LISTENING TO CHILDREN AND YOUNG PEOPLE WITH CANCER

Final Report July 2005

Dr. Faith Gibson, Lecturer in Children’s Nursing Research. Institute of Child Health and Great Ormond Street Hospital for Children NHS Trust

Prof. Alison Richardson, Professor of Cancer and Palliative Care. King’s College London

Susie Hey, Researcher in Child Health. Institute of Child Health

Maire Horstman, Principal Lecturer. London South Bank University

Chris O’Leary, Play Specialist. Great Ormond Street Hospital for Children NHS Trust

Centre for Nursing and Allied Health Professions Research, Institute of Child Health 7th Floor Old Building, Great Ormond Street Hospital, for Children NHS Trust Great Ormond Street London WC1N 3JH.

Tel 020 7813 8543

e-mail gibsof@gosh.nhs.uk
LAY SUMMARY

Introduction

There has been limited research carried out on the views of children and young people with cancer about their care and support needs during and after treatment. The focus of this study therefore, was to find out about these experiences, from the children themselves. Through finding out about their experiences we can begin to identify what helps to make their treatment and life with cancer easier and whether the service we provide meets their needs. As some research had focussed upon parents and older children’s views of cancer care, we sought to specifically talk to children and young people, even the very young. Talking to children and young people aged 4 to 19 years old would allow us to consider how their needs might change and may differ across the ages.

Methods

Thirty-eight children and young people aged 4 to 19 years took part in the project. They were either still on treatment, at the end of treatment or had finished treatment 6 to 18 months ago. Creative, age appropriate research techniques were used to help children and young people talk about their experiences and share views of services they had come across. Play and puppets were used to talk to the very young children, 4 and 5 years old. The use of familiar objects was thought useful to help the researcher to enter the world of the child. The ‘draw and write technique’ was used with the 6 to 12 year olds. This involved asking the child to draw a picture at the start of the interview of a child like them (for example who has just finished their treatment) and to write down what that child might be thinking and doing. This was then followed up with questions firstly relating to the child’s drawing and then about their experiences. Individual interviews and an activities day were carried out with the 13 to 19 year olds. Questions asked in all three different research methods reflected the child’s age and stage of treatment. The data were analysed and themes pulled out.

Results

Six main themes were identified:

1. As much like home as it can be
What children did not like about hospital were things that made hospital different to home, for example, not having family around. The young children talked about missing the parent who was not staying with them and their siblings. The older children and young people spoke more about the environment than the younger children. They wanted the hospital to be bright, colourful, comfortable and non clinical. They also wanted separate areas on the wards and separate waiting areas for young children and older children as they found hearing the younger children crying upsetting and noisy. Hospital food was a huge issue for the majority of the older children and young people.

2. The work of children
Toys, the playroom and activities were clearly very important features of hospital life across the age groups as they provided distraction and prevented boredom. Play specialists and play workers were viewed by younger children as having a key role in providing activities and many of them told stories about fun things they had done with play staff. The availability of toys and activities was an issue for many of the children and young people. They spoke about staying in bed all day having treatment and then when they were able to get out of bed finding that the playroom was closed and the
play staff had gone home. It was also important that the activities were age appropriate.

The young people often felt that they were able to amuse themselves and were content with just watching TV or reading, particularly when they were feeling unwell. They described being pestered by staff to take part in activities that were inappropriate or they did not feel like doing at the time.

3. Asking and telling - getting the balance right
The young children who were interviewed reported being told information about their illness and treatment from their parents and did not recall being given information by hospital staff. They said that they would ask their parents if they wanted to know anything about their treatment and this was not an issue for them. However, many of the older children wanted to be spoken to and given information directly by hospital staff. They wanted staff to use words that they understood, and to use the correct words for treatments and procedures, as they got older. A number of children found information overwhelming, saying that they would have preferred to be asked if they wanted information at that time or given the opportunity to ask questions about what was important to them. Asking questions was something that many of the children said that they found difficult and they wanted staff to recognise this and enable them to be able to ask.

Many of the older children felt that they were not given enough information about their illness and treatment. For example, some children mentioned the need for more information about steroids. Lack of information made the children worry that the changes they were experiencing would be permanent. The young people who were interviewed individually on the whole felt that they had been given adequate information and that doctors did speak to them directly.

4. The triad of support
The role of family, friends and hospital staff featured highly in the children and young people’s stories. These people provided them with support and helped them through the ‘hard times’. Parents were the main source of support. The older children and young people also spoke a lot about the role of doctors and nurses. They appreciated it when doctors and nurses listened to them, made an effort to get to know them and ‘chatted’ to them about their own life. It was important that hospital staff were sensitive to their needs and feelings. Staff not being sensitive was described as distressing, embarrassing and annoying. This insensitivity was mainly around being examined, not explaining things and, for older children, not being left alone when they wanted to be.

Friends were an important source of support for the young people. Many of this group said that they would speak to their friends about their worries. However, it was felt to be difficult to maintain contact with friends whilst in hospital.

5. How treatment affects my body and my life
The younger children spoke very little about their experiences of being ill and having treatment. When pressed to talk about what it was like having treatment, the children talked about the taste of their medicines. Medicines were viewed as acceptable as long as they did not taste bad.
The older children and young people talked more about having treatment and how treatment makes them feel. Needles were something which lots of the children found very stressful and worried about having. They spoke positively about having a Hickman line and not having to have needles. For some of the older children and young people there was a sense that treatment had to be done and so might as well be done quickly to get it over with:

Many of the children and young people spoke about how cancer and treatment placed limitations upon their lives. They often felt too tired and sick to do things. Being in hospital and being attached to a drip took away their freedom and limited their activities. For the children who attended hospital for day treatment, waiting was time consuming and boring.

When the young children were asked whether they ever felt worried when they were at the hospital some said that they did not get worried. Parents and siblings were mentioned most frequently as the person they would tell if they felt worried. However, a number of children said that they would not tell anyone, reasons given for this were wanting to be brave and strong and not wanting to appear silly.

Some of the older children reported feeling worried about the present and future. They sometimes found hospital ‘scary’ and worried about having needles and whether they would get better. For some children waiting to see the doctor and to have treatment made them worry more. Being left alone was particularly scary.

Worrying was not an issue for the young people interviewed, there was a sense that they just, ‘have to keep going’ and for some young people having cancer had made them appreciate life more.

Conclusion
This study provides an insight into children and young people’s experiences of cancer care services. The findings support previous work on the needs of children and young people with chronic illnesses and cancer. The children and young people in this study spoke about many aspects of hospital care and did not focus specifically upon treatment. Some findings reflect what was already known, such as the importance of food and a familiar environment, and therefore it was disappointing to see that change in some areas remains slow, possibly constrained by financial resources and space. Some findings were new, such as worries and concerns about the permanence of symptoms, and some added further detail to what is already known, such as the importance of personalising information giving. This research has many implications for the development of services, which are child oriented and meet the needs of children and young people with cancer. The findings of this project would benefit from being distributed widely as they offer important perspectives from children and young people about the cancer care they have received.
EXECUTIVE SUMMARY

Introduction
There has been little previous research on the views of children and young people with cancer about their care and support needs. This study focuses specifically upon finding out about the experiences of this group. Through finding out about their experiences we can begin to identify the needs of children and young people with cancer, what helps to make their treatment and life with cancer easier and whether current service provision meets their needs. It was intended that through talking to children and young people aged between 4 to 19 years old that this would enable us to consider how needs change and might be different across the different age groups.

Background
Research-based knowledge on children’s experiences from their viewpoint is important. It enables health care professionals to begin to understand the world of children, thereby helping them to provide child-centred, high quality care (Kortesluoma, Hentinen and Nikkonen, 2003). Historically, information about children’s views has been obtained via proxy accounts given by adults who know the child, such as parents and teachers. However, in order to provide services which are effective and genuinely meet the needs of children and young people, their views must be sought (Children and Young People's Unit, 2001). There is increasing recognition, supported through national and local policies, that children and young people should be involved in decisions that affect them. To that end The Children’s Task Force (www.dh.gov.uk/childrennsf) have made a clear commitment to listen to children and young people. This belief is enshrined in the National Service Framework that includes an assurance to providing services, which are designed and delivered around the needs of children where they will have more information, power and choice over the support and treatment they receive (Department of Health, 2004). Similar concerns are embedded in the recent Clinical Services for Children and Young People (National Institute for Clinical Excellence, NICE 2005).

Previous literature on childhood cancer is dominated by studies on the psychosocial effects of cancer on children and families and on coping and adjustment, with little priority given to views of care (Dixon-Woods, Young, and Heney, 2002). From the literature that does exist children and young people with cancer have provided important insights into what is important to them. In Horstman and Bradding's (2002) study, participants expressed the desire for doctors to talk directly to them and to give clear, honest information regarding their prognosis, diagnosis and treatment. The children spoke about feeling sad whilst in hospital as they missed their parents and friends and about feeling frustrated due to the limitations that being ill placed on their lives. They wanted nurses to take time to get to know them and find out about their interests. Ellis and Leventhal (1992) and Hooker (1997) also report on children and young people with cancer’s desire for information. Likewise, the young people in Wilkinson's (2003) study said that they appreciated being ‘told straight’ (p.69). They also valued being treated within a ward specifically for young people with cancer as they were near others with similar conditions and staff were used to working with teenagers. More recently, Gallini and Hooker (2005) report similar experiences and concerns from young people with cancer participating in a user group.

One of the problems faced by those seeking to obtain views from children is the lack of tools suitable to use with younger children (Horstman and Bradding, 2002). Involving young people in research also presents various challenges (Dashiff, 2001).
Researchers collecting data with children and young people are becoming more flexible in their approaches and beginning to use more creative methods that enable children and young people to give their views. A number of child-focused research methods are available for consideration by researchers. These are felt to hold the potential for success, especially when thought is given to the planning of the research with respect to age, experience and the ways in which children and young people feel most comfortable to communicate. The underlying philosophy of participatory research is that those being researched are not simply regarded as ‘subjects’ but are empowered to truly participate and have their voices heard. In participatory research there is a strong commitment to engaging with participants in a meaningful way and acknowledging that participants are the ‘experts’ on the research topics. When carrying out research that aims to enable children and young people to fully participate and give their views, the methods to be used must be considered very carefully. Age appropriate methods that are interesting, non-threatening and facilitate communication are essential.

**Aims of the study**
The aims of this study were:

1. To explore the perception of children and young people with cancer regarding their care and support needs.
2. To map the needs of children and young people with cancer from their perspective.
3. To gain an understanding of their views of current cancer care services, including positive experiences and issues that have been less positive.
4. To offer developmental work on fostering avenues of communication with children and young people with cancer.

**Methods**
Thirty-eight children and young people aged 4 to 19 years took part in the project. Participants were either still on treatment (n=20), at the end of treatment (n=9) or had finished treatment 6 to 18 months ago (n=9). Creative, age appropriate techniques were employed to enable participants to talk about their experiences and views of cancer care services. Play and puppets were used to talk to the 4 and 5 year olds. The ‘draw and write technique’ was used with the 6 to 12 year olds. The 13-19 year olds were engaged in individual interviews and an activities day. Data were analysed using thematic coding (Coffey and Atkinson, 1996).

**Findings**
Six main themes were identified from the data.

1. **As much like home as it can be**
   What the children did not like about hospital were things that made hospital different to home, for example, not having family around. The young children talked about missing the parent who was not staying with them and their siblings. The older children and young people spoke more about the environment than the younger children. They wanted the hospital to be bright, colourful, comfortable and non-clinical. They also wanted separate areas on the wards and separate waiting areas for young children and older children as they found hearing the younger children crying upsetting and noisy. Hospital food was a huge issue for the majority of the older children and young people.
2. The work of children
Toys, the playroom and activities were clearly very important features of hospital across the age groups as they provided distraction and prevented boredom. Play specialists and play workers were viewed by younger children as having a key role in providing activities and many of them told stories about fun things they had done with play staff. The availability of toys and activities was an issue for many of the participants. They spoke about staying in bed all day having treatment and then when they were able to get out of bed finding that the playroom was closed and the play staff had gone home. It was also important that the activities were age appropriate. Many of the older children felt that the toys were for young children.

The young people often felt that they were able to amuse themselves and were content with just watching TV or reading, particularly when they were feeling unwell. They described being pestered by staff to take part in activities that were inappropriate or they did not feel like doing.

