National Framework for Service Change in the NHS in Scotland

Child Healthcare Services In Scotland

Report of the workstreams on Specialised Paediatric Services And Children’s Health Services

March 2005
# NATIONAL FRAMEWORK FOR SERVICE CHANGE
IN THE NHS in SCOTLAND
CHILD HEALTHCARE SERVICES

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List of Recommendations

Context (paras 9-13)
1 In recognition of the significant inequalities in child health, there should be positive discrimination of allocation of resources in the implementation of Health for All Children (Hall 4) to ensure health promotion and support to the most vulnerable families. This is consistent with the recommendations of the work stream on Inequalities.

Age Profile (paras 53-59)
2 It is recommended that NHS Scotland adopts the guiding principle of the age for admitting children and young people to acute care in paediatric facilities as up to their 16th birthday, dependent upon their clinical need and patient choice.
3 For young people between the ages of 16 and 18 there should be discussion with their clinician(s) regarding where their care is best delivered, recognising their right of choice, unless there are clear clinical reasons which determine whether admission is to paediatric or adult services.
4 In adopting this principle it is acknowledged that further work will be need to be undertaken at regional and local level regarding the implications of this recommendation. Implementation will be complex and require an extended planning period. The commissioners of new facilities for children and young people will need to consider this in designing the qualities and style of service required.

Definition of Specialised Services (paras 60-68)
5 It is recommended that NHS Scotland adopts the definition of specialised paediatric services as described in this report and the range and definitions set out in the Department of Health Specialised Services Definition set, principally Definition 23 Specialised Services for Children, but also those others that relate to children. Commissioners of specialised services should draw on the guidance published by the RCPCH.

A Paediatric Critical Care Service for Scotland (paras 69-86)
6 Accident and Emergency Departments and Inpatient services for babies and children should be supported by the capability to provide – at least short term – critical care support for children. This needs to be backed up by 24 hour access to medical and nursing advice from lead critical care centres. Critical care undertaken outside a lead centre should be delivered in accordance with the standards set by the PIC Society and according to protocols developed in liaison with lead centres. Health Boards should review their current provision and develop action plans.

7 A National Managed Clinical Network for paediatric critical care is developed to link critical care services across Scotland to provide a co-ordinated support service for critically ill children.
The dedicated HDUs in Aberdeen, Dundee, Edinburgh and the soon to be established HDU in Glasgow should be developed into regional lead HDU centres within the national network, and the two PICUs in Edinburgh and Glasgow should be developed as the lead national PIC centres within the network – operating as a single PIC service on two sites.

Change is expected over the next 5-8 years as a result of the commitment to rebuild the children’s hospitals in Glasgow and Edinburgh. During this period of change the PICU service should be nationally commissioned for a minimum of 5 years to oversee the establishment of the national critical care network and explore ways in which arrangements between the two PIC units can be strengthened.

Regional Planning Groups should work with Ambulance services and referring clinicians to plan paediatric services across regions with a view to
- ensuring that the first hospital to which the child is taken is appropriate in relation to the child’s need for critical care support as far as possible.
- rapid and reliable transfer arrangements are in place to escalate the level of support when needed
- return transport arrangements are available as part of agreed discharge protocols

NSD project manages a detailed 2 year audit of high dependency care for children and neonates to provide information about the provision and outcomes of these services.

NHS Education Scotland should engage with the clinical specialist teams, the Educational Institutions, Colleges and Post Graduate Deans in discussions to adapt the existing arrangements for training accreditation so that training can be provided through rotational posting across a number of sites within one service, and to develop accelerated accredited training for nurses to advanced practitioner.

There should be appropriate investment to ensure that PICUs and HDUs are equipped to provide the support necessary. An immediate investment should be made in the PIC service in Glasgow to bring occupancy levels down to 80%. There must also be investment in nurse education and development.

**Patient Journeys and Pathways including Managed Clinical Networks** (paras 88-98)

NSD together with the regional commissioning groups should produce a national strategy on the development and approval of MCNs for Child Health by September 2005. This strategy will make recommendations about which MCNs should operate and interrelate at national, regional and at Health Board level. It will include a phased programme for MCN development over the next 5 years.
All networks should meet/work to meet the standards for MCNs set out in the guidance and performance management of MCNs should be strengthened through NHS Boards and Regional Planning Groups.

The first phase of the national programme should include proposals for MCNs emerging from the following sources:
- National Review Child Health Work streams - Children with Complex Needs, Child Protection, Cystic Fibrosis, Paediatric Critical Care
- Review of Paediatric Tertiary Services - Paediatric Neurology, Paediatric Gastroenterology, and Paediatric Oncology and Malignant Haematology, Paediatric Respiratory Medicine
- CAMHs – Network for Children with complex and Severe Mental Health Problems

NSD should take responsibility for establishing a prioritisation process.

As part of the development of Paediatric Oncology and Malignant Haematology (POMH) and in line with the model recommended for Paediatric Intensive Care, POMH will organise its services as a single service operating over a number of sites.

E-Health (paras 99-110)

The ITC infrastructure should be developed to support information transfer between all parts of NHS Scotland. These applications would be in the areas of patient records, diagnostic images, laboratory results.

Nationally agreed protocols should be developed reflecting the particular needs of children and young people and made available on specific websites for easy access to support local care delivery. These can form part of the Service Specification described later.

NHS Scotland ITC strategy should support the roll out of proven technologies to support delivery of specialised paediatric services in partnership with local services as a matter of urgency. The current Paediatric telemedicine projects should be funded recurrently from 2005 and expanded to become a Scotland wide Paediatric Telemedicine project by December 2007 which covers a wide range of paediatric specialities. It should be able to provide support that will allow links between the 4 children’s hospitals and other facilities that care for children.

The strategy for telemedicine and eHealth should incorporate its use for training, case conferences, case reviews, actual consultations, involvement of a range of professionals including AHPs and mobile phone technology in innovative ways.

Access to a paediatric consultant led radiology service 24 hours a day should be available across Scotland. This will need to be appropriately resourced in the specialist centres that are providing 24 hour cover for other board areas. The service would work on the principle that where ever possible the image would travel rather than the child.
**Information Technology** (paras 111-117)

23 ISD in partnership with the services should consider the implications and opportunities afforded by NHS Scotland adopting the Department of Health Specialised Services Definitions for Children for developing a minimum dataset. It should also consider how it would work with the Department of Health in its process of review and development of its definitions. This should be linked in with the work of the Maternal and Child Health Information Strategy Group.

24 The Action Plan of the MCHISG should be implemented over the next 3 years. Work on the use of CHI from birth and dataset development can be progressed immediately.

**Transport and Retrieval** (paras 118-130)

25 Further transport options should be considered in partnership with the Scottish Ambulance Service including retrieval for ill children and consideration of expanding the use of air transport.

26 There should be a single telephone number for contacting the retrieval teams with direct access to the consultant on call in either Glasgow or Edinburgh.

27 Transport and Retrieval Services should consider the particular needs of remote and rural areas in relation to emergency transport of children, reflected in a reduction in the total time between agreement to retrieve and arrival of the retrieval team. For children meeting the criteria for PICU retrieval, RHSC Glasgow and RHSC Edinburgh should develop mechanisms to offer interim clinical support from the appropriate PICU site while awaiting arrival of the retrieval team. This might involve remote biophysical telemetry monitoring. The role of the Scottish Ambulance Service and in particular the air ambulance service, is critical to achieving satisfactory response times. SEHD should ensure that SAS is strategically positioned to support rapid transfer of expert teams from specialist centres to stabilise patients in remote and rural areas and the transfer of increasing numbers of critically ill and injured neonates, children and adults over long distances to appropriate specialist centres.

28 Two further types of retrieval should be addressed – seriously ill children not requiring intensive care i.e. those requiring high dependency care, and children with severe head injury. This will require further work but is likely to involve a networked approach utilising the experience and infrastructure of the existing retrieval teams. It will involve quantifying likely demand and the development of thresholds and standards for care. This work has commenced through the Audit of HDU requirements commissioned by the Child Health Support Group and being carried out through NSD. There should be a clinical decision support system for transfer of significantly ill or injured children who do not technically justify PICU level care. This should support an integrated transport network configured to offer a stratified response defined by the needs of the child.
29 There should be urgent consideration of systems to ensure children can be transferred back to a more local hospital when intensive care is no longer required.

30 There should be continued dialogue between the Scottish Ambulance Service and NHS Boards to ensure that the new contract for air ambulance services adapts to the recommendations in this report.

31 In view of the number of recommendations regarding transport and retrieval services it is recommended that consideration is given to whether there would be benefit in integrating some aspects of the services to support improved transfer back to local services. The recent review of the Neonatal Transport Service recommended that this is planned on an all-Scotland basis, with the models of delivery in each region developed to be sensitive to local needs.¹

**Relationships between Care Providers** (paras 131-146)

32 Specialist centres should acknowledge responsibility for supporting local services through formalisation of their relationship with referring services. This formalisation of relationships should be set in a regional framework of care, based on the children’s hospitals with their referring services. The framework would set out a core minimum paediatric service provided at DGH level, e.g. respiratory, diabetes, neonatology, endocrinology, cystic fibrosis, and how the specialist centre supports this service through Service Specifications, see below.

33 Service Specifications should be agreed between NHS Boards hosting specialist children’s hospitals providing tertiary care services with all NHS Boards that refer children to them. These service specifications should include outreach and shared care arrangements for individual specialities that ensures as much local care as possible. They should also include (web-based) protocols/guidelines to support local care. Each region should establish a tertiary/secondary clinical forum to promote and monitor shared care arrangements across NHS Board boundaries.

34 With the changing nature of secondary paediatric services and the drivers for change around workforce and sustainability, all secondary paediatric services and the liaison with the specialist centres should be planned and organised on a regional basis. Appropriate decision making and funding mechanisms will need to accompany these planning and organisational structures.

35 NHS Boards and Regions should consider regional or joint appointments to provide specialist support locally where it is not possible to recruit to posts or retain staff in a single board area. Additionally Regional Planning Groups and NHS Boards should review the number of sites where secondary inpatient paediatrics are provided to maximise staff resource and avoid multi site working.

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¹ NHS Scotland Neonatal Transport Service: Report of Review Group established by Regional Planning Chief Executives’ Sub Group of the Board Chief Executives’ Group, September 2003
Support Systems for Families (paras 147-154)
36 NHS Boards should review their provision of paediatric services with reference to the European Association for Children in Hospital (EACH) Charter and put in place plans to address any issues identified.

37 Service providers should work together to ensure appropriate support is in place for parents who are far from home with a sick child. Parents should be fully involved in the planning of this support.

Involving Children and Young People (paras 155-162)
38 The views of children and young people should be invited for all services, which affect them. This should include every level of planning i.e. National, Regional, Board, Community Health Partnership, GP practice and hospital.

39 All services have a responsibility to provide information to parents and young people about their rights and put in place innovative mechanisms to encourage involvement in the planning and redesign of services. All patients and their families should be educated about their rights.

40 The Child Health Support Group should produce a report on the current status of involvement of children and young people in service planning and redesign and make recommendations on how this can be further developed.

Ambulatory Care (paras 163-165)
41 The development of Ambulatory Care should be encouraged as part of a strategy to provide more care closer to home. Regional planning groups and NHS Boards should develop ambulatory care plans for children including outpatient services in a range of sites including integrated community schools, rapid access clinics and common protocols. Protocols should be in place setting out clearly the criteria for children and young people who can be seen in ambulatory care units and transport arrangements should be in place and communicated.

42 A good practice conference should be organised to share the learning from established ambulatory care units in Scotland and to disseminate information from longer running projects in England and elsewhere.

Surgery for Children in DGHs (paras 166-176)
43 Paediatric surgery should be planned and organised on a regional basis with hub and spoke models and regular training courses for surgeons and anaesthetists by the specialist centres to ensure that skills in the DGHs are kept up to date. NHS Boards and regions must be sure that the standards referred to above are met in all hospitals providing paediatric surgery. The ability to meet these standards will determine the regional provision of paediatric surgery.

44 A national short life working group should be established to provide clear guidance to regions on elective and emergency provision of general surgery and anaesthesia for children taking into account workforce issues, training requirements and specifying actions required with Colleges, NES, SEHD,
NHS Boards and Regions. The group should also consider levels of care and provision of day surgery in DGHs and ambulatory care centres. The group should involve and take account of other surgical specialties that care for children, such as ENT, plastics, ophthalmology and orthopaedics. It will also need to address the issue of provision of emergency care and options for delivery of all DGHs caring for children cannot sustain an out of hours emergency service for surgery. It should address workforce and training issues including the role of NHS Boards and NES in planning future posts and training opportunities. The group should take account of existing standards from the Royal Colleges and good practice examples such as the joint post between Tayside and Lothian and outreach from RHSC Glasgow to Wishaw. The group should report within 3 months. The work of the Department of Health in England on provision of anaesthesia for children in DGHs can inform this work.

45 As dental surgery accounts for such a high proportion of paediatric surgical activity, a separate review should take place to make specific recommendations on where general anaesthesia for dental surgery should take place taking into account existing guidance.

46 The competency of services in meeting the standards referred to above should be inspected as part of Quality Improvement Scotland's Inspections. If DGH services are not able to conform to these standards children’s general surgery should all transfer to specialist centre or another DGH that meets the standards.

Provision of Care in Remote and Rural Areas (paras 177-184)

47 NHS Boards who deal with children from remote and rural areas (particularly tertiary services) should designate a member of staff as a remote and rural co-ordinator through whom elective care and discharge planning is managed. This post should be supported by an identified senior clinician in relevant Boards to act as a contact point for external clinical staff from remote areas. Telemedicine should facilitate this process.

48 NES should lead the development of dedicated training packages in paediatric care specific for remote and rural practice. These should be delivered locally in partnership with external partners and supported by national protocols/guidelines.

49 Urban Boards should offer expanded outreach support for remote areas to maximise local care. These visits should include a local educational opportunity whenever possible.

Primary Care and Self Care (paras 185-207)

50 Where feasible, NHS Boards should consider co-location of GP out of hours services and A&E services into a single functional unit, with opportunities for walk-in patients to be triage to GP care and reciprocal partnership working for appropriate emergencies.
All GPs should maintain their skills and competences in the care of children. The importance of child health should continue to be reflected in the availability of accredited training for GPs and feature strongly in the practice accreditation process.

Training and appointment of GPs with a special interest in child health should be continue to be developed. General Practices should continue to encourage identification of a GP who “leads” on child health issues and Community Health Partnerships should consider establishing a wider role and identifying a GP who can undertake the necessary additional training to support this role.

Nursing staff working in primary care who have contact with children e.g. public health nurses, health visitors, school nurses, practice nurses should maintain their skills and competences in the care and treatment of children. They should work in partnership with community paediatric nurses and specialist paediatric nurses.

There should be easy direct access to senior hospital staff for clinical advice about care and treatment of children in the community. While many children are referred to hospital for treatment appropriately a significant number could be dealt with by advice alone or seen at rapid access clinics rather than as an acute admission. The issues identified in the “Decide to Admit v Admit to Decide” National conference on unscheduled care are relevant to children. In each rota a consultant should be available either by bleep, call-back or secure email to enable direct advice to GPs where there is uncertainty about optimal clinical management. Technologies such as imaging transfer or video conferencing will be important tools to support this new way of working.

NHS Boards should develop local referral protocols and referral guidelines for childhood conditions for primary care practitioners. There are examples from Greater Glasgow and Grampian that could be used to prevent duplication of effort.

An audit should be undertaken to monitor the outcome of NHS 24 on the care of children and young people.

CHPs should ensure that there are effective pathways in place for the provision of health care services to vulnerable children. Implementation of proposals of Health for All Children (Hall 4) should support this. There should be proactive follow up of non attenders and effective integrated working with social work and education departments.

CHPS should ensure that they provide adequate access to emergency contraception for young people both within normal practice hours and out-of-hours.

CHPs should put in place plans to improve access for young people to primary care services. This could include the use of the internet and mobile phone access to health care advice as well as dedicated young peoples clinics.
60 Education of carers is an important component of routine professional care, and may significantly impact on future management of their children. A range of parent/carer advice leaflets on specific common conditions should be developed for national use, and be available during face-to-face consultations. This may be web-based for printing during consultation, and to allow easy updating and expansion.

61 There are a range of initiatives and policies to support parents and the management of childhood illness which should be incorporated to parenting programmes. (this needs further developed – awaiting a contribution from Children First)

**Emergency Care for Children and Young People** (paras 208-226)

62 Regional Planning Groups and NHS Boards should identify the level of care that should be provided at each of their emergency care sites in accordance with the proposed emergency care framework.

63 All emergency care sites should provide a safe and non-threatening environment for the treatment of children and young people and staff providing care in emergency Care sites should have a core set of skills and competencies to provide care to children and young people and access to support and advice from a registered children’s practitioner on a 24/7 basis.

64 A standard assessment method should be developed for use with children and young people at all emergency care facilities. This assessment method should recognise the severity of illness or injury, the degree of pain and distress and the potential vulnerability of the child or young person.

65 National guidelines and best practice statements should be developed for the management of common acute and potentially life threatening conditions for children and young people.

66 A multi-professional emergency care competency system should be developed by NHS Education for Scotland for practitioners who provide emergency care for children and young people. Once developed competencies should be maintained and updated.

67 The development of expanded roles for emergency care practitioners should consider the needs of children and young people and be undertaken under the guidance of NHS Education for Scotland and the relevant professional bodies.

68 NHS Boards should clearly identify which sites in their area will at all times provide emergency advanced imaging facilities for children and young people. This information should be shared with NHS 24, primary care teams, out-of-hours services and the Scottish Ambulance service.
Workforce and Role Development (paras 227-238)

69 Workforce planning mechanisms should work in tandem with and in support of service planning at national, regional and local levels.

70 The National Workforce Committee and NES with Regional Planning Groups should develop a workforce plan for specialised paediatric services and other secondary paediatric services identified as vulnerable.

71 An action plan for the development of community and hospital paediatric nursing will be developed by Regional Planning Groups using senior professional paediatric nursing advice, working collaboratively on an all-Scotland basis. This will be based on the recommendations of the RCN consultation entitled “Services for children and young people: preparing nurses for future roles: preparing nursing for young people” and the information gathered as part of developing this report (questionnaire, video conferences, Development event). It will address: recruitment and retention, developing local training opportunities via education outposts in areas of staff shortages and ensure systems are in place to ensure the maintenance of skills.

72 Formal links should be made between community paediatric nurses working in remote and rural areas and teams within the larger Boards to offer support, advice and access to ongoing training.

Care of Young People (paras 239-245)

73 NHS Boards should map out and review their services for young people (aged 12 – 16 years) and set out actions to develop services which provide for their specific needs. Boards should develop proposals for age appropriate care by the end of 2005.

74 NHS Boards should develop clear and cohesive arrangements for transition from child to adolescent services and from adolescent to adult care across the spectrum of chronic paediatric illness.

75 While a shift from adult to paediatric care for some young people should in theory be cost neutral, there will be cost implications in caring for more young people in paediatric settings. The SE Health Department and NHS Boards should develop a financial plan to underpin their action plan to develop age appropriate care.

76 NSD should similarly review provision for young people in nationally designated services.

77 Regional Planning Groups should designate at least one clinician with responsibility for adolescent hospital care. They should lead the development of good practice for all aspects of adolescent care, including transition into adult services.
Child and Adolescent Mental Health Services (paras 246-249)

78 The Scottish Executive and NHS Boards should work together to implement Children and Young People’s Mental Health: A Service Framework for Promotion Prevention and Care.

79 The recommendations of the CHSG working group on In-patient psychiatric care for children and young people should be implemented with urgency, starting with the work being taken forward by David Piggot on behalf of the Regional Planning Groups to consider funding and feasibility.

Child Protection (paras 253-261)

80 NHS information systems should ensure gathering of all information on a child at any point of contact with health services (between primary to tertiary care) with adequate flagging of key indicators of vulnerability and early inter agency intervention to support families and prevent escalation to crisis. Discussions should take place with NHS 24 on development of a central national health gateway for both carers and professionals and enable access either urgently or within a short time frame to the most appropriate health facility (for example A&E departments, child protection health services, addiction services, mental health services).

81 Services to children who are suspected of having been sexually abused should be provided as a national clinical network. This National Managed Clinical Network should consist of three regional networks for child protection and will develop common protocols, detailed standards re patient care and inter agency working, and provide centralised audit and evaluation of practice as well as ongoing educational curricula for all levels of health practitioners involved in child protection work. Regional networks can at their discretion come to an agreement to work together to create 2 networks which will feeding into a National Network or to opt to have a single national clinical network without regional feeder networks.

82 The National Clinical Network will ensure that a 24 hour service is in place for clinical urgent child protection cases. This is expected to involve only a small number of children and it is likely that some of these children will require to travel to the specialist.

83 Children suspected of having been sexually abused should be seen in a locality setting where possible. In the longer term telemedicine with tertiary centres will be a useful adjunct to help to give a second opinion but cannot replace clinical competence. This service will be developed by the Scottish Child Protection MCN. The development of this service requires a national telemedicine strategy and increased capacity of paediatric forensic expertise in national centres. The development of the MCN will be informed by the work of the RCPCH sub-committee on child protection.

Child Health Services for a New Century Scotland (paras 262-298)

84 The models for integrated services and planning described in this report should be implemented. Specialised paediatric services should be planned
nationally, secondary paediatric services should be planned and organised on a regional basis.

85 The Scottish Executive Health Department should provide strategic and corporate leadership in planning Specialised Paediatric Services. It should develop this capacity and work with the Regional Planning Groups, Child Health Support Group, National Clinical Lead and other partners in prioritising and planning services requiring a national approach.

86 Regional Planning Groups should establish Children’s Health Services Planning Groups under the leadership of a Chief Executive of one of its constituent NHS Boards.

87 Children, young people and their families should be involved in planning services.

88 The work programme and methodology set out by the Review of Tertiary Paediatric Services and the planning template should form the basis of planning for specialised paediatric services.

89 The role of the Child Health Support Group should be enhanced to provide expert advice and support to the service in planning and implementation of national policy and plans. The membership should be reviewed to support this enhanced role.

90 Specialised Paediatric Services should be developed through managed clinical networks, linking the specialist centres with local services and including children, young people and their families.

91 Regional Planning Groups should use the Financial Framework for Regional Planning to agree hypothecated funding to support the delivery of plans for children’s services agreed through the regional planning mechanisms.
INTRODUCTION

1 Delivering services that meet the healthcare needs of children will be a major determinant of the future well being of the population. This is the report of the Specialised Paediatric Services Action Team and the Child Health Support Group’s work on Children’s health services work stream. These two work streams have been brought together to form an integrated report for submission to the Advisory Group on the National Framework for Service Change in the NHS in Scotland to consider as part of their report to the Minister for Health and Community Care.

2 Thanks are expressed to each member of the Action Team and those colleagues who worked with them and attended Action Team meetings to contribute to the discussion. Thanks are also expressed to members of the Child Health Support Group and to all those who contributed to this work through interviews, consultation and workshops. We would also like to acknowledge the assistance of colleagues in ISD who supplied data on current activity.

BACKGROUND

3 The Specialised Paediatric Services Action Team (the Team) was established to consider the future shape of specialised paediatric services; its remit is set out in the commissioning document “Highly Specialised Care” and is included as Appendix 3. It is one of the work-streams identified for review under the National Framework for Service Change in the NHS in Scotland. This National Framework is being developed by an Advisory Group chaired by Professor David Kerr.

4 The theme of Highly Specialised Care was identified by the Advisory Group as an area which would benefit from consideration and two specific speciality areas were identified – specialised paediatric services being one and neurosciences the other. The neurosciences remit included paediatric neurosurgery, which required liaison between the work of the Action Teams and this was achieved through having the same project lead, regular meetings between the chairs of the Action Teams, project lead and expert advisors to the chairs of the Action Teams, and members of the Specialised Paediatric Services Action Team attending a meeting of the Neurosciences Action Team.

5 In addition, the Child Health Support Group (CHSG) was asked by the Advisory Group to undertake work on children’s health services up to the level of highly specialised care. (Remit and membership is included in Appendix 2) Children also have a particular focus in the work stream on Care in Local Settings and are included in the work on unscheduled care.

6 The work is set in the current policy context of the Scottish Executive and in particular in the areas relating to children’s health. It has drawn on previous
work and reports including the work of the Child Health Support Group. A bibliography of key documents is included at Appendix 4.

7 This report spans the spectrum of children’s health service issues across primary, secondary and tertiary services recognising the child and family’s interactions with all aspects of health care services. The health and development of children depends not only on health services but on a range of other influences including the home, the school, transport and other environmental factors, requiring joint working with other agencies. While the importance of integration of children’s services with other agencies is acknowledged, it should be noted that this report is primarily about NHS Services.

8 The Scottish Executive and the Child Health Support Group are developing an Action Framework for child health in Scotland to be published by the end of 2005. It will set out the precise actions, milestones and timescales to implement current strategies and policies for child health

CONTEXT

DRIVERS FOR CHANGE IN CHILD HEALTH

9 The public expects equitable access to safe, high quality, paediatric services. There are a number of key drivers impacting on the provision of paediatric services in Scotland including:

Demography:
- The decline in the birth rate and general ageing of the population mean that the numbers of children in the population are decreasing. It is forecast that this trend will continue.

Demand for services:
- Disease patterns in Scotland are changing. The prevalence of diseases such as diabetes, asthma, childhood cancer, and problems associated with being overweight, is increasing. On the other hand there is a falling incidence of injury during childhood, and the incidence of neural tube defects at birth has fallen as a result of antenatal screening.

- Improvements in maternity and neonatal care have led to increased survival rates for new born babies and children, with neonatal and infant mortality rates at historically low levels. The substantially increased survival rate of low birth weight and very premature babies is welcomed. Low birth weight babies are, however, more likely to have continuing healthcare needs.

- The survival rates for conditions such as congenital heart disease, Down’s syndrome (and other congenital anomalies), and childhood cancer, have improved markedly as a result of improved
treatments. The beneficiaries of these procedures will continue to require long term follow-up and management.

- Rising numbers of children are being diagnosed with attention deficit hyperactivity disorder and autistic spectrum disorders. These children require complex inter-agency management.
- The level of teenage suicides remains a concern.
- There has been a massive increase in awareness and activity relating the Child Protection.
- Scotland continues to have the highest rate of teenage pregnancies in Europe.

Clinical Practice:
- New technologies and therapies are continuously being developed. Some of these, such as Home Ventilation Services and Home Enteral Nutrition, can and should be delivered in the community, including at home.
- Multi-agency working is required for the management of complex cases. This approach is necessarily time-consuming.
- Audit and quality assurance are necessary for the development of services. They do create additional demands for front line staff.

Workforce:
- Workforce availability has been significantly influenced by the introduction of working time legislation. The roles of frontline staff require review and development.
- In an ageing population the total number of people of working age will fall progressively over time. This will have major implications for the workforce.
- The above pressures are magnified in paediatric services due to the small workforce. Staff caring for children require specific training and skills.
- Paediatric services face specific challenges in the recruitment and retention of paediatric trained doctors, nurses and Allied Health Professionals (AHP). These pressures will be felt across the service, specifically “Hospital at Night” will need to develop a discrete workstream to address these pressures.

Organisation of services:
- Currently children’s health services are at varying stages of development across Scotland.
- The growth in multi-agency working and inspection as described in the Integrated Children’s Services Guidance has a significant
impact on children’s health services. Closer and more flexible working arrangements will need to be in place, for example the proposed integrated assessment which will in its first phase concentrate on child protection.

- Organisation and location of children’s hospitals and specialist services which have changed significantly at the secondary care level over the past two decades with limited change at tertiary level in Aberdeen, Edinburgh and Glasgow and Dundee.

Inequalities:
- A significant number of children in Scotland experience inequalities in health status and in accessing healthcare services. The effects of poverty on children remain a concern as demonstrated by the higher rate of accidents, mental health problems and dental caries in children living in the more deprived areas.

The current provision of specialist paediatric services means that some care is only provided in one or two locations in Scotland and in some instances in other centres in the UK. This pattern of service provision has evolved due to either the scarcity of expertise or the investment required in technology and infrastructure, or both. Decisions about how these services are provided in the future need to be taken on a whole Scotland basis and in a context of that element of a child’s or young person’s care being part of a pattern of care of which the majority is provided as close to where they live as possible.

A number of recommendations have also been made about the location and provision of children’s services including the Kennedy enquiry into cardiac deaths in Bristol, CHSG Tertiary Services Report and the two National Service Frameworks for Children out for discussion in England and Wales. The main themes arising from these reports include:

- The establishment of clinical networks with clear referral mechanisms for patients.
- Diagnosis and treatment should be provided in age appropriate environments.
- Co-location with adult services especially in relation to the treatment and diagnosis of adolescent conditions.
- Ensuring appropriate referral between levels of care, ease and equity of access to specialist services.

These recommendations present specialist services in Scotland with a challenging agenda if we are to meet the aspirations and requirements that are being set. The current fragmented approach to service development will need to change to support an integrated service which improves access and equity of care and addresses the challenges presenting now and in the future.

**Recommendation**

In recognition of the significant inequalities in child health, there should be positive discrimination of allocation of resources in the implementation of Health for All Children (Hall 4) to ensure health promotion and support to the
most vulnerable families. This is consistent with the recommendations of the work stream on Inequalities.

**CURRENT ACTIVITY**

14 There are 4 teaching hospitals in Scotland in Glasgow, Edinburgh, Dundee and Aberdeen that provide paediatric tertiary services. They do not all provide all tertiary services and current service provision is described in more detail in Appendix 7. In this short summary of current activity, we have grouped the 4 teaching hospitals together as “the Children’s Hospitals”. These hospitals, as well as providing specialist services, also provide secondary care paediatric services for their local population. The majority of admissions and attendances to these hospitals relate to patients requiring services of a general as opposed to a specialist nature.

15 In 2003, there were 943,000 children aged 0-15 in Scotland, comprising 19% of the total population.

16 The health service needs of children are very different from the needs of adults. After a vulnerable period immediately after birth, children are at very low risk of death with only around 170 deaths per year in the age group 1-15, but they have a relatively high rate of contact with health services. Some of these services are in the form of preventive care, such as provision of immunisations and regular surveillance from Health Visitors. Most of the management of acute illness is carried out by General Practitioners and other members of the primary care team, but children also have a high likelihood of requiring hospital admission at some time during childhood.

17 Within primary care there are approximately 4200 GPs and 1500 Health Visitors. There are 69 hospitals in Scotland that deal with children, but in 2003/4, 48% of all admissions occurred in the four “Children’s Hospitals” (RHSC Glasgow, RHSC Edinburgh, Ninewells and Royal Aberdeen Children’s Hospital). Most of the other admissions were to District General Hospitals (DGHs) with dedicated children’s wards. Current service provision is provided in more detail in Appendix 7.

18 The following data outline the current level of activity within the primary care sector:

Table 1 - Contacts with primary care for children up to 16 years

<table>
<thead>
<tr>
<th>Annual number of contacts with Primary Care team</th>
<th>3.3 million</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Annual number of contacts with GP</strong></td>
<td>1.8 million</td>
</tr>
<tr>
<td><strong>Average annual number of contacts with GP per child:</strong></td>
<td></td>
</tr>
<tr>
<td>Age 0-11months</td>
<td>5.3</td>
</tr>
<tr>
<td>Age 1-4</td>
<td>2.7</td>
</tr>
<tr>
<td>Age 5-9</td>
<td>1.4</td>
</tr>
<tr>
<td>Age 10-15</td>
<td>1.4</td>
</tr>
<tr>
<td><strong>Average annual number of contacts with HV per child</strong></td>
<td>1.1</td>
</tr>
</tbody>
</table>
Planned number of total contacts during childhood relating to immunisation | 7
---|---
Total planned number of routine contacts for pre-school surveillance | 6

- Top five specific diagnoses in primary care: *Upper Respiratory Tract Infections, Skin conditions, Asthma, Infectious Diseases, Injuries*

19 In the first ten years of life, more than half of all children will have at least one hospital admission, although these are usually short. There has been a small reduction of 3% in admissions of children to hospital between the years 1999/2000 and 2003/4, but in the same period there has been a 5% reduction in the child population.

20 The following data outline the current level of activity within the secondary care sector (for year 2003/4)

| Annual number of admissions age 0-15 | 108,000 |
| Proportion of admissions classified as emergency | 57% |
| Annual number of all outpatient attendances | 366,000 |
| Annual number of new outpatient attendances | 172,000 |
| (30% of these occur in the four Children’s hospitals) |

- Top ten reasons for admission: **dental caries, respiratory infections, general infections, GI tract infections, head injuries, convulsions, otitis media, abdominal pain, lymphoid leukaemia, tonsillitis**
- Top ten surgical procedures: **tooth extraction, draining ear, excision of tonsil, operations on prepuce, closed reduction of fracture, IV injections, excision of appendix, placement of testes in scrotum, operations on muscles of the eye, diagnostic examination of bladder.**

21 It should be noted that the top ten diagnoses and procedures are similar for DGHs and for Specialist Children’s Hospitals, illustrating that much of the activity in the children’s hospitals is for secondary care.

**CURRENT RANGE AND ORGANISATION OF SERVICES**

22 Changes in population and patterns of disease have had a major impact on the configuration of children’s services and are expected to continue for the foreseeable future. This has been seen most recently in Tayside and Forth Valley and Lanarkshire with plans being put forward for reconfiguration in Ayrshire and Arran.

23 Changes in clinical practice have resulted in a shift in where care is provided for a range of conditions and this has resulted in fewer admissions to
hospitals for certain conditions, for example asthma and a decrease in 
paediatric surgical activity in relation to ear, nose and throat interventions\(^2\).

24 Changes in the workforce have also resulted in pressures on service delivery. These include the legislative changes introduced by the European Working Time Regulations as well as the improvements in training of clinical staff, for example the current introduction of Modernising Medical Careers, “Caring for Scotland, the Strategy for Nursing and Midwifery in Scotland”, and the national Allied Health Professions Strategy.

25 Specialised paediatric services are provided mainly through the three children’s hospitals in Aberdeen, Edinburgh and Glasgow, with a range of services being supplied from Ninewells Hospital in Dundee and other adult general hospitals in Scotland. Detailed information on the services provided in each of these hospitals is included as Appendix 7.

26 A small number of services are designated as national services, which are funded through separate funding streams and commissioned by the National Services Division, who also commission the small number of services provided outside Scotland.

27 NHS Boards are responsible for ensuring the provision of healthcare for their population. Where services are not provided within an NHS Board’s area, the Board makes arrangements for their provision with one or more of the Health Boards in whose area the service is provided. This is the case for the Health Boards who do not have specialised paediatric services provided locally. These arrangements include payment for services, however the financial structure does not always identify specialised services discreetly within these arrangements and there is risk of under recovery of costs, particularly as specialised services are usually high cost. Additionally as local services have developed more local shared care arrangements there can be problems in shifting resources away from the children’s hospitals to follow patient flows.

A VISION FOR CHILD HEALTH SERVICES

INTRODUCTION

28 All children and young people should receive effective, high quality, timely and accessible health services which are designed to meet their needs.

29 Children and young people and their families should receive appropriate information about their care and be involved in the planning of that care. They should also expect appropriate assessment and treatment information to be shared with their consent both with other health care staff and also with other agencies that provide care for children, notably local authorities. Services should be provided as close to home as possible if this can be achieved while ensuring safe, sustainable and cost-effective care.

\(^2\) ISD Admission and Discharge information, October 2004
Children, young people and their families can expect services to strive to ensure continuity of care, effective transition from child to adolescent services and from adolescent services into adult services.

**KEY PRINCIPLES OF SERVICE DELIVERY FOR CHILDREN AND YOUNG PEOPLE**

31 Care should be provided as close to home as possible where this is safe, sustainable and affordable.

32 There should be equity of access to services regardless of where a child lives.

33 Sustaining and developing local services is the responsibility of the whole system that commissions and provides child health services.

34 The availability of services depends on the skills and experience of the workforce and therefore training and workforce planning are essential components of this Framework.

35 Services should be planned and provided in partnership with children, young people and their families. Parents need support especially when accompanying their child to a non-local hospital.

36 Care should be provided in developmental stage appropriate environments. Young people up to age 16 should have the choice of care in a paediatric service and adolescents should have care and environments suited to their needs.

37 Services should be organised in way that promotes integration within health and between health and local authorities.

38 Services have a responsibility to ensure vulnerable children and children with disability are able to access services.

39 Services will be quality assured through regular audit and inspection. Quality standards across Scotland should be consistent.

40 Services should be evidence based and research supported.

41 Child health is closely related to good maternal health. The Framework for Maternity Services outlined in the Expert Group on Acute Maternity Services (EGAMS) is supported

**MODEL OF SERVICE**

42 Figure 1 depicts the model for fully integrated children and young people's health services. This model acknowledges the importance of integrated
services amongst health, social care, education services and voluntary sector services and other agencies such as the Police and Reporters' Administration. The need for “single system” working for all children’s services as recommended in “For Scotland’s Children” is strongly supported. This report however deals primarily with NHS Services as there are other frameworks, policies and guidance that address joint integrated services across health and local authorities. Local authorities and other partners have important roles in caring for sick children and we welcome their views on any of the recommendations.
Figure 1 Model of Integrated Care
In partnership with children, young people and their families, voluntary agencies, Local Authorities and other partners

Integrated Local Children’s Services Planning
Regionally based planning
Nationally based planning
Supra National Planning

Integrated Services
Local MCNs
Regional MCNs
National MCNs

Underpinning elements
Standards based: care pathways, protocol based care, ambulatory care, outreach and inreach, training and skills transfer, telemedicine, information sharing and transfer, shared care
The Specialised Services Action Team and the Child Health Support Group were keen to ensure that the work was focussed on needs of children and young people and their families rather than organisational boundaries. Therefore they worked closely together, whilst also working discretely to ensure a focus on the specific areas. Both areas of work were chaired by Peter Bates, a member of the National Advisory Group, the project lead for Child Health was a member of the Specialised Paediatric Services Action Team, they shared parts of their methodologies and the project leads for both areas developed the work together particularly the common key themes that emerged from the two specific areas of work, set out in Table 1 below. The outcome of both areas of work is this integrated report.

Table 1 – Key Themes

<table>
<thead>
<tr>
<th>Specialised Services</th>
<th>Common to both</th>
<th>Child Health Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current Organisation and range of services</td>
<td>Need for Change</td>
<td>General paediatric Surgery</td>
</tr>
<tr>
<td>Definition of Specialised Paediatric Services</td>
<td>Age Profile</td>
<td>Child and Adolescent Mental Health</td>
</tr>
<tr>
<td>Paediatric Intensive and High Dependency Care</td>
<td>Services for Young People and Transition</td>
<td>Remote and Rural care</td>
</tr>
<tr>
<td></td>
<td>Relationships between Care Providers</td>
<td>Children with complex needs (subject of a separate report)</td>
</tr>
<tr>
<td></td>
<td>Patient Journeys and Pathways</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Transport and transfer of ill children</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Support Systems for Families</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Information Requirements</td>
<td></td>
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<tr>
<td></td>
<td>Workforce Requirements</td>
<td></td>
</tr>
<tr>
<td></td>
<td>ITC infrastructure</td>
<td></td>
</tr>
</tbody>
</table>

The Specialised Paediatric Services Action Team met 6 times between August 2004 and February 2005. Its membership is drawn from across the NHS in Scotland and includes user representation. The list of members is included as Appendix 1.

The Chair of the Team asked the Royal College of Paediatrics and Child Health to identify an expert advisor for the duration of the work. Dr Anna Murphy agreed to perform this role.

The findings of the Team are drawn from a range of sources:
- discussions at the Team meetings which identified the key themes which needed to be addressed. These themes were then reviewed further by members of the team taking responsibility for doing this in partnership with other members of the Team and wider colleagues and bringing the discussion back to the Team at its meetings.
• Participation in the process led by the Secondary Care work stream of information gathering and discussion with the clinical community via questionnaire and video-interview with representatives from each NHS Board area see paragraphs 50 and 51 below
• Participation in the National Review Consultative Seminar held in January 2005
• Consideration of the report of the Review of Tertiary Paediatric Services undertaken under the auspices of the Child Health Support Group and led by Professor George Youngson and adoption of the key themes recommended

47 The methodology used to underpin the work of the secondary care work stream included a review of current research and literature, data analysis via questionnaires, video-conferencing discussions with clinical and managerial staff in each NHS Board, follow up interviews with professional groups and individuals, the National Review Child Health Consultative Seminar held in January 2005 to discuss emerging recommendations and follow-up workshops on 8 February 2005.

48 The Royal College of Paediatrics and Child Health conference on specialised services including feedback on the college information gathering exercise on specialised services also informed the secondary care work stream

49 The literature review identified key documents from the Royal Colleges including guidelines on clinical practice and policy documents. Colleagues from the Royal Colleges actively participated in the process and shared current thinking within the clinical community.

50 The Child Health Support Group issued questionnaires to all child health commissioners asking them to provide information about current service provision, problems in sustaining or developing services and potential solutions. Commissioners collate this information in conjunction with clinical staff in primary, secondary and tertiary sectors in each Health Board area.

51 Interviews were conducted with primary and secondary care practitioners and managers in each NHS Board area. These interviews were conducted by video link and involved representatives from Action for Sick Children (Scotland) and Children First. Further interviews were conducted with key professional groups including paediatric surgeons and anaesthetists. A detailed description of the process and results of the questionnaires and interviews are given in Appendix 5.

52 Significant consultation has therefore taken place across the clinical community in order to identify the issues and themes which need to be addressed in the medium to long term in order to ensure Scotland’s children continue to be able to receive clinical services which are able to keep pace with developments in technology and clinical practice. The English and Welsh National Service Frameworks (NSF) have been underpinned by significant research and extensive discussions with the clinical community, parents and voluntary organisations. The Royal Colleges in particular have played a
significant role in the development of the standards published within the NSFs. The Scottish work on child health planning and the development of services have already been influenced by this work. As part of the work of the CHSG in developing this paper it has been clear that there is support from within Scotland to adopt in principle the standards in the English and Welsh NSFs. NHSQIS in developing child health standards should take account of the English and Welsh NSFs and minimise duplication of effort.

**AGE PROFILE**

53 Currently there is no national policy advice relating to age in paediatric care, and practice differs across Scotland. The Children (Scotland) Act 1995\(^3\) defines a child as a person under the age of eighteen years for the purposes of support for children and their families including services from the NHS\(^4\). This definition is consistent with the United Nations Convention on the Rights of the Child and other legislative and UK service Frameworks\(^5\). It is also the definition adopted by the Child Health Support Group\(^6\).

54 The health care needs of children and young people up to the age of eighteen should be properly assessed and care provided in an appropriate environment by trained staff. For some young people, for example those with learning difficulties, this age range may extend beyond 18 years of age to 21 years of age. In all cases services should be age sensitive recognising when young people have specific needs of adult services and where they find themselves in between paediatric and adult services. In considering clinical needs, account should be taken of children and young people’s developmental needs at each stage of childhood and adolescence.

55 The new Mental Health (Care and Treatment) (Scotland) Act (2003) requires that all young people under the age of 18 who require hospital treatment by virtue of mental health problems should receive that treatment in surroundings which are appropriate to their developmental needs.

56 In considering current arrangements across Scotland and with reference to best practice, e.g. the Kennedy report on Cardiac Services in Bristol, the English NSF and the EACH Charter, paediatric services should be co-located with adult, maternity and neonatal services and services for young people should be recognised as discrete from adult and paediatric services. The need for paediatric services in Edinburgh and Glasgow to move to this configuration is acknowledged.

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\(^3\) Children (Scotland) Act 1995, section 93 (2)
\(^4\) Children (Scotland) Act 1995, section 21 (2) (b)
\(^5\) Commissioner of Children and Young People (Scotland) Act 2003, Getting the right start: The National Service Framework for Children, Young People and Maternity Services – Standard for Hospital Services, Department of Health, April 2003
\(^6\) Making It Work for Scotland’s Children: Child Health Support Group Overview Report 2003, p10
Recommendations

57 It is recommended that NHS Scotland adopts the guiding principle of the age for admitting children and young people to acute care in paediatric facilities as up to their 16th birthday, dependent upon their clinical need and patient choice.

58 For young people between the ages of 16 and 18 there should be discussion with their clinician(s) regarding where their care is best delivered, recognising their right of choice, unless there are clear clinical reasons which determine whether admission is to paediatric or adult services.

59 In adopting this principle it is acknowledged that further work will be need to be undertaken at regional and local level regarding the implications of this recommendation. Implementation will be complex and require an extended planning period. The commissioners of new facilities for children and young people will need to consider this in designing the qualities and style of service required.

SPECIALISED SERVICES

DEFINITION OF SPECIALISED SERVICES

60 Whilst recognising that specialised paediatric services are part of a continuum of care, they should be defined in a way that reflects their complexity and gives clarity to patients and the service. Agreement of a definition will also facilitate the development of robust information and data bases to support their future development. The definition would describe the nature and characteristics of the services as well as being specific enough for data gathering.

61 To define this clinical activity reference was made to the Specialised Services National Definitions set (2nd Edition), published by the Department of Health in 2001. Specifically Definition 23 relates to specialised services for children and defines specialised activity over a range of children’s services. This publication acknowledges that the identification of specialised conditions/treatments is complicated and should be considered as an iterative and dynamic process, with over time, new specialised services being introduced and others becoming more routine and ceasing to be specialised. More detailed information on these definitions is included as Appendix 8.

62 Specialised services tend, by their nature, to focus on relatively low volume activity. In paediatric practice the principal patient groupings dependent on such services are:

- Children whose condition is so serious or rare that all treatment relating to the condition would be considered specialised
- Children with severe or intractable variants of otherwise more common conditions
- Children in whom complex co-morbidity complicates the conduct of otherwise relatively straightforward procedures
- Neonates or very young children in whom even simple procedures necessitate specialised support services e.g. anaesthetics, neonatal intensive care
- Children in whom the need to repeat procedures that have not proved effective when first performed argues for specialist involvement

63 The services which provide such care are considered to be “specialised”. Although such specialised services will inevitably, and rightly, have interfaces with other services in primary and secondary care they are normally clearly defined in terms of the staff groups who deliver them and/or the localities at which they are provided.

64 In addition specialised services, by their nature, tend to be characterised by:
- Highly specific workforce challenges as a result of small staff numbers, specialised training needs and, in some cases, the significant time demands of providing shared care or outreach services.
- A relatively small volume of patients needing this service
- Complex interdependencies, often with other specialised services, as a direct result of the severity and complexity of the conditions displayed by many patients
- Strong links to research and innovative leading edge practice particularly in terms of technology dependent interventions and drug therapy
- Significant financial implications in terms both of revenue and capital investment

65 Although the above clinical scenarios (para 62) require care from specialised services it is equally true that such services only provide one element of the totality of care upon which an individual patient will depend. The contribution of specialised service to a child’s care will vary between some specialities in which most clinical care is considered to be specialised (e.g. oncology, cardiology, and psychiatry) to others in which only specific interventions or episodes of care would be so defined.

66 Where clinical conditions lead to reasonably predictable patterns of care the development of protocols and care pathways can provide clarity regarding those elements of care which can only be delivered in a particular setting or by specialist staff and those others which can be safely and adequately provided within secondary or primary care services. The development of such protocols and pathways therefore offers a further mechanism to define the role and boundaries of specialised services and their interaction with other areas of health care provision.

67 It is anticipated that definition of specialised services will bring greater clarity to the strategic planning and commissioning process. To support this activity the Royal College of Paediatrics and Child Health has recently published
detailed guidance on commissioning of tertiary and specialised services for children and young people.7

Recommendation

68 It is recommended that NHS Scotland adopts the definition of specialised paediatric services as described above and the range and definitions set out in the Department of Health Specialised Services Definition set, principally Definition 23 Specialised Services for Children, but also those others that relate to children. Commissioners of specialised services should draw on the guidance published by the RCPCH.

A PAEDIATRIC CRITICAL CARE SERVICE FOR SCOTLAND

69 The Specialised Paediatric Services Action Team identified the provision of paediatric intensive care (PIC) and high dependency care (HDC) as an immediate issue for NHS Scotland in the light of trends in activity and case mix that may not be sustainable within the current provision. The Action Team considered that the planning of PIC must be integrated with that of paediatric high dependency care and neonatal surgical intensive care (NSIC). There are critical interdependencies with a number of specialist paediatric services and thus the planning of PIC is a key factor in the planning of specialised paediatric services. Neonatal medical intensive care (NMIC) was excluded from this review as it is covered by the work of the Expert Group on Acute Maternity Services.

70 The particular issues to be addressed by the Specialised Paediatric Services Action Team were:

- An assessment of whether paediatric intensive care can continue to be sustained in Glasgow and Edinburgh as it is now for the foreseeable future, and neonatal surgical intensive care sustained in Glasgow, Edinburgh and Aberdeen.
- An assessment of the level of paediatric intensive care and neonatal surgical intensive care required for the population of Scotland, projecting this forward for 5-10 years.
- The preparation and initiation of a longer term exercise to collect information on High Dependency Care provided throughout NHS Scotland. This took the form of specifying the data items for a prospective audit through which information can be collected over 2 years in order to inform future planning of Specialist Paediatric Services.

71 This work was led on behalf of the Action Team by Deirdre Evans, a member of the Action team, who involved colleagues in the service widely. Dr Jennifer Armstrong led the specific work on High Dependency Care information. A full report of this work is included as Appendix 10.

7 Commissioning Tertiary and Specialised Services for Children and Young People, Royal College of Paediatrics and Child Health, May 2004
The work identified a number of key changes in practice in the areas of both PIC and HDC:

- Since 1997 there has been considerable reorganisation of paediatric intensive care in Scotland. The majority of paediatric intensive care is now delivered on 3 sites: Glasgow PIC Unit, Edinburgh PIC Unit and the Intensive Care Unit at the Institute for Neurosciences at the Southern General Hospital, Glasgow.
- Professional guidelines are increasingly recommending certain paediatric procedures are carried out only on sites with PIC backup.
- Since the establishment of the national paediatric transport service for critically ill and injured children, there has been an increasing trend towards transferring children to the Royal Hospitals for Sick Children in Edinburgh and Glasgow from hospitals in the rest of Scotland. Moreover there has been increasing joint working of the two PIC sites so that each cross covers the other, and together they provide a co-ordinated national service for the whole of Scotland reflecting the different case mix of patients in Edinburgh and Glasgow.
- The focus of individual specialised services on single sites, e.g. Cardiac surgery and interventional cardiology for children in Scotland, means the total number of PIC beds available to Scotland will have to be used flexibly to cope with fluctuations in need. As a result, there is an increasing need for the service to be run as a single national service on two sites.
- There has been an upward trend in referrals to Edinburgh and Glasgow which is set to continue, and spikes in need that exceed current capacity, for example when a high number of children with complex needs are in PIC for extended periods restricting the availability of beds for emergency admission.
- Increasingly more children requiring high dependency care (as distinct from intensive care) are being transferred by the critical care retrieval teams from Edinburgh and Glasgow. Largely these retrievals are requested from hospitals without the ability to provide paediatric high dependency care but trends suggest that consultants in district general hospitals that previously provided such care for children now consider that a transfer to specialist centres is required.
- On some occasions, transfer is arranged from hospitals with HDC facilities to the PIC Units in Edinburgh or Glasgow if a child's condition is deteriorating even if, in the event, only HDC rather than PIC is required on arrival.

