



# **National Steering Group for Specialist Children's Services**

## **Report on Children's Cancer Services in Scotland**

### **Option Appraisal – Children's Cancer**

## Index

<b>Executive Summary .....</b>	<b>3</b>
<b>1. Background .....</b>	<b>9</b>
• Introduction	
• Current service provision	
• The Options	
<b>2. Trends in Childhood Cancer .....</b>	<b>17</b>
<b>3. The Model of Care .....</b>	<b>27</b>
<b>4. The Non Financial Criteria .....</b>	<b>34</b>
<b>5. Assessment of the non financial criteria .....</b>	<b>52</b>
<b>6. Engaging with families .....</b>	<b>58</b>
<b>7. Resources and Costs .....</b>	<b>61</b>
<b>8. Uncertainty .....</b>	<b>65</b>
<b>9. Assessment of the Options .....</b>	<b>70</b>

## Appendices

<b>A. Levels of Care .....</b>	<b>77</b>
<b>B. Profile of activity, resources and services in each centre .....</b>	<b>78</b>
<b>C. Non-financial criteria and descriptors .....</b>	<b>81</b>
<b>D. Workforce estimates .....</b>	<b>83</b>
<b>E. Stakeholders involved in the appraisal .....</b>	<b>89</b>

## EXECUTIVE SUMMARY

### Background.

This is the third report on children's cancer services in Scotland in recent years. The earlier reports were:

- *The Review of Paediatric Oncology and Malignant Haematology Services in Scotland* (The Specialist Paediatric Services Sub Group and Scottish Paediatric Oncology and Haematology Services Group, 2004);
- *The Future of Cancer Services for Children and Young People in Scotland 2005*, (Children's Cancer Services in Scotland Working Group); and

These reports reflect concerns that the present configuration of services in Scotland may not be sustainable and that changes are needed to achieve continuing improvements in standards of care. In England, the National Institute for Health and Clinical Excellence (NICE) has produced guidelines setting out appropriate standards of care in their report *Improving Outcomes for Children and Young People with Cancer*.

The three Scottish Children's Hospitals each provide a comprehensive service for children and young people with cancer, and all are registered with the UK Children's Cancer and Leukaemia Group (CCLG) in recognition of this. This enables the individual hospitals to participate in national clinical trials. The individual hospitals have built up their service over the years in response to the needs of the children and the strengths of the medical staff.

The three children's hospitals currently see around 150 new diagnoses of childhood cancer each year in the 0-15 year age group: about 20 in Grampian, 55 in Lothian and around 75 in Glasgow. About one third of these cases are diagnosed with a leukaemia, about a quarter with a brain tumour, and the rest are small numbers of other cancers (e.g. bone tumours and lymphomas). There are a further 40 new cases each year in the 16-18 year age group, some of whom are seen in the children's hospitals.

### Drivers for Change

Nearly everyone who has been involved in this work over the last year readily acknowledges there is a need for change. The key drivers for change can be summarised as follows:

- Continuing the **improvement in Scottish services**, to increase survival rates to best international standards and increase access to clinical trials for all patients;
- **Achieving compliance** with NICE guidelines – the acknowledged best practice guidance; and
- **Responding to changing conditions** – the development of new children's hospitals in Edinburgh and Glasgow, changing working patterns, and the concerns over sustainability of the service in its current form.

## The appraisal process

The care of children with cancer is a very sensitive issue. Each child is an individual and, though they may have the same over-arching diagnosis, the intensity of their treatment and the clinical skills required will not be identical. For this reason, it is very difficult to build a fully comprehensive evidence profile since comparisons between service models, geographic areas, or across time periods cannot be made on a like-for-like basis.

The appraisal uses NICE guidelines '*Improving outcomes for children and young people with cancer*' as a benchmark. The guidelines provide a model for the future configuration of services for children and young people with cancer. They describe services being delivered through a defined network with identified Principal Treatment Centres (PTCs) and Shared Care Centres. Minimum levels of staffing and defined co-located services are identified by NICE for both principal treatment centres and shared care centres.

NICE also defines a spectrum of 4 levels of care, which for the first time clarifies the key components of a specialist service and staffing levels for children's cancer services in the UK. Level 4 care is delivered by a specialist unit, to Level 1, which can be provided by a District General Hospital with a 24/7 paediatric unit. The levels will enable the continued provision of children's cancer services in the children's hospitals in Aberdeen, Dundee, Edinburgh and Glasgow within a managed clinical network.

Under the model of care that has been developed, it is the diagnosis, staging and commencement of treatment that might be concentrated in fewer treatment centres working at Level 4 within Scotland. In order to carry out the appraisal, this approach was adopted to allow estimates to be made in relation to any change in activity for individual centres.

## The options for change

The focus of this study is to identify a model that offers a positive way forward for the service, defining the number of PTCs that Scotland can sustain, the participation of other centres in shared care arrangements, and the level at which each centre will operate. Defining the exact operating procedures and delivery model is beyond the scope of this study and must be addressed by the clinicians once the over-arching system is in place through the Managed Clinical Network (MCN).

The options for future service delivery were informed by the previous review (*The Future of Cancer Services for Children and Young People in Scotland 2005*) and in consultation with key stakeholders from each centre (the clinicians, managers, patients support groups and other medical staff). Five options were initially agreed for analysis:

- **Option 1: Status Quo** – the service continues in its current form. It is generally acknowledged that this is not a realistic and sustainable option, but is retained within the appraisal to demonstrate the changes from current conditions that will result under alternative options
- **Option 2: Status Quo Plus** – the Edinburgh, Glasgow and Aberdeen children's hospitals are brought into compliance with the NICE guidelines for a PTC. It is acknowledged that the recommended 5 consultants in a PTC is not an achievable or sensible target for Aberdeen given current patient numbers. Thus, the option

includes an improvement in staffing levels for Aberdeen, but not to the full NICE recommended level. The Aberdeen service therefore cannot comply with NICE guidelines in respect of 24/7 access to specialist medical cover, and immediate access to Paediatric Intensive Care Unit (PICU) and paediatric neurosurgery access

- **Option 3: Two PTCs** – Edinburgh and Glasgow operate as Principal Treatment Centres, compliant with NICE guidelines and supported by a national MCN.
- **Option 4: Single PTC** – Edinburgh is the sole PTC within the network (4a), or Glasgow is the sole PTC within the network (4b).

One of the key outcomes of this review process is to ensure that the future service provided for children and young people in Scotland with cancer can provide treatment and care that equals the best standards in European countries.

To comply with the changes taking place in working conditions and the available guidance from NICE, changes in the configuration of services in Scotland are necessary. The main concern is that, without such changes there are risks that it may not be possible to achieve continuing improvements in outcomes.

### **Criteria for evaluating the options**

A number of criteria have been used to compare and evaluate the different options. The criteria were developed in consultation with the individual hospitals, and then agreed at a combined focus group involving all hospitals and stakeholders. It is acknowledged that no outcome offers a panacea, and in each case there are both positive and negative consequences.

The criteria therefore take into account the possible effect on the quality of care, the implications for access to services, the sustainability of the workforce, and the wider implications of reconfiguration for other hospital services. The evidence used to assess the options against these criteria is set out in the report. Evidence on these issues is far from perfect, and any assessment of this evidence inevitably involves a substantial degree of judgement.

The financial implications of the options were assessed by the Directors of Finance from the 4 main Health Board areas, but unfortunately the costs of the one centre option were not developed. This would have required a significant amount of additional work, and the view of the Directors of Finance was that it was most unlikely that the costs of a single centre option would be less than the costs of a two-centre option.

### **Key findings and recommendations**

It must be stated from the outset that, in the light of differing opinions, the data and optimal service model are not universally accepted. There are known risks that act to counter each alternative approach. In response to this, the outcome of this study offers a reasoned and positive way forward for the service, but allows sufficient flexibility to refine the 'shared care' model to avoid unforeseen difficulties. This serves to minimise the risks, while moving towards a safe and sustainable long-term service.

Whichever option is adopted, significant investment in additional staffing will be required to achieve improvements in standards of care for children with cancer in Scotland. If the current pattern of services is retained, it is estimated that additional expenditure on revenue costs of around £1 million per annum would be necessary. It is very unlikely that concentrating some aspects of the service in two or in one PTCs would lead to any savings in revenue costs. In practice it is likely to give rise to further increases in revenue costs.

Overall, there are risks that the current situation is unsustainable in the long term given the *potential* retirement of key staff and the likely difficulties with recruiting like-for-like replacements. It is likely to be difficult to replicate the existing expertise within the current service pattern given low patient numbers available for training, and lack of planned succession. Concentration of some aspects of the service in one or two PTCs would help to address this problem.

More importantly, qualitatively, a higher concentration of patients can lead to improvements in standards of care by offering the most experience for clinicians and the required critical mass of patients to efficiently operate trials consistently for all. Higher patient numbers could also improve the potential for pro-active Research and Development to take place. This argument fits with NICE best practice guidance, and favours a move towards one or two PTCs.

However, concentrating Level 4 care in one or 2 centres has certain disadvantages. It means that some children and their families will be exposed to increased travel, and this results in increased expense, inconvenience and stress for these families. It has also raised concerns regarding the wider sustainability of other services in the children's hospital's not functioning as PTCs. Finally, a shared care model increases the number of children accessing more than one hospital with potential adverse effects on 'continuity of care' for these children and their families.

With these concerns in mind, it was agreed at a key stakeholder meeting that the MCN will be the basis for delivering improvements identified during the review process. The approach will need to be enhanced to achieve this; the key features of this would include the following:

- The focus for the operational delivery should be on a flexible network which results in the maximum delegation and delivery of safe services as locally as possible;
- Maximum delegation and delivery of safe services as locally as possible will be agreed between the identified PTC(s) and shared care centres working at levels 1, 2 and 3; This way of working would constitute a 'permissive' network.
- Identification and provision of key elements to support delivery of care, including in particular, robust research and development supported by clinical trial managers and data collection to ensure full access to clinical trials for patients;
- The need for resources both to bring the service to appropriate levels and further investment depending on the final model to support shared care across the country;
- Capacity should be built into the Network development process to allow care pathways be developed and implemented;

- All children and young people should be able to participate in the clinical trial that best suits their individual cancer and stage.

The link with the ongoing neurosurgery review was seen as a key element, as some of the highest risk children are those who require access to paediatric neurosurgery expertise. In the absence of a decision about the future location of complex paediatric neurosurgery, a decision has to be made to allow the service for children with cancer to move forward, the managed clinical network to develop, and the service to start to function as a single service for children with cancer in Scotland.

The overall assessment, therefore, based on the current evidence available, is that two PTCs (Option 3) represents the best means of configuring services for children with cancer in Scotland for the medium term. Glasgow is currently operating as a Level 4 centre and will continue to do so; and Edinburgh will require some investment to ensure it meets NICE guidelines to provide level 4 care. Aberdeen will provide a Level 3 service, and this will mean that a significant part of the treatment required for children from Grampian can continue to take place in Aberdeen. with Dundee operating at Level 2.

However, to enable Aberdeen to operate as a level-3 centre within the network, exact operating procedures for the 'permissive' MCN will require to be defined. This was not practical during the course of this review. It has been suggested that Aberdeen could continue to carry out some diagnostics, as the expertise currently exists to support this. The practical model must be established by the hospitals working within the new network. However, the key aspects will be to ensure the sustainability of Aberdeen by facilitating continued diagnostics, surgery and radiotherapy where local safe practice can be guaranteed.

The NICE guidance requires that shared care centres have formal contractual agreements with the PTC regarding their level of service. Through this process, it is possible for local centres to retain a high level of delivery, should the risks over sustainability prove false. However, if staff with key skills cannot be replaced, the PTC will have the capacity to absorb the transferred patients.

Any change in the service model will also have implications for some families. Policy options should therefore be considered to minimise the negative impacts associated with increased travel. This should include a review of the local Boards' funding arrangements for travel, and the provision of accommodation.

The advantages of this approach are that elements of diagnostics, surgery and treatment can be undertaken locally if the centre has the capability to deliver this care safely, supported by the main centre, without over-staffing each centre to meet NICE recommendations. Retaining some local services will minimise travel impacts for children and families.

A decision for change has to be made because the current situation is unsustainable and unlikely to enable services to develop in line with best standards. The approach highlighted should lead to investment and improvements in service provision, but will require buy-in from all key stakeholders in order for the process to work. The focus for the hospitals must now turn to designing the operation of the network within the new PTC framework.

The annual revenue cost of this option would be around £1.6 million higher than the current cost of the service in Scotland. The key benefits to children and their families include:

- All children with cancer in Scotland would have their treatment managed and co-ordinated by the Managed Clinical Network
- Any elements of care requiring 24/7 access to specialist medical care and PICU, will be delivered by a Level 4 centre
- Management of clinical trials across Scotland would be improved due to an increase in data managers
- Access to specialist pharmacy staff during chemotherapy treatment would be improved in Aberdeen, Dundee, Edinburgh and Glasgow
- The expansion of outreach nursing would improve the support available to children and their families who attend the centres in Aberdeen, Edinburgh and Glasgow.

Together with the general improvements in staffing that are necessary to achieve NICE standards across the country, this option would bring about a significant improvement in service to children and their families across Scotland and justify the additional expenditure required.



## 1. BACKGROUND

### 1.1 Previous Work

The provision of specialist services for children with cancer in Scotland has been the subject of two earlier reports:

- *The Review of Paediatric Oncology and Malignant Haematology Services in Scotland* by the the Specialist Paediatric Services Sub Group and Scottish Paediatric Oncology and Haematology Services Group, (2004); and
- *The Future of Cancer Services for Children and Young People in Scotland* by the Children's Cancer Services in Scotland Working Group (2005).

The National Institute for Health and Clinical Excellence also published guidance on services for children and young people with cancer in 2005, *Improving Outcomes for Children and Young People with Cancer*.

The impetus behind these studies has been a general concern that the current configuration of services for children with cancer may no longer be sustainable, and that changes are required to ensure that children will have access to the best possible standards of care.

The *Review of Paediatric Oncology and Malignant Haematology Services in Scotland* concluded that "by 2008 it will not be possible for to provide 24/7 consultant-led cover in one patient unit, far less the existing three tertiary units with the existing number of Consultants without significant re-design, additional staff and reconfiguration of services". This review noted that pressures were being brought on services as a direct result of:

- The need for continuous improvement in access and quality of healthcare;
- The abilities of individual hospitals to deliver low volume highly specialised services; and
- The impact of European working time legislation and the report on Modernising Medical Careers.

The report recommended that there should be an appraisal of a number of options for the future provision of children's cancer services in Scotland.

An initial appraisal of options was carried out by the Children's Cancer Services in Scotland Working Group, and the results were published in their report in 2005. This Group concluded that the guidelines being developed at that time by the National Institute for Health and Clinical Excellence in England "should constitute the terms of reference against which the Scottish service provides care and should be accepted as the appropriate context for governance purposes". The Group examined a number of options for reconfiguring services and recommended that a full option appraisal should be carried out, using the NICE guidelines, based on the status quo, a two-site option in Edinburgh and Glasgow, and a single-site option in either Edinburgh or Glasgow.

The NICE Guidelines, which were published in 2005, provide a detailed and thorough examination by experts of the best available evidence and were developed to provide recommendations on future service provision for children and young people with cancer. The guidelines provide an overview of children's cancer services in England

and Wales, and set out a template to aid future service planning. This template is based on the concept of Principal Treatment Centres (PTCs), delivering a sustainable range of services with defined minimum levels of staffing, supported by Paediatric Oncology Shared Care units. The latter may or may not provide elements of specialist cancer services.

The *Future of Cancer Services for Children and Young People in Scotland*, initially identified a model of care comprising 4 levels. This clearly articulated the treatment and care that would be provided from the PTC (Level 4) through to a District General Hospital (Level 1). These Levels of care and treatment have been further developed by NICE, and Appendix A describes them in detail.

The process of reviewing and appraising children's cancer services in Scotland has now gone on for some five years. This work has absorbed a significant amount of time for clinicians and managers, and the continuing uncertainty about the future development of services is unsettling both for staff and for the families of patients. It is important, therefore, that clear conclusions and recommendations should now be reached about the most effective way of building on the strengths of the existing services.

## **1.2 Current Services**

The treatment and support offered to children and young people with cancer has improved significantly over the last two decades. As a result of national and international collaboration in clinical trials, treatment has been refined and developed, and is now more intense. This has led to more children receiving treatment at any one time, and an aggressive approach to relapsed disease that would once have been considered palliative. This in turn generates resource demands from an increasing number of admissions and children who are sicker requiring supportive care

Historically, the three Scottish Children's Hospitals (the Royal Hospital for Sick Children Glasgow, the Royal Hospital for Sick Children Edinburgh, and the Royal Aberdeen Children's Hospital) have each provided a comprehensive service for children and young people with cancer, and all are registered with the Children's Cancer and Leukaemia Group (CCLG)<sup>1</sup>. This enables the individual hospitals to participate in national clinical trials. These hospitals have built up their services over the years in response to the needs of the children and the interests of the medical staff. As a result, each children's hospital has a different profile of staff, varies in size reflecting their catchment population, and has evolved different ways of working. A full profile of the children's cancer service in each of the Scottish children's hospitals was outlined in the 2004 *Review of Paediatric Oncology and Malignant Haematology Services in Scotland*

Yorkhill children's hospital in Glasgow is the largest of the three Scottish paediatric oncology units. There are currently seven consultant posts: five filled, one vacancy, and a locum. This exceeds the minimum number of five consultant staff posts recommended by NICE.

---

<sup>1</sup> CCLG Clinical Governance Research Group looks at survival by centre each year and scrutinises any anomalies. The registered hospitals receive an annual report which details 5 diagnostic groups and total number of patients, observed and expected numbers of deaths and a log-rank test for heterogeneity of survival. The results are shared with the individual centres, but currently this information is not available any more widely.

The unit sees an average of around 75 new children aged 0 -15 years with a cancer diagnosis each year. It is the recognised national paediatric bone marrow transplant unit in Scotland. It has a 16-bed Paediatric Intensive Care Unit (PICU), and will also have paediatric neurosurgery on site when it re-locates to the Southern General. It is the tertiary centre for the West coast of Scotland, and carries out shared care with Inverness (Raigmore Hospital) and Dumfries (Dumfries and Galloway Royal Infirmary).<sup>2</sup>

The Royal Hospital for Sick Children Edinburgh (RHSCE) is the second largest of the three centres, and sees around 55 new cases a year among children aged 0-15 years. It has an 8-bed PICU, and neurosurgery will be on site when it re-locates to the Royal Infirmary of Edinburgh site. Currently, there are four consultant posts; one vacancy. It does not meet the current NICE guideline for Consultant numbers, though it is close to the NICE standard of five consultant posts.

Shared care is practised with Ninewells Hospital in Dundee and patients from Tayside are admitted to Edinburgh for diagnostics, staging and initiation of treatment. Inpatient chemotherapy for children from Tayside is carried out in Edinburgh, with day case, outpatient chemotherapy and follow-up, along with supportive care, taking place in Ninewells.

The Royal Aberdeen Children's Hospital whilst being the smallest of the three children's hospitals in terms of activity, with around 20 new cases a year among children aged 0-15 years of age, has remained registered with the Children's Cancer and Leukaemia Group (CCLG). It has two consultant posts: one is a part time haematologist, and the other is a paediatrician. (The current paediatrician has a training in haemato-oncology.) The service provided by the two consultants equates to 1.2 whole time equivalents.

To date, the hospital has provided a service for the surrounding population, but the current haemato-oncology consultant rota cannot provide a 24/7 service. Shared care is practised with the Orkney and Shetland and Dr Gray's Hospital in Elgin.

Some developments have taken place since the publication of the report *Review of Paediatric Oncology and Malignant Haematology Services in Scotland in 2004*, the most significant being:

- A Consultant Paediatrician with some training in Haemato-oncology has been employed by NHS Grampian;
- A fourth Consultant post (Haematologist) was established in NHS Lothian in 2006, but a national shortage of Haematologists means this post has not been filled; and
- A seventh post (Haematologist) has been created in NHS Greater Glasgow and Clyde, but as yet has not been filled.
- Aberdeen has a new children's hospital which opened in 2005, and is co-located with adult and maternity services

---

<sup>2</sup> Shared care means that some of the treatment for children with cancer can be carried out in local hospitals closer to the family home.

- Edinburgh and Glasgow are planning new children's hospitals which will co-locate paediatrics with adult and maternity services in both cities. It should be noted neither new build will co-locate adult and paediatric cancer services.
- Establishment of a Managed Clinical Network with an identified Lead Clinician and Manager

All three children's hospitals have multi disciplinary teams and specialist expertise has been developed at nursing, social work, pharmacy and surgical level. A summary of the children's hospitals' activity and co-existing services is detailed in Appendix B.

### 1.3 The Option Appraisal

The current option appraisal commenced in September 2006, and during the course of the last 18 months a wide range of stakeholders have been engaged. Those consulted include:

- parents whose children have been affected by cancer;
- clinicians providing the service including doctors, nurses, radiologists, surgeons, pharmacists, clinical oncologists;
- senior health service managers;
- the voluntary sector; and
- Information Services Division (NHS National Services Scotland).

The options being considered in this appraisal of children's cancer services are based around the NICE Guideline concept of Principal Treatment Centres and Shared Care centres. These guidelines give a clear outline of how children's cancer services should be developed to achieve the best standards of care, and they have formed the basis of the appraisal to estimate what changes would be required to ensure the service is Scotland is able to comply.

PTCs are physical units with concentrated Oncology and Haematology expertise (a minimum of 5 consultants in haematology and paediatric oncology), with immediate access to Paediatric Intensive Care Unit (PICU) and Paediatric Neurosurgery and on-site access to a range of support services: Pathology, Radiology, Surgery. Currently there is not a recognised ideal number of new referrals annually to ensure a unit is viable, but 80 new diagnoses and 15 inpatient beds have been put forward by NICE as a suggested minimum.

The NICE guidelines suggest that Shared Care can be carried out by any 24-hour Paediatric unit that sees a minimum of 10 newly diagnosed childhood cancers per year. To provide safe care, there must be identified staff in place, and a written contract with a PTC. It is accepted that the numbers for shared care cannot be strictly applied in Scotland due to the rural nature of more remote parts. For example, Raigmore Hospital in Inverness sees less than 10 new diagnoses per year, but has a paediatrician with a special interest in children's cancer, an outreach oncology nurse specialist, and a social worker. The outreach nurse and social worker posts are funded by CLIC Sargent. The team provide shared care in conjunction with Glasgow, Edinburgh and occasionally Aberdeen

During this period of time the NICE Implementation of Guidelines Group (IOG) <sup>3</sup> have also developed a framework for Commissioners to identify the services, staff and governance arrangements that need to be in place to provide a service to improve outcomes for children and young people with cancer.

The '*Future of Cancer Services for Children and Young People in Scotland*', initially identified a model of care comprising four levels. These clearly articulated the treatment and care that would be provided from the specialist PTC through to a District General Hospital.