3. Asking and telling - getting the balance right
The young children who were interviewed reported being told information about their illness and treatment from their parents and did not recall being given information by hospital staff. They said that they would ask their parents if they wanted to know anything about their treatment and this was not an issue with them. However, many of the older children wanted to be spoken to and given information directly by hospital staff. They wanted staff to use words that they understood and to use the correct words for mediations and procedures, as they got older. A number of children found information overwhelming would prefer to be asked if they wanted information at that time or given the opportunity to ask questions about what was important to them. Asking questions was something that many of the children said that they found difficult and they wanted staff to recognise this and enable them to be able to ask.

Many of the older children felt that they were not given enough information about their illness and treatment. For example, some children mentioned the need for more information about steroids. Lack of information made the children worry that the changes they were experiencing would be permanent. The older teenagers who were interviewed individually on the whole felt that they had been given adequate information and that doctors did speak to them directly.

4. The triad of support
The role of family, friends and hospital staff featured prominently in the children and young people’s stories. These people provided the participants with support and helped them through the ‘hard times’. For the very young children, parents came across as being the most important people when they were in hospital. It was important that parents could stay and that they were always present. It was also important for the older children and the majority of the young people that their parents could stay.

The very young children rarely mentioned nurses and doctors unless prompted, however, the older children and young people spoke a lot about their role. They appreciated it when doctors and nurses listened to them, made an effort to get to know them and ‘chatted’ to them about their life. It was important that hospital staff were sensitive to the needs and feelings of the participants, Staff not being sensitive was distressing, embarrassing and annoying for participants. This insensitivity was mainly
around being examined, not explaining things and, for older participants, not being
left alone when they wanted to be.

Friends were an important source of support for the young people. Many of this
group said that they would speak to their friends about their worries. However, it was
difficult to maintain contact with friends whilst in hospital.

5. How treatment affects my body and my life
The younger children talked very little about their experiences of being ill and having
treatment. When pushed to talk about what it was like having treatment, the children
talked about the taste of their medicines. Medicines were viewed as acceptable as
long as they did not taste bad. The older children and young people spoke more about
having treatment and how treatment makes them feel. Needles were something which
lots of the children found very stressful and worried about having. For some of the
older children and young people there was a sense that treatment had to be done and
so might as well be done quickly to get it over with:

Many of the participants spoke about how the cancer and treatment placed limitations
upon their lives. They often felt too tired and sick to do things. Being in hospital and
being attached to a drip took away their freedom and limited their activities. Waiting
for treatment was a huge issue. For children who attend hospital for day treatment
waiting was time consuming and boring.

6. Worrying about now and the future
When the young children were asked whether they ever felt worried when they were
at the hospital some said that they did not get worried. Parents and siblings were
mentioned most frequently as the person they would tell if they felt worried.
However, a number of children said that they would not tell anyone, reasons given for
this were wanting to be brave and strong and not wanting to appear silly.

Some of the older children reported feeling worried about the present and future.
They sometimes found hospital ‘scary’, worried about having needles and whether
they would get better. For some children waiting to see the doctor and to have
treatment heightened their worry. Being left alone was particularly scary.
Worrying was not an issue for the young people interviewed. There was a sense that
they just, ‘have to keep going’ and for some young people having cancer had made
them appreciate life more.

Implications
This research has many implications for the development of services that are child
oriented and meet the needs of children and young people with cancer. Many of the
findings have resource implications in terms of external décor, toys and appropriate
activities, as well as people and education. Older children and young people were
able to express how they wanted to be treated by healthcare care professionals. Table
1 provides a summary of the implications.
<table>
<thead>
<tr>
<th>Key themes</th>
<th>Supporting quote</th>
<th>Implications for practice</th>
</tr>
</thead>
</table>
| As much like home as it can be | ‘it would be nicer if …the ward was painted so it was like nicer….like lots of bright colours and patterns and things for people to look at and read and pictures (Sarah, 13 years old) | • Clinical areas split by age group as older children found hearing the young children crying upsetting and noisy.  
• Need for more space in cubicles.  
• Need for privacy.  
• Bright, personalised hospital environment, and more like home.  
• Food which children and young people recognise and enjoy eating. |
| The work of children | ‘having something to do is really important, having the right things, lots of things for young children, don’t mix us up’ (Gemma, 10 years old) | • Toys and activities more accessible.  
• More play staff, particularly who are available at evenings and weekends  
• Playroom to have flexible opening times.  
• More toys and activities for older children and young people.  
• Appropriate level of education available. |
| Asking and telling - getting the balance right | ‘they tell you the medicine will make you better but they don’t tell you how it works’ (Jack, 12 years old) | • Speak directly to children and young people, rather than staff speaking to parents first.  
• Find out about the child’s preferences and whether they wish to be spoken to directly.  
• More information about how treatment works, side effects, waiting and medications such as steroids.  
• Update information and use more ‘grown-up’ words, as children get older.  
• As parents and health care professional share the role of information giving, preparation and support for both parties to get it right. |
| The triad of support | Parents: ‘they give you so much confidence, always being there, helping you…. they sort of do anything to make you feel comfortable and happy’ (Nick, 14 years old).  
Friends: ‘It (support from friends) just makes me more confident that I try and get through it’ (John, 17 years old).  
Hospital staff: ‘they talked to me and then I got to trust them and they were nice’ (Christopher, 12 years old) | • Important that parents can stay with children when they are in hospital.  
• Health care professionals need to recognise that children may feel scared when their parents are not there.  
• Keeping in touch with friends whilst in hospital is difficult; the use of an affordable telephone would help.  
• Health care professionals need to take the time to get to know children and young people, be sensitive to their needs and treat them as an individual. |
| How treatment affects my body and my life | ‘it really did make me feel very ill….it just drains you literally….it drains you of energy and makes you sick’ (Ian, 18 years old) | • Provide information on waiting and effects of treatment so children know what to expect.  
• Assist the development of coping strategies early in the treatment phase. |
| Worrying about now and the future | ‘I worry, I hope it won’t come back’ (Rob, 12 years old) | • Acknowledge that children and young people may feel scared and worried.  
• Try not to leave young children alone.  
• Assist the development of coping strategies. |
Conclusions
This study provides important insights into the aspects of cancer care that are important to children and young people with cancer. Using age appropriate creative data collection techniques enabled even very young children to talk about their experiences and give their views. The findings add detail to issues already apparent in the literature and a number of new findings also emerged. Some findings confirmed what was already known, and therefore it was disappointing to see that change in some areas of care remains slow, possibly constrained by financial resources and space. Some findings were new, such as worries and concerns about the permanence of symptoms, and some added further detail to what is already known, such as the importance of personalising information giving. The implications for cancer care services are discussed. Findings of this project would benefit from being disseminated widely as they offer important perspectives from children and young people about the cancer care they have received.

References


Wilkinson, J. 2003, "Young people with cancer--how should their care be organized?", European Journal of Cancer Care, vol. 12, no. 1, pp. 65-70.
ACKNOWLEDGEMENTS

This study was funded by Macmillan Cancer Relief. We would like to thank the charity for their generous support. This report has been produced to fulfil the criteria set by the funding body regarding dissemination of project findings. The content of this report has not been peer reviewed by Macmillan Cancer Relief.

Data collection would not have been possible without the cooperation of the following organisations: Great Ormond Street Hospital for Children NHS Trust, University College London Hospitals and The Royal Marsden Hospital. We would like to express our thanks to all the children and young people who took part in the project and for the support of their parents in giving us the opportunity to work with their children.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.0</td>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>2.0</td>
<td>Background</td>
<td>1</td>
</tr>
<tr>
<td>2.1</td>
<td>Policy and practice for listening to children and young people</td>
<td>1</td>
</tr>
<tr>
<td>2.2</td>
<td>Previous research on children and young people’s views of care</td>
<td>1</td>
</tr>
<tr>
<td>2.3</td>
<td>Giving children and young people a voice</td>
<td>3</td>
</tr>
<tr>
<td>2.4</td>
<td>Aims of the study</td>
<td>5</td>
</tr>
<tr>
<td>3.0</td>
<td>Methods</td>
<td>5</td>
</tr>
<tr>
<td>3.1</td>
<td>Setting and sample</td>
<td>5</td>
</tr>
<tr>
<td>3.2</td>
<td>Recruitment</td>
<td>5</td>
</tr>
<tr>
<td>3.3</td>
<td>Data collection methods</td>
<td>6</td>
</tr>
<tr>
<td>3.3.1</td>
<td>Play and puppets</td>
<td>6</td>
</tr>
<tr>
<td>3.3.2</td>
<td>Draw and write technique</td>
<td>6</td>
</tr>
<tr>
<td>3.3.3</td>
<td>Activities day and interviews</td>
<td>7</td>
</tr>
<tr>
<td>3.4</td>
<td>Ethical issues</td>
<td>7</td>
</tr>
<tr>
<td>3.5</td>
<td>Data analysis</td>
<td>7</td>
</tr>
<tr>
<td>4.0</td>
<td>Project milestones</td>
<td>8</td>
</tr>
<tr>
<td>5.0</td>
<td>Results</td>
<td>9</td>
</tr>
<tr>
<td>5.1</td>
<td>Participants</td>
<td>9</td>
</tr>
<tr>
<td>5.2</td>
<td>Findings</td>
<td>11</td>
</tr>
<tr>
<td>5.2.1</td>
<td>As much like home as it can be</td>
<td>11</td>
</tr>
<tr>
<td>5.2.2</td>
<td>The work of children</td>
<td>13</td>
</tr>
<tr>
<td>5.2.3</td>
<td>Asking and telling – getting the balance right</td>
<td>13</td>
</tr>
<tr>
<td>5.2.4</td>
<td>The triad of support</td>
<td>15</td>
</tr>
<tr>
<td>5.2.5</td>
<td>How treatment affects my body and my life</td>
<td>16</td>
</tr>
<tr>
<td>5.2.6</td>
<td>Worrying about now and the future</td>
<td>17</td>
</tr>
<tr>
<td>6.0</td>
<td>Discussion</td>
<td>18</td>
</tr>
<tr>
<td>7.0</td>
<td>Challenges</td>
<td>20</td>
</tr>
<tr>
<td>7.1</td>
<td>Recruitment</td>
<td>20</td>
</tr>
<tr>
<td>7.2</td>
<td>Practicalities of data collection</td>
<td>21</td>
</tr>
<tr>
<td>7.3</td>
<td>Data collection methods</td>
<td>21</td>
</tr>
<tr>
<td>8.0</td>
<td>Implications</td>
<td>21</td>
</tr>
<tr>
<td>8.1</td>
<td>Implications for Macmillan Cancer Relief</td>
<td>21</td>
</tr>
<tr>
<td>8.2</td>
<td>Implications for the provision of cancer services and service development</td>
<td>22</td>
</tr>
<tr>
<td>8.3</td>
<td>Implications for future research</td>
<td>24</td>
</tr>
<tr>
<td>9.0</td>
<td>Conclusion</td>
<td>25</td>
</tr>
<tr>
<td>10.0</td>
<td>References</td>
<td>26</td>
</tr>
<tr>
<td>10.0</td>
<td>Appendices</td>
<td>29</td>
</tr>
<tr>
<td>Appendix 1 Information sheets and poster</td>
<td>29</td>
<td></td>
</tr>
<tr>
<td>Appendix 2 Newsletters</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td>Appendix 3 Questions used in data collection</td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>Appendix 4 Ice breaker task</td>
<td>43</td>
<td></td>
</tr>
<tr>
<td>Appendix 5 Dissemination process and outcomes from project</td>
<td>44</td>
<td></td>
</tr>
</tbody>
</table>
# LIST OF TABLES

<table>
<thead>
<tr>
<th>Table Number</th>
<th>Title</th>
<th>Page Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Project milestones with dates achieved</td>
<td>9</td>
</tr>
<tr>
<td>2</td>
<td>Background details of participants</td>
<td>10</td>
</tr>
<tr>
<td>3</td>
<td>Reasons given for non-participation in the study</td>
<td>11</td>
</tr>
<tr>
<td>4</td>
<td>Themes</td>
<td>11</td>
</tr>
<tr>
<td>5</td>
<td>Themes from the children and young people’s accounts and implications for practice</td>
<td>23</td>
</tr>
</tbody>
</table>
1.0 INTRODUCTION
Over the past three decades, overall incidence of cancer in Europe has risen by 1% per year for children aged 0 to 14 years and by 1.5% per year for young people aged 15 to 19 years (Steliarova Foucher, Stiller, Kaatsch, Berrino et al, 2004). With cancer in children and young people on the increase, it is ever more important that the needs of this group are known and met. However, whether current service provision meets the needs of children and young people with cancer remains unclear. This study was undertaken to explore the experiences and needs of children and young people with cancer from their perspective. The purpose of this report is to provide a brief introduction to the background to the work, followed by an account of the data collection methods and findings. Following this, a commentary of what the findings contribute to the area and what they tell us about how the needs of children and young people might be met in the future are presented. As such studies are not without their challenges, the issues encountered during the course of the study and limitations of the study are also described.

