THE IMPACT OF CANCER ON A CHILD’S WORLD

The views of children aged 7 to 13 living with and beyond cancer
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1. DOCUMENT INFORMATION

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Target Audience
The National Cancer Survivorship Initiative

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For Study Evaluation

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2. EXECUTIVE SUMMARY

The care and support we offer children with cancer in the UK is among the best in the world, with survival rates at over 70%. With more children surviving it is important to understand the adverse effects of cancer and treatment. We can then make positive changes that will reduce, or even eliminate, the physical, emotional and social impact of cancer on children's lives.

Survivors of childhood cancer want to lead ordinary lives. To do that children need to be at home, or closer to home, be supported to attend school and be able to spend time with their friends.

Like all children, cancer survivors have the right to achieve their full potential. This encompasses educational achievement, social achievement and emotional stability. In summary, all children with cancer have the right to achieve the five Every Child Matters (ECM) outcomes, which are:

- Be healthy
- Stay safe
- Enjoy and achieve
- Make a positive contribution
- Achieve economic well-being

cancer have equal opportunities to achieve the five ECM outcomes. The work stream is clear that for services which seek to enable children and young people to achieve the ECM outcomes, guidance and policy must fully reflect the needs of cancer survivors.

There has been little reported direct consultation with children aged 7-13 years on their experience of living with and beyond cancer. This may be due to past consultations focusing mainly on parents’ views as well as the perceived complexity of consultation work with children. Recognising this lack of information about the expressed needs and wishes of young survivors, the NCSI commissioned CLIC Sargent to conduct the study.

Alongside the main consultation study, CLIC Sargent also wished to find out about the children’s perspectives on both the methodological approach and the participatory methods used during activity afternoons. This lead CLIC Sargent to commission an evaluation study of the activity workshops, led by the University of the West of England.

2.2 STUDY AIM

To develop a method for working with 7-13 year old cancer survivors to identify the key needs of this age group and how current provision may be developed and delivered to best meet these needs.

2.3 DEFINITION: CANCER SURVIVOR

There are several definitions of cancer survivorship. Children and young people have told CLIC Sargent they should be regarded as a survivor from day two, the day after diagnosis. This simple definition echoes the scope of survivorship described by the NCSI as being ‘anyone living following a cancer diagnosis. A survivor is therefore anyone ‘living with and beyond cancer’.

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1 CLIC Sargent is the UK’s leading children’s cancer charity
2 Department of Health, (2010), National Cancer Survivorship Initiative Vision
3 This definition was agreed at the National Survivors Conference 2008
4 Department of Health, (2010), National Cancer Survivorship Initiative Vision
2.4 STUDY APPROACH
Survivors aged 7 to 13 living in England were invited to tell CLIC Sargent about the impact of cancer on their world. The children were offered the option of giving their views in person at an activity afternoon or completing a postal activity pack.

The study has gathered rich quality narrative from six focus groups and the children’s postal activity packs, which combine written and illustrated contributions from children living with and beyond cancer.

The method used to consult children at the activity afternoons was independently evaluated by Coad (University of the West of England) and Carter (University of Central Lancashire). The findings are included in this report.

The information gathered from the activity afternoons and activity pack has been combined in the report to give a full picture of the needs of the group. If the statistical information reflects a specific method of enquiry rather than all participants, this will be noted in the text.

Where children’s quotations are used the name of the child has been changed to protect their anonymity. The child’s age and treatment information remain unchanged.

2.5 EVALUATION APPROACH
The aims of this study were to:

- Identify, evaluate and report any issues following each event which could potentially improve subsequent consultation exercises.

2.6 FINDINGS SUMMARY
Children have highlighted a number of intertwining issues that stem from their cancer diagnosis and treatment, the impact of which can be far reaching and affect many aspects of a child’s life.

The issues raised by children are encompassed within the six broad headings below. Some issues are relevant to more than one heading.

- The Effects of Cancer and Treatment
- School Life
- Friendships
- Home and Family Life
- Hospital
- Information and Public Awareness

2.6a EFFECTS OF CANCER AND TREATMENT
Many children are experiencing adverse effects as a result of their cancer diagnosis and treatment. These effects are physical, intellectual and emotional and can have great impact on not only a child’s health but also their education, social opportunities and friendships.

Children want to be able to do the same things as their friends and peers. They believe advice and support on maintaining fitness levels and leading a healthy lifestyle will help them to do that.

Tiredness and fatigue was commonly cited by children as having a negative effect on their ability to live their lives to the full. The physical impairments imposed on children by the adverse effects of cancer and treatment can limit social opportunities and ‘fun time’, causing social isolation; this in turn can exacerbate the emotional impact on the child.

Emotional issues such as fear of getting hurt and concerns about mortality were often reported, particularly in those who have experienced the
death of a friend. Other emotional issues such as lack of confidence and low self esteem were also prevalent, hair loss in particular having a significant impact on children's self esteem. Many children raised concern regarding the impact of their treatment on their intellectual development, particularly if it meant they had difficulty catching up and keeping up at school.

A full account of the issues raised by children about the physical, emotional and social effects of cancer and treatment can be found in section 8.1.

2.6b SCHOOL LIFE
Children made it clear that inclusion and active participation in school life are very important. They explained that the effect of their diagnosis and treatment on schooling is extensive; in fact, many reported prolonged absences from school.

These absences, combined with the physical and intellectual adverse effects mentioned in section 8.1, can result in reduced academic attainment, putting child survivors at a disadvantage compared with their peers.

Perhaps the most significant effect on school life is the impact on peer friendships; many children become estranged from friends during their treatment. Exclusion from physical education classes and active social games in the playground can also make children feel isolated from their peers.

Children said that being able to regularly attend school and receiving information on how to communicate with friends would potentially reduce social isolation.

A full account of the issues raised by children about the effects of cancer and treatment on school life can be found in section 8.2.

2.6c FRIENDSHIPS
As well as friendships developed at school, many children have friends they have made through social clubs or living locally. However, club membership and the ability to visit friend’s houses can be impaired by adverse effects and the inability of clubs and friends’ parents to provide appropriate support to meet the additional needs of a child living with cancer.

Friendships developed while at hospital are highly valued by children. Many children explained that they do not have the means to keep in touch with friends outside the hospital, and would welcome the opportunity to do so. Inevitably some children have experienced the death of a friend and this has impacted on their emotional wellbeing.

A full account of the issues raised by children about the effects of cancer and treatment on friendships can be found in section 8.3.

2.6d HOME AND FAMILY LIFE
Children value the support of their families highly. They appreciate the upheaval a cancer diagnosis causes to the entire family. Children acknowledged the disruption to family routine and spoke of their dissatisfaction at not being able to take part in usual family activities due to the adverse effects of treatment.

Some children struggle with their parents’ protective nature, wanting independence and to be treated like ‘a normal kid’. Disclosure can also be an issue, with some children wanting to be able to choose who is told about their diagnosis and treatment. Children also pointed out the emotional and social impact on siblings, suggesting more sibling support is needed.

A full account of the issues raised by children about the effects of cancer and treatment on home and family life can be found in section 8.4.

2.6e HOSPITAL
Many children have vivid memories of their treatment centre. The attitude of staff is particularly important to children, as it affects their willingness to attend hospital for treatment and out-patient clinics. Children would like all areas of the physical environment to
be bright, colourful and friendly; they also said that the availability of computer and gaming equipment is essential in the battle against boredom.

When discussing treatment, many children said that the opportunity to choose how medication is administered would reduce treatment-related anxiety. Food was a popular topic for discussion, with children questioning the quality and choice of hospital food. They also said that when not in hospital they would like access to round-the-clock support.

A full account of the issues raised by children in relation to the hospital environment and facilities, staff attitudes and treatment can be found in section 8.5.

2.6f INFORMATION AND PUBLIC AWARENESS

The limited communication pathways available to children can inhibit access to information, diminish their capacity to understand what is happening to them.

Children want information in accessible formats and would also like someone knowledgeable to talk to who can give them information and support on clinical and social issues. Children are passionate about the need for greater public awareness of cancer and treatment, with many wanting to champion the cause.

A full account of the information needs described by children and their views on public awareness can be found in section 8.6.

2.7 IMPROVEMENT SUMMARY

Providing children and their families with ongoing individualised support packages and information would help to improve the experience of children through their cancer journey. Integral to successful delivery of the support package is preparation for survivorship at the point of diagnosis through assessment and care planning, and provision of support through the identification of a named key worker or support coordinator.
3. METHODOLOGY

3.1 MODEL

The model was developed by a group of professionals working in the field of child health and research\(^5\). An appreciative inquiry (AI) model was used throughout the study to identify the needs of young cancer survivors. Fundamental to this approach is the desire to discover ‘what works well’ and ‘what could work better’\(^6,7\).

