



National Steering Group for Specialist Children's Services

Children's Cancer Services

Executive Summary

Background

A Review of Specialist Paediatric Services, highlighted in HDL(2003)43, produced a report on the *Future of Cancer Services for Children and Young People in Scotland*¹. One of the key recommendations was that an option appraisal using the NICE guidelines '*Improving outcomes for Children and Young People with Cancer*'² be undertaken to inform the future planning and delivery of cancer services to children and young people in Scotland.

This recommendation was in response to conclusions in the Review of Paediatric Oncology and Malignant Haematology³ that 'by 2008 it will not be possible to provide 24/7 consultant led cover in one inpatient unit, far less the existing three tertiary units with the existing number of Consultants without significant redesign, additional staff and reconfiguration of services'.

The children's hospitals currently see around 150 new diagnoses of childhood cancer each year in the 0-15 year age group, 19 in Grampian, 55 in Lothian and 76 in Glasgow. Just over a third of these cases are diagnosed with a Leukaemia, a third with a brain tumour, and the rest are small numbers of other cancers.

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.

The appraisal was to use NICE guidelines '*Improving outcomes for children and young people with cancer*' as a benchmark. The guidelines provided a blueprint model for the future configuration of services for children and young people with cancer. This describes services being delivered through a defined network with identified principal treatment centres 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.

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 comparable European countries.

To improve outcomes, it is essential that all children and young people are referred to a skilled multi disciplinary team at diagnosis, and receive the best possible treatment for their individual cancer. Outcomes for children's cancers have improved dramatically in the last 2 decades as a direct result of national and international collaboration in clinical trials².

¹ Future of Cancer Services for Children and Young People in Scotland, CCSiSWG

² '*Improving outcomes for Children and Young People with Cancer*' NICE 2005

³ Review of Paediatric Oncology and Malignant Haematology Services in Scotland, CHSG-Specialist Paediatric Services Sub Group and Scottish Paediatric Oncology and Haematology Group, May 2004.

NICE defined 4 levels of care, which for the first time clarified the key components of a specialist service and staffing levels for children's cancer services in the UK. These levels will enable the continued provision of children's cancer services in the children's hospitals in Aberdeen, Dundee, Edinburgh and Glasgow. This new model of care sets very clear standards and targets and the aim of this review process has been to ensure that the care provided in Scotland's hospitals can meet these demands.

It has been agreed by a key stakeholder group that the service will continue to be delivered through the basis of the four existing sites in Aberdeen, Dundee, Edinburgh and Glasgow as a managed clinical network, and identified Principal Treatment Centre(s) will support and be supported to deliver care across the Network.

The option appraisal

The option appraisal process has engaged with a large number of stakeholders as information and evidence has been gathered to populate the options:

- The status quo plus - leaving services as they are, with substantial investment to bring each centre in line with NICE guidelines.
- 2 Principal treatment centres (Level 4) in Edinburgh and Glasgow with a strong network of shared care in Aberdeen, Dundee, and identified District General Hospitals
- 1 Principal treatment centre (Level 4) in Edinburgh or Glasgow and a strong network of shared care.

Outcomes

Outcomes for children in Scotland currently match the rest of the UK, but lag behind some parts of Europe. This is in part explained by the time lag from diagnostic suspicion to diagnosis, rather than the inability of individual hospitals to provide the appropriate treatment.

The Network 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 of this should be on a devolved, permissive and 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 principal treatment centre(s) and shared care centres working at levels 1, 2 and 3;
- 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.

Risks

There are real pressures being experienced in the recruitment of staff to key disciplines. There is a 50% shortfall in current identified Consultant Haematologist posts. There are also particular short term issues in relation to the numbers of consultants in Edinburgh and Aberdeen which need to be addressed.

The decision on the future location of paediatric neurosurgery services has been recognised as potentially having a major impact on where neuro-oncology services are provided within Scotland. These recommendations allow the service to evolve and move forward while this is being decided.

There are real challenges currently in ensuring that children and young people can access the full range of clinical trials available for the treatment of cancer. This is likely to continue unless the service is developed appropriately.

