Camp Quality Impact Study

Family and Kids’ Camps

June 2021

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Executive Summary

Camp Quality's Family Camp and Kids' Camp programs provide significant benefits to the families and children who attend.

According to the Australian Childhood Cancer Registry, the incidence of childhood cancer between 2000 to 2017 have increased by 30%.[1] In 2000, there were 596 recorded incidences of cancer in children under 15 years in Australia, compared to 779 incidences of cancer in 2017.[2] In 2020, there were an estimated 870 children facing a childhood cancer diagnosis.[3] At the same time, mortality from all childhood cancers has decreased by 13% over the same period.[4]

The increasing number of children both suffering and surviving childhood cancer has caused great demand from families and children for support during and after treatment, as well as when readjusting to life after cancer. Camp Quality offers two camp programs, Family Camps and Kids' Camps. These camps have been specially designed by Camp Quality to help families on this journey, supporting them throughout treatment, after treatment and in the tragic case of bereavement.

The Family Camps are designed for the whole family. These Families have one or more of their children, aged 15 years or younger, who either have or had cancer. In some instances, they may also be in a state of bereavement.[5] Camp activities include a mix of traditional camp activities (such askayaking and games etc), kids only activities and adult only time.

The Kids' Camps are designed only for kids affected by cancer and their siblings aged 4 - 13 years old. Kids' Camps are run based on age, with three different age groups available: the Mini camps (designed for children aged 4-6 years old), the Junior camps (designed for children aged 7-9 years old) and the Middle camps (designed for children aged 10-13 years old). These camps aim to provide a positive experience for children through traditional camp activities which provide a fun, creative outlet to play and learn, and provide respite for their families.[6] Bereved siblings may also attend the Kids' Camps so long as they belong to the appropriate age group.

During 2018 and 2019, Camp Quality ran 79 Family Camps and 51 Kids' Camps for a total of 4,153 family caregivers, children with cancer and their siblings. These camps were run with the assistance of over 1000 volunteers. This report summarises the results of an impact study into Camp Quality's

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[1] Australian Childhood Cancer Statistics Online - Cancer Council Queensland (cancerqld.org.au), https://cancerqld.org.au/research/queensland-cancer-statistics/accr/

[2] Ibid.

[3] https://childrenscancer.canceraustralia.gov.au/about-childrens-cancer/statistics-childrens-cancers

[4] Ibid, n. 1 above.

[5] Camp Quality Program Logic – Family Camps provided by the General Manager – Programs and Services .

[6] Camp Quality Program Logic – Kids' Camps provided by the General Manager – Programs and Services .

Family and Kids' Camps during this period. This research centres on two surveys issued during 2021, one which which asked families to reflect on their camp experiences and the key benefits of these programs during 2018 and 2019, and another targeting volunteers experiences. This report focuses on the impact of the camps on the families and kids who attended. For the results of the volunteer survey, please refer to the Volunteer Impact Report.

Delivery of these camps involves not only significant funding, but over 1,000 volunteers. For a Kids' Camp there is roughly two volunteers for every one child. Between six to eight volunteers attend each Family Camp, assisting an average camp size of 32 kids and their family members. These volunteers contributed approximately one hundred and forty four thousand hours during 2018 and 2019, valued at $1.5 million at the average Australian wage. This ensures every child who attends the camp receives appropriate adult supervision and support, which provides the children's parents and primary carers with a short break from caring duties.

Camp Quality's purpose

Camp Quality's purpose is to give kids impacted by cancer the chance to be kids again in as safe, fun and supportive environment. Camp Quality's services and programs support children aged 15 years or younger, who are dealing with their own cancer diagnosis, or the diagnosis of someone they love, such as a parent, primary carer or sibling.

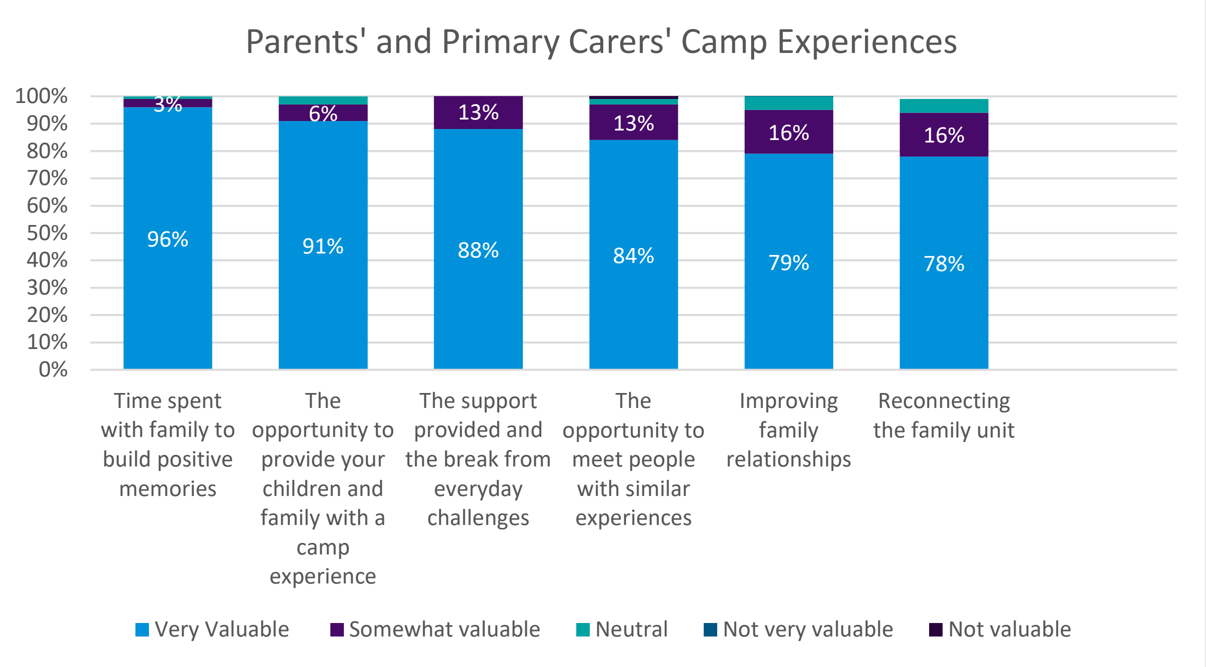
Camp Quality positively changes the cancer experience for children through entertaining, play-based education and recreation programs that strengthen mental wellbeing and improve the quality of life for kids facing cancer and their families: in hospital, online, at school and away from it all on camps and at retreats.

> *"Neuroblastoma robbed both my kids a whole year of their young lives (a year of hospital time for my youngest and a year of missing his mum for my eldest). Camp Quality gives back some quality time that, although doesn't make up for our experiences in 2010-11, reminds my kids that with support and kindness you can get through anything."*
>
> *– Family whose kids attended the Kids' Camps*

Results

The feedback from families who took part in the Camp Quality Family Camps and Kids' Camps was extremely positive. Parents and primary carers felt the camps were a valuable opportunity to reconnect as a family and build positive memories following, or during, treatment for cancer. They valued the ability to provide their children and families with a camp experience, whilst also receiving support and having a break from everyday challenges. Camps provided normalcy and an opportunity to have a break from thinking about cancer, a break from everyday challenges and the opportunity to experience fun camp activities in a supportive and safe environment.

