NATIONAL STEERING GROUP FOR SPECIALIST CHILDREN'S SERVICES IN SCOTLAND
MINUTES OF MEETING: 23 AUGUST 2006
THE LISTER, HILL SQUARE, EDINBURGH

Present
Malcolm Wright, Chair, Chief Executive, NHS Education Scotland
Dr Michael Bisset, Clinical Director, Royal Aberdeen Sick Children's Hospital
Myra Duncan, Regional Planning Director, South East and Tayside Regional Planning Group
Deirdre Evans, Director, National Services Division
Professor Stewart Forsyth, Medical Director, NHS Tayside
Jamie Houston, Consultant Oban and Lorne Hospital
Annie Ingram, North Regional Planning and Workforce Director, North Regional Planning Group
Morgan Jamieson, National Clinical Lead for Children and Young People's Health in Scotland
Heather Knox, West Regional Planning Manager West of Scotland Regional Planning Group
Anne Leigh-Brown, Information Services Division
Isabel McCallum, Clinical/Project Director – Reprovision of Royal Hospital for Sick Children, Edinburgh
Fiona Mercer, representing Helen Byrne
Jackie Sansbury, Director of Strategic Planning – NHS Lothian
Rebecca Strachan, Action for Sick Children Scotland
Iain Wallace, Associate Medical Director, NHS Greater Glasgow and Clyde, Women's and Children's Directorate

In Attendance
Dr Ian Bashford, Senior Medical Officer, Scottish Executive Health Department
Andrea Cail, Senior Project Manager, Children and Young People Specialist Services Team
Colin Cook, Head of Healthcare Planning and Support, Scottish Executive Health Department
Ken Mitchell, Senior Project Manager, Children and Young People Specialist Services Team
Mary Sloan, Child and Maternal Health Unit, Scottish Executive Health Department
Robert Stevenson, Head of Children's Specialist Services Team, Scottish Executive Health Department
Wendy Wilkinson, Workforce Unit, Scottish Executive Health Department

Apologies
Professor Sir Alan Craft, Past-President of the Royal College of Paediatrics and Child Health
Fiona Drimmie, NHS Education for Scotland
Dr Zoë Dunhill, Patients' Services Director and Community Paediatrician, Royal Hospital for Sick Children, Edinburgh
Ellen Finlayson, CLIC Sargent
Dr Rosie Ilett, Child and Maternal Health Unit, Scottish Executive Health Department
Jacqui Lunday, Scottish Executive Health Department
Dr Margaret McGuire, Nursing Officer, Scottish Executive Health Department
Professor George Youngson, Consultant Paediatric Surgeon, NHS Grampian

ITEM 1: WELCOME

1. Malcolm Wright in particular welcomed Andrea Cail and Ken Mitchell to their first meeting as Senior Project Managers for the National Steering Group. He reported a lot had been happening since the May meeting. Sub-groups to review cancer services, age appropriate care and general surgery have been established. Arrangements were in place for the communications, workforce and information workstreams. Close links were being developed with the Neurosciences and Remote and Rural workstreams implementing *Delivering for Health.*

ITEM 2: METABOLIC DISEASES

2. Malcolm reminded the meeting that Jennifer Armstrong had given a very helpful presentation at the last meeting, that the preferred option had been agreed and that the final report had been circulated. He invited Jackie Sansbury to update the Group.

3. Jackie Sansbury reported that since the last meeting, South Edinburgh and Tayside (SEAT) Regional Planning Group had discussed with Mike Grieve, Director of Operations at NHS Lothian to ascertain the position regarding the Medical Research Council the role of Dr Fitzpatrick. The outcome of that meeting was that Dr Fitzpatrick would be returning to his substantive post at the MRC at the beginning of 2007. The next steps would be to support the business case for a Managed Clinical Network (MCN) and steps would be taken to secure consultant cover for the service in Lothian. SEAT would be discussing this at its meeting on 25 August but it would then probably be referred to the Children's Group of SEAT. A proposal would be submitted to National Services Advisory Group (NSAG) in October.

4. Annie Ingram raised concerns about individual Boards being left to resolve issues for services that are clearly delivered on a regional and national basis. There were significant risks associated around resourcing these services and also clinical risk. It was pointed out that the sub-group had been established in response to a short term crisis in service provision that had been raised with the Children and Young People's Health Support Group and the report had identified some immediate short term solutions. It was a stepping stone towards the National Delivery Plan to be produced towards the end of 2007.

