NATIONAL STEERING GROUP FOR SPECIALIST CHILDREN'S SERVICES IN SCOTLAND MEETING: 22 MAY 2006
ROYAL BRITISH HOTEL, EDINBURGH

Present: Malcolm Wright, Chair, Chief Executive, NHS Education Scotland
Marilyn Barrett, National Workforce Planning, Scottish Executive Health Department
Dr Ian Bashford, Senior Medical Officer, Scottish Executive Health Department
Dr Michael Bisset, Clinical Director, Royal Aberdeen Sick Children's Hospital
Helen Byrne, Greater Glasgow and Clyde Health Board
Professor Sir Alan Craft, Past-President of the Royal College of Paediatrics and Child Health
Deirdre Evans, Director, NHS National Services Division
Ellen Finlayson, CLIC-Sargent
Dr Annie Ingram, North Regional Planning and Workforce Director
Morgan Jamieson, National Clinical Lead for Children and Young People's Health in Scotland
Heather Knox, West Regional Planning Manager
Isabel McCallum, Clinical/Project Director – Reprovision of RHSC Edinburgh
Jackie Sansbury, Director of Strategic Planning - NHS Lothian
Robert Stevenson, Project Director, Scottish Executive Health Department
Dr Iain Wallace, Associate Medical Director, NHS Greater Glasgow and Clyde, Women's and Children's Directorate
Professor George Youngson, Children and Young People's Health Support Group

In Attendance: Dr Sarah Gledhill, Child and Maternal Health Unit, Scottish Executive Health Department
Dr Rosie Ilett, Child and Maternal Health Unit, Scottish Executive Health Department
Andrea Cail, Project Manager, Scottish Executive Health Department
Dr. Jennifer Armstrong, NHS National Services Scotland

Apologies: Anne Leigh Brown, Information Services Division
Myra Duncan, SEAT Regional Planning Group
Dr Zoë Dunhill, Medical Director, Royal Hospital for Sick Children, Edinburgh
Professor Stewart Forsyth, Medical Director, NHS Tayside
Dr Jamie Houston, Oban and Lorne Hospital
Dr Margaret McGuire, Nursing Officer, Scottish Executive Health Department
Jacqui Lunday, SEHD
Rebecca Strachan, Action for Sick Children

Item 1: Agenda and introduction

1. Malcolm Wright welcomed everyone to the first meeting of the National Steering Group. He stated he felt privileged to Chair this Group, that the time was right to make radical changes and that the child health agenda was building momentum. He had been

encouraged by the Kerr review and the actions relating to child health in *Delivering for Health*. Although child health is not one of the Scottish Executive Health Department's top 12 priorities, he has been assured children are a priority. One thing the Group could consider would be a "National Health Service for Children" which could integrate services nationally, regionally and locally; and with local authorities. District General Hospitals (DGHs) and Community Health Partnerships (CHPs) should be included in building sustainable services. In workforce planning the Group should be proactive and not just reactive. It should look at networks of care and consider education and training. The commissioning and managing of services should be considered to create the best possible clinical service.

2. Malcolm went on to remind the Group that lots of reports and evidence had been produced and that we should now be focussing on delivering real improvements in services. He highlighted some of the areas that had already been identified as requiring action:

- The sustainability of metabolic services had to be considered
- The recommendations for cancer services had to be considered and models of care produced
- It would be critically important to consider neurosurgery in the planning of the new children's hospitals in Glasgow and Edinburgh. John Glennie had been appointed to chair work on a review of neurosurgery which would not be completed until well into 2007 – this Group should work with John Glennie's group. Clarity was needed on what John's group would be reviewing – all or only complex cases?
- A review of general surgery should be undertaken
- Workforce discussions shouldn't just be done with individual boards – getting satisfying careers should be considered
- The use of technology should be thought out – e.g. video conferencing, imaging.

3. With careful planning we should be able to produce 2 really good, co-located new hospitals in Edinburgh and Glasgow. Services must articulate with each other and the role of the existing Dundee and Aberdeen hospitals must be taken into account to produce a sustainable suite of services. There must be no losers – it must be a win/win/win/win situation for all 4 hospitals. The views of children, young people, clinicians, managers, MSPs, MPs and local government elected representatives must be sought. All 4 existing hospitals have good public support, including fund raising – this mustn't be lost.

