

# Review of Paediatric Oncology and Malignant Haematology Services in Scotland

A report commissioned by the Child Health Support Group as part of the  
Review of Specialist Paediatric Services

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## SUMMARY OF CONCLUSIONS AND RECOMMENDATIONS

1. The paediatric oncology and malignant haematology service in Scotland delivers a high quality, responsive service to children and young people with three centres in Aberdeen, Edinburgh and Glasgow participating in the United Kingdom Children's Cancer Study Group. With a range of other units participating in formal clinical links to the three units for example Dundee, Dumfries and Inverness.
2. With the advent of increasingly complex regimes of care and improved survival rates and the increasing number of children and young people with cancer has meant that the activity in these units has increased significantly over the past 20 years. Also with this move towards more complex and often intensive treatment has led to generating significant resource demands from increased admissions and sicker children who need more supportive care (report page 4).
3. Also the impact of national and European (SIOP) drug protocols results in over 95% of patients being involved in strictly controlled trials. The changing protocols are the chief driver for service resource utilisation and costs yet are effectively out with local control. Protocols are subject to economic evaluation yet this does not always identify full costs in practice, especially for support services (report page 4).
4. The full costs of these increases should be fully evaluated and discussed at NHS Board and Regional Planning level to ensure the costs are fully funded to ensure the future provision of services (report pages 7-20).
5. Currently the centres in Aberdeen, Edinburgh and Glasgow deliver what is described as tertiary centre provision, and shared care in Dundee, with varying levels of resources including staff and support from other clinical networks within the hospitals they are situated (report pages 7-20).
6. There is evidence of good communication links between the services and referral patterns that would indicate that the basis for a managed clinical network is already in place. However for this arrangement to develop into a formal MCN further support would be required from existing planning and management networks (report pages 7-20).
7. The level of service provided out with these units has varied in the past due to the geographical location, resource constraints and clinical interest in providing children's cancer services in local areas for example services in Dumfries and Inverness (report page 21-26).
8. With the advent of the new consultant's contract, European Working Time Directive and agenda for change it will no longer be possible to deliver care as it is currently structured around three tertiary centres in Scotland (report pages 30-31).
9. The service is currently under severe pressure and is expected to start experiencing difficulties in the next 12 months. This is based on the assumption that existing consultants remain in post for that period of time (report pages 21-26).
10. 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 numbers of consultants without significant redesign, additional staff and reconfiguration of services (report pages 21-26).
11. There are indications that other support services are facing workforce pressures and will be required to be considered in any development of models of care or option appraisal that is likely to take place for example paediatric pathology, radiology etc (report pages 21-26).

12. The provision of social work services is variable throughout the country and some assessment of future need should be made (report pages 21-26).

## **Recommendations**

13. Support is given to develop a Managed Care Network, models for delivery of care and the potential options for reconfiguration of services for paediatric oncology and malignant haematology patients in Scotland.

14. The Scottish Cancer Group, National Services Division, the Regional Planning Groups, and NHS Boards as a matter of urgency consider the implications of this report and take steps to ensure the future sustainability of paediatric cancer services for Scotland.

15. Each of the options identified on pages 30-31 should undergo a full option appraisal which should include the clinical benefits, ease of access, work force planning considerations and economic feasibility to consider their viability and sustainability over the short to medium term.

16. Any future option appraisal of the service should include benign haematological services as there is significant cross linkage in terms of staff and other resources used to treat paediatric oncology and malignant haematology services.

17. The provision of a high quality service to children and young people in Scotland is dependant on strong clinical networks at a local and national level provided by a multi disciplinary professional team. The multi professional nature of the team must be recognised and there is a need for an in depth workforce analysis on all disciplines providing support and care.

18. As clinical trials are developed by SIOF and UKCCSG discussion should take place with local NHS planning systems in Scotland to ensure they are properly resourced and fully implemented.

19. The impact of the late effects guidelines will mean an increase in outpatient workload, development of nurse specialist roles and more collaboration with adult services. Regional cancer networks in liaison with the three UKCCSG Centres in Scotland should review current practice against these guidelines as the number of long term survivors will increase steadily

20. If a formal Scottish MCN is developed for paediatric oncology and haematology a quality framework should be agreed with NHS QIS that takes account of the NICE standards development program.

21. Any model of service delivery that is agreed should set out the appropriate levels of care that will be provided in each unit in Scotland and determine what should be provided in shared care facilities in Scotland.

## INTRODUCTION

22. There has been an increase in the number of children developing cancer with 108 children per million in 1975-1979 to 132 per million in 1995-1999. However the prospects for children have changed dramatically with the ten year survival rate improving from 50% (1975-1979) to 76% (1995-1999)<sup>1</sup>. The reasons for this success are: -

- national consistency of treatment approaches and protocols through the United Kingdom (UKCCSG)
- high proportion of paediatric patients being treated in clinical trials
- Increasing intensity and duration of treatment regimes have also evolved from what was commonly for one year to a much more intensive three years<sup>2</sup>.

23. This has also led to a major increase in the number of children receiving treatment at any one time. Further more, children whose disease recurs are now almost all aggressively treated, where previously treatment may have been palliative. These developments have led to a major increase in the activity of units providing care for these patients.

24. The specific needs of children and young people have received increasing emphasis in recent years and various models of care have developed in a historical context that takes account of local geography in Scotland. Whilst outreach and shared care services operate in some areas this has not been possible or appropriate in others, due to resource considerations or identified need.

25. The increasing demands being placed on Paediatric Oncology and Malignant Haematology Services (POMHS) mirrors those of other tertiary specialist paediatric services in Scotland and requires review. The demands on the service is further contributed to by the need for continuous improvement in access and quality of health care, sustaining low volume highly specialised services and the impact of European working time legislation and changes in medical training. These service pressures also have to be seen in the context of a number of initiatives being progressed in relation to cancer services for children including the development of increasingly intensive treatment, new drug regimes and protocols and the development of specific standards for oncology services for children and young people by NICE and the European Directive on Clinical Trials.

26. The issues impacting on specialist paediatric tertiary services in Scotland mirror those facing adult acute services; however the impact is greater because low volume, highly specialised services are provided by limited numbers of staff. The need for a review of specialist paediatric services in Scotland is recognised as being a key element in ensuring the future provision of high quality care for children in the 21<sup>st</sup> century.

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<sup>1</sup> Childhood Cancer in Scotland, Information Services Division, NHS Scotland, 2004

<sup>2</sup> Quest for Cure, UK Children's Cancer Study Group-The First 25 Years, UKCCSG, 2002

## BACKGROUND TO THE REVIEW

27. The Specialist Paediatric Sub Group of the Child Health Support Group identified the need to review specialist paediatric services in Scotland after a range of issues were identified by service providers, NHS Boards and the Scottish Executive Health Department. Following further discussion with key participants, including representatives from the Scottish Paediatric Haematology and Oncology Group an NHS HDL was issued to establish the review on a formal basis.

28. Although many of the issues highlighted in this report have been recognised for some length of time, the advent of the new consultants' contract, impact of the EWTD and Agenda for Change has made the situation more acute in relation to the future sustainability of services.

29. Accreditation of all UKCCSG centres is taking place and the development of new protocols and initiatives involves the UKCCSG in line with the NICE recommendations. Accreditation of both tertiary level and shared care centres is under way in England with NICE currently developing standards for the provision of POMH services.

30. Since 1977 when the UKCCSG was created there has been a progressive trend of increased survival for children treated in these centres, showing particular benefit compared with those treated elsewhere. The Group introduces approximately 10 new or revised protocols each year. There is a clear move to more complex and often intensive treatment, generating significant resource demands from increased admissions and sicker children who need more supportive care. Also the impact of national and European (SIOP) drug protocols results in over 95% of patients being involved in strictly controlled trials. The changing protocols are the chief driver for service resource utilisation and costs yet are effectively out with local control. Protocols are subject to economic evaluation yet this does not always fit costs in practice. Clear need for a mechanism of "horizon scanning" to anticipate and evaluate future changes, and development of a regional or national funding mechanism is required.

31. The overall approach to this review of POMH services was summarised in Scottish Executive Health Department guidance<sup>3</sup> (see Annex 1) and covers the following areas:-

- Definition and scope
- Incidence and prevalence of conditions under consideration
- Mapping current services
- Review of current practice
- Workforce planning and training
- Quality standards/Outcome indicators
- Review of education and information
- Identify current research
- Implications for stakeholders
- Possible options for service delivery

32. This report draws on the issues described earlier in this section, desk research, key informant interviews and group work with practitioners involved in providing care.

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<sup>3</sup> Scottish Executive Health Department, Review of Specialist Paediatric Services, NHS HDL (2003) 43, September 2003

## DEFINITION AND SCOPE

33. The review covers services for children and young people presenting with cancer and malignant disease including leukaemia and related conditions using the International Classification of Childhood Cancer (ICCC) including the following diagnostic groups: -

- Leukaemia
- Lymphomas and reticuloendothelial neoplasms
- CNS and miscellaneous intracranial and intraspinal neoplasms
- Sympathetic nervous system tumours
- Retinoblastomas
- Renal tumours
- Hepatic tumours
- Soft tissue sarcomas
- Germ cell, trophoblastic and other gonadal neoplasms
- Carcinomas and other malignant epithelial neoplasms
- Other and unspecified malignant neoplasms

34. The CHSG has adopted the age range 0 to 18, for this exercise, but acknowledges that units participating in this process operate a flexible approach based on the circumstances of each case and services provided.

35. The NHS in Scotland aims to provide services that: -

- Provide a clinically effective and quality service to children suffering from cancer
- Maximise clinical outcomes for patients
- Reduce clinical risk to patients
- Develop a service to meet changing demands
- Provide a workforce that is skilled, competent and appropriately staffed
- Minimise cost pressure to services within the NHS
- Develop training and education for all staff
- Develop research and development

36. The main elements of this review are expected to include:-

- A review of current services and a look at its strengths and weaknesses
- Identify issues impacting on the future sustainability of services
- Make recommendations to ensure the future sustainability of provision.