Additionally there are a number of developments which need to be planned into PIC and HDC provision:

- There is a trend towards increasing volume and case mix complexity in specialist centres due to new techniques and technologies that can achieve survival and good outcomes for babies and children who would previously have died but now
require much higher nursing ratios, more intensive interventions and, in some cases, extended lengths of stay.

- There is a need for clarity on where paediatric neurosurgery will be provided in future. Much complex elective neurosurgery requires only HDC post operative care; the unpredictable and complex challenging workload comes from Head Injury. The management of Head Injury needs to be planned and addressed at a Scottish level to ensure appropriate patient pathways and transfer to suitable specialist care including PIC support.

- Expectations have risen - both by clinicians and parents and carers. As more can be achieved, the expectation is that outcomes will be positive in all cases.

- There is a potential development of integrating the neonatal surgical and neonatal medical facilities at RHSC Glasgow to provide improved mutual cross cover and support and increased flexibility.

- There are not universally in place planned “exit” or “step down” arrangements to transfer patients from the specialist intensive care units in Edinburgh and Glasgow to suitable neonatal IC or paediatric HDC facilities, where these exist, in children’s and maternity hospitals. This is exacerbated by the absence of a “return” transport service mirroring the retrieval service for the transport of critically ill and injured children.

Conclusions

74 There is wide recognition that current trends in activity and case mix complexity cannot be sustained within the existing levels of provision. The main limitation was highlighted as the availability of skilled staff rather than the physical bed or cot. There is therefore a need to develop a different approach to recruitment and continuing development of staff which provides accredited training opportunities for all staff groups within multi-disciplinary teams across the range of critical care. The conclusion from the trends described above is that in future this may cross more than one site.

75 The foundation for the management of critical illness in children in Scotland is high dependency care. All hospitals admitting children who are, or who may become, critically ill must be able to resuscitate and stabilise them. Hence hospitals that plan to provide a range of specialised services for children need to be able to arrange and provide high dependency support for short periods of time. Additionally there is broad agreement that the availability of critical care facilities is a pre-requisite to the provision of certain specialised paediatric and neonatal services. Such services require critical mass for sustainability and they cannot be provided piecemeal as a support service. Hence the location and availability of PIC/HDC/NSIC facilities are key drivers in the planning of specialist paediatric service.

76 Thus it is considered that the pattern of critical care required involves the continuing provision of critical care in as many locations as it is clinically effective and sustainable to do so. The retention of dedicated high dependency units in Aberdeen, Dundee, Edinburgh and Glasgow will support
the provision of a wide range of children’s services within these cities; and the capacity to support children’s services in local hospitals on an outreach basis.

77 The key is to ensure that there is rapid and reliable transfer to and from local hospitals to the major children’s hospitals that provide paediatric high dependency care, backed up by the ability to stabilise and resuscitate babies and children when necessary until transfer can be effected.

78 There is also a need for clear procedures to be in place for escalation of the intensity of care when required, for example, if a child’s condition deteriorates, including rapid and reliable intensive care transfer to and from the lead PICUs in Edinburgh and Glasgow.

Recommendations

79 Accident and Emergency Departments and Inpatient services for babies and children should be supported by the capability to provide – at least short term – critical care support for children. This needs to be backed up by 24 hour access to medical and nursing advice from lead critical care centres. Critical care undertaken outside a lead centre should be delivered in accordance with the standards set by the PIC Society and according to protocols developed in liaison with lead centres. Health Boards should review their current provision and develop action plans.

80 A National Managed Clinical Network for paediatric critical care is developed to link critical care services across Scotland to provide a co-ordinated support service for critically ill children.

81 The dedicated HDUs in Aberdeen, Dundee, Edinburgh and the soon to be established HDU in Glasgow should be developed into regional lead HDU centres within the national network, and the two PICUs in Edinburgh and Glasgow should be developed as the lead national PIC centres within the network – operating as a single PIC service on two sites.

82 Change is expected over the next 5-8 years as a result of the commitment to rebuild the children’s hospitals in Glasgow and Edinburgh. During this period of change the PICU service should be nationally commissioned for a minimum of 5 years to oversee the establishment of the national critical care network and explore ways in which arrangements between the two PIC units can be strengthened.

83 Regional Planning Groups should work with Ambulance services and referring clinicians to plan paediatric services across regions with a view to

- ensuring that the first hospital to which the child is taken is appropriate in relation to the child’s need for critical care support as far as possible.
- rapid and reliable transfer arrangements are in place to escalate the level of support when needed
- return transport arrangements are available as part of agreed discharge protocols
84 NSD project manages a detailed 2 year audit of high dependency care for children to provide information about the provision and outcomes of these services.

85 NHS Education Scotland should engage with the clinical specialist teams, the Educational Institutions, Colleges and Post Graduate Deans in discussions to adapt the existing arrangements for training accreditation so that training can be provided through rotational posting across a number of sites within one service, and to develop accelerated accredited training for nurses to advanced practitioner.

86 There should be appropriate investment to ensure that PICUs and HDUs are equipped to provide the support necessary. An immediate investment should be made in the PIC service in Glasgow to bring occupancy levels down to 80%. There must also be investment in nurse education and development.

INTERFACE ISSUES FOR SPECIALIST SERVICES AND FOR SECONDARY CARE SERVICES

PATIENT JOURNEYS AND PATHWAYS INCLUDING MANAGED CLINICAL NETWORKS

87 Care plans should be made for every child requiring referral to a specialised service. These will set out the pathway of care of the child through each episode of care and throughout the lifetime of their care and the standards at each stage (Ref NHS Quality Improvement Scotland Child Health Work plan and English and Welsh National National Service Frameworks). Managed clinical networks use this approach based on multi-disciplinary working.

88 Consistent high quality care across the patient journey requires to be assured. Care needs to be focused on the child and family’s needs and linked to standards at every stage of the journey. The creation of MCNs gives the opportunity for standard setting for partnership of care for the child and young person.

89 Communication between all parties is crucial to effective care from the point of diagnosis onwards and includes the parent and child/young person, primary care team, out of hours services, ambulance personnel, local paediatricians and support staff, including AHPs and community children’s nurses, and other partners such as Local Education Authorities, Social Work Departments and voluntary agencies.

90 A child’s journey of care into specialised services may start through contact with out of hours services, therefore there is a need to explore the opportunities of how to ensure that Out of Hours services, e.g. Accident and Emergency departments, Minor Injuries services, Primary Care Out of Hours
and NHS 24 are made aware of children with complex conditions, including named consultant contact information.

91 There was a strong feeling expressed within both work streams that there was a need to plan across geographical boundaries and to strengthen access to specialist advice. The Managed Clinical Network (MCN) was seen by many as a positive mechanism for achieving these aims particularly in services where currently service provision provides challenges e.g. child protection.

92 Managed Clinical Networks have been developing across Scotland since their promotion through the national acute services strategy in 1 May 1998. A number of different types MCNs are now in existence: National, Regional, Geographical, Chronic Disease, and Clinical Specialty. Most networks have gone through a number of emergent phases. These can be described as: emerging established and accredited. Not all MCNs will achieve accreditation.

93 The benefits of managed clinical networks should be extended to other areas of specialised paediatric services, including informal networks that have been developed. However this should be mapped on a national basis to consider the implications, particularly concerning the supporting infrastructure required to ensure the most effective arrangements are put in place, eg MCN administrative facilities to support a number of MCNs.

94 It is recognised that the current and continued review of paediatric oncology and malignant haematology in Scotland is being carried forward by the subgroup of the tertiary paediatric services review and support is given to the intention to promote a national service delivered from the existing UKCCSG (United Kingdom Cancer Study Group) centres in Scotland. Moreover there is support for the aspirations promoted by this group to -

- Implement the recently published guidelines by the National Institute of Clinical Excellence in relation to children’s cancer services
- Identify a lead clinician for this service
- Develop lead centres for certain malignant conditions in childhood
- Configuration of the service should be determined through option appraisal facilitated by an external chairman
- Consolidate shared care arrangements with level 1/2 centres
- Promote multidisciplinary working across all sites through formation and utilisation of a Scottish Paediatric Teleconferencing Network. This might be an appropriate medium for multidisciplinary team meetings across all sites.

NSD should consider this specialty for designated national service status.

Recommendations

95 NSD together with the regional commissioning groups should produce a national strategy on the development and approval of MCNs for Child Health by September 2005. This strategy will make recommendations about which MCNs should operate and interrelate at national, regional and at Health Board
level. It will include a phased programme for MCN development over the next 5 years.

96 All networks should meet/work to meet the standards for MCNs set out in the guidance and performance management of MCNs should be strengthened through NHS Boards and Regional Planning Groups.

97 The first phase of the national programme should include proposals for MCNs emerging from the following sources:
- National Review Child Health Work streams - Children with Complex Needs, Child Protection, Cystic Fibrosis, Paediatric Critical Care
- Review of Paediatric Tertiary Services - Paediatric Neurology, Paediatric Gastroenterology, and Paediatric Oncology and Malignant Haematology, Paediatric Respiratory Medicine
- CAMHs – Network for Children with complex and Severe Mental Health Problems

NSD should take responsibility for establishing a prioritisation process.

98 As part of the development of Paediatric Oncology and Malignant Haematology (POMH) and in line with the model recommended for Paediatric Intensive Care, POMH will organise its services as a single service operating over a number of sites.

E-HEALTH

99 The value of current telemedicine projects was commented on by many interviewees, with the benefits of the Scottish Paediatric Telemedicine Project being particularity noted. This project’s funding runs out during 2005 and is required to be secured to ensure continuity and evaluation against its original objects, and consideration of the applications it has been used for wider than its original purpose. Many saw even greater potential for the use of this technology in providing speedy access to specialist opinions, with particular benefits for remote and rural services.

100 A number of Boards identified diagnostic imaging of children as a service that could potentially be provided closer to a child’s home and prevent the need for travel to a tertiary centre. In a few areas there was a reluctance to undertake the actual test on a child due to problems with interpretation of results but in most areas the view was that children could have the test locally if there were effective tele-radiology links to ensure appropriate interpretation of results by a paediatric radiologist.

101 There are already examples of the use of telemedicine and videoconferencing to support a range of activities including remote consultation between clinical professionals, case review and case conferences and meetings, for example the Scottish Paediatric Telemedicine Project at RHSC Glasgow. This should be expanded on the basis of rolling out successful applications and exploring new ones, eg consultations with Hospital Play Specialists. This development
will require investment in training of staff in how to use this technology appropriately. Each new clinical development should be assessed and safety proven. Experience has shown that knowledge of local practice supports the use of telemedicine; therefore it should be developed in regional clusters, based on existing relationships between services.

102 Teleradiology is very complex and will need a national infrastructure, such as a national Picture Archiving and Communications System to support it in terms of quality image transfer and data storage. It is important that the infrastructure is in place to support, and in advance of, changes in practice.

103 Optimum benefits of teleradiology for children and young people will require specific paediatric radiology sessions, supported by protocols. Radiological equipment and CT scanners should have specific exposure factors worked out for children and the environment in which images are taken should be age appropriate in the same way as for other services for children and young people. Staff should also be trained and experienced in working with children, who often require more support during the taking of the image than adults. Children also require a longer time allocation and protocols should specifically reflect these particular needs.

104 Maintenance of good practice and protocol adherence can be supported by having clinical links between the paediatric centres and local referring units. Examples would be to have joint appointments and to develop ultrasonographers’ skills to perform routine ultrasound which then together with MR and CT scans could be done to protocol and reviewed and reported at the paediatric centres using tele-radiology links.

105 The application of telemmedicine in children’s out of hours services should take account of experience which indicates that most paediatric emergency imaging is “hands on”.

Recommendations

106 The ITC infrastructure should be developed to support information transfer between all parts of NHS Scotland. These applications would be in the areas of patient records, diagnostic images, laboratory results.

107 Nationally agreed protocols should be developed reflecting the particular needs of children and young people and made available on specific websites for easy access to support local care delivery. These can form part of the Service Specification described later.

108 NHS Scotland ITC strategy should support the roll out of proven technologies to support delivery of specialised paediatric services in partnership with local services as a matter of urgency. The current Paediatric telemedicine projects should be funded recurrently from 2005 and expanded to become a Scotland wide Paediatric Telemedicine project by December 2007 which covers a wide range of paediatric specialities. It should be able to provide support that will
allow links between the 4 children’s hospitals and other facilities that care for children.

109 The strategy for telemedicine and eHealth should incorporate its use for training, case conferences, case reviews, actual consultations, involvement of a range of professionals including AHPs and mobile phone technology in innovative ways.

110 Access to a paediatric consultant led radiology services 24 hour a day should be available across Scotland. This will need to be appropriately resourced in the specialist centres that are providing 24 hour cover for other board areas. The service would work on the principle that where ever possible the image would travel rather than the child.

INFORMATION TECHNOLOGY

111 Information concerning children’s health exists, but it is disjointed. The information concerning specialist paediatric services is of reasonable quality and usefulness because it relates particularly to hospital care, however it is not always flexible enough to support interpretation to inform service development, e.g. it does not easily reflect complexity of care.

112 The NHS needs to provide for all the healthcare needs of children who require specialist paediatric services rather than just providing the specialist services themselves. What these children need is an integrated package of care which includes not only their specialist hospital care, but also their outpatient care, their special primary care and community nursing needs, and the other needs which all children have, including immunization and child health surveillance. The information therefore has to reflect this integrated care, so that at an individual patient level, communication between professionals is facilitated, and at a population level, present services can be described, and future services planned and monitored. There is a need for properly integrated information across the child’s pathway of care and in the longer term, with information from Social Services and Education Departments.

113 NHS Scotland should be working towards a single integrated system, but in the interim, there are a number of systems which could be brought together or interfaced and this work needs to be progressed.

114 The recognition of the need for integrated information led to the setting up of the Maternity and Child Health Information Strategy Group (MCHISG). This group has now produced an action plan for the production of integrated information. This plan, although designed to address the needs of all children has a number of features which will help with the particular information requirements relating to the planning of Specialist Paediatric Services. These include the following:

• Formation of a national core dataset within a maternity and child health data store. This ensures that there is one record per child, and that information from a variety of sources is pulled together.
• Use of CHI and production of a CHI number at birth. This facilitates records being drawn together, and prevents children being "lost" to the system
• Use of the new “Generic Clinical System”, currently being procured. This will give specialist services within hospitals the ability to provide high quality data derived as a by-product of the clinical process rather than as a separate data collection process (as is done at present).

115 There is a need to ensure that information can be shared in an appropriate way across the NHS and with other agencies, thus any issues regarding confidentiality and security of information need to be resolved as a matter of urgency. The e-care Children’s Programme is running a pilot on personal care records to ensure children, young people and their families have appropriate information on their health.

Recommendations

116 ISD in partnership with the services should consider the implications and opportunities afforded by NHS Scotland adopting the Department of Health Specialised Services Definitions for Children for developing a minimum dataset. It should also consider how it would work with the Department of Health in its process of review and development of its definitions. This should be linked in with the work of the Maternal and Child Health Information Strategy Group.

117 The Action Plan of the MCHISG should be implemented over the next 3 years. Work on the use of CHI from birth and dataset development can be progressed immediately.

TRANSPORT AND RETRIEVAL

118 During the work of the both Action Teams the issue of transport was ever-present, particularly for those children not requiring the paediatric Intensive Care Retrieval service, children living in remote and rural locations and for those who were being transferred back to local services. The nature and demand for specialised paediatric services means that they will not be located in every hospital in Scotland. Therefore those children, young people and their families who live in areas where these services are not provided will be required to travel.

119 Respondents to the questionnaires and interviews highlighted the importance of discussing cases with senior clinical staff and the benefit of the PICU identifying the location of the bed for the transferred patient. A clear consistent support mechanism for identifying the appropriate transport selection is a priority. Many respondents identified the absence of a paediatric transport service for ill children who require transfer, but do not meet the full criteria of PICU-level care.
In responses from the remote & rural areas, some specific issues were raised relating to the ongoing clinical care of a seriously ill child, while awaiting arrival of the retrieval team. The particular vulnerabilities in remote locations were highlighted emphasising the importance of early referral for children with potential for further deterioration especially taking into account that geography and weather may justify early (anticipatory) transfer.

The critically ill and injured children’s retrieval service aims to provide a single contact point and direct access to the consultant on call for discussion/referral of seriously ill children considered to merit PICU retrieval. Comments received demonstrate that further work is required to ensure that:

- Referring doctors know what number to call
- There is direct access to the senior doctor on call for discussion and
- There is a consistent response on each case.

The key principles described earlier support as much care being delivered as close to where a child lives as possible, however there will be occasions where ill children will have to be transported to receive care. At all times the safety of the child and their clinical condition will be the prime considerations. The paediatric Intensive Care Retrieval service and neo-natal transport service provide examples of how this can be done and the Scottish Ambulance Service provide transport by surface and air.

It is also important for children and young people to return to their locality for care as soon as possible after their specialist care. Feedback during the work of the Team suggested that children were staying too long in specialist centres and improvements in this would be welcomed.

Recommendations

Further transport options should be considered in partnership with the Scottish Ambulance Service including retrieval for ill children and consideration of expanding the use of air transport.

There should be a single telephone number for contacting the retrieval teams with direct access to the consultant on call in either Glasgow or Edinburgh.

Transport and Retrieval Services should consider the particular needs of remote and rural areas in relation to emergency transport of children, reflected in a reduction in the total time between agreement to retrieve and arrival of the retrieval team. For children meeting the criteria for PICU retrieval, RHSC Glasgow and RHSC Edinburgh should develop mechanisms to offer interim clinical support from the appropriate PICU site while awaiting arrival of the retrieval team. This might involve remote biophysical telemetry monitoring. The role of the Scottish Ambulance Service and in particular the air ambulance service, is critical to achieving satisfactory response times. SEHD should ensure that SAS is strategically positioned to support rapid transfer of expert teams from specialist centres to stabilise patients in remote and rural areas and the transfer of increasing numbers of critically ill and injured children.
neonates, children and adults over long distances to appropriate specialist centres

127 Two further types of retrieval should be addressed – seriously ill children not requiring intensive care i.e. those requiring high dependency care, and children with severe head injury. This will require further work but is likely to involve a networked approach utilising the experience and infrastructure of the existing retrieval teams. It will involve quantifying likely demand and the development of thresholds and standards for care. This work has commenced through the Audit of HDU requirements commissioned by the Child Health Support Group and being carried out through NSD. There should be a clinical decision support system for transfer of significantly ill or injured children who do not technically justify PICU level care. This should support an integrated transport network configured to offer a stratified response defined by the needs of the child.

128 There should be urgent consideration of systems to ensure children can be transferred back to a more local hospital when intensive care is no longer required.

129 There should be continued dialogue between the Scottish Ambulance Service and NHS Boards to ensure that the new contract for air ambulance services adapts to the recommendations in this report.

130 In view of the number of recommendations regarding transport and retrieval services it is recommended that consideration is given to whether there would be benefit in integrating some aspects of the services to support improved transfer back to local services. The recent review of the Neonatal Transport Service recommended that this is planned on an all-Scotland basis, with the models of delivery in each region developed to be sensitive to local needs.8

RELATIONSHIPS BETWEEN CARE PROVIDERS

131 A complex system of relationships exists between care providers across Scotland. Children will gain access to specialised services through a number of routes. Some may be identified at birth as requiring specialised care and be referred from a local hospital maternity unit to a specialist neonatal or paediatric centre. Others may be identified by primary care teams and referred to local paediatric services that refer on to specialised services in sub speciality areas. The final group are those that access emergency services via SAS to Accident and Emergency Departments. In an emergency situation a child’s clinical need is paramount.

132 Specialised care frequently requires significant support from technology and specific equipment and specially trained staff, particularly where surgery is involved. Thus it is inefficient and uneconomic and often unsustainable to

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have duplication of this across a number of sites. Improved efficiency can be achieved if paediatric services remain distinct from, but are co-located with, adult and neo-natal services.

133 Specialised care is often at the forefront of medical advances and as such there is a strong link with Universities through research. There is also a co-dependency for teaching, education and development of medical, nursing and allied health professional staff. This has been the traditional role of the University Teaching Hospital. The nature of delivery of care in the future will require association between Universities and a range of healthcare providers across the spectrum of care both for research and teaching as well as skills development.

134 We heard of established and evolving informal clinical networks for a variety of tertiary specialities often supported by outreach clinics, and sometimes augmented by “inreach” clinical sessions by DGH paediatricians at tertiary centres. These arrangements support some shared care and reduce some visits to a specialist centre. However the spectrum and breadth of provision is patchy, often limited by lack of available outreach support from specialist Allied Health Professionals, and relatively dependent on individual or service motivation. There is enthusiasm from DGH clinicians and families for further expansion.

135 Where children are going to require on-going treatment, review and family support, the relationships across the care continuum require special attention. As far as is practicable on-going treatment and support should be delivered in the child’s community setting, primary care or in the local paediatric facility, delivered by local staff, working as part of a managed clinical network. Integrated information is an important aspect of facilitating this.

136 Supporting contact between children admitted to specialist hospital care remote from home and their families will typically contribute to prevention of secondary mental health problems, and in the case of those admitted for treatment of mental health problems, be a critical component of the treatment process.

137 Working as a part of a network develops the relationship between clinical staff, fostering trust, enabling true partnerships in care to work well, for the benefit of all concerned. It is important for local clinical teams to be involved and informed in discharge planning as this is the most likely point of contact for support in the local community. Specialist centres should seldom assume total care but where this is appropriate local paediatrics, as well as primary care, should be kept informed of progress. This principle applies equally to adult tertiary services where many children aged 13 years and over are often referred. Working in this way encourages integrated care, develops the local workforce and maximises the use of resources.

138 Feedback from areas participating in outreach and inreach arrangements indicates the benefits to patient care these have. They have brought about improved communication and professional links, and when provided on a
multi-disciplinary/multi-agency basis have provided educational opportunities. They have empowered local teams to take on the management of children’s care. The arrangements should be structured and formalised between the services and include standards and audit.

139 New technology can support the development of relationships, video conferencing, telemedicine, use of Picture Archiving and Communications systems and IT transfer points. Awareness and investment in these facilities is to be encouraged.

140 Specialist centres can actively support models of devolved or shared care to minimise disruption to children and their families and to support continuation of local services. The relationship can provide support for training and skills transfer in a variety of ways including specialists spending blocks of time in local services and local staff doing the reverse.

141 The current relationships should be formalised in terms of referral and discharge and centres should agree protocols with their referring services. Discharge of children and young people back to local services is a particular area that was commented on during the work. This needs to be planned carefully and include the services that will be providing the care locally. Attention should be paid to ensure there is sufficient investment in local services to provide care, particularly in terms of the skills required.

142 Some areas reported that they currently deliver paediatric services (including for example ENT or Orthopaedics) on a number of different sites in one NHS Board area. This has resulted in significant problems in delivering sustainable staffing and rotas.

Recommendations

143 Specialist centres should acknowledge responsibility for supporting local services through formalisation of their relationship with referring services. This formalisation of relationships should be set in a regional framework of care, based on the children’s hospitals with their referring services. The framework would set out a core minimum paediatric service provided at DGH level, e.g. respiratory, diabetes, neonatology, endocrinology, cystic fibrosis, and how the specialist centre supports this service through Service Specifications, see below.

144 Service Specifications should be agreed between NHS Boards hosting specialist children’s hospitals providing tertiary care services with all NHS Boards that refer children to them. These service specifications should include outreach and shared care arrangements for individual specialities that ensures as much local care as possible. They should also include (web-based) protocols/guidelines to support local care. Each region should establish a tertiary/secondary clinical forum to promote and monitor shared care arrangements across NHS Board boundaries.
With the changing nature of secondary paediatric services and the drivers for change around workforce and sustainability, all secondary paediatric services and the liaison with the specialist centres should be planned and organised on a regional basis. Appropriate decision making and funding mechanisms will need to accompany these planning and organisational structures.

NHS Boards and Regions should consider regional or joint appointments to provide specialist support locally where it is not possible to recruit to posts or retain staff in a single board area. Additionally Regional Planning Groups and NHS Boards should review the number of sites where secondary inpatient paediatrics are provided to maximise staff resource and avoid multi site working.

SUPPORT SYSTEMS FOR FAMILIES

During the interviews we heard that parents who accompany their child for care to a specialist centre often feel isolated and unsupported. Interaction with specialised services by children and their families is mostly for relatively short periods of time, however it is extremely stressful and potentially financially expensive, particularly for those who have to travel long distances.

Parents can sometimes experience frustration when their local doctor and/or consultant does not receive the notes or even a letter from the specialist, when a child has received tertiary service. The next time they are admitted to hospital or see their GP, the doctors do not have the full history available, and parents are asked all the questions to fill in the gaps.

Support needs to be culturally sensitive and integrated across the patient pathway and with other agencies, e.g. social care, and it is important that consideration is given to the play and educational needs of children during and after their treatment, provision of information to parents and children/young people, transport arrangements, childcare arrangements for siblings, accommodation for parents and families at the specialist centre etc.

Support systems for families accessing specialist services require to be robust and should be explored at the time of referral if not before. Good communication applies to all staff that care for children and information should be consistent and clear. It is vital to inform community services when the child with tertiary care needs goes home, as this can happen before the hospital specialist has been informed.

The European Association for Children in Hospital (EACH) is the umbrella organisation for member associations involved in the welfare of all children before, during or after a hospital stay. The EACH Charter (Appendix 9) sets out guidelines for ensuring that the organisation is child and family focused.

The Charter states that:

- The child’s stay in hospital should be as short as possible and parents should be invited to stay with their child
• Children and parents should be as involved as possible in all aspects of care, which involves the provision of as much information and support to children and parents as necessary in the most appropriate manner
• Children should be cared for together with others with the same developmental needs and should not be cared for in the same ward as an adult
• Children should be cared for by appropriately trained staff working as a team to ensure continuity of care
• Children should have opportunity for play, recreation and education, should be treated with tact and have their privacy respected and visiting hours should not be restricted for reasons other than the health of the sick child or visitor.

Recommendations

153 NHS Boards should review their provision of paediatric services with reference to the EACH Charter and put in place plans to address any issues identified.

154 Service providers should work together to ensure appropriate support is in place for parents who are far from home with a sick child. Parents should be fully involved in the planning of this support.

INVOLVING CHILDREN AND YOUNG PEOPLE

155 Issues and recommendations relating to the care of young people are included in the recommendations in the primary care and care of teenager sections of this report.

156 Children and young people should be the centre of consultation on services and should be asked for their views. There was strong feeling expressed at the child health seminar that children (and families) often weren’t listened to. Patient choice was a major element of the discussion. It was felt that service providers needed to be flexible. There is evidence that children and young people can be realistic in asking for the services they want and can be very ‘community spirited’ and altruistic in their views towards others

157 There is a need to ensure that patient information is appropriate for the age and stage of children and young people

158 It is important that staff working in the NHS are given the opportunity to develop effective communication skills in working with children and young people.

159 Transition was highlighted as an area requiring attention. Pockets of good practice exist and should be shared. A culture shift is needed and this will require training for all health professionals.
Recommendations

160 The views of children and young people should be invited for all services, which affect them. This should include every level of planning i.e. National, Regional, Board, Community Health Partnership, GP practice and hospital.

161 All services have a responsibility to provide information to parents and young people about their rights and put in place innovative mechanisms to encourage involvement in the planning and redesign of services. All patients and their families should be educated about their rights.

162 The Child Health Support Group should produce a report on the current status of involvement of children and young people in service planning and redesign and make recommendations on how this can be further developed.

DISTRICT GENERAL HOSPITAL SERVICES

AMBULATORY CARE

163 A number of Boards have already set up ambulatory care services which run on a day basis i.e. 8 am to 8 pm. These services seems to be working well and good practice is already being shared across Scotland. These services not only ensure the sustainability of local paediatric services but provide support for locally based community paediatric nursing.

Recommendations

164 The development of Ambulatory Care should be encouraged as part of a strategy to provide more care closer to home. Regional planning groups and NHS Boards should develop ambulatory care plans for children including outpatient services in a range of sites including integrated community schools, rapid access clinics and common protocols. Protocols should be in place setting out clearly the criteria for children and young people who can be seen in ambulatory care units and transport arrangements should be in place and communicated.

165 A good practice conference should be organised to share the learning from established ambulatory care units in Scotland and to disseminate information from longer running projects in England and elsewhere.

SURGERY FOR CHILDREN IN DGHs

166 There is variability around the country on how children requiring surgery are managed, depending on the experience and interests of individual surgeons and anaesthetists. The lower age range to perform surgery in DGHs ranges from 1 to 5 years with some DGHs also performing surgery on under one year olds on “some occasions”. There were concerns that current service arrangements may not be sustainable if more general surgeons did not
develop skills in paediatric care. There were concerns that if less paediatric surgery was performed in DGHs, vital skills would be lost to support emergency care of acutely ill children.

167 We also heard from a number of Boards that there were difficulties providing surgical specialties such as ENT, plastic surgery, orthopaedics and ophthalmology on different sites from paediatric in-patient provision. Surgeons in these specialties reported that they experienced difficulties in gaining consensus with their anaesthetic colleagues on provision of surgery in non-specialist centres for young children.

168 In DGHs general paediatric surgery is provided by general surgeons and by visiting specialist paediatric surgeons. It is widely accepted that surgeons and anaesthetists should not undertake occasional paediatric practice and must meet the standards for paediatric practice as agreed by British Association of Paediatric Surgeons and Royal College of Anaesthetists (RCA). Key aspects of these standards relate to the training, competence, experience and workload of the surgeons and anaesthetists, availability of staff trained in paediatric resuscitation, availability of a paediatrician 24 hours a day, radiological services for children, dedicated children’s wards and facilities, children’s nursing staff and the ability to provide high dependency care at least for a short time until safe transport to a specialist centre can be arranged.

169 For general surgery concerns about sustainability relate to the skills and training of surgeons but for other specialties, such as orthopaedics and ENT, the limitation in being able to provide surgery in DGHs relates more to the skills and experience of anaesthetists in caring for young children. Designated paediatric anaesthetists working in DGHs will typically undertake at least one children’s list each week. They are often nominated as the ‘lead’ for paediatric anaesthesia in their hospital. The RCA recommends that such individuals should have obtained at least 6 months or equivalent of paediatric anaesthetic training in a specialist centre. (From the Royal College of Anaesthetists’ Guidance on the Provision of Paediatric Anaesthetic Services).

170 There is recognition that all trained anaesthetists should be able to manage anaesthesia for common operations in children older than 5 years (British Paediatric Association, 1993).

171 There are arrangements in some of the specialist centres for provision of regular training updates for anaesthetists caring for children in DGHs. Senior House Officers (SHO) and Specialist Registrars (SpR) in anaesthesia undertake competency based training in paediatric anaesthesia. For paediatric/children’s anaesthetists working in the District Hospital, the RCA recommends that such individuals should have obtained at least 6 months or equivalent of paediatric anaesthetic training in a specialist centre. (From the RCA’s Guidance on the Provision of Paediatric Anaesthetic Services).

172 We heard different views on the workforce of the future for general surgery for children, with some respondents stating that specialist paediatric surgeons...
would be providing all this care over time as fewer general surgeons had the training and experience and others who felt that appropriate national and regional planning of training posts and consultant posts could reverse this trend. It may be that there will be different models in different regions but most respondents agreed that more care could be provided in local DGHs through outreach, hub and spoke models and appropriate regional planning.

**Recommendations**

173 Paediatric surgery should be planned and organised on a regional basis with hub and spoke models and regular training courses for surgeons and anaesthetists by the specialist centres to ensure that skills in the DGHs are kept up to date. NHS Boards and regions must be sure that the standards referred to above are met in all hospitals providing paediatric surgery. The ability to meet these standards will determine the regional provision of paediatric surgery.

174 A national short life working group should be established to provide clear guidance to regions on elective and emergency provision of general surgery and anaesthesia for children taking into account workforce issues, training requirements and specifying actions required with Colleges, NES, SEHD, NHS Boards and Regions. The group should also consider levels of care and provision of day surgery in DGHs and ambulatory care centres. The group should involve and take account of other surgical specialties that care for children, such as ENT, plastics, ophthalmology and orthopaedics. It will also need to address the issue of provision of emergency care and options for delivery of all DGHs caring for children cannot sustain an out of hours emergency service for surgery. It should address workforce and training issues including the role of NHS Boards and NES in planning future posts and training opportunities. The group should take account of existing standards from the Royal Colleges and good practice examples such as the joint post between Tayside and Lothian and outreach from RHSC Glasgow to Wishaw. The group should report within 3 months. The work of the Department of Health in England on provision of anaesthesia for children in DGHs can inform this work.

175 As dental surgery accounts for such a high proportion of paediatric surgical activity, a separate review should take place to make specific recommendations on where general anaesthesia for dental surgery should take place taking into account existing guidance.

176 The competency of services in meeting the standards referred to above should be inspected as part of Quality Improvement Scotland’s Inspections. If DGH services are not able to conform to these standards children’s general surgery should all transfer to specialist centre or another DGH that meets the standards.
PROVISION OF CARE IN REMOTE AND RURAL AREAS

177 Common themes emerged clearly during discussions with relevant areas. Dominant issues were perceived vulnerability of local clinical staff in providing high quality care for children with significant acute or chronic illness compounded by lack of immediate specialist support and the relatively small numbers involved.

178 There is a perceived lack of understanding of their special circumstances (geography, training, availability of equipment and facilities) that produces unhelpful responses when discussing individual cases with some urban based services. This is also seen in the quality of discharge planning after episodes of specialist care. Local clinical staff need advance warning and may need specific training related to individual children.

179 It is clear that there is a central role of education and training to support generalist activities in remote and rural practice. While there are informal established connections that allow staff to spend periods at urban units to maintain skills (e.g. anaesthetic placement at RHSC Glasgow) there is a need for expansion for other staff groups. While telemedicine usage has become almost routine in the remote locations, it remains relatively underdeveloped at some urban sites and could be very effective in allowing staff to access educational events in larger institutions.

180 The different needs of remote and rural settings require different solutions. Whilst rural settings might be served by outreach and transfer, remote settings need to ensure emergency safe services, because travel or transport is not always an option.

181 Transport and retrieval issues were also prominent (see elsewhere).

Recommendations

182 NHS Boards who deal with children from remote and rural areas (particularly tertiary services) should designate a member of staff as a remote and rural co-ordinator through whom elective care and discharge planning is managed. This post should be supported by an identified senior clinician in relevant Boards to act as a contact point for external clinical staff from remote areas. Telemedicine should facilitate this process.

183 NES should lead the development of dedicated training packages in paediatric care specific for remote and rural practice. These should be delivered locally in partnership with external partners and supported by national protocols/guidelines.

184 Urban Boards should offer expanded outreach support for remote areas to maximise local care. These visits should include a local educational opportunity whenever possible.
PRIMARY CARE AND SELF CARE

185 We were informed that children represent approximately 30% of the workload out-of-hours services and around 90% of children with health problems are seen and treated within primary care. It is important therefore that the role of the generalist in providing care for children is maintained.

186 There was evidence of some rearrangements in the organisation of out-of-hours care in some areas to integrate GP Out-of-Hours centres with A&E services.

187 Some Boards expressed the view that the shift to public health nursing had resulted in a reduction in health visitors’ work with individual families.

188 NHS Boards should ensure that the advice on integrated child health services for Community Health Partnerships (CHPs) is taken forward in establishing CHPs.

189 Concerns were expressed in some Board areas about the availability of community paediatric nurses. Clearly specialist nurses cannot provide all care for children in the community and district nurses, practice nurses and health visitors should be supported in their role with children and young people.

190 Support was expressed for the development of the role of GP with a special interest in child health. This role may be placed within a Community Health Partnership with a remit to lead/promote child health care, working with colleagues in nursing, schools, social work etc. In addition to participating in outpatient clinics, city based roles might undertake some hospital work to support integrated working.

191 There were expressions of concern that the new GMS contract had no specific child health content, reinforcing the perception of low priority, and risking a true drift in GP motivation to provide optimal preventive and therapeutic efforts.

192 A substantial proportion of the workload of NHS 24 relates to children. Concerns were raised that we are not currently evaluating and auditing the effectiveness of this role and that we needed an analysis of outcome for the child following calls to NHS 24.

193 The need for primary care to provide accessible services to vulnerable families and also to young people was emphasised in the feedback we received.

194 We received feedback that parents, particularly those with their first child, required more support in managing childhood illness. Parents deal with most minor illness in their children at home and informal support from experienced family members or friends can significantly improve such care, and reduce
natural anxiety that leads to increased demand on health services for unscheduled care. Early minor illness events in children of inexperienced or isolated parents, especially if they result in unnecessary medication or hospital referral, may lead to significant anxiety and a perception that their children are particularly vulnerable. Thus a cycle of recurrent demand for professional care may develop.

There is little evidence that anticipatory education makes a significant difference to parental response to such illness events. However, there is evidence that parents are particularly open to education about future care during acute consultations with professionals. A supportive reassuring approach during early consultations for acute illness combined with consistent specific advice about managing future similar episodes may significantly improve future parental care. For example, recent research has shown that educational interventions during an acute admission can substantially reduce subsequent asthma admissions and morbidity.

**Recommendations**

Where feasible, NHS Boards should consider co-location of GP out of hours services and A&E services into a single functional unit, with opportunities for walk-in patients to be triage to GP care and reciprocal partnership working for appropriate emergencies.

All GPs should maintain their skills and competences in the care of children. The importance of child health should continue to be reflected in the availability of accredited training for GPs and feature strongly in the practice accreditation process.

Training and appointment of GPs with a special interest in child health should be continue to be developed. General Practices should continue to encourage identification of a GP who “leads” on child health issues and Community Health Partnerships should consider establishing a wider role and identifying a GP who can undertake the necessary additional training to support this role.

Nursing staff working in primary care who have contact with children e.g. public health nurses, health visitors, school nurses, practice nurses should maintain their skills and competences in the care and treatment of children. They should work in partnership with community paediatric nurses and specialist paediatric nurses.

There should be easy direct access to senior hospital staff for clinical advice about care and treatment of children in the community. While many children are referred to hospital for treatment appropriately a significant number could be dealt with by advice alone or seen at rapid access clinics rather than as an acute admission. The issues identified in the “Decide to Admit v Admit to Decide” National conference on unscheduled care are relevant to children. In each rota a consultant should be available either by bleep, call-back or secure email to enable direct advice to GPs where there is uncertainty about optimal
clinical management. Technologies such as imaging transfer or video conferencing will be important tools to support this new way of working.

201 NHS Boards should develop local referral protocols and referral guidelines for childhood conditions for primary care practitioners. There are examples from Greater Glasgow and Grampian that could be used to prevent duplication of effort.

202 An audit should be undertaken to monitor the outcome of NHS 24 on the care of children and young people.

203 CHPs should ensure that there are effective pathways in place for the provision of health care services to vulnerable children. Implementation of proposals of Health for All Children (Hall 4) should support this. There should be proactive follow-up of non attenders and effective integrated working with social work and education departments.

204 CHPS should ensure that they provide adequate access to emergency contraception for young people both within normal practice hours and out-of-hours.

205 CHPs should put in place plans to improve access for young people to primary care services. This could include the use of the internet and mobile phone access to health care advice as well as dedicated young peoples clinics.

206 Education of carers is an important component of routine professional care, and may significantly impact on future management of their children. A range of parent/carer advice leaflets on specific common conditions should be developed for national use, and be available during face-to-face consultations. This may be web-based for printing during consultation, and to allow easy updating and expansion.

207 There are a range of initiatives and policies to support parents and the management of childhood illness should be incorporated to parenting programmes.

EMERGENCY CARE FOR CHILDREN AND YOUNG PEOPLE

208 The face of emergency care, with the traditional role of General Practitioners (GPs) and hospital accident and emergency (A&E) departments is changing. Nurse led minor injury facilities, out-of-hours services, NHS 24 and paramedic services have increased the choice and availability of emergency care providers.

209 Children and young people make up approximately 20% of the Scottish population but represent a significant proportion of accident and emergency
department attendances (25-30%)\(^9\) and calls to out-of-hours GP services. Children are more likely to be admitted to hospital as emergencies than as planned admissions. In spite of this a significant number of hospitals lack staff qualified in the care of children and young people and do not provide a child-friendly environment.\(^{10}\)

210 Young people have particular needs which are not always recognised or catered for. Often they are treated in a young paediatric setting with babies and young children or they receive emergency care in an adult dominated environment.

211 The emergency care situation can be a particularly anxious and stressful time for children and young people. This anxiety can be reduced by providing a welcoming and appropriate environment with staff who are confident in communicating with and treating children and young people.

212 A review of Emergency Care for Children and Young People has recently been undertaken on behalf of the Child Health Support Group\(^{11}\). This section represents a summary of its findings.

213 The variation in population density in Scotland is such that a ‘one size fits all’ approach to emergency care is not tenable. An emergency care framework for children and young people has been developed for the different types of emergency care facility available (Figure 2). The framework provides a template for optimal emergency care provision for children and young people.

214 The first contact for an acutely ill/injured child or young person with health services is often their primary care provider (general practice), an out-of-hours service, ambulance paramedics and increasingly, through telephone contact with NHS 24. Many emergencies can be managed at level 1.

215 Minor injury facilities provide a convenient local solution in many areas. However they can lack the full services and expertise of an A&E department, especially in terms of caring for children and young people. It is important that health care professionals and the public view their role realistically, understand their limitations and use them appropriately.\(^{12}\)

216 Level 2 facilities (ie general hospitals with an Accident and Emergency Department but without a Paediatric Inpatient Unit) may have facilities for assessing and observing children and young people over a period of time prior to making a decision about whether to discharge or not. However these facilities are often open for a limited number of hours during the day and

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\(^9\) Accident and Emergency Services for children: A report of a multidisciplinary working party. Royal College of Paediatrics and Child Health, June 1999

\(^{10}\) Emergency health services for children and young people, A guide for commissioners and providers, C Hogg, Action for Sick Children, 1997

\(^{11}\) Emergency Care. A consultation on emergency care for ill and injured children and young people in Scotland, CHSG, 2004

\(^{12}\) Children’s Attendance at a Minor Injury/Illness Service, Royal College of Paediatrics and Child Health, Feb 2002
children and young people who require admission need to be transferred to the local Inpatient Unit.

217 **Level 3** emergency care should be available from a general hospital with a paediatric in-patient unit which will have significantly more capacity to manage the unwell child or young person than a hospital without such facilities.

218 **Level 4**, can be provided by specialist children's hospitals or units, which provide paediatric intensive care and/ or High Dependency Care, paediatric surgery and a range of specialist services and advice, all of which are available on site.

**Figure 2: Tiered Framework for Emergency Care for Children & Young People**

219 It is recognised that it can be beneficial to co-locate children and young peoples services with adult services on the same site. This would be of particular benefit for emergency care situations that involve adult and child members of the same family.

**Recommendations**

220 Regional Planning Groups and NHS Boards should identify the level of care that should be provided at each of their emergency care sites in accordance with the proposed emergency care framework.

221 All emergency care sites should provide a safe and non-threatening environment for the treatment of children and young people and staff providing care in emergency Care sites should have a core set of skills and competencies to provide care to children and young people and access to support and advice from a registered children’s practitioner on a 24/7 basis.
A standard assessment method should be developed for use with children and young people at all emergency care facilities. This assessment method should recognise the severity of illness or injury, the degree of pain and distress and the potential vulnerability of the child or young person.

National guidelines and best practice statements should be developed for the management of common acute and potentially life threatening conditions for children and young people.

A multi-professional emergency care competency system should be developed by NHS Education for Scotland for practitioners who provide emergency care for children and young people. Once developed competencies should be maintained and updated.

The development of expanded roles for emergency care practitioners should consider the needs of children and young people and be undertaken under the guidance of NHS Education for Scotland and the relevant professional bodies.

NHS Boards should clearly identify which sites in their area will at all times provide emergency advanced imaging facilities for children and young people. This information should be shared with NHS 24, primary care teams, out-of-hours services and the Scottish Ambulance service.

WORKFORCE AND ROLE DEVELOPMENT

There is a clear need for workforce planning on a multi-disciplinary basis to support the models of care developed. This needs to incorporate identification of educational needs and delivery of educational programmes by the multiprofessional specialist services in conjunction with Universities and other educational institutions. In the future specialist teaching and training of staff will take place in a variety of settings across a network of care provision. This planning should be carried out in tandem with service planning and on an all-Scotland basis for specialised services, regional basis for secondary services and local basis for primary and community services.

It should be assumed that the NHS will always experience workforce pressures and should continually review its recruitment and retention strategies. It should continually explore the development of new roles, specific to the different settings of care delivery, for example advanced and extended practitioner roles and developing GPs with a special interest in paediatrics may be more appropriate for remote and rural settings as they will see more children routinely in their work than adult specialists. These new roles should be attractive to staff and offer career progression. The roles of clinical practitioner, AHP and nurse consultants, hospital play specialists and clinical support staff should be developed further. There will be a need to prepare parents and children for the new roles to give them confidence in them.
229 The provision of community nurses and their role in supporting the provision of more care closer to home was identified by a number of Boards. As was the need to ensure that there was adequate access to hospital based paediatric nursing advice in areas such as A&E and other specialities seeing a large number of children.

230 It is also clear that whilst some boards have no problems in terms of recruitment and retention of both paediatric nurses to work in hospital settings and paediatric nursing to work in the community other boards continue to struggle to employ a sufficient number of staff.

231 Ongoing professional development and maintenance of skills was a common theme, for all staff groups. This was linked with ensuring that staff have sufficient variety and challenge within their posts. One way to ensure this is through the introduction of rotations across community and acute sector provision for all staff groups.

232 In particular providing support to the small number of paediatric Allied Health Professionals working across Scotland and those adult specialists who come into contact with children in their work was raised. There is an opportunity to consider rotations in this respect as well as multi-professional support networks.

233 NHS Education for Scotland has committed itself to the development of an educational framework covering a wide range of services and drawing initially from the recommendations of the above reports. Early focus has been given to the recommendations of Dr Tom Beattie’s report on Emergency Care for ill and injured children and young people in Scotland and, in particular, the development of an integrated multi-professional competency based training and education package for practitioners who provide emergency care for children in Scotland. A comprehensive framework for consultation in the coming months will be prepared and consulted on and the Child Health Support Group and NES will work with the Regional Planning Groups to ensure its appropriate resourcing and implementation.

234 Additionally NES has already published an report “Promoting the Well-being and meeting the Mental Health Needs of Children and Young People”13 which sets out the range of competencies needed in a fit for purpose workforce.

Recommendations

235 Workforce planning mechanisms should work in tandem with and in support of service planning at national, regional and local levels.

236 The National Workforce Committee and NES with Regional Planning Groups should develop a workforce plan for specialised paediatric services and other

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secondary paediatric services identified as vulnerable.

237 An action plan for the development of community and hospital paediatric nursing will be developed by Regional Planning Groups using senior professional paediatric nursing advice, working collaboratively on an all-Scotland basis. This will be based on the recommendations of the RCN consultation entitled “Services for children and young people: preparing nurses for future roles: preparing nursing for young people” and the information gathered as part of developing this report (questionnaire, video conferences, Development event). It will address: recruitment and retention, developing local training opportunities via education outposts in areas of staff shortages and ensure systems are in place to ensure the maintenance of skills.

238 Formal links should be made between community paediatric nurses working in remote and rural areas and teams within the larger Boards to offer support, advice and access to ongoing training.

CARE OF PARTICULAR GROUPS

CARE OF YOUNG PEOPLE

239 The challenges of providing a specialist adolescent service was a common theme. There was a strongly held view that there should be greater attention given to defining and providing such a service. The discussion focused mainly on designated adolescent beds however access to a specialist adolescent paediatric medical and nursing or therapy opinion would also greatly enhance not only the care of young people but also aid their smooth transition into adult services.

240 Where children and young people are admitted to adult services, there is a need for these services to recognise the particular needs, including emotional and educational requirements, of young people and their families.

Recommendations

241 NHS Boards should map out and review their services for young people (aged 12 – 16 years) and set out actions to develop services which provide for their specific needs. Boards should develop proposals for age appropriate care by the end of 2005.

242 NHS Boards should develop clear and cohesive arrangements for transition from child to adolescent services and from adolescent to adult care across the spectrum of chronic paediatric illness.

243 While a shift from adult to paediatric care for some young people should in theory be cost neutral, there will be cost implications in caring for more young people in paediatric settings. The SE Health Department and NHS Boards
should develop a financial plan to underpin their action plan to develop age appropriate care.

244 NSD should similarly review provision for young people in nationally designated services.

245 Regional Planning Groups should designate at least one clinician with responsibility for adolescent hospital care. They should lead the development of good practice for all aspects of adolescent care, including transition into adult services.

CHILD AND ADOLESCENT MENTAL HEALTH SERVICES

246 Almost all Boards identified a lack of access to children and young people’s mental health services as a major problem. In most areas access to services appeared to be problematic due to the small size of the service and long waiting lists. This was compounded by recruitment difficulties in some areas particularly for clinical psychology. While many paediatricians discussed problems accessing specialist community CAMHS teams, there was an acknowledgement that building capacity of other staff in primary care, schools and residential units would be beneficial. Access to in-patient services for young people was also frequently identified as a problem particularly by Boards with no adolescent inpatient facility in their Board area.

247 Many Boards highlighted the management problems of young people with alcohol or drug problems or self-harm who presented as emergencies. There are often no appropriate facilities or staff to care for these young people and both adult and paediatric wards were considered inappropriate.

Recommendations

248 The Scottish Executive and NHS Boards should work together to implement Children and Young People’s Mental Health: A Service Framework for Promotion Prevention and Care.

249 The recommendations of the CHSG working group on In-patient psychiatric care for children and young people should be implemented with urgency, starting with the work being taken forward by David Piggot on behalf of the Regional Planning Groups to consider funding and feasibility.

