



Children and Young People's Specialised Services Project (CYPSS)

Consultation Document
2005



All Wales Standards for Paediatric
Gastroenterology, Hepatology and
Nutrition Services

Children and Young People's
Specialised Healthcare Services



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

**CHILDREN AND YOUNG PEOPLE'S
SPECIALISED SERVICES PROJECT (CYPSS)**

**All Wales Standards for Paediatric
Gastroenterology, Hepatology and
Nutrition Services**

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Foreword

Brian Gibbons, AM, Minister for Health and Social Services



The Welsh Assembly Government is committed to the children and young people of Wales. This document is one of a series which follows on from the recent consultation document, The National Service Framework for Children, Young People and Maternity Services. It addresses the specific needs of Children and Young People who need to access specialised healthcare.

The series of consultation documents will be published over the next 12 months and we believe that service commissioners and providers can work in partnership to deliver on these standards.

We ask that you participate in this series of consultations to help us develop the standards further and to ensure that they have the maximum impact on the health of children and young people with specialised healthcare needs.

Ensuring that quality services provided for our children and young people is the best investment we can make for the future of Wales.

A handwritten signature in black ink, appearing to read 'Brian Gibbons'.

Brian Gibbons AM
Minister for Health and Social Services

Consultation Questions

Responses are invited to this consultation document by **8th June 2005**.

Responses can be sent to the address at the end of the list of questions or sent electronically to: eiri.jones@wales.gsi.gov.uk Responses to the consultation will be made public. Normally, the name and address (or part of the address) of the author are published along with the response. If you do not wish to be identified please state this expressly in your response.

1. ***Please state your name, title and place of work (please also state if you want your name withheld from the publication of the results of this consultation).***

2. Some of the key actions within this document have been identified for early implementation and for delivery within 1 year of publication of the standards. Implementation of these key actions has been estimated to be low or no-cost because they are organisational issues or are already being planned for, or implemented, in many areas.

Do you agree that the early implementation key actions are the right ones to prioritise for early delivery? Please state which of these key actions you do not believe can be delivered by this deadline and why. Please also state if there are any other key actions which you believe could be delivered by the end of the first year following publication.

3. Each key action has the organisations which are responsible for the delivery clearly identified.

Are there any key actions which you feel that the organisation you work for is not responsible for delivering? Are there any key actions which you feel your organisation or another organisation could contribute to delivering that have not been listed next to a key action?

4. When you read this document (both the universal and service specific) you will notice that they address either universal or service specific issues.

5. ***Are there any important universal or service specific NEEDS of children, young people and their families which you feel have not been addressed by the key actions in this standards document?***

6. When writing the key actions, and in the Quality Assurance process, every attempt has been made to make each one clear, specific and measurable to allow for easier audit.

Are there any key actions which you feel do not meet the above criteria? If so, can you suggest a form of wording that would improve the key action?

7. These documents are aimed at service commissioners and providers, however we have developed the documents with the help of children, young people and their families and therefore hope that they are easily understandable. We have identified some key words in the glossary of each standards document.

Are there any terms or phrases used within this document that have not been included in the glossary, but which you feel require definition?

8. *Can you foresee any barriers to the implementation of these standards? If so, are there any actions which the Welsh Assembly Government should take to help overcome these barriers?*

9. *From those key actions which are NOT identified for early implementation (i.e. developmental key actions) please select the three that you feel will have the greatest impact on the specialised services for children and young people or are essential to develop and rank them in order of priority.*

10. *Do you have any other comments that you would like to make about this document?*

Please post your consultation responses to:

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Children and Young People's Specialised Services

Introduction

Currently, specialised services for the children and young people of Wales are delivered in an ad hoc and fragmented way. This was identified by the Specialised Health Service Commission Wales, when they undertook a review of specialised services^{1,2}. Following this review, the Minister for Health and Social Services announced that the future of specialised services for children would be through the development of Managed Clinical Networks (MCNs)³.

The Children and Young People's Specialised Services Project (CYPSSP) was established by the Welsh Assembly Government to take this work forward. The project's remit was to:

Develop high quality, equitable and sustainable specialised children's health services across Wales based upon the best available evidence and with children and their carers at the centre of all planning and provision.

This would be achieved by the following aims:

1. To develop service specific standards for Children's specialised services for the children of Wales
2. To enable equity of access for all children in Wales requiring specialised services through effective managed clinical network models.

The agreed specialised services for the project are:

- Neonatal Services
- Paediatric Neurosciences
 - neuro-surgery
 - neurology
 - neuro-disability
- Paediatric Oncology and Palliative Care
- Paediatric Critical Care (standards already published)

- Paediatric specialist surgery
 - General surgery (including neonatal surgery)
 - Trauma and orthopaedics
 - Ear Nose and Throat
 - Ophthalmology
 - Maxillo-facial

- Paediatric specialist medicine
 - Nephrology
 - Cardiology (and access to cardiac surgery)
 - Endocrinology
 - Gastroenterology/hepatology and nutrition
 - Metabolic
 - Respiratory

- Paediatric plastic surgery and burns

The Standards Document

The standards document is written from an All Wales perspective and applies to all children and young people with that health need, wherever they live in Wales^{4, 5, 6}.

