

NATIONAL STEERING GROUP FOR SPECIALIST CHILDREN'S SERVICES IN SCOTLAND
MINUTES OF MEETING: 6 JUNE 2007
SCHOOL OF NURSING AND MIDWIFERY, NINEWELLS CAMPUS, DUNDEE

Present:

Malcolm Wright, Chair, Chief Executive, NHS Education Scotland
Helen Byrne, Director of Acute Services Strategy Implementation and Planning,
NHS Greater Glasgow and Clyde
Joyce Davidson, Consultant Rheumatologist, NHS Greater Glasgow and Clyde
Dr Zoë Dunhill, Patients' Services Director and Community Paediatrician, Royal Hospital for Sick Children, Edinburgh
Deirdre Evans, Director, National Services Division
Professor Stewart Forsyth, Medical Director, NHS Tayside
Brenda Gibson, Consultant Haematologist, NHS Lothian
Sandra Hay representing Annie Ingram, North Regional Planning and Workforce Director,
North Regional Planning Group
Jamie Houston, Consultant, Oban and Lorne Hospital
Heather Knox, West Regional Planning Manager, West of Scotland Regional Planning Group
Morgan Jamieson, National Clinical Lead for Children and Young People's Health in
Scotland
Anne Leigh-Brown, Information Services Division
Adrian Margerison, Scottish Officer, Royal College of Paediatrics and Child Health
Isabel McCallum, Clinical/Project Director – Re-provision of Royal Hospital for Sick
Children, Edinburgh
Jackie Sansbury, Director of Strategic Planning, NHS Lothian
Professor George Youngson, Consultant Paediatric Surgeon, NHS Grampian

In Attendance

Andrea Cail, Senior Project Manager, Children and Young People's Specialist
Services Team
Rory Farrelly, Nursing Officer, Women and Children, Scottish Executive Health and
Wellbeing
John Froggatt, Head, Child and Maternal Health Division, Scottish Executive Health and
Wellbeing
Janet Garcia representing Jacqui Lunday, Scottish Executive Health and Wellbeing
David Hughes, SPRUN Managed Clinical Network Lead Clinician
Ken Mitchell, Senior Project Manager, Children and Young People's Specialist
Services Team
Derrick Pearce, Scottish Paediatric Renal Urology Network (SPRUN) Managed Clinical
Network Manager
Mary Sloan, Child and Maternal Health Unit, Scottish Executive Health and Wellbeing
Robert Stevenson, Head of Children and Young People's Specialist Services Team, Scottish
Executive Health and Wellbeing

Apologies

Dr Michael Bisset, Clinical Director, Royal Aberdeen Sick Children's Hospital
Colin Cook, Head of Healthcare Planning and Support, Scottish Executive Health
Department
Professor Sir Alan Craft, Past-President of the Royal College of Paediatrics and Child Health

Fiona Drimmie, Associate Postgraduate Dean, NHS Education for Scotland
Myra Duncan, Regional Planning Director, South East and Tayside Regional Planning Group
Ellen Finlayson, CLIC Sargent
Rosie Ilett, Child and Maternal Health Division, Scottish Executive Health Department
Dr Margaret McGuire, Nursing Officer, Scottish Executive Health and Wellbeing
Rebecca Strachan, Action for Sick Children Scotland
Iain Wallace, Associate Medical Director, NHS Greater Glasgow and Clyde, Women's and Children's Directorate
Wendy Wilkinson, Workforce Unit, Scottish Executive Health Department

ITEM 1: WELCOME AND APOLOGIES

1. Malcolm Wright welcomed everyone to the quarterly meeting of the National Steering Group for Specialist Children's Services in Scotland, particularly welcoming the sub-group leads who had been able to attend. He also welcomed Derrick Pearce and David Hughes who were to give a presentation on the Scottish Paediatric Renal Urology (SPRUN) Managed Clinical Network. Malcolm said he hoped to gain the views of the Group on the National Delivery Plan for Specialist Children's Services which was due to be produced by September.

ITEM 2: KEY ISSUES

- GENERAL SURGERY

2. Malcolm went on to say that the meeting would now discuss some of the key issues, the first being General Surgery and he invited George Youngson to speak to the meeting.