37. The services included in this report are based in Aberdeen, Edinburgh, and Glasgow which are designated by the United Kingdom Children's Cancer Study Group as specialist children's cancer centres<sup>4</sup> and Dundee which provides services based on a recognised shared care model. Services in other NHS Board areas reflect a mixture of outreach and shared care in Dumfries, Inverness and Kirkcaldy, with most of the other NHS Boards areas operating in reach to the UKCCSG centres and some community based care.

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<sup>4</sup> Quest for Cure, UK Children's Cancer Study Group- The First 25 Years, Sue Ablett, 2002



## INCIDENCE AND PREVALENCE

38. The recently published report *Childhood Cancer in Scotland*<sup>5</sup> gave an incidence of around 120 children diagnosed each year in Scotland with cancer, which accounts for less than 1% of the total neoplasms diagnosed for all age groups. Overall, boys have a higher age-standardised incidence rate than girls (132 per million for boys compared to 107 million for girls) and a higher mortality rate (46 per million for boys as opposed to 36 per million for girls). This translates into a cumulative risk of a 1 in 444 for boys and 1 in 594 for girls. There are almost 40 deaths from childhood cancer in Scotland per year. Two thirds of childhood cancer deaths were due to leukaemia or CNS tumours, with leukaemia accounting for the highest number of deaths for boys and CNS tumours in girls.

39. In boys, over 67% of cancers are represented by the three most common cancer diagnosis, Leukaemia's (34%), CNS and miscellaneous intracranial and intraspinal neoplasms (21%), and lymphomas and reticuloendothelial neoplasms (13 %). For girls the two most common cancers are Leukaemia (34%) and CNS tumours (24%). In addition to gender variation there are also differences between the age groups, with sympathetic nervous system tumours (SNS), Leukaemia and retinoblastoma commonest amongst infants up to one year old. The age group one to four years is dominated by leukaemia and CNS tumours. In the five to nine year age group, leukaemia, CNS tumours and lymphoma accounts for around 75% of malignancies in boys and leukaemia and CNS tumours for 65% of all malignancies in girls.

40. Over the period 1975-1999, the age and sex standardised incidence rate of childhood cancer increased significantly from 108 per million children in 1975-1979 to 132 per million children in 1995-1999. The increase was seen in most ICCG groupings and is statistically significant for soft tissue tumours, carcinomas, germ cell and hepatic tumours. Over the same period mortality rates decreased significantly from 53 per million children in 1975-1979 to 28 per million children in 1995-99.

41. Children living in the least deprived areas have higher incidence of childhood cancer compared to those living in the most deprived. In contrast to many adult cancers the mortality is higher for children living in the least deprived areas of Scotland as opposed to those living in the most deprived.

42. Detailed information on specific cancers and their outcomes is contained in the comprehensive report "Childhood Cancer in Scotland, Trends in incidence, mortality and survival 1975-1999".

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<sup>5</sup> *Childhood Cancer in Scotland, Trends in incidence, mortality and survival, 1975-1999*, Campbell et al, Information Services Division, NHS Scotland, 2004

## **CURRENT SERVICE PROVISION**

43. These service descriptions have been provided by each of the units involved in the review with more detailed information on work force issues contained in the following section.

### **Royal Aberdeen Children's Hospital**

44. There are approximately 14-16 new cancer patients registered per year, 4-5 with leukaemia or lymphoma, 3-4 brain tumours and the rest a mixture of childhood cancers.

45. The service at Royal Aberdeen Children's Hospital (RACH) is recognised by the UKCCSG for the provision of paediatric oncology and malignant haematology services and participates in the UK wide network of 22 centres.

46. The service has a clinical lead, Dr King who is trained as an adult haematologist and who has had a sub-speciality/interest in paediatric haematology and oncology for 17 years. Approximately fifty per cent of his time is dedicated to laboratory services and the remaining 50% to paediatric oncology and haematology (as with most NHS consultants this adds up to more than 1 WTE). He is essentially working single handed in dealing with benign and malignant haematology and solid tumours in children. While there is some cover from adult NHS colleagues concerns about Clinical Governance have led to the need to appoint a Locum to cover periods of leave.

47. There is a full in-patient service mainly utilising the medical ward, but there is also access to surgical wards when required. There is HDU provision on site but there is no PICU with backup provided from the network in Edinburgh or Glasgow as appropriate. The RACH is on the Foresterhill site along with the Aberdeen Royal Infirmary, Aberdeen Maternity Hospital and the University Medical School. This unique site gives the paediatric service access to full laboratory services including a paediatric pathologist, radiology services including CT, MRI and PET scanning and nuclear medicine investigations, and radiotherapy. The new RACH has a direct link corridor to allow access to these services.

48. There is a full out-patient facility, but no outreach clinics, due to the small number of patients, all of whom have different diagnosis and are at different stages of treatment. All out-patients are held in the Children's Hospital. There is a Joint-Oncology-Neurology-Endocrinology Follow-up Clinic with Dr. Mayo and Dr. Shah. As children get older they move on to a Late Effects Clinic run at Aberdeen Royal Infirmary by Dr. King, Dr Bevan (Endocrinologist) and Dr. Hurman (Radiotherapist).

49. There is one CLIC funded paediatric oncology outreach nurse attached to the RACH service. Her remit spans secondary and primary care with a major role in liaison with primary care and schools, and support of the patients and their families at home. This extends to involvement in palliative care. There is one Diana Nurse attached to RACH, but she does not deal in malignancy care.

50. The Sargent Cancer Fund for Children social worker resigned from her part time post in June 2002. There was a period when Sargent reviewed the services and no funding was available resulting in a major deficit in service provision.

Recently they have agreed to fund a part time post but no one has been appointed as yet. A list of team members are included in table 1.

**Table 1 Paediatric Oncology Team**

<b>Paediatric Oncology Team -RACH</b>		<b>WTE</b>
Dr King	Consultant Haematologist with an interest in oncology	0.5
	There is one CLIC funded post attached to the unit	1.0
	Paediatric Dietician	0.5
	Sargent SW agreed to part time funding (currently vacant)	
	Paediatric Pharmacist plus input from Chemotherapy CIVA service Provides chemotherapy dispensing at clinic and ward based chemotherapy service	0.5
WARD nursing staff	There are fully trained paediatric nurses in the wards in Aberdeen Children's Hospital with 2 G and 7 E grades who have undertaken a chemotherapy training course.	9.0
Other Staff involved	<ul style="list-style-type: none"> <li>• In the laboratory and investigational facilities within other parts of the site.</li> <li>• Routine x-ray and ultrasound service is provided by Paediatric Radiologists at RACH but CT, MRI and Nuclear imaging is available at ARI.</li> <li>• A full radiotherapy service is provided by adult based clinicians with Dr. Hurman providing the paediatric component of the service</li> <li>• A comprehensive paediatric surgery service delivered by 3 consultants (2 in post at the present time), led by Professor Youngson and Mr Driver.</li> <li>• A full adult neurosurgery service (3 consultants) led by Mr Currie, who has an interest in paediatric neurosurgery.</li> <li>• Anaesthesia is delivered by 6 paediatric anaesthetic consultants, with a full service.</li> <li>• There is a full paediatric medical service and sub-speciality interest delivered by a number of consultants within Aberdeen. <ul style="list-style-type: none"> <li>○ Cardiology – Dr Booth</li> <li>○ Respiratory – Dr Brooker, Dr Turner and Professor Helms</li> <li>○ Neurology – Dr Shah as part of the neurology network</li> <li>○ Endocrine/Diabetes – Dr Mayo</li> <li>○ Gastro Intestinal – Dr Bissett and Dr Mahdi</li> <li>○ Renal-Dr Auchterlonie</li> </ul> </li> </ul>	
Facilities we do not have	◆ PICU but do have access to HDU	

## **Cancer management**

51. The centre is part of the UKCCSG network with complex and explicit protocols, support and advice. The centre is part of the informal Scotland network (SPOG) with good support from and referral to Edinburgh and Glasgow. The majority of patients are managed within the UKCCSG Trials and Studies or MRC Leukaemia Trials. This is time consuming from the data management point of view as is the obtaining of appropriate informed consent. Good Clinical Practice for Clinical Trials will add significantly to this work.

52. The majority of patients with malignant haematological disorders are diagnosed and treated in Aberdeen but those requiring allogeneic bone marrow transplant are referred to Glasgow.

53. The majority of children with solid tumours are diagnosed and managed in Aberdeen. Certain children with brain tumours may be referred to Edinburgh for initial management depending on the complexity of surgery and potential need for PICU care. Children with bone tumours are jointly managed with either the Royal Orthopaedic Hospital at Stanmore or Edinburgh for endo prosthetic replacement of resected tumours. Children with retinoblastoma are managed jointly with either the Royal London Hospital or the Birmingham Children's Hospital. If it is thought a child may require PICU care at the time of the diagnosis they would be electively transferred for diagnosis and initial treatment to Edinburgh or Glasgow then return to Aberdeen for ongoing care.

### **Specific Issues for Future Service Provision**

54. The service in Aberdeen has secured funding for a General Consultant Paediatrician with an interest in oncology to attempt to sustain the future of the centre. However an appointment has still to be made with two failed attempts.

55. There is little mention of paediatric cancer services in the NOSCAN report with the cancer planning process focussing on the provision of adult services. Unless this is addressed the future sustainability of services may be compromised.

56. The dependency for funding posts through the voluntary sector has raised questions about the future sustainability of services such as specialist nurses and social work although CLIC is maintaining one post and the Sargent Cancer Fund for Children has agreed funding for a part-time post.

57. With a single handed specialty cover for sickness, study leave and holidays is provided by locum cover, staff in the RACH and support from other centres. This will have to be reviewed in relation to the new consultants' contract and EWTD.

58. However, dismantling the service would have a significant knock-on effect upon other specialist services delivered to children, such as anaesthesia, radiology, radiotherapy, chemotherapy, neurosurgery and general surgery. There would be a real concern about losing skills and competencies within this hospital to deal with children with cancer, and in future attracting a consultant dealing with cancer services would be difficult, as this would be an unattractive post.

