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THERAPEUTIC RECREATION CAMPING PROGRAMMES FOR CHILDREN WITH CHRONIC ILLNESSES, AND THEIR SIBLINGS

VOLUME II

Gemma Bridget Kiernan

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Degree of Doctor of Philosophy

University of Dublin, Trinity College

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APPENDICES

APPENDIX 1

INTRODUCTORY STUDY QUESTIONNAIRE

What you think of The Barretstown Gang Camp

We are trying to find out people's thoughts and feelings about The Barretstown Gang Camp. The questions on the next few pages ask you about yourself and about your views of camp. You do not have to answer these questions if you do not want to, but it would be helpful for us if you did.
Thankyou.

1. What is your name ?
_____

2. What age are you ?
_____ years old

3. What country are you from ?
_____

4. Are you a boy or a girl ?
(Please tick one box)

Boy [ ] Girl [ ]

5a. Have you ever been at a camp before ?
(Please tick one box)

Yes [ ] No [ ]

b. **If yes,** what was the name of the camp ?
_____

6. How did you feel about coming to Barretstown this year ?
(Please colour one face)

really liked | liked | neither liked nor disliked | disliked | really disliked



7. How would you rate the food in Barretstown ?
(Please colour one face)

really liked | liked | neither liked nor disliked | disliked | really disliked



8. What do you think of each of the following activities in Barretstown ?

Arts & Crafts:
(Please colour one face)

really liked | liked | neither liked nor disliked | disliked | really disliked



Canoeing:
(Please colour one face)

really liked | liked | neither liked nor disliked | disliked | really disliked



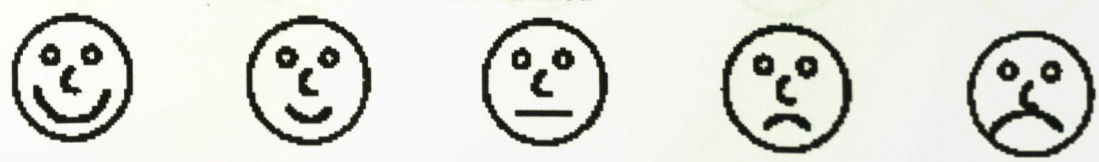
Music:
(Please colour one face)

really liked | liked | neither liked nor disliked | disliked | really disliked

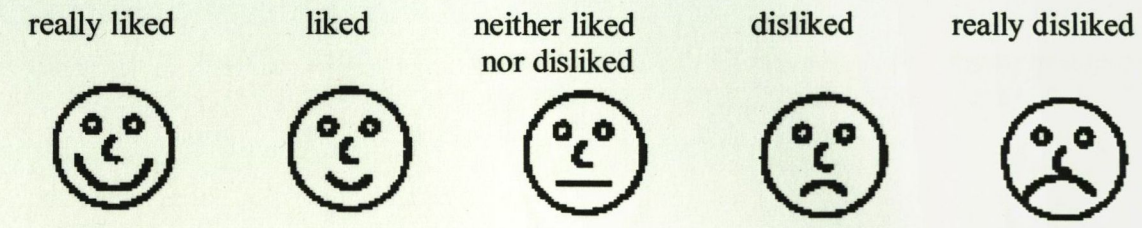


Fishing:
(Please colour one face)

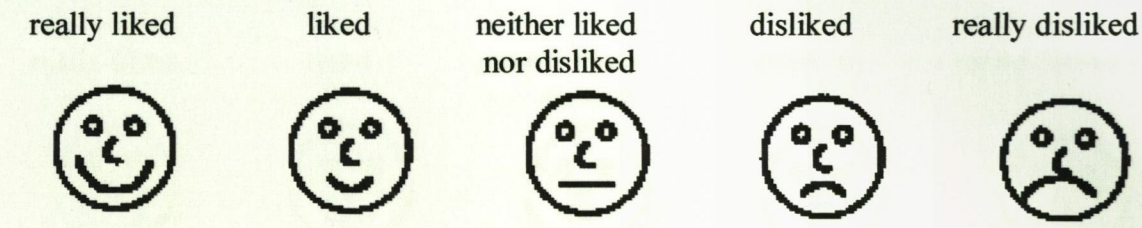
really liked | liked | neither liked nor disliked | disliked | really disliked



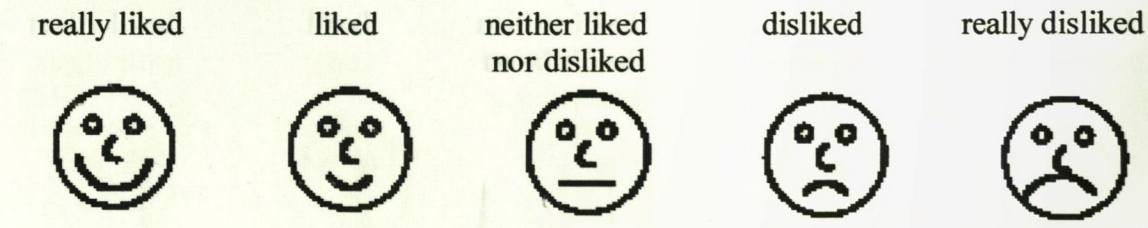
Theatre:
(Please colour one face)



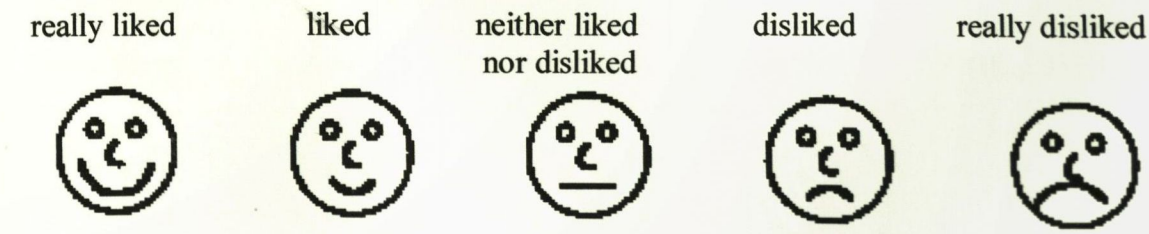
Archery:
(Please colour one face)



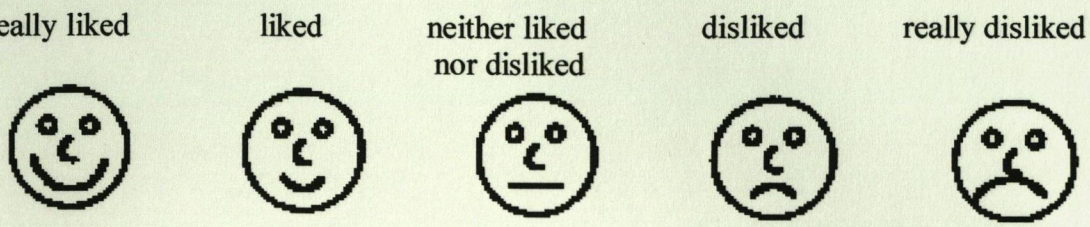
Wordsmith:
(Please colour one face)



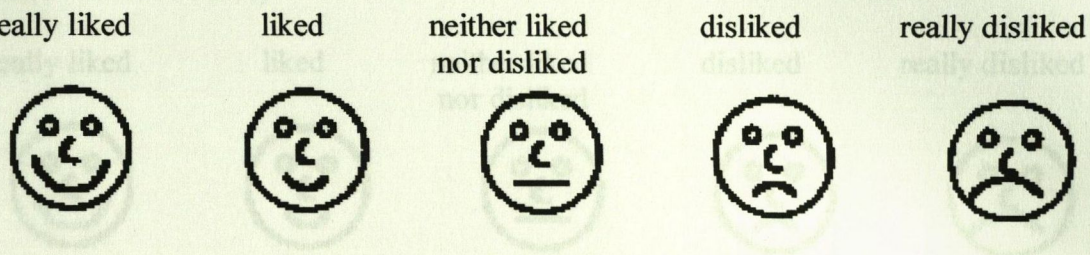
Woodwork:
(Please colour one face)



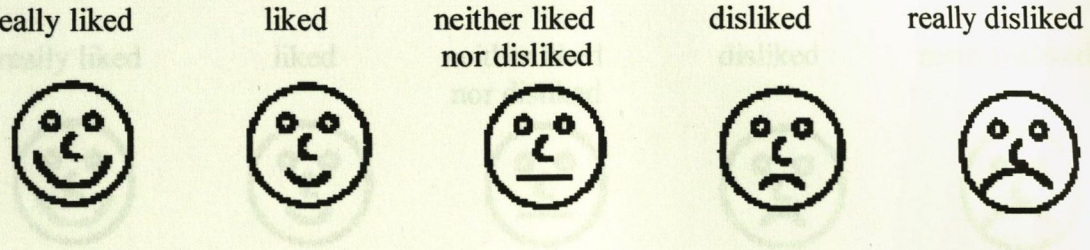
Horseriding:
(Please colour one face)



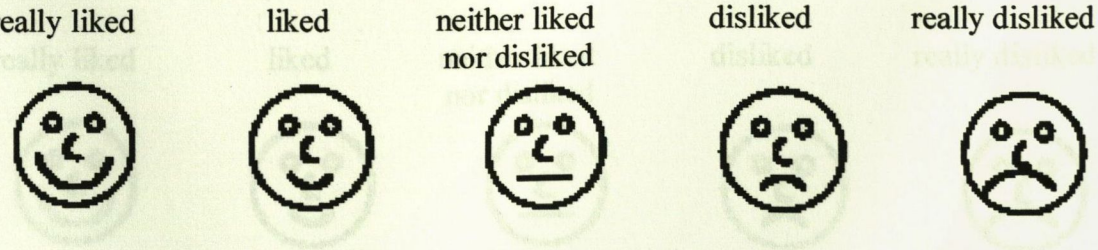
Photography:
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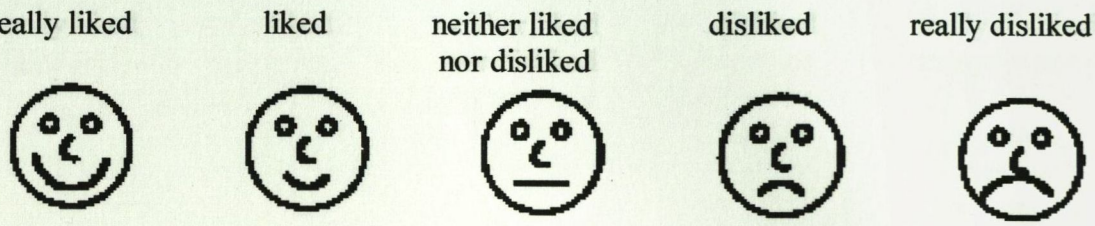
Adventure:
(Please colour one face)



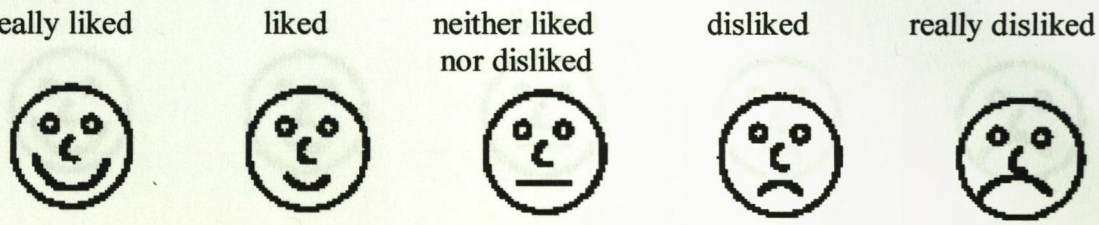
Crazy & Lazy:
(Please colour one face)



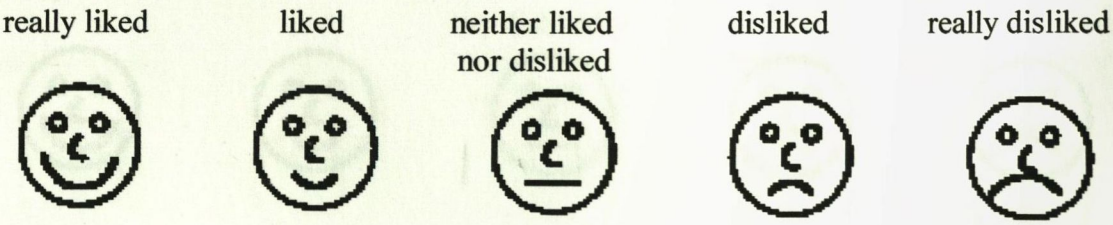
Camping:
(Please colour one face)



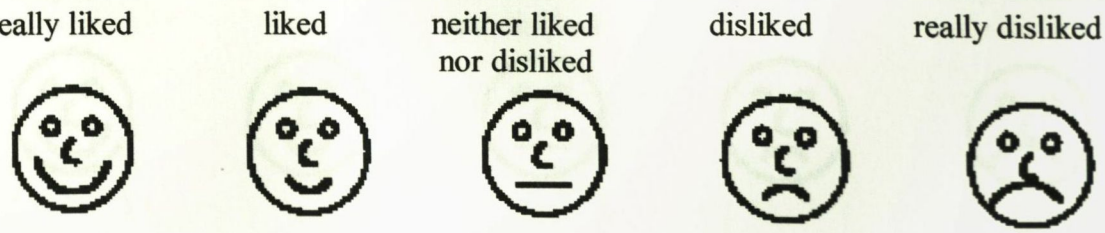
The Quest:
(Please colour one face)



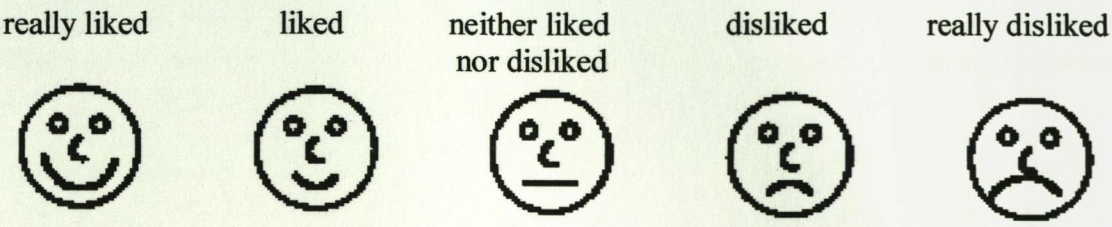
Rest Hour:
(Please colour one face)



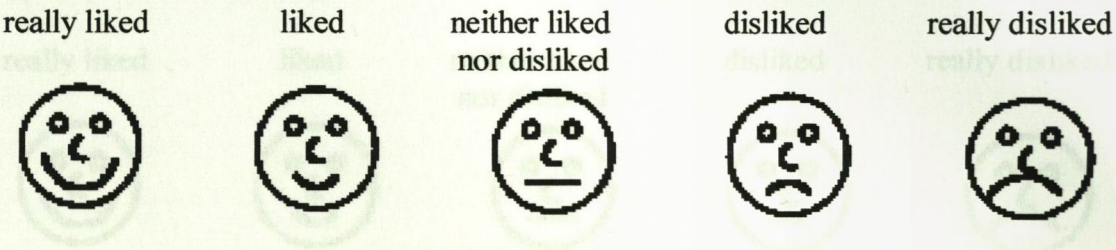
Evening Activities:
(Please colour one face)



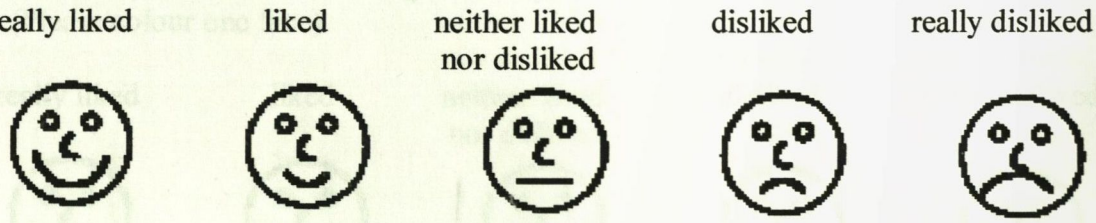
Chill/Hangout:
(Please colour one face)



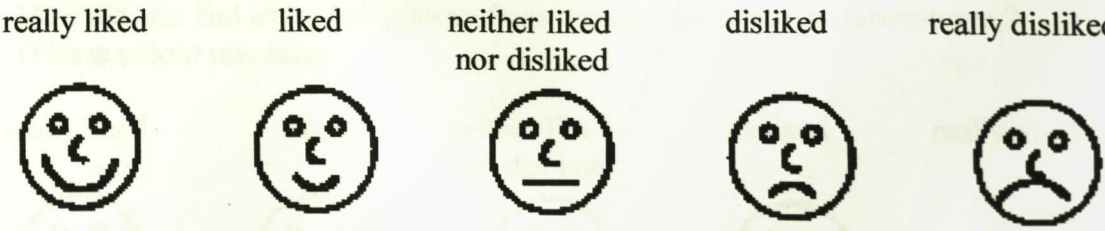
Special Projects:
(Please colour one face)



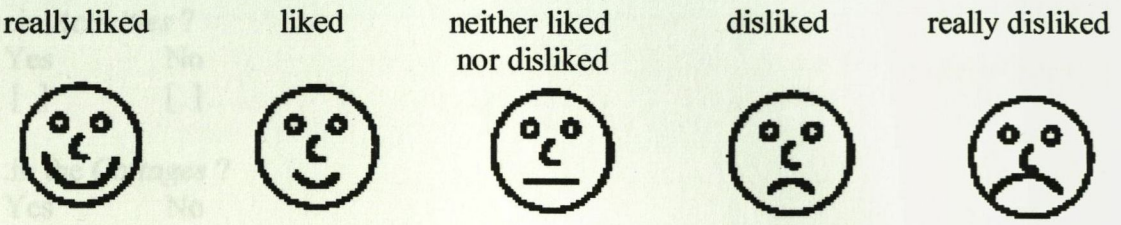
Cottage Chat:
(Please colour one face)



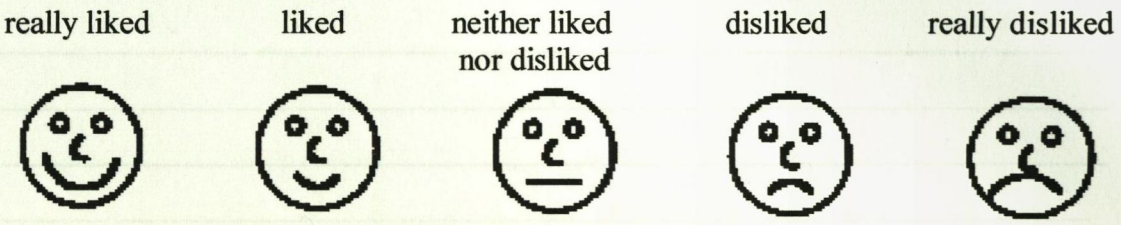
Cottage Clean Up:
(Please colour one face)



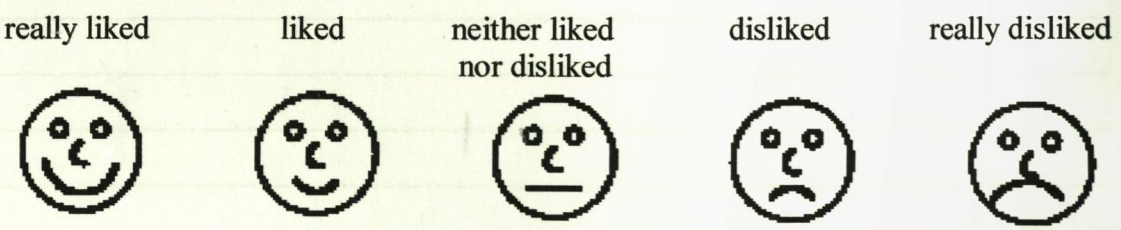
9. How did you feel about meeting people from other countries in Barretstown ?
(Please colour one face)



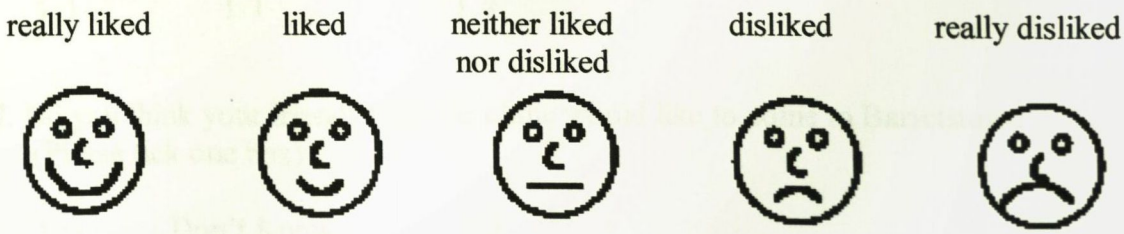
10. How do you feel about people speaking different languages in Barretstown ?
(Please colour one face)



11. How did you feel about visiting the Honey Hive ?
(Please colour one face)



12. How did you feel about being away from your family while in Barretstown ?
(Please colour one face)



13. Did you understand everything that was explained to you.....

..in *Activities* ?

Yes	No
[ ]	[ ]

..in the *Cottages* ?

Yes	No
[ ]	[ ]

14. What do you like most about camp ?

_____

_____

_____

_____

15. What do you like least about camp ?

_____

_____

_____

_____

16. Will you stay in contact with any of the people you met in Barretstwon ?
(Please tick one box)

Yes	Don't Know	No
[ ]	[ ]	[ ]

17. Do you think your friends from the clinic would like to come to Barretstown ?
(Please tick one box)

Yes	Don't Know	No
[ ]	[ ]	[ ]

18. If you were to describe Barretstown to a friend, what would you say ?

Please use this space to write or draw anything you would like about Barretstown.

THANK YOU VERY MUCH FOR ANSWERING THESE QUESTIONS.

APPENDIX 2

CIRCULAR SENT TO HOSPITALS IN CHILDREN'S HOME COUNTRIES OUTLINING THE PURPOSE AND NATURE OF THE RESEARCH

Dear

We very much enjoy having the *(nationality of children)* children in Barretstown for our summer camp programme. As we wish to continuously develop this camp programme we are doing an important research project with Trinity College in Dublin which I would like to tell you about.

This project is being carried out in 4 parts: 2 weeks before each child comes to Barretstown, while each child is in Barretstown, 2 weeks after each child returns home from Barretstown and 6 months later. Each part involves both the parents of the child and the child him/herself completing a questionnaire that asks for their views about our summer camp programme and also looks at the relation between the child's experience of our programme and how it may affect their feelings and health. The questionnaires have been translated into *(appropriate target language)*and freepost envelopes are provided for families to allow them to return the questionnaires to us easily.

Each family's decision to participate in this project is entirely voluntary. All families are assured that their answers to the questions will be kept completely anonymous and that all information they give will be treated with the utmost confidentiality. The feedback from all of the families will be instrumental in helping us to strengthen our camp programme for the children.

As you are involved in helping to co-ordinate the *(nationality of children)* children coming to Barretstown, you may find that the families mention this project to you. Your support of this project if talking with them would be greatly appreciated. Already, many Hungarian families have returned questionnaires to us. If you have any questions about this project yourself, or would like to receive a copy of the results in the future, please let us know.

Best wishes,

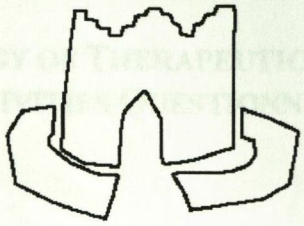
Gemma Kiernan
Programme Research and Development Co-ordinator

Dr.MacMacLachlan
Trinity College, Dublin

APPENDIX 3A

COVERING LETTER FOR CHILDREN (TIME 1)

The Barretstown Gang Camp



DEAR CAMPER

We are very excited about seeing you in The Barretstown Gang Camp in a couple of weeks! We are doing a project to find out about what the campers think of Barretstown. We are asking all the campers coming to Barretstown this summer to help us with it.

There are 4 parts in the project and each part asks you to fill out a questionnaire about Barretstown and about yourself. You do the first part of the project now and the other parts later on.

You get to come to Barretstown whether or not you take part in this project. If you will help us by doing all parts of this project, tick the box for **Yes**.

Yes, I will do the Barretstown project ☐

If you are doing this project and have ticked the box for yes, please turn to the next page to start filling out the questionnaire.

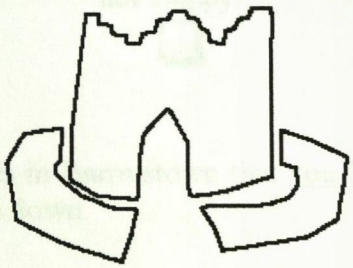
Thank you for your help.
See you in Barretstown.

Gemma Kiernan

APPENDIX 3B

CHILDREN: STRATEGY OF THERAPEUTIC RECREATION BASED ACTIVITIES QUESTIONNAIRE

The Barretstown Gang Camp



CAMPER QUESTIONNAIRE

This is the second part of the project for The Barretstown Gang Camp in Ireland. The questions on the next few pages ask you for your views about Barretstown. Please answer all the questions truthfully. There are no right or wrong answers. Your answers will not be shown with your name to anyone else.