These guidelines have been developed further by the NICE IOG group, and accepted by the Scottish Paediatric Oncologists / Haematologists. This has provided the basis on which the option appraisal has sought to capture what changes may happen to a child's treatment journey across the options being considered. (Appendix A)

As the appraisal commenced, the formal approval of national Managed Clinical Network status was achieved. A Network Lead and Network Manager were appointed in October 2007. All the Scottish Children's Hospitals have agreed to work within the managed clinical network.

An option appraisal for Neurosciences commenced in July 2007, and it has been recognised that the outcome of this piece of work will be a significant factor in determining the best configuration for Scottish children's cancer services

## **1.4 The Options**

The aim of this appraisal is to consider the costs and benefits of alternative options for reconfiguring cancer services for children in Scotland in the light of the issues raised in the earlier reports and based on the guidance set out by NICE.<sup>4</sup>

Broadly there are three alternatives:

- Retain the existing pattern of service: this would mean that Aberdeen, Edinburgh, and Glasgow would be Principal Treatment Centres and would continue to diagnose and treat patients – though some patients who require more specialist services would continue to be referred outwith the local centre for diagnosis and treatment;
- Establish two Principal Treatment Centres in Edinburgh and Glasgow;
- Establish a single Principal Treatment Centre in either Edinburgh or Glasgow.

On the basis of these broad alternatives the following specific options have been identified.

---

<sup>3</sup> Improving outcomes for Children and Young People with Cancer, Delivery of Cancer Services for Children within Principal Treatment Centres and Paediatric Oncology Shared Care Units: Information for Commissioners.

<sup>4</sup> *Improving Outcomes in Children and Young People with Cancer*. National Institute for Health and Clinical Excellence. August 2005

## **Option 1: The Status Quo**

This would retain the current configuration of services in Glasgow, Edinburgh, and Aberdeen with Dundee, Inverness and Dumfries providing shared care.

While this option would clearly not meet the standards set out in the NICE guidelines, or the European Working Time Regulations, it provides an essential baseline against which the costs and benefits of other options can be compared. It will show what the service currently costs, and any additional costs (or savings) associated with other options as well as additional benefits can then be identified. It is common to use a Status Quo option in option appraisals to provide a baseline.

## **Option 2: Status Quo Plus**

In this option, Glasgow, Edinburgh, and Aberdeen would become Principal Treatment Centres providing Level 4 care. It differs from Option 1 in that significant investment would take place to bring standards of care closer to those set out in NICE guidelines – e.g. improvements in medical staffing.

It assumes the three children's hospitals would function as Principal Treatment Centres. It has been agreed with staff in Aberdeen that raising the number of Consultants in Aberdeen for this option to meet the NICE guidelines is not realistic. The current workload would not support this number, and therefore it would be unlikely to attract staff. Aberdeen does not have an on-site Paediatric Intensive Care Unit and paediatric neuro-surgery unit. For this reason, this option would not achieve two of the key NICE standards - 24 hour specialist cover, and immediate access to a PICU.

Some concerns have been raised about the inclusion of this option in the appraisal since it had previously been recommended that the current appraisal should focus on a two-centre and a single-centre options.<sup>5</sup>

The previous appraisal of options for children's cancer services was – and was intended to be - a relatively simple appraisal of different options. For example, there was no assessment of the resource implications of the options, and no attempt was made to examine in any detail the implications of reconfiguration for travel by patients and relatives. Nor was there any detailed examination of the extent to which diagnostic and treatment services would be relocated under the different options.

Given the wider public and professional concerns that may be raised by any proposals to reconfigure services across Scotland, it seemed best to ensure that the current more detailed option appraisal should fully examine all of the main alternatives for delivering services for children with cancer in Scotland, including maintaining the existing configuration of services. It is for these reasons that the *Status Quo Plus* option has been included in the appraisal.

## **Option 3: A Two-Centre Solution**

Edinburgh and Glasgow would both be Principal Treatment Centres working at Level 4, with Aberdeen (Level 3) and Dundee and Inverness and Dumfries participating in shared care arrangements, working to an agreed level of care.

---

<sup>5</sup> The Future of Cancer Services for Children and Young People in Scotland: May 2005

It has been asked why Aberdeen could not be one of the two Principal Treatment Centres for Scotland. In practice, it is difficult to see how a two-centre solution involving Aberdeen and Glasgow or Aberdeen and Edinburgh could work given the geographical distribution of the population in Scotland. For example, if the two centres were Glasgow and Aberdeen, patients from Edinburgh are likely to travel to Glasgow as the closest centre. This would result in a significantly unequal distribution of workload, with Glasgow seeing perhaps 80% of the patients in Scotland and Aberdeen seeing only 20%. A similar unequal distribution is likely to result if Edinburgh and Aberdeen were the two centres.

Given the geographical distribution of Scotland's population, it seems inevitable that if there are going to be only two Principal Treatment Centres then these centres are likely to be Glasgow and Edinburgh.

#### **Option 4: A Single-Centre Solution**

This option has two versions: a single Principal Treatment Centre in Glasgow, or a single centre in Edinburgh. If Glasgow becomes the single centre, Edinburgh and Aberdeen would operate at Level 3 and Dundee would continue to participate in shared care arrangements. Equally, if Edinburgh becomes the single centre for Scotland, Glasgow and Aberdeen would operate at Level 3 and Dundee would participate in shared care.

### **1.5 The Issues**

The key components of the appraisal include:

- A detailed specification of the model of care in each option,
- The selection of non-financial criteria for appraising the options,
- An assessment of the benefits of the different options against these criteria, and
- The resource and cost implications of the options.

One of the main challenges in the appraisal was to define the model of care and the treatment pathways for certain childhood cancers, so as to estimate the change in the distribution of patient activity between centres for each of the options.

For the first 6 months of the appraisal, whilst guidance existed to identify what Level 4, 2 and 1 would constitute, no guidance existed to confirm what treatment and care would be provided at Level 3 – the level at which a children's hospital could operate if it was not a Principal Treatment Centre. Level 3 care was clarified by NICE and agreed with a core group of Scottish Lead Clinicians in April 2007. (Appendix A – Levels of Care) This allowed the work to move forward, and modelling to take place as described in Chapter 3, 'The Model of Care'.

### **1.6 The Criteria**

The appraisal examines the costs and benefits of the different options. While costs can be quantified and valued, it is much more difficult to quantify the implications of different options for quality standards - for example, standards of clinical care. The normal approach in option appraisals is to identify a set of non-financial criteria which

can be weighted and scored to reflect the expected benefits of different options. Non-financial criteria were developed for assessing the implication of different options for reconfiguring children's cancer services and these are detailed in chapter 4. Financial considerations are not included in this list. Separate estimates were made of the resource and cost implications of the options.



## 2. TRENDS IN CHILDHOOD CANCER

### 2.1 Recent Trends

Information on the incidence of childhood cancer in Scotland is based on data from the Scottish Cancer Registry.<sup>6</sup> Table 1 shows the average number of new cases diagnosed annually in Scotland over the period 2000-2004 for the age groups 0-15 and 16-18 years.

The figures have been expressed as annual averages over the 5-year period 2000-04 because numbers can fluctuate significantly from one year to another, especially when they are broken down into the different types of cancer. The latest year for which figures are available from the cancer registry is 2004. While the focus of the current work is cancer among children aged 0-15 years, the figures for younger people aged 16-18 are also shown as some of these patients may be treated in the children's hospitals.

On average there were 150 new cases annually of cancer in Scotland among children aged 0-15 years between 2000 and 2004 (including cases of non-malignant brain tumours). This represents an average annual incidence rate of 156.7 new cases per million children aged 0-15 years.

**Table 1: Annual child cancer registrations by age and diagnosis**

Diagnosis group	Annual average (2000 to 2004)		
	0 to 15	16 to 18	Total
Leukaemia	48	5	53
Brain / CNS*	35	5	40
Bone	9	3	11
Neuroblastoma	8	0	8
NHL	7	3	11
Other	43	24	67
<b>Total</b>	<b>150</b>	<b>40</b>	<b>190</b>

Source: Scottish Cancer Registry, ISD

Notes: 1. Includes all registrations of childhood cancers diagnosed in years 2001 to 2004 where patient is under 19 at time of diagnosis.  
 2. The figures for 5-year annual averages have been rounded to whole numbers. As a result there are small discrepancies in some of the total figures for individual diagnostic groups.  
 \*Childhood cancers are classified as all malignant neoplasms and non-malignant tumours of the brain and central nervous system.

Leukaemia is the commonest childhood malignancy accounting for about one third of all childhood cancers, followed by tumours of the central nervous system. The 'Other' diagnosis group in Table 1 covers a wide range of cancers including: renal tumours, soft tissue sarcomas, malignant bone tumours, retinoblastoma, carcinoma, germ cell,

<sup>6</sup> The Scottish Cancer Registry – part of the Information Services Division of NHS National Services Scotland - is responsible for the collection of information on all new cases of primary malignant neoplasms, carcinoma in situ, neoplasms of uncertain behaviour and (since 1 January 2000) benign brain and spinal cord tumours arising in residents of Scotland.

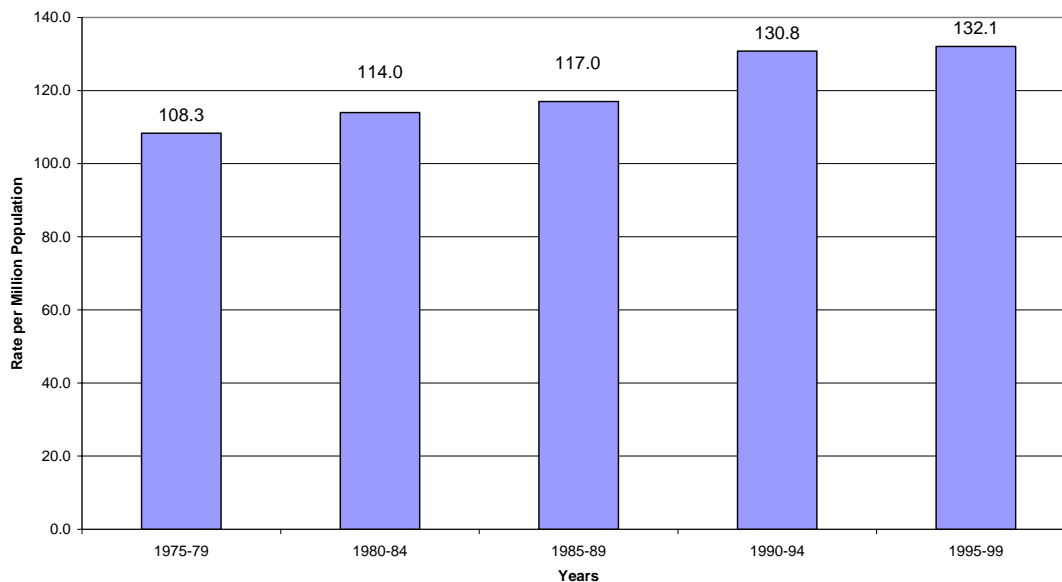
and hepatic tumours. The average number of new cases of each type of cancer seen annually in the 'other' category will be very small.

Trends in the incidence of childhood cancer were examined by Information Services Division (ISD) in the report *Childhood Cancer in Scotland: Trends in Incidence, Mortality and Survival, 1975-99* which was published in 2004. The figures in this report are not directly comparable with those in Table 1 for several reasons:

- The ISD report focused on children aged 0-14 years. However, 0-15 years is now generally used as definition of the childhood population group, and this is the basis of the figures shown in Table 1 above.
- The figures in Table 1 cover a more recent period than the data in the ISD report.
- The figures in Table 1 include children with non-malignant brain tumours. This is to bring the figures into line with the way in which they are generally presented in the rest of the UK. Children with non-malignant brain tumours were not included in the ISD report.

Despite these differences, the information in *Childhood Cancer in Scotland* provides a useful guide to the underlying trends in childhood cancer in Scotland since the mid 1970s. Between the years 1975-79 and 1995-99 the incidence of cancer per million population aged 0-14 years rose from 108.3 to 132.1 (Figure 1). This represents an average annual increase in incidence of 1.0% per annum. (This assumes that there was a uniformity of diagnosis and reporting throughout this period.)

Figure 2.1: Incidence of Cancer in Children Aged 0-14 (Rate per Million Population)



Source: ISD, *Childhood Cancer in Scotland, Trends in Incidence, Mortality and Survival, 1975-1999*, Edinburgh 2004.

The increase in the incidence of childhood cancer has occurred across all tumour types, although the highest rate of increase has occurred in 'other cancers' (Table 2).

**Table 2: Age and Sex Standardised Incidence Rates per Million Population (0-14)**

Type of Tumour	1975-79	1995-99	Growth Rate Per Annum %
Leukaemia	40.1	45.2	0.6
CNS	22.3	25.8	0.7
Lymphomas and RE Neoplasm's	10.1	11.9	0.8
Other cancers	35.8	49.2	1.6
Total	108.3	132.1	1.0

Source: ISD, *Childhood Cancer in Scotland, Trends in Incidence, Mortality and Survival, 1975-1999*, Edinburgh 2004

The incidence of childhood cancer and of specific types of cancer vary by age within the 0-14 age group (Table 3). The incidence among children aged 0-4 is almost double that of children aged 5-14 years.

**Table 3: Crude Incidence Rate of Childhood Cancer (0-14), 1975-1999**

Age Range	Crude Incidence Rate (per million population)
0-4	173.3
5-9	93.2
10-14	93.4
0-14	118.3

Source: ISD, *Childhood Cancer in Scotland, Trends in Incidence, Mortality and Survival, 1975-1999*, Edinburgh 2004

The ISD study shows differences in the incidence between NHS Board areas. However, because of the small numbers involved these differences are not statistically significant.

Two factors have driven changes in the number of cases of childhood cancer in Scotland over the period 1975-99:

- Demographic changes in the population aged 0-14 years.<sup>7</sup>
- Changes in the underlying incidence of childhood cancer.

Between 1977 and 1997 the number of children in the age range 0-14 years fell from 1,227,638 to 946,649, representing a reduction of 23%. Over the same period, however, the effect of this decline in the number of cancer cases was broadly balanced by a rise in the incidence of childhood cancers. As a result the number of childhood cancers diagnosed annually has remained relatively stable (Table 4).

<sup>7</sup> The marked differences in the incidence of childhood cancer between age bands within the 0-14 age range suggests that changes in the age structure of this population group may also be a significant influence on the overall crude incidence rate.

**Table 4: Incidence Rate, Population and Number of Cases of Childhood Cancer**

	1975-79	1995-99	Average Annual Change %
Incidence rate per million population aged 0-14	108.3	132.1	1.0
Population aged 0-14 years (000s)	1,227.6	946.6	-1.3
Annual number of cases (approximately)	133	125	-0.3

More recent figures indicate that the number of children aged 0-14 years diagnosed with cancer has remained stable at 125-130 per annum. Since the population of children aged 0-14 years has continued to decline in recent years, this would suggest that the crude incidence rate has also continued to increase.

## 2.2 Future Trends in Childhood Cancer

Changes in the number of cases of childhood cancer in Scotland over the medium and longer term will continue to depend on relative trends in the size and age structure of the population and in the underlying cancer incidence. The most recent 2006-based population projections from the General Register Office for Scotland show a continuing decline in the number of children (Table 5).

- The latest 2006-based projections show a much smaller rate of decline in the number of children aged 0-15 years than the earlier 2004-based projections. The total population in this age group is now projected to fall by 1.7% between 2007 and 2017, while the projected fall between 2007 and 2027 is 3.6%.
- There are significant differences in the projections for each age band within the 0-15 age range. Between 2007 and 2017, the youngest groups (aged 0-7) are projected to increase by almost 5%, whereas the population in the older age bands aged 8-15 are projected to fall by 7.7%.
- The difference in the projected population changes between age bands is significant because of the much higher incidence of childhood cancer among younger children.

**Table 5: Projected Changes in the Population Aged 0-15, 2007 to 2021**

Age Range	2007*	2017*	2027*	Change % on 2007	
				2017	2027
0 to 3	221.0	223.9	209.6	+1.3%	-5.1%
4 to 7	211.7	230.2	218.3	+8.7%	-3.1%
8 to 11	232.0	228.4	224.7	-1.5%	-3.1%
12 to 15	249.8	216.3	228.7	-13.4%	-8.4%
0 to 15	914.5	898.8	881.3	-1.7%	-3.6%

Source: General Register Office for Scotland

\* Population shown in '000s.

These projections are clearly subject to some uncertainty. They are based essentially on past trends and may not take fully into account more recent demographic changes, including the growth in the number of immigrant families.

The second key influence on future changes in the number of cases of childhood cancer is the trend in the incidence. The causes of the observed increase in the incidence rate of childhood cancer during the 1980s and 1990s are not clear, though it may reflect some changes in recording practices as well as changes in the underlying incidence. Inevitably, there must be considerable uncertainty in projecting forward possible trends in incidence in the medium and longer term.

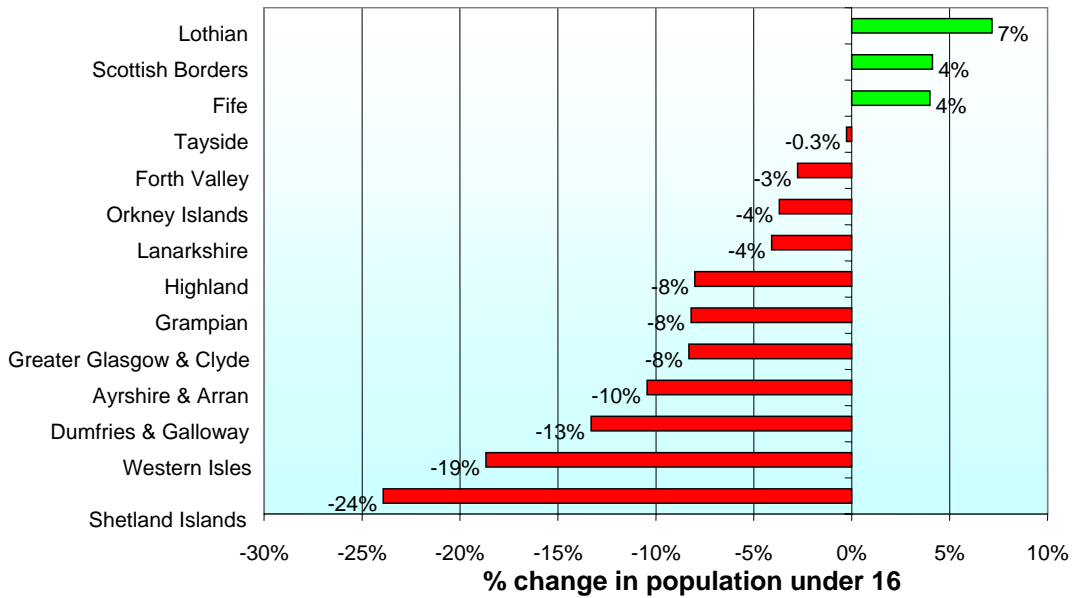
As an illustration of the possible effect of demographic changes and changes in the incidence of childhood cancer over medium and longer term, continuing growth of 1% per annum in the incidence would increase the number of new cases of childhood cancer diagnosed annually in Scotland by 10.5% between 2007 and 2017, and by some 22% between 2007 and 2027. This would increase the number of new cases from the recent figure of 150 per annum to 165 by 2017 and to 183 by 2027. The projected demographic changes shown in Table 5 would do little, if anything, to offset this projected growth in the number of cases – at least in the period to 2017.

### 2.3 Geographical Differences in Projected Population Trends

The projected changes in the population of Scotland have implications for the geographical distribution of cases of childhood cancer. The 2006-based projections from the General Register Office for Scotland show significant variations between NHS Board areas in the rate of decline in the population aged 0-15 years over the period 2006-2026 (Figure 2).<sup>8</sup>

<sup>8</sup> Figures for NHS Board areas are published for selected years. The period 2006-2026 has been used as it is the closest to the period 2007-2027 that has been used in examining the possible future trends in childhood cancer in Scotland.

**Figure 2: Percentage change in population aged 0 to 15 by NHS Board area - 2007 to 2027**



Source: General register Office for Scotland

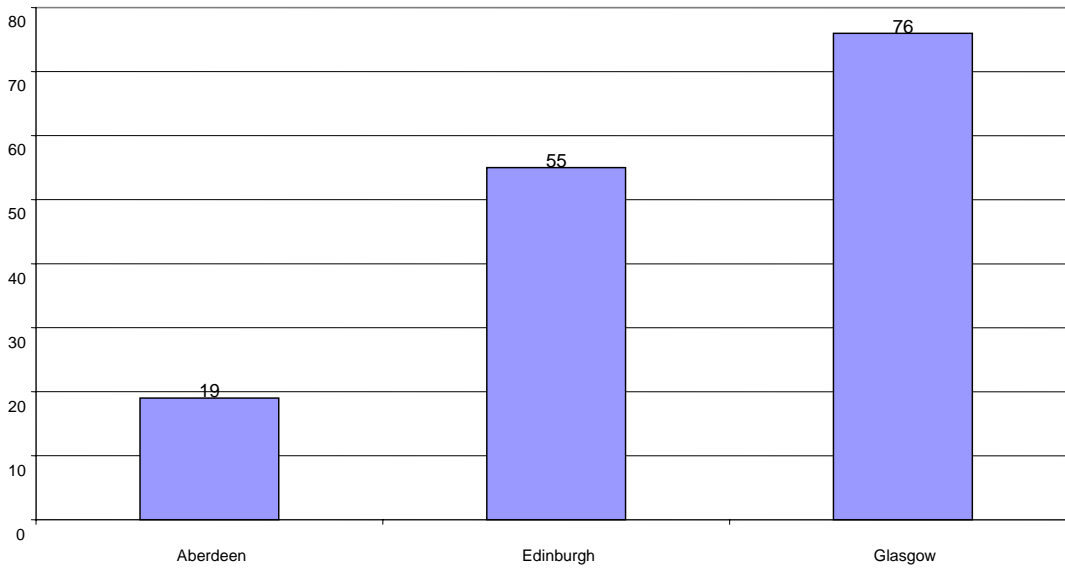
Notes (1) These projections are based on the year 2006.

The projections suggest that the childhood population in the West of Scotland Board areas is likely to fall significantly over the next 20 years, whereas the childhood population in the east of Scotland (Lothian, Borders and Fife) is projected to increase.

## 2.4 The Number of New Cases Annually in Each Centre

The average number of new cases seen annually in each children’s hospital in Scotland over the period 2000-2004 is shown in Figure 3. If the incidence of childhood cancer nationally continues to rise by around 1% per annum, then it is possible that all centres could see some increase in the number of new cases registered each year. The population projections by NHS Board area suggest that an increasing proportion of the new cases of childhood cancer in Scotland will be seen in the Sick Children’s Hospital in Edinburgh.