## **Dundee Shared Care Cancer Service**

59. There are approximately 10-12 new cases per year on average, with 38 children on treatment in 2001-2002 and 154 being off treatment<sup>6</sup> but still having active follow up. Because of the small numbers variation between years can make a large difference for example we diagnosed 22 new cases from Jan 2002-Dec 2002

60. Dr Wilkie along with the rest of the oncology team provides the co-ordination and day to day delivery of the Paediatric oncology service in Tayside. This is designated a shared care centre primarily with Edinburgh, but with network links to Glasgow and Aberdeen. There are explicit protocols, criteria and guidelines for treatment involving the following:

- Management of new patient with Suspected Leukaemia or solid tumour
- Management of Febrile Neutropenia
- Blood product guidelines
- Guidelines for use of central lines
- Tumour specific protocols (UKCCSG)
- Safe administration of Intrathecal drugs, part of TUHT training programme
- Incorporates written teaching programmes for nursing staff and medical staff at all levels of experience.

61. The current staff team involved in the provision of care for this group are included in table 2

62. All children presenting in Tayside with solid non CNS tumours are referred to RHSC Edinburgh for initial investigations and staging. Their plan of treatment is co-ordinated from RHSC although some of their chemotherapy is delivered in Ninewells. Chemotherapy delivered tends to be day case chemotherapy although in the past few years more complex chemotherapy has been delivered for some children. The delivery of chemotherapy ratio RHSC: Ninewells is 70:30. Changes in staffing and working hours will have an impact on this almost certainly restricting chemotherapy to day case or outpatient regimes in Dundee. Supportive care for these patients in terms of management of febrile neutropenia, parenteral nutrition, enteral nutritive support, haemopoietic factor support, and blood and platelet transfusion is normally provided in Ninewells. Follow up of these patients is based predominantly in Ninewells. This includes coordination of follow up investigations and other supportive care

63. The majority of children with primary CNS tumours are primarily dealt with in Ninewells utilising the expertise of Neurosurgery (Mr Ballantyne) and Paediatric Neurology (Dr Kirkpatrick & Dr Jollands). Initial assessment and surgery are generally carried out in Ninewells with referral to RHSC for multidisciplinary discussion at PNOG group and for treatment decisions regarding irradiation therapy and chemotherapy. Follow up investigations and supportive care is largely carried out in Ninewells by the Paediatric Oncology team. There is unlikely to be a change in this delivery unless there is a decision to have a one site Scottish option for Paediatric Neurosurgery.

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<sup>6</sup> CLIC Nurse Report, Tayside, December 2001- 2002, January 2003

64. For Acute Lymphoblastic Leukaemia all high risk cases, including infant ALL, are referred to Dr Thomas in RHSCE for diagnosis and induction. Standard risk ALL, including induction, have until now, been cared for mainly in Ninewells by Dr Wilkie and team. In light of new protocols and other external factors including the EWTD, MRD and Ethical Committee approval, this policy will have to be reviewed. Intrathecal drugs are usually delivered in Ninewells (NW). High intensity chemotherapy is delivered in RHSCE with out patient and day case chemotherapy being delivered in NW. The majority of care for ALL patients including most supportive care is delivered in NW. However with AML, almost all of the care is provided in RHSC with follow up and occasional supportive care being given as required. Shared care with Edinburgh reflects the high intensity of chemotherapy used and need for higher levels of supportive care delivered by a team of consultants who have experience of paediatric haematology /oncology.

65. Autologous Bone Marrow Transplants are carried out in RHSC Edinburgh with supportive care after first 6-8 weeks in NW. Allogeneic transplants are carried out in Yorkhill with supportive care in NW. Usually patients do not return to Dundee for shared care for 3-6 months after transplant and long term follow up tends to be in Yorkhill.

**Table 2. Paediatric Oncology Team -Ninewells**

<b>Paediatric Oncology Team –Ninewells</b>		<b>WTE</b>
Dr Wilkie	Consultant General Paediatrician with an interest in Paediatric Oncology and Haematology	0.5
Dr Peebles	Associate Specialist in Paediatrics with an interest in Haematology/Oncology	0.6
G Steel K McIntyre	Paediatric Oncology Liaison nurses	1.5
H Grossi	Paediatric Dietician	0.2
F McGillvray	Sargent SW	0.2
J Richards	Paediatric Pharmacist plus input from Chemotherapy CIVA service Provides chemotherapy dispensing at clinic and ward based chemotherapy service	0.5
WARD nursing staff	Oncology children nurse by a single team of nurses who also have General paediatric remit. Able to encourage and support chemotherapy and central line training. Not able to ensure chemotherapy nurse an/or central line trained nurse on each shift	6.0
Other Staff involved	<ul style="list-style-type: none"> <li>◆ Mr Ballantyne Neurosurgeon</li> <li>◆ Dr Kirkpatrick Paediatric Neurologist</li> <li>◆ Dr Greene Paediatric Endocrinologist</li> <li>◆ Mr Manson Paediatric Surgeon – joint contract with RHSCE</li> <li>◆ Consultant Haematologists ( 6 WTE) in Ninewells who provide laboratory back up</li> <li>◆ Dr Main Consultant Radiologist( interest in Paediatric)</li> <li>◆ Paediatric Anaesthetists x6 on rota</li> </ul>	
Facilities we do not have	<ul style="list-style-type: none"> <li>◆ 24 hour per day access to Paediatric Surgeons</li> <li>◆ PICU but do have facility to support intensive care in adult ITU prior to transfer</li> </ul>	

66. Palliative & Terminal care is also delivered for children in Tayside by the above team. This is family-centred and uses hospital and hospice care where appropriate but aiming to support families in their own homes. Patient management may require ongoing chemotherapy or intermittent radiotherapy which will involve patients travelling to RHSC. We rely largely on building a good relationship with primary care team and provide support and training to GPs and District nurses as well as an ongoing coordination of care for the child and family at home. 3-4 children require terminal care in Tayside per year.

67. Arrangements to ensure good quality shared care are managed through:

- A less formal Scottish Paediatric Cancer network for education called Scottish Paediatric Haematology and Oncology Group. Tayside group attend meetings regularly
- Dr Wilkie attends a haematology clinic monthly in RHSCE and Tumour board meeting and Paediatric Neuro oncology group meetings (each happen 2 monthly)
- Dr Wilkie, Dr Peebles, Registrars and Oncology nurses attend educational afternoon in RHSCE approximately 2 monthly each.

68. These joint educational and service meetings are essential to make the best use of the shared care model which is operating in this context as a managed clinical network. This allows the highest quality of care for patients as close to the patients home as possible whilst minimising travel and time away from home.

### **Specific Issues for Future Service Provision**

69. Cost pressures from voluntary sector where In Tayside there was a 0.6 WTE Sargent Fund SW post plus 0.4 WTE admin support. This has been reduced to 0.2 WTE in total in last year. There is a 0.5 WTE liaison nursing post funded by CLIC. This funding runs out in one year and is unlikely to be replaced. Both of these have had and will have an impact on the level of home and hospital care we can provide locally.

70. The European Working Time Directive and New Deal are having an ongoing impact including the following:

- New deal means there is substantially less continuity of care provided by junior staff. They have less experience and out of hours care needs to be provided more and more by Oncology team.
- EWTD means Trusts are looking at excessive consultant work loads. Provision of an oncology out of hour's service will not be possible in the future here as provided at the moment with Dr Wilkie being available except when on holiday.
- Consideration will need to be given to reduction of overall provision in Ninewells. Probably all new patients going to RHSC. This would require 3-4 children having additional care in RHSC per year.

### **Royal Hospital for Sick Children, Edinburgh (RHSCE)**

71. There are approximately 54 new cases referred to RHSCE (61 cases in 2002 and 64 in 2003) per year with just over half (54%) of these patients coming from the Lothian area. The remaining patients come mainly from Tayside and Fife accounting for 36%. Table 3 gives proportions of patients on treatment by Health Board of origin at census dates over the past three years.

**Table 3. Patients treated at RHSCE by NHS Board of Residence**

	<b>Lothian</b>	<b>Fife</b>	<b>Tayside</b>	<b>Borders</b>	<b>Lanark</b>	<b>Forth</b>	<b>Highland</b>	<b>Other</b>	<b>Total</b>
Oct-03	57.4%	24.1%	56%	7.4%	1.9%	0.0%	3.7%	0.0%	100.0%
Apr-03	51.1%	29.8%	10.6%	4.3%	2.1%	0.0%	2.1%	0.0%	100.0%
Apr-02	47.4%	35.1%	3.5%	5.3%	1.8%	3.5%	1.8%	1.8%	100.0%
Apr-01	52.5%	35.0%	0.0%	5.0%	0.0%	2.5%	5.0%	0.0%	100.0%
<b>Average</b>	<b>52.1%</b>	<b>31.0%</b>	<b>4.9%</b>	<b>5.5%</b>	<b>1.4%</b>	<b>1.5%</b>	<b>3.1%</b>	<b>0.4%</b>	<b>100.0%</b>
<b>Max</b>	<b>57.4%</b>	<b>35.1%</b>	<b>10.6%</b>	<b>7.4%</b>	<b>2.1%</b>	<b>3.5%</b>	<b>5.0%</b>	<b>1.8%</b>	
<b>Min</b>	<b>47.4%</b>	<b>24.1%</b>	<b>0.0%</b>	<b>4.3%</b>	<b>0.0%</b>	<b>0.0%</b>	<b>1.8%</b>	<b>0.0%</b>	

72. Of these children and young people 90% are in the 0 to 14 years age group and the remaining 10% being over 15 years. At that time a decision is made on the basis of the welfare of the patient before transferring them to the adult service.

73. At present 95% of children seen at RHSCE are treated on peer reviewed UKCCSG treatment protocols. Many are entered into two or three trials, including supportive care research at the same time. Some of these children remain on active treatment protocols for two to three years increasing the active treatment workload to 100 children per year.