Figure 1 – Parents and primary carers rating of their experience[7]



In Figure 1, parents and primary carers were asked to rank the value of their own experiences at camp. The most valuable experience was the time spent with family to build positive memories (96% of respondents ranked this as very valuable). Parents and primary carers reported the camps provided a chance to be together as a family and experience normal family life away from cancer.

> *"We are very grateful to Camp Quality for the wonderful opportunities to be able to attend the camps. It helped us to forget the hospital and gave us a bit of normalcy amidst staying at the hospital."*
>
> *– Family who attended both the Family Camps and Kids' Camps*

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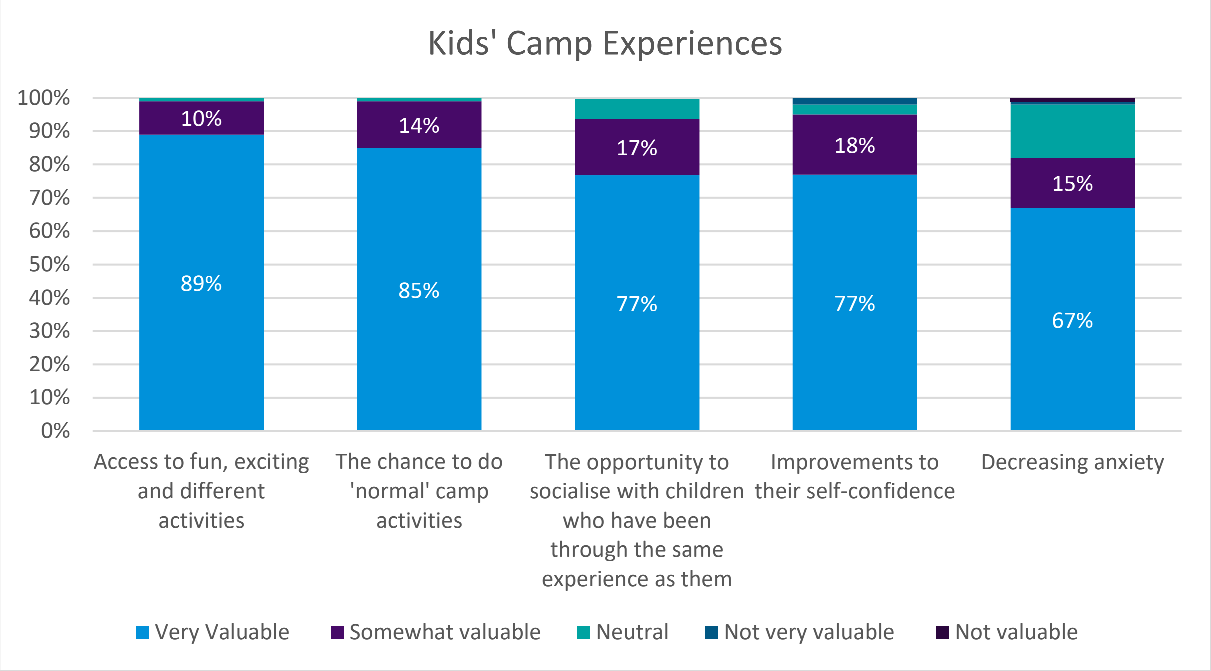
[7] Families were asked to rank how valuable (on a five-point scale from not valuable to very valuable) the Camp Quality experience was on the six criteria identified above. For detailed results, see Table 7.

Figure 2 – Percent of kids rating their experience as very valuable[8]



For the children attending camps, the most valuable experiences, shown in Figure 2, were the chance to do fun, exciting and different activities, with 89% of respondents ranking this as very valuable. Kids valued the opportunity to attend a camp and take part in ‘normal’ camp activities and saw their self-confidence improve following camp attendance (85%). They were able to get back to just being kids again, and take a break from cancer. At the same time, they were able to spend time with other children who had similar experiences with their own, or their sibling’s, cancer (77%), while being in an environment where they received plenty of adult support and encouragement, with many leaving camps having formed ongoing and lasting friendships. Improvements to children’s self-confidence and reductions to anxiety were also very valuable elements of the camp for 77% and 67% of respondents respectively.

Siblings recorded a 22% decrease in loneliness following camp. While for patients and parents and primary caregivers, loneliness decreased by 14% following the camps.

For both parents and primary caregivers and children attending the camp, the camps were a vauable opportunity to build relationships with people who had similar experiences relating to cancer (84% of parents and primary caregivers and 77% of children). Parents and primary carers and children were all likely to experience decreased loneliness following the camps. The largest impact on loneliness was noted in the sibling group where there was a 22% decrease in

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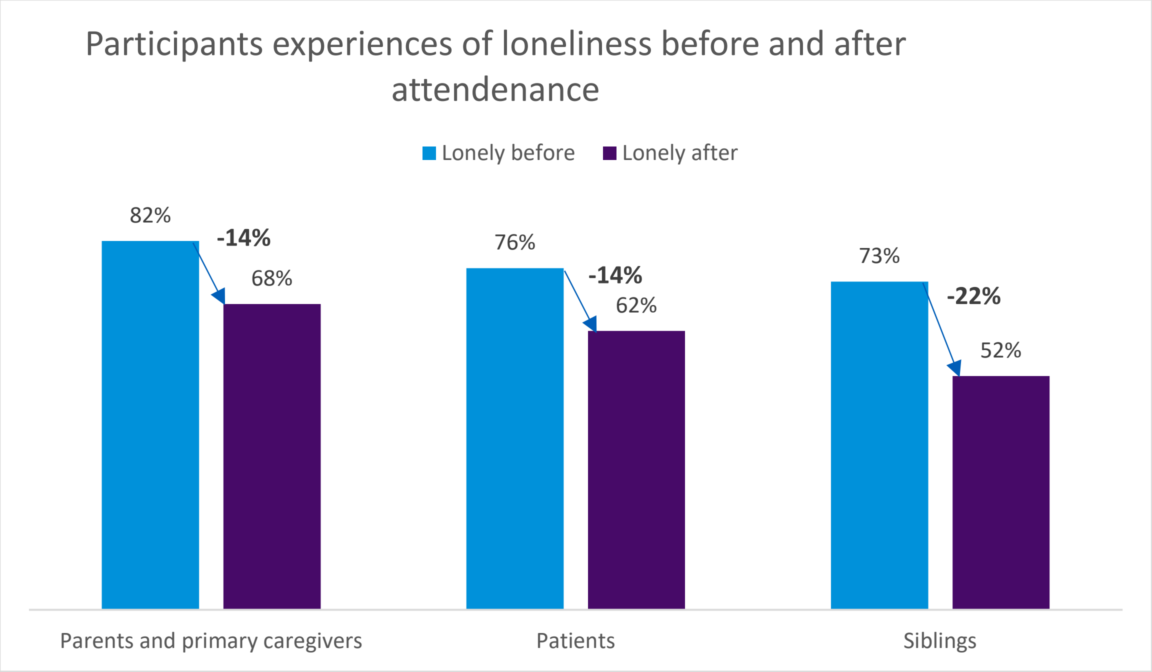
[8] Families were asked to rank how valuable (using a five-point scale from not valuable to very valuable) the Camp Quality experience was on behalf of their children on the five criteria identified above. For detailed results, see Table 6.

loneliness following camps. For parents and primary caregivers and patients, loneliness decreased by 14% following camps.

