

**REVIEW OF TERTIARY PAEDIATRIC  
SERVICES IN SCOTLAND  
DRAFT REPORT  
CHILD HEALTH SUPPORT GROUP**

CHSG

NOVEMBER 2004

## PREFACE

Tertiary services in paediatrics have seen a scale, pace and complexity of change within the Scottish health service of a degree that can make it difficult for its workers to keep abreast of the implication of these alterations to the service. However most, if not all, of these changes had service improvement, quality assurance, and the patient and staff safety at their heart. The current series of changes, statutory, commissioned, and contractual has truly tested the ability of the service to respond. Expertise and commitment are crucial ingredients of the service, current and past, and their retention is the essence of the future.

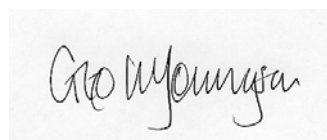
The coming together of several important and influential changes in medical education, workforce issues, working time legislation and role redefinition within healthcare makes an analysis of the current service an opportune and timely event.

This review comes about partly as a way of engaging those providing complex care for Scotland's children and sensing how we might steer a course through the predicted challenges of the next few years – to modernise and keep tertiary services proactive and responsive. This service lacks the flexibility which adult tertiary services enjoy due to the considerably smaller number of dedicated staff spread over a wide geographical area. The dependency upon this dedicated team makes it all the more important that these few are sustained, supported and developed when new ways of working are proposed.

The aim of this review is to ensure that tertiary care for Scotland's children is preserved at the highest level of quality whilst continuing and maintaining the provision of paediatric services where appropriate in other settings in Scotland. This review, therefore, explores difficult areas, builds on the expertise of the current workforce and makes recommendations that are needed to create a robust service for tertiary paediatrics in Scotland.

I can only thank the many people who have contributed directly and indirectly to this report, in giving up their valuable time and energy which has provided the impetus for the recommendations that will provide the foundation for the sustainable delivery of care for future generations of children and young people in Scotland.

The pace of change in NHS Scotland has increased with children being identified as a particular work stream in "The National Framework for Service Change in the NHS in Scotland". This report represents a major step forward in the ongoing debate and will be submitted from the CHSG as part of our contribution to that process.



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## EXECUTIVE SUMMARY

After visiting every NHS area in Scotland the Child Health Support Group was asked by the Minister for Health and Community Care to develop 5 streams of work which included this national review of specialist paediatric services. As well as the issues identified by the CHSG during these visits, the review considered the challenges facing the NHS in Scotland including:

- effect of the new deal, working time legislation and consultant contract upon individual's medical contribution to the service;
- agenda for change;
- shortened training programmes as part of modernising medical careers;
- changes in the demography of Scotland's children;
- advances in developments in medical care of seriously ill children;
- expectation for improving outcomes of care.

The fact that these services are provided by a relatively small number of carers in comparison to adult tertiary services reduces the flexibility of tertiary paediatrics in being able to respond to these disparate challenges.

The issues raised by the Kennedy Report into cardiac services for children in Bristol set a challenging context for Scotland's paediatric services as well as setting a framework to ensure continuous improvements in access to and quality of healthcare.

The review is firmly based in an approach developed after consultation with the service and involved four pilot specialties chosen for the first phase which covered complex respiratory, oncology and malignant haematology, gastroenterology and hepatology and neurology. A core group was established to act as a reference group which included Child Health Commissioners, regional planners, health professionals and lay participation (appendix one).

The approach covered the current status of the specialties involved, gaps in current provision, potential solutions and the opportunity to put forward models of care which would meet the requirements of a modern 21<sup>st</sup> century health service. Engagement with clinicians was an important part of the review process and specialty representation at review meetings was complemented with written presentations.

The outcomes from the review were considered at a national conference held on 11 June 2004 in Dunblane and this gave an opportunity for wider participation from health professionals and those who have experience of service provision. It also allowed expertise and experience from other review processes both within and outwith Scotland to expand and inform the review process.

This report is the first phase of a review process which will proceed to be considered by the Child Health Support Group and will constitute one part of the Action Framework for child health. The National Framework for Service Change and National Workforce Units as well as Quality Improvement Scotland and NHS Education Scotland are also destinations for the review recommendations.

The health, welfare and treatment of children and their families remain at the centre throughout this review recognising also that the services themselves need to be supported so they can provide optimal care. The recommendations from the review have been formulated when possible on scientific or published evidence and in keeping with output from the pilot reviews and outcomes based on discussion from the national conference.

The recommendations that have been identified during the review process have been grouped into the following categories:

- **Strategic and Organisational Aspects** that should be addressed to ensure tertiary services continue to be delivered in the future.
- **Workforce issues** including the development of staff fit for purpose and Agenda for Change, European Working Time Legislation and Modernising Medical Careers.
- The development of **Models of Care** that meet the challenges set out in this report.
- The need to deal with the **Age Barriers and Access to Services** and the inconsistencies that currently exist throughout Scotland.
- **Pilot Reviews-Speciality Specific Recommendations**
- **The Next Steps** which identify how the outcomes of the review should be progressed

The full review recommendations are provided below.

## RECOMMENDATIONS

### Strategic and Organisational Aspects

- i. The gaps in strategic and operation planning support provided to specialist paediatric services in Scotland and the issues described in this report would indicate that child health should be restored as a National Health Service priority by the Scottish Executive. (Page 21)
- ii. A clear management structure for children's health services in Scotland which includes national planning and collaborative commissioning for children and young people's services should be established. This would provide a professional and public profile for Children and Young People's Health Care in Scotland which will help to deal with the very pressing issues identified in this report. (Page 21)
- iii. The role of NHS Regional Planning Groups in respect of planning services for Children and Young People should be strengthened to meet the requirements of the Integrated Planning Guidance for Children's Services and collaborative working identified in the NHS (Reform) Act 2004. (Page 21)

- iv. The role of Child Health Commissioner should be reviewed by NHS Boards in light of recent developments in children's service planning and the recommendations made by the CHSG. (Page 21)

### ***Configuration of sites – "location/location/location"***

- v. That the Scottish Executive carries out a robust option appraisal exercise that reviews the potential options for providing sustainable paediatric tertiary services for Scotland. (Page 24)
- vi. Recognising the timescale for Regional Planning Groups and NHS Boards to complete the tertiary co-location exercise may take up to five years, collaboration between the 3 regional planning groups at a national level will be required to sustain tertiary services. (Page 24)

### ***Co-location of Paediatric Acute Services***

- vii. Children's specialist acute services should be co-located with adult, maternity and neonatal services; however the distinct nature of children's services as highlighted by the Bristol Inquiry (Kennedy Report) should be protected and preserved. (Page 25)
- viii. This should be progressed as a matter of urgency in Edinburgh and Glasgow where new co-located children's hospitals in Edinburgh and Glasgow are recommended. (Page 25)

### **Information and Data collection**

- ix. SEHD and NHS Scotland develop information systems and clinical databases that support the provision of a 21<sup>st</sup> century service fit for purpose. (Page 25)

### **Workforce Issues**

- x. This review demonstrated a significant shortfall in the numbers of specialists delivering the service in each pilot speciality. However the numbers required to deliver a sustainable Tertiary service to the population of Scotland will depend on the configuration of services and models of care adopted. Regional Planning Groups, NHS Boards and workforce planners need to take these factors into account when they define the numbers of specialist staff required. These issues need to be addressed in the context of the National Framework for Service Change (Page 27).
- xi. We commend the National Workforce Committee in conjunction with NES, NHS Boards and Regional Planning Groups reviews future work force requirements for paediatric services to ensure their sustainability by:
  - Defining the number of trainees required for succession planning.
  - Producing workforce models that identify the numbers of staff required to deliver the changes in service provision that are identified at a national, Regional and Board level. (Page 27).

- xii. The Scottish Executive and Postgraduate Deans should explore the potential to match post-CCT (Certificate of Completion in Training) to the workforce needs of specialist services. (Page 27)
- xiii. That NES, in conjunction with NHS Boards, Professional Organisations leads the establishment of an agreed curriculum that develops the core skills and competencies of staff to support the development of the Hospital at Night concept in Scotland This must ensure a consistency of approach so that staff in future are able to transfer to new areas and have their roles and competencies acknowledged and accepted. (page 29)
- xiv. The NHS in Scotland and NES develops new roles for health care workers that embraces the concepts of Advanced Practitioner, Clinical Site Practitioner, Nurse Consultant, AHP Consultant and Clinical Support Staff (Page 30)

### **Models of Care**

- xv. A clear mechanism needs to be established for the commissioning of MCN's in Scotland at both national and regional level that is sensitive to the needs of children and young people. (Page 31)
- xvi. Managerial and clinical governance arrangements should be reviewed for those informal networks already introduced. (Page 31)
- xvii. The review endorses early implementation of the "Hospital at Night" model in Scotland for meeting out-of-hours and emergency pressures and that NHS Boards review, as a matter of urgency, paediatric provision in their areas to ensure compliance. (Page 32)
- xviii. Telemedicine is seen as a key element of service development in 21<sup>st</sup> century services and the lessons from the STAF Telemedicine Project should be rolled out to the other paediatric specialities in Scotland. (Page 32)

### **Age Barriers and Access to Services**

- xix. NHS Scotland should adopt an age of up to their 16th birthday, dependent on their clinical need, for admitting children and young people to acute care. (Page 33)
- xx. The SEHD, Regional Planning Groups and NHS Boards should address the lack of provision of age sensitive services in Scotland especially for young people who find themselves caught in the existing fault line between paediatric and adult services. (Page 33)

## **Pilot Reviews-Speciality Specific Recommendations**

### ***Paediatric Gastroenterology***

- xxi. Each region should review its paediatric dietitian/nutrition service redefining the roles of nutrition nurse and dietitian as clinical leaders within each regional network. (Page 33)
- xxii. The 3 Regional Planning Groups assesses how they will ensure the provision consultant cross-cover for development of a continuous consultative service for Scotland. (Page 33)

### ***Paediatric Neurological Medicine***

- xxiii. Paediatric neurology should continue to develop regional managed clinical networks such that there is equity of access within regions. (Page 33)
- xxiv. Development of nurse and AHP provided services within each region must be developed to support regional neuro-disability care. (Page 33)
- xxv. Regional networks appear to be a solid method for providing services in this specialty and should include the following:
  - That a paediatric consultant is designated to take the lead for neurology/neurodisability in each NHS Board area
  - Tertiary outreach provision is developed for each NHS board area in Scotland
  - Age appropriate services are developed to enable transition as children grow older (Page 34)

### ***Paediatric Oncology and Malignant Haematology***

- xxvi. The review recommends development of a national cancer service for children and young people. (Page 34)
- xxvii. Reconfiguration of the service should be considered, as a matter of urgency, through use of an option appraisal exercise led by an external Chairman and including the parties with responsibilities for planning and management at regional level, as well as those responsible for delivery of the clinical service. (Page 34)
- xxviii. That NHS Scotland considers the NICE recommendations, which will be published in 2005, for providing children's cancer services and implements them in the Scottish context. (Page 34)

### ***Complex Respiratory Services***

- xxix. Consideration should be given to the home ventilation service for children becoming a national service with a lead centre with involvement and representation of the four specialist centres in Aberdeen, Dundee, Glasgow and Edinburgh. (Page 34)

- xxx. Services for cystic fibrosis in children become a national managed clinical network with a lead clinician and supporting infrastructure. (Page 34)
- xxxi. Complex respiratory care for example severe asthma, bronchoscopy services, physiological laboratory service be managed at regional levels. (Page 34)
- xxxii. Respiratory support teams including social work, physiotherapists, dietitians, specialist nurses and physiology technicians are developed in each region. (page 34)

### **Next Steps**

- xxxiii. This report will be submitted by the CHSG to the Specialist Paediatric Sub-group of the National Framework for Service in Change in Scotland to inform its conclusions and recommendations. (Page 35)
- xxxiv. Further work will be taken forward with the Scottish Paediatric Haematology and Oncology Group and Regional Planning Groups to develop and implement a model of care for providing this service on a Scottish wide basis in a sustainable way. (Page 35)
- xxxv. A number of services have been highlighted during the review as requiring action. Once the National Planning Framework has concluded, some services may still require review:
  - Neonatal Intensive Care
  - Metabolic disease
  - Endocrinology and Diabetes
  - Dermatology
  - Paediatric Radiology
  - Paediatric Pathology, Biochemistry and Haematology
  - Rheumatology
  - Immunology/ Infectious Disease (Page 35)
- xxxvi. The Child Health Support Group should work with the National Framework for Service Change Group to examine the interface between tertiary and secondary paediatrics. (Page 35)
- xxxvii. Because of the current pressures being experienced in paediatric intensive care services and in paediatric surgery, we are recommending that they are the subject of a specific study to evaluate:-
  - the current status of paediatric intensive care and in particular provision of high dependency throughout Scotland
  - the current method of service delivery at secondary level, in children's surgical specialties and the relationship of that activity with the tertiary sector. (Page 35)
- xxxviii. Involvement of patient's representatives, Allied Health Professional's, nursing and other staff should be fully engaged in these exercises. (Page 35)

## BACKGROUND TO THE REVIEW

1. Paediatric care in Scotland has a long tradition with Scottish children's hospitals and paediatric units contributing substantially to developments in children's medicine over the years. The flexibility of the service to react to national and local need continues but there are now certain influences, which constrain individual responsiveness and contributions, and yet, the expertise and responsibilities at tertiary care level resides in the hands of a relatively small number of clinical staff. This creates uncertainty and tension over the sustainability of these services at an institutional and even at national level.

