

**University of Southampton Faculty of Medicine (Cancer  
Sciences: Child Health and Human Development)**

**Sailing as an intervention to enhance psychosocial wellbeing in  
children and young adults treated for cancer**

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## 1.0 Abstract

### **Background:**

The Ellen MacArthur Cancer Trust (EMCT) provides sailing trips for children and young people with cancer. No studies have evaluated the service as a possible intervention for enhancing psychosocial wellbeing.

### **Aim:**

To establish the extent to which the EMCT sailing experience has had a positive impact on participants' lives.

### **Methodology:**

A cross-sectional mixed method cohort self-report questionnaire design was used. Children and young people with various cancer diagnoses completed feedback questionnaires. Participants <18 years had a questionnaire completed by a parent or guardian. IBM SPSS version 21 was used to produce descriptive statistics from the quantitative data and to see if there were age group or gender related differences. Two analysts using thematic analysis investigated responses to the open-ended questions.

### **Results:**

121 participants <18 years (53% female) and their parents, and 52 participants aged >18 years (28% females) completed feedback questionnaires.

80 (68.4%) participants aged <18 years (56.3% female) and 39 (78.0%) participants >18 years (56.4% female) said the trip had a positive impact on their lives.

102 (86.4%) <18 years (54.9 % female) and 47 (92.2%) >18 years (57.4% female) gained confidence. 113 (95.8%) <18 years (55.8% female) and 21 (95.5%,) >18 years

(57.1% female) gained new friends. 114 (96.6%) <18 years (53.5% female), and 46 (92.0%) >18years (56.5% female) gained new skills. 110 (95.7%) parents said their child (53.6% female) had gained independence from the trip.

Thematic analysis of the qualitative data revealed social interaction was the most consistently mentioned theme by both age groups and genders. Other recurrent themes were personal growth, the environment, motivation, enhanced positive feelings and educational experiences.

### **Conclusion:**

Participants benefited from the sailing experience in many ways. A psychosocial model of sailing has been generated from the results. Overall the EMCT sailing experience provides a challenging environment, facilitates social interaction and educational experiences, which positively enhances personal growth, motivation, confidence and independence.

### **3.0 Acknowledgements**

I cannot thank Kim my supervisor enough for all her time, constant support, help and guidance, and for allowing me the incredible opportunity to do this project. She has gone unbelievably above and beyond a supervisor's duty by inspiring and motivating me to want to do more.

I would like to thank everyone at the Ellen MacArthur Cancer Trust for answering any questions and I had and for all the fantastic work they do.

Thank you to all the children and young people who answered the questionnaires with their vibrant charismatic responses.

## **4.0 My contribution to the project**

This is a new study conducted by Dr. Kim Bull (my supervisor) and myself.

This project was initially difficult to categorise into a particular study design due to the methodology and sample used. I therefore sought help from the University and they advised that it was a Category C project and therefore external ethics approval was not warranted.

I completed an IRGA form, an ethics form, a project proposal form, and attached copies of a blank example questionnaire and a letter of confirmation from the Trust. All of this was sent as part of an application form to ERGO; who approved my project and it allowing me to commence the analysis of the data.

Firstly I counted and coded 173 anonymised questionnaires with an identification number. Under the initial supervision of Dr. Bull I inputted all the different variables and responses into the statistical software package IBM SPSS 21.

Whilst doing this necessary task I simultaneously conducted a literature search to gain a wider breadth of knowledge around the subject I was investigating and wrote a literature review of which has since been acknowledged at a presentation in the National Brighton Paediatric Conference.

I then used the software to statistically analyse the data. Dr. Bull guided me in setting up a syntax file to run the different combinations of crosstabs to demonstrate the descriptive statistics I would use in the report.

My literature review highlighted a useful qualitative study by Kiernan et al 2005<sup>1</sup>; Dr. Bull discussed their methodology and we agreed to base our analysis of the qualitative data from the questionnaires on their methodology.

I transferred the qualitative data from the SPSS file to a Word Document and inserted them into separate tables for each question with each identification number corresponding the response given by that particular participant (see appendix, figure 5). This made the data easier to visualize as I independently looked for any emerging themes.

Regular meetings were set up with Dr. Bull to discuss the findings of our qualitative analysis to identify if we found the same themes. After mutually agreeing on named themes I independently coded the data under the agreed themes. Our second meeting was to see if we agreed and to calculate a reliability score. We then came to an agreement regarding any discrepancies and coded the data to the most suitable theme. I then counted the frequency of the different themes that emerged from the responses inputted them into tables.

It was very clear from the beginning that important themes and comments were emerging from the questionnaires and therefore ongoing critical discussion and teamwork was necessary with Dr. Bull to explore the importance of the findings. This project was a huge learning process, during which I learnt a great deal from the countless thoughtful discussions regarding young people with cancer with Dr. Bull. I then independently wrote my report.

The project has inspired me to volunteer in therapeutic recreation for which I am currently awaiting an interview after a successful application.

Word Count: 500

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## Background

Children and young adults (CYA) with cancer's psychosocial wellbeing may be adversely affected as a consequence of this life disturbing illness<sup>2 3</sup>. The difficult period of the transition from patient to survivor may pose issues of decreased liveliness, increased anxiety and decreased self-esteem<sup>3</sup>. The important phase of gaining independence, autonomy and self-confidence<sup>4</sup> may be hindered by their illness<sup>4 5</sup>.

In the United Kingdom, psychosocial interventions have been developed in an *ad hoc* way and many are out-dated having been established for many years, and may not represent existing survival and treatment patterns. This highlights the need to update and develop current interventions to address psychosocial needs<sup>7 4 8</sup>.

Sailing trips offered by the Ellen MacArthur Cancer Trust (EMCT) are a form of therapeutic recreation (TR) that has been offered since 2003 to young people who are recovering from cancer<sup>9</sup>. The Trust's aim is to "rebuild young people's confidence"<sup>9</sup>. No studies have evaluated this service the Trust offers and the potential benefits to these children.

It is imperative for the Trust to gain information on whether the services they provide benefit the participants in order to continually improve and adapt the trip accordingly to their needs. Clinicians involved in the care of CYA's with cancer should have valid and reliable information concerning the support and services available beyond the hospital environment, as a patient's physical and emotional journey is ongoing after discharge from inpatient care.

## **Methodology**

### **Aims**

Determine if the EMCT sailing experience has benefited the participants in any way.

The study will also explore the participant's negative aspect of the trip.

### **Design:**

A cross-sectional mixed method cohort self-report questionnaire design was used.

### **Context:**

The EMCT works with all young people Principal Treatment Centres in the UK. These centres are responsible for caring for 95% of young people with cancer in the UK. The young people are chosen to come on the trips by their consultant, social worker or youth worker.

In 2013, 6% of young people in recovery from cancer in the UK participated in the Trust's trips<sup>9</sup>.

The Trust aims to increase this to 14.2% by 2016<sup>9</sup> and thus emphasises the importance of feedback and exploration of the benefits gained by the experience, in enabling them to retain a high standard of service.

### **Materials:**

Questionnaires already designed by the EMCT and medical professionals were used.

See appendix, Figure 1 and 2. They were developed for feedback purposes including EMCT organisational factors.

These questionnaires were not designed to psychometrically analyse the benefits gained from the experience.

See Figure 1 below demonstrating the question used in the analysis.

**Figure.1 List of the quantitative and qualitative questions used for analysis from the questionnaires**

**1. Benefits from the trip:**

- a) a) Did the trip have a positive impact on the participant's lives?

If coming on a Trust trip had a positive impact on your life since returning home (such as at school; with friends; and social life)? Explain how/why.

- b) Do you think you/ your child gained confidence, new friends, new skills and independence?

Details of benefiting in confidence; new skills; new friends; and independence: participants and parental response.

**2. Socialising with others who have had cancer:**

- a) Have you ever had any opportunities to socialise and interact with others who have had cancer?

Did you feel more at ease on your trip knowing that everyone else had experienced a similar illness, and why?

**3. Additional trips:**

- a): Do you believe that your child has benefited from additional trips with the Trust?

Expand on answers. Parental response.

- b) Why did you return to sail with the trip?

c) If someone asked you if they should come on a Trust trip what would you tell them, and why?

**4. Enjoyment:**

a) Did you/your children enjoy the trip?

What was the most enjoyable part of the trip?