Thank you.

1. What is your name?

Name:_____

2. What age are you?

_____ **years old**

3. How do you feel about being here in Barretstown?

Very Sad	Sad	Neither Sad nor Happy	Happy	Very Happy
❑	❑	❑	❑	❑

4. Are you doing any activities in Barretstown that you had never tried before coming here? **If yes**, please write them down

_____ _____ _____

_____ _____ _____

_____ _____ _____

5. How would you describe any of the people who look after you in camp?

_____

_____

_____

_____

_____

_____

6. How do you find being in Barretstown with people from different countries?

_____

_____

_____

_____

_____

_____

7. How much fun do you think each of the following activities were ? (Please tick <u>one box</u> for each activity. You can choose a box at either end or one of the boxes in between)

	Not at all				*A lot*
A. Arts and Crafts	❑	❑	❑	❑	❑
B. Canoeing	❑	❑	❑	❑	❑
C. Music	❑	❑	❑	❑	❑
D. Fishing	❑	❑	❑	❑	❑
E. Theatre	❑	❑	❑	❑	❑
F. Archery	❑	❑	❑	❑	❑
G. Wordsmith	❑	❑	❑	❑	❑
H. Woodwork	❑	❑	❑	❑	❑
I. Horseriding	❑	❑	❑	❑	❑
J. Video/Photography	❑	❑	❑	❑	❑
K. Adventure	❑	❑	❑	❑	❑
L. Camping	❑	❑	❑	❑	❑
M. The Quest	❑	❑	❑	❑	❑

8. How difficult were each of the following activities?
(Please tick <u>one box</u> for each activity. You can choose a box at either end or one of the boxes in between)

	Not at all				*A lot*
A. Arts and Crafts	❑	❑	❑	❑	❑
B. Canoeing	❑	❑	❑	❑	❑
C. Music	❑	❑	❑	❑	❑
D. Fishing	❑	❑	❑	❑	❑
E. Theatre	❑	❑	❑	❑	❑
F. Archery	❑	❑	❑	❑	❑
G. Wordsmith	❑	❑	❑	❑	❑
H. Woodwork	❑	❑	❑	❑	❑
I. Horseriding	❑	❑	❑	❑	❑
J. Video/Photography	❑	❑	❑	❑	❑
K. Adventure	❑	❑	❑	❑	❑
L. Camping	❑	❑	❑	❑	❑
M. The Quest	❑	❑	❑	❑	❑

9. How good were you at doing each of the following activities? (Please tick <u>one box</u> for each activity. You can choose a box at either end or one of the boxes in between)

	Not at all				*A lot*
A. Arts and Crafts	❑	❑	❑	❑	❑
B. Canoeing	❑	❑	❑	❑	❑
C. Music	❑	❑	❑	❑	❑
D. Fishing	❑	❑	❑	❑	❑
E. Theatre	❑	❑	❑	❑	❑
F. Archery	❑	❑	❑	❑	❑
G. Wordsmith	❑	❑	❑	❑	❑
H. Woodwork	❑	❑	❑	❑	❑
I. Horseriding	❑	❑	❑	❑	❑
J. Video/Photography	❑	❑	❑	❑	❑
K. Adventure	❑	❑	❑	❑	❑
L. Camping	❑	❑	❑	❑	❑
M. The Quest	❑	❑	❑	❑	❑

10. How much time to you spend thinking about or talking about what you did in each activity? (Please tick <u>one box</u> for each activity. You can choose a box at either end or one of the boxes in between)

	Not at all				*A lot*
A. **Arts and Crafts**	❑	❑	❑	❑	❑
B. **Canoeing**	❑	❑	❑	❑	❑
C. **Music**	❑	❑	❑	❑	❑
D. **Fishing**	❑	❑	❑	❑	❑
E. **Theatre**	❑	❑	❑	❑	❑
F. **Archery**	❑	❑	❑	❑	❑
G. **Wordsmith**	❑	❑	❑	❑	❑
H. **Woodwork**	❑	❑	❑	❑	❑
I. **Horseriding**	❑	❑	❑	❑	❑
J. **Video/Photography**	❑	❑	❑	❑	❑
K. **Adventure**	❑	❑	❑	❑	❑
L. **Camping**	❑	❑	❑	❑	❑
M. **The Quest**	❑	❑	❑	❑	❑

11. Do you think that you have learnt anything by doing the activities? Please write it down.

12. Please use this space to write anything else about Barretstown.

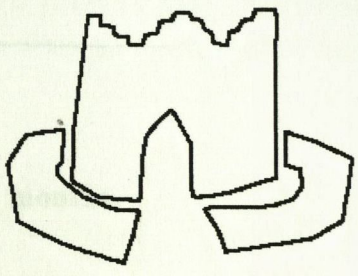
This is the end of this questionnaire. Thank you very much for answering all the questions.

You have now completed half of the Barretstown project. There are only another two parts left. The next part will be completed in your home in a couple of weeks.
Thank-you for all your help with this project.

APPENDIX 3C

CHILDREN: PRE-BARRETSTOWN QUESTIONNAIRE (TIME 1)

The Barretstown Gang Camp



CAMPER QUESTIONNAIRE

The questions on the next few pages ask you for your thoughts about Barretstown and about yourself. Please answer all the questions truthfully. There are no right or wrong answers. Your answers will not be shown with your name to anyone else.
Thank you.

PART 1

This part of the questionnaire asks you for your thoughts about The Barretstown Gang Camp.

1. What is your name?

Name:_____

2. What country are you from?

Country:_____

3. What age are you?

_____ **years** _____ **months**

4. What sex are you?
(Please tick one box)

Boy ❑ **Girl** ❑

5. How do you feel about coming to Barretstown this year ?

Very Sad	**Sad**	**Neither Sad nor Happy**	**Happy**	**Very Happy**
❑	❑	❑	❑	❑

6. Is there anything you are looking forward to about your stay in Barretstown? Please write it down.

_____

_____

_____

_____

_____

7. Is there anything that worries you about your stay in Barretstown? Please write it down.

_____

_____

_____

_____

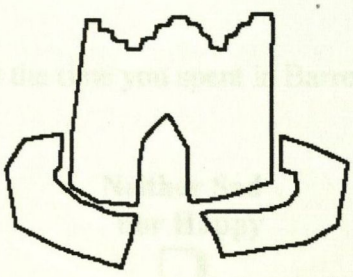
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This is the end of the first part of the questionnaire. Thank you for answering the questions. Please turn to the next page.

APPENDIX 3D

CHILDREN: POST-BARRETSTOWN QUESTIONNAIRE (TIME 2)

The Barretstown Gang Camp



CAMPER QUESTIONNAIRE

This is the third part of the project for The Barretstown Gang Camp in Ireland. Like the questionnaires you filled out before, the questions on the next few pages ask you for your thoughts about Barretstown and about yourself. Please answer all the questions truthfully. There are no right or wrong answers. Your answers will not be shown with your name to anyone else.

Thank you.

PART 1

This part of the questionnaire asks you about your views of The Barretstown Gang Camp.

1. What is your name ?

Name:_____

2. What age are you ?

_____**years old**

3. How do you feel now about the time you spent in Barretstown?
(Please tick one box)

Very Sad	**Sad**	**Neither Sad nor Happy**	**Happy**	**Very Happy**
❑	❑	❑	❑	❑

4a. Do you stay in contact with any of the other people you met in Barretstown ?
(Please tick one box)

Yes	**No**
❑	❑

b. If Yes, how do you stay in contact with them?
(Please tick either yes or no for each item)

	Yes	**No**
Letter-writing.....	❑	❑
Telephone conversations.....	❑	❑
Meet with them.....	❑	❑

Other way of staying in contact. What is it? _____

c. What countries are the people you stay in contact with from?

_____ _____ _____

5. Do you have any special memories of your stay in Barretstown?

Yes ❑ **No** ❑

If **Yes,** what are they?

_____

_____

_____

_____

_____

6. Did you learn anything from your stay in Barretstown that helps you in your life now?

Yes ❑ **No** ❑

If **Yes,** what did you learn?

_____

_____

_____

_____

_____

7. Would you like to change anything about your stay in Barretstown?

Yes ❑ **No** ❑

Please explain your answer.

_____

_____

_____

_____

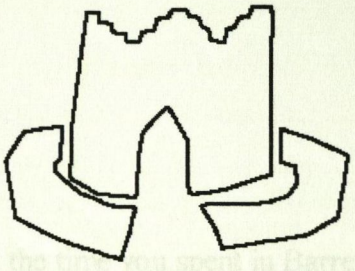
_____

This is the end of the first part of the questionnaire. Thank you for answering the questions. Please turn to the next page.

APPENDIX 3E

CHILDREN: POST-BARRETSTOWN QUESTIONNAIRE (TIME 3)

The Barretstown Gang Camp



CAMPER QUESTIONNAIRE

This is the final part of the project for The Barretstown Gang Camp in Ireland. Like the questionnaires you filled out before, the questions on the next few pages ask you for your thoughts about Barretstown and about yourself. Please answer all the questions truthfully. There are no right or wrong answers. Your answers will not be shown with your name to anyone else.

Thank you for all your help with this project.

PART 1

This part of the questionnaire asks you about your views of The Barretstown Gang Camp.

1. What is your name ?

Name:_____

2. What age are you ?

_____**years old**

3. How do you feel now about the time you spent in Barretstown?
(Please tick one box)

Very Sad	Sad	Neither Sad nor Happy	Happy	Very Happy
❑	❑	❑	❑	❑

4a. Do you stay in contact with any of the other people you met in Barretstown ?
(Please tick one box)

Yes	No
❑	❑

b. If Yes, how do you stay in contact with them?
(Please tick either yes or no for each item)

	Yes	No
Letter-writing.....	❑	❑
Telephone conversations.....	❑	❑
Meet with them.....	❑	❑

Other way of staying in contact. What is it? _____

c. What countries are the people you stay in contact with from?

_____ _____ _____

5. Do you have any special memories of your stay in Barretstown?

Yes ❑ **No** ❑

If **Yes,** what are they?

_____

_____

_____

_____

_____

6. Did you learn anything from your stay in Barretstown that helps you in your life now?

Yes ❑ **No** ❑

If **Yes,** what did you learn?

_____

_____

_____

_____

_____

7. Would you like to change anything about your stay in Barretstown?

Yes ❑ **No** ❑

Please explain your answer.

_____

_____

_____

_____

_____

This is the end of the first part of the questionnaire. Thank you for answering the questions. Please turn to the next page.

APPENDIX 3F

CHILDREN: PRE AND POST-BARRETSTOWN MEASURES FOR AFFECT

Physiological Hyperarousal-Positive and Negative Affect Scale for Children (PH-PANAS-C)

In this part of the questionnaire there are words that describe different feelings and emotions. For <u>each word</u> please tick one box that best describes how much you felt this way during the past few weeks.

	Never	A Little	Sometimes	A lot	Always
1. Interested	❑	❑	❑	❑	❑
2. Sad	❑	❑	❑	❑	❑
3. Frightened	❑	❑	❑	❑	❑
4. Alert	❑	❑	❑	❑	❑
5. Excited	❑	❑	❑	❑	❑
6. Ashamed	❑	❑	❑	❑	❑
7. Upset	❑	❑	❑	❑	❑
8. Happy	❑	❑	❑	❑	❑
9. Strong	❑	❑	❑	❑	❑
10. Nervous	❑	❑	❑	❑	❑
11. Guilty	❑	❑	❑	❑	❑
12. Energetic	❑	❑	❑	❑	❑
13. Scared	❑	❑	❑	❑	❑
14. Calm	❑	❑	❑	❑	❑
15. Miserable	❑	❑	❑	❑	❑
16. Jumpy	❑	❑	❑	❑	❑

	Never	A Little	Sometimes	A lot	Always
17. Cheerful	❑	❑	❑	❑	❑
18. Active	❑	❑	❑	❑	❑
19. Proud	❑	❑	❑	❑	❑
20. Afraid	❑	❑	❑	❑	❑
21. Joyful	❑	❑	❑	❑	❑
22. Lonely	❑	❑	❑	❑	❑
23. Mad	❑	❑	❑	❑	❑
24. Fearless	❑	❑	❑	❑	❑
25. Disgusted	❑	❑	❑	❑	❑
26. Delighted	❑	❑	❑	❑	❑
27. Downhearted	❑	❑	❑	❑	❑
28. Daring	❑	❑	❑	❑	❑
29. Gloomy	❑	❑	❑	❑	❑
30. Lively	❑	❑	❑	❑	❑

Thank you for answering these questions. Please turn to the next page.

Here are some more words that describe different feelings. As before, for <u>each word,</u> please tick one box that best describes how much you felt this way during the past few weeks.

	Never	A Little	Sometimes	A lot	Always
1. Dry mouth	❑	❑	❑	❑	❑
2. Sweaty hands	❑	❑	❑	❑	❑
3. Tingling (like pins & needles)	❑	❑	❑	❑	❑
4. Blushing	❑	❑	❑	❑	❑
5. Shaky	❑	❑	❑	❑	❑
6. Stomach Ache	❑	❑	❑	❑	❑
7. Cold flashes	❑	❑	❑	❑	❑
8. Dizzy	❑	❑	❑	❑	❑
9. Heart pounding	❑	❑	❑	❑	❑
10. Sweating when you are not hot	❑	❑	❑	❑	❑
11. Can't catch your breath	❑	❑	❑	❑	❑
12. Feeling of choking	❑	❑	❑	❑	❑
13. Hot flashes	❑	❑	❑	❑	❑
14. Numbness (like your foot's asleep)	❑	❑	❑	❑	❑
15. Pain in your chest	❑	❑	❑	❑	❑
16. Feeling like throwing up	❑	❑	❑	❑	❑

	Never	A Little	Sometimes	A lot	Always
17. Tight Muscles ----------	❑	❑	❑	❑	❑
18. Can't sit still ----------	❑	❑	❑	❑	❑

This is the end of this part of the questionnaire. Thank you for answering all the questions. Please turn to the next page.

APPENDIX 3G

CHILDREN: PRE AND POST-BARRETSTOWN MEASURES FOR PHYSICAL SYMPTOMS

Physical Symptoms Inventory (PSI[1])

[1] Questions 1-18 overlap with the PH-PANAS-C. They are re-presented here for clarity, but were not administered to children twice.

Here are some more words that describe different feelings. As before, for <u>each word,</u> please tick one box that best describes how much you felt this way during the past few weeks.

	Never	A Little	Sometimes	A lot	Always
1. Dry mouth	❑	❑	❑	❑	❑
2. Sweaty hands	❑	❑	❑	❑	❑
3. Tingling (like pins & needles)	❑	❑	❑	❑	❑
4. Blushing	❑	❑	❑	❑	❑
5. Shaky	❑	❑	❑	❑	❑
6. Stomach Ache	❑	❑	❑	❑	❑
7. Cold flashes	❑	❑	❑	❑	❑
8. Dizzy	❑	❑	❑	❑	❑
9. Heart pounding	❑	❑	❑	❑	❑
10. Sweating when you are not hot	❑	❑	❑	❑	❑
11. Can't catch your breath	❑	❑	❑	❑	❑
12. Feeling of choking	❑	❑	❑	❑	❑
13. Hot flashes	❑	❑	❑	❑	❑
14. Numbness (like your foot's asleep)	❑	❑	❑	❑	❑
15. Pain in your chest	❑	❑	❑	❑	❑
16. Feeling like throwing up	❑	❑	❑	❑	❑

	Never	A Little	Sometimes	A lot	Always
17. Tight Muscles	❑	❑	❑	❑	❑
18. Can't sit still	❑	❑	❑	❑	❑
19. Getting up to go to the toilet during the night	❑	❑	❑	❑	❑
20. Tiredness	❑	❑	❑	❑	❑
21. Loss of taste	❑	❑	❑	❑	❑
22. General Weakness	❑	❑	❑	❑	❑
23. Confused	❑	❑	❑	❑	❑
24. Unable to sleep	❑	❑	❑	❑	❑
25. Difficulty remembering things	❑	❑	❑	❑	❑
26. Diarrhoea	❑	❑	❑	❑	❑
27. Constipation	❑	❑	❑	❑	❑
28. Vomiting	❑	❑	❑	❑	❑
29. Nightmares	❑	❑	❑	❑	❑
30. Pains/aches	❑	❑	❑	❑	❑

This is the end of this part of the questionnaire. Thank you for answering all the questions. Please turn to the next page.

APPENDIX 3H

CHILDREN: PRE AND POST-BARRETSTOWN MEASURES FOR SELF ESTEEM (CHILDREN: 7-12 YEARS)

Self Perception Profile for Children (SPPC)

Here are some statements that ask you about what sort of person you are.
For each statement, decide whether you are more like the children on the left side of the page or the children on the right side of the page.
Then on the side of the page you have chosen, tick whether this part of the statement is sort of true for you or really true for you.
For each statement, you just <u>tick one box on the side of the page most like you.</u>

Before you start, you can try the example below.

1. **Read the example.**
2. **First decide whether you are more like the children on the left side of the page who would rather play outdoors, or whether you are more like the children on the right side of the page who would rather watch television. When you have decided which kind of child is most like you, go to that side of the page.**
3. **Now decide whether what it says on this side of the page is only sort of true for you or really true for you. If it's only sort of true, then put a tick in that box. If it's really true for you, you put a tick in that box.**
4. **Now you can start the other statements.**

<u>EXAMPLE</u>

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
1.	☐	☐	Some children would rather play outdoors in their spare time	**OR**	Some children would rather watch television in their spare time	☐ ☐

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
1.	☐	☐	Some children feel that they are very good at their school work	**OR**	Some children worry about whether they can do the school work given to them	☐ ☐
2.	☐	☐	Some children find it hard to make friends	**OR**	Some children find it easy to make friends	☐ ☐
3.	☐	☐	Some children do very well at all kinds of sports	**OR**	Some children don't feel that they are very good when it comes to sports	☐ ☐
4.	☐	☐	Some children are happy with the way the look	**OR**	Some children are not happy with the way they look	☐ ☐

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
5.	☐	☐	Some children often do not like the way they behave	**OR**	Some children usually like the way they behave	☐ ☐
6.	☐	☐	Some children are often unhappy with themselves	**OR**	Some children are quite pleased with themselves	☐ ☐
7.	☐	☐	Some children feel they are just as intelligent as other children their age	**OR**	Some children aren't so sure and wonder if they are as intelligent	☐ ☐
8.	☐	☐	Some children have a lot of friends	**OR**	Some children don't have very many friends	☐ ☐
9.	☐	☐	Some children wish they could be a lot better at sports	**OR**	Some children feel they are good enough at sports	☐ ☐
10.	☐	☐	Some children are happy with their height and weight	**OR**	Some children wish their height or weight were different	☐ ☐
11.	☐	☐	Some children usually do the right thing	**OR**	Some children often don't do the right thing	☐ ☐
12.	☐	☐	Some children don't like the way they are leading their life	**OR**	Some children do like the way they are leading life	☐ ☐
13.	☐	☐	Some children are quite slow in finishing their schoolwork	**OR**	Some children can do their schoolwork quickly	☐ ☐
14.	☐	☐	Some children would like to have a lot more friends	**OR**	Some children have as many friends as they want	☐ ☐
15.	☐	☐	Some children think they could do well at just about any new sports activity they haven't tried before	**OR**	Some children are afraid they might not do well at sports they haven't ever tried	☐ ☐
16.	☐	☐	Some children wish their body was different	**OR**	Some children like their body they way it is	☐ ☐
17.	☐	☐	Some children usually act the way they know they are supposed to	**OR**	Some children often don't act the way they are supposed to	☐ ☐

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	Really True for me	Sort of True for me			Sort of True for me	Really True for me
18.	☐	☐	Some children are happy with themselves as a person	**OR**	Some children are often not happy with themselves ☐	☐
19.	☐	☐	Some children often forget what they learn	**OR**	Some children can remember things easily ☐	☐
20.	☐	☐	Some children are always doing things with a lot of children	**OR**	Some children usually do things by themselves ☐	☐
21.	☐	☐	Some children feel that they are better than others their age at sports	**OR**	Some children don't feel they can play sports as well as others ☐	☐
22.	☐	☐	Some children wish their physical appearance (how they look) was different	**OR**	Some children like their physical appearance (how they look) the way it is ☐	☐
23.	☐	☐	Some children usually get in trouble because of things they do	**OR**	Some children usually don't do things that get them in trouble ☐	☐
24.	☐	☐	Some children like the kind of person they are	**OR**	Some children often wish they were someone else ☐	☐
25.	☐	☐	Some children do very well at their classwork	**OR**	Some children don't do very well at their classwork ☐	☐
26.	☐	☐	Some children wish that more people their age liked them	**OR**	Some children feel that most people their age do like them ☐	☐
27.	☐	☐	In games and sports, some children usually watch instead of play	**OR**	In games and sports, some children usually play rather than just watch ☐	☐
28.	☐	☐	Some children wish something about their face or hair looked different	**OR**	Some children like their face and hair the way they are ☐	☐
29.	☐	☐	Some children do things they know they shouldn't do	**OR**	Some children hardly ever do things they know they shouldn't do ☐	☐

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	Really True for me	Sort of True for me			Sort of True for me	Really True for me
30.	☐	☐	Some children are very happy being the way they are	**OR**	Some children wish they were different ☐	☐
31.	☐	☐	Some children have trouble figuring out the answers in school	**OR**	Some children almost always can figure out the answers ☐	☐
32.	☐	☐	Some children are popular with others their age	**OR**	Some children are not very popular with others their age ☐	☐
33.	☐	☐	Some children don't do well at new outdoor games	**OR**	Some children feel they are good enough at sports ☐	☐
34.	☐	☐	Some children think that they are good looking	**OR**	Some children think that they are not very good looking ☐	☐
35.	☐	☐	Some children behave themselves very well	**OR**	Some children often find it hard to behave themselves ☐	☐
36.	☐	☐	Some children are not very happy with the way they do alot of things	**OR**	Some children think the way they do things is fine ☐	☐

This is the end of this part of the questionnaire. Thank you for answering the questions. Please turn to the next page.

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APPENDIX 3I

CHILDREN: PRE AND POST-BARRETSTOWN MEASURES FOR SELF-ESTEEM (TEENAGERS; 13-16 YEARS)

Self Perception Profile for Adolescents (SPPA)

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Here are some statements that ask you about what sort of person you are.
For each statement, decide whether you are more like the teenagers on the left side of the page or the teenagers on the right side of the page.
Then on the side of the page you have chosen, tick whether this part of the statement is sort of true for you or really true for you.
For each statement, you just <u>tick one box on the side of the page most like you.</u>

Before you start, you can try the example below.

1. **Read the example.**
2. **First decide whether you are more like the teenagers on the left side of the page who would rather go to the cinema, or whether you are more like the teenagers on the right side of the page who would rather go to sports events. When you have decided which kind of teenager is most like you, go to that side of the page.**
3. **Now decide whether what it says on this side of the page is only sort of true for you or really true for you. If it's sort of true, then put a tick in that box. If it's really for you, you put a tick in that box.**
4. **Now you can start the other statements.**

<u>EXAMPLE</u>

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
1.	☐	☐	Some teenagers like to go to the cinema in their spare time	**OR**	Some teenagers would rather go to sports events in their spare time	☐ ☐

.....