DENTAL HEALTH

250 Dental health is worth separate consideration because dental disease is so widespread in Scotland, is preventable through regular tooth brushing with fluoride toothpaste, check-ups with a family dentists and good diet and is the most common reason for children and young people requiring admission to hospital.
The issues of access to NHS dentists are well documented elsewhere and acknowledged.

We support the recommendations in “Towards Better Oral Health in Children”

CHILD PROTECTION

A number of Boards identified problems providing some aspects of specialist child protection services particularly around examination of children suspected of having been sexually abused. Other Boards identified provision of specialist child protection services for children suspected as having been sexually abused as a potential problem in the future due to the need for specialisation and recruitment problems.

The definition, procedures and processes for child protection are currently being reviewed in Scotland. The investigation of children suspected of having been abused is only one important strand of protecting children. The overarching emphasis must be on all staff having a responsibility to protect children, including those working with adult patients.

The core elements are:

- Sharing of information at the point of earliest concern about a child between relevant professionals and agencies.
- Use of commonly agreed tools between agencies such as multi-agency needs and risk assessment tools.
- Ensuring gathering of best medical evidence and ongoing health care in accordance with locally agreed joint protocols/assessment and frameworks.
- Development of a value base within society and communities that children are our highest priority, and protecting them is everyone’s responsibility.
- Provision of appropriate training to clinical and non-clinical staff.

The majority of child protection concerns will have a primary care focus and will in the main focus around concerns about physical and emotional neglect. Whilst diagnosis and management of children suspected of having been sexually abused is a specialised field, most care and protection of children is undertaken by generalists and it cuts across all child health services.

Nationally standardised integrated care pathways will facilitate smooth passage between locality care, secondary care, tertiary care and back to locality care. Particular examples of cases requiring tertiary care in National centres are:

- infants with severe head injury
- intra abdominal rupture requiring surgical intervention
- serious non-accidental burns cases
- other complex non-accidental injuries, e.g. infant suffocation
- chronic poor nutrition due to extreme emotional and physical deprivation
- complex cases where children are suspected of having been sexually abused, particularly when involving multiple perpetrators

This is not an exhaustive list. Where children have to travel a long distance to attend a tertiary centre consideration will need to be given not only to the importance of accessing clinical expertise but also to the consequences of moving a child away from local social supports.

**Recommendations**

258 NHS information systems should ensure gathering of all information on a child at any point of contact with health services (between primary to tertiary care) with adequate flagging of key indicators of vulnerability and early inter agency intervention to support families and prevent escalation to crisis. Discussions should take place with NHS 24 on development of a central national health gateway for both carers and professionals and enable access either urgently or within a short time frame to the most appropriate health facility (for example A&E departments, child protection health services, addiction services, mental health services).

259 Services to children who are suspected of having been sexually abused should be provided as a national clinical network. This National Managed Clinical Network should consist of three regional networks for child protection and will develop common protocols, detailed standards re patient care and inter agency working, and provide centralised audit and evaluation of practice as well as ongoing educational curricula for all levels of health practitioners involved in child protection work. Regional networks can at their discretion come to an agreement to work together to create 2 networks which will feeding into a National Network or to opt to have a single national clinical network without regional feeder networks.

260 The National Clinical Network will ensure that a 24 hour service is in place for clinical urgent child protection cases. This is expected to involve only a small number of children and it is likely that some of these children will require to travel to the specialist.

261 Children suspected of having been sexually abused should be seen in a locality setting where possible. In the longer term telemedicine with tertiary centres will be a useful adjunct to help to give a second opinion but cannot replace clinical competence. This service will be developed by the Scottish Child Protection MCN. The development of this service requires a national telemedicine strategy and increased capacity of paediatric forensic expertise in national centres. The development of the MCN will be informed by the work of the RCPCH sub-committee on child protection.
MODEL OF COMMISSIONING AND PLANNING

CHILD HEALTH SERVICES FOR A NEW CENTURY SCOTLAND

262 This Framework acknowledges the importance of integrated services amongst the health service and its partners. It also recognises that different parts of the service will benefit from discrete arrangements for planning and commissioning and decision making to reflect the particular issues associated with them and that this should be carried out in partnership with children, young people and their families.

263 Supportive mechanisms and arrangements should be put in place to ensure integrated service planning and delivery which consistently put children and young people at the centre. These arrangements need to be such that there can be a proactive approach to identifying changes in need, services and the environment, consideration of the implications of these changes for children’s services and development of plans to address these implications on an all-Scotland, regional and local basis.

264 Acknowledging the specific work that has been done in the area of Child and Adolescent Mental Health, it is important that in planning for children’s health services this is included in a way that both supports the discretion of these services and integration within children’s health services.

265 NHS Scotland should build on the work of the Child Health Support Group (CHSG) and the momentum established through that work, connecting it strongly with the Service and providing a focus for Child Health.

266 The CHSG has undertaken two important phases of work to date – that of raising the profile of child health in Scotland and production of a work plan, which was presented to the Minister and resulted in the issue of an Health Department Letter setting out a range of pieces of work to be undertaken. These involved visits to all territorial NHS boards, production of reports following these visits with recommendations for the local service, and active support to these services to make changes; these changes have led to real improvements in services.

267 It has also commissioned work in a number of areas which are now coming to a point of decision and implementation. These include:
  • Review of Tertiary Paediatric Services, led by Professor George Youngson
  • Children and Young People’s Mental Health: A Framework for Promotion, Prevention and Care, led by Dr Graham Bryce
  • Report on CAMHS Inpatient Services by Bruce Dickie
  • Report on Emergency Care for Children by Dr Tom Beattie
  • Recommendations on HALL4 led by Dr Zoe Dunhill
  • These include a large number of recommendations which need to be prioritised and decisions made on changes that need to take place.
  • Appointment of a Clinical Lead for Children and Young People’s Health in Mr Morgan Jamieson
The CHSG has been charged by the Minister with production of an action framework which will be driven by the outcome of the National Framework for Service Change in the NHS in Scotland and informed by the range of reports that have already been submitted. It has initiated this piece of work which will translate a wide range of recommendations into a prioritised, time bound, costed plan, developed through a risk management approach focussed on broad programmes of action.

The CHSG has recognised the need to make a stronger connection with the service, particularly to support implementation and to bring their strength as an expert advisory group.

Feedback from the Service identified a need to plan, and in the case of specialised paediatric services, commission, child health services on a wider population basis than currently. An all-Scotland view needs to be taken in terms of the planning of those paediatric services where the need is small in terms of incidence and the skills, expertise and equipment to provide care is scarce. There is evidence for a strong strategic planning role in the Health Department to provide strategic and corporate leadership of highly specialised child health services that require a whole Scotland solution. There is also a need to plan for general secondary paediatric services on a regional basis, across larger populations than individual Health Boards.

The feedback also mirrored concerns expressed by the CHSG regarding the delivery of planning, the implementation of reports and outcomes of service reviews. It also raised the need to embed accountability for supra-Health Board services within the system in a way which facilitates their planned development on an equitable and consistent basis.

Therefore arrangements put in place need to give:

- Clarity of responsibilities at local, regional and national level
- Meaningful accountability focussed with Health Boards working collaboratively through regional planning groups and regional planning groups working with the Health Department and National Services Division on a national basis
- Strengthening of the role of the SEHD in setting the child health agenda, providing strategic planning leadership, particularly on services requiring an all-Scotland approach, and monitoring progress
- Closer links between the CHSG and Regional Planning Groups and NHS Boards to ensure that the work plan of the CHSG supports the priorities of Boards and Regions and that there are clear delivery mechanisms for implementation.
- An enhanced role for the CHSG in supporting the service through providing expert advice and supporting planning and implementation of national policy, which will require a revised remit and membership.
- Mechanisms for children, young people and their families and partner agencies to participate in planning and development of services
Therefore the model in Figure 3 is proposed which sets out the different levels of planning child health services.

**Figure 3 Planning Roles**

As referred to above there is recognition that current arrangements for the planning and delivery of specialised and general health services for children in Scotland are fragmented and that practice differs across Scotland. The subject of how these services are to be planned and organised in the future and the need for improved arrangements for this were significant issues throughout the discussions.

The Review of Tertiary Paediatric Services in Scotland\(^\text{14}\) identified that there are a number of vulnerable services which would benefit from an all-Scotland approach and NHS Boards reported the challenges they were facing concerning sustaining secondary paediatric services. They also identified some imaginative solutions which worked across Health Board boundaries. For example a joint appointment between Tayside and Lothian NHS Boards and supportive working arrangements between Grampian and Highland NHS Boards. The pressures identified earlier in the report are current, and the

\(^{14}\) Review of Tertiary Paediatric Services in Scotland Draft Report, Child Health Support Group November 2004
Service is concerned that these services should be prioritised for consideration.

276 A particular need to plan specialised paediatric services in a different way was identified. Specialised paediatric services are part of the spectrum of child health services and they should be integrated in a way that supports local delivery of care and sustainability of local services. The model described for specialised paediatric services both supports an all-Scotland approach to this element of care and integration with regional and local services.

277 These specialised paediatric services, as defined by the Department of Health Specialised Services Definition Set and referred to earlier in the report, should be regarded as a single service delivered through Managed Clinical networks across a number of locations. The services should be planned on an all-Scotland basis and managed and delivered through local Health Board systems. The single service approach will be delivered as:
   - a structure which gives clarity of accountability for planning and delivery of services planned at population levels larger than individual Health Boards.
   - a planning template for the review and development of the services individually and in a complementary way with due regard to interdependencies between the services and with other local services.

278 Strategic leadership should be provided by the Scottish Executive Health Department including developing a capacity to support planning of those child health services that require a national solution. It should also bring together the Regional Planning Groups, the CHSG and other partners in prioritising services which require a national approach and in planning these services. Involvement of children, young people and their families in this planning process is vital.

279 The remit and membership of the CHSG will need to be revised to support its enhanced role which will comprise:
   - Expert advice to Scottish Ministers on Child Health Policy
   - Expert Advice to Scottish Ministers on individual issues
   - Expert support to RPGs and NHS Boards on planning of services and implementation of national policy
   - Leadership on the development of comprehensive workforce planning for Child Health Services
   - Leadership on the development of comprehensive, multi-agency involvement of children and families in the planning and provision of Child Health Services.

280 The role of Regional Planning Groups will be fundamental to this approach taking responsibility for planning, commissioning and performance management of a wide range of secondary children’s health services; additionally they will work collaboratively on an all-Scotland basis providing consistency and equity in planning services that span regions. They will
provide planning integration to their constituent Health Boards in terms of local children’s services planning with partners.

281 Each Regional Planning Group should establish a Children’s Health Services Planning Group as one of their Service Planning Groups (HSG(2004)46) under the leadership of a Chief Executive of one of its constituent NHS Boards. This group will plan secondary children’s health services and through this identify those services which require either an all-Scotland or inter-regional approach. RPGs should ensure that there are close links between planning children’s health services and maternity and neonatal services.

282 Within these arrangements there is the opportunity to expand collaboration particularly through MCNs and on an inter-regional basis, and this should be encouraged, particularly between the East and North of Scotland.

283 This mechanism will facilitate the identification of those services which are very small and should be subject to explicit commissioning arrangements. The SEHD and Regional Planning Groups will work with the National Services Division in taking these forward for consideration for designation as a national service.

284 These arrangements are depicted in below in Figure 4 – Integrated Planning Model – Involvement and Accountability
The single service will work to a planning template. The template would consider and set out for each service within its national MCN, arrangements in the following areas:

- Demonstration of high quality care through the evidence base, agreed audit programme and information base
- Funding arrangements
- Workforce plan including education and training
- Patient pathways demonstrating integration of care
- Development of standards for services which are delivered consistently at every stage of the patient pathway
- Performance management of service delivery - measures
- A Scotland-wide overview of plans for investment in major buildings, equipment and staff resources, e.g. succession planning arrangements, capital developments
- Involvement of children, young people and their families in standard setting and performance management
- Relationship with regional and local MCN(s)
- Implications on other services

The planning template will be a dynamic tool, capable of responding to change in best practice and feedback from users. Consistent with this it will adopt and further develop the methodology used in the Review of Tertiary Paediatric Services in Scotland.

It will also be useful to inform planning activities at local NHS Board and Regional levels.

It will also set out explicitly the services’ part in sustaining local services through its relationship with local services, particularly in terms of training and skills transfer. This is described previously as the Service Template.

This approach supports national policy on Community Health Partnerships, Regional Planning, Community Planning and Joint Future. It recognises the interdependence with other paediatric services, e.g. anaesthetics, adult services, neonatology, and provide strategic leadership of specialist paediatric services.

An integrated approach will improve access and equity of care by doing away with the current fragmented approach to service development inherent in the current organisational arrangements. Children and young people will have access to a network of care with specialists at the core. The creation of a cohesive service gives the opportunity to prevent the collapse of individual small services.

A unified single service approach will increase collaboration, improve morale and improve planning to the benefit of children and young people. The scarce resources will be better planned and utilised across Scotland.
Recommendations

292 The models for integrated services and planning described above should be implemented. Specialised paediatric services should be planned nationally, secondary paediatric services should be planned and organised on a regional basis.

293 The Scottish Executive Health Department should provide strategic and corporate leadership in planning Specialised Paediatric Services. It should develop this capacity and work with the Regional Planning Groups, Child Health Support Group, National Clinical Lead and other partners in prioritising and planning services requiring a national approach.

294 Regional Planning Groups should establish Children’s Health Services Planning Groups under the leadership of a Chief Executive of one of its constituent NHS Boards.

295 Children, young people and their families should be involved in planning services.

296 The work programme and methodology set out by the Review of Tertiary Paediatric Services and the planning template should form the basis of planning for specialised paediatric services.

297 The role of the Child Health Support Group should be enhanced to provide expert advice and support to the service in planning and implementation of national policy and plans. The membership should be reviewed to support this enhanced role.

298 Specialised Paediatric Services should be developed through managed clinical networks, linking the specialist centres with local services and including children, young people and their families.

299 Regional Planning Groups should use the Financial Framework for Regional Planning to agree hypothecated funding to support the delivery of plans for children’s services agreed through the regional planning mechanisms.

This report was compiled on behalf of the Action Team by

Myra Duncan
Linda De Caestecker
Caroline Selkirk
Highly Specialised Care
Specialised Paediatric Services Action Team

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Myra Duncan  Advisor National Planning Team
Lorraine Currie  Child Health Commissioner, NHS Grampian
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Callum Kerr  General Manager, West Central Division, Scottish Ambulance Service
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*Catriona Renfrew  Director of Planning and Community Care, NHS Greater Glasgow
*Dr Charles Clark  Consultant in Public Health Medicine, NHS Lanarkshire
* From January 2005

In attendance:
Dr James Chalmers  Consultant in Public Health Medicine, Information and Statistics Division, National Services Scotland
Scottish Executive Child Health Support Group

The Child Health Support Group is an expert advisory group, established by the Minister for Health and Community Care in 2000 to bring together a wide range of professionals from across Scotland to co-ordinate and drive forward improvements in child health and the quality of child health services. It is a multi-agency and multi-disciplinary group, and the membership includes representatives from medicine, nursing, the allied health professions, NHS managers, the voluntary sector and from local authorities.

Remit

The Group works with the Scottish Executive, the NHS, local authorities and the voluntary sector to improve child health and children’s health services. The Group will:

- Provide expert advice to Scottish Ministers on the development and improvement of child health across all services
- Assist the identification of innovation and improvements in services nationally and locally
- Provide advice on development and evaluation of services with a focus on promoting child health and well-being
- Support the NHS in Scotland to strengthen local service provision and delivery of children's health and well-being
- Be a catalyst for the dissemination and implementation of best practice nationally, and
- Be a focus for communication between stakeholders concerned with child health, including children, young people and their families

Membership

Mr Malcolm Wright    Chairman    Chief Executive, NHS Education for Scotland
Professor Stewart Forsyth  Vice Chair    Clinical Director of Paediatrics, NHS Tayside
Mr Jonathan Best         Chief Executive, NHS Yorkhill
Dr Graham Bryce          Consultant Child & Adolescent Psychiatrist, NHS Yorkhill
Bronwen Cohen            Director, Children in Scotland
David Cumming            Head of Children’s Services, Social Work Department Glasgow City Council
Dr Zoë Dunhill           Patient Services Director, Children’s Services, NHS Lothian
Dr Sally Harkness        GP, Inverurie Medical Group
Ms Anne-Marie Knox       Child Protection Adviser, NHS Yorkhill
Dr Shiona Mackie         Director of Clinical Standards and Health Improvement, NHS Lanarkshire
Dr Anna Murphy           General Medical and Renal Consultant, NHS Yorkhill
Professor George Youngson  Professor of Paediatric Surgery, NHS Grampian
Caroline Selkirk  Director of Change & Innovation, NHS Tayside
Robert Stevenson  Child Health Support Group Co-ordinator, SEHD, Women & Children’s Unit
Dr Ian Bashford  Senior Medical Officer, SEHD
Dr Linda de Caestecker  Unit Head, SEHD Women & Children’s Unit
Jacqui Lunday  Allied Health Professions Officer, SEHD
Dr Mags McGuire  Nursing Officer, SEHD
Mary Sloan  Policy Officer, SEHD Women & Children’s Unit
Lindsey Wright  Policy Manager Child Health, SEHD Women & Children’s Unit

References:
Child Health Support Group HDL(2002)86
www.show.scot.nhs.uk/chsg/
NATIONAL PLANNING EXERCISE

COMMISSIONING DOCUMENT: HIGHLY SPECIALISED CARE

Definition

This work will;

- consider the future requirements for tertiary care in specialist centres (in this context we see tertiary services as those which are highly specialised and usually delivered in a few national or regional centres),
- identify the scale and scope of such activity during the day and at night,
- consider the relationships between the provision of tertiary and specialised care and 24 hour emergency care,
- have regard to the direction of travel signalled in reviews of acute services underway or about to get underway at the NHS Board level,
- have a particular focus on the planning and provision of highly specialised care such as neurosurgery services and paediatric tertiary services.

Background

The Acute Services Review, published in 1998, considered in some detail the provision of acute services to patients in Scotland. It made a number of far-reaching recommendations, including the need to develop a regional approach to service planning and the promotion of Managed Clinical Networks. Many of the issues considered in the Review remain at the forefront of public debate about the NHS – particularly the challenge of continuing to provide equity of access to specialised acute care. The Acute Services review identified 26 major hospitals across Scotland receiving acute medical emergencies. We need to set this alongside professional guidance which suggests that in order to attain “critical mass”, Acute Hospitals should serve a population of 400,000 to 500,000. There is a continuing tension between the increasing specialisation of care (and the implications this has for the medical and surgical cover) and of the demand for services to be delivered close to home. In a number of areas, including neurosurgery (and neurosciences) and children’s tertiary services, an analysis has been done of the issues and the development of a national framework provides an opportunity for follow up and implementation.

Objectives

The National Planning Team will report on the following;

- what health care services should be provided in the future in tertiary centres,
- the implications for the number and location of tertiary centres,
- the planning methodologies relevant to mapping tertiary and highly specialised care,
- to what extent specialised care services need to be planned at a national, regional or Board level,
- the implications for the planning and provision of neurosurgery (and neurosciences) and of tertiary children's services of the proposed planning methodology,
- the impact on the provision of intensive care and emergency care of any proposed reconfiguration of highly specialised or tertiary care,
- specific issues affecting remote and rural areas

Milestones

1. Membership of short-life working group identified by end June.
2. Steering Group to agree Commissioning Document at July meeting.
3. Data/analytical report by end October.
4. Report by end December (and report to Steering Group)

National Advisory Group Lead

Peter Bates
James Kennedy

National Planning Team Lead

Myra Duncan
NATIONAL FRAMEWORK FOR SERVICE CHANGE

COMMISSIONING DOCUMENT: CARE FOR CHILDREN

Definition

This work will;

- consider the healthcare of those people in Scotland aged 18 or less,
- take into account demographic and epidemiological trends,
- cover both planned and unscheduled care of young people,
- consider the whole journey of care,
- have regard to existing initiatives within the Health Department, particularly those arising from the work of the Child Health support Group, and
- provide a context for the work on children’s tertiary services and on unscheduled care for children also being taken forward through the development of the national framework for service change.

Background

The provision of health care to children is an important aspect of the national framework for service change. Children account for some 20% of the population of Scotland. They have specific requirements that need to be addressed – both now and for the longer term. It is also important to bear in mind that many adult health problems have their origins in childhood. The Child Health Support Group (CHSG) was set up by Ministers in 2000 to work with the Scottish Executive, NHS, local authorities and the voluntary sector to improve child health and children’s health services. This piece of work on the planning of children’s health care will build on the CHSG’s work as set out in the report ‘Making It Work for Scotland’s Children’.

Falling birth-rates and reductions in the number of children – especially in some of the more remote and rural communities – need to be factored in to the planning process. At present, there are over 2 million GP consultations for children each year in Scotland and a large proportion of out-of-hours calls are on behalf of children. Changes to the way in which such care is provided will have to take account of the particular needs of young people.

Objectives

The National Framework will report on the following;
• the implications for healthcare activity of the reductions in the numbers of children on the one hand and of the growth in childhood illnesses (such as asthma) on the other,

• the alternatives to traditional hospital based care for diagnosis and treatment of young people and the implications of those alternatives for patient pathways and the future role and structure of Scottish hospitals,

• the relationships between the provision and location of paediatric care and adult care,

• the implications of increasing specialisation of caring for children, including, for example paediatric surgery and anaesthesia.

• the transition from children’s care to adult care,

• the interface between healthcare, social care and education,

• the potential impact of new healthcare technologies,

• how to maximise the local delivery of care for children, and

• what services for children are best planned at a national, regional or Board level.

Milestones

1. Steering Group to agree Commissioning Document at July meeting.
2. Membership of action team identified by end July.
3. Data/analytical report by end September.
4. Final report by end December.

National Framework Advisory Group Lead

Peter Bates

National Planning Team Lead

Derek Feeley
# List of Key Documents that informed the Report

<table>
<thead>
<tr>
<th>Author/Publisher</th>
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<tbody>
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Child Healthcare Services in Scotland
APPENDIX 5 - Summary of Video-conferences
Thanks are expressed to Linda Fleming and her team at the Royal Hospital for Sick Children, Glasgow for organising the videoconferencing and putting together this appendix

PROCESS

Child Health Commissioners agreed that they would assist in accessing the views of the wider group of resident clinicians and stakeholders within their Health Board area, which took account of local contexts and challenges. Commissioners also agreed to co-ordinate service information for their local areas. It was acknowledged that this represented a real opportunity to influence the development of a national framework.

The process involved 3 distinct stages:

1. A series of questionnaires was circulated to each Health Board Commissioner in order to obtain a structured information base. One focused upon key aspects of existing services, the identification of problem areas and potential solutions now and over the next 5-10 years. A second focused upon the potential for moving care to local settings with the third providing information on existing provision of localised children’s tertiary services.

2. A two week programme of structured tele-interviews provided the service commissioners, supported by local clinical staff, the opportunity to review the content of the questionnaires but also to highlight service, priorities, other issues and major challenges for improving existing services within their own area as well as the national scene.

The main issues arising from the interviews were transcribed, circulated to all the participants and subject to review, the contents were approved.

3. A summary of the main ‘themes’ which had emerged from both the interviews and the content of the questionnaires became the subject of debate at a “Reflections Day” attended by senior clinical staff towards the end of November. The outcome of this day highlighted the service issues and opportunities which needed to be addressed in the developing Framework.

NATIONAL FRAMEWORK VIDEO INTERVIEWS

A number of common themes emerged during the video interviews with Scottish NHS Boards:

- The impact of the European Working Time Directive on the training of junior doctors. Less contact time with patients during training would mean that greater consultant input would be required.
- The training programmes for General Surgeons and for Anaesthetists did not routinely require specific training in paediatrics and many Boards were now finding it difficult to maintain elective services.
- The lack of Anaesthetists affected other specialties, such as ENT, where surgeons were routinely trained to deal with paediatrics.
• The need for appropriate facilities for older children and those in transition to adult services.
• The limited availability of child and adolescent mental health services.
• Issues associated with remoteness and rurality, including transfer times and the difficulty of maintaining very sick infants until transfer teams arrived.
• Access to training and education generally was also an issue.
• Support for families visiting sick children in distant hospitals.
• Greater support for formal clinical networks as a positive way forward. This was seen as a useful way to facilitate the earlier transfer of follow up care from the tertiary centres to local areas.
• Care close to home was also a factor in the wide support for the expansion of Telemedicine, particularly in relation to Diagnostic Imaging where the image could travel rather than the child.
• The particular challenges for the child and family who access multi-agency services to support the child with complex needs.
• The development of the role of the GP with a special interest in paediatrics
• A closer relationship between GP out-of-hours services and A&E services.
• Expansion of the role of Community Children’s Nurses
• Promote career pathways, especially for Child Protection Services. A Scotland wide MCN approach for Child Protection Services was proposed.
ARGYLL & CLYDE

Wednesday 10th November 2004

Dr Catriona MacDonald, Consultant in Public Health Medicine
Dr Haider Mamdani, Consultant Paediatrician
Ms Annie Hair, Children’s Service Development Manager
Dr Lesley Nairn, Consultant Paediatrician
Dr Mary Ray, Consultant Paediatrician
Mr Patrick Sweeney, Consultant in Dental Public Health

<table>
<thead>
<tr>
<th>1. <strong>MAIN PROBLEM AREAS</strong></th>
<th>2. <strong>POTENTIAL SOLUTIONS</strong></th>
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<tr>
<td>(a) Surgery / Anaesthesia: The sustainability of a local service. There are problems sustaining anaesthetics for all ages in the long-term. Planning the future of dental GA services is also an issue.</td>
<td>(a) West of Scotland review of sustaining anaesthetic services for younger children in DGHs. More day surgery could take place locally with support from tertiary centre. There is a plan to repatriate dental cases by developing a service at RAH.</td>
</tr>
<tr>
<td>(b) Impact of shorter junior doctor training on consultants workloads.</td>
<td>(b) Invest in a more consultant led service.</td>
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<tr>
<td>(c) Psychiatric inpatient services for Young People are dependent on Glasgow based services where access to the young people’s unit in Gartnavel hospital is extremely difficult.</td>
<td></td>
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<tr>
<td>(d) Care of children with complex needs</td>
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</table>
### 3. DEVELOPING LOCAL CARE

1. **General Surgery**
   
   (a) All children under the age of 3 years are referred to RHSC Yorkhill for treatment.

   (b) Anaesthetic colleagues share concerns if children under 5 years, with other health problems, receive their care locally with the absence of on site Paediatric Intensive Care facilities.

   (c) There are plans to develop day surgery in Ambulatory Care Centres and centralise inpatient provision on one site.

2. **Enhanced Nurse Training**

   (a) Nurses rotate between wards and the community, Community Children’s Nurses are essential to the model of locally provided care.

3. **Shared Care**

   (a) Shared care with specialist centre requires some formalising and enhancing as some patients could benefit from return to local outpatient clinics rather than travel to Yorkhill.

### 4. RECOMMENDATIONS TO IMPROVE EXISTING CHILD HEALTH SERVICES

(a) Examine transfer/transport arrangements to the Neurosurgical Unit at the Glasgow Southern General Hospital.

(b) West of Scotland approach for a paediatric anaesthetic rota.

(c) Health improvements/promotion must be a priority.
# Ayrshire & Arran

**Wednesday 10th November 2004**

**Mr Jim Carle, Assistant Director of Health Improvement**  
**Dr Mike Blair, Service Director Paediatrics**  
**Dr John McClure, Associate Medical Director**

<table>
<thead>
<tr>
<th><strong>1. MAIN PROBLEM AREAS</strong></th>
<th><strong>2. POTENTIAL SOLUTIONS</strong></th>
</tr>
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<tbody>
<tr>
<td>(a) Maintaining secondary level care from 2 general and 1 neonatal sites in the context of working time legislation.</td>
<td>The plan is to provide comprehensive in-patient paediatric services from Crosshouse Hospital in 2006.</td>
</tr>
</tbody>
</table>

## 3. DEVELOPING LOCAL CARE

1. **General Surgery**
   (a) Surgery is provided by adult specialists with a paediatric interest.  
   (b) In most cases surgery is provided to patients aged from 1 year but is dependent upon individual assessment of the child.  
   (c) General surgical training does not encompass paediatrics, therefore there are fewer young surgeons with a paediatric interest.

2. **Child Protection Services**
   (a) Dealing with physical abuse cases is part of the general paediatricians role but sexual abuse cases are at present the responsibility of a community associate specialist.

3. **Managed Clinical Networks**
   (a) Expand Managed Clinical Networks to enable more care to be delivered locally e.g. Cystic Fibrosis/Epilepsy.

4. **Diagnostic Imaging**
   (a) Well served for imaging facilities. CT/MRI images transmitted electronically to Yorkhill where necessary.
Contd Developing Local Care

5. **Shared Care**
   
   (a) Shared care arrangements for Oncology patients remain underdeveloped as total care and follow-up is provided from Yorkhill.

6. **Paediatric Intensive Care**
   
   (a) Referring hospital medical staff are expected to identify the available paediatric intensive care bed on some occasions. The development of a proforma to clarify the clinical information required by the transport team would be of value.

   (b) Response times are critical for maintaining the child’s condition and may be influenced (in Glasgow’s case) by a different arrangement within the ambulance service from that experienced in NHS Lothian.

7. **Initial Assessment**
   
   (a) Once paediatric services are centred upon a single site, a short stay assessment unit will be developed.

4. **RECOMMENDATIONS TO IMPROVE EXISTING CHILD HEALTH SERVICES**
   
   (a) Implement the proposal to deliver inpatient paediatric services on one site.

   (b) Expand the provision of consultants trained in the examination and management of suspected child sexual abuse.

   (c) Develop a national strategy for the implementation of paediatric based Managed Clinical Networks.

   (d) Exploit the potential of telemedicine in training, communications and imaging.
**1. MAIN PROBLEM AREAS**

| (a) | Coping with the European Working Time Directive and its capping of the total number of working hours in a week. |
| (b) | The increase in consultant supervision required to compensate for the reduced patient contact as a result of the above. |
| (c) | Developing nursing roles to encompass paediatrics. |

**2. POTENTIAL SOLUTIONS**

| (a) | The introduction of a generic rota for junior doctors across the hospitals will increase availability of medical staff but significant guidance will be required relating to children’s health care needs. |
| (b) | Secondment to local area for specialists to pass on skills. |
| (c) | More flexible use of nursing resource based on the underlying principle of the “team around the child.” |
### 3. Developing Local Care

**1. Role of CHPs**

(a) Merging GP out-of-hours service with A&E services.

(b) Shared outpatients clinics with GPs

(c) Better information and prescribing in Primary Care.

(d) Some testing could be performed locally to avoid travel to the tertiary centre.

(e) Tertiary centre needs to reassure families that aspects of care could be effectively delivered locally.

**2. General Surgery**

(a) Elective procedures limited to routine day cases.

(b) Do not anaesthetise children under 2 years.

(c) Concerns about providing emergency cover without surgical back up.

(d) General surgeons must be prepared for paediatric training to ensure that routine paediatric care is provided locally.

### 4. Recommendations to Improve Existing Child Health Services

(a) Work more closely with tertiary specialists to ensure that aspects of care are delivered locally wherever clinically appropriate.

(b) Develop IT systems to permit transmission of images to tertiary centre.

(c) Start planning transition to adult services much earlier than at present.

(d) Streamline the reporting mechanisms associated with partnership working with other agencies.
<table>
<thead>
<tr>
<th>1. MAIN PROBLEM AREAS</th>
<th>2. POTENTIAL SOLUTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Remote &amp; rural location makes it difficult to provide comprehensive and seamless care. Provision of outreach services from Dumfries to remote areas can be inefficient due to travelling time etc. This also has a significant impact on consultant availability at the parent hospital.</td>
<td>(a) Explore potential for specialists in remote and rural medicine. Extend existing range of follow-up clinics e.g. Nuclear Medicine. Provision of enhanced care at home by recruitment of specialist community nurses in order to manage patients with complex problems.</td>
</tr>
<tr>
<td>(b) No longer have a consultant Radiologist with paediatric interest thus the reliance on Yorkhill has increased. There is a recognition of a national shortage of radiologists and the impact for paediatrics is even more intense.</td>
<td>(b) Highlight problems with W of S planning group. Quantify workload outwith local services Explore with local consultants opportunities for developing special interests and support for extending outreach service Escalate the development of tele-radiology links.</td>
</tr>
<tr>
<td>(c) There are difficulties in providing adequate care for young people with complex disabilities including those with learning disabilities. Transitional care arrangements not well developed thus patients stay longer in paediatric care. Young people with some mental health and developmental problems require dedicated services. The volume of activity is relatively small. The service remains under developed.</td>
<td>(c) Develop dedicated facilities for appropriate care of young people. Development of holistic approach to young people’s services by raising their profile with adult clinical colleagues and exploring their interests in developing a dedicated young people’s consultant post.</td>
</tr>
</tbody>
</table>
### 3. DEVELOPING LOCAL CARE

1. **Role of CHPs**
   - (a) It is unlikely that service provision will change because of the model developing in Dumfries as there are already very close arrangements between health and other agencies.
   - (b) The challenge is to devolve services without reducing the effectiveness of regional programmes e.g. Immunisation services.

2. **General Surgery**
   - (a) In supporting the local service in Paediatric Surgery there is the inevitable tension between maintaining a skill base associated with treating younger children (essentially emergency care) and anaesthetising under 5yr olds. Dumfries currently copes – but manpower changes would disrupt this fragile model. Neonatal intensive care skills also need to be maintained locally.

### 4. RECOMMENDATIONS TO IMPROVE EXISTING CHILD HEALTH SERVICES

- (a) Promote Community Paediatric career pathway especially for Child Protection services.
- (b) Provision of centrally funded training programme for Children’s Community Nurses to work with the chronically ill child both at home and in school.
- (c) Better framework for joint clinics between health boards and tertiary centre (move away from relying on informal arrangements).
### Video Link-up Representatives

Caroline Inwood, Director of Nursing Services  
Dr Chris Steer, Consultant Paediatrician  
Maxine Moy, Lead Nurse for West Fife LHCC

<table>
<thead>
<tr>
<th>1. Main Problem Areas</th>
<th>2. Potential Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Manpower</td>
<td>(a) Build on network arrangements with neighbouring Health Boards.</td>
</tr>
<tr>
<td>(i) Consultant Manpower:</td>
<td>(i) Review children’s health needs on a multi-professional basis with a view to providing care differently e.g. Advanced Neonatal Nurse Practitioners</td>
</tr>
<tr>
<td>Consultant numbers</td>
<td>(ii) Manpower projections and education and training</td>
</tr>
<tr>
<td>(ii) Ageing Workforce:</td>
<td></td>
</tr>
<tr>
<td>community nursing and school nursing could well experience service gaps if replacement skills are not available.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>(b) Lack of emphasis on paediatrics in GMS contract</td>
<td>(b) Highlight as national issue</td>
</tr>
<tr>
<td>(c) Concentration on public health issues by Health Visitors, School Nurses and paediatric nurses is diverting resources away from clinical care</td>
<td>(c) Consider as part of manpower planning review</td>
</tr>
<tr>
<td>(d) Paediatric services are provided from 3 separate sites (Right for Fife does not provide a solution until 2009)</td>
<td>(d) Escalate paediatric solution</td>
</tr>
<tr>
<td>(e) No dedicated inpatient facilities for Young People in acute and mental health services</td>
<td>(e) Young People – raise profile of individual needs and secure appropriate facilities</td>
</tr>
<tr>
<td></td>
<td>CAMHS – Link into regional work but also highlight workforce issues nationally.</td>
</tr>
</tbody>
</table>
## 3. Developing Local Care

1. **General Surgery**
   
   (a) Lower age limits for General Surgery in Fife is around 6 years old

   (b) Any significant acute surgical problems transfer to RHSC(E)

   (c) Fewer of the emerging surgeons have paediatric training/expertise

2. **Community/Ambulatory based Services**
   
   (a) Problems in recruiting paediatric trained nurses (tends to be district nursing team with predominately adult skills)

   (b) Many services are being outreached

   (c) Upskill nurses using tele-video linking to extend range of care in ambulatory centre.

## 4. Recommendations to Improve Existing Child Health Services

(a) Fife colleagues agreed to reflect upon this section and respond via the questionnaire.
**FORTH VALLEY**

Wednesday 10\textsuperscript{th} November 2004

<table>
<thead>
<tr>
<th>1. <strong>MAIN PROBLEM AREAS</strong></th>
<th>2. <strong>POTENTIAL SOLUTIONS</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Insufficient numbers of clinical staff in post and in training.</td>
<td>(a) Expand workforce or explore an extended relationship with tertiary and other centres – or both.</td>
</tr>
<tr>
<td>(b) Existing communication technology is not underpinning service delivery.</td>
<td>(b) Develop an integrated system capable of linking acute networks and community health services. Communicate range of services in specialist centres/DGHs.</td>
</tr>
<tr>
<td>(c) Some services for children are delivered by adult specialists e.g. surgery.</td>
<td>(c) Maintain secondary care and transport to ensure that only highest intensity care is delivered centrally.</td>
</tr>
</tbody>
</table>
### 3. DEVELOPING LOCAL CARE

#### 1. General Surgery

(a) All children under 3 years for complex and urgent surgery transfer to Glasgow. Some elective procedures are undertaken locally. Treatment for children in the 3-5 year age range is dependent upon the on-call surgeon or anaesthetist.

(b) ENT, Ophthalmology patients are not cared for in a paediatric ward.

(c) If elective surgery is over overcentralised, competency levels in emergency situations may be an issue.

(d) Surgical follow ups for communication of results or other work, could be delivered locally to avoid travel for patients and families.

#### 2. Primary Care

(a) More community paediatric nursing will allow extended care at home.

#### 3. Psychiatry

(a) Explore the potential for more community based support from primary health care workers.

#### 4. Neonatal Services

On-call demands are challenging when endeavouring to sustain current service. Advanced Neonatal Nurse Practitioners capable of delivering level 2 Intensive Care would alleviate pressure on junior doctors.

### 4. RECOMMENDATIONS TO IMPROVE EXISTING CHILD HEALTH SERVICES

(a) Define age limits nationally or enable the skill of the team to define age limits for aspects of surgery and the procedure involved.

(b) Ensure that national workforce plans underpin service needs.

(c) Acknowledge that boundaries between Health Boards are artificial and should not represent barriers to service change.
### GRAMPIAN

**Wednesday 10\(^{th}\) November 2004**

<table>
<thead>
<tr>
<th><strong>1. MAIN PROBLEM AREAS</strong></th>
<th><strong>2. POTENTIAL SOLUTIONS</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Perceived threat to Paediatric services located in the North East of Scotland.</td>
<td>(a) Underline the importance of a children’s health service network for Scotland and remove uncertainty.</td>
</tr>
<tr>
<td>(b) Manpower shortages in psychology, S&amp;LT, medical, (including GPs) and paediatric nursing.</td>
<td>(b) Act as part of a regional network to sustain services and make jobs more attractive.</td>
</tr>
<tr>
<td>(c) Difficulties in competing with adult services/national priorities for service developments.</td>
<td>(c) Children’s services need to be a national priority.</td>
</tr>
</tbody>
</table>
### 3. Developing Local Care

1. **Paediatric Surgery**
   - (a) A comprehensive service is in place. Only cardiac surgery, transplant surgery and some complex spinal surgery is not provided locally.
   - (b) Only paediatric trauma service in Scotland.
   - (c) Paediatric surgery is sustainable in the longer term if over centralisation is stemmed as it is impossible to sustain the skills for an emergency service if elective services were to diminish.

2. **Role of CHPs**
   - (a) Formal guidance is required to support community GP led hospitals in the provision of paediatric care.
   - (b) Transfer more of the management of chronic illness in children from hospital to community services e.g. diabetes.
   - (c) Explore the development of “Health Suites” in schools to deliver a wide range of health care including health promotion initiatives.
   - (d) Explore a shared care model of paediatric nursing to enhance service relationships between secondary and primary care.

3. **Psychiatry**
   - (a) Develop existing services to meet the needs of young people.
   - (b) Increase therapeutic input to local authority residential schools

### 4. Recommendations to Improve Existing Child Health Services

- (a) Establish children as a Scottish NHS priority.
- (b) Support the development of Managed Clinical Networks to promote equity of care.
- (c) Provision of specific guidance for delivery of paediatric and maternity care in isolated units.
### GREATER GLASGOW

Dr A Ford, Clinical Director of Medicine, Mr C Davis, Clinical Director of Surgery, Dr A Watt, Clinical Director of Radiology, Mr J Redfern, General Manager, Clinical Board for Medicine, Child Health & Psychiatry, Mr D Daniels, Service Development Manager, Clinical Board for Anaesthesia & Surgery, Ms W Miller, Clinical Service Manager, Clinical Board for Anaesthesia & Surgery, Dr C Wright, Consultant Paediatrician, Dr K MacKay, Consultant Paediatrician, Ms S Dick, General Manager, Clinical Board for Laboratories, Diagnostic Imaging & Radiology, Mrs L Fleming, Director of Corporate Planning, Mr J Marshall Planning Manager Mrs F Mercer, Assistant Director, Children's Services, NHSGG, Dr I Cullen, GP & Chair of Child Health Clinical Forum

Monday 1st and Tuesday 2nd November 2004

#### 1. MAIN PROBLEM AREAS

| (a) | The lack of a dedicated service for young people (14-18) to smooth the transition to adult services, particularly for those with complex needs. The current age limit for acceptance of referral is the child’s 13th birthday although in chronic cases treatment will continue beyond this age. There are poor facilities for the 13-16/18 age group in adult acute units and there is a desire to provide an improved service for this patient group. |
| (b) | The impact of the consultant contract and European Working Time Directive on recruitment and retention of staff. |
| (c) | Split-site commitments for staff with joint adult/paediatric interests create difficulties in achieving a comprehensive on-call rota. |
| (d) | The reduction in paediatric surgery being undertaken away from RHSC (i.e. in surrounding DGHs) is diluting the skills for current DGH surgeons. There would appear not be any General Surgeons being appointed to DGH posts who have |

#### 2. POTENTIAL SOLUTIONS

| (a) | The provision of age appropriate facilities with staff trained to meet the specific needs of this age group. |
| (b) | Harmonising service needs with manpower planning and training. |
| (c) | Strategic national planning is required for the future provision of paediatric surgery in the West of Scotland DGHs. |
specified Paediatric Surgery as a specialist interest. There are issues surrounding the return of children with complex needs back to the local DGH or home when ready for discharge. Often neonatal surgical patients, ventilated patients or those with gastrointestinal problems have their transfer back delayed due to the inability of the local unit to support the patient – post discharge from Yorkhill.

| Improved discharge planning and skills review at DGH level in partnership with Tertiary Centre. |

### 3. DEVELOPING LOCAL CARE

1. **Paediatric Surgery**
   
   (a) A full range of general and specialist paediatric surgery is provided for all children up to the age of 13.

   (b) A high proportion of children in the West of Scotland attend Yorkhill for surgery and the majority of the under 5s. Current outreach surgical services are limited to routine day case procedures. Fewer and fewer anaesthetists are comfortable with and have regular experience of children under 5.

2. **GPs**
   
   (a) The GEMS out of hours service should be provided alongside paediatric A&E to reduce inappropriate A&E attendances and improve access to support services for GPs

   (b) Consider the development of a “family paediatrician” model to enhance the level of paediatric expertise within CHPs.

   (c) Discussions about service provision in CHPs is at a very preliminary stage but there is concern that some aspects of the child health services risk fragmentation in a very devolved model.

3. **Meeting Complex Needs**
   
   (a) The development of a key worker/co-ordinator role would improve the management of the diverse elements of the care of children with complex needs.
Contd Developing Local Care

4. Management of Illness in the Community

(a) Extend the use of protocols and education programmes to assist GPs and other Primary Care professionals to manage a wider range of conditions in the community.

(b) The Division has established a “Paediatrics for Primary Care Handbook” giving guidance to GPs on the treatment of a number of common medical and surgical conditions and offering suggested treatment by GP and advice on when it is appropriate to refer to Yorkhill. This handbook, which is now in its 2nd revision, has been well received by GPs. It is available electronically from the Yorkhill website.

5. CAMHS

(a) Develop specialist multi-disciplinary teams to enable the delivery of mental health services in primary care and new community schools.

6. Telemedicine

(a) The development of telemedicine is a valuable tool in inreach education. Currently in neonatal surgery, there is joint teaching/case presentation monthly with RHSC (Edinburgh).

(b) Telemedicine, whilst a valuable resource, has not had a significant impact on reducing the number of admissions to the tertiary centre.

4. Recommendations to improve existing Child Health Services

(a) A national strategic approach to manpower planning and training to meet future needs.

(b) Develop the concept of the GP with a special interest (family paediatrician).

(c) Implement SNAP recommendations to deliver mental health services in primary care and new community schools.

(d) Ensure that the neonatal intensive care service is included in the specialised service review as complexity of case load is continuously stretching neonatal nurse staffing pressures.
Friday 5\textsuperscript{th} November 2004

**HIGHLAND**

<table>
<thead>
<tr>
<th><strong>1. MAIN PROBLEM AREAS</strong></th>
<th><strong>2. POTENTIAL SOLUTIONS</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Insufficient consultant numbers.</td>
<td></td>
</tr>
<tr>
<td>(b) Relative remoteness causes anxiety about care of babies born in peripheral units requiring resuscitation.</td>
<td>(b) Neonatal nurse practitioners unlikely to get sufficient experience or maintain skills if appointed.</td>
</tr>
<tr>
<td>(c) Neonatal transport service can take up to 5 hours to reach remote areas.</td>
<td>(c) There may need to be increased investment in air transport to achieve faster turnaround.</td>
</tr>
<tr>
<td>(d) Management of children with psychiatric problems.</td>
<td>(d) Support recently established forum to develop closer working relationships with adult psychiatrists.</td>
</tr>
</tbody>
</table>
### 3. Developing Local Care

**1. Role of CHPs**

(a) Improved specialist nursing support – but recruitment difficulties exist.

(b) Specialist care is more self-contained in Highland due to travelling distances to other centres.

(c) Care plans are in place with tertiary specialist centres which reduce travelling requirements.

(d) Highland is moving to a combined child health service and so the prospect of CHPs fracturing specialist paediatrics from the community health services requires lots of exploration.

(e) Family Paediatrician – conceptual only at this stage. Unlikely to work in very remote areas. Referral from one GP to another is currently an uncommon model of care.

### 4. Recommendations to Improve Existing Child Health Services

(a) Support for appropriately functioning clinical networking.

(b) General Paediatricians with a specialist interest could reduce parent’s dependency on tertiary centre.

(c) A National Children’s Health Service model must recognise the complexity of work undertaken in Highland.
LANARKSHIRE

Wednesday 10\textsuperscript{th} November 2004

<table>
<thead>
<tr>
<th>1. MAIN PROBLEM AREAS</th>
<th>2. POTENTIAL SOLUTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Provision of comprehensive paediatric imaging service is hampered by absence of staff locally to interpret images.</td>
<td>(a) Expand use of Telemedicine for the interpretation of images.</td>
</tr>
<tr>
<td>(b) Difficulties associated with split site working between 3 DGHs.</td>
<td>(b) Encourage GPs, SAS and the public to refer direct to the local paediatric centre.</td>
</tr>
<tr>
<td>(c) Transitional care arrangements not well developed thus patients stay longer in paediatric care.</td>
<td>(c) Explore the potential to create a dedicated service for Young People, building on work achieved with the present diabetes service.</td>
</tr>
</tbody>
</table>
### 3. Developing Local Care

1. **General Surgery**
   
   (a) In addition to a visiting service from RHSC (Yorkhill) children’s surgical services are available for those aged 5 years and over.
   
   (b) Some surgery is provided on two sites, outwith the paediatric centre, which may not have “child friendly” facilities.

2. **Role of CHPs**
   
   (a) Working towards establishing a GP forum.
   
   (b) Re-designing paediatric workforce to deliver secondary care in a community setting.
   
   (c) Working towards repatriation of chronically ill children from tertiary centre to local services e.g. Cystic Fibrosis.

3. **Child Protection**
   
   (a) A comprehensive Child Protection service is in place.

### 4. Recommendations to Improve Existing Child Health Services

(a) Develop systems to support a local Diagnostic Imaging service

(b) Reduce reliance upon the tertiary centre for the provision of secondary care.

(c) Development of well supported networks to achieve equity of care.
## Video Link-up Representatives

**LOTHIAN**

Friday 5th November 2004

Dr Zoe Dunhill, Clinical Director Children’s Services  
Mr Robert Fraser, Project Manager Children & Young Peoples Strategy Review  
Dr David Simpson, Consultant Anaesthetist/Association Clinical Director  
Dr David Small, General Manager Women & Childrens Services  
Dr Ian Laing, Associate Clinical Director Neonatal Unit  
Dr Helen Hammond, Consultant Paediatrician and Acting Child Health Commissioner for Child Protection  
Mr Graham Lyell, Development Manager, Children’s Services

1. **Main Problem Areas**

   (a) Sustaining medical and surgical workforce across units by working more closely than before.

   (b) Absence of regional plans for maternal and child health services.

   (c) Planning arrangements for tertiary, secondary and community not yet fully integrated.

   Additional problem - given that RHSC Edinburgh is both a local DGH as well as a specialist centre. Tertiary specialists find it hard to deliver a comprehensive secondary service across the spectrum of conditions and meet rota requirements.

2. **Potential Solutions**

   (a) Building on the work already begun between St John’s and the Simpson Memorial hospitals, NHS Lothian is in discussion with all neighbouring health boards to deliver services in partnership.

   (b) Develop robust regional and local plans which take their lead from agreed national strategy and in particular, those for maternity services which will impact upon future service configuration and manpower issues.

   (c) Consider the introduction of a Children’s Services Board within NHS Lothian linking tertiary, secondary and community health services.

   (d) Colleagues are considering the development of an acute paediatric consultant who could act as a gatekeeper of referrals into hospital care and provide a level of cover for tertiary care but would not sub specialise.
3. **DEVELOPING LOCAL CARE**

1. **Role of CHPs**
   
   (a) CHPs bring an opportunity to look at a partnership model between community, secondary care and other agencies.
   
   (b) Community paediatrics are not devolving into CHPs but school nurses are.
   
   (c) A managed clinical network approach for the provision of child protection services (all abuse – sexual and physical - under one Scottish wide network) is currently being debated by a Royal College sub-group.
   
   (d) Develop GPs with special interest role.
   
   (e) Merge GP out of hours service with hospital A&E services.
   
   (f) Joint packages of care with local authority partners would ensure children with complex needs have their requirements met.
   
   (g) There is great scope to increase the number of children’s nurses.