**Figure 3: New Cancer Registrations Among Children Aged 0-15 Years, Annual Average (2000-04)**



**Children's Hospital**

Note: Figures for Dundee are not shown separately because all patients seen in Dundee will be referred to Edinburgh for diagnosis, though part of their treatment may then take place in Dundee.

**2.5 Total patient activity in children's cancer**

The total number of new patients seen annually in the 0 – 15 years age group in the three centres averages 150. However, some of these children will continue to be seen for several years, and therefore the number of children being seen with cancer in any one year will be significantly higher than 150.

Table 6 shows the total pattern of children's cancer activity across Scotland, counting both new registrations and returning patients. A 3-year average is presented for the period 2003 – 05 to avoid issues of confidentiality and variability between single years. The figures in Table 6 show that, on average, 371 children were seen annually as inpatient cases during the period 2003-05.

**Table 6: Total Scottish activity by age group and type: annual average (2003-05)**

Age	Type	Episodes	Patients	Bed days
0 – 15 years	In-patients	2,439	371	12,253
	Day cases	2,616	322	-
	<b>Total</b>	<b>5,056</b>	<b>432</b>	<b>12,253</b>
16 – 18 years	In-patients	329	71	2,159
	Day cases	477	63	-
	<b>Total</b>	<b>806</b>	<b>93</b>	<b>2,159</b>
<b>Total (all childhood cancers)</b>		<b>5,862</b>	<b>514</b>	<b>14,412</b>

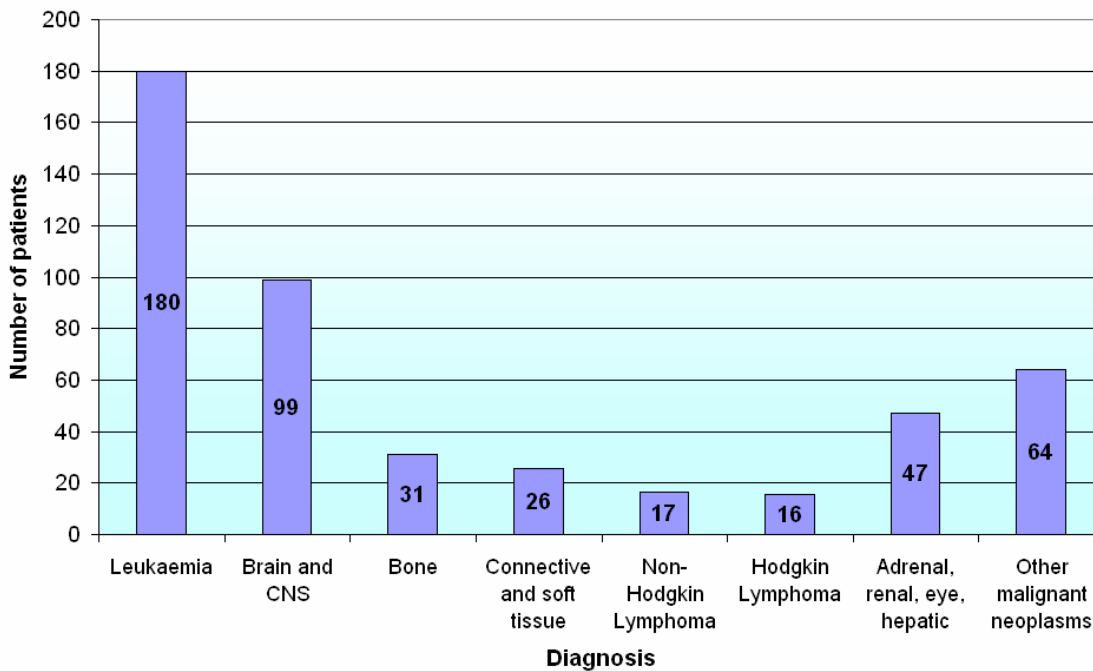
Source: ISD Scotland, SMR01

Notes:

- (1) An inpatient episode is the period of time which an inpatient spends under the care of a consultant within a significant facility within a specialty in a hospital. It starts with an inpatient admission and ends with an inpatient discharge.
- (2) A day case is a patient who makes a planned attendance to a specialty for clinical care, sees a doctor or dentist or nurse (as the consultants representative) and requires the use of a bed or trolley in lieu of a bed.
- (3) The number of 'patients' in this table includes new as well as return patients, the majority of patients have multiple episodes of in-patient and day case

Figure 4 illustrates the pattern of diagnoses across all patients in Scotland, aged 0-15 years. Patients can be diagnosed with multiple conditions, thus the sum of individual diagnoses exceeds the total number of children's cancer patients in Scotland. Leukaemia is the most common diagnosis with around 180 patients per annum, followed by brain & CNS with 99 patients.

**Figure 4: Total patients (inpatient and day case) by diagnosis, 0 – 15 years, Annual average (2003-05)**



Source: ISD, SMR01

Table 7 breaks down the Scottish total activity data by centre of treatment for the 4 core centres, illustrating total episodes, patients and bed days as an annual average across the period 2003-05.



**Table 7: Total activity by centre of treatment and type, age 0 to 15, Annual average (2003-05)**

Centre	Type	Episodes	Patients	Bed days
Aberdeen Children's Hospital	In-patient	273	40	1,429
	Day case	124	22	-
	<b>Total</b>	<b>397</b>	<b>43</b>	<b>1,429</b>
Edinburgh RHSC	In-patient	648	110	3,427
	Day case	1,299	125	-
	<b>Total</b>	<b>1,947</b>	<b>149</b>	<b>3,427</b>
Glasgow RHSC	In-patient	1,224	170	6,215
	Day case	940	146	-
	<b>Total</b>	<b>2,164</b>	<b>185</b>	<b>6,215</b>
Ninewells	In-patient	160	34	563
	Day case	183	28	-
	<b>Total</b>	<b>343</b>	<b>38</b>	<b>563</b>

Notes:

(1) An inpatient episode is the period of time which an inpatient spends under the care of a consultant within a significant facility within a specialty in a hospital. It starts with an inpatient admission and ends with an inpatient discharge.

(2) A day case is a patient who makes a planned attendance to a specialty for clinical care, sees a doctor or dentist or nurse (as the consultants representative) and requires the use of a bed or trolley in lieu of a bed.

(3) The number of 'patients' in this table includes new as well as return patients, the majority of patients have multiple episodes of in-patient and day case, total = actual number seen

## 2.6 Summary

- The most recent 2006-based population projections from the General register Office for Scotland show that the number of children in Scotland is expected to fall by less than 2% between 2007 and 2017 - a much smaller decline than was previously projected.
- If the incidence rate of childhood cancer continues to rise at around 1% per annum, there is likely to be a significant increase in the total number of new cases. The number of children diagnosed with cancer in Scotland each year could increase from the recent figure of 150 to around 165 by 2017.
- There are significant differences in the volume of new patient activity between the three centres. Glasgow sees about half of the new cases diagnosed annually in Scotland – around 75 new patients each year. Edinburgh sees about 55 new cases, while Aberdeen sees about 20 new cases per annum.
- It is unlikely that demographic changes and the trend in incidence will substantially alter the balance between centres over the next 10 years. However, the population projections suggest that an increasing proportion of cases will be seen in Edinburgh.
- The data on patient activity – inpatient, day case episodes and bed days need to be treated with some caution. Differences in methods of recording activity as well as differences in patterns of care may account for some of the variations between the three centres.

- The option appraisal will concentrate on the service provided for the 0 -15 year age group. It is acknowledged that some young people age 16 – 18 years are treated in children’s services, but this is not uniform. This is an area that will require further work. The data gathered for this option appraisal illustrates not only the number of new diagnoses per year in this age group (40), but also a large number of hospitals outwith the 3 children’s hospitals are involved in providing the full spectrum of treatment for this age group.

### **3. THE MODEL OF CARE**

The option appraisal as described in chapter 1, assumes a working model of status quo plus with three Principal Treatment Centres (Glasgow, Edinburgh, and Aberdeen), two PTC's (Edinburgh and Glasgow), or one PTC (Edinburgh or Glasgow), with a network of shared care delivered:

- in the children's hospitals not working as a PTC
- children's wards in District General Hospitals.

Different levels of care can be provided in different areas dependent on the local availability of staff and facilities. For the purposes of the appraisal, it has been assumed that in the two-centre option, Aberdeen will provide Level 3 care, and in the one-centre option, the children's hospitals not working as a PTC will provide Level 3 care.

#### **3.1 Assessment of the Impact of Each Option on Patient Activity in Each Centre**

A key element in appraising the implications of the different options for reconfiguring cancer services for children in Scotland is their effect on the level of patient activity in each centre. This information is necessary so that:

- The impact on staffing and other resources in each centre can be estimated, and
- Estimates can be made of the implications for children and families in terms of changes in travel patterns and overnight stays away from home.

Identifying the likely changes in patterns of patient activity has proved a particularly difficult aspect of this appraisal. Partly this reflects the many different forms of cancer from which children may suffer, and partly it reflects the range and complexity of services involved in the diagnosis and treatment of children.

Discussions with the hospital consultants in each centre has enabled estimates to be made of the likely changes in patient activity as a result of reconfiguration and this chapter describes the methods used and the results. Inevitably, these estimates are subject to some uncertainty; however, they appear to provide a realistic basis for identifying the changes in patient activity under each option. This information has been used to assess the effect of each option on the resources required in each centre and to estimate the impact on access for patients and their families.

#### **3.2 Treatment Pathway Descriptor**

The starting point in estimating likely changes in patterns of patient activity is establishing a model of care which describes the treatment pathways that would be followed for each type of cancer under the different options.

The approach currently being adopted in England is to clearly define within a network the key responsibilities for District General Hospitals wishing to provide shared care. In Scotland, the option appraisal is working with three children's hospitals acting as

designated Children's Cancer Leukaemia Group centres. These hospitals have an infrastructure in place to support cancer treatment, and experienced staff across the disciplines. In addition, there are a small number of designated shared care units including Ninewells, Raigmore Hospital in Inverness, and Dumfries and Galloway Royal Infirmary.

Ultimately, the model of care and support for Level 3 care will be determined by discussions between the PTC(s) and the Level 3 Children's hospitals. It would not have been practical to model in detail for each option the diagnostic and treatment pathways because these pathways can take many different forms, and each hospital has a slightly different approach to managing treatment. They are influenced by:

- The different forms of childhood cancer;
- The different stages that the cancer has reached;
- Differences between children in their response to treatment;
- Differences between hospitals in the range of services available; and
- The wide range of clinical trials currently underway - there are currently 44 CCLG clinical trials in operation in the UK. Entry into a clinical trial defines the pathway of treatment for individual children.

For all of these reasons, it was not possible to develop a comprehensive model for all of the different diagnostic and treatment pathways for children with cancer in Scotland. Instead, the approach used in this appraisal involves:

- Specifying the diagnostic and treatment pathways for a small number of selected conditions;
- Using a range of assumptions ('lower' and 'upper') to reflect the differences which may occur in the pathway followed by patients with a similar condition; and
- Assuming that these pathways can then be applied more generally to the different types of childhood cancer.

Table 1 identifies the average annual child cancer registrations by age and diagnosis for the years 2000-04 for Scotland. To estimate the impact of the different options in respect of workload and travel time for families, the treatment pathway for the following three childhood cancers were chosen:

- Acute Lymphoblastic Leukaemia;
- Medulloblastoma (brain tumour); and
- Ewing's sarcoma (a form of bone tumour which falls into the category of 'Other Cancers' in Table 1)

Taking the levels of care adopted from the NICE IOG group (Appendix A) with small modifications agreed by the Lead Scottish Haemato-Oncologists, the treatment pathways for these conditions were modelled accordingly in line with current clinical trial protocols for each of the diagnostic groups described above.

The Clinicians provided confirmation with respect to the average length of time a child would spend:

- as an inpatient (including emergency admissions)
- as a day case
- as an outpatient

It was agreed that this exercise could only give approximate estimates of patient activity, as,

- each child responds differently to treatment;
- for each of the three cancers there is more than one clinical trial/treatment pathway; and
- each hospital has a slightly different approach to the care being provided.

For all of these reasons, there will be differences in inpatient bed days, day case admissions, and outpatient visits in each Health Board area.

It has been assumed that shared care for each child would be agreed within the Managed Clinical Network to ensure there is appropriate and timely referral to the Level 4 centre(s). A treatment plan would indicate for each child which hospitals would enable some treatment to be given closer to home for children living a distance from the Level 4 centre(s). This has been estimated based on the practice of hospitals currently providing shared care, primarily the model of shared care that operates between Edinburgh and Dundee.

The success of shared care is dependent on:

- The experience and willingness of the Level 4 centre to promote and practice this approach, coupled with protected time in job plans for identified individuals to support and educate local teams;
- Identified doctors with protected time, and Specialist Nurse, Social Work and Pharmacy support being available in the hospitals providing shared care at all other levels.

Using the trial protocols as a template, the inpatient days, days cases and outpatient attendances were applied to each Health Board area for all the options assuming:

- Admission for diagnosis, staging and initiation of treatment for each cancer would take place in a Level 4 centre;
- Neurosurgery would take place in a Level 4;
- Surgery (insertion of a central line, tumour biopsy, tumour removal) would take place at a Level 3 or 4 centre; Level 3 Surgeons would be linked to a Tumour Board;
- Inpatient chemotherapy and day case admission for Lumbar Puncture would take place in a Level 3 centre and Level 4 centre;
- Radiotherapy could take place at a Level 3 or 4 centre;
- Outpatient Chemotherapy, 'follow up' and admission for febrile illness during treatment could take place in a Level 2, 3 and 4 centre.

As an illustration of how this method has been developed, Table 7 uses the treatment pathway during the first year for a child who is resident in Fife and has been diagnosed with leukaemia. This child could spend between 27 and 59 days as an inpatient during the first year.

- Under the current (Status Quo) option, the child would receive all inpatient, day case and the majority of outpatient care at the Royal Hospital for Sick Children in Edinburgh (RHSCE).
- Under the option in which Yorkhill became the single Level 4 centre for Scotland, the initial diagnosis, staging and commencement of treatment would be carried out in Yorkhill, but much of the remaining treatment – including the majority of inpatient chemotherapy, and all of the day cases and outpatient attendances - would continue to take place at the Royal Hospital for Sick Children in Edinburgh (Level 3). Between 7 and 29 inpatient days would be spent in the Principal Treatment Centre at Yorkhill, while the remaining 20-30 days of inpatient care would still be provided at RHSCE.

This example does not assume any outpatient care being delivered in Fife. It would be possible to further reduce travel for this family, but the convenience of care at a local level has to be balanced with the involvement of a third hospital in the treatment pathway. If Fife are willing to offer this service as part of the MCN, this discussion should take place with the family early in the treatment protocol so they are aware of all their treatment options. Ultimately, the PTC would agree with the family and networked hospitals the appropriate place for all aspects of treatment.

**Table 7: Treatment Pathway for a Child from Fife Diagnosed with Acute Lymphoblastic Leukaemia During the First Year**

	Option 1	Option 4b		
	Status Quo	Single Principal Treatment Centre (Glasgow)		
	RHSCE	Yorkhill	RHSCE	Total
Inpatient Days	27-59	7-29	20-30	27-59
Day Case Admissions	12-25	-	12-25	12-25
Outpatient Attendances	28 (min)	-	28 (min)	28 (min)

Table 8 provides another illustration based on a child from Grampian diagnosed with a brain tumour.

- Under the Status Quo option, the child would receive all inpatient, day case and outpatient care at the Royal Aberdeen Children’s Hospital.
- Under the option in which the Royal Hospital for Sick Children in Edinburgh became the single Level 4 centre for Scotland, the initial diagnosis, staging and commencement of treatment (surgery) would be carried out in Edinburgh, but much of the remaining treatment including radiotherapy would continue to take place in Aberdeen (Level 3). Between 7 and 14 inpatient days would be spent in the Principal Treatment Centre in Edinburgh, while the remaining 12-40 days of inpatient care would still be provided at Aberdeen.
- All of the day case and outpatient treatment would continue to be provided in Aberdeen.

**Table 8: Treatment Pathways for a Child from Aberdeen diagnosed with a brain tumour**

	<b>Option 1 Status Quo</b>	<b>Option 4a Single Principal Treatment Centre (Edinburgh)</b>		
	<b>RACH</b>	<b>RHSCE</b>	<b>RACH</b>	<b>Total</b>
Inpatient Days	19 up to 54	7 up to 14 (surgery only)	12 up to 40	19 up to 54
Day Case Admissions	8 up to 20		8 up to 20	
Outpatient visits				
-radiotherapy	35	-	35	35
- other	45	-	45	45

Similar pathways have been defined for children resident in each NHS Board area for the three selected childhood cancers and for each year of treatment. In general, the reconfiguration of services under the different options would not lead to any significant change in the pattern of care relating to day cases, outpatient attendances or overnight stays required for radiotherapy. There would, however, be a shift in the pattern of inpatient care because of the need for the diagnosis, staging, and commencement of treatment to be carried out in the Principal Treatment Centre.

Table 9 shows the effect on the place of treatment for a child from Ayrshire with a single PTC in Edinburgh. The initial diagnosis would take place in Edinburgh, but the majority of treatment would be provided in Glasgow as currently happens. This treatment path could be further developed to ensure this child receives some care closer to home if Crosshouse DGH were to provide Level 2 care. This could be some outpatient follow up and supportive inpatient care in-between chemotherapy treatments. However this may prove unsatisfactory to a family, as 3 different professional teams would then be involved.

**Table 9: Treatment pathway for a child in Ayrshire diagnosed with a Ewing's sarcoma**

	<b>Option 1 Status Quo</b>	<b>Option 4a Single Principal Treatment Centre (Edinburgh)</b>		
	<b>RHSCG</b>	<b>RHSCE</b>	<b>RHSCG</b>	<b>Total</b>
Inpatient Days	Up to 100	7 up to 10	Up to 88	Up to 100
Day Case Admissions	5		5	5
Outpatient visits	Up to 46		Up to 46	Up to 46
-radiotherapy	30		30	30
- other	16		16	16

### 3.3 Applying the Treatment Pathways

The pathways for the three selected conditions have been used to estimate the total change in the number of inpatient days in each of the existing centres using data on the number of children diagnosed annually with cancer in each NHS Board area. For example, about 11 children in Fife are diagnosed annually with cancer, of which four might be diagnosed with leukaemia. The assumptions made about the treatment pathway in Table 7 have been applied to estimate the total changes in the pattern of

inpatient activity for children with leukaemia from Fife under the different options. Similar calculations have been made for the children in each NHS Board area diagnosed with different forms of cancer.

Table 10 shows the changes that would occur in the number of new cases of childhood cancer seen annually in each centre under the different options.

- The two-centre option assumes that all of the children currently seen in Aberdeen would go to Edinburgh for the diagnosis, staging and commencement of treatment. In practice, it is difficult to predict at this stage whether all of these children would in fact go to Edinburgh. It is possible that some families from Grampian might prefer to go to Glasgow i.e because they have relatives there with whom they could stay.
- Under the single centre option all 150 new cases would go to this centre for diagnosis, staging and commencement of treatment.

**Table 10: Number of New Cases Annually in Each Centre Under Different Options**

	<b>Options for Configuring Services</b>			
	<b>Option 1 (Status Quo)</b>	<b>Option 3 Two Centres (Edinburgh &amp; Glasgow)</b>	<b>Option 4a One Centre (Edinburgh)</b>	<b>Option 4b One Centre (Glasgow)</b>
Aberdeen (RACH)	19	-	-	-
Edinburgh (RHSCE)	55	74	150	-
Glasgow (Yorkhill)	76	76	-	150
<b>Total</b>	<b>150</b>	<b>150</b>	<b>150</b>	<b>150</b>

Note: Option 2, Status Quo Plus, is not shown separately because the distribution of cases between centres would remain the same as in Option 1.

Table 11 shows the estimated number of inpatient bed days in each centre, based on the treatment pathways, and the change in these bed days under the different options. This is based on the average of the upper and lower estimates. For example, if Edinburgh became the single Principal Treatment Centre in Scotland (Option 4a), there would be an increase of 1,223 in the number of inpatient bed days required in the Royal Hospital for Sick Children in Edinburgh (compared with the status quo), and a corresponding reduction in the inpatient bed days at Aberdeen and Glasgow.



**Table 11: Estimated Changes in Inpatient Bed Days by Centre for Each Option (Average of Upper and Lower estimates)**

	Option 1 Status Quo	Option 3 Two Centres	Option 4a One Centre (Edinburgh)	Option 4b One Centre (Glasgow)
Aberdeen:				
- bed days	1,587	1,361	1,361	1,361
- changes in bed days		-226	-226	-226
Edinburgh:				
- bed days	4,274	4,500	5,497	3,193
- changes in bed days		+226	+1,223	-1,081
Glasgow:				
- bed days	5,840	5,840	4,843	7,147
- changes in bed days		0	-997	+1,307

### 3.4 Summary

The main purpose of this work has been to establish a method that will allow estimates to be made of the effect of the different options on the resources required in each centre and on the amount of travel required by patients and their families. This can only be done on the basis of assumptions about how patient activity would shift between centres under the different options. The method used to estimate these change relies on:

- establishing quite detailed treatment pathway descriptors for a selected number of childhood cancers;
- assuming that these selected descriptions can then be applied more generally to all childhood cancers.

It must be emphasised that this approach is only intended to provide a basis on which to estimate changes in resource requirements and in access for patients and families. It is not intended to be a detailed description of how treatment / care pathways and patient activity will change. This will require a thorough examination of each type of childhood cancer, and this work will be taken forward through the Managed Clinical Network over the next few years

## 4. THE NON FINANCIAL CRITERIA

### 4.1 Introduction

A decision about the future configuration of services for children with cancer in Scotland should be based, as far as possible, on evidence about the implications of the different options. This chapter reviews the available evidence and outlines the effects of these options using a range of criteria. It should be recognised that this is an area where evidence is incomplete, and judgements are required.

The criteria used in the appraisal of the different options were discussed and agreed at meetings with clinicians and managers. They are:

1. Standards of clinical care
2. Continuity of care
3. Relationship to other services
4. Workforce issues
5. Access to services for children and families
6. Implementation of changes
7. Impact on other services
8. Academic and research issues

This chapter reviews the available evidence, and provides an assessment of this evidence.

### 4.2 The Criteria

Appendix C provides a more detailed description of the non-financial criteria used to assess the options as described above

### 4.3 The Evidence

The evidence about the implications of the different options for these criteria is set out below, together with an assessment of the evidence.

#### 4.3.1. Standards of Clinical Care

##### Evidence

- For Scotland as a whole, the five-year survival rate from cancer among children aged 0-14 years increased from 50% in the period 1975-79 to 76% in the period 1995-99, The survival rate in Scotland is similar to the survival rate in England and Wales.

