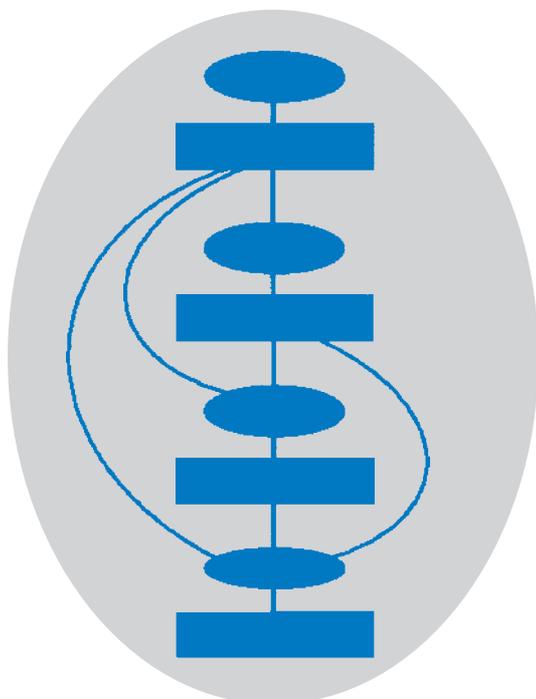


Guidance on Cancer Services

# Improving Outcomes in Children and Young People with Cancer

Analysis of the Potential Economic Impact  
of the Guidance



August 2005

A report commissioned by the National Collaborating Centre for Cancer

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- staff from Royal Colleges and
- all those people we contacted in connection with assessing financial support for the NHS from charitable sources.

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## Executive summary

A detailed costing exercise was conducted in order to estimate, where possible, the cost implications of implementing the key recommendations of the “*Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer*” in England and Wales. The analysis focuses on those aspects of the key recommendations that are likely to be of greatest consequence in terms of cost.

It is acknowledged that there is considerable uncertainty around the estimates presented and that there will be variation among cancer networks. Sensitivity analyses were conducted to account for uncertainty in the estimated costs. Further assessments will be needed at cancer network level and/or NHS trust level to determine the exact cost implications. Work is currently being carried out in the NHS in England, in connection with ‘Payment by Results’, to develop a better understanding of costs of treatment and care, and this may help these assessments in the future.

It should be noted that whilst one of the key recommendations on the Manual is that ‘*commissioning and funding for all aspects of care for children and young people with cancer, across the whole healthcare system, should be coordinated, to ensure there is an appropriate balance of service provision and allocation of resources*’, the cost implications addressed in this document focus on the costs incurred at principal treatment centres.

There will also be significant cost implications for those services, often located within local hospitals, that offer shared care facilities. The costs of increasing the support available to families closer to home, for example by the recommended continuing development of childrens community nursing teams, has not been addressed. It is also possible that there are potential cost savings resulting from changes introduced by the guidance. These have not been estimated in this analysis.

### **Staffing at principal treatment centres (PTCs)**

For the purposes of determining the economic implications of the Manual, staffing levels to provide a safe and sustainable service for a minimum activity level at PTCs have been estimated by the guidance development group (GDG) members. This estimate includes provision for any staffing implications of the Manual, such as attending multidisciplinary team (MDT) meetings and key worker provision. The staffing levels for nurses per patient bed were estimated using both Royal College of Nursing (RCN) recommendations and recommendations from the NICE guidance on *Improving Outcomes in Haematological Cancers*. NHS staff salary pay scales were used to calculate the current staffing cost 2004/5.

The costs discussed below are intended as a benchmark for commissioners. They will be indicative of a **minimum investment** in staffing levels at PTCs. This minimum level is intended to enable centres to provide a safe and sustainable service for children and young people, bed numbers and activity are considered. It is recognised that there will be a requirement for increased staffing in centres where children and young people with complex needs are treated, in centres that offer specialist services and at centres treating over 80 patients per year. However, the staffing levels presented will allow commissioners to compare the staffing levels that exist currently in their centres with the minimum recommended (bed numbers may also vary depending on levels of shared care undertaken).

The employment costs of the medical, nursing and other staff caring for children with cancer at a PTC with 15 beds and treating around 80 new patients per year is approximately £2.47 million per year ( $\pm 25\%$  range £1.85 million to £3.0 million). The estimated annual cost per bed at each centre treating children, at the proposed staffing level is around £165,000 ( $\pm 25\%$  range £124,000 to £206,000). The estimated annual cost per child with cancer, to provide a safe and sustainable service at the proposed level of staffing, is in the order of £31,000 ( $\pm 25\%$  range £23,000 to £38,700).

The cost calculations used for **young people do not include all the clinical**

**staff** who would be involved with the patients' care, primarily because tumours would be site-specific rather than age-specific. Ancillary, catering or administration workforce are not included in either estimate. These factors would need to be considered by commissioners.

A PTC for young people with cancer with minimum staffing levels for a unit with 8 beds caring for a minimum of 60 patients per year would cost an estimated £1.0 million per year ( $\pm 25\%$  range £0.75 million to £1.25 million). The annual employment costs per bed is estimated to be £124,700 ( $\pm 25\%$  range £93,500 to £156,000). For young people, the annual cost per new patient is estimated to be £16,600 ( $\pm 25\%$  range £12,500 to £20,800).

In many cases core staff at PTCs and some shared care centres have been funded through charitable sources. The minimum staffing levels described above should be considered by commissioners as core requirements for NHS funding. This could represent an additional NHS expenditure for children with cancer of around £0.24 million per PTC per year for outreach nurses and play specialists alone. Some sessional time has been funded through charities; this too should be considered by commissioners.

Any additional staff requirement as a result of the recommendations in the Manual would need to be considered by commissioners at a PTC level. Finance directors were asked to provide information regarding the level of investment in staffing children and/or young people with cancer for the financial year 2002/3. Using both the standard deviation from the finance directors survey, and the sensitivity analysis from the staffing levels to produce a safe and sustainable service, there is a resulting range of between -£0.22 million [representing a saving] to £2.21 million [representing a shortfall]. in a centre treating a mean of 80 new patients per year. This wide range could result from a difference in reporting methods by the finance directors and requires further investigation at a local level. It could also result from:

- differing levels of staffing required for treating children and young people with complex needs

- differing levels of shared care activity between centres
- some non-consultant grade doctors can be funded from other sources, such as training budgets,
- research staff may be funded directly through research monies.

It should be acknowledged that any additional staff requirement might not require new staff, some NHS staff might be redeployed or re-designated.

It was apparent from the needs assessment conducted to inform the development of the Manual that some centres had limited access to physiotherapists, speech and language therapists, occupational therapists, play specialists or clinical psychologists. It was also stated that 24-hour on-call systems had been withdrawn in some centres because of nursing staff shortages. In view of current NHS national staff shortages any required recruitment may not be immediate.

The full staffing requirement and other associated services for a shared care centre are complex to cost, and the data provided were incomplete. It has therefore not been possible to estimate the cost of providing shared care.

### **Multidisciplinary Teams (MDTs)**

The members of the MDTs based at principal treatment centres and shared care centres are outlined in the Manual. The attendance at MDT meetings for children and young people with cancer will vary according to need and whether the meeting is diagnostic, treatment, psychosocial or palliative.

It is anticipated that there will currently be approximately 25 core MDTs based at the principal treatment centres in England and Wales, comprising 17 UKCCSG centres plus 8 existing, or shortly to open Teenage Cancer Trust (TCT) units. Where new units for young people are developed, the number of MDTs will rise. In addition, there will be MDTs at non-principal treatment centres with shared care arrangements.

Members of MDTs for children and young people will generally be employed by the PTCs or shared care centres. Local commissioners will need to consider the opportunity costs of any increase in existing MDT meetings and some centres may need to employ additional staff as a consequence. In addition, consideration would need to be given to whether existing meetings are held within normal working hours. This has not always been the case in the past.

The Manual recommends that each PTC has an MDT coordinator. It is probable that not all teams currently have coordinators or adequate administrative support. It is anticipated that each coordinator would facilitate all MDTs for children and young people with cancer based at the PTC. It is assumed that this post would be full time, Clerical and Administrative Grade 4-5. The salary plus on-costs would be in the region of £21,500 per full time post per annum. Local commissioners would need to investigate whether the principal treatment centre has an existing coordinator in post.

Additional video conferencing equipment may be required in some PTCs and hospitals with shared care arrangements to facilitate MDT working. Teleconferencing offers the advantages that travel time is reduced, allowing for more efficient use of scarce specialist staff. This would principally impact on the shared care teams.

The cost of a video conferencing system with high-quality image transfer capability would be around £15,000 (£18,000 inclusive of VAT and delivery) per centre; comprising a mobile video conferencing unit, 2 plasma screens (for added functionality), and a visual presenter (Document Camera) for high magnification requirements, installation, software and 3 year maintenance contract.

### **Training and educational needs**

The training and educational needs of the core staff to be employed in the PTC to provide a safe and sustainable service have been estimated. The estimations for courses are based on existing course costs and with reference to the Royal Colleges. The costs of time have not been taken into account because CPD is

incorporated into current NHS contracts. It may be that some trusts will incur opportunity costs, in particular locum costs. This will need to be considered at both a PTC and a more local level.

The estimated annual costs associated with training and education for CPD of the core staff for each principal treatment centre that treats children would be around £75,200 ( $\pm 25\%$  range £56,400 to £94,000). The estimated annual cost of CPD for a young people's unit would be in the region of £31,500 ( $\pm 25\%$  range £23,600 to £39,400). This assumes a basic professional skill level as a baseline.

Additional calculations would be required at a cancer network or local level to calculate the costs relating to CPD for those staff employed at shared care centres and providing community support, and indeed any specific training that might be required in the PTC.

### **Place of care**

The estimated cost of planning, building and equipping 1 new unit for young people, with accommodation for both inpatients and day cases would require an expenditure of around £1.0 million with a range of between £0.75 million and £1.25 million.

Staffing one additional unit for young people would entail recurring annual costs of £1.0 million ( $\pm 25\%$  range £0.75 million to £1.25 million) per unit, based on the estimates for staffing to provide a safe and sustainable service for a unit with 8 beds treating 60 patients a year. This estimate includes nursing, activity coordinators and some medical support. Not all of the staff would be new, many might be redeployed from existing adult or paediatric wards. The estimate assumes that additional medical staff would be shared with other age groups.

Since these facilities are yet to be commissioned, the additional funding and staffing requirements will be incurred over a number of years in line with commissioning decisions.

### **Financial support for the NHS from charitable sources**

Members of the GDG considered it important to assess the extent to which charities support NHS services for children and young people with cancer. Therefore, although this is not an economic implication of the key recommendations in the Manual, it has been included for completeness.

The financial contribution to research and the care and support of children and young people with cancer from charitable sources is estimated to be between £32.9 million and £48.8 million per annum. This comprises of between £19.3 million and £32 million raised from charitable sources that specifically support children and young people with cancer, a further £13.5 million to £16.6 million contributed to children and young people as a result of fund raising by cancer charities focusing on people with cancer. It was not possible to estimate the charitable contribution to hospice services for children and young people with cancer. It is often the case that staff working in specialist centres and in the community are funded by charities. These include paediatric oncology outreach nurse specialists (POONS) who are often funded by charities including CLIC Sargent and Macmillan Cancer Relief. These charitable sources of funding currently form an essential aspect of the service provision for children and young people with cancer for both staffing and equipment.

## **1. Introduction**

The Manual has been developed to improve the provision of services for children and young people with cancer. This economic review serves to inform commissioners and trusts of some of the resource and cost implications of implementing the recommendations in the Manual. The Centre for the Economics of Health (CEI) at the University of Wales, Bangor has been commissioned to support this process by analysing the potential cost implications.

### **1.1 Scope**

In line with previous NICE service provision guidance the objectives of this economic analysis is to:

- Identify possible models of implementation, which will vary depending both on the baseline position and on the chosen means of achieving the targets set out in the guidance.
- Identify the key economic issues and cost drivers of guidance implementation.
- Estimate the costs of implementing the guidance where a model was identified, and in so doing provide a structure and methodology that Trusts may use to do their own analysis.
- Estimate the national cost implications of adopting the cancer guidance at a principal treatment centre level.
- Estimate the national current contribution made by charitable organisations for the support and provision of services for children and young people who have had a diagnosis of cancer.

The analysis does not aim to:

- Provide a definitive answer to the cost implications of the guidance for specific UK Children's Cancer Study Group (UKCCSG) centres or Teenage Cancer Trust (TCT) units (but to produce an indication of the

scale of costs involved for different paradigms focussing on the principal treatment centres).

- Analyse the health outcome consequences of meeting the guidance.
- Estimate the cost-effectiveness of implementing the guidance recommendations.

## **2. Process and Methods**

### **2.1 Integration of the economic review with the cancer service guidance**

The research into the cost implications of the guidance was developed in parallel with the production of the *Improving Outcomes Guidance for Children and Young People with Cancer*. Members of the Centre for Economics of Health (CEH) attended all the guidance development group (GDG) meetings, facilitating a full understanding of the guidance as it developed.

### **2.2 Literature and data searching**

Literature searches were conducted by NCC-C researchers and information specialists and by the Health Economics team at Bangor. Searches were conducted in order to identify any existing costing exercises, audits of cancer activity, cost of illness studies or models of treatment pathways. All literature was screened for economic content. Any emerging economic literature was referred to the economics group for appraisal.

In addition to the specific research questions raised by the GDG, searches were conducted of the economic literature relating to both:

- general issues of children and young people with cancer
- specific issues relating to the key recommendations of the guidance.

The databases searched by the Centre for the Economics of Health were MEDLINE, Cinahl, NHS EED, HTA and DARE. Searches were restricted to:

- studies in English
- publicly funded health services, i.e. similar systems to the NHS
- publications after 1990.

Unpublished data were obtained as a result of direct contact with members of the GDG, other expert clinicians and finance directors from cancer centres and trusts. The finance directors of each UKCCSG centre and TCT unit were invited

to participate in a survey requesting current levels of investment in services for children and young people with cancer. This is reported in Section 3.

### **2.3 Costs**

Procedural cost data were obtained, where possible, using Healthcare Resource Group (HRG) costs from Payment by Results<sup>1</sup>. HRG costs are produced by every trust in the country, using a very detailed bottom-up method which costs all elements of patients' care including theatre time, laboratory tests, pathology tests, minutes of nursing time, minutes of consultant time, physiotherapy, X-rays, ultrasound, pharmacy and overheads (administration, heating etc.)<sup>1</sup>. Data are available for inpatient elective and non-elective cases, as well as day cases. Where HRG costs were not available, financial directors at NHS trusts were consulted.

Staff salaries were primarily based on Whitley Council awards for 2004/05, obtained from the Department of Health (DH) website<sup>2</sup>. Further advice on calculating staffing costs was provided by the payroll managers of 3 NHS trusts. For each professional grade, a mid-point scale was chosen, upon which 20% employment on-costs plus a London weighting were added as appropriate. In some instances, salaries were neither available from standard sources<sup>3</sup> nor from the DH. Often these posts were funded by charities. Calculations for staff costs for play specialists detailed below are based on the National Association of Hospital Play Specialist recommendations<sup>4</sup>. Salaries for the social workers and teachers were based on Local Authority rates, again using salary scale mid points.

The impact of the Working Time Directive is not clear at this time, and has not been taken into account. However it will need to be considered by commissioners, as will the implementation of Agenda for Change and similar government initiatives<sup>5</sup>.

Very little recent costing data was found in the literature for the UK. There are some non-UK cost studies, but treatment patterns and cost structures are likely to be quite different so have not been included.

#### **2.4 Discussions with clinicians and other key professionals**

Advice from members of the GDG was sought to ensure that appropriate assumptions were made for future activity and staffing levels, to identify data sources and to assist in the interpretation of data. In addition, doctors, specialist nurses and finance directors from TCT units, UKCCSG centres and shared care centres were contacted to discuss activity and resource implications of future staffing levels and various aspects of the Manual. Information and advice was sought from the DH and Royal Colleges concerning current workforces. Data collected as part of the needs assessment, conducted by the National Public Health Service (NPHS) for Wales, was helpful to estimate costs<sup>6</sup>.

#### **2.5 Identification of key cost issues**

The CEI used the guidance development process, a formal survey of GDG members, preliminary data analysis and consultations with both clinical staff and finance directors to identify and prioritise the key cost issues. A proforma was produced to collate information on the extent to which key economic issues had been dealt with in previous guidance, and the extent to which literature was available for key questions relating to the Manual. Current annual budget estimates for both UKCCSG centres and TCT units were sought through a questionnaire administered to finance directors as part of the NPHS for Wales needs assessment (see Appendix A).

