DEVELOPING ALTERNATIVE MODELS OF FOLLOW-UP CARE IN YOUNG ADULT SURVIVORS OF CHILDHOOD CANCER

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LAY SUMMARY
Introduction
The number of childhood cancer survivors is increasing each year. The accepted view is that such patients should be followed up for life as a number of them may encounter problems years after their initial diagnosis due to the treatment received or problems associated with the cancer itself. This is placing demands on our ability to provide quality health care for this population. Added to this there is a lack of agreement amongst health care providers as to what form future long-term follow-up for childhood cancer survivors should take. Few studies have sought the views and opinions of young people. This study aimed to address this gap by finding out what young people who are survivors of childhood cancer would like from their follow-up service.

Methods
Twenty-six young people aged between 16-25 years of age and at least five years off treatment took part in this project. All were regular attenders at long-term follow-up clinics. Twenty-two of the young people participated in one-day workshops where creative research techniques were used (such as peer to peer interviews and mind-mapping) to gain their views. A further four young people took part in individual interviews where they were questioned about their views on long-term follow-up. We were also able to get the views of 14 cancer survivors who were clinic non-attenders through the use of a postal questionnaire.

Following on from these exercises 13 of the young people who were clinic attenders and who had taken part in either the workshops or interviews participated in a one day meeting where they worked alongside health care professionals to reach agreement on their ideal model of long-term follow-up care.

Results
1. Young people’s follow-up needs
From the data obtained from the workshops, interviews, and postal questionnaires, young people’s long-term follow-up needs were identified as belonging to one of five different categories:

a) A need for a positive relationship with health care professionals
It was important for young people to have a good relationship with those responsible for their care. Feeling remembered by doctors and having an interest taken in them was highly valued as was being on first name terms with their doctors and nurses.

b) Informational needs
To receive clear and concise information about their diagnosis, treatment, and possible long-term effects was a strong need of the young people questioned. The young people also wanted to be updated every time they went to clinic about new medical discoveries and advances and to have enough information so that they felt prepared if they encountered problems in the future. Young people also deemed having a patient held record or a summary sheet of the treatments received essential.

c) A need for communication
Being able to express their needs and concerns in a friendly and relaxed environment to someone who listens and takes their concerns seriously and who was in a position to provide advice was important for young people receiving follow-up care. Doctors
having time and being sensitive to the young person’s needs were critical to the young person’s perception of the quality of long-term follow-up services.

d) Parental involvement and need
Young people were concerned that their parents were not being given enough support and information to be able to understand the long-term consequences of cancer. The need for specialist support groups for parent of survivors was highlighted, as too was support for parents, which would enable the young people to gain independence and attend clinic alone, where preferred.

e) A need for health care professionals to have appropriate knowledge
Seeing a doctor with specialist knowledge about their disease and their individual case was a strong need spoken of by the young people. Having to repeat information in every consultation was viewed by the young people as having a negative effect on care and wasting valuable consultation time.

2. Young people’s views on the design and structure of long-term follow-up
Young people’s views on how long-term follow-up should be designed and structured were also identified. There was a strong preference to see a specialist doctor rather than a nurse or general practitioner as it was felt that neither had the specialist qualifications to attend to the young people’s follow up needs. Telephone, email or questionnaire follow-up was seen as no substitute for face-to-face communication due to its impersonal nature.

Young people in the workshops spoke of the desire to have a key worker to co-ordinate follow-up care. In the one-day meeting where the young people worked with health care professionals to reach agreement on models of follow-up care, the “key-worker” model was clearly preferred over other alternative models presented. These included a “nurse-led” model of care, a “levels of care” model influenced by disease and treatment and a “transfer v. transition” model. The key-worker model offered follow-up directed by the needs of the young person rather than the treatment they had received and was flexible in its approach to follow-up with a number of different follow-up options being available (e.g. face-to-face, telephone, email, GP, consultant).

Conclusion
This study provides important insights into what young people value and want from their long-term follow-up care, and how they feel that future service provision should be designed. By involving young adult survivors of childhood cancer in this type of research a voice has been given to what is in research terms, a silent, neglected and ever increasing population. The findings have implications for future practice and service provision. It is clear that informational, communication, and parental needs as well as the knowledge of doctors and young people’s relationships with them all need to be considered within the confines of the consultation. It is hoped that this study will have an important impact on how future follow-up care is designed for young people to make it more user friendly. This project would benefit from wide distribution both nationally and internationally as it offers important perspectives from the childhood cancer survivors’ perspective.
**EXECUTIVE SUMMARY**

**Introduction**

The number of childhood cancer survivors is increasing by 1200 each year (1). As a result, current service provision is gradually being put under strain with quality of care potentially compromised. Agreement and consistency in how future follow-up care should be designed and delivered is urgently needed, however health care professionals [HCPs] are yet to reach consensus. This study was undertaken to find out what young people who are receiving long-term follow-up for childhood cancer would like from their follow-up service. It also provided young people with the opportunity to work with HCPs to reach consensus on an alternative model of long-term follow-up.

**Background**

One in 1,000 young adults is a survivor of childhood cancer, and five-year post diagnosis survival rates for those with a childhood cancer diagnosis now exceed 70% (2). Today there are more than 15,000 adult survivors of childhood cancer in the United Kingdom [UK] compared to just 1,400 in 1971. These figures are comparable to survival rates in the United States and mainland Europe (2). Nevertheless despite such positive increases in survival rates it is estimated that approximately 60% of this population will have one or more treatment or disease related late effects with over 30% of these effects being classified as moderate or severe (3-6).

It is a long held view that all survivors of childhood cancer should be followed-up for life (7). Current methods of long-term follow-up are not consistent across cancer centres, and often influenced by the perspective of individual clinicians rather than specific guidelines for care. Taylor et al. (2004) highlight the disparity of long-term follow-up clinical practice in 17 of the 22 UKCCSG centres. It was found that while 96% of patients were followed-up to 5 years post treatment only 52% of clinicians follow-up all of their patients for life. Moreover, 45% of clinicians discharged some of their patients to other services (97% to their GP), 16% reportedly discharging all of their patients irrespective of tumour type to a GP or adult oncologist.

Wallace et al. (2001) propose that not all survivors of childhood cancer require the same level of long-term follow-up or intervention from teams responsible for their care. Wallace et al. (2001) suggest that the degree of follow-up a young person receives should be graded in relation to the treatment they have received. This is reflected in the recent NICE guidance, which state that: “there should be robust and appropriate surveillance of survivors, which will be intensive for those with significant anticipated adverse late effects of therapy and minimal for others who are likely to remain well” (p.78). The NICE guidance (2005) also highlight the need for separate late effects clinics and for age appropriate services for adult survivors of childhood cancer. The importance of key workers being assigned to each long-term follow-up patient and the development of individualised care plans are also emphasized in the guidelines.

Long-term follow-up care for childhood cancer survivors has been primarily driven by HCPs with sparse research having been undertaken into how young people view service provision. Yet since 2001 a number of policy documents and discussion papers have been produced highlighting the importance of the views of young people being heard (10-11).
The principle of incorporating users’ views in the development and evaluation of services is widely accepted (1, 12, 13.). Young people and their families must be reassured that continuing care will remain an important feature, throughout follow-up of children/young people, irrespective of the increasing numbers of survivors and resulting resource implications (14). This study aims to provide evidence to support alternative models of follow-up for childhood cancer survivors in which the dimensions of care valued and required by young people are central.

**Aims of the study**
The aims of this study were to provide answers to the following:

1) What dimensions of care are most valued by young people receiving long-term follow-up care?
2) What are the perceptions of young people and health care professionals regarding current approaches to long-term follow-up care?
3) What approach to long-term follow-up care would young people prefer to receive?
4) What are the views of both the young people and health care professionals on the proposed alternative models of care?

**Methods**
Twenty-six young people aged between 16-25 years of age and at least five years off treatment took part in this project. All were regular attenders at long-term follow-up clinics. Twenty-two of the young people participated in one-day workshops where creative research techniques were used (such as peer to peer interviews and mind-mapping) to gain their views. A further four young people took part in individual interviews where they were questioned about their views on long-term follow-up. The views of 14 young people who were clinic non-attenders were obtained through the use of a postal questionnaire. Data were analysed using thematic coding (15) by two researchers and the main themes were shared with young people, so that they had an opportunity to confirm the trustworthiness of the data. In addition to this 13 of the young people who were clinic attenders who had taken part in either the workshops or interviews participated in a one day consensus meeting where they worked alongside health care professionals to reach agreement on their ideal model of long-term follow-up care.

**Findings**

**1. Young people’s follow-up needs**
From the data obtained from the workshops, interviews, and postal questionnaires, young people’s long-term follow-up needs were identified as belonging to one of five different categories:

**f) A need for a positive relationship with health care professionals**
It was important for young people to have a good relationship with those responsible for their care. Feeling remembered by doctors and having an interest taken in them was highly valued as was being on first name terms with their doctors and nurses.

**g) Informational needs**
To receive clear and concise information about their diagnosis, treatment, and possible long-term effects was a strong need of the young people questioned. The young people also wanted to be updated every time they went to clinic about new medical discoveries and advances and to have enough information so that they felt
prepared if they encountered problems in the future. Young people also deemed having a patient held record or a summary sheet of the treatments received essential.

h) A need for communication
Being able to express their needs and concerns in a friendly and relaxed environment to someone who listens and takes their concerns seriously and who was in a position to provide advice was important for young people receiving follow-up care. Doctors having time and being sensitive to the young person’s needs were critical to the young person’s perception of the quality of long-term follow-up services.

i) Parental involvement and need
Young people were concerned that their parents were not being given enough support and information to be able to understand the long-term consequences of cancer. The need for specialist support groups for parent of survivors was highlighted, as too was support for parents, which would enable the young people to gain independence and attend clinic alone, where preferred.

j) A need for health care professionals to have appropriate knowledge
Seeing a doctor with specialist knowledge about their disease and their individual case was a strong need spoken of by the young people. Having to repeat information in every consultation was viewed by the young people as having a negative effect on care and wasting valuable consultation time.

2. Young people’s views on the design and structure of long-term follow-up
Young people’s views on how long-term follow-up should be designed and structured were also identified. There was a strong preference to see a specialist doctor rather than a nurse or general practitioner as it was felt that neither had the specialist qualifications to attend to the young people’s follow up needs. Telephone, email or questionnaire follow-up was seen as no substitute for face-to-face communication due to its impersonal nature.

Young people in the workshops spoke of the desire to have a key worker to co-ordinate follow-up care and to act as a point of contact for them. In the one-day consensus meeting where the young people worked with health care professionals to reach agreement on models of follow-up care, the “key-worker” model was clearly preferred over the other alternative models presented. These included a “nurse-led” model of care, a “levels of care” model based on diagnosis and treatment received and a “transfer v. transition” model. The key-worker model offered follow-up directed by the needs of the young person rather than the treatment they had received and was flexible in its approach to follow-up with a number of different follow-up options being available (e.g. face-to-face, telephone, email, GP, consultant).

Implications
This research has implications for CLIC Sargent and other organizations involved in the development, delivery and evaluation of cancer services. This report provides evidence of what young cancer survivors want to maximize their potential to live their lives the way they want to. This involves being fully informed to make choices and to make decisions about their health needs. Consultation with young people provides valuable feedback, which will be crucial for role and service development. The key-worker model of follow-up has important implications for charities, which may take the opportunity to financially support future service developments to meet the needs of young cancer survivors. Assembling these needs in a typology presents
those delivering and commissioning services a tangible measure of outcome that can be confidently described as what young people want from a follow-up service (Figure 1). The focus of future research should concentrate on three elements:

1. **Ensuring the typology is complete and fit for purpose:** through further consultation with young people and health care professionals using a Delphi process, followed by local development and testing.

2. **Evaluating the key worker model of follow-up care:** using a strategic process and realistic evaluation methods more suitable to the social context that is the real world of clinical practice.

3. **Developing young people as participants in the research process:** to involve young people in every stage of the research process, beginning with design of the evaluation study.

**Conclusions**

This study provides important insights into what young people value and want from their long-term follow-up care, and how they feel future service provision should be designed. By involving young adult survivors of childhood cancer a voice has been given to what is in research terms, a silent, neglected and ever increasing population. By highlighting the needs of young people who are survivors of childhood cancer, this research has many implications for future practice and service provision. It is clear that informational, communication and parental needs as well as the knowledge of doctors and young people’s relationships with them all need to be considered within the confines of the follow up consultation. It is hoped this study will have an impact on how future follow-up care is designed for young people and so make it more user friendly.

**References**


Figure 1 Typology of Young People’s Follow-Up Health Care Needs

1. Positive relationship with health care professionals
   1.1 Continuity
      • Young person feeling known and being remembered
      • Establishes and maintains support & trust
      • Sees the same team of doctors
   1.2 Friendliness
      • Referred to by first name
      • Interested in the young person as an individual

2. Informational Needs
   2.1 Diagnosis-related information
      • Type of cancer
      • Stage of cancer at diagnosis
      • Possible cause of cancer
      • Specific scientific information
   2.2 Post-treatment-related information
      • List of treatments received
      • Specific information about treatment and drug side effects
      • Degree of treatment
      • Effects of medication and impact on side effects
      • Effects of not taking prophylactic treatment
   2.3 Late-effects information
      • Effects of drugs on fertility
      • Effects on cardiac function
      • Effects of anti-itching
      • Effect on academic achievement
      • Symptoms/problems to be aware of and recognize

3. Needs related to communication processes
   3.1 Content of Communication in Consultation
      • Concerns medical and non-medical (friendship, fertility, insurance)
      • Directive advice
      • Health-promotion awareness (smoking, drinking, drugs, sex)
      • General chat
      • Reassurance and peace of mind
   3.2 Ease of Communication
      • Young people ask questions and put opinions on cancer and non-cancer issues
      • Assisted by Health Care Professionals
      • Health care professionals having a friendly and relaxed style
      • Awareness of boundaries between patient and professional
      • Treated sensitively
      • Being listened to
      • Taken seriously
   3.3 Enablers of communication
      • Friendly environment
      • Young person given encouragement to speak
      • Knowing the doctor they see
      • Communication directed at young person not parent/ICTV/Medical students or others in room
      • Confidentiality
      • Helpfulness of doctors
      • Young people’s needs being taken seriously
      • Treated as a person not a process
      • Feeling relevant
      • Young people talking on a level with the doctors (being trusted as an adult)
      • Young medical terminology/jargon
      • Doctors being honest and straightforward

4. Future Planning information
   • Forming relationships as a cancer survivor
   • Consequence issues
   • Miscarriages
   • IVF
   • Adoption
   • Job prospects
   • Education
   • Insurance
   • Foreign travel
   • Mortgages

5. Accessibility of information
   • Clear language
   • Correct terminology, but not medical jargon
   • Explaining things not clear
   • Clear answers to questions
   • Written information in different languages
   • High-quality information accessible on the internet

6. Layering of Information
   • Appropriate understanding and level of knowledge
   • According to readiness for more information
   • Additional detail and updating in subsequent consultations

7. Processes to Emphasize
   • Written information
   • After care booklet
   • Access to notes
   • Patient-held records
   • Time line with dates of diagnosis, treatment, remission and relapse
   • Treatment list
   • Summary

3. Needs related to communication processes
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      • Concerns medical and non-medical (friendship, fertility, insurance)
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      • Doctors being honest and straightforward

4. Communication between health care professionals
   • Within secondary care
   • Between other doctors and hospital departments
   • Referral to other doctors
   • Transfer of notes
   • Intraco and primary care
   • GP out of the loop
     • Need to keep updated
     • Letter sent to GP
     • To inform on drugs prescribed
     • Transfer of notes

5. Parental Involvement and Need
   5.1 Support for Parents
      • Receive reassurance about the young person’s condition to reduce anxiety and self-these
      • Availability of parent support groups for survivors
      • Helped to understand with appropriate written information and translation services
      • Supported through transition of young person’s independence

6. Health care professionals have appropriate knowledge
   6.1 Knowledge about disease
      • Specialist expertise
      • Referral to experts
      • Sharing knowledge with patient

6.2 Knowledge about care
   • Clear understanding
   • Read notes thoroughly
   • No need for young person to repeat case history
   • Doctors knowing case history
   • Young person does not have to explain what to do
ACKNOWLEDGEMENTS

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Alexandra Brownsdon (Survivors Group)
David Casewell (Young Cancer Voices)

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NOTATIONS AND ABBREVIATIONS

The following notations were used in direct quotations:

e.g. (f, 21, i/v): gender, age, data collection method.

f= female
m= male
i/v= interview
w/s= workshop

Reference is made throughout the report to members of the research team using initials:

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1.0 INTRODUCTION
The number of childhood cancer survivors is increasing by 1200 each year (National Institute for Clinical Excellence [NICE], 2005). As a result, current service provision is gradually being put under strain, with quality of care potentially compromised. Agreement and consistency in how future follow-up care should be designed and delivered is urgently needed, however health care professionals [HCPs] are yet to reach consensus. This study was undertaken to find out what young people who are receiving long-term follow-up for childhood cancer would like from their follow-up service. It also provided young people with the opportunity to work with HCPs to reach consensus on an alternative model of long-term follow-up.