Children were invited to contribute through key questions relating to home and family life, school and friendships. They were also asked to express what was important to them and what others need to know about children living with and beyond cancer. Integral to the study was a commissioned project which evaluated whether the data produced was grounded in the children’s feelings about their experiences of taking part in the activity workshops.

3.2 INCLUSION AND CONSENT

To maximise inclusion, CLIC Sargent developed two ways in which children could participate in the study.

Invitations to participate were sent to parents and carers for their child’s consideration through several routes, including:

- Records of families supported by CLIC Sargent
- Hospital staff such as CLIC Sargent Social Workers and Late Effects Nurses
- The National Association of Childhood Cancer Organisations (NACCPO), who disseminated the information to their members.

Information about the study was provided in a child-friendly format for children, with more detailed information for parents and carers. The detailed information clearly stated that the words ‘cancer’ and ‘leukaemia’ would be used in the study, to enable them to make an informed decision on whether to discuss the invitation with their child.

Consent to participate and to use the children’s input for reporting purposes were also sought from both the child and the responsible adult.

3.3 ETHICAL APPROVAL

The study was reviewed by members of the National Cancer Survivorship Initiative and a steering group of professionals working in the field of childhood cancer\(^8\). Ethical approval for the activity afternoons and evaluation tools were given by the Faculty Ethics Committee at the University of the West of England.

CLIC Sargent also commissioned an evaluation of the model of enquiry used at the activity afternoons. The findings are included in section 9. The children and their families were clear that they were consenting to participate in both the consultation and evaluation elements of the workshop.

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5 Details of the Model Planning Group Membership can be found in Appendix A
7 Carter, B; Coad, J (2009) Community Children’s Nursing in England. An appreciative review of CCN’s in England. DH. Contact authors
8 Details of the Steering Group Membership can be found in Appendix B
4. **ACTIVITY AFTERNOONS**

The impact of cancer on a child’s world

We want to know how cancer affects a child’s schooling, friendships and family life.

Is your child aged 7 to 13 and undergoing or completed treatment for cancer or leukaemia? If so, she is invited to help us improve the care and support given to 7 to 13 year olds living with and beyond cancer by:

- Taking part in a children’s activity afternoon
- or by completing a children’s activity pack

For more information:
Call 0117 311 2637
Email childrensvoices@clicsargent.org.uk
www.clicsargent.org.uk

4.1 **AIM**

The aim of the activity afternoons was to gather information on children’s experiences of cancer and related needs through informal and fun opportunities to participate.

4.2 **INCLUSION**

The activity afternoons were held during October and November 2009 at six venues across England which were appropriate for children and arts-based activities. The events were held during the school holidays and weekends to allow children to attend without disrupting their education.

To ensure children with additional or complex support needs were able to participate, parents were given the opportunity to describe any support needs their child might have on the consent forms. CLIC Sargent staff then discussed these needs with the parents prior to the events and made support arrangements where appropriate to enable the child to participate.

The activity afternoons included lunch and ran from 12 noon to 3.30pm. Taking lunch prior to the start of the sessions gave children and their families the opportunity to become familiar with the environment and to get acquainted with staff and each other. Group drawing activities and balloons were provided during lunch to help the children come together. The drawings they produced were also used as part of the activity session.

Parents and carers were encouraged to allow their child to take part in the sessions unaccompanied, to enable them to give open and honest feedback. A seating area was provided for those who wanted to remain within the vicinity, while others chose to leave and collect their child at the end of the session.

After lunch and an introduction, the children were divided into two groups. Due to the varied age and treatment status of the children it was decided to split the children according to how they interacted with others during lunch, to get a balance of those who were confident and those who were quieter.

The activity afternoons gave children the opportunity to debate issues with others with experience of cancer. As parents were not present, this method of enquiry ensured that only the children’s voices were heard, giving them an opportunity for dialogue and in-depth discussion of relevant issues. There were a number of learning points which emerged through the process of delivering the activity afternoons. Details of the learning points can be found in section 10.1.

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9 See section 9.1 and 9.2 for the evaluation of the overall organisation, welcome and exits for the activity afternoons
4.3 EVALUATION METHOD

Fig.1. The fit between the activity afternoons and the evaluation study.\footnote{See Coad et al (2010) Full report of An appreciative evaluation of CLIC Sargent’s participation strategy for school aged children with cancer. Contact author.}

The evaluation team consisted of four experienced researchers. Between them, they attended all six workshops.

The evaluation study used two main methods:

4.4 OBSERVATION OF ALL ASPECTS OF THE CONSULTATION EVENT

Participant observation was carried out over five core periods within the workshops. The evaluation team took detailed narrative field-notes recording impressions, quotations, and details of the children whom they were observing. Participant observation was used as it allowed the evaluation team to respond to the children and facilitators where necessary, but not to become overtly involved in the running or processes of the consultation activities.

Observation period 1: The initial period of observation occurred from the point when the consultation facilitators arrived at the research venue and were briefed by the Lead Facilitator. The observation continued through the setting up of the venue and the discussions between the facilitators and their preparation for running the activities. The focus of observation shifted as the children started to arrive and the evaluation team observed all aspects of:

- The way in which the children were greeted, introduced to facilitators and informed about the workshop
- How the facilitators invited the children and parents’ to consent to take part in the study
- How the children were introduced to each other
- How the facilitators engaged children with the settling-in activities
- The organisation of the welcome, lunch and the families’ departure
- How the move from the lunch activities to the first activity was facilitated

Observation periods 2 and 4: The evaluation team observed both ‘formal’ consultation activities, referred to as Activity 1 and 2. The evaluation team observed the level of the children’s engagement with the activities and made extensive and detailed notes of the dialogue between the children and the facilitators.

Observation period 3: The evaluation team observed how the children and facilitators interacted at break time and made field notes.

Observation period 5: The evaluation team recorded their observations of the closing stages of the workshop. This involved the lead facilitator thanking the children for their participation in the workshops and giving out ‘goody bags’. The children were taken to meet their parents and shared their experiences of the workshop, showing their parents their art work and the letters they had created.
4.5 ARTS-BASED APPROACHES

Arts-based evaluation activities had been designed to be undertaken between the main consultation events. These created a ‘breathing space’ for the children, allowing them to reflect on something other than their cancer or leukaemia.

For an illustration of the fit between the consultation study and the evaluation study please refer to Figure 1.

4.6 ACTIVITY 1 METHOD SUMMARY: GOOD/BETTER

Activity 1 focused on home and family life, schools and friendships. The aim was to ease children into thinking and talking about themselves and their life.

The facilitator began by asking what was good about the children’s home and family life, school and friendships through open questions such as “Who has a brother or sister?” or “Who likes school?”

Children were asked to think about the questions and write or draw their thoughts on a pre prepared balloon shape before taking part in a group discussion. This ensured that each child’s individual thoughts were recognised, as often children will echo the thoughts of their peers in a group setting. However, children weren’t pressured into writing or drawing; they were given the option of holding their thoughts in their mind if they preferred.

They were then asked to think about whether, or how, their cancer diagnosis affected their home and family life, school and friendships, and how things might be improved. Throughout this process it was repeatedly made clear to the children that if cancer had no impact on this area of their life then it was important to say so.

Activity 1 was digitally voice-recorded and written on flip charts. The work was also photographed to ensure the group discussions and feedback was accurately recorded.

After Activity 1 the two groups were reunited and asked to attend an evaluation session run by impartial facilitators before taking a break.

See section 9.3 and 9.4 for the evaluation report on Activity 1.
4.7 EVALUATION METHOD SUMMARY – ACTIVITY 1

The research team undertook the evaluation with the children, and the facilitators from the activity workshops were not present. The children were shown an illustration of a giant graphic thermometer, with space around the outside for the researcher to add coloured post-it notes.

The children were given stars to place on the chart to show whether they liked the activity or not. They were asked to rate the activity using scores from 1 to 10 and to tell the research team what they most liked and what could have been better.

Each child was given the opportunity to have their say, using fun, interactive games such as ‘quickest to put their hand in the air’, or ‘run to me if you liked Activity 1’.

4.8 ACTIVITY 2 METHOD SUMMARY: DEAR MIKE

The aim of Activity 2 was to give children the chance to reflect on Activity 1 and explain in words and pictures what is important to them and what they believe others should know about whether or how cancer impacts on their life.

