

# The Kids' Cancer Project Symposium Abstracts

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## **Dr Michelle Tennant**

Murdoch Children's Research Institute

Funding provided via Col Reynolds Research Fellowship

# RAD-VR: Creating Immersive Virtual Reality Environments to prepare paediatric patients for radiation therapy

## The project

To co-design a state-of-the-art, VR intervention to prepare children with cancer (3-18 years) and their families for radiation therapy through education, simulation and exposure techniques. RAD-VR will be implemented and evaluated as standard paediatric radiation oncology care, measuring efficacy (anxiety, health literacy) and impact in terms of reduced GA use.

## The problem

Radiation therapy (RT) is a cancer treatment frequently used in paediatric oncology to shrink and destroy cancer cells, often alongside surgery and chemotherapy. Acute distress is common among children and their carers undergoing RT due to intimidating environments, separation from parents, and the need for immobilisation devices and stillness during treatment. Procedural distress affects treatment adherence and increases reliance on general anaesthesia (GA) to ensure safe administration and compliance. Currently, all children under 3 and half aged 3–8 require GA for their treatment, which costs around \$30,000 per child. Concerns are growing about the neurodevelopmental impact of repeated GA exposure.

## The why

Radiation Therapy (RT) remains a cornerstone of treatment for paediatric cancers, particularly CNS tumours. Current clinical practice is to provide parent-directed education regarding the logistics and risks of RT; however, children rarely benefit from this mode of procedural education. General Anaesthesia (GA) is often required to ensure compliance. GA is also associated with significant anticipatory anxiety, requires fasting, increases the risk of medical complications, and adds burden to patients and families. It is also associated with negative postoperative behaviour changes in children, a slower recovery, sleep and eating disturbances, unknown longer term neurodevelopmental impacts and further medical trauma.



RAD-VR is an immersive virtual reality (VR) intervention that prepares children for radiation therapy (RT) through simulation and psychologist-led coaching. It allows children to virtually tour the hospital, observe another child's treatment, and experience RT in first-person view, helping them manage procedural distress. RAD-VR is safe, easy to use, and well received by patients, parents, and healthcare providers. It improves understanding of RT, reduces anxiety, enhances cooperation during sessions, and lowers the need for general anaesthesia. Parents report it helps children feel confident and unafraid, making RT less confronting and potentially avoiding GA altogether.

## **Our progress**

RAD-VR program of research commenced on February 1, 2025. Progress to date reflects the initial research planning period.

#### 1. Legal

- Research Collaboration and Intellectual Property Agreements between MCRI (sponsor) and trial site (Peter MacCallum Cancer Centre), drafted and in review
- Tender for VR developer to build RAD-VR experience, complete
- Service Level Agreement with selected company (Catalyst VR), complete

#### 2. Ethics & Governance Approvals

- Protocol (Phase 2 trial), in draft

#### 3. Consumer Participation

- RAD-VR presented to the Carer's Network, complete
- Recruiting for consumer advisory group (Phase 1 Co-design), in progress

#### 4. Project Management

- RAD-VR SharePoint, complete

#### 5. Public Awareness

- Invited panellist - HIC Health, Innovation and Community conference August 2025

#### 6. <u>Professional Development</u>

- Competitively selected for ANDHealth's 2025 ACTIVATE program, 6-month accelerator to support RAD-VR translation and scale-up strategy (Phase 3), in progress
- \*Disruptions: 6 weeks secondary parent leave 15/2/25 29/3/25

#### What's next

Phase 1 co-design - between September -December 2025 we will prototype RAD-VR with clinician and consumer advisors and our VR developers, ready for Phase 2 roll out at our institution within an implementation trial. I am keen to meet and talk with anyone else working in the digital health space. Also, anyone conducting implementation research. In parallel, I am planning for sustainability and seeking to produce a business case for RAD-VR to be implemented permanently as standard care. I would welcome any mentorship from a business lens to support this aspect of the project.



## **Dr Karin Plummer**

Griffith University, School of Nursing and Midwifery

Funding provided via Col Reynolds Research Fellowship

The DECIDE study: Codesign and evaluation of a co-designed e-health pain management decision aid for parents of children undergoing Bone Marrow Transplant

## The project

DECIDE is developing and evaluating an e-health decision aid to support parents in making informed decisions about their child's pain management with their clinicians during bone marrow transplant. Co-designed with families and clinicians, the tool aims to improve shared decision-making, reduce distress, and personalise pain care throughout the transplant process.