It has been suggested that survival rates among children in Scotland are somewhat lower than survival rates in certain European countries including Scandinavian countries and Germany. However, a study of childhood cancer survival<sup>9</sup> identified differences in approach to managing child health in these countries, and lower survival rates may reflect delays in referring children in the

---

<sup>9</sup> *Childhood cancer survival in Europe, 1978–1992 The EUROCARE Study*. European Journal of Cancer, Volume 37, Issue 6, Pages 671-672 J. Coebergh

UK to hospital for diagnosis and treatment rather than differences in the quality of care provided in hospital.

- It is not possible to compare survival rates for children diagnosed and treated in different centres within Scotland. Because of the relatively small numbers treated in each centre, the confidence limits around estimates of survival rates in each centre would be so wide as to make such comparisons of limited value. A lack of other clinical outcome based evidence makes comparisons between UK centres difficult.
- There is also no evidence available about other outcome measures such as the quality of life for children who survive or complications occurring during treatment. Even if such information were available, it would also be difficult to make meaningful comparison between centres within Scotland because of the small numbers.
- However, the guidelines on the diagnosis and treatment of children with cancer published by the National Institute for Health and Clinical Excellence (NICE) in 2005 provide the most comprehensive and detailed assessment of the available evidence. NICE noted that:

“there is evidence from observational studies and UK guidelines to support the recommendation that diagnostic investigations should be performed in specialist paediatric oncology centres with adequate specialist staff and resources.”

- NICE outline the levels of staffing and the services which are considered necessary to enable a hospital to function as a Principal Treatment Centre (PTC) and achieve the appropriate standards of care. In particular, they recommend that a PTC should have a minimum of 5 consultant oncologists/haematologists to ensure that specialist cover is available 24/7.
- NICE carried out a survey of children’s cancer centres in England and Wales in 2003 and collected information about the number of new patients seen annually in each centre.<sup>10</sup> A total of 18 centres provided this information. The figures were broken down into those patients aged 0-14 years and those aged 15 and over. Table shows 12 the size distribution of the centres.<sup>11</sup>

---

<sup>10</sup> *Improving Outcomes in Children and Young People with Cancer: An Assessment of the Need for Cancer Services for Children and Young People in England and Wales*. National Institute for Health and Clinical Excellence, August 2005

<sup>11</sup> One of the centres did not provide a breakdown of the age of new patients and has been excluded from this table.

**Table 12: Size of Children’s Cancer Centres in England and Wales in 2003 (Number of New Patients Annually)**

Number of New Patients Annually, Children Aged 0-14 Years	Number of Centres
Less than 50	2
50-74	5
75-100	3
More than 100	7

- Only two centres saw fewer than 50 new cases annually among children aged 0-14 years, and both of these centres also saw a substantial number of children aged 15 and over. If all children and young people are included in the figures, one of these centres saw between 75 and 90 patients annually, while the other saw around 100 new patients each year.
- Five of the centres saw between 50 and 74 new cases annually among children aged 0-14, while ten of the centres saw 75 or more new cases annually.
- Only one centre saw more than 150 new cases annually of children aged 0-14.

The figures in Table 12 need to be treated with some caution. First, they are several years old; and second, it is possible that the size of units in England may change as a result of reconfiguration of services following the NICE guidelines. These guidelines are only just being implemented in England and Wales. It is becoming clear that children’s cancer centres south of the border are amalgamating and concentrating expertise, but it will be some time before any measurable results of re-organisation are evident.

- NICE’s estimate of the costs of their recommended PTC was based on an assumption that centres with five Consultants should see around 80 cases per annum. At present, the average numbers of new cases of cancer in children aged 0-15 years seen annually in the three centres in Scotland are as follows:

New Cases Seen Annually (Children Aged 0-15 Years)<sup>1</sup>

Aberdeen	19
Edinburgh	55
Glasgow	76
Scotland	150

<sup>1</sup> This is the average number of cases seen annually in recent years.

These cases cover a range of different types of cancer including leukaemia’s, brain tumours, lymphomas, less common cancers e.g. retinoblastoma, and non malignant brain tumours.

## Implications of the Evidence

- The number of new cases of childhood cancer seen each year differs significantly between the three centres in Scotland. None of the centres achieves the figure of 80 cases which was used in the NICE guidelines when calculating the costs of establishing a PTC with the recommended level of resourcing, though Glasgow is close to this figure. The numbers seen in Edinburgh and Glasgow also appear to be quite low in comparison with some of the centres in England, but are similar in size to others (at least based on 2003 data).
- It is not possible to provide any evidence on clinical outcomes which would demonstrate whether the services currently provided in each centre in Scotland are unsatisfactory. Nor is it possible to produce clear evidence that would demonstrate a likely benefit in terms of outcomes from reconfiguring services by reducing the number of centres in which children are diagnosed. Nevertheless, the available evidence would indicate that the Royal Aberdeen Children's Hospital would find it difficult to attain Level 4 / PTC accreditation
- It must be emphasised, however, that it is the diagnosis, staging of the cancer, and commencement of treatment that would be provided in a Level 4 centre. A substantial part of the treatment would continue to be provided locally under the model of shared care at Level 3, as proposed for the service in Aberdeen
- Is there a case for further centralising the diagnosis, staging and initial treatment of children with cancer by establishing one Principal Treatment Centre for all children with cancer in Scotland? If all of the children from Grampian went to Edinburgh, this would increase Edinburgh's numbers to 74 new cases annually, very similar to the figure of 76 in Glasgow. These numbers are very close to the figure of 80 that was used in the NICE Guidelines, though this would still appear to be quite small compared with some of the centres in England – and as noted above the size of some units may increase.
- The establishment of a single PTC would represent a substantial change in the way that cancer services are provided for children in Scotland. There does not yet appear to be sufficient evidence to support the view that significant benefits in terms of improved outcomes might be achieved by concentrating certain aspects of the diagnosis and treatment for all children in Scotland in a single centre.
- If a single centre were to be established, there is no evidence to suggest that the standards of care would differ depending on whether the centre was in Glasgow or Edinburgh.

### 4.3.2 Continuity of Care

#### Evidence

- For children who receive all their treatment in a single centre, continuity of care is not really a problem. However, children whose care and treatment is shared between different hospitals are more likely to experience problems with continuity. Under the model of care agreed, concentrating part of the diagnosis

and treatment in a smaller number of PTCs, increases the number of children receiving shared care.

- Given the complexity of treatment pathways, trial protocols suggest that continuity of care is a vital component of this service, especially where children are moving between hospitals. In the discussions that were held with families of children with cancer, some expressed concerns about the effects of transferring between centres if communication is poor, and information not passed on in a timely way. This could result in delays with outpatient treatment, prescription dispensing and information inconsistencies. A small number of parents have experienced moving between 3 hospitals under the current system, and they identified key stress factors as:
  - A breakdown in, or apparent lack of, communication, between staff.
  - Different protocols for supportive care.
  - Being torn between outpatient departments as they get called back for what they see as similar follow up.
  - A lack of prior information about the hospital to which they are being transferred – e.g. sleeping arrangements for parents, facilities available at ward level, size of ward and staff complement.
- The survey of the views of families was not a formal piece of research and the evidence was essentially anecdotal. As such, it should be treated with caution. Nevertheless, the views expressed by families suggest that despite the best efforts of staff, problems with continuity of care can and do occur, and can add considerably to the stress levels of already anxious parents and children.
- Parents experiencing shared care spoke positively about the concept of a named person (nurse, social worker) who understands their treatment plan and can oversee their treatment journey pointing them in the right direction and co-ordinating their child's care
- NICE Guidelines state clearly 'A key worker should be identified for each child, young person and their family, to co-ordinate services and assess their support needs. There should be clear routes of communication between different care and treatment settings'
- A good model of shared care providing continuity exists between Ninewells and Edinburgh. The Paediatrician from Ninewells attends a clinic in Edinburgh on a monthly basis, and the Paediatric Outreach Oncology Nurses provide a vital link for families across the hospitals and community boundaries. Clear protocols exist identifying the responsibility of each centre, and the families are clear about what care is provided where.
- The three Children's Hospitals, along with Ninewells and Raigmore have Paediatric Oncology Outreach Nursing posts and CLIC Sargent social workers, all of whom act as communicators and are a vital link between the hospitals and families.
- Children and young people already move around the country: all children who require autologous Bone Marrow Transplant are referred to Glasgow; children with retinoblastoma go to Birmingham; and Aberdeen has referred children

requiring orthopaedic work to Stanmore. The key to continuity that has been identified by parents in Scotland is:

- Accurate, consistent, and timely information being passed between hospitals and families;
- Meeting the same staff for treatment and support which enables the child and parents to build up a relationship.

### **Implications of the Evidence**

- Regardless of the option, each child and family requires a key worker to coordinate service provision and ensure good communication between agents. This is a NICE requirement and when good communication channels are in place, the continuity of care should not be damaged when children and young people are transferred between centres. The key risk to treatment protocols being followed correctly is poor communication between centres.
- Reducing the number of PTCs will increase the number of 'patient transfers', for some families, thus potentially increasing the risk of poor communication. Three centres is likely to provide the smallest risk, two centres increases the risk as more children move between hospitals. A single centre for all children in Scotland potentially poses the largest risk as more than one hospital, and, in a minority of cases, 3 hospitals become involved in a child's treatment and care.
- The only way to avoid problems associated with continuity of care is to concentrate all the activity in one or two centres, but this would have more serious implications for access to services

#### **4.3.3 Relationship to Other Services**

##### **Evidence**

- NICE Guidelines state 'Principal Treatment Centres need 24 hour specialist medical and nursing staff cover and expertise in a wide range of cancers'. The three children's hospitals currently offer access to a wide range of specialist expertise and services which have evolved and developed to meet the needs of the population around them. The new children's hospital in Aberdeen is co-located with adult services, and the new hospital builds in Edinburgh and Glasgow will ensure the same.
- Appendix B details the current hospitals and co located services.
- The one service that does not follow this pattern is Radiotherapy. It is offered on-site in Aberdeen, but will not be on-site in Edinburgh and Glasgow, as the new children's hospitals will not be co-located with adult cancer services at the Western General and Gartnavel respectively. Currently, the Clinical Oncologists are working as part of the multi disciplinary team, and involved at the correct stages in the planning of the treatment pathway. Paediatric Anaesthetic cover is available on all 3 sites for the children who require it.

## Implications of the Evidence

- The absence of a Paediatric Intensive Care Unit in Aberdeen means that the current pattern of service does not meet the NICE guidelines for a PTC. Edinburgh and Glasgow will have the infrastructure in place required for a PTC.
- The link between children's cancer and paediatric neurosurgery has a major influence on the configuration of children's cancer services. Paediatric neurosurgery is currently provided in Edinburgh and Glasgow and occasionally, Aberdeen, but it is possible that in future this service will be centralised in one hospital. This would mean that all children with brain tumours would receive surgery in one children's hospital. NICE guidelines clearly state that a Level 4 centre must be co-located with paediatric neurosurgery

### 4.3.4 Workforce Sustainability

#### Evidence

- Under the terms of the European Working Time Regulation (EWTR) all medical staff will need to reduce the number of hours worked each week to 48, and the NHS will need to comply with this requirement by 2009. The main area of concern has been the impact of this requirement on emergency services, but it will have a more general impact on the requirement for staffing.
- Modernising Medical Careers means that the service contribution provided by medical staff in training will be significantly reduced, and therefore a higher proportion of the service will have to be provided by consultant staff. This will be a major issue from 2009 onwards
- A significant proportion of the consultant workforce in Scotland is aged 50 and over and there will therefore be a requirement to recruit significant numbers of consultants over the next 5-10 years to replace staff as they retire.
- An increasing proportion of medical staffing is provided by women, and this is particularly evident in paediatrics. A significant proportion may wish to work part time, and this will impact further on the requirement for additional consultant numbers in future.
- Difficulties have been experienced in recruiting consultant posts in Scotland in recent years. It was not possible to achieve the target of increasing consultant numbers for all specialties (adults and paediatrics) by 600 between 2003 and 2006.
- There continue to be significant numbers of vacancies among consultants. In 2006 the vacancy rate among all consultant posts was 7.0%, a slight reduction from the vacancy rate of 7.8% in 2005. There have been particular difficulties in recruiting consultants in paediatric haematology across the UK.
- Aberdeen now has one consultant haematologist (providing 0.5 of his time) and one consultant paediatrician with some training in Haemato-Oncology ( 0.7 WTE). However, it took some two years to fill the latter post, and the European training does not cover essential UK Haematology laboratory work.



- Edinburgh currently has two consultant paediatric oncologists and two consultant haematologist posts. One of these posts is vacant.
- Glasgow currently has 7 full time posts. 3 consultant paediatric oncologists, and 4 consultant haematologist posts One of these posts is filled by a locum and another post is vacant.
- All of the centres have therefore experienced difficulties in filling all of the established posts in paediatric haematology and oncology. Of course it is difficult to predict whether this problem will continue in the future. It has been pointed out recently that the number of doctors in training across the different specialities has increased significantly, and that as these doctors complete their training the problems experienced by the NHS generally in filling vacant posts may reduce. It should be noted that whilst there appears to be a UK wide shortage of paediatric haematologists, the same does not apply to paediatric oncologists.

### **Implications of the Evidence**

- There has been a trend towards the use of more complex technology in diagnosis and treatment generally in the NHS, and a similar trend is apparent within services for children with cancer. Methods of treatment are becoming more complex and specialised, and this is reflected, for example, in the increasingly complex regimes used to treat children, the growing participation in clinical trials, and the more stringent standards applied in these trials. This trend towards increased specialisation may favour the establishment of larger centres which can take advantage of the opportunities for greater specialisation.
- The evidence suggests that concentrating cancer services for children on a smaller number of sites would have advantages from the point of view of the medical workforce. The ability to recruit and retain staff may improve in larger centres, and such centres are also less vulnerable to the loss of one or two members of staff.
- NICE guidelines recommend that a Principal Treatment Centre should have 5 consultant staff, and to provide a 24 hour service it is likely that 7 Consultants will be required It would clearly not be possible to achieve this level of consultant staffing across three different centres in Scotland – especially given the relatively small number of patients seen in Aberdeen. The difficulties that have recently been experienced in expanding the number of consultant staff generally in Scotland, and the specific difficulties that have been experienced in filling all of the existing consultant posts in Aberdeen, Edinburgh and Glasgow reinforce this point.
- Concentration of services in a single PTC would probably mean that fewer consultant staff would be required than would be necessary if Scotland retained two PTCs in Edinburgh and Glasgow.

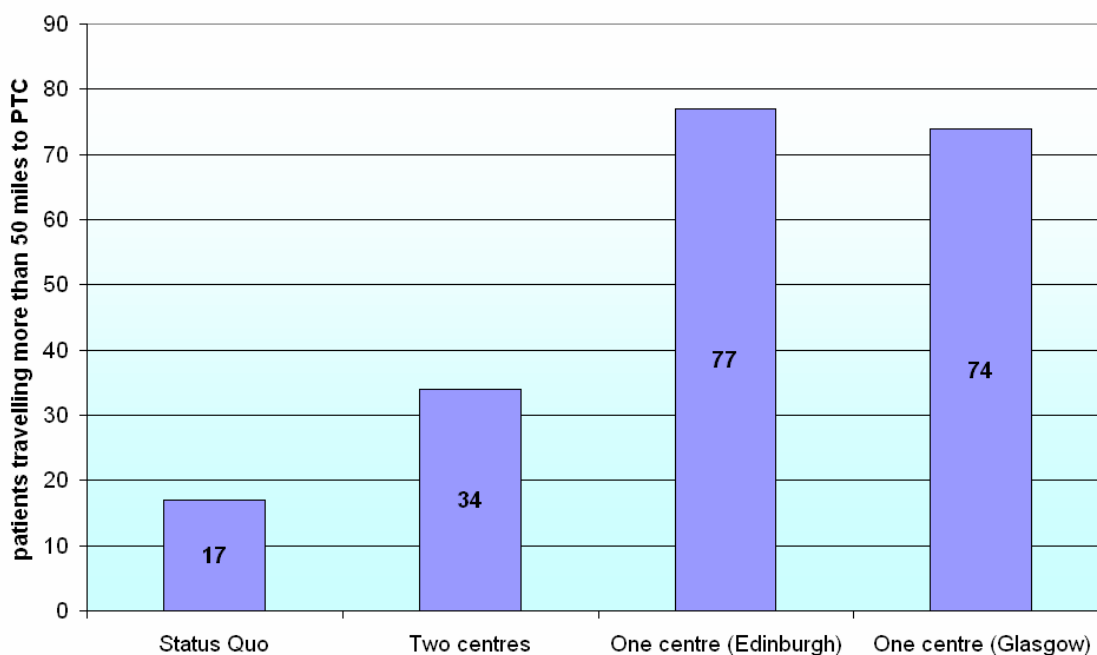
### 4.3.5 Access for Children's Services

Chapter 2 outlines the approach that has been taken to model the likely changes in patterns of patient activity. Using this model, it is possible to estimate the total travel implications for each current case under the proposed options by calculating the distance between the patient's home health board area and the allocated Principal Treatment Centre. Patients' home addresses are not known within the health board area, so average distances are based on the main hospital in each health board area – in many cases, where the patient was initially diagnosed.

#### Evidence

- Figure 5 illustrates the modelled results for the number of new patients who will have to travel more than 50 miles (one way) to reach a PTC. At present, only 17 of the 135 new patients and families are travelling more than 50 miles to reach a centre. Under the 2-PTC option (Edinburgh and Glasgow), this increases to 34 patients, while a single PTC would result in 74 or 77 families travelling for Edinburgh and Glasgow respectively. Clearly, reducing the number of PTCs increases the burden of patient and family travel.

**Figure 5: Number of patients travelling more than 50 miles to a PTC**

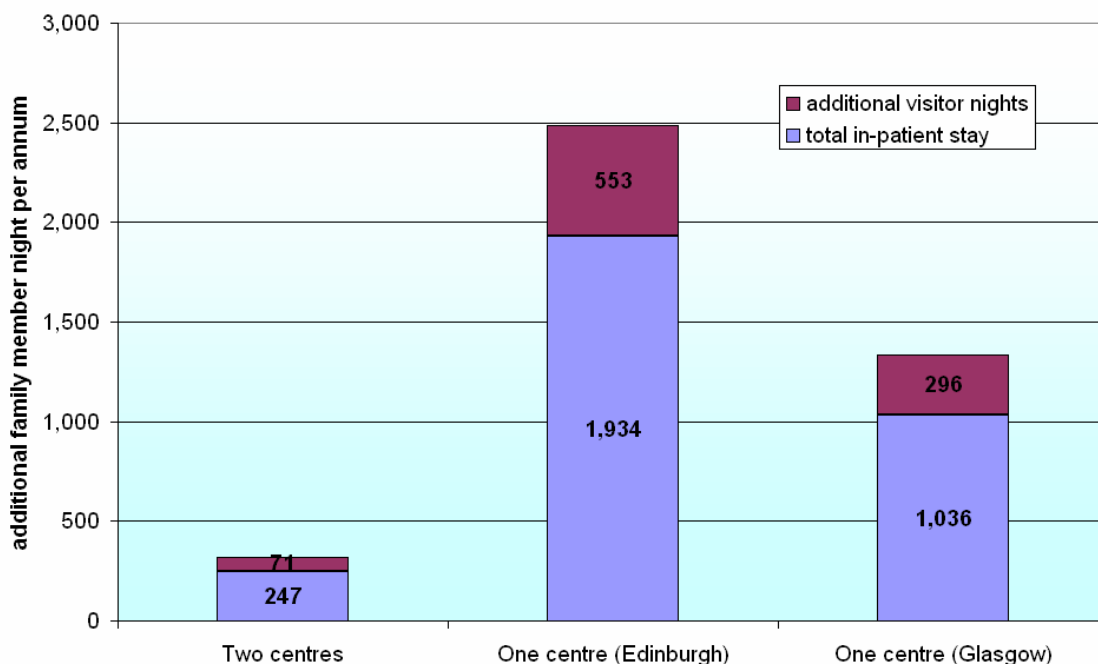


- **Travel:** When modelling family travel distances and costs, a number of assumptions have been made:
  - The initial stage of treatment in the protocol (the total bed days) represents a single visit to the PTC for the patient.
  - Each patient who is moving from their main place of treatment to a different PTC will require 2 additional follow-up outpatient visits per annum to the PTC.
  - Family members and other visitors will incur extra travel as a result of the patient's movement to a new PTC. For the model it is estimated that, together with the patients initial travel to the centre, family members will undertake an additional return trip each week of treatment.

- The AA state that the running costs for a new £13,000 vehicle, doing 10,000 miles a year, equates to 56.39p per mile (Automobile Association, 2006). Applying this rate gives an estimate of the total additional travel costs incurred under each option.
- **Overnight stays:** In addition to travel, family member and visitors are likely to have to spend more nights away from home when travelling to an alternative PTC. To estimate this cost, we have made the following assumptions:
  - CLIC Sargent: CLIC Villa has 7 rooms in Edinburgh, and 9 rooms in Glasgow for families to stay in which is equal to 13,260 bed night at full capacity (parents and siblings), delivered for £70,000 per annum per house<sup>12</sup>.
  - Assuming 75% occupancy throughout the year, this equates to a provision cost of £14 per visitor night. In cases where CLIC Villa and the hospital's own units are full, local hotels are used.
  - One family member is assumed to spend the entire duration of the initial in-patient stay in a provided unit, CS 'home from home' or a hotel.
  - In addition, for every week the patient spends in the PTC, visitors incur a further two bed nights.

Using these assumptions, Figure 6 illustrates the total nights spent by family members when travelling to a PTC that is not their main centre of treatment. The two centre option results in the fewest additional nights with 318. There is a significant step up with the single centre options, given that a far greater number of cases are moved, the Glasgow option resulting in 1,332 new nights and the Edinburgh option some 86% higher with 2,487.

