



**National Steering Group for Specialist Children's  
Services**

# **The National Delivery Plan for Children and Young People's Specialist Services in Scotland**

**A report from an Open Meeting to discuss the delivery  
plan, Inchyra Grange Hotel, Monday 26<sup>th</sup> November  
2007**

Andy Hyde  
Independent Consultant  
Conference writer

## INDEX

<b>1. Introduction.....</b>	<b>3</b>
<b>2. Context - The Challenges – why we have to get it right .....</b>	<b>4</b>
<b>3. Key points from Open Forum discussions.....</b>	<b>6</b>
Providing specialist children’s services in Scotland	
3.1 <i>Age Appropriate Care.....</i>	6
3.2 <i>Children’s Cancer Services.....</i>	7
3.3 <i>Complex Respiratory.....</i>	8
3.4 <i>Critical Care.....</i>	9
3.5 <i>Dermatology.....</i>	10
3.6 <i>Endocrinology.....</i>	11
3.7 <i>Gastroenterology.....</i>	12
3.8 <i>General Surgery.....</i>	12
3.9 <i>Remote and Rural.....</i>	13
3.10 <i>Rheumatology.....</i>	14
3.11 <i>Telemedicine.....</i>	15
<b>4. Delivering Sustainable Specialist Services for Scotland.....</b>	<b>17</b>
<i>Summary of key points from presentations     and Panel Debate including e-voting results</i>	
<b>5. Summary.....</b>	<b>22</b>
<b>6. Annexes.....</b>	<b>24</b>
<i>Annex A – Notice board comments</i>	
<i>Annex B – Presentation - Sir Alan Craft, Emeritus Professor of Child Health,     Newcastle</i>	
<i>Annex C – Presentation - Harry Burns, Chief Medical Officer, Scottish Government</i>	
<i>Annex D – Presentation - Derek Feeley, Director of Healthcare Policy and Strategy</i>	
<i>Annex E – Presentation - Cara Doran, Expert Patient Advisor, Cystic Fibrosis Trust</i>	
<i>Annex F – Presentation - Morgan Jamieson, National Clinical Lead for Children and     Young People’s Health</i>	
<i>Annex G – Presentation - Annie Ingram, North Regional Planning and Workforce     Director</i>	
<i>Annex H – Presentation - Deidre Evans, Director, National Services Division</i>	
<i>Annex I – Presentation - Stewart Forsyth, Medical Director, NHS Tayside and Vice     Chair of the Children and Young People’s Health Support Group</i>	
<i>Annex J – Full results of electronic voting session chaired by Brian Taylor.</i>	

# 1. Introduction

The event reported here was held on 26<sup>th</sup> November 2007, in preparation for the drafting of *The National Delivery Plan for Children and Young People's Specialist Services in Scotland*. Reviews had been undertaken in key areas of Children's services and their conclusions and recommendations were to be tested and discussed by over 190 participants attending from a variety of disciplines and organizations including patient representative groups.

The meeting was opened and chaired by Malcolm Wright, Chair of Children and Young People's Health Support Group. Participants heard a number of presentations during two sessions, putting their discussions in context and debating areas that would affect the future provision of children's services.

Presentations were given by:

- Sir Alan Craft, Emeritus Professor of Child Health, Newcastle
- Harry Burns, Chief Medical Officer, Scottish Government
- Derek Feeley, Director of Healthcare Policy & Strategy
- Cara Doran, Expert Patient Advisor, Cystic Fibrosis Trust
- Morgan Jamieson, National Clinical Lead for Children and Young People's Health
- Annie Ingram, North Regional Planning and Workforce Director
- Deidre Evans, Director, National Services Division
- Stewart Forsyth, Medical Director, NHS Tayside/Vice Chair, CYPHSG.

Links to all presentations are available as annexes attached to this document.

Between these sessions, an open forum was held consisting of discussions around each of the key service areas, ranging from age appropriate care to telemedicine. Discussions were held at tables focussing on each particular area, based on the World Café technique (<http://www.theworldcafe.com/>). Participants were invited to attend discussions that interested them, writing down their thoughts and comments. At the end of the event, comments and responses recorded by participants and facilitators were synthesised and collated in section 3 of this report.

***It should be emphasised that the events were attended by an invited audience, united by a common interest in, and concern about, the future of Specialist Children's Services in Scotland. The views expressed, many of which are reported, were made in a spirit of free and unhindered expression of opinion and belong to the participants. They do not necessarily reflect the views of The National Steering Group for Specialist Children's Services in Scotland or the Scottish Government, who sponsored the event.***

***It is not possible to present in the report all the diverse views and ideas expressed at the event, and an element of selection and analysis has been adopted in its preparation.***

## 2. Context - The Challenges – why we have to get it right

### Summary of Key Presentations

Malcolm Wright, Chair of Children & Young People's Health Support Group, opened the meeting by describing the work that had been undertaken prior to the event. During the past 18 months work had been undertaken to review the various areas involved in providing Specialist Children's Services. The review included representatives from clinical practice, patient groups, NHS planners and Scottish Government.

The review had confirmed that there are areas of concern around specialist children's services. There were serious pressures on those services and the workforce that provides them. There were issues around access to quality care across Scotland and known gaps in provision. There were concerns about providing care that is appropriate to the age of the child and about how we educate and train our staff for the future. Clinical outcomes in Scotland were not as good as the best in Europe.

And yet, the outcomes from this review, along with potential funding of up to £32 million over three years (subject to parliamentary approval) potentially represented the best opportunity in perhaps a decade to redesign and improve services. An action plan, partly informed by the day's discussions, would aim to do this based on six key principles:

1. That care should be provided as close to home as possible;
2. That there should be a presumption against central services;
3. That services were built around a strong infrastructure for Specialist Children's Services in Scotland, including new children's hospitals in Edinburgh and Glasgow and existing children's hospitals in Dundee and Aberdeen;
4. Networks of care were required at a national, regional and local level;
5. That health boards needed to be more accountable for the implementation of policy; and
6. The model that was taken forward should bring improvement and redesign of services.

