An exploration of parents' and professionals' roles in sharing illness and treatment information with children who have cancer:

FINAL REPORT
April 2011

Submitted on behalf of the research team:

Gibson F
Aldiss S
Bryan G
Forbat L
Horstman M
Kumpunen S
MacIntyre G
Ranasinghe N
Say T
Goulden N
RESEARCH TEAM

**Professor Faith Gibson**, Clinical Professor of Children and Young People’s Cancer care, Great Ormond Street Hospital for Children NHS Trust and London South Bank University

**Ms Susie Aldiss**, Researcher in Child Health, London South Bank University

**Dr Gemma Bryan**, Research Assistant, London South Bank University

**Dr Liz Forbat**, Co-director and Senior Research Fellow, Cancer Care, University of Stirling

**Ms Maire Horstman**, Principal Lecturer for Post-Qualifying Education, London South Bank University

**Ms Stephanie Kumpunen**, Research Assistant, London South Bank University

**Ms Ginny MacIntyre**, Parent advisor

**Mr Neil Ranasinghe**, Parent advisor

**Ms Tina Say**, Clinical Nurse Specialist for Haematology/Oncology, Great Ormond Street Hospital

**Dr Nick Goulden**, Consultant in Paediatric Haematology and Bone Marrow Transplant, Great Ormond Street Hospital for Children

Advisory Committee

Thank you to the following members: Zoe Berger, Psychologist Great Ormond Street Hospital for Children NHS Trust; Jamie Cargill, Clinical Nurse Specialist for Children with ALL Bristol Children’s Hospital; Julia Chisholm, Paediatric Oncologist Royal Marsden Hospital NHS Foundation Trust.
Executive Summary

Study aims
‘An exploration of parents’ and professionals’ roles in sharing illness and treatment information with children who have cancer’ was a two-phased exploratory study that aimed to first uncover how parents and health professionals shared complex information about acute lymphoblastic leukaemia (ALL), and second, to create an information-sharing package to better inform families about the diagnosis and treatment phases of ALL. The aims developed from the findings of one of our studies conducted from 2005-2007 that revealed significant roles for parents in fulfilling the communication and support needs of young children (Aldiss et al 2008, Gibson et al 2005, Horstman et al 2008).

Data collection and analysis
In phase one, parents’ and professional’s communication roles were uncovered through 55 semi-structured interviews, four online forum discussions, and two group interviews conducted with 28 parents and 26 health professionals at one cancer principal treatment centre from June 2009 to July 2010. Interviewee’s preferences for an intervention were also implicitly and explicitly drawn from during interviews. Data were analysed using grounded theory methods (Corbin & Strauss, 2008). Further interviews were conducted with health professionals who coordinated shared care at local hospitals or in the community for children being treated at the principal treatment centre where the study was based. Framework analysis is currently being used to analyse this data, and we will revise this report at a later date to include this work.

In phase two, the data collected in phase one was re-analysed with the purpose of drawing out content relevant to creating an information-sharing intervention.

Phase one: Findings
Parents’ information-giving roles were intuitively guided and remained largely unreco gnised throughout the treatment phases. The pre-diagnosis and initial diagnosis periods were particularly difficult, as parents were frightened, confused, and overwhelmed with information. Parents had far stronger perceptions of the information-giving roles played by health professionals. Despite many families in our study reporting to be happy overall with the information provided, they had negative opinions about communicative situations that could have been better handled. They also revealed significant gaps in knowledge about treatment and diagnosis where information was not provided in an organised manner.

Interactions between health professionals and families were marked by parents being expected to ask questions, but having limited understanding of complex medical information and little confidence that their methods of sharing information was correct. Parents, regardless of children’s ages, heavily buffered much of the information shared shortly following diagnosis. However, they also reported being led by their children’s questions, and having little time to prepare thoughtful answers, as questions often immediately preceded medical procedures during clinic appointments or after an event (e.g. television news report on ALL, overheard “adult” conversation). This was a difficulty among health professionals working on the hospital ward, as well
some of whom reported feeling unable to provide answers to questions outright without time to prepare. This may have stemmed from the limited interaction with children that nurses perceived as part of their daily roles. In outpatient day care, many health professionals reported feeling as if they had little impact on how parents told their children about their diagnosis, and suggested it was the role of the play specialists to work with families on such issues. Overall, it appeared that whilst a medical protocol outlined treatment, there was a gap in any type of protocol to guide communication. This resulted in a wide variation in the abilities to cope with and communicate complex information related to ALL to families. Although it is difficult to determine to what effect ethnic backgrounds and educational levels played in communication, we are quite certain that an inability to communicate in English was a significant barrier to parents who wanted to share information with their children.

Phase two: Intervention development

Key findings from phase one were reanalysed by the research team and a group of health professionals and parent advisors involved in the intervention development in order to create the information-sharing package called Harmonising Education on Leukaemia (HELP). Key findings included issues that parents found difficult to translate to children and family members, as well as gaps in current information-sharing practices. HELP is an intervention that provides guidance and advice on the complex information given to families via a website, DVD and hard copy leaflets.

Conclusion

The long-term outcomes of a successful intervention will ensure that parents will feel better supported in their care-giving roles and children will be better informed about their disease, treatment and side effects in the immediate and future contexts. As many children are surviving their cancer, they need more information about their disease to ensure that they can make decisions and choices in the future based on accurate information. If the intervention is successful within this population, it is likely adaptations could be made to transfer information to families of children undergoing treatment for other types of cancer or other complex diseases.
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>Background</td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td>Aims</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>Methods</td>
<td>3</td>
</tr>
<tr>
<td>4.1</td>
<td>Design</td>
<td>3</td>
</tr>
<tr>
<td>4.2</td>
<td>Recruitment, sample, and sampling</td>
<td>3</td>
</tr>
<tr>
<td>4.2.1</td>
<td>Parent group one (P1)</td>
<td>4</td>
</tr>
<tr>
<td>4.2.2</td>
<td>Parent group two (P2)</td>
<td>5</td>
</tr>
<tr>
<td>4.2.3</td>
<td>Health professional group one (PR1)</td>
<td>6</td>
</tr>
<tr>
<td>4.2.4</td>
<td>Health professional group two (PR2)</td>
<td>6</td>
</tr>
<tr>
<td>4.2.5</td>
<td>External health professional group</td>
<td>7</td>
</tr>
<tr>
<td>4.3</td>
<td>Data collection methods</td>
<td>7</td>
</tr>
<tr>
<td>4.3.1</td>
<td>Interviews with parent group one</td>
<td>8</td>
</tr>
<tr>
<td>4.3.2</td>
<td>Interviews with parent group two</td>
<td>9</td>
</tr>
<tr>
<td>4.3.3</td>
<td>Interviews with professional group one</td>
<td>10</td>
</tr>
<tr>
<td>4.3.4</td>
<td>Interviews with professional group two</td>
<td>11</td>
</tr>
<tr>
<td>4.3.5</td>
<td>Online forum discussions with professionals</td>
<td>11</td>
</tr>
<tr>
<td>4.3.6</td>
<td>Online forum discussions with parents</td>
<td>13</td>
</tr>
<tr>
<td>4.4</td>
<td>Ethical approval</td>
<td>13</td>
</tr>
<tr>
<td>4.5</td>
<td>Data analysis</td>
<td>15</td>
</tr>
<tr>
<td>4.5.1</td>
<td>Analysis of data from P1, P2, PR1, PR2</td>
<td>15</td>
</tr>
<tr>
<td>4.5.2</td>
<td>Analysis of interviews with external professionals</td>
<td>17</td>
</tr>
<tr>
<td>4.5.3</td>
<td>Applying Foucauldian analysis to the collected data</td>
<td>17</td>
</tr>
<tr>
<td>4.5.4</td>
<td>Re-analysis of collected data</td>
<td>17</td>
</tr>
<tr>
<td>5</td>
<td>Phase one: Findings</td>
<td>17</td>
</tr>
<tr>
<td>5.1</td>
<td>Before diagnosis</td>
<td>18</td>
</tr>
<tr>
<td>5.1.1</td>
<td>Carer roles before diagnosis</td>
<td>18</td>
</tr>
<tr>
<td>5.1.2</td>
<td>Ambiguity surrounding leukaemia as an illness</td>
<td>18</td>
</tr>
<tr>
<td>5.1.3</td>
<td>Unanswered questions</td>
<td>19</td>
</tr>
<tr>
<td>5.1.4</td>
<td>Summary of roles during the pre-diagnosis period</td>
<td>19</td>
</tr>
<tr>
<td>5.2</td>
<td>Coming to hospital</td>
<td>19</td>
</tr>
<tr>
<td>5.3</td>
<td>Diagnosis talk</td>
<td>20</td>
</tr>
<tr>
<td>5.3.1</td>
<td>The impact of the environment</td>
<td>20</td>
</tr>
<tr>
<td>5.3.2</td>
<td>The spiel</td>
<td>20</td>
</tr>
<tr>
<td>5.3.3</td>
<td>Following up diagnosis information after the talk</td>
<td>21</td>
</tr>
<tr>
<td>5.4</td>
<td>First week in hospital</td>
<td>22</td>
</tr>
<tr>
<td>5.5</td>
<td>Preparing to go home</td>
<td>24</td>
</tr>
<tr>
<td>5.5.1</td>
<td>Parent learning</td>
<td>24</td>
</tr>
<tr>
<td>5.6</td>
<td>Life as an out-patient family</td>
<td>26</td>
</tr>
<tr>
<td>5.6.1</td>
<td>Discourse changes over time</td>
<td>26</td>
</tr>
<tr>
<td>5.6.2</td>
<td>Parents’ carer and communication roles</td>
<td>26</td>
</tr>
<tr>
<td>5.6.3</td>
<td>Parents’ interactions with health professionals</td>
<td>26</td>
</tr>
<tr>
<td>Section</td>
<td>Title</td>
<td>Page</td>
</tr>
<tr>
<td>---------</td>
<td>----------------------------------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>5.6.4</td>
<td>Communication surrounding returning to normal life</td>
<td>27</td>
</tr>
<tr>
<td>5.6.5</td>
<td>Summary</td>
<td>27</td>
</tr>
<tr>
<td>5.7</td>
<td>Parents’ perceptions of sharing information with their child</td>
<td>27</td>
</tr>
<tr>
<td>5.8</td>
<td>Illness discourse</td>
<td>28</td>
</tr>
<tr>
<td>5.9</td>
<td>Parents’ strategies</td>
<td>28</td>
</tr>
<tr>
<td>5.10</td>
<td>Health professionals sharing information with children</td>
<td>29</td>
</tr>
<tr>
<td>6</td>
<td><strong>Phase two: Intervention development</strong></td>
<td>30</td>
</tr>
<tr>
<td>6.1</td>
<td>Aims of HELP</td>
<td>30</td>
</tr>
<tr>
<td>6.2</td>
<td>Format of HELP</td>
<td>31</td>
</tr>
<tr>
<td>6.3</td>
<td>Interventions in children’s cancer care</td>
<td>34</td>
</tr>
<tr>
<td>6.4</td>
<td>HELP online framework</td>
<td>34</td>
</tr>
<tr>
<td>6.5</td>
<td>Issue windows</td>
<td>36</td>
</tr>
<tr>
<td>6.5.1</td>
<td>How to prepare your child for treatment</td>
<td>36</td>
</tr>
<tr>
<td>6.5.2</td>
<td>What is a clinical trial?</td>
<td>37</td>
</tr>
<tr>
<td>6.5.3</td>
<td>Body Image</td>
<td>38</td>
</tr>
<tr>
<td>6.5.4</td>
<td>Eating and Nutrition</td>
<td>38</td>
</tr>
<tr>
<td>6.5.5</td>
<td>What are blood counts? Why are they important?</td>
<td>38</td>
</tr>
<tr>
<td>6.5.6</td>
<td>Effects on siblings and extended family</td>
<td>39</td>
</tr>
<tr>
<td>6.5.7</td>
<td>Going back to school</td>
<td>39</td>
</tr>
<tr>
<td>6.5.8</td>
<td>How to try to get life back to normal</td>
<td>39</td>
</tr>
<tr>
<td>6.6</td>
<td>Refining the tool</td>
<td>40</td>
</tr>
<tr>
<td>7</td>
<td>Implications</td>
<td>40</td>
</tr>
<tr>
<td>7.1</td>
<td>Implications of the study on research</td>
<td>40</td>
</tr>
<tr>
<td>7.2</td>
<td>Implications for clinical practice</td>
<td>41</td>
</tr>
<tr>
<td>8</td>
<td><strong>Study management and timeline</strong></td>
<td>41</td>
</tr>
<tr>
<td>8.1</td>
<td>Research Team</td>
<td>41</td>
</tr>
<tr>
<td>8.2</td>
<td>Advisory Committee</td>
<td>41</td>
</tr>
<tr>
<td>8.3</td>
<td>Intervention development group</td>
<td>42</td>
</tr>
<tr>
<td>8.4</td>
<td>Timeline</td>
<td>42</td>
</tr>
<tr>
<td>8.4.1</td>
<td>Challenges to data collection and analysis that impacted the timeline</td>
<td>42</td>
</tr>
<tr>
<td>9</td>
<td><strong>Dissemination strategy</strong></td>
<td>43</td>
</tr>
<tr>
<td>9.1</td>
<td>Publications</td>
<td>43</td>
</tr>
<tr>
<td>9.2</td>
<td>Presentations</td>
<td>43</td>
</tr>
<tr>
<td>10</td>
<td>Conclusion</td>
<td>43</td>
</tr>
<tr>
<td>11</td>
<td>References</td>
<td>44</td>
</tr>
</tbody>
</table>
List of Boxes

