Final Report on the Camp Quality Costing Study

Primary School Cancer Education Program

November 2020

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Executive Summary

This report summarises the results of a Social Return on Investment study into Camp Quality's Primary School Cancer Education Program in 2018 and 2019.

Scope and Purpose

The report provides information on the activities undertaken in Camp Quality's Primary School Cancer Education Program (PSCEP) from 1 January 2018 – 30 December 2019.

> "The puppet show was a massive confidence boost for my child who is a cancer survivor. The kids in his school became aware of what cancer and its side effects are and the kids stopped making remarks about his 'chemo' teeth and understood that it was a side effect of chemo and not bad hygiene. The educational puppet shows even gave him the confidence to show his scars which up until the show he was extremely conscious about."
>
> Survey Participant - Parent/carer of a child with cancer

Camp Quality's (CQ) purpose is to create a better life for every child living with cancer in Australia. They are committed to delivering national programs that build resilience and optimistic behaviours for all children (0-15 years) living with cancer in Australia, their siblings and families, and for children who have parents or carers living with cancer. CQ provides essential support services through every stage of the cancer journey from diagnosis, treatment, remission and bereavement.

The PSCEP is an educational puppet show which aims to dispel myths and create supportive communities for any child affected by cancer. The PSCEP helps teachers build a supportive school community for all school-age children affected by cancer. The program is offered to schools for free: to all primary school children and is supported by educational resources for teachers and students.

KPMG was engaged by CQ in August 2020 to update the evaluation for the PSCEP. The aim was to articulate and estimate the value of the impact of the PSCEP on the children, siblings and families affected by cancer who are known to CQ. Throughout this report, we refer to children who have/had cancer as *patients*. Siblings of these children who had/have cancer are referred to as *siblings*. Kids impacted by carer's cancer (KICC) are called *offspring*.

Method

Through discussion with the CQ team, the targeted and expected outcomes of the PSCEP were to:

1) Provide support to patients, siblings and offspring in relation to reintegration into school.
2) Provide evidence-based information and resources to teachers/staff to practically support a child through their cancer journey.
3) Reduce patients' and siblings' sense of isolation and bullying, increase confidence, sense of value and coping ability.

To confirm that the program outcomes are the most appropriate, KPMG analysed the PSCEP theory of change program logic, CQ PSCEP program documentation, interviews with CQ program managers and executives and a sample of relevant academic literature.

After confirming the key outcomes to be measured, the associated proxies were selected which represent the benefits of PSCEP outcomes. We refer to these as the benefits of the PSCEP. The benefits were then:

1) **Measured -** through a survey of the parents and carers of patients, siblings and offspring – see Section 3 Methods and Data Sources below. The survey was sent to all families who had children who fit the patients, sibling or offspring definition and had seen a CQ cancer education puppet show during 2018 and 2019. This garnered 68 complete responses from parents and carers on behalf of 123 children. A response was considered complete if all questions were answered.
2) **Calculated** - through reference to academic research and financial proxies – see Section 3 – estimate the benefits associated with the outcomes. The key benefits estimated include: avoided mental health expenditure, increased parental productivity, reduced school absenteeism and increased future income - see Section 4 Social Return on Investment - Measuring Benefits and Outcomes; and
3) **Converted to SROI** – was calculated by dividing the total benefits estimated dollar benefit created through the PSCEP by the dollar amount invested in delivering the PSCEP – see Section 4

Results

The total Social Return on Investment of PSCEP is 502%. For every dollar spent on the delivery of the PSCEP there is an estimated $5 of benefit generated.

During 2018 and 2019, the PSCEP visited 1,055 schools nationally, and provided 1,696 performances, attended by 257,842 school children.[1] Of this total a small subset of children are known to CQ: 408 of these children were living with or have recovered from cancer, 500 were siblings of these children and 704 of those children were kids impacted by a parent or primary carers' cancer. The results of this study show there is a significant return to the PSCEP program for all three stakeholders. The SROI of the program during 2018 and 2019 was 502%, meaning for every $1 spent on the PSEP, there was a $5 return on investment.

Children who have carer's with cancer were the most impacted stakeholder group, showing the importance of communicating cancer and its impacts in a child friendly, educational manner. Improvements to mental health noted as the core benefit of the program, with over $4.6 million dollars of benefits gained from this indicator. **$5,686 of benefit is received for every PSCEP performed,** with a cost per show of $1,132.[2]

Key Findings

- Of the total **$5 return on investment:**
    - The offspring group received the most benefit from the PSCEP. Of the total $5 return, **$3.35 is attributed to offspring**, representing a benefit of $9,141 per child who attended the PSCEP during 2018 and 2019 ("attending child"). This was mostly a result of this group requiring less treatment for mental health issues that arose from their carer's cancer or diagnosis.
    - The second largest benefit was received by the patient group. **$1.29 of total benefit is attributed to patients**, a benefit of $5,152 of benefits per attending child. Like the offspring group, most of the benefits were due to decreased requirements for mental health treatments.
    - Siblings received the smallest benefits. **$0.39 of the total benefit is attributed to siblings**, which had an ascribed benefit of $1,480 per child who attended the show.

> "The puppet show was such a help to my boys, as I was going through chemotherapy and radiation. So, their friends then knew what was happening to me and they didn't have to explain. They didn't feel sad or different. Their classmates loved it [the show]."
>
> Survey Participant – Parent/carer who has cancer

- The total benefits were measured across four key areas: (1) Avoided mental health expenditure; (2) Reduced school absence; (3) Increasing future income of children who attended the PSCEP; and (4) Increasing parental productivity.
    - The PSCEP survey found that the number of visits to a health care worker for mental health issues decreased by 60% after the PSCEP in children who have/had cancer, 38% in siblings of these children, and 33% in offspring. **This saved $4.6 million in expenses for the treatment of mental health issues** across patients, siblings and offspring. For every show delivered during 2018 and 2019, the benefits to mental health were estimated to be $2,738.
    - Parents and carers were able work an additional 6 days on average for each child with cancer, 2 days for each sibling and 13 days for each child impacted by carers cancer.

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[1] Statistics provided by Camp Quality's the PSEP Program Manager.

[2] Total benefit or cost divided by number of performances.

Meaning parents can productively contribute through work, with benefits equalling $2.7 million to families and the economy over 2018 and 2019. For every show delivered during 2018 and 2019, the benefits to improved parental productivity were estimated to be $1,614.

- Children with cancer attend 6 days more of school per year after the PSCEP. Their siblings attend 2 days more, while the children whose parents have/had cancer attend 13 days more. **Avoiding $1.3 million in lost learning benefits** over 2018 and 2019. For every PSCEP show performed during 2018 and 2019, the benefits to reducing school absence were estimated to be $783.
- Adults who were bullied as children earn between $70 and $200 less per week. **PSCEP decreased the instance of bullying among all children, with an estimated benefit of $936,000 in additional future earnings for these children.** This equated to $552 per PSCEP show delivered in 2018 and 2019.

Limitations and Assumptions

KPMG were engaged by CQ to support its calculation of the Social Return on Investment (SROI) of the of the PSCEP over 1 January 2018 – 31 December 2019. Where relevant, the narrative approach, calculation basis, sources and key assumptions used in calculating CQ's SROI are described in this report. However, we have not performed any procedures to verify or substantiate the accuracy or completeness of data contained within:

- statements and representations made by CQ personnel;
- the information, data and assertions (including any accounting, tax, legal, regulatory or commercial assumptions) provided by CQ personnel and used in the SROI calculation; or
- the excel model's calculated outputs (including results and data). (Collectively, the information).

To attribute impacts the PSCEP, KPMG have relied on survey data produced by CQ to the PSCEP for the period 1 January 2019 – 31 December 2019. Benefits are assumed to be consistent between 2018 and 2019, hence these survey results have been used to represent the benefit for the entire period: 1 January 2018 – 31 December 2019. All change in behaviour or outcomes observed and reported in the survey responses before and after the PSCEP were assumed to be attributed to CQ.

As the survey was not compulsory for CQ families, each respondent chose to complete it themselves. It is possible, as a result, there is selection bias within the sample. We have assumed for the purposes of measuring the SROI, that the sample of 68 families represents the entire population of CQ families 3,918.[3] As a counter point, we have not measured the residual impact on other beneficiaries outside of the CQ families. Over 257,000 children attended the PSCEP any, 'other' children who are impacted by anti-bullying messages, or 'other' children who are impacted by cancer in non-CQ families, are not known to CQ and hence not included in this study, it is our expectation that additional value will be generated for these 'other' familes that is not includedin the study.