2.0 BACKGROUND
2.1 Policy and practice for listening to children and young people
Research-based knowledge on children’s experiences from their viewpoint is important. It enables health care professionals to begin to understand the world of children, thereby helping them to provide child-centred, high quality care (Kortesluoma, Hentinen and Nikkonen, 2003). Historically, information about children’s views has been obtained via proxy accounts given by adults who know the child, such as parents and teachers. However, it is well recognised that children and adults have a different understanding and experience of the world (Thomas and O’Kane, 1998) which can lead to disparities in what is perceived as important (Garth and Aroni, 2003). In order to provide services which are effective and genuinely meet the needs of children and young people, their views must be sought (Children and Young People's Unit, 2001). There is increasing recognition, supported through national and local policies, that children and young people should be involved in decisions that affect them. To that end The Children’s Task Force (www.dh.gov.uk/childrennsf) have made a clear commitment to listen to children and young people. This belief is enshrined in the National Service Framework that includes an assurance to providing services, which are designed and delivered around the needs of children where they will have more information, power and choice over the support and treatment they receive (Department of Health, 2004). Similar concerns are embedded in the recent Clinical Services for Children and Young People (National Institute for Clinical Excellence, NICE 2005).

2.2 Previous research on children and young people’s views of care
Previous literature on childhood cancer is dominated by studies on the psychosocial effects of cancer on children and families and on coping and adjustment, with little priority given to views of care (Dixon-Woods, Young, and Heney, 2002). Nonetheless, literature concerning the views of hospital care of children and young people with chronic illnesses has provided important insights into what is important to children and young people. For example, Sartain, Clarke and Heyman (2000) interviewed children (aged 8-14 years) with chronic illness about how being in hospital compared to being at home. The children spoke about disruption to their routine, missing friends and school. Familiarity was also important, where many of the children reported that they brought things with them into hospital and arranged the furniture to make the hospital more like home. In a study involving children and
young people admitted to a general paediatric ward, Carney, Murphy, McClure, Bishop et al (2003) found that less than half of the participants (aged 4 to 17 years) in their study did not mention their treatment in hospital, revealing that for many children this was not the most important feature of their stay in hospital. Instead, participants spoke about the hospital environment and positive interactions with staff. Different aspects of hospitalisation were important to children of different ages, for example for young people positive staff interactions were frequently mentioned, whereas for young children having continuity with caregivers was valued.

It is becoming increasingly acknowledged that children and young people want to be given information and be involved in their care and consultations. In Carter, Lambrenos and Thursfield's (2002) study, young people sought to be involved in discussions about their chronic pain with health care professionals. They valued health care professionals who listened and responded to them as individuals and who demonstrated that they cared about them. Likewise, Garth and Aroni (2003) reported that boys with cerebral palsy wanted the doctor to talk to them during medical consultations rather than their parents and wanted to be given more information about medical procedures. They also wished for the opportunity to ask questions.

Similar findings have emerged in studies involving children and young people with cancer. In Horstman and Bradding's (2002) study with children with chronic illnesses (mainly cancer) participants expressed the desire for doctors to talk directly to them and to give clear, honest information regarding their prognosis, diagnosis and treatment. The children spoke about feeling sad whilst in hospital as they missed their parents and friends and about feeling frustrated due to the limitations that being ill placed on their lives. They wanted nurses to take time to get to know them and find out about their interests. Ellis and Leventhal (1992) and Hooker (1997) also report on children and young people with cancer’s desire for information. Likewise, the young people in Wilkinson's (2003) study said that they appreciated being ‘told straight’ (p.69) as was the practice on the ward they received their care from. They also valued being treated within a ward specifically for young people with cancer as they were near others with similar conditions and staff were used to working with teenagers. More recently, Gallini and Hooker (2005) report similar experiences and concerns from young people with cancer participating in a user group. The expertise of the centre and the availability of specialist hospital staff were seen to be important by young people in both these two studies. Children consulted for the recently developed NICE child and adolescent cancer service guidance spoke about feeling scared and bored when they were in hospital. (NICE, 2005) Activities were important in relieving boredom. Most of the children wanted staff to speak to them and they liked staff to be ‘funny’, ‘friendly’, ‘kind’ and ‘happy’.

Overall, previous research concerning children and young people with cancer has been criticised for giving little priority to their views of services (Dixon-Woods, Young and Heney, 2002). There is a paucity of research on children’s experiences of cancer care services and those that do exist have tended to concentrate on exploring the views of either older children or young people thus failing to reveal needs of young children and making it difficult to understand how needs might shift across the different age groups. Children’s lives change dramatically as they get older and begin to establish their autonomy. Their understanding of health and illness also changes. Therefore, it may be hypothesised that needs might also change, influenced by cognitive, psychological, psychosocial development as well as the social context.
2.3 Giving children and young people a voice

One of the problems faced by those seeking to obtain views from children is the lack of tools suitable to use with younger children (Horstman and Bradding 2002). It has been recommended that when carrying out research with children, researchers do not rely solely on verbal language. Curtin (2001) recommends including the use of techniques such as drawings as children have a different communication style to adults; they are more reliant upon non-verbal language and silence. Involving young people in research also presents various challenges (Dashiff, 2001). Although they have greater verbal communication skills than younger children, during this developmental stage when young people are establishing their independence and autonomy, communication with adults may be inhibited (Hanna and Jacobs, 1993). Researchers collecting data with children and young people are becoming more flexible in their approaches and beginning to use more creative methods that enable children and young people to give their views. For example, giving participants a camera and asking them to take photographs on a particular theme has been reported to facilitate communication and be an enjoyable and non-threatening method by which young people might give their views (Germain, 2004; Hanna and Jacobs, 1993).

A number of child-focused research methods are available for consideration by researchers. These are felt to hold the potential for success, especially when thought is given to the planning of the research with respect to age, experience and the ways in which children and young people feel most comfortable to communicate. The underlying philosophy of participatory research is that those being researched are not simply regarded as ‘subjects’ but are empowered to truly participate and have their voices heard. Thus, participatory research is particularly relevant to individuals or groups who have in the past often been regarded as ‘silent’ or disempowered in research, such as children and young people. In participatory research there is a strong commitment to engaging with participants in a meaningful way and acknowledging that participants are the ‘experts’ on research topics. When carrying out research that aims to enable children and young people to fully participate and give their views, the methods to be used must be considered very carefully. Age appropriate methods that are interesting, non-threatening and facilitate communication are essential.

One example, described by Greig and Taylor (1999) suggests that most young children find direct questions difficult and therefore require the researcher to enter the world that they are familiar with - the world of play, stories, dolls, drawing and puppets. For very young children, play is an extremely important part of their lives. Play serves many functions as well as being fun; through play children learn to interact with others, develop language skills, solve problems and discover their own potential. Play can help children to make sense of what is happening in their life. Play and puppets are often used in a therapeutic context with children to help children to explore their feelings and express themselves. Such methods also have potential to be used in research with young children. For example, the NICE guideline consultation with children aged 2 to 8 years involved the use of creative play techniques, such as free play with medical equipment, to enable children to give their views (NICE, 2005).
A further example is drawings, which have been used in previous research to facilitate communication between the child and the researcher, as well as to encourage trust and motivation in children (e.g. Backett-Milburn and Mckie, 1999; Sartain, Clarke and Heyman, 2000). The ‘draw and write’ technique (Pridmore and Bendelow, 1995) is becoming increasingly popular as a method of eliciting children’s views within the field of health. The technique involves asking children to draw a picture on a particular topic and write about what is happening in the picture (Pridmore and Bendelow, 1995). Previous research using this technique has primarily focused upon healthy children’s views on various topics, with data collection taking place within the classroom setting (e.g. Macgregor, Currie and Wetton, 1998; Williams, Wetton and Moon, 1989). The method has also been used successfully with sick children, (Horstman and Bradding, 2002). The technique does have some disadvantages (Backett-Milburn and Mckie, 1999). One of these is that it can be difficult to analyse, and indeed some published studies using the draw and write technique do not include an analysis of the drawings (e.g. Smith and Callery, 2005). Nonetheless the technique has many benefits when used appropriately and sensitively.

Group work can be a useful way of working with children and young people in a research context. Children and young people may be reticent when talking to adult strangers and may be more relaxed and more willing to share their perceptions when discussions are held with a group of peers. Heary and Hennessy (2002) provide a review of the use of focus groups in paediatric health care research and conclude that focus groups are a valuable means of eliciting children’s views on health-related matters, as long as the research question is appropriate to the method. They discuss various advantages of using focus groups with children and young people, such as, a large amount of data can be collected in a short period of time, the participants are acknowledged as experts and are therefore empowered and the pressure of responding is reduced as responsibility for responding is shared. Focus groups have been used in ‘workshops’ alongside other techniques to elicit the views of children and young people. Carter, Lambrenos, and Thursfield (2002) carried out a workshop for young people with chronic pain, which included a focus group, peer interviews and post-it pyramids (a ranking exercise whereby items are ranked according to their perceived importance). Punch (2002) used a range of interviewing strategies, including spider diagrams for brainstorming, and stimulus materials to ask 13 and 14 year olds about young people’s problems and coping strategies. A ‘secret box’ was also used into which the young people could place anonymous comments. The use of a mixture of techniques helped to make the interviews more enjoyable and recognised the diversity of young people’s tastes and skills. Punch (2002) also suggests that such tasks allow young people to think about what they want to say, rather than feeling pressured to give quick answers as in an interview.

It is clear from previous research that the use of age-appropriate, creative data collection techniques can enable children and young people to express their views and be supported to take an active, rather than passive role in research. This increasing evidence that serves to reveal the theories, processes, advantages and disadvantages of participatory research methods was drawn on extensively whilst planning the current study. A decision was made to use play and puppets, the draw and write technique, group work and individual interviews to explore the experiences and views of care of children and young people with cancer. Through finding out about their experiences the study sought to identify the needs of children and young people with cancer, what helps to make their treatment and life with cancer easier and whether current service
provision meets their needs. As previous work had focussed upon parents and older children’s views of care, this study aimed to balance this perspective by including very young children. It was anticipated that talking to children and young people aged 4 to 19 years old would enable a more complete picture to be revealed of how needs might change and may be different across the ages.

2.4 Aims of the study:
The aims of this study were:
1. To explore the perception of children and young people with cancer regarding their care and support needs.
2. To map the needs of children and young people with cancer from their perspective.
3. To gain an understanding of their views of current cancer care services, including positive experiences and issues that have been less positive.
4. To offer developmental work on fostering avenues of communication with children and young people with cancer.

3.0 METHODS
3.1 Setting and sample
A model of service provision in paediatric oncology has operated for many years in the United Kingdom (UK). Its main principle is that children and young people with cancer be referred to regional paediatric cancer centres to receive either part, or all of their care. There is a network of 21 recognised paediatric oncology centres distributed throughout the UK, with one centre in Ireland, with an overarching professional organisation body, the United Kingdom Children’s Cancer Study Group (UKCCSG). These centres provide the necessary expertise for cancer treatment across all ages and for all malignancies. Participants were recruited from three paediatric oncology centres (Great Ormond Street Hospital, The Royal Marsden Hospital and University College London Hospitals).

The care needs of children and young people are known to change through the experience of each individual’s illness, and there was a need to examine each stage to be able to define those needs, and so develop an appropriate service to meet them. Purposive sampling was therefore employed to ensure a mix in terms of ethnicity, gender, age, social background, diagnosis and point on cancer journey, namely:
- Around the time of diagnosis and treatment planning;
- During treatment;
- At the end of treatment;
- Six months to one year after successful treatment;
- Around the time of relapse/recurrence;
- Palliation.

Children and young people of different ages were approached:
- Under 5’s;
- Those at primary school;
- Those at secondary school.

3.2 Recruitment
At each of the centres, the researcher identified suitable participants with assistance from clinical staff. The researcher or clinical staff approached potential participants when they attended the hospital as an inpatient or outpatient. A letter was sent out to
members of a parent's group at one of the hospitals inviting them to take part and
posters were displayed in each of the centres inviting families to contact the
researcher if they were interested in receiving further information about the study.
Age appropriate information was provided to potential recruits and their families.
Before recruitment began, the information sheets and posters (Appendix 1) were
distributed to four children (Reference Group) for review and were amended
according to their comments. Families who expressed an interest in taking part were
given time to consider their decision. Confirmation of participation was ascertained
via telephone contact if the child was at home or at a face-to-face visit if in hospital
and demographic information was recorded. If the family declined to take part they
were asked if this information could be recorded to monitor whether a representative
sample of children had been obtained. Once recruited to the study all families, and
the Reference Group, were kept up-to-date through the dissemination of a newsletter
( Appendix 2).