There is an universal standards document that applies to all specialised services included in the project.

In addition to the universal standards, there is a document of service specific standards and key actions that apply only to the relevant speciality.

These standards should be read and used in conjunction with the Children's National Service Framework (NSF)⁷, in particular Chapter 2 which is relevant to all services and all children and young people.

To aid effective communication across the Primary, Secondary and Tertiary interface, it is proposed that a Directory of Specialised Services will be developed which will be updated annually.

Purpose of standards

The standards and their key actions have been developed to provide a foundation for service commissioners and providers to plan and deliver effective services⁸. They are to be used to benchmark current services and then inform the

development of robust future services to meet the specialised health needs of children and young people across Wales⁹.

Developing the standards

The standards for each service have been developed by an External Working Group (EWG) representative of the key stakeholders. The relevant membership detail is included as an appendix (Appendix 1) in each of the standards document.

The EWG members have given of their time and effort and their contribution is greatly appreciated. We are particularly grateful to all the children, young people and parents who have been involved in the development of this work^{10,11}.

The standards for each service have been Quality Assured by a Project Steering Group (SG) comprising of strategic external key stakeholders. The membership detail is included as an appendix (Appendix 2) in this standards documents.

A 3 month consultation period will follow the launch of this document which is being circulated widely. Following the consultation period, comments will be evaluated and the final documents published later in 2005.

Delivering the standards

Following consultation, the standards and key actions will be revised and published.

Once published they will be issued to commissioners and service providers who are responsible for the planning and delivery of future services⁸.

Some of the key actions can be delivered within the first year. We acknowledge however that due to workforce and financial constraints others will take some years to materialise. Thus each key action has a guide timescale as outlined in the following table and based on a 10 year plan to mirror the implementation of the NSF standards⁷.

<i>Category</i>	<i>Timescale</i>	<i>Level</i>
Short Term	Less than 1 year	Early implementation
Mid Term	1 – 3 years	Developmental
Long Term	4 – 10 years	Aspirational

Table 1: Timescales for implementation

Monitoring the standards

Standards will be monitored and audited by the relevant Network Group on an annual basis.

Managed Clinical Networks (MCNs)

These can be defined as:

“Linked groups of health professionals from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and Trust/Health Authority boundaries, to ensure equitable provision of high quality and clinically effective services.”¹²

Through the formal establishment of an MCN, children and young people requiring specialised healthcare will do so based on the following principle:

“Age appropriate, safe and effective (high quality) care delivered as locally as possible, rather than local care delivered as safely and effectively as possible”¹³.

Work on the proposed service models is currently under discussion at the Welsh Assembly Government and Health Commission Wales.

Paediatric Gastroenterology, Hepatology and Nutrition Services for the children and young people of Wales

Paediatric Gastroenterology is a clinical speciality comprising the investigation and management of disorders of the gastrointestinal tract (the oesophagus, stomach, pancreas, small intestine and colon) in infants, children and young people.

It also encompasses two related specialities, Hepatology (liver disease) and Clinical Nutrition¹⁴.

Some elements of Paediatric Gastroenterology services fall within the remit of general paediatricians¹⁵. These are common conditions, which in their simpler form would expect to be managed in a District General Hospital (DGH) setting.

Included amongst these conditions are:-

Food intolerance

Chronic constipation

Recurrent abdominal pain

However, the more complex or difficult of these conditions do require the expertise of the specialised service.

For specialised Gastroenterology, Hepatology and Nutritional services (Appendix 3), there has been identified a critical mass to ensure that teams caring for this group of infants, children and young people maintain their skills so that the children get optimum care. For this service, the identified population critical mass is 2 - 2.5 million. This would require three Whole Time Equivalent (WTE) Paediatric Gastroenterologists (specialist register) to deliver this service. (Appendix 4)

There is, as with most services, an overlap with other clinical services. In particular, the advice of a Paediatric Gastroenterologist may be sought for children with other health needs. These include:

Neurodisability, Paediatric Surgery, Neonatology, Cardiology, Oncology, Inborn Errors of Metabolism, Immunology and Infectious Diseases. Interface with Paediatric Intensive care is also required.

Good practice already exists across Wales and the standard document builds on this. This document should be used in conjunction with the British Society of

Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) documents^{14,15} and the evidence base in them identified by BSPGHAN.

Currently for South and Mid Wales, Cardiff acts as the lead centre, providing the full range of diagnostic services as outlined by BSPGHAN (Appendix 4). Newport and Swansea act as specialist centres¹⁵ providing many but not all of these services.