The benefits, as described in this report, are by their nature, estimates which will continually improve as methodology and research improves. Any suggestions or feedback on improving the enclosed calculations are welcome.

This report includes a summary of the SROI methodology applied, overview of the calculation and assumptions used, and a description of the value narrative for the impact of the PSCEP on mental health, school absenteeism, future income and parental productivity.

Future quantifications of CQ's PSCEP impact could improve by focusing on:

1) issuing the survey as part of the standard post-PSCEP performance process. The survey should be issued close to the puppet show as this will garner the most accurate responses from families, higher response rates will also allow the selection bias to be minimised;
2) surveying in-school outcomes from teachers. Teachers are well positioned to provide feedback on a child's behaviour inside school, such as absence from school, cohesion within the child's friendship and peer group, and presence of bullying;
3) considering benefits beyond the patients, siblings and offspring that attended the show. The general child population and the population of children who may have been affected by cancer, but whose families did not directly request the CQ cancer education puppet show; and
4) expanding understanding of parent experience and benefits of PSCEP through additional questions in the family survey.

We also make no confirmation or assessment of the commercial merits, technical feasibility or compliance with any applicable legislation or regulation of the chosen indicators or impacts selected. We provide no representation or warranty of accuracy, accuracy, completeness, reasonableness or reliability of the information.

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[3] Total number of families provided by Camp Quality Program Manager as at November 2020.

Contents

1 Introduction

Primary School Cancer Education Program (PSCEP)

Camp Quality's (CQ) purpose is to create a better life for every child living with cancer in Australia. CQ is committed to delivering national programs that build resilience and optimistic behaviours for all children (0-15 years) living with cancer in Australia, their siblings and families, and for children who have parents living with cancer. CQ provides essential support services through every stage of the cancer experience from diagnosis, treatment, remission and bereavement. CQ help in schools, homes, hospitals and in the community. With 60 staff based in six offices across capital cities and regional Australia, together with a footprint in eight of the nine Australian paediatric specialist hospitals, CQ has deep and comprehensive reach into target communities.

The PSCEP is an educational puppet show which aims to dispel myths and create supportive communities for any child affected by cancer. The PSCEP also aims to help teachers to build a supportive school community for any child affected by cancer. The program is offered free to schools and is supported by educational resources for teachers and students.

Traditionally the PSCEP focused on children living with cancer and their family members. However, CQ has actively expanded their offering to include children who have parents or carers with cancer. They seek to further develop the program in 2021 to include more serious topics such as bereavement.

During 2018 to 2019, the PSCEP visited 1,055 schools nationally, and provided 1,696 performances, attended by 257,842 school children. 480 of these children were children who are living with or have recovered from cancer, 500 were siblings of these children (Table 1). A further 704 of those children had a carer or parent with cancer.

Table 1 - Number of children known to CQ and impacted by cancer, who accessed the PSCEP in 2018 and 2019 (Australia wide)[4]

	2018-2019
Number of attendees living with cancer	480
Number of attendees with siblings with cancer	500
Number of attendees with parent/carer living with cancer	704

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[4] Camp Quality, 2018 and 2019, The PSEP statistics.

Objectives

KPMG was engaged by CQ in August 2020 to conduct a social return on investment (SROI) study of CQ’s PSCEP. The SROI measures the financial and social value delivered from CQ’s PSCEP. KPMG have sought to calculate the total cost of all activities relating to the PSCEP and has compared these to the value of the benefits obtained by stakeholders. The process aims to value the main outcomes of the PSCEP, however, only a portion of the outcomes can be measured as a result of data limitations. For these reasons, the findings should be considered conservative.

This study aims to estimate the impacts of the PSCEP on the 480 children who are living with or have recovered from cancer, 500 were siblings of these children, and 704 children had a carer or parent with cancer during 2018 and 2019. In order to estimate the impact of PSCEP, KPMG and CQ undertook a survey of 68 of families who collectively had 123 children who participated in the educational puppet show performed by the puppets during 2019.

As per the engagement letter dated 5 August 2020, the deliverable for this project was to be a final report (this document) outlining activities undertaken, key findings on the SROI study.

Purpose of the Report

This document is the Final Report for Camp Quality for the Costing Study undertaken on the PSCEP. Its purpose is to provide a transparent overview of methodology applied as well as survey information and other sources to support estimations and calculations made.

Section 2 outlines a literature review undertaken by the KPMG team which gathered information on the status of childhood oncology research. Section 3 outlines the methodology and results of the family survey, and Section 4 outlines the calculation and resulting SROI.

2 Literature Review

In the last few decades, treatment of childhood cancer has improved dramatically. Survival rates have increased from 65% in the late 1980's to approximately 80% today.[5] While cancer among 20-50 year olds, those who are likely to have young children, has increased.[6] The impacts of cancer on children and their families lasts much longer than the treatment itself.

Childhood cancer has been shown to challenge a child's academic and school engagement.[7,8] Short term impacts from the child's cancer treatment can lead to toxicities and poor immune system functioning, leading to increasing absenteeism. Absenteeism presents challenges to a child's development including disconnect from school, declining academic performance and increased social difficulties.[9] Children with cancer who are returning to school life after their treatment have been observed to have behavioural and emotional problems.[10]

In the long term, children may have permanent sensory defects, such as vision or hearing loss, or neurocognitive effects resulting from their treatment.[11] These impacts not only affect the child's current quality of life, but may also impact them later in life, such as in professional life, financial independence and relationships.[12]

Siblings of children with cancer report reduced parental attention, missing parents when their sibling is in treatment, jealousy, anger, loneliness, loss of a family way of life, worry and guilt. Group interviews with siblings of children with cancer illuminated key impacts on siblings:[13]

- **Personal losses.** The sibling cannot participate in activities they used to, such as sport due to cancer treatment becoming a priority.
- **Desire to better understand the cancer experience.** They have a sense of exclusion from the cancer experience, expressing that they wanted to better understand what their ill sibling was experiencing.

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[5] Peikert, M.L., Inhestern, L., Krauth, K.A., Escherich, G., Rutkowski, S., Kandels, D. and Bergelt, C., 2020. Returning to daily life: a qualitative interview study on parents of childhood cancer survivors in Germany. BMJ open, 10(3), p.e033730.

[6] O'Neill, C., O'Neill, C. and Semple, C., 2018. Children of Parents with Cancer: An evaluation of a psychosocial intervention.

[7] Hocking, M.C., Paltin, I., Belasco, C. and Barakat, L.P., 2018. Parent perspectives on the educational barriers and unmet needs of children with cancer. Children's Health Care, 47(3), pp.261-274.

[8] Yilmaz, M.C., Sari, H.Y., Cetingul, N., Kantar, M., Erermis, S. and Aksoylar, S., 2014. Determination of school-related problems in children treated for cancer. The Journal of School Nursing, 30(5), pp.376-384.

[9] Ibid n.4 above.

[10] Ibid n. 5 above.

[11] Ibid n.4 above.

[12] Ibid n. 5 above.

[13] Neville, A., Hancock, K. and Rokeach, A., 2016, September. The emotional experience and perceived changes in siblings of children with cancer reported during a group intervention. In Oncology nursing forum (Vol. 43, No. 5, p. E188). Oncology Nursing Society.

- **Exclusion from family life.** Siblings expressed that they felt left out, dismissed or not important due to not seeing their parents and family for extended periods of time or due to not spending as much time with the ill sibling.
- **Frustration toward their sick sibling.** Some siblings described having fewer privileges compared to the sick sibling. While others were frustrated that people asked continuous questions about their sibling and never checked on them.
- **Guilt, worry and empathy toward their sick sibling.** Others described feeling like they were to blame for their sibling's sickness or feeling sad when their sibling was left out of activities. They also wanted to understand more about cancer, and how it was affecting their sibling.
- **Pressure within the family unit.** Siblings described a feeling of not wanting to burden their parents with personal struggles. They did not want to bring up personal issues to avoid upsetting their parents leading to personal issues building up.

Having a parent diagnosed with cancer is a huge disruption for the whole family unit. Parents have reported not knowing how to communicate with their children about their illness or may be overwhelmed by dealing with their illness at the same time as parenting.[14] Children with parents who have cancer are at risk of developing a range of social and psychological problems including separation anxiety, depression, difficulties at school, leisure, family functioning and relationships.[15] However, their needs are often not recognised by the professionals supporting the patient, their parent, as part of the treatment and care plan.[16] Children with carers and parents with cancer have been shown to benefit from structured communication about their parent's illness.[17]

Beyond the effects on the child, cancer also affects parents and carers reintegration into daily life. Very few studies have focused on the reintegration of parents into daily life after their child has completed their treatment. One study investigated the experiences of parents with paediatric cancer survivors.[18] Through interviews with parents, the study considered cancer related changes in a parent's daily life during and after the intensive period of cancer treatment for their child.