CLIC Sargent proposed that Activity 2 be directed to Professor Sir Michael Richards, the National Cancer Director for the Department of Health (DoH) in England and Wales. This would allow the children to address their thoughts to an individual and show them how their input could effect change. The proposal was welcomed, and so Activity 2 became a child’s message to Professor Sir Michael Richards.

It was explained in the introduction that Professor Richards is an important doctor, who for the past ten years has been working really hard with the Government and hospitals to make things better for children and adults with cancer, and that part of his job is to write the plans that will change things and make services better. The children grasped the importance of the Professor’s position, with many asking questions about his role.

After the introduction children were given a large worksheet with the words ‘Dear Mike, this is what’s important to me’ printed across the top. The children were seated around a large table and given access to felt pens, coloured paper, stickers and glue to create their letter or artwork. A digital camera and printer were also available for anyone who wanted to include a photograph.

No boundaries were set on the subject matter for this activity or the methods children could use to express their thoughts.

All the facilitators worked with the children during Activity 2, asking questions to clarify the meaning of the children’s words and pictures, and giving support to those who needed it.

A photographic record was taken of this exercise and the activity sheets were scanned to create a digital record of the event.
After Activity 2, the children put their work on the wall. They were then asked to attend an evaluation session run by impartial facilitators, before being thanked for their participation and reunited with their family.

See sections 9.5 and 9.6 for the evaluation report on Activity 2.

4.9 EVALUATION SUMMARY – ACTIVITY 2

Once consent was given, the research team used a digital camera to photograph the workshop, from the initial ice-breaking activities to the end of Activity 2. These photos were then uploaded to a computer to produce a slideshow. The children were shown the images and asked specific questions about the event overall and about what they did and did not enjoy about Activity 2. Each child was given the opportunity to have their say.

4.10 ACTIVITY AFTERNOON CLOSURE SUMMARY

After the final evaluation children were given the option of showing their work to their peers. Some children were extremely proud of the work they had produced during Activity 2 and were keen to do this, while others chose not to. Children were then asked if they were happy for their families to see their work and given the option of removing any items they did not want their family to see.

After explaining how important the children’s feedback is and how their views will help to shape services in the future, the lead facilitator left the room to speak to the families. The remaining staff gave each child a thank-you gift comprised of a canvas ‘goodie bag’ containing a large pack of assorted sweets, a colourful wrist band and a survivor teddy bear key ring.

Before inviting the families to come and look at the children’s work, the lead facilitator explained that the children were happy for them to see the work on display. The families were also informed that some of the work might reflect thoughts and feelings that they were unaware their child had, and that some of the work could be highly emotive. The families were then reunited with their children to view the work.

See section 9.1 and 9.2 for the evaluation of the overall organisation, welcome and departures at the activity afternoons.
5. CHILDREN’S ACTIVITY PACK

163 activity packs were requested by parents of children who were unable to attend an activity afternoon, and 41 completed packs were returned.

The aim of the activity pack was to remove barriers to participation in the study by enabling children who were unable or did not want to attend an event to contribute by another method.

The activity pack echoed the subject matter of the activity afternoons and was presented as an activity or work book. It encouraged children to use words or illustrations to express their thoughts and feelings on the impact of cancer on their world. The pack included a page of coloured stickers that children could cut out and use in their work, and suggested other materials they might like to use.

Children were given approximately 1 month to complete and return the workbook. All feedback from the activity packs has been analysed and included in the study report.

The activity packs enabled children to make a contribution in their own time and produced a lot of rich data, which has contributed greatly to the content and value of the study. However, a number of learning points emerged which are detailed in section 10.2.
6. FINDINGS ANALYSIS

The dataset consisted of the transcriptions of the children’s discussions, the list of drawings and writing produced during Activity 2, and the completed activity packs.

The transcripts, lists and flipcharts were independently analysed by CLIC Sargent staff. They were looking for those key themes and issues which were mentioned most consistently and which generated excitement, interest, concern and debate. They used qualitative thematic analysis, guided by an appreciation of quantitative aspects of the data, such as the number of times each issue was mentioned.
7. **PARTICIPANT DIVERSITY**

7.1 **NUMBER OF PARTICIPANTS**

Children and families were very supportive of the study, and a total of 90 children took part. 49 children attended an activity afternoon and 41 children returned a completed postal activity pack.

7.2 **AGE AND GENDER**

Participant gender balance was good, with 43 males and 47 females taking part in the study. There was also a good age spread across the 7 to 13 age group with a minimum of 7 and a maximum of 16 participants of any one age.

7.3 **TREATMENT STATUS & DIAGNOSIS**

The majority of participants had completed treatment. 19 children (21%) were still on treatment and 71 children (79%) were off treatment\(^\text{11}\). Participant diagnosis is categorised in the table below.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Haematological</td>
<td>55</td>
</tr>
<tr>
<td>Kidney &amp; Renal</td>
<td>7</td>
</tr>
<tr>
<td>Retinoblastoma</td>
<td>2</td>
</tr>
<tr>
<td>Liver</td>
<td>2</td>
</tr>
<tr>
<td>Brain and spinal</td>
<td>12</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
</tr>
<tr>
<td>Bone/soft tissue Sarcoma</td>
<td>8</td>
</tr>
</tbody>
</table>

7.4 **ETHNICITY:**

The majority of participants (76) were White British. Other ethnicities represented were Other White (3), Indian (3), Pakistani (3), Caribbean (3), and Black and white Caribbean (2). Participants of other ethnic origin were not represented.

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
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<tr>
<td>Indian</td>
<td>3</td>
</tr>
<tr>
<td>White Irish</td>
<td>0</td>
</tr>
<tr>
<td>Pakistani</td>
<td>3</td>
</tr>
<tr>
<td>Other white</td>
<td>3</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>0</td>
</tr>
<tr>
<td>White &amp; Black Caribbean</td>
<td>2</td>
</tr>
<tr>
<td>Other Asian</td>
<td>0</td>
</tr>
<tr>
<td>White &amp; Black African</td>
<td>0</td>
</tr>
<tr>
<td>Caribbean</td>
<td>3</td>
</tr>
<tr>
<td>White Asian</td>
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<tr>
<td>African</td>
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<td>Other black</td>
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</tr>
<tr>
<td>Chinese</td>
<td>0</td>
</tr>
<tr>
<td>Other ethnic group</td>
<td>0</td>
</tr>
</tbody>
</table>

\(^{11}\) ‘Off treatment’ has been defined as ‘no longer undergoing active therapy to treat cancer’. However, children who are ‘off treatment, may still be having therapy to treat side effects of the cancer, its treatment or other underlying conditions.
7.5 RELIGION
The data shows that the majority of participants (54) were Christian. This was closely followed by (30) participants who recorded having no religion. Other faiths represented were Hindu (2), Muslim (2), and other religions (2). Members of the Buddhist, Jewish and Sikh faiths were not represented.

<table>
<thead>
<tr>
<th>Religion</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Christian</td>
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<td>Muslim</td>
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<tr>
<td>Buddhist</td>
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<td>Sikh</td>
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<tr>
<td>Hindu</td>
<td>2</td>
</tr>
<tr>
<td>Other religion</td>
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</tr>
<tr>
<td>Jewish</td>
<td>0</td>
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<tr>
<td>No religion</td>
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8. **KEY FINDINGS**

8.1 **EFFECTS OF CANCER AND TREATMENT**

There is no ‘one size fits all’ therapy for treating cancer. A child’s individual treatment plan is based upon their condition, the stage of their illness and their general health.

The three main ways to treat cancer are surgery, chemotherapy and radiotherapy. Treatment may consist of a combination of these, intended to eradicate the cancer. However, each comes with its own potential risks and side effects that can have a significant impact on a child’s health and wellbeing during treatment.

After treatment some children will continue or begin to experience problems, which vary according to the type of cancer and its treatment. These problems can include issues with:

- Puberty and fertility
- Growth and physical development
- Intellectual development
- The heart, lungs and kidneys.

Some children may also develop secondary cancers.

The consequences of these adverse effects can be short term, but some will manifest in a long term or chronic condition that the child may have to manage through adolescence into adulthood.

The effects highlighted by children who participated in this study can be placed in three categories: Physical, Emotional and Social Impact.

“Even though I am in remission from my cancer I am still not well because of the side effects from the bone marrow transplant. It’s been nearly five years and I just want to get back to normal – if I can remember what life was like before I had leukaemia.”

Joe, age 11
2 years post treatment; Leukaemia
8.1a PHYSICAL IMPACT

“I would like more time to do fun things with my family like we used to. We used to go on our bikes for family rides for miles. We used to go for walks on the beach after school. There is nothing I can do to change this until I get better and I am not so tired.”

