

Report March 2009

Making it happen

Prepared for
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1 Introduction

1.1. Overview

This report is of the national workshop held on March 11th 2009 to discuss progress in moving this agenda forward, identifying further organisational development issues and any further action required to implement the National Delivery Plan. The report summarises the presentations which took place on the day, notes the questions asked and answers given, and gives the key points made in each of the workshop sessions.

1.2 The National Delivery Plan for children and young people's specialist services in Scotland

The *Better Health, Better Care Action Plan (2007)* set out a new vision for the NHS in Scotland, with a particular focus on children and young people. These approaches build on the fundamental principles of equal access to services on the basis of need; and care which is free at the point of access. The delivery plan of children's specialist services in Scotland should reflect these principles.

The National Delivery Plan for Children and Young People's Specialist Services (2009) takes forward the recommendations from the review of specialist services completed by the Children and Young People's Health Support Group and builds on the responses to the subsequent public consultation exercise on the draft plan.

The National Delivery Plan Implementation Group has been established to lead and coordinate the process and has provided an additional £32 million over three years from 2008 to 2011 to facilitate the implementation of recommendations.

1.3 National workshop

The agenda:

- | | |
|---|---|
| 1. Welcome and introduction | Stewart Forsyth, Vice Chair, Children and Young People's Health Support Group |
| 2. Overview of the delivery plan | Morgan Jamieson, National Clinical Lead |
| 3. Implementation of the delivery plan | Caroline Selkirk, Chair, National Delivery Plan Implementation Group |
| 4. Breakout session 1 | |
| 5. Commissioning safe and sustainable services- the English perspective | Steve Arnold, Douglas McKelvie, Symmetrics |
| 6. Breakout session 2 | |
| 7. Plenary and the way forward | Malcolm Wright, Chair, Children and Young People's Health Support Group |

2. Making it happen

This section of the report summarises the presentations which took place on the day.

2.1 Overview of the national delivery plan

Stewart Forsyth, the Vice Chair of the Children and Young People's Health Support Group welcomed everyone and stated that the overarching objective of the national delivery plan was to improve specialist services and ensure that the complex matrix of services fitted together in the best way. He introduced Morgan Jamieson, the National Clinical Lead, who gave an overview of the delivery plan.

Morgan Jamieson set the context and history by summarising some of the key policy documents and reviews, which led to the national delivery plan. These included the review of *Tertiary Paediatric Services (2004)*, *Building a Health Service Fit for the Future (2005)*, *National Steering Group (2006)*, *Delivering a Healthy Future (2007)*, *Better Health, Better Care (2007)*, *National Delivery Plan Consultation (2008)* and *Improved facilities. Better Health, Better Care (2007)* highlighted the need for a mutual NHS where health was improved, inequalities and disadvantages addressed, early intervention took place and services were accessible, safe and of a high quality.

He pointed out that because of the significant investment that had been made of thirty-two million pounds over three years, those working in children's services had an opportunity to develop and improve services, which may not arise again. At present there are new children's hospitals or paediatrics services/hospitals in Aberdeen, Dundee, Crosshouse and Wishaw, and soon in Glasgow and Larbert. The government has made it clear that co-ownership of services is important and that the Scottish people should be involved so that any developments made are mutual. This means that families need to be part of the story for children's services. There was also a strong agenda around reducing inequalities and disadvantages, which can occur at a social, geographical and access level. Early intervention is also key and changes made at an early stage can significantly improve the life trajectory of a child; for example in rheumatology and diabetes services. Some services have needed immediate early investment and this is now being widened to incorporate wider services

The responses to the consultation stated that there was broad support for this work and acceptance of the early priorities and identified a range of further services that needed to be considered. Specific concerns were raised about CAMHS which were now being reflected in the allocation of a total of £2m Delivery Plan monies (£1m from each of years 2 and 3) for this specialty. There was also the reality of workplace challenges some of which are already reflected in the emerging requirement for consultants to be resident on call. The value of networking and telemedicine and the need for age appropriate care were also highlighted.

He summarised the key challenges necessary to take children's services forward. These included ensuring a "whole system" approach; reconciling local, regional and national priorities, pointing out that regional planning was already in place; balancing secondary and tertiary care; ensuring value for money and demonstrating success. Networking had to be better integrated and there was room to explore how the existing network model could be expanded as well as improved. Ongoing education and training was required because of the complexity of staff's roles. Equity could also be difficult to achieve when the playing field was not level in each region.

He concluded by saying that success needed to be demonstrable. In two/three years it is important that we can look at the system and see that there is a difference in how

things are done and in the resulting outcomes for children. This will be assisted by robust proxy clinical outcomes. This presentation is attached in the appendix.

2.2 Implementation of the national delivery plan

Caroline Selkirk, the Chair of the National Delivery Plan Implementation Group (NDPIG) spoke of the progress of the National Delivery Plan and how it would be further implemented in the future. The aim of the plan is to support best clinical practice, enhance service sustainability and improve children's outcomes, and it is important that this is done within agreed clinical priorities. The NDPIG meets every six weeks to assess progress.

She pointed out that this funding was the "*opportunity of a generation*". The National Steering Group completed their initial service review in 2007/08. The resources are to be allocated over three years: £2 million in the first year, £9 million in the second year and £19 million in the third year and this was agreed after thorough discussion by the NDPIG. The consultation was complete in June 2008 and, as a result, the priorities and investment agreed for 2008/2009 and the National Delivery Plan launched in January 2009.

The priorities endorsed for the first year were children's cancer, complex respiratory, metabolic diseases, general surgery, rheumatology and gastroenterology. There were some issues around the allocation of resources and how the proposed changes will be funded, the accountability of the relevant structures, the challenges of implementing staff training and development, and how achievable some of the timescales were within the NDP.

A number of services require further work and these include anaesthesia, allergy and immunology, burns, non interventional cardiology, child protection, non malignant haematology, neurology, palliative care, pathology, radiology, renal and urology, and surgical sub specialties. Any other outstanding issues must also be considered with a key focus on a whole system approach. In order to take this work forward the outputs of the workshops will be available to inform progress from the end of March. Between April and October 2009 there will be implementation and further work on service areas. The closing date for submission of proposals for implementation in 2010/2011 will be November. This has been brought forward this year to allow earlier decisions to be made about funding allocation. The vision for the future is that services will be developed in a way that is planned, sustainable, collaborative, equitable, safe and adequately resourced. Caroline reiterated that there must also be a clear relationship between the finances and an improved outcome and that best value must be maximised. This presentation is attached in the appendix.

2.3 Commissioning safe and sustainable specialist services- the English perspective

Steve Arnold and Douglas McKelvie from Symmetrics gave a presentation on work which they had undertaken in conjunction with the Department of Health in England to assist in planning specialist paediatric services. They pointed out that we must remember that paediatric services include both newborn babies and adolescents with quite different issues. The Department of Health wished to ensure that there were not individual service reviews and that children's services continued to link with adults' services. The drivers for change were medical workforce issues and configuration issues and the expected outcomes were that there was support for commissioners to assist in commissioning decisions and to assist development of a supra-regional strategy with an emphasis on the multi-speciality context of service delivery.

The review was clinically driven and led by the consultant paediatric cardiologist, Dr Ted Baker. They also established a clinical advisory group and the Royal Colleges

where closely involved in this work. The aim was to help commissioners of specialist services especially when there were intractable clinical problems.

The services reviewed were those within the National Definition of Paediatric Services, which were more likely to have critical inter-relationships which would, in turn, be more likely to affect configuration. Twenty-three services were selected: blood and marrow transplantation, clinical haematology (non-malignant), immunological disorders, metabolic medicine, oncology (inc haemato-oncology), burns, infectious diseases, respiratory medicine, cardiology, cardiothoracic surgery, neurology, major trauma (inc maxillo-facial and plastic surgery), orthopaedics and spinal surgery, nephrology, urology, endocrinology, gastroenterology, ENT (airway), neonatology, specialist paediatric surgery, paediatric critical care, and specialist paediatric anaesthesia. These services were entered into a matrix which showed which services had to be co-located, which had to be within a particular distance and which had an indirect relationship. This model enables groups to view how all the constraints operate together, tests out various strategies for locating services and discovers whether it is actually possible to meet all of the recommendations about how the services should be configured.