2. The pressures identified in the SEHD Circular HDL (2003) 43<sup>1</sup>, published in September 2003, sets out the basis for this Scottish wide review of paediatric tertiary services and described the overall process for taking the exercise forward. The pressures identified within the circular included:

- The issues that arose from the Bristol Royal Infirmary<sup>2</sup> paediatric cardiac surgery inquiry.
- the drive towards continuous improvement in access and quality of health care.
- the need to reduce waiting times.
- sustaining low volume highly specialised services in Scotland.
- the impact on the workforce of European working time legislation and changes in medical training.
- The need to ensure appropriate training and development opportunities for staff.

3. There has also been considerable activity undertaken in relation to the development of definitions for delivery of specialist services for children including the Scottish Executive Health Department –Guidance on Planning for Health Care Services<sup>3</sup>, Royal College of Paediatric and Child Health<sup>4</sup> and the Department of Health- Specialist Definitions for Children's Services<sup>5</sup>. Therefore we have utilised the following definition of tertiary services as a service that provides care for one or more of the following groups of children:

- with rare and severe medical problems
- with severe forms of more common conditions
- with common problems, complicated by co-morbidity
- at risk by virtue of their age (less than 44 weeks post conceptual age);
- who fail to respond to conventional therapy.

<sup>1</sup> NHS HDL (2003) 43 Review of Specialist Paediatric Services, September 2003

<sup>2</sup> Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary, January 2002

<sup>3</sup> NHS HDL (2002) 10, NHS Scotland: Guidance on Regional Planning for Health Care Services

<sup>4</sup> Commissioning Tertiary services for Children, Royal College for Paediatric and Child Health, May 2004

<sup>5</sup> Department of Health, Guidance on Arrangements for Commissioning specialised Services, March 2003

4. This review was promoted by the workforce pressures referred to below but also through recognition of the shift in design of postgraduate training as well as the development of new roles within healthcare. These are all making an important inroad into the way that treatment is delivered. The infrastructure and design of the services upon which this activity can take place continues to change quickly. Rather than merely reacting to these changes, future services can respond to the challenges contained in Modernising Medical Careers (MMC's), European Working-Time Directive (EWTd), Securing Future Practice, and Agenda for Change by creating a foundation that will ensure future sustainability.

5. It is acknowledged at the outset that this change affects not only those in the medical workforce, but all providers, including therapists, nursing staff, support services and indeed has a huge effect upon the other users of tertiary paediatrics. The reference to the term clinician throughout this report, is inclusive of therapists and nurses.

6. The reduction in individual working contributions in medicine is predicated by legislative change and the availability of mid-grade medical staffing. This has been emphasised by a shift from the service contribution of this group to education and learning (some of which is required from experience gained during service delivery) and at consultant level, by contractual agreement with employers which formalise a hitherto almost "laissez faire" approach.

7. Initial calculation of the size of the medical workforce required to provide continuity of care indicates that it will be an exception for any specialist paediatric unit within a single hospital to be self-sufficient at any grade of staffing. Indeed the cross covering arrangements which have been an essential element of meeting the needs of New Deal<sup>6</sup> and more recently European Working Time Directive<sup>7</sup> are a potential solution to meet the needs of cover at consultant level. There is an important element to this however, which is the level at which cross cover occurs. At mid-grade and junior medical staff level this is at unit level within hospitals. At consultant level, however the cross-cover needed to sustain the national service may need to be at national level, i.e. collaboration between existing hospitals.

8. There are many reconfiguration options available, which extend beyond merger and centralisation. The designation of national services, formation (either formally or informally) of managed clinical networks, development of outreach/inreach services, harnessing the power of tele-medicine, embracing the creation of multi-disciplinary teams to evaluate and stabilise acutely ill patients - are all examples of the options available to us. However the solutions to any given problem are only achieved through analysis, interpretation of the problem and commitment from staff working with children to deliver the change required to ensure the delivery of services in the future.

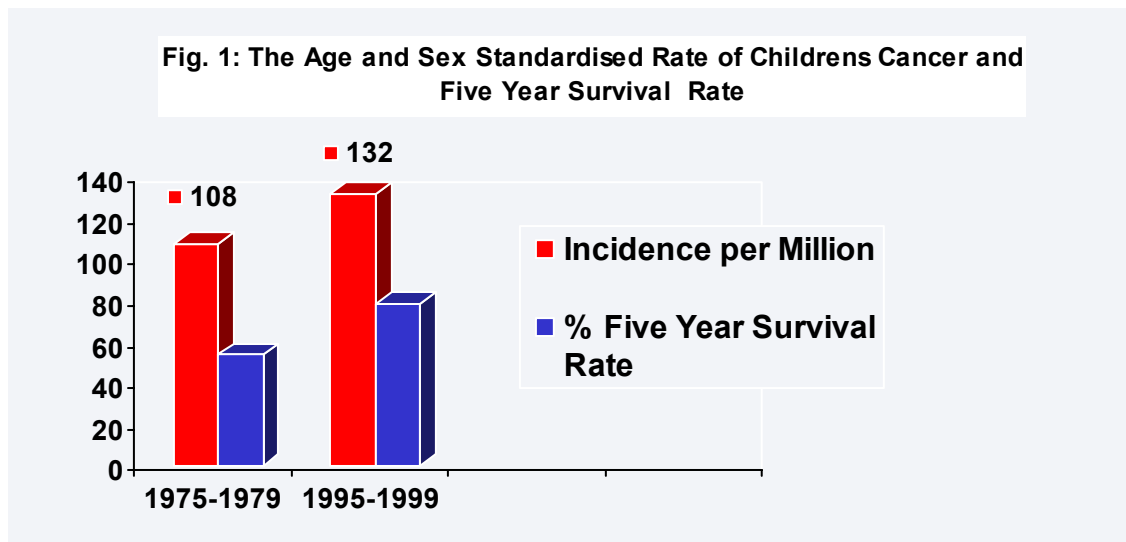
9. There is clearly recognition that the current design and delivery of tertiary services is unsustainable in the mid to long-term and indeed for some there is an immediate problem of continuity of the service at current levels of staffing. Added to

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<sup>6</sup> Junior Doctors, Contract Implementation guidance, HDL (2000) 17

<sup>7</sup> The Working Times Regulations 1998 (As Amended), Statutory Instrument 1998 no. 1833

that is the desire to maintain and increase standards of care and outcomes<sup>8</sup> (fig. 1) whilst also wishing to ease access to tertiary services from all parts of Scotland experiencing remoteness through either the geographic location (be that either rural or inner city) or having difficulty in communication with the health service for other reasons.



10. When undertaking the exercise it soon became apparent that the required information on workforce and activity was not readily available at a national level. Therefore, the process of analysis has involved data collection directly from tertiary services involving specialties where there was already a certain familiarity with the current pressures. The paediatric specialties of gastroenterology, oncology, complex respiratory disease and neurological services were chosen to lead us into the review. Both common and unique concerns have emerged from the evaluation process. It is the purpose of this review to take forward these concerns into subsequent phases of our work plan that will ultimately encompass all paediatric tertiary services, allied supporting services and the important interfaces with training and education with NHS Education Scotland and Scottish Universities.

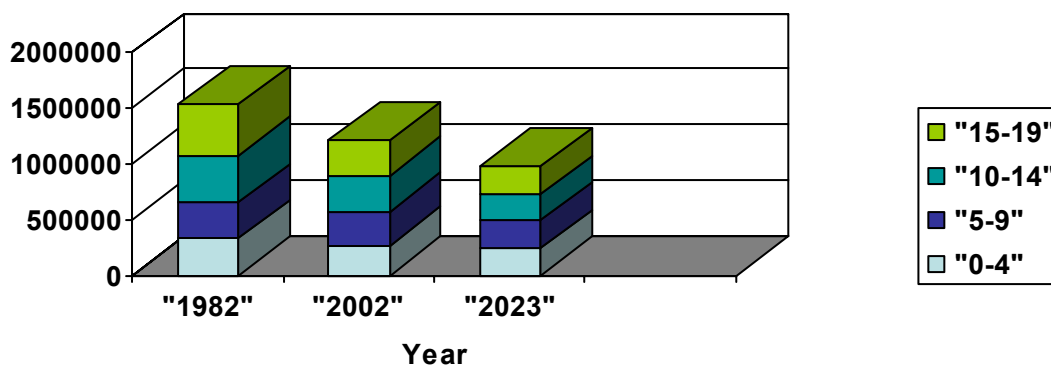
11. There is consistency of opinion throughout all elements of Child Health in Scotland that the priority previously enjoyed by Child Health, should be restored. The review also recognises that parallel strategic activity exists in the development taking place”, in the “National Framework for Service Change in the NHS in Scotland and the subsequent “Action Framework for the Health of Children and Young People in Scotland and it is expected that the outcome of this review will inform both processes.

12. However we need to recognise that ownership of the information gathered belongs to the contributors, i.e. clinicians delivering the service, those involved in the review including Child Health Commissioners and representatives of regional planning groups and where consensus exists there will be a duty of responsibility for healthcare planners to absorb these recommendations and respond.

<sup>8</sup>NHS Quality Improvement Scotland, Children’s Health Services Steering Group, Scoping Report, July 2004

13. The review also takes cognisance of the recent and projected decline in the numbers of young people age 0 to 19 years of age which has fallen by approximately 20% from 1982 to 2002 and is estimated to reduce by a further 20% by 2023<sup>9</sup> (see Fig. 2). However offsetting this is the recognition of absolute increases in the incidence of conditions and number of disease processes affecting tertiary services, the increasing intensity of therapeutic interventions, and a real need to provide ever improving outcomes in care (Fig. 1).

**Fig. 2: Population Projections 1982-2023**  
Source:GRO



### Current Service Provision

14. Scotland is in the main, a comprehensive internal provider of tertiary services for children. Some services are accessed however on a UK wide basis for certain aspects of care, for example, cardiothoracic transplantation, liver transplantation, surgery for hypoplastic left heart syndrome and treatment of retinoblastoma. Similarly, Scotland will provide some supra-regional services for other parts of the United Kingdom, as with Extra Corporeal Membrane Oxygenation. Services which are provided on a Scotland-wide level include cardiac surgery and interventional cardiology, nephrology and renal transplantation, bone sarcoma surgery and transport of critically ill and injured children.