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
1.	☐	☐	Some teenagers feel that they are just as intelligent as others their age	**OR**	Some teenagers wonder if they are as intelligent as others their age	☐ ☐
2.	☐	☐	Some teenagers find it hard to make friends	**OR**	Some teenagers wonder if they are as intelligent as others their age easy to make friends	☐ ☐
3.	☐	☐	Some teenagers do very well at all kinds of sports	**OR**	Some teenagers don't feel that they are very good when it comes to sports	☐ ☐

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	Really True for me	Sort of True for me			Sort of True for me	Really True for me
4.	☐	☐	Some teenagers are not happy with the way the look	**OR**	Some teenagers are happy with the way they look ☐	☐
5.	☐	☐	Some teenagers feel that they are ready to do well at a part-time job	**OR**	Some teenagers feel that they are not quite ready to handle a part-time job ☐	☐
6.	☐	☐	Some teenagers feel that if they are romantically interested in someone, that person will like them back	**OR**	Some teenagers worry that when they like someone romantically, that person won't like them back ☐	☐
7.	☐	☐	Some teenagers usually do the right thing	**OR**	Some teenagers often don't do what they know is right ☐	☐
8.	☐	☐	Some teenagers are able to make really close friends	**OR**	Some teenagers find it hard to make really close friends ☐	☐
9.	☐	☐	Some teenagers are often disappointed with themselves	**OR**	Some teenagers are quite pleased with themselves ☐	☐
10.	☐	☐	Some teenagers are quite slow in finishing their school work	**OR**	Some teenagers can do their school work quickly ☐	☐
11.	☐	☐	Some teenagers have a lot of friends	**OR**	Some teenagers don't have very many friends ☐	☐
12.	☐	☐	Some teenagers think they could do well at just about any new athletic activity	**OR**	Some teenagers are afraid they might not do well at a new athletic activity ☐	☐
13.	☐	☐	Some teenagers wish their body was different	**OR**	Some teenagers like their body the way it is ☐	☐
14.	☐	☐	Some teenagers feel that they don't have enough skills to do	**OR**	Some teenagers feel that they do have enough skills to do a job well ☐	☐
15.	☐	☐	Some teenagers are not dating the people they are really attracted to	**OR**	Some teenagers are dating those people they are attracted to ☐	☐

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	Really True for me	Sort of True for me			Sort of True for me	Really True for me
16.	☐	☐	Some teenagers often get in trouble for the things they do	**OR**	Some teenagers usually don't do things that get them in trouble	☐ ☐
17.	☐	☐	Some teenagers do have a close friend they can share secrets with	**OR**	Some teenagers do not have a really close friend they can share secrets with	☐ ☐
18.	☐	☐	Some teenagers don't like the way they are leading their life	**OR**	Some teenagers do like the way they are leading their life	☐ ☐
19.	☐	☐	Some teenagers do very well at their classwork	**OR**	Some teenagers don't do very well at their classwork	☐ ☐
20.	☐	☐	Some teenagers are very hard to like	**OR**	Some teenagers are really easy to like	☐ ☐
21.	☐	☐	Some teenagers feel that they are better than others their age at sports	**OR**	Some teenagers don't feel they can play sports as well as others	☐ ☐
22.	☐	☐	Some teenagers wish their physical appearance (how they look) was different	**OR**	Some teenagers like their physical appearance (how they look) the way it is	☐ ☐
23.	☐	☐	Some teenagers feel they are old enough to get and keep a paying job	**OR**	Some teenagers do not feel they are old enough yet, to really handle a job well	☐ ☐
24.	☐	☐	Some teenagers feel that people their age will be romantically attracted to them	**OR**	Some teenagers worry about whether people their age will be attracted to them	☐ ☐
25.	☐	☐	Some teenagers feel really good about the way they act	**OR**	Some teenagers don't feel that good about the way they often act	☐ ☐
26.	☐	☐	Some teenagers wish they had a really close friend to share things with	**OR**	Some teenagers do have a close friend to share things with	☐ ☐

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	Really True for me	Sort of True for me			Sort of True for me	Really True for me
27.	☐	☐	Some teenagers are happy with themselves most of the time	**OR**	Some teenagers are often not happy with themselves ☐	☐
28.	☐	☐	Some teenagers have trouble figuring out the answers in school	**OR**	Some teenagers almost always can figure out the answers in school ☐	☐
29.	☐	☐	Some teenagers are popular with others their age	**OR**	Some teenagers are not very popular with others their age ☐	☐
30.	☐	☐	Some teenagers don't do well at new outdoor games	**OR**	Some teenagers are good at new game right away ☐	☐
31.	☐	☐	Some teenagers think they are good looking	**OR**	Some teenagers think that they are not very good looking ☐	☐
32.	☐	☐	Some teenagers feel like they could do better at work they do for pay	**OR**	Some teenagers feel that they are doing really well at work they do for pay ☐	☐
33.	☐	☐	Some teenagers feel that they are fun and interesting on a date	**OR**	Some teenagers wonder about how fun and interesting they are on a date ☐	☐
34.	☐	☐	Some teenagers do things they know they shouldn't do	**OR**	Some teenagers hardly ever do things they know they shouldn't do ☐	☐
35.	☐	☐	Some teenagers find it hard to make friends they can really trust	**OR**	Some teenagers are able to make close friends they can really trust ☐	☐
36.	☐	☐	Some teenagers like the kind of person they are a lot of things	**OR**	Some teenagers often wish they were someone else ☐	☐
37.	☐	☐	Some teenagers feel that they are quite intelligent	**OR**	Some teenagers question whether they are intelligent ☐	☐
38.	☐	☐	Some teenagers feel that they are socially accepted	**OR**	Some teenagers wished that more people their age accepted them ☐	☐

TRINITY COLLEGE LIBRARY DUBLIN

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
39.	☐	☐	Some teenagers do not feel that they are very athletic	**OR**	Some teenagers feel that they are very athletic ☐	☐
40.	☐	☐	Some teenagers really like their looks	**OR**	Some teenagers wished they looked different ☐	☐
41.	☐	☐	Some teenagers feel that they are really able to handle a part-time job	**OR**	Some teenagers wonder if they are really doing as good a job as they should be ☐	☐
42.	☐	☐	Some teenagers usually don't go out with the people they would really like to date	**OR**	Some teenagers do go out with the people they really want to date ☐	☐
43.	☐	☐	Some teenagers usually act the way they know they are supposed to	**OR**	Some teenagers often don't act the way they are supposed to ☐	☐
44.	☐	☐	Some teenagers don't have a friend that is close enough to share really personal thoughts with	**OR**	Some teenagers do have a close friend that they can share personal thoughts and feelings with ☐	☐
45.	☐	☐	Some teenagers are very happy being the way they are	**OR**	Some teenagers wish they were different ☐	☐

This is the end of this part of the questionnaire. Thank you for answering the questions. Please turn to the next page.

TRINITY COLLEGE LIBRARY DUBLIN

APPENDIX 3J

CHILDREN: PRE AND POST-BARRETSTOWN MEASURES FOR QUALITY OF LIFE (PATIENTS)

Perceived Illness Experience Scale (PIE)

TRINITY COLLEGE LIBRARY DUBLIN

About yourself NOW

Here are some sentences about what other people have told us how their illness affects their lives. Please read them carefully. We would like you to tick one box for each sentence to show what you think.

You may feel that some sentences did apply to you when you were younger, but not now. We only want to know about NOW:

	Really disagree	Disagree	Neither disagree nor agree	Agree	Really agree
1. My illness stops me from doing games or sports I like	❑	❑	❑	❑	❑
2. I feel my illness has made me look different	❑	❑	❑	❑	❑
3. I get teased or picked on more than other people	❑	❑	❑	❑	❑
4. I find it difficult to control my weight	❑	❑	❑	❑	❑
5. I easily let my feelings get the better of me	❑	❑	❑	❑	❑
6. I wonder why I became ill	❑	❑	❑	❑	❑
7. I use my illness to get out of things I don't want to do	❑	❑	❑	❑	❑
8. I am not always able to join in with what my friends are doing	❑	❑	❑	❑	❑
9. I find it hard to learn things because of my illness	❑	❑	❑	❑	❑
10. I get cross about how much my illness spoils my life	❑	❑	❑	❑	❑
11. I worry about other people who have the same illness I had	❑	❑	❑	❑	❑
12. I am afraid other people won't like me because of my illness	❑	❑	❑	❑	❑
13. I only tell people about my illness if I really have to	❑	❑	❑	❑	❑

TRINITY COLLEGE LIBRARY DUBLIN

	Really disagree	Disagree	Neither disagree nor agree	Agree	Really agree
14. There are some days I can't be bothered to eat	❑	❑	❑	❑	❑
15. If my illness upsets me I try not to show it	❑	❑	❑	❑	❑
16. I feel sad about the way I look	❑	❑	❑	❑	❑
17. I am worried about aches and pains	❑	❑	❑	❑	❑
18. I feel left out of things at school or work	❑	❑	❑	❑	❑
19. The way I look has changed because of my illness and treatment	❑	❑	❑	❑	❑
20. Other people expect too much of my work	❑	❑	❑	❑	❑
21. I hate being reminded of my illness	❑	❑	❑	❑	❑
22. I feel other people try to put me down	❑	❑	❑	❑	❑
23. My parents make a fuss of me because of my illness	❑	❑	❑	❑	❑
24. I get cross when people ask about my illness	❑	❑	❑	❑	❑
25. My hair has been spoiled by the treatment	❑	❑	❑	❑	❑
26. My parents make a fuss about what I eat	❑	❑	❑	❑	❑
27. My illness makes many problems for my family	❑	❑	❑	❑	❑
28. I am usually too tired to go out in the evening	❑	❑	❑	❑	❑
29. I worry that people talk about me behind my back	❑	❑	❑	❑	❑
30. My parents treat me like a baby	❑	❑	❑	❑	❑
31. I can get away with a lot more in school or at work because of my illness	❑	❑	❑	❑	❑
32. I wish I knew other people with my illness	❑	❑	❑	❑	❑
33. I am afraid of doing sports where I might get hurt	❑	❑	❑	❑	❑
34. My parents use my illness to stop me doing things	❑	❑	❑	❑	❑

	Really disagree	Disagree	Neither disagree nor agree	Agree	Really agree
35. Some days I find the smell of food puts me off	❑	❑	❑	❑	❑
36. I feel I get blamed for things that aren't my fault	❑	❑	❑	❑	❑

This is the end of all parts of this questionnaire. Thank you very much for your time and help answering the questions. Please give this questionnaire to your parents/guardians to put in the envelope for posting to Barretstown.

APPENDIX 3K

CHILDREN: PRE AND POST-BARRETSTOWN MEASURES FOR QUALITY OF LIFE (SIBLINGS)

Sibling Perception Questionnaire (SPQ)

This is the last part of the questionnaire. Please circle one answer for each sentence that best describes how often you feel this way. Where there are blanks, please fill them in.

1. I can talk to my parents about my school work ----------Never A Little Sometimes Alot Always

2. I sometimes feel mad about my brother/sister's illness -----Never A Little Sometimes Alot Always

The reasons why it makes me mad are;

_____

_____

_____

_____

3. I worry that I can catch the illness from my brother/sister--Never A Little Sometimes Alot Always

4. I feel my friends worry about catching the illness from-----Never A Little Sometimes Alot Always
my brother/sister

5. I think about my brother/sister's illness----------Never A Little Sometimes Alot Always

Some things I think about are;

_____

_____

_____

_____

6. I still wonder why my brother/sister got sick----------Never A Little Sometimes Alot Always

7. I wish my parents would spend less time----------Never A Little Sometimes Alot Always
with my sick brother/sister

8. I wish there was something I could do to----------Never A Little Sometimes Alot Always
make my brother/sister feel better

9. I understand my parents have to spend ----------Never A Little Sometimes Alot Always
more time with my sick brother/sister

10. I feel I have too much to do around the ----------Never A Little Sometimes Alot Always
house since my brother/sister got sick

11. I am afraid of my brother/sister's illness----------Never A Little Sometimes Alot Always

Some things I am afraid of are;

12. Since my brother/sister got sick, I feel my parents ignore me ----------Never A Little Sometimes Alot Always

13. Since my brother/sister got sick we don't do as many things as a family ----------Never A Little Sometimes Alot Always

14. I wish my parents would spend more time me ----------Never A Little Sometimes Alot Always

15. I can talk to other people my age about my brother's/ sisters illness ----------Never A Little Sometimes Alot Always

16. I can talk to my parents about my brother/sister's illness --Never A Little Sometimes Alot Always

17. I can talk to other adults (like my teachers) about my brother's/sister's illness ----------Never A Little Sometimes Alot Always

18. I feel people are more interested in my brother's/sister's illness than they are in me ----------Never A Little Sometimes Alot Always

19. Since my brother/sister got sick people don't care how I feel ----------Never A Little Sometimes Alot Always

20. I feel I don't want to bother my parents with my worries--Never A Little Sometimes Alot Always

21. I wish I knew someone who understands how I feel about my brother/sister's illness --------Never A Little Sometimes Alot Always

22. My brother/sister's illness makes me sad ----------Never A Little Sometimes Alot Always

The reasons why it makes me sad are;

23. When my brother/sister got sick, my parents told me about it ----------Never A Little Sometimes Alot Always

The things I was told were;

This is the end of all parts of this questionnaire. Thank you very much for your time and help answering the questions. Please give this questionnaire to your parents/guardians to put in the envelope for posting to Barretstown.

APPENDIX 3L

CHILDREN: PRE AND POST-BARRETSTOWN MEASURES FOR SOCIAL SUPPORT (TIME 1)

Social Support Scale (SSS)

Here are some statements about yourself and other people.
As before, for each statement, decide whether you are more like the children on the left side of the page or the children on the right side of the page.
Then on the side of the page you have chosen, tick whether this part of the statement is sort of true for you or really true for you.
For each statement, you just <u>tick one box on the side of the page most like you.</u>

Before you start, you can try the example below.

1. **Read the example.**
2. **First, decide whether you are more like the children on the left side of the page who would rather do fun things with a lot of other people, or whether you are more like the children on the right side of the page who would rather do fun things with just a few people. When you have decided which child is most like you, go to that side of the page.**
3. **Now decide whether what it says on this side of the page is only sort of true for you or really true for you. If it's only sort of true, then put a tick in that box. If it's really true for you, you put a tick in that box.**
4. **Now you can start the other statements.**

<u>EXAMPLE</u>

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
1.	☐	☐	Some children like to do fun things with a lot of other people	**OR**	Some children like to do fun things with just a few people	☐ ☐

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
1.	☐	☐	Some children have parents who don't really understand them	**OR**	Some children have parents who really do understand them	☐ ☐
2.	☐	☐	Some children have classmates who like them the way they are	**OR**	Some children have classmates who wish they were different	☐ ☐
3.	☐	☐	Some children have a teacher who helps them if they are upset and have a problem	**OR**	Some children don't have a teacher who helps them if they are upset and have a problem	☐ ☐

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
4.	☐	☐	Some children have a close friend who they can tell problems to	**OR**	Some children don't have a close friend who they can tell problems to	☐	☐
5.	☐	☐	Some children have parents who don't seem to want to hear about their children's problems	**OR**	Some children have parents who do want to listen to their children's problems	☐	☐
6.	☐	☐	Some children have classmates that they can become friends with	**OR**	Some children don't have classmates that they can become friends with	☐	☐
7.	☐	☐	Some children don't have a teacher who helps them to do their very best	**OR**	Some children do have a teacher who helps them to do their very best	☐	☐
8.	☐	☐	Some children have a close friend who really understands them	**OR**	Some children don't have a close friend who understands them	☐	☐
9.	☐	☐	Some children have parents who care about their feelings	**OR**	Some children have parents who don't seem to care very much about their feelings	☐	☐
10.	☐	☐	Some children have classmates who sometimes make fun of them	**OR**	Some children don't have classmates who make fun of them	☐	☐
11.	☐	☐	Some children do have a teacher who cares about them	**OR**	Some children don't have a teacher who cares about them	☐	☐
12.	☐	☐	Some children have a close friend who they can talk to about things that bother them	**OR**	Some children don't have a close friend who they can talk to about things that bother them	☐	☐
13.	☐	☐	Some children have parents who treat them like a person who really matters	**OR**	Some children have parents who don't usually treat them like a person who matters	☐	☐

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
14.	☐	☐	Some children have classmates who pay attention to what they say	**OR**	Some children have classmates who usually don't pay attention to what they say	☐ ☐
15.	☐	☐	Some children don't have a teacher who is fair to them	**OR**	Some children do have a teacher who is fair to them	☐ ☐
16.	☐	☐	Some children don't have a close friend who they like to spend time with	**OR**	Some children do have a close friend who they like to spend time with	☐ ☐
17.	☐	☐	Some children have parents who like them the way they are	**OR**	Some children have parents who wish their their children were different	☐ ☐
18.	☐	☐	Some children don't get asked to play in games with classmates very often	**OR**	Some children often get asked to play in games by their classmates	☐ ☐
19.	☐	☐	Some children don't have a teacher who cares if they feel bad	**OR**	Some children do have a teacher who cares if they feel bad	☐ ☐
20.	☐	☐	Some children don't have a close friend who really listens to what they say	**OR**	Some children do have a close friend who really listens to what they say	☐ ☐
21.	☐	☐	Some children have parents who don't act like what their children do is important	**OR**	Some children have parents who do act like what their children do is important	☐ ☐
22.	☐	☐	Some children often spend their breaks in school alone	**OR**	Some children spend their breaks in school playing with their classmates	☐ ☐
23.	☐	☐	Some children have a teacher who treats them like a person	**OR**	Some children don't have a teacher who treats them like a person	☐ ☐
24.	☐	☐	Some children don't have a close friend who cares about their feelings	**OR**	Some children do have a close friend who cares about their feelings	☐ ☐

This is the end of this part of the questionnaire. Thank you for answering the questions. Please turn to the next page.

APPENDIX 4A

PARENTS: COVERING LETTER (TIME 1)



The Barretstown Gang Camp

(A Hole in the Wall Gang Camp)
Barretstown Castle, Ballymore Eustace, Co. Kildare, Ireland. Telephone: +353 45 864115 Fax: +353 45 864711
e-mail: info@barretstowngc.ie Site: www.barretstowngc.ie

Dear Parent,

We are very much looking forward to having your child in The Barretstown Gang Camp for our summer programme. As we wish to continuously develop this summer programme, we are asking all the children attending Barretstown this year and their parents/guardians to help us by taking part in an important project.

This project is being carried out in 4 parts: now, while your child is in Barretstown, 2 weeks after each child returns home from Barretstown and 6 months later. Each part involves you and/or your child completing a questionnaire that asks for your views about our summer programme and also looks at the relation between your child's experience of our programme and how it may have affect their feelings and health. Participation in this project is entirely voluntary, but it would be very helpful for Barretstown if you and your child take part.

In relation to part one, the questionnaire for you and your child are enclosed. The questionnaire on white paper is for you to complete and the questionnaire on coloured paper is for your child to fill in. If you have more than one child coming to Barretstown this summer, please complete these questionnaires only in relation to your child coming in the next two weeks. If your child needs help reading and understanding any of the questions, please help him/her, but do not influence his/her choice of responses. **Both your own and your child's answers to the questions will be kept completely anonymous and all information will be treated with the utmost confidentiality.**

Please use the provided freepost envelopes to return the questionnaires to us **BEFORE** your child comes to Barretstown. We very much hope that you will take part in this project. We look forward to hearing from you.

With best wishes,

Gemma Kiernan
Programme Research & Development Co-ordinator

APPENDIX 4B

PARENTS: COVERING LETTER (TIME 2)



The Barretstown Gang Camp

(A Hole in the Wall Gang Camp)
Barretstown Castle, Ballymore Eustace, Co. Kildare, Ireland. Telephone: +353 45 864115 Fax: +353 45 864711
e-mail: info@barretstowngc.ie Site: www.barretstowngc.ie

Dear Parent,

It was a pleasure having your child in The Barretstown Gang Camp this summer. We hope that your child enjoyed their 10 days with us. I would like to thank you and your child for doing the first two parts of our project which will help us develop our summer programme. We appreciate the time you and your child took to complete and return the questionnaires to us and your responses have been really helpful.

We are now in the third part of this research project and once more, we are asking parents/guardians of children who attended Barretstown this summer and the children themselves to complete similar questionnaires. As before, these questionnaires ask you and your child for your views about the summer programme and also look at the relation between your child's experience of our programme and how it may have affect their feelings and health.

Once again, participation in this project is entirely voluntary. However, it would be very helpful for Barretstown if you and you child take part especially since you have been so good as to complete the previous parts.

As before, the questionnaire marked 'parent/guardian questionnaire' is for you to complete and the questionnaire marked 'camper questionnaire' is for your child to fill in. If your child needs help reading and understanding any of the questions, please help him/her, but do not influence his/her choice of responses. **Both your own and your child's answers to the questions will be kept completely anonymous and all information will be treated with the utmost confidentiality.**

Please use the provided freepost envelopes to return the questionnaires to us **AS SOON AS POSSIBLE.** We greatly appreciate all your time and help with this project as it will help us develop our programme. We look forward to hearing from you.

Best wishes,

Gemma Kiernan
Programme Research and Development Co-ordinator

APPENDIX 4C

PARENTS: COVERING LETTER (TIME 3)



The Barretstown Gang Camp

(A Hole in the Wall Gang Camp)
Barretstown Castle, Ballymore Eustace, Co. Kildare, Ireland. Telephone: +353 45 864115 Fax: +353 45 864711
e-mail: info@barretstowngc.ie Site: www.barretstowngc.ie

Dear Parent/Guardian

We would like to thank you and your child for participating in our project to date to help us develop our summer programme. We appreciate the time you and your child took to complete and return the questionnaires to us and your responses have been really helpful.

We are now in the final part of this project and for the last time, we are asking parents/guardians of children who attended Barretstown during the summer and the children themselves, to complete similar questionnaires. As with previous parts, these questionnaires ask you and your child for your views about the summer programme and also look at the relation between your child's experience of our programme and how it may affect his/her feelings and health.

As you are aware, participation in this project is entirely voluntary. However, it would be very helpful for Barretstown if you and your child participate in this final part, especially since you have been so good as to complete all the previous parts.

As before, the questionnaire marked 'parent/guardian questionnaire' is for you to complete and the questionnaire marked 'camper questionnaire' is for your child to fill in. If your child needs help reading and understanding any of the questions, please help him/her, but do not influence his/her choice of responses. **Both your own and your child's answers to the questions will be kept completely anonymous and all information will be treated with the utmost confidentiality.**

Please use the provided freepost envelopes to return the questionnaires to us **AS SOON AS POSSIBLE**. We greatly appreciate all your help with this project as it is enables us to strengthen our programme. As a small token of our appreciation and as a memento of the time we shared with your child in Barretstown, we have enclosed a special photograph of Barretstown Castle for your family. We look forward to hearing from you in this final part of the project.

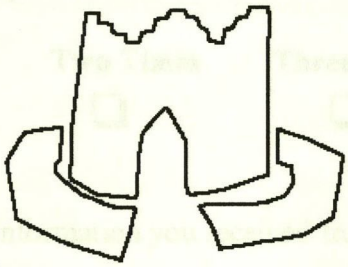
With thanks and best wishes,

Gemma Kiernan
Programme Research and Development Co-ordinator

APPENDIX 4D

PARENTS: QUESTIONNAIRE (TIME 1)

The Barretstown Gang Camp



PARENT/GUARDIAN QUESTIONNAIRE

PART 1

This part of the questionnaire asks you for your views about The Barretstown Gang Camp. Please answer all the questions honestly. Your responses will be kept confidential.

1. What is the name of your child attending Barretstown in a couple of weeks time?

Full Name of Child:_____

2. How many times before has your child been to Barretstown for a summer session? (Please tick appropriate box)

Never	One Time	Two Times	Three times	More
❑	❑	❑	❑	❑

3. How do you feel about the information you received from Barretstown this year telling you about the camp?
(Please tick appropriate box)

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
❑	❑	❑	❑	❑

4. Do you have any suggestions for improving the information you received from Barretstown this year? Please explain.

_____

_____

_____

_____

_____

_____

_____

_____

5. Do you have any hopes for your child in allowing him/her to come to Barretstown? Please explain.

6. Do you have any concerns for your child in allowing him/her to come to Barretstown? Please explain.

7. What are the pros and cons of being away from your child while he/she is in Barretstown?

PROS:

CONS:

This is the end of this part of the questionnaire. Please turn to the next page.

PART 2

Sent only to parents who had children with a life-threatening illness going to Barretstown

These are some questions about your child's illness and health. Remember, <u>all your responses will be kept strictly confidential.</u>

1. What illness does your child have?

Name of Illness:_____

2. How old was your child when his/her illness was first diagnosed?

_____**years**

3. Is your child currently on active treatment for his/her illness?
(Please tick the appropriate box)

Yes	**No**
❑	❑

4. Have there been any changes in your child's illness over the last 3 months?

Yes ❑ **No** ❑
(If **yes**, please explain)

_____

_____

_____

_____

_____

5. How would you rate your child's health over the last 3 months?

Very Poor	**Poor**	**Fair**	**Good**	**Very Good**
❑	❑	❑	❑	❑

6. Do any other members of your family have a chronic illness?
(Please tick appropriate box)

Yes ❑ **No** ❑

If Yes, which family members?

_____

_____

_____

_____

This is the end of this part of the questionnaire. Please turn to the next page.

PART 2

Sent only to parents who had <u>siblings</u> of children with a life-threatening illness going to Barretstown.

These are some questions about your children's health. Remember, <u>all your responses will be kept strictly confidential.</u>

1. How would you rate your child's state of health over the last month?

Very Poor	Poor	Fair	Good	Very Good
❑	❑	❑	❑	❑

2. Have there been any changes in your child's health over the last 3 months?

Yes ❑ No ❑

(If **yes**, please explain)

_____

_____

_____

_____

_____

The following questions ask you about your child who has an illness (who is <u>not going to Barretstown</u> in the next couple of weeks):

3. What illness does your child have?

Name of Illness:_____

4. Is your child currently on active treatment for his/her illness?
(Please tick the appropriate box)

Yes	No
❑	❑

5. Have there been any changes in your child's illness over the last 3 months?

Yes ❑ No ❑

(If **yes**, please explain)

_____

_____

_____

_____

_____

6. How would you rate this child's state of health over the last 3 months?

Very Poor	**Poor**	**Fair**	**Good**	**Very Good**
❑	❑	❑	❑	❑

7. Do any other members of your family have a chronic illness?
(Please tick appropriate box)

Yes	**No**
❑	❑

If **Yes,** which family members?

_____

_____

_____

_____

This is the end of this part of the questionnaire. Please turn to the next page.

