DONORS WITHOUT BORDERS: Rethinking how Australians fund childhood cancer research

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Contents.

1. Executive Summary 2

2. Prologue: The Lions’ Roar 4

3. MGSM, Health and Third Sector 6

4. Not-For-Profits: Philanthropy 10
   Overview 11
   State of Play 13
   Sources of Donor Dollars 16
   Future Directions 20

5. Health and Medical Research In Australia 28
   Overview 29
   State of Play 32
   Funding for Cancer Research 34
   Future Directions 35

6. Childhood Cancer: A Primer 40
   A Global Burden 40
   Childhood Cancers 42
   Causes of Childhood Cancer 42
   Types of Childhood Cancers 43
   Treatment of Childhood Cancers 44
   Survivorship 45
   Future of Cancer Treatments 46

7. Childhood Cancer Research: A Primer 48
   Slaying the Dragon 49
   The Plan of Attack: The Research Pipeline 50
   Targets of Attack: Cancer Research and the Cancer Continuum 56
   The Cost of Battle 58
   The Crusaders: Childhood Cancer Research Community in Australia 60

8. Moving Forward: A Call to Action 62
   Educate 63
   Collaborate 64
   Donate 65
   Applying ‘Educate, Collaborate, Donate’ To Eliminate Childhood Cancer 66

Appendices 67
1. Executive Summary

The Australian Lions Childhood Cancer Research Foundation (ALCCRF) focuses the efforts of Lions Australia’s 1400 clubs into one foundation with the vision of achieving 100% survival for kids with cancer. It was founded in the belief that Lions could make a difference in the childhood cancer research community.

Lions is renowned for its grassroots Angel investment strategies in health across the globe and is now taking on childhood cancer.

As part of this attack, Lions enlisted the Macquarie Graduate School of Management (MGSM) to provide a study of childhood cancer research and philanthropy in Australia, and make recommendations about how to better address the challenges facing donors in the battle against childhood cancer.
With the help of key opinion leaders in childhood cancer research, philanthropy, government and other stakeholders, the MGSM research team compiled the findings, analyses and evidence-based recommendations that make up this report ‘Donors without Borders: Rethinking Childhood Cancer Research Funding in Australia’.

It became evident that:

• Researchers are mainly driven by the excitement of discovery.
• Donors that give to health and medical research are mainly driven by personal experience with a disease.
• The health and medical research landscape in Australia is fragmented, complex, competitive; funding dollars are limited.
• The philanthropy landscape in Australia is fragmented, complex and crowded, and there is strong competition for the donor dollar.
• The available information on donor investments and research projects is limited and not readily accessible.

There was also a recurring theme throughout the journey:

• Team Treatment. Treatment of a child with cancer demands a ‘team’ approach. One only needs to walk into a ward of a childhood cancer treatment centre to observe the major changes in the transformation of the delivery of care to the patient.
• Team Science. Developing new treatments and cures to conquer childhood cancers requires new thinking. The new knowledge gained in the battles against cancers has shown us that multi-disciplinary and inter-disciplinary collaborations create opportunities for innovations.
• Team Donors? The fragmented yet well-meaning donor base for childhood cancer research has the potential to accelerate the development of new treatments and innovations in Australia that could impact children across the globe. Achieving this, however, would require informed giving and strategic directions for greater collaboration.

The report details why ‘Health and Medical Research’ is from Mars and ‘Philanthropy’ is from Venus, but the sectors need each other to accelerate cures and create stronger health systems to improve the quality of lives of peoples across the world. The key general finding of the report is that new thinking is required about how we approach childhood cancer research, given the rarity of childhood cancer, the new knowledge about ‘cancer’, the high costs of research and the extensive development time required for new therapies. While it is clear that investing in childhood cancer research is a gamble, increased collaboration is able to dramatically improve the odds. The report highlights the importance of and need for different forms of collaboration across all borders in order to help children ‘slay the dragon’ and achieve 100% survival rates for children with cancer.

“…‘Health and Medical Research’ is from Mars and ‘Philanthropy’ is from Venus...”

In particular, this report and accompanying video call for three clear actions to eliminate childhood cancer in Australia and across the globe!

1. Educate. Become an informed donor and spread the word.
2. Collaborate. Across all borders, thinking globally and acting locally.
3. Donate. Co-funding collaborative projects that transcend the borders in science, researchers, cancers and foundations.

The hope is that the childhood cancer community in Australia can translate the findings into tangible actions to build research capacity for childhood cancer research through informed giving. These lessons, in turn, can be shared with childhood cancer communities across the globe.

It is said that ‘it takes a village to raise a child’, but in fact ‘it takes a global village to save a child with cancer’.

Note: The report and the accompanying short animated video are designed as education and advocacy tools for direct donors, donor organisations, the research community, key stakeholders and the general population, and are available for use by foundations and advocates at no cost.
Lions meets the needs of local communities and the world through a global service network of 46,000 clubs and 1.36 million members. The world’s largest service club organisation performs community service in 209 countries, united by a shared core belief that ‘community is what we make it’.

The 1,400 clubs of Lions Australia have a proud history of achievement in disaster and emergency relief, community service and medical research. The fundamental belief in Lions that ‘we serve’, drives a range of health research and support activities in Australia that have transformed the lives of people around the globe. The organisation’s contributions to the development of the bionic ear, support for the young Fred Hollows and funding for a range of research initiatives involving diabetes, autism and cancer are testament to that conviction.
Lions Australia is committed to taking on cancer, the leading cause of death in Australia, on multiple fronts across the nation. It was in the Lions Human Immunology Laboratories at the University of Queensland where Dr Ian H Frazer AC worked towards the development of the first cervical cancer vaccine, Gardasil. Lions Australia has fronted prostate cancer with initiatives such as Blue Steel Week, purchases of state of the art equipment and forward-thinking education and awareness through an internationally acclaimed website. The Lion’s House Foundation provides affordable accommodation for families of patients from rural, interstate and outer metropolitan areas undergoing treatment in South Australia. Lions Cancer Institute funds research into the disease by supporting PhD Students in their studies into cancer and provides free cancer screenings to WA regional communities in partnership with the University of Western Australia. The Lions Medical Research Foundations in South Australia, Queensland and New South Wales fund medical research scholarships to Flinders and Adelaide Universities, as well as other medical research projects.

For nearly 40 years, Lions Australia has supported children with cancer. In the mid/70s the Kurilpa Lions Club supported Dr Trevor Olsen, Brisbane’s first clinical haematologist, with the purchase of a laminar flow bed which was donated to the Mater Hospital. At the time, Dr Olsen was treating a young boy whose father, Bernie Stevenson, was secretary of the Holland Park Lions Club. After watching his young son die from leukaemia, Bernie introduced Dr Olsen to the Holland Park Lions Club, and the Lions Leukaemia Foundation was formed on 9 October 1975. The new foundation set four goals: to provide medical care, patient support, fund research and to educate patients, their families and nursing staff. That foundation today is the Leukaemia Foundation, Australia’s peak body for blood cancer, providing free support services in every state and territory.

Lions formalised its support for childhood cancer research over 18 years ago in establishing the Lions Cord Blood Foundation and Childhood Cancer Research Appeal. Since then, Lions has raised in excess of $7 million for childhood cancer research.

Just five years ago, the Australian Lions Childhood Cancer Research Foundation (ALCCRF) was founded with the belief that Lions could make a difference in the childhood cancer research community by focusing the efforts of Lions Australia’s 1,400 clubs into one foundation with the vision of achieving 100% survival for kids with cancer. In 2014, ALCCRF funds four significant clinical research trials across Australia, and has achieved the Sydney Children’s Hospital Hall of Champions status (over $1 million in donations) in record time.

“...the Australian Lions Childhood Cancer Research Foundation (ALCCRF) was founded with the belief that Lions could make a difference in the childhood cancer research community...”

Lions, renowned for its grassroots Angel investment strategies in health across the globe, was now taking on childhood cancer. The ALCCRF’s commitment to fund the best scientific and clinical research in Australia led the foundation to enter into a strategic partnership with Macquarie Graduate School of Management (MGSM). The initiative was developed to help Lions determine how to achieve the ‘best bang for their buck’. ALCCRF and MGSM, in a commitment to service and engagement with the community, would then share the results with Australia’s cancer research community, the Lions’ global service network and beyond.

It is the hope of ALCCRF to inspire others to work together for a cure for childhood cancers. We believe ‘every child deserves a chance at a healthy life’. It is said that ‘it takes a village to raise a child’, but in fact ‘it takes a global village to save a child with cancer’.

Dr Joe Collins
Founding Chairman and Trustee, ALCCRF
The ALCCRF Trustees identified a need for a ‘strategic blueprint’ to advance their mission and fulfil their vision of 100% survival for children with cancer. They recognised that disease communities like breast cancer and juvenile diabetes had defined clear agendas and strategic priorities for funding.

Investing in childhood cancer research, however, was a different story. There was no ‘one plan’ for childhood cancer research in Australia, so they approached the Macquarie Graduate School of Management (MGSM) to explore the issues.

The ALCCRF Trustees identified a need for a ‘strategic blueprint’ to advance their mission and fulfil their vision of 100% survival for children with cancer. They recognised that disease communities like breast cancer and juvenile diabetes had defined clear agendas and strategic priorities for funding.
MGSM is globally ranked in the top 50 in the world by The Economist Which MBA? and holds AACSB accreditation, a hallmark of excellence in management education. It is the School’s mission to develop leaders with a global mindset who create sustainable value and are good citizens. Through our faculty, staff and students, MGSM aims to remain a leading example of innovative, high-impact, collaborative research.

As part of this mission, MGSM is committed to advancing the leadership and management skills in the health sector and philanthropic community. This project has been undertaken as an opportunity to both serve and contribute to the community in line with this mission. The project also underpins the Macquarie University Vice-Chancellor’s (Professor S. Bruce Dowton) Framing of Futures strategy for service and engagement, particularly in the Health and Third sectors.

The MGSM team, guided by a prestigious multi-sector Steering Committee, embarked on a challenging research journey across this complex terrain. The Committee included renowned academics, a health systems expert, an economic development strategist and a not-for-profit leader.

Initial findings from the literature reviews, web-based research and preliminary interviews undertaken for the study revealed that:

- Researchers are often driven by the excitement of discovery.
- Donors that give to health and medical research are often driven by personal experience with a disease.
- The health and medical research landscape in Australia is fragmented, complex and competitive, and funding dollars are limited.
- The philanthropy landscape in Australia is fragmented, complex and crowded, and there is strong competition among donor organisations for the individual donor dollar.
- The available information on donor investments and research projects is limited and not readily accessible.

It was also evident that in cultural terms it is as if ‘Health and Medical Research’ is from Mars, while ‘Philanthropy’ is from Venus. Yet these very different sectors need to better understand each other and collaborate more effectively in order to accelerate cures and create stronger health systems to improve the quality of lives of peoples across the world.

Childhood cancer communities across the globe face the additional challenge of making childhood cancer research a funding priority, given its rarity. As suggested by experiences in countries like the United States, United Kingdom and Canada, successful national plans to address such issues require respected leadership capable of convening and gaining consensus from the many stakeholders involved.

The hope of the MGSM research team and the Steering Committee is that the childhood cancer community in Australia can translate the findings outlined in this report into tangible actions to build research capacity for childhood cancer research through informed giving.

The ALCCRF Trustees identified a need for a ‘strategic blueprint’ to advance their mission and fulfil their vision of 100% survival for children with cancer.

Chapters 4 and 5 provide a snapshot or ‘state-of-play’ of the environments, issues and future directions for both sectors.

Chapters 6 and 7 seek to address the knowledge gaps evident in the donor community to create better informed donors.

Chapter 8 puts forward recommendations to progress the dialogue in the childhood cancer research community in Australia.
Acknowledgements

This report ‘Donors without Borders: Rethinking Childhood Cancer Research Funding in Australia’ and video ‘Donors without Borders for Childhood Cancer Research’ would not have been possible without the generous contributions of leadership in health, academia, government, NGOs, private sector and philanthropy who came together across borders for the greater good.

The initiative was fortunate to benefit from direct input from leaders in childhood cancer research, the cancer community, the general health and medical research community, key government stakeholders, the philanthropic community, academia, business, hospitals, and cancer survivors. We had the privilege of meeting exceptional minds from across the country in the childhood cancer and cancer community, who passionately believe in a future of hope for a child diagnosed with cancer, in Australia and across the globe.

We’d like to acknowledge the initiative and commitment of the Steering Committee who generously gave of their time, expertise and insights on the journey:

• Dr Joe Collins, whose vision, personal experience and passion for improving the impact of childhood cancer research inspired the project’s inception.
• Prof Mark Compton, AM whose leadership and expertise in health and life sciences guided us through the complexities of the sector and health systems delivery.
• Prof Guy W Ford, whose academic leadership in risk assessment and management guided us through the initial project phases.
• Prof Richard Badham, whose academic leadership in innovation, leadership and organisations guided us through the project completion.
• Mr Bob Buckley, whose leadership, expertise in fundraising and trust afforded us the opportunity to embark on the journey together.
We also recognise the Australian Lion’s Childhood Cancer Research Foundation Board of Trustees for their patience and trust which afforded us the opportunity to embark on the journey together: PCC Bob Buckley, Chairman; PDG John Thorpe, Deputy Chairman; Dr Joe Collins, Founding Chairman; PDG Jim Ede; PDG Peter Lamb; PDG Austin Lanphier; PDG John McIntosh; PCC Lindsay Marsden; PCC Tony Roney; and, PDG David Savage.

A special note of gratitude to the Australian Paediatric Cancer Registry (APCR), who, in collaboration with the Australian Association of Cancer Registries (AACR) and funded by Cancer Council Queensland (CCQ) compiled the latest childhood cancer statistics for Australia, presented in the Childhood Cancer Primer’s ‘Deadly Dozen’ (Chapter 6).

Presumably appreciation and respect to the ingenious Mark Fuda and the 7 Stories team, who generously contributed to the creation of the education and advocacy video ‘Donors without Borders for Childhood Cancer Research’ with their hearts, minds and wallets.

And finally, Professor S Bruce Dowton, Vice-Chancellor of Macquarie University, a paediatrician, clinical geneticist, molecular biologist, researcher and academic, who generously gave of his time and insight early in the project; Professor Alex Frino, Dean of MGSM; and the faculty and staff of MGSM who supported the initiative along the way.
4. Not-For-Profits: Philanthropy

The not-for-profit sector has grown at nearly double the rate of the mining sector, making it the fastest growing part of the Australian economy. In 2012–13, turnover in the not-for-profit (NFP) sector was well over $100 billion.\(^1\)

The size of the sector is due in great part to the broad array of products and services offered including hospitals, art organisations, schools and churches as well as grassroots and community fundraising charities. The United Nations System of National Accounts classifies NFP organisations into twelve groups or ‘industries’. It is important to note at this time that many of the organisations in the ‘childhood cancer community’ are not-for-profit organisations. Hospitals, hospital services, universities, Australia’s independent medical research institutes and social services all depend greatly on government grants for funding, and also compete for limited donor dollars.
Overview

Philanthropy and volunteering is a diverse industry in the NFP sector. It includes individual donors, family, community, and corporate foundations and those that manage, research and promote those activities. There is a surprising lack of general industry information but as a field of study global philanthropy is in its infancy.

External Environment

All organisations, including NFPs, have to address the challenges that arise in their business operating environments. Changes occur constantly and failure to respond can create problems or even the failure of the organisation. The table below provides a snapshot of the external environment facing the philanthropy and volunteering industry in the NFP sector.

NFP Sector (Philanthropy and Volunteering Industry)

<table>
<thead>
<tr>
<th>Drivers of Change</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Political</strong></td>
<td>1. Governments under pressure to tighten budgets increasingly turn to NFPs to deliver services and social outcomes; these, in turn, are susceptible to changes in funding policies.</td>
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<tr>
<td></td>
<td>2. Uncertainty in government policy is an issue – responding to change and uncertainty in government policy is a top priority for NFP boards.¹</td>
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<td>3. Increased regulation from government (e.g. ACNC, ATO) and increased pressures for transparency weigh on NFPs.</td>
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<td>4. Taxation policies for individuals and corporations may have either a positive or negative impact on the likelihood of donors continuing to donate and on the organisation obtaining new donors.</td>
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<tr>
<td><strong>Economic</strong></td>
<td>1. The performance of the economy (e.g. business cycles, GNP trends, interest rates, money supply, cost of living and inflation) is directly related to charitable donations.</td>
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<td></td>
<td>2. Jobs growth or decline will impact disposable income and available time for volunteering. For example, an increase in unemployment creates a decline in donations.</td>
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<tr>
<td></td>
<td>3. Increasing ‘costs of doing business’ have an effect on NFPs and on corporate philanthropy.</td>
</tr>
<tr>
<td><strong>Sociocultural</strong></td>
<td>1. Australians are generous, particularly around natural disasters, where the nation has been ranked as one of the most ‘giving’ nations in the world. There is however a relatively low level of charitable giving to health and medical research as a nation.</td>
</tr>
<tr>
<td></td>
<td>2. Ranked as one of the highest in the world for volunteering, 38% of Australians volunteer their time.</td>
</tr>
<tr>
<td></td>
<td>3. Growing expectations for transparency, effectiveness and ethics for this sector.</td>
</tr>
<tr>
<td></td>
<td>4. NFPs have been referred to as the ‘glue that hold communities together’, creating subcultures of people with shared values, which in turn builds resilience and community wellbeing.</td>
</tr>
<tr>
<td><strong>Technological</strong></td>
<td>1. Technological advances have created new opportunities for not-for-profit communications through the internet (e.g. websites, e-mail, and social media) with a great impact on fundraising and advocacy activities.</td>
</tr>
<tr>
<td></td>
<td>2. Websites, social media, mobile applications and texting have transformed the donor (and volunteer) landscape by turning the ‘passive consumer’ into an ‘active participant’.</td>
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<td></td>
<td>3. Growing trend for crowdfunding, an innovative practice to raise funds through contributions from a large crowd of people, via the internet.</td>
</tr>
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Why Donors Give

Personal experience with illness or disease is the strongest motivation for donating to health and medical research and all areas of research are important for donations. The individual donor’s decision to invest in childhood cancer research can be driven by:

- personal experience, e.g. proximity to a sick child or a grateful patient;
- the desire to make a positive difference in the world, e.g. improve health and save children’s lives across the world;
- impulse, e.g. emotional response to social media campaign;
- empowerment and/or justice, e.g. they want to do something active about the problem and it’s the ‘right thing to do’;
- and/or recognition, e.g. the attention that comes from donating.