15. In the Scottish context, tertiary paediatric services are provided in the 3 children's hospitals in Aberdeen, Edinburgh and Glasgow with a range of tertiary services also being supplied from Ninewells Hospital in Dundee and some other acute hospitals in Scotland. Mono-specialty tertiary care occurs in neonatal units outwith these hospitals and in some freestanding surgical units in Scotland (e.g. neurosurgery).

16. All of these issues identified a pressing need for a national review of specialist tertiary paediatric services co-ordinated on a national basis and the approach adopted is described in the following section.

<sup>9</sup> General Registrars Office, Scotland, Population Estimates, 2002

## REVIEWING TERTIARY SERVICES IN SCOTLAND

### Review Remit

17. The remit of the review was set out in HDL (2002) 86 and HDL (2003) 43 (see Appendix 2) with the overall co-ordination of the exercise overseen by the Specialist Paediatric Services Sub Group of the Child Health Support Group. A specific working group was also established, which will report separately, upon the services in place and the future requirements for the “Care of Acutely Ill and Critically Injured Children”.

18. HDL (2003) 43 described a template and methodology which provided a standardised approach for the review of tertiary services. Almost 20 specialities were identified as potential services that could participate in the review process. After discussion with a range of stakeholders including Regional Planning Groups and Child Health Commissioners it was agreed that four specialist areas would be considered in the pilot phase of the exercise. Each pilot area was reviewed using the following ten parameters identified in the methodology:

• definition and scope of speciality;	• quality standards/outcome indicators;
• incidence and prevalence of conditions under consideration;	• review of education and information;
• mapping current services;	• identify current research;
• review of current practice;	• implications for stakeholders;
• workforce planning and training;	• possible options for service delivery;

### Review Process

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

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

## Pilot Reviews

20. The Specialist Paediatric Services Sub Group invited clinicians from paediatric specialities to present an overview of the services they provided and the issues they expected would affect them in the coming years. After the launch of HDL (2003), 43 in September of that year four specialities were approached to pilot the methodology. It was recognised at the outset of the review that the review process should follow certain parameters:

- All tertiary services should ultimately be reviewed unless previously and recently subjected to a separate and specific review process for example paediatric intensive care, paediatric cardiology (as part of paediatric cardiac surgical review process) and paediatric nephrology (as part of the paediatric renal transplantation review).
- The outcomes, conclusions and recommendations are factually based on available information produced by clinicians for the purposes of the review.
- Clinical opinion should be the foundation of advice given, contribution to the process and recommendations made.
- The approach to the review would involve 3 separate phases with this initial phase acting as an opportunity to pilot the methodology before rolling out the approach to other specialities.
- In implementing the pilot phase concerns that the multiplicity of interactions involved in tertiary care may result in some groups of healthcare workers or sectors of care being overlooked was recognised.

21. Paediatric gastroenterology, oncology and malignant haematology, respiratory medicine and neurology were chosen as pilot reviews for a number of reasons, including the acute pressures being felt in current service provision and the emergence of networks from collaborative working amongst clinicians in Scotland. Existing networks that had a National/Scottish specialty focus were used as the access to clinical opinion and a lead clinician in each group was approached to co-ordinate the process. The groups who participated in the pilot reviews were: -

- SPHOG (Scottish Paediatric Haematology and Oncology Group)
- SPRING (Scottish Paediatric Respiratory Interest Group)
- SPGHNG (Scottish Paediatric Gastroenterology, Hepatology and Nutrition Group)
- SPNG (Scottish Paediatric Neurology Group)

22. All were willing contributors to the review process and the Child Health Support Group is indebted to these groups and their leads for their efforts.

23. Clinicians involved in the four specialties were asked to provide an overview of the factors described in the template and put forward which option best promoted a sustainable service. The full reports are available on request and summaries are included later in this report in appendix 3.

## National Conference 'Tertiary Services for Children in Scotland – Planning for the Future'

24. The outcomes from the pilot reviews were considered at a national conference "Tertiary Services for Children in Scotland – Planning for the Future" held on the 11 June 2004 (see appendix 3) along with input from the following keynote speakers:

- Malcolm Chisholm, Minister for Health and Community Care - Setting the Scene
- Professor Sir John Temple, author of "Future Practice and Securing Future Practice - Securing the Future – The Challenges"
- Dr Huw Jenkins, Director of Healthcare Services for Children and Young People, The National Assembly for Wales - The Welsh Experience
- Judith Ellis, Head of Nursing, Great Ormond Street Hospital - Promoting clinical excellence; advancing practice, research and education; development of the new nursing role

25. The aims of the conference were to:

- engage with patient representatives, clinicians, nurses, allied health professionals and staff working with children in Scotland;
- listen and learn from the current experience in the NHSiS;
- share information from work in other areas;
- consider standard setting and quality assurance for children's services;
- consider lessons from the pilot review;
- generate solutions to existing issues;
- consider what tertiary services will look like in the future and next steps needed to secure these objectives;

26. At the conference, the Minister for Health and Community Care made the following announcements which had a direct bearing on the future direction of the review process:

- The Child Health Support Group to develop an over-arching framework for action for child health, drawing together the existing plans, policies and strategies.
- The National Framework for Service Change in the NHS in Scotland will have a distinct stream of work dealing with the service change required to plan and deliver children's services in the longer term.
- The creation of a post for National Clinical Lead for Children and Young Peoples Health Services in Scotland to take the framework activity forward.

## **Public Involvement**

27. The importance and relevance of inclusion of the public in this process is self-evident and Action for Sick Children (Scotland) agreed to participate in the core group of the review to act as representatives of families and the public and to function as advocates. Many non-clinical bodies are essentially involved in the care of the users of tertiary paediatric services but for pragmatic reasons Action for Sick Children (Scotland) was considered, the most appropriate and accessible body for representative inclusion.

28. Similarly, the way in which changes in the service will affect nursing and AHP services underlines the substantial inter-dependency that tertiary services have upon each other and the need for consultation with these groups. Attempts at understanding the complex synergy should be reinforced by strengthening the participation of the “user groups” in the next phase.

## **Report Publication**

29. Documentation of each stage has been carried out by developing reports that will be considered by the Child Health Support Group in the expectation that they would be placed in the public domain. It is also anticipated that this report will inform the National Framework for Service Change in Scotland, Action Framework for Children and Young Peoples Health Services in Scotland and be a resource for a number of concurrent reviews being carried out by the Scottish Executive Health Department.

## CHALLENGES FOR TERTIARY SERVICES IN SCOTLAND

30. The pilot specialities provided the opportunity to explore the main issues that they are facing and will impact on the future sustainability of these services. The national conference allowed the opportunity for a wider group of participants involved in providing these services and those who use them to explore these issues in more depth and consider the wider implications for paediatric services in Scotland. These issues are now explored in more depth and recommendations made to move the agenda forward. The main areas raised during the review process are included in the following sections:

- **Strategic and Organisational Aspects** that should be addressed to ensure tertiary services continue to be delivered in the future.
- **Workforce issues** including the development of staff fit for purpose and Agenda for Change, European Working Time Legislation and Modernising Medical Careers.
- The development of **Models of Care** that meet the challenges set out in this report.
- The need to deal with the **Age Barriers and Access to Services** and the inconsistencies that currently exist throughout Scotland.
- **Pilot Reviews-Speciality Specific Recommendations**
- **The Next Steps** which identify how the review should be progressed

### Strategic and Organisational Aspects

31. The complexity of tertiary services makes it difficult to identify any one management system to oversee this sector of care. Indeed it is probably undesirable to have it so managed given the dynamic between primary, secondary and tertiary care. Regional concerns vary amongst the same specialty for example there are concerns over access to cystic fibrosis services within different parts of Scotland and indeed inflammatory bowel disease similarly in various regions<sup>10</sup>.

32. It is equally important that there is an overarching mechanism to ensure that Scotland contains sufficient resource to meet the need of patients requiring tertiary care and that it is not simply produced as an optional extra when considering appointments in children's hospitals. This national strategic approach has previously been deficient and tertiary services have often developed opportunistically through the enthusiasm and interest of individual consultants within a unit or at best through a perceived need within a region. National strategy has been lacking in this respect and inconsistent for a number of years. Indeed in the event of tertiary units establishing a national service this has not always been complemented with robust funding arrangements for example initially when paediatric intensive care, including retrieval services were established although this has now been resolved.

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<sup>10</sup> Speciality Pilot Review Reports, 2004

33. The importance placed on collaborative working between NHS Boards and Special Health Boards in the NHS (Reform) Act 2004 is recognised, hence the involvement of representatives of each planning group in the review core group. An important balance exists in sustaining specialist services at regional level within Scotland while maintaining equity of access at a national level. This in itself reinforces the need for regional consideration during formation of a national service and vice-versa the recognition of national requirement in the work of regional planning groups.

34. A consistent theme that has emerged throughout the review process has been the difficulty in getting tertiary paediatric service issues on the agenda of NHS Boards and Regional Planning Groups. The reason often cited for this is the lack of priority given to child health by NHS Scotland, however a clear pattern has emerged from the findings of the pilot reviews and discussions that have taken place during this exercise that the infrastructure supporting tertiary care delivery does not meet the demands of the modern NHS.<sup>11</sup>

35. The remit of the review was directed towards the integration of regional planning groups into the review's function. This acknowledges the importance of identifying optimal economies of size when considering healthcare within Scotland. This review takes this process one stage further and recognises that children constitute approximately 20 per cent of Scotland's population spread over a large geographical area and hence when considering these services at a tertiary level, an important aspect will be the national implication of local appointments. It is anticipated that the implementation of the review's findings while informing regional planning groups, will also inform the work of the National Framework for Service Change allowing both local and national need to be accommodated when developing and supporting tertiary services.

36. The pivotal and important role of Child Health Commissioners as identified in the Kennedy Report into the Bristol Enquiry<sup>12</sup> and Child Health Template<sup>13</sup> was also included within the review in both a representative presence on the core group but also through regular communication within the activity of the Child Health Support Group. The importance of the role is further described in the development of arrangements for the development of Integrated Children's Service Plans for 2005-2008<sup>14</sup> and the impact of Community Health Partnerships<sup>15</sup>

37. One of the demerits of the existing service is that the gain of identifying children's hospitals as distinctly different from adult hospitals, has the potential for introducing elitism into the service and for primary and secondary care to be considered as in some way less important. This is patently untrue but development of a corporate identity and an affiliation with a robust process of care would be at the same time supporting and supportive.

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<sup>11</sup>Speciality Pilot Review Reports 2004

<sup>12</sup> Recommendation 170, Report of the Public Inquiry in to children's heart surgery at the Bristol Royal Infirmary 1984-1995, 18 July 2001

<sup>13</sup> A Template for Child Health Services within Unified NHS Board Areas, Child Health Support Group, June 2001

<sup>14</sup> (Integrated Planning Guidance still to be released)

<sup>15</sup> (CHP Guidance still to be released)

38. The review recognised the gains illustrated by extension of the clinical services offered at Great Ormond Street to include services extending to other hospital sites for example Middlesex Hospital. This “badging” of the service was described at the National Conference as an extremely useful way of aggregating disparate elements of the workforce and creating a unity and momentum to the service without stripping out resources from adjacent or satellite units.

#### **Review Recommendations:**

- i. The gaps in strategic and operation planning support provided to specialist paediatric services and the issues described in this report would indicate that child health should be restored as a national health priority by the Scottish Executive.**
- ii. A clear management structure for children’s health services in Scotland which includes national planning and commissioning for children and young people’s services should be established. This would provide a professional and public profile for Children and Young People’s Health Care in Scotland which will help to deal with the very pressing issues identified in this report.**
- iii. The role of Children and Young People’s Regional Planning Groups is strengthened to meet the requirements of the Integrated Planning Guidance for Children’s Services and regional planning in the NHS (Reform) Act 2004.**
- iv. The role of Child Health Commissioner should be reviewed by NHS Boards in light of recent developments in children’s service planning and the recommendations made by the CHSG.**

#### ***Configuration of sites – “location/location/location”***

39. There are many factors which influence where tertiary services have developed. The population base, the affiliation with academic centres, the critical mass created by aggregation of services and the interdependency in other services are but some. Our real concern is whether Scotland’s population can sustain the same number of centres given other pressures relating to continuous service provision referred to earlier.