3. George began by saying that general paediatric surgery was a UK-wide and international problem. 50% of children were treated by adult surgeons outwith children's hospitals. He gave the example that of approximately 1,000 paediatric appendix operations in Scotland each year, 400 would be carried out in children's hospitals, the rest would be done in District General Hospitals (DGHs): many more children would be admitted to hospital that wouldn't need surgery. No graduates of surgical training since 1990 had chosen paediatric surgery as a speciality: there was a mismatch between choice and need. There was a governance issue: small volume = poor outcome.

4. George went on to point out that children differ physiologically from adults and have different requirements – as was highlighted in the Kennedy report recommendations. A surgeon has to have the competence to operate on children – presently there is an unplanned drift from children being treated in DGHs to specialist children's hospitals.

5. George reminded the meeting that *Delivering for Health* stated that a review should be undertaken of current patterns of general surgical care for children up to the age of 16, taking into account adjacent services and the families' needs. At present children are treated only up to the age of 12 in Edinburgh and 14 in Aberdeen. George recommended a public consultation exercise was required.

6. Problems were occurring because of the shrinking workforce and the Modern Medical Careers initiative. If services were centralised, training opportunities would be reduced and the workload of specialists would become "super saturated". Patients and families would

have to travel more causing family disruption: treatment would be delayed: a perception of poorer care would arise and the “golden hour” would be lost.

7. George informed the meeting that for the review, Information Services Division (ISD) had provided baseline facts but the data was poor due to the different systems used for collecting it. National questionnaires had therefore been issued to the 24 hospitals in Scotland which treat children. The sub-group had also undertaken fact finding/consultation site visits and had conducted video conferences. The Group had also looked at standards of care and had compared the services provided in the USA, Canada, Australia, Sweden and New Zealand – New Zealand was particularly similar to Scotland.

8. The workforce information which had been gained from the questionnaires showed that there were 135 on-call adult surgeons providing general surgical care for children under 16, excluding Glasgow Royal and Gartnavel: 56 of these would treat children aged between 5-12: 32 would treat the under 5s: 14 would treat the under 3s but this was mostly a “grandfather” workforce. The aged 12-16 workload will transfer to children’s hospitals.

9. George went on to set out proposed models of care for discussion:

- Specialist outreach service with local clinical lead
- Joint appointments between children’s hospitals and the DGHs (shared regional consultant posts)
- An over 12 adult-based service in DGHs with all those aged under 12 going to children’s hospitals
- A dedicated local lead surgeon with strong specialist contact
- A tiered model for service delivery.

10. He suggested there could be 3 Levels of Care:

- Hospitals dealing only with older children with simpler conditions
- In-house paediatricians with interested anaesthetists with dedicated children’s lists treating the over 5s
- Specialists and non-specialists treating some younger children.

11. He went on to say the pressure points could be:

- Elective surgery was OK but emergency surgery was not
- Advocacy and the planning process, including succession planning
- Variable facilities and training
- Variation in integration of medical paediatrics
- Strong anaesthetic services
- Rural care.

12. George thought that procedural guidelines for care pathway development should be produced for:

- Head injury
- Intussusception
- Incarcerated hernia
- Undiagnosed abdominal pain
- Peritonitis
- Burns
- Complicated appendicitis

- Surgery in the very young.
13. George pointed out the big headlines coming out of his work included:
- Only one surgeon was contracted to care for children in general surgery
 - Most hospitals had nowhere for interdisciplinary discussions to take place
 - Poor succession planning
 - Children's surgery was not a strategic priority
 - Heavy dependence on medical paediatrics
 - Poor engagement with regional planning
 - Poor adolescent facilities
 - Reasonable working relationship between the DGHs and the children's hospitals
 - A tiered model of care would be appropriate
 - Care pathways would be helpful
 - Shared appointments appeared popular.

14. The Group had produced 3 recommendations:

Recommendation 1. General paediatric surgery should be part of core training: formal arrangements should be put in place to upskill the workforce: local services should be preserved: care pathways should be developed to provide a basis for clinical decision-making.

Recommendation 2. Medical paediatrics should be involved in general children's surgery for emergency conditions of children under 5; for children of all ages with uncertain diagnosis: and for children of all ages in need of high dependency care. Better adolescent/teenage facilities and a venue to facilitate better, regular succession planning were needed.