Donor organisations, on the other hand, are generally driven by their mission.
4. Not-For-Profits: Philanthropy

**TERMS**

**Philanthropy**: derived from the Greek *philanthropos* means for the 'love of man' or 'love of humanity'. A philanthropist or philanthropic organisation practices philanthropy.

**Not-for-profit (NFP)**: or 'non-profit' does not operate for the profit, personal gain or other benefit of particular people. The broad NFP sector comprises 12 groups or industries.

**Charity**: a 'type of not-for-profit (NFP) organisation with a charitable purpose'.

'Philanthropy' and 'charity' are sometimes used interchangeably, however, the philosophies differ. For purposes of this report, charities are smaller and more personal, with a direct connection to those in need, and philanthropy is larger and more institutional.

**Donor**: the person who gives money voluntarily.

**Donor organisations**: term used to describe 'grant-founding organisation or philanthropic intermediary' (charities and philanthropies).

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**QUICK FACTS**

Australia has around 600,000 not-for-profits (NFPs) and as of 1 July 2014, there were 60,755 charities registered with the ACNC; the net number of charities has grown by 10 percent (nearly 5,700) since October 2011.

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**Drivers of Change**

<table>
<thead>
<tr>
<th>Drivers of Change</th>
<th>Impact</th>
</tr>
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</table>
| Environmental     | 1. Sustainable working practices can influence competition between donor organisations.  
2. Donor organisations are not immune to the increased pressures for individuals and organisations to reduce their carbon footprint.  
3. Natural disasters often affect demand for charity and NFP services, albeit on a short-term basis. |
| Legal             | 1. Legislation around privacy and data protection regulations impact the ways not-for-profits work.  
2. The increased use of multiple technologies for fundraising and advocacy make data protection and donor privacy issues more complex.  
3. Legislation impacting operations. For example, WHS regulations now apply to volunteers. |

**Key Forces in the NFP Sector (Philanthropy and Volunteering Industry)**

The potential sources of pressure within the philanthropy and volunteering industry are competitors, new entrants, substitutes, buyers and suppliers.

<table>
<thead>
<tr>
<th>Pressures</th>
<th>Impact</th>
</tr>
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<tbody>
<tr>
<td><strong>Bargaining power of donors</strong></td>
<td>1. Low. Donor funding is a small percentage of the total cost of health and medical research in childhood cancer.</td>
</tr>
<tr>
<td><strong>Suppliers of resources</strong></td>
<td>2. High. The donor pool is small, and high net wealth (HNW) or major donors are limited and underdeveloped in Australia. There is a relatively low level of charitable and philanthropic giving to health and medical research as a nation.</td>
</tr>
<tr>
<td><strong>Threats of substitutes</strong></td>
<td>3. Low. Charities are important to Australian communities. New models, for example, social enterprises, are in their infancy but growing quickly.</td>
</tr>
<tr>
<td><strong>Threats of new entrants</strong></td>
<td>4. High. Low barriers to entry, increase in number of charities is not sustainable.</td>
</tr>
<tr>
<td><strong>Rivalry among existing donor organisations</strong></td>
<td>5. High. Crowded playing field. Competition in the sector intensifies with increasing number of organisations competing for donor dollars.</td>
</tr>
</tbody>
</table>
State of Play

Complex, diverse and crowded

The Commonwealth’s Charities Act 2013 defines a charity as a ‘type of not-for-profit (NFP) organisation with a charitable purpose’. Charities register with the Australian Charities and Not-for-profits Commission (ACNC) to receive special tax concessions. Curtin University undertook a recent analysis of charities registered with the ACNC and underscored the charity sector’s economic importance, particularly the significant contribution to national employment and the little understanding of this complex sector. The sector reportedly grossed an estimated income of $100b in 2012-13 and employed almost a million people, while mobilising another 2 million as volunteers. It found that 10% of charities accounted for 90% of the income and jobs, while 20–30% of the charities may be inactive or have very low incomes. This is not surprising when large hospitals and educational institutes are lumped with small volunteer organisations in the ‘charities’ sector.

However, the rise in number of charities and increased competition for the donor dollar means that understanding and operating in this sector is not for the faint-hearted. People’s perceptions of how NFPs and charities should operate have been influenced by the increased competition for the donor dollar and advances in technology. Consequently, donor organisations are struggling with increased pressures for transparency and accountability from individual, business and government investors who are demanding better reporting and communicating. Charities Aid Foundation Australia found that 75% of donors do not believe that charities sufficiently communicate how their donations are used. On the other hand, there is also a fear that the trend for ‘corporate reporting’ and transparency will quell the emotional appeal used in attracting donations.

Varying levels of sophistication and governance

Organisations in the crowded landscape also have varying levels of sophistication and governance. The Not-for-Profit Governance and Performance Study conducted by research firm BaxterLawley for the Australian Institute of Company Directors, included directors from entities with an annual income of less than $250,000 through to those earning more than $20 million per year. The report highlights that NFPs are starting to collaborate, more particularly in the health, education and social services sector; 30% of boards have discussed mergers in the past year; NFP governance continues to evolve; and they struggle with performance metrics.

“...the rise in number of charities and increased competition for the donor dollar means that understanding and operating in this sector is not for the faint-hearted.”
4. Not-For-Profits: Philanthropy

**OBSERVATIONS FROM THE FIELD**

**Grant-Making Decisions**

Given the diverse range of donor organisations and differing levels of sophistication in governance, we found donor organisations adopted a wide range of practices in selecting projects for funding. On the more sophisticated end of the spectrum, one organisation uses a research advisory committee comprising cancer experts to determine the key research priorities and assessed projects for the organisation. At the other end, some organisations raise money for a disease and then proceed to 'shop around’ with a larger institution to ‘find them a project’. While this well-intended funding is welcomed, researchers advised us that at times these ‘earmarked projects’ were difficult to place. It is important to note that there are a limited number of renowned cancer experts in Australia, some of whom sit on the government's peer review committees as well as on research advisory committees for donor organisations. Esteemed researchers find it harder and harder to serve in many of these roles given the increasing number of donor organisations, and find it a significant drain on their time.

**Australian Giving**

Australia is a generous nation in times of need. Its response to the 2011 natural disasters elevated it to the 'most generous country in the world' status in the 2012 World Giving Index produced by Charities Aid Foundation (CAF), an international charity that looks at charitable behaviour of more than 130 countries. Despite having dropped six positions in 2013, in a typical month the percentage of Australians who give money to charity, volunteer their time or help a stranger is laudable and recognised on the global stage. However, philanthropy is in its infancy in Australia and there is always room for improvement.

Analyses of Australian giving trends show that fewer people are giving to charity but those who do are giving more. In 2013, charities received a total income of $107 billion, including 6.7% from donations and a further 1.3% from sponsorships. Although there has been an increase in the longer term trend in the amount given per donor, there is a decline in the proportion of taxpayers donating in recent years. According to NAB’s Charitable Giving Index, published in November 2014, Australians each donated $315 to charities annually, an increase of $43 from the previous year. JBTW's annual review of Australian Giving Trends (August 2014) confirmed that despite some signs of recovery over the past year, giving has remained flat since the GFC and points to further stagnation to June 2014.

**Medical Philanthropy or Giving to Health and Medical Research**

Giving to charity manifests itself in many ways. Australian volunteerism in terms of time spent is one of the highest in the world. As Research Australia (2013 Opinion Poll) has reported, however, Australia, as a nation, has a relatively low level of charitable and philanthropic giving to health and medical research. This means that when Australians make charitable and philanthropic donations it is generally to causes other than childhood cancer research. Donations, bequests and grants from philanthropic organisations and trusts are important sources of funding for childhood cancer research and health and medical research in general. However, less than half the population donates regularly to health and medical research; most regular donors donate less than $100, and tax deductions for donations are only are claimed only a little more than half the time, increasing the difficulty in obtaining donation information. Disease-specific organisations are the most likely to receive philanthropic support for health and medical research (55% of Australian donate to these organisations, compared to 37% to hospitals, 33% to MRIs and 4% to universities and academic institutes).

Research Australia endeavours to capture Australian sentiment towards health and medical research through annual opinion polls. Understanding general public sentiment creates opportunities for donor organisations to develop strategies to achieve their goals. For example, the 2012 poll showed that the number one reason for Australians not donating to research was the belief that funding for health and medical research is a government responsibility.

To shift perceptions, childhood cancer research advocates should therefore seek to strengthen public awareness of the need for increased governmental funding as well as design strategies to educate the general donor population on the importance of research. Childhood cancer research stakeholders advocating increased federal and state funding can also emphasise the 2014 poll results that showed 73% of Australians supported additional funding being directed to health and medical research, and 87% of taxpaying voters believed that 'research into diseases that affect children’ should be a priority for the federal government. As part of this initiative, ALCCRF, MGSM and Seven Stories have created an accompanying short animated video (http://alccrf.lions.org.au) designed as an education and advocacy piece for the general population, and for use by foundations and advocates at no cost.
Australian Giving to Cancer

Donors play a greater role in funding health and medical research in Australia than is often recognised. Current reporting practices make it nearly impossible to credit generous donors and philanthropists. Cancer Australia’s recent national audit\(^\text{20}\), for example, states that donors fund less than 1% of the cancer research projects and programs in Australia. While the Australian Government (NHMRC and other Australian Government departments and agencies) are reported as the largest funder of cancer research projects and research programs, and the reported contribution by philanthropy is underrepresented at <1% for projects between 2006–2011. What this neglects, however, is the substantial contribution of philanthropic funding to cancer research via cancer councils, cancer foundations, medical research institutes, hospitals, foundations and universities.

Individual donors, charities and philanthropists donate to ‘Cancer Councils’ (9%); ‘cancer foundations’ (7%); ‘medical research institutes, hospitals, foundations’ (2%); and ‘universities’ (1%) but the amount is virtually impossible to demonstrate given current reporting practices. While philanthropy is still young in Australia, in our estimation the donor contributions to cancer research are closer to 11%.

There is also an absence of available information on childhood cancer research investments at this time. While the dollar amounts of charitable giving is much lower as compared to the United States, philanthropists and donors can still play a catalysing role in health and medical research in Australia.

Improved and consistent reporting by donor organisations could potentially transform donor perceptions of their collective value, the impact they have on treatment of the disease, and the size and direction of future funding.

Charitable giving growth slowed to 6.4% in the year to August 2014, from a peak of almost 9% in early-2014. Difficult economic conditions appear to be playing a role, with sub-trend economic growth, a tepid labour market and subdued consumer confidence unsettling some donors. NAB surveys of consumer anxiety show that concerns over the cost of living remain elevated and in response, one area of spending where consumers are cutting back is charitable donations.\(^\text{21}\)

\textit{— NAB’s Charitable Giving Index – August 2014}\(^\text{22}\)
### Sources of Donor Dollars

Fundraising is a balance of science and art. It requires strategies and procedures to operate as well as strong relationship building and communication with donors.

#### 101 Childhood Cancer Donor Organisations

The childhood cancer community includes disease charities, medical services and treatment charities, medical research charities, and patient and family support charities. These organisations have a broad range of missions from supporting and treating sick children, working on cures for childhood cancers and promoting public awareness. This snapshot of over 100 organisations was created by reviewing online sites including, but not limited to, Philanthropy Australia, ProBono Australia, Third Sector Magazine, children’s hospital foundations, the Association of Australian Medical Research Institutes and the ACNC database. There is no single source of information for the construction of a comprehensive list that includes all the donor organisations relevant to childhood cancer in Australia.

1. Australian Cancer Research Foundation  
2. Australian Lions Childhood Cancer Research Foundation  
3. Anzac Research Institute  
4. Australian Rotary Health  
5. Bear Cottage  
6. Brainchild Foundation  
7. Cabrini Foundation  
8. Camp Quality  
9. Can Assist  
10. Cancer Australia  
11. Cancer Council Australia  
12. Cancer Council Australian Capital Territory  
13. Cancer Council Northern Territory  
14. Cancer Council Queensland  
15. Cancer Council South Australia  
16. Cancer Council Tasmania  
17. Cancer Council Victoria  
18. Cancer Council Western Australia  
19. Cancer In Kids Auxiliary @ RCH (CIKA)  
20. Cancer Voices Australia  
21. CanTeen  
22. Challenge - supporting kids with cancer  
23. Channel Nine  
24. Childhood Cancer Association, Inc  
25. Children’s Cancer Centre Foundation (CCCF)  
26. Children’s Cancer Institute (CCI)  
27. Children’s Hospital Foundation, Queensland  
28. Children’s Leukaemia and Cancer Research Foundation  
29. Children’s Medical Research Institute (CMRI)  
30. Constellation Project Australia  
31. Cure Brain Cancer Foundation  
32. Cure Cancer Australia Foundation  
33. Cure Our Kids  
34. Fight Cancer Foundation  
35. Friends of Ronald McDonald House  
36. Garvan Research Foundation  
37. Hanson Institute  
38. Harry Perkins Institute for Medical Research  
39. Hudson Maher Foundation  
40. Humpty Dumpty Foundation  
41. Hunter Medical Research Institute  
42. John Hunter Children’s Hospital, Newcastle  
43. Kid’s Cancer Centre – Sydney Children’s Hospital, Randwick  
44. Kids Cancer Alliance (KCA)  
45. Kids Research Institute, The Children’s Hospital at Westmead  
46. Kids with Cancer Foundation  
47. KOALA Kids  
48. Kolling Institute of Medical Research  
49. Leila Rose Foundation  
50. Leukaemia Auxiliary of The Royal Children’s Hospital (LARCH)  
51. Leukaemia Foundation  
52. Leukaemia Research Fund  
53. Lions Medical Research Foundation  
54. Little Heroes Foundation  
55. Ludwig Institute for Cancer Research  
56. Make-A-Wish Foundation  
57. Mater Foundation  
58. Menzies Research Institute  
59. Menzies School of Health Research  
60. Monash Children’s Hospital at Southern Health (SH)  
61. Monash Health Foundation  
62. Murdoch Children’s Research Institute (MCRI)  
63. My Room  
64. National Foundation for Medical Research and Innovation  
65. Nelune Foundation  
66. NeuroSurgical Research Foundation  
67. Peter MacCallum Cancer Foundation  
68. Ponting Foundation  
69. Prince Henry’s Institute of Medical Research  
70. Princess Margaret Hospital for Children Foundation (PMH)  
71. Queensland Children’s Medical Research Institute (QCMRI)  
72. Queensland Institute of Medical Research (QIMRI)  
73. Rally for Discovery  
74. Rare Voices Australia  
75. RCH Children’s Cancer Centre (CCC)  
76. Redkite  
77. Ronald McDonald House Charities  
78. Royal Children’s Hospital, Brisbane  
79. Royal Children’s Hospital, Melbourne  
80. South Australian Health and Medical Research Institute (SAHMRI)  
81. St Vincent’s Institute of Medical Research  
82. Starlight Children’s Foundation  
83. Steven Walter Children’s Cancer Foundation  
84. Sydney Children’s Hospital Foundation  
85. Sydney Kids Committee  
86. Telethon Kids Institute, Perth  
87. The Centenary Institute  
88. The Centre for Personalised Cancer Medicine, Adelaide  
89. The Children’s Medical Research Institute (CMRI)  
90. The Children’s Cancer Research Trust  
91. The Children’s Hospital at Westmead  
92. The Kids’ Cancer Project  
93. The Wesley Research Institute  
94. The Women and Children’s Health Research Institute  
95. Variety: The Children’s Charity  
96. Very Special Kids (VSK)  
97. Walter and Eliza Hall Institute of Medical Research  
98. Westmead Medical Research Foundation  
99. Westmead Millennium Institute  
100. Women’s and Children’s Hospital, Adelaide  
101. You Can
5 Types of Donors

NFPs that rely on donations need clear strategies, or a development plan for working with the following donor groups.

1. **Prospects.** People who haven’t yet donated but are potential supporters of childhood cancer research. Timing is important: they need to make a personal connection to your mission, have the funds and know how they can give so they can give, large or small. Message for the organisation: Be Donor Ready!

2. **Individual donors.** Individual donors give for many reasons. Collectively, individual donations are the backbone of the organisation, your most important group as they are likely to donate again and again, albeit smaller amounts.

3. **Major donors.** A major donor is an individual or family with the potential to make or procure a gift which would have a significant impact on the work of your organisation. A major donor is approached and/or ‘cultivated’ using personal relationship development fundraising techniques for the mutual benefit of the organisation and the donor. The gift may be of capital, revenue, time or influence. Cultivating major donors takes time (maybe years) but they tend to give large sums when they decide to give. While some major donors have the capacity to give a large sum annually, others give only strategically in special campaigns. Fundraising organisations must ensure that the ‘gifts’ are used in accordance to the donor’s stipulations. This process of ‘stewardship’ involves timely reports on the use and management of funds and honest communication. It is also important to agree and honour the expected level of recognition and range of benefits offered by the organisation as part of the scheme.

4. **Corporate donors.** These days, few corporations give large donations simply to be philanthropic. The movement for ‘corporate social responsibility’ and ‘creating shared value’ means that corporations may be looking for alignment of missions and other strategic considerations when giving. These donors require a completely different approach than individual and major donors, but should also be a part of an organisation’s development plan.

5. **Foundations.** Not-for-profit organisations that typically either donate funds, e.g. grants and support to other organisations, or provide the source of funding for its own charitable purposes, e.g. giving to childhood cancer research. A private foundation is typically endowed by a family or individual.

**Observations from the Field**

**Researchers’ views on donors**

Researchers expressed gratitude to the donors and recognised the growing importance of the philanthropic dollar. They are, however, challenged by the complexity of the landscape as there are multiple entities, differing criteria, differing processes, and competing demands on their time.