**Figure 6: Total family nights when travelling for PTC function**

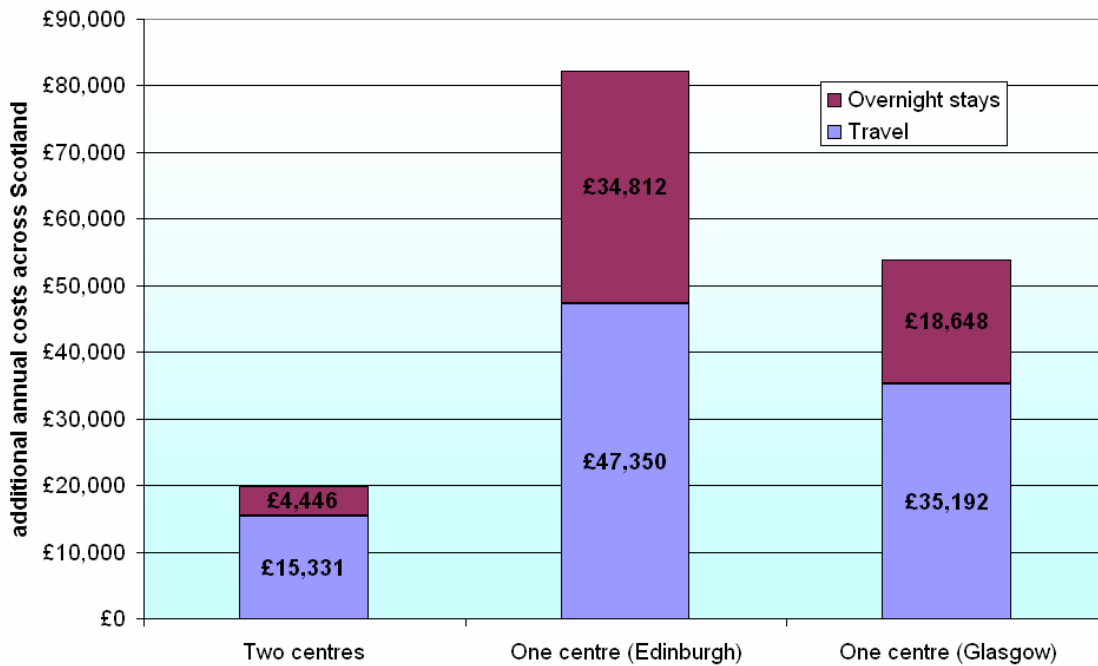


<sup>12</sup> Information provided by CLIC Sargent, 53 Bothwell St, Glasgow

For the single Edinburgh centre option, this is equivalent to 7 new beds required at 100% occupancy. Assuming there will be some crossover in patient admissions, this number will have to increase.

Combining the additional travel and overnight expenses gives an estimate of the total cost implication for each option, presented in Figure 4.3. Funding for these travel and overnight expenses is currently shared between the referring health boards, charities (such as CLIC Sargent) and the patients' families, thus will have a knock on impact on family incomes.

**Figure 7: Additional costs of travel and overnight stays for PTC options**



Under these modelled conditions, with a total cost of £82,162 the Edinburgh single PTC option is the most expensive in terms of additional family travel and overnight stays, some 53% greater than the equivalent cost for the single Glasgow centre. The two-centre option is the cheapest, costing some £20,000 per annum.

The population catchments for each option also offer an indication of the travel implications for families. Table 13 below presents the share of total population within 30 minutes, 1 hour and 2 hours driving time of the proposed PTC options.

Moving from the Status Quo to the two centre option means that the share of population within a 1-hour drive of a PTC falls from 84% to 70%. If there is a single PTC, then half the population is within 1-hour of Glasgow, and 38% within an hour of Edinburgh. However, Edinburgh has a larger catchment when extending the perimeter to a 2-hour drive.

**Table 13: Hospital catchment area and travel times**

Option	% of Scottish population within:		
	30 minutes	60 minutes	120 minutes
Status Quo	47.3%	83.8%	92.1%
Two centres – Edinburgh & Glasgow	41.6%	69.7%	81.4%
One centre – Edinburgh	15.3%	37.5%	80.0%
One centre – Glasgow	26.3%	49.0%	76.5%

Source: GIS maps

Moving from the Status Quo to the two centre option means that the share of population within a 1-hour drive of a PTC falls from 84% to 70%. If there is a single PTC, then half the population is within 1-hour of Glasgow, and 38% within an hour of Edinburgh. However, Edinburgh has a larger catchment when extending the perimeter to a 2-hour drive.

### Implications of the Evidence

- In terms of travel commitments and cost, there is a clear order of preference between the options. The Status Quo offers the least additional travel for children and families, while reducing the number of centres increases this burden.
- These additional travel and overnight expenses will have a knock-on effect for family incomes, which may also be less sustainable given the time-commitments for travel. This is likely to be the case for all options when taking on the commitment of care for a child with cancer, but may be exaggerated by more extreme travel conditions.
- NICE states that while inconvenient, the extra travel commitment to reach a PTC is generally accepted by children and families. There may also be a number of policy options available to ease the burden on family incomes, such as Board funding for extra travel and stays, or enhanced insurance for earners whose income is jeopardised.

#### 4.3.6 Implementation of Change

##### Evidence

It is not possible to provide any evidence on the extent of disruption that might be associated with reconfiguration of services. However, there are a few points to note.

- The treatment of children with cancer can continue over a period of up to 3 years, and treatment regimes have become increasingly complex. Changes to the way that services are delivered are more likely to cause disruption in these circumstances than in many other specialties where treatment of children is carried out over much shorter periods.
- It is difficult to predict how staff will react to changes in the way that services are configured. It is possible that some staff would not be prepared to continue working in hospitals which are no longer designated as Principal Treatment Centres. Given

the difficulties of recruiting staff, especially at consultant level, this could obviously create problems in maintaining a service.

- The extent to which staff - in particular, consultants - would be prepared to transfer from an existing centre to a different centre as a result of reconfiguration is clearly an unknown. But there must be a significant risk that some staff might not be willing to do so, and therefore new staff would have to be recruited to fill posts. Again, this might be difficult in the short term, though the amount of transfer that might be required would be limited since much of the treatment could continue to be carried out locally.
- Disruption would be a short-term transitional problem. This is not to under-estimate its importance, but it is a problem that would only last for a limited period. Clearly, many changes in the NHS involve some difficult transitional issues, but they are generally effectively managed and do not cause serious problems for patients.
- It is also worth noting that difficult problems may not be avoided by simply seeking to maintain the current configuration of services. Earlier reports on children's cancer services in Scotland have argued that the present structure of services is unsustainable, and services which are difficult to sustain because of problems in recruiting and retaining staff are also likely to face disruption.
- Because of the stage that this work is at, no thought has yet been given to how the changes could actually be implemented if a decision was taken to move from the existing service configuration to a two- or a one-centre solution. However, there would be scope to address issues relating to implementation and to phase the changes in over a period of time so as to minimise disruption. For example, children who have already started treatment could continue to complete their treatment in the same location, so minimising disruption to existing patients.

### **Implications of the Evidence**

- Retention of the existing pattern of services in Aberdeen, Edinburgh and Glasgow would involve less disruption to services than the other options which involve two PTCs or a single PTC in Edinburgh or Glasgow. However, as noted above, retaining the existing configuration of services is not without risks of disruption given the difficulties that have been experienced – and continue to be experienced – in filling consultant posts.
- A single centre solution is likely to involve more disruption to services than a two-centre solution in Edinburgh and Glasgow. There may be some differences in the extent of disruption depending on whether a single centre is located in Glasgow or Edinburgh. Glasgow is currently a significantly larger centre than Edinburgh.
  - There are 7 consultant posts in Glasgow, compared with 4 in Edinburgh.
  - Around 75 new cases are seen in Glasgow annually, compared with 55 in Edinburgh.
  - Glasgow also provides the bone marrow transplant service for patients across Scotland.
- In these circumstances, establishing a single PTC in Edinburgh is likely to involve a greater risk of disruption to services than a single PTC located in Glasgow.

#### **4.3.7 Impact on other services**

##### **Evidence**

- Oncology is interdependent on a number of other specialties including: non malignant haematology, surgery, radiology, pathology, PICU, radiotherapy, neurosurgery, It has been suggested that removing an aspect of the treatment pathway from individual hospital could have a detrimental affect on the ability of that hospital to provide expertise across the spectrum of children's treatment. The ability of a hospital to offer shared care is dependent on its ability to provide treatment, which is turn is dependent on sufficient activity to sustain expertise
- There is considerable overlap between malignant and "non-malignant" haematology services.
  - The medical staff providing both services includes many of the same personnel. Nursing and other staff would look after both groups of patients, often in shared in-patient and out-patient facilities.
  - Non-malignant haematological conditions may be life threatening. There is overlap in the types of treatment used, for example bone marrow transplantation for aplastic anaemia and thalassaemia major.
  - Many of the diseases use the principles of shared care similar to cancer care.
- Parallel discussions are taking place within Neuroscience, and whilst the outcome is not yet known, previous documents have suggested specialist children's neurosurgery should be concentrated on one site. This would include surgery for children with brain tumours. Strong concerns have been expressed in Lothian that removing this surgery would have a serious impact on the ability of NHS Lothian to retain a viable PICU.
- Paediatric Intensive Care has become a designated national service for the next 5 years on 2 sites, in Edinburgh and Glasgow. It has been stated that removing any aspect of the children's cancer service would affect Edinburgh's ability to run a PICU. Data supplied by NHS Lothian for this review suggests oncology accounts for approximately 10% of the Edinburgh PICU workload. Additional 'neurology workload' increases this to 17%. The data suggests the majority of this neurology workload is in relation to spinal surgery which for some procedures involves Orthopaedics and Neuroscience. NHS Lothian have represented their serious concerns about the impact of removing Paediatric Neurosurgery on their service and ability to provide specialist support.
- Concerns have been expressed about the wider impact of reconfiguring children's cancer service. The three Children's Hospitals have experienced surgeons who are involved in supportive surgery (insertion of lines) as well as biopsy and subsequent tumour removal. The former part of the workload is a significant proportion of the total paediatric oncology workload in each area, and is performed mainly in the diagnostic / initial treatment stage of the pathway. Concern has been expressed in NHS Grampian and Lothian that removing surgery related to this speciality would have a detrimental effect on the ability to recruit and retain experienced surgeons in the future.

- Paediatric Pathology services are available on all three sites. The pathologists work on a UK basis, sharing knowledge and expertise.
- Orthopaedic surgery is currently managed through the Sarcoma network on 2 sites for the under 12's and there is no support to change this approach
- Radiotherapy is currently delivered on three sites – The Western General, Edinburgh, The Beatson, Glasgow and Aberdeen Royal Infirmary. Each site has dedicated personnel to provide this service. There is a desire to retain radiotherapy on the 3 sites, but time to attend multi disciplinary meetings, and discuss subsequent management as part of a network would have to be factored in to job plans and resourced
- A review of Radiology is currently being managed through the D4H Diagnostics workstream. Radiology in the diagnostic phase for children's cancer services will account for approximately 50% of oncology radiology scan activity

### Data showing relevant activity across the three children's hospitals

Tables 14 - 16 provide some information on the volume of surgery, radiology and radiotherapy carried out in each centre for children with cancer.

**Table 14: Number of Surgical procedures performed for Children with Cancer in each Centre**

<b>Surgical procedures performed 2005</b>	<b>RACH Aberdeen</b>	<b>RHSC Edinburgh</b>	<b>RHSC Glasgow</b>
Central Line insertions	17	30	85
Port insertions	-	22	23
Resections	8	11	99
Biopsies	5	19	38
Source: RACH, RHSCE, RHSCG Oncology / Surgical teams			

The information on surgical procedures in Table 14 has been provided by the three hospitals. Their own figures are significantly different from those held by ISD, and should be treated with some caution. The differences in the number of surgical procedures between Edinburgh and Glasgow appear to be much greater than might be expected give the number of patients seen in each centre. It is possible that there may be differences between hospitals in methods of recording these procedures.



**Table 15: Radiology use by children's cancer patients, 2005**

	<b>Aberdeen</b>	<b>Edinburgh</b>	<b>Glasgow</b>
Total radiology activity by centre	16,243	26,794	44,595
Total assigned to oncology / haematology	Not available	1,382 (5.2%)	2,179 (4.9%)
Total departmental CT scans	156	395	1,025
Oncology use	N/A	106	214
%age of total CT activity		26.8%	20.9%
Total departmental MRI scans	315	1,321	1,715
Oncology use	N/A	260	240
%age of total MRI activity		19.7%	14%
Source: RACH, RHSCE and Yorkhill radiology departments			

**Table 16: Paediatric Radiotherapy Activity by Centre**

	<b>Aberdeen</b>	<b>Edinburgh</b>	<b>Glasgow</b>
Total Paediatric Oncology Radiotherapy Activity (number of cases) for children up to 16 yrs by centre 2002 – 04	16	59	92
Average annual activity (number of cases rounded)	5	19	31
Source: Clinical Oncologists providing Paediatric Radiotherapy, Edinburgh, Glasgow and Aberdeen			

Total Body irradiation is given in Glasgow, and there is no support at all from Edinburgh or Glasgow to move this. The expertise and equipment lie in Glasgow.

### Implications of the Evidence

- The evidence put together from discussions with a wide range of clinicians and managers highlights clear concerns about the implications of moving certain aspects of the children's cancer service from a hospital for the ability of that hospital to provide a whole range of services.
- This has been a difficult argument to assess. The statistical evidence set out above suggests that, on balance, the volume of activity that would shift between hospitals does not appear substantial.
- It is clear that the non-malignant haematology service is inextricably linked with malignant haematology / oncology, and the role of the Haematologist is fundamental to both services.
- The two PTC option appears to offer a solution with minimal impact in that it supports existing services in Glasgow and Edinburgh. There are consequences

for Aberdeen. However, if surgery, radiology and radiotherapy are managed through the network to ensure they are carried out locally where it is safe to do so, these services can be delivered in Aberdeen, and the impact could be minimised. This is dependant on Aberdeen being able to provide the staff who can:

- develop and retain skill sets by contributing to the multi disciplinary team management agreement for individual children through the network; and
- rotate through the main centre to ensure skills are up to date.

It also requires that Principal Treatment Centre(s) have the commitment and resources to provide an outreach service.

- There is a real commitment amongst all the Professions involved in this review to continue to provide services as far as possible in relation to surgery, radiotherapy, radiology, safely and locally through the managed clinical network. To enable this to happen will require an investment in IT facilities to enable regular multi-disciplinary conferencing and the relaying of imaging, as well as dedicated time identified in all job plans.
- The link with paediatric neurosurgery has been seen as having a major influence on the configuration of children's cancer services. If paediatric neurosurgery is located on a single site, the diagnosis, staging and surgery for children with brain tumours would also be managed in that location. This would mean that the other PTC in the two-site option would lose a significant part of the workload.
- Children with brain tumours account for about 25% of the total new cases seen annually in each centre for children's cancer and about one third of the cases excluding leukaemias. It has been argued that the loss of this work would raise serious doubts about the viability of centres in Edinburgh and Glasgow, because it would become difficult to recruit to a centre which did not carry out the initial diagnosis and staging work for children with brain tumours. It would then also become difficult to recruit doctors into training grades that wished to specialise in paediatric oncology.
- In effect, therefore, the argument is that providing complex neurosurgery on one site, will almost inevitably mean that children's cancer services should be co-ordinated by a single PTC. Shared care would continue to provide a significant part of the subsequent treatment for children with brain tumours after surgery.
- To ensure the impact on other services is minimised for a one-centre option, clear leadership would be required with support and assistance to move towards a model of care that maximises the use of available resources and scarce clinical skills through the managed clinical network. In turn this should enable care to be delivered safely, locally and minimised the impact across the three hospitals of a change in service delivery – a flexible, permissive model.

#### **4.3.8 Academic and Research Issues**

##### **Evidence**

- Accessing clinical trials is a vital component in the achievement of improved clinical outcomes. Survival rates for children with cancer have improved substantially over the last 2 decades as a result of national and international collaboration in trials.
- There are approximately 44 trials in existence, and the infrastructure to support running these trials is substantial. Research Nurses, data managers and pharmacists play a key role. One measure of how effective a centre is in managing a trial is the time taken from applying to run a trial to having all the documentation in place to proceed.
- The trials are managed in 3 phases. Phase 1 and 2 trials are the earliest trials in the life of a new drug or treatment. They are usually small trials, recruiting anything up to about 30 patients, although often a lot less. Not every children's cancer centre is able to offer access to these trials, because they are unable to recruit enough children to take part, and do not have the resources to manage them effectively.
- In discussion with clinicians, several have expressed strong support for establishing an academic appointment post in Scotland. This was seen as an important step in strengthening the research base and through this, contributing in the longer term to improvements in standards of care

##### **Assessment**

- In principle, an academic post serving all the centres would work for all the options. However, in practice it has been suggested that greater concentration of services, might improve the attractiveness of such a post.
- It has also been argued that clinical staff will find it easier to set aside dedicated time for research where there is a concentration of staff i.e. in a larger centre.
- A number of separate research projects have been managed in Edinburgh and Glasgow. Edinburgh has established a virtual centre for research into survivors of childhood cancer, and Glasgow has provided a service as one of only 5 laboratories in the UK to measure Minimum Residual Disease (MRD).
- Recruiting children to phase 1 and 2 trials would be best achieved if one centre co-ordinated this aspect of research, due to the numbers of children involved.

## 5. ASSESSMENT OF THE NON FINANCIAL CRITERIA

The previous chapter outlined the non-financial criteria that have been used to assess the merits of the different options, and provided a description of the available evidence and an assessment of this evidence. Given a range of different criteria, it is normal in an option appraisal to try to arrive at an overall assessment by carrying out a benefit weighting and scoring exercise. In this approach, the different criteria are assigned weights to reflect their relative importance, and the options are scored to reflect the extent to which they would achieve improvements against these criteria. The weights and scores are then combined to provide an overall 'benefit score' for each option.

### 5.1 Benefit Weighting and Scoring

A benefit weighting and scoring exercise was carried out at a relatively early stage in this appraisal. Those taking part in this exercise included clinicians and health service managers from the four centres, together with representatives from some of the voluntary bodies and other organisations. Families of children with cancer were not involved in this exercise. Instead, it was decided to engage separately with families to obtain their views but without asking them to undertake a formal weighting and scoring exercise.

The weights assigned to the different criteria were chosen from:

High (15), Medium (10), or Low (5)

Using this system, the following weights were agreed.<sup>13</sup>

**Table 17: Relative Weights**

Non-Financial Criteria	Relative Weight
Standards of clinical care	15
Clinical risk management	15
Continuity of care	10
Relationship to other services	15
Workforce issues	15
Access for patients and families	5
Patient choice	5
Implementation of change	5
Impact on other services	12.5
Academic and research issues	10

Note: There was a significant difference among members of this group about the relative importance to be assigned to the 'impact on other services': some argued that it should be given a high weight while others argued for a medium weight. The figure of 12.5 represents a compromise between these different views.

The different options were scored according to the extent to which it was felt that an option would have advantages or disadvantages when compared with the status quo.

<sup>13</sup> At this stage in the appraisal, the non-financial criteria included 'clinical risk management' and 'patient choice'. In further work, it has been felt that clinical risk management is not strictly separate from standards of clinical care. It was also felt that patient choice was closely linked to access for patients and families and did not really merit a separate criterion.

The scores were then combined with the above weights to provide an overall score for each option. These overall scores are summarised in Table 18. For comparison this table also shows the results of an earlier benefit scoring exercise carried out in 2005 by the Children’s Cancer Services in Scotland Working Group.<sup>14</sup>

**Table 18: Overall Benefit Scores**

<b>Option</b>	<b>Children’s Cancer Services in Scotland Working Group (August 2005)</b>	<b>Current Appraisal (February 2007)</b>
Three centres (Aberdeen, Edinburgh and Glasgow)	1,837	1,973
Two centres (Edinburgh and Glasgow)	2,448	5,278
One centre (Edinburgh or Glasgow)	2,370	6,113

Direct comparison between the two sets of scores needs to be treated with caution. The scoring systems used may have been rather different, and the two exercises may also have been structured and organised differently. Nevertheless, the relative scores are of interest.

- While the appraisal carried out by the Children’s Cancer Services in Scotland Working Group in 2005 indicated that a two-centre solution would be significantly better than a three-centre option, the benefit scoring exercise carried out in February this year as part of the current appraisal suggests a much stronger case for two-centres compared with three-centres.
- The 2005 appraisal also suggested that a one-centre solution might actually be marginally less effective than a two-centre option – though the difference was very small and not really significant given the imprecise nature of the method. In contrast, the scoring exercise in February suggests that a one-centre solution might be significantly better than a two-centre option.

In considering the results of the weighting and scoring exercise carried out as part of this appraisal in February 2007, there are several important points to note.

- a) First, a number of those who took part in the benefit scoring exercise in February of this year had serious concerns about the lack of information and evidence on which to base judgements about the different options. Indeed it was agreed that it was not possible to attempt to compare the relative merits of a single Principal Treatment Centre located in either Edinburgh or Glasgow because of the lack of information. At the time of this scoring exercise, it had not been possible to assemble the evidence outlined in the previous chapter – partly because it took longer to reach agreement about the model of care than

<sup>14</sup> *Children’s Cancer Services in Scotland Working Group: The Future of Cancer Services for Children and Young People in Scotland*. Scottish Executive 2005.

had been anticipated. For this reason alone, it would not be appropriate to give too much weight to the results of this exercise.

- b) Second, while the overall scores suggest significant differences in the assessment of options, a more detailed examination of the scores also shows that there were very marked differences in the way that options were scored by different groups. Representatives from Grampian tended to score highly the option that retains three PTCs in Scotland; representatives from Lothian tended to score highly an option that has two PTCs; and representatives from Glasgow favoured a single PTC. The results of such an exercise are, therefore, very sensitive to the composition of the groups taking part in the scoring of the options.
- c) Third, the scoring by Grampian representatives indicated that if three PTCs were not going to be retained they would strongly favour a single PTC rather than two PTCs. This reflects their concern that it is much easier to maintain effective working links with a single centre than with two different centres.
- d) Fourth, the weight that was given to access for patients and families in the benefit scoring exercise in February was relative low. It is questionable whether this relatively low weight reflects the current policy of the Scottish Government as set out in *Better Health, Better Care: A Discussion Document*.

*“In making decisions about the future configuration of services, we have stated that there will be a clear policy presumption against centralisation. That does not, of course, mean that there will never be an occasion when it makes sense to concentrate services. It does however mean that any such moves must result in benefits for patients and be subject to meaningful consultation and independent scrutiny to ensure that they are based on the best available evidence and give due weight to the views of local people.”*

The final point here would suggest that a higher weight should now be given to access to services by patients and families. As an illustration of the sensitivity of results, Table 19 shows the effect of altering the weight that was given to access in the February 2007 exercise.

**Table 19: Sensitivity of the Overall Scores in February to the Weighting for Access**

<b>Option</b>	<b>Low Weighting for Access</b>	<b>High Weighting for Access</b>
Three centres (Aberdeen, Edinburgh and Glasgow)	1,973	2,333
Two centres (Edinburgh and Glasgow)	5,278	5,158
One centre (Edinburgh or Glasgow)	6,113	5,433

The results of this suggest that the overall results are quite sensitive to the weight that is given to access.

- In particular, the difference between a two-centre option and a single centre narrows considerably when a higher weight is given to access.
- The difference between an option that retains three centres in Aberdeen, Edinburgh, and Glasgow and a two centre option also narrows, but remains substantial.

## 5.2 The next steps

It was considered whether carrying out a further benefit weighting and scoring exercise that would reflect the evidence that was outlined in the previous chapter would be beneficial. In the end it was decided not to repeat this exercise. As noted above, the overall results of the weighting and scoring exercise carried out in February 2007 was very sensitive to the views of particular groups. It seemed very likely that a further exercise would produce a similar pattern of results, and scoring exercises which are so sensitive to the views of different groups are perhaps of limited value.

To help move the debate forward, the February stakeholder group were invited to a meeting in October 2007 to discuss the evidence collected in the period between February and October in light of the concerns raised.