3.3 Data collection methods and procedure
Data were collected through the use of three participatory research methods, with the
addition of semi-structured interviews with some young people. Questions and
prompts were developed to reflect age and stage of cancer trajectory ( Appendix 3).
An ice breaker was developed and used in the activities day ( Appendix 4).

3.3.1 Play and puppets (4 and 5 year olds)
Greig and Taylor (1999) suggest that most young children find direct questions
difficult and therefore require the researcher to enter the world that they are familiar
with, the world of stories, dolls, drawing and puppets. It was decided that play and
puppets would be used to enable the 4 and 5 year olds in the study to talk about their
experiences. The research team included a play specialist (COL) who worked on an
inpatient ward for children with cancer at one of the hospitals involved in the study.
The play specialist carried out data collection with this age group whilst a second
researcher acted as an observer (SH). The observer’s role was to listen and make field
notes during the interview, the observer did not join in the conversation with the child
once the play specialist had started to ask the child the research questions. ‘Tweenie’
dolls or other soft toys were used as puppets to ask the children about their
experiences. To help the younger children to feel more comfortable the researcher
played a game or talked with the child about their interests and likes and dislikes
before the interview began.

3.3.2 Draw and write technique (6-12 year olds)
The ‘draw and write technique’ was selected for use with the 6 to 12 year olds. This
technique has many advantages. Virtually all school age children are familiar with
producing drawings and writing about them, therefore it is a child-friendly and non-
Drawing a picture first and asking the child to talk about their work puts them into the
role of ‘expert’ and they are given the message that their thoughts are valued (Yarrow,
1960). Each child was given a pencil and paper and prompted to do a drawing, for
example, ‘Think about a child like you who has finished the treatment to make them
better. Draw a picture of what that child is doing and thinking’ (prompt used for
children at the end of treatment). The drawing was used at the start of the interview to
help the child to begin to talk about their experiences and was followed up with
questions. The researcher made notes on the interaction. This method was
undertaken by one of the research team (MH) who had previous experience using the technique.

3.3.3 Activities day and interviews (13-19 year olds)
For the young people in the study two activities days were planned due to the potential of a wide variation in emotional and social maturity of individuals: one for 13-15 year olds and one for 16-19 year olds. There was however flexibility with this method to make allowances for children feeling too unwell to participate in a group, and to this end, semi-structured interviews were planned. Two researchers facilitated the activities day for 13 to 15 year olds (FG and SH). The day consisted of peer interviews followed by group discussion, a focus group and a written task (‘If you moved to a new town you did not know and there were two hospitals you could receive your care from, what would make you decide which one to go to?’). The peer interviews and focus group were tape-recorded. The group discussion was recorded in the form of spider diagrams. The young people were invited to bring someone along with them if they wished and an area was provided where the accompanying people could wait and have refreshments. Travel was reimbursed for all persons.

The interviews were undertaken by two members of the research team (SH and FG) and were tape-recorded. At the end of the interview the participants were asked to write down their response to a written task (see above). This gave the young people a chance to summarise the aspects of hospital care that were important to them.

In summary, twenty-six of the participants were interviewed at home, and eight in hospital (four were attending day clinic and four were inpatients). The interviews lasted between 15 (for very young children) and 50 minutes (for young people). The activities day lasted four hours, involved four young people and was held in a pizza restaurant. Most participants had one or both of their parents with them throughout the interview. In the case of children interviewed at home often siblings were also present. No parent remained with his or her child during the activities day.

3.4 Ethical issues
Participation in the project was discussed with parents and children/young people, with the emphasis on it being the child/young person’s decision to take part or not. Signed parental consent was obtained from individuals who were under 16 years of age. Depending upon their age, the children signed an assent form and young people aged 16 and above signed a consent form. The protocol was subject to ethical scrutiny at the NHS Trusts where data were collected and was approved by relevant Multi-Centre Research Ethics Committees. To ensure confidentiality participant’s names have been replaced by pseudonyms.

Prior to data collection, a discussion had taken place with parents to ensure that appropriate language was used throughout the interviews with younger children. Participants were given a toy or a voucher as a token of thanks for participating. They were not informed of this until after they had participated in order to avoid coercion.

3.5 Data analysis
The tape-recorded interviews and focus group were transcribed verbatim and the notes taken during the interviews were typed for analysis. These notes contained the interactions between the child and researcher, comments made by parents and siblings, observations and reflections made by the researchers. Only the comments
made by the children were included in the analysis. Other observations and the reflective comments will be presented in the discussion section as appropriate. The data were analysed separately, reflecting the three age groupings (4 and 5 year olds, 6 to 12 year olds and 13 to 19 year olds) and directed by the method of data collection. Analysis was undertaken in pairs led by the main researcher who had undertaken the data collection. A thematic analysis using the recommendations made by (Coffey & Atkinson 1996) was used to analyse all three sets of data with the addition of content analysis in the draw and write. This was adapted to the method and proceeded as follows:

1) The transcripts were analysed individually. As each transcript was read, notes were made in the margins on interesting or significant points the child said.
2) Codes were attached to segments of data. These segments could be one word, a phrase or a sentence. The codes were a summary of what the child seemed to be referring to or describing.
3) After each transcript had been coded, segments of data with similar codes were brought together to create categories of containing data that shared some common element.
4) The categories were discussed and refined and used to generate themes. As meanings can change when phrases are isolated, the original contexts of the phrases within the themes were checked.
5) Each theme was given a name that aimed to capture all the elements within that theme.

Following the analysis of transcripts, the spider diagrams, written exercises and notes made from listening to the peer interviews were read to check whether there were any other issues that had not been captured in the themes. No further issues were identified. The drawings were analysed for content and descriptions listed and counted.

Once the data sets had been analysed separately they were brought together through a process of integrated analyses. This allowed the research team to follow a thread, and actively seek out similarities and differences within and between groups.

4.0 PROJECT MILESTONES
The principal investigators (FG and AR) first met in early 2003 to develop the research proposal. The project team were established in 2004. Table 1 outlines the milestones achieved from 2003 when funding was confirmed, through to 30th June 2005 when all data had been collected and analysed and the final report written.
Table 1 Project milestones with dates achieved

<table>
<thead>
<tr>
<th>Milestone</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding received</td>
<td>July 2003</td>
</tr>
<tr>
<td>Commenced process of submission for ethical and R and D approval</td>
<td>Feb 2003</td>
</tr>
<tr>
<td>Received R and D approval at great Ormond Street Hospital</td>
<td>October 2003</td>
</tr>
<tr>
<td>Research fellow appointed</td>
<td>March 2004</td>
</tr>
<tr>
<td>Received R and D approval at other sites</td>
<td>April 2004</td>
</tr>
<tr>
<td>Commenced recruitment of participants</td>
<td>May 2004</td>
</tr>
<tr>
<td>Researcher left the project</td>
<td>July 2004</td>
</tr>
<tr>
<td>New researcher appointed</td>
<td>November 2004</td>
</tr>
<tr>
<td>Recomenced recruitment of participants</td>
<td>December 2004</td>
</tr>
<tr>
<td>Commenced data collection</td>
<td>December 2004</td>
</tr>
<tr>
<td>Completed data collection</td>
<td>May 2005</td>
</tr>
<tr>
<td>Data analysis commenced</td>
<td>May 2005</td>
</tr>
<tr>
<td>Preparation of final report and papers for publication commenced</td>
<td>May 2005</td>
</tr>
<tr>
<td>End date of project</td>
<td>June 2005</td>
</tr>
</tbody>
</table>

5.0 RESULTS
5.1 Participants
Fifty children and young people agreed to take part in the study. Forty-one had been approached to take part and given information about the study in person by the researcher or clinical staff. Five families contacted the researcher after receiving the letter sent to a parent’s group and four young people contacted the researcher after receiving a telephone call and information from a nurse at a centre. Not all children and young people who were recruited were able to take part; four withdrew from the study as they were not well and three cancelled the interview appointments because of other commitments or them being unwell. Two young people withdrew as they did not wish to be interviewed individually (they had been keen to attend the activities day that had to be cancelled for their age group due to poor uptake). One young person withdrew from the study on his parent’s request and one family did not give a reason for withdrawal. As data with the 4 and 5 year olds were collected during normal working hours, the researchers were unable to see one child who was recruited due to the child being at school and away during the school holidays. Table 2 provides background information about the 38 children and young people who did participate. The majority of participants had acute lymphoblastic leukaemia (ALL), which reflects the prevalence of this type of cancer in children compared to other cancers. The majority of children were on treatment. The study failed to recruit children to three groups: at diagnosis, relapse or palliation. The participants represented were a diverse group in terms of age, sex, ethnicity and type of treatment received. Data were collected from 10 children using play and puppets, 17 children using the draw and write technique, 4 young people attended the activities day and 7 young people were interviewed individually.
<table>
<thead>
<tr>
<th>Table 2 Background details of participants (n=38)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number (%)</strong></td>
</tr>
<tr>
<td><strong>Age</strong></td>
</tr>
<tr>
<td>Range</td>
</tr>
<tr>
<td>4-19 years old</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>20 (52.6%)</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>18 (47.4%)</td>
</tr>
<tr>
<td><strong>Ethnic group</strong></td>
</tr>
<tr>
<td>White British</td>
</tr>
<tr>
<td>29 (76.3%)</td>
</tr>
<tr>
<td>White Other</td>
</tr>
<tr>
<td>2 (5.3%)</td>
</tr>
<tr>
<td>Mixed – White and Black Caribbean</td>
</tr>
<tr>
<td>2 (5.3%)</td>
</tr>
<tr>
<td>Asian Other</td>
</tr>
<tr>
<td>2 (5.3%)</td>
</tr>
<tr>
<td>White Irish</td>
</tr>
<tr>
<td>1 (2.6%)</td>
</tr>
<tr>
<td>Black African</td>
</tr>
<tr>
<td>1 (2.6%)</td>
</tr>
<tr>
<td>Asian Pakistani</td>
</tr>
<tr>
<td>1 (2.6%)</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
</tr>
<tr>
<td>Acute Lymphoblastic Leukaemia</td>
</tr>
<tr>
<td>18 (47.4%)</td>
</tr>
<tr>
<td>Non-Hodgkin’s Disease</td>
</tr>
<tr>
<td>3 (7.9%)</td>
</tr>
<tr>
<td>Ewing’s sarcoma</td>
</tr>
<tr>
<td>3 (7.9%)</td>
</tr>
<tr>
<td>Osteosarcoma</td>
</tr>
<tr>
<td>3 (7.9%)</td>
</tr>
<tr>
<td>Wilms’ Tumour</td>
</tr>
<tr>
<td>2 (5.3%)</td>
</tr>
<tr>
<td>Hodgkin’s Disease</td>
</tr>
<tr>
<td>2 (5.3%)</td>
</tr>
<tr>
<td>Acute Myeloid Leukaemia</td>
</tr>
<tr>
<td>2 (5.3%)</td>
</tr>
<tr>
<td>Neuroblastoma</td>
</tr>
<tr>
<td>1 (2.6%)</td>
</tr>
<tr>
<td>Brain Tumour</td>
</tr>
<tr>
<td>1 (2.6%)</td>
</tr>
<tr>
<td>Pelvic primitive neuroectodermal tumour</td>
</tr>
<tr>
<td>1 (2.6%)</td>
</tr>
<tr>
<td>Tumour on outside of lung</td>
</tr>
<tr>
<td>1 (2.6%)</td>
</tr>
<tr>
<td>Cancer of the colon</td>
</tr>
<tr>
<td>1 (2.6%)</td>
</tr>
<tr>
<td><strong>Treatment received</strong></td>
</tr>
<tr>
<td>Chemotherapy alone</td>
</tr>
<tr>
<td>22 (57.9%)</td>
</tr>
<tr>
<td>Chemotherapy, radiotherapy and surgery</td>
</tr>
<tr>
<td>7 (18.4%)</td>
</tr>
<tr>
<td>Chemotherapy and surgery</td>
</tr>
<tr>
<td>5 (13.2%)</td>
</tr>
<tr>
<td>Chemotherapy and bone marrow transplantation</td>
</tr>
<tr>
<td>2 (5.3%)</td>
</tr>
<tr>
<td>Chemotherapy, radiotherapy, surgery and stem cell transplantation</td>
</tr>
<tr>
<td>1 (2.6%)</td>
</tr>
<tr>
<td><strong>Stage of cancer journey</strong></td>
</tr>
<tr>
<td>On treatment</td>
</tr>
<tr>
<td>20 (52.6%)</td>
</tr>
<tr>
<td>At the end of treatment</td>
</tr>
<tr>
<td>9 (23.7%)</td>
</tr>
<tr>
<td>6 to 18 months following successful treatment</td>
</tr>
<tr>
<td>9 (23.7%)</td>
</tr>
</tbody>
</table>