4. Malcolm summed up by saying the Group would be looking at specialist services in particular but would also be considering cross-cutting themes, e.g. workforce issues, transport and information. The work that the Group has been asked to take forward would be challenging and complex. Individual leads for each workstream were in the process of being identified, however, everyone would be expected to contribute. Everyone had been invited to join the Group for their individual expertise – Malcolm was particularly pleased that Sir Alan Craft had agreed to take part as he would be able to give the Group a UK-wide perspective.

Item 2: Role and remit

5. Robert Stevenson invited the Group to comment on the role and remit of the Group which had been circulated. During discussion it was pointed out that the specialist nature Group's work must not destabilise the rest of paediatric care. The whole care pathway must be considered to provide sustainable services – including links with CHPs and DGHs – and should not destabilise any services. Links should be retained between the 4 specialist centres – the role of the 4 centres should be formalised in supporting DGHs and CHPs.

6. The issue of timescales was discussed and the need to ensure that decisions are taken to support the development processes for the two new hospitals. The new hospital in Glasgow should be opened by 2010/2011 – an outline business case had to be submitted by December 2006. The target date for the new hospital development in Edinburgh is 2012. It was noted that representatives from the Edinburgh and Glasgow planning group are participating closely in both of the capital planning processes for the new hospitals.

7. Robert informed the Group that the requirement for public consultation would have to be considered if substantive changes in service delivery were proposed.

8. Malcolm summed up by saying the Group should be proactive, bearing in mind the timelines for the planning of the new hospitals. The remit was agreed, subject to minor amendments.

Action: Role and Remit of the Group to be amended to reflect the discussion.

Item 3: Planning assumptions

9. Robert Stevenson referred to the paper which had been circulated. He pointed out the first set of bullet points had come out of the work which had been led by George Youngson and which had been fed into Professor Kerr's review. The second set of bullet points contained the issues which had to be revisited and which had been included in *Delivering a Healthy Future* Action Framework. The aim of the Group should be to produce a national delivery plan for specialist children's services in Scotland. During discussion, it was suggested the language should be amended to emphasis the following points:

- Ensuring that services are not destabilised
- Networking of services on a regional basis with Aberdeen, Dundee, Edinburgh and Glasgow continuing to have a significant role.
- The National Delivery Plan should be based on the best available evidence
- Emphasise the value of any proposed change and be explicit on case for change and best clinical outcomes
- The impact of proposed change in age
- Taking account of the role of the general paediatrician and services provided in district general hospitals
- Services to planned and commissioned at a national, regional and local level where appropriate.
- Including references to 'children and young people'

Action:
Further comments to R Stevenson by 16 June 2006

The planning assumptions paper to be revised based on comments received.

Item 4: Models of care

10. Deirdre Evans explained she was presenting the paper in Stewart Forsyth's absence. The paper was intended to provide a Framework for the Group's work. It contained a review of the current distribution of specialist services. The Group would have to be specific about

what information it needed. The aim of the Group should be to provide care as close to home for as many children as possible; to sustain primary/secondary care; and to redesign services in 4 levels. The annexes of the paper were intended to provide basic information to help inform the review. A map was tabled showing which services were provided in each of the 4 main children's hospitals.

11. Deirdre reminded the meeting that 2 of the main drivers for change were the Working Time Directive and the Modernising Medical Careers. She also reminded the meeting that the definition of MCNs had first been put forward in 1998 had been adapted since. What is needed are well-managed services – a single service delivered on more than one site. All services should be planned at the same time and not in isolation from each other. Some services are delivered in one hub, some are delivered in 2, 3 or 4 hubs but it was suggested during discussion that hubs were not the most useful model. The 4 main children's hospitals should be at the heart of a wider regional network. A map should be produced pointing out what will be delivered where, and not pointing out what is being withdrawn.

12. The Group should decide on the specialist service that is required then propose how and where to it should be delivered. The Group should look at levels of care bearing in mind that at least 95% of services will continue to be provided in their current location. However smaller centres such as Inverness and Elgin should not be overlooked. The aim should be that a patient would receive most care in a local hospital but may have to attend a specialist centre once or on a few occasions. The approach should recognise that pathways of care are only as good as its weakest link – all links have to be excellent. The pathway starts with prevention, then diagnosis.

13. The issue of communication was discussed and that key messages should be agreed at the end of each meeting. It must be made clear that none of the existing children's hospitals are under threat.

14. Malcolm summed up by stating that the message from the Group should be that we would not be downgrading Dundee or Aberdeen and that message must be communicated clearly. The Regions would be encouraged to work together to plan stratified but unified services across Scotland.

Actions:
Annex B to be updated to include information on services based in Aberdeen, Dundee and Glasgow.