<table>
<thead>
<tr>
<th>Box</th>
<th>Interview questions with parent group 1 at first and second interview</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Box 2</td>
<td>Interview questions with parent group 2</td>
<td>10</td>
</tr>
<tr>
<td>Box 3</td>
<td>Interview questions with professional group 1</td>
<td>10</td>
</tr>
<tr>
<td>Box 4</td>
<td>Interview questions with professional group 2</td>
<td>11</td>
</tr>
</tbody>
</table>

List of Figures

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1</td>
<td>Lambert’s (2008) The Children’s ‘Visible-ness’ Continuum</td>
<td>2</td>
</tr>
<tr>
<td>Figure 2</td>
<td>Interview Guide at First and Second Interview with Parent Group One</td>
<td>9</td>
</tr>
<tr>
<td>Figure 3</td>
<td>Online forum homepage</td>
<td>12</td>
</tr>
<tr>
<td>Figure 4</td>
<td>Online discussion forum: example question</td>
<td>13</td>
</tr>
<tr>
<td>Figure 5</td>
<td>Successful Information Exchanges and Parent Learning</td>
<td>25</td>
</tr>
<tr>
<td>Figure 6</td>
<td>Components of HELP</td>
<td>32</td>
</tr>
<tr>
<td>Figure 7</td>
<td>Framework of information provided in HELP</td>
<td>35</td>
</tr>
</tbody>
</table>

List of Tables

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 1</td>
<td>Demographic characteristics of parent group 1</td>
<td>5</td>
</tr>
<tr>
<td>Table 2</td>
<td>Summary of sample, sample size and data collection methods</td>
<td>7</td>
</tr>
<tr>
<td>Table 3</td>
<td>Physical and emotional symptoms by age group</td>
<td>37</td>
</tr>
<tr>
<td>Table 4</td>
<td>Timeline for various stages of the project</td>
<td>42</td>
</tr>
</tbody>
</table>
1 Introduction

It is reported, “for virtually all parents, becoming a parent of a child with cancer marks a striking, biographical transition” (Dixon-Woods et al 2002). A major part of this biographical transition involves parents taking on new carer and information-sharing roles during their child’s treatment, most predominantly executive-like roles, managing what and how their children are told about their illness (Young et al 2003). Children aged four to ten years rely on their parents for all of their medical and non-medical information (Aldiss et al 2008, Gibson et al 2010). Parents have the onerous responsibility of first understanding the information, assessing the appropriate amount of information that should be available to their children, and then disclosing it. Many parents report a strong desire to take on information-giving roles with their families, and believe they are best positioned to discuss their child’s illness with their child. Over 80% of parents in one study wanted to be treated by hospital staff as their child’s treatment co-ordinator (Mitchell et al 2006). However, there is evidence that health professionals do not share information as well as is generally perceived, and some parents receive too little or too much information (Ringnér et al 2011). Furthermore, there is no clear definition of information, and its boundaries with patient education and social support are unclear (Ringnér et al 2011). There is clearly a greater need to recognise and better support the parental voice in managing communication with children, as well as with extended family and friends. This study explored parents’ and health professionals’ roles in sharing illness information with children who have acute lymphoblastic leukaemia (ALL) in phase 1 of the research. In phase 2, we created an intervention to better support parents in their information-sharing roles primarily with their child, as well as with their family.

2 Background

As a result of the shock and distress associated with hearing their child’s diagnosis, parents often understand less than half of what doctors say at the initial consultation (Kodish et al 2004). They are most distressed at the time of diagnosis and early stages of treatment (Kupst 1992). Stress further hinders information retention, making it extremely difficult for parents to relay and translate information to children following diagnosis (Mack et al 2004). Parental distress regarding treatment procedures remains high over the course of lengthy treatment for leukaemia (Kazak and Barakat 1995). Despite the inherent barriers, it is important that parents begin to share information with their child following diagnosis and build up complex information over time.

Children with cancer who receive information from their parents about treatment and prognosis during the initial stages are significantly less anxious and depressed than children who receive less information or information at a later stage (Last and van Veldhuizen 1996). When children become aware of ‘the facts’ there is an increased likelihood of them asking questions, expressing worries and a decreased feeling of loneliness and alienation (Chesler et al 1986, Last and van Veldhuizen 1996, Spinetta and Deasy-Spinetta 1981). Children report desiring information about a number of
important treatment related issues, such as the permanence of the effects of steroids, severity and length of side effects, prognosis, and pain (Claffin & Barbarin 1991, Ellis & Leventhal 1992, Gibson et al 2005, Horstman & Bradding 2002).

Parents’ and health professionals’ information-sharing roles can also impact children’s communication and decision making roles during treatment. Children are recognised as capable of shifting their visibility in their communication roles from being in the ‘foreground’ or ‘forefront’ of communication with health professionals to being in the ‘background’ or ‘overshadowed’ (Hinds 2004, Lambert 2008). Lambert (2008) describes children’s participation in communication as a continuum (Figure 1) that is determined by four factors:

1. The child’s desire to engage in communication;
2. The health professionals’ level of engagement or marginalisation of the child;
3. The parents’ recognition of the child as part of the communication process; and
4. The hospital environment itself.

![Figure 1: Lambert’s (2008) The Children’s ‘Visible-ness’ Continuum](image)

Being overshadowed in communication occurs when health professionals focus on their own agenda, and communicate directly with parents. This leads to children being only peripherally aware of what might occur during treatment, and hence unprepared and worried about the illness. While, being in the forefront of communication appears ideal, it is argued that no one side of the continuum is better than the other because some children do not want to be involved in communication and decision making. It is only when there is a conflict in children’s preferences that a shift should be made.

Children can shift into the forefront when parents and health professionals provide honest, accurate and complete information to children and encourage the asking of questions. It is suggested that instilling confidence in children that they will be able to handle the illness and related situations, they will be able to focus on themselves outside of the illness and find meaning in life and interactions with others. This allows children to view their lives as more ‘normal’, which is something many parents in our study reported as very difficult for them to deal with and communicate about.

Despite the evidence for a need to focus on parents’ and professionals’ roles in sharing information with children, there is still very little known about children’s preferences about gaining illness information in the UK. There is also currently little discussion of information-sharing support for families of children with cancer in the literature and no known rigorously-tested education or communication interventions
available for families. Our research team has developed a research programme
dedicated to exploring communication in children’s cancer care, and have attempted
to fill the void by creating a supportive information-sharing intervention called
Harmonising Education about Leukaemia for Parents (HELP). HELP is grounded in
our research and the surrounding literature, and will be discussed in detail in this
report.

3 Aims

The aims of this two-phase study were:

**Phase 1:**
To investigate the roles that parents and health professionals play in providing
children with information about acute lymphoblastic leukaemia (ALL) and to
understand how roles change over the duration of the child’s treatment.

**Phase 2:**
To develop and pilot an intervention to support parents in communicating and
sharing information about the diagnosis and treatment with their children.

4 Methods

4.1 Design
**Phase one: Exploring parents’ and health professionals’ roles in communication**
In phase one of the study we used a grounded theory design to elicit dominant
categories and concepts within communication surrounding treatment and diagnosis
(Corbin and Strauss 2008, Strauss and Corbin 1998). The data collected were used
to expand theoretical understandings of communication in children’s cancer care.

**Phase two: Developing a communication intervention**
In the second phase, we drew on the collected data for its content to inform the
development of an information-sharing online intervention. No further data collection
was carried out. See section 7 for further details about how data collected in phase
one was adapted and reanalysed in phase two. Hence, all details in the methods
section relate to phase one of the project.

4.2 Recruitment, sample, and sampling
The study sample included parents of children on and off treatment for acute
lymphoblastic leukaemia (ALL) \( n=28 \), and health professionals working at Great
Ormond Street Hospital for Children NHS Trust (GOSH) \( n=26 \). Participants were
divided into four groups: parent group 1 (P1), parent group 2 (P2), professional group
1 (PR1), and professional group 2 (PR2) based on the varied inclusion criteria and
data collection methods of each group.
Another group of health professionals were approached after the research team had completed data collection with these four groups of participants. These professionals were employed by Trusts that shared care of patients with GOSH. Shared care was a particular focus for many parents, hence the decision to recruit a further group of professionals not described in our initial proposal.

4.2.1 Parent group one (P1) (n=12)

Recruitment: Parents were recruited with the aid of two clinical nurse specialists on the outpatient unit. The recruitment period began in February 2009, and the first family agreed in June 2009; recruitment then ran until February 2010 when the research team was satisfied that a wide range of families were represented in the group.

Inclusion criteria: We approached families who had children within the ages of 3.8 and 10.9 years, up to four months after an initial diagnosis of ALL. There were no language requirements, or other criteria that would have eliminated eligibility other than the child being too unwell for his or her parents to take part.

Sample: Group P1 was composed of six ethnically-diverse, two-parent families of children who were between the ages of 3.8 and nine years at diagnosis (four male, two female). All families spoke English without the need for a translator; however, one family requested the presence of a translator during their first interview in case they did not understand the researcher’s questions. There were two families who declined to take part citing a lack of time.

Sampling: As each individual family agreed to take part, their demographic characteristics and responses during interviews influenced the recruitment of other families. The research team worked with the clinical nurse specialists who were recruiting families to seek out these families. For example, the family of a female aged between 8 and 10 years was sought out to explore the differences in communication styles. This is referred to as theoretical sampling (Strauss and Corbin 1998).
Table 1: Demographic Characteristics of Parent Group One

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Levels</th>
<th>Number in Group P1 (n=12 parents / n=6 families)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (Parent)</td>
<td>Female</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>6</td>
</tr>
<tr>
<td>Age of Parent (years)</td>
<td>30-35</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>36-40</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>41-45</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>46-50</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>51-55</td>
<td>1</td>
</tr>
<tr>
<td>Ethnic Group</td>
<td>British Asian (Indian)</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>British Asian (Bangladeshi)</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>White British</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>White Other</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>North African</td>
<td>1</td>
</tr>
<tr>
<td>Level of education*</td>
<td>A level or equivalent</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Higher education</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Degree (or equivalent)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>1</td>
</tr>
<tr>
<td>Gender of child</td>
<td>Female</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>4</td>
</tr>
<tr>
<td>Age of child (years)</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>2</td>
</tr>
</tbody>
</table>

* Totals in this section do not add to 12, as the form and all sections within were optional.

4.2.2 Parent group two (P2) (n=16)

Recruitment: Two clinical nurse specialists telephoned eligible families or approached them at clinic appointments between March and June 2010.

Inclusion criteria: Parents of children on treatment for ALL or completed treatment within the last five years. Children must have been aged 4-10 years at diagnosis.