40. It also recognises there are merits in some situations in condensing tertiary services to a single site and that a new tertiary centre for children has been suggested. Moreover a central location between Edinburgh and Glasgow would be equally advantageous and disadvantageous for these two large conurbations; however this model, whilst appropriate for the open “hot and cold” type of model is in conflict with the Kennedy recommendations of co-location unless there was a contemporaneous development of adult services on the same site.

41. The strategic decisions taken by the Scottish Executive will have a major bearing on the provision of tertiary services in the future and if we can maintain the current level of children's hospitals and inpatient units in Scotland. The major service issues that will impact on this are:

- How many Paediatric Intensive Care Facilities will be provided in Scotland? If there is to be one PICU instead of the existing two site model, then quite clearly a number of tertiary services will have to be provided from what ever site provides that service.
- The adoption of the Hospital and Night scheme would go some way to alleviate the workforce pressures that services are facing but will require investment in redesign, training and education.
- Investment in the children and young people's health workforce so that appropriate numbers of staff with the relevant skills are produced to meet the challenges of the future.

42. One of the main propositions being put forward at the current time to resolve these issues is the creation of one paediatric tertiary centre for Scotland. If the volume/outcome relationship was a simple one then merger would be given a force in strategic planning which it currently lacks. Volume/outcome relationships have been developed in few areas however paediatric intensive care and paediatric cardiac surgery are two where a direct benefit is seen. The medical literature however is devoid of references to volume /outcome studies in paediatric medicine apart from a few studies in relation to mortality and low birth rate infants.<sup>16</sup>

43. The counterbalance to immediately pursuing the centralisation agenda is the lack of capacity in existing centres to absorb additional activity and the need to plan expansion of existing or replacement facilities which can take as long as three to five years to realise significant capital build once the decision is taken to proceed.

44. This also has to be seen in the context of Scotland's geography where maintaining access to specialised services and interventions may require interactions with patients for relatively short periods of times. This has to be balanced with the large distances patients and their families and carers may have to travel to access these services. This is particularly important in relation to the evidence that is available that shows the child's recovery is enhanced if support is given from parents and carers during the healing process. The social and financial cost born by families, who find themselves in this situation, need to be discussed fully by those involved and addressed by the NHS in Scotland to alleviate what can be a very stressful experience which can result in high rates of family breakdown.

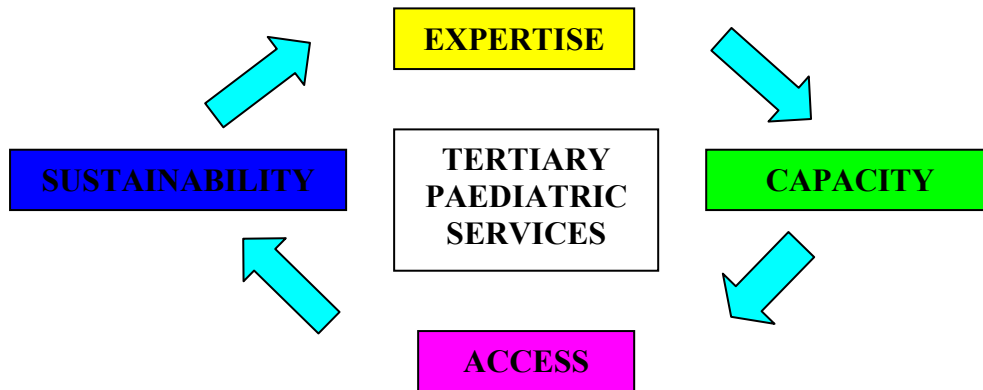
45. This drive towards centralisation should also be measured by the need to redesign services in way that takes account of the principle of providing care as close as possible to where the patient lives. Too often in the past the trend towards centralisation has been carried out without ensuring that services are in place to meet the requirements of providing care in either the secondary or primary care setting and redesigning services to meet the needs of patients.

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<sup>16</sup> Paediatrics 2002; 109: 745-751

46. Whilst the variables are numerous there are four important ones which impact on service delivery (see Fig 3):

Fig. 3 Key Variables impacting on the provision of Tertiary Paediatric Services



47. This balance applies not only to the three children's hospitals in Scotland but also to the children's inpatient facilities in acute general hospitals in Scotland.

48. Scotland has enjoyed a certain rivalry amongst centres which, for the most part, results in promoting output and standards of care. It is equally important that this does not result in elitism and divisiveness which demoralises and destabilises leading to unacceptable differentials in quality of care offered according to geographic location. Hence harnessing and utilising available expertise irrespective of the location is an objective best achieved through the network/collaborative approach to healthcare. This in turn fosters retention and recruitment equitably throughout Scotland and preserves a potential for high quality for care consistently.

49. The imperceptible divide between secondary and tertiary care extends itself to training where the difference between these services is expressed in training curricula in only a minor way. While it is acknowledged that the spirit of Modernising Medical Career's (MMC's) is focussed on producing a "judgement safe" generalist at an earlier stage, abbreviation of experiential learning and accelerating pattern of training is leading to the likely scenario that there will be the development of general CCT and post-CCT specialty training. This change may paradoxically produce fewer generalists and more specialists. Thus the specification of the next generation of graduates from specialist training is difficult to predict but tends to favour sustaining specialist services potentially at the expense of the secondary sector.

50. Recruitment of trained specialists will be more dependent on critical mass, overall specialty mix in the centre and training accreditation.

51. Preservation of existing boundaries of care has been challenged by the Temple Report "Securing Future Practice" and this report suggests that care provision would be best served by reflecting the existing economies of planning (3 regional planning areas). This would suggest a more formal aggregation of the north-east to include Highland/Grampian/Tayside. This is currently a functioning unit for a few paediatric services (neurology and gastroenterology) with different approaches

being utilised for in other specialties (oncology/paediatric surgery). Consistency across all specialties is commended along the lines of the second Temple Report.

52. Severance of existing patterns of referral need not be abrupt but an agreed regionalisation process requires effective management support which should be strengthened.

53. Access to tertiary services for rural communities is currently provided by a mix of providers. Children from Orkney and Shetland are referred to Grampian. Oncology in Highland is provided by Glasgow and endocrinology in Highland is provided by Lothian. Rationalisation of this service is overdue and a regional planning policy should achieve this. This should have the aim of producing consistent pathways of care so that interdisciplinary communication can be maximised.

**Review Recommendation:**

- v. That the Scottish Executive carries out a robust option appraisal exercise that reviews the potential options for providing sustainable paediatric tertiary services for Scotland.**
- vi. Recognising the timescale for Regional Planning Groups and NHS Boards to complete the tertiary co-location exercise may take up to five years, collaboration between the 3 regional planning groups at a national level will be required to sustain tertiary services. (Page 22)**

***Co-location of Paediatric Acute Services***

54. The existing paediatric tertiary centres have significant differences in their co-location arrangements; both Edinburgh and Glasgow have free standing children's hospitals though Royal Hospital for Sick Children Glasgow has historically shared a site with a large maternity hospital which provides regional and national services. We welcome the announcement from the Minister for Health and Community Care that will allow the provision of acute care for children in Glasgow to be provided with maternity and adult services on the same site. Similarly, location in central Edinburgh of Royal Hospital for Sick Children Edinburgh makes not only expansion difficult but access also problematic. The recommendation of the Kennedy Report on the Bristol Inquiry is that tertiary services should be provided as close as possible to Acute General Hospitals<sup>17</sup>. This is well-reflected in the design of Aberdeen's new children's hospital (Royal Aberdeen Children's Hospital) located distinctly as it is, as a separate institution within an inclusive medical campus, and, in Dundee where the paediatric unit has a discernible locus within the Ninewells University Hospitals setting. Within this arrangement in Dundee there is a newly developed Tayside Institute for Child Health (TICH).

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<sup>17</sup> Recommendations 178-180, Report of the Public Inquiry in to children's heart surgery at the Bristol Royal Infirmary 1984-1995, 18 July 2001

55. The review recognised the benefits of co-location with adult services facilitating as it does access to any adult service required by children, and also improving those services where clinicians provide both adult and paediatric care for example neurosurgery. It is also appreciated that separate maternity and paediatric services is an undesirable arrangement in relation to antenatal care, neonatal care requiring tertiary paediatric services radiology/surgery and the report concurs with the Kennedy recommendation in this regard.

#### **Review Recommendations:**

- vii. Children's specialist acute services should be co-located with adult, maternity and neonatal services; however the distinct nature of children's services as highlighted by the Bristol Inquiry (Kennedy Report) should be protected and preserved.**
- viii. This should be progressed as a matter of urgency in Edinburgh and Glasgow where new co-located children's hospitals in Edinburgh and Glasgow are recommended.**

#### **Information and Data collection**

56. Much of the data required for this review was of a type and format not routinely collected. The review found it advantageous to generate its own specific data particularly in describing the work of its pilot specialties. Whilst recognising that such data are an integral feature of a MCN some data were difficult to identify and extract. Where and when appropriate, figures were identified from ISD. However the data needed were not those routinely collected and even those pieces of information were often not validated through ISD.

57. This highlights some of the limitations in the current methods of data collection, in particular in those situations where care is multidisciplinary and where diagnostic and procedural coding is accorded to one clinical discipline. Outcome analysis would clearly benefit from a more accurate and relevant clinical database.

#### **Review Recommendation**

- ix. SEHD and NHS Scotland develop information systems and clinical databases that support the provision of a 21<sup>st</sup> century service fit for purpose.**

#### **Workforce**

58. Several external influences are coming together to affect workforce availability including, working time directives, consultant contract, modernising medical careers (influencing service contribution of staff and training) and agenda for change. These initiatives need to be seen in the context of creating a workforce that is fit for the future delivery of care.

59. Importantly there is also recognition that the work ethic of the modern workforce may differ from its predecessor. A different attitude to the work/life balance throughout the Western world will encourage a shift away from prolonged duty hours and service dependency for continuity of care being met by the current small numbers of individuals.

60. Equally it is important to highlight that the shift in work attitude will need to coincide with new methods of working and the hierarchical approach to tasks and patient care and lines of responsibility also need modernised. Experience, judgement and knowledge do not reside exclusively in any one sector of the workforce and a blend of professionals may produce more effective care than more traditional models of service delivery.

61. The impact of the European Working Time Directive has been highlighted as the major pressure on the future sustainability of services across Scotland. The reduction of junior doctor's hours has largely been accommodated, however we believe the impact on paediatric services has been proportionately more severe due to the relatively smaller number of doctors in junior grades compared to adult specialities and the nature of the services which are already largely consultant led<sup>18</sup>. The impact of the new consultant's contract and further reductions in the number of hours that all grades will have to embrace, puts a serious question mark over the future sustainability of services.

62. By 2009 units will be expected to have a rotas in place that meet the requirements of the EWTD. This will be dependent on the intensity of work patterns, models of care in place and cover arrangements if they want to provide a resident 24 hour/7 day on site cover. At the present time even if all the tertiary services were provided from one hospital site there would still not be enough consultant staff in some specialties to meet the required numbers to staff a rota if current models of working are maintained.

63. Tertiary care may be provided by clinicians who work exclusively in tertiary services but for many units consultant staffing will be provided by clinicians who straddle the divide between tertiary and secondary care who will have to provide general paediatric duties to local populations as well as their specialist interests at local or national level.

64. This makes the calculation of workforce requirements for each sub-specialty somewhat empiric since multi-tasking is an integral feature of such job descriptions. Similarly distinction between the elective and emergency components of tertiary services is an arbitrary process to a certain extent because of the fusion of clinical duties at these two separate levels.

65. Nonetheless the majority of children in need of tertiary care are clearly discernible as such and the requirements of their care can be extrapolated to determine the need of the service at national and regional level.