Important needs had been identified, but which were the most important? This event offered an opportunity to consider the issues, to test and weigh up the range of evidence and expert opinion put forward and to contribute to the conversation, developing a **collective sense of relative priorities**.

To set the open forum discussions in context, presentations from other speakers considered the challenges to providing specialist children's services and why it was important to 'get it right'.

Participants heard about the care of children in the UK viewed from a global perspective. The UNICEF report published earlier in the year had found the well-being of children in the UK to be among the worst in developed nations. Since there was a view that children have never been healthier why did the UK rate so poorly? It was suggested that surveillance and early diagnosis may have set other countries ahead of the UK in areas such as childhood cancers. Significant differences in the geographical distribution of, and access to, care may be contributing to the UK's poor record, for example the high prevalence of diseases such as diabetes and asthma.

This resonated with the picture in Scotland, but participants were urged to consider wider determinants of health. With growing evidence to suggest that children living in difficult circumstances grew up to have significant physical problems such as insulin resistance and heart disease as well as social difficulties, a key to good child health would be protecting them from negative determinants such as exposure to infection due to failure to immunise, the effects of post-natal depression and poor nutrition. Around 70,000 children in Scotland lived in a family with an alcohol or substance abuse problem. Clearly there was a need to invest significantly to improve the conditions of children in the early years and primary care was one area that presented opportunities to promote health.

Scotland faced challenges in providing equitable access to specialist services for children. Changing skill mixes, changing regulatory frameworks, a small number of specialists, a small population spread widely across a large geographical area, new complex technologies. Perhaps the biggest challenge would be matching services with population and its geography.

Some of these issues were brought into sharp relief when considering the care of children and young people with Cystic Fibrosis (CF), a complex disease which ideally requires a multi-disciplinary care team. It was estimated that 10% of people with CF did not have access to specialist care, a situation not helped by the funding of paediatric CF services through local health boards making joint working difficult. In comparison, adult services were National Services Division (NSD)-funded, resulting in specialist care being available to all adults. Managed networks potentially offered an infrastructure for better communications between specialists, greater access to specialist services for all and better support for patients and their families.

These were some of the themes that the Scottish Government's forthcoming Action Plan for Health and Wellbeing would be considering. After a period of open consultation with health professionals and the public, the action plan was likely to consider how NHS Scotland could sustain and improve Scotland's health, how to reduce health inequalities and how, on an ongoing basis, to improve the quality of Scotland's health services. To align itself with this direction of thinking, *The National Delivery Plan for Children and Young People's Specialist Services in Scotland* would therefore need to demonstrate how it could promote continuous improvement in healthcare, how it would improve the safety and efficiency of children's care and how that care could be made equitably accessible for all.

So the questions for the participants to consider during their discussions would include how to improve child health by making services better? How to ensure best value for investment? And how to do this while keeping patients and their families at the heart of the process? There was clearly variability in workforce, service provision, outcomes and implementation and a need for a more systematic approach across the country. These discussions, their recommendations and the following action plan were an opportunity to shape specialist children's services with unprecedented resources and participants needed to be clear about the agenda, focussing on creating a prioritised list of actions.

### 3. Key points from Open Forum discussions

#### 3.1 Age Appropriate Care

The Working Group had reported that the specific developmental, emotional and psycho-social needs of adolescent patients are well recognised but have traditionally been poorly addressed by the hospital services and facilities provided.

The recommendation, initially made in *Building A Health Service Fit For The Future*, to raise the age limit for children's services in Scotland to the 16<sup>th</sup> birthday needed to be accompanied by specific planning and investment to ensure that young people receive age appropriate care.

Recommendations were made on, amongst others, Training, Staffing and Facilities. Recommendation 5 was clear that where a formal adolescent unit or facility was not viable, Boards should ensure alternative means of delivering age appropriate care are provided.

**The report recognised and recommended that a working group on Transition should be established**, to scope the extent to which the existing range of adult services failed to address the needs of young people with specific chronic or complex or clinical conditions. The Group also recommended that the recommendations of the Transition Working Group of the Royal College of Physicians of Edinburgh be adopted and progressed.

**Transition issues featured prominently in discussions** and voluntary sector input was considered important, e.g. youth workers, condition specific organisations, peer support etc (this isn't reflected well enough in RCPE guidance.) Need to include primary care services in transition to support this process.

Parents had high levels of anxiety regarding transition to adult services; they believed there were less resources and reduced access.

**Participants discussed whether the period of transition should be extended to 18 years** - or even 21 in some specialties - as 16 was considered (by some/many?) to be too young. However, **flexibility in services in relation to all age limits up to 18**, was thought to be key. The needs of a young person with long-term chronic illness would not be the same as a 17 year old who is working and admitted for a short stay.

**Both adult and paediatric centres needed to work together**; some clarity was needed around how much responsibility adult services take for transition. **Transition care should be planned**, over a period of time (up to age 21) and not sudden. This would vary between specialty and individuals.

Careful consideration needed to be given to the appropriateness of mixing different clinical groups. Immuno-compromised young people may not be able to mix. (Teenage Cancer Trust has experience of this.)

**It was very important to ask young people what they want**, involving them in the development of age appropriate services.

**Training of staff on wards was considered vital**. There was concern that staff would

find it difficult to manage older children (especially if alcohol and drugs were an issue) in general paediatric wards.

It was noted that there was a lack of (or very poor), adult provision in some specialties, and an **overall lack of psychological support**. Remote and rural provision was highlighted, as was Hall 4.