This is also reflected in the ongoing nature of the relationships formed on camp. 66% of children have stayed in contact with other children from the camp, while 43% of parents and primary caregivers have stayed in contact with another family.

Figure 3 – Decrease in loneliness

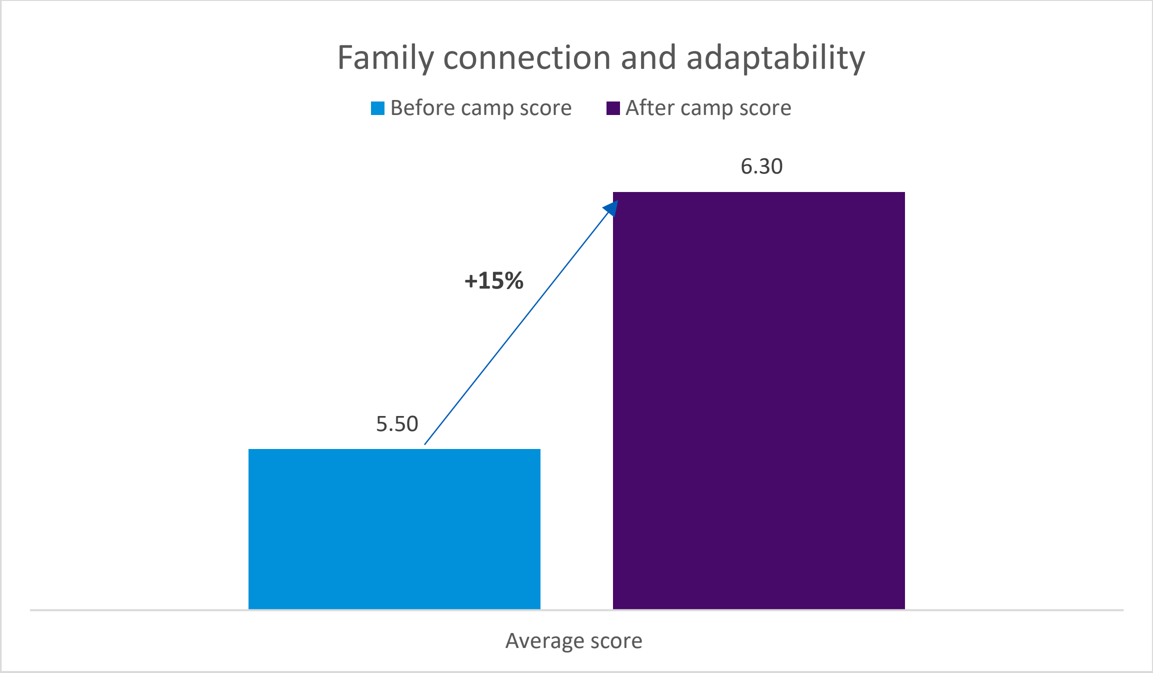


Family relationships improved as a result of attending camps. Families ranked their cohesion (emotional bonding) and adaptability (ability to change roles and relationships in response to stress) as having improved following camp.

There was a 15% increase in the family cohesion and adaptability score after attending camp (Figure 4), with the average score moving from 5.5 out of 8, to 6.3 out of 8. This indicates that overall, family relationships, measured by cohesion and adaptability, improved significantly following camp.

> *"The impact is powerful. The happiness it brings to the entire family especially the children is priceless. Without these camps, it would have felt so lonely and sad and depressing to have gone through the cancer journey. To not be able to relate to anyone."*
>
> *– Family who attended both the Family Camps and Kids' Camps*

Figure 4 – Improvement in family relationships



1 Introduction

Scope and Purpose

The report provides insight into the outcomes and impacts of Camp Quality's Family and Kids' Camps (camps) programs from 1 January 2018 – 30 December 2019.

Camp Quality exists to ensure Australian children going through the trauma of cancer treatment, or dealing with a loved one's cancer experience, don't miss out on the fun, connection and positivity of childhood. By supporting the whole family at every step of this difficult time, Camp Quality helps families stay connected, build powerful networks around them and create lasting, positive memories. Camp Quality provides essential services through every stage of the cancer experience from diagnosis, through treatment to remission. They also provides respite for people with more challenging circumstances, as well as palliative care and support in tragic case of bereavement.

CQ's camps programs during 2018 and 2019 primarily focused on two camp types: Family Camps and Kids' Camp.

Family Camps are designed for families with a child aged 15 years or younger who has been diagnosed with cancer, or have a parent or primary carer undergoing cancer treatment. Families may be eligible to attend camps when one or more of their children under 15 years has had cancer or if the family is in a state of bereavement.

The camp aims to provide an opportunity for families to relax and reconnect as a family and join a supportive community with similar experiences. The camp includes a range of traditional camp activities to participate in as a family, kids only activities, and parent only time.

Kids' Camps are designed for kids affected by cancer and their siblings aged 4-13 years old. The camps are separated into three sub-camps based on age group: Mini camp (4-6-year olds); Junior camps (7-9-year olds); and the Middle camps (10-13-year olds). These camps aim to provide a positive experience for children and respite for their families. These camps include traditional camp activities, and participation in excursions. The core focus of the camps is to encourage the kids and provide them with confidence, resilience and optimism through activities.

KPMG was engaged by CQ in December 2020 to conduct an evaluation for the camp programs. The aim was to articulate and understand the impact of the camps on the children, siblings,parents and primary carers affected by cancer who took part in the programs during 2018 and 2019. 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*. Their parents and primary caregivers are referred to as *parents and primary caregivers.* When grouped together, we refer to this group as *participants.*

During 2018 and 2019, camps for kids impacted by primary carers cancer (KICCs) were being piloted in WA only. Two camps for this group were run in 2019, so for the purposes of this assessment, this stakeholder group was not included.

During 2018 and 2019, Camp Quality delivered 79 Family Camps and 51 Kids' Camps to a total of 4,153 unique individual participants. Of this total, there were 1,075 patients, 1,775 siblings and 1,303 parents and primary caregivers (Table 1). Most attended between one and two camps during the period (Table 2). These camps focused on children living with cancer and their family members, including siblings and family caregivers.

CQ have since commenced expanding the camps offering to KICC (Kids Impacted by a Carers Cancer) families. Since CQ had only just began to pilot KICC Camps in 2019 this group was not included for the purpose of this analysis.

Table 1 - Number of stakeholders who accessed the camps in 2018 and 2019 (Australia wide)[9]

	2018-2019
Parents and Primary Caregivers	1,303
Patients	1,075
Siblings	1,775

Table 2 - Number of camp attendances

Stakeholder	Number of camps attended						
	1	2	3	4	5	6	Total
Parents and Primary Caregivers	999	243	54	7	0	0	1,303
Patients	572	345	121	27	8	2	1,075
Siblings	1,068	480	173	41	12	1	1,775
Total	**2,639**	**1,068**	**348**	**75**	**20**	**3**	**4,153**

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[9] Statistics provided by Camp Quality's National Family Program Manager, from an extract of the customer management system. Stakeholders include patients, siblings and parents and primary caregivers.