The following questions were asked and answers given:

- Q: Several questions related to the concern that this system was less likely to work in Scotland, which had a large rural and island population making, for example, co-location and proximity of services difficult.
- A: The speakers replied that they had used the South West because it was the most complex area, encompassing urban and rural areas. However they agreed that Scotland was more rural and also had the islands to consider. It was also recognised that this matrix specifically focussed on services within specialist children's hospitals
- Q: A certain number of professionals are needed to maintain accreditation. Did clinicians agree with the matrix?
- A: The speakers replied that the Royal Colleges were closely involved and challenged to give answers. If no answers were given then the Clinical Advisory Group made a judgment.
- Q: The proposed model had political realities and had these been discussed?
- A: The speakers replied that this was the next phase.
- Q: Did the model take account of clinicians travelling to the home?
- A: Yes

A comment was made from the floor that this was about specialist services and that such services may never be possible in a rural/island setting.

2.4 Plenary and the way forward

Malcolm Wright presented the key points arising from each of the eight workshop sessions. The points below are the key ones which arose. They are largely taken from the morning session. He allowed facilitators to add further comments:

2.4.1 Stakeholder engagement

Done well: real desire for consultation and engagement; variety of methods used to engage; peer consultation has worked well.

Key Issues: effective access through education systems; ensure those with complex needs are engaged; involve families and carers rather than child as symptom.

Future: Better methods for complaints and feedback; use existing networks more effectively; remember that they are also young people and use appropriate technology.

2.4.2 Role of networks

Done well: networks we have are treasures; philosophy is collaborative which allows networks to develop rather than a culture of competition.

Key Issues: funding (local versus national); communication is essential; importance of IT networks; trust is essential.

Future: move forward with funding and communication.

2.4.3 Clinical leadership and engagement

Done well: not discussed in detail

Key Issues: need for targets and benchmarking; consistency and consensus on models of care; ring-fenced time and support; support and representation at board level.

Future: education, information and support for frontline staff; national information and data systems.

2.4.4 Workshop roles, flexibility and skill mix

Done well: not discussed in detail

Key Issues: information on workforce skills/knowledge/expertise needs to be improved; data need to be collected on job plans/KSF teams; roles need to be defined across disciplines; currently working in silos (not team workforce plan).

Future: team workforce plan; Scotland wide plan; standardisation of roles, grades and rewards, recognition of commitment to training/time/support/mentoring.

2.4.5 Patient safety and improvement

Done well: new theme so not applicable

Key issues: feedback and education; recognise importance of adopting global trigger tool and patient safety programme.

Future: application of the system in a paper free environment; benefit from national framework.

2.4.6 Indicators, outcomes and data management

Done well: clinical involvement equals better buy in

Key Issues: defining outcomes (qualitative versus quantitative); standardised data collection methods; generic indicators versus specialism.

Future: short life working group involving clinicians to develop indicators; improved communication of data available.

2.4.7 Role of the DGH

Done well: evolved local networks; strong general paediatric services as opposed to over specialism (better than tertiary).

Key Issues: staff interests and aspirations having a negative impact on some specialities (e.g. child protection); risk of deskilling staff - avoided by better co-working with tertiary services.

Future: specialist services closer to home; clear steer to health boards (What expected of DGH? What support?).

2.4.8 Planning, commissioning and ensuring equity

Done well: building relationships, trust and insight across regions; opportunity to mix whole systems approach with speciality approach; delivering additional resources to frontline services.

Key Issues: clarity over accessing funds; lack of understanding of regional and national link; how to level support for bids in practical terms.

Future: better picture of future funding; clarity over how outcomes will be measured; ensure consistency of service development over boards/regions and the country; better feedback to those involved.

Summaries of each of the workshops are included in the appendices.

Malcolm Wright concluded by stating that it is likely that public spending in Scotland will be reduced. At the moment there is a good opportunity to develop services well and this must be done wisely. Financial accountability must be clear and the audit trail transparent. It is important that these significant financial resources result in better outcomes for children.

Appendices

Appendix 1	Presentations from National Workshop
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Appendix 4	Workshop: Clinical leadership and engagement
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Appendix 1 Presentations from National Workshop



NATIONAL WORKSHOP

“MAKING IT HAPPEN”

HAMPDEN

WEDNESDAY 11 MARCH 2009



Professor Stewart Forsyth

Vice Chair

Children and Young People's Health
Support Group

‘Welcome to the Workshop’



Morgan Jamieson

National Clinical Lead for Children and
Young People's Health in Scotland

‘Overview of the National Delivery Plan’



History and Context

- Review of Tertiary Paediatric Services (2004)
- Building a Health Service Fit for the Future (2005)
- National Steering Group (2006)
- Delivering a Healthy Future (2007)
- Better Health, Better Care (2007)
- National Delivery Plan Consultation (2008)
- Improved facilities



Better Health Better Care

- A mutual NHS
- Improving Health
- Addressing Inequality and Disadvantage
- Early Intervention
- Accessibility, Quality and Safety



Consultation Responses

- Broad support; appreciation of investment
- Acceptance of ‘early priorities’
- Need to incorporate range of specialities
- Specific concerns about CAMHS
- Reality of workforce challenges
- Value of networks and telemedicine
- Importance of age appropriate care



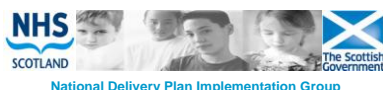
Key Themes

- ‘Whole system’ approach
- Importance of regional (and national) planning
- Sustainability
 - workforce
 - role of DGH
- Networking – more; integrated; enhanced
- Education and Training



Key Challenges

- ‘Whole system’ approach
- Reconciling local, regional, national priorities
- Balancing secondary and tertiary care
- Value for money
- Measuring success



National Delivery Plan Implementation Group

Caroline Selkirk
Chair

National Delivery Plan Implementation
Group

'Implementation of the National Delivery
Plan'



National Delivery Plan Implementation Group

Outcomes from consultation

- First year service priorities endorsed
 - Children's cancer
 - Complex respiratory (CF)
 - Metabolic diseases
 - General surgery
 - Rheumatology
 - Gastroenterology (added)



National Delivery Plan Implementation Group

Services requiring further work include:

- | | |
|-----------------------------------|----------------------------|
| • Anaesthesia | • Neurology |
| • Allergy and Immunology | • Palliative care |
| • Burns | • Pathology |
| • Cardiology – non interventional | • Radiology |
| • Child Protection | • Renal and urology |
| • Haematology – non malignant | • Surgical sub specialties |



National Delivery Plan Implementation Group

Progress – 2008/2009

- Framework established for developing proposals for 2009/2010.
- Carrying out review of further work required on service areas to be initiated in 2009/2010.
- Allocation letters due out in next few days.



National Delivery Plan Implementation Group

Background

- National Steering Group completed initial services reviews 2000/07/08
- Resources allocated of £2/£9/£19 over three years
- Consultation completed Jun 2008
- Priorities and investment agreed for 2008/2009
- National Delivery Plan implementation Group Established – September 2008
- National Delivery Plan launched January 2009



National Delivery Plan Implementation Group

Outcomes from consultation

- Proposals on the whole supported, however some issues around:
 - The allocation of resources and how the proposed changes will be funded;
 - The accountability of the structures associated with children and young people's specialist services;
 - The challenges of successfully implementing staff training and development; and
 - How achievable some of the timescales contained within the NDP were.



