

National Delivery Plan

**for Children and Young People's
Specialist Services in Scotland**

Draft for Consultation

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Ministerial Foreword

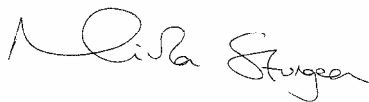


I would like to thank Malcolm Wright and the members of the National Steering Group for Specialist Children's Services in Scotland for carrying out the most comprehensive review of such services ever undertaken. I've been impressed by the level of commitment from those who have participated in this process, and all of those who provide care to some of the most vulnerable children and young people in Scotland.

The Scottish Government recognises this commitment, and the importance to our children of getting these services right. We will provide an extra £32 million over the next three years to support implementation of the National Delivery Plan. We are also supporting the development of new children's hospitals in Edinburgh and Glasgow, to complement what has already been achieved in Aberdeen and Dundee. All of this work will ensure that Scotland has one of the most modern networks of children's hospitals in Europe.

However, the National Delivery Plan also recognises that much specialist care is provided in the community linking in to District General Hospitals throughout the country. This model of care aims to provide the best possible care, as close to where people live, as possible.

This is our best opportunity in a generation to get the best services, and the best outcomes, for our children and young people. Please get involved, let us know what you think, and help us make sure we get it right.

A handwritten signature in black ink that reads "Nicola Sturgeon".

Nicola Sturgeon MSP

Deputy First Minister and Cabinet Secretary for Health and Wellbeing

Section 1 Introduction

Background

1. Specialist children's services¹ in Scotland, as elsewhere in the world, tend to be characterised by their complexity, low volume and dependence on small numbers of highly trained staff. Patterns of disease and treatment vary considerably from one specialty to another. As a result of this, a range of service models are required to address the needs of individual specialties.

2. Much valuable work has already been undertaken. Annex 1 documents the range of specialist activity that is now commissioned either as a national service within Scotland, or in some areas characterised by very low activity levels, from specialist centres elsewhere in the UK.

3. It is, however, recognised that there remains a significant range of individual services which continue to face real pressures in sustaining and delivering high quality clinical services and best outcomes for patients. There is also increasing recognition of the interdependence of key services and the consequent need to ensure that long term service planning is effectively co-ordinated across specialties.

4. In 2004, the Child Health Support Group (CHSG) conducted a review of specialist services in four pilot areas covering children's cancer, respiratory medicine, gastroenterology and neurology.

5. The resultant *Youngson Report* made specific recommendations on service provision, national planning, workforce issues and information technology development. A clear message from this exercise was that, for specialist services to be sustained and delivered across Scotland, there is a need for an effective pattern of clinical networks, with the shape and distribution of each network being specific to the specialty in question.

6. In 2005, the Specialist Paediatric Sub-group of the National Framework for Service Change (*Building a Health Service Fit for the Future*), recognised that the future planning of child health services should be underpinned by the following objectives:

- development of managed clinical networks at a regional and national level;
- redesign of services, using a four-level model of care that describes how services can be provided and organised at a local, district general hospital, regional and national level;
- provision of a specialist children's workforce that meets working time regulations and service requirements;

¹ *Building a Health Service Fit for the Future* included a more extensive description of such services and also supported the adoption of the definition of such services set out in the *Department of Health Specialised Services Definition Set No.23* (Specialised Services for Children). This National Delivery Plan has used these definitions as the foundation for taking forward the review process.

- development of specialist/consultant roles for nursing and Allied Health Professional (AHP) staff;
- the development of education, training and support to ensure that staff can provide a 21st century service;
- the development of regional and national planning for children and young people's specialist services.

7. The importance of addressing these issues was reinforced in *Delivering a Healthy Future: An Action Framework for Children and Young People's Health in Scotland*, which sets out a ten-year action plan to assist hospital and community-based health services to respond to the challenges of improving and maintaining children's health in the 21st century. The *Action Framework* has been recognised in *Better Health, Better Care* as underpinning the future development of specialist children's services.

8. To take these areas of activity forward, the *National Steering Group for Specialist Children's Services in Scotland* was established in 2006 with the aim of producing this **National Delivery Plan** – a commitment reinforced in *Better Health, Better Care*.

9. Information regarding the remit and membership of the Steering Group can be accessed from the Specialist Children's Services *website*.

10. Detailed work has been undertaken on a range of areas which included specific service reviews, planning and commissioning, networks, age appropriate care, models of care and a review of workforce requirements.

11. In undertaking its work, the National Steering Group (NSG) recognised that a number of other reports pertinent to aspects of specialist children's services had either recently been published, or were the subject of parallel work. For these reasons the following have not been included in this National Delivery Plan:

- *Health for All Children: Guidance on Implementation in Scotland (Hall 4)*
- *The Mental Health of Children and Young People: A Framework for Promotion, Prevention and Care*
- *Scottish Diabetes Framework: Action Plan*
- *Emergency Care Framework for Children and Young People*
- Neonatal Services – review being led by the Maternity Services Action Group
- Paediatric Neurosciences – review being led by the Neurosciences Implementation Group
- Remote and Rural Report
- Laboratory and Diagnostic Services.

12. The NSG has sought to avoid duplicating work already completed or underway, while also seeking to ensure that wherever relevant, the National Delivery Plan complements other national work streams. It is also recognised that this National Delivery Plan, even taken in conjunction with the workstreams identified above, does not address the full spectrum of specialist children's services. Further work is therefore required in respect of services including:

- Diagnostic radiology
- Pathology
- Burns
- Palliative care
- Ophthalmic
- ENT
- Dental surgery
- Immunology and allergy
- Renal and urology.

Stakeholder Involvement

13. The NSG has sought a wide range of opinions in developing the recommendations included in this National Delivery Plan. The NSG has either attended or organised over 100 meetings and received numerous comments and items of correspondence, many of which highlighted and reinforced the need for action in addressing the real challenges facing the delivery of specialist children's services.

14. The NSG has been particularly impressed by the children and young people, their families and carers who have at times overcome immense barriers in gaining access to the care required.

15. The NSG has also embarked on an extensive engagement exercise from October 2006 to January 2007, where a range of issues covering workforce, accessibility of services, age appropriate care, models of care and future trends were discussed (Annex 2).

16. There are excellent examples of involvement already in place. For example, the patient forums that have been established for the two new children's hospitals. However, the NSG would like to see involvement strengthened in the future especially in the development of Managed Clinical Networks (MCNs), as described in this document.

17. There were three particular issues highlighted during the involvement process which although strictly not part of the NSG remit, should be addressed as a matter of urgency by the Scottish Government. They were:

- Access to aids, equipment and adaptations to housing.
- The additional, and sometimes hidden costs, that are associated with many specialist health conditions for example travel, accommodation and child care.
- The pressures faced by families coping with a child or young person with serious or chronic health problems.

Recommendations

The Scottish Government should review the process for the provision of aids, adaptations and equipment for children and young people with specialist health needs.

The Scottish Government should consider the additional cost implications for children, young people and their families that arise from dealing with complex health conditions.

18. As well as the more general engagement process, the NSG has actively sought the views on specific services, for example children's cancer, which has resulted in an open and robust exchange of views.

19. The different workstreams produced over 80 recommendations which the NSG shared at a national open session on 26 November 2007. With almost 200 people attending, the discussion was both challenging and constructive. A full report from the day can be accessed on the [National Steering Group for Specialist Children's Services website](#).

20. This exercise represents the most wide ranging review of these services that has ever been undertaken and has extensively informed the development of this National Delivery Plan.

<p>We would welcome your views on the issues and recommendations raised in this section.</p>

Values and Principles

21. This section describes the values and principles the NSG has used to underpin the overall approach to this review and the subsequent recommendations made.

22. The broad aim of the National Delivery Plan is to provide the best clinical outcomes achievable for children and young people in an integrated service that improves access and quality of care. It focuses on the provision of specialist services, but should be interpreted bearing in mind that the vast majority of children's services in the NHS will continue to be provided in local communities rather than in hospitals.

23. The NSG has developed the National Delivery Plan by working with those who use and are involved in the planning, commissioning and delivery of specialist services, including Regional Planning Groups, NHS Boards, clinical staff, the voluntary sector, patient representatives and professional organisations.

24. In the wide-ranging reviews, consultations, meetings and discussions which have helped to develop the National Delivery Plan, the NSG has focussed on meeting the needs of current and future generations of children and young people.

25. This National Delivery Plan proposes an approach to service delivery and supporting mechanisms that aim to:

- make sure that services provided are better, quicker, safer and closer wherever possible, while recognising that children and young people may have to travel for some specialised services for more complex treatment;
- recognise the changing health needs of children and young people in Scotland and to plan services accordingly;
- improve services for the 21st century by providing a prioritised programme of service improvements;
- address barriers in accessing services based on geography and inequalities;
- recognise the dependence of children's specialties on the adequacy of general paediatric services;
- make the best use of new technologies and treatments, with remote imaging, electronic transfer of results and multi-site conferencing to decide on case management;
- identify the challenges and engage children and families, public and staff in developing solutions;
- develop new roles and skills to meet the child health challenges of the 21st century;
- make sure that specialist services are provided in the four children's hospitals in Aberdeen, Dundee, Edinburgh and Glasgow;
- support the development of two new hospitals for children and young people in Edinburgh and Glasgow, to complement the new provision in Aberdeen and Dundee;
- promote networking between the four children's hospitals and improve their links with the other children's services in their areas, for example, District General Hospitals and Community Health Partnerships.

Section 2 Why Change is Needed Now

26. Within Scotland there have been difficulties in sustaining the current pattern of delivery of specialist children's services. The main pressures relate to:

- Specialist services where the patient numbers are small, the clinical condition is complex and relatively rare. For some centres, the 'critical mass' is insufficient to retain clinical skills.
- The need to design services and develop staffing models that will meet the constraints of Working Time Legislation, the reduction in junior doctor hours and the impact of Modernising Medical Careers.
- The lack of data on the quality of service provision and clinical outcomes.
- The desire to support local service provision.
- The requirement for these services to be supported by an integrated information technology infrastructure that allows exchange of information across services.

27. The emerging picture is that models for the provision and organisation of specialist children's services need to specifically reflect the prevalence and complexity of clinical conditions, and the facilities and clinical expertise required to ensure Scottish children and young people have the best health outcomes.

28. In practice the models of care will be specific to each service and reflect the need to deliver specialist care throughout Scotland. This means that:

- some specialist inpatient services providing complex low volume care may be based in only one or two specialist centres, for example cardiac surgery, spinal surgery or paediatric intensive care;
- others requiring significant input from specialist teams may be provided in each of the four specialist children's hospitals, for example complex respiratory and gastroenterology;
- across the specialties, District General Hospital children's services and Community Health Partnerships should be supported to contribute effectively to clinical networks; and
- there should be increasing opportunities for specialist care to be provided in the community.

Specialist Children's Services – The Challenges

29. Although paediatrics is sometimes viewed as a single specialty, in practice the multiplicity of conditions that affect children and young people, and the range of specialist services that are required for their care, is at least as broad and complex as in the adult sector.

30. Some of the challenges currently facing specialist children's services relate to changes in the patterns of disease. Despite real improvements in many aspects of the health and care of children and young people over recent decades there remain clinical conditions:

- in which the incidence is rising, for example diabetes, inflammatory bowel disease;
- where welcome improvements in survival are inevitably increasing overall patient numbers, for example muscular dystrophy, extreme prematurity; and
- where some outcomes do not match those achieved in other countries, for example some cancers^{2 3}, cystic fibrosis^{4 5}.

In Scotland, there has been a fourfold rise in the incidence of childhood Crohn's disease over a 30-year period. This rise has been mirrored in most European countries, although the highest rates are found in Scotland. (Paediatric Gastroenterology, Hepatology and Nutrition Services in Scotland, May 2004.)

Around 1:3 very low birth weight babies (less than 1000g) will be disabled, half of them severely, and will require long term, and often complex, care.