Comments on Annex A to be forwarded to Stewart Forsyth by Friday 16 June 2006.

Comments on main paper to be forwarded to Stewart Forsyth by Friday 16 June 2006.

Paper to be revised on comments by group members.

A second map outlining the proposed future model of care for Scotland for the final report.

Item 5: Discussion paper on delivering services for children and young people

15. Morgan Jamieson pointed out that the paper highlighted ongoing work beyond the remit of this Group. He suggested that at the moment planning, delivery and commissioning of services were disconnected. While the Group's vision may extend to the creation of an NHS for children in Scotland this couldn't be done in one step. Regional planning was very important – in practice most services function at a regional level. Regional planning could strengthen DGHs. How Aberdeen and Dundee work together and how they work with DGHs should be looked at. The paper proposed that Regions should move towards commissioning as well as planning. With robust Regional commissioning in place inter-Regional collaboration could further strengthen national services.

16. During discussion, it was pointed out that although option 5 in the paper was radical it didn't mean it wasn't right. Scotland has less than 1 million children therefore Scotland needs a unified health care system with common standards delivering care locally, regionally and nationally. Options 3 and 4 were more realistic but the Group should consider what the right option is ultimately. The Group must not lose sight of the work done by CHPs – care for children is mostly delivered in primary care settings, not in hospitals. Children's services must be integrated with services delivered outwith the NHS and also with adult services, i.e. child-proofing services. The Group should consider moving towards the regional commissioning model and at network approaches to help with recruitment problems. Networks of care depend on local services. The Group should identify 2 or 3 good examples of a patient pathway from diagnosis onwards. Strong regional planning and commissioning would strengthen effective collaboration between health boards and local authorities. Regional planning/commissioning would have to be properly resourced because Health Boards, not the regions, control budgets.

17. Malcolm summed up by saying the Group supported regional planning and commissioning with a network infrastructure.

Action: Develop the paper and produce definitive proposals before the next meeting.

Item 6: Metabolic services

18. Jennifer Armstrong began her presentation by informing the meeting that there are around 500 metabolic diseases. 10-20 new cases present each year, with a range of severity. One in 4 children survives into adulthood. 6-8 new cases of Phenylketonuria (PKU) present each year: if this is diagnosed early, the illness can be prevented from progressing. The Group reviewing metabolic services looked at the following categories:
Category A – outpatient care
Category B – degenerative disorders
Category C – inpatients
Category D – PICU.

Categories A-C could and should be managed locally. There are approximately 20 PICU admissions to Yorkhill per year: around 3-6 to Edinburgh.

19. The services are too thinly spread. Some patients, depending on where they live, do not have access to optimal levels of care. Many adults present at adult hospitals but adult hospitals are unable to treat them. Yorkhill provides multi-disciplinary tertiary services, including adult services – a new consultant is due to start in August. Aberdeen has a multi disciplinary team (MDT), training of a paediatrician with a special interest is taking place,

and it provides an adult service too. Ninewells has a MDT but there may be an issue of succession planning – it has no adult service. Edinburgh has a MRC specialist trained to tertiary level. It was hoped this specialist could transfer half time to the NHS but this hasn't been possible. It has a MDT but no adult service. It has a paediatric secondary care service. There are 2 outreach centres in Dumfries and Galloway, and at Crosshouse.

20. A UK formal strategy group is reviewing commissioning etc – Jennifer suggests this Group should join up with the UK group. The Group could link with England to develop outcome indicators, PKU etc.

21. The problems in providing a metabolic service include:

- Efficiency – there is no 24 hour cover
- Effectiveness – there is a lack of knowledge about the diseases: including among A&E staff – clinicians need to be educated
- Accessibility – high cost drugs which can cost around £¼ million-£½ million per year.
- Sustainability – an application for MCN status will be lodged later in the year.

22. The Metabolic Services Group identified the following options for the future provision of care in Scotland:

- Status Quo

- Full time Tertiary specialist in Edinburgh with links to South East with parallel tertiary service in Glasgow. The Edinburgh tertiary specialist would take over the duties of the general paediatrician with an interest in Edinburgh. Outreach provision from each service in Edinburgh and Glasgow to Dundee and Aberdeen would be organised by each centre.

- General Paediatricians in Edinburgh, Dundee and Aberdeen with an interest in metabolic disease with outreach/inreach from tertiary clinicians in Glasgow.