National Delivery Plan Implementation Group

Progress – 2008/2009

- Investment in cancer, complex respiratory (CF), gastroenterology, general surgery, metabolic, neurology and rheumatology
- Establishment of MCNs in Child Sexual Abuse, Cancer, Cystic Fibrosis, Endocrinology, Rheumatology
- Investment in Telehealth, Education and Training, Outcomes and Infrastructure



National Delivery Plan Implementation Group

Key Dates

- March 2009
 - Outputs from workshop to inform process
 - Allocation letters out
- April-October 2009
 - Implementation
 - Further work on service areas
- November 2009
 - Submission of proposals for implementation in 2010/2011



Professor Stewart Forsyth
Vice Chair
Children and Young People's Health
Support Group

'The Workshops'



Steve Arnold and Douglas McKelvie
Associate
Symmetric SD Ltd

'Commissioning Safe and Sustainable
Specialist Services – The English
Perspective'



Malcolm Wright
Chair
Children and Young People's Health
Support Group

Plenary and
"The Way Forward"



Role of Networks – Key Themes

- Well – Networks we have are "treasures"; philosophy is collaborative which allows networks to develop rather than develop a culture of competition.
- Key Issues – Funding (local versus regional); communication is essential; importance of IT networks; Trust is an essential component of successful networks.
- Future – Move forward with funding and communications.



Workshops - topics

- What is currently being done well and should be maintained?
- What are the group's general views on the key issues that should be addressed?
- What needs to be done in the future?



Stakeholder Involvement – Key Themes

- Well – Real desire for consultation and engagement; variety of methods used to engage; peer consultation has worked well.
- Key Issues – Effective access through education system; ensure those with complex needs are engaged; involve families and carers rather than child as symptom
- Future – Better method for complaints and feedback; use existing networks more effectively; remember they are also young people and use appropriate technology e.g. Social networking



Clinical Leadership & Engagement – Key Themes

- Well – Nothing discussed.
- Key Issues – Need for targets and benchmarking; consistency and consensus on models of care; ring fenced time and support; support and representation at board level.
- Future – Education, information and support for frontline staff; national information and data systems.



National Delivery Plan Implementation Group

Workforce Roles, Flexibility and Skill Mix – Key Themes

- Well – Not discussed in detail.
- Key Issues – Information on workforce skills/knowledge and expertise needs to be improved; data needs to be collected on job plans/KSF teams; roles need to be defined across disciplines; currently working in silos (not team work force plan).
- Future – Team workforce plan; Scotland wide plan; standardisation of roles grades and rewards; recognition of commitment to training/time/support/mentoring.



National Delivery Plan Implementation Group

Indicators, Outcomes and Data Management – Key Themes

- Well – Clinical involvement equals better buy in.
- Key Issues – Defining outcomes (Qualitative vs quantitative); standardising data collection methods; generic indicators versus specialisms.
- Future – Short life working group involving clinicians to develop indicators; improved communications of data available.



National Delivery Plan Implementation Group

Planning, Commissioning and Ensuring Equity – Key Themes

- Well – building relationships, trust and insight across regions; opportunity to mix whole system approach with speciality approach; delivering additional resource to frontline services.
- Key Issues – Clarity over accessing funds; Lack of understanding of regional and national links; how to lever support for bids in practical terms.
- Future – Better picture of future funding; Clarity over how outcomes will be measured; ensure consistency of service development over Boards/regions and the country; better feedback to those involved.



National Delivery Plan Implementation Group

Patient Safety and Improvement - Key Themes

- Well – Not applicable.
- Key Issues – Feedback and education; recognise importance of adopting Global Trigger Tool and patient safety programme.
- Future – issues around the application of the system in a paper free; benefit from national framework.



National Delivery Plan Implementation Group

Role of the DGH – Key Themes

- Well – Evolved local networks (uniformity of national practice e.g. Renal); strong general paediatric services as opposed to over specialisation (better than tertiary?).
- Key Issues – Staff interests and aspirations having a negative impact on provision of some specialities (e.g. Child Protection); risk of deskilling staff – avoided by better co-working with tertiary service.
- Future – specialist services closer to home; clear steer to health boards (what expected of DGH's?/ what support?).



National Delivery Plan Implementation Group

National Delivery Plan

'The Beginning'

Have a Safe Journey
Home

Appendix 2 Presentation from Steve Arnold and Douglas McKelvie, Symmetrics

Commissioning Safe and Sustainable
Specialised Paediatric Services

A perspective from England

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

Workshop - Wednesday 11th March 2009

Steve Arnold
Douglas McKelvie
symmetric^{sd}

Commissioning
Safe and Sustainable
Specialised
Paediatric Services

A Framework of Critical Inter-Dependencies

• Allergy • Blood and marrow transplantation
• Burns • CAMHS • Cardiology • Cardiothoracic
surgery • Cleft lip and palate • Clinical Haematology
• Complex child & adolescent gynaecology • Cystic
fibrosis • Dermatology • Endocrinology • ENT (airway)
• Ear nose and throat surgery • Gastroenterology
• Haemophilia • Hepatology • HIV/AIDS treatment
and care • Immunological disorder • Infectious disease
• Major trauma • Malignant haematology • Medical
genetics • Metabolic medicine • Morbid obesity
• Neonatal intensive care • Nephrology • Nephrology
• Neurology • Neurosurgery • Non-malignant
haematology • Nutritional support • Oncology
• Ophthalmology • Oral & maxillofacial surgery
• Orthopaedics and spinal surgery • Paediatric critical
care • Pathology • Plastic surgery • Renal replacement
therapy • Respiratory medicine • Rheumatology
• Specialised paediatric anaesthesia • Specialist
paediatric surgery • Urology

Source:
http://www.dh.gov.uk/en/PublicationsandStatistics/Publications/PublicationsPolicyAndGuidance/DH_088068

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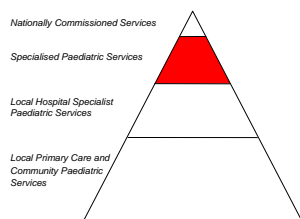


No. 1223, 14th November
2008; page 10

Commissioning Safe and Sustainable Specialised Paediatric Services Background

- Drivers for change:
 - Medical workforce issues – WTD; accreditation; potential future shortages; growing need for networks
 - Configuration issues – lack of clinically agreed reference points; single service reviews, not the 'whole' child; impact of change in adult services
- Project structure:
 - Steering Group, Clinical Advisory Group, Modelling Group
 - Supported by DH, NSCG, SCGs, Royal Colleges
 - Clinically led
- Expected outcomes:
 - Support for commissioners:
 - Framework – to assist commissioning discussions
 - Model – to assist development of a supra-regional strategy
 - Emphasis on multi-specialty context of service delivery

Commissioning Safe and Sustainable Specialised Paediatric Services Project focus



Commissioning Safe and Sustainable Specialised Paediatric Services Selection of services

- Specific criteria:
 - Within the National Definition Set of Specialised Paediatric Services
 - More likely to have critical inter-relationships
 - More likely to directly affect configuration
- Broad principles:
 - Diagnosis
 - Severity
 - Other underlying conditions
 - Complications
 - Age

Commissioning Safe and Sustainable Specialised Paediatric Services Services

1. Blood and marrow transplantation
2. Clinical haematology (non-malignant)
3. Immunological disorder
4. Metabolic medicine
5. Oncology (inc Haemato-oncology)
6. Burns
7. Infectious diseases
8. Respiratory medicine
9. Cardiology
10. Cardiothoracic surgery
11. Neurology
12. Neurosurgery
13. Major trauma (inc Maxillo-facial and Plastic surgery)
14. Orthopaedics and spinal surgery
15. Nephrology
16. Urology
17. Endocrinology
18. Gastroenterology
19. ENT (airway)
20. Neonatology
21. Specialist paediatric surgery
22. Paediatric critical care
23. Specialist paediatric anaesthesia

