularly for the children experiencing a parental cancer diagnosis. In other words, the price of not improving the quality of life and prolonging the survival of people diagnosed with non-curative cancer costs more than the financial investment in the treatment intervention. Whether we recognise that, and how we assess the cost-effectiveness of that treatment in the future, through our HTA processes, speaks volumes about the value we place on someone's life once they are diagnosed with cancer and the lifelong impact on their families.

The potential return on investment created by treating people with non-curative cancer and improving their quality of life and prognosis beyond five years, as demonstrated in this report, indicates that our current system of assessing the cost-effectiveness of medicines is not recognising the additional social value generated by cancer treatments. We must now shift our collective thinking from the simple cost of treatments to recognise their additional value and their impact on real people, because that upfront cost is an investment that can reap benefits in the future.

Cost-effectiveness analyses that continue to miss the social benefits of emerging treatments cannot be considered sufficiently person-centred. We need to prioritise and learn from the experiences of people affected by cancer when conducting our assessments and understand what they value most with regards to treatments. Through greater engagement of people with a lived experience of cancer in our HTA processes, we can change the way we value their lives and more accurately ascertain the real-world value of cancer treatments.

> This analysis offers greater insight into the real value of cancer technologies, therapies and services, the difference they can make to society and how we should consider their additional value.

We must now put the needs of people with cancer at the centre of the discussion of value and adapt how we assess the value of their treatment by prioritising them and capturing the social value delivered by their treatments. Otherwise, we must resign ourselves to counting the significant costs of neglecting to treat people and accept responsibility for the devastating consequences of failing to give people more time with their families.

We need to prioritise and learn from the experiences of people affected by cancer when conducting our assessments and understand what they value most with regards to treatments.

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