Donor-driven challenges include, but are not limited to:

- **Fragmented landscape.** At the moment there is poor ‘bang for the buck’ because there are well over 100 children’s cancer charities – Cancer Australia acts as a broker for some priority-driven research project but many philanthropic organisations find the parameters too limiting. Researchers need the money, but working with and managing donors is demanding and requires resources.

- **Earmarked donations.** Donor expectations of what/how things can be done are governed by ‘their experience of cancer’. There is a risk of ending up with research of lower quality vs dealing with a burning issue in a disease. There is also the risk of not meeting the needs of philanthropy because many have an ill-conceived concept of how research works. Not all research is easily transferred from one cancer to another.

- **Size of Projects.** Parents sometimes raise money for a specific disease but the population of sick children in Australia is small and managing expectations is difficult. Donors tend to want to fund projects that are discrete and small, but this is not an effective use of donors’ funds. There would be better projects if donors were more open to pooling funds for impact. Panachism is attributed to the small size of funding pools.

- **Project management.** Sometimes researchers are presented with unrealistic reporting requirements. Communications and relationship management can be complex and time-consuming.

- **Use of Funds.** Philanthropy can be very conservative: typically, philanthropists do not like funding facilities and infrastructure but this has been a key factor in higher survival rates. Some charities get very caught up on the detail and won’t fund specific things such as salaries for administrators – we understand this, but this is exactly where funds are needed if clinical trials are to be conducted correctly. Researchers and hospitals need to balance the needs of the clinic (not funded by government) with those of the clinical research associates and difficult decisions need to be made.

- **Relationship management.** Timelines for researchers and philanthropists differ. Researchers are required to spend a lot of time with the donors – is this the best use of their time? Mobility of researchers poses a problem for internal fundraising in hospitals or centres. Fundraising timeline is different than research timeline.

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**“Happier people give more and giving makes people happier, such that happiness and giving may operate in a positive feedback loop.”**


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**Donors without Borders: Rethinking how Australians Fund Childhood Cancer Research**
WHAT DONORS WANT

Donors want to feel valued and that their donations are having an impact. This is achieved through a ‘donor relationship management process’ also known as ‘stewardship’.

WHY DONORS MAY STOP GIVING

1. Many donors stop giving because of ‘communication failures’
   - Charity organisation or research organisation not fulfilling its mandate
   - Disagree with a change of focus
   - Loss of interest in the cause
   - Belief that they are no longer needed
   - Feel that there are more compelling causes
   - Charity organisation or research organisation has not kept in touch

2. Over-solicitation
   - Too many organisations asking
   - A single organisation asking too many times
   - Being asked to give again before being satisfied with what the charity did with the last gift.

3. Household circumstances change

INDIVIDUAL DONORS AND ADVISORS WANT TO AVOID BAD DONATIONS; FOUNDATIONS WANT TO MAXIMISE IMPACT

<table>
<thead>
<tr>
<th>Individuals</th>
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<tr>
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<td>Find acceptable and appropriate charity that fits their clients’ needs</td>
<td>Maximise impact by funding the most effective organisations</td>
</tr>
<tr>
<td>Care about legitimacy, respect, and where their money is going</td>
<td>Care about legitimacy, respect, and how well the charity fits with their client’s desires</td>
<td>High premium on effectiveness, much more so than other groups</td>
</tr>
</tbody>
</table>

RETURN ON PHILANTHROPY

All donors, whether giving spare coffee change for a colleague’s childhood cancer research drive or a ‘platinum level’ hospital foundation donor, want to believe that their contribution is making a difference. Increasingly, philanthropists want to understand their return on philanthropy, impact or ‘bang for their buck’.

Discussions of the social benefits and ‘impact investment’ can be a quite complex and emotional dialogue in childhood cancer, especially since many donors are driven by a personal experience with childhood cancer. Information about the potential and actual social benefits and impacts of the investment are also difficult to find and generate.

GuideStar, an information service specialising in reporting on US non-profit companies conducted comprehensive studies of donor behaviour, motivations, and preferences for charitable giving. They found that donors say that how well a non-profit performs is important, but few actively try to fund the highest performing non-profits. They also found that many donors want information to inform their philanthropic choices, particularly on the effectiveness of non-profits they have never before supported, but they are at a loss as to how to obtain the information.

INDIVIDUAL DONORS AND ADVISORS WANT TO AVOID BAD DONATIONS; FOUNDATIONS WANT TO MAXIMISE IMPACT

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Measuring performance and impact (change) is not the same. Donors and not-for-profits alike are deeply invested in creating the change they seek, as efficiently and as effectively as possible. Managing communications and expectations are challenging, but it is important to note that the central questions are the same: Did I do what I set out to do? Is it making the difference I seek? How can I do it better?29

Evaluating Investments
There is no ‘one-size fits all’ approach to the process of selecting recipient research organisations. Researchers within the same field may pursue different strategies to reach the same endpoint and research organisations are distinct and diverse. There are no guarantees of success or value to patient, but new knowledge through research is the only hope for many.

“There is no ‘one-size fits all’ approach to the process of selecting recipient research organisations.”

Informed giving ensures a better return on donor dollars. Our research found that in the general community there were very different levels of understanding of childhood cancer and the R&D process for finding better cures and treatments. Chapters 6 and 7 provide ‘primers’ for childhood cancer, and the research process for finding better treatments seeks to elevate the level of understanding of childhood cancer research for meaningful conversations and tangible actions. Appendix 2 provides further guidance to donor organisations on the topic of ‘impact’.

OBSERVATIONS FROM THE FIELD
For the most part, research is driven by the researcher’s burning desire to solve a scientific problem. Philanthropic funding for this research is raised and motivated by an emotional drive to save a child’s life. We are therefore challenged by competing success metrics when evaluating a ‘return on investment’ in childhood cancer research. Research investments and expected returns are not clear to philanthropy. Investments at different points of the cancer continuum will have differing levels of potential impact. Potential outcomes include, but are not limited to, lives saved, cancers averted, quality of life improved, contribution to science (journal articles), impact and changes to healthcare management (expenditures, policy) etc. What is the expected immediacy of impact—0–2 years; 2–4 years; 5+ years?

If childhood cancer research in Australia follows the Juvenile Childhood Diabetes Foundation approach and focuses on high quality journal publication as the primary measure of success, how will this impact the potential for blue-sky or ‘start-up/seed’ funding in childhood cancer research? Should there be venture capital without a ‘return on science’? Resources are limited and governments are not keen on funding infrastructure or longitudinal studies. How can impact be measured in these areas?
CASE STUDY

Faces of Major Donors

By understanding the motivations of affluent individual donors to contribute, those responsible for working with and advising the major donors can be more effective in helping them to successfully meet their giving objectives. The 7 Faces framework identifies seven major types of major donors and offers detailed strategies on how to approach them.

1. The **Communitarian** gives out of a sense of belonging to a community because ‘Doing Good Makes Sense’.
2. The **Devout** is motivated by faith and gives because ‘Doing Good is God’s Will’.
3. The **Investor** views money as a means to create social change and gives because ‘Doing Good is Good Business’.
4. The **Socialite** participates in philanthropy as a social activity and gives because ‘Doing Good is Fun’.
5. The **Altruist** sees philanthropy as a way to fulfil their life purpose and gives because ‘Doing Good Feels Right’.
6. The **Repayer** gives out of a sense of gratitude because ‘Doing Good in Return’.
7. The **Dynasts** are born into families with deeply embedded philanthropic traditions and gives because ‘Doing Good is a Family Tradition’.

Future Directions

Donors without Borders

Investing in research is a gamble, but collaboration improves the odds in the battle against childhood cancer. Winning the war will require new thinking in how projects are designed and funded. There are three key ways in which charities can work together: mergers, partnerships, and collaborations. These three options include: within collaborations, ideas like sharing resources; within partnerships, ideas such as combining fundraising efforts; and within mergers, two charities combining to become one entity.

Terms like ‘partnering’ and ‘collaboration’ are used frequently – but what does this mean? It is useful to think of collaboration as a spectrum of activity that ranges from loose coordination and informal information sharing to intense focused, collective impact campaigns.

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informal cooperation between donors</td>
<td>Donor organisations share grant agreement templates and evaluation best practices.</td>
</tr>
<tr>
<td>Coordination among donors with an issue</td>
<td>A donor joins an issue affinity group, learns about and shares knowledge and embraces best practices.</td>
</tr>
<tr>
<td>Participation in coalitions and alliances</td>
<td>A donor funds and joins a coalition and writes an op-ed advocating for the group’s policy agenda.</td>
</tr>
<tr>
<td>Collective impact through peer networks</td>
<td>A donor funds, joins and actively participates in collective action and holds itself and its peers accountable to common goals using agreed-upon metrics.</td>
</tr>
</tbody>
</table>

**Figure 2:** The Spectrum of Donor Collaboration.
Many foundations are driven by their mission or mindset to limit their work within a specific geography, e.g.: funds must be invested in the state in which they are raised. However, given the rarity of children’s cancers and the increasing costs of cancer research, it is not feasible to replicate world-class research infrastructure across all Australian communities. Organisations with these funding constraints are invited to ‘think globally and act locally’ by considering collaborations across geographic borders for greater impact, and funding the implementation of research outcomes in their healthcare delivery system to ensure children in their community have access to the new treatments. Much of the improvement in childhood cancer survival rates in the past 20 years is attributed to improved protocols in the standards of care, but not all children across globe readily have access to treatment. Given the rarity of childhood cancer and the development of international protocols for treatment, it is important to keep in mind that investments in childhood cancer research have the potential to impact the quality of life of a child across the dining room table, across the country and across the globe.

**CASE STUDY**

‘Participation in Coalitions and Alliances’:
Third Sector alliance to further national research priorities

Nine of Australia’s most prominent national community-supported cancer organisations (Bowel Cancer Australia, Cancer Australia, Cancer Council Australia, Cancer Voices Australia, Cure Cancer Australia Foundation, Leukaemia Foundation, Melanoma Institute, National Breast Cancer Foundation, Prostate Cancer Foundation) joined forces to create the Cancer Research Leadership Forum³³ [CRLF]. The alliance is dedicated to reducing the burden of cancer in Australia by uniting their voices. CRLF created a whitepaper ‘Towards a national cancer research plan’, convened stakeholders in the cancer community in a National Cancer Research Summit and compiled the results of the dialogue in ‘Maximising the Impact of Cancer Research Funding in Australia: A national resource to guide research investment and cancer outcomes’.

Many of the issues³⁴ and funding gaps raised during the National Cancer Research Summit echoed the Strategic Review of Health and Medical Research in Australia, and were reaffirmed by anecdotal evidence from our research in the field in interviews with key opinion leaders in childhood cancer research:

- Opportunity losses due to gaps in national coordination between the multiple funders of the research
- Challenges for current funding mechanisms to support research priorities and long-term research
- Onerous peer and ethical review processes
- Restrictions on research activity in the health system, and opportunities to better integrate and translate research into clinical care
- Core skill gaps, and the need for greater support for early to mid-career researchers, to attract and retain higher quality cancer researchers and build capacity
- The need to establish and maintain enabling infrastructure and technologies, and more adequately funded indirect research costs.

**OBSERVATIONS FROM THE FIELD**

Childhood cancer research in Australia relies on a fragmented donor base, and although well-intended and motivated, was unaware of a ‘better use/return of their philanthropic dollars’ for impact.
In 1999 and 2000, the American Cancer Society convened two meetings of representatives from 30 national organisations, both public and private, working in the field of childhood cancer with the intention of improving collaboration between stakeholders. The group concentrated its efforts in five principal areas:

1. **Access to care and patterns of care**
2. **Advocacy and professional issues**
3. **Long-term care and survivorship**
4. **Patient and family quality of life**
5. **Research priorities**

### Summary of Workgroup Recommendations

**Access to Care and Patterns of Care**
- Assure that all children and adolescents suspected of having cancer are referred initially to a paediatric cancer centre and have their care coordinated by the centre.
- Establish national standards of quality care for children and adolescents with cancer, both medical and psychosocial, as defined by healthcare professionals and patient advocates.
- Quantify current patterns, quality, and outcomes of all phases of childhood and adolescent cancer care.
- Increase participation of children and adolescents in all phases of approved clinical trials.

**Advocacy and Professional Issues**
- Ensure access to comprehensive, multidisciplinary cancer care for children and adolescents with cancer.
- Assess the need for fellowships and scholarships for training in all disciplines of paediatric oncology.
- Accelerate the application of new therapeutic technologies to children with cancer.

**Long-term Care and Survivorship**
- Develop a comprehensive intervention strategy to provide screening and/or treatment for survivors at risk for specific late effects consisting of the following three components: (i) identification of the concerns of survivors of childhood and adolescent cancer, their families, and their health care providers about late effects; (ii) development of educational materials designed to increase the knowledge of both survivors of childhood and adolescent cancer and their health care providers about these late effects; (iii) evaluation of the ability of these educational materials to motivate survivors to self-advocate in order to receive care for the late effects of childhood cancer.
- Using evidence-based methodology, establish a national standard for health maintenance of childhood cancer survivors, including physical, neuro-cognitive, and psychosocial functioning.
- Develop a national paediatric cancer survivor database consisting of existing survivors, and providing prospective enrolment.

**Patient and Family Quality of Life**
- Study the effects of childhood cancer on family function and quality of life (QOL) and develop appropriate culturally sensitive interventions for positive outcomes.
- Develop and implement QOL assessment tools that are specific for stages of disease and phases of care across the continuum of care.
- Define the required components of psychosocial support.

**Research Priorities**
- Develop the necessary infrastructure to support clinical research.
- Apply and develop efficient mechanisms for timely application of effective new treatments.
- Recruit, train, mentor, and retain skilled research professionals.
- Prioritize emerging research initiative.
CASE STUDY

A National Alliance for Childhood Cancer

The Alliance for Childhood Cancer represents more than twenty national patient advocacy groups and professional medical and scientific organisations.

- These organisations meet regularly in Washington, D.C., to share ideas and concerns and work collaboratively to advance policies leading to improved research, public education, and diagnosis, treatment, supportive care and survivorship for children and adolescents with cancer.

- The concept for the Alliance for Childhood Cancer emerged from the National Summit Meetings on Childhood Cancer in 1999 and 2000, sponsored by the American Cancer Society. The Summit participants created a task force to implement the recommendations from the summit. One recommendation was to establish an alliance of concerned parties that would increase awareness of childhood cancer, advance research and policies to prevent cancer and improve diagnosis, treatment, supportive care and survivorship of children and adolescents with cancer. The American Society of Clinical Oncology (ASCO) facilitated the groundwork and the Alliance for Childhood Cancer was officially launched on September 12, 2001. ASCO continues to provide support for the work of the Alliance.

Members

- Patient Advocate Seat
- Professional Society Seat

Partner Organisations

- American Brain Tumor Foundation
- American Pediatric Surgical Association
- American Psychological Association
- American Society for Radiation Oncology
- Cancer Support Community
- Chai Lifeline
- Kids V Cancer
- National Brain Tumor Society
- National Coalition for Cancer Survivorship
- Patient Advocate Foundation

Member Organisations

- American Academy of Pediatrics
- American Cancer Society
- American Cancer Society Cancer Action Network
- American Childhood Cancer Organization
- American Society of Clinical Oncology
- American Society of Pediatric Hematology/Oncology
- Association of Pediatric Hematology-Oncology Nurses
- Association of Pediatric Oncology Social Workers
- B+ Foundation
- Children’s Brain Tumor Foundation
- Children’s Cause for Cancer Advocacy
- Children’s Oncology Group
- CureSearch for Children’s Cancer
- Leukemia and Lymphoma Society
- National Children’s Cancer Society
- Pediatric Brain Tumor Foundation
- Sarcoma Foundation of America
- Society of Pediatric Psychology
- St. Baldrick’s Foundation
New Models of Philanthropy

Conventional Philanthropy

The childhood cancer community in Australia has many organisations that operate ‘conventionally’. Traditional or ‘conventional’ philanthropy serves an essential function in supporting major NFPs, touching many lives and providing assistance to many in need.

These organisations are the bedrock of philanthropy in Australia. However, each organisation functions alone, pursuing the strategies that it deems best, lacking the infrastructure to learn from one another’s best practices, the clout to influence government, or to scale to achieve national impact. The fragmented nature of the community could, however, be transformed with the development of a ‘national action plan’ for childhood cancer or alliance of organisations with the strength to influence directions or priorities for funding.

<table>
<thead>
<tr>
<th>What is the key question?</th>
<th>Conventional Philanthropy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Which organisation should I support and how much money do I give it?</td>
<td></td>
</tr>
<tr>
<td>Who is responsible for success?</td>
<td>Not-for-profits</td>
</tr>
<tr>
<td>What gets funded?</td>
<td>Individual Not-for-profits</td>
</tr>
<tr>
<td>What are the tools used?</td>
<td>Not-for-profit programs</td>
</tr>
<tr>
<td>How is the information used?</td>
<td>To compare grant requests</td>
</tr>
</tbody>
</table>

Venture and Catalytic Philanthropy

The turn of the new century saw the emergence of ‘new philanthropy’ characterised by wealthy individuals who take a hands-on approach to philanthropy, donating talent, experience, skills and access to networks as well as their money. Philanthropcapitalism, has been used to describe the actions of Bill Gates and Warren Buffet who adopt a business-like approach, prefer to maximise the impact of their money by becoming involved and embrace ‘giving while living’ rather than endowing foundations in perpetuity. ‘Venture philanthropists’ apply the principles of venture capital, giving the organisation management support, specialist expertise and financial resources, and aim for a social rather than a financial return. Venture philanthropy and social enterprise (a model that creates social change through some kind commercial enterprise) also play important roles by helping effective leaders scale impact. These approaches rely on a comprehensive assessment of the impact of giving, and therefore there is a need for clear measurable outcomes. The new catalytic approach to philanthropy seeks social change. Catalytic philanthropists differentiate themselves through four distinct practices: 1) they take responsibility for achieving the results they seek; 2) they engage others and mobilise a campaign for change; 3) they use all available tools to create change e.g. corporate resources, investment capital, advocacy and litigation; and 4) they create actionable knowledge to improve their own effectiveness and to influence the behaviours of others.
There is a growing trend overseas, particularly in medical philanthropy, for a new breed of donors in the form of venture or catalytic philanthropists. Organisations like FasterCures, a centre of the Milken Institute, is an action tank driven by a singular goal — to save lives by speeding up and improving the medical research system. The group seeks to speed the medical research process in the US, and among its activities provides tools and resources for venture philanthropists. This is not appropriate for all donors and does not imply that other philanthropic engagement is ineffective. Donors who are serious about solving a social problem can also take a catalytic role. Catalytic philanthropists will be the smaller set of donors who have the opportunity and desire for change.