#### **2.6 Cost analysis**

For each of the key issues identified, an estimate of the national and local cost consequences has been made wherever possible. The approach adopted for each issue is detailed in the relevant section.

The costs for each cancer network will vary dependent upon population base, health service facilities, staffing levels, local patient flows and case mix. Estimates are based on broad working assumptions concerning future staffing configurations. Commissioners and trusts will need to make further considerations of staffing levels based on their local situation.

## **2.7 Sensitivity analysis**

For each cost we chose a range of  $\pm 25\%$  to reflect uncertainty in the estimate. For consistency, it seemed important to use the same method to consider uncertainty throughout the document rather than a variety of different solutions relevant to each section. Uncertainties in our estimates include for example, current and future staffing levels and costs relating to any additional facilities. In addition there will be cost savings as a result of the Manual that are not possible to quantify at this time.

### **3. Costs associated with service provision for children and young people with cancer in England and Wales**

In order to set the context of this report we start by giving estimates of the current levels of annual investment in children and young people with cancer services in England and Wales. The reported costs are from an NHS and a charity perspective. It is acknowledged that there will be costs falling on the families of children and young people with cancer. However, their inclusion is beyond the scope of this report. Firstly, we will consider the costs of the services based at principal treatment centres, before describing the costs of shared care.

#### **3.1 Principal treatment centres (PTCs)**

A short financial questionnaire was sent to the finance directors of all United Kingdom Childhood Cancer Study Group (UKCCSG) centres and Teenage Cancer Trust (TCT) units in September 2003 (see Appendix A). This data was collected in cooperation with the needs assessment<sup>6</sup> undertaken by the NPHS for Wales to inform the development of the Manual.

Finance directors were asked to provide information regarding the level of investment in children and/or young people with cancer for the financial year 2002/3 focusing on staffing, drugs, radiotherapy and other NHS costs; a question relating to the contribution from non-NHS sources was also included.

Unfortunately the response rate was low, with only 5 responses from the 17 UKCCSG centres and 7 TCT units. All UKCCSG centres in England and Wales were telephoned in an attempt to maximise returns. Possible reasons for the low response rate include:

- not all the centres have a dedicated financial director/manager
- those that are in post have other roles to perform
- costing by disease is difficult where children and young people with cancer require access to many shared services and personnel such as radiology, pathology, anaesthetics and surgery.

Just as there is a variation in the activity and services available at the responding centres, there is likely to be a difference in the way services were costed. The sample of costs obtained represent around 30% of principal treatment centres for children with cancer.

The results of the survey are shown in Appendix A, Tables 1.1-1.2. Activity data is taken from the needs assessment<sup>6</sup>. Appendix A, Table 1.1 describes the level of investment in children and young people with cancer in 5 centres for the financial year 2002/3. The mean level of investment was £3.3 million (SD: £1.3 million); of which a mean of £2.0 million was invested in staff (SD: £1.0 million), £0.75 million in medication (SD: £0.6 million) and £1.0 in other NHS expenditure (SD: £0.7 million), a further £47,350 (SD: £53,500) was from charitable sources.

Costs per bed and per new patient were estimated from the information collected, presented in Appendix A, Table 1.2. The annual cost per bed was calculated by dividing the level of investment by the number of inpatient beds per centre. The annual cost per new patient was calculated by dividing the level of investment by the average number of new patients treated per year. The mean cost per bed per year was £220,200 (SD: £47,000); with mean staff costs per bed of £130,000 (SD: £36,000). When considering the costs per new patient at the responding centres the mean was £32,000 (SD: £12,000); of which the staff costs per new patient were £18,500 (SD: £7,500).

The estimated figures show a wide variation in both budget and service provision. There are a number of possible explanations for this including the variation between centres in activity, case mix, complexity of disease and proportion of shared care undertaken, as well as differences in methods of costing. Most centres have shared staff and services for which not all costs are included. Reporting differences are illustrated in the variation of budget spent on staffing, for example Appendix A, Table 1.1 shows a variation from 44-74%; it is usual for the NHS staff budget to be approximately 70% of the overall budget. It is also of

note that only one site was able to estimate costs for radiotherapy which are outlined in Appendix A, Table 1.3.

The estimated costs per patient vary across the sector from £14,000 per patient per annum where provision on site is very limited (see Appendix A, Table 1.1) to £43,000 per patient per annum where there is increased provision on site. The complex nature of disease in the patients referred to each centre will impact on the staffing levels, costs relating to service levels and treatment required at those sites. However of the centres that responded, the centre with the lowest annual cost per patient has the highest level of provision and the highest estimated annual bed cost, perhaps reflecting economies of scale.

Economies of scale may operate, as evidenced by the following:

- Centres that appear not to offer specialist services have the fewest beds (centres 1 and 16).
- One centre which has low annual patient activity has a cost per bed that is above the mean.
- The centre with the highest cost per bed also has a low number of beds.
- One centre with low staff cost per bed staff has the highest number of beds.
- The centre with the highest patient activity that offers specialist services is one of the most costly. However such specialist centres treat complex cases.

From data collected from 5 finance directors, it is estimated that the current level of NHS investment in cancer services for children and young people under 25 treated at UKCCSG centres in England and Wales in 2002/3 was around £55 million ( $\pm$  25% range £41.5 million to £69.0 million). This calculation is based on the mean total level of investment for children and young people multiplied by the number of centres.

The current level of annual investment by the Teenage Cancer Trust for young people with cancer was estimated to be £0.7 million per annum which was likely to increase to £1.8 million per annum over the next ten years<sup>7</sup>. Details of the annual investment by charities is presented in Section 8.

The needs assessment that was conducted to inform the development of the Manual<sup>6</sup> did request current staffing levels for those staff members directly involved in the care and treatment of children and young people with cancer. There were variations in the way some centres completed the survey, some included all staff irrespective of whether they were dedicated to cancer patients. In view of this variation, it was decided that it would not be reliable to estimate additional staffing requirements from the needs assessment.

In view of the lack of robust evidence concerning the required investment in staffing, the GDG have estimated the minimum staffing levels required at a principal treatment centre to maintain a safe and sustainable service. This is discussed in Section 4.

### **3.2 Shared care centres (SCCs)**

Shared care centres are based at secondary care level and are for children affiliated to one or more of the UKCCSG centres. The treatments and services available at SCCs are variable across England and Wales. The Manual states it will be appropriate and necessary for some elements of care to be provided by local hospitals, rather than the principal treatment centres, in a “shared care” arrangement. The local hospital may or may not provide specialist cancer services and the responsible team may be from paediatric or adult services, depending on age and the nature of condition.

Table 8 of the Manual recommends the core components of shared care arrangements. These include having a lead nurse specialist and a lead pharmacist at the non principal treatment centre. In centres where this is not already the case there will be cost implications. Where inpatient care is provided, the RCN guidance should be used to support appropriate inpatient staffing levels.

The full staffing requirement for a shared care centre is more complex to cost. Enquiries were made direct to hospital trusts providing shared care to ascertain current costs. Only three trusts were able to provide data because it was difficult for them to dissect out the specific costs for shared care. The only cost data returned was relating to medication. Appendix A, Table 1.4 has been included to give an indication of the activity levels and medication costs. The activity data was insufficient to use as a base for costs without further investigation which was beyond the scope of this review.

Caring for children and young people with cancer has significant cost implications across local health economies, both in the provision of shared care arrangements at district general hospitals, and the support of community nursing teams for children. It was reported that in some paediatric shared care centres the increased use of community nursing teams has reduced the length of inpatient admissions to hospital.

## **4. Core staffing components of principal treatment centres for children and young people**

In order to estimate the costs for a safe and sustainable service for children and young people with cancer, minimum staffing levels have been estimated, and are discussed below. The objective in undertaking this exercise is to enable commissioners to consider the staffing levels in their local principal treatment centre and where necessary increase the staffing level. It is acknowledged that there will be differences between centres in line with case mix and the age of the patients treated, together with the complexity of disease and stage of treatment. However, a minimum “safe and sustainable level” has been estimated by the GDG for each centre.

### **4.1 Methods**

Staffing levels to provide a safe and sustainable service for a minimum activity level have been estimated by the GDG members. Nursing staffing levels were estimated from RCN recommendations<sup>8</sup> supported by NICE guidance on *Improving Outcomes in Haematological Cancers*<sup>9</sup>. NHS staff salary pay-scales, obtained from the Department of Health (DH)<sup>2</sup> were used to calculate the current staffing cost 2004/5. See Section 2 for further information.

### **4.2 Cost of staffing at principal treatment centres**

The full time equivalent (FTE) staffing levels, together with an estimated employment cost, for staff dedicated to the care of children or young people with cancer are outlined in Appendix B, Tables 2.1 and 2.2, respectively. It is anticipated that clinical and other specialist posts would be undertaken by 2 or more individuals to ensure adequate leave and sickness cover. It is likely that the staffing levels will exceed the minimum in some settings depending on activity levels, case mix, intensity of treatment and types of referrals to the centres.

#### **4.2.1 Staff costs per centre**

The total employment costs of the medical, nursing and other staff caring for children with cancer at a PTC with 15 beds treating around 80 new patients per year is approximately £2.47 million per year ( $\pm 25\%$  range £1.85 million to £3.0 million), see Appendix B, Table 2.1 and 2.3.

For a PTC treating young people with cancer the minimum staffing levels for a unit of 8 beds caring for a minimum of 60 new patients per year would cost an estimated £1.0 million ( $\pm 25\%$  range £0.75 million to £1.25million). The cost calculations used for young people do not include all clinical staff who would be involved with the patients' care, primarily because tumours would be site-specific rather than age-specific. Ancillary, catering or administration workforce are not included in either estimate. These factors would need to be considered by commissioners.

#### **4.2.2 Staff costs per bed**

The estimated annual cost per bed at each centre treating children, at the proposed staffing level is around £165,000 ( $\pm 25\%$  range £124,000 to £206,000). In a centre dedicated to the treatment and care of young people the annual employment cost per bed is estimated to be £124,700 ( $\pm 25\%$  range £93,500 to £156,000) see Appendix B, Table 2.3.

#### **4.2.3 Staff costs per new patient**

The estimated annual cost per child with cancer, to provide a safe and sustainable service at the proposed level of staffing, is in the order of £31,000, ( $\pm 25\%$  range £23,200 to £38,700) see Appendix B, Table 2.3. For young people the annual employment cost per new patient is estimated to be £16,600 ( $\pm 25\%$  range £12,500 to £20,800).

#### **4.3 Costs of additional staff**

Any additional staff requirement as a result of the guidance would need to be considered by commissioners at a PTC level. The data collected from finance

directors would indicate that the mean cost of staffing is around £18,500 per new patient per year. The total cost of providing a safe and sustainable service is estimated to be £31,000 per patient per year. This suggests a possible shortfall in investment in staff per new patient in all but one of the PTCs surveyed. Using both the standard deviation from the finance directors survey, and the sensitivity analysis from the staffing levels to produce a safe and sustainable service, there is a resulting range of between -£0.22 million [representing a saving] to £2.21 million [representing a shortfall]. This is shown in Appendix B, Table 2.4. This wide range could result from a difference in reporting methods by the finance directors and requires further investigation at a local level. It could also result from:

- differing levels of staffing required for treating children and young people with complex needs
- differing levels of shared care activity between centres
- some non-consultant grade doctors can be funded from other sources, such as training budgets
- research staff may be funded directly through research monies.

It should be acknowledged that any additional staff requirement might not require new staff, some NHS staff might be redeployed or re-designated.

Although staff costs per bed were estimated from the finance directors' reports and also for providing a safe and sustainable service, it was not felt appropriate to use these to calculate the additional staff costs. This was because the new patient/bed ratio reported by the finance directors was variable and significantly greater than in the proposed model, possibly reflecting the level of complex cases.

Guidance from the Royal College of Nursing recommends that in specialist areas such as children's oncology units a third of the beds should be staffed to high dependency levels; a ratio of 1:2 nurses to patient beds<sup>8</sup>. The remainder of the beds should be staffed at a ratio of 1:3, unless there are a large number of patients under 2 years of age when the ratio of nurses to patients may need to be

higher. The actual number of nurses that this means in any given centre will depend on factors such as shift patterns, local practice in the time allowance incorporated for staff absences and whether or not a shift supervisor model is in place, as recommended in the Manual. Table 2.1 and 2.2 in Appendix B give nursing numbers based on a crude calculation taking these factors into account. This guidance is further supported by the recommendation from the NICE Guidance on *Improving Outcomes in Haematological Cancers*<sup>9</sup> which states that patients with a haematological cancer who are neutropenic require a nurse: patient ratio of 1:2.

Further investigation of staffing would need to be conducted at PTC level to estimate additional nurses by grade that might need to be employed. There is a marked variation in the numbers of allied health professionals (AHPs) employed in the centres, (Table 31 of the needs assessment<sup>6</sup>). Some centres have limited access to physiotherapists, speech and language therapists, occupational therapists, play specialists or clinical psychologists.

The needs assessment<sup>6</sup> reported that staff shortages prevented services, such as a 24-hour on call system for palliative care, from operating in some centres. An increased level of MDT working and the named key worker will create a further burden on staff time. These services can only be sustained if there are adequate numbers of appropriately trained staff as described above.

It is acknowledged that not all children and young people are treated in specialist centres; approximately 90% of all children are treated at UKCCSG centres<sup>10</sup>. Many of these patients, however, receive elements of their care in shared care centres and from community nursing teams. This is supported in the Manual which recommends that *'age appropriate, safe and effective services (should be delivered) as locally as possible.'* Caring for children and young people with cancer has an impact on shared care centres at district general hospitals, and on community nursing teams often based in primary care trusts, particularly in terms of staffing costs which are not currently recognised. It has been the case that

core staff at PTCs and shared care centres have been funded through charitable sources, the minimum staffing levels described above should be considered by commissioners as core requirements for NHS funding. This could represent an additional NHS expenditure for children with cancer of around £0.24 million per PTC per year for outreach nurses and play specialists alone. Some sessional time has been funded through charities; this too should be considered by commissioners. The contribution that charities make to the care of children and young people with cancer is considered in Section 8.

One of the uncertainties that the 25% margin attempts to control for is that even at the principal treatment centre level, it is not always possible to separate the costs of caring for young patients in general, from those patients with cancer, or from young adults and other adults who are hospitalised.

## 5. Multidisciplinary teams

In this section the costs involved in implementing the recommendations for the suggested levels of multidisciplinary team (MDT) working at principal treatment centres and at other treatment centres for children and young people are considered.

A key recommendation of the Manual states that:

*“Care should be delivered throughout the patient pathway by multidisciplinary teams (MDTs), including all relevant specialist staff. Membership and governance of these teams should be explicit and include clearly defined responsibility for clinical and managerial leadership.”*

The members of the MDTs based at principal treatment centres and shared care centres are outlined in Tables 4-6 of the Manual. As stated in the Manual the membership of the MDTs for children and young people with cancer is wide, and attendance at MDT meetings will vary according to need and whether the meeting is diagnostic, treatment, psychosocial or palliative.

It is anticipated that there will currently be 25 core MDTs based at the principal treatment centres in England and Wales, comprising 17 UKCCSG centres plus 8 existing, or shortly to open, Teenage Cancer Trust (TCT) units. In addition, there will be MDTs at non-principal treatment centres with shared care arrangements.

The opportunity cost will vary across cancer networks according to the current frequency and attendance at MDT meetings. In addition, consideration would need to be given to whether existing meetings are held within normal working hours. This has not been the case in the past with 91% of respondents reporting that meetings were held either at lunch time or outside normal working hours<sup>11</sup>. The members of MDTs for both children and young people, generally, will be employed by the PTCs or shared care centres. Local commissioners will need to

consider the opportunity costs of any increase in existing MDT meetings and some centres may need to employ additional staff as a consequence.

In addition to the age specific MDTs, there are disease specific tumours which need consideration by either a specialist MDT or through liaison with other specialist MDTs, as outlined in the relevant section of the guidance. The costs of such teams have been, or will be, included in other site specific guidance.

Factors such as the number of teams serving the cancer network, which team members travel and the distances travelled (or the cost package for video conferencing charges) will impact on the annual cost of running MDTs and should be investigated independently by each cancer network.

### **5.1 Additional staff requirements**

In some centres where the MDT will need to meet more frequently as a result of the recommendations in the Manual, then additional staffing may be required. The suggested minimum staffing levels to ensure a safe and reliable service have included provision for staff to attend weekly MDT meetings.

Shortages of specialist neurosurgeons, radiologists, histopathologists, oncologists, psychologists and AHPs<sup>12</sup> will hamper development of full MDTs in the short and the long term. Methods may need to be considered to share neighbouring expertise when there is a shortage of personnel.