Key impact identified by the mentioned study of reintegration into daily life were: [19]

- **Changing work hours:** Reducing work hours compared to before the disease. Parents, particularly the mothers of the surveyed group, appreciated flexible working and support from their employers as their children with cancer required additional support or health care.
- **Changing family life:** Childhood cancer diagnoses affect the entire family structure, including organisational challenges, changing task allocations within the family and the siblings of the child drifting out of focus. However, family resilience also improved.
- **Recovery in partner relationships:** Most parents' relationships strengthened following the cancer treatment.
- **Social activities:** Social isolation can occur with parents during the cancer treatment stage and after.

The PSCEP's educational approach focuses on informing children with cancer, siblings of children with cancer, kids impacted by carer's cancer and the broader community. It aims to help ease transitions back into day to day life for children with cancer and educate their siblings and children with parents

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[14] O'Neill, C., O'Neill, C. and Semple, C., 2018. Children of Parents with Cancer: An evaluation of a psychosocial intervention.

[15] O'Neill, C., O'Neill, C. and Semple, C., 2018. Children of Parents with Cancer: An evaluation of a psychosocial intervention.

[16] Arber, A. and Odelius, A., 2018. Experiences of oncology and palliative care nurses when supporting parents who have cancer and dependent children. Cancer nursing, 41(3), pp.248-254.

[17] Ibid, n. 11 above.

[18] Peikert, M.L., Inhestern, L., Krauth, K.A., Escherich, G., Rutkowski, S., Kandels, D. and Bergelt, C., 2020. Returning to daily life: a qualitative interview study on parents of childhood cancer survivors in Germany. BMJ open, 10(3), p.e033730.

[19] Ibid.

who have cancer so that they have a shared vocabulary to understand and explain cancer. The literature review indicated four key areas of impact over patients, siblings and offspring of which the CQ educational puppet show has influence over.

By enhancing a child's understanding of the experience of cancer, the PSCEP is predicted to help offset some emotional and psychological problems, and teach coping mechanisms for dealing with sadness, anger and confusion. We hypothesised that this would benefit a child's mental health resulting in less visits to health care professionals for mental health issues.

While, the PSCEP is also predicted to improve re-entry into schooling and enhance academic achievement of children who have survived cancer.[20] In addition, increasing social connection with peers, and helping the peers understand the impacts and effects of cancer. We predict that this will make children feel more comfortable in their reintegration into schooling, whist ensuring that their peers are supportive, welcoming and will reduce the instance of bullying. This in combination will make each child more willing to go to school, and as a result they will be less absent from school, gaining more value from the schooling experience and preventing longer term impacts from childhood bullying.

As their children can attend school more frequently, their parents can also begin to adjust back into a more regular life. From the potential to go back to work more frequently to re-establishing social normalcy.

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[20] Helms A.S., Schmiegelow K., Brok J., Johansen C., Thorsteinsson T., Simovska V. & Larsen H.B. (2016) *European Journal of Cancer Care* 25, 170-179, p. 175.

3 Methods and Data Sources

Social Return on Investment (SROI)

The standardised approach to the SROI for the PSCEP involved:

1) Assessing the involvement of stakeholders and ensuring that all those people impacted by the PSCEP were represented in the measurement and valuation of the social value of the PSCEP.
2) Articulating the theory of change for the program to evaluate how increased benefits are derived for stakeholders through the data collected.
3) Valuing (or 'monetising') benefits which involves making decisions about allocating resources between different program outcomes to recognise the values to different stakeholders.
4) Providing a transparent rationale for the valuation of benefits and the corresponding SROI such that the analysis is replicable and accurate.
5) Testing of the SROI result with CQ to test the validity of assumptions, valued benefits and SROI.

Overview of Data Sources

The team utilised a range of data analytical techniques, both quantitative and qualitative in nature.

- **Quantitative information** was used to identify changes over time to child, sibling, and offspring in response to the PSCEP. The primary source of qualitative data was a survey issued to families of children who had participated in the PSCEP during 2019. However, we have also drawn from sources like the ABS or academic literature where necessary.
- **Qualitative information** was captured through a review of the PSCEP documentation, qualitative survey answers, and academic literature. These sources were reviewed to understand how the PSCEP contributes to effective patient, sibling and offspring mental and physical wellbeing outcomes and the reason for observable change.

As the SROI analysis relied upon the survey data and available literature/data, assumptions were developed, tested and validated in the application of this literature to the context of the PSCEP. Where we have made assumptions, we have informed the reader.

It was identified that CQ was missing information on the impact of the PSCEP on families and the children who participated during 2018 and 2019. Hence a survey was developed collaboratively with CQ to address this data gap.

The aim of the SROI assessment was to set up an impact measurement framework for CQ to use to continue to measure their impact in future periods. For this reason, the survey questions were general and could be redeployed in the future. In addition, the impact pathways identified link directly to the survey questions, making analysis of CQ's impact both more relevant to the PSCEP and to enhance efficiency in future analysis. For all documents reviewed by KPMG see Appendix 1: Documents Reviewed.

The PSCEP Survey Findings

The vast majority of surveyed families felt that the PSCEP was very valuable for their kids, offering age appropriate information about cancer. It improved their mental health, built a sense of community and confidence in discussing cancer.

Qualitative results

Overall feedback

Overall, families felt that the PSCEP was a valuable education tool presented in an age appropriate manner. The messages in the puppet show and the inclusion of the audience helped deliver the information about cancer in an entertaining manner. Some examples extracted from the survey results include:

> "The (cancer education) program is a wonderful education tool and the kids really enjoy the show and take a lot away from the messages within. I would hope in future other kids could get the puppets to visit their school closer to their diagnosis date. "- Survey Participant - Parent/carer of a child with cancer
>
> "These puppet shows are such a great way for teaching students the cause and effects of cancer in an age appropriate way."- Survey Participant - Parent/carer of a child with cancer
>
> "Very good, informative, feeling of acceptance. Like the option of the child going up on the stage with the puppets to have him up there to engage and identify with his experience." - Survey Participant - Parent/carer of a child with cancer
>
> "Due to demand it took some time to get the puppets to come to the school, which was perfectly understandable. It would be good if more funding was available to increase the number of shows." - Survey Participant - Parent/carer who has cancer

Improving Mental Health – Inclusion

Families felt that the puppet show improved their feelings of inclusion and understanding of each other's experiences.

> "I felt the school community as a whole had a better understanding of what we were experiencing as a family and how to approach us."- Survey Participant - Parent/carer of a child with cancer
>
> "It was an exemplar experience for the siblings, to feel included and understood in the somewhat isolating experience of cancer."- Survey Participant - Parent/carer of a child with cancer

Improving Mental Health – Starting a conversation

The puppet show helped inform conversations and improved the ability of participants to communicate about cancer.

> “The puppet show was such a help to my boys, as I was going through chemotherapy and radiation. So, their friends then knew what was happening to me and they didn't have to explain. They didn't feel sad or different. Their classmates loved it.”- Survey Participant – Parent/carer who has cancer

> “I think the puppet show is a great way of starting a conversation among the children and parents. I would love to see it being done every year as I know we had another two diagnosed in the last year. It doesn't just help my child but children who are newly diagnosed to understand they have places to go for more answers. “- Survey Participant - Parent/carer of a child with cancer

> “There are several other children at their school who are affected by cancer. And they are able to openly discuss their experiences whenever the situation arises. It’s not a secret anymore. ”- Survey Participant- Parent/carer who has cancer

Reducing School Absence

Parents and carers stated that their children had improved confidence in returning to school.

> “Having the puppets come to the school helped our son who was doing treatment at the time not feel so nervous about attending school.”- Survey Participant - Parent/carer of a child with cancer

Reducing Bullying

The PSCEP successfully educated the peers of children impacted by cancer, building empathy, reducing bullying and improving their children’s confidence.

> “The puppet show was a massive confidence boost for my child who is a cancer survivor. The kids in his school became aware of what cancer and its side effects are and the kids stopped making remarks about his 'chemo' teeth and understood that it was a side effect of chemo and not bad hygiene. The puppet show even gave him the confidence to show his scars which up until the show he was extremely conscious about”- Survey Participant - Parent/carer of a child with cancer

> “My daughter had been teased because I had lost all my hair and other children had told her I was going to die. After the show everyone in the class was very kind to her and seemed to have a better understanding/ more empathic attitude.” - Survey Participant - Parent/carer who has cancer

Quantitative

The survey aimed to measure impacts from the PSCEP puppet show through a before and after model or ‘treatment’ model where the PSCEP visit is the treatment. We use the ‘before the PSCEP’ answers to quantify the child’s base state and the state that the child would continue to be in had the intervention not occurred. While the after state is used to quantify the effect of the PSCEP. We then measure the impact of the program by comparing the before and the after state.