**5. Negative parts of the trip:**

a) What was the least enjoyable part of the trip?

b) Did you/ they find anything Difficult o the trip? If so, what?

**Participants:**

All CYAs from 8 to 24 years of age who participated in the EMCT sailing trips and completed a questionnaire in the summer of 2013 (see appendix, Figure 3, for the different trips on offer). Children <18 years also had a questionnaire completed by a parent.

**Methods:**

Questionnaires were handed out to the participants on the last day and they posted them to the Trust after completion.

The Trust paired the parent and <18 questionnaires together and anonymised them by removing the surnames.

The questionnaires were all coded with identification numbers; all the data was gathered and transferred onto IBM SPSS version 21 to produce descriptive statistics from the raw quantitative questionnaire data, to see if there were age group or gender related differences between responses.

The qualitative data was transferred from SPSS into tables formed on Microsoft Word. (See example in appendix, Figure 4).

The qualitative data was subjected to thematic analysis based on and adapted from the methodology described in the study by Kiernan et al 2005<sup>1</sup>.

Stage 1:

Two analysts independently reviewed the responses and identified any themes emerging from the data. This required several evaluations.

Stage 2:

Analysts met and revealed which themes they thought had emerged to discover if they had come up with the same themes.

They discussed the themes and gave examples of the responses they thought would define the theme. The consensus list of theme headings was broad enough to enable sufficient analysis of the responses to each question; the name and number of theme headings was agreed upon.

Stage 3:

Analysts independently used the agreed list of theme headings and a definition list as a coding frame to determine the incidence of theme within the participant's responses.

Table 1 provides a breakdown of the interrater reliability for each theme that emerged.

Stage 4:

The second meeting was to calculate the interrater percentage of agreement.

Agreement rate of 75%<sup><</sup> was established as reliable, overall interrater reliability was 82.5%<sup>10</sup>. See Table 1 for breakdown of the percentage reliability for each theme.

**Table 1. Interrater reliability percentage: for each theme that emerged from the responses, for every question used in the report.**

<b>Theme</b>	<b>Reliability (%)</b>
Gratitude	97.8
Social	71.7
Education	82.7
Confidence	90.6
Motivation	87.5
Environment	75.2
Personal growth	69.4
Enhanced positive feelings	77.2
Independence	98.1
None	92.3
Sickness	100
Activities	86.4
Emotions	87.6
Leaving	78.3
Routines	89.3
Personal limitations	88.9
Facilitated communication	92.6
Not needing to talk about cancer	90.0
Feelings of being normal	100.0

Shared understanding	89.2
No one judges	100.0
Contrast with peers	100.0
Feeling at ease	90.0
Less isolated	100.0
No impact	100.0
<b>Total</b>	<b>82.5</b>

Note: The first analysis was conducted on the question involving the participant's most enjoyable part of the trip. The reliability scores for the themes that emerged from this question have not been included within the total reliability scores.

Stage 5:

Any discrepancies led to redefining the themes and reaching a consensus about the classification of themes.

Stage 6:

Frequency of theme occurrence within age categories and gender was calculated.

## 6.0 Results

121 participants <18 years (53% female) and their parents, and 52 participants aged >18 years (28% females) completed the questionnaires.

Many of the reoccurring themes emerged for each question; see below Table 2 for the list of the themes, definitions and examples. Only the themes that were mentioned by >10 participants or parents are discussed in the results section; unclassified comments are not discussed. Direct quotations include some spelling mistakes written by the participants.

**Table 2. Table containing the list of all the themes that emerged throughout the questionnaire with their definitions and examples how they apply to the sailing trips.**

Theme	Definition	Example
Leisure Activities	<ul style="list-style-type: none"> <li>Any mention of activity offered</li> <li>Consequence of an activity</li> </ul>	<ul style="list-style-type: none"> <li>Sailing</li> <li>Barbecue</li> <li>Playing games</li> <li>Eating</li> <li>Getting wet</li> </ul>
Environment	<ul style="list-style-type: none"> <li>Wider extraneous/natural environment</li> </ul>	<ul style="list-style-type: none"> <li>Places mentioned</li> <li>Weather</li> </ul>

	<ul style="list-style-type: none"> <li>• Environment that is provided by the trust</li> <li>• Atmosphere created</li> <li>• Different types of boat</li> <li>• Different types of trips</li> <li>• Organisational aspects</li> <li>• Requirements of the environment</li> <li>• Consequence of the environment</li> <li>• Explanations and information given to participants</li> </ul>	<ul style="list-style-type: none"> <li>• Being on the boat</li> <li>• Atmosphere created</li> <li>• Wildlife</li> <li>• Places of which activities take place.</li> <li>• Volunteers</li> <li>• Facilities and staff</li> <li>• Ellen Macarthur</li> <li>• The Trust</li> <li>• Friendly, and welcoming</li> <li>• Pekoes</li> <li>• Yachts</li> <li>• Group size</li> <li>• Food offered</li> <li>• Journey</li> <li>• Length of stay:</li> </ul>
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		<p>wanting it longer</p> <ul style="list-style-type: none"> <li>• Living/sleeping arrangements</li> <li>• Moving/ walking around the boat and to the showers</li> <li>• Movement of boat</li> <li>• Boat tipping.</li> </ul>
Social	<ul style="list-style-type: none"> <li>• Communicating,</li> <li>• Meeting people</li> <li>• Relating to others with same condition</li> <li>• Social skills</li> <li>• Enjoying company of staff and volunteers</li> <li>• Feeling less isolated</li> </ul>	<ul style="list-style-type: none"> <li>• Friends</li> <li>• Volunteers</li> <li>• Talking wildly</li> <li>• Being part of a special group/ team</li> <li>• Joining in</li> <li>• Interaction</li> </ul>

<p>Enhanced positive emotions</p>	<ul style="list-style-type: none"> <li>• Conveyance of positive emotions</li> <li>• Sense of fun, excitement, laughing, joking</li> <li>• Uplifting expressions with <b>emphasis</b> to emphasise positivity after: fantastic, awesome, legendary, invigorating</li> <li>• Details on why it is amazing</li> <li>• Positive reactions to the experience</li> <li>• Positive boost to mood</li> </ul>	<ul style="list-style-type: none"> <li>• Excitement</li> <li>• Laughing</li> <li>• Joking</li> <li>• Exclamation marks, capital letters</li> <li>• Best trip ever, highlight of my summer, time of my life.</li> <li>• Happiness (doesn't include general comments about enjoyment)</li> <li>• Loved and great not included (general positive statements without exclamation marks or detail)</li> </ul>
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Personal Growth	<ul style="list-style-type: none"> <li>• Being given responsibilities and feeling helpful</li> <li>• Feelings of self-worth</li> <li>• Being in control</li> <li>• Self-achievement</li> <li>• Challenging factors</li> <li>• Wonderful memories of positive experience (as opposed to treatment related memories)</li> <li>• Personal development</li> <li>• Physical development</li> <li>• Overcoming fears/anxieties,</li> </ul>	<ul style="list-style-type: none"> <li>• Turning wheel</li> <li>• Being allowed to do things</li> <li>• Importance</li> <li>• Completing a challenge</li> <li>• Being successful at something</li> <li>• Without the fear of being judged</li> <li>• Having a break from the routine</li> <li>• Not worried about what others think</li> <li>• Live every day to the fullest</li> <li>• Appreciation of other people's 'journeys'</li> </ul>
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	<ul style="list-style-type: none"><li>• Learning to put things into perspective</li><li>• Being able to relax</li><li>• Sense of freedom</li><li>• Maturity</li><li>• Feelings of being normal/ less different,</li><li>• Belief in/new awareness of ones abilities</li><li>• Change in perspective</li><li>• Change in self-perception</li><li>• Life changing experience</li><li>• Increased self esteem</li><li>• More positive</li></ul>	
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	<p>outlook on life</p> <ul style="list-style-type: none"> <li>• Maturity</li> <li>• Feeling privileged</li> </ul>	
Educational experiences	<ul style="list-style-type: none"> <li>• Doing something for the first time</li> <li>• Something new or rarely available,</li> <li>• Experience out of the ordinary/ unique</li> <li>• Opportunities of a lifetime</li> <li>• Experiences gained</li> </ul>	<ul style="list-style-type: none"> <li>• First time sailing</li> <li>• Learning something new</li> </ul>
Confidence	<ul style="list-style-type: none"> <li>• Any mention including pre-trip confidence</li> <li>• No change in confidence</li> <li>• Self- assurance</li> </ul>	<ul style="list-style-type: none"> <li>• Increased confidence</li> <li>• Self-confident</li> </ul>