The day comprised a series of presentations in response to the request from the group in February for more evidence, an 'expert opinion' was provided, and facilitated workshops were organised in an attempt to reach an agreement about how best to configure the service. A model from the South West of England was put forward as an example of how the Scottish service might work. In this model, Bristol Children's Hospital working as a Level 4 centre, is supported by and supports treatment and care in 8 District General Hospitals throughout the South West of England. Its largest shared care centre is approximately 70 miles away, and works at Level 3. Staffed by a team including 2 Paediatricians with a 'special interest', it sees around 25 new cases of childhood cancer per year.

- The 4 working groups did not reach a full consensus about the number of Principal Treatment Centres, but agreed that the future service model should be that of a managed clinical network, operating in a 'permissive' way. This would recognise the expertise currently available in the 3 centres
- The issue about the number of Principal Treatment Centres was seen as inextricably linked to the future provision of paediatric neurosurgery. There continue to be differing views about the appropriate number of PTCs for Scotland. NICE guidelines clearly state that a PTC should have immediate access to a PICU and paediatric neurosurgery. Initial reports in Scotland suggest complex paediatric neurosurgery should be provided from a single prime site. However, the absence of evidence to support this hypothesis means this is unlikely to materialise in the near future.
- It was agreed that to ensure that the impact on other services is minimised for a one-centre option, clear leadership would be required with support and assistance to move towards a model of care that maximises the use of available resources and scarce clinical skills through the managed clinical

network. In turn this should enable care to be delivered safely, locally and minimised the impact across the three hospitals of a change in service delivery – a flexible, permissive model. Within this model each hospital would work to an agreed Level of Care.

### 5.3 Summary

Ideally, it would be helpful to use evidence to point to an overall conclusion about the option which is 'best' in terms of the non-financial criteria. In practice, this is not possible for several reasons. First, the evidence is far from perfect, and different interpretations are placed on this evidence. Second, there may also be differences in the weight that people attach to different criteria. As noted above, for example, the overall assessment may be quite sensitive to the weight that is given to access. Third, an option which is regarded as advantageous from the point of view of some criteria may be considered unattractive in relation to other criteria.

The criteria that tend to support some measure of centralisation of services are:

- Clinical standards of care;
- Workforce issues (sustainability of services); and
- Academic and research issues

But by no means all of those who have been consulted during the course of this review would agree with this interpretation of the evidence in relation to these particular criteria. And, of course, there are also differences of view about the degree of centralisation that can be justified by these considerations.

The criteria that tend to favour maintaining the status quo (albeit with improvements in services) are:

- Continuity of care;
- Access for patients and families; and
- Impact on other hospital services.

Again, there are clearly differences of view about the interpretation of the evidence relating to these criteria.

An issue that has attracted particular concern during this review has been the potential adverse effects on other hospital services of withdrawing certain aspects of the services for children with cancer. This has been a difficult issue to assess. In some respects, the volume of patient activity that would be affected by establishing two Principal Treatment Centres or a single PTC, would not appear to be very great. However, some of the concerns raised may relate to the wider implications of a series of changes in the configuration of hospital services for children rather than the specific implications of reconfiguring children's cancer services.

It may be that reconfiguration of children's cancer services in isolation would not necessarily have a major effect on other hospital services. However, the cumulative effect of reconfiguring a number of children's services may be more significant. Given the strength of views that have been expressed on this issue by clinical and management staff in NHS Grampian and NHS Lothian, it is clear that the importance of this issue should not be underestimated. It is, however, an issue which is difficult to



assess when looking at children's cancer services in isolation. It needs to be examined in relation to the wider pattern of changes that may take place across several hospital services for children.

## 6. ENGAGING WITH FAMILIES

In carrying out the appraisal of options for configuring services for children with cancer, it was important to meet families currently using the service across the country to hear their views. In the timescale for this appraisal it was not possible to organise a systematic piece of research into the views of families. Nevertheless, the discussions which have taken place in recent months provide a useful insight into the views of the families of children with cancer in Scotland.

The purpose of this exercise was to obtain the views of families about the current services and the issues to which they attach priority. The aim was not to consult them about the options being considered in this appraisal. Families will be invited to take part in a formal consultation process once the appraisal has been completed. The outcome of the appraisal will form part of the National Delivery Plan for Specialist Children's Services.

Parents were invited to meetings in Ayrshire, Glasgow and Edinburgh through local systems and staff, and a visit to a clinic in Dundee allowed parents to talk in between appointments. The CLIC Sargent Specialist Nurse in Inverness took questionnaires to 3 families who would have found it difficult to travel to a meeting, and the Glasgow CS Social Workers identified a family in Dumfries and the Islands to talk on the phone. Three meetings took place in Grampian to cover the more distant areas and a number of families opted to give opinions by phone.

Across the country over 60 parents have participated in this exercise.

The meetings with parents covered the following issues:

- What makes a 'good service' for children and young people with cancer?
- What do you value about the service currently being received?
- What would make the service better?
- What has been your experience of shared care arrangements?

### 6.1 What Makes a Good Service?

Unsurprisingly, parents are concerned to ensure that their children receive the best possible care, and are prepared to travel as far as required to achieve this. At the same time, families also saw being within reach of family and friends as being vital at key times, particularly around the time of the initial diagnosis when they are in a state of shock. Clearly, there is a difficulty in balancing this willingness to travel any distance to achieve the best possible care with the desire to have the close support of family and friends.

Families involved in these discussions had all had a fast and instant response at diagnosis and identified having access to a specialist medical team who are experienced in dealing with cancer and young people was identified as being paramount. Access to Specialist 'on call' staff thereafter to look after children if anything went wrong was also important

Families attach great importance to communication – a recurring theme in many of the discussions with parents. They wish to be kept closely informed about the

condition of their child and the progress of treatment, and this requires close and effective communication with staff.

Families also spoke frequently about the support provided by the specialist outreach nurse. They spoke very positively about the importance of the outreach nurse and the link which the nurse provides between home and the main centre and the shared care centre.

Some of the issues raised by families, though not directly related to the quality and effectiveness of the clinical care provided, were obviously seen as important aspects of the experience of care for the patients and their parents - for example, the standard of the accommodation for parents, the availability of good quality food in hospital, regular contact with the Consultant, and the general friendliness of staff.

## **6.2 What Do You Value About the Service You Receive?**

Inevitably there was a fair degree of overlap between the responses to this question and the responses to the previous question. However, there are a few additional points worth noting:

- Families who had access to a local shared care centre attached considerable value to this. It reduced significantly the amount of travel compared with going to the main treatment centre and was less disruptive to family life.
- Families also valued the contribution of the voluntary organisations such as CLIC Sargent, CS Family Support in Glasgow, and CCLASP in Edinburgh. For example, families who do not have their own transport valued the transport provided by CCLASP.

## **6.3 What Would Make the Service Better?**

A theme which was raised quite frequently by parents was the facilities available. Specific issues raised included:

- Better facilities for parents;
- Better food for patients; a number of parents described the quality of the food as poor;
- Parking facilities in hospital – both the availability and the cost;
- More cubicles (for privacy), though some parents felt that cubicles can be very isolating when children are hospitalised for long periods.

In relation to care and treatment, families raised a number of issues.

- Several families stressed the importance of the 'key worker' in helping to maintain continuity. Some parents felt that they ended up being the link between different professionals, often transmitting important clinical information.
- Some families felt that there was a need for greater clarity around what could be done in the main centre and what could be done locally.
- Where different hospitals are involved in the care and treatment of children, parents stressed the importance of continuity through shared protocols.

## 6.4 Experience of Shared Care

The experience of parents involved in shared care arrangements varied. Generally, families in Tayside spoke positively about their experience of the shared care arrangements between Ninewells and the treatment centre in Edinburgh. They welcome the reduction in travel as a result of a significant part of the treatment taking place in Ninewells. They also felt that there was clarity about who had responsibility for the different aspects of their children's treatment.

As might be expected, it is the families who live a significant distance from the main treatment centre (generally at least two hours) that found visits to the main centre particularly difficult. Several families in this position spoke about the major impact which lengthy visits to the main centre had on their family life.

## 6.5 Any other issues

Some of the parents were acutely aware of the option appraisal and work that had been carried out in previous reviews. Families in 2 of the children's hospitals raised the following points

- they valued having 'specialist teams' available in their local children's hospital.
- Whilst understanding the concept of a managed clinical network and the levels of care being proposed, they were not satisfied that a children's hospital operating at anything less than Level 4 would enable 'specialists' to be recruited and retained
- The 'knock on' effect of this on other children's services was of concern to them

## 6.6 Summary

This brief survey of the views of families is not a systematic piece of research, and for this reason the results need to be treated with some caution. However, there are a number of themes which emerge.

- First, while parents are undoubtedly willing to travel significant distances to secure the best care for their children, it is clear that this can cause considerable difficulties for families.
- Second, families appear to accept that it may be necessary to travel to different hospitals for diagnosis and treatment, and in many circumstances this seems to work quite well. But there are concerns that communication is not always maintained effectively in these circumstances.
- Third, families' ability to cope with the illness and the associated disruption to their family life can be made better by addressing relatively simple matters relating to accommodation, food, parking, etc.
- Fourthly, it is clear that parents in Aberdeen were focused on the option appraisal and the risk they felt it posed to their local service. They expressed strong support for the continuation of the service in its current format, and concern at the recruitment problems being experienced in all the centres.

## 7. RESOURCES AND COSTS

This chapter sets out estimates of the likely resource implications of the different options that have been considered for the future configuration of children's cancer services in Scotland. These estimates show:

- The likely changes in staffing levels – the key area of change;
- The cost implications including non-staff costs;

It should be emphasised at the outset that the estimates are inevitably subject to some uncertainty, and in some respects are incomplete. However, they are considered sufficiently accurate for the basic purpose of assessing the option which represents the best means of delivering services for children with cancer in Scotland. A more detailed assessment of resource implications would be necessary to guide the implementation of the preferred option.

- The changes in patient activity under the different options are quite small, and more detailed planning at local level will be required to identify the precise impact of these changes on staffing levels.
- In some areas it has been difficult to identify staffing levels because the staff caring for children with cancer are also involved in the care of children with other conditions. For example, in Grampian and Tayside the nurses who care for children with cancer are part of the children's medical ward and cannot be identified separately.
- The impact on capital costs has not been identified. Because the shifts in patient activity between centres are small, it is unlikely that there will be any significant effect on capital expenditure in most of the options.

### Workforce

Table 20 summarises the clinical workforce requirements under the different options. More detailed information about the underlying assumptions for the different groups of staff are provided in Appendix 3. These staffing figures are based on discussions that have taken place with staff in each centre, but they need to be examined in more detail by local management.

There are several points to note about the estimates in this table.

First, the proposals being considered in this appraisal are not simply about reconfiguring services between the centres in Scotland. A key aim is to improve standards of care across Scotland generally, and this is reflected in the increases in staffing levels under the Status Quo Plus option. To achieve these improvements in standards of care would require increases in staffing in nearly all of the staff groups shown in Table 20.

- NICE guidelines indicate that 5 WTE consultant posts (haematologists and paediatric oncologists) are required in a Principal Treatment Centre. This suggests a minimum of some 15 consultant posts under

- the Status Quo Plus option, together with medical staff in Tayside.<sup>15</sup> The Status Quo Plus option would lead to increases in consultant staffing in Aberdeen, Edinburgh and Dundee. Glasgow already has 7.0 WTE consultant posts and would not therefore require any increase in staffing to comply with NICE guidelines.
- Other areas that would see significant increases in staffing levels in the Status Quo Plus option include, outreach nursing staff, clinical trials co-ordinators, social workers, and pharmacy staff. Some of these posts currently rely on funding from charitable sources e.g CLIC Sargent

**Table 20: Staffing Levels (WTE)**

Centre	Option 1 Status Quo	Option 2 Status Quo Plus	Option 3 Two PTCs	Option 4a One PTC (Edinburgh)	Option 4b One PTC (Glasgow)
Consultants	12.8	16.0	15.2	13.2	13.2
Nursing					
- ward	71.7	77.2	84.2	78.0	73.2
- support	13.3	13.3	14.8	12.6	11.0
- outreach	8.5	11.0	11.5	10.5	10.5
Clinical Trials Coordinators	4.7	6.0	5.0	5.0	5.0
Social Workers	7.0	8.8	8.8	8.8	8.8
Pharmacy staff	7.7	9.9	9.4	10.9	10.9
Pathology	5.4	5.4	4.4	4.6	4.6
Clinical oncology	0.5	1.3	1.3	1.3	1.3

1. It has not been possible to produce reliable measures of the implications of the different options for ward nursing staff – partly because of the difficulties of identifying separately the staff who care for children with cancer.

2. The figures for clinical oncology relate to the number of sessions rather than WTEs.

A second issue that the appraisal addresses is the extent to which centralising some of the diagnosis and treatment of children with cancer in one or two Principal Treatment Centres might lead to some savings in staff costs. The workforce figures suggest that there might be some savings in staff numbers from concentrating the initial diagnosis and treatment of children in two centres rather than the existing three centres. However, the changes involved are quite small. Much of the treatment for patients from Grampian would continue to be provided in Royal Aberdeen Children's Hospital and there is some doubt about whether it would be possible in practice to realise such savings, especially where the reductions involve less a than a single WTE.

It is possible, therefore, that under Option 3 - where children from Aberdeen would come to Edinburgh (and possibly Glasgow) for the initial diagnosis and commencement of treatment – there would be relatively limited scope for savings in

<sup>15</sup> Medical staff in Inverness and Dumfries also provide care and treatment for children with cancer under shared care arrangements with Yorkhill. However, the number of children who receive shared care in Inverness and Dumfries are quite small, and it is not possible to identify separately the medical staffing input.

Aberdeen.<sup>16</sup> Edinburgh would incur some additional costs because of the additional inpatients stays and the net effect might be an increase in costs.

Table 20 suggests that establishing a single Principal Treatment Centre for Scotland (in either Glasgow or Edinburgh) might lead to some savings in staff costs compared with Status Quo Plus – at least in the areas of medical staffing and nursing. Again, however, there are some doubts about whether these savings could be realised in practice. Even on the assumptions set out in Table 20 it is worth noting that in many areas the levels of staffing would still be higher than at present.

## Costs

The Directors of Finance in NHS Greater Glasgow and Clyde, Lothian, Grampian, and Tayside have estimated the likely costs of some of the options under consideration. In carrying out this work, the staffing estimates have been reviewed and there are some slight differences with those shown in Table 20. Table 21 shows estimated annual revenue costs for Options 1-3.

To achieve the standards set out in NICE guidelines (i.e. the Status Quo Plus option) requires a significant increase in costs of almost £0.8m in Lothian and Glasgow. (There would also be some additional costs in Grampian and Tayside which might increase this figure to around £1 million).

Moving from Option 2 to Option 3 would involve further significant additional costs in Lothian, and would increase the cost of this service in Lothian and Glasgow to £1.4 million. (When the additional revenue costs in Grampian and Tayside are taken into account, the total additional costs of Option 3 compared with Option 1 would be around £1.6 million).

**Table 21: Annual Revenue Costs<sup>1</sup>**

Centre	Option 1 Status Quo £'000	Option 2 Status Quo Plus £'000	Option 3 Two Centres £'000
Glasgow	7,426	7,744	7,744
Lothian	4,991	5,463	6,088
Grampian			
Tayside			
Total	12,417	13,207	13,832
Additional Costs <sup>2</sup>	-	790	1,402

1. The Table shows the additional revenue costs that would be incurred in Lothian and Glasgow. There would also be some additional revenue costs in Grampian and Tayside in Options 2 and 3.

2. The additional annual revenue costs incurred in Options 2 and 3 represent the increase compared with the status quo (Option 1).

The Directors of Finance recognise that there is some uncertainty about the scale of the cost changes in moving from Option 2 to Option 3. However, their considered view is that the transfer of patient activity from Grampian to Lothian would result in limited

<sup>16</sup> As noted earlier in this report, it cannot be assumed that all of the children from Grampian would come to Edinburgh. Some might go to Glasgow. However, for the purposes of estimating the impact on costs it has been assumed as a working assumption that all of the Grampian children would transfer to Edinburgh for the initial diagnosis and commencement of treatment.

savings in Grampian but would lead to a significant step up in costs in Lothian, and therefore a significant increase in the overall costs of service provision.

It has not proved possible to estimate the annual revenue costs associated with the options which involve a single Principal Treatment Centre in either Glasgow or Edinburgh. This would require a significant amount of additional work, and the view of the Directors of Finance is that it is very unlikely that a single centre would lead to any saving in the overall costs of service provision. The more likely outcome, is that a service configured around a single PTC - whether in Glasgow or Edinburgh – would have higher annual revenue costs than a service based on two PTCs.

The transfer of patient activity to a single PTC could also have implications for capital costs. However, it should be noted that there are plans to invest in new children's hospitals in both Edinburgh and Glasgow. The location of a single PTC for children with cancer would have implications for the size of the children's hospital where it is located. However, there should be a broadly offsetting reduction in the scale of investment required elsewhere, and therefore the establishment of a single PTC should not affect the overall scale of investment required in the new children's hospitals.

Reconfiguration of services for children with cancer clearly raises important issues about the funding of any changes – both the overall change in annual revenue costs and the distribution of these costs between different NHS Boards. These are issues which cannot be addressed as part of this appraisal exercise, but they are issues that will need to be considered in deciding on the future configuration of services.



## 8. UNCERTAINTY

This chapter has sought to follow the Treasury guidance in the Green Book on methods of option appraisal in the public sector.<sup>17</sup> The Green Book emphasises the extent to which many of the key assumptions used in option appraisals are subject to uncertainty, and stresses the need to take this into account – for example, by examining the sensitivity of the appraisal results to variations in key assumptions.

This chapter looks at some of the main areas of uncertainty and how this uncertainty might affect the different options that have been appraised.

### 8.1 Demography and Epidemiology

Two obvious areas of uncertainty which will affect the number of new cases diagnosed annually in Scotland in the medium and longer term are: (a) demographic change and, (b) the underlying trend in the incidence of cancer among children aged 0-15 years. If the incidence of childhood cancer continues to rise at 1% per annum, then the most recent 2006-based population projections suggest that the number of new cases of childhood cancer might rise to about 165 by 2017 (bearing in mind these numbers also include children with non malignant brain tumours).

This 'central' estimate is, however, subject to a significant margin of error. As an illustration, a variation of  $\pm 10\%$  around this estimate of 165 would mean that the number of new cases diagnosed annually might vary between 150 and 180. The finance data suggest that the average cost of treating a child with cancer is around £100,000. An increase in the number of new cases from 150 to 165 could add to £1.5m to the costs of this service – perhaps less given that certain costs are fixed. An increase from 150 to 180 new cases per annum could add up to £3m to the annual revenue costs of providing this service.

Demographic changes could also affect the distribution of new cases between the three centres. Table 8.1 shows the sensitivity of caseload (new cases annually) in each centre to differences in the overall number of new cases nationally in Scotland on the assumption that the distribution of cases between centres remains unchanged.

In practice, it is unlikely that the distribution of cases will remain constant. The latest population projections from the General Register Office for Scotland indicate that the childhood population in the east of Scotland will increase significantly in the medium and longer term, while the populations in the west of Scotland Board areas and in Grampian are projected to fall. This would suggest that the number of new cases seen annually in the Edinburgh would be somewhat higher than shown in Table 8.1, while the numbers seen in Glasgow and Aberdeen would be somewhat lower.

---

<sup>17</sup> *The Green Book: Appraisal and Evaluation in Central Government*. HM Treasury

**Table 22: New Cases Annually by Centre in 2017 Based on Alternative Assumptions About the Number of Cases Nationally**

	<b>Activity Assuming 150 New Cases<sup>1</sup></b>	<b>Activity Assuming 165 New Cases<sup>2</sup></b>	<b>Activity Assuming 180 New Cases<sup>3</sup></b>
Aberdeen	19	21	23
Edinburgh	55	61	66
Glasgow	76	84	91
	150	165	180

Notes:

(1) This assumes that the number of new cases annually among children aged 0-15 years remains at the current level of 150 per annum.

(2) This assumes that the incidence continues to grow at 1% per annum and takes into account the 2006-based population projections.

(3) This projection of new cases assumes higher than expected growth in incidence and/or higher than projected growth in the population aged 0-15 years.

The key issue is whether this change could affect the *relative* costs and benefits of the different options. In practice, it seems unlikely that variations in the underlying assumptions about demography or epidemiology would have a significant effect on the assessment of the *relative* costs and benefits of the different options. However, it might be argued that significant growth in the number of new cases annually of childhood cancer could weaken the case for having a single Principal Treatment Centre since a higher caseload would increase the sustainability of two PTCs. A higher caseload nationally would have little effect, however, on the sustainability of Aberdeen as a Principal Treatment Centre.

## **8.2 Non-Financial Criteria**

The appraisal has examined the evidence about different non-financial criteria and has assessed the implications for the different options. There are significant uncertainties in this assessment, though it is not possible to quantify in any meaningful sense the implications of this uncertainty.

### *Standards of Care*

The quality and effectiveness of the care and treatment provided to children are central to decisions about the future configuration of services. The NICE guidelines are intended to improve standards of care and ultimately this should be reflected in better outcomes for children with cancer. While acknowledging the uncertainty about the extent to which these changes will lead to improved outcomes, it should also be recognised that the NICE recommendations are based on the considered views of experts in the care and treatment of children with cancer.

### *Continuity of Care*

Centralising the diagnosis, staging, and commencement of treatment in two or one Principal Treatment Centre(s) could weaken the continuity of care provided to children with cancer because the model of shared care would increase the number of transfers between hospitals for some children.

The establishment of clear protocols, the use of a key worker, and more effective methods of communication should help to address this issue, but there remains some

(unquantifiable) risk that continuity of care may suffer if children have to transfer more frequently than at present between different centres.

### *Workforce Sustainability*

One of the drivers for change in the configuration of services for children with cancer has been concerns about the ability to recruit and retain staff and to comply with the European Working Time Regulation. The evidence suggests that all of the existing centres have experienced difficulties in recruiting and retaining staff in recent years. However, the fact that problems of recruitment and retention have been experienced in the past does not necessarily mean that these problems will continue to be experienced in the future.

What can be argued is that there are clearly some risks around workforce sustainability in this area, and concentration of services to some degree would improve the likelihood of being able to manage these risks if they prove to be serious problems in practice.

### *The Weight Attached to Different Criteria*

The assessment of the relative costs and benefits of different options depends to some extent on the weight attached to the different non-financial criteria. The benefit scoring exercise that was undertaken at a relatively early stage in this appraisal was based on the assumptions about these weights and on the scores assigned to the different options. As noted earlier, this exercise was felt to be of limited value. Nevertheless, it provides a means of illustrating the sensitivity of any overall assessment of non-financial benefits to alternative assumptions about the weights.

The following table (reproduced from the chapter on non-financial criteria) shows the effects on the overall scores of different weights for the criterion 'access'.