Although the management of Duchenne Muscular Dystrophy (DMD) is improving, in comparison with best European practice, Scotland and the UK lag behind Denmark. In a country with the same population size and birth incidence of DMD as Scotland, they have twice the number of adult DMD survivors; 79 in Denmark compared with 39 in Scotland.

² Cancer Research UK: Children's Cancer Statistics

³ EURO CARE-3 publishes new childhood cancer survival figures

⁴ UKCCF Database, CF Trust, Annual Data Report 2004

⁵ Canadian Cystic Fibrosis Trust, *Report of the Canadian Cystic Fibrosis Patient Data Registry 2002*

Since 1970 the infant mortality for cystic fibrosis has fallen from 16% to 1% and median life expectancy increased from 20 years to an estimated 40 years for someone born in 1990. (*Lung and Asthma Information Agency*)

31. In addition to these emerging clinical challenges, many of the more difficult problems facing specialist children's services arise because the numbers of children accessing individual services is often not large, particularly compared with the adult sector. By way of example, around 30,000 adults develop cancer each year in Scotland compared with less than 200 children and young people. While the number is fortunately small, this poses significant challenges to the provision of sustainable and accessible services. The lower activity levels in no way reduce the need for specialist expertise or facilities in the management of the individual patient.

32. This pattern of small services with a limited specialist workforce distributed, sometimes unevenly, across the country raises significant problems regarding sustainability and consistency:

- the loss of a single member of staff can threaten a local or regional service;
- provision of 24/7 access to specialist advice is often impractical at a local or even regional level;
- low activity levels are reflected in restricted professional training capacity across the UK which can materially affect training and recruitment;
- small cohorts of staff in District General Hospital services are required to develop a significant range of specialist knowledge if elements of care are to be provided locally. Maintaining, refreshing and replacing such expertise can be difficult for both the organisation and the individual practitioner;
- services may be dependent for specialist input on clinicians from the adult sector. This raises issues regarding individual clinician's experience in paediatric practice and the capacity to make replacement appointments.

The specialist consultant base for most paediatric medical specialties in Scotland is under 10 consultants spread across the whole country, and in many specialties the consultant cohort is less than 5.

Many specialist nurses or allied health professionals (AHP) are either single handed practitioners or part of small professional groups making peer support and development a challenge.

33. As well as the challenges around sustainability, these issues also result in significant variations with regard to equity of access and quality of service. Access is a key issue for children and their families. Where care cannot be provided locally, attendance at a geographically distant hospital can be difficult for the child and substantially disruptive for parents, carers and other family members while also causing other problems such as loss of schooling, financial difficulties and time off work. Where the nature of a child's condition requires multiple attendance or prolonged hospitalisation these effects are magnified in ways that can become a significant threat to family life.

34. In response to these challenges, there is a clear requirement for specialist children's services to be planned and delivered in a well structured and consistent manner across Scotland. No individual Health Board is self-sufficient in terms of specialist children's services, and most services operate at a regional or national level with a requirement for patients, staff and services to cross NHS Board, and often regional, boundaries.

35. However, delivering cross-boundary services also raises significant issues in regard to:

- ensuring integrated care across primary, community, secondary and specialist provision;
- the co-ordination of service planning and prioritisation;
- consistency of funding, including the funding of individual care packages and drug treatments;
- variations in employment arrangements;
- governance and accountability at a whole system level.

36. The provision of specialist services to children and young people therefore faces real challenges which require to be fully understood and intentionally addressed if Scotland is to ensure consistent, high quality, equitable and sustainable services and the best of outcomes for the children and young people who face their own challenges in terms of serious, life limiting or long-term conditions.

Do you think that the key challenges facing specialist children's services are sufficiently described?

Are there any additional challenges that you think should be highlighted?

Section 3 The Way Forward – A National Delivery Plan

37. In the development of this National Delivery Plan, the National Steering Group (NSG) recognised that the primary task within its remit was the establishment of ‘a service framework that provides the best clinical outcomes achievable for children and young people’. In particular, the future provision of specialist children’s services in Scotland should ensure:

- sustainable services;
- best clinical outcomes; and
- local access, wherever possible.

38. A substantial amount of work has been undertaken in respect of each of the individual specialist service workstreams hosted by the NSG. These are:

- Cancer Services
- Complex Respiratory and Cystic Fibrosis
- Critical Care
- Dermatology
- Endocrinology
- Gastroenterology, Hepatology and Nutrition
- General Surgery of Childhood
- Inherited Metabolic Disease
- Rheumatology.

39. Each workstream has developed a report incorporating a list of recommendations for action to ensure the security and development of the relevant services, leading to the progressive improvement of patient outcomes and experiences, over the next few years. These reports offer extremely valuable insights into the pressures and future requirements within individual specialties. The executive summaries and full reports of each workstream are available at the [NSG website](#).

40. The NSG realised that effective service delivery would depend fundamentally on the creation of structures and processes that could support both the immediate and on-going planning, commissioning, organisation and delivery of services on an integrated, country-wide basis.

41. As a result, the emphasis of the National Delivery Plan is not only on the valid, and sometimes clamant needs of the individual specialty services, but also on the infrastructure and processes that will identify pressures and recommendations to be addressed in a consistent, effective and integrated manner.

42. The NSG also recognised that the provision of **age-appropriate care** is a theme that cuts across the spectrum of specialist services, as well as being relevant to young people requiring primary or secondary care. Many of the young people accessing specialist services will have chronic conditions that involve a significant dependence on hospital-based services. Incoming changes in the upper age limits

for children's hospital services provide the opportunity to develop facilities and services focused on the specific needs of adolescent patients as well as robust processes of transition. **Section 5** addresses some of these issues, fuller details of which are contained in the report on Age Appropriate Care, which can be accessed on the [NSG website](#) .

Further Work

43. As identified earlier in this National Delivery Plan, the work undertaken for the development of the Plan has not covered all the specialty services relating to children. A number of other services were identified during the review process and highlighted to the NSG. Particular areas in which there are known to be concerns about the pattern and sustainability of current service models and where work has been initiated include:

- Diagnostic services including radiology and pathology
- Palliative Care
- Immunology and Allergy
- ENT, Ophthalmic and Dental Surgery
- Critical Care - High Dependency Care
- Paediatric Burns
- Renal and Urological.

44. Some of these have been incorporated into wider reviews including adult services, but there is a specific need to ensure that the elements of the service intended for children and young people is explicitly sustainable. The NSG will require to give consideration, over and above such work as has already been undertaken, as to how the needs of these services should be reviewed and proposals for their development produced. For the present, however, the NSG would wish to identify whether those involved in specialist children's services agree that these specific services do require further consideration and whether there are any other specialties which also require to be included in any ongoing work.

We would welcome your views on the this aspect of the Plan.

Section 4 Making it Happen - Supporting Service Delivery

45. This section of the National Delivery Plan, **Making it Happen**, addresses a number of identified service-specific **Priority Actions** as well as laying out key proposals relating to:

- the role of networks;
- planning and commissioning;
- workforce; and
- performance management.

46. The recommendations from the individual workstreams demonstrate many common themes. The most prominent of these is the need within many services for the creation of a networked service approach (reflected in almost half of the recommendations), either on a regional or national basis. Many of the recommendations regarding MCNs, reiterate actions identified in *Delivering a Healthy Future* which Regional Planning Groups and the National Services Division (NSD) of NHS National Services Scotland are already charged to progress against agreed timescales.

47. The reports offer extremely valuable guidance regarding the way forward within each specialty. However, it is recognised that individual recommendations will require to be assessed and prioritised through formal NHS planning processes. These may either comprise the local, regional and national arrangements already in operation or, over time, the revised and enhanced processes currently being discussed by the NHS Directors of Planning Group which are due to be produced by the end of 2008.

48. The process of assessing and prioritising individual service recommendations should be informed by key criteria including:

- the sustainability or vulnerability of the service;
- the likelihood of improved clinical outcomes;
- the deliverability and timescales of the proposed service changes;
- the impact on service accessibility; and
- the magnitude of the anticipated clinical and service benefits.

49. The NSG will therefore undertake further work, in parallel with the consultation exercise, to:

- refine the criteria and processes for prioritising investment in specialist services for children and young people in Scotland; and

- align the workstream reports and recommendations with an agreed template to support clear prioritisation and decision-making.

50. Initial recommendations are highlighted in the following sections, and these recommendations will be further refined based on comments received during the consultation process.

Priority Areas For Action

51. There is a particular need to address the challenges facing **children's cancer services** in Scotland, to ensure that the service is placed on a secure footing for the future. This should both accord with best practice and support local access wherever possible, for the substantial part of each child's journey of care.

52. In addition to children's cancer services, **inherited metabolic diseases** and **cystic fibrosis**, in which the volume and pattern of clinical activity and the long term planning and sustainability of the service argue for the immediate establishment and strengthening of existing National MCNs supported by appropriate investment.

53. Within **paediatric rheumatology** services in Scotland, immediate pressures and shortcomings in the service require early investment in the form of additional consultant and AHP staffing.

54. Although it is by definition a 'general' rather than a 'specialist' service, over recent decades the **general surgery of childhood** has faced a number of challenges that are comparable to those experienced in many specialist areas. These challenges include skill maintenance, vulnerability of staffing levels and sustainability of local access. As a consequence, this service has been the subject of a specific workstream, the key recommendations of which have been included in the National Delivery Plan. This is done with a particular view to halting and reversing the substantial drift of general surgical activity from local to specialist hospitals, which has been seen both in Scotland and in many other countries in recent years.

55. As well as the recommendations in the individual reports covering the topic areas identified above, the NSG has made a number of recommendations throughout this National Delivery Plan including:

- Planning of services
- Workforce
- Establishment of MCNs
- Improving Quality – Performance Management.

56. All of these service areas will benefit from the proposed investment in MCNs:

- Telemedicine
- Workforce
- Education and training
- Planning.

Children's Cancer Services

Background

57. *A Review of Specialist Paediatric Services*, highlighted in HDL(2003)43, produced a report on the *Future of Cancer Services for Children and Young People in Scotland*⁶. One of the key recommendations was that an option appraisal, using the National Institute for Health and Clinical Excellence (NIHCE) guidelines *Improving Outcomes for Children and Young People with Cancer*⁷, be undertaken to inform the future planning and delivery of cancer services for children and young people in Scotland.

58. This recommendation was in response to conclusions in the *Review of Paediatric Oncology and Malignant Haematology*⁸, that 'by 2008 it will not be possible to provide 24/7 Consultant led cover in one inpatient unit, far less the existing three tertiary units with the existing number of Consultants without significant redesign, additional staff and reconfiguration of services'.

59. The children's hospitals currently see around 150 new diagnoses of childhood cancer each year in the 0-15 year age group (19 in Grampian, 55 in Lothian and 76 in Glasgow). Just over a third of these cases are diagnosed with a Leukaemia, a third with a brain tumour, and the rest are small numbers of other cancers. There are a further 40 new cases each year in the 16-18 year age group, some of whom are seen in the children's hospitals.

60. The appraisal was to use NIHCE guidelines *Improving Outcomes for Children and Young People with Cancer* as a benchmark. The guidelines provided a blueprint model for the future configuration of services for children and young people with cancer. This describes services being delivered through a defined network with identified Principal Treatment Centres (PTCs) and shared care centres. Minimum levels of staffing and defined co-located services are identified by NIHCE for both PTCs and shared care centres.

61. One of the key outcomes of this review process is to ensure that the future service for children and young people in Scotland with cancer will provide treatment, care and outcomes that equal comparable European countries.

62. To improve outcomes, it is essential that all children and young people are referred to a skilled multi-disciplinary team at diagnosis, and receive the best possible treatment for their individual cancer. Outcomes for children's cancers have improved dramatically in the last two decades as a direct result of national and international collaboration in clinical trials². As a consequence, for the great majority of children and young people, access to high quality modern treatment is best assured by inclusion in the clinical trial relevant to their cancer type.