Independence	<ul style="list-style-type: none"> <li>• Being away from home</li> <li>• Doing things without parents</li> <li>• Being on their own</li> <li>• Doing things for themselves</li> </ul>	<ul style="list-style-type: none"> <li>• Taking medications by themselves</li> </ul>
Motivation	<ul style="list-style-type: none"> <li>• Incentive to do and try new things</li> <li>• Taking up new interests</li> <li>• Sparking new interest</li> <li>• New motivation to do something they were previously reluctant to do</li> <li>• Encourage enthusiasm,</li> </ul>	<ul style="list-style-type: none"> <li>• Finding a passion</li> </ul>

	<ul style="list-style-type: none"> <li>• Looking forward to something</li> <li>• Having more energy to do things</li> <li>• Do more things</li> </ul>	
Routines	<ul style="list-style-type: none"> <li>• Getting up early</li> <li>• Chores</li> <li>• Cooking and cleaning</li> </ul>	<ul style="list-style-type: none"> <li>• Getting up at 4am</li> </ul>
None/ no issues	<ul style="list-style-type: none"> <li>• Doesn't include positive statements</li> <li>• References to none</li> <li>• Clear expression of no</li> <li>• Clear indication that nothing was a miss</li> </ul>	<ul style="list-style-type: none"> <li>• Doesn't include non-specific answers</li> <li>• Didn't struggle with much</li> </ul>
Unclassifiable	<ul style="list-style-type: none"> <li>• Pre-trip statement of child unless giving more information</li> </ul>	<ul style="list-style-type: none"> <li>• Didn't want to go home</li> </ul>

	<p>whether they have improved or not.</p> <ul style="list-style-type: none"> <li>• Don't include any positive comments</li> <li>• General positive comments that lack details it, great time</li> <li>• General statements unrelated to the child</li> </ul>	<ul style="list-style-type: none"> <li>• Benefited from the whole experience, "child" has had a fabulous time and is full of it</li> <li>• Loved it</li> <li>• Great time</li> </ul>
Gratitude	<ul style="list-style-type: none"> <li>• Direct message to the trust,</li> <li>• Praising</li> <li>• Clear expressions of thank you</li> <li>• Appreciation</li> </ul>	<ul style="list-style-type: none"> <li>• You are great</li> <li>• Keep up the good work</li> </ul>
Personal limitations	<ul style="list-style-type: none"> <li>• Due to illness</li> </ul>	<ul style="list-style-type: none"> <li>• Pain</li> </ul>

## 6.1 Benefits from the trip

### a) Did the trip have a positive impact on the participant's lives?

119 (68.7%) of the participants <18 years (56.3% female) and 39 (78.0%) of the participants >18 years (56.4% female) said the trip had a positive impact on their lives. 29 (24.8%) of participants <18 years (44.8% female) and 11 (22.0%) > 18 years (45.5% female) were not sure.

8 (6.8%) of participants <18 years (6.8%) and no participants >18 years said it had no positive impact on their lives.

**If coming on a Trust trip had a positive impact on your life since returning home (such as at school; with friends; and social life)? Explain how/why.**

86 (49.7.%) of the participants responded to this question. Parents were not asked this question. See Table 3 for the frequency of emerging themes.

**Table 3. Number of participants who mentioned each theme in response to the question: If coming on a Trust trip had a positive impact on your life since returning home such as at school, with friends and social life explain how/why?**

Theme	<18s (n=42)		>18s (n=44)	
	Male (n=21)	Female (n=21)	Male (n=20)	Female (n= 24)
Social (%)	7(33.3)	6(28.6)	10(50.0)	5(20.8)
Confidence (%)	4(19.0)	5(23.8)	5(25.0)	7(29.2)

Personal growth (%)	4(19.0)	5(23.8)	4(20.0)	6(25.0)
Motivation (%)	0(0)	5(23.8)	4(20.0)	7(29.2)

**n= total number of participants who completed the question**

The social aspect of the trip was mentioned the most, and adult males appear to benefit the most from this aspect. The responses varied, some explained the positive impact had increased their communication with friends and social skills when they returned home.

*"...I think the trip has helped me to become a bit more outgoing..."* (162, adult female)

*"I now also find it easier to talk to my friends about my experience."* (25, male child)

Being able to relate with others and express themselves more openly with those who have had cancer in comparison to their peers at home were added reasons.

*"I have never talked to my friends who haven't experienced cancer so much about it and I have known them for years, but the new friends that I made, I had known them for less than a day and I could really open up about my cancer"* (39, female child).

Increased confidence was mentioned by both age categories and gender.

*“The confidence I gain from trust trips impacts every part of my life” (128, female child)*

*“I feel more confident when I go to my secondary school” (36, female child).*

Comments regarding personal growth encompassed important concepts of increased self-awareness of capabilities, reflecting on experiences, making memories, challenging oneself and feeling braver.

*“...made me realise how much physical activity I am capable of if I push myself just a bit more...” (51, male child)*

*“Its made me realise I can try new things and still manage to achieve them regardless of what I have been through” (123, adult female)*

*“I feel braver and I took my mind off leaving school...” (20, male child)*

*“Made me realise that though have got an illness I still can do stuff the way other people can. ie. Work, college eat” (169 adult female)*

One participant reported a change in perspective towards her illness after returning home from the trip, this benefited herself, family and friends.

*“Makes me appreciate life general more and gives me a more positive aditude to my illness therefore making my friends + family happier ”. (42, female child).*

A sense of relaxation and freedom was mentioned in conjunction with the environment.

*“Being outdoors for so long has made me feel so calm. The sea is so big and I feel v. open and free. We had so much choice with what we wanted to do on board and that made me feel very relaxed..”* (37, female child)

Feelings of self-worth and importance were noted as a positive impact from the trip.

*“...Feel good about myself, most of my friends can not sail.”* (7, male child).

*“I feel as though I am important...”* (15, female child)

One participant discussed her anxiety before she came on the trip; she later explained how the trip had helped her put things into perspective after seeing others going through the same thing.

*“Before the trip I suffered a period of severe anxiety and the trip allowed me to see others in a same or worse condition which helped me”.* (4, female child)

The participants who mentioned motivation discuss the incentive to try new things, determination and becoming more adventurous.

*“I feel motivated to do more in life (university and fitness)”* (135, female adult).

*“I am more determined to succeed in work”,* (168, male adult).

The participants who did not believe it had impacted them positively mentioned it was too soon after the trip to report enhancements.

“...*too early to know...*”. (163, female adult)

## **b) Gaining in confidence, new friends, new skills and independence**

### **Confidence**

102 (86.4%) of participants <18 years (54.9% female) and 47 (92.2%) >18 years (57.4% female) reported gaining confidence.

112 parents (97.4%) said their child (52.7 parents of females) had gained confidence.

2 parents of males (1.7%) said they were unsure.

1 parent of a female (9%) said they had not benefited by gaining in confidence.

### **New friends**

113 (95.8%) of participants <18 years (55.8% female) and 21 (95.5%) >18 years (57.1% female) said yes to benefiting by gaining new friends.

111 parents said their child (53.2% female) had benefited by gaining new friends.

### **New skills**

114 (96.6%) participants < 18 years (53.5% female), and 46 (92.0%) > 18 years (56.5% female) said they had gained new skills.

114 parents (99.1%) said their child had gained new skills (52.6% parents of females) whilst the remaining 1 parent of a male reported ‘not sure’.

**Independence**

110 (95.7%) parents said their child (53.6% parents of females) had gained independence.

3 parents of males (2.6%) reported 'not sure' to increased independence.

1 parent of a female (0.9%) said they had not gained any independence.