2. **Paediatric Surgery**

   (a) There is a mixed economy of specialist units with 24-hour cover and general surgeons, with a paediatric interest, providing care in DGHs. It will be inevitable that emergency surgery will drain to the centre with 24-hour cover.
   
   (b) Training programmes in anaesthetics do not include paediatrics - thus staff attend Edinburgh to keep up their skills to sustain elective activity in DGHs.
4. **RECOMMENDATIONS TO IMPROVE EXISTING CHILD HEALTH SERVICES**

(a) Children should be an NHS Scotland priority.

(b) Development of a national/regional workforce plan for a range of specialties.

(c) Provision of a co-located children’s hospital with adult specialties.

**General Comment**

(a) To enable us to care for children more effectively an improved information technology infrastructure is required.

(b) The need to profile service requirements and build in clinical workforce including nurses AHPs etc.

**Neonatology**

(a) Significant changes in practice over the past 5 years

(b) Children not on ventilators for long but are more demanding particularly regarding nursing care.

(c) Promote in utero transfers for high-risk mothers.

(d) Review the number of neonatal intensive care units in Scotland to achieve uniformity of expertise and agreed protocols for delivering care.

(e) The speed of neonatal retrieval is a critical factor. Transport by air will reduce travel time but aircraft availability is limited. Current procurement exercise needed to take these factors in to account.
## ORKNEY

Wednesday 10th November 2004

<table>
<thead>
<tr>
<th>1. MAIN PROBLEM AREAS</th>
<th>2. POTENTIAL SOLUTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Visiting Consultant Paediatrician from Aberdeen only. Clinical skills supply unable to meet demand.</td>
<td>(b) Establish if retrieval procedure includes a single point of contact for the referring hospital. Currently reviewing hospital configuration to identify nursing staff who can be trained in paediatric resuscitation.</td>
</tr>
<tr>
<td>(b) Transfer of sick baby can be time consuming depending on response times of retrieval teams</td>
<td>(c) Further explore video links and online training modules. Curriculum needs to be more relevant to rural areas e.g. midwives trained in resuscitation techniques for babies &gt; 28 days.</td>
</tr>
<tr>
<td>(c) Training and Education for Medical and Nursing staff, including AHPs, is limited by geography.</td>
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</tr>
</tbody>
</table>

**VIDEO LINK-UP REPRESENTATIVES**

Ms Kathleen Bree, Director of AHP & Nursing
Ms Rhoda Walker, Assistant Director of AHP & Nursing
Dr Charles Siderfin, Managed Clinical Networks Co-ordinator/Hospital GP
Dr John Scott, Consultant Anaesthetist
### 3. DEVELOPING LOCAL CARE

#### 1. General Surgery

(a) Paediatric surgery from the age of 2 years is carried out locally but very dependent upon individual consultant arrangements. This practice does not meet Royal College guidelines but top up skills training undertaken on mainland.

(b) Non-paediatric nursing staff undertake the post operative care.

(c) Specialist centres care for children < 2 years and more complex procedures. The islands circumstances for after care must be understood.

#### 2. Child Protection

(a) The service is largely provided from the mainland and this is viewed as beneficial by the island community.

#### 3. Psychiatry

(a) Mainland outpatient support has been very difficult. Video case conferencing may provide a suitable alternative.

#### 4. Equipment Needs

(a) Specialist equipment for individual children is sometimes provided after the child’s requirements have altered.

### 4. RECOMMENDATIONS TO IMPROVE EXISTING CHILD HEALTH SERVICES

(a) Recognise the remote and rural dimension in the emergency management of sick children.

(b) Review provision of child psychiatry for rural locations.

(c) Explore innovative ways to access education and training.

(d) Acknowledge families sense of isolation when accompanying a child who is being treated on the mainland.
SHETLAND

Friday 5th November 2004

Dr Sarah Taylor, Director of Public Health
Ms Elizabeth Robinson, Health Promotion
Dr Susan Bowie, GP (special interest in Child Health)

<table>
<thead>
<tr>
<th>1. MAIN PROBLEM AREAS</th>
<th>2. POTENTIAL SOLUTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Geographical location - Distance both result</td>
<td>(a) Continue to invest in paediatric resuscitation training to stabilise patient before arrival of specialist transfer team.</td>
</tr>
<tr>
<td>- Weather in isolation</td>
<td></td>
</tr>
<tr>
<td>Communication links – Paediatric retrieval team takes an average of 5 hours, but can take up to 36 hours, to reach the receiving airport – depending upon weather conditions.</td>
<td></td>
</tr>
<tr>
<td>(b) The population (22,000) does not support the provision of inpatient beds for children. This results in adult physicians/surgeons caring for the critically ill child with consequential governance issues. If care is needed beyond an overnight stay the child is transferred to the mainland for ongoing treatment.</td>
<td>(b) A programme of training for all general staff to raise the awareness of common health problems of children and their particular needs - recognising their fragility.</td>
</tr>
<tr>
<td>(c) There has been a 3 year gap (compensated for by a locum appointment) since a community paediatrician left the islands.</td>
<td>(c) An appointment has been made; a GP with a specialist interest in children who is regularly supported by a visiting Consultant from Aberdeen.</td>
</tr>
</tbody>
</table>
3. **DEVELOPING LOCAL CARE**

(a) Visiting consultant surgeon performs a range of day surgery.

(b) Overnight stays have care on mainland.

(c) Anaesthetising of children under 1 year (for elective work) undertaken on mainland.

(d) Routine programme of skills updating is undertaken on mainland.

(e) Telemedicine links exist in all remote practices but no substitute for “hands on” care.

(f) Scope for building on existing model for supporting families of children with special needs. This is provided through integration with Health Visitor and School Health Services with support from specialist nurse – the model needs expansion by additional resources.

4. **RECOMMENDATIONS TO IMPROVE EXISTING CHILD HEALTH SERVICES**

(a) Recognise remote and rural medicine as a specialism.

(b) Setting of standards must be realistic when relating to remote and rural areas. Training programme for consultant workforce must embrace these factors.

(c) Even greater investment in the neonatal transport service to improve journey times (weather permitting) could re-shape the services further.
TAYSIDE

Wednesday 10th November 2004

<table>
<thead>
<tr>
<th><strong>1. MAIN PROBLEM AREAS</strong></th>
<th><strong>2. POTENTIAL SOLUTIONS</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Timely access to mental health services.</td>
<td>(a) Increase capacity across a whole range of professionals.</td>
</tr>
<tr>
<td>(b) Surgical service does not enjoy 7 day cover.</td>
<td>(b) Formalise already developed links with Edinburgh Sick Children’s Hospital to support general surgeons caring for children.</td>
</tr>
<tr>
<td>(c) Young People (14 years and older) will be in either paediatric or adult facilities. Transitional care arrangements also not well developed thus patients stay longer in paediatric care.</td>
<td>(c) In the first instance undertake a service mapping exercise to quantify demand for dedicated Young People’s services.</td>
</tr>
</tbody>
</table>
3. **DEVELOPING LOCAL CARE**

Children’s health needs are largely met within Tayside and the balance of care in local settings is near to an optimum level.

1. **General Surgery**
   
   (a) Initial contact is with Paediatrician, unless an acute problem necessitates transfer to Edinburgh
   
   (b) Surgical service does not enjoy 7 day cover.

2. **Primary Care**
   
   (a) Explore the potential to reduce A&E referrals through a primary care based assessment service.
   
   (b) Expand the role of primary care in the management of chronic illness.
   
   (c) Concern that new GMS contract provides insufficient incentives to meet chronic disease management or long term illness.
   
   (d) If the out of hours service continues to be problematical to staff, hospital A&E services could experience increased attendances

3. **Role of CHP**
   
   (a) There were opportunities for GPs and Specialist Nurses to manage chronic disease across localities – based on the principles of an MCN.
   
   (b) Concerns that as Health Visitors become more Public Health orientated that the time and support for the needs of the individual child and family may be lost
### 4. RECOMMENDATIONS TO IMPROVE EXISTING CHILD HEALTH SERVICES

<table>
<thead>
<tr>
<th>Recommendation</th>
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<tbody>
<tr>
<td>(a) Mental Health Services – Increase capacity across a range of professionals to support early intervention.</td>
</tr>
<tr>
<td>(b) Formal co-ordination of Networks.</td>
</tr>
<tr>
<td>(c) Maintaining a child health focus on primary prevention thus preventing health issues in later life.</td>
</tr>
<tr>
<td>(d) Diverting resources as a result of a declining child population would be a false economy.</td>
</tr>
</tbody>
</table>
**WESTERN ISLES**

Wednesday 10\(^{th}\) November 2004

<table>
<thead>
<tr>
<th>1. MAIN PROBLEM AREAS</th>
<th>2. POTENTIAL SOLUTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Sustaining a comprehensive children’s health service. Significant proportions of the child population require therapy and educational support but expert services can be difficult to sustain due to geography.</td>
<td>(a) Need very constructive support from mainland Health Boards. Need enhanced technological links for training and treatment.</td>
</tr>
<tr>
<td>(b) Turn around times for Air Ambulance retrieval team can often take several hours. Support is essential for the longer term resuscitation of newborn infants, if consultant led services becomes unsustainable. The telemedicine link could also assist/support the practitioner in deciding if retrieval is necessary.</td>
<td>(b) Develop more formal links to expert centres to reassure staff during the stabilisation period while waiting for the retrieval team. Extend midwives role to cover resuscitation and intubation and recognise that maintenance of skills will be a problem if infrequently practised. Upskilling existing staff on mainland results in loosing a scarce local resource.</td>
</tr>
</tbody>
</table>
3. **DEVELOPING LOCAL CARE**

(a) There is designated Child Protection lead who works across all agencies. Strategically service is sound but needs full time nurse dedicated to the service.

(b) Philosophy opposed to send children away from the Islands for care. Current service aims to manage chronic disease locally but accept transfer for acute care.

4. **RECOMMENDATIONS TO IMPROVE EXISTING CHILD HEALTH SERVICES**

(a) Provide facilities locally wherever clinically appropriate

(b) Mainland Health Boards must consider how to provide services for rural/remote Boards.

(c) Resources should permit specialist to visit child in home setting
The points listed below are the significant issues, beyond the descriptions of the Boards’ services and relationships to tertiary centres, identified in the questionnaires that were not covered by the interview summaries.

<table>
<thead>
<tr>
<th>Health Board</th>
<th>Additional Issues from Questionnaire</th>
<th>Questionnaire rec’d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Argyll &amp; Clyde</td>
<td>Ophthalmology, Otolaryngology and Orthopaedic Surgery are provided locally for children over the age of 3. The future provision of dental GA is dependent on the outcome of the review of paediatric and anaesthetic services across NHSA&amp;C.</td>
<td>YES</td>
</tr>
<tr>
<td>Ayrshire &amp; Arran</td>
<td>There are difficulties in attracting Consultants in Paediatric Surgery &amp; Anaesthesia. It is planned to provide comprehensive inpatient paediatric services in Crosshouse from 2006, which should ease pressures. Improve information/IT capabilities to allow more informed decisions on service planning and delivery.</td>
<td>YES</td>
</tr>
<tr>
<td>Borders</td>
<td>An expanded Community Children’s Nursing Team would allow more children to be cared for at home. The development of Hospital at Home paediatric team would also allow more care at home. Shared GP/Paediatrician outpatient clinics would enable GPs to learn to deliver more care locally. Short-term funding for projects and the new GP contract are limiting factors in developing children’s services in Primary Care.</td>
<td>YES</td>
</tr>
<tr>
<td>Dumfries &amp; Galloway</td>
<td>More appropriate training in holistic care for General Paediatricians is suggested. Currently most expect to be either hospital or community Paediatricians. Merging GP out-of-hours with paediatric A&amp;E would be unhelpful in this area. GP manpower is limited in rural areas. Develop the potential of community nurses to provide more of an acute service.</td>
<td>YES</td>
</tr>
<tr>
<td>Fife</td>
<td>There is no general paediatric surgery locally for children under 12. There is some ENT, ophthalmology and orthopaedic surgery. Out of hours and weekend cover for neonates is a problem. Lack of suitable accommodation could prevent further delivery of services in the community. GP training and upskilling of non-clinical staff must include quality checks.</td>
<td>YES</td>
</tr>
<tr>
<td>Forth Valley</td>
<td>There is a range of local outreach clinics supported by the tertiary centre.</td>
<td>YES – section 3 only</td>
</tr>
<tr>
<td>Health Board</td>
<td>Additional Issues from Questionnaire</td>
<td>Questionnaire rec’d</td>
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<tr>
<td>Grampian</td>
<td>Grampian wishes to develop a rotation of trained staff from hospital to community and to explore the merits of aligning Paediatricians from RACH with clusters of GP practices. Improve the alignment of HVs/School Nursing/Community Paediatrics around the Integrated School model. RACH/Dr Gray’s provide services up to 14 years. Supplying a clinical team for transfer between Elgin and Aberdeen can be difficult – national retrieval is for PICU only.</td>
<td>YES</td>
</tr>
<tr>
<td>Greater Glasgow</td>
<td>The age limit at Yorkhill is 13 years, although there are exceptions to this. Outreach services are provided to a number of DGHs throughout the country. A Paediatrics for Primary Care Handbook offers guidance to GPs on the treatment of a range of common medical and surgical conditions and advice on when to refer to Yorkhill. Limiting factors in expanding the range of services in CHPs include the time available to Primary Care staff to undertake additional duties and the time for secondary care staff to provide the necessary consultative support and specialist education/training.</td>
<td>YES</td>
</tr>
<tr>
<td>Highland</td>
<td>There are dedicated children’s theatre lists and a governance framework for surgery is being developed. There are also anaesthetists, ENT surgeons and Ophthalmologists with a special interest in children. Children under 46 weeks gestational age are not operated on.</td>
<td>YES – Section 3 only</td>
</tr>
<tr>
<td>Lanarkshire</td>
<td>Currently implementing 111 recommendations from a Review of Children’s Services. The shift of services to Primary Care includes some minor surgery and some outpatient clinics held in Health Centres. All Children’s Services will be managed in CHPs. Finance and the capacity of the Estate are limiting factors.</td>
<td>YES</td>
</tr>
<tr>
<td>Lothian</td>
<td>The age limit at RHSC Edinburgh is 13 years. The availability of General Paediatricians who are specifically trained and who wish to work in a DGH as clinicians, clinical supervisors and educational supervisors is an issue. A paediatric and child health workforce plan for Lothian/ South East Scotland would be helpful. Number of HVs required to meet Hall 4.</td>
<td>YES</td>
</tr>
<tr>
<td>Orkney</td>
<td>The local hospital is managed by GPs. Consultant input is provided by visiting staff from Aberdeen. There is no on-island CT scanner.</td>
<td>YES</td>
</tr>
<tr>
<td>Shetland</td>
<td></td>
<td>NO</td>
</tr>
<tr>
<td>Health Board</td>
<td>Additional Issues from Questionnaire</td>
<td>Questionnaire rec’d</td>
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<tr>
<td>Tayside</td>
<td>The availability of appropriate accommodation in community clinics is an issue. There is potential for greater nurse led management of chronic conditions in General Practice through an MCN style approach between secondary/primary care. There is concern about the GMS contract not incentivising the shift of care and a lack of understanding in the secondary service of its implications. The electronic Child Health Record will enhance communication between professionals.</td>
<td>YES</td>
</tr>
<tr>
<td>Western Isles</td>
<td></td>
<td>NO</td>
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</table>
HEALTH SERVICES FOR CHILDREN AND YOUNG PEOPLE IN SCOTLAND

SUMMARY REPORT FROM THE SECOND CONSULTATIVE SEMINAR ON THE INITIAL FINDINGS ON CHILD HEALTH FOR THE NATIONAL FRAMEWORK FOR SERVICE CHANGE IN THE NHS

TUESDAY 8 FEBRUARY 2005

1. NATIONAL FRAMEWORK FOR SERVICE CHANGE IN THE NHS

CHILD HEALTH WORK STREAMS

National Review

• Framework is being steered by an expert Advisory Group chaired by David Kerr, Rhodes Professor of Cancer Therapeutics and Clinical Pharmacology at Oxford University

The question the Kerr review is addressing is:
• How can the NHS plan and deliver better healthcare services in Scotland for the longer term?

Professor Kerr is due to report to the Health Minister in summer 2005.

There are 11 areas of work (called ‘work streams’), each of which is chaired by a member of the Advisory group and has a project lead from the Scottish Executive Health Department. The work draws on experts from across the health and social care systems and their partner organisations (e.g., voluntary agencies).

Child Health Work Streams

• Specialised Paediatric Services
• Secondary Services (includes all services from self-care to the boundary with tertiary services)
• Care in Local Settings which includes Children with Complex Needs

Also contributing to:
• Unscheduled Care
• Remote and Rural Access

Methodology

• Secondary Care
  • Review of existing reports and literature
  • Data analysis
  • Questionnaires
  • Interview by video link
  • Further interviews with professional groups and individuals

• Children with Complex Needs
  • In conjunction with Scottish Complex Needs Group
  • Review of existing reports and literature
  • Meetings
  • Email contributions to emerging drafts

Secondary Care: Key themes

• Ways of working
  • Links between DGHs and specialist centres
• MCN’s
• Development of roles (e.g., GPs with a special interest in paediatrics)

• Configuration of services and model of care
  • Regional planning
  • Ambulatory care

• Needs of specific groups
  • Mental health
  • Teenagers

Principles
• Care should be provided as close to home as possible
• Equality of access regardless of geography
• Sustaining and developing local services is the responsibility of all those who care for children
• Services planned and provided in partnership with children and families

2. WORKSHOPS

2.1 CARE OF TEENAGERS/INVOLVING CHILDREN & YOUNG PEOPLE

BACKGROUND INFORMATION

Care of Young People: issues
• Where should they be looked after?
• Who should look after them?
• How should they be looked after?

Why single out young people?
• Developmental stage:
  • Particular period of intellectual and emotional development
  • Physical development

• Psychosocial factors impact on health
• Teenagers are at high risk for mental health problems
• The teenage years are an important time for learning health-related behaviours

Examples of current patient population profiles
• Yorkhill - Young People aged 12-23 years
  • 9,088 bed days which is 23% of total hospital population
  • 39% surgical
  • 49% medical

• 10-18 year olds in NHS Greater Glasgow Hospitals
  • 8,084 inpatients
  • 3,660 day cases
  • 19,481 outpatients
  • 55% of in-patients and 66% of day cases are seen in adult hospitals

Other issues
• What should the age limit be? – 16? 18? By developmental stage?
• What would be the effects of a change in the age limit?
  • Emergency medicine
  • Acute medical/surgical care including trauma
• Chronic illness
• Who looks after young people?
  • Paediatricians?
  • Adolescent medicine specialists?
  • Adult physicians?

• What are the implications for training?
• A culture shift is required:
  • Different approach to patient care
  • Pregnancy, substance abuse, alcohol

• How do we handle the transition to adult care?
• Environment:
  • Children’s Hospital +/- Adolescent Unit
  • Adolescent Hospital
  • Adult Hospital

• Resources:
  • Not cost-neutral
  • Age-appropriate area/facilities
  • Surgical equipment etc
  • Staffing

Tell it as it is: the young person’s perspective

• We need to define our terms of reference
• Developmental stage as a key criteria
• Problems using age as a ‘cut off’:
  • Involve - elicit views of young people
  • Identify their priorities
  • Respond to/anticipate needs
  • Implement change
  • Evaluate progress
  • An ongoing collaborative process.
  • Whose transition?

Progress
• Much has been achieved but there is a need for an evidence based approach to national planning
• Change in practice requires setting the infrastructure in place - facilities debate
• Specialty specific - is there an exemplar of good practice?
• Resource issues v culture shift: what are the barriers to change?
• Complex needs - building on exemplars of good practice (generally ‘condition specific’)
• Implementing research findings - models from North America?
• The healthcare team - changing the culture/what are the barriers?
• Moving on from the limitations - subsuming adolescent needs (children and young people)

What do the professionals think?

• How can we move on from the models identified? Policies need to be relevant and effective
• Barriers need to be explored
• What is the agenda for education?
• Involving young people – needs to be more than rhetoric
• The healthcare journey – this should be a process of planned care
What the adolescent population say: lessons from research

- Issues of autonomy and control
- Challenging paternalism
- Information and 'knowing' enough to know what to ask
- One size does not fit all - reference to the changing dynamic of 'adolescent' needs
- Age of Legal Capacity (Scotland Act 1993) and parental needs

Areas requiring attention

- Influencing agenda
- The emotional and psychological imperatives - adolescent sense of coherence
- Impact of persistent paediatric culture
- The health education message
- Societal expectations and healthcare provision - the contradiction
- The impact of lifestyle and high-risk behaviours

Resources

- Can real progress be made in the absence of new resources? Creative use of existing strengths is required
- Vision and commitment - a 'full team' commitment is needed
- Transition does not happen in the absence of a planned journey
- The young person as a discrete service user
- Closer to paediatrics than to adult services?

Pragmatism and the new order

- What are we trying to achieve?
- How can we go about achieving change?
- Can we realistically provide another 'client specific' service?
- Look to the positive benefits of an informed adolescent population
- Quality and standards of care - everyone's concern

The voice of adolescents

- 'The persistence of the paediatric culture'
- 'We are sent a message that we should be dependent - and are thus incompetent, and not mature enough to know what we need' (Fox et al International Journal of Adolescent Medical Health 2002 vol. 14, issue 1, pages 3-7)
- Is it surprising, therefore, that the behaviours of young people can often reflect the frustration associated with this lack of real understanding of their developmental, emotional and physical needs?

Health services for children and young people in Scotland

- Who should participate?
- Users - children and young people
- Providers - health professionals and voluntary agencies
- Carers - parents, siblings, 'significant others'

- Participation involves
  - Ownership
  - Involvement
  - Responsibility
• Reward

• Participation – why should they?
  • What project?
  • Whose project?
  • Why this project?
  • How long?
  • What outcome?

• Helping participation
  • Active
  • Equitable
  • Supportive
  • Fair
  • Rewarding - personal, financial, altruistic, etc

• Barriers to Participation of children, young people and families
  • Preconceived ideas
  • Unclear goals
  • Lack of mutual respect
  • Excessive demands
  • Lack of time limits
  • Lack of outcomes
  • Lack of reward
  • Other priorities - e.g. education, fun

• Questions
  • What level of participation?
  • How to facilitate participation
  • How to make participation representative
  • How to evaluate

MAIN POINTS FROM GROUP DISCUSSION

Care of Teenagers
• Neither paediatric nor adult services are meeting the needs of these groups
• Care of young people needs to take psychological, social, educational and emotional needs into account as these affect health
• There is a high incidence of mental health problems in young people
• Transition to adult services is problematic and needs work
• Working towards transition needs to start earlier to build up independence and responsibility for their own health

Involvement of Children and young people
Consider:
• Who to involve
• For what project
• What are the outcomes?
• How long will it last?
• Results must be acted upon
• What should the reward be?
• Children and young people can be realistic in asking for the services they want and can be very ‘community spirited’ and altruistic in their view towards others
• Young people should be consulted and asked what they want to be called – teenagers? Young people? Adolescents? Young adults?
• Parents should be involved too, and children and young people should be made aware of what parents think (‘they should consider their parents too’). The best models involve a holistic approach which includes the whole family and friends. There are currently good models in diabetes services.

• Parents need universal services that also cover transition periods. Good information only tends to be available if the child is diagnosed with an illness at birth. A checklist of support networks is required.

• Professionals require education and training in how to involve children and young people. Professionals have a different set of values from children and young people so they need to be flexible.

• Reappraise the child’s/young person’s knowledge in conjunction with move to secondary school. A pack on children’s and young people’s rights at an older age would be useful. A similar pack could be produced for parents. This would help parents to begin to let young people take responsibility for their own care and health. Young people also need to know that they do not need to ‘go it alone’ at a certain age, and how to exercise choice in a meaningful way.

• Ask children and young people (and parents) what they want to participate in, as well as what questions they want to ask when reviewing services.

• True participation involves ownership, involvement, responsibility, reward. Barriers to participation include the ‘adult baggage’ children often carry; children not being clear about their role; the level of commitment required; lack of reward.

• The danger with having an upper age limit is that young adults are not receiving a good service. Also, other pressures emerge (e.g. peers are hugely influential), so that they may no longer accept treatment that they had received as a child.

• More counselling services should be available; these could be provided by email.

• Discussion focused on offering support to families of children and young people with chronic illness early on in the illness and suggested a discharge planning checklist to make sure that all areas of support were offered before discharge from initial admission to hospital.

• Children and young people should be the centre of the consultation and should be asked for their views. There was strong feeling that children (and families) often were not listened to, and that choices should be offered. Patient choice was a major element of the discussion, as was the need for service providers to be flexible.

• Yorkhill has been developing a teenage contract and has involved focus groups of young people in the process.

• There was discussion about the role of peer support for young patients.

• There was considerable discussion regarding age limits for paediatric services and the difficulty of using a particular age when in fact it is the level of maturity that matters. Paralleling the education system may be beneficial. It was noted that the UN Convention applies up to 18 years of age. It was felt young adults older than 18 also need similar support systems. There was support for a move to 16 years for paediatric services, but a need for flexibility was noted.

• It was suggested that patient information be arranged into different packages according to age and that children and young people graduate from one stage to another. A ‘fresh start’ package should be offered to S1 age children to go through information about their diagnosis and illness,
and that they be encouraged to take on more responsibility for their illness over the next few
years, and at the same time parents be supported to ‘withdraw’ gradually. The important role of
parents throughout the young people’s illness was emphasised, as was the need to allow friends
to be involved too.

• It was felt important to space out stresses (e.g. not changing service at exactly the same time as
leaving school).

• A lot of the discussion focused on secondary and tertiary care, but it was emphasised that
similar principles apply to primary care and that services need to be accessed in such a way as to
maintain privacy.

• Similarly a lot of the discussion focussed on paediatric services but it was felt that young people
in adult services need the same consideration and have the same rights as young people in the
paediatric service.

• Service providers should be focused on the patient (and not targets) and management should
be built around the needs of individual patients. The increasing number of targets for healthcare
providers was noted. In particular doctors should be non-judgemental, have good communication
skills and above all should listen to young people.

• Seeking young people’s views was a major theme. This could be done through a website or
using other modern technologies (e.g. SMS, email etc). Also using questionnaires in outpatient
departments and in wards asking about the service and asking for suggestions to improve
service. Data on children and young people’s views are scarce at present. Any information
obtained should be acted upon and rewarded appropriately.

• Is it absolutely necessary not to use mobiles in hospital, as these are young people’s main
source of communication?

• There are probably areas of good practice scattered around and these should be shared.

• There are some websites available for young people to ask health-related questions and
could be expanded (e.g. a ‘healthy young scot’ website).

• All patients and their families should be educated about their rights.

• Standards should be developed around the care of children and young people, and should be
met. There could be a named person in each centre to ensure this happens.

• The mental health needs of young people with illness need to be identified and addressed. Early
intervention and prevention would be better than crisis management. A multidisciplinary approach
to the care of young people is crucial. Non-adherence to treatment is an important issue for
young people and their management needs to take this into account.

• Just as children require an age-appropriate environment in hospital so do young people. Neither
paediatric nor adult services routinely provide this at present. There was enthusiasm for the
development of adolescent facilities for all young people, and where appropriate, the co-location
of paediatric, adolescent and adult services on one site. Adolescent services could include young
adults.

• Transition was highlighted as an area requiring attention. Pockets of good practice exist and
should be shared. The need to involve adult services was identified. A culture shift is needed and
this will require training for all health professionals.

• Education services need to be involved and the health needs of young people with chronic
illness need to be considered in school. The Additional Support for Learning Bill covers this group, but they are often overlooked.

- Good communication was seen as crucial for transition between paediatric and adult services and between primary, secondary and tertiary services. A unified IT system would promote this.

- Routine canvassing of views should be common practice (e.g. filling in questionnaires on discharge from hospital), although services would need to act upon the feedback collected.

- Age-appropriate facilities are required so that, for example, young people have chairs they can sit in comfortably.

- Role models are required, people whose specific task is to advocate the principles of involving children and young people.

- Develop documents to be issued to schools detailing the health services that are available locally (separate leaflets for primary and secondary schools).

- More adolescent care modules should be developed for the education and training of health professionals.

**Key points**
- Children and young people’s views should be obtained in order to better target services to their healthcare, psychological, emotional and intellectual needs (i.e. appropriate to their age)
- Good practice should be identified and shared
- All patients and their families should be educated about their rights
- Standards should be developed for the care of children and young people in hospital and should be met
- The needs of parents of children and young people with illness should be met
- A multidisciplinary approach to the care of young people is needed.
- Young people should be looked after in an age-appropriate environment
- Transition to adult services requires close co-operative working between adult and paediatric services
- Communication between services is needed

### 2.2 EMERGENCY CARE FOR CHILDREN

**BACKGROUND INFORMATION (facilitator’s slides)**

**Main themes (from report on Emergency Care for Children issued by the Child Health Support Group)**

- A four-tier emergency care framework should be used as a benchmark model for emergency care services for children and young people

- A three-tier multi-professional competency framework is recommended for emergency care practitioners

- A consistent approach is required so that advice provided by a GP in Edinburgh on what to do in an emergency situation is the same as that provided by a GP in Wick. To this end

- A standard assessment method should be developed for triaging children and young people at emergency care sites
• Guidelines and best practice statements should be developed for emergency conditions for children and young people

• All Emergency care practitioners must communicate clearly with children and young people and actively involve them in their care and treatment. They need to be able to deal with them at a level that is appropriate to their stage of development

• Emergency care practitioners must understand the legal rights children and young people have to consent to treatment and to refuse consent to treatment

• All emergency care sites should have adequate pain control policies for children and young people

• Imaging examinations such as x-rays require expert interpretation and should be reported by radiologists. Increasing and more effective use should be made of technology such as telemedicine. Professional roles may also be expanded so that, for example, scans can be carried out by different professionals

• Emergency care sites should have a named individual (drawn from a range of professions) responsible for the overall organisation of clinical care for children and young people at the site

• Emergency care sites should utilise short stay/ambulatory facilities to reduce admissions/transfers of children and young people

• All emergency care sites should have defined transfer protocols for children and young people. This should be based on the ‘one-stop’ principle and should also include arrangements for transferring children and families back home

• Onward care should be clearly identified for potential self-harm patients

• All emergency care contacts by children and young people must be documented and notified to the relevant primary care team. This is an important concept due to changes in the way services are being provided (e.g. introduction of NHS 24, increasing role of paramedics)

• All emergency care providers must be able to identify repeat attendance by children and young people.

**Key Messages**

• There is broad support for the report

Main issues from consultation:

• Implementation in rural areas

• Availability of resources for implementation

• Need to invest in IT

• Development of education and training framework is essential

• Development of workforce fit for the future.
MAIN POINTS FROM GROUP DISCUSSION

• Sixty to seventy per cent of those children who present for emergency care are trauma patients, many with minor injuries. Most are managed locally and that should remain the case. What is needed is an adaptable workforce that can manage the changing trends in disease and ill health.

• In remote and rural areas, practitioners providing emergency cover (including GPs, nurses, paramedics, AHPs etc) need to have a high level of skills to be able to manage the situations they might encounter. Practitioners need to decide at what level they will be practising and identify the standards that apply to that level, then acquire the knowledge and skills required and implement appropriate services. Educational support will be required to ensure that skill levels are maintained in areas where these skills are used infrequently due to the small number of cases seen.

• How do you capture the intuitive aspects of care, that is, the understanding of families GPs develop over several years?

• An overarching structure is required that identifies what levels of emergency care is required, who will provide it and ensures that they have the necessary skills and training to meet the needs of the population they serve (e.g. standardised assessment tool). The aim is that regardless of who provides the care, the outcome is the same. NHS QIS may be the body to drive the standards for this forward.

• There are problems with transport to and from out-of-hours centres. In extreme cases, parents have been found walking the streets in the middle of the night having been discharged from care without the means to get home. Contingency plans are required for when families cannot plan transport, and this needs to take into account the condition of the child who may have a limb in plaster or be in severe pain.

• NHS 24 probably needs to adapt some of its processes to meet the needs of paediatric emergency care (e.g. revising the distances it recommends people to travel to find services).

• The three children's hospitals in Scotland could be more flexible in employing nurses. Currently the vast majority of staff are RSCN's. Training needs to be developed to allow RGN's to work with children. This could be modular based.

• There is a need to 'join up' all workforce planning for paediatric care and all staff groups. We need to know what numbers of staff will be needed in the future with what skills. Modular based training will be important in training the future workforce. More training in ambulatory care is needed. Also need to decide how to support the workforce when planning service change. NHS Education is involved in this process. One model would be to have a common emergency paediatric care element in the training of all specialist groups (e.g., respiratory or neurology specialists). More information regarding the education and training that is available for the different professional groups needs to be shared more widely. There may be opportunities for different staff groups to undertake training together (e.g. for asthma care).

• Career pathways need to be defined more clearly (e.g. from staff nurse to nurse consultant), although there are clearly budget implications around the issue of staff development.

• The incidence of true critical illness is very low (e.g. around 1 in 10,000 in population of under-13s for meningococcal meningitis). This creates certain problems, for example, how can we be sure a nurse in a minor injuries unit would pick up the subtle early indications of a potentially critical condition that a consultant might even miss? The key is to manage the known risk and ensure that staff have access to expert advice from paediatric specialists. Face-to-face triaging may pick up more clues than a telephone-based system. The best telephone systems involve
direct access for callers to health professionals, not through call handlers who have no healthcare knowledge. A range of flexible services is required to provide equality of access; for example, not every household has easy access to a telephone, and some families may not be able to communicate effectively the real nature of their problem.

• Scarce resources need to be used wisely; for example, do you have GPs visiting children at home or bring the children in to the GP by paying for taxis if required?

• The ‘ideal scenario’: multidisciplinary teams in primary care centres (e.g. GP surgeries, minor injuries units) staffed by a mix of staff (GPs, nurses, AHPs etc) with the range of skills needed to cope with a wide range of presenting problems.

• There is a tension between providing care as locally as possible and having the critical mass of patients to maintain skills and services. Public expectation needs to be managed: we cannot do everything in the way we would ideally want to. We need to identify people who can say ‘I don’t know this but I know someone who does’. We need to identify the correct outcomes and recognise that there will be different ways of getting there in different areas.

• The definition of emergency care needs to be clarified: might be ‘the spectrum of unscheduled care’. We need to increase the opportunities people have to access this spectrum of unscheduled care. There may be a key role for primary care in collating all the information about resources and services.

• Common IT systems are required with basic information about children’s health in all categories

• The threshold between primary care and access to services for children with complex needs should be agreed. This should involve social services and education professionals because health cannot be seen in isolation.

• The role of pharmacists needs to be clarified. They are often the first point of contact for families in the community.

**Key points**

• Importance of education and training, including competency framework for emergency care of children, that is multidimensional to capture the degree of specialisation required by professionals operating at different levels in different areas who see varying numbers of children requiring emergency care (e.g. urban areas, remote and rural areas)

• Importance of standard response to ensure children and young people and their families receive consistent advice and treatment across the country

• Importance of linking workforce planning for all professions

• Developing the role of NHS 24 in supporting emergency care for children

• How to identify the needs of and support vulnerable families who require emergency care

• Managing the level of risk to balance incidence of critical illness with the majority of emergency care which can be treated locally
2.3 PRIMARY & SECONDARY CARE FOR CHILDREN

BACKGROUND INFORMATION

Current drivers for change in primary care

- Implementation of GMS Contract
- Creation of Community Health Partnerships (CHPs)
- Production of Integrated Children Services Plans
- Implementation of Health for all Children (Hall 4)

Issues Raised

- There is concern that the new GMS contract has no specific child health content, reinforcing the perception that child health is a low priority, and risking a true drift in GP motivation to provide optimal preventive and therapeutic efforts.
- There is evidence of some rearrangements in the organisation of out-of-hours care in some areas and some beneficial physical fusion in staffing of GP out-of-hours centres with A&E services.
- Some NHS Boards have expressed the view that the shift to public health nursing had resulted in a reduction in health visitors’ work with individual families.
- There is a general lack of resources to implement significant change in primary care for child services.

Potential solutions

- NHS Boards should take the opportunity of the new out-of-hours GMS contract arrangements to co-locate local GP and A&E services into a single functional unit, with opportunities for walk-in patients to be triaged to GP care and reciprocal partnership working for appropriate emergencies.
- A new role as GP with a special interest in child health should be developed. This role should have a formal link with acute paediatric clinicians and include running hospital outpatient clinics.
- The lessons from Starting Well, the Child Health Demonstration project, should assist Boards in planning for implementation of Hall 4.
- There should be a focus on child health in CHPs based on guidance in the additional advice note on promoting child health.

MAIN POINTS FROM GROUP DISCUSSION

Key points

- Important to maintain generalist paediatric role right across the spectrum of primary care.
- The role of community paediatric nurses particularly in the care of children with complex needs.
- Importance of training for GPs, district nurses and others in aspects of paediatric care and of providing these staff groups with information about resources and services that are available.
- Competencies, education and training.
- Need to assess the role and competencies required of staff in NHS 24 in relation to paediatric care.
- Role of GPs with a special interest in paediatrics in Community Health Partnerships. This should include a link to hospital services so that GPWSI can act as support for other staff in primary care and as a means of helping the GPWSI to feel part of the paediatric team.
- Proactive role for primary care services in relation to vulnerable children, linking in with local authority services and devising ways of making services more accessible.
- Specific role for primary care in relation to the care of teenagers, in particular to improve access to services.
- Range of care provided by out-of-hours services.
- Skill mix.
HEALTH SERVICES FOR CHILDREN AND YOUNG PEOPLE IN SCOTLAND

SUMMARY REPORT FROM A CONSULTATIVE SEMINAR ON THE INITIAL FINDINGS ON CHILD HEALTH FOR THE NATIONAL FRAMEWORK FOR SERVICE CHANGE IN THE NHS

WEDNESDAY 12 JANUARY 2005

INTRODUCTION

Malcolm Wright
Chair, Child Health Support Group/Chief Executive, NHS Education for Scotland

This is an extremely important event for paediatric services in Scotland. We are at a critical stage in a number of significant pieces of work that have been in progress over the last 12-18 months and which are coming to fruition at around the same time.

One of the main purposes of this seminar is to inform the conclusions and recommendations of the National Framework for Service Change, an extensive review of the NHS being undertaken by Professor David Kerr, Rhodes Professor of Cancer Therapeutics and Clinical Pharmacology at Oxford University. The aim of the review is find ways of better planning and delivering services for people in Scotland in the longer term.

The review involves 11 areas of work, each of which is chaired by a member of the advisory group and has a project lead appointed from the Scottish Executive Health Department. The work draws on experts from across the health and social care systems and their partner organisations such as voluntary agencies.

Child health features strongly in the review. It occupies two of the 11 areas of work, which are; child health across primary, community and secondary settings; and specialised paediatric services, and Professor George Youngson’s work around specialist paediatric services has been important to this area of work and should be influential in helping to refine the recommendations in the National Framework review. Both areas of work are chaired by Peter Bates, Director of Health Service Delivery (Acting) and Chair, NHS Tayside Board.

Child health is also a significant feature of several other of the areas of work including: neurosciences and highly specialised care; care in local settings in conjunction with the Scottish complex needs group.

The purpose of this seminar is to test out some of the thinking and recommendations coming out of that work. It should be stressed that the reports have not been written yet and this is an opportunity for the child health community in Scotland to make known what are the main recommendations that we would like to see emerging in the final reports.

Two other important developments for paediatric services are the imminent appointment of a clinical lead for child health which signals the importance attached to the child health care clinical community, and the commitment by NHS Education for Scotland to devise an educational framework to underpin child health services.
SPECIALIST PAEDIATRIC SERVICES

INITIAL FINDINGS FOR THE NATIONAL FRAMEWORK FOR SERVICE CHANGE IN THE NHS IN SCOTLAND

Professor Stewart Forsyth
Vice Chair, Child Health Support Group/Clinical Group Director
Women and Children’s Services
NHS Tayside

Specialist Services - Why Change?

The need for change arose out of a number of pressures that have been building up in these services over the past few years. These include:

• New technologies and therapies
• Expectations of users and providers
• Tend to be expensive
• Scarce skills and expertise
• Quality and safety assurance
• Vulnerability of services
• Changes in provision of paediatric services
• Interdependencies between specialised and secondary care
• Fragmented approach to planning and investment in services.

Underpinning principles

The action team adopted three underpinning principles in its action plan, which are that:

• Scotland’s geography requires a distributed pattern of service that can be accessed by children both close to and remote from major centres
• Specialist services should be provided locally if clinically safe and sustainable
• Specialist services are one component of the continuum of care for children.

Information and consultation

The Action Team has met five times. It has considered previous work in this area and current policy initiatives, including the Children’s NSFs in England and Wales, as well as the current policy documents in Scotland. Video-conference sessions have been held in each Health Board to engage as widely as possible with health professionals across Scotland. The report of the Review of Tertiary Services for Children in Scotland was presented to the group and accepted. This seminar is another element in the consultation process.

The action team made the assumption that specialist paediatric services include:

• Intensive care
• Rare conditions
• Complex common conditions
• Complex technology
• Conditions causing concern at secondary level.

Services should be age and clinical condition sensitive. The action team wanted to be clear about what age range it was considering. The NSF for England considers children to be under the age of 19 years, and for Wales under 18 years. In some areas of Scotland there is an age limit of 13-14 years, particularly in the acute sector.
The action team decided that the following should be adopted as guiding principles:

- Children and young people up to the age of 16 should be admitted to the paediatric environment
- Children and young people between 16 and 18 years of age should be given a choice on where they wish to be admitted
- Clinical condition should be considered as a factor
- Transition between paediatric and adult services should be managed more effectively than currently the case
- Services and environments that meet the needs of adolescents should be made available
- Paediatric services should be co-located with adult, maternity and neonatal services.

Critical factors for effective specialist services

- Relationships between specialist and local services
- Availability of high dependency and intensive care
- Workforce requirements
- Transport
- Information technology
- Support for families.

Relationships between specialist and local services

- Clinical arrangements should include
  - referral routes
  - protocols of care
  - shared care
  - discharge and repatriation
  - outreach and inreach services
  - support for training and skills transfer from tertiary services to the local area
  - a number of the components of these services could be enhanced if developed within the framework of national MCN development.

The action team has made a number of statements in relation to care of the critically ill child, high dependency care, paediatric intensive care and neonatal surgical intensive care.

The critically ill child

- All hospitals admitting children who are, or who may become, critically ill must be able to provide appropriate resuscitation and stabilisation
- Hospitals providing a range of specialised in-patient services for children should have high dependency support available.

High dependency care

- High dependency care units are currently available in Aberdeen, Dundee, Edinburgh and Glasgow and these should be retained
- High dependency care is also provided in most paediatric in-patient units, although information on total high dependency activity not available.
- An audit to ascertain level and quality of high dependency care in Scotland is to be undertaken

Paediatric intensive care

- Significant improvements in clinical outcomes have been achieved by focussing PICU on two sites in Scotland (previously there were 14)
- There is no evidence indicating that further improvements would be expected if all PICU was centralised in Glasgow
• Centralisation of PICU would require the withdrawal of a range of other highly specialised services from Edinburgh.

**Neonatal surgical intensive care**

• Neonatal surgical intensive care is currently provided in Aberdeen, Edinburgh and Glasgow
• The retention of neonatal surgical intensive care in these locations is considered to be both necessary and sustainable.

Features of the model of care proposed by the action group include:

• A single service delivered across a number of sites using a network approach at national, regional and local level, in an effort to address the current fragmented nature of service provision
• The service should be planned and delivered collaboratively at national, regional and local level across the pathway of care
• Standards set for each stage of the pathway
• Strategic clinical and managerial leadership
• High quality care based on evidence, audit and consistent information
• A Scotland-wide overview of investment in staff, equipment and infrastructure.

**National issues**

These include:

• Configuration of services
• Workforce planning and development
• Clinical standards development
• Information management
• Performance management.

**CHILD HEALTH SERVICES**

**INITIAL FINDINGS FOR THE NATIONAL FRAMEWORK FOR SERVICE CHANGE IN THE NHS IN SCOTLAND FROM THE CHILD HEALTH SUPPORT GROUP**

Dr Linda de Caestecker  
Women and Children’s Unit  
Scottish Executive Health Department

Dr Jack Beattie  
Consultant Paediatrician  
Yorkhill Operating Division

The Child Health Support Group was asked to look in particular at secondary paediatric care but also sought information on primary care and child protection as well as other service areas such as mental health.

**Methodology**

The group reviewed some of the existing work of the Child Health Support Group, such as the review of emergency care, report on paediatric tertiary services (Professor Youngson’s work), the framework for child and adolescent mental health, and the development of health for all children. Data on paediatric activity provided and analysed by ISD was also considered.
The aim was to make the process as inclusive as possible to take advantage of the vast pool of experience and ideas that exist in Scotland, so a range of data collection methods was used:

- Questionnaires were sent to each NHS Board asking about service provision, service availability, potential solutions and examples of good practice
- Co-ordinated by the child health commissioner in each health board area, a range of clinicians and managers were interviewed by video link to gain more detail on these subjects at a local level. Also involved were some of the voluntary organisations such as Action for Sick Children and Children in Scotland
- Further interviews with professional groups and individuals
- Review of existing reports and literature
- Data analysis

This seminar is another part of the consultation process.

**Key themes**

The majority of care takes place at the primary care level with a small amount of care delivered by specialist services. The primary care level overlaps with secondary care through community child health and school health. Specialist care is provided in one or more of the four children’s hospitals. There is also a small amount of supra-regional care that is provided outside Scotland.

We need planning processes that match this model with national, regional and local planning. Developing MCN’s, common protocols, standards, patient pathways, and systems of training and continuing professional development will help to draw these levels into an integrated service.

Regional planning would help to improve existing services and increase the degree of integration between the specialist centres and DGHs as well as helping to increase the number of services (e.g., general surgery for children) that are available at local level. Regional planning would also provide a more coherent approach to ambulatory care.

This model assumes that the regional planning groups will come together to undertake this national planning. The Community Health Partnerships are seen as the main NHS vehicle for achieving the integration of child health services with local authority services.

The group also came to the view that the Child Health Support Group should review its role and membership to have a more effective relationship with the regional planning groups and with the boards, to ensure that the priorities of these groups are fed into the work of the Child Health Support Group.

Key issues relating to the ways in which professionals work include:

- The sustainability of services in DGHs and the benefits of establishing links between DGHs and specialist centres
- The role of MCN’s
- Development of roles.

The group anticipates different ways of working being developed – already we are seeing a blurring of the traditional boundaries between DGHs and tertiary centres and primary care and these may well be wiped out in the future. We will be working in a framework setting, both locally and nationally, and our roles will change, based on current trends in professional development.

Regional planning is a major issue, and some of the restrictions imposed in the past by health boards tending to work in isolation have to be removed to offer better care for children. Ambulatory care is also a key feature of services that needs to be developed further in the future.
We need to recognise that there are special needs for special groups, for example, in mental health where the different kinds of children’s illnesses need to be tackled specifically. Also, children’s needs in different age groups, from toddlers to teenagers, vary and so the services they require are different.

**Principles**

Certain key principles underpin the initial findings and recommendations from the group. These are:

- Care should be provided as close to home as possible. This is probably the most important principle and is the key to the future of paediatric care. Developing such local care is everybody’s problem, not just for GPs and primary care services
- Equality of access regardless of geography
- Services planned and provided in partnership with children and families
- Care in environment appropriate to developmental stage
- Ongoing training and specialist support critical to sustaining local services
- New ways of working and technologies should be optimally used and are fundamental to progress in the future
- Standards and monitoring must underpin service delivery
- Integrated care should be delivered across traditional professional and service (social work/education) boundaries.

**Planning model**

The Scottish Executive Health Department:

- Sets the policy context and agenda for child health
- Supports inter-regional planning
- Monitors progress in implementing policy
- Performance management of regions

Three national planning groups working together on a national basis to:

- Carry out national planning and commissioning for specialist paediatric services, taking into account national policy, priorities and Child Health Support Group advice
- Agree a work plan of Child Health Support Group and reviewing outputs.

Three regional planning groups working together on a national basis to:

- Carry out national planning and commissioning for specialist paediatric services, taking into account national policy, priorities and Child Health Support Group advice
- Agree a work plan of Child Health Support Group and reviewing outputs.

Three regional planning groups carry out regional planning of general and sub-speciality paediatric services and feed into the work taking place at national level.

The Child Health Support Group supports activity at all these levels.