PART 3

This final part of this questionnaire asks you for some background information.

1. What is your relationship to the child attending Barretstown?

Relationship to child:_____

2. How much did you help your child to complete his/her own questionnaire.

No help	**A Little help**	**A lot of help**
❑	❑	❑

3. Please write today's date.

Date:_____

4. Please write any comments you have about Barretstown, your child, or this research project.

_____

_____

_____

_____

_____

_____

_____

_____

This is the end of the questionnaire. Thank you very much for your time and help answering the questions.

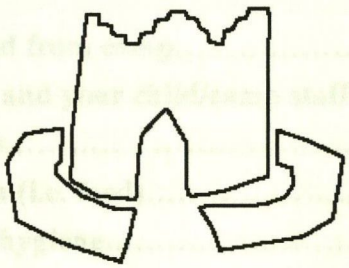
Please return this completed questionnaire and your child's completed questionnaire in the stamped addressed envelope to:

Gemma Kiernan
Programme Research and Development Co-ordinator
The Barretstown Gang Camp
Ballymore Eustace
Co. Kildare
Ireland

APPENDIX 4E

PARENTS: QUESTIONNAIRE (TIME 2)

The Barretstown Gang Camp



PARENT/GUARDIAN QUESTIONNAIRE

This questionnaire asks you for your views about The Barretstown Gang Camp and about your child. Please answer all the questions honestly. <u>Your responses will be kept confidential.</u>

1. How do you feel about the following arrangements made by Barretstown Gang Camp for your child:

	Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied
transport of your child to and from camp	❑	❑	❑	❑	❑
level of contact between you and your child/camp staff	❑	❑	❑	❑	❑
adequacy of medical services	❑	❑	❑	❑	❑
standard of general nutrition (i.e. food)	❑	❑	❑	❑	❑
maintenance of your child's hygiene	❑	❑	❑	❑	❑
programme of camp activities	❑	❑	❑	❑	❑
camp staff caring for your children	❑	❑	❑	❑	❑

2. How has your child settled back to home and everyday life since returning from Barretstown?

3. How do you feel your child got on in Barretstown?

4. Do you feel that your child benefited from his/her experience in Barretstown? Please explain.

5. Do you have any worries about your child's experience in Barretstown? Please explain.

6. Do you have any suggestions about how your contact with and your child's experience of Barretstown can be improved? Please explain.

Sent only to parents who had children with a life-threatening illness going to Barretstown

7. Have there been any changes in your child's illness over the last month?

Yes ❑ **No** ❑

(If **yes**, please explain)

_____

_____

_____

_____

8. How would you rate your child's health over the last month?

Very Poor	**Poor**	**Fair**	**Good**	**Very Good**
❑	❑	❑	❑	❑

Sent only to parents who had <u>siblings</u> of children with a life-threatening illness going to Barretstown.

7a. Have there been changes in your child's health over the last month?

Yes ❑ **No** ❑

(If **yes**, please explain)

_____

_____

_____

_____

_____

7b. How would you rate your child's state of health over the last month?

Very Poor	**Poor**	**Fair**	**Good**	**Very Good**
❑	❑	❑	❑	❑

In relation to your child who has an illness:

8a. Have there been any changes in your child's illness over the last month?

Yes ❑ **No** ❑

(If **yes**, please explain)

_____

_____

_____

_____

_____

8b. How would you rate this child's state of health over the last month?

Very Poor	**Poor**	**Fair**	**Good**	**Very Good**
❑	❑	❑	❑	❑

---

9. What is your relationship to the child attending Barretstown?

Relationship to child:_____

10. How much did you help your child to complete his/her questionnaire.

No help	**A Little help**	**A lot of help**
❑	❑	❑

11. Please write today's date.

Date:_____

12. Please write any comments you have about Barretstown, your child, or this research project.

This is the end of the questionnaire. Thank you very much for your time and help answering the questions.

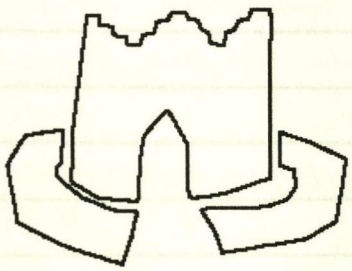
Please return this completed questionnaire and your child's completed questionnaire in the stamped addressed envelope to:

Gemma Kiernan
Programme Research and Development Co-ordinator
The Barretstown Gang Camp
Ballymore Eustace
Co. Kildare
Ireland

APPENDIX 4F

PARENTS: QUESTIONNAIRE (TIME 3)

The Barretstown Gang Camp



PARENT/GUARDIAN QUESTIONNAIRE

This questionnaire asks you for your views about The Barretstown Gang Camp and about your child. Please answer all the questions honestly. <u>Your responses will be kept confidential.</u>

1. What is the name of your child who attended Barretstown last summer ?

   Full Name of Child:_____

2. Does your child talk now about the time he/she spent in Barretstown ?

   Yes ❑ No ❑

   (Please explain)

3. Do you feel that your child benefited from his/her experience in Barretstown in the long term?

   Yes ❑ No ❑

   (Please explain)

4. Do you have any worries about your child's experience in Barretstown in the long term?

Yes ❑ No ❑

(Please explain)

5. Do you have any suggestions now about how your contact with and your child's experience in Barretstown can be improved?

Yes ❑ No ❑

(Please explain)

Sent only to parents who had children with a life-threatening illness going to Barretstown

6. Was your child on active treatment for his/her illness in the weeks following his/her stay in Barretstown?

Yes ❑ No ❑

7. Is your child currently on active treatment for his/her illness?

Yes ❑ **No** ❑

8. Have there been any changes in your child's illness over the last 6 months?

Yes ❑ **No** ❑

(If **yes**, please explain)

_____

_____

_____

_____

9. How would you rate your child's state of health over the last 6 months?

Very Poor	**Poor**	**Fair**	**Good**	**Very Good**
❑	❑	❑	❑	❑

Sent only to parents who had <u>siblings</u> of children with a life-threatening illness going to Barretstown.

6. Have there been changes in your child's health over the last 6 months?

Yes ❑ **No** ❑

(If **yes**, please explain)

_____

_____

_____

_____

_____

7. How would you rate your child's state of health over the last 6 months?

Very Poor	**Poor**	**Fair**	**Good**	**Very Good**
❑	❑	❑	❑	❑

In relation to your child who has an illness:

8a. Was your child on active treatment for his/her illness in the weeks following his/her brother/sister's stay in Barretstown?

Yes ❑ No ❑

8b. Is your child currently on active treatment for his/her illness?

Yes ❑ No ❑

9a. Have there been any changes in your child's illness over the last 6 months?

Yes ❑ No ❑
(If **yes**, please explain)

_____

_____

_____

_____

_____

9b. How would you rate this child's state of health over the last 6 months?

Very Poor	**Poor**	**Fair**	**Good**	**Very Good**
❑	❑	❑	❑	❑

---

10. What is your relationship to the child attending Barretstown?

Relationship to child:_____

11. How much did you help your child to complete his/her questionnaire.

No help	**A Little help**	**A lot of help**
❑	❑	❑

12. Please write today's date.

Date:_____

13. Please write any comments you have about Barretstown, your child, or this research project.

_____

_____

_____

_____

_____

_____

_____

_____

This is the end of the questionnaire. Thank you very much for your time and help answering the questions.

Please return this completed questionnaire and your child's completed questionnaire in the stamped addressed envelope to:

Gemma Kiernan
Programme Research and Development Co-ordinator
The Barretstown Gang Camp
Ballymore Eustace
Co. Kildare
Ireland

APPENDIX 4G

REMINDER CARD TO RETURN QUESTIONNAIRES AT EACH TIME PERIOD



The Barretstown Gang Camp

(A Hole in the Wall Gang Camp)
Barretstown Castle, Ballymore Eustace, Co. Kildare, Ireland. Telephone: +353 45 864115 Fax: +353 45 864711
e-mail: info@barretstowngc.ie Site: www.barretstowngc.ie

Dear Parent/Guardian

Following our questionnaire which was sent to you a couple of weeks ago we would like to thank you for all your time and assistance with our project to help us develop The Barretstown Gang Camp summer programme. If you have not yet been able to send the questionnaire from this part of the project back to us and would still like to do so, please return the questionnaire to Gemma Kiernan, Programme Research & Development Co-ordinator, The Barretstown Gang Camp, Ballymore Eustace, Co. Kildare, Ireland.

Thank you for all help

Best wishes,

Gemma Kiernan

APPENDIX 5A

FACTOR ANALYSES OF MEASURES: GUIDELINES

PSYCHOMETRIC EVALUATION OF MEASURES[1] FOR CHILDREN

FACTOR ANALYTIC TECHNIQUES: BACKGROUND INFORMATION AND CRITERIA FOR ANALYSIS

In evaluating the psychometric properties of the measures used in Part 2 of this study to assess children's well being, factor analytic techniques were employed. As previously outlined (i.e. Chapter 3; Method section), the children's responses to the measures administered at Time 1 were factor analysed since they represented the pre-intervention or baseline assessment and comprised the highest number.

- The appropriateness of factor analysis for each of the measures was determined by the adequacy of sample size. At a general level, it is recommended that factor analysis is suitable where the sample size is greater than 100 (Cooper, 1998). Other researchers vary from advocating that the sample size needs to be at least 5 times greater than the number of variables (Hair et al, 1995), to 10 times greater than the number of variables (e.g. Nunally, 1978). There are other findings indicating that factor analysis is acceptable when the sample size is greater than the number of variables as long as the factor loadings are high (Barrett & Kline, 1981; Guadagnoli & Velicer, 1988). In factor analysing the measures in this study, a sample size that was at least 5 times greater than the number of variables was deemed necessary. In the case of measures where the sample size was not 5 times greater than the number of variables, each of the subscales in the measure were separately factor analysed. The appropriateness of factor analysis for each of the measures was also decided by

[1] Each measure factor analysed with the sample of children in this research has the prefix 'R' for 'revised' to differentiate it from the original form.

the overall significance of the correlation matrix assessed by the Kaiser-Meyer Olkin Measure of Sampling Adequacy (KMO) and by the Bartlett Test of Sphercity.

- Where the measures used in this study had been previously factor analysed, the approach taken by the original author to establish the factor structure of that measure, was replicated as closely as possible. That is, the approach taken by the original author largely determined the type of rotation to use, the method of extraction to employ, and the number of factors to extract. Where the measures in this study had not been previously factor analysed, the original author's preconceived ideas about the number of subscales in that measure, coupled with the purpose for which the measure would be used in later analyses and the data at hand, indicated the type of rotation to use, the method of extraction to employ, and the number of factors to extract.

- A number of estimation criteria were employed to make judgements regarding the retention of factors. These included the eigenvalues (Kaiser, 1961), the percentage of variance explained (Hair et al, 1995), the scree test (Cattell, 1966) and the interpretability of resulting factor structures (Gorsuch, 1983).

- In terms of item selection, items that have factor loadings of .30 or greater are considered to meet the minimal level for inclusion; loadings of .40 are considered more important, and loadings of .50 or greater are considered practically significant (Hair et al, 1995). The constitution of a 'significant loading' on a factor can also vary with sample size, for example, a loading of .4 or above is considered

significant when the sample size is 200 or higher (see Hair et al, 1995). The criteria for retention of an item in this study was that it had to have a loading of .4 or greater on one factor (Hair et al, 1995). In addition, to ensure a parsimonious solution, where an item loaded on more than one factor, it was decided that the difference in loading between factors must be at least .2 to retain that item on the factor where it had the higher loading.

- The reliability of each factor analysed measure and their inherent subscales was established using Cronbach's coefficient alpha which is based on internal consistency estimating the proportion of variance due to all common factors among the items (Cronbach, 1951). While an alpha co-efficient of .7 or greater is generally considered optimal, a co-efficient of .6 or higher was considered acceptable for the factor analytically derived scales in this research. This was because in some cases, some of the original scales/subscales being used in this research had a co-efficient of .6 or lower (e.g. Eiser et al, 1995; Eiser et al, 1999).

APPENDIX 5B

FACTOR ANALYSIS OF THE PHYSIOLOGICAL HYPERAROUSAL-POSITIVE AND NEGATIVE AFFECT SCALE FOR CHILDREN (PH-PANAS-C)

FACTOR ANALYSIS: PH-PANAS-C

FACTOR ANALYSIS OF PH-PANAS-C WITH THE ORIGINAL SAMPLE (Laurent et al, 1999)

The psychometric properties of the PA and NA scales were initially examined by Laurent et al (1999) with a sample of American school children (N = 349, mean age = 11.6 years, S.D. = 1.5). This analysis occurred in several steps;

- First, corrected item-total correlations were generated for the entire 15 item PA and 15 item NA scales. An item was considered weak if it had a corrected item–total correlation less than or equal to .30.

- Separate factor analyses were conducted for the PA and NA scales. Each scale was subjected to a common unrotated factor analysis (i.e. principal axis factoring (PAF). Guided by the recommendations of Gorsuch (1997) oblique rotations were also used in the factor analysis and the structure matrix was examined to determine the relationship of each item to the factor.

- Once Laurent et al (1999) had identified the PA and NA items to retain, a PAF was conducted with the 27-item PANAS-C scale. Laurent et al (1999) reasoned that the item selection procedures and the theoretical underpinnings of the PANAS-C favoured 2 components emerging from the factor analysis. Therefore, the analysis was done specifying a 2-factor solution.

- The reliabilities of the scales were established using Cronbach's Alpha.

- There is preliminary information regarding the psychometric properties of the PH scale (Laurent et al, 1998). As part of a larger study with the PANAS-C, 245 school children (Grades 4-12) completed the PH-C. Item total correlations and Cronbach alpha co-efficients were obtained.

FACTOR ANALYSIS OF PH-PANAS-C WITH THE SAMPLE IN THIS STUDY

Sample

This sample comprised 240 children; 126 boys (52.5%) and 114 girls (47.5%) with a mean age of 11.4 years (S.D.=2.3). Of these, 197 children (82.1%) had been diagnosed with a chronic illness, and 43 children (17.9%) were siblings of children with a chronic illness. In relation to children with an illness, 162 children (82.1%) had been diagnosed with a form of cancer, 15 (7.7%) had a haematological related illness, 9 (5.1%) had an immunodeficiency related illness and 5 (2.6%) had a renal related illness. There were 6 children (3%) whose illnesses were not indicated. The children were from 16 European countries (see Table 5B.1 for a breakdown).

Table 5B.1: Number and percentage of children from each country who completed the PH-PANAS-C

Country	Number	Percentage
England	63	26.3%
Ireland	59	24.6%
Germany	20	8.3%
Spain	18	7.5%
Hungary	15	6.3%
Czech Republic	12	5.0%
Poland	11	4.6%
Sweden	9	3.8%
Russia	8	3.3%
Iceland	7	2.9%
Switzerland	5	2.1%
Cyprus	4	1.7%
Denmark	3	1.3%
Austria	3	1.3%
Norway	2	0.8%
Georgia	1	0.4%

Procedure

The ratio of the sample size to the number of variables in this part of the research exceeded the recommended 5-1 ratio (Hair et al, 1995). This provided an adequate basis for the calculation of the correlations among variables in the factor analyses. To correspond with Laurent et al's (1999) approach, corrected item total correlations, principal axis factoring with an oblique rotation using the structure matrix, and Cronbach's Alpha were employed to explore the factor structure and reliability of the PH-PANAS-C with the population of children in this study.

Results

Positive Affect Scale

Table 5B.2 presents the corrected item total correlations and the results of a factor analysis using principal axis factoring and examining the unrotated and oblique rotations for the PA scale in the PANAS-C.

Table 5B.2: Corrected item-total correlations and factor analysis of the PA scale

PA Scale	Item-Total Correlations	Unrot	Factor 1	Factor 2	Factor 3
Interested	.39	.46	.31	-.53	.15
Alert	.20	.22	.20	-.03	.42
Excited	.22	.30	-.56	-.56	-.04
Happy	.51	.63	.55	-.57	.22
Strong	.43	.48	.34	-.18	.66
Energetic	.45	.59	.47	-.33	.23
Calm	.15	.18	.12	-.22	-.06
Cheerful	.52	.63	.63	-.39	.31
Active	.50	.59	.64	-.21	.27
Proud	.37	.42	.23	-.44	.38
Joyful	.46	.57	.53	-.39	.19
Fearless	.13	.13	.17	.16	.33
Delighted	.50	.59	.47	-.51	.27
Daring	.32	.37	.45	.01	.31
Lively	.48	.60	.69	-.17	.27
Eigenvalue:		3.4	.92	.56	.53
% of variance:		26.6%	22.9%	6.2%	3.7%

The Kaiser-Meyer-Olkin measure of Sampling Adequacy (KMO) was .82 and Bartlett's test of the correlation matrix was significant at the $p < .0001$, confirming that factor analysis was an appropriate procedure to use with the data at hand. Table 5B.2 indicates that the items *calm*, *fearless*, *alert* and *excited* failed to meet the item total correlation of being greater than or equal to .30. In relation to reliability, the alpha co-efficient for the scale was .75. With regard to the factor analysis, the unrotated analysis showed that

some items had low/unacceptable loadings on the unrotated first factor (e.g. *calm, fearless, alert* and *excited*). As such, and to correspond with Laurent et al's (1999) approach, the oblique rotation was examined. As is evident from Table 5B.2, this revealed 3 factors with cross loadings on factors. The items *calm* and *fearless* failed to load properly on any one factor. The item *alert* had a low loading on the third factor. In light of the low item total correlations and the factor loadings, it was therefore decided to exclude the items *calm, fearless, alert* and *excited* (although the item *excited* loaded on the second factor, its low corrected item total correlation led to a decision to exclude this also). Following Laurent et al's approach, the 11 remaining PA items were then subjected to a second factor analysis (see Table 5B.3) and an alpha reliability coefficient was computed.

Table 5B.3: Corrected item-total correlations and factor analysis for the 11-item PA scale

Item	Item Total Correlations	Unrotated Solution	Factor 1	Factor 2
Interested	.38	.45	.49	.31
Happy	.52	.63	.70	.40
Strong	.41	.43	.36	.43
Energetic	.48	.54	.38	.62
Cheerful	.55	.63	.65	.48
Active	.53	.61	.43	.70
Proud	.36	.41	.45	.27
Joyful	.51	.58	.55	.50
Delighted	.51	.58	.61	.42
Lively	.48	.56	.43	.60
Daring	.32	.37	.26	.43
Eigenvalue:		3.8	2.7	2.6
% of variance:		34.2%	28.4%	5.2%

The Kasier-Meyer-Olkin Measure of Sampling Adequacy (KMO) (.84) and the results of the Bartlett Test of Sphercity ($p < .0001$) indicated the appropriateness of factor

analysis for examining this data. As expected, the corrected item-total correlations continued to exceed the .30 criterion (range = .32 to .55) and Cronbach's alpha co-efficient was .79. The unrotated solution revealed 2 factors, but all items loaded highly on the first factor. When the factor matrix underwent an oblique rotation, most items experienced significant cross-loadings on the 2 factors. It is interesting to note that these 2 factors corresponded to what Laurent et al (1999) found, and named a 'Pleasantness' factor (i.e. happy, cheerful, delighted, joyful, interested, proud) and an 'Aroused/Activated' factor (active, energetic, lively, daring and strong). The factors were sufficiently correlated with each other (.64) to follow Laurent et al's (1999) approach and replace them with 1 factor and therefore, view the PA scale as uni-dimensional.

Comparison between the Results of the Factor Analysis with Original Sample (Laurent et al, 1999) and Factor Analysis with the Sample in this Research for the PA Scale

The items *alert*, *fearless* and *daring* were eliminated from their PA scale as a result of factor analysis with the original sample (Laurent et al, 1999). The items *alert*, *fearless*, *calm* and *excited* were eliminated from the PA scale following factor analysis with the sample in this research. There is therefore overlap in the exclusion of the items *alert* and *fearless* and in the emergence of a uni-dimensional scale.

Negative Affect Scale

Table 5B.4 shows the corrected item total correlations and the results of the factor analysis for the NA scale with the sample in this research.

Table 5B.4: Corrected item-total correlations and factor analysis of the NA scale

Item	Item-Total Correlations	Unrotated Solution
Sad	.54	.61
Frightened	.52	.60
Ashamed	.47	.53
Upset	.55	.60
Nervous	.44	.49
Guilty	.42	.48
Scared	.58	.68
Miserable	.58	.61
Jumpy	.27	.29
Afraid	.49	.55
Lonely	.45	.51
Mad	.24	.26
Disgusted	.42	.55
Downhearted	.54	.59
Gloomy	.42	.47
Eigenvalue:		4.8
% of variance:		31.9%

The Kaiser-Meyer-Olkin measure of Sampling Adequacy (KMO) was .84 and the correlation matrix as assessed with the Bartlett test was significant where $p < .0001$, thereby indicating that factor analysis was an appropriate procedure to use with the data from the NA scale. With regard to the corrected item total correlations, Table 5B.4 conveys that the items *mad* and *jumpy* failed to meet the .30 cut off point followed by Laurent et al (1999). The Cronbach alpha reliability co-efficient for the scale was .83. As Table 5B.4 shows, all items loaded adequately onto the first unrotated factor with the exception of the items *mad* and *jumpy*. On the basis of the corrected item total correlations and the results of the factor analysis, these items (i.e. *mad* & *jumpy*) were excluded. As all other items loaded adequately onto the first factor, it was decided to follow Laurent et al's (1999) approach and not examine the rotated solution. The corrected item total correlations, and a second factor analysis were subsequently conducted for the remaining 13 items (see Table 5B.5) and their reliability checked.

Table 5B.5: Corrected item-total correlations for factor analysis for the 13-item NA scale

Item	Item-Total Correlations	Unrotated Solution
Sad	.56	.61
Frightened	.54	.62
Ashamed	.49	.54
Upset	.55	.60
Nervous	.44	.49
Guilty	.38	.44
Scared	.60	.69
Miserable	.57	.61
Afraid	.52	.57
Lonely	.48	.51
Disgusted	.41	.45
Downhearted	.53	.58
Gloomy	.42	.48
Eigenvalue:		4.6
% of variance:		35.6%

The Kasier-Meyer-Olkin Measure of Sampling Adequacy (KMO) (.85) and the results of the Bartlett test ($p < .0001$) continued to indicate the appropriateness of factor analysis for examining this data. Table 5B.5 shows that the corrected item total correlations for all 13 items were acceptable, and they all loaded adequately onto the unrotated first factor. The reliability of the scale without the items *mad* and *jumpy* increased slightly (i.e. from .83 to .85). All 13 items were therefore retained in the NA scale.

Comparison Between the Results of the Factor Analysis with Original Sample (Laurent et al, 1999) and Factor Analysis with the Sample in this Research for the NA Scale

All items were retained in the NA scale as a result of factor analysis with the original

sample (Laurent et al, 1999). The items *mad* and *jumpy* were eliminated from the NA scale following factor analysis with the sample in this research.

R-PANAS-C

Having factor analytically derived a PA scale (11 items) and a NA scale (13 items), a principal axis factor analysis was conducted with the resulting 24-item Revised Positive and Negative Affect Scale (R-PANAS-C) (see Table 5B.6). Following Laurent et al's (1999) approach, a 2-factor solution was requested to ascertain the uniqueness of each factor.

Table 5B.6: Factor analysis of the 24-Item R-PANAS-C scale

Item	Factor 1	Factor 2
Interested	-.03	.48
Happy	-.23	.58
Strong	-.22	.41
Energetic	-.18	.53
Cheerful	-.26	.61
Active	-.25	.57
Proud	-.06	.40
Joyful	-.26	.60
Delighted	-.20	.59
Lively	-.32	.64
Sad	.60	-.32
Frightened	.57	-.30
Ashamed	.55	-.12
Upset	.59	-.21
Nervous	.49	-.23
Guilty	.43	-.04
Scared	.65	-.33
Miserable	.62	-.26
Afraid	.55	-.36
Lonely	.51	-.34
Disgusted	.47	-.02
Downhearted	.58	-.15
Gloomy	.51	-.25
Eigenvalue:	4.5	3.9
% of variance:	22.0%	8.3%

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was an acceptable .82, and the correlation matrix as assessed with Bartlett's test was significant where $p < .0001$. This suggests that factor analytic techniques were appropriate for this data. Table 5B.6 conveys that a separate, robust PA and NA factor emerged, with a correlation that attested to their uniqueness (-.34).

Comparison between PANAS-C Scale (Laurent et al, 1999) and R-PANAS-C scale

As with the PANAS-C, 2 distinct and meaningful factors emerged in the R-PANAS-C, 1representing Positive Affect and 1 representing Negative Affect.

Physiological Hyperarousal Scale

In replication of Laurent et al's (1999) approach, the corrected item correlations and Cronbach's alpha co-efficient were established for the PH scale with the sample in this research. Additionally, it was decided to factor analyse the PH scale with the sample in this research. The procedures used for the PA and NA scales (i.e. principal axis factoring with unrotated solutions and rotated solutions using structure matrix) were followed. Table 5B.7 shows the corrected item total correlations and results of the factor analysis for the 18-item PH scale.

