



# Family Research Project Results

Sharing the  
Journey...  
so far!



## The results are in!

In 2010, Camp Quality conducted an extensive Family Research Project. The aim of this research was to develop a broader understanding of the needs of children with cancer and their families, how these needs were being met by Camp Quality and other organisations, and to identify further scope to enhance Camp Quality's programs.

The research we conducted included Camp Quality families, Camp Quality volunteer companions and health care professionals throughout Australia. This research has been an important part of our commitment to better meet and adapt to the changing needs of families. We are very thankful to those that participated in this project with the feedback provided being invaluable.

Enclosed in this brochure is a snapshot of the results which we are thrilled to be sharing with you.

Again, thanks for sharing this journey with us so far. We look forward to sharing more exciting updates with you as we create the future of our programs, informed by these results.

Simon Rountree



Camp Quality CEO

## How did we do it?

### We worked with our research partner, ARTD Consultants, to undertake

- » A review of publications to understand what exists and what is needed – over 100 references
- » Camp Quality family focus groups – 51 groups in 18 locations around Australia
- » Survey to Camp Quality families – 2,333 mailed with 21% response
- » Online survey to 255 Health Professionals with 20% response
- » Survey to 1,481 Camp Quality volunteer companions with 28% response

## What did we want to find out?

### We wanted our research to cover two distinct areas

#### Cancer specific

- » Experiences and needs of our families
- » Who is meeting the needs of families?
- » Where are the gaps?

#### Experience with Camp Quality

- » Where do we meet needs?
- » Where we don't meet needs?
- » Suggestions for improvements

# Research Results Snapshot

The focus of the research was all about the needs of children with cancer, their siblings and their parents. This is a snapshot of what we found out.

## Children with cancer

### Greatest needs

- » Support from parent/carer
- » Honest information about their cancer
- » Emotional support
- » Help to adjust to life outside hospital
- » Back to school support
- » Family time and play
- » Ability to re-establish friends
- » Help to deal with boredom

### Needs most likely to be unmet

- » Help to deal with the uncertainty about the future
- » Help to deal with feeling frustrated and being unable to do things others can do
- » The need to talk to someone their own age who had gone through a similar experience (especially older children)

## Siblings

### Greatest needs

- » Information about their siblings cancer and changes ahead
- » Contact with their brother/sister and being included
- » Contact with parents
- » Information and involvement in decisions
- » Support from friends
- » Recreation and fun
- » Emotional support
- » Time out from added responsibilities

### Needs most likely to be unmet

- » Friends that understand what they are going through
- » Time with parents and carers (this was partially met)
- » Help to manage and express feelings
- » Information about their sibling's cancer

## Parents

### Greatest needs

- » Practical and emotional support
- » Support to spend time with other children
- » Honest information about immediate and long term effects of cancer
- » Help to reintroduce fun and respite with family
- » Connect with others on a similar journey
- » Help to cope with feelings of sadness, guilt, anxiety and stress

### Needs most likely to be unmet

- » Help to deal with stresses on the family and relationship with spouse
- » Help to cope with feelings of sadness, guilt, anxiety and stress
- » Information, counselling and support groups
- » Opportunity for time to themselves
- » Help to cope with household duties

## Feedback on Our Current Programs

We also asked questions about our programs to understand where our strengths are and to seek suggestions for how we can improve. This is a snapshot of the results.

### Recreation Program

#### Benefits

- » Builds parent relationships through networking
- » Positive anticipation
- » Chance to recharge
- » Family time to rebound
- » Develop new skills

#### Suggested improvements

- » More camps for younger children
- » More camps in regional areas
- » More opportunities for siblings
- » Greater variety in activities

### Performance and Education Program

#### Benefits

- » Helps reduce teasing /bullying
- » Promotes a greater understanding
- » Encourages respect /tolerance

#### Suggested improvements

- » Broaden scope to include more on the different stages of the journey
- » Link puppets to education resources

### Hospital Program

#### Benefits

- » Fun and laughter
- » Reduces stress and boredom
- » Helps children feel better and more connected

#### Suggested improvements

- » More frequent visits
- » Meet and greets in hospital
- » Assistance with going home from hospital

## To sum up

- » **Camp Quality is clearly providing valuable support**
- » **Support is contributing to a range of identified psychosocial and practical needs**
- » **There are some psychosocial needs of families that are not currently being met**
- » **Current programs could be adapted to meet unmet needs**
- » **Need to broaden support, increase access and improve equitable participation**
- » **New programs and services are needed**

More from our comprehensive research results, including where families currently find support, how families access our services and additional feedback from our volunteer companions can be found on our website at [campquality.org.au/familyresearch](http://campquality.org.au/familyresearch)

## Where do we go from here?

Whilst the results clearly demonstrate that our programs provide valuable support to children living with cancer, their siblings and parents, we have the opportunity to use these results to create new and improved services for families living with cancer in Australia.

Our dedicated team is busy reviewing and shaping our programs and services to meet the needs highlighted throughout the Family Research. By developing a long term strategy incorporating this feedback, we can make immediate and ongoing improvements to our programs and services. We look forward to sharing these exciting developments with you as they progress.

Thanks for reviewing this snapshot of the Family Research Results. We appreciate that you are taking the time to share this journey with us.

If you would like more details just log onto our website at [campquality.org.au/familyresearch](http://campquality.org.au/familyresearch)

Remember to stay tuned for more exciting updates.

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