5. It was confirmed the metabolic diseases service would be within the scope of a national service or it could evolve into a network service. The National Steering Group noted that there were still some issues which could precipitate further problems and there was a need for a sustainable service in 4 sites across Scotland.

6. The meeting supported the establishment of an MCN as a first step, however national commissioning should be considered as a longer-term solution. The Group would continue to monitor developments and get regular updates on progress.
Action: Jackie Sansbury to report back on progress at the next meeting.

ITEM 3: CANCER SERVICES

7. Malcolm reminded the meeting that children's cancer services had been identified as requiring urgent attention and invited Andrea Cail to address the meeting.

8. Andrea reported that the sub-group looking at children's cancer services had met for the first time on 11 August and that the preliminary steps had begun for the option appraisal, with the intention of completing this by the end of the year. The National Institute for Clinical Excellence (NICE) guidelines would be used, i.e. a principal treatment centre and shared care centres. The 4 main centres would be visited and meetings would take place with District General Hospital (DGH) clinicians. An MCN was being considered and a proposal would be submitted to NSAG in October.

9. During discussion it was suggested a key decision would be whether one primary treatment centre was needed or two – Edinburgh and/or Glasgow - and that a robust recommendation would have to be made. This should be included in the Option Appraisal. More care should be delivered on a network basis, as close to home as possible, to avoid patients having to travel. The Teenage Cancer Trust and CLIC Sargent were included in the sub-group and patient representatives were involved in the Option Appraisal, user engagement would be crucial. Clinicians and nursing staff at shared care level should also be engaged. The Option Appraisal must include training.

10. Clear agreement must be reached on what high quality, sustainable services can be expected where. The format, weighting and scoring of the Option Appraisal would be very important. Alistair Munro, who is undertaking the Option Appraisal, and Sir Alan Craft, who is chairing this sub-group were seen as making good progress.

11. Malcolm Wright summed up by stating the timetable was achievable, but challenging. Thorough engagement with a wide range of stakeholders was crucial. While reviewing individual services, other services must be taken into account. The model of single service children's cancer services for Scotland within a network was essential. Training must also be considered.

Action: Andrea Cail to consider options re involving patients in this work.

The paper on cancer services to be re-circulated.

ITEM 4: AGE APPROPRIATE CARE

12. Morgan reported the membership of this Sub-Group was being finalised and would meet for the first time on 7 September. It was necessarily a large group to include representation from various disciplines and professionals across Scotland. The remit would be considered at the first meeting, transitional arrangements should be included. The implications of raising the age limits for children's hospital services in Scotland to the 16th birthday would be different in each Board. Clinical practice would be affected and therefore staff from adult services must be engaged. Bed numbers may not be huge: 10-15 beds were in use in adult services at any one time in Yorkhill by 14 and 15 year olds.

13. During discussion the following points were raised.

- Many staff in adult hospitals were not aware of the pending age limit change – a health department letter (HDL) should be issued.
- This change had implications for capacity, resources, buildings etc –
- a representative from chief operating level should be on the sub-group.
- Adolescent-friendly services must also be delivered.
- The interface between adult and children's services should be considered.

14. The Royal College of Physicians is working on a transitions programme which this sub-group should tap into – 2 stages should be developed, paediatric to adolescent services and adolescent to adult services. This is not always well done – cystic fibrosis services are an exemplar. The scoping exercise for this could be huge for chronic long-term diseases.

15. Malcolm summed up by saying the gathering of data would be important and that this sub-group should link in to other groups and services, eg education.
Action: Morgan to update the Group at the next meeting.

ITEM 5: GENERAL SURGERY

16. Malcolm informed the Group that a sub-group was being set up and would meet for the first time on 25 September in Perth. He invited Ken Mitchell to give an update.

17. Ken suggested that the paper which had been circulated was self-explanatory. The membership of the Group was being finalised and he was in the process of gathering information to identify the issues.

18. During discussion, concerns were raised that this sub-group would be focusing on general surgery.. It would be important not to de-stabilise other services and to work with the regions to avoid duplication of work. All members of all the sub-groups should be clear why they are on the group, whether in a personal capacity or representing a region. They should be clear on their role and on who they should feed back to.
Action: the 3 chairs of the paediatric regional groups to discuss with regional colleagues how best to take this forward.

19. Malcolm summed up by saying the meeting agreed this sub-group should move forward as outlined in the paper. This national work should link into regional work and that the wider implications of this review should be taken into account.