Table 5B.7: Corrected item total correlations and factor analysis of the 18-item PH scale

Item	Corrected Item Total Correlations	Unrotated Solution
Dry Mouth	.49	.53
Sweaty hands	.34	.39
Tingling	.26	.32
Blushing	.22	.32
Shaky	.39	.49
Stomach ache	.20	.33
Cold Flashes	.53	.54
Dizzy	.28	.39
Heart Pounding	.37	.51
Sweating when not hot	.25	.38
Can't catch breath	.35	.48
Feeling of Choking	.25	.34
Hot Flashes	.32	.45
Numbness	.32	.49
Pain in chest	.44	.50
Feeling like throwing up	.49	.54
Tight Muscles	.41	.48
Can't sit still	.22	.29
Alpha:	.68	
Eigenvalue:		4.1
% of variance:		22.7%

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was an adequate .75, and the correlation matrix as assessed with the Bartlett test was significant where $p < .0001$, suggesting the appropriateness of factor analysis for this data. As indicated in Table 5B.7, the item total correlations were relatively low for all items. Those items that failed to meet the .3 cut off point included *Tingling*, *Blushing*, *Stomach Ache*, *Dizzy*, *Sweating when not Hot*, *Feeling of Choking* and *Can't Sit Still*. With regard to the factor analysis, the scree plot suggested taking 1 factor. Table 5B.7 presents the loadings for the unrotated solution. The majority of items had a significant loading on the first factor and on no other factor. Exceptions included those items that had corrected item total correlations below .3, and the item *Sweaty Hands*. Given that the

results of the unrotated solution produced a clear picture that made conceptual sense, it was decided to use this as opposed to the oblique rotated structure matrix[1]. On the basis of the corrected item-total correlations and the unrotated solution therefore, the items *Tingling*, *Blushing*, *Stomach Ache*, *Dizzy*, *Sweating when not Hot*, *Feeling of Choking*, *Can't Sit Still* and *Sweaty Hands* were excluded. The corrected item total correlations and a factor analysis for the remaining items were computed (see Table 5B.8) and their reliability checked.

Table 5B.8: Corrected item total correlations and factor analysis of the 10-item PH scale

Item	Corected Item Total Correlations	Unrotated Solution
Dry Mouth	.47	.55
Shaky	.40	.50
Cold Flashes	.43	.51
Heart Pounding	.41	.47
Can't catch breath	.43	.50
Hot flashes	.35	.43
Numbness	.36	.43
Pain in Chest	.40	.46
Feeling Like Throwing up	.44	.52
Tight Muscles	.44	.51
Eigenvalue:		3.1
% of variance:		31.0%

The Kasier-Meyer-Olkin Measure of Sampling Adequacy (KMO) (.82) and the results of the Bartlett test ($p<.0001$) indicated the appropriateness of factor analysis for examining this data. Table 5B.8 shows that, as expected, all of the corrected item total correlations were above .3. All items loaded adequately onto the unrotated first factor. The reliability of the scale also increased (from .68 to .75). All 10 items were therefore

[1]The oblique rotation was examined and revealed 6 factors. Some factors were comprised of only 2 items and, as such, it did not offer as meaningful an interpretation of the scale as the unrotated factor matrix.

retained in the PH scale.

Comparison between PH Scale (Laurent et al, 1999) and R-PH scale

In contrast to the PH scale, the R-PH scale contains fewer items. The items *Tingling, Blushing, Stomach Ache, Dizzy, Sweating when not Hot, Feeling of Choking, Can't Sit Still and Sweaty Hands* are not included in the R-PH scale.

R-PH-PANAS-C

A principal axis factor analysis, with an oblique rotation, was conducted with the 34-item R-PH-PANAS-C scale and the structure matrix examined (see Table 5B.9). Both the item selection procedures and the theoretical underpinnings of the PH- PANAS-C (Laurent et al, 1999) favoured 3 components emerging from the factor analysis. The analysis was therefore performed specifying a 3-factor solution.

Table 5B.9: Factor Analysis of the 34-item R-PH-PANAS-C

Item	Factor 1 (NA)	Factor 2 (PH)	Factor 3 (PA)
Scared	.63	.13	-.33
Miserable	.62	.16	-.28
Sad	.62	.07	-.31
Frightened	.60	.09	-.30
Upset	.58	.08	-.20
Downhearted	.58	.24	-.15
Ashamed	.57	.04	-.09
Afraid	.55	.15	-.35
Lonely	.50	.10	-.34
Gloomy	.48	.24	-.27
Nervous	.48	.21	-.21
Disgusted	.46	.25	-.03
Guilty	.43	.18	-.03
Cold Flashes	.09	.54	-.01
Shaky	.21	.52	-.02
Feeling Like Throwing Up	.27	.52	-.14
Tight Muscles	.06	.52	.06
Dry Mouth	.15	.51	-.03
Pain in your Chest	.14	.47	-.06
Can't Catch Your Breath	.17	.44	-.07
Heart Pounding	.18	.39	.07
Hot Flashes	.04	.39	.09
Numbness	.04	.31	.06
Lively	-.31	.04	.64
Cheerful	-.26	.04	.64
Active	-.26	-.02	.61
Joyful	-.27	.05	.60
Delighted	-.19	.08	.58
Happy	-.24	.08	.56
Energetic	-.17	-.06	.55
Interested	-.04	.07	.48
Strong	-.20	-.07	.43
Proud	-.08	.02	.38
Daring	-.02	-.07	.37
Eigenvalue:	4.7	2.6	4.0
% of Variance:	16.3%	7.7%	4.6%

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was .79 and Bartlett's test of the correlation matrix was significant where $p<.0001$. Table 5B.9 shows that 3 distinct factors emerged, 1 corresponding to Positive Affect, 1 to Negative

Affect and 1 to Physiological Hyperarousal. This scale demonstrated adequate internal consistency (Cronbach Alpha Co-efficient = .70).

Comparison between PH-PANAS-C Scale (Laurent et al, 1999) and R-PH-PANAS-C Scale

The PH-PANAS-C contained 48 items, whereas the R-PH-PANAS-C is shorter containing 34 items.

The R-PH-PANAS-C (see below) represents the instrument used to investigate the results of children's experience in Barretstown.

THE REVISED PHYSIOLOGICAL HYPERAROUSAL, POSITIVE AND NEGATIVE AFFECT SCHEDULE FOR CHILDREN (R-PH-PANAS-C)

Positive Affect scale (11 items):

1. Lively
2. Cheerful
3. Active
4. Joyful
5. Delighted
6. Happy
7. Energetic
8. Interested
9. Strong
10. Proud
11. Daring

Negative Affect scale (13 items):

1. Scared
2. Miserable
3. Sad
4. Frightened
5. Upset
6. Downhearted
7. Ashamed
8. Afraid

9. Lonely
10. Gloomy
11. Nervous
12. Disgusted
13. Guilty

Physiological Hyperarousal scale (10 items):

1. Cold Flashes
2. Shaky
3. Feeling Like Throwing Up
4. Tight Muscles
5. Dry Mouth
6. Pain in your Chest
7. Can't Catch Your Breath
8. Heart Pounding
9. Hot Flashes
10. Numbness

APPENDIX 5C

FACTOR ANALYSIS OF THE PHYSICAL SYMPTOMS INVENTORY (PSI)

FACTOR ANALYSIS: PSI

FACTOR ANALYSIS OF PSI: APPROACH TAKEN

As the PSI was developed for the purpose of this research, there were no pre-existing guidelines for evaluating its psychometric properties. An exploratory approach was therefore taken, as follows;

- In terms of factor analysis, the 'principal component' method of extraction with an orthogonal rotation was chosen. It is advocated that the principal component method of extraction be used when the objective is to summarise most of the original information into a minimum number of factors for prediction purposes (Hair et al, 1995). In this instance, it was intended that the role of physical symptoms in predicting the children's experience of the Barretstown programme would form part of the later analysis. While there is considerable debate over whether a factor or a component model is more appropriate, empirical research has demonstrated a similarity of the results in many instances (Tabatchnick & Fidell, 1989; Kline, 1994).

- The internal reliability for the overall factor analytically derived scale and the reliability of each subscale was calculated using Cronbach's Alpha.

FACTOR ANALYSIS OF PSI WITH THE SAMPLE IN THIS STUDY

Sample

This sample comprised 240 children; 126 boys (52.5%) and 114 girls (47.5%) with a mean age of 11.4 years (S.D. = 2.3). Of these, 197 children (82.1%) had been diagnosed with a chronic illness, and 43 children (17.9%) were siblings of children with a chronic illness. In relation to children with an illness, 162 children (82.1%) had been diagnosed with a form of cancer, 15 (7.7%) had a haematological related illness, 9 (5.1%) had an immunodeficiency related illness, and 5 (2.6%) had a renal related illness. There were 6 children (3.0%) whose illnesses were not indicated. The children were from 16 European countries (see Table 5C.1 for a breakdown).

Table 5C.1: Number and percentage of children from each country who completed the PH-PANAS-C

Country	Number	Percentage
England	63	26.3%
Ireland	59	24.6%
Germany	20	8.3%
Spain	18	7.5%
Hungary	15	6.3%
Czech Republic	12	5.0%
Poland	11	4.6%
Sweden	9	3.8%
Russia	8	3.3%
Iceland	7	2.9%
Switzerland	5	2.1%
Cyprus	4	1.7%
Denmark	3	1.3%
Austria	3	1.3%
Norway	2	0.8%
Georgia	1	0.4%

Procedure

The ratio of the sample size to the number of variables in this part of the research exceeded the recommended 5-1 ratio (Hair et al, 1995). This provided an adequate basis for the calculation of the correlations among variables in the factor analyses. Since there were no preconceptions about the number of factors that might best represent the data, the number of factors to extract was not specified and the scree plot was employed to guide selection. It suggested taking 1, 4 or 8 factors. Using the principal component method of extraction with an orthogonal rotation, each of these solutions were requested (with a .4 cut-off point for loadings on factors) in order to find the one which best represented the data. The grouping of the items in the 4-factor solution made the most conceptual sense. The eigenvalues for each factor were greater than 1, and the solution accounted for 35% of the variance.

Results

The results from the 4-factor solution are shown in Table 5C.2.

Table 5C.2: Factor Analysis of the 30-item PSI

Item	Factor 1	Factor 2	Factor 3	Factor 4
Heart Pounding	.64			
Hot Flashes	.60			
Pains/Aches	.54			
Sweating when not hot	.53			
Tight Muscles	.52			
Sweaty Hands	.49			
Shaky	.46			
Numbness	.42			
Blushing				
Tingling				
Dizzy				
Constipation				
Diarrhoea				
Stomach Ache		.76		
Feeling Like Throwing up		.70		
Cold Flashes		.55		
Pain in your chest		.51		
Vomiting		.43		
Dry mouth		.41		
Getting up to go to toilet in night			.62	
Nightmares			.60	
Difficulty remembering things			.54	
Can't sit still			.53	
Unable to sleep			.53	
Confused				
Tiredness				.67
General Weakness				.57
Can't catch breath				.45
Feeling of choking				
Loss of taste				
Eigenvalue:	3.4	2.6	2.4	2.2
% of Variance:	11.4%	8.5%	8.0%	7.4%

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy was .72 and the overall significance of the correlation matrix assessed with the Bartlett test was significant where $p < .0001$, suggesting the appropriateness of factor analysis to understand the data at hand. As indicated in Table 5C.2, some items did not load above the .4 cut-off

point on any of the factors. These 8 items including *Tingling, Blushing, Dizzy, Constipation, Diarrhoea, Confused, Feeling of Choking and Loss of Taste* were therefore excluded. The final R-PSI therefore consisted of 22 items and 4 distinct and meaningful factors. The first factor labelled the 'Temperature/Sensation' subscale consisted of 8 items; *Heart Pounding, Hot Flashes, Pains/Aches, Sweating when not hot, Tight Muscles, Sweaty Hands, Shaky & Numbness.* The second factor labelled the 'Nausea-Related' subscale comprised 6 items; *Stomach Ache, Feeling Like Throwing up, Cold Flashes, Pain in your Chest, Vomiting and Dry Mouth.* The third factor labelled the 'Sleep/Restlessness-Related' subscale consisted of the items *Getting up to go to the toilet during the night, Nightmares, Difficulty remembering things, Can't sit still* and *Unable to sleep.* The fourth factor called the 'Fatigue-Related' subscale consisted of 3 items; *Tiredness, General Weakness & Can't Catch Breath''* The internal reliability co-efficients for each of these subscales and the overall revised PSI are shown in Table 5C.3.

Table 5C.3: Internal reliability for each of the subscales in the R-PSI and the Total R-PSI

Subscale	Alpha
Temperature/Sensation	.70
Nausea-Related	.50
(Excluding 'Stomach ache')	*.66*
Sleep/Restlessness-Related	.61
Fatigue-Related	.60
Total R-PSI	.74
(Excluding 'Stomach ache')	*.81*

As can be seen from Table 5C.3, the internal reliability of the Temperature/Sensation subscale was adequate. Although the reliabilities of the Sleep/Restlessness-Related subscale and the Fatigue-Related subscale were lower, they may still be considered

acceptable. However, the reliability of the Nausea-Related subscale was low. When this was explored further by ascertaining the reliability of the scale if each individual item was deleted, it was found that excluding the item *Stomach Ache* increased the reliability of the scale from .50 to .66. In turn, the reliability of the total R-PSI without *Stomach Ache* increased from .74 to a moderately high .81. Although *Stomach Ache* does 'fit well' with the other items in this factor, in view of these findings regarding reliability, it was decided to exclude it from the scale. The R-PSI scale therefore consisted of 21 items divided into 4 subscales.

The R-PSI (written below) represents the measure used to investigate the results of children's experience in Barretstown.

THE REVISED PHYSICAL SYMPTOMS INVENTORY (R-PSI)

Temperature/Sensation subscale (8 items):

1. Heart Pounding
2. Hot Flashes
3. Pains/Aches
4. Sweating when not hot
5. Tight Muscles
6. Sweaty hands
7. Shaky
8. Numbness

Nausea-Related subscale (5 items):

1. Feeling like throwing up
2. Cold flashes
3. Pain in your chest
4. Vomiting
5. Dry mouth

Sleep/Restlessness-Related subscale (5 items):

1. Getting up to go to the toilet in the night
2. Nightmares
3. Difficulty remembering things
4. Can't sit still
5. Unable to sleep

Fatigue-Related subscale (3 items):

1. Tiredness
2. General Weakness
3. Can't catch breath

APPENDIX 5D

FACTOR ANALYSIS OF THE SELF PERCEPTION PROFILE FOR CHILDREN (SPPC)

FACTOR ANALYSIS: SPPC

FACTOR ANALYSIS OF SPPC WITH THE ORIGINAL SAMPLE (Harter, 1985)

The psychometric properties of the SPPC were initially examined by Harter (1985) with 3 separate samples of American children in Grades 6,7 & 8. The format of the analysis was as follows;

- Individual factor analyses for the SPPC were conducted for each of the 3 samples of children. The Global Self-Worth subscale was not included in these analyses since Harter (1985) maintains that it is determined in part by how competent or adequate one is in the other subscales that are deemed important by each child. Hence it is unlikely that it will systematically emerge as a distinctive factor. The method of factor extraction was unspecified. An oblique rotation was performed, and the pattern matrix was examined.

- The reliabilities of each of the subscales based on Cronbach's Alpha were established with 4 separate samples of American school children in the 3rd to 8th grades.

FACTOR ANALYSIS OF SPPC WITH THE SAMPLE IN THIS STUDY

Sample

This sample comprised 191 children; 99 boys (52%) and 92 (48%) girls with a mean age of 10.8 years (S.D. = 1.9). Most of the children in this sample had been diagnosed with a chronic illness (n = 148; 77.5%) and the others were siblings of children with

chronic illnesses (n = 43; 22.5%). Of those children with a chronic illness, the majority had a form of cancer (n = 116 children; 78.4%). Some children had a haematology related illness (n = 12; 8.1%), an immunodeficiency related illness (n = 9; 6.1%) or a renal related illness, (n = 5; 3.4%), There were a few instances where the life threatening illness that children had was not specified (n = 6; 4.1%). The children were from 15 European countries (see Table 5D.1 for a breakdown).

Table 5D.1: Number and percentage of children from each country who completed the SPPC

Country	Number	Percentage
England	53	27.7%
Ireland	52	27.2%
Hungary	12	6.3%
Spain	12	6.3%
Czech Republic	11	5.8%
Poland	9	4.7%
Sweden	8	4.2%
Russia	8	4.2%
Germany	7	3.7%
Iceland	6	3.1%
Cyprus	4	2.1%
Austria	3	1.6%
Denmark	3	1.6%
Norway	2	1.0%
Georgia	1	0.5%

Procedure

The ratio of the sample size to the number of variables in this part of the research exceeded the recommended 5-1 ratio (Hair et al, 1995), thereby providing an adequate basis for the calculation of the correlations between variables. A 5-factor solution was requested (to reflect the 5 subscales in the original SPPC) using the principal component method of extraction and an oblique rotation. However, it did not provide an

interpretable solution. In order to find the factor pattern which best represented the data, the number of factors was initially unspecified and the output examined. An 8-factor solution emerged but it could not be adequately interpreted. Consequently, a 6-factor solution was requested following analysis of the scree plot. The 6-factor solution, as depicted by the pattern matrix, provided the best representation of the data.

Results

The results of the 6-factor solution are shown in Table 5D.2.

Table 5D.2: Factor Analysis of the 36-item SPPC

	Factor 1 Social Acceptance	Factor 2 Behaviour Conduct	Factor 3 Athletic Compet. (games)	Factor 4 Physical Appear.	Factor 5 Athletic Compet. (sports)	Factor 6 Scholastic Compet.
Have a lot of friends	.79					
Popular with others	.66					
Do things with a lot of kids	.61					
Easy to have friends	.55					
Most kids like me	.48		-.42			
Don't do things shouldn't		.68				
Don't get in trouble		.68				
Like the way I behave		.63				
Usually do the right thing		.52	.41			
Act the way supposed		.49				
Good at new outdoor games			-.65			
Play rather than watch games			-.62			
Behave well		.48	.59			
Wish could be better at sports			-.59		.46	
Make friends	.42		-.50			
Like physical appearance as is				.78		
Like body the way is				.71		
Happy with height & weight				.71		
Like face & hair				.67		
Happy with way look				.65		
Are attractive or good looking				.57		
Do well at sports					.81	
Better than others at sports					.69	
Good at new sports					.54	

	Factor 1 Social Acceptance	Factor 2 Behaviour Conduct	Factor 3 Athletic Compet. (games)	Factor 4 Physical Appear.	Factor 5 Athletic Compet. (sports)	Factor 6 Scholastic Compet.
Can figure out answers						-.79
Do schoolwork quickly						-.75
Just as intelligent						-.71
Remember things						-.53
Good at schoolwork					.42	-.51
Do well at classwork						-.44
Eigenvalue:	3.4	3.1	3.1	3.6	3.1	3.5
% of variance:	17.8%	12.1%	10.1%	7.4%	4.9%	4.5%

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was .73 and Bartlett's test of the correlation matrix was significant where $p < .0001$, thereby indicating the suitability of factor analysis for use with this data. As can be seen from Table 5D.2, 6 distinct factors emerged. As is also evident from Table 5D.2, some items loaded onto 2 factors. These items were excluded since their loadings on the 2 factors were similar. The first factor to emerge was called the 'Social Acceptance' subscale and it contained 4 items relating to degree to which children feel they have friends and are popular. The second factor was labelled the 'Behavioural Conduct' subscale and it also contained 4 items tapping the extent to which children like the way they behave, act the way they are supposed to and avoid getting into trouble. The third factor was labelled the 'Athletic Competence (games)' subscale and it contained 2 items relating to children's feeling of competence in games. The fourth factor was labelled the 'Physical Appearance' subscale and it contained 6 items relating to children's feelings of competency about the way they look. The fifth factor was called the 'Athletic Competence (sports)' subscale and it contained 3 items looking at the degree to which children feel competent in sports. The final factor to emerge was called the 'Scholastic

Competence' subscale and it contained 5 items relating to children's feelings of competency in the realm of scholastic performance. The results of this factor analysis resulted in a 24-item R-SPPC and adding the Global Self-Worth subscale to this, culminated in a 30-item R-SPPC.

With regard to reliability, the internal consistency of each subscale, including the Global Self-Worth subscale in the R-SPPC and the internal consistency of the overall R-SPPC was established using Cronbach's Alpha (see Table 5D.3).

Table 5D.3: Reliability co-efficients for each of subscales in the R-SPPC and the overall scale

Subscale	Alpha
Social Acceptance	.62
Behavioural Conduct	.50
Athletic Competence (games)	.60
Physical Appearance	.77
Athletic competence (sports)	.69
Scholastic Competence	.41
Global Self-Worth	.60
Overall R-SPPC	.82

With the exception of the Scholastic Competence subscale (.41) and the Behavioural Conduct subscale (.50), the reliabilities were adequate for each of the other subscales to maintain their inclusion in the R-SPPC. When the Scholastic Competence subscale and the Behavioural Conduct subscale were excluded, the reliability of the R-SPPC increased from .82 to .85.

Comparison between the Results of the Factor Analysis with Original Sample (Harter, 1995) and Factor Analysis with the Sample in this Research for the SPPC

The subscales which emerged from the factor analysis with the sample in this research to form the R-SPPC were, to a large extent, similar to the existing subscales in the SPPC (i.e. Harter, 1985). The Physical Appearance subscale in the R-SPPC is exactly the same as the Physical Appearance subscale in the SPPC in terms of the number and content of items. The Scholastic Competence subscale in the R-SPPC contains all the items from the Scholastic Competence subscale in the SPPC, with the exception of 1 item pertaining to children feeling that they are/are not very good at their schoolwork which was excluded because it cross loaded. The Social Acceptance subscale in the R-SPPC is also similar to the Social Acceptance subscale in the SPPC, but does not contain 2 of the original items which were excluded due to inadequate or cross loadings (i.e. *'finding it hard/easy to make friends'* and *'wanting/not wanting more children to like them'*). Likewise, the Behavioural Conduct subscale in the R-SPPC is the same as the Behavioural Conduct subscale in the SPPC with the exception of 2 items which were excluded due to inadequate or cross loadings (i.e. *'doing/not doing the right thing'* and *'behaving and not behaving very well'*). However, two subscales; Athletic Competence (games) and Athletic Competence (sports) emerged in the R-SPPC to represent the Athletic Competence subscale in the SPPC. The differentiation between athletic competence in games and athletic competence in sports may be important for children with a life threatening illnesses (formed the larger proportion of the sample). That is, games and sports may represent very different things to them and participation in each may be determined by the effects of their illness. For example, it is likely that while a child is on active treatment, their energy levels may not be very high and while they may still participate in games, they may be curbed in their participation of sports.

With the 2 subscales in the R-SPPC representing different aspects of Athletic Competence, there is only 1 item not included from the Athletic Competence subscale in the SPPC. The item pertaining to children '*wishing/not wishing they could do better at sports'* was excluded because it cross-loaded on factors.

The resulting 21-item R-SPPC (see below) was used to interpret the results of children's experience in Barretstown.

THE REVISED SELF PERCEPTION PROFILE FOR CHILDREN (R-SPPC)

Social Acceptance subscale (4 items):

1. Some children have a lot of friends OR Some children don't have very many friends.
2. Some children are popular with others their age OR Some children are not very popular with others their age.
3. Some children are always doing things with a lot of children OR Some children usually do things by themselves.
4. Some children find it hard to make friends OR Some children find it easy to make friends.

Athletic Competence (games) subscale (2 items):

1. In games and sports, some children usually watch instead of play OR In games and sports, some children usually play rather than just watch.
2. Some children don't do well at new outdoor games OR Some children feel they are good enough at sports.

Physical Appearance subscale (6 items):

1. Some children are happy with the way they look OR Some children are not happy with the way they look.
2. Some children are happy with their height and weight OR Some children wish their height or weight were different.

3. Some children wish their body was different OR Some children like their body the way it is.
4. Some children wish their physical appearance (how they look) was different OR Some children like their physical appearance (how they look) the way it is.
5. Some children wish something about their face or hair looked different Or Some children like their face and hair the way they are.
6. Some children think that they are good looking OR Some children think that they are not very good looking.

Athletic Competence (sports) subscale (3 items):

1. Some children do very well at all kinds of sports OR Some children don't feel that they are very good when it comes to sports.
2. Some children think they could do well at just about any new sports activity they haven't tried before OR Some children are afraid they might not do well at sports they haven't ever tried.
3. Some children feel that they are better than others their age at sports OR Some children don't feel they can play sports as well as others.

Global Self-Worth subscale (6 items):

1. Some children are often unhappy with themselves OR Some children are quite pleased with themselves.
2. Some children don't like the way they are leading their life Or Some children do like the way they are leading their life.