74. RHSCE operates as a tertiary centre under the protocols established by the UKCCSG. The clinical service is currently provided by two clinical oncologists, one appointed through funding by SCAN in 2002 and one consultant haematologist. There is on site access to specialist services for Paediatric Intensive Care, neurosurgery, bone marrow transplantation and bone/sarcoma surgery. Patients have to be transferred to the Western General Hospital (In Edinburgh) for radiotherapy, liver transplants to Birmingham, shared care with Birmingham for retinoblastoma and some patients to Glasgow for bone marrow transplantation. (Allogeneic transplants and Matched unrelated donor transplants to Glasgow and Autologous transplants stay in Edinburgh) MIBG therapy is carried out at the Beatson Cancer Centre in Glasgow. For the type and numbers of staff see table 4



**Table 4 Paediatric Oncology Team RHSC - Edinburgh**

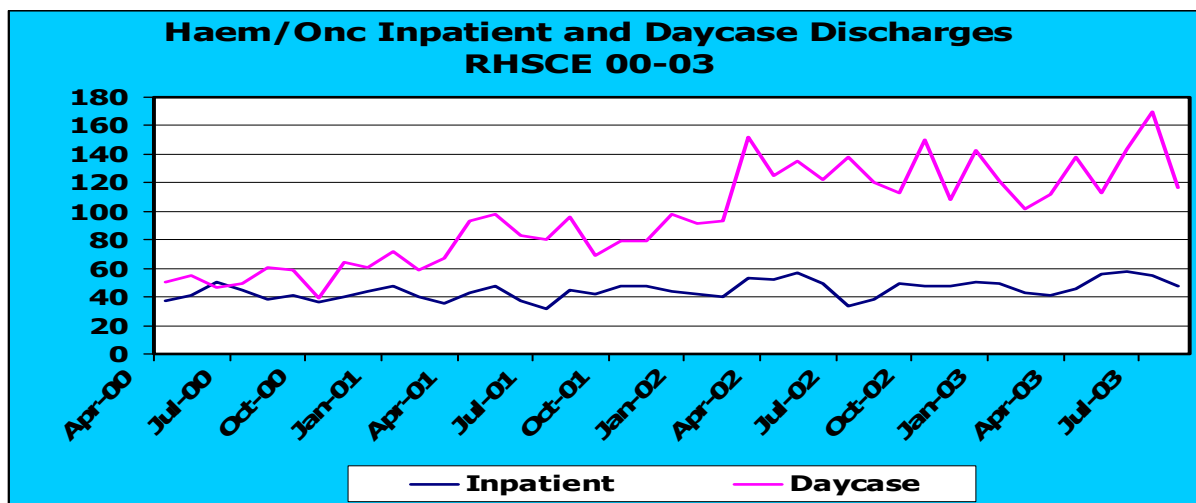
<b>Paediatric Oncology Team – RHSCE</b>		<b>WTE</b>
Consultant Staff	Clinical service is currently provided by two clinical oncologists, one appointed through funding by SCAN in 2002 and one consultant haematologist.	3
Medical Staff		
Ward and Day care nursing staff	Staff provide care to both orthopaedic and oncology patients in the Ward led by a G grade Ward Sister. They also provide day care provision and outpatients	33.75
Community based staff	two Paediatric Oncology Outreach Nurses funded by CLIC and a Macmillan funded nurse post specifically for the 13 – 24 age group	3
Pharmacy	Provided from pharmacy team	N/A
Psychology	Provided from the psychology team	0.3
Social work	Provided in the hospital	1.5
Education		N/A
Other Staff involved	Provided by teams within the RHSCE	N/A

75. A total of 33.75 WTE nursing staff are employed in the cancer team with 25 WTE trained staff in the Ward led by a G grade Ward Sister. There are also two Paediatric Oncology Outreach Nurses funded by CLIC and a Macmillan funded nurse post specifically for the 13 – 24 age group. CLIC provides a home from home for parents and other children with the potential to accommodate 8 families in family bedrooms. There is access to the following specialist services on site: -

- Pharmacy
- Occupational therapy
- Physiotherapy
- Rehabilitation
- Pain management
- Psychology
- Nutrition
- Oral health
- Specialist Endocrinology Services
- Fertility Counselling
- Fertility preservation
- Social work
- Paediatric Oncology Outreach
- Non-Directive Play Therapy
- Dedicated theatre session
- Data manager

76. The integrated service comprises a dedicated Outpatient facility, Outreach nursing team and inpatient and day care services on Ward 4. This is a mixed speciality ward with 8 inpatient Haem/Onc beds, 4 haem/onc day care beds and 8 beds for elective orthopaedics. The day care service has expanded dramatically over the past 3 years, helping to stabilise inpatient activity against a background of increasing treatment intensity (see Figure 1):

Figure 1. Inpatient and Day case Discharges RHSCE 00-03



77. There is an increase in the outreach workload with the new ALL 2003 protocol predominately being delivered on an outpatient / day care basis. An increase in MIBG therapy and lack of local paediatric community nurse support in some areas has contributed to this growth. Both oncologists do outpatient clinics in Dundee.

78. The increasing complexity of chemotherapy and stringent clinical governance requirements, particularly with regard to preparation and administration of cytotoxic chemotherapy (HDL 2001(13)), has increased both drug acquisition costs and the demand on pharmacy time and facilities. The Chemocare pharmacy system is currently being implemented to aid management of chemotherapy protocols and prescribing. Demand on dietetics, laboratories and other support services has also increased markedly. Enteral feeding is now frequently required with the referral rate rising by 300% in the last year.

### Specific Issues for Future Service Provision

79. Issues were raised in relation to the work force requirements to deal with the junior doctors 'New Deal', new consultants' contract and European Working Time Directive with the middle grade rota currently not being compliant.

80. Increase in treatment intensity resulting from changes to national UKCCSG treatment protocols, leading to increased resource demand, escalating costs and increased clinical risk. Anticipation and management of the impact of the new protocols is a major issue. Work is underway to develop a system to horizon scan and evaluate new developments.

81. Establishing a commitment to Managed Clinical Networks in cancer as the preferred method of delivering high quality, clinically effective care

82. The pivotal place of Pharmaceutical care in minimising the risk of cancer chemotherapy and ensuring the effective coordination of care. Effective capacity planning in pharmaceutical services is crucial.

83. Recruitment and retention of specialist nursing staff: The effective management of risk means that the service is increasingly reliant on highly trained nurses to deliver cytotoxic chemotherapy and care for high dependency patients. We need to maximise the contribution of nurses to service design, delivery and evaluation. However, it is proving increasingly difficult to recruit experienced staff and takes 6 months to train an E grade nurse to administer chemotherapy. Investment in the training, education, support and development of the nurse workforce is a critical factor.

84. Talks with the Teenage Cancer Trust are ongoing for the provision of a designated Teenage and Young People unit within Edinburgh, as lack of provision of dedicated facilities for adolescents is seen as being a major issue. A business plan will shortly be put before Lothian NHS Board

85. The potential to develop a new children's hospital linked to adult provision in Edinburgh on the New Royal Infirmary site is seen as being a suitable way forward.

## **Royal Hospital for Sick Children, Glasgow**

86. There are approximately 80-90 new cases of childhood malignancy referred to the Royal Hospital for Sick Children, Glasgow per annum. Patients are referred mainly from Health Boards in the West of Scotland ranging from Highlands & Islands in the North to Dumfries & Galloway in the South. More than 50% of patients come from out with Greater Glasgow Health Board. A significant number of patients are referred from all over Scotland for specialist treatment. 80% of patients are in the 0 – 14 year age group. Patients are accepted up to their 17<sup>th</sup> birthday, although a number continue to be treated or followed-up beyond this age

87. Many children with ALL remain on active treatment protocols for 2 – 3 years after diagnosis and this translates to an active treatment workload of 150 children per year (based on 4 years, 2000 – 2003). At least 90% of children are treated on peer-reviewed MRC or UKCCSG treatment protocols.

88. Patients are treated in a recently refurbished (1996) dedicated 22-bedded unit which consists of 16 cubicles with parent-folding beds, 2 x 2-bedded rooms with parent folding beds and 2 laminar air-flow rooms for bone-marrow transplantation. There is an en-suite pharmacy suite within the Unit which is staffed separately to the main hospital pharmacy. There is a playroom, adolescent room and a parent facility of 3 bedrooms, sitting room, kitchen and shower room. Alternative parent accommodation is provided in CLIC flats for 5 families (within 5 minutes walk of the hospital). An adjacent day-care facility provides a 4-bedded day ward with 4 treatment rooms and dedicated nursing staff separate to the ward compliment. A summary of the staffing complement is listed in table 5.

**Table 5 Paediatric Oncology Team – RHSC Glasgow**

<b>Paediatric Oncology Team RHSC Glasgow</b>		<b>WTE</b>
Consultant Staff	The Unit has a Consultant compliment of 3 consultant paediatric haematologists and 2 consultant paediatric oncologists with funding available for a 6 <sup>th</sup> post	5 1 Vac
Medical Staff	At present there is SPR training in paediatric haematology and a trainee in paediatric oncology will hopefully be appointed later this year. There are 2 full-time equivalent staff grades covering both the ward and the day-care unit. There are 2 SPRs and 4 SHO 3s/clinical fellows	11
Ward nursing staff	There are 2 WTE G grades plus 1 G-grade nurse educator plus 5 WTE F grades, 23 WTE E grades, 9 WTE D grades within the ward	40
Day care nursing staff	There is 1 WTE G grade, 1.47 WTE F grade, 2.72 WTE E grade, 1 WTE I grade and 1 WTE H grade within the day-care section.	7
Community based staff	3 Paediatric Outreach Oncology Nurses	3
Pharmacy	There are 4 WTE pharmacists & 2.5 WTE pharmacy technicians	6.5
Psychology	0.4 whole-time psychologist	0.4
Social work	2.5 WTE social workers and 1 WTE social work assistant.	3.5
Education	1 teacher, 2 play therapists	

89. The Unit is accredited by the JCHMT for higher specialist training in paediatric oncology and haematology. At present there is SPR training in paediatric haematology and a trainee in paediatric oncology will hopefully be appointed later this year. There are 2 full-time equivalent staff grades covering both the ward and the day-care unit. There are 2 SPRs and 4 SHO 3s/clinical fellows. Junior medical staff work exclusively in the haematology/oncology Unit and there is dedicated out-of hours cover.