Sixteen families declined to take part in the study (4 females and 12 males). Table 3 details the reasons given for non-participation in the study. This group included mainly boys aged 13 to 19 years who did not wish to take part. All families with children aged 4 and 5 years who were approached said that they would like to take part.
Table 3: Reasons given for non-participation in the study

<table>
<thead>
<tr>
<th>Data collection method</th>
<th>Reason for non-participation</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Draw and write (6-12 year olds)</td>
<td>Parent said child not comfortable talking/shy</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Family not interested</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Too busy with other appointments</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>No reason given</td>
<td>1</td>
</tr>
<tr>
<td>Activities day/interviews (13-19 year olds)</td>
<td>Young person not interested</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Too far to travel to activities day (declined offer of individual interview)</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>No reason given</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Moving away from area</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Young person said that they do not like talking</td>
<td>1</td>
</tr>
</tbody>
</table>

5.2 Findings
When data analyses were integrated, six themes emerged (Table 4).

Table 4. Themes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Theme 1</td>
<td>As much like home as it can be</td>
</tr>
<tr>
<td>Theme 2</td>
<td>The work of children</td>
</tr>
<tr>
<td>Theme 3</td>
<td>Asking and telling - getting the balance right</td>
</tr>
<tr>
<td>Theme 4</td>
<td>The triad of support</td>
</tr>
<tr>
<td>Theme 5</td>
<td>How treatment affects my body and my life</td>
</tr>
<tr>
<td>Theme 6</td>
<td>Worrying about now and the future</td>
</tr>
</tbody>
</table>

5.2.1 As much like home as it can be
The drawing below (Figure 1) depicts many of the features of hospital that were reflected in this theme.

Figure 1: Drawing by Jack, 12 years old.
What the children did not like about hospital were things that made hospital different
to home, for example, not having family around. The young children talked about
missing the parent who was not staying with them and their siblings. Beds were
mentioned as being different to home and were not liked. One way that young
children made being in hospital more like home was to bring their toys with them.
Older children and young people personalised their space by bringing things from
home such as photographs of their pets and bed covers and cushions.

The older children and young people spoke more about the environment than the
younger children. They wanted the hospital to be bright, colourful, comfortable and
non clinical, ‘it doesn’t feel like a clinical boring hospital….the way it is laid out and
everything, it’s not just white painted walls, there is wallpaper and carpet’ (Ian, 18
years old). They also wanted separate areas on the wards and separate waiting areas
for young children and older children as they found hearing the younger children
crying upsetting and noisy. The participants who were cared for on a ward
specifically for teenagers valued the fact that they were with people their own age,
that the staff were used to working with people their age and in general that,
‘everything is geared up for teenagers’ (Anthony, 18 years old).

The older participants wanted a choice of whether they had a bed on an open ward or
in a private room. Some of them liked the open ward as it enabled them to meet other
people more easily and meant they were not alone. One girl commented, ‘it’s also
quite nice not to have a lot of privacy because everyone’s in it together, like a family
kind of’ (Sarah, 13 years old). However having curtains was not ideal as it meant that
if they wished to have a private conversation or were upset about something they
could be overheard. Children and young people who preferred to be on an open ward
wanted more space in order to have their belongings around them, which was
prevented on some of the wards as the beds were close together.

Many of the participants spoke about being in isolation when they were admitted to
their local hospital. This was conveyed as being a difficult time for younger children,
as they were unable to use the playroom. Older participants spoke about the isolation
as if they were imprisoned:

‘Some of the rooms are just four walls and it’s all like, you are staying in a prison
really’ (Jess, 13 years old).

‘You get chucked on your own for about 7 days and you can’t get out’ (John, 17 years
old).

Hospital food was a huge issue for the majority of the older children and young
people. They talked about the food being cold, not being cooked properly and tasting
of ‘rubber’. They were reliant upon their parents bringing in food and getting take-
away food whilst they were in hospital, which was clearly costly. They wanted to
have a wider choice of food, to be able to order food when they wanted to eat and to
have facilities where they or their parents could prepare food themselves. It was also
important that the food was familiar to them, ‘chicken la cremo. I was like, what the
hell is that? I don’t even know what it is let alone eat it’ (Emma, 15 years old). The
very young children did not talk about hospital food.
5.2.2 The work of children

Toys, the playroom and activities were clearly very important features of hospital across the age groups as they provided distraction and prevented boredom. Play specialists and play workers were viewed by younger children as having a key role in providing activities and many of them told stories about fun things they had done with play staff. When the young children were asked questions such as, ‘what is there at the hospitals you go to?’, typical responses were, ‘I bring some toys’, ‘lots of toys’, ‘two playrooms’ and ‘TV’. This group mentioned very few other features about hospital.

The availability of toys and activities was an issue for many of the participants. They spoke about staying in bed all day having treatment and then when they were able to get out of bed finding that the playroom was closed and the play staff had gone home. For example, one girl said that staff should, ‘keep the video cupboard open it is always shut, the art room with all the stuff in it is always locked, the play person is hardly ever there. Sometimes they leave the stuff out, when she leaves the stuff out to make a mask she doesn’t even leave glue, cellotape’ (Lisa, 6 years old). It was also important that the activities were age appropriate. Many of the older children felt that ‘all the toys are baby things’ (Sam, 7 years old).

The young people often felt that they were able to amuse themselves and were content with just watching TV or reading, particularly when they were feeling unwell. They described being pestered by staff to take part in activities that were inappropriate or they did not feel like doing, ‘I wasn’t into all this like let’s do gluing and sticking stuff….it’s like they really push you to go and do something…. I know when I want to do things and I just don’t need them coming in and trying to make me do all these things….it got on my nerves’ (Louise, 17 years old). The young people wanted to be able to keep up with their schoolwork whilst they were in hospital when they felt well enough however, some participants found that the work in the hospital school was not always at their level.

5.2.3 Asking and telling - getting the balance right

The young children who were interviewed reported being told information about their illness and treatment from their parents and did not recall being given information by hospital staff. For example,

Researcher: ‘Has anyone told you that you don’t have to have medicines anymore?’
Ellie: ‘Mummy’
Researcher: ‘Did anyone at the hospital tell you?’
Ellie: ‘No’ (Ellie, 6 years old)

The young children said that they would ask their parents if they wanted to know anything about their treatment and this was not an issue with them. However, many of the older children wanted to be spoken to and given information directly by hospital staff, ‘they speak to Mum first, they should talk to me first’ (Christopher, 12 years old). They wanted staff to use words that they understood and to ‘use posher words’ rather than ‘baby words’ as they got older. For some children it was very important that staff used the correct words for medications, such as saying ‘ametop’ instead of ‘magic cream’. A number of children did find information overwhelming and they would have preferred to be asked if they wanted information at that time or given the opportunity to ask questions about what was important to them. Asking
questions was something that many of the children said they found difficult and they wanted staff to recognise this and enable them to be able to ask.

Many of the older children felt that they were not given enough information about their illness and treatment, ‘they tell you the medicine will make you better but they don’t tell you how it works’ (Jack, 12 years old). Lack of information was an issue for participants who took part in the focus group, one girl wanted doctors to, ‘just make sure that you talk to them (the patient) before you do anything, talk to them properly’ (Jess, 13 years old). However, the older teenagers who were interviewed individually on the whole felt that they had been given adequate information and that doctors did speak to them directly. Being given information about waiting was a big issue for many participants. They wanted to be given information about why they had to wait and how long they would have to wait for, ‘they could tell me what was going to happen and when it will happen that would help, they just keep you waiting and they don’t tell you why’ (Rob, 9 years old). Some participants mentioned the need for more information about steroids. Lack of information made the children worry that the changes they were experiencing would be permanent, ‘I hated the steroids because I couldn’t stop eating. I was worried I was always going to eat like that….. I got really fat and I was worried I would stay like that. I think they should warn people about that’ (Jack, 12 years old). Figure 2 shows how unhappy steroids made one girl feel.

**Figure 2. Drawing by Charlotte, 6 years old.**

![Drawing by Charlotte, 6 years old.](image)

The older children and young people wanted to be given choices in their treatment and appreciated it when the various options were explained to them, ‘I think it’s better when the doctor tells you everything….it’s your body and they are going to do stuff to it and you want to know everything that could happen’ (Thomas, 13 years old). One boy spoke about wishing he had been given more information and choice about a nasogastric tube, ‘the tube stopped me eating, they put it in because I didn’t want to eat, it stopped me eating, it tugged my nose and hurt the back of my throat when I swallowed so I stopped eating. It was better when I had it out, I managed, if they had
talked to me about it more I would have managed without it’ (Christopher, 12 years old).

5.2.4 The triad of support
The role of family, friends and hospital staff featured prominently in the children and young people’s stories. These people provided the participants with support and helped them through the ‘hard times’. For the very young children, parents came across as being the most important people when they were in hospital. It was important that parents could stay and that they were always present, ‘didn’t like being on my own in a room, it was scary when Mummy had to go’ (Lisa, 6 years old).

Parents were important as they provided comfort and it was parents who the children said they would tell if they were upset or worried. It was also important for the older children and the majority of the young people that their parents could stay. Parents were the main source of support for participants, ‘they give you so much confidence, always being there, helping you…. they sort of do anything to make you feel comfortable and happy’ (Nick, 14 years old). Siblings were also important and many of the children missed their siblings when they were in hospital.

The very young children rarely mentioned nurses and doctors unless prompted, however, the older children and young people spoke a lot about their role. They appreciated it when doctors and nurses listened to them, made an effort to get to know them and ‘chatted’ to them about their life. This made them feel ‘special’ and like, ‘a person and not a patient’. For example:
‘I loved Dr. G. he was kind, he came to see me every day and he knew I had all my animals so whenever he came he asked about my animals and looked at my pictures. If he couldn’t come himself the person he sent he told to ask me how the animals are’ (Izzy, 7 years old)

Nurses played a particularly important role. They were perceived as ‘kind’, ‘fun’ and ‘helpful’. Overall, the participants knew the nurses better than doctors and felt more comfortable talking to them. Reasons given for this difference was that nurses were around more on the ward, whereas doctors are busy, ‘more formal’ and changed more often. For the young people, nurses chatting to them helped them to pass the time whilst they were in hospital and some said that they looked forward to seeing the nurses. Many of the children wanted the nurses to play with them however, they were perceived as often being too busy. It was important that nurses were reliable, a few children spoke about nurses promising to come to see them and later realising that they had gone home, ‘sometimes they say they will play a game and then they don’t come back….promised to come back but I knew when it was 8 o’clock she was not coming back’ (Hannah, 7 years old).

It was important that hospital staff were sensitive to the needs and feelings of the participants, ‘J the play leader, she made it easier cos she noticed when I was bored or sad and used to come and talk to me and give me things to do’ (Rob, 9 years old). ‘R made it easier because she held my hand when I was frightened’ (Emma, 7 years old). Staff not being sensitive was distressing, embarrassing and annoying for participants. This insensitivity was mainly around being examined, not explaining things and, for older participants, not being left alone when they wanted to be.
‘About six doctors come in, in the morning and stand around you and stare at you and you just feel like hitting the lot of them because it’s like they don’t even need to be there really. I swear they just stand around and stare at you whilst one doctor

15
examines you and you feel like crap and you look like crap…I just hated that’ (Louise, 17 years old).

‘They’re not very sensitive about how I feel sometimes, like I know this sounds silly but if I just want to be left alone they won’t leave me alone and they’ll just come in and that might sound silly but I get, it makes me even worse cos sometimes I just wanna be on my own’ (Jess, 13 years old).

Friends were an important source of support for the young people. Many of this group said that they would speak to their friends about their worries. However, it was difficult to maintain contact with friends whilst in hospital. It was not easy for friends to visit as the hospital was far from their home and they could not speak on the telephone as it was expensive and mobile phones could not be used on the ward. The younger children missed playing with their friends when they were in hospital.

5.2.5 How treatment affects my body and my life
The younger children talked very little about their experiences of being ill and having treatment. Their explanations of why they take medicines were simplistic, for example, ‘to get rid of the bad guys’ (Alexander, 4 years old) and ‘to make me feel better’ (Amy, 4 years old). When pushed to talk about what it was like having treatment, the children talked about the taste of their medicines. Medicines were viewed as acceptable as long as they did not taste bad.