Local planning is linked to children’s services planning (at NHS Board and CHP level)
Initial recommendations

District General Hospitals

- Regional planning: three regional planning groups
- Sustaining/ developing DGH paediatrics
  - Minimise inpatient split-site working. One of the major challenges raised in all of the consultations carried out by the group was that of split-site working for consultants. The group recognises the restriction on development that that poses. Regional planning groups should work towards eliminating split-site working as far as possible
  - Regional or joint appointments can be used to help overcome the uneven spread of skills across health board areas, for example, in diabetes or neurosciences
- Development of ambulatory care – much still needs to be done across the country to develop this, including:
  - Regional plans
  - Out-patient clinics on a range of sites
  - Protocols
  - Good practice national conference on ambulatory care in all its forms to learn lessons from the work already carried out in Scotland and England.
- Specialist centre liaison – service templates are required for
  - Outreach and inreach
  - Shared care
  - Protocols and guidelines
  - Parental support services and facilities
  - Transition
  - Tertiary/secondary clinical forum.
- Retrieval and transport
  - Improve communication
  - Consider needs of remote and rural areas. The group recommends that these areas should have a special arrangement to acknowledge their vulnerability. There is concern in these areas about the ability to maintain children while they are awaiting retrieval – waiting times need to be shortened and advice should be available to maintain children until the retrieval team arrives
  - Two further types of retrieval service required
    - Serious head injury
    - Seriously ill but not requiring ICU (i.e., HDU)
- Importance of transfer back, particularly to remote and rural areas, and perhaps a dedicated co-ordinator is required in DGHs to deal with this issue.
- General surgery and anaesthesia for children. There is serious concern about the sustainability of surgery in DGHs:
  - Regional planning required
  - Standards already developed
  - Workforce needs
  - Involvement of NHS QIS is needed in the monitoring and management of such care outwith tertiary centres
  - National short-life working group is required to report to regional planning groups on how support for surgery for children can be taken forward on a regional basis. In some areas this may mean a single site for all surgery but in many others with greater resources and larger volumes of patients and more expertise, a number of DGHs could provide paediatric surgery in conjunction with a tertiary centre.
- Managed Clinical Networks:
  - NSD and regional commissioning groups
  - 5-year National Strategy (September 2005)
  - National, regional & Health Board level
• Some priority areas were identified:
  - Children with complex needs
  - Child protection (forensic services)
  - Cystic fibrosis.
• IT and telemedicine
  - Continued development across Scotland is needed, based on the Yorkhill model, each children’s centre has a telemedicine service to link it with the other areas
  - Diagnostic imaging services – ‘Move the image, not the child’. A national 24-hour consultant-led radiology service for children may be required integrated to provide acute reporting to minimise the transfer of children just to get a CT scan. The group recognises the resource implications of this but believes it is an important issue
  - CHI-based integrated child health record. The child health information strategy group needs to look in greater detail at the lack of systems to support this.
• Development of roles:
  - The group is aware that the role of the DGH paediatrician is changing and that much care is directed to consultant paediatricians. This trend is likely to continue with the increase in numbers of consultants and this is seen as a benefit because evidence shows us that senior care is better care and chances of admission in these circumstances are lower, of early discharge higher and of inappropriate investigations lower. GPs should have greater access to consultant advice. The group is not suggesting that every child referred to hospital should be discussed with the on-call consultant before admission, but the group is recommending that given the degree in difficulty in decision making in child health there should be much easier access to allow such decisions to be discussed with senior staff, not just in acute care but also for out-patient referrals
  - Paediatric nursing has a major role to play in protecting and maintaining local care and the group suggests that the RCN should take forward a working group and action plan to produce benefits in terms of recruitment, training and maintenance of skills. This particular area needs special attention.
  - Paediatric community nursing – an action plan is required, and support for/liaison with remote areas should be improved
  - DGH paediatricians – they should carry out more direct clinical care, and new appointments should include a community child health component, which may include covering a patch, linkage to a group of GP practices to optimise relationships and minimise inappropriate referrals
  - Advice from senior paediatricians should be directly available to GPs.
• Primary care. The groups recognise the fundamental importance of primary care working in partnership with child health services in hospital. Concern was raised in some areas about the lack of a primary care component in child health planning especially in relation to the new GMS contract. We recommend that:
  - Specific child health targets should be included in the GMS contract
  - Liaison between out-of-hours services and children in A&E should be improved. The contribution of NHS 24 to this is valuable in directing some of that traffic and in particular the special notes facility in relation to vulnerable children
  - GPs with a special interest to act as a resource for colleagues and act as an ‘inreach’ to paediatric services
  - Lessons from Starting Well need to be acted on
  - Development of CHPs in relation to child health, but how this should take place requires clarification.
• Mental health. Concerns were raised about the transfer of children to tertiary centres for examination and the group recommends a telemedicine system to help minimise the number of transfers. Attention to several areas is required:
  - CAMHS at all levels.
  - Service Framework
  - In-patient service
  - Workforce planning and development
Questions for the workshops

- Do you agree with the recommendations?
- Who is responsible for implementing them and in what timescale?
- What are the gaps?
- What further work is required?

EMERGING FINDINGS: ISSUES FOR THE AFTERNOON WORKSHOPS

Dr Zoë Dunhill
Consultant Paediatrician
Clinical Director Children’s Services
NHS Lothian University Hospitals

Main issues

- Emergency care at all levels
- Care of young people according to their needs
- Specialist services for children report: Chair Professor Youngson
- Coherent workforce planning across all disciplines (recruitment and retention issues, the Temple report)
- Need for consistent agreed quality standards relating to the child's and family's journey through care (emergency or routine)
- The child's and family's experience of care should influence how care is organised and the geography of Scotland presents particular challenges in relation to this.
- Enhanced work needed to consult families, children and young people. There is also a need to improve the way in which we capture the child's and family's experiences and incorporate them into care. This needs to be carried out with local authority colleagues
- Proposal to adopt standards in Scotland equivalent to those published as part of the English Welsh NSF for Children documents, particularly in relation to the patient journey for care of asthma and of autism. Dr Kate McKay has been appointed to work with NHS QIS on patient journey standards.

Emergency care for children

- Child Health Support Group visits identified this as an issue
- Report published by Child Health Support Group for consultation November 2004 (Chair Dr Tom Beattie)
- Links to unscheduled care group of National Framework
- Summary of recommendations and consultation responses
  - Report welcomed
  - Specific issues raised for care of children in remote and rural areas
  - Concern about availability of resources (human, e.g., trained paediatric nurses, and financial)
  - Need to invest in IT
  - Developing and retaining the workforce
  - Education and training framework required to underpin process.

Care of teenagers

- Paediatric services to care for young people up to age 16 years. There may be specific issues relating to substance misuse and gynaecology and obstetric services which need to be
considered

• NHS Boards to review provision for young people up to age 18 years
• Need for universal appropriate transition arrangements (cf best practice in Scotland, e.g., cystic fibrosis, diabetes)
• Designated staff at regional planning level are needed to improve transition arrangements through service redesign and ensuring developmental-stage-appropriate care is provided.

Specialist services

• Need to ensure that patients can move between primary, secondary and tertiary care
• Investment required in IT
• Workforce pressures issues highlighted as major factor
• Services should be planned and provided on national, regional, and local basis
• Retain all four children's hospitals
• Regional plans for secondary paediatrics likely to lead to fewer DGHs providing paediatrics
• Development of ambulatory care models
• Improved liaison between specialist centres and DGHs.

Managed clinical networks

• Need to build on the work of existing strong MCN’s (e.g., CLEFTSIS and the developing MCN for epilepsy)
• Need to support and establish MCN’s in children's services according to consistent standards
• Clear links between regional and national MCN’s are required.
• The recommendations for MCN’s in the Tertiary Services report (Prof. Youngson) should be accepted
• Increased patient involvement in MCN’s
• NSD & Regional Commissioning groups.
  - Five-year National Strategy (September 2005)
  - National, regional and Health Board level
• Some priority areas identified
  - Children with complex needs
  - Child protection (forensic services)
  - Cystic fibrosis.

Workforce planning

• Need to understand first the model of care and design of services. We need a clear understanding of how care is going to evolve to 2020 so that workforce planning can be carried out in a sensible way
• Impact of MMC across disciplines driving models of care
• NHS Boards and regional planning groups should develop posts and training based on service needs.
• New roles. We need to ensure that the correct education and training is in place to allow nursing and AHP colleagues to take on some of the work carried out by doctors safely and effectively, where that is appropriate
• Issues relating to geography, demography and recruitment and retention of staff (potential solutions include increased use of joint appointments across health board areas).

Questions for the workshops

• Workshop facilitators will provide more in-depth analysis on issues
• Are there any gaps?
• What are the three to six action points that should feature in the National Framework report?
• Take the opportunity to influence decisions that will affect you.
CHILDREN WITH COMPLEX NEEDS: INITIAL FINDINGS FROM THE CARE IN LOCAL SETTINGS SUB-GROUP

Dr Patricia D. Jackson  
Chair of Scottish Complex Needs Group  
Consultant Paediatrician  
NHS Lothian

The group gathered its information in discussions with a wide range of professionals in, for example, primary care and community colleagues, neurodisability, pain management. Inter-agency collaboration is essential to meeting the needs of this group of children. Most parents and children want to be like others and have their needs met by local services but, because these children have diverse, unusual and sometimes difficult to manage problems, primary care colleagues will not necessarily see many of these children in their working career. In order to facilitate local care there needs to be a network of appropriate specialist support that is readily accessible to them.

The group primarily focused on the physical health needs of children, but there are children with complex needs who fit into the learning disability, psychiatric and challenging behaviour sector and it is to be hoped that these needs would be dealt with in collaboration with the CAMHS team.

Definition

- Complex needs require multi-professional interventions and support, such that no one agency or discipline has a monopoly
- Children have severe or profound impairment in at least three of the following areas:
  - Motor
  - Speech and language
  - Vision
  - Hearing
  - Cognitive ability
  - Behaviour
  - Additional chronic health needs

PLUS

- Need for at least two additional resources
- Therapy services
- Additional nursing care needs
- Additional educational resources
- Additional social care resources
- Mental health services.

Needs are sustained for more than six months and are ongoing.

In practical terms, the child we are talking about could be, for example, a boy with inherited neurodegenerative disorder who has a younger brother who is also affected. He may have another unaffected sibling. The boy is fed via gastrostomy, asthmatic and has severe spasticity and nocturnal spasms. He has a Baclofen pump for symptom control, managed by the neurology team. Services involved in his care include palliative care team and pain team link, and tissue viability nurse. He has changing equipment needs and is due to transfer to adult services.

It is clear that the number of services involved, the number of clinics this boy has to attend and the amount of information coming into the primary care team is really extreme. We need to
examine how we support local services to absorb information and also to cater at a local level for components of the care that they can manage.

This boy is out in the community living a life: for example, he attends school and he does a particular type of dirt-track wheelchair racing that requires regular equipment changes.

The illustration may equally be a young person with muscular dystrophy, or a young child to be discharged from hospital due to severe cerebral palsy and ventilation difficulties, or a child with intractable epilepsy. The group agreed that it is the particular management issues and specialist needs that are different and the complexity that is the same in these examples – the complexity is the common thread, not the diagnostic label.

**Number of children with complex needs in Scotland**

- An estimated 7,200 children in Scotland meet the definition of children with complex needs (accurate figures are not available in Scotland and the estimate is based on estimates from other countries)
- 3,321 of these children are registered on the special needs system
- The proportion of children with complex needs using combinations of services:
  - 2 services 27%
  - 3 services 35%
  - 4 services 28%
  - 5 services 9%
  - 6 services 1%

**Model of care**

The group concluded that it would be useful to develop a model of care approach. The model recognises that there would be larger groups within the complex needs grouping that have add-on particular protocols that would be used on a regular basis such as for children with ventilation needs or muscular dystrophy – there might be sufficient children to require a specific protocol to be developed relating to them. Central to the model is the aim of making sure that children can be discharged from the neonatal unit or paediatric care unit or wherever they have started their journey because of their illness. Planning can then be carried out in collaboration with the local team, identifying what type of specialist support is required.

The model is dependant on a key worker being closely involved in the care co-ordination and discharge planning. The child is at the centre of the model, there is a mechanism for planning the discharge and there is a key person responsible for implementing the plan and linking things together. Assessments in the process should not duplicate the work of other people involved in the process – the ideal is a unified, integrated assessment and this should feed into the special needs system assessment and co-ordinated support plan for education for supporting children in the school environment.

**Principles**

- Child and family centred:
  - Children with complex needs are first and foremost children
  - Children and families will be fully involved in planning and influencing the provision of care; services should not happen to you, they are something you need and you should able to decide for yourself
- Offer choice:
  - Boards should be able to offer services and/or direct payments to families (to enable families to buy in support themselves) in line with the current legislation within local authority services
- Integrated and co-ordinated services:
  - Support children in using general and local services wherever possible
- Co-ordinated across health, local authority and voluntary sector providers by key worker
- Identify a named paediatrician who will co-ordinate secondary and tertiary health services

- Integrated planning systems and timely decision making:
  - Share appropriate information (with consent) in order to ensure greater co-ordination of care and improved quality of services
  - Timely decisions to be made about the funding of packages of care and the provision of equipment – the life of some of these children can be short, so it is pointless saying this is what you need and you might get it in six months. This will depend on how quickly we can move information across the services as well as between the health, social services and education sectors

**Care co-ordination and key worker services for disabled children in the UK**

- Key working: ‘Parents want a single point of contact with services and an effective, named person to get what they need for their child in terms of services’

(From report on a questionnaire sent to 225 local authorities in the UK by Veronica Greco, Patricia Sloper and Katy Barton, Social Policy Research Unit, York University. January 2004)

**What is a key worker?**

It is important to stress that the key worker is somebody who co-ordinates but not necessarily delivers care. It is a role for which people need to be trained; it is not a role that people just ‘drop into’. The role is appreciated by parents and by other professionals because it reduces the amount of time they have to spend co-ordinating rather than delivering services.

The York study (Greco et al) demonstrated that in areas where key working and care co-ordination is adopted it does result in reductions in professionals’ time being spent on such issues and improved experiences of parents of the system.

A key worker is a named person whom the family can approach for advice about, and practical help with any problem related to the disabled child.

The key worker has responsibility for collaborating with professionals from their own and other services to ensure access to, co-ordination of and delivery of services from different agencies.

Key workers may be designated, that is, key working is their job (17% of key workers are in this category), or non-designated, that is, fulfil the role in conjunction with another role (e.g., therapist, paediatrician, nurse) (73%). Non-designated key workers need to be careful about the caseload they accept and there are various specifications for that.

**Some of the secondary and tertiary health services supporting children with complex needs**

- Neurologist
- Pain management specialist
- Home ventilation service
- Respiratory physician
- Palliative care specialist
- Physiotherapist
- Paediatrician with an interest in children with complex needs
- Speech and language therapist
- Community nurses
- Epilepsy liaison nurse
- Plus primary care, education, social work, the voluntary sector.
Advantages of Neuro-disability and Complex Care Network

The establishment of a Neuro-disability and Complex Care Network would provide the opportunity to share knowledge and seek advice so that we are not 'reinventing the wheel' every time to do something – somebody else may already have designed a management system for a child with similar needs to someone we are caring for.

Specific advantages would include:

- Development of integrated pathways and protocols for treatment of specific types and groups of conditions
- Further development of national standards for provision of services and packages of care
- Examination of the options for more outreach services
- Examination of the options for more combined/shared clinics, for example, in muscular dystrophy with the combination of respiratory and musculoskeletal and orthopaedic specialists
- Integration and joint working at secondary and tertiary levels to support delivery of more care in local settings via primary healthcare team.

Funding

- ‘Decision making around funding was perceived to be a difficult area as was obtaining clarity about budgets across all agencies concerned. There was a lack of control and flexibility around the sums of money provided. The funding available was unpredictable and it was not always clear where the source of funding was, or indeed where the actual sources of funding should be’ (Perth Consensus conference Jan 2004)
- A joint health and local authority funding mechanism in each board is essential to addressing these issues

Key recommendations

- Introduction of key worker who works across agencies to co-ordinate services for children and their families
- Neuro-disability and Complex Care Network
  - To join up secondary and tertiary services and so make it easier to provide local services
  - To evaluate and develop effective and efficient ways of working and providing service
  - Joint funding streams

It’s all about being included: How difficult can that be?

‘Always have an obsessional on the team’ – someone who can think about all the things that could go wrong and planning for them

Think about, for example, a child of school age with hyperventilation syndrome and a degree of learning disability. Below is the range of aspects of the child’s life that had to be planned for and services involved in the planning and delivery of care to get the child home from hospital:

- Ventilation planning: Specialist respiratory support team
- Therapy provision: SALT, OT, Physio, Dietician
- Equipment provision: Joint equipment store (hopefully)
Child Healthcare Services in Scotland

• Housing/heating Local authority and/or housing association
• Primary health care Primary care/CHP colleagues
• Acute care provision Tertiary and DGH support
• Education provision Local authority education department
• Leisure activity, family breaks, Social work and voluntary agency
  parental and sibling support

If effective care co-ordination takes place, primary care colleagues will have a knowledge of what they need to do and how to handle certain situations, for example, if the child has a chest infection at what stage is hospital admission necessary and if yes, is that via A&E or direct to the HDU/PICU? Or would the same therapy team caring for the child at home be able to link through to the hospital? Or who to contact if the ventilator broke down at school?

WORKSHOPS

GENERAL SURGERY & ANAESTHESIA FOR CHILDREN IN DGHs

BACKGROUND INFORMATION

General Surgery for Children

Current provision

• Shrinking workforce
• Leapfrogging of local services
• Deskilling in DGHs
• Withdrawal of local services

Reasons for current situation

• Few have expressed an interest in paediatric surgery as a career
• There is a mismatch between trainees’ aspirations and service needs
• Occasional surgical or anaesthetic practice and governance issues.

Current activity of adult general surgeons

• There are 77 members of the ABGI in Scotland, 43 of whom do not operate on children
• The majority of adult surgeons treating children are located in DGHs (around 21%) with far smaller numbers located in universities (around 7%) and remote and rural areas (5%)
• The majority carry out fewer than ten operations per year (either elective or emergency procedures) with 5% or fewer carrying out between ten and 20 procedures, 20-30, or more than 30
• Furthermore, nearly 25% of the current surgical workforce say that their successor will not carry out paediatric surgery (only around 7.5% say their successor will).

SPR’s Sub-specialty training in general surgery: Scotland

• General(l-3) 39
• Upper GI/Laparoscopic 13
• Lower GI 12
• Hepato-biliary/transplant 2
Child Healthcare Services in Scotland

Appendix 6

- Vascular 10
- Breast 6
- Renal transplant 1
- Paediatric 0
- Endocrine 0

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Implications of Change

Children's Hospitals: DGHs:

- Capacity
- Strain on transport services
- Access to specialist
- Dilution of index cases for specialists and common general surgical

- Travel for assessment rather than treatment
- Delay in treatment
- Family disruption
- Loss of golden hour
- Potentially poorer care of acute surgical

Potential solutions

- Direct trainees/remodel training
- Better outreach care for elective conditions
- More consultants/collaboration
- Tele-assessment
- Creation of consortia for emergencies with 'nodes' for local care of acute and common conditions. May be based on three regions. The model would need to eliminate 'competitiveness'
- Dedicated transport system
- Newer and bigger children and young people's hospitals.

MAIN POINTS FROM GROUP DISCUSSION

- The level of anaesthetic provision and surgical and radiological skills and expertise varies across the country – the required level may not be available locally
- There is a range of views in the profession, from ‘children’s surgery has to be carried out by paediatric surgeons’ to ‘children’s surgery may be carried out by general surgeons with an interest in children’
- It is vital that DGHs maintain the resources and level of skills for sick children, therefore, professionals working in anaesthetic departments must maintain competence by working on children’s lists
- There is a real problem in attracting general surgeons into paediatrics – some feel it is ‘not glamorous’
- Population spread – in urban areas patients can travel to a main centre. In, for example, Grampian the population is more widespread and many are more remote from a main centre: 130,000 people face more than 90 minutes travelling time before they reach hospital
- Patient assessment and the post-operative period could both happen locally, but the ‘procedure’ may well need to take place in a main centre. In Ayrshire, for example, patients and their families want routine procedures carried out locally, but are willing to travel for more complex interventions.
• In the future the job plans of paediatric surgeons may have to include substantial travelling time (for example, in the case of the Lothian/Tayside joint appointment)
• It is recognised that complex cases, children under three years of age and neonates should be treated by paediatric surgeons, but, for example, in the west coast large population bases are self-contained
• There should be clear rules about the age boundary. Any decisions must be guided by anaesthetists, although there are differing views among the anaesthetic profession about whether or not an ‘age rule’ is necessary. There appear to be concerns relating to governance in some areas.
• No general surgical trainees are completing higher specialist training
• A potential ‘meltdown’ in paediatric surgical care is threatened because there are no successors to the current surgeons – trainees can dictate what they want to do and it is not currently paediatric surgery
• A survey of surgeons showed that those treating children are in the 50-55+ years age bracket and so are nearing retirement
• A large majority of surgeons who operate on children are demonstrating occasional practice in the ‘routine’ procedures
• Issues for sub-specialties:
  - Experts can be located somewhere other than in the paediatric unit
  - Sub-specialists also need to organise regional networks to accommodate children.

FEEDBACK FROM WORKSHOP

• Regional service delivery needs to flow from proactive planning and requires some ring-fenced funding
• We should have a national policy framework, delivered regionally, adapted into solutions to meet local needs
• It is important to build on existing models of effective practice such as the Lothian/Tayside or Yorkhill/Wishaw models
• A clear statement is needed that care should be delivered locally to ensure surgeons are encouraged to take up posts at DGHs
• A short-life working group is needed to define standards and make recommendations about joint appointments. The group may need to include ENT, orthopaedic, plastics, anaesthetic and NSD representation
• The principle that care must be delivered locally should always be applied
• It is unlikely that DGHs will be able to sustain emergency care other than resuscitation for children, but further work is required.

NATIONAL PLANNING AND COMMISSIONING OF HIGHLY SPECIALISED CHILDREN’S SERVICES

BACKGROUND INFORMATION

Findings from work to date

• Individual boards working to own agenda
• Lack of joined up service or workforce planning
• Comparable data and information hard to come by
• Funding mechanisms do not always support activity flows.

Philosophy for future

• Raise the profile of children’s services
• Single-service for children in Scotland, provided on a number of sites which maintains local access, provides consistency and equity of care based on protocols/pathways, and makes best use of scarce specialist resources.
Policy context

- Integrated Children's Services Planning 2005-2008: Guidance
- For Scotland's Children: Changing Children's Services Fund
- Regional Planning - HDL (2004) 46
- Establishment of Community Health Partnerships

Regional planning

- While regional planning has been around for some time, progress inconsistent across three groups (North, West and South East)
- Used to plan regional services - now planning services for region
- DGH sustainability seen as key issue
- Some successes to date
- New HDL - raising the profile and expectations.

Examples of successes

- Neonatal transport
- Cancer MCN's
- CHD developments
- Plastic surgery
- Interventional radiology
- Learning disability MCN.

SEAT - Work in progress

- Vision for region including role of MCN’s
- Regional Workforce Planning - understanding of baseline, implications of pay modernisation and MMC
- Regional contracts?
- Working together to achieve waiting times targets
- Performance management and governance.

Questions for workshop

- How do we bring together services into a single service within the current policy context while maintaining the inter-linkages between specialised and DGH services?
- How do we plan and commission these services?

MAIN POINTS FROM WORKSHOP DISCUSSION

There is a need to develop a coherent planning mechanism and a coherent plan for Child Health Services in Scotland. The planning process needs to be clearly articulated from CHPs through to Health Boards through to Regional Planning Groups through to a new national planning mechanism to be established under the auspices of the Scottish Executive.

There are good examples south of the border where these sorts of issues have been addressed with populations the same size as Scotland. There are mechanisms there that we can learn from.

The remit of Child Health Support Group needs to refocus to move us into the next phase of work as does the membership. There needs to be a strong sense of ownership from Regional Planning Groups and Board Chief Executives and linked in with this there are a number of decisions which need to be taken sooner rather than later around specific services: Haematology, Oncology and
Neurosurgery are cases in point.

There is a need to work through how we ensure that children and young people are able to influence the planning of children's services at all levels. With the establishment of Regional Planning and National Planning in a much more substantive form, there is a danger that, as this moves away from local Health Boards and local communities then the input is more difficult to achieve. There is a stream of work undertaken by Graham Bryce and Children in Scotland can help in this.

The concept of an advocacy programme was discussed and whether this could be utilised as a possible way forward.

There is a strong need to undertake comprehensive workforce planning and workforce development for Child Health Services. This needs to be done on a multi-professional basis at both regional and national level. We need to have a national overview to decide what the workforce needs to look like in the future given the changes in models of care and how to develop that workforce through training and education on a multi-professional basis.

FEEDBACK FROM WORKSHOP

• A coherent system of planning that informs Community Health Partnerships on an inter-agency basis is needed. This should be done at health board level. Specific services that need to be planned at a national level with a national overview, but regional planning also needs to be developed. Chief Executives need to be involved in planning to give a sense of ownership to it. There is also a need to sort out the landscape of the various groups and committees that are meeting right now and having a clearly described coherent system of planning that runs from frontline delivery right through to national planning and co-ordination. A decision-making mechanism about how to deal with the various recommendations being issued in areas such as haematology, oncology and neurosurgery - how do we translate the real service pressures there are in that area into what is going to be done about them and who has the authority to make those kind of decisions?
• We need to involve children and young people in planning. The question is how do we involve them systematically as planning moves further away from local health boards and local communities to regional groups and a national level? What are the modes of advocacy? What other organisations that should be involved to ensure that this happens?
• The workforce needs to be developed and we need to get much cleverer around workforce planning for children's services. There is also a need for national overview – what does the workforce need to look like in the future given the changes in models of care and how do we develop that workforce through training and education? Any training and education should be carried out on a coherent multi-professional basis.

PAEDIATRIC INTENSIVE & HIGH DEPENDENCY CARE

BACKGROUND INFORMATION

High Dependency Care (HDC)

• The foundation for the management of critical illness in children in Scotland is high dependency care
• All hospitals admitting children who are, or who may become, critically ill must be able to resuscitate and stabilise them
• Hence hospitals that plan to provide a range of specialised services for children need high dependency support and the sustainability of tertiary children's services depends on access to HDC
• HDC is defined as a level of care of children whose severity of illness and dependency require
specialised skills and a nurse staffing ratio of 0.5 :1 child. It is also called ‘Level 1’ intensive care
• Can support the provision of a wide range of paediatric services needed by significant numbers
of children. HDC is currently available in the major cities in Scotland
• Information on the total amount of HDC provided is not available and is needed to plan
children’s services – admissions are estimated at 5,000 a year
• The Action Team has therefore initiated an audit to ascertain the level and quality of HDC
provided in Scotland.

PIC and Neonatal Surgical Intensive Care

• There is a spectrum of care for critically ill children from high dependency to highly intensive
care. This is referred to as ‘Levels 2-4’ PIC according to the dependency on nursing support
1:1 to 2:1, and over in rare cases
• Needed in some emergencies and as back up for major surgery and for highly specialised
treatments
• Excludes neonatal medical 1C because care needs are different - NMIC links to maternity care
• Needed only by a few children in Scotland each year - with most needing only level 2 –level 3
and only rare cases needing level 4.

PICU

• Total numbers around 1,000 admissions a year in Scotland.
• Levels 2-3 PIC provided in Edinburgh and Glasgow but not in other cities. Both sites provide
skilled retrieval teams for critically ill and injured children throughout Scotland. Level 4 PIC
(including extra corporeal life support) provided only in Glasgow where all cardiac surgery,
interventional cardiology, renal transplant, interventional fetal medicine and allogenic bone
marrow transplant are provided. Number of admissions each year:
  - Glasgow around 600
  - Edinburgh around 400
• UK comparisons:
  - The PICA Net survey 2001/02, published March 2004, reported on 24 units ranging
from activity of 80 -1,400 cases a year. Both Scottish units are within the middle group of
units - in common with 11 units. Only four units care for more than 1,000 cases a year.

Neonatal Surgical Intensive Care

• Neonatal surgical intensive care is provided in Aberdeen, Edinburgh and Glasgow – around 500
admissions a year. Neonatal transport teams are organised regionally – predominantly for
neonatal medical intensive care.

Initial findings of Action Team:

• Scotland’s geography requires a distributed pattern of service that can be accessed by children
both close to and remote from the major cities
• A central aim of the National Framework is therefore to plan the provision of services close to
home as far as is sustainable and clinically safe to do so.

Pattern of critical care for children

• What pattern would achieve the aim of ensuring the continuing provision of critical care for
children in as many locations as it is clinically effective and sustainable to do so?
MAIN POINTS FROM GROUP DISCUSSION

High dependency care

- Hospitals which have acute receiving facilities should be able to deliver high dependency care (HDC). To achieve this, a set of national standards should be agreed. This may not involve having a designated high dependency unit, but the hospital should have suitably trained staff and sufficient resources to provide HDC to children who need it until they are stabilised for transfer. Skills should include the ability to assess children and make decisions about their care and transfer. The initial assessment is crucial to reduce the number of transfers children experience and so minimise the risks faced. If the initial assessment is carried out by a GP with the knowledge and experience to recognise what care is required and where it is available, then the child is more likely to be sent initially to a hospital with paediatric services.
- Clear guidelines need to be established in relation to where ambulances take seriously ill children. The number of journeys these children have to make should be minimised as they may be extremely vulnerable during travel. Ambulance staff need to be trained to support decision making, or protocols need to be agreed, so that children are taken to the appropriate hospital rather than just the nearest one -- if the nearest hospital does not have the requisite skills and resources, the child will need to be transferred again, increasing the number of journeys experienced in a vulnerable state.
- Resolving these points will require decisions to be made about whether we have a national or regional centres to receive and care for such children.

Paediatric intensive care

- The average number of bed days per case in Scotland is increasing and the case mix seen by units is changing. The different mix of specialties offered in, for example, Yorkhill increases the number of patients being seen each year.
- Who is to decide how many cases a paediatric intensive care unit (PICU) needs to see each year to maintain standards and skills? Education and training of staff is a problem area. Should the units in Glasgow and Edinburgh be seen as a ‘virtual’ single unit, with staff rotating through each one to gain the necessary experience and teaching? This may cause problems with accreditation of units (a problem experienced in England), although paediatric surgeons rotate through three centres. The two units should be seen as complementary. Training programmes should be accredited rather than units and trainees will attend one unit for particular experience (e.g., cardiac care at Yorkhill and neurology and head injury management at RHSC in Edinburgh).
- There is a need to ensure that children are cared for in a PICU and not in an adult unit.

Transport and retrieval:

- Guidelines need to be agreed for the transfer of children between specialities and hospitals, including for those who require specialist treatment but not necessarily intensive care. The number of children who fall into this category needs to be ascertained because that will have important implications for the existing two transport systems. The introduction of the transport systems has been a success and they provide a strong foundation for any future development. The ambulance service needs to be involved at an early stage in planning any strategic changes to the transport systems. Strategies are required, at a national level, to cover transfer of children to hospital and also staff to child (to provide care close to home). Guidelines on transport should include transporting the patient (and family if required) home.
- Patients with a head injury should be seen at a hospital with a CT scanner with a system to allow images to be sent for reporting to appropriately skilled and experienced radiology staff even if that is a different location from that of the scanner. This would help in the decision making process and help to reduce the number of transfers.
- In remote and rural areas, and also in more urban areas where the necessary skills and resources are scarce (e.g., split sites in Lanarkshire), there is often a problem with access to
major centres and not just for intensive care or HDC. Should children from these areas be transferred directly to Edinburgh or Glasgow, or via another local hospital where there is a certain level of expertise?

- If HDC capacity is increased, what would be the effect on the number of patients requiring transfer to a PICU? Potentially, because children would be treated appropriately more quickly with less need for transfer, numbers may drop.

**FEEDBACK FROM WORKSHOP**

- All present agreed with the Action Team’s plan to audit the number of children requiring high dependency care in Scotland
- All hospitals admitting children who are or may become critically ill must have staff suitably trained in resuscitation and stabilisation and must be equipped to deal with children requiring high dependency care
- The workshop members strongly endorsed the ‘one journey concept’. A child should not be taken to the nearest hospital, but should be taken to the hospital that has clinical staff to assess the severity of a child’s illness and to initiate the appropriate management. Examples are children with head injuries. Also, in Lanarkshire, there are three A&E departments but only one of the hospitals has paediatricians and inpatient beds on site. It is therefore logical that a sick child should be taken to the hospital with the paediatric back up and not the nearest A&E unit. This will have to be decided on a region by region basis in conjunction with the Scottish Ambulance Service
- There needs to be a strategic redesign of the Paediatric Retrieval/Transport Service. This requires close dialogue between clinicians and the SAS. Types of transfers to be considered include: intensive care patients; high dependency care patients; and back transfers.

**CARE IN LOCAL SETTINGS FOR CHILDREN WITH COMPLEX NEEDS**

**MAIN POINTS FROM GROUP DISCUSSION**

**Views on key worker**

- Good idea from different agencies
- Talk in language all professions understand
- Funding is a major issue
- Should a child with complex needs have a health key worker only?
- Training for the key worker is essential
- Strengthens the knowledge of agencies to know what is available
- The key worker would be consistent in the child’s life - so is a teacher an appropriate choice for the role?
- Should there be one key worker for co-ordinated support plan and other issues?
- The local area co-ordinator is not the same as a key worker
- Need to establish criteria for the key worker role
- ‘Key has to open doors and fit all the locks’
- High level, joint working/language required
- Children and families report a big difference when they have a key worker.

**Joint funding**

- Health sometimes ‘goes in with’ local authority groups which have no money, so what can they offer?
- Funding often comes in the form of non-recurring monies
- Opportunity – local authority child service plans and health plans should be joined up
- The development of Community Health partnerships (CHPs) may lead to a bottom up approach
- The Scottish Executive should push for joint funding or funding to follow each child
Child Healthcare Services in Scotland  

• Currently difficulties arise for parents/agencies when parents move areas  
• A national budget for funding should be established  
• Sound statistical information is required  
• Regional planning level needs to be developed.

**National network**

• What are the quality standards?  
• There are only a few professionals who are specialised  
• The geographical spread of the network is unequal at present  
• It would be helpful to examine areas of good practice to find out why they work well  
• There are good arguments for a managed clinical network (MCN), but development needs to be bottom up not top down. Also there will be difficulties if local services do not exist – different from other networks  
• Children with complex needs require care strongly based on a multi-agency model  
• The definition of cases needs to be the same across agencies  
• A clear message needs to be sent out about what is entailed and what the key worker will do – this may help attract funding  
• The co-ordinated support plan provides common ground  
• This is not about developing ‘hospital at home’, but how to cope with needs locally  
• An integrated assessment framework is essential  
• Accreditation/requirements not just standards are needed.

**Workforce**

• Can regional planning groups look at the workforce available?  
• Consideration needs to be given to solutions  
• Funding should follow the person for life  
• Funding needs to be flexible over time as needs change  
• Primary care services need to be involved in networks - how can this be achieved?

**FEEDBACK FROM WORKSHOP**

• The concept of the key worker is valuable and should be implemented in Scotland  
• A Neuro-disability and Complex Care Network should be established in Scotland, although it should be fundamentally different from existing MCN structures because it would need to be a multi-agency network involving the wide range of organisations in health, social services and the voluntary sector. Combined with clear standards for care of children with complex needs, this would help to significantly improve access to and quality of care in all areas of the country  
• New ways of funding such care also need to be developed – a national budget based on the individual needs of these children and should follow them into adulthood.

**SPECIALIST SERVICES FOR CHILDREN**

**BACKGROUND INFORMATION**

**MAIN POINTS FROM GROUP DISCUSSION**

*In delivering specialist services what is required to maximise local access?*

The focus should be on standards of care – minimum standards for each area. The safety and quality of service needs to be assured and we should avoid trying to duplicate specialist services/children’s hospitals locally, which is not required. Equity should be to a consistent level of care.
A framework is needed which sets out the minimum or core paediatric service that should be available locally (in DGHs) (e.g., respiratory, diabetes, neonatology, endocrinology, community, cystic fibrosis) to give guidance and clarity on what should be provided locally. The entry point should be via a GP with special interest in paediatrics referring to a paediatrician to referring on to a specialist service. Utilising the GP with special interest in paediatrics would be a better model for remote and rural areas than having adult specialists dealing with children as GPs see more children.

This framework should be planned regionally and resources identified to bring the region up to core level. This would mean less sensitivity to fortuitous special interests. The framework would include standards and audit.

Current networks which are dependent upon individuals’ enthusiasm should be formalised to ensure succession.

There is a role for Regional Planning Groups to look at the configuration of paediatric services and to plan these at secondary level. They have a role in commissioning and quality assurance. The test will be whether NHS Boards will concur. Regional planning needs more leverage over budgets/finance, local ownership.

Inreach initiatives are valued, for example, in the Borders (inreach for cystic fibrosis, diabetes, epilepsy). This helps to improve communication, provide educational opportunities, develop professional links, and is local needs-driven. This is currently an informal arrangement, but could be developed into more a formal arrangement and could/should be extended to cover nurses and AHPs. Currently nursing inreach does take place on a case by case basis, particularly to support a child’s discharge. However, inreach is not achievable everywhere due to distance and the need for backfill while staff receive further education and training.

Outreach is valued, but that is where it is more than just attendance to do a clinic (e.g., outreach as part of educational opportunity for the multidisciplinary team). Most successful outreach is where there is wide professional link up, across agencies. It empowers local teams to take on the management of patients, supports sub-specialisation and knowledge transfer. This model could be built on to include standards and audit. Examples include Dumfries & Galloway Neurology and Cystic Fibrosis (CF - annual review of patients – multidisciplinary team review with specialists, in-year local management).

Is there a role for adult specialists in the care of children?

There is a wide age range and this will depend on the pathology. Shared adult and children’s posts do exist. It will be different for surgical and medical specialties. The direction that training is taking is an issue – unless it is configured in training people with the necessary expertise will not be produced. There is a volume issue in terms of maintaining skills in working with children.

There is a need for support locally in anaesthesia, radiology and laboratories. National services risk deskill in local areas as only elective work might be dealt with.

Professionals need to work together to manage the transition from paediatric to adult services.

Professional and training links need to be developed. A good example of this is the care of diabetes in the young network which includes adult and paediatric clinicians.

What are the information needs of specialist paediatric services in the future?

A robust national IT system would support communication for NHS Scotland.

The issues of confidentiality with regard to transfer of information need to be sorted out.
There is potential in having clinical protocols and guidelines agreed nationally, but they need to be available nationally through a website which is easy to access.

There are opportunities to develop the use of video-conferencing for clinical, training and other purposes.

Additional issues raised but not discussed:

- Transport from remote areas
- Recruitment into the service – what are we doing to attract young people into careers in the NHS across the spectrum?
- Need to consider neonatal and maternity services when considering paediatric services – they are interlinked

FEEDBACK FROM WORKSHOP

- How do we achieve a balance between providing services locally and maintaining the quality and safety of services?
- There is an opportunity to develop a framework outlining the key services that could be expected to be provided in paediatric services in DGHs working with tertiary centres. Regional planning would be central to developing such frameworks in each area and filling gaps in care that may appear between locally and nationally planned services
- Both inreach and outreach services, especially when offered in conjunction with education and skills transfer, are valued initiatives
- What is the future role in child health services of adult specialists? It may be that they have a role to play in sustaining child health services in remote and rural areas. GPs, who may see large numbers of children, could also develop paediatric skills to help sustain local services in remote and rural areas
- Protocols and guidelines may be developed which could be worked to in local areas, in partnership with tertiary centres
- Telemedicine, video-conferencing and other IT developments need to be developed to support local services

WORKFORCE PLANNING

BACKGROUND INFORMATION

Future pressures

- 2004: The new consultant contract implemented
- 2004: 58-hour working time limit for training grades
- 2005: All doctors subject to annual appraisal and revalidation
- 2005: Foundation programmes begin
- 2006: FY2 posts replace SH01 posts
- 2007: ‘Run through’ specialist training begins
- 2009: 48-hour working time limit for training grades

Medical paediatric workforce in Scotland: the current situation

- Disproportionate dependence on non-consultant grade doctors
- Relatively large number of units providing acute general paediatric and neonatal care with no clear regional agenda.

Key message from Securing Future Practice: Shaping the New Medical Workforce for Scotland
• The medical workforce can only be secured by simplifying its structure, through service redesign and effective national and regional planning. This will deliver the doctors and the service Scotland needs.

**Workforce Planning: Delivering the vision**

• Delivering the vision will depend on successfully integrating workforce modelling and clinical service profiling in a continuous cycle of improvement

• Key documents are:
  - Future Practice: A Review of the Scottish Medical Workforce 2002

• According to the Scottish Integrated Workforce Planning Group (2002)
  - Workforce planning should be crucially dependent on and fully integrated with service planning
  - Services should be delivered by teams and workforce planning should aim to achieve the appropriate multidisciplinary mix of skill in the team
  - Workforce planning should understand and influence mechanisms which affect supply and demand.

How will this be achieved, by whom and when?

(Workforce review completed separately)

**CLOSING REMARKS**

**Peter Bates**
**Director of Health Service Delivery (Acting)/Chair**
**NHS Tayside Board**

The work undertaken by members of all the professions and staff caring for children, and the consistent standard of that care, is enormously appreciated not just by children and their families but also by Ministers.

Professor David Kerr who is chair of the National Framework for Service Change is responsible for a co-ordinated report which will be put before the Minister for Health and Community Care, Andy Kerr, who will decide what action is to be taken subsequently. The Minister will want to satisfy himself that the clinical community has been properly consulted and involved in the preparations of the report.

The first draft reports from the different action teams involved in the National Framework for Service Change review are expected to be completed between the end of January and middle of February. The final report is expected to go to the Minister between late spring and early summer. This timescale will allow consultation to continue over the next two to three months, which will include a series of innovative consultation sessions at the end of February/beginning of March - interactive, dynamic sessions where mixed groups of clinicians will be asked to discuss and vote on groupings of recommendations and streams of work. The aim is to arrive at as high a degree of consensus as possible throughout NHSScotland on the recommendations that appear in the final report.
Current Range and Organisation of Specialist Paediatric Services in Scotland

1 Current Organisation of Specialist Paediatric Services

NHS Boards are responsible for ensuring the provision of healthcare for their population. Specialised paediatric services are provided mainly through the three children’s hospitals in Aberdeen, Edinburgh and Glasgow, with a range of services being supplied from Ninewells Hospital in Dundee and other adult hospitals in Scotland. Where services are not provided within a Health Board’s area, the Health Board makes arrangements for their provision with one or more of the Health Boards in whose area the service is provided. Some specialised services are provided outwith these hospitals, e.g. neonatal care, neurosurgery. A small number of services are designated as national services, which are funded through separate funding streams and managed by the National Services Division, who also manage the arrangements for the small number of services provided outside Scotland.

2 Nationally Funded Services

The services listed below, at the locations listed below, are funded at an “all Scotland” or “all UK” level as of 1 April 2005.

<table>
<thead>
<tr>
<th>Service</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult cystic fibrosis services</td>
<td>Aberdeen Royal Infirmary</td>
</tr>
<tr>
<td></td>
<td>Western General Hospital, Edinburgh (includes outreach service in Dundee)</td>
</tr>
<tr>
<td></td>
<td>Western Infirmary, Glasgow</td>
</tr>
<tr>
<td>Amylodosis (diagnosis and advice on management - not drug costs)</td>
<td>* Royal Free Hospital, London</td>
</tr>
<tr>
<td>Brachial plexus injury</td>
<td>Victoria Infirmary, Glasgow</td>
</tr>
<tr>
<td>Breast cancer screening</td>
<td>Ayrshire Central Hospital, Irvine</td>
</tr>
<tr>
<td></td>
<td>Forresterhill, Aberdeen</td>
</tr>
<tr>
<td></td>
<td>Nelson Mandela Place, Glasgow</td>
</tr>
<tr>
<td></td>
<td>Raigmore Hospital, Inverness</td>
</tr>
<tr>
<td></td>
<td>Ardmillan House, Edinburgh</td>
</tr>
<tr>
<td></td>
<td>Ninewells Hospital, Dundee</td>
</tr>
<tr>
<td>Cardiothoracic transplantation:</td>
<td>Glasgow Royal Infirmary (Adult)</td>
</tr>
<tr>
<td>- heart transplantation / advanced heart failure</td>
<td></td>
</tr>
<tr>
<td>Heart, heart /lung and lung transplantation including ventricular assist devices</td>
<td>Freeman Hospital, Newcastle (Adult and child)</td>
</tr>
<tr>
<td></td>
<td>Papworth Hospital, Cambridge (Adult)</td>
</tr>
<tr>
<td></td>
<td>Harefield Hospital, London (Adult)</td>
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<tr>
<td></td>
<td>Great Ormond Street Hospital, London (Child)</td>
</tr>
<tr>
<td>Service</td>
<td>Location</td>
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<tr>
<td>--------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Cervical screening cytopathology EQA and</td>
<td>Aberdeen Royal Infirmary (Cytopathology EQA)</td>
</tr>
<tr>
<td>proficiency schemes</td>
<td>Ninewells Hospital (Proficiency scheme)</td>
</tr>
<tr>
<td></td>
<td>Wishaw Hospital (Technical EQA)</td>
</tr>
<tr>
<td>Choriocarcinoma Services:</td>
<td>Ninewells Hospital</td>
</tr>
<tr>
<td>Diagnosis of hydatidiform moles</td>
<td>* Charing Cross Hospital, London</td>
</tr>
<tr>
<td>Treatment</td>
<td>* Weston Park Hospital, Sheffield</td>
</tr>
<tr>
<td></td>
<td>Ninewells Hospital</td>
</tr>
<tr>
<td></td>
<td>* Charing Cross Hospital, London</td>
</tr>
<tr>
<td></td>
<td>* Weston Park Hospital, Sheffield</td>
</tr>
<tr>
<td>Cleft lip and palate surgery service</td>
<td>Children’s Hospitals in Glasgow, Edinburgh and Aberdeen</td>
</tr>
<tr>
<td>Clinical scientist training schemes</td>
<td>Ninewells Hospital (Molecular Geneticists, Biochemists, Cytogeneticists)</td>
</tr>
<tr>
<td></td>
<td>Royal Infirmary of Edinburgh (Microbiologists)</td>
</tr>
<tr>
<td></td>
<td>Aberdeen Royal Infirmary (Medical Physicists)</td>
</tr>
<tr>
<td>Cochlear implantation</td>
<td>Crosshouse Hospital, Kilmarnock (Adult and Child)</td>
</tr>
<tr>
<td></td>
<td>Royal Infirmary, Edinburgh (Adult)</td>
</tr>
<tr>
<td>Colorectal cancer screening pilot - third round</td>
<td>Ninewells Hospital, Dundee</td>
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<tr>
<td></td>
<td>Aberdeen Royal Infirmary</td>
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<tr>
<td></td>
<td>Victoria Hospital, Kirkaldy</td>
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<tr>
<td>Craniofacial surgery</td>
<td>* Great Ormond Street Hospital, London</td>
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<tr>
<td></td>
<td>* Radcliffe Infirmary, Oxford</td>
</tr>
<tr>
<td></td>
<td>* Birmingham Children’s Hospital</td>
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<tr>
<td></td>
<td>* Royal Liverpool Children’s Hospital, Alder Hey</td>
</tr>
<tr>
<td>Cystic fibrosis audit database</td>
<td>University of Dundee</td>
</tr>
<tr>
<td>Donor transplant co-ordination</td>
<td>Donor co-ordinators are based in Aberdeen, Dundee, Glasgow, Edinburgh and Inverness, but work throughout the country</td>
</tr>
<tr>
<td>Endoprosthetic replacement for primary bone</td>
<td>Western Infirmary, Glasgow</td>
</tr>
<tr>
<td>tumours (in England – primary malignant bone</td>
<td>University College London Hospitals NHS Foundation Trust</td>
</tr>
<tr>
<td>tumour service)</td>
<td>Royal National Orthopaedic Hospitals NHS Trust,</td>
</tr>
<tr>
<td></td>
<td>Stanmore</td>
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<tr>
<td></td>
<td>Royal Orthopaedic Hospitals NHS Trust, Birmingham</td>
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<tr>
<td></td>
<td>Newcastle upon Tyne Hospitals NHS Trust</td>
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<tr>
<td></td>
<td>The Robert Jones &amp; Agnes Hunt Orthopaedic &amp; District Hospitals NHS Trust</td>
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<td></td>
<td>Oswestry</td>
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<td></td>
<td>North Bristol NHS Trust</td>
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<tr>
<td></td>
<td>Nuffield Orthopaedic Centre NHS Trust, Oxford</td>
</tr>
<tr>
<td>Epidermolysis bullosa services</td>
<td>* Great Ormond Street (paediatric)</td>
</tr>
<tr>
<td></td>
<td>* Birmingham Children’s Hospitals (paediatric)</td>
</tr>
<tr>
<td></td>
<td>* St Thomas’ Hospital, London (adult)</td>
</tr>
<tr>
<td>Gaucher’s disease (diagnosis and management)</td>
<td>* Addenbrooke’s Hospital, London (Adults)</td>
</tr>
<tr>
<td>Service</td>
<td>Location</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>* Royal Free Hospital, London (Adults)</td>
<td></td>
</tr>
<tr>
<td>* Great Ormond Street Hospital, London (Child)</td>
<td></td>
</tr>
<tr>
<td>* Royal Manchester Children’s Hospital (Child)</td>
<td></td>
</tr>
<tr>
<td>Gynaecological reconstruction</td>
<td>*Queen Charlotte’s Hospital, London</td>
</tr>
<tr>
<td>Histopathology EQA</td>
<td>Ninewells Hospital</td>
</tr>
<tr>
<td>HIV/HCV specialist laboratory tests</td>
<td>Regional Virus Laboratories in Edinburgh and Glasgow</td>
</tr>
<tr>
<td>Hyperbaric medicine</td>
<td>Aberdeen Royal Infirmary</td>
</tr>
<tr>
<td>Inpatient psychiatric service for deaf children and adolescents</td>
<td>*Springfield Hospital, London</td>
</tr>
<tr>
<td>Interventional fetal therapy</td>
<td>Yorkhill Hospital</td>
</tr>
<tr>
<td>Intestinal failure</td>
<td>*St Mark’s Hospital, London</td>
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<tr>
<td></td>
<td>*Hope Hospital, Salford</td>
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<tr>
<td></td>
<td>NB See Managed Clinical Network below for home parenteral nutrition in Scotland</td>
</tr>
<tr>
<td>Liver transplantation</td>
<td>Royal Infirmary, Edinburgh (Adult)</td>
</tr>
<tr>
<td></td>
<td>St James Hospital, Leeds (Adult)</td>
</tr>
<tr>
<td></td>
<td>University Hospitals, Birmingham (Adult)</td>
</tr>
<tr>
<td></td>
<td>Birmingham Children’s Hospital (Child)</td>
</tr>
<tr>
<td></td>
<td>King’s College Hospital, London (Child)</td>
</tr>
<tr>
<td></td>
<td>Royal Free, London (Adult)</td>
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<tr>
<td></td>
<td>Addenbrookes Hospital, Cambridge (Adult)</td>
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<tr>
<td></td>
<td>Freeman Hospital, Newcastle (Adult)</td>
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<tr>
<td>Molecular genetics</td>
<td>Aberdeen Royal Infirmary</td>
</tr>
<tr>
<td></td>
<td>Ninewells Hospital, Dundee</td>
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<tr>
<td></td>
<td>Western General Hospital, Edinburgh</td>
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<tr>
<td></td>
<td>Yorkhill Hospital, Glasgow</td>
</tr>
<tr>
<td>Newborn blood spot screening</td>
<td>Yorkhill Hospital (Scottish Neonatal Screening Laboratory)</td>
</tr>
<tr>
<td>Ophthalmic oncology (includes proton beam treatment where necessary)</td>
<td>Western Infirmary, Glasgow</td>
</tr>
<tr>
<td></td>
<td>(proton beam at Clatterbridge Hospital, Liverpool)</td>
</tr>
<tr>
<td>Paediatric bladder extrophy</td>
<td>* Great Ormond Street Hospital</td>
</tr>
<tr>
<td></td>
<td>* Manchester Children’s Hospital</td>
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<tr>
<td>Paediatric bone marrow transplantation</td>
<td>Yorkhill Hospital, Glasgow</td>
</tr>
<tr>
<td>Paediatric cardiac services (cardiac surgery, interventional cardiology, neonatal cardiology)</td>
<td>Yorkhill Hospital, Glasgow</td>
</tr>
<tr>
<td>Paediatric extracorporeal life support (ECLS)</td>
<td>Yorkhill Hospital, Glasgow</td>
</tr>
<tr>
<td></td>
<td>* Newcastle upon Tyne Hospitals NHS Trust</td>
</tr>
<tr>
<td></td>
<td>* University Hospitals of Leicester NHS Trust</td>
</tr>
<tr>
<td></td>
<td>* Great Ormond Street Hospital for Children NHS Trust</td>
</tr>
<tr>
<td>Paediatric renal transplantation</td>
<td>Yorkhill Hospital, Glasgow</td>
</tr>
<tr>
<td>Paediatric spinal surgery</td>
<td>Royal Hospital for Sick Children, Edinburgh</td>
</tr>
<tr>
<td>Pancreas and simultaneous pancreas / renal transplantation</td>
<td>Royal Infirmary, Edinburgh (Adult)</td>
</tr>
<tr>
<td>Service</td>
<td>Location</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Photobiology</td>
<td>Dundee Teaching Hospital</td>
</tr>
<tr>
<td>Pre-implantation genetic diagnosis</td>
<td>Joint Glasgow Royal Infirmary and Yorkhill Hospital, Glasgow</td>
</tr>
<tr>
<td>Prion disease service</td>
<td>*St Mary’s Hospital, London</td>
</tr>
<tr>
<td>Psuedomyxoma peritonei of the appendix</td>
<td>* North Hampshire Hospital, Basingstoke</td>
</tr>
<tr>
<td>Pulmonary thromboendarterectomy</td>
<td>* Papworth Hospital, Cambridge</td>
</tr>
<tr>
<td>Pulmonary vascular service</td>
<td>Western Infirmary, Glasgow</td>
</tr>
<tr>
<td>Rare neuromuscular disease</td>
<td>*Hammersmith Hospital, London *Institute of Genetics, Newcastle *John Radcliffe Hospital, Oxford *National Hospital for Neurology and Neurosurgery, London</td>
</tr>
<tr>
<td>Recombinant and commercial blood products</td>
<td>* Glasgow Royal Infirmary * Royal Infirmary, Edinburgh</td>
</tr>
<tr>
<td>Reconstructive Surgery for Congenital Malformations of the female genital tract</td>
<td>* Queen Charlottes Hospital, London</td>
</tr>
<tr>
<td>Reference laboratory services (since 1 April 2005 commissioned through Health Protection Scotland, NHS National Services Scotland)</td>
<td>Royal Infirmary of Edinburgh (Mycobacteria, Neisseria Gonorrhoea) Western General Hospital, Edinburgh (E-coli O157) Stobhill Hospital, Glasgow (Legionella, Meningococcus, Pneumococcus, Parasitology, Salmonella) Glasgow Royal Infirmary (MRSA, Trace elements) Raigmore Hospital (Toxoplasma) Public Health Laboratory Service, Colindale, London, (Specialist reference services not provided in Scotland.)</td>
</tr>
<tr>
<td>Retinoblastoma</td>
<td>*Royal London Hospital, London *Birmingham Children’s Hospital</td>
</tr>
<tr>
<td>Scottish Poisons and Information Bureau (since 1 April 2005, commissioned as an integral part of the UK National Poisons Information Service by the English Health Protection Agency)</td>
<td>Royal Infirmary of Edinburgh</td>
</tr>
<tr>
<td>Secure forensic mental health services for adolescents</td>
<td>* Roycroft Unit (Newcastle) * Gardener Unit (Salford) * Ardenleigh (Birmingham)</td>
</tr>
<tr>
<td>Severe combined immunodeficiency and related disorders (SCIDs)</td>
<td>* Newcastle General Hospital for Sick Children * Great Ormond Street Hospital, London</td>
</tr>
<tr>
<td>Single organ retrieval team</td>
<td>Royal Infirmary of Edinburgh</td>
</tr>
<tr>
<td>Small bowel transplantation (service evaluation)</td>
<td>* St James Hospital, Leeds (Adult) * Addenbrooke’s Hospital, Cambridge (Adult) * Birmingham Children’s Hospital (Child)</td>
</tr>
</tbody>
</table>
Service | Location
---|---
Specialist paediatric liver disease service (including Kasai procedure) | *King’s College Hospital, London
*Birmingham Children’s Hospital
*St James University Hospital, Leeds

Spinal injuries (including high dependency home ventilation) | Queen Elizabeth National Spinal Injuries Unit, Southern General Hospital, Glasgow

Stem cell transplants for children with severe rheumatoid arthritis | *Great Ormond Street Hospital, London
*Freeman Hospital, Newcastle

Supra-renal and thoraco-abdominal aortic aneurysms | Royal Infirmary of Edinburgh

Transport of critically ill children | Royal Hospitals for Sick Children, Edinburgh and Glasgow

### 2.1 National Managed Clinical Networks

The administrative costs of the following National Managed Clinical Networks are supported nationally but the costs of treatment co-ordinated through the networks are funded locally.