Appropriately attributing impact is a crucial component of measuring impact. It acknowledges that not all absence from school, for example, can be attributed to the activities included in the PSCEP. A child with cancer may be absent from school due to treatment of their cancer, or for reasons unknown to the researcher. For this reason, the before and after survey model is considered the best approach as it measures the change in absence. We further differentiated absence from school due to reasons that are unaffected by the PSCEP (e.g. illness) from reasons that would be affected by the program (e.g. emotional wellbeing).

CQ sent the survey to all families who had children who participated in the PSCEP during 2019, resulting in responses from 126 families. Only completed surveys were used for this analysis, resulting in a complete set of 68 responses for analysis, representing 123 children who had taken part in the PSCEP during 2019. Key demographic information is represented for the parent/carer who completed the survey in Table 2, and for their children in Table 3.

Table 2 - Survey sociodemographic details of parent/carer

Sociodemographic of surveyed parent		n	%
Number of families surveyed		68	
Gender			
	Male	1	1%
	Female	67	99%
Primary Carer			
	Female primary carer	57	84%
	Male primary carer	1	1%
	Partner	5	7%
	Other	5	7%
Number of children per family			
	1	28	41%
	2	27	40%
	3	11	16%
	4	2	3%

Most families who completed the survey had 1-2 children. The female parent/carer was most likely to complete the survey (99%), and most likely to be the primary carer in the instance that their children were sick (84%). Within the children's demographics, there was a roughly even split between male (46%) and female children (54%). 33% of children captured in the survey had/have cancer, 36% of children were siblings of a child who has/had cancer, and 29% were kids impacted by carers cancer.

Table 3 - Sociodemographic information of children

Sociodemographic of children		n	%
Number of children surveyed		123	
Gender			
	Male	57	46%
	Female	66	54%
Cancer type			
	Child has/had cancer	40	33%
	Child is a sibling of a child who has/had cancer	44	36%
	Child has a parent who has/had cancer	36	29%
	Other	3	2%

The PSCEP puppet show was most effective at increasing the parent/carers overall optimism and happiness as a result of building awareness and understanding of cancer within their child's school, with 90% of families ranking the PSCEP extremely or very effective at achieving this outcome. This was followed by 85% of families who said that the program was extremely or very effective at increasing feelings of support within their school community or network (Table 4).

Table 4 - Effectiveness of the PSCEP

How effective was the puppet show in	n	%
Increasing your confidence in responding to questions from the school/other parents and/or your child/ren's peers about cancer treatment and its side effects.		
Extremely Effective	24	36%
Very Effective	30	45%
Somewhat Effective	7	11%
Not Very Effective	3	5%
Not Effective	2	3%
Increasing your happiness and optimism through being able to support your child/ren's confidence to return to school.		
Extremely Effective	26	38%
Very Effective	28	41%
Somewhat Effective	7	10%
Not Very Effective	4	6%
Not Effective	3	4%
Increasing your child/ren's reports that they are getting along better with his/her friends after the show.		
Extremely Effective	15	22%
Very Effective	37	54%
Somewhat Effective	8	12%
Not Very Effective	3	4%
Not Effective	5	7%
Increasing your feelings of belonging to a supportive school community/network.		
Extremely Effective	24	35%
Very Effective	34	50%
Somewhat Effective	7	10%
Not Very Effective	1	1%
Not Effective	2	3%
Increasing your overall wellbeing, optimism and happiness as a result of building awareness and understanding of cancer within the school.		
Extremely Effective	28	41%
Very Effective	33	49%
Somewhat Effective	4	6%
Not Very Effective	1	1%
Not Effective	2	3%

Children across all groups are much more likely to suffer from distractibility before compared to after the PSCEP (Table 5). This effect appears to be largest in children who have cancer. Restlessness and inability to pay attention and difficulty getting along with friends have also decreased in all groups.

Table 5 - Changes in academic problems before and after the PSCEP performance

Academic problems	Children who have/had cancer				Siblings of children who have/had cancer				Child of a parent who has/had cancer			
	Before		After		Before		After		Before		After	
	n	%	n	%	n	%	n	%	n	%	n	%
Distractibility	16	40%	10	25%	11	25%	7	16%	13	36%	5	14%
Restlessness/inability to pay attention	13	33%	10	25%	7	16%	5	11%	11	31%	8	22%
Difficulty getting along with friends	8	20%	5	13%	5	11%	3	7%	11	31%	9	25%
Boredom	8	20%	8	20%	5	11%	3	7%	10	28%	9	25%
Hyperactivity	6	15%	7	18%	6	14%	4	9%	8	22%	7	19%
Other	3	8%	3	8%	0	0%	0	0%	2	6%	1	3%

4 Social Return on Investment

Key Findings

Overall, for every $1 spent on the program the total benefit is $5. Offspring (KICC) were the group that benefited the most from the program, with $3.35 of this return allocated to this group.

Table 6 and Table 7 surmise the results of the SROI analysis. Table 6 displays results by outcome, while Table 7 shows results per stakeholder group. The outcomes of the PSCEP are outcomes 1-3 on the left side of Table 6. While the quantified benefits are listed along the top of the table. Each benefit is quantified using a combination of survey data and reputable data from sources such as the ABS. Survey data is used to attribute impact to the PSCEP activities. The method, data sources and key assumptions used to calculate each benefit is described in ‘Measuring Benefits and Outcomes’ below on p. 15.

Three key outcomes of the PSCEP were measured:

1) Provide support to patients, siblings and families in relation to reintegration into school.

2) Provide resources to teachers/staff to practically support a child throughout their cancer journey.

3) Reduce patients and sibling's sense of isolation, increase confidence, sense of value and coping ability.

Benefits in Table 6 have been arbitrarily split for each outcome based on which benefit is assumed to be most influenced by each outcome. However, we believe that each of these outcomes is interrelated. School attendance, for example, will be in part determined by a child’s experiences with bullying and mental health. While a parent’s productivity is linked to their children attending school.

This analysis demonstrates that outcome 3 is most effective, delivering $5.6 million in benefits. This is followed by outcome 1, which delivers $3.2 million in benefits. Outcome 2 provides the least benefits, at $812,895.

Table 6 – SROI Results per outcome[21]

Outcome	Reduced school absence	Avoided expenditure on mental health treatments	Increasing future incomes	Increased productivity for parents	Total quantifiable benefits for each outcome	SROI
Outcome 1	1,061,974	$ -	$ -	$2,189,606	$3,251,579	
Outcome 2	$265,493	$ -	$ -	$547,401	$812,895	
Outcome 3	$ -	$4,642,851	$935,919	$ -	$5,578,770	
Total	**$1,327,467**	**$4,642,851**	**$935,919**	**$2,737,007**	**$9,643,244**	**502%**
Benefit per show[22]	**$783**	**$2,738**	**$552**	**$1,614**	**$5,686**	

The stakeholder group benefiting most from the PSCEP is the children of parents/carers with cancer (Offspring). With the benefit received by this group equalling $3.35 in benefits for every $1 invested. For every child in the offspring group that attends the PSCEP, there is a benefit of $9,141.

Table 7 - SROI Results per stakeholder group[23]

Stakeholder group	Reduced school absence	Avoided expenditure on mental health treatments	Increasing future income	Increased productivity for parents	Total quantifiable benefits for each outcome	SROI[24]	Benefits per child[25]
Patient	$ 297,789	$ 1,280,753	$ 275,465	$ 613,990	$ 2,467,997	129%	$5,142
Sibling	$ 92,051	$ 368,436	$ 89,530	$ 189,794	$ 739,811	39%	$1,480
Offspring (KICC)	$ 937,627	$ 2,993,661	$ 570,925	$ 1,933,223	$ 6,435,436	335%	$9,141
Total	**$ 1,327,467**	**$ 4,642,851**	**$ 935,919**	**$ 2,737,007**	**$ 9,643,244**	**502%**	

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[21] Calculations of each benefit is available in Appendix 2. Benefits are attributed arbitrarily between the three outcomes based on our understanding of the key relationships between the desired outcome and the proxy benefit. However, we believe that all three outcomes are inextricably interrelated. Reduced school absence and parental productivity are attributed 80% to outcome 1 and 20% to outcome 2 based on percentage of time spent on each outcome. Improved mental health and avoided bullying are 100% attributed to outcome 3.