**Qualitative part of the questions on confidence, new friends, new skills and independence**

**Table 4. Number of participants who mentioned each theme in response to the question: Details of benefiting in confidence, new skills, new friends and independence.**

Theme	Parent-report under 18s (n=104)		Child-report under 18s (n=113)		Over 18s (n=46)	
	Male (n= 49)	Female (n= 55)	Male (n=51)	Female (n= 62)	Male (n=21)	Female (n= 25)
Social (%)	22(44.9)	33(60.0)	39 (76.5)	51 (82.3)	19(90.5)	21(84.0)
Education (%)	6(12.2)	13(23.6)	39(76.5)	49 (79.0)	10(47.6)	13(52.0)
Confidence (%)	21(42.9)	15(27.2)	30(58.8)	36 (58.1)	8(38.1)	15(6.0)
Personal Growth (%)	12(24.5)	5(9.1)	9 (17.6)	13 (21.0)	2(9.5)	7 (28.0)
Motivation (%)	6(12.2)	11(20.0)	3(5.9)	7(11.3)	4(19.0)	2(8.0)
Independence (%)	12(24.5)	14 (25.5)	0(0)	0(0)	0(0)	0(0)
Enhanced positive feelings (%)	7(14.3)	12(21.8)	0(0)	0(0)	0(0)	0(0)

**n= total number of participants who responded to the question**

Below the answers to the likert scale questions, participants were provided the opportunity to expand on these answers.

159 (91.9%) of the participants and 104 (85%) of the parents responded to the question.

Table 4 demonstrates the themes that emerged from the responses.

The most common themes were social benefits; which included meeting and gaining friends, improvements in social skills and working as part of a team.

*"...making new friends- everyone was so kind. Something more powerful than our illness brought us together and I am very happy to have met such kind and fun people". (37, female child)*

*"...When I first met everyone I didn't talk but by the end I didn't stop..." (28, female child)*

*"...I would never normally talk to new people especially adults..." (94, female child)*

The importance of being with others who have also experienced cancer and feeling part of a unique group spontaneously arose from the open question.

*"...I am intrigued to meet other people like me who have had cancer- it's a unique club to be apart of..." (151, female adult)*

Educational benefits included learning new skills, transferrable skills such as tying knots; others mentioned this was their first experience of sailing.

*"I had never been sailing before and I wasn't sure I could but the trip changed this I learnt lots of new skills from tying knots to steering the ship". (162, female adult)*

Only the parents mentioned benefiting in independence and enhanced personal feelings. Comments included being happy away from home and family and doing things on their own such as taking medication.

*“Time away from family has had a positive impact on “child”; she hasn’t had us watching every move...”* (94, parent of a female child)

*“It has enriched “child’s” life experience and help to make her an independent, confident young woman”.* (64, parent of female child)

Parents and participants believed there was an enhancement in self-confidence.

*“child” was very nervous about going on the trip especially reaction to her scars. Everyone was so unfussed by physical appearances that she gained a huge amount of self confidence”.* (49, female child)

*“Confidence: Realise why should I hide”* (67, female child)

One participant mentioned a negative experience with a volunteer, which affected negatively on her confidence.

*“...confidence was up and down due to some volunteers actions”.* (164, adult female)

Participants noted they had benefited through a new awareness of one’s abilities as well as a change in self-perception.

*"...this trip has made me realise that I'm capable of much more than I give myself credit for"* (156, female adult).

*"I was surprised at how many activities I was able to do..."* (51, male child)

*"...he knows if he puts his mind to it he can do anything"* (25, Parent of male child).

In line with this new change in self-perception are feelings of self-assurance and self-belief.

*"I have come back feeling alot better in myself. I have now learnt to just be yourself and live every moment you have..."* (33, female child)

Attending the trip gave the participants a sense of normality and not feeling different.

*"It made me feel that I could be who I am, as it showed me I wasn't different..."* (34, female child)

Participants noted a positive change in perspective on their illness and their life.

*"It also reminded me to make the best of everything..."* (88, female child)

*"...it almost makes the unpleasantness and disruption of being unwell, dare I say, worth it."* (151, adult female)

The trip gave opportunities for the participants to challenge themselves and gain feelings of self-accomplishment.

*“This was the first time in 4 years I could fully participate and the first opportunity in a long time I could test my strength...” (173, adult female)*

Enhanced personal feelings included feeling positive and happy, which their parents noted on their return home.

*“She came back in a far more positive mood”.* (87, parent of a female child)

## **6.2 Socialising**

### **a) Opportunities to socialise and interact with others who have had cancer.**

36 (65.5%) of participants < 18 (58.3% female) and 16 (80%) of participants >18 (50.0% female) had previous opportunities to socialise with others who have had cancer before the trip, whilst the rest had never had this opportunity.

### **b) Being at ease with others who have also had cancer.**

85(49.1%) of participants responded to this open-ended question.

See Table 5 for list of themes that emerged for this question only as it explored the social theme in further depth.

See Table 6 for list of themes and frequencies mentioned.

**Table 5. Table of themes with their definitions and examples**

Theme	Definition	Example
Feeling less isolated	<ul style="list-style-type: none"> <li>• Not feeling alone</li> </ul>	<ul style="list-style-type: none"> <li>• Being with others</li> </ul>
Enhanced communication	<ul style="list-style-type: none"> <li>• Talking about treatments, illness and medication</li> <li>• Feelings of being able to talk and ask questions</li> </ul>	
Not needing to talk about the cancer	<ul style="list-style-type: none"> <li>• Opportunity to forget about the cancer</li> <li>• No need to explain</li> </ul>	
Shared understanding	<ul style="list-style-type: none"> <li>• Having something in common</li> <li>• Understanding each other</li> </ul>	
Feeling at ease with others	<ul style="list-style-type: none"> <li>• Feeling more open</li> </ul>	

Contrast with peers	<ul style="list-style-type: none"><li>• Do things that they couldn't do with friends at home</li></ul>	
Feeling normal/ less different	<ul style="list-style-type: none"><li>• Not being treated differently</li><li>• Not feeling the odd one out</li></ul>	
No impact	<ul style="list-style-type: none"><li>• Made no difference</li></ul>	
Not being judged	<ul style="list-style-type: none"><li>• Judging physical appearances</li><li>• Not caring what people think</li></ul>	

**Table 6. Number of participants who mentioned each theme in response to the question:****Being at ease with others who have also had cancer.**

Theme	Child-report under 18s (n=54)		Over 18s (n=17)	
	Male (n=25)	Female (n= 29)	Male (n=8)	Female (n= 9)
Shared understanding (%)	12(48.0)	11(37.9)	4(50.0)	7(77.8)
Facilitating communication (%)	9(36.0)	9(31.0)	4(50.0)	4(44.4)
Not needing to talk about cancer (%)	5(20.0)	3(10.3)	0(0)	2(22.2)
Feeling at ease (%)	3(12.0)	4(13.8)	1(12.5)	2(22.2)

n= total number of participants who responded to the question

Having a shared understanding was mentioned the most; having something in common and something to relate to were reasons for feeling at ease around others.

*"...Everyone is a lot more understanding about you having to rest or take medication etc..."* (16, female child)

*"Yes, because we all know what each other has gone through and understand each other."* (168, adult male)

Participants noted increased socialising amongst each other as it allowed them to talk about medications, treatments as well as feeling more open, comfortable and not secretive about health issues.

*"...was great to discuss with others about their experience..."* (21, male child)

*"Yes because I didn't feel I had to hide my illness and medication around others"* (2, female child)

In contrast to this some mentioned that it provided a social environment in which they felt they did not need to speak about cancer, this was also positive.

*"We did not really mention it we just had a good time and forgot all about why we where there it was like a holiday."* (52, female child)

### 6.3 Additional trips

#### a) Benefiting from additional trips

61 (98.4%) of parents (51.6% with daughters) agreed their child had benefited from an additional trip, whilst the remaining 1.6% said they were 'not sure'.

#### How did they benefit from the additional trips?

53 (43.8%) of parents responded to the question.

Table 7 displays the emerging themes from the responses.

**Table 7. Number of the children's parents who mentioned each theme in response to the question: How they benefited from additional trips.**

Theme	Parent-report under 18s (n=53)	
	Male (n=25)	Female (n= 28)
Social (%)	7(28.0)	8(28.6)
Motivation (%)	8(32.0)	6(21.4)
Confidence (%)	5(20.0)	5(17.9)

n= total number of participants

Parents note the social environment of the additional trips allow on-going friendships to develop further as well as additional opportunities to be around others in the similar situation.

*“Although being around others who've had or still have similar serious illnesses means they can speak to each other about it, I also believe they can ignore it, to certain extent as no-one is centre focus which can be the case at home.”* (94, parent of female)

Parents mention their child has benefited by gaining motivation as they have something to look forward to after they receive an invitation from the Trust, as well as sparking a new interest.