2 Method

During 2021, a survey was sent to all families who had attended at least one of the Family Camps and/or Kids' Camps during 2018 and 2019 and had children who were patients or siblings.[10] The Family Caregiver Survey garnered 179 complete responses from parents and primary caregivers on behalf of 323 children.[11] A survey was considered complete where the respondent had answered all compulsory questions.

Both quantitative and qualitative analysis techniques were used over the surveys. Quantitative responses are summarised and provided in the Results section.

- **Qualitative information** was captured through a review of the camps documentation, qualitative survey answers, and academic literature. These sources were reviewed to understand how the camps contribute to effective patient, sibling, and family caregiver outcomes. Qualitative responses from the family survey were categorised by themes and analysed using a textual analysis.
- **Quantitative information** was used to identify changes, over time, in response to the camps. The source of qualitative data was a survey issued to families who had participated in the camps during 2018 and 2019.

To help form the basis of the survey questions, KPMG conducted a detailed review of camp documentation, provided by the Camp Quality team. Program documentation included previous surveys, program logic, previous research projects and program reviews. This information was then used to inform a theory of change, documented below, on the camp programs for each stakeholder group.

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[10] As the KICCs programs were only piloted during 2019, they were excluded for the purposes of the survey. These camps were first piloted with two camps run in Western Australia, in 2019.

[11] Survey responses were cleansed to remove partial responses. Respondents who did not fit in the target population (eg. a primary carer with cancer) were also removed from the analysis.

Literature Review

In the last few decades, treatment of childhood cancer has improved dramatically. Survival rates have increased from 65% in the late 1980s to approximately 80% today.[12] In Australia, the incidence of childhood cancer increased by 30% between 2000 and 2017; meanwhile mortality from childhood cancer has decreased by 13%.[13] As the number of children and families diagnosed with cancer and surviving cancer increases, so does the number of families requiring help either readjusting to life after cancer, or understanding how to cope with the impact it has on their life.

The short-term impacts from a child's cancer treatment can lead to toxicities and poor immune system functioning. In some cases, the physical impact of cancer treatment can reduce a child's self-esteem, for example where disabilities mean they cannot participate in 'normal' activities.[14] Self-esteem is a crucial element of childhood development, which can protect children from mental distress and enable them to cope better with stressful and difficult life situations. Lack of self-esteem has been linked with school attendance and the presence of psychiatric disorders and depression.[15]

In the long term, children may have permanent sensory defects, such as vision or hearing loss, or neurocognitive effects resulting from their treatment.[16] 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.[17]

Social implications for the child who had/has cancer

Beyond the physical impacts of cancer, survivors of childhood cancer report higher levels of family attachment and therefore less independence and more reliance on their parents or caregiver.[18] They are also likely to be more anxious and socially introverted.[19] This results in children with cancer finding it harder to make close friends or lack confidence in social situations such as school. In one study, 19% of cancer survivors were shown to have

19% of cancer survivors had no close friends (compared with 8% of the control group) and were less likely to use friends as their confidants.

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[12] 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.

[13] Australian Childhood Cancer Statistics Online - Cancer Council Queensland (cancerqld.org.au), https://cancerqld.org.au/research/queensland-cancer-statistics/accr/

[14] 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.

[15] Hosogi, M., Okada, A., Fujii, C., Noguchi, K. and Watanabe, K., 2012. Importance and usefulness of evaluating self-esteem in children. BioPsychoSocial medicine, 6(1), pp.1-6.

[16] Ibid n.14 above.

[17] Ibid n.14 above.

[18] Ibid n.15 above.

[19] Ibid n.15 above.

no close friends (compared to the control of 8%) and were less likely to use friends as their confidants.[20]

Lack of social connection and absence of social relationships is a significant risk factor for mortality and morbidity, particularly as the population ages.[21] Loneliness has been shown to impair functioning, sleep, mental and physical health. People who are more socially connected tend to show better resilience to hardship.[22] Moreover, they show better health patterns and behaviour including regular exercise, consuming a balanced diet and following medical and heath advice.[23]

Siblings' experience

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. A study by Neville et al (2006) interviewed siblings of children with cancer in a group setting.[24] This revealed that siblings tend to experience personal losses from not being able to participate in activities that they used to, prior to the cancer diagnosis of their sibling. They also felt excluded from the cancer experience and didn't fully understand what their sibling was experiencing. Feeling excluded from family life, or distance from family was also a common feature in these children's experiences.

Within some siblings, Neville et al (2006) noted that this manifested in frustration toward their ill sibling, who they felt got more attention and interest than they did. At the same time, they may feel guilt or empathy towards their ill sibling. 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.

Family disruption and fragmentation

Childhood cancer also has documented impacts on parents and primary carers. During the treatment of cancer, family structures are frequently disrupted due to one parent caring for the ill child through hospital stays for treatment. After their child has finished treatment for cancer, parents may struggle with reintegration into daily life, struggle with greater stress and anxiety and experience negative

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[20] Barrera, M., Shaw, A.K., Speechley, K.N., Maunsell, E. and Pogany, L., 2005. Educational and social late effects of childhood cancer and related clinical, personal, and familial characteristics. Cancer, 104(8), pp.1751-1760.

[21] Cacioppo, J.T. and Cacioppo, S., 2014. Social relationships and health: The toxic effects of perceived social isolation. Social and personality psychology compass, 8(2), pp.58-72.

[22] Richards, L., 2016. For whom money matters less: social connectedness as a resilience resource in the UK. Social indicators research, 125(2), pp.509-535.

[23] Umberson, D. and Karas Montez, J., 2010. Social relationships and health: A flashpoint for health policy. Journal of health and social behavior, 51, pp.S54-S66.

[24] 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.

effects on family functioning.[25],[26],[27] Psychological problems reported by parents include uncertainty, fear of losing their child and unhappiness.[28]

Parents document changing work hours compared to before the disease, for example, mothers surveyed in Peirkert et al (2020) reported appreciating flexible working arrangements and support from their employers as their children with cancer required additional support or health care. [29] Changing work hours, in addition to the financial strain of cancer treatment itself can put a strain on family finances in the period following treatment.[30],[31] Furthermore, parents document feeling socially isolated in both the cancer treatment and the period following treatment.[32]

Positive effects of camps

Previous studies on the impact of childhood camps on siblings and children who have / had cancer, found significant positive effects from attending camps.[33],[34] Packman et al (2004) followed the impacts of Camp Okizu Siblings camp, a camp which includes siblings only. The camp includes a facilitated discussion among the siblings where they can share their family situations and share tips on coping. Siblings also had support from camp counsellors who provide consistent, positive feedback and are specially trained in techniques for recognising and reinforcing positive behaviours. The study found that the sibling's post-traumatic stress disorder (PTSD) severity scores and anxiety scores, significantly reduced following the camp. Further to this, their quality of life and self-esteem scores also significantly improved.