This report provides a brief introduction on the background to the project and why it was necessary to undertake it. This is followed by an account of the data collection methods and procedures employed, prior to the findings being presented and outcome measures developed. The report concludes with a discussion on how the reported observations and outcomes developed may shape the future of long-term follow-up care. Methodological issues and challenges encountered during the course of the study are identified and addressed.

2.0 BACKGROUND
2.1 Survivorship and the need for follow-up
One in 1,000 young adults is a survivor of childhood cancer, and five-year post diagnosis survival rates for those with a childhood cancer diagnosis now exceed 70% (Stiller et al., 2004). Today there are more than 15,000 adult survivors of childhood cancer in the United Kingdom [UK] compared to just 1,400 in 1971. These figures are comparable to survival rates in the United States and mainland Europe (Stiller et al., 2004).

Nevertheless despite such positive increases in survival rates it is estimated that approximately 60% of this population will have one of more treatment or disease related late effects with over 30% of these effects being classified as moderate or severe (Lackner et al., 2000; Oeffinger et al., 2000a, 2000b; Stevens et al., 1998). Such effects include cardiac dysfunction, cognitive impairment, infertility, early menopause, mobility problems, loss of bone density and thyroid deficiency (Stevens et al., 1998). There are also long-term psychosocial late effects associated with a childhood cancer diagnosis and these should not be underplayed as they can seriously impinge on a young person’s quality of life. Self-esteem, peer and familial relationships, employment and educational attainment have also been found to be a source of difficulty and distress in as many as 30% of childhood cancer survivors (Patenaude & Kupst, 2005; Kazak et al., 1997; Hobbie et al., 2000). Together these findings strongly suggest that long-term follow-up care for young adult survivors of childhood cancer should be holistic and consider both physical and psychological needs.

2.2 Current status of long-term follow-up care
The view of some professionals is that all survivors of childhood cancer should be followed-up for life (D'Angio, 1975). There is still, however, a dearth of evidence to support the view that long-term follow-up can impact on survival rates and quality of life. This has led some researchers to question the efficacy of providing such a service, particularly with the ever-increasing number of survivors (Brada, 1995). Current methods of long-term follow-up are not consistent across cancer centres, and often influenced by the perspective of individual clinicians rather than specific
guidelines for care. Agreement is lacking as to the outcomes of care to be achieved. Lack of consensus is not only potentially compromising care, but can also be viewed as putting an additional strain on already overstretched services in terms of labour and cost intensiveness: where no evidence exists that care is effective. To resolve these issues it is imperative that national standards are developed and packages of care devised to achieve optimal outcomes for the population of cancer survivors.

Taylor et al. (2004) highlight the disparity in long-term follow-up clinical practice in 17 of the 22 UKCCSG centres. It was found that while 96% of patients were followed-up to 5 years post treatment only 52% of clinicians follow-up all of their patients for life. Moreover, 45% of clinicians discharged some of their patients to other services (97% to their General Practitioner [GP]), and 16% reportedly discharging all of their patients irrespective of tumour type to a GP or adult oncologist. The current approach to long-term follow-up is clearly haphazard with different models of care between centres and even within the same specialist centre. The introduction of some level of consistency in the process of care of follow-up would be advantageous. The NICE guidelines (2005) suggest different levels of monitoring for different groups of long-term survivors: “there should be robust and appropriate surveillance of survivors, which will be intensive for those with significant anticipated adverse late effects of therapy and minimal for others who are likely to remain well” (p.78).

This links to the work by Wallace et al. (2001) who propose that not all survivors of childhood cancer require the same level of long-term follow-up or intervention from teams responsible for their care. Wallace et al. (2001) suggest that the degree of follow-up a young person receives should be graded in relation to the treatment they have received. For example, someone who had a Grade 1 Wilms’ tumour and either surgery alone or in combination with low dosage chemotherapy might be followed up by telephone or postal questionnaire on an annual or two yearly basis, whereas someone who had received treatment for a brain tumour would be classified as having a high level of need and would be followed up for life (at what frequency) in a specialist late effects clinic by a dedicated late effects team. Such distinctions are defined further in Table 1. However, the reality is that these levels have not been subjected to scrutiny. How easy or appropriate it may be to categorize individuals as either a level 1, level 2 or level 3 patients has yet to be articulated in terms of individual need or clinical outcome.

The NICE guidelines (2005) also highlight the need for separate late effects clinics and for age appropriate services for adult survivors of childhood cancer. Taylor et al. (2004) found that only 51% of follow-up clinics saw survivors in a specialist long-term follow-up clinic separate from patients on active treatment. The guidelines stress the importance of multi-disciplinary teams including National Health Service [NHS] funded psychological support staff for young people. Shortages of nurses specifically trained in long-term follow-up care have been reported (Taylor et al., 2004). The importance of key workers being assigned to each long-term follow-up patient and the development of individualised care plans are also emphasized in the guidelines.
Table 1: Proposed levels of follow-up (Wallace et al., 2001)

<table>
<thead>
<tr>
<th>Level</th>
<th>Treatment</th>
<th>Method of follow-up</th>
<th>Frequency of follow-up</th>
<th>Examples of tumours</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Surgery alone&lt;br&gt;Low risk chemotherapy</td>
<td>Postal or telephone</td>
<td>1-2 years</td>
<td>Wilms’ stage 1 or 2&lt;br&gt;Langerhans cell histiocytosis (singles system disease)&lt;br&gt;Germ cell tumours</td>
</tr>
<tr>
<td>2</td>
<td>Chemotherapy&lt;br&gt;Low dose cranial irradiation less than or equal to 24 Gy</td>
<td>Nurse or primary care led</td>
<td>1-2 years</td>
<td>Majority of patients (e.g. ALL in first remission)</td>
</tr>
<tr>
<td>3</td>
<td>Radiotherapy, except low dose cranial irradiation&lt;br&gt;Megatherapy</td>
<td>Medically supervised long-term follow-up clinic</td>
<td>Annual</td>
<td>Brain tumours&lt;br&gt;Post bone marrow transplantation&lt;br&gt;Stage 4 patients (any tumour type)</td>
</tr>
</tbody>
</table>

2.3 Accessing views of young people

Long-term follow-up care for childhood cancer survivors has been primarily driven by HCPs with little research having been undertaken into how young people view service provision. Yet since 2001 a number of policy documents and discussion papers have been produced and disseminated by the Department of Health [DH] highlighting the needs of young people and the importance of their views being heard and their opinions sought (DH, 2001; 2003). The Department for Education and Science Green Paper “Youth Matters” (2005) stresses the importance of making young people active in their own care and wanting “young people to have more direct involvement in all stages of service design, development, delivery and evaluation. By involving them, we can help to ensure that they will share ownership of decisions and use facilities and services responsibly, and that the investment of public, private or charitable funds is directed to meet their real needs” (p.37).

The National Service Framework for Children, Young People and Maternity Services [NSF] (2004) developed by the Children’s Task Force advocates informing and empowering young people by involving them in service development and providing them with patient choice in order to reduce care inequalities. Standard 3 of the NSF states that: “children and young people and families receive high quality services which are co-ordinated around their individual and family needs and take account of their views” (2004, p.6).

This means that age and comprehension level appropriate information must be provided by services which “listen and respond” to patient needs. Age appropriate care is also seen as being vital to young people. Standard 4 of the NSF advocates thorough and careful planning of transitional care for young people to adult services. The need for holistic care is highlighted by Standard 6 of the NSF in that “All children and young people who are ill, or thought to be ill, or injured will have
timely access to appropriate advice and to effective services which address their health, social, educational and emotional needs throughout the period of their illness” (2004, p.7).

The principle of incorporating users’ views in the development and evaluation of services is widely accepted (DH, 2000; Tritter et al., 2004; NICE, 2005). Building patient experience into the development of cancer services will go some way to ensure that services are patient centred. Young people and their families must be reassured that continuing care will remain an important feature throughout the follow-up of children/young people, irrespective of the increasing numbers of survivors and resulting resource implications (Gibson & Soanes, 2001). This study aims to provide evidence to support the development of new models of follow-up for childhood cancer survivors in which, the dimensions of care valued and required by young people are central.

2.4 Aims of study
The aims of this study were to provide answers to the following:

1) What dimensions of care are most valued by young people receiving long-term follow-up care?
2) What are the perceptions of young people and health care professionals regarding current approaches to long-term follow-up care?
3) What approach to long-term follow-up care would young people prefer?
4) What are the views of both the young people and health care professionals on the proposed alternative models of care?

3.0 OVERVIEW OF STUDY
This study is underpinned by the Medical Research Council [MRC] framework on the evaluation of complex interventions to improve health, which incorporates theory-generating and exploratory-descriptive phases (theoretical/pre-clinical, phase 1 modeling), before moving onto more traditional intervention studies (Phase2, Phase3 and Phase, 4) (MRC, 2000). The theoretical (pre-clinical) phase involves the establishment of a theoretical platform upon which to lay the foundations of the intervention. This phase guides the study design and is an essential element where no interventions have been previously trialled.

In more detail, the Phase 1 modelling stage of the MRC framework identifies and defines the components of the intervention (e.g. aspects that will form part of it), which are then tested using qualitative approaches such as focus groups and case studies. Phase 2, the pilot randomised control trial, involves developing an intervention to be tested, estimating sample size and testing feasibility and acceptability before finalising the intervention. Phase 3, the definitive randomised control trial is the stage where the fully delineated intervention is trialled and evaluated. Phase 4, is the final stage and involves long-term implementation of the intervention, and is concerned with how well the intervention works over time and its replicability by others. This study focused on the theoretical (pre-clinical) phase and Phase 1(Figure 1).
3.1 Stage 1 of the research – Theoretical Phase
This involved a comprehensive review of current practice from the perspectives of young people and HCPs in relation to long-term follow-up and consisted of a number of activities:

A literature review using systematic methods was conducted to identify existing guidelines, evidence and practices employed in the long-term follow-up of childhood cancer survivors and to assess the degree to which young people’s follow-up preferences have been measured.

Workshops and semi-structured interviews were conducted to identify the dimensions of care most valued by young people and their preferences for long-term follow-up.

Postal questionnaires were sent to known non-attendees at clinic to identify the dimensions of long-term follow-up most valued by this group and their preferences for long-term follow-up. Telephone interviews had initially been anticipated as being used to collect data from non-attendees, but this was found not to be a successful means of engaging this population in research.

3.2 Stage 2 of the research – Phase 1 Modelling
This involved devising the structure and components of a number of alternative models of long-term follow-up care and exploring these with young people and HCPs in a one-day consensus meeting. Young people who participated in the workshops and interviews in the theoretical phase were invited to take part in this meeting, to work alongside specialist HCPs, to develop alternative models of care and to come to an agreement on how future follow-up care should be designed.

4.0 METHODS
4.1 Setting
Within the UK there are twenty-one regional paediatric oncology centres providing specialist care and expertise for children and young people with all forms of cancer at all points on the cancer journey. Together these centres comprise the United Kingdom Children’s Cancer Study Group (UKCCSG). Four UKCCSG centres (Great Ormond Street Hospital for Children NHS Trust, The Royal Marsden, Birmingham Children’s Hospital and Leeds Teaching Hospital) participated in this multi-centre study. Each of these centres varies in the number of patients seen and approach to long-term follow-up care (Table 2).
<table>
<thead>
<tr>
<th></th>
<th>Birmingham Children’s Hospital</th>
<th>St James’ Hospital Leeds</th>
<th>Royal Marsden Hospital London</th>
<th>Great Ormond Street Hospital for Children NHS Trust London</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients seen annually</td>
<td>648</td>
<td>700</td>
<td>643</td>
<td>741</td>
</tr>
<tr>
<td>Seen at specialist centre</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Paediatric Oncology Unit</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Frequency of clinics</td>
<td>Weekly</td>
<td>5 clinics per month</td>
<td>Weekly oncology, twice a month brain tumours</td>
<td>5 clinics per month</td>
</tr>
<tr>
<td>CNS specialist in late effects</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Nurse led clinic</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transition Clinic</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transfer to tertiary setting - adult team at 18</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transfer to tertiary setting - Satellite team</td>
<td>✓</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
</tbody>
</table>

**Table 2: The structure of long-term follow-up clinics at the four participating UKCCSG centres**

**4.2 Sample**

For the purpose of this study young people aged between 16 to 25 years who were at least five years post the end of treatment were approached to participate. Both regular clinic attendees and non-attendees were eligible to participate in the study. Non-attendees were defined as having two consecutive non-attendance or two failed appointments out of five offered appointments in a five-year period. Young people of this age were chosen as they are reaching maturity, developing autonomy and independence and may wish to be actively involved in their follow-up plans. Purposive sampling techniques were used in order to obtain a good range of diagnoses, sex, age and ethnicity that was reflective of the make up of each individual clinic (Appendix 1a).

**4.3 Recruitment**

At each of the four UKCCSG centres involved in the study the nurse responsible for long-term follow-up, in collaboration with long-term follow-up consultants and database managers, identified suitable participants using their patient databases. Letters and information packs, including information for parents, were distributed by each of the centres inviting young people to contact the research fellow if they were interested in participating or needed further information. In addition one of the centres also approached young people attending follow-up clinic and gave them information packs in person. Posters were also displayed in each of the centres inviting young people to contact the research fellow (HA) about the study if they were interested in receiving further information (Appendix 1b).
Regular clinic attendees were sent information packs inviting them to take part in a workshop with the option of a telephone interview if they preferred (Appendix 2a). Clinic non-attendees were sent information packs inviting them to take part in a telephone interview with the option of taking part in a workshop if they preferred (Appendix 2b). The reason that attendees and non-attendees were given different options was based on our perception that the latter group would represent a harder population to engage and might be more amenable to taking part, the fewer demands that were place on them.

Young people were given the option of returning a reply slip to the researcher in a stamped addressed envelope, telephoning or emailing. Centres sent out follow-up letters to young people who had not responded three weeks after receiving the initial letter.

Due to the lack of response from non-attendees it became necessary to select a further sample to recruit (see 6.3.2.1). This second group were sent a postal questionnaire by three of the four centres (one centre had exhausted their list of potential recruits) along with information on how to complete and return it (Appendix 2c).

4.4 Ethical Issues
The study protocol was submitted and approved by the Great Ormond Street Hospital for Children NHS Trust/Institute of Child Health Research Ethics Committee which acted as the main REC and the local ethics committees of the UKCCSG centres involved, as well as all relevant R and D approval was gained. Signed consent was obtained from young people. In order to ensure confidentiality no names are used in this report.

With respect to the workshops, interviews and consensus meeting all of the young people were informed that they could withdraw from the study at any time if they felt that they did not wish to participate. They were also informed that if anything concerned or upset them they could discuss the issue in confidence with either FG or HA. The young people who took part in the semi-structured interviews were told that they did not have to answer a question if they did not want to and were also free to stop the interview at any point.

The young people were each given a voucher as a token of thanks for participating. To avoid coercion they were not informed they would receive the voucher until after they had participated. Travel expenses for the young person and an accompanying friend or relative were also reimbursed.

4.5 Project Management
At the outset project management processes were established to ensure communication and input from collaborating centres. Representation on the steering group reflected clinical and methodological expertise, alongside user perspectives. A total of four steering group meetings were held with minutes were taken at these meetings. The principal investigators (FG, GL, and AR) first met in early 2003 to develop the research proposal. The sites for data collection were established in 2004. Table 1 outlines the milestones achieved from when funding was confirmed in June 2004.
through to 2005 when all data had been collected and analysed and the final report written.

<table>
<thead>
<tr>
<th>Milestone</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding received</td>
<td>June 2004</td>
</tr>
<tr>
<td>Commenced process of submitting proposal for ethical and R &amp; D approval</td>
<td>Oct 2004</td>
</tr>
<tr>
<td>Research Fellow appointed (HA)</td>
<td>December 2004</td>
</tr>
<tr>
<td>Received MREC approval</td>
<td>October 2004</td>
</tr>
<tr>
<td>Received R &amp; D approval at Great Ormond Street Hospital</td>
<td>November 2004</td>
</tr>
<tr>
<td>Received R&amp;D approval at Birmingham</td>
<td>March 2005</td>
</tr>
<tr>
<td>Received R &amp; D approval at RMH</td>
<td>February 2005</td>
</tr>
<tr>
<td>Received R&amp;D approval at Leeds</td>
<td>November 2004</td>
</tr>
<tr>
<td>Recruitment commenced (phase 1)</td>
<td>January 2005</td>
</tr>
<tr>
<td>Workshops run</td>
<td>April-June 2005</td>
</tr>
<tr>
<td>Data analysis commenced</td>
<td>June 2005</td>
</tr>
<tr>
<td>Interviews with young people</td>
<td>July 2005</td>
</tr>
<tr>
<td>Postal questionnaires designed</td>
<td>June 2005</td>
</tr>
<tr>
<td>Postal questionnaires distributed</td>
<td>July 2005</td>
</tr>
<tr>
<td>Questionnaires returned and analysed</td>
<td>August 2005</td>
</tr>
<tr>
<td>Development of protocol for consensus meeting (phase 2)</td>
<td>August 2005</td>
</tr>
<tr>
<td>Consensus Meeting</td>
<td>September 2005</td>
</tr>
<tr>
<td>Development of needs tool</td>
<td>September 2005</td>
</tr>
<tr>
<td>Preparation of final report and papers for publication commenced</td>
<td>September 2005</td>
</tr>
<tr>
<td>End date of project</td>
<td>November 2005</td>
</tr>
</tbody>
</table>

**Table 3: Project milestones with dates achieved**

4.6 Presentation of the data collection, procedure and findings
For the sake of clarity Stage 1 and Stage 2 data collection, procedure, findings and outcomes will be presented separately. The observations and implications of the findings from Stage 1 and Stage 2 will be discussed together in section X devoted to the discussion.