[22] Calculated based on the 1,696 shows during 2018 and 2019.

[23] Calculations available in Appendix 2.

[24] SROI is calculated as total quantifiable benefit divided by total investment cost. The total SROI of 502% is split between the three stakeholder groups.

[25] Calculated as total benefit for each stakeholder group divided by the number of patients, sibling or offspring benefited.

As demonstrated in Table 7, offspring were the group which benefited the most from the PSCEP during 2018 and 2019. This is partially the result of this group being the largest with 704 offspring having participated in the PSCEP during 2018 and 2019. This group received a benefit of $6.4 million, equating to $3.35 of benefits per $1 invested. Despite the larger number of offspring who participated in the PSCEP during 2018 and 2019, the benefit is also the largest on a per child basis at $9,141.

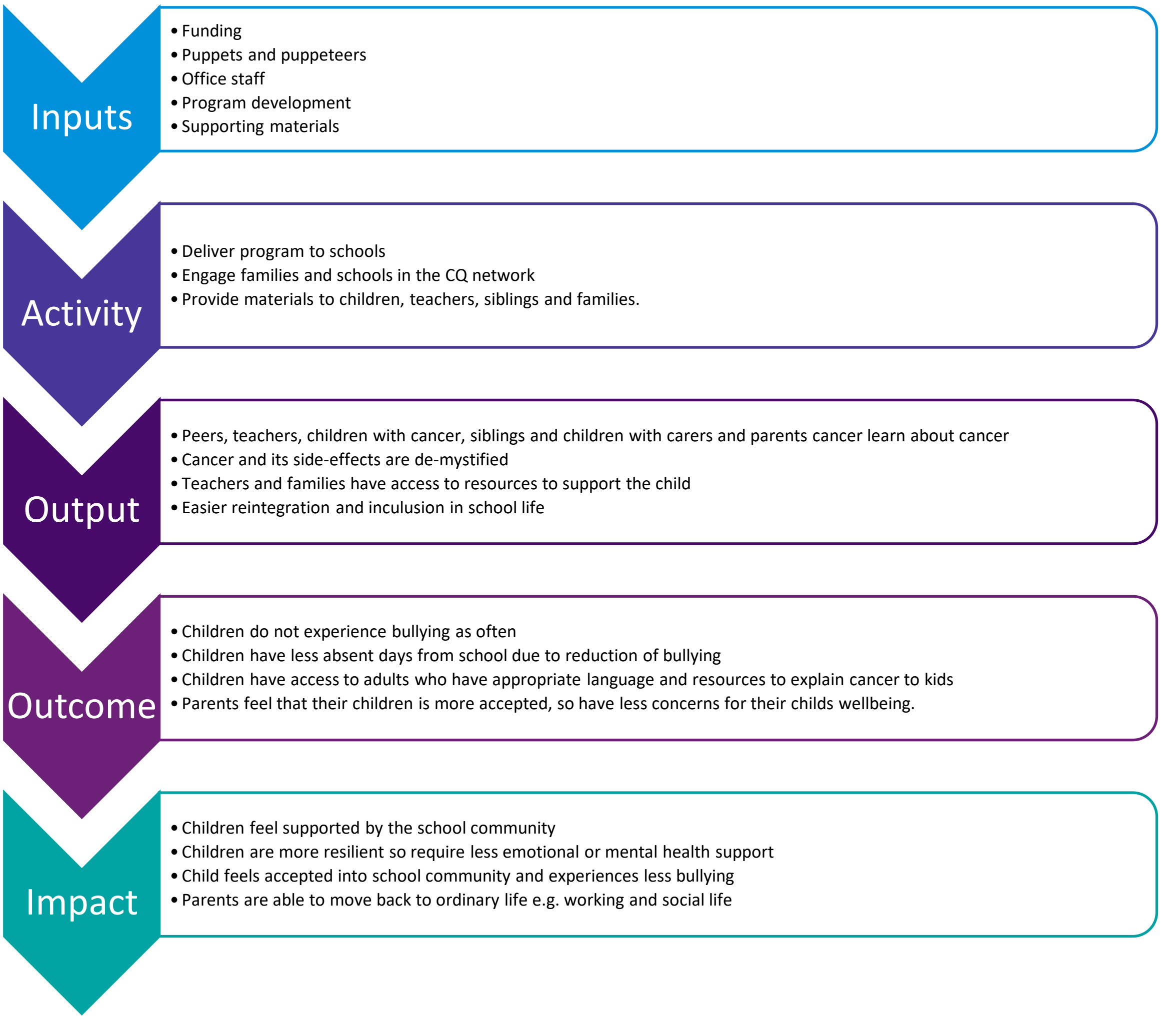
The patient stakeholder group benefited the second most, with the 480 children in this group receiving over $2.4 million in benefits, equating to a SROI of 129%, or $1.29 per $1 invested. For every child in this group who saw the puppet show in 2018 and 2019, the benefit was $5,142.

The sibling group was the least impacted. With 500 siblings having attended the PSCEP in 2018 and 2019, they received a benefit of just over $1 million. This equates to a SROI of 39%, or $0.39 cents of benefit to every $1 invested. This equates to $1,480 per child who participated in the PSCEP.

Theory of Change

Figure 1 summarises the theory of change of the PSCEP. The outputs, outcomes and impacts demonstrate the key benefits of the PSCEP which was used to form the basis of the survey questions and measurement of the benefits of the PSCEP.

Figure 1 – The PSCEP Theory of change



Inputs

- Funding
- Puppets and puppeteers
- Office staff
- Program development
- Supporting materials

Activity

- Deliver program to schools
- Engage families and schools in the CQ network
- Provide materials to children, teachers, siblings and families.

Output

- Peers, teachers, children with cancer, siblings and children with carers and parents cancer learn about cancer
- Cancer and its side-effects are de-mystified
- Teachers and families have access to resources to support the child
- Easier reintegration and inculusion in school life

Outcome

- Children do not experience bullying as often
- Children have less absent days from school due to reduction of bullying
- Children have access to adults who have appropriate language and resources to explain cancer to kids
- Parents feel that their children is more accepted, so have less concerns for their childs wellbeing.

Impact

- Children feel supported by the school community
- Children are more resilient so require less emotional or mental health support
- Child feels accepted into school community and experiences less bullying
- Parents are able to move back to ordinary life e.g. working and social life

Measuring Benefits and Outcomes

From the outcomes identified above and literature review, KPMG identified four core financial proxies to measure the benefits of the PSCEP. These are (1) improving mental health, (2) increasing school attendance, (3) increasing future income, and (4) increased parental productivity. Overall, these outcomes assist children with cancer, their siblings and children whose parents or carers have cancer with reintegrating into daily life including school, supporting families and children through cancer and increasing social connection.

Table 8 - PSPE program outcomes and measurement proxies

Outcome	Proxy
1) Provide support to patients, siblings and families in relation to reintegration into school	Improving mental health Increasing school attendance Increasing future incomes of children impacted by cancer Increasing parental productivity
2) Provide resources to colleagues/staff to practically support a child through their cancer journey	
3) Reduce patients and siblings' sense of isolation, increase confidence, sense of value and coping ability	

Improving Mental Health

The PSCEP survey found that the number of visits to a health care worker for mental health issues decreased by 60% after the PSCEP in children who have/had cancer, 38% in siblings of these children, and 33% in offspring. This saved a total of $4.6 million dollars in expenses for the treatment of mental health over 2018 and 2019.

Childhood cancer is often traumatic not just for the child with cancer, but also for family members, and siblings.[26],[27] While children whose parents have cancer have been found to have an increased risk of developing a range of social or physiological problems post-cancer.[28] Studies have shown that the way that cancer is communicated to these children can either cause and exacerbate mental health issues or help relieve them. For example, one study of children whose parents have cancer found that an intervention that demystifies cancer, helps children feel less isolated, teaches them how to communicate their feelings and how to cope with sadness, anger and confusion had a positive impact on the child's mental wellbeing.[29] Parents experienced the added benefit of feeling like the burden of discussing cancer with their children was lifted.

By providing child appropriate content describing and demystifying cancer, as well as soothing a child's potential anxiety about returning to school and reintegrating into normal life, and increase feelings of support, community and belonging, it is expected that the child will experience less mental health struggles such as anxiety and depression.

From the PSCEP survey, it was found that 43% of children who have/had cancer, 41% of their siblings, and 56% of children with carers cancer had required treatment mental for health issues at some point over 2019 (Table 9).