Joe, age 11
2 years post treatment; Leukaemia

Children primarily referred to the physical effects or impairments they now face in relation to how they impact on their school and family life. They were particularly concerned about things they can no longer do, or find difficult as a result of their illness and treatment.

Children also said that prolonged tiredness and fatigue is a significant barrier preventing them from participating in activities that interest them. This issue was highlighted by 17% of activity pack respondents who spoke of the impact tiredness and fatigue has on their quality of life.

Hair loss associated with Chemotherapy was commonly discussed, as many of the children had received or were undergoing this treatment. Children said this very visible side effect singled them out as different from their friends and peers. Children said the visible side effects associated with steroid treatment such as facial bloating and puffiness (Cushing’s syndrome) and increased appetite and weight gain can also have a negative impact on self esteem.

Some children require ongoing therapy to treat side effects of the cancer, its treatment or other underlying conditions. These children said that the routine of taking tablets, daily injections, application of creams, physiotherapy and maintaining a prosthesis can leave little time for fun. The issue of ‘fun time’ is compounded for those who go to bed early due to fatigue.

The importance of being active and leading a healthy lifestyle was frequently mentioned, with swimming being an activity missed by many children during treatment. Children said they found it difficult to maintain a healthy lifestyle and keep fit both during and after treatment, suggesting that advice and support in this area would be valued and could have a positive impact on their quality of life.

The connection these children have made between healthy lifestyle and improved quality of life echoes emerging evidence from studies with adult cancer survivors. This evidence suggests that leading a healthy lifestyle can have a positive influence on reducing the side effects of treatment, disease progression and incidence of relapse.12

Many children highlighted the impact on their intellectual ability and development, mainly in the context of their schooling. They expressed frustration and concern at having a poor memory and experiencing difficulties in organising their thoughts and understanding instructions since their treatment. Further accounts of the intellectual impact described by children can be found in section 8.2a.

Other issues raised by children relating to the physical effects of cancer and treatment include:

- Visible scaring
- Restricted growth
- Heart palpitations
- Reduced bone mineral density
- Specialist diets and weight gain
- Sensory and speech impairments
- Manual dexterity and mobility impairments
- Motor coordination and balance impairments
- Care of a prosthesis
- Reliance on specialist equipment, e.g. wheelchairs & hearing aids.

12 Department of Health, (2010), National Cancer Survivorship Initiative Vision
8.1b EMOTIONAL IMPACT

Children were very open about the emotional impact of their cancer diagnosis, making some extremely emotive statements through their artwork and writing.

Some children were clearly concerned that they were not given enough information about their chances of relapse, and said they would rather know the facts than fear the unknown. For some, this fear has arisen after experiencing the death of a friend due to cancer. These children expressed feelings of sadness and loss for their friend as well as concerns for their own mortality.

The possibility of getting hurt while playing and having to be hospitalised was often referred to, with several children stating that the cancer might return if they were injured. This sense of fragility and the misconception that cancer can develop through an injury or trauma seemed to be drawn from the protective attitudes of parents or carers.

Many children suffering adverse effects from their cancer or treatment talked about wanting to be ‘normal’, while those who were not experiencing adverse effects were happy to be ‘normal’ again. Anxiety about fitting in at school and academic attainment also featured high on the children’s list of concerns.

“I think that at night I will relapse and die. I’m scared that when I play I will badly hurt myself and will need to go to hospital. I don’t know what will happen to me, I hope I won’t die.”

Jodie, age 9
2 years post treatment; Leukaemia

“I can’t forget about it and I think about it every day. Sometimes I start to cry if I really think about it.”

Stacey, age 12
2 years post treatment; Leukaemia

“Well, my family is scared that my cancer might come back and they tell me that if it comes back I would not survive. My mum doesn’t like it when I play action games and throw myself about because she thinks if I knock myself the cancer might come back.”

Ben, age 9
6 years post treatment; Wilms Tumour

“Being treated with cancer has made me less independent, less confident and I don’t like trying or doing different things. It also affects my mum and dad as well because I need them more than usual.”

Lucy, age 13
2 years post treatment; Medulloblastoma

Other issues relating to the emotional impact of cancer and treatment which were raised by children include:

- Wanting emotional support
- Post traumatic stress
- Feeling powerless, isolated and sad
- Needle phobia
The impact of cancer on a child’s world
The views of children aged 7 to 13 living with and beyond cancer

8.1c SOCIAL IMPACT

“ I would love to be treated like any other normal person. I have had the all clear but people still treat me different. ”
Josh, age 12
2 year off treatment; Non Hodgkins Lymphoma

The combination of the physical and intellectual impairments and the emotional impact of a cancer diagnosis and treatment can greatly affect a child’s social world, limiting their social opportunities and experiences.

Children talked about not only being different in physical appearance and ability but also being treated differently by parents, teachers, friends and peers.

Children want to lead ordinary lives and to be treated like everyone else. A detailed account of the social impact of cancer described by children can be found within the School Life, Friendships, and Home and Family Life sections which follow.

8.2 SCHOOL LIFE

“I missed the first three years of school because of my cancer. The cancer has damaged how I think so I get things wrong at school. It’s like I banged my head and it didn’t get better for three years and I can’t think very well, that’s what it’s like.”
Alice, age 7
On treatment; Leukaemia

Children have said that after their physical health, disruption to their education is one of the most devastating impacts of cancer on their world.

Attending school is a huge part of a child’s life. It provides structure and stability, while enabling...
them to learn and develop social, emotional and behavioural skills which will help them achieve the five ECM outcomes and reach their full potential.

Children highlighted three categories in relation to their school life: Academic Achievement, School-based Friendships and Inclusion.

8.2a ACADEMIC ACHIEVEMENT

“I want more help to catch up with other children in our class. Not many people understand what I am talking about. I used to find school easy but now I have had cancer I find it very tricky."

Eleanor, age 8
2 years post treatment;
Metastatic medulloblastoma

Children have told us that the consequences of a disrupted education are: lower academic attainment; reduced opportunity for social experiences, leading to social isolation; and diminished emotional wellbeing.

They have highlighted school as being of major importance, expressing concern about their prolonged absence from school and/or the number of classes they missed while on treatment. Many are still regularly missing classes post treatment, due to hospital appointments and/or the adverse effects of cancer or treatment.

Children recognise that their absence from school impacts on their level of academic achievement and their potential future career prospects, putting them at a disadvantage compared to their peers. Many children struggle to keep up with lessons or catch up on their return to school. The most frequently used words by children at the activity afternoons in relation to school were catch up, keep up, more help and work hard.

They are troubled by intellectual issues such as poor memory, difficulties in processing information, problems organising their thoughts, and low concentration levels. Combined with the physical effects of fatigue, these difficulties create a barrier to learning for many children. Some said their skill levels had regressed since their treatment, and that they found core subjects like Maths and English far more difficult than they had previously.

Children receiving additional assistance at school spoke positively about having a support assistant, but often said they were still struggling to keep up with their peers.

Hospital schools and home tutors were also mentioned by children, but with few details. Some children said they found hospital school fun and helpful, while others said the hospital school didn’t help them keep up with their education and that they struggled on their return to school. They were also divided in their opinion of the usefulness of home tutors.

Those children who were able to catch up with their education were proud of their achievement. Some saw the extra effort required to accomplish this as a positive exercise, enabling them to appreciate the benefits of working hard and continuing to do so.
8.2b SCHOOL-BASED FRIENDSHIPS

Sometimes I feel left out from my school friends and I sometimes lack confidence with groups of my friends. I know I look different as I have lost my hair and I feel upset sometimes as I am unable to do some of the activities like P.E.

Louise, age 10
On treatment; Leukaemia

How to tell peers about cancer and its treatment was highlighted as a matter of importance by 18% of children who took part in an activity afternoon. Some children said they didn’t mind telling class mates themselves while others said they would prefer someone else to do this. In both cases the children said it was very important for all children to be given information about cancer.

Those with visible signs of their cancer treatment, such as hair loss, scarring, prosthesis or the use of specialist equipment and adaptations, said that their peers’ curiosity and frequent questions could be annoying and upsetting. Some children said they had been bullied because of their physical appearance, which made them feel sad and angry. When asked what was important to them, 11% of children at the Activity Afternoons mentioned their experience of being bullied.

See section 8.3 for children’s views on the impact of cancer and treatment on friendships outside school.

8.2c INCLUSION

At play time my friends are either running, playing football or something energetic.

Adam, age 10
On treatment; Leukaemia

Children expressed dissatisfaction with their low fitness levels both during and after treatment. They said that their restricted ability to take part in active social games and keep up with their peers during break times was a cause for concern.