3. Some children are happy with themselves as a person OR Some children are often not happy with themselves.
4. Some children like the kind of person they are OR Some children often wish they were someone else.
5. Some children are very happy being the way they are OR some children wish they were different.
6. Some children are not very happy with the way they do a lot of things OR Some children think the way they do things is fine.

APPENDIX 5E

FACTOR ANALYSIS OF THE SELF PERCEPTION PROFILE FOR ADOLESCENTS (SPPA)

FACTOR ANALYSIS: SPPA

FACTOR ANALYSIS OF SPPA WITH THE ORIGINAL SAMPLE (Harter, 1988)

The psychometric properties of the SPPA were initially examined by Harter (1988) with 4 separate samples of American teenagers in Grades 8, 9, 10 & 11. The format of this analysis was as follows;

- Individual factor analyses were conducted for the SPPA for each of the 4 samples of children. The Global Self-Worth subscale was not included in these analyses since Harter (1985) maintains that it is determined in part by how competent or adequate one is in the other subscales that are deemed important by each teenager. Hence, it is unlikely that it will systematically emerge as a distinctive factor. The method of factor extraction was unspecified. An oblique rotation was performed, and the pattern matrix was examined.

- The reliabilities of each of the subscales, based on Cronbach's Alpha, were established for each of the 4 samples.

FACTOR ANALYSIS OF SPPA WITH THE SAMPLE IN THIS STUDY

Sample

This sample comprised 36 teenagers; 18 boys (50%) and 18 girls (50%). Their mean age was 14.5 years (S.D. = 1.2). They had been diagnosed with a form of cancer (n = 32; 88.9%), a haematology related illness (n = 3; 8.3%), or an immunodeficiency

related illness (n = 1; 1.8%). The teenagers were from 5 European countries (see Table 5E.1 for a breakdown).

Table 5E.1: Number and percentage of children from each country who completed the SPPA

Country	Number	Percentage
Germany	12	33.3%
England	9	25.0%
Ireland	6	16.7%
Switzerland	5	13.9%
Spain	4	11.1%

Procedure

In view of the fact that there are 45 questions in the SPPA and only 36 teenagers in this sample, it was considered more statistically appropriate to examine the corrected item total correlations and alpha reliability co-efficients for each subscale and to factor analyse each of the subscales separately. This resulted in a sample size of 36 being used to in a factor analysis of each 5-item subscale. This procedure at least ensures that the sample size is 5 times greater than the number of variables (Hair et al, 1995). Corrected item total correlations were employed since the main purpose here was to assess the degree to which the items comprising each subscale can legitimately be treated as measuring a single construct (Mueller, 1986). A high degree of internal consistency is therefore desirable and consequently, it was decided that items with a corrected item total below .30 would be treated with caution and their performance assessed in the factor analysis before deciding to exclude them. In relation to factor analysis, as with the SPPC, Harter (1988) did not specify which method of extraction was employed. Corresponding with the R-SPPC, it was decided therefore to use the principal components method of extraction (e.g. Tabatchnick & Fidell, 1989; Kline, 1994). One

factor was requested for each subscale, but an oblique rotation could not be requested with only one component. The unrotated solution was therefore examined.

Results

Table 5E.2: Corrected item total correlations, reliability co-efficients and factor analysis of the Scholastic Competence subscale

Subscale Items	Corrected Item Total Correlations	Unrotated Solution
Feeling Smart	.39	.62
Finishing Schoolwork	.43	.63
Doing well at Class work	.48	.68
Figuring out answers	.68	.82
Feeling intelligent	.68	.83
Eigenvalue:		2.6
% of variance:		52.0%
Alpha reliability:	.75	

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was .65 and Bartlett's test of the correlation matrix was significant where $p < .0001$, thereby indicating the suitability of factor analysis to use with this data. Table 5E.2 shows that the corrected item total correlations were above .3 for each item. The results of the 1 factor solution show that all items loaded adequately onto the first factor explaining an adequate amount of variance (52.0%). The reliability co-efficient for the subscale was acceptable (.75). It was therefore decided to retain all items in the Scholastic Competence subscale.

Table 5E.3: Corrected item total correlations, reliability co-efficients and factor analysis of the Social Acceptance subscale

Subscale Items	Corrected Item Total Correlations	Unrotated Solution
Making Friends	.47	.80
Many Friends	.30	.54
Hard/Easy to Like	.44	.78
Popularity with others	.33	.56
Socially Accepted*	.26	*Excluded*
Eigenvalue:		1.8
% of variance:		46.1%
Alpha reliability:	.59	
Alpha reliability with item excluded:	.61	

As can be seen from Table 5E.3, the item relating to being *'socially accepted'* failed to meet the corrected item total cut-off point of .30. A factor analysis of all of the items revealed that while the factor loadings for all items were adequate, the Kaiser-Myer-Olkin Measure of Sampling adequacy was low (.54), Bartlett's Test of Sphercity was not significant ($p > .05$) and the percentage of variance explained was 38%, This suggested that factor analysis was not suitable for this group of items. On the basis of the corrected item total correlations and the results of the factor analysis it was therefore decided to exclude the item pertaining to *'being socially accepted'* from the scale and to redo the factor analysis and the reliability analysis. The results of this factor analysis are presented in Table 5E.3. While the Kaiser-Myer-Olkin Measure of Sampling Adequacy was still low, Bartlett's Test of Sphercity was significant at the .01 level. The percentage of variance increased (46.1%) and as expected, the reliability of the scale also increased (from .59 to .61). As such, it was decided to retain all items, with the exception of *'being socially accepted'* in the Social Acceptance subscale.

Table 5E.4: Corrected item total correlations, reliability co-efficients and factor analysis of the Athletic Competence subscale

Subscale Items	Corrected Item Total Correlations	Unrotated Solution
Doing well at sports	.87	.93
Doing well at new sports	.60	.73
Playing sports as well as others	.61	.76
Doing well at outdoor games	.49	.63
Feeling athletic	.77	.88
Eigenvalue:		3.2
% of variance:		63.1%
Alpha reliability:	.85	

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was .72 and Bartlett's test of the correlation matrix was significant where $p < .0001$, thereby indicating the suitability of factor analysis to use with this data. Table 5E.4 indicates that with regard to the Athletic Competence subscale, the corrected item total correlations were above .3 for each item. The results of the 1-factor solution show that all items loaded adequately onto the first factor explaining a large amount of the variance (60.1%). The reliability co-efficient for the subscale was relatively high (.85). It was therefore decided to retain all items in the Athletic Competence subscale.

Table 5E.5: Corrected item total correlations, reliability co-efficients and factor analysis of the Physical Appearance subscale

Subscale Items	Corrected Item Total Correlations	Unrotated Solution
Happiness with way look	.57	.77
Wishing body was different	.68	.84
Liking physical appearance	.61	.80
Thinking good looking	.34	.52
Like their looks	.45	.62
Eigenvalue:		2.6
% of variance:		51.8%
Alpha reliability:	.76	

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was .74 and that Bartlett's test of the correlation matrix was significant where $p < .0001$, thereby indicating the suitability of factor analysis to use with this data. Table 5E.5 also shows that the corrected item total correlations were above .3 for each item. The results of the 1-factor solution show that all items loaded adequately onto the first factor explaining 51.8% of the variance. The reliability co-efficient for the subscale was acceptable (.76). It was therefore decided to retain all items in the Physical Appearance subscale.

Table 5E.6: Corrected item total correlations, reliability co-efficients and factor analysis of the Job Competence subscale

Subscale Items	Corrected Item Total Correlations	Unrotated Solution
Readiness to handle part time job	.20	.83
Skills to do a job*	-.08	*Excluded*
Feeling old enough to do job	.24	.60
Doing well at work*	.07	*Excluded*
Ability to handle work/do a good job	.36	.88
% of variance:		60.6%
Eigenvalue:		1.8
Alpha reliability:	.30	
Alpha reliability with item excluded:	.64	

As can be seen from Table 5E.6, all items, with the exception of the item pertaining to '*Doing well at work*', failed to meet the corrected item total cut-off point of .30. When all of the items were factor analysed, the Kaiser-Meyer-Olkin Measure of Sampling Adequacy was .51, Bartlett's Test of Sphercity was not significant ($p > .05$), the percentage of variance was 34.9% and the reliability of the scale was very low (.30). However, the 3 items with the higher corrected item total correlations did have significant loadings; - '*Readinesss to handle a part time job*', '*Feeling old enough to do a job*' and '*Ability to handle work/do a good job*'. This suggested that factor analysis was inappropriate for all of the 5 items together, but that it might be worth conducting another factor analysis with the 3 items that did load significantly and to examine the reliability coefficient for these 3 items. These results are presented in Table 5E.6. The Kaiser-Myer-Olkin Measure of Sampling Adequacy was .57 and Bartlett's Test of Sphercity was significant where $p < .001$. The percentage of variance explained was acceptable (60.6%) and there were adequate factor loadings for all 3 items. The reliability of this 3-item Job Competence subscale was .64 thereby ensuring its inclusion in the R-SPPA.

Table 5E.7: Corrected item total correlations, reliability co-efficients and factor analysis of the Romantic Appeal subscale

Subscale Items	Corrected Item Total Correlations	Unrotated Solution
Others liking them back	.30	.67
Dating people attracted to	.32	.72
People attracted to them	.44	.80
Feeling fun & interesting*	.08	*Excluded*
Going out with people like to date*	-.26	*Excluded*
% of variance:		53.5%
Eigenvalue:		1.6
Alpha reliability:	.30	
Alpha reliability with item excluded	.55	

As can be seen from Table 5E.7, the items relating to *'feeling fun and interesting'* and *'going out with people who you like to date'* failed to meet the corrected item total cut-off point of .30. When all of the items were factor analysed, the Kaiser-Meyer-Olkin Measure of Sampling Adequacy was .60, Bartlett's Test of Sphercity was not significant ($p > .05$), the percentage of variance was 39.7% and the reliability of the scale was very low (.30). This suggested that factor analysis was inappropriate for all of these items together. On the basis of the corrected item total correlations, and the factor analysis, it was decided to exclude the items relating to *'feeling fun and interesting'* and *'going out with people who you like to date'* and to redo the factor analysis and the reliability coefficient for the remaining 3 items. The results of this are presented in Table 5E.7. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy was .60 and Bartlett's Test of Sphercity approached significance ($p = .06$). The adequate factor loadings are called into question by the fact that factor analysis cannot be considered as an appropriate statistical test for this data. Additionally, while the reliability of the

Romantic Appeal subscale increased with the exclusion of the 2 items, its reliability is still unacceptable (.55). It was therefore decided to exclude this subscale from the R-SPPA.

Table 5E.8: Corrected item total correlations, reliability co-efficients and factor analysis of the Behavioural Conduct subscale

Subscale Items	Corrected Item Total Correlations	Unrotated Solution
Doing right thing*	.10	*Excluded*
Getting into trouble	.22	.75
Feeling good about way act*	-.04	*Excluded*
Doing things should/shouldn't	.46	.79
Acting the way supposed to	.32	.59
% of variance:		51%
Eigenvalue:		1.5
Alpha reliability:	.41	
Alpha reliability with items excluded:	.52	

As can be seen from Table 5E.8, the items relating to *'doing the right thing'*, *'getting into trouble'* and *'feeling god about the way one acts'* failed to meet the corrected item total cut-off point of .30. When all of the items were factor analysed, the Kaiser-Meyer-Olkin Measure of Sampling Adequacy was .38, Bartlett's Test of Sphercity was just significant ($p = .02$), the percentage of variance was 32.4% and the reliability of the scale was unacceptably low (.41). Two items failed to load significantly on the first factor; *'doing the right thing'* and *'feeling good about the way one acts'*. On the basis of the corrected item total correlations, and the factor analysis, it was decided to exclude these 2 items and to redo the factor analysis and the reliability coefficient for the remaining 3 items. The results of this are presented in Table 5E.8. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy was .57 and Bartlett's Test of Sphercity was not significant ($p > .05$). The adequate factor loadings for all 3 items is called into question

by the fact that factor analysis cannot be considered as an appropriate statistical test for this data. Additionally, while the reliability of the Behavioural Conduct subscale increased with the exclusion of the 2 items, its reliability is still unacceptably low (.52). It was therefore decided to exclude this subscale from the R-SPPA.

Table 5E.9: Corrected item total correlations, reliability co-efficients and factor analysis of the Close Friend subscale

Subscale Items	Corrected Item Total Correlations	Unrotated Solution
Making close friends*	.19	*Excluded*
Close friend to share secrets	.51	.71
Close friend to share things	.60	.79
Making friends to trust	.52	.75
Close friend to share personal thoughts	.37	.71
% of variance:		54.7%
Eigenvalue:		2.2
Alpha reliability:	.66	
Alpha reliability with item excluded:	.70	

As can be seen from Table 5E.9, the item relating to '*making close friends*' failed to meet the corrected item total cut-off point of .30. When all of these items were factor analysed, the Kaiser-Meyer-Olkin Measure of Sampling Adequacy was .61, Bartlett's Test of Sphercity was significant where $p < .001$ and the percentage of variance was 45.3%. However, the item relating to '*making close friends*' failed to load adequately onto the first factor. On the basis of the corrected item total correlation, and its poor factor loading, it was decided to exclude this item and to redo the factor analysis. These results are presented in Table 5E.9. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was .58 and Bartlett's Test of Sphercity was significant where $p < .0001$, thereby indicating the suitability of factor analysis to use with this data. The

reliability of the subscale with this item excluded increased (from .66 to 70.). The Close Friend subscale for the R-SPPA therefore consisted of 4 items.

Table 5E.10: Corrected item total correlations, reliability co-efficients and factor analysis of the Global Self-Worth subscale

Subscale Items	Corrected Item Total Correlations	Unrotated Solution
Disappointed/Pleased with self	.45	.84
Like/Don't like way leading life	.18	.64
Happy/Not happy with self most of the time*	-.03	*Excluded*
Like kind of person are/wish to be someone else*	.05	*Excluded*
Happy being the way are/Wish to be different	.41	.79
% of variance:		57.6%
Eigenvalue:		1.7
Alpha reliability:	.40	
Alpha reliability with items excluded:	.62	

As can be seen from Table 5E.10, 3 items failed to meet the corrected item total cut-off point of .30; *'Like/Don't like the way leading life'*, *'Happy/not happy with self'* and *'like the kind of person one is/wish to be different'*. When all of the items were factor analysed, the Kaiser-Meyer-Olkin measure of Sampling Adequacy was .57, Bartlett's Test of Sphercity was not significant (p> .05), the percentage of variance was 34% and the reliability of the scale was low (.40). However, the 3 items with the higher corrected item total correlations did have significant loadings on the factor; - *'Disappointed/Pleased with self'*, *'Like/Don't Like the way leading life'* & *'Happy with the are/Wish to be different'*. This suggested that factor analysis was inappropriate for all of the 5 items together, but that it might be worth conducting another factor analysis with the 3 items that did load significantly and to examine the reliability coefficient for

these 3 items. These results are presented in Table 5E.10. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was .60 and Bartlett's Test of Sphercity was significant where $p < .01$. The percentage of variance explained was acceptable (57.6%) and there were adequate factor loadings for all 3 items. The reliability of the Global Self-Worth subscale was still relatively low (.62), but acceptable enough maintain its inclusion in the R-SPPA.

Overall, the factor analysis resulted in a 29-item scale with 7 subscales. The reliability of the 29-item scale was .86. Thus, the R-SPPA scale has high internal consistency.

Comparison between the results of the factor analysis with original sample (Harter, 1995) and factor analysis with the sample in this research for the SPPA

The subscales which emerged from the factor analysis with the sample in this research to form the R-SPPA were, to a large extent, similar to the existing subscales in the SPPA (i.e. Harter, 1985). The Scholastic Competence subscale, the Athletic Competence subscale and the Physical Appearance subscale in the R-SPPA are exactly the same as those in the SPPA in terms of the number of items. The Social Acceptance subscale in the R-SPPA contains all the items from the Social Acceptance subscale in the SPPA, with the exception of 1 item (i.e. *'being socially accepted'*). Similarly, the Close Friend subscale in the R-SPPA contains all the items from the Close Friend subscale in the SPPA with the exception of 1 item (i.e. *'making close friends'*). The Job competence subscale in the R-SPPA contains 3 of the 5 items from the SPPA (the items pertaining to the *'skills to do a job'* and *'doing well at work'* were excluded). The Global Self-Worth subscale in the R-SPPA also contains 3 of the 5 items from the SPPA (the items pertaining to *'being happy with the self'* and *'liking the kind of person*

one is' were excluded). Finally, the R-SPPA does not contain the Romantic Appeal and Behaviour Conduct subscales from the SPPA since both were excluded.

The 29-item R-SPPA (see below) represents the instrument used to investigate the results of teenagers' experience in Barretstown.

THE REVISED SELF PERCEPTION PROFILE FOR TEENAGERS (R-SPPA)

Scholastic Competence subscale (5 items):

1. Some teenagers feel that they are just as intelligent as others their age OR Some teenagers wonder if they are as intelligent as others their age.
2. Some teenagers are quite slow in finishing their school work OR Some teenagers can do their school work quickly.
3. Some teenagers do very well at their class work OR Some teenagers don't do very well at their class work.
4. Some teenagers have trouble figuring out the answers in school OR Some teenagers almost always can figure out the answers in school.
5. Some teenagers feel that they are quite intelligent OR Some teenagers question whether they are intelligent.

Social Acceptance subscale (4 items):

1. Some teenagers find it hard to make friends OR Some teenagers find it easy to make friends.
2. Some teenagers have a lot of friends OR Some teenagers don't have very many friends.
3. Some teenagers are very hard to like OR Some teenagers are really easy to like.
4. Some teenagers are popular with others their age OR Some teenagers are not very popular with others their age.

Athletic Competence subscale (5 items):

1. Some teenagers do very well at all kinds of sports OR Some teenagers don't feel that they are very good when it comes to sports.
2. Some teenagers think they could do well at just about any new athletic activity OR Some teenagers are afraid they might not do well at a new athletic activity.
3. Some teenagers feel that they are better than others their age at sports OR Some teenagers don't feel they can play sports as well as others.
4. Some teenagers don't do well at new outdoor games OR Some teenagers are good at new games right away.
5. Some teenagers do not feel that they are very athletic OR Some teenagers eel that they are very athletic.

Physical Appearance subscale (5 items):

1. Some teenagers are not happy with the way they look OR Some teenagers are happy with the way they look.
2. Some teenagers wish their body was different OR Some teenagers like their body the way it is.
3. Some teenagers wish their physical appearance (how they look) was different OR Some teenagers like their physical appearance (how they look) the way it is.
4. Some teenagers think they are good looking OR Some teenagers think that they are not very good looking.
5. Some teenagers really like their looks OR Some teenagers wished they looked different.

Job Competence subscale (3 items):

1. Some teenagers feel that they are ready to do well at a part-time job OR Some teenagers feel that they are not quite ready to handle a part-time job.
2. Some teenagers feel like they could do better at work they do for pay OR Some teenagers feel that they are doing really well at work they do for pay.
3. Some teenagers feel that they are really able to handle a part-time job OR Some teenagers wonder if they are really doing as good a job as they should be.

Close Friendship subscale (4 items):

1. Some teenagers do have a close friend they can share secrets with OR Some teenagers do not have a really close friend they can share secrets with.
2. Some teenagers wish they had a really close friend to share things with OR Some teenagers do have a close friend to share things with.
3. Some teenagers find it hard to make friends they can really trust OR Some teenagers are able to make close friends they can really trust.
4. Some teenagers don't have a friend that is close enough to share really personal thoughts with OR Some teenagers do have a close friend that they can share persona; thoughts and feelings with.

Global Self-Worth subscale (3 items):

1. Some teenagers are often disappointed with themselves OR Some teenagers are quite pleased with themselves
2. Some teenagers don't like the way they are leading their life OR Some teenagers do like the way they are leading their life.

3. Some teenagers are very happy being the way they are OR Some teenagers wish they were different.

APPENDIX 5F

FACTOR ANALYSIS OF THE PERCEIVED ILLNESS EXPERIENCE SCALE (PIE)

FACTOR ANALYSIS: PIE

FACTOR ANALYSIS OF PIE: APPROACH TAKEN

Although the PIE had not previously been factor analysed, Eiser (1999) has acknowledged the need to employ multivariate techniques to confirm the measure and its subscales. In terms of factor analysing the PIE with the sample of children in this research, the following approach was taken;

- The 'principal component' method of extraction with an orthogonal rotation was chosen. It is advocated that the principal component method of extraction be used when the objective is to summarise most of the original information into a minimum number of factors for prediction purposes (Hair et al, 1995). In this instance, the role of perceived illness experience in predicting the children's experience of the Barretstown programme would form part of the later analysis. While there is considerable debate over whether a factor or a component model is more appropriate, empirical research has demonstrated a similarity of the results in many instances (Tabatchnick & Fidell, 1989; Kline, 1994).

- Eiser et al's (1995, 1999) classification of the PIE to comprise 9 distinct subscales provided some preconceived ideas about the number of factors to extract and the content of factors in terms of items, but the data at hand was also examined to establish the most suitable approach to adopt.

- The reliability co-efficients using Cronbach's Alpha were established for each factor derived.

FACTOR ANALYSIS OF PIE WITH THE SAMPLE IN THIS STUDY

Sample

This sample comprised 184 children; 105 boys (57.1%) and 79 girls (42.9%) with a mean age of 11.6 years (S.D. = 2.3). With regard to illness, 156 children (87.2%) had been diagnosed with a form of cancer, 15 children (8.4%) had a haematology related illness, 5 children (2.8%) had a renal related illness and 3 children (1.7%) had an immunodeficiency related illness. The children were from 16 European countries (see Table 5F.1 for a breakdown).

Table 5F.1: Number and percentage of children from each country who completed the PIE

Country	Number	Percentage
England	38	20.7%
Ireland	31	16.8%
Germany	20	10.9%
Spain	17	9.2%
Hungary	15	8.2%
Czech Republic	12	6.5%
Poland	11	6.0%
Sweden	8	4.3%
Russia	8	4.3%
Iceland	6	3.3%
Switzerland	5	2.7%
Cyprus	4	2.2%
Denmark	3	1.6%
Austria	3	1.6%
Norway	2	1.1%
Georgia	1	0.5%

Procedure

The ratio of the sample size to the number of variables in this part of the research exceeded the recommended 5-1 ratio (Hair et al, 1995). This provided an adequate basis for the calculation of the correlations among variables in the factor analyses. Numerous solutions were requested in order to find the one which best represented the data. When 9 factors were specified (.4 cut-off point for loadings on factors), to correspond with the number of subscales comprising the PIE, it yielded the most interpretable solution. However, the content of all 9 factors did not make conceptual sense. The scree plot suggested taking 2 or 6 factors. The results of the first 6 factors could be meaningfully interpreted.

Results

The results of the 9-factor solution, in which the first 6 factors can be meaningfully interpreted, are shown in Table 5F.2.

Table 5F.2: Factor Analysis of the PIE: 6-factor solution

Content	Factor Loading
Factor 1 (School/Peer Rejection)	
I find it hard to learn things because of my illness	.68
Other people expect too much of my work	.60
I get teased or picked on more than other people	.58
I feel other people try to put me down	.53
I feel left out of things at school or work	.45
I am afraid other people won't like me because of my illness	.45
I feel I get blamed for things that aren't my fault	.44
Eigenvalue:	***3.1***
% of variance:	***8.7%***
Factor 2 (Thinking about Illness)	
I hate being reminded of my illness	.77
I get cross when people ask about my illness	.69
I only tell people about my illness if I really have to	.55
I wonder why I became ill	.52
Eigenvalue:	***2.6***
% of variance:	***7.3%***
Factor 3 (Physical Appearance)	
I feel my illness has made me look different	.81
The way I look has changed because of my illness/treatment	.76
My hair has been spoiled by the treatment	.51
Eigenvalue:	***2.5***
% of variance:	***7.0%***
Factor 4 (Interference with Activity)	
My illness stops me from doing games or sports I like	.72
I am not always able to join in with what my friends are doing	.72
I am afraid of doing sports where I might get hurt	.61
Eigenvalue:	***2.4***
% of variance:	***6.7%***
Factor 5 (Parental Responses)	
My parents treat me like a baby	.76
My parents make a fuss of me because of my illness	.63
My parents make a fuss about what I eat	.59
My parents use my illness to stop me doing things	.56
Eigenvalue:	***2.3***
% of variance:	***6.3%***
Factor 6 (Manipulation)	
I can get away with a lot more in school or at work because of my illness	.69
I use my illness to get out of things I don't want to do	.65

Content	Factor Loading
My illness makes many problems for my family	.54
Eigenvalue:	***2.2***
% of variance:	***6.0%***

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was .76 and Bartlett's test of the correlation matrix was significant where $p < .0001$, thereby indicating the suitability of factor analysis for use with this data. The first 6 factors represented a total of 24 items and a cumulative variance of 42%. The first factor, labelled the 'School/Peer Rejection' subscale consisted of 7 items. All items pertain to children's perceptions of how their illness affects their schoolwork, and their relations with their school and other peers. The second factor, labelled the 'Thinking about Illness' subscale, consisted of 4 items. These items centre on children's consideration of their illness and their reactions to disclosures about their illness with others. The third factor to emerge, the 'Physical Appearance' subscale comprised 3 items, all of which share the common theme of children's perceptions of how their illness has affected the way they look. The fourth factor, called the 'Interference with Activity' subscale, contains 3 items that examine the extent to which illness can hinder children from taking part in games or sports or from joining in the activities of friends. The fifth factor to emerge, labelled the 'Parental Responses' subscale contained 4 items, all of which contain the word '*parent*' and refer to how the children consider their parents treat them in light of their illness. Finally, the sixth factor, called the 'Manipulation' subscale contained 3 items. These items centre on how children may use their illness to 'get away with more'.