Table 9 - Percentage of children requiring treatment for mental health issues[30]

	Percentage
Children who have/had cancer	43%
Siblings of children who have/had cancer	41%
Children who have/had carers with cancer	56%

As a result of the PSCEP, visits to health care practitioners for mental health issues decreased by 60% in children who have/had cancer, 38% in siblings and 33% in children who have/had carers with cancer. The results of health care visits are displayed in Table 10. The difference between the state before the PSCEP and after the PSCEP is the effect.

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[26] Hocking, M.C., Paltin, I., Belasco, C. and Barakat, L.P., 2018. Parent perspectives on the educational barriers and unmet needs of children with cancer. Children's Health Care, 47(3), pp.261-274.

[27] O'Neill, C., O'Neill, C. and Semple, C., 2018. Children of Parents with Cancer: An evaluation of a psychosocial intervention.

[28] Ibid.

[29] O'Neill, C., O'Neill, C. and Semple, C., 2018. Children of Parents with Cancer: An evaluation of a psychosocial intervention.

[30] CQ PSEP Family Survey, 2020.

Table 10 - Change in visits to healthcare workers for mental health issues[31]

Number of visits to healthcare professional	Children who have/had cancer		Siblings of children who have/had cancer		Kids impacted by carers cancer	
	Before	**After**	**Before**	**After**	**Before**	**After**
General Practitioner	17	3	7	6	100	66
Psychologist	48	28	32	17	97	75
Social Worker	22	3	6	2	26	6
Occupational Therapist	16	12	2	0	20	15
Counsellor	15	1	6	8	28	19

As the number of visits to a healthcare worker reduces, it reduces treatment costs associated with these visits, hence saving each family for associated costs and the government for Medicare benefits. But it also prevents issues like depression and anxiety from influencing a child's life more in the future.

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[31] CQ PSEP Family Survey, 2020.

We estimate the costs of mental health care based on the Medicare benefits schedule as shown in Table 11.

Table 11 - Mental Healthcare costs

Mental Healthcare professional	Cost per session	Data source
General Practitioner	$ 73.95	Medicare Benefits Scheme, item 2700
Psychologist	$ 90.70	Medicare Benefits Scheme, item 80000 - 80071
Social worker	$ 90.70	Medicare Benefits Scheme, items 80150, 80155, 80160, 80165 and 80170
Occupational therapist	$ 90.70	Medicare Benefits Scheme, items 80125, 80130, 80135, 80140 and 80145
Counsellor	$ 90.70	Medicare Benefits Scheme, item 80000 - 80071

To calculate the benefits from improving mental health of children affected by the PSCEP, we multiply the number of children affected, identified in Table 1, by the percentage of children who have mental health issues. This results in the approximate number of children affected by the puppet show who will have mental health issues (Table 9). We then multiply this by change in number of visits to mental health workers (Table 10), the cost of visiting the respective mental health worker (Table 11).[32]

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[32] Calculated in Appendix 2: Calculations.

Reduced School Absence

Children with cancer attend 6 days more of school per year after the PSCEP. Their siblings attend 2 days more, while the children whose parents have/had cancer attend 13 days more. Avoiding $1.3 million in lost learning benefits over 2018 and 2019.

PSCEP-like programs have been shown to improve re-entry into schooling and enhance academic achievement of children who have survived cancer, as well as relieving signs of depression.[33] In addition, it aims to increase a sense of social connection with peers, and help the peers understand the impacts and effects of cancer.

The PSCEP focuses on making a child feel more comfortable in their reintegration into schooling and ensuring that their peers are supportive and welcoming. This in combination will make each child more willing to go to school, and as a result they will be less absent from school and gain more benefits from the schooling experience.

During 2018 and 2019, a total of 5.16 million children were enrolled in government schools in Australia, costing state and national governments $106 billion. Therefore, the average yearly cost for each student to be educated is $20,490 per year. Based on a 200-day schooling year, for every day that a student is not present at school, there is $102 in lost benefits to the student. For every day that a child isn't present at school, they lose valuable time learning and waste investment in education by state, territory and national governments.

Table 12 – Cost of schooling[34]

	2018	2019	Source
Number of students enrolled in government schools	2,558,169	2,558,169	ABS 4221.0 - Schools, Australia, 2019 and 2018.
Cost of operating schools on all levels of government (state, territory and national)	$51,469,000,000	$54,130,000,000	5518.0.55.001 - Government Finance Statistics, Education, Australia, 2017-18 and 2018-19

Table 13 demonstrates the results from the CQ survey which found that in total, children with cancer were absent from school 13 days less than prior to the PSCEP. Siblings were absent 4 days less, and children who have a carer or parent with cancer were absent 25 days less.

As the PSCEP aims to reduce the emotional burden on children and instances of childhood bullying, we took a conservative approach and attributed only the days absent from school due to the child's emotional wellbeing or bullying to the PSCEP.

The benefits of the PSCEP reducing school absence is then quantified by multiplying the number of children affected, identified in Table 13, by the average cost of schooling per student per day ($102) and multiplying the product by the change in absenteeism resulting from childhood bullying and emotional wellbeing (Table 13).

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[33] Helms A.S., Schmiegelow K., Brok J., Johansen C., Thorsteinsson T., Simovska V. & Larsen H.B. (2016) *European Journal of Cancer Care* 25, 170-179, p. 175.

[34] Note, cost of schooling includes government schools only, it does not include independent or religious schools.

Table 13 – Change in days absent from school before vs after the PSCEP[35]

Reason for absence	Children with cancer		Siblings of children with cancer		Kids impacted by carers cancer	
	Before	After	Before	After	Before	After
Illness	15	11	5	3	10	6
Issues relating to cancer and cancer treatment	20	17	8	6	9	4
Bullying	4	3	5	6	13	7
Emotional wellbeing	10	6	4	5	8	7
Difficulty learning	8	7	4	3	12	4
Total	**56**	**43**	**26**	**22**	**52**	**27**

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[35] CQ PSEP Family Survey, 2020.

Increasing Future Income

Adults who were bullied as children earn between $70 and $200 less per week. PSCEP decreased the instance of bullying among all children, with an estimated benefit of $936,000 in additional future earnings for these children.

Children with cancer are particularly at risk of bullying with self-reported bullying being considerably higher in cancer survivors (32.5%) than compared with the general population (25%).[36] Bullying tends to be verbal and targeted at the physical side effects of cancer and cancer treatment, which can differentiate the child from their peers.[37]

The effects of bullying are well documented. In the short term, those that experience bullying in childhood are more likely to experience mental health issues and may suffer from increased anxieties around returning to school, increasing school absenteeism.[38] In the longer term, bullying has been associated with numerous problems in adulthood including an increased likelihood of unemployment, lower earnings, and lower savings.[39] A 2018 longitudinal study found that there are substantial and durable individual and societal economic impacts of bullying for decades after that bullying had occurred.[40]

Studies indicate that peer programs can successfully reduce instances of bullying in children with cancer.[41,42,43] The change in instance of bullying due to the PSCEP can therefore be quantified in the increasing earning potential in the long term for each child affected. As earnings in the future are also available as either spending or investing in the future, the future income is a direct benefit and inflow into the future economy. Impacts of increased spending dollars will also have a multiplier effect increasing the benefit beyond what is quantified in this study.

One study considered the impacts of childhood bullying at the age of 7 and 11 controlling for social class, adversity, low parental involvement, childhood IQ, and childhood emotional and behavioural problems. The results of this study for the impact of bullying on earning potential is summarised in Table 14. Salary was self-reported and did not include individuals who are self-employed, unemployed or economically inactive.

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[36] Collins, D.E., Ellis, S.J., Janin, M.M., Wakefield, C.E., Bussey, K., Cohn, R.J., Lah, S. and Fardell, J.E., 2019. A systematic review summarizing the state of evidence on bullying in childhood Cancer patients/survivors. Journal of pediatric oncology nursing, 36(1), pp. 55-68.

[37] Ibid.