Around 19% of activity pack respondents raised the issue of inclusion in physical education classes; in fact, some children were completely excluded. Children saw their inability to join in with games and active classes as another factor that identified them as different from their peers.

For some children, adult intervention in the process of making friends at school has alienated them...
even further from their peers. An example used by several children was the use of a ‘buddy bench’ at school, where a child waits on the buddy bench until a ‘friend’ asks them to play. While well meaning, this process can cause children to feel anxious and isolated if no one invites them to play.

Children taking medication during the school day said that this routine sometimes disrupted their lessons, as well as using up valuable ‘fun time’ during break and lunch.

Attending after school clubs could be difficult due to tiredness. In fact, some children were unable to access these clubs at all because of their additional support needs.

Some children saw the move from primary to secondary school as a fresh start, free from the stigma of cancer, while others felt relevant information about their support needs had not been passed on.

Some children felt that teachers lacked awareness of their support needs, and did not consider or allow for their visual or hearing impairments in the classroom.

8.3 FRIENDSHIPS

“I really liked all my friends and it’s quite upsetting that they don’t talk to me or contact me.”
Stacey, age 12
2 years post treatment; Leukaemia

“I made loads of friends there but I wish I could see them again.”
Kirsty, age 11
7 years post treatment; Wilms Tumour

Children have highlighted three specific friendship groups: school-based peer friendships, social groups, and hospital-based friendships.

The impact of cancer on social opportunities and friendships is undoubtedly one of the most significant issues for children. For many this is unquestionably linked to disruptions in their education and ability to attend school. Issues raised by children around school-based friendships are explained in section 8.2b.

8.3a SOCIAL GROUPS
Children also talked about friendships made through groups such as Brownies, Cubs and sports clubs. Many children on treatment or needing support for adverse effects said it is difficult to maintain friendships developed through social clubs. This is often because the children can no longer attend the club due to the physical effects of treatment, such as fatigue, or because the club is unable to provide the support they need to attend.

8.3b HOSPITAL-BASED FRIENDSHIPS

Children highly value friendships developed in hospital during treatment, because of shared experiences and a common understanding of the physical and emotional effects of cancer. Children said they missed friends they made at the hospital and expressed a wish to maintain these friendships after treatment.

Some children said they had little or no opportunity to meet other children with
cancer due to their outpatient treatment; they would have liked the chance to do so.

Survival rates of children with cancer are currently over 70%, however, as highlighted in the emotional impact section, peer support networks developed within this group will inevitably lead to some children experiencing the death of a friend.

This kind of bereavement can have a significant effect on a child’s emotional wellbeing, with children not only mourning the loss of a friend but also questioning their own mortality. The fear of death can be a particular issue for those who have been diagnosed with the same cancer as a friend who has died.

8.4 HOME & FAMILY LIFE

Pets were often considered a significant part of the family by children, with many including them in their drawings and discussions about home and family life.

8.4a IMPACT ON THE FAMILY

"My family are very important as they had to go though it all as well with me, like they all had the cancer with me."  
Michael, age 9  
On treatment; Leukaemia

The most commonly used word by children at the activity afternoons in relation to home and family life was ‘important’. Children described the impact of cancer on their family, and spoke of how this affects their relationships with parents and siblings.

Home is the best place that kids can think of.

Sophie, age 13  
1 year post treatment; Retinoblastoma

Children are extremely thankful for the love and support of their family. Many say that the family’s collective experience of cancer has brought them closer together, but recognise that a cancer diagnosis affects the whole family, impacting on its emotional, social and economic stability.
Children talked about missing their family during inpatient treatment and the importance of keeping the family together. Several children also said that they would have liked provision for more than one parent to stay at the hospital during their treatment.

Children have expressed frustration at prolonged disruption to family routine and regret being unable to do the things they used to do as a family. They cited the immediate and long-term adverse effects of treatment as the main cause of disruptions to their family routine.

However, the children’s feedback from the activity afternoons suggests that for many the impact of cancer on the family lessened after the completion of active treatment. The data shows that 25% of children on treatment used the word ‘important’ in relation to family in Activity 2, compared to 4% of those who were off treatment.

See section 8.1 for children’s accounts of the adverse effects of cancer and treatment on physical, emotional and social wellbeing.

8.4b PARENTS

“It tends to come up a lot in conversation, especially when mum just meets someone she has to tell them about my life […] mum and dad always mention it, I hate it. They don’t understand – even if they say they do they don’t!”

Sian, age 13
1 year post treatment; Leukaemia

Many children said their parents worry about them more than they did before their diagnosis. Children appreciate that their parents want to protect them, but some feel their parents’ anxiety has made them overprotective, so that they stifle the child’s freedom. Children also mentioned lack of privacy and control as issues; some children became frustrated because their parents would divulge information about their illness and experiences without consulting them.

Parents’ anxiety about relapse could inhibit childrens’ social experiences, with many children saying that parents don’t like them playing active games in case they get hurt.

Some children acknowledged the financial pressures placed on families by their illness. For example, some mentioned that a parent had given up work to care for them, or specifically mentioned the strain of meeting inflated travel insurance costs.
8.4c SIBLINGS

Children spoke of the emotional and social impact on their siblings. Some claimed that their siblings were often nicer to them than they had been before their diagnosis and talked of siblings being sad when they had to go into hospital for treatment.

Children said that when the focus of the family routine revolves around the ‘sick’ child and their treatment, it can cause some friction and rivalry between siblings. Some siblings can then become upset and angry because of the effect their brother or sister’s illness has on their life.

Other children, who had become used to enjoying their parents’ full attention during treatment, discussed feeling out of favour once their treatment was over and they had to share their parents’ attention once again.

Children said their diagnosis had also affected their siblings’ life outside the family, in areas such as friendships, and suggested that siblings should receive more support.

8.5 HOSPITAL

Children were not asked specific questions about hospital and their treatment. Instead, the study questions were constructed to allow children to focus on how their diagnosis and treatment currently impacted on their life. This allowed those who wished to talk about treatment procedures and where they took place to do so, but did not lead children who had completed treatment to focus on past experiences and memories linked to their diagnosis.

Children spoke of their current links with the hospital and their treatment. Some reflected on past experiences compared with the present. Some who now have little or no contact with the hospital chose to highlight their positive and negative experiences while at hospital.

The children’s views and comments have been categorised under the following three headings: Staff Attitudes, Environment and Facilities, and Treatment.
8.5a  STAFF ATTITUDES

“How nice the doctors are makes you feel better about being in hospital.”

Sophie, age 12
10 years post treatment; Rhabdomyosarcoma

The importance of positive staff attitudes cannot be underestimated. Children were very clear that these attitudes could greatly affect their experience at hospital. Nice, friendly and helpful staff made them feel better about being in hospital and had an impact on their feelings when they were at home preparing to return.

Some children expressed great appreciation and respect for their doctors and nurses, naming them specifically in their artwork and drawings to thank them for the help they had received.

“How doctors, nurses, consultants, social workers are just like family to me.”

Amy, age 12
On Treatment; Leukaemia

8.5b  ENVIRONMENT AND FACILITIES

Children said that having a bright, welcoming and friendly environment with lots to do is important when in hospital. This should apply to all areas accessed by children, including inpatient areas, outpatient areas and doctors’ offices.

Issues around space and privacy were raised, and the children said they would like bigger rooms. One child specifically highlighted the difficulties of sharing a toilet with several children experiencing side effects of treatment.

Boredom and the importance of having fun while at hospital were highlighted by a number of children in reference to both inpatient and outpatient stays. Children said they enjoy using computers and games consoles and these should be made more available. Children also said that it’s important to have time to play with parents and that they would like more group activities and games on the wards.

Several children initiated conversations about hospital food at the activity afternoons, with many questioning the choice and quality of food available. Some children said they refused to eat hospital food and that their parents had to bring in home cooked food or purchase meals elsewhere.
8.5c  TREATMENT

Children said that they want their treatment closer to home and that it is important to have access to round-the-clock medical support. Several children highlighted the value of the support they received from their community nurse. Others who did not receive this service said they would like to have done so.

This echoes the findings of CLIC Sargent’s More Than My Illness report, which recommends a model of quality community-based services for children with cancer and their families.\(^{13}\)

Understandably, children said they disliked having treatment. They wanted it to be kept as short as possible with reduced side effects. They would also like to be given a choice of how medication is administered and expressed the belief that this would reduce treatment-related anxiety.

A number of children said they disliked being on a drip. One child said that something as simple as having the correct length line would hugely improve their quality of life while on a drip.