*“Each year "child" looks forward to this trip more than anything else he does”* (118, Parents of a male child)

*“These trips have given "child" a real interest in watersports and she will be joining a sailing club on a saturday morning.”* (73, parent of a female child)

Parents also noted the further increase in confidence that their children gain from an additional trip.

*“Her progress in coping is wonderful for her confidence- to see how much better she is this year than last yr...”* (72, parent of a female child)

### **b) Why did you return to sail with the trip?**

93 (53.8%) of participants responded to this question.

**Table 8. Number of participants who mentioned each theme in response to the question: Why they return to sail with the Trust?**

Theme	Child-report under 18s (n=121)		Over 18s (n=52)	
	Male (n=29)	Female (n= 33)	Male (n=14)	Female (n= 17)
Social (%)	8 (27.6)	17(51.5)	8(57.1)	6(35.3)
Enhanced positive feelings (%)	10(34.5)	14(42.4)	2(14.3)	0(0)
Education (%)	6(20.7)	8(24.2)	1(7.1)	2(11.8)
Activities (%)	6(20.7)	4(12.1)	3(21.4)	4(23.5)

n= total number of participants

Table 8 demonstrates the emerging themes and frequencies.

The social aspect of the trip was the most common reason for returning. Meeting up with old friends, being around people who understand and having the opportunity to socialise with different people were embedded within the responses.

*“I love returning to see old friends and really enjoy being around people who have had similar experiences to me.” (108, male child)*

Other reasons were because the trip was fun the first time round, which was themed under the heading: enhanced positive emotions.

*“Because it was awesome the first time round and a lot of fun.”* (59, male child)

Participants mentioned they enjoyed the activities and sailing in the previous trips and therefore wanted to return.

*“I have really enjoyed the opportunity to sail”* (110, male child).

The educational aspect of the trips allowed participants to learn new things in previous trips and this provided them with the motivation to want to gain more experience and learn more.

*“Any experience I can get can add value.”* (121, male child)

**c) If someone asked you if they should come on a Trust trip what would you tell them, and why?**

168 (97.1%) of participants responded to question.

Every participant would have recommended the trip to a friend from the responses.

Table 9 demonstrates the emerging themes.

**Table 9. Number of participants who mentioned each theme in response to the question: If someone asked you if they should come on a Trust trip what would you tell them, and why?**

Theme	Child-report under 18s (n=117)		Over 18s (n=51)	
	Male (n=55)	Female (n=62)	Male (n=24)	Female (n= 27)
Social (%)	18(32.7)	33(53.2)	3(12.5)	8(29.6)
Enhanced Positive Feelings (%)	26(47.2)	31(50.0)	8(33.3)	7(25.9)
Education (%)	10(18.2)	19(30.6)	4(6.6)	7(25.9)
Personal Growth (%)	6(10.9)	11(17.7)	5(20.8)	7(25.9)
Environment (%)	4(7.3)	10(16.1)	5(2.1)	7(25.9)
Confidence (%)	5(9.1)	7(11.3)	1(4.1)	2(3.8)
Activities (%)	4(7.3)	5(8.1)	3(12.5)	7(3.7)

n= total number of participants that responded to this question

Enhanced positive feelings were the most common reason to recommend to a friend. Participants particularly noted the element of fun the trip brought to them as well as emphasising how good the trip was by using strong emotive words. Many compared it to no other experience they have ever had before in their life.

*“Yes, it will be one of the most enjoyable experiences of your life.”* (118, male child)

*“...recommend to anyone willing to throw themselves into an extremely fun week.”* (171, female adult)

Participants would tell a friend that it is a great way of meeting people, and that these people on the trip are understanding of their situations. The trip also allows for close friendships to form.

*“... all the things about treatment that no one at home gets, everyone gets here, so you can be completely yourself and make friends who really understand”* (70, female child)

*“It's good to be around people that understand what you've been through...”* (158 female male)

The trip has valuable educational experiences, out of the ordinary learning experience, and allows the participants to practice new sailing skills.

*“...try loads of new activities you may never get the chance to do again”* (74, female child)

*"...you learn so many new skills"* (45, female child)

Personal growth reasons were recommended; they would tell a friend that the experience is life changing, a good escape from daily life and worries as well as changing the participant's perspective on life.

*"...get away from day to day life..."* (58, male child)

*"...and escape from everything back home..."* (41, female child)

*"You will come back with a new outlook on life"* (67 female child)

One participant's reason for recommending the trip was it allowed for time to reflect and learn more about themselves.

*"...You also learn a bit more about yourself..."* (163, adult female)

Acquiring worthy feelings of self-achievement, privilege and creating pleasant memories were important reasons from participants.

*"... you will come away feeling like you have achieved so much..."* (123, adult female)

*"...you get so many good memories..."* (70, female child)

Participants mentioned they would have recommended the trip due to the increased confidence gained from the trip.

*"...you will come away feeling confident..."* (122, adult female)

Comments about the environment included positive comments about the helpful and experienced staff, the weather, the sleeping arrangements, having plenty to do, and having the opportunity to meet Ellen MacArthur.

*"The staff also make it really flexible and make sure everyone is included..."* (145, adult female)

*"meeting ellen because she is such an inspirational woman"* (73, female child)

Not everyone noted a positive experience; there was one negative comment by a female participant who expressed her strong opinions against having physical limitations, showing that not everyone's experience with this factor was a positive one.

*"I would advise them if they were weak or not into activities not to come along as can spoil it for others."* (adult female)

The fact that the trip offered a range of activities and that these included not so common activities such as knot tying, sailing, and high ropes were mentioned as reasons for participants to recommend to their friends.

*"A real mix of activities..."* (144 male, over 18)

## 6.4 Enjoyment

### How much did they enjoy the trip?

116 (99.1%) of participants < 18 years (54.3% female) and 52 (100%) of > 18 years said they enjoyed the trip.

One female participant under the age of 18 (0.9%) rated the satisfactory response "it was ok".

98 (86.0%) of parents said their child (57.1 female) loved the trip the highest rating, 16 (14%) said they really enjoyed it (25% females): the second highest rating.

Children who completed the feedback forms that included the question: did you enjoy the sailing: 7 (100%) of the participants (28.6% female) said yes.

### What was you most enjoyable part of the trip?

113 (93.3%) of the participant's parents, 173 (100%) of the participants responded to this question.

See Table 10 for the most common emerging themes.

**Table 10. Number of participants who mentioned each theme in response to the question:****What was you most enjoyable part of the trip?**

Theme	Parent-report under 18s (n=113)		Child-report under 18s (n=117)		Over 18s (n=52)	
	Male (n=54)	Female (n=59)	Male (n=53)	Female (n= 64)	Male (n= 24)	Female (n= 28)
Leisure Activities (%)	31(57.4)	32(54.2)	34(64.2)	46 (71.9)	21(87.5)	21(75.0)
Social (%)	21(38.9)	30 (50.8)	15(28.3)	22(34.4)	13(54.1)	17(60.1)
Enhanced Positive feelings (%)	7(13.0)	8(13.6)	17(32.1)	15(23.4)	4(16.7)	14(50.0)
Environment (%)	12(22.2)	11(18.6)	8(15.1)	13(20.3)	3(12.5)	4(14.3)
Learning (%)	5(9.3)	8(13.6)	4(7.5)	15(23.4)	2 (8.3)	5(17.9)

The leisure activities on offer were stated the most enjoyable part which ranged from the water activities: kayaking, crabbing and sailing, to the on land activities: such as high ropes, archery and games.

*“Everything! She loved the different activities, games at the centre, free time, climbing, windsurfing.”* (69, parent of female child)

The social part of the trip was frequently mentioned; meeting new friends and working as part of a team and being with others who have had cancer was enjoyable.

*“Meeting new people and making new friends because it's nice to make some new friends, especially with people who can understand, to some degree what you've been through.”* (117, male child)

Strong positive feelings were created from the sense of fun, joking and laughing they had experienced.

*“Meeting old friends and making some new ones as it allowed me to have loads of fun, talk loads and make friends hopefully for life.”* (88, female child)

*“All of it because it was fun.”* (46, male child)

Freedom from daily routines and being relaxed due to the tranquil social environment were enjoyable factors.

*“Meeting new people because when you are at home you are surrounded by people that have no idea what you have been through so coming on the trip you can really relax ...”*  
(117, male child)

Feelings of self-achievement were an enjoyable aspect as the trip offered opportunities to conquer challenges and overcome fears as well as being given responsibilities.