## The problem

Children undergoing bone marrow transplant experience prolonged and severe pain, but parents often feel ill-equipped to make informed decisions about pain management. Despite best intentions, uncertainty and communication barriers can result in under-treated pain or decisional regret. Currently, no tailored tools exist to guide parents through these complex choices. DECIDE addresses this gap by providing structured, evidence-based, and timely support for shared pain management decision-making.

By improving parental confidence and clinician-family communication, the study seeks to reduce pain and decisional conflict and regret during one of the most intensive treatments in paediatric oncology.

## The why

The DECIDE study is a crucial initiative that addresses an urgent need, identified by consumers, to improve pain management. This will be achieved by promoting collaboration between healthcare providers and parents, who will work together to make informed decisions regarding pain management. This approach ensures that decision- making is transparent, informed and personalised to meet the unique needs of each patient. Improved pain management during HSCT therapy has many benefits, including reducing patient distress, minimising the risk of medical traumatic stress, and optimising time to analgesia.



DECIDE is a digitally delivered, co-designed decision aid that supports shared decision making about complex pain-related care. It combines trauma-informed communication, evidence summaries, and personalised prompts in a format parents can access when and where they need it. The study uses mixed-methods, co-design approach that includes reviews of the evidence, audit of current pain management practices and workshops to ensure content is relevant and usable. What makes DECIDE innovative is its integration of design thinking, digital delivery, and real-world clinical insight to support shared decision-making in one of the most complex aspects of paediatric cancer care.

## **Our progress**

We have completed Phase One of the DECIDE study, including formation of a multidisciplinary Steering Group, a systematic review, and interviews with parents and clinicians to explore decisional needs and conflicts in managing children's pain during bone marrow transplant (BMT). To complement this, we are conducting a retrospective audit to map current pain management practices, including opioid and adjuvant use, referral patterns, and adverse events. Findings from the review, audit, and interviews have informed the development of a prototype digital decision aid, designed to support shared pain management decisions during BMT. The study has received ethical approval and endorsement from the Australian and New Zealand Children's Haematology and Oncology Group.

Outputs to date include a pain decision needs framework for the DECIDE protype, a clinical summary of pain management options, and co-design-derived content priorities. Preliminary findings have been presented at national pain and oncology conferences, with manuscripts currently in preparation.

#### What's next

We are now advancing the co-design phase of the DECIDE study, drawing on insights from families, clinicians, and evidence synthesis to build a digital prototype that supports shared decision-making around pain during transplant. Development of the prototype is underway, incorporating trauma-informed communication, structured prompts, and accessible evidence summaries. The next step is acceptability testing with families and clinical teams to assess usability and relevance in practice. Feedback from this phase will guide refinements before we move into the final stage: real-world evaluation of DECIDE in clinical settings.

We welcome collaboration on digital implementation, culturally responsive adaptation, and future multicentre trial planning.



## **Dr David Mizrahi**

The Daffodil Centre, University of Sydney

Funding provided via Col Reynolds Research Fellowship

## From the ward to the playground: An active approach to childhood cancer

## The project

My program of research is investigating the role of physical activity in children impacted by cancer. We explore barriers and facilitators among families and health professionals (via qualitative methodology), quantify physical muscle and cardiorespiratory deficits (via international collaboration) and deliver an online randomised trial of tailored exercise to survivors.

## The problem

Physical activity is a key modifiable health behaviour for physical and psychological health. Young people impacted by cancer experience challenges in becoming physically active, which may increase their risk for future health complications. This is further complicated as many cancer services do not embed widespread physical activity support, so families lack appropriate guidance. My research program explores ways to promote physical activity to families and health professionals, to ensure young people are supported as they grow up with tools to improve their physical and psychological wellbeing and manage their health.

#### The why

Many children live with physical and psychological health consequences from their lifesaving treatment. This can leave them behind their peers as they grow up, which can further stigmatise them psychosocially. Survivors generally have low physical activity as a result, and thus as they grow up, they may be at even greater risk for cardiometabolic risk factors.

Innovations are needed in current models of care to support young people to find physical activities that are enjoyable and beneficial for them, so they can foster lifelong positive health behaviours, normalise their peer relationships and improve their health.