⁶ *Future of Cancer Services for Children and Young People in Scotland*, CCSiSWG, 2006

⁷ *Improving outcomes for Children and Young People with Cancer*, NIHCE, 2005

⁸ *Review of Paediatric Oncology and Malignant Haematology Services in Scotland*, CHSG-Specialist Paediatric Services Sub Group and Scottish Paediatric Oncology and Haematology Group, May 2004.

63. NIHCE defined four levels of care which, for the first time, clarified the key components of a specialist service and staffing levels for children's cancer services in the UK. This model provides a clear framework within which children's cancer services can continue to be sustained within the children's hospitals in Aberdeen, Dundee, Edinburgh and Glasgow. There will also be opportunities to apply the levels of care in such a way as to support elements of children's cancer care in some of the larger District General Hospitals children's units, thereby minimising travel for children and their families. The new model of care sets clear standards and targets and the aim of this review process has been to ensure that the care provided in Scotland's hospitals can meet these demands.

64. It has been agreed by a key stakeholder group that the service will continue to be delivered, based around the four existing sites in Aberdeen, Dundee, Edinburgh and Glasgow, as a MCN, within which identified PTCs will support, and be supported to deliver care across the Network.

The option appraisal

65. The option appraisal process engaged with a large number of stakeholders in order to gather information and evidence to populate the agreed options:

- Status Quo 'Plus' - leaving services as they are, with substantial investment to bring each centre in line with NIHCE guidelines.
- Two PTCs (Level 4) in Edinburgh and Glasgow with a strong network of shared care in Aberdeen, Dundee, and identified District General Hospitals.
- One PTC (Level 4) in Edinburgh or Glasgow and a strong network of shared care.

66. The review process and option appraisal focused primarily on services for children and young people under 16 years of age, most of whom are already cared for within the current pattern of children's cancer services. There is, however, a significant incidence of cancer in the 16-18 year age group (40 new cases per annum). There are concerns, reflected in other centres within and beyond the UK, that outcomes are often poorer in this age group for whom models of care provided in adult services may not best reflect their developmental and clinical needs.

67. The incoming change in the age bands for children's hospital services (up to 16th birthday with flexibility to 18 years of age), taken in conjunction with the emergent recommendations for age appropriate care contained within the National Delivery Plan, provide an opportunity to reconsider the best model for cancer care for this age group. The NSG will give consideration as to how this issue should be progressed, although if consultees have views on cancer services for young people age 16+, they should include them in their comments on this section.

Outcomes

68. Overall, outcomes for children in Scotland match the rest of the UK, but lag behind some other comparable countries in Europe. The Network will be the basis for delivering improvements identified during the review process. The approach will need to be enhanced to achieve this; the key features of this would include the following:

- the focus for the operational delivery of this should be on a devolved, permissive and flexible network which results in the maximum delegation and delivery of safe services as locally as possible;
- this will be agreed between the identified Level 4 services and shared care centres working at Levels 1, 2 and 3;
- identification and provision of key elements to support delivery of care, including in particular, robust research and development supported by clinical trial managers and data collection;
- the need for resources both to bring the service to the appropriate levels identified in the final report, and further investment to support shared care across the country;
- capacity should be built into the Network development process to allow care pathways to be developed and implemented;
- all children and young people should be able to participate in the available existing clinical trial that best suits their individual cancer and stage.

Risks

69. There are real pressures being experienced in the recruitment of staff to key disciplines. This is not unique to Scotland. Across the UK around 25% of the current Consultant Haematology posts will fall vacant in the next three years with current trainee numbers being insufficient to fill them. Future recruitment, not only to individual hospitals, but within Scotland as a whole, requires there to be clarity and confidence regarding a future model of service which:

- supports best clinical practice;
- allows individual professional development;
- offers acceptable patterns of work, study and on-call.

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

Recommendations

The children's cancer service in Scotland should be planned on a national basis through the National MCN and delivered according to the levels of care described in the full report, Option Appraisal for Children's Cancer Services in Scotland, 2008

National funding should be provided to strengthen the network by filling skill gaps and achieve the required pattern of care across Scotland.

The NSG and National MCN should advise on the investments required. NSD should oversee the deployment of funding made available by the Scottish Government to implement the recommendations of this report. NSD should also monitor the performance of the networked service in achieving accessible, high quality services and improved clinical outcomes for children with cancer in Scotland.

The service pattern for Scotland should be developed in accordance with the following principles:

- The children's cancer service in Glasgow (which currently takes more than 50% of new cases, conforms with a Level 4 service and provides the national bone marrow transplant service) should continue to provide Level 4 care, to develop shared care services and to support other centres as appropriate.***
- In the absence of any agreement about the location of paediatric neurosurgery and, accordingly, any agreement about the co-location with cancer services, the children's cancer service in Edinburgh should be resourced to provide Level 4 care.***
- Adequately resourced shared care services should be provided in Aberdeen (Level 3^{*}); Dundee (Level 2) and agreed DGHs** (Level 1).***

The National MCN should operate on a permissive basis that facilitates the delivery of local shared care and develops care pathways and progress measures targeted at supporting the progressive improvement in patient outcomes.

NHS Boards should review arrangements for 'on call' in the children's hospitals and take steps to ensure the service for children with cancer meets the requirements of the European Working Time Regulations in all the children's hospitals, appropriate to the level of care being adopted.

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

** Inverness and Dumfries currently offer elements of cancer care and Ayrshire and Forth Valley have been identified as potential additional centres. It should be noted that the development of such shared care models at a local hospital level will be influenced by activity levels and will require intentional resourcing, particularly in terms of specialist nursing and the sessional commitments of Consultants with a specialist interest.

We would welcome your views on the recommendations for the future of Children's Cancer Services in Scotland.

Cystic Fibrosis and Inherited Metabolic Diseases

71. In addition to children's cancer services, national service planning is seen as the way forward to secure sustainable, equitable services and to improve clinical outcomes for children with inherited metabolic diseases and cystic fibrosis.

72. Both services are characterised by well-defined patient populations and a dependence on a small number of specialist staff across the clinical disciplines.

73. In the case of inherited metabolic diseases there have been, and remain, significant issues in regard to Consultant and AHP staffing, which renders the service vulnerable, hindering equitable appropriate service delivery. These issues will be addressed by the creation of a National Managed Network, but the stability of the service, and its further development, will require additional national planning and investment.

74. Cystic fibrosis services are characterised by significant variability in adequacy and accessibility across Scotland. Key determinants of outcomes such as formal annual review and access to new treatments are inconsistent; overall there are a significant number of areas in which service gaps have been identified. The report produced in the context of the National Delivery Plan sets out a number of developments seen as necessary to ensure consistent high quality care. There is recognition that progress can best be managed and achieved in the context of a national programme of work to strengthen existing services through the development of a National Managed Network.

75. Implementing recommendations in these reports will ensure sustainable and accessible services of high quality to children across Scotland with cystic fibrosis and inherited metabolic diseases. These reports can be accessed on the [NSG website](#) .

Recommendations

NSD should work with NHS Boards to establish a National Managed Network for children with cystic fibrosis by 2008.

NSD, in partnership with NHS Boards, should take forward a programme of work using the funding allocated by the Scottish Government to strengthen children's specialist services.

We would welcome your views on the approach being proposed for cystic fibrosis.

We would welcome your views on the approach being proposed for inherited metabolic disease.

Paediatric Rheumatology

76. Musculoskeletal conditions are a major cause of disability in children. Inadequately treated they can significantly affect physical, social and educational progress.

77. In Juvenile Idiopathic Arthritis (JIA), the most frequent condition in paediatric rheumatology, there is good evidence that early diagnosis, tight disease control and new treatments can prevent the irreparable joint damage, disability and associated visual loss that otherwise accompany this condition.

78. The resourcing and development of paediatric rheumatology services in Scotland has lagged behind many other areas of the UK and many other paediatric sub-specialties. Until recently most children with rheumatic diseases in Scotland had been managed either by general paediatricians or adult rheumatologists with no specific training in paediatric rheumatology. There are few nurses or AHPs with specific expertise in this area. The first, and only, full-time NHS clinical post in the specialty was established as recently as 2005, several years behind other regions in the UK.

79. As a result, service provision and take-up has varied considerably across the country with existing data suggesting that there are still significant numbers of children and young people with JIA and other rheumatic conditions who are not accessing specialist care.

80. The report of the paediatric rheumatology workstream has identified a number of key steps and investments required if an equitable high quality service is to be provided and sustained. Key to these is the need for an early appointment of an additional full-time specialist consultant post. Options exist to base the post either in Edinburgh or Glasgow, but the fundamental basis of the position would be a clear commitment to the provision and development of paediatric rheumatology services across Scotland.

81. The NSG has recognised the importance of such an appointment for the immediate stabilisation of the service.

82. It is also seen as essential that paediatric rheumatology services be organised as a national MCN. This will provide the framework within which further investment and service developments can best be progressed.

83. The report of the paediatric rheumatology workstream can be accessed on the [NSG website](#).

Recommendation

Funding is made available to appoint a full-time paediatric rheumatology consultant post to support the delivery of networked services in Scotland.

We would welcome your views on the recommendation for the future of Children's Rheumatology services in Scotland.

General Surgery of Childhood

84. Across the UK, there has been a progressive withdrawal of adult general surgeons from the surgical care of children. This is now approaching a critical stage, as many of the current older generation of surgeons are retiring and are being replaced with surgeons who have no preparatory training in children's surgery.

85. The NSG's review of general surgical services for children looked at the quality and sustainability of these services across Scotland. The review report states that the implications of failure to provide a local service could be enormous. For every child who may require a general surgical operation, there will be three or four who will simply require assessment with no surgical intervention. If this service is not available in each locality, then not only will specialist centres be overwhelmed, but transport providers could face increased demand on their services. Families, children and young people will suffer inconvenience and distress from potential delays in receiving treatment.

86. The nature of the problem differs across the geographical zones of Scotland and there is no single solution for the whole country. The review report offers several options and it will be for each NHS Board to choose the solution that will best fit their area's needs.

87. There is no evidence to suggest that, in terms of quality of outcome, the existing model of care is unsatisfactory. The review report defines the care required as its primary concern and the facilities, manpower and other resources needed to support this plan.

88. There is a real urgency in addressing the issues in children's general surgery, as there will be retirements of the current adult surgeons providing children's general surgery as early as 2008. The new hospital projects in Edinburgh and Glasgow and the requirement for them to provide services for children up to the age of 16 (and 18 in some cases) also impacts on the requirement for urgent solutions.

Recommendations

Within one year each NHS Board should examine the current local service for the provision of general surgery of childhood and develop strategic plans, in conjunction with regional specialist hospitals as appropriate, to ensure the sustainability and development of the service.

Local services (including remote and rural hospitals) must be able to provide diagnostic care, resuscitation and stabilisation as a minimum clinical standards set.

All hospitals must develop a multi-disciplinary forum, where the surgical care of children can be reviewed, discussed, planned, and audited on a regular cycle. Communication between Specialist Centres and District General Hospitals must be reinforced.

In the short term (0 to 2 years), four regional Consultant appointments should be made in Scotland, to support District General Hospitals in the provision of general surgery of childhood.

Care pathways should be developed for specific conditions to provide the basis for clinical decision making across Scotland and be implemented by 2009.

In all District General Hospital settings action should be taken to ensure that medical paediatrics is integral to the service for the general surgery of childhood. The input of the medical paediatric team is particularly important in:

- ***emergency conditions in children under five years;***
- ***children of all ages with diagnostic uncertainty; and***
- ***children of all ages needing high dependency care.***

Recommendations should be made to relevant training bodies to have the general surgery of childhood incorporated as a mandatory element of core training in general surgery.