<table>
<thead>
<tr>
<th>Network</th>
<th>Network office location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bone and soft tissue sarcoma</td>
<td>Western Infirmary, Glasgow</td>
</tr>
<tr>
<td>Cleft lip and palate</td>
<td>Perth Royal Infirmary</td>
</tr>
<tr>
<td>Hepatobiliary and pancreatic cancer</td>
<td>Edinburgh Royal Infirmary</td>
</tr>
<tr>
<td>Home parenteral nutrition</td>
<td>Perth Royal Infirmary</td>
</tr>
<tr>
<td>Paediatric renal medicine</td>
<td>Yorkhill Hospital</td>
</tr>
<tr>
<td>Phototherapy</td>
<td>Perth Royal Infirmary</td>
</tr>
<tr>
<td>Scottish muscle group</td>
<td>Yorkhill Hospital</td>
</tr>
</tbody>
</table>

**Key to table above**

Normal type – services funded at listed locations for residents of Scotland by National Services Division, NHS National Services Scotland. These are the designated Scottish national specialist services and are fully “commissioned” by National Services Division – ie strategically planned, clinically and financially performance managed, and funded.

*Locations in Italics* – services funded on UK basis by Department of Health in England (open to all residents of the UK)

* Service funded via National Services Division from pooled NHS Board funds on a purely financial basis. Clinical performance assessed by NSCAG in England.

### 2.2 National Services for children provided in Scotland

As indicated above, NSD commissions several nationally designated services for Scottish children of all ages, from neonates to teenagers. The following national paediatric services are provided in Scotland:

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5
Paediatric cardiac services – encompassing cardiac surgery, interventional cardiology and neonatal cardiology

Most cardiac surgery, interventional cardiology and neonatal cardiology is provided for Scotland’s children at the Royal Hospital for Sick Children, Yorkhill, Glasgow. The service provides open and closed cardiac surgery for all congenital and acquired heart disease for children up to and including 16 years of age, with the exception of transplantation and surgery for hypoplastic left heart syndrome. This is a very rare condition which affects two to four babies per year in Scotland, and surgery is currently carried out in Birmingham.

Interventional cardiology is a developing area and as technology and techniques have progressed, there has been a shift away from surgery toward less invasive procedures. This has meant that cases which still require surgical intervention have tended to be more complex. Cardiac surgery covers a range of procedures of varying degrees of complexity. 50% of children undergoing surgical procedures this year were less than one year of age, and 25% were neonates within 30 days of birth. In total for 03/04 there were 291 surgical procedures and 217 interventional cardiology procedures. There are around 65 neonatal cardiology procedures each year.

Paediatric Intensive care retrieval

There are two national teams operating to coordinate and carry out the retrieval of critically ill and injured children, who require transport from their local hospital to a paediatric intensive care unit (PICU). The teams operate from the Royal Hospitals for Sick Children in Glasgow and Edinburgh. In 03/04, Edinburgh received 168 referrals (including five from outwith Scotland) and undertook 128 retrievals. Glasgow received 193 referrals (11 from outwith Scotland) and undertook 137 retrievals. The teams are responsible for ensuring the child’s appropriate care during transfer, which can in some cases be to a PICU outwith Scotland (for instance, to the paediatric liver transplant unit in Birmingham’s Sick Children’s Hospital). Patients can be transported by ambulance or by air, the decision depending on the patient’s location and the severity of their condition.

Paediatric renal transplantation

The Scottish service for children requiring kidney transplants is provided from Yorkhill Children’s Hospital in Glasgow. Although adult renal transplantation is locally funded, paediatric renal transplantation is funded at a national level, as it is much less common. It was designated as a national service from April 2002. The service undertakes both cadaveric transplantation (where the organ has been donated by someone who has died) and living related donor transplants. It also provides for one year of post-transplant follow-up care. Adult live donors are cared for at the Western Infirmary, also in Glasgow. A total of 8 transplants took place in 03/04

Paediatric extra-corporeal life support

The paediatric extra corporeal life support (ECLS) service at the Royal Hospital for Sick Children, Yorkhill, Glasgow, is a designated national service. ECLS involves the use of
a machine external to the body to provide temporary life support to patients with cardiac or pulmonary failure, and is used for children and babies with conditions such as congenital diaphragmatic hernia or meconium aspiration syndrome. The Scottish service is one of four in the UK, and plays a key role in supporting the national cardiac surgery programme. Of the cases supported 54% had neonatal respiratory failure and 19% were older children with respiratory failure, and 27% had primary cardiac failure. It can be necessary to undertake ECLS for a number of days the average being 11 days. The unit also admits patients for consideration of ECLS, in 03/04 an additional 11 patients were admitted, who improved with conventional care and did not require ECLS treatment. A total of 21 children received ECLS in 03/04 all apart from two coming from the west of Scotland.

**Interventional Fetal Therapy**

The service at the Yorkhill Hospital in Glasgow provides treatment for specific fetal conditions such as severe Rhesus isoimmunisation, neonatal alloimmune thrombocytopenia, fetal parvovirus infection, and congenital lung and bladder malformations. This is a recently established national service and is developing. Activity is expected to rise to 35 treatments a year.

**Cleft Lip and Palate surgery**

Surgery to repair cleft lip and palate takes place in the Children’s Hospitals in Aberdeen, Edinburgh and Yorkhill Hospital, Glasgow. Some children require a number of procedures throughout their childhood and up to 20 years of age. Around 90 children each year require surgery.

**Endoprosthetic replacement of primary bone tumour**

The designated specialist service has been established in North Glasgow University Hospitals Division, with Yorkhill Hospital providing the service for children. Surgeons in Edinburgh and Aberdeen - who have existing expertise in this area – continue to provide input to the adult service. Activity is around 12 procedures a year of which 2-3 are children. Some children – highly complex cases – are still referred onto London or Birmingham.

**Newborn bloodspot screening**

Screening for phenylketonuria (PKU), congenital hypothyroidism and cystic fibrosis is provided by Yorkhill Hospital for all babies born in Scotland. Bloodspots are taken from babies’ heels a few days after birth and are sent to the laboratory at Yorkhill. Biochemical and molecular testing is undertaken to determine whether the baby has one of these rare disorders. There are around 50,000 births a year in Scotland and there is a high uptake of screening.

**Bone marrow transplantation**

This service provides bone marrow transplantation for children with leukaemia (vast majority), metabolic disorders and immunodeficiency diseases. Some severe combined
immunodeficiency cases (SCIDs) are treated in specialist units in England. There are strict national guidelines, to which the unit adheres. The transplants are carried out in the Bone Marrow Transplant unit at Yorkhill Hospital.

The assessed need is 10 to 14 per annum.

**Spinal surgery**

A new national service from 1 April 2005, this service provides operative treatment for three groups of children at the Royal Hospital for Sick Children in Edinburgh:

1. Idiopathic disease - The majority of which are teenagers with around 10% of the group comprising very young children.
2. Congenital group – These are children born with abnormalities of the spine.
3. Neuromuscular group – For example cerebral palsy and Duchenne and a miscellaneous group with rarer conditions for example Marfans syndrome.

The estimated need is for some 120 children a year.

**Cochlear Implants**

22 paediatric cochlear implants are undertaken each year at Crosshouse Hospital in NHS Ayrshire and Arran for children with congenital and acquired (mostly post meningitic) hearing loss. The service provides assessment and surgery together with the essential follow up care, much of which is now undertaken on an outreach basis at hospitals around Scotland.

**Paediatric Managed Clinical Networks**

There are formal and informal national and regional networks to support some children’s services including cleft lip and palate care, specialist muscle disorder management, renal medicine, intestinal failure / home parenteral nutrition, epilepsy, neurology, general paediatric surgery and in-patient psychiatry.

**Paediatric primary pulmonary hypertension**

This service is delivered on a shared care basis with Great Ormond Street (GOS), London, Yorkhill Hospital and the Scottish Pulmonary Hypertension Unit in Glasgow. In 2003/04, 3 children were being treated. Regular joint clinics are provided by GOS clinicians in Yorkhill to care for these children.

### 2.3 Services Provided outside Scotland

**Specialised Services Provided in England for Residents of Scotland**

NSD has for several years provided a financial risk sharing arrangement for NHS Boards in Scotland to cover the costs of Scottish access to designated English National...
Specialist services. This involves a small range of highly specialist services needed rarely by residents of Scotland, for example, pseudomyxoma peritonei of the appendix.

Since 1 April 2002, NSD has commissioned specialised services from Trusts in England. These arrangements replace the previous Out of Area Treatment (OATs) funding flows and supersede existing NHS Board service agreements. The commissioned services range from large-scale agreements covering all services within a Trust to individual packages of care on a named patient agreement basis.

There are 35 categories of specialised services:

- cancer
- blood and marrow transplantation
- haemophilia and bleeding disorders
- women's health
- disability equipment
- spinal services
- brain injury rehabilitation
- neurosciences
- burn care
- cystic fibrosis
- renal services
- home parenteral nutrition
- cardiology and cardiac surgery
- HIV and Aids
- cleft lip and palate
- immunology
- allergy services
- hepatology, hepatobiliary and pancreatic surgery
- infectious diseases
- specialised vascular services
- medical genetic services
- learning disability
- mental health
- children's services
- specialised dermatology services
- specialised pathology services
- specialised rheumatology services
- specialised endocrinology services
- hyperbaric treatment services
- specialised respiratory services
- specialised pain management services
- specialised ear surgery
- specialised colorectal services
- specialised orthopaedic services
- specialised morbid obesity services

The specialised services definitions can be found on the DH website at: http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/SpecialisedServicesDefinition/fs/en

Notes

1. These are broad headings and do not cover all care within these specialities. Non-specialised elements of care continue to be funded through the OATs matrix or by provider-to-provider charging.

2. Wales and Northern Ireland have their own separate health systems and treatment for Scottish residents in those countries is not included in these arrangements.

2.4 Specialised Services for children provided in England

The table below shows the transfers and activity that took place outside Scotland in 2003/04
<table>
<thead>
<tr>
<th>Condition</th>
<th>Hospital</th>
<th>Number of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retinoblastoma</td>
<td>Birmingham</td>
<td>3</td>
</tr>
<tr>
<td>Bladder Exstrophy</td>
<td>Great Ormond Street Hospital</td>
<td>24</td>
</tr>
<tr>
<td>Specialist Paediatric Liver Disease</td>
<td>Kings –London Leeds</td>
<td>22 (plus 23 outpatients)</td>
</tr>
<tr>
<td>SCIDS</td>
<td>Newcastle Freeman’s</td>
<td>I Transplant</td>
</tr>
<tr>
<td>Endoprosthesis</td>
<td>Royal National Orthopaedic Hospital</td>
<td>4 outpatients</td>
</tr>
<tr>
<td></td>
<td>Royal Orthopaedic Hospital</td>
<td>1 operation plus three outpatients.</td>
</tr>
<tr>
<td></td>
<td>UCLH</td>
<td>1</td>
</tr>
<tr>
<td>Cardiothoracic Transplant</td>
<td>Newcastle</td>
<td>1</td>
</tr>
<tr>
<td>Craniofacial</td>
<td>Great Ormond Street Hospital</td>
<td>5</td>
</tr>
<tr>
<td>Epidermylosus bullosa</td>
<td>Great Ormond Street Hospital</td>
<td>8 new 14 outpatients</td>
</tr>
<tr>
<td>Small Bowel transplant</td>
<td></td>
<td>0</td>
</tr>
<tr>
<td>Hypoplastic left heart surgery</td>
<td>Birmingham</td>
<td>No available data</td>
</tr>
<tr>
<td>Some elements of bone marrow transplant</td>
<td>Bristol, Manchester</td>
<td>–</td>
</tr>
<tr>
<td>In patient forensic psychiatry</td>
<td>Newcastle</td>
<td>–</td>
</tr>
<tr>
<td>In patient mental health services for deaf children</td>
<td>Manchester</td>
<td>–</td>
</tr>
</tbody>
</table>

Other activity
The NSCAG services (UK National Services such as paediatric liver transplant) do not break down their activity by region, so information on Scottish use of those services is not easily available.

3 Nature and Provision of Specialist Paediatric Services in Royal Hospital for Sick Children, Glasgow (Yorkhill)

Medical Services

Community Child Health Services (CCHS)
These are provided in four child development centres and school health services are linked to this sector model. A number of specialist city wide services are delivered through CCHS including those linked to Child Protection and Looked After and Accommodated Children (both of which have close links with the new child protection unit established within the hospital). Audiology/hearing impairment is managed on a citywide basis with close links to ENT. Universal Neonatal Hearing Screening will be rolled out across Greater Glasgow from October 2005.

Other citywide services include community autism (with close links to the Scottish Centre for Autism) and physical impairment (with close links to the department of neuroscience). A number of small specialist allied health professional and clinical psychology services are also provided on a citywide basis (with close professional links to the hospital and other CCHS). All have close strategic and operational interagency links with services in education and children and families social care and transition links with adult services.
Supporting early discharge from hospital is the hospital based community children’s nursing team. This and the respite service (Home is Where the Help Is) for complex needs children provide specialist input across NHS Greater Glasgow.

**Cystic Fibrosis (CF)**
The CF team is a multidisciplinary group working with approximately 150 children and young people with cystic fibrosis from across the West of Scotland. Care is provided in hospital, community and at home. Inpatients are managed across three medical wards providing flexibility in the management of specific microbiological needs of CF patients. The team provides a Home Intravenous Antibiotic Service thus allowing a large proportion of care to be managed from home. Strong transition links with colleagues working in the adult respiratory medicine service are in place while there are also informal networking arrangements in place for shared care across the region for the core client group. All children linked to the service receive an annual review.

**Dermatology**
Glasgow has one of the largest paediatric dermatology services in the UK. A senior medical team is supported by specialist nursing, allied health professionals (AHP) and clinical psychology staff all trained in working with children and young people with a range of skin disorders. Close links with a range of other hospital based paediatric departments are in place including respiratory medicine, plastic surgery and haematology / oncology as well as links with staff working in primary care. MRI and laser technology supports the department's investigation facilities.

**Diabetes**
The recent appointment of a second consultant has helped consolidate the multidisciplinary team of specialist doctors, nurses and allied health professionals working in one of the busiest paediatric diabetes services in the UK. While the majority of care is provided in the community, outpatient and a small inpatient level of care are also well supported. Strong links across the West of Scotland have been established with the department providing a strong focus in clinical education to colleagues working outwith Greater Glasgow. The department continues to develop the provision of insulin pumps to children and young people with diabetes and is involved in the development of managed clinical network (MCN).

**Endocrinology**
There are 2 consultant paediatric endocrinologists working with a specialist team in the diagnosis and management of childhood and adolescent problems in growth and puberty, and endocrine disorders. Largely an outpatient based service, a substantial amount of specialist outreach provision across the West of Scotland has also been formalised. Providing a successful service for children and young people with endocrine disorders requires strong links with paediatric departments in a variety of clinical areas. The management of late effects of childhood cancer is also an important specialist area of care.

**Infectious Diseases and Immunology (IDI)**
The service is split into three main areas: infectious diseases, immunodeficiency and allergy. The allergy clinic offers a regional service for diagnosis and management of
allergic disorders. Education for families in the management of anaphylaxis, including
the use of injectable adrenaline is provided. Close links with colleagues in community
child health are also in place. A consultant led team is supported by specialist nurse
practitioners working in the hospital day care unit. The ID service has been set up as a
consultative resource for tertiary sub specialists in the diagnosis and management of
unusual cases, in particular infections which may have been acquired abroad and
advising on infection control issues. Current work in progress is the development of a
managed clinical network for paediatric immunology and the expansion of the supporting
multidisciplinary team.

Neonatal Intensive Care
The Queen Mother’s Hospital provides a comprehensive range of services to the
newborn, with referrals from other Glasgow hospitals and from maternity units across
the West of Scotland. Many of these infants are transferred in utero to take full
advantage of the co-located tertiary services.

The unit has 10 intensive care and 18 special care cots. It is able to offer a tertiary
service for all aspects of neonatal care including investigatory and therapeutic
techniques. It accepts infants from all areas of Scotland and co-hosts the Regional
Neonatal Transfer Service.

The Unit is a referral centre for the diagnosis of cardiac malformations and subsequent
investigation and treatment, including interventional cardiology and Paediatric cardiac
surgery. The Unit also has an essential role in the initial management and transfer of
possible ECLS patients.

Nephrology
The paediatric nephrology service provides a multidisciplinary approach to the
management of children with acute and chronic renal disease. There are also links to
other specialist on-site tertiary services. The service is located in a self-contained
inpatient, day care and outpatient facility. The team has recently appointed a 5th
paediatric renal consultant and builds on a number of associated multidisciplinary
developments that have taken place in the past 2 years. The service is nationally
accredited for paediatric renal transplantation and is currently in the process of
establishing a national managed clinical network for paediatric renal medicine. The
team also supports access to a paediatric renal consultant service in the Royal Hospital
for Sick Children, Edinburgh.

Neuroscience
A multidisciplinary team supports the diagnostic service for children with actual or
suspected neurodevelopmental disorders, neurodegenerative disorders and acute
neurological disorders. It also supports the investigation for paroxysmal disorders and
the management of children with epilepsy. Rehabilitation for children with acquired
brain injury is provided and a comprehensive neuromuscular service has been
established. Close links with other specialist paediatric tertiary services, child
development centres and colleagues in community child health / child adolescent
psychiatry are in place. Plans to develop a shared consultant post with adult services in
neurophysiology, specialist nursing in epilepsy, a consultant neuropsychologist, a dietician (to lead the epilepsy ketogenic clinic) and a consultant in neurodisability are well established. Presently the department is leading on the development of a national paediatric epilepsy network and is also a major stakeholder in the National Muscle Network.

Paediatric Gastroenterology, Hepatology and Nutrition (PGHN)
A consultant led multidisciplinary team supports a PGHN service that receives over 500 secondary / tertiary referrals per year for children with disorders of gastrointestinal tract, hepatobiliary system and nutritional needs across Greater Glasgow and the West of Scotland. A comprehensive, diagnostic and interventional endoscopy service is in place to support this work. A specialist inflammatory bowel clinic has also been established with input from colleagues working in paediatric surgery and endocrinology. All children with acute and chronic liver disease are managed within the service with joint clinics established with colleagues working across supra-regional centres for transplantation. A nutritional support team focuses primarily on parenteral nutrition both within the hospital and at home.

Paediatric Haematology / Oncology
The department provides a comprehensive regional service for the diagnosis and management of children with leukaemia and solid tumours from within a self contained inpatient / day care unit with on site pharmacy provision. National accreditation for paediatric bone marrow transplantation (BMT) has recently been approved while the unit also hosts the regional haemophilia centre. Transplant facilities are currently being re-developed and improved facilities for adolescents will also be progressed. A strong multidisciplinary team has close links with various on site services. There are also strong links with adult services at the Beatson Oncology Unit, Institute of Neuroscience (SGH) and adult BMT / haemophilia services. There are shared care arrangements with a number of district general hospitals. The department is actively involved in the current national option appraisal for delivery of paediatric haematology / oncology services.

Paediatric Medicine
A full Paediatric Medicine service is provided for children up to their 13th birthday for the population of Greater Glasgow, as well as a tertiary service for the West of Scotland. Within this specialty there are strong clinical links with a full range of tertiary medical sub-specialties, which are detailed below. Facilities include isolation areas for children with infection. The service is also supported by an Ambulatory Care Unit located within the hospital.

Respiratory Medicine
The respiratory service provides a multidisciplinary approach to the investigation of children with acute or chronic lung disease, cystic fibrosis and other complex respiratory conditions. The unit provides one of the busiest bronchoscopy services in the UK. The respiratory function laboratory has the most up to date technology to carry out various lung volume measurements. Referrals are accepted from all over Scotland for diagnosis and management of problems of sleep disordered breathing. There are also close links to the Scottish Muscle Network and the Maxillo-facial unit at Canniesburn Hospital. The multidisciplinary cilia function service, provided in collaboration with paediatric pathology, is also provided within the hospital. The respiratory service also has one of
the largest paediatric ventilatory support services in the UK and is currently involved in the development of a national managed clinical network for home ventilatory support.

**Inpatient Child Psychiatry**
The service provides a tertiary level (tier 4) inpatient and day patient service for children with severe and complex psychiatric disorders, up to the age of 12 years. An application for national accreditation in delivering multidisciplinary care to users of the 9-place service is currently under consideration. A proposal for a nationally accredited managed clinical network is also being prepared for consideration in 06 / 07. The multidisciplinary team have close links with a variety of stakeholders including other specialist paediatric tertiary hospital providers, child and adolescent community / specialist psychiatry teams (including self harm) and community child health services. Close links with adolescent inpatient psychiatry are also well established.

**Liaison Psychiatry**
The specialist multidisciplinary liaison team provides psychiatric support to children, young people and families who are inpatients or frequent attendees to the hospital. Significant numbers of referrals are for complicated psychiatric disorders associated with physical illness, neuropsychiatric disorders, complex pain disorders and self-injury. The team has close links with a number of hospital sub-specialist areas including the department of neuroscience and the pain management service. The team also has close links with the acute paediatric clinical psychology team and other specialist child and adolescent psychiatry services.

**Other Child / Adolescent Psychiatry Services**
Located within the hospital campus there are two other child and adolescent psychiatry services. The Scottish Centre for Autism (SCA) is a tertiary diagnostic centre for Autistic Spectrum Disorder while the child and adolescent academic psychiatry team, linked to Glasgow University, is involved in research into psychiatric disorders.

A range of secondary care specialist child and adolescent psychiatry services are established across Greater Glasgow including 8 community sector teams and city wide mental health teams for Looked After and Accommodated Children, Learning Disability, Eating Disorders, Self Harm, Early Intervention and Forensic Medicine. All have close links with services in education and children and families social care and good transition links with adult services.

**Surgical Services**

**Burns Services (RHSC)**
This service, provided by a multi-disciplinary team which includes a visiting plastic surgeon, delivers treatment and care to children suffering from thermal injuries to the population of Glasgow and the West of Scotland. Severe and complex burn injuries are admitted directly to the paediatric intensive care unit (PICU). A full range of support services from dietetics, occupational therapy, physiotherapy and microbiology.
Cardiology and Cardiac Surgery (RHSC)
The Medical Cardiology Unit is the major paediatric tertiary referral service for the child population of Scotland and works closely with the Paediatric Cardiac Surgery programme to provide an overall Cardiac service. A full range of cardiovascular diagnostic and treatment services is provided to all age groups from the fetus to adolescence.

Diagnostic services are centred in the Cardiac Investigation Department, which also houses the Cardiac Catheterisation Laboratory allows the full range of diagnostic and interventional procedures to be undertaken.

Dental
There is a comprehensive, consultant led secondary service provided from the Dental Suite. It also provides a service for children with special needs and those who require general anaesthesia. There are strong links with other tertiary specialties, including the Cleft Lip and Palate Service.

Neonatal Surgery
The Neonatal Surgery service is located in the Dan Young Neonatal Surgical Intensive Care Unit and provides care for neonates requiring surgery.

The Unit, which receives referrals from the West of Scotland and beyond, provides specialist facilities and services for the management of a wide range of surgical conditions, including patients requiring extra corporeal life support for which RHSC is one of only 4 service providers in the UK.

Ophthalmology
The Paediatric Ophthalmology service receives referrals from GPs and Ophthalmology Units throughout Scotland.

In addition to the management of squint and common eye conditions for Glasgow and the West of Scotland, expert care is provided for a range of conditions, including retinopathy of prematurity and eye disorders presenting in infancy and childhood. Ophthalmic Oncology, Paediatric Neuro-Ophthalmology and a Vision Assessment Clinic are also provided.

Otolaryngology / ENT
The department provides a full secondary paediatric service for the children of Greater Glasgow.

Additionally, the department provides a full tertiary service for neonatal and paediatric patients from the West of Scotland. These services include complex airway management and infant tracheostomy, congenital and acquired head and neck injuries and developmental and oncological conditions. The department has strong links with other specialties in the management of patients with multiple pathology.

Paediatric General Surgery
A comprehensive service in Paediatric General Surgery is provided, covering all secondary and tertiary surgical procedures. Within this specialty there is a number of
consultants with a special interest who provide services in Spina Bifida, Hydrocephalus, Gastroenterology, Therapeutic Endoscopy, Vascular Access, Plastic Surgery and Neurosurgery.

**Trauma & Orthopaedics**
The service provides comprehensive secondary care for children from Greater Glasgow and a range of tertiary services for children from across the West of Scotland.

There is also a range of tertiary services provided by surgeons with a special interest, which includes neuromuscular conditions, hip disorders, spinal deformity, bone and soft tissue tumours, brachial plexus palsy and metabolic bone disease.

**Other Services**

**Clinical Biochemistry**
The department provides a comprehensive 24 hour clinical biochemistry service to The Royal Hospital for Sick Children, The Queen Mother's Hospital and the Community Child Health Service. In addition, a specialist service is available which caters for the antenatal and postnatal laboratory diagnosis of inherited metabolic disease. This service is provided for hospitals within Glasgow, other Health Boards in Scotland and various centres outwith Scotland.

**Clinical Genetics**
There are a variety of different Genetics Outpatient Clinics. The General Genetics Clinics provide a service for families affected by a wide range of different genetic diseases or chromosomal disorders. In addition, there are several specialist clinics for various genetic disorders e.g. neuromuscular diseases, neurofibromatosis, haemoglobinopathies and cancer. Patients of all ages and entire families can be referred to any of the clinics. The Glasgow and West of Scotland Clinical Genetics Centre is a regional service and out-patient clinics are also held within Ayrshire Central Hospital, Dumfries & Galloway Royal Infirmary, Falkirk & District Royal Infirmary, Inverclyde Royal Hospital, Royal Alexandra Hospital, Stirling Royal Infirmary and Wishaw General Hospital.

**Cytogenetics**
The Division of Cytogenetics is a West of Scotland regional service and provides a fully comprehensive chromosome analysis service for both constitutional and acquired abnormalities using a full range of standard cytogenetic techniques as well as molecular cytogenetic technology.

**Haematology**
The haematology department provides a comprehensive 24 hour diagnostic and clinical advisory haematology and blood banking service to the Royal Hospital for Sick Children, The Queen Mother's Hospital and the Community Child Health Service. It supports the Regional Paediatric Haemophilia Centre, the National Allogeneic Bone Marrow Transplant Programme and the Regional Cordiocentesis Programme. A molecular haematology laboratory within the department provides a diagnostic service for leukaemia and chimeric status post-transplant. In addition, it is one of five UK
laboratories measuring minimal residual disease in children treated on national leukaemia trials.

**Microbiology**
The Microbiology Department provides 24 hour diagnostic services to The Royal Hospital for Sick Children, The Queen Mother's Hospital and the Community Child Health Service from the well child with common infections to the severely immunocompromised host e.g. transplant patients. Specialist advice is available on test interpretation and on antibiotic choice and infection control.

**Molecular Genetics**
The Molecular Genetics Department is a centrally funded national service which is part of the Scottish Molecular Genetics Consortium with the laboratories in Edinburgh, Dundee and Aberdeen. Referrals often come from clinical geneticists based in the West of Scotland Regional Genetics Centre at Yorkhill but the department also serves the whole of Scotland for particular disorders through the Consortium.

**Newborn Screening programme**
Newborn screening is a nationally funded service which carries out testing for Phenylketonuria, congenital hypothyroidism and cystic fibrosis in all babies born in Scotland.

**Paediatric Radiology**
The department provides a fully comprehensive 24 hour Diagnostic Imaging Service with all modalities on site: radiography, fluoroscopy, ultrasound, CT, MRI, nuclear medicine and a neonatal ultrasound service. Requests are accepted from Paediatricians working in hospitals and Community Child Health Departments throughout the West of Scotland and there is an increasing demand from other West of Scotland hospitals for paediatric radiology input from Yorkhill.

**Pathology**
The Pathology Department provides a specialist combined Paediatric and Perinatal Pathology diagnostic service on a supraregional basis to Paediatric and Maternity Units in Central, the West and South West of Scotland. A range of histopathological techniques including electron microscopy, enzyme histochemistry, immunocytochemistry and ciliary beat frequency analysis is available.

**Pharmacy**
The Pharmacy Department provides a specialised paediatric general dispensing service, clinical pharmacy service, specialist medicines information on the use of medicines in neonates and children and in pregnancy and breastfeeding, an aseptic unit licensed by the Medicines Control Agency and a satellite pharmacy providing service to the Haematology / Oncology Unit.

**Pregnancy Screening programme**
This is a West of Scotland regional service (also including Highland and the Western Isles) which provides testing for chromosome abnormalities and neural tube defects in pregnant women including a new combined ultrasound and biochemical screening test in the first trimester.
**Scottish Muscle Network**
Glasgow was designated the Scottish Muscle Centre in 1999 and has been funded as a national service since April 2004. The service includes data collection and it facilitates co-operation between the many specialties involved in the management and research of neuromuscular disorders. The Muscle Centre aims to provide a coordinated, multidisciplinary approach to patient management; to promote research and to provide information for both the public and health professionals.

### 4 The nature and provision of Specialist Paediatric Services in The Royal Hospital For Sick Children, Edinburgh

**Medical Services**

**Dermatology**
Paediatric Dermatology is an overlap elective specialty between Paediatrics and Dermatology involving the management of children with a variety of cutaneous conditions. There are clear links with allergy services, medical paediatrics and primary care. The majority of outpatients assessments take place based within adult services at Lauriston Place. There is consultant sessional capacity to provide one monthly diagnostic clinic at RHSC. There is no formal Adolescent Dermatology service.

**Endocrinology and Diabetes**
These specialities are offered as local, regional and national services. They are offered through secondary and tertiary care, by a multi professional team. There has been increasing incidence of diabetes mellitus, and increasing referrals of children with endocrine problems. An outreach service is delivered by RHSC to Inverness, Dumfries, Borders and Fife, with specialists from St John’s Hospital working as part of the specialist team.

**Gastrointestinal**
The paediatric gastroenterology, hepatology and nutrition (PGHAN) service is a regional service for South East Scotland which covers all aspects of children’s gastroenterology. Patients are referred from Lothian, Fife, Borders, Central Scotland Lanarkshire, Dumfries, and Highland. There are strong links with paediatric gastroenterology colleagues in Glasgow, Aberdeen and Dundee as part of a Scottish Group (SPGANG) and links with colleagues in referring district general hospitals.

**General Paediatric Medicine**
Patients who present to the general medical paediatric service are linked into any necessary specialist services – medical, surgical or anaesthetic after general medical teams have carried out initial assessment. (Asthma, bronchiolitis, croup, febrile convulsions and other seizures. Pneumonia, lower respiratory infections, urinary tract infections, meningitis, diarrhoea and vomiting.) Many children with complex illness or speciality conditions present first to the general paediatric service or for initial stabilisation during acute crises.
Genetics
The Paediatric Genetic Services are a subset of the Regional Genetics Services. Our remit is to provide diagnosis, genetic counselling and management/screening services to children with rare genetic disorders and malformation syndromes. There is no formal out-of-hours service for clinical genetics.

Haematology and Oncology
This speciality offers local and regional tertiary services, and includes malignancy (including leukaemia and bone tumours) and Haemophilia / Haemoglobinopathy and immune disorders. Most patients requiring admission attend the ward directly, bypassing general practice and A&E. An outreach service offered from RHSC, assists primary care physicians, and a shared care service is offered with Ninewells, Dundee, to ensure that, where possible, care can be delivered as locally as possible for the child patient. The speciality is dependent on paediatric pathology, radiology, neurosurgery, radiology (at the WGH), intensive care, pharmacy, dietetics and laboratory support (including transfusion).

Inherited Metabolic Diseases
Most Inherited metabolic disease or inborn errors of metabolism (IEM) present early in life as an acute intoxicating illness, often in the newborn period when protein and carbohydrate feeds are first introduced. The major links within the specialty are to paediatric biochemistry, metabolic dietetics, clinical paediatrics pharmacy and intensive care services. The service covers Lothian, Fife and Borders for newborn screening referrals and tertiary referrals. Existing services currently follow 44 patients with phenylketonuria. 10 patients with fatty oxioxidation disorder, 6 patients with galactosaemia and another 55 patients with various other rare inborn errors in metabolism. All the newborn screening referrals are received for Lothian, Fife and Borders.

Paediatric Intensive Care
Paediatric Intensive Care provides all Level 2 and Level 3 Care for the Royal Hospital for Sick Children, Edinburgh. It is one of two units in Scotland. Level 1 Care (HDU) under ITU supervision is provided for some patients. The following surgical services are provided for – Neurosurgery, Plastic Surgery including Burns, Orthopaedic Surgery including Scoliosis Surgery, Paediatric General and Neonatal Surgery and ENT. The following medical services are provided for - General Medical Paediatrics, Respiratory Paediatrics, Medical Cardiology, Neurology, Gastroenterology and Endocrinology. PICU Care is provided for patients from other Health Boards via the National Retrieval Service NSD funded), this service then impacts on local neurology and child protection services, medical paediatric ward capacity and local paediatric plastic surgery service, occupational therapy and dietetics.

Neuroscience
This speciality includes the investigation, care and management of children with acute and chronic neurological, neurosurgical and developmental disorders. There is a neurophysiology service as well as rehabilitation of children with acute brain injury and services for children with cerebral palsy.

Renal Service
A safe and equitable service for children with renal disease in Lothian can only be achieved by continuing close collaboration with the Scottish centre for paediatric nephrology in RHSC Yorkhill, Glasgow. Edinburgh will therefore be part of an MCN. Edinburgh now has a paediatrician with an interest in nephrology, although this is in a locum capacity. It has been proposed that she will be primarily responsible for renal service provision in Edinburgh, with close consultation and continuing input from the paediatric nephrologists in Glasgow who offer the 24/7 support.

**Respiratory Disease**
This speciality delivers a local, regional and national service. The conditions managed include asthma, cystic fibrosis, general respiratory problems, sleep study service for airway obstruction, congenital malformations, technology dependent (ventilator, tracheostomy, home oxygen), chronic neonatal lung disease, allergy, bronchoscopy, immune deficiency. It has both elective and emergency activity and requires 24 hour cover.

**Rheumatology**
Paediatric Rheumatology is an overlap elective specialty between Paediatrics and Rheumatology involving the management of children with a variety of musculoskeletal complaints. There is a clear link with Orthopaedics and the Chronic Pain Service, ophthalmology and medical paediatrics and community paediatrics. A theatre session is required monthly for joint injections performed under general anaesthetic.

**Surgical Services**

**Paediatric Surgery**
Paediatric surgery offers secondary services for Lothian, and tertiary services for Borders, Fife, Tayside and Forth Valley. Sub specialities include acute abdomen, neonatal surgery, trauma, urology, GI and cancer surgery. There is evidence of a significant increase in secondary and tertiary referrals from outwith Lothian. The service offered is both elective and emergency, day case practice continues to increase.

**Cardiology**
Paediatric cardiology includes interventional cardiology, adults children and foetuses with congenital cardiac disorders, congenital and acquired heart rhythm disorders, acquired myocardial or coronary artery disorders and major part in evaluation of normal murmurs and elimination of cardiac causes for chest pain, dizziness, syncope, palpitations. There are major links to PICU, cardiac surgery, neonatology, general paediatrics and, when available, adult congenital cardiac specialists. There is a centralised service for inpatient provision for cardiac surgery and interventional cardiology, which leads to good collaboration between the cardiology and cardiac surgeon consultant specialists involved. There is an outreach service from RHSCE to east coast hospitals

**ENT**
This speciality delivers a local, regional and national service, with secondary and tertiary care. Paediatric ENT Services encompass a broad perspective of all routine problems (e.g. Tonsils, Adenoids, Glue Ear etc). Tertiary services are provided for West Lothian, Borders and Fife.
Ophthalmology
Paediatric Ophthalmology services cover all aspects of visual health in children, ranging from the organisation of population vision screening, to complex ocular surgery procedures. Services are sited in the community, at the Sick Children’s Hospital, Princess Alexandra Eye Pavilion and St John’s Hospital. Approximately 2,200 paediatric ophthalmology new patients are seen in Lothian each year. The majority of new patients per year are Lothian patients, but approximately 150 cases per year are from Borders/Fife, and these tend to be complex cases, many of whom require surgery. A small number of cases (less than 10 per year) are referred from other parts of Scotland or England.

Orthopaedic Surgery
Elective Orthopaedic Surgery has major links with Paediatric Neurology, Oncology, Rheumatology and Plastic Surgery. Emergency orthopaedics includes Fractures, acute musculoskeletal sepsis and acute orthopaedic conditions (e.g. transient synovitis, slipped upper femoral epiphysis). The transfer of emergency surgery and orthopaedics from West Lothian is likely to increase the number of children with fractures that are admitted to RHSC. Five Orthopaedic Surgeons provide an acute musculoskeletal service. One surgeon delivers the present scoliosis service, who is due to retire in 2005. It is likely that RHSC will be designated a National Centre for spinal deformity surgery shortly.

Plastic Surgery
Reconstructive surgery for: congenital anomalies including cleft lip and palate, facial anomalies, ear anomalies including microtia, hand anomalies, genital anomalies including hypospadias, vascular malformations and skin lesions. The services provided are local, regional and national, depending on the surgeon and the subspecialty. The service has emergency and elective components and requires 24/7 cover per week. The MCN Cleft surgery is delivered for Lothian, Borders, Fife, Tayside and Highlands and is funded by NSD.

Scoliosis
This service has recently been designated as a National Service from April 2005, through the National Services Division (NSD). There is now a National Clinical Network with the capacity to take the lead on National standards and ensure equity of access to high quality care irrespective of patient location or condition. Outreach clinics will continue to take place at Yorkhill, led by the Edinburgh Team.

Other Services

Biochemistry / Haematology
Biochemistry provides a specialist paediatric metabolic service for all of Lothian, Fife and Borders, with regular referrals for part of the service from Tayside, Grampian and Northern England. Haematology provides a specialist service for white cell function testing for Lothian, Fife and the Borders. It provides an elective as well as an emergency service which is required 24/7 per week.

Microbiology / Infection Control
The Microbiology Service (based at RIE) provides a full range of bacteriology services for Lothian University Division, including Children’s Services. Results of laboratory tests are reported through the laboratory computer system (APEX).

**Dentistry**
Paediatric Dentistry is the practice and teaching of research in the comprehensive preventive and therapeutic oral health care of children from birth to adolescence. As such the speciality deals with all conditions of the hard and soft oral tissues ranging from diseases that manifest locally such as dental caries and erosion to those that have systemic implications. Dental specialities: Oral Surgery, Orthodontics, Restorative Dentistry, Oral Medicine, Dental Public Health in the EDI/Edinburgh, Glasgow and Dundee Dental Hospitals and Schools and Fife and the Borders.

**Child Protection**
This consultant delivered specialty offers a local and regional service for children who disclose or are suspected of being abused. Close working relationships exist between community paediatricians and colleagues in Forensic Medicine, Education, Social Work and the Police force.

**Paediatric Pharmacy**
The Pharmacy Service provides a specialised paediatric general dispensing, aseptic dispensing, clinical pharmacy and medicines information service. Procurement and distribution of medicines is mainly provided off-site.

**Radiology**
The radiology department in RHSC provides a fully comprehensive diagnostic radiology service, with all modalities on site – radiography, fluoroscopy, ultrasound, CT, nuclear medicine and MR. Many services within RHSC are very dependent on the availability of 24/7 radiological services. Referrals come from all specialties within RHSC, elsewhere in Lothian, SE Scotland and further afield. The presence of a dedicated paediatric MR scanner means that children are referred from all over SE Scotland, many needing GA. 35% of MR patients have non-Lothian addresses, about half of these attend only for MR & are not RHSC patients.

**Virology**
The Specialist Virology Centre (based at RIE) provides a full range of virological services for LUHD and Lothian GPs including an out of hours service. There is close liaison with RHSC which includes Infection Control advice overseeing near-patient testing for respiratory syncytial virus (RSV). Virology processes over 80,000 specimens per year, approximately 7% of which are from RHSC with reference work also being carried out for Fife and the Borders.

5 **The nature and provision of Specialist Paediatric Services at the Royal Aberdeen Children’s Hospital.**

**General Paediatric Medicine**
A full paediatric service is provided in the Royal Aberdeen Children’s Hospital for the children of Grampian, Orkney and Shetland (population 570,000). A smaller paediatric
Child Healthcare Services in Scotland  

Appendix 7

unit in Elgin provides a service for Moray (60,000). As well as a new purpose built inpatient facility, there are outpatient services both in general paediatrics and in a wide range of tertiary specialities and outpatient general paediatric service is also provided for Orkney and Shetland. By April 2005 there will be 11 consultant general paediatricians in post to provide this service. All consultants have a special interest and seven also have dual accreditation in tertiary sub-specialities.

Cardiology
Aberdeen is linked in with the Scottish Paediatric Cardiology Network. A one stop diagnostic service is provided at all clinics (inc. ECG and echocardiography). Follow-up of all patients is carried out locally. Interventional and operative procedures are carried out in Glasgow.

Respiratory Medicine
A full secondary and tertiary respiratory service is provided by three consultant staff. This includes specialist asthma and cystic fibrosis clinics. Full respiratory function (except ciliary function) services are available in a dedicated laboratory. A paediatric bronchoscopy service is provided locally. Respiratory medicine is a major interest of the academic department of Child Health. Children requiring home ventilation receive shared care with Glasgow.

Gastroenterology, Hepatology and Nutrition
Two consultant staff provide a full tertiary gastroenterology and nutrition service. Network services are also provided for the North of Scotland (1.2 million population) with endoscopy services in Aberdeen and Dundee and clinics in Aberdeen, Dundee and Inverness. Nutrition services provided jointly with nursing and dietetic colleagues support over 100 enterally fed children at home. Hepatology services are provided jointly with King’s College Hospital, London.

Diabetes and Endocrinology
Almost 200 diabetic children in Grampian, Orkney and Shetland are cared for in Aberdeen. Outreach clinics are also provided in Aberdeenshire and the Islands. A newly appointed consultant colleague is due shortly to add additional support to this team. A tertiary endocrinology service is provide. Both services are supported through informal network arrangements with other Scottish centres.

Inherited Metabolic Disease
A local service is provided, external referral is rarely required but when necessary the service links in with centres in London, Newcastle and Glasgow.

Neurology / Neuroscience / Neurodisability
The neurology service is provided and supported through the North of Scotland Neurology Network by two consultant colleagues in Dundee. A botox service, specialist epilepsy clinic, supported by specialist nurse, and neurophysiology service are all housed within RACH. A paediatric neurosurgery service is also available within the hospital. A secondary and tertiary neurodisability service is provided and a dedicated child development centre is sited a quarter of a mile from the children’s hospital.
Renal Medicine
A consultant is supported by a specialist nurse and dietitian with outreach clinics from RHSC, Glasgow providing a tertiary care renal service for Grampian. In addition, a full radiological investigation and paediatric urology service is available in house.

Rheumatology
Regular clinics are provided, centres in London and Glasgow are rarely required to provide tertiary opinions.

Haematology / Oncology
This is consultant led service with the vast majority of new patients with neoplastic disease being diagnosed and treated on site. This is the only Scottish service with Paediatric Surgery, Neurosurgery and Radiotherapy all on one site. Patients on the most complex treatment protocols or those requiring ITU are cared for jointly with colleagues in Glasgow.

Dermatology
The paediatric dermatology service provides diagnostic and treatment services for children up to 14 years of age. This is provided by a consultant who works across both paediatric and adult services.

Clinical Genetics
A service for both children and adults, based on the same site as RACH, is provided by four clinical geneticists.

Radiology Imaging
A 24hr service is provided optimised for Paediatrics. Computed plain film and dental imaging, ultrasound and screening examinations are undertaken within RACH and available to the NNU. These images are sent via PACS throughout RACH including Theatres, Wards, A/E and OPD, and to the NNU.

General Paediatric Surgery
A comprehensive Paediatric Surgical service covering all secondary and tertiary surgical procedures is provided. The only exception to this is surgery for Biliary Atresia and Bladder Exstrophy which in England are supra-regional and which are sent to the dedicated centres in England. A consultant delivered service is provided. In addition, General Surgical trainees are taught in the surgery of childhood. A full surgical oncology service is delivered in collaboration with the Paediatric Oncologists. With colleagues in A&E and Orthopaedics, a comprehensive trauma service is provided.

Neonatal Surgery
Aberdeen has a regional neonatal unit and provides a full range of surgical services for this, including oesophageal atresia, NEC, abdominal wall defects, bowel atresias, diaphragmatic hernia and inguinal hernia surgery. A central venous access service is provided when required. Only babies requiring ECMO support or with bladder extrophy will be transferred to Glasgow or England respectively. All other neonatal procedures are performed locally.
ENT
With the exception of complex airway assessment and infant tracheostomy, a full secondary and tertiary paediatric ENT service is provided locally. In addition, a full emergency ENT service is provided. The service is provided by adult ENT surgeons who have a varying number of sessional commitments to the paediatric service.

Ophthalmology
A comprehensive secondary and tertiary paediatric ophthalmology service is provided locally. The only exceptions are congenital glaucoma, retinoblastoma and ptosis which are rare conditions in children and are referred to supra-regional centres in London. In addition, a full emergency service is provided. The service is provided by 2 ophthalmologists with a specialist paediatric interest.

Orthopaedics
A comprehensive secondary and tertiary paediatric orthopaedic service is provided locally, including a bone / sarcoma oncology service with the lead consultant in the MCN for paediatric sarcomas based in Aberdeen. In addition, a full trauma service is provided. The service is provided by 3 orthopaedic surgeons with a specialist paediatric interest.

Burns and Plastics
A comprehensive secondary and tertiary paediatric plastic surgical service is provided locally including a congenital hand abnormality clinic and a cleft palate service (as part of CLEFTSIS, the MCN in Scotland). With the exception of major burns, which are resuscitated and stabilised in Aberdeen and then transferred to the single Scottish centre, a full emergency service is provided. The service is provided by 3 plastic surgeons with a specialist paediatric interest.