<u>Project 1</u>: qualitative interview study of families and health professionals to explore how to support children who are undergoing active treatment, with the goal to innovate current models of care and explore implementation strategies.

<u>Project 2</u>: epidemiological study using St Jude (US) data to explore deficits in cardiorespiratory fitness, muscle mass and upper/lower muscle strength in young survivors and identify children at high-risk for deficits.

<u>Project 3</u>: A randomised clinical trial of online delivered tailored exercise delivered by exercise physiologists to children around Australia (MERRIER Study). The program is 5 sessions, consistent with Medicare's current model for implementation.

## **Our progress**

<u>Project 1</u>: We conducted 28 interviews (17 health professionals, 11 consumers). Thematic analysis identified key barriers: 1. Lack of funded hospital-based programs and dedicated exercise staff, 2. Treatment-related side-effects, 3. Variability in referral patterns, 4. Need for flexible, patient-centred approaches. Four key facilitators were identified: 1. endorsement for being active during different treatment phases, 2. Parents' desire for structured, individualized exercise guidance, 3, Innovative strategies to promote engagement (e.g., utilising technology) and providing simple equipment (e.g. resistance bands, bike pedals). Manuscript being drafted.

<u>Project 2</u>: 478 participants from St Jude (US). Analysis ongoing, manuscript being drafted. Exercise intolerance was present in 55.2%, reduced lower body strength in 39.3%, reduced upper body strength in 28.2%, and 5.7% reduced lean muscle mass.

<u>Project 3</u>: The MERRIER Study is recruiting families from Camp Quality. To date, 22 children aged 5-18 have been enrolled (9 randomised to intervention, 6 control).

#### What's next

<u>Project 1</u>: After this publication, we open opportunities for new analyses of St Jude data. I am also co-leading (with Dr Lauren Ha) a Global Consortium study of 10+ already agreed sites internationally to explore fitness deficits and cardiovascular risk factors in young survivors.

<u>Project 2</u>: Our exploration using the RE-AIM framework will explore implementation factors for implementing a physical activity program/service during active treatment. We will be submitting grants to pilot its implementation, and welcome advice and collaboration in different settings.

<u>Project 3</u>: We have partnered with world-leading Wearables Hub (Sydney Uni) to analyse and interpret our activity tracker data. We will explore implementation factors for Camp Quality to deliver personalised exercise programs in the future.



## **Ms Rachel Edwards**

Queensland Children's Hospital

Funding provided via Col Reynolds Research Fellowship

# Optimising symptom management in paediatric oncology patients: Symptom PROMPT

## The project

This study evaluates the use of patient-reported outcome measures (PROMs) and nurse-led interventions to improve symptom assessment and management for children undergoing bone marrow transplantation. It aims to enhance nurse knowledge, integrate systematic screening into care, and improve quality of life and treatment outcomes for paediatric cancer patients.

## The problem

Children undergoing bone marrow transplantation (BMT) for cancer experience severe and often under-recognised symptoms that impact their quality of life. Despite evidence supporting symptom screening using patient-reported outcome measures (PROMs), these tools are rarely used in routine paediatric oncology care. Nurses—key to symptom management—often lack resources, skills, knowledge and confidence to act on symptom data, particularly psychological symptoms. This project addresses the critical gap in systematic symptom assessment and management. By equipping nurses with training and validated tools, the study aims to improve timely symptom recognition and response, ultimately reducing distress and enhancing outcomes for young people with cancer.

## The why

Children, adolescents, and young adults undergoing cancer treatment, particularly bone marrow transplantation, face intense and complex symptoms that can significantly affect their physical and emotional wellbeing. When symptoms are not systematically assessed or addressed—especially psychological distress—they can lead to unnecessary suffering, reduced treatment adherence, and long-term health impacts. Current care does not routinely include patient-reported outcome measures (PROMs), leaving the young persons' voice unheard, symptoms potentially unrecognised, and not managed. Addressing this gap is critical to improving symptom control, enhancing communication between patients and clinicians, and ensuring holistic, patient-centred care that supports recovery and long-term quality of life.