Wu et al (2016)'s cross-sectional study of cancer camps found that both siblings and patients, regardless of demographic type and camp factors (eg. camp involving siblings only, patients only, or both), benefit from the camps. Campers who had attended multiple camps tended to show higher results, however, the difference was small. In other instances, participating in camps has been shown

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[25] Ibid, n.14 above.

[26] Woźniak, K. and Iżycki, D., 2014. Cancer: a family at risk. Menopause review, 13(4), p.253.

[27] 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..

[28] Ibid n. 24 above.

[29] Ibid n. 26 above.

[30] Wakefield, C.E., McLoone, J.K., Evans, N.T., Ellis, S.J. and Cohn, R.J., 2014. It's more than dollars and cents: the impact of childhood cancer on parents' occupational and financial health. Journal of psychosocial oncology, 32(5), pp.602-621.

[31] Hosoda, T., 2014. The impact of childhood cancer on family functioning: a review. Graduate Student Journal of Psychology, 15, pp.18-30.

[32] Ibid n. 27 above.

[33] Packman, W., Fine, J., Chesterman, B., vanzutphen, K., Golan, R. and Amylon, M., 2004. Camp Okizu: Preliminary investigation of a psychological intervention for siblings of pediatric cancer patients. Children's Health Care, 33(3), pp.201-215.

[34] Wu, Y.P., McPhail, J., Mooney, R., Martiniuk, A. and Amylon, M.D., 2016. A multisite evaluation of summer camps for children with cancer and their siblings. Journal of psychosocial oncology, 34(6), pp.449-459.

to improve social health, enhance constructions of self, improve quality of life, sense of normalcy and attitude.[35]

For families and the parents of patients, camps provide respite and relief from the physical and mental strains of caring.[36] Parents may feel that they have improved perceptions of their child, reduced stress and support from the camp environment.

Limitations and Assumptions

KPMG were engaged by CQ to support its assessment of the impact of the camps over 1 January 2018 – 31 December 2019. Where relevant, sources and key assumptions 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; or
- the information, data and assertions (including any accounting, tax, legal, regulatory or commercial assumptions) provided by CQ personnel and used in the report.

The 2018 and 2019 period were chosen due to the disruption to CQ's camps that occurred as a result of Covid-19 in 2020. This meant that very few camps were run during this period. Camps recommenced in limited States in October 2020.

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 that the sample of families and volunteers represents the entire population of 683 families.[37]

As the survey was commissioned in 2020 and sent in 2021, the survey was asking individuals to recall an impact from a distance of time ago. As time passes, memories may reduce and therefore the responses to the survey are likely best estimates. A survey issued closer to the camp would ensure more accurate responses going forward.

Survey sample

Families

Respondents to the family survey were majority female and identified as Australian. The following largest groups identified as Asian Australian and European Australian. Most respondents had more than one child, with a majority having either two or three children. During 2018 and 2019, most families noted that their child had recovered from cancer (51%). A smaller number were currently undergoing treatment for cancer (39%) and fewer were in bereavement (3%). Responses in the other

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[35] Neville, A.R., Moothathamby, N., Naganathan, M., Huynh, E. and Moola, F.J., 2019. "A place to call our own": The impact of camp experiences on the psychosocial wellbeing of children and youth affected by cancer–A narrative review. Complementary therapies in clinical practice, 36, pp.18-28.

[36] Lindsey, B., 2014. Therapeutic Camps and their Impact on the Family of Children with Special Health Care Needs: A Mixed Method Study.

[37] Total number of families and volunteers were provided by Camp Quality's National Family Program Manager for 2018 and 2019, as an extract from the CQ customer management system.

category included where the child was in palliative care, stabilisation of the cancer and ongoing maintenance of cancer. There was a roughly equal split between patients and siblings.

Table 3 – Family survey respondent summary

Sociodemographic of surveyed parent		n	%
Number of families surveyed		179	
Number of children		323	
Gender			
	Male	18	10%
	Female	160	89%
	Prefer not to say	1	1%
Ethnicity			
	African Australians	1	1%
	Asian Australians	16	9%
	Australians	127	71%
	European Australians	16	9%
	Indigenous Australians	0	0%
	South Sea Islanders	1	1%
	Prefer not to say	2	1%
	Other	15	8%
Number of children per family			
	1	19	11%
	2	92	51%
	3	47	26%
	4	13	7%
	5+	8	4%
Cancer journey stage			
	Bereavement	6	3%
	Child had recovered from cancer	91	51%
	Child was in treatment for cancer	69	39%
	Other	11	6%
Child stakeholder group			
	Patient	157	49%
	Sibling	166	51%
Camps attended			
	Both Kids' and Family Camps	69	39%
	Family Camps only	63	35%
	Kids' Camps only	47	26%

3 Results

Family Survey

Summary of results

Survey findings from the Family survey show that kids attending the camps benefited from having access to fun and exciting camp activities. This was followed by the opportunity to have 'normal' camp experiences which can lead to improvements to self-confidence, resilience and optimism. Parents most appreciated the opportunity to spend time as a family, provide their children with a camp experience, and the support provided by other families and the CQ community and having a break from everyday challenges.

As demonstrated in Table 6, parents responding to the survey noted that the most valuable elements of the camps were the access to fun, exciting and different activities, with 89% of survey respondents noting that this was a very valuable element of their child's camp experience and a further 10% noted this was somewhat valuable. The second most valuable element of the camps for the kids' experience was the chance to do 'normal' camp activities. This was ranked as very valuable by 85% of participants, with a further 14% noting this as somewhat valuable. This was closely followed by improvements to self-confidence, which was ranked as very valuable by 77% of respondents and somewhat valuable by 14%. 67% of children indicated that attending camp was very valuable in decreasing feelings of anxiety.

77% of survey respondents noted that the opportunity to socialise with other children who have been through similar experiences was very valuable, followed by a further 17% who indicated it was somewhat valuable. The camps also improved feelings of loneliness in both siblings and patients, with a 22% decrease and a 14% decrease in loneliness respectively. Many children continued to stay in contact with other children following camp, with 66% of children staying in contact with another child following camp.

Parents and primary caregivers who attended the Family Camps were asked to identify what the most valuable elements of their camp experience were, documented in Table 7. The most valuable element of survey respondents' own camp experiences was spending time with family and building positive memories. 96% of respondents noted that this was a very valuable element of the Family Camps experience. Families documented a 15% increase on the highest scores of family relationships, meaning that overall families were closer and more adaptive to stress following the camp. This was followed by the opportunity to provide the children and the family with a camp experience, which was ranked as very valuable by 91%. This is followed by support and having a break from everyday challenges which was noted as very valuable by 88%.

84% stated that the opportunity to socialise and meet people from a similar background was very valuable. This is supported by the 14% improvement in loneliness following camp and the 43% of parents and primary caregivers who stayed in contact with other families following camp.