*“...because I did something I thought I couldn't do since my brain tumour...”*(72, female child)

*“It felt good to be in control of the boat...”* (50, male child)

One parent noted that one of their child enjoyed feeling equal to others.

*“...Its one of a few times in the year he feels an equal and not different...”* (117, parent of male child)

The environmental aspect of the trip which included the Trust and it's organisation, being at sea, the places visited, views, weather, wildlife and the presence of Ellen MacArthur were all mentioned as most enjoyable things.

*“Sailing back from the barbeque at Newtown Creek to Cowes at sunset...”* (4, female child)

*“Child” has gone about Mill point and how lovely it was...”* (27, parent of a female child)

## **5. Negative aspects of the trip**

### **a) Least enjoyable aspect of the trip**

110 (90.9%) parents and 159 (91.9%) of the participants responded to the question.

See table 11 for the most common themes that emerged.

**Table. 11 Number of participants who mentioned each theme in response to the question: What was the least enjoyable part of the trip?**

Theme	Parent-report under 18s (n=110)		Child-report under 18s (n=111)		Over 18s (n=48)	
	Male (n= 52)	Female (n= 58)	Male (n=52)	Female (n= 59)	Male (n=22)	Female (n= 26)
None	17(32.7)	18(31.0)	11(21.2)	9(15.2)	8(36.4)	4(15.4)
Environment	13(25.0)	14(24.1)	18(34.6)	26(44.1)	5(22.7)	12(46.2)
Leisure activities	4(7.7)	5(8.6)	10(19.2)	9(15.2)	2(9.1)	5(19.2)
Social	1(1.9)	7(12.1)	2(3.8)	7(11.9)	3(13.6)	1(3.8)
Leaving	14(26.9)	17(29.3)	5(9.6)	6(10.2)	0(0)	1(3.8)
Routine	1(1.9)	6(10.3)	4(7.7)	9(15.3)	1(4.5)	2(7.7)
Being sick	5(9.6)	1(1.7)	5(9.6)	6(10.2)	0(0)	0(0)

n= total number of participants

Although the question directly asks for the least enjoyable parts, some participants have spontaneously mentioned positive and general comments about the trip.

The most frequent response was “none” least enjoyable things, these included responses which explained they felt there was no unpleasant experiences during the trip.

*"child" made no mention of least enjoyable things at all!"* (89, parent of female child)

The environment was frequently mentioned and included negative comments about the toilets, small living space, sleeping arrangements, food, the weather and getting wet.

*"Having to put on already wet wet suits because they were cold and uncomfortable. Also, some people should have been encouraged to join in activities as they were unsure"* (74, female child)

Some of the leisure activities that were being offered were the least enjoyable parts due to various personal reasons including uninterested and too difficult.

*"Kanoing, because I got bored/ tired quickly, too long of an activity"* (141, adult male)

Although some games and activities were noted as needing improvement, they still provided an element of fun to the participants.

*"The operation mosquito was really fun but think it can be improved slightly. Also the quiz was good fun but slightly too long"* (122, adult female)

Leaving and being sick were themes that had not been mentioned in the questions above and were unique to the negative aspects of the trip.

*“Going home because the trip was too good and it was sad saying goodbye to my friends...”* (104, male child)

*“feeling sick on the boat”* (57, male child)

Some found the socialising unpleasant due to falling out with friends, saying goodbye to friends and having little opportunity to mix with other groups.

*“When everyone cheated at UNO and when I had a fallout with my best friend ‘child’ ”.*  
(50, male child)

Routines and chores involving waking up early, curfews and washing up were also mentioned. However, one participant mentioned they would have liked to take part in more routines.

*“Washing up, because it was boring.”* (98, male child)

*“I didn't like the fact we couldn't take part in making or preparing our own food”* (94, female child)

**b) Participant's difficulties whilst on the trip?**

105 (86.8%) of parents and 151 (87.3%) of participants responded to this question.

Table 12 shows the emerging themes to this question.

**Table 12. Number of participants who mentioned each theme in response to the question:**

**Experience any difficulties on the trip?**

Theme	Parent-report under 18s (n=105)		Child-report under 18s (n=108)		Over 18s (n=43)	
	Male (n=47)	Female (n=58)	Male (n=49)	Female (n=59)	Male (n=20)	Female (n=23)
None	45(95.7)	32(55.2)	27(55.1)	29(49.1)	6(30.0)	7(30.4)
Activities	0(0)	0	7(14.3)	12(20.3)	7(35.0)	7(30.4)
Personal limitations	4(8.5)	12(20.7)	2(4.1)	4(6.7)	2(10.0)	3(13.0)
Environment	0(0)	0(0)	2(4.1)	10(16.9)	3(15.0)	4(17.4)
Routines	1(2.1)	2(3.4)	1(2.0)	3(8.6)	3(15.0)	0(0)
Social	3(6.4)	3(5.2)	1(2.0)	3(8.6)	0(0)	3(13.0)

The majority of participants reported no difficulties.

*"No "child" managed everything..."* (22, parent of male child)

Difficulties contributable to personal limitations were stated. The most frequent being from parents of female children. Limitations were attributable to their individual illness and disabilities, which included their leg prosthesis, stamina, memory problems, food issues and pain.

*"I found it a bit difficult to walk around the front/ top of the boat but that was because of my disability (prosthetic leg)." (30, female child)*

Social difficulties included participants not getting on, talking to others, making friends and inadequate time spent with other boat groups.

*"I found that getting on with some people was difficult," (114, adult male)*

Waking up early, making and carrying their own beverages were reported as challenging routines.

*"Making own tea and carry it back at lunch/ meal times..." (72, female child)*

Environmental difficulties included comments regarding the weather and moving around the boat.

*“Try to get to our rooms with the big crashing waves” (1, female child)*

*“...having no wind for pico's ...we didn't move” (73, female child)*

Although the difficulties were mentioned, the supportive environment created by the staff and volunteers was frequently mentioned.

*“...the staff were excellent at motivating me” (138, female adult)*

*“...there was always someone there to help in particular the nurse Emma who was lovely...” (156, female adult)*

*“At first, I found climbing the wall and the high ropes difficult because I'm scared of heights but thanks to the volunteers and Bradwell staff I built up my confidence” (104, male child)*

Although the educational aspect of the trip was found to be enjoyable by most, some found this aspect difficult as new skills and remembering new things were found to be challenging.

*“...remembering all the different knots as their not common to me” (female 159, over 18)*

### **c) Suggestions and any other information about the trips**

79 (86.8%) of the parents, 143 (78.0%) of the participants responded.

See Table 13 for the emerging themes in response to this open- ended question.

**Table 13. Number of participants who mentioned each theme in response to the question: Any suggestions for improvement/ any other information the Trust should know about?**

Theme	Parent-report under 18s (n=121)		Child-report under 18s (n=121)		Over 18s (n=52)	
	Male (n=39)	Female (n=40)	Male (n=41)	Female (n=52)	Male (n=19)	Female (n=23)
Environment (%)	7(17.9)	1(10.0)	13(31.7)	17(32.7)	7(36.8)	10(43.5)
Gratitude (%)	8(20.5)	8(20.0)	13(31.7)	17(32.8)	8(42.1)	7(30.4)
None (%)	0(0)	0(0)	11(26.8)	18(34.6)	4(21.1)	6(26.1)
Social (%)	4(10.3)	4(10.0)	4(9.8)	8(15.4)	5(26.3)	6(26.1)
Motivation (%)	6(15.4)	8(20.0)	6(14.6)	13(25.0)	1(5.3)	4(17.4)
Activities (%)	0(0)	0(0)	6(14.6)	9(17.3)	3(15.8)	4(17.4)
Enhanced Positive Feelings (%)	2(5.1)	1(10.0)	5(12.2)	7(13.5)	1(5.3)	4(17.4)

n= total number of participants

Suggestions included mixing up the groups, sleeping arrangements, the places visited, a longer trip, the food on offer and particular boats they should reuse .

*“The only improvement could be made to these trip is to run longer trips. 5 days is too short!”* (118, male child)

*“Make the beds and other living quarters better. Also would be nice to have snacks on offer during the day.”* (81, female child)

*“I believe you could do something on the Isle of White instead of staying in Cowes as it would be interesting and fun to spend time on land...”* (56, male child)

The friendly and supportive atmosphere created, knowledge that the volunteers had experienced cancer and the presence of Ellen MacArthur on the boat were praised.