90. Nursing staff have an extended role providing phlebotomy, cannulation and chemotherapy services. Outreach nurses provide a community-based service in addition to palliative and terminal care. There is a hospital pain team which provides advice and support.

91. A full range of services are provided on site based on the criteria used by the UKCCSG. There is access to:

- Diagnostic radiology including CT and MRI
- Specialist pharmacy
- Paediatric Pathology
- Occupational Therapy
- Physiotherapy
- Rehabilitation
- Pain management
- Psychology
- Nutrition
- Oral Health
- Specialist Endocrinology services
- Fertility counselling and preservation
- Play specialist
- Social work
- Teachers
- Data management

92. There is a dedicated theatre session for bone-marrow aspirates and lumbar punctures. There is access to neurosurgery on site, but patients are sent to the Institute of Neurological Sciences at the Southern General Hospital for specialist neurosurgery. Bone-sarcoma surgery is carried out on site by a dedicated orthopaedic surgeon. All paediatric surgeons insert Hickman Lines/Portacaths, but 2 have a special interest in malignancy. All allogeneic bone-marrow transplants in Scotland are performed within the Unit. Radiotherapy is available at the nearby Beatson Institute. There is access to paediatric anaesthesia, intensive care and a high-dependency unit. Patients are transferred for liver and retinoblastoma surgery to Birmingham Children's Hospital.

93. There are outreach clinics in Inverness and Dumfries and a shared care arrangement with Ninewells in Dundee.

94. Support for parents and families are provided through a Sibling Support Group, Parent Group discussion and relaxation, away residential weekends for teenagers and a newsletter.

95. CLIC fund a nurse, a play specialist and provides accommodation for parents and siblings in Cruachan House in Glasgow. Also the voluntary sector through McMillan and Sargent Fund provides a range of services.

96. The Bone-Marrow Transplant Unit will be refurbished in 2004 to provide improved facilities which will include laminar flow, increased natural light, en-suite facilities, a family/play area and consultation/out-patient unit. The cost of refurbishment is being met by £500,000 grant from NOF with the remainder being provided by the Trust and departmental funds. In addition, agreement has been reached with the Teenage Cancer Trust for a development of a teenage facility. This will be 6-bedded and have both inpatient and outpatient facilities. The Teenage Cancer Trust will provide in the region of £500,000 and fundraising will provide the remainder.

### **Specific Issues for Future Service Provision**

97. The Unit at present has 22 beds and refurbishment of the Bone Marrow Transplant Unit and Teenage Cancer Trust Unit will increase the number of beds by a compliment of 3. However, bed-borrowing remains a problem and frequently runs at 20-25%. With appropriate funding office space within the Day-care Unit could be relocated and refurbished to provide more in-patient facilities.

98. The European Directive on working hours has significantly impacted on the ability to maintain a dedicated middle grade rota, although this continues at present. Middle-grade staff are absent the day after on-call and this impacts on continuity of care and reduces the number of middle-grade staff during working day hours. At present, Consultant cover ward patients on a 1:5 rota, laboratory haematology on a 1:3 rota and bone-marrow transplantation on a 1:2 rota. The new Consultant contract, with its dedication to on-call, will limit the daytime Consultant sessions available.

99. The Consultant Contract and the European Directive on working hours will negatively impact on staffing levels. The extent to which the new Consultant Contract will impact is as yet unclear. There is funding for a 6<sup>th</sup> Consultant post. Ideally the Unit would prefer to ring-fence this funding for an Academic appointment in the hope that this would improve its profile and attract experienced middle-grade staff. The good candidate might also bring with him/her funding for clinical fellow posts, which might have some input to the middle-grade rota and ease its pressure. The Leukaemia Research Fund would view the appointment of an Academic Haematologist favourably and, whilst this individual is unlikely to contribute to the day-to-day work of the Unit, might make some contribution to the on-call.

100. Retention and recruitment in all disciplines has proved difficult. At present the nursing compliment is full, but there is a rapid turnover and training and bringing new members of staff up to an appropriate level of competency is a challenge. There/

has been an expansion in the number of Consultant Haematology and Oncology posts advertised and inadequate numbers in training. Even with funding, it may be difficult to recruit appropriately trained and experienced staff.

101. At present there are 0.4 whole-time equivalent psychology sessions. There is potential charitable funding for further psychology session, but such individuals have proved difficult to recruit. It has also proved difficult to recruit appropriately experienced pharmacists.

102. Further developments including a refurbished bone-marrow transplant unit and Teenage Cancer Trust Unit will increase the demands on staffing and, if operated as semi-independent units, will require independent staffing.

103. Bed-borrowing is unsatisfactory as these children are nursed in general wards by personnel who lack the appropriate experience. Efforts should be made to increase the number of beds within the Unit and end this practice.

## WORKFORCE PLANNING AND TRAINING

104. The main issues that effect the workforce development, recruitment and retention of staff and the future sustainability of NHS services in Scotland have their greatest effect on small volume, highly specialised services such as oncology and malignant haematology. There are a number of reports which have been produced in Scotland that highlight these issues including: -

- The Recruitment, Training and Retention of Medical Laboratory Scientific Officers, Scottish Medical and Scientific Advisory Committee, May 2001
- Facing the Future, Scottish Executive Health Department, November 2001
- Future Practice, Proposals of an Advisory Group Commissioned by the Scottish Executive to Review the Scottish Medical Workforce, Professor John Temple, July 2002
- A Scottish Executive Review of Speech and Language Therapy, Physiotherapy and Occupational Therapy for Children and Speech and Language Therapy for Adults with Learning Disabilities and Autistic Spectrum Disorder, Scottish Executive Health Department, September 2003

105. These documents highlighted the work force pressures faced by groups of staff in the NHS and made recommendations on how these issues should be addressed. Professor John Temple in "Future Practice" highlighted ten key messages some which pertain particularly to specialist paediatric services, including:-

- The core issue is the delivery of a 24-hour acute care service for primary and secondary care
- We need more doctors to support a specialist delivered service.
- Scotland should be organised around larger regional health economies than exist at present.
- Team delivered care is an overarching theme.
- Travel, time increases clinical risk for emergency care, but so can lack of capacity, critical mass or experience in a small unit.
- We need the right incentives to recruit the doctors we require and to retain enough of those we already have.

106. The impact of European working time legislation has already been felt in relation to junior medical staff. Its effect on consultant grades will become apparent from 2005 to 2008. This also needs to be seen in the context of clinical governance and the development of specific quality standards for services.

107. The impact of Agenda for Change has still to be assessed for a range of staff including nursing. However it could provide the opportunity, along with the development of the nurse consultant role to provide a range of services to this group of patients.

108. The service is currently provided in three tertiary centres, as designated by the United Kingdom Children's Cancer Study Group; in Aberdeen, Edinburgh and Glasgow. There are three shared care centres in Dundee, who mainly liaise with Edinburgh, and Dumfries and Inverness, who mainly liaise with Glasgow. Other services are either provided to NHS Board areas on an out reach basis or by patients travelling to one of the tertiary centres.



109. Workforce data is not routinely provided for the provision of these services. Therefore the data shown in the tables below is based on information provided by the participating units themselves during the production of this report.

### **Medical Staff**

110. There are 19 Whole Time Equivalent medical staff providing the oncology and malignant haematology services in the three designated tertiary centres in Scotland. This equates to three whole time equivalent paediatric consultant oncologists in post, two in Edinburgh and one with one vacancy to be filled later this month, in Glasgow. There are also 4.5 WTE consultant haematologists, three in Glasgow and one in Edinburgh and 0.5 WTE in Aberdeen also providing an oncology service. The remainder of the services at consultant level are provided by general paediatricians on a shared care basis in Dundee, Dumfries, Kirkcaldy and Inverness (see Table 6).

**Table 1 Staff Group – Medical**

LOCATION	CENTRE TYPE (Tertiary Link)	STAFF GROUP- MEDICAL							
		Onc	Haem	General Paed	Ass Spec	Clin Fell	Staff Grades	SPR	SHO
Glasgow	Tertiary	2 <sup>7</sup>	3		2	3	2	2	4
Grampian	Tertiary	0	0.5						
Lothian	Tertiary	2	1				1	2	1
Tayside	Shared Care (LOTH)	N/A	N/A	0.5	0.6				
D&G	? Out reach/shared care (GLAS)	N/A	N/A	1 sess	N/A	N/A	N/A	N/A	N/A
Fife	?Out reach/shared care (LOTH)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Highland	?Shared Care (GLAS)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A

Source locally provided data October 2003

111. The marked difference between this service and workforce figures for adult services is the relatively low number of junior to consultant ratio. 'Future Practice' highlights the issue of junior medical staff providing the bulk of services for some specialties, but this is certainly not the case for paediatric oncology and malignant haematology. The relatively low number of senior specialist registrars, associate specialists and staff grades raise particular issues in ensuring a steady stream of appropriately trained staff to form the consultant work force of the future.

112. The service also uses clinical networking as a key feature of the service with strong links between the different tertiary units and shared care centres. There are links with other specialist services within hospitals with general paediatric staff and

<sup>7</sup> In the process of being filled March 2004

other specialist clinicians providing support. However the existing informal network is largely provided with out some of the key elements and supporting infrastructure described in Scottish Executive guidance on the provision of Managed Clinical Networks<sup>8</sup>.

## **Nursing Staff**

113. The inpatient unit in Glasgow is a dedicated paediatric oncology and haematology ward staffed by a combination of general paediatric qualified nurses and nurses with specialist training in oncology and haematology who deliver chemotherapy, palliative care etc. The inpatient unit in Edinburgh is shared with orthopaedics and is staffed by a mixture of specially trained paediatric oncology and haematology nurses and general paediatric nursing staff. In Aberdeen there are three dedicated beds within a general medical ward which are staffed by general paediatric nurses including two G and seven E grades with chemotherapy and other specialist training (see table 7).