Formal arrangements should be made through NHS Education for Scotland, colleges and specialty associations for continuous professional development of surgeons and anaesthetists involved in the general surgery of childhood, and for all clinicians (including nurses, therapists and anaesthetic assistants) treating children.

<p>We would welcome your views on the recommendations outlined for the provision of General Surgery of childhood.</p>
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Role of Networks

89. Networked service models ideally create links between specialist centres and also all the elements of the patient's journey, in both community and hospital settings. They create an environment in which:

- agreed patient pathways support consistent high quality care;
- multi-disciplinary working can be encouraged and supported;
- data-sharing and robust clinical audit can foster improved outcomes;
- staff with highly specialised expertise can support others in the provision of high quality and safe practice;
- children, young people and their families can meaningfully contribute to the creation of service models that address their needs;
- service planning and resource allocation can be informed and supported to use a 'whole system' approach to service development; and
- performance management can be more clearly linked to relevant clinical outcomes.

90. Analysis of the reports provided by individual specialties for the National Delivery Plan, show that almost half of the recommendations either propose the creation of a network where none currently exists, or relate to developments that can most realistically be progressed under the framework of a networked service model.

91. As a result, a key focus of this National Delivery Plan must be on the intentional and inclusive use of networks of service delivery across the range of specialist children's services. Such an approach should ensure the benefits of networks are made available to all relevant individual services, and also should be undertaken in a way that handles the resultant 'network of networks' within the context of the overall strategy for the provision of specialist children's services throughout the country.

Managed Clinical Networks

92. The perceived value of networks to specialist children's services is already seen in the significant number of specialties that have adopted the approach of the MCN since its introduction in 1998. The list of existing national children's MCNs is included in Table 1. In addition, regional MCNs have been created in gastroenterology, neurology (both in North region) and child protection (West region).

93. The desire for a more strategic use of MCNs was reflected in the publication, in 2007, of a *Strategy for Managed Clinical Networks in Specialist Children's Services*, developed through collaboration between the Children and Young People's Health Support Group (CYPHSG), NSD and Regional Planning Groups .

94. The Strategy recognised that there are a number of specialties for which agreement already exists, as identified in the *Action Framework*, regarding the benefits of an MCN-based approach, Table 1.

Table 1: Services for which a Managed Clinical Network has been proposed

Child Protection*	Cystic Fibrosis
Critical Care	Emergency Care
Gastroenterology*	Neurology*
Complex Respiratory/Home Ventilation	Remote and Rural Services
Complex Needs	

*These specialties currently exist as networks in some regions but not others.

95. The introduction of these MCNs should be progressed as a matter of priority and within the timescales recommended in the existing guidance (by 2009). This process will be facilitated by investment in the network support infrastructure as described elsewhere in this section.

96. The above list is not seen as exclusive or exhaustive and there is a clear recognition that there are, and will continue to be, other elements of specialist children’s services that could, and should, benefit from this form of networking. In that regard a number of speciality reports, for example, Rheumatology and Endocrinology have identified the creation of an MCN as being central to the future development of the service.

Recommendations

Arrangements should be put in place, through Regional Planning Groups and NSD, for the early introduction of MCNs (or comparable network models) in those specialist children’s services already identified in existing guidance (see Table 1) by 2008-2009.

Advice should be sought from National Services Advisory Group (NSAG) on the suitability of national MCNs for rheumatology and endocrinology.

97. Key to the ongoing utilisation of MCNs within specialist children’s services will be the existence of effective planning arrangements, operating at a national level, that can:

- prioritise individual specialist services for consideration as potential MCNs;
- discern whether an MCN is the most appropriate service model for the speciality in question or whether other models should be considered;
- agree whether an MCN would operate most efficiently at a national or regional level;
- give consideration to all specialities that may benefit from networking; and

- ensure that the individual specialty networks are taken forward in the context of the overall delivery of specialist children's services in Scotland.

98. These arrangements will require to be aligned with the overall planning and commissioning framework, recommendations for which are set out elsewhere in this National Delivery Plan. However, the creation of a national forum, operating in collaboration with regional planning, which can ensure a sustained 'whole system' approach to the future development of networks, is seen as a key element in the future delivery of specialist children's services.

Recommendation

Arrangements should be established by NSD to ensure the planning and co-ordination of existing and future MCNs and other comparable network models takes place in the context of the overall delivery of specialist children's services in Scotland by 2008.

Infrastructure

99. Many existing specialist MCNs have been introduced with dedicated administration and management arrangements. In practice, however, the creation and subsequent maintenance and development of an MCN includes many elements that are independent of the specialty in question. There is, significant potential benefit in terms of cost effectiveness, efficiency and skill enhancement, in the development of a single shared infrastructure which is specifically staffed and resourced to support the range of MCNs, current and planned, in specialist children's services.

100. This approach would be most effective if organised on the basis of regional 'hubs' operating as a virtual single system with appropriate operational management and accountability arrangements.

101. The creation of such an infrastructure would:

- allow the 'network of networks' to be managed as a whole and as part of an overall approach to specialist children's services;
- provide a local resource to clinicians and others involved in network activities;
- ensure a common overall approach to networking within different specialties;
- provide the generic skills, IT and information management infrastructure necessary for good data management and audit; and
- support both regional and national MCNs.

Recommendation

The existing support arrangements for MCNs in specialist children's services should be extended and strengthened to provide an infrastructure, with both regional and national accountability, that can fully support the introduction, operational management and ongoing development of all networks in specialist children's services in a co-ordinated 'whole system' manner by 2008-2009.

We would welcome your views on the proposals that planning and co-ordination capacity need to be increased regionally and nationally to support the development and maintenance of networks.

Managed Service Networks

102. The capacity to share information, support best practice, encourage staff and user engagement and inform planning and resourcing decisions enables MCNs to play a key role in ensuring the consistency and coherence of service delivery.

103. However, individual elements of a regional or national MCN are independently managed within their respective health board areas. The network as a whole has no direct responsibility for resource management, service operation or staff deployment.

104. While there is a perceived benefit in networks with identified responsibility for service provision, the only formally agreed mechanism by which this can currently be achieved in Scotland is through the creation of a designated national service commissioned by NSD. The value of such nationally designated services is well recognised with regard to specialist children's services, with several already in place (Annex 1).

105. National service designation is not however, necessary or appropriate in every case. The work undertaken in developing the National Delivery Plan, has identified the potential benefits of developing a 'networked service model' operating at a level below that of a nationally designated and commissioned service, but with clear accountability for service delivery. This model currently applies to the Scottish Neonatal Transport Service, which is planned on an all-Scotland basis and delivered by regional teams, with clear accountability to the NHS Boards Chief Executives Group. Although such a model could apply to other elements of the NHS in Scotland, it should offer potential advantages for specialist children's services in addition to those provided by an MCN, operating at regional or national level.

106. Developmental models for such networks have been introduced in two specialties in the North region (Gastroenterology and Neurology). It is, however, acknowledged that additional work is required to formalise the approach, agree operational and governance arrangements for such managed service networks, ensuring that they offer true added value alongside MCNs and nationally designated services.

Recommendation

A short-life working group should be established by the Scottish Government, including engagement with NSD, Regional Planning Groups and Directors of Planning, to further explore the concept of 'managed service networks', and to bring forward proposals for their structure, operational management and governance by 2008.

We would welcome your views on the concept of a managed service network model for specialist services for children.

Telemedicine

107. In addition to its established role in supporting direct clinical care, telemedicine is increasingly becoming an integral part of networking. As described in the Paediatric Telemedicine Report which can be accessed on the [*NSG website*](#), telemedicine and video conferencing is already being used within existing MCNs to support a range of activities including case conferences, clinical consultations, network management and education, Table 2.

Table 2: Use of Video Conferencing in Current Networks

Network	MCN/Informal Network	Use of Video Conferencing
Genital anomalies	MCN	National MCN using video conferencing for executive meetings, outpatient clinics and case discussion.
Renal	MCN	National MCN using video conferencing for clinical case discussion.
Child and Adolescent Mental Health	MCN	National MCN using video conferencing for executive meetings and clinical case discussion.
Cancer	MCN	National MCN using video conferencing for case discussion, tumour boards and management meetings.
Gastroenterology	Informal	Bi-monthly case discussion and education with multi-disciplinary team.
Child Protection	MCN	Regional MCN, video conferencing used for executive group meetings.
Endocrine	Informal	Weekly multi-disciplinary meeting.
Palliative Care	Informal	Monthly multi-disciplinary meeting.
Neurology	Informal	Regional MCN, multi-disciplinary team meetings and education. Some case conferences.

108. Further to these existing uses, several of the individual speciality workstreams within the National Delivery Plan have identified that telemedicine-based approaches are key to the future development of services and networked models of care. In that regard, the value of telemedicine relates not only to supporting more remote services, but also in offering effective links between paediatric units and hospitals.

109. The Paediatric Telemedicine Report contains detailed proposals for an investment programme, based on the tiered service model described in the *Emergency Care Framework*, that would equip all key sites providing children's services to a level that would support their effective engagement in networked models of care.

Recommendations

A funded investment programme should be established to develop the paediatric telemedicine infrastructure in line with the proposed tiered service model (2008-2011).

Improvements in infrastructure should be supported by appropriate training packages to maximise effective use of video-conferencing and telemedicine (2008-2009).

The potential contribution of telemedicine should be evaluated during the approval process for all new networks for specialist children's services.

We would welcome your views on the proposals for telemedicine.

Planning and Commissioning

110. *Building a Health Service Fit for the Future* (2005) acknowledged that 'current arrangements for the planning and delivery of specialised and general health services for children are fragmented with practice differing across Scotland', and noted the need for 'an all-Scotland approach (to specialised children's services) with integration with regional and local services'. A number of the recommendations from this review have been implemented, however the lack of capacity in key areas has limited progress.

111. NHS Boards retain overall responsibility for the planning and commissioning of specialist children's services in Scotland, with NSD having delegated responsibility for a limited number of nationally designated services. There are already a significant number of services in place that are provided as part of Scottish and UK wide service agreements (see Annex 1).

112. Each Regional Planning Group has a Children and Young People's Health Services Planning Group, which takes forward the planning of services identified by their constituent NHS Boards as a priority for regional collaboration.

113. *Better Health, Better Care* includes an action to review the approach to planning across NHS Scotland by the end of 2008. In particular, this review will:

- develop a clear planning framework which integrates previously disparate approaches to service, financial and workforce planning;
- clarify roles and responsibilities for planning at a national, regional and local level, including a definition of which services should be planned at which level in the planning hierarchy;
- make recommendations about appropriate resource allocation, to ensure that the 'planning system' can function efficiently;
- produce planning guidance (renewable annually) which will map out the direction of travel for NHS Scotland, and ensure strategic alignment across Boards by enabling planning decisions at every level to be made with reference to this direction.

114. The review, which is due to be completed by the end of 2008, will be led by the Scottish Government Healthcare Planning Team in conjunction with the Directors of Planning from across NHS Scotland.

115. The Scottish Government has recently allocated £32 million over the next three years to support the implementation of this National Delivery Plan. This is in addition to the investment that is expected from NHS Boards in core service provision for these services over the same time period.

Emerging Picture

116. A number of issues have been identified in the processes for planning, commissioning and delivery of specialist services that have resulted in:

- variability in service provision;
- differences in accessibility of services for patients between NHS Boards and regional areas;
- differences in outcomes for patients dependant on where they live in Scotland;
- services where outcomes are not meeting the best available in other countries; and
- delayed, incomplete or non-implementation of service reviews, mainly due to failure on agreement of resource requirements, for example Cystic Fibrosis (2002).