*“Great time I love how the volunteers have had cancer so they understand, its all really friendly...”*(83, female child)

*“Also hearing Ellen, Ian and Norman on our boat was amazing it really nice that all of them took a week out of there summer to spend time with us..”*(116, female child)

*“He was spoken very highly of the skipper Charles who seems to have helped him through the trip.”* (Parent of an under 18 male)

Gratitude emerged frequently in both participants and their parents where they praised and thanked the trust for providing a great opportunity.

*"This was a wonderful opportunity and we are so grateful that "child" was given the chance to do this. Thank you so much to all those involved!" (parent of a female, 27, under 18)*

*"We really appreciate the chance he had to go on the trip and think its a fabulous thing the Trust is doing for young people with cancer. Thank you." (parent of under 18 male, 50)*

*"...keep making young people feel important, I have the best time and will keep this experience with me forever. Thank to the team and Ellen for a great time..."(female, 133, over 18)*

*"You have made my childhood summer holidays amazing and I can never thank you enough. Your work is incredible and you should all be very proud of what you have achieved for all these kids, as I know there are people there these trips make even more of an impact on than me (e.g. the ones on treatment). You are all incredible and I'm so grateful. Thank you xxx"(female, 70, under 18)*

At least 30% of all participants mentioned they had no suggestions on how the trust could improve de to satisfaction with the service offered.

Participants commented positively about being with others and making strong friendships and parents noticed they had more to contribute to conversations.

*"...I feel like I've made some lifelong friends and it's amazing how four days can change anything for the better..." (156, female, over 18)*

*"Child" enjoyed being on a boat with people from different hospitals and comparing their drug regime etc. It gave him more confidence to talk to new people" (parent of an under 18 male, noting a positive effect the socialising has on his confidence)*

*"When her school friends talk about their holidays she has something great to contribute about Ellen Macarthur trust!"(72, parent of an under 18 female)*

One parent noted a negative aspect of the socialising as her child was bullied on the trip.

*"Child" did mention that a couple of the older boys picked on him and this was repeated to staff who dealt with the situation and told "child" to stay away from them.*

*"Child" does seem to suffer this at home too and may be due to his size and sensitive nature." (parent of an unde 18 male, 19)*

Participants commented that the trip had left them feeling motivated to want to come back, do more sailing and to volunteer.

*"has given me the sailing bug and I can't wait to do it again. I would definitely love to become a volunteer"(male, 51, under 18)*

*"She desperately wants to come back as a volunteer.."(Parent of female, 62)*

Participants positively mentioned the enjoyment gained through the activities and how they would like to do more.

*“really enjoyed all the activities..”* (89, female under 18)

*“...maybe do the packing shed again because that was actually really fun :)...”* (female under 18, 89.)

Very positive reactions to the experience were seen by the use of exclamation marks, underlining, and capital letters to describe how much they had fun, and enjoyed the trip.

*“best time of my life...”* (under 18, female, 35)

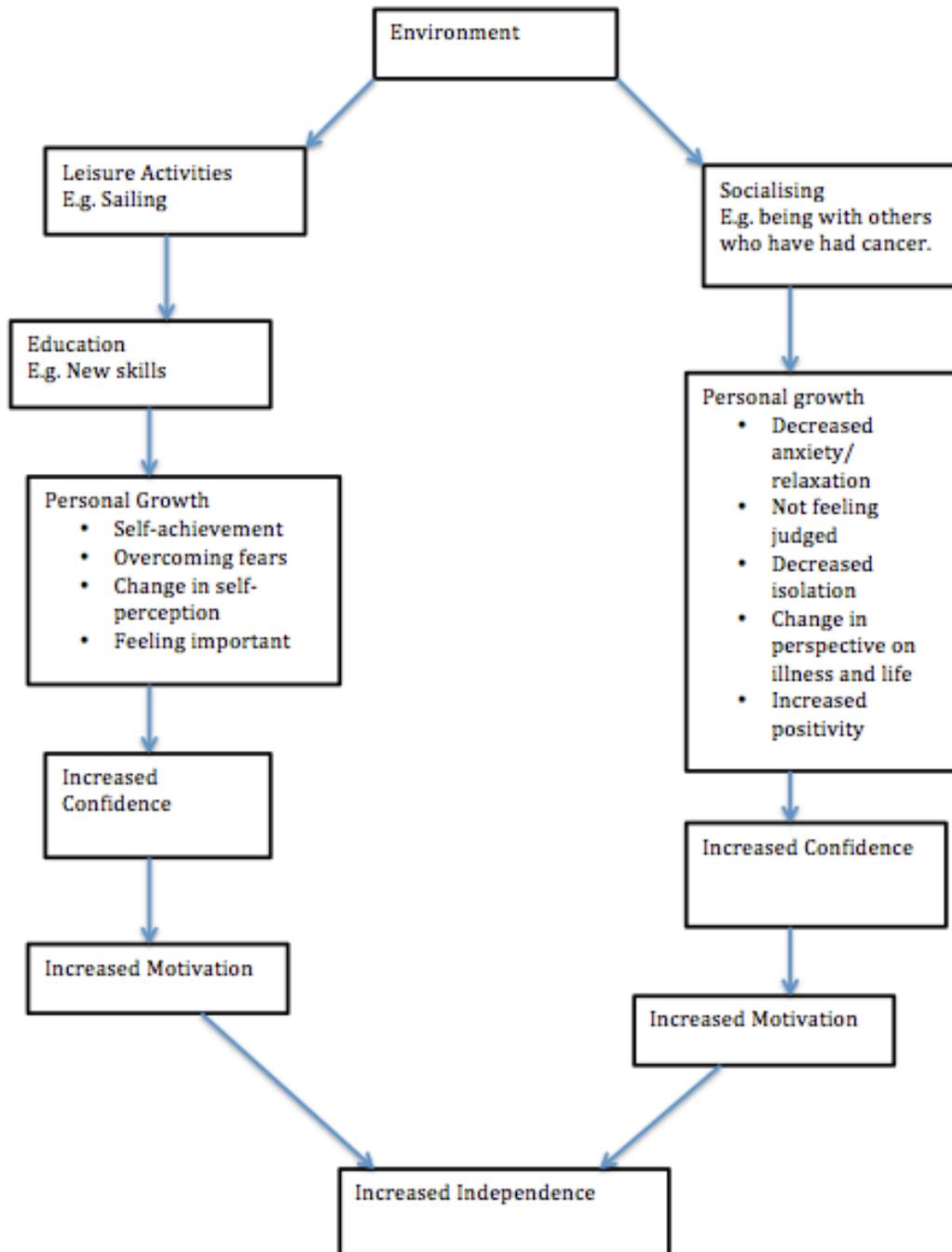
*“Bradwell is always the best week of the year and the amount I laugh is unbelievable”,*  
(88, female child)

## **7.0 Discussion**

The results would suggest strongly that participants had definitely benefited from the trips; either through enjoyment or gaining personal benefits in areas that included socialising with others who have had cancer, increased confidence, gaining independence, increased motivation to do things, enhanced positive feelings, feelings of gratitude and an opportunity to allow for personal growth.

The Trust provides a supportive environment that facilitates enhancements in the participant’s personal development. See Figure 2 below.

Figure 2. Roberts-Bull Model of Enhanced Psychosocial Wellbeing from Sailing



The model explains that the activities offer team building opportunities which promote socialising, new friendships and fun<sup>11</sup>.

The activities prove challenging and provide an excellent learning opportunity where the participant gains new skills, competencies and overcome any fears previously employed.

Gaining competencies and overcoming fears provide feelings of self-achievement as seen by other programmes<sup>12</sup>. This may lead to changes in self-perception and a new realisation of capabilities; this boost self-esteem of which may have been lost after experiencing the side effects of treatment<sup>4</sup>.

A second path to increased confidence is the opportunity to socialise with people who have also experienced cancer and can understand, this is especially important as evidence suggests this population are at increased risk of feeling isolated<sup>5</sup>. Having something in common facilitates communication, which decreases feelings of isolation. Knowing they were around people who understood them made them feel as if they were not being judged upon which leads to relaxation and decreased anxiety associated with what others think. This is particularly beneficial as this population are at increased risk of negative psychological consequences which may impair their coping skills<sup>4</sup>.