5.0 STAGE 1 THEORETICAL PHASE
5.1 Data Collection Methods and Procedure
Data collection involved a number of qualitative and quantitative techniques across the two stages of the study using reflexive and responsive approaches. This is in line with the MRC framework recommendations. In order to maximize young people’s participation in the study flexibility was of key importance. This age group are considered particularly difficult to engage in research as they often feel inhibited by members of the opposite sex (Curtis, 2004) and are still establishing their own identities and autonomy (Hanna & Jacobs, 1993). Young people who are receiving follow-up may also be concerned that their treatment could be affected by their participation in such research if they believe comments made could be attributed to them (Dashiff, 2001).

In the first stage of the study (theoretical phase) three different methods of data collection were selected: workshops, semi-structured interviews and postal questionnaires, whilst in stage two (modelling phase) data were collected within the arena of a consensus meeting. Participatory research methods such as workshops and consensus meetings are considered a strong and valid method of data collection.
as they are guided by the philosophy of empowering the individual and enabling their voice to be heard (Coad & Lewis, 2004).

Workshops were employed as a way of getting groups of young people with similar needs together at a single event to work over the course of a day with their peers on activities that could provide insight into their views of long-term follow-up care. Workshops involving young people have been employed with great success by researchers investigating issues such as chronic pain (Carter et al., 2002). Carter et al. (2002) advocate the use of workshops with multiple guided activities (including peer interviews, focus group discussions and diamond ranking exercises where issues are ranked according to importance) as they provide a patient-centred approach that is fluid and engaging. Interviews and focus groups have also been successfully used with adolescents with cancer in research examining self-identity and esteem (Woodgate, 2005). Other researchers have employed spider diagrams in brainstorming sessions as a way of getting young people to think about issues holistically (Punch, 2002). As recommended by Dashiff (2001) workshops took place outside of the hospital environment and without staff whom were responsible for the young people’s treatment and care. This was considered to be important to ensure that the young people felt they had privacy and could talk freely.

Semi-structured interviews were designed from themes that emerged during the workshop days. This method was used to incorporate the views of those who either could not or did not want to come to the workshops. It was felt important that young people who took part in this method of data collection were also interviewed outside the hospital and indeed outside of the home in locations convenient to the young person (e.g. cafes, libraries): this was so that they could feel relaxed and have the confidence to speak openly and honestly about their experiences (Dashiff, 2001).

Postal questionnaires for non-attendees were also designed from themes that emerged during the workshops. This was considered to be the best method for gauging a response as invitations to attend workshops and participate in interviews had failed in the initial stages of recruitment. It was important that non-attendees views were sought as often those who have fallen out of the service loop are the ones most in need of service improvement and change (Johnson et al., 2004).

By developing the interviews and questionnaires from the workshop data it was felt that the issues of the young people would be more readily addressed rather than the research team putting forward their own views and biases on follow-up care and service management.

5.1.1 Literature Review
Using systematic methods a review of the literature in relation to the long-term needs of childhood cancer survivors was undertaken. Medline (Winshrs, PubMed, Gateway), Web of Science, Psychinfo, CancerLIT and Highwire were all searched. The following search terms were used: cancer, young person, young adult, adolescent, teenage* (where * is a truncation sign), child*, survivor*, follow-up, long-term, health, care, preferences, transition*, transfer. No date restrictions were placed on the search terms: the databases were searched up to July 2005. However, only studies published in the English language were searched for. In addition the reference lists of the studies identified were hand searched for suitable studies. A consultant with a special interest in long-term follow-up (GL) was also asked about suitable studies. To be included in the study all papers had to have examined long-
term follow-up services for childhood cancer survivors. Commentary papers were acceptable, but policy documents were not included in the review itself. Studies looking at adult follow-up services following diagnosis and treatment for cancer were excluded from the review.

5.1.2 One-day Workshops
Four workshops were held at sites local to each of the participating UKCCSG centres. Each was of four hours duration and facilitated by two members of the research team (HA and FG). Within each of these workshops the following activities were employed:

(i) **Peer interviews** – young people working in pairs interviewed each other in the style of a magazine interview on their feelings and attitudes towards long-term follow-up. The young people were asked to think of questions to ask, but were also given some written prompts to guide them if they seemed to be struggling with identifying questions themselves. Some young people chose to personalise this list of prompts. These interviews were tape-recorded.

(ii) **Headline generation** – young people remained in their original pairings and based on the information they had gained about their partner during the interview were asked to come up with headlines/phrases that reflected their views and feelings on long-term follow-up.

(iii) **Group Discussion** – the headlines generated by young people during the interviews were used as the basis for group discussion. Mind maps were created as the thoughts of the young people were recorded both on paper and on tape.

(iv) **Written exercise** – the Who, why, when, What, How, Why of follow-up care. This was a short written exercise, which young people completed individually. It comprised six questions about the structure and process of long-term follow-up (Appendix 3a).

5.1.3 Semi-structured interviews
The interviews were undertaken by one of the researchers (HA) with young people who were regular clinic attendees but who were unable to attend the workshop day. All interviews were tape-recorded. Interview participants also completed the written exercise used in the workshop days (Appendix 3b for interview protocol).

5.1.4 Questionnaires
Postal questionnaires were sent to non-attendees of the long-term follow-up clinics. The questionnaires were designed by two of the researchers (HA and FG) and were reviewed by AR and GL. They were developed from information that had been gained during the workshops. The questionnaire consisted of three sections (Appendix 3c):

- Section A) Views on clinic (10 questions);
- Section B) How you would like things to be (4 questions);
- Section C) About you (2 questions).

Closed questions were used to establish diagnosis, clinic attendance patterns, personnel seen and follow-up preferences. These were used in combination with open-ended questions where young people could express their feelings about attending clinic, informational needs and the type of follow-up contact they would prefer.
5.2 Data Analysis

Workshops and interviews

The tape-recorded peer interviews and semi-structured interviews (where quality allowed) were transcribed verbatim. Two members of the research team (HA and FG) undertook the qualitative data analyses of the transcripts. A thematic analysis using the recommendations made by (Coffey & Atkinson, 1996) was used and proceeded as follows:

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

This process was also undertaken with the data generated from the mind-mapping exercise, following conversion into text form, and the written information from the “who, when, what, how, why” exercise.

Questionnaires

Data were entered onto an Excel database and analysed descriptively. Open-ended questions were reviewed to identify themes.

Once the data sets had been analysed separately they were brought together at the level of interpretation (Sandelowski, 2000). This allowed the research team to follow a thread to illuminate further each of the main categories.

5.3 Stage 1(Theoretical phase) Results

The findings from the literature review will briefly be discussed before the findings from the different data collection exercises are presented in full. These findings form the theoretical platform upon which any intervention as defined by the MRC framework (2000) must be based.

5.3.1 Literature review

Twenty-two papers that met the eligibility criteria and examined long-term follow-up services for childhood cancer survivors were isolated from the computerized literature search and six further studies were identified through hand searching. This led to a total of twenty-eight papers for inclusion in the review. Two thirds of these papers were American, the rest were from Western Europe. Specifically, thirteen of the papers were commentary papers (Gibson & Soanes, 2001; Gibson, 2004; Goldsby & Ablin, 2004; Harvey et al., 1999; Hobbie, 1986; Hobbie & Hollen, 1993; Hudson et al., 2004; Jereb, 2000; Philips, 2003; Richardson et al., 1999; Viner, 2003; Von der Weid & Wagner, 2003; Wallace et al., 2001). Seven were concerned with guidelines (Children’s Oncology Group, 2003; Eshelman et al., 2004; Landier et al., 2004; Masera et al., 1996; NICE, 2005; The Scottish Intercollegiate Network [SIGN], 2004; UKCCSG, 2005). Only five papers that had directly asked young people about their health care needs. Three of these studies were questionnaire based
(Eiser et al., 1996; Eiser et al., 1999; Oeffinger et al., 2004), the fourth involved a Delphi panel (Zebrack et al., 2004) and the fifth involved focus groups (Earle et al., 2005). The remaining six papers comprised one Delphi panel of health care experts (Mertens et al., 2004), two case or chart reviews and two questionnaires directed at clinicians (Oeffinger et al., 1998; Taylor et al., 2004).

The guideline papers described the guidelines and outlined how they could be operationalised in clinical practice, whilst the commentary papers discussed how long term follow-up needs should be met and how future follow-up care might be organized. The questionnaire studies, which were undertaken with the young people, were not-in depth and so taken together the review highlights the overwhelming need for an in-depth examination of young people’s perceptions and views of long-term follow-up following a childhood cancer diagnosis. This review will be published separately from this report.

5.3.2 Workshop, questionnaire and interview data
5.3.2.1 Participants
Two hundred and twenty one young people who regularly attended long-term follow-up clinic were approached to take part in the study. Thirty-six young people agreed to participate (16.29%); however, ultimately twenty-six young people participated (twenty-two in the workshops and four in the in-depth interviews). This gave a recruitment rate of 11.76%. Refusal slips were received back from 21 young people, only one gave a reason for not being able to attend and that was for exams. One hundred and sixty one young people defined as clinic non-attendees were approached (56 to take part in telephone interviews, 105 sent postal questionnaires). Fourteen non-attendees took part in the study by completing questionnaires giving an overall recruitment rate of non-attendees of 8.70% (13.33% of young people sent questionnaires). Table 4 shows the characteristics of the young people who participated in the study.
<table>
<thead>
<tr>
<th></th>
<th>Workshop Attendees</th>
<th>Interviews</th>
<th>Non-attenders</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number</strong></td>
<td>22</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean age</td>
<td>19 years 4 months</td>
<td>20 years 6</td>
<td>20 years 9</td>
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<td>Range</td>
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<td>months</td>
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<tr>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11 (42.3%)</td>
<td>4 (100%)</td>
<td>3</td>
</tr>
<tr>
<td>Female</td>
<td>15 (47.7%)</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td><strong>Ethnic group</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>21 (80.8%)</td>
<td>3 (75%)</td>
<td>14 (100%)</td>
</tr>
<tr>
<td>Asian Chinese</td>
<td>2 (7.8%)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Asian Pakistani</td>
<td>1 (3.8%)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Black Caribbean</td>
<td>1 (3.8%)</td>
<td>1 (25%)</td>
<td>-</td>
</tr>
<tr>
<td>Mixed – White and black caribbean</td>
<td>1 (3.8%)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute Lymphoblastic Leukaemia</td>
<td>10 (45.45%)</td>
<td>2 (50%)</td>
<td>4 (28.58%)</td>
</tr>
<tr>
<td>Wilms’ Tumour</td>
<td>4 (18.17%)</td>
<td>1 (25%)</td>
<td>3 (21.43%)</td>
</tr>
<tr>
<td>Neuroblastoma</td>
<td>2 (9.08%)</td>
<td>-</td>
<td>1 (7.14%)</td>
</tr>
<tr>
<td>Acute Myeloid Leukaemia</td>
<td>1 (4.55%)</td>
<td>-</td>
<td>2 (14.28%)</td>
</tr>
<tr>
<td>Hodgkins Disease</td>
<td>1 (4.55%)</td>
<td>-</td>
<td>1 (7.14%)</td>
</tr>
<tr>
<td>Non-Hodgkins Lymphoma</td>
<td>1 (4.55%)</td>
<td>-</td>
<td>1 (7.14%)</td>
</tr>
<tr>
<td>Optic Nerve Glioma</td>
<td>1 (4.55%)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>PNET (primitive neural-ectodermal tumour)</td>
<td>1 (4.55%)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Dermatofibrosarcoma</td>
<td>1 (4.55%)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Protuberans</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Germ cell tumours</td>
<td>-</td>
<td>1 (25%)</td>
<td>1 (14.28%)</td>
</tr>
<tr>
<td><strong>Age at Diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5yrs</td>
<td>18 (81.82%)</td>
<td>3 (75%)</td>
<td>9 (64.29%)</td>
</tr>
<tr>
<td>6-10yrs</td>
<td>2 (9.09%)</td>
<td>1 (25%)</td>
<td>3 (21.43%)</td>
</tr>
<tr>
<td>11-16yrs</td>
<td>2 (9.09%)</td>
<td>-</td>
<td>1 (7.14%)</td>
</tr>
<tr>
<td>No information</td>
<td>-</td>
<td>-</td>
<td>1 (7.14%)</td>
</tr>
<tr>
<td><strong>Years off treatment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5-9 years</td>
<td>8 (36.37%)</td>
<td>1 (25%)</td>
<td>1 (7.14%)</td>
</tr>
<tr>
<td>10-14 years</td>
<td>10 (45.45%)</td>
<td>1 (25%)</td>
<td>6 (42.86%)</td>
</tr>
<tr>
<td>15 years</td>
<td>4 (18.18%)</td>
<td>2 (50%)</td>
<td>6 (42.86%)</td>
</tr>
<tr>
<td>No information</td>
<td>-</td>
<td>-</td>
<td>1 (7.14%)</td>
</tr>
<tr>
<td><strong>Attendance at follow-up clinic</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Every 3-6 months</td>
<td>9 (40.91%)</td>
<td>1 (25%)</td>
<td>Information not available</td>
</tr>
<tr>
<td>Annually</td>
<td>1 (4.55%)</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Every 18mths</td>
<td>5 (22.72%)</td>
<td>2 (50%)</td>
<td></td>
</tr>
<tr>
<td>Every 2 years</td>
<td>-</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Every 5 years</td>
<td>-</td>
<td>1 (25%)</td>
<td></td>
</tr>
<tr>
<td>Discharged to GP</td>
<td>-</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>No information</td>
<td>-</td>
<td>-</td>
<td></td>
</tr>
</tbody>
</table>

Table 4: Demographics of clinic attendees who participated in the study
5.3.2.2 Stage 1 (theoretical phase) Findings
Data analysis revealed six categories:
(i) Components of long-term follow-up
(ii) Need for a positive relationship with health care professionals
(iii) Informational needs
(iv) Needs related to communication processes
(v) Parental needs and support
(vi) Need for health care professionals to have appropriate knowledge

The first of these categories “Components of long-term follow-up” was concerned with the structural and procedural dimensions of long-term follow-up as perceived by the young people. The five remaining categories relate to young people’s specific follow-up care needs. Due to the difference, in terms of content and focus, between the first category and the remaining five will be presented and discussed separately.

(i) Components of Long-term follow-up
This incorporates the elements that young people deemed essential in relation to the content and organisation of their follow-up care. It can be divided into a) the structure of long-term follow-up which relates to the framework of follow-up and preferences regarding site of care, HCPs providing follow up, frequency of contact and b) the process of follow-up.

(ia) The structure of long-term follow-up
Site of care
Young people expressed a number of different views relating to where they would like their follow-up care to be situated. Some expressed a preference for receiving their follow-up local to their home; however a number of the young people were happy to continue being seen in the environment where they were currently receiving follow-up as they liked the familiar environment and felt relaxed and secure there. A couple of young people liked the fact that there were young children with cancer in the clinics when they attended as they regarded themselves as symbols of hope for them. However in contrast to this some found it uncomfortable and would prefer to be seen in an age appropriate setting: “it brings back a lot of memories. Don’t want to look at that when going to follow-up. Clinic should be chilled out. A little boy all hooked up to a machine… I don’t want to look at that” (f, 23 i/v).

In general, this population viewed adult clinics with suspicion. There was uncertainty in terms of these clinics operated and were regarded as “less friendly”, “less informative”, “so many patients – a conveyor belt”. Primary care settings were generally also not favourably viewed. It was felt that whilst the GP clinic was local it was impersonal and rushed and GPs were not able to meet their very specific needs “not able to help to the level wanted”.

Providers of follow-up
In terms of whom the young people wanted to see during a follow-up consultation, medical consultants were seen as providing the gold standard of care, possessing “specialist knowledge” and of being more in touch than both nurses and GPs:

“My consultant is far more in tune with what kind of needs I have” (m, 17 w/s).
“I like going to hospital cos I feel they are specialists, they know more about cancer, they know it all. Even if it was my GP back home I would still prefer going to the hospital” (f, 21 i/v).

“I wouldn’t like to go along and just be checked out by a nurse, I would like to see someone (Dr) and see what is going on” (f, 16 i/v).

Seeing a nurse was regarded as acceptable in terms of general check-ups and often they were regarded as a confidante: “nurse helps with preliminary check ups, able to tell her anything” (m, 20 w/s).