**Table 7. Inpatient Nursing Staff by Grade and by Unit**

	<b>Nurse Grade</b>	<b>H</b>	<b>G</b>	<b>F</b>	<b>E</b>	<b>D</b>	<b>C</b>	<b>B</b>	<b>A</b>
<b>NHS Area</b>	<b>Total</b>								
Glasgow	46.72		2	5.22	21.94	9			8.56
Grampian <sup>9</sup>	29.4 <sup>10</sup>		2		7				
Lothian	33.5 <sup>11</sup>	1	1	2	17	6		4	2.5
Tayside	N/A	N/A	N/A	N/A	6	N/A	N/A	N/A	N/A
D&G	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Highland	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A

Source: Locally provided data by each unit October 2003

114. Both Aberdeen and Glasgow have dedicated nursing staff providing day care and outreach services, whilst ward staff provide day care services in Edinburgh led by a designated Day Care Sister (see Table 8). Dundee, Kirkcaldy, Dumfries and Inverness provide outpatient facilities and in some cases outpatient chemotherapy and inpatient treatment of febrile neutropenia.

<sup>8</sup> Promoting the development of Managed Clinical Guidelines in NHS Scotland, Scottish Executive Health Department, NHS HDL (2002) 69

<sup>9</sup> Staff are General Paediatric with 2G Grades and 7E Grades having undertaken a chemotherapy training course

<sup>10</sup> The nursing staff are not dedicated to oncology only and form part of a general paediatric ward complement

<sup>11</sup> The nursing staff are not dedicated to oncology only and form part of an oncology/orthopaedic combined ward complement

**Table 8. Nursing Staff WTE Day Care/Outpatients by Grade**

	Nurse Grade	I	H	G	F	E	D	C	B	A
NHS Area										
Glasgow		1	1	1	1.47	2.72				
Grampian				1		1	3.85			2.4
Lothian		Provided by Inpatient Nursing Staff								

Source: Locally provided data October 2003

115. A range of community based and palliative care services are provided by number of different specialist staff and community based paediatric nursing teams in different locations in Scotland (see table 9). A significant number of these posts are funded by non NHS sources or on short term funding streams such as the Diana Nursing Initiative.

116. A number of requests have been made to the three centres in Scotland to provide further shared care, out reach or community based services in other Health Board areas. Increasing use of specially trained nurses has gone some way to relieve existing pressures in the system and develop services to meet increasing demand for locally delivered chemotherapy, pain relief and palliative care services. These nurse led initiatives could be expanded to provide services in other areas. An approach that is also being developed for adult services through the Cancer Regional Planning Networks

117. However, the advent of the new consultants' contract and the implementation of European Working Time Legislation will place additional strain on already overstretched services. Further detailed work should be undertaken to review the role of nursing to see how it could be better utilised in line with the development of the "nurse consultant" and "nurse practitioner" role.

### **Social Work**

118. This service is essential for the delivery of a holistic approach to these patients and their families. Social work provision has been reduced in Dundee from 0.6 WTE SW post and 0.4 WTE admin support to 0.2 WTE in total, now being provided. In Aberdeen the Sargent Cancer Fund for Children, social worker, resigned from her part time post in June 2002. There was then a period during which Sargent reviewed the services and no funding was available resulting in a major deficit in service provision. Recently Sargent have agreed to fund a part time post but no one has been appointed as yet. While in Edinburgh there is 1.5 WTE social work input into the service funded through the Sargent Fund. In Glasgow there is one WTE social worker, one part time social worker and one WTE social work assistant, jointly funded by the Glasgow Council and the Sargent Fund. The provision of social work services is variable throughout the country and some assessment of current and future need is required.

**Table 9. Staff Group Nursing –Community Based by NHS Board**

<b>Location</b>	<b>Centre Type</b>	<b>Community</b>	<b>Palliative</b>
Glasgow	Tertiary	POON <sup>12</sup> x 3	REACT Nurse <sup>13</sup>
Grampian	Tertiary	CLIC Nurse <sup>14</sup>	
Lothian	Tertiary	POON <sup>15</sup> x2(CLIC) Adolescent CNS	PCCN <sup>16</sup>
Tayside	Shared Care	PONS <sup>17</sup> x1.5	PONS
A&A		CCNS/T <sup>18</sup>	
A&G		CCNS/T	
Borders		CCNS/T	
D&G	Shared Care	CCNS/T	
Fife		CCNS/T	CCNS/T
Forth Valley		CCNS/T	
Highland	Shared Care	CCNS/T	
Lanarkshire		CCNS/T	
Orkney	N/A		
Shetland	N/A		
Western Isles	N/A		

Source: SEHD Community Nursing Directory 1992

### **Clinical Psychology**

119. In Aberdeen and Dundee there is no direct access to clinical psychology whereas in Edinburgh there is access to 0.3 WTE and in Glasgow to 0.4 WTE psychologists. All centres would welcome further psychology input and some assessment of need is required.

### **Other Professional Support**

120. The provision of a high quality service to children and young people in Scotland is dependant on strong clinical networks at both local and national level provided by a multi disciplinary professional team. The multi-professional nature of the team must be recognised and there is a need for an in depth workforce analysis on all disciplines providing support and care.

<sup>12</sup>POON = Paediatric Oncology Outreach Nurses providing cover for the West of Scotland

<sup>13</sup>REACT

<sup>14</sup>CLIC = Cancer Leukaemia in Children

<sup>15</sup>OON = Oncology Outreach Nurse

<sup>16</sup>PCCN = Palliative Care Community Nurse

<sup>17</sup>PONS = Paediatric Oncology Nurse Specialist

<sup>18</sup>CCNS/T = Community Nursing Children's Service/Team

## **Specific Issues for Future Service Provision**

121. An immediate review needs to be initiated to assess the impact of the new consultant's contract and the introduction of European Working Time Legislation. This must include the future training and education requirements to guarantee the workforce for the future

122. Further development of the extended role of nursing, doctors and other professional groups in relation to the provision of services in both inpatient and outreach settings should be assessed.

123. An in-depth workforce planning exercise needs to be undertaken in conjunction with the development of the preferred future model of service delivery that includes the key staff groups and links to other clinical networks both local and national.

## QUALITY STANDARDS/OUTCOME INDICATORS

124. In Scotland the overall approach to quality assurance is being developed by Quality Improvement Scotland, by activity co-ordinated through the Regional Cancer Planning Networks and the Scottish Executive Performance Assessment Framework which has a specific waiting time target for children receiving treatment within one month of diagnosis. This is monitored quarterly & consistently achieved by all the units in Scotland.

125. For over 25 years the United Kingdom Children's Cancer Study Group (UKCCSG) has been involved in developing a UK approach to improve the quality services through the following functions: -

- To develop and run high quality trials.
- Education and communication
- Development of training programmes for doctors entering the speciality
- The development of clinical guidelines for the entire range of children's cancers.

126. The UKCCSG centres are also involved in a development process, led by NICE who are currently reviewing the provision of paediatric oncology and malignant haematology services on a UK wide basis. This is the initial step in developing service standards which NICE intend to launch in February 2005. This review will cover all aspects of service delivery including specialist input from other support services as well as direct patient care. Quality Improvement Scotland will consider the implications for the service north of the border during 2004-05.

127. There are 22 centres in the UK designated by the UKCCSG with Aberdeen, Edinburgh and Glasgow currently holding this status in Scotland. During 1977 to 1981 only 54% of children were initially referred to a UKCCSG centre but by 1995-98 this figure had risen to 86%. Similarly, in 1977-81 the care of children with brain tumours was mainly organised through neurological and radiotherapy units with only a third of patients being seen at UKCCSG Centres; however by 1995 to 1998 this figure had risen to 80%.

128. The UKCCSG also has links with the International Paediatric Oncology Society (SIOP) and operates clinical trials on a UK and international basis. The UKCCSG introduced a code of conduct for clinical trials in 1999 which is now in its third edition. Clinical trials are divided into three phases: -

129. New agents or novel formulations of established drugs are first tested in what are known as Phase 1 trials. The primary aim of 'Phase 1' Trials is to find the maximum tolerated dose that can be safely administered, and these studies usually involve a small number of patients. Once a safe dose of drug has been established, this can then be taken into a 'Phase 2' Trial.

130. In 'Phase 2' Trials, the aim is to look at tumour response in a range of tumours, usually in children with recurrent disease. If the results are encouraging the drug is taken forward to 'Phase 3'. This involves the drug being taken forward to a large and often randomised study comparing its effects with other well established treatments.

131. Approximately 90%-95% of patients in the three Scottish centres are on recognised drug protocols from the UKCCSG for both the common and some of the rarer cancers.

132. The UKCCSG has a number of groups looking at key areas of developmental interest including a New Agents Group and a Late Effects Committee. Guidelines were produced by the UKCCSG for the follow up and treatment of long term survivors in 1995. There are a number of side-effects of the interventions in cancer treatment and these include hormone deficiencies and learning difficulties; the latter most often due to cranial radiotherapy. Infertility and cardiomyopathy are other significant problems. In about 4% of children secondary cancers can develop. More recently A set of guidelines<sup>19</sup> have produced by SIGN on the “Long term follow up of survivors of childhood cancer’ which covers the following areas: -

- Assessment and achievement of normal growth
- Achievement of normal progression through puberty and factors affecting fertility
- Assessment of thyroid function
- Early identification, assessment and treatment of cardiac abnormalities
- Assessment and achievement of optimum neurodevelopment and psychological health.

### **Specific Issues for Future Service Provision**

133. As clinical trials are developed by SIOP and UKCCSG discussion should take place with local NHS planning systems in Scotland to ensure they are properly resourced and fully implemented.