Recommendations

	Action	By when
1.	The children's cancer service in Scotland should be planned and commissioned on a national basis, and delivered according to the levels of care described in the full draft report for Cancer Services for Children and Young People in Scotland 2007. A managed clinical network is being established, and this will support the delivery of care and treatment in a permissive way, accepting that the current level of expertise across the country allows a degree of flexibility within the levels.	2009
2.	<p>The framework for the network will be determined by the location of complex paediatric neurosurgery</p> <ul style="list-style-type: none"> • If Paediatric Neurosurgery has a prime site located in Glasgow, Scotland will have 1 Level 4 centre for children's cancer, based in Glasgow, with Aberdeen and Edinburgh operating at Level 3, and Dundee at Level 2, with identified DGHs (currently Inverness and Dumfries) at Level 1. • If Paediatric Neurosurgery has a prime site located in Edinburgh, RHSCE and RHSCG could both provide elements of Level 4 care, with networked services as described above. 	2008
3.	The MCN to develop care pathways starting with the more common cancers to ensure clarity across the network about referral pathways and place of treatment.	2008/09
4.	<p>The MCN to develop progress measures that are more closely aligned to improving patient outcomes, to assess the implementation of the Children's Cancer Service Network in Scotland. The following examples have already been put forward to centres by the Childhood Cancer and Leukaemia Group Clinical Governance committees as part of a number of measures to assess outcomes:</p> <ul style="list-style-type: none"> • Randomisation rates in phase III trials by centre; • Time to opening of studies by centre. 	2009

5.	Consideration should be given to clinical posts being appointed by the Network with a defined hospital base to support the delivery of shared care and maximise available expertise.	2009
6.	The information gathered during the option appraisal relating to the treatment of young people age 16-18 should be the basis to review current practice against national guidelines and outcomes.	2009/10
Regional / Local		
7.	Support for the development of, and commitment to the network identifying named Paediatricians / Nurses in District General Hospitals to provide shared care where the number of new diagnoses of children with cancer are 10 or more per year (in line with NICE). This number will need to be flexible to accommodate the more remote and rural DGHs. To date, Ayrshire and Forth Valley have identified they would like to provide shared care.	2008/09
8.	Health Boards to review arrangements for 'on call' in the children's hospitals and take steps to ensure the service for children with cancer is meeting European Working Time Regulations in all the children's hospitals appropriate to the level of care being adopted.	2008

Conclusion

This set of recommendations allows the service to move forward and develop using the concept of a permissive network in a way that is sustainable and takes account of national guidance.

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
Level 1	<ul style="list-style-type: none"> • Initial contact • Diagnostic suspicion • Palliative/Terminal care • Emergency care 	<ul style="list-style-type: none"> • Initial contact • Diagnostic suspicion • Palliative/Terminal care • Emergency care • OP chemotherapy 	<p style="color: blue;">Agreed in principle, but remove O/P chemotherapy. This to be negotiated on individual child basis in remote areas.</p>
Level 2 (level 1 care +)	<ul style="list-style-type: none"> • Management of the ill/septic child • Blood product support • Outpatient Chemotherapy • Psycho–social care 	<ul style="list-style-type: none"> • Management of the ill/septic child • Blood product support • Outpatient Chemotherapy • Psycho–social care • Day case Chemotherapy 	<p style="color: blue;">Agreed in principle, but acknowledged that protocols for day case chemotherapy would be developed through the MCN.</p>
Level 3 (levels 1 and 2 +)	<ul style="list-style-type: none"> • Day case chemotherapy (infusion) • Intrathecal chemotherapy • Imaging (follow up) • Late effects follow up with Endocrinologist 	<ul style="list-style-type: none"> • Day case chemotherapy (infusion) • Intrathecal chemotherapy • Imaging (follow up) • Late effects follow up with Endocrinologist • In patient 24hr Chemotherapy excluding administration of high dose Methotrexate • Excludes diagnosis and initiation of treatment * (see note on page 7) 	<p style="color: blue;">Agreed in principle</p> <p style="color: blue;">* (see note on page 7)</p>
Level 4 (Tertiary)	<ul style="list-style-type: none"> • Diagnosis, staging and management • Paediatric Neuro Oncology • Bone Marrow Transplantation • Phase I/II studies • Academic base/research • Training 	<ul style="list-style-type: none"> • Diagnosis, staging and management • Paediatric Neuro Oncology • Bone Marrow Transplantation • Phase I/II studies • Academic base/research • Training 	<p style="color: blue;">Agreed in principle and add 'Management of Relapsed disease'</p>

* For some children with more common cancers, for example acute lymphoblastic leukaemia diagnosis, would probably still take place in Aberdeen. However, there are many types for childhood cancer, some extremely rare, and it is proposed more complex cases would be referred to a larger centre initially, but return to Aberdeen for treatment. This to be formally agreed by the Managed Clinical Network which will clarify treatment pathways.