Urology
With the exception of Bladder Exstrophy, a comprehensive paediatric urology service is provided. This includes renal surgery, hypospadias repair and complex bladder surgery. A full paediatric urodynamic service is provided locally by one of the Paediatric Surgeons and referrals are received from the other children’s hospitals for management of neuropathic bladder. A combined Spina Bifida clinic is also provided. In addition, it is part of the Scottish Genital Anomaly Network which has applied for MCN status to manage complex genital anomalies. There is an informal network with the Paediatric Urologists at Yorkhill and operate jointly both here and there on complex cases.

Neurosurgery
A general neurosurgery service for children, including neonates is provided. This includes all emergency and most elective cranial and spinal surgery but, when prolonged ventilation is anticipated, patients are transferred to Edinburgh. There is a designated paediatric subspecialist, with the two other neurosurgeons doing emergency surgical procedures. The theatres in the RACH are fully equipped for paediatric neurosurgery. The main conditions for referral elsewhere are craniofacial anomalies (Glasgow) and interventional radiology (Edinburgh).
Gastrointestinal Surgery
A comprehensive secondary and tertiary GI surgical service is provided locally, in close
co-operation with the East Coast MCN in Paediatric Gastroenterology. A minimal access
(laparoscopic) setup provides much of this service which puts us ahead of many
centres. The exception is with surgery for Biliary Atresia which is referred to the English
supra-regional service.

Cardiac Surgery
No paediatric cardiac surgery is performed in Aberdeen.

Thoracic Surgery
A comprehensive secondary and tertiary elective and emergency thoracic surgical
service is provided locally. This includes lung resection, thoracic tumour excision,
empyema surgery and bronchoscopy.

Transplant Surgery
No paediatric transplant surgery is performed in Aberdeen.

Maxillofacial Surgery
Emergency and elective maxillo-facial surgical provision is available locally.

Anaesthesia
We have 6 paediatric anaesthetists who provide a comprehensive service including
HDU/early PICU care and a paediatric pain service. The lead clinician for HDU is a
paediatric anaesthetist. They provide a consultant run elective and emergency service
for all ages from neonates to adolescence using the full range of general and regional
anaesthetic techniques.

Other Services

Accident & Emergency Department
Attendances: 20,466 new cases each year
A&E Admissions (RACH): 850 each year (under care of A&E staff)
Resuscitation room (RACH): 600 each year

The A&E department is situated in the Children’s Hospital and sees all emergency
cases and unplanned admissions. It is co-located with the adult A&E department
although operates separately. There is 24 hour access to all specialities as well as full
imaging (including CT) and laboratory support. RACH is unique in Scotland in having
on-site emergency neurosurgical provision for children. The A&E department utilises
beds in the 10 bedded multidisciplinary Paediatric Assessment Unit where children are
admitted under the care of the A&E staff.

High Dependency Unit
An HDU with 4 commissioned beds (out of an available 8) provides Level 2 care for all
medical and surgical specialities, and provides initial management of children awaiting
retrieval for ITU. A total of 330 children were admitted to the unit of which 28 were
subsequently transferred to ITU elsewhere (2004 figures).
Neonatal Intensive Care (on Foresterhill site)
The Neonatal Unit at the Aberdeen Maternity Hospital is the Tertiary Neonatal facility for the North of Scotland. There are approximately 6000 deliveries in the region. The facility provides tertiary maternity and neonatal care for all high-risk pregnancies in the region. The neonatal unit has, on average, 800-900 admissions per annum. There are facilities for management of babies requiring Nitric Oxide, HFOV and neonatal surgery. Surgical facilities are available on-site making this the referral centre in the North of Scotland, Highlands and Islands for neonates requiring surgical care. As well as providing cover for the unit, the consultants also provide a consultant run Neonatal Transport for the North of Scotland, Highlands and Islands.

Pharmacy
There is a pharmacy within RACH which provides full paediatric pharmacy services including provision of chemotherapy for oncology patients.

Child Protection
The child protection service has a purpose built child protection suite and is supported by a senior child protection nurse, the general paediatricians, social work and police.

Dentistry
There is a dedicated day case dental anaesthetic unit within the theatre suite backed up by an out patient pre-admission clinic. No dental anaesthesia occurs outwith RACH. There is a special needs dental service within the hospital and a paediatric orthodontic unit on the Foresterhill site. More complex procedures are carried out by the maxillofacial service, which has lists in the paediatric theatre.

Laboratory services
Other than the Blood Transfusion Centre, all laboratory services are located in one building on the Foresterhill site, as is RACH. This allows co-operation in sample analysis, for example haematology, immunology and genetics in leukaemia diagnosis and for liaison over cases such as childhood cancers.

Clinical Biochemistry
Full routine service available 24 hours per day. Majority of analyses are available on site with referral to national reference centres as appropriate ie specialised enzyme assays, urinary catecholamine metabolites.

Genetics
Routine service available for cytogenetic analyses for disorders such as Downs Syndrome, leukaemia and solid tumour genetics. Molecular genetics is available for leukaemia and other tumours. Antenatal testing including chorionic villous samples. The laboratory participates in the Scottish consortium for genetic analyses where individual centres are recognised for specific disease diagnostic testing.

Haematology
Full routine service available 24 hours per day. In addition to blood counts, basic coagulation tests and haematric assays, more specialised testing is available for diagnosis and monitoring of inherited and acquired bleeding disorders and inherited
thrombophilias. Bone marrow samples are reported with the appropriate cytochemical stains. There is close collaboration with immunology in the diagnosis of leukaemias.

**Immunology**
Full routine service for diagnosis and monitoring of allergy and other immunological diseases, lymphocyte typing and typing of leukaemias and lymphomas.

**Medical Microbiology/Virology**
Full routine service available 24 hours per day. As with other laboratories, most of the tests are done locally with use of national reference centres as appropriate. The Aberdeen laboratory is a national reference centre for certain tests.

**Pathology**
Full service for all children’s pathology with a Consultant Paediatric Pathologist leading. There is access to routine histopathology and cytopathology, supported by cytochemistry, immunocytochemistry and electron microscopy as required. The national (UK) network of paediatric pathologists provides support and rapid opinions on difficult cases.

**Blood Transfusion**
The regional blood transfusion centre is situated on the Foresterhill site but separate from the laboratory building. It provides a routine blood banking service together with specialised testing for tissue typing and some immunology/white cell function testing. Support for haemopoietic stem cell transplantation is available.

6 Child Health Services in Tayside

In Tayside there is a comprehensive Child Health Service based upon local provision and regional and national clinical networks. In recent years significant service re-design has been undertaken to retain high quality sustainable services within Tayside and also to provide a service for North East Fife.

**General Paediatric Medicine**
In patient care is provided in the new purpose built unit within Ninewells Hospital. Out patient services are provided in Ninewells Hospital, Perth Royal Infirmary and several outreach clinics in community hospitals in Perth & Kinross and Angus. There is an ambulatory day care unit in Perth Royal Infirmary. There are a range of specialist and general outreach services supported by doctors, nurses and other disciplines. Eleven consultants participate in the Acute Service.

**Cardiology**
Tayside is linked with the Scottish Paediatric Cardiology Network with one stop diagnostic service being provided at all clinics. Links with the tertiary centre in Glasgow are strengthened by local co-ordination of the service by a Consultant Paediatrician and the availability of an outreach Paediatric Cardiology Nursing Service.

**Respiratory Medicine**
A full secondary and tertiary respiratory service is provided by 3 consultant staff. This includes asthma and cystic fibrosis clinics. There is a full respiratory function laboratory
including ciliary function. Paediatric bronchoscopy service is provided outwith Tayside. Respiratory Medicine and lung biology is a major research interest of the Maternal & Child Health Sciences Division. Children who require home ventilation receive shared care with Glasgow but supported by our local outreach nursing service.

**Gastroenterology, Hepatology and Nutrition**
This service is provided by a local Consultant Paediatrician and a visiting tertiary Paediatric Gastroenterologist from Aberdeen working within the North of Scotland Paediatric Gastroenterology & Nutrition Network. This service is supported by dedicated sessions for a nutrition nurse and paediatric dietetics. There is also close collaboration with the Adult Gastroenterology Service. Hepatology services are provided jointly with King’s College Hospital, London.

**Diabetes and Endocrinology**
The Diabetes and Endocrinology Service is provided by tertiary trained staff and is part of the Diabnet Network which includes Tayside, Fife and Forth Valley.

**Inherited Metabolic Disease**
This service is provided locally by a senior clinical academic and is supported by local Biochemistry and Genetics personnel. The service works closely with the Metabolic Service in Glasgow.

**Neurology / Neuroscience / Neurodisability**
The Neurology Service is provided by 2 local tertiary trained Paediatric Neurologists who provide the North of Scotland Neurology Network. This service is supported by a Neurophysiology Service, Outreach Nursing Service and Paediatric Neurosurgical Services, both locally and in Edinburgh. There is a dedicated Child Development Centre and consultants with responsibility for neurodevelopment and also complex needs. There is a purpose built unit to support children with severe learning difficulties.

**Renal Medicine**
This service is co-ordinated by a local Consultant who contributes to the national Paediatric Nephrology Network. The service is supported by the visiting Paediatric Nephrology Team from Glasgow and also there is a local full radiological service.

**Rheumatology**
This service is provided by a senior academic in collaboration with a local Adult Consultant Rheumatologist and contact with other national centres.

**Haematology / Oncology**
This service is provided locally by a formal shared care service with the Royal Hospital for Sick Children in Edinburgh. The service is supported by local elective Paediatric Surgery, Neurosurgery and Radiotherapy.

**Dermatology**
The Paediatric Dermatology Service is supported by a local Consultant Dermatologist who has had extensive training in Paediatric Dermatology.

**Clinical Genetics**
Radiology Imaging
A 24 hour service is provided for Paediatrics with full radiological imaging techniques being available. There is a Consultant Radiologist with paediatric interest.

General Paediatric Surgery
This service is provided as part of a network with the Royal Hospital for Sick Children in Edinburgh. The Network enables most elective general paediatric and paediatric urology surgery to be provided locally. More major surgery and most of the acute surgery is undertaken in Edinburgh. With colleagues in A&E and Orthopaedics a comprehensive trauma service is provided.

Neonatal Surgery
Emergency and major neonatal surgery is undertaken in the Royal Hospital for Sick Children in Edinburgh. Minor and some elective surgery is undertaken in Dundee.

ENT
A full range of ENT procedures, including the management of complex airway and infant tracheostomy, are provided locally and there is close collaboration with the Paediatric Respiratory Service.

Ophthalmology
A comprehensive and some tertiary paediatric ophthalmology is provided locally. A full emergency service is provided and there are 2 ophthalmologists who have specialist paediatric interest.

Orthopaedics
A comprehensive secondary and some tertiary paediatric orthopaedic service is provided locally. There are formal links between the orthopaedic surgeon with an interest in Paediatrics and the service at the Royal Hospital for Sick Children. There is a full trauma service provided.

Burns and Plastics
A comprehensive secondary and tertiary paediatric plastic surgery service is provided locally including a congenital hand abnormality clinic and a cleft palate service (as part of CELFTSIS, the MCN in Scotland which is co-ordinated from Dundee). With the exception of major burns which are resuscitated and stabilised in Dundee and then transferred to the single Scottish centre, a full emergency service is provided.

Urology
This is provided through the Paediatric Surgical Network with the Royal Hospital for Sick Children. Investigation, day case surgery and some of the in patient surgery is undertaken locally. There is close collaboration between the general paediatric surgeons and the local urology service.

Neurosurgery
Neurosurgery for ventriculo-peritoneal shunts, head injury and some brain tumours are undertaken locally. There is close collaboration with the neurosurgical units in Edinburgh and Glasgow.

**Gastrointestinal Surgery**
Emergency and major gastrointestinal surgery is undertaken in Edinburgh. There is an acute and elective service for less serious conditions.

**Transplant Surgery**
No paediatric transplant surgery is undertaken in Dundee and Tayside.

**Maxillofacial Surgery**
Emergency and elective maxillofacial surgery is provided locally.

**Anaesthesia**
There are 6 Consultant Anaesthetists who have a special interest in Paediatric Anaesthesia who provide an on call service and also the elective Paediatric Anaesthetic Service.

**Other Services**

**Accident & Emergency Department**
The A&E Service in Tayside is consultant based and they have been trained in Paediatric A&E. There is full imaging and laboratory support and on site emergency neurosurgical provision.

**HDU**
There is an HDU in the children’s unit with 5 beds (2 that can offer isolation). This is supported by a Consultant Paediatrician with an interest in high dependency care and also led by a senior nurse with experience in paediatric intensive care.

**Neonatal Intensive Care**
Neonatal Intensive Care is provided in Ninewells Hospital. There are 4100 deliveries per annum in the region and approximately 360 admissions to the unit per annum. Full conventional neonatal intensive care is provided by 5 neonatal consultants. There are telemedicine communications with Royal Hospital for Sick Children in Glasgow. The unit contributes to the North of Scotland Neonatal Transport Service.

**Pharmacy**
There is a pharmacy service within Ninewells Hospital and there is a Senior Paediatric Pharmacist who takes responsibility for the provision of all aspects of the service.

**Child Protection**
There is a comprehensive Child Protection Service with a daytime on call rota and a purpose built child protection examination suite. There is also a Consultant Nurse in Child Protection and she is supported by 3 Senior Child Protection Nurses.

**Dentistry**
There is a dedicated day case dental anaesthetic unit within Ninewells Hospital.

**Laboratory Services**
All of the laboratory services are located within Ninewells Hospital.

**Clinical Biochemistry**
There is a full routine microbiology service, many of the assays being available on microsamples.

**Genetics**
There is a routine service for cytogenetic analyses and also clinical genetic support.

**Haematology**
There is a full routine haematology service in Ninewells Hospital.

**Immunology**
There is a full routine service for dimers and the monitoring of allergy and other immunological diseases.

**Medical Microbiology / Virology**
There is a full routine service available 24 hours per day within Ninewells Hospital.

**Pathology**
A full service for children’s pathology although there are specific links with Aberdeen for neuropathology.
Department of Health Specialised Services Definitions

The Department of Health together with the NHS in England have agreed a set of definitions for specialised services to support planning, commissioning, delivery and performance management of these services. The second edition of the Definition Set, covering 35 services, was published in December 2002. Additionally Statutory Instrument No 2375, The National Health Service (Functions of Strategic Health Authorities and Primary Care Trusts and Administration Arrangements) (England) Regulations 2002, defines specialised services as those services with planning populations of more than one million people.

Broadly, specialised services are those with low patient numbers but which need a critical mass of patients to make treatment centres cost effective. Particular challenges for these services include training specialist staff, supporting high quality research programmes, and making the best use of scarce resources like expertise, high tech equipment and donated organs.

In the English NHS specialised services are subject to different commissioning arrangements than other NHS services. Very highly specialised services are commissioned by the Department of Health under the auspices of the National Specialist Commissioning Advisory Group and other specialised services are commissioned on a collaborative basis by Primary Care Trusts. Collaborations are at both Regional and Local level through Regional and Local Specialised Commissioning Groups. These levels tend to fall into planning catchment populations, at a Regional level of between 3 – 6 million with around 8-15 specialist centres in the country and on a Local level of between 1 and 3 million with around 20 to 30 specialist centres in the country. However not all specialised services fall neatly into one of these groups and patterns of provision do differ markedly around the country. Equally specialised services are not fixed in time, as a disease/condition/treatment becomes more common, so the number of specialist centres dealing with that disease/condition and providing treatment may increase.

The services included in the Specialised Services National Definition Set (2nd edition) were developed through national working groups and subject to national consultation. They identify activity that should be regarded as specialised and subject to collaborative commissioning arrangements. Each definition is divided into two sections, the first one provides descriptions of the various services covered and the second section includes specific issues considered to be important by the working group concerned. A list of the definition sets is attached to this appendix.

Definition 23 refers to Specialised Services for Children, however there are a number of other definitions which refer to all ages and thus should be considered relevant to children. A number of the definitions have been endorsed by relevant national organisations.
Specialised Services National Definition Set (2nd edition).

Specialised Services National Definition Set
Specialised Services National Definition Set: 1 Specialised cancer services (adult)
Specialised Services National Definition Set: 2 Specialised services for blood and marrow transplantation (all ages)
Specialised Services National Definition Set: 3 Specialised services for haemophilia and other related bleeding disorders (all ages)
Specialised Services National Definition Set: 4 Specialised services for women's health
Specialised Services National Definition Set: 5 Assessment and provision of equipment for people with complex physical disabilities (all ages)
Specialised Services National Definition Set: 6 Specialised spinal services (all ages)
Specialised Services National Definition Set: 7 Complex specialised rehabilitation for brain injury and complex disability (adult)
Specialised Services National Definition Set: 8 Specialised neurosciences services (adult)
Specialised Services National Definition Set: 9 Specialised burn care services (all ages)
Specialised Services National Definition Set: 10 Cystic fibrosis
Specialised Services National Definition Set: 11 Specialised renal services (adult)
Specialised Services National Definition Set: 12 Home parenteral nutrition (adult)
Specialised Services National Definition Set: 13 Specialised cardiology and cardiac surgery (adult) including cardiothoracic transplantation (all ages)
Specialised Services National Definition Set: 14 Specialised services for HIV/AIDS treatment and care services (all ages)
Specialised Services National Definition Set: 15 Cleft lip and palate services (all ages)
Specialised Services National Definition Set: 16 Specialised clinical immunology services (all ages)
Specialised Services National Definition Set: 17 Specialised services for allergy (all ages)
Specialised Services National Definition Set: 18 Specialised services for infectious diseases (adult)
Specialised Services National Definition Set: 19 Specialised services for hepatology
Specialised Services National Definition Set: 20 Medical genetic services (all ages)
Specialised Services National Definition Set: 21 Specialised learning disability services
Specialised Services National Definition Set: 22 Specialised mental health (adult)
Specialised Services National Definition Set: 23 Specialised services for children
Specialised Services National Definition Set: 24 Specialised dermatology services (adult)
Specialised Services National Definition Set: 25 Specialised pathology services (all ages)
Specialised Services National Definition Set: 26 Specialised rheumatology services (adult)
Specialised Services National Definition Set: 27 Specialised endocrinology services (adult)
Specialised Services National Definition Set: 28 Hyperbaric treatment services (adult)
Specialised Services National Definition Set: 29 Specialised respiratory services (adult)
Specialised Services National Definition Set: 30 Specialised vascular services (adult)
Specialised Services National Definition Set: 31 Specialised pain management services (adult)
Specialised Services National Definition Set: 32 Specialised Ear Surgery (all ages)
Specialised Services National Definition Set: 33 Specialised colorectal services (adult)
Specialised Services National Definition Set: 34 Specialised orthopaedic services (adult)
Specialised Services National Definition Set: 35 Specialised morbid obesity services (all ages)

References:
Guidance on Commissioning Arrangements for Specialised Services, Department of Health, March 2003
Specialised Services for Children – Definition No. 23, Department of Health
Annotations

to the

Charter for Children in Hospital

The EACH Charter

The EACH Charter\(^1\) is a list of the rights for all children before, during or after a stay in hospital. The goal of EACH – European Association for Children in Hospital – and its member organisations is to achieve a binding commitment to the implementation of these rights in all European countries.

- **Parents are invited** to provide or arrange to provide the support and care their children need.
- **Those in public office are invited** to create the framework within which the parents may become active in the care of their child in hospital.
- **Those involved in the care of sick children are invited** to get acquainted with the rights of children in hospital and to act in accordance with those rights.

These Annotations to the Charter are intended to provide a better understanding of the ten points of the EACH Charter for the rights of children in hospital.

The Annotations were prepared for the 7\(^{th}\) EACH Conference in December 2001 in Brussels by the authors of the EACH-Charter of 1988 and are offered as a useful supplement to the Charter.*

The EACH Charter and the Annotations to the EACH Charter

are to be understood in the following context:

- All rights mentioned in the Charter and all measures taken or derived from the Charter must in the first place be in the best interests of children and enhance their well-being.

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\(^1\) **Notes:**

- The EACH Charter was adopted by the 1\(^{st}\) European Conference in Leiden/NL in May 1988.
- The Annotations were adopted by the 7\(^{th}\) European Conference in Brussels in December 2001.
The terms marked with * are explained in more detail in the attached Glossary to avoid misunderstandings and to give a more precise idea of the meaning of the Charter.

The rights mentioned in the Charter apply to all sick children, regardless of their illness or age or disability, their origin or their social or cultural background, or of any possible reason for treatment or forms or places of treatment, whether as in-patients or out-patients.

The EACH Charter is in line with corresponding and binding rights stipulated in the UN Convention on the Rights of the Child and refers to children as being aged from 0 – 18.

The present document has been prepared to assist in the implementation of the EACH Charter, some of whose goals are still unachieved in Europe, such as:

- The right of children to have their parents with them in hospital is sometimes restricted and made subject to a particular age or illness of the child or to the social standing of the family.
- The special needs of adolescents in hospitals are often not sufficiently addressed.
- In the daily hospital routine little regard still is given to what we know today about the psychological, emotional and social needs of children of different ages and developmental stages, their origin or their social or cultural background.
- Pain control for children is still a neglected area.
- Guidance for staff on established practice for action when a sick child shows signs of abuse or maltreatment is often missing.
- Children are still being admitted to adult wards.

When implementing the Charter in all European countries it furthermore it has to be considered that

- Health care is subject to varying economic conditions and constraints.
- Health services are organised differently from country to country.

The following members of EACH adopted the Annotations

Austria: Verein Kinderbegleitung
Belgium: HU Association pour l'Humanisation de l'Hopital en Pédiatrie
Denmark: SBB Nobab-Danmark
Finland: Suomen Nobab Finland
France: APACHE Association pour l'Améliorisation des Conditions d'Hospitalisation des Enfants
Animation Loisirs à l'Hopital
Child Healthcare Services in Scotland

Appendix 9

Germany: AKIK Aktionskomitee Kind im Krankenhaus Bundesverband e.V.
Greece: Association of Social Pediatric Friends
Iceland: Umhyggja Nobab-Iceland
Ireland: Children in Hospital Ireland (CHI)
Italy: A.B.I.O. Associazione per il Bambino in Ospedale
Japan: NPHC Network for Play Therapy & Hospital Environment for Children
Netherlands: Kind en Ziekenhuis
Norway: Nobab Norge
Portugal: IAC Instituto de Apoio à Criança, Dept. Humanisation of Child Attendance
Sweden: Nobab Sweden
Switzerland: Swiss Association for Children in Hospital
United Kingdom Action for Sick Children(England)
Action for Sick Children (Scotland)
AWCH Association for the Welfare of Children in Hospital (Wales)

Article 1

Children* shall be admitted to hospital only if the care* they require cannot be equally well provided at home or on a day basis.

- Before admitting a sick child to a hospital* all forms of appropriate care* shall be explored whether at home, in a day clinic or comparable forms of treatment, in order to find the most suitable solution.
- The rights of sick children must be respected whether they are cared for at home or in hospital.
- There should be a regular review of the type of care according to the child’s condition so that there is no unnecessary continuation of hospital stay.
- All necessary information, assistance and support shall be given to parents if their children are cared for at home or on a day basis.
Article 2

Children in hospital shall have the right to have their parents* or parent substitute* with them at all times.

- The right of all children to have their parents with them at all times without restriction is an integral part of the care for children in hospital.
- If parents are unable or unwilling to take an active role in the care of their child, the child is entitled to receive this care from a suitable substitute carer*, who is accepted by the child.
- Children’s rights to have their parents with them at all times, includes all situations where they need or possibly might need their parents, e.g.
  - during the night, whether or not the child may wake up
  - while having treatments and/or examinations with or without local anaesthesia, with or without sedation
  - during induction of anaesthesia and immediately upon recovery
  - during periods of coma or semi-consciousness
  - during resuscitation, when parents must be offered full support

Article 3

(3.1) Accommodation* should be offered to all parents and they should be helped and encouraged to stay.

- The staff members* responsible for admitting a child shall invite all parents to stay without setting any particular criteria.
- Staff members shall advise, encourage and support parents in making a decision about staying in hospital with their child, based on the parents’ appreciation of their home situation.
- Hospitals shall provide sufficient and suitable space and infrastructure to enable parents to be admitted along with their sick children. This should include the bed space together with bathroom, sitting and dining facilities and storage space for personal belongings.

(3.2) Parents should not need to incur additional costs or suffer loss of income.
- No additional costs shall arise for parents when staying with their child. They should be entitled to
  - free overnight stay
  - free or subsidised food.

- Parents who are unable to attend work or fulfil duties at home shall not incur any loss of income or incur other costs due to:
  - staying in hospital with their child
  - the full-time care of their child in hospital or
  - the daily care of healthy siblings at home by other persons.

- Assistance should be provided where financial circumstances prevent a parent from staying with or visiting a child (e.g. travelling cost and other expenses).

- Parents shall be entitled to leave with pay for the duration of the child’s illness to cover the loss of income.

(3.3) In order to share in the care* of their child, parents should be kept informed about ward routine* and their active participation encouraged.

- The staff shall facilitate the parents’ active participation in caring for their child by
  - giving parents full information regarding their child’s care and about ward routine*;
  - arranging with parents the elements of care they want to take over;
  - supporting the parents in doing this;
  - accepting their decisions;
  - discussing with them changes needed if their care is not helpful to the child’s recovery.

Article 4

(4.1) Children and parents shall have the right to be informed in a manner appropriate to age and understanding.

- Information for children should:
  - be based on age and understanding and take into account the child’s level of development;
  - understand the child’s immediate situation;
  - appreciate his capacity to comprehend information and express his views;
- encourage questions, answer the questions raised and comfort children when they express concerns or fears;
- include appropriately prepared verbal, audio-visual and written information, supported by illustrative models, play or other media presentations;
- whenever practicable information should be given in the presence of the parents.

- Information for **parents** should:
  - be clear and comprehensive;
  - consider the parents’ present situation especially their feelings of fear, sorrow, guilt, anxiety or stress regarding their child’s condition;
  - encourage questions;
  - satisfy the need for information by directing parents to extra information sources and support groups;
  - provide parents with unrestricted access to all written or pictorial documentation regarding the illness of their child;

- The child or a sibling should not be used as an interpreter for the parents.

- Information to meet both the child’s and its parent’s needs should
  - be provided continuously from admittance to discharge of the patient;
  - include information regarding care after discharge;
  - be provided in a stress free, secure and private environment without pressure of time;
  - be given by experienced staff competent to communicate information in a way which can be readily understood:
  - repeated as often as necessary to facilitate understanding;
  - be checked by the staff member to ensure that the information given has been properly understood by both the child and the parents

- Children have the right to express their own views and providing they have sufficient competence to understand the matter, they may veto their parents’ access to their health information. In such a case staff are required to proceed with the utmost care to properly evaluate the situation. Protection, counsel and support shall be given to the child. But hospital staff should ensure that the necessary counsel and support are also given to the parents who might be in need of psychological and social help and advice.

(4.2) **Steps should be taken to mitigate physical and emotional stress.**

- **To reduce** physical and emotional stress and pain experienced by children preventive measures have to be taken, which should:
  - be adapted to the individual needs of the child
- provide information and programmes to prepare children and parents for a stay in hospital, whether planned or emergency;
- provide preparation information prior to planned procedures;
- encourage continuous contact with parents, siblings and friends;
- offer play and recreation activities suitable to the child’s age and development;
- ensure effective up-to-date pain management to avoid or reduce pain incurred by medical treatment, whether during examination, intervention or pre- or post-operatively;
- grant sufficient periods of rest between treatments;
- support parents whose children are receiving palliative care;
- prevent feelings of isolation and helplessness;
- try to avoid or reduce situations or actions described by the child as stress inciting;
- recognise fears or concerns of the child whether or not explicitly expressed and act upon them;
- be aware that a child may become stressed by being isolated or as a reaction to the condition of other patients and take appropriate action;
- feature stress free and appropriately equipped rooms allowing children and parents the opportunity to retreat
- avoid use of restraints

To mitigate unavoidable physical or emotional stress, pain, and suffering children and parents should be offered:
- ways of dealing with painful situations or actions experienced as negative;
- support for parents as well as measures ensuring their protection from too much strain while caring for their child;
- contact with social services, psychologists
- contact when requested with minister of religion, self-help groups, patient / parent-help groups and cultural groups.

Article 5

(5.1) Children and parents have the right to informed participation in all decisions involving their health care*

The right to participate in the health care of the child requires from staff members:
- adequate information to the child and the parents regarding their child’s immediate health condition, the proposed forms, risks, and merits of treatment or therapy and its goals as well as the measures to be taken.
- adequate information on alternative forms of treatment
- advice and support to parents enabling them to evaluate the proposed way of proceeding
to appreciate and make use of the child’s and parent’s knowledge, experiences, descriptions and observations on the general health situation or present condition of the child.

- Prior knowledge of all measures that need to be taken is a pre-condition for the active involvement of children and parents in decision making.

(5.2) Every child shall be protected from unnecessary medical treatment and investigation.

- In this context any form of medical treatment or investigation of a child is unnecessary, if no benefit for the individual child can be derived.

**Article 6**

(6.1) Children shall be cared* for together with children who have the same developmental needs* and shall not be admitted to adult wards*.

- The care of children together with children who have the same developmental needs, includes, but is not limited to
  - rest;
  - entertainment;
  - joint or similar activities;
  - activities for children of a mixed age group;
  - separate rooms and activities according to age and gender,
  - particular efforts being made to provide separate accommodation for adolescents;
  - protective measures for children with specific illnesses.

- The special needs of adolescents should be taken care of by providing appropriate infrastructure as well as recreational opportunities.

- Any form of segregation of children must be avoided, in particular cultural segregation.

- The care of children together with adults on the same ward is not acceptable, and consequently means:
  - children shall not be admitted to or cared for in adult wards;
  - adults shall not be admitted to or cared for in children’s wards;
  - separate provision should be available for the treatment of children and adults in areas such as reception, emergency rooms, surgery, outpatient and day care facilities as well as examination and therapy rooms.
(6.2) There should be no age restrictions for visitors to children in hospital.

- Visiting hours for siblings and friends shall not be restricted based on the age of the visitor, but based on the condition of the sick child and the health of the visiting children.

**Article 7**

Children shall have full opportunity for play, recreation and education suited to their age and condition and shall be in an environment designed, furnished, staffed and equipped to meet their needs.

- Children have the right to an environment which meets the needs of children of all ages and situations wherever in the hospital they are being cared for. This applies also to day facilities or other areas where children are being treated or examined.

- Extensive possibilities for play, recreation and education should
  - be available in the form of appropriate play materials;
  - ensure adequate periods of time for play seven days a week;
  - provide for the abilities of all age groups cared for in the facility;
  - inspire creative activities by all children;
  - allow for the continuation of the level of education already reached.

- Sufficient suitably qualified staff should be available to meet the needs of children for play, recreation and education regardless of the state of health and age of the children. All staff in contact with children should have an understanding of the needs of children for play and recreation.

- The architecture and interior design of such an environment must incorporate appropriate features for all age groups and types of illnesses treated in the facility. The environment should be adaptable to the needs of different age groups and not be focused on one particular age group.

**Article 8**

Children shall be cared for by staff whose training and skills enable them to respond to the physical, emotional and developmental needs of children and families.
Specific professional training, skills and sensitivity are required for staff caring for sick children. Only on the basis of these qualifications are they able to meet with the special needs of children and their parents.

All hospitals or other health care providers admitting children should ensure that children are examined, treated and cared for by staff with specific paediatric education, knowledge and experience.

If a child needs to be treated by non-paediatric staff, such treatment may only be carried out in co-operation with staff specially trained and qualified to care for children.

The ability and sensitivity of staff shall be maintained at a high level by appropriate training and continuing education.

To know and address the needs of families is a pre-condition for being able to support parents in the care of their child and if necessary organise support or alternative care for the child to relieve the strain on the family.

Qualified staff are capable of recognising and reacting in an appropriate way to all forms of child abuse.

Staff members will support parents in particular to cope with critical situations a child might endure. This applies especially to life-threatening situations.

When a child is dying or dies, the child and his/her family must be given whatever support, care and assistance they need to help them cope. Staff should undertake appropriate bereavement training. Information regarding the death of the child should be given sympathetically, sensitively, in private and in person.

**Article 9**

**Continuity of care should be ensured by the team caring for children.**

- Continuity of care includes continuity in the provision of the child’s treatment and continuity among the staff providing their care.

- Continuity of care should apply both in the hospitals and following transition to home or day care. This can be achieved by all those involved communicating and working together as a team.
Team work requires a limited and defined number of persons working together as a group whose action is based on complementary levels of knowledge and consistent standards of care *, focused on the physical, emotional, social and psychological well-being of the child.

**Article 10**

Children shall be treated with tact and understanding and their privacy shall be respected at all times.

- Tact and understanding in dealing with children requires the need to:
  - include the right to be a child;
  - consider their dignity, view, needs, individuality and their state of development, taking account of any disability or special need;
  - make the willingness of the staff for dialogue apparent;
  - create a friendly and trusting atmosphere;
  - take into consideration the religious belief and cultural background of the child and the family.

- Regardless of age or state of development the protection of the privacy of children shall be secured at all times and must include:
  - protection against physical exposure;
  - protection against treatment and behaviour which diminishes self respect or makes the child feel ridiculous or humiliated;
  - the right of personal retreat, to be alone;
  - the right of private communication with staff;
  - the right of undisturbed association with close family members and friends.

*Brussels, December 9, 2001*
National Framework for Service Change Action Team on Specialised Paediatric Services

Final Report on Paediatric Intensive and High Dependency Care
The foundation for the management of critical illness in children in Scotland is high dependency care.
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1. Introduction

1.1 Reasons for review / background

1. The Specialised Paediatric Services Action Team identified the provision of paediatric intensive care (PIC) and high dependency care (HDC) as an immediate issue for NHS Scotland in the light of trends in activity and casemix that may not be sustainable within the current provision. The Action Team considered that the planning of PIC must be integrated with that of paediatric high dependency care and neonatal surgical intensive care (NSIC). There are critical interdependencies with a number of specialist paediatric services and thus the planning of PIC is a key factor in the planning of specialised paediatric services.

2. Neonatal medical intensive care (NMIC) was excluded from this review because the medical needs of most critically ill newborn babies can be met in neonatal intensive care units within maternity hospitals. The clinical needs of this group differ from babies with major congenital anomalies that require surgical or other complex interventions and the skills of a specialist multidisciplinary team. In conditions such as diaphragmatic hernia the surgeons and neonatologists work as a close team to provide combined care. Neonatal medical intensive care, on the other hand, is a relatively high volume service and is fundamentally linked to maternity care. Any changes and developments of NMIC need to be planned as part of maternity care.

3. The particular issues addressed by the Specialised Paediatric Services Action Team were:
   a. An assessment of whether paediatric intensive care can continue to be sustained in Glasgow and Edinburgh as it is now for the foreseeable future, and neonatal surgical intensive care sustained in Glasgow, Edinburgh and Aberdeen;
   b. An assessment of the level of paediatric intensive care and neonatal surgical intensive care required for the population of Scotland, projecting this forward for 5-10 years.
   c. The preparation and initiation of a longer term exercise to collect information on High Dependency Care provided throughout NHS Scotland.

1.2 Approach to task

4. The Action Team stipulated that work on the first 2 headings should focus on current service provision at the Royal Hospitals for Sick Children in Edinburgh and Glasgow, and the Southern General Hospital.

5. The preparation and initiation of the longer term exercise to collect information on High Dependency Care was to cover all NHS Scotland, and this work was led by Dr Jennifer Armstrong, a Consultant in Public Health Medicine at NSD. It took the form of consulting colleagues to agree and specify the data items for a prospective audit through which information can be collected over 2 years in order to inform future planning of Specialist Paediatric Services.

6. The paediatric intensive care and neonatal surgical intensive care work was led by Mrs Deirdre Evans, Director NSD, on behalf of the Action Team and many other members of the
action team were actively involved. The Chairman, Mr Peter Bates took a keen personal interest and visited the two children’s hospitals in Glasgow and Edinburgh.

7. The work involved the compilation, analysis, and consideration of statistical information about critical care for infants and children; literature review; face to face and telephone interviews; visits to the hospitals; and correspondence.

8. The Action Team is indebted for the help and support of a wide range of individuals in this exercise. The team would like to thank all the staff of the specialist children’s hospitals and NHS Boards - both clinicians and managers - who provided expert advice and detailed information within short timeframes. Particular thanks are due to Dr John Sinclair, Dr David Simpson, and Mr Carl Davis who, with Mrs Evans, are the co-authors of this report and who provided the expert input and literature review; Mr Bob Fraser, Mr David Daniels, and Mr Jim Miller who compiled and analysed the statistics; and Miss Isabel McCallum, Professor George Youngson, Dr A McIntyre, Ms M Taylor, Dr G Wilson and Dr R Wilkie for their considered advice and guidance.

2. Need for service

2.1 Description of conditions treated

9. Initially developed to provide support after major surgery, paediatric intensive care is now used with good effect in the management of a variety of critical illnesses and injuries in children. The Paediatric Intensive Care Society has published a clear, widely agreed, definitions of paediatric intensive care based on levels of dependency on nursing support, the need for ventilation and whether there is single or multiple organ failure. No common definition of high dependency care exists. A full spectrum of care is needed and the required staffing levels per bed vary significantly from one end of the spectrum to the other. Definitions of each level of care are bandings within the full spectrum rather than distinct levels of care.

10. Information on paediatric critical care in Scotland has largely been derived from the Scottish Paediatric Intensive Care Audit (SPICA 1997). This covered PIC across Scotland (and NSIC in Edinburgh) but excluded NSIC in Glasgow and HDC. Hence there is little information about the provision of HDC in Scotland.

11. There are agreed protocols and admission criteria for PIC and neonatal surgical intensive care in Scotland. High dependency care is known to be provided in many hospitals in Scotland and admission criteria for high dependency care are thought to vary across Scotland. Some high dependency children are cared for at home on home ventilatory support.

2.2 Needs for Paediatric Intensive Care

12. The Scottish Paediatric Intensive Care Audit (SPICA 1997) identified that approximately 1000 children per annum require intensive care in Scotland. Current activity levels support these figures (see below).

13. The SPICA audit identified a need for 25 PIC beds in Scotland.
14. Since the Scottish Paediatric Intensive Care Audit was conducted there has been considerable reorganisation of paediatric intensive care in Scotland. In 1997 intensive care was being delivered to children in 14 different locations. Now many fewer units around Scotland provide intensive care including, for example, ongoing ventilation support for children beyond 24 hours. The majority of paediatric intensive care is now delivered on 3 sites: Glasgow PIC Unit, Edinburgh PIC Unit and the Intensive Care Unit at the Institute for Neurosciences at the Southern General Hospital, Glasgow.

15. Professional guidelines are increasingly recommending certain paediatric procedures are carried out only on sites with PIC backup.

16. Since the establishment of the national paediatric transport service for critically ill and injured children, there has been an increasing trend towards transferring children to the Edinburgh Hospital for Sick Children and Yorkhill Hospital from hospitals in the rest of Scotland. Moreover there has been increasing joint working of the two PIC sites so that each cross covers the other, and together they provide a co-ordinated national service for the whole of Scotland.

17. Cardiac surgery and neurosurgery services both require PIC facilities and these services are high users of PIC. All cardiac surgery and interventional cardiology for children in Scotland has been provided in Yorkhill since July 2000, as is renal transplantation, interventional fetal medicine, allogenic bone marrow transplantation and extra-corporeal life support (ECLS). Future decisions on other specialised services may also involve one centre providing a service for all children in Scotland. The total number of PIC beds available to Scotland will have to be used flexibly to cope with fluctuations in need. As a result, there is an increasing need for the service to be run as a single national service on two sites.

18. Superimposed on the trends towards centralisation of PIC services, there has been an upward trend in referrals to Edinburgh and Glasgow which is set to continue, and spikes in need that exceed current capacity. There has been significant improvement in the survival of extremely low birthweight babies over the last decade, which have a high rate of serious morbidities and challenging needs for critical care.

2.3 Needs for Neonatal Surgical Intensive Care

19. Over the last 30 years the nature of neonatal surgical conditions has gradually changed. The incidence of conditions such as neural tube defects has diminished but in its place have come greater numbers of other conditions such as gastroschisis, congenital diaphragmatic hernia, patients requiring extracorporeal life support and premature infants requiring complex multidisciplinary care with major neonatology and other specialist input.

20. The Glasgow neonatal surgical service provides both a regional service for the West of Scotland (similar to that provided by Aberdeen and Edinburgh for the North and East of Scotland) and a national service for those babies requiring specific expertise only available in Glasgow. It has seen a rise in the number of admissions, now stabilising around 325 per year. Data on complexity of case mix have been gathered at Yorkhill since 1997.
Activity in Edinburgh is included within the PIC figures and is not available separately. Information from Aberdeen on neonatal surgical activity similarly is not recorded separately from other neonatal data.

2.4 Needs for High Dependency Care

21. The foundation for the management of critical illness in children in Scotland is high dependency care. All hospitals admitting children who are, or who may become, critically ill must be able to resuscitate and stabilise them. Hence hospitals that plan to provide a range of specialised services for children need high dependency support and the sustainability of tertiary children’s services depends on access to HDU care.

22. As indicated above, robust information on the levels of HDU care provided in Scotland are not available. Literature suggests that numbers will be at least 5 times the levels of PICU required. The numbers of admissions to HDU a year may therefore be over 5,000.

23. The numbers of children requiring high dependency care (as distinct from intensive care) being transferred by the critical care retrieval teams from Edinburgh and Glasgow are increasing. Largely these retrievals are requested from hospitals without the ability to provide...
paediatric high dependency care but trends suggest that consultants in district general hospitals that previously provided such care for children now consider that a transfer to specialist centres is required.

24. On some occasions, transfer is arranged from hospitals with HDC facilities to the PIC Units in Edinburgh or Glasgow if a child’s condition is deteriorating even if, in the event, only HDC rather than PIC is required on arrival.

25. Information is needed on the availability of HDC facilities with suitably trained and skilled staff; admission criteria to HDC; the numbers of children needing HDC; the severity and nature of their illnesses; patient pathways, including decision processes around escalation to higher levels of critical care; the quality and outcomes of HDC provided; and arrangements for children to return to step down care as close to home as possible when appropriate.

26. For these reasons the Action Team recommends the initiation of a prospective audit of HDC in Scotland to collect the following data items:

- Entry criteria
- Demographic details including preadmission treatment and admission details
- Diagnosis with concomitant factors
- Progress with monitoring/intervention details and indicate if level of care changed
- Complications/drug treatment
- Transfer details
- Outcome
- Resources available – e.g. medical/nurse staffing
- Discharge details

Data collection should allow severity of illness score to be calculated and correlate against resource used.

2.5 Current Activity and Trends

27. There is a trend towards increasing volume and casemix complexity in specialist centres due to new techniques and technologies that can achieve survival and good outcomes for babies and children who would previously have died but now require much higher nursing ratios, more intensive interventions and, in some cases, extended lengths of stay. A recent paper on “Fetal Infants” demonstrates a 36% survival to discharge of patients admitted to NIC with a birth weight < 500g and in the discussion talks about increasingly complex needs of these children. This is an example of a group of children who are more likely to require access to PIC in infancy and childhood.

28. Clinicians at specialist centres report an increasing reluctance of staff in District General Hospitals to admit or take back babies and children as knowledge and skills in paediatric and neonatal critical care diminish in local hospitals.

29. There are not universally in place planned “exit” or “step down” arrangements to transfer patients from the specialist intensive care units in Edinburgh and Glasgow to suitable neonatal IC or paediatric HDC facilities, where these exist, in children’s and maternity
hospitals. This is exacerbated by the absence of a “return” transport service mirroring the retrieval service for the transport of critically ill and injured children.

30. Long term ventilated children present an increasing problem. An increase in the number of patients requiring this type of support has occurred since the SPICA audit. The majority of complex patients present to Glasgow because Yorkhill provides a number of specialist services (cardiac surgery, major airway surgery, ECLS, etc.). They do so either for initial treatment or for ongoing management after failed weaning strategies in other centres. This has resulted in prolonged periods when Glasgow’s PICU capacity is significantly reduced by patients whose needs are compatible with care in a ward or community based setting. A significant number of these patients are subsequently ventilated in the respiratory ward in Yorkhill and from that point onwards do not appear in Glasgow’s PICU figures. The impact on intensive care resources of this patient group is difficult to predict but there has been a clear and rapid rise in numbers over the last few years. Future plans need to take this into account.

31. There is wide recognition that current trends in activity and casemix complexity cannot be sustained within the existing levels of provision. Needs are already outstripping existing services. Figures and an analysis of trends in activity are set out below. The key statistical indicator used is “weighted occupied bed days”. This measure provides a crude but effective indicator of the impact of casemix on the service. It is essential to adjust basic occupied bed day rates in intensive care to reflect the dependency levels of bed occupants since staffing ratios (predominantly nursing) vary more than four fold from the most complex cases to the least. The main limitation at present on the availability of intensive care in both paediatric and neonatal surgical settings is usually not the physical availability of a bed or cot but of the skilled staff to care for the occupant. At times when a few very high dependency patients are in the PIC Unit or neonatal surgical IC Unit, not all physical bed spaces available can be staffed (staff need to double up to provide the care needed for the high dependency patients.)

2.6 Unmet need

32. The number of occupied bed days is self limiting because when there are no PIC, NSIC, and or HDC beds available, elective surgery is postponed or cancelled, or children are transferred to another centre (occasionally in England), or discharged to home / step down hospital care early. (This primarily affects children and not neonates since this is a very rare event in neonatal surgery.)

33. The existing level of PIC provision in Glasgow is already inadequate. Elective surgery is cancelled on a regular basis and patients are being transferred from Glasgow to Edinburgh.
### 2.7 PIC / HDC Activity – Discharges

34. The following table sets out PICU and HDU discharges from 2000/01 to present.

<table>
<thead>
<tr>
<th>Year</th>
<th>Aberdeen</th>
<th>Dundee</th>
<th>Edinburgh</th>
<th>Glasgow - Yorkhill</th>
<th>Glasgow-Southern General</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PIC HDC</td>
<td>PIC HDC</td>
<td>PIC HDC</td>
<td>PIC HDC</td>
<td>PIC HDC</td>
</tr>
<tr>
<td>2000/01</td>
<td>N/K</td>
<td>N/K</td>
<td>296</td>
<td>632</td>
<td>30</td>
</tr>
<tr>
<td>2001/02</td>
<td>210</td>
<td>106</td>
<td>337</td>
<td>591</td>
<td>35</td>
</tr>
<tr>
<td>2002/03</td>
<td>303</td>
<td>97</td>
<td>356</td>
<td>624</td>
<td>23</td>
</tr>
<tr>
<td>2003/04</td>
<td>315</td>
<td>88</td>
<td>409</td>
<td>625</td>
<td>17</td>
</tr>
<tr>
<td>2004/05</td>
<td>116 (to August 2004)</td>
<td>27 (to July 2004)</td>
<td>169 (to August 2004)</td>
<td>(not available)</td>
<td>22 (projected FY)</td>
</tr>
</tbody>
</table>

* There are as yet no designated HDC beds at Yorkhill. There is an interim facility in Ward 4B.

### 2.8 PIC / HDC unadjusted Occupied Bed Days

35. The following table sets out PIC and HDC occupied bed days (OBDs) from 2000/01 to present.

<table>
<thead>
<tr>
<th>Year</th>
<th>Aberdeen</th>
<th>Dundee</th>
<th>Edinburgh</th>
<th>Glasgow - Yorkhill</th>
<th>Glasgow-Southern General</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PIC HDC</td>
<td>PIC HDC</td>
<td>PIC HDC</td>
<td>PIC HDC</td>
<td>PIC HDC</td>
</tr>
<tr>
<td>2000/01</td>
<td>N/K</td>
<td>N/K</td>
<td>1465</td>
<td>2957</td>
<td>70</td>
</tr>
<tr>
<td>2001/02</td>
<td>411</td>
<td>797</td>
<td>1381</td>
<td>2957</td>
<td>81</td>
</tr>
<tr>
<td>2002/03</td>
<td>711</td>
<td>753</td>
<td>1840</td>
<td>3439</td>
<td>76</td>
</tr>
<tr>
<td>2003/04</td>
<td>705</td>
<td>511</td>
<td>1634</td>
<td>3338</td>
<td>42</td>
</tr>
<tr>
<td>2004/05</td>
<td>235 (to August 2004)</td>
<td>278 (to July 2004)</td>
<td>744 (11 months data)</td>
<td>3641 (11 months data)</td>
<td>40 (26 (projected FY))</td>
</tr>
</tbody>
</table>
2.9 PIC / HDC Weighted Occupied Bed Days

36. **Casemix adjusted number of PIC occupied bed days.** This information is only available retrospectively from Yorkhill (and only for 2004/05 to date – 11 months) and the Southern General. It is now being prospectively collected in both Edinburgh and Glasgow.

<table>
<thead>
<tr>
<th>Year</th>
<th>Glasgow, Yorkhill, PICU only - OBDs</th>
<th>Pro rata to a full year - OBDs</th>
<th>Uprated by dependency level - WOBDs</th>
<th>Glasgow, Southern General - OBDs</th>
<th>Glasgow, Southern General - WOBDs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year 04/05</td>
<td>04/05 (11months)</td>
<td>04/05</td>
<td>04/05(P)</td>
<td>03/04</td>
<td>03/04(P)</td>
</tr>
<tr>
<td>Level 1 /HDU</td>
<td>Not in PIC beds</td>
<td>N/A</td>
<td>42</td>
<td>26</td>
<td>21</td>
</tr>
<tr>
<td>Level 2</td>
<td>1836</td>
<td>2003</td>
<td>2003</td>
<td>42</td>
<td>40</td>
</tr>
<tr>
<td>Level 3</td>
<td>1510</td>
<td>1647</td>
<td>2470</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Level 4</td>
<td>145</td>
<td>158</td>
<td>316</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>ECLS/Haemo*</td>
<td>150</td>
<td>164</td>
<td>410</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>3641</td>
<td>3972</td>
<td>5199</td>
<td>84</td>
<td>66</td>
</tr>
</tbody>
</table>

* For these particular patients a ratio of 2.5 nurses per bed on average is required.

2.10 PIC / HDC Days at Full Occupancy

37. Activity in critical care beds is not even throughout the year. There are spikes of very high activity and times of relative lower activity. It is not possible to achieve average occupancy rates comparable with normal adult ward bed provision because facilities and staff need to be used flexibly to match the fluctuations in demand.