This mixed-methods study uses a novel, collaborative approach by co-developing interventions with key stakeholders, including clinicians and families, to ensure relevance and feasibility. It combines quantitative symptom data from validated PROMs with qualitative insights from interviews and focus groups to explore real-world implementation in a specialist paediatric BMT setting. A pre-post design evaluates changes in nurse knowledge, attitudes, and behaviours following tailored training. It integrates routine symptom screening into clinical care—an underused but evidence-backed strategy—aiming to transform how symptoms are identified and managed, improving quality of life and setting a foundation for national scale-up.

## **Our progress**

Since the project's launch in October 2024, key milestones have been achieved. Governance processes have been completed, including the QUT funding agreement, deed of variation, and the CHQ contract and ethics. Strong collaborations have been established with the BMT clinical team at Queensland Children's Hospital and the ANZCHOG Nurses Research Group. A systematic literature review was completed, alongside parent and patient interviews and review of medical records. Patient recruitment continues. The online module, developed in the pilot study has been completed by 81 staff since October 2024. Three in-person skills development workshops were delivered, attended by 26 staff. Preliminary findings from the pilot study were presented at the Maddie Riewoldt's Vision Symposium and a project update was delivered to the ANZCHOG TACTIC group. Additionally, the project lead has served as a Research Ambassador for The Kids' Cancer Project (TKCP) at K'Day, strengthening engagement and advocacy for research in paediatric oncology.

#### What's next

In the coming months, key stakeholder focus groups will be conducted to explore barriers and enablers to implementing symptom screening into routine care. We will also be exploring IT solutions for integrating PROMs into clinical systems, and welcome advice or collaboration from teams experienced in digital health integration. Interviews with BMT nursing staff will be commenced to understand their perceptions of symptom management; we invite interest from other national sites to contribute to this work. Thematic analysis of all interview transcripts will follow, informing the development of practical, scalable implementation strategies.

We welcome support and shared learning from the broader paediatric oncology and digital health communities to strengthen the impact and sustainability of this research.



## **Dr Christine Signorelli**

University of New South Wales // Sydney Children's Hospital

Funding provided via Project Research Grant

The 'Engage' program: An equitable model of comprehensive cancer survivorship care for young cancer survivors

## The project

'Engage' is an evidence-based, survivorship care program for young cancer survivors. It has been built to help survivors navigate survivorship care for the well-documented physical and psychosocial impacts of cancer and build survivors' self-management skills, through personalised, practical support that empowers survivors and improves long-term outcomes.

## The problem

Engage addresses a key challenge that young survivors face in finding age-appropriate care that meets their significant and diverse unmet physical, psychological, and social needs, especially after treatment ends. These survivors face lifelong health risks, emotional distress, and difficulties in navigating complex healthcare systems. Our sustainable program ensures survivors receive appropriate, timely survivorship assessment, care planning, and intervention tailored to each survivor's unique constellation of developmental needs and chronic conditions. Addressing these gaps with tailored survivorship care is critical to empower young survivors to manage their health confidently and improve their long-term wellbeing.

#### The why

Children and adolescents/young adults (AYAs) with cancer have complex physical and psychosocial needs that often intensify when treatment ends. Despite being expected to resume education, work, and social life, many struggle with the lasting impacts of their diagnosis, which can affect long-term health, wellbeing, and life opportunities.

Successful transition back to "normal" life is critical to future functioning in survivorship, yet current systems often lack the time, resources, and tailored approaches needed to prepare them adequately. Without dedicated, age-appropriate survivorship care, this priority population risks poorer health outcomes and diminished quality of life well into adulthood.



The 'Engage' program is an innovative, distance-delivered survivorship model—built on years of collaboration with young cancer survivors, clinicians, and community partners. It combines comprehensive health assessment, nurse consultations, multidisciplinary case review, and a personalised survivorship care plan with tailored recommendations for survivors and their GPs. This approach ensures equitable access, particularly for those facing health or geographic disadvantage, and directly strengthens survivor–GP relationships. Engage shifts survivorship care from hospital-centric to patient-centred, empowering survivors to self-manage complex, lifelong health needs. Its collaborative design and real-world feasibility position it to transform survivorship care and reduce long-term inequities in health outcomes.

## **Our progress**

Over several years, our team has demonstrated the clinical effectiveness of Engage through a pilot (n=27) and large-scale evaluations in NSW hospitals involving >220 survivors and >30 stakeholders. We established its feasibility, safety, acceptability, and positive impact on survivors' quality of life and care experiences, particularly for rural and mobile young Australians. Process mapping and evaluation have produced an adaptable Implementation Framework and targeted tools for embedding Engage into care pathways.