Table 4 - Rankings of the most valuable elements of the camps programs for kids

Thinking about your child's / children's camp experience(s), how valuable were they using the scale below?	%
The opportunity to socialise with children who have been through the same experience as them	
Not valuable	0%
Not very valuable	0%
Neutral	6%
Somewhat valuable	17%
Very valuable	77%
Grand Total	**100%**
Access to fun, exciting and different activities	
Not valuable	1%
Not very valuable	0%
Neutral	1%
Somewhat valuable	10%
Very valuable	89%
Grand Total	**100%**
The chance to do 'normal' camp activities	
Not valuable	1%
Not very valuable	0%
Neutral	1%
Somewhat valuable	14%
Very valuable	85%
Grand Total	**100%**
Improvements to their self-confidence	
Not valuable	0%
Not very valuable	2%
Neutral	3%
Somewhat valuable	18%
Very valuable	77%
Grand Total	**100%**
Decreasing anxiety	
Not valuable	1%
Not very valuable	1%
Neutral	16%
Somewhat valuable	15%
Very valuable	67%
Grand Total	**100%**

Table 5 - Rankings of the most valuable elements of the camps, for parents and primary caregivers

Thinking about your camp experience, how valuable were the following on a scale of not valuable to very valuable.	%
The support provided and the break from everyday challenges	
Not valuable	1%
Not very valuable	0%
Neutral	0%
Somewhat valuable	11%
Very valuable	88%
Grand Total	**100%**
The opportunity to meet people with similar experiences	
Not valuable	1%
Not very valuable	0%
Neutral	2%
Somewhat valuable	13%
Very valuable	84%
Grand Total	**100%**
The opportunity to provide your children and family with a camp experience	
Not valuable	0%
Not very valuable	0%
Neutral	3%
Somewhat valuable	6%
Very valuable	91%
Grand Total	**100%**
Time spent with family to build positive memories	
Not valuable	0%
Not very valuable	0%
Neutral	1%
Somewhat valuable	3%
Very valuable	96%
Grand Total	**100%**
Improving family relationships	
Not valuable	0%
Not Very valuable	1%
Neutral	5%

Thinking about your camp experience, how valuable were the following on a scale of not valuable to very valuable.	%
Somewhat valuable	16%
Very valuable	79%
Grand Total	**100%**
Reconnecting the family unit	
Not valuable	0%
Not Very valuable	1%
Neutral	5%
Somewhat valuable	16%
Very valuable	78%
Grand Total	**100%**

Discussion

Normalcy and a break

A key theme in the most valuable elements of the camps offered by Camp Quality, in both the children group, and the parents / primary caregiver group, was the opportunity to have camp experiences and a break from the challenges that come with cancer.

- 89% of parents and primary caregivers ranked the access to fun and exciting camp experiences as a very valuable element of camp for their children.
- 85% also ranked the chance to do 'normal' camp activities as very valuable for their children.
- 91% of parents and primary caregivers ranked the opportunity to have camp experiences with their family as very valuable.

Families noted that they feel grateful for the experience in attending the camp, including how it provided distraction from their regular stays at hospital. It also provides a chance for families to momentarily forget about cancer.

> *"Family Camps are what we look forward to also. It allows us to bond with other families as well as become closer as a family. It is a blessing to be invited to all the camps. It relieves the stresses and for a few days, makes us forget about cancer. About the worries and just be carefree." – Family who attended the Family Camp*

In some instances, families acknowledged they would not have been able to afford the same experience outside of Camp Quality. One family noted that this was particularly important due to changes in their ability to work.

> *"… it's a great opportunity to have a couple of days away, which otherwise can be difficult to afford, particularly when you have to stop working due to treatment and ongoing complications associated with the treatment." - Family who attended both the Family Camps Kids' Camps*

> *"Kids Camps have been excellent for both my kids. Having had to isolate so much in their early years, being in a room full of other kids was not something they remembered - to the point they found other kids "too loud"! They missed out on play dates, kindergarten etc. Kids Camps are excellent to give them a bit of normalcy back..." – Family who attended the Kids' Camp*

Changes in loneliness and social connection outside the family

Families who attended the camps showed an improvement in feelings of social connection, support and improved their social network, leading to an overall decrease in loneliness across the surveyed population. As shown in Table 5, 82% of respondents noted the opportunity to socialise with other children who have shared experiences as being a very valuable element of the Kids' Camps.

Respondents reported feeling more supported as a result of attending camps both from the Camp Quality staff, other families and hearing similar stories to their own. In some cases, this gave families a sense of not being alone.

> *"We loved the Family Camps such a positive experience, we felt supported and cared for by the staff. A fun family break to take our minds off other stresses in our lives" – Family who attended both the Family Camps and Kids' Camps*

> *"Camp Quality is an extraordinary charity that provides relief from anxiety and stress surrounding having a child going through cancer. It is the best time to reconnect as a family, meet similar families and have the children enjoy themselves. The camps are so well run, well supervised and there is great support. We value belonging to such an amazing and supportive group." – Family who attended the Family Camp*

> *"I spoke with other parents, and [my husband] even managed to have a chat with another dad who shared his story and my husband was blown away by the realisation that it 'wasn't just him'. It is hard for the men; society expects them to be strong but frankly the women are often stronger, and the men struggle quite a bit. "– Family who attended both the Family Camps and Kids' Camps*

Families noted that the opportunity to connect with people who were going through similar experiences was very valuable. One family noted that they felt this connection was just as important, if not more important where the family is bereaved. Although bereaved families were a small subset of campers in 2018 and 2019, there were strong indications that they want to remain part of the Camp Quality community.

> *"To get to know others who are going through the same thing, even after the child with cancer has passed away is very important for the [w]hole family to stay connected to a group they now feel part of and will always feel part of. Just because the child has passed does not mean the family does not need the help. It [often] means they need help now more than*

> *ever, let them be part of the Camp Quality family because that's where their connections now lie. With that in other families and their children." – Family who attended both the Family Camps and Kids' Camps*

For kids who attend the camp, parents feel that they have continuing connections from camp. This includes making friends, but also connecting with people who have similar experiences, as was the case with the parents.

> *"My daughter still talks about her [time at] camp and [her] buddy [even] after a few years. It was a time when she felt like the centre of attention when at home it seemed like it was on her brother and his illness." – Family who attended both the Family Camps and Kids' Camps*

> *"Being around other kids who have had similar experiences was invaluable. It greatly helped with self-confidence and decreased anxiety while on camp. As was the amount of fun and activities!" – Family whose children attended the Kids' Camp*

> *"It encourages our children to be open about their feelings with other children and siblings going through the same situations and helps them build lifelong bonds with new friendships" – Family whose children attended the Kids' Camp*

Camps provided the opportunity for children to connect with other children, but also for families and parents to find connections with other parents. The children and families attending the camp were generally more socially connected following the camps. 66% of children have sometimes or often stayed in contact with other children from the camp, while 43% of parents and primary caregivers have stayed in contact with another family some of the time or often.

Table 6 - Percentage of continuing relationships after camp

Survey participants with continuing relationships following camp		%
Patients/siblings		
	Often	14%
	Some of the time	52%
	Hardly ever or never	34%
	Total	**100%**
Parents and primary caregivers		
	Often	2%
	Some of the time	41%
	Hardly ever or never	57%
	Total	**100%**

This is further evidenced by the reduction in loneliness felt by participants. Loneliness of participants across the survey population was measured based on whether the survey respondent considered they either felt:

- that they lack companionship;
- left out; or
- isolated from others.