[38] Holt, M., Vivolo-Kantor, A., Polanin, A., Jr., Holland, K., Degue, S., Matjasko, J., . . . Reid, G. (2015). Bullying and suicidal ideation and behaviors: A meta-analysis. Pediatrics, 135, E496-E509. doi:10.1542/peds.2014-1864

[39] Brimblecombe, N. et al., 2018, Long term economic impact associated with childhood bullying victimisation, Social Science & Medicine, pp. 134-141

[40] Brimblecombe, N. et al., 2018, Long term economic impact associated with childhood bullying victimisation, Social Science & Medicine, pp. 134-141

[41] Charlton, A., Pearson, D., & Morris-Jones, P. H. (1986). Children's return to school after treatment for solid tumors. Social Science & Medicine, 22(12), 1337-1346. doi:10.1016/0277-9536(86)90097-3

[42] Chekryn, J., Deegan, M., & Reid, J. (1986). Normalizing the return to school of the child with cancer. Journal of the Association of Pediatric Oncology Nurses, 3(2), 20-24. doi:10.1177/104345428600300206

[43] Gregory, K., Parker, L., & Craft, A. W. (1994). Returning to primary school after treatment for cancer. Pediatric Hematology & Oncology, 11(1), 105-109. doi:10.3109/0888 0019409141907

Table 14 - Impacts of bullying in 50 years[44]

Impacts of bullying	Women	Men
Mean weekly earnings (AUD) from paid employment - Never bullied	$2,776.34	$4,974.09
Mean weekly earnings (AUD) from paid employment - Occasionally bullied	$2,695.98	$4,902.95
Mean weekly earnings (AUD) from paid employment - Frequently bullied	$2,566.77	$4,895.30

Changes in bullying were then measured through the survey to see what affect, if any, the PSCEP had on the instance of bullying in the sample. These results are summarised in Table 15. The percentage of children in the occasionally or frequently bullied category decreased as more children moved into the 'never bullied' category. Across all stakeholder groups there was a decrease in children who were 'occasionally bullied'.

To calculate the benefits from increasing future income of children affected by the PSCEP, we multiply the number of children affected, identified in Table 1, by the change in frequency of bullying (Table 15). We then multiply this by change earnings depending on the frequency of bullying (Table 14).

Table 15 - Changes in frequency of bullying before vs after the PSCEP[45]

Bullying effects in children	Children who have/had cancer					Siblings of children who have/had cancer					Child of a parent who has/had cancer				
	Before		After			Before		After			Before		After		
	n	%	n	%		n	%	n	%		n	%	n	%	
Female															
Never	6	32%	9	47%		20	80%	21	84%		10	50%	12	60%	
Occasionally	10	53%	8	42%	↓	1	4%	0	0%	↓	7	35%	7	35%	↓
Frequently	1	5%	0	0%	↓	1	4%	1	4%	→	3	15%	1	5%	↓
Male															
Never	13	62%	14	67%		12	63%	13	68%		9	56%	11	69%	
Occasionally	5	24%	4	19%	↓	4	21%	3	16%	↓	3	19%	1	6%	↓
Frequently	0	0%	0	0%	→	1	5%	1	5%	→	1	6%	1	6%	→

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[44] Note: this table is based on research from Brimblecombe, N. et al., 2018, Long term economic impact associated with childhood bullying victimisation, Social Science & Medicine, pp. 134-141, which was reported in GBP in 2008. KPMG have inflated the value by 50 years and converted it to AUD for reporting in the table.

[45] CQ PSEP Family Survey, 2020.

Parental Productivity

Parents and carers were able work an additional 6 days on average for each child with cancer, 2 days for each sibling and 13 days for each child impacted by carers cancer. Meaning parents can productively contribute through work, with benefits equalling $2.7 million to families and the economy over 2018 and 2019.

There are often permanent changes to carers ability to work as a result of cancer. For example, mothers of survivors are likely to work fewer hours compared to their work pre-cancer.[46] When a child is absent from school, a parent's ability to work is compromised. This indicator uses the average daily earnings of an adult as a proxy of the value of a day not spent caring for their child. This could be value captured through employment, leisure, social, self-care or other activities.

Using the average weekly earnings from the ABS for 2018 and 2019 (Table 16), we developed a daily rate of pay assuming a 5 day working week (Weekly pay divided by 5 days).

Table 16 - ABS Average total earnings weekly pay[47]

	Male	Female	Person
Nov-18	$1,460.50	$996.50	$1,225.00
Nov-19	$1,497.40	$1,027.60	$1,256.20

From the survey, we determined that 84% of the time, the child's primary carer is female, 1% of the time they are male, and 15% of the time they are other (e.g. grandparents) (see Table 2, above). We then took the daily rate for the appropriate gender from Table 16. For the other category, where we could not determine these persons gender based on survey information (i.e. the 'other category'), we used the person rate in Table 16.

Days absent from school are calculated in reduced school absence, above on page 19. The resulting benefit is calculated based on the number of days a child is absent, times the forgone pay of their parent or carer. This assumes that when a child is absent from school, they will need to be cared for by their parent or carer. The above benefits then form the numerator of the SROI calculation demonstrated in Table 6 – SROI Results per outcome and Table 7 - SROI Results per stakeholder group.

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[46] Peikert, M.L., Inhestern, L., Krauth, K.A., Escherich, G., Rutkowski, S., Kandels, D. and Bergelt, C., 2020. Returning to daily life: a qualitative interview study on parents of childhood cancer survivors in Germany. BMJ open, 10(3), p.e033730.

[47] Adapted from: Australian Bureau of Statistics, November 2019 and November 2018, item 6302.0 - Average Weekly Earnings, Australia.

Investment

CQ provided the following costing for the PSCEP based on their audited financial statements from 2018 and 2019. These are shown in Table 17 below. Direct staff costs are allocated based on the percentage of staff effort on the program. Other direct costs are the dollar amount spent to deliver the service.

Indirect costs are allocated based on level of efforts (%) by type (program/fundraising/administration) then allocated to each revenue/program stream based on number of FTE engaged in each stream. Other indirect costs include admin costs and people, culture and IT costs.

Table 17 – The PSCEP Costs[48]

Education Program	Jan - Dec 2018 Actual $	Jan- Dec 2019 Actual $
Costs		
Direct Staff cost	536,750	422,432
Other direct cost	149,885	158,144
Total Direct costs	686,634	580,576
Indirect staff cost	146,259	125,203
Other indirect cost	208,632	172,812
Total Indirect costs	354,891	298,015
Total Costs	**1,041,525**	**878,591**

The costs for 2018 and 2019 are then added to obtain the total investment for the period of $1,920,116. This forms the denominator of the SROI calculation demonstrated in Table 6 – SROI Results per outcome and Table 7 - SROI Results per stakeholder group.

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[48] Camp Quality Audited financial accounts, 2018 and 2019.

5 Appendix

Appendix 1: Documents Reviewed

Document
The PSCEP Survey Results 2016
2016 KPMG Report, Camp Quality Costing Study
The PSCEP Theory of Change 2016
The PSCEP Objectives and Outcomes 2016
Camp Quality Integrated Report 2018 and 2019
The PSCEP Objectives and Outcomes 2020
The PSCEP Development Plan 2020
National Schools feedback 2018 and 2019
Education Expenses 2018 and 2019 from audited financial statements
The PSCEP Statistics 2018 and 2019

Appendix 2: Calculations

Improving Mental Health

Type	#			Unit	Source/assumptions
	Patients	*Siblings*	*Offspring*		
Number of participants	480	500	704	No. people	**Camp Quality, PSCEP Statistics CY2018 to CY2019**
	Patients	*Siblings*	*Offspring*		
Percentage of children with mental health issues	43%	41%	56%	%	**Question 17, Camp Quality, Family Survey 2020**
Visits to health care professionals (before PSCEP)					
	Patients	*Siblings*	*Offspring*		
General Practitioner	17	7	100	No. sessions	**Question 18, Camp Quality, Family Survey 2020**
Psychologist	48	32	97		
Social worker	22	6	26		
Occupational therapist	16	2	20		
Counsellor	15	6	28		
	118	53	271		
Visits to health care professionals (after PSCEP)	*Patients*	*Siblings*	*Offspring*		
General Practitioner	3	6	66	No. sessions	**Question 18, Camp Quality, Family Survey 2020**
Psychologist	28	17	75		
Social worker	3	2	6		
Occupational therapist	12	-	15		
Counsellor	1	8	19		
	47	33	181		
Change	-71	-20	-90		
	-60%	-38%	-33%		
Cost of visiting a healthcare professional					
General Practitioner	74			$	**Medicare Benefits Scheme, item 2700**
Psychologist	91				**Medicare Benefits Scheme, item 80000 - 80071**
Social worker	91				**Medicare Benefits Scheme, items 80150, 80155, 80160, 80165 and 80170**

Occupational therapist	91		**Medicare Benefits Scheme, items 80125, 80130, 80135, 80140 and 80145**
Counsellor	91		**Medicare Benefits Scheme, item 80000 - 80071**

Impact

(Number of patients, sibling or offspring) *Percentage with mental health * (Visits to health care professionals before PSCEP – Visits to health care professionals after PSCEP) * Cost of health care professional