- A low weighting suggests that a single Principal Treatment Centre might offer significant advantages over two centres.
- A relatively high weighting for access produces a much narrower difference in the scores between a single centre and a two-centre solution. (A high weighting also narrows the overall scores between a three-centre option (Status Quo Plus) and the two-centre option, but the difference still remains large.

The weighting and scoring exercise also suggested that the difference in the overall scores between options was very sensitive to the people taking part in this exercise.

- Staff from Glasgow tended to give the highest score to a single-centre solution;
- Staff from Edinburgh favoured a two-centre configuration of services;
- Staff from Grampian favoured retention of the existing configuration of services with three centres.

**Table 23: Sensitivity of the Overall Scores in February to the Weighting for Access**

Option	Low Weighting for Access	High Weighting for Access
Three centres (Aberdeen, Edinburgh and Glasgow)	1,973	2,333
Two centres (Edinburgh and Glasgow)	5,278	5,158
One centre (Edinburgh or Glasgow)	6,113	5,433

### 8.3 Costs

The implications of the different options for staffing levels and annual revenue costs are also uncertain. The cost estimates made by the Directors of Finance indicate that reducing the number of Principal Treatment Centres is likely to lead to an increase in costs. For example, a comparison of Option 2 (Status Quo Plus) and Option 3 (two centres) suggests that a two-centre solution would increase costs by almost £0.6m. Although it has not been possible to obtain estimates of the annual revenue costs of a single-centre solution, it is thought likely that this would lead to a further increase in annual revenue costs.

A reduction from three to two PTCs is thought unlikely to give rise to any significant capital costs. However, a single PTC is likely to involve more significant capital costs because of the additional volume of work that be undertaken in this centre.

While there are uncertainties about the magnitude of the costs estimates, they are considered to be sufficiently robust to show the direction and the scale of change.

- Implementing the NICE guidelines within the existing configuration of services will require significant investment in staffing.
- Centralising some aspects of the service in two or one PTCs will involve further significant expenditure.

### 8.4 Summary

Many decisions about the provision of services rest on assumptions which may be subject to a significant margin of uncertainty. In this case there are significant uncertainties relating to:

- medium and longer term trends in demography and in the incidence of childhood cancer;
- the benefits associated with reconfiguring services;
- the cost implications of these changes.

In practice, it is considered very unlikely that the number of new cases annually in Scotland will fall below the recent figure of 150 per annum. A more likely scenario is a significant increase in the number of cases.

The cost estimates, though uncertain are considered sufficiently accurate for the purposes of this exercise. They indicate that significant expenditure will be required both to meet the NICE standards and to reconfigure services.

The key areas of uncertainty relate to the extent to which reconfiguration would produce significant improvements in standards of care, and whether the risks associated with sustainability of services are sufficiently serious to support the case for reconfiguration.

## **9. ASSESSMENT OF THE OPTIONS**

This report has considered a range of options for configuring services in Scotland for children with cancer, and has set out information about the potential benefits and costs of these options. It has also identified some of the main areas of uncertainty in the appraisal. Some of the available evidence on this issue is limited, and the choice of the option that represents the best solution inevitably requires a considerable element of judgement.

There are several points that should be emphasised at the outset. First, a decision about the future development of services for children with cancer is not simply about the number of Principal Treatment Centres. The NICE guidelines set out appropriate standards of care, and the implementation of these standards in Scotland will require significant investment in this service irrespective of the number of Principal Treatment Centres.

Second, under the model of care that has been outlined, it is the diagnosis, the staging of the cancer, and the commencement of treatment that would be centralised in some of the options. This has been proposed as a solution to ensure that all children in the future will have access to the best standards of care, whilst minimising the travel burden for families.

Much of the ongoing treatment that children require would continue to be provided locally through shared care arrangements. For example, if children from Grampian were in future to go to the Royal Hospital for Sick Children in Glasgow or Edinburgh for the diagnosis, staging, and commencement of treatment, a substantial part of their care would continue to be carried out in Aberdeen. Clinical staff in Aberdeen would still, therefore, have a major role to play in the treatment of children with cancer and would, of course, work closely with staff in Glasgow or Edinburgh in determining the diagnosis and the treatment regime.

Families in Grampian have expressed concern that this approach will diminish the role of the specialist clinicians in the North. However, the recruitment of specialist oncologists and haematologists to an area with less than 20 new diagnoses / year will be really challenging, and this model would enable Grampian to continue to provide a high level of care that is safe and sustainable.

Third, an important factor behind the reviews that have taken place of children's cancer services in Scotland in recent years has been concern about the sustainability of the current services – and, in particular, concerns about the ability to recruit and retain specialist consultant staff. It is clear that the European Working Time Regulation, the impact of Modernising Medical Careers, and the need to maintain specialist clinical skills in an environment where diagnostic and treatment regimes are becoming increasingly complex, are going to pose a real and increasingly difficult challenge for hospitals with relatively small caseloads. These issues, though difficult to quantify, are regarded by some as key considerations in determining the appropriate configuration of services for children with cancer in Scotland.

### **9.1 Status Quo Plus**

The options considered in this appraisal draw on the NICE guidelines, and on discussions with staff in each centre. Under the option that is described as Status Quo Plus, the existing pattern of services would be retained, but there would be a number

of changes intended to bring about improvements in services for all children with cancer in Scotland. These changes would involve considerable expansion in the number of staff in Aberdeen and Edinburgh to enable both centres to operate as Principal Treatment centres. For example there would have to be increases in:

- the number of medical staff (haematologists and paediatric oncologists);
- the number of specialist outreach nursing staff who play an important role in the service provided to the families of children with cancer;
- pharmacy staff with a special interest in the treatment of children with cancer. They are closely involved in the provision of chemotherapy – a vital part of the treatment provided to many children with cancer;
- clinical trials co-ordinators who are responsible for supporting the trials which have played an increasingly important part in raising the standards of care for children with cancer. Some of these clinical trials coordinators might consist of nurse research staff, which would also help to strengthen the support available for clinical trials in Scotland.

The best estimate provided by the Directors of Finance is that the improvements proposed under the Status Quo Plus option would add around £1 million to the total annual revenue costs of this service. This is not an insignificant sum, but it is considered that it would be justified by the improvements in services. Even with this investment it is recognised that, based on current activity patterns, Aberdeen could not realistically move to the levels of consultant staffing (5 or more consultants providing '24-hour specialist medical cover' and 'expertise in a wide range of cancers') envisaged in the NICE guidelines for a Principal Treatment Centre. There would also be no on-site access to PICU facilities. Therefore, adoption of the 'Status Quo Plus' model would continue a pattern of service in Scotland in which comprehensive Level 4 care is being provided to children in a setting that does not accord with best practice guidance for the delivery of safe high quality care.

#### **Key Additional Improvements Under Status Quo Plus**

- Children in Aberdeen and Edinburgh would benefit from an enhanced level of consultant staffing. In particular, it would bring Edinburgh up to Level 4 as specified in the NICE guidelines. However, it is unlikely this can be achieved for Aberdeen;
- Management of clinical trials could be improved due to an increase in data managers;
- Access to specialist pharmacist staff during chemotherapy treatment would be improved in Aberdeen, Dundee, Edinburgh, and Glasgow;
- The expansion in outreach nursing would improve the support available to children and their families who attend the centres in Aberdeen, Edinburgh, and Glasgow;
- Families would also benefit from increased social work support in Aberdeen, Dundee, and Glasgow. This would be dependant on funding and agreement with CLIC Sargent.

## 9.2 Two Principal Treatment Centres

Under the other options that have been considered in this appraisal – two PTCs or a single PTC – the improvements outlined above would still take place. However, there are a number of additional improvements that would result from concentrating the diagnosis, staging, and initial treatment in two Principal Treatment Centres.

The case for having two PTCs rather than retaining the existing configuration is essentially about the future position of the centre in Aberdeen. There is no evidence to suggest that there have been any deficiencies in the standards of care provided to children in Aberdeen, and parents in Grampian have expressed a uniformly high opinion of the quality of care that their children receive and of the commitment and support provided by clinical staff.

Nevertheless, there must be some concerns about the relatively small number of new cases of cancer seen in Aberdeen each year, and the ability of a small centre to manage the full range of clinical trials. The current Aberdeen service is dependant on two consultants (1.2 WTE), and is therefore unable to provide access to a local Specialist 24 hours / day. It would not however be practical to increase staffing in Aberdeen to the levels recommended in the NICE guidelines because of the small number of children seen. This option therefore proposes that the primary responsibility for the provision of Level 4 care in Scotland, including diagnosis, staging and initiation of treatment, should lie with two Principal Treatment Centres in Edinburgh and Glasgow.

This model would retain Level 3 care in Aberdeen and thereby ensure that the largest part of most cancer care for children remained local which is that of ongoing treatment and support. Beyond that, the meeting of key stakeholders in October 2007 also recognised that the existence of a well-structured cancer network could allow a degree of flexibility in the application of the NICE guidance, respecting the current level of expertise available in Aberdeen. Full analysis of the potential impact of an effective and supportive Managed Clinical Network could not practically be analysed in the timeframe of this review. There is however, agreed potential, based on operating service models elsewhere in the UK, for Aberdeen to continue to provide all elements of care for selected patients, and this would be managed through the Clinical Network on a case by case basis. Such an approach would preserve local care wherever possible while ensuring no compromise in the quality or safety of care or access to the benefits of clinical trials.

The practicalities of this model require to be agreed and established by the hospitals working within the new network. However one key aspect will be the facilitation of continued surgery, radiology and radiotherapy where local safe practice can be guaranteed.

This development:

- achieves a higher level of consistency with the guidelines set out in the report from NICE - and these guidelines provide the most authoritative and wide-ranging review of the appropriate standards of care for children with cancer that have been carried out in the UK;
- is supported by the majority of consultant staff in Scotland and is also supported by an independent expert from England as opposed to the Status Quo Plus option; and



- is the conclusion that was also reached in the earlier report, *The Future of Cancer Services for Children and Young People in Scotland*.

Estimates prepared by the Directors of Finance in Greater Glasgow and Clyde, Lothian, Grampian, and Tayside indicate that establishing 2 Principal Treatment Centres instead of three, would give rise to a further increase in annual revenue costs of the order of £0.6 million. While there is some uncertainty about this figure, the advice of the finance staff consulted is that this option would certainly lead to a further significant increase in costs. There may also be some additional capital cost involved as a result of the extra work that would now take place in Edinburgh (or Glasgow), though this additional cost is unlikely to be significant.

The additional improvements in service that would be achieved as a result of establishing two Principal Treatment Centres are:

**Key Additional Improvements Under Option 3  
(Two Principal Treatment Centres in Edinburgh and Glasgow)**

- The concentration of the diagnosis, staging, and commencement of treatment in Edinburgh or Glasgow for the majority of children, would further improve the opportunities for children to benefit from participation in a wider range of clinical trials;
- All children would receive any higher risk treatment episodes in a centre which has on-site access to 24/7 specialist medical care, and a Paediatric Intensive Care Unit;
- There would be a further slight increase in outreach nursing support for families from Grampian – a necessary development because of the additional time that families from Grampian will spend away from home.
- Concentration of some aspects of the service in Edinburgh and Glasgow may improve the sustainability of the service. Patients would be less vulnerable to the loss of a consultant through sickness, leave, or staff turnover.

Clearly, these benefits as a result of moving from Option 2 (Status Quo Plus) to Option 3 (Two Centres) need to be balanced against the reduction in access to services for families. Even though much of the treatment for children who currently attend the centre in Aberdeen could continue to take place there, it would be necessary for some families to attend Edinburgh (or Glasgow) for the diagnosis, staging and initial treatment. The additional travel involved, and the time spent away from home would be a significant burden on these families.

Again, it is a judgement as to whether the increase in expenditure required as a result of centralising some aspects of the service in two Principal Treatment Centres is justified by additional benefits. The potential additional benefits are significant, and would appear to justify the additional costs of establishing two Principal Treatment Centres for Scotland.

### 9.3 A Single Principal Treatment Centre

Finally, this appraisal has also considered whether there is a case for establishing a single Principal Treatment Centre for all children with cancer in Scotland. A single PTC could be located in either Edinburgh or Glasgow. Again, it is worth emphasising that if such a PTC was established, much of the treatment for children would still continue to be provided in local shared care centres.

It has been considered whether there would be further benefits to children and families from establishing a single PTC – i.e. in addition to the benefits that could be achieved with two PTCs.

#### **Key Additional Improvements Under Option 4 (A Single Principal Treatment Centre in Edinburgh or Glasgow)**

- Potentially, there could be a further improvement in terms of access for children to a wider range of clinical trials, particularly phase 1 and 2. The concentration of expertise and children in a single centre might increase the number of trials in which children with cancer could be entered, and thus increase the benefits of this approach to treatment to a much larger group of children
- Concentration on a single PTC might also improve the sustainability of the service. With a larger number of consultant staff, the service would be even less vulnerable to the loss of one or two consultants, and perhaps a large centre would find it easier to recruit and retain specialists.

However, these potential benefits are uncertain, and in practice may be limited. It must be noted, though, that some staff in Glasgow consider the benefits would be more substantial in respect of recruitment and retention of staff, the concentration of expertise, and the establishment of an academic post to support the development of the best standards of care across the service in Scotland. The Grampian team involved in the option appraisal also indicated that if certain aspects of the service are to be centralised, they would prefer to see a single PTC established rather than two PTCs.

At the same time, it has to be acknowledged there are some disadvantages in establishing a single large PTC for all children in Scotland. A single PTC would be a very large centre seeing around 150 new cases each year. Further work is also required to examine the care and treatment provided to the 16 -18 year old age group. If this work were to be brought into the domain of children's services in the future, the option of one PTC is less tenable

- There would be a much greater impact on access if the diagnosis, staging and commencement of treatment are concentrated in one centre. While, much of the treatment would continue to be provided locally, as at present, in shared care centres, the number of families affected by this more wide-ranging reconfiguration of services would be considerable.

- There are also concerns about the wider impact on other hospital services of undertaking such a wide-ranging reconfiguration of services. The number of children affected by reducing the number of PTCs from three to two is quite small – some 15-20 new cases annually, and the wider impact on hospital services in Aberdeen as a result of this change seems likely to be limited. Establishing a single centre would be likely to have a potentially larger impact on hospital services in Edinburgh or Glasgow.
- Although the annual revenue costs of a service which is concentrated in a single PTC have not been explicitly estimated, the best judgement of the Directors of Finance's is that this would probably give rise to some further increase in annual revenue costs. Because the scale of reconfiguration would be much greater, it is also likely that this option would give rise to significant additional capital costs

On balance, therefore, there is currently no clear evidence of net clinical or service benefit to support the option of establishing a single Principal Treatment Centre for children with cancer in Scotland. Such an option is likely to offer limited additional benefits compared with the option of establishing two PTCs in Edinburgh and Glasgow. It also has some significant disadvantages – particularly in relation to access for patients and their families; and it is likely to involve a further significant increase in costs (both revenue and capital).

If a single PTC were to be established, the choice would lie between Edinburgh and Glasgow. In principle, both locations would be able to achieve the necessary standards of care and would have access to a similar range of services. It could be argued that since Glasgow is already a larger centre, hosting the national bone marrow transplant service and the larger PICU, there would be less disruption involved in establishing a single PTC in Glasgow rather than in Edinburgh.

## **Conclusion**

An important issue that has not been taken into account in this appraisal is the future provision of paediatric neurosurgery in Scotland which remains under review. Around one quarter of new childhood cancer diagnosis in Scotland is related to children with brain tumours – around 30 new cases per year. It is recognised that the NICE guidelines clearly link level 4 care with the provision of paediatric neurosurgery. If a decision is taken in the future to centralise paediatric neurosurgery in one location, then it would be necessary to consider the implications for the number and location of PTCs for children with cancer.

However, a decision has to be made now to allow the service for children with cancer to move forward, the managed clinical network to develop, and the service to start to function as a single service for children with cancer in Scotland. The overall assessment, therefore, based on the current evidence available, and in the absence of a decision about neurosurgery, is that two Principal Treatment Centres (Option 3) represents the best means of configuring services for children with cancer in Scotland for the medium term. Aberdeen will provide a Level 3 service, Glasgow is currently operating as a Level 4 centre, and Edinburgh will require some investment to ensure it meets NICE guidelines to provide level 4 care.

Central to the effective operation of this approach is the concurrent development of a supportive managed network with clear patient pathways and an intentional commitment to shared and local care wherever safely possible

Together with the general improvements in staffing that are necessary to achieve NICE standards across the country, this option would bring about a significant improvement in services and would justify the additional expenditure required.

## APPENDIX A

### LEVELS OF CARE – Cancer Services for Children and Young People in Scotland.

LEVELS OF CARE	CORE ELEMENTS – Service Review 2004	ADDITIONS – NICE Implementation Of Guidelines Group 2007	Agreement amongst Lead Scottish Clinicians 08/05/07
<b>Level 1</b>	<ul style="list-style-type: none"> <li>Initial contact</li> <li>Diagnostic suspicion</li> <li>Palliative/Terminal care</li> <li>Emergency care</li> </ul>	<ul style="list-style-type: none"> <li>Initial contact</li> <li>Diagnostic suspicion</li> <li>Palliative/Terminal care</li> <li>Emergency care</li> <li><b>OP chemotherapy</b></li> </ul>	<p>Agreed in principle, but <b>remove O/P chemotherapy</b>. This to be negotiated on individual child basis in remote areas.</p>
<b>Level 2</b> (level 1 care +)	<ul style="list-style-type: none"> <li>Management of the ill/septic child</li> <li>Blood product support</li> <li>Outpatient Chemotherapy</li> <li>Psycho–social care</li> </ul>	<ul style="list-style-type: none"> <li>Management of the ill/septic child</li> <li>Blood product support</li> <li>Outpatient Chemotherapy</li> <li>Psycho–social care</li> <li><b>Day case Chemotherapy</b></li> </ul>	<p>Agreed in principle, but acknowledged that protocols for day case chemotherapy would be developed through the MCN.</p>
<b>Level 3</b> (levels 1 and 2 +)	<ul style="list-style-type: none"> <li>Day case chemotherapy (infusion)</li> <li>Intrathecal chemotherapy</li> <li>Imaging (follow up)</li> <li>Late effects follow up with Endocrinologist</li> </ul>	<ul style="list-style-type: none"> <li>Day case chemotherapy (infusion)</li> <li>Intrathecal chemotherapy</li> <li>Imaging (follow up)</li> <li>Late effects follow up with Endocrinologist</li> <li><b>In patient 24hr Chemotherapy excluding administration of high dose Methotrexate</b></li> <li><b>Excludes diagnosis and initiation of treatment</b></li> </ul>	<p>Agreed in principle</p> <p>*See footnote</p>
<b>Level 4</b> (Tertiary) all care	<ul style="list-style-type: none"> <li>Diagnosis, staging and management</li> <li>Paediatric Neuro Oncology</li> <li>Bone Marrow Transplantation</li> <li>Phase I/II studies</li> <li>Academic base/research</li> <li>Training</li> </ul>	<ul style="list-style-type: none"> <li>Diagnosis, staging and management</li> <li>Paediatric Neuro Oncology</li> <li>Bone Marrow Transplantation</li> <li>Phase I/II studies</li> <li>Academic base/research</li> <li>Training</li> </ul>	<p>Agreed in principle and add 'Management of Relapsed disease'</p>

\* Level 3 centres would retain diagnostic elements for common cancers. Retention of diagnostic component for rarer cancers will depend on development of appropriate care pathways by the Children and Young People's Cancer Network.

## APPENDIX B

### CHILDREN'S CANCER SERVICES IN SCOTLAND PROFILE OF ACTIVITY, RESOURCES AND SERVICES IN EACH CENTRE

	Aberdeen	Edinburgh	Glasgow	Scotland
<b>Patient Activity (Annual Data)</b>				
New cases diagnosed:				
- leukaemia	6.0	17.2	24.6	47.8
- brain / CNS	4.6	13.0	17.6	35.2
- NHL	0.8	2.6	4.0	7.4
- other cancers	7.8	22.6	29.2	59.6
- total	19.2	55.4	75.4	150.0
Total patients seen	43	149	185	432
Inpatient episodes:				
- elective admission	147	261	445	881
- emergency admission	95	218	669	1,111
- transfer	31	169	110	314
- total	273	648	1,224	2,306
Occupied bed days	1,429	3,427	6,215	11,633
Bone marrow transplant bed days	-	-	1,023	1,023
Day Cases (episodes)	124	1,299	940	2,545
New and returning OP (2004/05)	-	1,511	6,934	8,445
Surgical procedures: (2005)				
- central line insertions	17	30	85	
- ports		22	23	
- resections	8	11	99	
- biopsies	5	19	38	
Radiotherapy (No.of Children / yr)	5	19	31	55
Radiology (2005)				
Total radiology activity / centre	16,243	26,794	44,495	
%age assigned to oncology	-	5.2%	4.9%	
<b>Resources</b>				
Available Staffed In patient Beds	8	8	22	38
Day Care beds		4	4	8
Consultants (WTE):				
- haematologists	0.5	2*	4*	6.5
- paediatric oncologists	0.7	2	3	5.7
Associate Specialists	-	1		
Staff Grades	-	1	27 sessions	

	<b>Aberdeen</b>	<b>Edinburgh</b>	<b>Glasgow</b>	
Ward nurses and Day care (WTE)		14.5	57.24	
Nursing Assistants		6	7.33	
Specialist outreach nurses (WTE)	1	3	3	
Clinical trials coordinators	0.7	1	3	
Social workers	0.5	2	4	
Pharmacy staff (oncology service)	1	2.5	4	
Pathology (WTE)	1	1.6	2.8	
Clinical oncology(sessions/wk)	0.05	0.1	0.3	
<b>Services Available</b>				
Core components of PTC				
Paediatric Surgeon with expertise	2 with interest	2 with interest	2 with interest	
On site: Paed Anaesthetics	Yes	Yes	Yes	
Paed Radiology	Yes	Yes	Yes	
Paed Pathology	Yes	Yes	Yes	
Designated Oncology Pharmacist	Yes	Yes	Yes	
Designated Lead Psychology	No	Yes	Yes	
<b>Immediate access to</b>				
PICU	No (HDU)	Yes – 8 beds	Yes – 16 beds	
Paed Neurosurgical services	No	Yes	Yes	
Other tertiary Paed Specialists	Yes	Yes	Yes	
Dental services	Yes	Yes	Yes	
Pain Management team	No	Yes	Yes	
Palliative care team	No	No	No	

Notes:

New cases diagnosed annually:

- Includes all those in the 0-15 age group
- Case numbers are based on aggregations across home health board areas on the following basis:
  - Aberdeen = cases from Grampian, Orkney and Shetland
  - Dundee = cases from Tayside
  - Edinburgh = cases from Borders, Fife and Lothian
  - Glasgow = cases from Argyll & Clyde, Ayrshire & Arran, Dumfries & Galloway, Forth Valley, Greater Glasgow, Highland, Lanarkshire and Western Isles
- Due to small numbers, 5-year annual averages are presented for the period 2000 – 2004

Total patients seen annually:

- Includes both day cases and in-patients, all those in the 0-15 age group
- Due to small numbers, 3-year annual averages are presented for the period 2003 – 2005

#### Radiotherapy

- Due to small numbers, 3-year annual averages are presented for the period 2003 – 2005

#### Inpatient episodes / Day cases / Occupied bed days:

- Includes all those in the 0-15 age group
- Due to small numbers, 3-year annual averages are presented for the period 2003 – 2005

#### Staff

\* indicates vacancies as described in the paper 7. Resources p63

### SHARED CARE – Current profile

Shared Care	Ninewells	Dumfries	Raigmore
Core Components of Shared Care			
At least 10 new children / year	12	3	5
Paediatrician with Special Interest	Yes	Yes	Yes
Dedicated time	0.6 WTE		6 hours / week
Associate Specialist	0.5 WTE	-	-
Specialist Nurse / Named Nurse	1.2 WTE	Named Nurse	1.0 WTE
Named Pharmacist	0.2WTE	-	Yes
Inpatient episodes	160	-	-
- elective admission	28	-	-
- emergency admission	129	-	-
- transfer	23	-	-
Occupied bed days	563	-	-
Day cases - episodes	183	-	-
Outpatient attendances (average / year inc off treatment follow up)	800	-	-

During this exercise, Crosshouse (Ayrshire) and Stirling Royal Infirmary have expressed interest in providing shared care in the future.