<table>
<thead>
<tr>
<th></th>
<th>Venture Philanthropy</th>
<th>Catalytic Philanthropy</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the key question?</td>
<td>How can I help to scale up effective not-for-profit organisations?</td>
<td>How can I catalyse a campaign that achieves measurable impact?</td>
</tr>
<tr>
<td>Who is responsible for success?</td>
<td>Not-for-profits</td>
<td>Funders</td>
</tr>
<tr>
<td>What gets funded?</td>
<td>Capacity building at individual not-for-profits</td>
<td>Multi-sector campaign</td>
</tr>
<tr>
<td>What are the tools used?</td>
<td>Not-for-profit programs</td>
<td>All possible tools and donor resources</td>
</tr>
<tr>
<td>How is the information used?</td>
<td>To increase organisational effectiveness</td>
<td>To support the campaign and motivate change</td>
</tr>
</tbody>
</table>

**Figure 3:** Common Versus Catalytic Donor Mind-set.

Goal: Give grants to worthy charities.

Goal: Leverage across sectors to create change.
CASE STUDY

HIV/AIDS Advocacy as Model for Catalysing Change

"HIV/AIDS movement was born out of fear and anger. The activists who led this movement acknowledge that there was no master plan at the beginning. They were individuals who were not brought together by choice but rather by a crisis, and they banded together out of desperation and fear. They charted their own course, focused a nation’s attention on a specific disease, created the political will, and forged relationships with policy makers and regulators that resulted in saving the lives of millions of people."

People affected by HIV rallied together and created an advocacy movement that demanded change and got real results. The elements of the HIV/AIDS advocacy model included:

1. **Attention**: Creating the political will to transform policies.
2. **Knowledge and Solutions**: Shaping the discussion and getting answers.
3. **Community**: Working together for the same cause.
4. **Accountability**: Implementing strategy that holds all stakeholders accountable.
5. **Leadership**: Inspiring and motivating people to act on a shared vision.

Michael Manganiello, HCM Strategists and Margaret Anderson, FasterCures
References

27. Ibid
31. Ibid
43. Ibid.
44. Ibid.
Health and medical research is a core component of the Health sector which includes health professionals, consumers, businesses, not-for-profit organisations and governments. Its purpose is to achieve better health outcomes.

In Australia, health and medical research supports innovation in its $135b p.a. health sector and is vital for delivering health outcomes, creating national wealth and ensuring efficiency in the health system. This chapter adopts a holistic view of health and medical research ‘industry’ and seeks to provide childhood cancer research advocates with a clearer picture of the context and ‘industry’ in which childhood cancer researchers operate. It is through innovation in health and medical research that better treatments and cures can be achieved for children with cancer.
Overview

*Health and Medical Research* takes place in universities and hospitals, health services and medical research institutes, government agencies, as well as pharmaceutical, biotechnology and medical device companies. Health and medical research embraces a range of different disciplines including biology, engineering, biotechnology, epidemiology, medicine, psychology, nursing, allied health, population studies, information technology, mathematics, economics and health services research. For any one disease, different disciplines need to work together. The health and medical research ‘industry’ within the health sector is diverse and highly complex with many stakeholders and types of activities, as depicted in the figure above.

"The health and medical research ‘industry’ within the health sector is diverse and highly complex with many stakeholders and types of activities..."
WHY RESEARCHERS RESEARCH? 
A study commissioned by Research Australia found that researchers are predominantly motivated by the ‘excitement of discovery’, rather than salary, community recognition or the potential for personal wealth from the commercialisation of their discoveries. Publications are viewed as a more important research outcome than the patenting of research findings or creation of new businesses. While some view publications as a measure of productivity versus research impact, it is acknowledged that it is a key metric in formula funding and therefore an important output and benefit of their research careers.

External Environment
All organisations in the health and medical research ‘industry’ have to address the challenges that arise in their business operating environments. Changes occur constantly and failure to respond can create problems or even the failure of the organisation.

Health Sector (Health and Medical Research Industry)

<table>
<thead>
<tr>
<th>Drivers of Change</th>
<th>Impact</th>
</tr>
</thead>
</table>
| **Political**      | 1. Federal and state government budgeted health expenditure dramatically affects the available funding pool for the many research organisations.  
2. Government changes to policies for health and medical research investments e.g. NHMRC, ARC, Cancer Australia, strategic priorities, proposed Medical Research Future Fund, priority-driven research, training and retention programs, and infrastructure have an impact on research organisations.  
3. The Federal Government is under pressure to turn around a low level of business expenditure on research and development (BERD), and investment policies affect the sector.  
4. Changes to taxation policies impact research organisations (public, private and NFP), as well as incentives or disincentives for alliances and output activities.  
5. Health insurance policies and practices impact the research organisations and health system implementation. |
| **Economic**       | 1. The performance of the economy (e.g. Unemployment rates, business cycles, GNP trends, interest rates, money supply, cost of living and inflation) influences governments’ capacity to allocate funds to health and medical research.  
2. Business investment is not solely dependent on economic conditions since projects are multi-year, but economic conditions can still affect their projects.  
3. Rising cost of healthcare delivery and ‘cure vs care’ tensions impact available resources for research.  
4. Rising cost and variable costs of research impact research capacity and output.  
5. Globalisation of research teams and funding opportunities impact research organisation.  
6. New market opportunities in developing countries create opportunities for researchers.  
7. General economic conditions, the cost and quality of local scientific research, and the level of government support affect business expenditure on research and development (BERD), and this in turn impacts the sector.  
8. Falling funding levels in Australian scientific research have led to an increasing level of collaboration between not-for-profit research institutions and private companies and groups, e.g. Cooperative Research Centres (CRCs), which have created a greater commercial imperative in the research process. |
FUTURE FUNDING?

The Medical Research Future Fund (MRFF) provides a sustainable investment in health and medical research that will have significant benefits for both the health of our population and for our economy.

– Dr Chris Roberts, CEO and President, Cochlear Limited and MGSM alumnus

QUICK FACTS

The Association of Australian Medical Research Institutes (AAMRI) is the peak body for medical research institutes (MRIs) across Australia. AAMRI’s member organisations are internationally recognised leaders in health and medical research. Their research ranges from fundamental biomedical discovery through to clinical research and the translation of research findings from bench to bedside.

The 45 members are primarily co-located with major teaching hospitals and provide a unique interface between research and healthcare delivery. Over 10,000 staff and students are employed in Australia’s independent medical research institutes.

Drivers of Change | Impact
---|---
Sociocultural | 1. Ageing population and higher incidence of chronic disease.
| 2. Population distribution (rural vs metro), regional economies.
| 3. Consumer demand for better health services, increased longevity and quality of life.
| 4. Crowdfunding for innovation.
Technological | 1. Advances in technology have brought large benefits but have also been a major driver of increased health spending.
| 2. Opportunity for sharing of infrastructure between research groups.
| 4. Increased importance of bio-banking and big data for evidence-based research, electronic submissions of publications.
| 5. Streamlining of grant application processes online.
Environmental | 1. Sustainable work practices can influence organisations’ performance.
| 2. Research organisations are not immune to the increased pressures for individuals and organisations to reduce their carbon footprint.
Legal | 1. Legislation around privacy and data protection regulations.
| 2. Ethics in health and medical research and implementation of outcomes.

Key Forces in the Health Sector (Health and Medical Research Industry)

The potential sources of environmental pressures for health and medical research organisations are competitors, new entrants, substitutes, buyers and suppliers.

Pressures | Impact
---|---
Bargaining power of research organisations | Medium. Australian health and medical research is supported by Commonwealth and State governments, private companies and the not-for-profit sector. Health and medical research takes place in academic institutions, medical research institutes, hospitals and private companies. Players in the industry range from large, multinational corporations competing for numerous government and private contracts to smaller, geographically specific institutions that lack resources but may specialise in a particular field of research.
Suppliers of resources | Low. Health and medical research takes place in academic institutions, medical research institutes, hospitals and private companies.
Threats of substitutes | High. Research by nature is competitive; the globalisation of research creates opportunities for mobility of the world’s best researchers and sources of funding.
Threats of new entrants | Low. Barriers to entry because the costs of setting up a research facility are extremely high (highly qualified staff, equipment and processes).
Rivalry among existing research organisations | High. Competition for investment is intense; researchers by nature are generally competitive, are mobile, and funding is limited. Modern health and medical research demands greater collaboration for innovation.
Key opinion leaders provided the following general thoughts on ‘good research’ in the childhood cancer research space:

- It must be solution-driven;
- A truly translatable project based on solid basic research;
- Ends up in a clinical trial and has evidence of impact on health policy or practice;
- Impacts the current model of care;
- Has considered the end game and all the ‘touchpoints’ from the beginning;
- Involves clinicians; a project that can move from a state to a national and international level.

There are eminent scientists in Australia producing world class research. Sustaining and developing this level of expertise and creating a climate for future innovators demands a clear strategy and funding for developing future researchers and clinicians. The role of philanthropy in funding this pipeline of innovators is yet to be defined, but is important for the future of childhood cancer research in Australia.

**State of Play**

**Complex and underfunded**

The timely publication of the 2013 Strategic Review of Health and Medical Research in Australia (the ‘McKeon Report’) included in-depth analyses and a recommended blueprint for delivering ‘Better Health through Research’ for Australians. The report highlighted the complexity, structural issues and lack of funding.

**Yet Innovative**

In 2014, Australia achieved its highest ranking (17) in the Global Innovation Index Report which measures the pace of innovation of more than 140 countries. Despite its short history Australia has created a number of inventions in the last 200 years that places it at a level well above what would be expected for a country of its population. Transformational advances in health and medicine such as the electronic pacemaker (1926), the use of lithium carbonate in the treatment of bipolar disorder (1948), the bionic ear (1978) and the world’s first vaccine to prevent cervical cancer Gardasil (1990) have put Australia on the global stage of research and development. Australia is home to world leading researchers who collaborate with researchers across the world.

**Funding for Health and Medical Research**

Across the world governments, private companies and philanthropists invest in health and medical research but the demand for funding exceeds the supply. Governments (with taxpayers and voters) and private companies (with shareholders) make more conservative investments, leaving large funding gaps.

Australian governments invest approximately $4 billion per year in health and medical research, mostly from the Federal Government. The National Health and Medical Research Council (NHMRC) is the Commonwealth’s primary agency for funding health and medical research, and approves fewer than 20% of all applications received68. Half of Australian health and medical research takes place in academic institutions.

**International comparisons**

The United States government gave its National Institutes of Health (NIH) $30 billion in annual funding in 2013; the European collective government spent over $29 billion; Japan’s government $9 billion; and in 2012 the Australian government gave over $850 million to the National Health and Medical Research Council (NHMRC) which allocated 1,300 grants across the country. Leading OECD countries have set investment targets of at least 3% of total GDP for competitiveness.

The Australian Government currently invests 0.075 percent of its GDP in health and medical research, just 64 percent of the OECD average. Australia does not have large philanthropic organisations like the Wellcome Trust (with an endowment of just over $29 million) or a Bill and Melinda Gates Foundation, that have defined health and medical research in the UK and US.

The proposed $20 billion perpetual Medical Research Future Fund (MRFF) has ‘the potential to improve lives of Australians, transform the economy and reduce future health expenditures’59 – potentially levelling the playing field in Australia. However there is a need to manage expectations in regards to this fund. The Abbott Government expects to make its first distribution of $20 million to medical research in the 2015–2016 financial year, but it is not until 2022–23 that it is projected to distribute about $1 billion a year bringing the level of government support to a more competitive OECD level during the next decade.
### Figure 5: Australia’s investment in health and R&D as a proportion of GDP is slightly below the OECD average.\(^6\)

<table>
<thead>
<tr>
<th>Country</th>
<th>Public Health Expenditure as % of GDP</th>
<th>Government Health R&amp;D as % of GDP</th>
</tr>
</thead>
<tbody>
<tr>
<td>US</td>
<td>9.1</td>
<td>0.31</td>
</tr>
<tr>
<td>France</td>
<td>11.8</td>
<td>0.05*</td>
</tr>
<tr>
<td>Germany</td>
<td>11.6</td>
<td>0.04</td>
</tr>
<tr>
<td>Denmark</td>
<td>11.5</td>
<td>0.08*</td>
</tr>
<tr>
<td>Canada</td>
<td>11.4</td>
<td>0.10</td>
</tr>
<tr>
<td>Switzerland</td>
<td>11.4*</td>
<td>0.00*</td>
</tr>
<tr>
<td>Sweden</td>
<td>10.0</td>
<td>0.01</td>
</tr>
<tr>
<td>UK</td>
<td>9.8</td>
<td>0.11*</td>
</tr>
<tr>
<td>OECD Average</td>
<td>9.6</td>
<td>0.11*</td>
</tr>
<tr>
<td>Australia</td>
<td>8.7</td>
<td>0.09</td>
</tr>
<tr>
<td>Japan</td>
<td>8.5*</td>
<td>0.03*</td>
</tr>
<tr>
<td>Israel</td>
<td>7.8</td>
<td>0.01*</td>
</tr>
</tbody>
</table>


### Figure 6: Target R&D Benchmarks for top 20 OECD Nations – Country Targets (not actual).\(^5\)

Leading OECD countries have adopted R&D targets of at least 3% of GDP.

![Diagram showing R&D benchmarks for top 20 OECD nations.](image)

The National Research Investment Plan (2012) recommends an R&D target of 3% of GDP.

Average 3.2

Source: Australian Government, National Research Investment Plan, 2012; OECD; UNESCO
QUICK FACTS
Research Australia® is an alliance of 160 members and supporters advocating for health and medical research in Australia. Independent of government, Research Australia's activities are funded by its partners, donors and supporters from leading research organisations, academic institutions, philanthropy, community special interest groups, peak industry bodies, biotechnology, medical technology and pharmaceutical companies, small businesses and corporate Australia.

OBSERVATIONS FROM THE FIELD
Government funding for childhood cancer research is not a national priority in Australia, but it is the biggest killer of Australian children from disease.

Sources of Funding For Health and Medical Research
The table below details expenditure on health and medical research by the source of funding – i.e. who pays for it, as distinct from who actually does it in 2010–2011.

<table>
<thead>
<tr>
<th>Source</th>
<th>Australian Government</th>
<th>States and Territories</th>
<th>Private Non-profit</th>
<th>Business</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>$million</td>
<td>3,297</td>
<td>776</td>
<td>259</td>
<td>1,220</td>
<td>5,552</td>
</tr>
<tr>
<td>% of total</td>
<td>59</td>
<td>14</td>
<td>5</td>
<td>22</td>
<td>100</td>
</tr>
</tbody>
</table>

Source: for all except business is AIHW, Health Expenditure Australia, 2010–11 p.76. Business sourced from ABS, 8104.0 R&D Businesses, Australia, 2010–11 Table 3, sum of Health and Human Pharmaceutical Products.

Funding for Cancer Research
Cancer Australia’s recently published National Audit, Cancer Research in Australia: an overview of funding to cancer research programs in Australia 2006 to 2011, builds on Cancer Australia’s previous audit of 2003 to 2005, and provides a comparison of direct funding to cancer research projects and programs nationally and internationally.

Key Highlights of the Report
- **Funding:** More than $1 billion was provided between 2006 and 2011, a total of $1.3 billion from 2003 to 2011. Total funding more than doubled and the number of research projects progressively increased from 2003 to 2011. The Australian Government provided 66% of total funding ($856 million).
- **Collaboration:** Between 2006 and 2011, 90% of research projects were supported by a single funding source. The percentage of research projects from 2003 to 2011 that involved collaborators increased from 58% to 65%.
- **Funding to tumour-specific research:** increased more than 3-fold from 2003 to 2011 and total funding and the number of research projects increased for all tumour types, with the notable exception of cancer of unknown primary. The funding to research projects and programs investigating specific tumour types did not always correlate well with the burden of the disease.
- **Research categories:** Total funding and the number of research projects increased from 2003 to 2011 in all cancer research categories, except for Prevention. In proportional terms, funding decreased to the research category of Biology and increased to Early Detection, Diagnosis and Prognosis, and Treatment.
- **International Comparisons:** The national pattern of funding to cancer research categories in Australia was broadly similar to Canada and the UK.
Future Directions

Future of Health Care and Role of Research

Healthcare systems in the industrialised world are in crisis with unprecedented pressures from markets, policy, rising costs and providers. Fundamental changes are required. A transformation to an overarching strategy driven by the creation of ‘value-based healthcare’, or maximising value for patients (achieving the best outcomes at the lowest cost) is at the centre of new and evolving patient-centric delivery systems. It is believed that by following a patient-centric approach ‘every segment of the health care system benefits: patient health improves; payers reduce costs and premiums become more efficient; providers improve the quality and safety of their clinical practice and the industry reduces its financial burden to provide health insurance to employees’.

Research will play a critical role in the evolution to patient-centric systems as it relies on an increased use of evidence in the development of health care practice and policy as well as in the development of new technologies in implementation.

New Source of Funding?

The proposed $20 billion perpetual Medical Research Future Fund (MRFF) has ‘the potential to improve lives of Australians, transform the economy and reduce future health expenditures’ – levelling the playing field for Australia.