Respondents were able to respond 'Often', 'Some of the time' or 'Hardly ever or never' to the above three criteria. If they responded 'Often' or 'Some of the time' to any of the above questions they were classified as lonely. The total number of participants who self-reported feeling lonely before compared to after the camps reduced by 17% (Table 8)

Table 7 - Changes in loneliness

Lonely before			
Stakeholder type	**Before**	**After**	**Change**
Parents and primary caregiver	82%	68%	-14%
Patient	76%	62%	-14%
Sibling	73%	52%	-22%
Total	**77%**	**60%**	**-17%**

Reconnecting the family

The most valuable element of the camps, particularly the Family Camps for the parents, was the opportunity to spend time as a family and create positive memories. This was noted as very valuable by 96% of families. 79% also noted that they found improvements to their family relationships to be very valuable.

Families noted that the Family Camps helped them experience laughter and joy, but also reconnect after treatment.

> *"It really helped me and the children to find the enjoyment life can bring and laughter in life. Brought us closer together" – Family who attended both the Family Camps and Kids' Camps*
>
> *"The Family Camps had such a positive impact on my child with cancer as well as our entire family. We all felt less isolated and could relate to the other families. There was a shared sense of fight and hope. The attendance at these camps definitely brought us closer as a family." – Family who attended the Family Camp*
>
> *"Camp Quality is an extraordinary charity that provides relief from anxiety and stress surrounding having a child going through cancer. It is the best time to reconnect as a family, meet similar families and have the children enjoy themselves. The camps are so well run, supervised and there is great support. We value belonging to such an amazing and supportive group." – Family who attended the Family Camp*

Separate kids' and adults' activities were noted as important in building trust within the family. One family referenced feeling like their children can't cope without them and allowing the parents to reconnect.

> *"The afternoon of separate kids'/ adults' activities was a turning point for us in spending time away from our daughter. We didn't think she would manage. We hadn't spent time just us in a couple in years." – Family who attended the Family Camp*
>
> *" The camps really made us as a family (I guess I mean we parents, not the young kids) realise that it's similar for everyone who goes through this awful experience, you can't rush it or make everything better, and you just have to keep on trucking... At times I have arrived at a camp feeling hopeless (about my marriage, about my kids' resilience) and have left feeling that it is not the time to give up on anything, and to keep calm and carry on." – Family who attended both the Family Camps and Kids' Camps*

A frequently used measure of family relations is family cohesion and adaptability.[38],[39] Cohesion being the degree of emotional bonding between family members. Adaptability refers to the family's ability to change roles and relationships in response to stress.

Families were asked in the survey to assign rankings to their family's cohesion and adaptability, then they were assigned a score based on their answer, where 1 indicates that the family has a very low score on cohesion and adaptability, and 4 indicates a very high score (see Table 10 and Table 11).

Table 8 - Cohesion scores

Cohesion	Score
Disengaged (very low cohesion)	1
Separated (low to moderate cohesion)	2
Connected (moderate to high cohesion)	3
Enmeshed (very high cohesion)	4

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[38] Lei, X., 2018. Study on Relationship Between Family Cohesion and Adaptability, and Quality of Life of Caregivers of Children with ASD. SOCIAL WELFARE: INTERDISCIPLINARY APPROACH, 1(8), pp.132-144.

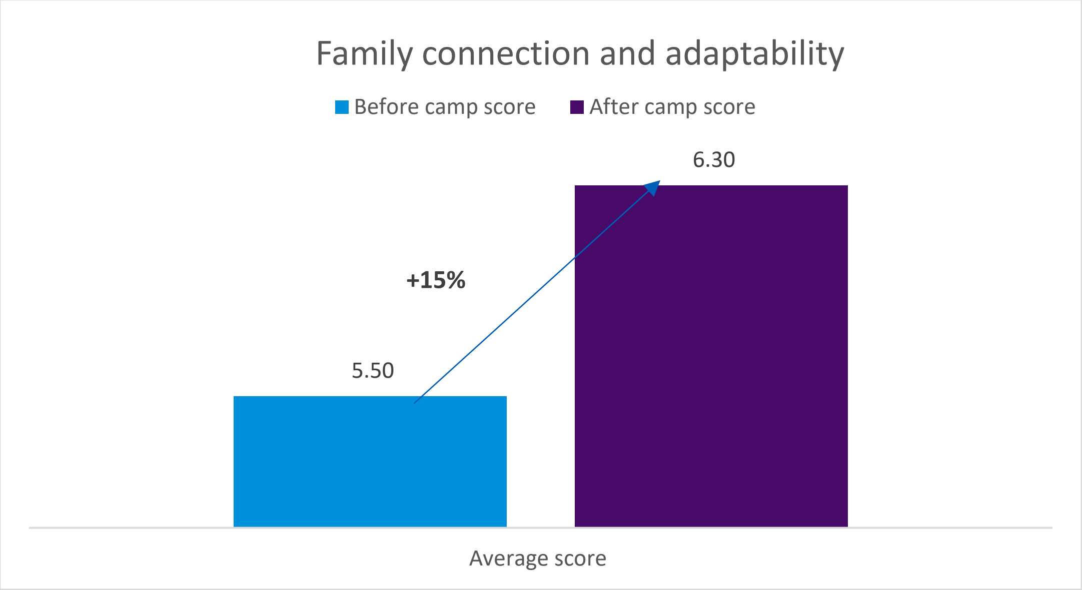
[39] Place, M., Hulsmeier, J., Brownrigg, A. and Soulsby, A., 2005. The Family Adaptability and Cohesion Evaluation Scale (FACES): an instrument worthy of rehabilitation?. Psychiatric Bulletin, 29(6), pp.215-218.

Table 9 - Adaptability scores

Adaptability	Score
Ridged (very low adaptability)	1
Structured (low to moderate adaptability)	2
Flexible (moderate to high adaptability)	3
Cohesive (very high adaptability)	4

Across the two indicators, the highest available score is 8, indicating the best possible relationship within the family (highly cohesive and adaptable). Families who have a high score have been shown to have better family functioning[40] and quality of life.[41] The lowest score available is a 2, indicating that the family is neither highly cohesive nor adaptable in stressful situations. These families have a very low sense of closeness or emotional bonding and are poor at adapting and changing roles in stressful situations. Following the camps, there was a 15% increase in the family cohesion and adaptability score after attending camp (Figure 4), with the average score moving from 5.5 out of 8, to 6.3 out of 8. This indicates that overall, family relationships, indicated by cohesion and adaptability, improved significantly following camp.

Figure 5 – Improvement in family relationships



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[40] Ibid n. 43, above.

[41] Ibid n. 44, above.

4 Discussion

Overwhelmingly, the feedback gathered from families who took part in the Camp Quality Family Camps and Kids' Camps showed they found the experience to be positive. Families felt the camps were an opportunity to reconnect as a family and build positive memories, following or during treatment for cancer. They valued the ability to provide their children and families with a camp experience, whilst also receiving support and having a break from everyday challenges. Camps provided normalcy, and an opportunity to have a break from thinking about cancer, but also improved parents' resilience.