In addition to the core clinical staff participating in the MDT, the Manual recommends that each PTC has an MDT coordinator. A team coordinator is essential to ensure the efficient functioning of all the various MDT meetings. Patient case notes, and pathology and radiology results need to be available for the meeting, the decisions recorded and communicated appropriately. The coordinator has the task of ensuring that decisions are carried out, a register is kept, data is collected and patients are considered for appropriate trials.

It is probable that not all teams currently have coordinators or indeed administrative support. It is anticipated that each coordinator would be contracted to facilitate all MDTs for children and young people with cancer based at the PTC. It is assumed that this post would be full time, Clerical and Administrative Grade 4-5. The salary plus on-costs would be in the region of £21,500 per FTE post per annum<sup>2</sup>. Not all principal treatment centres have a coordinator in post, the exact number is not known at this time.

## **5.2 Video Conferencing**

Although video conferencing is not specifically recommended in the Manual, it is recognised that this may be useful for some MDT meetings (especially linking with shared care centres),

Additional video conferencing equipment may be required in some PTCs and hospitals with shared care arrangements to facilitate MDT working. The cost of a video conferencing system with high quality image transfer capability would be around £15,000 (£18,000 inclusive of VAT and delivery) per centre<sup>13</sup>; comprising a mobile video conferencing unit, 2 plasma screens (for added functionality), and a visual presenter (Document Camera) for high magnification requirements, installation, software and 3 year maintenance contract.

National initiatives<sup>14,15</sup> are in place to ensure that electronic patient recording systems, such as Picture Archiving Communication System (PACS), are installed throughout England and Wales. Where this is not yet in place, additional IT equipment may be required to facilitate MDT meetings. Local commissioners will need to take such issues into account.

## **5.3 Discussion**

The establishment of MDTs for cancer services for children and young people where none currently exist may have significant resource implications. The cost of service re-configuration for an individual principal treatment centre will vary according to the existing MDT configuration and staffing levels, as well as the future MDT configurations and the other variables described above. This emphasises the need to investigate these costs in each cancer network.

Teleconferencing offers the advantages that travel time is reduced, allowing for more efficient use of scarce specialist staff. This would principally impact on the shared care teams.

Additional staff may need to be recruited to allow existing staff the time to attend meetings, as well as to provide holiday and sickness cover. Current shortages of staff will hinder both the development and operation of the MDTs. Furthermore, the needs assessment<sup>6</sup> conducted to inform the development of the Manual would indicate that some centres are stretched to provide current services.

## **6. Continuing professional development (CPD)**

A key recommendation of the Manual states that:

*“The need for trained specialist staff across all disciplines, able to work with children and young people with cancer, should be included in workforce development plans by cancer networks, to ensure the provision of a sustainable service”.*

### **6.1 Background**

‘Continuing Professional Development. Quality in the new NHS’<sup>16</sup> was published by the Department of Health in July 1999. CPD had been defined in the earlier document ‘A First Class Service: Quality In The New NHS’<sup>17</sup> as “a process of lifelong learning for all individuals and teams which meet the needs of patients and deliver the health outcomes and healthcare priorities of the NHS and which enables professionals to expand and fulfil their potential”. CPD was envisaged to extend to the majority of health professionals and would include learning from clinical audit; work based learning through the processes of coaching, mentoring, job rotation and shadowing; learning sets and work based projects in addition to attending courses. Education providers would be encouraged to deliver flexible, modular education and training with students studying in the workplace, home and classroom. The report noted that CPD is financed from a range of sources such as local training and development budgets, charitable and educational trusts and industry sponsorship with health professionals sharing financial responsibility for their own professional development. In ‘Working Together – Learning Together. A Framework for Lifelong Learning for the NHS’<sup>18</sup> it is noted that most professions are “considering arrangements for some form of mandatory re-registration or re-validation, or strengthening their current requirements”.

### **6.2 CPD in medicine**

The discussion of CPD in the field of medicine has been primarily focused in the postgraduate training of doctors to equip them to work as general practitioners

and specialists in the NHS. After attaining a first medical qualification, to qualify as a paediatric oncologist requires a further two years of general professional training in paediatrics as a senior house officer, followed by a further five years as a specialist registrar during which an oncology speciality would be developed. On successful completion of this training the candidate becomes a consultant. CPD for consultants involves activities such as attending lectures, leading grand rounds, writing and presenting papers and attending meetings and symposia. The Royal College of Paediatrics and Child Health recommended that consultants are allocated an annual budget by their trust of approximately £3,000 and time to carry out these activities (see Appendix C, Table 3.1). However in reality there may be wide variation in this allocation.

### **6.3 CPD in nursing**

Nurses who train in the UK can either undertake a Diploma in Higher Education (Nursing Studies) over three years of full time study or a Bachelor of Nursing (Hons) degree course over three to four years. Both courses are structured so that the first year is a common foundation programme during which the basic principles of nursing are introduced. Students then branch into a specialty choosing between adult, children's, mental health or learning disability nursing.

Nurses in the UK are required to maintain their registration by meeting the post-registration education and practice (PREP) standards set by their regulatory body, the Nursing and Midwifery Council (NMC). This contains two components, a PREP practice standard which specifies the minimum hours of practice required to renew their registration and PREP CPD which requires nurses to undertake and record learning activity since they last registered. Both unstructured/informal learning activity and structured/formal learning from seminars, courses and clinical supervision are acceptable.

Until 31 March 2001 the English National Board for Nursing Midwifery and Health Visiting (ENB) was responsible for approving programmes that led to recordable qualifications. That role is now shared between the NMC, the Department of

Health and the higher education institutions. A large range of post-registration courses are offered, encompassing diploma, degree and masters level courses. However there is no longer a central registry of courses kept and nurses are advised by the NMC to contact individual education providers or to search for courses using the internet (see Appendix C, Table 3.2). In addition higher education institutions and organisations such as The Royal College of Nursing offer short courses on specialist topics which do not lead to a recordable qualification.

The loss within the UK of the ENB 240 course on the 'Care of the Child with Cancer' removed a stable benchmark of specialist education from within the specialty. Those wishing to undertake specialist education at degree level now have a limited number of options, with a degree in either child health or in cancer at one of those few institutions which provide specific modules or programmes which address the care of children and young people with cancer. There is a new framework for a degree in children's cancer nursing, which is available as a distance learning course.

Masters level education and preparation is increasingly recognised as essential for nurses taking on clinical nurse specialist or nurse practitioner roles, as, for example would be required in developing nurse practitioners in long term follow-up. This is inevitably undertaken on a very individual basis. There are an increasing number of masters courses and 'student designed' awards which focus on independent clinical practice that can provide appropriate preparation for such roles.

#### **6.4 CPD for allied health professionals**

Some courses offered to nurses by higher education institutions are available for interprofessional learning. Other professions that would have contact with paediatric oncology patients, such as radiologists, have their own requirements for CPD. In addition multidisciplinary study modules are available at NHS trusts. The Royal Marsden NHS Foundation Trust, for example, has 40 such courses,

including a 10 day module “Caring for a Child/Teenager with Cancer in a Non-Specialist Setting” at £480 per module<sup>19</sup>.

### **6.5 Training for play specialists**

A Professional Diploma in Specialised Play for Sick Children and Young People is available in 10 colleges in the UK<sup>4</sup>. The fees are approximately £600-£1000. The training is one year, part time and it offers a minimum placement of 200 hours in a hospital setting for people who are not already in employment. The qualification is designed to give a competency in the provision of play for children and teenagers.

### **6.6 CPD costs**

An estimated cost for CPD has been calculated on the basis of a mean cost per module of £754 for key nursing, AHP and scientific staff (see Appendix C, Table 3.2). This figure is based on Table 3.2, plus the costs described above. The CPD for doctors was estimated to be £3000, as above. The costs of time have not been taken into account because CPD is incorporated into current NHS contracts. It may be that some trusts will incur opportunity costs, in particular locum costs. This will need to be considered at a PTC level.

The estimated annual costs associated with training and education for CPD of the core staff for each principal treatment centre that treats children would be around £75,200 ( $\pm$  25% range £56,400 to £94,000) see Appendix C, Table 3.3. The estimated cost of CPD for a unit for young people would be in the region of £31,500 ( $\pm$  25% range £23,600 to £39,400), see Appendix C, Table 3.4. This assumes a basic professional skill level as a baseline. Further costs relating to the basic training costs of AHPs, clinicians and nurses are available in Curtis and Netton<sup>3</sup>.

Additional calculations would be required at a cancer network or local level to calculate the costs relating CPD for those staff employed at shared care centres and providing community support, and indeed any specific training that might be required in the PTC.

## **7 Other potential cost implications**

### **7.1 Specialist paediatric diagnostic services**

The diagnosis section of the Manual states that:

*“Histopathological diagnosis of paediatric tumours can be difficult due to their relative rarity, the overlapping morphological phenotypes, the increasing use of small core biopsies for primary diagnosis and the different interpretation of pathological features in the context of paediatric as opposed to adult cases. Many tumours are unique to children and specialist knowledge is essential.*

*The requirements for the histopathological diagnosis of tumours in young people are very similar. There is clearly an overlap with tumours of the paediatric age group, but also the other tumours that are increasingly common in teenagers and young adults (such as lymphomas, bone tumours and germ cell tumours) all require very specific expertise for their correct diagnosis and assessment.*

#### **7.1.1 Background**

The Department of Health is currently modernising pathology services, and the workforce issues in particular are being considered by The Cancer Workforce Initiative<sup>12</sup>. It has been recognised that there are currently too few trained paediatric pathologists<sup>12</sup>. As a result, various initiatives are in place to increase training opportunities. It will take some time for these improvements to have an impact on current shortages.

#### **7.1.2 Current workforce**

In England there are 28 paediatric pathologists, including 2 academic posts, of which 7 are single handed, and in addition there are 7 part timers. There are currently 12 vacancies. In Wales there are 2 academic paediatric pathologists and no vacancies. Currently in England there are 7 pathologists training to have

a specialty in paediatrics, and 4 vacancies. There are none in Wales. The situation will be further exacerbated in the next five years as 5 pathologists will be retiring<sup>20</sup>.

Discussions with representatives from the Royal College of Pathologists acknowledge that in view of the current shortage not all diagnostic MDTs have a participating paediatric pathologist<sup>21</sup>. Local commissioners need to take this into account, particularly in areas where there are single handed or part-time pathologists.

The Manual recommends that all paediatric tumours are reviewed by specialist paediatric pathologists. Again local commissioners need to consider if this is current practice.

In addition, the diagnostic MDTs for young people will require input from a variety of histo/cytopathologists, because some patients will be initially diagnosed by a disease specific MDT. This will have local impact in areas of extreme shortage of pathologists with a high workload.

The recommended minimum staffing levels outlined in Section 4 consider all aspects of the Manual. The recommendation is for each PTC for children to have available 0.5 FTE pathologist dedicated to children with cancer, comprising 2 or more individuals to cover holiday and sickness. It may be that in some PTCs, an increase in pathology time may be required. In view of national shortages any additional staff may not be immediately appointed.

The guidance on *Improving Outcomes in Haematological Cancers*<sup>9</sup> has relevant costing information concerning pathology laboratories.

## **7.2 Imaging**

The diagnosis section of the Manual states that:

*“The provision of MRI scanning should be sufficient to ensure that*

*suspected cases of CNS and other malignancies can be investigated rapidly”.*

There are currently 223 MRI scanners and between 200 and 230 CT scanners in the UK; the capital costs per scanner are £0.75 million and £0.45 million respectively. Government initiatives are underway to upgrade all CT and MRI and facilities<sup>22</sup>. Costs per MRI scan recorded in the National Tariff are £352, and CT scans for radiotherapy planning are £96<sup>1</sup>. Additional costs would be incurred for younger patients as a result of the Manual recommendation that a play therapist or key worker be in attendance.

It is not anticipated that the Manual will have any impact on provision as such scans are currently routinely conducted. As with other areas of service provision for child and young people with cancer, staff shortages is the area of concern for service delivery. In 2002 the Royal College of Radiologists anticipated that a further 228 additional radiologists per year would be required throughout the NHS in England and Wales by 2005; this did not include any provision for 24 hour service availability. The current training provision is producing only about 80 new radiologists per year.

### **7.3 Protected theatre time and access to paediatric anaesthetists**

The key recommendations of the Manual state that:

*“Theatre and anaesthetic sessional time should be adequately resourced for all surgical procedures, including diagnostic and supportive procedures, in addition to other definitive tumour surgery. Anaesthetic sessional time should also be assured for radiotherapy and painful procedures. The paediatric surgeon with a commitment to oncology should have access to emergency theatre sessions during routine working hours”.*

#### **7.3.1 Costs related to theatre service**

An attempt was made to get costs for procedures not currently included in the HRGs and protected theatre time from finance directors and other sources.

However it proved very difficult to get these data. It is recognised that the provision of protected theatre sessions as recommended in the Manual will have cost implications.

### **7.3.2 Access to paediatric anaesthetists**

The diagnosis section of the Manual recommends that:

*“Flexible, workable systems should provide appropriate staff and facilities to allow all diagnostic procedures to be undertaken quickly within routine working hours, and there should be protected time for theatre access and adequate paediatric surgical, radiological and anaesthetic sessions”*

The needs assessment<sup>6</sup>, conducted to inform the development of the Manual, indicated that there may be a need for an increase in the numbers of paediatric anaesthetists. The recommendation is for each PTC to have available a minimum of 0.7 FTE anaesthetists dedicated to children with cancer. Local commissioners would need to investigate this at a local level to ensure that this minimum is met by 2 or more individuals.

## **7.4 Computerised prescribing**

The treatment section of the Manual states that:

*“Funding should be made available for provision and maintenance of electronic prescribing systems for chemotherapy.”*

### **7.4.1 Background**

Computerised prescribing enables a secure electronic transfer of prescriptions between the clinic (or GP), pharmacy and the Prescription Pricing Authority and has potential to reduce errors while ensuring that all prescribing is recorded.

A national program of improvements to information technology has been commissioned<sup>24</sup>; the government has committed £6.2 billion to the strategy which will include the introduction of computerised prescribing and electronic

transmission of prescriptions (ETP). Some UKCCSG centres have a dedicated computerised chemotherapy prescribing system in place. The National Program for Information Technology aims for all prescribing to be electronic by 2010 and for all hospitals providing chemotherapy to have an electronic prescribing system in place by 2006<sup>13</sup>.

The costs involved are detailed below for reference, it is unclear whether this expenditure is part of the cost implications of the Manual or a cost relating to the national strategy for the whole of the NHS.

#### **7.4.2 Methods**

An electronic search of NHS EED, HTA and DARE was performed. It did not reveal any oncology related papers on electronic prescribing systems. A review article from the USA was identified but not considered sufficiently robust or of sufficient relevance to this analysis<sup>25</sup>.

The costs of ETP would be dependent on a number of variables. The costs obtained were based on the following broad requirements:

- Single principal treatment centre (PTC).
- Up to 4 shared care centres, all of which might deliver chemotherapy and may include another PTC.
- 6 concurrent users in the main PTC, about 2 or 3 at each centre.
- Interfaces to other hospital systems:
  - pathology
  - patient administration system (PAS)
  - radiotherapy scheduling system.

The costs for each principal treatment centre have been broadly estimated to be between £125,000 and £175,000<sup>26</sup>, comprising either:

- a. Single principal treatment centre (PTC), with 4

shared care centres, with one interface for pathology, PAS and radiotherapy schedule system, plus training, project management and implementation £125,000

Or

b. Two PTCs, 3 shared care centres, two interfaces for pathology and pharmacy, one for radiotherapy schedule system, plus training, project management and implementation £175,000

These approximate costs are indicative only. Other systems are commercially available. Each principal treatment centre would have a variety of needs relating to interfaces with different systems and centres requiring separate specification and costing. This would be for local clinical staff and managers to decide.

It is not possible to say at the moment how many principal treatment centres do have electronic prescribing in place. As with other areas of the Manual further consideration would need to be taken at a local level.

## 7.5 Key workers

The Manual states in the key recommendations that:

*“Appropriately skilled, professional key workers should be identified to support individual children and young people, and their families by:*

- *coordinating their care across the whole system and at all stages of the patient pathway*
- *providing information*
- *assessing and meeting their needs for support”.*

Literature searches did not identify any evidence concerning the costs of key workers in this area. However, key workers are employed to ensure continuity of care of disabled children. Two different models of key worker interventions are

found in the UK, either an individual is specifically employed to be a key worker for up to 30 children (range 12-40) or an existing worker is nominated to be a key worker for upwards of 3 children (range 1-35)<sup>27</sup>. The economic impact would depend on which model is adopted.