MRFF and Impact on Philanthropy

Speculation that stronger government investment will reduce the likelihood that Australians will donate is not supported by experiences in Australia and overseas. In fact, Research Australia convened researchers, patient advocacy groups, philanthropic foundations and international experts who were positive that more investment would in fact stimulate and increase giving.

a. Polls and Action. Public opinion polls demonstrate that Australians give high priority to health and medical research and want to give. Australians want to be involved, support, and take action to fight diseases such as cancer, motor neuron diseases, multiple sclerosis, diabetes and schizophrenia. 73% of Australians support additional federal funding being directed to health and medical research.

b. Australian experience. Historically, when federal government investment increased in health and medical research during the Howard era (2000 and 2004), following the Wills review and then again between 2004 and 2009 in response to the Grant review, philanthropic giving not only remained strong but continued to grow.

c. International experience. The presence of well-known research funds e.g. Wellcome Trust (UK) and Gates Foundation (US) has not dampened community giving in the UK and the US.

New Models of Collaboration

Accelerating the pace of ground-breaking research that can get new therapies to patients quickly will require changing the culture of science through innovation, collaboration and translational research.
The Kids Cancer Alliance (KCA) brings together leading doctors and scientists working in child cancer medicine and research across NSW to improve the care of children with cancer.

KCA is a translational cancer research centre (‘bench to bedside’), taking new discoveries from their development in the laboratory, all the way through to their translation in the clinic. KCA encompasses the three child cancer-focused medical research institutes and the three clinical care centres in NSW, in partnership with two major universities that support their research efforts – the University of NSW and the University of Sydney.

The member medical research institutes include Children’s Cancer Institute, Children’s Medical Research Institute, and the Kids Research Institute. Their member child cancer care centres are Sydney Children’s Hospital, The Children’s Hospital at Westmead (which together make up the Sydney Children’s Hospital Network, SCHN), and John Hunter Children’s Hospital in Newcastle. Together, these hospitals treat more than 40% of Australia’s 600 newly-diagnosed child cancer patients each year.

Combined, these institutes and child care centres employ more than 400 laboratory scientists and clinicians working on child cancer who, in the past five years alone, have published over 700 research papers in scientific and medical journals and been awarded in excess of $86 million in research funding.

CASE STUDY

INNOVATIVE PARTNERSHIP (NFP-Academia-Private)

The Children’s Oncology Drug Alliance (CODA) unites the research and resources of UNSW Australia and its commercialisation arm, NewSouth Innovations, childhood cancer research charity The Kids’ Cancer Project, ASX-listed Australian biotechnology company Novogen, and Nationwide Children’s Hospital, Columbus, Ohio, to accelerate development of a treatment purpose-built for neuroblastoma – the most common form of cancer in infancy. The Alliance will progress clinical trials of a unique form of anti-cancer therapy originally developed by Professor Gunning’s UNSW research team and funded by The Kids’ Cancer Project. Now being taken forward commercially by Novogen, the drug class known as anti-tropomyosins has been specifically tailored to selectively target the structure of the cancer cell, causing it to collapse without adversely impacting healthy cells.

QUICK FACTS

Cancer Australia’s four strategies for maximising the benefit and impact of cancer research funding through national and international collaborations:

1. Co-funding
   Opportunities and funding models exist to co-fund research. A co-funding model could increase the impact and delivery timelines of a range of cancer research. Co-funding could also increase investment in areas such as prevention research.

2. Targeted research investment
   Research funding investment could be prioritised for cancers that have a high impact and burden of disease.

   Given the increasing research focus on genetic and epigenetic factors which are common across tumour types, this also presents an opportunity to foster funding which supports research activity across tumour streams.

3. Research collaborations
   Funders of cancer research could foster research collaboration by developing and implementing funding models that value and reward national and international collaborations.

4. International funding
   The similar cancer research funding pattern across different countries identifies areas of common research endeavour and need. This provides opportunities to collaborate, direct and co-fund future research funding investments, and establish an international collaborative that funds priority research across different countries.
CASE STUDY

TEAM SCIENCE

Most medical research is typically about ‘a narrowly focused investigator beavering away, one small grant at a time’ but ‘advances in genetic profiling of malignancies and the mutations that cause them’ are telling scientists and physicians to work differently74. Stand Up to Cancer (SU2C) is an organisation started by entertainment-industry figures in the US unhappy with the progress against America’s most deadly disease. SU2C raises money and then grants it to teams in the form of unusually large sums (up to $18 million) to produce results in a short time, initially three years. The American Association for Cancer Research monitors chosen projects and a scientific committee reviews each team semi-annually. The ‘team model’ challenges the medical ecosystem and teams are judged by patient outcomes and not by the number of research papers published.

First SU2C Paediatric Cancer Research Dream Team

John Maris, MD, director of the Centre for Childhood Research at The Children’s Hospital of Philadelphia (CHOP), is leading the first ever paediatric ‘Dream Team’ dedicated to creating new treatments for the most challenging childhood cancers. The paediatric Dream Team will have $14.5 million in funding over four years, provided by Stand Up To Cancer and St. Baldrick’s Foundation. Crystal L. Mackall, MD, chief of the Paediatric Oncology Branch of the National Cancer Institute (NCI), is co-leader alongside Dr. Maris. Members of the Dream Team include world-renowned paediatric cancer researchers and clinicians from two disciplines: genomics, which is the study of genes and their functions; and immunotherapeutics, which are treatments that use the body’s own immune system to fight disease. The goal is to rapidly translate promising basic research into transformative, targeted treatments that will improve cure rates in children’s cancer.

OBSERVATIONS FROM THE FIELD

There is a general acceptance of a greater need for collaboration in childhood cancer research. The sharing of information, infrastructure and resources is starting to take place in pockets, but only a small portion of the childhood cancer research community in Australia is working together consistently. The NSW government, recognising the importance, is now incentivising collaboration for funding. Collaborating with and including the ‘right people’ in research resonated with opinion leaders. For example, partnerships between researchers and clinicians are a must. Innovators may seek to find solutions but clinicians aren’t always consulted in the design and implementation process. Consequently, there is little impact because the initiatives cannot be implemented due to existing systems, practices, etc. Several leaders mentioned the need for NHMRC to incentivise collaboration across the entire cancer continuum to ‘standards of care’. The whole patient journey needs to be considered and this demands collaboration.

A critical and fundamental issue is that there is a small pool of sick children in Australia, making clinical trials even more difficult. The importance of NANT, COGS and international collaborations mean that boundaries are evaporating. Childhood cancer research advocacy groups in the United States mobilise around the same issues, that is, clinical trial sizes, access to government funding and services despite the larger population.

It appears that cancer research, specifically childhood cancer research, would benefit from greater collaboration at different levels:

- National level – regionally and within states (administrative and ethics approvals across jurisdictions; clinical trials; tumour banks; infrastructure)
- International level – clinical trials
- Links to adult cancers
- Links to advances in medicine, technology

The scarcity of resources, small pool of sick children available for trials and the nature of the diseases indicate a need for greater collaboration within the research community, philanthropy and government. Leaders also mentioned that a greater collaboration within the philanthropic sector i.e. leveraging funds, projects and information sharing, would create opportunities for increased funding, efficiencies, and ‘bang for your buck’.
CASE STUDY

INNOVATIVE MODEL FOR CANCER RESEARCH

The Moon Shots Program at the University of Texas MD Anderson Cancer Center, is inspired by America’s drive to put a man on the moon. The ambitious and comprehensive action plan seeks to ‘make a giant leap for patients’, to rapidly and dramatically reduce mortality and suffering in several major cancers. Six multi-disciplinary groups are adopting a collaborative approach to target eight cancers: lung, prostate, melanoma, breast and three types of leukaemia. The teams are judged by patient outcomes and not by the number of research papers published.

**Figure 7:** Likely Future Developments in Health and Medical Research (HMR)\(^7\)

Future developments are likely to be driven by changes in healthcare delivery and research.
References


52. Ibid.


61. Ibid.


6. Childhood Cancer: A Primer

Worldwide, every 3 minutes, a child is diagnosed with cancer. The number of new cases of childhood cancer continues to rise, with wide disparities in access to health services and outcomes among countries.  

A Global Burden

It is estimated that 175,000 children develop cancer every year across the world, including over 800 Australian children. One in five of these children will not survive. That totals over 96,000 children that die in a year from cancer, including 150 young Australians. These numbers, although devastating to the families and their immediate communities, are still not compelling enough for governments and the pharmaceutical industry to make funding new treatments for childhood cancers a priority.
Childhood cancers are the leading cause of death among children in developed countries like Australia, the United States, United Kingdom and Europe. In developing countries, many children who have cancer are never diagnosed, are diagnosed too late or are diagnosed where treatment is limited or not available. Childhood cancer incidence rates are therefore generally documented as higher in developed countries. Children diagnosed with cancer in the developed world also have a more positive outlook than those in the developing world, where there is a greater frequency of reported deaths from infectious diseases or malnutrition.

The incidence, or number of new cases diagnosed each year, of different types of cancers vary between different regions of the world and between ethnic groups in the same country. Some causes for the differences can be explained, while others are not so clear. For example, the AIDS epidemic is linked to the high incidence of Kaposi sarcoma in Central and East Africa, while the Chernobyl nuclear disaster is credited for the high incidence of thyroid carcinoma in Belarus. Other geographic variations in incidence are less clear. For example, children in developing countries are at higher risk of retinoblastoma and Hodgkin’s disease but at lower risk of acute lymphoblastic leukaemia (ALL). Black children in the US, but not the UK, have a lower incidence of ALL than white children. Overall, Britain has a lower childhood cancer rate than most Western industrialised countries. Australia and the US have some of the highest rates. The reasons for these differences are not clear.

Researchers from around the world are working to find cures and better treatments to combat childhood cancer. Given the nature of the global medical community, a discovery made in a big city in the US can save the life of a child in a developing country; an innovative therapy developed in Sydney can transform treatment for a sick child in the Caribbean, and so forth. In regard to outcomes, however, economic forces and health system realities create disparities across the globe, despite the availability of effective treatment for many childhood cancers.

Finding cures and improving the quality of lives of all children with cancer demands collaboration across all levels and across all borders. Philanthropic donors and donor organisations can play a major role in this transformation. It is said that ‘it takes a village to raise a child’, and ‘it takes a global village to save a child with cancer’.

**Figure 8:** Ratio of mortality to incidence by cancer type, by country per capita income, and geographic region; children 0–14.

**TERMS**

_Cancer_: Cells are the basic building blocks of all living things and the body is made up of trillions of them. _Cancer_ is a group of _over 100 diseases_ characterised by abnormal cells growing out of control. In most cases cancer cells form tumours, or in the case of leukaemia, the cells involve the blood and blood-forming organs and circulate through tissues. Different types of cancer behave very differently, growing at different rates and responding to treatments differently.
OBSERVATIONS
FROM THE FIELD
There has been a major shift in addressing ‘Children’s Cancer’.
1. Treatment demands a team approach, a major change in the transformation of the delivery of service and patient care.
2. An acceptance that childhood cancer’s problem is its rarity. It is a condition with no proven environmental causes, a constellation of rare diseases. Childhood cancer is referred to as a disease of the genes and there is greater discussion around a future in genomic, pharmacogenomics and personalised medicinal advances.

Childhood Cancers
Cancer is the leading cause of death in Australia, where more than 43,200 people died from cancer in 2011. Cancer Council Australia estimates 128,000 new cases of cancer will be diagnosed this year; the number is set to rise to 150,000 by 2020. That means 1 in 2 Australian men and 1 in 3 Australian women will be diagnosed with cancer by the age of 85.

Depending on the data source, childhood cancers refer to ages 0–14, 0–18 or 0–19 years. Patients aged 15–19 years are sometimes included within the adolescent/young adult (AYA) population rather than children. Childhood cancer is much less common than adult cancer; in fact, it is quite rare. It currently accounts for less than 1% of all cancers, although childhood cancer rates have been rising slightly for the past few decades. While some of the increase is due to improvement in diagnosis and registration, it is a widely-held belief that there is also an increase in underlying risk.

The types of cancer that affect children are often different from those that develop in adults. Some childhood cancers are the result of changes to DNA in cells that take place early in life, sometimes before birth. For the most part, unlike adults, childhood cancers are not strongly linked to lifestyle or environmental risk factors. Some childhood cancers tend to respond better than adult cancers to treatment such as chemotherapy (aka ‘chemo’). Children’s bodies also tend to handle chemotherapy better than adults’ bodies. Cancer treatments such as chemo and radiation can, however, cause long-term side effects.

Causes of Childhood Cancer
The causes of childhood cancers are largely unknown. Scientists have identified risk factors for childhood cancers, but most children with cancer don’t have any of these risks and many children that have risk factors won’t go on to develop the cancer. Known risk factors include:

A. Inherited medical conditions: Genetic conditions can increase a child’s risk of developing some cancers, e.g. Down’s syndrome children are 10 to 20 times more likely to develop leukaemia.
B. Development problems in utero: Wilm’s tumours (kidney cancer) and retinoblastomas (eye cancer) begin in the mother’s womb.
C. Exposure to infections: In rare cases Epstein Barr virus (EBV) can contribute to the development of cancers such as Hodgkin’s lymphoma and Burkitt’s lymphoma.
D. Exposure to radiation: Children exposed to radiation after the atomic bombing in Japan and the Chernobyl nuclear disaster in Belarus had a greater risk of developing cancer. Radiotherapy for cancer treatment increases the risk for children developing another type of cancer later on.
E. Previous cancer treatments: Past chemo treatments can increase the risk of acute leukaemia many years later in children and adults.
### Types of Childhood Cancers

The International Classification of Children Cancer (ICCC) groups childhood cancers into 12 types. The classification of childhood cancer is based on:

1. form and structure of the tumour (morphology) and
2. its location (primary site).

#### The Deadly Dozen: Types of Cancers that affect Children

<table>
<thead>
<tr>
<th>Diagnostic group</th>
<th>Incidence^a</th>
<th>Mortality^b</th>
<th>5-year relative survival estimate</th>
<th>(5%) CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Average cases per year (%)</td>
<td>Average deaths per year (%)</td>
<td><strong>5-year relative survival estimate</strong> (95%CI)^c</td>
<td></td>
</tr>
<tr>
<td>All childhood cancers</td>
<td>641.2 100.0</td>
<td>94.0 100.0</td>
<td>82.3</td>
<td></td>
</tr>
<tr>
<td>I. Leukaemias</td>
<td>213.0 33.2</td>
<td>21.8 23.2</td>
<td>86.4</td>
<td></td>
</tr>
<tr>
<td>II. Lymphomas</td>
<td>64.4 10.0</td>
<td>2.8 3.0</td>
<td>93.1</td>
<td></td>
</tr>
<tr>
<td>III. Tumours of the central nervous system (CNS)</td>
<td>140.8 22.0</td>
<td>37.4 39.8</td>
<td>72.1</td>
<td></td>
</tr>
<tr>
<td>IV. Neuroblastoma</td>
<td>45.0 7.0</td>
<td>10.0 10.6</td>
<td>72.5</td>
<td></td>
</tr>
<tr>
<td>V. Retinoblastoma</td>
<td>16.0 2.5</td>
<td><strong>G</strong></td>
<td><strong>97.7</strong></td>
<td></td>
</tr>
<tr>
<td>VI. Renal tumours</td>
<td>31.0 4.8</td>
<td>3.2 3.4</td>
<td>88.8</td>
<td></td>
</tr>
<tr>
<td>VII. Hepatic tumours</td>
<td>10.6 1.7</td>
<td>2.6 2.8</td>
<td>69.6</td>
<td></td>
</tr>
<tr>
<td>VIII. Malignant bone tumours</td>
<td>24.0 3.7</td>
<td>3.2 3.4</td>
<td>74.9</td>
<td></td>
</tr>
<tr>
<td>IX. Soft tissue sarcomas</td>
<td>36.6 5.7</td>
<td>9.0 9.6</td>
<td>72.2</td>
<td></td>
</tr>
<tr>
<td>X. Germ cell tumours</td>
<td>28.8 4.5</td>
<td>2.0 2.1</td>
<td>90.3</td>
<td></td>
</tr>
<tr>
<td>XI. Other malignant epithelial neoplasms and melanomas</td>
<td>28.8 4.5</td>
<td>****</td>
<td><strong>92.8</strong></td>
<td></td>
</tr>
<tr>
<td>XII. Other and unspecified malignant neoplasms</td>
<td>2.2 0.3</td>
<td>****</td>
<td><strong>80.2</strong></td>
<td></td>
</tr>
</tbody>
</table>

---

^a Statistical Data kindly provided by Australian Paediatric Cancer Registry (APPCR), in collaboration with the Australian Association of Cancer Registries (AACR) and funded by Cancer Council Queensland (CCQ), (2014).

^b Diagnostic group: Groups defined using the International Classification of Childhood Cancers, version 3 (ICCC-3).

^c Incidence: New cases diagnosed.

^d Mortality: Excludes children who died from cancer after 15 years of age.

^e Five-year relative survival rate. Relative survival estimates were calculated using the hybrid period method for children with cancer who were at risk of death between 1 Jan 2002 and 31 Dec 2011, except in the first year following diagnosis where the risk period was extended to 1 Jan 2001 and 31 Dec 2011.

^f 95% CI = 95% confidence interval.

^g ** Details have been suppressed because the average count was < 1 per year (total count <5).
QUICK FACTS

**Treatment Side Effects**
Side effects occur when healthy cells are damaged. These may be immediate or may take years to develop. Children experience different side effects with different chemotherapy and radiation treatments. The most common include, but are not limited to:

- Appetite problems
- Constipation
- Dehydration
- Diarrhoea
- Fatigue
- Fever
- Hair Loss (Alopecia)
- Low Platelet Count (Thrombocytopenia)
- Low Red Blood Cell Count (Anaemia)
- Low White Blood Cell Count (Neutropenia)
- Mouth Sores and Dry Mouth
- Nausea and Vomiting
- Pain
- Skin Change
- Weight Gain or Weight Loss

**DETECTING CHILDHOOD CANCER**

Children with cancer may or may not experience the following symptoms or signs. These symptoms may also be caused by a medical condition that is not cancer. The Pediatric Oncology Resource Center (US) captures many of the symptoms in an acronym:

- C: **Continued, unexplained weight loss**
- H: **Headaches, often with early morning vomiting**
- I: **Increased swelling or persistent pain in the bones, joints, back, or legs**
- L: **Lump or mass, especially in the abdomen, neck, chest, pelvis, or armpits**
- D: **Development of excessive bruising, bleeding, or rash**
- C: **Constant, frequent, or persistent infections**
- A: **A whitish color behind the pupil**
- N: **Nausea that persists or vomiting without nausea**
- C: **Constant tiredness or noticeable paleness**
- E: **Eye or vision changes that occur suddenly and persist**
- R: **Recurring or persistent fevers of unknown origin**

**Treatment of Childhood Cancers**

In Australia, over 1,000 children are currently on anti-cancer therapy or in the early stages of follow-up. Most children and teens with cancer are treated at specialised cancer centres designed for them. Being treated at these centres offers the advantage of a team of specialists who know the differences between adult and childhood cancers, as well as the unique needs of children and teens with cancers, and their families. This team usually includes paediatric oncologists, surgeons, radiation oncologists, pathologists, paediatric oncology nurses and nurse practitioners. These centres have psychologists, social workers, child life specialists, nutritionists, and rehabilitation and physical therapists who support and educate the entire family.