117. In England, a recent review of planning and commissioning of services led by Professor Sir David Carter, indicated that services that had patient numbers of up to 400 and certainly less than 1000, provided a critical mass for a collective approach to planning and commissioning. This approach was supported by:

- the creation of 10 new Strategic Commissioning Groups (SCG), covering populations of 3 to 6.5 million;
- the creation of commissioning arrangements to support these groups; and
- guidance identifying that each SCG should progress the planning and commissioning of the 35 services identified in the Specialist Services Definitions Set, through a rolling transition programme starting with 10 services during 2007/2008.

118. The relative size of budgets for these groups ranged from £133 million to £670 million in 2006/2007 (NSD comparable budget is £137 million). The lessons learned from the Carter Review mainly relate to the provision of services planned at a national level within Scotland and those provided on a UK basis, because of their relatively small numbers and the limited availability of staff with the relevant skills to treat patients with rare conditions.

119. However, any solutions to providing services in a Scottish context will have to reflect the different service and organisational requirements, particularly with regard to:

- dispersed geographical populations;
- increased levels of deprivation; and
- different organisational arrangements for the NHS in Scotland.

120. In addition, many aspects of secondary child health services also have a strong regional dimension with significant interdependence between the regional children's hospitals and their partner DGHS.

121. Since its inception, the NSG has recognised the importance of delivering specialist children's services in a coherent and equitable way across Scotland and the consequent need for planning and commissioning arrangements that support such an approach.

122. The planning and commissioning of specialist children's services has been one of the identified work streams of the NSG with a preliminary discussion paper being circulated in 2006. Subsequent discussions identified strong support for the need for robust arrangements at Regional and National level which would not only plan services at the appropriate level, but also have the capacity either to 'commission' them, or ensure their delivery in ways that support the desired equity inherent in an all-Scotland approach.

Recommendation

The Scottish Government should put in place formal structures to enable the planning and commissioning of those specialist children's services which require to be organised on a national basis. These structures should work in close collaboration with Regional Planning to ensure that regional decisions are taken forward within the overall national context.

Delivering Services

123. The individual NSG work streams have made recommendations on the planning, commissioning and delivery of care, including the identification of those services that should be delivered at a national, regional and local level. The initial outputs from the specialist children's review process would indicate that current approaches should be adjusted to reflect that position (see Table 3).

124. While most of the service reviews have indicated that elements of care provided will be delivered at national, regional and local levels, they advocate that equitable and sustainable service provision requires a 'whole system' approach to service planning that recognises the national and regional dimensions of specialist care. In practice the provision of *local* care is often highly dependent on the existence of a strong national service infrastructure.

125. The developing picture is one of different service models, which provide sustainable services, based around the four children’s hospitals, linked to District General Hospitals and community provision. This will require support from a robust planning and commissioning infrastructure.

Table 3: Specialist Children’s Services reviews - suggested approach to delivering services and how they should be planned and commissioned

Service	Numbers (approx)	Delivered	Planned/Commissioned
Children’s Cancer	400	N/R/L	National
Cystic Fibrosis	425	N/R/L	National
Emergency Care	9,828	N/R/L	Regional
Gastroenterology	3,000	N/R/L	Regional
Respiratory	3,000	N/R/L	Regional
Metabolic	550	N/R/L	National
General Surgery	6,000	N/R/L	Regional
Paediatric Intensive Care	1,400	N	National (currently)
Endocrinology	1,400	N/R/L	National/Regional
Dermatology	4,500	N/R/L	Regional
Rheumatology	1,000	N/R/L	Regional

N = National R = Regional L=Local

Key Elements of Service Delivery Models

126. The majority of secondary care services will continue to be delivered at a community level through Community Health Partnerships, supported by their local DGH. Local needs will be identified and addressed through an integrated approach to the planning, commissioning and delivery of services involving NHS Boards and their partner Local Authorities.

127. Within each of the regions, the specialist children’s hospitals will deliver regional, secondary and tertiary services and also support and collaborate with District General Hospital children’s units to facilitate local care. The children’s hospitals will also work in an integrated manner to ensure a coherent national approach to the delivery of more specialised services.

128. These arrangements are illustrated in Table 4 and the map at Annex 2. The map summarises the locations at which individual services can be accessed, and confirms the extent to which the majority of key services are, and will continue to be, provided within each region. Aside from the outcome of the ongoing discussions regarding neurosurgery services in Scotland, this National Delivery Plan envisages no change to the overall distribution of services in Scotland, although within individual specialties the levels of service provision across the four children's hospitals will require to reflect the models of care that support best clinical outcomes.

Table 4: Organisation of acute inpatient services for children and young people in Scotland

Lead Regional Provider	Region	NHS Boards
Royal Aberdeen Children's Hospital & Tayside Children's Hospital, Ninewells	North	Highland*, Grampian, Orkney, Shetland, Tayside*
Royal Hospital for Sick Children Edinburgh [#]	South East & Tayside	Borders, Dumfries and Galloway*, Fife, Forth Valley*, Lothian, Tayside*
Royal Hospital for Sick Children (Yorkhill) Glasgow [#]	West	Ayrshire and Arran, Dumfries and Galloway*, Forth Valley*, Greater Glasgow & Clyde Highland*, Lanarkshire, Western Isles

[#] currently provide national services accessed by all Boards

*NHS Boards that participate in more than one planning region

129. Currently there are services that are not provided in Scotland and arrangements will continue to be made with centres elsewhere in the United Kingdom, for example Cardiothoracic transplant (Newcastle), Bladder exstrophy (Great Ormond Street), Specialist Liver Disease (London, Birmingham), In-patient forensic psychiatry (Newcastle), (see Annex 1).

Recommendations

That funds should be allocated, from the resources made available by the Scottish Government to develop the specialist children's services identified below to establish and strengthen national MCNs, and that NSD should work through the national MCNs to deploy funds and monitor results achieved:

- **Children's cancer**
- **Cystic fibrosis**
- **Metabolic.**

The following should be planned at a regional level by the existing Child Health Regional Planning Groups:

- **Dermatology**
- **Emergency Care**
- **Endocrinology**
- **Gastroenterology**
- **General surgery**
- **Respiratory**
- **Rheumatology**
- **Critical Care (High Dependency).**

We would welcome any comments you may have on the recommendations in this section of the National Delivery Plan.

Workforce

130. The *Action Framework*, identified a range of issues that impact on the sustainability of specialist services for children across Scotland. Workforce sustainability is key to future service sustainability and there are a number of challenges to be addressed to ensure continuity and development of specialist services for children in NHSScotland.

131. Changing models of care identified for specialist children's services have implications for the workforce, both in terms of the way it is organised and the flexibility required given the relatively small pool of staff. An obligation to provide support between levels of care will be essential, and this has implications for the way jobs are constructed and the expectations of NHS Boards. Whilst geography is important, the challenges do not necessarily differ across the geographical areas of Scotland, however, that does not mean there will be one all-Scotland solution that will resolve all issues.

132. A flexible workforce will be required, with a range of skills and competencies. This will include specialist skills, general skills and new skills such as remote diagnosis and supporting clinical decision-making in a non-specialist workforce. Modern communication technology and techniques will support local care, extend the availability of the specialist workforce and allow the wider workforce to develop and maintain new skills.

133. The majority of staff (apart from doctors) who work in children's services have generalist paediatric roles. The need for specialist nursing and AHP roles has been highlighted by a number of specialist services. Post registration education and training for higher level competencies in specialist roles is an issue which needs to be addressed with NHS Education for Scotland. There are also a number of issues relating to the training of doctors, particularly in sub-speciality areas and for roles where doctors have a special interest. The contribution of clinical academics to service delivery is an area that requires to be considered further, particularly when vacant posts may not be replaced with like for like.

134. There are a number of drivers for change impacting on the workforce in specialist children's services which are described in the following paragraphs.

Demographics

135. The Scottish population is ageing and so is the NHS workforce. The demographic changes within the population of Scotland will impact on the shape of the workforce and the skills and competencies required to deliver services. Immigration, increasing survival of children with complex needs and the potential changes to caseload in different geographical areas all have implications for the way in which children's services are planned and provided. An older workforce raises two potential risks – loss of experience and the possibility of being unable to replace like with like. Succession planning is vital and needs to be considered along with other solutions.

Changing Models of Care

136. Models of care for specialist children's services for the future are more likely to be based on a network approach, planned and delivered at essentially two levels - regional and national. This will require alliances between specialist centres, District General Hospitals and other services where children will be seen but where there are no specialist paediatricians on site (for example, rural general hospitals and community hospitals). In these circumstances, the networks will be required to support delivery of service, training and education.

Pay Modernisation

137. The consultant contract, introduced in April 2003, linked consultant pay more closely to the number of hours worked. This gave NHS organisations more say in consultants clinical activities through an annual 'job planning' process. Implementation brings benefits to productivity, although organisation of rotas needs careful consideration.

138. Agenda for Change (AfC) is the new pay and career progression system in place for non medical staff. An annual review process, supported by personal development plans based on the AfC Knowledge and Skills Framework, will assist staff to develop their skills within existing posts and to support career progression. Implementation of the new system is progressing. To ensure sustainability of specialist paediatric services, Job Evaluation Committees should work to ensure that variances between posts, especially specialist posts, within and across NHS Boards are monitored and any inconsistencies highlighted and corrected as appropriate.

Modernising Medical Careers (MMC)

139. The ongoing modernisation of medical careers is changing the way junior doctors are trained. Within paediatrics, there has been a move to determine speciality training numbers on an all-Scotland basis. While practical, given the small number of trainees, this could have an impact on local systems in delivery of direct care. MMC is intended to move towards 'trained doctor delivered care' but the transition phase could have an impact on the direct care commitments of consultants.

140. The longer-term benefits of shortened training times, if supported by a corresponding expansion of consultant numbers will improve the service. However, the consultant delivered service will require enhanced multi-disciplinary team working and role development for all other health disciplines. This will take time to achieve and in some circumstances the need is yet to be defined. Even where it is defined, the training programmes need to be developed.

Working Time Regulations (WTR)

141. Compliance with the requirements of the WTR has proven challenging for the NHS. By 2009, all doctors in training will require to comply with the regulations which will limit the working time available to an average of 48 hours per week. In Paediatrics, this legal requirement will challenge specialist staff, given the small numbers of staff available to cover a 24-hour roster, and may require additional 'trained' doctors.

Gender and Age

142. The majority of the NHS workforce is female. A census undertaken in 2007 (based on a format used by the Royal College of Paediatrics and Child Health) confirmed that amongst the medical staff caring for children, 62% of the workforce is female (241 women). A higher proportion of women in the workforce is often accompanied by increased part-time working, increased turnover and a greater incidence of career breaks. All affect continuity of service delivery which is an important consideration in workforce planning.

143. The proportion of women who follow a specialist career path is lower than their male counter parts. Only 29 (43%) in the group of 67 Consultants who work exclusively in specialist children's services are female. The reasons for this are multi-factorial, although anecdotal evidence suggests that training patterns, including the possible need to move around the country, is a significant deterrent. Given the increasing dependence of the medical workforce on female doctors, this represents a significant risk to the sustainability of specialist services.

144. Of the 384 staff identified in the census, 63 doctors (16.4%) are 55 years of age or over and likely to retire in the next five years. Of males, 20.6% are over 55, compared to 14.1% of female staff. In that regard, many current consultants continue to be employed on a 12 Programmed Activities (PA) contract, but are likely to be replaced by a 10 PA contract.

Nursing and Allied Health Professional Workforce

145. Nurses and AHPs make a significant contribution to the delivery of children's specialist services across tertiary, secondary and primary care levels. AHPs also support children receiving specialist services or those with complex needs to participate in education.

146. Nursing and AHP roles include support for the management of challenging, life limiting and long term conditions, particularly during transitions of care. For the AHP this may also include the diagnosis, treatment and continuing management of functional problems, motor, communication and metabolic disorders especially in the case of multiple and complex pathologies.