A key worker for each patient would provide a structured route for coordination and continuity of care throughout the patients illness and follow up, including between centres and shared care. It has been shown that there is an inadequate provision of staff who are likely to fulfil this function. The Manual suggests that the key worker might change during the course of the patients care.

Within UKCCSG centres the role of key worker will most usually be undertaken by a paediatric oncology outreach nurse specialists (POONS). At present the case load carried by POONS varies from centre to centre, but as the needs assessment exercise demonstrated there is a shortage in many centres. Some centres have established other models of care and support, developing the role of a more disease-specific specialist nurse, such as leukaemia, orthopaedic oncology, bone marrow transplant or neuro-oncology nurse specialists who take the role of the key worker for defined patient groups<sup>28</sup>. They operate either across the length of the patient pathway through treatment, or for defined episodes of care. Nurses in shared care units, other treatment sites or in the community, may also take on the role of key worker for individual patients.

There is a general lack of identified key workers for young people, although there are nurse specialists for teenagers and young adults in a number of both centres for children and young people<sup>28</sup>. This is a role which needs to become more established, and clearly this will have an economic impact.

The UKCCSG centres and TCT units have around 1900 new patients per year<sup>6</sup>, with a range of 60-172 per centre. If the model adopted was to employ a new member of staff to be a key worker responsible for 30 patients then 95 new members of staff would be required across England and Wales, with a range of

3-8 per cent. This calculation is based on the assumption that for every 20 new patients there would be at least a further 10 on the existing caseload<sup>28</sup>. The recommended staffing levels in Appendix B, Table 2.1 and 2.2 include provision for key workers.

The actual cost of employing key workers will vary according to activity and local staffing levels. It should be noted that for some principal treatment centres extra funding may not be required as this role may already be undertaken by another member of staff e.g. the clinical nurse specialist. Further work concerning the economic impact will need to be conducted at the local level. This analysis does not consider the economic implications of key workers at the shared care centres because the situation is more complex.

## **7.6 Protocol based care**

It is possible that an increase in protocol based care may result in cost savings as a result of improvements in outcomes. It is not possible to estimate at present the level of this potential saving.

## **7.7 Place of care**

The key recommendations of the Manual states that:

*“All care for children and young people under 19 years must be provided in age appropriate facilities. Young people of 19 and older should also have unhindered access to age appropriate facilities and support when needed”.*

The Manual does not anticipate any increase in provision of age appropriate facilities for children at present, nor does it estimate a projected number of additional units for young people. However, there is a need for increased provision of age appropriate facilities for young people adjacent to areas of existing expertise in adjoining paediatric or adult oncology centres. Exact location would need to be considered by commissioners at a local level.

The Teenage Cancer Trust (TCT) estimates that it costs over £1.0 million to plan, build, and equip each new unit for young people with accommodation for both inpatients and day cases<sup>29</sup>. The TCT aims to increase the current provision of 8 TCT units in England and Wales to 20 units to enable all young people with cancer to be treated in age appropriate facilities<sup>29</sup>.

Each new unit for young people would require further expenditure of approximately £1.0 million in capital costs alone; the  $\pm 25\%$  to allow for uncertainty (bed numbers and facilities) would give a range of between £0.75 and £1.25 million.

Staffing one additional unit for young people would entail recurring annual costs of £1.0 million ( $\pm 25\%$  range £0.75 million to £1.25 million) per unit, based on the estimates for staffing to provide a safe and sustainable service for a unit with 8 beds treating 60 patients a year, see Appendix B, Table 1.2. This estimate includes nursing, activity coordinators and some medical support. Not all of the staff would be new, a few might be redeployed from existing adult or paediatric wards. The estimate assumes that additional medical staff would be shared with other age groups.

As with other aspects of the Manual the costs relating to any additional facilities for young people would not be an immediate cost and the revenue required would vary across cancer networks in line with existing provision, activity or need and expertise.

It should be noted that some of the costs outlined above could be offset against income generated for units treating young people from other service providers who were not able to offer age-appropriate facilities in their localities. The relevant HRG tariff for inpatient stays is around £2000 and around £900 per day case. There would be cost savings in other areas of cancer services where young people have been previously treated, such as adult or paediatric wards. However, it is not possible to quantify these savings.

The costs of services provided by TCT units are explored further in the next section.

## **8. Financial support from charitable sources for children and young people with cancer**

### **8.1 Objective**

The objective of this section is to identify charitable funding contributions to the research and care and support of children and young people with cancer in England and Wales in 2003 in order to make a broad estimate of the current extent of charitable support in the provision of direct services.

### **8.2 Contextual overview**

The knowledge that charities provide considerable financial contributions towards the provision of health care services in the UK is not new. In 2000, it was estimated that in London alone, charities contributed £500 million a year to health care with £200 million of this going directly to hospitals<sup>30</sup>. Funding from charities provided approximately 10% of the London NHS budget. The greater proportion of charitable contributions supports research, refurbishment and expansion of hospital buildings and clinical equipment.

Identifying the important role that charities play in supporting NHS services is not easy. The current exercise was an attempt to quantify the amount of charitable funding that contributes to direct services for children and young people with cancer in England and Wales.

The Charity Commission lists around 200,000 registered charities in England and Wales, of which around 650 are raising funds for cancer<sup>31</sup>. Cancer charities range from large national organisations with paid workers to small local charities relying on volunteers. Their aims and activities also vary widely and may involve funding hospices, contributing to capital projects, providing psychosocial support to patients and their families, supporting research or financing posts for health and allied professionals working in hospitals and community services. A similarly large number of charities work to promote the interests of children and young

people and some of their funds will undoubtedly be directed to young cancer patients.

Cancer research in 2000 attracted £180 million per annum in funding across the UK, of which £20 million came from the government<sup>30</sup>. Two hundred and fifty charities are estimated to support cancer research in the UK<sup>32</sup>.

It was hoped to establish the degree to which service provision for children and young people with cancer in England and Wales relied upon charitable support in one year. However, many difficulties were encountered and are described in detail in the discussion section. What is reported here is an attempt to estimate the overall financial contribution made by charities to research and to the care and support of children and young people with cancer in England and Wales in 2003.

### **8.3 Methods**

Charities involved in fundraising for children and young people with cancer and for hospices providing institutional and or community-based care for these children and adolescents were identified. The lists of hospices and charities were compiled from several sources. Firstly, members of the Children and Young People with Cancer Guidance Development Group were surveyed for contact details of charities operating in their area. Next, the websites of Macmillan Cancer Relief, National Alliance of Childhood Cancer Parent Organisations (NACCPO), CancerBACUP and the Charities Commission that list support groups for children and young people with cancer and their families and fundraising charities, were consulted. Keyword searches were undertaken on the Charities Commission Register using common cancers of childhood such as leukaemia, brain tumours, neuroblastoma, non-Hodgkin's lymphoma, Hodgkin's disease and retinoblastoma.

A further search was also made on the internet for hospices in England and Wales which care for children and teenagers. Finally, each charity that was

contacted was asked to name any other charities they were aware of working in the field.

For ease of analysis the charities identified were subdivided into three groups:

- charities that were primarily established to support children and young people with cancer
- charities established for other reasons but which direct some of their expenditure to supporting children and young people with cancer
- charities established to support the running of a hospice caring for children and teenagers.

For the first two groups, the Charities Commission website<sup>33</sup> was used to identify the total expenditure for each charity in 2003 or for the closest preceding year. In order to establish the proportion of those funds that directly supported young people with cancer, an annual report or statement of accounts was sought from which to extract data, either via the internet or by email with follow up by phone. By comparing the reported total expenditure with the funds directed to supporting children and young people with cancer, an estimate of the proportion of funding supporting these services was made.

## **8.4 Results**

### **8.4.1 Charities established primarily to support children and young people with cancer**

The first category of charity surveyed comprised those established primarily to provide support for children and young people with cancer, and their families; this group constituted the majority of charities identified. Forty two charities were identified in this group and a brief description of the objectives and the total expenditure for 2003, or the closest preceding year, of each of these charities is shown in Appendix D, Table 4.1.

The total expenditure reported by each charity on the Charities Commission register includes monies spent on raising funds and overheads. Total expenditures for each charity were summed to yield a total expenditure of approximately £30 million.

Charities were contacted directly and annual financial reports were sought on the internet in order to establish how much of the total expenditure was directly supporting cancer services for children and young people. This data suffered from a low response rate and detailed information was only obtained for 15 charities (36%) in this category. In addition, extrapolation from the internet at times involved averaging over several years. Charities were also asked where possible to break expenditure down to show financial contributions to staff costs, capital projects, accommodation, care grants, research and education. In order to adequately represent the variation among the charities a brief description of each follows Table 4.2 in Appendix D.

By comparing the results from the survey of the Charities Commission register with information drawn from annual reports, websites and responses from individual charities we estimated that an average of 85% of expenditure goes towards the care of children and young people with cancer, including support, respite and social care and research as well as direct services. The remaining 15% of expenditure covers the costs incurred in raising these funds.

A total expenditure of £30 million was reported in the Charity Commissions register by the 42 charities we identified whose primary objective was to assist children and young people living with cancer and their families. Applying the estimate that 85% of the total expenditure goes directly to this patient group, while acknowledging the uncertainty of the estimate, we calculated that an estimated £26 million was directed by this group of charities in 2003 to research and the care and support of children and young people living with cancer. Using the previously applied range of  $\pm 25\%$  to allow for uncertainty in factors such as the proportion spent on fundraising and the contribution from those charities not

identified, this resulted in a range of £19.3 to £32.2 million. A summary of results for charities established primarily to support children and young people with cancer is shown in Appendix D, Table 4.3. It was not possible, however, to estimate the proportion of this amount that pays for core services that should be funded by the NHS.

#### **8.4.2 Other (non-hospice) charities which support children and young people with cancer**

The second group that was considered comprised those charities that allocated a portion of their funding to children and young people with cancer. This encompassed a large range of organisations and included those charities established to support cancer patients in general, charities involved with a specific form of cancer, or with diseases relating to a specific body organ and charities supporting illness in childhood. Again the scale of these charities varied between very large, established national organisations to small localised charities. We estimated that as many as 1000 charities undertook activities which could potentially benefit children and adolescents with cancer. It was not feasible to locate details for all of these and so our analysis was based on a limited sample of 104 charities from this group. Appendix D, Table 4.4 shows the total expenditure in 2003 for charities who direct part of their expenditure to supporting children and young people with cancer.

The second area of uncertainty was the amount that these charities could be expected to direct to support children and young people with cancer. Both the needs assessment “An Assessment of Need for Child and Adolescent Cancer Services in England and Wales”<sup>6</sup> and official statistics indicate that 1% of all new cancer cases occur in people under the age of 25.

Charities were asked to estimate the amount that had been directed to supporting services for children and young people with cancer. Most charities found it extremely difficult to isolate this component from their overall activities and were unwilling to attempt to do so. Consequently, an exceptionally low

response rate was achieved with only three estimates. Estimates of the percentage of the total expenditure which these three charities directed to support children and young people ranged between 0.3 to 3% and are shown in Appendix D, Table 4.5 (this is followed by a brief description of each charity).

Combining this information to provide a meaningful summary required numerous assumptions to be made, involving a degree of uncertainty. We attributed 1% of all new cancer cases to children and young people, and used this as the basis to apportion expenditure by charities while acknowledging the uncertainty of this estimation method.

Total expenditure per charity for the 2003 year in this group of charities ranged from £50 to £301 million (mean: £5.6 million; SD: £31.4 million). When charities with a total expenditure greater than £20 million were excluded, mean expenditure was reduced to £604,000 (SD: 1.7 million). This figure was used to avoid overestimation of the contributions of the remaining 900 charities for which no data were available. Assuming these charities direct 1% of their annual total expenditure to support cancer services for children and young people, we estimated the total charitable contribution of these groups to be £6 million ( $\pm 25\%$  £4.5 million to £7.6 million). To this was added the known contribution of £9 million from Cancer Research UK, resulting in a final figure ranging between £13.5 million and £16.6 million. A summary of results for other (non-hospice) charities which support children and young people with cancer is shown in is shown in Appendix D, Table 4.6.

Another source of funding is the New Opportunities Fund which was established as a lottery distributor in 1998 when the UK National Lottery was established. This has recently been renamed as the Big Lottery Fund. Cancer related funding opportunities vary between England and Wales. In England there are 2 funding streams for palliative care, one for adults and one for children with total programme awards for £20.6 million and £40.7 million respectively. In Wales there is one funding stream for palliative care worth £3.5 million. Since the New

Opportunities Fund is not a registered charity its contributions were not included in this section.

### **8.4.3 Hospices**

The third group is charities which support the work of hospices for children and adolescents, only a small proportion of whose patients will have a diagnosis of cancer. We located 31 hospices (administered by 28 organisations) in England and Wales providing care for children and young people. Several other hospices which are still in a pre-operational establishment phase were excluded since they could not supply the required data. We contacted all 28 administering organisations and received ten responses (36%) to our request for information.

However, it is possible that the hospices that responded are not representative of hospices in general, because the proportional expenditure seems quite high. Relatively few children with cancer are cared for in children's hospices and it is very difficult to assess the use of adult hospice resources by young people with cancer. In view of this and other uncertainties, we have not estimated the costs of hospice use.

## **8.5 Discussion**

In total, we identified, 42 charities directly involved in supporting children and young people with cancer, 104 charities that direct some of their resources to supporting this group of service users and 28 organisations involved in running hospices in England and Wales. Combining the collated information to provide a meaningful summary value proved to be extremely difficult. A number of complications and methodological problems were encountered in estimating the charitable contributions made to the provision of cancer services for children and young people in the England and Wales. These included:

- double counting errors caused by some charities distributing part of their funds on to other charitable organisations; for instance the Katie Trust contributed £6,000 to Sargent Cancer Care for Children; Children with

- Leukaemia passed £10,000 to Children's Leukaemia in Childhood (CLIC), and the Lisa Thaxter Trust directed funds to the UKCCSG
- difficulty isolating the component directed to children from cancer charities or identifying the amount directed towards children with cancer from charities supporting ill children
  - no adjustment was made for charities that extended their activities beyond England and Wales
  - different financial years were used by different organisations
  - charities sampled were not selected randomly and may not be representative of all charities involved in supporting children and young people with cancer
  - extrapolating from the sample required numerous assumptions to be made.

## **8.6 Conclusions**

Our investigation of charitable funding contributions to cancer services for children and young people with cancer in England and Wales in 2003 identified a number of methodological difficulties and is a broad estimate rather than a definitive measure of the current amount of charitable support in the provision of these services.

We estimate that between £19.3 million and £32 million is raised from charitable sources to specifically support children and young people with cancer and a further £13.5 to £16.6 million is contributed to children and young people as a result of fund raising by cancer charities focusing on people with cancer. It was not possible to estimate the charitable contribution to hospice service. Therefore the contribution to services for children and young people with cancer is estimated to be between £32.9 and £48.8 million per annum. It is likely that the actual amount will be in the mid to upper range as there are other donations that have not been taken into account in this analysis. Examples could include equipment presented or cash donations direct to hospitals and cancer centres all of which might not been included in this estimate.

It has not been possible to determine exactly what percentage of the total figure goes directly to support NHS services for children and young people with cancer and what proportion is spent on research or on activities that would be beyond the scope of the NHS, such as respite care, holiday provision and social workers.

## 9. Overall Conclusions

Implementation of the Manual is likely to have a significant cost impact and commissioners need to consider the final resource implications at a local level. It is likely that most PTCs will need extra funding for additional staff, to enable core staff, in some cases currently resourced by charities, to be funded from NHS sources and to ensure each centre has all the necessary equipment.

The level of uncertainty surrounding these estimates is high and there will be significant variability between cancer networks. We have attempted to allow for the uncertainty of the estimates by applying a  $\pm 25\%$  margin.

The Manual has made recommendations for minimum staffing levels to provide a safe and sustainable service for the treatment of children and young people with cancer. This has been calculated for a PTC for children with cancer, with 15 beds and treating around 80 new patients per year, to have a total resource requirement of approximately £2.47 million per centre per year ( $\pm 25\%$  range £1.85 million to £3.0 million). Evidence from finance directors would indicate that there is an apparent under spend of around £1.0 million (range between -£0.22 million [representing a saving] to £2.21 million [representing a shortfall] in a centre treating a mean of 80 new patients per year). The annual cost of CPD for the staffing level as recommended by the Manual is around £75,200 ( $\pm 25\%$  range £56,400 to £94,000). This assumes a basic professional skill level as a baseline.