	Patients	Siblings	Offspring	Total
General Practitioner	$ 213,686	$ 15,160	$ 991,238	$ 1,220,083
Psychologist	$ 374,410	$ 278,903	$ 786,667	$ 1,439,979
Social worker	$ 355,689	$ 74,374	$ 715,151	$ 1,145,214
Occupational therapist	$ 74,882	$ 37,187	$ 178,788	$ 290,857
Counsellor	$ 262,086	$(37,187)	$ 321,818	$ 546,718
Total	$ 1,280,753	$ 368,436	$ 2,993,661	$ 4,642,851

Reducing School Aabsence

Type	#	Unit	Source/assumptions
Number of patients	480	No. people	Camp Quality, PSCEP Statistics CY2018 to CY2019
Number of siblings	500	No. people	Camp Quality, PSCEP Statistics CY2018 to CY2019
Number of offspring	704	No. people	Camp Quality, PSCEP Statistics CY2018 to CY2019
Average annual cost per student			
2018	20,119.47		ABS 4221.0 - Schools, Australia, 2019
2019	20,860.71		
Average	20,490	$ per year	Calculated as an average of 2018 and 2019 based on ABS data - only includes government schooling. Does not include independent and religious schools.
Number of days in the school year	200	No. days	https://www.infoplease.com/world/social-statistics/school-years-around-world
Daily cost of school per student	$ 102.45		calculated (Average annual cost of school per child/number of school days per year)
Average number of days missed in a school before PSCEP			
Patients	14	No. days	Average absent days are calculated from the Family survey as the mid-point between the number of days absent in question 14 of the Camp Quality survey. E.g. if the parent answered question 14 with their child having 1-5 days absent from school, then we would code this answer with (1+5)/2 = 3 days on average.
Siblings	9		
Offspring	22		
Average number of days missed in a school after PSCEP			
Patients	8	No. days	
Siblings	8		
Offspring	9		

Impact		Calculation
Patients	$297,789	**No. patients * (daily cost of school per student) * (Average number of days missed before PSCEP by patients – Average number of days missed after PSCEP by patients)**
Siblings	$92,051	**No. siblings * (daily cost of school per student) * (Average number of days missed before PSCEP by siblings – Average number of days missed after PSCEP by siblings)**
Offspring	$937,627	**No. offspring * (daily cost of school per student) * (Average number of days missed before PSCEP by offspring – Average number of days missed after PSCEP by offspring)**
Total	$1,327,467	

Increasing Future Income

Type	**#**			**Unit**	**Source/assumptions**
	Patients	*Siblings*	*Offspring*		
Number of participants	480	500	704	No. people	**Camp Quality, PSCEP Statistics CY2018 to CY2019**
Gender of children	*Patients*	*Siblings*	*Offspring*		**Question 4 and 12, Camp Quality, Family Survey 2020.**
Male	48%	57%	56%		
Female	53%	43%	44%		

Difference in percentage of children who have been bullied (before vs after)

	Patients	*Siblings*	*Offspring*		
Female					**Question 14, Camp Quality, Family Survey 2020**
Never	14%	5%	13%		
Occasionally	-10%	-5%	0%		
Frequently	-5%	0%	-13%		
Male					
Never	5%	4%	10%		
Occasionally	-5%	-4%	-10%		
Frequently	0%	0%	0%		

Difference in mean yearly earnings from paid employment

	Women	Men		
Never bullied	$ -	$ -	AUD $ inflated to 2068	**Data input calculated from Brimblecombe, N. et al., 2018, Long term economic impact associated with childhood bullying victimisation, Social Science & Medicine, pp. 134-141. Study results were converted from GBP to AUD and inflated using RBA's estimated inflation rate to 2068.**
Occasionally bullied	$ 4,178.93	$ 3,699.70		
Frequently bullied	$ 10,897.81	$ 4,097.46		

Impact

(Number of patients, siblings or offspring) * (% female children) * (female difference in mean yearly) + (Number of patients, siblings or offspring) * (% male children) * (male difference in mean yearly earnings)

$ Income in 2068 based on frequency of bullying	**Patients**	**Siblings**	**Offspring**	**Total**
Never	$ -	$ -	$ -	$ -
Occasionally	$ 144,690.75	$ 89,529.89	$ 144,699.27	$ 378,919.91
Frequently	$ 130,773.76	$ -	$ 426,225.58	$ 556,999.34
Total	$ 275,464.51	$ 89,529.89	$ 570,924.85	$ 935,919.25

Parental Productivity

Type	#	Unit	Source/assumptions
Number of patients	480	No. people	**Camp Quality, PSCEP Statistics CY2018 to CY2019**
Number of siblings	500	No. people	**Camp Quality, PSCEP Statistics CY2018 to CY2019**
Number of offspring	704	No. people	**Camp Quality, PSCEP Statistics CY2018 to CY2019**
Average carer daily earnings			**Average of all employees average weekly earnings from the ABS and then divide by 5 to get average daily earnings, assuming a person works 5 days per week.**
Female	$ 202	$ per day	
Male	$ 296		
Persons	$ 248		
Primary carer type			
Female parent is primary carer	84%		**Question 2 and 6 of Camp Quality, Family Survey 2020.**
Male parent is primary carer	1%		
Other	15%		
Average number of days missed in a school before PSCEP			**Average absent days are calculated from the Family survey as the mid-point between the number of days absent in question 14 of the Camp Quality survey. E.g. if the parent answered question 14 with their child having 1-5 days absent from school, then we would code this answer with (1+5)/2 = 3 days on average.**
Patients	14	No. days	
Siblings	9		
Offspring	22		
Average number of days missed in a school after PSCEP			
Patients	8	No. days	
Siblings	8		
Offspring	9		

Impact

(No. patients, siblings or offspring) * Primary carer type * (Average number of days of school missed before PSCEP - Average number of days of school missed after PSCEP) * $ daily average earning (by primary carer type)

Patients	$613,990
Siblings	$189,794
Offspring	$1,933,223
Total	$2,737,007

Appendix 3: Updates Since 2016 Costing Study

KPMG was engaged to conduct an update of the Costing Study completed in 2016. The total SROI of the program in 2020 is 502%, for every dollar spent on the PSCEP there is a $5 return on investment. This is compared to 648% in 2016, meaning for every $1 invested in the PSCEP in 2016 resulted in a total benefit of $6.48.

The results of this report should be viewed as a more conservative assessment compared to 2016. This is due to the use of the Survey, outlined in Section 3 of this report, to attribute the benefits to each PSCEP outcome and distribute the benefit between stakeholders. While the 2016 report used academic literature to measure the benefit. The change in methodology resulted in a measurement of the PSCEP that is both more attributable, using actual data gathered from families whose children attended the PSCEP, and more conservative than the measurement undertaken in 2016.

Additionally, the cost per child has increased since 2016. In 2016, the cost of the program per child impacted (patients, siblings, and offspring) was $885.[49] While the average cost of the program per child in 2018 and 2019 increased to $1,140 per child.[50] This is due, in part, to a decrease in the number of children per year who saw the program in 2018 and 2019, reducing variable costs, while fixed costs have remained consistent through the years. While the program itself has not changed between 2016 and 2019, CQ team members noted that the focus of the program has shifted towards delivery to the offspring stakeholder.

For 2020, we have added to the quantification to capture more of the impact of the PSCEP. Firstly, we have captured the future income of children affected by the PSCEP based on academic literature which indicates that patients, siblings and offspring were more likely to suffer bullying without the PSCEP, which affects their future earnings. Secondly, we have used survey data not only to attribute the impact to the PSCEP, but also to separate out the impact on different stakeholder groups which the PSCEP targets. This will assist CQ in understanding which stakeholders receive the largest benefit and define focus areas for the program going forward.

Despite the more conservative estimate, the results demonstrate that the PSCEP has a significant positive impact on the patients, siblings and offspring, as well as families who partake in the program.

Table 18 - 2016 evaluation results

Outcomes	Reduced school absence	Avoided expenditure on mental health treatments	Increasing future incomes	Increased productivity for parents	Total quantifiable benefits for each outcome	SROI
Outcome 1	$ 6,017,678	$ -	$ -	$ 40,252	$ 6,057,930	
Outcome 2	$ 1,305,015	$ -	$ -	$ -	$ 1,305,015	
Outcome 3	$ -	$ 161,377	$ -	$ -	$ 161,377	
Total	**$ 7,322,693**	**$ 161,377**	**$ -**	**$ 40,252**	**$ 7,524,322**	**648%**

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[49] In 2016, total investment was $1,160,708, and the total number of patients, siblings and offspring was 1311. Sourced from KPMG 2016 Costing Study.

[50] For 2018 and 2019, the total investment by CQ into the PSEP was $1,920,116, and the total number of patients, siblings and offspring was 1684.

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