147. Building a different nursing and AHP workforce⁹ that is skilled, competent, effective and efficient, is pivotal to the long term sustainability of specialist children's services. Clinical leadership in a range of specialties and services is increasingly being provided by nurses and AHPs as well as medical consultants. Therefore, future plans for sustainable service provision should exploit AHP, nursing expertise and leadership capabilities to deliver integrated services that improve access and quality of care for patients. Nursing and AHP consultants and specialist practitioner posts are already delivering these services in a range of adult specialities; however the education programmes are not available in paediatrics in Scotland.

148. What is absolutely clear from early exploration of workforce challenges for nurses and AHPs, is the need to provide a focused approach to succession planning and develop a range of training opportunities, including rotations for junior and middle grade staff, to support capacity building and skills development. An important driver of the support provided to children with complex or life limiting conditions and their families, is enabling them to achieve their full potential and participate in learning. The Additional Support for Learning Act and the previous policy of supporting children into mainstream school, has been introduced with only limited additional support from the AHP or wider healthcare workforce. There are, therefore existing capacity issues that require to be addressed in the delivery of services to children and families.

149. In addition to the need to build a workforce that can provide specialist skills and expertise there is a need to address a number of immediate workforce issues.

Capacity to Deliver Core Services

150. There is a need to explore further the core services that require to be delivered by nurses and AHPs in the context of sustainable clinical teams. Such work should take account of those specialist services where it is essential to operate on a 52 week basis, and address gaps though the provision of a predictable absence allowance. Concurrent gaps in community services should be identified through the mapping project for AHP and Nursing in Community Services. A mapping project on AHP and Nursing in Community Services for Children with Complex Needs, was commissioned by the Chief Nursing Officers Directorate in 2007. The full results of the mapping project will be available in June 2008. Early feedback however, highlights the need for skill mix, multi-professional working and the importance of case management.

⁹ Allied Health Professions Definitions

Skill Mix

151. The issues relating to skill mix require to be understood not only within individual clinical disciplines, but across specialist teams as a whole if maximum efficiency and clinical outcomes are to be achieved. The introduction of the four tier structure of role development will include assistant practitioners, senior and advanced and consultant practitioners. These roles will contribute positively to the redesign and improvement of the service, providing greater flexibility and capacity. The frameworks for *Developing Nursing Roles* and for *Role Development in the Allied Health Professions*, published in 2005, provide templates for the development of specialist roles within the professions.

Redesign

152. Opportunities to think radically about the way nurses and AHPs can support and deliver specialist children's services, for example with nurse and AHP led clinics should be actively pursued. Such clinics would create additional capacity for medical colleagues. There will be a need to provide expert facilitation and redesign methodologies to support and develop the changing roles and improve quality of service.

Succession Planning

153. Whilst the very nature of specialist children's services demands staff with clinical credibility and expertise, there is a need to ensure sustainability through robust succession planning. There is a tendency for services to have few opportunities for succession planning, and NHS services are vulnerable where they are provided by small numbers of single handed experienced practitioners. Services need to explore options for service delivery that will allow more junior staff to work within children's services, these junior staff will need to be supported by robust training and development to speed up the attainment of the required skills and competencies. This will involve scoping of education needs at undergraduate and post graduate levels, and identifying training opportunities.

New Roles

154. Significant opportunities exist within specialist children's services to develop new and extended roles for nurses and AHPs. Nurse and AHP advanced practitioners and consultants have the potential to support the development and redesign of services with medical colleagues and to provide professional clinical leadership.

Data collection

155. Currently, nationally collected medical workforce data may identify whether a consultant has a specialist role, but it is not sufficiently refined to collect a sub-speciality interest. The census described earlier in this section established a baseline of career grade staff. It included general/speciality split, special interest, base location, age and gender, and has identified the percentage contribution of the generalist paediatricians to speciality care.

156. Nationally collected nursing workforce data identifies nurses who have a specialist qualification. A number of staff working in specialist roles do not have a formal qualification as such training programmes often do not exist. For the purpose of this exercise it was seen as crucial that this information was collected. A census similar to the one for medical staff was developed to provide information on the levels of specialist practice in Scotland. However, the pilot of the questionnaire was not successful. There is currently no nationally collected data for AHPs working in specialist roles.

157. The need to improve the quality of workforce data collected within NHS Scotland in relation to specialist services is crucial to workforce planning. Full implementation of Scottish Workforce Information Standards System (SWISS) over time will address many of these issues.

Recommendations

NHS Education for Scotland (NES) should establish the requirements for post registration accredited training and education for nursing and AHP staff in specialist children's services and take forward as appropriate.

NES should establish a range of continuing professional development programmes to support medical and surgical staff working within specialist children's services.

By 2011, NHS Boards in conjunction with NES, to implement workforce development plans to ensure sufficient nurses and AHPs are available and ready to work within specialist children's services at advanced practice level.

NHS Boards, Regional Planning Groups and NSD should develop an implementation plan to address workforce requirements for national/regional identified networks by 2009.

A national framework to support future workforce planning for specialist children's services should be developed by Boards and Regions by 2009.

NHS Boards in conjunction with Regional Planning Groups and Information Services Division (ISD) should develop a more robust mechanism to gather accurate workforce data by 2009.

SWISS Programme Board to take account of workforce data issues and concerns within specialist children's services in relation to the future development of SWISS.

NHS Boards and Regional Planning Groups should ensure workforce planning for specialist children's services takes account of multi-disciplinary team working and service delivery by trained doctors, as well as the requirements of working time regulations.

NHS Boards should review the demography of their specialist paediatric consultant workforce, including clinical academics who provide service commitment, and develop succession plans for services at risk.

NHS Boards and Regional Planning Groups should develop workforce plans to address the clinical, psycho-social and developmental needs of adolescent patients as part of their overall workforce plans.

NHS Boards and Regional Planning Groups should address the specific needs of the specialist children's service staff working in remote and rural areas in their workforce plans.

NHS Boards should ensure that issues of variances between posts, within and across Boards, are being monitored as part of AfC implementation to ensure that any inconsistencies are highlighted and corrected as appropriate, including those within specialist paediatric services.

<p>We would welcome your views on the recommendations outlined regarding workforce, education and training.</p>
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Improving Quality - Performance Management

158. The range of initiatives for the NHS in Scotland described in *Better Health, Better Care* and the recently published HEAT targets in the Local Delivery Plan guidance for 2008/2009, has set a number of challenges for those involved in the delivery of child health services. The increasing reductions in waiting times covering, for example, diagnostic services (reduction to 6 weeks) and access to treatment (reduction to 18 weeks) by 2011, will require a greater focus on redesign and increasing capacity within services.

159. The increased emphasis on addressing inequalities and improving clinical outcomes will mean a much more robust approach to investment in services as Scotland strives to meet the best outcomes available in comparable European countries.

160. In that regard, a recurring theme in the work of the NSG was concern about the lack of quality outcome measures and readily accessible data in respect of specialist children's services. Even where data is available (eg. cancer, cardiac surgery), it often relates to mortality and survival and fails to address other markers of good clinical outcomes. There is a need for further focussed work to be undertaken to identify meaningful and measurable outcomes to inform the ongoing development of specialist children's services.

170. The establishment of the *NHSScotland Efficiency and Productivity Programme* will bring greater coherence to this landscape within NHSScotland. This approach can be applied to improving quality in services for children, with a particular focus on streamlining current service provision and supporting staff to develop the necessary skills and competencies to work in a range of environments. The establishment of a **Child Health Collaborative Programme** offers a potential way to address some of the specific delivery and training issues identified in this National Delivery Plan, as well as other elements of the wider child health agenda, and to engage frontline staff in developing solutions to local needs and circumstances.

171. Increased public involvement in specialist children's services, and the establishment and operation of Managed Clinical/Service Networks, including effective engagement with the voluntary sector, should be a priority for the organisations involved in delivering health care in Scotland. The creation of a **Child Health Alliance** would support such involvement in a systematic way which brings added value to the services.

172. The investment of £32 million over three years to ensure that the objectives of this National Delivery Plan improve services and outcomes for children and young people, are a measure of the commitment to this area from the Scottish Government. The Scottish Government will be seeking regular annual updates on progress from NHS Boards as they implement this National Delivery Plan.

Recommendations

The Children and Young People's Health Support Group (CYPHSG) in conjunction with NHS Quality Improvement Scotland should establish a programme of visits based on the National Delivery Plan by 2009.

The NSG, in collaboration with ISD, establish a short-life working group to develop a measurable range of clinical outcome indicators that will allow improvements in specialist children's services to be assessed over time (2008).

NHS Boards, Regional Planning Groups and NSD to produce progress reports on an annual basis to monitor the implementation of the National Delivery Plan.

That a Child Health Collaborative Programme be established for Scotland which supports delivery of the National Delivery Plan, and the wider child health agenda, and improves efficiency through redesign, creating additional capacity and supporting the change process described in this National Delivery Plan.

A Child Health Alliance, acting as a network for the voluntary sector and patient representative organisations, aiming to improve patient and carer participation in the development of services, should be established.

Are the proposed recommendations sufficient to monitor the implementation of the National Delivery Plan?

We would welcome your views on the establishment of a:

- 1. Child Health Collaborative Programme**
- 2. Child Health Alliance**

Section 5 Age Appropriate Care

173. The last fifty years have seen an increasing recognition of the need for health service planning and provision to take account of the specific needs of adolescent patients. These issues are by no means confined to young people using specialist services, but they are of particular importance for this group given that they are often frequent users of services including, in particular, hospital facilities.

174. *Building a Health Service Fit for the Future* (2005) recommended that 'NHS Scotland should adopt the guiding principle that the age for admitting children and young people to acute care in paediatric facilities is up to their 16th birthday', and that 'for young people between the ages of 16 and 18 there should be discussions with their clinician(s) regarding where care is best delivered'.

175. To progress these recommendations, and the wider requirement to develop services that properly address the particular needs of young people, a working group was set up to bring forward proposals for inclusion in the National Delivery Plan. A summary of their findings is given here with the full report available on the [NSG website](#) .

176. How these issues will manifest themselves and be addressed will vary significantly across Scotland, but there is a fundamental need for NHS Boards and others who plan and commission services, to ensure that much more explicit attention is given to the specific needs of young people including those with serious and chronic conditions.

Training

177. Many staff have received little training in the physical, emotional, psycho-social and legal issues for adolescents. As a result, they often lack confidence in dealing with young people. A training needs analysis is required of the generic skills involved in adolescent care. After that, the appropriate training must be made available for all relevant staff within the NHS in Scotland.

178. The change in the age limit for children's services will expose some clinical staff to conditions and clinical scenarios which are not commonly encountered in their present practice. Individual NHS Boards and hospitals will need to assess and address any particular training needs relevant to their own staff groups.

Facilities

179. The Scottish Office report *At Home in Hospital* (1993), is one of several over recent decades to recognise that good practice in the hospital care of adolescents includes the provision of discreet accommodation which supports 'privacy, flexibility of regime and independence', and incorporates space for social, recreational and educational activities.

180. In practice the current provision of adolescent facilities in Scottish hospitals remains extremely limited and is often confined to the selective use of single rooms, or small bed bays as required.

181. The consistent preference of young people, wherever clinically possible, is to be accommodated with their own peer group. Evidence from other centres internationally suggests that the development of wards which can accommodate young people with a range of medical and surgical conditions, is entirely feasible and is not contrary to the continued delivery of high quality clinical care.

182. Circumstances and opportunities will vary from a specialist children's hospital to a rural general hospital but there is a need, across the country, for NHS Boards to review current activity patterns and to identify appropriate arrangements for the in-patient care of young people that address their particular needs. Further guidance on this issue is contained in the Age Appropriate Care Working Group Report, which can be accessed on the [NSG website](#) .

Staffing

183. The particular psycho-social and emotional needs of young people dictate a need for access to an additional range of skills and services. These include clinical psychology, youth and social work, play therapists and specialists and chaplains skilled in addressing the spiritual needs of young people sometimes facing challenging situations. It is important to recognise the contribution of such disciplines as an integral part of adolescent care that requires to be identified and resourced.