The Manual recommends that PTCs for young people with cancer have minimum staffing levels. To staff a unit with 8 beds caring for a minimum of 60 new patients per year would cost an estimated £1.0 million ( $\pm 25\%$  range £0.75 million to £1.25 million). The estimated cost of CPD for a unit for young people would be in the region of £31,500 per annum ( $\pm 25\%$  range £23,600 to £39,400). Each additional unit for young people that is commissioned would cost around £1.0 million to plan, build and equip, plus a further annual staffing investment of

£1.0 million ( $\pm$  25% range £0.75 million to £1.25 million).

The most significant resource implication is likely to be the workforce requirements, as a result of overcoming existing shortages of staff. The costs of employing additional workforce personnel will vary across cancer networks in line with existing provision and local arrangements. This will be for local commissioners to estimate guided by the recommended staffing levels.

Re-structuring of services into multidisciplinary teams is suggested in the Manual and in some centres this recommendation may constitute a change to current practice, which will affect shared care centres as well as primary treatment centres. The staff involved will, however, will generally already be employed by the NHS and should already be contracted to attend MDT meetings. The guidance recommends that an MDT coordinator is appointed to facilitate each PTC, this will have a cost impact where this is not current practice.

Video conferencing equipment may be required in some principal treatment centre in order to reduce travelling and to enable the MDT to function more effectively. The cost of a mobile unit with high quality image transfer capability would be around £15,000 (£18,000 including VAT and delivery) including installation, training and maintenance contract. The costs of lines vary in line with local arrangements and have not been included here. It would need to be considered by local commissioners.

It may be that some principal treatment centres will require an electronic prescribing system as a result of the guidance and in line with current national directives. Cost estimates have been obtained that would be between £125,000 and £175,000 depending on the specification. This estimate was based on a principal treatment centre with up to 4 shared care centres, all of which might deliver chemotherapy with up to 6 concurrent users. Some centres work with a much larger number of shared care centres, although not all of them provide chemotherapy services.

Respondents to the recent needs assessment exercise<sup>6</sup> commented that staff shortages prevented services such as a 24-hour on-call systems for palliative care from operating. An increased level of MDT working, need for improved 24-hour on-call system for palliative care, and the named key worker will create a further burden on staff time. Such services can only be sustained if there are adequate numbers of appropriately trained staff as recommended in the minimum staffing levels. Any recruitment of specialised staff to enable the guidance to be fulfilled will not be immediate in view of the current shortages of many specialised staff.

The cost implications of the Manual have focused on the costs at principal treatment centres. There will be significant cost implications in shared care facilities and in primary care trusts that have not been possible to estimate here. It should be noted that one of the key recommendations of the Manual is that *'commissioning and funding for all aspects of care for children and young people with cancer, across the whole healthcare system, should be coordinated, to ensure there is an appropriate balance of service provision and allocation of resources'*. This can only be addressed at the local level, by commissioners working through both cancer networks, and the developing children's networks. It is also the case that there are potential cost savings that will result from the Manual that have not been possible to quantify.

The value of charitable contributions to research and the care and support of children and young people cannot be understated. The estimated contribution to support for children and young people with cancer is estimated to be between £32.9 million and £48.8 million per annum. It is likely that the actual amount of charitable contributions is nearer the upper margin as there are donations from members of the public direct to hospitals, and smaller charities that have not been included in this analysis.

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# **Appendix A**

## **Details of survey of UKCCSG/TCT Financial Directors**

**Table 1.1 Questionnaire responses of estimated level of investment in children and young people with cancer for financial year 2002/3.**

Centre <sup>a</sup>	New patients per annum	Beds	Care on site	Staffing £ (% of total) <sup>c</sup>	Drugs £ (% of total)	Other NHS £ (% of total)	Charity £ (% of total)	Total £
<b>13</b>	102 (10% > 15 years all < 18 years)	19, of which 4 teenage beds + 2 day case	BMT and neurosurgery	3,076,020 (73)	613,474 (15)	395,775 (9)	122,816 (3)	4,208,085
<b>5</b>	60 (5% > 15 years all < 17 years)	14 + 4 day case beds	BMT and neurosurgery	1,179,000 (45)	552,000 (21)	858,000 (33)	14,000 (1)	2,603,000
<b>3</b>	90-100 (All < 18 years)	10 dedicated + 2 shared care	BMT and retinoblastoma	1,364,700 (44)	611,800 (19)	1,165,600 (36)	5,000 (<1)	3,147,100
<b>2</b>	172 (4% > 15 years, all < 16 years)	18, of which 4 teenage beds	BMT, neurosurgery and retinoblastoma	3,084,504 (64)	1,707,479 (35)	0	47,594 (1)	4,838,577
<b>16</b>	106 (All < 16 years)	g <sup>b</sup>	Some specialist bone/sarcoma surgery	1,084,000 (74)	250,000 (17)	131,000 (9)	Not completed	1,465,000
<b>Mean</b>	<b>107</b>	<b>14</b>		<b>1,957,645</b>	<b>746,951</b>	<b>993,549</b>	<b>47,353</b>	<b>3,252,552</b>
<b>SD</b>	<b>41</b>	<b>4</b>		<b>1,029,770</b>	<b>557,598</b>	<b>708,624</b>	<b>53,544</b>	<b>1,328,540</b>

a. NPHS survey code from Griffiths, Fone and Sandifer, Interim Report into Child and Adolescent Cancer Services Needs Assessment for England and Wales, October 2003<sup>6</sup>.

b. Additional beds were available for those over adolescents over 15 but no dedicated beds.

c. Other NHS costs for centre 3 includes £23,700 budget for radiotherapy, £131,000 direct consumables, £336,300 pathology, £27,500 diagnostic imaging, £52,500 pharmacy support, £140,000 theatres, £48,800 patient services, £21,000 dietetics, £21,000 other therapy services and £363,800 overheads.

**Table 1.2 Annual costs calculations at UKCCSG centres/TCT units in England and Wales (ordered by staff cost per bed).**

<b>Centres</b>	<b>Mean cost per bed</b>	<b>Staff costs per bed</b>	<b>Mean cost per new patient</b>	<b>Staff costs per new patient</b>
<b>13</b>	221,478	161,896	41,256	30,157
<b>5</b>	185,929	84,214	43,383	19,650
<b>2</b>	268,865	171,361	28,137	17,933
<b>3</b>	262,258	113,725	33,127	14,365
<b>16</b>	162,778	120,444	13,821	10,226
<b>Mean</b>	<b>220,262</b>	<b>130,328</b>	<b>31,945</b>	<b>18,466</b>
<b>SD</b>	<b>46,397</b>	<b>35,986</b>	<b>11,852</b>	<b>7,468</b>

**Table 1.3 Costs from one NHS trust of radiotherapy services for children and young people with cancer during 2003.**

<b>Patients</b>	<b>Number</b>	<b>Total estimated cost/year (£)</b>	<b>Estimated cost per child (£)</b>	<b>Range per child (£)</b>
<b>Children up to age of 15 years</b>	15	£52.6k	£3.5k	£336.00-£5,580.00
<b>Young people 16 to 23 year olds</b>	12	£39k	£3.24k	£900 - £5,000

**Table 1.4 Activity levels reported from 3 shared care centres.**

	<b>New patients per year</b>	<b>Average no. treated per year</b>	<b>OP contacts</b>	<b>Home visits by nurses</b>	<b>Day case admissions</b>	<b>Inpatient activity</b>	<b>Bed days</b>	<b>Average stay</b>	<b>Estimated drug budget 2002/3</b>
1	9	40		458	134			2.8	£113,032*
2	16			1040	159		492	5	£72,617
3	19	16	700	900			517		

\* Growth hormone for previous oncology patients included (£92,358)

## Example information letter and questionnaire sent to finance directors

11<sup>th</sup> September 2003

Dear Director of Finance

### FINANCIAL QUESTIONS FOR THE GUIDANCE ON CANCER SERVICES: IMPROVING OUTCOMES IN CHILD AND ADOLESCENT CANCER

You may be aware that the National Collaborating Centre for Cancer (NCCC) have been commissioned by the National Institute for Clinical Excellence to produce **Guidance on Cancer Services: Improving Outcomes in Child and Adolescent Cancer**. My colleague Rhiannon Tudor Edwards and I, from the Centre for the Economics of Health, are working together with the NCCC and the Guidance Development Group to assess the economic consequences of the guidance.

We propose to start the process by finding out what the current investment budget for child and adolescent cancer is. This information together with the information gathered from the enclosed questionnaire pack will enable us to estimate the current service provision costs for child and adolescent cancer services.

We are interested to know the **level of investment in child and/or adolescent cancer for the financial year 2002/03** at your centre or unit. We realise that this is not a straightforward exercise, particularly for adolescents, many of whom might be referred to adult services, but a best estimate would be helpful. For those centres that see a mixed age range, it would be helpful to have separate information for children under 15 years of age and those between 15 and 23 years of age. If this is not possible, then please could you give an approximate level of investment for children and young people under 23. **Please could you complete the enclosed form and return it preferably by email to [p.linck@bangor.ac.uk](mailto:p.linck@bangor.ac.uk), or a hard copy to the above address by 17<sup>th</sup> October 2003 .**

All information that is collected during the course of the research will be kept strictly confidential and will not be used for any other purpose. All data will be held securely.

We would be very grateful for your assistance in this important research. If you have any queries or comments then please do not hesitate to contact me.

Yours faithfully

Pat Linck

Research Officer

Email [p.linck@bangor.ac.uk](mailto:p.linck@bangor.ac.uk)



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**FINANCIAL QUESTIONS FOR THE GUIDANCE ON CANCER SERVICES:  
 IMPROVING OUTCOMES IN CHILD AND ADOLESCENT CANCER**

Name of the UKCCSG Centre: .....

Or Teenage Cancer Trust Unit: .....

Please would you give a contact name and email address for further financial information.

Name: .....

Email: .....

Level of investment in child and/or adolescent cancer for the financial year 2002/3

	<b>Children aged 0-14 years</b>	<b>Young people, aged 15-23 years</b>	<b>If separation is not possible, 0- 23 years</b>
<b>Staffing</b>			
<b>Drugs</b>			
<b>Radiotherapy</b>			
<b>Other NHS</b> .....			
<b>Estimate of non-NHS revenue funding from charity/voluntary sector</b>			
<b>Total</b> <b>If a breakdown of NHS costs is not possible please give a best overall estimate</b>			

Thank you very much for your assistance. If you have any queries or comments then please do not hesitate to contact me.

Pat Linck, Research Officer

Phone 01248 382397

## **Appendix B**

**Estimated staff costs required at principal treatment centres to provide a safe and sustainable service for children and young people with cancer**

**Table 2.1 Core components of a principal treatment centre treating approximately 80 new patients per year in 15 beds for a safe and sustainable service (children).**

Personnel	Minimum FTE for a sustainable service	Annual Salary + 20% on-costs (£)
Designated lead clinician, (included in estimates below)		
<ul style="list-style-type: none"> <li>Paediatric oncologists</li> <li>Paediatric haematologists</li> </ul>	5.0	476,118
At least 2 Clinical oncologists with expertise in paediatric radiotherapy	0.7	66,657
Paediatric surgeon with expertise in specialist oncology	0.5	47,612
Adequate middle grade cover (non consultant career staff grade)	2.0	104,774
<b>Other specialised services necessary on site as required for site specific expertise:</b>		
<ul style="list-style-type: none"> <li>Paediatric anaesthetists</li> </ul>	0.7	66,657
<ul style="list-style-type: none"> <li>Paediatric pathology</li> </ul>	0.5	47,612
<ul style="list-style-type: none"> <li>Paediatric radiologists</li> </ul>	0.6	57,134
<ul style="list-style-type: none"> <li>Designated paediatric oncology pharmacist (Band 7/8)</li> </ul>	1.5	60,948
<ul style="list-style-type: none"> <li>Psychological and psychiatric services (Psychologist Grade A/B)</li> </ul>	1.0	52,191
<b>Nursing establishment</b>		
Identified lead nurse (Grade H/I)	1.0	37,957
<b>Specialist trained nurses for In-patients</b>		
<ul style="list-style-type: none"> <li>Grade G</li> </ul>	2.0	64,996
<ul style="list-style-type: none"> <li>Grade F</li> </ul>	5.3	150,156
<ul style="list-style-type: none"> <li>Grade E</li> </ul>	21.0	523,072
<ul style="list-style-type: none"> <li>Grade D</li> </ul>	8.8	195,083
<b>Specialist trained nurses for day patients</b>		
<ul style="list-style-type: none"> <li>Grade G</li> </ul>	1.0	32,498
<ul style="list-style-type: none"> <li>Grade E</li> </ul>	4.0	99,633
Paediatric oncology outreach nurses (Grade G/H)	5.0	172,473
<b>Core Allied Health Professionals:</b>		
<ul style="list-style-type: none"> <li>Dietitians</li> </ul>	1.0	31,493
<ul style="list-style-type: none"> <li>Physiotherapists</li> </ul>	1.0	31,493
<ul style="list-style-type: none"> <li>Occupational therapists</li> </ul>	0.2	6,299
<ul style="list-style-type: none"> <li>Play Specialists</li> </ul>	3.0	71,425
Designated social workers	Not NHS funded	
<b>Research support: Usually funded via research monies</b>		
<ul style="list-style-type: none"> <li>Research nurse (Grade G/H)</li> </ul>	1.0	34,495
<ul style="list-style-type: none"> <li>Data managers (C&amp; A Grade 4/5)</li> </ul>	2.0	43,129
<b>Total</b>		<b>2,473,935</b>

**Table 2.2 Core components of a principal treatment centre treating 60 new patients per year in 8 in-patient beds for a safe and sustainable service (young people)**

<b>Personnel</b>	<b>Minimum FTE for a sustainable service</b>	<b>Annual Salary + 20% on-costs (£)</b>
Designated lead clinician	0.2	19,045
<ul style="list-style-type: none"> <li>• Lead haematologist</li> <li>• Other consultant staff with expertise in the care of malignancies seen in this age group</li> </ul>	0.5	47,611
Adequate middle grade cover (non consultant career staff grade)	1.0	52,387
Other specialised services necessary on site as required for site specific expertise:		
<ul style="list-style-type: none"> <li>• Radiology</li> <li>• Pathology</li> <li>• Designated oncology pharmacist</li> </ul>	Funded via site specific cancer services	
<ul style="list-style-type: none"> <li>• Psychological and psychiatric services</li> </ul>	1.0	52,191
<b>Nursing establishment</b>		
<ul style="list-style-type: none"> <li>• Identified lead nurse (Grade H/I)</li> </ul>	1.0	37,957
<b>Specialist trained nurses for In-patients</b>		
<ul style="list-style-type: none"> <li>• Grade G</li> </ul>	1.0	32,498
<ul style="list-style-type: none"> <li>• Grade F</li> </ul>	1.0	28,601
<ul style="list-style-type: none"> <li>• Grade E</li> </ul>	11.1	277,228
<ul style="list-style-type: none"> <li>• Grade D</li> </ul>	4.6	103,394
<b>Specialist trained nurses for day patients</b>		
<ul style="list-style-type: none"> <li>• Grade G</li> </ul>	0.5	17,224
<ul style="list-style-type: none"> <li>• Grade E</li> </ul>	2.1	52,805
Specialist outreach nurses (Grade G/H)	3.5	120,731
<b>Core Allied Health Professionals:</b>		
<ul style="list-style-type: none"> <li>• Dietitians</li> </ul>	0.8	25,195
<ul style="list-style-type: none"> <li>• Physiotherapists</li> </ul>	1.0	31,493
<ul style="list-style-type: none"> <li>• Occupational therapists</li> </ul>	0.2	6,299
<ul style="list-style-type: none"> <li>• Activity coordinator</li> </ul>	2.0	47,617
Designated social workers	Not NHS funded	
<b>Research support: Usually funded via research monies</b>		
<ul style="list-style-type: none"> <li>• Research nurse (Grade G/H)</li> </ul>	1.0	34,495
<ul style="list-style-type: none"> <li>• Data managers (C&amp; A Grade 4/5)</li> </ul>	0.5	10,782
<b>Total</b>		<b>997,554</b>

**Table 2.3 Annual estimated staff employment costs per bed and per new patient in a PTC for children and a PTC for young people.**

	<b>Total Staff cost</b>	<b>Staff costs per bed</b>	<b>Staff costs per new patient</b>
<b>PTC for children treating 80 patients in 15 beds</b>	<b>2,473,935</b>	<b>164,929</b>	<b>30,924</b>
(Minus 25%)	1,855,451	123,697	23,193
(Plus 25%)	3,092,419	206,161	38,655
<b>PTC for young people treating 60 patients in 8 beds</b>	<b>997,554</b>	<b>124,694</b>	<b>16,626</b>
(Minus 25%)	748,166	93,521	12,469
(Plus 25%)	1,246,943	155,868	20,782