However, there was the general consensus that unless they were specially trained in long-term follow-up they did not have adequate knowledge to be responsible for the young person’s long-term care. It was also felt that in comparison to hospital consultants, GPs were rushed, lacked specialist knowledge and had less time to devote to this particular group so could only offer limited help:

“GPs don’t understand problems, don’t take them seriously” (m, 16 w/s).

“GP’s may not meet needs, don’t know enough” (m, 20 w/s).

Young people said that it would “feel strange” if they only saw a GP and had no contact with the hospital. However, there were some who felt that their GPs could provide some form of follow-up service as they were local and “easier to access”: “if I needed to talk to anyone now, I would more than likely just make a Drs appointment at my local GP and ask him whether that’s to do with my illness or anything” (f, 20 w/s).

Services Available
Most of the young people in the study felt that they would benefit from having a key contact person at the hospital that could manage and direct their care:

“Someone to call up…quick chat…any problems or questions medical or non-medical…just call and ask” (f, 20 w/s).

“…even if not to do with illness, but other problems…point of contact” (f, 19 w/s).

“Someone who can find the answers out” (m, 23 w/s).

The young people also spoke of the importance of having access to staff be it through email or telephone contact. Where this was in place it was strongly valued. Counselling and psychosocial support were also highlighted as important, as was access to a support group dedicated to childhood cancer survivors.

A number of young people also strongly expressed the wish to act as mentors to young people undergoing cancer treatments and they viewed continued attendance at the follow-up clinic as an opportunity for helping to initiate such a scheme: “if they said to me go to (the hospital) and talk with all of the kids, I would do it straightaway, I would love it so just to talk with other…Because the way the doctors and your Mum talks to you, your parents talk to you its completely different if you are talking to someone that is a friend you can ask them the real nitty, gritty questions” (f, 20 w/s).
**Attendance**
Regular clinic attendance was strongly preferred. Those who were attending on a biannual basis felt that it had started to lose meaning for them. Most of the sample was happy with how often they were attending and acknowledged that those with more complex needs may need to be seen more often. Some expressed that they would like to have a choice in whether or not they attended or not as a couple felt that it was unnecessary unless they had a reason for going. Taking time out of school, college or work and then having to wait around for an appointment was one of the main reasons that young people were put off attending.

(ib) The process of long-term follow-up
Young people regarded the purpose of their long-term follow-up consultation as a face-to-face encounter where medical and non-medical concerns are addressed, height, weight and bloods are taken, referrals are made for further tests and screens if necessary, health is monitored, and information is provided about medical and lifestyle issues: “they look at me, check me over. If need be a couple of tests finds out what’s going on and yeah action had been taken if there’s a problem” (m, 17 w/s).

Where an aspect of the desired follow-up care was missing, concern arose: “I would feel happier just sort of being checked up like blood tests and things cos I don’t have blood tests anymore. I went to check ups last year, they weighed me and did my height and I said “oooh can I have my thumb pricked?”, and she said “no, not anymore”, and I was sort of thinking isn’t that the main thing you have to do to check my blood because that’s the most serious thing about my illness.” (f, 22, i/v).

“Blood tests equal a reason for me needing to be there” (f, 23, i/v).

To all involved in the study face-to-face consultations were seen as crucial. Telephone and/or email contact were not accepted as a reasonable substitute:

“Could do it over the phone as just a chat, but wouldn’t want it” (m, 20 w/s).

“I don’t feel you can tell if someone is well enough just talking to them on the phone” (f, 16 i/v).

Similarly, whilst some of the young people who were attending clinic every two years received questionnaires to monitor their health in the interim they did not want this in place of a consultation: “would feel a bit gutted, to be honest disappointed if they didn’t want to see me and did just send me a questionnaire” (f, 23 i/v).

Consultations were regarded by young people, as an important and secure environment, where health-related information could be discussed. Such information could relate directly to the consequences of childhood cancer and the treatments involved e.g. fertility and conception, or related to issues such as mortgages, jobs and insurance premiums, which, until such an issue arose, young people were not aware their diagnosis (often twenty years earlier) could affect. Health promotion was also a key aspect of the consultation which young people valued (e.g. advice on sunbathing, smoking, drinking, and sexual health).

(ii-vi) The needs of young people
The following themes, which clearly emerged from the data, relate to the long-term follow-up needs of young people who are survivors of childhood cancer:

(ii) Need for a positive relationship with health care professionals  
This concerned the value young people placed on having a good relationship with those responsible for their follow-up care. Young people placed high importance on relational continuity, seeing the same staff when at hospital:

“It’s nice to have a familiar face. Nice to have a familiar person you kind of like built a friendship with, even though it’s just only a doctor or a nurse, it’s still nice to have someone your are used too. Um, yeah it’s nice to get to know a face and you kind of like get a bit of a trust and know the person who has helped you out. You don’t feel, you don’t feel so intimidated I suppose, it’s nice to know that you have got someone who has like been with you all the way” (f, 16 w/s).

“Usual Doctor knows you, feels as though you are moving on” (f, 16 w/s).

“I prefer going to see people who know me, who treated me throughout my whole life and who know what’s going on” (f, 20, w/s).

Feeling as though the doctors remember them and that they take an interest in them as a person was also important. Some people saw their relationship with their doctor as more of a friendship: “consultant is like your best friend” (m, 20 w/s).

It meant a lot to the young people to be on first name terms with their doctors. Where this was lacking young people felt less able to confide in staff or to express how they felt.

(iii) Informational needs  
This is defined as a requirement that young people receive information that is not only clear and coherent in content, but is at a level suitable for the young person’s stage of maturity and cognitive functioning. Young people felt that they needed to have specific information about their diagnosis and the possible reasons for initially becoming ill: “I couldn’t tell you know what actually happened. I couldn’t tell you why it happened…I just know that its to do with your blood…I could research it myself on the internet, but if someone could sit down and explain it to me now…then I would be really interested in that” (f, 20 w/s).

Yet some young people were reticent to ask HCPs: “I don’t really know that much about it. I’ve heard stuff and been sent leaflet…just have a list of drugs, but no, I don’t ask them I never know what questions to ask. I don’t know if I should ask.” (f, 23 w/s).

Some participants in the study were unable to name their cancer and could not recall being told. One young woman reported until recently thinking that leukaemia was not cancer (she had been diagnosed with ALL aged 9 years of age): “I received a booklet which said “Surviving Cancer” …I didn’t know I had cancer” (f, 20 w/s).
A number of young people were not personally aware of what treatments they had received for their illness and wanted to know more about these, to have a written summary, and to be told why they had received particular treatments and what side effects they might experience. For example one young woman reported not being informed of the effects of radiation on the skin and being out in the sun: “I had severe sun damage to my skin and it came up really, really blotchy and I became poorly with it and I went to my follow-up clinic, which was just after and I said you know this is obviously something to do with... and it was mainly my face and he said that’s due to the radiation and it was a new doctor I was seeing and he said “...you should have been told this ages ago to seriously wear a hat, you put protection on, there is no factor, its full protection, full block on your face, and you should have been told this”. And I was never told that radiation, especially to my face, radiation was really serious and he said I was extremely lucky so that was...I felt a bit sort of worried about that, that they hadn’t told me beforehand. I was fine, it was just a bit blotchy, but I sort of felt well I could’ve well, you know, that couldn’t have happened if I had known.” (f, 22 w/s).

The young people also felt they needed to know more about the drugs they were currently taking and what the effects would be if they did not adhere to taking them: “following treatment to see whether I need to be on all my tablets long-term or whether I will be taken off of them and things like that” (f, 23).

A very important issue for young people was being informed about the long-term effects of their illness on fertility, their heart, and academic achievement amongst other things. One young man in the study expressed not being able to father children as a “silent mourn he often has” (m, 23 w/s). Young people also wanted to be prepared for any possible effects that might occur later in life by receiving adequate information as to what these might be: “there are things they have said like side effects and things that I don’t know about, like when I am older and I think I would like to know about that cos I haven’t had any side effects up til now, but I would like to know of anything else that hasn’t happened, but could happen. I don’t want to get a shock. I would rather know it is coming so I can get on with my life and know what to do rather than sitting there in the back of my mind wondering I don’t know what is going on, what is going to happen. I would rather just know if there is a little chance or huge chance of getting it” (f, 16 i/v).

Where such information had been provided it was felt to be of significant benefit to the young person:

“Last time I went I saw a nurse and she talked to me beforehand. She said I was old enough to understand about the late effects. I asked her quite a lot of questions. It was just me and her. My parents didn’t come. She just basically went through all the treatment I had, all the drugs I have had and just the effects some of them could have and she asked if I had experiences any of them. That was nice” (f, 21 i/v).

“I asked for a special session with my Doctor to discuss everything that happened” (f, 21 w/s.)

It was of key importance to the young people that in order to maximize their understanding of the aforementioned issues HCPs presented the information in an accessible way, using clear language, avoiding jargon and providing high quality
written resources in different languages both in hard copy and accessible via the internet. Young people really benefited from this where it was in place: “yeah, I have got a booklet saying everything about that and I have read it all. Its really good” (f, 16 w/s).

The young people felt that as they got older doctors needed to repeat information about their illness. They did not want to just learn the basics from their parents and they wanted to fully understand what had happened to them so that they would then have some ownership of their illness. Young people did not want to have to rely on their parents whom they often felt they could not discuss things with or who did not understand the illness fully themselves: “she just comes up with her own theories, she believes in what she wants to believe in and because she is old and old fashioned she is not going to change her views because she has grown up with her own traditional set of views” (f, 20 w/s).

(iv) Need for Communication
This was defined as the requirement that young people be able to express their concerns and feelings in confidence in a friendly and relaxed environment without fear that they are not being listened to or not having their views taken seriously: “I have always been shy, but they always make it welcoming so I feel really good” (f, 16 w/s).

Young people felt that communication within consultations should be friendly and relaxed, that there should be someone there who was willing to listen to their concerns and provide advice and guidance accordingly. They wanted the doctor to communicate with them in an open and straightforward manner and to be consistent: “the other doctor always told me I was 2 pounds over weight and made a big deal of it. He said my weight was fine (she pressed me into losing weight). I lost half a stone. Then this time when I went I saw a different doctor and he told me I was on the borderline of being overweight. I just don’t get it. They tell me I am overweight I lose more than I have to then I am still overweight” (f, 23 i/v).

It was important for young people to feel they could express how they were feeling and to ask questions, to be helped by HCPs where they could not formulate what they wanted to say, and to feel that what they were saying was being taken seriously:

“My new doctor is brilliant, he lets me talk completely freely and he doesn’t question anything...he is completely free and easy and I feel a lot happier” (f, 22 w/s).

“New doctor is nice, friendly and down to earth. I always felt really uncomfortable, never had anything to say, awkward to say anything. Other doctors don’t know how to talk to children or young adults. New doctor really listened and didn’t pass you of” (f, 23 i/v).

If the young person knew the doctor they were going to see and they got on with them, they had the confidence to speak openly as they saw it as a friendly environment in which they would not have to re-tell their case history: “in the clinic with the doctor who has been seeing me for the last few years so I felt comfortable talking to her” (m, 18 w/s).

The young people liked to feel they had time in consultations and were be put off from voicing their concerns if the doctor acted in a hurried manner:
“Sometimes you feel as though you’re a bit rushed...they don’t say look I haven’t got time anymore, but that is how it feels” (f, 22 w/s).

“I am in and out and I waited half an hour for that” (f. 23 w/s).

Another barrier to communication was where young people felt that their needs were being treated insensitively. Two young people spoke of going to consultations with concerns about weight and of feeling depressed, but feeling that the doctor concerned was not interested in what they had to say: “I had a very serious concern. I felt a bit depressed about things, and I am not really a depressive sort of person...for a year I was really, really low, really lethargic and I didn’t know what it was...and she said “well I don’t think you are depressed because I think if you had depression you would know about it” and I said “yes, but I feel depressed” She said “well I don’t think so” and I felt so stupid” (f, 22 w/s).

Other patients felt that the doctor talked to their parents rather than them: “she was patronising...never talked to me...always talked to my mum. She’d never talk to me really. When we sat down she would always ask my mum. I thought I can get out quicker if my mum’s not there so I went in and she said “is your mum not here?” I said she is waiting outside she gave me a piece of paper and then went and gave the sheet to my mum. Next time when I went, went in on my own 5 minutes after she got my mum in and talked to my mum about me all the time. I just thought that was so rude” (f, 23 i/v).

Young people also felt uneasy about voicing their concerns when medical students were present in the room: “it’s quite intimidating because normally there are about five other people in the room so I don’t feel that I can talk” (f. 17 w/s).

Another aspect of communication that young people highlighted as being important was communication between different HCPs, either within the same hospital or between primary and secondary care. The young people felt that there was a need for this to be improved as often notes went missing or their GP had not been informed about their changing health needs: “when I went to my GP for a headache or something he said “is there any past history I should know about” and I said “well yeah I had Leukaemia” and he said “Well I don’t believe it, how have I not known about that?” And I said “well I don’t know, but you should have known” (f, 22 w/s).

(v) Parental Involvement and Needs
This category reflects the need for the demands placed on parents, even years after the illness, to be recognized, and for them to be offered appropriate support. It also incorporates the dependency of the young people on their parents.

Young people felt that even though follow-up care was for them, there needed to be provision for their relatives and guardians as they had had to go through all the pain, worry and stress of having a child seriously ill, and maybe still did not understand what had happened: “my mum doesn’t speak English and she is very, very old fashioned, she is from a totally different culture (Chinese) and her attitude is different she doesn’t actually believe in science and all those explanations she comes up with her own myths and theories about why things happen. Her theory is that
illness has come about because you didn’t take care of your health or yourself, she thinks that the more extreme illnesses are not entirely natural” (f, 20 w/s).

There was a feeling that their parents were isolated:

“Mum never wants to talk about it, she carries it with her…” (f, 23 i/v).

“There’s no-one she can really talk to about it” (f, 20 w/s).

It was felt by a number of young people that parents needed to be offered support whether informally or by means of a dedicated support group:

“To be honest I didn’t think they had had enough support, I know they still get quite upset taking about it Even now they still can’t really talk about it” (f, 21 i/v).

“Someone to answer their questions” (f, 20, w/s).

Young people felt that this would be beneficial, as it would enable them to go to clinic on their own, without their parents feeling out of the loop and a web of suspicion being created.

A number of young people in the study placed a lot of reliance on their parents in terms of making appointments and reminding the young people of them, asking questions in consultations and making notes. Some young people valued the presence of their parents in consultations to untangle medical jargon: “mum translates for me…it’s good if I’m not really listening” (m, 17 w/s).

Some young people liked to feel that their parents were involved as they had been with them through it from the start: “my parents come with me all the time, they always want to come, even though I’m 21 and I’m living here (with boyfriend) they always want to come they want to know what’s going on and what the doctors are saying…My parents will come with me the rest of the time I am going there. They have always been there” (f, 21 i/v).

However, others preferred to not involve their parents in their follow-up care: “I go on my own…I prefer it. It is about me and I can tell her (doctor) what I think” (f, 16 i/v).

(vi) Need for health care professionals to have appropriate knowledge
This relates to young people feeling the need to be seen by HCPs with specialist knowledge about their disease and also with a good knowledge about their case and individual needs.

Young people felt reassured if they saw someone who knew them and their disease: “I like going to hospital cos I feel they are specialists they know more about cancer they know it all.” (f, 21 i/v).

It was important to have doctors who would refer them on to others if they did not have the specialist knowledge to deal with their problem. Young people felt it tiring and unhelpful when each time they went to the hospital consultation they saw a doctor who was unfamiliar with their case and thus lacked knowledge and insight: “they should have all the information in front of them, they shouldn’t need to re-ask
questions they already know the answers to or should know the answers to” (f, 16 w/s).

5.3.2.3 Summary of Stage 1 findings
Using innovative and creative methods of data collection to engage young adult survivors of childhood cancer about their views on long-term follow-up services, strong and robust data were generated. Young people were able to provide a clear definition of their long-term follow-up needs and aspects they felt needed to be addressed, and also provided insight into how they would like future service provision to be designed.

With reference to this young people expressed a strong preference to be seen face-to-face by a consultant rather than a nurse or a GP in primary care, although access to a key contact person (not necessarily s doctor) was also a high priority for them. They wanted to receive comprehensive checks and tests as required in their follow-up consultation. A hospital setting for follow-up was generally preferred over a GP clinic, but adult hospital clinics were not a popular option. Telephone and email contact were seen as no substitution for face-to-face contact time. Most of the young people were content with how regularly they were attending clinic so did not feel a need for a change.

Young people would seem to be looking for a service, which provides answers to questions about their illness, effects of treatment they have had and how these may possibly impact on their later life. It is important for the young people that information concerning their illness is built up over time and that they are provided with a record of what they have been through so that they may gain some ownership of their diagnosis.