Education

184. The *Standards in Scotland Schools Act* (2000), and related guidance indicate that teaching should 'normally begin after five working days following admission (to hospital), provided the child's state of health makes this desirable'. If a prolonged stay can be anticipated in advance, then teaching should proceed immediately. An effective collaboration is needed between hospitals which admit young people (including those in the adult sector), and their local educational services, with prompt and consistent referral procedures. Hospitals must also provide the privacy, space, time and equipment needed to minimise potential educational loss.

Transition

185. At some stage, young people with long-term conditions will transfer to adult-orientated services. It has increasingly been recognised that the successful transfer of care should be handled in a well planned and co-ordinated process with which the young person and their family are fully engaged.

186. Currently the transition to adult services often takes place at a stage where the young person is still adapting to the developmental changes of adolescence. The proposed change in age limits for hospital services for children offers the option of greater flexibility regarding the age of transition, although there will always be a need to address these matters at an individual level in ways that are sensitive to a young person's clinical needs, maturity and choice.

187. Another significant issue is the fact that medical advances are increasingly supporting the survival into adulthood of children and young people with life-limiting conditions. Such conditions were previously minimally reflected in adult practice, which leaves a service gap. This raises significant challenges in respect of service configuration and staff training, but innovative and achievable solutions must be identified and provided.

Recommendations

NHS Boards should identify opportunities to provide dedicated hospital facilities to suit their local volume and pattern of adolescent use, or alternatively develop other means of meeting the needs of this group.

Based on a training needs analysis by NHS Education for Scotland (2008), all staff dealing with adolescent patients should receive generic training in the care of young people by 2012.

A working group should be established to scope the extent to which the current range of adult services does not fully address the pattern of long-term conditions experienced by young people.

Services dealing with long term conditions in young people should have in place arrangements that ensure well-structured transition from children's to adult services, in a manner appropriate to the individual's clinical needs and maturity.

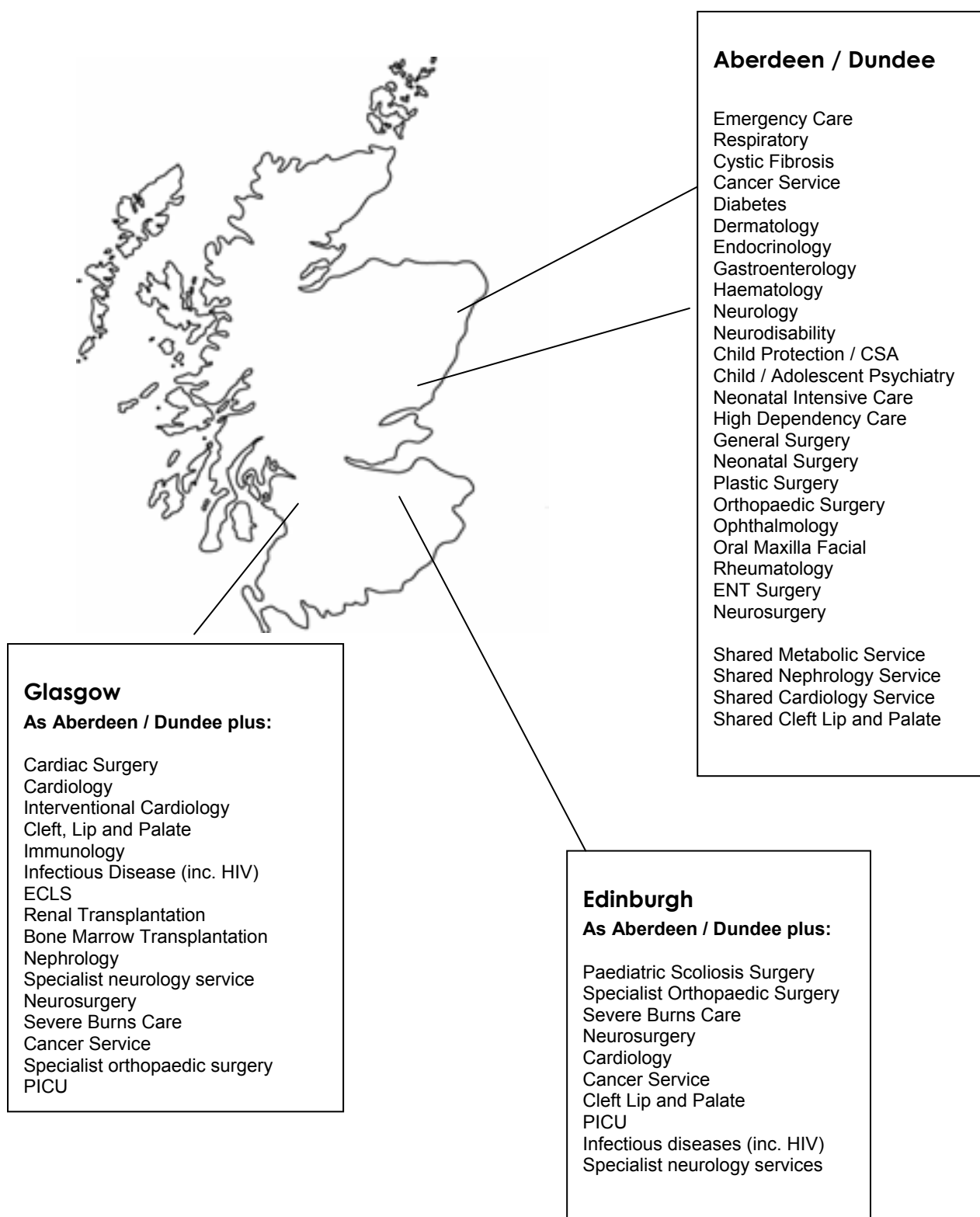
Clinical leads for adolescent services should be identified at hospital and regional level.

<p>Are there any aspects of age appropriate care provision not sufficiently covered within either the text or recommendations?</p>

Children's services planned and commissioned at a UK and Scotland and Scottish MCNs

Specialist Childrens Services – UK	Specialist Childrens Services – Scotland	Managed Clinical Networks
Alstrom syndrome service	Cardiac (surgery, interventional cardiology and neonatal cardiology)	
Bladder extrophy	Cochlear Implantation	
Cardiothoracic, liver and small bowel transplantation	Bone Marrow Transplantation	Childrens Cancer Bone and soft tissue sarcoma
Craniofacial surgery	Complex airways management in children	
Epidermolysis bullosa	Cleft Lip and Palate	Cleft Lip and Palate
Interventional fetal therapy	Molecular Genetics	Scottish Muscle Group Genital anomalies
Pulmonary hypertension	Spinal surgery	
Persistent hyperinsulinaemic hypoglycaemia of infancy	ITU Retrieval	
Obstetric brachial plexus surgery	PICU	
Rare neuromuscular disease	Extra Corporal Life Support	
Rare mitochondrial disease	Renal Transplantation	Renal disease
Retinoblastoma	In patient psychiatry for children to age 12	Complex child and adolescent mental health services
Reconstructive surgery for congenital malformations of the genital tract	Mental health services for deaf children and adolescents	
Secure forensic learning disability and mental health services for children and adolescents		Inherited metabolic disease
Severe combined immunodeficiency disorders		Paediatric epilepsy
Specialist liver disease		Home parenteral nutrition
Stem cell transplantation for juvenile idiopathic arthritis and connective tissue disorders		Burns care
Vein of Galen		

Proposed distribution of Specialist Children’s Services across the three Regions and four Children’s Hospitals



Executive Summary – Public Engagement Report - May 2007

Rocket Science was commissioned by the Scottish Executive Health Department to engage with parents, carers, children, young people and health care professionals to understand their views about specialist children's health services in Scotland and how the services could be improved.

This report provides:

- The context in which the engagement was commissioned and undertaken
- The views of parents, carers and health care professionals in relation to 5 key identified areas
- The views of children and young people on their experiences and suggestions for future development
- A summary of key findings

Context

The Scottish Executive established the Children and Young People's Health Support Group (CYPHSG) in 2005 in response to a number of key recommendations made by Professor David Kerr's review of the NHS in Scotland in relation to child health. Specifically the Executive asked the CYPHSG to carry out an in-depth review of specialist children's services in Scotland. A NSG, chaired by Malcolm Wright, Chief Executive of NHS Education Scotland, and a project team was established to lead the activity. This group will ensure the actions in relation to specialist services are implemented and will produce a 'National Delivery Plan for Specialist Children's Services in Scotland'. This public engagement is a first step in broader involvement in this work and was intended to inform the development of the delivery plan.

Methods

Ten 'general' public engagement events were held across Scotland, catering for all constituent groups. We also organised targeted events to increase participation: 3 children/young people events, 1 health professional event and 1 parent/carer event. An electronic survey was established to provide an opportunity for those who could not attend events to submit their views.

Findings

The public engagement events for parents, carers and health professionals were organised around five key areas: workforce, accessibility of services, age appropriate care, models of care and future trends. The issues below are a summary of some of the main discussions and views of participants.

Workforce

- Multi-agency working is becoming increasingly important and beneficial. This approach would benefit from explicit guidelines for allocation of a lead professional or key worker role.
- The general trend is for health professionals to progress along specialist training routes; this has particular implications for rural areas where the population size is too small to support a specialist service.
- The further development of communication skills for working with children and young people was suggested as a priority.
- Parents required greater consistency in service and improved communication from health care professionals.

Accessibility of services

- There is a need to deliver health care around children and families. Parents whose children have complex needs often find their own lives degenerating as a result of their child's condition and they want improved support from services.
- Participants acknowledged some element of travel and that support for the logistics of this travel could be improved. It is hoped the development of community outreach clinics will make tertiary services more accessible in local areas.
- Parents and carers feel GPs have too much of a gatekeeper role around access to services. Some felt they had to fight for referrals due to lack of staff resources.
- Flexible appointment would be preferable to fixed times and that too many services only offer 9-5 appointments.
- Hospital facilities for some parents and carers were reported to be poor.
- Many parents and carers do not follow the procedures due to lack of knowledge about how they work.

Age appropriate care

- The contrast between children and adult services is quite stark with less support in adult services. Different transition ages may be appropriate for different conditions
- There are issues regarding paediatric specialisms which do not have an adult counterpart.
- Children's services taking on older children will have significant impact on resources.
- Older children have different needs to younger children and there are extensive arguments for specific adolescent units.
- Services currently cannot cope with palliative care for children, especially those with learning disabilities.
- Educational provision for children in hospital is very patchy.

Models of care

- Major issue is the level at which specialist children's services should be planned and commissioned.
- Joint care pathways should be established across health board boundaries to exploit expertise.
- It was noted that Community Health Partnerships are attempting to take services more local while there is growing recognition of the need to plan nationally.
- One single NHS for children in Scotland was suggested.
- Current managed clinical networks include only NHS professionals; it was suggested these should also include social work and education services.
- Services do not share information with each other around particular issues.
- The variability of services across Scotland is a significant issue

Future trends

- Children with more and more complex conditions are surviving into adulthood, but participants thought that the health service was not doing enough to anticipate increased future demand
- Participants felt that there is an expectation from professionals that parents and carers will just carry on caring as children move into adulthood, without acknowledging that proper support is required to fulfil this role
- Participants agreed that care should be about local access, and hospitals should be the last place for children to end up
- Participants hoped that more streamlined IT means that services will be faster, cheaper and easier to deliver.
- Participants agreed that there needs to be a focus on prevention rather than cure, particularly for conditions which are costly to treat when they reach an advanced stage.
- It was felt that Scotland's changing population is an issue, both in terms of the numbers of children, as well as where their parents are from.
- Participants felt that some families have greater, sometimes unreasonable, expectations and beliefs around entitlement to care
- It was hoped that scientific knowledge of particular conditions would improve in the future, to meet the needs of children with rare or complex conditions more effectively.