Children with cancer need treatment aimed at their particular kind of cancer, yet only 2 drug therapies have been developed specifically for children. Seldom are new therapies developed just for children, primarily because of the small number of paediatric patients relative to the adult cancer patient population.

Children are therefore treated with drug therapies developed for adults, but in much higher doses. Because of the toxicity, children experience significant side effects and late treatment effects or late effects, including secondary cancers later in life. Sadly, three out of five survivors will experience late effects.

Recent studies show that of the more than 10,000 adult survivors of child cancer in Australia today, one third will experience a major health problem in adulthood. Although new treatments for childhood cancer have decreased the number of deaths from a primary cancer, the number of late effects in childhood cancer survivors increases with time since treatment, and with older age. Survivors may not live as long as people who did not have cancer. The most common causes of death in childhood cancer survivors are:

1. relapse of the primary cancer
2. a second cancer forms and
3. heart and lung damage.

As well as finding new ways to treat those forms of cancer which still have a poor prognosis, a major challenge facing the childhood cancer research community today is how to make treatments safer and minimise the risk of treatment-related harm.

“... a major challenge facing the childhood cancer research community today is how to make treatments safer and minimise the risk of treatment-related harm.”
Late Effects

Cancer treatments (surgery, chemo, radiation, or stem cell transplant) may cause health problems for childhood cancer survivors after treatment – these are known as 'late effects'. Three out of five survivors develop late effects that affect health and quality of life. Late effects in childhood cancer survivors may impact the following:

- Organs, tissues and body function.
- Growth and development.
- Mood, feelings and actions
- Thinking, learning and memory
- Social and psychological adjustment
- Risk of second cancers

---

**Survivorship**

Prior to the 1960s, childhood cancer was almost always fatal; only 3 in 10 children (30%) were successfully treated. Advances in cancer treatment mean that today almost 80 percent of children diagnosed with cancer are alive at least five years after diagnosis. Many ultimately will be considered cured. As a consequence, there is growing interest in the long-term health of these survivors.

In Australia today, 1 in 900 young adults between 16 and 45 years is a survivor of childhood cancer, totalling nearly 10,000 survivors. There are more than 33,000 five-year survivors of childhood cancer alive in the UK and of the nearly 12 million cancer survivors alive in the United States, at least 328,000 were originally diagnosed when they were under the age of 21.

Survival rates for most childhood cancers vary greatly according to the type of cancer. Overall survival rates are 70-80% across all types.

- Retinoblastoma (eye cancer) 99%
- Acute lymphoblastic leukaemia (a cancer of the blood cells) 90%
- Acute myeloid leukaemia 50–60%
- Brain stem gliomas 20%

---

**QUICK FACTS**

Late Effects

Cancer treatments (surgery, chemo, radiation, or stem cell transplant) may cause health problems for childhood cancer survivors after treatment – these are known as 'late effects'. Three out of five survivors develop late effects that affect health and quality of life. Late effects in childhood cancer survivors may impact the following:

- Organs, tissues and body function.
- Growth and development.
- Mood, feelings and actions
- Thinking, learning and memory
- Social and psychological adjustment
- Risk of second cancers

---

**Figure 9:** Five-year survival rates for selected childhood cancers, Great Britain, diagnosed during 2001-2005.
PERSONALISED MEDICINE AND TECHNOLOGICAL ADVANCES

With the cost of decoding an individual’s genome expected to fall in the next two to three years to $1000 from its current price range of $10,000 to $25,000, the market for genome decoding in developed countries will explode. This will lead to a greater understanding of disease and the development of new therapies, but will raise complex privacy and cost-benefit issues.

Future of Cancer Treatments

The use of genetic information has played a major role in the development of personalised medicine, selecting the best medicine at the right dose with the lowest risk of side effects. Since children metabolise treatments differently, personalised medicine may be the key to maximising response while minimising toxicity. This requires the matching of a particular drug or drug combination to the characteristics of a child with cancer, or their tumours. In other words, since each child and their tumours are different ‘custom-designed therapies’ may be the answer. Genetics and the new fields like pharmacogenomics (combining pharmacology and genomics) have the potential to transform childhood cancer research.

Researchers have been developing new immunotherapies, either administered alone or used in combination with standard chemotherapy, radiation therapy and/or surgery for paediatric patients, and new drugs that target specific parts of cancer cells have been developed. These targeted drugs work differently from standard chemotherapy drugs as it involves targeting to the cancer’s driver(s) that make it grow. The knowledge of the disease guides the treatment.

**Figure 10:** Childhood Cancer – Current long-term outcomes.

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>34%</td>
<td>Die within 30 years</td>
</tr>
<tr>
<td>19%</td>
<td>Survive at least 30 years but suffer mild or moderate chronic health conditions</td>
</tr>
<tr>
<td>25%</td>
<td>Survive at least 30 years but suffer life-threatening or disabling chronic health conditions</td>
</tr>
<tr>
<td>22%</td>
<td>Live at least 30 years and don’t suffer chronic health conditions</td>
</tr>
<tr>
<td>20%</td>
<td>Die in years 1 to 5</td>
</tr>
<tr>
<td>14%</td>
<td>Die in years 6 to 30</td>
</tr>
<tr>
<td>19%</td>
<td>Survive at least 30 years but suffer life-threatening or disabling chronic health conditions</td>
</tr>
<tr>
<td>25%</td>
<td>Survive at least 30 years but suffer mild or moderate chronic health conditions</td>
</tr>
<tr>
<td>22%</td>
<td>Live at least 30 years and don’t suffer chronic health conditions</td>
</tr>
</tbody>
</table>

6. Childhood Cancer: A Primer

Donors without Borders: Rethinking how Australians Fund Childhood Cancer Research

Donors without Borders: Rethinking how Australians Fund Childhood Cancer Research
References


80. Ibid.

81. Ibid.


89. Ibid.


7. Childhood Cancer Research: A Primer

‘If you know the enemy and know yourself, you need not fear the result of a hundred battles. If you know yourself but not the enemy, for every victory gained you will also suffer a defeat. If you know neither the enemy nor yourself, you will succumb in every battle.’

– Sun Tzu, The Art of War
Slaying the Dragon

Understanding childhood cancers requires research from a ‘micro’ to a ‘macro’ level. New knowledge is needed at the molecular level of biology, cells, tissues, organs, human and population health levels. Research outcomes at one level create opportunities to answer new questions at a different level, so childhood cancer research moves back and forth, often involving an iterative process with feedback loops that may or may not lead to useful outcomes.

FIGURE 11: Research Spectrum ‘Micro’ to ‘Macro’ and back.¹¹³

QUICK FACTS

The linear model of innovation was developed over time. First, by natural scientists (in academia and industry) who explored the links between basic and applied research. Second, by researchers in business and commerce interested in the strategic importance of technology for industry (development). Third, by economists who looked at the dynamics and impact of research on the overall economy and society (diffusion). While innovation does not always proceed in a simple step-by-step fashion, and it may be ‘pulled’ by demand as well as ‘pushed’ by research, the linear model captures the basic building blocks.

1. Research:
   the creative work undertaken on a systematic basis to increase knowledge.¹¹⁴

2. Researchers:
   the scientists, doctors, nurses, psychologists, students and epidemiologists who research.

3. Cancer research:
   the study of what causes cancer; how cancers form; the different ways to treat cancer; and how cancers can be prevented and/or the lowering the risks of cancers.

4. Childhood cancer research:
   the study of cancers that affect children ranging from 0–19, the Deadly Dozen.
Innovation, Research and Development

Developing new treatments and cures to conquer childhood cancer requires ‘new ideas’, ‘new thinking’, ‘new processes’ and sometimes ‘new devices’ – in short: innovation. There are many definitions for innovation and the established theoretical framework developed for understanding the innovation process is known as the ‘linear model of innovation’\(^\text{17}\). According to this model, innovation occurs through a process of moving from basic research, through applied research, to the development of new products and processes, to their diffusion.

Stages of Attack

There are three general stages of health and medical research\(^\text{118}\):

1. **Basic or Discovery Research:**
   Earliest stage of research, carried out for ‘the advancement of knowledge’ in a lab.

2. **Translational Research:**
   Application of basic research discovery results to develop new ways to diagnose, treat or prevent a disease, e.g. identification of biomarkers, target and pathway validation, development and testing in animal models.

3. **Clinical Research:**
   Research in humans aiming to develop approved treatment for patients. Before a new treatment can become part of a standard treatment it needs to go through a series of phases to test safety, dosages, efficacy, side effects and to test if the new treatment is better than the current best standard treatment.
Stage 1: Basic or Discovery Research

Basic Research

Scientists from many disciplines (e.g. Cell Biology, Molecular Biology, Chemistry, Bioengineering, Bioinformatics, Systems Biology, Immunology, Genetics, Physics) contribute to our understanding of cancer through basic research. Although some disciplines are straightforward, they often overlap. These researchers seek to understand what makes a cancer cell different to a normal cell.

Observations from the Field

Literature reviews and interviews with leaders in childhood cancer research both highlighted the importance of investing in the translational and clinical research stages for developing new and improved treatments for children with cancer. However, it was also emphasised that many basic biological questions remain unanswered, and investment in discovery can lead to new ideas and developments in applied medicine. Solid quality basic research is a fundamental and important form of medical research.

Stage 2: Lost in Translation: the Valley of Death

Translational Research

The pathway bridging the discovery on the laboratory ‘bench’ to testing drugs or therapies in a clinic ‘bedside’ is known as translational research or ‘bench to bedside’. Many good ideas and potentially life-saving therapies fall into what is known as the ‘valley of death’, created by structural, intellectual and funding barriers preventing the translation of basic research discoveries into clinical applications. This gap widened when governments and large pharmaceutical companies became more conservative in their investments in medical R&D processes. Governments funded more basic research while the pharmaceuticals and venture capitalists started to invest in later-stage clinical research where a focus on costs and risks of investing secured higher returns on their capital, leaving the translation process relatively under-funded.

The cost for advancing through the development process generally increases exponentially as the project moves down the development pipeline. Some of the challenges in the translation stage are attributed to research silos and lack of collaborative project teams that integrate the different phases of the translation process. Researcher training and career paths are designed around the individuals and not teams, yet translational research often requires multidisciplinary and interdisciplinary expertise. Basic researchers and clinical researchers are trained to think differently, but increased collaboration between the two improves the chances of success of the potential treatment.

The blueprint for delivering ‘Better Health Through Research’ in the 2013 Strategic Review of Health and Medical Research in Australian (the ‘McKeon Report’) emphasised the need for improved translation research, stressing the importance of strengthening the connection between health and medical researchers and the delivery of healthcare services. This connection is extremely important in childhood cancer.

Case Study

Fever and neutropenia (low number of cells in immune system) is a common complication of the treatment of cancer. Neutropenic fevers are the most common emergency in children with cancer, with a risk for rapid progression to septic shock. Children’s cancer treatment centres have developed clear guidelines for the management of children presenting with fevers. Optimal care is for the child to be assessed and have antibiotics within one hour of presentation. However, a retrospective audit of management of children in rural and regional centres in Australia showed that this does not occur and a new management plan for these children was developed, thanks to a collaborative project between two eminent researchers in NSW and Queensland.

Terms

Biomarker: Short for biological markers are assessment measures, e.g. blood pressure or cholesterol levels, are used as indicators of normal biological processes to develop or plan a therapeutic intervention.

Basic researchers and clinical researchers are trained to think differently, but increased collaboration between the two improves the chances of success of the potential treatment.
The pathway from basic scientific discovery to improved patient outcomes is a complex and iterative process for both commercial (e.g., drugs and medical devices) and non-commercial (e.g., health services, health economics) activities. The NIH Framework is useful for understanding translation in both.

- **Early Translation (T1)** – Basic science, and Phase I and II Clinical Trials
- **Late Translation (T2)** – Observational Studies, Phase III, Trials and guidelines for clinical practice
- **Dissemination (T3)** – Clinical education, conferences, marketing, and Therapeutic Good Administration (TGA) approval, and Pharmaceutical Benefits Scheme (PBS) listing
- **Adoption (T4)** – Studies assessing policy proposals

### NIH Research Translation Framework

![Diagram of NIH Research Translation Framework]

**Non-Commercial Research Activity**

- **(T1)** – From discovery research to health applications (test, interventions)
- **(T2)** – From health application to evidence guidelines
- **(T3)** – From guidelines to practice
- **(T4)** – From health practice to population health outcomes


Non-commercial translation is very relevant in public health research, health services research, health system innovation and evidence-based policy.

- **(T1)** – From discovery research to health applications (test, interventions)
- **(T2)** – From health application to evidence guidelines
- **(T3)** – From guidelines to practice
- **(T4)** – From health practice to population health outcomes
**Figure 14:** Commercial Drug and Therapy Development in the US.122

<table>
<thead>
<tr>
<th>Stage</th>
<th>Timeframe</th>
<th>Funding</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Investigational New Drug (IND) Application</td>
<td>1–6 years</td>
<td>Largely Public</td>
<td>NIH, DoD</td>
</tr>
<tr>
<td>New Drug Application (NDA)</td>
<td>5–10 years</td>
<td>Largely Industrial and For-Profit FDA Oversight</td>
<td>Undersigned Area</td>
</tr>
<tr>
<td>Clinical Development</td>
<td>1–2 years</td>
<td>Largely Public</td>
<td>NIH, DoD</td>
</tr>
<tr>
<td>Clinical Trials</td>
<td></td>
<td>Mix of Government and Private Funding</td>
<td>Undersigned Area</td>
</tr>
</tbody>
</table>

“Valley of Death”

**Figure 15:** Commercial Drug or Therapy Development in Australia.123

<table>
<thead>
<tr>
<th>Stage</th>
<th>Timeframe</th>
<th>Funding</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic Research</td>
<td></td>
<td>Largely Public</td>
<td>How biological processes work normally – and what goes wrong in abnormal situations to cause disease.</td>
</tr>
<tr>
<td>Development</td>
<td></td>
<td>Mix of Government and Private Funding</td>
<td>Applying new knowledge to work out ways to correct or overcome the abnormality – emergency of new therapy.</td>
</tr>
<tr>
<td>Pre Clinical</td>
<td></td>
<td>Largely Public</td>
<td>Lab and animal testing.</td>
</tr>
<tr>
<td>Phase I</td>
<td>1–6 years</td>
<td>Largely Public</td>
<td>Testing safety, activity and side effects in 20–80 healthy people.</td>
</tr>
<tr>
<td>Phase II</td>
<td>5–10 years</td>
<td>Largely Industrial and For-Profit FDA Oversight</td>
<td>Testing that the medicine has the desired effect in 100–300 patients.</td>
</tr>
<tr>
<td>Phase III</td>
<td>1–2 years</td>
<td>Largely Industrial and For-Profit FDA Oversight</td>
<td>Testing significance of clinical benefits and side effects in 1000–5000 patients.</td>
</tr>
<tr>
<td>Registration</td>
<td></td>
<td>Largely Industrial and For-Profit FDA Oversight</td>
<td>Evaluation and registration by the Therapeutic Goods Administration.</td>
</tr>
<tr>
<td>PBS</td>
<td></td>
<td>Largely Public</td>
<td>Application for listing on the pharmaceutical benefits scheme.</td>
</tr>
<tr>
<td>Marketing</td>
<td></td>
<td>Largely Public</td>
<td>Marketing and distribution to medical profession.</td>
</tr>
</tbody>
</table>

**Medical research leading to new medicines**

Development of new medicines is a process with a long lead time, taking on average 15 years. It starts with basic research discoveries made in a laboratory and ends with a new medicine available to patients.
Stage 3: Clinical Trials

Clinical Research

Only once basic research has been effectively translated into a viable therapy can the clinical trials begin to study, test or verify how well the potential new medical solutions work in children with cancer. It is only after a new treatment proves safe and efficient in a clinical trial that it is possible for it to become a new standard of care or best practice medical treatment.

Clinical trials are used to determine effective and safe treatment for a disease, and not all new treatments turn out to be superior to current ones. Each trial is aimed at improving survival rates, reducing side effects or late treatment effects.

Clinical trials are standard practice in cancer treatment for children, adolescents and young adults. Treatments tested include:

• Drugs – such as chemotherapy, hormones, antibiotics or targeted drugs
• Radiation therapy
• Surgery
• Other treatments, such as high dose treatment with bone marrow support
• Palliative care – treatment that helps the symptoms of cancer
• Counselling and psychological support
• Complementary and alternative therapies
• Ways to combine treatments

Clinical Trials in Australia

Each clinical trial requires a pool of children and young adults with cancer. Given the relatively low numbers of children with cancer in each individual community, the quest for a cure usually requires collaborative clinical trials in order to recruit a sufficient number of patients.

Childhood cancer trials are funded by drug or device companies, government, and donor organisations. Each clinical trial is led by a principal investigator, who may be a medical doctor. The clinical studies also have a research team that may include doctors, nurses, social workers and other health care professionals.

The majority of trials being conducted in Australia are registered by the Australian New Zealand Clinical Trials Registry (ANZCTR) and in the clinical.gov registry from the United States. The World Health Organisation keeps a database of all trials on the International Clinical Trials Registry Platform (ICTPR) where ultimately all clinical trials will be registered.