Sample: Parents with children aged four to thirteen years (n=16, from 12 families) who had been selected based on particular characteristics unexplored in interviews to date (e.g. single parents). A translator was only used with one family. Parents of six separate families declined to take part citing they were uninterested (n=5) or had time constraints (n=1).

Sampling: We approached parents who were from**:
- Single-parent families (n=2)
- Families in which children were having/had medical complications whilst on treatment (i.e. children are/were very poorly) (n=3)
- Families who had challenged their child’s medical treatment (n=3)
• Families where the father acted as the primary carer, or alternatively was not often very visible at the hospital (n=2)
• Families who were having/underwent difficult experiences at shared care hospitals (n=4)
• Families who had atypical social experiences (e.g. moved country during treatment) (n=2)

** Parents could have been recruited based on more than one sampling characteristic, but were allocated to one to clarify the sampling rationale for this report.

Demographic information beyond these characteristics was not sought from families, as the first four parents interviewed declined filling in the form. However, it should be noted that children in these families were almost all nearing the end of treatment (only one was off treatment).

4.2.3 Health professional group one (PR1) (n=11)

Recruitment: Participants were invited by the researcher via email within three days of being mentioned in an interview with parent group one.

Inclusion criteria: A staff member at GOSH.

Sample: The sample was composed of specialist nurses (n=4), a social worker (n=1), play specialists (n=2), consultants (n=2), and registrars (n=2). Three health professionals were nominated to take part more than once, but two of those approached to take part in a second interview declined because they felt they did not have any new information to add; the other took part again in the online forum instead of another interview. A number of the health professionals nominated were not able to be contacted because they had left the Trust (e.g. students nurses, maternity leave) (n=4) or worked for other Trusts, often at the families’ local hospitals that shared care with GOSH (n=8). See section 4.2.5 for more details.

Sampling: A system of nomination from parent group 1 was used to determine which individuals to invite.

4.2.4 Health professional group two (PR2) (n=15)

Recruitment: An email invitation was sent to all 84 haematology/oncology staff nurses at GOSH.

Inclusion criteria: Any staff nurse working in the haematology/oncology unit at GOSH.

Sample: The sample included outpatient ward (day care) nurses (n=4), inpatient ward nurses (n=7), outreach nurses (n=2), a specialist nurse (n=1), and a nurse practitioner (n=1).
Sampling: Initially purposive sampling was used, then theoretical sampling. This is because a number of nurses originally agreed from the outpatient unit, and we then specifically recruited inpatient unit nurses to understand both perspectives.

4.2.5 External health professional group (n=8)
Recruitment: The chief investigator sent out an email invitation to 27 health professionals at 16 Trusts involved in care of children currently under shared care treatment. There were 2 particular health professionals who were sought out, because they had been mentioned in interviews by parent group one or two. Another 22 were recruited because they were mentioned as key shared care contacts by the clinical nurse specialists at GOSH. A further 3 individuals were included because they were members of the Children’s Cancer and Leukaemia Group (CCLG).

Inclusion criteria: Health professionals were asked to take part if they were employed by a Trust that shared care of patients with GOSH.

Sample: The sample included nurses (n=5) and paediatricians (n=3).

Sampling: Purposive sampling was used for all participants recruited for this group.

4.3 Data collection methods
Three different qualitative data collection methods were used including individual interviews (face-to-face and telephone), online forum discussions, and focus groups. A summary of recruitment data, sample size in each group, and methods of participation are available in Table 2. Data was collected over 22 months between June 2009 and April 2011.

Table 2: Summary of Sample, Sample Size and Data Collection Methods

<table>
<thead>
<tr>
<th>Group</th>
<th>Sample</th>
<th>Number approached</th>
<th>N</th>
<th>Data collection method</th>
<th>Sample in each data collection method</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>Parents</td>
<td>14</td>
<td>12</td>
<td>Interview at 3-4 time points</td>
<td>12 (who took part in 26 interviews)</td>
</tr>
<tr>
<td>P2</td>
<td>Parents</td>
<td>22</td>
<td>16</td>
<td>Online forum discussion</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Interview</td>
<td>13</td>
</tr>
<tr>
<td>PR1</td>
<td>Health professionals</td>
<td>12</td>
<td>11</td>
<td>Individual interview</td>
<td>11</td>
</tr>
<tr>
<td>PR2</td>
<td>Nurses</td>
<td>84</td>
<td>15</td>
<td>Online forum discussion</td>
<td>3</td>
</tr>
<tr>
<td>SC</td>
<td>Health professionals</td>
<td>11</td>
<td>8</td>
<td>Individual interview</td>
<td>8</td>
</tr>
</tbody>
</table>
4.3.1 Interviews with parent group one

Individual interviews were held with parents and health professionals recommended by parents to capture in-depth experiences of communicating with children, as well as to understand how children, parents and professionals interact to negotiate and build meaningful understandings. Interview schedules were semi-structured to allow for meanings and responses to be grounded and jointly constructed (Mishler 1996). Interview schedules were adapted between each interview with parent group one to seek out new information or confirm our interpretations of previous interviews. For example, in the first two interviews we asked parents about their experiences of diagnosis and initial stages of treatment (Box 1). They replied with detailed accounts of the pre-diagnosis period.

| Can you tell me the story about how your child was diagnosed with leukaemia? |
| When did you first start to think about how you would explain this to your child? |
| Who did you talk to about how you might do this? |
| Was there any person that was particularly helpful at this time? |
| What did (s)he do that was specifically helpful? |
| Who decided who would tell your child? |
| Did you think about who was the right person to do this? |
| Were there any books or leaflets that helped you? |
| What role did other parents in the ward play? |
| What was the hardest part about telling your child their diagnosis? |

**Box 1: Interview Questions with Parent Group One at First and Second Interview**

During interviews one and two, parents had described how they had generally taken on information giving roles, but they were not asked specifically enough about actions and words that were used to undertake their roles. In interview 3 with group P1, the research team was seeking information about particular medical procedures. We also wanted more detail surrounding side effects that parents mentioned as problematic and emotionally challenging to explain to their child. We attempted to use probes to get detailed information in interviews one and two, but decided to implement a visual interview guide to determine whether a visual reminder in addition to a set of questions would be helpful (Figure 2). Parents appreciated having the guide in front of them and talking between particular issues, rather than following a structured interview guide.
4.3 Interviews with parent group one

Interviews with parent group one were conducted at GOSH, in their homes, at their work places, in cafes, and via telephone. Parents in group P1 took part in three or four interviews over a period of 10 months (interview 1 - within four months, interview 2 - between two and six months, interview 3 - between three and eight months, and interview 4 - between four and twelve months), either with their spouse present or independently. Interviews were held from 30 June 2009 until 29 April 2010. Families decided together whether the child and their siblings would be present prior to beginning the interview; children often sat in to listen for a short time. Interviews with parent group one were on average longer than those in parent group two, ranging between 11 and 105 minutes.

4.3.2 Interviews with parent group two

Interviews with parent group two took place at GOSH, in their homes, and via telephone. Data were collected between 7 April 2010 and 4 July 2010. When interviews involved a two-parent couple, they were interviewed together. Young children and their siblings were present during all but one face-to-face interview. Interviews lasted between 9 and 34 minutes.

Parents were asked similar questions to those in parent group one, however questions were phrased in a way that asked parents to reflect on their child’s entire treatment experience. Some of the questions asked of this participant group are seen in Box 2.

Figure 2: Interview Guide at First and Second Interview with Parent Group One

Interviews with parent group one were conducted at GOSH, in their homes, at their work places, in cafes, and via telephone. Parents in group P1 took part in three or four interviews over a period of 10 months (interview 1 - within four months, interview 2 - between two and six months, interview 3 - between three and eight months, and interview 4 - between four and twelve months), either with their spouse present or independently. Interviews were held from 30 June 2009 until 29 April 2010. Families decided together whether the child and their siblings would be present prior to beginning the interview; children often sat in to listen for a short time. Interviews with parent group one were on average longer than those in parent group two, ranging between 11 and 105 minutes.

4.3.2 Interviews with parent group two

Interviews with parent group two took place at GOSH, in their homes, and via telephone. Data were collected between 7 April 2010 and 4 July 2010. When interviews involved a two-parent couple, they were interviewed together. Young children and their siblings were present during all but one face-to-face interview. Interviews lasted between 9 and 34 minutes.

Parents were asked similar questions to those in parent group one, however questions were phrased in a way that asked parents to reflect on their child’s entire treatment experience. Some of the questions asked of this participant group are seen in Box 2.
Were there times in hospital where you would have liked a nurse, doctor, play specialist, social worker, etc. to speak with your child or help you speak with your child? If so, what issues were they?

Did you feel that you had enough information about non-medical issues, like how your family life may change, what to feed your child, how to treat your child, etc.? Describe some of the non-medical questions you had or have.

Open communication with families is seen as best policy among health professionals, can you think of issues you felt were difficult to talk about openly with your child?

Many parents and children have read the book *Joe has Leukaemia* or other helpful books, if similar information was available in a DVD or CD-ROM format, do you think you would refer back to it more or less? Would you find it useful? Why?

**Box 2: Interview Questions with Parent Group Two**

### 4.3.3 Interviews with professional group one

All interviews with health professionals in professional group one occurred in private meeting rooms at GOSH as one-time events between 27 July 2009 and 3 March 2010. Interviews ranged in length between 39 and 129 minutes. Professionals were asked questions that focused around diagnosis as a distinct event and treatment and tests as a series of events, as well as about their communication roles overall. A varied number of relevant probes were asked of each professional (Box 3).

Can you describe how you are involved in communicating diagnoses to parents (and children)? How is “what is going to be said to parents” discussed among professionals before and after diagnosis has been told? How do you become involved in discussions? How were you involved in discussions with Mum?

What do you consider most important (in regard to communication) about relaying to parents about diagnosis?

What do you say or do to be helpful to parents at this time? How do you decide what is “best” for each family?

What role do you play in helping parents tell their child about the diagnosis?

IF NO ROLE- Who may do this on the ward? What does this person do? How do you know?

How does ethnicity influence your communication style?

In what ways do you facilitate a supportive network between families?

Which books or leaflets do you refer to most often for your own information? Which books or leaflets do you refer to most in conversations with families? Which books or leaflets do you suggest to parents for themselves most often? Which books or leaflets do you suggest to parents for their children most often?

What is the hardest part about being involved in communicating a diagnosis to a parent? Child?

**Box 3: Interview Questions Related to Diagnosis with Professional Group One**
4.3.4 Interviews with professional group two (individual and group)

All interviews with health professionals in professional group two were face-to-face, one-time individual interviews in private meeting rooms at GOSH. They lasted between 9 and 16 minutes, and were undertaken between 4 December 2009 and 4 July 2010. On two occasions, one-hour long, face-to-face group interviews took place first with three and then with four inpatient-unit nurses. The same interview schedule was used for individual and group interviews (Box 4), but significant more discussion and researcher probing was present in group interviews. For the first group interview, the chief investigator and the researcher were present, for the second group interview, only the researcher was present.

<table>
<thead>
<tr>
<th>Open communication between health professionals, parents and children is seen as the best policy, what do you do to facilitate open communication?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are there times when using open communication is difficult? If so, how do you change your way of communicating?</td>
</tr>
<tr>
<td>How do you think children learn about their ALL diagnosis and what treatment is required?</td>
</tr>
<tr>
<td>How do you know what information is given to a child? How do you find out?</td>
</tr>
<tr>
<td>Parents speak about getting lots of ALL medical information from medics, how do you, as a nurse, compliment information given by your colleagues?</td>
</tr>
<tr>
<td>How do you describe your role in helping parents give information to their child?</td>
</tr>
<tr>
<td>Do you ask parents about how they give information?</td>
</tr>
<tr>
<td>In the period of time leading up to diagnosis and in the first week following diagnosis, how can nurses be most helpful about giving information to parents? And to children?</td>
</tr>
</tbody>
</table>

Box 4: Interview Questions with Professional Group Two

4.3.5 Online forum discussions with professionals

A pilot online discussion was moderated by the researcher between 7 and 21 December 2009. The research team specifically targeted health professionals with this data collection method first in order to learn to troubleshoot any problems. The discussion was hosted on a website called Campfire (http://campfirenow.com/), with a study-particular website (https://campfirenow.com/communicationstudy2009) purchased on a monthly basis. The researcher initially invited participants to join via providing only a link to the website. This allowed them to create their own username and password. A user guide was created for participants. However, one week into the forum, Campfire changed its privacy policy and all participants who had been invited had to be re-invited. The researcher had to reassign user names and the invitation came direct from the website, instead of from the researcher’s email address. The entire process caused confusion for the participants and research team, but no participants had posted on the website when the process was changed, hence no data was compromised. There were also significant issues in ensuring that health professionals could use the website whilst at work due to the firewalls put in place at all Trusts following the Data Protection Act (1998). See section 4.4 point 3a for details about the approval process. In the end, there were 84 participants invited, 10 who
agreed (12%), 4 who signed in (5% of all invited, 40% of those who agreed), and 0 posts on the discussion forum.