The internal consistency reliability co-efficients (Cronbach's Alpha; Cronbach, 1951),

for each of the subscales in the R-PIE and the composite 24 item R-PIE, are shown in Table 5F.3.

Table 5F.3: Internal consistency reliability for each of the subscales in the R-PIE and the composite R-PIE

Subscale	Alpha
School/Peer Rejection	.76
Thinking about Illness	.65
Physical Appearance	.68
Interference with Activity	.64
Parental Responses	.64
Manipulation	.61
Composite R-PIE	.84

The alpha reliability co-efficients for each of the subscales in the R-PIE demonstrate a modest degree of internal consistency. The alpha reliability co-efficient for the composite R-PIE indicates a high degree of internal consistency.

Comparison between the original subscales in the PIE (Eiser et al, 1995, 1999) and the subscales which emerged from factor analysis with the sample in this research (i.e. R-PIE)

The 6-factor solution which emerged overlaps, to some extent, with the subscales in the original PIE. Specifically, the School/Peer Rejection subscale in the R-PIE is an amalgamation of the PIE School and Peer Rejection subscales. The Physical Appearance subscale and the Interference with Activity subscale in the R-PIE mirror their respective subscales in the original PIE, but contain fewer items. However, while the Thinking about Illness subscale, the Parental Responses subscale, and the Manipulation subscale in the R-PIE, conform closely to the Disclosure, Parental Behaviour and Manipulation subscales, in turn, in the original PIE, they also include

items from other subscales in the PIE. No meaningful factors emerged to encompass the Preoccupation with Illness and Food subscales in the original PIE.

The empirically derived R-PIE (written below) represents the measure used to investigate the results of patients' experience in Barretstown.

THE REVISED PERCEPTION OF ILLNESS EXPERIENCE SCALE (R-PIE)

School/Peer Rejection subscale (7 items):

1. I find it hard to learn things because of my illness
2. Other people expect too much of my work
3. I get teased or picked on more than other people
4. I feel other people try to put me down
5. I feel left out of things at school or work
6. I am afraid other people won't like me because of my illness
7. I feel I get blamed for things that aren't my fault

Thinking about Illness subscale (4 items):

1. I hate being reminded of my illness
2. I get cross when people ask about my illness
3. I only tell people about my illness if I really have to
4. I wonder why I became ill

Physical Appearance subscale (3 items):

1. I feel my illness has made me look different
2. The way I look has changed because of my illness and treatment
3. My hair has been spoiled by the treatment

Interference with Activity subscale (3 items):

1. My illness stops me from doing games or sports I like

2. I am not always able to join in with what my friends are doing
3. I am afraid of doing sports where I might get hurt

Parental Responses subscale (4 items):

1. My parents treat me like a baby
2. My parents make a fuss of me because of my illness
3. My parents make a fuss about what I eat
4. My parents use my illness to stop me doing things

Manipulation subscale (3 items):

1. I can get away with a lot more in school or at work because of my illness
2. I use my illness to get out of things I don't want to do
3. My illness makes many problems for my family

APPENDIX 5G

FACTOR ANALYSES OF THE SIBLING PERCEPTION QUESTIONNAIRE (SPQ)

FACTOR ANALYSIS: SPQ

FACTOR ANALYSIS OF SPQ WITH THE ORIGINAL SAMPLE (Carpenter & Sahler, 1991)

The psychometric properties of the SPQ were assessed by Carpenter & Sahler (1991) with a group of 140 siblings attending a camping programme in New York. They were evenly divided by sex and their mean age was 11.3 years (range = 6-17 years).

- A factor analysis using the principal component method of extraction with a varimax (orthogonal) rotation was conducted on a 23-item SPQ.
- The internal reliabilities of each of the factor analytically derived subscales, based on Cronbach's Alpha, were established.

FACTOR ANALYSIS OF THE SPQ WITH THE SAMPLE IN THIS STUDY

Sample

This sample comprised 39 children; 14 boys (36%) and 25 girls (64%). Their mean age was 10.6 years (S.D = 1.8). A total of 20 children (51.3%) had a brother or sister with a form of cancer, 8 children (20.5%) had a brother or sister with a haematology related illness and in the case of the remaining 11 children (28.2%), the type of their brother/sisters illness was not reported. The majority of children (n = 23; 59%) were from Ireland and the rest were from England (n = 16; 41%).

Procedure

In view of the fact that there are 23 questions in the SPQ and only 39 children in this sample, it was considered more statistically appropriate to examine the corrected item total correlations and alpha reliability co-efficients for each subscale and to factor analyse each of the subscales separately to examine if they loaded highly onto one factor. This resulted in a sample size of 39 being used in a factor analysis where the number of items in each subscale was 9 or less. This procedure at least ensured that the sample size approached the recommended ratio of being 5 times greater than the number of variables (Hair et al, 1995). Corrected item total correlations were employed since the main purpose here was to assess the degree to which the items comprising each subscale can legitimately be treated as measuring a single construct (Mueller, 1986). A high degree of internal consistency is therefore desirable and consequently, it was decided that items with a corrected item total below .30 would be treated with caution and their performance assessed in the factor analysis before deciding whether to exclude them. In relation to factor analysis, corresponding with the approach taken by Carpenter & Sahler (1991) the principal component method of extraction was used with an orthogonal solution. However, as only one factor was requested for each subscale, the unrotated solution only was given and therefore analysed.

Results

Table 5G.1: Corrected item total correlations, reliability co-efficients and the results of factor analysis for the Interpersonal Relations subscale

Subscale Items	Corrected Item Total Correlations	Unrotated Solution
I wish my parents would spend less time with my sick brother/sister	.63	.77
I feel I have too much to do around the house since my brother/sister got sick	.34	.40
Since my brother/sister got sick I feel my parents ignore me	.76	.85
Since my brother/sister got sick we don't do as many things as a family	.37	.42
I wish my parents would spend more time with me	.58	.73
I feel people are more interested in my brother/sisters illness than they are in me	.69	.83
Since my brother sister got sick people don't care how I feel	.52	.73
I feel I don't want to bother my parents with my worries	.59	.63
I wish I knew someone who understands how I feel about my brother/sisters illnesss	.43	.50
% of variance:		44.8%
Eigenvalue:		4.0
Alpha reliability co-efficient:	.83	

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was .74 and Bartlett's test of the correlation matrix was significant where $p < .0001$, thereby indicating the suitability of factor analysis to use with this data. Table 5G.1 shows that the corrected item total correlations were above .3 for each item. All items loaded adequately onto the first factor explaining 41.8% of the variance. The reliability co-efficient for the subscale was high (.83). It was therefore decided to keep all items in the Interpersonal subscale.

Table 5G.2: Corrected item total correlations, reliability co-efficients and the results of factor analysis for the Intrapersonal Relations subscale

Subscale Items	Corrected Item Total Correlations	Unrotated Solution
I sometimes feel mad about my brother/sisters illness	.50	.60
I think about my brother/sisters illness	.59	.80
I still wonder why my brother/sister got sick	.59	.73
I wish there was something I could do to make my brother/sister feel better	.44	.70
I understand my parents have to spend more time with my sick brother/sister	-.09	Excluded
My brother/sisters illness makes me sad	.66	.88
% of variance:		56.1%
Eigenvalue:		2.8
Alpha reliability co-efficient:	.71	
Alpha reliability co-efficient with item excluded:	.80	

As represented in Table 5G.2, the corrected item total correlations for all items in the Intrapersonal scale were above .3 with the exception of the item '*I understand my parents have to spend more time with my sick brother/sister*' (-.09). In terms of factor analysis, the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was .58 and Bartlett's test of the correlation matrix was significant where $p < .0001$, thereby indicating the suitability of factor analysis for use with this data. All items with the exception of the item '*I understand my parents have to spend more time with my sick brother/sister*' loaded signficantly on the first factor. Examination of the theme inherent in this item suggested that it is unlike the other items in the scale in the sense that it refers to other people whereas the other items refer to feelings that the child might be experiencing. It was therefore excluded from the Intrapersonal subscale and the remaining items were re-factor analysed. The Kaiser-Meyer-Olkin Measure of

Sampling Adequacy (KMO) was .78 and Bartlett's Test of Sphercity was significant where $p < .0001$, thereby indicating the suitability of factor analysis for this data. As indicated in Table 5G.2, all 5 items loaded well on the first unrotated factor which explained an adequate amount of the variance (56.1%). Table 5G.2 also shows that the reliability of the scale increased to .80. All 5 items were therefore retained in the Intrapersonal subscale.

Table 5G.3: Corrected item total correlations, reliability co-efficients and the results of the factor analysis for the Communication subscale

Communication subscale	Corrected Item Total Correlations	Unrotated Solution
I can talk to my parents about my school work	-.05	Excluded
I can talk to other people my age about my brother/sisters illness	-.49	-.60
I can talk to my parents about my brother/sisters illness	.48	.68
I can talk to other adults (like teachers) about my brother/sister's illness	.09	Excluded
When my brother/sister got sick my parents told me about it	.30	.75
% of variance:		45.6%
Eigenvalue:		1.4
Alpha reliability co-efficient	.001	
Alpha reliability co-efficient with items excluded	.01	

As Table 5G.3 shows, 2 items failed to meet the corrected item total correlation of .3; *'I can talk to my parents about my school work'* and *'I can talk to other adults (like teachers) about my brother/sisters illness'*. In addition, the reliability of the scale was extremely low (.001). In terms of factor analysis, the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was low (.42), though Bartlett's test of the correlation matrix was significant where $p < .0001$. When all of the items were factor analysed they

had acceptable loadings on the first factor. However, in view of the extremely low reliability of the subscale, it was decided to exclude the 2 items with unacceptable corrected item total correlations. This increased the reliability of the scale to .01. Table 5G.3 shows the results when the remaining 3 items underwent a second factor analysis. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was .56 but Bartlett's test of the correlation matrix was not significant ($p > .05$) thereby indicating that factor analysis was not suitable to use with this data. All 3 items loaded well on the first unrotated factor explaining an adequate amount of the variance. While this factor makes conceptual sense and has acceptable loadings, the fact that it has such low reliability and the Bartlett test results culminated in a decision to exclude it from the R-SPQ.

Table 5G.4: Corrected item total correlations, reliability co-efficients and the results of factor analysis for the Fear of Disease subscale

Fear of Disease subscale	Corrected Item Total Correlations	Unrotated Solution
I worry that I can catch the illness from my brother/sister	.36	.75
I feel my friends worry about catching the illness from my brother/sister	.34	.75
I am afraid of my brother/sister's illness	.31	.68
% of variance:		52.4%
Eigenvalue:		1.6
Alpha reliability co-efficient	.48	

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was .62 and Bartlett's test of the correlation matrix was significant where $p<.05$, thereby suggesting the suitability of factor analysis for use with this data. As Table 5G.4 shows, the corrected item total correlations were acceptable. The results of the factor analysis showed that all items loaded well on the unrotated first factor and explained an

adequate amount of the variance. However, in view of the low reliability of the Fear of Disease factor, it was decided to exclude it from the R-SPQ.

Overall, the factor analysis resulted in a 14-item scale (R-SPQ) with 2 subscales. The reliability of this R-SPQ, as established using Cronbach's alpha, was high (.84).

Comparison between the Results of the Factor Analysis with Original Sample (Carpenter & Sahler, 1991) and Factor Analysis with the Sample in this Research for the SPQ

The Interpersonal subscale that emerged from the factor analysis with the sample in this research to form part of the R-SPQ contains the same items as the original Interpersonal subscale in the SPQ (i.e. Carpenter & Sahler, 1991). The Intrapersonal subscale in the R-SPQ contains the same items as the original Intrapersonal subscale in the SPQ with the exception of the item *' I understand my parents have to spend more time with my sick brother/sister'*. However, the R-SPQ does not contain the Communication and Fear of Disease subscales from the SPQ, since both were excluded.

The 14-item R-SPQ (see below) represents the instrument used to investigate the results of siblings' experience in Barretstown.

The Revised Sibling Perception Questionnaire (R-SPQ)

Interpersonal subscale (9 items):

1. I wish my parents would spend less time with my sick brother/sister
2. I feel I have too much to do around the house since my brother/sister got sick
3. Since my brother/sister got sick I feel my parents ignore me
4. Since my brother/sister got sick we don't do as many things as a family
5. I wish my parents would spend more time with me
6. I feel people are more interested in my brother/sisters illness than they are in me
7. Since my brother sister got sick people don't care how I feel
8. I feel I don't want to bother my parents with my worries
9. I wish I knew someone who understands how I feel about my brother/sisters illness

Intrapersonal subscale (5 items):

1. I sometimes feel mad about my brother/sisters illness
2. I think about my brother/sisters illness
3. I still wonder why my brother/sister got sick
4. I wish there was something I could do to make my brother/sister feel better
5. My brother/sisters illness makes me sad

APPENDIX 5H

FACTOR ANALYSIS OF THE SOCIAL SUPPORT SCALE

FACTOR ANALYSIS: SSS

FACTOR ANALYSIS OF SSS WITH THE ORIGINAL SAMPLE (Harter, 1985)

The psychometric properties of the SSS were initially examined by Harter (1985) with 2 elementary school samples of American children (grades 3-6) and 2 middle school samples of American children (grades 6-8). The analysis included the following stages;

- Individual factor analyses for the SSS were conducted for each of the 4 samples of children. The method of factor extraction was unspecified. An oblique rotation was performed, and it appears that the pattern matrix was examined. The number of factors was determined by a combination of the magnitude of the eigenvalues and interpretability.

- The reliabilities of each of the subscales, based on Cronbach's Alpha, were established with all 4 samples of American school children.

FACTOR ANALYSIS OF SSS WITH THE SAMPLE IN THIS STUDY

Sample

This sample comprised 228 children; 118 boys (51.8%) and 110 girls (48.2%). Their mean age was 11.4 years (S.D. = 2.3). Most of the children had been diagnosed with a chronic illness (n = 186; 81.6 %), and the others were siblings of children with chronic illlnesses (n = 42; 18.4 %). Of those children with a chronic illness, 150 children (80.6%) had a form of cancer, 15 children (8.1%) had a haematology related illness, 10 children (5.4%) had an immunodeficiency related illness, and 5 children (2.7%) had a

renal related illness. There were a few instances where the chronic illness that children had was not specified (n = 6; 3.2%). The children were from 16 European countries (see Table 5H.1 for a breakdown).

Table 5H.1: Number and percentage of children from each country who completed the SSS

Country	Number	Percentage
England	60	26.3%
Ireland	57	25.0%
Germany	19	8.3%
Spain	16	7.0%
Hungary	14	6.1%
Czech Republic	12	5.3%
Poland	11	4.8%
Sweden	8	3.5%
Russia	8	3.5%
Iceland	7	2.2%
Switzerland	5	2.2%
Cyprus	4	1.8%
Denmark	3	1.3%
Austria	3	1.3%
Norway	2	0.9%
Georgia	1	0.4%

Procedure

The ratio of the sample size to the number of variables in this part of the research exceeded the recommended 5-1 ratio (Hair et al, 1995), thereby providing an adequate basis for the calculation of the correlations between variables. A 4-factor solution was requested to correspond with the number of subscales in the original SSS using the principal component method of extraction and an oblique rotation. However, the results of the 4-factor solution could not be meaningfully interpreted. In order to find the factor pattern which best represented the data, the number of factors to extract was unspecified and the output examined. A 5-factor solution emerged and a review of the eigenvalues,

percentage of variance and the scree plot indicated this was appropriate. The pattern matrix was used to interpret the solution.

Results

The results of the 5-factor solution are shown in Table 5H.2.

Table 5H.2: Factor Analysis of the 24-item SSS scale

Item	Factor 1 Classmate (isolation/ bullying)	Factor 2 Friend	Factor 3 Teacher	Factor 4 Parent	Factor 5 Classmate (acceptance)
Making fun of them	.80				
Getting asked to play in games	.77				
Breaks in school	.74				
Close friend like to spend time with*	.49	.40			
Close friend to talk to		.84			
Close friend who understands		.82			
Close friend to tell problems to		.78			
Close friend who listens*	.44	.58			
Close friend who cares *	.45	.49			
Teacher who cares			.74		
Teacher who is fair			.73		
Teacher who treats them like a person			.69		
Teacher who helps them			.64		
Teacher who cares if they feel bad			.61		
Teacher who helps them do their best			.47		
Parents who care about their feelings				.70	
Parents who like them the way they are				.66	
Parents who treat them				.64	

Item	Factor 1 Classmate (isolation/ bullying)	Factor 2 Friend	Factor 3 Teacher	Factor 4 Parent	Factor 5 Classmate (acceptance)
like a person who matters					
Parents who understand them				.56	
Whether parents act like what child does is important*				.52	.46
Parents hearing about problems*				.47	.41
Classmates who can become friends					-.67
Classmates who pay attention to what is said					-.55
Classmates who like them the way they are					-.52
Eigenvalue:	4.5	4.0	4.0	3.6	2.8
% of variance:	27.5%	14.9%	9.5%	5.8%	4.7%

* = excluded item

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was .85 and Bartlett's test of the correlation matrix was significant where $p < .0001$, thereby indicating the suitability of factor analysis for use with this data. As represented in Table 5H.2, some items (denoted by a *) loaded onto 2 factors. These items were excluded since their loadings on the two factors were similar (i.e.<.2). The first factor to emerge was labelled the 'Classmate (isolation/bullying)' subscale. It contained 3 items relating to the degree to which children feel that they are isolated from and bullied by their classmates. The second factor to emerge, the 'Friend Support' subscale contained 3 items pertaining to the extent to which children feel they have a close friend that they can confide in and who understands them. The third factor was the 'Teacher Support' subscale. It contained 6 items which assess the extent to which children feel their teachers care about and help them. The fourth factor was the 'Parent Support' subscale. It contained 4 items which examine whether children consider they have parents who

understand and care for them. Finally the 'Classmate (acceptance)' subscale contained 3 items relating to the extent to which children feel accepted by their classmates. The results of this factor analysis resulted in an 18-item R-SSS that accounted for a cumulative variance of 62.4%.

With regard to reliability, the internal consistency of each subscale in the R-SSS and the internal consistency of the overall R-SSS was established using Cronbach's Alpha (see Table 5H.3).

Table 5H.3: Reliability co-efficients for the subscales in the R-SSS and the overall scale

Subscale	Alpha
Classmate (Isolation/Bullying)	.72
Friend	.86
Teacher	.77
Parent	.62
Classmate (Acceptance)	.70
Overall Scale	.85

The reliabilities for each of the subscales in the R-SSS can be considered adequate to high. The internal reliability of the overall R-SSS is high.

Comparison between the Results of the Factor Analysis with Original Sample (Harter, 1985) and Factor Analysis with the Sample in this Research, for the SSS

The subscales which emerged from the factor analysis with the sample in this research to form the R-SSS were, to a large extent, similar to the existing subscales in the original SSS. The Close Friend, Teacher Support and Parental Support subscales in the R-SSS correspond with those in the SSS, but contain fewer items. The emergence of 2 factors (i.e. Classmate (isolation/bullying) and Classmate (acceptance)) to encompass

the original Classmate Support subscale is appropriate given the sample of children in this research. It may reflect the fact that children with life-threatening illnesses, and their siblings, separate the experience of feeling isolated and bullied, which they may encounter because of their experience of illness, as something distinctly different to whether they are accepted by their classmates.

The R-SSS (see below) was used to interpret the results of children's experience in Barretstown.

The Revised Social Support Scale (R-SSS)

Classmate (isolation/bullying) subscale (3 items):

1. Some children have classmates who sometimes make fun of them OR Some children don't have classmates who make fun of them.
2. Some children don't get asked to play in games with classmates very often OR Some children often get asked to play in games by their classmates.
3. Some children often spend their breaks in school alone OR Some children spend their breaks in school plying with their classmates.

Close Friend subscale (3 items):

1. Some children have a close friend who they can talk to about things that bother them OR Some children don't have a close friend who they can talk to about things that bother them.
2. Some children have a close friend who really understands them OR Some children don't have a close friend who understands them.
3. Some children have a close friend who they can tell problems to OR Some children don't have a close friend who they can tell problems to.

Teacher Support subscale (6 items):

1. Some children have a teacher who helps them if they are upset and have a problem OR Some children don't have a teacher who helps them if they are upset and have a problem.

2. Some children don't have a teacher who helps them to do their very best OR Some children do have a teacher who helps them to do their very best.
3. Some children do have a teacher who cares about them OR Some children don't have a teacher who cares about them.
4. Some children don't have a teacher who is fair to them OR Some children do have a teacher who is fair to them.
5. Some children don't have a teacher who cares if they feel bad OR Some children do have a teacher who cares if they feel bad.
6. Some children have a teacher who treats them like a person OR Some children don't have a teacher who treats them like a person.

Parent Support subscale (5 items):

1. Some children have parents who don't really understand them OR Some children have parents who really do understand them.
2. Some children have parents who care about their feelings OR Some children have parents who don't seem to care very much about their feelings.
3. Some children have parents who treat them like a person who really matters OR Some children have parents who don't usually treat them like a person who matters.
4. Some children have parents who like them the way they are OR Some children have parents who wish their children were different.

Classmate (acceptance) subscale (3 items):

1. Some children have classmates who like them the way they are OR Some children have classmates who wish they were different.

2. Some children have classmates that they can become friends with OR Some children don't have classmates that they can become friends with.
3. Some children have classmates who pay attention to what they say OR Some children have classmates who usually don't pay attention to what they say.

APPENDIX 6

CHILDREN'S AND PARENTS' FEEDBACK ABOUT THE BARRETSTOWN PROGRAMME BEFORE, DURING AND AFTER CHILDREN'S PARTICIPATION; A QUALITATIVE PERSPECTIVE

ANALYSES[1]

Children: Pre-Barretstown Questionnaire (Time 1)

Sibling Perception Questionnaire: Analysis of open-ended questions

Question 1: The reasons why my brother's/sister's illness makes me mad are.....

A total of 21 siblings, from a sample of 43 siblings (48.8%), gave reasons as to why their brother's/sister's illness makes them mad. Table 6.1 provides a synopsis of the themes that emerged.

Table 6.1: The reasons why my brother's/sister's illness makes me mad are...: predominant themes

Themes	Number (%) of times theme mentioned
Sibling feels 'left out'	9 (36.0%)
Unfairness of illness for brother/sister	7 (28.0%)
Relationship with brother/sister suffers	6 (24.0%)
Never makes sibling mad	4 (16.0%)

Question 2: Some things I think about my brother/sister's illness are.....

A total of 28 siblings, from a sample of 43 siblings (65.1%), answered about the things they think about in relation to their brother's/sister's illness. Table 6.2 summarises the themes that emerged.

[1] Throughout the presentation of results, the term 'children' encompasses both children (7-12 years) and teenagers (13-16 years), and both patients and siblings, unless otherwise specifically stated.

Table 6.2: Some things I think about my brother's/sister's illness are...: predominant themes

Themes	Number (%) of times theme mentioned
Progress/outcome of illness	20 (51.3%)
Never think about it	7 (17.9%)
Reasons for brother/sister's illness	3 (7.7%)
People teasing brother/sister	1 (2.6%)

Question 3: Some things I'm afraid of about my brother's/sister's illness are.....

A total of 32 siblings, from a sample of 43 siblings (74.4%), answered about the things they are afraid of about their brother's/sister's illness. Table 6.3 summarises the themes that emerged.

Table 6.3: Some things I'm afraid of about my brother's/sister's illness are...: predominant themes

Themes	Number (%) of times theme mentioned
Never afraid	13 (33.3%)
Progress/outcome of illness	13 (33.3%)
Medical treatments	4 (10.3%)
Being 'left out'	2 (5.1%)
That illness is contagious	1 (2.6%)

Question 4: Some things that make me sad about my brother's/sister's illness are....

A total of 37 siblings from a sample of 43 siblings (86.0%) answered about the things that make them sad about their brother's/sister's illness. Table 6.4 summarises the themes that emerged.

Table 6.4: Some things that make me sad about my brother's/sister's illness are...: predominant themes

Themes	Number (%) of times theme mentioned
Unfairness of illness for brother/sister	12 (30.8%)
Never sad	7 (17.9%)
Feeling 'left out'	5 (12.8%)
Progress/outcome of illness	4 (10.3%)
Reasons for brother/sister's illness	1 (2.6%)

Question 5: When my brother/sister got sick, the things my parents told me about it are.....