Finally, **palliative care was raised**. There was a lack of appropriate adult respite/residential resources for young people with complex disabilities and health care needs. Would this be considered in the final recommendations?

### 3.2 Children's Cancer Services

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

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

The option appraisal process has engaged with a large number of stakeholders as information and evidence has been gathered to populate 3 options set out in the Executive Summary on Children's Cancer Services.

The executive summary recommends that children's cancer services in Scotland be planned and commissioned on a national basis and delivered according to the levels of care described in the full draft report for Cancer Services for Children and Young People in Scotland 2007.

There was no table top discussion in respect of levels of care for cancer and cancer centre options. There was also no discussion in respect of palliative care branch of Managed Clinical Network (MCN) for children with cancer and non cancer diagnosis.

Input into network and commissioning to ensure charity services support reflects the needs of the service pathways of care.

Models of Regional and National Commissioning. NSD commissioned, combined Regional Commissioning. \*Adolescent inpatient Child and Adolescent Mental Health Services (CAMHS), \*Children's Hospices (one Board to commission on behalf of all). Investment in capacity of network and clinical services needs to be matched by a much smaller level of investment in commissioning.

However, 1 or 2 centres divisive, better to agree pragmatic "centres of excellence", e.g. haematology & BMTX in Glasgow and solid tumours in Edinburgh. Whatever the option

appraisal, the MCN needs strong support and funding to engage successfully with all stakeholders. MCN success will promote and support service change.

Need to know where services are going to be delivered from – i.e. a decision. To be able to develop a robust workforce plan to underpin this.

Comprehensive child and family care – Families need to get on with their lives while their child has a chronic illness. MCN in cancer care needs to ensure that as much as possible is delivered close to home.

Paediatric neurosurgery, where is the paediatric cancer representation on this? Option appraisal and what outcome is available to support the decision?

The following points were also raised:

- Commissioning and resourcing needs to be explicit and available
- Single service/MCN how will it be different?
- Some staff – lead clinician – network manager
- Palliative care integral to strategy and network
- Quality of life built into network outcomes
- Network role in strengthening earlier diagnosis etc
- Role of primary care essential

### 3.3 Complex Respiratory

The review of paediatric respiratory medicine in Scotland had highlighted the fact that although respiratory conditions were the commonest cause of paediatric hospital admission, there was still inequitable access to services across the country. It had recognised that this was apparent in areas such as Cystic Fibrosis (CF) but there were other conditions that were less well represented that probably had similar inequities of access. It had concentrated on CF and Long-term ventilation/sleep disorder breathing with a view to creating positive effects and templates for developments for other respiratory disorders.

Along with other specialties it had recognised the need for a Managed Clinical Network and alongside this the resource, including extra staff, to deliver tertiary services in paediatric respiratory medicine.

Participants confirmed that this was a complex area. Patients were often referred from Paediatric Intensive Care Units and were far from home. **They might have acute requirements as well as the need to manage chronic conditions** and the number of patients was increasing year on year. Children with long-term ventilation (LTV) in particular often had complex needs, sometimes other medical or special educational needs. Indeed, performance management should be measured using **quality of life** indicators as well as life expectancy.

Whilst the development of a network appeared to have support, there were a number of consequences and requirements that such a development raised. For example, could the network perhaps act as an employer and manage staff/resources? A workforce managed



and funded by a national network could be flexible rather than tied to an area. This chimed with others who commented that there was a need to talk about the development of a **service** rather than what is needed in tertiary care or specialist centres. There was need to think more innovatively about funding being allocated nationally, targeted where it is needed rather than 'hoarded' by individual regions. But a national network would also be a challenge for national commissioning and participants warned that funding from local health boards was not a good model to encourage working across borders. Some commented that there was a need for regional commissioning.

**Workforce issues** featured prominently in discussions with participants suggesting that regional planning was not working. It was considered that regional employers with staff delivering care locally with support from specialist centres could improve services.

**Young people themselves needed to have a voice in service design.**

A gap between neonatal and adult CF services was described. The middle ground was thought to be 'patchy and poorly funded' and transition services needed to have time factored in for questions and to make patients and families feel involved. Participants considered the English method of specialist commissioning which didn't differentiate between child and adult services.

The importance of psychological support was mentioned as was the confusion surrounding the role of advanced nurses. Participants weren't sure that where the role fitted into the regulatory framework and there seemed to be no incentive for nurses to undertake specialist training in this area. Similarly, there appeared to be little training for or support for AHPs to become skilled in respiratory conditions.

Regarding **education and training**, participants highlighted the need for better provision in small clinics 'to turn a special interest into a specialism' and saw the value of rotating staff around centres while highlighting the problems surrounding backfill to allow this to happen.

Finally, participants considered the link with the discussions around critical care. Were complex respiratory problems, they wondered, an example of 'dispersing' high dependency care?

### 3.4 Critical Care

The summary from the Critical Care working group had highlighted the importance that the Kerr report had placed on sustainable paediatric critical care and high dependency care (HDC) and that it was 'an immediate issue for NHS Scotland'.

*A critical illness or injury is a relatively rare event, however it is imperative that the hospital admitting the child must be able to resuscitate, stabilise and manage the child until transferred to a more specialised facility (if required). The ability of hospitals to deliver high dependency care on an unscheduled basis is a fundamental keystone to sustain critical care services.*

The unscheduled nature of the admission of a critically ill child could have significant impact on a hospital, its staff and their training needs.

Participants highlighted the **importance of communications leading up to the admission of children to critical care**. Children may be referred to an emergency department via a parent, a GP or by NHS 24. All possible links in the chain would need to know which nearest hospital was able to at least stabilise the child.