To feel relaxed in consultations and to be put at ease by doctors and nurses was felt strongly. They also wanted to feel that their needs were being taken seriously and that staff had time for them. Relational continuity was important, with young people valuing seeing the same team of people, and staff using first names terms and seeming to take an interest in them. It was important for the young people to be seen by staff who were knowledgeable about their disease and case so that they did not have to repeat their case history or have to explain what usually happens in their follow-up visit. The young people also emphasized a strong need for support for their parents so that they could better understand the disease, talk to other parents in a similar situation, and also be guided through the young person’s transition into adulthood.

5.3.2.2.4 Outcomes from Stage 1
Given the richness and resonance of these data it was decided to develop the concerns of the young people into a typology of need. A typology is the systematic classification or analysis of classes with common characteristics: it is concerned with grouping rather than defining relationships (Sokol, 1974). Typologies are commonly used across the social, medical and physical sciences as a means of identifying and categorizing discrete data. The typology was developed through further analysis of data within the five categories of need: Components of long-term follow-up: (i) Informational needs (ii) Needs related to communication processes (iii) Need for health care professionals to have appropriate knowledge (iv) Need for a positive relationship with health care professionals (v) Need for parental support.
Two of the researchers (HA and FG) re-examined all of the segments of data within each category of need and then guided by the data broke down each category into subcategories which were then labeled, using as far as possible the original data and hence young persons words. This was achieved through dialogue between the researchers (HA and FG) who asked three questions of each segment of data:

1. What does the data refer to?
2. What does it have in common with other data?
3. How does it differ from other segments of data?

At this preliminary stage each segment of data could be ascribed to more than one code. Comparisons were then undertaken by the two researchers to identify further similarities and differences between the segments in each code to ensure that each segment was coded only once. These data, which were assigned to each subcategory was achieved by consensus between the two researchers. Labels were then assigned to each of the components of the subcategories, the responsibility remaining to maintain the young person’s terms and vocabulary as much as possible. An independent researcher who specializes in typological data then assessed and made comments on the typology developed, this led to minor amendments in terminology being made, but no alterations to the structure. A copy of the typology may be found below (Figure 2).
Figure 1: Typology of Young People’s Follow-Up Health Care Needs

1. Positive relationship with health care professionals
   1.1 Continuity
      • Young person feeling known and being remembered
      • Establishes and maintains rapport & trust
      • Sees the same team of doctors
   1.2 Friendliness
      • Referred to by first name
      • Identified in the young person as an individual

2. Informational Needs
   2.1 Diagnosis-related information
      • Type of cancer
      • Stage of cancer at diagnosis
      • Possible cause of cancer
      • Specific scientific information
   2.2 Post-treatment related information
      • List of treatments received
      • Specific information about treatment and drugs received
      • Purpose of treatments
      • Side effects of treatment
      • Effects of not taking medication directed at side effects
      • Effects of not taking prophylactic treatment
   2.3 Late-effects information
      • Effects of drugs on fertility
      • Effects on cardiac function
      • Effects on hearing
      • Effects on academic achievement
      • Symptoms/problems to be aware of and recognize

3. Needs related to communication processes
   3.1 Ease of Communication in Consultation
      • Concerns medical and non-medical (friendship, fertility, insurance)
      • Directives advice
      • Health promotion awareness (smoking, drinking, drugs, etc)
      • General chat
      • Reassurance and peace of mind
   3.2 Ease of Communication
      • Young people to ask questions and get opinions on cancer and non-cancer issues
      • Assisted by Health Care Professionals
      • Health care professionals having a friendly and relaxed style
      • Awareness of boundaries between patient and professional
      • Treated sensitively
      • Being listened to
      • Taken seriously
   3.3 Enablers of communication
      • Friendly environment
      • Young people given encouragement to speak
      • Knowing the doctor they see
      • Communication directed at young person not parent/HIV/AIDS medical information or others in room
      • Confidentiality
      • Helpfulness of doctors
      • Young people’s needs being taken seriously
      • Treated as a person not a process
      • Feeling relaxed
      • Young people talking as a lead with the doctors (being treated as an adult)
      • Using medical terminology/jargon
      • Doctors being honest and straightforward

4. Communication between health care professionals
   4.1 Communication within secondary care
      • Between other doctors and hospital departments
      • Referral to other doctors
      • Transfer of notes
      • Transfers between secondary and primary care
      • On/Off the loop
      • Need to keep updated
      • Letters sent to GP
   4.2 Communication between secondary and primary care
      • To inform on drugs prescribed
      • Transfer of notes

4. Professional involvement and Need
   4.1 Support for Patients
      • Support and reassurance about the young person’s condition to reduce anxiety and self-blame
      • Availability of peer support groups for survivors
      • Helped to understand with appropriate written information and translation services
      • Supported through transition of young person’s independence

5. Health care professionals have appropriate knowledge
   5.1 Knowledge about disease
      • Specialist expertise
      • Referred to experts
      • Sharing knowledge with patient
   5.2 Knowledge about care
      • Clear understanding
      • Read notes thoroughly
      • No need for young person to repeat care history
      • Doctors knowing case history

Young person does not have to explain what to do
6.0 STAGE TWO (MODELLING PHASE)
In Stage two of the study a consensus meeting was held. This approach was chosen as a means of enabling the young people who had participated in Stage 1 of the data collection to work together with HCPs from the study sites involved to develop the alternative models of follow-up care together, vote for their preferred model and make recommendations for clinical practice. Consensus methods are increasingly used as approaches in a ‘tool kit’ of methods for successful user involvement (Chambers et al., 2003; Tritter et al., 2004). In terms of the MRC framework it is this phase, which enables the identification and definition of components that will form part of any subsequent intervention.

6.1 Data collection, methods and procedure
6.1.1 Consensus Meeting
A one-day consensus meeting was held with 13 young people who had participated in the workshops and semi-structured interviews (10 workshops, 3 interviews), and six HCPs from three of the four UKCCSG centres involved in the study. The HCP group comprised two long-term follow-up consultants, two Clinical Nurse Specialists in long-term follow-up, one endocrinology nurse with an interest in late effects and one senior staff paediatric oncology nurse.

The purpose of this meeting was to feed-back the results of Stage 1 data collection methods to the young people to ensure that their views were adequately represented and for them to work with HCPs to develop alternative models of follow-up care that could address their needs. The consensus meeting was facilitated by an independent consultant (Jane Maitland [JM]), who works with several multi-national companies, as well as small charities. JM was involved from the initial planning stage in Spring 2005. The consensus meeting took place in the conference facilities at the Scout Association Headquarters, Baden Powell House in Central London. The notes concerning discussion points and the mood and atmosphere of the day were taken by AR and Susie Hey (research fellow from another project) respectively. An agenda for the consensus meeting may be found in Appendix 4.

Following introductions and a short icebreaker exercise, findings from Stage 1 (theoretical phase) of the study were fed back to the group by HA. The young people and HCPs were then asked to comment on the findings. It was noted by the two observers in the room that the young people did not initially feel comfortable asking questions. The facilitator enabled progress by requesting each of the groups to work together to discuss the presentations. This then facilitated general discussion.

The young people and HCPs were allocated into four groups by HA to work on selling four different models of long-term follow-up care. Allocation of the young people was made on the basis of and knowledge the research team had gained from previous contact with them in respect of how they worked in a group. Health care professionals were allocated on the basis that they did not work with young people from their own centre. Each group was allocated one model.

Each group was given a set of instructions by the facilitator. They were told that their task was to promote a model of long-term follow-up and to sell it to the rest of the group. Each group was assigned a different model to work on and instructed that they had to create a mood-board (a form of visual stimulus material, comprising a large board covered with images (often cut from magazines) and designed to represent a mood, atmosphere or feeling) or web page that would be eye catching and
would convey the important elements of the model they were promoting. These models had been developed by FG and GL following data collected in Stage 1, which was added to their own existing nursing and medical knowledge of the patient group, current and potential service provision. The groups were each given a selection of coloured paper, tissue paper, pens, stickers, magazines, glue and scissors to work with and allowed 45 minutes to discuss and prepare their mood-boards.

The models were as follows:

**Purple Model:**
This was a nurse-led consultation model. Instead of seeing a doctor young people would see a nurse who decided, following an initial assessment, whether a consultation with a doctor was also required. This change of care would take place when the young person reached 16-18 years and was already receiving follow-up. The late effects specialist nurse would be based at the specialist centre, working alongside the late effects medical consultant, and take on the role of ‘key worker’ for the young person. Young people received this type of follow-up yearly - two yearly until the young person was comfortable to transfer to a general hospital where they would continue to be seen by a specialist nurse who was able to refer young people to appropriate consultants e.g. endocrinologist, fertility expert, psychologist.

**Blue Model:** this model was based on the Wallace et al. (2001) Levels of Care model. It contained a number of options of follow-up directed by treatment received and was health care professional driven. There were different types of follow-up using this model, these included postal questionnaires, and telephone, e-mail, GP and nurse or medical consultant led care. This change of care would take place when the young person reached 16-18 years and was already receiving follow-up.

- For young people who are unlikely to have any long-term health problems in association with the type of treatment they received there was a choice of follow-up. Young people would either a) receive a questionnaire from their specialist centre every 1-2 years, this would be completed and posted back to their centre. The questionnaire would contain details of a person to contact, their ‘key worker’, at the specialist center if they had any concerns or worries. Or, b) would be able to visit their GP at any time if they had worries or concern.

- For young people whose treatment may cause health problems over time, or require follow-up testing, there was a choice of follow-up. Young people could either a) receive regular follow-up with their GP. Their GP would be able to refer to appropriate specialist care as required with advice from the specialist centre. The GP would take on the role of ‘key worker’. Or b) young people could opt to receive their follow-up from a specialist nurse, either face-to-face at the specialist centre, via the telephone or, e-mail. The specialist nurse would be able to refer to appropriate specialist care as required.

- For young people whose treatments would more than likely lead to some health problems in the future, there was no choice. All young people in this group would be seen at a specialist center by a medical consultant who specializes in their particular health problem. In some cases this meant that young people might be seen by more than one specialist.

**Orange Model:** this model contained a number of options of follow-up directed by the need of the young person, rather than by the treatment they received. The young
person could choose from a number of approaches to follow-up using this model, these included follow-up by GP, telephone or e-mail follow-up by specialist nurse, face-to-face with a specialist nurse, or being seen by an appropriate medical consultant who cares predominantly for adults. This change of care would take place when the young person was 16-18 years and already receiving follow-up. Young people would decide on the timing and place of follow-up. This was however flexible, and relied on young people being assigned a ‘key worker’ at their specialist hospital.

**Red Model**: this model retained the current emphasis of medical led follow-up care. Young people would receive this type of follow-up yearly- two yearly, from a specialist centre, irrespective of the treatment received or preferences of the young person. The care of the young person would continue by either:

a) Outreach care from the specialist center to a general hospital;
b) Transfer to a doctor in a general hospital who predominantly cared for adults with cancer;
c) Transfer to a doctor in a general hospital who specializes in a particular health problem.

Having completed the mood boards each group were then required to present their model to the rest of the group. They were given ten minutes and a further ten minutes for each model to be evaluated by the group. At the end of the presentations the group were required to rank the models of follow-up according to preference: 1= model they would most like, 2= second favourite, 3= third favourite, 4= model they would least like.

**6.2 Stage 2 (Modeling Phase) Findings**

In terms of the MRC framework for complex interventions the consensus meeting was undertaken in order to identify and define alternative models of long-term follow-up upon which interventions could be based. The uniqueness of this approach was that it sought to combine professional and users perspectives in the process.

**6.2.1 Presentation of the categories of young people’s follow-up needs**

The young people all agreed that feedback from the workshop and interviews reflected their views and felt that all of their concerns had been addressed. Additional issues raised by HCPs included whether young people had reported cognitive deficits and memory as a problem, and whether regular and thorough check-ups were necessary and beneficial to the young person attending follow-up. Addressing the first issues it was stated that some young people had reported difficulty in retaining all of the information they received in their consultations particularly if the language being used was unfamiliar. In respect of the necessity of check ups and tests in clinic the young people took the lead in responding. One young person (m, 20) said that it was important for doctors to find out what young people wanted in terms of a physical examination. A second young person (m, 23) said that his doctor informed him of what checks he could do himself and he found this to be very beneficial. One young woman said that they would feel as though they were missing out if they did not have a physical examination (f, 23).

**6.2.2 Advantages and Disadvantages of the proposed alternative models of care**

Table 5 shows the key components of each alternative model of follow-up and their respective advantages and disadvantages as identified by the young people.
<table>
<thead>
<tr>
<th>Model</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
</table>
| Orange Model  
Key-worker Model | - Driven by young person and their needs  
- Flexible  
- Something for everyone  
- Key-worker is advocate someone to look after and help the young person  
- Patient choice  
- Something for everyone  
- Not restrictive  
- Works if in different geographical locations | - How often would a HCP be seen  
- Availability of emergency assistance not incorporated into the model  
- Not preventative, only utilized when problem arises? |
| Purple Model  
Nurse-led model | - Nurse easier to talk to  
- Knows you well  
- Opportunity to express yourself  
- Comfortable environment  
- Option of telephone conversation if feel uncomfortable with face-to-face contact | - Nurse not as specialist as a doctor  
- May worry that things have been missed as not seen a doctor  
- Relies on good communication  
- Transition unclear |
| Red Model  
Transfer v transition | - Treated like an adult  
- Transferred when ready  
- Go to adult centre where seen by whichever specialist needs to see you depending on need  
- Local hospital, no need to travel | - Patient choice is missing  
- Depends on what exists locally  
- Big jump for some people between services  
- Transition must be carefully managed to be successful |
| Blue Model  
Levels of care (Wallace et al, 2001) | - Element of choice within levels 1 and 2.  
- Do not have to visit clinic e.g. email/telephone  
- Straightforward to explain which level young person should be in  
- May encourage young people to attend if there is a clear framework | - Restricted patient choice  
- Levels determined by health care professionals  
- Want to be able to see doctor when want to  
- If in level 1 may still want face-to-face appointment  
- If nurse specialist seen, needs to have appropriate knowledge  
- Young person may not feel ready to go without face-to-face contact |

Table 5: Advantages and Disadvantages of each of the alternative models of follow-up

The Orange “key-worker” model (Figure 3) was seen to possess several advantages over the other models, was flexible and incorporated choice. The young people were able to choose which form of follow-up they preferred (email, telephone, nurse contact, doctor contact, GP contact) and care was coordinated by a key worker who acted as their advocate and advisor. The advantages were seen to outweigh the disadvantages of this model. The only disadvantages cited related to uncertainty as to how often follow-up would be, what treatment would be available in a medical emergency and the fact that some young people might only get in contact with a key-worker once a problem arose rather than receiving regular check-ups and advice.
The Purple “nurse-led” model (Figure 4) was viewed as being a friendly and relaxed approach with someone whom the young people were familiar with, but it felt that specialist care was missing and that this could only be achieved by having access to a doctor. The young people were also unclear on how transition would be managed in this model.
The Red “transfer v transition” model (Figure 5) was regarded as advantageous in that young people felt they were being treated like an adult and being given some responsibility for their own follow-up and that transfer could be undertaken at and age and stage that suited them somewhere local to them. However, it was felt that it was not certain if each area of the UK would have the same services available and that if this were the case then patient choice would be lost. It was felt that transition would only be undertaken successfully by means of careful and appropriate management.
The Blue “levels of care” model (Figure 6) was regarded as being straightforward and easy to understand by the young people. It was felt that there was some flexibility of movement between levels 1 (minimal risk) and level 2 (intermediate risk), which meant that clinic attendance was not always necessary. Nevertheless young people were not happy with the feeling of being categorized by HCPs rather than being treated as an individual. They felt that some of their peers might not feel ready to be discharged from annual follow-ups to simply telephone or questionnaire contact and this could lead to non-attendance and late-effects not being identified. The young people also felt that choice as to whether or not a doctor is seen should remain as their needs may change over time.
6.23 Ranking Exercise

The results of the ranking exercise to determine the preferred model of follow-up care are displayed in Table 6. Twelve young people (one had left earlier in the day) and 6 HCPs voted, assigning 4 points to their favourite model, 3 for their second favourite 2 points for their third favourite and 1 point for their least preferred model of care. The Orange “key-worker” model was found to be the model most preferred with 15 out of 18 people ranking it as their first or second choice. The red “transfer to transition” model was placed second followed by the purple “nurse-led” model and the blue “levels of care” model in joint third place.