The older children and young people talked more about having treatment and how treatment makes them feel, ‘It made me feel so awful and sick and just God like kind of ill that I just didn’t even think anyone could feel…I never felt so disgusting in my whole life’ (Louise, 17 years old). Needles were something which lots of the children found very stressful and worried about having. They spoke positively about having a Hickman line and not having to have needles. For some of the older children and young people there was a sense that treatment had to be done and so might as well be done quickly to get it over with:

‘They tried guided imagery which was alright but I preferred just being held and they do it as quick as possible’ (Christopher, 12 years old).

‘It was just a case of getting on with it’ (Anthony, 18 years old).

Waiting for treatment was a huge issue. For children who attend hospital for day treatment waiting was time consuming and boring, ‘I sit and I am bored, waiting, waiting, WAITING, had to wait our turn’ (Beth, 6 years old).

Many of the participants spoke about how the cancer and treatment placed limitations upon their lives. They often felt too tired and sick to do things, ‘sometimes I don’t feel like playing anything’ (Amy, 4 years old). Figure 3 shows a child attached to their drip thinking about what they will do when they are well. Being in hospital and being attached to a drip took away their freedom and limited their activities.

‘I often get hooked up’ (James, 4 years old)

‘Four days trapped inside that one space’ (Sarah, 13 years old)
For the young people not being able to go out and do things made them feel less ‘normal’. Many of the participants said that they missed going to school or nursery. They also missed activities such as swimming.

**Figure 3. Drawing by Hannah, 7 years old.**

5.2.6 **Worrying about now and the future**

When the young children were asked whether they ever felt worried when they were at the hospital some said that they did not get worried. Only one child who said they did feel worried said what they worried about, this was ‘having injections’. Parents and siblings were mentioned most frequently as the person they would tell if they felt worried. However, a number of children said that they would not tell anyone, reasons given for this were wanting to be brave and strong and not wanting to appear silly:

‘I talk to no one because I am strong. I’m the strongest’ (James, 4 years old).

‘If I talk to so many people they’ll think I’m silly’ (Amy, 4 years old).

Some of the older children reported feeling worried about the present and future. As Figure 4 shows they sometimes found hospital ‘scary’. They worried about having needles and whether they would get better. For some children waiting to see the doctor and to have treatment heightened their worry. Being left alone was particularly scary. The presence of parents, a nurse or someone else to play with and being giving things to do helped them to feel less scared. A few children said that they had been or were frightened of dying, particularly when they were first diagnosed. Two children who had just finished treatment worried that the cancer might come back.
Worrying was not an issue for the young people interviewed, with many of them saying that they were scared and shocked when they were first diagnosed but since then did not worry too much. There was a sense that they just, ‘have to keep going’ and for some young people having cancer had made them appreciate life more.

‘I really value the times that I can actually go out and do things’ (Sarah, 13 years old).

‘Live life to the full, do what you want to do, don’t worry about money and all that, mainly try to work round it and get the best out of life’ (Emma, 15 years old).

6.0 DISCUSSION
This study provides an insight into children and young people’s experiences of cancer care services. The research questions the study aimed to address were concerned with exploring the participants’ views of services and their perceptions of their care and support needs. The study also hoped to contribute to work on participatory methods of research to enable children and young people to give their views. It was clear from the comments by parents and participants that many of the participants had thought in advance about what they would like to say and that they appreciated the opportunity to express their views.

Similar to the findings in Carney et al’s (2003) study, the participants in this study spoke about many aspects of hospital care and did not focus specifically upon treatment. The things that came across as important to them were: relationships with hospital staff, play and activity resources, family and friends and the hospital environment. When the participants did speak about treatment they spoke mainly about the waiting, needles, information and restrictions cancer and its treatment placed on their lives.

This study supports previous work on the needs of children and young people with chronic illnesses and cancer. Many of the issues raised in this study, were also raised,
by children consulted for the NICE child and adolescent cancer service guidance (NICE, 2005). The issues around hospital food, the hospital environment, play resources, injections and waiting for treatment have been discussed previously in the literature. Yet, disappointingly, there seems to have been little improvement and it is very clear that many of these issues still remain. In contrast according to the participants in this study, some issues around hospital care that have been reported previously do appear to have improved. The majority of children and young people in this study reported having good relationships with nurses and that they felt they were, on the whole, treated as an individual. The young people in the study who were interviewed individually reported that they had been given adequate information about their cancer and treatment and felt able to ask questions.

Through focusing upon children and young people’s experiences, this study revealed a number of issues that have not been particularly mentioned in any previous studies. This study also included very young children which enables the consideration of how children’s needs change as they get older. Similar to the findings of Carney et al (2003), differences in the aspects of hospitalisation that were important to participants of different ages were apparent. These differences fit with theories of child development. For example, children spoke a great deal about people who support them. For the very young children their parents were the most important people to them when they were in hospital. As the children got older they viewed the role of hospital staff, particularly nurses, as increasingly more important. The older children reported that they looked forward to seeing the nurses when they were attending hospital. For the young people in the study, in addition to parents and health care professionals, friends were an extremely important source of support. Difficulties in maintaining contact with friends whilst in hospital was an issue, particularly for young people.

Information giving and receiving was a major issue for the children in this study. The importance of doctors and nurses talking directly to children and providing information has been reported many times in the literature (e.g. Ellis and Leventhal, 1992; Hooker, 1997; Horstman and Bradding, 2002; Wilkinson, 2003). The younger children received information from their parents, which they appeared to be happy with. As parents were relied upon to provide these children with information this has implications for the support parents are given in order to fulfil this role. It was clear from talking to the older children that information needed to be updated and more information provided as they got older and could understand more about their illness and body. Whereas information may be withheld in an effort to try and protect children with cancer, there are indications in the literature that the provision of information is associated with better adjustment in the child, communication within the family and compliance with treatment (for a review see Eiser and Havermans, 1992). There were clearly implications of a lack of information, such as leaving children with worries about the permanence of symptoms.

This study provides support for research showing that children do have a good understanding of illness, if they are provided with information. Although in the past it was assumed that children’s understanding of illness was basic and followed a developmental progression paralleling shifts in cognitive processes (e.g. Bibace and Walsh, 1980; Burbach and Peterson, 1986; Perrin and Gerrity, 1981), the influence of experience and social and cultural factors is increasingly acknowledged. More recently, the application of a Piagetian based stage approach to children’s
understanding of illness has been criticised (Eiser, 1989; Sigelman, Maddock, Epstein and Carpenter, 1993) and several studies have shown that children with histories of chronic illness have a more mature understanding of illness than those who have no such medical histories (e.g. Crisp, Ungerer, and Goodnow, 1996; Kendrick, Culling, Oakhill and Mott, 1986; Redpath and Rogers, 1984). Information overload was a problem for some children in this study highlighting the need for health professionals to take their cues from the child and find out what the child would like to know when giving information. Techniques such as ‘scaffolding’ (Bruner, 1983; Wood, 1989) may be useful when giving children information. Scaffolding involves first asking the child what they already know and then giving information that builds on this knowledge and fills in any gaps. This also enables the person giving the information to address any misunderstandings the child may have.

Play and activities were extremely important to the children in the study. A report by Save the Children Fund (1989) suggests that play aids normality for children in hospital as it offers experiences of the familiar in the unfamiliar world of the hospital. Some of the young participants did speak about how bringing toys from home helped when they were staying in hospital and the older participants spoke about personalising their space. Play and activities also provided distraction for the participants and helped to prevent boredom. The distraction of play also seemed to help participants cope with being in hospital and having treatment. Young people spoke about the importance of support from their family and friends in helping them to cope. Active coping, such as sharing worries with others and information seeking is reported to reduce anxiety compared to more avoidant coping strategies such as denial and displacement (Peterson, 1989). The children in this study did report having some worries and feeling anxious about being left alone and having needles. It could be beneficial for these children to be taught strategies in advance to cope. Also, as information can reduce anxiety (Peterson, 1989; Alderson 1993), the giving of information may assist children’s coping.

7.0 CHALLENGES
A number of challenges arose during the course of the study that centred on the following areas:

1. Recruitment
2. Practicalities of data collection
3. Data collection methods

7.1 Recruitment
The project had aimed to include children who were at the following points in the treatment trajectory: at diagnosis and treatment planning, around the time of relapse/reoccurrence and palliation. It was difficult to recruit children to the ‘at diagnosis and treatment planning’ group due to children commencing treatment promptly following diagnosis. Even when children were recruited soon after diagnosis, it was typically a number of weeks before data were collected from them, thus they then fell into the ‘on treatment’ group. There were also concerns among hospital staff about approaching families at this very difficult time, added to concerns about over-researching. The views of children receiving palliative care were unable to be obtained, as when recruitment for the project was taking place, the palliative care teams were not visiting many children. Two children who were recruited whilst on treatment and then became palliative were unable to take part due to being too ill.
7.2 Practicalities of data collection
Arranging appointments with families to collect data was difficult. Many families had to cancel appointments as their child was unwell on the day or they were busy attending other appointments. As detailed previously, a number of children withdrew from the study for these reasons. For children who attended school, researchers had to be flexible and offer appointments during school holidays, after school or at weekends. As the majority of data were collected within the child’s home, this resulted in a lot of time spent travelling by the researchers. Due to the wide geographical area covered by the three hospitals it often took a whole day to see one participant. During a visit to a child’s home to collect data, the child often wanted the researcher to stay to play a game or to look at toys following the interview. Parents’ were also keen to tell the researchers about their experiences and views, thus extending the visit time and was felt by the researchers to be important.

7.3 Data collection methods
On the whole, data collection techniques worked well to engage with participants. The researchers felt that the majority of children were able to give their views. However, the techniques were not suitable for all participants. Some of the younger children thought that the ‘Tweenie’ dolls were for babies and did not wish to use them during the interview, yet it was not easy for them to speak with the researchers directly. A few of the older children chose not to draw. This was due to them not being well enough or being worried about their drawing skills. For future work it may be better to have a number of techniques to hand from which a child can select. This would reflect the individuality of children and the variations in their preferences. For example, in this study, instead of drawing, one child chose to share the contents of a box he had kept with items related to his treatment and time in hospital. He spoke about what each item meant to him and how it related to his experiences. This technique worked well and could be used for future work.

The activities day was difficult to organise for many reasons. Some of the young people approached to attend did not feel comfortable to talk as part of a group. Travelling to a central venue was a problem, particularly for young people who were still receiving treatment. The activities day for 16 to 19 year olds was cancelled, as the few young people who were interested in attending could not attend on the same day. Interviews did work well with the young people in the study and they appeared at ease talking to the researchers. The young people who were interviewed in hospital said that the interview gave them something to do.

8.0 Implications
This research has many implications for Macmillan Cancer Relief, the provision of cancer services and service development, and for future research.

8.1 Implications for Macmillan Cancer Relief
Macmillan Cancer Relief is committed to campaigning for access to high quality care and to making sure that the voice of people affected by cancer is heard by everyone concerned with cancer services. This report provides an indication of what quality might mean for children and young people in terms of their care. Consultation with children and young people provides valuable feedback, which can be used for role and service development. Work such as this project, which seeks to enable children and young people to have their voices heard, needs to continue and could perhaps be undertaken in partnership with other children’s charities. It is clear that through the
use of creative age appropriate techniques, even very young children can express their views. For instance, children as young as 2 years old were consulted for the NICE guidelines, and we successfully engaged with children as young as 4 years. This study has provided further detail from the field on the methods that can be used in future work to engage with children and young people.