Commissioning Safe and Sustainable Specialised Paediatric Services Matrix

Specialised Paediatric Service	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23
1. Blood and marrow transplantation																							
2. Clinical haematology (non-malignant)																							
3. Immunological disorder																							
4. Metabolic medicine																							
5. Oncology (inc Haemato-oncology)																							
6. Burns																							
7. Infectious diseases																							
8. Respiratory medicine																							
9. Cardiology																							
10. Cardiothoracic surgery																							
11. Neurology																							
12. Neurosurgery																							
13. Major trauma (inc Maxillo-facial and Plastic surgery)																							
14. Orthopaedics and spinal surgery																							
15. Nephrology																							
16. Urology																							
17. Endocrinology																							
18. Gastroenterology																							
19. ENT (airway)																							
20. Neonatology																							
21. Specialist paediatric surgery																							
22. Paediatric critical care																							
23. Specialist paediatric anaesthesia																							

Commissioning Safe and Sustainable Specialised Paediatric Services Matrix - detail

Specialised Paediatric Service	A	B	C	D	E	F	G	H	I	J
	BMT	Haem	Immun	Met med	Onc	Burns	Infect dis	Resp med	Cardio	Card surg
1 Blood and marrow transplantation					3		2	3	1	
2 Haematology (non malignant)			1						1	
3 Immunological disorder	2	1					3	2		
4 Metabolic medicine		2						1	2	
5 Oncology (inc Haem oncology)	1						1	3	1	1
6 Burns										
7 Infectious diseases			2					1	1	
8 Respiratory medicine			1				2		3	
9 Cardiology								1		3*
10 Cardiothoracic surgery		1						2		
11 Neurology		1	1	2			1	2	1	

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Commissioning Safe and Sustainable Specialised Paediatric Services Scoring system

- GREEN – indirect or no relationship
- AMBER 1 – planned intervention, as required
- AMBER 2 – visit by specialist or transfer of care, next day
- AMBER 3 – integrated service; visit/transfer within 4 hours
- AMBER 3* – without co-location, limited range of services
- RED – absolute dependency requiring co-location

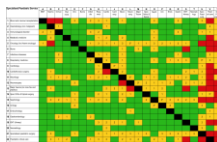


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Commissioning Safe and Sustainable Specialised Paediatric Services Implications

- Clarifies what does (and does not) need to be co-located
- Recognises the cumulative impact of RED relationships:
 - Combined dependencies
 - Core services
- Offers a unique contribution to commissioning:
 - Clinically agreed reference points to inform wider debate
 - Basis for the future planning of specialised paediatric centres



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Specialised Paediatric Services Multi-site Model

Population and Accreditation Constraints

- a **minimum** number of consultants is required to meet the needs of the child population
- if a **maximum** number of consultants is exceeded 'accreditation' requirements may not be met

Workforce Constraints

- there is a **finite number** of consultants, limiting the number of departments

Constraints arising from the Interdependencies

- Locating Service A at Location 1 will mean
 - Co-locating Services D and F there
 - Services B, C, G and K must be at Locations within given transfer times
 - And as Services D, F, B, C, G and K are 'switched on' further interdependency requirements are triggered
 - And so on
 - And so on

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11

Population and Accreditation Constraints
 - a minimum number of consultants is required to meet the needs of the child population
 - if a maximum number of consultants is exceeded 'accreditation' requirements may not be met
Workforce Constraints
 - there is a finite number of consultants, limiting the number of departments
Constraints arising from the Interdependencies
 - Locating Service A at Location 1 will mean
 - Co-locating Services D and F there
 - And as Services D, F, B, C, G and K are 'switched on' further interdependency requirements are triggered
 - And so on

Model Purpose

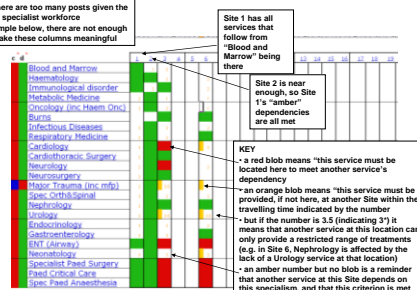
- enable group to view **how all the constraints operate together**
- test out various **strategies for locating** Services
- discover **whether it is actually possible** to meet all its recommendations about how Services should be configured

The best approach is for an **"expert group"** to **iterate** through a sequence of experiments and learn from this

There is probably **not "one right answer"**

columns C and D track respectively:
 - whether there are not enough/too many consultants for child population
 - whether there are too many posts given the size of the specialist workforce
 In the example below, there are not enough Sites to make these columns meaningful

The Multi-Site Model



symmetric^{sd}

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Commissioning Safe and Sustainable Specialised Paediatric Services

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Appendix 3 Workshop: Stakeholder Engagement

What is being done well and should be maintained?

- There is a real desire for consultation and engagement.
- A variety of methods have been used to engage, including different media, focus groups, role playing the roles of hospital staff and having youth representatives on forum.
- Peer consultation worked well, where young people were trained to consult with others. The young people gained skills and confidence and were also able to access groups, which were more difficult to reach through traditional methods.
- Glasgow has a paid person to carry out consultation and this has been successful.
- The “*discovery interview technique*”, where patients’ stories are listened to, has proved an excellent technique for gaining insight.
- The transitional services (young people to adult) are usually good particularly in cystic fibrosis and diabetes. Work in the field of diabetes has gone well in a number of areas and lessons can be learned from this.
- Several examples of successful techniques for consulting including talking mats and *special smiles*, to help children with dental needs.

What are the key issues?

- How to access young people more effectively through education systems; this was easier in some areas than others.
- Need to ensure that those with complex needs are engaged by using alternative methods, for example verbal rather than written and adapting written materials.
- The whole family needs to be engaged rather than treating the child as a disease: families often don’t know what support is available to them and clinical staff need to consider this when treating their child.
- In some cases parents and carers are excluded from communications, particularly parents of adolescents, when they may be excluded from appointments.
- Not all young people who are ill are in children’s hospitals and it is this group who are often the most marginalised.
- Keen to get access to children in special needs schools.
- Adolescence can be a difficult time for all children and this group have additional challenges: specially trained nurses for adolescents would be helpful.
- Continue to consider how consultation can best be done with those with communication issues.
- Peers and friends of children should be considered especially for life-limiting

illnesses.

- Financial issues can be complex, for example around who is responsible for school adaptations which allow young people to communicate.
- Information leaflets are being adapted better for young people and should also consider those with particular needs.

What needs to be done in the future?

- Those with complex needs will require more resources, time and intensive support in order to engage and this has to be allowed for: for example children with learning disabilities may not be able to read.
- The method for giving feedback and complaints must be made explicit and how such feedback needs to inform future service delivery: everyone says that complaints are listened to but how?
- Existing networks are there and should be used and developed. However it is also necessary to engage people who are not part of networks.
- Feedback must be given after consultations rather than asking people their opinion and disappearing. True engagement requires ongoing communication.
- Young people with illnesses want to be seen as young people rather than just illnesses. More effective consultation could be done by text, social networking sites, or second life technology. Mixed methods will ensure most effective engagement. Enable them as a young person, not as an illness.
- Consultation should be resourced beyond the production of the final report.
- There is a school intranet service “Glow” which helps schools to communicate with each other and this could be used for children with health care needs.
- NHS must adopt a whole system approach so that education and communication are integrated and that the whole family is considered.
- Full engagement of clinical, statutory and voluntary staff is required.
- Funding should be decided early for advance planning.
- Make sure work which has been done doesn’t get lost.
- Some information leaflets have been adapted for young people, e.g. “*Have your say*”. This needs to continue and to be adapted for particular needs.

Appendix 4 Workshop: Clinical leadership and engagement

What is being done well and should be maintained?

The discussion within both breakout session 1 and 2 focussed on key issues and what needs to be done in the future therefore there is nothing to be reported in relation to what is being done well at present although it was agreed that there were lots of examples of excellent leadership.

What are the key issues?