A second discussion took place 22 March to 30 April 2010. As the research team was more familiar with the website and the data protection agreement, this data collection procedure was not nearly as problematic as the first. There were 16 participants invited (including all of those who had agreed to participate in the pilot and others recommended in interviews since December 2009). These participants were asked to take part online, but also had the option of taking part in interviews. There were 14 who agreed to take part (88%), 12 who preferred the online forum discussion (86% of those who agreed) and two who preferred interviews (14% of those who agreed). Only six signed in online (50%) and six dropped out (50%). Only two participants posted responses.

The questions posted online for both forums followed the interview schedule used with professional group two. Each question and independent discussion board were located in individual windows that appeared when the question was clicked on (Figure 3). The answers provided online, compared to the interviews with group PR2, were not as detailed as those provided in interviews (Figure 4). The questions posted online were directly taken from the interview schedule with parent group two.

Figure 3: Online Discussion Forum Homepage
4.3.6 Online forum discussions with parents

An online discussion was moderated by the researcher between 1 April and 3 May 2010 on the website (https://campfirenow.com/communicationstudy2010). However, once again, very few participants took part. There were 21 participants invited to choose between the online forum and interviews, and 18 agreed (86%) in total. From within those 18 participants, only six preferred the online forum discussion (33% of those who agreed), whilst eight preferred to be interviewed (44%) and four individuals dropped out (22%). Of the six who agreed to the forum, only three signed in (50%) and only two posted responses online; none completed the online survey to evaluate their experiences using the website.

4.4 Ethical approval

The research team gained ethical approval at the North West London Research Ethics Committee One on 5 February 2009, subject to the need for particular changes to participant information sheets. As the study progressed, several components were added to the study, which necessitated five substantial amendments.

1. Substantial amendment 1 was sought on 23 March 2009 in order to include a demographic sheet for participants. The amendment was initially not given a favourable opinion, and suggestions were made to ensure that participants knew the demographic form was confidential and optional. The amendment was resubmitted on 20 April 2009 and approved on 30 April 2009.

2. Substantial amendment 2 was sought on 16 May 2009 in order to extend the age range of children included in the study from 4-10 to 3.8-10, as well as the
time period in which families can be approached for recruitment from one month to four months. The amendment was approved on 27 May 2009.

3. Substantial amendment 3 was sought on 28 October 2009 in order to ensure that we could ask individuals taking part in online discussion forums during data collection to complete an online evaluation of their experiences with the forums. The amendment was approved on 2 November 2009.

   a. A minor amendment was filed on 11 March 2010 to ensure that parents and professionals using the online forums on computers at Great Ormond Street Hospital would not share personal information or information about other patients. The IT team at Great Ormond Street Hospital would not allow access to the site where the online forum was hosted until it was agreed that all participants would agree to sign a data protection/confidentiality form. The form asked individuals to not mention their name or the name of any other person online. If staff violated the agreement they agreed that they would be fired from their post. If parents violated the agreement they agreed that they would be asked to leave the study. The researcher was to report any participants who violated the agreement as soon as possible after an incident. The websites were also subject to GOSH and NHS-level audit and any violations would result in the disciplining of senior level GOSH staff. This minor amendment did not require ethical approval and was implemented immediately.

4. Substantial amendment 4 was sought on 7 June 2010 in order to speak with health professionals who are employed at NHS Trusts that share care of patients with Great Ormond Street Hospital (i.e. external health professionals). This was approved on 6 August 2010.

   a. Separate research and development (R&D) approval was sought for each Trust from which health professionals were being recruited. Emails were sent to 16 Trust R&D managers listed on the R&D forum (http://www.rdforum.nhs.uk/) on 19 August 2010. Emails were followed up with telephone calls based on responses. All but one Trust replied to our initial request. The process of gaining approval at the Trusts continued until 3 March 2010, at which point 1 R&D managers had sent approval letters. Another approval letter was sent after that date, for a total of ten sites. At Trusts where participants had not replied to the invitation to take part in the study, the researcher no longer pursued R&D approval (n=4).

5. Substantial amendment 5 was sought on 15 February 2011 to ensure that the Committee was happy with the recruitment techniques and data collection procedures that would be used to create the video portions of the intervention under development. The Sub-Committee emailed with questions about the consent procedure for parents and children appearing on videos at Great
4.5 Data analysis
Data analysis occurred in two phases. In phase one the research team used grounded theory to examine the collected data. Foucauldian discourse analysis will also be used to examine data through a different lens after the main study has been completed for the social science audience. In phase two particular excerpts from the collected data were reanalysed by the research team, advisory committee, and an intervention development group with a focus on creating content grounded in our collected data.

Phase 1: Exploring parents’ and health professionals’ roles in communication
4.5.1 Analysis of data from P1, P2, PR1, PR2 groups
Interviews were professionally transcribed by one individual who has worked with our research team in the past. The researcher then searched for incorrectly transcribed words and phrases, and created pseudonyms for participants and individuals mentioned in interviews. The data were then uploaded into a computer software program called NVivo 8, which is often used by qualitative researchers to organise data. Collected data were added to NVivo as interviews continued, and analysis occurred iteratively.

The research team used a prescriptive method of grounded theory advocated by Corbin and Strauss (2008) to guide data collection and analysis, as opposed to the classic version of grounded theory advocated by Glaser and Strauss (1976). Grounded theory is the most rigorous method of providing preliminary or exploratory research in an area in which little is known (Glaser and Strauss 1976). The process is inductive and theories arise from, or are ‘grounded’ in the raw data; thus, it provides meaning and understanding like other qualitative methods, but also generates theory. Our process of concurrent data collection and analysis occurred in five stages:
Stage 1
We examined relevant literature surrounding parents’ and children’s information preferences, theoretical understandings about the communication roles parents take on after their child is diagnosed with cancer, conceptual theory about children’s roles in communication, and research in the communication roles of health professionals play in children’s cancer care.

Stage 2
We asked ourselves ‘sensitising questions’ about the basic social psychological processes of parents, children, and extended families such as the worry and uncertainty caused by a diagnosis and individual prognosis of the child, and a lack of knowledge of ALL (Glaser and Strauss 1967, Corbin and Strauss 2008);

Stage 3
Two researchers read each transcript line by line and discussed their initial impressions and the key themes that should be further explored (i.e. open coding) (Corbin and Strauss 2008);

Stage 4
A group of four researchers from the team then generated ‘axial codes’ from the open codes by moving our basic into high-level concepts and looked at their relationships with other concepts. In order to develop the codes, the researchers met several times for analysis meetings. The open and axial codes were shared with the research team for their input on two occasions. New codes emerged as others were taken out as they appeared to not have sufficient evidence in the data.

Stage 5
Three researchers from the team used analytical tools throughout the coding phases to create an understanding of the dimensions and properties of categories of each concept and recorded analysis via memos, visual maps, and diagrams of the coding developments. Visual maps and memos were drawn during analysis meetings, and then recreated using NVivo 8 and re-examined at following analysis meetings.
4.5.2 Analysis of data from interviews with external professionals
A framework analysis was used to examine the themes from the eight shared care interviews. As this analysis is ongoing, delayed by approval processes, we will update this final report for Dimbleby Cancer Care with the findings from this section of the project.

4.5.3 Applying Foucauldian analysis to the collected data
In addition to the grounded theory and framework analysis, we plan to examine the collected data using a Foucauldian critical perspective (Foucault 1973, Foucault 1977) for publication in a social science journal. We will draw on Foucault’s structuralist interpretations of medical institutions and link them to the spaces in which the different phases of treatment take place for ALL patients and their families. We will explore the language used in these spaces to determine how discourses begin and change, and understand the implications of the language used within those spaces on power (Foucault 1973). The purpose of the perspective on the data is to provide an alternative interpretation of communication skills used in the hospital environment and to illuminate further the history of how communication about cancer has developed. When disseminated to health professionals it may aid in encouraging the prioritisation for communication and give a rationale for change outside that which is already provided by NHS policy objectives.

Phase 2: Developing a communication intervention
4.5.4 Re-analysis of collected data
In the second phase of the study, the research team reanalysed selected collected data and invited parent advisors and health professionals from across England to contribute to the development of the intervention on 12 July 2010. The selected data included information where parents mentioned particular difficulties and provided advice to the research team about what an intervention for parents should include. To undertake analysis, we grouped the findings from phase one of the study into the chronological phases of medical treatment, examined relevant literature on communication, collected varied information leaflets and books already in production, and drew on our personal experiences. Some of the codes included in the re-analysis included: gaps in information; what do parents want to know first? what do children want to know first?; and information given at the local hospital.

We additionally held an evening event on 30 March 2011 attended by 15 staff members from the principal treatment centre to contribute to their opinions of the development of the intervention. Between these meetings the research team continued in weekly meetings to discuss the development of the intervention.

5 Phase One Findings
In order to create a clear distinction between the findings in phase 1 and phase 2 of the study, they are discussed in two separate sections.

Phase 1 of the research examined the research data collected via individual and group interviews and online forums with parents and health professionals in groups
P1, P2, PR1 and PR2. It also included data collected in interviews with health professionals who worked at Trusts that shared care with GOSH; however, this data is currently still in the data collection and analysis phases of the research process. Findings will be shared with Dimbleby Cancer Care in a separate report.

The phase one findings are discussed within the context of relevant literature. They are divided into two parts based on larger themes:

1. Parents’ and professionals’ perceptions of roles throughout treatment
   o This first part explores parents’ opinions and beliefs about their roles, as well as those of health professionals as carers and communicators following a chronological narrative starting before a diagnosis has been confirmed.

2. Communication with children
   o The second part of the section explores how parents and health professionals communicated with children during our study.

Part 1: Parents’ and professionals’ perceptions of roles throughout treatment

5.1 Before diagnosis

5.1.1 Carer roles before diagnosis
Reflecting back on the time leading to diagnosis, many parents implicitly suggested they had not fulfilled their carer role by not noticing earlier that their child had become ill. Some parents told stories about the time before diagnosis with shock and disbelief still in their voices. For example, “his ears were almost transparent. But I couldn’t see. I was so busy doing other things with him…I couldn’t notice that. I don’t know why I didn’t notice it” (P1.01&08.I2). Others said, “she always had bruises, but we never thought it could be something serious. You know kids; they always bang themselves against something” (P1.05.I1). Parents never explicitly said that they had not fulfilled their parenting roles by missing key symptoms and signs. They did, however, suggest that they felt intuitive sense at the time that something was wrong with their child and should have known it was more serious. Some parents explicitly blamed their general practitioners (GPs) or other health professionals for missing the symptoms when their child’s diagnosis was delayed. Those same parents blamed themselves for trusting their GP or health professional. When health professionals suspected leukaemia and sensitively informed parents of their suspicions, parents reported feeling a sense of relief to know what was being looked for, but no less worried about their child.

5.1.2 Ambiguity surrounding leukaemia as an illness
Parents talked about not understanding the meaning of leukaemia and seeking information via the Internet or gaining information from family and friends. One mother confessed, “I just didn’t know what it was. I knew it was something very worrying, but I didn’t know it was a cancer” (P1.01.I1). Parents who knew the words leukaemia and cancer immediately felt a sense of urgency and had “perceptions of the worst” (P1.10.I1). Families found themselves having to explain leukaemia to their extended family in different languages and methods to suit their levels of understanding. They sometimes called it a type of cancer, a bone marrow illness or bone marrow cancer. Parents suggested that the lack of understanding about the illness and the challenges they encountered explaining it to family and friends might have been due to the fact
that “a lot of people don’t know leukaemia in general, even adults” (P1.03&05.I2). These parents further suggested that it was the responsibility of doctors and people in the health business to use social media to inform people about the illness. Interestingly, health professionals did not describe themselves as educators or communicators of illness-related information to anyone other than the parents of their patients. It appears that there is an aspect of public education that parents believe is lacking from health professionals’ roles.