Neither unit has dedicated Paediatrician time for Children with Cancer, both have a Children's Community Nursing Team.



## APPENDIX C NON FINANCIAL CRITERIA AND DESCRIPTOR

Criteria	Description
<p><b>1. Standards of Clinical Care</b></p>	<p>The best evidence on standards of care is provided by measures of clinical outcomes – for example, survival rates for children with cancer, the quality of life for children, or complications occurring during treatment. In practice, evidence of this nature is limited. However, some Information is available on survival rates for children with cancer.</p> <p>Clinical trials play a very important part in the care and treatment of children with cancer. The ability to offer Phase I/II studies to patients in Scotland is essential and the scope for doing so will be greater if treatment is concentrated in a smaller number of centres.</p> <p>NICE guidelines identify the staffing levels, skills, and services required to ensure the best standards of care.</p>
<p><b>2. Continuity of Care</b></p>	<p>This criterion is concerned with the way in which continuity of care for a children, young people and their families may vary across the options.</p> <ul style="list-style-type: none"> <li>• Care needs to be sustained across organisations and professional boundaries.</li> <li>• Continuity is important in the treatment and follow up of the original disorder, its sequelae or relapse, or in the event of palliative care being required.</li> <li>• Good communication has been identified as a key component to the success of continuity of care by families who contributed to the NICE Guidelines, and the families who have offered opinions during this process.</li> </ul>
<p><b>3. Relationship to other Services</b></p>	<p>This criterion is concerned with the extent to which the hospitals in each option are able to offer ready access to a full range of services necessary for them to function as a Principal Treatment Centre - neurosurgery, radiotherapy, nephrology, cardiology and paediatric intensive care.</p>
<p><b>4. Workforce Issues</b></p>	<p>Many of the issues that have been raised in relation to workforce sustainability relate to consultant medical staffing. However, the choice of option will also have implications for workforce recruitment and retention in other areas.</p> <ul style="list-style-type: none"> <li>• Recruitment of paediatric haematologists and paediatric oncologists may be easier in large centres rather than in a hospital which treats a relatively small number of children.</li> <li>• Opportunities for staff, including nurses, to specialise in the care of different forms of childhood cancer may be easier in a large centre.</li> </ul>

	<ul style="list-style-type: none"> <li>Centres with a relatively large number of staff may be less vulnerable to the loss of one member of staff through sickness, leave, or staff turnover.</li> </ul>
<b>5. Access for children and Families</b>	<p>Reconfiguring services for children with cancer could have a significant effect on patients and families because of the additional travel that may be involved, and the additional time that families may have to spend away from home.</p> <p>In terms of travel to a designated PTC, NICE states: <i>“Access to such facilities should be with the least inconvenience to patients and families, but the rarity of cancer in these age groups means that treatment may involve considerable travel for families, often beyond a closer, but less appropriate cancer facility. <b>This is generally well accepted by patients and families, but does impose additional burdens on them</b>”.</i> (p104)</p>
<b>6. Implementation of Changes</b>	<p>Significant changes to the configuration of children’s cancer services could give rise in the short term to some disruption which would adversely affect the quality of care delivered to patients and their families.</p>
<b>7. Impact on other services</b>	<p>This criterion is concerned with the effect that the options being presented will have in the long term on the ability of the children’s hospitals to provide a full range of paediatric expertise if there is a service redesign for Children’s Cancer. The services affected might include:</p> <ul style="list-style-type: none"> <li>Surgical services</li> <li>Paediatric intensive care</li> </ul>
<b>8. Academic and research issues</b>	<ul style="list-style-type: none"> <li>The concentration of clinicians in a smaller number of centres may also provide the critical mass that allows them to sustain clinical services to patients while at the same time finding the time required to participate in research.</li> <li>The scope for developing an academic role in children’s cancer services in Scotland may also be greater where services are concentrated.</li> </ul>

## APPENDIX D: WORKFORCE ESTIMATES

### Workforce implication by option

1. This section outlines the estimates that have been made of the workforce implications of the different options for reconfiguring cancer services for children. The workforce areas that have been considered are:

- Medical (consultant level posts):
  - Oncology and haematology
  - Pathology
  - Radiotherapy
- Ward nursing
- Outreach nursing
- Clinical trials co-ordinators
- Social workers
- Pharmacy staff

All of the staffing figures shown are Whole Time Equivalents (WTE).

### Medical Staff

2. Table 1 shows the estimates of the number of consultant staff (paediatric haematologists and oncologists) required in each centre under the different options.

**Table 1 – Consultant Medical Staffing: Paediatric Oncology & Haematology (Whole Time Equivalents) Paediatrician WTE**

Centre	NICE Guidelines <sup>1</sup>	Option 1 Status Quo	Option 2 Status Quo Plus	Option 3 Two PTCs	Option 4a One PTC (Edinburgh)	Option 4b One PTC (Glasgow)
Aberdeen	5	1.2	2.8	2.0	2.0	2.0
Dundee	-	0.6	1.2	1.2	1.2	1.2
Edinburgh	5	4.0	5.0	5.0	7.0	3.0
Glasgow	5	7.0	7.0	7.0	3.0	7.0
<b>Total</b>	<b>15</b>	<b>12.8</b>	<b>16.0</b>	<b>15.2</b>	<b>13.2</b>	<b>13.2</b>

1. NICE recommends that a Principal Treatment Centre should have 5 consultant staff including at least two paediatric haematologists and at least two paediatric oncologists.

3. To meet the NICE Guidelines, the current configuration of services would require at least some 15 WTE consultant posts. Currently there are an estimated 12.8 WTE consultant staff posts spread across the three centres in Glasgow, Edinburgh and Aberdeen, and in the shared care centre in Dundee.

- Glasgow already exceeds the number of consultant posts recommended in the NICE guidelines (1 post is filled by a Locum, 1 is vacant)
- Edinburgh has four posts (1 vacancy)
- Aberdeen has two consultant staff whose total input is 1.2 WTE.

4. In **Option 2** (Status Quo Plus) it has been assumed that the number of consultant staff in Edinburgh would have to increase from 4 to 5 to meet the recommended NICE standards.

5. In Aberdeen the number of consultant staff (WTE) identified by the local team as required to provide a safe service would increase to 2.8 in Option 2. This still falls short of the 5 posts recommended in NICE, but clearly it would be difficult to establish 5 posts in a centre which has around 15-20 new patients per annum. In Option 3 and 4 where Aberdeen would be a shared care centre, the number of consultant staff would be 2.0 WTE. These assumptions have been agreed with consultant staff, and supported by senior management in Aberdeen.

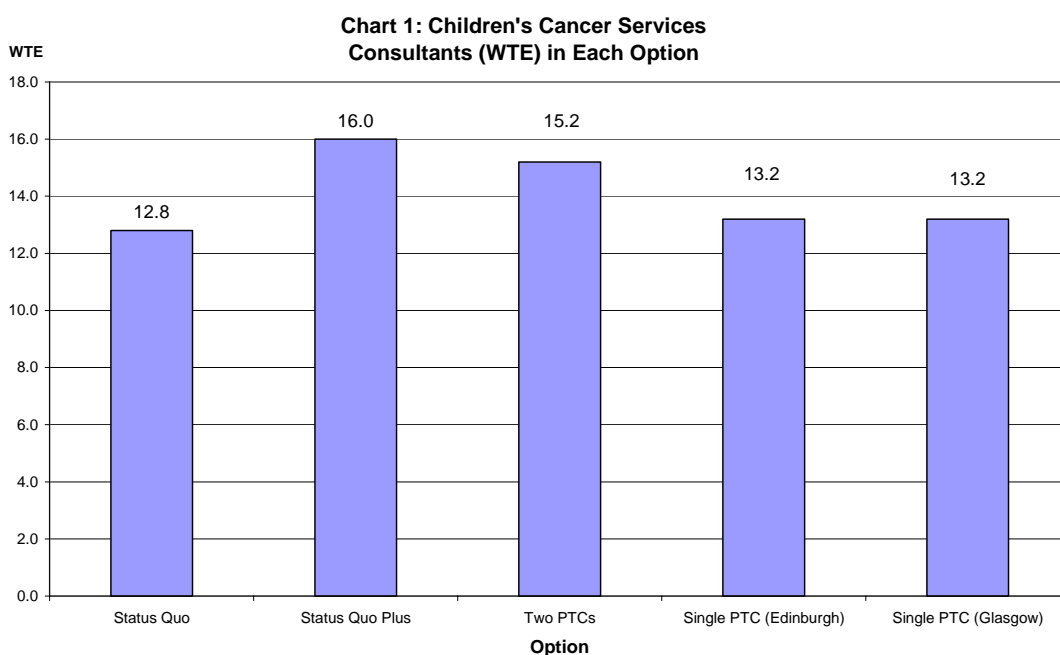
6. In Dundee, which would continue to function as a shared care centre, it has been assumed that there would be a small increase in medical staffing from 0.6 to 1.2 WTE. Currently an Associate Specialist post (0.5) provides support to the Consultant.

7 In **Option 3** (Two PTCs in Edinburgh and Glasgow) it has been assumed that the number of WTE medical staff in Edinburgh would remain at 5 – the additional work that would be undertaken there in this option is not felt by the Edinburgh Clinicians to be sufficient to justify any further increase in consultant staffing.

8. In **Options 4a and 4b**, it has been assumed that a single PTC would require 7 WTE staff and, as a shared care centre, Edinburgh or Glasgow would require 3.0 WTE. There would be no change in medical staffing in Aberdeen or Dundee compared with Option 3.

9. The overall differences in consultant staffing in paediatric haematology and oncology are summarised in Chart 1. Bearing in mind the uncertainties surrounding some of the estimates, the figures suggest that:

- Options 2 and 3 would both require a significant increase in medical staffing compared with the status quo – perhaps around 3 WTE consultant posts.
- Chart 1 also suggests that there may be potentially significant savings of 2-3 consultant posts from having a single PTC rather than 2 or 3 PTCs. However, a single PTC would still require slightly more consultant staff than the status quo.



## Ward Nursing

10. The available estimates of nurse staffing are shown in Table 2. The nurses in Grampian and Tayside are part of the staff complement for the children's medical ward and cannot be identified separately for children with cancer. Grampian has 12 WTE nurses who are trained to give chemotherapy to inpatients and day care / out patients.

11. The nurse complement for option 4 has been calculated using the guidelines published by the RCN for children's oncology units. (Appendix 2). This calculation has been made on the assumption that option 4a and 4b see the respective centre carrying out bone marrow transplant, and with a maximum of 28 beds. In reality the practice of shared care would reduce these bed numbers, but more work is required to understand the full implications.

**Table 2 - Ward Nurse Staffing**

Centre	Option 1 Status Quo		Option 2 Status Quo Plus		Option 3 Two PTCs		Option 4a One PTC (Edinburgh)		Option 4b One PTC (Glasgow)	
	Nurses	Support Staff	Nurses	Support Staff	Nurses	Support Staff	Nurses	Support Staff	Nurses	Support Staff
Aberdeen	-	-	-	-	-	-	-	-	-	-
Dundee	-	-	-	-	-	-	-	-	-	-
Edinburgh	14.5	6	20	6	27	7.5	58	8.0	15.2*	3.0
Glasgow	57.24	7.33	57.24	7.33	57.24	7.33	20.0**	4.6	58	8.0
<b>Total</b>							<b>78.0</b>	<b>12.6</b>	<b>63.2</b>	<b>11.0</b>

\* Calculated based on up to 8 beds to provide shared care

\*\* Calculated based on up to 12 beds to provide shared care due to larger catchment area for Level 3 care.

## Specialist Outreach Nurses

12. The estimates shown in Table 3 indicate that there would be an increase in outreach nurse staffing in all of the options relative to the Status Quo. The increase is as a result of teams identifying the need for a post to support families with a child with a brain tumour (Edinburgh), the need for a post to cover teaching/on call and palliative care (Glasgow), and in Aberdeen to provide a 24/7 service to a large rural area. Six of these posts are currently 50% funded by CLIC Sargent.

**Table 3 - Outreach Nurse Staffing**

Centre	Option 1 Status Quo	Option 2 Status Quo+	Option 3 Two PTCs	Option 4a One PTC (Edinburgh)	Option 4b One PTC (Glasgow)
Aberdeen	1.0	1.5	2.0	2.0	2.0
Dundee	1.5	1.5	1.5	1.5	1.5
Edinburgh	3.0	4.0	4.0	4.0	3.0
Glasgow	3.0	4.0	4.0	3.0	4.0
<b>Total</b>	<b>8.5</b>	<b>11.0</b>	<b>11.5</b>	<b>10.5</b>	<b>10.5</b>

### Clinical Trials Co-ordinators

13. The role of clinical trials coordinators is seen as an increasingly important - and expensive - part of this service because of the continuing increase in the role and standards of clinical trials. There would be a significant increase in the number of coordinators under Status Quo Plus, from a current figure of 4.7 to 6.0. In the two PTC and one PTC options, the number of coordinators would fall slightly to 5.0. It is envisaged that these posts in the 1 centre option would potentially outreach to the other centres.

**Table 4 - Clinical Trials Coordinator Staffing**

Centre	Option 1 Status Quo	Option 2 Status Quo Plus	Option 3 Two PTCs	Option 4a One PTC (Edinburgh)	Option 4b One PTC (Glasgow)
Aberdeen	0.7	1.0	0.0	0.0	0.0
Dundee	0.0	0.0	0.0	0.0	0.0
Edinburgh	1.0	2.0	2.0	5.0	0.0
Glasgow	3.0	3.0	3.0	0.0	5.0
<b>Total</b>	<b>4.7</b>	<b>6.0</b>	<b>5.0</b>	<b>5.0</b>	<b>5.0</b>

### Social Workers

14. The number of social workers would increase at Aberdeen and Glasgow in Status Quo Plus compared with the present position. This proposed increase has been identified by staff as desirable to cope with the workload. This has been discussed with CLIC Sargent who fund all the Social Work posts, and the final number and location of posts would be decided by the Charity once the outcome of the appraisal is known. The Glasgow posts include a Team Leader and 3 Social Workers. The increase identified is to provide a service to Young People. In addition CLIC Sargent also funds 3 Social Works posts for Young People, 2 at the Beatson, Glasgow, and 1 at the Western General in Edinburgh. These are not included in the table below.

**Table 5 - Social Work Staffing**

Centre	Option 1 Status Quo	Option 2 Status Quo Plus	Option 3 Two PTCs	Option 4a One PTC (Edinburgh)	Option 4b One PTC (Glasgow)
Aberdeen	0.5	1.0	1.0	1.0	1.0
Dundee	0.5	0.8	0.8	0.8	0.8
Edinburgh	2.0	2.0	2.0	2.0	2.0
Glasgow	4.0	5.0	5.0	5.0	5.0
<b>Total</b>	<b>7.0</b>	<b>8.8</b>	<b>8.8</b>	<b>8.8</b>	<b>8.8</b>

### Pharmacy Staff

15. Again, the pattern in Table 6 suggests an increase in staffing in moving from Option 1 to Option 2, with possibly some savings if the number of PTCs reduces from three to two. There is a significant increase over all other options when moving to a single PTC. The posts identified are pharmacists who are involved with the service. Each centre has a named Pharmacist to oversee this specialist area.

16. It is anticipated for the option 4a and 4b an extra post will be required to support shared care appropriately. In these options it has been assumed the children's hospital not acting as PTC would require less Pharmacy posts due to the decreased workload.

17. An anxiety has been expressed about the ability to recruit specialist Pharmacy staff in the future.

**Table 6 - Pharmacy Staffing**

Centre	Option 1 Status Quo	Option 2 Status Quo Plus	Option 3 Two PTCs	Option 4a One PTC (Edinburgh)	Option 4b One PTC (Glasgow)
Aberdeen	1.0	1.5	1.0	1.0	1.0
Dundee	0.2	0.4	0.4	0.4	0.4
Edinburgh	2.5	3.0	3.0	6.5	3.0
Glasgow	4.0	5.0	5.0	3.0	6.5
<b>Total</b>	<b>7.7</b>	<b>9.9</b>	<b>9.4</b>	<b>10.9</b>	<b>10.9</b>

## Supporting services

### Pathology

18. NICE Guidelines suggest 0.5 WTE dedicated pathology staff in each PTC. The table below identifies the staff in post and available to provide this service for the status quo. It does not reflect the amount of time allocated to the paediatric oncology / haematology workload.

This has been described as a service working at the edge in respect to workload, and removing the work from individual centres for options 4a and 4b would remove the job satisfaction associated with it, but not have a significant impact on workload. A MLSO would be required to support this workload in the single PTC option.

**Table 7 - Medical Staffing – Pathology**

Centre	Option 1 Status Quo	Option 2 Status Quo Plus	Option 3 Two PTCs	Option 4a One PTC (Edinburgh)	Option 4b One PTC (Glasgow)
Aberdeen	1.0	1.0	-	-	-
Dundee	-	-	-	-	-
Edinburgh	1.6	1.6	1.6	1.8	1.6
Glasgow	2.8	2.8	2.8	2.8	3.0
<b>Total</b>	<b>5.4</b>	<b>5.4</b>	<b>4.4</b>	<b>4.6</b>	<b>4.6</b>

## Clinical Oncology

19. NICE Guidelines suggest that a baseline minimum of 0.7 WTE staff divided between 2 clinical oncologists are required in a PTC. Discussions with the Radiotherapists have identified none of the hospitals currently meet this requirement for dedicated sessional time.

20. Glasgow currently have 3.5 sessions allocated / week to the service with the flexibility to put in up to 3.5 sessions as required. The centre carries out total body irradiation for the children receiving bone marrow transplants. The 'as required' sessions are not reflected in the work plans, and therefore not recognised formally.

21. Edinburgh have one dedicated session per week which is insufficient to cope with the current workload, and there are potential clinical governance issues in relation to this. Aberdeen has a clinical oncologist who has paediatric radiotherapy as his responsibility which accounts for under half a session per week. A second person in Aberdeen is currently being trained to take over when the current clinical oncologist retires.

**Table 8 – Clinical oncology staffing**

Centre	Option 1 Status Quo	Option 2 Status Quo Plus	Option 3 Two PTCs	Option 4a One PTC (Edinburgh)	Option 4b One PTC (Glasgow)
Aberdeen	0.05	0.05	0.05	0.05	0.05
Dundee					
Edinburgh	0.1	0.5	0.5	0.7	0.5
Glasgow	0.35	0.7	0.7	0.3	0.7
<b>Total</b>	<b>0.5</b>	<b>1.25</b>	<b>1.25</b>	<b>1.25</b>	<b>1.25</b>

### Resource Differences Between Options

22. The figures set out in this note provide an initial estimate of some of the resource implications of the different options, based on discussion with clinical staff in each centre. Clearly further work is required on these estimates: there are gaps in some of the figures, and there are also some apparent inconsistencies in the figures provided by different centres.

### APPENDIX E

Participants in the option appraisal benefit assessment days

Name	Representing
Malcolm Wright	Chair – National Steering Group
Sir Alan Craft	Child Health - University of Newcastle
Dr J Beattie	RCPCH
Hilary Davison	NHS QiS
Deirdre Evans	NSD
Ellie Johnston	NSD
Anne Wilson	Action for Sick Children
Ellen Finlayson	CLIC Sargent
Simon Fuller	Teenage Cancer Trust
Valerie Simpson	CCLASP
David Sullivan	NHS Grampian
Dr Derek King	Royal Aberdeen Children's Hospital
Dr Veronica Neefjes	Royal Aberdeen Children's Hospital
Heather Kelman	NHS Grampian



Dr Leslie Wilkie	NHS Grampian
Dr Mike Bisset	Royal Aberdeen Children's Hospital
Dr Rosalie Wilkie	Ninewells, Dundee
Prof Stewart Forsyth	Ninewells, Dundee
Caroline Selkirk	NHS Tayside
Peter Williamson	NHS Tayside
Jackie Sansbury	NHS Lothian
Isabel McCallum	RHSCE
Dr Hamish Wallace	RHSCE
Dr Angela Thomas	RHSCE
Sandra Mair	NHS Lothian
Professor Minns	RHSCE
Helen Byrne	NHS GGC
Dr Milind Ronghe	RHSCG
Dr Brenda Gibson	RHSCG
Jamie Redfern	RHSCG
Dr Iain Wallace	RHSCG
Rosslyn Crocket	NHS GGC
Dr Andrew Watt	Scottish Paediatric Radiologists
Dr Dave Simpson	SSCCCS
Dr Allan Howatson	Scottish Paediatric Pathologists
Karon McDowall	Pharmacy (National)
Dr Frances Yuille	Scottish Paediatric Clinical Oncologists
Alasdair Munro	Health Economics Research Unit
Russell Whyte	DTZ
Keith Jeffrey	External Facilitator, Roberts Partnership
John Froggat	SGHD
Robert Stevenson	SGHD
Morgan Jamieson	SGHD
Dr Louise Smith	SGHD
Claire Tester	SGHD
Rory Farelly	SGHD
Andrea Cail	SGHD
Mary Sloan	SGHD

### **Participants in the overall process**

Professor Sir Alan Craft – External Professional Advisor

Parents – Aberdeen, Inverurie, Elgin, Inverness, Dundee, Edinburgh, Ayrshire, Glasgow, Dumfries and Galloway

Directors of Finance, NHS Grampian, Tayside, Lothian, GGC

Scottish Paediatric Oncology Outreach Nurses

Scottish CLIC Sargent Social Workers

Information Services Division