<table>
<thead>
<tr>
<th>Tally</th>
<th>Orange “key-worker”</th>
<th>Purple “nurse-led”</th>
<th>Red “transfer v transition”</th>
<th>Blue “levels of care”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Favourite</td>
<td>Count (Score)</td>
<td>Count (Score)</td>
<td>Count (Score)</td>
<td>Count (Score)</td>
</tr>
<tr>
<td></td>
<td>10 (40)</td>
<td>3 (12)</td>
<td>2 (8)</td>
<td>3 (12)</td>
</tr>
<tr>
<td>2nd favourite</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5 (15)</td>
<td>5 (15)</td>
<td>10 (30)</td>
<td>2 (6)</td>
</tr>
<tr>
<td>3rd favourite</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 (6)</td>
<td>1 (2)</td>
<td>3 (6)</td>
<td>7 (14)</td>
</tr>
<tr>
<td>Least liked</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>0 (0)</td>
<td>9 (9)</td>
<td>3 (3)</td>
<td>6 (6)</td>
</tr>
<tr>
<td>Total</td>
<td>18 (61 pts)</td>
<td>18 (38 pts)</td>
<td>18 (47 pts)</td>
<td>18 (38 pts)</td>
</tr>
</tbody>
</table>

Table 6: Results of the ranking exercise to determine the preferred alternative model of care

6.3 Summary of Stage 2 findings

The one-day consensus meeting provided positive feedback and support for the findings of Stage 1 data collection and allowed for future models of care as outlined by the research team to be developed by young people in collaboration with the health care professionals.
Of the four models that were suggested, the “key worker” (orange) model was preferred to the transitional, nurse led and levels of care models. This was unsurprising given the comments made by young people in Stage 1 data collection emphasising the need to have a contact person at the hospital who would provide a link between services that needed to be accessed and the patient. This model also gave the young people an element of control over their care compared to the other three models that were either HCP driven or perceived to be inflexible in their structure.

6.4 Outcomes from Stage 2
Dialogue between young people and HCPs has made it possible to articulate and develop an alternative model of follow-up care. This model, referred to as the “key-worker” model of care is underpinned by a number defining features:

1. **Preparation for transition.** At 16-18 years of age (dependent upon the young person’s level of maturity and comprehension) the late effects team at the original site of care and the young person will discuss the implications of the cancer diagnosis, treatments received, and possible long-term effects. A written summary of their diagnosis and treatments along with useful information such as the “after-care” booklet, and website addresses of appropriate websites e.g. where further information may be accessed will be provided to the young person. Through discussion with the young person would enable a suitable key-worker to be allocated.

2. **Identification of a key worker.** The key-worker has a series of roles:
   - Acts as first point of contact between the young person and follow-up services;
   - Coordinates and monitors follow-up care;
   - Liaises between primary and secondary care and between different hospital departments.

   The key worker is likely to be from the late effects team at the original paediatric care site, but not necessarily involved in follow-up (this all depends upon the young person and their level of need). Explanation of the different approaches to follow-up would be one of the immediate responsibilities of the key worker.

3. **Choice in method of follow-up.** Different types of follow-up are available and made use of as appropriate, directed by the need of the young person supported by the key worker. The methods available include face-to-face appointments at either a specialist centre or local hospital with a doctor or nurse, GP follow-up or telephone, email or postal contact. The flexibility and transfer between methods of follow-up would be fundamental to the success of the model.

4. **Flexibility.** This is an important feature of this model, e.g. key worker and method of follow-up, and would be subject to regular review by the key-worker and young person.

This model is represented in Figure 7.
7.0 DISCUSSION
This project has clearly addressed the main aims of the study by detailing the dimensions of care most valued by young people, their perceptions of current methods of long-term follow-up, an understanding of the approaches to follow-up that young people would prefer, and their views on alternative models of care. This study has also fulfilled the theoretical and phase 1 modelling criteria of the MRC guidelines for complex interventions. It has provided strong theoretical data to underpin the design of a future trial of different methods of follow up. The project has also gone beyond the original study remit by providing indicators of person centred care in respect of follow-up that will require further development. This research provided a unique opportunity for young people not only to have their views on long-term follow-up heard but to also to work alongside HCPs in order to inform and shape future service delivery. Young people valued these interactions and the opportunity to work together on the development of a service that they will continue to experience at first hand. This was demonstrated not only in the continued participation of the young people through the two stages of the study, but by feedback given.

Figure 7: The proposed “key-worker” model of long-term follow-up
7.1 Dimensions of care valued by young people

The dimensions of care most valued by young people are manifest in their specific needs related to information, communication, involvement of parents, and the knowledge of HCPs and their relationships with them.

It is evident from the workshops and interviews that some young people felt in the dark about their respective conditions, the treatments they had received and the possibility of late effects. This supports the findings of Zebrack et al. (2004) where lack of information about diagnosis and treatment was highlighted as a key concern by a Delphi panel of young adult survivors. It has also been suggested that lack of illness information can lead to negative affect and in extreme instances post-traumatic stress disorder as young people try to piece together what they have been through (Patenaude & Kupst, 2005; Kazak et al., 1997; Hobbie et al., 2000). For young people, in this study at least, it would seem essential that HCPs do not simply inform their parents of the consequences of their illness and treatment regimens at the time of diagnosis, but that information is repeated and updated at different points over time and directed at the young people themselves in an accessible and comprehensible form (Young et al., 2003).

Understanding what they have been through, the treatments they have undergone and possible life-long implications enables young people to have ownership of their illness (Zebrack et al., 2004). It has been shown that HCPs underestimate this need (Hooker, 1997). This may be reinforced through the use of patient held records and treatment summaries which young people are eager to have in their possession. This has also been advocated by SIGN Guidelines (2004) and the recent NICE guidelines (2005), which state that: “a summary of treatment received and complications experienced should be available to the patient and healthcare professional. This should include details of the total doses of chemotherapy, details of radiotherapy and surgery, and information on existing or anticipated late effects” (p. 78).

Feeling that follow-up care is individualised is a dimension of care highly regarded by young people in this study. This was discernible through the need for positive relationships with staff, feeling known and remembered and having relational continuity. Goldsby & Ablin (2004) argue that the bond and rapport young people have with their paediatric oncologists means that in turn late effects are more likely to be identified; however, others have disagreed with this (Brada, 1995). Yet for young people it was disheartening to have to repeat their “cancer story” to different HCPs on more than one occasion and this was a notable barrier to follow-up.

Receiving specialist care from experts in the field was a dimension of care valued by the young people in this study. Paediatric oncology doctors were regarded, as being the most informed whilst GPs and nurses were viewed with some caution, as they were perceived to lack the necessary skills required carrying out long-term follow-up. This confirms the finding of Zebrack et al. (2004). Yet these views held by young people may be due to naivety as to the role of nurses such as CNSs. Such nurses are highly trained and skilled and in some parts of the United States, have been leading long-term follow-up clinics for over 20 years (Hobbie, 1986). Although this nursing role is only beginning to be described in the UK (Morrison, 2005), there are clear arguments and benefits for further expansion (Gibson & Soanes, 2001; Soanes et al., 2004; Hollis, 2005). The views of young people in this study may have been reflective of their experience that included limited exposure to a CNS undertaking the specialist role of long-term follow-up care. Future studies
might reveal changes in these perceptions as the advanced role of the children’s cancer nurse becomes more universal.

Positive communication between young people and HCPs is vital in long-term follow-up. Young people are a particularly difficult age group to engage with (Curtis, 2004; Hanna & Jacobs, 1993). Therefore additional effort needs to be made by HCPs in providing young people with a friendly, relaxed and welcoming environment where the young person feels that their needs are being taken seriously and that confidence’s would not be broken. Open and improved communication channels between primary and secondary care and different specialities within secondary care is something that young people felt could be improved and this has been reflected in previous studies (Zebrack et al, 2004, Taylor et al., 2004, Mertens et al., 2004).

Young people felt that there was a strong need for specialist support groups and information provision for parents in order to reduce the burden on young people. Whilst such provision is uncommon in the UK it is in place in some US clinics (Hobbie, 1986). Having provision for someone to guide parents through the transition from desperately ill child to an independent and autonomous adult was something that the young people in this study felt was necessary, and has been reported by others (Young et al., 2003). Nevertheless it should be noted that some young people were quite happy for their parents to still be involved in their follow-up visits and care.

7.2 Perception of current approaches to long-term follow-up

No measurement of satisfaction was undertaken in this study in relation to current long-term follow-up service provision. Previous research (Eiser et al., 1996) has suggested high levels of satisfaction with clinic follow-up (70%) yet this study by Eiser et al. (1996) is potentially flawed by the fact that questionnaires were administered whilst young people were attending clinic so they many not have felt comfortable expressing their feelings freely if they perceived it might influence the quality of care they were receiving. Nevertheless in this current study it was possible to get a strong idea of how young people wanted their long-term follow-up care designed and structured and the respective processes it would involve. Overwhelmingly, young people were very happy with the service they were receiving. The data revealed variation in relation to the centres involved and perceived individual needs. Reflections on the environment and personnel dominated discussions to reveal both positive and negative reflections on the current service.

Clinics situated in paediatric environments for many of the young people were not viewed as ideal. A number of young people expressed discomfort at being around young children who were undergoing aggressive cancer treatments (Von der Weid & Wagner, 2003). However, such environments did contain the personnel who young people saw as key to their care (e.g. paediatric oncologists and endocrinologists). Moreover, adult clinics were regarded as faceless, overcrowded and impersonal by the young people, and GP clinics were seen as being rushed and lacking the relevant specialist personnel. This adds weight to the current suggestions that the ideal clinic setting for this age group may be an age-appropriate clinic staffed by clinicians familiar to young people. The NSF for Children, Young People and Maternity Services states that: "all young people have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood" (Standard 4) (p.
6). Clearly, future models of follow-up will need to consider transition in terms of need and readiness to move on (McDonagh, 2005).

Stories of expert doctors and nurses, whom they had formed a relationship with featured in many accounts and were valued by all young people. Expert knowledge about diagnosis, treatments received and risk factors underpinning continued health surveillance have been recognised as indicators of comprehensive quality care for cancer survivors (Harvey et al., 1999): noted previously to be of importance by HCPs (Masera et al., 1996) and cancer survivors (Zebrack et al., 2004). Not surprisingly doctors, their role and valued support, featured more than reflections on any other HCP. This is reflective of the perceived pivotal role of doctors in the four centres, despite there being specialist-nursing input at three of the four centres. Future models of follow-up will need to reassure young people that expert knowledge is not just the privilege of doctors. Historical perspectives of a service will need to be challenged using supportive and systematic strategies.

7.3 Reflections on the alternative model of follow-up care
Transition, preparation, informing, supporting and continued health surveillance feature in the model, all of which have been noted to be of importance when developing appropriate services (Harvey et al., 1999; Goldsby & Ablin, 2004; Por, et al., 2004; Zebrack et al., 2004; McDonagh, 2005). The NICE guidelines (2005, p.78) make consistent reference to the role of a key worker. In addition, the SIGN guidelines state: “there is an important role for a designated key worker for each patient to co-ordinate care. Depending upon the needs of the individual patient an appropriate key worker should be drawn from the multidisciplinary team” (2004, Section 2.3). The young people in this study, in the absence of reading these policy documents, concur with current thinking. Findings from this study reveal indicators that might be used to measure the success of any future model. Principally, success will be dependent on the role of the key worker and the relationship established with the young person.

8.0 CHALLENGES
During the course of this project a number of challenges arose concerning the following areas:

1. Recruitment
2. Data collection practicalities
3. Data collection methods

8.1 Recruitment
The project aimed to garner the views of both clinic attendees and non-attendees in order to get a complete picture of perceptions and attitudes towards long-term follow-up services; however, many problems were encountered in respect of recruiting both groups to the project. Due to the geographical setting of the study, the Research Fellow was unable to play an active role in recruitment and so reliance was placed on nurses and database managers within the long-term follow-up teams at each centre to recruit patients. Nurses were already stretched in their day-to-day job so finding time to devote to selecting and sending out information packs and reminder letters to the young people was difficult. Databases at some of the centres were also not-up-to-date so patient selection often proved problematic. Particularly in respect of the non-attendee population a significant number of information packs were returned either to the centres involved or to the Institute of Child Health with “addressee unknown”. In one instance information pack was sent to a young person
who unbeknownst to the contacting centre had died two days previously: the centre concerned followed this up.

In retrospect recruitment may have been facilitated by an amendment to protocol enabling the Research Fellow to attend follow-up clinics and approach young people in clinics. Face-to-face recruitment has proved in previous studies to be more appropriate and would have reduced the burden on clinical staff locally. However, in this case this was not deemed to be practical as some of the young people only attend clinic once every five years, and the centres involved were spread across England.

Recruitment may also have been hindered by the fact that workshops were run between April - June 2005, which for many young people is a busy time for school and university examinations. Young people were also required to give up one day of their weekend to participate in the workshops. For many who have Saturday jobs this was not feasible. Flexibility underpinned the whole project, but on reflection it may be concluded that recruitment of young people who have busy lives may always present challenges, not all of which can be overcome successfully in a single study.

8.2 Data collection practicalities

It was necessary for the workshops to be run at weekends between April – June 2005, but for many young people this marked their examination period and so they could not attend. Young people who had Saturday jobs also found attending difficult. The centres also have patients from a large geographical spread so attending the workshops often meant a two-hour journey even if they took place in the same City as the hospital site. Whilst a number of young people consented to take part in the study and assured the Research Fellow a day before the workshops that they would be attending, there was a high-rate of non-attendance. Reasons left on the Research Fellows answer phone typically involved apologies for oversleeping. A follow-up call to each non-attendee may have revealed other reasons that could have been useful in future studies.

8.3 Data collection methods

The data collection methods used with the young people was highly successful and engaging. They produced a wealth of quality data. A wide variety of young people took part and with the exception of one young person at one of the workshops and a second at the consensus meeting, all were happy to participate in the activities. In these two instances observations revealed an element of discomfort and a desire to be elsewhere. Both young people were enabled to make a decision about continuing participation, and left after a period of time.

The workshop days were difficult to organise, as non-hospital venues providing suitable space at a reasonable price were difficult to find. The initial planned workshop dates also had to be postponed due to slow recruitment rates. The consensus meeting was also difficult to coordinate as although the date of the meeting had been set many months beforehand a number of HCPs from the centres found it difficult to attend and were unable to find suitable replacements. The importance of planning and maintaining good communication thought the period of data collection was reinforced following these difficulties.

9.0 IMPLICATIONS

This research has many implications for CLIC Sargent, the provision of cancer services and service development, and for future research.
9.1 Implications for CLIC Sargent
CLIC Sargent is the UK's largest children’s cancer charity. They have a strong voice both nationally and internationally. The vision of CLIC Sargent is “to see a world where all children and young people with cancer live life to the full”. This report provides evidence of what young cancer survivors want to maximize their potential to live their lives the way they want to. This involves being fully informed in order to make choices and take decisions about their own health needs. Consultation with young people provides valuable feedback to professionals. Work such as this project, which seeks to engage with a group considered difficult to recruit to studies, needs to be continued and would benefit from continued support from the charity to find ways for young people to become research participants in projects to evaluate and improve services. It is clear that young people would value and indeed were proactive in leading a discussion on the advantages of having a key worker. The key-worker model of follow-up has important implications for charities such as CLIC Sargent as the resource and workforce implications that might arise as a consequence of this new role have yet to be assessed.

9.2 Implications for practice and service developments
This research has many implications for the development of services to meet the needs of young cancer survivors. This qualitative study has enabled the voices of young people to be reported. This report is evidence of both met and unmet needs. Assembling these needs in a typology presents those delivering and commissioning services a tangible indicator of outcome that can be confidently described as what young people want from a follow-up service (Figure 2). The typology has the potential to serve a number of purposes:

1. To inform service development of the nature and extent of follow-up needs required by young people who have had cancer;
2. As a guide for HCPs in cancer services to measure best practice and to benchmark;
3. As a guide for young people when deciding whether a follow-up service is meeting their needs.
4. As a guide for HCPs to use in consultations with young people.
5. To develop transitional packages of care.

In order to fulfil all these purposes the typology would need to be constructed and individualised to be a useful instrument. Local implementation by the UKCCSG centres would be encouraged. Whilst there are guidelines available about how follow-up care should be administered and what late effects need to be observed, to date this is the only instrument that details in a practical and useable format the follow-up care needs of young people.

Appropriate local and national dissemination will provide the vehicle to present the study and to create dialogue with HCPs in the UKCCSG centers to consider comprehensive approaches to follow-up care nationally. Likewise, dissemination to young people and their families who participated in the study and future families receiving care will be important. See Appendix 5 for our plans for dissemination.

9.3 Implications for future research
The focus of future research will need to concentrate on three elements:
- Ensuring the typology is complete and fit for purpose;
- Evaluating the key worker model of follow-up care;
- Developing young people as research participants.
Further consultations with young people will need to be undertaken to ensure the typology is complete. This would ensure that any gaps are filled and inconsistencies clarified. A number of methods would enable this process and facilitate the inclusion of a greater sample of young people reflective of the populations served by UKCCSG centers throughout the UK and Ireland. One method would be a Delphi survey. Once complete the typology would need to be constructed to ensure fitness for purpose. Use in practice, local development and testing would reveal different modes of use of the typology. There is also potential for international collaboration that may situate the typology as a complement to other guidelines already available.

The key worker model must be evaluated both from a patient satisfaction viewpoint and in terms of DNA rates, cost/benefit and health outcomes. The MRC framework (2000) directs research to the next stages of an exploratory trial; a definitive randomized controlled trial and long-term implementation. The feasibility and benefits of this strategic approach needs to be debated. A more practical yet creative method may need to be sought to influence and evaluate current service provision (Pawson & Tilley, 1997). There is a potential for the Department of Health to play a significant role supporting such work financially through its research and development programme.