5.1.3 Unanswered questions
Parents described the pre-diagnosis period in a very negative way, whereby they had several unanswered questions; sometimes this was due to health professionals’ uncertainties about possible diagnoses. One father said, “information was overflowing left and right, and I think it was not the way to handle [the time waiting for a diagnosis]” (P1.05.I1). Parents also discussed the difficulty in gaining information particularly about leukaemia before their child was diagnosed; with one parent stating: “we couldn’t quite understand why we were still waiting to get confirmation, not realising that it wasn’t until they took a sample of bone marrow that they could confirm it was leukaemia and what type of leukaemia it was” (P1.02&04.I1). Other parents described this waiting without information as frustrating for themselves and their daughter, as she was “hooked in”, and they couldn’t tell her anything about what was happening (P2.15&16). They found it difficult to gain information before they could begin to understand how to move on from there. Parents also discussed how it would have been extremely useful before going to their principal treatment centre to have direct information on what to expect in discussions about their child’s diagnosis or prognosis. They suggested that a conversation with a clinician at the local hospital or reliable Internet website could have acted as a ‘bridge’ that could have better prepared them to get the news about their child's diagnosis (P1.03&05.I4). Furthermore, some parents recommended that one key health professional at the local hospital should be assigned to children who are suspected to have leukaemia in order to take on information-sharing roles with their parents before diagnosis and throughout treatment.

5.1.4 Summary of roles during the pre-diagnosis period
Parents’ roles as carers and communicators are very difficult to fulfil in the pre-diagnosis period, as parents have little knowledge about leukaemia and little ability to ask questions. Parents perceived that health professionals had important roles in sharing information with them and the public, including recognising the need for information pre-diagnosis, sharing information with parents if they asked for it, and providing rationales for all decisions being made by the multidisciplinary team.

5.2 Coming to hospital
Many of the parents we interviewed suggested they were given inadequate information from staff at their local hospital about a possible diagnosis of cancer until it could be confirmed at a specialist hospital using a particular medical test. This resulted in a small number of parents being shocked to be taken to the haematology/oncology ward at the initial transfer to the specialist hospital. One parent described her situation:
“I asked them, ‘Why are you transferring me to haematology and oncology, when oncology is cancer and haematology is blood? And that means that he has leukaemia.’ ‘Oh we can’t tell you that just yet.” (P2.17&18)

Once at the hospital, one family described they saw a child who was clearly a cancer patient. For a number of days while their child was being treated as an inpatient, they believed their child would change as soon as treatment began having an effect. Their reaction was described as:

“We believed that when we left [the principal treatment centre], we would leave with a child like that. He would have no hair by the time we left, that’s what I thought was going to happen. We didn’t realise that there was an induction and that these things happen gradually…we didn’t know what kind of a child we would have tomorrow or the next week.” (P1.09.I1)

Communication was particularly central when parents arrived at a new specialist hospital. In practice, it is important that health professionals discuss parents’ expectations and assumptions they have, in addition to important medical information. This may help parents alleviate their feelings of anxiety.

5.3 Diagnosis talk

5.3.1 The impact of the environment

One mother had been given very little information before a doctor revealed her child’s diagnosis. She said a nurse approached her while in the waiting room to say that a consultant wanted to speak to her in a private room and that the room was being prepared. The moment reminded her of previous experiences with cancer and she became full of fear. She described her experience:

“I knew at that point that it was really serious because that’s the same thing they’d done, the way they set the room up, when they were telling me that my dad was dying. So I knew then that it was really, really bad. So I think it had probably crossed my mind what it was.” (P1.09.I1)

The manner in which families are told about the diagnosis can set the tone for the entire treatment and can have lasting impacts on the lives of all family members (Masera et al 2003, Randall and Wearn 2005). For some parents, their experiences in obtaining a diagnosis are so protracted and traumatizing that they shape subsequent relationships with health professionals in unhelpful ways (Dixon-Woods et al 2002).

5.3.2 The spiel

Health professionals who were present at diagnosis talks revealed that they assumed that nurses and other health professionals would follow up with families to clarify complex issues and misunderstandings from the ‘spiel’ that was generally shared with families at diagnosis. The information discussed in the spiel was described as a tacit understanding amongst all health professionals. One nurse said,
“I work really closely with the consultants, so I can predict what they’re going to say in a given situation because I’ve sat there 90 times while they’ve done that talk. And it’s always the same…so I know what they’re going to say, or what I think they’re going to say. And also you know, that they’ve work with me long enough that they know that I know the process as well. So, we’re quite lucky in terms of our relationships and how we negotiate and how we talk to families.” (PR1.01)

In regard to explicit information sharing about what is discussed between the multidisciplinary team, one consultant added, “we don’t normally need to discuss what needs to be said to parents, because it’s all pretty standard now…the information that gets given is exactly the same” (PR1.06). The basis of the spiel is on the protocol and required treatments that are given to all families; however, health professionals say that the information they provided in addition to the standard was based on their perceptions of families’ knowledge, families’ questions, and degree of family’s reception and acceptance of the disease-related information. Many doctors said they tried to individualize information giving, by suggesting, “If a family wants numbers I give them numbers”, however that hardly seemed to be sufficient individualization.

The problematic situation with the spiel was that the agenda of the conversation was in the hands of doctors who had given the same speech numerous times. They saw it was normal to provide certain pieces of information, but they made assumptions about what those were. At diagnosis parents had very little knowledge about leukaemia and did not understand their social role within the hospital system. They did not understand that the more they asked of the consultant, the more they would receive. Nor did they know what information outside of the spiel they were missing out on that could be helpful for their understandings of leukaemia. The burden of guiding conversation and seeking knowledge appeared to be unfairly shifted to parents in the period of time surrounding diagnosis.

Despite these heavy criticisms of the spiel, there was also evidence in our data that few health professionals intentionally built up information over time and would continue speaking into significant detail if parents confirmed that they were happy for them to continue, which contests the general assumptions that parents should guide the diagnosis discussion based on their questions.

5.3.3 Following up diagnosis information after the talk

Upon revealing the diagnosis, health professionals immediately clarified complex issues with the aid of four to five leaflets on treatment. However, information sharing at this time was challenged by parents feeling overwhelmed with information and having little capacity to retain information. While many families described the initial diagnosis talk as clearly explained, they also revealed that they forgot much of what had been discussed, and hence could not accurately pass the information on to others. One parent in our study suggested that it would be helpful if a week or two after diagnosis one person went back to the family and asked “Now that you’ve had time to take this in, is there anything now that you want to ask that you didn’t think to task at the beginning” (P1.11.I2)? Researchers support parents’ requests, suggesting it is a requirement in the era of open and honest information that parents have a safe
environment where they can express their feelings and have the reality of the initial stage of treatment explained again (McGrath 2002). There was no evidence in our interviews that formal discussions like this ever happened.

Health professionals made assumptions about who was giving out particular types of information. It was assumed that the social worker or play specialist would provide a certain book to a child or piece of advice to parents about translating information to their child. However, it did not appear that there were procedures in place to ensure that families who were referred to these professionals were followed up later by those who had referred them (or others) to determine whether the book or piece of advice had been given and the family was satisfied. The absence of a comprehensive formal protocol of follow up may have contributed to the deficiency of information shared in the first week of diagnosis, as well as throughout treatment. It may have also resulted in a lack of professional accountability to ensure parents and children were well equipped to understand the complexity of the diagnosis and treatments. The implementation of a formal communication protocol may help; however, an improvement in information sharing with parents and children may require a change in the way communication is prioritised at all stages of treatment altogether across the hospital system.

5.4 First week in hospital
Throughout the first week in hospital, parents had meetings with up to ten different health professionals, each providing an introduction to their area of specialist knowledge. Parents found this overwhelming saying,

“You wanted to know everything, but you didn’t know how to deal with everything. You didn’t know which bits you had to remember, and which bits you had to ignore – not ignore, but which bits you could forget perhaps.” (P2.02)

Social workers spoke about logistical issues of being in hospital, ward nurses talked about particular medicines, and specialist intravenous nurses visited to discuss the choice of central line and procedure of surgical insertion, for example. Parents suggested they had to ask each health professional who entered their child’s room a number of questions to build up a full picture of what the diagnosis and treatment of ALL looked like. As one parent noted,

“I guess the challenge back to the medical profession is that there’s no single person with a complete picture and there is no single version or opinion. There’s no finding that. So every doctor we speak to will give us, the whole picture is obviously 100% and everyone we speak to – they all know something like 60%, but they all know different percents. You’ve got to keep asking lots of different people to keep building it up and beyond that 60%.” (P1.10.I3)

Most parents felt that visits from health professionals were well coordinated. One family commented that they would have felt better prepared if someone had told them, “These are the people who will be coming to see you and this is why they’re
coming to see you” (P1.11&12.I2). They further suggested that a better explanation of roles was required saying,

“You associate social workers with people who need social workers, an in our normal, and in our pre-leukaemia days obviously we had no need to contact, come in to contact with social workers. So I think perhaps, even just, you know, an information sheet of the people that will now be part and parcel of your lives for the next two years that might have been useful.” (P1.11&12.I2)

When health professionals were faced with questions from outside of their area of specialist knowledge they suggested to parents that another professional would address that concern (despite having adequate knowledge to discuss the issue themselves). In one interview a health professional argued she did not because,

“I didn’t want to step on anybody’s toes, like confuse [the parents], because I wanted to get to know them to really find out how much they had been given, because I think it’s very hard to suddenly go in and a family give you, bombard you with all these questions, and you go in and you say, ‘This is what happens, this is what we do,’ etc. etc.” (PR1.04)

The focus on specialist knowledge was then prioritised over families’ perceived information needs. Parents discussed difficulty in finding out the length of stay required in hospital (in order to sort out childcare) or support to explain to their child the reason for the stay in hospital. They also reported finding it difficult to get explanations of certain procedures that were being done on their child. One family said,

“There were nurse coming in with medication all the time. And I must admit, sometimes I had to say, ‘Well, what’s this for, what’s that for?’ I don’t feel that was particularly well explained what she was, you know the tablets she was having.” (P1.11&12.I1)

Health professionals speaking only about their areas of specialist information was also problematic as there was no defined date by which each family must have heard about particular issues associated with treatment. Unless it was very clear that families had never received or forgotten major information no one followed it up, and no one was held accountable for not sharing that information. We have significant evidence that very essential information was missed with some families, which lead to prolonged worries and a general sense of uncertainty.