This work, underpinned by strong clinical, research, and community partnerships, provides the expertise, infrastructure, and evidence base to co adapt the program for AYAs – the next step in our program of work.

#### What's next

Our next step is to adapt and expand Engage for adolescent and young adult (AYA) cancer survivors, co-designing the program with survivors, clinicians, and community partners to ensure it addresses their unique medical, psychosocial, and practical needs after treatment. We will refine and test the new AYA model in diverse settings, including rural and underserved communities, and evaluate its clinical effectiveness, cost-effectiveness, and scalability.

We welcome advice on sustainability strategies and health system integration, collaboration from clinicians, community organisations, and survivor advocates to strengthen engagement and reach, and support for technology solutions, training resources, and policy translation to embed survivorship care nationally.



## Ms Chelsea Valentin

Sydney Children's Hospital Network

Funding provided via Col Reynolds PhD Top-Up Scholarship

## The Role of Occupational Therapy in Paediatric Oncology

## The project

Medical advancements have resulted in increased survival rates for children affected by cancer. However, little research has focused on children's development and their participation in life during and after treatment. With the potential to improve outcomes, it is essential to understand the role of occupational therapy in this vulnerable population.

## The problem

The impact of cancer on a child's physical health and psychosocial wellbeing is well documented, lessening a child's ability to engage in normal developmental activities, form relationships, achieve academically, and maintain long-term wellbeing into adulthood.

However, there is an unmet need in literature focusing on a child's developmental and participation outcomes both during and after cancer treatment. With its core role to enable meaningful engagement in everyday life, this research examines occupational therapy (OT) in childhood cancer and will ultimately inform clinical practice by developing clinical guidelines that include OT as an integral component of holistic acute childhood cancer care.

## The why

Childhood cancer impacts the ability to participate in daily routines (e.g. self-cares, play/leisure, school/productivity and rest). Emerging research has illustrated the crucial role OT has in paediatric oncology, through its unique role to promote health and wellbeing by enabling children to participate in activities they need/want to do.

Evidence suggests that OT should be an integral component of paediatric cancer care to optimise daily function and participation. However, the paucity of evidence addressing OT for children affected by cancer, particularly in early childhood (0-5 years), means no standardised clinical guidelines exist to ensure OTs continuously provide quality evidence-based care.



My research program aims to i) understand health professionals' perspectives on current OT practices in paediatric oncology; and to ii) understand the developmental needs and experiences of children and their families throughout cancer treatment. Bridging both the clinical and research landscapes, this multi-perspective project draws on clinicians, academics and patients/families to build evidence-based OT practice in paediatric oncology, beginning with a systematic review on the impact of cancer on childhood development and how OT can mitigate these effects. Collectively, these data will ultimately inform standardised clinical guidelines to maximise a child's developmental outcomes and participation in everyday life.

## **Our progress**

Key achievements include the completion of a systematic review, investigating the impact of childhood cancer on development, as well as the role of OT in mitigating these effects. 364 articles were identified as eligible for the review, with early results suggesting less than 20 papers globally examining OT interventions in the context of childhood cancer.

To support my work, I have been successful in obtaining two PhD top up scholarships, from Maridulu Budyari Gumal and The Kids' Cancer Project. I am committed to disseminating the findings of my work and raising awareness of the potential for OT in paediatric oncology, including my Randwick Emerging Researcher's Symposium poster and recent presentation at the Sydney Children's Hospital Network Grand Rounds.

The development of both a scientific advisory committee and a consumer advisory committee is underway to ensure the voices of these crucial stakeholders will inform this research project and its outcomes.

#### What's next

My research will next evaluate current clinical OT practices across Australia and New Zealand, then navigate how OT can best support the lived experiences of patients and families affected by childhood cancer. These findings will ultimately contribute to establishing evidence-based clinical guidelines. This has the potential to significantly transform the healthcare system and clinical practice to provide best-quality outcomes for all children affected by cancer.

Relevant clinician-researchers in the field of allied health and paediatric oncology are welcome to collaborate on this research. In addition, families of a child with cancer or childhood cancer survivors who are eager to support my research are greatly welcome to share their experience. This collaboration will shape my ongoing research plan and protocol.