Young people appreciated the participatory research methods used throughout this study, once we had been successful with recruitment. Involving young people at a much earlier time point in the research and in a more focused way may influence recruitment and overall participation. Enabling young people to participate in the design and conduct of future research will extend our use of participatory research (Kirby, 1999, 2004; Moules, 2005).

10.0 CONCLUSION

By involving young adult survivors of childhood cancer in research concerned with future follow-up care a voice has been provided to what is in research terms, a silent, neglected and ever increasing population of service users. As a result this project has provided important insights into what young people value and want from their long-term follow-up care, and how they feel that future service provision should be designed. Of particular interest is the finding that the young people’s preferences for long-term follow-up differ dramatically from those advocated by health care professionals (e.g. Wallace et al., 2001); this conclusion is specific to this group of young people as with any qualitative study generalisations are not possible. This highlights the need to undertake further research and why the voice of the service-user in each treatment center needs to be heard and considered when designing services. By developing a typology and an alternative model of care focusing on a key-worker model this research has provided tangible outcomes for practitioners to use in developing and evaluating services that are patient centred.

11.0 REFERENCES


41) National Institute for Clinical Excellence (20005). Service Guidelines “Improving Outcomes in Children and Young People with Cancer” www.nice.org.uk


50) Punch, S. (2002). Interviewing strategies with young people: the “secret box” stimulus material and task-based activities, *Children and Society*, 16 (1) 45-56


Childhood Cancer.


Recruiting centre identifies 20 potential participants from their database and clinic lists. This needs to be completed by Friday 25th February 2005.

Information packs sent out from recruiting centre.

Recruiting centre records on datasheet who has been contacted and date pack sent. Helen informed of number (not names) of people contacted via email h.aslett@ich.ucl.ac.uk

Young person contacts Helen direct (either by email or telephone) if they would like to participate.

Helen informs staff at recruiting centre about the young people who have responded

If Helen does not hear from young people after two weeks …
- follow up letters sent out by recruiting centre to non-responders.
- Number of non-responders recorded.

With either method, when young person has agreed to participate, the date and time of the workshop to be attended is arranged.

Young people contact Helen by email/telephone. Helen provides them with brief information about the study and takes their contact details.

Young person is sent an information pack by Helen.

Helen makes a follow-up call to young person after a week to confirm that they have received the information.

- Young person consents to participate in the study.
- Alternatively a follow-up call is made 24-48 hours later to confirm participation.
- Basic demographic information is recorded.

If young person does not wish to participate in the study
- reasons for refusal are obtained
- basic demographic information is recorded.
Recruitment of Clinic Non-Attenders (n=10)

Defined as: “Two consecutive non attendances or 2 failed appointments out of 5 offered appointments in a five year period”.

Method of Recruitment

10 young people who fulfil the DNA criteria to be identified by the recruiting centre from database searches.

Recruiting centre mails out information packs to young people. This needs to be completed by 5th February 2005.

Recruiting centre records onto datasheet patients’ details and informs Helen via email (h.aslett@ich.ucl.ac.uk) number of packs and date of distribution.

- Helen records on a database the names of young people who make contact.
- Two-week period is allowed from distribution to first contact.
- If not heard by that time Helen to confirm names of responders to the recruiting team.
- Follow-up letter sent to non-responders by recruiting centre.
- Young person contacts Helen by telephone/email if they wish to participate.
- If they express an interest they will be given the opportunity to either undertake telephone interview/workshop.

If not enough responses received the recruiting centre selects more suitable young people from their database and distributes information packs in the same way as described above.
Developing new approaches to long-term follow-up care
A chance for you to have your say

This research study explores with young people their needs when receiving follow-up care after being treated for cancer. We plan to work with young people to find out new ways of delivering follow-up care.

If you are a young person between the ages of 16-25 years and are more than 5 years from your last treatment, and are interested in helping us with this task, and telling us how you think services could be made better for you, please speak with one of the health care professionals in the clinic or take a tear off slip below and contact us direct.

Thank you for your interest

Principal Investigators
Dr Faith Gibson, Dr Gill Levitt

Professor Alison Richardson

Research Fellow in Child Health
Dr Helen Aslett

This research is funded by CLIC and has been approved by the Institute of Child Health/Great Ormond Street Multi-Research Ethics Committee
Dear
Re: Developing alternative models of follow-up with young people who have been treated for cancer

I am writing to you about the above project, which aims to consult with young people who have been treated for cancer. You have been sent this letter by the medical team at the hospital where you are receiving follow-up care as a suitable participant. We would like you to take part in a workshop to obtain your views on the health services you receive. If you would rather express your views in a telephone interview then please let us know and we will send you out the relevant information.

We would like you to read the enclosed information sheet that describes the project. The information sheet explains what the project is all about and what it would involve for you (if you wish to, and are able, to take part in the project).

As you will see from the information sheet there are a team of researchers on this project: Dr Faith Gibson, Professor Alison Richardson, Dr Gill Levitt and Dr Helen Aslett. If you require any further information before making a decision then please contact Dr Helen Aslett on h.aslett@ich.ucl.ac.uk 020 74059200 ext. 0720. If the information we have provided is sufficient and you would like to participate then please ring Dr Helen Aslett who will ask to take down your contact details and arrange a time to ring you regarding the details of your participation in this project.

Many thanks for your time.

Yours sincerely

Dr Faith Gibson
Lecturer in Children’s Nursing Research
On behalf of the Project Team

Institute of Child Health
Great Ormond Street Hospital for Children
APPENDIX 2a LETTER TO ATTENDERS

February 2005
Developing alternative models of follow-up with young people who have been treated for cancer

Here is some information about a project you have expressed an interest in. It explains what the project is about and what it would involve for you, if you wish to and are able to take part.

The aim of the study:
Our aim is to consult with young people like you to find out what they want from their health service. We want to make sure that we are meeting the needs of young people like yourself who have been treated for cancer by delivering follow-up of maximum benefit with least intrusion.

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

How is the study to be done?
In this study we will be talking to young people between the ages of 16-25 years from 4 hospitals that treat young people who have had cancer across the UK. We will organise for young people to come together on two separate occasions (spaced about four months apart) to discuss their views of current follow-up services and what might be important aspects of any future service that was to be developed.

On each occasion (probably about 4 hours over lunch, which we will provide) you would be invited to join the research team at a suitable venue; here you will meet other young people around the same age as you. First of all we will spend some time getting to know each other. After this you will be invited to choose a partner to interview. We will supply you with some questions to ask, but through the interview you may think of some different questions, which you can also ask. This is a two-way process in which you will have an opportunity to ask and answer questions: like
a reporter for a newspaper when asking questions. We will ask you to write down or record the answers. We will come back together as a group and talk about the experience of doing this exercise. We will use what is written down on the notepads to help us. We would then work in two groups, using post-it notes on a wall, for you to show us what is most important and least important of what we have discussed. While you are having lunch the researchers will draw these two exercises together into a series of questions that we can use to explore in a group discussion. So that we do not lose any of the words spoken we will tape record this final activity. Finally, you will model what you want from a follow up service using an activity that will enable you to draw on the previous activities to develop ‘the ideal service that would meet your needs’. We will photograph the visual materials you develop so that we do not lose any of your creativity.

The results from this day will be presented at a meeting of healthcare professionals who work at a number of hospitals across England. At this meeting they will consider and try to agree on ways in which follow up care might be changed. To do this they will hear about your views and listen to findings from other studies.

You will then be invited to participate in a second meeting to hear about the results of this day and discuss what you think about their ideas and the degree to which they match your own. This second day will be conducted in much the same way as the first.

**What are the risks and discomfort?**

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

**Who will have access to the research records?**

All information will be treated in the strictest confidence. Only the researchers will have access to the detailed data collected during the activity days. Whilst the results from each of these days will be fed back to healthcare professionals no young person will be personally identified. You will have the opportunity to obtain a brief report of the study once it is complete. We will send you a regular newsletter about how the study is going over the next year.

**What are the potential benefits?**

To you at this time there are no immediate benefits. But we do hope that the knowledge we gain from our study will assist us in ensuring that the service we provide in the future is appropriate and designed to meet the needs of children and young people with cancer.
**Do I have to take part in the study?**
No, your involvement is totally voluntary. If you do not wish to take part in this study your treatment and care now and in the future will not be affected in any way. If you find after attending the first day you do not wish to return for the second meeting this will not be a problem. You will not be asked to provide us with a reason as to why you don’t wish to attend.

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

**Details of how to contact the Researcher:**
There are four members in the research team:
- Dr Faith Gibson (Lecturer in Children’s Nursing Research, Great Ormond Street Hospital)
- Professor Alison Richardson (Chair in Cancer and Palliative Care Nursing, Kings’ College London)
- Dr Gill Levitt (Consultant in Late Effects, Great Ormond Street Hospital)
- Dr Helen Aslett (Research Fellow, Great Ormond Street Hospital)

To make communication with the team easier we have identified two main people who you will be communicating with:

You can contact either Dr Helen Aslett or Faith Gibson: see contact details below.

**Dr Helen Aslett**  
**Research Fellow in Child Health**  
**Tel: 0207 405 9200 extension 0720**  
**h.aslett@ich.ucl.ac.uk**  
**Or write to:**  
**Centre for Nursing and Allied Health Professions Research**  
**7th floor Old Building**  
**Great Ormond Street Hospital for Children NHS Trust Great Ormond Street**  
**London, WC1 N3JH**

**Dr Faith Gibson**  
**Lecturer in Children’s Nursing Research**  
**Tel: 020 7813 8543**  
**Gibsof@gosh.nhs.uk**

**Or write to:** Same address as above
Developing alternative models of follow-up with young people who have been treated for cancer

Information for parents
We would like to inform you about a study that your child has been approached to participate in.

The aim of the study
Increasing attention is being paid to involving patients, including children and young people, in local service development. Previous studies have identified differences between the views of children themselves and the views of adults close to them. Our aim is to consult with young people to find out what they want from the health service. We want to make sure that we are meeting the needs of young people by finding out more about their experiences when receiving follow-up care at the hospital.

Why is the project being done?
We value the views and opinions of young people who are currently receiving NHS care. How young people experience this care and treatment, and what they see as important has received little attention in the past. We want to identify the needs of young people with cancer from their point of view in order to gain an understanding of views of current cancer care services, including positive experiences and issues, which have been less positive. We will be asking young people what would be important aspects of future follow-up they would like to receive. Our aim is to use the experiences of young people to inform the development of alternate models of follow-up care. We will be sharing what we find with colleagues at your treatment centres and three others in the United Kingdom.

How is the study to be done?
In this study, we will be talking to boys and girls between the ages of 16-25 years from 4 hospitals that treat young people with cancer in the UK. We are planning to use research techniques that are age specific to enable us to tap into the direct experience and points of view of young people. With your child we will be using a number of techniques as part of a workshop to help them to tell their story. Three of our research team, Faith Alison and Helen will be working with your child on these days. They all have experience working with children and young people in previous research studies. In addition Faith and Helen have considerable years experience...
caring for children and children with cancer. If your child agrees to take part in this study, we will arrange a date and time that for them to join us at a suitable venue. Our workshop has four parts to it: peer interviews, a priority setting exercise, a focussed discussion and a modelling exercise. Our aim within all these exercises is to enable your child to share their experiences with others and to ultimately develop alternate models of follow up. We have identified some questions alongside a story that provides an example of what we currently mean by follow-up care. Young people will ask of each other these questions, it is their responses that they will be prioritising. This will be followed up by a group type interview in which the questions we ask will have been shaped by the previous two exercises. The final activity will ask the young people to model what they would want to see in a follow-up service. We will be tape recording the interviews, so that we do not miss any of what is spoken and taking photos of any materials used and developed by the young people. We will repeat similar exercises in a second day following consultation with health care professionals from the 4 treatment centres about the models developed by young people. This final day ensures that we are truly involving young people in the consultation process by taking back to them discussions held with health care professionals.

What are the risks and discomfort?

We do not expect any. But we recognise that coming together in a group can cause some initial worry. We will aim to make the experience as relaxed as possible, making the communications creative and fun. We will make use of a graffiti wall (where the young people can use post its to scribble thoughts about the activities and post on the wall) in the room where we are working so that your child can give us feedback throughout the day. But, if they do find the activities difficult they can leave at any point in the day, they can return later in the day if they wish or not at all. If they do want to leave they will need to make their feelings known to one of the research team, who would be able to spend some time with your child outside of the group. Your child can choose to bring one of their parents with them or a friend; we will provide a room for you with refreshments. Travel expenses will be refunded in full and refreshments provided.

Who will have access to the case/research records?

All information will be treated in the strictest confidence. Only the researchers will have access to the data collected during this study. You will have the opportunity to obtain a brief report of the study once the study is completed. We will be communicating with your child throughout the study using a newsletter. They will also receive a report written specifically for young people.

What are the potential benefits?

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

Do they have to take part in the study?
No, their involvement is totally voluntary. If they do not wish to take part in this study your treatment and care now and in the future will not be affected in any way. If you have concerns about your child participating in the study, in the first instance we would encourage you to discuss your concerns with your child. As a family we would encourage you to reach a shared decision on whether to participate or not.

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

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There are four members in the research team: Dr Faith Gibson (Lecturer in Children’s Nursing Research, Great Ormond Street Hospital), Professor Alison Richardson (Chair in Cancer and Palliative Care Nursing, Kings’ College London), Dr Gill Levitt (Late Effects Consultant) and Dr Helen Aslett (Research Fellow, Great Ormond Street Hospital). To make communication with the team easier we have identified two main people who you will be communicating with:

**Details of how to contact the researchers:**

*Dr Helen Aslett*
Research Fellow
Tel: 0207 405 9200 extension 0720 [h.aslett@ich.ucl.ac.uk](mailto:h.aslett@ich.ucl.ac.uk)

Or write to:
Centre for Nursing and Allied Health Professions Research  
7th floor Old Building  
Great Ormond Street Hospital for Children NHS Trust  
Great Ormond Street  
London, WC1N 3JH

*Dr Faith Gibson*
Lecturer in Children’s Nursing Research  
Tel: 020 7813 8543 [Gibsof@gosh.nhs.uk](mailto:Gibsof@gosh.nhs.uk)

Or write to:
Same address as above
Dear
Re: Developing alternative models of follow-up with young people who have been treated for cancer

I am writing to you about the above project, which aims to consult with young people who have been treated for cancer. You have been sent this letter by the medical team at the hospital where you are receiving follow-up care as a suitable participant. We would like you to take part in a telephone interview to obtain your views on the health services you receive. If you would rather express your views in a group situation we are also holding a series of one day workshops, one of which you would be very welcome to attend. If you decide this is preferable for you then please let us know and we will send you out the relevant information.

We would like you to read the enclosed information sheet that describes the project. The information sheet explains what the project is all about and what it would involve for you (if you wish to, and are able, to take part in the project).

As you will see from the information sheet there are a team of researchers on this project: Dr Faith Gibson, Professor Alison Richardson, Dr Gill Levitt and Dr Helen Aslett. If you require any further information before making a decision then please contact Dr Helen Aslett on h.aslett@ich.ucl.ac.uk 020 74059200 ext. 0720. If the information we have provided is sufficient and you would like to participate then please ring Dr Helen Aslett who will ask to take down your contact details and arrange a time to ring you regarding the details of your participation in this project.

Many thanks for your time.

Yours sincerely

Dr Faith Gibson
Lecturer in Children’s Nursing Research
On behalf of the Project Team
Developing alternative models of follow-up with young people who have been treated for cancer

Here is some information about a project you have expressed an interest in. It explains what the project is about and what it would involve for you, if you wish to and are able to take part.

The aim of the study:
Our aim is to consult with young people like you to find out what they want from their health service. We want to make sure that we are meeting the needs of young people like yourself who have been treated for cancer by delivering follow-up of maximum benefit with least intrusion.

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

How is the study to be done?
In this study we will be talking to young people between the ages of 16-25 years from 4 hospitals that treat young people who have had cancer across the UK. We will be talking to young people over the telephone on two occasions spaced about four months apart. We will send some questions and information about the interviews ahead of time. But you will also have the opportunity to make suggestions other than in the areas covered by the interviewer. With your permission, we would like to tape record the interview, so we do not miss any of the points you talk about. The first interview will explore your experiences of follow up, what care you might like to receive in the future and what this might look like.
The results from the first interviews will be presented to healthcare professionals who work at a number of hospitals across England. At this meeting they will consider and try to agree on ways in which follow up care might be changed. To do this they will hear about your views and listen to findings from other studies conducted throughout the world. You will then be invited to participate in a second interview to hear about the results of this meeting and discuss what you think about their ideas and the degree to which they match your own.

What are the risks and discomfort?
We do not anticipate any. The interviews will obviously take up some of your time but we will try our best to schedule them at a time most convenient for you. We anticipate each interview will last no longer than 30 minutes. But we recognise that being interviewed can cause some initial worry. We will aim to make the experience as relaxed as possible. We hope by sharing with you, ahead of time, possible areas to be talked that this will allay some of your worries. But, if you do find the interviews in any way difficult you can stop them at any point. We will, if you don’t mind, call you the day following each interview to ask if you have any outstanding questions, issues or worries.