A number of key issues and challenges were identified;

- Time - Having the time to ensure that effective clinical leadership and engagement can be successfully developed and implemented and acknowledging that it will take time to achieve successful clinical leadership.
- Bureaucracy - Bureaucracy is and will be a barrier to effective clinical leadership and engagement.
- Resources - Working with limited resources (staffing and financial) can restrict effective clinical leadership and engagement.
- Education, training and support - The need to educate, train and support those who are to 'lead' as well as those who are frontline staff.
- Networks – Networks were seen as a key avenue of clinical leadership engagement.
- Networks were also viewed as a potential avenue through which clinical leads and individuals at a local and regional level could contribute and feed in to the national decision making process; however, it was felt that many networks are currently ad hoc and informal with membership being limited to a small group of people who know one another.
- Networks frequently operated in isolation and that there was a lack of communication between networks locally, regionally and nationally.
- Leads did not always see networks as a priority and in some cases it was too time consuming to attend all of their meetings.
- Paediatric information gathering and data recording – This is currently fragmented, with little or no continuity between health boards on what information and data is collected, how it is collected and how it is recorded. This has resulted in difficulties in obtaining accurate, relevant or in-depth data and information when required, e.g. to justify the need for the funding and resourcing of certain aspects of paediatric care.
- The need to create robust and sustainable models of care for the future.
- The need to set national targets and to benchmark standards.
- The need to involve children, young people and their carers:
“Involving young people themselves in a meaningful way”
- The need for clinical leads to play a central role in training and educating.

The two breakout groups also identified a number of challenges:

- To ensure paediatric leadership and engagement is effective.
- To ensure that there is a uniform and consistent approach to paediatric clinical leadership and engagement throughout Scotland.
- To ensure that there is clarity and transparency in paediatric clinical leadership.
- Balancing priorities – to ensure that all aspects of paediatric care are well led and that one area of care does not take precedence over, and to the detriment of, another.
- How to effectively involve children, young people, their families and carers and ensure that their views and experiences are incorporated into future service change, development and delivery.
- Creating developing and retaining good working relationships locally, regionally and nationally.
- Managing people's expectations.
- Making frontline staff feel valued.
- Ensuring that multidisciplinary/interdisciplinary working is successful and effective.
- Making staff at a local/regional level feel that they have ownership of what is a nationally delivered/driven plan.
- Ensuring that staff are aware of the delivery plan, the changes and developments that will take place and how this will affect them.
- Political support for change and development.

What needs to be done in the future?

- Ensure that the right infrastructure is in place to successfully lead and deliver paediatric care in Scotland.
- Developing a leadership plan - To ensure successful and effective clinical leadership and engagement there is a need for a "*grand plan*".
- Develop a consistent and uniformed approach to clinical leadership and engagement throughout Scotland.
- Two initiatives suggested were the introduction of a national set of leadership targets and a set of national standards.
- Clinical leadership at Board level - For clinical leadership to be effective it was felt that there was a need for lead representation at Board level.
- Support for clinical leadership at Board level - As well as having clinical leadership representation at Board level there also needs to be support, at Board level, for such leadership.
- Clinical leads must play a role in national decision making, service and policy development on paediatric care.

- Clinical leads must play a key role in educating and informing.
- Ring fencing time for clinical leads - This was required to ensure that leads have time, e.g. to attend networks, committees, clinics, meetings, conferences, workshops and symposiums; to inform colleagues about what clinical leadership is; time for self development, e.g. to attend training and development initiatives; and to make a *real* contribution to the local, regional and national decision making process.
- The provision of support for clinical leads.
- The need to provide financial support, developmental support and support in terms of staffing for clinical leads was referred to.
- Developmental support - Support for clinical leads in terms of self development was seen as highly beneficial.
- Staffing & team work - To be a successful clinical lead it is necessary to have good administrative and clerical support.
- A clinical lead cannot be effective on his or her own: teamwork is important.
- Develop and adopt a consistent approach to collecting and recording information on paediatric care throughout Scotland. At present this is inconsistent and means that time can be wasted doing inefficient searches.
- Type of information recorded - Look at what type of information is recorded and check that this is the most useful. Service users should be involved in this.
- Regularly up date and successfully manage IT systems to ensure that they run efficiently and effectively. This will require substantial investment in IT and staff.
- Networks need to become more obligatory and less ad hoc.
- Networks need to share information and learn from one another.
- Networks need to define and refine their roles, aims and objectives.
- Investment in network management is required.
- Transparency in leadership - Clinical leads are often 2-3 year tenures. As a result there needs to be clarity in what a lead's role(s), aims and objectives are so that they can work effectively and efficiently in that allotted time and, when their tenure comes to an end, these responsibilities can be smoothly transferred on to the next appointed lead.
- A consultation process on work force planning is required.

Appendix 5 Workshop: The Role of Networks

What is being done well and should be maintained?

Overall participants were enthusiastic about the role of networks.

- Managed networks work well in Scotland and are “*treasures*.”
- The Scottish Government’s philosophy is collaborative which enables the development of networks rather than developing a culture of competition which happens in other locations outside of Scotland, for example in foundation trusts in England.
- The ethos in Scotland is the child is at the centre.
- Some indicated that there is a good commitment to telemedicine although more needs to be done to develop this further.
- Developing networks cuts across so many themes and issues.
- “*Someone in Oban can have the same care as someone in Glasgow*” if the networks work properly.
- Networks can provide support at all levels - a Scottish service can be provided.
- E library - it is a good resource for getting information on many topics across Scotland.

What are the Key Issues?

- Trust- extremely important for networks to work properly. There is a lot of mistrust at present and working with patients and families trust must be established. Underlining trust, good communications must exist; IT links need to be developed which can assist developing the required trust. Patients and families need to know they are being listened to. There is concern that professionals often don’t speak to each other. Do clinicians trust other results from other areas? Protocols must be put in place. Skills need to be respected.
- There is the need to make sure parents/patients are at the centre of the process and to work with the voluntary sector.
- Local services often feel disempowered when patients have to go to specialist hospitals/services.
- Networks need to interface with local services. Care needs to be provided on the local level.
- Funding - local versus regional. Concerns were expressed over how we direct our funding. There is not enough money for all. How do we enhance the funding we have?
- Ownership - how do we support local forums so they feel part of the networks? How do we engage the District General Hospitals so they feel ownership of networks also? Ownership of the networks must be felt at all levels of the health service. Local colleagues at District General Hospitals need to be empowered so that they feel they are part of the networks.

- There are good paediatric networks established but health boards can opt out. Networks need to be supported across the board. There needs to be an obligation on the part of health boards to engage in networks.
- It is often difficult to participate in the number of networks that exist, although, when networks work they can provide so much in resources and training.
- A Scottish Service can be provided but we need to get over our regionalism in order for our service to be a Scottish service.
- There is a need for more sensitivity between specialist hospitals/services and general hospitals.
- Adolescents - who is to support adolescents when they have no family support? It was also expressed that there needs to be more flexibility with 16 to 18 year olds when they move from adolescent services to adult services. Although many may be at the adult age threshold their maturity level does not match their age.

What needs to be done in the future?

- What is the vision for the next networks? How do we get involved?
- Networks have a role to play with regard to education and training – ensuring that this is generic across Scotland.
- Telemedicine - this needs to be developed further. Development of this will contribute to better communications, although concerns were voiced that this may reduce people's "*network ability*".
- It is important now and in the future that parents and patients are involved in the networks.
- There needs to be a robust discussion on clinical governance.
- Role of national networks should include identifying priorities.
- E library - parents and patients could develop videos/DVDs for educational purposes to add to the E library. We must look beyond DVDs – something that Yorkhill Hospital has begun to explore.
- There is a need to continue to develop a network of networks and to link them up. Failure to do this will lead to isolation. This is of particular relevance if dealing with multiple specialties.
- How do we move from national clinical networks to national service networks?

Appendix 6 Workshop: Workforce Roles, Flexibility and Skill Mix

What is being done well and should be maintained?