Australian and New Zealand Children’s Haematology/Oncology Group (ANZCHOG) is the leading body in Australia and New Zealand for professionals in the field of paediatric blood diseases and cancer. The Australian Children’s Cancer Trials Registry (ACCT) is the clinical trials arm of ANZCHOG and lists all clinical trials open to children and adolescents with cancer or blood disorders, currently in progress at the children's cancer centres in Australia and New Zealand:

1. Children’s Hospital at Westmead
   Sydney, NSW
2. Christchurch Hospital
   Christchurch, NZ
3. John Hunter Children’s Hospital
   Newcastle, NSW
4. Lady Cilento Children's Hospital
   Brisbane, QLD
5. Monash Medical Center
   Clayton, VIC
6. Princess Margaret Hospital
   Perth, WA
7. Royal Children’s Hospital
   Melbourne, VIC
8. Starship Children’s Health
   Auckland, NZ
9. Sydney Children’s Hospital
   Sydney, NSW
10. Women and Children’s Hospital
    Adelaide, SA
International Cancer Groups with Trials in Australia

- Children’s Oncology Group (COG) conducts clinical trials devoted exclusively to children and adolescents with cancer at more than 200 member institutions, including major universities, cancer centres and teaching hospitals in the United States, Canada and sites in Europe and Australia.

- New Approaches to Neuroblastoma Therapy (NANT) is a consortium of university and children’s hospitals funded to test promising new therapies for high-risk neuroblastoma and conducts early clinical trials to test new drugs and new combinations of drugs so that promising therapies can be tested internationally.

**TYPES OF CLINICAL TRIALS**

### Phase 0 trials

**AIM:** Gather preliminary data on effect of drug on human body.

- First-in-human studies for drugs that have been previously tested in animals.
- Usually a single drug dose is given to 10–15 people.
- The dose of drug given is below what is thought to have a therapeutic effect.

### Phase I trials

**AIM:** Test Safety and best drug dosage.

- First tests of a treatment in humans and involves approximately 15–30 people.
- The research team notes major and minor side effects. This helps researchers to work out the best dose and the best way to give the trial treatment.
- Phase I trials are usually only suitable for people with incurable cancer who have had all the known effective treatments for their cancer. People take part in these trials in the hope that the treatment may extend their life or improve their quality of life. Most often though, the reason to enter Phase I trials is to help people with cancer in the future.
- If a Phase I trial shows that the new treatment is safe it will go on to Phase II testing.

### Phase II trials

**AIM:** Test how well the new treatment works against cancer and monitor side effects.

- Usually involves less than 100 people.
- Generally involves people who have already had cancer treatment. The chance of the treatment being tested in a Phase II trial effective depends on the type and extent of the cancer and its response to previous treatment.
- If the new treatment shows promising effects (efficacy) against cancer and is safe then it is tested in Phase III trials.

### Phase III trials

**AIM:** Test if the new treatment is better than the current best standard treatment.

- Involves hundreds to thousands of people.
- The trials are usually conducted through doctors’ offices, hospital clinics and cancer centres around the country and around the world. They test treatments in real life settings, not the controlled circumstances under which Phase I and II trials are usually conducted.
- To learn if one treatment in a Phase III clinical trial is better, a child with cancer is assigned randomly to a new treatment group or the standard treatment group (called study ‘arms’) at random. Each treatment has been shown to be effective in other studies but not yet compared to each other or the current best treatment. Usually, one treatment arm is the ‘standard’ or the best proven current treatment. The other (new) treatment has some changes or additions to determine if they cure the disease in more children, control disease longer, cause fewer or less serious side effects, or change the number of days spent in the hospital. If a clinical trial is not currently available at the time a child is diagnosed, a child receives the best standard treatment. Children in the trial are monitored carefully to see the effect of the treatment on the cancer, and on the length and quality of life.
- Assigning children randomly is a process like flipping a coin that assures that each child has a fair and equal chance of being assigned to either/any of the treatments. In most studies, we do not know which treatment is better until all the children taking part in the clinical trial have completed treatment and have been observed for several years. However, if one of the treatments is already found to be better than the others while the trial is still going on, the trial is stopped, and all children are given the better treatment. If for any reason the treatment plan is found to be not the best for the child, the plan will be changed.
- If the new treatment works better, it may become the new standard treatment. In general, the new treatment needs to go through more than one Phase III trial for the treatment results to be accepted.

### Phase IV trials

**AIM:** Assess any long-term side effects of a new treatment after a drug has been licensed for use and put on the market.

- Long-term monitoring that sometimes occurs after a drug has been licensed for use and put on the market. Phase IV trials are to assess any long-term side effects of a new treatment. There are very few Phase IV trials.
Targets of Attack: Cancer Research and the Cancer Continuum

Research projects in childhood cancer may have multiple objectives, but defining a primary focus of attack e.g. ‘cancer prevention’ or ‘treatment’ and identifying a targeted site, puts the research being undertaken into context.

**Figure 16:** Common Scientific Outline (CSO) Seven Cancer Research Categories.  

1. **Biology**
   - Research included in this category looks at the biology of how cancer starts and progresses as well as normal biology relevant to these processes.

2. **Aetiology**
   - Research included in this category aims to identify the causes or origins of cancer – genetic, environmental, and lifestyle, and the interactions between these factors.

3. **Prevention**
   - Research included in this category looks at identifying interventions which reduce cancer risk by reducing exposure to cancer risks and increasing protective factors. Interventions may target lifestyle or may involve drugs or vaccines.

4. **Early Detection, Diagnosis, and Prognosis**
   - Research included in this category focuses on identifying and testing cancer markers and imaging methods that are helpful in detecting and/or diagnosing cancer as well as predicting the outcome or chance of recurrence.

5. **Treatment**
   - Research included in this category focuses on identifying and testing treatments administered locally (such as radiotherapy and surgery) and systemically (treatments like chemotherapy which are administered throughout the body) as well as non-traditional (complementary/alternative) treatments (such as supplements, herbs). Research into the prevention of recurrence is also included here.

6. **Cancer Control, Survivorship, and Outcomes Research**
   - Research included in this category includes a broad range of areas: patient care and pain management; tracking cancer cases in the population; beliefs and attitudes that affect behaviour regarding cancer control; ethics, education and communication approaches for patients and health care professionals; supportive and end-of-life care; and health care delivery in terms of quality and cost effectiveness.

7. **Scientific Model Systems**
   - Research included in this category looks at the development of new animal models, cell cultures and computer simulations and their application to other studies across the spectrum of cancer research.

---

**TERMS**

**CLINICAL TRIALS**

**Cancer Status:** The extent the cancer has spread.
- Early or Local: The cancer is located in the organ in which it started or it has spread to local lymph nodes. It has not spread to distant sites.
- Locally advanced: The cancer may be larger in size and may have spread to local lymph nodes.
- Locally recurrent: The cancer has recurred at the same site of the primary cancer.
- Metastatic/Widespread: The cancer has spread to other organs distant from the site the cancer started.
- Not applicable: The clinical trial is a prevention trial or other trial where cancer stage is not relevant.

**Recruitment Status:**
- Open: Participants are currently being recruited and enrolled.
- Closed: Participants are not being recruited.
- Not yet recruitment: Participants are not yet being recruited or enrolled.
**Figure 17:** Cancer Control Continuum.\(^{130}\)

### The Cancer Control Continuum

**Focus**

<table>
<thead>
<tr>
<th>Prevention</th>
<th>Detection</th>
<th>Diagnosis</th>
<th>Treatment</th>
<th>Survivorship</th>
</tr>
</thead>
</table>
| Tobacco control  
Diet  
Physical activity  
Sun exposure  
Virus exposure  
Alcohol use  
Chemoprevention | Pap test  
Mammography  
FOBT  
Sigmoidoscopy  
PSA | Informed decision-making | Health services and outcomes research | Coping  
Health promotion for survivors |

**Crosscutting Issues**

- Communications
- Surveillance
- Social Determinants of Health Disparities
- Genetic Testing
- Decision-Making
- Dissemination of Evidence-Based Interventions
- Quality of Cancer Care
- Epidemiology
- Measurement

Adapted from David B. Abrams, Brown University School of Medicine.

**Figure 18:** Funding to Cancer Research Categories 2003–2011.\(^{131}\)

<table>
<thead>
<tr>
<th>Year</th>
<th>Biology</th>
<th>Antilog</th>
<th>Prevention</th>
<th>Early Detection, Diagnosis &amp; Prognosis</th>
<th>Cancer Control, Survivorship &amp; Outcomes Research</th>
<th>Treatment</th>
<th>Scientific Model Systems</th>
</tr>
</thead>
<tbody>
<tr>
<td>2003-2005</td>
<td>51%</td>
<td>7%</td>
<td>5%</td>
<td>8%</td>
<td>19%</td>
<td>9%</td>
<td>1%</td>
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<tr>
<td>2006-2008</td>
<td>38%</td>
<td>10%</td>
<td>2%</td>
<td>13%</td>
<td>27%</td>
<td>7%</td>
<td>3%</td>
</tr>
<tr>
<td>2009-2011</td>
<td>32%</td>
<td>8%</td>
<td>2%</td>
<td>16%</td>
<td>28%</td>
<td>9%</td>
<td>4%</td>
</tr>
</tbody>
</table>

**Quick Facts**

The CSO is complemented by a standard cancer type coding scheme that helps us understand the ‘site or location of the cancer’ (e.g. brain, liver, blood) (Appendix 1).
Cancer Research Categories

1. The International Cancer Research Partnership (ICRP), established in 2000, developed the Common Scientific Outline (CSO) system organised around seven broad categories of scientific interest in cancer research (Figure 16).

2. This ICRP framework is based on a long established model of the ‘cancer control continuum’ (Figure 17). This model was developed in the mid-70s and remains a good framework to begin discussions on targeted areas of cancer research. Although somewhat simple and shorthand, it describes and can be used to plan where philanthropy can add value in cancer research, e.g. cancer prevention, early detection, diagnosis, treatment, survivorship and end-of-life.

3. This framework can be used to identify targeted areas of cancer research funding. For example, Cancer Australia’s audit captured and analysed national investments for cancer research categories and tumour sites using this model. This captures cancer research in general, however, there was no information presented on childhood cancers as a group (Figure 18). It would, however, be possible to use this framework to compare and contrast the childhood cancer research portfolios of public, non-profit, and governmental research agencies.

The Cost of Battle

From a research funding perspective, the major research cost components for any project are grouped into three major categories:

**Figure 19:** Three Categories of Research Costs

- **Direct Research Costs**
  - Salaries (researchers, technicians, PhD students, etc.)
  - Laboratory maintenance and operational expenditure (consumables and lab supplies, minor equipment costs, access charges for equipment, animal house costs, etc.)

- **Indirect Research Costs**
  - Facilities maintenance (rent, electricity, heating, air-conditioning, cleaning, waste removal, facilities management, etc.)
  - Administration costs (costs for salaries of administrative staff, IT support, business development offices, financial management, human resources and OH&S)

- **Capital Costs**
  - Building construction costs
  - ‘Core’ shared large equipment costs
Funding to cover the research costs of a project can come from diverse sources which may cover only specific activities. Grants that fund only for direct research costs, for example, create additional funding gaps and increases competition for accessing funding for indirect costs. Costs also vary widely. Charities and philanthropy can play a major role in addressing these funding gaps and accelerate cures by understanding the funding gaps of a project. Philanthropic funding for large capital investments such as a building is celebrated widely and we should also commend donors that make research sustainable by sponsoring the development of careers and ‘keeping the lights on’.

**SALARY COSTS**

The need for investing in attracting, retaining and training human resources for quality research and building Australia’s research capability in childhood cancer research surfaced time and time again throughout our research journey. Philanthropy can accelerate research by funding technical and administrative positions. The table below depicts the NHMRC Salary Scale which is only a portion of the total costs for the human resource component. This does not include ‘on-costs’ such as superannuation, workers compensation, leave, conference travel, etc. Attracting, retaining and developing the right staff is critical to the success of the research project.

<table>
<thead>
<tr>
<th>Personnel Support Packages</th>
<th>$ Per Annum</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSP1 – Technical support – non-graduate personnel</td>
<td>52,699</td>
</tr>
<tr>
<td>PSP2 – Junior graduate research assistant</td>
<td>65,805</td>
</tr>
<tr>
<td>PSP3 – Experienced graduate research assistant/ Junior postdoctoral research officer</td>
<td>72,359</td>
</tr>
<tr>
<td>PSP4 – Experienced postdoctoral researcher (i.e. a researcher who would normally be considered as a named investigator on the research application and/or approaching the NHMRC CDF (formerly CDA) scheme or equivalent)</td>
<td>85,466</td>
</tr>
<tr>
<td>PSP5 – Senior experienced postdoctoral researcher (i.e. a researcher who would normally be considered as a named investigator on the research application and is more than 10yrs post-doctoral and/or would be expected to have applied for or held an NHMRC CDF (formerly CDA) or equivalent)</td>
<td>92,019</td>
</tr>
</tbody>
</table>
The Crusaders:
Childhood Cancer Research Community in Australia

Cancer Community in Australia
There is no single source of information for a comprehensive list of cancer research centres, with links to childhood cancer. This snapshot was created by reviewing recommended websites during the research period.

- The Australian Paediatric Cancer Registry
- Australian Cancer Research Foundation
- Cancer Australia
- Cancer Council Australia
- Cancer Council Australian Capital Territory
- Cancer Council Northern Territory
- Cancer Council Queensland
- Cancer Council South Australia
- Cancer Council Tasmania
- Cancer Council Victoria
- Cancer Council Western Australia
- Cancer Nurse Society of Australia
- Cancer Voices Australia
- Cure Cancer Australia Foundation
- Australian and New Zealand Children's Haematology/Oncology Group (ANZCHOG)
- Clinical Oncology Society of Australia (COSA)
- Psycho-Oncology Co-Operative Research Group (POCOG)
- John Hunter Children's Hospital, Newcastle
- Sydney Children's Hospital Network, (SCHN)
- The Children's Hospital at Westmead
- Kids Cancer Alliance
- The Children's Medical Research Institute (CMRI)
- Children's Cancer Institute
- Kids Research Institute, The Children's Hospital at Westmead
- Kid's Cancer Centre - Sydney Children's Hospital, Randwick
- Royal Children's Hospital, Melbourne
- Royal Children's Hospital Brisbane
- Telegen Kids Institute
- Camp Quality (Advocacy)
- Constellation Project Australia / Cure Our Kids (Advocacy)
- Cancer Institute NSW
- Queensland Children's Medical Research Institute (QCMRI)
- Children's Health Service, Queensland
- Women's and Children's Hospital
- Children's Hospital Foundation (QLD)
- Brainchild Foundation
- Leukaemia Foundation
- Rare Voices
- National Breast Cancer Foundation
- Ovarian Cancer Australia
- Prostate Cancer Foundation Australia
- Lung Foundation Australia
- National Breast Cancer Foundation
- Breast Cancer Network Australia
- Myeloma Foundation Australia
- Melanoma Institute
- Bowel Cancer Australia
- Prostate Cancer Foundation
- The Centre for Personalised Cancer Medicine
- Paediatric Integrated Cancer Service (PICS)
- Monash Children's at Southern Health (SH)
- Peter MacCallum Cancer Centre (Peter Mac)
- The Royal Children's Hospital (RCH)
- RCH Children's Cancer Centre (CCC)
- Anzac Research Institute
- Children's Cancer Institute (CCI)
- The Centenary Institute

QUICK FACTS

CLINICAL TRIALS COSTS
Securing funding for clinical trials is fundamental in the development of new treatment for children with cancer. It is very expensive to run clinical trials in Australia, the third most expensive country in the world to run a clinical trial. The research costs include:

- treatments
- research staff to run the trial and collect the data
- staff and computer technology to analyse the results
- administrative costs - paperwork, overseeing the plan, data collection, results
- costs of extra tests or hospital stays for participants.

OBSERVATIONS FROM THE FIELD
It is estimated that the cost of enrolling a child in a clinical trial averages between the range of $10,000 – $50,000 per child, mostly depending on drug costs, and type of trial. This does not factor pre-clinical and post-clinical costs.
References


Ibid.


Ibid.


8. Moving Forward: A Call to Action

This initiative first set out to better understand the challenges of donors and researchers on the frontlines in the battles against childhood cancers. One of the key findings from the journey was the differing levels of sophistication and governance in donor organisations as well as ‘knowledge gaps’ about childhood cancer and the research process.

It is our hope that the ‘childhood cancer primer’ and the ‘childhood cancer research primer’ begin to help address these gaps. The following twelve strategic recommendations or ‘calls to action’ are designed with the intent to further dialogue in the childhood cancer community which translate to meaningful actions.

The accompanying education and advocacy video (http://alccrf.lions.org.au) stipulates three key actions (educate, collaborate, and donate) to eliminate childhood cancer in Australia and around the globe. This chapter delves into their meaning and provides linkages to key areas of this report.
Educate

1. Educate yourself and spread the word; with knowledge comes the power to change.

**DONORS**

Become an informed donor by learning about childhood cancer issues, the importance of childhood cancer research and the research process. Review the primers (Chapters 6 and 7) and stay abreast of local and international advances in childhood cancer research. No need to be a ‘content expert’ but trying to ‘speak the language’ is always appreciated, respected and can improve communications in donor-researcher relationships.

**RESEARCHERS**

Learn to effectively communicate research in lay terms and assist donors in understanding how their donations add value to and create hope for patients.

2. Remember to walk in someone else’s shoes, honouring and respecting the differences.

**DONORS**

Understand researcher motivations, the competitive nature of research and research funding as well as the research process. Review Chapters 5 and 7, which help you understand the environment in which researchers operate and the long road to discovery for better treatments. Remember that researchers are predominantly motivated by the excitement of the discovery (from Mars).

**RESEARCHERS**

Understand donor motivations (Venus) and expectations to build stronger relationships.