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<sup>18</sup> Scottish Health Workforce Plan 2004 Baseline, National Workforce Unit, Scottish Executive Health Department, 2004

66. Succession planning has similarly often been influenced more by the requirement of any one institution rather than a national review. This is a complex event in tertiary paediatrics though Scotland's need may vary significantly. Moreover some specialties have no specialist training programme within Scotland and this makes recruitment from UK programmes a more vulnerable and unpredictable event. Prospective workforce planning in these circumstances appears to have much to commend it as a closer alliance between national workforce authorities and specialist training agencies.

67. The structural change inherent in the "proposals for progressive training" contained in Modernising Medical Careers provides a chance to co-ordinate needs of the service with the graduates of specialist training programmes. RCPCH recognises this and this is reflected in the current modelling process being utilised through its training grid. The emergence of the National Workforce Unit should now allow the supervisory role of the national need as well as the regional need to be considered when planning tertiary services.

**Review Recommendations:**

- x. **This review demonstrated a significant shortfall in the numbers of specialists delivering the service in each pilot speciality. However the numbers required to deliver a sustainable Tertiary service to the population of Scotland will depend on the configuration of services and models of care adopted. Regional Planning Groups, NHS Boards and workforce planners need to take these factors into account when they define the numbers of specialist staff required. These issues need to be addressed in the context of the National Framework for Service Change.**
- xi. **We commend the National Workforce Committee in conjunction with NES, NHS Boards and Regional Planning Groups reviews future work force requirements for paediatric services to ensure their sustainability by:**
  - **Defining the number of trainees required for succession planning**
  - **Producing workforce models that identify the numbers of staff required to deliver the changes in service provision that are identified at a national, Regional and Board level.**
- xii. **The Scottish executive and postgraduate deans should explore the potential to match post-CCT (Certificate of Completion in Training) to the workforce needs of specialist services.**

***Emergency pressures***

68. This aspect of care challenges the service most of all – not merely by the acute nature of the problems presenting but also by virtue of the unpredictability being a constant and testing the reserve of the service to respond at any point in time.

69. The National Workforce baseline 2004 document suggests there has been no overall reduction in workforce availability at mid-grade medical level with the reduction in working week as part of New Deal compliance and working time implementation being offset by an absolute increase in the number of junior doctors. However this mathematical approach fails to accommodate the notion that these doctors are significantly less experienced than their predecessors and the burden of care has increasingly fallen upon the consultant body.

70. The size of consultant workforce in tertiary paediatrics has remained moderately static in comparison to the acquisition of workload. There is recognition that the paediatric population has been progressively falling since 1970 but evidence exists to suggest that this decline in population has been offset by an increase in both the intensity of care required in the tertiary sector as well as an absolute increase in the number of some childhood conditions for example childhood cancer, inflammatory bowel disease such as Crohn's Disease and respiratory ailments, including asthma.

71. Of significance is the transfer of workload which in previous years has been accommodated by staff previously in training positions. Progressive change in the educational/clinical climate has shifted for those doctors, with the balance moving inexorably towards educational rather than service primacy. The void in delivery of the service has been backfilled by consultant activity. Indeed earlier promotion to consultancy through a more accelerated training programme following the implementation of Calman reforms is now to be complemented by fundamental changes to training contained in Modernising Medical Careers. The size of the cadre at training level has increased but their service contribution in real terms has reduced as has their ability. Thus the nature of the task being devolved has changed with more routine work as well as more emergency work accommodated by consultants.

72. Involvement in emergency care is now a substantial part of the consultant role but constraints imposed by EWTD on the availability of all grades of staff makes new approaches to provision of continuous emergency access and treatment inevitable.

73. Alternatives to the traditional hierarchical approach with different tiers of staff within specialties being variously deployed on emergency call is now required. Trials of multidisciplinary teams dedicated to emergency out-of-hours work have been recognised as feasible. "The hospital at night" model of groups of carers of different designation but with core competencies in resuscitation and stabilisation along with assessment ability are sufficient to produce a robust triage and rescue role appears to be a product applicable to tertiary paediatrics. This type of service provision has now been prescribed by the Department of Health as in the appropriate mechanism for producing compliance with the EWTD in those centres that have been unable to achieve compliance.

74. The review believes that this type of multidisciplinary workforce will be an inevitable development and would endorse early implementation.

75. Clinical site practitioners have been developed in tertiary hospitals in England and traditional nursing roles have been up skilled following appropriate training and assessment to produce effective night cover in specialist units. This is simply

making effective use of the expertise that resides in the non-medical care team members and develops skills and competencies such as prescribing and procedures to a specified menu of care. This model will be institutionally based and responsibility for development is within each hospital. However there is an opportunity for training programmes to be developed at national level.

**Review Recommendation:**

**xiii. That NES, in conjunction with NHS Boards, Professional Organisations leads the establishment of an agreed curriculum that develops the core skills and competencies of staff to support the development of the Hospital at Night concept in Scotland This must ensure a consistency of approach so that staff in future are able to transfer to new areas and have their roles and competencies acknowledged and accepted.**

***Role revision – opportunistic versus strategic***

76. The confluence of several factors provides the opportunity to consider “who does what” in tertiary paediatrics a timely one. The contribution of time to emergency services has not previously been defined.

77. Remodelling of emergency services should therefore follow certain strategic principles which will encourage each hospital to abandon traditional types of cross-cover and instead produce multidisciplinary teams who can “rove and rescue” throughout the hospital. They can field concerns, access and implement immediate care and make specialist opinion contact. That specialist opinion may be available within hospital/region/or Scotland according to the recommendations of each specialty grouping in this review.

78. Traditional roles in the UK have failed to include the “physician assistant” practitioner upon which many hospitals in the USA are heavily dependent. Given the pressures upon services, it is timely that this role be considered as an option for meeting some of these pressures. The clinical site practitioner job plan goes some way to meeting the “advanced practitioner” role as follows:

- assessment/care of sick children
- acting as senior clinician for example leading the night team.
- providing clinical/managerial support for nurses and junior doctors
- providing a range of intensive skills for example pain control, ordering investigations, X-ray interpretation
- taking a lead on complaints/child protection/resuscitation

79. While having the potential to de-skill the consultant base this development is counterbalanced by maximising the potential of any healthcare worker coming into this role and the review encourages the Scottish Executive Health Department to partner NES in exploring role revision and role innovation.

### **Review Recommendation:**

- xiv. The NHS in Scotland and NES develops new roles for health worker that embraces the concepts of nurse and AHP consultant, advanced practitioner, clinical site practitioner and clinical support staff.**

## **Models of Care**

### ***Managed Clinical Networks***

80. The Managed Clinical Network was a product of the acute services review completed in 1997 (and has received much attention). Its features were such that it was considered as the counterbalance or the “antidote” to centralisation or merger as a mode for sustaining hard-pressed or vulnerable medical specialties. New paediatric services have been officially designated as an MCN, cleft lip and palate being one. However even with the absence of an administrative infrastructure of central funding, the MCN model has provided a basis for collaborative service provision by clinicians within several specialties in Scotland.

81. The utilisation of MCN’s was identified as key building block in all of the four pilot reports<sup>19</sup> and are seen as a way of delivering a modern 21<sup>st</sup> century service in the future. Networks, either formal or informal, have emerged in gastroenterology in Tayside and Grampian, in paediatric neurology in a variety of areas in Scotland, and a national network for children with genital anomalies covering the whole of Scotland. The essential features of collaboration amongst clinicians and institutions have fostered improved care without the identified infrastructure of data management and accountability through clinical governance. Indeed these networks have developed in the absence of any central commissioning process and without designated funding for their support.

82. Alternative configurations for tertiary paediatric services include giving a specialty a designated national service status. This is usually confined to services with small numbers of patients with rare conditions. Examples currently with this arrangement within paediatric care include paediatric intensive care retrieval service, paediatric cardiology and cardiac surgery, paediatric renal transplantation, and the surgical staffing element of the cleft lip and palate MCN.

83. Such funding arrangements involve “top-slicing” the budget given to Health Board areas however there is a break-even point beyond which such a strategy begins to prejudice the ability of each region to utilise its budget according to local need. However there is an evident benefit for some services to be subject to this kind of management.

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<sup>19</sup>The Four Pilot Review Reports, May 2004

### Review recommendations:

- xv. **A clear mechanism needs to be established for the commissioning of MCN's in Scotland at both national and regional level that is sensitive to the needs of children and young people.**
- xvi. **Managerial and clinical governance arrangements should be reviewed for those informal networks already introduced.**

### *Hospital at Night*

84. This approach is based on an original concept by Dr. Elisabeth Paice, Dean Director of London who was concerned about the effects of out of hours working on patients and staff from traditional models of providing out of hours care.<sup>20</sup>

85. The Hospital at Night model proposes that to have effective clinical care a hospital has to have one or more multi-disciplinary teams who between them have the full range of skills and competencies to meet the patients acute episode needs. It marks a shift away from out of hours cover that moves away from care based on the particular specialism and recognises that there has to be a shift in resources to the critical time of 5 pm to 10 pm to maximise the amount of activity that takes place at that time thus reducing the pressures faced by staff out of hours particularly between midnight and 8 am. This recognises that non-medical staff will have the opportunity to take on a proportion of work traditionally done by doctors at night and is based on the fact that unnecessary duplication of work is reduced especially through a reduction in multiple clerking.<sup>21</sup>

86. However in relation to paediatrics and maternity services the hospital at night programmes highlighted that the adult model does not easily translate across to the paediatric model. Most critically, the clinical competencies required are often specific to these specialties and are therefore likely to need speciality specific strategies. However the project identified aspects<sup>22</sup> of the Hospital at Night model which they believe would be valuable including:

- The model may work well in speciality specific units for example children's hospitals
- Use of activity audit to provide an evidence base for future staffing models
- Drawing work into the day-particularly non-urgent work
- Use of integrated medical and nursing handover
- Changes in skill mix to reflect workload for example greater use of support staff and extended nursing role.

87. As we can see in appendix 4 on the national conference this approach has already been adopted within Great Ormond Street in London although the model would have to be further adapted to take account of the emergency aspect of the work in children's hospitals and units in Scotland.

<sup>20</sup> Findings and Recommendations from Hospital at Night Project, Modernisation Agency, June 2004

<sup>21</sup> Findings and Recommendations from Hospital at Night Project, Modernisation Agency, June 2004

<sup>22</sup> Findings and Recommendations from Hospital at Night Project, Modernisation Agency, June 2004

### **Other Models Currently Being Used**

88. Other arrangements which facilitate sharing of patient care beyond secondary and tertiary sectors include:

- outreach services for example paediatric nephrology;
- “scoop and run” for example PICU retrieval services;
- “hot and cold” (separating elective and emergency services which is less applicable to most paediatric services but may be applied to a certain extent to paediatric neurology);
- “acting-up” (utilising facilities normally applied to secondary care). The use of high dependency beds to level 2 care for a finite period (maximum 24 hours) is an example as is the use of burns facilities normally functioning at “burn unit” level but acting-up to perform at “burns centre” level for the care of a serious burn. This model assumes availability capacity and available expertise.
- Tele-medicine – while available for sometime, modern communication techniques, digital information transfer and telecommunications have been slow in being applied to clinical settings and have been restricted to certain specialties for example image transfer in neurosurgery and minor injury management. Clinical care could benefit from increased utilisation of this technology by clinical staff. Such interaction could be between institutions but even have a place within individual hospitals.