Who will have access to the research records?
All information will be treated in the strictest confidence. Only the researchers will have access to the detailed data collected during the telephone interviews. Whilst the results from each of the interviews will be fed back to healthcare professionals no young person will be personally identified. You will have the opportunity to obtain a brief report of the study once it is complete. We will send you a regular newsletter about how the study is going over the next year.

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

Do I have to take part in the study?
No, your involvement is totally voluntary. If you do not wish to take part your treatment and care both now and in the future will not be affected in any way. If, after agreeing to take part and having participated in the first telephone interview you feel you would rather not be interviewed a second time that will not be a problem.

Who do I speak to if problems arise?
If you have any complaints about the way in which this research project has been, or is being conducted, please, in the first instance, discuss them with the researcher. If problems are not resolved, or you wish to comment in any other way, please contact the Chairman of the Research Ethics Committee; by post via Research and
The research team includes:
There are four members in the research team:
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Professor Alison Richardson (Chair in Cancer and Palliative Care Nursing, Kings’ College London)
Dr Gill Levitt (Consultant in Late Effects, Great Ormond Street Hospital)
Dr Helen Aslett (Research Fellow, Great Ormond Street Hospital)

To make communication with the team easier we have identified two main people who you will be communicating with:

You can contact either Dr Helen Aslett or Faith Gibson: see contact details below.

Dr Helen Aslett  
Research Fellow  
Tel: 0207 405 9200 extension 0720  
h.aslett@ich.ucl.ac.uk  
Or write to:  
Centre for Nursing and Allied Health Professions Research  
7th floor Old Building  
Great Ormond Street Hospital for Children NHS Trust  
London, WC1 N3JH

Dr Faith Gibson  
Lecturer in Children’s Nursing Research  
Tel: 020 7813 8543  
Gibsof@gosh.nhs.uk  
Or write to: Same address as above
APPENDIX 2b INFORMATION SHEET FOR PARENTS OF NON-ATTENDERS

Developing alternative models of follow-up with young people who have been treated for cancer

Information for parents

We would like to inform you about a study that your child has been approached to participate in.

The aim of the study
Increasing attention is being paid to involving patients, including children and young people, in local service development. Previous studies have identified differences between the views of children themselves and the views of adults close to them. Our aim is to consult with young people to find out what they want from the health service. We want to make sure that we are meeting the needs of young people by finding out more about their experiences about the follow-up care provided at the hospital.

Why is the project being done?
We value the views and opinions of young people who are currently receiving NHS care. How young people experience this care and treatment, and what they see as important has received little attention in the past. We want to identify the needs of young people with cancer from their point of view in order to gain an understanding of views of current cancer care services, including positive experiences and issues, which have been less positive. We will be asking young people what would be important aspects of future follow-up they would like to receive. Our aim is to use the experiences of young people to inform the development of alternate models of follow-up care. We will be sharing what we find with colleagues at your treatment centres and three others in the United Kingdom.

How is the study to be done?
In this study, we will be talking to boys and girls between the ages of 16-25 years from 4 hospitals that treat young people with cancer in the UK. With your child we will be undertaking to interview them using the telephone. This approach allows your child to negotiate the most appropriate time for them to be interviewed. It also
means that they do not have to come along to the hospital. We will be sending some questions and information about the interview in advance. However, there will be an opportunity for your child to make suggestions that have not been included in our questions. With your child’s permission we plan to tape this interview and take brief notes. We will be interviewing your child on two occasions: firstly to explore their experiences of follow-up, what care they would like to receive from follow-up and what that service might look like, secondly following a consultation exercise with health care professionals from the 4 treatment centres about the models developed by young people. This final interview ensures that we are truly involving young people in the consultation process by taking back to them discussions held with health care professionals.

What are the risks and discomfort?

We do not expect any. But we recognise that being interviewed can cause some initial worry. We hope that initial information shared about the interview will allay some of these worries. Through the interview we will aim to make the experience as relaxed as possible, making the communications supportive and guided by the pace of the young person. We will be undertaking a follow-up call after each interview to ensure that there are no un-resolved issues that may have caused distress.

Who will have access to the case/research records?

All information will be treated in the strictest confidence. Only the researchers will have access to the data collected during this study. You will have the opportunity to obtain a brief report of the study once the study is completed. We will be communicating with your child throughout the study using a newsletter. They will also receive a report written specifically for young people.

What are the potential benefits?

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

Do they have to take part in the study?

No, their involvement is totally voluntary. If they do not wish to take part in this study your treatment and care now and in the future will not be affected in any way. If you have concerns about your child participating in the study, in the first instance we would encourage you to discuss your concerns with your child. As a family we would encourage you to reach a shared decision on whether to participate or not.

Who do I speak to if problems arise?

If you have any complaints about the way in which this research project has been, or is being conducted, please, in the first instance, discuss them with the researchers. If problems are not resolved, or you wish to comment in any other way, please contact the Chairman of the Research Ethics Committee; by post via Research and Development Office, Institute of Child Health, 30 Guilford Street, London, WC1N 1EH, or the Committee administrator will put you in contact with him.
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Or write to:
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7th floor Old Building
Great Ormond Street Hospital for Children NHS Trust
Great Ormond Street
London, WC1 N3JH

Dr Faith Gibson
Lecturer in Children’s Nursing Research
Tel: 020 7813 8543 Gibsof@gosh.nhs.uk

Or write to:
Same address as above
APPENDIX 2c LETTER TO ACCOMPANY POSTAL QUESTIONNAIRE

June 2005

Dear

Re: Developing alternative models of follow-up with young people who have been treated for cancer

I am writing to you about the above project, which aims to consult with young people who have been treated for cancer, to gain a better understanding of their follow-up care. We are contacting young people who attend clinic regularly as well as those who do not. By doing this we want to get a clear picture of what young people think of the service and whether it meets their needs. We are approaching young people from 4 centres in the UK and have permission from these centres to contact you. We would like you to complete the attached questionnaire to obtain your views on the health services you have received.

Before completing the questionnaire, we would like you to read the enclosed information sheet that describes the project. The information sheet explains what the project is all about. Please return the completed questionnaire in the Stamped Addressed Envelope provided.

If you require any further information about the project or completing the questionnaire, please contact Dr Helen Aslett on h.aslett@ich.ucl.ac.uk 020 74059200 ext. 0720.

Many thanks for your time.

Yours sincerely

Dr Faith Gibson
Lecturer in Children’s Nursing Research
On behalf of the Project Team
APPENDIX 2c INFORMATION SHEET FOR POSTAL QUESTIONNAIRES

Developing Alternative Models of Follow-Up with Young People Who Have Been Treated For Cancer

Here is some information about a project you have expressed an interest in. It explains what the project is about and what it would involve for you, if you wish to and are able to take part.

**The aim of the study:**
Our aim is to consult with young people like you to find out what they want from their health service. We want to make sure that we are meeting the needs of young people like your self who have been treated for cancer by delivering follow-up of maximum benefit with least intrusion.

**Why is the project being done?**
How young people experience care and treatment, and what they perceive as important once treatment has finished has received little attention in the past. We want to identify the needs of young people with cancer from their perspective in order to better understand their views of current cancer care services, including positive experiences and things that have been less positive. We will be able to share what we find with colleagues at your treatment centre and other centres throughout the UK. Our aim is to use your experiences to inform how we meet the needs of young people receiving follow-up care in the future.

**How is the study to be done?**
In this study we will be gaining the views of young people between the ages of 16-25 years from 4 hospitals that treat young people who have had cancer across the UK. The questionnaire will explore your experiences of follow up, what care you might like to receive in the future and what this might look like. The results from of this will then be presented to healthcare professionals who work at a number of hospitals across England. At this meeting they will consider and try to agree on ways in which follow up care might be changed. To do this they will hear about your views and listen to findings from other studies conducted throughout the world.
What are the risks and discomfort?
We do not anticipate any. The questionnaire will take up some of your time but we anticipate it taking no longer than 30 minutes to complete.

Who will have access to the research records?
All information will be treated in the strictest confidence. Only the researchers will have access to the data. Whilst the results of the questionnaires will be fed back to healthcare professionals no young person will be personally identified. You will have the opportunity to obtain a brief report of the study once it is complete. We will send you a regular newsletter about how the study is going over the next year.

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

Do I have to take part in the study?
No, your involvement is totally voluntary. If you do not wish to take part your treatment and care both now and in the future will not be affected in any way. If, after agreeing to take part and having participated in the first telephone interview you feel you would rather not be interviewed a second time that will not be a problem.

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

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7th floor Old Building
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Great Ormond Street
London, WC1 N3JH

Faith Gibson
Lecturer in Children’s Nursing Research
Tel: 020 7813 8543 Gibsof@gosh.nhs.uk

Or write to: Same address as above

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APPENDIX 3
APPENDIX 3a – WRITTEN EXERCISE

Ways of long-term follow-up

**What** form would you like your follow-up care to take?

**Who** would you like to be seen by?

**When** would you like to be seen?

**Where** would you like to be seen?

**Why** would that make a difference?

**How** would this improve things for you and others?

Anything else?
APPENDIX 3b INTERVIEW PROTOCOL SUGGESTED QUESTIONS (TO BE GUIDED BY YOUNG PERSON)

How often do you go to clinic?
When did you last go?
How easy is it for you to get to clinic?
Describe for me what going to clinic is like.
Who do you usually see when you go to clinic?
Do you know their names?
Do you find the Doctors and Nurses are easy to talk to?
Are you able to talk about everything that concerns you in your consultation?
Do you get the chance to ask questions?
Do you think the Drs and nurses at the hospital take your concerns seriously?

Informational needs
Do you receive enough information about yourself and how to look after yourself?
Do you feel you know enough about your illness and what you have been through?
Do you feel you know enough about possible long-term effects of having been ill?
If you have not attending clinic recently, what would make you more likely to attend or to keep in contact with the medical team at your hospital?

Clinic environment
How do you feel about going to a clinic where there are young children present?
Would you prefer to be in an adult clinic?
A clinic dedicated to other people in a similar position to yourself?

Your views on follow-up
How do you feel about attending clinic?
What do you feel works in terms of your follow-up?
What would you like to see changed?
What about if you kept going to the clinic but only saw a nurse, how would you feel about that?
What form would you like your follow-up care to take?
If you had a choice where would you like to be seen?
Would you rather have a different form of follow-up?
E.g. at a GP surgery?
By postal questionnaire?
Telephone?
Who would you like to be seen by?
How often would you like to be seen?
APPENDIX 3c POSTAL QUESTIONNAIRE

Developing Alternative Models of follow-Up in Young People Who Have Been Treated For Cancer

Please complete the questionnaire below, remember this is your chance to have your say so please think carefully about the questions we ask and feel free to use the space provided below each question to expand on your answer.

Section A: Your views on clinic

A1. When did you last go to clinic?
   - Within past six months □
   - 6mths-1yr □
   - 1-2yrs □
   - 2-4yrs □
   - 5yrs+ □

A2. When you last went to clinic who did you see? (please tick all that apply)
   - Nurse □
   - Doctor (usual one) □
   - Doctor (different one) □
   - Psychologist □
   - Physiotherapist □
   - Endocrinologist □
   - Support worker □
   - Counsellor □
   - Occupational Therapist □
   - Other □

A3. Did you find you were able to talk about everything that concerned you in your consultation?
   - Yes □
   - No □
   - If no, please write down what things you feel were important, but did not get a chance to tell them about.

A4. Do you think you have received enough information about how to look after yourself and how to take care of your health?
   - Yes □
   - No □
   - If no, what more information would you like to be given?

A5. How did you feel about attending clinic on this occasion?
   - ____________________________

A6. Did you find the Doctors and Nurses easy to talk to?
   - Yes □
   - No □
   - If no, why?

A7. Do you think the Drs and nurses at the hospital take your concerns seriously?
   - Yes □
   - No □
   - If no, please state why you feel this way

A8. Do you feel you know enough about your illness and what you have been through?
   - Yes □
   - No □
   - If no, what else would you like to know

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Questionnaire 03NS16 version 1 14th June 2005

A9. Do you feel you know enough about possible long-term effects of having been ill?
Yes □ No □
If no, what would you like to know? ____________

__________________________
__________________________
__________________________
__________________________

A10. What factors would influence your decision to attend clinic or to keep in contact with the hospital? Please comment
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Section B: How you would like things to be
This section lets you state your views on what form you would like the follow-up care for your illness to take. It may be that rather than attend clinic you would just like to be phoned up by a hospital nurse once a year, or you would like to have email based consultations where you can write about any concerns you have and a Dr or Nurse replies to you. Perhaps you would prefer to see someone at your local GP surgery, or you might prefer going to clinic, but it may be that you don’t feel you get to see the people whom you would like to see. This is your chance to think about these things and to let us know what you would prefer.

B1. What form would you like your follow-up care to take? (Please tick all that apply)
See a Dr at the clinic where I received my treatment □
See a nurse at the clinic where I received my treatment □
See a Dr at a clinic that sees adults with cancer □
See a nurse at a clinic that sees adults with cancer □
See my GP □
See a practice nurse at my GP surgery □
Receive no follow-up care □
Other (please state) __________________________

Please provide a brief explanation of your choice(s)
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

B2. What type of contact would you prefer? (Please tick all that apply)
Face to face □ Email □ Telephone □ Questionnaire □
Please provide a brief explanation of your preference(s)
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

B3. How often would you like to be seen/ have this form of contact?
Every 6 months □ Once a year □
Every 12 months □ Every 2 years □
Every 5 years □ When I have a problem □
Never □

B4. If you prefer face-to-face contact, when would you like to be seen?
Weekday □ Weekend □ Evening □

B5. How could follow-up be improved for you and others? Please comment
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
Section C: About You.

C1. What type of cancer did you have?
   - Acute Lymphoblastic Leukaemia (ALL)
   - Acute Myeloid Leukaemia (AML)
   - Wilms Tumour
   - Neuroblastoma
   - Hodgkin's Disease
   - Non-Hodgkin's Lymphoma
   - Optic Nerve Glioma
   - Other (please state)
   - Don't know

Thank you very much for taking the time to complete this questionnaire. If there is anything else you wish to add please do so here.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

If you would like to receive information about the results of the project please write your address below.

________________________________________________________________________

Thank you for your time

Please return this questionnaire in the stamped addressed envelope provided to:
Dr Helen Aslett, CNAHPR 7th Floor Old Building, Great Ormond Street Hospital, Great Ormond Street. LONDON WC1N 3EH
# APPENDIX 4: CONSENSUS MEETING AGENDA

<table>
<thead>
<tr>
<th>Time</th>
<th>Item</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.30am</td>
<td>Coffee</td>
<td></td>
</tr>
<tr>
<td>11.00am</td>
<td>Start: Welcome, housekeeping, overview of agenda, ground rules and objectives</td>
<td></td>
</tr>
<tr>
<td>11.15am</td>
<td>Introductions and icebreakers</td>
<td></td>
</tr>
<tr>
<td>11.45am</td>
<td>Presentation of the project findings to date and key themes</td>
<td>HA presents young people’s data back to them</td>
</tr>
<tr>
<td>12.15pm</td>
<td>Questions from the floor</td>
<td></td>
</tr>
<tr>
<td>12.30pm</td>
<td>Allocation into teams /explanation of “moodboard” exercise and “selling” of model of care</td>
<td>Each team assigned a colour of model rather than name of model</td>
</tr>
<tr>
<td>1.00pm</td>
<td>Lunch</td>
<td></td>
</tr>
<tr>
<td>1.30pm</td>
<td>Teams prepare “moodboard”</td>
<td>Four groups work individually to prepare their moodboard</td>
</tr>
<tr>
<td>2.15pm</td>
<td>Exercise and Debrief</td>
<td>Groups bought back together. Moodboards put up in different corners of the room. The group moves to the relevant corner and the team takes 10 minutes to “sell” their model. They then have a 10 minute discussion with the wider group. Move to the next team. Bring back to the group</td>
</tr>
<tr>
<td>3.35pm</td>
<td>Coffee Break</td>
<td></td>
</tr>
<tr>
<td>3.50pm</td>
<td>Vote on preferred model</td>
<td>Ranking exercise undertaken by young people and health care professionals</td>
</tr>
<tr>
<td>4.pm</td>
<td>Closing and thanks</td>
<td></td>
</tr>
<tr>
<td>4.15pm</td>
<td>Ends</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX 5. DISSEMINATION PROCESS AND OUTCOMES FROM THE PROJECT

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

1. Production and distribution of a report to the young people who participated in the study.
2. Presentation of findings to collaborating centers.
3. Presentations at local, national and international meetings and conferences.
4. Submission of short reports to Candlighters Newsletter and the family resource Contact.
5. Submission of papers for publication in peer reviewed journals.

Conference and Meeting Presentations

- “Young people’s needs and preferences for long-term follow-up care in cancer”. Paper presented to the UKCCSG Late Effects Special Group, Leicester University, October 2005.

Papers to be written and submitted for publication

- Data based paper presenting the study as a whole. To be submitted to the British Journal of Cancer.
- A paper on the typology of follow-up need and the needs assessment tool. To be submitted to BMJ.