For North Wales, the Royal Liverpool Children's Hospital acts as the lead centre.

Some children will need to access services identified as "Supra-Regional". These are highly specialised Hepatology and Intestinal Failure services currently delivered in three centres; Birmingham, Leeds & London (King's). Access to these services for the children of Wales will be through the identified Lead and Specialist centres.

Standard 1: Access to Gastroenterology, Hepatology and Nutrition

Rationale: All children identified with a Gastroenterology, Hepatology and Nutritional health need will have access to high quality, evidence based care provided by appropriately trained multi-disciplinary teams

Key Actions:

<i>Key Action</i>	<i>Responsible Organisation</i>	<i>Timescales</i>
1.1 Children with conditions on the NSCAG Gastroenterology list (appendix 3) are discussed with a specialist Paediatric Gastroenterologist ¹⁵ .	LHBs Trusts	Less than 1 year
1.2 Telephone access to specialist advice is available for primary and secondary care Mon - Fri 9am - 5pm. Telephone access to specialist advice is available for primary and secondary care 9am - 5pm every day.	HCW Lead and Specialist Centres	1-3 years 4-10 years
1.3 Telephone access to specialist nursing advice is available to families and professionals Mon - Fri 9am - 5pm. Telephone access to specialist nursing advice is available for primary and secondary care 9am - 5pm every day.	HCW Lead and Specialist Centres	1-3 years 4-10 years
1.4 Plans are made for every child requiring review by a member of the specialist team, including: (i) immediate in-patient transfer to a lead/specialist centre (ii) out-patient/day case appointment at a lead/specialist centre (iii) outreach specialist clinic appointment at the local DGH	HCW LHBs Trusts Lead and Specialist Centres	Less than 1 year Less than 1 year 1-3 years
1.5 When emergency access to DGH is required, processes are in place to ensure this occurs.	LHBs Trusts	Less than 1 year

Standard 2: Resourcing of Gastroenterology, Hepatology and Nutrition Services

Rationale: Gastroenterology, Hepatology and Nutrition services are staffed with appropriate, multi-disciplinary professionals who are fully trained. Services are fully equipped to deliver care across the network.

Key Actions:

<i>Key Action</i>	<i>Responsible Organisation</i>	<i>Timescales</i>
2.1 A fully established, multi-disciplinary team exists in the lead centre consisting of: (appendix 4).	HCW Lead Centres	1-3 years
2.2 At each DGH where children are seen there is a named link paediatrician.	LHBs Trusts	Less than 1 year
2.3 Outreach medical services exist between the specialist and local units.	HCW LHBs Lead and Specialist Centres Trusts	1-3 years
2.4 Outreach nursing services exist between the specialist and local units.	HCW LHBs Lead and Specialist Centres Trusts	1-3 years
2.5 Paediatricians with an interest in Gastroenterology working in a DGH have a minimum of 2 sessions a week dedicated to this special interest ¹⁴ .	LHBs Trusts	1-3 years*
2.6 In centres undertaking Endoscopy in children and young people, procedures normally take place on regular dedicated Paediatric Endoscopy lists with general anaesthesia delivered by anaesthetists with paediatric training (<i>anaesthetic standards for children's services will be developed as part of the CYPSS Project</i>).	HCW Lead and Specialist Centres	Less than 1 year

<i>Key Action</i>	<i>Responsible Organisation</i>	<i>Timescales</i>
Facilities are available in these centres for endoscopy to be carried out as an emergency when necessary.		
2.7 Nutritional support services for children with complex disorders are delivered by multi-disciplinary teams with specific paediatric training, and dedicated time and resources.	HCW Lead and Specialist Centres Trusts	1-3 years

Standard 3: Care of the child and family

Rationale: The child and the family receive holistic, child and family centred care.

Key Actions:

<i>Key Action</i>	<i>Responsible Organisation</i>	<i>Timescales</i>
3.1 Specialist Psychology support is available for all children and families who access Gastroenterology, Hepatology and Nutrition care from tertiary services.	HCW Lead and Specialist Centres	1-3 years

Standard 4: Communication

Rationale: There is effective two-way communication from local to specialist care and back and between professionals and children, young people and their families

Key Actions:

All key actions in are in universal document

Standard 5: Evidence base, Professional Education and Training

Rationale: All members of the Managed Clinical Network are trained to the required standard to deliver a high quality evidence based service.

Key Actions:

All key actions in are in universal document

Glossary

This glossary should be used in conjunction with the glossary provided in the Children's NSF.

Education Providers	Providers of commissioned health education.
Health Commission Wales (HCW)	Commissioners of specialised services.
Lead Centres	Trusts delivering specialised services.
Local Health Boards (LHBs)	Commissioners of local primary and secondary services.
Trusts	All Trusts delivering children's services.
Supra-Regional	A specialist centre providing highly specialised services on a UK wide basis.
Universal Standards And Key Actions	Standards and key actions which apply to all of the specialised services.