## Ms Jacqueline Hunter

University of Melbourne // University of New South Wales

Funding provided via Col Reynolds PhD Top-Up Scholarship

# **Exploring the Psychosocial Impact of Genomic Testing and Surveillance for Cancer Predisposition in Children**

## The project

This is an exploratory, psychosocial study. We aim to better understand families' experiences of germline genomic testing for genetic cancer predisposition in children with cancer, as well as families' experiences of routine cancer surveillance for children with a cancer predisposition syndrome.

## The problem

Germline genomic testing is now available to all children diagnosed with cancer in Australia, exposing families to complex choices, information, and uncertainty. Little is known about how this testing affects families emotionally, psychologically, and practically. For families whose child is found to have a cancer predisposition syndrome, the added burden of ongoing cancer surveillance, often invasive and burdensome, is also underexplored.

Our project addresses this critical gap by investigating families' experiences to inform how genomic testing and cancer surveillance for genetic cancer predisposition in children are delivered, focusing on minimising distress and maximising satisfaction and clinical outcomes.

## The why

Evidence shows that genomic testing and surveillance for genetic cancer predisposition can be distressing, burdensome, and anxiety-inducing for families - especially when children, adolescents, or young adults are involved. This age group is already navigating significant developmental, emotional, and psychosocial challenges, and the added uncertainty of genetic cancer predisposition can further disrupt their wellbeing and family dynamics.

To ensure that these complex processes are delivered in ways that minimise distress and negative impacts, it is critical to incorporate the perspectives of those directly affected into models of care. Doing so will improve patient and family experiences and enhance clinical outcomes.



This project utilises a multi-perspective, longitudinal, mixed-methods design to capture the complex experiences associated with genetic cancer predisposition in children. First, we conducted a systematic review to synthesise current evidence on families' perspectives and experiences with genetic or genomic testing and identify gaps in evidence.

Building on this, we collected in-depth data via questionnaires and interviews collected as part of psychosocial components embedded within larger clinical studies, across multiple participant groups (parents, patients, and clinicians) at multiple sites. Our novel approach integrates diverse perspectives over time and is embedded in clinical research, ensuring real-world relevance and supporting translation into practice.

## **Our progress**

This study has so far resulted in two publications; a systematic review published in Genetics in Medicine (doi: 10.1016/j.gim.2024.101197) and an original article exploring healthcare professionals' experiences of an Australian germline genomic testing study, the PREDICT study, published in Cancer Medicine (doi: 10.1002/cam4.70680).

We have also completed our psychosocial study of families' experiences of the PREDICT study, which included 128 families (187 parents and 19 patients), with a manuscript currently under submission at British Journal of Cancer. We have recruited 13 families with a child with a cancer predisposition syndrome to our surveillance study, SMOC Junior, and data collection remains ongoing. Through SMOC junior, we have developed a partnership with the Sydney Children's Hospital Genetic Cancer Risk Clinic and are working with them to implement new clinical processes and develop future grant applications. We have disseminated project findings at five conferences and received \$22,450 in additional funding or awards.

#### What's next

In the next phase of this project, we will continue recruitment and data collection for the SMOC Junior Study. Pending an ethics amendment, we plan to begin interviews with patients aged 12 and over participating in SMOC Junior to gain deeper insights into their experiences with surveillance. We are actively disseminating our findings at national and international conferences, including an upcoming poster presentation at the 2025 International Paediatric Oncology Congress (SIOP) in Amsterdam.

We welcome collaboration and input from the community in several areas, including feedback on our completed studies, opportunities to disseminate or build on our findings, and future collaborations that extend or apply our research in new contexts.



## Ms Megumi Lim

Queensland University of Technology

Funding provided via Col Reynolds PhD Top-Up Scholarship

# Financial Relief for Families affected by Childhood Cancer: A Discrete Choice Experiment

## The project

Financial hardship is a significant challenge for families of children with cancer, often exacerbated by reduced income and increased expenditure.

This study aims to identify the preferences of parents and carers regarding financial aid programs for childhood cancer and explore heterogeneity in these preferences based on demographic factors.

## The problem

For financial aid programs to be effective, it is important to understand the preferences of affected families and explore differences in these preferences across subgroups.

Identifying these preferences and their variation can guide policymakers and charities in prioritising and implementing proposed changes to financial aid models, ensuring they better meet the needs of affected families.