ITEM 6: PAEDIATRIC INTENSIVE CARE AND HIGH DEPENDENCY CARE

20. Deirdre Evans reported the work that the National Services Division (NSD) was engaged in was based on the *Delivering for Health* workstreams. A High Dependency Audit was in hand. Paediatric Intensive Care was transferring to national commissioning – there would be no change in delivery but there would be different funding arrangements. Other streams of work – eg planning for the 2 new children's hospitals – were looking at bed numbers. Deirdre pointed out that there were 20 paediatric intensive care beds in Scotland and not 22 as stated in the paper which had been circulated and that there were 1,100 paediatric intensive care admissions per year.

21. Statistics were being compiled to assess the number of beds needed, 13-16 year olds would be included in this projection – adolescents should also be included. If these suggest more beds are needed, Deirdre sought suggestions on how best to take this forward.

22. Discussions should take place on how best Edinburgh, Glasgow, Dundee and Aberdeen could work together – in 2005 the facilities in Aberdeen and Dundee were not used to full capacity. Beds are not always staffed – High Dependency Unit (HDU) beds could be upgraded to intensive care beds for 24 hours – this happens now in the 2 main centres. A

judgement was required on what percentage occupancy should be worked on – 75% was suggested.

23. Deirdre summed up by saying that rota management was being done at the 2 main sites. She suggested that people should get together to develop a network and to map out what services should be where. *Delivering for Health* stated that a national paediatric critical care network should be established from 2006.

ITEM 7: DRAFT PROJECT PLAN SUMMARY

24. Malcolm stated that the Project Plan Summary had been amended to reflect progress since the last meeting. Robert Stevenson reminded the meeting that the Plan gave an overview of what's happening. It now included workstreams which should be considered for inclusion eg ophthalmology, urology, renal medicine, haematology and Ear, Nose and Throat (ENT). Decisions on how to prioritise all the work steams would have to be taken, linking in at Board and regional level.

25. Communication on the work of the Group could be done through the Delivering for Health website.
Action: circulate list of membership of each sub-group.
Colin Cook to arrange membership of each sub-group to be included in the *Delivering for Health* website.

ITEM 8: PLANNING ASSUMPTIONS

26. Morgan informed the meeting that the paper had been revised in light of comments at the last meeting and that he was meeting with key individuals and groups to discuss the implications.

27. Robert suggested the planning assumptions paper which had been circulated needed to be more explicit. It should identify how to provide more care locally and get across better the quicker, safer, closer message.

28. It was suggested that the sustainability of services and the "win, win, win, win" messages for the 4 children's hospitals wasn't reflected strongly enough and that the reference to Paediatric Intensive Care Units (PICU) had to be more explicit. It was also pointed out that a rural general hospital is not necessarily the same as a district general hospital (DGH). The paper did not point out that the planning of services should be based on evidence and that the needs of children, young people and their families must be the basis for service planning. However, the meeting agreed to adopt the paper, subject to amendment.
Action: Morgan to revise paper in light of further discussion with key stakeholders.

ITEM 9: MODELS OF CARE

29. Stewart Forsyth stated this was a sensitive area of work. He referred to the paper that was tabled, pointing out that the number of hubs (page 4) would differ across conditions. A pragmatic review had been undertaken since the last meeting. He had looked at the services provided in the 4 main children's centres and questioned whether these were appropriate. He suggested most of the children's specialist services did seem appropriate although delivery could be refined. Some services were being considered ie: cleft lip and severe burns.

30. Stewart suggested this paper could form the basis for the rest of the Group's specialist services work, including workforce planning. Reassurance must be given to clinicians that centres would not close, that services would not be cut and that most things would not change. The paper could be used as guidance or a toolkit for taking work forward.

31. It was suggested that the paper should pick up "hotspots" and outline more specifically the level of care that should be provided at each centre. What is provided in DGHs and in the community should be included. What is provided in each region should be mapped out, to include secondary care etc. This paper was intended as a first step, the next step would give more detail. Ownership of pathways of care needed to be set out.

32. Morgan Jamieson reported that he had received a few comments on the commissioning paper. Some had challenged how commissioning would work in practice and suggested more detail should be included. Morgan had met with Heather Knox, Myra Duncan and Annie Ingram – the next stage would be to take the paper to the regional planning groups. The commissioning of funding for networking services would need to be addressed.

33. Malcolm summed up by saying the commissioning, Models of Care and the planning assumptions papers should be submitted to the paediatric regional planning groups and would form the basis of the public engagement which was planned for the later in the year.
Action: members to share the paper with colleagues to seek comments on the configuration of services.