#### **Review Recommendation:**

**xvii. The review endorses early implementation of the hospital at night model in Scotland for meeting out-of-hours and emergency pressures and that NHS Boards, review as a matter of urgency, paediatric provision in their areas to ensure compliance.**

**xviii. Telemedicine is seen as a key element of service development in a 21<sup>st</sup> century service and the lessons from the STAF Telemedicine Project should be rolled out to the other paediatric specialities in Scotland.**

### **Age Barriers and Access to Services**

89. The use of age to control access to paediatric services has been a difficult issue in this review since there has been, in the past, no policy advice relating to age in paediatric care in Scotland. As a consequence emergency admissions have been restricted to children up to age 12 in Edinburgh and Glasgow, 14 in Aberdeen, up to age 16 in Inverness with a continuity of care provided by many units until 18. This is contrast to the age cut-off of 18 years specified by the National Services Framework in England and Wales and for recognising that there are areas where young people have specific needs of adult services (notably pregnancy/maternity care and orthopaedics/trauma surgery). The position in England is noted where children and young people are admitted to Acute facilities up to their 16<sup>th</sup> birthday.

90. As identified previously, the Scottish childhood population is in decline. Adjusting the paediatric admission policy to create a standardised approach across Scotland and raising the age would free up capacity within the adult sector.

91. The availability of transitional care arrangements in a number of specialties is recognised as a gap in current care provision for young people in Scotland. Definition of age limits will allow better prospective planning for the transition process. We also need to recognise that patient choice may come into play as young people may have preference to where they are treated. These issues will have a higher profile as the role of the Commissioner for Children and Young People in Scotland develops.

**Review Recommendations:**

- xix. NHS Scotland should adopt an age of up to a young person's 16th birthday, dependent on their clinical need, for admitting children and young people to acute care.**
- xx. The Scottish Executive Health Department, Regional Planning Groups and NHS Boards should address the lack of provision of age sensitive services in Scotland especially for young people who find themselves caught in the existing fault line between paediatric and adult services.**

**Pilot Reviews-Speciality Specific Recommendations**

92. As well as common themes identified in this report the pilot reviews identified a number of issues that related specifically to the speciality involved in the exercise (see appendix 3). The review group came to the conclusion that a number of these specific recommendations should be highlighted at this stage of the process.

***Paediatric Gastroenterology***

- xxi. Each region should review its paediatric dietitian/nutrition service redefining the roles of nutrition nurse and dietitian as clinical leaders within each regional network.**
- xxii. The 3 Regional Planning Groups assesses how they will ensure the provision consultant cross-cover for development of a continuous consultative service for Scotland.**

***Paediatric Neurological Medicine***

- xxiii. Paediatric neurology should continue to develop regional managed clinical networks such that there is equity of access within regions.**
- xxiv. Development of nurse and AHP provided services within each region must be developed to support regional neuro-disability care.**

**xxv. Regional networks appear to be a solid method for providing services in this specialty and should include the following:**

- **That a paediatric consultant is designated to take the lead for neurology/neurodisability in each NHS Board area**
- **Tertiary outreach provision is developed for each NHS Board area in Scotland**
- **Age appropriate services are developed to enable transition as children grow older**

#### ***Paediatric Oncology and Malignant Haematology***

**xxvi. The review recommends development of a national cancer service for children and young people.**

**xxvii. Reconfiguration of the service should be considered, as a matter of urgency, through use of an option appraisal exercise led by an external Chairman and including the parties with responsibilities for planning and management at regional level, as well as those responsible for delivery of the clinical service.**

**xxviii. That NHS Scotland considers the NICE recommendations, which will be published in 2005, for providing children's cancer services and implements them in the Scottish context.**

#### ***Complex Respiratory Services***

**xxix. Consideration should be given to the home ventilation service for children becoming a national service with a lead centre with involvement and representation of the four specialist centres in Aberdeen, Dundee, Glasgow and Edinburgh. (Page 32)**

**xxx. Services for cystic fibrosis in children become a national managed clinical network with a lead clinician and supporting infrastructure.**

**xxxi. Complex respiratory care for example severe asthma, bronchoscopy services, physiological laboratory service be managed at regional levels.**

**xxxii. Respiratory support teams including social work, physiotherapists, dietitians, specialist nurses and physiology technicians are developed in each region.**

### **THE NEXT STEPS**

93. The prominence of the work that was started in 2003 has been enhanced by the establishment of specialist paediatric services as a distinct stream of work under the auspices of the National Framework for Service Change in the NHS in Scotland. We will be forwarding the recommendations to the Specialist Paediatric Services Group chaired by Peter Bates, Acting Assistant Chief Executive of NHS Scotland. The CHSG will also be taking forward a key piece of activity on Secondary and Primary Care which will feed into the overall National Framework process.

94. The review will be extended, following completion of the first phase, to review those tertiary paediatric specialties, which have not yet been subject to external scrutiny. In that regard, it is noted that nephrology and renal transplantation, paediatric cardiac surgery and cardiology, and paediatric intensive care have all been subject to some form of national analysis.

95. However given the pressures faced by paediatric surgery and intensive care services we are recommending that they should be taken forward as separate exercises. The intention remains that this exercise and the work of the National Framework will be consolidated in an Action Framework for Children and Young People's Health.

### **Next Steps**

**xxxiii. This report will be submitted by the CHSG to the Specialist Paediatric Sub-group of the National Framework for Service in Change in Scotland to inform its conclusions and recommendations.**

**xxxiv. Further work will be taken forward with the Scottish Paediatric Haematology and Oncology Group and Regional Planning Groups to develop and implement a model of care for providing this service on a Scottish wide basis in a sustainable way.**

**xxxv. A number of services have been highlighted during the review as requiring action. Once the National Planning Framework has concluded, some services may still require review:**

- Neonatal Intensive Care
- Metabolic disease
- Endocrinology and Diabetes
- Dermatology
- Paediatric Radiology
- Paediatric Pathology, Biochemistry and Haematology
- Rheumatology
- Immunology/ Infectious Disease

**xxxvi. The Child Health Support Group should work with the National Framework for Service Change Group to examine the interface between tertiary and secondary paediatrics.**

**xxxvii. Because of the current pressures being experienced in paediatric intensive care services and in paediatric surgery, we are recommending that they are the subject of a specific study to evaluate:-**

- the current status of paediatric intensive care and in particular provision of high dependency throughout Scotland
- the current method of service delivery at secondary level, in children's surgical specialties and the relationship of that activity with the tertiary sector.

**xxxviii. Involvement of patient's representatives, Allied Health Professional's, nursing and other staff should be fully engaged in these exercises.**

## Members of the CHSG Specialist Paediatric Sub Group

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## CONTRIBUTIONS

Contributions were also received from the following individuals and groups

- lead clinicians from the 4 pilots and their specialty colleagues in the Scottish Specialty Associations; Dr Mike Bisset, Dr Neil Gibson, Dr Rob McWilliam, Dr Hamish Wallace
- representatives from:
  - Regional Planning groups;
  - Child Health Commissioners;
  - National Workforce Unit;
  - Quality Improvement Scotland;
  - Royal College of Paediatrics and Child Health;
  - Action for Sick Children (Scotland);
  - children's nurses;
  - the 3 children's hospitals;
  - Women and Children's Unit members;
  - delegates at the National Conference;
- speakers and panellists at the National Conference including:
  - Mr Malcolm Chisholm, Minister for Health
  - Professor Sir John Temple
  - Dr Huw Jenkins
  - Ms Judith Ellis MBE
  - Dr M Armstrong, Chief Medical Officer
  - Mr Derek Feeley, National Planning Team
  - Fiona Smith, Royal College of Nursing

And for the full report of the conference Mr. Steven Black

**BACKGROUND REPORTS AND SUPPLEMENTARY INFORMATION**

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Child Support Group Work plan HDL (2002) 86  
[http://www.show.scot.nhs.uk/sehd/mels/hdl2002\\_86.pdf](http://www.show.scot.nhs.uk/sehd/mels/hdl2002_86.pdf)

Review of Specialist Paediatric Services HDL (2003) 43  
[http://www.show.scot.nhs.uk/sehd/mels/HDL2003\\_43.pdf](http://www.show.scot.nhs.uk/sehd/mels/HDL2003_43.pdf)

Tertiary Paediatric Services for Children in Scotland – Planning for the Future  
Delegate Booklet, June 2004  
<http://www.show.scot.nhs.uk/chsg/Index.htm>

Full Conference Report

Pilot Review Reports <http://www.show.scot.nhs.uk/chsg/Index.htm>

## SUMMARY OF THE NATIONAL CONFERENCE AND PILOT REVIEWS

### Securing the Future –The Challenges

The many drivers for change form the backdrop to any examination of service provision. Scotland is only one of two countries in Europe in which the population is falling (Germany is the other) and there will be a fall equivalent to the whole of Tayside disappearing between now and 2031. The profile of the Scottish population is also changing and the predictions which is particularly stark and the predictions are that by 2031 there will be many more older people and fewer young people<sup>23</sup>, a situation which will bring its own problems and challenges for healthcare services

A macro economy of sufficient size to be able to redirect and reorganise is required when planning and changing service delivery. To achieve that now will take all 15 Health Boards working together in groupings that are genuinely collaborative and co-ordinated. This will mean that the current regional groups that have evolved will play a pivotal role in the future planning and delivery of care.

In most parts of the UK, people are moving away from the centre. In Scotland, the trend is for people to move to the central belt, particularly the young, a process, which again will create its own problems for health care provision. In five Health Board areas the populations are predicted to rise (e.g. Lothian, Forth Valley, Borders, Fife and interestingly Shetland, the latter by only a small amount), but to fall in the rest of the country, in particular the Western Isles where a fall of 17% (or 5,000 people) is predicted. Doctors are also migrating and it is with increasing difficulty that they are recruited to some of the more remote areas.

The report 'Securing Future Practice' considers four fundamental questions:

- What kind of service do we need to staff?
- What kinds of doctor do we need?
- How do we provide for education, training and career development?
- How do we secure the workforce?

Public expectation is that service delivery is by trained doctors or, by doctors in training who are properly supervised and act within their competence. In addition, the public expects that the service should be as local as possible, that is, what can be delivered locally, safely and appropriately. Doctors themselves expect to work differently; those graduating today have a different work ethic from their predecessors and their likely life-style preferences must be taken into consideration.

The service needs to come to accept the demands of the European Working Time Directive. More care workers need to be found and in the UK the drive in, for example, nursing and medicine has been based on recruitment on overseas, a situation that cannot be sustained and in some cases, may be considered unethical. Scotland needs to 'grow its own'; the process has started but will take seven to 14

<sup>23</sup> Securing Future Practice, Professor Sir John Temple, 2004

years to produce significant results. Skill mix is another potential solution and currently, service providers try to make sure staff are doing the job they want to and have been trained for and are not doing something that someone else can do. The fundamental problem is that Scotland is short of doctors, particularly trained doctors.

The report Future Practice (2002) states: 'The supply of doctors now and in the future will not meet the demand if we retain current patterns of service delivery.' Decisions need to be taken about which unit; locality, hospital or community will do what. This may mean having three types of unit:

- The hospital at the hi-tech end of the service where major investigations and treatments take place.
- Somewhere for elective procedures to take place
- Even smaller units carrying out day care treatments.

Staff would need to be pooled to meet the needs of these three units. In this model, 90% of the patients would still be treated where they would have been treated before; only 10% would move.

The geography of Scotland creates problems not shared in other parts of the UK. The population in remote and rural areas, which is less than 4% of Scotland's entire population, have a right to fair access to services, even if residents accept, certain restrictions on access by virtue of the fact that they choose to live in these areas.

Again, Future Practice (2002), it states: 'Travel time increases risk for emergency care, but so can lack of capacity, critical mass or experience in a small unit.' That still applies, and effective emergency care can only be sustained if a real partnership develops between small and large centres. This also probably means pooling of staff on a rotational basis. Transport services, making the best use of land and, particularly on the west side of the country, water (although this does not mean lifeboats) and air, need to be reviewed.

The kind of doctors required in the service in the future will depend on what they will be expected to do. The critical and defining role of a doctor is diagnosing clinical problems and determining management; that does not necessarily mean performing the treatment or carrying out the various facets of diagnosis.