For the kids attending camp, the chance to do fun, exciting and different activities was the most valuable element of the camp experience. Kids valued the opportunity to participate in 'normal' camp activities and parents saw their child's self-confidence improve following the camps. Kids were able to get back to just being kids and have a break from cancer. They were able to spend time with other kids who had similar experiences and backgrounds to them in an environment where they received plenty of adult support and encouragement, with many leaving camps with ongoing friendships.

Further to the above, the following key outcomes were also found:

- A 17% reduction overall in feelings of loneliness, from before, compared to after camps
- A 15% improvement in family cohesion and adaptability scores.

Future measurements of CQ's camps impact could improve by focusing on:

- issuing the survey as part of the standard pre-camp and post-camps performance assessment process; and
- extending impact measurement to KICC which were not a major group within the camp attendances in 2018 or 2019; however, they are now a group which CQ is focusing on going forward.

The survey should be issued close to the camp as this will garner the most accurate responses from families and allow the selection bias to be minimised. Surveying families both before and after camp will also garner the most accurate responses in the actual change that has occurred as a result of the camps.

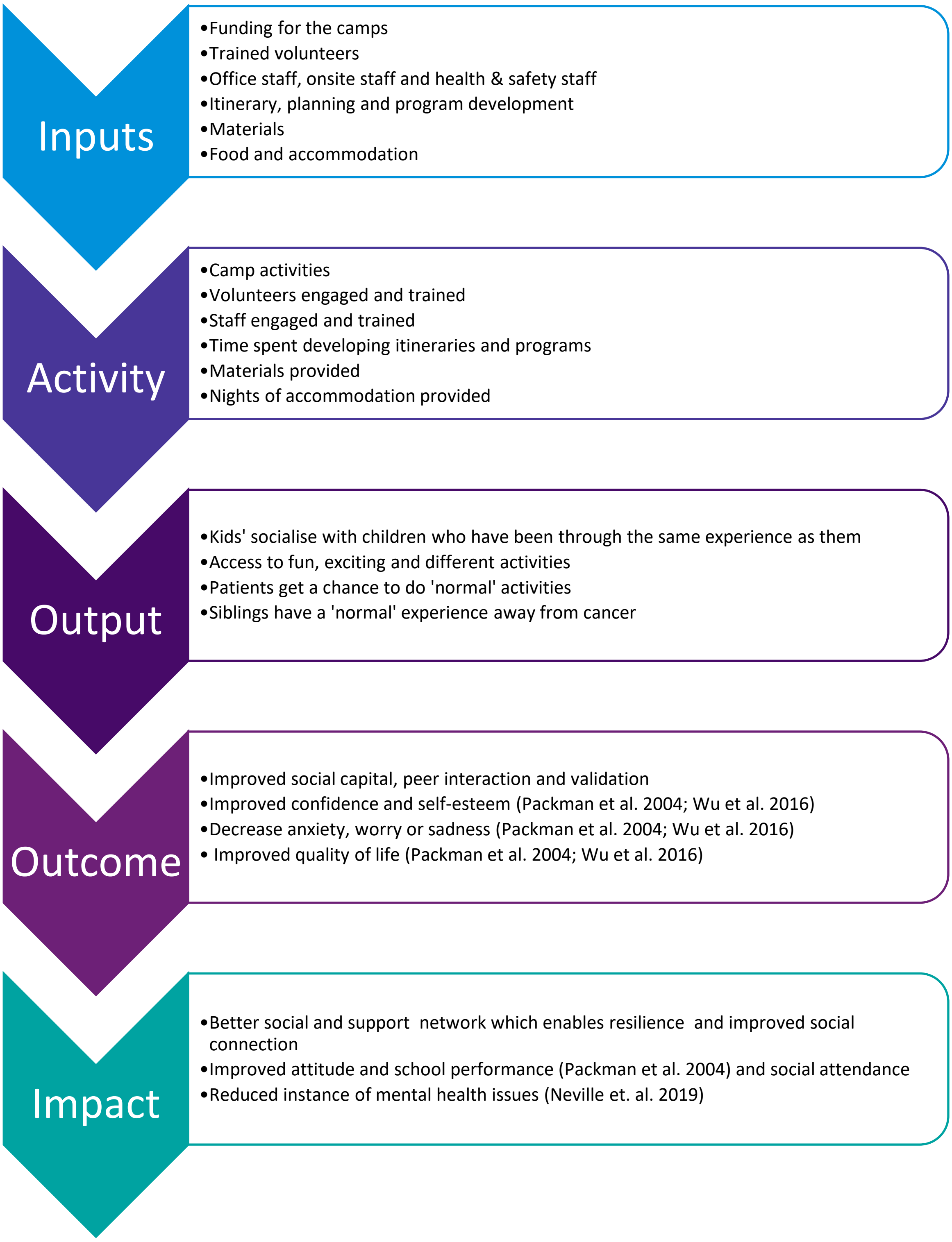
5 Appendix

Theory of Change

The theories of change below summarise the outputs, outcomes and impacts which demonstrate the key benefits of the camps which formed the basis of the survey questions and measurement of the benefits of the CQ camps.

Inputs are defined as the resources required to carry out an activity. Activity is defined as those activities where the effects can be measured or analysed. An output is the result of this activity. The outcome is then the change in the lives of the population, and the impact is the change in wellbeing over the longer term.

Figure 6 - Theory of change for patients and siblings



Inputs

- Funding for the camps
- Trained volunteers
- Office staff, onsite staff and health & safety staff
- Itinerary, planning and program development
- Materials
- Food and accommodation

Activity

- Camp activities
- Volunteers engaged and trained
- Staff engaged and trained
- Time spent developing itineraries and programs
- Materials provided
- Nights of accommodation provided

Output

- Kids' socialise with children who have been through the same experience as them
- Access to fun, exciting and different activities
- Patients get a chance to do 'normal' activities
- Siblings have a 'normal' experience away from cancer

Outcome

- Improved social capital, peer interaction and validation
- Improved confidence and self-esteem (Packman et al. 2004; Wu et al. 2016)
- Decrease anxiety, worry or sadness (Packman et al. 2004; Wu et al. 2016)
- Improved quality of life (Packman et al. 2004; Wu et al. 2016)

Impact

- Better social and support network which enables resilience and improved social connection
- Improved attitude and school performance (Packman et al. 2004) and social attendance
- Reduced instance of mental health issues (Neville et. al. 2019)

Figure 7 - Theory of change for parents

Inputs

- Funding for the camps
- Trained volunteers
- Office staff onsite staff and health and safety staff
- Itinerary, planning and program development
- Materials
- Food and accommodation

Activity

- Camp activities
- Volunteers engaged and trained
- Staff engaged and trained
- Time spent developing itineraries and programs
- Materials provided
- Nights of accommodation provided

Output

- Parents have the opportunity to socialise with parents who have similar experiences
- Access to and opportunity to provide activities to their children that they may not have been able to afford.
- Distraction from daily life and cancer

Outcome

- Improved social capital
- Lower financial burden and stress
- Opportunities to build memories with their children
- respite and recovery

Impact

- Better social and support network which enables resilience
- Less mental health issues relating to financial hardship

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