Other children disliked attending regular check-up appointments at the hospital and said it had taken a long time to obtain specialist equipment such as a wheelchair.

8.6  INFORMATION AND PUBLIC AWARENESS

The need for independence and the concept of power and empowerment are key factors in relation to information and public awareness. Children highlighted two areas where there is room for improvement: the need for information and support for child survivors on clinical and social matters, and the need to raise cancer awareness among the public.

Children said they want some control over their own lives; the right information can enable them to make informed decisions about their future. Children also want to use their experiences of cancer to help others, partly as a way of saying thank you for the support they had received.

8.6a  INFORMATION FOR CHILD SURVIVORS

Children spoke of the limited availability of information for child survivors. This is partly due to the narrow communication pathways available to children. Their two main sources of information were parents and doctors, but parents didn’t always have the answers and children were often too embarrassed to ask doctors certain questions.

Some children at the activity afternoons appeared somewhat lost when talking about information, having no idea where to get help beyond their parents. Several said they didn’t want to worry their parents. Instead, they would like access to someone knowledgeable who would listen to them, answer clinical questions and support them with social issues arising from their cancer and treatment.

\(^{13}\) CLIC Sargent, (2009), More Than My Illness
Children also said that they would like to be informed of what is happening during treatment; for example, how long an inpatient stay might be. They would prefer to receive information in accessible formats, such as workshops for newly diagnosed children and their families.

8.6b RAISING PUBLIC AWARENESS
Many children saw their knowledge and understanding of cancer and treatment as positive and spoke about the need for raising public awareness of cancer and treatment. Children believed there would be benefits in providing information to all children, with some children suggesting that cancer awareness be made part of the National Curriculum.

They spoke passionately about wanting to help make things better for others with cancer, and believed both telling their story and fundraising were important and a good way to make a positive difference. Those who had fundraised for cancer charities or raised awareness of cancer-related issues were proud of their achievement, while others asked how they could get involved.
9. STUDY EVALUATION

The evaluation’s findings are broken down into what worked well and what could work better in terms of:

- Overall organisation, welcome and departures
- Activity 1
- Activity 2

9.1 OVERALL ORGANISATION, WELCOME AND DEPARTURE: WHAT WORKED WELL?

Overall, the organisation of recruitment, invitations and posters was excellent. Those who expressed an interest in the consultation were promptly sent information sheets and their details were efficiently recorded.

The lead facilitator demonstrated excellent awareness and knowledge of all the children and families who were attending the workshops. If the children had any ‘special needs’ or particular requirements, they were addressed appropriately and sensitively.

All facilitators arrived well in advance of the children, were briefed effectively and were available to meet and greet the children and their families. On arrival the children and families were reassured that the facilitators were expecting them because they greeted each family by name.

Facilitators were prepared during a briefing session run on the day by the CLIC Sargent User Participation Manager, who also acted as lead facilitator. This was consistent across all workshops. The briefing included information about the background of the project, an in-depth description and explanation of each activity, and an explanation of what to expect.

Support facilitators had read the information in advance and during the briefing session they asked specific, often insightful questions about how the activities had worked in previous sessions. After the first event, the lead facilitator also provided examples of work produced from previous sessions to help the support facilitators understand what could be expected.

All the venues had ‘meet and greet’ areas, where parents and children would be welcomed to the event by the facilitators. One venue was a zoo, which the children really enjoyed.

Children wrote their own name badges and the facilitators used this time to build rapport with the children and their families. Parental and child consent and understanding of the purpose of the event was checked and all the families were invited to join in a welcome lunch which was set up prior to their arrival.

Some parents (on average one or two in each venue) chose to stay throughout the event and waited in comfy, welcoming chairs that were a little distance away from where the children took part in the workshop activities.

Activity rooms were booked in advance. A range of rooms were provided across the six workshop events. There was usually one large room as well as separate small activity rooms, some light and airy. All the rooms were prepared in advance and were designed for arts-based activities with a good range of tables and chairs. Disabled and first aid facilities were available in all venues.

Food and refreshments had been ordered in advance. Tea, coffee and juice was available for all children and families from the time they arrived. In general, lunch arrived promptly at 12 noon, and some venues provided additional snacks throughout the day.

In general, lunch was ‘tasty’ and a great success, with children talking animatedly about the food. They tended to prefer fairly simple food, explaining that they ‘liked crisps and sandwiches’ and ‘liked lunch, sausages and sandwiches’. The lead facilitator had been careful to ensure that the food would be ‘child friendly’, as many of the venues usually catered for more adult tastes. One of the children noted that
lunch was ‘not things I normally eat but I liked them’.

Interestingly, although the day had been planned with a balance between activities and breaks, one of the children explained that they would have liked ‘longer lunch and breaks’.

A range of children attended, including both boys and girls; either on or off treatment (with visible hair loss) for cancer or leukaemia, and with a wide range of ages and physical abilities.

Each event began with ice-breaker activities for the children, including balloons and colouring, which helped to settle them down. On arrival, some children started to play with the balloons, which helped to get them to interact and play successfully, and enabled the facilitators to establish rapport.

One colouring activity - a photocopied picture of child at school - was put out ready for children to colour in during the arrival period. This had a somewhat mixed response from the children, as some of them thought it ‘a bit boring’.

A second ice-breaking activity was used to facilitate more active participation. This included drawing an outline around one of the children on a large piece of paper and then placing it on the floor or wall for all the children to colour in. One of the children reported that they ‘liked being drawn around’ and the others also seemed to enjoy this activity. One of them felt reassured by their previous experience of ‘drawing around [my] body, I have done this before’.

While the ice-breaking activities took place, facilitators took time to build rapport with parents, who were then invited to let their children go and join in the main activities. At this stage, the parents appeared confident and relaxed about letting the children go and join in the main activities. At this stage, the parents appeared confident and relaxed about letting the children participate in the activities and most felt comfortable leaving their children. Some parents gave their children provided additional support and reassurance, assuring them that they would be close at hand if needed.

All but two children engaged in the workshop activities without their parents. Once everyone was seated, the facilitators and the evaluators introduced themselves and shared something about themself such as their favourite TV programme. The children told the evaluation team that they enjoyed this activity. One said ‘it did not feel like school’ - which was perceived to be a good thing.

Once the children were grouped together, the lead facilitator explained the purpose of the ice-breaker activities and what would happen to the work that the children produced. The ice-breaker activities and this introduction gave the facilitators an opportunity to get to know the children better. It also helped them group the children according to age, gender and personality.

On the whole, the general introduction worked very well, although a few children were quiet and appeared a bit reticent or puzzled. However, the lead facilitator checked they knew why they were at the workshop, and some children put their hands up to ask questions or answer her questions.

A reassuringly typical response when asked about their understanding was ‘I understood what I was supposed to be doing’. No children objected to staying and taking part in the activities.

The lead facilitator also stressed that there were no right or wrong answers to any of the questions they would be asked, and that she was interested in what was important to them. They were also reassured that they did not have to answer any questions if they chose not to, and that they could stop participating at any time they wished.

Children were divided into two groups for Activity 1, the size of which depended on attendance. The lead facilitator decided who would work together, and normally two facilitators worked together with each group. For Activity 2 all children and facilitators came together.

Overall the children felt that the activities were ‘fun’ and ‘brilliant’. Typically they said ‘I don’t usually like writing but today it was fun’ and ‘yes I think it was worth it’.
Some children commented that they preferred drawing and talking alongside one another, whilst for some children talking outside their family about their cancer or leukaemia was a new experience: ‘I don’t normally talk about personal things’ and ‘it is good ‘cos it meant you don’t just keep it in your family, you can talk to other children too’.

The conclusion of the consultation workshop was handled very sensitively. Children were asked if they were happy to share their work with their parents and families and they all agreed. Parents returned to collect their children, and following a supportive talk with the lead facilitator about what the children had done they were invited to look at the children’s ‘work’.

The parents were warned that the children had sometimes been quite frank about their feelings and that this might be bit upsetting for them. Two parents did become visibly upset at seeing their child’s work but both said that it was a ‘good thing’ as it helped them understand what their children felt about cancer or leukaemia.

All the children were given ‘thank you’ goody-bags, which they seemed to appreciate immensely.

9.2 OVERALL ORGANISATION, WELCOME AND DEPARTURE: WHAT COULD WORK BETTER?

Each of the six workshops took place in a different venue, with new facilitators for each event, so the briefing session also included a period of getting to know each other.

The lead facilitator had to be very clear and informative when preparing the facilitators before each event. She undertook this by email and telephone as well as during the briefing session on the day.