**Table 2.4 Calculation to estimate the additional employment cost per PTC for children treating 80 new patients per year.**

<b>Data source</b>	<b>Cost per patient (£)</b>	<b>Range (£)</b>
Finance directors	18,466 S.D. 7468	11,000 to 25,900
Safe and sustainable service	30,924 (± 25%)	23,200 to 38,600

	<b>Cost per patient (£)</b>	<b>Cost per centre treating 80 patients (£)</b>
Difference in means	(30,924 – 18,466)	996,640
Lower range	(23,200 – 25,900)	*-219,300
Upper range	(38,650 – 11,000)	2,212,600

\* Represents a saving

# **Appendix C**

## **Training and education**

**Table 3.1: Post-registration course and CPD for clinicians<sup>a</sup>.**

Offered by	Course Title	Duration	Cost
Royal College of Paediatrics & Child Health	Paediatrics and Child Health.	2 years general professional training in paediatrics then 5 years in higher specialist training.	Approx £50,000
Local NHS Trust	CPD for consultants	Ongoing	Approx £3,000 pa + leave.

a. From phone conversation Royal College of Paediatrics & Child Health

**Table 3.2 Post-registration courses offered by Universities for nurses working with children and young people with cancer.**

Education Provider	Course Title	Cost of BSc Degree	Cost per module
<i>School of Nursing and Midwifery Studies, University of Wales College of Medicine</i>	BSc (Hons) in Nursing Children and Young People with Cancer	£2,110	Module 1 20 CATS <sup>1</sup> £370 Module 2/3 30 CATS £530 Module 4 40 CATS £680
<i>School of Nursing and Midwifery, University of Southampton</i>	BSc (Hons) Clinical Practice or Healthcare Studies. BSc (Hons) Child and Adolescent Cancer Care	From £5,346 <sup>2</sup>	Type A 20 credits £ 593 Type B 20 credits £ 791 Type C 20 credits £1,190
<i>Faculty of Health and Social Care, London South Bank University</i>	BSc (Hons) Professional Practice: Childhood Cancer Nursing	£4350	Level 3 15 credits £450-£600
<i>School of Nursing, The University of Nottingham</i>	BSc (Hons) Health Care Studies, Child Health Care (Oncology)	£2,556	10 credits from £213

1. CATS: Credit Accumulation and Transfer Scheme. This is a UK-wide scheme used across further and higher education to signal how 'hard' and long courses are. 1 'CAT' is equivalent to a notional 10 hours of study so 60 CATS indicate around 600 hours study.

2. Varies depending on choice of topics.

**Table 3.3 Costs of training the core staff at each PTC for children\***

Profession	FTE	Annual cost of CPD
Designated lead clinician, (included in estimates below)		
<ul style="list-style-type: none"> <li>Paediatric oncologists</li> <li>Paediatric haematologists</li> </ul>	5.0	15,000
At least 2 Clinical oncologists with expertise in paediatric radiotherapy	0.7	2,100
Paediatric surgeon with expertise in specialist oncology	0.5	1,500
Adequate middle grade cover (non consultant career staff grade)	2.0	6,000
<b>Other specialised services necessary on site as required for site specific expertise:</b>		
<ul style="list-style-type: none"> <li>Paediatric anaesthetists</li> </ul>	0.7	2,100
<ul style="list-style-type: none"> <li>Paediatric pathology</li> </ul>	0.5	1,500
<ul style="list-style-type: none"> <li>Paediatric radiologists</li> </ul>	0.6	1,800
<ul style="list-style-type: none"> <li>Designated paediatric oncology pharmacist (Band 7/8)</li> </ul>	1.5	1,508
<ul style="list-style-type: none"> <li>Psychological and psychiatric services (Psychologist Grade A/B)</li> </ul>	1.0	754
<b>Nursing establishment:</b>		
Identified lead nurse (Grade H/I)	1.0	754
<b>Specialist trained nurses for In-patients:</b>		
<ul style="list-style-type: none"> <li>Grade G</li> </ul>	2.0	1,508
<ul style="list-style-type: none"> <li>Grade F</li> </ul>	5.3	3,770
<ul style="list-style-type: none"> <li>Grade E</li> </ul>	21.0	15,834
<ul style="list-style-type: none"> <li>Grade D</li> </ul>	8.8	6,786
<b>Specialist trained nurses for day patients:</b>		
<ul style="list-style-type: none"> <li>Grade G</li> </ul>	1.0	754
<ul style="list-style-type: none"> <li>Grade E</li> </ul>	4.0	3,016
Paediatric oncology outreach nurses (Grade G/H)	5.0	3,770
<b>Core Allied Health Professionals</b>		
<ul style="list-style-type: none"> <li>Dietitians</li> </ul>	1.0	754
<ul style="list-style-type: none"> <li>Physiotherapists</li> </ul>	1.0	754
<ul style="list-style-type: none"> <li>Occupational therapists</li> </ul>	0.2	8
<ul style="list-style-type: none"> <li>Play Specialists</li> </ul>	3.0	2,262
Designated social workers	Not NHS funded	
<b>Research support:</b>		
<ul style="list-style-type: none"> <li>Research nurse (Grade G/H)</li> </ul>	1.0	754
<ul style="list-style-type: none"> <li>Data managers (C&amp; A Grade 4/5)</li> </ul>	2.0	1,508
<b>Total</b>		75,240
(minus 25%)		56,430
(plus 25%)		94,050

\*Costs for doctors are based on pro-rata proportion of an annual recommended budget for CPD, whereas other staff are costed on a mean course cost.

**Table 3.4 Costs of training the core staff at each PTC for young people\***

<b>Profession</b>	<b>FTE</b>	<b>Annual cost of CPD</b>
Designated lead clinician	0.2	600
<ul style="list-style-type: none"> <li>• Lead haematologist</li> <li>• Other consultant staff with expertise in the care of malignancies seen in this age group</li> </ul>	0.5	1500
Adequate junior and middle grade cover (non career staff grade)	1.0	3,000
<b>Other specialised services necessary on site as required for site specific expertise:</b>		
<ul style="list-style-type: none"> <li>• Radiology</li> <li>• Pathology</li> <li>• Designated oncology pharmacist</li> </ul>	Funded via site specific cancer services	
Psychological and psychiatric services	1.0	754
<b>Nursing establishment:</b>		
Identified lead nurse (Grade H/I)	1.0	754
<b>Specialist trained nurses for In-patients:</b>		
• Grade G	1.0	754
• Grade F	1.0	754
• Grade E	11.1	8,294
• Grade D	4.6	3,770
<b>Specialist trained nurses for day patients:</b>		
• Grade G	0.5	754
• Grade E	2.1	2,262
<b>Specialist outreach nurses (Grade G/H)</b>	3.50	3,016
<b>Core Allied Health Professionals:</b>		
• Dietitians	0.8	754
• Physiotherapists	1.0	754
• Occupational therapists	0.2	754
• Activity coordinator	2.0	1,508
Designated social workers	Not NHS funded	
<b>Research support: usually funded via research monies</b>		
• Research nurse (Grade G/H)	1.0	754
• Data managers (C& A Grade 4/5)	0.5	754
<b>Total</b>		31,490
(minus 25%)		23,618
(plus 25%)		39,363

\*Costs for doctors are based on pro-rata proportion of an annual recommended budget for CPD, whereas other staff are costed on a mean course cost .

## **Appendix D**

# **Charities Supporting Cancer Research and Cancer Services for Children and Young People**

**Table 4.1 Total Expenditure for 2003 or closest preceding year by active charities established with a primary goal of supporting children and young people with cancer, as reported on the Charities Commission website.**

	<b>CHARITY</b>	<b>Area of Operation</b>	<b>FINANCIAL YEAR</b>	<b>Total Expenditure</b>	<b>DESCRIPTION</b>
1	Anthony Clifford Trust Fund	England & Wales	06/02/01 to 05/02/02	30,663	Relieve poverty of families of children under 16 with leukaemia and advance education about cancer and leukaemia in children.
2	Camp Quality UK	England & Wales	1/01/03 to 31/12/03	54,203	Promotion of welfare of children and young people with illnesses, especially cancer, through appropriate holidays and activities.
3	Camp Simcha - Children With Cancer	England & Wales & outside	01/01/02 to 31/12/02	87,959	Relief of suffering of Jewish children with cancer or other life threatening illness
4	Cancer and Leukaemia in Childhood (CLIC)	England & Wales & beyond	01/01/03 to 31/12/03	7,040,000	Relief for children and young people with leukaemia or cancer and further research into problems arising from these diseases.
5	The Candlelighters Trust	West Yorkshire	01/03/03 to 29/02/04	822,295	Relief from suffering from a malignant disease or life threatening haematological disorder.
6	Charlie's Challenge	Kent	01/07/02 to /30/06/03	57,836	Relief of children with brain tumours and support related research at the Maudsley Hospital and Guy's Hospital.
7	Childhood Cancer Organisation for Parents and Relatives (COPARS)	Cambridgeshire	01/04/02 to 31/03/03	6,454	Alleviate the hardship and distress of childhood cancer to patients, family and friends and provide education and support for the same.
8	Childhood Cancer Unit Parents' Association (Ccupa)	Southeast England	01/05/02 to 30/04/03	7,591	Provides advice, information and support to parents and educates the public and those working with children with cancer.
9	Childhood Eye Cancer Trust (CECT)	England & Wales	01/07/02 to 30/06/03	133,768	Relief for children with retinoblastoma through grants, services, research and information.
10	Children's Cancer Support Group (CHICs)	Merseyside	01/12/02 to 30/11/03	119,501	Relief of children with leukaemia and associated disease and support of their parents.
11	Children's Leukaemia Society	Wales	01/02/02 to 31/01/03	34,276	Relief of children under 16 suffering from leukaemia.
12	The Children's Leukaemia Trust	England & Wales	01/07/02 to 30/06/03	54,236	Provide facilities and staff for children with leukaemia undergoing bone marrow transplantation and support research in this area.
13	CHIN-UP	Northeast England and Cumbria	01/04/02 to 31/03/03	1,967	Fundraising for children's hospice for NE England
14	Chris Lucas Trust	England & Wales & beyond	01/04/02 to 31/03/03	2,128	Funding of research post into rhabdomyosarcoma at times and places deemed appropriate by the trustees and dissemination of results.
15	Christian Lewis Trust Cancer Care For Children	England & Wales	01/09/02 to 31/08/03	619,016	Relief of neuroblastoma and related childhood cancers through research and the comfort of sufferers.
16	The Claire Lemmon Fund	Dorset	01/04/02 to 31/03/03	15,038	Outings and holidays for children with cancer and leukaemia & families.
17	Claire Sadler Trust Fund	Dorset	01/04/03 to 31/03/04	9,510	Relieve teenagers and young adults suffering with cancer particularly by provision of holidays, trips and outings.
18	DJMF Child Cancer Concern	Essex, greater London	01/04/02 to 31/03/03	3,260	Relief for children and young persons primarily with non-Hodgkins lymphoma, research funding, holidays and relief of financial hardship.
19	Doctor John Owen Holiday Trust for Sick Children	Wales	01/08/02 to 31/07/03	2,028	Relief of children with cancer or leukaemia in particularly holiday accommodation for the benefit of these children and their families.
20	Edwards Trust	West Midlands	6/04/02 to 5/04/03	471,494	Support research, provide relief and advance education by increasing awareness of complementary approaches to childhood cancers.
21	The Foundation for Children with Leukaemia	England & Wales & beyond	01/01/03 to 31/12/03	9,674,837	Relief of children suffering from leukaemia and promotion of research into causes, treatment and cure for the disease.

22	Help Adolescents with Cancer (HAWC)	England & Wales	01/11/02 to 31/10/03	26,871	Funding counselling and social activities for adolescents with cancer and their families, and friends.
23	The Joshua Gilbert Rhabdomyosarcoma Appeal	Greater London	Financial statements not posted on Charities Commission's online Register.		Relief of children with rhabdomyosarcoma tumours and research into causes and treatment of these tumours.
24	The Katie Trust	England & Wales	01/04/01 to 31/03/02	22,278	Relief from financial hardship for child cancer victims and their families and to advance research into child cancer.
25	Laura Crane Trust	England & Wales & beyond	01/04/02 to 31/03/03	108,999	Relief of persons suffering from cancer primarily aged between 15-25 and particularly by the provision of funding for research.
26	Leucan	West Sussex	01/04/02 to 31 03/03	3,735	Relieve suffering of children and young people with leukaemia or cancer and their families including bereavement.
27	LIFT (Basildon and Thurrock)	Essex – Basildon	31/05/02 to 30/05/03	3,089	Relief of children with cancer or leukaemia undergoing treatment at Basildon Hospital.
28	Lisa Thaxter Trust	England & Wales	01/04/02 to 31/03/03	88,468	Relieve children suffering from cancer by provision of treatment facilities and financial assistance for research.
29	Llandough LATCH	Llandough	01/01/02 to 31/12/02	390,766	Relief of children suffering with cancer and leukaemia and their families.
30	The National Alliance of Childhood Cancer Parent Organisations (NACCPO)	England & Wales	01/04/02 to 31/03/03	1,261	Information and support service for children with cancer and their families, and raising public awareness about childhood cancer.
31	Neuroblastoma Research Fund	Merseyside	01/01/03 to 31/12/03	28,337	Relief of sickness and promotion and dissemination of research.
32	The Neuroblastoma Society	UK	01/01/03 to 31/12/03	147,104	The relief of children suffering from neuroblastoma
33	North of England Children's Cancer Research Fund	North of England	01/04/02 to 31/03/03	633,545	Promote and support research into causes and treatment of childhood cancer by funding research posts and projects at Newcastle University
34	Parents Association For Seriously Ill Children (PASIC)	Derby/Lincoln/ Nottingham hires	01/09/02 to 31/08/03	27,483	Relief of suffering of children with cancer and relief of financial needs among their parents and families.
35	The Rainbow Centre for Children	Gloucestershire, Kent, Somerset	01/09/01 to 31/08/02	169,050	Relieve suffering of cancer or other life-threatening illness patients, especially children, and their families by advice and counseling.
36	Royal Orthopaedic Bone Tumor Service (Rohbts)	Shropshire	01/06/02 to 31/05/03	7,354	Relief of sickness for children with bone tumours, provision of holiday facilities for them and families,,relief of poverty and promote research.
37	Samantha Dickson Research Trust	Hampshire	01/04/03 to 31/04/04	425,070	Research into causes of childhood brain tumours particularly gliomas and relief of patients suffering from malignant gliomas.
38	Sargent Cancer Care For Children	England & Wales	01/04/02 to 31/03/03	6,992,145	Alleviate suffering of children and young people with cancer and provide care and assistance to them and their family.
39	Society Of Parents Of Children With Cancer (Spocc)	Shropshire, West Midlands	01/04/02 to 31/03/03	29,569	To promote the relief of children with cancer particularly by psychological and social support, travel, outings holidays.
40	Teenage Cancer Trust	England & Wales	01/07/02 to 30/06/03	1,338,618	Relief of cancer and related diseases in young people by provision of capital costs, research costs, funding nurses, seminars and conferences
41	Trent Regional Health Area Parents Association of Children with Tumours and Leukaemia (PACT)	Derbyshire, Lincolnshire, Nottinghamshire, South Yorkshire	01/04/02 to 31/03/03	182,605	Relief care and welfare of children with leukaemia and tumours particularly those who reside in the Trent Regional Health Authority area.
42	United Kingdom Children's Cancer Study Group (UKCCSG)	England & Wales & beyond	01/12/02 to 30/11/03	465,813	Promotion of research at 22 centres in UK funded by Ca Research UK
	<b>TOTAL</b>			<b>30,340,220</b>	

**Table 4.2 Funding contributions in the UK, 2003 from national & local charities established specifically to support cancer services<sup>1</sup> for children and young people.**

Charity	Staff costs	Capital Projects	Accommodation	Care Grants	Research	Education	Other	Total
<b>National Charities</b>								
Children with Leukamemia <sup>2</sup>	£60,000	£1,250,000	£783,350	£250,503	£3,563,930	2,091,545	£182,058	£8,181,386
Christian Lewis Trust cancer care for children <sup>3</sup>	£96,813							£229,212
CLIC <sup>4</sup>	£3,160,000	£1,580,000	£1,106,000	£632,000	£869,000		£553,000	£7,900,000
The Joshua Gilbert Rhabdomyosarcoma Appeal <sup>5</sup>					£52,000			£52,000
The Laura Crane Trust <sup>6</sup>								£57,143
The Lisa Thaxter Trust <sup>7</sup>		£1,000		£10,370	£28,804		£24,100	£64,274
The Neuroblastoma Society <sup>8</sup>								£131,450
Sargent Cancer Care for Children <sup>9</sup>	£2,000,000		£1,000,000					£3,000,000
TCT <sup>10</sup>	£95,000	£500,000					£66,666	£661,666
<b>National Charities sub-total</b>	<b>£5,411,813</b>	<b>£3,331,000</b>	<b>£2,889,350</b>	<b>£892,873</b>	<b>£4,513,734</b>	<b>£2,091,545</b>	<b>£825,824</b>	<b>£20,277,131</b>
<b>Local Charities</b>								
Candlelighters <sup>11</sup>	£121,000	£95,458	£10,000	£60,434	£442,046			£800,000
COPARS <sup>12</sup>								£6,454
The Katie Trust <sup>13</sup>								£45,203
LATCH <sup>14</sup>	£47,648	£113,187	£10,961	£109,119	£8,174		£69,223	£358,312
NECCR <sup>15</sup>					£300,000			£300,000
PASIC <sup>16</sup>								£30,000
<b>Local Charities sub-total</b>	<b>£168,648</b>	<b>£208,645</b>	<b>£20,961</b>	<b>£169,553</b>	<b>£750,220</b>	<b>£0</b>	<b>£69,223</b>	<b>£1,539,969</b>
<b>TOTAL</b>	<b>£5,580,461</b>	<b>£3,539,645</b>	<b>£2,910,311</b>	<b>£1,062,426</b>	<b>£5,263,954</b>	<b>£2,091,545</b>	<b>£895,047</b>	<b>£21,817,100</b>

1 Note that some of these charities do not confine their activities within England and Wales but rather operate throughout the UK.