- Half time tertiary specialist appointed by Lothian but work within the clinical network of tertiary consultants in Scotland to:

    - Plan outreach/inreach with secondary care specialist consultants in Edinburgh, Dundee and Aberdeen
    - Joint clinics and review meetings with Scottish clinicians
    - On call cover with 24 hour access for secondary care specialist and cover for PICU
    - This option would retain a 0.5 general paediatrician with an interest in Edinburgh

23. Option 3 – planning would be required as to how it could be delivered by people on the ground. There would be a planned outpatient clinic and 24-hour telephone support. A local link person would be required. Clinicians and managers would have to work together locally. If a clinically unstable case presented, he/she would be transferred to Glasgow.

24. Option 4 was the preferred option, followed by Option 3. Scotland could link into the UK Advisory Group to develop operation links and to develop research/training (linking also with universities). There are currently insufficient trainees in the UK. Options 4 and 3 will be further developed.

25. The Group also recommended that a needs assessment for adult services should be carried out as currently a large number of adults have to attend paediatric units.

26. The potential to redesign services was considered and proposals were made for example dieticians often see patients instead of a specialist, DGH dieticians could be taught how to deal with specialist PKU and could link in with specialist dieticians. However we need to recognise that there are shortages in other staff groups as well

27. During discussion it was suggested that ideally one consultant with a specialist interest should be based in each of the teaching hospitals. Children could be treated locally but with specialist tertiary specialists available by telephone and undertaking outreach. Clear protocols should be put in place: treatment could be led by a dietician rather than a doctor.

28. Jackie Sansbury informed the group that Lothian was urgently looking at the situation in their area and will update Malcolm Wright on any progress made. However it should be recognised that designating metabolic diseases as an MCN would not be the answer to all the problems.

29. Malcolm Wright summed up by highlighting that Options 3 and 4 would require additional resources; the situation in Edinburgh requires urgent attention and a bid for MCN status should be submitted while recognising this wouldn't solve all the problems. He thanked Jennifer Armstrong for the work she had done and confirmed the meeting accepted the main conclusions in the report.

Actions:

The National Steering Group recognised that action should be taken to implement the report recommendations and endorsed the report for submission to the Children and Young People's Support Group.

The NSG recommended that the options described in the report for the provision of services in the South East of Scotland should be taken forward including:

- **Discussions with the MRC on the potential for securing a continued clinical commitment.**
- **The creation of general paediatric post with a specialist interest .**

The NSG recommended that the establishment of a National MCN for Metabolic Diseases should be pursued as a matter of urgency

Item 7: Workforce

30. Annie Ingram reported that the North of Scotland regional planning group was reviewing the child health workforce. The findings of the pilot reviews led by George Youngson feature in regional workforce plans, however this is not just a regional issue, everyone should work together – a working group should be set up. A review on medical

workforce has begun – a number crunching exercise would be carried out to look at baseline staffing levels. Work already completed would be taken into account. The aim was to describe what the future workforce for children's services should look like. Cancer would be reviewed quickly. Neonatal workforce would not be included as the work to be done by Wai-yin Hatton should cover that.

31. During discussion, it was pointed out that an early warning system was needed to avoid crisis situations. The West of Scotland children's planning group has also discussed workforce and could perhaps assist. Short term solutions shouldn't jeopardise long term solutions. A risk analysis would be helpful – a methodology should be developed. There is a proactive project ongoing looking at nursing workforce.

Action: volunteers to join a working group to review workforce were requested: contact Annie Ingram.

Items 8, 9 and 10

32. The Steering Group were invited to look at the papers submitted for these items.

- Information
- Communications – open public consultations would take place in October-December
- Project Plan summary

Actions:

Send comments on the papers circulated for items 8, 9 and 10 to the lead authors by Friday 16 June.

Members to volunteer or nominate individuals to participate in the workstreams identified in the Project Summary Plan.

Issue Action Plan arising from this meeting.

Item 11: Arrangements for future meetings

33. The Steering Group would meet quarterly in Aberdeen, Dundee, Edinburgh, Glasgow and Inverness, with dates to be arranged. The Core Group, whose membership was in place, would meet more frequently.

34. Malcolm summed up by saying this had been a very positive meeting and outlined the key themes.

- The NSG recognised that planning and commissioning should take place nationally, regionally and locally, bearing in mind the role of DGHs and CHPs.
- A suite of coherent services should be provided in each of the 4 main centres on a win/win/win/win basis. It would be very important to communicate this to the service to allay fears.
- Specialist services, in particular metabolic diseases and cancer, required urgent attention and that clinicians, managers, children and young people should all be engaged in the review process.