Some facilitators were youth workers and social workers who knew some of the children attending the workshops. This may have helped settle these children more quickly, but it also meant that rapport had to be built with other families from a different baseline.

Facilitators’ skills and abilities were variable, with some more able to ensure that the activities were as much fun as possible whilst still gaining salient information. Others seemed to struggle with the facilitation role.

Some of the venues were more attractive to the children than others and their suitability varied across the six events. Some rooms were specifically suited for arts and crafts activities because they were spacious and had natural or good light, whilst others were more formal and dark.

Two of the venues were based in CLIC Sargent offices, which worked well on Saturday as they were quiet but caused distractions on weekdays, as deliveries and normal office work continued.

However, these venues benefited from the presence of designated CLIC Sargent reception staff, who were available to help welcome the families and check paperwork.

One aspect for consideration when organising such events is that often there is limited control over the quality and types of food provided.

The lead facilitator had many discussions with caterers at booking/prior to events and had given clear, consistent instructions about the food being child friendly. However, in some venues the food provided included more sophisticated sandwiches and delicate canapés! As one of the children explained, ‘the sandwiches were too fancy for me!’

The parents told the evaluation team that there was a good choice of hot and cold food, but some of the children did not feel the same. However, plenty of fruit, snacks and juice were generally available throughout the afternoon.

Two children reported that because the hot items arrived later than the rest of the food, and they had started the activities, they ‘sadly missed out on the chips’. Several told the evaluation team that they wanted more ‘normal food’ and not the ‘adult food’.
9.3 ACTIVITY 1: WHAT WORKED WELL?

The aim of Activity 1 was to find out whether having or having had cancer or leukaemia had an impact on the children’s home life, family, school and friends.

Children were generally divided into two groups. They were invited to use the balloon and book shapes provided to write or draw what was good about their home, families, school life and friends.

The children appreciated the activity’s structure and ‘liked [the] different cut-outs of paper balloons and books, it makes it nice and creative’ and ‘liked how it was set up with lots of paper and pens of different colours. Liked choice cos normally don’t get that’.

Children were then asked to talk about what they had written, while the facilitators recorded their comments on a flip chart. Overall the children ‘enjoyed activities’ and explained that there was ‘nothing bad – I liked everything’ and they ‘didn’t mind the activity at all’ and there was ‘nothing boring’.

In two different venues, two facilitators had clearly prepared for the workshop and showed the children pictures of their cats and funny stories that related to their pets. In both locations, the children told the evaluation team that they really liked this, and it was observed that the children talked more enthusiastically as a result.

Another facilitator used humour to discuss where people live, saying ‘does anyone live in a castle?’ These opening questions helped settle the children into the activity and allowed the focus to shift towards potentially more sensitive areas.

Overall the children talked positively about the chance of ‘talking to others with same thing, talking and drawing’. As one child explained ‘talking to others, not had chance to do that before’ and another explained they liked ‘sharing ideas with people who’ve been through the same and understand what you’re on about.’ One child appreciated ‘being asked questions on how school had changed because of cancer’.

However, talking was not always easy, and some of the children explained that they ‘liked it all but awkward talking about family, didn’t know what to say’ and that ‘talking about family, shy don’t really have many friends, don’t like talking about family in group’. The children liked the ‘fact that there were people that understood you’.

Children had a range of abilities and writing skills, which were accounted for during activities, but mostly notably by the more experienced facilitators. Not surprisingly, some children liked writing whilst others did not.

One child was clearly pleased to be able to use a new skill, as they stated they ‘liked that we had some time to write up stuff ‘cos have just started to like writing at school’. Another child told us ‘I could have done more writing cos I’m good at that and used to writing more than that’.
Some children did not like to talk whereas others were very chatty or found talking easier, such as one child who liked ‘talking because it’s not as hard as writing - it’s fun’.

However, some of the children still found the activity challenging: ‘I didn’t like having to think about the past because it was hard to remember – not upsetting but hard to remember’. One of the children explained ‘I least liked thinking’.

Some children felt a bit let down by the fact that the facilitators had not steered the discussion specifically to cancer and more challenging aspects of having cancer. Two of the children explained this: ‘I thought more things would happen like talking about things that would be wrong and how to solve them but I liked talking’ and ‘I could have talked more about cancer, I kept thinking whether we were going to do this but we didn’t’.

In some cases, the team observed a clear reluctance by a few children to write, draw and/or speak. As one child succinctly summed it up ‘I like the drawing; writing was the most rubbish!’ Some children told the team that they found the writing exercises made their hands hurt or they found it boring, ‘didn’t like writing’ and ‘preferred everything else’.

Sometimes participation reflected the children’s age, as younger children, i.e. those aged 7 or 8, were quieter and more prone to shyness, whilst older children aged 12-13 were generally more talkative. However, it is also true that some of the younger children were bright and bubbly and the vibrant soul of the group.

Children with learning difficulties were also observed to have some problems doing Activity 1. Facilitators dealt with this well on the whole and employed a range of strategies to let the children participate on their own terms.
9.5 ACTIVITY 2: WHAT WORKED WELL?

Generally, children really enjoyed this activity and overall they ‘preferred the second activity’ to the more static first activity. They enjoyed being together and the activity was seen to be fun and they ‘liked doing the drawing and letter.’ This activity was often the most animated and lively. The children quickly got involved with the activity and found a chair next to ‘friends’ from the ice-breaking activities or from Activity 1.

The boys tended to work with the boys and the girls worked with girls, which was especially noticeable with those children aged 10 years and above. However, there was plenty of cross-talk and exchange across the groups. Some of the older children were clearly establishing friendships with peers from their own age groups and the evaluation team witnessed contacts being exchanged on at least two occasions.

There were ample materials such as glue, coloured pens and ‘safe scissors’ provided to make their letter to Mike and they seemed to enjoy the stickers, cutting out and using glue. The children used drawing, text and other resources to create their letter. Again, colouring-in was a valued activity; ‘I liked the colouring best in this activity’.

The lead facilitator invited the children to have their photograph taken, and the digital print was then used to illustrate the letter. The children who opted to be photographed enjoyed seeing their image as part of their letter. All the final pieces of work were fixed on the walls. The children stood around the lead facilitator and appeared to enjoy sharing their letters.

One child who had said very little in Activity 1 began to furiously write all about his cancer and what ‘Mike’ could do for other ‘kids like me’. Another child wrote about the leukaemia even though her parents had told the lead facilitator that she really did not remember it. She did not appear at all upset and said again ‘I hope this helps other kids’.

Other comments included: ‘I enjoyed writing the letter to Dr Mike so he can change things and make it better for other people who have cancer’ and ‘he is a special doctor and it is good to put things our ideas down’.

Clearly, the age range and activities need to be flexible in a mixed range of children but overall this worked well. Facilitators also seemed to enjoy being with the children as a larger group and often were very enthusiastic and joined in with the letter writing!

9.6 ACTIVITY 2: WHAT COULD WORK BETTER?

The issue of writing a letter to Dr Mike Richards received a mixed response. Most of the children had little idea who he was. This bothered a few of them, but the majority appeared to be happy writing a letter to someone who might make a difference.

Some of the children who felt awkward about writing to someone they had never heard of, felt that writing to someone more well known in the media would be better. For example, one child said they should write to ‘Gary Lineker, the footballer, because his child had cancer and recovered’. Another child said it should be the Prime Minister ‘because he needs to know’.
Some of the younger children required more input from the facilitators to engage with this activity, possibly because they were less confident with their writing skills than the older children. When this occurred, the facilitators reminded them that artwork could be used to construct the letter.

Although there was a range of resources available, some children thought there could be a greater choice of art materials and one child said ‘I think the pens were boring’. Many of the children wanted ‘more drawing’ time but overall they preferred Activity 2 to Activity 1.
10. WHAT CAN BE DONE DIFFERENTLY?

10.1 ACTIVITY AFTERNOON
LEARNING POINTS

What could be done differently in the future?

Overall the evaluation demonstrated that the children felt that the activities were ‘fun’ and ‘brilliant’ but there are aspects that could be done differently for future workshops.

Length of activity: An hour per activity is too long. The activities need to be shorter in duration.

Social time: The importance of down-time and social time should not be underestimated. This needs to have a fun element and provide children with the chance to let off steam in some way. Playing with the balloons provided a suitable activity that was both safe and energetic.

Activities: Overall, although the activities were accessible to all the children, the older children could have potentially been stretched and challenged more if they had been in a more age/ability appropriate group.