Recommendation 3. Develop a model of care to fit the needs of DGHs and the specialist hospitals with shared, regionally appointed, consultants.

15. George concluded by saying existing services should be retained: planning needs to be better: consultant surgeons need assistance: different solutions will be needed for different locations and that a National Consultation Plan was required.

16. Malcolm pointed out that this would impact on the planning for the new children's hospitals and that there was a political will to keep services local. During discussion the following points were raised:

- This raised significant issues for children's nurses: recruitment/retention was not a problem and there was good collaborative working between the operating theatres and recovery but there were Continuous Professional Development (CPD) access issues
- The review had not thrown up any quality issues: sustainability was the problem
- The age profile of the staff and no succession planning was a big problem
- Only 4 joint appointments would be required with outreach services being provided and modular training, eg 6 months training in Yorkhill to upskill
- Developing care pathways would eliminate duplicating work
- The patient journey was very important
- Analgesia for children must be sorted out
- Training should include 3 or 6 months paediatric training.

17. Malcolm Wright summed up by thanking George and suggesting there was strong support for the review conclusions. He agreed a consultation event should take place and that NHS Education for Scotland (NES) should link in on training issues.

Action: Presentation to be circulated and Group members to send comments to George: Mary Sloan/All

Organise a General surgery workshop for August: Ken Mitchell

- WORKFORCE

18. Sandra Hay reported on behalf of the Sub-Group lead, Annie Ingram. Sandra informed the meeting the Group was looking at the data contained in the questionnaires which had been issued. A census of medical paediatricians had been completed and the data was being cleansed and analysed. NES had been asked to provide data on junior doctors and a nursing census was due to be completed by the end of June. The problem with other professionals was that they did not spend 100% of their time on children's services. The Workforce sub-group hoped to work up examples of the position in 1, 3, 5 and 10 years time for a couple of the workstreams.

19. During discussion the following problem areas were raised

- Radiology was a problem: the Royal College of Paediatrics and Child Health (RCPCH) were discussing this, taking into account child protection issues
- Ophthalmology
- Need to identify which specialties need formal paediatric education – the universities should be involved (NES has a child health group – contact, Helen Mackinnon)
- NHS Board and regional workforce plans did not go into enough detail: the National Delivery Plan should include a map of what is where, trends and education/training needs. Recommendations must be based on evidence
- Workforce considerations must be included in each workstream
- Regional Planning Groups, and the sub-groups, must avoid duplication of work and gaps must be identified
- Concern that NES was not connected enough with the work of the National Steering Group.

20. Malcolm summed up by thanking Sandra Hay and Annie Ingram for their work so far. He suggested the Group needed support from the Scottish Executive and that workforce issues had strong links with education and training.

Action: John Froggatt to liaise with the National Workforce Unit and discuss how they could assist.

Project Managers to liaise with each other to avoid duplication of work.

- MANAGED CLINICAL NETWORKS (MCNs)

21. Morgan Jamieson reported that a long cycle had been completed. The finalised Strategy contained only minor amendments to that which had been circulated previously. He had had discussions with Colin Cook on how best to circulate the Strategy. Colin was to issue it as a policy document.

22. During discussion it was pointed out:

- MCNs will be included in the National Delivery Plan

- The Strategy should be issued as soon as possible to help implementation of the Action Framework – it should be issued in the fastest possible way – either as a letter from the National Steering Group or by a Health Department Letter (HDL)
- A number of MCNs had now been set up, need to prioritise what MCNs should now be developed and identify resources
- The Strategy would be very helpful, in particular in protecting individual initiatives. An MCN Manager could take on more than one MCN but this should not be a mixture of adult and paediatric

23. Malcolm acknowledged the huge amount of work that had been put in to developing the Strategy.

Action: John Froggatt to discuss how the Strategy is issued.

Morgan Jamieson to consider the next steps for implementation of the strategy.

- NEUROSCIENCES

24. Malcolm reported the National Implementation Group had now been set up and that members of the National Steering Group should meet with key people to get an update and to ensure that children's services are included.