In the future services will be delivered by trained doctors. Currently in Scotland 38% of all doctors working are in training; even by 2012, this may have been reduced to 30%. Scotland needs a greater number of trained, judgement-safe (i.e. competent in their field of specialist practice including general practice) doctors. A smaller number of trained doctors who are judgement-safe but who have also acquired the additional competencies for more advanced or in-depth specialist care in their field of practice will also be required. In the future, the majority of doctors will be judgement-safe; they will deal with common emergencies, be able to stabilise and transfer patients with rarer problems and have a wide range of service ability. Only a small number will train beyond that, determined by service need.

New ways of training doctors will be needed, taking into account constraints, such as the European Working Time Directive. The current training is too long, particularly in Scotland. For example, the average length of time to reach consultant level currently is 14 years, not all of which involves being educated. This length of time needs to be shortened and there are moves afoot to achieve that. The European Working Time Directive will cut down, potentially by half, the number of hours in a doctor's training, reducing the opportunities for learning and teaching. In the document Modernising Medical Careers, how trainees can be turned into trained doctors much sooner is considered.

An accelerated system will mean introducing skills training centres. Simulation is an expensive but effective way to train people in basic skills. It also assists trainees to practice in a safe environment that is as realistic as possible, but where there is not the potential to harm people. Having done all that, more must be done to retain staff in the service. That will be helped by service redesign; however, more effective promotion of the profession is required.

The Securing the Future report concludes:

***'The medical workforce can only be secured by simplifying its structure, through service redesign and by effective national and regional planning. This will deliver the doctors and the service Scotland needs.'***

### **The Lessons from Wales**

The political and strategic drivers indicate that children have been at the forefront of health care strategy in Wales for several years. This is exemplified by the development of the following administrative framework:-

- Minister for Children in Wales in post since the inception of the National Service Framework in 2001
- Cabinet sub-committee for children & young people
- Children & Young People Partnerships, to try to put into practice multidisciplinary working between health and social care services
- Children's Commissioner
- Director of Health Care Services for Children.

The purpose of the Director of Health Care Services for Children's role is, on behalf of NHS Wales and working closely with professional advisers including the Chief Medical Officer, to lead the drive for innovation and continuous improvement and the

development and implementation of service standards and performance management across children's health care in Wales. It is also to provide strategic leadership and be responsible for implementation of children's healthcare strategies and the associated NSF. The Director is involved in four main areas of work:

- NSF
- Tertiary Services (CYPSSP, see below)
- Food & Fitness Task Force
- Ten-year healthcare strategy development.

The overarching aim for the NSF in Wales is that 'All children and young people achieve optimum health and well-being and are supported in fulfilling their potential.' The NSF has been developed as a partnership by setting standards for health and social care and with close links to education, housing, transport, the voluntary and other stakeholders (including children and young people and parents and carers.

A Tertiary Services Review was carried out in Wales (2002) which made recommendations for changes in services. This resulted in policy development followed by a Ministerial announcement. The outcome was to pilot standards and a service model for a managed clinical network (MCN) in gastroenterology.

The MCN was based on the accepted and documented principles, all of which had to be married up for the process to succeed:

Equity of access for all irrespective of postcode  
Management as close to home as possible  
Management by fully trained specialists, using best available experience and facilities.

The definition of an MCN used in the project was:

***“Linked groups of health professionals and organisations from primary, secondary and tertiary care working in a co-ordinated manner, unconstrained by existing professional/Trust/Health Authority boundaries to ensure equitable provision of high quality, clinically effective services.”***

Subsequently, standards for the MCN were developed:

- Children and young people with conditions on the NSCAG list are discussed with a specialist
- Appropriate and timely plans are made for every child requiring specialist review, for example, immediate in-patient transfer to a specialist centre; an out-patient appointment at a specialist centre; outreach specialist clinic appointment at a local district general hospital
- Specialist care is delivered in a multidisciplinary fashion with adequate staffing to allow seamless continuity of care

- Timely and appropriate communication between specialist services and all other levels of care
- Appropriate verbal and written confirmation for children and young people and families specialist follow-ups as close to home as possible (outreach/transition services).

There are perhaps specific issues which apply in Wales that may or may not be faced in Scotland, including:

- Links to other tertiary services in England
- The North and South Wales difference
- The need for a political (why this is happening) explanations as well as a professional one
- The need to ensure that children, young people, and their families are at the centre of service provision.

The major work embarked upon in Wales is all part of a ten-year planning process. It will also include a workforce development group. Success will depend in part on the funding that is available but also the management of patients' and public expectation.

<p><b>Promoting Clinical Excellence; Advancing Practice, Research and Education; Development of the New Nursing Role</b></p>
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Development of new methods of service delivery, accompanied by new roles has allowed Great Ormond Street Hospital for Sick Children to meet several of the common challenges posed to Tertiary Services.

This work has involved new role development and some of the new roles include:

- Advanced nursing practice roles
- Nurse consultants (autonomous decision makers who have honed their skills through interdisciplinary education courses)
- Allied Health Professional consultants
- Clinical Site Practitioners.
- Housekeepers
- Patient environment team leaders
- Modern matrons/senior nurses
- Administrative and clerical staff
- Clinician assistants
- Patient Advocacy and Liaison Officers and child advocates
- Social workers based on-site
- Information staff (a role which includes maintaining a dynamic and frequently accessed website)

It is accepted that parallels between Scottish children's hospitals and Great Ormond Street, which is exclusively a tertiary centre, may not be particularly appropriate. This is all the more so since Great Ormond Street does not face the same need to provide accident and emergency services for locality.

Of these many new roles, substantial success has been achieved in redefining clinical practice in clinical duties. In this regard clinical site practitioners have been important developments.

Clinical site practitioners are generic, high trained, highly motivated children's nurses. Aspects of their role include:

- Assessment/care of sick children: the clinical site practitioners can refer patients into PICU
- Acting as a senior clinician for the Trust, leading the night team
- Providing clinical/managerial support for nurses and junior doctors: part of their role involves education and training of sub-specialty staff, for example, in the renal unit when a child is experiencing respiratory problems with which the staff are unfamiliar, the clinical site practitioners will go in and educate the staff in to look after the child
- Providing the full range of intensive care skills, including ECG, ordering investigations, X-ray interpretation, pain control
- Taking the lead on complaints, child protection, resuscitation, major incidents.

An audit of the role was carried out, and it reached two significant conclusions about its benefits:

- Two clinical site practitioners and three middle-grade doctors can provide adequate cover to the paediatric wards at night, provided they work a team across specialties
- Based on two phases of 28 nights, the likelihood of five staff being required together is five hours in 1,120.5 (one in 225 or 0.004%).

This demonstrates that the new team is working much more efficiently than the previous configuration.

The clinical site practitioners have the 'space' to use their talents, thereby facilitating much more decision making closer to the point of impact. The advantages of this include:

- Speeding up decisions and reaction times
- Releasing creative, innovative capacity
- Increased job satisfaction, motivation and commitment
- Elimination of layers of management.

Another important function at Great Ormond Street is to listen to children, parents and families, to help build choice into the service. The Hospital operates:

- A national patient survey
- Patient Advice and Listening services
- A Family Forum.

This level of communication helps staff to deal with what parents say is their greatest frustration – the seeming lack of integration between different elements of service. Integration of tertiary services with primary and secondary care is crucial. One method is to name a lead clinician for a child and family so that they can identify with one person in amongst the numerous staff members with whom they come into contact.

### **Summary of Pilot Reviews and Conference Workshops**

A number of key areas were discussed in more detail at the national conference in workshops covering:

- Redesign to deliver
- Patient's journey
- Workforce, succession planning, recruitment
- Lessons from the tertiary reviews
- Developing the role of health care professionals

A synopsis of the pilot reviews was also presented by the clinical leads from each speciality with a number of key issues identified that were common across each of the specialist areas including the following:

- an urgent need to address the shortfall of specialist cover for emergency and elective pressures;
- the need to review the workforce requirements for the provision of specialist paediatric services in light of the Securing Future Practice report
- inconsistencies in provision and difficulties accessing paediatric specialist services throughout Scotland;
- realisation of the benefits of collaboration between specialist units;
- solutions to 24/7 emergency availability differed amongst the specialties ranging from immediate availability of a specialist opinion (oncology) to the need for specialty advice being available by telephone in most instances for secondary and other tertiary services (respiratory).

The pilot review reports also identified a number of areas for further work, some solutions for the complex issues identified and recommendations for considerations by the Scottish Executive Health Department, NHS Services Scotland, Regional Planning Groups and NHS Boards.

Options to address these pressures were presented and whilst diverse, the need for a network either at regional (MCN's in neurology, cystic fibrosis, or gastroenterology) or more often national (designated national services in oncology/malignant haematology) emerged. The workshops yielded a diverse range of concerns, including sustainability of the services, interdependency upon other services, and the impact of the European Working Time Directive.

The issue of a single tertiary centre for Scotland was raised; however, the implications for acute care in other parts of Scotland need to be factored into the equation. If practical solutions are not found to the workforce issues already

identified then this may become the only realistic alternative to provide sustainable tertiary services in the future.

Moreover, it is evident that even at current levels of staffing, the service is unsustainable in the short term, when responding to contractual changes and working-time regulations.

Expansion of the specialist consultant workforce, children's nursing, allied health professionals and other staff forms a consistent ingredient of any recommendation being put forward by professional bodies. However the impact of some of the proposed changes will determine how many and with what competencies will be required to provide the service for the future. It will however, presumably be determined by the intensity of that type of work. It will also require a high-level collaboration between the units at a regional and national level to ensure the requisite integration of rotas.

Important items of discussion produced by workshops and are discussed throughout in this document included the following:

- an increased involvement in nursing and AHP services;
- family expectations;
- defining levels of care;
- the need for consolidation and networking;
- the availability of increased resources;
- emergency pressures;
- scale of change;
- integration with secondary services;
- managed clinical networks – local, regional and national;
- stripping of services out of secondary care;
- interdependency of specialist services upon all aspects of NHS in Scotland
- All tertiary referrals to hospitals and services should develop multi-specialty call teams for dealing with emergency pressures out-of-hours utilising existing experience in all sectors of the clinical team.
- Each specialty should take advantage of this review to analyse current and future service provision indicating the professional opinion on the optimal configuration of the service in Scotland. This process may be facilitated by an option appraisal exercise.

A summary of the presentations on the pilot reviews are given below.

### **Paediatric Gastroenterology, Hepatology and Nutrition Services in Scotland**

Services in this area have changed out of all recognition over the last 10-15 years. The main reasons for this are changes in the spectrum of diseases and number of patients seen. Examples of these changes include:

- Coeliac disease: the recorded incidence is 1 in 2000 but the real incidence is likely to be as high as 1 in 120. The majority of the 'silent' cases are asymptomatic, but are important to find because they are at increased risk of anaemia, osteoporosis and intestinal cancer. Attempts to screen high risk

groups (for example, type 1 diabetic children) are compromised by flaws in screening services

- Crohn's disease: there has been a fourfold increase in incidence over the last 30 years. In Scotland now there are around 90 new cases each year with a total annual workload of around 600 cases.
- Children on Home Enteral Nutrition (HEN): 10 years ago, few children were on HEN but the development of safe insertion techniques and improved support services has led to a significant increase. Now there are more than 600 children in Scotland known to be on HEN (does not include data for district general hospitals), 50% of whom have neurological handicaps and who are likely to require HEN for the rest of their lives. This is, therefore, an increasing workload for services year on year.

The current configuration of services in Scotland at March 2004<sup>24</sup>:

<b>Region Covered</b>	<b>Service Location</b>	<b>Workforce</b>
<b>East</b>	RHSC Edinburgh Kirkcaldy & Dumfries - clinics	1.0 WTE PGHN Consultants 2.0 WTE Specialist Nurse 0.5 WTE Specialist Dietitian
<b>North</b>	RACH Aberdeen Ninewells - clinic and endoscopy Inverness - clinic (Sept 04)	1.3 WTE PGHN Consultants 1.0 WTE Specialist Nurse 0.5 WTE Specialist Dietitian
<b>West</b>	RHSC Glasgow No outreach services	2.1 WTE PGHN Consultants 1.0 WTE Specialist Nurse 1.0 WTE Specialist Dietitian

Currently, services are delivered by a range of practitioners – consultants in PGHN, specialist nurses, paediatric dietitians – and are characterised by:

- A high standard of service in the main centres
- A lack of sufficient resources to meet demand
- Variable support for paediatricians and dietitians in district general hospitals
- No guaranteed 24/7 access to specialists
- No guarantee that children aged 12 and under are referred to paediatric GHN services.
- Identified gaps in services.