2 From annual report to Dec 2003 at [www.leukaemia.org/annualreport2003.pdf](http://www.leukaemia.org/annualreport2003.pdf).

3 From Trustees Report and Financial Statement

4 From annual report to Dec 2003 at [www.clc.org.uk/resources/documents/clc\\_annual\\_review.pdf](http://www.clc.org.uk/resources/documents/clc_annual_review.pdf)

5 From Charity Update, 2003 at <http://www.jg-rabdo.com/> Includes all of UK

6 From information at [www.lauracrane.org/main.htm](http://www.lauracrane.org/main.htm) Based on average annual fundraising over 7 years used to fund research and support for patients.

7 From personal correspondence with Geoffery Thaxter 20/08/04. nb 'other' revenue expenditure was mostly information provision for families. Grants made to UKCCSG, Studentship,

8 From annual report to Dec 2003 at <http://web.ukonline.co.uk/nsoc/finances2003.htm>

9 From personal correspondence

10 From personal correspondence

11 From personal correspondence with Sally Amos 27/07/04.

12 From information at <http://members.lycos.co.uk/copars>

13 From information at [www.katietrust.org](http://www.katietrust.org)

14 From personal correspondence with Denise Henderson 03/08/04

15 From telephone conversation to NECCR

16 From telephone conversation to PASIC

## NATIONAL CHARITIES

**Children with Leukaemia** is the national charity dedicated to conquering childhood leukaemia. The four goals are to support research into the causes of childhood leukaemia and into more effective treatments with fewer side effects, assist in the development of six centres of excellence and support of patients and families. Support activities includes funding nursing posts, supporting other charities, participating in a programme of treatment for children from eastern Europe and providing hospital and holiday accommodation.

**Cancer and Leukaemia in Childhood (CLIC)** funds research, and supports patients and families. Its activities include coordinating teenage social support groups, providing hospital and holiday accommodation, giving care grants to families to cover bills and funding staff who work within the NHS setting. Currently, across the UK, CLIC funds 37 nursing posts, 9 play specialists at regional oncology centres, 9 doctors and have endowed funding for the Chair of Paediatric Oncology at Bristol Childrens Hospital,

**Christian Lewis Trust Cancer Care for Children** is a national charity supporting children with cancer and their families every day in every way. The charity's aims are to make a difference in the life of a child with cancer and their family by improving their quality of life and by providing emotional and practical support to their affected families during this enormously stressful period.

**The Joshua Gilbert Rhabdomyosarcoma Appeal.** Rhabdomyosarcoma is a rare type of cancer which predominantly occurs in children. It is highly aggressive and results in the death of about 30% of those children who develop this type of tumour. The appeal raises money to provide research fellowships for worthwhile research projects which seek a cure for this form of cancer.

**The Laura Crane Trust** funds research into cancers which occur among 13-25 year olds. The trust also supports measures to improve the quality of life for teenage cancer patients, both during and in the aftermath of their illness such as funding a hospital-

based social worker, a hospital-based activities coordinator and recreational equipment and contributing to the cost of a purpose built Teenage Cancer Trust Unit.

**The Lisa Thaxter Trust** funds research projects including one in Africa. It supports International Childhood Cancer Day and funds the publication which provides information, advice and support to the families of children and young people with cancer. It also supports an organisation for the siblings of children with cancer and funds holidays for them.

**The Neuroblastoma Society** The sole purpose of the Society is the relief of children suffering from neuroblastoma, and to achieve this it raises funds for medical research into improving both diagnosis and treatment of the disease. The Society also offers an opportunity for parents to give each other mutual help, support and comfort.

**Sargent Cancer Care for Children** funds 90 Sargent care professionals who provide a range of services. These include social workers, family support workers, grants, residential accommodation for families, mentoring and youth programmes.

Sargent care professionals and care staff work in partnership with medical and nursing staff and become part of the multidisciplinary team.

**Teenage Cancer Trust (TCT)** builds, adapts and equips specialist units within the NHS setting to care for adolescents with cancer. The TCT will be expanding the current funding stream over the next 10 years. They forecast that £4 million will be spent in their centres in Glasgow, Leeds, London and Cardiff, a further £2.6 million has been allocated to NHS posts, giving a total amount of £6.6 million. A further £11.1 million is currently under negotiation, comprising, £40,000 per annum into a patient and family support pilot in London and Home Counties via UCLH, and the appointment of a Professor of Adolescent Cancer Medicine and team attached to one of the Schools of Medicine (yet to be determined) at £250,000 pa plus inflation for 10 years.

## LOCAL CHARITIES

**Candlelighters** is a Yorkshire based charity at the Specialist Unit at St. James's University Hospital in Leeds. It is dedicated to promoting research into childhood cancer and supporting the 150 children and teenagers referred each year with cancer and their families. Candlelighters raises funds to improve the facilities for children being treated at the Unit in Leeds; to purchase the latest medical equipment for the ward, outpatients clinic and bone marrow transplant unit; toys, books, games and videos which make the children's time in hospital more pleasant; to encourage support groups for parents, siblings and teenagers and to provide holiday breaks.

**Childhood Cancer Organisation for Parents and Relatives Support (COPARS)** was established at Addenbrookes Hospital in Cambridge as a support group for the families of children with cancer on Ward C2, both during and after treatment. Volunteers visit families at the ward and there is an organised programme of events throughout the year providing an opportunity for COPARS families to meet and to have fun together.

**The Katie Trust** is focused in the North-East of England and Cumbria and aims to support research and patients and their families. It funds two PhD studentships at the Northern Institute of Cancer Research in Newcastle upon Tyne into cancers which affect children. It has provided financial assistance with transport and funeral costs for families in hardship, and has provided mobility aids for patients. The Trust has financially contributed towards a care worker's post, based in Newcastle upon Tyne and is planning to make a contribution towards funding for a specialist teenage years care worker to operate in the North-East later this year.

**Llandough Aims to Treat Children with Cancer and Leukemia with Hope (LATCH)** is a local charity based in Cardiff, providing support, maintenance and development of the oncology units at Llandough Hospital. It has assisted with the purchase of research equipment and funding for a research doctor as well as funding social workers and community nurses in the development of a

community support team. The charity assists children and their families emotionally and practically with financial aid and with travel, clothing, holidays and accommodation for parents at Llandough Hospital.

**North of England Children's Cancer Research Fund (NECCR)** aims to raise money to continue research into the causes and treatment of childhood cancers. The NECCR supports a team of doctors, scientists, statisticians and research nurses at the Children's Cancer Unit in the University of Newcastle upon Tyne.

**The Parents Association for Seriously Ill Children (PASIC)** is a registered charity, formed in 1977 for children who had been diagnosed with cancer. It is there to provide support to any families in that situation, especially in the East Midlands, but also nationally. It was felt that the best kind of support would come from parents who had been in a similar position with the help of consultants from the Queen's Medical Centre, Nottingham. It now supports more than 250 families with practical help, financial help or information and advice. It helps to pay additional bills (eg. heating, telephone, travel expenses) for families and any additional equipment costs; it organises social events for families, including siblings; it offers specialised bereavement support; special support for teenagers; it provides a network for parents to stay in touch and provide mutual support; also a regular newsletter keeps families updated.

**Table 4.3 Summary of estimated expenditure for charities established primarily to support children and young people with cancer.**

Number of Charities identified	41
Total Expenditure during 2003	£30,340,220
Range of Expenditure	£1,261-£9,674,837
Mean Expenditure	£740,005
Estimated % of total expenditure for charitable purpose	85%
Estimate of total expenditure for charitable purpose	£25,789,187
Estimate of total expenditure for charitable purpose $\pm$ 25%	£19,341,890-£32,236,484

**Table 4.4 Active charities directing some support to children and young people with cancer as reported on Charities Commission Website for 2003 or closest preceding year.**

	CHARITY	Area of Operation	FINANCIAL YEAR	Total Expenditure	DESCRIPTION
1	Action for sick children	England & Wales	01/01/03 to 31/12/03	75,606	Promote the welfare of sick children at home and in hospitals and provision of information and liaison services.
2	The Adrian Pope Charitable Trust	Staffordshire	05/10/02 to 04/10/03	5,000	Relief of patients with brain tumours by grants research support.
3	Afiya Trust	England & Wales	01/04/02 to 31/03/03	348,975	Advance of health of persons from minority groups.
4	African Caribbean Leukaemia Trust	England & Wales	01/08/02 to 31/07/03	165,189	Relief and support of leukaemia sufferers, public education and promotion of research.
5	Aintree Hospitals Leukaemia Fund	Merseyside	01/01/03 to 31/12/03	20,936	Financing the work at the Haematology Department of the Aintree Hospital. Research and treatment of patients suffering from leukaemia.
6	Andrea's Gift	West-Yorkshire and Leeds	01/01/03 to 31/12/03	602	Promote research into causes and cures of paediatric and adult brain tumours and provide relief for patients and their families and carers.
7	Annette Fox Leukaemia Research Fund	West-Yorkshire and Bradford	01/04/02 to 31/03/03	90,013	Relief of sickness and promotion of research for leukaemia, lymphoma and other related haematological diseases.
8	Association for Children with life-threatening or terminal conditions and their families (ACT)	England & Wales	01/04/02 to 31/03/03	153,581	Information & education service, publish leaflets for families & campaign for palliative care.
9	The A -T Society	England & Wales & beyond	01/01/03 to 31/12/03	176,711	The relief of sickness among people suffering from Ataxia Telangiectasia.
10	Atkinson Morley's Hospital Neurosciences Research Foundation	Greater London	01/04/02 to 31/03/03	137,155	Undertake and promote research in neurosciences and publish results.
11	Birmingham Heartlands and Solihull NHS Trust (Teaching) - Leukaemia	West Midlands	01/04/02 to 31/03/03	2,787,000	A subsidiary fund of the Birmingham Heartlands and Solihull NHS Trust (Teaching), for any charitable purposes relating to the NHS.
12	Birmingham Heartlands Leukaemia Support Group	Birmingham	01/04/03 to 31/03/04	41,135	Relief of suffering by provision of advice
13	Bob Champion Cancer Trust	England & Wales	01/07/02 to 30/06/03	334,773	Research into testicular cancer and other malignant disease including Hodgkins disease and non-Hodgkins lymphoma particularly children and young adults and patient care at the Royal Marsden Hospital.
14	Boston Cancer and Leukaemia Fund	Lincolnshire	01/04/02 to 31/03/03	568,429	A subsidiary fund of the United Lincolnshire Hospitals NHS Trust Charitable Fund for any charitable purposes relating to the NHS.
15	The Bournemouth Leukaemia Fund	Dorset, Hampshire	01/01/03 to 31/12/03	35,033	Education and research into leukaemia and support for work at the Royal Victoria Hospital Boscombe, Bournemouth and other hospitals.
16	Brain & Spine Foundation	England & Wales	01/04/02 to 31/03/03	439,950	Research into neurological disease
17	Brain Tumour Foundation	Surrey, West Sussex	01/04/02 to 31/03/03	27,858	Public education about brain tumours and relief of sickness and distress of people suffering with brain tumours and their carers and families.
18	Brain Tumour Research Campaign (Way Ahead)	England & Wales & Europe	01/04/02 to 31/03/03	6,810	Promote research and its publication.
19	Brain Tumour UK	England & Wales	01/01/03 to 31/12/03	148,797	Promote research and provide advice, support and financial assistance to people with the disease and their family and carers.
20	The British Brain Tumour Association	England & Wales	06/04/02 to 05/04/03	288	Relieve sickness and distress of people with the disease and promote

					research and its dissemination and publication.
21	British Liver Trust	England & Wales	01/04/02 to 31/03/03	426,077	Research into disorders of the liver
22	British Thyroid Association	England & Wales & beyond	01/04/02 to 31/03/03	93,763	Provide advice, support, relief and treatment of people with thyroid disorders, and to support research.
23	Bromley Area Leukaemia Support Group	Greater London – Bromley	01/11/02 to 31/10/03	22,035	Relief of sickness and poverty of persons with leukaemia.
24	Cancer Black Care	Greater London	01/01/02 to 31/12/02	429,983	Relief of need among cancer patients from specified ethnic groups and education in causes and prevention of cancer.
25	The Cancer/Leukaemia Fund	Merseyside	01/04/02 to 31/03/03	165,400	Subsidiary of The St Helens and Knowsley Hospitals Charitable Fund for any charitable purpose relating to the NHS.
26	Cancer Research UK	England & Wales	01/04/03 to 31/03/04	301,318,327	Promote health by research into nature, cause, diagnosis, prevention, treatment and cure of all forms of cancer.
27	Carol's Smile	England & Wales	01/03/03 to 29/02/04	44,025	Relief of suffering from lymphoma, particularly Hodgkin's disease and promotion and dissemination of research into the same.
28	Changing Faces	England & Wales	01/04/03 to 31/03/04	698,397	Assist those with facial and other physical disfigurement by counselling and training and promote knowledge about disfigurement.
29	The Co-operative Clinical Cancer Therapy Trust Fund	England & Wales	01/04/02 to 31/03/03	680,751	Maintain co-operation between clinics by recording and disseminating results of clinical therapy and research into malignant disease.
30	Cornwall Leukaemia Trust	Cornwall-Carrick	01/01/03 to 31/12/03	8,836	Relief from leukaemia and related disorders by provision of buildings, equipment and facilities at the Royal Cornwall Hospital Treliske.
31	Cure Leukaemia	West-Midlands - Birmingham	01/11/01 to 31/10/03	881	Relief of persons suffering from leukaemia and undertaking research into causes, prevention and treatment.
32	Derbyshire Leukaemia Research Fund	Derbyshire	01/04/03 to 31/03/04	58,562	Provision of facilities for research into leukaemia and related diseases.
33	Donna's Dream House Charity	Cheshire, Cumbria, Lancashire, Nth Yorkshire Merseyside,	22/05/02 to 21/05/03	72,652	Relief for children with life-threatening illnesses by the provision of holiday accommodation for such children and their families
34	East Kent Blood Trust	Kent-Thanel-Margate	01/04/02 to 31/03/03	11,992	Promotion and dissemination of research into blood diseases including haemophilia, leukaemia and AIDS.
35	Elimination Of Leukaemia Fund	Kent, Surrey	01/07/02 to 30/06/03	452,067	Promote research into leukaemia, relieve suffering, hardship and distress of patients and their dependants, and support other charitable organisations with similar objectives.
36	The Exeter Leukaemia Fund	Devon	01/09/02 to 31/08/03	372,521	Relief of persons with leukaemia and related diseases in Devon.
37	The Friends of the Leukaemia and Lymphoma Unit (The General Infirmary at Leeds)	North-Yorkshire, West Yorkshire, Leeds	01/12/01 to 30/11/02	25,954	Relief of persons with leukaemia, lymphomas and related disorders.
38	Gordon McLeod Leukaemia Fund	Hertfordshire – Worcestershire	01/09/03 to 31/08/04	7,275	Research into and education of the public about leukaemia and related malignancies and relief of patients with these disorders.
39	Gwynedd Haematology and Cancer Relief Fund	Conwy and Gwynedd	01/04/02 to 31/03/03	10,304	Relief of patients with haematology disorders, promotion of research, training of staff, purchase of publications and equipment.
40	Gwynedd Haematology and Cancer Unit Fund	Conwy, Gwynedd, Anglesey	01/04/02 to 31/03/03	1,173,017	Subsidiary of North West Wales NHS Trust Charitable Fund for any charitable purposes relating to the NHS.
41	Haematology and Leukaemia Trust Fund	South Yorkshire	01/04/03 to 31/03/04	329,236	Subsidiary of Rotherham General Hospitals NHS Trust General Charity,