25. Concerns were raised that:

- The different timescales were a problem: the National Delivery Plan to be drafted by September - the Neurosciences Implementation Group was not due to report until December at the earliest
- The timescale also conflicted with the planning of the new children's hospitals.
- The timescale could not be changed: a needs assessment was necessary
- Adult colleagues wouldn't allow paediatric decisions to be taken before adult decisions are made
- The outputs of the Neurosurgery review must be included in the National Delivery Plan
- Patient pathways had to be considered, linking in to other specialties, ie cancer, general paediatrics etc. May be merit in looking at that for different problems, eg shunts, head injuries
- There should be a nursing representative on the Neurosciences group
- Discussions were due to take place with the Neurosciences Implementation Group had reluctantly agreed to set up a paediatric group
- Paediatric requirements need to be clarified.

Action: Concerns over the differing timescales to be raised with Colin Cook

- PICU/HDU

26. Deirdre Evans reported that the NHS Board Chief Executives had agreed to increase funding from £6.7m to £10.5m and this would further increase up to £11m from next year, against a background of severe constraints. National Services Division (NSD) was working with the units to develop a single service on 2 sites and to maximise the best use of these resources. Julie Adams then reported that the group overseeing the setting up of PICU as a single service had now been disbanded. Recruitment, education and training would now be

looked at by a smaller group. The most cost effective way of delivering a paediatric retrieval service was considered, as was transfers and critical care. Jackie Sansbury expressed an interest in contributing to the work of the retrieval group.

27. Deirdre went on to report a Project Initiation Document was being drawn up. This would be shared with Chief Executives and with the Scottish Executive. This was a daunting exercise.

28. Malcolm summed up by acknowledging the major progress and the level of investment in PICU services.

- HDU Audit

29. Most hospitals had now submitted data for the last 7 months. The data was being tidied and would be sent back to the hospitals. Linkage had been set up with the SMR data and diagnosis, and feedback would be given to other groups.

30. Malcolm thanked Deirdre and Julie.

- Children's Cancer

31. Andrea Cail reported that a financial data gathering exercise was underway and that data has been gathered to try to establish the effect of the options on other services within each children's hospital. The NICE Implementation Guidelines Group had a Scottish representative. The implementation of the guidelines are causing anxiety nationally as centres apply them to practice. NICE had issued more information on levels of care – centres not operating as level 4 will be able to deliver more than was previously thought. The neuroscience review was causing concern as it will report after the option appraisal. Andrea reported though that the cancer sub-group was on track to feed into the draft National Delivery Plan by September.

32. The option appraisal meeting would be re-run at end August/beginning of September considering whether the service should be run from 3 regional centres, 2 national centres or one national centre. Clinical data will be applied across the options: a template had been devised for staffing.

33. The Grampian position was delicate. From the previous Craft report, it should be level 3. The moving of diagnostics to a level 4 service was causing concern. Andrea had still to meet with parent representatives from Grampian.

34. During discussion it was pointed out:

- Tiered levels was a good way to go forward but people would be anxious until the levels had been published
- Presumptions against centralisation had to be taken into account
- The option appraisal meeting in August/September would probably not produce a clear outcome – choices will have to be made for inclusion in the National Delivery Plan
- If key services are to be based in the south of Scotland, with some in the central belt and not much in the north, it will be difficult to present. Need clear messages of why this is being proposed
- Practical solutions need to be found

- Patient journey must be considered: as much care as possible should be provided locally
 - Opportunity to develop an MCN – but they can be a way of getting patients into the big centres: need to make them work locally too
 - Local services are important but patients/parents are happy to travel to get the best care
 - One-third of all cancers are sarcomas and the sarcoma MCN is enabling safe treatment for children in Aberdeen, Glasgow and Edinburgh maximising available expertise.
 - Very good preparation will be required for the reconvened Option Appraisal meeting, ground rules will have to be set with clear idea of what outcomes are expected
 - If outcome agreed, what happens next, who makes the decisions at what level?
- SCOTTISH PAEDIATRIC RENAL UROLOGY NETWORK (SPRUN)

35. Malcolm reminded the meeting that the SPRUN annual report had been circulated. He then invited Derrick Pearce, the MCN Manager, to address the Group.

36. Derrick reported that the MCN had been established in 2003 and had been formally designated by NSD in 2005. It had been mandated to improve and develop services. It was service-centred, family centred, multi-agency across Scotland and treated 30 conditions.