- every hospital should be able to stabilise;
- which hospitals should be 'open' to children? Effective communications about where to go – but even with this some will still go to nearest hospital;
- Scottish Ambulance Service and NHS 24 need to know which hospital could stabilise – all has to be joined up;
- recognise needs of hospitals with inpatient paediatrics but without adequate HDU;
- could High dependency care be 'dispersed' to closer to home to facilitate ITU discharge;

### 3.5 Dermatology

The working group had highlighted the increase in atopic conditions nationally and the severe effects that skin problems and allergies could have on a child's development.

The recommendations had ranged from the creation of a paediatric dermatology fellowship to encourage practitioners into the subject, to the development of a national allergy network and liaison nurse network. The group had also recognised the interdependence with specialties such as psychology and dietetics to provide a comprehensive service.

Participants agreed that the **support of dieticians and psychology colleagues** was vital but that access to these services was limited and not equitable across Scotland. It was thought that clinical psychology was particularly difficult to access because most services are based in child and adolescent mental health teams.

It was highlighted that allergies could be common and the generic skills needed to deal with these should be present in primary care and at DGH level. Much of the work lended itself to common protocols that were widely implemented. However, some complex allergy cases required input from dermatology, respiratory, GI and ENT and this would need to be reflected in the membership of, and input to, the **network**.

**It was highlighted that there is no dermatology paediatric training for nurses.** NES was developing training and core paediatric competencies in dermatology were being launched in December 2007. The group suggested **mandatory child protection training for all Dermatology nurses**.

### 3.6 Endocrinology

The working group had reported a relatively healthy status of paediatric endocrinology in Scotland with a good level of consultants with a good quality of care provided in a number of specialist centres. The challenge would be providing sustainable, locally accessible services.

Recommendations of the group had focussed on the establishment of a national service network for endocrinology services, a medium term review of workforce need and the development of care pathways, laboratory recommendations and other national standards for endocrine care.

Participants considered that groups such as the Scottish Paediatric Endocrine Group and the Scottish Genital Anomaly Network were excellent expert resources on which to draw from and build upon. The latter was thought to be an example of good networking among endocrinologists and **the development of a network at national level was endorsed**. Participants felt that research and audit were key to its development and that it would need to be **well resourced and managed in order to be effective**. They identified the need for a **network manager** that would champion its development and make it work. One commented that the Knowledge Exchange contains a lot of information and wondered if this could be the core of the network?

A question that was posed was what are the biggest service risks and how can the network work to reduce these?

The need for more **data** was apparent, particularly around outpatients. Participants suggested the collection of prevalence/incidence data as a 'by-product' of standardised clinical records, using **national data standards**.

There was a call to **increase the number of pathways and protocols** to standardise care with an evidence base, pathways that describe the well child through diagnosis and treatment to managed supported self care. The ability and capacity to work on a shared care basis was discussed and the need for administrative support to facilitate protocols and standards and care pathways was highlighted. Consensus was needed to agree on interventions where the evidence base is currently lacking.

**Transition services** were a discussion point, the need to plan them and to provide timely information and support to patients and carers. There was a call to 'make samples and results travel', not patients. Could this improve **equity of access**?

In terms of the workforce, participants discussed the idea of a **local Multidisciplinary team** in each health board area that would have good links with the national network and staff with endocrinology expertise – including paediatricians, nurse specialists and psychology support. They wondered if endocrinology **training** was available to nurses and AHPs and the wider workforce. The reliance of endocrine services upon good **laboratory services** was also highlighted and therefore the need for a good communications infrastructure.

### 3.7 Gastroenterology

A Review of Paediatric Gastroenterology services in Scotland published in 2004 identified a number of areas for development which have been reflected in the recommendations of the steering group. In particular, the variation in services available evidenced by the lack of paediatricians with gastroenterology specialist knowledge in the west of Scotland.

*'...Without adopting a consistent approach to data collection, referral pathways and standard setting, children continue to be treated sub-optimally in non specialist and adult services, and outcomes across Scotland for children remain variable'*

The report called for the development of a managed service network in each region, a review of Paediatric Gastroenterology, Hepatology and Nutrition (PGHAN) service provision, the development of a wider national network comprising clinicians and patient/parent representatives. Crucially, the development of national standards/guidelines and care pathways and a consistent approach to data through the development of a national data base was recommended.

**Participants supported the recommendation for a national database**, emphasising the importance of funding its development properly since good data would be vital to inform outcomes and service quality and to determine priorities. However, it was clear from discussions that regional MCNs were key to the management of data at a local and national level and that there were already problems in developing networks in some regions. **Until this was addressed, a national MCN was unlikely to develop, presenting an obstacle to obtaining good data.**

It was clear though that networks were important and, in particular, the **inclusion of dieticians and nurses**. The support of dietetic and psychology colleagues was viewed as vital, not only in providing a good service (one suggestion was that dieticians could run review clinics) but also for developing **innovative practice**. Despite this, access to dieticians was described as 'poor'.

There was a role for specialists to raise awareness of conditions with GPs and the public in order to reduce delays in diagnosis. The comment was made, for example, that children with autism and learning disability were sometimes not referred to gastroenterology. Paediatric gastroenterology was a service central to, and impacting upon, just about every other specialty. There was, however, a lack of recognition of senior posts.

### 3.8 General Surgery

The review of general surgery for young people had highlighted considerable concern over the sustainability of the service in Scotland. The situation was described as 'critical' since many of the current generation of surgeons were retiring and being replaced with surgeons who had 'no preparatory training in children's surgery'. Problems already exist in providing a service and these were set to get worse. Whilst there was no indication that the quality of the service is unsatisfactory, the recommendations focused on a range of steps towards a service that plans for local, institutional and regional needs, including four regional appointments to support the larger DGHs in the General Surgery of Children.