- The role of Advanced Practitioners and Practitioners with Special Interests was identified as working well. The concept of Advanced Practitioners and those with special interests was viewed positively as it allows individuals to enhance/develop skills. This then facilitates opportunity to develop roles in the various disciplines and individuals can undertake a wider range of tasks.
- This concept was seen to have had some positive impact in respect of Allied Health Professionals. Example cited was rheumatology (individuals trained to give joint injections) but recognition that more work and development is required
- The positive effect of Advanced Practitioners is not seen to have come in nursing at present.
- Nurses not recognised as being able to diagnose and treat patients, and being able take on a wider role. In hospital services, programmes for development of Advanced Nursing Practitioners is not available. Time to do this is also an issue.
- Also important to ensure that in developing Advanced Nursing Practitioners, they are still able to fill the gaps in their previous roles

What are the key issues?

Information on workforce roles and skills.

- The available information on the workforce skills, and expertise needs improved.
- Due to the way Information Services Division (ISD) collect and collate the data
- Job role definitions may differ from the way they are defined in practice
- Job descriptions don't reflect individuals job plans/personal development plans or the Knowledge Skills Framework.
- Difficult to identify what skills are available from the way information is categorised.
- Question raised on how quality assurance is achieved.
- Inconsistent banding at national level, different grades for same jobs in different health board areas.
- Information not collected often enough.

Planning.

- Workforce planning is not consistent across Health Board Areas.
- A silo approach is adopted as opposed to a team workforce plan.
- This approach doesn't address workforce issues, for example there is resource in general surgery but concern because outreach surgery does not

deal with emergency.

- In medical looking at medical, nursing looking at nursing, there is a need to look at how the disciplines work together and link all the requirements of the service
- Boards covering workload plans at '*too high a level*' – missing out on detail.
- Need for linkages with Local Areas and Staff Development.
- Communication on what is a specialism.
- Need to plan strategically for Special Interests (in some cases this is by luck rather than design).
- Succession planning is also a problem particularly at more senior levels/niche roles.

Perceived gaps in skills/ expertise

- Potential shortage in medical services: thus need to develop other roles to address.
- Consultant Practitioners are not going to be sustainable.
- Areas of special interest often developed due to a personal interest as opposed to what is needed within organisation.
- Concern over medical workforce –shortage in future; lack of understanding of amount of clinical work in organisation.
- Important that key roles and skills are not lost through change in structure and job roles, examples highlighted were Health Visitors and Public Health Nurses.
- Shortage of junior doctors – unlikely to change and again not sustainable.
- Paediatrics is an unpopular specialism: undergraduates only spend 4-8 weeks on and takes time to get level of expertise required.
- Only a small number of Fellows.
- Recognise role of National Development Plan and funding for specialist services but must remember there is an obligation to 'look after children on a continuum pathway' and funding is needed for this.
- Whilst acknowledge need for specialism, a core workforce is still essential.
- Demographics a potential problem.

Training and recruitment

- Lack of clear information on workforce skills' impacts on trainers; more clarity needed.
- Can be limited interest in attending training; needs to be delivered locally and individuals need to be given time/support to attend.
- Numbers for nursing is set by the Government. For Allied Health Professionals this is not the case so mismatch between numbers and what is

needed.

- For those who do undertake training, roles are not there for them to go into and put theory into practice.
- Roles not available.
- Management want to keep people in roles previously held.
- Can be limits to number of specific grades within a team; example maybe only one grade eight allowed so limited opportunity for progression and/or promotion.
- Individuals are not rewarded for training undertaken.
- Secondary care is being delivered via a number of routes, i.e. Community, Social Work, Local Authority and Education. However NHS Education for Scotland (NES) is not involved in the training/education across all these areas. Individuals in Social Work etc will have own training/planning structures.
- Thus there is a need for holistic thinking and this will facilitate more collaboration.
- Issues regarding training will impact on capacity to recruit.
- Challenges recruiting for particular roles; included specialist nurses and dieticians. Constantly '*Robbing Peter to Pay Paul*' – taking and upskilling services in some areas but then losing in others.

Political Agenda

- Changes in management policy approximately every three years but this driven by political agenda. Felt this transition is not managed well. Some perception that health sector needs to be better at responding effectively to Government policy.
- Can lose skills.
- Example- Agenda for Change has caused problems with grading structure; some advance practitioners have specialists skills but not appropriately graded.

What are the future requirements?

- Need for a team level plan and this has to be turned into a Scotland Wide Plan.
- Baseline information on the workforce for all groups.
- Need to share good practice and learn from each other.
- There is a need to standardise roles, grades and rewards.
- Recognise and support the level of commitment required for training; address workload/need for peer support and mentoring.
- Individuals need to have opportunity to work in the roles they have trained for.

-
- Recognise specialist community roles (specialism does not just apply in the acute services).
 - Improve clinical psychologist planning.
 - Need clarity of funding for training.

Appendix 7 Workshop: Patient safety and improvement

What is being done well and should be maintained?

The discussion within this breakout session was focussed on key issues and what needs to be done in the future rather than what is being done well at present.

What are the key issues?

Because of the 'new' topic matter, the issues raised by participants were not expressed as key issues, as possibly more thought would have to be given to their impact. They would best be described as initial thoughts, comments or observations rather than a discussion. These were:

- A Paediatric Global Trigger Tool (PGTT) was thought to be a useful tool. [A Global Trigger Tool was developed in USA and is a system identifying adverse events (harm) and measuring the rate of adverse events over time. This is a useful way to tell if changes being made are improving the safety of the care processes. The Trigger Tool methodology includes a retrospective review of a random sample of 20 patient records using “triggers” (or clues) to identify possible adverse events. The tool is being developed and tested for children in the acute setting in Scotland].
- The NHS is good at implementing processes, but what happens to results is just as important. There has to be education and feedback for staff. It is unfortunate that, like other government initiatives, people think that introducing new procedures is about blame and not improvement.
- Certain areas in Yorkhill Hospital use paper-free systems, for example, the Intensive Care Unit. It was queried whether it was possible to use this tool, which examines retrospectively 30 days after discharge, without a paper trail or paper records. The application of the system in a variety of different settings is an issue. The response to its application in paper free systems was that the minimal information was required and this included patient name and unit number. Key to applying the Paediatric Global Trigger Tool in this situation is access to laboratory results to find out the results of “triggers” eg Pulsox.
- Hospitals may have separate recording systems for different departments. In order to use the Paediatric Global Trigger Tool, health professionals would need access to case notes located on other systems.
- The process of determining adverse events often begins with the clinician thinking, “*Something doesn't feel right*”. There is a need to look at the care of the patient and if the triggers have been carried out. In the case of a patient with diabetes, glucose levels may be very high and so there will be a record of medicines administered. The review team can observe retrospectively if a change in dosage has taken place and identify what happened.
- Patients with physical and learning disabilities with complex needs who present with one risk element (e.g. choking is a risk and they are fed by a gastric tube) but it might be another unrelated element that causes harm. One of the benefits of using a Paediatric Global Trigger Tool is its ability to capture all that data (e.g. in the Microbiology Module and Oxygen Module). The use of triggers will identify many risk factors. For example if there is hypoxia, one would ask if there was a problem with the trachea. One would ask if there was a commission or an omission of care. The answers should help to direct one down a line of enquiry. The system should help the clinical

decision making and cases of children with complex needs.