Review of practice in the late 1990s indicated that about 50% of children with, for example, inflammatory bowel disease were managed by adult specialists, often surgeons not gastroenterologists. Initial investigation is often sigmoidoscopy and

<sup>24</sup> Paediatric Gastroenterology, Hepatology and Nutrition Services in Scotland, The Scottish Paediatric Gastroenterology, Hepatology and Nutrition Group, May 2004

studies have shown that this may increase length of time to diagnosis from 12 to 20 weeks. Other problems related to management by adult specialists include:

- Nutrition therapy is less likely to be offered
- Growth and development is less likely to be monitored (growth may be impaired as a consequence of the disease).

Clear guidance exists on how and where children should be treated:

- BSPGHAN – Guide for Purchasers, which informs service commissioners what to look for
- Nutritional standards from NHS QIS and BAPEN, including that all children should have access to nutritional support teams
- The National Service Framework for Children.

This guidance and the findings of research studies, all agree that children should not be seen in adult service environments.

Capacity is an issue but there has in the past, been no systematic approach to workforce planning and training through out Scotland. This is a UK issue because specialists will move around the four countries. Currently in Scotland, there is a recognised training programme for doctors, nurses and dietitians, however, we need to ensure closer links with the national training programme. What is required is a national strategy for specialist services.

The main current problems for services are:

- No easy access to services for up to 50% of children
- Existing levels of PGHN staff are unable to cope with the workload.

Any future service model needs to address these problems as well as provide equity of access for all children outside the main centres. The potential service structure to solve these problems would feature:

- A national PGHN service for Scotland
- Outreach services to cover all of Scotland's children
- A 24/7 telephone advice service for advice from consultants
- Doubling of medical, nursing and dietetic staff; all three staff groups need to be increased together to provide an adequate service.

The pilot study group's optimal configuration of PGHN services in Scotland is to develop:

- The current services in PGHN with proper staffing and resourcing of each of the three regional centres
- Comprehensive services for the whole of Scotland, to support the clinical workload of district general hospitals with the creation of a PGHN Network. Supporting staff in nursing and dietetics is essential to the development of these services
- The provision of expertise for the assessment and care of uncommon, high-intensity medical and surgical problems which require acute and chronic tertiary 24-hour specialist expertise
- A multi-professional service for children receiving HEN, led by specialist's nurses and dietitians.

Regional networks appear to be a robust method for providing services in this specialty. Good integration already exists at national level between the regions but this service is heavily dependent, particularly in south east Scotland, upon an academic group who spend a disproportionate amount of time on their clinical service this needs consolidation by the appointment of further NHS service consultants in addition to the existing staff complement.

The West Region has significant gaps in service cover and this appears to result in inequity of access. Both south east and west appear to lack outreach services, which has been successfully achieved in the north east network. The review supports the immediate expansion of gastroenterology in the west and south east with further expansion in 5 years.

The use of specialist nurses should be expanded the dependency in the adult sector of nurse practitioners is noted. This may or not be the basis for a model of care in paediatric sector but outreach services could be strengthened by the development of the gastroenterology team comprising specialty nurse, dietitian and gastroenterologist in each region.

## **Paediatric Neurological Medicine**

The aims of the paediatric neurology service in Scotland are:

- Together with neurodisability services, to provide accurate diagnosis, appropriate information and effective care to children and their families, enabling them to enjoy the best possible quality of life.
- For as many of these children as possible to become independent, tax-paying and voting adults.

Currently, services are generally provided via a system of local and national networks. A uniform standard of service is maintained through meetings, networking and so forth. Established networks, which input to standards and provide information, include the Scottish Muscle Network and North of Scotland Child Neurology Network. A managed clinical network for epilepsy is being developed.

Scotland has eight consultant paediatric neurologists (one per 500,000, BPNA 1998) but recommendations from 1998 suggest 11 are needed. Consultants currently work 60 hours, although that allowance does not include time for district general hospital networking. In the UK overall, training of paediatric neurologists is on target for the recommended necessary expansion, although Scotland is a net exporter of paediatric neurologists to all parts of the world.

More work is required to establish standards and outcome indicators, for example, for epilepsy (SIGN, NICE), brain injury, and specialist investigations for example what are appropriate waiting times for children.

Education and information is available in a range of media. Some is web-based (e.g. from the Scottish Muscle Network). Some units provide in-house education, although this is mainly for nurses and AHPs. Literature is generally available, for example,

from voluntary groups and the pharmaceutical industry, and paediatric neurology centres produce their own literature. Parents are involved in planning and running networks (e.g. Scottish Muscle Network and developing epilepsy network) which helps to keep them informed.

Research in this area is collated and promulgated through networks and SIGN. There is a compelling need for audit of current practice and standards (e.g. respiratory management in neurological disorders).

All specialties interface, at some time, with paediatric neurology services. Apart from obviously patients/families, the list includes:

- Neurodisability
- Neurosurgery
- Laboratory services
- Education services
- Nurses and AHPs
- Wheelchair services
- Child psychiatry
- All paediatric medical and surgical specialties
- Adult neurology, disability, respiratory medicine, and orthopaedic services.

There are several possible options for service delivery:

- Maintaining the status quo, although taking account of the European Working Time Directive would mean either decreasing output by 33% or increasing capacity by 50%
- Continue network development (improved effectiveness but not efficiency)
- Develop outreach (NESCAN, Dumfries). Outreach provision in Scotland is well behind the situation in England
- Resolve anomalies, for example, if you live in Dumfries you have to travel to Edinburgh for an MRI scan
- Develop nurse and AHP provided services (e.g. epilepsy, cerebral palsy, neuromuscular services)
- Improve collaboration with neurodisability and adult services.

The specialty recommends the following for existing individual parts of the paediatric neurology service:

### **Paediatric Oncology and Malignant Haematology**

There are around 1,400 new cases of childhood cancer (i.e. in children under 15) in the UK each year, and between 120-140 cases each year in Scotland. There are around 40 deaths each year in Scotland. The huge success story is the steady increase in five-year survival rates since the 1960s, in some cancers as high as 80%. (Fig 1)

Issues that will have an influence on services include:

- The number of staff, in particular the European Working Time Directive. To sustain services, capacity needs to be increased significantly

- Clinical governance, including standards of care, equality of access.
- Increase in intensity of treatment because of UKCCSG and SIOP protocols

Factors, which influence the patient's journey through services, are:

- Presenting symptoms
- Diagnosis (biopsy/excision)
- Staging (imaging)
- Treatment plan (surgery, radiotherapy, chemotherapy)
- Geography (rurality, travel), many patients have to travel great distances for treatment and support
- Supportive care
- Education of the patient/family, preferably at home
- Palliative care, preferably at home.

There are 22 UKCCSG centres in the UK. Currently there are three centres providing services in Scotland

- Glasgow (5 consultants)
- Edinburgh (3 consultants)
- Aberdeen (1 consultant).

Four levels of care are provided:

<b>LEVELS OF CARE</b>	<b>ELEMENTS</b>
Level One (This level of care should be available at every district general hospital with a paediatric unit).	<ul style="list-style-type: none"> <li>• Initial contact</li> <li>• Diagnostic suspicion</li> <li>• Palliative/terminal care</li> <li>• Emergency care</li> </ul>
Level Two (which is Level one care plus)	<ul style="list-style-type: none"> <li>• Management of ill/septic child</li> <li>• Blood product support</li> <li>• Out-patient chemotherapy</li> </ul>
Level Three (which is levels one and two plus)	<ul style="list-style-type: none"> <li>• In-patient chemotherapy</li> <li>• Intrathecal chemotherapy (high risk procedure)</li> </ul>
Level Four -Tertiary (which is levels one, two and three plus)	<ul style="list-style-type: none"> <li>• Diagnosis, staging and management</li> <li>• Paediatric Neuro-oncology</li> <li>• Bone marrow transplantation</li> <li>• Phase I/II studies</li> <li>• Academic</li> <li>• Training.</li> </ul>

Care is provided by all members of the multidisciplinary team. Treatment for young children is challenging, for example, chemotherapy lasts for many months, and surgery can be extensive.

Unresolved issues for paediatric oncology services in Scotland are:

- Academic needs of professionals (these are continually increasing and there is a need to be able to train the specialists of the future)

- Dealing with late effects (need to improve SIGN guidelines)
- Teenage and young adolescent children
- Supportive therapies – pathology, radiotherapy, PICU
- Recruitment and retention of medical and nursing staff.

The specialties that support cancer care, and are fundamental to an effective service, are under severe pressure with the current configuration of services unsustainable in the short to medium term.

The group's recommendations are

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

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

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

Dedicated inpatient provision, with access to a range of diagnostic and treatment facilities appropriate to the level of care to be provided

The review also supports the view that the optimal configuration is best presented through an option appraisal process which includes the following:

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

Aberdeen, Dundee and mixture of outreach clinics with some shared care in other NHS Board areas for example, Ayrshire and Arran, Dumfries and Galloway, Fife, Forth Valley, Highland, Dumfries and Galloway and Lanarkshire

## **Paediatric Respiratory Medicine**

Tertiary respiratory services for children see a core of "difficult to manage" patients, that is those with uncommon problems in common disorders for example severe asthma. Other facets and activities of the service include:

- Caring for children with rare complex disorders, for example interstitial lung disease, and technology-dependent children for example those on home ventilation; technology-dependent children is a group that is presenting an increasing workload and that encompasses social issues
- Supporting other specialist services for example ITU, oncology, cleft lip and palate. It is important to take account of the 'knock-on' effect of developments in other areas and the need to look after children whose respiratory problems are secondary to another illness and they are looked after by non-respiratory specialists
- Providing a specialist opinion/Specialist investigation/Planning and initiating management/Disease monitoring
- Liaison with secondary paediatrics
- Education and training. In relation to this, it will be important to explore new ways of working, a process which should involve all professions concerned with child health
- Research, audit, guideline development.

Much of the work carried out by the service is new, that is, it did not exist 10 years ago. Some disorders are treated today that were not treated previously, and new factors are leading to new health problems for example obesity in children.

Currently, the service comprises four university teaching centres and some district services where there are highly skilled specialists. However, services are patchy and tend to rely on clinician interest and enthusiasm to maintain and develop the service. Lines of communication are unclear. There is a large and increasing demand from other speciality services.

However, the service does have certain strengths:

- A young consultant work force
- Some good investigative equipment which is shared between areas
- Talented specialist nurses/AHPs
- A strong academic base
- Availability of audit tools
- Scottish Paediatric Respiratory Interest Group (SPRING)
- Backing from patient/parent groups (e.g. the Cystic Fibrosis Trust).

Potential future configurations may feature:

- A few single centre services
- Two units with full sleep and ventilation services, also supporting PICU

- Three centres doing bronchoscopy
- Four appropriately staffed units with lung function and basic sleep diagnostics, supporting local secondary care. This would require doubling the workforce and some specialist services could not be sustained over four centres.

Problems facing on-call services include:

- The fact it is a 'hands-on' specialty at consultant level
- The balance between secondary/tertiary patients in larger centres.
- Should there be a national on-call telephone advice service? This would require better links than exist currently. An audit would need to be carried out to establish demand and show how effective the system would be.
- Should patients transfer to the site at which the on-call consultant is based?

Managed clinical networks need to:

- Develop shared protocols/guidelines (SIGN)
- Provide as much care as close as possible to the patient's home
- Develop clear lines of communication and referral
- Agreed outcomes and audit
- Be adequately resourced.