External Working Group Members

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Dr Peter Dale, (Joint Chair) Consultant Paediatrician

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Project Steering Group Members

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Irene Allen Head of Branch Welsh Assembly Government

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The aspects of paediatric gastroenterology that should be regarded as specialised are:

Gastroenterology

- Intestinal failure
- Inflammatory bowel disease
- Gastrointestinal bleeding
- Complex motility disorders including the severe end of constipation and gastro-oesophageal reflux
- Protracted diarrhoea (greater than 3 weeks duration and weight loss)
- Congenital transport disorders
- Multiple food intolerances
- Coeliac disease (unless pathology and paediatric dietetic service available locally)
- Pancreatitis
- Pancreatic exocrine insufficiency other than cystic fibrosis

Hepatology

- Neonatal hepatitis syndromes
- Childhood chronic liver disease
- Surgical liver disease
- Jaundice not due to uncomplicated hepatitis A infection

Nutrition

- Home parenteral nutrition
- Nutrition for complex disorders whether supportive or primary treatment
- Gastrostomy and jejunostomy tube feeding

Specialised investigations

- Upper and lower GI endoscopy
- Liver biopsy
- Intestinal biopsy
- Rectal biopsy
- Oesophageal pH monitoring
- Breath hydrogen tests
- Pancreatic function tests
- Motility studies and manometry

Appendix 4

The British Society of Paediatric Gastroenterology and Nutrition has agreed that in order for a centre to function as a specialist unit, various criteria need to be met.

A population base of 2.5 million

Two to three trained paediatric gastroenterologists to provide on call cover

Paediatric endoscopy service in a child friendly setting with at least 75 procedures per consultant per year

Specialist nursing staff

Specialist dietetic support

Specialist speech and language therapy support

Specialist psychological support

Specialist pharmacy support

Access to a specialist dentist

A full range of allied services including paediatric and neonatal surgery, neonatal medicine and paediatric intensive care are required.

A full range of diagnostic services including:-

Paediatric radiology/imaging

Endoscopy

pH studies

Paediatric histopathology

A multidisciplinary nutritional care team

Links with the adult services

Links with other centres

Links with the supra-regional hepatology services

References

1. Specialised Health Commission for Wales (May 2002) *Review of Tertiary Services for the Children of Wales*. Pontyclun: SHCW.
2. Specialised Health Commission for Wales (June 2002) *A Special Service: The future of specialised healthcare for the children of Wales*, Pontyclun: SHCW.
3. Welsh Assembly Government (Oct 2002). *Health and Social Services Committee papers*. HSS-18-02(p.3). Cardiff: WAG.
4. Welsh Office (1998) *Quality Care and Clinical Excellence*. Cardiff: Welsh Office.
5. National Public Health Service (NPHS) (2004) *A Profile of the Health of Children and Young People in Wales*, Cardiff: NPHS.
6. Townsend P. (2001) *NHS Resource Allocation Review: Targeting Poor Health*. Vol. 1, Cardiff: National Assembly for Wales.
7. Welsh Assembly Government. (2004) *National Service Framework for Children, Young People and Maternity Services in Wales Consultation Document*. Cardiff: WAG.
8. Welsh Assembly Government (June 2003) *NHS Planning and Commissioning Guidance*, WHC (2003) 063, Cardiff: Welsh Assembly Government.
9. Welsh Assembly Government (June 2003) *The Review of Health and Social Care in Wales* [advised by Derek Wanless], Cardiff: Welsh Assembly Government.
10. Contact a Family (September 2003) *The National Service Framework for Children, Young People and Maternity Services. Parent Consultation - Acute and Chronic Illness and Injury Module Report*. Cardiff: Contact a Family.
11. Welsh Assembly Government (September 2003) *Signposts Two, Putting public and patient involvement into practice in Wales*. Cardiff: WAG.
12. Baker, C D. Lorimer, A R. 2000 *Cardiology: the development of a managed clinical network*. BMJ. Vol 321 No 7269, 4 November 2000, 1152-3.
13. National Institute for Clinical Excellence (November 2004) *Improving Outcomes in Children and Young People with Cancer First Consultation*. London: NICE.

14. British Society of Paediatric Gastroenterology, Hepatology and Nutrition, (September 2003) *A Guide for Purchasers of Paediatric Gastroenterology, Hepatology and Nutrition Services*. London: BSPGHAN.
15. British Society of Paediatric Gastroenterology, Hepatology and Nutrition, (October 2002). *Report of the BSPGHAN Working Group to develop Criteria for DGH Gastroenterology, Hepatology and Nutrition Services*. London: BSPGHAN.