134. The impact of the Late Effects guidelines will mean an increase in outpatient workload, development of nurse specialist roles and more collaboration with adult services. Regional cancer networks in liaison with the three UKCCSG Centres in Scotland should review current practice against these guidelines as the number of long term survivors will increase steadily

135. If a formal Scottish MCN is developed for paediatric oncology and haematology a quality framework should be agreed with NHS QIS that takes account of the NICE standards development program.

136. Any model of service delivery that is agreed should set out the appropriate levels of care will be provided in each unit in Scotland and determine what should be provided in shared care facilities for example the four level model of shared care developed by Birmingham’s Children’s Hospital

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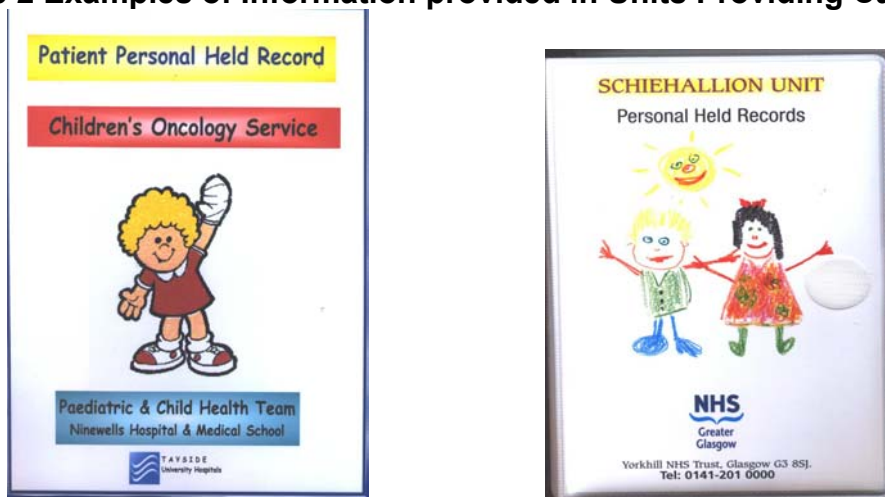
<sup>19</sup> Long term follow up of survivors of childhood cancer, A national clinical guideline, Scottish Intercollegiate Guidelines Network, 2004

## REVIEW OF PATIENT EDUCATION AND INFORMATION

137. The units participating in this review process provide a range of information and support to children and families who come in to contact with their services. This includes specifically produced Personal Held Records (see fig. 2) that contain information on: -

- Personal information
- Patient Care
- Mouth care
- Healthy eating
- Chemotherapy
- Play
- What happens in the ward, theatre, at home and in clinics
- What other support and information is available is available from the voluntary sector etc

**Figure 2 Examples of Information provided in Units Providing Care**



138. This information is supplemented by support from staff and more focussed specialist advice and training on dealing with specific issues such as subcutaneous injections of heparin, naso-gastric feeding, long line dressing etc.

139. The Units also provide or participate in a range of initiatives such as support groups and targeted activities for siblings, adolescents and bereavement counselling.

140. Many of these activities are supported by national voluntary sector organisations such as Cancer & Leukaemia In Children, Sargent Cancer Care for Children and local groups for example Tayside Children with Cancer or Leukaemia.

141. This section provides a brief snapshot of the very important activity that is undertaken in this field and the very specialist information that is provided by the units and voluntary organisations that support patients and their families. The units can be contacted for a fuller description of what specific information they provide.



## IDENTIFY CURRENT RESEARCH

142. Over 90% for children are entered into clinical trials based on SIOP and UKCCSG guidelines which follow protocols agreed at a UK level. All of the units involved in this review are directly involved in these trials including Aberdeen and Dundee. There are also a number of specific Cancer Tumour boards in operation or in the process of being established. As well as these strictly controlled trials the Units are involved in number of research projects a some examples of recent work are provided below:

### RHSCE:

- Virtual Centre for Research for survivors of childhood cancer
- Cryopreservation unit for freezing gonadal tissue
- Male fertility after childhood cancer.
- Apo E and cognitive ability after childhood cancer
- Studies of male reproductive function and testis morphology after treatment of childhood cancer.
- Studies of male reproductive function and testis morphology after treatment of childhood cancer.

### RHSCG:

- MRD – one of the five UK laboratories providing a service fro measuring Minimal Residual Disease in MRC ALL2003 for all of Scotland, Newcastle and Ireland (RHSCG).
- BPSU study on thrombosis in childhood.
- MRV study of line-related thrombosis.
- Several pharmaceutical studies related to coagulation factors and antifungal therapy.
- Epidemiological studies – various.

## POSSIBLE OPTIONS FOR SERVICE DELIVERY

143. A number of options for the future provision of paediatric oncology and malignant haematology services have identified by participants in this review. The service, as configured in the past and the fact that there are relatively small numbers of patients requiring highly specialised treatment requires a fresh approach. There is a real risk that because of these small numbers of patients, children's cancer, will continue to be overshadowed by the adult cancer agenda. There are two routes that could be explored further for the planning of services in the future:-

- Reviewing the role of the regional planning networks for cancer to make them more sensitive to the needs of low volume highly specialised services.
- Exploring the feasibility of a nationally commissioned service through the Scottish Cancer Group and National Services Division.

144. As well as the planning, commissioning and configuration issues that have been identified, a number of key themes have emerged during this process including: -

- Development of a formal national Managed Clinical Network involving the three UKCCSG centres and services provided in other NHS Board areas.
- The provision of shared care services, including outreach where appropriate.
- Implementation of training and education models to develop an appropriately experienced workforce that meets future service requirements.
- Dedicated inpatient provision, with access to a range of diagnostic and treatment facilities appropriate to the level of care to be provided

145. The advent of the European Working Time Directive has already had an impact on the numbers of staff available for junior doctor rotas. This problem will be amplified when the Directive is rolled out to include consultant grades and the need to provide cover specialist units. Nurses and other staff are and will become even more crucial in maintaining services by enhancing their roles through the provision of more complex tasks.

146. However it is unlikely, even with these changes, that the current provision of services will be sustainable in the future. Alternative roles for staff and different configurations for inpatient, shared care and outreach models of delivery will have to be considered. Potential options for service reconfiguration that have been put forward during this review have included the following; -

- The current model which includes three inpatient facilities in Aberdeen, Edinburgh and Glasgow, with shared care in Dundee, outreach provision with some shared care in Dumfries, Kirkcaldy, and Inverness and in reach from areas of Scotland to the UKCCSG centres.

- An extended outreach/shared care model which includes three inpatient facilities in Aberdeen, Edinburgh and Glasgow, with shared care in Dundee, and outreach provision with some shared care in other NHS Board areas for example, Ayrshire and Arran, Dumfries and Galloway, Fife, Forth Valley, Highland, Dumfries and Galloway and Lanarkshire.
- Two inpatient facilities in Edinburgh and Glasgow providing oncology and haematology services with shared care in Aberdeen, Dundee and a mixture of outreach clinics with some shared care in other NHS Board areas for example, Ayrshire and Arran, Dumfries and Galloway, Fife, Forth Valley, Highland, Dumfries and Galloway and Lanarkshire.
- The consideration of a two site option with one site providing haematology services and the other providing oncology with shared care in Aberdeen, Dundee and a mixture of outreach clinics with some shared care in other NHS Board areas for example, Ayrshire and Arran, Dumfries and Galloway, Fife, Forth Valley, Highland, Dumfries and Galloway and Lanarkshire.
- One Inpatient facility, with shared care in either Edinburgh or Glasgow, Aberdeen, Dundee and mixture of outreach clinics with some shared care in other NHS Board areas for example, Ayrshire and Arran, Dumfries and Galloway, Fife, Forth Valley, Highland, Dumfries and Galloway and Lanarkshire

147. Each of these options would have to go through an option appraisal which should include the clinical benefits, ease of access, work force planning considerations and economic feasibility to consider their viability and sustainability over the short to medium term.



## SCOTTISH EXECUTIVE

Health Department  
Directorate of Service Policy and Planning

Dear Colleague

### Review of Specialist Paediatric Services

#### Summary

This letter outlines arrangements for a Scotland-wide review of specialist paediatric services to support development of regional planning in Scotland, led by the Child Health Support Group. It describes:

- the background to the review
- the methodology
- proposed timescales and outputs

#### **Background**

The Minister for Health and Community Care established the Child Health Support Group (CHSG) in 2000 to harness professional expertise in driving forward improvements in child health and in the quality of child health services across Scotland. A review of Specialist Paediatric Services is included in the Group's current work plan (see HDL 86/2002)<sup>20</sup>. This was based on recognition of the need to take a strategic approach to the planning and development of specialist services in the light of key policy and service imperatives including:

- the issues that arose from the Bristol Royal Infirmary<sup>21</sup> paediatric cardiac surgery inquiry
- the drive towards continuous improvement in access and quality of health care
- the need to reduce waiting times
- sustaining low volume highly specialised services in Scotland
- the impact on the workforce of European working time legislation and changes in medical training
- the need to ensure appropriate training and development opportunities for staff

<sup>20</sup> Scottish Executive, Health Department, Child Health Support Group, NHS HDL (2002) 86, 28<sup>th</sup> November 2002

<sup>21</sup> Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary, January 2002

Women and Children's Unit  
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26 September 2003

#### **Addresses**

##### For action

Regional Planning Group Chairs  
NHS Board Chief Executives

##### For information

Chief Executives, NHS Trusts  
Directors of Public Health  
Directors of Finance  
Nursing Directors, NHS Boards  
Directors of Planning  
Medical Directors NHS Trusts  
Nursing Directors NHS Trusts  
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These issues are not exclusive to specialist paediatric services. However the comparatively small numbers of both patients and professional staff providing these services, coupled with demographic change and geographical considerations, present some specific challenges for sustaining these services.

The CHSG has established a working group, chaired by George Youngson, Professor of Paediatric Surgery, which has agreed the methodology for the review in consultation with Regional Planning Groups, specialist clinicians and Child Health Commissioners (For membership of the Working Group see Annex 1).