Benefiting through socialising with others may be perceived as social support of which can be sub-categorised as a form of "appraisal support"<sup>13 14</sup>. This involves seeing and comparing others in the same situation to promote self-evaluation and thus provide affirmation. This in turn strengthens their self-esteem of which may be beneficial when interpreting stressful situations in an applicable manner<sup>13</sup>.

Gaining knowledge and an appreciation of other's experiences allowed the participants to put things into perspective and have a more positive outlook on life.

This increased positivity and social skills allow the participants to feel happiness and confidence. This fuels the motivation to participate in more activities and meet more people independently. This cycle may be strengthened with additional trips.

The increased confidence gained from the trip can be important in helping them cope with stressful life situations, for example when they have to face peers and strangers who may question their physical appearance during and after treatment<sup>15</sup>. The independence gained is invaluable as this is very often lost as they rely completely on their increasingly over-protective parents during treatment<sup>5 16</sup>.

These gains add to the existing evidence that TR is beneficial for psychosocial wellbeing and it could be hypothesised that it may improve health related quality of life as seen by other programmes<sup>11 12 17-19</sup>.

Although the experiences were reported as mainly positive, some found difficulties in socialising and the activities. Negative emotions, leaving the trip and missing friends were mentioned. A recent review has highlighted this as a nuance from other TR programmes noting that this separation may leave the participants feeling more lonely<sup>15</sup>. Negative aspects specific to sailing were the routines and being sick.

### **Strengths**

The strengths of this study include the large sample size, good response rate (81.1% of participants, and 63.0% of parents) to the qualitative questions that allows the findings to be generalisable to the participating group. The interrater reliability percentage was high (82.5%) thus proving reliable analysis of the data.

### **Limitations**

Limitations of the study include the wording of the questions; they may have prompted particular responses. The likert type scales were poorly designed in differentiating between answers and may have contributed to the ceiling effects in the quantitative data. Ideally three analysts would have been used to ensure greater reliability and validity of the coding process; they would have re-evaluated and coded the responses in accordance to the final theme definitions; consequentially lower interrater reliability is

seen in the questions that were analysed at the beginning of the process and also some responses may not accurately represent the final theme definition list.

More in-depth methods including interviews and focus groups could have been used to enhance the understanding of the participant's views at different time periods during and after the trip to evaluate the long-term benefits of the trip.

It is useful to interpret the findings as exploratory in nature and further research into this area with health related evidence-based outcomes in mind is necessary to truly understand the implications of the sailing trips<sup>1 18</sup>.

### **Conclusion**

Despite the limitations of this exploratory study, it has highlighted that the EMCT sailing trips are important in offering a unique social experience that benefits the participants by boosting elements of their personal development, confidence and independence.

Word count: 3961

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# 9.0 Appendix

## Figure 1. Example questionnaire: Under 18 return to sail feedback 2013




### Under 18 Return to Sail Parents Feedback 2013

Your Name:.....

Your Child's Name:.....

Trip Dates:.....

- How would you rate the communication between yourself and the Trust prior to the trip (Please Circle)  
 Very Good    Good    OK    Missed key information    Rubbish
- Is there anything that we can do to improve our communication and literature?  
 .....
- How much do you feel your child enjoyed the trip? (please circle)  
 Loved it    Really enjoyed It    Ok    Could've been better    Did not enjoy It
- What were their most enjoyable parts of the trip, and why?  
 .....
- What were their least enjoyable parts of the trip, and why?  
 .....
- Did they find anything during the trip particularly difficult? If so, what?  
 .....
- What do you think your child gained from the trip?  
 .....

**Please Turn Over**

1

- Do you think that your child benefited from coming on another trip with the Trust by gaining in (Please Circle);  
 Confidence    Strongly agree    Yes    Not Sure    No    Strongly disagree  
 New Skills    Strongly agree    Yes    Not sure    No    Strongly disagree  
 New Friends    Strongly agree    Yes    Not Sure    No    Strongly disagree  
 Independence    Strongly agree    Yes    Not sure    No    Strongly disagree
- Please could you expand on your answers above  
 .....
- Is there anything else that you think we should know?  
 .....
- We often write case studies for our website and promotional material about the Young People who sail with us, would you be happy for us to contact you about this?  
 Yes    No    Not sure
- How did you find our online photo system to use.  
 Very easy    Easy    Ok    Difficult    Very difficult
- Do you believe that your child has benefited from additional trips with the Trust?  
 Strongly agree    Agree    Don't know    Disagree    Strongly disagree
- Please could you expand on your answers above  
 .....
- Are there any comments you wish to make or any suggestions on how we could improve what we do?  
 .....

Thank you for your time

2

**Figure.2. Example questionnaire: Under 18 First Time Trip Feedback**

**Under 18 Parents Feedback 2013**

Your Name:.....

Your Child's Name: .....

Trip Dates:.....

Hospital that your child was treated at:.....

1. How would you rate the communication between yourself and the Trust prior to the trip (Please Circle)

Very Good    Good    OK    Missed key information    Rubbish

2. Is there anything that we can do to improve our communication and literature? .....

3. How much do you feel your child enjoyed the trip? (please, circle)

Loved it    Really enjoyed it    Ok    Could've been better    Did not enjoy it

4. What were their most enjoyable parts of the trip, and why? .....

5. What were their least enjoyable parts of the trip, and why? .....

6. Did they find anything during the trip particularly difficult? If so, what? .....

7. How much did they enjoy the food on the trip? (Please Circle)

It was perfect    Liked most of it    It was Ok    Didn't like it

8. If you mentioned above that your child did not like the food please let us know how we can improve it. ....

**Please Turn Over**

9. Do you think that your child benefited from coming on the trip with the Trust by gaining in (Please Circle):

Confidence    Strongly agree    Yes    Not Sure    No    Strongly disagree

New Skills    Strongly agree    Yes    Not sure    No    Strongly disagree

New Friends    Strongly agree    Yes    Not Sure    No    Strongly disagree

Independence    Strongly agree    Yes    Not sure    No    Strongly disagree

10. Please could you expand on your answers above. ....

11. Is there anything else that you think we should know? .....

12. We often write case studies for our website and promotional material about the Young People who sail with us, would you be happy for us to contact you about this?

Yes    No    Not sure

13. How did you find our online photo system to use

Very easy    Easy    Ok    Difficult    Very difficult

14. Are there any comments you wish to make or any suggestions on how we could improve what we do? .....

**Thank you for your time**

**Figure 3. List of trips on offer.**

- 18 - 24 Year Old First Time Trip
- 18 - 24 Year Old Bradwell
- 18 - 24 Year Old Jolie Brise
- Under 18 First Time Trip
- Under 18 Round the Island
- Under 18 Residential Return to Sail
- Under 18 East Coast Cruising
- Under 18 Return to Sail Parents

Figure 4.

Example of Word Document showing two pages of the tables used to analyse the qualitative data.

		Under 18s difficulties whilst on the trip.	n	e	e	r	a	pr	c	m	pr	L	boac	sick
1	female.	Try to get to our rooms with the big crashing waves												
2	male.	Just moving around and the boat was white sailing, but I soon got used to it												
3	female.	No												
4	female.	No everything was explained through subtitles and we had a book to help us understand it												
5	male.	N/A												
6	male.	No												
7	female.	No												
8	male.	Only my port, which I'm used to												
9	male.	No												
10	male.	No												
11	male.	No												
12	male.	I didn't find anything difficult.												
13	female.	No. Maybe just not knowing people before going on trip.												
14	female.	Learning the different parts of the guitar												
15	female.	No												
16	male.	No												
17	female.	It was quite easy, I didnt struggle with much.												
18	male.	No												
19	male.	Just the life												
20	male.	Just the life												
21	male.	jacket. There were no bad parts because the trip was great.												
22	female.	Nothing was difficult												
23	male.	Moving about on the boat, but I got used to it in the end												
24	male.	Yes, tying a knot, I had to be shown by Ed (but it was still fun)												
25	male.	No everything was explained in a easy to understand way.												
26	female.	Getting up early in the morning												
27	female.	No												
28	female.	No												
29	female.	At first it was a bit hard to talk to people but within a few hours we were all laughter and joking and it was great												
30	female.	I found it a bit difficult to walk around the front/ top of the boat but that was because of my disability (prosthetic leg) but apart from that I managed to do everything												
31	male.	no I didnt												
32	female.	no I didnt												
33	male.	It was so brilliant												

**Note:** Identification number, gender, age category and themes are included in the table to count up the frequencies.