Despite these criticisms, many parents in our study commented on being very happy with how information was shared with them and continually revisited at clinic appointments. One parent said,
“I think the initial problem really was more the fact it was just that there was so much information to take on board. But I wouldn’t say there was anything new, you know, sort of information that we have now that we would have sort of looked back and said, ‘Wish we had that information at the beginning’ to be quite honest.” (P1.04.I3)

5.5 Preparing to go home

In preparation to take their child home, parents were guided through one paper form in their shared care booklet full of tick boxes addressing whether certain aspects of care had been discussed. The form was filled out often immediately before the child’s discharge, generally after one week in hospital. Parents were sometimes rushed through all of the tick boxes in ten minutes, and health professionals commented in interviews that the boxes did not address issues outside of medical aspects of care giving. Nurses on the inpatient wards suggested the reason for inadequate communication was because medical tasks took priority and occupied much of their time, and patients with ALL are in the hospital for a short amount of time making it difficult to make a connection with families. This resulted in negative consequences for parents and families who created assumptions about the timing for treatment, for example. One mother suggested the tick box process was far too rushed for her. She said,

“I obviously either hadn’t taken it in or hadn’t been prepared fully for what even those first eight weeks involved. I didn’t appreciate that we would be going in every Friday and every Friday she’d be having a lumbar puncture and a bone marrow test.” (P1.11&12.I2)

Some parents were rushed through important concepts of medical care, including a number of mothers who suggested they felt uncomfortable with giving their child chemotherapy at home. They coped by asking further questions and telling themselves that it is just something they have to deal with. One mother described her difficulties and told us her story:

“Mercaptopurine, it’s a cytotoxic drug, when I saw that stuck on the label I was like, what is that? They gave me a leaflet, but I never had time to read it. So I asked the pharmacist what does this cytotoxic drug mean…she said it’s just a drug that you have to be very careful with and that’s all she told me…So then I found it and it says poison, you know cytotoxic means poison. You know it was very hard for me to give him that medication.” (P1.01.I1)

5.5.1 Parent learning

No real discussion or support was given to parents on how to help their child understand and cope with this difficult time. One mother suggested that the research team should include in the intervention some warning to parents about the carer roles, as it was not made clear to her by health professionals. She said,
“While you’re [at the principal treatment centre], it’s not like you’re in hospital. I think while you’re here, I think it needs to be kind of made clear that this is actually an education process. When you go there, you’re going to the [principal treatment centre] to be educated in what you need to do to manage your child’s care. It’s not something that’s going to be done to him, but it’s a collaboration really. Maybe other people caught on to that. I didn’t.” (P1.09.13)

There is evidence that parents find the language surrounding diagnosis, treatment and prognosis complex. Parents undertake a steep learning curve, whereby some parents immediately take in as much information as possible, whilst others slowly build up information over time (McGrath et al 2007). Some parents in our study felt rushed to first learn about treatments and side effects, and then pass it on to their child. In another study it has been emphasised that the key ingredients for successful information exchanges include health professionals being honest and sensitive, aware of parents’ information overload, and understanding of the shock and denial that may come with a diagnosis (McGrath et al 2007). The data in this study echoed those findings that communication and parents’ abilities to learn about the diagnosis, treatment and prognosis are enabled when parents and health professionals match their readiness to learn and individually suitable amounts of information.

Figure 5: Successful Information Exchanges and Parent Learning
5.6 Life as an outpatient family

5.6.1 Discourse changes over time
Parents initially monitored and described their child’s treatment progress using the phases outlined in the clinical trial treatment protocol. At the diagnosis talk, health professionals described the treatment using this framework. Many families then used the treatment protocol to track appointments and share information about the treatment with their other family members. In our initial interviews we heard parents discussing the week of treatment their child was on, and the types of medications and expected side effects for phases. Some researchers report that parents are obliged to learn a completely new language when their child is diagnosed with leukaemia (McGrath et al 2007). It was perceived that parents used this medical-based language to demonstrate their competence in their child’s treatment to health professionals. As treatment continued, some families lost track of weeks and were used to the routine of attending clinic and no longer needed a visual reminder. Their language remained clinically focused in regard to procedures and tests, but appeared to lose the sense of urgency attached to learning a new language associated with treatment.

5.6.2 Parents’ carer and communication roles
Many parents described feeling more in control of their child’s health due to their larger care giving roles. Despite significant feelings of uneasiness in knowing exactly how to care for their child, some parents said that they were much more comfortable with the information they were being provided one month after diagnosis. One parent said, “We know exactly what we can expect, and the expectations that we are likely to have are quite hopeful. So we are feeling much better than before” (P1.03.I1). However, his partner who primarily took their child to local hospital appointments described in a separate interview (that occurred within the same week) feeling very confused and anxious about waiting for minimal residual disease test results that would affect their child’s treatment, and worried about the medications and side effects that would happen with their child starting a new block of treatment. Like many other families, parents coped with information differently, and this was often linked to the carer role in the principal treatment centre. Parents who did not attend hospital often suggested they were less in touch with the information, but trusted their partners’ translations of information. One father suggested he preferred the “KISS principle (i.e. keep it simple, stupid!)”.

5.6.3 Parents’ interactions with health professionals
As time on treatment continued, parents reported fewer interactions with health professionals as clinic appointments were further apart and test results were not shared as frequently. One family said,

Mother: “We never get any results. We never know. We go every three months for a lumbar puncture, and they just say, ‘Oh she’s fine, if there’s anything, we will let you know.’ But even if it’s fine, we want to know.”

Father: “We want to know, just tell us, ‘Yes, it’s fine, we looked at this, we looked at that. And everything looks fine to us. So we continue with this until the next lumbar puncture” (P1.03.05.I4).
Other studies have echoed these findings suggesting that parents often praised hospital care, but were displeased with clinic care. During this time, they reported feeling inadequately communicated with about test results, which was important because of the large time gap between appointments. Families also wanted facts and information including written tests results for reassurance and to aid memory. Patients later on want to know more about treatments, fertility status and options, everyday living (e.g. how to talk to their friends and employers about the illness) for example, but found that little information was provided. When it was discussed, there was no support for the ‘emotional things that go with it’ (p. 2884). Another study has reported decreased communication occurred because nurses had knowledge about how to better support parents’ needs when children were in hospital, but found it difficult to implement their knowledge because it then put them into a power position where parents became dependent on them (Bruce et al 2002).

5.6.4 Communication surrounding returning to normal life

In other studies, parents reported feeling disappointed at how difficult it was to achieve normality in daily lives after diagnosis, suggesting health professionals had not created realistic expectations at diagnosis (Earle et al 2007). Parents argued that maintenance, even years after diagnosis, was ‘supposed to be a lot easier’ (Earle et al 2007 p 157). Mothers also reported feeling guilty about questioning whether life would return back to normal up to 27 months after diagnosis, and suggested that treatment ‘doesn’t get any easier’. ‘To me it’s got harder’ (Earle et al 2007 p 158). The difficulties were attributed to having difficulty in normally parenting a child that is affected by therapy drugs, then eventually feeling well, and likely developmentally transitioning throughout the 2-3 year treatment as well.

5.6.5 Summary

Although many parents reported satisfaction with almost all of the information they had received, it appeared as if they only retrospectively realised that they were allowed to have preferences about what should be discussed and how information should be shared. They preferred face-to-face conversations over leaflets whilst at the hospital because they could gain information about their child specifically if needed. Meetings with their child’s consultant were very infrequent, yet parents valued these times and wanted more opportunities later on in treatment, not just at diagnosis and then again shortly afterwards. They also wanted to privately receive information at a time before their child so that they could deal with the emotional aspects prior to talking with their child about it.

Part 2: Communicating with Children

5.7 Parents’ perceptions of sharing information with their child

Parents translated information to their child based on their assumptions of their child’s reactions to emotion-provoking discussions. Parents argued that they knew their child best and had played important information-giving roles with their child in the past. They believed that information should be provided to their child at the right time, with a suitable amount of detail, in the right environment, and by the right person. This was different for each child.
Parents reported that they and their child felt that as soon as they had experienced maintenance therapy (usually within 16 weeks of diagnosis) that everything felt as if it repeated. The procedures, treatments, and medicines stayed the same; hence a level of comfort was built by most families if the child was reacting to treatment well and was experiencing few new side effects. As children’s questions were often led by treatment they asked fewer questions, and more psychosocial issues become problematic such as when the child should return to school. Some parents discussed their communication roles during this time as simply keeping their child updated with what is going with treatment, and telling the child when days off school should be taken off in advance, for example. Their information-sharing role appeared to be concerned with logistic issues. Although not explicitly discussed in our data collection with parents, our results appear to echo those of Young et al. (2003) who suggested that throughout the illness some parents felt that their executive-type roles of information sharing had transformed to more of a partnership with their children, where communication was much more open than during diagnosis and early treatment. Other parents described continuing to orchestrate when and what their child was told. These findings have implications for our understanding of roles and the design of our intervention.

5.8 Illness discourse
For parents to adapt to their new carer and communication roles after diagnosis, they introduced medical jargon into their vocabulary to translate to health professionals that they were capable of taking care of their child. However, when talking with their child, their vocabulary changed to reflect their assumptions about age-appropriate or ‘child-friendly’ terms. Parents controlled the discourse used around the home, especially with their other children. This included avoiding words such as cancer and leukaemia, and instead using words they had learned at hospital such as ‘bad blood’ or ‘good cell vs. bad cell’. Parents suggested they had decided to not use the “c word” because they were not always able to be around the child, for example when the child returned to school, to be able to explain what is meant by the word cancer. They were worried about the negative outcomes attached to cancer that their child might hear about. Parents particularly avoided the word ‘cancer’ because they believed that leukaemia was much more treatable, which resulted in younger children in our study believing they had leukaemia, but not cancer.

5.9 Parents’ strategies
Parents described their communication strategies as intuitive and instinctive. Their stories were not planned, and they would change the storyline iteratively if the child did not accept or understand concepts. However, if their child appeared to understand the storyline, parents continued and built on their initial discussions over time. For example, families created their own understandings of treatment-related side-effects, such as hair loss, and linked it to seasonal events throughout the year, such as the leaves falling off of/appearing on trees. Other families drew on annual life events, such as Islamic men shaving their heads during pilgrimage. Information provided throughout treatment was put into a context for children that fit into their understandings of life outside of illness.
Parents also reported being led by their children’s questions, and having little time to plan thoughtful answers, as questions often immediately preceded medical procedures during clinic appointments or after an event (e.g. television news report on ALL, overheard “adult” conversation). One mother described feeling obliged to discuss the illness with her daughter too soon after diagnosis because her daughter was concerned about her crying. In another study, parents reported to prefer to be informed about their child’s diagnosis before the child was informed themselves to avoid ‘breaking down’ in front of their child, as well as to be able to ask key questions. Older children expressed mixed responses to this practice. Some were comforted by the fact that their parent was ready to support them, while others felt betrayed by having parents informed before them (Young et al 2003).

Parents wanted to be able to share information with their children in their own time. Conflict between health professionals and parents occurred when parents buffered too much information or took ‘too long’ to tell their child what was happening. Many parents of older children asked their child, “are you ready to hear about lumbar punctures?”, for example, and were led by the child’s response. Exchanging information in this way allowed children to feel constantly supported and parents to feel as if they were satisfying the individual information needs of their child.

When parents were asked about how they prepared to share information with their child in our interviews, they said that they were never sure that what they were telling their child was the best information or that the information was given in the best way. Many families justified their unstructured approaches saying “no one actually said to us, ‘right, as parents you need to give guidance in that way’” (P1.02&04.11). They suggested they felt as if they had very little support from health professionals to share information with their child. This led to worries in parents. One mother doubted herself saying, “as a parent I worry that I have told him too much. I’ve told him what’s right, but you know like, could I have changed it in any way” (P1.01.I3)? Researchers report that parents often feel ill equipped to handle discussions with their children about life and death issues and may be reluctant to engage in open communication with them about a potentially life threatening illness in order to reduce distress for their children and themselves (Barnes et al 2000). However, parents in our study admitted feeling more supported in their information-sharing roles when health professionals shared stories about how other parents had translated information to their child at inappropriate times and in insufficient quantities. It appeared health professionals used this technique to encourage open communication within families when parents were unsure about the amount of information to share with their child. Other parents reported feeling much better about communicating with their child when health professionals gave them direct advice.

5.10 Health professionals sharing information with children

No clinician seemed to see their role as providing information to children. Many suggested that they were there to make sure parents were “well informed and as comfortable as they could be” and that then parents would pass information on to their child. Health professionals generally viewed speaking with children as the role of the parent, and rarely engaged in direct information sharing with them. Parents did not necessarily object with this behaviour, as they saw themselves as the ones
guiding conversation, not their child. Some junior staff did not see it necessary to provide information to children under a certain age, five years for some and eight for others.

Health professionals argued they did not share information with children often because they had a perception that children were scared of them or scared of the information they were sharing. One professional suggested,

“Obviously children quite often want to know what is happening, but they’re too scared to ask doctors. They go their mums and dads first rather than a doctor who’s this random stranger who sticks this needle into them.” (PR1.06)

“So it’s giving information, but at the same time, don’t scare them so much. I think that’s the thing because at the end of the day – yes, they want information and they need to know some information, but they’re children, they can get quite scared quite easily” (PR1.06).