8.2 Implications for the provision of cancer services and service development
This research has many implications for the development of services that are child oriented and meet the needs of children and young people with cancer. Many of the findings have resource implications in terms of external décor, toys and appropriate activities, as well as people and education. Older children and young people were able to express how they wanted to be treated by healthcare care professionals. Table 5 provides a summary of suggested implications for services.
### Table 5 Themes from the children and young people’s accounts and implications for practice

<table>
<thead>
<tr>
<th>Key themes</th>
<th>Supporting quote</th>
<th>Implications for practice</th>
</tr>
</thead>
</table>
| **As much like home as it can be** | ‘it would be nicer if …the ward was painted so it was like nicer….like lots of bright colours and patterns and things for people to look at and read and pictures’ (Sarah, 13 years old) | • Clinical areas split by age group as older children found hearing the young children crying upsetting and noisy.  
• Need for more space in cubicles.  
• Need for privacy.  
• Bright, personalised hospital environment, and more like home.  
• Food which children and young people recognise and enjoy eating. |
| **The work of children** | ‘having something to do is really important, having the right things, lots of things are for young children, don’t mix us up’ (Gemma, 10 years old) | • Toys and activities more accessible.  
• More play staff, particularly who are available at evenings and weekends  
• Playroom to have flexible opening times.  
• More toys and activities for older children and young people.  
• Appropriate level of education available. |
| **Asking and telling - getting the balance right** | ‘they tell you the medicine will make you better but they don’t tell you how it works’ (Jack, 12 years old) | • Speak directly to children and young people, rather than staff speaking to parents first.  
• Find out about the child’s preferences and whether they wish to be spoken to directly.  
• More information about how treatment works, side effects, waiting and medications such as steroids.  
• Update information and use more ‘grown-up’ words, as children get older.  
• As parents and health care professional share the role of information giving, preparation and support for both parties to get it right. |
| **The triad of support** | **Parents**: ‘they give you so much confidence, always being there, helping you…. they sort of do anything to make you feel comfortable and happy’ (Nick, 14 years old).  
**Friends**: ‘It (support from friends) just makes me more confident that I try and get through it’ (John, 17 years old).  
**Hospital staff**: ‘they talked to me and then I got to trust them and they were nice’ (Christopher, 12 years old) | • Important that parents can stay with children when they are in hospital.  
• Health care professionals need to recognise that children may feel scared when their parents are not there.  
• Keeping in touch with friends whilst in hospital is difficult; the use of an affordable telephone would help.  
• Health care professionals need to take the time to get to know children and young people, be sensitive to their needs and treat them as an individual. |
| **How treatment affects my body and my life** | ‘it really did make me feel very ill….it just drains you literally….it drains you of energy and makes you sick’ (Ian, 18 years old) | • Provide information on waiting and effects of treatment so children know what to expect.  
• Assist the development of coping strategies early in the treatment phase. |
| **Worrying about now and the future** | ‘I worry, I hope it won’t come back’ (Rob, 12 years old) | • Acknowledge that children and young people may feel scared and worried.  
• Try not to leave young children alone.  
• Assist the development of coping strategies. |
Appropriate, local and national dissemination will provide the vehicle to present the study and to create dialogue with health care professionals so that further implications and recommendations can be developed, focused on local need, and action plans developed. Likewise, dissemination to children, young people and their families who participated in the study and future families receiving care will be important. See Appendix 5 for our plans for dissemination.

8.3 Implications for future research
To complete the picture revealed by children and young people on treatment or soon after treatment, future research would need to be sensitive and creative to include those at the most difficult time of the cancer journey, such as the time of diagnosis and when receiving palliative care. One approach would be to use longitudinal studies to follow the child from diagnosis, through to wherever their cancer journey takes them, to find out more about their needs and service delivery when receiving long-term follow-up and palliative care. For these hard to reach groups, single centre studies might be the most appropriate in order for research teams to support clinicians on a daily basis in their role of recruitment.

Information giving, the timeliness, the way it is given, who gives it, and what is said was a consistent theme throughout the study. The role of information giving would seem to be shared by parents and health care professionals. Future research should examine the role of information giving from these two perspectives. Techniques such as scaffolding information for young children and computer software for older children and young people in order to individualise, pace and add depth to information over time would seem appropriate techniques to explore. Such techniques would need to be developed and tested with children and young people.

Even young children were able to describe things that helped such as hand holding, taking their mind off it and things to look forward to. Such coping strategies would benefit by being shared with children early on in their diagnosis to benefit from the experiences of other children. Research should be developed to teach and test such interventions with children of different ages and culture in order to increase our understanding of their use and value.

The research techniques used in the study were child-centred and participatory, however these are not the only techniques available and those used were shown not to be suitable in all cases. Developing and refining research techniques to enable the researcher to draw on a ‘tool box’ of techniques would facilitate flexibility to individualise the technique to the child, group or setting. These require confidence and competence to use and would therefore need to be well thought out in the phase of research design. Some of the younger children found the puppets ‘babyish’ and yet found communicating with the researchers difficult. For the very young children one approach might be to teach and support parents to be co-researchers. Clearly from this study and others, parents are their child’s constant companion throughout their experience in hospital and at home, where they take on a nursing and supportive role. With support, mirroring practice, they would enable their child to articulate thoughts and feelings to another person, in this case a researcher. For the young people, the activities day which brought young people together to talk and share their views, appealed to some, but not others: particularly boys and the older group of young people. In future research it might be useful to explore the role of young people who had finished treatment as co-researchers. This is a role developed already to work
with healthy groups such as young people in care, in education settings and with user groups. Within the context of children with a chronic illness, and in particular children who are receiving treatment and have periods of feeling very unwell, this is less well developed. It may however have benefits in facilitating engagement through a peer group, rather than researchers, which may be less threatening, more appealing, more fun and of more value to the research participant.

9.0 CONCLUSION
This study provides important insights into the aspects of cancer care that are important to children and young people with cancer. Using age appropriate creative data collection techniques enabled even very young children to talk about their experiences and give their views. Some findings reflect what was already known, such as the importance of food and a familiar environment, and therefore it was disappointing to observe that change in some areas remains slow, possibly constrained by financial resources and space. Some findings were new, such as worries and concerns about the permanence of symptoms, and some add detail to research now emerging on the role of personalising information giving. Overall, findings challenge health care professionals to think about the care they offer and the context within which this takes place. This will benefit from being disseminated widely and in doing so will contribute a valuable perspective on the care children and young people have received.
10.0 REFERENCES


Garth, B. & Aroni, R. 2003, "'I value what you have to say'. Seeking the perspective of children with a disability, not just their parents", *Disability and Society*, vol. 18, no. 5, pp. 561-576.


Hooker, L. 1997, "Information needs of teenagers with cancer: developing a tool to explore the perceptions of patients and professionals", *Journal of Cancer Nursing*, vol. 1, no. 4, pp. 160-168.


Wilkinson, J. 2003, "Young people with cancer--how should their care be organized?", *European Journal of Cancer Care*, vol. 12, no. 1, pp. 65-70.


11.0 APPENDICES

Appendix 1 Information sheets and poster

Information sheet youngest group
Listening to children and young people with cancer

We thank your mum or dad for reading this information to you.

WHAT IS A STUDY?

A study is what you do when you want to learn more about something or find out something new. A study can help doctors and nurses and other people in the hospital find out which medicines can help children get better. In this study, we want to find out from you what you thought about your time in hospital, what you liked about it and what you did not like about it. We want you to tell us if there was anything the nurses or doctors could have done or told you to make it easier for you.

WHO WILL TAKE PART?

We will be talking to other children the same age as you and some children who are older than you.

WHAT WILL I NEED TO DO?

If you say yes to join our study we will come and talk you, either in hospital or in your own home. It will be Chris that comes to talk to you she is a member of our project team. You will have already met Susie, another member of our team, when she came to talk to you and your mum and dad about this study. Susie will be with Chris when she comes to meet you. They will only be with you for a short time. Chris will ask you some questions about your time in hospital. We know that sometimes it is hard to find the right words to say what you want. Chris will be able to help you. Chris is our play specialist, you will; remember
meeting someone like Chris in your hospital. Like when you were in hospital Chris will use toys and puppets to help you to find the right words. So that Susie can remember what you say she will write some things down in her notebook.

**WHAT ARE THE GOOD THINGS ABOUT THIS STUDY?**

We hope to find out what boys and girls think about their time in hospital and the sorts of things that helped them or did not help them to feel better.

**ARE THERE ANY BAD THINGS ABOUT THE STUDY?**

We don’t think so. When we come to see you your mum or dad will be there as well. If you get tired when we are talking we can always stop and have a break.

**WHAT SHALL I DO NOW?**

Now your mum or dad has told you about the study, you think. Talk with your mum or dad or another grown up. If you would like to talk to your doctor or nurse let them know by asking your mum or dad to ask them to talk to you. After all this you can tell your mum or dad if you want to talk with us or not. If you do not want to talk with us then that is OK.

**DO I HAVE TO SAY YES?**

You do not have to say yes. If you say yes at the beginning you can change your mind any time. If you say no or want to stop being in the project this won’t make a difference to the way that the nurses or other people look after you.

**My Name is: Susie Hey**
**Telephone No: 0207 405 9200 extension 0720**
Information sheet middle group

Listening to children and young people with cancer

We thank your mum or dad for helping you to read this information.

WHAT IS A STUDY?

A study is what you do when you want to learn more about something or find out something new. A study can help doctors and nurses and other people in the hospital find out which medicines can help children get better. In this study, we want to find out from you what you thought about your time in hospital, what you liked about it and what you did not like about it. We want you to tell us if there was anything the nurses or doctors could have done or told you to make it easier for you.

WHO WILL TAKE PART?

We will be talking to other children the same age as you and some children who are older than you.

WHAT WILL I NEED TO DO?

If you say yes to join our study we will come and talk you, either in hospital or in your own home. You will meet Màire, a member of our project team. You will already have met Susie, another member of our project team when she came to talk to you and your mum and dad about this study. Màire will be with you for just over one hour. She will ask you some questions about your time in hospital. We know that sometimes it is hard to find the right words to say what you want. In order to help you with this Màire will be asking you draw a picture that tells us about what was good and not so good about your time in hospital. You don’t have to be great at drawing. We will ask you some questions about the picture you have drawn. Màire will need to take these pictures away with her but we can return them to you when our study is finished.
So that Màire does not forget some of the things you have said she might write some things in her notebook.

**WHAT ARE THE GOOD THINGS ABOUT THIS STUDY?**

We hope to find out what boys and girls think about their time in hospital and the sorts of things that helped them or did not help them to feel better.

**ARE THERE ANY BAD THINGS ABOUT THE STUDY?**

We don’t think so. When we come to see you your mum or dad will be there as well. If you get tired when we are talking we can always stop and have a break.

**WHAT SHALL I DO NOW?**

Now you have read about our study you need to think about whether you want to join it or not. Talk with your mum or dad or anyone else you wish. If you would like to talk to your doctor or nurse let them know by asking your mum or dad to ask them to talk to you. After all this you can tell your mum or dad if you want to talk with us or not. If you do not want to talk with us then that is OK.

**DO I HAVE TO SAY YES?**

You do not have to say yes. If you say yes at the beginning you can change your mind any time. If you say no or want to stop being in the study this won’t make a difference to the way that the nurses or other people look after you.

My Name is: Susie Hey  
Telephone No: 0207 405 9200 extension 0720
Listening to children and young people with cancer
We are writing to invite you to participate in this study.

The aim of the study
Our aim is to consult with young people to find out what you want from your health service. We want to make sure that we are meeting the needs of young people like yourself who have cancer.

Why is the project being done?
How young people experience care and treatment, and what they perceive as important has received little attention in the past. We want to identify the needs of young people with cancer from their perspective in order to gain an understanding of views of current cancer care services, including positive experiences and issues, which have been less positive. We will be able to share what we find with colleagues at your treatment centre and other centres throughout the UK. Our aim is to use your experiences to inform how we deliver care to young people in the future.

How is the study to be done?
There are three parts to our study, all done in one day (probably about 4 hours over lunch, which we will provide). You will join the research team, at Great Ormond Street Hospital in a room, which is not part of the ward area. Here you will meet other boys and girls the same age as you. First of all we will spend some time getting to know each other after which you can choose a partner to interview. We will supply you with some questions to ask, but through the interview you may think of some different questions, which you can also ask. This is a two-way process in which you will have an opportunity to ask and answer questions: like a reporter for a newspaper when asking questions we will ask you to write down the responses. We will come back together as a group and talk about the experiences shared within the group using what is written on notepads to help us. We would then work in two groups using post-its on a wall for you to show what is most important and least important of what we discuss. While you are having lunch (provided by us) the researchers will draw these two exercises together into a series of questions that we can use to explore in a group type interview, called a focus group. So that we do not lose any of the words spoken we will tape record this final activity.

What are the risks and discomfort?
We do not anticipate any. But we recognise that coming together in a group can cause some initial anxiety. We will aim to make the experience as relaxed as possible, making the interactions creative and fun. We will make use of a graffiti wall...
(where you can write anything you like about the day on post its and stick them on the wall) in the room where we are working so that you can give us feedback throughout the day. But, if you do find the activities difficult you can leave at any point in the day, you can return later in the day if you wish or not at all. If you do want to leave you need to make your feelings known to one of the research team, who would be able to spend some time with you outside of the group. You can bring one of your parents with you or a friend; we will provide a room for them with refreshments. We will provide travel expenses for you and a parent/friend to join us.

Who will have access to the case/research records?
All information will be treated in the strictest confidence. Only the researchers will have access to the data collected during this study. You will have the opportunity to obtain a brief report of the study once the study is completed.