- The use of an early warning system (PEWS) was dependant on the quality of case notes. It was agreed that there was real variation in the quality of case notes among clinicians, some being good and others, appalling. It was suggested that the Paediatric Global Trigger Tool should help to flag up the issue that problems have not been documented. The fact that an Early Warning Score was not documented is a trigger. This led to a general discussion on the quality of record keeping: a recent QIS Audit identified the need for a clinician's signature and storage of records in alphabetical order – as a minimum.
- A suggested pathway where there are missing notes is to look at the Discharge Summary to see if there is an indication of harm, examine the flowchart and look for any omissions where a patient is being moved between departments.
- For the Paediatric Global Trigger Tool to work, the clinician needs to get the necessary information from patient's case notes. By looking back at medicine Modules in a random sample of cases, a review team may identify incorrect dosages of medicine administered to patient. On closer inspection, it may be the case that staff have made simple arithmetical errors in the calculation of dosages, e.g. taking into account requirements affected by the age and weight of a patient. The solution may be something as simple as introducing the use of a calculator to staff. Also, the review team could find that the timing of administering the medicines had an adverse effect and once detected, this can be remedied. Using a Paediatric Global Trigger Tool was seen as solution-focussed as when the cause of an adverse event is identified, a solution can be found.
- Dumfries and Galloway Health Board has been operating Early Warning System Scores (PEWS) in their children's wards and they had seen a reduction in crash calls.
- A proposed launch of the Paediatric Global Trigger Tool was raised and it was suggested that it might piggyback on a timetabled Scottish Patient Safety event. Each health board which has a programme manager would be able to point staff in the right direction to pilot/test the tool.
- The issues of staff time taken to use a trigger tool was raised, as it required three health professionals to review up to 20 randomised cases.
- There was a question around how the tool would be applicable to primary care setting rather than the acute setting.

What needs to be done in the future?

Group participants welcomed in general the inclusion of children's requirements in patient safety. In specific, the need for a national framework was recognised.

Three participants took up the invitation to note individual comments on post it notes. These were:

- In order to implement this tool and reduce adverse events, feedback and education is needed for NHS staff.
- A support network for exchange of ideas around improving patient safety for children would be useful for NHS staff.
- The adoption of such a tool in a community setting would be very useful.

Appendix 8 Workshop: Indicators, Outcomes and Data Management

What is being done well and should be maintained?

- Standard Quality Indicators - The use of the “*Better Health Better Care*” quality indicators as a Framework for developing indicators was well received. These indicators include: Equity; Efficiency; Effectiveness; Patient Centeredness; Safety and Timeliness. These measures were regarded as a good framework for developing indicators across all specialisms and by clinicians and commissioners alike.
- Clinical Involvement - It was generally agreed that clinical involvement in the development of indicators and the methods used to gather the data resulted in both a higher quality of dataset and better staff take up in its implementation and outputs.
- NDP Information Programme - The Information Services Division’s Women and Children’s Health Information Programme will offer lessons in data management and will produce models of good practice, which should extend to build the capacity of services. The Managed Clinical Network programme has been well received in its aims to improve child health through the provision of quality health information.
- Case Studies on Good Practice - Within Children’s Health services there are examples of good practice where quality indicators have been agreed and data are collected which highlight good outcomes. One is the “*Clefts*” System which works effectively, collects a range of data consistently and produces information which allows measurement nationally.

What are the key issues?

- Balancing the Clinical Outcomes with the Operational Performance - There were consistent comments made about the actual definition of “the outcomes”, what these should be and striking a balance between the qualitative indicators and the quantitative, more measurable indicators. This was often described as clinical versus operational.
- Holistic versus Specialisms - It was recognised in both groups that we need to compare the establishment and measurement of generic broad indicators as well as specific data sets within specialist services.
- Compatibility of Systems - -A key area of concern was the lack of standardised data collection methods. This widespread issue relates to the non compatibility of datasets and systems both across health boards and within specialist services.

“IT systems are key to the success of what we do. There is a gaping hole in patient data and currently we don’t have the clinical systems in place to collect the required data.” Consultant Paediatrician

“There are various datasets in existence, for example for cystic fibrosis.....but the data is not meaningful as it’s not measuring like for like.” Consultant Paediatrician.

“14 NHS Boards and each have their own system. With Boards moving into PMS, we need functionality now to make links happen

and join the systems up.”

“We suffer from a lack of IT Infrastructure – there is no consistent clinical system to underpin the data.” Service Commissioner

- Patient Satisfaction - Patient satisfaction is often not directly linked to the quality of technical clinical intervention. An example used to describe this was if a parent has had a bad experience with staff not returning calls, they will still give negative feedback on their experience regardless of the quality of the clinical service. The indicators we establish need to accommodate patient perceptions and quality of life measurements.
- Defining Measurement Priorities - The NDP contains both an action plan for its implementation and a vision for the measurement of activity, which will evaluate its impact. The completion of tasks on the action plan are not comparable as measurements of clinical effectiveness and these need to be differentiated with a time line agreed for their implementation.

What needs to be done in the future?

- Clinical Relevance - Integrate the data collection processes in working practices by making databases a useful tool for clinicians in managing a patient's health. The data collection process should start at the clinical interface end and provide clinicians with information so that they buy into the data collection process.
- Measuring Holistic Impacts - There is a need to developing better “*Quality of Life*” measurement indicators through a clinician led patient management system, which is child centred. This type of data is not currently being gathered effectively. It was felt that this could in part be achieved by connecting the NDP data management work with the GIRFEC (getting it right for every child) vision, objectives and indicators.

“The NDP needs to measure the quality of the technical outcome and also measure and evaluate the way in which a service is delivered”
Consultant Paediatrician

- Core Dataset across Specialisms - Develop a core set of outcome measures that would be the same for all services, and focus on a minimum dataset consistently applied and more easily managed and interrogated.
- Communication Plan - Better communication of what datasets exist and where they can be accessed. Ideally this would involve a mapping study, which scoped out the ranges of Information Management systems and highlighted their accessibility to clinicians.
- Development Plan - Developing a short life working group, involving clinicians, to develop indicators. It is a very complex area and we need to develop a language where people mean the same thing.

Appendix 9 Workshop: The role of the DGH

What is being done well and should be maintained?

- Everywhere there are good examples of local networking which have led to the evolution of some examples of uniformity of practice nationally e.g. renal.
- General paediatrics done well within DGHs, better overall care is provided by everyone providing general rather than over specialisation. Strength in core general work force (perhaps better than tertiary?).
- Evolving understanding of importance of joined up planning at a regional level.
- Recognition of whole multi-disciplinary team and National Development Plan gives opportunity to enhance the service.
- In West of Scotland – clinical interface groups sits below regional planning group so each DGH is represented, although not always good at feeding back to clinicians.

What are the key issues?

- Some specialities not well catered for in individual DGHs because of interest and aspirations of staff, good example is child protection but applies to other specialities.
- Run risk of deskilling staff within DGHs (as don't make many clinical decisions), avoided by better co-working within tertiary services.
- Joined up planning at all levels (service delivery and regional and national planning).
- Accreditation – sustainability of medical workforce, working time directive.
- Transition from children to adult services. Particular problems for children accessing tertiary services moving to adult services at a local level. (Example of good practice in this area was Forth Valley as they have a well-established team who work well together.) Hard for parents too as they will have had one paediatrician who was the co-ordinator of the care but when move to adult will see lots of different people.
- Would be too hard to get enough specialists into each area on the list of specialist services in the presentation.
- *"Fooling ourselves to think we can provide specialist services, things have moved on a lot since we trained."*
- Differences between services provided according to geography e.g. one DGH saw children with Crohns whereas another said they would not like patients with this disease to come through DGH as Gastroenterology is *"poor in the DGH"*. Another example given was Shetland would want to provide more specialist care to avoid travel.
- Example given where a young girl came in with a tumour on her cheek and despite the fact she could see the hospital from where she lived and they had a new, top of the range MRI scanner, she had to travel to the tertiary centre.

"Travelling is inconvenient for patients. Tertiary should see that the

patient lives 40 miles away and that there is a hospital closer.”

- Less capacity in general paediatrics, outpatient space is a huge issue which means challenging to set up outreach clinics and have to compete with adult clinics.
- Shortage of Junior Doctors – more difficult to get from India and Pakistan than before.
- Mistake to make child protection a speciality, with the exception of sexual abuse

“Can’t ship child with bruises on their face 20-30 miles away.”

- Child protection specialists often lack confidence/not comfortable to give an opinion and make a decision.
- Paediatricians can be bad at telling managers that they cannot do something because they do not have time so they absorb more work which is not good for the patients and their parents.
- Families need to have confidence in local services, do not train community children’s nurses anymore.
- Regional service e.g. specialist speech and language therapist – not good at making it work; do not make the most of these people.
- Consultants in DGHs still feel disconnected with specialists.
- Practicalities of having a consultant for example working and living in Dumfries and having to do 2 days in Glasgow.
- Effective service delivery dependent upon how well integrated health boards are with local councils.