There was one child who initially appeared to be the exception in our sample. His mother described health professionals always starting off the conversation and him continuing with questions that led to further conversations with professionals. She said that he also continually asked her questions as well “mummy why this, mummy why that?” and that encouraged her to continue providing him with information (P1.01.I3). However, over time after many painful procedures the mother said, “He’s very wary of doctors now, he wasn’t like that before, he’d just go on and on” (P1.01.I2). It appears that procedures and discussions should happen separately, and this should be clearly explained to children. Information provided during these times should be discussed with parents beforehand and a storyline should be worked out to ensure that it can be built upon over time.

6 Phase Two: Intervention Development

Phase two of the research project drew on data collected in phase one to create an intervention-sharing intervention called Harmonising Education about Leukaemia for Parents (HELP).

6.1 Aims of HELP

The aims of HELP include:

1. To help families become aware of the breadth and depth of information available to them about ALL, and make decisions about which information to access and when to access (i.e. harmonise information).
   - We hypothesise that having more information will decrease parenting stress and increase parenting self-efficacy to fulfil their information-giving role.
   - In the area of genetic conditions researchers have determined that information given to parents about their child’s illness, especially
surrounding morbidities, risks, and implications for their future, most helped them deal with their feelings of panic, fear and anxiety (Metcalfe et al 2008).

2. To help parents translate complex information about ALL to their children by providing lay explanations of treatment and related issues in varied forms.
   - We hypothesise that the varied formats will contribute to decreasing parenting stress and increasing parenting self-efficacy, which in turn will increase parents’ satisfaction with their child’s health care.
   - In order for parents to feel efficacious, they must have: the knowledge of appropriate child care responses; confidence in their own abilities to carry out those tasks; and the beliefs that children will respond to their tasks and family members and friends will be supportive of their efforts (Coleman and Karraker 1997).

3. To encourage families to have discussions and ask health professionals questions.
   - We hypothesise that this may create more positive attitudes to relationships between parents and children.
   - Parents in other studies report unintentionally neglecting to share information with the affected children and their unaffected siblings. They only shared information they believed their child needed to know and could handle at the time. They also found that openness in discussions did not lessen the psychological and emotional pain of living with the illness, but communication empowered families and enabled individuals to discuss concerns as they arose—children were reported to have become more emotionally and psychologically resilient (Metcalfe et al 2008).

4. To better equip children, through acquiring knowledge about ALL, to be active participants in their health care and decision-making during treatment.
   - We hypothesise that children who receive more information from their parents via the HELP information package will increase their knowledge about their illness and result in them becoming more involved in decision making during the first six months of treatment.
   - Children with cancer who were reminded before each clinic appointment about the purposes of a medical visit, and saw modelled interpersonal and communication skills via a video generally became more involved and satisfied with their roles. Physicians also more frequently addressed the child and provided care recommendations directly to the child (Lewis et al 1991).

6.2 Format of HELP
HELP was designed to function as an online, DVD, and hard copy tool. It will be used to accompany the leaflets on medicines and procedures, children’s books, and shared care booklets that are already given out to families in standard care. It will be composed of a number of a number of components that will work together to provide
information to parents in a variety of formats using written and visual descriptions (Figure 6). For example, a number of short summaries will be included across a child’s treatment phases that feature basic level information and further information on medical and non-medical issues that parents have reported as important to discuss. Within online summaries, there will be links to a glossary of key terms and videos of parents and professionals providing basic information about diagnosis and treatment-related issues. Summaries will also feature other Internet-based tools for parents and children such as games, books, and diagrams. These tools are hosted on many charity websites. The tool will include a discussion board for parents to interact online, as well as a private messaging service. Lastly, printable discussion guides will be available for each treatment phase for parents to take with them to clinic appointments or to use at home when visited by professionals.

In speaking with families about the format of the intervention during our final interviews, we asked them about their preferences of receiving information. Many parents preferred for their children to have books similar to Joe has Leukaemia, a book given to nearly all families when starting treatment. Parents suggested online information for themselves and extended family early on in treatment. They further suggested DVDs as a family resource that could be used in the privacy of their living rooms and then follow up with a family discussion at home. A DVD could also be lent out to extended family members with questions about ALL. To illustrate parents’ preferences of the format of HELP, two quotes are displayed below:
“I don’t know how many hours we spend just looking things up. So to have one website, particularly that was endorsed by [the principal treatment centre], I do think would be good – that tells you everything that you need to know. So rather than being told, ‘Don’t look at a website’ they could have said, ‘Well look, you know, there is a website, and you can look at this whenever you feel ready to’. I think that would be really good.”

(P1.03&05.I4).

“If it is in a DVD that is better because we have others in our family, some of them, they can speak English and some of them they cannot. But if they see the DVD, they can come to know more about something. And you can sit back together and you can see everything, yes, rather than read.” (P1.04.I4).

The entire range of information provided by HELP will be available online, as nearly all families in the UK within the age range of the parents involved in the study have access to the Internet. Any information from the website that is able to be written to a DVD (i.e. all content except Internet-based links) will be offered to families in a DVD format so that they can access information even if they do not have Internet access or prefer this format. Furthermore, written leaflets will summarise key information at each treatment phase, and a separate leaflet will contain discussion guides for parents to bring to clinic appointments with health professionals. Parents will also be provided leaflets to help them guide through the online and DVD portions of HELP.

While most parents in our final interviews agreed that an information package would have been helpful, other parents were happy with how standard information had been provided to them. They emphasised that an information package would not be useful initially, but may be useful in later treatment:

“I can’t think how you can prepare someone for something like this, if you know what I mean. I don’t think you can kind of give pre-packed information packs about it and say, ‘Here you go, here’s an information pack.’ I mean they give you the shared care booklet, which has a lot of things in it. I mean now I understand it. At the time I was like, ‘Wow, what’s this?’ But now you realise that actually it’s quite an important document and we have to keep hold of it” (P1.02.I4).

Parents’ comments highlighted the fact that information packages given out to families in standard care are not well explained, and in order for families to benefit from having access to HELP it is necessary to ensure it is well explained. It is therefore important for the research team to develop a thoughtful and systematic delivery method for HELP, whereby each key component is described in detail and accessed with parents present. It is then important that the research team train health professionals delivering HELP to fully understand all of the key components available in the different formats. This will be undertaken once funding has been secured to evaluate HELP.
6.3 Interventions in children’s cancer care
In order to ensure HELP was grounded in research, the research team examined key features of communication interventions used with families undergoing treatment for children’s cancer care. We found that the most promising interventions during treatment appear to be those that are carefully timed and tailored to specific outcomes rather than those that rely on general outcomes. Kazak (2005) suggested interventions that build on strengths while mitigating symptoms for the broadest group of patients. Additionally, Piersol et al. (2008) made a number of suggestions to enhance communication directed towards health professionals, which we have included in various components of HELP, such as the discussion guides, as well as videos of health professionals, parents and other children providing advice. These included:

- allotting a significant amount of time to ensure complete understanding of the diagnosis, treatment options, and remission outcomes
- providing information about support groups for parents or siblings having similar experiences
- using stress and coping screening tests and referrals to psychologists if parents or children are above baseline stress levels
- providing tours of cancer treatment facility (e.g. where procedures will be done, locations of playrooms)
- facilitating meetings between families on the same ward
- introducing all people who will later be involved earlier than when their work will start (e.g. physiotherapist introducing self near diagnosis)
- providing information about social services available (e.g. where families can reside during treatment, restaurants near hospital, facilities for washing)
- providing outlets for children to play to decrease anxiety levels
- enhancing the communication between parents and health care providers during the diagnosis phase of leukaemia via an advocate being available and present to support and counsel parents after the diagnosis is given (Piersol et al 2008).

6.4 HELP online framework
In order to organise key findings from phase one data collection relevant to HELP, we used the Medical Research Council United Kingdom Acute Lymphoblastic Leukaemia (MRC UKALL) 2003/2011 clinical trial protocol as a timeline for the intervention. Each phase of treatment is represented as a window (e.g. consolidation, maintenance, etc.) that links to smaller windows of questions (e.g. What should I bring to stay in the hospital? How will family life change?) (Figure 7). When each smaller window is clicked on HELP displays a paragraph of basic concepts in the basic information section. It also displays a further information section that presents external links, diagrams, and links to other highly relevant issues within HELP. Both basic and further information sections link directly to a glossary of terms window hosted on the HELP website.
Figure 7: Framework of Information Provided in HELP
6.5 Issue windows
The windows featured in HELP were carefully selected and linked to a particular phase in treatment. In our interviews, parents created lists of issues that should have been discussed in the first few months of treatment. With the help of health professionals and parent advisors, we developed parents’ lists and advice to other parents into key issues. Some of these key issues are discussed in sections 6.5.1 through 6.5.8.

6.5.1 How to prepare your child for treatment
Parents suggested that they shared information with their children before painful procedures in order to ensure that their child did not lose trust in them. One mother said:

“I just felt it’s an obligation for me...to be straight with her because I don’t want her to lose trust in us. I don’t want for us to say ‘oh, don’t worry’ and then they come with a big needle.” (P1.03.I1)

During painful procedures children begged their parents to stop forcing them to undergo the treatment. Parents described this as a very emotionally difficult experience that they did not discuss after the fact. Similarly other parents suggested they had to explain side effects of treatment numerous times because their young children blamed them for the changes in their bodies. For example, one mother described her five-year-old son asking her to stop making his hair fall out. He asked her, “Can you let it grow a bit longer?” She described having to repeatedly explain to him that, “we don’t have control over what happens with the medicine” (P1.02.I2). Young children have magical thinking at young ages, hence it is important that parents make it clear which procedures and side effects to expect and create a plan on how to talk about children’s worries surrounding these issues.

Children aged 6-12 years report feeling worried, fearful of painful medical procedures and of the unknown, as well as socially and physically isolated in dealing with problematic aspects in relation to disease and treatment (Enskar et al 1997, Hedström et al 2003) (Table 3).
### Table 3: Physical and Emotional Symptoms by Age Group *(Hedström et al. 2003)*

<table>
<thead>
<tr>
<th>Age</th>
<th>Physical symptoms</th>
<th>Emotional symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-3 years</td>
<td>pain resulting from diagnostic procedures and treatments, nausea and pain resulting from disease</td>
<td>confinement, feeling of uneasiness, and worry before medical procedures</td>
</tr>
<tr>
<td>4-7 years</td>
<td>pain resulting from diagnostic procedures and treatments, fatigue, nausea</td>
<td>feeling of alienation, confinement, feeling of uneasiness, and worry before medical procedures</td>
</tr>
<tr>
<td>8-12 years</td>
<td>pain resulting from diagnostic procedures and treatments, nausea, and oral medication</td>
<td>worry about death, confinement, feeling of alienation</td>
</tr>
</tbody>
</table>

The research evidence suggests that children of all ages feel worry about medical procedures and also find the pain from diagnostic procedures and treatments very distressing, hence parents and carers should pay specific attention to ensuring these issues are addressed. We believe that by preparing parents to discuss these issues with their child and by teaching them techniques to help their child deal with worry and pain that this will decrease their child’s anxiety, and therefore their own anxiety. There is significant evidence that children and young people found it helpful when health professionals prepared them for invasive treatments by speaking directly to them and using understandable language *(Mitchell et al. 2006)*. Evidence from the published literature will be referenced in areas of the website to allow parents to seek out further information if desired.

**6.5.2 What is a clinical trial?**

A father of a child who was often unable to stay in hospital or even attend clinic appointments due to his job suggested he wanted broader information as soon as possible following his child’s diagnosis to be able to make a decision about taking part in the UKALL 2003 clinical trial. He also wanted information to refer back to general information time and time again. He suggested that an intervention had the role of,

“Laying out the treatment for a year or two year plan...I know we were sort of given plans for one month, but just explain a bit more about these intense blocks of treatment, when they are, what the maintenance period is after that. A little bit more about the clinical study as well. The clinical programme that we were a part of. A bit more information with that at the beginning because it would make it a little bit easier with the decision whether to be part of that or not because I know that was a little bit nervous for us as well.”