## The why

Reliance on financial aid may be attributed to the higher out-of-pocket costs associated with childhood cancers, which are a consequence of the aggressive and unpredictable nature of the disease, and the demands of managing the medical sequelae of cancer survivorship. These factors hinder parents from maintaining or returning to employment.

Despite the availability of charities and financial support programs, many families report experiences such as near-homelessness, food insecurity, and prolonged financial recovery.



The objectives of our study were to (1) quantify the relative importance of key factors influencing access to financial assistance and (2) examine whether parental or child health-related and demographic characteristics impact these preferences.

To achieve this, we employed a discrete choice experiment (DCE) study design, where participants made trade-offs between different attributes in hypothetical scenarios that mimic real-world decision-making. Based on the random utility maximisation model (RUM), this method assumes that individuals make rational choices and select the option that maximises their overall utility (satisfaction).

## **Our progress**

The manuscript has been submitted to Supportive Care in Cancer and currently under review.

#### What's next

I would like some advice around how the study findings can be disseminated and implemented.



## **Dr Lauren Ha**

University of New South Wales

Funding provided via Project Research Grant

A digital health education program to improve childhood cancer survivors' self efficacy to engage in physical activity

## The project

'Making Moves' (formerly known as iBounce) is a co-designed digital program that aims to engage childhood cancer survivors in physical activity. It includes online modules, exercise videos and tailored consultations with an Exercise Physiologist. My project aims to assess the effectiveness of Making Moves and concurrently explore its implementation potential.

## The problem

My project addresses critical inequities in access to physical activity support for childhood cancer survivors, including those living in regional and remote Australia. Currently, there is no exercise service tailored to the unique needs of this population. This gap places survivors at greater risk of long-term health issues such as cardiovascular disease, obesity, and poor psychosocial outcomes.

My project responds to this unmet need by providing online physical activity education and individualised support. Additionally, my implementation trial will explore ways to support implementation of the intervention in the real world.

## The why

Childhood cancer survivors may face long-term health problems, including cardiovascular disease and obesity. These late effects are worsened by physical inactivity and sedentary behaviours. Regular physical activity is safe and improves survivors' physical and psychosocial health, yet >85% are inactive and have poor fitness levels. For families living in regional/rural Australia, access to specialised care is limited and travel is financially taxing.

The lack of age-appropriate resources and exercise guidance for childhood cancer survivors presents a critical gap. Therefore, encouraging physical activity in survivors is essential, as poor lifestyle habits in childhood may continue into adulthood, compounding long-term health risks.



My project is a Type I Hybrid Effectiveness-Implementation trial. To date, digital health physical activity interventions have shown to be feasible and acceptable among survivors and families. However, few studies have examined the factors that are crucial to their real-world implementation. The traditional process from intervention development to implementation is estimated to take an average of 17 years. My research is novel and bold, as hybrid study designs offer a potential solution to this delay by accelerating the process by examining both the effectiveness of the intervention and its implementation.

## **Our progress**

We are close to completing long-term follow-up with all participants in the intervention. Our preliminary findings show survivors significantly increased their physical activity self-efficacy scores (p<.01), aerobic fitness levels (p<.05) and muscular strength (p<.05). A notable finding of our research was that the baseline fitness levels of participants (mean age 13 years) were equivalent to the fitness level of 60–69-year-old elderly population. This discovery is important as it spotlights survivors' less than optimal physical health and emphasises the need for health behaviour interventions that will improve health outcomes.

Regarding our implementation trial, we have completed all data collection and analysis and are currently preparing the manuscript for publication. We have further successfully published two articles and one letter to the editor in high impact journals from this project. We are also partnering with the charity, Little Big Steps, to expand Making Moves to support children newly diagnosed with cancer.

#### What's next

Upcoming plans for the project include finalising data collection and analysis for the Making Moves effectiveness trial. We are nearing completion of long-term follow-up with all participants and are excited to begin analysing the full dataset. In parallel, we remain on track to submit findings from our implementation trial for publication in a high-impact journal. These results will provide critical insights into both the effectiveness and real-world delivery of our intervention.

We welcome collaboration with researchers and clinicians interested in implementation science, digital health, health behaviours and childhood cancer care, as well as support in developing implementation strategies to tailor Making Moves across diverse settings.