38. The PICUs and neonatal surgical ICUs are resourced to provide a patient to nurse ratio of 1:1 round the clock, seven days a week per bed. The variations in case mix require different levels of staffing according to the needs of the patients – ranging from 0.5 nurses per patient to 2 or more nurses per patient in very high dependency cases (e.g. ECLS cases). There has been an increase in the number of children and babies needing nursing ratios of more than 1:1 and as a result not all available physical bed spaces are available. **This report recommends that the staffing ratio to beds is increased to reflect casemix without at this stage increasing the physical number of bed spaces.** Any calculation of the proportional increase required needs to be based on an assumption on the average annual occupancy rate achievable.

39. It is reasonable to assume that an average annual weighted occupancy rate of 80% is an appropriate target to accommodate peaks and troughs in activity. Occupancy rates higher than this are not sustainable and lead to cancellations of elective activity and unplanned transfers of children out of ICU.

40. The information set out in the table above on occupied bed days in the 14 PIC beds at Yorkhill weighted according to the dependency levels of patients demonstrates that current weighted occupancy rates have exceeded 100% in the part year 2004/05. (5199 weighted OBDs against 5110 available). For around 35% of the year the PICUs in Edinburgh and Glasgow are at full occupancy of the available staffed beds (taking into account dependency
levels) and during spikes of activity there is a need to supplement staffing above the allocated complement to cope with pressures and cancel elective work.

41. In order to make more staffed bed spaces available to bring down occupancy rates to 80%, an assessment of the number of days on which additional nursing staff were required to meet needs beyond funded staffing levels was undertaken. The conclusion was that an increase in nursing staff of some 7.5% based on Yorkhill figures is required. If nursing is taken as an indicator of the total impact of high dependency patients on medical, pharmacy, imaging, laboratory and other support services, an overall increase in resource is required of approximately 7.5% at present.

42. The analysis concluded however that no further physical bed spaces are required and this conclusion is supported by available literature that suggests that current bed numbers are sufficient to meet the needs of the Scottish child population of around 1 million.

2.11 PIC/HDC Transfers / Cancellations of Elective Activity – No bed available

43. The PICU service in Scotland works as far as possible as a single service on two sites (at the Royal Hospitals for Sick Children in Glasgow and Edinburgh) supported by two “transfer of critically ill and injured children” teams. The neonatal intensive care services are supported by a network of regional specialist neonatal retrieval teams operating within Scotland as a co-ordinated supra regional service. When one centre is full, retrieval teams will use any flexibility possible to ensure that children needing critical care can be admitted to suitable facilities in Scotland. Only on very few occasions have children had to be transferred to England because there was no bed available in Scotland.

44. There are however constraints on the flexibility available. Several specialist paediatric services are provided on only one site for Scotland and children requiring such services need to be admitted to a critical care bed on the site of the other services required. Paediatric cardiac surgery, interventional cardiology, neonatal cardiology, renal transplantation, ECLS, are provided only in Yorkhill, Glasgow. Paediatric spinal scoliosis surgery is provided only in Edinburgh.

45. In addition there are shared care arrangements between Yorkhill and hospitals in the West of Scotland; and between Edinburgh Sick Children’s Hospital and hospitals in the East of Scotland that need to be taken into account in selecting the PICU site for a critically ill or injured child.

46. Information was requested on the numbers of occasions on which elective procedures had to be cancelled, or children had to be transferred out of Scotland, because no critical bed was available. This primarily affects Yorkhill since the bulk of elective specialised procedures requiring critical care back up are centralised at Yorkhill.

47. Yorkhill reports that in the last full year there were 20 cancellations because no ITU bed was available.
2.12 Neonatal surgical intensive care

The following charts show trends in the numbers of bed days in neonatal surgical intensive care in Glasgow since April 2003 and the dependency levels of patients.
2.13 Impact of 12 to 16 year olds arising from extension of age range of children’s services to 16.

48. Designated national specialist children’s services provide for children up to age 16 at present. Children with complex needs therefore tend to stay in the paediatric service up to age 16 and are already cared for in the PICUs. There will be additional activity in the areas of trauma and head injury. The trauma peak\(^5\) starts to rise at 16 with male casualties from road traffic accidents reaching 6/1000 but it is in the later teens where it peaks at 18/1000 and remains above 10/1000 into age 20s. Detailed information has not been obtained for this report but information for planning would be available from the UK PICaNet data which includes information on age of children admitted to PICUs in England and that coupled with Edinburgh’s and Glasgow’s data and WardWatcher data from Scotland’s adult ICUs should give an accurate number for children. It will not, however, quantify any current unmet need in this age group.
3. Current Service

3.1 Paediatric Intensive and High Dependency Care

49. Paediatric Intensive Care is provided in Yorkhill Hospital, Glasgow (RHSC, Yorkhill) and the Royal Hospital for Sick Children in Edinburgh (EHSC). There are dedicated HD units in the children’s hospitals in Aberdeen, Dundee, Edinburgh and there is an interim facility in Glasgow pending the opening of a dedicated facility in April 2005.

50. EHSC has 8 PIC beds (including 2 transport), 6 HDU beds (2 can be upgraded to PIC), and 3 neonatal surgical cots.

51. RHSC, Yorkhill has 14 PIC beds (including 2 transports) of which 6 are designated cardiac surgery PIC beds and 6 are general PIC beds. While there are no “designated” High Dependency beds in RHSC there is an interim facility located on ward 4B together with further beds on ward 5A the main Cardiac Surgery/ Cardiology ward. Here it is worth noting that a new combined PICU/HDU facility is currently under construction and is scheduled to be commissioned by April 2005. The new build PICU/HDU opening in April 2005 will have 16 PICU beds and 12 HDU beds making 28 critical care beds in total. HDU beds in Yorkhill at present include; 4 Surgical HDU beds, 6 long term ventilated beds, variable sized Oncology HDU, Renal Unit, and General medical wards as well as the Cardiology and Cardiac HDU.

3.2 Transport of critically ill and injured children

52. The beds referred to as transport beds above involve the provision of additional staffing to retrieve and care for children through the transport of critically ill and injured children service. At present the transport service for critically ill and injured children undertakes approximately 300 transfers per year to the two PICUs in Scotland. Staffing for 4 continuously operating intensive care beds is provided for with the bulk of the resource allocated to provision of nursing staff.

53. Air transport resources are centralised in Glasgow: helicopter and fixed wing air ambulances are based in Glasgow with a search and rescue helicopter in Prestwick. This allows an access advantage to remote and rural areas provided the Glasgow unit has the capacity to transfer and admit all patients referred. At present the Glasgow unit is unable to exploit the concentration of air transport resources available as it has insufficient capacity to admit many patients. Under present policies the admitting unit undertakes the transfer on the majority of occasions.

54. Neonatal transport both for neonates requiring surgical intensive care is undertaken by the neonatal transport network and not the transport of critically ill children service.

3.3 Neurosurgery PIC

55. The Institute of Neurosciences (INS) at the Southern General Hospital, Glasgow, has specific adult intensive care and high dependency provision but no designated paediatric critical care provision. Paediatrics patients who require critical care are managed within the adult ITU. No child has been transferred due to a lack of ITU beds. There are qualified paediatric
nursing staff within INS and they are utilised as widely as required. INS has recently secured additional funding from the West of Scotland NHS Boards and is in the process of appointing an additional half-time equivalent paediatric neurosurgeon and two additional paediatric neuro-anaesthetists to support the neurosurgical activity within Glasgow.

3.4 Neonatal Surgical Intensive Care

56. The Neonatal Surgery Service in Glasgow is based in the Dan Young Neonatal Surgical Intensive Care Unit (Ward 2B) at Yorkhill. The Unit provides a service for surgical neonates in the West of Scotland and beyond. The Unit has 23 cots – 6 intensive care/maximum dependency and 12 high dependency incubators. The remaining 5 cots are designated as special care. There are 7 cubicles, 2 of which are equipped for intensive care.

57. The unit has seen a rise in the number of admissions, now stabilising around 325 per year. More obvious has been the increase in the degree of complexity of cases and the availability of newer modalities of treatment. The Unit has expanded its traditional role over the last decade and has been at the forefront of recent advances in intensive care and is now the main location in Scotland for the management of severe congenital diaphragmatic hernia, especially those that have been antenatally diagnosed. It is also the centre for neonatal ECLS. Mortality has been decreasing; the average mortality for the past 5 years was 1.4%.

58. The neonatal units in Aberdeen and Edinburgh also provide regional services for the surrounding NHS Board areas and babies requiring joint surgical and neonatologist care in the north and east of Scotland are transferred into these services by the neonatal transport network.

3.5 Relationships / interdependencies with other services

59. Planning of PIC/HDC care cannot be done in isolation. It needs to be carried out in conjunction with the planning of tertiary specialist children’s services. The impact of the availability of critical care facilities on elective procedures that need PIC/NSIC and / or HDC back up needs to be taken into account.

60. This report centres on paediatric and neonatal surgical intensive care, but discussion must also include all services for which on site paediatric intensive and high dependency care provide essential support. Critical care is required to permit complex surgical and medical care to be undertaken and is necessary for the delivery of complex surgical care, for the management of surgical care in children with complex co-morbidity and for the management of medical paediatric cases that require or are likely to require airway, ventilatory or cardiovascular support. The following surgical services could not be provided without onsite PIC/HDU support:

- Neurosurgery
- Plastic Surgery (complex)
- Burns (major)
- Orthopaedic / Trauma (major) – airway or cardiovascular support
- Scoliosis Surgery
- General Surgery (complex) - airway or cardiovascular support.
61. In summary, any surgical or medical practice that generates or is likely to generate a need for respiratory or cardiovascular support. At the present time there is an urgent need to bring paediatric neurosurgery, particularly the management of severe head injury in children, into the paediatric intensive care domain rather than in an adult intensive care environment.
4. Workforce

4.1 Medical staff

62. The present complement of medical staff in Edinburgh is:
Consultants (on rota) : 5
Retrieval fellows : 5 (from 01/04/05)
Clinical Fellows : 5
Junior posts are recognised by the RCPCH and the RCA for SpR training but the unit does not have intercollegiate committee recognition for training in paediatric intensive care medicine.

63. The present complement of medical staff in Glasgow is:
Consultants (on rota): 6
SHOs : 6
SpRs (or more experienced fellows): 6
Yorkhill has full recognition from the Intercollegiate Committee for training of doctors in paediatric intensive care medicine, and has degree level training in PICN for nurses at the Caledonian University.

4.2 Sustainability

64. There needs to be a minimum complement of six consultants contributing to a PICU rota and there are particular challenges in achieving compliant medical rotas to cover PICU, retrieval of critically ill children and ECLS. There is scope for reviewing the roles and duties that are presently undertaken by clinical fellows, taking this forward as part of an extended nurse practitioner project with the aim of delivering an academic and competency based programme. This major piece of work extends well beyond paediatric intensive care practice and NES Scotland clearly has a pivotal role in this.

4.3 Nursing Staff

65. There are a total of 71.94 WTE nursing staff and 0.5 WTE non-nursing staff working in the intensive care unit at Edinburgh RHSC, of which 65.94 WTE have direct patient care responsibilities. Of this 1.00 WTE G Grade and 1.00 WTE F Grade also act as Education Coordinator and Education Facilitator within the unit in addition to their clinical input. Staff who are not included in the 71.94 WTE total are the Critical Care Coordinator whose responsibility it is to lead and provide operational management for the unit and the Retrieval Coordinator who is responsible for supporting and developing the retrieval service. There are 6 WTE CSW / nursing auxiliaries and 0.5 WTE Play Coordinator who support the nursing staff in the unit. 11 senior / experienced staff have completed the education package and competency assessment for the required expanded role for inclusion on the Retrieval Team.
<table>
<thead>
<tr>
<th>GRADE</th>
<th>NUMBER OF STAFF</th>
<th>ROLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>H grade</td>
<td>2.00 WTE</td>
<td>Critical Care (ITU / HDU / SNNU) &amp; Retrieval Coordinators</td>
</tr>
<tr>
<td>G Grades</td>
<td>7.00 WTE</td>
<td>Direct Patient Care / shift co-ordination + Education Co-ordinator</td>
</tr>
<tr>
<td>F Grades</td>
<td>11.94 WTE</td>
<td>Direct Patient Care + Education facilitator</td>
</tr>
<tr>
<td>E Grades</td>
<td>35.00 WTE</td>
<td>Direct Patient Care</td>
</tr>
<tr>
<td>D Grades</td>
<td>12.00 WTE</td>
<td>Direct Patient Care</td>
</tr>
<tr>
<td>CSW / Nursing Auxiliaries</td>
<td>6.00 WTE</td>
<td>Nursing Support (CSW have SVQ2 development)</td>
</tr>
<tr>
<td>Play Coordinator</td>
<td>0.50 WTE</td>
<td>Play Support</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>74.44 WTE</strong></td>
<td></td>
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</table>

66. There are a total of 95.7 WTE nursing staff working in the intensive care unit at Yorkhill, of which 91.1 WTE have direct patient care responsibility. Staff who are not included in the 91.1 WTE total, are the Critical Care Co-ordinator whose responsibility it is to lead and provide operational management for the unit, a Lecturer Practitioner who is responsible for developing nurse education within the unit, and a 0.5 WTE Retrieval Sister who is responsible for supporting and developing the retrieval service. There are two nursing auxiliaries who support the nursing staff in the unit.

<table>
<thead>
<tr>
<th>GRADE</th>
<th>NUMBER OF STAFF</th>
<th>ROLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>I Grades</td>
<td>2 WTE</td>
<td>Critical Care Co-ordinator &amp; Lecturer Practitioner</td>
</tr>
<tr>
<td>H grade</td>
<td>0.5 WTE</td>
<td>Retrieval Nurse</td>
</tr>
<tr>
<td>G Grades</td>
<td>9 WTE</td>
<td>Direct Patient Care</td>
</tr>
<tr>
<td>F Grades</td>
<td>16 WTE</td>
<td>Direct Patient Care</td>
</tr>
<tr>
<td>E Grades</td>
<td>55 WTE</td>
<td>Direct Patient Care</td>
</tr>
<tr>
<td>D Grades</td>
<td>11.7 WTE</td>
<td>Direct Patient Care</td>
</tr>
<tr>
<td>Nursing Auxiliaries</td>
<td>2</td>
<td>Nursing Support</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>95.7 WTE</strong></td>
<td></td>
</tr>
</tbody>
</table>

4.4 Staffing, training/ teaching / research

67. Anticipated further developments in modernising the workforce have the potential to impact on the future sustainability of the current pattern of care. In order to ensure that staff in training acquire appropriate experience of the full range of care, it will be increasingly difficult for centres with small volumes of work – or a restricted casemix – to maintain training accreditation under current practice on accreditation, with possible implications for recruitment and retention of staff. There is an increasing recognition; however, that an approach needs to be found to ensure staff can be trained within service models that meet patient needs, rather than the pattern of service being dictated by the need to train staff.

68. Models of rotational training across different hospitals that allow staff in training to build up experience in all required areas through placements in different units are becoming more common. In paediatric A&E and other disciplines this already takes place. There would be
clear benefits in relation to the breadth of experience staff in training could obtain from rotational training placement in the ICUs in Edinburgh and Glasgow, and perhaps also high dependency units in other cities. This would imply that rather than a unit being accredited for training, the service would be accredited and such an approach would support the continuing provision of intensive care and high dependency care on several sites.

69. Paediatric and neonatal critical care staffing is under pressure from increased activity and increasing casemix complexity. Nurse staffing is the biggest constraint on current availability of PIC services in the UK at present. In future medical staff in training (up to and including specialist registrars) will play a smaller part in service delivery. Consultants will play a greater part with many of the roles and duties previously undertaken by junior doctors being carried out by nursing staff working at advanced practitioner level.

70. To train such staff there need to be new arrangements now for accelerated progression through nursing grades within a structured higher specialist education programme for nurses. Such a education programme needs academic education (Degree and MSc programmes) and clinical competency assessment with formal accreditation of programmes developed. It will take up to 5 years to develop the skilled nursing workforce that is required to take on the expanded roles including some duties currently undertaken by junior medical staff at present.
5. Clinical effectiveness

71. One means of assessing the clinical effectiveness of PIC is by examining mortality rates for children treated in PICU. Mortality data has been studied by the PIC service to assess the trends following the significant change of practice and rationalisation of PIC after the SPICA report.

5.1 Scottish Paediatric Intensive Care Audit (SPICA 1999)

This report was based on 1997 data and sets the baseline against which the impact of the subsequent rationalisation of PIC can be assessed.

<table>
<thead>
<tr>
<th>Paediatric Intensive Care Admissions</th>
<th>1051</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of presenting units</td>
<td>51</td>
</tr>
<tr>
<td>Number of Units delivering PIC</td>
<td>14</td>
</tr>
<tr>
<td>Number of Patient Transports</td>
<td>195</td>
</tr>
</tbody>
</table>

72. The crude and standardised mortality rates are set out in the table below. In both cases low figures represent fewer deaths and improved outcome. Any figure less than 1.0 in standardised mortality is a positive outcome. The figures demonstrate the beneficial impact that the rationalisation of PIC facilities in Scotland from 14 to 2 units has had.

<table>
<thead>
<tr>
<th></th>
<th>CMR (Crude Mortality Rate)</th>
<th>SMR** (Standardised Mortality Ratio)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SPICA 1997</td>
<td>9.4</td>
<td>0.8</td>
</tr>
<tr>
<td>Post SPICA 1999 - 2002</td>
<td>4.9 *</td>
<td>0.51 *</td>
</tr>
</tbody>
</table>

*RHSCE data collected June 1999 – November 2002
** Standardised Mortality Ratio = Observed Outcome Predicted Outcome
PIM Methodology Shann et al
(1,134 admissions)

5.2 Recent data from the UK Paediatric Intensive Care Outcome Study (PICOS)

73. The UK Paediatric Intensive Care Outcome Study (PICOS) analysed data on 10,385 admissions to 18 paediatric intensive care units within the UK (05/03/01 – 03/03/02). The Edinburgh PICU took part in this study and submitted completed datasets on 335 admissions. The Glasgow service did not participate. The outcome analysis indicates that the Edinburgh PICU benchmarked favourably with other UK centres. Outcome analysis, using the favoured severity of illness scoring system (PIM), did not provide any evidence of improved outcome relating to unit throughput.
74. The Edinburgh PICU has provided data on all PICU admissions since 1999 indicating throughput, crude mortality rate, standardised mortality rate and length of stay. (according to PIM methodology)

<table>
<thead>
<tr>
<th>Year</th>
<th>Admission</th>
<th>CMR (%)</th>
<th>SMR (PIM 1)</th>
<th>LOS (days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>00/01</td>
<td>296</td>
<td>4.4</td>
<td>0.47</td>
<td>4.9</td>
</tr>
<tr>
<td>01/02</td>
<td>337</td>
<td>4.8</td>
<td>0.52</td>
<td>4.1</td>
</tr>
<tr>
<td>02/03</td>
<td>356</td>
<td>5</td>
<td>0.56</td>
<td>5.2</td>
</tr>
<tr>
<td>03/04</td>
<td>409</td>
<td>4.9</td>
<td>0.59</td>
<td>4.0</td>
</tr>
</tbody>
</table>

75. Of the 18 units participating in PICOS patient throughput was as follows:

<table>
<thead>
<tr>
<th>Admissions</th>
<th>No of Units</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt; 1,000</td>
<td>4</td>
</tr>
<tr>
<td>500 – 1,000</td>
<td>4</td>
</tr>
<tr>
<td>&lt;500</td>
<td>10 (including RHSC(E))</td>
</tr>
</tbody>
</table>

5.3 PICANet

76. The most recent PICANet report (2003/2004) indicates that there are 22 Trusts / Units delivering paediatric intensive care in England and Wales. Annual throughput ranges from 1050 – 80 cases per annum and breakdown as follows:

<table>
<thead>
<tr>
<th>Admissions</th>
<th>No of Units</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt; 1,000</td>
<td>3</td>
</tr>
<tr>
<td>500 – 1,000</td>
<td>9</td>
</tr>
<tr>
<td>250 -500</td>
<td>5</td>
</tr>
<tr>
<td>&lt;250</td>
<td>5</td>
</tr>
</tbody>
</table>

77. Both Scottish PICUs are committed to participating in and submitting datasets to the UK Paediatric Intensive Care Database. (PICANet – Paediatric Intensive Care Audit Network) on an ongoing basis to allow comparisons of outcomes achieved with those of the rest of the UK.
6. Costs of service

6.1 NHS Board Funding

78. NHS Boards have, since 2002, worked collaboratively to pool funds nationally to pay for the PIC services in Edinburgh and Glasgow. This is in recognition of the need for both sites to operate as a single service to meet the clinical needs and service pressures. NHS Fife has acted as the lead commissioner for general PIC provision on behalf of all NHS Boards.

79. The current NHS Board funding of the 6 general PIC beds at Yorkhill is £2.917 million in 2004/05. The current amount provided to Edinburgh for the 6 general PICU beds there is £3.007 million. These figures are still under discussion and may need to be increased to take account of superannuation changes.

5.2 National funding of PIC

80. In addition to the NHS Board funding of general PIC provision, national funding for the 6 PIC beds dedicated to the cardiac surgical service is provided through National Services Division for paediatric cardiac surgery and interventional cardiology patients.

81. A contribution to the total costs of PIC at Yorkhill is also included in national Service Agreements for paediatric renal transplantation, and national funding for the provision of the transport of critically ill children service is provided to both Yorkhill and Edinburgh.

| Cardiac surgery and interventional cardiology IC | £2,045,974 |
| ECLS IC | £281,880 |
| Transport of critically ill and injured children | £851,436 Yorkhill  
£858,655 Edinburgh |
| **Total national funding of PIC** | **£4,037,945** |

5.3 Total NHS Scotland funding of PIC  

| £9.962 million |
7. Planning for the next 10 years

82. Scotland’s geography requires a distributed pattern of service that can be accessed by children both close to, and remote from, the major cities. A central aim of the National Framework is therefore to plan the provision of services as close to home as far as is sustainable and clinically safe to do so.

83. Hence the action team considers that the pattern of critical care required involves the continuing provision of critical care in as many locations as it is clinically effective and sustainable to do so. The retention of dedicated high dependency units in Aberdeen, Dundee, Edinburgh and Glasgow will support the provision of a wide range of children’s services within these cities; and the capacity to support children’s services in local hospitals on an outreach basis.

84. The key is to ensure that there is rapid and reliable transfer to and from local hospitals to the major children’s hospitals that provide paediatric high dependency care, backed up by the ability to stabilise and resuscitate babies and children when necessary until transfer can be affected.

85. There is also a need for clear procedures to be in place for escalation of the intensity of care when required, for example, if a child’s condition deteriorates, including rapid and reliable intensive care transfer to and from the lead PICUs in Edinburgh and Glasgow.

86. Neonatal surgery and associated intensive care needs to be developed in conjunction with a fetal medicine programme and with integrated neonatal medical and surgical expertise in the care of these patients and their families.
8. Conclusions

8.1 Is PIC sustainable on two sites into the foreseeable future?

87. There is no absolute “yes/no” answer to this question. There is no numerical “cut off” on sustainability although in relation to critical mass, the Paediatric Intensive Care Society Standards Document 2001\(^2\) states that “hospitals that are not currently admitting to intensive care and ventilating at least 100 children per annum (corresponding to a minimum of 300 ventilator days per annum) should not continue to provide intensive care for children”.

88. The Edinburgh PICU cares for around 400 PIC cases a year; Glasgow cares for some 600-650. In the UK, the PICA Net survey (2001/02, published March 2004) reported on 24 units in the UK providing PIC ranging from activity of 80 – 1,400 cases a year. Both Scottish units are within the middle group in this range – in common with 11 units in the UK. Only 4 units care for more than 1,000 children a year.

89. Intensive care depends on skilled staff. The main factor in sustainability is therefore the continuing ability of both units to attract and retain the skilled staff required. This in turn depends upon having the right work profile – a mix of elective and emergency work, and a mix of challenging and routine cases.

90. As described above, the respective roles of junior medical staff in training and nursing staff seem likely to change. The reliance on junior medical staff in providing PIC is now diminishing.

91. As regards patient outcomes, the clinical benefits of centralisation appear to have been already achieved in the move since 1997 from 14 to 2 units. No significant further improvements in clinical outcome are predicted if the two existing units are brought together on one site.

92. There are clear advantages in sustaining two PIC units in Scotland since this supports the continuing provision of a range of specialised services and therefore provides better patient and parent access.

93. Whether or not two units are in practice sustainable is not a scientific absolute but a judgement as to whether there will continue to be sufficient skilled and motivated staff to make the service sustainable into the future. There was no dissent expressed that two sites are sustainable for at least 5 years. The issue hangs on whether new staff will be willing to join the service in future to replace existing staff so that the service is sustainable in the long term. A view shared by many is that the service is sustainable on two sites if the work profile is right.

8.2 How much PIC is required?

94. The figures set out above (in section on PIC/HDU activity) on weighted occupied bed days demonstrate that current occupancy rates exceed 100% and therefore leave no scope
to accommodate the current need. Services are under pressure and complex elective work is regularly being postponed due to the lack of PIC and NSIC availability.

95. The physical bed spaces available cannot be used to capacity because they cannot all be staffed when children requiring levels 3 and 4 intensive care are being cared for.

96. Rather than more physical bed spaces, the analysis of occupied bed days by the dependency levels of patients suggested that what is needed to meet needs is an increase in the numbers of staff. At present pressures in Glasgow are more acute than Edinburgh since all level 4 PIC is in Glasgow together with the cardiac surgery patients that are heavy users of the more intensive levels of PIC.

97. An analysis of the number of days in which the levels of nursing staff required exceeded the funded levels (a breakdown of bed use taking into account the dependency of patients is included in the annex) suggests that the level of additional investment required is around a 7.5% increase in the funding of PIC in Yorkhill - falling predominately on the designated national services in respect of the needs of cardiac and ECLS patients. Actual nursing requirements will need to be kept under review to assess whether the new integrated PIC/HDU facility that is due to open in Yorkhill from April 2005 will have a beneficial impact on nurse staffing needs. (This has been the experience in similar adult facilities.)

98. There needs to be continuing collection and monitoring of information on “weighted occupied bed days” in both neonatal and paediatric intensive care to inform the continuing review of staffing levels in these services and ensure that staffing keeps pace with patient needs.

8.3 What information should be collected on High Dependency Care provided throughout NHS Scotland

99. The foundation for the management of critical illness in children in Scotland is high dependency care.

100. Information is needed on the availability of HDC facilities with suitably trained and skilled staff; admission criteria to HDC; the numbers of children needing HDC; the severity and nature of their illnesses; patient pathways, including decision processes around escalation to higher levels of critical care; the quality and outcomes of HDC provided; and arrangements for children to return to step down care as close to home as possible when appropriate.

95. For these reasons the Action Team has initiated a prospective audit of HDC in Scotland to collect the following data items:

- Entry criteria
- Demographic details including preadmission treatment and admission details
- Diagnosis with concomitant factors
- Progress with monitoring/intervention details and indicate if level of care changed
- Complications/drug treatment
- Transfer details
• Outcome
• Resources available – e.g. medical/nurse staffing
• Discharge details

Data collection should allow severity of illness score to be calculated and correlate against resource used.
9. Recommendations

96. The Paediatric Intensive Care Society Standards Document 2001\(^2\) states that:

“Children who become critically ill in the community will usually present to their local hospitals requiring resuscitation. They have a right to expect the severity of their illness to be recognised and to receive competent treatment and resuscitation where appropriate........

Any hospital admitting children who are, or who may become, critically ill must be able to resuscitate and stabilise them.”

The Action Team endorses this view and recommends that inpatient services for babies and children are supported by the capability to provide – at least short term – critical care support for children. This needs to be backed up by 24 hour access to medical and nursing advice from lead critical care centres, and critical care undertaken outside a lead centre should be delivered in accordance with the standards set by the PIC Society and according to protocols developed in liaison with lead centres.

97. There is therefore a need to link critical care services across Scotland to provide a co-ordinated support service for critically ill children. It is recommended that a National Managed Clinical Network for paediatric critical care is developed.

98. The severity of a child’s condition can change quickly. There is therefore a need for rapid and reliable transfer arrangements to be in place to escalate the level of support when needed, and to transport babies and children to an HDU or PICU that can provide the critical care required by the child if this is not available on site.

99. That said, the number of transfers of a sick child should be kept to a minimum and Regional Planning Groups should work with Ambulance services and referring clinicians to plan paediatric services across regions with a view to ensuring that the first hospital to which the child is taken is appropriate in relation to the child’s need for critical care support as far as possible. This will require regional networking of children’s services and ambulance services, protocols and decisions on lead hospitals admitting children.

100. Because there is little information at present about the provision and outcomes of high dependency care for children and neonates at present, a detailed audit of high dependency care in Scotland is required and should take place over the next two years. This will be a significant exercise and will be an importance source of information for planning inpatient child health services in the future. The Action Team recommends that this work is put in hand immediately and is project managed by NSD hand in hand with the establishment of a national critical care network.

101. The dedicated HDUs in Aberdeen, Dundee, Edinburgh and the soon to be established HDU in Glasgow should be developed into regional lead HDU centres within the national network, and the two PICUs in Edinburgh and Glasgow should be developed as the lead national PIC centres within the network – operating as a single PIC service on two sites.
102. Within the critical care network, consideration should be given to the ways in which the links between the two PICUs could be strengthened to enable them to function as a single service – while retaining their integral position within the management structures of NHS Lothian and NHS Glasgow. The Action Team noted that major rebuilds of the children’s hospitals in Glasgow and Edinburgh were planned within the next 5-8 years and recommends that the service should be nationally commissioned for at least 5 years to oversee the establishment of the national critical care network and to stabilise the existing PIC service during a time of anticipated change.

103. This pattern of critical care described above is considered as one that can support the continuing provision of a wide range of specialised services for children on a number of sites maximising access for children, whilst ensuring that high quality care is delivered through a supportive clinical network linking local hospitals to centres of expertise.

104. In order to ensure that the training needs of staff can continue to be met within such a pattern of service, the colleges and Post Graduate Deans should be engaged in a discussion with a view to adapting the existing arrangements for training accreditation so that training can be provided through rotational posting rather than expecting all skills to be able to be gained on one site.

105. As nurses take on wider roles in critical care and retrieval services, new arrangements should be developed for nurse training including accelerated progression within a structured higher specialist programme to advanced practitioner.

106. There is clear evidence that PIC services are currently under pressure. The Action Team therefore recommends that there should be appropriate investment to ensure that PICUs and HDUs are equipped to provide the support necessary. An immediate investment should be made in the PIC service in Glasgow to bring occupancy levels down to 80%.
Appendices

1. References and sources

1. Calculation of the need for Paediatric Intensive Care Beds (Arch Dis Child 1995; 73;505-507)
2. PICS Standards document 2001 appendix1
4. Should paediatric intensive care be centralised? Trent versus Victoria. (Lancet 1997; 349;1213-1217)
5. Fetal infants (PEDIATRICS Vol. 113 No. 6 June 2004)
6. SPICA Audit (1997)
7. HDC for children – report of expert advisory group for the department of health 2001
9. HDC Scoring System, Yorkhill 2004
| PICU Occupied Bed Days | Lothian | Tayside | Borders | Fife | D&G | L'nrkshire | Grampian | A&A | Forth Valley | Highland | Greater Glasgow | Western Isles | Shetland | A&C | Orkney | Other | Total | Month 5 | Average LOS |
|------------------------|---------|---------|----------|-----|-----|------------|----------|-----|-------------|----------|--------------|-------------|-----------|-----|------|-------|-------|-------|--------|------------|
| 00/01                  | 599     | 175     | 68       | 244 | 13  | 21         | 185      | 36  | 41          | 58       | 11           | 5           | 7         | 0   | 1    | 1465  | 714   | 4.9   |
| 01/02                  | 628     | 92      | 65       | 261 | 38  | 33         | 67       | 11  | 64          | 90       | 6            | 3           | 1         | 11  | 0    | 1381  | 563   | 4.1   |
| 02/03                  | 625     | 147     | 130      | 468 | 4   | 180        | 122      | 30  | 69          | 33       | 12           | 2           | 0         | 16  | 0    | 1840  | 914   | 5.2   |
| 03/04                  | 833     | 92      | 43       | 181 | 16  | 48         | 139      | 34  | 63          | 110      | 4            | 0           | 6         | 14  | 13   | 1634  | 648   | 4.0   |
| 04/05 (YTD Month 5)    | 371     | 86      | 59       | 46  | 5   | 20         | 61       | 2   | 8           | 40       | 18           | 1           | 8         | 3   | 11   | 744   | 4.4   |

| PICU Discharges        |         |         |          |     |     |            |          |     |             |          |              |             |           |     |      |        |       |       |
| 00/01                  | 153     | 22      | 16       | 42  | 1   | 8          | 15       | 10  | 13          | 9        | 2            | 1           | 1         | 2   | 0    | 1      | 296   | 128   |
| 01/02                  | 163     | 21      | 18       | 52  | 7   | 10         | 18       | 3   | 13          | 16       | 4            | 3           | 1         | 5   | 0    | 3      | 337   | 135   |
| 02/03                  | 143     | 36      | 32       | 54  | 1   | 19         | 23       | 8   | 22          | 12       | 1            | 2           | 0         | 1   | 0    | 2      | 356   | 138   |
| 03/04                  | 190     | 20      | 21       | 56  | 4   | 13         | 34       | 6   | 21          | 23       | 2            | 0           | 1         | 4   | 4    | 10     | 409   | 166   |
| 04/05 (YTD Month 5)    | 65      | 20      | 14       | 21  | 2   | 7          | 12       | 1   | 5           | 7        | 3            | 1           | 3         | 1   | 4    | 3      | 169   |

| HDU Occupied Bed Days  |         |         |          |     |     |            |          |     |             |          |              |             |           |     |      |        |       |       |
| 00/01                  | 576     | 28      | 9        | 165 | 1   | 23         | 17       | 5   | 7           | 89       | 4            | 0           | 1         | 0   | 0    | 3      | 928   | 336   |
| 01/02                  | 1006    | 27      | 50       | 339 | 7   | 8          | 12       | 5   | 11          | 5        | 1            | 1           | 1         | 2   | 2    | 4      | 1481  | 392   |
| 02/03                  | 791     | 64      | 20       | 439 | 3   | 22         | 14       | 7   | 19          | 8        | 6            | 1           | 0         | 4   | 1    | 7      | 1406  | 440   |
| 03/04                  | 534     | 36      | 25       | 142 | 3   | 12         | 24       | 3   | 21          | 25       | 1            | 1           | 1         | 0   | 4    | 5      | 837   | 376   |
| 04/05 (YTD Month 5)    | 192     | 12      | 11       | 21  | 0   | 1          | 6        | 0   | 6           | 0        | 1            | 1           | 2         | 3   | 18   | 1      | 275   | 1.1   |

<p>| HDU Discharges         |         |         |          |     |     |            |          |     |             |          |              |             |           |     |      |        |       |       |
| 00/01                  | 293     | 15      | 7        | 29  | 1   | 3          | 2        | 4   | 6           | 6        | 2            | 0           | 1         | 0   | 0    | 2      | 371   | 145   |
| 01/02                  | 285     | 19      | 17       | 53  | 4   | 6          | 6        | 1   | 5           | 4        | 1            | 1           | 1         | 2   | 1    | 2      | 408   | 167   |
| 02/03                  | 266     | 27      | 9        | 48  | 1   | 13         | 12       | 6   | 15          | 6        | 1            | 1           | 0         | 2   | 1    | 5      | 413   | 134   |
| 03/04                  | 280     | 19      | 14       | 57  | 4   | 4          | 16       | 2   | 10          | 16       | 1            | 1           | 1         | 0   | 3    | 5      | 433   | 186   |
| 04/05 (YTD Month 5)    | 97      | 11      | 6        | 15  | 0   | 1          | 4        | 0   | 3           | 0        | 1            | 0           | 1         | 3   | 4    | 1      | 147   |</p>
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April 2003 /March 2004 (366 days) Range(0 -10 beds)
- < 6 beds occupied = 228 days (62%)
- 6 or more beds occupied = 138 days (38%)
- > 6 beds occupied = 74 days (20%)

April 2004/January 2005 (305 days) Range (0-10 beds)
- < 6 beds occupied = 189 days (62%)
- 6 or more beds occupied = 116 days (38%)
- > 6 beds occupied = 75 days (25%)

April 2003 /March 2004 (366 days) Range(0 -10 beds)
- < 6 beds occupied = 228 days (62%)
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April 2004/January 2005 (305 days) Range (0-10 beds)
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- 6 or more beds occupied = 116 days (38%)
- > 6 beds occupied = 75 days (25%)
## Royal Hospital for Sick Children (Edinburgh) Paediatric Intensive Care Bed Occupancy

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### Regional Split

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<th>2002/03</th>
<th>2003/04</th>
<th>2004/05 (Proj.)</th>
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</thead>
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<td>HDU</td>
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<td>100.00</td>
<td>100.00</td>
<td>100.00</td>
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### SMR1: Patients Admitted to ITU RHSC by HB of Residence 2000-2004  
Yorkhill Hospital, Glasgow - Activity

<table>
<thead>
<tr>
<th>Health Board</th>
<th>2000/01</th>
<th>2001/02</th>
<th>2002/03</th>
<th>2003/04</th>
</tr>
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<td>Median stay</td>
<td>No Stay ALOS</td>
<td>Median stay</td>
</tr>
<tr>
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<td>51 238 4.7 2.0</td>
<td>41 214 5.2 2.0</td>
<td>50 299 6.0 2.0</td>
<td>61 303 5.0 2.0</td>
</tr>
<tr>
<td>Borders</td>
<td>2 5 2.5 2.5</td>
<td>8 16 2.0 1.5</td>
<td>7 21 3.0 2.0</td>
<td>81 424 5.2 3.0</td>
</tr>
<tr>
<td>Argyll &amp; Clyde</td>
<td>74 204 2.8 1.5</td>
<td>68 351 5.2 2.0</td>
<td>55 302 5.5 1.0</td>
<td>7 89 12.7 3.0</td>
</tr>
<tr>
<td>Other UK</td>
<td>5 40 8.0 3.0</td>
<td>6 61 10.2 6.5</td>
<td>8 27 3.4 1.5</td>
<td>7 89 12.7 3.0</td>
</tr>
<tr>
<td>Fife</td>
<td>21 97 4.6 3.0</td>
<td>18 121 6.7 2.0</td>
<td>22 110 5.0 2.0</td>
<td>14 36 2.6 1.5</td>
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<tr>
<td>GGHB</td>
<td>217 1243 5.7 1.0</td>
<td>205 675 3.3 1.0</td>
<td>172 1264 7.3 1.0</td>
<td>173 1148 6.6 2.0</td>
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<tr>
<td>Highland</td>
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<tr>
<td>Lanarkshire</td>
<td>107 469 4.4 1.0</td>
<td>82 535 6.5 2.0</td>
<td>101 447 4.4 2.0</td>
<td>101 432 4.3 2.0</td>
</tr>
<tr>
<td>Grampian</td>
<td>23 144 6.3 3.0</td>
<td>28 129 4.6 2.0</td>
<td>28 174 6.2 2.0</td>
<td>27 109 4.0 2.0</td>
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<td>0 0 0.0 0.0</td>
<td>1 3 3.0 3.0</td>
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<tr>
<td>Orkney</td>
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<td>2 13 6.5 6.5</td>
<td>4 55 13.8 4.5</td>
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<tr>
<td>Lothian</td>
<td>31 146 4.7 2.0</td>
<td>40 179 4.5 2.0</td>
<td>39 286 7.3 2.0</td>
<td>47 145 3.1 2.0</td>
</tr>
<tr>
<td>Tayside</td>
<td>29 82 2.8 2.0</td>
<td>28 231 8.3 2.5</td>
<td>36 149 4.1 2.0</td>
<td>36 300 8.3 2.5</td>
</tr>
<tr>
<td>Forth Valley</td>
<td>31 152 4.9 2.0</td>
<td>37 213 5.8 2.0</td>
<td>52 162 3.1 2.0</td>
<td>33 107 3.2 1.0</td>
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<td>Western Isles</td>
<td>4 4 1.0 1.0</td>
<td>2 2 1.0 1.0</td>
<td>7 40 5.7 7.0</td>
<td>3 9 3.0 3.0</td>
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<tr>
<td>Dumfries &amp; Gall</td>
<td>20 77 3.9 2.0</td>
<td>22 157 7.1 3.0</td>
<td>18 48 2.7 1.0</td>
<td>8 66 8.3 3.0</td>
</tr>
<tr>
<td>Shetland</td>
<td>2 16 8.0 8.0</td>
<td>0 0 0.0 0.0</td>
<td>2 6 3.0 3.0</td>
<td>1 1 1.0 1.0</td>
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<tr>
<td>Total</td>
<td>632 2957 4.7 2.0</td>
<td>591 2957 5.0 2.0</td>
<td>624 3439 5.5 2.0</td>
<td>625 3338 5.3 2.0</td>
</tr>
</tbody>
</table>

| Average % Occupancy | 64.3 | 62.3 | 66.0 | 62.2 |

Although the bed complement is 14 the above occupancy is based upon the number of available physical beds which are staffed.  
Bed occupancy rates should not be used as a measure of workload as they take no account of patient dependency.
**Analysis of PICU Bed Occupancy by Days**

<table>
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<tr>
<th>Beds</th>
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<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
</tr>
</thead>
<tbody>
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<td>6</td>
<td>28</td>
<td>35</td>
<td>62</td>
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<td>2001/02</td>
<td>0</td>
<td>1</td>
<td>6</td>
<td>11</td>
<td>18</td>
<td>38</td>
<td>52</td>
<td>55</td>
<td>69</td>
<td>55</td>
<td>44</td>
<td>14</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>2002/03</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>9</td>
<td>20</td>
<td>37</td>
<td>58</td>
<td>58</td>
<td>68</td>
<td>45</td>
<td>42</td>
<td>20</td>
<td>4</td>
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<tr>
<td>2003/04</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>20</td>
<td>29</td>
<td>55</td>
<td>69</td>
<td>61</td>
<td>50</td>
<td>46</td>
<td>22</td>
<td>5</td>
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<tr>
<td>Apr-Aug 04</td>
<td>0</td>
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<td>4</td>
<td>3</td>
<td>20</td>
<td>17</td>
<td>29</td>
<td>30</td>
<td>18</td>
<td>3</td>
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<table>
<thead>
<tr>
<th></th>
<th>Median Occupied Beds</th>
<th>Average Occupied Beds</th>
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</thead>
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<tr>
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<td>2001/02</td>
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<td>2003/04</td>
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<td>9.6</td>
</tr>
<tr>
<td>Apr-Aug 04</td>
<td>11</td>
<td>10.5</td>
</tr>
</tbody>
</table>

The Division endeavours to keep 1 bed vacant for emergencies. Therefore the unit is often considered "full" in respect of elective admissions (i.e. potential admissions where a measure of choice exists e.g. a procedure planned for the next day, a transfer patient etc) when 13 beds of the 14 available beds are occupied.

Arrangements for the transfer of patients to RHSC Edinburgh are triggered when this level of occupancy is reached.

Data source: HISS
Nos of Days PICU was at 100% Staffed Occupancy

<table>
<thead>
<tr>
<th></th>
<th>Full Days</th>
<th>Half Days</th>
<th>Impact</th>
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<tbody>
<tr>
<td>Aug 03 - July 04</td>
<td>68</td>
<td>125</td>
<td>This equates to 35.7% during this 12 month period.</td>
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</table>
Cancellations Due to no ITU Beds Available

<table>
<thead>
<tr>
<th>Cancellation No</th>
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<tbody>
<tr>
<td>2003/04</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>13 Cardiac Surgery, 4 Paediatric Surgery, 3 ENT Surgery</td>
</tr>
</tbody>
</table>

The occasions when a cancellation is "logged" relates to those events where planned surgery is not possible due to the lack of a guaranteed intensive care bed.

In many cases the patient is already in hospital and although a planned procedure is "cancelled" in respect of the intended date/time when it was due to be undertaken, the patient's condition precludes discharge and readmission and the patient is therefore retained in hospital and the procedure reinstated as soon as a space in PICU is available. Such deferments have not been included in the above numbers.
### Dependency Scores

**April 2003 – July 2004**

<table>
<thead>
<tr>
<th>Scores</th>
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<tr>
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</tr>
<tr>
<td>Depend Score</td>
</tr>
<tr>
<td>Days</td>
</tr>
<tr>
<td>Apr - Jul 04</td>
</tr>
<tr>
<td>Depend Score</td>
</tr>
<tr>
<td>Days</td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th>Median Dependency</th>
<th>Average Dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>2003/04</td>
<td>13.5</td>
</tr>
<tr>
<td>Apr - Jul 04</td>
<td>14.5</td>
</tr>
</tbody>
</table>

This table shows the impact of the dependency of patients on nursing numbers. It shows the equivalent number of beds that could be staffed at a nurse patient ration of 1:1 and the frequency in terms of the number of days the required nursing levels were higher that the funded 14 beds.
Patient Dependency

The use of occupied beds or percentage occupancy does not accurately reflect the workload in PICU. It is more appropriate to use dependency scores based on levels of care.

Table 5 shows the dependency levels for 2003/04 and April - July 2004. It will be noted that the average dependency for these periods was 12.9 and 14.1 compared with average bed occupancy of 9.6 and 10.5 as shown on Table 2. It should be noted that the 10.5 value represents a 5 month period but the 14.1 value is a 4 month period.

Dependency is therefore the limiting resource factor as there have been occasions when the unit had only 11 beds occupied but no beds open due to the dependency score of those 11 patients being 17.

The Paediatric Intensive Care Society Standards document 2001 sets out the different levels of nurse dependency required by paediatric intensive care patients. For information a description of the Society's Standards are shown below.

**Level I High dependency care requiring nurse: patient ratio of 0.5 : 1**
Close monitoring and observation required but not requiring acute mechanical ventilation. Example would include the child who is stable and awaiting transfer to a general ward; receiving intravenous fluids or parental nutrition. Children requiring long term chronic ventilation (with tracheostomy) are included in this category as are children receiving short term nasal CPAP.

**Level II Intensive Care requiring nurse: patient ratio of 1:1**
The child requiring continuous nursing supervision who is usually intubated and ventilated (including endotracheal CPAP). Also the unstable non-intubated child, for example some cases with acute upper airway obstruction who may be receiving nebulised adrenaline. The recently extubated child. The dependency of a level 1 patient increases to level II if the child is nursed in a cubicle.

**Level III Intensive Care requiring nurse: patient ratio of 1.5:1**
The child requiring intensive supervision at all times, who needs additional complex therapeutic procedures and nursing. For example unstable ventilated children on vasoactive drugs and inotropic support or with multiple organ failure. In addition the dependency of a level II patient increases to level III if the child is nursed in a cubicle.

**Level IV Intensive Care requiring nurse: patient ratio of 2:1**
Children requiring the most intensive interventions such as unstable or levelIII patients managed in a cubicle:those on ECMO, and children undergoing renal replacement therapy.
Paediatric HDU Activity - 5 beds
Ninewells Hospital, NHS Tayside

<table>
<thead>
<tr>
<th></th>
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<th>2002-03</th>
<th>2003-04</th>
<th>Apr 04 - July 04</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discharges</td>
<td>106</td>
<td>97</td>
<td>88</td>
<td>27</td>
</tr>
<tr>
<td>Occupied Bed Days</td>
<td>797</td>
<td>753</td>
<td>511</td>
<td>278</td>
</tr>
<tr>
<td>Available Bed Days</td>
<td>1753</td>
<td>1714</td>
<td>1434</td>
<td>473</td>
</tr>
<tr>
<td>%age Occupancy</td>
<td>45.50%</td>
<td>43.90%</td>
<td>35.60%</td>
<td>58.80%</td>
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</table>
### Royal Aberdeen Children's Hospital High Dependency Unit Activity 2001-2004

#### RACH High Dependency Unit Activity - Number of Discharges [Including All Transfers Out]

<table>
<thead>
<tr>
<th></th>
<th>April-March 2001/02</th>
<th>April-March 2002/03</th>
<th>April-March 2003/04</th>
<th>April-August 2004/05</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discharges</td>
<td>210</td>
<td>303</td>
<td>315</td>
<td>116</td>
</tr>
</tbody>
</table>

#### RACH High Dependency Unit Activity - Number of Admissions [Including All Transfers In]

<table>
<thead>
<tr>
<th></th>
<th>April-March 2001/02</th>
<th>April-March 2002/03</th>
<th>April-March 2003/04</th>
<th>April-August 2004/05</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admissions</td>
<td>208</td>
<td>305</td>
<td>315</td>
<td>116</td>
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</table>

#### Total number of occupied bed days

<table>
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<th>April-March 2002/03</th>
<th>April-March 2003/04</th>
<th>April-August 2004/05</th>
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</thead>
<tbody>
<tr>
<td>Occupied Bed Days</td>
<td>411</td>
<td>711</td>
<td>705</td>
<td>235</td>
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<tr>
<td>Month/Year</td>
<td>No Occupied Beds</td>
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<td>2 Occupied Beds</td>
<td>3 Occupied Beds</td>
</tr>
<tr>
<td>------------------</td>
<td>------------------</td>
<td>----------------</td>
<td>-----------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>April-March</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2001/02</td>
<td>130 Nights</td>
<td>118 Nights</td>
<td>67 Nights</td>
<td>37 Nights</td>
</tr>
<tr>
<td>2002/03</td>
<td>40 Nights</td>
<td>91 Nights</td>
<td>122 Nights</td>
<td>76 Nights</td>
</tr>
<tr>
<td>2003/04</td>
<td>37 Nights</td>
<td>114 Nights</td>
<td>102 Nights</td>
<td>80 Nights</td>
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<tr>
<td>April-August</td>
<td>25 Nights</td>
<td>60 Nights</td>
<td>36 Nights</td>
<td>25 Nights</td>
</tr>
</tbody>
</table>

Ward 2 HDU [which had 6 beds] was replaced by Ward HDU [which has 4 beds] in June 2002.
The 3 nights in 2003/04 where there were more than 4 beds occupied were 24th, 25th, & 26th January [the time of the move from old RACH to new RACH].

**Number of full days at 100% occupancy**

<table>
<thead>
<tr>
<th>Month/Year</th>
<th>Number</th>
</tr>
</thead>
<tbody>
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<tr>
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</tr>
<tr>
<td>April-August</td>
<td></td>
</tr>
<tr>
<td>2004/05</td>
<td>7</td>
</tr>
</tbody>
</table>

**Number of elective cases cancelled due to HDU being full**: 0 for all years

**Number of children transferred to other units due to HDU being full**: 0 for all years
<table>
<thead>
<tr>
<th>Period</th>
<th>Number of Children Admitted</th>
</tr>
</thead>
<tbody>
<tr>
<td>April-March 2000/2001</td>
<td>12</td>
</tr>
<tr>
<td>April-March 2001/02</td>
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