A total of 29 siblings, from a sample of 43 siblings (67.4%), answered about the things their parents told them when their brother/sister got sick. Table 6.5 outlines the themes that emerged.

Table 6.5: When my brother/sister got sick, the things my parents told me about it are...: predominant themes

Themes	Number (%) of times theme mentioned
Description of precautions/treatments	15 (40.5%)
Name and description of illness	13 (35.1%)
Prognosis	8 (21.6%)
Never told anything/don't remember	4 (10.8%)

Parents: Pre-Barretstown Questionnaire (Time 1)

Patients

How would you rate your child's state of health over the last 3 months?

Overall, from a sample of 237 parents, the majority rated their children's health as being 'Very good' (n = 87; 44.2%) and 'Good' (n = 76; 38.6%) in the 3 months prior to their participation in the Barretstown programme. A number of parents rated their children's health as being 'Fair' (n = 29; 14.7%). A couple of parents indicated that their child's health was 'Poor' (n = 2; 1.0%) and no parents considered that their child's health was 'Very poor'. In 3 instances (1.5%), parents did not indicate their child's state of health.

Siblings

How would you rate your child's state of health over the last 3 months?

Overall, from a sample of 43 parents, the majority rated their children's health as being 'Very good' (n = 30; 69.8%) in the 3 months prior to their participation in the Barretstown programme. A few parents rated their children's health as 'Good' (n = 3; 7%) or 'Fair' (n = 3; 7%). No parents considered that their child's health was 'Poor' or 'Very poor'. In 7 instances (16.2%), parents did not indicate their child's state of health.

Do you have any suggestions for improving the information you received from Barretstown this year. Please explain.

A total of 157 parents, from a sample of 240 parents (65.4%), answered the question regarding suggestions for improving the information they received from Barretstown

before their child participated in the programme. Table 6.6 provides a synopsis of the themes that emerged.

Table 6.6: Parents' suggestions for improving the information they received from Barretstown: predominant themes

Themes	Number (%) of times theme mentioned
Information doesn't require improvement	96 (38.6%)
Information needs to be in recipient's language	21 (8.4%)
More information about Barretstown set up	20 (8.0%)
Information needs to be sent earlier	13 (5.2%)
More information regarding travel arrangements	9 (3.6%)
More information pertaining to their child	4 (1.6%)
Use additional modes of information dissemination	4 (1.6%)

What are the pros and cons of being away from your child while he/she is in Barretstown?

A total of 212 parents, from a sample of 240 parents (88.3%), answered the question regarding the pros and cons of being away from their child while he/she is in Barretstown. Table 6.7 provides a synopsis of the themes that emerged.

Table 6.7: Parents' delineation of the pros and cons of being away from their children while they are in Barretstown: predominant themes

Themes	Number (%) of times theme mentioned
Pros	
Benefits for child	97 (39.9%)
Break for the child	72 (29.6%)
Break for the family	68 (28%)
No pros	14 (5.8%)
Cons	
Child will be missed by family	94 (38.7%)
No cons	64 (26.3%)
Worries about child's psychological well-being	26 (10.7%)
Worries about child's physical health	17 (7.0%)
Lack of contact with child	14 (5.8%)
Travel related concerns	4 (1.6%)

Please write any comments you have about Barretstown, your child, or this research project.

A total of 120 parents, from a sample of 240 parents (50%), wrote comments about Barretstown, their child, and/or the research project. Table 6.8 provides a synopsis of the themes that emerged.

Table 6.8: Parents' comments about Barretstown, their child, and/or the research project: predominant themes

Themes	Number (%) of times theme mentioned
Barretstown	
Value of Barretstown as an experience	43 (17.8%)
Expression of gratitude	20 (8.3%)
More information about Barretstown set up	9 (3.7%)
Previous positive experiences in Barretstown	7 (2.9%)
Child	
Child is happy about going to Barretstown	19 (7.9%)
Parent is happy about child going to Barretstown	17 (7%)
Parent hopes that child will benefit from Barretstown	13 (5.4%)
Child has concerns about going to Barretstown	7 (2.9%)
Lack of contact during child's stay in Barretstown	4 (1.7%)
Research Project	
Positive feedback	27 (11.2%)
Negative feedback	12 (5.0%)

Children: Strategy of Therapeutic Recreation Based Activities Questionnaire (during stay in Barretstown)

Are you doing any activities in Barretstown that you had never tried before coming here? If yes, please write them down.

Of the 394 children comprising the sample, 290 children (73.6%) reported that they were doing activities that they had never tried before. Table 6.9 shows the frequencies with which children mentioned specific activities that they were doing in Barretstown that they had never tried before.

Table 6.9: Frequency with which children mentioned activities in Barretstown that they had never tried before

Activity	Frequency mentioned (%)
Canoeing	81 (20.6%)
Horseriding	48 (12.2%)
Archery	45 (11.4%)
Fishing	34 (8.6%)
Adventure	30 (7.6%)
Video/Photography	21 (5.3%)
Woodwork	12 (3.0%)
Arts and Crafts	9 (2.3%)
Camping	4 (1.0%)
Theatre	4 (1.0%)
Music	1 (0.3%)
Wordsmith	1 (0.3%)

Please use this space to write anything about Barretstown?

A total of 284 children, out of a sample of 394 children (72.1%), wrote about Barretstown. Table 6.10 provides a synopsis of the themes that emerged.

Table 6.10: Please use this space to write anything about Barretstown: predominant themes

Themes	Number (%) of times theme mentioned
Positive comments re. experience	232 (60.4%)
Desire to return	63 (16.4%)
Negative comments re. experience	26 (6.8%)
Description of surroundings	21 (5.5%)
Expression of gratitude	16 (4.2%)
Suggestions for improvement	13 (3.4%)

Children: Post-Barretstown Questionnaire (Time 2)

Do you have any special memories of your stay in Barretstown?

Overall, 147 children from a sample of 151 children (97.4%), answered the question about whether they had special memories of their stay in Barretstown after a 2 week interval. Table 6.11 provides a summary of the themes that emerged.

Table 6.11: Children's special memories of their stay in Barretstown after a 2 week interval: predominant themes

Themes	Number (%) of times theme mentioned
Activities	87 (57.2%)
People/friends met	33 (21.7%)
Staff	28 (18.4%)
Everything	23 (15.1%)
Experiential aspects of the programme	11 (7.2%)
No special memories	10 (6.6%)
Specific objects	6 (3.9%)
Animals	5 (3.3%)
Natural setting	5 (3.3%)
Food	2 (1.3%)

Would you like to change anything about your stay in Barretstown?

Overall, 147 children from a sample of 151 children (97.4%), answered the question about whether they would like to change anything about their stay in Barretstown 2 weeks after their participation in the programme. Table 6.12 provides a summary of the themes that emerged.

Table 6.12: Children's views about what they would like to change about their stay in Barretstown after a 2 week interval: predominant themes

Themes	Number (%) of times theme mentioned
Nothing	109 (28.3%)
Duration of stay	15 (9.9%)
Organisational related aspects	10 (6.6%)
Food	7 (4.5%)
Facilities	6 (3.9%)
Degree of supervision	3 (2.0%)
Phone policy	1 (.7%)

Sibling Perception Questionnaire: Analysis of open-ended questions

Question 1: The reasons why my brother's/sister's illness makes me mad are.....

A total of 20 siblings, from a sample of 24 siblings (83.3%), gave reasons as to why their brother's/sister's illness makes them mad, 2 weeks after their participation in the Barretstown programme. Table 6.13 provides a synopsis of the themes that emerged.

Table 6.13: The reasons why my brother's/sister's illness makes me mad are...: predominant themes

Themes	Number (%) of times theme mentioned
Sibling feels 'left out'	7 (28%)
Unfairness of illness for brother/sister	6 (24%)
Never makes sibling mad	6 (24%)
Reasons for brother/sister's illness	1 (4.0%)

Question 2: Some things I think about my brother's/sister's illness are.....

A total of 21 siblings, from a sample of 24 siblings (87.5%), answered about the things they think about in relation to their brother's/sister's illness, 2 weeks after their participation in the programme. Table 6.14 summarises the themes that emerged.

Table 6.14: Some things I think about my brother's/sister's illness are...: predominant themes

Themes	Number (%) of times theme mentioned
Progress/outcome of illness	11 (42.3%)
Never think about it	5 (19.2%)
Reasons for brother's/sister's illness	3 (11.5%)
Life without brother/sister being sick	1 (3.8%)
Medicines/treatments	1 (3.8%)

Question 3: Some things I'm afraid of about my brother's/sister's illness are.....

All 24 siblings (100%) answered about the things they are afraid of about their brother's/sister's illness, 2 weeks following their participation in the Barretstown programme. Table 6.15 summarises the themes that emerged.

Table 6.15: Some things I'm afraid of about my brother's/sister's illness are...: predominant themes

Themes	Number (%) of times theme mentioned
Never afraid	17 (65.4%)
Progress/outcome of illness	6 (23.1%)
Medical treatments	1 (3.8%)

Question 4: Some things that make me sad about my brother's/sister's illness are....

A total of 22 siblings, from a sample of 24 siblings (91.7%), answered about the things that make them sad about their brother's/sister's illness, 2 weeks after they participated in the Barretstown programme. Table 6.16 summarises the themes that emerged.

Table 6.16: Some things that make me sad about my brother's/sister's illness are...: predominant themes

Themes	Number (%) of times theme mentioned
Never sad	12 (46.2%)
Progress/outcome of illness	5 (19.2%)
Unfairness of illness for brother/sister	3 (11.5%)
Feeling 'left out'	1 (3.8%)
Reasons for brother's/sister's illness	1 (3.8%)

Question 5: When my brother/sister got sick, the things my parents told me about it are.....

A total of 21 siblings, from a sample of 24 siblings (87.5%), answered about the things their parents told them when their brother/sister got sick, 2 weeks after their participation in the Barretstown programme. Table 6.17 outlines the themes that emerged.

Table 6.17: When my brother/sister got sick, the things my parents told me about it are...: predominant themes

Themes	Number (%) of times theme mentioned
Name and description of illness	11 (42.3%)
Description of precautions/treatments	8 (30.8%)
Prognosis	3 (11.5%)
Never told anything/don't remember	2 (7.7%)
Allowed to ask questions	1 (3.8%)

Parents: Post-Barretstown Questionnaire (Time 2)

How do you feel about the following arrangements made by The Barretstown Gang Camp for your child.....

Table 6.18: Level of satisfaction with arrangements made by Barretstown for children

Arrangement *(N = 151)*	V.Satis.	Satis.	Neither Sat/Diss	Diss.	V. Diss.	No Response
Transport of child to/from camp	117 (77.5%)	20 (13.2%)	5 (3.3%)	1 (.6%)	3 (2%)	5 (3.3%)
Level of contact with child/staff in camp	72 (47.7%)	37 (24.5%)	27 (17.9%)	8 (5.3%)	2 (1.3%)	5 (3.3%)
Adequacy of medical services	106 (70.2%)	25 (16.6%)	10 (6.6%)	2 (1.3%)	2 (1.3%)	6 (4%)
Standard of nutrition (food)	78 (51.7%)	37 (24.5%)	18 (11.9%)	9 (6%)	4 (2.6%)	5 (3.3%)
Maintenance of child's hygiene:	88 (58.3%)	43 (28.5%)	14 (9.2%)	2 (1.3%)	2 (1.3%)	2 (.1.3%)
Programme of camp activities:	133 (88.1%)	11 (7.3%)	0 (0%)	2 (1.3%)	3 (2%)	2 (1.3%)
Camp staff:	132 (87.4%)	10 (6.6%)	1 (.6%)	2 (1.3%)	4 (2.6%)	2 (1.3)

Patients

How would you rate your child's state of health over the last month?

Overall, from a sample of 127 parents, the majority of parents rated their child's health as being 'Very good' (n = 71; 55.9%) in the month encompassing both the time in Barretstown and the time since Barretstown. A number of parents rated their child's health as being 'Good' (n = 39; 30.7%) or 'Fair' (n = 30; 23.6%). One parent indicated

that their child's health was 'Poor' (n = 1; 0.7%) and no parents considered that their child's health was 'Very poor'. In 3 instances (2.4%), parents did not indicate their child's state of health.

Siblings

How would you rate your child's state of health over the last 3 months?

Overall, from a sample of 24 parents, the majority of parents rated their child's health as being 'Very good' (n = 13; 54.2%) in the in the month encompassing both the time in Barretstown and the time since Barretstown. A number of parents rated their child's health as 'Good' (n = 9; 37.5%) and a couple of parents rated their child's health as 'Fair' (n = 2; 8.3%). No parents considered that their child's health was 'Poor' or 'Very poor'.

How has your child settled back to home and everyday life since returning from Barretstown?.

A total of 145 parents, from a sample of 151 parents (93.4%), answered the question about how their child had settled back to home and everyday life since returning from Barretstown 2 weeks previously. Table 6.19 summarises the predominant themes that characterised their responses.

Table 6.19: Parents' views about how their child settled back to home and everyday life 2 weeks following his/her participation in the Barretstown programme: predominant themes

Themes	Number (%) of times theme mentioned
Very well/no problems	110 (73.8%)
Initial difficulties, but then settled fine	33 (22.1%)
Positive changes in child	14 (9.4%)
Negative changes in child	2 (1.3%)

How do you feel your child got on in Barretstown? Please explain.

A total of 142 parents, out of a sample of 151 parents (94%), answered the question about how they felt their child got on in Barretstown, 2 weeks after their child had returned from Barretstown. Table 6.20 summarises the predominant themes that characterised their responses.

Table 6.20: Parents' feelings about how their child got on in Barretstown: predominant themes

Themes	Number (%) of times theme mentioned
Positive experience	115 (77.7%)
Psychosocial benefits	29 (19.6%)
Difficulties/problems	8 (5.4%)
Expression of gratitude	2 (1.4%)

Do you have any worries about your child's experience in Barretstown? Please explain.

A total of 137 parents, out of a sample of 151 parents (90.7%), answered the question about whether they had worries about their child's experience in Barretstown 2 weeks following their participation in the programme. Table 6.21 summarises the predominant themes that characterised their responses.

Table 6.21: Parents' worries about their child's experience in Barretstown after a 2 week interval: predominant themes

Themes	Number (%) of times theme mentioned
No worries	132 (88%)
Homesickness/lack of contact	3 (2%)
Not knowing staff	2 (1.3%)
Food	1 (.7%)

Do you have any suggestions about how your contact with and your child's experience of Barretstown can be improved?

A total of 108 parents, out of a sample of 151 parents (71.5%), answered the question regarding suggestions about how their contact with and their child's experience of Barretstown could be improved, 2 weeks after their child had returned from Barretstown. Table 6.22 summarises the predominant themes that characterised their responses.

Table 6.22: Parents' suggestions about how their contact with and their child's experience of Barretstown can be improved: predominant themes

Themes	Number (%) of times theme mentioned
No suggestions for improvements – all fine	68 (46.9%)
<u>Contact</u>	
More contact between parents and children during camp	17 (11.8%)
Provide more information about Barretstown	10 (6.9%)
<u>Child's experience</u>	
Children be encouraged to keep in contact with each other after Barretstown	5 (3.4%)
Child should be able to return to Barretstown	4 (2.7%)
Need to match age groups for accommodation needs	3 (2.1%)
Eliminate discrimination	1 (0.7%)
Improve the food in Barretstown	1 (0.7%)

Please write any comments you have about Barretstown, your child, or this research project.

A total of 114 parents, from a sample of 151 parents (75.5%), wrote comments about Barretstown, their child and/or this research project, 2 weeks after their child had returned from Barretstown. Table 6.23 summarises the predominant themes that characterised their responses.

Table 6.23: Parents' comments about Barretstown, their child and/or the research project

Themes	Number (%) of times theme mentioned
Barretstown	
Expression of gratitude	60 (42.3%)
Value of Barretstown as an experience	30 (21.1%)
Child	
Child has happy memories	38 (27%)
Suggestions to improve child's experience	16 (11.3%)
Personal/psychological benefits for child	15 (10.6%)
Social benefits for child	9 (6.3%)
Negative aspects to child's experience	8 (5.6%)
Cultural experience for child	2 (1.4%)
Research Project	
Positive feedback	9 (6.3%)
Negative feedback	7 (4.9%)

Children: Post-Barretstown Questionnaire (Time 3)

Do you have any special memories of your stay in Barretstown?

A total of 117 children out of a sample of 119 children (98.3%) answered the question about whether they had special memories of their stay in Barretstown after a 6-month interval. Table 6.24 summarises the principal themes that emerged.

Table 6.24: Children's special memories of their stay in Barretstown after a 6-month interval: predominant themes

Themes	Number (%) of times theme mentioned
Activities	58 (49.2%)
People/friends met	31 (36.3%)
Staff	16 (13.6%)
Enjoyment/fun	15 (12.7%)
No special memories	12 (10.2%)
Specific objects	10 (8.5%)
Animals	7 (5.9%)
Everything	6 (5.1%)
Natural setting	4 (3.4%)
Experiential aspects of the programme	2 (1.7%)

Would you like to change anything about your stay in Barretstown?

Overall, 116 children, out of a sample of 119 children (97.5%), answered the question about whether they would like to change anything about their stay in Barretstown after a 6-month interval. Table 6.25 provides a summary of the themes that emerged.

Table 6.25: Children's views about what they would like to change about their stay in Barretstown after a 6-month interval: predominant themes

Themes	Number (%) of times theme mentioned
Nothing	87 (73.1%)
Organisational related aspects	12 (10.1%)
Degree of supervision	6 (5.0%)
Duration of stay	6 (5.0%)
Food	4 (3.4%)
Facilities	3 (2.5%)
Phone policy	1 (0.8%)

Sibling Perception Questionnaire: Analysis of open-ended questions

Question 1: The reasons why my brother's/sister's illness makes me mad are.....

A total of 18 siblings, from a sample of 23 siblings (78.3%), gave reasons as to why their brother/sister's illness makes them mad, at a 6-month interval following their participation in the Barretstown programme. Table 6.26 provides a synopsis of the themes that emerged.

Table 6.26: The reasons why my brother's/sister's illness makes me mad are...: predominant themes

Themes	Number (%) of times theme mentioned
Never makes sibling mad	11 (47.8%)
Unfairness of illness for brother/sister	5 (21.7%)
Reasons for brother's/sister's illness	2 (8.7%)
Sibling feels 'left out'	1 (4.3%)

Question 2: Some things I think about my brother's/sister's illness are.....

A total of 18 siblings, from a sample of 23 siblings (78.3%), answered about the things they think about in relation to their brother's/sister's illness at a 6-month interval following their participation in the Barretstown programme. Table 6.27 summarises the themes that emerged.

Table 6.27: Some things I think about my brother's/sister's illness are...: predominant themes

Themes	Number (%) of times theme mentioned
Progress/outcome of illness	12 (54.5%)
Never think about it	4 (18.2%)
Treatments/medicines	1 (4.5%)
My life if brother/sister hadn't got sick	1 (4.5%)

Question 3: Some things I'm afraid of about my brother's/sister's illness are.....

All 23 siblings (100%) answered about the things they are afraid of about their brother/sister's illness at a 6-month interval following their participation in the Barretstown programme. Table 6.28 summarises the themes that emerged.

Table 6.28: Some things I'm afraid of about my brother's/sister's illness are...: predominant themes

Themes	Number (%) of times theme mentioned
Never afraid	17 (73.9%)
Progress/outcome of illness	5 (21.7%)
That illness is contagious	1 (4.3%)

Question 4: Some things that make me sad about my brother's/sister's illness are....

A total of 21 siblings, from a sample of 23 siblings (91.3%), answered about the things that make them sad about their brother's/sister's illness at a 6-month interval following their participation in the Barretstown programme. Table 6.29 summarises the themes that emerged.

Table 6.29: Some things that make me sad about my brother's/sister's illness are...: predominant themes

Themes	Number (%) of times theme mentioned
Never sad	9 (39.1%)
Unfairness of illness for brother/sister	6 (26.1%)
Progress/outcome of illness	5 (21.7%)
Feeling 'left out'	1 (4.3%)
Reasons for brother's/sister's illness	1 (4.3%)

Question 5: When my brother/sister got sick, the things my parents told me about it are.....

A total of 22 siblings, from a sample of 23 siblings (95.7%), answered about the things their parents told them when their brother/sister got sick at a 6-month interval following their participation in the Barretstown programme. Table 6.30 outlines the themes that emerged.

Table 6.30: When my brother/sister got sick, the things my parents told me about it are...: predominant themes

Themes	Number (%) of times theme mentioned
Name and description of illness	14 (60.9%)
Description of precautions/treatments	9 (39.1%)
Prognosis	4 (17.4%)
Never told anything/don't remember	4 (17.4%)
All questions answered	1 (4.3%)

Parents: Post-Barretstown Questionnaire (Time 3)

Patients

How would you rate your child's state of health over the last 6 months?

Overall, from a sample of 96 parents, the majority of parents rated their child's health as being 'Very good' (n = 48; 50%) in the 6 months since their child had returned home from Barretstown. A number of parents rated their child's health as being 'Good' (n = 30; 31.3%) or 'Fair' (n = 30; 13.5%). Two parents indicated that their child's health was 'Poor' (n = 2; 2%) and no parents considered that their child's health was 'Very poor'. In 3 instances (3.1%), parents did not indicate their child's state of health.

Siblings

How would you rate your child's state of health over the last 6 months?

Overall, from a sample of 23 parents, the majority of parents rated their child's health as being 'Very good' (n = 20; 86.9%) in the 6 months since their child had returned home from Barretstown. Two parents rated their child's health as 'Good' (n = 2; 8.7%) and parents considered that their child's health was 'Fair' 'Poor' or 'Very poor'. In 1 instance (4.3%), parents did not indicate their child's state of health.

Does your child talk now about the time he/she spent in Barretstown?

A total of 115 parents, out of a sample of 119 parents (96.6%), answered about whether their child talks about the time he/she spent in Barretstown 6 months following their participation in the programme. Table 6.31 delineates the main themes that emerged.

Table 6.31: Parents' comments about whether their child talks about the time he/she spent in Barretstown: predominant themes

Themes	Number (%) of times theme mentioned
Activities	39 (33.6%)
Other children/friends	39 (33.6%)
Great memories of a good time	38 (32.8%)
Staff	27 (23.3%)
Like to return to Barretstown	18 (15.5%)
Fun	16 (13.8%)
Never talks about Barretstown	7 (6.0%)
Teamwork	2 (1.7%)
Independence	2 (1.7%)
Criticisms of Barretstown	2 (1.7%)
Natural surroundings	1 (0.9%)

Do you have any worries about your child's experience in Barretstown in the long term? Please explain.

A total of 114 parents, out of a sample of 119 parents (95.8%), answered the question about whether they had worries about their child's experience in Barretstown. Table 6.32 summarises the predominant themes that characterised their responses.

Table 6.32: Parents' worries about their child's experience in Barretstown after a 6-month interval: predominant themes

Themes	Number (%) of times theme mentioned
No worries	110 (96.5%)
Lack of contact	2 (1.6%)
Child not with friends	1 (.8%)
No opportunity for child to go again	1 (.8%)

Do you have any suggestions about how your contact with and your child's experience of Barretstown can be improved?

A total of 113 parents, out of a sample of 119 parents (94.9%), answered the question regarding suggestions about how their contact with and their child's experience of Barretstown could be improved, 6 months after their child had returned from

Barretstown. Table 6.33 summarises the predominant themes that characterised their responses.

Table 6.33: Parents' suggestions about how their contact with and their child's experience of Barretstown can be improved: predominant themes

Themes	Number (%) of times theme mentioned
No suggestions for improvements – all fine	78 (18.9%)
Contact	
More contact between parents and children during camp	11 (9.3%)
Provide more information about Barretstown	10 (8.5%)
Parents should have the opportunity to go to Barretstown	2 (1.7%)
Child's experience	
Children be encouraged to keep in contact with each other after Barretstown	6 (5.1%)
Need to match age groups for accommodation needs	3 (2.5%)
Improve the food in Barretstown	1 (0.8%)
Children should be allowed to see outside Barretstown	1 (0.8%)
Child should be able to return to Barretstown	1 (0.8%)

Please write any comments you have about Barretstown, your child, or this research project.

A total of 86 parents, out of a sample of 119 parents (72.3%), wrote comments about Barretstown, their child and/or this research project, 6 months after their child had returned from Barretstown. Table 6.34 summarises the predominant themes that characterised their responses.

Table 6.34: Parents' comments about Barretstown, their child, and/or the research project

Themes	Number (%) of times theme mentioned
Barretstown	
Expression of gratitude	34 (29.3%)
Value of Barretstown as an experience	25 (21.6%)
Child	
Child has happy memories	27 (23.3%)
Suggestions to improve child's experience	11 (9.5%)
Personal/psychological benefits for child	12 (10.3%)
Social benefits for child	5 (4.3%)
Negative aspects to child's experience	7 (6.0%)
Cultural experience for child	2 (1.7%)
Research Project	
Positive feedback	10 (8.6%)
Negative feedback	4 (3.4%)