What are the potential benefits?
To you at this time there are no immediate benefits. But we do hope that the knowledge we gain from our study will assist us in ensuring that the service we provide in the future is appropriate and designed to meet the needs of children and young people with cancer.

Do I have to take part in the study?
No, your involvement is totally voluntary. If you do not wish to take part in this study your treatment and care now and in the future will not be affected in any way.

Who do I speak to if problems arise?
If you have any complaints about the way in which this research project has been, or is being conducted, please, in the first instance, discuss them with the researcher. If problems are not resolved, or you wish to comment in any other way, please contact the Chairman of the Research Ethics Committee; by post via Research and Development Office, Institute of Child Health, 30 Guilford Street, London, WC1N 1EH, or the Committee administrator will put you in contact with him.

Details of how to contact the Researcher:
You can contact either Susie or Faith: see contact details below.

**Susie Hey**
Researcher in Child Health
Tel: 0207 405 9200 extension 0720 S.Hey@ich.ucl.ac.uk
Or write to:
Centre for Nursing and Allied Health Professions Research
7th floor Old Building
Great Ormond Street Hospital for Children NHS Trust
Great Ormond Street
London, WC1N 3JH

**Dr Faith Gibson**
Lecturer in Children’s Nursing Research
Tel: 020 7813 8543 Gibsfo@gosh.nhs.uk
Or write to:
Same address as above
LISTENING TO CHILDREN and YOUNG PEOPLE with CANCER

This research study explores perceptions of children and young people with cancer regarding their care and support needs. It aims to provide a more complete understanding of their needs at different points:

- At diagnosis
- On treatment
- Following successful completion of treatment
- Or
- At a later stage whilst receiving care

We need this information to enable us to provide the most appropriate service to meet the specific needs of children and young people.

If you have a son or daughter between the age of 4-18 years with a cancer diagnosis and receiving care related to the specific time points we have highlighted above and would like to find out more about the study please ring Susie Hey on 020 7405 9200 extension: 0720

Thank you for your consideration

Principal Investigators
Dr Faith Gibson & Professor Alison Richardson

Researcher in Child Health
Susie Hey

This research has the permission of Institute of Child Health/Great Ormond Street Multi-Research Ethics Committee
This newsletter is to let you know where we are up to with the research project ‘listening to children and young people with cancer’.

By doing this project we are trying to find out what children and young people like you think about their time in hospital.

What has happened already?
So far we have talked to 32 children and young people aged between 4 and 19 years old who go to Great Ormond Street Hospital, The Middlesex Hospital and The Royal Marsden Hospital. We still have some more children to talk to.

On 10th April we held an activities day for 13 to 15 year olds. This took place in Pizza Express. The 4 people who came along had lots to tell us about their experiences of hospital, what they liked and how they thought things could be improved. They interviewed each other in pairs and took part in a focus group (which is like a group interview). They told us about how they like doctors and nurses to talk to them, what it is like staying in hospital and having treatment, about the difficult times they have been through and how important their family and friends are to them.

What are we going to do next?
The project ends at the end of June 2005. When we have finished talking to everyone who is taking part in the project we will write a report that puts together what each of you has told us. We will send this report to the staff at the hospitals that work with children and young people with cancer to let them know the good things you have said about them and how you think your care can be improved. We will send you a copy of the report too so that you can see what we have written and what the other people who have taken part have said. We won’t mention anybody’s real name in the reports that we write; each person who has taken part will be given a made-up name instead.

Best wishes to you and your family from the project team.....
Faith, Susie, Alison, Maire and Chris.

If you or family have any questions about the project please phone or email Susie Hey

Tel: 020 74059200 ext. 0720

Email: s.hey@ich.ucl.ac.uk
**Listening to children and young people with cancer - project newsletter**

**Issue 1**

December 2004

---

This newsletter is to let you know what is happening with the research project 'listening to children and young people with cancer' that you have helped us with already or may help us with soon.

By doing this project we are trying to find out what children like you think about their time in hospital, what they like about it and what they do not like about it.

**What has happened already?**

The project started in March 2004. A group of children looked at the information leaflets and posters we had made and gave us some great advice on what they should say and look like.

In November a new researcher, called Susie started working on the project.

In December we started to ask children at Great Ormond Street Hospital about what they think about their time in hospital. So far, 14 children have said they would like to be part of the project.

---

**What are we going to do next?**

We are going to carry on talking to children about their time in hospital. If you haven't talked to us yet, we will be in touch with you in January.

We have put up some posters at The Middlesex Hospital to tell the children there about the project and we are going to start talking with children at that hospital about what they think. We are also going to start to talk with children at the Royal Marsden Hospital in the new year.

The project finishes at the end of May 2005.

---

Season's greetings to you and your family from the project team.....

Faith, Susie, Alison, Maire and Chris.

---

If you or family have any questions about the project please phone or email Susie Hey

Tel: 020 74059200 ext. 0720

Email: s.hey@ich.ucl.ac.uk
Appendix 3. Questions used in data collection

**Puppetry and Imaginative play:**

**Questions (using named examples of dolls):**

**Question 1 - around time of diagnosis:**

Fizz has been going to see the doctor at the hospital, have you been going to see
anyone at the hospital?

Fizz is not sure why she is going to hospital. Has anyone told you? What did they
say?

Fizz wants to know what its like in your hospital?
How do you feel when you are there?
Is there anything you like doing when you are there?
Is there anything you don’t like about being there?
What kinds of things were done to you in hospital?
Who do you play with?
If your not sure about something, who can you talk to or ask?

**Question 2 – during treatment:**

Jake is having some special medicines, do you have any medicines, has anyone told
you about them?
What are they called?
How do you get given your medicines?
How do the medicines help you?

Jake has to sleep in hospital sometimes: do you have to stay in hospital?
How do you feel when you stay in hospital?
What’s your room like?
What things are nice when you stay in hospital?
What don’t you like about being in hospital?
What do you miss when you are in hospital?
What’s it been like at home since you’ve been coming to hospital?
Have some things changed? School, friends, family outings etc.
Who comes to visit you at home?
Who comes to visit you in hospital?
Who do you talk to when you are worried or have question?

**Question 3 – at end of treatment:**

Bella is not going to have any more medicines now, she won’t have to come to
hospital as much as before, how about you?
Who has told you about this?
How do you feel about not coming to hospital as much?
Have you still got your line?
Is it going to come out now?
How do you feel about that?
Will you miss coming to hospital as much?
What will you miss?
Will it be different at home/school now?
How does it feel not having to take your medicines everyday?
Has anyone told you why you don’t need them anymore?
Do you think about your illness?
Shall we ask Bella if she has any questions?

**Question 4 – Six months to one year after successful treatment:**
Milo had to go to hospital last year from some special medicines, he had an illness did you have to go to hospital?
What do you remember about it?
Who talked to you about your illness?
Were you ever worried?
What nice things can you remember about coming to hospital?
What were not so nice things?
How are you feeling (use cards)

**Question 5 – Around the time of relapse/recurrence:**
Fizz went to the hospital and mummy and daddy and the doctor said she needed more medicines – has this happened to you?
What have they told you?
What do you think about that?
Has anyone explained why you need more medicines?
How are you feeling (use cards)
Who would it be helpful to talk to?
Do you feel different from the last time?
Let’s see if Fizz has any question.

**Question 6 – Palliation:**
Bella is feeling fed up – she has been feeling poorly for a long time now, Bella wants to know how do you feel?
Has anyone asked you how you are feeling?
What would help Bella or you at the moment?
Is there anything you would like here to make you feel more comfortable?
Where do you like being best, home or hospital? Why is that place the best?
Who do you want with you?

**Draw and write technique:**
**Questions:**
**Question 1 - Around time of diagnosis:**
Think about a child just like you who has just been told they have ..... and are going to have medicine and treatment to make them better.
Draw a picture of what that child is doing and what they are thinking.

Follow up question :- is there anything that child would like to know about what is going to happen.

**Question 2 - During treatment:**
Think about a child like you who is having medicine (treatment) for ....
Draw a picture of what that child is doing and what they are thinking.

Follow up question :- is there anything that child could ask the people looking after her/him to do to make it easier for them what would it be.
Question 3 - At the end of treatment:

Think about a child just like you who has just finished medicine and treatment to make them better. Draw a picture of what they are doing and what they are thinking.

Follow up question:- if that child could ask the doctors and nurses anything about what would make it better, what would that be?

Question 4 - Six months to one year after successful treatment:

Think about a child just like you who has been treated for … and has been better since (date). Draw a picture of how that child would have liked hospital to be different if they were ill again.

Follow up question:- What did the people who looked after you do that made it easier for you when you were ill.

Question 5 - Around the time of relapse/recurrence:

Think about a child just like you who thought they were all better and now they have been told they are sick again. Draw a picture of a child somewhere in a hospital, what they are doing and what they are thinking.

Follow up question:- if that child could ask any question at all right now about what was going to happen what would that child ask.

Question 6 – Palliation:

Think about a child just like you who has been ill on and off for a long time. Draw a picture of what that child is doing and what they are thinking.

Follow up question:- What could the people who look after them do to make it easier for that child.

Activities day:
Example questions for peer interviews:
The researchers have identified a number of brief questions for the young people to ask of each other in the peer interviews:
- Tell me a bit about your illness.
- What is the most challenging issue you face with cancer today?
- Tell me about your experience in the hospital.
- What did the people who look after you do that made it easier for you when you were ill?
- What could the people who look after you do to make it easier when you are ill?

We will be encouraging the young people to expand on these if they wish.
The questions for the focus groups will be developed from the themes from the two previous exercises.

**Interview Schedule for Individual Interviews with 13-19 year old Participants**

**Questions for participants who are on treatment**

1. Tell me a bit about your illness.

**Treatment**

1. Tell me about your experiences in the hospital.
2. What sort of treatment have you had so far?
3. When you have your treatment do you have to stay in hospital or do you go for the day?
4. How often do have to go to hospital?
5. How easy is it for you to get to the hospital?
6. What happens when you are there?
7. What’s it like having treatment?
8. How does the treatment make you feel?
9. What is it like to stay in hospital?
10. How does it compare to being at home?

**People**

1. Who comes with you when you go to hospital?
2. Who comes to see you when you stay in hospital?
3. Who do you talk to when you are in hospital?
4. Who do you talk to if want to know something?
5. Who do you talk to when you are worried about something?
6. Are you able to talk to the doctors and nurses?
7. What sort of things do you talk about?
8. What do the people who look after you do that make it easier for you when you are ill?
9. What else could the people who look after you do to make it easier for you when you are ill?
10. How much are you involved in your treatment and care?
11. How would you like to be involved?
12. Do you get asked your opinions/wishes?
13. Are you listened to?
14. Do you get enough support?

**Facilities/Ward Environment**

1. Describe what the ward looks like.
2. How do you think the ward could be improved?
3. Is it comfortable?
4. Do you have enough privacy?
5. What things do you do when you are in hospital?
6. Is there enough to do?
7. What else could there be to do?
8. Are the things to do on the ward appropriate for people your age?

What things do you like about hospital?
What don’t you like about hospital?
What would you change about the hospital if you could?

If you could give one piece of advice to everyone who works with young people with cancer what would it be?

**Hospital choice exercise.**

If you moved to a new town you did not know and there were two hospitals you could receive your care from, what would make you decide which one to go to?

Response to be written down.
Appendix 4. The ‘ice breaker’

<table>
<thead>
<tr>
<th>Q1</th>
<th>Q2</th>
<th>Q3</th>
<th>Q4</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your favourite band/singer?</td>
<td>What is your favourite TV show?</td>
<td>What food do you like best?</td>
<td>What was the last film you saw?</td>
</tr>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Appendix 5. Dissemination process and outcomes from project.

A number of dissemination strategies are proposed to the funding body, these include:

1. Production and distribution of child and parent information to participants in the study.
2. Production of posters outlining main findings to be displayed in clinical areas and patient waiting and treatment areas.
3. Presentation at local, national and international meetings.
4. A series of papers for publication are in the process of being written:

- The first will be a composite paper reporting the results from all participants in the project. Suggested publication: Social Science and Medicine.

- The second will focus upon the results from the data collection with the 6 to 12 year olds using the draw and write technique. This paper will focus upon the usefulness of this method to enable children to give their views. It is planned to submit this paper to Children’s Health Care.

- The third will focus upon the data collected with the 4 and 5 year olds using play and puppets. This paper will focus upon the usefulness of this method to enable very young children to give their views. It is planned to submit this paper to Children and Society.

- The final paper will focus on data collection with the 13 to 19 year olds. Again this paper will comment on the methods used with this age group. It is planned to submit this paper to Cancer Nursing.