What needs to be done in the future?

- Provide specialist services/resource services closer to children’s homes to avoid deskilling.
- Clear steer to health boards about what is expected of DGHs – provision and what support can be expected to allow this to happen.
- Expectation management at what can realistically be achieved once allocated the £32 million.
- Improved discharge process – do not always work with DGH colleagues. Should engage with DGH to see what is available locally before making promises to families.
- Improved networks and communication.
- Promote general paediatrics.
- Provide more education/training for specialist nurses e.g. diabetes. Could go to tertiary centres and get expert training. Added value at a local level.
- Appreciate tertiary units are specialists but need to see that DGHs can help.

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- DGHs have to have ownership of networks and know what they want them to provide.
 - *"Boards need to look at regional rather than just their own patch."*
 - Consultants, AHPs and nurses could do one day a month in a tertiary centre to build networks and have the opportunity to do specialist work that is of interest to them, e.g. gastroenterology.
 - Need to upskill people at a local level so a home visit does not take up most of the day for a nurse, it's not efficient.

Appendix 10 Workshop: Planning, Commissioning & Ensuring Equality of Service

What is being done well and should be maintained?

- Key point is that the NDP “*has stimulated very good regional and national debate*” beneficial in “*raising greater awareness of paediatric services.*”
- The fact that a “*need to develop a sustainable service across multiple disciplines*” had been identified was also an important point.
- Building relationships/trust/insight across regions.
- Delivering additional resource to frontline services.
- Opportunity to mix whole system approach with speciality approach.
- Healthy debate between boards and tertiary centre re make up of bids.
- Charting current services to visualise future difference of investment. For example, a mapping process used in Tayside region was found to be beneficial in highlighting the issues requiring focus. This approach was then described as being extended to other areas, because of its utility.
- Moving quickly (although perhaps too quickly).
- Clinical leadership and engagement.
- Regional planning groups empowered.

What are the key issues?

- Difficulties in complexity and time dependent nature of service provision - makes delivery fundamentally challenging.
- Finite resources and how to match these to needs – what do we mean by ‘*same level of care*’ – must be appropriate and safe delivery and this will vary across specialisms.
- Needs assessment is at the crux of the whole – it needs to be dynamic and ongoing because things vary.
- A lack of clarity was noted in general over how to lever support for bids in practical terms. Example given - one clinician expressed extreme vagueness over identifying relevant parties to engage with to develop bids. This discussion then revealed difficulties in terms of practicalities of linking in with many different regional planning groups – i.e. if specialism bridges many different geographic areas. However others then pointed out that regional planning groups have links/networks in place to facilitate joined up working and this should avoid the duplication of effort for clinicians.
- There were some concerns over the appropriateness of what gets funded from which source – e.g. Cochlear implant funding concern voiced – as being an inappropriate and overly weighty demand on the funding stream being discussed
- There was an over riding message relating to a need for greater clarity over

how funding works – who will be the winners and losers compared to previous years, also in relation to continuity of funding in the future.

- There was an articulated need to see something more for the money being spent - from the government perspective - '*additionality*'.
- Significant financial risk in terms of how funds will be allocated - concerns from local areas, cross boundary flows and sharing information. Slightly different mechanisms about how the money is distributed across the country – new territory, a process about how to move forward – not determined, work in progress.
- The role of primary care in 'specialist services' was an important discussion theme. Some felt there was undue neglect of other models whereby primary care professionals could be engaged in delivery and support of 'specialist' services, under certain circumstances, provided incentives are put in place. The need to explore alternatives to taken for granted solutions was suggested.
- Whole patient journey through services has an impact on planning. It was important not to lose sight of the human dimension to the process – dealing with children and families.
- Coherence over service provision.
- Process appears top down.
- Must not lose sight of the highly politicised arena within which planning and delivery occur.
- Equity – to ensure some 'services' are not disadvantaged.
- Lack of key infrastructure in the first place may impact on outcomes for some parties.
- Challenges of establishing interoperability of IT services on the ground. Work across boundaries can therefore be operationally difficult.
- Consider context relevant appropriateness of model of care – consider how these might adapt to circumstances, e.g. tertiary care may be delivered via secondary or even primary care teams with specialist skill/interest where relevant - question is would this model work elsewhere and the need to consider the alternative options.
- How were discussions happening – e.g. for AHPs ? Feeling of being left out of some of the initial discussions. Clinicians predominantly involved. Lack of established presence and depth of insight from all viewpoints. If you aren't at the table how can you then influence decisions? Clear concern that you must have a toe in the water at the outset. Feeling of possible neglect of allied health professions.
- Concern around the actual practicality of filling vacancies when recruitment for certain personnel is dictated by funding coming on stream simultaneously across regions (resulting in competition for staff).
- The requirement for representative input across the board – need to include ground level and not just medical personnel.
- Feeling of being rushed in this process.

- Dumfries and Galloway – financial support so historically limited, that there is an issue of how to demonstrate improvement from a position of historical cutbacks.
- Capture knowledge - need to elicit feedback about the engagement process – real need to learn from the lessons of the first stages.
- Non ‘specialist’ services still need attention.
- One size doesn’t fit all.
- Harmonisation of national strategies and regional priorities.
- Transport infrastructure needs to be in place to enable transportation of patient – and government needs to be aware of this issue but politics and the costs get in the way of retrieval of child – so there is a mismatch between knowing what needs to be put in place and the reality of what government is prepared to fund. These things are achievable but infrastructures need to be in place. Independent core service dedicated to retrieval.
- Issue of how admissions/onward transfers to other specialist services are currently measured and does this correctly reflect the reality of logistical issues and service provision.
- Need to “*think differently*” – e.g. Shetland have had to develop innovative ways of working and delivering services – this creativity needs to be mainstreamed.
- Avoid backfilling – retro-fitting, maybe we need to influence politicians to shape design that is appropriate instead of ‘doing what it says on the can’.
- Do you challenge the NDP or do what it says on the tin?
- Lines are wavy – don’t go in straight lines (between tertiary and secondary) – the children are real people and the clinicians have to work with that.
- Contrast in ways of working – only saw the children’s hospital model [in the previous SD presentation of the English case study].
- “*But what is exercising our minds is the other part – that should we be planning overall services against the child in the remote location?*”
- Reduce the impact on children who have to access services – by considering the “*users*” perspectives.
- Integration with acute services – point is need to look at the whole perspective.

What needs to be done in the future?

- Clarity over funding post year three/continuity of funding.
- Greater clarity on what should be planned and resourced nationally.
- Improved needs assessment.
- Clarity over how outcomes will be measured.
- Communication and joint working.

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- Need to ensure consistency of support for services across the country..
 - *“Need to manage expectations – we won’t manage to sort everything and we don’t want that to create an impression this has not been positive– there have been successes”.*
 - There was noticeable vagueness about commissioning services in general, voiced repeatedly. There is a need to deliver greater understanding of commissioning processes.
 - Empowering and valuing the role of primary care in the paediatric context and recognising the role of community support in the wider picture.
 - More need to engage with people on the ground and wider cross section of staff groups.
 - Need to maintain specialist competency and there needs to be recognition of the level of skill required and shift away from downgrading pay scales - this has recruitment implications. Equally there are issues to do with best use of resource in terms of redistributing less skilled components of certain roles to others and thereby maximising productivity of highly skilled labour.
 - Clearer articulation of how technically to go about putting together a bid.
 - Find out where good practice happens and transfer this, e.g. adult services have a better interface with CHPs – learn from others.
 - Ensure sufficient depth of engagement with all stakeholders to ensure equity.
 - Public health and population drivers need to be better understood.
 - Morality was mentioned by one person as an issue in the mix.
 - More feedback on how priorities are decided
 - Development of community and DGH liaison.