*'...The general surgery of childhood should therefore be another service that is available to children in their own locality with the proviso being that, in terms of standards of care, local care is safe and sufficient'*

Participants recognised that the development of local services would need to take **regional planning and commissioning** into account. Indeed, individual health boards would need to consider their paediatric surgical requirements and strategies in partnership with other boards in the region although some concern was raised that health boards might not work together for regional gain.

This highlighted the importance of **regional leadership** in planning. One surgical division in particular expressed support for the recommendation of regional appointments, commenting that their general surgeons would be keen to develop their paediatric skills if supported by a regional specialist. This could potentially support emergency care and elective surgery services locally. Participants emphasised that these regional appointments would need to be experienced, credible candidates and **the question was raised – are 4 regional appointments enough?**

The appointments should be accompanied by **formal arrangements to support CPD** which, participants agreed, was essential to maintaining skills. It was considered that the funding for this training should be **ring fenced and held by a non-teaching hospital**. General surgeons should be able to **influence training curriculums** and it would need to be clear to surgeons in training that future general surgery roles would require them having gained paediatric skills.

In terms of implementing **care pathways**, participants highlighted the need to involve paediatricians and to ensure that nurses, ODPs and AHPs were trained to care for children before, during and after surgery. **Joint planning** would be required to enable multi-disciplinary meetings and forums and the use of telemedicine to facilitate virtual teams was suggested as a way to improve communications.

### **3.9 Remote and Rural**

The steering group had concurred with several reports that had been published in recent years, highlighting the difficulties faced by local clinical staff in providing high quality care for children in remote and rural settings. The small number of patients and staff involved, a perceived lack of understanding of the circumstances faced by staff and the variable quality of discharge planning after episodes of specialist care were themes that had emerged.

Participants **agreed with the need for networks** and made it clear that NHS boards should be made accountable for establishing them, backed up with **formal agreements and resources**. In addition to networks identifying individuals involved in paediatric medicine, a need for a **directory of childcare services** available in remote and rural areas was identified. It was suggested that in order to develop the best model, other examples of delivering remote and rural care further afield should be studied.

Education and training was discussed in its various forms. RAR staff should be enabled to attend rotations in specialist centres but this would only be possible if teams were

enhanced to allow for other staff to cover absence. Teams in different geographical areas would need different skill mixes and the need to ensure that paediatric medicine was on general medical curricula was highlighted. The question was raised - does the funding of education around the needs of remote and rural issues need to be ring-fenced?

The role of 'mainland' boards was discussed in relation to the provision of support for 'island' boards in areas such as training and telemedicine. Indeed it was commented that there was a 'fundamental' importance in strengthening e-health and telemedicine frameworks in RAR teams and services. Participants thought that regional planning groups had a role to play in creating formal arrangements regarding education and training and other support for RAR staff.

Issues around the role of the Scottish Ambulance Service were clearly an important area of discussion. There was a call for the SAS to be more 'fully engaged' and for its responsiveness to be improved. There was perhaps a role for the service to help resolve retrieval issues and for SAS staff to deliver HDU retrieval rather than retrieval teams which might be a more expensive resource. Whatever their role, it was felt that the SAS needed to be more aligned to service delivery.

Concerns were also expressed about the review of community nursing and the potential loss of the expertise of health visitors. Some participants considered that the service should be building on the skills of health visitors when in fact the role appeared to be disappearing. There was 'inequitable' access to children's community nurses and the group wondered if specialist nurses could offer 'expert' care and support services if they were trained in areas such as learning disabilities and complex needs? This would reduce the need for patients to travel long distances to see specialists. Similarly, the role of GPs in identifying chronic conditions and special health requirements – in short delivering **good paediatric primary care** - was highlighted.

### 3.10 Rheumatology

The review of paediatric rheumatology in Scotland found that service development has lagged behind other parts of the UK.

*'..Improved outcomes will only be achieved if all affected children have rapid access to an expert specialist service. Currently, suboptimal outcomes with disability and visual impairment are common in Scotland as a result of inadequate resources and inequity of access to specialist care'*

The recommendations from the steering group focused on the appointment of extra paediatric rheumatology staff including a specialist nurse, consultant nurse and a consultant/advanced practitioner physiotherapist, as well as establishing a Managed Clinical Network and a parent network.

In their discussions, **participants endorsed the recommendation for the development of a Managed Clinical Network**, giving this suggestion much support. This would have a key role in addressing other issues raised including the need for communication between boards, and the **identification of specialist staff**. It was thought that examples of other networks that work well should be considered and that the timing of recommendation

number 6 (that Regional Planning teams should scope / establish robust data to support local service development and work with the MCN in its delivery) **should be brought forward**.

Participants identified a need for **education** in general and for a **National Education and Training and Practice Development** programme in particular. They highlighted the key role of nurses in developing clinical practice and leading the network. **Transition services**, from children's clinics, through to teenage clinics and on to an adult service would be key, as would **equity of access** to specialist services across the country.

Overall, there was support for the recommendations, but several comments indicated that participants thought them **too modest and that more was needed with a longer term vision**. Concerns were also identified regarding the **sustainability** of the recommendations including:

- how to increase the profile of the specialty in general and rheumatology training for paediatricians in particular?
- Would there be appropriate rheumatology support for four children's hospitals?

### 3.11 Telemedicine

The review group had reported that telemedicine was playing an increasing role in the healthcare of children and young people in Scotland, supporting remote diagnosis and treatment, preventing unnecessary patient transfers, enabling timely and safe transfer when required and enhancing communication with parents.

Telemedicine was already supporting the activities of several networks which were seen as a key element of the delivery of specialist children's services and proposals had been developed to provide an effective telemedicine network between all sites delivering such services.