37. A Steering Group had been set up consisting of 35 members from all disciplines/backgrounds and geographic areas. A core team had been set up too. The Network was based at Yorkhill but it was a national service with over 100 members and had 25 families linking in directly. The child/young person was at the centre of SPRUN's service model.

38. The MCN focused on promoting local delivery and supporting paediatricians with special interest. It had multi-disciplinary teams and each Health Board knew who its link urology person was. The challenges it faced included:

- Lack of nephrologists
- Local team buy in
- Local resourcing
- Financial sustainability – SPRUN also received charity funding.

39. Teleconference clinics took place to allow local paediatricians to get specialist advice. This could be challenging in terms of time, technology/technical support and access/participation of radiology. Tele-conferencing for parents was being considered.

40. The workforce pressures would increase but training events took place – a training needs questionnaire would be issued. The annual report set out a huge action plan which included long term planning, local team development, strengthening tele-conferencing, planning and integration. The aim was to empower local teams while retaining a centre of excellence. NHS Board/Community Health Partnership (CHP) acceptance was crucial – at present there was reluctance to support appointments to the Network.

41. Derrick summed up by saying SPRUN had clear vision and objectives: it was family-centred and multi-disciplinary: it received external financial support: it was a ready forum for agreeing protocols but it still needed NHS Board/CHP ownership and robust financial planning. The key was commitment by local teams and good communication.

42. Concern was expressed that the annual report did not contain a financial report. It was conceded that in running a Network in the national sense, it was difficult to get priority from Boards – the National Steering Group was asked to give guidance on how finances could be handled. It was suggested the next stage should be a mapping exercise of finances, workforce etc.

43. Malcolm Wright thanked Derrick Pearce and David Hughes and acknowledged Anne Murphy's contribution to the setting up of SPRUN.

- NATIONAL DELIVERY PLAN

44. Robert Stevenson reported that a timetable had been worked up and had been circulated to members. An economic appraisal had been commissioned to look at activity, costs etc for all workstreams and was due to report at the end of August. This would be a key piece of work – it would flag up success and sustainability issues. Public engagement and public consultation would be important – many workstreams would like to host seminars and workshops. Robert suggested instead of the next quarterly meeting of the National Steering Group on 5 September, a consultation stakeholder event could be held instead and a meeting to discuss the National Delivery Plan could take place in October.

45. However, during discussion it was pointed out that:

- A lot of information had already been gathered to enable the National Delivery Plan to be drafted
- The September date should be retained to consider the first draft of the Plan
- The Plan would be a dynamic document: different services would be at different stages of development
- It would be vital to agree the key elements – what were the big decisions that would impact on other services
- What was required of Boards and timescales would have to be set out
- The interim reports indicated most of the workstreams were on target to deliver within the timescale but the National Delivery Plan would be ready in December at the earliest, however Boards set their priorities in September-December
- Extra resources would be needed – the extra funding for PICU might not be replicated elsewhere
- An outline of the National Delivery Plan could be produced by 5 September but evidence would be needed to back up recommendations
- It would be important to get it right but a national conference wouldn't be possible until October
- The RCPCH would be willing to assist.

46. Malcolm summed up by stating that slippage was unacceptable, there was a clear expectation to produce a National Delivery Plan in September but he didn't underestimate the difficulties and complexities. Sub-groups should set a timetable and if members couldn't attend meetings in person they should send representatives. It was important for the planning of the new children's hospitals to produce the National Delivery Plan on time. The Group had no control over neurosciences, but it did have control over cancer and recommendations should be drafted by September. The workforce work had to be pulled together. Progress had been made on MCNs, planning and commissioning, and general surgery: other workstreams had to be project managed. The economic appraisal would be crucial. The

National Delivery Plan should be drafted to include things that are known now but acknowledging that it contained gaps. Boards and regions must be clear on what they need to do.

**Action: Robert Stevenson to review the impact of recent decisions on the achievability of the project outcomes and to update the risk register to reflect the real situation.
Produce outline National Delivery Plan for Specialist Children's Services in Scotland for 5 September meeting.**

47. Malcolm brought the meeting to a close by reminding members that the report on the public engagement exercise had been circulated.

**Action: members to send any comments on the minutes of the previous meeting to Robert Stevenson
The meeting on 5 September would go ahead to discuss the outline National Delivery Plan
A major stakeholder event to take place in September/October.**