	General Charity				for any charitable purposes relating to the hospital or NHS.
42	Haematology Care Group	West Bromwich	01/04/02 to 31/03/03	10,954	Welfare of people suffering from leukaemia, lymphoma and other blood disorders and their families.
43	Haematology Fund Charity	East Sussex – Kent	01/04/02 to 31.03/03	712,000	Subsidiary of Maidstone and Tunbridge Wells NHS Charitable Fund, for any charitable purposes relating to the hospital or NHS.
44	Horace Hayhurst Memorial Fund	England & Wales	17/02/03 to 16/02/04	17,623	Research into leukaemia and related diseases of the blood.
45	The James Orton Fund for Leukaemia Relief	West-Midlands – Birmingham	01/06/02 to 31/05/03	285	Relief of sickness and need for those with leukaemia or a related disease.
46	Jeremiahs Journey	Southwest England	01/07/02 to 30/06/03	36,497	Bereavement support for children.
47	The Jessie May Trust	Bath, NE Somerset & Bristol	01/04/02 to 31/03/03	248,589	Palliative care in the community for children and young persons with terminal diseases and education of health professionals.
48	Karen Morris Memorial Trust	UK and beyond	01/06/02 to 31/05/03	9,664	Relief of people with leukaemia and promotion of research
49	The Kay Kendall Leukaemia Fund	England & Wales	06/04/02 to 05/04/03	1,096,818	For research into and treatment of leukaemia.
50	The Kent Leukaemia and Cancer Equipment Fund	Kent - Maidstone	01/04/02 to 31/03/03	151,075	Relief of cancer and leukaemia patients at the Maidstone General and other Kent hospitals including provision of screening facilities.
51	The Laura Centre (COPE)	Leicester-Allextion	01/09/02 to 31/08/03	237,213	Intergenerational bereavement service.
52	The Lee Smith Research Foundation	Greater London	01/07/02 to 30/06/03	5,118	Support for medical research into treatment and cure of leukaemia.
53	The Leicester Haematology Research Fund	Leicestershire	01/10/02 to 30/09/03	5,299	Promotion of research and meeting the cost of additional care facilities not available under NHS for patients with leukaemia/related diseases.
54	Leuka 2000	England & Wales	01/01/03 to 31/12/03	205,434	Promote research and provide and maintain specialist units for treatment of leukaemia patients.
55	The Leukaemia and Lymphoma Research Fund	Tyne and Wear	01/04/02 to 31/03/03	927,249	Subsidiary of City Hospitals Sunderland NHS Trust Charitable Funds for any charitable purposes relating to the NHS.
56	Leukaemia Busters	Hampshire	01/04/03 to 31/03/04	90,758	Equipping, staffing and maintenance of antibody unit at Southampton General Hospital and support research into leukaemia and lymphoma.
57	Leukaemia Care Society	England & Wales & beyond	01/04/03 to 31/03/04	487,671	Promote the welfare of people suffering from leukaemia and allied blood disorders and relieve the needs of patients and families.
58	Leukaemia Fund	Lancashire	01/04/03 to 31/03/04	801,000	Subsidiary of Pennine Acute Hospitals NHS General Charitable Fund, for any charitable purposes relating to the NHS.
59	Leukaemia Fund Charity	Greater London	01/04/02 to 31/03/03	25,358,000	Subsidiary of Greater Ormond Street Hospital Children's Charity.
60	Leukaemia Research Appeal for Wales	Wales	01/04/01 to 31/03/02	61584	Relief for persons with leukaemia resident in Wales and promotion of research at University Hospital of Wales.
61	Leukaemia Research Fund	England & Wales	01/04/02 to 31/03/03	21,717,474	To encourage, promote and assist research into leukaemia and its related conditions.
62	The Leukaemia Society (UK)	England & Wales	01/04/02 to 31/03/03	65,195	Relieve those with leukaemia and bone marrow diseases, educate the public, promote research and maintain a bone marrow donor data bank.
63	Leukaemia Survivors Research Charity	Greater London	01/04/02 to 31/03/03	25,358,000	Subsidiary of Greater Ormond Street Hospital Children's Charity.
64	The Leukaemia Unit Appeal for the Metropolitan Borough of Dudley	West-Midlands, Dudley	01/04/02 to 31/03/03	45,234	Relief of sickness by construction and maintenance of units in Dudley for treatment of residents with leukaemia and related diseases.
65	LINC The Leukaemia and Intensive Chemotherapy Fund	Gloucestershire, Herefordshire, Worcestershire	01/04/02 to 31/03/03	29,767	Relief of patients undergoing chemotherapy at Gloucestershire Oncology Centre, advancement of staff education and support research into leukaemia and related conditions.
66	Lymphoma and Leukaemia Fund (Wales)	England & Wales	01/03/02 to 28/02/03	52,776	Relief for persons with lymphoma or leukaemia resident in Wales

					particularly at Singleton Hospital, Swansea and promotion of research.
67	Macmillan Cancer Relief	England & Wales & beyond	01/01/03 to 31/12/03	82,231,000	Assist cancer sufferers by grants, further cancer education, grants to hospitals, hospices, nursing, convalescent or holiday homes, any other activities to lessen suffering and preserve health of patients & others
68	Marie Curie Cancer Care	England & Wales & beyond	01/04/01 to 31/03/03	72,077,000	To promote the welfare and relief of people with cancer and investigate the causes, distribution and treatment and to promote its cure.
69	The Mark Ridgwell Leukaemia Trust	England & Wales	06/04/02 to 05/04/03	89,043	Purchase of equipment and promotion of research into leukaemia.
70	Mary Obolensky Underwood Foundation for Leukaemia Research	England & Wales	01/10/02 to 30/09/03	8,455	Relief of patients, promotion of research and public education for leukaemia and other malignant diseases.
71	The Medical Academic Festival Orchestra and Choir	Greater London	01/11/02 to 31/10/03	4,643	Promote research into a range of diseases including leukaemia.
72	Musgrove Leukaemic Group Somerset	Somerset -Taunton	01/03/02 to 28/02/03	86,676	Relief for persons with leukaemia resident in Wales particularly at Musgrove Park Hospital, Taunton and promotion of research.
73	National Cancer Alliance	England & Wales & beyond	01/05/02 to 30/04/03	175,700	Public education on cancer and its treatment and the relief of sickness by developing services and resources.
74	North Tees and Hartlepool NHS Trust Leukaemia Fund	North Yorkshire Stockton-on-Tees	01/04/02 to 31/03/03	516,000	Subsidiary of North Tees and Hartlepool NHS Trust General Charitable Fund, for any charitable purposes relating to the NHS.
75	The Pat Broadbent Leukaemia Fund	Greater Manchester	01/04/03 to 31/03/04	38,693	Relief for people with leukaemia at Manchester Royal Infirmary by provision and maintenance of facilities, grants and research promotion.
76	The Paul Vander Molen Foundation	England & Wales	01/02/03 to 31/01/04	3,500	Relief for people with leukaemia, promotion of research, advance of public education and provision of recreational facilities.
77	Penelope Tanner Samaritan Charitable Fund	Buckinghamshire, Gloucestershire, Oxfordshire	01/04/02 to 31/03/03	10,549,225	Subsidiary of Oxford Radcliffe Hospitals Charitable Fund and other related charities. Specifically to support patients with leukaemia whilst at the hospital and at home.
78	Philip Simons Memorial Charitable Fund	Buckinghamshire, Gloucestershire, Oxfordshire	01/04/02 to 31/03/03	10,549,225	Subsidiary of Oxford Radcliffe Hospitals Charitable Fund and other related charities. One specific aim is to support research into leukaemia at the hospital.
79	The Pinderfields Leukaemia and Haematology Fund	West Yorkshire	01/04/02 to 31/03/03	2,208	Relief of people with cancer, leukaemia and other blood disorders particularly by provision of equipment at Pinderfields Hospital.
80	The Plymouth and District Leukaemia Fund	Cornwall, Plymouth	01/01/03 to 31/12/03	63,176	Relief for people with leukaemia in Plymouth and district by promotion of local research and provision of equipment and facilities.
81	The Rainbow Trust Children's Charity	England & Wales	01/07/02 to 30/06/03	2,349,860	Respite care for families with children with life threatening diseases or bereaved. Outreach teams to visit families and education of the public.
82	R B Gray Charitable Trust	England & Wales	06/04/02 to 05/04/03	11,052	Supporting charities established for relief of a range of illnesses including leukaemia and charities conducting research into these.
83	The Richard Thomas Leukaemia Fund	Hertfordshire	01/08/02 to 31/07/03	19,130	Support work at Byrd Ward of Northwick Park Hospital including staff training and purchase of equipment facilities and services.
84	Royal Hallamshire Hospital Leukaemia and Myeloma Research Trust	South Yorkshire – Sheffield	01/04/02 to 31/03/03	22,039	To finance research into leukaemia and myeloma at the Royal Hallamshire Hospital Sheffield and disseminate findings.
85	Royal Liverpool Children's Charitable Fund	Merseyside	01/04/03 to 31/03/04	694,508	Comprised of 40 subsidiary funds including the Alder Hey Leukaemia Research Fund.
86	Royal Liverpool University Hospital Andria Butler Fund	Lancashire - Merseyside	01/04/02 to 31/03/03	1,328,260	Subsidiary of Royal Liverpool & Broadgreen University Hospitals NHS Trust Charitable Funds for any charitable purposes relating to the NHS.

87	Royal Liverpool University Hospital Leukaemia Fund	Lancashire - Merseyside	01/04/02 to 31/03/03	1,328,260	Subsidiary of Royal Liverpool & Broadgreen University Hospitals NHS Trust Charitable Funds for any charitable purposes relating to the NHS.
88	Simon Cohen Memorial Trust	England & Wales	01/08/03 to 31/07/04	350	Relief of sickness and advancement of education about leukaemia.
89	The Spencer Bourn Foundation for Leukaemia Research	Herefordshire	01/10/02 to 30/09/03	1,424	Promotion of research into leukaemia at the County Hospital, Hereford.
90	Stoke Mandeville Hospital Carl Todd Oncology Charity	Bedfordshire, Buckinghamshire, Hertfordshire.	01/04/02 to 31/03/03	844,000	Subsidiary of Stoke Mandeville Hospital Charitable Fund for any charitable purposes relating to the hospital or NHS
91	Stuart Martin Memorial Fund	Greater London, Kent, Dartford	26/07/02 to 25/07/03	50	Relief of sickness particularly amongst children with leukaemia at GOSH and other hospitals and other local charitable purposes.
92	The Sue Harris Bone Marrow Trust	England & Wales	01/08/01 to 31/07/02	33,909	Promote research into leukaemia and disseminate results, relief especially for those of the Jewish faith, relief of poverty.
93	The Tracy Sollis Leukaemia Trust	England & Wales	01/01/03 to 31/12/03	23,988	Prevention and relief of leukaemia primarily through research.
94	T.R.E.B.L.L.E Trust Fund Charity	Berkshire, Buckinghamshire	01/04/03 to 31/03/04	380,806	Subsidiary of Heatherwood and Wexham Park Hospitals Trust General Fund for any charitable purposes relating to the NHS.
95	The Tyneside Leukaemia Research Association	Cumbria, Tyne and Wear, Newcastle upon Tyne	01/01/01 to 31/12/03	1,113,018	Encourage and support research into causes and treatment of leukaemia. To raise funds and co-operate with organisations with similar objectives.
96	Umuada Ngwa Charitable Trust	England & Wales & beyond	01/09/02 to 31/08/03	1,392	Relief of need, sickness and distress in children in Africa, relief of sickness for children with leukaemia in the UK and promotion of African languages and culture in the UK.
97	United Kingdom Brain Tumour Society	England & Wales	01/01/03 to 31/12/03	148,797	Research into cause and cure, advice, support and financial assistance.
98	The University of Newcastle upon Tyne Development Trust – Jeffcock Medical Research Fund	Tyne & Wear - Newcastle upon Tyne	01/04/02 to 31/03/03	1,803,554	Subsidiary of The University of Newcastle upon Tyne Development Trust Charities. Specifically to fund research into cancer and leukaemia through research fellowships and studentships.
99	Wessex cancer trust	Wessex	6/04/02 to 05/04/03	904,764	Relief from cancer, promote research and educate public.
100	West Yorkshire Forget Me Not Trust	West Yorkshire	1/01/03 to 31/12/03	17,684	Support of children & their families in West Yorkshire with extraordinary medical needs.
101	The Williams Haematology Charitable Fund	Greater London	01/04/02 to 31/03/03	296,800	Subsidiary of The Lewisham Hospital NHS Trust Charitable Fund specifically for research into and staff training about leukaemia.
102	World Cancer Research Fund UK	England & Wales & beyond	01/10/02 to 30/09/03	8,238,934	To promote, fund, support and encourage research as to the causes and treatment of cancer for the general benefit of the public.
103	Yeovil Hospital NHS Leukaemia Research Trust	Dorset – Somerset	01/04/02 to 31/03/03	341,000	Subsidiary of East Somerset NHS Trust General Charitable Fund specifically for research into leukaemia.
104	Young minds	England & Wales	01/04/02 to 31/03/03	1,274,412	Education about and relief of children and families suffering psychological or emotional disturbance.
	<b>TOTAL</b>			<b>£587,269,708</b>	

**Table 4.5 Charities established to support cancer patients in general, those with a specific form of cancer, diseases relating to a specific body organ or charities supporting illness in childhood that distribute a portion of their funding to children and young people with cancer.**

<b>Cancer Charities</b>	<b>Year</b>	<b>Expenditure to Children</b>	<b>Total Expenditure</b>	<b>% to children/young people with cancer</b>
Cancer research UK	01/04/03 to 1/03/04	9,000,000	301,318,327	3.0 %
Macmillan	01/01/03 to 1/12/03	245,000	82,231,000	0.3 %
<b>Non-cancer Charities</b>	<b>Year</b>	<b>Expenditure to Children</b>	<b>Total Expenditure</b>	<b>% to children/young people with cancer</b>
Changing Faces	01/04/03 to 1/03/04	156,846	576,205	0.3 % of child clients had cancer

**Cancer Research UK** supports and undertakes a comprehensive programme of research in institutes, hospitals, universities and medical schools throughout Britain and Northern Ireland. The research portfolio targets all aspects of cancer and covers work in four broad subject areas: the biology and causes of cancer, developing cancer treatments, cancer prevention and improving quality of life.

**Macmillan Cancer Relief** is a UK charity that works to improve the quality of life for people living with cancer by funding specialist Macmillan nurses, doctors and other health professionals to deliver care, building cancer care centres, giving financial support to those in need and providing a range of information and support services, including a telephone helpline, publications and local cancer information centres and assisting local self help and support groups.

**Changing Faces** has a primary focus on disfigurements affecting the face, but their work also has relevance to disfigurements of other parts of the body. The charity addresses disfigurements of any origin, whether present at birth or acquired later in life. The charity supports and represents people with disfigurements by working to build their self-confidence and self-belief, ensuring they receive effective health care and rehabilitation and working to increase public awareness and knowledge about disfigurement.

**Table 4.6 Summary of estimated expenditure by other (non-hospice) charities which support children and adolescent with cancer.**

Number of charities sampled	104
Total expenditure for sampled charities during 2003	£587,269,708
Range of Expenditure for sampled charities	£50-£301,318,327
Average Expenditure for sampled charities	£5,646,824
Average Expenditure for charities with total expenditure < £20,000,000	£604,183
Estimated % of total expenditure to children and adolescent with cancer	1%
Estimated total number of charities	1000
Estimate of total expenditure for charitable purpose	£6,041,820
Estimate of total expenditure for charitable purpose $\pm$ 25% + £9,000,000 from Cancer Research UK	£13.5m to £26.6m