Participants agreed that **telehealth would play a significant role in the future development of Managed Clinical Networks**. It could provide reassurance and rapid decision making for parents, aid staff in discharge planning and connect patients with less common conditions with the few staff available nationally. It was critical, then, that the infrastructure and technical support was robust and that existing resources and staff were better coordinated. There was also a lack of information about what was currently available for those not 'in the know'. **Multi-site bridging was identified as the 'most shaky part of the current system'**.

Participants saw a role for Managed Clinical Networks in developing good practice for the use of telehealth, recommending who should attend meetings and considering the added value the use of telehealth could bring (e.g. When to use videoconferencing or teleconferencing). There were different models for using telemedicine; time-sensitive communications and regular meetings.

Looking forward, participants highlighted the importance **of clinical champions for**

**telehealth.** They considered that **ease of use** and **reliability** would be critical to uptake and, perhaps most importantly, **new ways of working would require new ways of thinking**, a willingness to share and collaborate, likely to mean a culture change among healthcare professionals. One of the next steps would be providing telehealth in patient homes and participants commented that future uses for the tools were likely to be unforeseen and unexpected.

The demand for online support, particularly among families, was likely to grow and participants cited an example of a virtual hospice in Canada. Greater use would mean the need for greater capacity and **the current speed of the networks would most likely be too slow in the future. National planning would be needed to monitor and remedy this.**



## 4. Delivering Sustainable Specialist Services for Scotland

After the Open Forum participants heard presentations about networking, workforce development, planning, commissioning and performance management - issues that would need to be tackled in order to take recommendations for specialist children's services forward. Discussion was opened up to audience debate in each case and specific questions were posed, using electronic voting to gain immediate feedback.

**Managed Clinical Networks (MCNs)** were recognised as providing opportunities for collaborating, sharing information and good practice, potentially bringing consistency of care, a way to engage with service users and a support mechanism for local services. Indeed, vulnerable, isolated services could benefit greatly from them, connecting to other service providers throughout the country.

MCNs were now an established model in NHS Scotland with a good track record and many examples were to be found in Specialist children's services. However, they had grown to meet their own needs, at different rates, perhaps using different models. There was, it was suggested, a need to develop networks strategically, to consolidate support for them and create an infrastructure for emerging networks.

This was confirmed by over 83% of participants who agreed when presented with the statement **MCNs represent a useful approach that should be strategically rolled out to all relevant specialist children's services**, with just over 35% strongly agreeing.

In order to develop networks strategically, there would need to be prioritisation, a way to identify those networks that were most suited to development. Networks would also need to be developed at an appropriate level - Local, regional or national – ensuring that specialities weren't overlooked while retaining a national perspective to SCS overall. Central facilitation, support and infrastructure might help to sustain networks.

When asked **how valuable it would be to have the various MCNs for Specialist Children's Services managed as a single joined-up system**, almost 36% felt that this would be very helpful and over 42% thought it would be helpful. Only 20% felt that it would be unhelpful or make no difference.

There was also discussion around a need for an **MCN 'plus' – a network model operating at a level between an MCN and Nationally designated services**. When asked, participants were less sure about this with 28% voting 'Not sure' and almost 20% disagreeing.

Palliative care appeared to be missing from the service reviews published as part of the work leading up to the event. It was not clear whether palliative care would require an MCN or should it be part of each MCN? However, while the MCNs were aimed at specialist children's services, there was no reason why primary care practitioners could not access these and develop networks around 'non-specialist' issues.

A suggestion for one, national children's service rather than networks-of-networks was not felt to be mutually exclusive to the development of more specialist networks but there was no clear answer about who would be responsible for regional / national commissioning around MCNs.

A census had been carried out earlier in 2007, collecting data on paediatric practitioners with a view to gaining a picture of how to **Develop the Workforce for the Future**. A Key message that emerged from the work was that workforce demographics were changing. The workforce was getting older. In addition, the number of children was getting smaller. These factors combined to give a complex picture, compounded by the fact that staff data collected centrally appeared to be inaccurate due to reporting difficulties. Perhaps a national method of collecting workforce data was not optimal?

The census revealed that there were 384 doctors and 220 consultants in paediatric services in Scotland. 57% of the workforce within children's services were consultants. 67% of the workforce spent 100% of their time providing paediatric services. 63% of paediatric workforce was female. It also highlighted the small groups of paediatric staff resident in DGHs suggesting the fragile nature of services in terms of sustaining a local workforce.

A significant proportion of staff were over the age of 55 suggesting that there were significant challenges ahead in delivering services with an ageing workforce.

The report from the work had made 26 recommendations including

- a need to consider the quality, refinement, sharing and collection of data
- a consistent approach to basing workforce projections on population need
- the consideration of new roles for new models
- the identification of 'at-risk' specialities and plan for the future

Other recommendations covered the consideration of networks at a national and regional level, the need for training programmes that were fit for purpose and for leadership throughout the processes ahead.

Workforce issues would present significant challenges in years to come and participants were asked to consider whether some of the models that they had discussed in the open forum were deliverable within the constraints of workforce pressures? What were the priorities? Did they include the at-risk specialities likely to be affected by workforce age? How could good quality data be more effectively collected?

There was some lively debate around issues relating to workforce.

**The gender of the workforce** was brought up as a potential challenge – despite an increasing proportion of the workforce and of trainees being female, it appeared that many senior appointments continued to be male. This was possibly due to these posts being less attractive to women due to lifestyle issues and this might need to be addressed in the near future if the paediatric workforce was to be sustainable.

Some wondered if a **Regional Clinical Lead** was required to take a regional model forward.

The problem of the ageing workforce was reiterated. The National Delivery Plan needed to have a clear focus on the fact that despite training a good number of paediatricians,

Scotland was going to see the number of doctors falling dramatically in the near future. This would be a significant challenge to delivering **general paediatric care** as well as specialist care. Was there more that could be done to make these roles more attractive to retain older staff such as reducing night-time work?