Other parents who acted as the primary carer for their child reported the importance of having the full two-to-three-year treatment protocol available to them immediately following diagnosis, but recognised that they did not take in all information provided to them at the outset.
"I think although I knew they did say it was a two year treatment, I think I might have liked to have had a fuller picture of what the treatment involved, because we were just given the first eight weeks, was it? And not even that. I remember when, when we were discharged and we were given the appointment list for coming in to Great Ormond Street. I was surprised at how many appointments there were." (P1.11&12.I3)

Parents have a number of concerns surrounding clinical trials, as the information provided is very confusing. The new UKALL 2011 clinical treatment protocol will include a number of randomisations including one on the first day of treatment. It is therefore very important that information about clinical trials be available immediately at diagnosis. The HELP website will feature parents describing their experiences of decision-making. Face-to-face discussions are sometimes facilitated between families by health professionals when big treatment decisions need to be made. In the absence of a family with whom to have a discussion, it may be a helpful substitute.

6.5.3 Body Image
We know that children worry about side effects associated with treatment, particularly the effects related to their body and temperament (Gibson et al 2010). It appeared during interviews that parents were just as concerned, if not more at times. Parents talked about struggling more than their child with changes in the child’s face and body. They discussed losing the child they knew and recognised it as something they would not talk about with their child. Some parents thought about having a child without hair and a round face and stomach and contemplated not having any photos taken during that time at the beginning of treatment. When parents were informed that changes in their child’s body would come and go throughout treatment, they were much more relaxed about accepting about new treatment phases. It is therefore important in this issue window to include information about body image for parents to help explain information to their children, as well as help parents cope with the changes in their child.

6.5.4 Eating and Nutrition
Parents suggested that they used their intuition and conducted their own research about what to feed their child, particularly during periods of neutropenia, as they felt they were not provided sufficient information. Furthermore, they felt as if they were provided strict guidelines in information leaflets, but staff provided more lenient guidelines. This caused parents to feel conflicted in what to feed their child, which was one of the areas in which parents felt as if they could play a large role in improving the health of their child. The nutrition section of the intervention provides prescriptive guidance, and discusses the conflicting guidance offered in the various linked resources.

6.5.5 What are blood counts? Why are they important?
Many parents, even those who were medically trained, and especially those parents who did not act as the primary carer of the child, wanted basic information from the initial diagnosis talk and the first week of treatment to be revisited in discussions with health professionals throughout treatment. One mother of a child off treatment still did
not understand the significance of blood counts, and parents of children on treatment for over ten months still did not understand the meaning of their child being ‘low risk’ versus ‘high risk’. She reported,

“I think I would have liked somebody to have gone much more thoroughly into the blood counts and why they matter and at what point you need to have chemo, what point you need to stop chemo. And like the neutrophils, the white blood cells and, you know, why they’re important. That would have been useful.”(P2.14)

6.5.6 Effects on siblings and extended family
Many parents felt worried about their ill child, particularly when in hospital. They also worried about their other children at home. Parents felt conflicted about neglecting their other children, but also felt as if they had no alternative other than to attend to their ill child first and then to their other children. This was in regard to meal preparation, provision of snacks or medicines, as well as general attention. In order to ensure the siblings of their ill child were not negatively affected by the treatment, some parents decided to send their child to stay with extended family members where they knew that the child would receive more attention than at home. There was little evidence that younger siblings knew why they were sent away and many parents did not discuss what was occurring at home and at hospital. Parents believed they were protecting their children who would be negatively impacted by seeing their sibling experiencing negative emotions whilst at the hospital. They also believed that younger children would not understand the issues; hence it was not necessary to discuss them. In this issue window, we have included information about how to explain to children, especially young children, about treatment, medicines, and side effects. Parents are provided a rationale as to why it is important to discuss these issues with siblings, and links to online storybooks about being a sibling to an ill child are given. As HELP is updated over time, we hope to add in videos of siblings talking about their experiences in hospital and at home.

6.5.7 Going back to school
Parents suggested there were no clear guidelines about when and how to transition their child back into school after starting treatment. They asked for clearer decision-making aids and more information at earlier time points about services, such as personal tutors, that were available to them only after their child had been absent from school for long periods of time. In HELP, there is detailed information about these issues, as well as contact information for a team at the hospital that can set up a return to school plan with the child’s teacher and school. We have linked to resources such as The Royal Marsden’s “Pupils with Cancer: A Guide for Teachers” (https://www.ssatrust.org.uk/Academies/sponsors/Documents/Pupils%20with%20cancer%20-%20a%20guide%20for%20teachers.pdf)

6.5.8 How to try to get life back to normal
Many parents within two-parent families had conflicting opinions about how to cope with treatment, and when life would return to normal. Other parents within the same family had similar opinions about maintaining life as normal, but conflicting opinions about how to document this period of their lives (e.g. write about it, take photos, etc.).
One father refused to take photos of the family whilst the child appeared ill because he did not want his child to feel connected to leukaemia and cancer in later life. Whereas, his partner wanted to take photos with her child and use the photos to revisit this time period as the child was older and had questions about treatment. We have provided information developed by a team of clinical psychologists, nurses, and social workers that recognises that families can cope in different ways.

6.6 Refining the tool
Input from professionals and parent’s has continued to shape and refine HELP. The development of HELP has, we accept, taken more time than we allowed in our original proposal. As mentioned, we were unsure what the intervention would look like, so it was difficult to be accurate with the time it would take to develop. But we are confident in the end result, and there is consensus in the research team that what has been created is much more than we anticipated. Our plan is to continue to build HELP through the coming months. This is beyond our funded period but researcher time has been allocated to this work. Medical illustration at GOSH are already contracted to undertake this work using current funding from this grant. Our intention is to include podcasts, video clips, and interviews with parents and professionals in the issue boxes. The development of HELP has captured the attention of professionals at GOSH who are supporting the work with their time and support with some costs. Clearly generic information, such as ‘what is a clinical trial’ can be uploaded as a podcast to be used by all families (see GOSH site for examples http://www.gosh.nhs.uk/gosh_families/information_sheets/video.html). HELP is a tool generated by parents for parents to use and to use with their child and other family members.

7 Implications

7.1 Implications of the study on research
The implications of this study on research is a continued building upon our theories and models (Gibson et al 2010) that contribute to the available knowledge on communication processes in children’s cancer care. The series of communication studies we have undertaken since 2004 are underpinned by the Medical Research Council (MRC) complex intervention evaluation framework (Craig et al 2008). Our next step in the developmental process is to evaluate the effectiveness of HELP using mixed methods (Blackwood et al 2010). From 2012 to 2015 we aim to implement a randomised controlled trial evaluation. We will be testing whether a comprehensive, interactive information package (HELP) can increase parents’ competence, confidence and knowledge in sharing information about ALL with their child, in comparison to parents receiving standard information during their child’s treatment. If the intervention is successful within this population, it is likely adaptations could be made to transfer information to families of children undergoing treatment for other types of cancer or other complex diseases.
7.2 Implications for clinical practice
Parents implicitly described their importance of their roles in communicating information, but emphasised the importance of health professionals’ roles in ensuring accurate and timely information is given to families. Most families want information about the diagnosis before it is certain; however this depends on individual families. It is the role of health professionals at local hospitals and primary treatment centres to provide information before a diagnosis, as well as throughout treatment. It appears there is a significant role for health professionals to maintain contact with families after children have started maintenance therapy.

There is further room for improvement for individual clinicians and trainers of clinicians. We hypothesised that the problems associated with the delivery of specialist information may be associated with training. Training defines how health professionals view their roles. However this training can be trumped by socialisation in the workplace, whereby good communication skills can be lost due to the way in which the multi disciplinary team works together. We also noticed a significant need for more training on health professional avoidance of issues that are difficult to explain or emotionally challenging to discuss. As our research team is based at the largest training university for children’s nurses in London, we will ensure that the findings are shared with all lecturers on staff, as well as with our colleagues at other universities.

8 Study Management and Timeline

The study was managed by a research team and advisory committee, which were both led by Professor Faith Gibson at Great Ormond Street Hospital for Children and London South Bank University.

8.1 Research Team
Members of the research team divided work into smaller analysis and report writing and dissemination teams. Four members of the research team undertook all grounded theory analysis and shared results with the advisory committee at two time points. Framework analysis is currently being used to analyse interview data with health professionals with contracts outside of the principal treatment centre. Two members of the research team are undertaking all analyses of this data. After the completion of these analyses, three members of the team will undertake further Foucauldian analysis. All members of the research team are listed on all publications, but four take the lead on writing and editing.

8.2 Advisory Committee
The advisory committee was composed of health professionals based at three Trusts across South England. Over the last two years, the advisory committee has met with the research team on three occasions to provide criticism and advice on recruitment, analysis methods, and results. They have also been involved in the development of the intervention in the latter half of the project, some joining the intervention development group.
8.3 Intervention Development Group
In the second phase of the study, an informal group of researchers, health professionals, parent advisors joined together to re-analyse data from phase one, review the current information available to families, as well as write content for the issue windows in HELP.

8.4 Timeline

<table>
<thead>
<tr>
<th>Stage of research</th>
<th>Dates conducted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment</td>
<td>February 2009 – March 2011</td>
</tr>
<tr>
<td>Data collection</td>
<td>June 2009 – April 2011</td>
</tr>
<tr>
<td>Data analysis</td>
<td>July 2009 – April 2011</td>
</tr>
<tr>
<td>Intervention development</td>
<td>July 2010 – April 2011</td>
</tr>
<tr>
<td>Dissemination</td>
<td>May 2010 – October 2012</td>
</tr>
</tbody>
</table>

8.4.1 Challenges to data collection and analysis that impacted the timeline
The research team had a number of setbacks recruiting participants for parent group one initially.

1. Recruitment of parents for parent group one took much longer than expected. The initial approval was given 5 February 2009 and data collection began on 30 June 2009. Between February and June 2009, there were few families within one month of diagnosis of ALL within the age range we were seeking.

2. It was additionally difficult to recruit parents to take part in interviews for group P2, as we were recruiting all of them via telephone, and it was very difficult to catch parents at home, and only some parents had provided mobile numbers.

3. The recruitment of health professionals for the external interviews was a lengthy process. The research team began seeking R&D approval on 19 August 2010 and continued until 3 March 2011. The R&D managers requested a number of documents and clarifications, and these bureaucratic issues prevented a smooth transition from the approval of the substantial amendment to the start of data collection.

4. The primary researcher on the project decreased her hours from four days to two days per week in October 2010, and continued to work 2 days per week until December 2010. In January 2011, this researcher reduced her hours again to one day per week and continued on phase one analysis. This reduction in hours was necessary to accommodate her 2nd MSc at London School of Hygiene and Tropical Medicine. A new primary researcher began in January 2011 and took on phase two work and data collection with the external health professionals. There was a time lag between the two primary researchers switching roles due to a lengthy recruitment process.

5. The intervention, HELP, is far larger and intricately detailed than we could have imagined at the outset of this research project. There have been significant developments since a researcher was brought on board in January 2011 to focus on its creation.
9 Dissemination strategy

9.1 Publications
The research team will produce a study results leaflet that will be sent out to the homes of all families who took part. Health professionals will also receive a study leaflet and a presentation of the results. The parent advisors on the team are also part of the Children’s Cancer and Leukaemia Group (CCLG); hence the research team will work on developing a publication of results in the CCLG magazine, 'Contact'. The two academic publications planned as a result of this work will be published in high impact social science journals. We aim to submit manuscripts to Social Science & Medicine by July 2011 and Qualitative Health Research by September 2011.

9.2 Presentations
The research team have presented at two conferences on methods and the intervention development process. These were the 2010 International RCN Nursing Research Conference, and the Royal College of Paediatrics and Child Health Annual Conference 2011.

These can be cited as:


We have intentions on presenting at two additional conferences to discuss the communication theory and the full intervention, including the 43rd (abstract submitted) and 44th Congress of the International Society of Paediatric Oncology (2011 and 2012).

10 Conclusion
This study adds to the mounting research evidence that there are significant communication roles for parents and health professionals in sharing information with children. Parents’ roles should be particularly recognised because of the inherent challenges associated with learning about a new diagnosis, coping with a new carer and communication roles, and then having the responsibility to ensure children and family are informed in the best way at the best time with little guidance on how to do this. There is a significant role for an intervention and we hope that our intervention, Harmonising Education about Leukaemia for Parents (HELP) will ensure that parents will feel better supported in their care-giving roles and children will be better informed about their disease, treatment and side effects in the immediate and future contexts.
11 References