### **The Methodology**

There are some twenty medical paediatric specialities in Scotland centred in one of the four tertiary centres, in Edinburgh, Glasgow, Aberdeen and Dundee, with local secondary care in acute services in general NHS hospitals. Each speciality might benefit from review and many have strong links with others. However the review proposes to pilot the methodology with one speciality in the first instance - paediatric oncology and haematology. Thereafter the method will be applied in up to four other specialities including: gastroenterology and neurology. If this method proves fruitful, subsequent speciality reviews may be carried out, as necessary, by Regional Planning Groups.

The Working Group has prepared a template on which the review will be based. This sets out ten areas for data collection (Annex 2). The Group will work with existing clinical and service networks to gather this information and use this to inform discussion of the options for future development of these networks based on a Managed Clinical Network approach. The Group wishes to adopt a consistent approach to the review that is also flexible enough to take account of the individual characteristics of each speciality. The ten areas include:

- Definition and scope (define and detail those aspects of service to be provided)
- Incidence and prevalence of conditions under consideration
- Mapping current services
- Review of current practice
- Workforce planning and training
- Quality standards/Outcome indicators
- Review of education and information
- Identify current research
- Implications for stakeholders
- Possible options for service delivery

The reviews are expected to identify practical solutions in ensuring the future sustainability of the services under consideration.

### **Proposed Approach**

The initial pilot review of oncology and haematology is expected to report in November 2003. The preliminary findings will inform the remaining pilot areas. The CHSG will convene a conference in Spring 2004 to allow key stakeholders in these five specialities and the regional planning groups to consider the overall approach and the outputs from the review process, with a view to identifying preferred options for development in these areas

of service. Thereafter the lessons learned in reviewing these can be applied to other specialities.

**Action Required**

Regional Planning Group Chairs and NHS Board Chief Executives are asked to draw the content of this letter to the attention of all staff with responsibility for and interest in the provision of specialist paediatric services in their area.

Yours sincerely

**IAN GORDON**

**Director of Service Policy and Planning**

*Annex 1*

**Membership of Child Health Support Group- Specialist Paediatric Services Sub Group**

George Youngson	CHSG member, Chairman
Jim Beattie	Scottish Committee, Royal College of Paediatrics & Child Health
Linda de Caestecker	Lead Child Health Commissioner, NHS Greater Glasgow - representing West of Scotland Regional Planning Group
Morgan Jamieson	Medical Director, Yorkhill NHS Trust - representing West of Scotland Regional Planning Group
Lorraine Currie	Lead Child Health Commissioner, NHS Grampian - representing North of Scotland Regional Planning Group
Deirdre Evans	Director, National Services Division
Hilary Davison	NHS Quality Improvement Scotland
Jackie Hyland	Lead Child Health Commissioner, NHS Fife
Gwen Garner	Action for Sick Children Scotland
Annie Ingram	North Regional Planning Group Co-ordinator
Jackie Sansbury	South East & Tayside Regional Planning Group
Caroline Selkirk	Lead Child Health Commissioner, NHS Tayside - representing South East & Tayside Regional Planning Group
Isabel McCallum	Director of Nursing , Lothian University Hospitals NHS Trust
Irene McKune	Deputy Director of Nursing, Yorkhill Hospital NHS Trust

**SEHD**

Ian Bashford	SEHD Senior Medical Officer
Jackie McRae	SEHD Women & Children's Unit
Robert Stevenson	Child Health Support Group Co-ordinator, SEHD Women & Children's Unit
Lindsey Wright	SEHD Women & Children's Unit

**SPECIALIST PAEDIATRIC SERVICES**

**PILOT REVIEW METHODOLOGY**



## 1. INTRODUCTION

1.1 A clear agenda for modernisation of specialist services is emerging in NHS Scotland. This is driven by the outcomes from the Report of the Inquiry into child deaths following cardiac surgery at Bristol Royal Infirmary<sup>22</sup>, workforce pressures linked to changes in European Working Time Legislation training arrangements for medical staff and the New Deal for Junior Doctors. . Alongside key objectives from the Scottish Executive including:

- Securing safe and sustainable services.
- Improving access to health care.
- Improving the quality of healthcare and in particular reducing waiting times.
- Empowering health professionals to improve services.
- Better integration of services, to smooth the patient pathway.

These issues make a strong case for review of specialist paediatric services.

1.2 The Child Health Support Group Specialist Paediatric Services Sub Group identified 10 areas that should be included in pilot work to review certain small volume paediatric specialities. This pilot work constitutes the second phase of the review process and the Sub-Group is providing the following guidelines to promote a common approach across the specialities involved in this phase of the exercise.

1.3 The specialities for the pilot phase (Annex A) have been identified through discussions with Clinicians, Regional Planning Group representatives, the CSHG and SEHD.

## 2. PILOT REVIEW PROCESS

2.1 The Child Health Support Group sub-group on Specialist Paediatric Services will work with existing clinical networks and fully engage with Regional Planning Groups to carry out pilot reviews, of key specialities based on the 10 key areas of activity listed below:

- Definition and scope (Define and detail those aspects of service to be provided)
- Incidence and prevalence of conditions under consideration
- Mapping current services
- Review of current practice
- Workforce planning and Training
- Quality Standards/Outcome indicators
- Review of education and information
- Identify current research
- Implications for stakeholders
- Possible options for service delivery

2.2 It is expected that the review should produce potential options for delivering improvements in specialist services based on a sound evidential approach.

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<sup>22</sup> Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary, January 2002

2.3 After the pilot phase has been completed the intention is to consider the outcomes from the exercise at a conference in spring 2004. The conference will focus on the lessons learned from the pilot reviews and the implications for applying the approach to other specialist paediatric services..

2.4 The CHSG Sub-Group will approach existing clinical networks or groups in each of the identified pilot specialities for information about the following aspects of need, demand and service provision in their area. The pilot review report will be expected to cover each of the following areas.

### **Definition and Scope**

2.5 Give a description of the speciality and conditions to be included in the review and major links with other services that may have an impact on the delivery of the speciality on a regional basis.

### **Incidence and Prevalence**

2.6 Incidence and prevalence of the most important conditions and problems managed by the speciality. What this means in terms of how many cases are seen at NHS Board, regional and national level

### **Mapping of Current Services**

2.7 The clinical networks should identify the distribution of clinicians involved in the present delivery of care, and in consultation with the different service providers review caseloads by area where possible, and document the challenges in sustaining the service at present.

2.8 The clinical networks, supported where necessary by the CHSG Sub-Group, should work with Information Services Division to identify the activity on children and young people aged 18 and under within their speciality. This may identify where need and demand appears most concentrated. Existing referral pathways and gaps in current service provision should also be described.

### **Review of Current Practice**

2.9 Colleges and clinical networks should help us identify the characteristics of the disease and its course, and treatment processes and outcomes. The review should also describe the extent of the current evidence base for treatment and existing protocols. Emphasis should be given to well-established quality standards of care.

### **Workforce Planning and Training**

2.10 The Scottish Executive Health Department is currently reviewing the workforce requirements needed to meet the demands of working time legislation. This provides a useful model to apply to data gathered for the speciality pilot reviews to help identify gaps that will be produced by compliance with the European working time directive.

2.11 The pilots should identify the necessary steps to consolidate succession planning. They should also identify the necessary education and training infrastructure.

### **Quality Standards/Outcome Indicators**

2.12 This area should describe any relevant standards impacting on the specialist area under review. These may include standards agreed with NHS QIS, SIGN guidelines, College guidelines and requirements and any policy objectives for the NHS for example in the Performance Assessment Framework<sup>23</sup>, waiting times, environmental standards accessibility etc. Where applicable the standards described in the National Service Framework<sup>24</sup> for England and Wales should be taken into account when considering service delivery.

2.13 The review should consider current arrangements for audit, the involvement of patients<sup>25</sup> and relevant voluntary sector organisations, and identify any shortfalls in these areas.

### **Education and Information**

2.14 Clinical networks should advise on what information and resources are available for education of patients and parents about the disease, the services and other forms of support available.

### **Current Research**

2.15 The role of academic institutions, links between services and clinical training and research should be assessed when considering options for future service delivery.

### **Involvement of Stakeholders**

2.16 Tertiary services, by their nature, depend on other specialities and secondary and primary care for care provision, and service redesign will affect the relationships between these service tiers. The pilots should be fully aware and able to describe the extent to which any reconfiguration of service will influence and will be influenced by other services.

2.17 The pilots should also ensure that patient and lay representation inclusion is achieved in their work.

### **Possible Options for Service Delivery**

2.18 The aim of the review process is to offer solutions to problems of sustainability in key specialties, if necessary by reconfiguration of existing services. The questions for consideration at this stage include:

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<sup>23</sup> Performance Assessment Framework: Self Assessment in Health Services for Children and Young People 2002-2003

<sup>24</sup> Getting the Right start: The National Service Framework for Children, Young People and Maternity Services-Standard for Hospital Services, Department of Health, April 2003

<sup>25</sup> Patient focus and Public Involvement, Scottish Executive Health Department, December 2001

### **NHS HDL (2003) 43**

- What services should be provided at a national, regional and local level and how should the service evolve to meet identified pressures?
- Which children and which conditions are likely to need direct involvement of a specialised service, and which should be managed according to agreed protocols and schemes of care?
- How should services be reorganised in order to simplify and smooth the care pathway?
- What role can clinical networks play to improve the integration of services, whether within NHS Boards, across a region or in the Scottish context?
- How should parents and users be consulted and involved in service redesign?
- What is needed to secure good transition from paediatric to adult services for teenage patients in each speciality?

**Annex A Medical Paediatric Specialities Identified for Review**

<b>Recent/Current Reviews</b>	<b>Suggested Pilot Areas</b>	<b>Remaining Areas</b>
Nephrology PICU and Anaesthesia Cardiology and Cardiac Surgery Pathology Neonatology Accident & Emergency*	Complex respiratory disease Endocrinology/diabetes Gastroenterology Neurology Oncology/Haematology	Radiology Clinical Genetics Dermatology Major Burns Immunology Infectious Diseases Rheumatology Neurodisability Metabolic diseases

\*Already committed to carrying out service rev