When considering at-risk specialities that are particularly fragile, perhaps **proleptic appointments** could be considered as could the extension of nursing and AHP roles.

There was an opportunity to use roles such as advanced nurse practitioners to meet short-term workforce needs but in some cases education wasn't available in Scotland to train them. Specialities needed to define their workforce requirements in order to assess the training needs and there was then a role for NES to aggregate that need from across Scotland to develop training that was accessible locally.

The outcomes from Agenda for Change had been a demotivating factor for some specialist nurses who had been banded inconsistently and lower than expected. Similar problems had affected others in the multi-disciplinary teams that operate in Children's services including secretarial staff.

When asked to vote on the question **Have we got an adequate workforce to redesign specialist child health services at a national, regional and local level?** Participants quite clearly felt that Scotland didn't. With only just over 4% agreeing that the workforce was adequate, almost 70% disagreed with 26% registering that they weren't sure.

Participants were then asked to vote for the top priority for preparing the workforce to meet the challenge of improving specialist children's services. **Developing new roles** and **creating additional workforce capacity** were felt to be equally important (both at almost 38% of the vote) with **education and training** slightly less important at just over 24%.

Many of the issues discussed had raised points that involved the **Planning and Commissioning of Services**. Participants had heard that while access to services was generally good, there was a need for careful planning of escalation paths, for example, in cases when children needed special care. Similarly, if the use of networks and networked services was to increase, NHS boards would need effective planning to be able to work together, to ensure clinical governance and to ensure a sustainable workforce, highlighted by issues discussed already during the day.

Having established that good planning was vital, participants heard that although services appeared to be meeting 90% of children's needs; there was a gap in planning and commissioning on an inter-regional basis. If a future MCN 'plus' model – a network model operating at a level between an MCN and Nationally designated services – were to be used, there would need to be planning and commissioning structures put into place.

When asked if **the existing arrangements for planning and commissioning specialist children's services meet the needs of children** participants clearly thought not, with almost 74% disagreeing.

There was a strong message also that **more planning/commissioning capacity should be created at a national and regional level** with almost 85% of participants agreeing with this.

But if these ideas, recommendations and plans were to come about how would progress be measured? **Would enhancing performance management help to more effectively implement the National Delivery Plan?**

There were a number of national, regional and local delivery plans, HEAT targets and others, but not all outcome measures were child-health specific. Not all child health issues were included in targets, perhaps due to Specialist children's services not being seen as a national priority.

The Action Framework was cited as an example of a document containing actions and timescales relating to child health and members of the CYPHSG would be visiting health boards in 2008 to review progress in child-health specific areas.

There were other future developments to look forward to. There would be joint inspections of children's services, looking at multi-agency provision and the development of child health outcomes which would be crucial to measure child health improvements.

**So what outcomes should be developed to assess performance in SCS?**

**How would we make sure we have the specialist services in place?**

**What would need to be included in the national delivery plan to ensure its implementation?**

There was a debate around the benefits of targets and performance indicators, with general agreement that they could be beneficial if used carefully and not to cause further inequalities of access to services. It was necessary to know if clinical centres were performing well and targets could raise awareness of service importance at health board level. However, it was noted that service users should be involved in deciding what the targets should be.

Indicators or outcomes were often seen as 'end points' whereas when working with children these may only be measurable in the long term. There was a suggestion that services could be measured against compliance with care pathways, using significant events on that pathway and that this could measure the quality of care provided rather than simply a clinical outcome.

But if good data wasn't available before an intervention how could performance and value for money be measured later? In addition, having heard about possible future workforce problems, it was suggested that targets may not be met in the future because of staffing problems rather than poor care. So targets had to be made with this in mind.

Clearly, setting targets would be a complex issue.

74% of participants agreed with the statement that **performance management arrangements for child health services in Scotland should be enhanced**, with over 35% strongly agreeing. An even greater proportion agreed that **more specific outcome indicators/targets needed to be developed for specialist children's services**.

When asked about the visits to health boards by CYPHSG members, there was good agreement (just over 48%) that this could make a **positive contribution to the delivery plan implementation**, but a significant proportion of participants (almost 32%) were not sure.

In contrast, when asked **if the Joint Children's Services Inspections would be an adequate mechanism to monitor the performance of specialist children's services** around 62% of participants disagreed, almost 24% strongly disagreeing.

## 5. Summary

A range of issues arose throughout the event, during questions after presentations, during focussed discussion sessions and from the afternoon debate and voting. It became clear that certain important messages or themes were common to many or all specialist services:

- There is a general lack of access to colleagues and services in **dietetics and psychology** and yet these provide a central support to all disciplines.
- **Transition services** are currently inadequate and need to be better planned and resourced.
- Specialist children's services are truly multi-disciplinary, requiring **good team work** from consultants through to administrative staff
- The **Managed Clinical Networks** model is popular and has potential to enhance and sustain services. MCNs do, however, need to be properly managed and resourced. Infrastructure for local and regional networks has to be well developed before creating national networks.
- Uncertainty among participants about **MCN 'plus'**, a network model operating at a level between an MCN and Nationally designated services, may reflect a lack of clarity of what the model would offer. Other models of networking should be studied to inform development in Scotland.
- There is a need for **better data** to determine service needs and to measure performance improvements.
- **Young people** themselves should be consulted about the design of services
- **MCNs represent a useful approach** that should be strategically rolled out to all relevant specialist children's services
- it would be to valuable have the various MCNs for Specialist Children's Services **managed as a single joined-up system,**
- **NHS Scotland does not have an adequate workforce** to redesign specialist child health services at a national, regional and local level. However, concerns were raised that it will be difficult to recruit if **funding is seen to be short-term.**
- **Developing new roles** and **creating additional workforce capacity** were felt to be equally important priorities for preparing the workforce to meet the challenge of improving specialist children's services with **education and training** slightly less so
- The existing arrangements for planning and commissioning specialist children's services **do not meet the needs of children**
- More planning/commissioning capacity should be created **at a national and regional level**

- **Performance management arrangements** for child health services in Scotland should be enhanced
- **More specific outcome indicators/targets** need to be developed for specialist children's services.
- Visits to health boards by CYPHSG members could make a **positive contribution to the delivery plan implementation**, (although a significant proportion of participants were unsure about this).
- **Joint Children's Services Inspections** don't represent an adequate mechanism to monitor the performance of specialist children's services.