**DONORS**

Seek to better manage donor-researcher relationships by understanding each other’s ‘needs, wants and wishes’. (Appendix 3)

3. Define your expected returns.

**DONORS**

Understand and define the expected ‘return on philanthropy’ and ‘impact’ of the investment. Informed giving ensures a better return on donor dollars. Measuring performance and impact (change) are not the same, distinguish between expected performance metrics and expected outcomes. Work with researchers to understand the future value of the project to a young patient with cancer. Add value to patients as efficiently and as effectively as possible. (Appendix 2)

**RESEARCHERS**

Understand and define expected communication during the project and recognition after the project.

4. Communicate your worth.

**ACROSS ALL SECTORS**

Strive for sharing better quality data and access to it, effective reporting, and improved communications on performance and impact, essential to securing and sustaining future funding.
Collaborate

5. Think and act across traditional boundaries.

**DONORS**

Work with other foundations in the cancer research community; learn from other disease groups’ achievements.

**RESEARCHERS**

Seek to design interdisciplinary and multi-disciplinary projects; include clinicians and encourage different donor groups to collaborate on funding initiatives.

6. Encourage and support national plans for action.

**DONORS + RESEARCHERS**

The development of a National Cancer Plan and a National Childhood Cancer Action Plan for strategic direction (pages 22-23).

7. Encourage and support national alliances.

**DONORS + RESEARCHERS**

National Alliance of Childhood Cancer to implement and sustain an inclusive implementation of the Childhood Cancer Action Plan.

8. Support advocacy for increased federal investment in health and medical research – especially for childhood cancer research.

**DONORS + RESEARCHERS**

Advocacy and policy work are powerful tools for change. United voices, relentless persistence and a long-term view are required.

9. Think global and act local.

**DONORS + RESEARCHERS**

Think big and collaborate across geographic borders for greater impact. Given the rarity of childhood cancer and international protocols for treatment remember that when you invest in childhood cancer research you have the potential to impact the quality of life of a child across the dining room table, across the country and across the globe.
Donate

10. Invest in the change you seek.

- Take the higher risks and drive a field forward, increasing the likelihood that governments or private investors will also invest in the future. Review Chapter 7 to understand the funding gaps and where your investments can accelerate the development of better treatments.

11. Invest in overcoming strategic funding gaps as identified by the key opinion leaders interviewed.

- i. Disruptive innovations and ‘blue-sky’ thinking
- ii. Seed and venture capital for ‘pre-NHMRC’ projects
- iii. Longitudinal studies
- iv. Early and mid-career talent development
- v. Funding for ‘pre-clinical’ and clinical trial gaps

Investment priority areas of interests:

- vi. Research pipeline: Investment in each stage is equally important although there is a push for more ‘translational’ research; every little bit helps
- vii. Cancer Continuum Research Categories: Focus on ‘Treatment’ and ‘Prevention’


- Fund collaborative projects – transcend borders across sciences, researchers and all cancers.

- Co-fund with other foundations, private sector and governments – nationally and internationally leveraging funds for better projects.
  
Applying ‘Educate, Collaborate, Donate’
To Eliminate Childhood Cancer

Educate:

- The most common solid tumour of childhood\(^{137}\).
- Site: sympathetic nervous system (adrenal gland, neck, chest or abdomen); may follow the line of the spinal cord from abdomen to child’s skull (Chapter 6)
- A very complex cancer\(^{138}\):
  - Low-risk and intermediate-risk forms of neuroblastoma may regrow (relapse) after surgery or chemotherapy. These children are usually cured with standard techniques such as surgery or chemotherapy.
  - In 10% of children with high-risk neuroblastoma the disease will not respond to chemotherapy (refractory).
  - In 40 to 50% of cases, the disease will go away at some point but eventually relapse during or after treatment.
  - A child with high-risk neuroblastoma who relapses after initial treatment is considered incurable with conventional therapies\(^{139}\).

The target: MYCN gene

- A gene called MYCN, is found in high levels in neuroblastoma tumours. This gene has been shown to be critical to the development of aggressive neuroblastoma, and patients whose tumours have multiple copies of this gene (as shown by a routine test done at the time of diagnosis) have a particularly poor outcome\(^{140}\).

The plan of attack:

- The drug Difluoromethylornithine (DFMO) is a proven drug for curing ‘African Sleeping Sickness’ and was identified as a promising drug in that it targets an enzyme important in neuroblastoma growth. A combined treatment of DFMO and the ‘non-steroidal anti-inflammatory drug’ celecoxib (Celebrex), tested in laboratory cancer models was demonstrated to slow tumour progression more effectively than the chemotherapy drugs alone. The Phase I Clinical Trial would monitor the safety and best drug dosages (Chapter 7) for attacking this MYCN-driven cancer in children.

Sourcing and Funding Challenge

- DFMO is not readily accessible given that production is limited by its uses (and profitability), i.e. African sleeping sickness, depilatory creams.

Collaborate:

- International Clinical Trial: The research is led by Dr David Ziegler, an Australian researcher at the Children’s Cancer Institute and Paediatric Oncologist at Sydney Children’s Hospital Randwick, member of the Kid’s Cancer Alliance and NANT. The international collaboration will run across 16 hospitals in Australia and the United States.

Donate:

- ALCCRF and The Kid’s Cancer Project addressed the funding gaps in the Phase I Clinical Trial by providing the resources for the purchase and sourcing of DFMO for a 3-year period.

The promising trial has commenced in Australia and internationally.

References

Appendices
APPENDIX 1: Cancer types
(International Cancer Research Partnership)\textsuperscript{141}

A
Adrenocortical Cancer
Anal Cancer

B
Bladder Cancer
Blood Cancer
Used for blood cancers other than
Hodgkin’s Disease, Leukemia/Leukaemia,
Myeloma, Non-Hodgkin’s Lymphoma
Bone Cancer, Osteosarcoma/Malignant
Fibrous Histiocytoma
Bone Marrow Transplantation
Brain Tumour/Tumor
Breast Cancer

C
Cardiotoxicity/Heart Cancer
Cervical Cancer
Colon and Rectal Cancer

E
Ear Cancer
Endometrial Cancer
Esophageal/Oesophageal Cancer
Eye Cancer

G
Gallbladder Cancer
Gastrointestinal Tract
Used for GI cancers other than Colon
and Rectal, Esophageal/Oesophageal,
Gallbladder, Liver, Pancreatic,
Small Intestine and Stomach
Genital System, Female
Used for female genital system cancers
Genital System, Male
Used for male genital system cancers
other than Penile, Prostate and Testicular

H
Head and Neck Cancer
Used for Head and Neck cancers other than
Laryngeal, Nasal Cavity and Paranasal
Sinus, Oral Cavity and Lip, Parathyroid,
Pharyngeal, Salivary Gland, and Thyroid
Heart Cancer/Cardiotoxicity
Hodgkin’s Disease

K
Kaposi’s Sarcoma
Kidney Cancer

L
Laryngeal Cancer
Leukemia/Leukaemia
Liver Cancer
Including Bile Duct cancer
Lung Cancer
Including Mesothelioma

M
Melanoma
Myeloma
Including Multiple Myeloma

N
Nasal Cavity and Paranasal Sinus Cancer
Nervous System
Used for nervous system cancers
other than Brain, Eye, Neuroblastoma,
Pituitary, Primary CNS Lymphoma
and Retinoblastoma
Neuroblastoma
Non-Hodgkin’s Lymphoma
Not Site-Specific Cancer
includes Fundamental research (fluids,
secretions, milk lymph, blood components,
cell lines and cell fractions, etc.) and
research that applies to all types of cancer
Appendix 1: Cancer types

O
Oesophageal/Esophageal Cancer
Oral Cavity and Lip Cancer
Ovarian Cancer

P
Pancreatic Cancer
Parathyroid Cancer
Penile Cancer
Pharyngeal Cancer
Pituitary Tumour
Primary CNS Lymphoma
Primary of Unknown Origin
Prostate Cancer

R
Respiratory System
Used for respiratory cancers other than Lung and Nasal Cavity and Paranasal Sinus cancers
Retinoblastoma

S
Salivary Gland Cancer
Sarcoma
Includes Chondrosarcoma, Ewing’s Sarcoma, Fibrosarcoma, Osteosarcoma, Rhabdomyosarcoma, Soft Tissue Sarcoma and Uterine Sarcoma
Sarcoma, Rhabdomyosarcoma, Childhood
Includes chondrosarcoma, Ewing’s sarcoma, and Fibrosarcoma
Sarcoma, Soft Tissue
Includes connective tissue, muscle, liposarcoma and leiomyosarcoma
Skin Cancer
Small Intestine Cancer
Stomach Cancer

T
Testicular Cancer
Thymoma, Malignant
Thyroid Cancer

U
Urinary System
Used for urinary cancers other than Bladder, Kidney, Wilm’s Tumour

V
Vaginal Cancer
Vascular System
Vulva Cancer

W
Wilms’ Tumour

References

APPENDIX 2: Charting Impact

Understanding and communicating the organisation’s impact has become a hot topic of conversation in philanthropy. The Independent Sector, a leadership network for nonprofits, foundations, and corporations in the US recommends starting with the five key questions below to encourage strategic thinking. The answers can form a report or snapshot of the organisation at a point in time creating opportunities for organisations to communicate effectively with donors on how it tracks or impacts over time.

A. What is the organisation aiming to accomplish?
B. What are your strategies for making this happen?
C. What are your organisation’s capabilities for doing this?
D. How will the organisation know if it is making progress?
E. What have or haven’t you accomplished so far?

More sophisticated or well-established foundations may want to apply the FasterCures framework, which measures an organisation’s processes as well as its contribution to the field of disease research in evaluating an organisation’s impact. The framework focuses evaluation efforts on 4 key drivers, each with several specific metrics of organisational success.

<table>
<thead>
<tr>
<th>Operational Performance</th>
<th>Accountability</th>
<th>Collaboration</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Strategy and Planning</td>
<td>• Knowledge Sharing</td>
</tr>
<tr>
<td></td>
<td>• Milestones and Monitoring</td>
<td>• Cooperative Research</td>
</tr>
<tr>
<td></td>
<td>• Management</td>
<td>• Strategic Partnerships</td>
</tr>
<tr>
<td></td>
<td>• Financial Sustainability</td>
<td>• Global Research</td>
</tr>
<tr>
<td></td>
<td>• Technology Transfer and Commercialisation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Community Engagement</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Field Contribution</th>
<th>Research Effectiveness</th>
<th>Resource Building</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>• Strategy Achievements</td>
<td>• Tools and Resource Development</td>
</tr>
<tr>
<td></td>
<td>• Portfolio Congruence</td>
<td>• Training and Career Development</td>
</tr>
<tr>
<td></td>
<td>• Scientific Advancement</td>
<td></td>
</tr>
</tbody>
</table>

1. **Accountability**: 6 mechanisms to ensure funds are used effectively to achieve goals.
   
a. Strategy and Planning
   
   **Example**: Does the research organisation have a strategic plan that states goals and understanding of the field? Does the research organisation seek external advice from experts?
   
b. Milestones and Monitoring
   
   **Example**: How does the research organisation track progress?
   
c. Management
   
   **Example**: Who runs the organisation and what is their background?
   
d. Financial Sustainability
   
   **Example**: Does the organisation have a funding plan to attract a diverse set of donors?
   
e. Technology Transfer and Commercialisation
   
   **Example**: How will an organisation engage with industry if an early-stage discovery has development potential?
   
f. Community Engagement
   
   **Example**: How does the research organisation communicate with consumers and patient advocates?
2. **Collaboration**: Evaluating an organisation’s capacity to collaborate is important since ‘collaboration is critical to successful innovation in disease research’

   a. Knowledge Sharing  
   **Example**: How does the organisation share data, experience and resources?

   b. Cooperative Research  
   **Example**: Does the organisation participate in multi-institutional (multiple organisations) and interdisciplinary (different sciences) research? Is there a clinician on the project?

   c. Global Research  
   **Example**: Does the organisation fund or work with top researchers from around the world? If not, why not?

   d. Strategic Partnerships  
   **Example**: How does the organisation work with other organisations working on childhood cancer or with adult cancer?

3. **Research Effectiveness**: Understanding the organisation’s impact on the scientific landscape and patients’ wellbeing.

   a. Strategic Achievements  
   **Example**: What is the organisation’s track record in achieving its scientific milestones?

   b. Portfolio Congruence (Alignment)  
   **Example**: Does the R&D program support the organisation’s mission? What is the breakdown of projects by stage of research and type of intervention (i.e. disease understanding, prevention, diagnosis, treatment)?

   c. Scientific Advancement  
   **Example**: What is the organisation’s most important scientific milestone?

4. **Resource Building**: Understanding the organisation’s capacity to build resources to advance a research agenda to advance its mission.

   a. Tools and Resource Development  
   **Example**: Has the organisation identified and have a plan for accessing tools and resources (e.g. predictive animal models, databases, biobanks, patient registries, clinical trial infrastructure, information technology platforms and data standards and protocols)?

   b. Training and Career Development  
   **Example**: Does the organisation support training and career development as a priority? If not, why not? Are there critical gaps that should be addressed?

---

**References**


APPENDIX 3: Managing better donor-researcher relationships

In collaboration with Dr Lara Moroko, MGSM

Health and Medical Research is from Mars and Philanthropy is from Venus, but the sectors need each other. Any therapist will tell you that to have a successful relationship, first you need to know ‘what you want’. The same applies in successful donor-researcher relationships – grounded in realism and aspirational for the future. Donor organisations and researchers need to ‘stand in front of the mirror’ and gain insights on their drivers, wants and wishes before entering into and expecting a long-term partnership.

Define and Understand Drivers.

Donors: The individual donor’s decision to invest in childhood cancer research can be driven by personal experience, e.g. proximity to a sick child or a grateful patient; the desire to make a positive difference in the world, e.g. improve health and save children’s lives across the world; impulse, e.g. emotional response to social media campaign; and/or recognition, e.g. the attention that comes from donating. Donor organisations, on the other hand, are generally driven by their mission.

Researchers: A study commissioned by Research Australia found that researchers are predominantly motivated by the excitement of discovery, rather than salary, community recognition or the potential for personal wealth from the commercialisation of their discoveries. Publications are viewed as a more important research outcome than the patenting of research findings or creation of new businesses. While some view publications as a measure of productivity versus research impact, it is acknowledged that it is a key metric in formula funding and therefore an important output and benefit to their research careers.

Typically, donors and researchers have a basket of drivers. They often have a latent hierarchy of drivers which can be categorised as ‘needs’, ‘wants’ and ‘wishes’. The key is to know and understand what each party brings to the table, what is negotiable and what would be considered a ‘deal-breaker’. Honest and direct communications make for sustainable donor-researcher relationships.

Sample Framework for Donors

1. Defining ‘Needs’ or ‘Must Havens’
   a. What area of cancer research is important to me?
      Example: I want to make a difference and have an interest in the _______ (e.g. prevention, diagnosis, treatment, survivorship) of childhood cancer.
   b. Who do I want to help?
      Example: I want to help children diagnosed with cancers that _______ (e.g. the highest mortality rates; the treatment causes terrible side effects; most likely to relapse or get secondary cancers).
   c. Understanding the funding challenges faced by researchers, do I have a preference for funding R&D for new treatments or development of tools and resources to support R&D?
      Example: I want to fund _______ (e.g. the training and development of an early career researcher; pre-clinical trial activities for a new drug therapy; and/or ensure quality data is maintained and is accessible to researchers).
d. What stage of the medical R&D pipeline should I support?

Example: I want to fund projects in the ________ stage of research, e.g. translational research (bench to bedside); clinical trials; translational research to implement new protocols in the health system.

e. Am I interested in funding investigator-initiated (bottom up) ideas or being more directive (top-down) in the grant-making process?

Example: I want to fund Prof X study on Y, or I seek to fund Cancer A only?

2. Defining ‘Wants’ or ‘Desirable Qualities in the Researcher/Research Organisation’:

a. Objective Wants

i. What are the qualities in the researcher I want and can independently verify?

ii. What is the researcher’s track record?

iii. Is the researcher associated with an organisation I trust?

b. Subjective Wants

i. What are the qualities in the researcher/research organisation that I want and can judge for myself?

ii. Is their approach/project clear to me?

iii. Do I feel confident in the team?

iv. Will they provide enough feedback on the project throughout all stages?

v. Will they value my suggestions?

3. Defining ‘Wishes’ or ‘Factors that although not necessary for the success of the project will increase donor engagement and satisfaction’

a. Recognition. How will I be recognised for my contribution?

b. Respect. Will I only hear from them when they are running out of money, or am I a valued contributor?
Figure Index

**Figure 1**: Proportion of funding to cancer research projects and research programs by funding source in the period 2006 to 2011. 15

**Figure 2**: The Spectrum of Donor Collaboration. 20

**Figure 3**: Common Versus Catalytic Donor Mind-set. 25

**Figure 4**: Health and Medical Research Funding and Activity Flows in Australia. 29

**Figure 5**: Australia’s investment in health and R&D as a proportion of GDP is slightly below the OECD average. 33

**Figure 6**: Target R&D Benchmarks for top 20 OECD Nations – Country Targets (not actual). 33

**Figure 7**: Likely Future Developments in Health and Medical Research (HMR). 38

**Figure 8**: Ratio of mortality to incidence by cancer type, by country per capita income, and geographic region; children 0-14. 41

**Figure 9**: Five-year survival rates for selected childhood cancers, Great Britain, diagnosed during 2001-2005. 45

**Figure 10**: Childhood Cancer – Current long-term outcomes. 46

**Figure 11**: Research Spectrum ‘Micro’ to ‘Macro’ and back. 49

**Figure 12**: Linear Model of Innovation. 50

**Figure 13**: Three Stages of Health and Medical Research. 50

**Figure 14**: Commercial Drug and Therapy Development in the US. 53

**Figure 15**: Commercial Drug or Therapy Development in Australia. 53

**Figure 16**: Common Scientific Outline (CSO) Seven Cancer Research Categories. 56

**Figure 17**: Cancer Control Continuum. 57

**Figure 18**: Funding to Cancer Research Categories 2003–2011. 57

**Figure 19**: Three Categories of Research Costs. 58
CANCER

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