Views of children and young people

The engagement with children and young people revealed:

- Consistency in view on positives and negative aspects of their experience of using specialist children's health services.
- Good experiences included care given by staff, being visited by friends, support to keep up with school work and being provided with entertainment and activities.
- Bad experiences included feeling intimidated by doctors, feelings of isolation, painful procedures, boredom and appointment waiting times.

- Having to use specialist services had a big impact on the majority of participants; this usually related to the amount of time people had to spend in hospital and the type of treatment required
- There were mixed views of the age-appropriateness of services: some felt they were too childish, others felt they were 'just right'. Most acknowledged it became more difficult for teenagers to be mixed with young children.
- Very few young people reported 'never' having a say in decisions that affect them with the majority stating this happened 'sometimes'. Many felt they had been 'told what's going on' but not necessarily involved in making decisions.
- Many young people felt that health professionals should communicate at a level more appropriate to the age of the patients.
- Mixed views on extent of involvement in design of services with some young people extensively involved due to local initiatives and others experiencing little or no involvement.
- All involved had opinions on how to create the 'ideal' service and expressed a desire to be involved and consulted on future plans and how to make improvements to the hospital experience.

Membership of National Steering Group for Specialist Children's Services in Scotland

Malcolm Wright, Chair	Chief Executive, NHS Education Scotland
Sharon Adamson	West of Scotland Regional Planning Group
Michael Bisset	Clinical Director, Royal Aberdeen Sick Children's Hospital
Helen Byrne	NHS Greater Glasgow and Clyde
Charles Clark replaced by Lorraine Currie	Chair, Child Health Commissioners' Group
Sir Alan Craft	Past-President of the Royal College of Paediatrics and Child Health
Fiona Drimmie	NHS Education for Scotland
Myra Duncan	Regional Planning Director, South East and Tayside Regional Planning Group
Zoë Dunhill	Clinical Director/Consultant Paediatrician, Children's Services, NHS Lothian University Hospitals Division
Deirdre Evans	Director, National Services Division
Ellen Finlayson	CLIC Sargent
Stewart Forsyth	Medical Director, NHS Tayside
Jamie Houston	Consultant, Oban and Lorne Hospital
Annie Ingram	North Regional Planning and Workforce Director, North Regional Planning Group
Morgan Jamieson	National Clinical Lead for Children and Young People's Health in Scotland
Heather Knox	Regional Planning Director, West of Scotland
Anne Leigh-Brown replaced by Alastair Philp	Information Services Division
Adrian Margerison	Scottish Officer, Royal College of Paediatrics and Child Health
Isobel McCallum	Clinical/Project Director – Re-provision of Royal Hospital for Sick Children Edinburgh
Jackie Sansbury	Director of Strategic Planning – NHS Lothian
Rebecca Strachan replaced by Anne Wilson	Action for Sick Children Scotland
Iain Wallace	Associate Medical Director, NHS Greater Glasgow and Clyde, Women's and Children's Directorate
Professor George Youngson	Consultant Paediatric Surgeon, NHS Grampian

SCOTTISH GOVERNMENT REPRESENTATION

Ian Bashford replaced by Louise Smith	Senior Medical Officer, Health Directorate
Andrea Cail	Senior Project Manager, Children and Young People Specialist Services Team
Colin Cook	Head of Healthcare Planning and Support, Health Directorate
Rory Farrelly	Nursing Officer, Women and Children, Health Directorate
John Froggatt	Child and Maternal Health Division, Health Directorate
Jacqui Lunday	Allied Health Professions Officer, Health Directorate
Margaret McGuire	Nursing Officer, Health Directorate
Ken Mitchell	Senior Project Manager, Children and Young People Specialist Services Team
Robert Stevenson	Head of Children's Specialist Services Team, Health Directorate
Wendy Wilkinson replaced by Joanne Gillies	Workforce Unit, Health Directorate

Glossary

AfC	Agenda for Change
AHP	Allied Health Professional
CHP	Community Health Partnership
CHSG	Child Health Support Group
CSA	Child Sexual Abuse
CYPHSG	Children and Young People's Health Support Group
DGH	District General Hospital
DMD	Duchenne Muscular Dystrophy
ECLS	Extracorporeal Life Support
ENT	Ear, Nose and Throat
GP	General Practitioner
HDL	Health Department Letter
HIV	Human Immunodeficiency Virus
ISD	Information Services Division
ITU	Intensive Treatment Unit
JIA	Juvenile Idiopathic Arthritis
MCN	Managed Clinical Network
MMC	Modernising Medical Careers
NES	NHS Education for Scotland
NHS	National Health Service
NIHCE	National Institute for Health and Clinical Excellence
NSG	National Steering Group
NSD	National Services Division
PA	Programmed Activity
PICU	Paediatric Intensive Care Unit
PTC	Principal Treatment Centre
SCG	Strategic Commissioning Groups
SWISS	Scottish Workforce Information Standards Systems
WTR	Working Time Regulations

National Delivery Plan

For Children and Young People's Specialist Services in Scotland In Scotland

Response Sheet

This consultation exercise is intended to help shape the provision of health care and other services for children and young people in Scotland. This response paper should be read in conjunction with the report *National Delivery Plan – for Children and Young People's Specialist Services in Scotland*

You need not comment on all of the content of the document and can focus on those areas in which you have a particular interest.

Responding to this consultation paper

We are inviting written responses to this consultation paper by **Tuesday 27th May 2008**. Please send your response to: childandmaternalhealth@scotland.gsi.gov.uk , or via the Internet, or to

The Child and Maternal Health Division
Scottish Government Health Department
Ground Rear
St Andrew's House
Edinburgh EH1 3DG
Fax: 0131 244 4775

Handling your response

We need to know how you wish your response to be handled and, in particular, whether you are happy for your response to be made public. Please complete and return the **Respondent Information Form** as this will ensure that we treat your response appropriately. If you ask for your response not to be published we will regard it as confidential, and we will treat it accordingly.

All respondents should be aware that the Scottish Government are subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise.

Next steps in the process

Where respondents have given permission for their response to be made public (see the attached Respondent Information Form), these will be made available to the public in the Scottish Government Library by end July 2008. We will check all responses where agreement to publish has been given for any potentially defamatory material before logging them in the library or placing them on the website. You can make arrangements to view responses by contacting the SG Library on 0131 244 4565. Responses can be copied and sent to you, but a charge may be made for this service.

What happens next?

Following the closing date, all responses will be analysed and considered along with any other available evidence to help us reach a decision. The draft National Delivery Plan will be adjusted to reflect comments received and the intention is that it will be published in the summer of 2008 as guidance from the Scottish Government.

Comments and complaints

If you have any queries or comments about how this consultation exercise has been conducted, please send them to: Gillian Garvie, The Child and Maternal Health Division , Scottish Government Health Department, Ground Rear, St Andrew's House, Edinburgh EH1 3DG. E-mail: gillian.garvie@scotland.gsi.gov.uk. If you would like this response sheet in another format or language, please contact Mary Sloan on 0131 244 4086.

RESPONDENT INFORMATION FORM: National Delivery Plan – for Children and Young People’s Specialist Services in Scotland

Please complete the details below and return it with your response. This will help ensure we handle your response appropriately. Thank you for your help.

Name:

Postal Address:

1. Are you responding: (please tick one box)
- (a) as an individual go to Q2a/b and then Q4
- (b) **on behalf of** a group/organisation go to Q3 and then Q4

INDIVIDUALS

2a. Do you agree to your response being made available to the public (in Scottish Government library and/or on the Scottish Government website)?

- Yes (go to 2b below)
- No, not at all We will treat your response as confidential

2b. Where **confidentiality is not requested**, we will make your response available to the public on the following basis (**please tick one** of the following boxes)

- Yes, make my response, name and address all available
- Yes, make my response available, but not my name or address
- Yes, make my response and name available, but not my address

ON BEHALF OF GROUPS OR ORGANISATIONS:

3 The name and address of your organisation **will be** made available to the public (in the Scottish Government library and/or on the Scottish Government website). Are you also content for your **response** to be made available?

- Yes
- No We will treat your response as confidential

SHARING RESPONSES/FUTURE ENGAGEMENT

4 We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for the Scottish Government to contact you again in the future in relation to this consultation response?

- Yes
- No

National Delivery Plan – for Children and Young People’s Specialist Services in Scotland

If you wish to comment on the National Delivery Plan please use this response sheet and use the consultation document.

Section 1- Introduction

1. We would welcome your views on the issues and recommendations raised in this section.

Section 2 - Why Change is Needed Now

2. Do you think that the key challenges facing specialist children’s services are sufficiently described.

3. Are there any additional challenges that you think should be highlighted.

Section 3 - The Way Forward – A National Delivery Plan

4. We would welcome your views on this aspect of the plan.

Section 4 - Making it Happen - Supporting Service Delivery

CHILDREN'S CANCER SERVICES

5. We would welcome your views on the recommendations for the future of Children's Cancer Services in Scotland.

CYSTIC FIBROSIS AND INHERITED METABOLIC DISEASES

6. We would welcome your views on the approach being proposed for cystic fibrosis.

7. We would welcome your views on the approach being proposed for inherited metabolic disease.

PAEDIATRIC RHEUMATOLOGY

8. We would welcome your views on the recommendation for the future of Children's Rheumatology services in Scotland.

GENERAL SURGERY OF CHILDHOOD

9. We would welcome your views on the recommendations outlined for the provision of General Surgery of childhood.

ROLE OF NETWORKS

10. We would welcome your views on the recommendations outlined in this section.

Managed Service Networks

11. We would welcome your views on the concept of a service network model for specialist services for children.

Telemedicine

12. We would welcome your views on the recommendations for telemedicine.

PLANNING AND COMMISSIONING

13. We would welcome any comments you may have on the recommendations in this section of the National Delivery Plan.

WORKFORCE

14. We would welcome your views on the recommendations outlined regarding workforce, education and training.

IMPROVING QUALITY - PERFORMANCE MANAGEMENT

15. Are the proposed recommendations sufficient to monitor the implementation of the National Delivery Plan.

16. We would welcome your views on the establishment of a:

- Child Health Collaborative programme
- Child Health Alliance

SECTION 5 Age Appropriate Care

17. Are there any aspects of age appropriate care provision not sufficiently covered within either the text or recommendations.

Further copies of this document are available, on request, in audio and large print formats and in community languages. Please contact 0131 244 3581

Jeśli chciałby/chciałaby Pan/i otrzymać tłumaczenie tego dokumentu, proszę o kontakt z biurem Prokuratury Okręgowej.

اس دستاویز کی مزید کاپیاں آڈیو کیسٹ پر اور بڑے حرف کی چھپائی میں اور کمیونٹی کی زبانوں میں طلب کیے جانے پر دستیاب ہیں، براہ مہربانی اس پتے پر رابطہ کریں:

এই ডকুমেন্ট-এর (দলিল) অভিভিক্তা কপি, অডিও এবং বড়ো ছাপার অক্ষর আকারে এবং সম্প্রদায়ের লোক ভাষায় অনূদানের মাধ্যমে পাওয়া যাবে, অনুগ্রহ করে যোগাযোগ করুন:

Gheibhear lethbhreacan a bharrachd ann an cruth ris an èistear, ann an eò mòr agus ann an cànanain coimhearsnachd. Cuir fios gu:

इस दस्तावेज/कागजात की और प्रतियाँ, माँगें जाने पर, ऑडियो टैप पर और बड़े अक्षरों में तथा कम्यूनिटी भाषाओं में मिल सकती हैं, कृपया संपर्क करें:

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此文件有更多備份，如果需要，語音版本和大字體版本及少數種族語言版本也可提供，請聯絡：

يمكن أن تطلب النسخ الأخرى من هذا المستند كالتسجيل الصوتي والخط الكبير ونسخ بلغات أخرى، يرجى الاتصال على:



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