## Notice board Comments

***Participants were encouraged to write their thoughts onto tablecloths during focussed discussions. However, if participants had comments that were unrelated to the particular discussion, but related to specialist children's services in general, they were asked to post their thoughts onto noticeboards around the venue. A summary of these is represented here. It is not possible to present all of the diverse views and ideas expressed on the notice boards, and an element of selection and analysis has been adopted in the following section.***

***The views expressed were made in a spirit of free and unhindered expression of opinion and belong to the participants. They do not necessarily reflect the views of The Scottish Government, who sponsored the event.***

### Workforce

- Many comments from delegates that workforce is not just about medics.
- Need to engage with AHP groups directly.
- Comments that Nurses/ AHPs are key and can take on extended roles to improve service provision given support/ training/ education.
- Need highly specialist multi disciplinary team to support specialist services at regional level. Dearth of AHPs who are moving into specialist roles due to lack of training/ lack of junior grade posts.
- Workforce – new roles required, however, require to be delivered by additional workforce capacity, but how will the diminishing workforce be replaced.
- The Nurse Consultant role in specialties could be key to leadership in nursing services - very few of these posts in Scotland.
- More attention needs to be given to the role of the full child health team, not just medical staff.

### Networks

Many comments parked about networks – summed up below.

- Commissioning services are part of a whole and need to be commissioned on this basis.
- MCN – should establish network office at each of the 4 children's hospitals.
- Cannot have MCN without infrastructure locally who can implement MCN at local level. You run the risk of having guidelines/ standards of care that will never be met due to lack of resources locally.
- Smaller networks regionally should link to other larger networks for support.
- Need a model somewhere between MCN and national service which allows standards of care to be developed, but funds staff locally to implement these allowing each centre, regardless of geography, to provide highly specialist services.



## Palliative Care

- Several comments left around children's palliative care not being included.
- Co-ordinated care includes palliative care for those who need it (cancer services), at national, regional and local level.
- Would it be suitable for managed care network?

## Children's Cancer Services

Many comments left, mainly duplicating cancer table discussion, but:

- Some delegates concerned that cancer centre options were not discussed at the table discussion.
- Paediatric neurosurgery, where is the paediatric cancer representation on this group?

## Agenda for Change

- Inconsistent for nurses.
- Mechanisms exist to agree and match posts through one specialist centre so that similar posts are re-numerated at the same band.

## Education and Training

- Education to differing professional groups in different geographical areas should be properly co-ordinated to improve the cost and benefit.
- NES should allow training of sub specialist paediatricians and realise cross border export/ import is inevitable.
- Education and training budgets should be part of any network plans.

## Performance Management

- Need to look at some of the target dates - seem to be putting implementation of the recommendations before needs assessment work to assess real need for the service, e.g. Gastroenterology, Rheumatology.
- What are the outcome measures to justify further funding – how do we measure performance? \*throughput, \*morbidity, \*mortality, \*waiting times, \*quality of life.
- A lot of the recommended actions have a ££ tag – where is the evidence/ business case information to support these figures?

## Review of Community Nursing

- Many people noted general concern about the review of community nursing.

### Involving Families

- Vital to involve and get views of children, young people and (not just) parents in the whole process.

### Cleft Services

One delegate left a number of comments about Cleft Services.

- All non surgical must be recognised as part of national service, not just surgery.
- Cleft – moving age from 13 – 16 years and beyond represents a significant issue for dental services in Glasgow children’s hospital.
- Cleft (Glasgow) – under provision in 2 key areas \*Specialist Nursing, \*Psychology.

### Additional Comments

- Urgent need to review and strengthen specialist services in paediatric allergy.
- Why childhood diabetes is not considered a specialist service for children?
- More emphasis needs to be given to the psycho social aspects of care.
- Any decisions on specific specialties should be tested for their impact on other specialties/ services before final agreement.
- Bed provision in new children’s hospitals.

**Sir Alan Craft, Emeritus Professor of Child Health, Newcastle**

**Presentation**



Alan Craft2.1.ppt



Alan Craft2.2.ppt



Alan Craft2.3.ppt

**Harry Burns, Chief Medical Officer, Scottish Government**

**Presentation**



Harry Burns.ppt

**Derek Feeley, Director of Healthcare Policy and Strategy**

**Presentation**



Derek Feeley.ppt

**Cara Doran, Expert Patient Advisor, Cystic Fibrosis Trust**

**Presentation**



Cara Doran.ppt

**Morgan Jamieson, National Clinical Lead for Children and Young People's Health**

**Presentation**



Jamieson,  
Morgan.ppt

Annie Ingram, North Regional Planning and Workforce Director

Presentation



Annie Ingram.ppt



**Deidre Evans, Director, National Services Division**

**Presentation**



Deidre Evans.ppt

## Annex I

**Stewart Forsyth, Medical Director, NHS Tayside and Vice Chair, CYPHSG**

### **Presentation**



Stewart Forsyth.ppt

## Results of voting session chaired by Brian Taylor



Developing the  
Workforce.ppt



Performance  
Management.ppt



Planning &  
Commissioning.ppt



Specialist Children's  
Services.ppt