ITEM 10: LINKS WITH OTHER *DELIVERING FOR HEALTH* WORKSTREAMS

10.1: Neurosciences

34. Robert Stevenson reported that Malcolm Wright had been invited onto the Neurosciences Group. Malcolm reported that he had met with John Glennie, who was chairing this Group, and with Will Scott from the Scottish Executive.

35. It was suggested neurologists and paediatricians should be included in this Group. Although there was discussion about whether there should be more than one centre, the meeting was reminded that *Delivering for Health* recommended one centre. This is a complex issue and the Neurosciences Group would be working to different timescales from the National Steering Group on Specialist Children's Services and from the Groups planning the new children's hospitals in Edinburgh and Glasgow. The meeting agreed to keep a watching brief on this Group's work.

10.2: Remote and Rural

36. Annie Ingram tabled a paper and informed the meeting that she had been asked to be the Project Director for the Remote and Rural project. She went on to say that focus groups had taken place in 6 Remote General Hospitals to find out what services each provided. Adolescents and adolescent mental health had been raised as issues. The project aims to produce a model for providing services in all remote and rural areas in Scotland. This must include a model on supporting the care of an acutely ill child before transfer. NHS Health

Scotland (NES) must be involved. The services required and the skills needed to deliver them must be addressed.
Action: members to volunteer to join Group or nominate representatives to Annie Ingram.

ITEM 11: MANAGED CLINICAL NETWORKS (MCNs)

37. Morgan Jamieson reported that the third and final meeting of the Group looking at MCNs had met on 21 August. A broad strategy document had been accepted with minor amendments. Morgan would discuss it with Deirdre Evans before circulating it to the Group before or at the next meeting. The National Steering Group would have to advise on prioritisation and should work with regional planning groups to take a strategic approach across Scotland to regional MCNs.

38. Although strong representations were made that the MCN document must include service delivery, it was pointed out this would raise accountability issues. MCNs would not be in existence indefinitely – networks should deliver care.
Action: Colin Cook to consider the interface between MCNs and service delivery networks.

MCN Strategy document at be considered at the meeting in December

ITEM 12: INFORMATION

39. Anne Leigh-Brown reported that a sub-group was being set up to consider the needs of the National Steering Group and of the regional planning groups. It would provide a coordination role to avoid duplication. The first meeting would take place on 5 September. It would be helpful to know early what information the sub-groups would be looking for ISD to provide.

ITEM 13: WORKFORCE

40. Annie Ingram reported that she was to Chair this sub-group as well. She emphasised that the individual sub-groups should also consider workforce in their reviews and to articulate to the workforce sub-group what their requirements were. The Royal Colleges were also doing work on workforce and Annie was trying to obtain data from them.

41. Appropriate links must be made between workforce issues, how to deliver services and training needs. Short and long-term solutions were required. The recommendations of each sub-group should include costed workforce requirements and the National Steering Group could then consider them and challenge what was recommended if necessary.
Action: sub-group leads to check their remit includes addressing workforce issues and to liaise with Workforce Sub Group on any proposed developments.

ITEM 14: COMMUNICATION

42. Robert Stevenson reported the first meeting of the Communication Sub-Group had taken place and the Group had firmed up what it was trying to achieve. A public engagement exercise would be initiated with meetings established in Aberdeen, Dundee, Edinburgh, Glasgow and Inverness later in the year.. Opportunities would be taken to publicise the work

of the National Steering Group, eg in replying to press queries. It had been suggested that key articles would be included in the NHS bulletin; a newsletter would be issued; people who had corresponded with Ministers/the Executive would be invited to attend: an interactive website would be set up: children, young people and families would be targeted: a clear audit would be put in place to show engagement had occurred: Stewart Forsyth was leading the Group.

43. It was suggested that engagement with children could be carried out through existing networks.

Action: members to send comments on the Communications Plan to Robert Stevenson.

ITEM 15: MINUTES OF PREVIOUS MEETING: 22 MAY 2006

44. The minutes of the previous meeting were agreed subject to one amendment:

Page 6, paragraph 19, fourth line from top of page: delete "It" and insert "Yorkhill". Sentence then to read "Yorkhill has a MDT but no adult service."

ITEM 16: MATTERS ARISING

45. There were no matters arising.

ITEM 17: DATE OF NEXT MEETING

The next meeting will take place on Tuesday 5 December at 2pm in Conference Rooms A & B, St Andrew's House, Edinburgh.