10.1a ACTIVITY 1:
This activity felt quite formal and repetitive, and the facilitators tended to find it hard to support. It was quite a slow activity, and children who wanted to talk had to wait until the writing part of the activity had been completed. This seemed to stall the potential flow of ideas. Here are some suggestions for improving this activity in future events: The value of having a scribe was unclear, as the flip charts were not referred to during the session. These may not be required for future workshops unless records are needed for report writing purposes.

The time taken to help children understand what was expected from Activity 1 was time consuming (this seemed to reflect the degree to which the facilitators had really understood what was expected of them). The use of prompts such as photographs would potentially be beneficial and help the children participate more actively and enjoyably.

There were some challenges around talking about ‘families and home’, although the children talked more freely around ‘school and friends’. One option would be to initially ask who is in the child’s family before asking what is good about family life.

10.1b ACTIVITY 2:
This activity generally worked very well, but in future it might be useful to consider allowing the children greater choice in deciding who to write to/make a collage for. This would allow them to share their ideas with someone they can relate to. This could be a celebrity and/or sports personality. A wider range of materials is needed to facilitate choice if children wish to produce a collage.

Timing the co-ordinated finish of activities: This creates challenges. Facilitators need to have some activities available with which to engage the children if their group finishes early. Conducting an evaluation of the methods used reduced the time available to discuss issues relating to cancer.

Facilitator experience and expertise: People who are experienced group facilitators and comfortable with using arts-based activities are essential to ensuring the smooth running of workshops. It is very difficult to adequately prepare facilitators on the day of the event. Facilitator training could be enhanced by using a demonstration video.

Venues: Rooms need to be child friendly, have plenty of light and be an appropriate size.

Group dynamics: Group size does influence dynamics, but then so does the age range and mix of abilities and needs. The wider the range, the greater the challenge to ensure that everyone can join in and/or enjoy the same things. Older
children who could write quickly and easily were often held back by younger children who wrote more slowly, although this difference was less obvious when the children were talking together.

10.2 ACTIVITY PACK LEARNING POINTS

What could be done differently in the future?

10.2a LINES OF QUESTIONING:

The depth of answers that the respondents provided were sometimes limited due to the open-ended questions used. More specific questions could be asked in future studies, now that the issues for this age group have been identified.

10.2b SUBJECT MATTER:

The subject matter might influence the children's willingness and ability to answer questions for the reasons shown below. These points should be considered in future work with this age group:

- Sensitive subject matter may affect children's willingness to acknowledge the issues
- Children may not know how to express the true impact of cancer on their life
- Children may feel it's disloyal to give information on issues around come and family life.

10.2c LITERACY:

Children's literacy is definitely a factor in their ability to communicate their views through this study method.

Children with limited literacy skills may need the support of parents to complete the pack. This may compromise some of the children's answers, as they may not want to mention things that would upset their parents.

It was stated in some returned packs that the child was unable to write due to the adverse effects of their cancer or treatment. In these cases parents completed the pack on the child's behalf. In one or two cases it was suspected that the contributions were not the words of a child, so this information was not included.
11. CONCLUSION

11.1 STUDY METHOD – ACTIVITY AFTERNOONS

Undertaking an evaluation alongside the activity afternoons was an innovative model and gave added value to this project. The evaluation highlighted that school-aged children had clear views both about their experiences of contributing to research and the sorts of activities they enjoy participating in.

The children generally preferred talking to writing and more active engagement to more passive involvement. They took their role as participants seriously and clearly wanted to contribute their ideas as they wanted to make things better for other children and families.

The atmosphere of and activities used within the workshops appeared to create a safe and stimulating environment in which the children were able to share their experiences about the impact that cancer and leukemia had on their lives. The findings were illuminating and very positive overall.

CLIC Sargent believes that the study models used for the consultation worked well in gathering the views of children. Drawing on this, and by addressing the learning points highlighted in the report, a strong toolkit for future consultations with children can be developed.

11.2 IMPROVING THE SURVIVORSHIP EXPERIENCE FOR CHILDREN

Cancer and treatment has a marked impact on many survivors of childhood cancer in both the short and long-term.

Children have told CLIC Sargent that they recognise cancer has changed their lives, limiting some opportunities which would be considered the norm for children of their age.

Children said that where possible they have adjusted to accommodate the impairments caused by their illness and treatment so that they can get on with life. Many feel optimistic and confident they will achieve their aspirations for the future.

Despite this optimism, inevitably the negative impact of a cancer diagnosis often leads to children having additional support needs, which for some are not being met.

It was clear from the views expressed by children that for many of them joint working and planning across medical, education and social care services had at times been poor. This had resulted in an uncoordinated approach to their support. The result was that children missed out and fell behind at school, struggled to maintain friendships and found it difficult to be part of wider social groups and networks.

The issues raised by children in this report describe the challenges they face in achieving what they want from life. Children living with and beyond cancer need timely and appropriate support to enable them to meet these challenges and accomplish educational achievement, social achievement and emotional stability. In doing so children will be allowed to realise the ECM outcomes and reach their full potential.

Providing children and their families with ongoing personalised support packages and information will help to improve the experience of children throughout their cancer journey.

The following actions are integral to the successful delivery of a personalised support package for children living with and beyond cancer and their families:

- All children and their families participate in developing a personal assessment and care plan at the point of diagnosis to include clinical, emotional, social, and practical support
A named key worker or support coordinator is appointed to lead and monitor the delivery of the care plan from the start of the child’s treatment through to long-term care.

As part of a personalised assessment and care plan, the following areas highlighted by children need to be considered:

**Be Healthy**
- Appropriate information and support is available on how children can maintain fitness levels and live a healthy lifestyle.
- Information on cancer and treatment is available for children and families to enable them to make informed decisions.
- The child’s family supports their wish to lead an active and healthy lifestyle.
- Children are included in active games and Physical Education classes at school.
- Children are encouraged to continue attending social groups.

**Stay Safe**
- The whole family are offered support.
- Children feel safe in their surroundings.
- Care professionals are child friendly, and have positive attitudes and working practices.
- The hospital and other care environments receiving children are bright and welcoming.

**Enjoy & Achieve**
- Children are supported to help them maintain school attendance.
- Children receive academic support in school.
- Children are supported to help them maintain academic progress whilst away from school.
- Children are supported to maintain friendships through school and other peer social groups outside school.
- Children are provided with treatment at home or close to home.

**Make a Positive Contribution**
- Children’s ability to make a positive contribution is recognised.
- Organisations listen to the views of children and act on what they’ve heard.
- Children are actively involved in making decisions that affect them.
- Children are able to participate in developing new information and services which aim to support them.

**Achieve Economic Wellbeing**
- Academic, social and emotional support for children is available from diagnosis, to allow the child to reach their full potential in the long term.

*Please take all this information into account and do good with it.*
# APPENDIX A: MODEL PLANNING GROUP MEMBERSHIP

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Place of Work</th>
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<tbody>
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<tr>
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<tr>
<td>Andrew Cooper</td>
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<tr>
<td>Lesley Nicol</td>
<td>Social Work Team Leader</td>
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</tr>
<tr>
<td>Dr Jane Coad</td>
<td>Senior Research Fellow</td>
<td>University of West England</td>
</tr>
<tr>
<td>Professor Bernie Carter</td>
<td>Professor of Children’s Nursing</td>
<td>University of Central Lancashire</td>
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## APPENDIX B: STEERING GROUP MEMBERSHIP

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<tr>
<td>Dara de Burca</td>
<td>Director of Services</td>
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<tr>
<td>Lydia Morgan</td>
<td>PA to Director of Services</td>
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<td>Fay Scullion</td>
<td>Senior Development Manager</td>
<td>Macmillan</td>
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<tr>
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<td>Great Ormond Street Hospital</td>
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<td>Dr Helen Jenkinson</td>
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<td>The Christie NHS Foundation Trust</td>
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<td>Leila Barron</td>
<td>Area Manager</td>
<td>Action for Children</td>
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<td>Tanya Urquhart</td>
<td>Macmillan CNS Long Term Follow Up/ Late Effects</td>
<td>Sheffield Children's NHS Foundation Trust</td>
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## APPENDIX C: PROJECT TEAM MEMBERSHIP

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<td>Bridget Matthews</td>
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APPENDIX D: RESEARCH TEAM MEMBERSHIP

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</tbody>
</table>
APPENDIX E: REFERENCES:

- Department of Health, (2010), National Cancer Survivorship Initiative Vision. DoH
- Every Child Matters: www.everychildmatters.gov.uk
THE IMPACT OF CANCER ON A CHILD’S WORLD

The views of children aged 7 to 13 living with and beyond cancer

CLIC Sargent
2010

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